	that any data items collected locally that are in existing national datasets or are within the NHS Data Dictionary are in line with these data definitions and codes when collected.								
3.2.6.	Members know what information from the locally agreed minimum dataset of information they will be expected to present on each patient so that they can prepare and be ready to share this information (or have delegated this to another member if they cannot attend) prior to and/or at the meeting.	Not in place Use of a MDT proforma would help to ensure a minimum dataset is completed for each patient being presented	F	NIP	F	F	F	P	F

Organisation/administration during MDT meetings

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
3.3.1.	It is clear who wants to discuss a particular patient and why they are being discussed.	P Use of MDT proforma would help to improve this	P Sometimes patients are listed and it is not clear	P	F	F	F	F	F

			why they are being discussed Use of MDT proforma would help to improve this						
3.3.2.	A locally agreed minimum dataset of information is presented on each patient including diagnostic information (pathology and radiology), clinical information (including co-morbidities, psychosocial and specialist palliative care needs) and patient history, views and preferences – the focus is on what the team need to hear to make appropriate recommendations on the patient in question. It may not, for example, be necessary to show/discuss the pathological or radiological findings in all cases.	P Improve listing of patients by indicating which aspects need to be reviewed e.g. pathology, radiology	F	P	F	P	F	F	F

3.3.3.	There is access to all relevant information at the meeting including patient notes, test results/images/samples (past and present) and appointment dates (or a proforma /summary record with the necessary information) along with access to PAS, radiology & pathology systems etc – relevant past material should be reviewed prior to the meeting if it is not accessible during the meeting.	F	F	F	F	F	F	P	F
