POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
MH	Hospital	Adult Care - Mental Illness Acute Care	Cloughmore, Willows (Acute Admissions), Silverwood, Bronte & Rosebrook (PICU) wards, Bluestone	I/P	Occupied Beddays	24,528
MH	Hospital	Adult Acute - Mental Illness	Bluestone	O/P	Outpatient Atts	3,989
MH	Hospital	Adult Acute - Mental	Bluestone	Day Case	Con Led Atts	85
MH	Hospital	Adult Acute - Mental	Bluestone	Day Hospital	Day Atts	3,976
MH	Hospital	Child & Adolescent Psychiatry	Cloughmore, Bluestone	I/P	Beddays	115
MH	Hospital	Adult Acute - Mental	DHH	O/P	Outpatient Atts	5,611
MH	Hospital	Adult Acute - Mental	DHH	Day Care	Con Led Atts	2,102
MH	Hospital	Adult Acute - Mental	St Lukes	O/P	Outpatient Atts	4,862
MH	Hospital	Adult Acute - Mental	STH	Day Care	Con Led Atts	
MH	Hospital	Continuing Care /Rehabilitation	DHH	Day Care	Con Led Atts	1,4[illegible]
MH	Hospital	Continuing Care /Rehabilitation	St Lukes	Day Care	Con Led Atts	[illegible]
MH	Hospital	Specialist Brain Injury (mental Health)		I/P	Beddays	

SCHEDULE 5b - ACTIVITY PROGRAMME OF CARE: MENTAL HEALTH

POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
MH	Hospital	Psychiatric Liaison to Unscheduled Care Services	DHH ED	O/P	Sessions / Hours	TBC
MH	Hospital	Psychiatric Liaison to Unscheduled Care Services	CAH ED	O/P	Sessions / Hours	TBC
MH	Hospital	Psychology Support to Inpatient Beds	Bluestone		Face to Face contacts	588
MH	Hospital	Addiction Services		O/P	TBC	7,912
MH	Other Comm / PSS	Eating Disorders		O/P	Outpatient Atts	2,524
MH	Other Comm / PSS	Eating Disorders		Day Services	Day Atts	
MH	Other Comm / PSS	CAMHs Crisis and Home Treatment Team		O/P	Face to Face contacts	
MH	Other Comm / PSS	CAMHs Eating Disorders Team		O/P	Face to Face contacts	
MH	Other Comm / PSS	CAMHs Addictions Team		Day Services	Day Attendances	
MH	Other Comm / PSS	Community Addictions Team		Day Services	Day Attendances	10,155

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POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
MH	Other Comm / PSS	Mental Health Addictions - Tier 3 Service		TBC	TBC	
MH	Other Comm / PSS	ASD Adult Diagnosis Outpatient Clinic	Statutory	O/P	Outpatient Atts	
MH	Other Comm / PSS	Home Helps	Statutory		Total hours delivered	
MH	Domiciliary Care	Meals on wheels			Number of Meals	
MH	Nursing	Nursing - Auxiliary			Face to Face contacts	
MH	Nursing	Nursing - Community Psychiatric			Face to Face contacts	38,029
MH	Nursing	Nursing - District			Face to Face contacts	1,517
MH	Nursing	Nursing - Health Visiting			Face to Face contacts	1,025
MH	Nursing	Nursing - Treatment Rooms			Face to Face contacts	
MH	Nursing	Nursing - Other Specialist Nursing			Face to Face contacts	587
MH	AHP	Clinical Psychology			Face to Face contacts	8,754
MH	Other Comm / PSS	Peer Advocate - Unscheduled Care			Face to Face contacts	
MH	Other Comm / PSS	Psychiatric Liaison Service			Face to Face contacts	
MH	Other Comm / PSS	Psychotherapy			Face to Face contacts	
MH	Nursing Home Care	Nursing Home Care - Total	IS & Stat		Purchased Bed Days	44,925
MH	Residential Home Care	Residential Care Home - Total	IS & Stat		Purchased Bed Days	19,824
MH	Social Work	Social Workers			Active caseload	5,042
MH	Social Work	Social Workers - Family Support & Assistance	Protection		Active caseload	
MH	Residential Care Home	Step Up / Step Down Facilities				
MH	Residential Care Home	Supported Living			Packages of Care	22
MH		TOTAL				

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POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Propos: Based on Notes column
LD	Domiciliary Care	Adult Supported Living	Statutory		Hours delivered	
LD	Residential Care Home	Adult Supported Living			Packages of Care	2:
		Permanent Adult Family Placement			Packages of Care	
LD	Residential Care Home	Adult Supported Living	Voluntary		Beddays	
LD	Residential Care Home	Children Supported Living			Beddays	
		Equipment and Community Care Appliances			Expenditure/Budget	
LD	Other Comm / PSS	Advocacy Services				
LD	Other Comm / PSS	Care Management Practitioner				
LD	Nursing	Challenging Behaviour Nursing				
LD	Other Comm / PSS	Child & Adolescent Psychiatry			Face to Face contacts	
LD	Other Comm / PSS	Child Care Centre			Child referrals	
LD	Residential Care Home	Childrens Respite Funding				
LD	Other Comm / PSS	Community / Clinical Medical Officer			Face to Face contacts	
LD	Other Comm / PSS	Consultant Psychiatrist				
LD	Other Comm / PSS	Day care services	Private		Attendances	40,5
LD	Other Comm / PSS	Day care services	Statutory		Attendances	8,8:
LD	Other Comm / PSS	Day care services	Private		Adults in Receipt	1:
LD	Other Comm / PSS	Day care services	Statutory		Adults in Receipt	4(
LD	Other Comm / PSS	Day Opportunities			Adults in Receipt	5:

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SCHEDULE 5b - ACTIVITY PROGRAMME OF CARE: LEARNING DISABILITY

POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposa Based on Notes columo
LD	Other Comm / PSS	Community Dental			Face to Face Contacts	6,52
LD	Other Comm / PSS	Community Dental Education				
LD	Other Comm / PSS	**Domiciliary Care - TOTAL**			**Total hours delivered**	**369,2**
LD	Domiciliary Care	Domiciliary Care - Independent	Private		Total hours delivered	103,22
LD	Domiciliary Care	Domiciliary Care - Independent	Voluntary		Total hours delivered	
LD	Domiciliary Care	Domiciliary Care - Statutory	Statutory		Total hours delivered	69,42
LD	Domiciliary Care	Domiciliary Care - Dual			Total hours delivered	
LD	Domiciliary Care	Domiciliary Care - SDS / Direct Payment Hours			Total hours delivered	196,59
LD	Other Comm / PSS	Home Helps	Statutory		Total hours delivered	
LD		Hospital - Learning Disability - Muckamore Abbey				
LD						
LD		**Bed Category**	**Hospital Ward Name**	**Type**	**Currency**	
LD	Hospital	Delayed Discharge Unit	Bluestone	I/P	Beddays	
LD	Hospital	Adult- Assessment	Bluestone - Dorsy	I/P	Beddays	2,920
LD	Hospital	Outpatients	Bluestone - Dorsy	O/P	Cons Led Att	
LD						
LD	Domiciliary Care	Meals on wheels			Number of Meals	
LD	Nursing	Nursing - Auxiliary			Face to Face contacts	
LD	Nursing	Nursing - District			Face to Face contacts	2,119
LD	Nursing	Nursing - Health Visiting			Face-to-Face contacts	

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POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposa Based on Notes column
LD	Nursing	Nursing - Learning Disability			Face to Face contacts	4,19
LD	Nursing	Nursing - Paediatric			Face to Face contacts	
LD	Nursing	Nursing - Other Specialist			Face to Face contacts	4,87
LD	AHPs	Audiology			Face to Face contacts	
LD	AHPs	Clinical Psychology			Face to Face contacts	5,18
LD	Other Comm / PSS	Rehab Worker				
LD	Nursing Care Home	Nursing Home Care - Total	IS & Stat		Purchased Bed Days	75,07
LD	Residential Care Home	Residential Care Home - Total	IS & Stat		Purchased Bed Days	42,94
LD	Social Work	Social Workers			Active caseload	2,95
LD	Social Work	Social Workers - Family Support & Assistance	General Family Support		Active caseload	
LD	Social Work	Social Services Training (PSS)				
LD	Social Work	Community Social Services				
LD	Other Comm / PSS	Community Development Teams				
LD	Other Comm / PSS	Recurrently funded Named Care Package (client initials)				

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SCHEDULE 5b - ACTIVITY PROGRAMME OF CARE: LEARNING DISABILITY

POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
		Learning Disability Specialist Teams				
LD		Learning Disability Crisis Response Team			Contacts	3,15(
LD		Learning Disability Epilepsy Service			Contacts	3,23-
LD		Learning Disability Forensic Team			Contacts	10,40
		TOTAL				

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POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
PDIS	Other Comm / PSS	Blind Centre				
PDIS	Other Comm / PSS	Cedar Foundation Outreach Scheme				
PDIS	Other Comm / PSS	Child & Adolescent Psychiatry			Face to Face contacts	
PDIS	Other Comm / PSS	Child Care Centre			Child referrals	
PDIS	Other Comm / PSS	Clinical Medical Officer			Face to Face contacts	
PDIS	Other Comm / PSS	Day care services	Statutory		Attendances	9,347
PDIS	Other Comm / PSS	Day care services	Voluntary		Attendances	9,905
PDIS	Other Comm / PSS	Day care services	Private		Adults in Receipt	27
PDIS	Other Comm / PSS	Day care services	Statutory		Adults in Receipt	94
PDIS	Other Comm / PSS	Day Opportunities			Adults in Receipt	65
PDIS	Other Comm / PSS	Community Dental			Face to Face contacts	701
PDIS	**Domiciliary Care**	**Domiciliary - Total**			**Total hours delivered**	**412,790**
PDIS	Domiciliary Care	Domiciliary Care - Independent	Private		Total hours delivered	196,488
PDIS	Domiciliary Care	Domiciliary Care - Independent	Voluntary		Total hours delivered	
PDIS	Domiciliary Care	Domiciliary Care - Statutory	Statutory		Total hours delivered	101,892
PDIS	Domiciliary Care	Domiciliary - Dual	Statutory		Total hours delivered	-

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SCHEDULE 5b - ACTIVITY PROGRAMME OF CARE: PHYSICAL DISABILITY

POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
PDIS	Domiciliary Care	Domiciliary Care - SDS / Direct Payment Hours			Total hours delivered	114,488
PDIS	Other Comm / PSS	Home Helps	Statutory		Total hours delivered	
PDIS	Other Comm / PSS	Low Vision Outreach Pilot		other		
PDIS	Domiciliary Care	Meals on wheels			Number of Meals	
PDIS	Hospital	Neurology (MS and Acquired Brain Injury Patients)			Purchased Bed Days	
PDIS	Nursing	Nursing - Auxiliary			Face to Face contacts	
PDIS	Nursing	Nursing - District			Face to Face contacts	10,780
PDIS	Nursing	Nursing - Health Visiting			Face to Face contacts	362
PDIS	Nursing	Nursing - Marie Curie			Face to Face contacts	
PDIS	Nursing	Nursing - School			Face to Face contacts	
PDIS	Nursing	Nursing - Treatment Rooms			Face to Face contacts	
PDIS	Nursing	Nursing - Other Specialist			Face to Face contacts	542
PDIS	Nursing	Nursing - Macmillan			Face to Face contacts	
PDIS	AHPs	Audiology			Face to Face contacts	
PDIS	AHPs	Clinical Psychology			Face to Face contacts	TBC
PDIS	Other Comm / PSS	Rehabilitation Assistants			Face to Face contacts	
PDIS	Other Comm / PSS	Proj Dev Worker for 16-25 Year Olds				
PDIS	Nursing Care Home	Nursing Care Home - Total	IS & Stat		Purchased Bed Days	19,40
PDIS	Residential Care Home	Residential Care Home - Total	IS & Stat		Purchased Bed Days	1,69
PDIS	Residential Care Home	Respite - MS Patients			Respite Beds	
PDIS	Other Comm / PSS	Sensory services			Block	
PDIS	Social Work	Social Workers			Active caseload	1,911

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POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
PDIS	Other Comm / PSS	Recurrently funded Named Care Package (client initials)				
PDIS	Other Comm / PSS	Special Schools				
PDIS	Other Comm / PSS	Statutory Day Services Thompson House				
PDIS	Hospital	Thompson House			Packages of Care	
PDIS	Other Comm / PSS	Community Development Teams				
PDIS	Residential Care Home	Adult Supported Living			Packages of Care	15
PDIS	Residential Care Home	Supported Accomodation - Statutory				
PDIS						
		TOTAL				

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POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
HPROM	Other Comm / PSS	Clinical Medical Officer / Paediatric Medical			Face to Face contacts	
HPROM	Other Comm / PSS	Community Health Development Specialist				
HPROM	Other Comm / PSS	Control of Infection			Face to Face contacts	
HPROM	Other Comm / PSS	Community Dental Health Education				
HPROM	Other Comm / PSS	Community Dental Screening				
HPROM	Other Comm / PSS	Community Dental			Face to Face contacts	2,070
HPROM	Nursing	Nursing - Family Planning			Face to Face contacts	
HPROM	Other Comm / PSS	Health Development Posts				
HPROM	Other Comm / PSS	Health Preceptions Project				
HPROM	Other Comm / PSS	Health Promotion Officer			Block	
HPROM	Nursing	Nursing - Auxiliary			Face to Face contacts	
HPROM	Nursing	Nursing - Community Psychiatric			Face to Face contacts	
HPROM	Nursing	Nursing - District			Face to Face contacts	3,922
HPROM	Nursing	Nursing - Health Visiting			Face to Face contacts	37,078
HPROM	Nursing	Nursing - Paediatric			Face to Face contacts	
HPROM	Nursing	Nursing - School			Face to Face contacts	
HPROM	Nursing	Nursing - Treatment Rooms			Face to Face contacts	
HPROM	Nursing	Nursing - Community Midwifery			Face to Face contacts	
HPROM	Nursing	Family Planning Services			Face to Face contacts	4,221
HPROM	Nursing	Other Specialist Nursing			Face to Face contacts	4,89[illegible]
HPROM	AHPs	Audiology			Face to Face contacts	
HPROM	AHPs	Clinical Psychology			Face to Face contacts	
HPROM	Other Comm / PSS	Other Community				
HPROM	Other Comm / PSS	Paediatric Medical			Face to Face contacts	
HPROM						
HPROM		**Non Acute Services on Hospital Sites:**				
HPROM	Other Comm / PSS	Breast Screening				
HPROM	Other Comm / PSS	Cervical Screening				
HPROM	Other Comm / PSS	Diabetes Service				
HPROM	Other Comm / PSS	Public Health Laboratory				
		TOTAL				

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POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
PRIM	Other Comm / PSS	Behaviour management				
PRIM	Nursing	Nursing - Challenging Behaviour				
PRIM	Other Comm / PSS	Chronic disease management				
PRIM	Other Comm / PSS	Chronic Heart (Telemonitoring)				
PRIM	Other Comm / PSS	Clinical Psychology			Face to Face contacts	
PRIM	Other Comm / PSS	Community Paediatrics / Clinical Medical Officer			Face to Face contacts	
PRIM	Other Comm / PSS	Community Development Health Workers				
PRIM	Other Comm / PSS	Community Diabetes Service			Face to Face contacts	
PRIM	Other Comm / PSS	Community Dental			Face to Face contacts	298
PRIM	Other Comm / PSS	Community Dental Education			Face to Face contacts	
PRIM	Other Comm / PSS	Dermatology				
PRIM	Nursing	Nursing - Family Planning			Face to Face contacts	
PRIM	Other Comm / PSS	GP Musculo Skeletal Triage				
PRIM	Other Comm / PSS	GP Orthopaedic Triage				
PRIM	Other Comm / PSS	GP Out of Hours				
PRIM	Other Comm / PSS	Health Promotion Officer			Block	
PRIM	Other Comm / PSS	Intensive weight management				
PRIM	Other Comm / PSS	ICATS service: Orthopaedics		Tier 2	Episodes of Care	
PRIM	Other Comm / PSS	ICATS service: Ophthalmology		Tier 2	Episodes of Care	
PRIM	Other Comm / PSS	ICATS service: Urology		Tier 2	Episodes of Care	
PRIM	Other Comm / PSS	ICATS service: ENT		Tier 2	Episodes of Care	
PRIM	Other Comm / PSS	ICATS service: Dermatology		Tier 2	Episodes of Care	
PRIM	Nursing	Nursing - Home Oxygen Service			Total Face to Face contacts	TBC
PRIM	Nursing	Nursing - Home Oxygen Service			New Assessment	336
PRIM	Nursing	Nursing - Home Oxygen Service			Review Assessment	TBC
PRIM	Nursing	Nursing - Auxiliary			Face to Face contacts	
PRIM	Nursing	Nursing - District			Face to Face contacts	33,910
PRIM	Nursing	Nursing - Health Visiting			Face to Face contacts	14,655
PRIM	Nursing	Nursing - Paediatric			Face to Face contacts	
PRIM	Nursing	Nursing - Marie Curie			Face to Face contacts	
PRIM	Nursing	Nursing - Other Specialist Nursing			Face to Face contacts	11,587

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Received from SPPG on 03/11/2023. Annotated by the Urology Services Inquiry.

SCHEDULE 5b - ACTIVITY PROGRAMME OF CARE: PRIMARY CARE

POC	2012 SRF Grouping	Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal Based on Notes column
PRIM	Nursing	Nursing - School			Face to Face contacts	
PRIM	Nursing	Nursing - Diabetes Technician			Face to Face contacts	
PRIM	Nursing	Nursing - Treatment Rooms			Face to Face contacts	
PRIM	Nursing	Nursing - Diabetes Specialist Nursing			Face to Face contacts	TBC
PRIM	Other Comm / PSS	Orthopaedic Triage				
PRIM	Other Comm / PSS	Pain Clinic				
PRIM	Nursing	Nursing - Pallitative Care				
PRIM	AHPs	Audiology			Face to Face contacts	
PRIM	AHPs	AHP - Orthoptics			Face to Face contacts	854
PRIM	AHPs	Physio Triage				
PRIM	Other Comm / PSS	Pulmonary Lab				
PRIM	Other Comm / PSS	Pulmonary services				
PRIM	Other Comm / PSS	Respiratory services - PIT stop				
PRIM	Other Comm / PSS	Rheumatology				
PRIM	Other Comm / PSS	Sexual health Improvement Model				
PRIM	Social Work	Social Workers			Active caseload	
PRIM	Nursing	Stroke team				
PRIM	Other Comm / PSS	Other Community				
PRIM	Other Comm / PSS	Diagnostic Services - Imaging				
PRIM	Other Comm / PSS	Diagnostic Services - Labs				
PRIM	Other Comm / PSS	Diagnostic Services - Other				
PRIM	Other Comm / PSS	Home Dialysis				
PRIM	Other Comm / PSS	Daycare Facilities - Independent				
PRIM	Other Comm / PSS	Daycare Facilities - Statutory				

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2019/20 - ALLIED HEALTH PROFESSIONALS — Elective

Service Line Descriptor	Sector	Type	Currency	19/20 Draft Proposal
Physiotherapy Total			New Patients Seen	**30420**
Physiotherapy - MSK/Adult etc			New Patients Seen	29508
Paeds Community Health			New Patients Seen	912
Occupational Therapy Total			New Patients Seen	**7980**
Acute/LD/PD etc			New Patients Seen	7404
Paediatrics			New Patients Seen	576
Dietetics Total			New Patients Seen	**5604**
Paediatric			New Patients Seen	1212
Adult			New Patients Seen	4392
Speech and Language Total			New Patients Seen	**2772**
Adult Community			New Patients Seen	420
Paeds Community			New Patients Seen	2028
Adult Learning Disability			New Patients Seen	324
Podiatry Total			New Patients Seen	**5928**
Core			New Patients Seen	5928
Orthoptics Total			New Patients Seen	**2412**
General Adult			New Patients Seen	300
General Paediatric			New Patients Seen	2112

PC Appendix 8

Schedule 6:

Service Specification for Provision of Urgent Primary Care Out of Hours in NI

Health and Social Care Board

2019-2020

Service Specification

For the provision of

Urgent Primary Care Out of Hours in N Ireland

Authorised by: Dr Sloan Harper
Date: 30.10.19
Version: v 1

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1 Circulation and amendment history

Circulation

This is a controlled document and must be authorised and approved by the Director of Integrated Care as commissioner who is responsible for control and circulation of this document. This document is held centrally on http://primarycare.hscni.net/wpfb-file/service_spec_ooh_2016-17_final_19-07-16-pdf-4/ in the GP Out of Hours section and is available to all staff required to access it. Hard copies of the document may be printed but will be treated as uncontrolled and must be verified against the main copy held on the intranet.

Amendment history

Version	Date	Comment	Authorised By
v0.1	12/08/2008	First version	Out of Hours Steering Group
v0.2	03/12/2008	Governance section amended, Medicines Management section removed, standards updated.	Out of Hours Steering Group
v0.3	07/10/2011		HSCB
v0.4	23/10/2012	Pg 12 section 7 added, pension scheme and working time added plus other minor wording changes.	Dr Harper
v0.5	25/06/2013	Update to priority names to bring in line with Adastra and amendment to Medicines section; Appendix 2.	Dr Harper
v0.6	19/05/2015	Updates to section 3.7 following a BSO audit and to take account of Directive 2011/24/EU on the application of patient rights in cross-border healthcare and minor amendments through the document.	Dr Harper

V0.7	09-06-16	Updates to 1. Frequency of reporting performance data 2. Updated escalation plan and reporting to HSCB 3. Standardising unfilled shifts using % hours filled against planned capacity 4. Updated **AIF1(GMS)**	Dr. Harper
V0.8	12.10.17	Updated references to DHSSPS to read Department of Health	Dr Harper
V0.9	26.10.18	Inclusion of Dr Ciara McLaughlin's name on copy list when submitting GP OOH Escalation Reports (Page 28, Section 6.4) Change of dates to read 2018-19	Dr Harper
V1.0	30.10.19	**Page 10, Section 13** - wording updated and strengthened to reflect that 'patients should normally be given an appointment time' rather than 'patients should normally be given an indication of when they will be seen'. **Page 11, section 4.5 Governance** - section amended to reflect fact that the Controls Assurance Process ceased effective from 1/4/18 and replaced with a requirement for all ALBs to provide assurance to policy leads in the Department.	Dr Harper

		Page 16, Section 4, Compliance - wording updated to keep consistent with revised wording in Page 10, Section 13 (see above for details) **Page 21, Section 4.9, Patient Pathway** - wording updated to keep consistent with revised wording in Page 10, Section 13 and Page 16, Section 4 (see above for details)	

2 Introduction

This document sets out the specification and service requirements for:

- the core Urgent Primary Care Out of Hours Service across N Ireland
- the access, output and reporting standards to which the service must adhere.

Any additional services will be separately commissioned.

3 Definition of terms used in this document

3.1 Out of Hours period

As defined in The Health and Personal Social Services (General Medical Services Contracts) Regulations (Northern Ireland) 2004:

(a) the period beginning at 6.30pm on any day from, and including, Monday to Thursday and ending at 8am on the following day;

(b) the period between 6.30pm on, and including, Friday and 8am on the following Monday; and

(c) any public holiday or local holiday agreed with the Health and Social Care Board (HSCB) (see Appendix 1).

Out of Hours Primary Care must be provided during the above times with any additional times or local arrangements being undertaken with commissioner agreement.

3.2 Urgent care

As defined in the Department of Health discussion document 'The Direction of Travel for Urgent Care' published in October 2006.

"Urgent care is the range of responses that health and care services provide to people who require - or perceive the need for - urgent advice, care, treatment or diagnosis. People using services and carers should expect consistent and rigorous assessment of the urgency of their care

need and an appropriate and prompt response to that need."

3.3 Visiting patient

As defined in The Health Services (Cross-Border Health Care) Regulations (Northern Ireland) 2013:

Visiting patient means an individual for whom a Member State other than the UK is the Member State of affiliation within the meaning of Article 3(c) of Directive 2011/24/EU.

3.4 Prescription form

As defined in The Health and Personal Social Services (General Medical Services Contracts) Regulations (Northern Ireland) 2004:

Prescription form means a form provided by the Business Services Organisation and issued by a prescriber to enable a person to obtain pharmaceutical services.

3.5 Home visits

References to "consultations at a patient's home or place of residence" are all subject to the caveat that there shall be no home or residential visits outside the Northern Ireland jurisdiction.

4 Specification of service

4.1 Service Aim

To provide a comprehensive, safe and efficient Urgent Primary Care Out of Hours Service to the N Ireland population, the non-resident transient population who are entitled to General Medical Services (GMS) for primary care urgent conditions that cannot wait, until the patient's own GP surgery is next open and also to visiting patients exercising rights in cross-border healthcare under Directive 2011/24/EU.

Under the above Directive individuals from other EEA Member States (visiting patients) are able to access out of hours services on an ad hoc basis and for which they will be charged a fee. The fee for primary medical services costs is set out in The Statement of Health Service Treatment Costs which can be accessed on the Department's website. The Directive does not require providers to accept visiting patients if this would be to the detriment of ensuring sufficient access for residents in N Ireland.

A GP or provider shall not be required to consult with any patient at their home or place of residence, where that home or place of residence is outside N Ireland.

4.2 Response to an urgent care need

The response to an urgent care need must take into account the clinical urgency of the situation with robust assessment and prioritisation of urgency that is the most urgent calls will be responded to first. An appropriate response, following telephone triage, may include:

- referral to daytime GP service
- telephone advice, reassurance and advice on self-care
- face-to-face consultation with a clinician in a healthcare facility or patient's residence
- admission to hospital or referral to a more appropriate service such as ambulance, Emergency Department, Minor Injuries Unit, mental health, social services, nursing service, dental service or pharmacy.

When there is referral to another service then as far as possible, where systems permit, the patient's details should be passed automatically to the service the person is being referred to. The principle for the patient is 'contact or tell us once'. The patient should be referred or signposted appropriately in a timely manner.

4.3 Vision

The vision is for a single point of contact for the patient for urgent primary medical services that cannot wait until the GP surgery is next open and for a co-ordinated network forming part of a matrix of care in order to provide the most appropriate and effective response, ideally locally to the patient, ensuring high quality care at this stage of the patient journey.

The Strategic Direction is set out within the current "Strategic Framework for GP Out of Hours" approved by the then DHSSPS Minister January 2014.

4.4 Service deliverables

The main service deliverables for Urgent Primary Care Out of Hours include:

1) Call handling

2) Triage

3) Telephone advice

4) Provision of primary care treatment or appropriate referral to another service based on clinical need

5) Face-to-face consultations in a healthcare facility or the patient's home or place of residence (paragraph 3.5 refers) if required based on clinical need

6) Safe use and control of medicines including prescribing, administration to patients and disposal in line with best practice and legislative requirements including compliance with NI prescribing guidelines and policies. In relation to visiting patients a GP or provider shall not prescribe on a prescription form but may prescribe by way of a private arrangement.

7) Communication and education:
   - the service has a role in educating the public on the service provided, how to contact the service and appropriate use of the service; informing the public of other healthcare organisations or services that maybe appropriate for the person including relevant patient pathways, and timely and accurate referrals
   - communication with daytime GPs including any changes to accessing the service or the service provided and any inappropriate use of the service by their patients

a. Facilitate GP ST3 and ST2 Training for Northern Ireland Medical and Dental Training Agency (NIMDTA) - supervised on-the-job training will be provided for GP ST3 and ST2 trainees by GP trainers or Out of Hours educational supervisors who are trained by NIMDTA as being eligible to undertake this role

8) Robust governance for all aspects of the service

9) Service development - continuously seeking to improve all aspects of the service

10) Offer and administer the HSC Pension Scheme locally for eligible staff in line with Department of Health guidelines. http://www.hscpensions.hscni.net

11) HSCB monitor the appraisal history of all GPs on the PMPL. Out Of Hours providers should check the PMPL list on a regular basis to determine if any of the GPs working in this organisation have conditions.

12) Appraisal for all GPs will be the responsibility of NIMDTA.

13) When a patient is referred for a face-to-face consultation in a healthcare facility they should be informed of the closest available centre to where they are phoning from however may attend a different centre if they so wish. Patients should normally be given an appointment time and details should be forwarded to the appropriate OOH Centre in advance of the patient's attendance. Accessible and seamless care with a single point of contact for patients with effective triage at first point of contact prioritising and providing care within the timescales outlined in section 4.9

14) Patients are normally expected to make initial contact with the service by telephone. However some patients walk into the service without phoning first. The service is not routinely for walk-in patients however should a patient walk-in, triage and any treatment required must be completed in line with the timescales outlined in the standards.

15) Providers must seek commissioner agreement for provision of any services outside the remit of this Service Specification.

4.5 Governance

Robust governance arrangements must be in place to comply with 'The Quality Standards for Health and Social Care' from the Department of Health, any Service Level Agreement or Service and Budget Agreement from the GP Out of Hours commissioner and all relevant legislation. In addition, the Provider will ensure as a minimum the implementation of the following:

1) **Governance Arrangements:**
Provider should ensure that suitable and appropriate assurance arrangements are in place for:
- Financial management, human resources, fleet management, equipment, information technology, fire safety, cleanliness and infection control, records and information management (including maintenance of up-to-date GP Practice details as per BSO website http://www.hscbusiness.hscni.net/services/1816.htm), performance management, management of complaints and incidents, continuous professional development, contingency, service continuity and resilience ensuring compliance with all legislative requirements.

2) **Risk Management:**
Specific risk registers should be maintained and kept under regular review.

3) **Medicines Management:**
Provider should ensure that suitable and appropriate assurance arrangements are in place in respect of Medicines Management. This includes, but is not limited, to the implementation and use of Standard Operating Procedures at all stages of the medicines supply chain from ordering, transport, receipt, storage, prescribing, supply/administration and disposal, including the records to be kept at all stages. Particular attention should be paid to the management and use of controlled drugs and providers should have adequate systems in place to ensure drug alerts, safety alerts and defective medicinal products alerts are acted upon in line with good risk management and governance practice.

4) **Clinical Governance:**
Robust mechanisms for clinical governance should be in place including regular trend and spot audit of all staff who are engaged in patient contact, written operational protocols and risk assessment of complaints and incidents ensuring compliance with the HSCB Procedure for the Reporting and Follow up of Serious Adverse

Incidents and to ensure notification of all SAIs and adverse incidents to the commissioner.

5) Ensure appropriate procedures are in place for carrying out checks in relation to the protection of children and vulnerable adults as well as appropriate operational protocols.

6) Provide assurance of compliance / implementation of agreed regional guidance, aiming to ensure that doctors are not working excessive hours by working for one provider or for different providers. Provide assurance that procedures are in place to define working time guidelines for staff working in GP Out of Hours in order to assist the process of ensuring patient safety.

7) Local GP Out of Hours Governance, Performance and Contract review meetings are held with GP Out of Hours providers. Details are outlined in Appendix 2.

8) Mutual organisations should ensure that robust organisation governance arrangements are in place. These include a Steering Council, Audit and Remuneration committees that meet on a regular basis. Any funding required outside of budget must be authorised by the HSCB as commissioner prior to implementation.

9) Documented financial procedures, cost centres and formal procurement processes should be in place with a purchase order system ensuring that value for money is achieved. Financial controls should be in place in relation to processing payments. Bank reconciliations should be prepared and reviewed by two separate staff members.

10) An asset register should be in place.

11) A records retention and information governance policy should be in place. Policies and procedures should be reviewed on a regular basis to ensure that they are up-to-date, relevant and reflect current HSCB and Department of Health guidance/legislation. When policies are developed they should have a review date as well as appropriate version control.

12) A policy should be in place in relation to business travel as well as staff travel, expenses and subsistence. Any staff who are using their personal vehicles for business usage provide appropriate, up to date duty of care documentation. Duty of care documentation should

include; valid insurance (including business usage), a valid driving licence, an up to date MOT certificate (if applicable) and vehicle registration documents.

4.6 Principles

To be effective the Out of Hours primary care service must be:

Patient centred with effective access and demand management

1. patient focused and developed with the involvement of patients and stakeholders where patient's needs are met and patient safety is assured ensuring that patients are clear on the scope of the service ensuring that it is fair and equitable for all on the basis of need

2. administered to ensure measures and pathways are in place to identify and deal appropriately with patients with particular needs such as palliative or end-of-life care, mental health, learning or other physical disabilities, language or communication difficulties including where English is not the first language, challenging behaviour

3. support the principles of equality of opportunity and human rights protecting and respecting the dignity of all patients thereby maintaining public confidence in the service

4. co-ordinated to ensure clear, effective and timely communication with the public, staff, daytime GPs, other healthcare organisations and the commissioner

5. flexible enough to deal with local circumstances as well as capacity to deal with the peaks and troughs of demand

6. managed to ensure that the environment is conducive to the delivery of good quality care and that capacity is matched to demand

Learning and accountable organisation focussed on quality and health outcomes

7. quality assured ensuring consistency of quality and effective service delivery and able to assure safety of the public and staff

8. adequately resourced but efficient, cost-effective and able to demonstrate value for money

9. clinically effective and governed, evidence based and built on best practice with continuing professional development, audit, appraisal, feedback and training provided in a supportive environment for staff

10. performance managed, responsive to feedback and adaptable in light of any lessons learned ensuring that the skills of staff are such that a consistent high quality service is provided and that a robust system is in place to share lessons learned with the commissioner and other relevant organisations

Innovative and co-ordinated

11. sustainable and innovative in order to cope with the changing environment and developed in collaboration with other healthcare services and organisations providing clear patient pathways and seamless referrals when appropriate

12. resilient and adequately tested for service continuity with business continuity plans in place

13. strongly and professionally led with an effective management and staffing structure that has clear roles, responsibilities and accountabilities defined

14. well managed with appropriate governance and management responsibility ensuring compliance with all legislative, medicines management and employment requirements with regularly updated operating procedures ensuring quality and cost-effectiveness

15. regularly monitored for staff performance and appropriate use and reasons for patient contacts to the Out of Hours service.

4.7 Standards of service

Access

1. A single telephone number with sufficient telephone lines and call handlers available to answer all calls within 60 seconds after the end of any introductory message which should be no more than 30 seconds long with no more than 5% of calls abandoned.

2. Out of Hours services are available and accessible to patients and their representatives during the Out of Hours period defined in section 3.2 and any additional times agreed with the commissioner.

3. Patient contacts (either by telephone or walk-in) are assessed and responded to, based on clinical need and professional judgement with robust mechanisms to identify emergency calls and prioritise urgent contacts. Calls will be categorised on initial contact and must then be disposed of as follows:

   Triage:

   1) **Emergency (Life-Threatening)**: these calls should be passed to 999 ambulance within 3 minutes at whatever point they are identified as a 999 call.
   2) **Acute (Triage Immediately)**: these calls should go for immediate triage
   3) **Urgent (Triage Within 20 Minutes)**: appointment given at initial contact or triage within 20 minutes by a health professional.
   4) **Routine (Triage Within 1 Hour)**: triage within 1 hour by a health professional.

   5) **Face-to-face consultation:**

   The health professional will determine if a person needs a face-to-face consultation and the appropriate timescales. A face-to-face consultation, if required, usually takes place at an Out of Hours centre or occasionally at a patient's home or place of residence.

   a. **Acute (Within 1 Hour)**: face-to-face consultation within 1 hour if required after completion of triage.

   b. **Urgent (Within 2 Hours)**: face-to-face consultation within 2 hours if required after completion of triage.

6) **Routine (Within 6 Hours)**: face-to-face consultation within 6 hours if clinically appropriate after completion of triage.

    a. **Repeat callers**: health professionals should ensure they are aware of and have read the notes of any previous contacts (with the respective Out of Hours Provider) concerning that patient particularly those over the 110 hours preceding the call. The health professional should ascertain the reason why the person phoned back. If the person is not seen there should be clear documentation of the reasons why the person is not seen.

Compliance

KPI Performance for patient contacts will be monitored and providers will be deemed to be compliant when average performance on a monthly basis is as follows:

1) Full compliance when 95% and over meet the above criteria
2) Partial compliance 90% to 94.9% for the above criteria
3) Non-compliance when less than 90% meet the above criteria

If call volumes are exceeding normally expected volumes providers are asked to escalate issues in line with the system outlined in Appendix 3.

4. The patient only needs to make one telephone call to the Out of Hours service and if a base face-to-face visit is required, should be able to attend the Out of Hours centre that is operational nearest to them if they so choose. Patients should normally be given an appointment time and details should be forwarded to the appropriate OOH Centre in advance of the patient's attendance.

5. Patients are informed of approximate timescales at all stages in the patient journey and always contacted if an agreed home visit or appointment time is delayed.

6. Patients unable to communicate effectively in English will be provided with an interpretation service within 15 minutes of initial contact. Visiting patients will bear the cost of such services. Appropriate provision must be made for patients with impaired hearing or impaired sight to contact and use the service.

7. Patients will be issued with a prescription, if required, when a community pharmacy is accessible or the condition does not require immediate treatment. Private prescription arrangements will apply to

visiting patients. Out of Hours centres are expected to hold a stock of commonly required medicines for immediate supply should this be required. Out of Hours providers should generally not deal with repeat prescriptions unless in exceptional circumstances.

Output

8. Full clinical details of all Out of Hours consultations are supplied to the patient's GP by 9.00am on the next working day, ideally electronically. In relation to visiting patients a record of the Out of Hours consultation should be provided to the visiting patient either in writing or electronically.

9. The provider should assist the HSCB in monitoring the workload passed onto other services through providing agreed specified information. Such information will be collated with other HSCB data, to support analysis across the region, promoting efficient and effective integrated care. Such information requirements will be driven by commissioning. Examples include:

    - number of referrals to Emergency Department
    - number of referrals to 999 or ambulance as well as referrals from NIAS
    - number of referrals to mental health services
    - number of referrals to community nursing services
    - number of referrals to social services
    - number of referrals from and to daytime GP
    - number of referrals from nursing homes
    - number of visiting patient consultations

10. Providers should address any agreed metrics relating to performance, agreed with the HSCB, where there is significant variance. The HSCB will agree performance management processes for individual professionals with Providers.

11. Providers to submit performance data on a monthly basis to the Regional OOH support team.

12. Management plans, special notes and protocols should be in place for dealing with patients with special needs where appropriate e.g. palliative care, child protection, frequent callers, learning disability, hearing or sight impairments etc. The HSCB will agree with Providers suitable Governance arrangements to standardise operational

protocols. A process should be in place for ensuring that these are regularly reviewed and updated as required.

13. The provider complies with regional guidance including regionally endorsed NICE guidance and has an audit schedule to ensure compliance.

14. Providers should ensure that they have in place all necessary insurance for staff, premises, vehicles, public or products liability.

Quality

15. Out of Hours services comply with all appropriate 'Quality Standards for Health and Social Care' in Northern Ireland (available at https://www.health-ni.gov.uk/publications/quality-standards-health-and-social-care-documents). The key themes are:
    - corporate leadership and accountability of organisations
    - safe and effective care
    - accessible, flexible and responsive services
    - promoting, protecting and improving health and social well-being
    - effective communication and information.

    Patient experience, outcomes and satisfaction are regularly and continually assessed. They must audit a random sample of patient experiences of the service (for example 1% per quarter) and appropriate action taken on the results as a minimum on an annual basis.

16. Staff satisfaction is assessed as a minimum on an annual basis.

17. Complaints are acknowledged within the HSC Complaints procedures timelines and all appropriate action taken and learning implemented.

18. As far as possible all telephone calls and consultation details are recorded and subject to regular random audit. Providers should aim to audit 1% of calls per annum using a recognised and accredited template e.g. RCGP toolkit. Providers should also aim to audit a minimum of 4 calls/cases per clinician per year using an accredited template e.g. RCGP toolkit as well as continuing clinical audits of service provision.

19. Data is stored in line with Data Protection requirements. Records are kept in line with HPSS records management policies. The HSCB will agree performance management processes for individual professionals with Providers.

Reporting

Local GP Out of Hours Governance, Performance and Contract review meetings are held with GP Out of Hours providers. Details are outlined in Appendix 2.

20. Out of Hours services will be expected to demonstrate adherence to and achievement of the principles defined in section 3.8. In addition on an ongoing basis reporting will be required on:

1) performance against standards in section 3.9

2) contacts, dispositions and outcomes by locality and by GP practice

3) details of complaints, compliments, suggestions, patient surveys, patient outcomes, referrals to other services, response times, Root Cause Analysis and any actions taken

4) financial position (income and expenditure)

5) clinical governance, risk management processes and service development plans including any proposed changes

6) report to the Head of GMS any clinical or professional concerns in relation to a GP and any action taken. This would also include circumstances when GP's salaried / sessional contact is terminated. The Head of GMS will ensure that any relevant information about poorly performing doctors is notified to Out of Hours providers as appropriate

7) Inform Head of GMS of any significant change in status by 10.00am the next day after the OOH period including action proposed or taken. This is in addition to any notifications to HSCB/PHA that may have taken place during the out of hour's period. See Appendix 3 for summary escalation plan and proposed report template

8) The HSCB will agree reporting arrangements with each Provider taking cognisance of existing Governance and reporting arrangements, seeking co-terminus operational process, minimising administrative workload

9) Other information may be asked for as required e.g.:

10) reasons for patient contacts, trends, seasonal adjustments, number of repeat or frequent callers, number of walk-in patients, number of visiting patients, number of patients who do not turn up for appointments and any demand reduction techniques or innovations (following implementation of an agreed dataset, standardised clinical coding, and informational outcomes and the availability of reporting functionality in the Out of Hours database)

11) training plan which is reviewed annually

12) Unfilled capacity as measured by % hours (GP & Nurse) filled against hours (GP & Nurse) planned

13) quantity of medication issued from stock and quantity of expired stock

14) As a minimum formal update reports should be completed on a quarterly basis with a full annual report to be completed on all aspects of the service. Adverse incidents or significant service disruption will be notified immediately to the commissioner in line with any existing policy. Significant proposed service changes will be agreed in advance with the commissioner. The commissioner may request additional reports as necessary.

15) HSCB records prescribing data and supplies COMPASS reports to GP Out of Hours providers. HSCB will monitor and feedback on prescribing patterns.

4.8 Location of service

Location of centres and opening times will be agreed with the commissioner. As far as possible face-to-face base consultations should be provided in an existing adequately resourced healthcare facility. Safety of staff, accessibility for patients and access to required resources should be taken into consideration when determining locations and opening times. Call handling and triage must be located and co-ordinated to ensure the

response time standards are met. Call handlers and any other triage staff must have access to GP advice if required for clinical safety. Home visits must be co-ordinated.

4.9 Patient pathway

1. Patient calls in on single number.
2. Calls are answered next in line.
3. Call handlers have supervised and governed autonomy to prioritise calls for triage, depending on the degree of urgency. Call handlers are trained and supported to identify serious and life threatening conditions for immediate attention and transfer to 999 and to accurately categorise other calls.
4. Calls are categorised and triaged next in line in order of category i.e. acute category calls first, urgent second and routine third.
5. Patients should normally be given an appointment time and details should be forwarded to the appropriate OOH Centre in advance of the patient's attendance.
6. Ideally home visit dispatch is controlled centrally, for operational efficiency.

5 GP Out of Hours Standards for Patients

GP Out of Hours services comply with all relevant 'Quality Standards for Health and Social Care' in Northern Ireland and the standards below.

Standard	Description or Timescales
1. Service availability	GP Out of Hours is available when your GP Surgery is closed. This can vary slightly in areas but is usually between 6.00pm and 8.00am on weekdays, all weekend and public holidays.
2. Accessing the service	Single phone number.
3. Answering your phone-call	Within 60 seconds.

4. Responding to your call	The urgency of your call will be assessed (triaged). The response times are as follows: **Triage:** - **Emergency (Life-threatening)**: these calls are more appropriately dealt with by 999 and will be passed to 999 ambulance within 3 minutes. -**Acute or Urgent**: appointment given at initial contact or triage within 20 minutes by a health professional. We will aim to triage any acute calls as soon as possible. - **Routine**: triage within 1 hour by a health professional. **Face-to-face consultation:** The health professional will determine if a person needs a face-to-face consultation and the appropriate timescales. A face-to-face consultation, if required, usually takes place at an Out of Hours centre or occasionally at a patient's home or place of residence. - **Acute**: face-to-face consultation within 1 hour if required after completion of triage. - **Urgent**: face-to-face consultation within 2 hours if required after completion of triage. - **Routine**: face-to-face consultation within 6 hours if clinically appropriate after completion of triage. This type of call may be more appropriately dealt with by your daytime GP. If you need a face-to-face visit you will be given an indication of when you will be seen and should be able to attend the Out of Hours centre that is open nearest to where you are. Occasionally, when required, you will be visited at home. We would ask that you keep

	appointments or inform us if you cannot keep or no longer require the appointment. If deemed appropriate at any point you may be referred to another service e.g. 999, Emergency Department, social services, nursing, mental health etc.
5. Informing your daytime GP	Details of your consultation with GP Out of Hours will be sent to your GP by 9.00am the following morning. Visiting patients will be provided with a record of the out of hours consultation either in writing or electronically
6. Patient experience	Regularly monitored with a minimum of an annual patient satisfaction survey.
7. Dealing with a complaint	Acknowledged and responded to in writing within HSC Complaint procedure timelines.
8. Call recording and monitoring	All calls to and from GP Out of Hours are recorded and randomly audited. All data is stored in line with Data Protection requirements.
9. Communication	The GP Out of Hours phone number will be on the answering machine of your daytime GP surgery, in the telephone directory and on our website. www.gpoutofhours.hscni.net Language interpretation will be provided within 15 minutes of initial contact where required. Appropriate provision will be made for those with impaired hearing and sight.

10. Medicines	If you need any medication Out of Hours you will generally be given a prescription unless immediate treatment is required. Private prescription arrangements will apply to visiting patients. For Minor Ailments you can attend most pharmacies directly for medication when they are open, without contacting GP Out of Hours. Note that any repeat prescriptions should be dealt with by your daytime GP and in some cases your local pharmacy (unless in emergencies).

6 Appendices

Appendix 1 GMS Public Holidays

GMS Public Holidays are defined as:

Christmas Day
Boxing Day
New Year's Day
Easter Monday
Easter Tuesday
St. Patrick's Day or equivalent
Both May Bank Holidays
July Bank Holiday
End of August Bank Holiday

Appendix 2 - Terms of reference for local GP Out of Hours Governance, Performance and Contract review meetings

Aim: The primary focus of the local governance, performance and contract review meetings is monitoring delivery of the GP Out of Hours Service Specification and ensuring safe and effective delivery of the GP Out of Hours service.

Objectives:

1. To confirm appropriate clinical governance is in place to ensure adequate staffing and service organisation to deliver the KPIs.

2. To provide assurance of a robust governance structure in each provider.

3. To provide assurance that business continuity is in place for all aspects of the service.

4. To ensure appropriate processes are in place to manage complaints and any adverse incidents.

5. To provide assurance around use of funding.

6. To provide a forum to discuss any issues around service delivery, any concerns or feedback and any potential service developments.

Background

The service to be delivered, performance KPIs and governance required for GP Out of Hours are documented in the GP Out of Hours Service Specification which is updated as required. The GP Out of Hours Service Specification is embedded in the Service and Budget Agreement (SBA) with Trusts, ensuring its delivery is a contractual requirement, and through the SLA or contract with Mutual providers. Each provider has been allocated a HSCB Medicines Management / Governance Advisor.

The meetings

- Quarterly meetings chaired by the Business Support Manager or nominee in each provider area with relevant senior provider management staff, both operational and clinical as well as commissioning staff, local and regional

- Process for meetings e.g. standing items for every meeting and those that can be reviewed on an annual or bi-annual basis. It is proposed that the medicines management, statistics, KPIs, complaints and adverse incidents, financial position etc. will likely be reviewed at each meeting. Other areas could be scheduled for less frequent review. Updates to any other items such as risk registers, business continuity can be reviewed as appropriate.

- The meetings will provide a challenge function, ensuring that the service provided is of the expected standard, and that appropriate action is taken to address deficiencies or perceived risk as well as identifying learning.

- Out of Hours organisations will be required to submit performance data on a monthly basis to the Regional OOH support team. All other papers for the meeting at least a week in advance of the meeting so HSCB staff can review the papers in advance of the meeting.

Appendix 3 – GP OOH Escalation Plan

Introduction

Revised March 2016 to incorporate guidance from the Regional Unscheduled Escalation Plan. The regional plan identifies four escalation levels and actions to be considered for normal working and during periods of heightened pressure. It gives consideration and identifies responsibilities within each level of escalation.

Trust OOH Providers must work closely with their local Trusts & NIAS in order to update and embed within their own emergency plans.

No individual indicator should be considered in isolation. The focus should be on a collective suite of information that acts as an early pressure to allow timely escalation in response to trigger points that are well understood by all staff.

This plan does not cover patient or staff redirection from base to base. However any patient redirection from base to ED should be discussed with NIAS (Hospital Ambulance Liaison Officer or Duty Control Officer) and the local Trust ED/Director.

Green - Normal Working	Actions
1. Call volume within forecast	None
2. No anticipated base closures	None
3. Sufficient clinical staff cover	None
4. 90% of urgent calls triaged within 20 minutes and 90% of routine calls triaged within 1 hour	None
Yellow – Escalation Principles of normal working apply with additional yellow escalation measures actioned	**Actions**
1. Call volume 20% above forecast	None
2. Staff redeployed to meet demand (up to 1 base closed for base visits or partial reduction in hours in up to 2 bases)	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed;
3. Standby staff called in	None
4. 90% of urgent calls triaged within 30 minutes and 90% of routine calls triaged within 3 hours	None
5. Additional cover available from	None

another Out of Hours provider	
Advise other OOH providers, NIAS, local Trust ED (need check local details) of any change status All base closures or reduction in base opening hours to be notified to HSCB by 10am the next day	
Amber – Escalation Principles of normal working with yellow escalation measures in place with additional amber actions	**Actions**
1. Call volume 20-50% above forecast	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed
2. No more standby or other staff available to come in	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed
3. No additional support available from another Out of Hours provider	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed
4. More than 1 base closed or partially closed	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed;
5. 90% of urgent calls triaged within 40 minutes and 90% of routine calls triaged within 6 hours	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed
Advise other OOH providers, NIAS, local Trust ED (need check local details) of any change status All base closures or reduction in base opening hours to be notified to HSCB by 10am the next day	
Red – Escalation Principles of normal working, yellow & amber measures in place and red escalation actions applied	**Actions**
1. Call volume > 50% above forecast	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed
2. Able to mainly only deal with urgent calls	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed;
3. Triage of routine calls is greater than 6 hours	Supervisor or lead clinical person on duty to ensure Out of Hours Manager or Clinical Lead oncall is informed;

Advise other OOH providers, NIAS, local Trust ED (need check local details) of any change status Inform Trust Director & CEO (need check local details) Inform HSCB/PHA Senior Manager on call HSCB to liaise with Department of Health All base closures or reduction in base opening hours to be notified to HSCB by 10am the next day

GP OOH Escalation Status Report

GP OOH providers should notify Integrated Care, HSCB of any significant change in status by 10am the next day after the OOH period. This is in addition to any notifications to HSCB/PHA that may have taken place during the out of hour's period.

Name of OOH Service	
Name & Status person notifying	
Contact details	
Date & time of notification	
Escalation status	
Brief summary of problem or problems	
Actions taken during out of hours period	
Follow up to be taken after out of hours period	
Any other information	

Notifications should be sent to Dr. Margaret O'Brien with a copy to Dr Richard Orr, Dr Ciara McLaughlin & Mr Gerry Desmond Margaret.O'Brien@hscni.net Richard.orr@hscni.net Ciara.mclaughlin@hscni.net Gerry.Desmond@hscni.net

Appendix – Adverse & Interface Incidents

Adverse Incidents (AIs)

Practices are encouraged to inform the HSCB about adverse incidents which have led to patient harm or could lead to wider learning.
The practice fills in an Adverse Incident form and sends it to the governance lead in the area team.
http://primarycare.hscni.net/download/DocLibrary/GMS/Governance/Risk%20management/Adverse%20incidents/AI_Report_Form_GMS__May_2014.doc

For most clinical AIs the governance lead will ask for Medical Adviser input.

Serious Adverse Incidents (SAIs). You and the governance lead will need to consider if the AI should be treated as an SAI, which is a Board wide system for SAIs from Trusts as well as primary care.
Note that if you decide it is an SAI there are quite tight time lines for reports and oversight by a HSCB group. There is also an expectation that the patient or family will be informed about the SAI **by the practice** as early as possible.

The criteria for an SAI (in summary) include:

1. Serious injury or unexpected/unexplained death

2. Unexpected serious risk to a service user and/or staff member and/or member of the public arising

3. Unexpected or significant threat to provide service and/or maintain business continuity

4. Serious assault occurring within a healthcare facility (*including homicide and sexual assaults*)

5. Serious incidents of public interest or concern involving theft, fraud, information breaches or data losses.

6. Where a service user is known to Mental Health services (including Child and Adolescent Mental Health Services (CAMHS) or Learning Disability (LD) within the last two years)
   a. suspected suicides and serious self harm
   b. serious assault within the community

Interface Incidents

Where an AI or SAI has arisen because of interface problems between GP and Trust you will need to inform the Trust and help co-ordinate the investigations. The trusts have a single point of contact for AIs/SAIs which can be Chief Executives office, Medical Director, Primary Care Associate Director etc. The Area Team governance lead will know who to contact in each Trust.

Please email completed Word document (*not scanned*) to:

[Irrelevant information redacted by the USI] insert

Adverse Incidents

Guidance on communication following a Serious Adverse Incident (SAI) - January 2015

Adverse Incident Reporting - ....part of Risk Management with Clinical Governance. Learn from incidents, share knowledge across practices and prevent reoccurrence

Revision to Adverse Incident Form - (HSCB letter 16 December 2014)

AIF1 (GMS) Dec 2014 - Completed AIF1 (GMS) forms should be emailed to the local HSCB Office.

East (Belfast) - [Irrelevant information redacted by the USI]

North - [Irrelevant information redacted by the USI]

West - [Irrelevant information redacted by the USI]

South – [redacted]

South East – [redacted]

Appendix 1 - Serious Adverse Incident criteria

Appendix 2 - Overview of Adverse Incident Reporting in GMS

Appendix 3 - GMS Governance Personnel

Appendix 4 - key Questions in Reporting AI

Health and Social Care Board

AIF1(GMS) REPORTING OF ADVERSE INCIDENTS by GENERAL MEDICAL SERVICES

Reported by:

1. Name: 3. Contact Telephone No:

2. GP / Manager / Nurse / Other (please delete) 4. Practice ID No:

5. Date of Incident: 6. Date Aware: 7. Date of Report:

8. Patient Involved? Yes / No (please delete) 9. Age: 10. Sex:

11. Medication Incident? Yes / No (please delete) (includes prescribing/ dispensing/ drug related/ other)

12. If Yes please give name of medication:

13. Other HSC Organisation Involved? Yes / No (please delete)(e.g. trust/ pharmacist/ dentist/ OOH/ etc)

14. If Yes give sufficient details to allow followup e.g. location / consultant / hospital number etc

15. Brief summary of incident (Should not contain personal detail of patient)

16. Possible Cause / Contributory Factors

17. Action taken at practice with regard to this event:

18. Action taken at practice to prevent recurrence:

19. Has there been family /user /carer involvement regarding the incident ? Yes / No / N/A (please delete)

20. If Yes – Please give details:

21. Other organisations notified by Practice? Yes / No (please delete)

(e.g. Police / Coroner / Professional Regulatory Body / CSM/ NIAC/ HSE/ Trust / Other.)

22. If Yes – Please give details:

23. Other comments:

HSCB Use Only: FPS Reference No [DN – prefix with N/S/E/W]

Logged by Date

Schedule 7:

Pharmaceutical Requirements

Schedule 7 - Service and Budget Agreement Pharmaceutical Requirements 2019/20

1. **Northern Ireland Formulary**

   All Trusts to ensure the formulary is embedded within prescribing practice through active dissemination.

   Evidence of the level of implementation of the NI formulary within secondary care.

   Annual proportion of total items dispensed for inpatients that constitute NI Formulary chapter choices in 2019/20 by Trust.

2. **Managed Entry of New Drugs**

   All Trusts should put in place arrangements to manage regional monthly managed entry recommendations including monitoring, reporting and disinvestment arrangements.

   Evidence of Level of compliance

   Trusts to provide HSCB with quarterly assurance that approved new drugs are consistently available in a timely fashion and prescribed in line with NI Managed Entry Process.

3. **Regional MORE Programme**

   All Trusts to ensure 100% compliance with local delivery against the Regional MORE Programme in both the inpatient and outpatient settings such that all targets are met.

   Evidence of Level of Compliance

   Trusts to report compliance through to MORE Programme Board.

4. **Medicines Reconciliation**

All Trusts should comply with NICE guidance https://www.nice.org.uk/guidance/ng5 by ensuring that in an acute setting, they accurately list all of the person's medicines (including prescribed, over-the-counter and complementary medicines) and carry out medicines reconciliation within 24 hours or sooner if clinically necessary, when the person moves from one care setting to another.

Evidence of Level of Compliance

Trusts to provide quarterly reports which set out the level of compliance with which patients are having their medicines reconciled on admission and at discharge in line with NICE guidance.

5. **28 Day Discharge**

All Trusts should have their own policy for supply of 28 days' of medicines to patients on discharge from hospital, and a regional composite document should be developed to provide an over view of the key common principles. Trusts should be adhering to their policy.

Evidence of Level of Compliance

Trusts to provide copies of the above documents to HSCB. Trusts to provide annual report on volume of activity.

6. **Medicines Optimisation Services (Older People and Mental Health)**

All Trusts should have in place medicines optimisation teams and establish a Trust specific work plan consistent with the regional steering groups.

Evidence of Level of Compliance

Trusts to provide baseline reports for the two respective service areas, Older People and Mental Health.

HSC BOARD PERFORMANCE REPORT – 2014/15 (Month 7 – October 2014)

Purpose

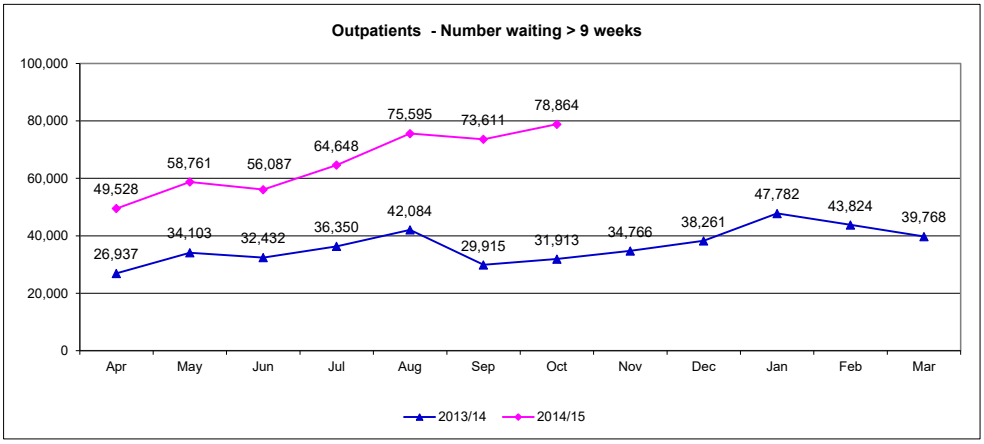
This paper provides Board members with an assessment of performance against the 2014/15 standards and targets set out in the Minister's Commissioning Plan Direction (Northern Ireland) 2014. The position regionally and by Trust at the end of October 2014 for the targets and standards that the Board is responsible for monitoring and where monitoring information is currently available is set out in Annex A.

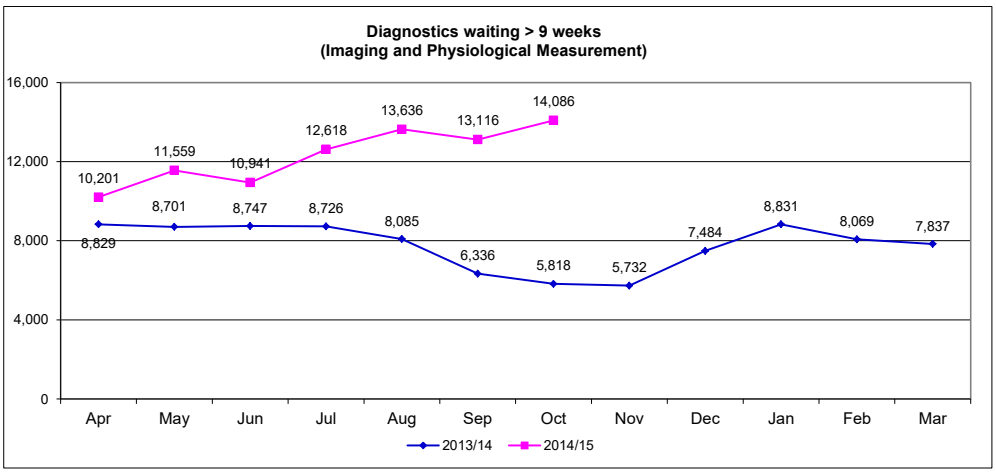
Performance

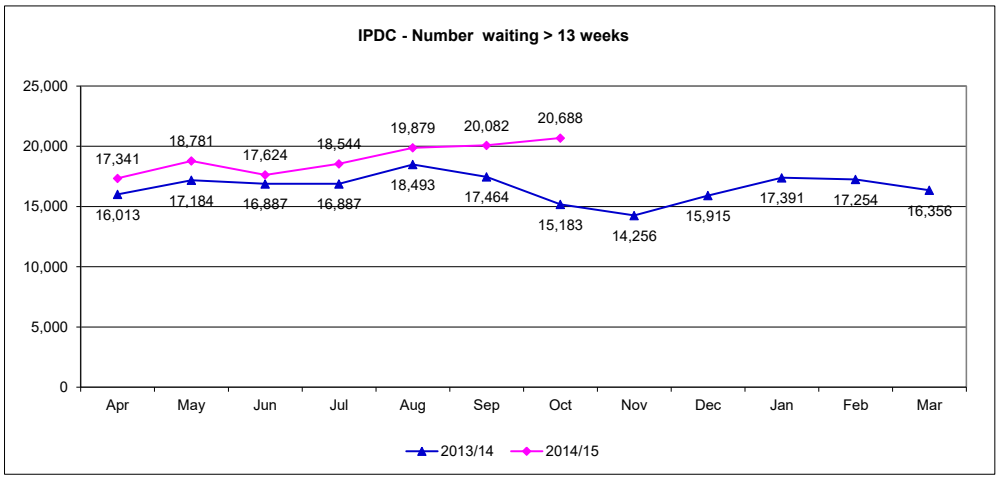
The key performance challenges, including the reasons for the current performance and the actions being taken to address these, largely remain as reported at previous Board meetings. An update on performance in a number of these areas is provided below – full details are provided in Annex A.

1. Elective Care (including Diagnostics)

The number of patients waiting longer than the maximum waiting times for elective access has increased from the position at the end of September – at the end of October 2014, 78,864 outpatients were waiting longer than nine weeks; 14,086 patients were waiting longer than nine weeks for a diagnostic test; and, 20,688 patients were waiting longer than 13 weeks for treatment.







As previously reported, approximately half of the increase in 9-week outpatient waits since end of March 2014 can be attributed to the underdelivery of core capacity in all Trusts across a range of specialties. In relation to patients waiting longer than 13 weeks for inpatient and daycase treatment, all of the increase since the end of March 2014 is as a result of the underdelivery of core activity.

The Board has now written to Trusts to confirm the withdrawal of funding totalling £2.1m in specialities where there has been a continued underdelivery of core capacity during quarters one and two of 2014/15. In addition, any other specialties where there has been a significant underdelivery of core activity during the first six months of this year have been highlighted to Trusts for consideration of withdrawal of funding at end of quarter three if agreed levels of core activity continue to not be fully delivered.

Given the scale of the underdelivery of core capacity in the first half of the year and the associated increase in waiting times, the Board required Trusts to produce elective improvement plans for a number of specialties detailing the forecast improvement in delivery of core and waiting times over the rest of this year to March 2015. Performance

against the plans is being monitored to ensure that progress is on track to deliver the agreed outcomes and, in any areas where this is not the case, these are raised at the regular elective performance meetings with the relevant Trust to discuss what remedial actions the Trust plans to take.

In addition, in view of the extent of the underdelivery of core activity and concerns about the Trusts chronological management of routine patients, the Board has advised Trusts of its intention to undertake an audit of waiting list management processes. The arrangements for this are currently being finalised.

In relation to diagnostics, at end of October 2014, 14,086 patients were waiting longer than nine weeks.

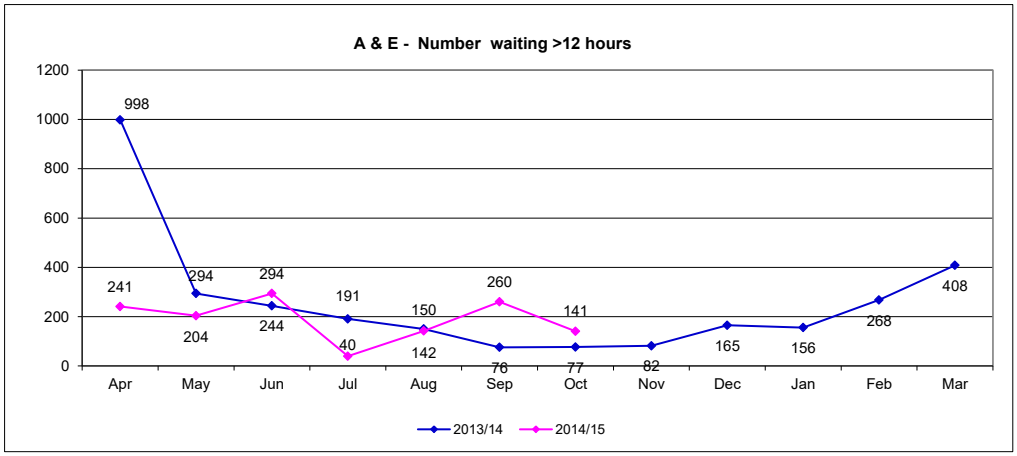
Test	No >9 weeks at 31.10.14
Imaging	
MRI	3,176
Non-obstetric Ultrasound	3,107
CT Scan	1,228
Other	430
Physiological Measurement	
Cardiology	4,278
Audiology	1,145
Urodynamics	373
Neurophysiology	233
Other	116
TOTAL	**14,086**

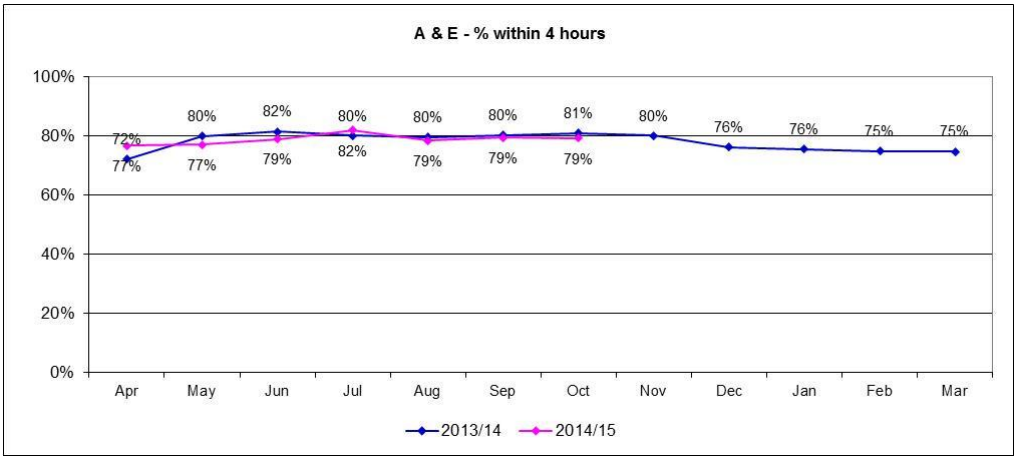
Following the outcome of the October monitoring round, the Board has written to Trusts to confirm further non-recurrent funding to undertake additional radiology activity in Q3/Q4 to deliver improved waiting times by March 2015. The Board will monitor Trusts' progress at the regular elective performance meetings to ensure the agreed outcomes are delivered, both in terms of activity and waiting times.

The inability to fund further additionality in the second half of 2014/15, other than in diagnostics, will inevitably lead to a further increase in elective waiting times by March 2015. Given this position and the need to minimise the impact on waiting times, the Board has stressed the need for the Trusts to ensure the full delivery of the agreed volumes of core elective activity in all specialties along with strict chronological management of waiting lists.

2. A&E (4-hour and 12-hour standards)

There has been a reduction in the number of patients who waited longer than 12 hours during October 2014 (141) compared with September 2014 (260). The overall trend, for the year to date, continues to be an improving one – from April to October 2014, 1,322 patients have waited longer than 12 hours compared to 2,030 during the same period last year, a 35% reduction.





The majority of the breaches of the 12-hour standard during October 2014 were in the Belfast Trust (111 out of a total of 141). As previously reported, given the deterioration in the 12-hour position and lack of progress in 4-hour performance, the Board has escalated this performance issue with Belfast Trust at Chief Executive level and has sought assurance on the steps the Trust is taking to secure the improved performance.

Four-hour performance regionally remains unchanged compared to the previous month and with the same period last year – 79%.

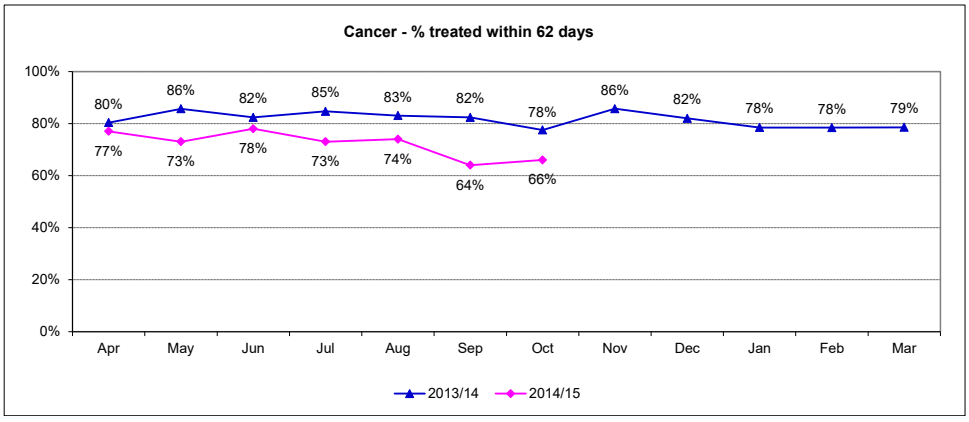
Non-recurrent funding has been made available to Trusts to support the implementation of their ED Improvement Plans and to put in place measures to respond to the increased pressures associated with the winter period. Trusts were required to submit details of the proposed utilisation of this funding that will have the greatest impact in responding to increased pressures during the forthcoming winter months. In doing so, Trusts have outlined how they propose to improve flow and expand capacity in hospital and community settings. Trusts' plans have been submitted to the Department for approval.

3. Cancer Services

There has been a continued improvement in performance against the 14-day breast cancer standard during October 2014 – 100% of urgent referrals were seen within 14 days.

Performance against the 31-day standard (98% of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat) remains strong at 96% regionally.

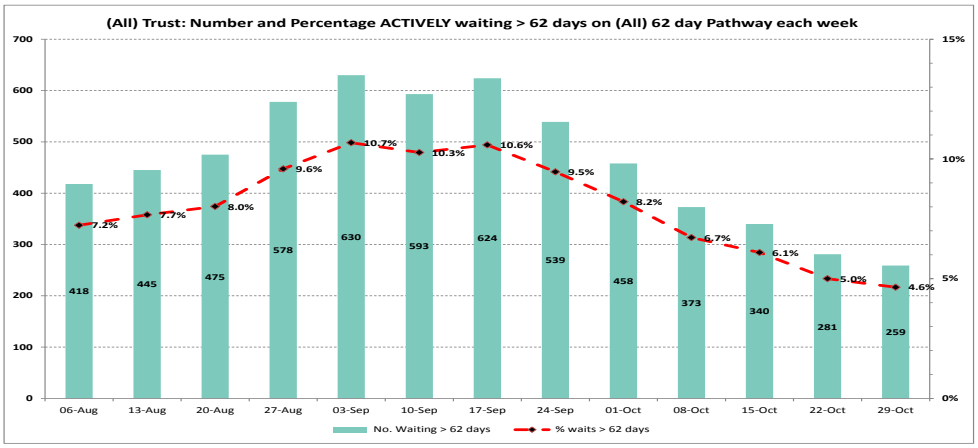
Performance against the 62-day standard has remained broadly unchanged – during October 2014, 66% of patients urgently referred with a suspected cancer began their first definitive treatment within 62 days. It should be noted that performance in the Western Trust remains strong – in the year to end of October 2014, 91% of patients began their first definitive treatment within 62 days.



Given the limited progress towards achievement of the 62-day standard in 2013/14, the Board has introduced enhanced monitoring arrangements from April 2014 and regional monthly cancer performance meetings have been established.

Similar to the approach taken with the 14-day breast cancer, the Board is undertaking dedicated performance and service improvement work with Trusts. This approach includes a strong focus on treating the longest waiting patients and, as the target is based on completed waits in month, the recent deterioration in 62-day performance is not unexpected as it reflects that a higher proportion of patients treated in month were the longest waiters.

As a result of this focus on the longest waiting patients, the proportion of patients actively waiting longer than 62 days has reduced from over 10% in August to 4.6% at the end of October. It is expected that this improved position will be reflected in performance in relation to completed waits in the coming months.

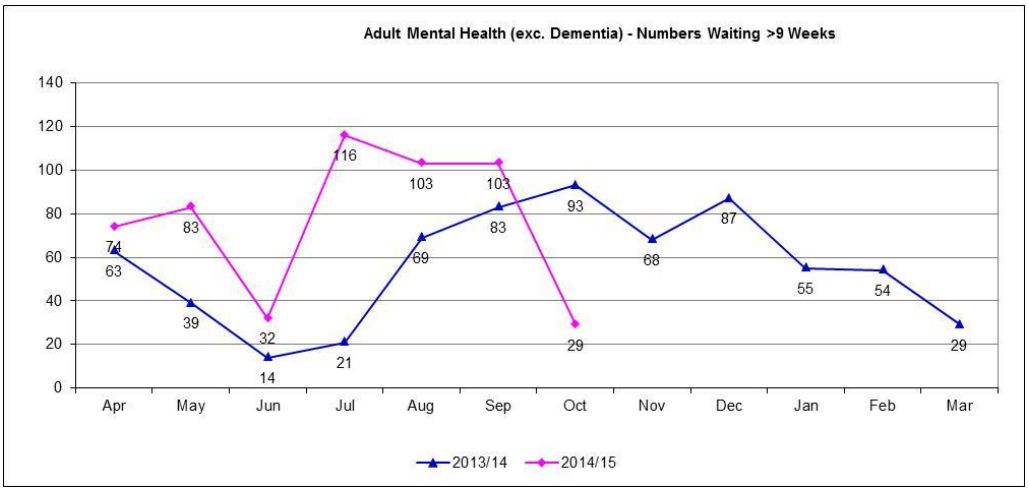


A significant proportion of the longest waits continue to be on the urological cancer pathway and, until recently, the majority of these were in the Northern and South Eastern Trusts. As previously advised, the Northern Trust was required to take urgent action to reduce the length of time patients were waiting on the urological pathway. These actions included securing additional capacity from the Western Trust, particularly for diagnostic tests. As a result, the number of patients waiting longer than 62 days on the urology pathway in the Northern Trust has reduced from 140 in August to 18 at the end of November.

In relation to South Eastern Trust, the Board remains concerned at the limited progress that has been made - at the end of November, over half (69 out of a total of 125) of the patients waiting beyond 62 days on the urological pathway were in the South Eastern Trust. Given this position, the Board has put in place a weekly performance process to ensure a continued focus on targeting the longest waits.

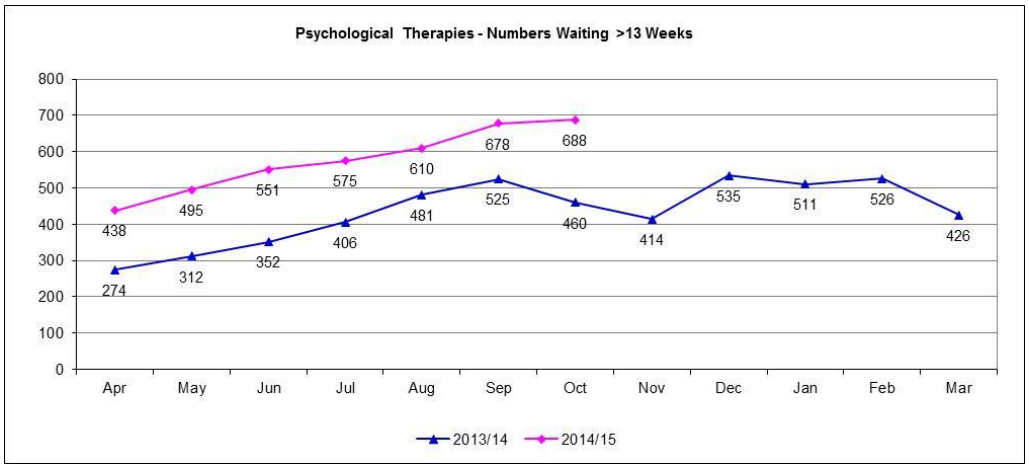
4. Adult Mental Health Services (9 weeks)

There has been a significant reduction in the number of patients waiting longer than nine weeks to access adult mental health services – 29 at end of October 2014.



5. Psychological Therapies (13 weeks)

The number of patients waiting longer than 13 weeks to access psychological therapies has continued to increase during 2014/15 – 688 patients were waiting longer than 13 weeks at the end of October.



The majority (74%) of patients waiting longer than 13 weeks to access psychological therapies at the end of October 2014 were in Belfast (142) and South Eastern (365) Trusts. The Board has confirmed funding for South Eastern Trust to recruit additional staff and is currently reviewing how the Trust is proposing to utilise this in-year to improve the waiting time position.

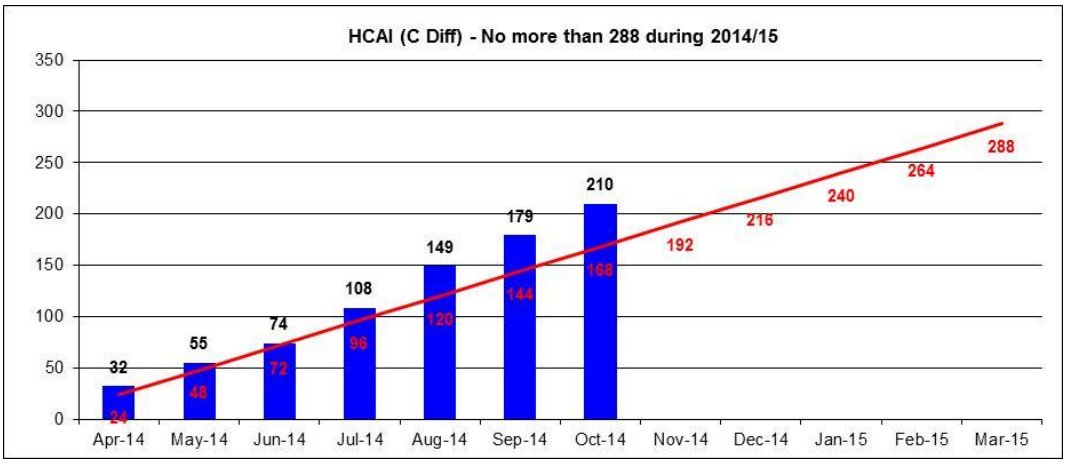
6. Resettlement (Mental Health and Learning Disability)

In order to ensure achievement of the Ministerial target that all long stay patients in learning disability and psychiatric hospitals are resettled to appropriate places in the community by 31 March 2015, Trusts are required to resettle 49 learning disability patients and 42 mental health patients in 2014/15. Regionally, at the end of October 2014, five learning disability and 15 mental health patients have been resettled.

As previously reported, Trusts have identified a number of patients who currently will require to remain in hospital after 31 March 2015, some of whom are detained under the Mental Health Order. They are also advising the Board that a number of patients will not be resettled as planned resettlement accommodations will not be ready for occupation until after 31 March 2015.

7. Healthcare Acquired Infection

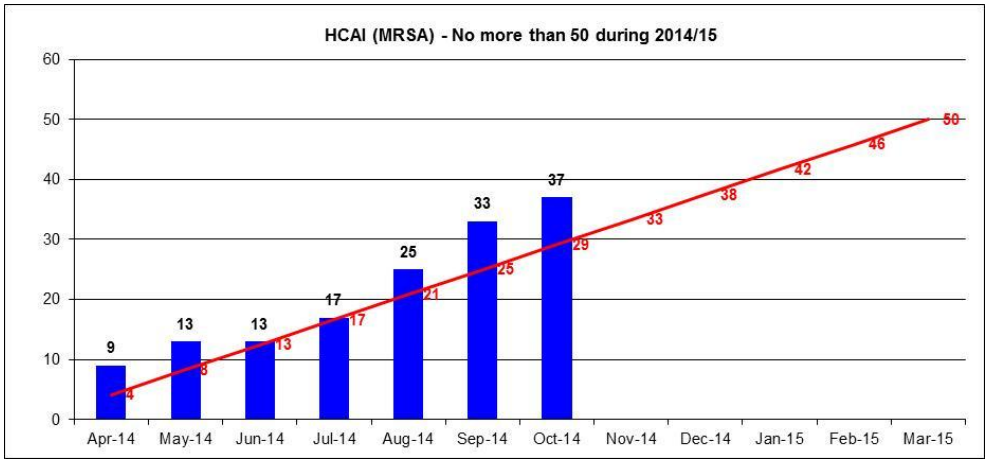
Clostridium Difficile Infections (CDI) (target: no more than 288 during 2014/15) – regionally during the period April to October 2014, there have been 210 cases of *C. Difficile* against a target profile to have had no more than 168 cases.



At end of October 2014, all Trusts have exceeded their respective seven month target profiles.

Trust	C.Diff - No more than 288 during 2014/15			
	2014/15 Maximum	2014/15 Profile (April - October 2014)	2014/15 Actual (April - October 2014)	Variance (actual vs 14/15 target profile)
Belfast	105	61	79	18
Northern	56	33	34	1
South Eastern	50	29	33	4
Southern	32	19	24	5
Western	45	26	40	14
Region	**288**	**168**	**210**	**42**

MRSA Bloodstream Infections (MRSA) (target: no more than 50 during 2014/15) – regionally in the year to end of October 2014, there have been 37 episodes of MRSA against a target profile to have had no more than 28 cases.



At end of October 2014, all Trusts other than South Eastern have exceeded their respective seven month target profile – Southern Trust has exceeded its annual target maximum.

Trust	MRSA - No more than 50 during 2014/15			
	2014/15 Maximum	2014/15 Profile (April - October 2014)	2014/15 Actual (April - October 2014)	Variance (actual vs 14/15 target profile)
Belfast	16	9	12	3
Northern	11	6	9	3
South Eastern	11	6	5	-1
Southern	3	2	4	2
Western	9	5	7	2
Region	**50**	**28**	**37**	**9**

The Public Health Agency is continuing to work with all Trusts to minimise the number of cases of C. Difficile and MRSA. The specific actions remain as reported in last month's Board paper.

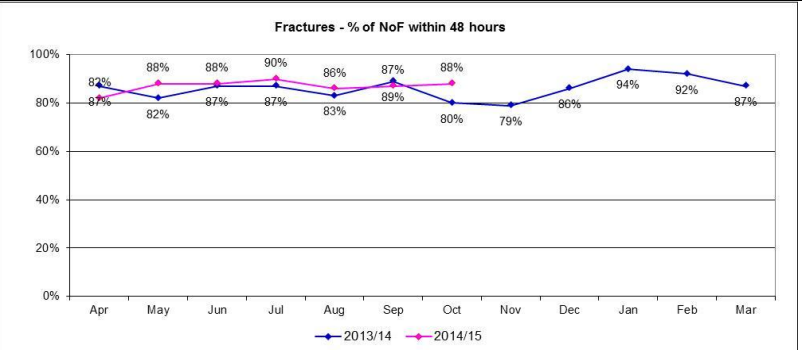
Conclusion

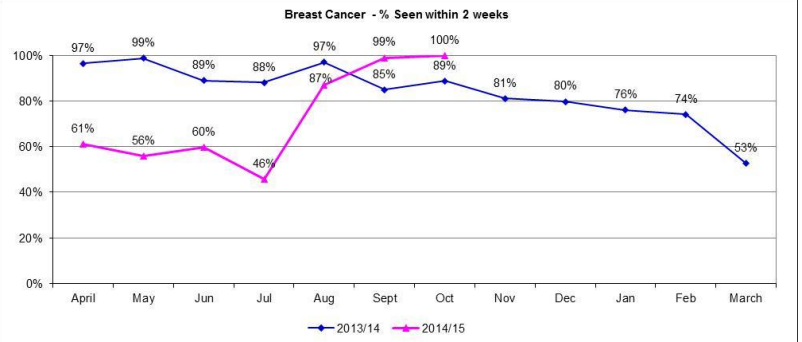
More detail on the actions being taken in relation to these and other performance areas will be provided by the relevant Directors at the Board meeting.

Michael Bloomfield
Director of Performance and Corporate Services
December 2014

Annex A

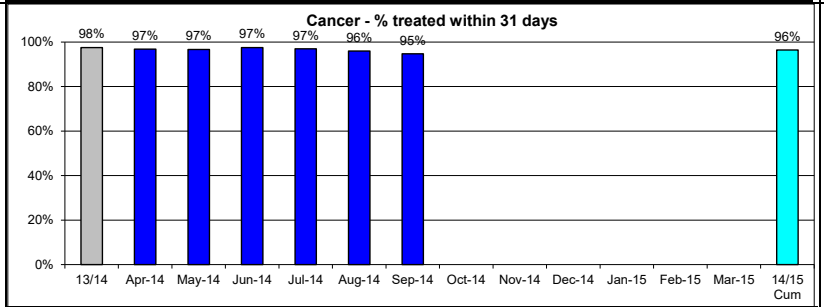
SUMMARY OF PERFORMANCE AGAINST 2014/15 COMMISSIONING PLAN DIRECTION STANDARDS AND TARGETS

<table>
<tr><th>STANDARD (from April 2014)
TARGET (by March 2015 unless stated otherwise)</th><th>Trend Analysis</th><th>Comments</th></tr>
<tr><td colspan="3">To improve the quality of services and outcomes for patients, clients and carers, through the provision of timely, safe, resilient and sustainable services in the most appropriate setting.</td></tr>
<tr><td>Hip Fractures (Standard) – from April 2014, 95% of patients, where clinically appropriate, wait no longer than 48 hours for inpatient treatment for hip fractures.</td><td> 

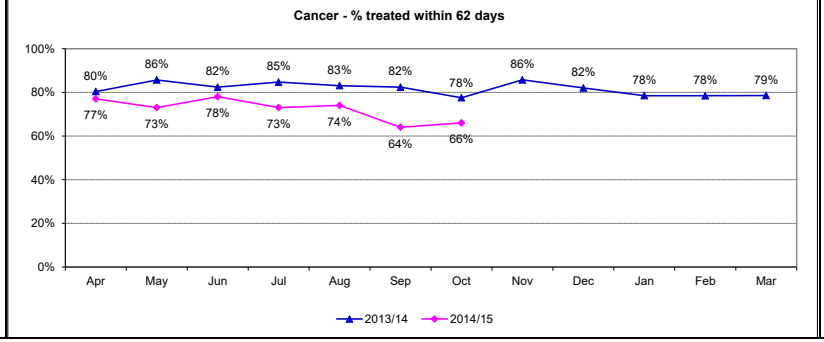
<table>
<tr><th rowspan="2">Trust</th><th colspan="4">Fracture NoF- % within 48 hours</th></tr>
<tr><th>Aug-14</th><th>Sep-14</th><th>Oct-14</th><th>14/15 Cum.</th></tr>
<tr><td>Belfast</td><td>94%</td><td>94%</td><td>82%</td><td>91%</td></tr>
<tr><td>Northern</td><td></td><td></td><td></td><td></td></tr>
<tr><td>South Eastern</td><td>56%</td><td>75%</td><td>96%</td><td>73%</td></tr>
<tr><td>Southern</td><td>78%</td><td>76%</td><td>92%</td><td>88%</td></tr>
<tr><td>Western</td><td>94%</td><td>86%</td><td>91%</td><td>88%</td></tr>
<tr><td>Region</td><td>86%</td><td>87%</td><td>88%</td><td>87%</td></tr>
</table></td><td>Regionally during October 2014, 88% of patients, where clinically appropriate, received inpatient treatment for hip fractures within 48 hours.</td></tr>
<tr><td>Cancer care services 1 (Standard) – from April 2014, all urgent breast cancer referrals should be seen within 14 days.</td><td> 
</td><td>There has been a continued improvement in performance against the 14-day breast cancer standard during October 2014 – 100% of urgent referrals were seen within 14 days.</td></tr>
</table>

Cancer care services 2 (Standard) – from April 2014, at least 98% of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat.		Performance against the 31-day standard (98% of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat) remains strong at 96% regionally.
Cancer care services 3 (Standard) – from April 2014, at least 95% of patients urgently referred with a suspected cancer should begin their first definitive treatment within 62 days.		Performance against the 62-day standard has remained broadly unchanged – during October 2014, 66% of patients urgently referred with a suspected cancer began their first definitive treatment within 62 days. It should be noted that performance in the Western Trust remains strong – in the year to end of October 2014, 91% of patients began their first definitive treatment within 62 days. Full details of the issues and actions to address are provided above (pages 5 and 6).

Trust	Cancer Services (Breast) - % within 14 days			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	100%	99%	100%	**95%**
Northern	100%	100%	100%	**52%**
South Eastern	87%	100%	100%	**47%**
Southern	60%	98%	100%	**70%**
Western	100%	100%	100%	**100%**
Region	**87%**	**99%**	**100%**	**73%**



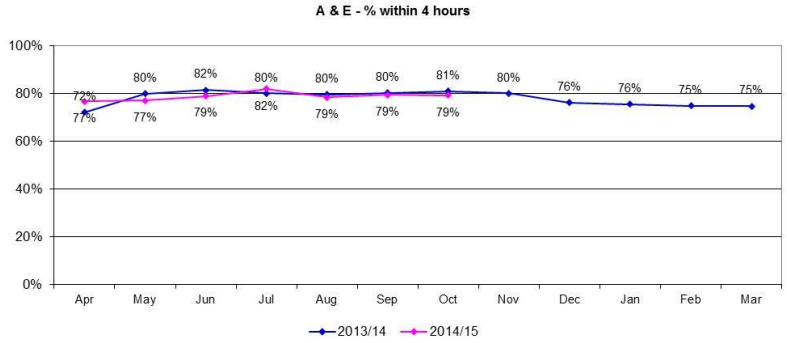
Trust	Cancer Services - % <31 days			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	93%	90%		**94%**
Northern	99%	97%		**98%**
South Eastern	96%	96%		**97%**
Southern	99%	100%		**99%**
Western	100%	100%		**100%**
Region	**96%**	**95%**		**96%**



	Trust / **Cancer Services - % <62 days**	

Trust	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	64%	45%		
Northern	55%	64%		
South Eastern	81%	57%		
Southern	86%	83%		
Western	90%	86%		
Region	**74%**	**64%**		

Unscheduled care 1 (Standard) – from April 2014, 95% of patients attending any Type1, 2 or 3 Emergency Department are either treated and discharged home, or admitted, within four hours of their arrival in the Department



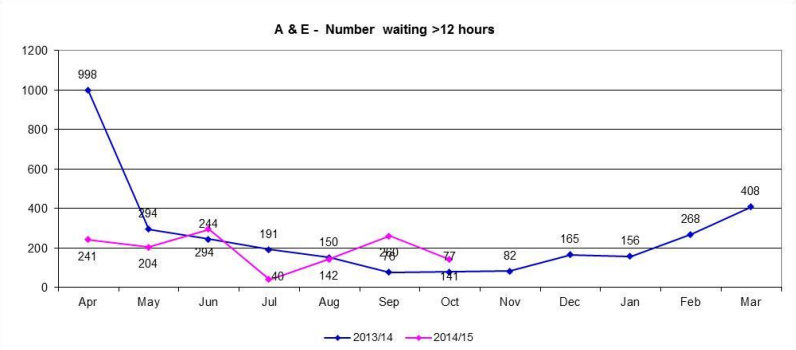
Trust	A&E - % treated within 4 hours			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	71%	71%	74%	**73%**
Northern	71%	76%	74%	**73%**
South Eastern	82%	81%	81%	**82%**
Southern	87%	86%	87%	**84%**
Western	85%	86%	83%	**85%**
Region	**79%**	**79%**	**79%**	**79%**

There has been a reduction in the number of patients who waited longer than 12 hours during October 2014 (141) compared with September 2014 (260). The overall trend, for the year to date, continues to be an improving one – from April to October 2014, 1,322 patients have waited longer than 12 hours compared to 2,030 during the same period last year, a 35% reduction.

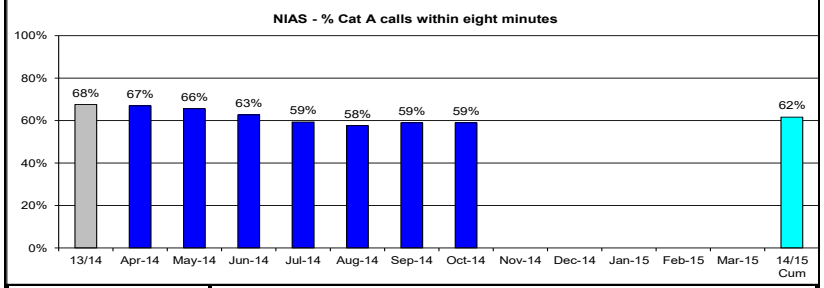
The majority of the breaches of the 12-hour standard during October 2014 were in the Belfast Trust (111 out of a total of 141).

Four-hour performance regionally remains unchanged compared to the previous month and with the same period last year – 79%.

Further details on the actions to address are provided above (page 4).

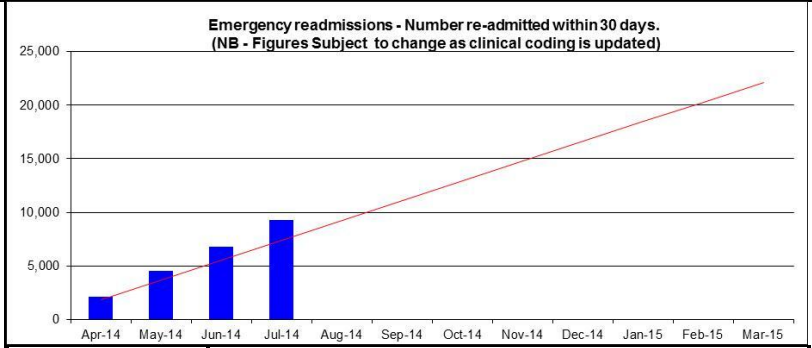
STANDARD (from April 2014) **TARGET** (by March 2015 unless stated otherwise)	**Trend Analysis**	**Comments**
Unscheduled care 2 (Standard) – from April 2014, no patient attending any Emergency Department should wait longer than 12 hours.		

Trust	A&E - No. treated within 12 hours			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	139	211	111	**887**
Northern	2	21	7	**333**
South Eastern	1	28	22	**99**
Southern	0	0	1	**3**
Western	0	0	0	**0**
Region	**142**	**260**	**141**	**1322**

Unscheduled care 3 (Target) – by March 2015, 72.5% of Category A (life threatening) calls responded to within eight minutes, 67.5% in each LCG area.		Regionally in the year to end of October 2014, 62% of Category A (life threatening) calls were responded to within eight minutes (target: 72.5% by March 2015). The decline in performance in recent months has largely been as a result of difficulties the Trust has experienced in securing adequate levels of staffing to cover evening and weekend rotas due to a number of vacant posts; higher than normal levels of sickness absence; and, a low uptake of available overtime. In addition, the Trust has experienced an unexpected increase in demand for Category A calls associated with the introduction of the Card 35 scheme. In relation to the issues associated with the introduction of Card 35, the Trust has a plan in place and the resolution of this issue is expected to result in improved performance in the coming months.

Trust	NIAS % Cat A calls within 8 minutes			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	69%	71%	69%	**73%**
Northern	51%	53%	54%	**55%**
South Eastern	52%	53%	53%	**56%**
Southern	54%	53%	56%	**56%**
Western	60%	62%	61%	**63%**
Region	58%	59%	59%	**62%**

Hospital readmissions (Target) – by March 2015, secure a 5% reduction in the number of emergency readmissions within 30 days (using 2012/13 data as the baseline).



Trust	Emergency Readmissions (5% reduction within 30 days)			
	Profile Reduction (April - July 2014)	Actual (April - July 2014)	Variance (Actual vs profile)	% Variance (Actual vs profile)
Belfast	1,800	2,679	879	49%
Northern	1,315	1,522	207	16%
South Eastern	1,507	1,709	202	13%
Southern	1,334	1,479	145	11%
Western	1,422	1,854	432	30%
Region	**7,378**	**9,243**	**1,865**	**25%**

Trusts are permitted three months to complete clinical coding. Cumulatively in the year to end of July 2014, there have been 9,243 emergency readmissions within 30 days against a reduction profile of 7,378.

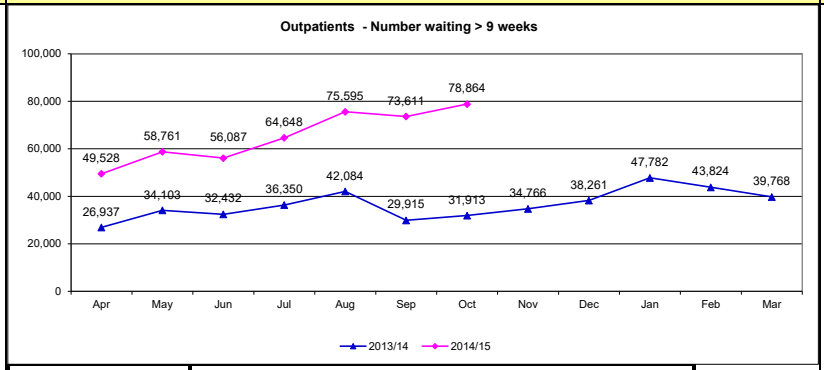
Elective care 1 (Outpatients) (Standard) – from April 2014, at least 80% of patients wait no longer than nine weeks for their first outpatient appointment and no patient waits longer than 15 weeks.

Trust	Outpatients - % waiting <9 weeks				
	30.06.14	31.07.14	31.08.14	30.09.14	31.10.14
Belfast	54%	49%	43%	45%	45%
Northern	58%	56%	51%	54%	53%
South Eastern	70%	66%	58%	58%	55%
Southern	69%	62%	55%	58%	57%
Western	71%	67%	60%	64%	63%
Region	**61%**	**57%**	**51%**	**52%**	**52%**

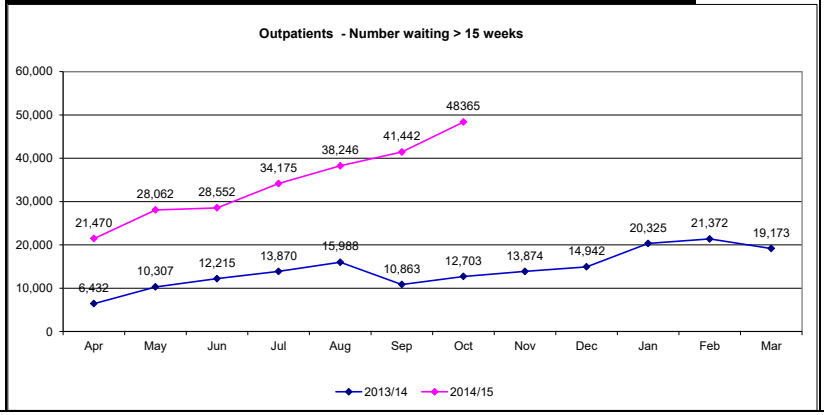
The number of patients waiting longer than the maximum waiting times for elective access has increased from the position at the end of September – at the end of October 2014, 78,864 outpatients were waiting longer than nine weeks; 14,086 patients were waiting longer than nine weeks for a diagnostic test; and, 20,688 patients were waiting longer than 13 weeks for treatment.

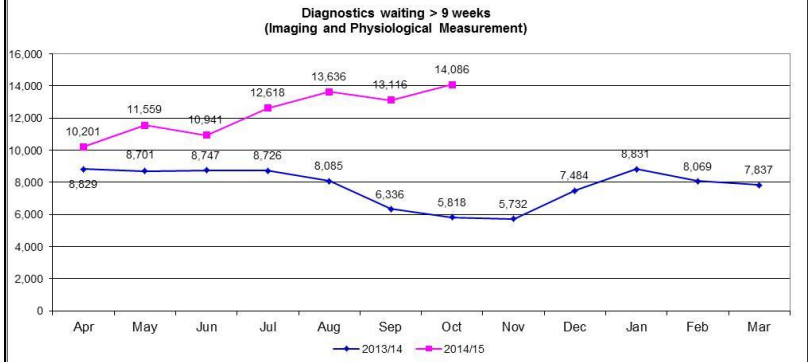
Full details of the actions are provided on pages 2 and 3 above.

STANDARD (from April 2014) **TARGET** (by March 2015 unless stated otherwise)	**Trend Analysis**	**Comments**

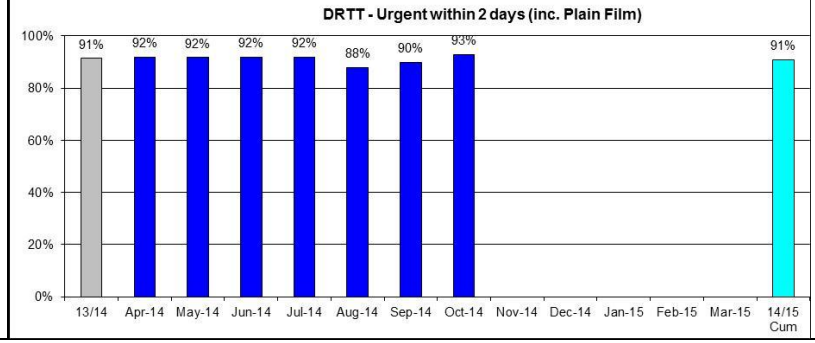


Trust	Outpatients - No. waiting >9 weeks		
	30.06.14	**30.09.14**	**31.10.14**
Belfast	28,091	35,942	37,257
Northern	9,025	9,558	11,058
South Eastern	7,000	11,260	12,882
Southern	6,856	10,407	11,039
Western	5,115	6,444	6,628
Region	**56,087**	**73,611**	**78,864**



<table>
<tr><th>**STANDARD** (from April 2014)
TARGET (by March 2015 unless stated otherwise)</th><th>Trend Analysis</th><th>Comments</th></tr>
<tr><td></td><td>
<table>
<tr><th rowspan="2">Trust</th><th colspan="3">Outpatients - No. waiting >15 weeks</th></tr>
<tr><th>30.06.14</th><th>30.09.14</th><th>31.10.14</th></tr>
<tr><td>Belfast</td><td>17,198</td><td>23,252</td><td>25,364</td></tr>
<tr><td>Northern</td><td>4,651</td><td>4,852</td><td>6,539</td></tr>
<tr><td>South Eastern</td><td>2,649</td><td>5,494</td><td>7,211</td></tr>
<tr><td>Southern</td><td>1,959</td><td>4,577</td><td>5,468</td></tr>
<tr><td>Western</td><td>2,095</td><td>3,267</td><td>3,783</td></tr>
<tr><td>**Region**</td><td>**28,552**</td><td>**41,442**</td><td>**48,365**</td></tr>
</table>
</td><td></td></tr>
<tr><td>**Elective care 2 (Diagnostics) (Standard)** – from April 2014, no patient waits longer than nine weeks for a diagnostic test.</td><td>


<table>
<tr><th rowspan="2">Trust</th><th colspan="5">Diagnostics - No. waiting >9 weeks</th></tr>
<tr><th>30.06.14</th><th>31.07.14</th><th>31.08.14</th><th>30.09.14</th><th>31.10.14</th></tr>
<tr><td>Belfast</td><td>6,325</td><td>6,219</td><td>5,648</td><td>5,173</td><td>5,310</td></tr>
<tr><td>Northern</td><td>2,527</td><td>3,662</td><td>4,352</td><td>4,806</td><td>5,182</td></tr>
<tr><td>South Eastern</td><td>667</td><td>760</td><td>887</td><td>817</td><td>858</td></tr>
<tr><td>Southern</td><td>1,183</td><td>1,533</td><td>2,225</td><td>1,824</td><td>2,184</td></tr>
<tr><td>Western</td><td>239</td><td>444</td><td>524</td><td>496</td><td>552</td></tr>
<tr><td>**Region**</td><td>**10,941**</td><td>**12,618**</td><td>**13,636**</td><td>**13,116**</td><td>**14,086**</td></tr>
</table>
</td><td>The number of patients waiting longer than nine weeks for a diagnostic test has increased - at the end of October 2014, 14,086 patients were waiting longer than nine weeks.

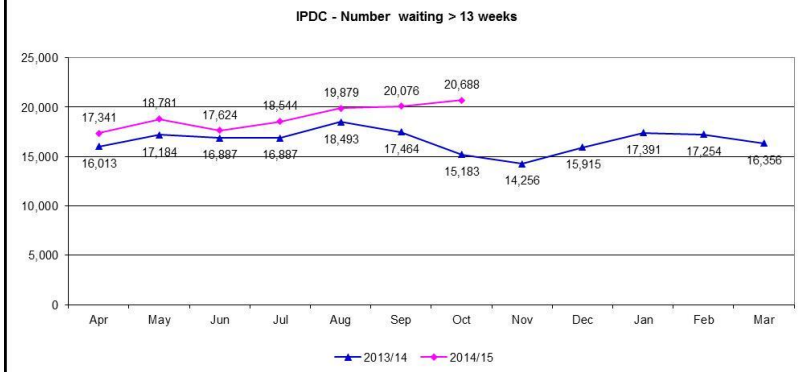
Details of the actions are provided on pages 2 and 3 above.</td></tr>
<tr><td>**Elective care 3 (Diagnostic Reporting) (Standard)** – from April 2014, all urgent diagnostic tests are reported on within two days of the test being undertaken.</td><td>


</td><td>Regionally at the end of October 2014, 93% of urgent diagnostic tests were reported on within two days of the test being undertaken.</td></tr>
</table>

Trust	DRTT (urgent) - % within 2 days (inc plain film)			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	88%	89%	92%	**88%**
Northern	98%	98%	98%	**98%**
South Eastern	97%	96%	97%	**96%**
Southern	74%	84%	89%	**86%**
Western	93%	91%	93%	**92%**
Region	**88%**	**90%**	**93%**	**91%**

Elective care 4 (Inpatient/Daycase) (Standard) – from April 2014, at least 80% of patients and daycases are treated within 13 weeks and no patient waits longer than 26 weeks.

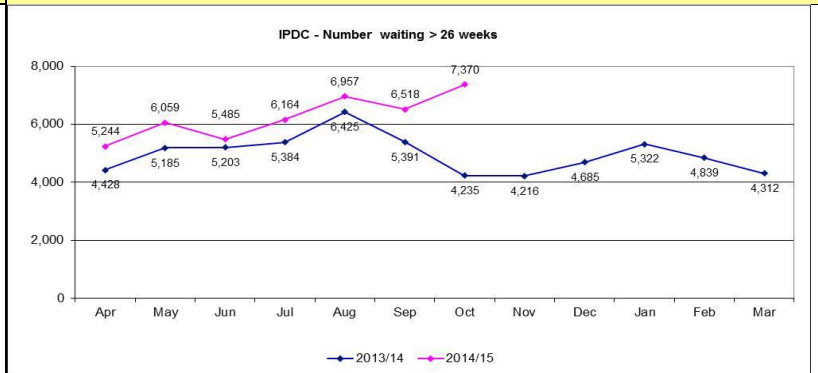
Trust	Inpatient & Daycases - % waiting <13 weeks				
	30.06.14	31.07.14	31.08.14	30.09.14	31.10.14
Belfast	53%	52%	49%	47%	47%
Northern	82%	82%	81%	83%	85%
South Eastern	80%	81%	78%	75%	74%
Southern	74%	72%	71%	72%	72%
Western	70%	70%	70%	70%	69%
Region	**65%**	**64%**	**62%**	**61%**	**61%**



Trust	Inpatient & Daycases - No. waiting >13 weeks				
	30.06.14	31.07.14	31.08.14	30.09.14	31.10.14
Belfast	11,189	11,823	12,743	13,012	13,307
Northern	1,066	1,139	1,164	1,029	865
South Eastern	1,015	1,096	1,296	1,402	1,575
Southern	2,010	2,110	2,219	2,263	2,329
Western	2,344	2,376	2,457	2,370	2,612
Region	**17,624**	**18,544**	**19,879**	**20,076**	**20,688**

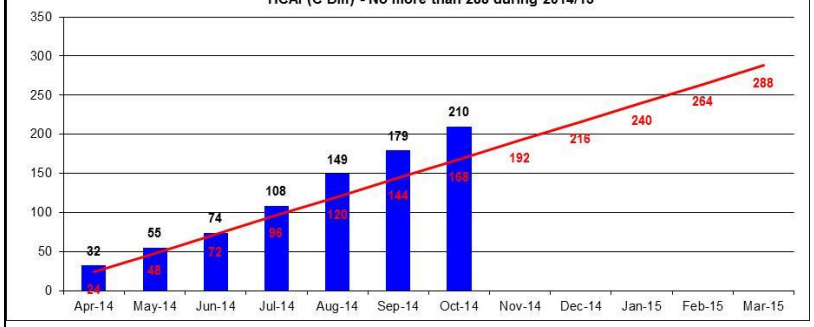
The number of patients waiting longer than the maximum waiting times for elective access has increased from the position at the end of September – at the end of October 2014, 78,864 outpatients were waiting longer than nine weeks; 14,086 patients were waiting longer than nine weeks for a diagnostic test; and, 20,688 patients were waiting longer than 13 weeks for treatment.

Full details of the actions are provided on pages 2 and 3 above.



Trust	Inpatient & Daycases - No. waiting >26 weeks				
	30.06.14	31.07.14	31.08.14	30.09.14	31.10.14
Belfast	3,913	4,317	4,854	4,764	5,300
Northern	201	221	270	193	119
South Eastern	227	276	287	337	390
Southern	463	585	743	654	776
Western	681	765	803	570	785
Region	**5,485**	**6,164**	**6,957**	**6,518**	**7,370**

Healthcare acquired infections (Target) – by March 2015, secure a further reduction of 9% in MRSA and Clostridium difficile infections compared to 2013/14.



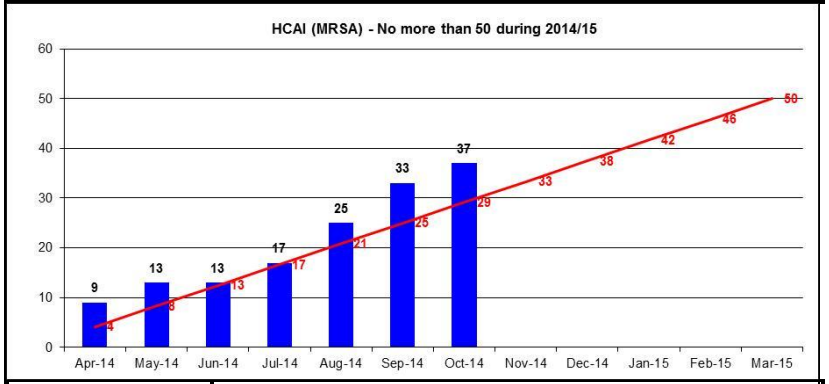
Regionally during the period April to October 2014, there have been 210 cases of *C. Difficile* against a target profile to have had no more than 168 cases. All Trusts have exceeded their respective seven month target trajectory.

Regionally in the year to end of October 2014, there have been 37 episodes of MRSA against a target profile to have had no more than 28 cases. All Trusts other than South Eastern have exceeded their respective seven month MRSA target profile – Southern Trust has exceeded its annual target maximum.

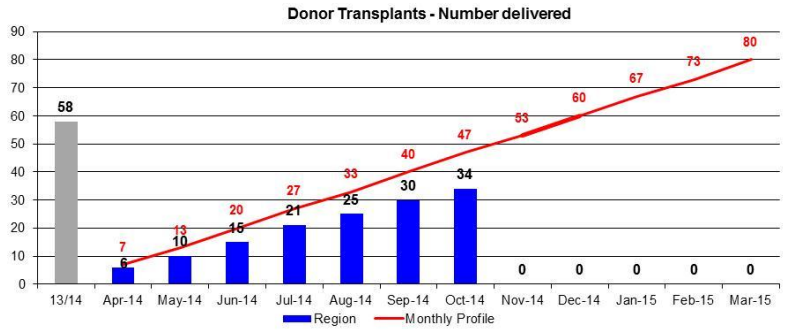
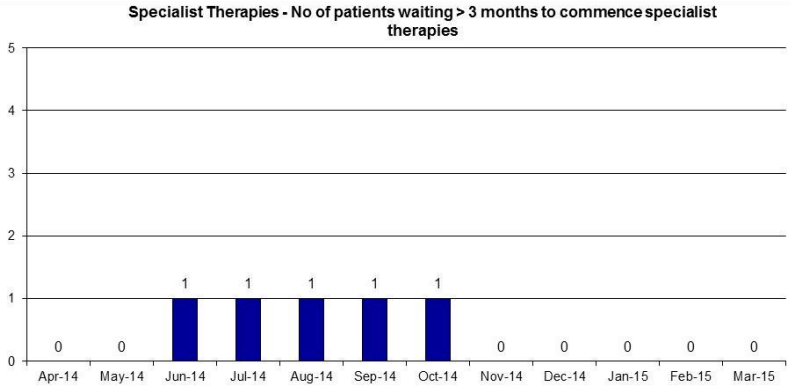
The Public Health Agency is continuing to work with all Trusts to minimise the number of cases of C. Difficile and MRSA. The specific actions remain as reported in last month's Board paper.

STANDARD (from April 2014) **TARGET** (by March 2015 unless stated otherwise)	**Trend Analysis**	**Comments**

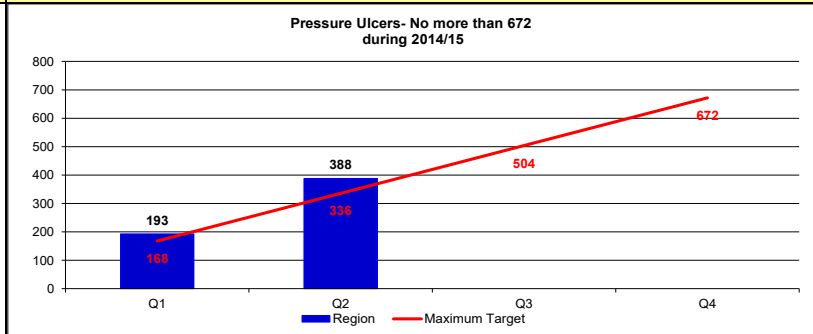
Trust	C.Diff - No more than 288 during 2014/15			
	2014/15 Maximum	2014/15 Profile (April - October 2014)	2014/15 Actual (April - October 2014)	Variance (actual vs 14/15 target profile)
Belfast	105	61	79	18
Northern	56	33	34	1
South Eastern	50	29	33	4
Southern	32	19	24	5
Western	45	26	40	14
Region	**288**	**168**	**210**	**42**



Trust	MRSA - No more than 50 during 2014/15			
	2014/15 Maximum	2014/15 Profile (April - October 2014)	2014/15 Actual (April - October 2014)	Variance (actual vs 14/15 target profile)
Belfast	16	9	12	3
Northern	11	6	9	3
South Eastern	11	6	5	-1
Southern	3	2	4	2
Western	9	5	7	2
Region	**50**	**28**	**37**	**9**

Organ Transplants (Target) – by March 2015, ensure delivery of a minimum of 80 kidney transplants in total, to include live, DCD and DBD donors.		Regionally in the year to end of October 2014, 34 kidney transplants have been delivered.
Specialist drugs (Standard) – from April 2014, no patient should wait longer than three months to commence NICE approved specialist therapies for rheumatoid arthritis, psoriatric arthritis, ankylosing sponylitis or psoriasis.		At the end of October 2014, one patient in the Southern Trust was waiting longer than three months to commence NICE approved specialist therapies for rheumatoid arthritis, psoriatric arthritis, ankylosing sponylitis or psoriasis.
Stroke patients (Standard) – from April 2014, ensure that at least 12% of patients with confirmed ischaemic stroke receive thrombolysis.	**Trust** / **Stroke patients - % received thrombolysis** **May-14** / **Jun-14** / **Jul-14** / **Cum. (April - July 14)** Belfast 18% 13% 18% **18%** Northern 10% 5% 20% **13%** South Eastern 16% 6% 11% **11%** Southern 8% 14% 14% **15%** Western 33% 43% *Not available *Not available **Region** **14%** **11%** *Not available *Not available ***Western Trust information was not available due to delays in clinical coding.**	Trusts are permitted three months to complete clinical coding. Cumulatively in year to end of July, each Trust, with the exception of South Eastern, has achieved the standard to ensure that at least 12% of patients with confirmed ischaemic stroke receive thrombolysis. Western Trust information is not available due to delays in coding.

Pressure ulcers (Target) – by March 2015, secure a 10% reduction in pressure ulcers in all adult inpatient wards.



Trust	Pressure Ulcers - 10% reduction by March 2015			
	Profile Reduction (Q2)	Actual (Q2)	Variance (Actual vs profile)	% Variance (Actual vs profile)
Belfast	121	154	33	27%
Northern	52	71	20	38%
South Eastern	53	58	5	9%
Southern	29	42	14	47%
Western	82	63	-19	-23%
Region	336	**388**	**52**	**15%**

At the end of quarter two, there have been 388 incidences of pressure ulcers in adult inpatient wards against a target reduction profile to have had no more than 338 cases in the first half of this year.

The Trusts have reached 100% compliance in rolling out the implementation of the Skin Bundle across all hospital inpatient wards (at the end of March 2014) which is aimed at reducing pressure ulcers and increasing staff awareness of the factors that lead to pressure ulcers. Trusts are committed to keep pressure ulcer prevention as a priority in their Quality Improvement Plans. The initial increase in the incidence of pressure ulcers is an expected outcome of the spread and increase in awareness.

A small pilot study in the RVH has shown that whilst there has been an increase in reporting of pressure ulcers there has been an actual decrease in the occurrence of the most severe grades (grades 3 & 4).

To improve the management of long-term conditions in the community, with a view to improving the quality of care provided and reducing the incidence of acute hospital admissions for patients with one or more long term conditions.

Allied Health Professionals (AHP) (Standard) – from April 2014, no patient waits longer than nine weeks from referral to commencement of AHP treatment.

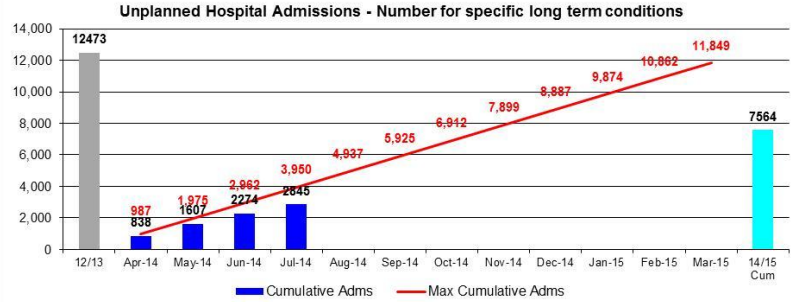
Speciality	30.6.14	31.7.14	31.8.14	30.9.14	31.10.14
Physio	3576	4446	5740	6129	6420
OT	3068	3636	4415	4361	4349
Dietetics	971	1078	1119	1234	1251
Speech & Language					891
Podiatry					761
Orthoptics					19
Multi-Disciplinary					63
Region	**7615**	**9160**	**11274**	**11724**	**13754**

Trust	>9wks for Physiotherapy, OT & Dietetics only				>9wks all AHP services
	30.6.14	31.7.14	31.8.14	30.9.14	31.10.14
Belfast	3155	3912	4844	5118	5145
Northern	1669	2217	2909	3350	4069
South Eastern	281	255	328	312	378
Southern	478	606	700	627	1605
Western	2032	2170	2493	2317	2557
Region	**7615**	**9160**	**11274**	**11724**	**13754**

As previously reported, formal reporting of AHP performance was suspended during quarter one of 2014/15 to allow Trusts to apply the revised AHP waiting time definitions and to put in place arrangements to consistently report performance in line with these definitions. This exercise has now been completed across all AHP services and returns submitted by Trusts show that at the end of October 2014, 13,754 patients were waiting longer than nine weeks from referral to commencement of treatment. The majority (79%) of the breaches at the end of October are in physiotherapy (6,420) and occupational therapy (4,349).

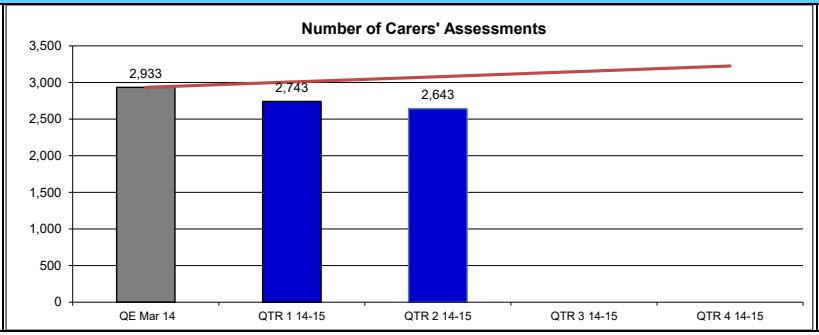
Information up to the end of September relates only to physiotherapy, occupational therapy and dietetics.

The AHP demand and capacity exercise undertaken by the PHA has been concluded and the Board and PHA are meeting with

		each of the Trusts over the coming weeks to share the findings from this exercise and to agree the steps to be taken to address the waiting time position going forward.
Unplanned admissions (Target) – by March 2015, reduce the number of unplanned admissions to hospital by 5% for adults with specified long term conditions (using 2012/13 data as the baseline).		Trusts are permitted three months to complete clinical coding. Cumulatively in the year to end of July 2014, there were 2,845 unplanned admissions to hospital by adults with specified long term conditions against a maximum reduction profile of 3,950.

Trust	Unplanned Hospital Admissions for specificed longterm conditions - 5% reduction			
	Profile Reduction (April - July)	Actual (April-July)	Variance (Actual vs profile)	%Variance (Actual vs profile)
Belfast	964	899	-65	-7%
Northern	895	583	-312	-35%
South Eastern	769	667	-102	-13%
Southern	638	457	-181	-28%
Western	684	239	-445	-65%
Region	**3,950**	**2,845**	**-1105**	**-28%**

To promote social inclusion, choice, control, support and independence for people living in the community especially older people and

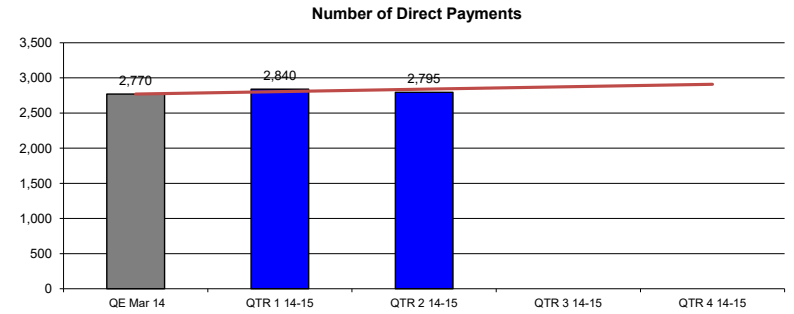
Carers' assessments (Target) – by March 2015, secure a 10% increase in the number of carers' assessments offered.		Regionally at the end of September 2014, 2,643 carers' assessments had been offered against a profile target of 3,080.

STANDARD (from April 2014) **TARGET** (by March 2015 unless stated otherwise)	**Trend Analysis**	**Comments**

Trust	**Carers' assessments - 10% increase by March 2015**		
	QE Mar 14	**QTR 1 14-15**	**QTR 2 14-15**
Belfast	**496**	556	594
Northern	**764**	686	717
South Eastern	**589**	500	489
Southern	**704**	697	537
Western	**380**	304	306
Region	**2933**	**2743**	**2643**

*Quarterly return

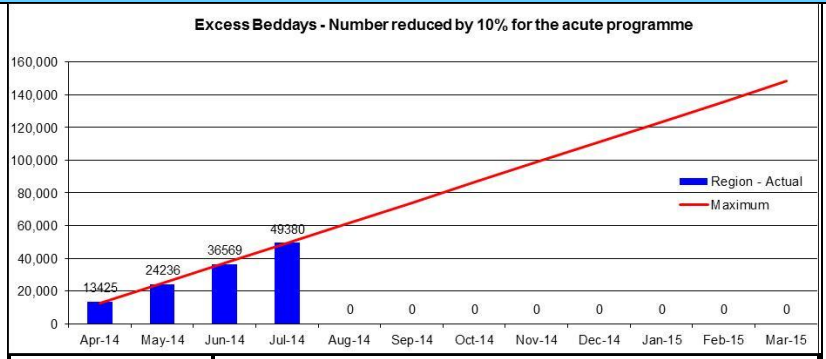
Direct payments (Target) – by March 2015, secure a 5% increase in the number of direct payments across all programmes of care.

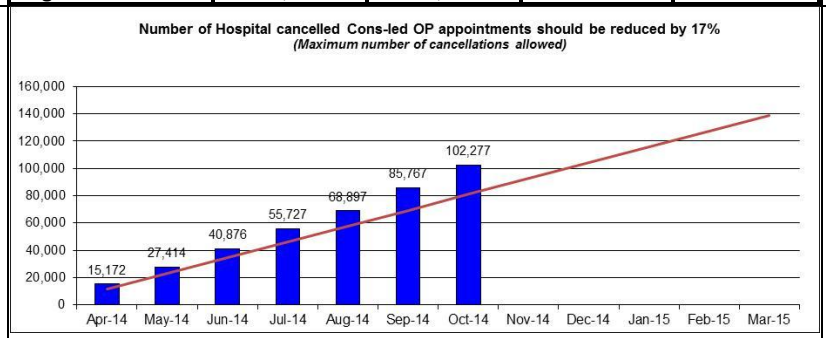


Trust	**Direct Payments - 5% increase by March 2015**			
	Profile Target (Q2)	**Actual (Q2)**	**Variance (Actual vs profile)**	**% Variance (Actual vs profile)**
Belfast	513	498	-15	-3%
Northern	624	587	-37	-6%
South Eastern	600	572	-28	-5%
Southern	712	719	7	1%
Western	388	419	31	8%
Region	**2,839**	**2,795**	**-44**	**-2%**

*Quarterly return

At the end of September 2014, 2,795 direct payments were in place against a target profile of 2,839.

<table>
<tr><th>STANDARD (from April 2014)
TARGET (by March 2015 unless stated otherwise)</th><th>Trend Analysis</th><th>Comments</th></tr>
<tr><td colspan="3">To improve productivity by ensuring effective and efficient allocation and utilisation of all available resources, in line with priorities.</td></tr>
<tr><td>Unnecessary hospital stays (Target) – by March 2015, reduce the number of excess bed days for the acute programme of care by 10% (using 2012/13 data as the baseline).</td><td> 

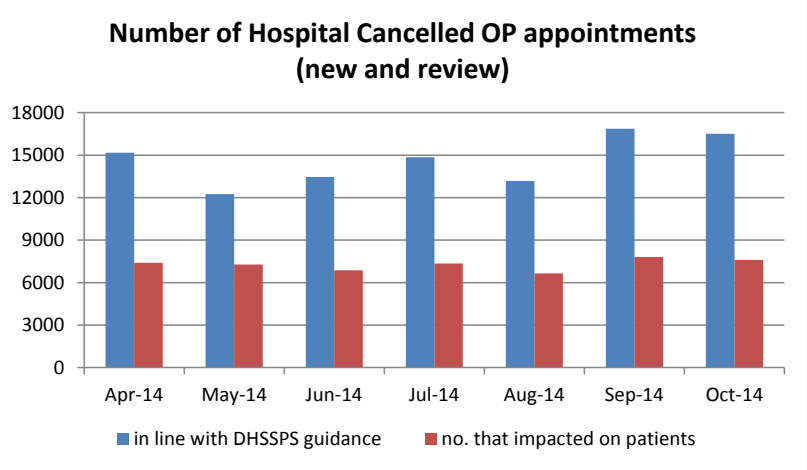
<table>
<tr><th rowspan="2">Trust</th><th colspan="4">Unnecessary Hospital Stay - 10% reduction by March 2015</th></tr>
<tr><th>Profile Reduction (April-July)</th><th>Actual (April-July)</th><th>Variance (Actual vs profile)</th><th>% Variance (Actual vs profile)</th></tr>
<tr><td>Belfast</td><td>22,482</td><td>21,270</td><td>-1,212</td><td>-5%</td></tr>
<tr><td>Northern</td><td>9,072</td><td>9,422</td><td>350</td><td>4%</td></tr>
<tr><td>South Eastern</td><td>7,690</td><td>6,666</td><td>-1,024</td><td>-13%</td></tr>
<tr><td>Southern</td><td>4,138</td><td>6,549</td><td>2,411</td><td>58%</td></tr>
<tr><td>Western</td><td>6,005</td><td>5,473</td><td>-532</td><td>-9%</td></tr>
<tr><td>Region</td><td>49,387</td><td>49,380</td><td>-7</td><td>0%</td></tr>
</table></td><td>Trusts are permitted three months to complete clinical coding. Cumulatively in the year to end of July 2014, there were 49,380 excess bed days for the acute programme of care.</td></tr>
<tr><td>Cancelled Clinics (Target) – by March 2015, reduce the number of hospital cancelled consultant-led outpatient appointments by 17%.</td><td> 
</td><td>Regionally in the year to the end of October 2014, there were 102,277 hospital cancelled consultant-led outpatients against a target profile to have no more than 80,939.

The Board is continuing to monitor and report the number of hospital cancelled consultant-led outpatient appointments in line with the latest definitions and guidance outlined by the Department of Health Statistics Branch in their Quarterly Outpatient Activity Statistical Return (Version 3 August 2011 refers) however, it should be noted that the way in which cancelled clinics are recorded means that the cancellation rates reported are overstated as a number of the reasons recorded on PAS for cancellation will not result in lost capacity.

At the request of the Health Committee, a Short Life Working Group was set up to establish how information on cancelled</td></tr>
</table>

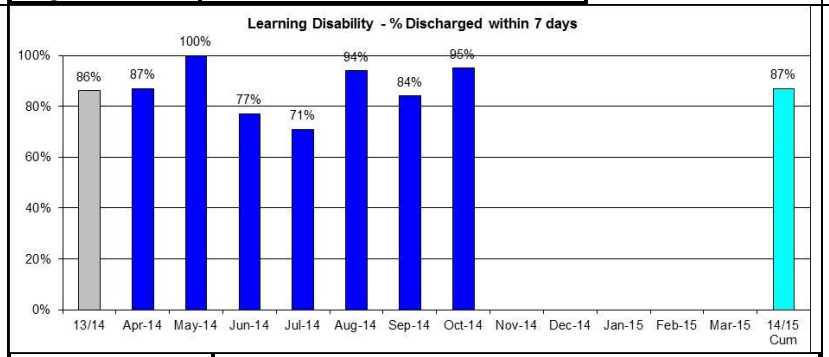
STANDARD (from April 2014) **TARGET** (by March 2015 unless stated otherwise)	**Trend Analysis**	**Comments**

Trust	Cancelled Clinics (17% reduction)		
	2014/15 Target (April - October 2014)	2014/15 Actual (April - October 2014)	Variance (actual vs 14/15 target profile)
Belfast	37,004	47,637	10,633
Northern	11,422	14,758	3,336
South Eastern	11,181	15,174	3,993
Southern	7,376	9,887	2,511
Western	13,956	14,821	865
Region	**80,939**	**102,277**	**21,338**



appointments could be recorded in order to be able to identify where there has been a direct impact on patients and to quantify actual lost capacity.

As a result of this work, information on the number of hospital cancelled consultant-led outpatient appointments that had an impact on patients is now available. Regionally, for the period 1 April to 31 October 2014, the number of hospital cancelled consultant-led outpatient appointments that had an impact on patients was 50,959.

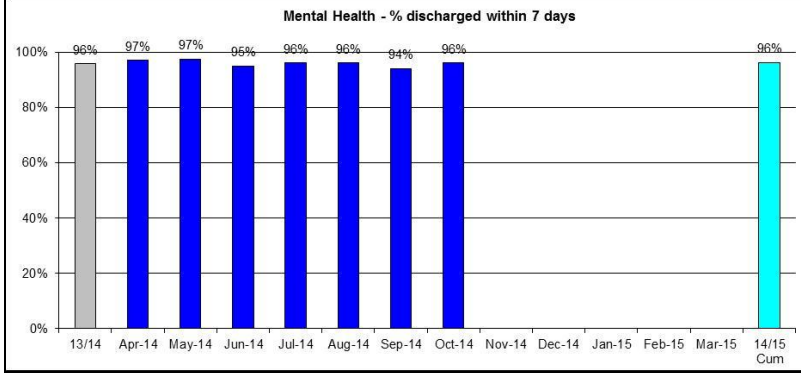
<table>
<tr><th>STANDARD (from April 2014)
TARGET (by March 2015 unless stated otherwise)</th><th>Trend Analysis</th><th>Comments</th></tr>
<tr><td></td><td>
<table>
<tr><th>Trust</th><th>No. of cancelled OP appts with direct impact on patients (1.4.14-31.10.14)</th></tr>
<tr><td>Belfast</td><td>24,174</td></tr>
<tr><td>Northern</td><td>7,394</td></tr>
<tr><td>South Eastern</td><td>6,694</td></tr>
<tr><td>Southern</td><td>5,198</td></tr>
<tr><td>Western</td><td>7,499</td></tr>
<tr><td>Region</td><td>50,959</td></tr>
</table>
</td><td></td></tr>
<tr><td>Patient discharge 1 (Standard) – from April 2014, ensure that 99% of all learning disability discharges take place within seven days of the patient being assessed as medically fit for discharge, with no discharge taking more than 28 days.</td><td>


<table>
<tr><th rowspan="2">Trust</th><th colspan="4">Learning Disability - % discharge within 7 days</th></tr>
<tr><th>Aug-14</th><th>Sep-14</th><th>Oct-14</th><th>14/15 Cum</th></tr>
<tr><td>Belfast</td><td>67%</td><td>100%</td><td>100%</td><td>87%</td></tr>
<tr><td>Northern</td><td>100%</td><td>80%</td><td>86%</td><td>92%</td></tr>
<tr><td>South Eastern</td><td>100%</td><td>60%</td><td>100%</td><td>83%</td></tr>
<tr><td>Southern</td><td>100%</td><td>100%</td><td>*n/a</td><td>85%</td></tr>
<tr><td>Western</td><td>100%</td><td>100%</td><td>100%</td><td>87%</td></tr>
<tr><td>Region</td><td>94%</td><td>84%</td><td>95%</td><td>87%</td></tr>
</table>
</td><td>Regionally during October 2014, 95% of learning disability discharges took place within seven days and one took longer than 28 days.</td></tr>
</table>

	Trust / **Learning Disability - No. discharged >28 days**	

Trust	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	1	0	0	**4**
Northern	0	1	1	**2**
South Eastern	0	2	0	**4**
Southern	0	0	0	**1**
Western	0	0	0	**0**
Region	**1**	**3**	**1**	**11**

Patient discharge 2 (Standard) – from April 2014, ensure that 99% of all mental health discharges take place within seven days of the patient being assessed as medically fit for discharge, with no discharge taking more than 28 days.



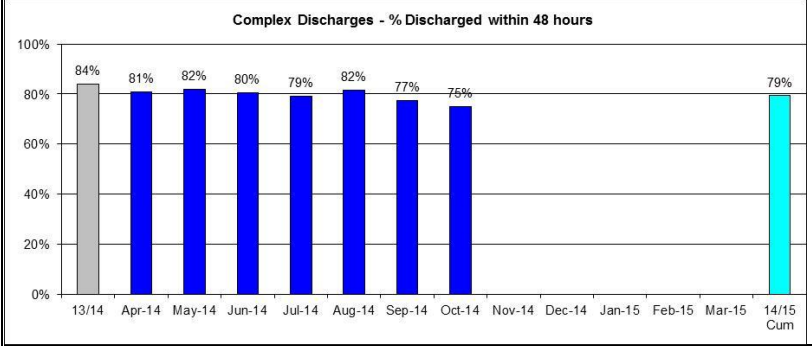
Trust	Mental Health - % discharge within 7 days			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	100%	100%	100%	**99%**
Northern	100%	96%	92%	**98%**
South Eastern	94%	85%	96%	**93%**
Southern	95%	96%	95%	**96%**
Western	96%	98%	99%	**97%**
Region	**96%**	**94%**	**96%**	**96%**

Regionally during October 2014, 96% of mental health discharges took place within seven days and five took longer than 28 days.

	Trust / **Mental Health - No. discharged >28 days**	

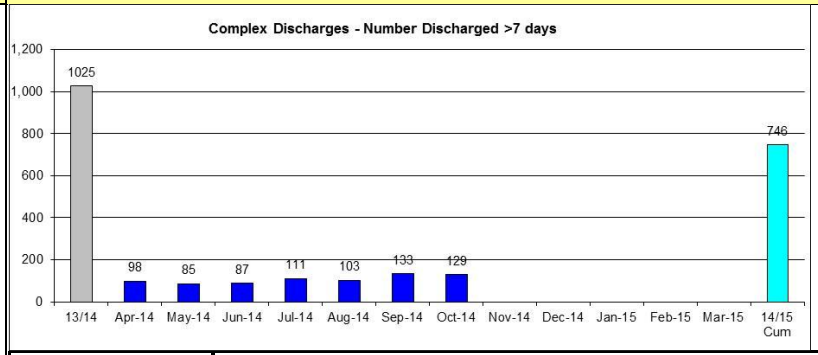
Trust	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	0	0	0	**4**
Northern	0	1	3	**4**
South Eastern	2	11	0	**25**
Southern	1	2	1	**13**
Western	3	2	1	**21**
Region	**6**	**16**	**5**	**67**

Patient discharge 3 (Standard) – from April 2014, ensure that 90% of complex discharges from an acute hospital take place within 48 hours, with no complex discharge taking more than seven days.



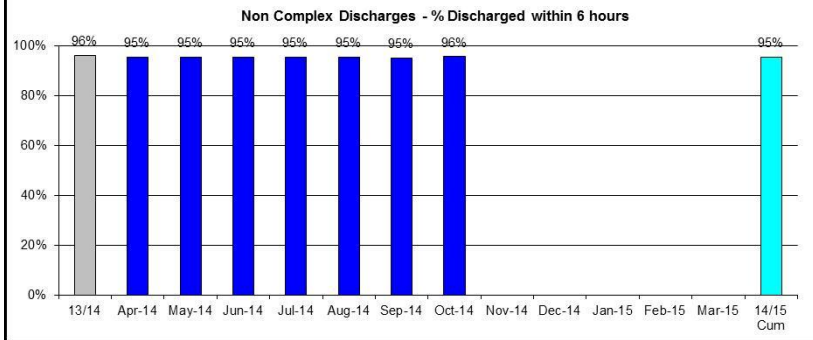
Trust	Patient Discharges - % < 48 hours			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	53%	59%	49%	**57%**
Northern	88%	80%	82%	**84%**
South Eastern	81%	75%	72%	**77%**
Southern	98%	89%	93%	**94%**
Western	88%	87%	85%	**88%**
Region	**82%**	**77%**	**75%**	**79%**

Regionally during October 2014, 75% of complex discharges from an acute hospital took place within 48 hours, 129 took more than seven days.



Trust	Patient Discharge - No >7 days			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	40	47	37	**240**
Northern	18	29	28	**154**
South Eastern	20	36	37	**192**
Southern	1	4		**9**
Western	24	17	26	**147**
Region	**103**	**133**	**129**	**746**

Patient discharge 4 (Standard) – from April 2014, ensure that all <u>non-complex discharges</u> from an acute hospital take place within six hours.



Trust	Patient Discharge - % within 6 hours			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	97%	98%	97%	98%
Northern	95%	95%	95%	95%
South Eastern	92%	91%	93%	92%
Southern	92%	91%	93%	92%
Western	97%	96%	97%	96%
Region	**95%**	**95%**	**96%**	**95%**

Regionally during October 2014, 96% of non-complex discharges from an acute hospital took place within six hours.

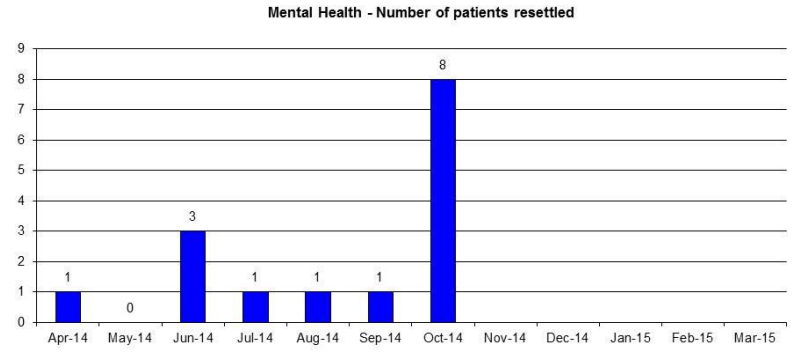
To ensure the most vulnerable in our society, including children and adults at risk of harm are looked after effectively across all our

Resettlement 1 (Target) – by March 2015, resettle the remaining long-stay patients in learning disability hospitals to appropriate places in the community.

Trust	Learning Disability 2014/15 - Number Resettled			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	0	0	2	**2**
Northern	-1	1	0	**1**
South Eastern	1	0	0	**2**
Southern	0	0	0	**0**
Western	0	0	0	**0**
Region	**0**	**1**	**2**	**5**

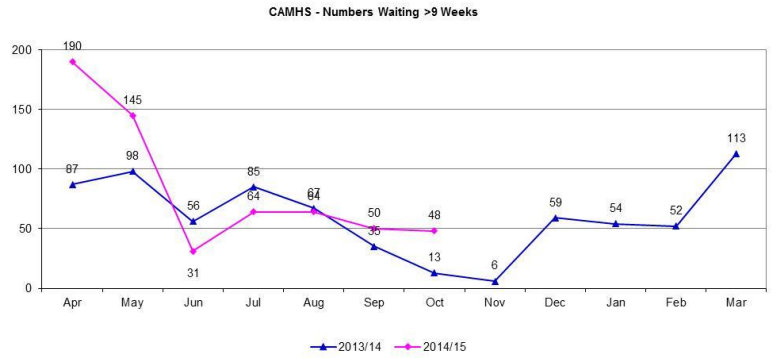
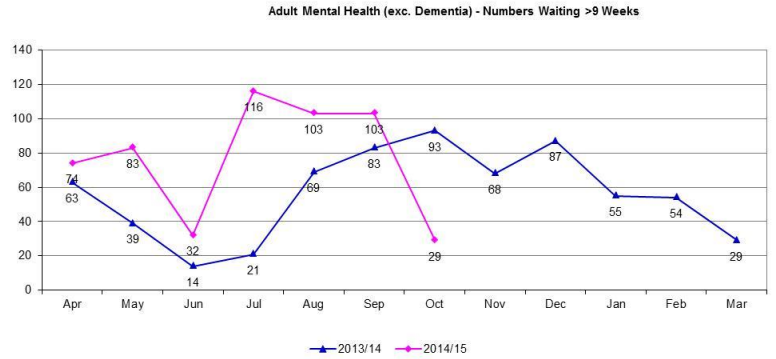
In order to ensure achievement of the Ministerial target that all long stay patients in learning disability and psychiatric hospitals are resettled to appropriate places in the community by 31 March 2015, Trusts are required to resettle 49 learning disability patients and 42 mental health patients in 2014/15. Regionally, at the end of October 2014, five learning disability and 15 mental health patients have been resettled.

Resettlement 2 (Target) – by March 2015, resettle the remaining long-stay patients in psychiatric hospitals to appropriate places in the community.



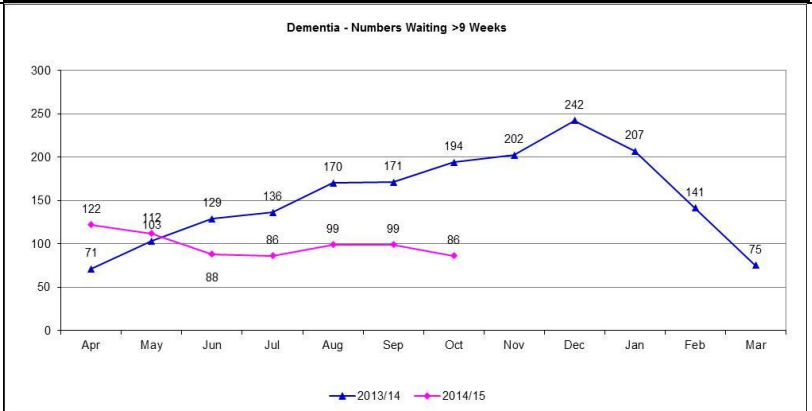
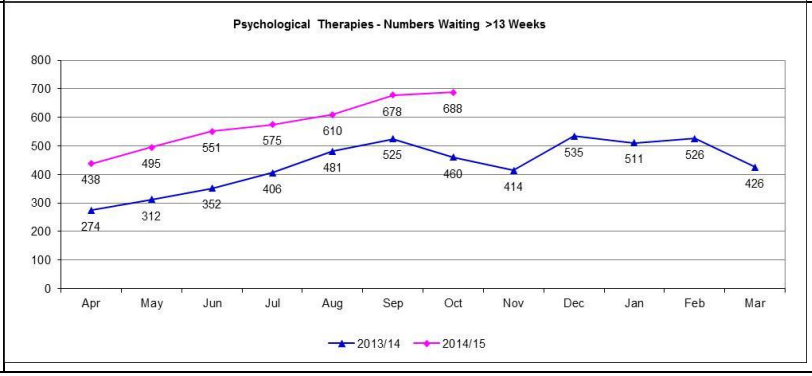
Trust	Mental Health 2014/15 - Number Resettled			
	Aug-14	Sep-14	Oct-14	14/15 Cum
Belfast	1	0	0	**3**
Northern	0	0	0	**0**
South Eastern	0	1	5	**6**
Southern	0	0	3	**6**
Western	0	0	0	**0**
Region	**1**	**1**	**8**	**15**

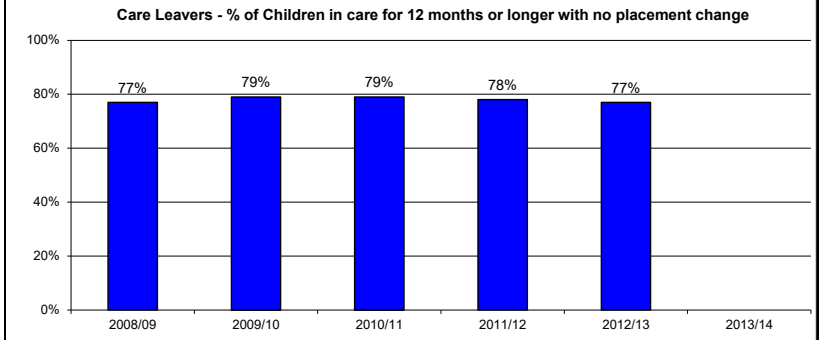
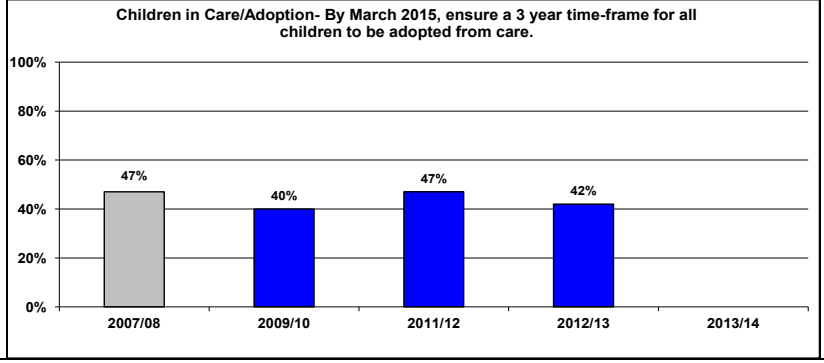
As previously reported, Trusts have identified a number of patients who currently will require to remain in hospital after 31 March 2015, some of whom are detained under the Mental Health Order. They have also advised the Board that a number of patients will not be resettled as planned resettlement accommodations will not be ready for occupation until after 31 March 2015.

Mental health services 1 (Standard) – from April 2014, no patient waits longer than nine weeks to access <u>child and adolescent mental health services</u>.	 **Trust** / **CAMHS - No > 9 weeks** **Aug-14** / **Sep-14** / **Oct-14** Belfast 5 2 0 Northern 59 48 48 South Eastern 0 0 0 Southern 0 0 0 Western 0 0 0 **Region** **64** **50** **48**	Regionally at the end of October 2014, 48 patients were waiting longer than nine weeks to access child and adolescent mental health services (CAMHS). All of the patients waiting longer than nine weeks are in the Northern Trust. The Trust has submitted an action plan to secure improved performance in 2014/15 however, the Board has accepted that there is a residual capacity gap which it is working with the Trust to address.
Mental health services 2 (Standard) – from April 2014, no patient waits longer than nine weeks to access <u>adult mental health services</u>.		There has been a significant reduction in the number of patients waiting longer than nine weeks to access adult mental health services – 29 at end of October 2014.

	Trust / **Adult MH - No > 9 weeks**	

Trust	Adult MH - No > 9 weeks		
	Aug-14	Sep-14	Oct-14
Belfast	61	64	18
Northern	1	0	0
South Eastern	3	0	0
Southern	30	35	10
Western	8	4	1
Region	**103**	**103**	**29**

Mental health services 3 (Standard) – from April 2014, no patient waits longer than nine weeks to access dementia services.		Regionally at the end of October 2014, 86 patients were waiting longer than nine weeks to access dementia services. Almost all of the patients waiting longer than nine weeks were in the Southern Trust (85), with one patient waiting longer than nine weeks residing in the Western Trust.
Mental health services 4 (Standard) – from April 2014, no patient waits longer than 13 weeks to access psychological therapies (any age).		The number of patients waiting longer than 13 weeks to access psychological therapies has continued to increase during 2014/15 – 688 patients were waiting longer than 13 weeks at the end of October. The majority (74%) of patients waiting longer than 13 weeks to access psychological therapies at the end of October 2014 were in Belfast (142) and South Eastern (365) Trusts. The Board has confirmed funding for South Eastern Trust to recruit additional staff and is currently reviewing how the Trust is proposing to utilise this in-year to improve the waiting time position.

	Trust / **Psychological Therapies - No >13 weeks**: **Aug-14** / **Sep-14** / **Oct-14** Belfast 84 / 143 / 142 Northern 123 / 115 / 97 South Eastern 322 / 330 / 365 Southern 18 / 27 / 22 Western 63 / 63 / 62 **Region 610 / 678 / 688**	
Children in care 1 (Standard) – from April 2014, increase the number of children in care for 12 months or longer with no placement change to 85%.	 **Trust** / **2007/08** / **2008/09** / **2009/10** / **2010/11** / **2011/12** / **2012/13** Belfast 81% / 79% / 83% / 84% / 84% / 78% Northern 81% / 78% / 78% / 78% / 74% / 76% South Eastern 80% / 82% / 78% / 81% / 79% / 78% Southern 71% / 59% / 73% / 66% / 70% / 75% Western 85% / 83% / 83% / 82% / 85% / 79% **Region 80% / 77% / 79% / 79% / 78% / 77%**	Performance against this target is reported annually. Monitoring information for 2013/14 and 2014/15 will not be available until end 2014 and 2015 respectively.
Children in care 2 (Target) – by March 2015, ensure a three year time frame for 90% of children who are to be adopted from care.		Performance against this target is reported annually. Monitoring information for 2013/14 and 2014/15 will not be available until end of 2014 and 2015 respectively.

<table>
<tr><th>STANDARD (from April 2014)
TARGET (by March 2015 unless stated otherwise)</th><th>Trend Analysis</th><th>Comments</th></tr>
<tr><td></td><td>
<table>
<tr><th>Trust</th><th>2007/08</th><th>2009/10</th><th>2011/12</th><th>2012/13</th></tr>
<tr><td>Belfast</td><td>75%</td><td>31%</td><td>59%</td><td>41%</td></tr>
<tr><td>Northern</td><td>33%</td><td>38%</td><td>29%</td><td>44%</td></tr>
<tr><td>South Eastern</td><td>20%</td><td>33%</td><td>57%</td><td>64%</td></tr>
<tr><td>Southern</td><td>63%</td><td>42%</td><td>50%</td><td>50%</td></tr>
<tr><td>Western</td><td>20%</td><td>100%</td><td>60%</td><td>19%</td></tr>
<tr><td>Region</td><td>47%</td><td>40%</td><td>47%</td><td>42%</td></tr>
</table>
</td><td></td></tr>
<tr><td>Children in care 3 (Standard) – from April 2014, ensure that all school-age children who have been in care for 12 months or longer have a Personal Educational Plan (PEP).</td><td></td><td>Performance against this target is reported annually. Monitoring information for 2014/15 will not be available until September 2015.</td></tr>
</table>

HSC BOARD PERFORMANCE REPORT – 2014/15 (Month 12 – March 2015)

Introduction

The purpose of this paper is to provide Board members with an end of year review of performance against the standards and targets set out in the Minister's Commissioning Plan Direction 2014/15 that the Board is responsible for monitoring and where end of year monitoring information is currently available.

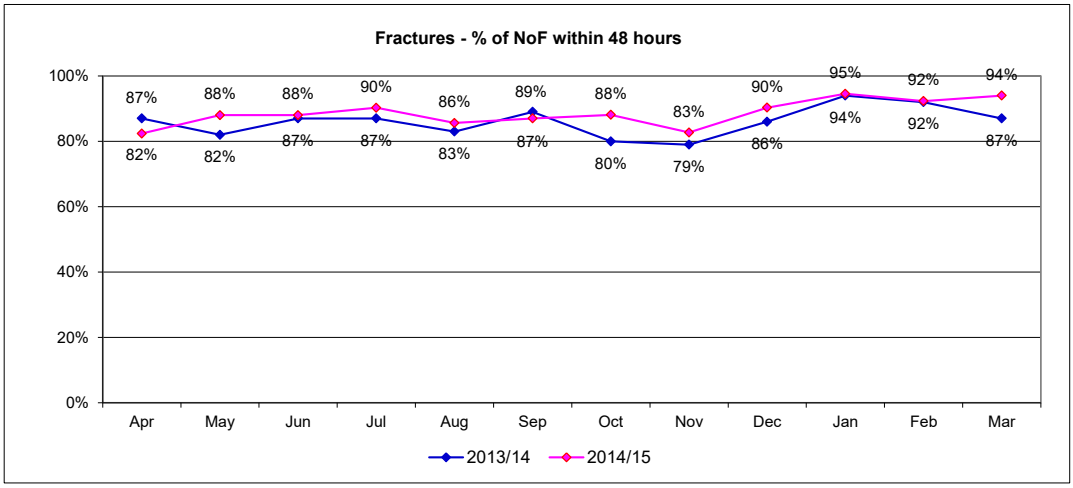
Due to the three month period allowed to facilitate coding within Trusts, the end of year performance in relation to a small number of target areas (hospital readmissions, stroke/thrombolysis, unplanned admissions for patients with specified long-term conditions, pressure ulcers and excess bed days) is not available. Similarly, performance in relation to the three children in care standards/targets (placement change, adoption and personal education plans (PEP)), will not be available until later in 2014/15 due to the annual reporting cycle associated with these target areas. An update on end of year performance in these areas will be provided at a future Board meeting.

An end of year assessment of Trusts' performance against the indicators set out in the Minister's Indicators of Performance Direction 2013/14 will be provided at the June Board meeting.

Year-end Performance by Priority Area

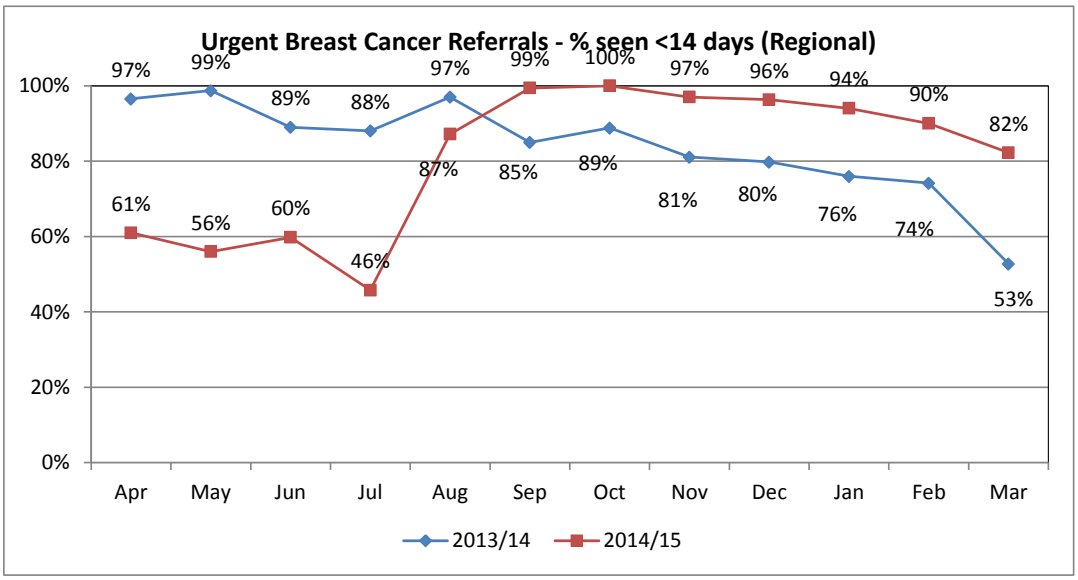
PRIORITY AREA: TO IMPROVE THE QUALITY OF SERVICES AND OUTCOMES FOR PATIENTS, CLIENTS AND CARERS THROUGH THE PROVISION OF SAFE, RESILIENT AND SUSTAINABLE SERVICES

- *Fractures* – during 2014/15, 89% of patients, where clinically appropriate, received inpatient treatment for hip fractures within 48 hours (standard: 95%). This represents an improvement from the position in 2013/14 (86%). In particular, it should be noted that performance has improved significantly from December 2014.



Trust	Fracture NoF- % within 48 hours							
	13/14 Cum	Jun-14	Sep-14	Dec-14	Jan-15	Feb-15	Mar-15	14/15 Cum
Belfast	87%	91%	94%	89%	100%	95%	99%	91%
Northern								
South Eastern	77%	81%	75%	93%	78%	89%	84%	80%
Southern	91%	92%	76%	92%	100%	100%	88%	92%
Western	90%	86%	86%	89%	90%	85%	93%	89%
Region	**86%**	**88%**	**87%**	**90%**	**95%**	**92%**	**94%**	**89%**

- *Cancer (14 days)* – cumulatively during 2014/15, 81% of urgent breast cancer referrals were seen within 14 days compared to 84% during 2013/14. It should be noted however, that there has been a significant improvement in performance in the second half of 2014/15 compared to last year.

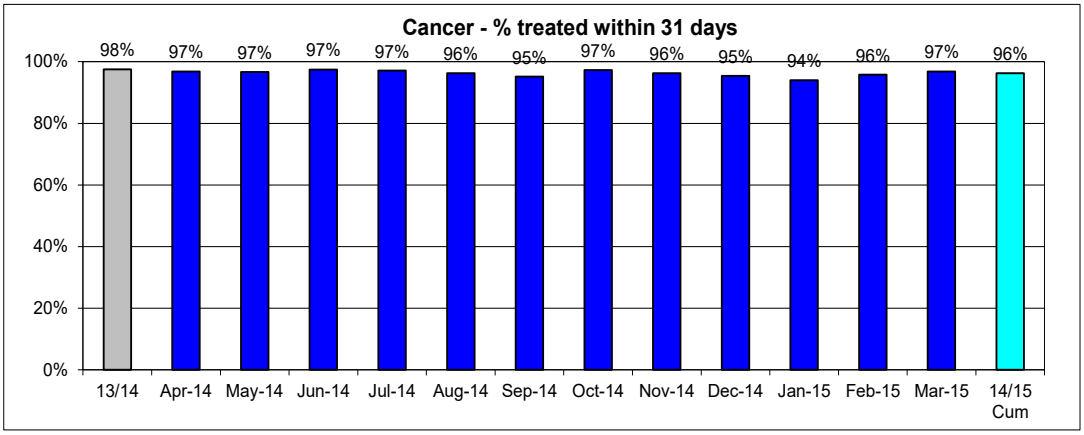


Trust	Cancer Services (Breast) - % within 14 days							
	13/14 Cum	Jun-14	Sep-14	Dec-14	Jan-15	Feb-15	Mar-15	14/15 Cum
Belfast	97%	99%	99%	83%	79%	55%	27%	83%
Northern	76%	27%	100%	100%	100%	100%	100%	71%
South Eastern	81%	21%	100%	100%	100%	100%	98%	68%
Southern	64%	62%	98%	100%	100%	100%	99%	83%
Western	98%	100%	100%	100%	98%	100%	100%	99%
Region	**84%**	**60%**	**99%**	**96%**	**94%**	**90%**	**82%**	**81%**

In delivering this improved position, the Board met regularly with all Trusts in dedicated cancer performance and improvement meetings and also with individual Trusts as required. The focus of these meetings was to apply the models of best practice that exist within Northern Ireland across all Trusts to ensure a consistent approach to delivery of the 14-day standard. This included ensuring that existing triple assessment capacity is maximised through using the most appropriate pathways for routine and review patients and in the implementation of effective triage practice in line with good practice. Additional clinics were also undertaken and recurrent investment has been put in place in South Eastern and Northern Trusts.

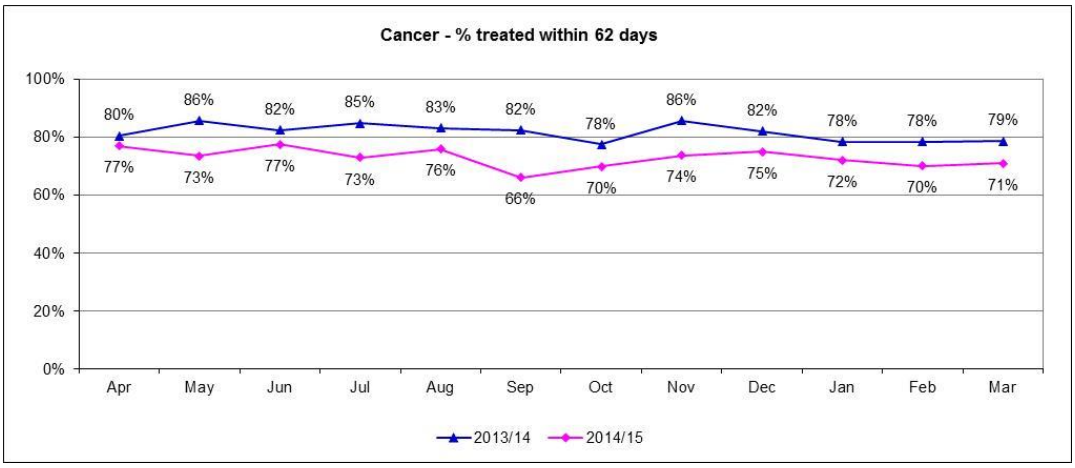
While four of the five Trusts have maintained or substantially maintained the 100% standard since September 2014, performance in Belfast Trust has deteriorated – during March 2015, 27% of urgent referrals were seen within 14 days. The Board is working with Belfast Trust to develop increased flexibility in the service to take account of peaks and troughs in demand and the Trust expects performance to improve during quarter one of 2015/16 with additional clinics coming into effect from mid-April. In addition, there are a number of recording issues which are currently being addressed.

- *Cancer (31 days)* – regionally during 2014/15, 96% of cancer patients commenced treatment within 31 days of the decision to treat (standard: 98%), compared with 98% in 2013/14.



Trust	Cancer Services - % <31 days					
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum
Belfast	96%	96%	91%	91%	94%	93%
Northern	99%	100%	97%	99%	100%	99%
South Eastern	97%	97%	96%	95%	99%	97%
Southern	99%	98%	100%	100%	98%	99%
Western	100%	100%	100%	100%	100%	100%
Region	**98%**	**97%**	**95%**	**95%**	**97%**	**96%**

- *Cancer (62 days)* – regionally during 2014/15, 73% of patients urgently referred with a suspected cancer began their first definitive treatment within 62 days (standard: 95%), compared with 82% in 2013/14.



Trust	Cancer Services - % <62 days					
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum
Belfast	79%	74%	52%	74%	63%	**66%**
Northern	80%	75%	64%	68%	67%	**68%**
South Eastern	76%	73%	58%	56%	59%	**64%**
Southern	88%	79%	83%	91%	96%	**85%**
Western	90%	94%	87%	94%	87%	**92%**
Region	**82%**	**77%**	**66%**	**75%**	**71%**	**73%**

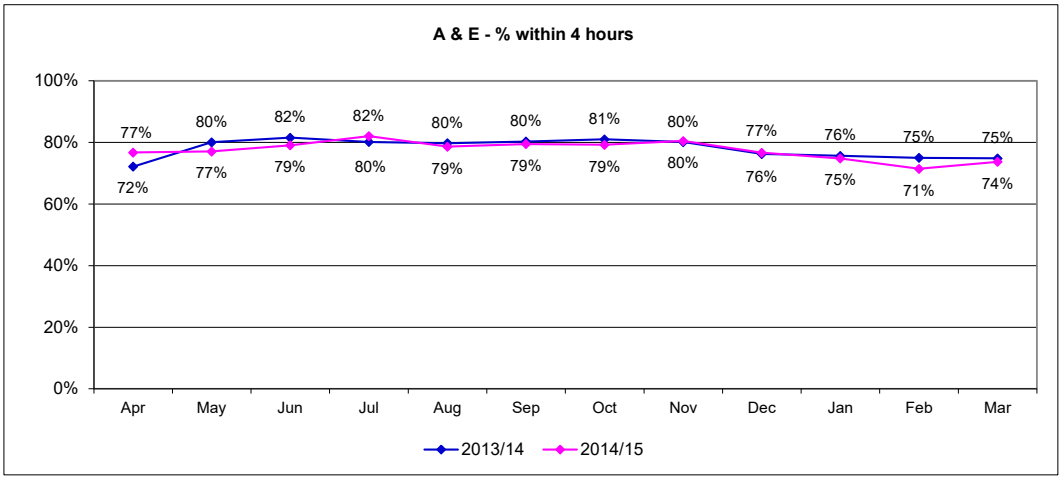
The Board has a performance process in place with Trusts specifically around improving cancer performance. During 2014/15, Trusts have continued to focus on treating the longest waiting patients and, as performance against the 62-day cancer access standard is based on completed waits in month, the pace of progress towards achievement of the 95% standard is as expected as it reflects that a higher proportion of patients treated in month were the longer waiters.

The impact of the focus on treating the longest waits has been evidenced by the significant reduction in the number of patients actively waiting longer than 62 days on the urological cancer pathway since January 2015 – in Belfast Trust, the number of patients has reduced from 70 to 29 and, in Northern Trust, the number has reduced from 46 to seven.

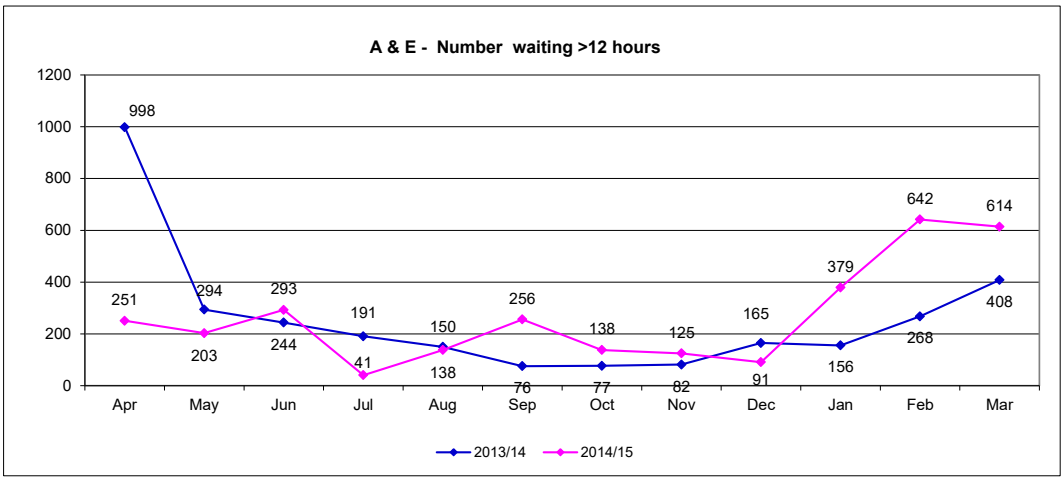
Performance against the 95% standard in the Western Trust has remained strong throughout 2014/15 – cumulatively, 92% of patients began their first definitive treatment within 62 days. Performance in the South Eastern Trust however, has continued to be well below the required level – during 2014/15, 64% of patients began their first

definitive treatment within 62 days. Furthermore, at the end of March 2015, 127 patients in South Eastern Trust were waiting longer than 62 days (48% of the regional total). This performance issue is the subject of ongoing discussion between the Board and Trust.

- *A&E (4-hour and 12-hour standards)* – regionally during March 2015, 74% of patients attending an Emergency Department were treated and discharged, or admitted within four hours of arrival (standard: 95%) and 614 patients waited longer than 12 hours. This compares to 75% (4 hours) and 407 (12 hours) in March 2014.



Trust	A&E - % treated within 4 hours					
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum
Belfast	73%	72%	71%	71%	69%	72%
Northern	77%	75%	76%	68%	64%	71%
South Eastern	80%	83%	81%	78%	80%	81%
Southern	82%	82%	86%	86%	80%	84%
Western	81%	88%	86%	82%	77%	83%
Region	**78%**	**79%**	**79%**	**77%**	**74%**	**78%**



Trust	No waiting > 12 hours in A&E					
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum
Belfast	517	223	207	44	312	1,756
Northern	1,027	63	21	1	194	663
South Eastern	1,224	6	28	45	100	713
Southern	96	1	0	1	1	14
Western	245	0	0	0	7	25
Region	**3,109**	**293**	**256**	**91**	**614**	**3,171**

There was a material reduction in the number of patients waiting longer than 12 hours in Emergency Departments during the first three quarters of 2014/15 – from April to December 2014, 1,536 patients waited longer than 12 hours compared to 2,278 during the same period in 2013/14, a reduction of 742 (33%).

In relation to the deterioration in performance during the final quarter of 2014/15, it should be noted that regionally there was a 3.8% increase in attendances at the larger Type 1 and Type 2 emergency departments and a 2% increase in admissions compared with the same period last year. Furthermore, during quarter four, Trusts experienced an 11% increase in the number of attendances by patients aged 80 or over and an 3% increase in the number of patients who were triaged as category 2 (very urgent) or 3 (urgent). All of these factors combined will have contributed to the increased pressures experienced by Trusts in the latter part of 2014/15.

The majority of the breaches of the 12-hour standard in 2014/15 were in the Belfast Trust, 1,756 out of a total of 3,171 – this compared with 517 in Belfast Trust during 2013/14. It should be noted however, that there has been a sizeable reduction in the number of patients who have waited longer than 12 hours in the remaining four Trusts during 2014/15 compared to 2013/14.

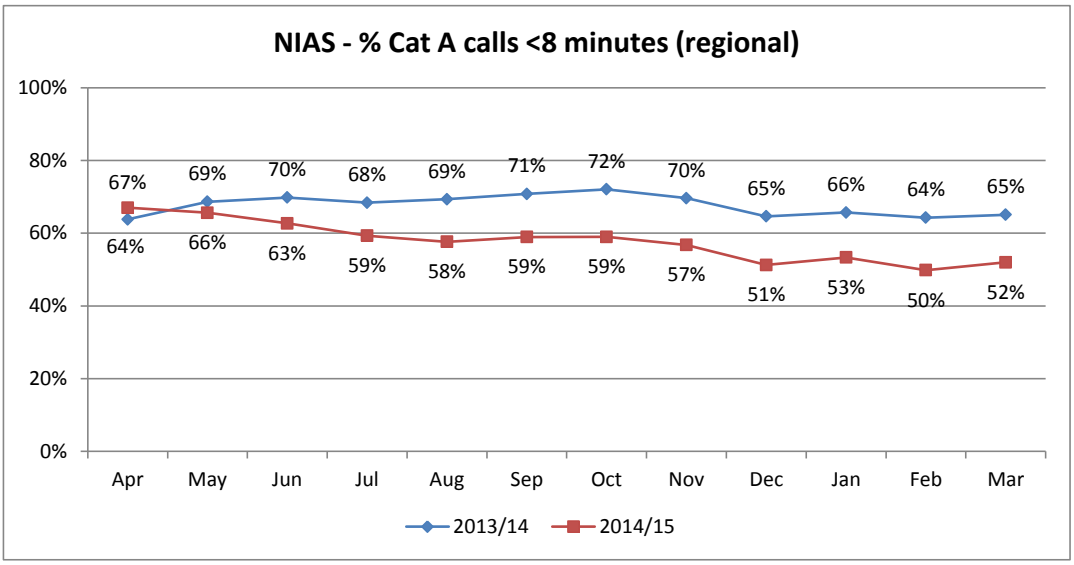
In relation to the 4-hour standard, regionally during 2014/15, 78% of patients attending an Emergency Department were treated and discharged, or admitted within four hours of arrival – this is unchanged from 2013/14.

During 2014/15, the Board undertook a series of re-audits of Trusts' implementation of a number of the 18 key actions to improve the unscheduled care pathway. The re-audit process is currently in its final phase and a summary paper of the findings is expected to be available by end of June 2015. The findings from the audits and agreed actions

will be monitored at the regular performance meetings with Trusts to ensure improvements are secured in 2015/16.

Improving performance against the 4 and 12 hours standard remains a priority for the Board and it is continuing to work with Trusts to expand 7 day services to improve patient flow, taking forward recommendation from the Unscheduled Care Task Group.

- *Ambulance Response Times* – regionally during 2014/15, 58% of Category A calls were responded to within eight minutes (target: 72.5% by March 2015, 67.5% in each LCG area). This performance compares with 68% during 2013/14.



LCG	% Cat A calls within 8 minutes					
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum
Belfast	81%	75%	71%	59%	60%	69%
Northern	60%	56%	53%	46%	45%	52%
South Eastern	62%	59%	53%	46%	49%	53%
Southern	63%	58%	54%	47%	48%	53%
Western	67%	64%	62%	57%	55%	60%
Region	**68%**	**63%**	**59%**	**51%**	**52%**	**58%**

In relation to the current Category A performance, NIAS has indicated that the number of calls responded to in 2014/15 was 11% higher than in 2013/14, and this has had an adverse impact on the 8-minute response time. This needs to be viewed in the context of overall activity, particularly in relation to categorisation of Health Care Professionals (HCP) calls (previously categorised as GP urgent calls) and the introduction of the Card 35 scheme. Changes proposed to the application of the Card 35 scheme are due to be implemented early in 2015/16.

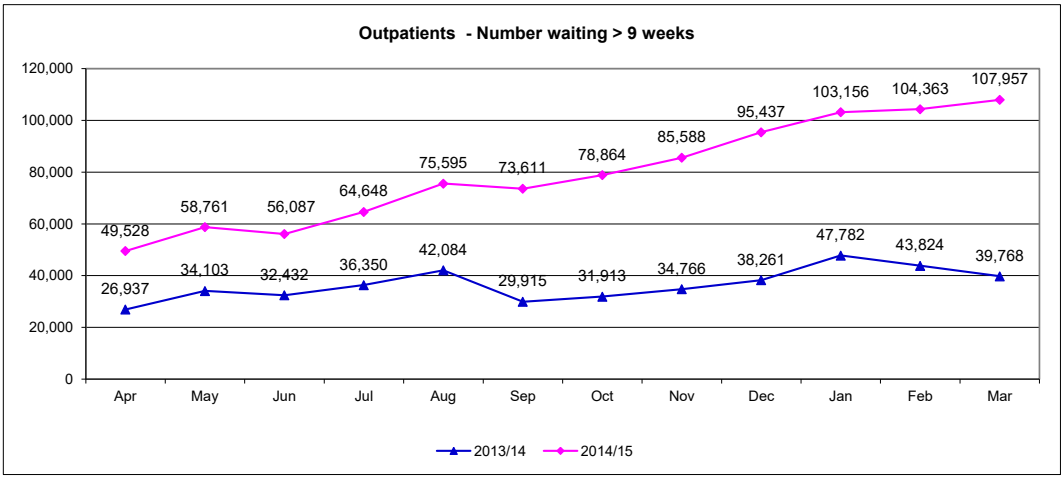
Other issues impacting on response times in 2014/15, and which are being addressed by NIAS, include a significant recruitment and training process for operational staff, and a continued focus on the management of absence. In addition, the Board will be working with NIAS to take forward a detailed demand and capacity exercise during 2015/16.

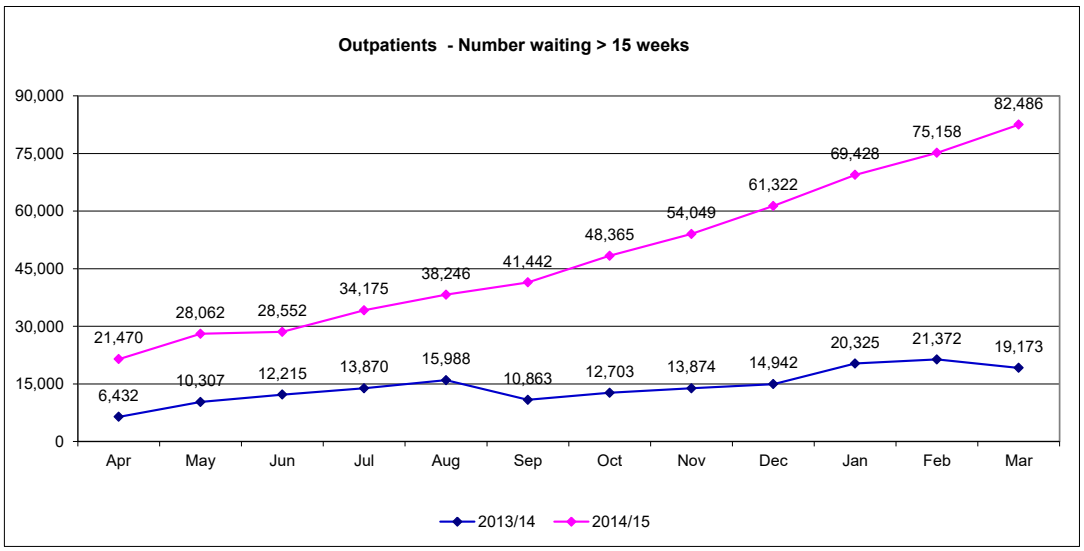
- *Elective Care (including Diagnostics)*

Outpatients – regionally at the end of March 2015, 44% of patients were waiting less than nine weeks for a first outpatient appointment (standard: 80%), compared to 69% at the end of March 2014.

Trust	Outpatients % waiting <9 weeks				
	31.3.14	30.6.14	30.9.14	31.12.14	31.3.15
Belfast	60%	54%	45%	40%	39%
Northern	66%	58%	54%	46%	46%
South Eastern	80%	70%	58%	45%	42%
Southern	77%	69%	58%	48%	48%
Western	79%	71%	64%	55%	54%
TOTAL	**69%**	**61%**	**52%**	**44%**	**44%**

At the end of March 2015, 107,957 patients were waiting longer than nine weeks for a first outpatient appointment and 82,486 were waiting longer than 15 weeks. This represents a significant increase compared to the position at the end of March 2014.



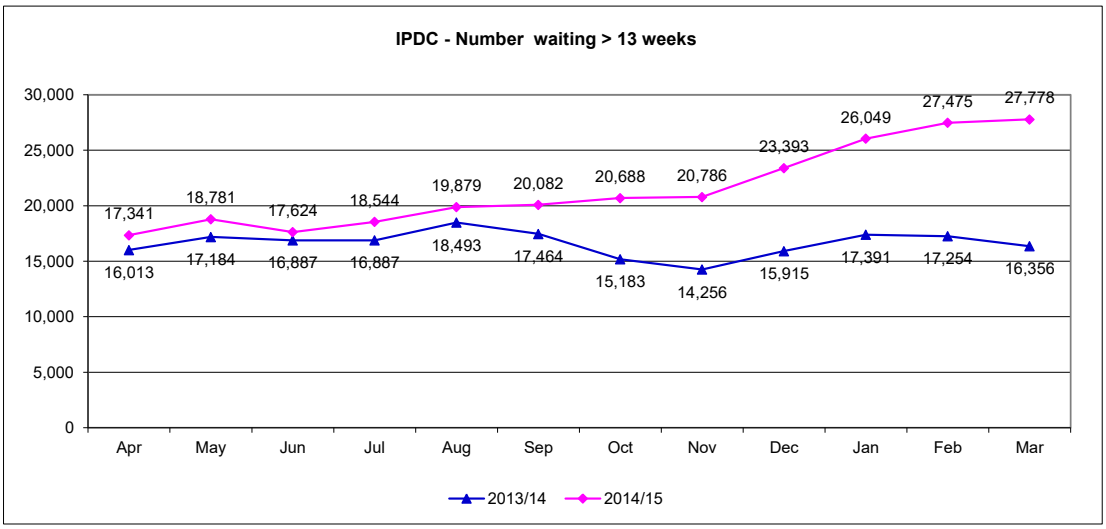


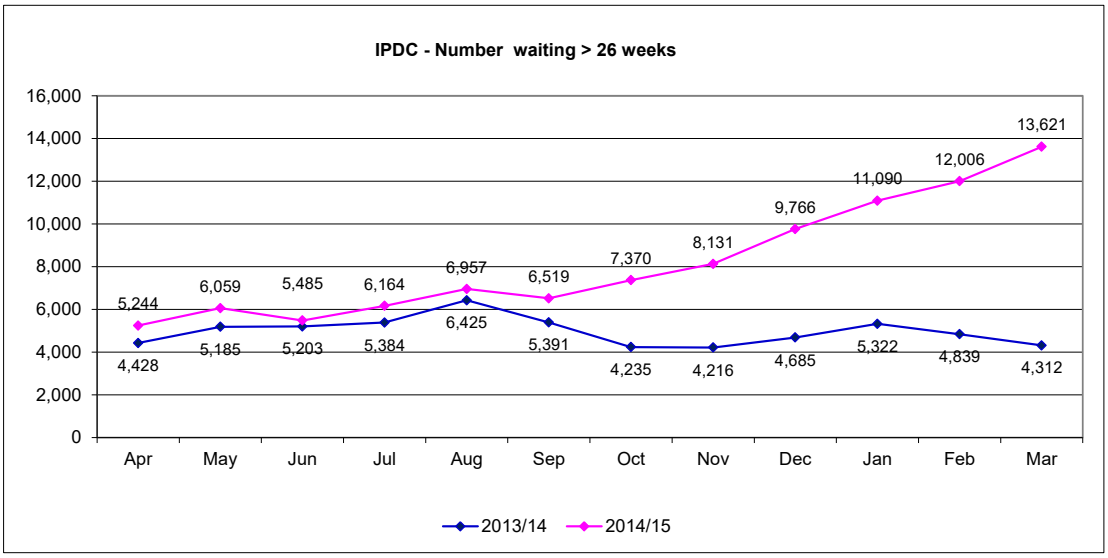
Outpatients	>9 weeks					>15 weeks				
	31.3.14	30.6.14	30.9.14	31.12.14	31.3.15	31.3.14	30.6.14	30.9.14	31.12.14	31.3.15
Belfast	21,688	28,091	35,942	43,520	47,748	12,730	17,198	23,252	30,667	38,649
Northern	6,708	9,025	9,558	12,157	13,589	3,240	4,651	4,852	7,680	10,268
South Eastern	3,630	7,000	11,260	17,057	20,457	883	2,649	5,494	10,459	15,510
Southern	4,569	6,856	10,407	13,875	15,950	1,205	1,959	4,577	7,440	10,847
Western	3,173	5,115	6,444	8,828	10,213	1,115	2,095	3,267	5,076	7,212
TOTAL	**39,768**	**56,087**	**73,611**	**95,437**	**107,957**	**19,173**	**28,552**	**41,442**	**61,322**	**82,486**

Inpatients and Daycases – regionally at the end of March 2015, 52% of patients were waiting less than 13 weeks for inpatient or daycase treatment (standard: 80%), compared to 67% at the end of March 2014.

Trust	IPDC % waiting <13 weeks				
	31.3.14	30.6.14	30.9.14	31.12.14	31.3.15
Belfast	54%	53%	46%	45%	40%
Northern	85%	82%	83%	80%	76%
South Eastern	86%	80%	76%	68%	57%
Southern	75%	74%	71%	65%	69%
Western	72%	70%	70%	63%	55%
TOTAL	**67%**	**65%**	**61%**	**57%**	**52%**

Overall, during 2014/15 waiting times for inpatient and daycase treatment have increased compared to 2013/14 – at the end of March 2015, 27,778 patients were waiting longer than 13 weeks for treatment and 13,621 were waiting longer than 26 weeks.





IPDC	>13 weeks					>26 weeks				
	31.3.14	30.6.14	30.9.14	31.12.14	31.3.15	31.3.14	30.6.14	30.9.14	31.12.14	31.3.15
Belfast	10,828	11,189	13,016	14,099	16,446	3,286	3,913	4,765	6,609	8,630
Northern	888	1,066	1,029	1,088	1,419	185	201	193	202	329
South Eastern	621	1,015	1,402	2,004	2,966	78	227	337	665	1,380
Southern	1,855	2,010	2,263	2,969	2,541	253	463	654	1,131	1,162
Western	2,164	2,344	2,372	3,233	4,406	510	681	570	1,159	2,120
TOTAL	**16,356**	**17,624**	**20,082**	**23,393**	**27,778**	**4,312**	**5,485**	**6,519**	**9,766**	**13,621**

The increase in waiting times in the first half of 2014/15 was due to a combination of increased referrals and an underdelivery of commissioned volumes of core activity by Trusts across a range of specialties. During quarters one and two, non-recurrent funding was available to enable Trusts to undertake additional activity to maintain waiting times in elective care specialties where there was an agreed recurrent gap between demand and funded capacity. Typically, funding was provided to deliver approximately 20,000 additional new outpatient assessments and 6,000 inpatient/daycase procedures in each quarter. The delivery of core position has improved in quarters three and four therefore, the inability to fund additionality in the second half of 2014/15 accounts for the majority of the increase in waiting times.

During quarters one and two of 2014/15, the number of patients waiting longer than nine weeks for a first outpatient appointment increased by 33,843. More than half of this increase (59%) can be attributed to underdelivery of commissioned volumes of core activity across a range of specialties in all Trusts. However, during quarters three and four, underdelivery of core accounts for 18% of the increase in nine week waiters, with the balance (approximately 28,000) being as a result of no funding being available for additional outpatient activity.

OUTPATIENTS - Q1/Q2 (1.4.14 - 30.9.14)						
Number OPs >9 weeks (31.3.14)	Number OPs >9 weeks (30.9.14)	Variance (nn)	Delivery of Core (1.4.14-30.9.14)			
			Expected	Delivered	Variance (nn)	Variance (%)
39,768	73,611	33,843	197,161	177,332	-19,829	-10%

OUTPATIENTS - Q3/Q4 (1.10.14-31.12.14)						
Number OPs >9 weeks (30.9.14)	Number OPs >9 weeks (31.3.15)	Variance (nn)	Delivery of Core (1.10.14-31.3.15)			
			Expected	Delivered	Variance (nn)	Variance (%)
73,611	107,957	34,346	197,160	190,896	-6,264	-3%

In relation to inpatient/daycase treatment, the increase in the number of patients waiting longer than 13 weeks during quarters one and two (3,726) can be fully attributed to underdelivery of core however, in the second half of the 2014/15 60% of the increase is accounted for by underdelivery of core.

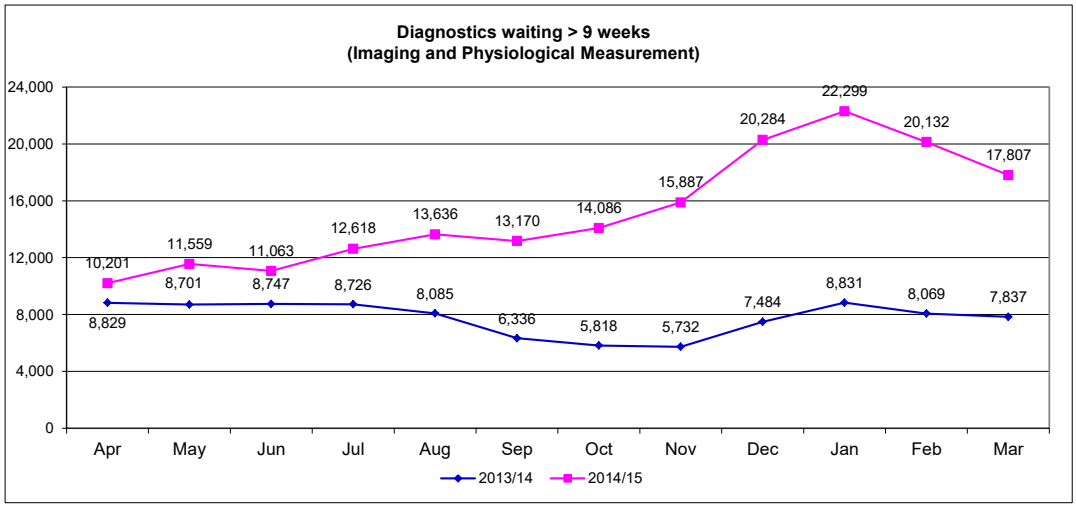
INPATIENT/DAYCASES - Q1/Q2 (1.4.14 - 30.9.14)						
Number IPDC >13 weeks (31.3.14)	Number IPDC >13 weeks (30.9.14)	Variance (nn)	Delivery of Core (1.4.14-30.9.14)			
			Expected	Delivered	Variance (nn)	Variance (%)
16,356	20,082	3,726	79,576	74,049	-5,527	-7%

INPATIENT/DAYCASE - Q3/Q4 (1.10.14-31.12.14)						
Number IPDC >13 weeks (30.9.14)	Number IPDC >13 weeks (31.3.15)	Variance (nn)	Delivery of Core (1.10.14-31.3.15)			
			Expected	Delivered	Variance (nn)	Variance (%)
20,082	27,778	7,696	79,585	74,936	-4,649	-6%

At end of March 2015, a number of patients had been waiting longer than 52 weeks for outpatient assessment (3,600) and inpatient/daycase treatment (2,000) in a range of specialties across all Trusts. Given the current financial position there is unlikely to be any significant additional outpatient or inpatient/daycase activity in 2015/16 in specialties where there is a recurrent gap between funded capacity and demand and,

regrettably, this will result in a further increase in the number of patients waiting longer than the Ministerial maximum waiting time standards for elective care. In view of the financial position and the waiting time position, the focus of the Board will be to ensure that Trusts deliver the commissioned volumes of core activity in 2015/16 to minimise the increase in waiting times and continue to target the longest waiting patients to achieve the best possible waiting time outcomes.

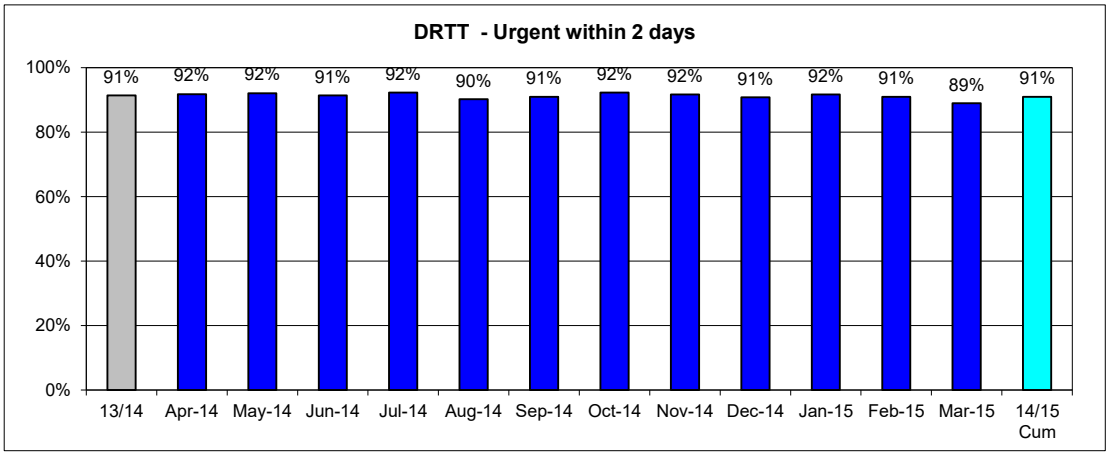
- *Diagnostics* – the length of time patients have waited for a diagnostic test has improved during the final quarter of 2014/15. At the end of March 2015, 17,807 patients were waiting longer than nine weeks.



Trust	Diagnostics (>9 weeks)				
	31.3.14	30.6.14	30.9.14	31.12.14	31.3.15
Belfast	5,154	6,317	5,174	7,370	7,729
Northern	1,258	2,527	4,806	7,395	5,847
South Eastern	299	797	817	1,010	1,288
Southern	740	1,183	1,888	3,697	2,673
Western	386	239	485	812	270
TOTAL	**7,837**	**11,063**	**13,170**	**20,284**	**17,807**

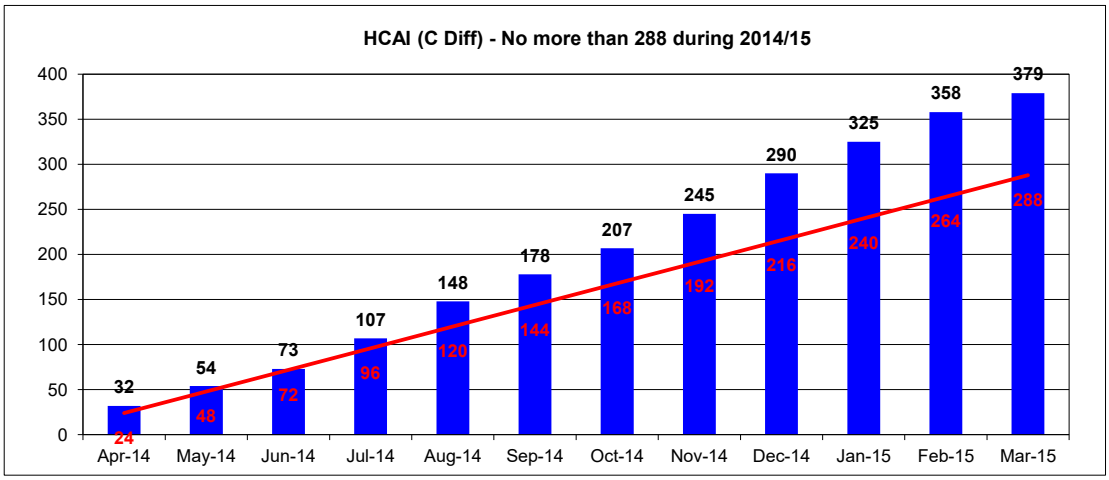
Given that diagnostics are essential in diagnosing patient conditions and enabling a treatment plan to be put in place for patients, the Board has prioritised the allocation of the limited funding currently available for elective care in 2015/16 for diagnostics. As a result, waiting times are expected to improve further during 2015/16.

- *Diagnostic Reporting (Urgent)* – cumulatively during 2014/15, 91% of urgent diagnostic tests, including plain film x-rays, were reported on within two days of the test being undertaken (standard: 100%). This position is unchanged from 2013/14.



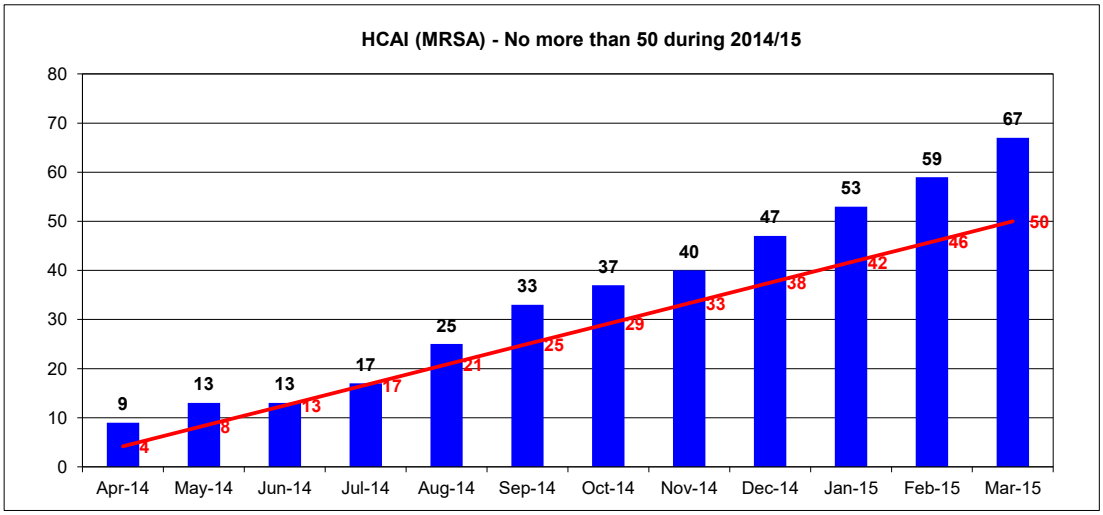
Trust	DRTT (urgent) - % within 2 days (inc plain film)					
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum
Belfast	87%	89%	89%	90%	89%	89%
Northern	98%	98%	98%	97%	98%	98%
South Eastern	96%	97%	96%	97%	96%	96%
Southern	88%	87%	84%	83%	77%	84%
Western	92%	90%	91%	92%	85%	91%
Region	**91%**	**91%**	**90%**	**91%**	**88%**	**91%**

- *Healthcare associated infections (C. difficile)* – regionally, the 2014/15 target to have no more than 288 cases of C. Difficile has not been achieved – there have been 379 episodes of C. Difficile during 2014/15. All Trusts exceeded their target levels for 2014/15.



Trust	C.Diff - No more than 288 during 2014/15		
	2014/15 Maximum	2014/15 Actual	Variance
Belfast	105	140	35
Northern	56	62	6
South Eastern	50	67	17
Southern	32	39	7
Western	45	71	26
Region	**288**	**379**	**91**

- *Healthcare Associated Infections (MRSA)* – regionally, the 2014/15 target to have no more than 50 cases of MRSA has not been achieved – there have been 67 cases of MRSA during 2014/15.

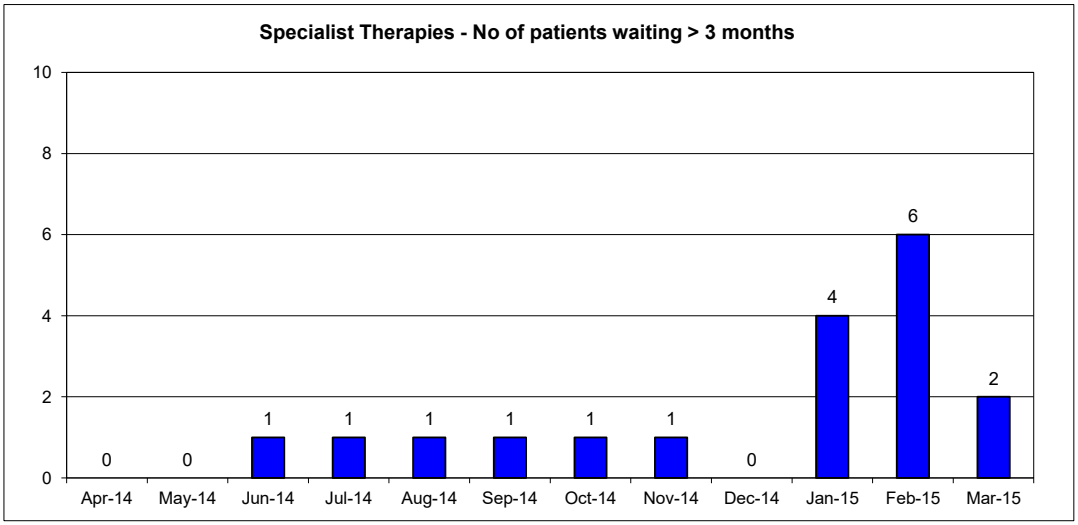


With regard to individual Trusts, the number of cases of MRSA in Northern and South Eastern Trusts was within their respective target levels for 2014/15 however, the remaining Trusts exceeded their target levels – during 2014/15, Belfast Trust had 28 cases of MRSA against a target to have no more than 16; Southern Trust had nine cases against a target maximum of three; and, Western Trust had 12 cases of MRSA against target maximum of nine.

Trust	MRSA - No more than 50 during 2014/15		
	2014/15 Maximum	2014/15 Actual	Variance
Belfast	16	28	12
Northern	11	11	0
South Eastern	11	7	-4
Southern	3	9	6
Western	9	12	3
Region	**50**	**67**	**17**

- *Organ Transplants* – during 2014/15, Belfast Trust delivered a total of 98 kidney transplants, including live, DCD (donation after cardiac death) and DBD (donation after brain death) donors (target: 80 by March 2015).

- *Specialist drug therapies* – at the end of March 2015, two patients were waiting longer than three months to commence NICE approved specialist therapies for rheumatoid arthritis, psoriatic arthritis, ankylosing sponylitis or psoriasis (standard: 3 months).

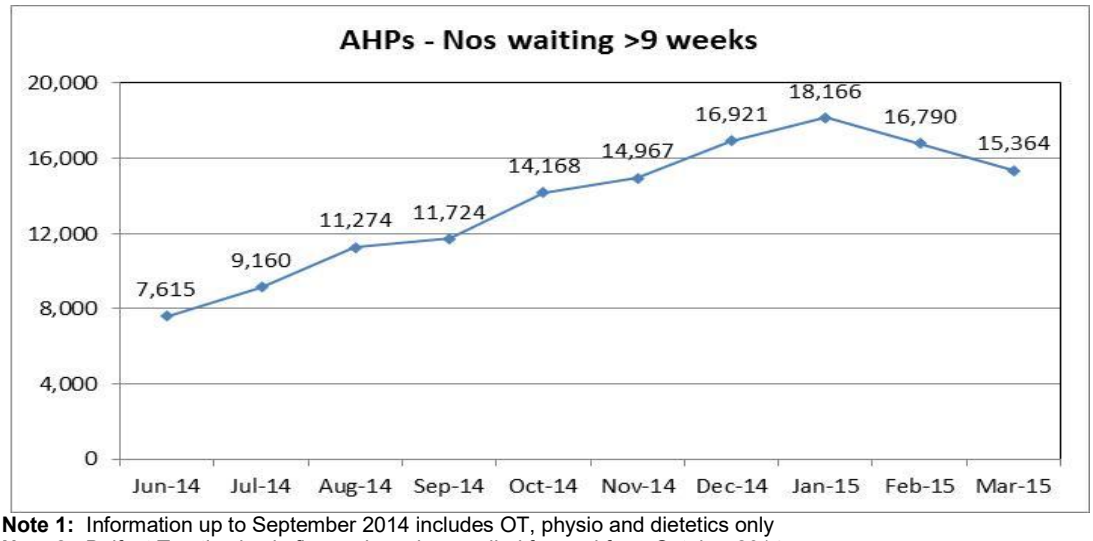


Trust	Specialist Drugs (rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis or psoriasis) - No >3 months				
	Mar-14	Jun-14	Sep-14	Dec-14	Mar-15
Belfast	0	0	0	0	1
Northern	0	0	0	0	0
South Eastern	0	1	0	0	1
Southern	0	0	1	0	0
Western	0	0	0	0	0
Region	**0**	**1**	**1**	**0**	**2**

PRIORITY AREA: TO IMPROVE THE MANAGEMENT OF LONG-TERM CONDITIONS IN THE COMMUNITY, WITH A VIEW TO IMPROVING THE QUALITY OF CARE PROVIDED AND REDUCING THE INCIDENCE OF ACUTE HOSPITAL ADMISSIONS FOR PATIENTS WITH ONE OR MORE LONG TERM CONDITIONS

- *AHP* – given the variation in the AHP information that was being reported by Trusts and the inconsistencies in how the definitions were being applied, formal reporting of AHP performance was suspended during quarter one of 2014/15 to allow Trusts to apply the revised AHP waiting time definitions and to put in place arrangements to consistently report performance in line with these definitions.

This work has been completed and waiting time information has been available for all AHP services from October 2014 – regionally at the end of March 2015, 15,364 patients were waiting longer than nine weeks from referral to commencement of AHP treatment.



Note 1: Information up to September 2014 includes OT, physio and dietetics only
Note 2: Belfast Trust's physio figures have been rolled forward from October 2014

Trust	number of patients waiting >9wks (all AHP services)		
	Oct-14	Dec-14	Mar-15
Belfast	5,559	5,654	5,659
Northern	4,069	5,071	4,004
South Eastern	378	567	362
Southern	1,605	2,437	2,425
Western	2,557	3,192	2,914
Region	**14,168**	**16,921**	**15,364**

Note 1: Belfast Trust's physio figures have been rolled forward from October 2014

Regionally, three quarters of the breaches of the nine week maximum waiting time standard at the end of March 2015 continue to be in two AHP professions (physiotherapy and occupational therapy) – at the end of March 2015, 7,591 and 3,879 patients were waiting longer than nine weeks from referral to commencement of treatment for physiotherapy and occupational therapy respectively.

AHP	Number of patients waiting >9wks by profession		
	Oct-14	Dec-14	Mar-15
Physio	6,770	8,265	7,591
OT	4,349	4,823	3,879
Dietetics	1,251	1,318	832
SLT	891	1,286	1,877
Podiatry	761	1,100	912
Orthoptics	83	87	15
MDT	63	42	258
Region	**14,168**	**16,921**	**15,364**

Note 1: Belfast Trust's physio figures have been rolled forward from October 2014

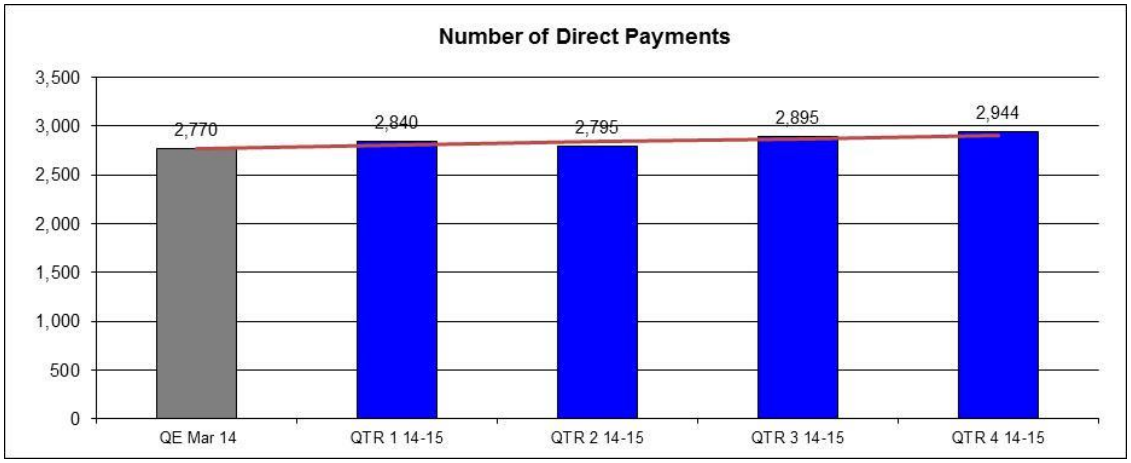
Issues over the accuracy of AHP information remain and the Board and PHA are meeting with Trusts to discuss the findings from the demand and capacity exercise and to agree the steps to be taken to ensure more robust information is available to inform actions to reduce waiting times in 2015/16.

TO PROMOTE SOCIAL INCLUSION, CHOICE, CONTROL, SUPPORT AND INDEPENDENCE FOR PEOPLE LIVING IN THE COMMUNITY, ESPECIALLY OLDER PEOPLE AND THOSE INDIVIDUALS AND THEIR FAMILIES LIVING WITH DISABILITIES

- *Carers' assessments* – regionally at the end of March 2015, 3,076 carers' assessments had been offered (target: 3,226 by March 2015).

Trust	Carers' Assessments (+10%)			
	Baseline (March 2014)	2014/15 Target	2014/15 Actual	2014/15 (Variance)
Belfast	496	546	649	103
Northern	764	840	723	-117
South Eastern	589	648	585	-63
Southern	704	774	762	-12
Western	380	418	357	-61
Region	**2,933**	**3,226**	**3,076**	**-150**

- *Direct Payments* – regionally the target to increase the number of direct payments across all programmes of care by 5% (to 2,909) has been achieved.



Trust	Direct Payments (+5%)			
	Baseline (March 2014)	2014/15 Target	2014/15 Actual	2014/15 (Variance)
Belfast	501	526	518	-8
Northern	609	639	624	-15
South Eastern	586	615	618	3
Southern	695	730	742	12
Western	379	398	442	44
Region	**2,770**	**2,909**	**2,944**	**36**

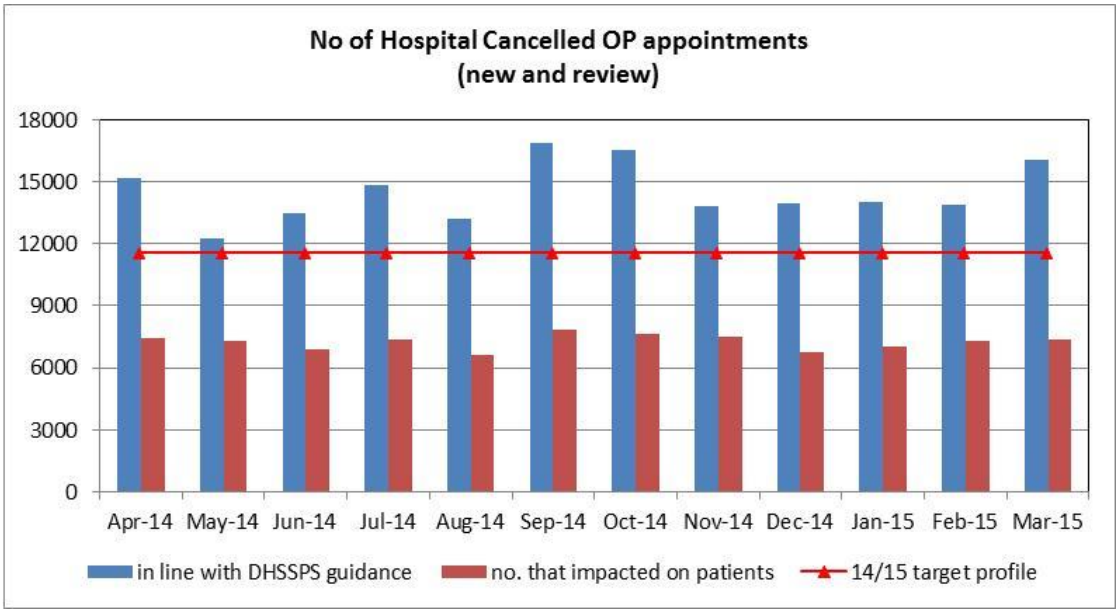
PRIORITY AREA: TO IMPROVE PRODUCTIVITY BY ENSURING EFFECTIVE AND EFFICIENT ALLOCATION AND UTILISATION OF ALL AVAILABLE RESOURCES, IN LINE WITH PRIORITIES

- *Cancelled clinics* – during 2014/15, the Board has continued to monitor and report the number of hospital cancelled consultant-led outpatient appointments in line with the latest definitions and guidance outlined by the Department of Health Statistics Branch in their Quarterly Outpatient Activity Statistical Return (Version 3 August 2011) however, it should be noted that the way in which cancelled clinics are recorded means that the cancellation rates reported are overstated as a number of the reasons recorded on PAS for cancellation will not result in lost capacity.

  At the request of the Health Committee (in February 2013), a Short Life Working Group was set up to establish how information on cancelled appointments could be recorded in order to be able to identify where there has been a direct impact on patients and to quantify actual lost capacity. As a result of this work, information on the number of

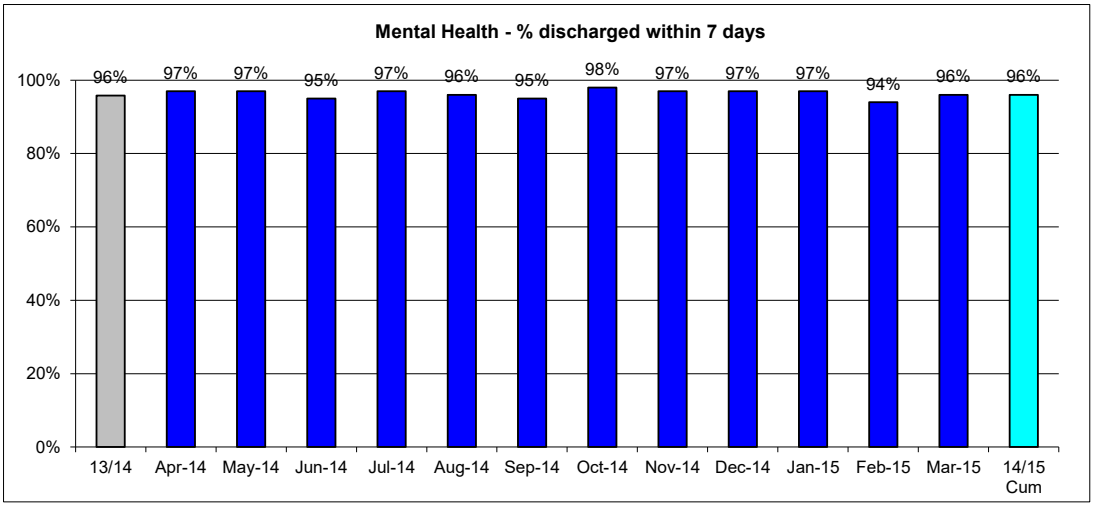
hospital cancelled consultant-led outpatient appointments that had an impact on patients is now available.

Regionally during 2014/15, 173,947 consultant-led outpatient appointments (new and review) were cancelled and, of these, 86,899 are considered to have had a direct impact on patients (target: 17% reduction by March 2015, i.e. no more than 138,753 hospital cancelled consultant-led outpatient appointments during 2014/15).



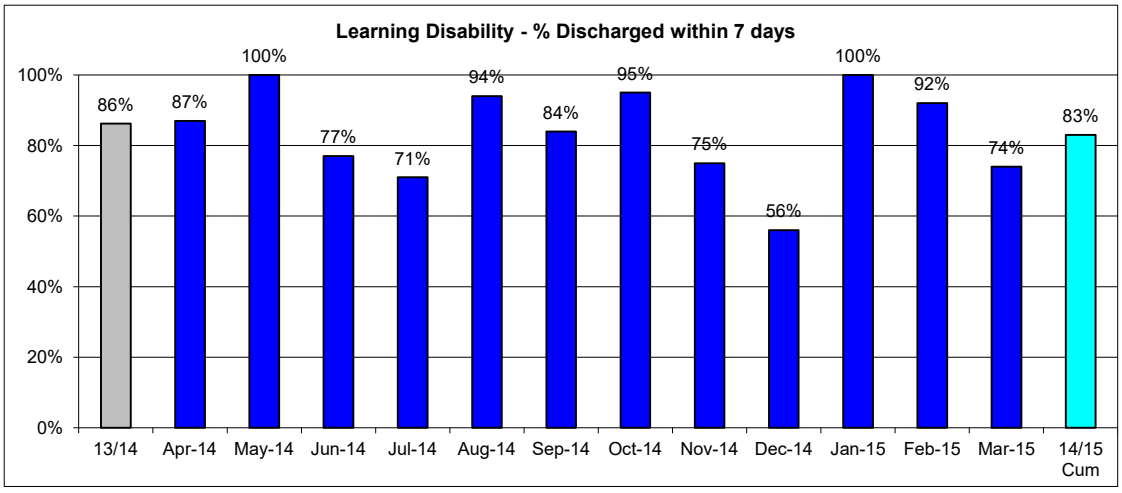
Trust	Cancelled Consultant led OP Clinics (new and review) (-17%)			
	2014/15 Target Maximum	2014/15 Actual	2014/15 Variance	2014/15 Number that had an impact on patients
Belfast	63,436	80,329	16,893	40,655
Northern	19,580	26,225	6,645	12,979
South Eastern	19,167	24,714	5,547	11,246
Southern	12,645	17,326	4,681	9,055
Western	23,925	25,353	1,428	12,964
Region	**138,753**	**173,947**	**35,194**	**86,899**

- *Patient Discharge (mental health)* – regionally during 2014/15, 96% (4,748 out of 4,929) of mental health discharges took place within seven days of the patient being assessed as medically fit for discharge and 97 took longer than 28 days (standard: 99% within seven days and none longer than 28 days). This compares with 96% within seven days in 2013/14 and 65 longer than 28 days (August 2013 to March 2014).



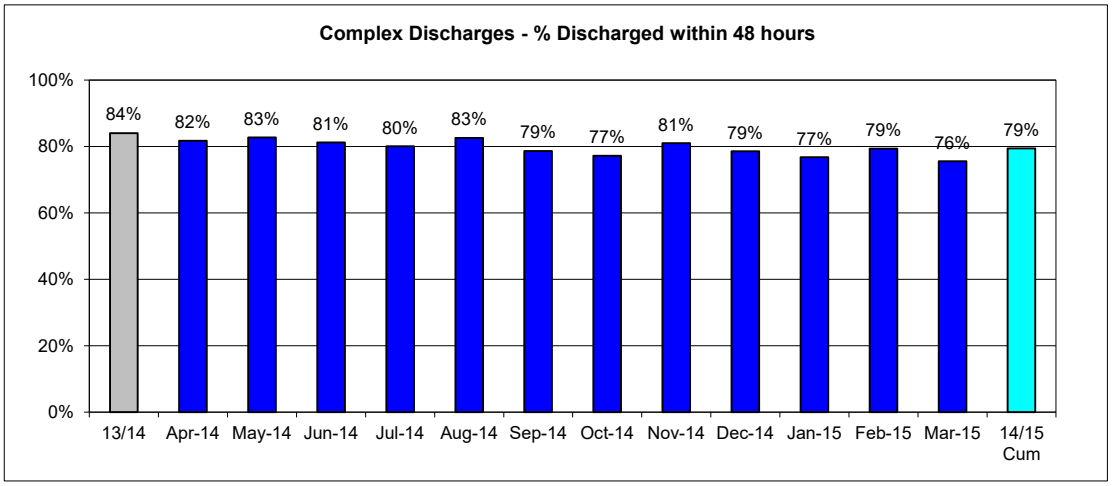
Trust	Mental Health - % discharge within 7 days						2014/15 No >28 days
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum	
Belfast	100%	98%	100%	95%	97%	98%	8
Northern	94%	100%	100%	100%	100%	100%	0
South Eastern	95%	88%	85%	100%	95%	94%	33
Southern	95%	97%	96%	94%	93%	95%	24
Western	96%	94%	98%	96%	96%	97%	32
Region	**96%**	**95%**	**95%**	**97%**	**96%**	**96%**	**97**

- *Patient Discharge (learning disability)* – regionally during 2014/15, 83% (152 out of 184) of learning disability discharges took place within seven days of the patient being assessed as medically fit for discharge and 26 took longer than 28 days (standard: 99% within seven days and none longer than 28 days). This compares with 86% within seven days in 2013/14 and 17 longer than 28 days (August 2013 to March 2014).



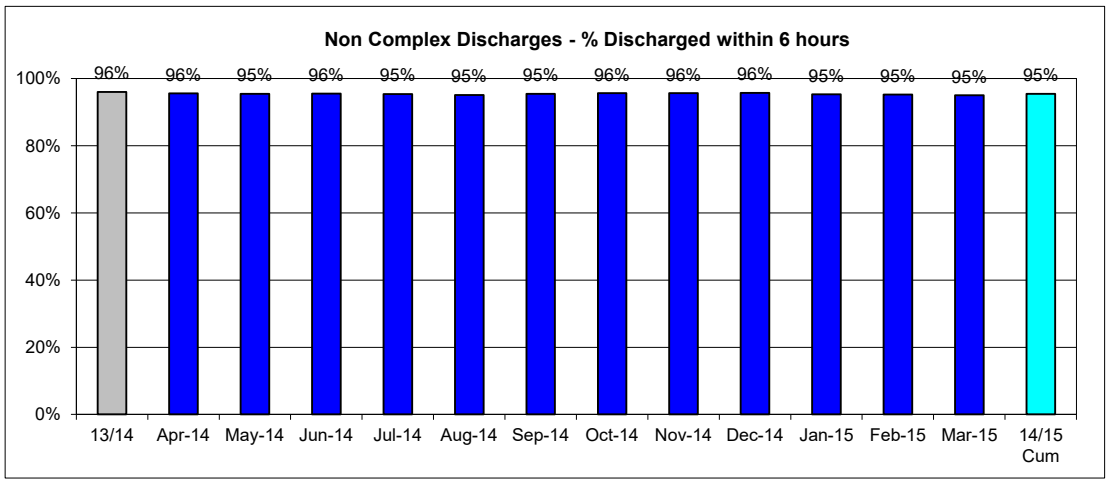
Trust	Learning Disability - % discharge within 7 days						2014/15 No >28 days
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum	
Belfast	91%	100%	100%	50%	40%	79%	12
Northern	96%	no discharges	80%	75%	100%	91%	3
South Eastern	94%	100%	60%	50%	100%	82%	6
Southern	72%	50%	100%	0%	67%	74%	4
Western	87%	33%	100%	67%	50%	84%	1
Region	**86%**	**77%**	**84%**	**56%**	**74%**	**83%**	**26**

- *Hospital Discharges (complex)* – regionally during 2014/15, 79% of complex discharges from an acute hospital took place within 48 hours and 1,518 took longer than seven days. (standard: 90% within 48 hours and none longer than seven days). During 2013/14, 84% took place within 48 hours and 1,025 took longer than seven days.



Trust	Complex Discharges - % < 48 hours						2014/15 No >7 days
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum	
Belfast	64%	60%	59%	55%	46%	55%	486
Northern	88%	87%	81%	87%	82%	85%	280
South Eastern	82%	75%	76%	68%	68%	75%	439
Southern	96%	95%	94%	95%	94%	96%	23
Western	90%	89%	87%	86%	83%	87%	290
Region	**84%**	**81%**	**79%**	**79%**	**76%**	**79%**	**1,518**

- *Hospital Discharges (non-complex)* – regionally during 2014/15, 95% of non-complex discharges from an acute hospital took place within six hours (standard: 100%). This position is broadly unchanged from 2013/14 – 96%.



Trust	Non-Complex Discharge - % within 6 hours					
	13/14 Cum	Jun-14	Sep-14	Dec-14	Mar-15	14/15 Cum
Belfast	98%	98%	97%	97%	98%	98%
Northern	96%	96%	95%	95%	94%	95%
South Eastern	93%	92%	92%	93%	92%	92%
Southern	93%	92%	93%	94%	93%	93%
Western	96%	96%	97%	96%	95%	96%
Region	**96%**	**96%**	**95%**	**96%**	**95%**	**95%**

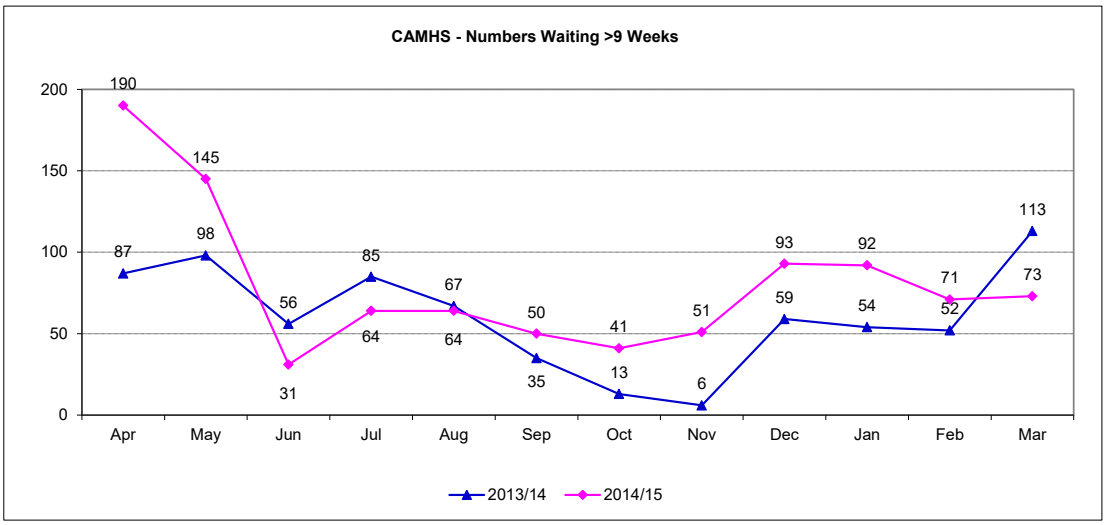
PRIORITY AREA: TO ENSURE THE MOST VULNERABLE IN OUR SOCIETY, INCLUDING CHILDREN AND ADULTS AT RISK OF HARM, ARE LOOKED AFTER EFFECTIVELY ACROSS ALL OUR SERVICES

- *Resettlement (Learning Disability and Mental Health)* – in order to ensure achievement of the Ministerial target that all long stay patients in learning disability and psychiatric hospitals are resettled to appropriate places in the community by 31 March 2015, Trusts were required to resettle 49 learning disability patients and 43 mental health patients during 2014/15. Regionally, at the end of March 2015, 13 learning disability and 20 mental health patients have been resettled. A detailed update on the resettlement programme is attached at Tab A.

RESETTLEMENT	LEARNING DISABILITY		MENTAL HEALTH	
	2014/15 Target	Total number resettled at 31.3.15	2014/15 Target	Total number resettled at 31.3.15
Belfast	23*	6	10	3
Northern	11	2	6	1
South Eastern	13	4	7	7
Southern	1	0	10	8
Western	1	1	10	1
TOTAL	**49**	**13**	**43**	**20**

* 1 patient deceased

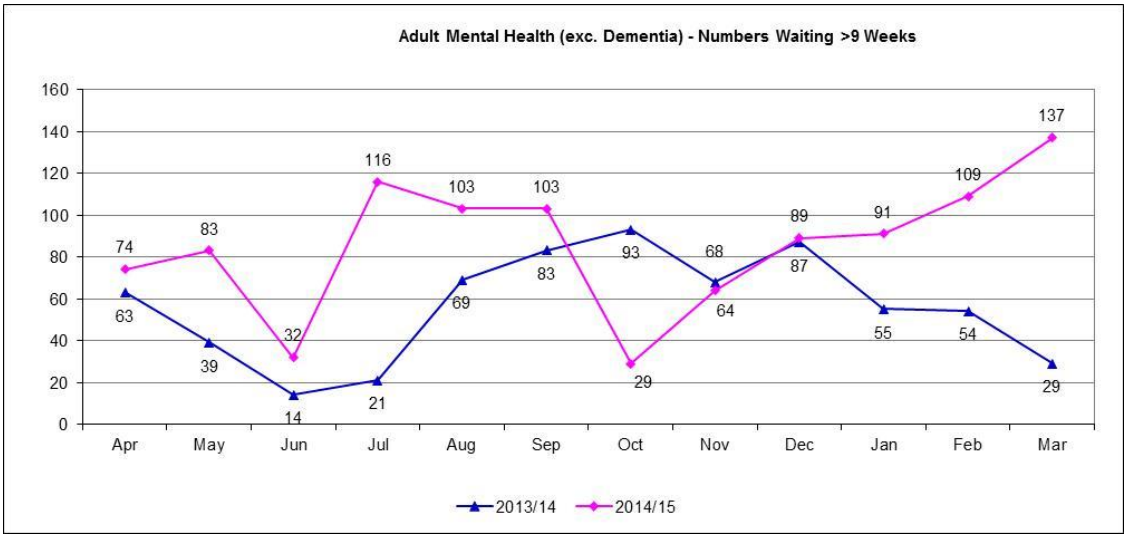
- *CAMHS (9 weeks)* – regionally at the end of March 2015, the number of patients waiting longer than nine weeks to access child and adolescent mental health services has reduced compared to the position at the end of March 2014. At the end of March 2015, 73 patients were waiting longer than nine weeks – compared to 113 at the end of March 2014. It should be noted that 72 of the patients waiting longer than nine weeks at end of March 2015 are in the Northern Trust.



Trust	CAMHS - No > 9 weeks				
	Mar-14	Jun-14	Sep-14	Dec-14	Mar-15
Belfast	1	3	2	2	1
Northern	112	28	48	91	72
South Eastern	0	0	0	0	0
Southern	0	0	0	0	0
Western	0	0	0	0	0
Region	**113**	**31**	**50**	**93**	**73**

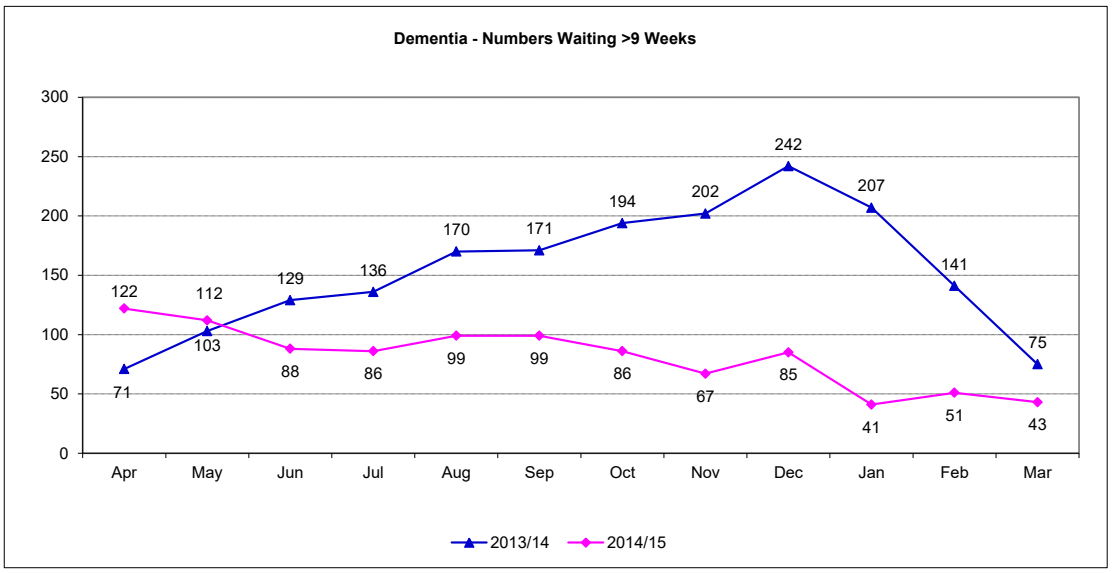
The Northern Trust has reported that this position is as a result of a shortfall in capacity due to staffing issues (vacancies and sickness absence). The Trust has a recovery plan in place to achieve the nine-week maximum waiting time standard by July 2015.

- *Adult Mental Health Services (9 weeks)* – regionally at the end of March 2015, the number of patients waiting longer than nine weeks to access adult mental health services has increased compared to the position at the end of March 2014. At the end of March 2015, 137 patients were waiting longer than nine weeks, an increase of 108 compared to the previous year.



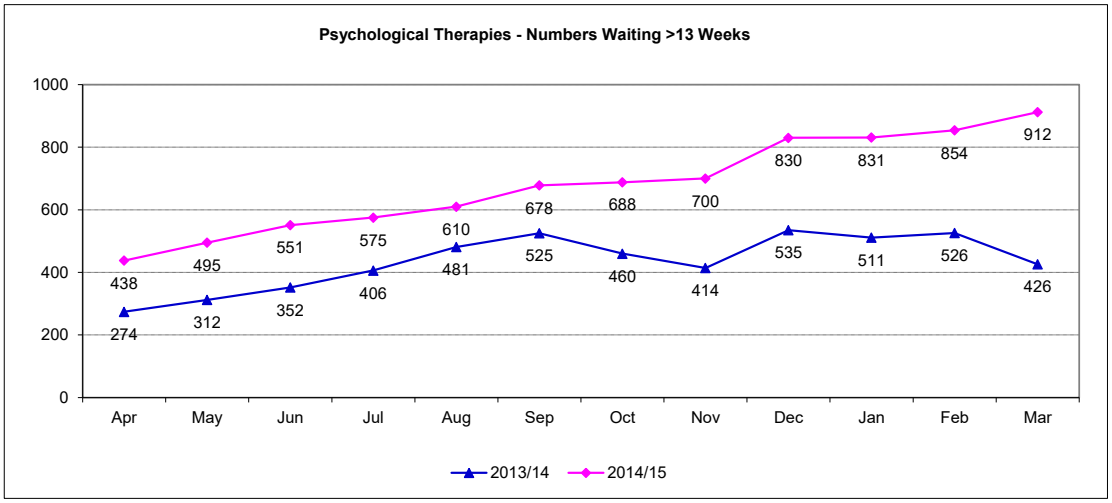
Trust	Adult MH - No > 9 weeks				
	Mar-14	Jun-14	Sep-14	Dec-14	Mar-15
Belfast	27	28	64	36	35
Northern	2	0	0	2	0
South Eastern	0	0	0	15	0
Southern	0	1	35	9	65
Western	0	3	4	27	37
Region	**29**	**32**	**103**	**89**	**137**

- *Dementia Services (9 weeks)* – regionally at the end of March 2015, 43 patients were waiting longer than nine weeks to access dementia services, compared to 75 at the end of March 2014.



Trust	Dementia Services - No > 9 weeks				
	Mar-14	Jun-14	Sep-14	Dec-14	Mar-15
Belfast	0	0	0	0	0
Northern	1	0	0	5	0
South Eastern	0	0	0	0	0
Southern	74	88	99	79	41
Western	0	0	0	1	2
Region	**75**	**88**	**99**	**85**	**43**

- *Psychological Therapies (13 weeks)* – regionally, the number of patients waiting longer than 13 weeks to access psychological therapies has continued to increase during 2014/15 – at the end of March 2015, 912 patients were waiting longer than 13 weeks compared to 426 at the end of March 2014.



Trust	Psychological Therapies > 13 wks				
	Mar-14	Jun-14	Sep-14	Dec-14	Mar-15
Belfast	148	124	143	168	164
Northern	78	128	115	64	112
South Eastern	200	254	330	481	487
Southern	0	7	27	32	54
Western	0	38	63	85	95
Region	**426**	**551**	**678**	**830**	**912**

More than half (53%) of patients waiting longer than 13 weeks to access psychological therapies at the end of March 2015 were in South Eastern Trust. A paper providing a detailed update on the issues impacting on waiting time performance in psychological therapies and the actions being taken to address these was provided at the March 2015 Board meeting.

Conclusion

More detail on the actions being taken in relation to these and other performance areas will be provided by the relevant Directors at the Board meeting.

Michael Bloomfield
Director of Performance and Corporate Services
May 2015

Tab A

Long Stay Resettlement

Introduction

In line with a Ministerial Target that no-one should be living unnecessarily in a Mental Health or Learning Disability Hospital, the Board has been overseeing a Resettlement Programme.

Senior Board staff, in partnership with Trusts and NIHE colleagues, have been commissioning new homes in the community with appropriate care and support.

New Supported Living, Residential and Nursing home services have been developed to meet individual assessed needs.

In addition to the success of the movement from hospitals to community settings the Board has also commissioned independent Quality of Life Assessments from Advocacy Providers such as Mencap and Bryson Care Group.

Learning Disability Resettlement

At 1 April 2007, the total long stay population (Primary Targeting List) in learning disability hospitals in Northern Ireland was 347. This was identified as the Primary Targeting List population to be resettled.

Between 1 April 2007 and 31 March 2015, 269 long stay patients were resettled:

	Number Resettled (by year)
2007/08	39
2008/09	36
2009/10	14
2010/11	27
2011/12	24
2012/13	42
2013/14	74
2014/15	13
Total	**269**

A total of 43 patients were deceased over this period.

At 31 March 2015, 35 long stay patients remained in learning disability hospitals. These patients are categorised as follows:

	Number
Planned to be resettled by 31 March 2016	28
Planned to be resettled after 31 March 2016	4
Patients remaining in treatment/detained or legal challenge to being resettled	3
Total	**35**

32 patients have plans for resettlement which had not commenced by 31 March 2015. This is due to some schemes being delayed due to procurement, planning permission

issues and being new builds. Almost two thirds (20) of these patients are planned to commence resettlement during summer 2015 with the longest four planned to be resettled into a new build which will not be completed until the 2016/17 financial year.

Mental Health Resettlement

The total long stay population (Primary Targeting List) in psychiatric hospitals in Northern Ireland was 472 at 1 April 2007. This was identified as the Primary Targeting List population to be resettled.

Between 1 April 2007 and 31 March 2015, 288 long stay patients were resettled:

	Number Resettled (by year)
2007/08	7
2008/09	86
2009/10	56
2010/11	38
2011/12	25
2012/13	27
2013/14	29
2014/15	20
Total	**288**

A total of 161 patients were deceased over this period.

At 31 March 2015, 23 long stay patients remained in psychiatric hospitals. These patients are categorised as follows:

	Number
Planned to be resettled by 31 March 2016	11
Planned to be resettled after 31 March 2016	5
Patients remaining in treatment/detained or legal challenge to being resettled	7
Total	**23**

Resettlement plans are in place for 16 patients which had not commenced by 31 March 2015. This is due to some schemes being delayed due to procurement, planning permission issues and being new builds. Five of these patients are planned to be resettled into new builds which will not be completed until the 2016/17 financial year.

Quality of Life Questionnaires

This overview report will provide the initial findings from the Quality of Life questionnaires completed so far by residents of Muckamore Abbey Hospital who have been resettled into the community. The purpose of these questionnaires is to see if betterment has been met.

Breakdown of numbers

To date, the Board has received quality of life information on 81 individuals. Of these, 60 were from Bryson and 21 were from Mencap. Below is a breakdown of how many of each questionnaire has been completed, starting from the initial questionnaire which was completed before the resident had been resettled up to 12 months after their resettlement, and the same for Family and Carer questionnaires.

Initial – 71
6 week – 8
3 month – 43
6 month – 35
12 month – 31
Family initial – 43
Family 6 week – 7
Family 3 month – 22
Family 6 month – 22
Family 12 month - 21

There are various reasons for the discrepancy in numbers. Some reasons given on the questionnaires were that quality of life assessment was started after the individual had been resettled so there is no initial questionnaire completed although in several instances a note has been included that initial questionnaires will be sought. There is also a very small number of completed 6 week assessments which seems to be because only a small number of individuals received these. The low number of family questionnaires compared with individual questionnaires is mainly due to the individual not having any family or having no family contact for various reasons such as family fallout or the family requesting not to be contacted. Questionnaires are still being received so these gaps in numbers may reduce as more questionnaires are submitted.

Main points and themes

At a glance, the overall opinion is an extremely positive one. In almost all assessments a major theme has been the feeling from individuals and their families that betterment has been met through the move to the community. It should be noted that in the initial questionnaires almost all families and carers were very pessimistic and negative about moving their family member out of the hospital setting where they felt they were well cared for and safe and there were worries that medical care would not be as good outside the hospital setting. These feelings change dramatically in the follow up questionnaires where family members noted how they had seen vast improvements in their loved one's quality of life and communication with other residents and staff. This view was mirrored by the individuals and the MDT. A very small number of residents found it hard to settle in and get used to their surroundings but within 6 months this issue seems to resolve itself. One issue that families and MDTs have found is that essential equipment, such as power packs for wheelchairs, took a long time to be fitted and delivered. Another positive trend that has come out of these questionnaires is that individuals have a lot more choice in the community than they did in the hospital with regards to the food they want to eat, clothes they want to wear and things they like to do. Individuals have also indicated that they have much more opportunity to get out and socialise with others in the community and pursue interests and activities which has improved their overall quality of life.

HSC BOARD PERFORMANCE REPORT – 2016/17 (Month 9 – December 2016)

Purpose

This paper provides Board members with an assessment of performance against the 2016/17 standards and targets set out in the Minister's Commissioning Plan Direction (Northern Ireland) 2016. The position regionally and by Trust at the end of December 2016 for the targets and standards that the HSCB is responsible for monitoring and where monitoring information is currently available is set out in Annex A.

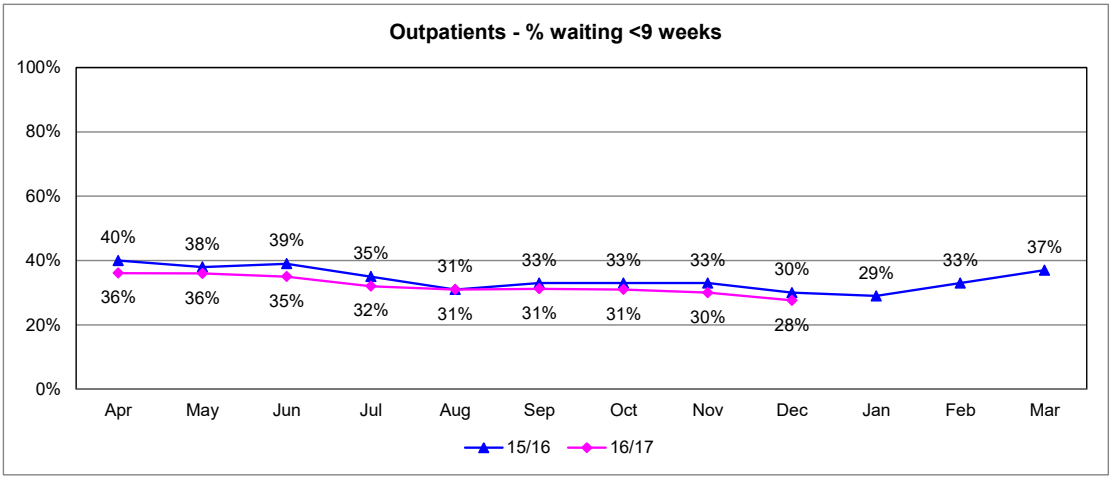
Performance

The key performance challenges, including the reasons for the current performance and the actions being taken to address these, largely remain as reported at previous Board meetings. An update on performance in a number of these areas is provided below – full details are provided in Annex A.

In addition, a paper on Pressure Ulcer Prevention is attached at Annex B.

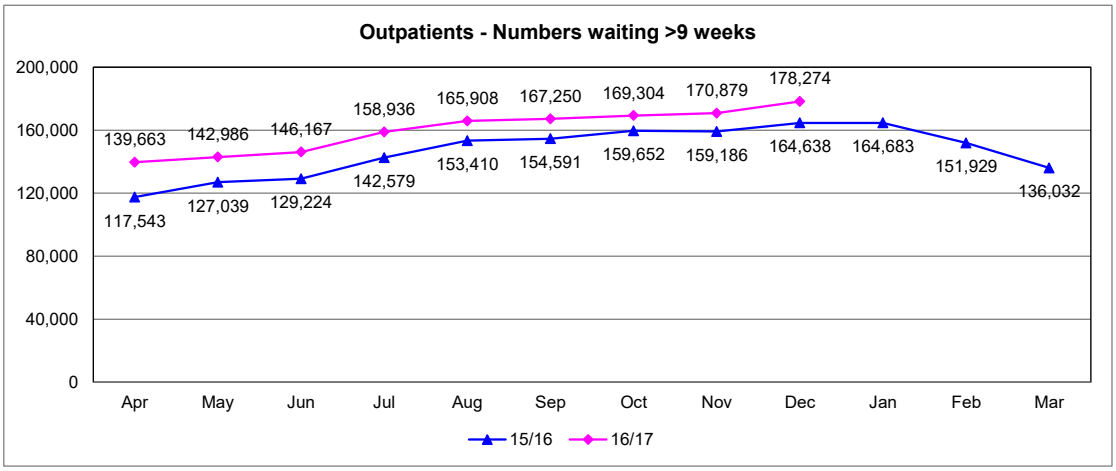
1. Elective Care (including Diagnostics)

At the end of December 2016, 28% of patients waiting for a first outpatient appointment were waiting less than nine weeks.

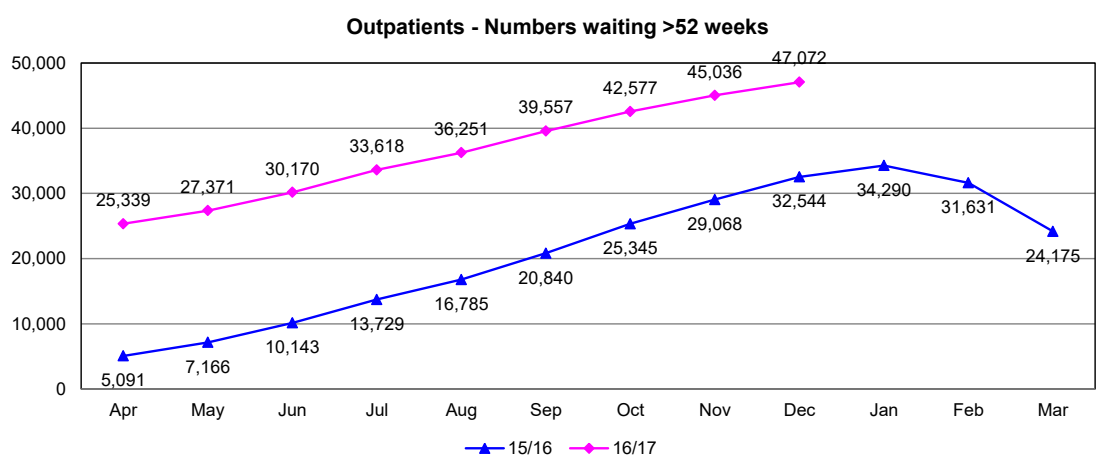


Trust	OP - % waiting <9 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	32%	32%	32%	31%	29%	27%	28%	28%	28%	25%
Northern	47%	43%	42%	42%	38%	36%	36%	35%	35%	32%
South Eastern	34%	35%	36%	34%	31%	29%	30%	29%	27%	24%
Southern	40%	39%	38%	38%	35%	33%	34%	34%	34%	31%
Western	42%	41%	41%	39%	35%	34%	35%	36%	35%	33%
Region	**37%**	**36%**	**36%**	**35%**	**32%**	**31%**	**31%**	**31%**	**30%**	**28%**

The number of outpatients waiting longer than nine weeks has continued to increase – at the end of December 2016, 178,274 patients were waiting longer than nine weeks compared to 170,879 at the end of November (+7,395). The number waiting longer than 52 weeks has increased from 45,036 at the end of November to 47,072 at the end of December (+2,036).

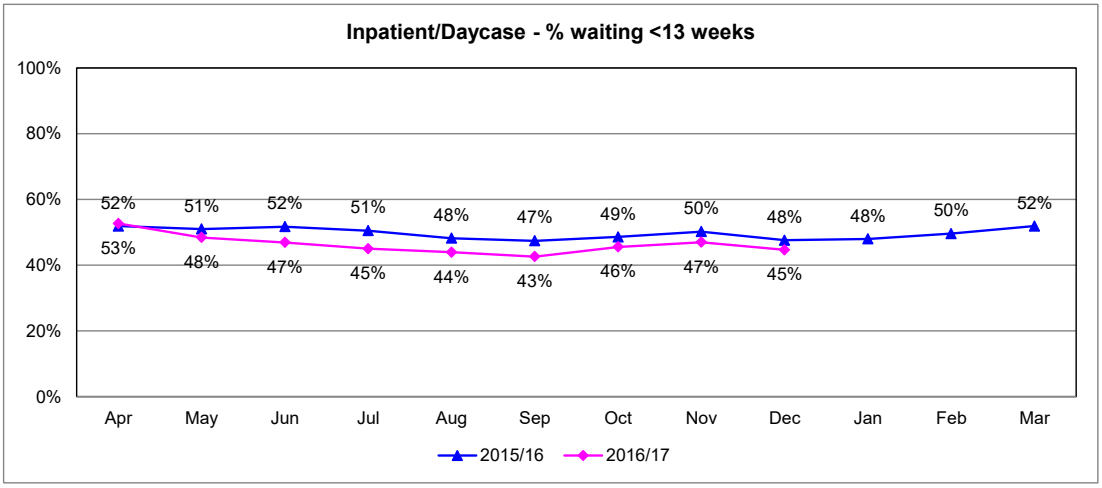


Trust	OP No waiting >9 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	59,234	60,068	60,836	61,148	65,307	67,701	67,658	67,940	68,310	70,405
Northern	12,609	14,731	15,691	15,286	17,935	18,900	18,507	19,309	19,422	20,010
South Eastern	28,022	27,246	27,480	29,019	32,038	34,264	35,604	36,861	38,135	40,642
Southern	20,408	21,665	22,654	23,242	25,282	26,099	25,907	26,038	26,169	27,367
Western	15,759	15,953	16,325	17,472	18,374	18,944	19,574	19,156	18,843	19,850
Region	**136,032**	**139,663**	**142,986**	**146,167**	**158,936**	**165,908**	**167,250**	**169,304**	**170,879**	**178,274**



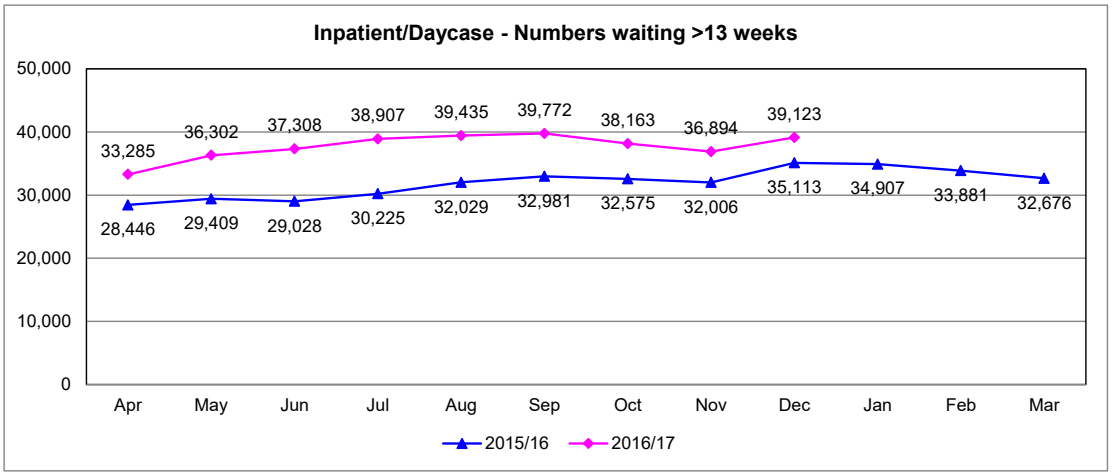
Trust	OP No waiting >52 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	15,431	15,749	16,967	18,455	19,849	21,093	22,939	24,273	25,280	26,100
Northern	651	1,062	1,220	972	1,698	2,077	1,955	2,463	2,701	2,576
South Eastern	3,850	3,861	3,661	4,116	4,689	5,197	6,019	6,593	7,296	8,425
Southern	1,696	1,991	2,388	2,821	3,278	3,546	3,827	4,151	4,413	4,320
Western	2,547	2,676	3,135	3,806	4,104	4,338	4,817	5,097	5,346	5,651
Region	**24,175**	**25,339**	**27,371**	**30,170**	**33,618**	**36,251**	**39,557**	**42,577**	**45,036**	**47,072**

The proportion of patients waiting less than 13 weeks for <u>inpatient or daycase treatment</u> has reduced – at the end of December 2016, 45% of patients were waiting less than 13 weeks compared to 47% at the end of November.

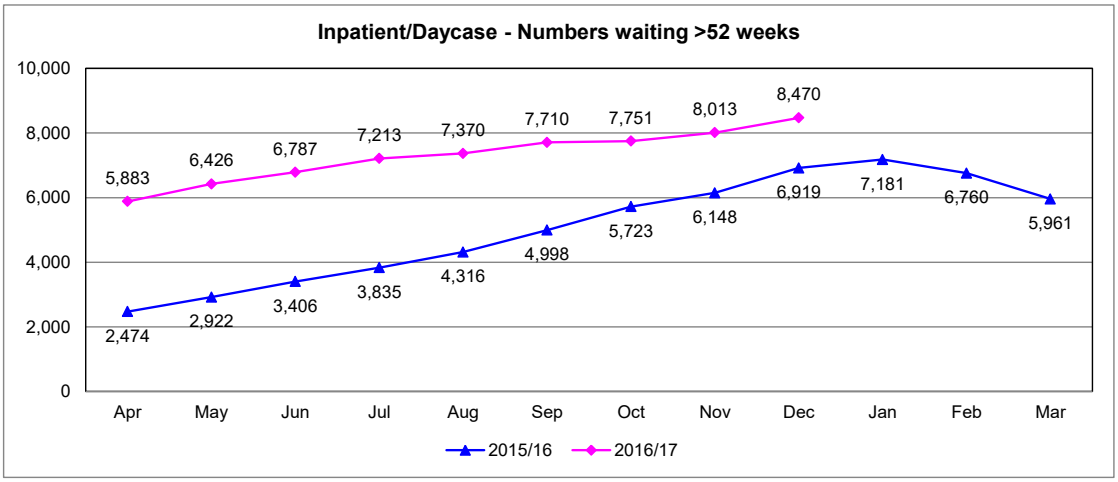


Trust	IPDC - % waiting <13 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	43%	47%	41%	39%	37%	37%	36%	38%	38%	36%
Northern	71%	68%	65%	63%	62%	62%	63%	67%	71%	68%
South Eastern	52%	52%	49%	47%	45%	44%	44%	49%	52%	53%
Southern	64%	63%	60%	59%	56%	53%	52%	54%	55%	53%
Western	50%	49%	47%	48%	45%	43%	43%	44%	44%	42%
Region	**52%**	**53%**	**48%**	**47%**	**45%**	**44%**	**43%**	**46%**	**47%**	**45%**

The number of patients waiting longer than 13 weeks for inpatient or daycase treatment has increased – at the end of December 2016, 39,123 patients were waiting longer than 13 weeks compared to 36,894 at the end of November (+2,229). The number of patients waiting longer than 52 weeks for treatment has also increased albeit to a lesser extent than those waiting longer than 13 weeks – at the end of December 2016, 8,470 patients were waiting longer than a year compared to 8,013 at the end of November (+457).



Trust	IPDC - No waiting >13 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	16,542	16,099	17,856	18,688	18,956	18,761	19,003	18,602	18,238	19,051
Northern	2,684	2,709	2,841	2,786	2,892	2,816	2,592	2,298	2,002	2,220
South Eastern	4,443	4,495	4,799	5,036	5,214	5,308	5,246	4,628	4,158	4,149
Southern	3,154	3,396	3,754	3,850	4,242	4,497	4,638	4,542	4,390	4,796
Western	5,853	6,586	7,052	6,948	7,603	8,053	8,293	8,093	8,106	8,907
Region	**32,676**	**33,285**	**36,302**	**37,308**	**38,907**	**39,435**	**39,772**	**38,163**	**36,894**	**39,123**



Trust	IPDC - No waiting >52 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	3,097	2,887	3,173	3,300	3,436	3,552	3,764	3,815	3,970	4,185
Northern	26	32	36	46	55	48	43	42	36	30
South Eastern	1,074	985	1,065	1,137	1,208	1,126	1,094	915	803	791
Southern	446	476	505	516	578	603	699	783	846	881
Western	1,318	1,503	1,647	1,788	1,936	2,041	2,110	2,196	2,358	2,583
Region	**5,961**	**5,883**	**6,426**	**6,787**	**7,213**	**7,370**	**7,710**	**7,751**	**8,013**	**8,470**

As previously reported, given the ongoing financial challenges and the gap between funded health service capacity and patient demand, it is inevitable that elective waiting times will continue to increase in 2016/17.

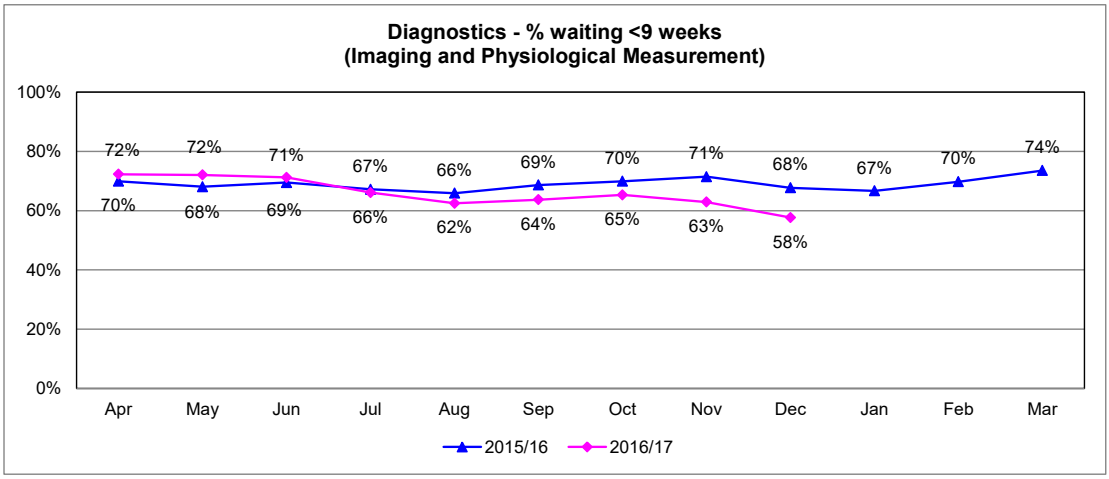
Trusts are continuing to undertake the additional in-house activity associated with the allocation of non-recurrent funding for elective care in Q3/Q4 of 2016/17. Trusts are targeting those areas where the additional elective activity will have the greatest impact in addressing patient safety issues and long waiting times.

The increase in waiting times seen in the first nine months of this year has been further compounded by an underdelivery of commissioned volumes of core elective activity across a range of specialties by all HSC Trusts – regionally during the first nine months of 2016/17, there has been a 9.2% (28,549) underdelivery of new outpatient core activity compared to 5.8% during the same period in 2015/16. In relation to delivery of commissioned volumes of inpatient/daycase volumes, there has been a 7.3% (8,532) underdelivery of core activity during the period April to December 2016 compared to 6.8% during the same period last year.

As previously reported, the HSCB has required Trusts to produce elective improvement plans for a number of specialties detailing the forecast improvement in delivery of core and waiting times in the second half of this year. The HSCB is continuing to monitor performance against the Trusts' plans to ensure that progress is being made to deliver

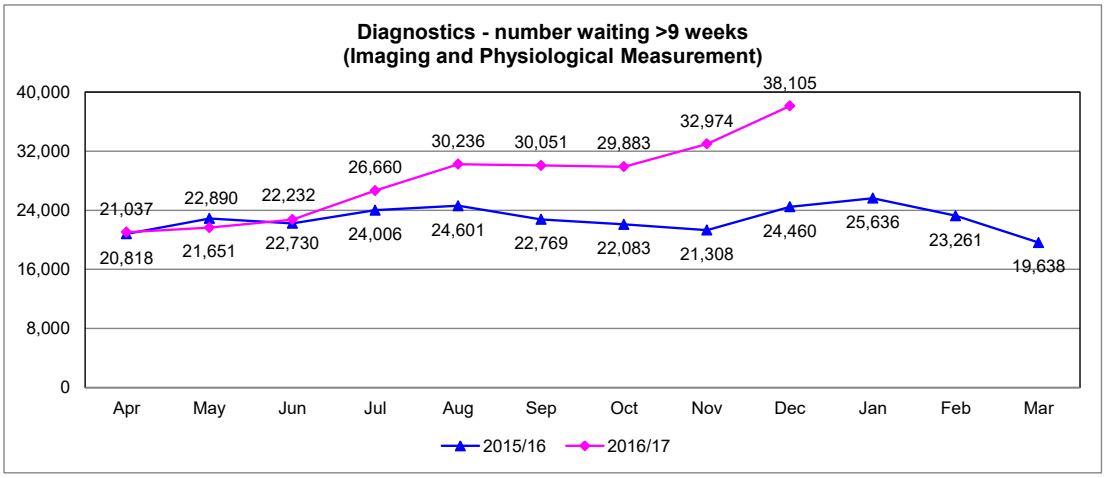
the agreed outcomes. Where progress is not in line with Trusts' plans, this is escalated between the HSCB and the relevant Trust to agree what remedial actions the Trust plans to take.

The proportion of patients waiting less than nine weeks for diagnostics has reduced – at the end of December 2016, 58% were waiting less than nine weeks compared to 63% at the end of November.

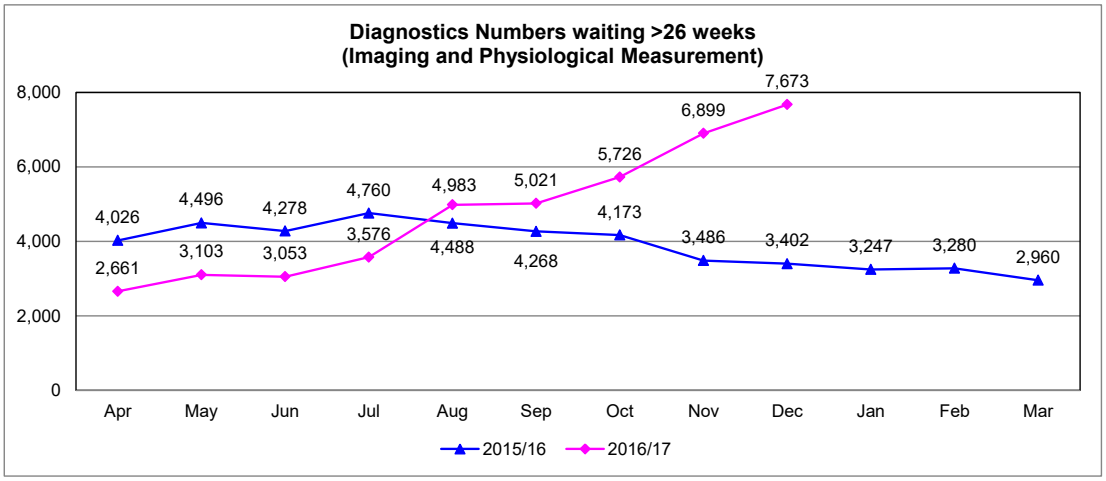


Trust	Diagnostics - % waiting <9 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	65%	63%	64%	61%	57%	52%	51%	52%	50%	44%
Northern	66%	71%	71%	73%	65%	63%	68%	73%	74%	70%
South Eastern	83%	79%	78%	76%	73%	72%	74%	75%	71%	66%
Southern	77%	73%	71%	72%	69%	66%	68%	65%	62%	57%
Western	97%	97%	95%	94%	88%	83%	82%	83%	81%	76%
Region	**74%**	**72%**	**72%**	**71%**	**66%**	**62%**	**64%**	**65%**	**63%**	**58%**

Regionally the number of patients waiting longer than nine weeks for a diagnostic test has increased – at the end of December 2016, 38,105 patients were waiting longer than nine weeks compared to 32,974 at the end of November (+5,131). The number waiting longer than 26 weeks has also increased, from 6,899 at the end of November to 7,673 at the end of December (+774).



Trust	Diagnostics - No waiting >9 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	8,813	9,648	9,982	10,545	12,813	14,466	14,577	14,748	16,465	18,927
Northern	5,334	4,435	4,259	3,835	5,282	6,150	5,413	4,624	4,666	5,298
South Eastern	1,570	2,037	2,128	2,289	2,511	2,587	2,438	2,399	2,805	3,334
Southern	3,721	4,699	4,911	4,769	5,059	5,619	5,824	6,518	7,272	8,260
Western	200	218	371	530	995	1,414	1,643	1,594	1,766	2,286
Region	**19,638**	**21,037**	**21,651**	**21,968**	**26,660**	**30,236**	**29,895**	**29,883**	**32,974**	**38,105**



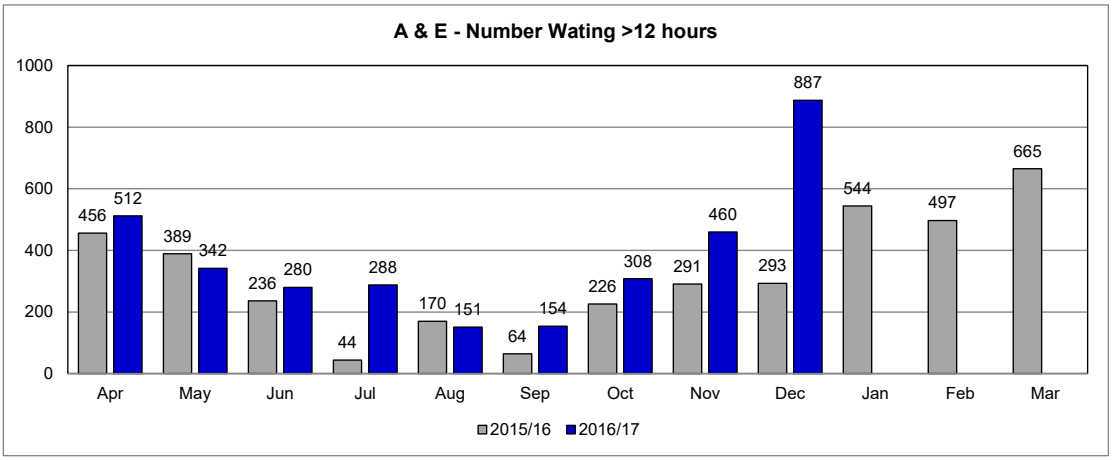
Trust	Diagnostics No waiting >26 weeks									
	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	1,231	1,364	1,858	1,794	2,254	3,406	3,525	3,899	4,835	5,538
Northern	1,584	1,166	1,080	1,064	1,079	1,126	1,017	1,068	893	642
South Eastern	94	78	101	118	166	261	300	376	605	611
Southern	51	51	62	65	75	188	225	383	532	736
Western	0	2	2	0	2	2	0	0	34	146
Region	**2,960**	**2,661**	**3,103**	**3,041**	**3,576**	**4,983**	**5,067**	**5,726**	**6,899**	**7,673**

Trusts are continuing to undertake the additional diagnostic activity associated with the non-recurrent funding allocated in-year therefore, the continued increase in waiting times is a matter of concern. The HSCB has been exploring the reasons for the increase at its recent round of performance meetings with Trusts and understands that, in some areas, the additional activity associated with the non-recurrent funding has been completed but is not yet reflected in the numbers waiting and, in others, all of the additional activity will be undertaken in Q4. Furthermore, there are a number of modalities where the growth in waiting times is due to increased patient demand and the HSCB is exploring the possibility of funding additional activity in these areas.

2. Emergency Department (ED) (4-hour and 12-hour standards)

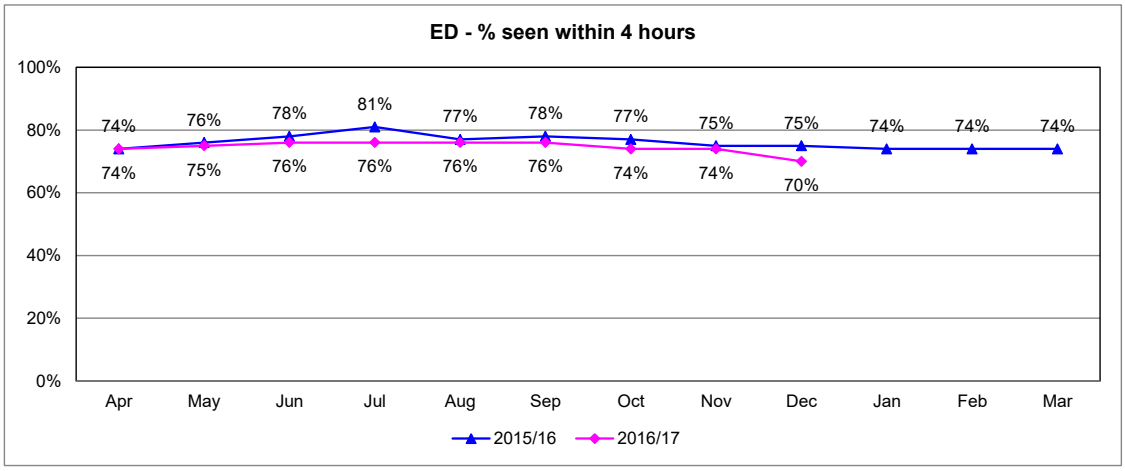
Regionally during the month of December 2016, 887 patients waited longer than 12 hours in ED – this is an increase on the previous month (460) and on the same month last year (293).

During the first nine months of 2016/17, there has been an increase in the number of patients who waited longer than 12 hours (3,382) compared with the same period last year (2,169). There has been an increase in the number of patients waiting longer than 12 hours in four of the five Trusts – Belfast, Northern, Southern and Western Trusts. In contrast, there has been a slight reduction in the number of patients who waited longer than 12 hours in South Eastern Trust – 906 in 2016/17 (April to December) compared to 937 during the same period in 2015/16.



A&E - 12 hours												
Trust	2016/17										2015/16	
	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum (1.4.16-31.12.16)	Dec-15	15/16 Cum (1.4.15-31.12.15)
Belfast	136	91	72	13	28	78	95	110	159	**782**	18	**650**
Northern	74	87	96	184	24	46	118	163	275	**1,067**	89	**522**
South Eastern	171	74	75	86	83	24	52	133	208	**906**	175	**937**
Southern	82	63	24	3	0	0	13	18	143	**346**	2	**13**
Western	49	27	13	2	16	6	30	36	102	**281**	9	**47**
Region	**512**	**342**	**280**	**288**	**151**	**154**	**308**	**460**	**887**	3,382	**293**	2,169

In relation to the 4-hour standard, regionally during December 2016, 70% of patients were treated and discharged, or admitted within four hours – this is a reduction on the previous month (74%) and on the same month last year (75%).



A&E - % <4 hours												
Trust	2016/17										2015/16	
	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum (1.4.16-31.12.16)	Dec-15	15/16 Cum (1.4.15-31.12.15)
Belfast	72%	72%	75%	76%	78%	76%	74%	76%	72%	**74%**	75%	**76%**
Northern	66%	67%	67%	62%	65%	67%	68%	67%	65%	**66%**	65%	**66%**
South Eastern	81%	84%	82%	81%	80%	83%	81%	80%	75%	**81%**	80%	**81%**
Southern	77%	76%	76%	81%	79%	78%	74%	73%	70%	**76%**	79%	**81%**
Western	75%	77%	77%	80%	75%	77%	73%	73%	67%	**75%**	75%	**80%**
Region	**74%**	**75%**	**76%**	**76%**	**76%**	**76%**	**74%**	**74%**	**70%**	**75%**	**75%**	**77%**

Considerable efforts were made across the HSC in planning for the winter with preparatory work commencing much earlier than in previous years, and a particular focus on Christmas and the New Year period. Plans were developed based on a number of planning scenarios and included detail across the wider urgent care pathway to support patient flow.

For the Christmas / New Year holiday period, regional ED attendances were up 6% across the nine larger Emergency Departments compared to the same period last year, and within this some sites experienced much higher increases which were well above planning scenarios. During the same period, NIAS arrivals were 4% higher than last year.

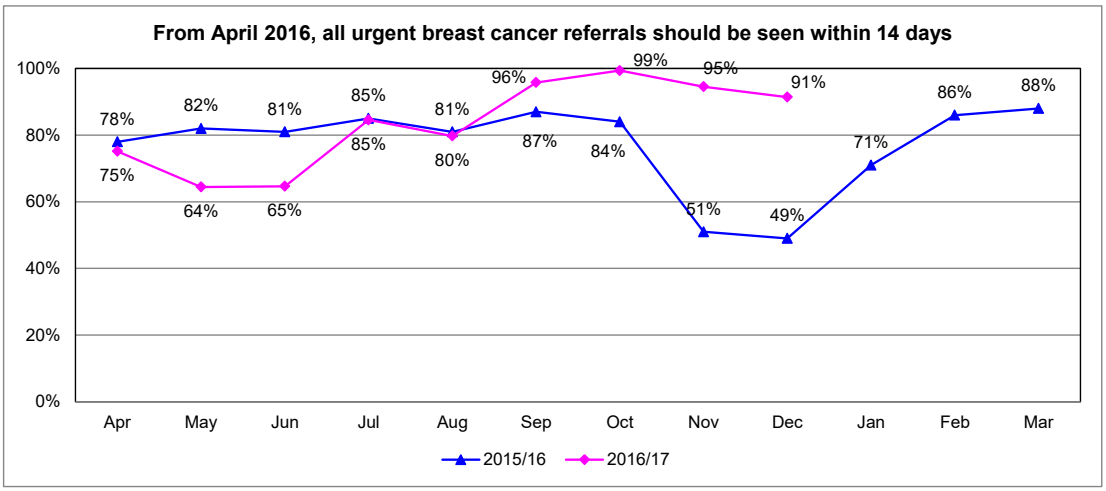
One of the main reasons for the increased pressures experienced across the holiday period was the significant number of patients who had completed their acute episode stay in hospital and whose discharge into the community or home setting was delayed for a variety of reasons including in-house process issues, the availability of domiciliary care packages, nursing home capacity and availability of step-down beds in the community. A number of hospital sites and community facilities were further challenged from both a bed capacity and staffing perspective due to outbreaks of Norovirus over the period.

The HSCB maintained a significant oversight across the region, with daily monitoring of the position at individual sites, and management of media and Ministerial briefings as required. Due to extent of unscheduled care pressures immediately following the holiday period, the HSCB established regular regional teleconference calls with all Trusts including NIAS and Primary Care to monitor the position and inform briefings to the Minister and Department.

3. Cancer Services

Breast Cancer (14 days)

Regionally performance against the 14-day breast cancer standard has deteriorated – during December 2016, 91% of urgent breast cancer referrals were seen within 14 days compared to 95% during November. It should however be noted that 100% of urgent referrals were seen within 14 days during December in Belfast, South Eastern and Western Trusts, and 97% in Northern Trust.



Trust	Cancer Services (Breast) - % within 14 days										
	15/16 Cum	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	**43%**	65%	72%	64%	87%	83%	99%	99%	99%	100%	**86%**
Northern	**78%**	92%	100%	100%	97%	99%	100%	100%	100%	97%	**98%**
South Eastern	**66%**	29%	14%	27%	100%	97%	100%	100%	100%	100%	**73%**
Southern	**93%**	69%	13%	7%	14%	12%	78%	98%	70%	39%	**46%**
Western	**99%**	100%	100%	100%	100%	100%	100%	100%	100%	100%	**100%**
Region	**76%**	**75%**	**64%**	**65%**	**85%**	**80%**	**96%**	**99%**	**95%**	**91%**	**83%**

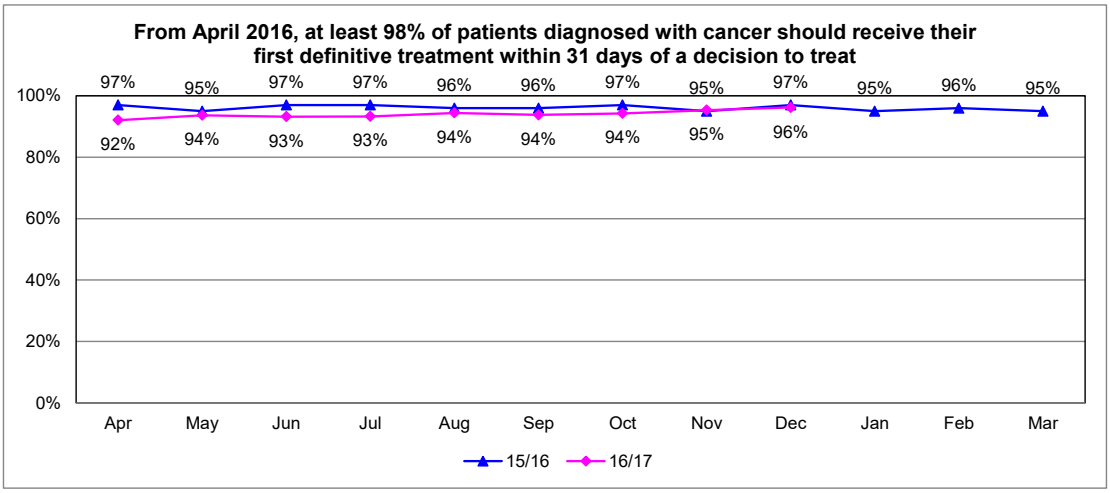
The deterioration in the regional position is primarily as a result of a decline in performance in the Southern Trust – during December 2016, 39% of urgent breast cancer referrals were seen within 14 days compared to 70% in November. The issues impacting on the Trust's performance have been reported in detail at previous Board meetings.

As a result of collaborative working across the HSC, which facilitated the transfer of Southern Trust patients to other Trusts for assessment, and the extension of existing Southern Trust staff's working hours to enable the operation of a fourth breast clinic the Trust's performance had improved (98% in October 2016). However, performance declined in November and December due to the Trust being unable to continue to provide the necessary level of additional capacity. The position was further compounded in December due to the loss of capacity over the Christmas and New Year holiday period.

The Trust is continuing to progress a number of actions to address this position including the appointment of a replacement breast surgeon and a breast radiologist (both part time) who are due to start at the end of February and April 2017 respectively. In addition, the Trust has put in place a low risk clinic staffed on temporary arrangements by a surgical registrar. Regional collaboration is also continuing, with patients being transferred to other Trusts in December and January and, subject to capacity, February. Whilst these arrangements are temporary and subject to capacity being available in other Trusts, the Trust will seek to sustain these transfers until the fourth clinic is sustainable. The Trust is currently working with clinicians in this regard.

Cancer (31 days)

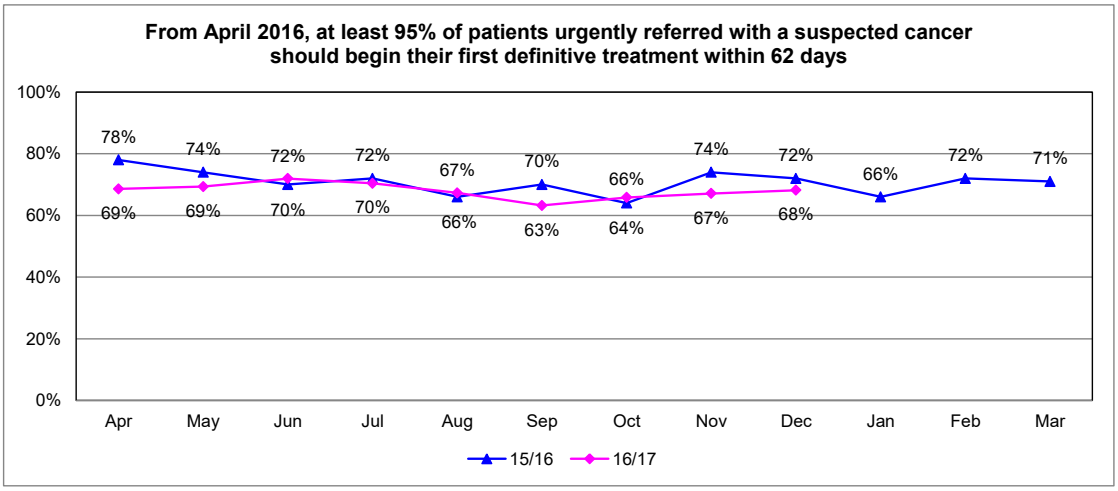
Regionally during December 2016, 96% of cancer patients commenced treatment within 31 days of the decision to treat (standard: 98%).



Trust	Cancer Services - % <31 days										
	15/16 Cum	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	**93%**	89%	90%	88%	91%	94%	90%	92%	93%	94%	**91%**
Northern	**98%**	84%	91%	87%	84%	82%	94%	95%	93%	93%	**89%**
South Eastern	**96%**	90%	95%	99%	94%	96%	94%	91%	95%	97%	**95%**
Southern	**100%**	100%	99%	99%	100%	99%	98%	97%	99%	99%	**99%**
Western	**100%**	100%	100%	100%	100%	100%	100%	100%	100%	100%	**100%**
Region	**96%**	**92%**	**94%**	**93%**	**93%**	**94%**	**94%**	**94%**	**95%**	**96%**	**94%**

Cancer (62 days)

There has been a further slight improvement in performance against the 62-day standard – during December 2016, 68% of patients urgently referred with a suspected cancer began their first definitive treatment within 62 days compared to 67% in November.



Trust	Cancer Services - % <62 days										
	15/16 Cum	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	**59%**	57%	64%	60%	58%	59%	60%	60%	65%	64%	**61%**
Northern	**72%**	70%	65%	77%	72%	72%	70%	70%	71%	69%	**71%**
South Eastern	**60%**	45%	55%	58%	70%	48%	36%	34%	38%	40%	**46%**
Southern	**88%**	91%	84%	83%	81%	78%	82%	88%	83%	91%	**85%**
Western	**91%**	86%	95%	89%	83%	88%	79%	86%	86%	82%	**86%**
Region	**71%**	**69%**	**69%**	**72%**	**70%**	**67%**	**63%**	**66%**	**67%**	**68%**	**68%**

Given the lack of progress towards achievement of the 62-day cancer access standard regionally, the HSCB is continuing to have bi-monthly Director-level cancer performance meetings with each Trust. The focus of these meetings is on the longest waits and to seek assurances from Trusts that the longest waiting patients are treated as progress is made towards improving performance to the required standard.

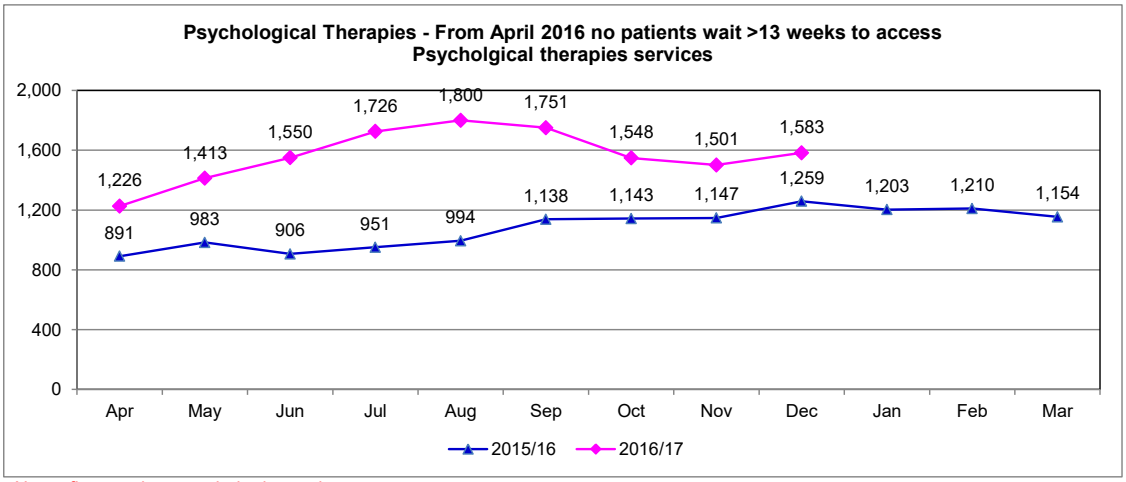
There has been a slight improvement in performance in the South Eastern Trust – during December 2016, 40% of patients urgently referred with a suspected cancer began their first definitive treatment within 62 days, compared to 38% in November and 34% in October. A significant proportion (approximately half) of the patients waiting

longer than 62 days in the Trust are on the urological cancer pathway. As a result of meetings between the HSCB and Trust, it has been acknowledged that the main reason for this position is a delay in patients receiving flexible cystoscopies. In order to address this, the HSCB has allocated non-recurrent funding to the Trust to undertake an additional 200 flexible cystoscopies in Q4 of this year. This additional activity is expected to bring about a significant improvement in the Trust's 62-day urology performance in 2017/18. It should however be noted that, given the focus on the longest waits and as performance is reported on the basis of 'completed waits' i.e. the time from the date an initial suspected urgent cancer referral is received by the Trust to the date that the patient receives their first definitive treatment (or been found to not have a cancer), a further deterioration in performance in the short term would not be unexpected.

As previously reported, the Cancer AD forum will continue to meet and will focus on addressing the longer term strategic issues to improve cancer pathways.

4. Psychological Therapies (13 weeks)

Regionally, the number of patients waiting longer than 13 weeks to access psychological therapy services has remained broadly unchanged in recent months – at the end of December 2016, 1,583 patients were waiting longer than 13 weeks compared to 1,501 at the end of November.



Note: figures above exclude dementia

Month	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	338	310	361	409	422	437	435	355	330	355
Northern	142	166	229	252	328	278	217	162	118	115
South Eastern	566	593	601	674	708	773	726	698	696	733
Southern	10	16	47	43	62	83	74	66	63	61
Western	98	141	175	172	206	229	299	267	294	319
2016/17	**1,154**	**1,226**	**1,413**	**1,550**	**1,726**	**1,800**	**1,751**	**1,548**	**1,501**	**1,583**

(excluding Dementia)

Psychological Therapies Services - Breach Analysis December 2016						
Service	**Belfast**	**Northern**	**South Eastern**	**Southern**	**Western**	**Region Total**
Adult Mental Health	44	3	386	38	171	642
Primary Care Hub	0	0	0	0	0	0
Older People-Functional Services	0	0	25	0	7	32
Adult Learning Disability	13	68	27	0	48	156
Children's Learning Disability	3	44	5	0	5	57
Adult Health Psychology	191	0	290	23	7	511
Children's Psychology	42	0	0	0	5	47
Psychosexual Services	61	0	0	0	76	137
Neurodisability Services	0	0	0	0	0	0
Specialist Trauma Care	1	0	0	0	0	1
Trust Total	**355**	**115**	**733**	**61**	**319**	**1,583**

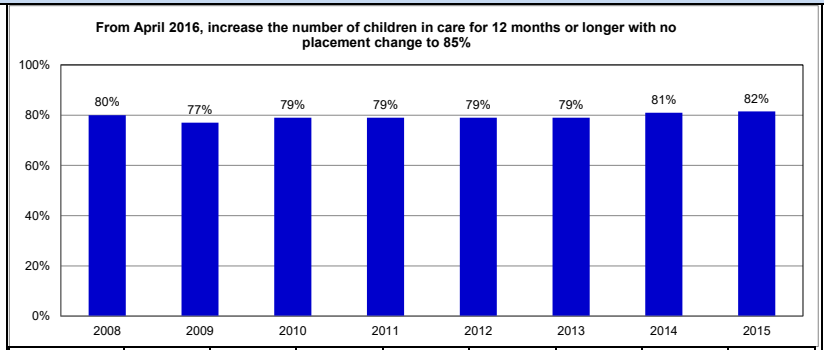
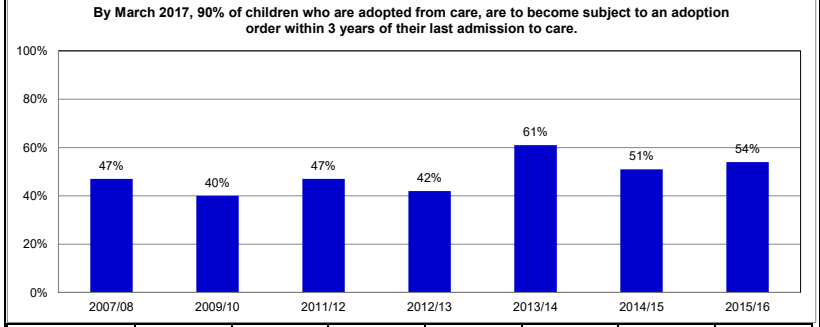
A paper providing a detailed update on the issues impacting on waiting time performance in psychological therapies was provided at the October 2016 Board meeting and the HSCB is continuing to work closely with Trusts to take forward the actions set out within the paper.

Conclusion

More detail on the actions being taken in relation to these and other performance areas will be provided by the relevant Directors at the Board meeting.

Michael Bloomfield
Director of Performance and Corporate Services
February 2017

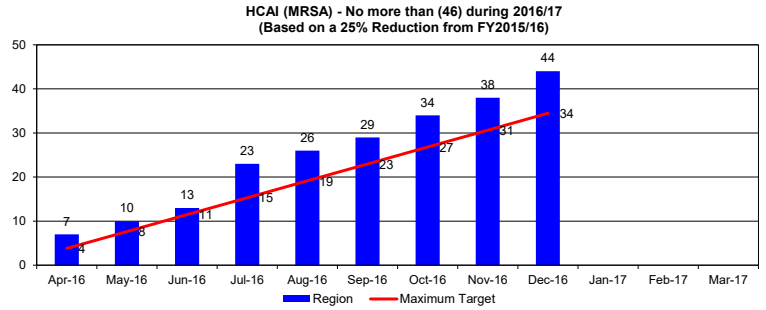
SUMMARY OF PERFORMANCE AGAINST 2016/17 COMMISSIONING PLAN DIRECTION STANDARDS AND TARGETS

Children in care 1 (standard) – during 2016/17, ensure that the proportion of children in care for 12 months or longer with no placement change is at least 85%.	 **Trust** / **2008** / **2009** / **2010** / **2011** / **2012** / **2013** / **2014** / **2015** Belfast 81% 79% 83% 84% 84% 79% 84% 84% Northern 81% 78% 78% 78% 75% 77% 78% 82% South Eastern 80% 82% 78% 81% 81% 82% 79% 82% Southern 71% 59% 73% 66% 72% 78% 81% 81% Western 85% 83% 83% 82% 86% 80% 81% 78% **Region** **80%** **77%** **79%** **79%** **79%** **79%** **81%** **82%** Source: CIB (these figures are based on Dept returns) 'Year' is school year not financial year)	Performance against this target is reported annually in arrears. Regionally during 2015 (school year), the proportion of children in care for 12 months or longer with no placement change was 82%. Monitoring information for 2016 will not be available until August 2017.
Children in care 2 (standard) – during 2016/17, ensure a three year timeframe (from date of last admission) for 90% of children who are adopted from care.	 **Trust** / **2007/08** / **2009/10** / **2011/12** / **2012/13** / **2013/14** / **2014/15** / **2015/16** Belfast 75% 31% 59% 41% 78% 63% 92% Northern 33% 38% 29% 44% 61% 75% 61% South Eastern 20% 33% 57% 64% 52% 69% 80% Southern 63% 42% 50% 50% 56% 25% 32% Western 20% 100% 60% 19% 57% 25% 38% **Region** **47%** **40%** **47%** **42%** **61%** **51%** **54%** **Source: CIB (these figures are based on Dept returns) 'Year' is school year not financial year)**	During 2015/16, there was a 3-year timeframe for 54% of children adopted from care.

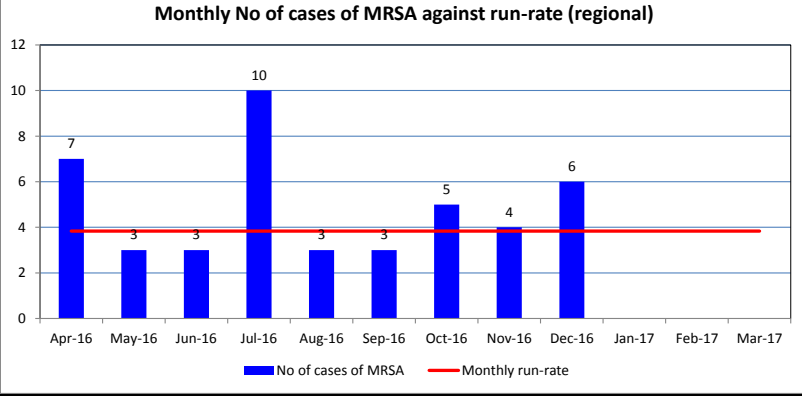
STANDARD / TARGET	Trend Analysis	Comments

Aim: to provide high quality, safe and effective care; to listen to and learn from patient and client experiences; and to ensure high levels of patient and client satisfaction

Healthcare acquired infections (target) – by March 2017, secure a reduction of 25% in MRSA and *Clostridium difficile* infections compared to 2015/16, i.e. no more than 46 cases of MRSA and no more than 302 cases of C. Difficile during 2016/17.



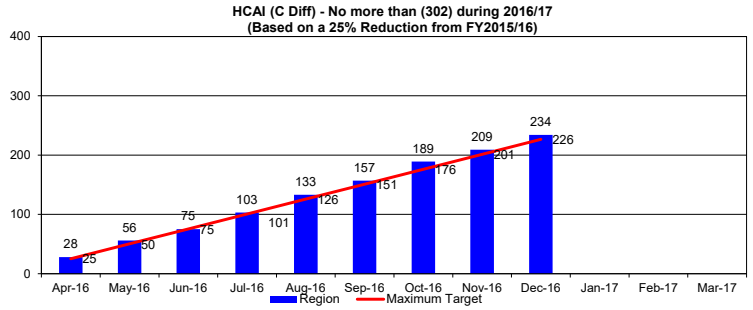
Trust	2015/16 Actual	2016/17 Target Maximum	2016/17 Target Profile (Apr-Dec)	2016/17 Actual (Apr-Dec)	Variance (actual vs target)
Belfast	34	18	14	14	0
Northern	21	10	8	9	1
South Eastern	9	6	5	13	8
Southern	2	5	4	5	1
Western	9	7	5	3	-2
Region	**75**	**46**	**34**	**44**	**10**



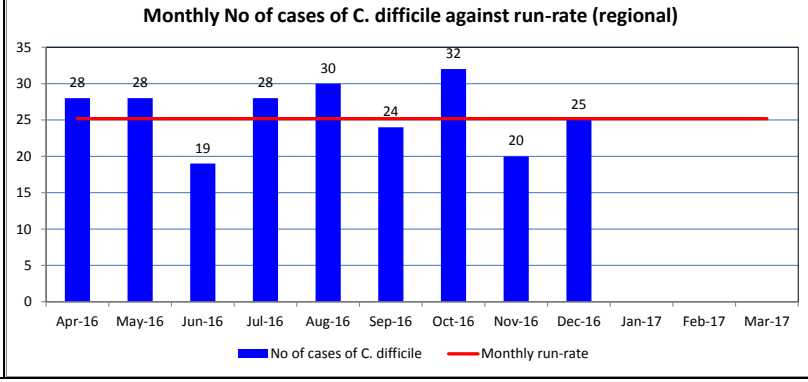
Regionally in the year to the end of December 2016, there have been 44 reported MRSA infections against a 9-month target profile to have had no more than 34.

At the end of December 2016, performance in Belfast, Northern, Southern and Western Trusts is ahead of, or broadly in line with, their respective 9-month target profiles however, South Eastern Trust has exceeded its annual target maximum by eight.

STANDARD / TARGET	Trend Analysis	Comments

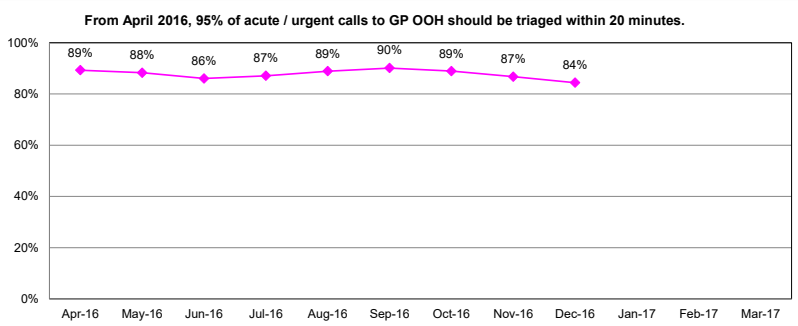
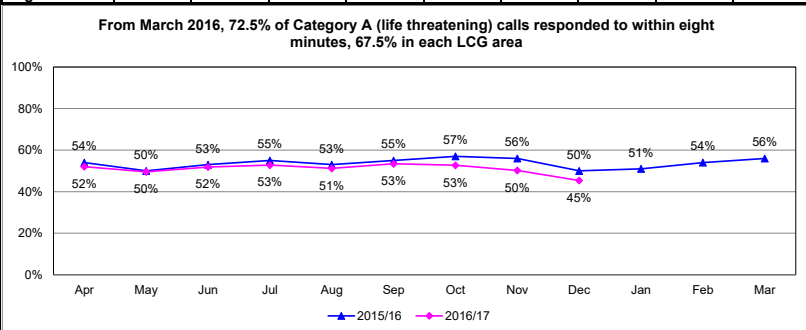
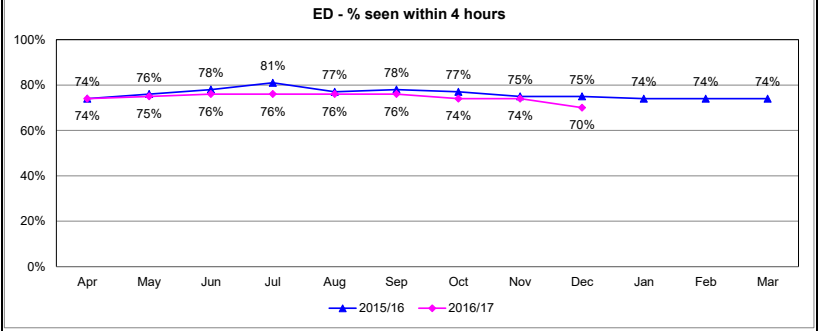


Trust	2015/16 Actual	2016/17 Target Maximum	2016/17 Target Profile (Apr-Dec)	2016/17 Actual (Apr-Dec)	Variance (actual vs target)
Belfast	129	110	83	93	10
Northern	59	57	43	34	-8
South Eastern	86	55	41	45	3
Southern	53	32	24	23	-1
Western	64	48	36	39	3
Region	**391**	**302**	**226**	**234**	**8**



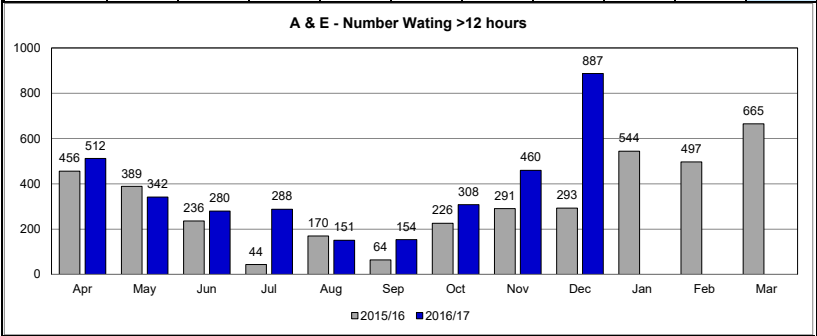
In relation to C. Difficile, regionally at the end of December 2016, there have been 234 infections against a 9-month target profile to have had no more than 226.

With regard to performance in individual Trusts, at the end of December 2016 performance in Northern and Southern Trusts is ahead of their respective 9-month target profiles however, Belfast, South Eastern and Western Trusts have exceeded their target profiles for this period.

STANDARD / TARGET	Trend Analysis	Comments
GP out-of-hours (standard) – from April 2016, 95% of acute/urgent calls to GP OOH should be triaged within 20 minutes.	 **Trust / Apr-16 / May-16 / Jun-16 / Jul-16 / Aug-16 / Sep-16 / Oct-16 / Nov-16 / Dec-16** Belfast 89% 91% 88% 87% 87% 91% 92% 88% 89% Northern 94% 94% 94% 94% 95% 96% 94% 95% 91% South Eastern 85% 81% 79% 78% 82% 79% 82% 82% 79% Southern 83% 80% 75% 81% 79% 84% 80% 77% 77% Western 91% 91% 87% 87% 92% 92% 92% 87% 85% **Region 89% 88% 86% 87% 89% 90% 89% 87% 84%**	During December 2016, 84% of acute/urgent calls to GP OOH were triaged within 20 minutes.
Unscheduled care 1 (standard) – from April 2016, 72.5% of Category A (life threatening) calls responded to within eight minutes, 67.5% in each LCG area.	 **Month / Apr / May / Jun / Jul / Aug / Sep / Oct / Nov / Dec / 16/17 Cum** Belfast 60% 58% 63% 64% 64% 64% 65% 63% 57% **62%** Northern 45% 46% 45% 45% 41% 45% 44% 43% 37% **43%** South Eastern 43% 41% 45% 48% 45% 51% 50% 47% 40% **45%** Southern 54% 44% 48% 46% 47% 49% 48% 43% 41% **47%** Western 55% 57% 57% 59% 58% 57% 55% 54% 50% **56%** **2016/17 52% 50% 52% 53% 51% 53% 53% 50% 45% 51%**	Regionally during December 2016, 45% of Category A calls were responded to within eight minutes. Ambulance response times have been impacted by an increase in the number of calls responded to and staffing issues. The Trust is taking forward a significant recruitment and training programme and expects the staffing position to improve during the second half of this year. In addition, the HSCB will be working with NIAS to take forward a detailed demand and capacity exercise over the next six months.
Unscheduled care 2 (standard) – from April 2016, 95% of patients attending any Type1, 2 or 3 Emergency Department are either treated and discharged home, or admitted, within four hours of their arrival in the Department; and no patient should wait longer than 12 hours.		Regionally during December 2016, 70% of patients were treated and discharged, or admitted within four hours – this is a reduction on the previous month (74%) and on the same month last year (75%). In relation to the 12-hour standard, regionally during the month of December 2016, 887 patients waited longer than 12 hours in ED – this is an increase on the previous month (460) and on the same month last year (293). Further details are provided at pages 7-9 above.

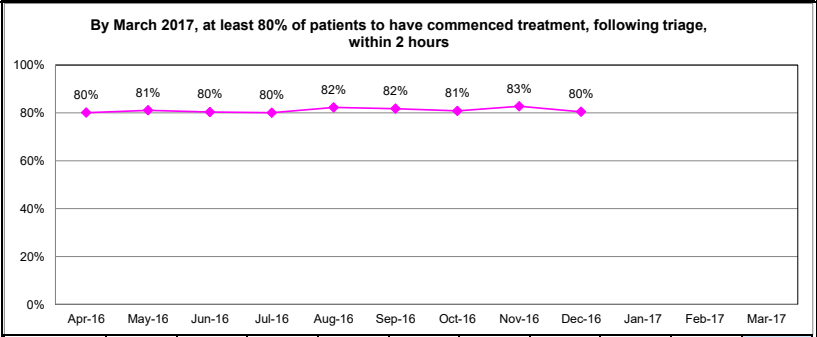
STANDARD / TARGET	Trend Analysis	Comments

Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	16/17 Cum
Belfast	71%	72%	75%	76%	78%	76%	74%	76%	72%	**74%**
Northern	66%	67%	67%	62%	65%	67%	68%	67%	65%	**66%**
South Eastern	81%	84%	82%	81%	80%	83%	81%	80%	75%	**81%**
Southern	77%	76%	76%	81%	79%	78%	74%	73%	70%	**76%**
Western	75%	77%	77%	80%	75%	77%	73%	73%	67%	**75%**
2016/17	**74%**	**75%**	**76%**	**76%**	**76%**	**76%**	**74%**	**74%**	**70%**	**75%**



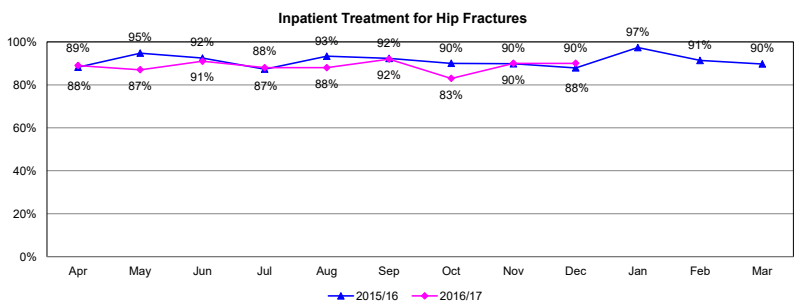
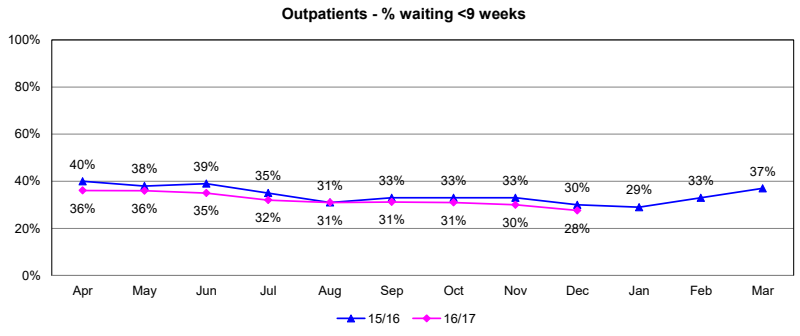
Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	16/17 Cum
Belfast	*136*	*91*	*72*	*13*	*28*	*78*	*95*	*110*	*159*	**782**
Northern	*74*	*87*	*96*	*184*	*24*	*46*	*118*	*163*	*275*	**1,067**
South Eastern	*171*	*74*	*75*	*86*	*83*	*24*	*52*	*133*	*208*	**906**
Southern	*82*	*63*	*24*	*3*	*0*	*0*	*13*	*18*	*143*	**346**
Western	*49*	*27*	*13*	*2*	*16*	*6*	*30*	*36*	*102*	**281**
2016/17	**512**	**342**	**280**	**288**	**151**	**154**	**308**	**460**	**887**	**3,382**

Unscheduled care 3 (target) – by March 2017, at least 80% of patients to have commenced treatment, following triage, within 2 hours.



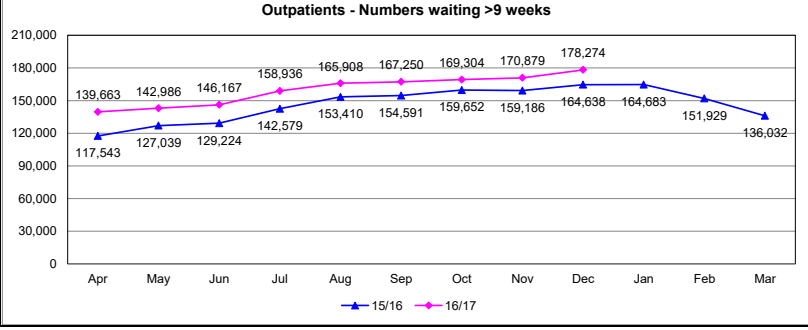
Trust	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	76.5%	75.1%	78.1%	78.8%	83.2%	80%	78%	83%	79%	**79%**
Northern	69.2%	71.0%	68.9%	63.5%	67.3%	70%	75%	76%	79%	**71%**
South Eastern	90.0%	91.4%	89.6%	86.0%	89.3%	88%	89%	89%	84%	**89%**
Southern	76.8%	76.5%	76.0%	81.2%	81.3%	80%	78%	77%	78%	**78%**
Western	87.9%	92.0%	88.6%	89.4%	88.0%	90%	85%	89%	83%	**88%**
Region	**80%**	**81%**	**80%**	**80%**	**82%**	**82%**	**81%**	**83%**	**80%**	**81%**

Regionally during December 2016, 80% of patients commenced treatment, following triage, within 2 hours.

STANDARD / TARGET	Trend Analysis	Comments
Hip fractures (standard) – from April 2016, 95% of patients, where clinically appropriate, wait no longer than 48 hours for inpatient treatment for hip fractures.		Regionally during December 2016, 90% of patients, where clinically appropriate, received inpatient treatment for hip fractures within 48 hours – this is unchanged from the previous month.
Elective care 1 (Outpatients) (standard) – by March 2017, 50% of patients should be waiting no longer than nine weeks for an outpatient appointment and no patient waits longer than 52 weeks.		At the end of December 2016: • 28% of patients were waiting less than nine weeks for a first outpatient appointment; • 178,274 people were waiting longer than nine weeks; and • 47,072 were waiting longer than a year. Further details are provided at pages 1-5 above.

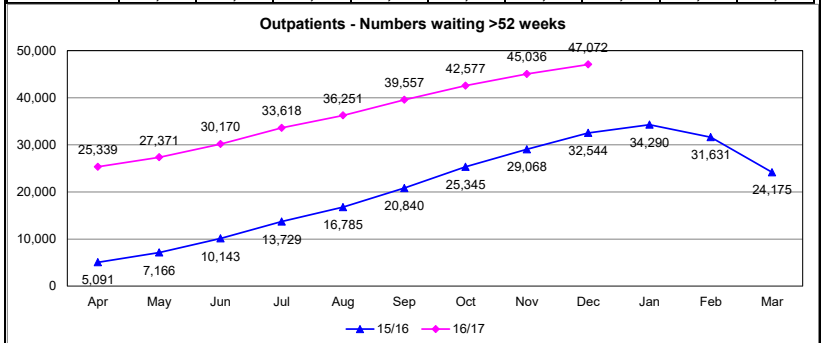
Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	16/17 Cum
Belfast	91%	95%	97%	96%	98%	95%	71%	99%	94%	**93%**
Northern										
South Eastern	84%	81%	82%	75%	65%	68%	81%	82%	80%	**77%**
Southern	87%	92%	94%	81%	100%	100%	100%	83%	86%	**91%**
Western	97%	75%	81%	83%	94%	97%	94%	86%	93%	**89%**
2016/17	**89%**	**87%**	**91%**	**88%**	**88%**	**92%**	**83%**	**90%**	**90%**	**89%**

Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	32%	32%	31%	29%	27%	28%	28%	28%	25%
Northern	43%	42%	42%	37%	36%	36%	35%	35%	32%
South Eastern	35%	36%	34%	31%	29%	30%	29%	27%	24%
Southern	39%	38%	38%	35%	33%	34%	34%	34%	31%
Western	41%	41%	39%	36%	34%	35%	36%	35%	33%
16/17	**36%**	**36%**	**35%**	**32%**	**31%**	**31%**	**31%**	**30%**	**28%**



STANDARD / TARGET	Trend Analysis	Comments
	Outpatients - Numbers waiting >52 weeks	

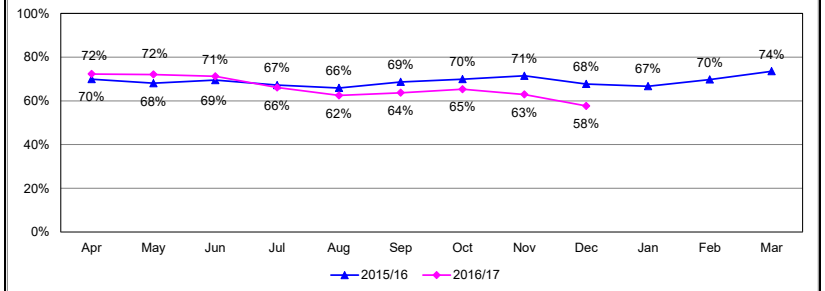
Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	60,068	60,836	61,148	65,307	67,701	67,658	67,940	68,310	70,405
Northern	14,731	15,691	15,286	17,656	18,900	18,507	19,309	19,422	20,010
South Eastern	27,246	27,480	29,019	32,038	34,264	35,604	36,861	38,135	40,642
Southern	21,665	22,654	23,242	25,282	26,099	25,907	26,038	26,169	27,367
Western	15,953	16,325	17,472	18,653	18,944	19,574	19,156	18,843	19,850
16/17	**139,663**	**142,986**	**146,167**	**158,936**	**165,908**	**167,250**	**169,304**	**170,879**	**178,274**



Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	15,749	16,967	18,455	19,849	21,093	22,939	24,273	25,280	26,100
Northern	1,062	1,220	972	1,698	2,077	1,955	2,463	2,701	2,576
South Eastern	3,861	3,661	4,116	4,689	5,197	6,019	6,593	7,296	8,425
Southern	1,991	2,388	2,821	3,278	3,546	3,827	4,151	4,413	4,320
Western	2,676	3,135	3,806	4,104	4,338	4,817	5,097	5,346	5,651
16/17	**25,339**	**27,371**	**30,170**	**33,618**	**36,251**	**39,557**	**42,577**	**45,036**	**47,072**

Elective care 2 (Diagnostics) (standard) – by March 2017, 75% of patients should wait no longer than nine weeks for a diagnostic test and no patient waits longer than 26 weeks.

Diagnostics - % waiting <9 weeks (Imaging and Physiological Measurement)



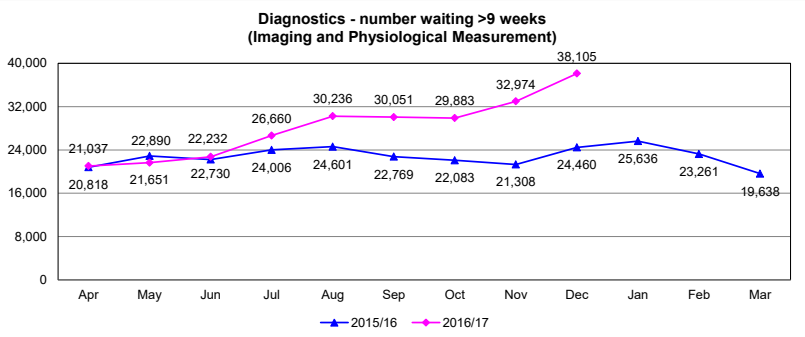
Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	63%	64%	61%	57%	52%	51%	52%	50%	44%
Northern	71%	71%	73%	65%	63%	67%	73%	74%	70%
South Eastern	79%	78%	76%	73%	72%	74%	75%	71%	66%
Southern	73%	71%	72%	69%	66%	66%	65%	62%	57%
Western	97%	95%	94%	88%	83%	82%	83%	81%	76%
2016/17	**72%**	**72%**	**71%**	**66%**	**62%**	**64%**	**65%**	**63%**	**58%**

At the end of December 2016:

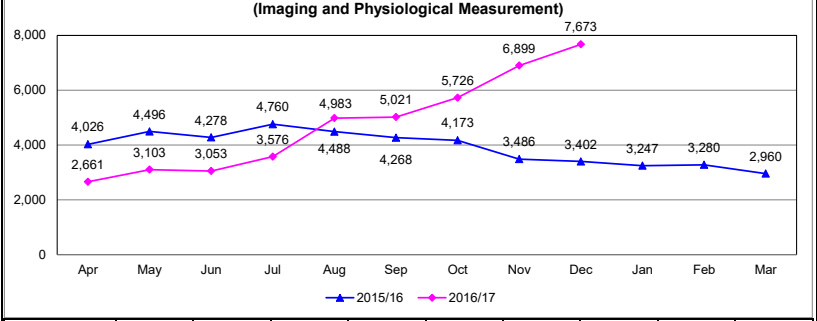
- 58% of patients were waiting less than nine weeks for a diagnostic test;
- 38,105 patients were waiting longer than nine weeks; and
- 7,673 were waiting longer than 26 weeks.

Further details are provided at pages 5-6 above.

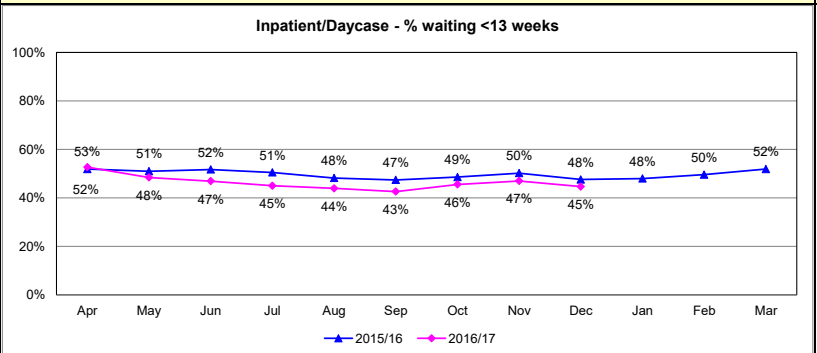
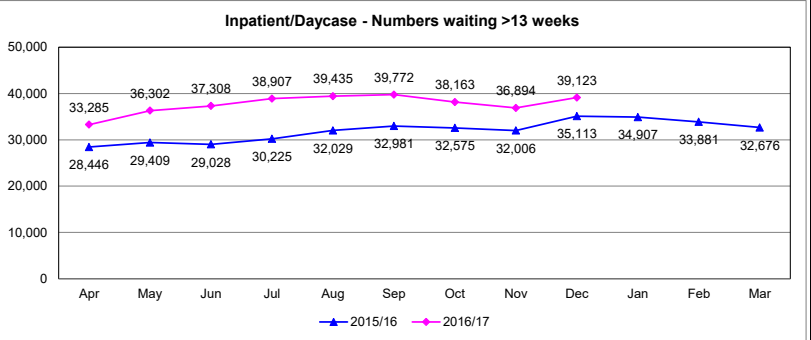
STANDARD / TARGET	Trend Analysis	Comments

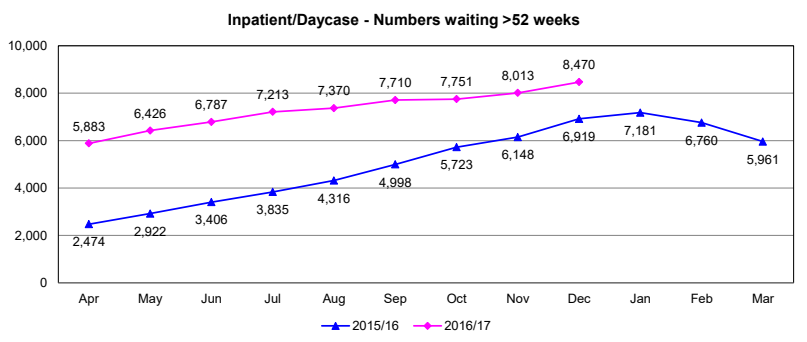


Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	9,648	9,982	10,545	12,813	14,466	14,304	14,748	16,465	18,927
Northern	4,435	4,259	4,597	5,282	6,150	5,413	4,624	4,666	5,298
South Eastern	2,037	2,128	2,289	2,511	2,587	2,478	2,399	2,805	3,334
Southern	4,699	4,911	4,769	5,059	5,619	6,220	6,518	7,272	8,260
Western	218	371	530	995	1,414	1,636	1,594	1,766	2,286
2016/17	**21,037**	**21,651**	**22,730**	**26,660**	**30,236**	**30,051**	**29,883**	**32,974**	**38,105**

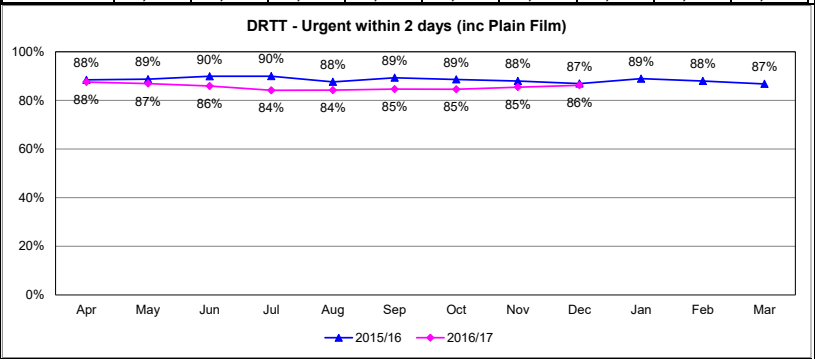


Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	1,364	1,858	1,794	2,254	3,406	3,457	3,899	4,835	5,538
Northern	1,166	1,080	1,076	1,079	1,126	1,017	1,068	893	642
South Eastern	78	101	118	166	261	316	376	605	611
Southern	51	62	65	75	188	231	383	532	736
Western	2	2	0	2	2	0	0	34	146
2016/17	**2,661**	**3,103**	**3,053**	**3,576**	**4,983**	**5,021**	**5,726**	**6,899**	**7,673**

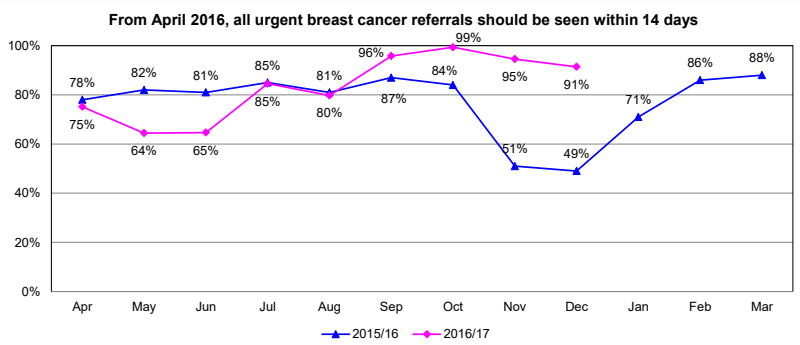
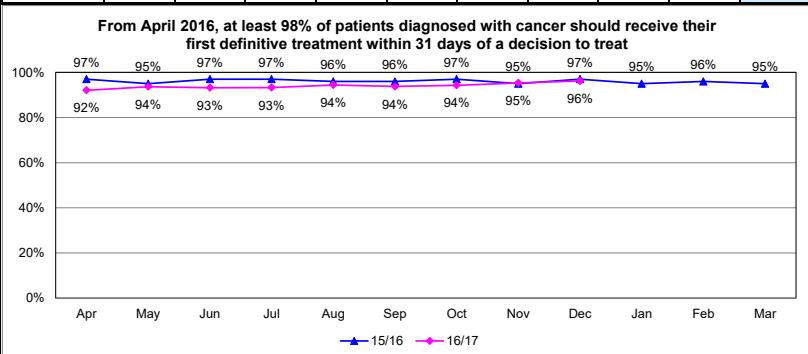
STANDARD / TARGET	Trend Analysis	Comments
Elective care 3 (Inpatient/Daycase) (standard) – by March 2017, 55% of patients should wait no longer than 13 weeks for inpatient/daycase treatment and no patient waits longer than 52 weeks.	 **Month** / **Apr** / **May** / **Jun** / **Jul** / **Aug** / **Sep** / **Oct** / **Nov** / **Dec** Belfast 47% 41% 39% 37% 37% 36% 38% 38% 36% Northern 68% 64% 63% 62% 62% 63% 67% 71% 68% South Eastern 52% 49% 47% 45% 44% 40% 49% 52% 53% Southern 63% 60% 59% 56% 53% 52% 54% 55% 53% Western 49% 47% 48% 45% 43% 43% 44% 44% 42% **2016/17** **53%** **48%** **47%** **45%** **44%** **43%** **46%** **47%** **45%**  **Trust** / **Apr** / **May** / **Jun** / **Jul** / **Aug** / **Sep** / **Oct** / **Nov** / **Dec** Belfast 16,099 17,856 18,688 18,956 18,761 19,003 18,602 18,238 19,051 Northern 2,709 2,841 2,786 2,892 2,816 2,592 2,298 2,002 2,220 South Eastern 4,495 4,799 5,036 5,214 5,308 5,246 4,628 4,158 4,149 Southern 3,396 3,754 3,850 4,242 4,497 4,638 4,542 4,390 4,796 Western 6,586 7,052 6,948 7,603 8,053 8,293 8,093 8,106 8,907 **2016/17** **33,285** **36,302** **37,308** **38,907** **39,435** **39,772** **38,163** **36,894** **39,123**	At the end of December 2016: • 45% of patients were waiting less than 13 weeks for inpatient or daycase treatment; • 39,123 patients were waiting longer than 13 weeks; and • 8,470 were waiting longer than a year. Further details are provided at pages 1-5 above.

STANDARD / TARGET	Trend Analysis	Comments
		

Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	2,887	3,173	3,300	3,436	3,552	3,764	3,815	3,970	4,185
Northern	32	36	46	55	48	43	42	36	30
South Eastern	985	1,065	1,137	1,208	1,126	1,094	915	803	791
Southern	476	505	516	578	603	699	783	846	881
Western	1,503	1,647	1,788	1,936	2,041	2,110	2,196	2,358	2,583
2016/17	**5,883**	**6,426**	**6,787**	**7,213**	**7,370**	**7,710**	**7,751**	**8,013**	**8,470**

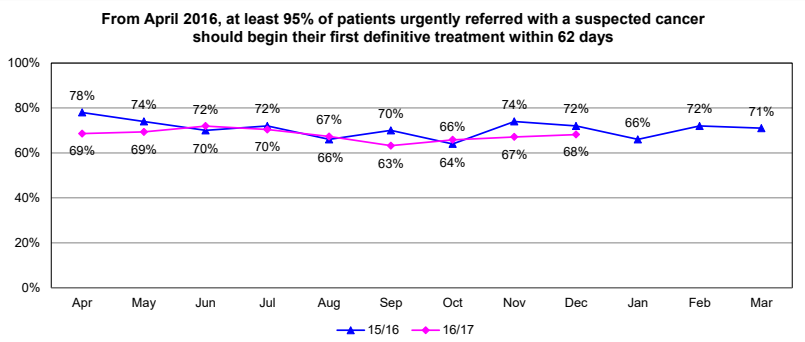
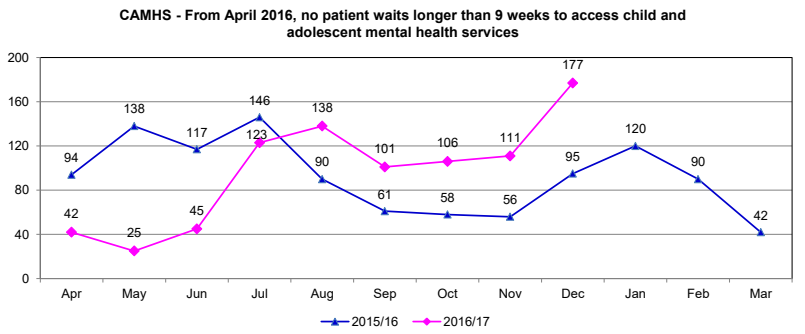
Elective care 4 (Diagnostic Reporting) (standard) – from April 2016, all urgent diagnostic tests should be reported on within two days.		Regionally during December 2016, 86% of urgent diagnostic tests were reported on within two days. This compares with 85% in November 2016 and 87% in the December 2015.

Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	87%	87%	86%	83%	87%	86%	85%	82%	85%
Northern	92%	91%	85%	84%	84%	85%	86%	92%	83%
South Eastern	96%	94%	93%	94%	93%	94%	91%	93%	93%
Southern	77%	79%	79%	77%	73%	75%	74%	78%	83%
Western	94%	91%	95%	94%	92%	92%	92%	88%	94%
2016/17	**88%**	**87%**	**86%**	**84%**	**84%**	**85%**	**85%**	**85%**	**86%**

STANDARD / TARGET	Trend Analysis	Comments
Cancer care services 1 (standard) – from April 2016, all urgent breast cancer referrals should be seen within 14 days.		Regionally during December 2016, 91% of urgent breast cancer referrals were seen within 14 days. Further details are provided at pages 9-10 above.
Cancer care services 2 (standard) – from April 2016, at least 98% of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat.		Regionally during December 2016, 96% of cancer patients commenced treatment within 31 days of the decision to treat. This is a slight improvement on the previous month (95%) and compares with 97% in December 2015.

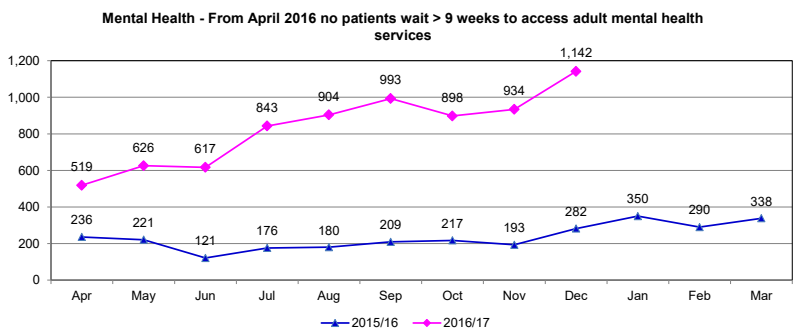
Month	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	16/17 (YTD)
Belfast	65%	72%	64%	87%	83%	99%	99%	99%	100%	**86%**
Northern	92%	100%	100%	97%	99%	100%	100%	100%	97%	**98%**
South Eastern	29%	14%	27%	100%	97%	100%	100%	100%	100%	**73%**
Southern	69%	13%	7%	14%	12%	78%	98%	70%	39%	**46%**
Western	100%	100%	100%	100%	100%	100%	100%	100%	100%	**100%**
2016/17	**75%**	**64%**	**65%**	**85%**	**80%**	**96%**	**99%**	**95%**	**91%**	**83%**

Trust	Cancer Services - % <31 days										
	15/16 Cum	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	**93%**	89%	90%	88%	91%	94%	90%	92%	93%	94%	**91%**
Northern	**98%**	84%	91%	87%	84%	82%	94%	95%	93%	93%	**89%**
South Eastern	**96%**	90%	95%	99%	94%	96%	94%	91%	95%	97%	**95%**
Southern	**100%**	100%	99%	99%	100%	99%	98%	97%	99%	99%	**99%**
Western	**100%**	100%	100%	100%	100%	100%	100%	100%	100%	100%	**100%**
Region	**96%**	**92%**	**94%**	**93%**	**93%**	**94%**	**94%**	**94%**	**95%**	**96%**	**94%**

STANDARD / TARGET	Trend Analysis	Comments
Cancer care services 3 (standard) – from April 2016, at least 95% of patients urgently referred with a suspected cancer should begin their first definitive treatment within 62 days.		During December 2016, 68% of patients urgently referred with a suspected cancer began their first definitive treatment within 62 days. This compares with 67% in the previous month and 72% in December 2015. Further details are provided at pages 11-12 above.
Mental health services 1 (standard) – from April 2016, no patient waits longer than nine weeks to access <u>child and adolescent mental health services</u> (CAMHS).		At the end of December 2016, 177 patients were waiting longer than nine weeks to access CAMHS compared to 111 at the end of November 2016. The continued strong performance in Northern, South Eastern and Southern Trusts should be noted. <u>Belfast Trust</u> had previously advised that it expected to recover the 9-week maximum waiting time standard by end of October 2016 however, this outcome was not achieved due to an increased level of sickness absence across the service. The Trust has revised its recovery plan and has put a range of measures in place to improve the position including recruiting to vacant posts, backfill arrangements and additional clinics however, it does not expect the waiting time position to improve in the short term. The increase in the number of patients waiting longer than nine weeks in the <u>Western Trust</u> area has been as a result of staff vacancies. The Trust has advised that it is in the process of recruiting to these vacant posts and is confident that the waiting time position will improve by end of March 2017.

Trust	Cancer Services - % <62 days										
	15/16 Cum	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	**59%**	57%	64%	60%	58%	59%	60%	60%	65%	64%	**61%**
Northern	**72%**	70%	65%	77%	72%	72%	70%	70%	71%	69%	**71%**
South Eastern	**60%**	45%	55%	58%	70%	48%	36%	34%	38%	40%	**46%**
Southern	**88%**	91%	84%	83%	81%	78%	82%	88%	83%	91%	**85%**
Western	**91%**	86%	95%	89%	83%	88%	79%	86%	86%	82%	**86%**
Region	**71%**	**69%**	**69%**	**72%**	**70%**	**67%**	**63%**	**66%**	**67%**	**68%**	**68%**

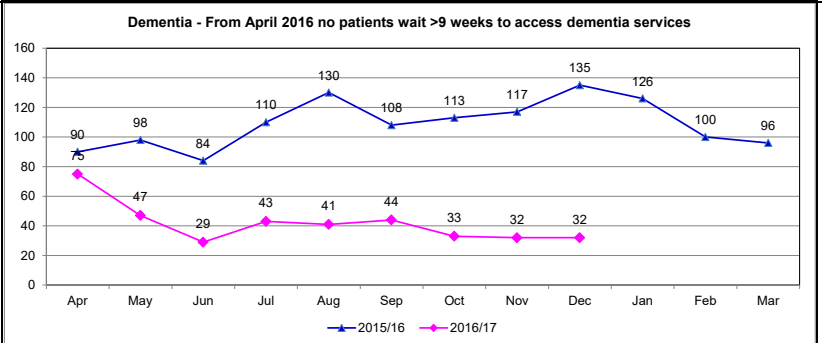
Month	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	32	35	12	13	59	66	39	56	44	90
Northern	0	0	0	0	0	0	0	0	0	0
South Eastern	0	0	0	0	0	0	0	0	0	0
Southern	0	0	0	0	0	0	0	0	0	0
Western	10	7	13	32	64	72	62	50	67	87
2016/17	**42**	**42**	**25**	**45**	**123**	**138**	**101**	**106**	**111**	**177**

STANDARD / TARGET	Trend Analysis	Comments
Mental health services 2 (standard) – from April 2016, no patient waits longer than nine weeks to access adult mental health services.		Regionally at the end of December 2016, 1,142 patients were waiting longer than nine weeks to access adult mental health services compared to 934 at the end of November 2016 (+208). The majority (76%) of patients waiting longer than nine weeks are waiting for the primary care mental health team and almost all (833 out of 868) were in Belfast (448) and Southern (385) Trusts. Belfast Trust is continuing to undertake additional activity to address the backlog of patients waiting longer than nine weeks however, due to a loss of core capacity as a result of staffing issues (e.g. vacancies and sickness absence) and the anticipated reduction in capacity over the Christmas/New Year period, the impact of the additionality is not yet evident in the waiting time position. The Southern Trust has advised that it is taking forward a number of initiatives including the rollout of primary care hubs which will deliver an improved waiting time position.

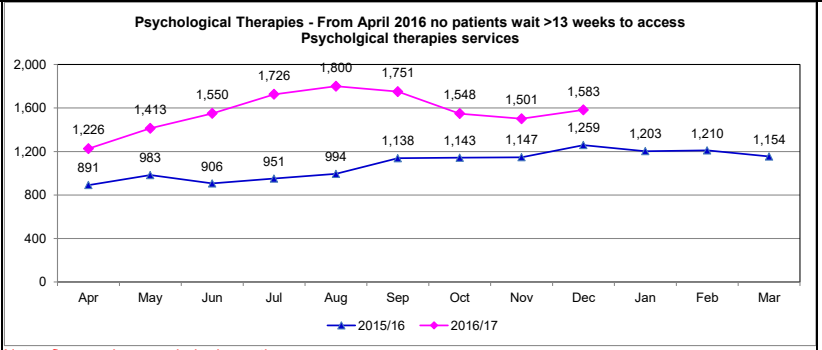
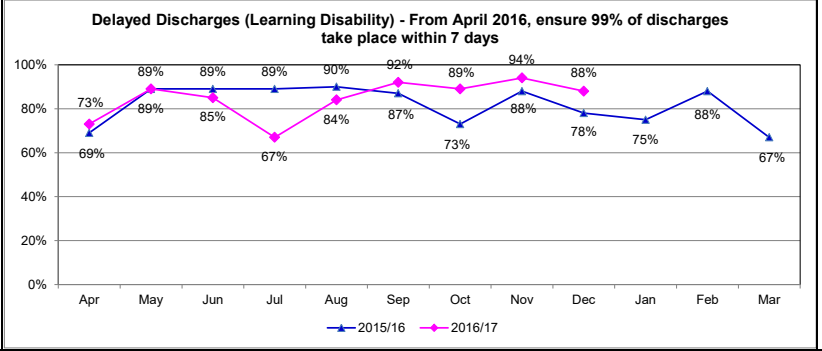
Month	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	246	441	497	474	575	551	609	496	504	676
Northern	3	4	4	2	3	1	0	0	0	0
South Eastern	0	0	0	1	0	0	0	0	0	0
Southern	81	61	104	123	213	276	275	314	357	409
Western	8	13	21	17	52	76	109	88	73	57
2016/17	**338**	**519**	**626**	**617**	**843**	**904**	**993**	**898**	**934**	**1,142**

Mental Health Services - Breach Analysis December 2016

Service	Belfast	Northern	South Eastern	Southern	Western	Region Total
Addiction Services	217	0	0	1	5	223
Community Mental Health Teams	9	0	0	16	11	36
Community Mental Health Teams for Older People	0	0	0	6	4	10
Eating Disorder Services	2	0	0	1	1	4
Forensic Services	0	0	0	0	1	1
Personality Disorder Services	0	0	0	0	0	0
Primary Care Mental Health Team	448	0	0	385	35	868
Trust Total	**676**	**0**	**0**	**409**	**57**	**1,142**

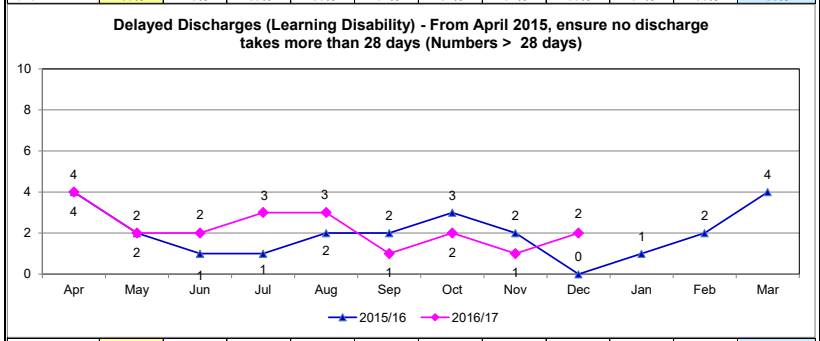
Mental health services 3 (standard) – from April 2016, no patient waits longer than nine weeks to access dementia services.		At the end of December 2016, 32 patients were waiting longer than nine weeks compared to 96 at the end of March 2016.

Month	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16
Belfast	0	0	0	0	0	0	0	0	0	0
Northern	0	0	0	0	0	0	0	0	0	0
South Eastern	26	30	30	25	30	22	24	24	20	19
Southern	69	44	17	4	13	15	11	2	2	3
Western	1	1	0	0	0	4	9	7	10	10
2016/17	**96**	**75**	**47**	**29**	**43**	**41**	**44**	**33**	**32**	**32**

STANDARD / TARGET	Trend Analysis	Comments
Mental health services 4 (standard) – from April 2016, no patient waits longer than 13 weeks to access psychological therapies (any age).	 Note: figures above exclude dementia **Month** / Mar-16 / Apr-16 / May-16 / Jun-16 / Jul-16 / Aug-16 / Sep-16 / Oct-16 / Nov-16 / Dec-16 Belfast: 338 / 310 / 361 / 409 / 422 / 437 / 435 / 355 / 330 / 355 Northern: 142 / 166 / 229 / 252 / 328 / 278 / 217 / 162 / 118 / 115 South Eastern: 566 / 593 / 601 / 674 / 708 / 773 / 726 / 698 / 696 / 733 Southern: 10 / 16 / 47 / 43 / 62 / 83 / 74 / 66 / 63 / 61 Western: 98 / 141 / 175 / 172 / 206 / 229 / 299 / 267 / 294 / 319 **2016/17**: **1,154** / **1,226** / **1,413** / **1,550** / **1,726** / **1,800** / **1,751** / **1,548** / **1,501** / **1,583** (excluding Dementia) **Psychological Therapies Services - Breach Analysis December 2016** **Service** / **Belfast** / **Northern** / **South Eastern** / **Southern** / **Western** / **Region Total** Adult Mental Health: 44 / 3 / 386 / 38 / 171 / 642 Primary Care Hub: 0 / 0 / 0 / 0 / 0 / 0 Older People-Functional Services: 0 / 0 / 25 / 0 / 7 / 32 Adult Learning Disability: 13 / 68 / 27 / 0 / 48 / 156 Children's Learning Disability: 3 / 44 / 5 / 0 / 5 / 57 Adult Health Psychology: 191 / 0 / 290 / 23 / 7 / 511 Children's Psychology: 42 / 0 / 0 / 0 / 5 / 47 Psychosexual Services: 61 / 0 / 0 / 0 / 76 / 137 Neurodisability Services: 0 / 0 / 0 / 0 / 0 / 0 Specialist Trauma Care: 1 / 0 / 0 / 0 / 0 / 1 **Trust Total**: **355** / **115** / **733** / **61** / **319** / **1,583**	Regionally, the number of patients waiting longer than 13 weeks to access psychological therapy services has remained broadly unchanged in recent months – at the end of December 2016, 1,583 patients were waiting longer than 13 weeks compared to 1,501 at the end of November. A paper providing a detailed update on the issues impacting on waiting time performance in psychological therapies was provided at the October 2016 Board meeting and the HSCB is continuing to work closely with Trusts to take forward the actions set out within the paper.
Patient discharge 1 (standard) – from April 2016, ensure that 99% of all learning disability discharges take place within seven days of the patient being assessed as medically fit for discharge, with no discharge taking more than 28 days.		Regionally during December 2016, 88% (15 out of 17) of learning disability discharges took place within seven days of the patient being assessed as medically fit for discharge, and two took more than 28 days.

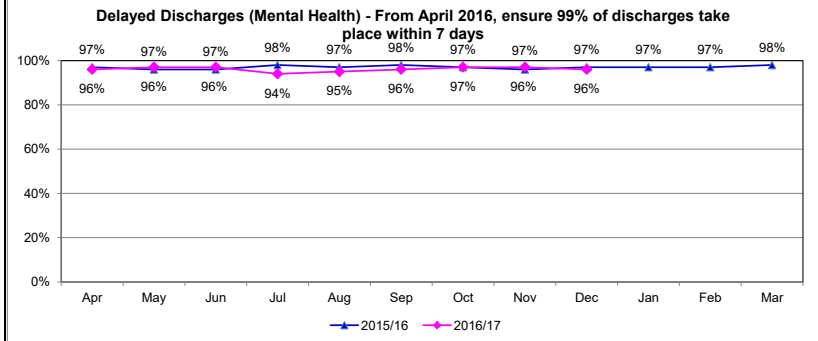
STANDARD / TARGET	Trend Analysis	Comments

Month	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	76%	60%	100%	100%	67%	83%	100%	50%	100%	67%	**80%**
Northern	90%	67%	80%	80%	100%	0%	100%	80%	100%	100%	**82%**
South Eastern	79%	100%	80%	100%	#DIV/0!	75%	67%	100%	100%	100%	**88%**
Southern	81%	100%	100%	100%	33%	100%	100%	100%	67%	100%	**88%**
Western	86%	100%	100%	67%	100%	100%	100%	100%	100%	83%	**92%**
2016/17	**83%**	**73%**	**89%**	**85%**	**67%**	**84%**	**92%**	**89%**	**94%**	**88%**	**86%**



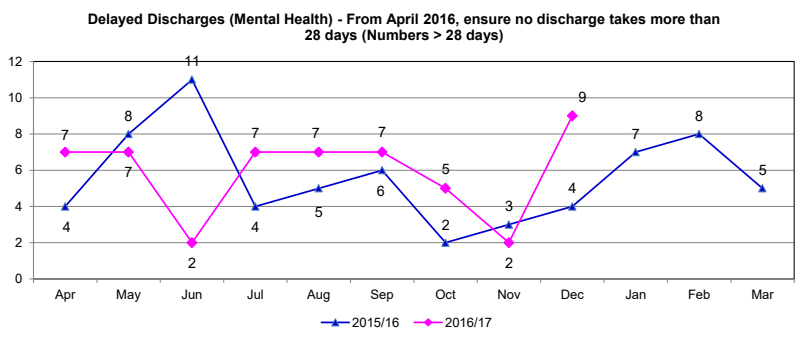
Month	Mar-16	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	16/17 Cum
Belfast	7	2	0	0	1	1	0	1	0	1	**6**
Northern	4	2	1	1	0	1	0	1	0	0	**6**
South Eastern	5	0	1	0	0	1	1	0	0	0	**3**
Southern	2	0	0	0	2	0	0	0	1	0	**3**
Western	6	0	0	1	0	0	0	0	0	1	**2**
2016/17	**24**	**4**	**2**	**2**	**3**	**3**	**1**	**2**	**1**	**2**	**20**

Patient discharge 2 (standard) – from April 2016, ensure that 99% of all <u>mental health</u> discharges take place within seven days of the patient being assessed as medically fit for discharge, with no discharge taking more than 28 days.

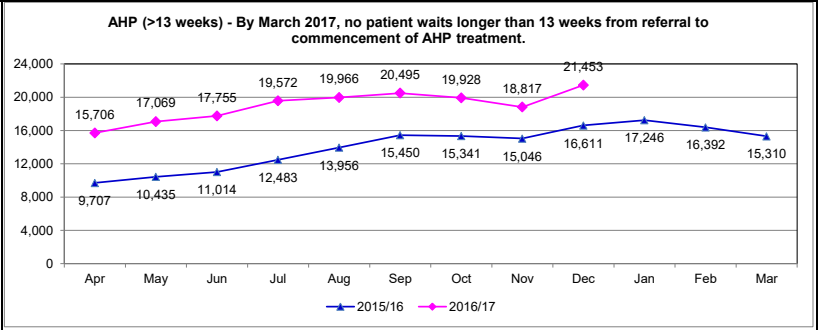


Month	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	96%	91%	96%	98%	98%	95%	92%	100%	96%	98%	**96%**
Northern	100%	100%	100%	99%	100%	100%	100%	100%	100%	100%	**100%**
South Eastern	97%	99%	97%	99%	94%	87%	98%	100%	96%	97%	**97%**
Southern	95%	94%	94%	93%	86%	93%	90%	90%	96%	92%	**92%**
Western	98%	96%	98%	98%	95%	98%	97%	97%	99%	96%	**97%**
2016/17	**97%**	**96%**	**97%**	**97%**	**94%**	**95%**	**96%**	**97%**	**97%**	**96%**	**96%**

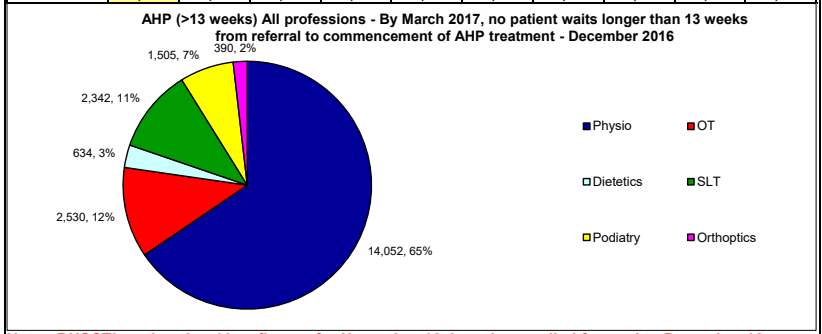
Regionally during December 2016, 96% (368 out of 382) of <u>mental health</u> discharges took place within seven days of the patient being assessed as medically fit for discharge, and nine took more than 28 days.

STANDARD / TARGET	Trend Analysis	Comments
		

Month	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	16/17 Cum
Belfast	17	4	1	1	1	1	3	0	2	1	**14**
Northern	1	0	0	0	0	0	0	0	0	0	**0**
South Eastern	6	0	0	0	2	2	1	0	0	1	**6**
Southern	20	2	4	0	1	3	1	4	0	4	**19**
Western	23	1	2	1	3	1	2	1	0	3	**14**
2016/17	**67**	**7**	**7**	**2**	**7**	**7**	**7**	**5**	**2**	**9**	**53**

Allied Health Professionals (AHP) (target) – by March 2017, no patient should wait longer than 13 weeks from referral to commencement of treatment by an allied health professional.	 Note: BHSCT's orthoptic w/time figures for November 16 have been rolled forward to December 16.	At the end of December 2016, 21,453 patients were waiting longer than 13 weeks from referral to commencement of AHP treatment. Regionally, two thirds (14,052) of the patients waiting longer than 13 weeks at the end of December were waiting for physiotherapy. During 2015/16, the HSCB and PHA worked with Trusts to complete a demand and capacity exercise to ensure there is sufficient capacity in each of the AHP services to meet patient demand. As all available funding in the current year has been allocated directly to Trusts, the HSCB has advised Trusts of the need to identify funding to reduce AHP waiting times from within available resources.

Month	Mar-16	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Belfast	**1,759**	2,279	3,186	3,766	4,054	4,457	4,592	4,549	3,981	4,684
Northern	**7,214**	7,247	7,407	7,287	7,926	7,897	7,963	7,866	7,766	8,125
South Eastern	**185**	233	290	291	421	519	631	622	456	716
Southern	**3,459**	3,412	3,866	4,215	4,841	4,828	5,177	4,963	4,997	6,040
Western	**2,693**	2,535	2,320	2,196	2,330	2,265	2,132	1,928	1,617	1,888
2016/17	**15,310**	**15,706**	**17,069**	**17,755**	**19,572**	**19,966**	**20,495**	**19,928**	**18,817**	**21,453**



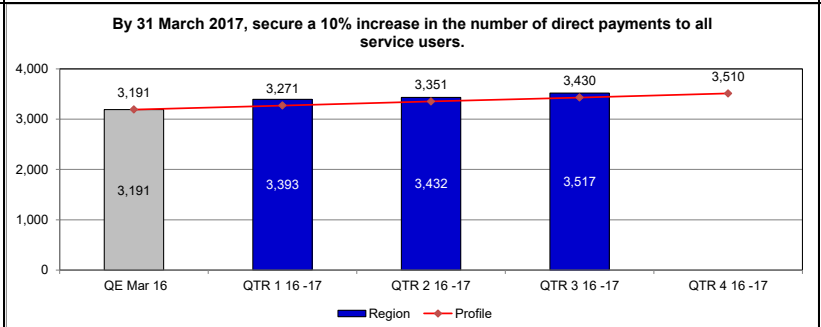
Note: BHSCT's orthoptic w/time figures for November 16 have been rolled forward to December 16.

STANDARD / TARGET	Trend Analysis	Comments

Profession	Mar-16	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Physio	7,797	8,371	9,709	10,495	11,635	11,948	12,626	12,433	12,287	14,052
OT	2,887	2,777	2,646	2,482	2,761	2,662	2,420	2,545	2,217	2,530
Dietetics	543	559	615	647	747	744	748	534	417	634
SLT	2,064	2,199	2,351	2,288	2,220	2,235	2,334	2,263	2,140	2,342
Podiatry	2,000	1,766	1,662	1,689	1,884	1,835	1,771	1,629	1,382	1,505
Orthoptics	19	34	86	154	325	542	596	524	374	390
2016/17	**15,310**	**15,706**	**17,069**	**17,755**	**19,572**	**19,966**	**20,495**	**19,928**	**18,817**	**21,453**

Note: BHSCT's orthoptic w/time figures for November 16 have been rolled forward to December 16.

Direct payments (target) – by March 2017, secure a 10% increase in the number of direct payments to all service users.

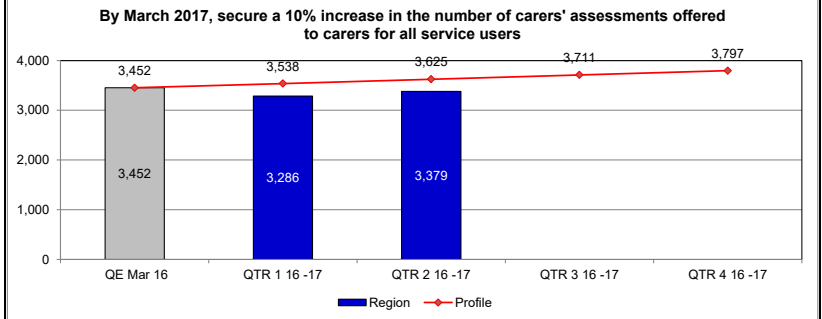


Quarter	QE Mar 16	QTR 1 16 -17	QTR 2 16 -17	QTR 3 16 -17	QTR 4 16 -17
Belfast	**541**	577	578	585	
Northern	**659**	671	692	694	
South Eastern	**709**	836	784	847	
Southern	**748**	740	763	742	
Western	**534**	569	615	649	
Region	**3,191**	**3,393**	**3,432**	**3,517**	
Profile	**3,191**	**3,271**	**3,351**	**3,430**	**3,510**

In order to achieve the 10% target increase by March 2017, Trusts will be required to have a total of 3,510 direct payments in place across all programmes of care by March 2017.

Performance against this target is reported quarterly – regionally at the end of Q3 (December 2016), 3,517 direct payments were in place against 9-month target profile of 3,430 (+87).

Carers' assessments (target) – By March 2017, secure a 10% increase in the number of carers' assessments offered to carers for all service users.



Quarter	QE Mar 16	QTR 1 16 -17	QTR 2 16 -17	QTR 3 16 -17	QTR 4 16 -17
Belfast	**805**	879	1,055		
Northern	**626**	792	671		
South Eastern	**778**	547	613		
Southern	**926**	774	783		
Western	**317**	294	257		
Region	**3,452**	**3,286**	**3,379**		
Profile	**3,452**	**3,538**	**3,625**	**3,711**	**3,797**

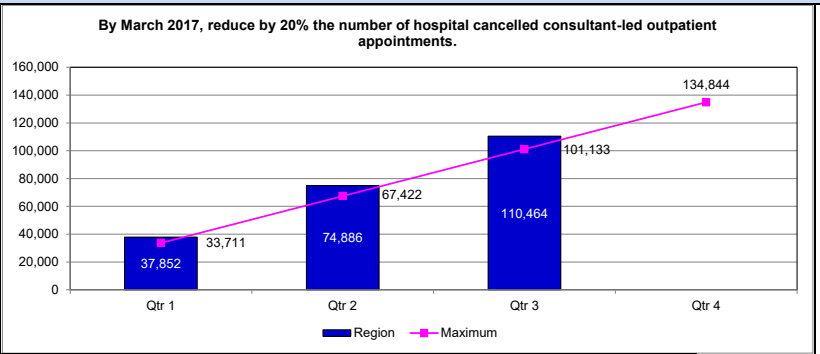
In order to secure the 10% target increase by March 2017, Trusts will be required to offer a total of 3,797 carers' assessments during 2016/17.

Performance against this target is reported quarterly – regionally at end of September 2016, 3,379 carers' assessments have been offered to carers for all service users against a 6-month target profile to have offered 3,625 (-246). An update on performance to end of December 2016 will be provided in the report for the March Board meeting.

STANDARD / TARGET	Trend Analysis	Comments

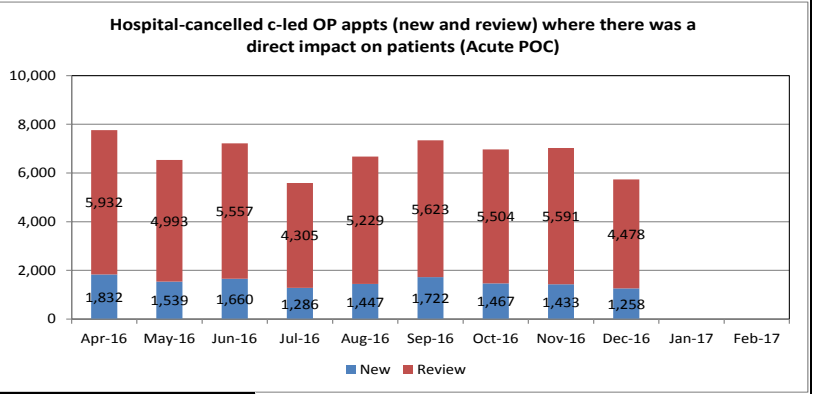
Aim: to ensure that services are efficient and provide value for money in terms of outcomes achieved and costs incurred.

Hospital cancelled OP appointments (target) – by March 2017, reduce by 20% the number of hospital-cancelled consultant-led outpatient appointments.



Trust	14/15	Qtr 1	Qtr 2	Qtr 3	Qtr 4	Max Allowed
Belfast	78,910	16,919	34,552	51,823		63,128
Northern	24,045	5,423	9,849	13,940		19,236
South Eastern	24,052	5,038	9,982	14,409		19,242
Southern	16,524	3,785	7,804	11,854		13,219
Western	25,024	6,687	12,699	18,438		20,019
Maximum	168,555	33,711	67,422	101,133	134,844	134,844
Region	**168,555**	**37,852**	**74,886**	**110,464**	**0**	

Figures do not include Beechcroft, Muckamore Abbey, Grangewood and Lakeview



2016/17 (Apr-Dec)		
New	Review	Total
5,743	23,298	**29,041**
2,272	6,100	**8,372**
1,404	5,478	**6,882**
1,537	5,060	**6,597**
2,688	7,276	**9,964**
13,644	**47,212**	**60,856**

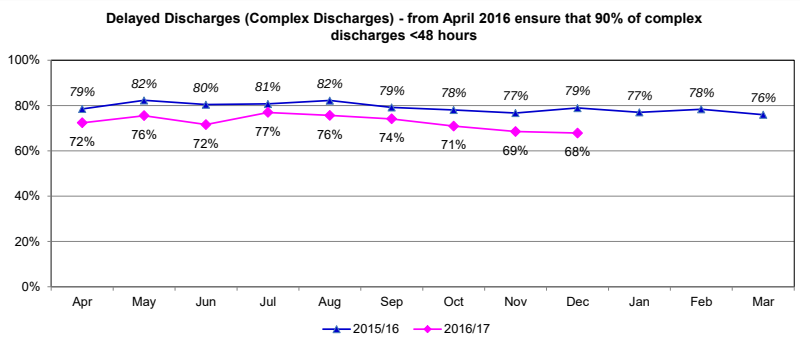
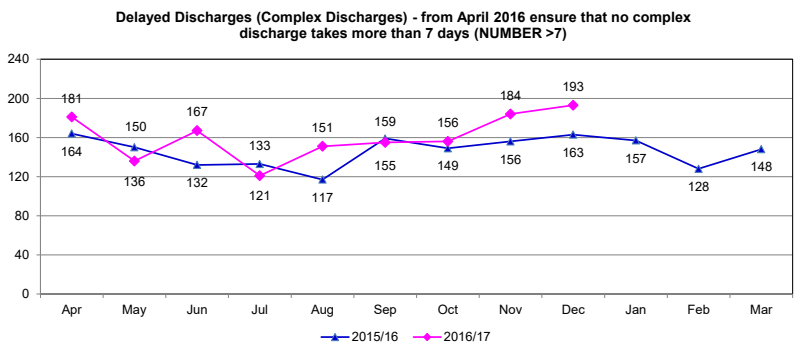
Performance against this target will be reported quarterly during 2016/17.

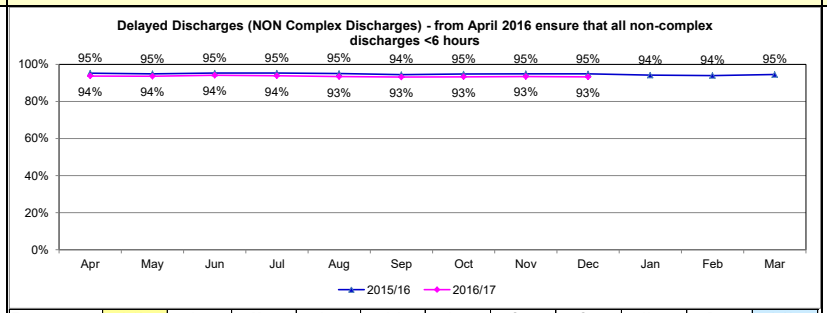
For 2016/17, performance against this target is being monitored in line with the latest definitions and guidance outlined by the Department of Health Statistics Branch in their Quarterly Outpatient Activity Statistical Return (Version 12 July 2015 refers) (QOAR). It should be noted that recording cancelled clinics in this way means that the cancellation rates reported are overstated as a number of the reasons recorded on PAS for cancellation will not result in lost capacity, e.g. minor changes to clinic arrangements, such as changes to the start and finish times, result in that clinic having to be cancelled and rescheduled on Trust systems.

In February 2013, the Health Committee recognised this position and, as a result, a Short Life Working Group was set up to establish how information on cancelled appointments could be recorded in order to be able to identify where there has been a direct impact on patients and to quantify actual lost capacity. As a result of this work, information on the number of hospital cancelled consultant-led outpatient appointments that had an impact on patients has been available since 2014/15 and performance was reported in this way during 2015/16.

Data sourced in line with the QOAR guidance shows that during the first nine months of 2016/17, there were 110,464 hospital-cancelled consultant-led outpatient appointments (new and review) across all programmes of care against a target profile to have cancelled no more than 101,133 (+9,331).

Data collected as a result of the arrangements put in place to identify where hospital cancellations have directly impacted on patients show that during the same period, 60,856 hospital-cancelled consultant-led outpatient appointments (new and review) across the acute programme of care are considered to have had a direct impact on patients.

STANDARD / TARGET	Trend Analysis	Comments
Complex discharges (standard) – from April 2016, ensure that 90% of complex discharges from an acute hospital take place within 48 hours, with no complex discharge taking more than seven days.	 **Trust of Residence (ToR)** / **15/16** / **Apr** / **May** / **Jun** / **Jul** / **Aug** / **Sep** / **Oct** / **Nov** / **Dec** / **16/17 Cum** Belfast 54% 41% 50% 49% 55% 51% 52% 43% 43% 40% **48%** Northern 86% 86% 87% 80% 84% 81% 79% 74% 73% 73% **81%** South Eastern 78% 60% 59% 63% 71% 75% 68% 69% 62% 71% **66%** Southern 92% 92% 93% 91% 94% 91% 98% 93% 98% 85% **94%** Western 81% 69% 77% 74% 75% 77% 77% 78% 76% 72% **75%** No ToR 88% 85% 86% 89% 100% 92% 67% 77% 78% 100% **87%** **2016/17** **79%** **72%** **76%** **72%** **77%** **76%** **74%** **71%** **69%** **68%** **73%**  **Trust of Residence (ToR)** / **15/16** / **Apr** / **May** / **Jun** / **Jul** / **Aug** / **Sep** / **Oct** / **Nov** / **Dec** / **16/17 Cum** Belfast 585 61 47 52 36 52 39 49 72 74 **482** Northern 316 36 24 30 26 37 42 39 33 24 **291** South Eastern 393 25 31 39 27 18 27 23 38 43 **271** Southern 48 2 1 2 0 4 2 4 1 10 **26** Western 405 56 32 43 32 39 43 39 38 42 **364** No Trust of Resi 9 1 1 1 0 1 2 2 2 0 **10** **2016/17** **1,756** **181** **136** **167** **121** **151** **155** **156** **184** **193** **1,444**	Regionally during December 2016, 68% of complex discharges from an acute hospital took place within 48 hours and 193 took more than seven days.

STANDARD / TARGET	Trend Analysis	Comments
Non-complex discharges (standard) – from April 2016, ensure that all non-complex discharges from an acute hospital take place within six hours.	 **Trust** / **15/16** / **Apr** / **May** / **Jun** / **Jul** / **Aug** / **Sep** / **Oct** / **Nov** / **Dec** / **16/17** Belfast / 97% / 97% / 97% / 97% / 97% / 96% / 96% / 96% / 96% / 96% / **97%** Northern / 95% / 94% / 93% / 95% / 95% / 95% / 95% / 94% / 95% / 95% / **94%** South Eastern / 91% / 87% / 88% / 87% / 89% / 86% / 87% / 87% / 87% / 87% / **87%** Southern / 92% / 91% / 90% / 92% / 91% / 92% / 91% / 91% / 91% / 91% / **91%** Western / 97% / 96% / 96% / 97% / 96% / 96% / 95% / 96% / 95% / 95% / **96%** **2016/17** / **95%** / **94%** / **94%** / **94%** / **94%** / **93%** / **93%** / **93%** / **93%** / **93%** / **94%**	Regionally during December 2016, 93% of non-complex discharges from an acute hospital took place within six hours.
Delivery of funded capacity (target) - by March 2017, to reduce the percentage of funded activity associated with elective care service that remains undelivered.		Regionally during the first nine months of 2016/17, there has been a 9.2% (28,549) underdelivery of new outpatient core activity compared to 5.8% during the same period in 2015/16. In relation to delivery of commissioned volumes of inpatient/daycase volumes, there has been a 7.3% (8,532) underdelivery of core activity during the period April to December 2016 compared to 6.8% during the same period last year. Further details are provided at page 5 above.

Annex B

Health and Social Care Board

Public Health Agency

Pressure Ulcer Prevention 2015-16

(January 2017)

Produced by HSCB Information, PMSID in conjunction with the QSE Team (PHA)

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10.0 Compliance with SKIN bundle

11.0 Root cause analysis tool

12.0 Sharing of regional learning

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1.0 Introduction

The HSC is committed to being recognised internationally, but especially by the people of Northern Ireland, as a leader for excellence in health and social care. The Q2020 Strategy[1] aims to protect and improve the quality of health and social care in Northern Ireland, we are committed to measuring improvements; and in doing so, ensuring that lessons from the information are learned, areas of high performance are duplicated and areas of lower performance are supported to improve.
The Commissioning Plan[2] is a response to the Commissioning Plan Direction[3] issued by the Minister for Health, Social Services and Public Safety, 2015/2016 and identifies the key strategic priorities. These identify the safety and quality indicators which must be included in Quality Improvement Plans (QIPs) developed by Trusts. The HSC framework requires the Health and Social Care Board (HSCB) and Public Health Agency (PHA)[4] to gain assurance on progress with regional safety and quality priorities through QIPs.

The HSCB and PHA are committed to ensuring safe, high quality services and putting patients, clients and their carers at the heart of everything we do. The meaning and/or significance of a Pressure Ulcer varies from person to person and the impact on patients cannot be underestimated. The purpose of this document is to provide measurement related to prevention of pressure ulcers which is one of the six quality improvement priorities identified for 2015/16.
The information contained within this report has been supplied by HSC Trusts via a quarterly collection of data on the PHA SharePoint site. Occupied bed-days have been supplied by Department of Health (DOH). Information supplied by Trusts is correct at time of print of this report; however it is subject to change, as recording practices and audit findings are reviewed by Trusts through the Patient Safety Officers. The occupied bed-days information has been provided by the DOH.

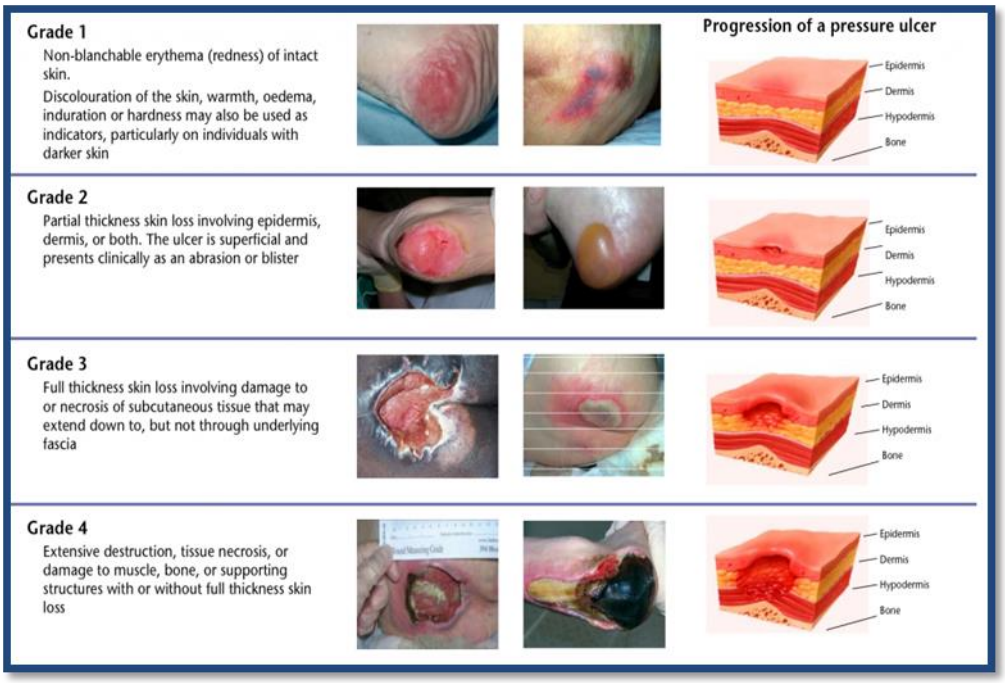
2.0 What is a pressure ulcer?

A pressure ulcer is an area of localised damage to the skin and underlying tissue caused by pressure, shear, friction or a combination of these (EPUAP 2014)[5]. They are most likely to occur when a hard bony

[1] The Q2020 Strategy, A Ten Year Strategy to protect and improve quality in health and social care, 2011
[2] The Health and Social Care Board (HSCB) and Public Health Agency (PHA) Joint Commissioning Plan, 2015
[3] The Health and Social Care Commissioning Plan Direction (Northern Ireland) 2015
[4] DHSSPS, Framework Document, September 2011
[5] Prevention and Treatment of Pressure Ulcers: Quick Reference Guide National Pressure Ulcer Advisory Panel, European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance (2014)

area covered by a thin layer of tissue is in contact with a hard surface, such as a bed, trolley, theatre table, wheelchair etc.

The body can withstand high interface pressures for a very short period of time. It is when the pressure is not regularly relieved that damage occurs and a pressure ulcer develops. Elderly patients, those with a long term medical illness/disease/condition are particularly vulnerable because their skin usually becomes thinner and more fragile with age. Pressure sores can develop in a matter of hours. There are four recognised grades of pressure ulcers in the EPUAP 2014 wound classification (see diagram below).



Whilst some pressures ulcers are unavoidable, many are avoidable see definitions below.

Avoidable	Unavoidable
Avoidable means that the person receiving care developed a pressure ulcer and the provider of care did not do one of the following: • evaluate the person's clinical condition and pressure ulcer risk factors • plan and implement interventions that are consistent with the persons' needs and goals, and recognised standards of practice • monitor and evaluate the impact of the interventions or revise the interventions as appropriate	**Unavoidable' means that the person receiving care developed a pressure ulcer even though the provider of the care had evaluated the person's clinical condition and pressure ulcer risk factors using the following:** • planned and implemented interventions that are consistent with the persons needs and goals and recognised standards of practice • monitored and evaluated the impact of the interventions and revised the approaches as appropriate • or the individual refused to adhere to prevention strategies in spite of education of the consequences of non-adherence

3.0 Preventing pressure sores

It is much better to prevent pressure sores than to treat them once they have happened. The National Institute for Health and Care Excellence (NICE)[6], Healthcare Improvement Scotland[7] and the European Pressure Ulcer Advisory Panel (EPUAP)[8] have guidelines on pressure sores. They all recommend that a member of the health care team looking after you should assess your risk of developing pressure sores and create a plan to prevent them.

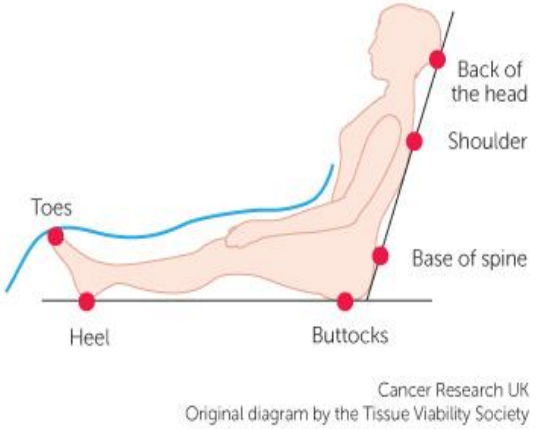
The areas of skin most at risk of getting sore depends on whether you are lying down or sitting. The following diagrams show the areas most at risk.

[6] The National Institute for Health and Care Excellence (NICE) Guidelines - Pressure ulcers: prevention and management of pressure ulcers [CG179] 2014

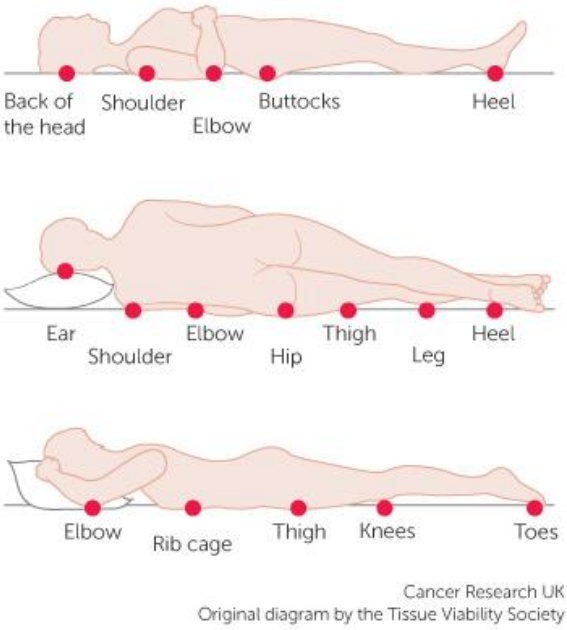
[7] http://www.healthcareimprovementscotland.org/our_work/patient_safety/tissue_viability.aspx

[8] Prevention and Treatment of Pressure Ulcers: Quick Reference Guide National Pressure Ulcer Advisory Panel, European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance (2014)

Sitting



Lying



In some people, the skin breaks down and creates a wound. There is then a risk that the wound can get infected. This can be a serious problem. It is very important to treat infections quickly.

4.0 The Impact of Pressure Sores on Patients

The impact of pressure sores on patients may be highly significant: prolonged immobilization, loss of independence, socio-vocational impact (interruption of regular activities). Pressure sores may lead to death if untreated, but should never progress further than the stage of reddened skin if prevention measures are taken.

Pressure ulcers are a major cause of morbidity in acute and non-acute care. They cause pain and distress often requiring prolonged treatment, restricting individuals' independence and quality of life. Pressure ulcers are a largely preventable adverse event and an important measure of the quality of care within the organisation. Dealey et al. (2012)[9] notes that the cost of treating pressure ulcers relates to the severity of the wound, with costs increasing from £1,214 for a grade 1 pressure ulcer to £14,108 for a grade 4 pressure ulcer. However the human costs include pain, injury, distress, loss of mobility and an increased risk of death. The impact of pressure ulcers is psychologically, physically and clinically challenging for both patients and NHS staff. The following extracts are

[9] Dealey C1, Posnett J, Walker A., Journal of Wound Care. 2012 Jun;21(6):261-2, 264, 266. The cost of pressure ulcers in the United Kingdom.

real stories from people who have been affected by pressure sores
taken from www.your-turn.org.uk

A 77-year old grandmother suffered a stroke, she was rushed to hospital for treatment. An infection contracted while she was in hospital would prove far more dangerous to her health than the stroke itself. A couple of weeks into this lady's stay in hospital her relatives realised something wasn't quite right. She wasn't her usual self and although the family knew she was still recovering from the stroke, they sensed there was more to it. It was at this point that staff at the hospital told the relatives that the patient had developed a pressure sore on her lower back and buttocks. Her grand-daughter says: "I didn't really know what a pressure sore was or how serious they could be and so although I was concerned for Nan, at this stage I wasn't unduly worried." After six weeks stay in hospital and still suffering from a pressure sore, the patient was discharged and admitted to a private nursing home. The family specifically found a home that claimed to have experience and knowledge in treating pressure sores. Her pressure ulcer was a Grade 3 by this stage (Grade 1 being the least serious and Grade 4 potentially lethal) and so they were really adamant about her being looked after by a nursing home that was up to speed in pressure sores management and would give her the best possible care. And so it came as a tremendous shock to the relatives when just six weeks after her admittance to the nursing home, she received a call from the police to say that her grandmother had been rushed to Hospital and was part of an ongoing investigation into the standard of care at the nursing home. One resident had died as a result of complications from a pressure sore and several others had extremely severe pressure sores. The family were absolutely devastated. They had trusted the nursing home to give their relative the very best possible care. They had been told by the home they were very experienced in pressure sore care and management and the family had no reason to disbelieve them. Upon admittance to hospital for the second time, it was noted that the sore had deteriorated and was now the worst it could be – a life threatening Grade 4. When her grand-daughter saw the sore, she was completely devastated. It was just like a huge weeping and infected crater in her lower back and buttocks. She was horrified and just couldn't understand how it could have got to this state. She adds: "Nan was fighting for her life with something that was totally avoidable. She was vulnerable and needed care and yet she ended up in a truly awful state". "Although this patient is now well on the road to recovery the relatives still feel extremely angry and resentful at the trauma her family and the patient were subjected to. Her grand-daughter says: "I had no idea that pressure sores could kill. If I'd had the slightest notion of just how serious they can be, I would have been demanding that my Nan was moved regularly and would have been checking her vulnerable areas." Having said that, surely we should all expect that our families receive the basic requirements of care? Surely it is not asking too much that patients who are unable to move themselves are turned regularly? This lady is now in a wonderful nursing home and her wound has nearly recovered. She has lived with the pain, discomfort and distress of a pressure sore for more than a year. It was entirely avoidable and something that no one should have to put up with.

A fifty year old lady developed a pressure sore after a major operation. She had an epidural for pain relief and as a result lost sensation from the knees down. Consequently she rubbed the top layer of skin off the heels of her feet without even realising it. She says: "Once I got the feeling back in my legs a day or two after my surgery when the epidural was removed, I realised my heels were sore. It was almost like when you wear ill-fitting shoes and they rub the skin off your toes, but this was my heels." She alerted the nursing staff who treated it with cream. She says: "No-one actually told me what the problem was and it never occurred to me that it was a pressure sore as I always thought they were some sort of awful ulcer type damage to the skin. My heels were sore for months after the operation and I had to continue to rub moisturiser into them myself to reduce the discomfort and pain."

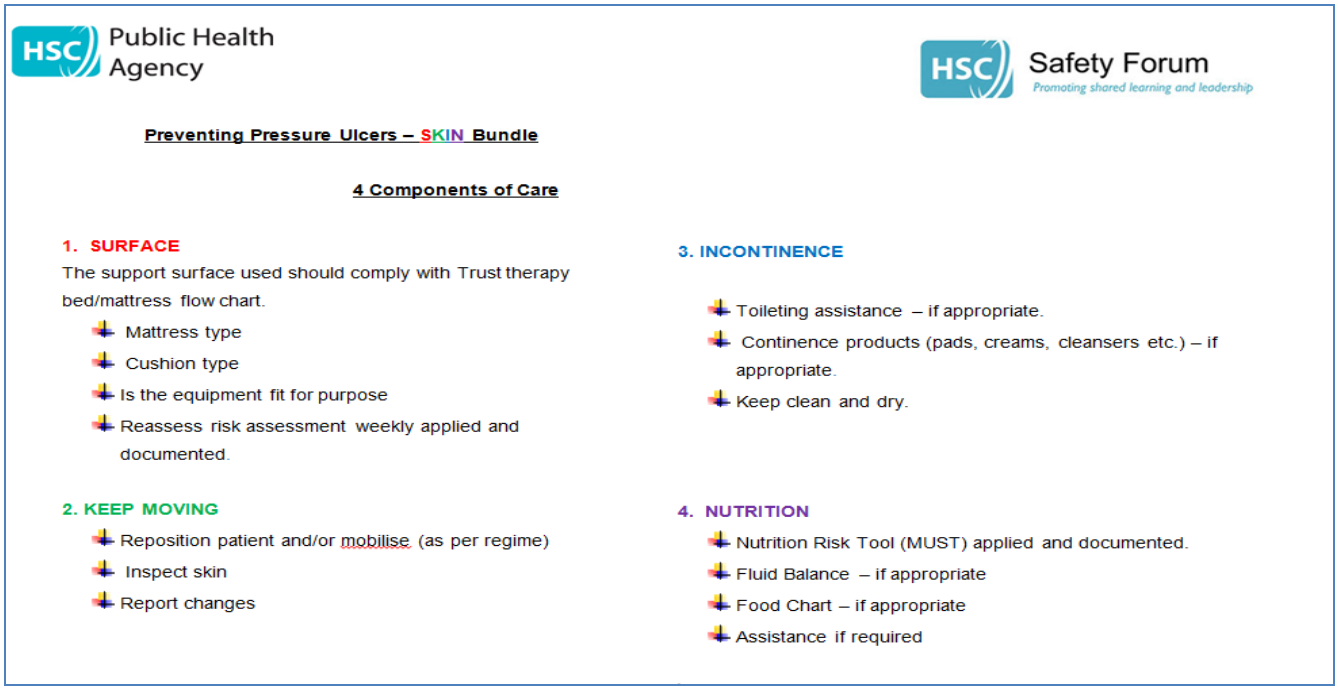
Hopkins et al[10] reports the findings of a pilot study exploring the experience of older people living with pressure ulcers. Analysis of this study revealed three main themes, all with associated subthemes: pressure ulcers produce endless pain; pressure ulcers produce a restricted life; coping with a pressure ulcer. The endless pain theme had four subthemes: constant presence, keeping still, equipment pain and treatment pain. Some patients found that keeping still reduced their pain. Several patients also reported that pain was exacerbated by their pressure relieving equipment and at dressing change. There were three subthemes for the restricted life theme: impact on self, impact on others and consequences. Patients found that the pressure ulcer restricted their activities and had an impact on their families. In addition, for some, the restrictions delayed their rehabilitation. To cope with their pressure ulcers, patients developed ways of accepting their situation or comparing themselves with others. With this in mind, a collaborative was established in Northern Ireland, to ensure a consistent approach was developed to implement best practice for pressure ulcer prevention.

5.0 Commissioning Plan Target

The 2015/16 Commissioning Plan[11] requirement states: "From April 2015, establish a baseline for the incidents of pressure ulcers (grade 3 & 4) occurring in all adult inpatient wards and the number of those which were unavoidable. Trusts will monitor and provide reports on bundle compliance and the rate of pressure ulcers per 1,000 bed days."

Trusts are committed to ensuring pressure ulcer prevention is a priority. As part of their QIPs, pressure ulcer incidence is monitored and information submitted to HSCB and PHA on a quarterly basis.
The SKIN Bundle was developed in 2004 at St Vincent's Medical Centre[12], a 528-bed hospital in Florida, US. It was introduced in Wales in 2009 through Transforming Care[13], a ward-based programme for Wales that aimed to improve patient care by reducing pressure ulcers. The SKIN Bundle (see diagram below) is an evidence based collection of interventions proven to prevent pressure ulcers. SKIN is an acronym that prompts nurses to remember four key elements of good skin care: **S**urface selection, **K**eep moving, **I**ncontinence management, and **N**utrition.

[10] Hopkins A, Dealey C, Baile S, Defloor T Worboys F, Journal of Advanced Nursing, (September 2006) Patient stories of living with a pressure ulcer
[11] HSCB/PHA Commissioning Plan 2015/16
[12] Joint Commission Journal on quality and Safety, (September 2006) Volume 32 Number 9
[13] http://www.1000livesplus.wales.nhs.uk/transforming-care



HSC Public Health Agency

HSC Safety Forum
Promoting shared learning and leadership

Preventing Pressure Ulcers – SKIN Bundle

4 Components of Care

1. SURFACE

The support surface used should comply with Trust therapy bed/mattress flow chart.

- Mattress type
- Cushion type
- Is the equipment fit for purpose
- Reassess risk assessment weekly applied and documented.

2. KEEP MOVING

- Reposition patient and/or mobilise (as per regime)
- Inspect skin
- Report changes

3. INCONTINENCE

- Toileting assistance – if appropriate.
- Continence products (pads, creams, cleansers etc.) – if appropriate.
- Keep clean and dry.

4. NUTRITION

- Nutrition Risk Tool (MUST) applied and documented.
- Fluid Balance – if appropriate
- Food Chart – if appropriate
- Assistance if required

The PHA supports HSC Trusts through the Regional Pressure Ulcer Prevention Group to implement SKIN in all hospitals in Northern Ireland, using the Institute for Healthcare Improvement's (IHI) Model for Improvement[14] – plan, do, study, act – to test and implement the bundle through face to-face collaboration and through sharing and learning across the organisations. The IHI Model for Improvement is a simple and reusable model for introducing rapid change, resulting in sustained improvement. In addition within each Trust the pressure ulcer safety cross to measure incidents of pressure damage, has transformed attitudes – staff have gone from accepting pressure damage as inevitable for some patients to scrutinising care to ensure everything was being done to prevent pressure ulcers from occurring.

The Regional Pressure Ulcer Prevention Group provides advice, support and shares regional learning across Northern Ireland. It focuses on sustainable strategies for pressure prevention and management across the Health and Social Care Trusts.

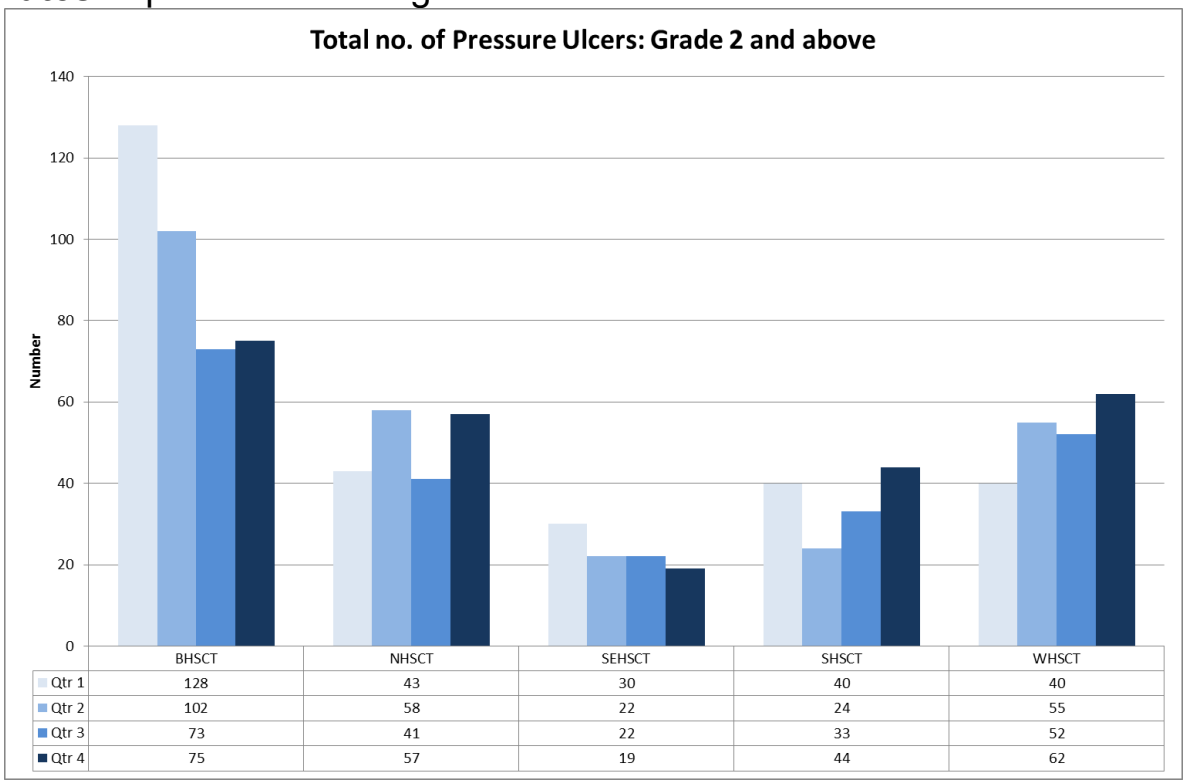
The NICE guidelines[15] recommend that pressure ulcers of grade 2 and above are reported locally as incidents. This ensures that information is gathered about the circumstances of the pressure ulcer and helps prevent future incidents.

[14] Langley GL, Moen R, Nolan KM, Nolan TW, Norman CL, Provost LP. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance (2nd edition). San Francisco: Jossey-Bass Publishers; 2009.
[15] National Institute for Healthcare Excellence Guidelines - Pressure ulcers: prevention and management of pressure ulcers [CG179] 2014

The higher the grade of pressure ulcer, the more severe the injury to the skin and underlying tissue. Grade 3 or 4 pressure ulcers can develop quickly, for example, in susceptible people, a full-thickness pressure ulcer can sometimes develop in just one or two hours. However, in some cases, the damage will only become apparent a few days after the injury has occurred.

6.0 Baseline numbers and rates of pressure ulcers

The following graphs show the15/16 **regional baseline numbers** and **rates** of pressure ulcers grade 2 and above.

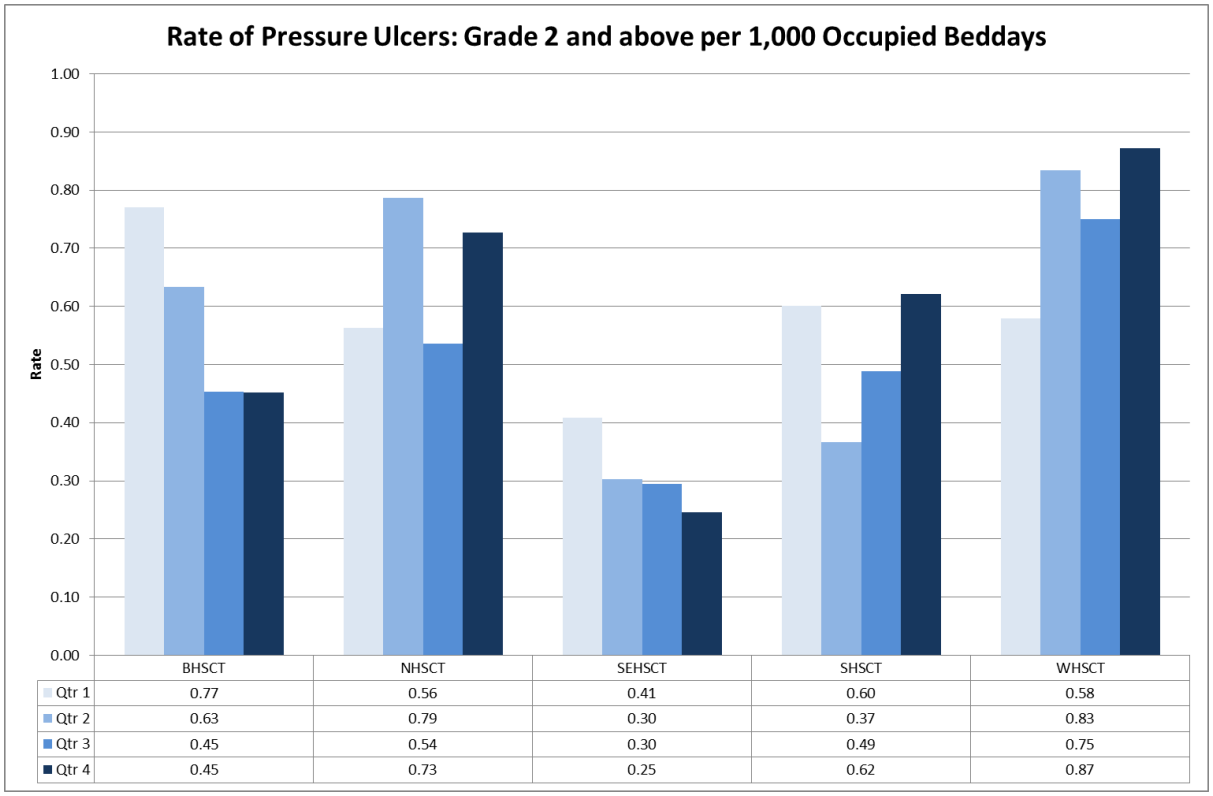


	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Qtr 1	128	43	30	40	40
Qtr 2	102	58	22	24	55
Qtr 3	73	41	22	33	52
Qtr 4	75	57	19	44	62

It should be noted that there is a variance each Trust in relation to the number of wards included in the monitoring. The below table provides an overview of the number of wards each Trust has implemented quality improvement for pressure ulcers, which equates to 100% total within the adult inpatients areas wards for each Trust.

Total number of acute adult in patient wards*					
	BHSCT	**NHSCT**	**SEHSCT**	**SHSCT**	**WHSCT**
Total	70	29	31	26	31

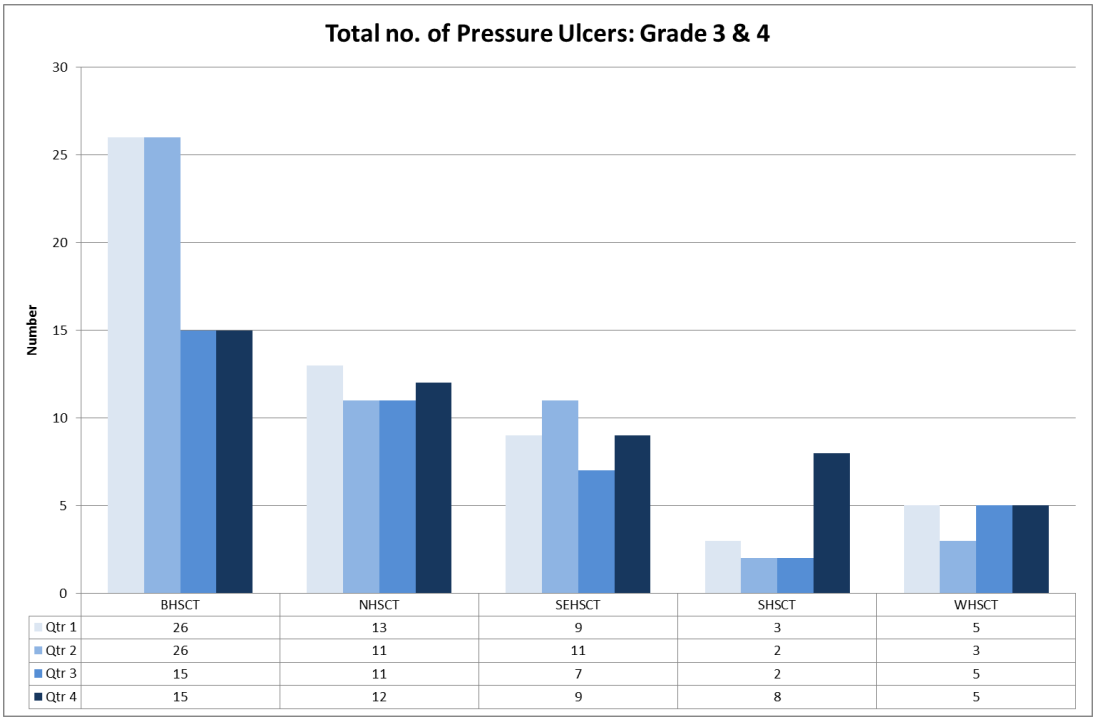
**when measuring the spread of quality improvement bundles the total number of adult inpatient wards may vary slightly within each Trust for a variety of reasons including; the appropriateness of the bundle within the particular area, the opening / closure of wards and/or re-categorisation of wards.



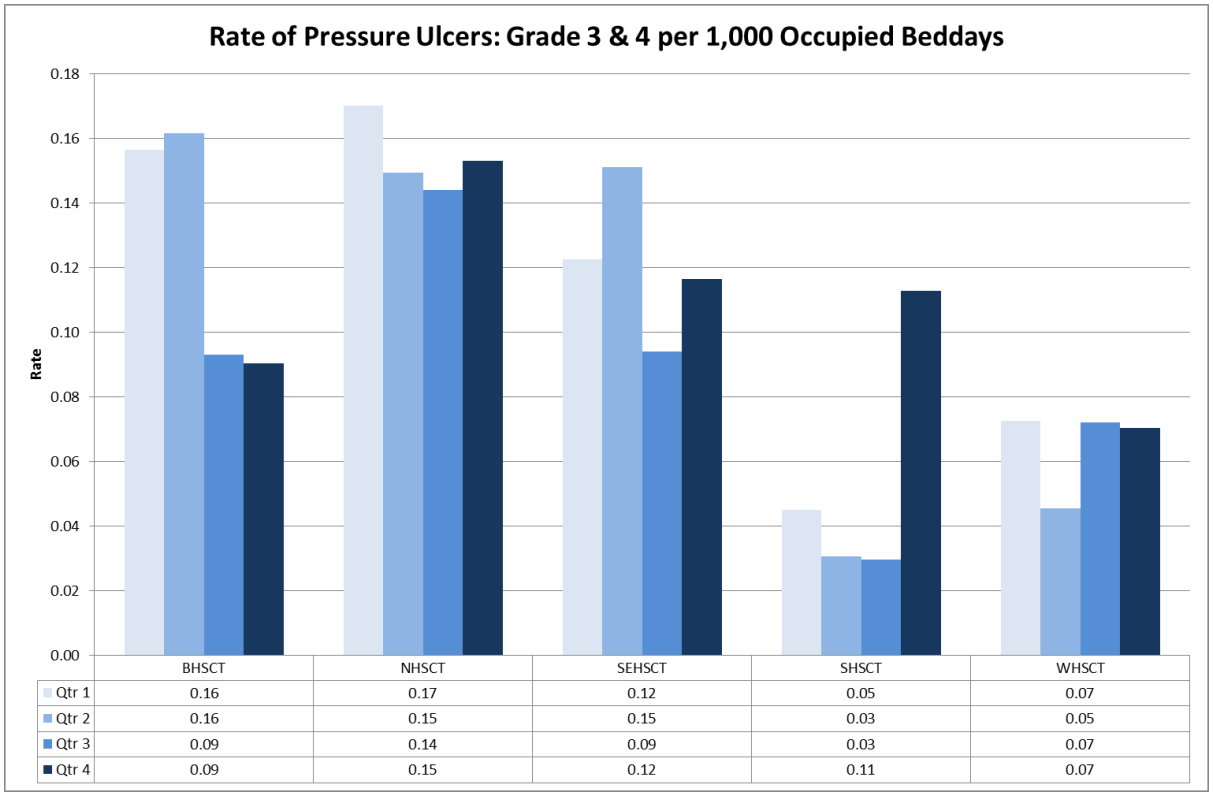
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Qtr 1	0.77	0.56	0.41	0.60	0.58
Qtr 2	0.63	0.79	0.30	0.37	0.83
Qtr 3	0.45	0.54	0.30	0.49	0.75
Qtr 4	0.45	0.73	0.25	0.62	0.87

7.0 Baseline information for grade 3 & 4 pressure ulcers

The following charts show the **total number & rate of grade 3&4 pressure ulcers** that were recorded each quarter by Trusts during 2015/16:



	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Qtr 1	26	13	9	3	5
Qtr 2	26	11	11	2	3
Qtr 3	15	11	7	2	5
Qtr 4	15	12	9	8	5



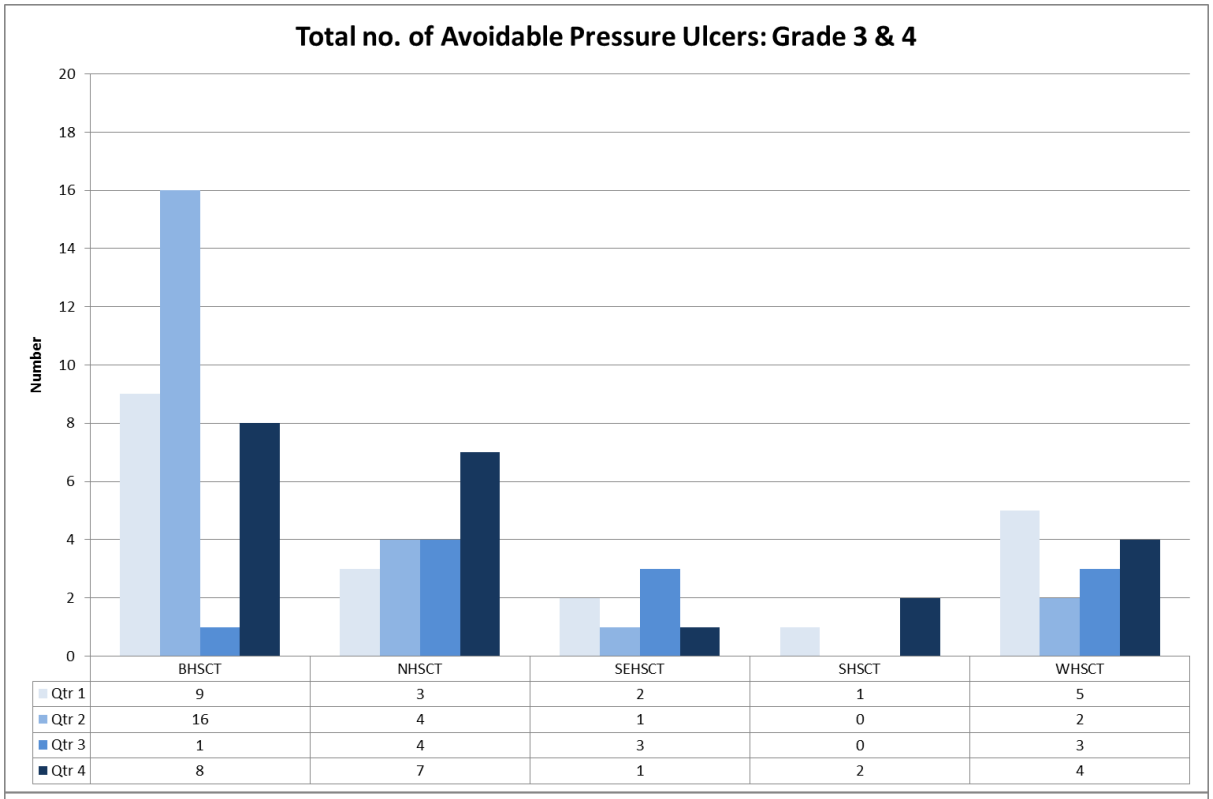
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Qtr 1	0.16	0.17	0.12	0.05	0.07
Qtr 2	0.16	0.15	0.15	0.03	0.05
Qtr 3	0.09	0.14	0.09	0.03	0.07
Qtr 4	0.09	0.15	0.12	0.11	0.07

During 2015/16 all Trusts except Belfast focused on establishing baseline numbers for the incidents of grade 3 & 4 pressure ulcers occurring in all adult inpatient wards. BHSCT, as a pilot, had established their baseline data during 2014/15.

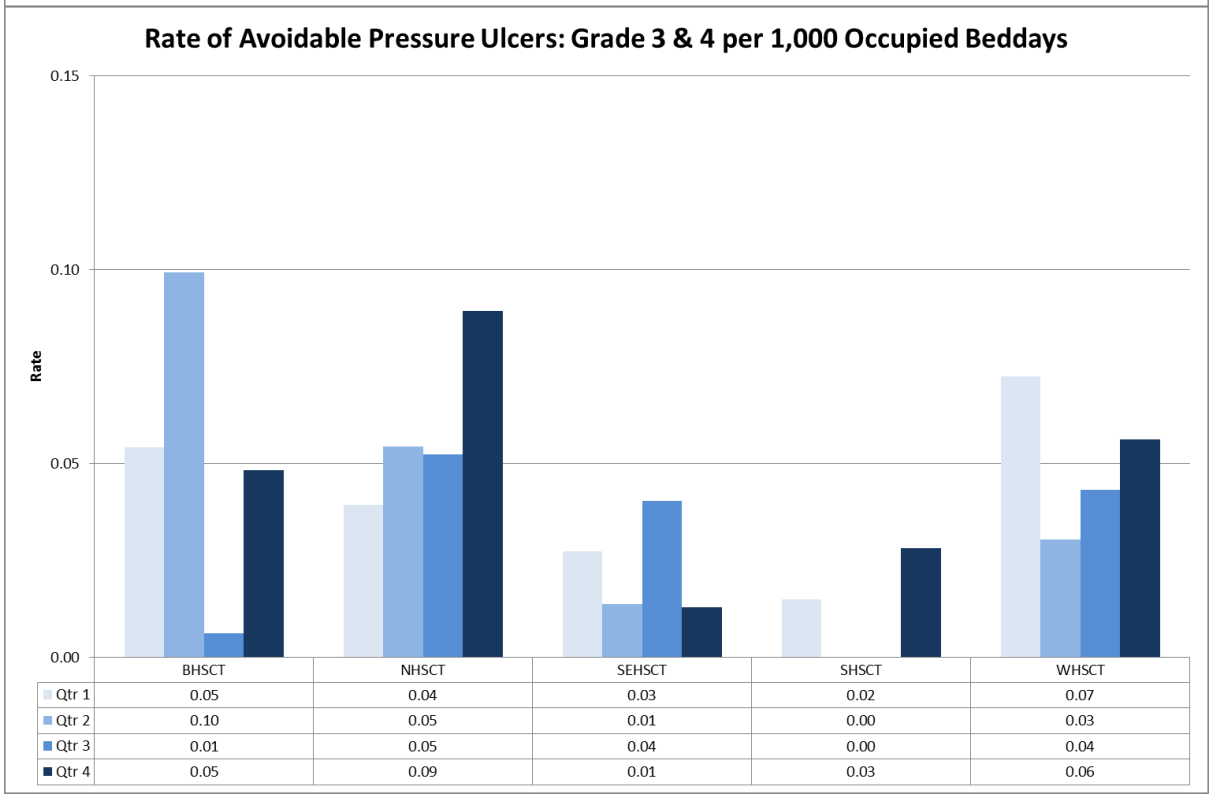
8.0 Prevention of avoidable grade 3 & 4 pressure ulcers

At the Regional Pressure Ulcer Prevention Group, Trusts had agreed to focus on prevention of avoidable grade 3 & 4 pressure ulcers, as these create deeper cavity wounds causing more pain and suffering to patients. This focuses on the more serious harm caused by pressure ulcers.

The following charts show the **number & rate** of **avoidable** grade 3 & 4 pressure ulcers that were recorded each quarter by Trusts during 2015/16:



	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Qtr 1	9	3	2	1	5
Qtr 2	16	4	1	0	2
Qtr 3	1	4	3	0	3
Qtr 4	8	7	1	2	4

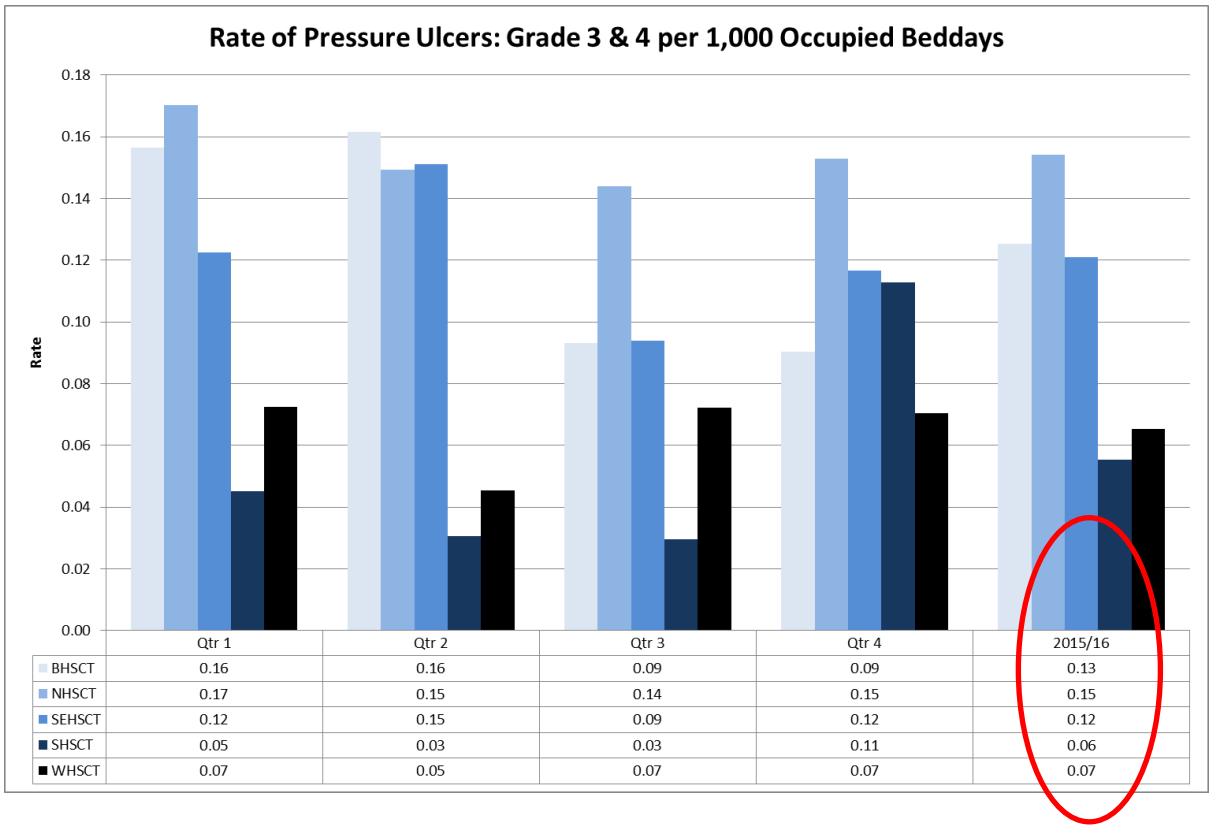


	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Qtr 1	0.05	0.04	0.03	0.02	0.07
Qtr 2	0.10	0.05	0.01	0.00	0.03
Qtr 3	0.01	0.05	0.04	0.00	0.04
Qtr 4	0.05	0.09	0.01	0.03	0.06

BHSCT had a significant rise in the number of grade 3 and 4 in Quarter 2 (1st July to 30th September 2015). However, it is important to note that the data should be analysed over a period of time and not on individual data points. In 2015/16 BHSCT had set a 10% reduction target in the number of grade 3 & 4 avoidable pressure ulcers in all adult inpatients; they exceeded their target and had 34 avoidable pressure ulcers across the Trust in 15/16 compared to 42 during 2014/15.

During 2016/17 Trusts are working towards a % reduction in the number of grade 3 & 4 avoidable pressure ulcers in all adult inpatients from their baseline figures.

9.0 Regional Overview



	Qtr 1	Qtr 2	Qtr 3	Qtr 4	2015/16
BHSCT	0.16	0.16	0.09	0.09	0.13
NHSCT	0.17	0.15	0.14	0.15	0.15
SEHSCT	0.12	0.15	0.09	0.12	0.12
SHSCT	0.05	0.03	0.03	0.11	0.06
WHSCT	0.07	0.05	0.07	0.07	0.07

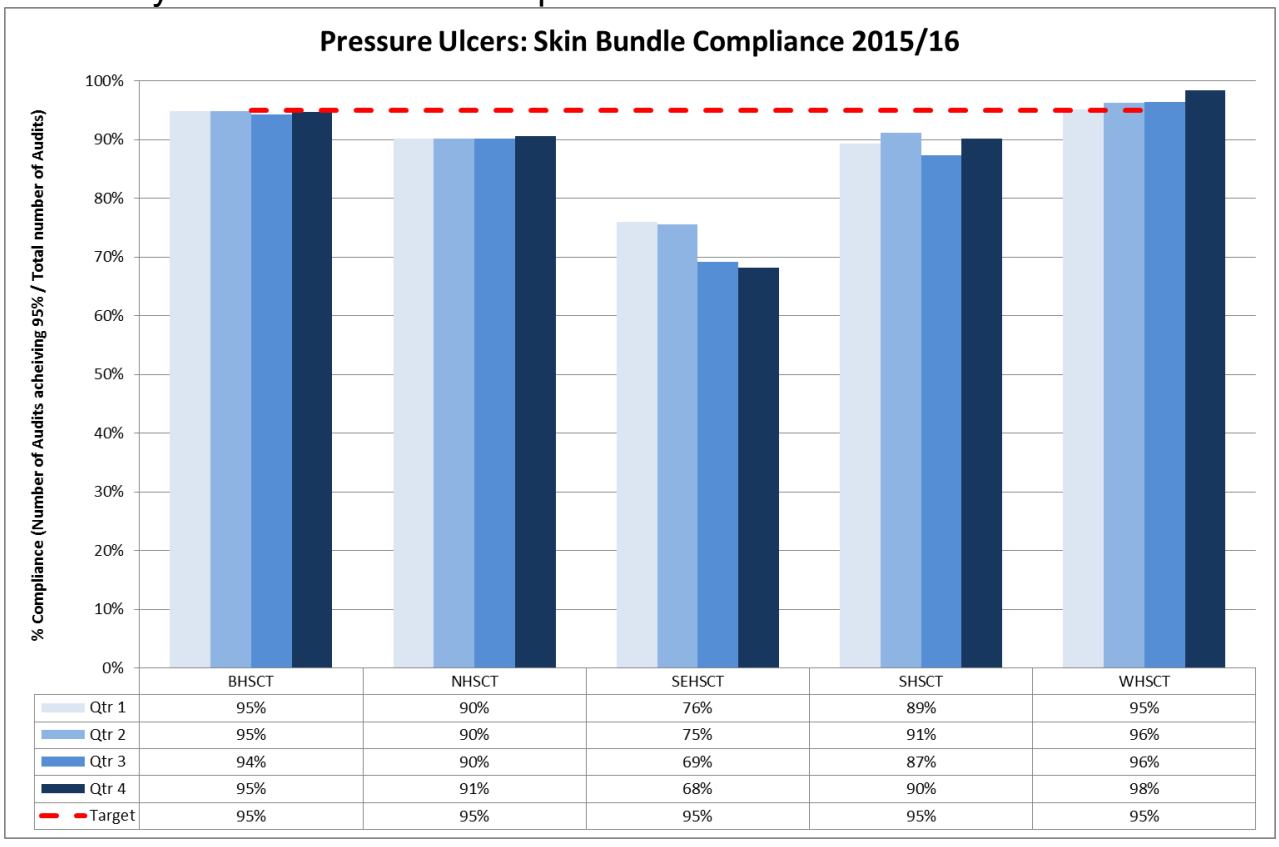
Regionally, the 2015/16 annual Trust range of pressure ulcer incidence rates grade 3 & 4 reported between 0.06% and 0.15% per 1,000 occupied bed days.

The total number of reported pressure ulcers (grade 2 and above) during 2015/16 was 1,020. Of these 198 (19%) were grade 3 & 4. Of the 198 grade 3 & 4 pressure ulcers, 122 (62%) were recorded as unavoidable and 76 (38%) as avoidable.

There are a number of individual hospital Trusts in England report pressure ulcer incidence rates per 1000 bed days as part of the NHS England Open and Honest Care Driving Improvement initiative. [16] At the end of March 2016 the reported pressure ulcer incidence rates for these Trusts range between 0 - 1.69% per 1000 bed days. It should be noted that this initiative uses incident rates to compare improvement over time, but not for the purpose of comparison between Trusts as it is recognised that differences in the ways that organisations collect data and the patients that they care for, and the services they provide, all mean that direct comparisons are not possible.

10.0 Compliance with SKIN bundle

The following chart shows the percentage compliance with the Skin Bundle by Trust for each of the quarters in 2015/16:



	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Qtr 1	95%	90%	76%	89%	95%
Qtr 2	95%	90%	75%	91%	96%
Qtr 3	94%	90%	69%	87%	96%
Qtr 4	95%	91%	68%	90%	98%
Target	95%	95%	95%	95%	95%

Throughout 2015/16, Belfast and Western Trusts have continually met, or almost met, the target of 95% compliance. As a result the WHSCT have reduced the number of audits performed in Q4 in areas where they had sustained over 95% compliance over the past six quarters and also where they had achieved 1,000 plus pressure ulcer free. The South

[16] NHS England Open and Honest Care Driving Improvement initiative

Eastern Trust was measuring elements additional to the regional documentation which resulted in lower compliance rates in comparison to other Trusts. The documentation has been changed to mirror the regional documentation from April 2016 therefore next year's reporting should be comparative with other Trusts.

The following table shows more detail with the number of audits carried out in each Trust during each of the four quarters in 2015/16 with Regional compliance of the Skin Bundle:

	Skin Bundle % Compliance						Total Audits				
TRUST	Target	Q1	Q2	Q3	Q4	Total	Q1	Q2	Q3	Q4	Total
BHSCT	95%	95%	95%	94%	95%	**95%**	4593	4556	3600	4059	**16808**
NHSCT	95%	90%	90%	90%	91%	**90%**	833	789	643	599	**2864**
SEHSCT	95%	76%	75%	69%	68%	**72%**	441	608	674	503	**2226**
SHSCT	95%	89%	91%	87%	90%	**89%**	372	363	387	378	**1500**
WHSCT	95%	95%	96%	96%	98%	**96%**	895	847	735	240	**2717**
REGION	95%	93%	93%	98%	92%	**92%**	7134	7163	6039	5779	**26115**

The region as a whole has met the 95% target in quarter 3 of 2015/16, with an average % compliance of Skin Bundle over the 2015/16 year of 92% (24,056 of 26,115 audits being compliant). There are individual ward areas that are at 1,000 plus pressure ulcer free days, in these areas there has been a reduction in audits.

11.0 Root cause analysis tool

Root cause analysis of pressure ulcer incidents can help to identify local priorities for action. All Trusts from 1 April 2015 are undertaking Root Cause Analysis (RCA) on each individual reported incidence of grade 3 & 4 pressure ulcer to identify and share learning to prevent future reoccurrences.

Trusts have reported the following key findings from RCAs to date and are working with the individual areas to implement improvements relating to each finding:

Key findings of causal factors resulting in pressure ulcers grade 3 & 4
• Pressure from a hard surface – such as a bed or wheelchair • Pressure that is placed on the skin through involuntary muscle movement – such as muscle spasms • Moisture – which can break down the outer layer of the skin (epidermis)

12.0 Sharing of Regional Learning

The Regional Pressure Ulcer Group meets on a quarterly basis. This group is led by the PHA and membership comprises a multidisciplinary team across the 5 HSC Trusts. At each meeting progress is monitored, support and advice is given and regional learning is shared in relation to the prevention and management of pressure ulcers. The group have identified the following learning and this has been shared and actioned across all Trusts.

- **Risk assessments** are performed for all inpatients on admission, if they are moved to another area and if their condition deteriorates. The group has contributed to the development of the regional nursing documentation relating to pressure ulcer prevention and management.
- **A skin inspection** should be done on every patient within 6 hours of admission, and re-inspection should occur every 8 to 24 hours, depending on the status of the patient. This practice is being promoted across all adult inpatient wards.
- **The pressure ulcer prevention plan** should include interventions that minimise or eliminate friction and shear, minimize pressure with off-loading, manage moisture, and maintain adequate nutrition and hydration. The SKIN bundle messages outlined below are key to achieving this and are shared with all staff and on induction and any training provided:
    - Surface – make sure people have the right support including support for patients with muscle spasm or involuntary muscle movement;
    - Skin – early skin inspection means early detection;
    - Keep moving – keep people mobile;
    - Incontinence – keep patients dry and clean and free from moisture, this includes urine, faeces and sweat;
    - Nutrition – make sure people have a MUST risk assessment on admission if they are moved to another area and if their condition deteriorates. A good diet with plenty of fluids, Is essential particularly for elderly patients or those who are at risk.
- **Pressure ulcer treatment is evidence-based** and includes a patient assessment and wound evaluation, including the following

elements: history and physical, wound description/staging, etiology of pressure, psychosocial needs, nutritional status, and bacterial colonization/infection. Dr Jeannie Donnelly, Tissue Viability Nurse, BHSCT represents N.I on the European Pressure Ulcer Advisory Panel (EPUAP) and the European pressure ulcer conference will take place in the Waterfront Hall, Belfast, between 20-22 September 2017. The conference theme is: 'One Voice for Pressure Ulcer Prevention and Treatment. Challenges and Opportunities for Practice, Research and Education'.

- **Document** all risk assessments, skin inspection findings, pressure ulcer prevention interventions and treatments. A consistent documentation format is used across all HSC Trusts.
- In addition to the regionally agreed RCA tool, the group has developed a regionally agreed dataset to determine pressure ulcer incidents and ensure consistency in approach across NI's HSC Trusts.
- **Education** is provided to the patient, family, caregivers and health care team members regarding prevention and treatment of pressure ulcers. A regional pressure ulcer prevention leaflet, for patients and carers has been developed and is being used by all Trusts. The purpose of this leaflet is to provide patients and carers with information on pressure ulcers, how they develop and the steps they can take to prevent them. In addition, a multidisciplinary eLearning tool has been developed and tested within BHSCT and has been shared with the regional group with agreement to use this as a regional tool.
- **Communication** of pressure ulcer development, risk assessment, skin inspection results, and treatments should be consistent. Any change in skin condition is communicated to direct and indirect care providers as soon as observed.
- Each of the 5 Trusts has a number of wards that have reached 1,000 plus pressure ulcer free days and many of these **celebrated their local success** on National Stop Pressure Ulcer day.

13.0 Conclusion

During 2015/16 the HSCB and PHA have worked with Trusts to monitor progress, support, advise and share regional learning in relation to the management of pressure ulcer prevention priority. The focus of this work has been on implementing and sustaining good practice, particularly in relation to grade 3 and 4 pressure ulcer incident rate. The SKIN Bundle is a simple, holistic approach implemented across all inpatient settings in Northern Ireland, to ensure all patients receive the appropriate care to prevent pressure damage. Using the pressure ulcer safety cross to measure incidents of pressure damage in each Trust has transformed attitudes – staff have gone from accepting pressure damage as inevitable for some patients to scrutinising care to ensure everything was being done to prevent pressure ulcers from occurring. The IHI Model for Improvement is a simple and reusable model for introducing rapid change, resulting in sustained improvement. The HSCB and PHA will continue to gain assurances from Trusts on the implementation of the pressure ulcer priorities to improve the quality of services and achieve better outcomes to patients and clients.

HSCB / SOUTHERN TRUST SERVICE ISSUES and PERFORMANCE MEETING – ACTIONS / ISSUES REGISTER – 1 February 2017

ATTENDEES: **TRUST** – Aldrina Magwood, Dr Richard Wright (T/C), Angela Mc Veigh, Esther Gishkori, Lesley Leeman, Lynn Lappin, Heather Trouton
HSCB – Michael Bloomfield, Dean Sullivan, Fionnuala McAndrew, Brid Farrell, Lisa McWilliams, Caroline Cullen, Colin Bradley, Jill Young
DoH – Alison Jeynes

Issue	Action	Lead Responsibility / Deadline
REFORM AND MODERNISATION		
• The Trust delivered a presentation on its reform programme and provided an outline of the initiatives being taken forward in each of the following Directorates: - Acute; - Medical; - Older People and Primary Care; - Children and Young People's Services; - Mental Health and Disability Services. • The HSCB (MB) acknowledged the work that the Trust had done to date and also the planned programme of reform and advised that it would be useful to focus on one or two specific areas at future meetings to allow more detailed discussion.	**Action 1:** Trust to provide the HSCB (FMcA) with further details on the transition of young people from Intellectual Disability (ID) CAMHS to Adult Learning Disability or MHD Service. **Update:** Additional information provided on 1.3.17.	**Trust** (Aldrina Magwood) **10.2.17**
2016/17 CPD STANDARDS/TARGETS		
Elective Care		
Washthrough from 2015/16 and IS Paused Patients • The Trust (AM) confirmed that all of the activity associated with the 2015/16 washthrough and IS paused patients had been completed. *Additional In-house Activity (Q1/Q2 and Q3/Q4)* • The Trust (AM) confirmed that all activity associated with the non-recurrent funding allocated for additional elective activity in Q1/Q2 (£700k) was complete. • Despite highlighting that it could have done more additional elective activity in Q1/Q2 had funding been available, the Trust had returned £500k of the Q3/Q4 allocation (£750k). A costed plan setting out details of the additional activity to be delivered and the associated costs remained outstanding.	**Action 2:** Trust to submit costed delivery plan for £250k. **Update:** costed plan received 21.2.17.	**Trust** (Aldrina Magwood) **3.2.17**

Issue	Action	Lead Responsibility / Deadline
• The HSCB (MB) asked the Trust to reconsider if any additional in-house capacity could be secured in the event that further non-recurrent funding became available in-year. *NOP and IPDC Waiting Times* • The HSCB (MB) advised that the Department had indicated that the Ministerial announcement expected in February 2017 on the HSC reform agenda would include a target for Trusts to ensure that all patients waiting longer than 52 weeks at the end of March 2017 for a first outpatient appointment or for inpatient/daycase treatment were seen/treated by end of March 2018. • The HSCB outlined the scale of the challenge for the Southern Trust – at end of December 2016, c4,300 OPs were waiting longer than 52 weeks and c880 patients were waiting longer than a year for treatment. • The Trust (LLe) highlighted that a number of those waiting longer than 52 weeks were in specialties where the service was provided on an outreach basis by another Trust, e.g. ophthalmology and were therefore outwith the control of the Trust. *Delivery of Core* • HSCB (MB) noted the improvement in the Trust's delivery of core position for IPDC in 2016/17 (1.4.16-30.11.16) (-2%) compared to the same period in 2015/16 (-3.9%). However, the deterioration in NOP was highlighted (from +1.9% in 2015/16 to -5.4% in 2016/17), in particular during the months of July and December. • The Trust (LLe) provided assurance that it reviewed the delivery of core position at specialty level on a monthly basis to understand the reasons for any underdelivery – the main specialties currently impacting on performance were orthopaedics, breast family history and breast surgery and the Trust was continuing to closely monitor these. • The HSCB (MB) advised that it would be seeking an update from the Trust on the reasons for underdelivery at specialty level at year-end. • In relation to progress against the Trust's delivery of core improvement plans, the HSCB (MB) highlighted that there were a small number of specialties where performance at the end of December was not in line with the Trust's planned position. Furthermore, there were a number of specialties where the forecast position for 2016/17 (full year) showed a deterioration on the actual delivery of core position for 2015/16. • The Trust (LLe) provided an update on the following specialties: - *ENT* – one consultant (out of a total complement of five) had left in-year and this had impacted on NOP capacity. Delivery of core for IPDC had been impacted by elective cancellations. - *Orthopaedics (OP)* – delivery of core elective capacity had been impacted by an increase in trauma	**Action 3:** Trust to consider if further additional in-house capacity was available in-year.	**Trust** (Aldrina Magwood) **3.2.17**

Issue	Action	Lead Responsibility / Deadline
demand and the Trust did not expect to recover this position in-year. • In relation to Thoracic Medicine (OP), the Trust had submitted a plan which projected 11% underdelivery of core in 2016/17. This compared with a 14% overdelivery of core in 2015/16. The HSCB advised that this was not an acceptable position and would be discussed in more detail at the next cancer/elective performance meeting. *Diagnostics* • The HSCB (MB) reported that despite the significant level of non-recurrent funding that had been allocated to the Trust (£1.16m) in 2016/17 to undertake additional diagnostic activity, the number of patients waiting longer than nine weeks had continued to increase – at the end of December 2016, 8,260 patients were waiting longer than nine weeks compared to 3,721 at the end of March. In particular, there had been a sharp increase in the number of patients waiting longer than 26 weeks – from 51 at the end of March to 736 at end of December. • At the end of December 2016, the Trust was overdelivering against agreed activity volumes (core and, where relevant, WLI and IS) for CT and Plain Film however, there was a 6% underdelivery of activity in both NOUS and MRI. ***Update:*** *MRI SBA was amended (15,550) and as a result, underdelivery reduced to -3%.* • The Trust (AM) advised that there had been procurement issues with the mobile CT scanner which had resulted in it not being available for a period of time and this had impacted on the waiting time position. The scanner was now back in operation (from December 2016) however, an early decision was required in relation to funding to enable it to be retained from 1.4.17. The Trust advised that the increase in CT waiting times (+800 since March 2016) was primarily as a result of increased unscheduled care demand and a change in the pathway for patients with a head injury (all patients now had to be scanned). The Trust highlighted the overdelivery of commissioned volumes of activity (core and additionality) - +15% at 31.12.16. ***Update (8.2.17):*** *Trust forecast end of year waiting time of 58 weeks for cardiac CT and 26 weeks for general CT.* • In relation to MRI, the number of patients waiting longer than nine weeks had increased from 142 at the end of March 2016 to 1,120 at the end of December. The HSCB highlighted that the underdelivery of core (380 / 3%) in this modality would go some way to addressing this position. The Trust advised that the MRI scanner was operating 8am-8pm Monday to Friday and was in use at weekends. ***Update (8.2.17):*** *Trust advised that a number of staff had been off sick in November and December and this had impacted on delivery of core.* • For NOUS, there was a 6% underdelivery of core at end of December 2016 and the number of patients	**Action 4:** Thoracic Medicine delivery plan to be discussed at next cancer/elective meeting. **Update:** discussed at meeting with Trust on 8.2.17.	HSCB **(Lisa McWilliams)** 8.2.17

Issue	Action	Lead Responsibility / Deadline
waiting longer than nine weeks had increased from 918 at the end of March 2016 to 2,014 at the end of December. ***Update (8.2.17):*** *The Trust advised that the delivery of core position was due to a combination of long term sickness absence and vacancies which the Trust had been unable to backfill. Trust forecast an end of year waiting time of 48 weeks and advised that all >26 week waits were MSK.* • In summary, the Trust (LLe) advised that it expected to deliver the approved volumes of additional activity and that waiting times would improve in Q4 as a result however, there would be patients waiting longer than 26 weeks at end of March 2017 in some sub-specialty areas. *Endoscopy* • The HSCB (MB) acknowledged that the number of patients waiting longer than nine weeks for an endoscopy had reduced from 972 at the end of August 2016 to 705 at the end of December. However, there was a significant underdelivery of core activity – 21.8% (1.4.16-31.12.16). With regard to the additional activity associated with the non-recurrent funding that had been allocated to the Trust (c£1m), c1,500 out of a total volume of c2,200 had been delivered. • As previously reported, a nurse endoscopist who had delivered 16% of the total SBA had left the Trust and this had had a significant impact on the delivery of core in 2016/17. The Trust advised that two nurse endoscopists were being trained however they would not be operational until September 2017. As a result, the Trust expected to be in a position to deliver commissioned volumes of core endoscopy activity from mid 2017/18. • In order to minimise the impact of the capacity shortfall in-year, the Trust had secured IS capacity for 680 scopes funded from within existing Trust resources however, notwithstanding this additionality, the Trust expected to underdeliver core by c1,100 (13%) in 2016/17 (as per delivery plan submitted 2.3.17) and have patients waiting longer than nine weeks at end of March 2017. *AHPs* • The HSCB (MB) noted the sharp increase in the number of patients waiting longer than 13 weeks for AHP treatment during December – 6,040 at the end of December compared to 4,997 at the end of November. • The HSCB sought an update from the Trust in relation to the additional AHP activity included in its Q1/Q2 elective delivery plan (£182k) and also progress with recruitment of staff associated with the agreed recurrent capacity gap (14.2WTE). • The Trust (AMcV) advised that the recruitment process was underway for 14.5WTE permanent staff – the majority of the new appointments were due to start in February 2017 and the Trust expected the increase in waiting times to halt once these staff were in post.		

Issue	Action	Lead Responsibility / Deadline
• In relation to the additional activity, the Trust (LLe) stated that this was for new and review patients and only new referrals seen in additional clinics would impact on the waiting time position. The Trust was continuing to undertake additional activity however, not to the same level as in Q1/Q2 as opportunities were limited as a number of temporary staff had left to take up posts in other Trusts. • The Trust reported that it was delivering agreed volumes of commissioned AHP activity and where this was not the case it was as a result of vacancies.		
Unscheduled Care		
Daisy Hill Hospital • The HSCB (DS) sought the Trust's assessment of the issues affecting ED performance in Daisy Hill Hospital (DHH) in 2016/17 compared to 2015/16. HSCB also made reference to the improvement in performance at Antrim Area Hospital following its 100% day. • The Trust (AM) advised that it had been in contact with the NHSCT to discuss the approach to the 100% day and also to share in any learning opportunities. • The Trust reported that that a number of factors had impacted on DHH's ED performance this year including: a 15% increase in ED attendances; an outbreak of norovirus which had closed two wards; capital works; and, staffing issues. In addition, some of the reform initiatives (Acute Care at Home) had not yet been rolled out to Newry and Mourne. • The HSCB (MB) advised that this issue would be discussed in more detail at the next unscheduled care meeting. • In relation to delayed discharge, the Trust (EG) acknowledged that there were opportunities to improve the discharge process and it would be taking forward work to ensure that when patients were medically fit for discharge they would be discharged to a nursing home or other home with appropriate support, i.e. discharge to assess. Furthermore, the Trust would be reviewing "social admissions" to understand the reasons for admission and to identify opportunities to prevent or reduce the number of these admissions. *4 and 12 hours* • HSCB (MB) highlighted that there had been a reduction in the Trust's 4-hour performance in each month in 2016/17 compared to the corresponding month last year. In relation to the number of patients who waited longer than 12 hours, this had increased significantly from 13 in 2015/16 (1.4.16-31.12.16) to 346 in 2016/17 (1.4.16-31.12.16).		

Issue	Action	Lead Responsibility / Deadline
Winter Resilience • The Trust (AM) advised that it was working with Seamus McGirr's team to review the winter resilience planning process. In addition, the Trust was reviewing the reform initiatives that had been put in place to determine what impact these had had. The findings from both exercises were expected by end of March 2017. • The resilience plan for 2017/18 was due to be completed by end of June 2017. *Champion Wards* • The Trust (EG) advised that the initial focus of this work had been on discharge – Ann McVey, Barry Conway and ward managers were working with Simon Dodds to take this work forward. • The HSCB (DS) emphasised that the Trust should develop the relevant skills in a small number of wards to identify issues and then expand the skill set to other wards across the Trust. In summary, the HSCB (MB/DS) highlighted that there were a number of areas where the Trust's performance was significantly worse than two years ago (e.g. elective care, unscheduled care, diagnostics, AHP, endoscopy) and this was a matter of concern. The HSCB advised that it would be happy to provide support to the Trust to identify and/or address the reasons for this position.		
Cancer Services		
14-day Cancer • The HSCB (MB) highlighted that there had been a continued deterioration in the Trust's performance against the 14-day standard since October (39% in December). • The Trust (HT) advised that Belfast Trust had provided capacity for six Southern Trust patients per week and Northern and South Eastern Trusts were providing capacity when it was available. Achievement of the 2-week wait was challenging however, where patients were not seen within 14 days, the maximum wait was currently 16-18 days. • The Trust advised that it was aiming to return to 100% by April however, there were significant risks to achieving this due to the uncertainty of available additional capacity in other Trusts. In the interim, performance was likely to deteriorate further as the next available appointment slots were on 8 February. • The HSCB (MB) stressed the need for the Trust to inform the HSCB immediately of any risk to this position and it would get involved in discussions with other Trusts as appropriate. • Further to the regional workshop that took place in October 2016 to consider options for the longer-term		

Issue	Action	Lead Responsibility / Deadline
sustainability of breast assessment services, the HSCB was preparing a next steps paper for consideration by SMT. *31-day Cancer* • The HSCB acknowledged the Trust's continued strong performance in this area – 99%. *62-day Cancer* • 62-day cancer performance would be discussed in detail at the cancer/elective performance meeting on 8 February.		
Mental Health Services		
• The Trust's continued strong waiting time performance in CAMHS and dementia services was acknowledged. *Adult Mental Health* • There had been a continued increase in the number of patients waiting longer than nine weeks for adult mental health services – at the end of December 2016, 409 patients were waiting longer than nine weeks compared to 81 at the end of March 2016. • The Trust (LLe) advised that the majority of adult mental health waits related to primary mental health care where increasing demand and more recent challenges with workforce have led to inability to maintain the waiting time. The challenges in this area had been highlighted in the Trust's TDP over the last few years. • The Trust was focused on redressing the increasing waiting list in PMHC and explored options to increase capacity. These include: - IS contract with PRAXIS to increase capacity for Step 2 interventions. The contract is set in the context of the move to Talking Therapy Hubs and capacity within the contract has recently been increased. - further contractual capacity has been secured with Inspire (NIAMH/Care call) to deliver Step 3 interventions for 150 of those waiting longest for an initial appointment. This contractual arrangement is short term due to non-recurrent funding and needs to be evaluated. This capacity would take some time to embed and while improvement was expected it may not be in this		

Issue	Action	Lead Responsibility / Deadline
financial year. Furthermore, sustainability of any improvement would be dependent on evaluation and the recurrent funding position. • The Trust advised that it also had a focus group looking at maximising existing Trust capacity including recruiting to vacant posts and an additional three Band 6 senior practitioner posts and three Band 7 CBT posts. Due to delays in progressing the recruitment process through BSO, it was unlikely that the impact of this additional capacity would be evident in-year. *Psychological Therapies* • At the end of December 2016, 61 patients were waiting longer than 13 weeks to access psychological therapy services. • The Trust was taking forward a number of actions to address the waiting time position including a waiting list validation exercise and recruitment to vacant posts. Given the delays in the recruitment process referred to above, the impact of the additional capacity associated with new appointments would not be evident until mid-2017/18. • The Trust also anticipated that the Inspire contract referred to above would support demand in psychological therapies.		
SERVICE DELIVERY RISKS		
Urology • The Trust advised that it was undertaking a urology review in response to an SAI raised by the Trust. This exercise would include a review of GP referral letters which had not been triaged on receipt and patient records for a cohort of patients who had already attended outpatients but where clinical letters/outcomes may not have been processed promptly. The Trust stated that if any patients were identified as requiring further actions (e.g. diagnostics etc), they would be added to the waiting list at their original date of referral therefore, there was a risk that a number of long waiters would appear on the urology waiting list. *Glenview Private Nursing Home* • The Trust (AM) confirmed that the residents in Glenview Private Nursing Home had all been relocated. • The HSCB (FMcA) acknowledged the speed with which the Trust and others (including NIAS and finance) had managed the situation.		

Issue	Action	Lead Responsibility / Deadline
Daisy Hill Hospital (DHH) • The Trust (RW) advised that one of the ED consultants in DHH had recently retired and no replacement had been appointed. While the ED was fully staffed with locums there was a risk in relation to the sustainability of the service given that there was only one permanent consultant in post. *Bannview Medical Practice* • Following the decision for the Trust to take over responsibility for Bannview Medical Practice, the Trust (AMcV) highlighted the need to bring stability to staff and, in this context, a range of HR issues needed to be addressed. To this end, a meeting was arranged for the following week to agree the MoU and to discuss options. *CT Scanner* • The Trust advised that the timescale for the second CT scanner was May 2018.		

NICaN Urology Cancer Clinical Reference Group Terms of Reference (TOR)

Prepared for and agreed by NICaN Urology Clinical Reference Group in adherence with Manual for Cancer Services Urology Measures Version 1.0 January 2014

Date Agreed by CRG	Version	Comments/changes
2 October 2008	1.0	Agreed at Urology Regional Group Meeting
August 2013	2.0	Agreed following changes in group membership
Month 2016	3.0	To be agreed at CRG

NICaN Urology Clinical Reference Group Terms of Reference

Purpose

All NICaN site specific groups are multi-disciplinary with representation of professionals from across the care pathway. The clinical reference groups aim to ensure that mechanisms are in place to involve service users in the planning and review of Cancer services and ensure active engagement of all relevant professionals across the Network.

The NICaN Urology Clinical Reference Group (CRG) will bring together those interested in the planning, development and delivery of Urology cancer services in Northern Ireland for those with, or suspected of having Urology cancer. It will give leadership to, and continuously develop, Urology cancer care in Northern Ireland.

In order to ensure high quality person centred care, the Group will:

- be the authoritative source of expertise and guidance to planners, commissioners and providers of services;
- indicate service reconfiguration, and resource implications required to achieve the highest quality care;
- review existing standards and guidelines and develop regionally agreed standards of care which are periodically monitored/audited; and
- Prioritise resources within Urology cancer service developments.

Objectives

The NICaN Urology Clinical Reference Group should work collaboratively to deliver the following key core objectives:

I. Service Planning: The NICaN Urology CRG should ensure that service planning
- Is in line with national guidelines and standards
- Considers the full patient pathway
- Promotes high quality care and reduces inequality
- Takes account of patient and carers views
- Recognises opportunities for service and workforce redesign
- Establishes common guidelines

II. Service Improvement/Redesign: The NICaN Urology CRG should commit to service improvement and redesign by ensuring:
- Responsiveness to pathway issues highlighted at regional cancer operational meetings / Trust performance meetings
- Regular participation in service improvement/redesign and

ensuring that evidence of such is readily available to support resource applications etc

III. Service Quality Monitoring and Evaluation
- Agree on priorities for data collection and support the development of regionally agreed clinical data sets
- Review the quality and completeness of data, recommending corrective action where necessary
- Facilitate processes which allow for service users/carers to evaluate services
- Produce audit data and participate in open review
- Monitor progress on meeting national cancer measures and ensure action plans are agreed

IV. Service delivery
- Assist in the delivery of Trust priority areas (e.g. access, Cancer Service Framework) through the development of appropriate guidelines and protocols that support delivery.

V. Education & workforce
- Participate in relevant training and development events to facilitate sharing of best practice and service development.
- Undertake regular sharing of audit information.

VI. Research and Development
- The Urology CRG should agree a common approach to research and development and ensure participation in nationally recognised studies whenever possible.

Core Membership

Membership will be open to all those interested in the planning, development and delivery of Urology cancer services in Northern Ireland and should be representative of all key stakeholder communities relevant to the disease area. The representation on the Urology CRG should be such that the NICaN Board agree to authorise it as the source of the Network's clinical opinion on matters relating to Urology Cancer.

The Manual for Cancer Services Urology Measures sets out the agreed membership for the clinical reference group:[1]
- A named chair who should be a core member of one of the associated MDTs
- A core member from each of the associated MDTs
- A urology surgeon
- Representation covering both clinical and medical oncology
- A radiologist

[1] http://www.cquins.nhs.uk/?menu=resources_measures_Urology_January2014

- A histopathologist
- A urology nurse specialist
- Two user representatives (one of the NHS employed members of the group should be nominated as having specific responsibility for users issues and information for patients and carers
- Secretarial/admin support

A member of the CRG should be nominated as responsible for ensuring that recruitment into clinical trials and other well designed studies is integrated into the function of the CRG.

Trust Cancer Executive Directors provided details of their nominations to the Urology Group in August 2013 – these reflect core membership of their Trust MDM. The table below sets out the confirmed nominations as of June 2018:

Named Representative	Role	Trust or other
Mr Patrick Keane Mr Hugh O'Kane Mr Chris Hagan Dr Darren Mitchell Mr Gerry McCarthy Dr Alison Clayton Prof Joe O'Sullivan Dr Lin Shum Dr Jackie Harney Dr Jonathan McAleese Dr Fionnuala Houghton Dr Suneil Jain Mr Ali Thwaini Ms Samantha Thompson Dr Declan O'Rourke Dr Arthur Grey	Consultant Urologist Consultant Urological Surgeon Consultant Urologist Consultant Clinical Oncologist Anaesthetist Consultant Medical Oncologist Consultant Uro-pathologist Consultant Oncologist Consultant Clinical Oncologist Consultant Oncologist Consultant Oncologist Consultant Oncologist Consultant Urologist Clinical Nurse Specialist – Urology Consultant Pathologist Consultant Radiologist	Belfast Trust
Mr Paul Downey Dr Dianne Kirkpatrick Dr Barry Patterson Dr Jackie Jamieson	Consultant Urologist Consultant Radiologist Consultant Radiologist Consultant Pathologist	**Northern Trust**
Dr Michael Reilly Mr Colin Mulholland Dr Igho Deigbe Ms Kerry Chambers	Consultant Radiologist Consultant Urologist Consultant Pathologist Clinical Nurse Specialist Uro-oncology	**Western Trust**
Mr Sam Gray Mr Brian Duggan Mr John McKnight Dr Peter Ball	Consultant Urologist Consultant Urologist Consultant Urologist Consultant Radiologist	**South Eastern Trust**

Named Representative	Role	Trust or other
Ms Patricia Thompson	Clinical Nurse Specialist Urology	
Mr Aidan O'Brien Dr Gareth McClean Ms Kate O'Neill	Consultant Urologist Consultant Pathologist Clinical Nurse Specialist Urology	**Southern Trust**
Mr John Morrison Ruth Moore /	Patient / Public representative AHP Representative	
Sinead Lardner Sarah Donaldson	NI Cancer Registry NICaN Network Co-ordinator	
Extended Membership		
Ms Davinia Lee Ms Gillian Traub Ms Lisa Houlihan	Cancer Services Manager Lead Cancer Nurse Haematology Services Manager	Belfast Trust
Mary Jo Thompson Caroline Lynas Robert McCormac	Cancer Services Manager Service Improvement Lead Information Manager	South Eastern Trust
Ms Pat McClelland Ms Moyra Mills	Cancer Services Manager Service Improvement Lead	Northern Trust
Ms Fiona Reddick Ms Mary Haughey	Cancer Services Manager Service Improvement Lead	Southern Trust
Ms Bridget Tourish	Cancer Services Manager	Western Trust
Loretta Gribben	PHA Nurse Consultant	NICaN

Clinical Lead

Mr Mark Haynes, Consultant Urologist SHSCT

There will continue to be a distribution list for interested parties to ensure that communication in relation to the work of the group continues within the wider urology community.

It is the responsibility of Core Members to report back within their own professional group and to ensure adequate consultation and involvement in key areas of the regional group work plan.

Frequency of Meetings

Clinical reference should meet regularly with meetings agreed in advance by Clinical Lead. All attendance should be recorded and minutes agreed following each meeting.

Accountability and reporting arrangements

The Groups authority will come from its credibility. This credibility will be evidenced by the application of the Group and its member's knowledge and expertise. It will be the principal source of advice to indicate the service reconfiguration, and resource implications required to achieve the highest quality care.

Individual members will be accountable to their own profession and are responsible for reporting back to their own multi-disciplinary teams. The Lead/Chair of the group will be held accountable to the NICaN Board, via a member of the NICaN management team, for the delivery of the agreed work plan. The Lead/Chair will be responsible for reporting to the NICaN Board annually.

Attendance at Committee Meetings

In order to keep up to date with progression of the regional group work plan, it is crucial that members attend regularly. If a nominated member fails to attend 3 consecutive meetings, a new nomination will be sought. Contact will be made with the member following non-attendance at 2 consecutive meetings to establish reasons for non-attendance.

Southern Health and Social Care Trust

Operational Policy
Urology Cancer Service

MDT Clinical Lead	**Mr. A. O'Brien**
Clinical Director of Cancer Services	**Dr. R. Convery**
Trust Cancer Executive Lead	**Mrs. D. Burns**

April 2015

The following Operational Policy for the Southern Health and Social Care Trust (SHSCT) Urology Multidisciplinary Team (MDT) provides an overview of the service, how it is accessed by patients and coordinated through both the local and regional teams.

Two other documents have been developed, which should be read in conjunction with this operational policy. They are the Annual Work plan, which outlines the direction of the service in the incoming year and the Annual Report, which details the work completed in the past year, any achievements and areas of work outstanding which need to be rolled into the incoming year.

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1. INTRODUCTION

The Southern Health and Social Care Trust (SHSCT) was formed on 1 April 2007 and is responsible for the services which were formerly delivered by four smaller Trusts: Armagh and Dungannon Trust, Craigavon and Banbridge Community Trust, Craigavon Area Hospital Group Trust and Newry and Mourne Trust.

In addition to primary and community services, SHSCT provides all the acute hospital services for its resident population, including emergency care, diagnostics, inpatient and day case operative procedures, endoscopy, and inpatient acute care with intensive care services available in Craigavon Hospital.

1.1 Southern Trust Urology Services

The Southern Health and Social Care Trust has provided a Urology service for patients living the southern area of Northern Ireland since 1992, when one consultant urologist was appointed. A second consultant urologist was appointed by Craigavon Area Hospital Group Trust in 1996. Since then, the service has increased incrementally in size and capacity, with a sixth consultant urologist appointed in 2014. Particular features of the service have been the provision of Extracorporeal Shock Wave Lithotripsy at the Stone Treatment Centre at Craigavon Area Hospital since 1998, and the provision of all outpatient services at a dedicated unit, the Thorndale Unit, since 2007. This unit moved to a new location within the hospital in 2013, with increased capacity, to enable all outpatient consultations to be conducted there, in addition to ultrasound scanning, prostatic biopsies, flexible cystoscopy, urodynamic studies and intravesical chemotherapy. The Unit is staffed by Clinical Nurse Specialists, Staff Nurses and Health Care workers, in addition to visiting Radiographers and Radiologists.

A review of urological service provision in Northern Ireland was conducted in 2008/09, resulting in a reconfiguration of responsibilities for services to be provided to changed geographical areas and by three separate teams of urologists. Team South, based at Southern Health and Social Care Trust (SHSCT), took on responsibility for the provision of services to the population of County Fermanagh, with effect from 1st January 2013. County Fermanagh has a population of 61,175.

More recently, SHSCT has agreed to provide urological services to the population of and surrounding Cookstown, County Tyrone, bringing the entire catchment population to 427,000.

Since their commencement in 1992, urological services have been based in the Department of Urology at Craigavon Area Hospital. When the future configuration of all cancer services was advised in the Campbell Report of 1996, Craigavon Area Hospital was designated a Cancer Unit in 1997. In addition to all of the urological services provided at Craigavon Area Hospital, some core services have been provided at Daisy Hill Hospital in Newry since 1992 by a consultant general surgeon with an interest in urology. As the number of consultant urologists has increased in recent years, it has also been possible to provide endoscopic and day case surgery at South Tyrone Hospital in Dungannon, in addition to outpatient clinics at Banbridge Polyclinic, Armagh Community Hospital and South West Acute Hospital in Enniskillen, County Fermanagh.

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Urology Services by Site

	Outpatients	**Endoscopy**	**Day Surgery**	**Inpatient Surgery**
	x	***x***	***x***	***x***
	x	***x***	***x***	***x***
	x	***x***	***x***	
	x			
	x			
	x			

1.2 Southern Trust Urological Cancer Services

Since its commencement in 1992, the Department of Urology has endeavoured to provide a complete spectrum of urological cancer services. Surgical services included radical surgery for renal and upper tract carcinoma, radical cystectomy with urinary diversion or orthotopic bladder replacement for bladder cancer, radical prostatectomy for prostatic carcinoma, in addition to the surgeries for penile and testicular carcinoma. The service also included the provision of immunotherapy for advanced renal cell carcinoma and the provision of systemic chemotherapy for advanced transitional cell carcinoma.

Several significant developments have taken place during the past two decades. The complement of medical and clinical oncologists in Northern Ireland has increased markedly. This has facilitated subspecialisation in the provision of chemotherapeutic and radiotherapeutic services in both centralised and devolved settings. Implementation of the recommendations of the Campbell Report has led to the establishment of a Cancer Centre in Belfast, and to the establishment of dedicated services at the Cancer Units, such as the Mandeville Unit at Craigavon Area Hospital. The expansion of oncological services has also led to increased recruitment to clinical trials. In urological cancer, this has increasingly led to multicentre, national and international trials being led by the Cancer Centre in Northern Ireland.

Compliance with National Institute for Health and Care Excellence's (NICE) 'Improving Outcome Guidelines' led to the centralisation of radical pelvic surgery for bladder and prostatic cancer to the Belfast Trust in 2011. Before then, it also led to the establishment of MultiDisciplinary Teams (MDTs) in each Cancer Unit in addition to a Specialist MDT in Belfast Trust. Central to the role and activities of MDTs has been to meet regularly at MultiDisciplinary Meetings (MDMs) to oversee the diagnosis, assessment and management of all patients with a new diagnosis of cancer, and when significant developments occur in the progress of their cancer.

2. SOUTHERN TRUST MDT AND MDM

A MDT for Urological Cancer at the Southern Trust was formally established in April 2010. Mr. Mehmood Akhtar, Consultant Urologist, was its Lead Clinician and Chair of its MDM from April 2010 until March 2012. Since April 2012, Mr. Aidan O'Brien, Consultant Urologist, has been its Lead Clinician. With increasing numbers of consultant urologists, the functions of Lead Clinician and of Chair of MDM have been separated to enhance active participation in and responsibility for MDM. Since August 2014, a rota has been established for chairing MDM by Mr. O'Brien and two colleagues, Mr. Anthony Glackin and Mr. Mark Haynes.

The MDM takes place every Thursday afternoon at 2.15 pm, with the exception of public holidays, and on the rare occasion when it is not possible to have a meeting due to some other significant event requiring the participation of MDT members. The Chair of each MDM will have been decided when scheduling takes place at least one month previously. Scheduling has also ensured that time is allocated to the appointed Chair to preview in detail each Wednesday all of the cases to be discussed at MDM the following day. All of the required clinical summaries, results and reports of investigations will have been provided to the appointed Chair for preview. It also enables all multidisciplinary participants to preview cases and to prepare their contributions to the discussion of cases. This provision has greatly enhanced the quality of scrutiny and preparation for discussion of each case.

When discussion of each patient at MDM has been completed, an agreed Plan of further assessment or management is appended in type to the previous clinical summary and narrative. Following termination of the MDM, the entire narratives and Plans are checked by the Chair for their accuracy prior to inclusion in the Cancer Patient Pathway System (CaPPS). The reports are then sent to the family doctor of each patient, in addition to other clinicians as direct referrals or Inter Trust Transfers as agreed at MDM.

3. UROLOGY MDT LEAD CLINICIAN

Mr. O'Brien was nominated Lead Clinician by fellow members and formally appointed by Dr. R. Convery, Clinical Director of Cancer Services, in April 2012 (Appendix 1: Letter of Appointment).

3.1 Responsibilities of the Lead Clinician

- Consolidation of the MDT and its activities within the wider urological service.
- Development of the concept and responsibilities of the MDT in its delivery of cancer services.
- Oversight of systems to ensure that all cases of cancer or suspected cancer referred to the service, are referred in an informative and timely manner for their discussion at MDM.
- Chairing or delegating the chairing of MDM.
- Arrangement and oversight of systems to ensure that patients are reviewed following MDM in a timely manner.
- Organising and chairing Business Meetings to advance the development of MDT and its activities.
- Development of an Operational Policy for MDT.
- Compiling Annual Reports and Work Plans.
- Chairing an Annual General Meeting to agree Reports and Plans
- Attending the Urology NSSG meetings (as the Lead Clinician is considered an integral member of the NSSG).
- Ensuring a high quality integrated service, which meets local, regional and national standards.
- Participation in the regular review of the regional guidelines.
- Ensuring collection of appropriate cancer minimum dataset, working with the cancer management team.
- Developing an audit programme and review of outcomes.
- Ensuring governance arrangements are in place.

4. MDT MEMBERSHIP

Membership of the Urology MDT has consisted of core members and extended members in accordance with the Manual for Cancer Services: Urology Measures.

4.1 Core Membership 14-2G-101

Four consultant urological surgeons are core members. These are:

- Mr. Aidan O'Brien
  MDT Lead Clinician, MDM Chair, Consultant Urological Surgeon
  Covered by Mr. Glackin, Mr. Suresh, Mr. Haynes

- Mr. Anthony Glackin
  MDM Chair, Consultant Urological Surgeon
  Covered by Mr. O'Brien, Mr. Suresh, Mr. Haynes

- Mr. Mark Haynes
  MDM Chair, Consultant Urological Surgeon
  Covered by Mr. O'Brien, Mr. Glackin, Mr. Suresh

- Mr. Kothadaraman Suresh
  Consultant Urological Surgeon
  Covered by Mr. O'Brien, Mr. Glackin, Mr. Haynes

The remaining core members include:

- Dr. Fionnuala Houghton
  Consultant Clinical Oncologist
  Covered by Specialist Registrar

- Dr. Judith Carser
  Consultant Medical Oncologist
  Covered by Dr. Houghton or Specialist Registrar

- Dr. Marc Williams
  Consultant Radiologist
  Covered by Dr. M. McClure

- Dr. Gareth McClean
  Consultant Histopathologist
  Covered by Dr. R. Shah or Dr. K. Dedic
  Dr.Gareth McClean has taken part in an EQA scheme and possesses certificate for this – (please refer to evidence folder).

- Mrs. Kate O'Neill
  Core Nurse Member, Clinical Nurse Specialist
  Covered by Mrs. J. McMahon and by Mrs. Dolores Campbell

- Mrs. Stephanie Reid
  Palliative Care Nurse Practitioner
  Covered by another member of the Palliative Care Nursing Team

- Mrs. Shauna McVeigh
  MDT Co-ordinator, Cancer Tracker
  Covered by Mrs. M. Dabbous and Mrs A. Turkington

4.2 Extended Membership 14-2G-105

Extended members include:

- Mr. Michael Young
  Consultant Urological Surgeon
  Covered by Specialist Registrar

- Mr. John O'Donoghue
  Consultant Urological Surgeon
  Covered by Specialist Registrar

- Mr. Robin Brown
  Consultant General Surgeon at Daisy Hill Hospital, Newry

- Dr. Mary Daly
  Consultant Psychologist
  Covered by Mrs. M. Duggan

- Dr. Tracy Anderson
  Consultant in Palliative Care Medicine
  Covered by Clinical Nurse Specialist

4.3 Additional Roles of Members

Three consultant urological surgeons, Mr. O'Brien, Mr. Glackin and Mr. Suresh, two Clinical Nurse Specialists, Mrs.O'Neill and Mrs. McMahon, and Ms. Stephanie Reid, Palliative Care Nurse Practitioner, have completed the Advanced Communication Skills Course, enabling them to practise at Level 2 for the psychological support of cancer patients and their carers.

Mrs. O'Neill, MDT Core Nurse Member and Clinical Nurse Specialist, has been nominated as having specific responsibility for users' issues and distribution of information to patients and their carers. An emphasis on newly diagnosed cancer patients has been identified as a priority for 2015/16.

Dr. Carser, Consultant in Medical Oncology, was nominated in 2014 to have specific responsibility for recruitment of patients into clinical trials

conducted by the Cancer Centre in Belfast. Increased recruitment has resulted in patients with urological cancer being the largest cohort of patients in clinical trials related to cancer in Northern Ireland.

5. MDT CO-ORDINATOR AND CANCER TRACKER

Mrs. Vicki Graham was the Urology MDT Co-ordinator and Cancer Tracker from April 2010 until October 2014. She was replaced by Mrs. Marie Dabbous until April 2015. Mrs. Shauna Mc Veigh is the current Urology MDT Co-ordinator and Cancer Tracker. A Co-ordinator / Tracker has been present at every MDM. Cover is provided by the Cancer Services Team to ensure that has been and continues to be so.

5.1 Responsibilities of the MDT Co-ordinator

The MDT Co-ordinator has an extensive number of responsibilities which include:

- Tracking all patients remaining on 31 and 62 day pathways to initiation of their definitive treatment
- Ensuring all cancer patients are discussed at the MDT meeting
- Insertion of Clinical Summaries and Updates into CaPPS.
- Tracking all patients for whom investigations have been requested, to ensure that appointments have been arranged at appropriate times and to schedule them for discussion at MDM with investigative reports uploaded unto CaPPS.
- Disseminating all uploaded information on all patients to be discussed at each MDM to all MDT members one day prior to each MDM.
- Recording the MDT attendance for every MDM.
- Liaising with the Specialist MDT Co-ordinator prior to any MDM when it is intended to discuss patients with that MDT.
- Liaising with MDM Chair to ensure that all information, particularly MDM Plans, are accurately recorded in CaPPS.
- Ensuring that MDM Plans are sent to Family Doctors.
- Ensuring that Direct Referrals or Inter Trust Transfers are implemented.

- Ensuring that all information recorded on CaPPS is copied to the Clincal Records of all patients discussed at MDM.
- Ensuring that all patients with cancer or suspected cancer progress along agreed pathways in a timely manner so as to meet cancer access targets, and to raise delays with the MDT.

6. MDT CORE NURSE MEMBER

The Department of Urology at Craigavon Area Hospital employs two Clinical Nurse Specialists (CNS). Mrs K O'Neill is a Band 7 Urology CNS employed by the Trust on a full time basis (5 days). Mrs J McMahon is a Band 7 Urology CNS employed by the Trust over 4 days (32.5 hours). Both have worked in Urological Nursing for many years, and are experienced in performing urodynamic studies, flexible cystoscopy and transrectal, ultrasound guided, prostatic biopsies. They have been further supported by the appointment of two Band 6 practitioners experienced in urodynamic studies and the provision of intravesical chemotherapy. Mrs. O'Neill has been nominated the Core Nurse Member of the Urology MDT and whose responsibility it is to oversee the responsibilities of all Nursing Practitioners / Key Workers involved in the ongoing assessment and management of cancer patients, as outpatients.

6.1 Responsibilities of the Core Nurse Member

- Participating in service development.
- Holding additional specialist knowledge and experience.
- Contributing to multi-disciplinary assessment and patient care.
- Leading on patient communication issues.
- Ensuring that regular psychological assessment of each patient following a diagnosis of a urological cancer is undertaken, in order to provide specific expert nursing care, advice, support and counselling and where necessary onward referral for specialist psychological input.
- Acting as the key worker or be responsible for nominating the key workers for patients under care of the MDT, dealing with the team in line with the Trust Key Worker Policy.

- Acting as the patient's advocate and counsel when informed discussion may lead to choices being made concerning treatment options or quality of life issues.
- Acting as a specialist resource for patients and the clinical team by the provision of comprehensive advice, information, education and training.
- Participating in educational programmes for nurses and other health care disciplines as appropriate.
- Participating in the provision of information to patients and their carers regarding their disease, treatment and services available at all stages of their disease process.
- Maintaining a support network and contact point for patients/relatives and carers from diagnosis throughout treatment and beyond.
- Being involved in clinical audit.
- Utilising research in the nurse's specialist area of practice

7. OPERATIONAL POLICY FOR KEY WORKERS 14-2G-113

This guideline details the roles and responsibilities of the Key Worker. For the purpose of this policy, the Key Worker will be defined as 'the person who, with the patient's consent and agreement, takes a key role in co-ordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice' (Manual of Cancer Standards).

7.1 Identification of the Key Worker

The identification of the Key Worker(s) will be the responsibility of the designated MDT Core Nurse member.

It is the joint responsibility of the MDT Clinical Lead and of the MDT Core Nurse Member to ensure that each Urology cancer patient has an identified Key Worker and that this is documented in the MDM record and the patient's case notes. In the majority of cases, the Key Worker will be a Urology Clinical Nurse Specialist (Band 7) or Practitioner (Band 6).

Patients and families should be informed of the role of the Key Worker. Contact details are given with written information.

As patients progress along the care pathway, the Key Worker may change. Where possible, these changes should be kept to a minimum. It is the responsibility of the Key Worker to identify the most appropriate healthcare professional to be the patient's next Key Worker. Any changes should be negotiated with the patient and carer prior to implementation, and a clear handover provided to the next Key Worker.

Urology Clinical Nurse Specialists and Practitioners should be present or available at all patient consultations where the patient is informed of a diagnosis of cancer, and should be available for the patient to have a further period of discussion and support following consultation with the clinician, if required or requested. They may also be present, and should be available, when patients attend for further consultations along their pathway.

Due to the lack of Key Workers, it will be a priority of the MDT Lead Clinician and Nurse Member to advocate with the Southern Trust the training and/or appointment of adequate numbers of Key Workers to ensure that the standards of practice, detailed in this Section, are fulfilled.

7.2 Main responsibilities of Key Workers

- Act as the main contact person for the patient and carer at a specific point in the pathway.
- Offer support, advice and provide information for patients and their carers, accessing services as required.
- Ensure continuity of care along the patient's pathway and that all relevant plans are communicated to all members of the MDT involved in that patient's care.
- Ensure that the patient and carer have their contact details, that these contact details are documented and available to all professionals involved in that patients care.

- Ensure that the next Key Worker has the appropriate information about the patient to fulfil the role.
- Support the patient in identifying their needs, review these as required and co-ordinate care accordingly.
- Liaise and facilitate communication between the patient, carer and appropriate health professionals and vice versa.
- Assist to empower patients as appropriate.

8. **MDT QUORUM** **14-2G-102 and 14-2G-104**

The Southern Trust Urology MDT has been cognisant of the minimum attendance of its members required to have MDMs quorate, as stipulated by the Urology Local MDT Measures, as follows:

- One urological surgeon
- One clinical oncologist
- One medical oncologist (where the responsibility for chemotherapy has not been taken by the clinical oncologist)
- One imaging specialist
- One histopathologist
- One urology nurse specialist
- One MDT co-ordinator

It has been the policy of the Southern Trust MDT to have a minimum of two consultant urological surgeons present at each MDM, and it will continue to be so.

In earlier years, it had not been possible to have a clinical oncologist present at or video-linking with MDM. With the appointment of Dr. Fionnuala Houghton, it has been possible to have her, or her deputy, video-link with MDM on more occasions. There has been the additional benefit that Dr. Houghton and her deputies have been competent in advising on chemotherapeutic management options for patients.

Since the appointment of Dr. Judith Carser as Consultant Medical Oncologist, MDM has had the benefit of her attendance, which has additionally enhanced recruitment of patients to clinical trials.

Dr. Marc Williams is the Lead Consultant Urological Radiologist, who has been covered by or accompanied by Dr. Mark McClure, Consultant Radiologist, to facilitate the presence of an imaging specialist at most MDMs. Both are experienced urological radiologists, and particularly in the field of MRI scanning. The current unavailability of cover for Dr. Williams presents a significant challenge to ensuring that the management of cancer and suspect cancer patients is completed within target times, in addition to MDT quoracy.

All MDMs have been attended to date by a histopathologist, a urology nurse specialist and a MDT co-ordinator.

In the event of a MDM not being quorate, it has been and will remain the policy of the Southern Trust MDT that the discussion of patients, who definitively do not require the input of the absent member, should proceed. Otherwise, discussion will be deferred to the next MDM, and it will be the responsibility of the Co-ordinator to reschedule the patient, and to notify the absent member of the deferment.

Multidisciplinary meetings have not been held on public holidays or when Trust Mortality & Morbidity meetings have been scheduled. It has only been on other rare occasions when the MDT Lead Clinician, in consultation with other members, will cancel a scheduled MDM. This policy will remain in place. On all of these occasions, it has been the MDT policy to have one of the three Chairs preview the patients who would have been discussed at the cancelled meeting, so that further investigations can be arranged, and on condition that the patients will be discussed at a later MDM, and before any management decisions are made.

9. THE MULTIDISCIPLINARY MEETING 14-2G-103

This section of the Operational Policy is in acknowledgement of the central role of the Multidisciplinary Meeting in the assessment and management of patients suspected of cancer, diagnosed with cancer and throughout their further course. There is only one Urology Local MDT and MDM for the catchment area and its population of the Urological Service of the Southern Trust, as previously described.

9.1 Time and Venue of Meetings

The MDM takes place in the Medical Education Centre at Craigavon Area Hospital each Thursday afternoon, except on those occasions described elsewhere in this Policy. The Meeting takes place in a room with Video Conferencing facilities, enabling communication by video to Daisy Hill Hospital, Newry, and with the Specialist MDM in Belfast.

The MDM commences at 2.15 pm. Video conferencing with the Specialist MDT is scheduled to take place at 3.30 pm, or as soon as is mutually convenient thereafter. It is the policy of the Southern MDT that all MDMs should finish by 5 pm at the latest. It has been the experience of the MDT that the number of cases to be discussed has had to be limited to 45 in order to enable the MDM to finish by 5 pm.

9.2 Preparation for Meetings 14-2G-109

It has been agreed by MDT core members that it is the responsibility of urological surgeons to provide a clinical summary regarding each patient to be discussed at MDM for the first time, and an update when patients are to be discussed again at a later juncture in their clinical course. The clinical summaries and updates are to be provided to the MDT Co-ordinator. They are to be provided in a textual format suitable for uploading unto CaPPS as a permanent record and suitable as a correspondence to Family Doctors and to other clinicians to whom patients may be referred at a later date. It is therefore optimal that text is in the dated past tense and in the third person. It is not the responsibility of the MDT co-ordinator to construct

either a clinical summary or update from dictated correspondence as the latter is usually contextually different, and unsuitable for CaPPS.

Patients may also be referred to the Co-ordinator by other clinicians, whether Urology MDT members, such as oncologists, or clinicians from other specialties or hospitals. It is the responsibility of the MDT Co-ordinator to request provision of a clinical summary adequate to enable MDM discussion.

In the case of referral of a patient for MDM discussion by a radiologist or histopathologist, the MDM co-ordinator will request the Consultant Urologist who may have already cared for the patient to provide a clinical summary, or the Chair of the MDM to provide a clinical summary if the patient is new to the Urological Service.

It is also the responsibility of clinicians to provide appropriate textual updates to the MDT Co-ordinator at significant junctures in patients' assessments and management, such as when treatment is initiated or when referral for treatment has been made. In particular, it is the responsibility of urological surgeons to provide dated, succinct, textual descriptions of operative findings and procedures.

It is the responsibility of the MDT Co-ordinator to ensure that patients have been given appointments for investigations at appropriate times, and to schedule those patients for MDM discussion as previously agreed. It is the responsibility of the MDM Co-ordinator to upload on CaPPS the reports of those investigations, such as radiological and histopathological reports.

When all such information, provided in appropriate format, has been uploaded onto CaPPS, it is the responsibility of the MDT Co-ordinator to disseminate the uploaded information to all MDT members one day prior to each MDM so that optimal preparation can be undertaken.

It is also the policy of the Urology MDT that the MDT Co-ordinator will identify those patients who are furthest along on their timed pathway and at greatest risk of breaching. The identity of these patients is also disseminated one day prior to each MDM so that plans for their further management can be scheduled by the

responsible urological surgeon and notified to the MDT at the commencement of each MDM.

9.3 Chairing of Meetings

The chairing of MDMs is shared by Mr. O'Brien, Mr. Glackin and Mr. Haynes on a rotational basis. The person appointed to chair each MDM is decided at least one month previously, when a period of time is also allocated to the appointed Chair to preview all cases one day prior to the MDM.

9.4 Structure of Meetings

The Chair of each MDM welcomes MDT members at the commencement of the meeting at 2.15 pm. The meeting may begin with housekeeping announcements, such as confirmation of the next MDM and its Chair.

The Chair will raise the issue of any patients at risk of breaching their target timeline. If the responsible surgeon is unable to review the patient within an appropriate time, the Chair exercises the right to make other arrangements for the patient's review. Similarly, if a patient cannot be scheduled for surgery within an appropriate time, the Chair exercises the right to make alternative arrangements, if possible.

The Chair may then preview any patients that may be scheduled for discussion with the Specialist MDT by video link later in the afternoon, in order to ensure that all information is available for that discussion.

9.5 Patient Assessment and Treatment Planning 14-2G-111

The Chair then proceeds with the discussion of each listed patient. Having previewed each case, the Chair will have familiarised himself with the detail of each case, and will be able to focus on the pertinent issues for discussion. It is the responsibility of the Chair to ensure that each patient is adequately discussed. It is the responsibility of the Chair to ensure that all of the patient's needs are discussed,

in so far as is possible. It is the responsibility of the Chair to ensure that an agreed Plan of management is concluded, and documented in real time as the MDM Plan. The MDM Plan should include identification or reaffirmation of the patient's Key Worker, or the need to have a Key Worker identified at next patient consultation, and the need for Holistic Needs Assessment, or provision for needs if an Assessment has already been conducted, and needs identified.

9.6 MDM Documentation 14-2G-104

It is the responsibility of the MDM Co-ordinator to make a documentary record of the MDM, including a record of attendance, and it is the responsibility of the Chair to approve that record.

It is the responsibility of both the MDM Chair and the MDT Co-ordinator to ensure the accuracy of the completed textual record of Clinical Summaries, Updates and MDM Plans of all patients discussed at the MDM, and so that the documentation, in correspondence format, may be sent without delay to Family Doctors and to other clinicians to whom it had been agreed patients would be referred.

9.7 Protocol for Patient Management between Meetings

Whilst the purpose of a MDT discussing the assessment and management of patients at weekly MDMs is to ensure that both have been discussed and optimised in a considered manner, there will be occasions when the assessment and / or management of a patient cannot be deferred until the next MDM. It does remain the right and the responsibility of clinicians to ensure that deferral does not contravene the patient's best interest and outcome. In such cases, it is the Policy of the MDT to recommend that assessment and management of such patients in such circumstances be advanced in consultation with other MDT members, and on condition that the patient will be discussed at the next scheduled MDM.

9.8 Membership and Attendance 14-2G-104

It is the policy and the practice of the MDT to maintain and update a record in its Operational Policy of the names and roles of all core and extended MDT members.
It is the responsibility of the MDT Lead Clinician to ensure the accuracy of these records.

It is also the policy and practice of the MDT to maintain a record of attendance of all members at MDM, so that a record of the attendance of each individual member can be calculated and included in the Annual Report, and the quoracy of each MDM can similarly be determined and included in the Annual Report.

10. MDM BUSINESS MEETINGS

As the Southern Trust Urological Service has increased in size and as referrals have increased in number, and as the resulting challenges and incapacities have emerged, it has become necessary for the Urology MDT to hold regular Business Meetings to address and resolve these issues. Issues discussed to date have included:

- Extension of core membership of MDT
- Advanced triage of Red Flag referrals
- Provision of Clinical Summaries and Updates to MDT Co-ordinator
- Development of Key Workership

It is the policy of MDT to continue to hold regular Business Meetings, at least on alternate months, in order to advance these and other issues as they emerge.

11. CO-ORDINATION OF CARE AND PATIENT PATHWAYS 14-2G-106 and 14-2G-110

The entire purpose of the Urology MDT is to ensure that the assessment and management of all patients suspected of or found to have a urological cancer receive agreed treatment that is consistent and equitable, and which is compliant with the Guidelines and Policies of the Northern Ireland Cancer Network (NICaN) Site Specific Group in Urology, which in turn has adopted their Guidelines and Policies, in so far as is possible and practicable, from those detailed in 'Improving Outcomes in Urological Cancers' by the National Institute for Clinical Excellence. The NICaN Draft Urology Cancer Clinical Guidelines 2015 accompany this Operational Policy. It has been emphasised by the NICaN Site Specific Group in Urology that these Draft Guidelines will be reviewed by all urological surgeons providing cancer services in Northern Ireland during 2015 – 16 to identify those guidelines to which adherence is not possible due to incapacities, and those which may be considered inappropriate or inapplicable to Northern Ireland, so that definitive guidelines can be agreed with the Northern Ireland Health and Social Care Board.

The demands of and the services provided by the Urology MDT are set in the context of all urological demands and services provided by the Southern Trust Urological Service. The co-ordination of care of patients suspected of or found to have a urological cancer, and the pathways they follow, have been developed in that context.

11.1 Urology Referral Pathways 14-2G-109

All referrals from Primary Care have been centralised in recent years to a single referral and booking centre located at the Craigavon Area Hospital. All such referrals are digitalised. However, patients suspected of having a urological cancer, or having symptoms or clinical findings associated with an increased risk of having a urological cancer, are designated Red Flag status in compliance with NICaN referral guidelines and pathways. All Red Flag referrals are similarly made electronically or by fax to the Office of Cancer Services at Craigavon Area Hospital, where they are recorded, prior

to distribution daily to the Urologist-on-Call for triage. This marks the first step in the Urology Care Pathways agreed by NICaN in 2009 (Appendix 4).

11.2 Triage of Red Flag Referrals 14-2G-109

There had been an aspiration to subject all Red Flag referrals to advanced triage, whereby the Urologist would review all clinical information available on the Electronic Care Record, determine whether further investigation would be required, and with a view to contacting the patient to advise of such, to request those further investigations to be performed prior to first consultation. However, due to the varied duties associated with being Urologist-on-Call, it was not always possible to have the time to conduct advanced triage. It was therefore agreed that the MDT Policy was that advanced triage was not obligatory, but remained preferable, if time permitted.

If time does permit, it is the MDT Policy that patients are contacted, preferably by telephone, to advise of requested investigations, in order to avoid patients being caused confusion or anxiety by receipt of unexpected appointments.

Triaged Red Flag referrals are returned to the Office of Cancer Services where staff will arrange an appointment at a New Clinic or at any other clinic that may have been requested at triage. The triaging Urologist may also elect to have the patient discussed at MDM without further investigations requested, or following further investigation, and prior to first consultation. If that course of action is considered optimal by the triaging consultant, it is imperative that the patient is advised by telephone, that the Office of Cancer Services is informed and that a Clinical Summary is submitted to the MDT Co-ordinator. An appointment for consultation will then be arranged following discussion at MDM.

11.3 New Clinics 14-2G-107 and 14-2G-108

With regard to Red Flag referrals, the Southern Trust Urology Service had conducted Haematuria Clinics and Prostatic Diagnostic Clinics for several years, in addition to other dedicated clinics, such as LUTS and Stone Clinics. With the need to provide

equitable access to all Red Flag referrals, it was decided by the Service in 2014 to establish New Patient Clinics along the lines promoted by Guy's Hospital, London.
The New Clinic service began in October 2014. There are four New Clinics each week, all held in the Thorndale Unit. The maximum configuration of a New Clinic is that it will be staffed by two Consultant Urologists and by one Specialist Registrar, and at which a maximum of 24 patients will attend, 9 for each Consultant and 6 for the Registrar. The numbers of patients appointed are reduced pro rata depending upon attending doctors. Red Flag referrals are given priority of appointment. Each Consultant Urologist has one New Clinic each week (Appendix 2).

The New Clinics are also staffed by Clinical Nurse Specialists and Practitioners, Health Care Assistants and Radiographers, in order to facilitate patient having further assessment during their visit to the New Clinic. Further investigations available include ultrasound scanning of the urinary tract, mictiometry, flexible cystoscopy and transrectal, ultrasound guided, prostatic biopsies. It is also usually possible to have scrotal ultrasound scanning performed if there is a suspicion of testicular tumour. The purpose of advanced triage and of attendance at the New Clinic is that the New Clinic appointment has an enhanced prospect of having the patient reassured and discharged, requiring more complex assessment, listed for MDM discussion or placed on a waiting list for surgery.

11.4 Patient Review following MDM discussion

If it has been agreed at MDM that the patient is to be reviewed to be advised of the further assessment or management as recommended by the MDT and stipulated in the MDM Plan, a Review Appointment will be made at the Oncology Review Clinic of the responsible Consultant Urologist. Each is provided with six oncology review slots per week (Appendix 2). This number can be adjusted to accommodate increased numbers. It is the policy of the MDT that all patients are reviewed by the end of the first week following their MDM discussion. If that is not possible, the Chair of MDM may exercise the right to allocate the review of any patient to that of another consultant, if possible, and if it is considered pertinent to do so.

When it has been concluded by MDT at MDM that a patient's further management may have options, as may be the case in organ confined, prostatic carcinoma, then the patient will be advised of all of those options at review, and will be provided with textual information regarding each option. Importantly, it is the policy of MDT that such patients be offered the opportunity of referral to consultant specialists relating to each management modality, such as oncologists, for their further advice, so that the patient may arrive at an optimally informed choice.

11.5 Further Patient Follow-Up

Further management, review and reassessment of patients is very dependent upon the nature of their cancer, and by the Clinical Management Guidelines pertaining to their specific cancer (as detailed in the NICaN Draft Urology Cancer Clinical Guidelines). Due to the increasing numbers of patients requiring follow-up, and the limited capacity to do so in addition to the assessment and management of newly diagnosed patients, the Urology MDT is committed to the principles of Transforming Cancer Follow-Up (TCFU). These have been applied to the development of seven follow-up pathways for patients with prostate cancer, encompassing the entire spectrum of treatment modalities. The implementation of these pathways is critically dependent upon the availability of Clinical Nurse Specialists. There are inadequate numbers of Clinical Nurse Specialists in Urological Cancer services at present. It is the policy of MDT to promote the training and employment of more.

12 RELATIONSHIP WITH THE NORTHERN IRELAND CANCER NETWORK (NICaN) 14-2G-106 and 14-2G-112

The Northern Ireland Cancer Network (NICaN) is a multidisciplinary body established by the Department of Health to ensure the development of cancer services to the highest possible standards, consistent with considered best practice. The Network is subdivided into a number of Site Specific Groups, Urology being one. Each has a Lead Clinician and Chair, and its membership includes representatives of each Local MDT, allied specialists and patient representatives.

Mr. O'Brien, Lead Clinician of the Southern Trust Urology MDT, was appointed Lead Clinician and Chair of the Northern Ireland Cancer Network's Site Specific Group in Urology (NICaN Urology) in January 2013. As he has chaired all meetings of NICaN since then, the Local MDT has been represented at all meetings of the Group.

In addition, several core members of the Local MDT have video linked with most Group meetings since January 2013. In particular, these have included Dr. Gareth McClean, Consultant Histopathologist, who has compiled the Clinical Management Guidelines for Histopathology for NICaN Urology, and Mrs. Kate O'Neill, MDT Core Nurse Member, who has compiled the Clinical Management Guidelines for Nursing for NICaN Urology.

NICaN Urology has drafted global Clinical Management Guidelines encompassing all aspects of Urological Cancer diagnosis and management. In doing so, it is apparent that several inadequacies and incapacities compromise the provision of aspects of care which NICaN Urology would aspire to provide, whilst others may be considered inapplicable or inappropriate in Northern Ireland. NICaN Urology has committed to addressing and resolving these issues with the Commissioners of the Health and Social Care Board of Northern Ireland.

13. SUPPORTIVE CARE AND REHABILITATION SERVICES

A comprehensive range of supportive care and rehabilitation services are available for Urology cancer patients. Referral to these services can be made by members of MDT, directly or by way of MDM, by Key Workers, while some can be accessed by patients directly.

13.1 Physiotherapy Services

A wide range of physiotherapy is available at Craigavon Area Hospital and to varying degrees at all the other hospitals within the catchment area of the Urology Service.

13.2 Stoma Care Services

A readily accessible, stoma care service is available at Craigavon Area Hospital.

13.3 Clinical Psychology & Counselling Services

Dr. Mary Daly, Consultant Clinical Psychologist, is an extended member of the Urology MDT, and is based in the Bluestone Unit at Craigavon Area Hospital.
Two nurse counsellors, Mrs Mavis Dougan and Ms Terri Deehan, have been funded by Cancer Focus NI, are based at Craigavon Area Hospital.

13.4 Community Continence Services

There is a Community Continence Service serving the entire catchment area and its population. Referrals are made by email and by any member of the MDT, Key Workers and other nursing staff, at any time. The response to referrals is impressively prompt. The service is highly regarded by MDT.

13.5 Pre-chemotherapy Education Sessions & Helpline

All patients requiring chemotherapy are invited to attend a pre-chemotherapy education session in the Mandeville Unit at Craigavon Area Hospital. A 24 hour Helpline service is available for advice and support for patients who are receiving chemotherapy.

13.6 Complimentary Therapies

A reflexologist provides complimentary therapies on Mondays and Tuesdays in the Mandeville unit at Craigavon Area Hospital. Cancer Focus NI also provides Art therapy at Craigavon Area Hospital.

13.7 Welfare Services

Citizens Advice Bureau (CAB) representative Siobhan Edgar offers financial and benefits advice. Nursing staff record details of patients requiring CAB consultation and Siobhan then phones the patient to arrange a suitable appointment.

13.8 Macmillan Cancer Support

Macmillan Cancer has an information hub in the reception foyer of Craigavon Area Hospital. In association with the Southern Trust, Macmillan also conduct a six-week course called **H.O.P.E** (Helping to Overcome Problems Effectively) aimed at helping patients with cancer manage the day-to-day impact of living with the disease.

13.9 Support Groups

The Southern Trust has developed strong partnerships with local charities and support centres. These agencies also provide feedback to the teams regarding our local services. Generic support groups meet once per month in CAH and occasionally in Southern Area Hospice in Newry. Cancer Choices in Donaghmore, County Tyrone, and Charis near Cookstown, County Tyrone, both offer support to patients, their families and carers.
They offer a range of services such as complementary therapies, counselling, welfare rights advice and short courses etc. Action Cancer similarly provides complementary therapies for children and young people at its outreach centre in Lurgan, County Armagh.

14. PATIENT INFORMATION 14-2G-114

Patients are offered written information to explain their diagnosis when it is imparted to them, and to detail support that is available for them following a cancer diagnosis. Patients with prostate cancer are provided with Prostate UK Information Booklets regarding the various treatment options available to them, to enable them to make an informed choice regarding their future management.

Additional information is available on-line on the NICaN website. Patient information is made available on request in different languages and formats for those patients from different ethnic minorities or disabilities.

Patients are offered information by appropriate staff in a phased manner relevant to the stage of their journey. For teenager and young adults, additional support is provided through the Regional Teenager and Young Adult (TYA) service, and appropriate information leaflets are available.

15. PERMANENT RECORD OF CONSULTATION 14-2G-115

It is the policy of the MDT that patients should be offered a permanent record of their diagnostic consultation and later consultations, if required. This permanent record will detail the diagnosis, management options and plan, and review arrangements.
The MDT will discuss whether it would be appropriate to adapt the Policy to make available to patients copies of their MDM documentation.

16. PATIENT FEEDBACK 14-2G-116

Feedback on patient's experience will be sought using a range of mechanisms including patient surveys, focus groups, complaints, compliments, and participation in the patient and public involvement processes within the Trust.

In addition, the MDT will conduct a survey of user experience offered on a regular basis, and every two years at a minimum. This survey shall include specific questions concerning the conduct of outpatient consultations, the support of key workers, access to a permanent record of consultation and the range of patient information provided. The survey findings will be presented and discussed at an MDT Business Meeting, in addition to Regional Urology Audit Meetings, and an action plan agreed. A Patient Experience Survey has been designed, and will be distributed to patients in May 2015 (Appendix 3: Patient Experience Survey 2015).

There has recently been a Regional Cancer Patient Experience Survey (CPES) undertaken throughout Northern Ireland. This involved patients in the Southern Trust. It is expected that full results of this survey will be available end of May 2015.

17. AUDIT AND SERVICE IMPROVEMENT 14-2G-117

The Urology MDT will allocate one of its Business Meetings, at least once annually, to decide on the need for audit and to review the results of audits that have been performed. The MDT has appointed Mr. A. Glackin as the Audit Lead responsible for the development of an audit programme.

Mr. M. Haynes has been nominated as the Service Improvement Lead with the principle responsibility of advising the Lead Clinician and MDT of service improvement measures to be considered and adopted.

18. CLINICAL TRIALS 14-2G-118

Clinical trials in Urological Cancers are conducted in Northern Ireland, either as participants in UK and International studies, or designed by the Cancer Centre in Belfast. Recruitment of Urological Cancer patients to clinical trials now accounts for over 20% of all cancer patients recruited to cancer clinical trials in Northern Ireland.
Dr. Judith Carser, Consultant Medical Oncologist, is the MDT member responsible for recruitment of patients to trials.

Mrs. Leanne McCourt is the Cancer Clinical Trials Nurse for the Southern Trust. It is her responsibility to co-ordinate the portfolio of trials agreed by the Steering Committee of the Northern Ireland Cancer Trials Network. The Research Nurse co-ordinates study set-up, the running of the trial, data management and other duties required depending on each protocol.

19 COMMUNICATION WITH GENERAL PRACTITIONERS 14-2G-119

The Chair of each MDM is responsible, in conjunction with the MDM Co-ordinator, for ensuring the accuracy and completeness of all documentation pertaining to each patient discussed at MDM, and in particular, the MDM Plan relating the MDT's advice regarding each patient's further assessment and / or management. Having done so, it is the responsibility of the MDM Co-ordinator to send that information, in

letter format, to the patient's General Practitioner (GP). It has been the combined responsibility of the Chair and the Co-ordinator to ensure that all letters have been posted to the GP within 24 hours of each MDM. It is the intent of the MDT to explore other means of ensuring that GPs are informed within 24 hours without comprising patient confidentiality or data protection.

The MDT has completed an audit against the timeliness of notification to GPs of the diagnosis of cancer. (It is intended that results of this audit will be available for Peer Review site visit in June 2015.)

20 ATTENDANCE AT ADVANCED COMMUNICATIONS SKILLS TRAINING PROGRAMME 14-2G-120

It is recommended that all core members of the Multidisciplinary Teams having direct clinical contact with patients should attend the National Advanced Communication Skills Training Programme. Some newly appointed team members have yet to attend a course and this has been highlighted as an area of priority.

The Training Programme was organised by NICaN until 2015. From 2015, it will be provided locally by individual Trusts. Facilitators have been identified within the Southern Trust, and those requiring training have been identified and placed on a waiting list pending confirmation of dates.

This operational policy will be reviewed on an annual basis, or more frequently if required, in response to changes in regional and national guidelines and to feedback from patients and service users. All members of the MDT are expected to adhere to the contents of the operational policy and are valued for the role that each individual plays within the wider team and service.

Aidan O'Brien,
MDT Lead Clinician,
April 2015.

APPENDIX 1:

Southern Health and Social Care Trust

10 April 2012.

Dear Mr. O'Brien,

Re: Clinical Lead for the Urology Multidisciplinary Team

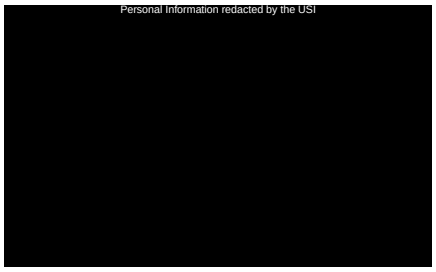
I understand that the Urology Cancer Multidisciplinary Team have nominated you as the Lead Clinician for the service.

I would like to confirm your position as Clinical Lead for the Urology Cancer Service from the 1st April 2012. This term of office will be for an initial 3 years, after which time it will be reviewed.

The role and responsibilities for the Lead Clinician are detailed in the Operational Policy for the service.

I would like to welcome you to the wider Cancer team and thank you for your agreement to act as the Clinical Lead.

Yours sincerely,



Dr. Rory Convery,
Clinical Director of Cancer Services,
Southern Health and Social Care Trust.

APPENDIX 2: CONSULTANT ACTIVITY SCHEDULE

Mr O'Brien

Activity	Occurrence	Comment
Operating Inpatients	Wednesday 12pm-8pm	Weekly
Operating Day Cases	Tuesday AM	Twice per month
New OP Clinic	Tuesday PM	Weekly
Oncology Review	Friday AM Monday AM	Weekly – 6 Oncology Reviews per clinic Once per month – Enniskillen 6 oncology reviews

Mr Young

Activity	Occurrence	Comment
Operating Inpatients	Tuesday 12pm-8pm	Weekly
Operating Day Cases	Monday AM	First Monday in month
New OP Clinic	Thursday PM	Weekly
Oncology Review	Friday PM	Weekly – 6 Oncology Reviews per clinic

Mr Glackin

Activity	Occurrence	Comment
Operating Inpatients	Friday 9am-5pm	Weekly
Operating Day Cases	Tuesday AM	Twice per month
New OP Clinic	Wednesday AM	Weekly
Oncology Review	Friday AM	Weekly – 6 Oncology Reviews per clinic

Mr Haynes

Activity	Occurrence	Comment
Operating Inpatients	Monday 12pm-8pm	Weekly
Operating Day Cases	Wednesday PM	Twice per month
New OP Clinic	Wednesday AM	Weekly
Oncology Review	Friday AM	Weekly – 6 Oncology Reviews per clinic

Mr Suresh

Activity	Occurrence	Comment
Operating Inpatients	Wednesday 8am-12pm Friday 1:30pm-5:30pm	Weekly
Operating Day Cases	Tuesday AM	Twice per month
New OP Clinic	Tuesday PM	Weekly
Oncology Review	Tuesday AM	Weekly – 6 Oncology Reviews per clinic

Mr O'Donaghue

Activity	Occurrence	Comment
Operating Inpatients	Tuesday 8am-12pm Wednesday 8am-12pm	Weekly
Operating Day Cases	Wednesday PM	Twice per month
New OP Clinic	Thursday PM	Weekly
Oncology Review	Monday PM	Weekly – no oncology slots but will change from June 2015.

APPENDIX 3:

Southern Health and Social Care Trust

Patient Experience Survey 2015

Help us Improve our Urological Cancer Service

Dear Sir/Madam

This questionnaire is about your visits to hospital. We want to know what patients feel we are doing well in providing Urological Cancer Services. This questionnaire is anonymous; you do not have to give your name or any personal details. We are giving this questionnaire to a number of patients with similar conditions.

The results obtained from the questionnaire will help us to look at the service we provide to our current and future patients and help us improve upon the service we offer to patients and their families.

Please base your answers on your experience in the Southern Health and Social Care Trust, even though you may have been given your diagnosis in another trust. **Please think about the team you are currently with, when answering the questions.**

Please return using the freepost envelope enclosed with this questionnaire.

Thank you for your co-operation.

Question 1

In Southern Trust, who first spoke to you about your cancer diagnosis and 'what happens next'?

1. Consultant ☐
2. Consultant and specialist nurse ☐
3. Another doctor ☐
4. Specialist nurse ☐
5. Someone else e.g. surgeon. Please write in space below ☐

Question 2
Did you feel that the person who spoke to you about your cancer/planned treatment did so in a caring and sensitive manner?

1. Yes ☐
2. No ☐
3. I cannot remember ☐

Question 3
Were you given the opportunity to have a family member or friend present with you when you were told your diagnosis or had important discussions about your treatment in Southern Trust?

1. Yes ☐
2. No and I would have appreciated someone being with me ☐
3. I did not want anyone with me ☐

Question 4a
How were you told you had cancer in the Southern Trust?

1. In person ☐
2. By phone call ☐
3. In a letter ☐
4. I cannot remember ☐

Question 4b
Did you receive any unexpected appointments?

1. Yes ☐
2. No ☐

We hope that patients do not receive appointments which they were not expecting. If you received unexpected appointments, we would be grateful if you would provide details below. Were they for an outpatient consultation or for investigations, such as scans? Did they cause confusion, concern or anxiety?

Question 5
Did you want to ask questions during your consultation?

3. Yes ☐
4. No ☐

Question 6
Were you given an opportunity to ask any questions during your consultation?

1. Yes ☐
2. No ☐

Question 7
If you asked questions did you understand the answers?

1. Yes, completely ☐
2. Yes, to some extent ☐
3. No ☐
4. I did not ask questions ☐

Question 8
Were you told what would happen next?

1. Yes ☐
2. No ☐
3. I cannot remember ☐

Question 9
Was the environment in which you were given your diagnosis/had important discussions private?

1. Yes ☐
2. No ☐

Question 10

Were you given the opportunity to speak to a Clinical Nurse Specialist when you were seen in Southern Trust and told about your cancer and planned treatment?

1. Yes ☐
2. No ☐

Question 11
Did you require further information and support from the Clinical Nurse Specialist in addition to your clinic appointment?

1. Yes ☐
2. No ☐

Question 12
If you did require further information and support from the Clinical Nurse Specialist, did you find this beneficial?

1. Yes ☐
2. No ☐

Question 13
Patients are ideally meant to have a 'Key Worker' when diagnosed with cancer. Were you given the contact details of a Clinical Nurse Specialist/Key Worker in case you needed more information and support or had questions about your illness or treatment?

1. Yes ☐
2. No ☐
3. I do not remember ☐

Question 14
Were you given a written record of your consultation, e.g. diagnosis/diagram/what happens next?

1. Yes ☐
2. No but I would have liked one ☐
3. No but I did not want one ☐
4. I was offered this but did not want it ☐
5. I cannot remember ☐

Question 15
Were you offered written information about your cancer/treatment?

1. Yes ☐
2. Yes but I did not want it ☐
3. No ☐
4. I cannot remember ☐

Question 16
Were you offered written information about the multidisciplinary team (MDT) who would be involved in your care and what they do?

1. Yes ☐
2. Yes but I did not want it ☐
3. No ☐
4. No, but I wouldn't have wanted it ☐
5. I cannot remember ☐

Question 17

Were you given written information about other sources of support during your visits to us? Tick all the relevant boxes

1. Financial support ☐
2. Other hospital services ☐
3. Local support groups ☐
4. Local support centre ☐
5. National support organisations/ helpline ☐
6. Services offering psychological, social and spiritual/cultural support? ☐
7. Was offered but declined ☐

Question 18
Did you feel your holistic needs (i.e. emotional, practical, physical, psychological, spiritual, and financial) were addressed during your cancer journey?

1. Yes ☐
2. No ☐
3. No, but I would have wanted it ☐
4. I cannot remember ☐
5. To some extent ☐

Question 19
Overall, how would you rate the *quality* of the information provided to you about your condition and treatment?

1. Excellent ☐
2. Very good ☐
3. Good ☐
4. Fair ☐
5. Poor ☐
6. I was not offered any information ☐
7. I was offered but refused ☐

Question 20
Overall, how would you rate the *quantity* (amount) of the information provided to you?

1. Too much ☐
2. About right ☐
3. Not enough ☐
4. I was not offered any information ☐
5. I was offered but declined ☐

Question 21

Did you feel you were able to decline either verbal or written information if you did not want it?

1. Yes ☐
2. No ☐

The following will help us to analyse you answer:

Gender	Age	Diagnosis	Treatment

In which hospital did your receive your diagnosis?

1. Craigavon Area Hospital ☐
2. Daisy Hill Hospital ☐
3. South Tyrone Hospital ☐
4. South West Acute Hospital ☐
5. Armagh Community Hospital ☐
6. Banbridge Polyclinic ☐

When were you diagnosed?

1. 1-3 months ago ☐
2. 3-6 months ago ☐
3. 6-12 months ago ☐
4. Greater than 12 months ago ☐

Was there anything particularly good about the care you have received?

Was there anything that could be improved?

Any other comments?

APPENDIX 4:

Urology Care Pathways

Cancer Care Pathways outline the steps and stages in the patient journey from referral through to diagnostics, staging, treatment, follow up, rehabilitation and if applicable onto palliative care.

Timed effective care pathways are central to delivering quality and timely care to patients throughout their cancer journey and to the delivery of an equitable service. These pathways have been developed following with reference to available best practice guidance. They represent an 'ideal' pathway that can be adapted for local use. The timelines on the pathway are intended to facilitate the proactive management of patients within the access standards and it is to be noted that for some urological tumours, the patient will move much quicker through the pathway (e.g. testicular cancer).

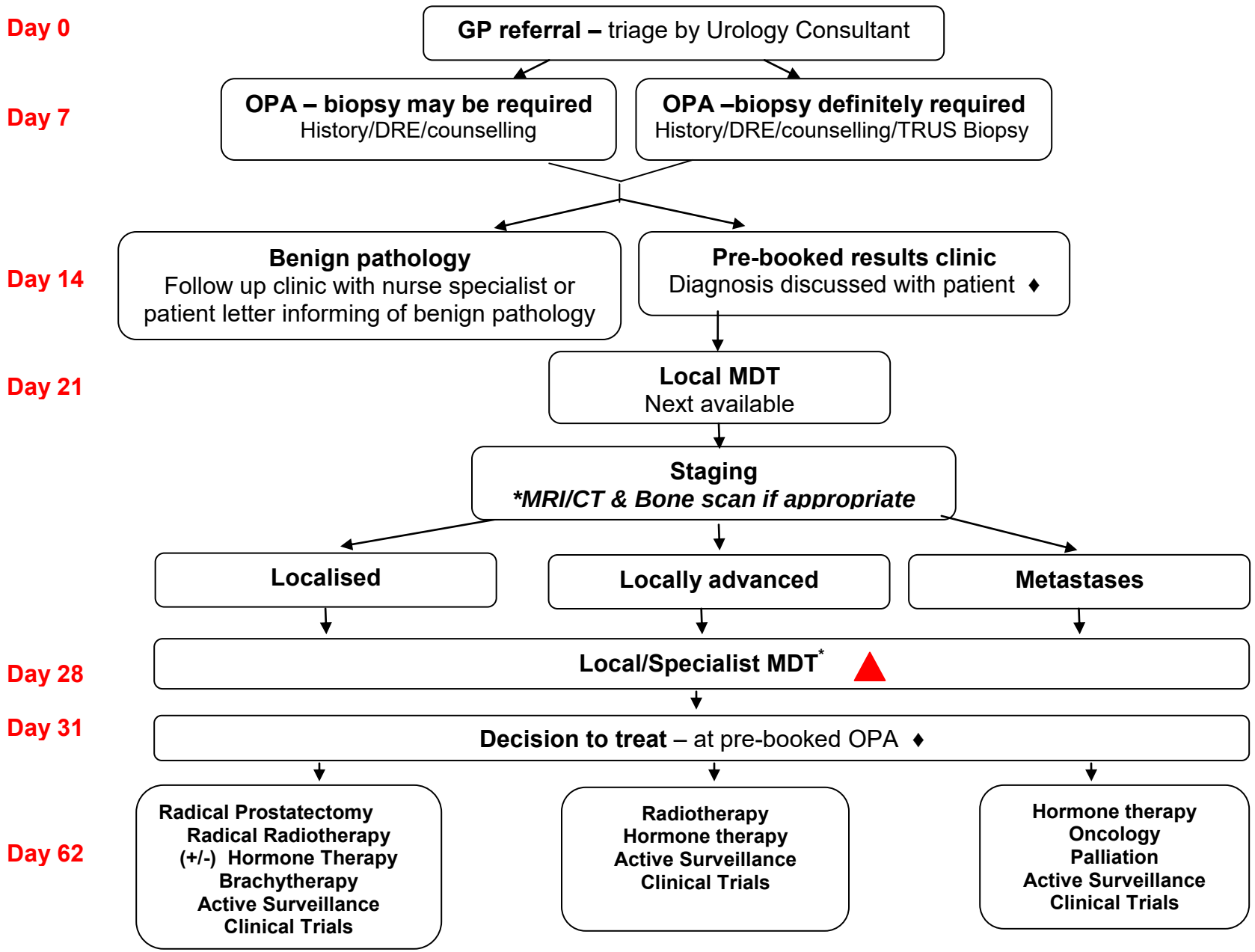
The pathways are in draft form and amendments have been made following discussion at the workshop of the NICaN Regional Urology group held on Thursday 2nd October, 2008.

Document History

V1 Draft discussed at workshop 2/10/08
V2 Draft discussed 29/1/09 and amendments noted
Version 3 circulated for final comments 26/02/09
Pathways agreed at regional meeting 23/4/09

NICaN Regional Urology Group
Final Care Pathways for Urological Cancer

Prostate Pathway



♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

* CT necessary only when clinically indicated

NICaN Regional Urology Group
Final Care Pathways for Urological Cancer

Renal Tumour

MAXIMUM WAIT	PATHWAY	GOOD PRACTICE & QUALITY PARAMETERS
	GP referral	See NICaN referral guidelines, 2007
	One Stop Haematuria Clinic Flexible cystoscopy + Upper Tract Imaging/ History Physical	Inform MDT coordinator on of results.
	Renal Tumour	
	Stage tumour	
	Patient discussed at MDT Δ	▪ Letter from MDT to GP ▪ Proactive pathway manag ▪ PACS ▪ Regionally agreed dataset d'base (NICR)
	Other point of entry (A&E, Incidental Findings) → Outpatient's appointment Treatment options discussed Decision to treat ♦	***** Manual of Cancer Service Standards Oncology Protocols (to include Clinical Trials)**

PT1a B	PT2	PT3a	PT3b	PT4 M1
Laparoscopic Treatment of choice ? Partial ? Open Surgery ? Laparoscopic	Laparoscopic ? Open	Open ? Laparoscopic	Open ? Laparoscopic Vascular Surgeon Cardiac Bypass	? Debulk + Immunotherapy Embolisation Radiotherapy Palliative Care New drugs

Renal Preservation

Partial Nephrectomy
Open/ Laparoscopy
Auto transplant
Radio Frequency Ablation
Cryotherapy

Follow UP ♦

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points *****NICE*

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

NICaN Regional Urology Group
Final Care Pathways for Urological Cancer

Testicular Cancer Pathway

Maximum Wait	*Pathway*

GP Referral received
Testicular Cancer suspected

Assessment of clinical presentation (Lump)

Diagnostic tests
Ultrasound

Equivocal

Testicular Cancer Confirmed
Decision to treat

CXR Tumor Marker
Book CT

Patient discussed at MDT Δ

Outpatient's appointment ♦
CT/Histology

Metastatic

Oncology

Oncology Outpatient's appointment ♦

Patient discussed at MDT

Surveillance | Chemotherapy | Radiation | Clinical Trial | Sperm Bank

Post Chemo Mass/ RPLND

Follow UP ♦

Good Practice & Quality Parameters

NICaN Referral Guidelines, 2007
Swelling or mass in body of testis

Improving Outcomes guidance in Urological cancers. 2002

Inform MDT coordinator on receipt of results.

Orchidectomy +- Prosthesis

- ***GP letter from MI***
- Proactive pathway man
- PACS
- Regionally agreed datas d'base (NICR)

***** Manual of Cancer Service Standards**
Oncology Protocols (to include Clinical Trials)

Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points *****NICE

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

NICaN Regional Urology Group
Final Care Pathways for Urological Cancer

Transitional Cell Carcinoma

MAXIMUM WAIT

PATHWAY

GP referral / other point of entry (A&E, incidental findings)

Flexible cystoscopy + Upper Tract Imaging/ History Physical

Upper Tract

Bladder Tumour

Superficial

Muscle Invasive

TURBT
Single shot MitomycinC

CT Chest, Abdomen

Grade and stage tumour

Patient discussed at MDT Δ

Laser
Local Excision
Nepho-Ureterectomy
Laparoscopy
Pluck

Outpatient's appointment
Treatment options discussed
Decision to treat ♦

Superficial treatment options

Invasive treatment options

PTaG3 BCG

PT1G3 Re-resect BCG

? Bladder Preservation /radio/chemo

? Radical Surgery/ reconstruction

Palliation

Neo-adjuvar Chemo

PTa Eastoscopic Follow up

Register only

Follow UP ♦

GOOD PRACTICE & QUALITY PARAMETERS

See NICaN referral guidelines, 2007

Improving outcomes for Urological cancers, 2002

Inform MDT coordinator on of results.

- Letter from MDT to GP
- Proactive pathway manag
- PACS
- Regionally agreed dataset d'base (NICR)

***** Manual of Cancer Service Standards Oncology Protocols (to include Clinical Trials)**

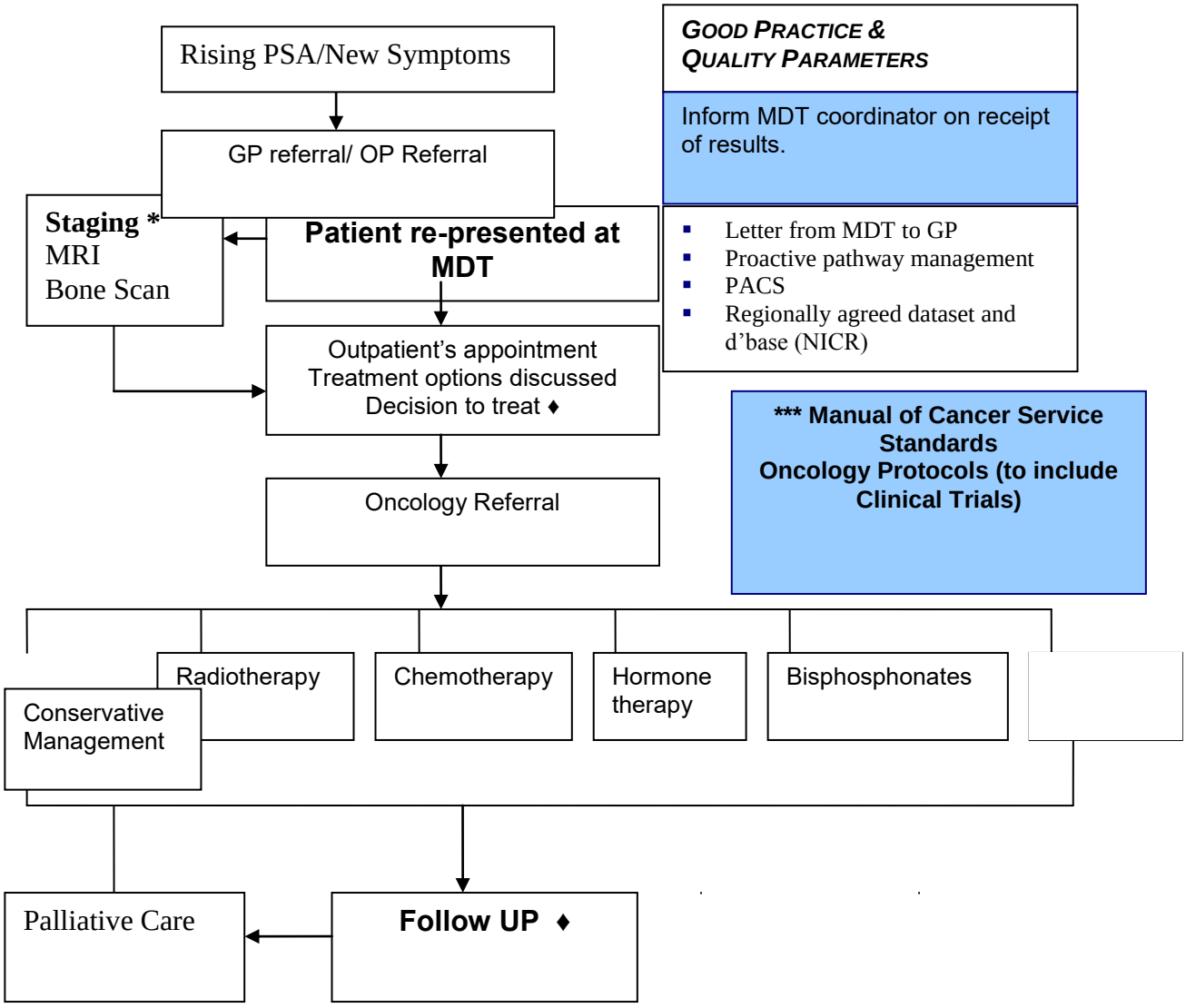
*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points *****NICE*

Patient support & informa

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

NICaN Regional Urology Group
Final Care Pathways for Urological Cancer

Castration Resistant Prostate Cancer



* MRI/Bone Scan as clinically indicated

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

NICaN Regional Urology Group
Final Care Pathways for Urological Cancer

Penile Cancer Pathway

MAXIMUM WAIT	PATHWAY

GP Referral received
Penile Cancer suspected

Biopsy/Stage Tumour
CT/MRI

Option for local review ♦

Patient discussed at MDT Δ

Outpatients Appointment
Decision to treat ♦

Localised | **Groins*** | **Advanced***

Surgery
- Amputation
- Penile preservation
- Glansectomy

Lymph Node Dissection
- Therapeutic
- Prophylactic

Radiation

Chemo Radiation

Pelvic Lymph Node Dissection
Open Laparoscopy

Chemo Radiation

Palliative Care

Clinical Trials

Follow UP ♦

GOOD PRACTICE & QUALITY PARAMETERS

NICaN Referral Guidelines, 2007

Improving Outcomes guidance in Urological cancers. 2002

Inform MDT coordinator on receipt of results.

- Proactive pathway manag
- PACS
- Regionally agreed dataset d'base (NICR)

***** Manual of Cancer Service Standards Oncology Protocols (to include Clinical Trials)**

Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points *****NICE

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

NICaN Regional Urology Group
Final Care Pathways for Urological Cancer

References

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  http://www.nice.org.uk/guidance/index.jsp?action=byID&o=10889
- NICE (2008) Prostate Cancer: Diagnosis and Treatment
  http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11924
- British Association Of Urological Surgeons Guidelines
  http://www.baus.org.uk/
- European Association Of Urology
  http://www.europeanurology.com/

NICaN Urology Cancer Clinical Guidelines

March 2016

Document Title	Guidelines for the Referral, Diagnosis, Treatment and Management of Urological Cancer
Document Date	March 2015 – version 1.1 January 2016 – version 1.2 March 2016 – version 1.3
Document Purpose	This guidance has been produced to support the diagnosis, treatment and management of urological cancer. Treatment decisions for individual patients require the weighing of a multiplicity of factors, which cannot all be accounted for in a CMG. The CMG provides a description of the range of treatment options available for a clinical scenario. To maximise the benefit of multi-professional working management strategies for the individual are best discussed with a multidisciplinary meeting (MDM).
Authors	Surgical: New NI guidelines have been developed by Ali Thwaini, Consultant Urologist, BHSCT, for Bladder, Prostate, Penile, Renal Cell, Testicular & Upper Urinary Tract Urothelial Cell Carcinomas Imaging: Yorkshire Cancer Network Imaging Guidelines (These guidelines have been adopted by the Network group as they reflect NI Practice) Pathology: Royal College of Pathologists Standards and Minimum Datasets for reporting Cancers (These guidelines have been adopted by the Network group as they reflect NI Practice) Systemic Anti-cancer Therapy Protocols: Reference to separate guidance developed on behalf of the NI Cancer Network and the HSCB Radiotherapy Protocols: These guidelines have been adopted by the Network group as they reflect NI Practice) Urological Nursing Sections: Kate O'Neill (SHSCT), Kerry Chambers (WHSCT), Patricia Thompson (SEHSCT), Hazel Kerr (SEHSCT) Follow up section: Transforming Cancer Follow Up Project team

Version 1	Original Draft
Version 1.1	Reformatted with inclusion of new Surgical guidelines, Imaging, Pathology, Clinical Nurse Specialist, Follow Up and Specialist Radiographer Sections
Version 1.2	Discussed at the Regional Urology Network Group Meeting on 29th January 2016
Version 1.3	Amendments following circulation January2016 Population base adjusted to reflect updated NISRA figures and NW urology population base NG12 Urology referral guidelines replace red flag guidelines Reference to guidance regarding 150 robotic prostatectomies requirement removed

Regional Agreements	Electronically agreed and issued 18th March 2016 (of note any change in commissioning arrangements will require inclusion)
Agreed:	
Review:	April 2017

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1.0 INTRODUCTION

Urological cancers include a range of tumours with different presentations including:

- Prostate cancer
- Bladder cancer
- Kidney cancer
- Testicular cancer
- Penile cancer

Prostate cancer is a form of cancer that develops in the prostate. Advanced prostate cancer can spread to other parts of the body. It accounts for 24% of all new cancers in UK males, and in 20-30% of cases, prostate cancer spreads to other locations in the body. In Northern Ireland, the average number of cases per year between 2009-2013 was 1,039 per year (figures provided by NI Cancer Registry).

Bladder cancer is any of several types of malignant growths of the urinary bladder and isthe 4th most common male tumour. The most common type of bladder cancer begins in cells lining the inside of the bladder and is called transitional cell carcinoma. Incidence of bladder cancer is higher in males than in females, with over 6,400 cases in 2009 in males compared to under 2,400 in females. In Northern Ireland, the average number of cases per year between 2009-2013 was 211 per year, with a breakdown of 150 males and 61 females (figures provided by NI Cancer Registry).

Kidney cancer is a form of cancer that develops in the kidneys. Kidney cancer is often asymptomatic until an advanced stage. In approximately one third of cases, the tumour is detected incidentally during imaging carried out for other reasons. The two most common types of kidney cancer, reflecting their location within the kidney, are renal cell carcinoma (RCC) and urothelial cell carcinoma (UCC) of the renal pelvis.

In Northern Ireland, the average number of cases per year between 2009-2013 was 288 per year, with a breakdown of 173 males and 115 females (figures provided by NI Cancer Registry).

Testicular cancer or cancer of the testicles is one of the less common cancers. It usually affects younger men between the ages of 15 and 49. Testicular cancer is relatively uncommon, accounting for just 1% of all cancers that occur in men. The most common type of testicular cancer is known as ‘germ cell testicular cancer’, which accounts for around 95% of all cases. In Northern Ireland, the average number of cases per year between 2009-2013 was 65 per year (figures provided by NI Cancer Registry).

Penile cancer is a rare type of cancer that occurs on the skin of the penis or within the penis. In the UK, around 550 men are diagnosed with cancer of the penis each year. It

most commonly affects men over 60 years of age. Over the last 30 years, the number of penile cancer cases has increased by more than 20%, possibly due to changes in sexual practices.

2.0 NETWORK CONFIGURATION OF THE UROLOGY CANCER SERVICES

Northern Ireland Cancer Network has three cancer MDTs which diagnose and treat patients with urological cancers. These are held at the following locations:

- Craigavon Area Hospital – Southern HSC Trust
- Belfast City Hospital – combined team for Belfast HSC Trust and South Eastern HSC Trust
- Altnagelvin Hospital – combined team for Western HSC Trust & Northern HSC Trust

The catchment populations of these MDTs are shown below:

Urology MDT	**Catchment**[1]
SHSCT	366,000
Combined for: BHSCT and SEHSCT	 366,000 341,085
Combined for: WHSCT and NHSCT	 297,000 467,000 *Of note the population base for urology is 480,000 representing the upper two thirds of both the NHSCT & WHSCT*
Total	**1,830,000**

Each MDT meets on a weekly basis. All MDTs have named surgeons who deal with urological cancers.

[1] *Source: NISRA, 2013 MYEs*

3.0 REFERRAL GUIDELINES FOR UROLOGY CANCER

Patients can be referred to their local hospital as 'red flags' (i.e. suspect cancer) by their GPs under the following NICE guidance:

This section is a direct lift from the NICE NG12 Suspect Cancer: Recognition and Referral (June 2015).

Prostate cancer

Refer men using a suspected cancer pathway referral (for an appointment within 2 weeks) for prostate cancer if their prostate feels malignant on digital rectal examination. **[new 2015]**

Consider a prostate-specific antigen (PSA) test and digital rectal examination to assess for prostate cancer in men with:

- any lower urinary tract symptoms, such as nocturia, urinary frequency, hesitancy, urgency or retention **or**
- erectile dysfunction **or**
- visible haematuria. **[new 2015]**

Refer men using a suspected cancer pathway referral (for an appointment within 2 weeks) for prostate cancer if their PSA levels are above the age-specific reference range. **[new 2015]**

Bladder cancer

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for bladder cancer if they are:

- aged 45 and over and have:
    - unexplained visible haematuria without urinary tract infection **or**
    - visible haematuria that persists or recurs after successful treatment of urinary tract infection, **or**
- aged 60 and over and have unexplained non-visible haematuria **and** either dysuria or a raised white cell count on a blood test. **[new 2015]**

Consider non-urgent referral for bladder cancer in people aged 60 and over with recurrent or persistent unexplained urinary tract infection. **[new 2015]**

Renal cancer

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for renal cancer if they are aged 45 and over and have:

- unexplained visible haematuria without urinary tract infection **or**
- visible haematuria that persists or recurs after successful treatment of urinary tract infection. **[new 2015]**

Testicular cancer

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for testicular cancer in men if they have a non-painful enlargement or change in shape or texture of the testis. **[new 2015]**

Consider a direct access ultrasound scan for testicular cancer in men with unexplained or persistent testicular symptoms. **[new 2015]**

Penile cancer

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for penile cancer in men if they have either:

- a penile mass **or** ulcerated lesion, where a sexually transmitted infection has been excluded as a cause, **or**
- a persistent penile lesion after treatment for a sexually transmitted infection has been completed. **[new 2015]**

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for penile cancer in men with unexplained or persistent symptoms affecting the foreskin or glans. **[new 2015]**

3.1 Haematuria Referral Guideline – please see Appendix 1

4.0 UROLOGY CARE PATHWAYS

Cancer Care Pathways outline the steps and stages in the patient journey from referral to diagnostics, staging, treatment, follow up, rehabilitation and if applicable onto palliative care.

Timed effective care pathways are central to delivering quality and timely care to patients throughout their cancer journey and to the delivery of an equitable service.

Please see **appendix 2** for the care pathways for:

- Prostate
- Renal Tumour
- Testicular Cancer Pathway
- Transitional Cell Carcinoma
- Castration Resistant Prostate Cancer
- Penile Cancer Pathway

5.0 REGIONAL GUIDELINES FOR THE IMAGING OF UROLOGICAL CANCERS

Document Title	**Guidelines for the Imaging of Urological Cancers**
Document Date	**March 2015 – Version 2**
Document Purpose	**This guidance has been produced to support the diagnosis, treatment and management of urological cancer** **Treatment decisions for individual patients require the weighing of a multiplicity of factors, which cannot all be accounted for in a CMG. The CMG provides a description of the range of treatment options available for a clinical scenario. To maximise the benefit of multi-professional working management strategies for the individual are best discussed with a multidisciplinary meeting (MDM).**
Authors	**Dr Arthur Grey – Consultant Radiologist** **Dr Stephen Vallelly – Consultant Radiologist** **Dr Eoin Napier – Consultant Radiologist**
Version Changes	**Version 1 – issued to Regional Group 7/4/11** **Version 1.1 – the updated Yorkshire Cancer Network Imaging Guidelines for the Investigation and Treatment of Urological Cancers were reviewed by the authors in September 2014 and they agreed to adopt the updated guidelines as they reflected NI Practice. The guidelines were circulated to the Urology Network Group for sign off on 17 April 2015. Copies of the Yorkshire Cancer Network Imaging Guidelines are available at http://www.ycn.nhs.uk/**

6.0 REGIONAL PATHOLOGY GUIDELINES FOR UROLOGICAL CANCERS

Document Title	**Regional Pathology Guidelines for Urological Cancers**
Document Date	**Version 2 29th January 2016**
Document Purpose	**The guidance has been produced to support the pathological diagnosis and staging of Urological Malignancies**
Author	**Dr G McClean**
Evidence	**Royal College of Pathologists Standards and Minimum Datasets for reporting Cancers;** **Dataset Adult Renal Parenchymal Cancer Histopathology Reports Nov 2006** https://www.rcpath.org/resourceLibrary/dataset-adult-renal-parenchymal-cancer-histopathology-reports.html **Dataset for penile and distal urethral cancer histopathology reports July 2015** https://www.rcpath.org/resourceLibrary/dataset-for-penile-and-distal-urethral-cancer-histopathology-reports.html **Dataset for histopathology reports for prostatic carcinoma (2nd edition) October 2009** https://www.rcpath.org/resourceLibrary/dataset-for-histopathology-reports-for-prostatic-carcinoma.html **Dataset for the histological reporting of testicular neoplasms May 2014** https://www.rcpath.org/resourceLibrary/dataset-for-the-histological-reporting-of-testicular-

	neoplasms.html **Dataset for tumours of the urinary collecting system** **(renal pelvis, ureter, urinary bladder and urethra) (2nd edition) April 2013** https://www.rcpath.org/resourceLibrary/dataset-for-tumours-of-the-urinary-collecting-system--renal-pelvis--ureter--urinary-bladder-and-urethra.html

Version changes

Version 1 – 23rd March 2015

Version 2 – 29th January 2016. Replacement of dataset for penile histopathology with dataset released July 2015. Update of website addresses for all datasets.

Statement:

Via Consultation with Pathologists at all Trusts it has been confirmed that all Pathologists in Northern Ireland are reporting to the standards laid down by the Royal College of Pathologists in the following College Publications and that there is no additionality of practice.

Dr Gareth McClean

7.0 REGIONAL SYSTEMIC ANTI-CANCER THERAPY PROTOCOLS FOR UROLOGICAL CANCERS

Document Title	**Systemic Anti-cancer Therapy Protocols**
Document Date	**2015**
Document Purpose	Please refer to separate NICaN guidance documents for the Systemic Anti-cancer Therapy Protocols for Bladder, Penile, Testicular Germ Cell tumours, Prostate and Renal Cell. These documents are available on the NICaN website **www.cancerni.net.**

8.0 REGIONAL RADIOTHERAPY PROTOCOLS FOR UROLOGICAL CANCER

Document Title	**Radiotherapy Protocols**
Document Date	**2015**
Document Purpose	Radiotherapy is delivered in the Northern Ireland Cancer Centre at the Belfast City Hospital with a second department due to open in Altnagelvin in 2016. The Cancer Centre is equipped with 10 Linear Accelerators and a full range of conventional and CT simulation equipment. The Radiotherapy Department employs approximately 90 radiographers. The department is accredited by ISO9000 and Charter mark standards. There is a modern treatment planning system with 10 planning terminals. A comprehensive radiology service is available within the Cancer Centre and in the main City Hospital. IMRT is routinely delivered for radically treating prostate cancer, radiotherapy may also be used palliatively for all urological cancers. Further details of treatment regimens and fractionations are contained within treatment protocols are located in the radiotherapy department. For further information please contact Joanne McCarthy Clinic Coordinator joanne.mccarthy@ Personal information redacted by USI cristiona.mccavana Personal information redacted by USI

9.0 REGIONAL GUIDELILNES FOR THE SURGICAL TREATMENT AND MANAGEMENT OF UROLOGY CANCER

Document Title	**Guidelines for the Surgical Treatment and Management of Urological Cancer**
Document Date	March 2011 – Final Version January 2016 – Version updated and finalised
Document Purpose	This guidance has been produced to support the diagnosis, treatment and management of urological cancer Treatment decisions for individual patients require the weighing of a multiplicity of factors, which cannot all be accounted for in a CMG. The CMG provides a description of the range of treatment options available for a clinical scenario. To maximise the benefit of multi-professional working management strategies for the individual are best discussed with a multidisciplinary meeting (MDM)
Authors	Ali Thwaini, BHSCT
Version Changes	It was agreed at the Urology Network Meeting on 11th June 2014 to review the Surgical components of the EAU guidelines for urological cancers. Mr Ali Thwaini has developed new Urological surgical guidelines to reflect practice within NI. It was agreed at the Urology Network Meeting on 17th April 2015 that the EAU guidelines for Kidney would continue to be adopted by the Network group until the guideline has been reviewed by the relevant core members to highlight exceptions in practice in NI.

9.1 Bladder Cancer Surgical Guidelines (2014)

Bladder Cancer

Epidemiology:
Bladder cancer is the ninth most commonly diagnosed cancer worldwide, with more than 380,000 new cases each year and more than 150,000 deaths per year, and an estimated male-female ratio of 3.8:1. At any one time, 2.7 million people have a history of urinary bladder cancer. Recently, overall and stage-specific age-adjusted incidence rates of bladder cancer have been analysed in the U.S. (5 year survival and mortality rates between 1973 and 2009). Although the analysis of the Surveillance, Epidemiology and End Results (SEER) database implies some limitations it is worrying to note that in the last 30 years the mortality rate associated with bladder cancer has not changed substantially, highlighting gaps in diagnosis, monitoring and management of these patients (3). At the initial diagnosis of bladder cancer, 70% of cases are diagnosed as non-muscle-invasive bladder cancer (NMIBC) and approximately 30% as muscle-invasive bladder cancer (MIBC). Among patients treated with radical cystectomy because of MIBC, 57% had muscle invasion at presentation, while 43% were initially 8 MUSCLE-INVASIVE AND METASTATIC BLADDER CANCER - LIMITED UPDATE APRIL 2014 diagnosed with NMIBC that progressed despite organ-preserving treatment (4). Approximately one-third of patients diagnosed with MIBC have undetected metastases at the time of treatment for the primary tumour (5), while 25% of patients who undergo radical cystectomy present with lymph node involvement at the time of surgery.

Risk factors:
Tobacco smoking:

- is the most well-established risk factor for bladder cancer, causing 50-65% of male cases and 20-30% of female cases
- the incidence of bladder cancer is directly related to the duration of smoking and the number of cigarettes smoked per day
- the risk of bladder cancer is also higher in those who start smoking at a young age or who are exposed to environmental tobacco smoke during childhood
- the reduction of bladder cancer was about 40% within 1-4 years of quitting smoking and 60% after 25 years of cessation.

Occupational exposure:

- is the second most important risk factor for bladder cancer. Work-related cases have accounted for 20-25% of all bladder cancer cases in several series.
- substances involved in chemical exposure include benzene derivatives and aryl amines (2-naphthylamine, 4-ABP, 4,4'-methylenedianiline, and o-toluidine), and it is likely to occur in occupations in which dyes, rubbers, textiles, paints, leathers, and chemicals are used .

- risk of bladder cancer due to occupational exposure to carcinogenic aromatic amines is significantly greater after 10 years or more of exposure; the mean latency period usually exceeds 30 years.
- carcinogens can be inactivated by a metabolic acetylation pathway. The presence of an NAT2 slowacetylation genotype has been associated with a higher risk of bladder cancer (16), suggesting that patients who are slow acetylators may be more susceptible to bladder cancer than rapid acetylators. Other risk factors include phenacetin, which the International Agency for Research on Cancer (IARC) included in 1987 among proven human carcinogens. Some studies have suggested that the risk of bladder cancer due to phenacetin is dose-dependent; however, the data concerning its metabolite acetaminophen are controversial.

Radiotherapy: Increased rates of secondary bladder malignancies have been reported after external-beam radiotherapy (EBRT) for gynaecological malignancies, with relative risks of 2-4.

Dietary factors have been considered to be related to bladder cancer; however, the links remain controversial. Currently, there is limited evidence of a causal relationship between bladder cancer and dietary factors.

Bladder schistosomiasis (bilharzia) is the second most common parasitic infection after malaria, with about 600 million people exposed to infection in Africa, Asia, South America, and the Caribbean.

Chronic urinary tract infection: bladder cancer, particularly invasive squamous cell carcinoma, has been linked to the presence of chronic urinary tract infection (UTI) distinct from schistosomiasis. A direct association between bladder cancer and UTIs has been observed in several case-control studies, which have reported a two-fold increased risk of bladder cancer in patients with recurrent UTIs in some series.

Chemotherapy: The use of cyclophosphamide, an alkylating agent used to treat lymphoproliferative diseases and other nonneoplastic diseases, has been correlated with subsequent development of MIBC, with a latency period of 6-13 years. Acrolein is a metabolite of cyclophosphamide and is responsible for the increase in the incidence of bladder cancer. This effect occurs independently of the association of haemorrhagic cystitis with the same treatment and was counteracted with concomitant application of mercapto-ethanesulfonate (MESNA).

Synchronous and metachronous upper urinary tract tumours: In some cases, there is an association between upper tract urothelial carcinoma (UTUC) and bladder cancer.

- The incidence of UTUC after a diagnosis of NMIBC has been reported to be between 1.7% and 26%. Although synchronous UTUC and NMIBC are uncommon, 46% of UTUCs are invasive. In a retrospective review of 1,529 patients with primary non-muscle-invasive bladder carcinoma who underwent initial examination of the upper urinary tract with excretory urography, those with a tumour in the bladder trigone were almost six times more likely to develop a synchronous tumour in the upper urinary tract. Examination of the upper urinary tract alone in patients with a tumour in the trigone or with multiple bladder tumours was capable of diagnosing 41% or 69% of UTUCs, respectively.
- In multiple and high-risk tumours, there is an increased risk of tumour recurrence in the upper urinary tract.
- Carcinoma in situ (CIS) in the bladder is an important risk factor for subsequent upper urinary tract recurrence . It has been shown in various studies that tumour involvement of the distal ureter at RC is an independent risk factor for metachronous upper urinary tract (mUUT) recurrence, with an approximate 2.6-fold increase in the relative risk.
- The overall incidence of bladder cancer developing after treatment for UTUC has been reported in the literature as 15-50%.

Gender:

- women were more likely to be diagnosed with primary muscle-invasive disease than men (85% vs. 51%).
- women are more likely to be older than men when diagnosed, with a direct effect on their survival. In addition, delayed diagnosis is more likely in women after haematuria is observed, as the differential diagnosis in women includes diseases that are more prevalent than bladder cancer.
- Differences in the gender prevalence of bladder cancer may be due to other factors besides tobacco and chemical exposure. In a large prospective cohort study, postmenopausal status was associated with an increase in bladder cancer risk, even after adjustment for smoking status.

Ethnic and socioeconomic status: There are limited data on this topic, but a study based on 13,234 cases diagnosed in the SEER database in the period 1979-2003 showed that the survival time from diagnosis was significantly lower among cancer cases in patients with low socioeconomic status (SES) compared with those with higher SES. Hazard ratios for all causes and cancer-specific mortality among blacks in comparison with whites for eight of the most common types of cancer combined lost statistical significance after adjustment for SES factors and treatments. However, blacks still had unfavourable prognoses in comparison with whites even after adjustment for SES and treatment for tumours such as breast, colorectal, and urinary bladder cancer (44).

Genetic factors: There is growing evidence that genetic susceptibility factors and family associations may influence the incidence of bladder cancer. The relationship between family history of cancer and risk of bladder cancer was examined in the Spanish Bladder Cancer Study. It was found that family history of cancer in first-degree relatives was associated with an increased risk of bladder cancer; the association being stronger among younger patients. Shared environmental exposure was recognised as a potentially confounding factor.

TNM classification of urinary bladder cancer (2009)

T - Primary Tumour
Tx Primary tumour cannot be assessed
T0 No evidence of primary tumour
Ta Non-invasive papillary carcinoma
Tis Carcinoma in situ: “flat tumour”
T1 Tumour invades subepithelial connective tissue
T2 Tumour invades muscle
T2a Tumour invades superficial muscle (inner half)
T2b Tumour invades deep muscle (outer half)
T3 Tumour invades perivesical tissue:
T3a Microscopically
T3b Macroscopically (extravesical mass)
T4 Tumour invades any of the following: prostate stroma, seminal vesicles, uterus, vagina, pelvic wall, abdominal wall
T4a Tumour invades prostate stroma, seminal vesicles, uterus, or vagina
T4b Tumour invades pelvic wall or abdominal wall
N - Regional Lymph Nodes
Nx Regional lymph nodes cannot be assessed
N0 No regional lymph-node metastasis
N1 Metastasis in a single lymph node in the true pelvis (hypogastric, obturator, external iliac, or presacral)
N2 Metastasis in multiple lymph nodes in the true pelvis (hypogastric, obturator, external iliac, or presacral)
N3 Metastasis in common iliac lymph node(s)
M - Distant Metastasis
M0 No distant metastasis
M1 Distant metastasis

World Health Organization grading for bladder cancer

1973 WHO grading
Urothelial papilloma
Grade 1: well differentiated
Grade 2: moderately differentiated
Grade 3: poorly differentiated

2004 WHO grading
Flat lesions Hyperplasia (flat lesion without atypia or papillary aspects)
Reactive atypia (flat lesion with atypia)
Atypia of unknown significance
Urothelial dysplasia
Urothelial CIS is always high-grade
Papillary lesions
Urothelial papilloma (completely benign lesion)
Papillary urothelial neoplasm of low malignant potential (PUNLMP)
Low-grade papillary urothelial carcinoma
High-grade papillary urothelial carcinoma

Non-muscle-invasive (Ta, T1 and CIS) Bladder Cancer

Diagnosis and Initial Treatment Steps

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

Papillary (Ta, T1) Tumours

The diagnosis of papillary BC ultimately depends on cystoscopic examination of the bladder and histological evaluation of the resected tissue.

The standard initial therapy for Ta and T1 papillary bladder tumours is complete macroscopic transurethral resection (TURB), including a part of the underlying muscle. TURB should be performed systematically in individual steps, which Non-muscle invasive (Ta, T1, CIS) Bladder Cancer 11 are described in the full version of the guidelines. Small tumours (< 1 cm) can be resected en bloc, including a part of the underlying muscle. Larger tumours should be resected separately in fractions, which include the exophytic part of the tumour, the underlying bladder wall with the detrusor muscle and the edges of the resection area. The specimens from different fractions must be referred to the pathologist in separate containers.

A second TURB 2-6 weeks after initial resection is recommended in the following situations:

- After incomplete initial TURB, if there was no muscle in the specimen after initial resection (with exception of Ta low grade (G1) tumours);
- In all T1 tumours and in all high grade (G3) tumours (except primary CIS).

CIS

CIS is diagnosed by a combination of cystoscopy, urine cytology, and histological evaluation of multiple bladder biopsies.

Biopsies are taken from suspect areas. In patients with positive urine cytology and no papillary tumour, multiple biopsies from normal looking mucosa including prostatic urethra (random

biopsies) are recommended. If equipment is available, photodynamic diagnosis (PDD) is a useful tool to target the biopsy in these patients. Urine cytology is useful in the diagnosis and follow-up of CIS. CIS cannot be eradicated by TURB and further treatment is mandatory.

Guidelines for primary assessment of NMIBC	GR
Patient history should be taken and recorded regarding all important information with a possible association with bladder cancer, including risk factors and suspicious symptoms.	A
Renal and bladder US may be used during the initial work-up in patients with haematuria.	C
At the time of the initial diagnosis of bladder cancer, CT urography (or IVU) should be performed only in selected cases (e.g., tumours located in the trigone).	B
Cystoscopy is recommended in all patients with symptoms suggestive of bladder cancer. It cannot be replaced by cytology or by any other non-invasive test.	A

Guidelines for primary assessment of NMIBC	GR
Cystoscopy should describe all macroscopic features of the tumour (site, size, number and appearance) and mucosal abnormalities. A bladder diagram is recommended.	C
Voided urine cytology is advocated to predict high grade tumour before TURB.	C
Cytology should be performed on fresh urine with adequate fixation. Morning urine is not suitable because of the frequent presence of cytolysis.	C

TURB	GR
TURB should be performed systematically in individual steps: • bimanual palpation under anaesthesia; • insertion of the resectoscope, under visual control with inspection of the whole urethra; • inspection of the whole urothelial lining of the bladder; • biopsy from prostatic urethra (if indicated); • cold-cup bladder biopsies (if indicated); • resection of the tumour; • bimanual palpation after resection; • protocol formulation; • formulation of order form for pathological evaluation.	C
Perform resection in one piece for small papillary tumours (< 1 cm), including part from the underlying bladder wall.	B
Perform resection in fractions (including muscle tissue) for tumours > 1 cm in diameter.	B
Biopsies should be taken from abnormal-looking urothelium. Biopsies from normal-looking mucosa (trigone, bladder dome, and right, left, anterior and posterior bladder walls) are recommended only when cytology is positive or when exophytic tumour has a non-papillary appearance.	C
Biopsy of the prostatic urethra is recommended for cases of bladder neck tumour, when bladder CIS is present or suspected, when there is positive cytology without evidence of tumour in the bladder, or when abnormalities of the prostatic urethra are visible. If biopsy is not performed during the initial procedure, it should be completed at the time of the second resection.	C
Biopsy of the prostatic urethra should be taken from abnormal areas and from the precollicular area (between 5 and 7 o'clock position) using a resection loop. In primary non-muscle-invasive tumours when stromal invasion is not suspected, the cold-cup biopsy with forceps can be used.	C
If equipment is available, fluorescence-guided (PDD) biopsy should be performed instead of random biopsies when bladder CIS or high-grade tumour is suspected (e.g., positive cytology, recurrent tumour with previous history of a high-grade lesion)	B
The specimens from different biopsies and resection fractions must be referred	C

TURB	GR
to the pathologist in separate containers and labelled separately.	
TURB protocol must describe all steps of the procedure, as well as the extent and completeness of resection.	C
A second TURB is recommended in the following situations: • after incomplete initial TURB; • if there is no muscle in the specimen after initial resection, with exception of Ta G1 tumours and primary CIS; • in all T1 tumours; • in all G3 tumours, except primary CIS.	A
When done, a second TURB should be performed within 2-6 weeks after initial resection.	C

Classification and pathological report	GR
Depth of tumour invasion is classified according to the TNM system.	A
For histological classification, 1973 and 2004 WHO grading systems are used. Until the WHO 2004 is validated by more prospective trials and incorporated into prognostic models, both classifications should be used.	A
Whenever the terminology NMIBC is used in individual cases, the tumour stage and grade should be mentioned.	A
The pathological report should specify tumour location, tumour grade, depth of tumour invasion, presence of CIS, and whether the detrusor muscle is present in the specimen.	A
The pathological report should specify the presence of LVI or unusual histology	C

CIS = carcinoma in situ;
CT = computed tomography;
IVU = intravenous urography;
LVI = lymphovascular invasion;
PDD = photodynamic diagnosis;
US = ultrasound;
TURB = transurethral resection of the bladder

Prognostic Factors and Adjuvant Treatment

It is recommended to stratify patients according to prognostic factors into three risk groups that will facilitate treatment recommendations. Their definition, which takes into account the EORTC risk tables probabilities of recurrence and especially progression, can be found in Table 3. For individual prediction of the risk of tumour recurrence and progression at different intervals after TURB, application of EORTC risk tables and calculator (http://www.eortc.be/tools/bladdercalculator/) is strongly recommended.

Table 3: Treatment recommendations in Ta, T1 tumours and CIS according to risk stratification

Risk Category	**Definition**	**Treatment recommendation**
Low-risk Tumours	Primary, solitary, Ta, LG/ G1, < 3 cm, no CIS	One immediate instillation of Chemotherapy
Intermediate risk tumours	All cases between categories of low and high risk	One immediate instillation of Chemotherapy followed by further instillations, either chemotherapy for a maximum of 1 year or 1-year full dose BCG
High-risk Tumours	Any of the following: • T1 tumours; • HG/G3 tumours; • CIS; • Multiple and recurrent and large (> 3 cm) Ta G1G2 tumours (all these conditions must be presented)	Intravesical full dose BCG instillations for 1-3 years or cystectomy (in highest-risk tumours)
Subgroup of highest-risk tumours	T1G3 associated with concurrent bladder CIS, multiple and/or large T1G3 and/or recurrent T1G3, T1G3 with CIS in prostatic urethra, micropapillary variant of urothelial carcinoma, LVI	Radical cystectomy should be considered
	BCG failures	Radical cystectomy is recommended

CIS = carcinoma in situ; HG = high-grade; LG = low-grade; LVI = lymphovascular invasion

Since there is considerable risk for recurrence and/or progression of tumours after TURB, adjuvant intravesical therapy is recommended for all stages (Ta, T1, and CIS). Immediate postoperative

instillation of chemotherapy within 6 hours after TURB is recommended in tumours presumed to be at low or intermediate risk, except in cases of bladder perforation or severe bleeding. The choice of drug (mitomycin C, epirubicin, or doxorubicine) is optional. Intravesical chemotherapy reduces the risk of recurrence but not progression and is associated with minor side-effects. Intravesical immunotherapy with Bacillus Calmette-Guérin (BCG) (induction and maintenance) is superior to intravesical chemotherapy in reducing recurrences and in preventing or delaying progression to muscle-invasive bladder cancer. However, intravesical BCG is more toxic. The individual choice

of further intravesical adjuvant therapy depends on the patient's risk (Table 3). In patients at highest risk of progression (Table 3), radical cystectomy should be considered in patients with BCG failure since they are unlikely to respond to further BCG therapy; radical cystectomy is therefore the preferred option.

Recommendations for adjuvant therapy in Ta, T1 tumours and for therapy of CIS	GR
Smokers with confirmed NMIBC should be counselled to stop smoking.	B
The type of intravesical therapy should be based on risk groups.	A
One immediate chemotherapy instillation is recommended in tumours presumed to be at low or intermediate risk.	A
In patients with low-risk tumours, one immediate instillation of chemotherapy is recommended as the complete adjuvant treatment.	A
In patients with intermediate-risk Ta tumours, one immediate instillation of chemotherapy should be followed by 1-year full-dose BCG treatment, or by further instillation of chemotherapy for a maximum of 1 year.	A
In patients with high-risk tumours, full-dose intravesical BCG for 1-3 years is indicated.	A
In patients with CIS in the epithelial lining of the prostatic urethra, TUR of the prostate followed by intravesical instillation of BCG can be offered.	C
In patients at highest risk of tumour progression (Table 3), immediate radical cystectomy should be considered.	C
In patients with BCG failure, radical cystectomy is indicated.	B
In patients with BCG failure ineligible for radical cystectomy, gemcitabine or MMC in combination with hyperthermia are options.	C

Intravesical chemotherapy	GR
One immediate instillation should be administered within 24 hours after TURB.	C

One immediate instillation of chemotherapy should be omitted in any case of overt or suspected intra- or extra-peritoneal perforation (after extensive TURB, or bleeding requiring bladder irrigation).	C
The optimal schedule of further intravesical chemotherapy instillation and its duration is not defined and should not exceed 1 year.	C
If intravesical chemotherapy is given, it is advised to use the drug at its optimal pH and to maintain the concentration of the drug during instillation by reducing fluid intake.	B
The length of individual instillation should be 1-2 hours.	C

BCG intravesical immunotherapy	GR
Absolute contraindications of BCG intravesical instillation are: • during the first 2 weeks after TURB; • in patients with macroscopic haematuria; • after traumatic catheterization; • in patients with symptomatic urinary tract infection.	C
The management of side effects after BCG intravesical instillation should reflect their type and grade	C

BCG = bacillus Calmette-Guérin;
CIS = carcinoma in situ;
MMC = mitomycin C;
TUR = transurethral resection;
TURB =transurethral resection of the bladder

Follow-up for Non-Muscle Invasive Bladder Tumours

As a result of the risk of recurrence and progression, patients with Ta, T1 bladder tumours and with CIS need to be followed up. However, the frequency and duration of cystoscopy and imaging should reflect the individual patient's degree of risk.

When planning the follow-up schedule and methods, the following aspects should be considered:

- The prompt detection of muscle-invasive and HG/G3 nonmuscle-invasive recurrence is crucial because a delay in diagnosis and therapy can be life-threatening.

- Tumour recurrence in the low-risk group is nearly always low stage and LG/G1.

Small, non-invasive (Ta), LG/G1 papillary recurrence does not present an immediate danger to the patient, and early detection is not essential for successful therapy (LE: 2b).

Fulguration of small papillary recurrences on an outpatient basis could be a safe option that reduces the therapeutic burden.

- The first cystoscopy after TURB at 3 months is a very important prognostic indicator for recurrence and progression. The first cystoscopy should thus always be performed.

3 months after TURB in all patients with Ta, T1 tumours and CIS.

- In tumours at low risk, the risk of recurrence after 5 recurrence-free years is low.
- Discontinuation of cystoscopy or its replacement with less invasive methods can be considered.
- In tumours originally intermediate- or high-risk, recurrences after 10 years tumour-free are not unusual. Therefore, lifelong follow-up is recommended.
- The risk of upper urinary tract recurrence increases in patients with multiple and high-risk tumours.
- Positive urine test results have a positive impact on the quality of performed follow-up cystoscopy). It supports the adjunctive role of urine tests during follow-up.

The following recommendations are only based on retrospective experience.

Recommendations for follow-up	GR
The follow-up of Ta, T1 tumours and CIS is based on regular cystoscopy.	A
Patients with low-risk tumours should undergo cystoscopy at 3 months. If negative, subsequent cystoscopy is advised 9 months later, and then yearly for 5 years.	C
Patients with high-risk tumours should undergo cystoscopy and urinary cytology at 3 months. If negative, subsequent cystoscopy and cytology should be repeated every 3 months for a period of 2 years, and every 6 months thereafter until 5 years, and then yearly	C
Patients with intermediate-risk Ta tumours should have an in-between follow-up scheme using cystoscopy and cytology, which is adapted according to personal and subjective factors.	C
Regular (yearly) upper tract imaging (CT-IVU or IVU) is recommended for high-risk tumours.	C
Endoscopy under anaesthesia and bladder biopsies should be performed when office cystoscopy shows suspicious findings or if urinary cytology is	B

Recommendations for follow-up	GR
positive	
During follow-up in patients with positive cytology and no visible tumour in the bladder, R-biopsies or biopsies with PDD (if equipment is available) and investigation of extravesical locations (CT urography, prostatic urethra biopsy) are recommended.	B

CIS = carcinoma in situ;
CT-IVU = computed tomography intravenous urography;
IVU = intravenous urography;
PDD = photodynamic diagnosis;
R-biopsies = random biopsies.

Bladder Cancer – Muscle invasive and metastatic

DIAGNOSIS AND STAGING

Primary diagnosis

Symptoms: Painless haematuria is the most common presenting complaint. Others include urgency, dysuria, increased frequency, and in more advanced tumours, pelvic pain and symptoms related to urinary tract obstruction.

Physical examination: including rectal and vaginal bimanual palpation. A palpable pelvic mass can be found in patients with locally advanced tumours. In addition, bimanual examination under anaesthesia should be carried out before and after TURB, to assess whether there is a palpable mass or if the tumour is fixed to the pelvic wall. However, considering the discrepancy between bimanual examination and pT stage after cystectomy (11% clinical overstaging and 31% clinical understaging), some caution is suggested with the interpretation of bimanual examination.

Endoscopic bladder imaging: Ultimately, the diagnosis of bladder cancer is made by cystoscopy and histological evaluation of resected tissue. In general, cystoscopy is initially performed in the office using flexible instruments. If a bladder tumour has been visualised unequivocally in earlier imaging studies, such as computed tomography (CT), magnetic resonance imaging (MRI), or ultrasound (US), diagnostic cystoscopy may be omitted and the patient can proceed directly to TURB for histological diagnosis. A careful description of the cystoscopic findings is necessary. This should include documentation of the site, size, number, and appearance (papillary or solid) of the tumours, as well as a description of mucosal abnormalities. Use of a bladder diagram is recommended. The use of photodynamic diagnosis could be considered, especially if a T1 high-grade tumour is present, to find associated CIS. The additional presence of CIS may lead to a modified treatment

plan. Photodynamic diagnosis is highly sensitive for the detection of CIS; with experience, the rate of false-positive results may be similar to that with regular white-light cystoscopy.

Urinary cytology and urinary markers: Examination of voided urine or bladder washings for exfoliated cancer cells has high sensitivity in high-grade tumours (LE: 3) and is a useful indicator in cases of high-grade malignancy or CIS. Positive urinary cytology may originate from a urothelial tumour located anywhere in the urinary tract. Evaluation of cytology specimens can be hampered by low cellular yield, UTIs, stones or intravesical instillations, but for experienced readers, specificity exceeds 90% (LE: 2b). However, negative cytology does not exclude tumour. Cytology should be performed on fresh urine with adequate fixation. Early morning urine is not suitable as cytolysis may often be present. There is no known urinary marker specific for the diagnosis of invasive bladder cancer.

Random bladder and prostatic urethral biopsy: Bladder tumours are often multifocal and can be accompanied by CIS or dysplasia. These lesions may present themselves as velvet-like, reddish areas, indistinguishable from inflammation, or may not be visible at all. The biopsies from normal-looking mucosa in patients with invasive bladder tumours, so-called random biopsies (R-biopsies) show a low yield. Fluorescence cystoscopy is performed using filtered blue light after intravesical instillation of a photosensitiser, such as 5-aminolevulinic acid (5-ALA), and more recently, hexaminolaevulinate (HAL), following approval by the European Medicines Agency. It has been confirmed that fluorescence-guided biopsy and resection are more sensitive than conventional procedures in detecting malignant tumours, particularly CIS (9-12) (LE: 2a). However, false-positive results may be induced by inflammation, or recent TURB or intravesical instillation therapy. A recent multicentre, prospective, international trial showed that, in experienced hands, the rate of false-positive results is no higher than that seen for regular, white-light cystoscopy (7). Material obtained by random or directed biopsies must be sent for pathological assessment in separate containers. The involvement of the prostatic urethra and ducts in men with bladder tumours has been reported. The exact risk is not known, but it seems to be higher if the tumour is located on the trigone or bladder neck, in the presence of bladder CIS, and in multiple tumours (LE: 3). Involvement of the prostatic urethra can be determined either at the time of primary TURB or by frozen section during the cystoprostatectomy procedure. A frozen section has a higher negative predictive value and is more accurate.

Second resection: In the case of high-grade non-muscle-infiltrative tumour, residual disease is observed in 33-53% of patients (18-24). In order to reduce the risk of understaging, a second TURB resection is often required to determine the future treatment strategy. In consultation with the patient, orthotopic neobladder should be considered in case reconstructive surgery does not expose the patient to excessive risk (as determined by comorbidity and age). Age greater than 80 years is often

considered to be the threshold after which neobladder reconstruction is not recommended, however, there is no exact age for strict contraindication. In most large series coming from experienced centres, the rate of orthotopic bladder substitution after cystectomy for bladder tumour is up to 80% for men and 50% for women. Nevertheless, no randomized controlled studies comparing conduit diversion with neobladder or continent cutaneous diversion have been performed. Diagnosis of urethral tumour before cystectomy or positive urethral frozen section leads to uretrectomy and therefore excludes neobladder reconstruction. If indicated, in males urethral frozen section has to be performed on the cysto-prostatectomy specimen just under the verumontanum and on the inferior limits of the bladder neck for females. When there are positive lymph nodes, orthotopic neobladder can nevertheless be considered in case of N1 involvement (metastasis in a single node in the true pelvis) but not for N2 or N3 tumours. Oncological results after orthotopic neobladder substitution or conduit diversion are similar in terms of local or distant metastasis recurrence, but secondary urethral tumours seem less common in patients with neobladder compared with those with conduits or continent cutaneous diversions.

Imaging for staging MIBC: The treatment and prognosis for MIBC is determined by tumour stage and grade. In clinical practice, CT and MRI are the imaging techniques used. The purpose of using imaging for staging MIBC is to determine prognosis and provide information to assist treatment selection. Tumour staging must be accurate to ensure the correct choice of treatment is made. Imaging parameters required for staging MIBC are:

- extent of local tumour invasion;
- tumour spread to lymph nodes;
- tumour spread to the upper urinary tract and other distant organs (e.g., liver, lungs, bones, peritoneum, pleura, and adrenal glands).

CT imaging for local staging of MIBC: The advantages of CT include high spatial resolution, shorter acquisition time, wider coverage in a single breath hold, and lower susceptibility to variable patient factors. Computed tomography is unable to differentiate between stages Ta and T3a tumours, but it is useful for detecting invasion into the perivesical fat (T3b) and adjacent organs. The accuracy of CT in determining extravesical tumour extension varies from 55% to 92% and increases with more advanced disease.

MRI for local staging of invasive bladder cancer: Magnetic resonance imaging has superior soft tissue contrast resolution compared with CT, but poorer spatial

resolution. In studies performed before the availability of multidetector CT, MRI was reported as more accurate in local assessment. The accuracy of MRI for primary tumour staging varies from 73% to 96% (mean 85%). These values were 10-33% (mean 19%) higher than those obtained with CT. Dynamic contrast-enhanced (DCE) MRI may help to differentiate bladder tumour from surrounding tissues or post-biopsy reaction, because enhancement of the tumour occurs earlier than that of the normal bladder wall, due to neovascularisation. In 2006, a link was established between the use of gadolinium-based contrast agents and nephrogenic systemic fibrosis (NSF), which may result in fatal or severely debilitating systemic fibrosis. Patients with impaired renal function are at risk of developing NSF and the non-ionic linear gadolinium-based contrast agents should be avoided (gadodiamide, gadopentetate dimeglumine and gadoversetamide). A stable macrocyclic contrast agent should be used (gadobutrol, gadoterate meglumine or gadoteridol). Alternatively, contrast-enhanced CT could be performed using iodinated contrast media (LE: 4).

TREATMENT

Recommendations for treatment failure of non-muscle-invasive bladder cancer

Recommendations	GR
In all T1 tumours at high risk of progression (i.e., high grade, multifocality, CIS, and tumour size, as outlined in the EAU guidelines for non-muscle-invasive bladder cancer [7]), immediate radical treatment is an option	**C**
In all T1 patients failing intravesical therapy, radical treatment should be offered.	**B**

CIS = carcinoma in situ

NEOADJUVANT CHEMOTHERAPY

Advantages and disadvantages:

- Chemotherapy is delivered at the earliest time-point, when the burden of micrometastatic disease is expected to be low.
- Potential reflection of in vivo chemosensitivity.
- Tolerability of chemotherapy and patient compliance are expected to be better before rather than after cystectomy.
- Patients might respond to neoadjuvant therapy and reveal a favourable pathological status, determined mainly by achieving pT0, a negative lymph node status, and negative surgical margins.

- Delayed cystectomy might compromise the outcome in patients not sensitive to chemotherapy (8,9), although published studies on the negative effect of delayed cystectomy only entail series of chemonaive patients. There are no trials or large patient series indicating that delayed surgery, due to neoadjuvant chemotherapy, has a negative impact on survival.

Conclusions	**LE**
Neoadjuvant cisplatin-containing combination chemotherapy improves overall survival (5-8% at 5 years).	1a
Neoadjuvant treatment of responders and especially patients who show complete response (pT0 N0) has a major impact on OS.	2
Currently, no tools are available to select patients who have a higher probability to benefit from neoadjuvant chemotherapy. In the future, genetic markers, in a personalised medicine setting, might facilitate the selection of patients for neoadjuvant chemotherapy and to differentiate responders from non-responders.	

Recommendations	**GR**
Neoadjuvant chemotherapy is recommended for T2-T4a, cN0M0 bladder cancer and should always be cisplatin-based combination therapy.	A
Neoadjuvant chemotherapy is not recommended in patients who are ineligible for cisplatin-based combination chemotherapy.	A

RADICAL SURGERY AND URINARY DIVERSION

Radical cystectomy is the standard treatment for localised MIBC in most western countries. Recent interest in patients' quality of life (QoL) has increased the trend toward bladder preservation treatment modalities, such as radio- and/or chemotherapy. Performance status (PS) and age influence the choice of primary therapy, as well as the type of urinary diversion, with cystectomy being reserved for younger patients without concomitant disease and with a better PS. The value of assessing overall health before recommending and proceeding with surgery was emphasised in a multivariate analysis. The analysis found an association between comorbidity and adverse pathological and survival outcome following radical cystectomy. PS and comorbidity have a different impact on treatment outcome and must be evaluated independently. Controversy remains about age, radical cystectomy and the type of urinary diversion. Cystectomy is associated with the greatest risk reduction in disease-related and non-disease-related death in patients aged > 80 years. The largest, retrospective, single-institution study on cystectomy to date found that patients aged > 80 years had increased postoperative morbidity but

not increased mortality. Although some patients successfully underwent a neobladder procedure, most patients were treated with an ileal conduit diversion. It is particularly important to evaluate the function and QoL of elderly patients using a standardised geriatric assessment, as well as carrying out a standard medical evaluation.

Each network should agree clear guidelines on treatment and follow up of bladder cancer which ensure that cystectomy is considered for patients with muscle-invasive or high-risk recurrent disease. Cystectomy is a complex operation which should be undertaken only by specialist surgeons working in cancer centres. Ideally, all radical cystectomies undertaken in each network should be carried out by a single team. Teams providing this form of surgery should carry out a cumulative total of at least 50 radical operations (cystectomies or radical prostatectomies) for bladder or prostate cancer per year.

Timing and delay of cystectomy:

Patients treated > 90 days after the primary diagnosis showed a significant increase in extravesical disease (81 vs 52%). Delay in cystectomy affects treatment outcome and the type of urinary diversion. In organ-confined urothelial cancer of the bladder, the average time from primary diagnosis to cystectomy was 12.2 months in patients who received a neobladder and 19.1 months in those who received an ileal conduit. This was even more noticeable with organ-confined invasive cancer; the average time to surgery was 3.1 months with a neobladder and 15.1 months with an ileal conduit (8). Similar results have been observed in a series of 247 patients: recurrence-free survival and OS were significantly better in patients treated before 90 days compared to others treated after 90 days.

LN removal at the time of cystectomy:

The extent of LND has not been established to date. Standard lymphadenectomy in bladder cancer patients involves removal of nodal tissue cranially up to the common iliac bifurcation, with the ureter being the medial border, and including the internal iliac, presacral, obturator fossa and external iliac nodes (10). Extended lymphadenectomy includes all lymph nodes in the region of the aortic bifurcation, and presacral and common iliac vessels medial to the crossing ureters. The lateral borders are the genitofemoral nerves, caudally the circumflex iliac vein, the lacunar ligament and the lymph node of Cloquet, as well as the area described for standard lymphadenectomy. A super-extended lymphadenectomy extends cranially to the level of the inferior mesenteric artery.

Morbidity and mortality from cystectomy:

The perioperative mortality was reported as 1.2-3% at 30 days and 2.3-5.7% at 90 days. In a large single-centre series, early complications (within 3 months of surgery) were seen in 58% of patients. Late morbidity is usually due to the type of urinary diversion. Early morbidity associated with radical cystectomy for NMIBC (at high risk for disease progression) is similar and no less than that associated with muscle-invasive tumours. In general, lower morbidity and (perioperative) mortality have been observed by surgeons and in hospitals with a higher caseload and therefore more experience.

Survival:

According to a multi-institutional database of 888 consecutive patients undergoing radical cystectomy for bladder cancer, the 5-year recurrence-free survival was 58% and the cancer-specific survival was 66%. Recent external validation of postoperative nomograms for bladder-cancer-specific mortality showed similar results, with 5-year OS of 45% and cancer-specific survival of 62%. Recurrence-free survival and OS in a large single-centre study of 1,054 patients was 68% and 66% at 5 years and 60% and 43%, at 10 years, respectively. The 5-year recurrence-free survival in node-positive patients who underwent cystectomy was considerably less at 34-43%. However, in patients with a low level of lymph node metastasis, the survival is better. In a surgery only study, the 5-year recurrence-free survival was 76% in patients with pT1 tumours, 74% for pT2, 52% for pT3, and 36% for pT4. Another study reported 10-year disease-specific survival and OS rates of 72.9% versus 49.1% for organ-confined disease (defined as pT < 3a), and 33.3% versus 22.8% for non-organconfined disease. A trend analysis according to the 5-year survival and mortality rates of bladder cancer in the United States, between 1973 and 2009 with a total of 148,315 bladder cancer patients, revealed an increased stage-specific 5-year survival rate for all stages, except for metastatic disease. However, no changes in mortality were recorded among localized and regional stage. In patients with visceral metastases an increase in mortality rates was observed, but differences were minor, and hardly of any clinical importance.

Recommendations:

Recommendations	**GR**
Radical cystectomy is recommended in T2-T4a, N0 M0, and high-risk non-MIBC (as outlined above).	A
Do not delay cystectomy for > 3 months because it increases the risk of progression and cancerspecific mortality.	B
Preoperative radiotherapy is not recommended in subsequent cystectomy with urinary diversion.	A
Lymph node dissection should be an integral part of cystectomy. Extended	B

Recommendations	GR
LND is recommended.	
The urethra can be preserved if margins are negative. If no bladder substitution is attached, the urethra must be checked regularly.	B
Laparoscopic cystectomy and robot-assisted laparoscopic cystectomy are both management options. However, current data have not sufficiently proven the advantages or disadvantages for oncological and functional outcomes.	C
Before cystectomy, the patient should be fully informed about the benefits and potential risks of all possible alternatives, and the final decision should be based on a balanced discussion between patient and surgeon.	B
Pre-operative bowel preparation is not mandatory. “Fast track” measurements may reduce the time of bowel recovery.	C
An orthotopic bladder substitute should be offered to male and female patients lacking any contraindications and who have no tumour in the urethra or at the level of urethral dissection.	B

NON-RESECTABLE TUMOURS

Recommendations	LE	GR
In patients with inoperable locally advanced tumours (T4b), primary radical cystectomy is a palliative option and cannot be offered as curative treatment.		B
In patients with symptoms palliative cystectomy may be offered. Prior to any further interventions, surgery-related morbidity and quality of life should be fully discussed with the patient.	3	B

BLADDER-SPARING TREATMENTS FOR LOCALIZED DISEASE

Transurethral resection of bladder tumour (TURBT)

Recommendation	LE	GR
Transurethral resection of bladder tumour (TURB) alone is not a curative treatment option in most patients.	2a	B

External beam radiotherapy (EBRT)

Based on available trials, a Cochrane analysis has demonstrated that radical cystectomy has an overall survival benefit compared to radiotherapy. However, external radiotherapy is an alternative treatment in patients unfit for radical surgery. The target dose for curative radiotherapy for bladder cancer is 60-66 Gy, with a

subsequent boost using external radiotherapy or interstitial brachytherapy. The daily dose is usually 1.8-2 Gy and the course of radiotherapy should not extend beyond 6-7 weeks to minimize the repopulation of cancer cells. The use of modern standard radiotherapy techniques results in major, related, late morbidity of the urinary bladder or bowel in less than 5% of tumour-free patients. Overall, 5-year survival rates in patients with MIBC range between 30% and 60%, depending on whether they show a complete response (CR) following radiotherapy. Cancer-specific survival rates are between 20% and 50%.

Conclusions:

Conclusions	**LE**
External beam radiotherapy alone should only be considered as a therapeutic option when the patient is unfit for cystectomy or a multimodality bladder-preserving approach.	3
Radiotherapy can also be used to stop bleeding from the tumour when local control cannot be achieved by transurethral manipulation because of extensive local tumour growth.	3

Recommendation:

Recommendation	**GR**
Surgical intervention or multimodality treatment are the preferred curative therapeutic approaches because they are more effective than radiotherapy alone.	B

Chemotherapy

Chemotherapy alone rarely produces durable CRs. In general, a clinical CR rate of up to 56%, as reported in some series, must be weighed against a staging error of > 60%. Response to chemotherapy is a prognostic factor for treatment outcome and eventual survival, though it may be confounded by patient selection. For very selected patients, a bladder-conserving strategy with TURB and systemic cisplatin-based chemotherapy, preferably with MVAC, may allow long-term survival with intact bladder. However, this approach cannot be recommended for routine use.

Conclusion:

Conclusion	**LE**
With cisplatin-based chemotherapy as primary therapy for locally advanced	2b

tumours in highly selected patients, complete and partial local responses have been reported.	
Recommendation	**GR**
Chemotherapy alone is not recommended as primary therapy for localized bladder cancer.	A

Multimodality bladder-preserving treatment

Recent organ-preservation strategies combine TURB, chemotherapy and radiation (1,2). The rationale for performing TURB and radiation is to achieve local tumour control. Application of systemic chemotherapy, most commonly as methotrexate, cisplatin and vinblastine (MCV), aims at the eradication of micrometastasis. Many protocols use cisplatin and/or 5-FU and, recently, gemcitabine with radiation, because of their established role as radiosensitizers. Cisplatin-based chemotherapy in combination with radiotherapy, following TURB, results in a CR of 60-80%.

Conclusions:

Conclusions	**LE**
In a highly selected patient population, long-term survival rates of multimodality treatment are comparable to those of early cystectomy.	3
Delay in surgical therapy can compromise survival rates.	2b

Recommendations	**GR**
Transurethral resection of bladder tumour alone cannot be offered as a standard curative treatment option in most patients.	B
Radiotherapy alone is less effective than surgery and is only recommended as a therapeutic option when the patient is unfit for cystectomy or a multimodality bladder-preserving approach.	B
Chemotherapy alone is not recommended as primary therapy for MIBC.	A
Surgical intervention or multimodality treatments are the preferred curative therapeutic approaches as they are more effective than radiotherapy alone.	B
Multimodality treatment could be offered as an alternative in selected, well-informed, well-selected and compliant patients, especially for whom cystectomy is not an option.	B

ADJUVANT CHEMOTHERAPY

Adjuvant chemotherapy after radical cystectomy for patients with pT3/4 and/or lymph node positive (N+) disease without clinically detectable metastases (M0) is under debate and still infrequently used.

The general benefits of adjuvant chemotherapy include:

- Chemotherapy is administered after accurate pathological staging, therefore treatment in patients at low risk for micrometastases is avoided.
- No delay in definitive surgical treatment.

The drawbacks of adjuvant chemotherapy are:

- Assessment of in vivo chemosensitivity of the tumour is not possible and overtreatment is an unavoidable problem.
- Delay or intolerability of chemotherapy, due to postoperative morbidity.

Conclusions:

Conclusion	**LE**
Neither randomised trials nor two meta-analyses have provided sufficient data to support the routine use of adjuvant chemotherapy.	1a
Recommendations	GR
Adjuvant chemotherapy should only be given within clinical trials, whenever possible.	A
Adjuvant cisplatin based combination chemotherapy may be offered to patients with pN+ disease if no neoadjuvant chemotherapy has been given.	C

METASTATIC DISEASE

Conclusions	LE
In a first-line setting, PS and the presence or absence of visceral metastases are independent prognostic factors for survival.	1b
In a second-line setting, negative prognostic factors are: liver metastasis, PS > 1 and low haemoglobin (< 10 g/dL) 1b Cisplatin-containing combination chemotherapy can achieve median survival of up to 14 months, with long-term disease-free survival reported in ~15% of patients with nodal disease and good PS.	1b
Single-agent chemotherapy provides low response rates of usually short duration.	2a
Carboplatin combination chemotherapy is less effective than cisplatin-based	2a

Conclusions	LE
chemotherapy in terms of complete response and survival.	
Non-platinum combination chemotherapy produces substantial responses in first- and second-line settings, but has not been tested against standard chemotherapy in patients who are fit or unfit for cisplatin combination chemotherapy.	2a
There is no defined standard chemotherapy for unfit patients with advanced or metastatic urothelial cancer.	2b
Vinflunine reaches the highest level of evidence ever reported for second-line use.	1b
Post-chemotherapy surgery after partial or complete response may contribute to long-term diseasefree survival.	3
Zoledronic acid and denosumab have been approved for all cancer types including urothelial cancer, because they reduce and delay skeletal related events in metastatic bone disease.	1b

Recommendations	GR
First-line treatment for fit patients: Use cisplatin-containing combination chemotherapy with GC, PCG, MVAC, preferably with G-CSF, or HD-MVAC with G-CSF.	A
Carboplatin and non-platinum combination chemotherapy is not recommended.	B
First-line treatment in patients ineligible (unfit) for cisplatin: Use carboplatin combination chemotherapy or single agents.	C
For cisplatin-ineligible (unfit) patients, with PS2 or impaired renal function, as well as those with 0 or 1 poor Bajorin prognostic factors and impaired renal function, treatment with carboplatin-containing combination chemotherapy, preferably with gemcitabine/carboplatin is indicated.	A
Second-line treatment: In patients progressing after platinum-based combination chemotherapy for metastatic disease, vinflunine should be offered. Alternatively, treatment within a clinical trial setting may be offered.	A
Zoledronic acid or denosumab is recommended for treatment of bone metastases.	B

9.2 Prostate cancer

Epidemiology

Prostate cancer is the most common cancer in elderly males in Europe. It is a major health concern, especially in developed countries with their greater proportion of elderly men in the general population. The incidence is highest in Northern and Western Europe (> 200 per 100,000), while rates in Eastern and Southern Europe have showed a continuous increase. There is still a survival difference between men diagnosed in Eastern Europe and those in the rest of Europe. Overall, during the last decade, the 5-year relative survival percentages for prostate cancer steadily increased from 73.4% in 1999-2001 to 83.4% in 2005-2007.

There are three well-established risk factors for PCa:

- increasing age;
- ethnic origin;
- heredity

Genetics:

- If one first-line relative has PCa, the risk is at least doubled. If two or more first-line relatives are affected, the risk increases by 5-11-fold.
- A small subpopulation of individuals with PCa (about 9%) have true hereditary PCa. This is defined as three or more affected relatives, or at least two relatives who have developed early onset disease, i.e. before age 55.
- Patients with hereditary PCa usually have an onset six to seven years earlier than spontaneous cases, but do not differ in other ways.

Geography:

- The frequency of autopsy-detected cancers is roughly the same in different parts of the world.
- This finding is in sharp contrast to the incidence of clinical PCa, which differs widely between different geographical areas, being high in the USA and northern Europe and low in South-East Asia.
- However, if Japanese men move from Japan to Hawaii, their risk of PCa increases. If they move to California their risk increases even more, approaching that of American men.

Metabolic syndrome and prostate cancer:

- Metabolic syndrome is weakly and non-significantly associated with the risk of PCa, but associations vary with geography.
- Among single components of the syndrome (body mass index, dysglycaemia or dyslipidaemia, high triglycerides, low HDL cholesterol) only hypertension and waist circumference >102 cm were associated with a significantly greater risk of PCa, increasing it by 15% (p = 0.035) and 56% (p = 0.007), respectively.

Chemoprevention in prostate cancer:

- Currently, there are no data to suggest that medical intervention would effectively reduce progression of PCa.
- Several 5-alpha-reductase inhibitors (5-ARIs) have been studied to assess their effect on reducing risk of developing PCa. Although it seems that 5-ARIs have a potential benefit in preventing or delaying the development of PCa (~25%, only of Gleason 6 cancer), this must be weighed against treatment-related sideeffects as well as the potential increased risk of high-grade PCa. None of the available 5-ARIs have been approved for this indication.

SCREENING FOR PROSTATE CANCER:

Prostate cancer screening is one of the most controversial topics in urological literature. The main summary of findings from literature published on PCa screening is the Cochrane review published in 2013. Its findings are as follows:

- Screening was associated with an increased diagnosis of PCa (RR: 1.3; 95% CI: 1.02-1.65).

- Screening was associated with more localized disease (RR: 1.79; 95% CI: 1.19-2.70) and less advanced PCa (T3-4, N1, M1) (RR: 0.80; 95% CI: 0.73-0.87).

- From the results of five RCTs, representing more than 341,000 randomized men, no PCa-specific survival benefit was observed (RR: 1.00; 95% CI: 0.86-1.17). This was the main objective of all the large trials.

- From the results of four available RCTs, no overall survival benefit was observed (RR: 1.00; 95% CI: 0.96-1.03).

ERSPC: at 11 years of median follow-up, there was a 21% reduction in PCa-specific mortality and a 29% reduction after adjustment for non-compliance. However, there is still no overall survival benefit.

Thus, an individualized risk-adapted strategy for early detection might be offered to a well-informed man with a least 10-15 years of individual life expectancy. Men who have less than a 15-year life expectancy are unlikely to benefit based on the PIVOT and the ERSPC trials. Screening is associated with minor and major harms such as overdiagnosis and overtreatment.

Recommendations:

Recommendations	**LE**	**GR**
An individualized risk-adapted strategy for early detection might be offered to a well-informed man with a good performance status and at least 10-15 years of life expectancy.	3	B
Early PSA testing in men at elevated risk of having PCa: • men over 50 years of age • men over 45 years of age and a family history of PCa • African-Americans • men with a PSA level of > 1 ng/mL at 40 years of age • men with a PSA level of > 2 ng/mL at 60 years of age	2b	A
A risk-adapted strategy might be considered (based on initial PSA level), which may be every 2 years for those initially at risk, or postponed up to 8 years in those not at risk. 3 C The age at which early diagnosis of PCa should be stopped is influenced by life expectancy and performance status; men who have < 15-year life expectancy are unlikely to benefit based on the PIVOT and the ERSPC trials.	3	A

DIAGNOSIS:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

Digital rectal examination:

- Most prostate cancers are located in the peripheral zone of the prostate and may be detected by DRE when the volume is about 0.2 mL or larger.
- In about 18% of all patients, PCa is detected by a suspect DRE alone, irrespective of the PSA level.
- A suspect DRE in patients with a PSA level up to 2 ng/mL has a positive predictive value of 5-30%.
- An abnormal DRE is associated with an increased risk of a higher Gleason score and should therefore be considered an indication for prostate biopsy.

Prostate-specific antigen (PSA):

PSA is a kallikrein-like serine protease produced almost exclusively by the epithelial cells of the prostate, which is organ- but not cancer specific. Thus, serum levels may be elevated in the presence of benign prostatic hypertrophy (BPH), prostatitis and other non-malignant conditions. The level of PSA as an independent variable is a better predictor of cancer than suspicious findings on DRE or transrectal ultrasound (TRUS).

PSA and the risk of prostate cancer:

PSA level (ng/mL)	Risk of PCa (%)	Risk of Gleason > 7 PCa (%)
0.0-0.5	6.6	0.8
0.6-1.0	10.1	1.0
1.1-2.0	17.0	2.0
2.1-3.0	23.9	4.6
3.1-4.0	26.9	6.7

Practical modifications of serum PSA value that may improve the specificity of PSA in the early detection of PCa have been described. They include:

- PSA density;
- PSA velocity; defined as the absolute annual increase in serum PSA (ng/mL/year).
- PSA doubling time: the exponential increase in serum PSA over time, reflecting a relative change.
- age-specific reference ranges;
- The free/total PSA ratio: between 4 ng/mL and 10 ng/mL and a negative DRE, PCa was found on biopsy in 56% of men with f/t PSA < 0.10, but in only 8% of men with f/t PSA > 0.25.

PCA3: is an increasingly studied new biomarker that is detectable in urine sediments obtained after three strokes of prostatic massage during DRE. The costly Progensa urine test for PCA3 is now commercially available. The amount of the prostate-specific non-coding mRNA marker PCA3 normalized against PSA mRNA (urine sediment) gives a PCA3 score. This is superior to total PSA and percent-free PSA in the detection of PCa in men with elevated PSA levels as it shows slight but significant increases in the area under the receiveroperator characteristics curve (AUC) for positive biopsies. The main current indication for the PCA3 urine test may be to determine whether a man needs a repeat biopsy after an initially negative biopsy outcome, but its cost-effectiveness remains to be shown.

Prostate biopsy:

- Indications: PSA level and/or a suspicious DRE.
- The first elevated PSA level should not prompt an immediate biopsy.
- The PSA level should be verified after a few weeks by the same assay under standardized conditions (i.e. no ejaculation, no manipulations such as catheterisation, cystoscopy or transurethral resection, and no urinary tract infections) in the same diagnostic laboratory, using the same methods.
- It is now considered the standard of care to perform prostate biopsies guided by ultrasound.

Types of prostatic biopsy:

- Transrectal approach is used for most prostate biopsies, with ultrasound-guided periprostatic block as state-of-the-art. The British Prostate Testing for Cancer and Treatment (PROTECT) Study recommended 10 core biopsies, with > 12 cores being not significantly more conclusive.
- Transperineal approach is another alternative used by some urologists, with less incidence of biopsy related sepsis, but requires sedation or general anaesthetic (GA). There are two types:
  - Template biopsy requiring 24-30 cores using the brachytherapy grid and is performed under GA, with higher tumour detection rate (38%), but with a higher incidence of acute urinary retention (AUR) (up to 10%).
  - Targeted biopsy, which requires less cores and is more tolerated and less incidence of AUR.

- Diagnostic transurethral resection of the prostate: is a poor tool for cancer detection.

- Transition zone sampling during baseline biopsies gives a very low detection rate and should therefore be confined to repeat biopsies.

- Indications for a repeat biopsy are:
  - rising and/or persistently elevated PSA;
  - suspicious DRE, 5-30% risk of cancer;
  - atypical small acinar proliferation (ASAP), 40% risk of cancer;
  - extensive (multiple biopsy sites) prostatic intra-epithelial neoplasia (PIN), 20-30% risk of cancer.
  - **Consider multiparametric MRI (using T2- and diffusion-weighted imaging) for men with a negative transrectal ultrasound 10–12 core biopsy to determine whether another biopsy is needed.**
  - **Do not offer another biopsy if the multiparametric MRI (using T2- and diffusion-weighted imaging) is negative, unless any of the risk factors above is present.**

- An isolated high-grade PIN as finding is no longer considered an indication for repeat biopsy.

- Antibiotics prior to biopsy: Oral or intravenous antibiotics are state-of-the-art treatment. Optimal dosing and treatment time vary. Quinolones are the drugs of choice, with ciprofloxacin being superior to ofloxacin, but increased resistance to quinolones associated with a rise in severe infectious complications after biopsy has been reported in the past few years.

- Percentage of complications per biopsy session, irrespective of the number of cores:

Complications	**Percentage of biopsies affected**
Haematospermia	37.4
Haematuria > 1 day	14.5
Rectal bleeding< 2 days	2.2
Prostatitis	1.0
Fever > 38.5°C (101.3°F)	0.8
Epididymitis	0.7
Rectal bleeding > 2 days ± requiring surgical intervention	0.7
Urinary retention	0.2
Other complications requiring hospitalisation	0.3

The role of imaging

- **TRUS:** Grey-scale TRUS is not adequately reliable at detecting areas of PCa. It is therefore used as a guide to direct systematic biopsies of the prostate gland.

- **Multiparametric MRI:**
  - has excellent sensitivity for detecting aggressive Gleason > 7 cancers
  - mMRI is particularly good at accurately detecting anterior tumours that are usually missed by systematic biopsy and therefore trigger a (targeted) repeat biopsy.
  - cost-effectiveness of mMRI as a triage test before the first biopsy has not been assessed.
  - Inter-reader variability is also a current concern, especially outside reference centres.

Recommendations for the diagnosis of prostate cancer:

Recommendations	LE	GR
Prostate cancer should be graded according to the ISUP 2005 modified Gleason grading system. 2a A The decision to biopsy should be based on PSA testing and DRE.	2b	A
For initial diagnosis, a core biopsy of 10-12 systematic transrectal or transperineal peripheral zone biopsies should be performed under ultrasound imaging guidance.	2a	B
Transrectal prostate needle biopsies should be taken under antibiotic protection.	1b	A
Local anaesthetic by periprostatic infiltration is recommended for prostate needle biopsies.	1a	A
Prostate core biopsies from different prostatic sites should be submitted separately for processing and pathology reporting.	3	A
Processing and reporting of prostatectomy specimens by pathology should follow the guidelines provided by the 2010 ISUP consensus meeting.	3	A

STAGING FOR PROSTATE CANCER

T - Primary tumour	
TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
T1	Clinically inapparent tumour not palpable or visible by imaging
T1a	Tumour incidental histological finding in 5% or less of tissue resected
T1b	Tumour incidental histological finding in more than 5% of tissue resected

T1c Tumour identified by needle biopsy (e.g. because of elevated PSA level) T2 Tumour confined within the prostate T2a Tumour involves one half of one lobe or less T2b Tumour involves more than half of one lobe, but not both lobes T2c Tumour involves both lobes T3 Tumour extends through the prostatic capsule T3a Extracapsular extension (unilateral or bilateral) including microscopic bladder neck involvement T3b Tumour invades seminal vesicle(s) T4 Tumour is fixed or invades adjacent structures other than seminal vesicles: external sphincter, rectum, levator muscles, and/or pelvic wall
N - Regional lymph nodes
NX Regional lymph nodes cannot be assessed N0 No regional lymph node metastasis N1 Regional lymph node metastasis
M - Distant metastasis
MX Distant metastasis cannot be assessed M0 No distant metastasis M1 Distant metastasis M1a Non-regional lymph node(s) M1b Bone(s) M1c Other site(s)

- Provisional treatment intent should be determined (radical or non-radical) before decisions on imaging are made.
- Imaging should not be routinely offered to men who are not candidates for curative intent.
- Isotope bone scans should be offered when hormonal therapy is being deferred through watchful waiting to asymptomatic men who are at high risk of developing bone complications.
- Multiparametric MRI (or CT if MRI is contraindicated) should be offered for men with histologically proven prostate cancer if knowledge of the T or N stage could affect management.
- Urological cancer MDTs should assign a risk category (below) to all newly diagnosed men with localised prostate cancer.

Risk stratification for men with localised prostate cancer

Level of risk	PSA		Gleason score		Clinical stage
Low risk	<10 ng/ml	and	≤6	and	T1–T2a
Intermediate risk	10–20 ng/ml	or	7	or	T2b
High risk[1]	>20 ng/ml	or	8–10	or	≥T2c

[1] High-risk localised prostate cancer is also included in the definition of locally advanced prostate cancer.

- CT of the pelvis should not be offered to men with low- or intermediate-risk localised prostate cancer (see table 1).
- Isotope bone scans should not be routinely offered to men with low-risk localised prostate cancer.
- Positron emission tomography imaging should not be offered for prostate cancer in routine clinical practice.

TREATMENT:

LOCALIZED PROSTATE CANCER (stage T1-T2c, Nx-N0, M0):

DEFERRED TREATMENT (ACTIVE SURVEILLANCE/ WATCHFUL WAITING):

Definitions:

Active surveillance is active monitoring, aiming at the proper timing of curative treatment; an active decision not to treat the patient immediately.

- The patient remains under close surveillance, and treatment is prompted by predefined thresholds indicative of the presence of a potentially life-threatening disease, while taking the patient's life-expectancy into consideration.

- The treatment options are intended to be *curative*.
- Aim is to reduce overtreatment in patients with clinically confined very low-risk PCa, without giving up the option of curative treatment.

Patients selected for active surveillance:

The various series have applied several eligibility criteria for enrolment in active surveillance programmes (D'Amico, Epstein, PRIAS, etc.):

- clinically confined PCa (T1-T2);
- Gleason score < 7 for most studies;
- PSA < 10-15 ng/mL;
- prostate cancer volume criteria on biopsies, e.g. number of positive biopsies, maximum cancer involvement of biopsy.

Protocol for active surveillance

There are several studies with variable protocols for the active surveillance patients. However, NICE recommends the following:

Timing	**Tests** [1]
At enrolment in active surveillance	Multiparametric MRI if not previously performed
Year 1 of active surveillance	Every 3–4 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3] Every 6–12 months: DRE[4] At 12 months: prostate rebiopsy
Years 2–4 of active surveillance	Every 3–6 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3]

	Every 6–12 months: DRE[4]
Year 5 and every year thereafter until active surveillance ends	Every 6 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3] Every 12 months: DRE[4]
[1] If there is concern about clinical or PSA changes at any time during active surveillance, reassess with multiparametric MRI and/or rebiopsy. [2] May be carried out in primary care if there are agreed shared-care protocols and recall systems. [3] May include PSA doubling time and velocity. [4] Should be performed by a healthcare professional with expertise and confidence in performing DRE.	

Triggers for active treatment:

- A PSA doubling time (PSADT) with a cut-off value ranging between < 2 and < 4 years.
- Gleason score progression to > 7 during systematic follow-up biopsies, at intervals ranging from one to four years.
- Patients' requests for treatment are based mainly on anxiety.
- Radiological progression, supported with an updated biopsy.

Recommendations:

Recommendations - active surveillance	LE	GR
Active surveillance is an option in patients with the lowest risk of cancer progression: over 10 years of life-expectancy, cT1-2, PSA < 10 ng/mL, biopsy Gleason score < 6 (at least 10 scores), < 2 positive biopsies, minimal biopsy core involvement (< 50% cancer per biopsy).	2a	A
Follow-up should be based on DRE, PSA and repeated biopsies. The optimal timing for follow-up is still unclear.	2a	A
Patients with biopsy progressions should be recommended to undergo active treatment.	2a	A

Watchful waiting is the delayed application of palliative treatment options. The rationale behind watchful waiting is the observation that PCa often progresses slowly, and is predominantly diagnosed in older men in whom there is a high incidence of co-morbidity and related high competitive mortality. Watchful waiting can be considered as an option for treating patients with localized PCa and a limited life-expectancy, or for older patients with less aggressive cancers.

Recommendations:

Recommendations - watchful waiting	LE	GR
Watchful waiting may be offered to all patients not willing to accept the side-effects of active treatment, particularly patients with a short life-expectancy.	1b	A
When on watchful waiting, the decision to start any non-curative treatment should be based on symptoms and disease progression.	1a	B

RADICAL PROSTATECTOMY

- Radical prostatectomy can be offered to men with intermediate-risk localised prostate cancer.
- Radical prostatectomy can be offered to men with high-risk localised prostate cancer when there is a realistic prospect of long-term disease control.
- Patients for radical prostatectomy should be referred to urological cancer team that has a specialist interest in urological cancer and all team members must attend a majority of meetings. The team should carry out a cumulative total of at least 50 radical operations for prostate or bladder cancer per year.
- Commissioners of urology services should consider providing robotic surgery to treat localised prostate cancer.
- Commissioners should ensure that robotic systems for the surgical treatment of localised prostate cancer are cost effective by basing them in centres that are expected to perform at least 150 robot-assisted laparoscopic radical prostatectomies per year.

Low risk prostate cancer (cT1-T2a, Gleason score < 6 and PSA < 10 ng/mL):

- Patients should be informed about the results of two randomized trials comparing retropubic RP versus watchful waiting (WW) in localized PCa.
- In the SPCG-4 study, the survival benefit associated with RP was similar before and after 9 years of follow-up and was also observed in men with low-risk PCa, and was confined to men < 65 years of age.

- In the PIVOT trial, a preplanned subgroup analysis of men with low-risk tumours showed that RP did not significantly reduce all-cause mortality.
- The decision to offer RP in cases of incidental cancer should be based upon the estimated probability of clinical progression compared to the relative risk of therapy and potential benefit to survival.
- In stage T2a patients with a 10-year life expectancy, RP is one of the recommended standard treatments, as 35-55% of these patients will show disease progression after 5 years if not treated.
- Extended pelvic lymph node dissection (eLND) is not necessary in low-risk PCa because the risk for positive lymph nodes does not exceed 5%.

Intermediate-risk, localized prostate cancer (cT2b-T2c or Gleason score = 7 and/or PSA 10-20 ng/mL):

- Radical prostatectomy is one of the recommended standard treatments for patients with intermediate risk PCa and a life expectancy of > 10 years.
- The prognosis is excellent when the tumour is confined to the prostate, based on pathological examination
- Although active monitoring could be proposed for some selected patients with intermediate-risk localized tumours, however, when the tumour is palpable or visible on imaging and clinically confined to the prostate, disease progression can be expected in most long term survivors.
- An eLND should be performed in intermediate-risk PCa if the estimated risk for positive lymph nodes exceeds 5%.
- Limited LND should no longer be performed because this misses at least half of the nodes involved

High-risk localized and locally advanced prostate cancer (Gleason score 8-10 and/or PSA > 20 ng/mL):

- RP is a reasonable treatment option in selected patients.
- RP is offered after all treatments have been discussed at the multidisciplinary team, with the pros and cons of each therapy has been considered by the patients with regard to their own individual circumstances.
- If RP is performed, pelvic eLND must be performed, because the estimated risk for positive lymph nodes is 15-40%.
- The patient must be informed about the likelihood of a multimodal approach.
- Neoadjuvant androgen depriviation therapy before RP does not provide a significant DSF or OS advantage over prostatectomy alone.

Complications and functional outcome in RP and RALP:

Complication, mean %	Retropubic RP	RALP
Continence*	80-97	89-100
Potency *	51-81	26-63
Peri-operative death	0.1	0.04
Readmission	3.0	3.5
Reoperation	2.3	0.9
Vessel injury	0.04	0.08
Nerve injury	0.4	0.4
Ureteral injury	1.5	0.1
Bladder injury	0.05	0.07
Rectal injury	0.5	0.3
Bowel injury	0	0.09
Ileus	0.8	0.8
Deep vein thrombosis	1.0	0.3
Pulmonary embolism	0.5	0.3
Pneumonia	0.5	0.05
Myocardial infarction	0.2	0.2
Haematoma	1.6	0.7
Lymphocele	3.2	0.8
Anastomotic leakage	10.0	3.5
Fistula	0.07	0.03
Bladder neck/anastomotic stricture	2.2	0.9
Sepsis	0.2	0.1
Wound infection	2.8	0.7

RALP = robot-assisted laparoscopic prostatectomy
RP = radical prostatectomy
***** The major limitations of the included studies were the frequent retrospective study design and the use of different assessment tools preventing a proper comparison between techniques and series.

RADIOTHERAPY

Radical Radiotherapy:

- There have been no randomized studies comparing radical prostatectomy (RP) with either external-beam radiotherapy (EBRT) or brachytherapy for localized prostate cancer (PCa).

- The National Institutes of Health (NIH) consensus statement in 1988 stated that external irradiation offers the same long-term survival results as surgery.
- EBRT provides a QoL at least as good as that following surgery. A recent systematic review has provided a more sophisticated overview of outcomes from trials that meet the criteria for stratifying patients by risk group, standard outcome measures, numbers of patients, and minimum median follow-up period.
- Radiotherapy continues to be an important and valid alternative to surgery alone for curative therapy.
- Intensity-modulated radiotherapy (IMRT), with or without image-guided radiotherapy (IGRT), is the gold standard for EBRT.
- All centres that do not yet offer IMRT should plan to introduce it as a routine method for the definitive treatment of PCa.
- Radiotherapy can be offered to men with intermediate-risk localised prostate cancer.
- Radiotherapy can be offered to men with high-risk localised prostate cancer when there is a realistic prospect of long-term disease control.
- Radiotherapy should be offered for localised prostate cancer a minimum dose of 74 Gy to the prostate at no more than 2 Gy per fraction.
- Men with intermediate- and high-risk localised prostate cancer should be offered a combination of radical radiotherapy and androgen deprivation therapy, rather than radical radiotherapy or androgen deprivation therapy alone.
- Men with intermediate- and high-risk localised prostate cancer should be offered 6 months of androgen deprivation therapy before, during or after radical external beam radiotherapy.
- Androgen deprivation therapy can be continued for up to 3 years for men with high-risk localised prostate cancer and the benefits and risks of this option should be discussed with them.
- Incidence of late toxicity and outcome by Radiation Therapy Oncology Group (RTOG) grade (from EORTC trial 22863):

Toxicity	Grade 2 %	Grade 3 %	Grade 4 %	Any significant toxicity (> grade 2)%
Cystitis	4.7	0.5	0	5.3
Haematuria	4.7	0	0	4.7
Urinary stricture	4.7	1.3	1	7.1
Urinary incontinence	4.7	0.5	0	5.3
Overall GU toxicity	12.4	2.3	1†	15.9

Toxicity	Grade 2 %	Grade 3 %	Grade 4 %	Any significant toxicity (> grade 2)%
Proctitis	8.2	0	0	8.2
Chronic diarrhoea	3.7	0	0	3.7
Small bowel obstruction	0.2	0.2	0	0.5
Overall GI toxicity	9.5	0.2	0	9.8
Leg oedema	1.5	0	0	1.5
Overall toxicity*	19.0	2.7	1	22.8
Potency after 1 year	--	--	--	55
Secondary malignancy	--	--	--	0.16

- Men with signs or symptoms of radiation-induced enteropathy should be offered care from a team of professionals with expertise in radiation-induced enteropathy.
- The nature and treatment of radiation-induced enteropathy should be included in the training programmes for oncologists and gastroenterologists.
- Full investigations should be carried out, including flexible sigmoidoscopy, in men who have symptoms of radiation-induced enteropathy to exclude inflammatory bowel disease or malignancy of the large bowel and to ascertain the nature of the radiation injury.
- Caution should be used when performing anterior wall rectal biopsy after brachytherapy because of the risk of fistulation.

Immediate (adjuvant) post-operative external irradiation after RP:

There's currently conflicting evidence with biochemical free and overall survival advantages of adjuvant versus salvage radiotherapy in the following post RP patients:

- Patients classified as pT3 pN0.
- Positive margins (highest impact)
- Capsule rupture, and/or invasion of the seminal vesicles

- with a PSA level of < 0.1 ng/mL.

RADICALS trial outcome is awaited. However, currently two options can be offered in the framework of informed consent. These are:

- Immediate adjuvant radiotherapy to the surgical bed (79,81-83,86) after recovery of urinary function; or
- Clinical and biological monitoring followed by salvage radiotherapy (SRT) before the PSA exceeds 0.5 ng/mL.
- Immediate post-operative radiotherapy after radical prostatectomy, even to men with margin-positive disease, other than in the context of a clinical trial.

Post radiotherapy biochemical failure:

- After primary RT, with or without short-term hormonal manipulation, the RTOG-ASTRO Phoenix Consensus Conference definition of PSA failure (with an accuracy of > 80%) is any PSA increase > 2 ng/mL higher than the PSA nadir value, regardless of the serum concentration of the nadir.
- In patients with BCF who are candidates for local salvage therapy, prostate multiparametric MRI can guide biopsy.
- Selected patients with localized PCa at primary treatment and histologically proven recurrence without evidence of metastatic disease should be treated with salvage RP (SRP).
- Due to the increased rate of treatment-related complications and side effects, SRP and salvage brachytherapy should only be performed in experienced centres.
- Permanent seed implantation, high-intensity focused ultrasound (HIFU) and cryosurgical ablation are treatment options in carefully selected patients without evidence of metastasis and with histologically proven local recurrence.

Experimental therapeutic options to treat clinically localized PCa:

- High frequency focused ultrasound (HIFU) has been shown to have a therapeutic effect in low-stage PCa, but prospective randomized comparison studies are not available to support its routine use.
- Cryotherapy for PCa compares unfavourably with external-beam radiation for the preservation of sexual function. Similarly this modality should be used in the context of clinical trials.
- Focal therapy of any sort is investigational, and the follow-up and retreatment criteria are unclear.

- In patients who are unfit for surgery or radiotherapy, cryotherapy can be an alternative treatment for PCa but cannot be recommended as a therapeutic alternative outside clinical trials.
- If HIFU is offered, the lack of long-term comparative outcome data (> 10 y) should be discussed with the patient.

LOCALLY ADVANCED PROSTATE CANCER (stage T3-T4, Nx-N0, M0):

DEFERRED TREATMENT

- Only indicated in selected patients with non-poorly differentiated T3 tumours and a life expectancy of less than 10 years.
- Significant risk factors associated with a worse outcome hence indications of active treatment are:
  - patients with a baseline PSA > 50 ng/mL.
  - in patients with a baseline PSA < 50 ng/mL, a PSADT of < 12 months carries the risk of PCa related death (approximately 7.5-fold).

RADICAL RADIOTHERAPY

- In patients with locally advanced PCa T3-4 N0 M0, concomitant and adjuvant hormonal therapy for a total duration of 3 years, with external-beam irradiation for patients with WHO 0-2 performance status, is recommended, as it improves the overall survival.
- In a subset of patients with T2c-T3 N0-X and a Gleason score of 2-6, short-term androgen deprivation therapy ADT before and during radiotherapy can be recommended, as it may favourably influence the overall survival.

ADT monotherapy:

- ADT monotherapy can be offered to patients with locally advanced disease who are unwilling or unable to receive any form of associated local treatment.
- Immediate castration should be considered in the most aggressive situations (PSA > 50 ng/mL, PSADT < 12 months).
- Otherwise a wait-and-see policy with deferred treatment at clinical progression is a reasonable option.

RADICAL PROSTATECTOMY

- RP is optional in highly selected patients with cT3b-4 N0 or any cT N1 PCa in the context of a multimodality approach.
- When nodal involvement is detected after surgery:
  - Adjuvant ADT is recommended when > 2 nodes are involved;
  - Expectant management is optional when the patient has undergone eLND and < 2 nodes show microscopic involvement.

Focal therapeutic options:

High-intensity focused ultrasound and cryotherapy should not be offered to men with locally advanced prostate cancer other than in the context of controlled clinical trials comparing their use with established interventions.

METASTATIC PCa (stage M1):

ANDROGEN DEPREVATION THERAPY (ADT):

- In patients with symptomatic metastatic prostate cancer, ADT is recommended to palliate symptoms and to reduce the risk for potentially catastrophic sequelae of advanced disease (spinal cord compression, pathological fractures, ureteral obstruction, extraskeletal metastasis).

- In patients who are asymptomatic from their metastatic disease:
  - Immediate ADT can be used to defer progression to a symptomatic stage and prevent serious disease progression-related complications.
  - An active clinical surveillance protocol is an acceptable option in clearly informed patients if survival is the main objective.

- Anti-androgens are initially used to reduce the risk of the ‘flare-up’ phenomenon in patients with advanced metastatic disease who are to receive an LHRH agonist.

- It may be sufficient to give an anti-androgen for some weeks of concomitant use, starting treatment on the same day as an LHRH analogue is started, or for up to 7 days before the first LHRH analogue injection.

- Anti-androgens as monotherapy can be considered as an option in highly selected and motivated patients with a low PSA.

- Intermittent ADT:
  - When this method is used, it should reproduce what has been used in clinical trials; treatment is usually stopped when the PSA level is < 4 ng/mL (M1) and < 0.5-4 ng/mL (relapsing). Treatment is usually re-started when the PSA is > 4-10 (relapsing) and > 10-20 ng/mL (M1).
  - This can be used in patients with asymptomatic metastatic disease and are very motivated, with a major PSA response after the induction period.
  - Other cohort includes patients relapsing after radiotherapy; patients with a clear response after the induction period.

Contraindications of ADT

Therapy	**Contraindications**	**LE**	**GR**
Bilateral orchiectomy	Psychological reluctance to undergo surgical castration.	3	A
Oestrogens	Known cardiovascular disease.	2b	B
LHRH agonists monotherapy	Patients with metastatic disease at high risk for clinical 'flare-up' phenomenon.	2b	A
ADT, anti-androgen	Localized PCa as primary monotherapy (except in some high-risk localized situations in patients unwilling or unable to receive any form of local treatment).	1b	A

DEFERRED TREATMENT:

- Only indicated in asymptomatic patients with a strong wish to avoid treatment-related side-effects
- If a deferred treatment policy is chosen for a patient with advanced PCa, close follow-up must be possible.

RADICAL RADIOTHERAPY

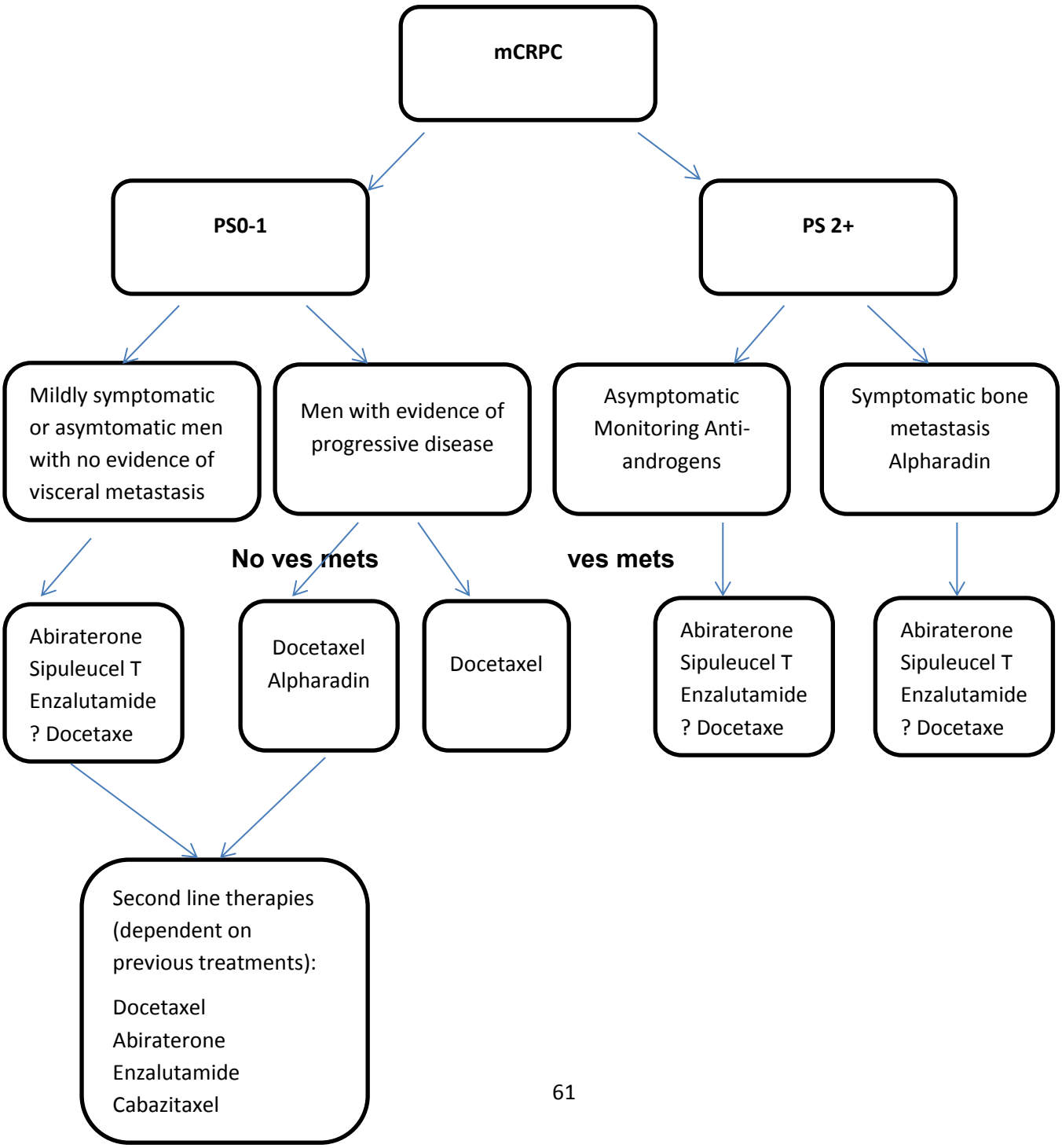
- In patients with very high-risk PCa c-pN1 M0, with no severe comorbidity, pelvic external irradiation and immediate long-term adjuvant hormonal treatment is recommended, as it may improve the overall survival, disease-specific failure rate, metastatic failure rate, and biochemical control.

CASTRATION-RESISTANT PCa (CRPC)

Defined as:

- Castrate serum testosterone < 50 ng/dL or 1.7 nmol/L plus either:
  - Biochemical progression: Three consecutive rises of PSA, 1 week apart, resulting in two 50% increases over the nadir, with PSA > 2 ng/mL. or
  - Radiological progression: The appearance of two or more bone lesions on bone scan or enlargement of a soft tissue lesion using RECIST (Response Evaluation Criteria in solid tumours).

Flowchart of the potential therapeutic options after PSA progression following initial hormonal therapy:



- Patients with mCRPC should be counselled, managed and treated by a multidisciplinary team.

FOLLOW UP

Guidelines for follow-up of prostate cancer patients with curative intent/watchful waiting:

- Men should be clearly advised with prostate cancer about potential longer-term adverse effects of treatment and when and how to report them.
- Men with prostate cancer who have chosen a watchful waiting regimen with no curative intent should normally be followed up in primary care in accordance with protocols agreed by the local urological cancer MDT and the relevant primary care organisation(s). Their PSA should be measured at least once a year.
- PSA levels for all men with prostate cancer who are having radical treatment should be checked at the earliest 6 weeks following treatment, at least every 6 months for the first 2 years and then at least once a year thereafter.
- DRE is not routinely offered to men with localised prostate cancer while the PSA remains at baseline levels [NICE].
- After radical prostatectomy, a serum PSA level of more than 0.2 ng/mL can be associated with residual or recurrent disease.
- After radiation therapy, a rising PSA level over 2 ng/mL above the nadir PSA, rather than a specific threshold value, is the most reliable sign of recurrent disease.
- Both a palpable nodule and a rising serum PSA level can be signs of local disease recurrence.
- Detection of local recurrence by imaging studies is only recommended if it will affect the treatment plan. In most cases, a biopsy is not necessary before second-line therapy.
- Routine bone scans and other imaging studies are not recommended in asymptomatic patients with no signs of biochemical relapse. If a patient has bone pain or other symptoms of disease progression, re-staging should be considered irrespective of the serum PSA level.
- In asymptomatic patients, a disease-specific history and a serum PSA measurement supplemented by DRE are the recommended tests for routine

follow-up. These should be performed at 3, 6 and 12 months after treatment, then every 6 months until 3 years, and then annually [EAU].

- After at least 2 years, follow-up can be performed outside hospital (for example, in primary care) by telephone or secure electronic communications to men with a stable PSA who have had no significant treatment complications, unless they are taking part in a clinical trial that requires formal clinic-based follow-up. Direct access to the urological cancer MDT should be offered and explained.

Guidelines for follow-up of prostate cancer patients on ADT:

- Patients should be evaluated at 3 and 6 months after the initiation of treatment.
- As a minimum, tests should include serum PSA measurement, DRE, serum testosterone, and careful evaluation of symptoms in order to assess the treatment response and side effects.
- In patients undergoing intermittent androgen deprivation, PSA and testosterone should be monitored at set intervals during the treatment pause (one or three months).
- Follow-up should be tailored for the individual patient, according to symptoms, prognostic factors and the treatment given.
- In patients with stage M0 disease with a good treatment response, follow-up is scheduled every 6 months, and as a minimum should include a disease-specific history, DRE and serum PSA determination.
- In patients with stage M1 disease with a good treatment response, follow-up is scheduled for every 3 to 6 months. As a minimum, this should include a disease-specific history, DRE and serum PSA determination, and is frequently supplemented with haemoglobin, serum creatinine and alkaline phosphatase measurements. The testosterone level should be checked, especially during the first year.
- Patients (especially with M1b status) should be advised about the clinical signs that could suggest spinal cord compression.
- When disease progression occurs, or if the patient does not respond to the treatment given, follow-up needs to be individualized.
- In patients with suspected progression, the testosterone level must be checked. By definition, CRPC is based on the assumption that the patient has a testosterone level of at least < 50 ng/mL.
- Routine imaging of stable patients is not recommended.

9.3 PENILE CANCER

Penile carcinoma is mostly a squamous cell carcinoma (SCC) but other types of carcinoma exist as well. It usually originates from the epithelium of the inner prepuce or the glans. Also, penile SCC occurs in several histological subtypes. Penile SCC shares similar pathology with SCC of the oropharynx, the female genitalia (cervix, vagina and vulva) and the anus and it is therefore assumed that it also shares to some extent the natural history.

EPIDEMIOLOGY

- In Western countries, primary penile cancer is uncommon, with an incidence of less than 1.00 per 100,000 males in Europe and the United States.

- Incidence is also affected by race and ethnicity in North America, with the highest incidence of penile cancer found in white Hispanics (1.01 per 100,000), followed by a lower incidence in Alaskan, Native American Indians (0.77 per 100,000), blacks (0.62 per 100,000) and white non-Hispanics (0.51 per 100,000), respectively.

- In contrast, in some other parts of the world such as South America, South East Asia and parts of Africa the incidence of penile cancer is much higher and can represent 1-2% of malignant diseases in men.

- Penile cancer is common in regions with a high prevalence of human papilloma virus (HPV). The annual age-adjusted incidence is 0.7-3.0 per 100,000 men in India, 8.3 per 100,000 men in Brazil and even higher in Uganda, where it is the most commonly diagnosed cancer in men.

- There are no data linking penile cancer to HIV or AIDS.

- In European countries, the overall incidence has been stable from the 1980s until today. Recently, an increased incidence has been reported from Denmark and the UK.

- A longitudinal study from the UK has confirmed a 21% increase in incidence over the period 1979-2009.

- The incidence of penile cancer increases with age, with an age peak during the sixth decade of life. However, the disease does occur in younger men.

RISK FACTORS AND PREVENTION

Risk factors	Relevance
• Phimosis	OR 11-16 versus no phimosis
• chronic penile inflammation (balanoposthitis related to phimosis) • balanitis xerotica obliterans (lichen sclerosus)	Risk
• sporalene and UV-A phototherapy for various dermatologic conditions such as psoriasis	Incidence rate ratio 9.51 with > 250 treatments
• smoking	5-fold increased risk (95% CI: 2.0-10.1) versus nonsmokers
• HPV infection condylomata acuminata	22.4% in verrucous SCC and 36-66.3% in basaloid-warty
• Rural areas, low socio-economic status, unmarried	Risk
• multiple sexual partners early age of first intercourse	3-5-fold increased risk of penile cancer

- Neonatal circumcision reduces the incidence of penile cancer in countries and cultures where this is routinely practiced.
- The lowest incidence of penile cancer is reported from Israel amongst Jews (0.3/100,000/ year).
- Medical circumcision in adult life does not influence the incidence of penile cancer.
- The controversial discussion about any preventive value of neonatal circumcision must take into consideration that circumcision removes about 50% of the tissue that can develop penile cancer.
- The protective effect of neonatal circumcision against invasive penile cancer (OR 0.41) - which does apparently not apply to CIS (OR 1.0) - is much weaker when the analysis is restricted to men without a history of phimosis (OR 0.79, 95% CI 0.29-2).

TNM clinical and pathological classification of penile cancer (2009)

T - Primary Tumour
Tx Primary tumour cannot be assessed T0 No evidence of primary tumour Ta Non-invasive carcinoma Tis Carcinoma in situ T1 Tumour invades subepithelial connective tissue T1a Tumour invades subepithelial connective tissue without lymphovascular invasion and is not poorly differentiated or undifferentiated (T1G1-2) T1b Tumour invades subepithelial connective tissue with lymphovascular invasion or is poorly differentiated or undifferentiated (T1G3-4) T2 Tumour invades corpus spongiosum and/or corpora cavernosa T3 Tumour invades urethra T4 Tumour invades adjacent structures
N - Regional Lymph Nodes
Nx Regional lymph nodes cannot be assessed N0 No palpable or clinically visible inguinal lymph-node N1 Palpable mobile unilateral inguinal lymph node N2 Palpable mobile multiple unilateral or bilateral inguinal lymph nodes N3 Fixed inguinal nodal mass or pelvic lymphadenopathy, unilateral or bilateral
M - Distant Metastasis M0 No distant metastasis M1 Distant metastasis
Pathological classification The pT categories correspond to the clinical T categories. The pN categories are based upon biopsy or surgical excision.
pN - Regional Lymph Nodes
pNX Regional lymph nodes cannot be assessed pN0 No regional lymph node metastasis pN1 Intranodal metastasis in a single inguinal lymph node pN2 Metastasis in multiple or bilateral inguinal lymph nodes pN3 Metastasis in pelvic lymph node(s), unilateral or bilateral or extranodal extension of any regional lymph node metastasis
pM - Distant Metastasis
pM0 No distant metastasis pM1 Distant metastasis
G - Histopathological Grading
GX Grade of differentiation cannot be assessed G1 Well differentiated G2 Moderately differentiated G3-4 Poorly differentiated/undifferentiated

Premalignant penile lesions (precursor lesions)

Lesions sporadically associated with SCC of the penis • Cutaneous horn of the penis • Bowenoid papulosis of the penis • Lichen sclerosus (balanitis xerotica obliterans)
Premalignant lesions (up to one-third transform to invasive SCC) • Intraepithelial neoplasia grade III • Giant condylomata (Buschke-Löwenstein) • Erythroplasia of Queyrat or Bowen's disease • Paget's disease (intradermal ADK)

Histological subtypes of penile carcinomas, their frequency and outcome

Subtype	**Frequency (% of cases)**	**Prognosis**
common SCC	48-65	depends on location, stage and grade
basaloid carcinoma	4-10	poor prognosis, frequently early inguinal nodal metastasis
warty carcinoma	7-10	good prognosis, metastasis rare
verrucous carcinoma	3-8	good prognosis, no metastasis
papillary carcinoma	5-15	good prognosis, metastasis rare
sarcomatoid carcinoma	1-3	very poor prognosis, early vascular metastasis
mixed carcinoma	9-10	heterogeneous group
pseudohyperplastic carcinoma	< 1	foreskin, related to lichen sclerosus, good prognosis, metastasis not reported
carcinoma cuniculatum	< 1	variant of verrucous carcinoma, good prognosis, metastasis not reported
pseudoglandular carcinoma	< 1	high grade carcinoma, early metastasis, poor prognosis
warty-basaloid carcinoma	9-14	poor prognosis, high metastatic potential (12) (higher than in warty, lower than in basaloid SCC)
adenosquamous carcinoma	< 1	central and peri-meatal glans, high grade carcinoma, high metastatic potential but low mortality
mucoepidermoid carcinoma	< 1	highly aggressive, poor prognosis
clear cell variant of penile carcinoma	1-2	exceedingly rare, associated with HPV, aggressive, early metastasis, poor prognosis, outcome lesion dependent, frequent lymphatic metastasis

DIAGNOSIS AND STAGING

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer:
  GPs should refer men with suspicious penile lesions such as growths, swelling at or near the glans, painless ulcers which do not appear to be due to infection, or other unexplained abnormalities such as plaques on the skin or foreskin of the penis, to a local urological cancer team.

Recommendations for the diagnosis and staging of penile cancer

Recommendations	**GR**
Primary tumour: • Physical examination, recording morphology, extent and invasion of penile structures. • MRI with artificial erection in selected cases with intended organ preserving surgery.	**C**
Inguinal lymph nodes: • Physical examination of groins, recording number, laterality and characteristics of inguinal nodes. • If nodes are not palpable, invasive lymph node staging in high-risk patients. • If nodes are palpable, a pelvic CT may be indicated, PET/CT is an option.	**C**
Distant metastases: • In N+ patients, abdomino-pelvic CT scan and chest X-ray are required for systemic staging. • PET/CT scan is an option. • In patients with systemic disease or with relevant symptoms, a bone scan may be indicated.	**C**

TREATMENT

Patients with penile cancer should be managed by specialist penile cancer teams working at the supra-network level. Such teams should serve up to four networks, with a combined population base of at least four million for penile cancer and expect to manage a minimum of 25 new patients each year. The team should include members of the specialist urological cancer team who work in the cancer centre within which it is based, and it should also have access to expertise in plastic surgery.

All penile cancer cases should be discussed with the supranetwork team prior to proposed treatment if not referred directly to that team.

Local care is classed as:
(i) The diagnostic process only.
Local care should be carried out by local teams for their catchment.

It should also be carried out by specialist teams and supranetwork teams for the local catchment of their host locality.

Specialist care is classed as:
(i) Resection (except in cases needing penile reconstruction or lymph node resection).

All resections should be carried out in the host hospital of the team.

(ii) Radiotherapy and chemotherapy. The site(s) where this is carried out should be agreed in the
network guidelines.

Specialist care may be delivered by:

- A specialist urological team without a supranetwork interest in penile cancer provided this is agreed in the network guidelines and with the relevant supranetwork team. It should not be delivered by local urological teams.

- A supranetwork team for referring specialist teams provided this is agreed in the network guidelines.

- The supranetwork team for the local catchment of their host locality.

Supranetwork care is classed as:
Resection in cases needing penile reconstruction or lymph node resection.

All resections should be carried out in one of the hospitals named as part of the facilities of the host locality. All such operations should be carried out in the same hospital.

Supranetwork care should be delivered by the *supranetwork team only.* This is not subject to alteration by the network guidelines.

- The aims of the treatment of the primary penile cancer lesion are complete tumour removal with as much organ preservation as possible while radicality of the treatment should not be compromised.
- A local recurrence in itself has little influence on long-term survival so that organ preservation strategies are justified.
- There are no randomised controlled trials for any of the surgical management options of localised penile cancer, neither are there any observational studies comparing different surgical approaches or studies comparing surgical and non-surgical treatment modalities.
- The available studies all have one or more form of bias such as bias of selection, performance, detection, attrition, selective reporting or publication. Thus, the overall quality of the existing evidence must be regarded as low.
- Penile preservation appears to be superior in functional and cosmetic outcomes and should be offered as the primary treatment modality to men with localised penile cancer.
- Histological diagnosis with local staging must be obtained in all cases, especially if non-surgical treatment modalities are considered
- The treatment of the primary tumour and that of the regional nodes can be done as staged procedures.
- In both cases, it is essential to remove all malignant tissue with negative surgical margins.
- Patients must be counselled about all relevant treatment modalities.
- There are a variety of local treatment modalities for small and localized penile cancer including
    - excisional surgery,
    - external beam radiotherapy,
    - brachytherapy and laser ablation which are used to treat localized invasive disease.

Treatment of superficial non-invasive disease (CIS)

- For penile CIS, topical chemotherapy with imiquimod or 5-FU is an effective first-line treatment.
- Toxicity and adverse events of these topical treatments are relatively low but the efficacy is limited.
- Complete responses have been reported in up to 57% of cases of CIS.
- For the reason of a high rate of persistence and/or recurrence, close and long-term surveillance of such patients is required.
- If topical treatment fails it should not be repeated. Laser treatment can be used for CIS.
- Photodynamic control may be used in conjunction with CO2 laser treatment.
- Alternatively, total or partial glans resurfacing can be offered as a primary treatment modality for CIS and as a secondary treatment in case of treatment failure with topical chemotherapy or laser therapy.
- Glans resurfacing is a surgical technique which consists of complete abrasion of the glandular epithelium with covering by a split skin graft.
- With glans resurfacing for presumed non-invasive disease, up to 20% of patients are found to have superficial invasive disease.

Treatment of invasive disease confined to the glans (category Ta/T1a)

- Penis-preserving strategy is recommended.
- Prior to conservative treatment modalities, it is mandatory to obtain histopathological diagnosis by biopsy.
- All patients must be circumcised before considering conservative non-surgical treatment modalities.
- For tumours confined to the prepuce, radical circumcision alone may be curative, if negative surgical margins are confirmed by definitive histology.
- For all surgical treatment options, the intra-operative assessment of surgical margins by frozen section is recommended as tumour-positive margins lead to local recurrence.
- Total removal of the glans (glansectomy) and prepuce does have the lowest recurrence rate among the treatment modalities for small penile lesions (2%).
- Negative surgical margins are imperative when using penile-conserving treatments and a margin of 5 mm is considered oncologically safe.
- Treatment choice should depend on tumour size, histology including stage and grade, localization especially relative to the meatus, as well as patient preference as there are no documented differences in the long term local recurrence rates between surgery, laser and radiation therapy.

Summary of reported complications and oncological outcomes of local treatments

treatment	complications	local recurrence	nodal recurrence	cancer-specific deaths
Nd:YAG laser	none reported	10-48%	21%	2-9%
CO2-laser	bleeding, meatal stenosis(both < 1%)	14-23%	2-4%	none reported
Lasers (unspecified)	bleeding (8%), local infection 2%	11-26%	2%	2-3%
Moh's micrographic surgery	local infection 3%, meatal stenosis 6%	32%	8%	3-4%
Glans resurfacing	none reported	4-6%	not reported	not reported
Glansectomy	none reported	8%	9%	none reported
Partial penectomy	not reported	4-13%	14-19%	11-27%
Brachytherapy	meastal stenosis> 40%	10-30%	not reported	not reported
Radiotherapy	urethral stenosis 20-35%, glans necrosis10-20%	not reported	not reported	not reported

Recommendations for stage-dependent local treatment of penile carcinoma

Recommendations			
Primary tumour	Organ-preserving treatment is to be considered whenever possible	LE	GR
Tis	• Topical treatment with 5-fluorouracil or imiquimod for superficial lesions with or without photodynamic control. • Laser ablation with CO2 or Nd:YAG laser. • Glans resurfacing.	3	C
Ta, T1a (G1, G2)	• Wide local excision with circumcision CO2 or Nd:YAG laser surgery with circumcision.	3	C

Recommendations			
	• Laser ablation with CO2 or Nd:YAG laser. • Glans resurfacing. Glansectomy with reconstructive surgery, with or without skin grafting. • Radiotherapy by external beam or as brachytherapy for lesions < 4 cm.		
T1b (G3) and T2 confined to the glans	• Wide local excision plus reconstructive surgery, with or without skin grafting. • Laser ablation with circumcision. • Glansectomy with circumcision, with reconstruction. • Radiotherapy by external beam or brachytherapy for lesions < 4 cm in diameter.	3	C
T2 with invasion of the corpora cavernosa	• Partial amputation and reconstruction. • Radiotherapy by external beam or brachytherapy for lesions < 4 cm in diameter.	3	C
T3 with invasion of the urethra	• Partial penectomy or total penectomy with perineal urethrostomy.	3	C
T4 with invasion of other adjacent structures	• Neoadjuvant chemotherapy followed by surgery in responders. Alternative: palliative external beam radiation. • Local recurrence after conservative treatment Salvage surgery with penis-sparing treatment in small recurrences or partial amputation. • Large or high stage recurrence: partial or total amputation	3	C

Management of regional lymph nodes

- The development of lymphatic metastases in penile cancer follows some anatomic rules.
- The inguinal and the pelvic lymph nodes are the regional drainage system of the penis.
- The superficial and deep inguinal lymph nodes are thereby the first regional nodal group reached by lymphatic metastatic spread.
- Spread to the inguinal lymph nodes can be uni- or bilateral from any primary penile cancer.
- The second regional lymph node groups are the ipsilateral pelvic lymph nodes.

- Pelvic nodal disease does not seem to occur without ipsilateral inguinal lymph node metastasis and cross-over metastatic spread from one inguinal side to the other pelvic side has never been reported in penile cancer.
- Further metastatic lymph node spread from the pelvic nodes to paraaortic and paracaval nodes is outside the regional lymph node drainage system of the penis and is therefore classified as systemic metastatic disease.
- The management of regional lymph nodes is decisive for long-term patient survival.
- Cure can be achieved in metastatic disease confined to the regional lymph nodes.
- Lymphadenectomy is the treatment of choice for patients with inguinal lymph node metastases but multimodal treatment combining surgery and polychemotherapy is often indicated.
- Management of the regional lymph nodes should be stage-dependent. In clinically node-negative patients (cN0), there is a definite risk of micro-metastatic lymph node involvement in about 25% of cases which is related to local tumour stage and grade.
- In clinically positive lymph nodes (cN1/cN2), metastatic disease is highly likely and no time should be wasted on antibiotic treatment before surgical treatment.
- With enlarged fixed inguinal lymph nodes (cN3), multimodal treatment by chemotherapy and surgery is indicated. Capsular penetration and extranodal extension in lymph node metastasis even if present in only one node carries a high risk of progression and is classified as pN3 which also requires multimodal treatment.

Recommendations for treatment strategies for nodal metastases

Regional lymph nodes	**Management of regional lymph nodes is fundamental in the treatment of penile cancer**	**LE**	**GR**
No palpable inguinal nodes (cN0)	• Tis, Ta G1, T1G1: surveillance. • > T1G2: invasive lymph node staging by bilateral modified inguinal lymphadenectomy or DSNB.	2a	B
Palpable inguinal nodes (cN1/cN2)	Radical inguinal lymphadenectomy.		
Fixed inguinal lymph nodes (cN3)	• Neoadjuvant chemotherapy followed by radical inguinal lymphadenectomy in responders. • Pelvic lymphadenectomy Ipsilateral pelvic lymphadenectomy is indicated if two or more inguinal nodes are involved on one side (pN2) and in extracapsular nodal metastasis (pN3).	2a	B

Regional lymph nodes	Management of regional lymph nodes is fundamental in the treatment of penile cancer	LE	GR
Adjuvant chemotherapy	• Indicated in pN2/pN3 patients after radical lymphadenectomy • Radiotherapy Radiotherapy is not indicated for the treatment of nodal disease in penile cancer.	2b	B

Chemotherapy

- Multimodal treatment can improve patient outcome in many tumour entities.
- The value of adjuvant chemotherapy after radical inguinal lymphadenectomy in node-positive penile cancer has a long-term disease-free survival (DFS) as opposed those without chemotherapy of (84% vs 39% respectively).
- There is limited evidence to support the use of neoadjuvant chemotherapy for patients with fixed, unresectable nodal disease, particularly with a triple combination including cisplatin and a taxane, whenever feasible.

Recommendations for chemotherapy in penile cancer patients

	LE	GR
Adjuvant chemotherapy (3-4 cycles of TPF) is an option for patients with pN2-3 tumours.	2b	C
Neoadjuvant chemotherapy (4 cycles of a cisplatin and taxane-based regimen) followed by radical surgery is recommended in patients with non-resectable or recurrent lymph node metastases.	2a	B
Chemotherapy for systemic disease is an option in patients with limited metastatic load.	3	C

FOLLOW UP

Recommendations for follow-up in penile cancer

	Interval of follow-up Years 1-2	**Interval follow-up Years 3-5**	**Examinations examination and investigations**	**Minimum duration of follow-up**	**GR**
Primary tumour: penile preserving treatment	3 months	6 months	Regular physician or self examination Repeat biopsy after topical or laser treatment for CIS.	5 years	C
Amputation	3 months	1 year	Regular physician or self examination	5 years	C
Recommendations for follow-up of the inguinal lymph nodes: Surveillance	3 months	6 months	Regular physician or selfexamination	5 years	C
pN0 at initial treatment	3 months	1 year	• Regular physician or self examination. • Ultrasound with FNAB optional.	5 years	C
pN+ at initial treatment	3 months	6 months	• Regular physician or selfexamination • Ultrasound with FNAC optional, • CT/MRI optional.	5 years	C

9.4 Renal Cell Carcinoma

Epidemiology:

- Renal cell carcinoma (RCC) represents 2-3% of all cancers.
- In 2012, there were approximately 84,400 new cases of RCC and 34,700 kidney cancer-related deaths in the European Union.
- In Europe, overall mortality rates for RCC increased up to the early 1990s, and stabilised or declined thereafter. Mortality has decreased since the 1980s in Scandinavian countries and since the early 1990s in France, Germany, Austria, the Netherlands, and Italy. However, in some European countries (Croatia, Estonia, Greece, Ireland, Slovakia), mortality rates still show an upward trend.
- Different RCC types have specific histopathological and genetic characteristics.
- There is a 1.5:1 male predominance, with peak incidence between 60 and 70 years.
- Having a first-degree relative with kidney cancer also increases the risk of RCC.
- Literature results are inconclusive regarding the association of specific dietary habits and occupational exposure to RCC.
- Moderate alcohol consumption appears to have a protective effect for unknown reasons.
- Effective prophylaxis includes avoidance of cigarette smoking and obesity.

Aetiology:

- Smoking:
  - The RR of RCC for ever-smokers is 1.38 times higher than that for non-smokers
  - A strong dose-response relationship between number of cigarettes smoked and increased risk of RCC has been established; Smokers with a history of ≥20 pack-years have an increased risk of RCC 1.35 times that of never-smokers

- Obesity:
  - Increasing body weight and body mass index (BMI) incrementally increases the risk of developing RCC
  - Being overweight (BMI 25–29.9 kg/m2) increases the risk of RCC by 1.35 times versus BMI

- Hypertension and antihypertensive therapy:
  - The presence of hypertension is estimated to increase the RR of RCC by 1.4–1.9 times compared with normotensive individuals
  - Systolic blood pressure ≥160 mmHg increases the RR of RCC by 2.5 times versus <120 mmHg.

- Diastolic blood pressure ≥100 mmHg increases the RR of RCC by 2.3 times versus <80 mmHg.
- Treatment with diuretics also increases the risk of RCC (OR 1.43), but this is only significant in women

- End-stage renal disease:
  - Patients undergoing dialysis for end-stage renal disease are estimated to have a 3.6 times higher RR of developing renal cancer than healthy individuals.

- Renal cancer syndromes:

Disease	**Renal and other tumours**	**Gene mutation**
Von Hippel–Lindau disease	Clear cell RCC: Clear cell renal cysts Retinal and central nervous system haemangioblastomas, phaeochromocytoma, pancreatic cyst and endocrine tumour, endolymphatic sac tumour, epididymal and broad ligament cystadenomas	VHL
Birt-Hogg-Dubé syndrome	Hybrid oncocytic RCC, chromophobe RCC, oncocytoma, clear cell RCC multiple and bilateral Cutaneous lesions (fibrofolliculoma +++, trichodiscoma, acrochordon), lung cysts, spontaneous pneumothorax, colonic polyps or cancer	Folliculin (FLCN)
Hereditary papillary RCC	Type 1 papillary RCC: multiple and bilateral	MET
Hereditary leiomyomatosis and RCC	Type 2 papillary RCC: solitary and aggressive Uterine leiomyoma and leiomyosarcoma, cutaneous leiomyoma and leiomyosarcoma	Fumarate hydratase
Tuberous sclerosis complex	Angiomyolipoma, clear cell RCC, cyst, oncocytoma: bilateral and multiple Facial angiofibroma, subungual fibroma, hypopigmentation and café au lait spots, cardiac rhabdomyoma, seizure, mental retardation, CNS tubers, lymphangioleiomyomatosis	TSC-1 TSC-2
Familial clear cell RCC	Clear cell RCC	Unknown

Diagnosis:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.
- Many renal masses remain asymptomatic until the late stages of the disease.
- More than 50% of renal cell carcinomas (RCCs) are detected incidentally when noninvasive imaging is used to investigate a variety of nonspecific symptoms and other abdominal diseases.
- The classic triad of flank pain, gross haematuria and palpable abdominal mass is now rare (<10%).
- Other clinical symptoms include new onset varicocele or bilateral lower extremity oedema; these symptoms should initiate radiological examinations.
- Renal Cell Carcinoma Paraneoplastic syndromes are found in approximately 30% of patients with symptomatic RCCs.
- A few symptomatic patients present with symptoms caused by metastatic disease, such as bone pain or persistent cough.

Investigations:

- Radiological and other investigations of RCC Radiological investigations of RCC include CT imaging, before and after intravenous contrast to verify the diagnosis and provide information on:
    - function and morphology of the contralateral kidney
    - assess tumour extension
    - extrarenal spread
    - venous involvement
    - enlargement of lymph nodes and adrenals.
- Abdominal US and magnetic resonance (MR) imaging are supplements to CT.
- Contrast enhanced US can be helpful in specific cases (e.g., chronic renal failure with a relative contraindication for iodinated or gadolinium contrast media, complex cystic masses, and differential diagnosis of peripheral vascular disorders such as infarction and cortical necrosis).

- Magnetic resonance imaging can be used in patients with possible venous involvement, or allergy to intravenous contrast.
- Chest CT is the most accurate chest staging; a routine chest X-ray should be done as a minimum only.
- Indications of renal biopsy:
  - for histological diagnosis of radiologically indeterminate renal masses
  - to select patients with small renal masses for surveillance approaches
  - to obtain histology before ablative treatments
  - to select the most suitable form of targeted pharmacologic therapy in the setting of metastatic disease.
- Total renal function should always be evaluated.
- In patients with any sign of impaired renal function, a renal scan and total renal function evaluation should be undertaken to optimise the treatment decision.

Staging system:

The current UICC 2009 TNM (Tumour Node Metastasis) classification is recommended for the staging of RCC.

T - Primary tumour	
TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
T1	Tumour ≤ 7 cm in greatest dimension, limited to the kidney
T1a	Tumour ≤ 4 cm in greatest dimension, limited to the kidney
T1b	Tumour > 4 cm but ≤ 7 cm in greatest dimension
T2	Tumour > 7 cm in greatest dimension, limited to the kidney
T2a	Tumour > 7 cm in greatest dimension but ≤ 10 cm
T2b	Tumour > 10 cm limited to the kidney
T3	Tumour extends into major veins or perinephric tissues, but not into the ipsilateral adrenal gland and not beyond Gerota's fascia
T3a	Tumour grossly extends into the renal vein or its segmental (muscle-containing) branches, or tumour invades perirenal and/or renal sinus (peripelvic) fat but not beyond Gerota's fascia
T3b	Tumour grossly extends into the vena cava below diaphragm
T3c	Tumour grossly extends into vena cava or its wall above the diaphragm or invades the wall of the vena cava
T4	Tumour invades beyond Gerota's fascia (including contiguous extension into the ipsilateral adrenal gland)
N - Regional lymph nodes	
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis

N1	Metastasis in a single regional lymph node
N2	Metastasis in more than one regional lymph node
M - Distant metastasis	
M0	No distant metastasis
M1	Distant metastasis

Histopathological classification:

Fuhrman nuclear grade is the most commonly used grading system. The most aggressive pattern observed defines the Fuhrman grade. The most common histological subtypes of rCC are below:

Histological subtype	**Frequency (%)**
clear cell RCC	80-90%),
papillary RCC	10-15%),
chromophobe RCC	4-5%
collecting duct carcinoma	1%

- Generally, the RCC types have different clinical courses and responses to therapy.

Recommendations for diagnosis and staging of RCC:

Recommendations for the diagnosis and staging of RCC	GR
The Fuhrman grading system and classification of RCC subtype should be used	B
In a patient with one or more suspicious laboratory or physical findings, the possible presence of RCC should be suspected	B
Contrast-enhanced abdominal CT and MRI are recommended for the work-up of patients with RCC. These are the most appropriate imaging modalities for renal tumour staging prior to surgery	A
A chest CT is most sensitive for assessment of the lung, but at least a plain chest radiograph should be taken for clinical staging	A
In patients at risk for bone metastases (raised alkaline phosphatase level or bone pain), further evaluation with a bone scan is needed	A
Evaluation of renal function is recommended before treatment decision in any patient in whom renal impairment is suspected	B
Percutaneous biopsy is recommended in active surveillance strategies in order to stratify the follow-up according to tumour histology	B

Recommendations for the diagnosis and staging of RCC	GR
Percutaneous biopsy is always required before ablative therapy and systemic therapy without previous pathology	A
When biopsy is indicated, good-quality needle cores should be obtained with a coaxial technique in order to increase the safety of the procedure and maximize its diagnostic yield	B

Recommendations for “other renal tumours”:

Recommendations for “Other renal tumours”	LE	GR
Except for angiomyolipomas, most of these less common renal tumours cannot be differentiated from RCC on the basis of radiology and should therefore be treated in the same way as RCC.	3	C
Bosniak cysts ≥ type III should be treated surgically. When possible, a nephron-sparing procedure should be performed in Bosniak type III.	3	C
In oncocytomas verified on biopsy, follow-up is an option.	3	C
In angiomyolipomas, treatment (surgery, thermal ablation, and selective arterial embolisation) can be considered in only very well selected cases. A nephron-sparing procedure is preferred	3	C
In advanced uncommon types of renal tumours, a standardised oncological treatment approach does not exist.	4	C

Bosniak classification of renal cysts:

Bosniak category	**Features**	**Work-up**
I	Simple benign cyst with a hairline-thin wall without septa, calcification, or solid components. Same density as water and does not enhance with contrast medium.	Benign
II	Benign cyst that may contain a few hairline-thin septa. Fine calcification may be present in the wall or septa. Uniformly high-attenuation lesions < 3 cm in size, with sharp margins without enhancement.	Benign
IIF	These may contain more hairline-thin septa. Minimal enhancement of a hairline-thin septum or wall. Minimal thickening of the septa or wall. The	Follow-up. Some are malignant.

Bosniak category	Features	Work-up
	cyst may contain calcification, which may be nodular and thick, with no contrast enhancement. No enhancing soft-tissue elements. This category also includes totally intrarenal, non-enhancing, high attenuation renal lesions > 3 cm. Generally well-marginated.	
III	These are indeterminate cystic masses with thickened irregular walls or septa with enhancement.	Surgery or active surveillance Over 50% are malignant
IV	Clearly malignant containing enhancing soft-tissue components.	Surgery. Most are malignant

Guidelines for primary treatment for RCC:

- Based on the available oncological and QoL outcomes, the current evidence suggests that localised renal cancers are best managed by nephron-sparing surgery (partial nephrectomy) rather than by radical nephrectomy, irrespective of the surgical approach.
- Radical nephrectomy with complete removal of the tumour-bearing kidney with perirenal fat and Gerota's fascia is currently recommended only for patients with localised RCC, who are not suitable for nephron-sparing surgery due to locally advanced tumour growth, when partial resection is technically not feasible due to an unfavourable localisation of the tumour or local growth.
- Complete resection of the primary RCC either by open or laparoscopic surgery offers a reasonable chance for cure.
- If pre-operative imaging is normal, routine adrenalectomy is not indicated.
- Lymphadenectomy should be restricted to staging because extended lymphadenectomy does not improve survival.
- In patients who have RCCs with tumour thrombus and no metastatic spread, prognosis is improved after nephrectomy and complete thrombectomy.
- Embolisation of the primary tumour is indicated in patients with gross haematuria or local symptoms (e.g. pain), in patients unfit for surgical intervention, and before surgical resection of large skeletal metastases. No benefit is associated with tumour embolisation before routine radical nephrectomy.

Nephron sparing surgery (NSS):

- Absolute indications for partial nephrectomy are
  - anatomical or functional solitary kidney or
  - bilateral RCC.
- Relative indications are
  - a functioning opposite kidney affected by a condition that might impair renal function and
  - hereditary forms of RCC with a high risk of developing a tumour in the contralateral kidney.
- Elective indications also localised unilateral RCC with a healthy contralateral kidney, which is the recommended approach, when technically feasible, since recurrence-free and long-term survival rates are similar to those for radical nephrectomy.
- Even in selected patients with a tumour diameter of up to 7 cm, nephron-sparing surgery has achieved results equivalent to those of a radical approach.
- If the tumour is completely resected, the thickness of the surgical margin (> 1 mm) does not correlate with the likelihood of local recurrence.
- If RCCs of larger size are treated with nephron-sparing surgery, follow-up should be intensified, as there is an increased risk of intrarenal recurrences.
- These procedures should only be delivered under the care of members of the specialist urology team and this is not subject to change by the network's own guidelines (National Cancer Action Team- Manual of Cancer Services 2011).

Laparoscopic radical and partial nephrectomy:

- Laparoscopic radical and partial nephrectomy Laparoscopic radical nephrectomy has a lower morbidity compared with open surgery.
- It has become an established surgical procedure for RCC.
- Whether done retro- or transperitoneally, the laparoscopic approach must duplicate established, open surgical, oncological principles.
- Long-term outcome data indicate equivalent cancer-free survival rates versus open radical nephrectomy.
- Thus, laparoscopic radical nephrectomy is now considered the standard of care for patients with T1 and T2 RCCs, who are not treatable by nephron-sparing surgery.
- Laparoscopic radical nephrectomy should not be performed in patients with T1 tumours for whom partial resection is indicated. Laparoscopic and robot assisted nephron-sparing surgery has become available treatment options in experienced hands.
- Laparoscopic partial resection has a risk for longer intraoperative ischaemia time than open partial nephrectomy and therefore carries a higher risk for reduced long-term renal function.
- The oncological outcome seems comparable in available series.

- Robotic-assisted partial nephrectomy requires further evaluation and more mature data before any conclusive technical recommendations can be made.
- Conclusion: Radical nephrectomy, preferably laparoscopic, is recommended for patients with localised RCC, who are not suitable for nephron-sparing surgery. Nephron-sparing surgery is the standard of care despite the surgical approach.

Minimally invasive alternative treatment:

- Minimally invasive techniques, such as ablation with percutaneous radio-frequency, crytherapy, microwave, and high-intensity focused US (HIFU), are suggested alternatives to surgery.
- Microwave therapy should only be used within the context of research.
- Potential advantages of these techniques include reduced morbidity, outpatient therapy, and the ability to treat high-risk patients not fit for conventional surgery.
- These experimental treatments might be recommended for selected patients with small, incidentally found, renal cortical lesions, elderly patients, patients with a genetic predisposition to multiple tumours, patients with a solitary kidney, or patients with bilateral tumours.
- The oncological efficacy remains to be determined for both cryotherapy and RFA, which are the most often used minimally invasive techniques.
- Current data suggest that cryoablation, when performed laparoscopically, results in fewer re-treatments and improved local tumour control compared with RFA.
- Current evidence on the safety and efficacy of percutaneous radiofrequency ablation (RFA) for renal cancer in the short and medium term appears adequate to support the use of this procedure provided that normal arrangements are in place for clinical governance, consent and audit, and provided that patients are followed up in the long term.
- For both treatments, tumour recurrence rates are higher compared with nephron-sparing surgery.
- Further research is needed to determine the oncological success rate and complications associated with these procedures.
- NICE encourages collection and publication of data on the long-term outcomes of these procedures.

Adjuvant therapy:

- Adjuvant tumour vaccination may improve the duration of the progression-free survival (PFS), which is especially important in patients at high risk of metastases, e.g. T3 RCC. Cytokine therapy does not improve survival after nephrectomy.
- Although there is no current data supporting adjuvant therapy with targeting agents, three worldwide phase III randomised trials are ongoing.

- Outside controlled clinical trials, there is no indication for adjuvant therapy following surgery.

Surgical treatment for metastatic RCC (mRCC):

- Nephrectomy of the primary tumour is curative only if surgery can excise all tumour deposits.
- For most patients with mRCC, nephrectomy is palliative.
- In a meta-analysis of two randomised studies, comparing nephrectomy + immunotherapy versus immunotherapy alone, increased long term survival was found in patients who underwent prior nephrectomy.
- For targeting agents, there is no current knowledge whether cytoreductive surgery is advocated before or after successful medical therapy. The CARMENA and SURTIME trials comparing cytoreductive nephrectomy with neoadjuvent/adjuvant (respectively) targeted therapy versus control arms of nephrectomy alone are awaited.
- However, in the absence of available evidence data, cytoreductive nephrectomy is recommended when possible.
- Complete removal of metastases contributes to improved clinical prognosis.
- Metastasectomy should be carried out in patients with resectable disease and a good PS.
- It should also be considered in patients with residual and respectable metastatic lesions, who have previously responded to systemic therapy.

Radiotherapy for metastasis:
For selected patients with non-resectable brain or osseous lesions, radiotherapy can induce significant symptom relief.

Systemic chemotherapy for mRCC:
Chemotherapy as monotherapy should not be considered effective in patients with mRCC.

Immunotherapy for mRCC:

- Interferon-alpha monotherapy is no longer recommended as first-line therapy for mRCC.
- Interferon alpha monotherapy still has a role only in selected cases (good performance status, clear cell type, lung metastases only).
- Interleukin-2 has more side effects than INF-α.
- High-dose IL-2 is associated with durable complete responses in a limited number of patients.

- Interleukin-2 can be considered as monotherapy in selected patients with a good prognosis profile.
- A combination of bevacizumab and IFN-α is more effective than IFNα in treatment-naïve, low-risk and intermediate-risk tumours.
- Vaccination therapy with tumour antigen 5T4 showed no survival benefit over the first-line standard of care.

Recommendations:

Recommendations for immunotherapy	**GR**
Monotherapy with IFN-α or high-dose bolus IL-2 can only be recommended as a first-line treatment for mRCC in selected patients with clear cell histology and good prognostic factors.	A
Bevacizumab + IFN-α is recommended as first-line therapy in low-risk and intermediate-risk patients.	B
Cytokine combinations, with or without additional chemotherapy, do not improve the overall survival in comparison with monotherapy.	A

Drugs targeting VEGF or mammalian target of rapamycin (mTOR):

- Recent advances in molecular biology have led to the development of several novel agents for the treatment of mRCC.
- In sporadic clear cell RCC, HIF accumulation due to von Hippel-Lindau (VHL) inactivation results in overexpression of VEGF and PDGF, both of which promote neoangiogenesis and contributes to the development and progression of RCC.
- At present, several targeting drugs have been approved both in the USA and in Europe for the treatment of mRCC:
- Their general inability to produce durable CRs necessitates chronic treatment in most patients
- The benefits must therefore be weighed against the overall burden of treatment, including acute and chronic toxicity, time and cost.

Recommendations:

Recommendations	**GR**
Sunitinib is recommended as first-line therapy in favorable-risk and intermediate-risk patients.	A
Bevacizumab + IFN-α is recommended as first-line therapy in favourable-risk and intermediate-risk patients.	A
Sorafenib is recommended as a second-line treatment for mRCC after	A

Recommendations	GR
cytokine failure.	
Pazopanib is recommended as first-line or after cytokine failure in favourable-risk and intermediaterisk patients.	A
Temsirolimus is recommended as first-line treatment in poor-risk patients.	A
Everolimus is recommended as second-line treatment after failure of tyrosine kinase inhibitors.	A
Axitinib is recommended as second-line treatment after failure of cytokines or tyrosine kinase inhibitors.	A

EAU recommendations for first and second line systemic therapy in mRCC:

Treatment	Risk or prior treatment	Recommended agent
First-line	Low- or intermediate-risk mRCC	Sunitinib Bevacizumab + IFN-a Pazopanib
	High-risk mRCC	Temsirolimus
Second-line	Prior cytokine therapy	Sorafenib Pazopanib
	Prior VEGFR therapy Prior mTOR inhibitor therapy	Everolimus Clinical trials

Surveillance following surgery for RCC:

- The aim of surveillance is to detect either local recurrence or metastatic disease while the patient is still surgically curable.
- There is no evidence for whether early versus later diagnosis of recurrence improves survival.
- Depending on the availability of new effective treatments, more strict follow-up schedules may be required, particularly as there is a higher local recurrence rate after cryotherapy and RFA.
- At present there is no evidence-based standard for the follow-up of patients with RCC as well as the optimal duration of follow-up.
- It is therefore a need for a surveillance algorithm that monitors patients after treatment for RCC that recognises not only the patient's risk profile but also treatment efficacy.

Algorithm for surveillance following treatment for RCC taking into account patient risk profile and treatment efficacy

Risk profile	**Treatment**	**Surveillance**						
		6 months	1 year	2 years	3 years	4 years	5 years	After 5 years
Low	RN/PN only	US	CT	US	CT	US	CT	Discharge
Inter-mediate	RN/PN/cryo/ RFA	CT	US	CT	US	CT	CT	CT alternate 2 years
High	RN/PN/cryo/ RFA	CT	CT	CT	CT	CT	CT	CT alternate years

Recommendations:

Recommendations	LE	GR
Surveillance after treatment for RCC should be based on a patient's risk factors and the type of treatment delivered.		C
For low-risk disease, CT/MRI can be used infrequently.	4	C
In the intermediate-risk group, intensified follow-up should be performed, including CT/MRI scans at regular intervals in accordance with a risk-stratified nomogram.	4	C
In high-risk patients, the follow-up examinations should include routine CT/MRI scans.	4	C
There is an increased risk of intrarenal recurrences in larger-size (> 7 cm) tumours treated with nephron-sparing surgery, or when there is a positive margin. Follow-up should be intensified in these patients		C

9.5 Testicular Cancer

Background:

- Testicular cancer represents between 1% and 1.5% of male neoplasms and 5% of urological tumours in general, with 3-10 new cases occurring per 100,000 males/per year.
- Data from the Surveillance Epidemiology and End Results (SEER) Program during the years 1973 to 1998 show a continuing increased risk among Caucasian men in the USA only for seminoma.
- Only 1-2% of cases are bilateral at diagnosis.
- There is a clear predominance (90-95%) of germ cell tumours
- Peak incidence is in the third decade of life for non-seminoma, and in the fourth decade for pure seminoma.
- Familial clustering has been observed, particularly among siblings
- Epidemiological risk factors for the development of testicular tumours are:
    - history of cryptorchidism or undescended testis (testicular dysgenesis syndrome)
    - Klinefelter's syndrome
    - familial history of testicular tumours among first-grade relatives (father/brothers)
    - the presence of a contralateral tumour or TIN
    - infertility.

PATHOLOGICAL CLASSIFICATION

The recommended pathological classification (modified from the 2004 version of the World Health Organization [WHO] guidance) is shown below:

- **Germ cell tumours**
    - Intratubular germ cell neoplasia, unclassified type (IGCNU)
    - Seminoma (including cases with syncytiotrophoblastic cells)
    - Spermatocytic seminoma (mention if there is sarcomatous component)
    - Embryonal carcinoma
    - Yolk sac tumour
    - Choriocarcinoma
    - Teratoma (mature, immature, with malignant component)
    - Tumours with more than one histological type (specify percentage of individual components)
- S**ex cord/gonadal stromal tumours**
    - Leydig cell tumour
    - Malignant Leydig cell tumour

  - Sertoli cell tumour - lipid-rich variant - sclerosing - large cell calcifying
  - Malignant Sertoli cell tumour
  - Granulosa cell tumour - adult type - juvenile type
  - Thecoma/fibroma group of tumours
  - Other sex cord/gonadal stromal tumours
    - incompletely differentiated
    - mixed
  - Tumours containing germ cell and sex cord/gonadal stromal (gonadoblastoma)
- **Miscellaneous non-specific stromal tumours**
  - Ovarian epithelial tumours
  - Tumours of the collecting ducts and rete testis
  - Tumours (benign and malignant) of non-specific stroma.

DIAGNOSIS:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

- **Clinical examination.**
- **Testicular imaging:**
  - US serves to confirm the presence of a testicular mass and to explore the contralateral testis.
  - Its sensitivity in detecting a testicular tumour is almost 100%, and it has an important role in determining whether a mass is intra- or extratesticular
  - Ultrasound of the testis has to be performed in young men without a palpable testicular mass who have retroperitoneal or visceral masses or elevated serum human chorionic gonadotrophin (hCG) or AFP or in men consulting for fertility problems
  - Ultrasound may be recommended in the follow-up of patients at risk, when other risk factors than microlithiasis are present (e.g. size < 12 ml or

atrophy, inhomogeneous parenchyma). Solely, the presence of microlithiasis is not an indication for a regular scrotal US
    - MRI of the scrotum offers a sensitivity of 100% and a specificity of 95-100%, but its high cost does not justify its use for diagnosis.
- **Serum tumour markers at diagnosis**
    - AFP (produced by yolk sac cells)
    - hCG (expression of trophoblasts)
    - LDH (lactate dehydrogenase).
- **Inguinal exploration and orchidectomy**
- **Organ-sparing surgery:** indicated in:
    - In synchronous bilateral testicular tumours
    - metachronous contralateral tumours
    - in a tumour in a solitary testis with normal pre-operative testosterone levels
    - organ preserving surgery can be performed when the tumour volume is less than 30% of the testicular volume and surgical rules are respected
    - the rate of associated TIN is high (at least up to 82%)
    - all patients must be treated with adjuvant radiotherapy (16-20 Gy) at some point.

STAGING

Serum tumour markers:

- The mean serum half-life of AFP and hCG is 5-7 days and 2-3 days, respectively.
- Tumour markers have to be re-evaluated after orchidectomy to determine half-life kinetics.
- Marker decline in patients with clinical stage I disease should be assessed until normalisation has occurred.
- Markers before start of chemotherapy are important to classify the patient according to the International Germ Cell Cancer Collaborative Group (IGCCCG) risk classification.
- The persistence of elevated serum tumour markers after orchidectomy might indicate the presence of metastatic disease (macro- or microscopically), while the normalisation of marker levels after orchidectomy does not rule out the presence of tumour metastases.
- During chemotherapy, the markers should decline; persistence has an adverse prognostic value

Radiological staging:

- Abdominopelvic CT offers a sensitivity of 70-80% in determining the state of the retroperitoneal nodes.
- Magnetic resonance imaging (MRI) produces similar results to CT in the detection of retroperitoneal nodal enlargement.
- MRI can be helpful when abdominopelvic CT or US are inconclusive, when CT is contraindicated because of allergy to contrast media, or when the physician or the patient are concerned about radiation dose.
- There is no evidence to support the use of the fluorodeoxyglucose (FDG)-PET in the staging of testis cancer.
- It is recommended in the follow-up of patients with seminoma with any residual mass at least 6 weeks after chemotherapy in order to decide on watchful waiting or active treatment.
- The use of FDGPET is not recommended in the re-staging of patients with non-seminomatous tumours after chemotherapy.

Recommended tests for staging at diagnosis

Test	**Recommendation**	**GR**
Serum tumour markers	AFP hCG LDH	A
Abdominopelvic CT	All patients	A
Chest CT	All patients	A
Testis US (bilateral)	All patients	A
Bone scan	In case of symptoms	
Brain scan (CT/MRI)	In case of symptoms and patients with metastatic disease with multiple lung metastases and high beta-hCG values	

Further investigations

Fertility investigations: Total testosterone LH FSH Semen analysis	B
Sperm banking should be offered	A

TNM classification for testicular cancer (UICC, 2009):

pT Primary tumour

pTX Primary tumour cannot be assessed

pT0 No evidence of primary tumour (e.g. histological scar in testis)

pTis Intratubular germ cell neoplasia (testicular intraepithelial neoplasia)

pT1 Tumour limited to testis and epididymis without vascular/lymphatic invasion: tumour may invade tunica albuginea but not tunica vaginalis

pT2 Tumour limited to testis and epididymis with vascular/lymphatic invasion, or tumour extending through tunica albuginea with involvement of tunica vaginalis

pT3 Tumour invades spermatic cord with or without vascular/lymphatic invasion

pT4 Tumour invades scrotum with or without vascular/lymphatic invasion

N Regional lymph nodes clinical

NX Regional lymph nodes cannot be assessed

N0 No regional lymph node metastasis

N1 Metastasis with a lymph node mass 2 cm or less in greatest dimension or multiple lymph nodes, none more than 2 cm in greatest dimension

N2 Metastasis with a lymph node mass more than 2 cm but not more than 5 cm in greatest dimension, or multiple lymph nodes, any one mass more than 2 cm but not more than 5 cm in greatest dimension

N3 Metastasis with a lymph node mass more than 5 cm in greatest dimension

pN Pathological

pNX Regional lymph nodes cannot be assessed

pN0 No regional lymph node metastasis

pN1 Metastasis with a lymph node mass 2 cm or less in greatest dimension and 5 or fewer positive nodes, none more than 2 cm in greatest dimension

pN2 Metastasis with a lymph node mass more than 2 cm but not more than 5 cm in greatest dimension; or more than 5 nodes positive, none more than 5 cm; or evidence or extranodal extension of tumour

pN3 Metastasis with a lymph node mass more than 5 cm in greatest dimension

M Distant metastasis

MX Distant metastasis cannot be assessed

M0 No distant metastasis

M1 Distant metastasis

M1a Non-regional lymph node(s) or lung

M1b Other sites

S Serum tumour markers

Sx Serum marker studies not available or not performed

S0 Serum marker study levels within normal limits

	LDH (U/l)		hCG (mIU/mL)		AFP (ng/mL)
S1	< 1.5 x N	and	< 5,000	and	< 1,000
S2	1.5-10 x N	or	5,000-50,000	or	1,000-10,000
S3	> 10 x N	or	> 50,000	or	> 10,000

Prognostic-based staging system for metastatic germ cell cancer (International Germ Cell Cancer Collaborative Group (IGCCCG):

Good-prognosis group	
Non-seminoma (56% of cases) 5-year PFS 89% 5-year survival 92%	All of the following criteria: • Testis/retroperitoneal primary • No non-pulmonary visceral metastases • AFP < 1,000 ng/mL • hCG < 5,000 IU/L (1,000 ng/mL) • LDH < 1.5 x ULN
Seminoma (90% of cases) 5-year PFS 82% 5-year survival 86%	All of the following criteria: • Any primary site • No non-pulmonary visceral metastases • Normal AFP • Any hCG • Any LDH
Intermediate prognosis group	
Non-seminoma (28% of cases) 5-year PFS 67% 5-year survival 72%	• Testis/retroperitoneal primary • AFP 1,000 - 10,000 ng/mL or • No non-pulmonary visceral metastases • hCG 5,000 - 50,000 IU/L or • LDH 1.5 - 10 x ULN
Seminoma (10% of cases) 5 years PFS 75% 5-year survival 80%	All of the following criteria: • Any primary site • Non-pulmonary visceral metastases • Normal AFP • Any hCG • Any LDH
Poor prognosis group	
Non-seminoma (16% of cases) 5-year PFS 41% 5-year survival 48%	Any of the following criteria: • Mediastinal primary • Non-pulmonary visceral metastases • AFP > 10,000 ng/mL or • hCG > 50,000 IU/L (10,000 ng/mL) or • LDH > 10 x ULN
Seminoma	No patients classified as poor prognosis

Prognostic factors for occult metastatic disease in testicular cancer

	For seminoma	For non-seminoma
Pathological (for stage I)		
Histopathological type invasion of the primary tumour	• Tumour size (> 4 cm) • Invasion of the rete testis	• vascular/lymphatic • Proliferation rate > 70% • Percentage of embryonal carcinoma > 50%
Clinical (for metastatic disease)		
• Primary location • Elevation of tumour marker levels • Presence of non-pulmonary visceral metastasis		

TREATMENT: STAGE I GERM CELL TUMOURS

Supranetwork Testicular Team

- The minimum catchment population for the specialist treatment of testicular cancer is two million.
- Supranetwork teams for testicular cancer deliver supranetwork care for their referring catchment.
- The minimum catchment population of two million means that currently no cancer network in England should host more than one such team on the basis of their own network population and some networks will not be able to host a team, needing to refer such patients to a team in a neighbouring network.
- In order that supranetwork teams for testicular cancer experience the full range of practice for the disease, they are required to deliver all of the care including local care to at least part of their network, usually the local catchment of their host locality. For testicular teams to add their full potential value to patient care, some surgical procedures and their immediate post-op care are required to be restricted to certain named hospitals.

Stage I seminoma

- After modern staging procedures, about 15-20% of stage I seminoma patients have subclinical metastatic disease, usually in the retroperitoneum, and will relapse after orchidectomy alone.

Surveillance

- The actuarial relapse rate is in the order of 15-20% at 5 years, and most of the relapses are first detected in infra-diaphragmatic lymph nodes.
- In patients with low risk the recurrence under surveillance is as low as 6%.
- Chemotherapy, according to the IGCCCG classification, is a possible treatment for seminoma relapse under surveillance.
- The overall cancer-specific survival rate reported under surveillance performed by experienced centres is 97-100% for seminoma stage I.
- The main drawback of surveillance is the need for more intensive follow-up, especially with repeated imaging examinations of the retroperitoneal lymph nodes, for at least 5 years after orchidectomy.
- There is a small but clinically significant risk of relapse more than 5 years after orchidectomy for stage I seminoma, which supports the need for long term surveillance.

Adjuvant chemotherapy

- Compared with adjuvant radiotherapy, studies did not show a significant difference with regard to recurrence rate, time to recurrence and survival after a median follow-up of 4 years.
- Adjuvant carboplatin therapy using a dosage of one course AUC 7 is an alternative to radiotherapy or surveillance in stage I seminoma.

Adjuvant radiotherapy

- Seminoma cells are extremely radiosensitive.
- Adjuvant radiotherapy to a para-aortic (PA) field or to a hockeystick field (para-aortic and ipsilateral iliac nodes), with moderate doses (total 20-24 Gy), will reduce the relapse rate to 1-3%.
- After modern radiotherapy, nearly all relapses will first occur outside the irradiated field (supradiaphragmatic lymph nodes or in the lungs).
- Adjuvant irradiation of supradiaphragmatic lymph nodes is not indicated in seminoma stage I. With regard to the irradiation dose, the MRC recently finished a large randomised trial of 20 Gy versus 30 Gy PA radiation in stage I seminoma that showed equivalence for both doses in terms of recurrence rates.
- The rate of severe radiation-induced long-term toxicity is < 2%. Moderate chronic gastrointestinal (GI) side-effects are seen in ~5% of patients, and moderate acute GI toxicity in ~60%.

Retroperitoneal lymph node dissection (RPLND)

- Post RPLND incidence of retroperitoneal relapses is high (9.5%).
- This policy should not be recommended in stage I seminoma.

Risk-adapted treatment

- Using tumour size > 4 cm and rete testis invasion, patients with seminoma stage I may be subdivided into a low-and high-risk group of occult metastatic disease.
- Patients with and without both risk factors have a risk of occult disease of 32% and 12%, respectively.
- These risk factors were introduced by an analysis of retrospective trials (29). A prospective trial based on these risk factors (no risk factors: surveillance; both risk factors: two courses of carboplatin AUC 7) showed the feasibility of a risk-adapted approach.
- Early data with limited follow-up indicate that patients without either risk factor have a 6.0% risk of relapse at 5 years.
- Patients in the high risk group treated with carboplatin experienced a 1.4% relapse rate at mean follow-up of 34 months.
- However, given the fact that cure is achieved in ~100% in patients with stage I seminoma whatever therapy used (adjuvant radiotherapy, adjuvant chemotherapy, or surveillance) and that the relapse rate in large surveillance series not using risk factors is ~15-20%, indicates a risk of over-treatment. Therefore, the therapeutic decision should be shared with an informed patient.

Guidelines for the treatment of seminoma stage I

Guidelines	**GR**
Surveillance is the recommended management option (if facilities available and patient compliant).	A
Carboplatin-based chemotherapy (one course at AUC 7) is recommended.	B
Adjuvant treatment is not recommended for patients at very low risk.	A
Radiotherapy is not recommended as adjuvant treatment.	A

NSGCT stage I

- Up to 30% of NSGCT patients with clinical stage I (CS1) disease have subclinical metastases and will relapse if surveillance alone is applied after orchidectomy

Surveillance

- The largest reports of the surveillance strategy indicate a cumulative relapse rate of ~30%, with 80% of relapses occurring during the first 12 months of follow-up, 12% during the second year and 6% during the third year, decreasing to 1% during the fourth and fifth years, and occasionally even later.

- About 35% of relapsing patients have normal levels of serum tumour markers at relapse.
- About 60% of relapses are in the retroperitoneum. Despite very close follow-up, 11% of relapsing patients presented with large-volume recurrent disease.
- Based on the overall cancer-specific survival data, surveillance within an experienced surveillance programme may be offered to patients with non-risk stratified clinical stage I non-seminoma as long as they are compliant and informed about the expected recurrence rate as well as the salvage treatment.

Primary chemotherapy

- Two courses of chemotherapy with cisplatin, etoposide and bleomycin (PEB) as primary treatment for high-risk patients (having ~50% risk of relapse) are recommended , with a relapse rate of only 2.7% was reported, with very little long-term toxicity.
- Adjuvant chemotherapy do not seem to adversely affect fertility or sexual activity.
- Long term (> 20 years) side effects of adjuvant chemotherapy in this setting are currently unknown.
- It is important to be aware of slow-growing retroperitoneal teratomas after primary chemotherapy.

Risk-adapted treatment

- It is based on the risk factor vascular invasion.
- Risk-adapted treatment is an equally effective alternative treatment of choice in CS1 NSGCT.
- If applied, patients with vascular invasion are recommended to undergo adjuvant chemotherapy with two cycles of PEB, and patients without vascular invasion are recommended to undergo surveillance.
- The Swedish-Norwegian Testicular Cancer Project (SWENOTECA) recently showed that in a large population-based study with a risk-adapted approach within a management programme and a median follow-up of 4.7 years, the relapse rate was 3.2% for patients with vascular invasion treated with only one adjuvant PEB.
- Taken together, ~300 patients with high-risk CS I have been adjuvantly treated with 1 x PEB with a follow-up of > 5 yrs. As long as 1 x PEB has not been proven superior or at least equivalent to 2 courses PEB, this adjuvant treatment cannot be recommended outside of a clinical trial or a prospective registry.

Retroperitoneal lymph node dissection

- If performed, ~30% of patients are found to have retroperitoneal lymph node metastases, which corresponds to pathological stage II (PS2).
- 10% of the PS1 patients relapse at distant sites.
- The main predictor of relapse in CS1 NSGCT is histopathological evidence of vascular invasion by tumour cells in, or near, the primary tumour in the testis.
- For CS1, patients without vascular invasion have only a 15-20% risk of relapse on surveillance, compared with a 50% relapse rate in patients with vascular invasion.
- The risk of relapse for PS1 patients is < 10% for those without vascular invasion and ~30% for those with vascular invasion.
- If two (or more) courses of cisplatin-based chemotherapy are given adjuvant to RPLND in PS2 cases, the relapse rate is reduced to < 2%, including teratoma relapse).
- The risk of retroperitoneal relapse after a properly performed nerve-sparing RPLND is very low (< 2%), as is the risk of ejaculatory disturbance or other significant side-effects.
- If there is a rare indication to perform a staging RPLND, a laparoscopic or robot-assisted RPLND is feasible in expert hands. This minimal-invasive approach cannot be recommended as a standard approach outside of a specialised laparoscopic centre.
- In a randomised comparison of RPLND with one course of PEB chemotherapy, adjuvant chemotherapy significantly increased the 2-year recurrence-free survival to 99.41% (confidence interval [CI] 95.87%, 99.92%) as opposed to surgery, which had a 2-year recurrence-free survival of 92.37% (CI 87.21%, 95.50%).
- Therefore, one course of adjuvant PEB is superior to RPLND with regard to recurrence rates in patients unstratified for risk factors . In the SWENOTECA data mentioned in section 7.3.3 it was also found that one adjuvant PEB reduced the number of recurrences to 3.2% in the high-risk and to 1.4% in the low-risk patients.

CS1S with (persistently) elevated serum tumour markers

- If the marker level increases after orchidectomy, the patient has residual disease. If RPLND is erformed, up to 87% of these patients have pathologically documented nodes in the retroperitoneum (165). An
- US examination of the contralateral testicle must be performed, if this was not done initially.
- The treatment of true CS1S patients is still controversial. They may be treated with three courses of primary PEB chemotherapy and with follow-up as for CS1B patients after primary chemotherapy, or by RPLND. The presence of vascular invasion may strengthen the indication for primary chemotherapy as most CS1S with vascular invasion will need chemotherapy sooner or later anyway.

Guidelines for the treatment of NSGCT stage I

NSGCT stage 1	**GR**
CS1 risk-adapted treatments based on vascular invasion or surveillance without using risk factors are recommended treatment options.	A
Risk-adapted treatments for CS1 based on vascular invasion	
CS1A (pT1, no vascular invasion): low risk	
If the patient is willing and able to comply with a surveillance policy, long-term (at least 5 years) close follow-up should be recommended.	A
In low-risk patients not willing (or suitable) to undergo surveillance, adjuvant chemotherapy or nerve-sparing RPLND are treatment options. If RPLND reveals PN+ (nodal involvement) disease, chemotherapy with two courses of PEB should be considered.	A
CS1B (pT2-pT4): high risk	
Primary chemotherapy with two courses of PEB should be recommended (one course of PEB within a clinical trial or registry).	A
Surveillance or nerve-sparing RPLND in high-risk patients remains an option for those not willing to undergo adjuvant chemotherapy. If pathological stage II is revealed at RPLND, further chemotherapy should be considered.	A

TREATMENT: METASTATIC GERM CELL TUMOURS

The treatment of metastatic germ cell tumours depends on:

- the histology of the primary tumour;
- prognostic groups as defined by the IGCCCG.

Low-volume metastatic disease (stage IIA/B)
Seminoma:

- The standard treatment for stage IIA/B seminoma has been radiotherapy.
- The radiation dose delivered in stage IIA and IIB is approximately 30 Gy and 36 Gy, respectively.
- The standard radiation field compared with stage I will be extended from the PA region to the ipsilateral iliac field (the hockey-stick field).
- Overall survival is almost 100%. Conversely, dose reduction to 27 Gy has been associated with 11% of relapses.

Non-seminoma

- Initial chemotherapy is recommended in all advanced cases of NSGCT (except for stage II NSGCT disease without elevated tumour markers, which alternatively can be managed by primary RPLND or surveillance to clarify stage).
- If surveillance is chosen, one follow-up after 6 weeks is indicated to document whether the lesion is growing, remaining stable or shrinking.
    - A shrinking lesion is likely to be of non-malignant origin and should be observed further.
    - A stable or growing lesion indicates either teratoma or an undifferentiated malignant tumour.
    - If the lesion is growing without a corresponding increase in the tumour markers AFP or beta-hCG, RPLND should be performed by an experienced surgeon because of suspected teratoma.
    - Patients with a growing lesion and a concomitant increase in the tumour markers AFP or beta-hCG should not undergo surgery; they require chemotherapy with PEB according to the treatment algorithm for patients with metastatic disease and IGCCCG recommendations.
- An alternative to the surveillance strategy in marker-negative II A/B non-seminoma with suspicion of an undifferentiated malignant tumour is a (CT-guided) biopsy, if technically possible.
- There is insufficient published data on PET scans in this situation.
- Patients not willing to undergo primary chemotherapy have the option of primary nerve-sparing RPLND with adjuvant chemotherapy (two cycles of PEB) in case of metastatic disease.
- Primary chemotherapy and primary RPLND are comparable options in terms of outcome but side-effects and toxicity are different, allowing for involvement of the patient in selecting the treatment of choice. The cure rate with either approach will be close to 98%.

Advanced metastatic disease

- The primary treatment of choice for advanced disease is three or four cycles of PEB combination chemotherapy, depending on the IGCCCG risk classification. This regimen has proven superiority to cisplatin, vinblastine and bleomycin (PVB) in patients with advanced disease.
- Good prognosis group (IGCCCG Classification):
    - standard treatment consists of three cycles of PEB
    - in very selected cases where bleomycin is contraindicated, four cycles of EP.
- Intermediate prognosis group (5-year survival rate of ~80%):
    - four cycles of PEB as standard treatment.
- Poor prognosis group (5-year progression-free survival is 45-50%):
    - standard treatment consists of four cycles of PEB, or etoposide and ifosfamide (PEI) with similar effect but more toxicity.

- poor-prognosis patients should be transferred to a reference centre because a better outcome was reported for intermediate and poor prognosis patients who had been treated within a clinical trial in a high volume centre.
- There are no general recommendations for treatment modifications for patients with a poor general condition (Karnofsky < 50%) or extended liver infiltration (> 50%).
- Patients with extended pulmonary infiltration are at risk for acute respiratory distress syndrome: adapting the doses of the PEB regimen in the first cycle of chemotherapy (only 3 days of EP without bleomycin) was suggested to reduce the risk of early death in this setting.

Residual tumour resection

- A residual mass of seminoma should not be primarily resected, irrespective of the size, but controlled by imaging investigations and tumour markers.
- FDG-PET has a high negative predictive value in patients with residual masses after treatment of seminoma but false positive results can be a problem and scans should not be performed < 2 months after chemotherapy.
- In patients with residuals of > 3 cm, FDG-PET should be performed in order to gain more information on the viability of these residuals.
- In patients with residuals of < 3 cm, the use of FDG-PET is optional.
- On progression, salvage therapy is indicated (chemotherapy, salvage surgery, radiotherapy) .
- In patients with concurrent hCG elevation, progressing seminoma after first-line chemotherapy should be treated by salvage chemotherapy (or radiotherapy if only small volume recurrence is present).
- Progressing patients without hCG progression should undergo histological verification (e. g. by biopsy or open surgery) before salvage chemotherapy is given. In the case of non-seminoma and complete remission after chemotherapy (no tumour visible), residual tumour resection is not indicated.
- The long-term relapse rate in this patient group is 6-9%, however, one third of the late relapsing patients will not survive.
- In the case of any visible residual mass and marker normalisation, surgical resection is indicated. In patients with lesions < 1 cm, there still is an increased risk of residual cancer or teratoma although the role of surgery in this setting is debated.
- In persistent larger volume retroperitoneal disease, all areas of primary metastatic sites must be completely resected within 4-6 weeks of completion of chemotherapy.
- If technically feasible, a nerve-sparing procedure should be performed.

- Overall, following PEB induction chemotherapy, only 10% of residual masses contain viable cancer, 50% contain mature teratoma, and 40% contain necrotic-fibrotic tissue.
- As yet, no imaging investigations, including PET or a prognosis model, are able to predict histological differentiation of the non-seminomatous residual tumour. Thus, residual tumour resection is mandatory in all patients with residual disease > 1 cm.
- The extent of surgery should be based on the risk of relapse of an individual patient and quality of life issues. If possible, all the masses should be resected, because a complete resection, in the setting of viable malignant cells, is more critical than recourse to post-operative chemotherapy.
- There is growing evidence that “template” resections in selected patients yield equivalent long-term results compared to bilateral systematic resections in all patients.
- Mere resection of the residual tumour (so called “lumpectomy”) should not be performed.
- The histology may diverge in different organ sites. Resection of contralateral pulmonary lesions is not mandatory in case pathologic examination of the lesions from the first lung shows complete necrosis.

Consolidation chemotherapy after secondary surgery

- After resection of necrosis or mature/immature teratoma, no further treatment is required.
- In the case of incomplete resection of other germ cell tumour pathologies, two adjuvant cycles of conventionally dosed cisplatin-based chemotherapy may be given in certain subgroups (e.g. ‘poor prognosis’ patients).
- After complete resection of ‘vital’ tumour < 10% of the total volume, especially in patients with an initially good prognosis group according to IGCCCG, the relapse rate is very low and adjuvant chemotherapy is not beneficial for preventing further relapse.
- The prognosis will definitely deteriorate if vital malignant neoplasm is found in resection specimens after second- and third-line chemotherapy. In this latter situation, post-operative chemotherapy is not indicated and is unable to improve the prognosis.

Systemic salvage treatment for relapse or refractory disease

- Cisplatin-based combination salvage chemotherapy will result in long-term remissions for about 50% of the patients who relapse after first-line chemotherapy (255). The.

- Regimens of choice are four cycles of PEI/VIP (etoposide, ifosfamide, cisplatin), four cycles of TIP (paclitaxel, ifosfamide, cisplatin) or four cycles of VeIP (vinblastine, ifosfamide, cisplatin)
- Due to the lack of evidence, it is therefore of the utmost importance that these rare patients are treated within clinical trials and at experienced centres.

Treatment of brain metastases

- Brain metastases occur in the frame of a systemic relapse and rarely as an isolated relapse.
- The longterm survival of patients presenting with brain metastases at initial diagnosis is poor (30-40%)
- 5-year survival-rate for brain metastasis as a recurrent disease is even poorer (2-5%)
- Chemotherapy is the initial treatment in this case, and some data support the use of consolidation radiotherapy, even in the case of a total response after chemotherapy.
- Surgery can be considered in the case of a persistent solitary metastasis, depending on the systemic state, the histology of the primary tumour and the location of the metastasis.

FOLLOW-UP AFTER CURATIVE THERAPY

Recommended follow-up schedule in a surveillance policy: stage I non-seminoma

Procedure	**Year**	**Year**	**Year**	**Year**
	1	**2**	**3-5**	**6-10**
Physical examination	4 times	4 times	Once/year	Once/year
Tumour markers	4 times	4 times	Once/year	Once/year
Plain radiography chest	Twice	Twice		
Abdominopelvic CT	Twice (at 3 and 12 months)			

Recommended follow-up schedule after retroperitoneal lymphadenectomy or adjuvant chemotherapy: stage I non-seminoma

Procedure	**Year**	**Year**	**Year**	**Year**

	1	2	3-5	6-10
Physical examination	4 times	4 times	Once/year	Once/year
Tumour markers	4 times	4 times	Once/year	Once/year
Plain radiography chest	Twice	Twice		
Abdominopelvic CT	Once	Once		

Recommended follow-up schedule for post-orchidectomy surveillance, radiotherapy or chemotherapy: stage I seminoma

Procedure	**Year**	**Year**	**Year**	**Year**
	1	**2**	**3-5**	**6-10**
Physical examination	4 times	4 times	Once/year	Once/year
Tumour markers	4 times	4 times	Once/year	Once/year
Plain radiography chest	Twice	Twice		
Abdominopelvic CT	Once	Once		

Recommended minimum follow-up schedule in advanced NSGCT and seminoma

Procedure	**Year**	**Year**	**Year**	**Year**
	1	**2**	**3-5**	**Thereafter**
Physical examination	4 times	4 times	Twice/year	Once/year
Tumour markers	4 times	4 times	Twice/year	Once/year
Plain radiography chest	Twice	Twice	Twice/year	Once/year
Abdominopelvic CT	Twice	Twice	As indicated	As indicated
Chest CT	As indicated	As indicated	As indicated	As indicated
Brain CT	As indicated	As indicated	As indicated	As indicated

9.6 Upper Urinary Tract Urothelial Cell Carcinomas

Epidemiology:

- Upper urinary tract urothelial cell carcinomas (UUT-UCCs) are uncommon and account for only 5-10% of urothelial carcinomas
- The estimated annual incidence of UUT-UCCs in Western countries is about one or two new cases per 100,000 inhabitants.
- Pyelocaliceal tumours are about twice as common as ureteral tumours.
- In 8-13% of cases, concurrent bladder cancer is present.
- Recurrence of disease in the bladder occurs in 30-51% of UUT-UCC patients
- Recurrences in the contralateral upper tract are observed in 2-6%.
- 60% of UUT-UCCs are invasive at diagnosis.
- Upper urinary tract urothelial cell carcinomas have a peak incidence in people in their 70s and 80s, and UUT-UCC is three times more prevalent in men than in women.
- There are familial/hereditary cases of UUT-UCCs linked to hereditary nonpolyposis colorectal carcinoma (HNPCC)

Risk factors:

- Tobacco and occupational exposure remain the principal exogenous risk factors for developing these tumours. Exposure to tobacco increases the relative risk of developing a UUT-UCC from 2.5 to 7
- UUT-UCC “amino tumours” are related to occupational exposure to certain aromatic amines. These aromatic hydrocarbons are used in many industries (e.g., dyes, textiles, rubber, chemicals, petrochemicals, and coal). They are responsible for the carcinogenicity of certain chemicals, including benzidine and β-naphthalene. The estimated risk (odds ratio) of developing UCC after exposure to aromatic amines is 8.3.
- Upper urinary tract tumours resulting from phenacetin consumption almost disappeared after the product was banned in the 1970s.
- Although the incidence of Balkan endemic nephropathy is also on the decline, roles have been proposed for aristolochic acid and the consumption of Chinese herbs in the physiopathology and induction, respectively, of this nephropathy.
- One polymorphism specific to UUT-UCC has been reported so far. A variant allele, SULT1A1*2, which reduces sulfotransferase activity, enhances the risk of developing UUT-UCC.
- Epidermoid carcinoma of the UUT is associated with chronic inflammatory and infectious disease arising from stones in the UUT.

TNM classification of UUT-UCC (2009)

T - Primary Tumour
Tx Primary tumour cannot be assessed

T0 No evidence of primary tumour Ta Non-invasive papillary carcinoma Tis Carcinoma in situ T1 Tumour invades subepithelial connective tissue T2 Tumour invades muscle T3 (Renal pelvis) Tumour invades beyond muscularis into peripelvic fat or renal parenchyma (Ureter) Tumour invades beyond muscularis into periureteric fat T4 Tumour invades adjacent organs or through the kidney into perinephric fat
N - Regional Lymph Nodes
Nx Regional lymph nodes cannot be assessed N0 No regional lymph-node metastasis N1 Metastasis in a single lymph node 2 cm or less in the greatest dimension N2 Metastasis in a single lymph node more than 2 cm but not more than 5 cm in the greatest dimension or multiple lymph nodes, none more than 5 cm in greatest dimension N3 Metastasis in a lymph node more than 5 cm in greatest dimension
M - Distant Metastasis M0 No distant metastasis M1 Distant metastasis

World Health Organization grading for bladder cancer

1973 WHO grading
Urothelial papilloma
Grade 1: well differentiated
Grade 2: moderately differentiated
Grade 3: poorly differentiated

Diagnosis:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

Imaging:

CT Urogram (CTU)

- CTU is the gold standard for exploration of the upper urinary tract and has replaced intravenous excretory urography.
- It must be conducted under optimal conditions, particularly with acquisition of an excretory phase.
- The detection rate of UUT-UCC is satisfactory for this type of imaging: 96% sensitivity and 99% specificity for polypoid lesions between 5 and 10 mm.
- Sensitivity drops to 89% for polypoid lesions < 5 mm and 40% for polypoid lesions < 3 mm.

Magnetic resonance imaging (MRI):

- MRI urography is indicated in patients who cannot be subjected to a CTU.
- The detection rate of MRI is 75% after contrast injection for tumours < 2 cm.
- MRI urography with contrast injection, however, remains contraindicated in selected patients with severe renal impairment (< 30 ml/min creatinine clearance) due to the risk of nephrogenic systemic fibrosis.
- Magnetic resonance urography without contrast is less helpful compared with CTU in diagnosing UUT-UCCs.

Cystoscopy and urinary cytology

- Positive urine cytology is highly suggestive of UUT-UCC when bladder cystoscopy is normal and if CIS of the bladder or prostatic urethra has been excluded.
- Cytology is less sensitive for UUT-UCC than for bladder tumours, even for high-grade lesions, and it should ideally be performed in situ (i.e. in the renal cavities).
- A positive cytology may be valuable in staging because it has been associated with muscle-invasive and nonorgan-confined disease.

Diagnostic ureteroscopy

- Ureteroscopy is a better approach to diagnose UUT-UCCs.
- Flexible ureteroscopy is especially useful when there is diagnostic uncertainty, when conservative treatment is being considered, or in patients with a solitary kidney.
- The possible advantages of ureteroscopy should be discussed in the preoperative assessment of any UUT-UCC patient. Combining ureteroscopic biopsy grade, ipsilateral hydronephrosis, and urinary cytology may help decision making on radical nephroureterectomy (RNU) versus endoscopic treatment.

Guidelines for the diagnosis of UUT-UCC

Recommendations	GR
Urinary cytology	A
Cystoscopy to rule out a concomitant bladder tumour	A
CTU	A

Prognostic factors:

- Upper urinary tract urothelial cell carcinomas that invade the muscle wall usually have a very poor prognosis.
- The 5-yr specific survival is < 50% for pT2/pT3 and < 10% for pT4.
- Tumour stage and grade: the primary recognised prognostic factors.
- Age: poor prognosis with advanced age at diagnosis.
- Gender: no relation.
- Tumour location: no relation.
- Lymphovascular invasion: is present in approximately 20% of UUT-UCCs and an independent predictor of survival.
- Extensive tumour necrosis: is an independent predictor of clinical outcomes in patients who undergo RNU.
- The tumour architecture (e.g., papillary vs. sessile) of UUT-UCCs appears to be associated with prognosis after RNU. A sessile growth pattern is associated with worse outcomes (LE: 3) (8,63,69).
- The presence of concomitant CIS in patients with organ-confined UUT-UCC is associated with a higher risk of recurrent disease and cancer-specific .

Treatment

Localised disease:

- Radical nephroureterectomy (RNU)with excision of the bladder cuff is the gold standard treatment for UUT-UCCs, regardless of the location of the tumour in the upper urinary tract
- The RNU procedure must comply with oncologic principles, which consist of preventing tumour seeding by avoiding entry into the urinary tract during tumour resection.
- Resection of the distal ureter and its orifice is performed because it is a part of the urinary tract with considerable risk of recurrence.
- After removal of the proximal part, it is almost impossible to image or approach it by endoscopy during follow-up.
- Plucking/endoscopic resection of the distal ureter (apart from ureteral stripping) are non-inferior to excision of the bladder cuff.

- A delay > 45 d between diagnosis and resection of the tumour constitutes a risk for disease progression.
- Lymph node dissection associated with RNU is of therapeutic interest and allows for optimal staging of the disease.
- Lymphadenectomy in pN+ allows for reduction of the tumour mass to guide patients towards adjuvant treatments.
- Anatomic sites of lymphadenectomy have not yet been clearly defined.
- The number of lymph nodes to be removed depends on the tumour location.
- Lymphadenectomy appears to be unnecessary in cases of TaT1 UUT-UCCs.
- The safety of laparoscopic RNU has not yet achieved final proof. In early experience, there were reports of retroperitoneal metastatic dissemination and dissemination along the trocar pathway when large tumours were manipulated in a pneumoperitoneal environment.
- Recent data, however, show a tendency towards equivalent oncologic results between laparoscopic RNU and open surgery.
- In addition, the laparoscopic approach appears to be superior to open surgery only with regard to functional outcomes.
- When considering laparoscopic RNU the following precautions must be considered:
    - Entering the urinary tract should be avoided.
    - Direct contact of the instruments with the tumour should be avoided.
    - Laparoscopic RNU must take place in a closed system.
    - Morcellation of the tumour should be avoided, and an endobag is necessary to extract the tumour.
    - The kidney and ureter must be removed en bloc with the bladder cuff.
    - Invasive, large (T3/T4 and/or N+/M+), or multifocal tumours are contraindications for laparoscopic RNU, until proven otherwise.

Guidelines for radical management of UUT-UCC: radical nephroureterectomy

Indications for RNU for UUT-UCC	GR
Suspicion of infiltrating UUT-UCC on imaging	B
High-grade tumour (urinary cytology)	B
Multifocality (with two functional kidneys)	B
Techniques for RNU in UUT-UCC Open and laparoscopic access are equivalent in terms of efficacy	B
Bladder cuff removal is imperative	A
Several techniques for bladder cuff excision are acceptable except stripping	C
Lymphadenectomy is recommended in case of invasive UUT-UCC	C

Conservative surgery

- Conservative surgery for low-risk UUT-UCCs allows for preservation of the upper urinary renal unit while sparing the patient the morbidity associated with open radical surgery
- Conservative management of UUT-UCCs can be considered in imperative cases (renal insufficiency, solitary functional kidney) or in elective cases (i.e. when the contralateral kidney is functional) for low-grade, low-stage tumours.
- The choice of technique depends on technical constraints, the anatomic location of the tumour, and the experience of the surgeon.
    - Ureteroscopy: Endoscopic ablation can be considered in highly selected cases (96,97,98) and in these situations:
        - A flexible rather than a rigid ureteroscope, laser generator, and pliers (pluck) for biopsies are available.
        - The patient is informed of the need for closer, more stringent surveillance.
        - A complete resection is advocated.
    - Segmental resection:
        - It provides adequate pathologic specimens for definitive staging and grade analysis while also preserving the ipsilateral kidney.
        - Segmental resection is possible for the treatment of low- and high-risk tumours of the distal ureter .
        - It is necessary, however, to ensure that the area of tissue around the tumour is not invaded.
        - Segmental resection of the iliac and lumbar ureter is associated with a failure rate greater than that for the distal pelvic ureter.
        - Open resection of tumours of the renal pelvis or calices has almost disappeared.
        - Resection of pyelocaliceal tumours is technically difficult, and the recurrence rate is higher than for tumours of the ureter.
    - Percutaneous access:
        - It is considered for low-grade or non-invasive UUT-UCCs in the renal cavities.
        - This treatment option may be offered to patients with low-grade tumours in the lower caliceal system that are inaccessible or difficult to manage by ureteroscopy.
        - A theoretical risk of seeding exists in the puncture tract and in perforations that may occur during the procedure.
        - This approach, however, is being progressively abandoned due to enhanced materials and advances in distal-tip deflection of recent ureteroscopes.
    - Adjuvant topical agents:
        - BCG or mitomycin C in the urinary tract by percutaneous nephrostomy via a three-valve system open at 20 cm (after

complete eradication of the tumour), or even through a ureteric stent is technically feasible after conservative treatment of UUT-UCCs or for the treatment of CIS.

- The medium-term results are similar to those observed for the treatment of bladder tumours but have not been confirmed in long-term studies.

Guidelines for conservative management of UUT-UCC

Indications for conservative management of UUT-UCC	**GR**
Unifocal tumour	B
Small tumour	B
Low-grade tumour (cytology or biopsies)	B
No evidence of an infiltrative lesion on MDCTU	B
Understanding of close follow-up	B
Techniques used in conservative management of UUT-UCC	
Laser should be used in case of endoscopic treatment	C
Flexible ureteroscopy is preferable over rigid ureteroscopy	C
Open partial resection is an option for pelvic ureteral tumours	C
A percutaneous approach remains an option in small low-grade caliceal tumours unsuitable for ureteroscopic treatment	C

Advanced disease:

- There are no benefits of RNU in metastatic (M+) disease, although it can be considered a palliative option.
- Because UUT-UCCs are urothelial tumours, platinum-based chemotherapy is expected to produce similar results to those seen in bladder cancer.
- Limited evidence to support the used of neoadjuvant chemotherapy in RNU.
- Adjuvant chemotherapy (depending on patient fitness and renal function) achieves a recurrence-free rate of up to 50% but has minimal impact on survival.
- Adjuvant radiotherapy may improve local control of the disease.
- When given in combination with cisplatinum, it may result in a longer disease-free survival and longer overall survival.
- Radiation therapy appears to be scarcely relevant nowadays both as a unique therapy and associated with chemotherapy as a tumour adjuvant.

Follow-up

- Strict follow-up of UUT-UCC patients after surgical treatment is mandatory to detect metachronous bladder tumours.
- Bladder recurrence after treatment of a primary UUT-UCC varies considerably from 15% to 50%. Thus the bladder should be observed in all cases.
- A prior history of bladder cancer and upper tract tumour multifocality are the risk factors most often reported for bladder tumours following UUT-UCCs.
- The surveillance regimen is based on cystoscopy and urinary cytology for at least 5 yr.
- When conservative treatment is performed, the ipsilateral upper urinary tract requires careful follow-up due to the high risk of recurrence.

Guidelines for follow-up of UUT-UCC patients after initial treatment

After RNU, over at least 5 yr	**GR**
Noninvasive tumour Cystoscopy/urinary cytology at 3 mo and then yearly	C
MDCTU every year	C
Invasive tumour Cystoscopy/urinary cytology at 3 mo and then yearly	C
MDCTU every 6 mo over 2 yr and then yearly	C
After conservative management, over at least 5 yr	
Urinary cytology and MDCTU at 3 mo, 6 mo, and then yearly	C
Cystoscopy, ureteroscopy and cytology in situ at 3 mo, 6 mo, and then every 6 mo over 2 yr, and then yearly	C

10.0 UROLOGICAL NURSING

It is well-documented that the CNS plays an essential role within the cancer multidisciplinary team (MDT) in providing high-quality care from diagnosis throughout the patient journey (National Peer Review Programme, 2014). The National Institute for Clinical Excellence (NICE) (2002) called for major changes in improving outcomes for patients with Urological Cancers. In particular they recommended that the CNS should have specific knowledge and expertise and should be trained in advanced communication skills. More recently, NICE (2014) emphasised that the CNS can ensure that patients have information that is tailored to their individual needs, therefore enhancing shared decision making. The CNS is also in an excellent position to provide individualised care following treatment which promotes cancer survivorship (National Cancer Survivorship Initiative, 2011). A recent Macmillan census on specialist nurses workforce in Northern Ireland (2014) has highlighted that cancer care teams of the future will need to have more flexibility working with people who are living with cancer. This census emphasised that the role of the CNS must be optimised to support those living in the community with a diagnosis of cancer.

The combination of improved life expectancy, advancements in diagnostics and treatment, and increased use of PSA testing in primary Care have all contributed to a significant rise in Urological cancer diagnosis. In Northern Ireland the number of new cases of Urological cancers diagnosed annually has increased and the associated workload creating significant challenges for Urological cancer teams and further demands on Uro-Oncology Clinical Nurse Specialists (CNS).

10.1 Responsibilities of the Uro-oncology Specialist Nurses

All patients should be assigned a key worker (usually a CNS) at the time of diagnosis, and appropriate arrangements should be in place to facilitate easy access to the key worker during working hours and an appropriate source of advice in his/her absence, as per National Cancer Peer Review standards. All patients should be offered a holistic needs assessment (HNA) at diagnosis and subsequently if their disease status changes. Patients should be offered advice and support to address any immediate concerns – physical, mental, spiritual or financial – on completion of the HNA with onward referrals made as necessary.

The responsibilities of the uro-oncology CNS include, ensuring patients undergoing investigations for suspected cancers have adequate information and support. On diagnosis, the CNS has a supportive role and will help ensure that the patient and significant others are equipped to make informed decisions regarding their ongoing treatment and care. The CNS may have a role in the review of patients following treatment for urological cancer. The CNS also has a key role in equipping the patient to live with and beyond the urological cancer, as advocated by the National Cancer Survivorship Initiative (2011). National Cancer Survivorship Initiative (2011) has also recommended the use of Holistic Needs Assessment (HNA) by the CNS to assess patient's needs for physical, psychological, social, spiritual and financial support at key points of their journey. A structured pack has been provided for use by professionals to assist with this process (NCAT, 2010). This HNA approach and subsequent care planning is a process which would ensure that people's needs are met in a timely and appropriate way and that resources are targeted to those who need them most. As a result of the HNA patients should be appropriately referred or signposted to any required support services.

Where cystectomy is considered, the involvement of the Stoma Therapist and/or Urology Clinical Nurse Specialist soon after diagnosis is essential. Patients should be offered the opportunity to meet a patient who has had a cystectomy and urinary diversion to help the decision making process. Patients who may have problems with urinary incontinence should be given information about local continence services.

11.0 SUPPORTIVE AND PALLIATIVE CARE

Supportive care is available to people with cancer and their carers throughout the patient pathway, from pre-diagnosis onwards and is a term used to describe all services that may be required to support people with cancer and their carers(NICE,2004). It is identified by NICE (2004) that patients and carers may have a series of problems preceding diagnosis (when cancer is suspected) which may include physical and anxiety related symptoms which require appropriate management, and information should be available for patients at this stage if they require it. As recognised by NICE (2004) supportive care is the responsibility of all health and social care professionals involved in delivering care and effective communication within teams will enable a seamless transition from one service to another if and when required.

Patients with advanced urological cancer may benefit from supportive and palliative care. Palliative care is defined by the World Health Organization (WHO, 2014) as an approach that improves the quality of life of patients and their families, facing the problems associated with life threatening illness. Uncontrolled symptoms can adversely affect quality of life and a patient's ability to cope with their illness, therefore, early identification, thorough assessment and treatment of pain and other problems, physical, psychological and spiritual, is essential (WHO 2014). The overall goal of palliative care is to help manage the symptoms and difficulties that may arise with disease progression, through appropriate support and intervention.

Palliative Care is an integral part of the multidisciplinary team and patients may require palliative care at different stages of the patient pathway (NICE, 2004). Generalist palliative care is the level of care required by most people and is provided by non-palliative/ end of life care specialist's i.e. primary and secondary health care teams (Living Matters, Dying Matters, 2010). Specialist palliative care may be required for those patients with more demanding care needs, i.e. unresolved symptoms and complex psychosocial, end of life and bereavement issues (Living Matters, Dying Matters, 2010).Referral to Specialist Palliative Care may be made at any time in the course of the disease when the patient wishes and would benefit from it.

References:

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World Health Organisation (2014) http://www.who.int./cancer/palliative/definition/en/

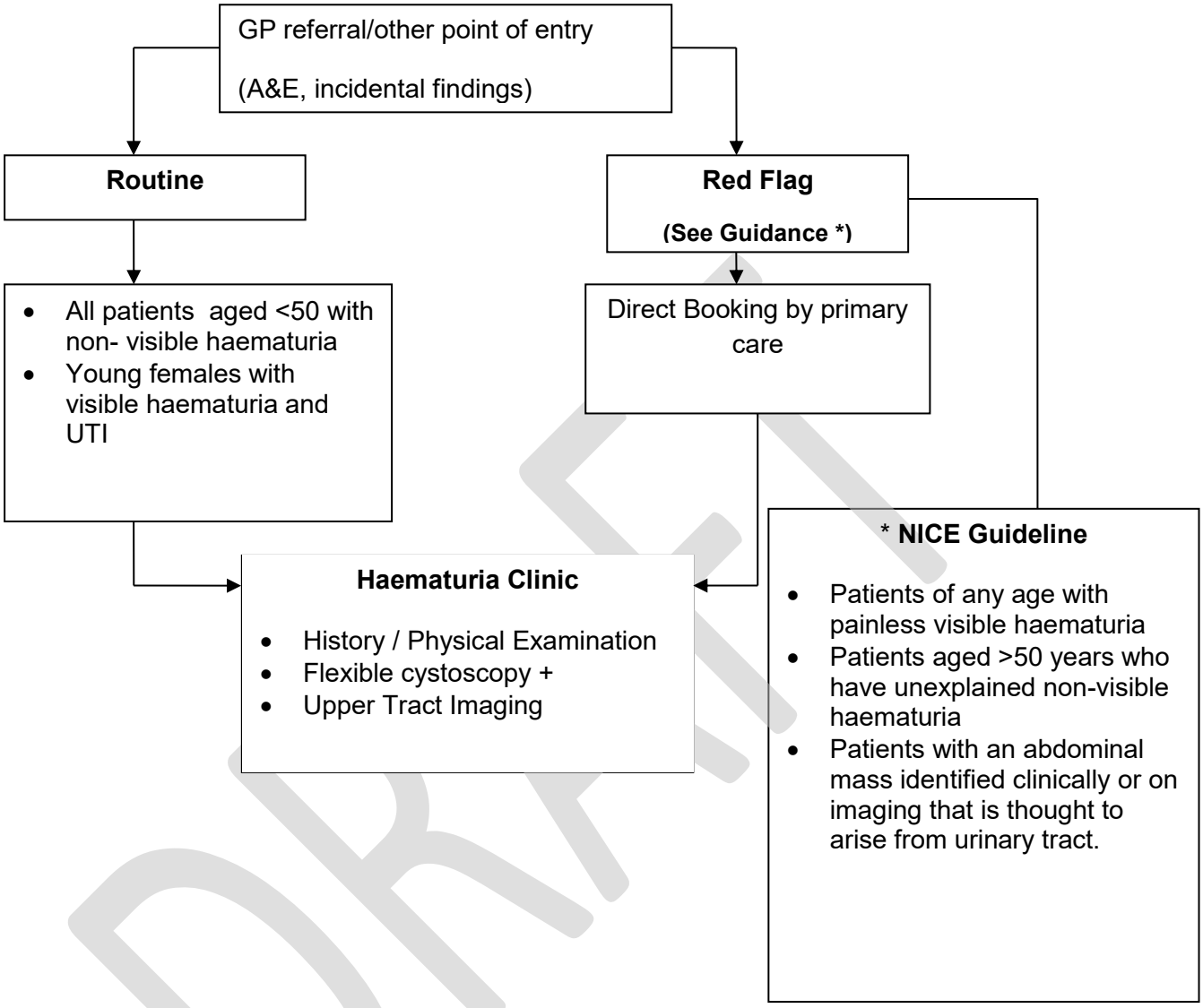
APPENDICES

1. **Haematuria Referral Guideline**

2. **Urology Care Pathways:**
   Prostate Pathway,
   Renal Tumour
   Testicular Cancer Pathway
   Transitional Cell Carcinoma
   Castration Resistant Prostate Cancer
   Penile Cancer Pathway

3. **Guidelines for nurse led follow up prostate cancer pathways**

Haematuria Referral Guideline



NOTE: Please Consider Nephrology referral as well as referral to haematuria clinic if the patient has any of the following:

- Diabetes
- Proteinuria
- Hypertension

Appendix 2; Urology Care Pathways

Cancer Care Pathways outline the steps and stages in the patient journey from referral through to diagnostics, staging, treatment, follow up, rehabilitation and if applicable onto palliative care.

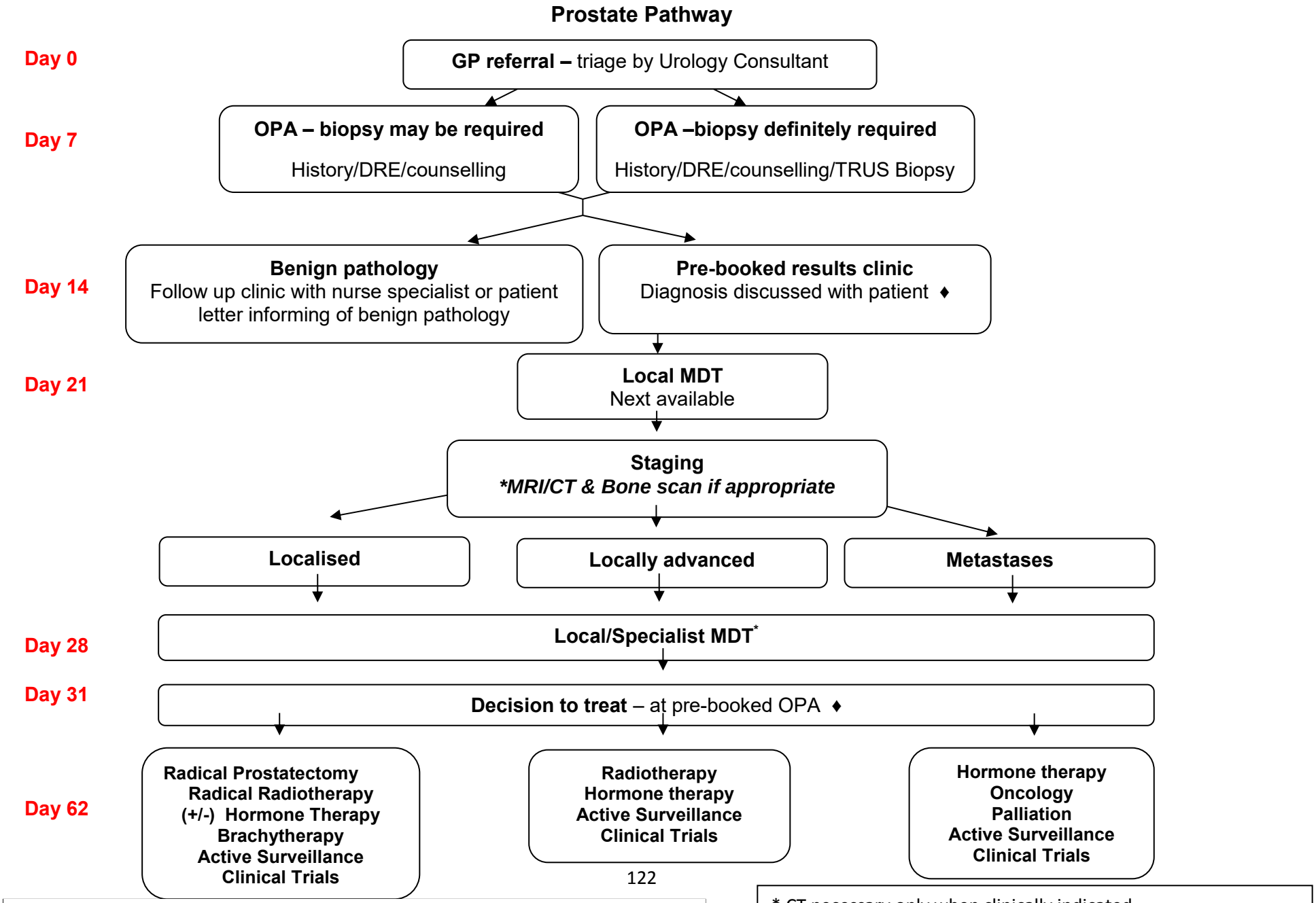
Timed effective care pathways are central to delivering quality and timely care to patients throughout their cancer journey and to the delivery of an equitable service. These pathways have been developed following with reference to available best practice guidance. They represent an 'ideal' pathway that can be adapted for local use. The timelines on the pathway are intended to facilitate the proactive management of patients within the access standards and it is to be noted that for some urological tumours, the patient will move much quicker through the pathway (e.g. testicular cancer).

The pathways are in draft form and amendments have been made following discussion at the workshop of the NICaN Regional Urology group held on Thursday 2nd October, 2008

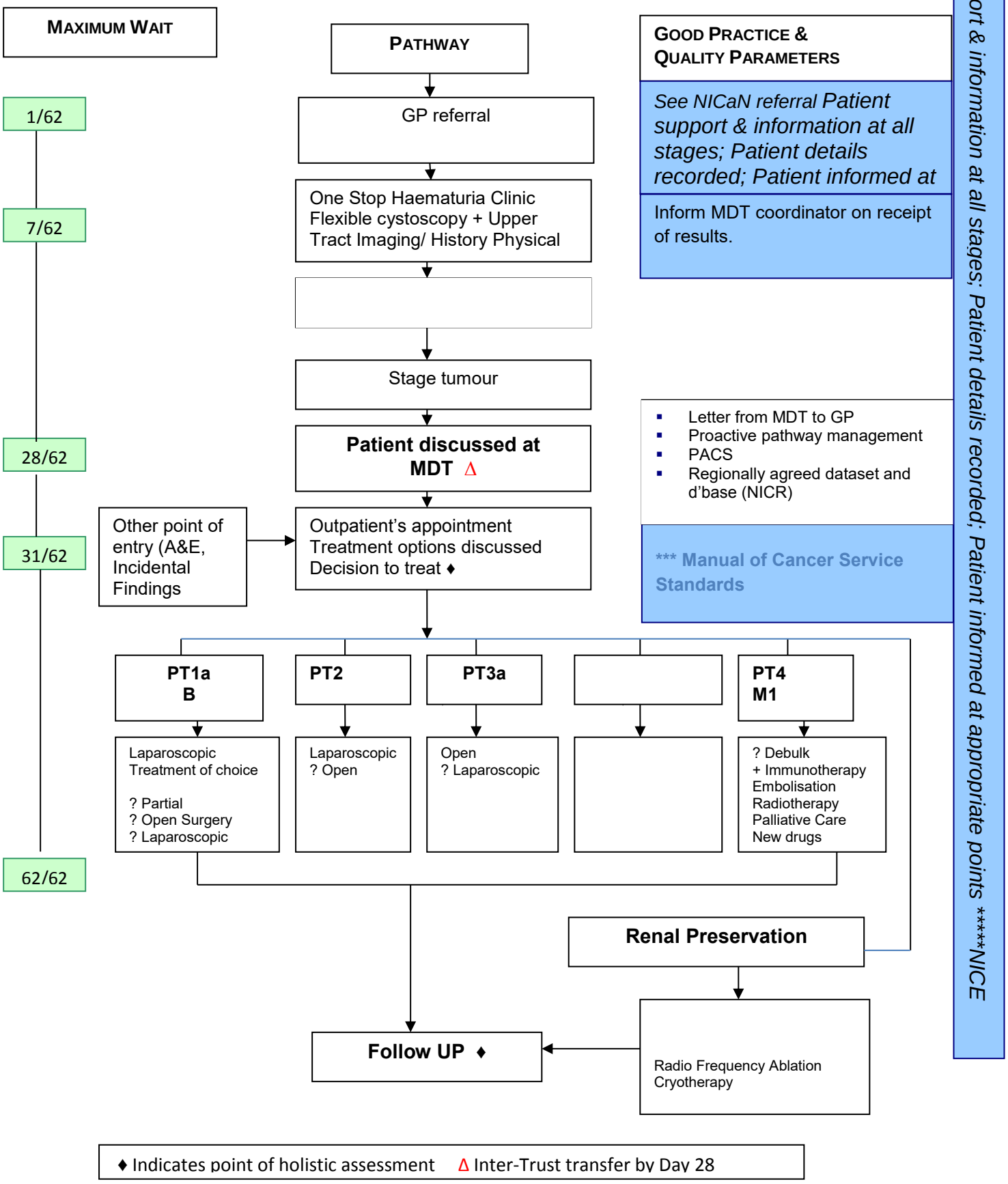
Document History

V1 Draft discussed at workshop 2/10/08
V2 Draft discussed 29/1/09 and amendments noted
Version 3 circulated for final comments 26/02/09
Pathways agreed at regional meeting 23/4/09

Appendix 2 of NICaN Urology Cancer Clinical Guidelines



Renal Tumour



♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

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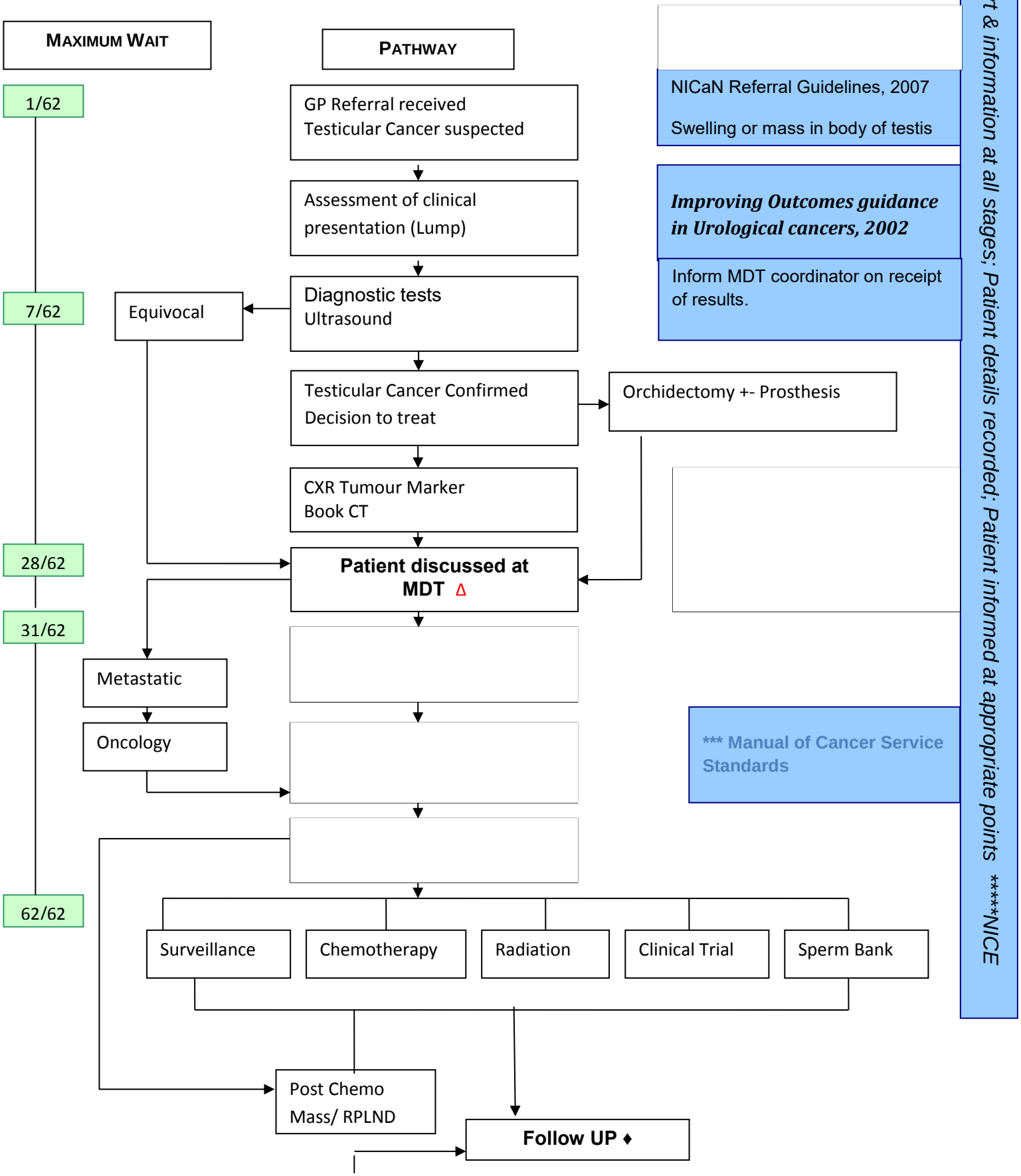
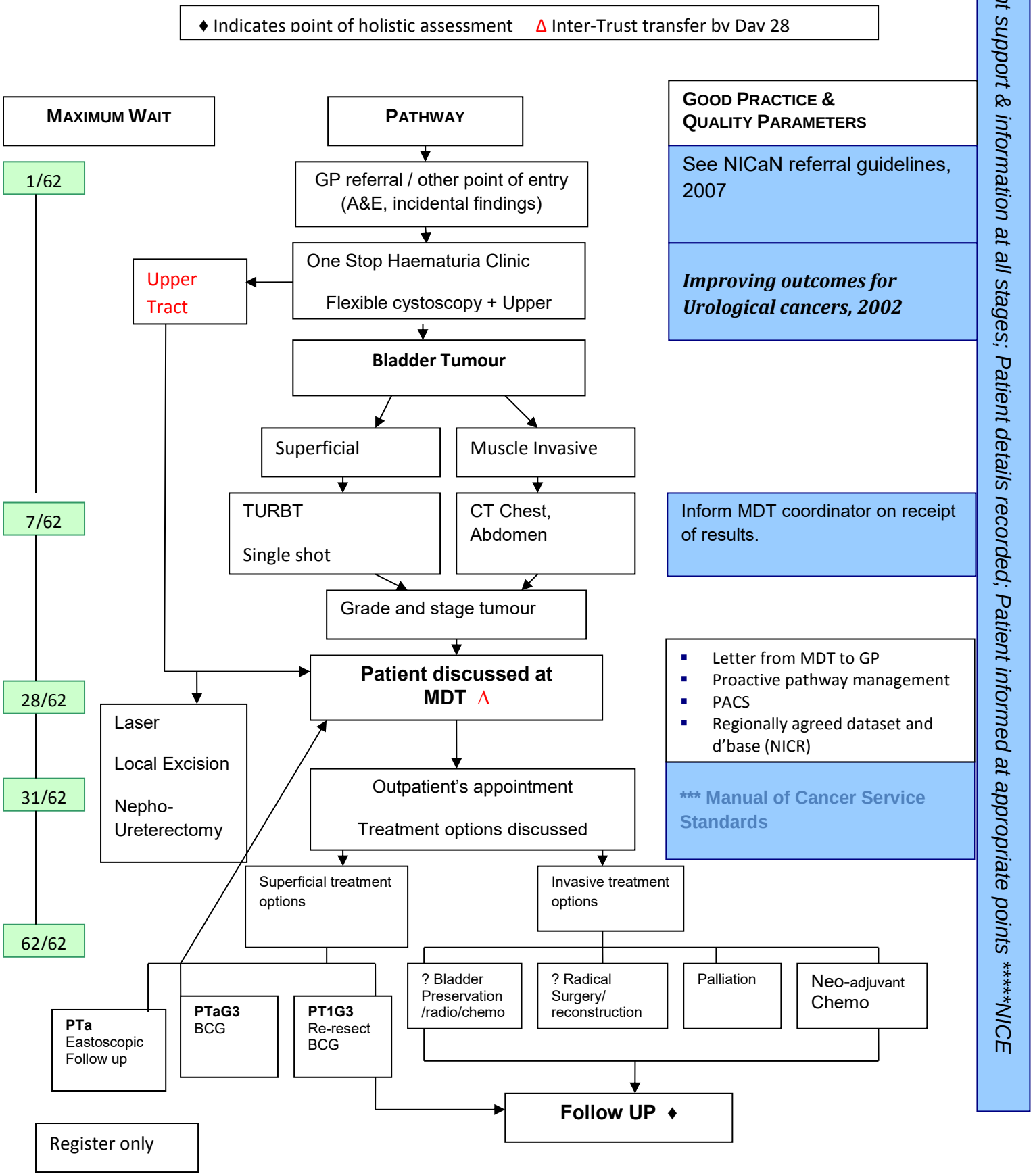
Testicular Cancer Pathway

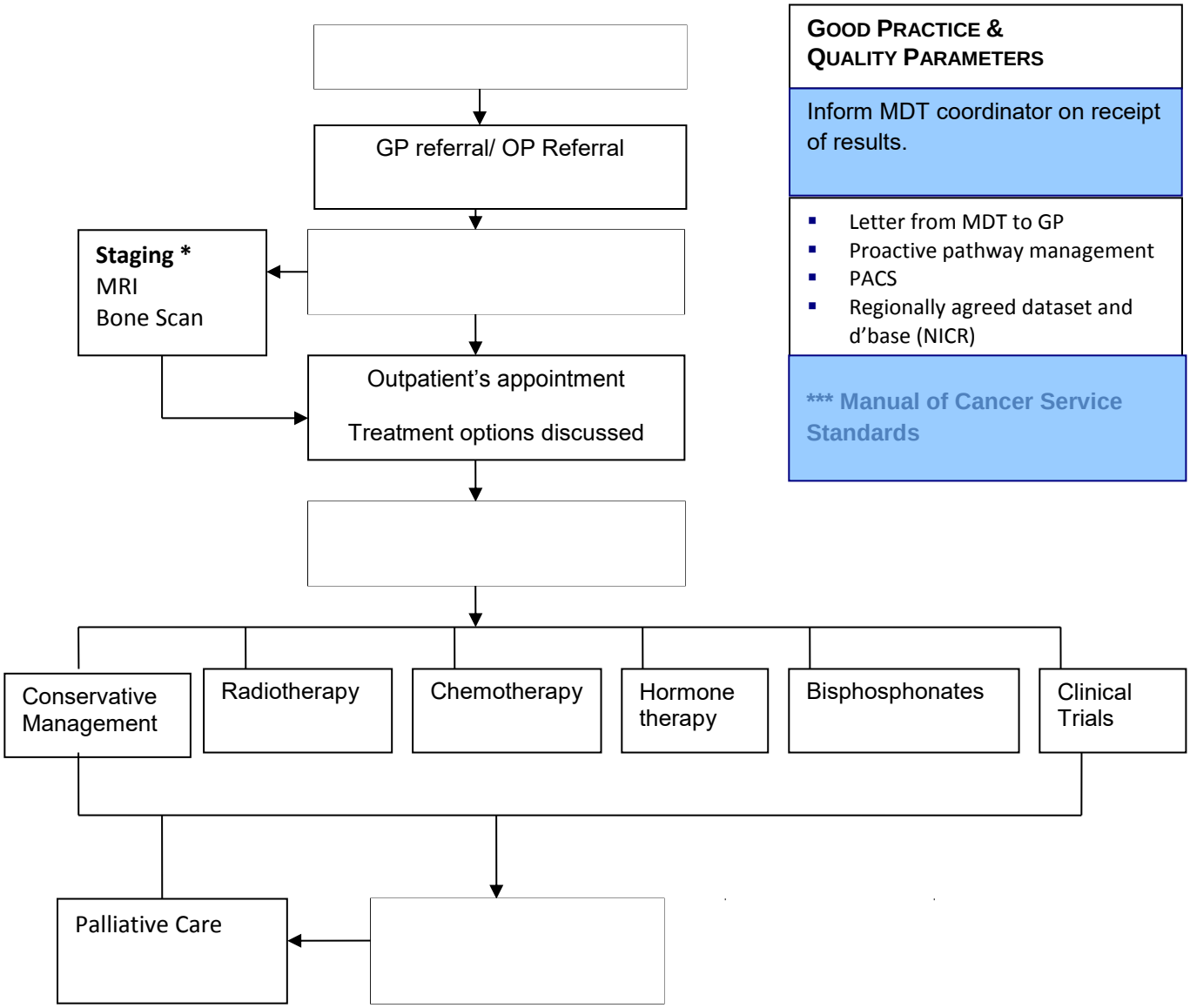


♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

Appendix 2 of NICaN Urology Cancer Clinical Guidelines



Castration Resistant Prostate Cancer



GOOD PRACTICE & QUALITY PARAMETERS

Inform MDT coordinator on receipt of results.

- Letter from MDT to GP
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

*** Manual of Cancer Service Standards

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE

* MRI/Bone Scan as clinically indicated

Appendix 2 of NICaN Urology Cancer Clinical Guidelines

Penile Cancer Pathway

MAXIMUM WAIT	PATHWAY	GOOD PRACTICE & QUALITY PARAMETERS
1/62	GP Referral received Penile Cancer suspected	NICaN Referral Guidelines, 2007
	Biopsy/Stage Tumour CT/MRI	***Improving Outcomes guidance in Urological cancers, 2002***
28/62	Results Clinic Option for local review ♦	Inform MDT coordinator on receipt of results.
31/62	**Patient discussed at MDT** Δ	▪ *GP letter from MDT* ▪ Proactive pathway management ▪ PACS ▪ Regionally agreed dataset and d'base (NICR)
	Outpatients Appointment Decision to treat ♦	
62/62	**Localised** / **Groins*** / **Advanced***	
	Surgery - Amputation - Penile preservation - Glansectomy	Lymph Node Dissection - Therapeutic - Prophylactic	Pelvic Lymph Node Dissection Open Laparoscopy
	Radiation	Chemo Radiation	Chemo Radiation
			Palliative Care
	Clinical Trials		
	Follow UP ♦		

Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points *****NICE*

V1.3 ♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

References

- NICE (2002) Improving Outcomes in Urological Cancer
  http://www.nice.org.uk/guidance/index.jsp?action=byID&o=10889
- NICE (2008) Prostate Cancer: Diagnosis and Treatment
  http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11924
- British Association Of Urological Surgeons Guidelines
  http://www.baus.org.uk/
- European Association Of Urology
  http://www.europeanurology.com/

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Policy Code / Reference No:

Trust Logo

Add Trust Name

Title:	**Guidelines for Nurse Led Assessment and Follow up of patients with stable Prostate Cancer**			
Author(s)	*Adapted from SET*			
Ownership:				
Approval by:	**NICaN Urology NSSG Group**		**Approval date:**	**29th November 2013**
Operational Date:			**Next Review:**	
Version No.	**3**	**Supercedes**	**N/A**	
Links to other policies	**Policy for consent to examination, Treatment and Care, European Association of Urologists (Feb, 2012) Guidelines on Prostate Cancer**			

1.0 INTRODUCTION / PURPOSE OF GUIDELINE

This document outlines the guiding principles for nurse led prostate cancer follow-up and should be closely followed. However these guidelines are only a foundation and it is recommended that nurses maintain their continuing education in this specialist area of care.

The aim of this guideline is to set a minimum standard for nurse led assessment and follow up of patients with prostate cancer which will:

- Enable the follow up of patients with prostate cancer who are on the watchful wait or hormone treatment pathway
- Promote the education of patients about their disease management and potential for self directed aftercare
- Monitor patient progress and enable detection of progression and refer to the appropriate Consultant Urologist
- Enable holistic assessment
- Identify late effects of treatment quickly, provide support and signpost to the appropriate service if necessary
- Inform patients about and refer them to specialists services that can help with their medical, practical, emotional and rehabilitation needs
- Support patients living with and beyond cancer
- Offer patients a choice of follow-up

1.1 Objectives

The objectives of this guideline are to improve and maintain standards of clinical practice and quality of care patients receive by:

- Providing evidence based guidance for establishing and maintaining a nurse led clinic for the assessment of patients with prostate cancer, promoting excellence in the care that is delivered
- Reducing variation in clinical practice and encouraging uniformity of practice
- Providing a framework from which individual practitioners can apply their own level of clinical expertise and competency
- To ensure that all patients entering the prostate cancer follow up service are on the appropriate risk stratified pathway (Appendix 5 & 6)
- Helping nurses and health care providers to make informed decisions, aiding the education process and reducing the risk of clinical negligence
- Identifying competencies for nursing care
- Aiding development of locally agreed guidelines
- Promoting audit

1.2 Background

The NHS is undergoing radical changes particularly in its approach to cancer. Traditional nursing roles are being challenged in a bid to meet the demands of the changing NHS climate. Prostate cancer follow up forms a substantial part of the urology outpatient workload. Nurse led clinics are becoming increasingly common, offering patients an alternative method of follow up either via more convenient clinics or the telephone. By developing these new roles and services, nurse are playing a key role in increasing patient choice, reducing waiting times, increasing accessibility to services and improving the quality of care

New standards have been developed within the Cancer Services Framework that are intended to ensure that patients experience the best possible quality of life after treatment by:

- providing new models of follow-up which focus on health and wellbeing
- improving access to psychological support

2.0 DEFINITIONS/SCOPE OF THE GUIDELINE

These guidelines should be used by suitably trained health care professionals who are providing nurse led follow up to patients with prostate cancer. Patients will enter nurse led follow up services on a clearly defined follow up pathway following discussion at MDM.

Recommended exclusion criteria

- Patients who do not wish to be followed up by a nurse
- Patients who require adjuvant treatment in the form of radiotherapy or chemotherapy
- Patients with dementia/short term memory loss (unless meeting patients with carer present)
- Patients who develop resistance to Hormone Therapy during follow up and require referral to oncologist
- Patients deemed unsuitable for review at a nurse led clinic by the consultant in charge

3.0 ROLES/RESPONSIBILITIES

Implementation of these guidelines is the responsibility of those involved in nurse led follow-up of prostate cancer patients.

Accountability is a key concern for all registered nurses today. Professional accountability is defined as being responsible for your actions and for the outcomes of these actions as part of the framework of clinical Governance, which aims to provide good quality, cost-effective evidence based care (Tilley & Watson 2004)

Nurses need to be aware of their limitations as well as their clinical competence. If there are any areas in which they do not feel clinically competent to undertake an activity they should decline the activity until the appropriate learning and practice activities have been achieved to demonstrate competency (NMC 2008)

Nurses are responsible for ensuring their own educational preparation and experience to safely perform the role. They should maintain documented evidence of completion of continuing education and of demonstrating clinical competence

Competencies required for assessing patients with prostate cancer can be found in (Appendix 2)

4.0 KEY GUIDELINE PRINCIPLES

4.1 Key Policy Statement

The purpose of the nurse led clinic is to enhance the quality of care and to promote the health and well being of patients who have been treated for prostate cancer. The clinic will also facilitate the provision of emotional support for patients and their families/carers requiring the opportunity to discuss treatment or care options
Nurse led clinics have been shown to improve the quality of care in the following ways:

- Provide continuity of care for patients and their family
- Provide information, education and support
- Be accessible to patients and their family
- Release consultant time to see more complex patients
- Apply the principles of transforming cancer follow up

A risk stratified model of aftercare in line with the National Cancer Survivorship Initiative will be utilised and patients will be stratified into different arms of the follow up pathway according to their staging and personal characteristics by the Consultant.

Risk stratified means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, (what type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short term and long term) and the person (whether they have other illnesses or conditions, and how much support that they feel they need).

This will include the ongoing follow up of patients who are clinically stable and are stratified into the relevant pathway

Watchful waiting	(Pathway 1)
Active surveillance	(Pathway 2)
Raised PSA – negative biopsy	(Pathway 3)
Post radical surgery	(Pathway 4)
Post brachytherapy	(Pathway 5)
Post radical radiotherapy	(Pathway 6)

4.2 Policy Principles

Patients with prostate cancer who are on the pathways outlined above will be risk stratified into a pathway as discussed below

- Self-Care with Support and Open Access
    - No routine outpatient attendances
    - Stable disease pattern
    - After treatment with curative intent
    - Holistic assessment completed and care plan agreed
    - Information and/or some form of educational intervention
    - Surveillance tests with results by post or phone co-ordinated by a provider
    - Ability to re access system with/without reference to GP
- Shared Care – where patients continue to have face to face or telephone contact with professionals as part of continuing follow up.
    - Planned follow up either as an outpatient or planned phone follow up
    - Clinical examination required
    - High clinical or individual risks identified (disease, treatment, person)
    - Multi professional input required
    - Patients with co-morbidities
    - Those who decline or are considered to be unable to self manage

4.3 Long-term follow-up

Definitive guidance on the long term follow-up for patients with prostate cancer is included within the pathways which are concordant with NICE and European Association of Urologists Clinical Management Guidelines on Prostate Cancer.

4.4 Telephone Review Protocol

A telephone review service enables the Clinical Nurse Specialist to follow up patients through an alternative route and thereby reduce unnecessary hospital appointments for patients who have stable disease and are not fit to travel.

This service will be offered to those patients referred to the nurse led clinic and a telephone assessment protocol will be utilised. See appendix 7

4.5 Holistic Needs Assessment (HNA)

The HNA is used to identify and address patient's needs and concerns. The HNA may build on action plans developed from previous assessments. The HNA should

be conducted during the follow-up appointment. The patient or carer is encouraged to complete the form and the assessor uses this as a guide to explore their needs and collaboratively develop an appropriate action or care plan

An agreed Holistic Needs Assessment (HNA) tool will be utilised within the aftercare pathways

4.6 Support Information and Education

The consultant or clinical nurse specialist should offer patients support information tailored to the individual. This should cover as a minimum:

- Disease Progression
- Fatigue
- Pain
- Urinary Symptoms
- Finances/benefits
- Nutrition/exercise
- Signposting
- Health and well being

4.7 Rapid Access Protocol

Prostate cancer follow-up is the responsibility of the MDT. All patients should be able to access the Consultant responsible for their care through the Urology CNS. Any patient that contacts the Urology CNS with worrying symptoms will be seen by a Consultant promptly. If necessary, their case should be discussed by the MDT.

4.8 Triage Protocol

Each patient will be able to contact the Urology CNS outside of scheduled follow up appointments The Urology CNS will triage the patient on their concerns/issues to the most appropriate member of the Urology team or refer on to other agencies accordingly. Outcomes may include:

- Face to face consultant appointment promptly
- Face to face Nurse led clinic (where appropriate)
- Advised to contact GP
- Advised to attend the emergency department
- Signpost to other support agencies e.g. Citizens Advice Bureau (CAB), AHP, Counselling

Only clinical issues will result in a clinical appointment.

5.0 IMPLEMENTATION OF POLICY

5.1 Dissemination

Urology Clinical Nurse Specialists

Urology Consultants

Oncologists

6.0 MONITORING

Monitoring of these guidelines is the responsibility of the Urology Nurse under the direction of the line manager.

7.0 EVIDENCE BASE / REFERENCES

Evidence:

BAUN (2008) Guidelines for nurse-led assessment and follow up of men with stable prostate cancer British Association for Urological Nurses
Cox A, Jenkins V, Catt S, Langridge C, Fallowfield LJ Information needs and experiences: an audit of UK cancer patients. European Journal of Oncology Nursing 2006; 10(4):263-72, doi:10.1016/j.ejon.2005.10.007
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http://www.cancerimprovement.nhs.uk/documents/CSC_High_Impact.pdf
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NI Cancer Registry (2007) Survival of cancer patients in Northern Ireland: 1993-2004 http://www.qub.ac.uk/researchcentres/nicr/FileStore/PDF/Survival/Filetoupload,81422,en.pdf

Nursing and Midwifery Council (NMC): The Code: Standards of conduct, performance and ethics for nurses and midwives (2008)

Service Framework for Cancer Prevention, Treatment and Care (2011)

Tilley, S. Watson, R. (2004) Accountability in Nursing and Midwifery. 2nd Edition. London: Blackwell Publishing.

8.0 CONSULTATION PROCESS

Cancer Services User Forum

NICaN Regional Urology Group

9.0 APPENDICES / ATTACHMENTS

See attached

10.0 EQUALITY STATEMENT

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In line with duties under the equality legislation (Section 75 of the Northern Ireland Act 1998), Targeting Social Need Initiative, Disability discrimination and the Human Rights Act 1998, an initial screening exercise to ascertain if this policy should be subject to a full impact assessment has been carried out.
The outcome of the Equality screening for this policy is:

Major impact ☐

Minor impact ☐

No impact ☐

SIGNATORIES

(Policy – Guidance should be signed off by the author of the policy and the identified responsible director).

_____ **Date:**
Name
Title:

_____ **Date:**
Name
Title:

_____ **Date:**
Name
Title:

_____ **Date:**
Name
Title:

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Appendix 1

Prostate Cancer Review Assessment Form

Name…….

Unit No……..

DOB……

Consultant…… GP……

Date:……. Time…….

Type of review: Telephone □ Clinic Contact □

Treatment Pathway: Hormone Treatment □Watchful Waiting □

Histology Gleason's Score …….. TNM ……

PSA

PSA Trigger.....

Date of PSA……..... Current PSA..... Previous PSA.....

PSA obtained from ECR……

Record what was discussed with patient

Changes in Urinary Symptoms

Storage	Yes / No
Voiding	Yes / No
Pain	Yes / No
Haematuria	Yes / No

If yes to any of the above, please comment and record advice given

General Symptoms

Hot Flushes	Yes/No
Tiredness	Yes/No
Weight gain	Yes/No
Breast Pain	Yes/No
Bone pain	Yes/No
Sexual Problems	Yes/No
Change in bowel pattern	Yes/No

Additional comments

Problems and concerns

Has patient had a Holistic Needs Assessment Yes/No

If yes, Date of HNA ……..

Discuss resolution of any problems identified in previous HNA □

Are there any new concerns Yes/No

- Financial
- Psychological
- Information and Support

Please record any issues

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Follow up

Nurse Led follow up 3 months yes/no 6months Yes/No

Referral to:

Urologist Yes/No
Oncologist Yes/No

Letter to GP □
Letter to Consultant □

Signature of CNS……

Appendix 2
Competencies for Nurse-led Follow-up

Competencies required assessing patients with stable prostate cancer include:

- Advanced nurse practitioner/clinical nurse specialist having been employed for a minimum of twelve months working with a urologist/oncologist in the follow up setting

- Demonstrate a full understanding of the network site specific group pathways for prostate cancer. As agreed by the local tumour network

- To be enrolled in or be undertaking, a programme of study in their specialist area of nursing practice which has been accredited for at least 20 CAT points at level 3 (DH2004) e.g. Health Assessment module

- Have advanced communication skills – to have enrolled in, or be undertaking a recognised course/module in communication skills (DH 2004)

- In order to run a clinic the individual must be a core member or extended member of the urology multidisciplinary team

- To be able to demonstrate knowledge of the disease trajectory in Prostate Cancer

- To be able to demonstrate knowledge of risk stratified pathways

- To have competent consultation and symptom analysis skills. To have worked under supervision for a minimum of six months and have been deemed competent by the consultant urologist/oncologist

- To be able to demonstrate knowledge of the tests and investigation required during follow up of prostate cancer patients

- To be competent at performing DRE (if appropriate)

- To be competent in the assessment of lower urinary tract symptoms (LUTS) and facilitate onward referral to LUTS clinic is required

- To be competent in bladder palpation

- To be competent in the assessment of bladder empting

- To demonstrate ability to advise on erectile dysfunction and know where and how to refer to appropriate service

- To be able to demonstrate knowledge of survivorship issues

- To be able to demonstrate knowledge of rehabilitation services

- Demonstrate knowledge of drugs and treatments used in prostate cancer including side effect

Appendix 3

Guideline for Nurse Led Assessment Protocol

Actions
Discuss • Nurse led clinic • History/treatment to date • Timeline for routine follow up such as PSA, DRE and Admission Profile
Physical Examination
Carry out physical assessment including: • Digital Rectal Examination (DRE) • International Prostate Symptom Score (IPSS) if required
Symptoms
Is the patient experiencing any symptoms . • Hot Flushes • Ask about pain – any new pain lasting more than a week (use locally agreed pain scale) • Weight loss/gain • Fatigue • Sexual dysfunction • Neurological symptoms – Numbness, tingling or odd sensations in limbs • Lower Urinary tract symptoms • Haematuria • Gynaecomastia • Change in bowel habit • Deterioration in renal function Is the patient experiencing any symptoms suggestive of local or metastatic disease • Abdominal /Pelvic /Skeletal pain • Weight loss • Anorexia • Nausea or vomiting

Ask about any other symptoms/concerns
• PSA at each visit if rising discuss with consultant • Admission Profile at each visit • FBP at first visit • Ultrasound renal tracts following discussion with Consultant
Perform holistic assessment suggested tools: • Macmillan Concerns Checklist & Care-plan
Nurse to check information has been provided and tailored to the individual patient. This will include information about: • Timeline for tests and investigations • Survivorship programme • Rapid Access to service • Contact numbers • What symptoms need to be reported • Consequences and side effects of the treatment • Holistic Assessment • Rehabilitation services
Discuss and offer referral to: • Community Health and Well-being Clinics • Signposting to other services
Care plan Letter to patient Letter to GP & referring consultant with copy of assessment form,

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To include:

- Date and time of nurse consultation
- Patients identifiable details
- Diagnosis
- Treatment,
- Assessment summary,
- Most recent PSA reading
- Date of next nurse appointment
- Potential or actual problems identified during the consultation.

Adapted from BAUN (British Association for Urological Nurses) - Guidelines for nurse-led assessment and follow up of men with stable prostate cancer (2008)

Appendix 4

Problem Management Plan

This plan will help to identify the appropriate actions when there is a change in the patients condition/needs during nurse led assessment and follow-up of patients with prostate cancer.

Problem	Management plan
Sudden Rise in PSA	Repeat PSA as determined by consultant
Lower urinary tract symptoms that are more bothersome to the patient	Refer to LUTS clinic Urinalysis to exclude UTI Refer or discuss with appropriate consultant
Haematuria	Exclude UTI Assess lower urinary tract symptoms Refer for investigations
Hot flushes	Give support and advice and discuss with consultant
Pain - new onset bone pain	Request investigations – bone profile, pain and neurological assessment(use locally agreed pain scale) Consider MSCC Appropriate referral to urologist/ oncologist for further management
Change in bowel habit	Assess asking about change in consistency regularity. Give advice or refer to specialist as appropriate
Weight loss	If unexplained weight loss refer to consultant. Refer to dietician if appropriate
Gynaecomastia	Discuss with consultant and if required refer to oncologist
Deterioration in renal function	Discuss and if appropriate refer back to urologist Assess for poor bladder emptying by post void residual scan Order USS of renal tracts if appropriate

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Problem	Management plan
Weight gain, fatigue general malaise and anaemia	Give advice Consider referral for physical activity programme Check haemoglobin and if below normal levels discuss with consultant
Sexual Dysfunction	Assess for erectile dysfunction Give advice and consider referral to ED clinic if appropriate
Psychological needs	At time of the assessment any psychological concerns identified through use of NICaN Concerns Checklist will be discussed with the patient. Refer as appropriate to: Health and well being clinics Support groups Counselling Service Clinical psychologist
Financial concerns	Refer to CAB
Information needs	Discuss information needs Give written information if appropriate Consider onward referral if required Refer to Macmillan Information and Support Centre

Adapted from BAUN (British Association for Urological Nurses) - Guidelines for nurse-led assessment and follow up of men with stable prostate cancer (2008)

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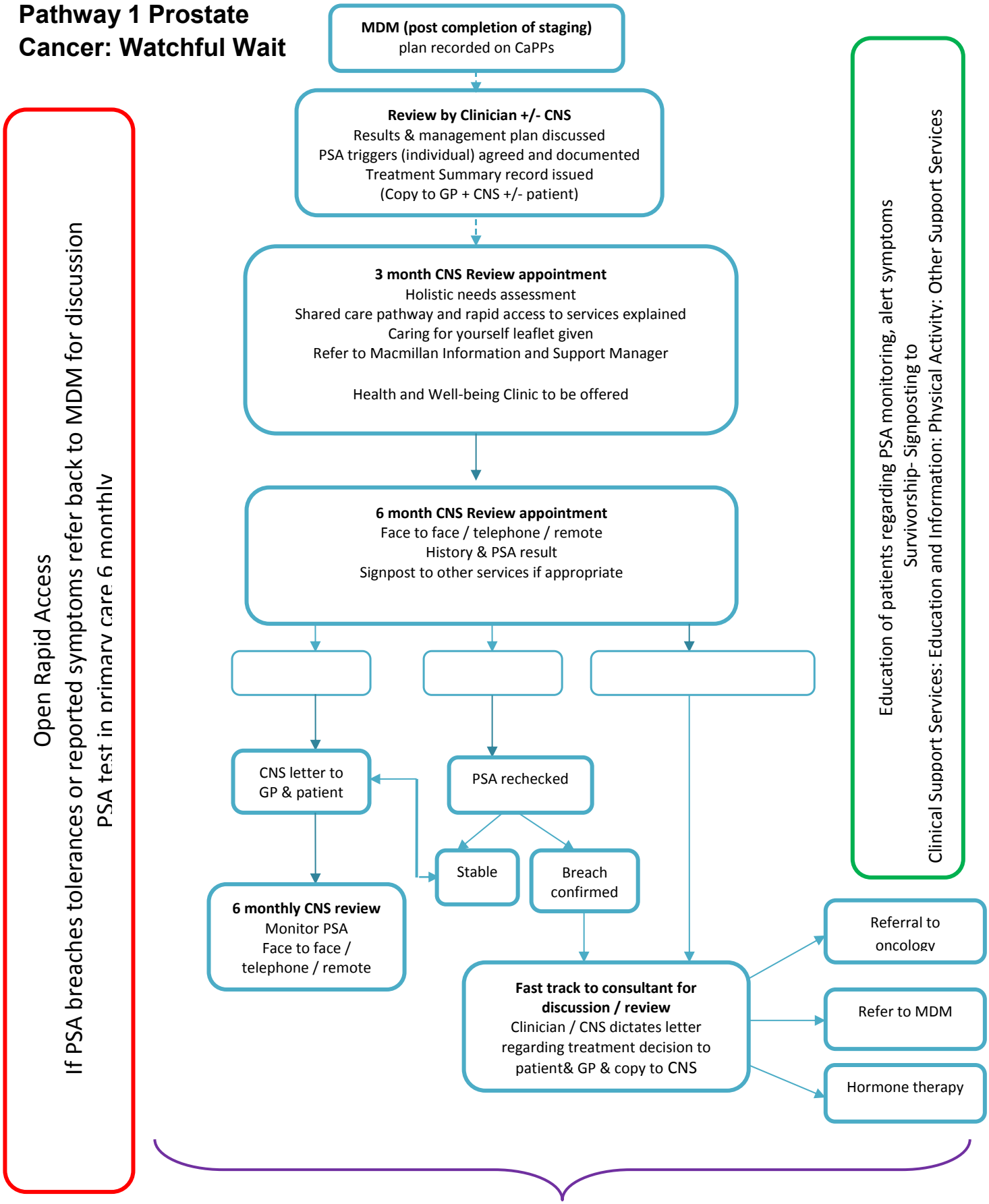
Pathway 1 Prostate Cancer: Watchful Wait



Watchful waiting – Adapted from NICE Guidance 2008

'Watchful Waiting is the form of continued review of Prostate Cancer patients for whom future therapeutic intervention with curative intent has been considered to be inappropriate'.

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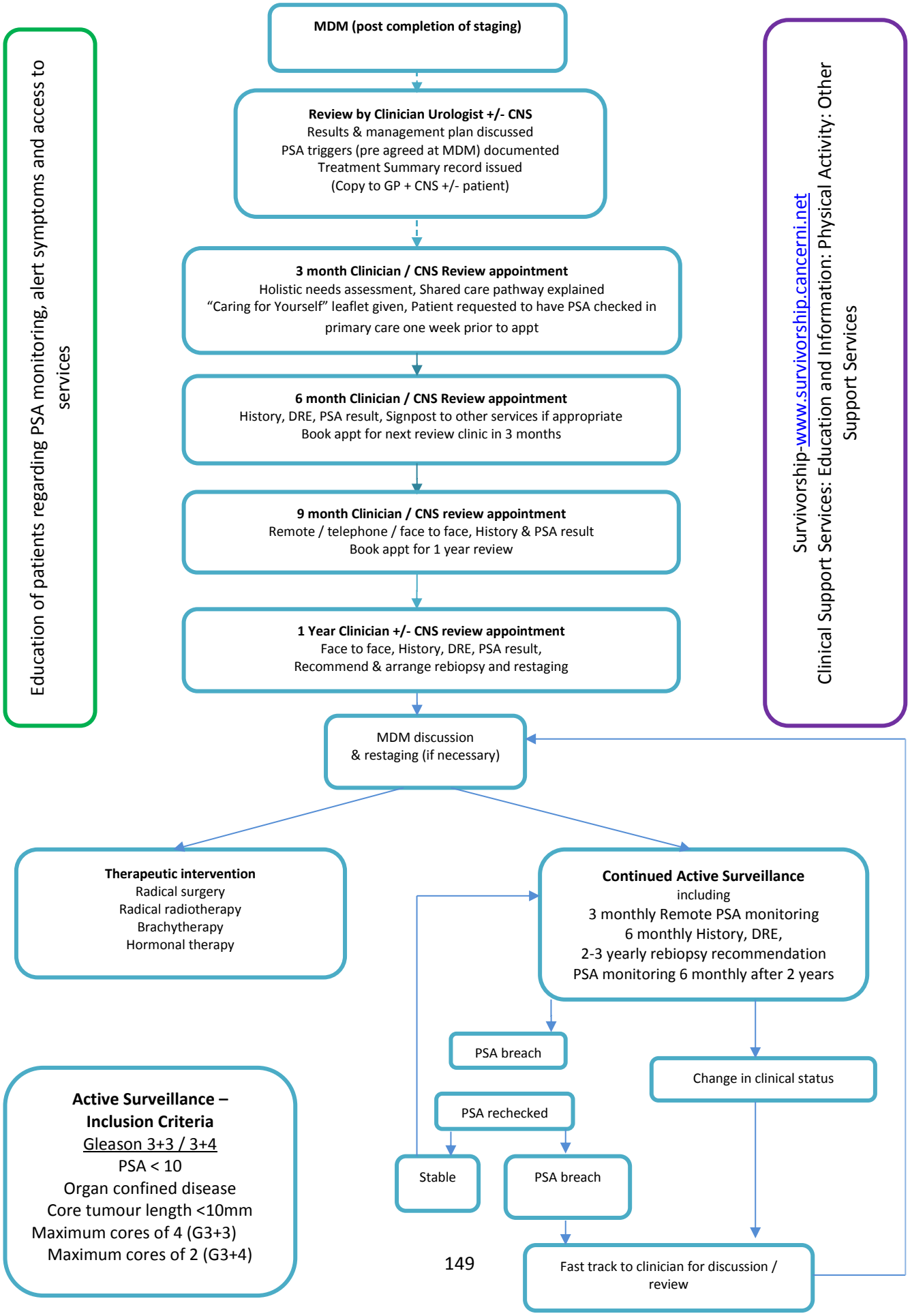
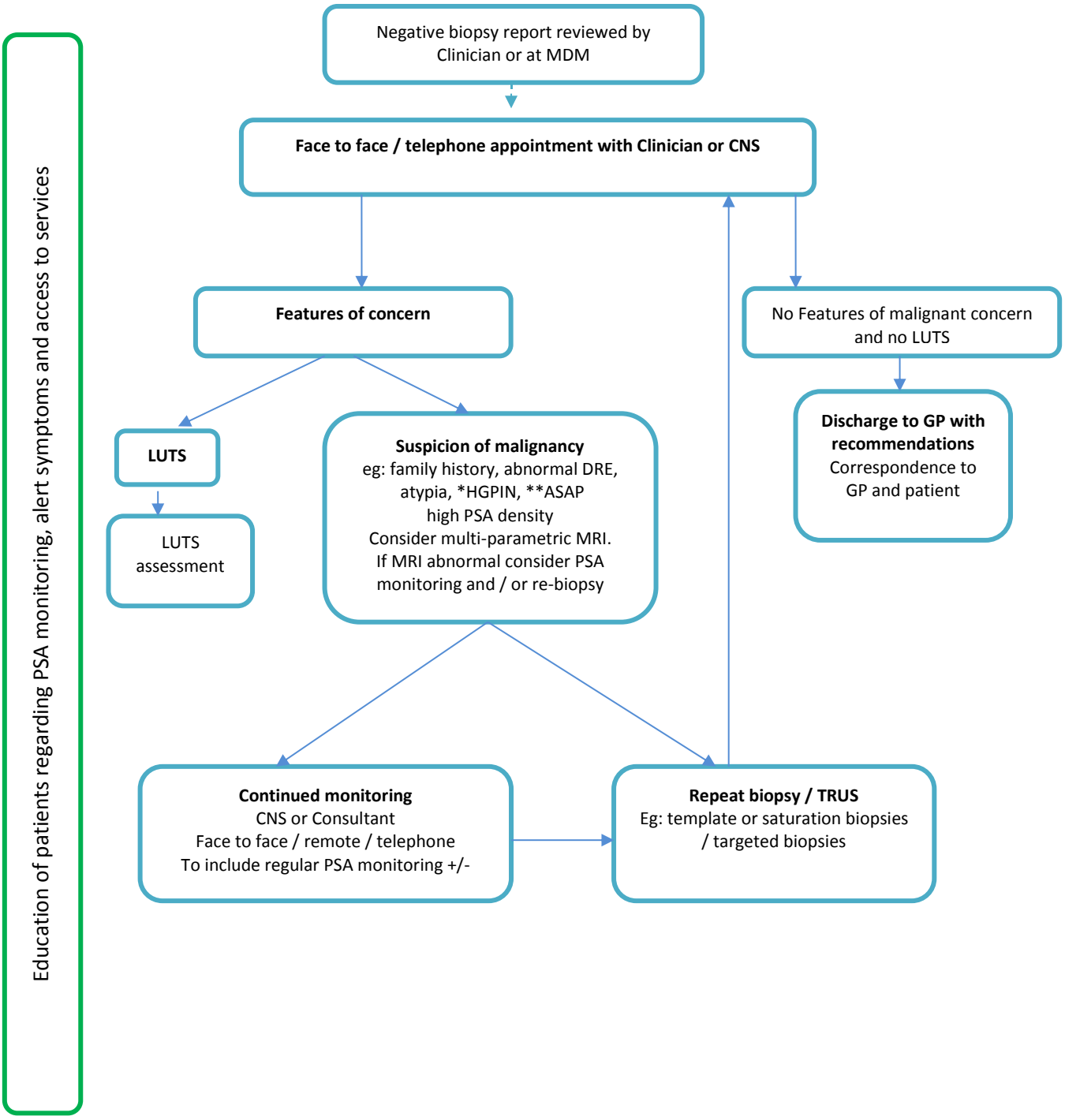
Pathway 2 **Prostate Cancer: Active Surveillance**



Pathway 3 Raised PSA & Negative Biopsy



*HGPIN – High grade prostatic intra-epithelial neoplasia
**ASAP – Atypical small acinar proliferation

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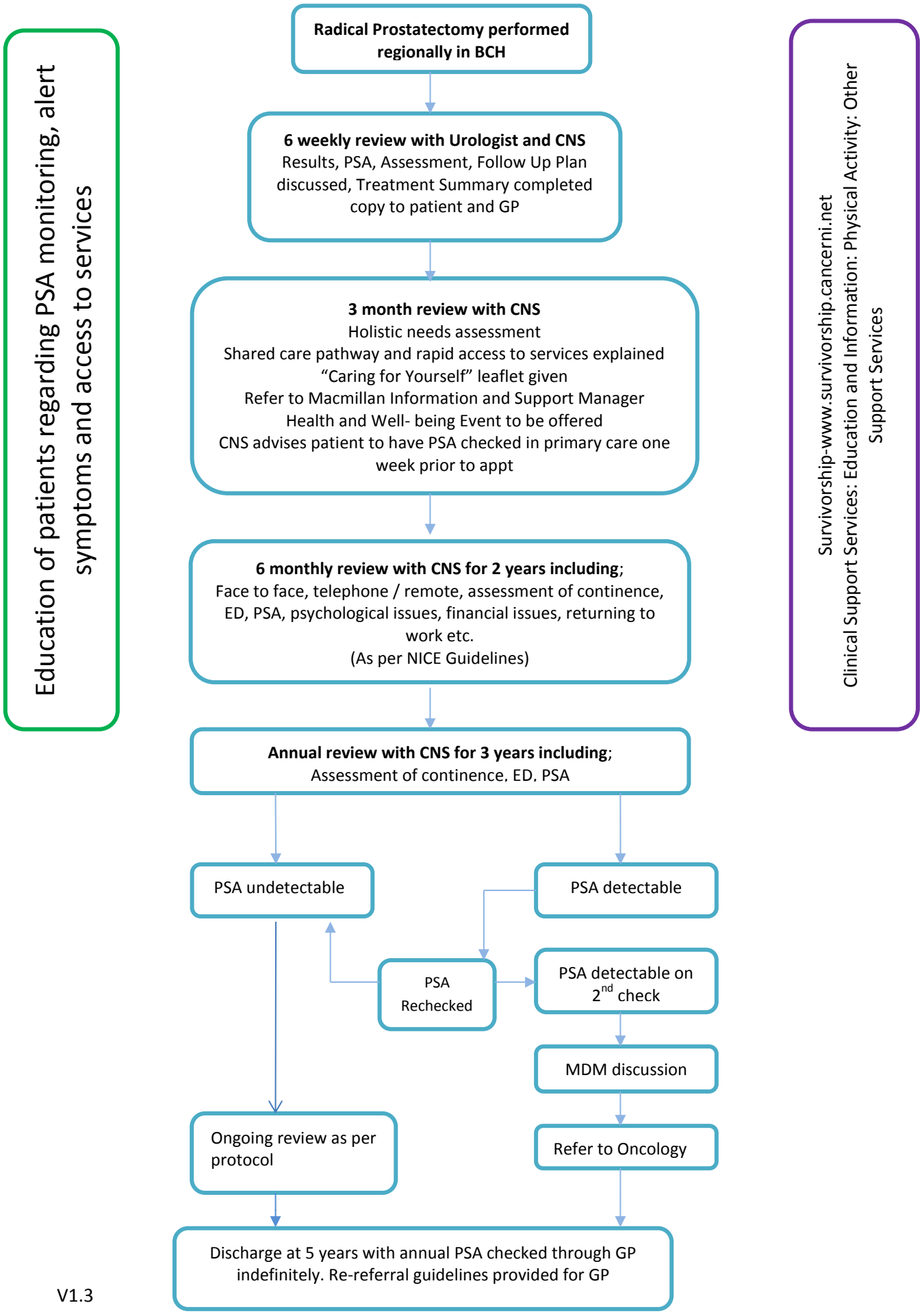
Pathway 4 **Prostate Cancer: Radical Surgery – Negative margins**



V1.3

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Pathway 5 Prostate Cancer: Permanent Prostate Brachytherapy (LDR)

Permanent Prostate Brachytherapy Implant performed (Pt discharged)

Post implant AUR management if required

4week Post implant CT scan and QA/peer review (PSA, IPSS, Dosimetry to database)

3month - Radiographer telephone review (PSA to database)

6month - Consultant led clinical review (PSA, IPSS,IIEF,EPIC to database)

6monthly Consultant led clinical review.
GP check PSA every 3-6months
(PSA, IPSS,IIEF,EPIC to database)
Transfer to annual review at 3years if PSA <1ng/ml & falling

12monthly clinical review
GP check PSA every 6 months
(PSA, IPSS,IIEF, EPIC to database)
Discharge to GP care at 5 years if PSA <1ng/ml & falling

GP information letter re biochemical and clinical triggers and re-referral pathway

Sigmoidoscopy by experienced practitioner at year 5, 10, 15 If deemed fit for procedure

Education of patients regarding PSA monitoring, alert symptoms and access to services

Rising PSA Year 0 – 3 could be benign PSA bounce.
PSA 3monthly with clinical review.
MRI/CT/IBS if:
1 PSA level>10ng/ml
2 Clinically indicated

Survivorship-www.survivorship.cancerni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Selection criteria for Permanent Prostate Brachytherapy

Clinical inclusion criteria:
Organ confined prostate cancer T1 or T2
Estimated life expectancy >10yrs
Gleason 6 and PSA <15ng/ml
Gleason 7 and PSA <15ng/ml

Clinical exclusion criteria for brachytherapy:
Prostate volume >50ml (> 65ml prior to hormonal cytoreduction)
IPSS >9. (Would consider for implant is <15 & Qmax >12ml/sec)
Life expectancy <5years
Large or poorly healed TURP defect
Unacceptable operative risk
Relative contraindications for brachytherapy:
Large median lobe

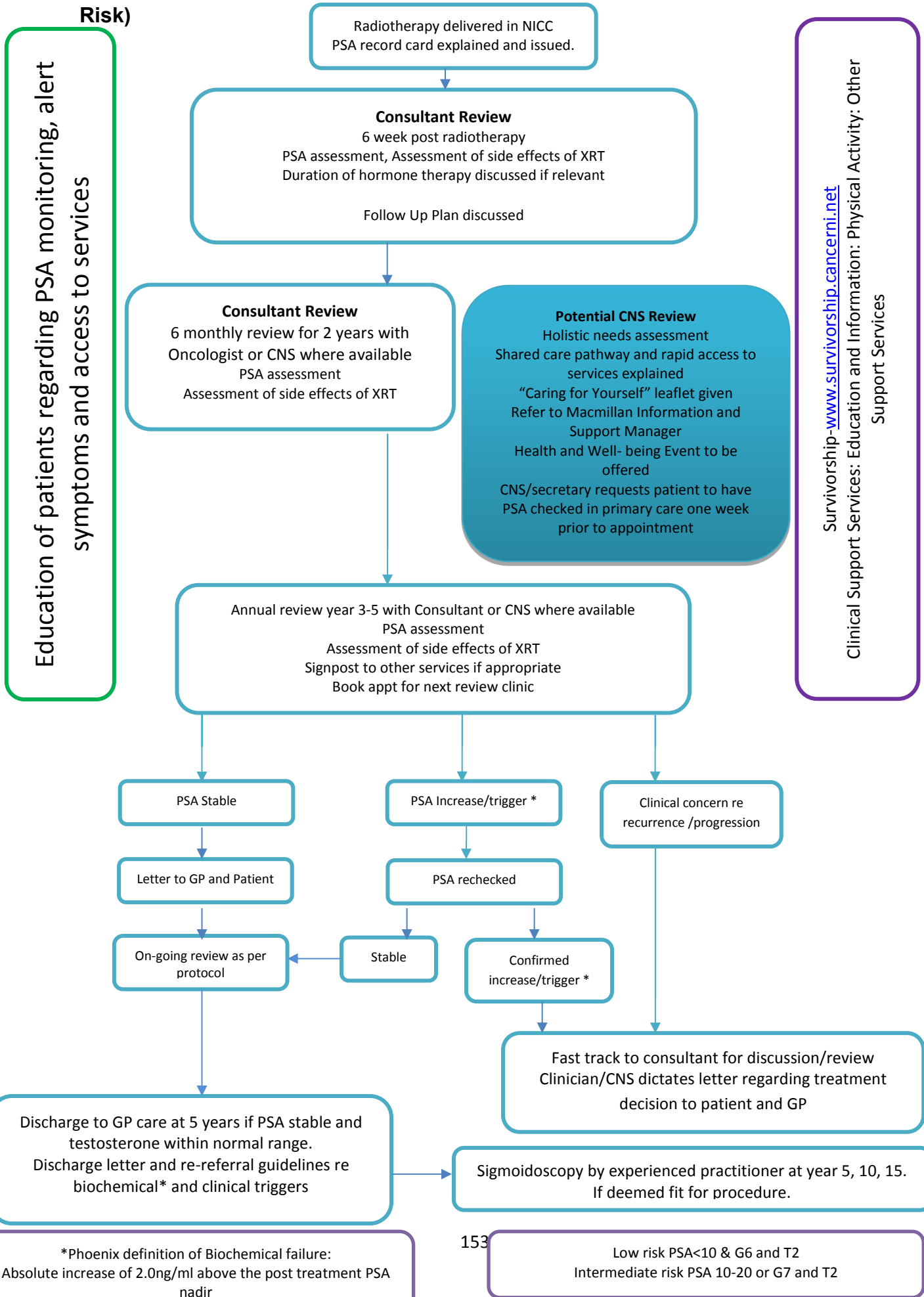
Selection criteria for combined Permanent Prostate Brachytherapy + EBRT

Selected men with:
High volume Gleason 7 or
Low volume Gleason >7 or
Early T3a disease
May be suitable for dose escalation with combination therapy and should be referred for discussion to central

Received from SPPG on 03/11/2023. Annotated by the Urology Services Inquiry.

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 6: Prostate Cancer: Radiotherapy+/-Hormones (Low Intermediate Risk)



NICaN Board

Mossley Mill, Newtownabbey

9:30a.m – 12.30pm, Monday 26th February 2018

Attendees	Apologies
Eatock, Dr Martin	Anderson, Cara
Gavin, Dr Anna	McKay, Geraldine
Gishkori, Esther	Stewart, Dr David
Gribben, Loretta	
Johnston, Jackie	
Leonard, Caroline	
Magee, Joe	
McAleese, Dr Jonathan	
McCarthy, Dr Miriam	
McCaughey, Hugh	
McGoran, Seamus	
Mitchell, Dr Mike	
Monteverde, Heather	
O'Brien, Clodagh	
O'Hagan, Margaret	
Scullin, Dr Paula	
Reilly, Dr Michael	

Guests in attendance:

Dr Anne-Marie McClean, Adept Clinical Fellow

Dr Damien Bennett, ST5 Speciality Registrar, Public Health Agency

Section A – Updates from last meeting

1 Welcome and Introductions

Hugh McCaughey welcomed the Board Members to the meeting.
Apologies were given as above.

It was noted that Professor Joe O'Sullivan and Mr Jim McGuigan would no longer be members of NICaN Board due to changes in roles. The Chair thanked them for their service on the Board. Members were informed that Ms Nicola Porter, PPI representative, has decided to step down from the NICaN Board. The Chair noted she has been a valued member of NICaN Board for more than 10 years. A number of Board members noted their thanks and appreciation for the dedication and commitment she had provided to the Board.
Dr Paula Scullin, Dr Mike Mitchell and Mr David McCaul were welcomed on to the Board.

Minutes and Matters Arising
The December 2017 minutes were agreed. Matters arising were as follows:

- Cancer Services Indicator Framework – The document has been submitted to the Service Frameworks Programme Board and is being considered.
  ACTION
  Mr Joe Magee to provide an update on next steps with regards to the Cancer Services Indicator Framework.
- Secondary use of data – Mr Jackie Johnston reported that without an NI Assembly there are legislative challenges for the regulations for secondary uses of data.
  ACTION
  Mr Joe Magee to follow up and progress.

Section B Strategic Issues/Developments

2 Review of non-surgical oncology

Mr Hugh McCaughey reported that a paper has gone to the Transformation Implementation Group (TIG) outlining the structure and the membership for the review. There will be an overseeing programme board and a core review team with representatives from each Trust and relevant disciplines. A quality improvement approach will be taken with prototype testing taking place throughout the review process. A further paper will go to TIG in the next few weeks. This will be circulated to NICaN Board members following approval at TIG.

There was discussion regarding membership of the Programme Board. It was noted that there was currently no representation from the PHA or NIMDTA and that this should be considered. There were also concerns expressed regarding the timescales which were seen as ambitious.

ACTION
TIG paper to be circulated with NICaN Board Minutes.

3 Reconfiguration of breast assessment services

Dr Miriam McCarthy reported the key recommendations of the Review of Breast Assessment Services.
The aim is to go out to public consultation in late Spring/early Summer with final recommendations anticipated in the Autumn.

4 Non medical prescribing (NMP)

Mrs Loretta Gribben provided an update on behalf of Mrs Cara Anderson. Trusts have submitted individual plans for the implementation of NMP but many of them are outside the budget envelope so queries have been sent back. What is clear is that there are significant constraints:

1. The nurses trained in NMP are CNS and AOS nurses so they are not easy to backfill
2. Most of the plans are reliant on ability to recruit backfill

Currently most of the plans for NMP are reliant on pharmacists and it is recognised it is likely to take a number of years to train the required numbers of NMPs. This training needs to be supported by a regional competency framework for nursing and pharmacy and a sub group has been established to develop this.

It was noted there is a general need to increase recruitment to oncology nursing posts to provide backfill for release of those taking up the roles of NMPs.

ACTION

Cara Anderson to update on progress of NMP at next NICaN Board Meeting.

4 Improving the effectiveness of MDTs

Dr Martin Eatock reported that the first meeting of the MDT effectiveness steering group was held on the 25th January 2018. A baseline position will be established by each tumour site to look at what opportunities there are to protocolise patient pathways. Streamlining of the core membership of MDTs will also be addressed and this may require discussion with the NHS England peer review team. The Urology Clinical Reference Group is progressing with a pilot of protocolised treatment pathways for low risk bladder cancer. Any changes will be closely monitored and audited to assess the impact on outcomes.

ACTION

Dr Martin Eatock to update at the next meeting

6 Reporting Information System for Oncology and Haematology (RISOH)

Ms Clodagh O'Brien provided an update on behalf of Mrs Cara Anderson. Mrs Cara Anderson has been appointed as RISOH SRO. Implementation has been divided into the two services (Oncology and Haematology) and then two key areas of functionality:

1. Electronic Patient Record (EPR); recording of all clinical information including nursing documentation and creation of patient letters (onward interface to NIECR is operational)
2. Electronic Prescribing (EPX); electronic prescribing (using the regionally agreed protocols), pharmacy verification and validation followed by real time drug administration recording.

As of February 2017:

• Oncology EPR was implemented in WHSCT during November 2016 and then in all remaining sites during April 2017.

•Oncology EPX was implemented in BHSCT during November 2017 and currently 95% of all patients have their SACT prescribed on RISOH. Roll out continued with WHSCT in January 2018, NHSCT and SHSCT in February 2018. SEHSCT will complete the implementation in March 2018.

Feedback has generally been positive. Belfast Trust reported additional time for nurses to record administration of drugs but there seems to be no significant impact on clinic running times. Belfast Trust is undertaking a time and motion study to enable Trust colleagues to understand the potential impact.

The Oncology component of the project is to close at the end of March 2018.

RISOH will focus on Haematology from April 2018. The Haematology Electronic Prescribing project

will run until the end of March 2019.

Haematology EPR has gone fully live in BHSCT during October 2017 with partial go live in SHSCT, WHSCT and SEHSCT.

It is not currently live in Northern Trust due to significant staffing issues.

RISOH has not encountered any outages since 23rd October 2017. BSO are completing their Significant Event Audit process and a draft is being produced. This will be reviewed by RISOH project board to pick up any actions as required. The last outage in October 17 was caused by an unexpected knock on effect of moving RISOH from the old to the new datacentres. This substantial process of moving and decommissioning the old data centres will be completed by BSO by the end of March 2018. All tasks that had medium to high risk for RISOH availability have now been completed without any further events.

Technical issues have been encountered that are affecting two areas of functionality; Insightive (data interrogation tool) and Healthcare at Home (third party system access). Both issues are expected to be resolved by early March 2018.

ACTION
Mrs Cara Anderson to provide update at next meeting.

7 Optimising Clinical Leadership

Loretta Gribben reported that an exploratory meeting has taken place with the Chief Nursing Officer, Charlotte McArdle and Heather Monteverde, Macmillan Cancer Support to discuss nursing leadership. The current lead cancer nurses have operational roles and are working at full capacity. There are no cancer consultant nurses or advanced cancer nurse practitioners that work across Trust boundaries or link with academia/clinical research.

A paper is currently being prepared for the CNO. This will give a broad overview of the current cancer nursing workforce and will look at how advanced nursing roles are used in models from other disease areas within NI and within cancer in the UK.

ACTION
Loretta Gribben to update at next meeting

8 CNS workforce Expansion

Mrs Loretta Gribben updated that we are in year 3 of the 6 year tapered funding model. Work is ongoing to develop regional referral criteria and referral process and to formalise handovers from CNSs to key workers in the community. Work is ongoing to finalise the regional key performance indicators associated with the expansion. A regional cancer CNS conference will be held on 25th April 2018.

9 NICaN Programme of Work 18/19

Ms Clodagh O'Brien reported on the proposed programme of work for 2018/19. The majority of the work programme has been discussed under separate agenda items at the NICaN Board meeting. Two additional issues identified were:

- the development of a sustainable staffing model for the network
- a review of the governance arrangements of the network

These are to be discussed in this afternoon's NICaN Fit for the Future Workshop.

Section B Improving Patient Pathways

10 Peer Review

Ms Clodagh O'Brien provided an update on behalf of Mrs Cara Anderson.

Skin - An IPT for the extension of the MDM by 1 hour, to support implementation of revised service specification and to address increased volume of patients, has been submitted and is under review. Recurrent funding is available and it is anticipated that the extended MDM should be operational from April 18.

Urology - Pressure on the specialist MDM has been alleviated by investment in the local MDM in SET from 1st Nov 17. This has taken approximately 25 discussions per week away from Belfast Trust and has already significantly improved flow.

Partial nephrectomy is still being provided on 3 sites. Work needs to proceed to look at the establishment of a centralised service in Belfast Trust. Discussions at Urology Programme Implementation Group (PIG) have suggested that this service should also include provision of hemi-nephrectomy and pyeloplasty in order to create a large enough team and deliver resilience.

Sarcoma – An IPT has been approved and funding obtained to support reconfiguration to a single regional meeting hosted by Belfast Trust.

Upper GI – There has been significant investment in the surgical service in Belfast to allow Southern

Trust patients to move to Belfast from February 2018.

S**ingle Integrated Haematological Malignancy Diagnostic Service (SIHMDS).** The IT requirement for the service has been included in the system specification for the new Laboratory Information Management Systems (LIMS). Resource will be required to support the establishment of an integrated reporting team to lead development of standard operating procedures ahead of LIMS. This is currently being scoped.

Waiting times
Waiting times for urology and upper GI continue to be challenging. Ongoing work to redesign the management pathways for these disease areas is being undertaken by the respective CRGs which, once implemented, should help to address the pressures. It was noted that urology waits are primarily linked to diagnostic waits.
Waiting times for plastics outpatients continue to be challenging. It is expected that this will be addressed by the work of the Regional Plastic Surgery and Burns Group.

Update on Year 4 Paediatric Peer Review Actions
Paper tabled.

Proposed Programme of Visits 2018-2020
Ms Clodagh O'Brien referenced the paper circulated prior to the meeting. NHS England has closed their CQUINs Cancer Peer Review website. Future peer review reports will be available on the Quality Surveillance Information System (QSIS) website.

There was discussion regarding which HSC organisation was responsible for acting on Peer Review findings. There was clarification that HSC Trusts are responsible for developing action plans to address serious concerns or immediate risks. The HSCB will address *regional* issues identified within the peer review process.

11 Advanced Communication Skills Training (ACST) Sustainability
Mrs Loretta Gribben had circulated a paper prior to the meeting. She highlighted that ACST is a mandatory peer review requirement for core members of MDTs and recent research has demonstrated the benefits of undergoing training. The current model is unsustainable due to difficulty in the release of trainers from their other clinical duties, in order to provide the training. The paper included an options appraisal and support was sought for the preferred option, to explore local provision of ACST using a different licence provider. The importance of engagement by the HSC Trusts to facilitate the development of a sustainable model for delivery of this was emphasised. NICaN Board approved the preferred option.

ACTION
Mrs Loretta Gribben to contact Trust Directors to seek nominations to a Task and Finish group for the development of a sustainable ACST model.

12 Scalp Cooling
Dr Martin Eatock reported that the SACT CRG have completed a review of the evidence for scalp cooling. The evidence, whilst indicating some effect on the prevention of hair loss is not conclusive and does not definitively describe which patients should be offered scalp cooling. The evidence of an effect on quality of life is contradictory. In discussion it was agreed that the lack of evidence regarding the clinical effectiveness and cost effectiveness would mean this would be a low priority for commissioning given the other competing priorities.

Mrs Heather Monteverde suggested it would be useful to have an agreed text for Trusts on the regional position.

ACTION

Dr Martin Eatock and Dr Paula Scullin to agree a statement and circulate to the Trusts.

12 Cancer MDT Patient Information Systems Review

The license for the current Cancer Patient Pathway System (CaPPS) MDT management system is due to expire in March 2019. A group has been established to consider the service requirements beyond March 2019 and how these can be met.

Dr Damien Bennett provided an update that the Group had developed a broad high level specification for the requirements of a cancer patient information system. He emphasized that the Group considered it was important that a future system should be able to collect the relevant data to enable submission to national audits and that data collection should be automated, where possible. NICaN Board approved the specification presented and provided approval to move to the scoping of a detailed system specification.

Dr Paula Scullin suggested that it would be important that staff are not entering the same data into multiple systems. There was discussion about Encompass and the need for a solution between the end of the CaPPS contract with the current provider Kainos in March 2019 and Encompass go live which is expected in 5-7 years.

13 Cancer Patient Experience Survey (CPES)

Clodagh O'Brien informed the Board that the next CPES is planned for May 2018 and will be jointly funded by Macmillan Cancer Support and the HSCB. Professor Roy McClelland from the Privacy Advisory Committee has provided advice on the data governance issues.

ACTION

Ms Clodagh O'Brien Board to update on progress at next meeting

Section D – Any other Business

Dr Miriam McCarthy reported that the Plastics and Burns Regional Group is being established and a skin cancer PPI representative is required. She sought approval from the Board to approach Mike Moran who is member of the Skin Clinical Reference Group.

Dr Anna Gavin informed the Board that a peer review visit to the NI Cancer Registry is taking place on the 4th -5th June. She requested a nomination from the NICaN Board to participate.

Dr Anna Gavin also reported on a recent large CRUK study on patient reported outcomes for men with prostate cancer. It was agreed this should be presented by the Registry at the next Urology CRG.

ACTION

Terms of reference for the cancer registry peer review are to be circulated with the Board minutes

Date of next meeting

Thursday 24th May 9.30am-12.30pm venue to be confirmed

Department of Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

GUIDANCE IN RELATION TO THE

HEALTH AND SOCIAL CARE COMPLAINTS PROCEDURE

Revised April 2019

REVISIONS TO HSC COMPLAINTS PROCEDURE

Title	Update/Action	Date Effective
Guidance in relation to the Health and Social Care Complaints Procedure	Introduced in place of: Complaints in Health and Social Care: Standards and Guidelines for Resolution and Learning	01 April 2019
Complaints in Health and Social Care: Standards and Guidelines for Resolution and Learning	Introduced in place of: (HPSS) Complaints Procedure 1996	01 April 2009
Health and Personal Social Services (HPSS) Complaints Procedure 1996	Revoked and replaced with new Guidance	31 March 2009

AMENDMENTS TO COMPLAINTS DIRECTIONS

Directions	Details	Date Effective
Directions to the Regional Business Services Organisation on Procedures for dealing with Health and Social Care Complaints	The **BSO Directions** were amended for the first time at: • Paragraph 2 (Interpretation) of the principal Directions (a) update to Northern Ireland Public Services Ombudsman • Paragraph 2 (Interpretation), where the definition of an SAI was added; • Paragraph 7(1) (No investigation of complaint) where sub-paragraph 7(1)(m) was added in regard to SAIs; and • Paragraph 7(4) where paragraph 7(4A) was added	01 April 2019

Directions	Details	Date Effective
	in regard to SAIs.	
Directions to the Regional Agency for Public Health and Social Well-Being on Procedures for Dealing with Health and Social Care Complaints	The **PHA Directions** were amended for the first time at: • Paragraph 2 (Interpretation) of the principal Directions (a) update to Northern Ireland Public Services Ombudsman • Paragraph 2 (Interpretation), where the definition of an SAI was added; • Paragraph 7(1) (No investigation of complaint) where sub-paragraph 7(1)(m) was added in regard to SAIs; and • Paragraph 7(4) where paragraph 7(4A) was added in regard to SAIs. • Paragraph 7 (No investigation of complaint) of the principal Directions—the definition of vulnerable adults policy or procedures was updated to adult safeguarding procedures or protocol	01 April 2019
Directions to the Health and Social Care Board on procedures for dealing with Complaints about Family Health Services Practitioners and Pilot Scheme Providers	The **HSC Board Directions** were amended for the third time at: • Paragraph 2 (Interpretation) of the principal Directions (a) update to Northern Ireland Public Services Ombudsman • Paragraph 2 (Interpretation), where the definition of an SAI was added; • Paragraph 7(1) (No	01 April 2019

Directions	Details	Date Effective
	investigation of complaint) where sub-paragraph 7(1)(m) was added in regard to SAIs; and • Paragraph 7(4) where paragraph 7(4A) was added in regard to SAIs. • Paragraph 7 (No investigation of complaint) of the principal Directions—the definition of vulnerable adults policy or procedures was updated to adult safeguarding procedures or protocol • Paragraph 12 (Referring a complaint) of the principal Directions, for sub-paragraph (5)(b) substitute(b) The HSC Board Complaints Manager acts impartially as "honest broker" to the complainant and Practice/Practitioner in the resolution of the complaint.	
Health and Social Care Complaints Procedure Directions	The **Main Directions** were amended for the second time at: • Paragraph 2 (Interpretation) of the principal Directions (a) update to Northern Ireland Public Services Ombudsman • Paragraph 2 (Interpretation), where the definition of an SAI was added; • Paragraph 7(1) (No investigation of complaint) where sub-paragraph 7(1)(m) was added in regard to SAIs; and • Paragraph 7(4) where	01 April 2019

Directions	Details	Date Effective
	paragraph 7(4A) was added in regard to SAIs. • Paragraph 7 (No investigation of complaint) of the principal Directions—update to adult safeguarding procedures or protocol • Paragraph 12 (Referring a complaint) of the principal Directions, for sub-paragraph (5)(b) substitute(b) The HSC Board Complaints Manager acts impartially as "honest broker" to the complainant and Practice/Practitioner in the resolution of the complaint. • Paragraph 14 (Response) of the principal Directions omit sub-paragraph (7).	
Complaints about Family Health Services Practitioners and Pilot Scheme Providers **(Amendment)** Directions (Northern Ireland) 2013	The **HSC Board Directions** were amended for the second time in regard to the handling of complaints under paragraph 12(5)(b) at: • Paragraph 18(c) (Response) was amended to include sub-paragraph 18(c)(i) to respond to the complainant within 20 days when the HSC Board has been asked to act as 'honest broker'; and • Sub-paragraph 18(c) (ii) to respond to the complainant within 10 days in all other cases.	02 September 2013 **2013 N0. 12**
Health and Social Care Complaints Procedure Directions **(Amendment)** (Northern Ireland) 2009	The **Main Directions** were amended for the first time at: • Paragraph 2	02 September 2013 **2013 N0. 11**

Directions	Details	Date Effective
	(Interpretation), where the definition of an SAI was added; • Paragraph 7(1) (No investigation of complaint) where sub-paragraph 7(1)(m) was added in regard to SAIs; and • Paragraph 7(4) where paragraph 7(4A) was added in regard to SAIs.	
Directions to the Regional Business Services Organisation on Procedures for dealing with Health and Social Care Complaints	The Directions were introduced. Known as **BSO Directions**	26 July 2010
Directions to the Regional Agency for Public Health and Social Well-Being on Procedures for Dealing with Health and Social Care Complaints	The Directions were introduced. Known as **PHA Directions**	26 July 2010
Amendment Directions to the Health and Social Care Board on procedures for dealing with complaints about Family Health Services Practitioners and Pilot Scheme Providers	The **HSC Board Directions** were amended for the first time in respect to monitoring and the requirement by the Family Practitioner Services or pilot scheme provider to obtain consent from the complainant was removed at: Paragraph 21(2)(a) in regards to what the practitioner must send to the HSC Board and the timescale: and Paragraph 21(2) (b) in regards the practitioner sending the HSC Board quarterly complaints.	01 October 2009
Directions to the Health and Social Care Board on procedures for dealing with complaints about Family	The Directions were introduced. Known as **HSC Board Directions**	01 April 2009

Directions	Details	Date Effective
Health Services Practitioners and Pilot Scheme Providers		
Health and Social Care Complaints Procedure Directions (Northern Ireland) 2009	The Directions were introduced. Known as **Main Directions**	01 April 2009

BACKGROUND

The HSC Complaints Procedure*, 'Complaints in Health and Social Care: Standards and Guidelines for Resolution and Learning'* was developed and published in 2009*.* It replaced the former Health and Personal Social Services (HPSS) Complaints Procedure 1996 and provided a streamlined health and social care (HSC) complaints process that applies equally to all HSC organisations. As such it presented a simple, consistent approach and set out complaints handling procedures with clear standards and guidance for both HSC staff who handle complaints and for the public who may wish to raise a complaint across all HSC services.

The HSC Complaints Procedure (published 2009) was developed in conjunction with HSC organisations and publically consulted on before being finalised and published. It reflected the changing culture across HSC services and demonstrated an increased emphasis regarding the promotion of and need for **safety and quality** in service provision as well as the need to be open and transparent; and to learn from complaints and take action in order to reduce the risk of recurrence.

The key principles remain unchanged however this document follows a review and refresh of the HSC Complaints Procedure in order to bring it up to date for 2019. Any changes or improvements in complaints handling across the HSC are set out in detail. The document has been renamed the '*Guidance in relation to the Health and Social Care Complaints Procedure' or 'HSC Complaints Procedure'* for short. Updates include the:

- details on the new government department name introduced under the Departments Northern Ireland Act 2016[1];
- details of the role of the Northern Ireland Public Services Ombudsman (NIPSO) known as 'the Ombudsman' further to changes introduced under the Public Services Ombudsman Act (Northern Ireland) 2016[2];
- removal of the restriction on providing electronic responses to complainants;
- removal of the ability for HSC staff to complain to the Ombudsman about the way they have been dealt with under the Complaints Guidance;
- clarity on the role and remit of the honest broker in complaints handling;
- updated information on complaints about Independent Sector Providers (ISPs); and
- process for dealing with complaints and serious adverse incidents that are subject to legal proceedings.

This single tier process aims to provide:

- a strengthened, more robust, local resolution stage;
- an enhanced role for commissioners in monitoring, performance management and learning;
- improved arrangements for driving forward quality improvements across the HSC; and
- improved arrangements for the delivery of responses to complainants.

[1] Departments Northern Ireland Act 2016: http://www.legislation.gov.uk/nia/2016/5/section/1/enacted
[2] Public Services Ombudsman Act (Northern Ireland) 2016: http://www.legislation.gov.uk/nia/2016/4/enacted

The HSC Complaints Procedure presents HSC organisations with detailed, yet flexible, complaints handling arrangements designed to:

- provide effective local resolution and learning;
- improve accessibility;
- clarify the options for pursuing a complaint;
- promote the use and availability of support services, including advocacy;
- provide a well-defined process of investigation;
- promote the use of a range of investigative techniques;
- promote the use of a range of options for successful resolution, such as the use of independent experts, lay persons and conciliation;
- resolve complaints quickly and efficiently;
- provide flexibility in relation to target response times;
- provide an appropriate and proportionate response within reasonable and agreed timescales;
- provide clear lines of responsibility and accountability;
- improve record keeping, reporting and monitoring; and
- increase opportunities for shared learning across the region.

The standards for complaints handling are designed to assist HSC organisations in monitoring the effectiveness of their complaints handling arrangements locally and build public confidence in the process. The eight specific standards of HSC are:

Standard 1: Accountability
Standard 2: Accessibility
Standard 3: Receiving complaints
Standard 4: Supporting complainants and staff
Standard 5: Investigation of complaints
Standard 6: Responding to complaints
Standard 7: Monitoring
Standard 8: Learning

More details on each of the standards are provided in Annex 1 of this document.

It is recognised that sometimes, and even in despite of the best efforts of all concerned, there will be occasions when local resolution fails. Where this happens the complainant will be advised of their right to refer their complaint to the Ombudsman. The HSC Organisation also reserves the right to refer complaints to the Ombudsman.

This revised guidance in relation to the HSC Complaints Procedure is effective from 01 April 2019. It will be known as *'Guidance in relation to the Health and Social Care Complaints Procedure'*.

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SECTION 1 – INTRODUCTION

Purpose of the HSC Complaints Procedure

1.1 This document is an updated version of the HSC Complaints Procedure which was first published in 2009 and sets out how HSC organisations should deal with complaints raised by people who use or are waiting to use their services. It replaces any previous or existing guidance with effect from 01 April 2019 and continues to provide a streamlined complaints process which applies equally to all HSC organisations, including the HSC Board, HSC Trusts, Business Services Organisation (BSO), Public Health Agency (PHA), NI Blood Transfusion Service (NIBTS), Family Practitioner Services (FPS), Out of Hours services pilot schemes and HSC prison healthcare. As such, it presents a simple, consistent approach for both HSC staff who handle complaints and for the public who may wish to raise a complaint across all HSC services.

1.2 The HSC Complaints Procedure continues to promote an organisational culture in health and social care that fosters openness and transparency for the benefit of all who use it or work in it. It is designed to provide ease of access, simplicity and a supportive and open process which results in a speedy, fair and, where possible, local resolution. The HSC Complaints Procedure provides the opportunity to put things right for service users as well as learning from the experience and improving the safety and quality of services. Dealing with those who have made complaints delivers an opportunity to re-establish a positive relationship with the complainant and to develop an understanding of their concerns and needs.

Local resolution

1.3 The purpose of local resolution is to enable the complainant and the organisation to attempt a prompt and fair resolution of the complaint.

1.4 HSC organisations should work closely with service users to find an early resolution to complaints. Every opportunity should be taken to resolve complaints as close to the source as possible, through discussion and negotiation. Where possible, complaints should be dealt with immediately. Where this is not possible, local resolution should be completed within 20 working days of receipt of a complaint (10

working days within FPS settings). The expectations of service users should be managed by HSC staff and any difficulties identified in being able to resolve a complaint within 20 days by local resolution should be communicated to the service user immediately.

1.5 Local procedures should be easily accessible, open, fair, flexible and conciliatory and should encourage communication on all sides. They should include a well-defined process for investigating and resolving complaints. Complainants must be advised of their right and be signposted to refer their complaint to the Ombudsman if they remain dissatisfied with the outcome of the HSC Complaints Procedure.

Principles of an effective Complaints Procedure

1.6 The HSC Complaints Procedure has been developed around four key principles:

- **openness and accessibility** – flexible options for pursuing a complaint and effective support for those wishing to do so;
- **responsiveness** – providing an appropriate and proportionate response;
- **fairness and independence** – emphasising early resolution in order to minimise strain and distress for all; and
- **learning and improvement** – ensuring complaints are viewed as a positive opportunity to learn and improve services.

Learning

1.7 Effective complaints handling is an important aspect of clinical and social care governance arrangements. Lessons learned during the complaints resolution process will assist organisations to make changes to improve the quality of their services and safeguard high standards of care and treatment. Increased efforts should be made to promote a more positive culture of not just resolving complaints but also learning from them. Furthermore, by highlighting the potential added value of complaints and subsequent quality and safety improvements made within HSC organisations the process becomes more acceptable and amenable to all.

1.8 Complaints are seen as a significant source of learning within health and social care and provide opportunities to improve:

- outcomes for services users;
- the quality of services; and
- service user experiences.

1.9 How HSC organisations handle complaints is an indicator of how responsive they are to the concerns of service users and/or their representatives. An increase in the number of complaints is not in itself a reason for thinking the service is deteriorating. The important point is to handle complaints well, take appropriate action and use the lessons learned to improve quality and safety.

What the HSC Complaints Procedure covers

1.10 The HSC Complaints Procedure deals with complaints about care or treatment, or about issues relating to the provision of health and social care. Complaints may, therefore, be raised about services provided by, for example:

- HSC Board
  - commissioning and purchasing decisions (for individuals)
- HSC Trusts
  - hospital and community services
  - registered establishments and agencies where the care is funded by the HSC
  - HSC funded staff or facilities in private pay beds
  - HSC prison healthcare
- Business services organisation (BSO)
  - services provided relevant to health and social care
- Public Health agency (PHA)
- Northern Ireland Blood Transfusion Service (NIBTS)
- Family practitioner Services (FPS)

1.11 The HSC Complaints Procedure may be used to investigate a complaint about any aspect of an application to obtain access to health or social care records for deceased patients under the Access to Health Records (NI) Order 1993[3] as an alternative to making an application to the courts.

[3] Access to Health Records (NI) Order 1993 applies only to records created since 30 May 1994.

What the HSC Complaints Procedure does not cover

1.12 Complaints about private care and treatment or service; which includes private dental care[4] or privately supplied spectacles are not dealt with in this guidance. In addition those services which are not provided or funded by the HSC, for example, provision of private medical reports are also not covered under the HSC Complaints Procedure.

1.13 Complaints may be raised within an HSC organisation which need to be addressed, but the complaint or aspects of it may not fall within the scope of the HSC Complaints Procedure. When this occurs, the HSC organisation should ensure that there are other processes in place which can be referred to in order to deal with these concerns. For example:

- staff grievances
- an investigation under the disciplinary procedure
- an investigation by one of the professional regulatory bodies
- services commissioned by the HSC Board
- requests for information under Freedom of Information or access to records under the General Data Protection Regulation (GDPR)
- independent inquiries and criminal investigations
- the Children Order Representations and Complaints Procedure
- adult safeguarding
- child protection procedures
- Coroners cases
- legal action
- Serious Adverse Incidents (SAIs)
- Whistleblowing[5]

[4] The Dental Complaints Service deals with private dental and mixed health service and private dental complaints and can be contacted via the General Dental Council at http://www.gdc-uk.org/
[5] Public Interest Disclosure (Northern Ireland) Order 1998

1.14 Complaints received that appear to indicate the need for referral under any of the processes listed above should be immediately transferred to the Complaints Manager for onward transmission to the appropriate department. Where a complaint is referred to any of these other processes it will be the responsibility of the officers involved to ensure that information is given to complainants on the reason for the referral; how the new process operates; their expectations for involvement in the process; anticipated timescales and the named officer/organisation the complainant can contact for ongoing communication. If any aspect of the complaint is not covered by the referral it will continue to be investigated under the HSC Complaints Procedure. In these circumstances, investigation will only be taken forward if it does not, or will not, compromise or prejudice the matter being investigated under any other process.

Staff Grievances

1.15 HSC organisations should have separate procedures for handling staff grievances.

Disciplinary Procedure

1.16 Disciplinary matters are not covered under the HSC Complaints Procedure. Its purpose is to focus on resolving complaints and learning lessons for improving HSC services. It is not for investigating disciplinary matters though these can be investigated by the HSC organisation and may be referred to a Professional Regulatory Body (see paragraph 1.20 below). The purpose of the HSC Complaints Procedure is not to apportion blame, but to investigate complaints with the aim of satisfying complainants whilst being fair to staff.

1.17 Where a decision is made to embark upon a disciplinary investigation, action under the HSC Complaints Procedure on any matter which is the subject of that investigation must cease. Where there are aspects of the complaint not covered by the disciplinary investigation, they may continue to be dealt with under the HSC Complaints Procedure.

1.18 The Chief Executive (or designated senior person[6]) must advise the complainant in writing that an investigation is being dealt with under appropriate Trust staff procedures. They also need to be informed that they may be asked to take part in the process and that any aspect of the complaint not covered by the investigation will continue to be investigated under the HSC Complaints Procedure.

1.19 In drafting these letters, the overall consideration must be to ensure that when investigation is required the complainant is not left feeling that their complaint has only been partially dealt with.

Investigation by a Professional Regulatory Body

1.20 A similar approach to that outlined above should be adopted in a case referred to a professional regulatory body (Annex 3). The Chief Executive (or designated senior person) must inform the complainant in writing of the referral. This should include an indication that any information obtained during the complaints investigation may need to be passed to the regulatory body. The letter should also explain how any other aspect of the complaint not covered by the referral to the regulatory body will be investigated under the HSC Complaints Procedure.

Services Commissioned by the HSC Board

1.21 Complaints about the HSC Board's commissioning decisions regarding purchasing of services may be made by, on or on behalf of any individual personally affected by a commissioning decision taken by the HSC Board. The HSC Complaints Procedure may not deal with complaints about the merits of a decision where the HSC Board has acted properly and within its legal responsibilities. Where general concerns about commissioning issues are raised with the HSC Board a full explanation of the HSC Board's policy should be provided. These issues should not, however, be dealt with under the HSC Complaints Procedure.

[6] A designated Senior Person should be a Director (or Nominee)

Requests for Information/Access to Records

1.22 Although use and disclosure of service user information may be necessary in the course of handling a complaint, the complainant, or indeed any other person, may at any time make a request for information which may, or may not, be related to the complaint. Such requests should be dealt with separately under the procedures set down by the relevant HSC organisation for dealing with requests for information under the Freedom of Information Act 2000[7] and requests for access to health or social care records under the General Data Protection Regulation (GDPR)[8].

Independent Inquiries and Criminal Investigations

1.23 Where an independent inquiry into a serious incident or a criminal investigation is initiated, the Chief Executive (or designated senior person) should immediately advise the complainant of this in writing. As the HSC Complaints Procedure cannot deal with matters subject to any such investigation, consideration of those parts of the original complaint must cease until the other investigation is concluded.

1.24 When the independent inquiry or criminal investigation has concluded, consideration of that part of the original complaint on which action was suspended may recommence if there are outstanding matters remaining to be considered under the HSC Complaints procedure.

Children Order Representations and Complaints Procedure

1.25 Arrangements for complaints raised under the Children Order Representations and Complaints Procedure are outlined in Annex 15. The HSC Board and HSC Trusts should familiarise themselves with Part IV of, and paragraph 6 of Schedule 5 to, the Children (NI) Order 1995[9].

[7] Freedom of Information Act 2000: http://www.legislation.gov.uk/ukpga/2000/36/contents
[8] General Data Protection Regulation (GDPR): https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr
[9] Children (NI) Order 1995: http://www.legislation.gov.uk/nisi/1995/755/contents

Adult Safeguarding

1.26 Where it is apparent that a complaint relates to abuse, exploitation or neglect of an adult at risk of harm then the regional '*Adult Safeguarding Operational Procedures*' (September 2016[10]) and the associated *'Protocol for Joint Investigation of Adult Safeguarding Cases'* (August 2016[11]) should be activated by contacting the Adult Protection Gateway Service at the relevant HSC Trust[12]. The HSC Complaints Procedure should be suspended pending the outcome of the adult safeguarding investigation and the complainant advised accordingly. However, if there are aspects of the complaint that do not cause the aforementioned Operational Procedures and associated Protocol to be activated, then these should continue to be investigated under the HSC Complaints Procedure. However, only those aspects of the complaint not falling within the scope of the safeguarding investigation will continue via the HSC Complaints Procedure.

Child Protection Procedures

1.27 Any complaint about individual agencies should be investigated through that agency's complaints procedure. Appeals which relate to decisions about placing a child's name on the Child Protection Register should be dealt with through the Child Protection Registration Appeals Process. The Safeguarding Board for Northern Ireland (SBNI) Child Protection procedures manual outlines the criteria for appeal under that procedure. These include when the:

- ACPC procedures in respect of the case conference were not followed;
- information presented at the case conference was inaccurate; incomplete or inadequately considered in the decision making process;
- threshold for registration/deregistration was not met;
- category for registration was not correct.

[10] Adult Safeguarding Operational Procedures:
http://www.hscboard.hscni.net/download/PUBLICATIONS/SAFEGUARDING%20VULNERABLE%20ADULTS/guidance_and_protocols/Adult-Safeguarding-Operational-Procedures.pdf
[11] Protocol for Joint Investigation of Adult Safeguarding Cases:
http://www.hscboard.hscni.net/download/PUBLICATIONS/SAFEGUARDING%20VULNERABLE%20ADULTS/guidance_and_protocols/Protocol-for-joint-investigation-of-adult-safeguarding-cases.pdf
[12] Information about and contact details for HSC Trusts can be accessed at the following link - https://www.nidirect.gov.uk/articles/who-contact-if-you-suspect-abuse-exploitation-or-neglect

Coroners Cases

1.28 With the agreement of the Coroner's Office, where there are aspects of the complaint not covered by the Coroners investigation they will continue to be dealt with under the HSC Complaints Procedure. Once the Coroners investigation has concluded, any issues that are outstanding in relation to the matters considered by the Coroner may then be dealt with under the HSC Complaints Procedure.

Legal Action

1.29 Even if a complainant's initial communication is through a solicitor's letter it should not be inferred that the complainant has decided to take formal legal action.

1.30 If the complainant has either instigated formal legal action, or advised that he or she intends to do so, the complaints process should cease. The Chief Executive (or designated senior person) should advise the complainant and any person/member of staff named in the complaint of this decision in writing. However, those aspects of the complaint not falling within the scope of the legal investigation will continue via the HSC Complaints Procedure.

1.31 It is not the intention of the HSC Complaints Procedure to deny someone the opportunity to pursue a complaint if the person subsequently decides **not to take legal action**. If he/she then wishes to continue with their complaint via the HSC Complaints Procedure and requests this, the investigation of their complaint should commence or resume. However, any matter that has been through the legal process to completion cannot also be investigated under the HSC Complaints Procedure.

Serious Adverse Incidents (SAI)

1.32 Complaints may indicate the need for a Serious Adverse Incident (SAI) investigation. When this occurs, the Chief Executive (or designated senior person), must advise the complainant and any person/staff member named in the complaint in writing that an SAI investigation is under way. They must also indicate to all concerned that the HSC Complaints Procedure may still continue during the SAI investigation. However, only those aspects of the complaint not falling within the scope of the SAI investigation will continue via the HSC Complaints Procedure.

1.33 The overall consideration must be to ensure that when the investigation is through the SAI process, the complainant is not left feeling that their complaint has only been partially dealt with.

SECTION 2 – MAKING A COMPLAINT

What is a complaint?

2.1 A complaint is "**an expression of dissatisfaction that requires a response**". Complainants may not always use the word "complaint". They may offer a comment or suggestion that can be extremely helpful. It is important to recognise those comments that are actually complaints and therefore need to be handled as such.

Promoting access

2.2 Standard 2: *Accessibility* provides the criteria by which organisations should operate (Annex 1 refers). Service users should be made aware of their right to complain and given the opportunity to understand all possible options for pursuing a complaint. Complainants must, where appropriate, have the support they need to articulate their concerns and successfully navigate the system. They must also be advised on the types of help available, for example, through front-line staff, the Complaints Manager and the Patient and Client Council (PCC). HSC organisations should promote and encourage more open and flexible access to the HSC Complaints Procedure and other less formal avenues in an effort to address barriers to access.

Who can complain?

2.3 Any person can complain about any matter connected with the provision of HSC services. Complaints may be made by:

- a patient or client;
- former patients, clients or visitors using HSC services and facilities;
- someone acting on behalf of existing or former patients or clients, providing they have obtained the patient's or client's consent;
- parents (or persons with parental responsibility) on behalf of a child; and
- any appropriate person in respect of a patient or client unable by reason of physical or mental capacity to make the complaint himself or who has died e.g. the next of kin.

Consent

2.4 Complaints by a third party should be made with the written consent of the individual concerned. There will be situations where it is not possible to obtain consent, such as when the:

- individual is a child and not of sufficient age or understanding to make a complaint on their own behalf;
- individual is incapable (for example, rendered unconscious due to an accident; judgement impaired as a result of a learning disability, mental illness, brain injury or serious communication problems);
- subject of the complaint is deceased; and
- delay in the provision of consent may result in a delay in the resolution of the complaint.

2.5 Where a person is unable to act for him/herself, his/her consent shall not be required.

2.6 The Complaints Manager, in discussion with the Chief Executive (or designated senior person), will determine whether the complainant has sufficient interest to act as a representative. The question of whether a complainant is suitable to make representation depends, in particular, on the need to respect the confidentiality of the patient or client. If it is determined that a person is not suitable to act as a representative, the Chief Executive (or designated senior person) must provide them with information in writing outlining the reasons the decision has been taken. More information on consent can be found in the DoH good practice in consent guidance[13].

2.7 Third party complainants who wish to pursue their own concerns can bring these to the HSC organisation without compromising the identity of the patient/client. The HSC organisation must consider the matter then investigate and address the issue and any concerns identified fully. A response will be provided to the third party on any issues which may be addressed without breaching patient/client confidentiality.

[13] https://www.health-ni.gov.uk/articles/consent-examination-treatment-or-care

Confidentiality

2.8 HSC staff should be aware of their legal and ethical duty to protect the confidentiality of the service user's information. The legal requirements are set out in the General Data Protection Regulations (GDPR) which controls how personal information is used by organisations, businesses or the government. Additional requirements are detailed in the Human Rights Act 1998 (HRA) which requires public authorities to act in a way which is compatible with the list in the European Convention on Human Rights (the Convention). The Common Law Duty of Confidentiality must also be observed. Ethical guidance is provided by the respective professional bodies. A service user's consent is required if their personal information is to be disclosed. More detailed information can be found in the DoH guidance entitled *Code of Practice on Protecting the Confidentiality of Service User Information* [14]published January 2012.

2.9 It is not necessary to obtain the service user's express consent to the use of their personal information to investigate a complaint. Even so, it is good practice to explain to the service user that information from his/her health and/or social care records may need to be disclosed to the complaint investigators, but only if they have a demonstrable need to know and for the purposes of investigating. If the service user objects to this, it should be explained to him/her that non-disclosure could compromise the investigation and his/her hopes of a satisfactory outcome to the complaint. The service user's wishes should always be respected, unless there is an overriding public interest in continuing with the matter.

Third Party Confidence

2.10 The duty of confidence applies equally to third parties who have given information or who are referred to in the service user's records. Particular care must be taken where the service user's records contain information provided in confidence, by, or about, a third party who is not a health or social care professional. Only

[14] DoH Code of Practice:
https://www.health-ni.gov.uk/publications/dhssps-code-practice-protecting-confidentiality-service-user-information

information which is relevant to the complaint should be considered for disclosure, and then only to those *within* the HSC who have a demonstrable 'need to know' in connection with the complaint investigation. Third party information must not be disclosed to the service user unless the person who provided the information has expressly consented to the disclosure.

2.11 Disclosure of information provided by a third party outside the HSC also requires express consent. If the third party objects, then information they provided can only be disclosed where there is an overriding public interest in doing so.

Use of Anonymised Information

2.12 Where anonymised information about a patient/client and/or third parties would suffice for investigation of the complaint, identifiable information should be omitted. Anonymising information does not of itself remove the legal duty of confidence but, where all reasonable steps are taken to ensure that the recipient is unable to trace the patient/client or third party identity, it may be passed on where justified by the complaint investigation. Where a patient/client or third party has expressly refused permission to use certain information, then it can only be used where there is an overriding public interest in doing so.

How can complaints be made?

2.13 Complaints may be made in a variety of formats including verbally, written or electronic. Should a verbal complaint be made the complainant should be asked to formalise their complaint in writing. If the complainant is unable to put their complaint in writing then Trust staff or the Patient Client Council can provide assistance. It is helpful to establish at the outset what the complainant wants to achieve in order to avoid confusion or dissatisfaction and subsequent complaints. HSC organisations should be mindful of technological advances specifically in regard to email communications and must adhere to their relevant Information Technology (IT) policies and procedures. Complaints Managers should also consider local arrangements to ensure there is no breach of patient/client confidentiality in the management of information surrounding complaints.

2.14 Complaints may be made to any member of staff, for example receptionists, clinical or care staff. In many cases complaints are made orally and front-line staff may either resolve the complaint "on the spot" or pass it to the Complaints Manager. It is important that front-line staff receive the appropriate complaints handling training including refresher training according to extant local procedures. They must also be supported to respond sensitively to the comments and concerns raised and be able to distinguish those issues which would be better referred elsewhere for more detailed investigation. Front line staff should familiarise themselves with Section 75 of the Northern Ireland Act 1998 which changed the practices of government and public authorities so that equality of opportunity and good relations are central to policy making, policy implementation, policy review and service delivery[15]. (See Flowchart page 50)

Options for pursuing a complaint

2.15 Some complainants may prefer to make their initial complaint to someone within the relevant organisation who has not been involved in the care provided. In these circumstances, they should be advised to address their complaint to the Complaints Manager, an appropriate senior person or, if they prefer, to the Chief Executive. All HSC organisations have named Complaints Managers. The following paragraphs outline the options available to complainants who want to raise complaints in relation to:

- Family Practitioner Services;
- Regulated Establishments and Agencies; and
- Independent Sector Providers.

Family Practitioner Services (family doctors, dentists, pharmacists, opticians)

2.16 Family Practitioner Services (FPS) are required to have in place a practice-based complaints procedure which forms part of the local resolution mechanism for settling complaints. A patient may approach any member of staff with a complaint about the service or treatment he/she has received.

[15] Section 75 of the Northern Ireland Act 1998
https://www.legislation.gov.uk/ukpga/1998/47/section/75

2.17 Alternatively, the complainant has the right to lodge his/her complaint with the HSC Board's Complaints Manager if he/she does not feel able to approach immediate staff (see flowchart page 51).

2.18 Where requested, the HSC Board will act impartially as "honest broker" to the complainant and Practice/Practitioner in either the resolution of a complaint or by assisting all parties in reaching a position of understanding. The objective for the HSC Board should be, wherever possible, to restore the trust between the patient and the Practice/Practitioner staff. This will involve an element of mediation on the part of the HSC Board or the offer of conciliation services where they are appropriate. The HSC Board's Complaints Manager should seek with the complainant's agreement to involve the FPS Complaints Manager as much as possible in resolving the issues. The HSC Board's Complaints Manager is also available to Practice/Practitioner staff for support and advice.

2.19 The HSC Board has a responsibility to record and monitor the outcome of complaints lodged with them.

2.20 The HSC Board will provide support and advice to FPS in relation to the resolution of complaints. It will also appoint Independent Experts, Lay Persons or Conciliation Services, where appropriate.

2.21 Complainants must be advised of their right to refer their complaint to the Ombudsman if they remain dissatisfied with the outcome of the practice-based complaints procedure.

Regulated Establishments and Agencies

2.22 All regulated establishments and agencies[16] must operate a complaints procedure that meets the requirements of applicable Regulations, relevant Minimum Standards and the HSC Complaints Procedure. This includes:

- Effectively publicising the arrangements for dealing with complaints and ensuring service users, clients and families are aware of such arrangements;
- Ensuring that any complaint made under the complaints procedure is investigated;
- Ensuring that time limits for investigations are adhered to;
- Advising complainants regarding the outcomes of the investigation; and
- Maintaining a record of learning from complaints that is available for inspection.

2.23 Complainants must also be advised of their right to refer their complaint to the Ombudsman if they remain dissatisfied with the HSC Complaints Procedure. It is for the Ombudsman to determine whether or not a case falls within that office's jurisdiction.

2.24 Complaints may be made by service users or persons acting on their behalf providing they have obtained the service user's consent. Complaints relating to contracted services provided by the registered provider or agency may be received directly by the service provider or by the contracting Trust. Complainants should be encouraged to raise their concerns, at the outset, with the registered provider or agency. The registered provider is required by legislation to ensure the complaint is fully investigated. The general principle in the first instance would be that the registered provider or agency investigates and responds directly to the complainant.

2.25 However, individuals placed in a regulated establishment or who have their service provided by a regulated agency may, if they prefer, raise their concerns through the HSC Trust that commissioned the care on their behalf (see flowchart on page 52) as the commissioning Trust has a continuing duty of care to the service user and should participate in local resolution as necessary.

[16] Residential and nursing homes as well as Voluntary Adoption Agencies are examples of regulated establishments and agencies.

2.26 Where complaints are raised with the HSC Trust, the Trust must establish the nature of the complaint and consider how best to proceed. For example, the complaint may be about an aspect of the "care plan" and can, therefore, only be fully dealt with by the Trust. The complaint may also trigger the need for an investigation under child protection or protection of vulnerable adults' procedures or indeed, might highlight non-compliance with statutory requirements. It is not the intention to operate parallel complaints procedures, however, if the RQIA is notified of a breach of regulations or associated standards it will review the matter and take whatever appropriate action is required. It is important, therefore, that Trusts work closely with the registered providers, other professionals and the RQIA to enable appropriate decisions to be made.

2.27 HSC Trusts must assure themselves that regulated establishments and agencies that deliver care on their behalf are effective and responsive in complaints handling. Service users may approach the Ombudsman if they remain dissatisfied. It is possible that referrals to the Ombudsman where complaints are dealt with directly by the registered provider without HSC Trust participation in local resolution will be referred to the HSC Trust by the Ombudsman for action.

2.28 Copies of all correspondence relating to regulated sector complaints should be retained. The RQIA will use this information to monitor all regulated services including those services commissioned by the HSC Trust.

2.29 Voluntary Adoption Agencies became regulated by the RQIA in 2010 and in due course, these arrangements will extend to Fostering Agencies services which will also be regulated by the RQIA.

Independent Sector Providers

2.30 This section of the guidance has been developed for use in complaints against Independent Service Providers (ISP) in contract with HSC Trusts. Complaints against regulated establishments and agencies, such as, residential and nursing homes should be handled in accordance with paragraphs 2.22 to 2.28 above. On occasions HSC organisations contract with ISPs to provide services for patients/clients. An example where this may be the case is in the maintenance of waiting lists for elective forms of treatment.

2.31 Such contracts are agreed and managed by HSC Trusts and procured in accordance with public procurement law. ISPs may have their own premises or may be permitted to use Trust premises, equipment and facilities.

2.32 Trusts must be assured that ISPs with which they contract have appropriate governance arrangements in place for the effective handling, management and monitoring of all complaints. This should include the appointment of designated officers of suitable seniority to take responsibility for the management of the in-house complaints handling procedures, the investigation of complaints and the production of leaflets, or other literature (available and accessible to patients/clients) that outline the provider's complaints procedure.

2.33 Complaints relating to contracted services provided by ISPs may be received directly by the ISP or by the contracting Trust. The general principle in the first instance would be that the ISP investigates and responds directly to the complainant. Independent Sector Providers are required to notify Trusts of any complaints received without delay and in any event within 72 hours. Trusts can then determine how they wish the complaints to be investigated (see flowchart on page 53).

2.34 Where complaints are raised directly with the Trust, it must establish the nature of the complaint and consider how best to proceed. The Trust may simply refer the complaint to the ISP for investigation, resolution and response or it may decide to investigate the complaint itself where it raises serious concerns or where the Trust deems it in the public interest to do so. This may also be considered preferable should the Trust premises and/or staff have been involved (see flowchart on page 53).

2.35 In all cases, appropriate communication should be made with the complainant to inform them which organisation is leading the investigation into their complaint.

2.36 In complaints investigated by the ISP:

- A written response will be provided by the ISP to the complainant and copied to the Trust;

- Where there is a delay in responding within the target timescales the complainant will be informed and where possible provided with a revised date for conclusion of the investigation; and

- The letter of response must advise the complainant that they may progress their complaint to the Trust for further consideration if they remain dissatisfied. The Trust will then determine whether the complaint warrants further investigation and, if so, will confirm who should be responsible for conducting it. The Trust will work closely with the ISP to enable appropriate decisions to be made.

2.37 The complainant must also be informed of their right to refer their complaint to the Ombudsman if they remain dissatisfied with the outcome of the complaints procedure.

2.38 It is possible that referrals to the Ombudsman, where complaints are dealt with directly by the ISP without Trust participation in local resolution, will be referred to the Trust by the Ombudsman for action.

2.39 Trusts should have agreed arrangements in place to ensure that ISPs regularly provide information relating to all complaints received and responded to directly by them. This information should be made available to the Trust for monitoring purposes. The ISP must keep a record of complaints, the subsequent investigation and its outcome and any action taken as a result. This record must be submitted to the Trust no longer than 10 working days after the end of each quarter for complaints closed in the period. This should include details of the number, source and type(s) of complaint, action taken and outcome of investigation.

2.40 The ISP should also indicate if the learning from complaints has been disseminated to all relevant staff. The ISP must review their complaints procedure on an annual basis and in this annual review shall include a review of the outcome of any complaints investigations during the preceding year to ensure that where necessary any changes to practice and procedure are implemented. This annual review must be available for inspection by Trust staff on request.

What information should be included in the complaint?

2.41 A complaint need not be long or detailed, but it should include:

- contact details;
- who or what is being complained about, including the names of staff if known;
- where and when the events of the complaint happened; and
- where possible, what remedy is being sought – e.g. an apology or an explanation or changes to services.

2.42 Standard 4: *Supporting complainants and staff* provides the criteria by which organisations should operate (Annex 1 refers). Advice and assistance is available to complainants and staff at any stage in the complaints process from the Complaints Manager. Independent advice and support for complainants is available from the PCC (detailed in Section 5 – Roles and responsibilities). Independent advocacy and specialist advocacy services are also available (Annex 7 refers).

What are the timescales for making a complaint?

2.43 A complaint should be made as soon as possible after the action giving rise to it, normally within six months of the event. HSC organisations should encourage those who wish to complain to do so as soon as possible after the event. Investigation is likely to be most effective when memories are fresh and the relevant evidence such as records of treatment will be easier to source.

2.44 If a complainant was not aware that there was potential cause for complaint, the complaint should normally be made within **six months** of their becoming aware of the cause for complaint, or within **twelve months** of the date of the event, whichever is the earlier.

2.45 There is discretion for the Complaints Manager to extend this time limit where it would be unreasonable in the circumstances of a particular case for the complaint to have been made earlier and where it is still possible to investigate the facts of the case. This discretion should be used with sensitivity and impartiality. The complainant should be advised that with the passage of time the investigation and response will be based largely on a review of records.

2.46 In any case where a Complaints Manager has decided not to investigate a complaint on the grounds that it was not made within the time limit, the complainant can request the Ombudsman to consider it. The complainant should be advised of the options available to pursue this further.

2.47 The Complaints Manager must consider the content of complaints that fall outside the time limit in order to identify any potential risk to public or patient safety and, where appropriate, the need to investigate the complaint if it is in the public's interest to do so or refer to the relevant regulatory body.

SECTION 3 – HANDLING COMPLAINTS

Accountability

3.1 Standard 1: *Accountability* provides the criteria by which organisations should operate (Annex 1 refers). Accountability for the handling and consideration of complaints rests with the Chief Executive (or Clinical Governance Lead in FPS settings). The HSC organisation must designate a senior person within the organisation:

- to take responsibility for the local complaints procedure;
- to ensure compliance with the regulations; and
- to ensure that action is taken in light of the outcome of any investigation.

In the case of HSC Trusts, a Director (or a Clinical Governance Lead in FPS setting) should be designated. All staff must be aware of, and comply with, the requirements of the complaints procedure. These arrangements will ensure the integration of complaints management into the organisation's governance arrangements.

3.2 Where care or treatment is provided by an independent provider, for example residential or nursing home care, the commissioning body must ensure that the contract includes entitlement, by the HSC organisation, to any and all documentation relating to the care of service users and a provision to comply with the requirements of the HSC Complaints Procedure.

Performance Management

3.3 Complaints provide a rich source of information and learning from complaints should be considered a vital part of the HSC organisation's performance management strategy. HSC organisations need to be able to demonstrate that positive action has been taken as a result of complaints and that learning from complaints is embedded in the organisation's governance and risk management arrangements.

3.4 Complaints should be used to inform and improve the standard of service provision. HSC organisations should aim for continuous change and improvement in their performance as a result of complaints. Where something has gone wrong or

fallen below standard the organisation has the opportunity to improve and avoid a recurrence. By making sure that lessons from complaints are taken on board and followed up appropriately, services and performance can be greatly improved for the future.

Co-operation

3.5 Local arrangements must ensure that a full and comprehensive response is given to a complainant and that there is the necessary co-operation in the handling and consideration of complaints between:

- HSC organisations;
- Regulatory authorities e.g. professional bodies, DOH, Medicines Regulatory Group (MRG);
- The Ombudsman; and
- The RQIA.

3.6 This general duty to co-operate includes answering questions, providing information and attending any meeting reasonably requested by those investigating the complaint.

Complaints Manager

3.7 HSC organisations must appoint:

- A senior person within the organisation to ensure compliance with the relevant Complaints Directions[17] and to ensure that action is taken in light of the outcome of any investigation; and
- A Complaints Manager to co-ordinate the local complaints arrangements and manage the process.

[17] DoH Complaints Directions: https://www.health-ni.gov.uk/publications/hsc-complaints-directions

3.8 The Complaints Manager or whoever is designated on their behalf must be readily accessible to both the public and members of staff. The Complaints Manager should:

- deal with complaints referred by front-line staff;
- be easily identifiable to service users;
- be available to complainants who do not wish to raise their concerns with those directly involved in their care;
- provide advice and support to vulnerable adults;
- consider all complaints received and identify and appropriately refer those falling outside the remit of the complaints procedure;
- provide support to staff to respond to complaints;
- be aware of and advise on the role of the Medical Defence Organisations (MDOs)[18] to assist staff requiring professional indemnity[19];
- have access to all relevant records (including personal medical records);
- take account of all evidence available relating to the complaint e.g. witness to a particular event;
- identify training needs associated with the complaints procedure and ensure those needs are met;
- ensure all issues are addressed in the draft response, taking account of information obtained from reports received and providing a layman's interpretation to otherwise complex reports;
- compile a summary of complaints received, actions taken and lessons learnt;
- maintain and appropriately store records;
- assist the designated senior person in the examination of trends, monitoring the effectiveness of local arrangements and the action taken (or proposed) in terms of service improvement; and

[18] There are 3 MDOs, the Medical Defence Union (MDU), Medical and Dental Defence Union of Scotland (MDDUS), and Medical Protection Society (MPS).
[19] Since 16 July 2014 and the introduction of the Health Care and Associated Professions (Indemnity Arrangements) Order 2014, all registered healthcare professionals are legally required to have adequate and appropriate insurance or indemnity to cover the different aspects of their practice in the UK.

- assist the designated senior person in ensuring compliance with standards, identifying lessons and dissemination of learning in line with the organisation's governance arrangements.

3.9 Complaints Managers should involve the complainant from the outset and seek to determine what they are hoping to achieve from the process. The complainant should be given the opportunity to understand all possible options available in seeking complaint resolution. Throughout the process, the Complaints Manager should assess what further action might best resolve the complaint and at each stage keep the complainant informed.

Publicity

3.10 HSC organisations must ensure that the complaints process is well publicised locally. This means that service users should be made aware of:

- their right to complain;
- all possible options for pursuing a complaint, and the types of help available; and
- the support mechanisms that are in place.

3.11 Ready access to information can make a critical difference to the service user's experience of HSC services. Information about services and what to expect, the various stages involved in the complaints process, response targets and independent support and advice should be available. Clear lines of communication are required to ensure complainants know who to communicate with during the lifetime of their complaint. The provision of information will improve attitudes and communication by staff as well as support and advice for complainants.

3.12 Local information should:

- be visible, accessible and easily understood;
- be available in other formats or languages as appropriate;
- be provided free of charge; and
- outline the arrangements for handling complaints, how to contact complaints staff, the availability of support services, and what to do if the complainant remains dissatisfied with the outcome of the complaints process.

Training

3.13 All staff should be trained and empowered to deal with complaints as they occur. Appropriately trained staff will recognise the value of the complaints process and, as a result will welcome complaints as a source of learning. HSC staff have a responsibility to highlight training needs to their line managers. Line managers, in turn, have a responsibility to ensure needs are met to enable the individual to function effectively in their role and HSC organisations have a responsibility to create an environment where learning can take place. It is essential that staff recognise that their initial response can be crucial in establishing the confidence of the complainant.

Actions on receipt of a complaint

3.14 Standard 3: *Receiving Complaints* provides the criteria by which organisations must operate (Annex 1 refers).

3.15 All complaints received should be treated with equal importance regardless of how they are submitted. Complainants should be encouraged to speak openly and freely about their concerns and should be reassured that whatever they may say will be treated with appropriate confidence and sensitivity. Complainants should be treated courteously and sympathetically and where possible involved in decisions about how their complaint is handled and considered. The first responsibility of staff is to ensure that the service user's immediate care needs are being met. This may require urgent action before any matters relating to the complaint are addressed.

3.16 The involvement of the complainant throughout the consideration of their complaint will provide for a more flexible approach to the resolution of the complaint. Complaints staff should discuss individual cases with complainants at an early stage and an important aspect of the discussion will be about the time it may take to complete the investigation especially if it is likely to exceed the 20 working day target for any reason. Early provision of information and an explanation of what to expect should be provided to the complainant at the outset to avoid disappointment and subsequent letters of complaint. Each complaint must be taken on its own merit and responded to accordingly. It may be appropriate for the entire process of local

resolution to be conducted informally. Overall, arrangements should ensure that complaints are dealt with quickly and effectively in an open and non-defensive way.

3.17 Where possible, all complaints should be registered and discussed with the Complaints Manager in order to identify those that can be resolved immediately, those that require formal investigation, or those that should be investigated and managed outside of the HSC Complaints Procedure by other means. Front-line staff will often find the information they gain from complaints useful in improving service quality. This is particularly so for complaints that have been resolved "on the spot" and have not progressed through the formal HSC Complaints procedure. Mechanisms for achieving this are best agreed at organisational level.

Acknowledgement of Complaint

3.18 A complaint should be acknowledged in writing within **2 working days** of receipt. FPS complaints should be acknowledged within **3 working days** in line with legislative requirements (see Legal Framework at Annex 2). The acknowledgement letter should always thank the complainant for drawing the matter to the attention of the organisation. A copy of the complaint and its acknowledgement should be sent to any person involved in the complaint unless there are reasonable grounds to believe that to do so would be detrimental to that person's health or well-being.

3.19 There should be a statement expressing sympathy or concern regarding the issue that led to a complaint being made. This is a statement of common courtesy, not an admission of responsibility.

3.20 It is good practice for the acknowledgement letter to be conciliatory, and indicate that a full response will be provided within **20 working days**. FPS acknowledgement should indicate that a full response will be provided within **10 working days**. As soon as the HSC organisation becomes aware that the relevant response timescale is not achievable they must provide the complainant with an explanation. The complainant must be updated every 20 working days on the progress of their complaint by the most appropriate means. All contact with the complainant must be recorded by the HSC organisation.

3.21 The acknowledgement should:

- seek to confirm the issues raised in the complaint;
- offer opportunities to discuss issues either with a member of the complaints staff or, if appropriate, a senior member of staff; and
- provide information about the availability of independent support and advice.

3.22 Complaints Managers should provide the complainant with further information about the complaints process. This may include locally produced information leaflets or those provided by the Ombudsman's Office or the RQIA. It is also advisable to include information about the disclosure of patient information at this stage.

Joint Complaints

3.23 Where a complaint relates to the actions of more than one HSC organisation the Complaints Manager should notify any other organisations involved. The complainant's consent must be obtained before sharing the details of the complaint across HSC organisations. In cases of this nature there is a need for co-operation and partnership between the relevant organisations in agreeing how best to approach the investigation and resolution of the complaint. It is possible that the various aspects of the complaint can be divided easily with each organisation able to respond to its own area of responsibility. The complainant must be kept informed and provided with advice about how each aspect of their complaint will be dealt with and by whom.

Out of Area Complaints

3.24 Where the complainant lives in Northern Ireland and the complaint is about events elsewhere, the HSC Board or HSC Trust that commissioned the service or purchased the care for that service user is responsible for co-ordinating the investigation and ensuring that all aspects of the complaint are investigated. HSC contracts must include entitlement, by the HSC organisation, to any and all documentation relating to the care of service users and a provision to comply with the requirements of the HSC Complaints Procedure.

Investigation

3.25 Standard 5: *Investigation* provides the criteria by which organisations must operate (Annex 1 refers). HSC organisations should establish a clear system to ensure an appropriate level of investigation. The purpose of investigation is not only "resolution" but also to:

- ascertain what happened or what was perceived to have happened;
- establish the facts;
- learn lessons;
- detect misconduct or poor practice; and
- improve services and performance.

3.26 An investigation into a complaint may be undertaken by a suitable person appointed by the HSC organisation. Investigations should be conducted in a manner that is supportive to all those involved, without bias and in an impartial and objective manner. The investigation must uphold the principles of fairness and consistency. The investigation process is best described as listening, learning and improving. Investigators should be able to seek advice from the Complaints Manager/senior person, wherever necessary, about the conduct or findings of the investigation.

3.27 Whoever undertakes the investigation should seek to understand the nature of the complaint and identify any issues not immediately obvious. Complaints must be approached with an open mind, being fair to all parties. The complainant and those identified as the subject of a complaint should be advised of the process, what will and will not be investigated, those who will be involved, the roles they will play and the anticipated timescales. Everyone involved should be kept informed of progress throughout. Staff involved in the investigation process should familiarise themselves with Section 75 of the Northern Ireland Act 1998.

Assessment of the complaint

3.28 It is unrealistic to suggest that all complaints should be investigated to the same degree or at the same level. HSC organisations must ensure that a robust risk assessment process is applied to all complaints to allow serious complaints, such as those involving unsafe practice, to be identified. The use of assessment tools to risk assess and categorise a complaint may be helpful in determining the course of action to take in response. It can help ensure that the process is proportionate to the seriousness of the complaint and the likelihood of recurrence.

Investigation and resolution

3.29 The HSC organisation should use a range of investigating techniques that are appropriate to the nature of the complaint and to the needs of the complainant. Those responsible for investigation should be empowered to choose the method that they feel is the most appropriate to the circumstances.

3.30 The investigator should establish the facts relating to the complaint and assess the quality of the evidence. Depending on the subject matter and complexity of the investigation the investigator may wish to call upon the services of others. There are a number of options available to assist HSC organisations in the resolution of complaints. These should be considered in line with the assessment of the complaint and also in collaboration with the complainant and include the involvement of:

- senior managers/professionals at an early stage;
- honest broker;
- independent experts;
- lay persons; and
- conciliators.

3.31 It is not intended that HSC organisations utilise all the options outlined above as not all these will be appropriate in the resolution of the complaint. Rather HSC organisations should consider which option would assist in providing the desired outcome. The HSC Board will provide the necessary support and advice to FPS in relation to access and appointment of these options, where appropriate.

Completion of Investigation

3.32 Once the investigator has reached their conclusion they should prepare the draft report/response. The purpose is to record and explain the conclusions reached after the investigation of the complaint. The Department's *HSC Regional Template and Guidance for Incident Investigation/ Review Reports*[20] will assist HSC organisations in ensuring the completeness and readability of such reports.

3.33 Where the complaint involves clinical/ professional issues, the draft response must be shared with the relevant clinicians/ professionals to ensure the factual accuracy and to ensure clinicians/ professionals agree with and support the draft response.

3.34 All correspondence and evidence relating to the investigation should be retained. The Complaints Manager should ensure that a complete record is kept of the handling and consideration of each complaint. Complaints records should be kept separate from health or social care records, subject only to the need to record information which is strictly relevant to the service user's on-going health or care needs.

3.35 HSC organisations should regularly review their investigative processes to ensure the effectiveness of these arrangements locally.

[20] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/HSC%20%28SQSD%29%2034-07_0.pdf

Circumstances that might cause delay

3.36 Some complaints will take longer than others to resolve because of differences in complexity, seriousness and the scale of the investigative work required. Others may be delayed as a result of circumstance, for example, the unavailability of a member of staff or a complainant as a result of holidays, personal or domestic arrangements or bereavement. Delays may also be as a result of the complainant's personal circumstances at a particular time e.g. a period of mental illness, an allegation of physical injury or because a complaint is being investigated under another procedure (as outlined in paragraphs 1.12 to 1.14).

Periods of acute mental illness

3.37 If a service user makes a complaint during an acute phase of mental illness, the Complaints Manager should register the complaint and consideration should be given to delaying the complaint until his/her condition has improved. A delay such as this will need either the agreement of the complainant or someone who is able to act on his/her behalf including, where appropriate, consultation with any advocate. The decision about whether a complainant is well enough to proceed with the complaint should be made by a multi-disciplinary team, and the Complaints Manager should refer regularly to this team to establish when this point has been reached.

Physical Injury

3.38 Where a complainant is alleging physical injury, a physical examination should be arranged without delay and with the consent of the injured person. Medical staff undertaking the physical examination should clearly report their findings. If a person refuses a physical examination, or if his or her mental state (for example, degree of agitation) makes this impossible, this should be clearly documented.

3.39 Whatever the reason, as soon as it becomes clear that it will not be possible to respond within the target timescales, the Complaints Manager should advise the complainant and provide an explanation with the anticipated timescales. While the emphasis is on a complete response and not the speed of response, the HSC

organisation should, nevertheless, monitor complaints that exceed the target timescales to prevent misuse of the arrangements. The complainant must also be updated every 20 working days on the progress of their complaint by the most appropriate means. All contact with the complainant must be recorded by the HSC organisation.

Responding to a complaint

3.40 Standard 6: *Responding to complaints* provides the criteria by which organisations must operate (Annex 1 refers). A response must be sent to the complainant within **20 working days of receipt** of the complaint (**10 working days within FPS**) or, where that is not possible, the complainant must be advised of the delay (as per paragraph 3.39 above).

3.41 Where appropriate, HSC organisations must consider alternative methods of responding to complaints whether through an immediate response from front-line staff, a meeting, or direct action by the Chief Executive (or senior person). It may be appropriate to conduct a meeting in complex cases, in cases where there is serious harm/death of a patient, in cases involving those whose first language is not English, or, for example in cases where the complainant has a learning disability or mental illness. Where complaints have been raised electronically the HSC may reply electronically whilst ensuring they adhere to the relevant Information Technology (IT) policies and procedures and maintain appropriate levels of confidentiality according to Trust policies and procedures**.**

3.42 Where a meeting is scheduled it is more likely to be successful if the complainant knows what to expect and can offer some suggestions towards resolution. Complainants have a right to choose from whom they seek support and should be encouraged to bring a relative or friend to meetings. Where meetings do take place they should be recorded and that record shared with the complainant for comment.

3.43 The Chief Executive (or Clinical Governance Lead) may delegate responsibility for responding to a complaint, where, in the interests of a prompt reply, a designated senior person may undertake the task (or the governance lead within FPS settings). In such circumstances, the arrangements for clinical and social care governance must ensure that the Chief Executive (or Clinical Governance Lead) maintains an overview of the issues raised in complaints (including those FPS complaints lodged with the HSC Board), the responses given and be assured that appropriate organisational learning has taken place. HSC organisations should ensure that the complainant and anyone who is a subject of the complaint understand the findings of the investigation and the recommendations made.

3.44 The response should be clear, accurate, balanced, simple and easy to understand. It should avoid technical terms, but where these must be used to describe a situation, events or condition, an explanation of the term should be provided. The letter should:

- address the concerns expressed by the complainant and show that each element has been fully and fairly investigated;
- include an apology where things have gone wrong;
- report the action taken or proposed to prevent recurrence;
- indicate that a named member of staff is available to clarify any aspect of the letter;
- advise of their right to refer their complaint to the Ombudsman if they remain dissatisfied with the outcome of the complaints procedure; and
- advise of the availability of the Patient and Client Council to provide assistance in making a submission to the Ombudsman.

Concluding Local Resolution

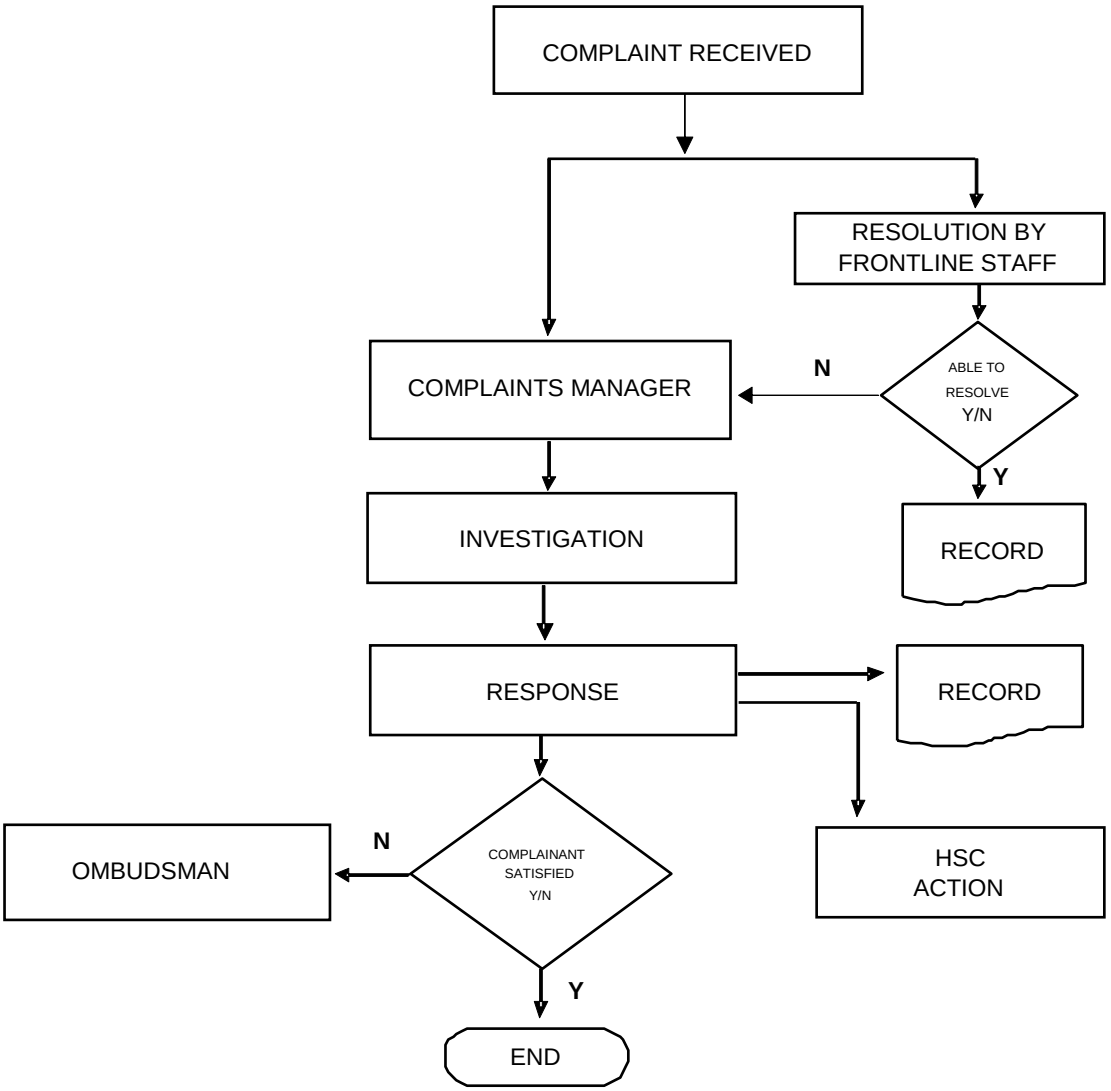
3.45 The HSC organisation should offer every opportunity to exhaust local resolution. While the final response should offer an opportunity to clarify the response this should not be for the purposes of delaying "closure". Complainants should contact the organisation within one month of the organisation's response if they are dissatisfied with the response or require further clarity[21]. There is discretion for the Complaints Manager to extend this time limit where it would be unreasonable in the circumstances for the complainant to have made contact sooner.

3.46 Once the final response has been signed and issued, the Complaints Manager, on behalf of the Chief Executive/Clinical Governance Lead, should liaise with relevant local managers and staff to ensure that all necessary follow-up action has been taken. Arrangements should be made for any outcomes to be monitored to ensure that they are actioned. Where possible, the complainant and those named in the complaint should be informed of any change in system or practice that has resulted from the investigation into their complaint.

3.47 This completes the HSC Complaints Procedure. There is a statutory obligation on all HSC organisations to signpost to the Ombudsman upon completion of the complaints procedure. Please refer to Annex 5 for details on the requirements for signposting.

[21]Inserted 5th June 2013 per letter from Director of Safety, Quality & Standards Directorate

HOSPITAL OR COMMUNITY COMPLAINTS FLOWCHART



FAMILY PRACTITIONER SERVICE COMPLAINTS FLOWCHART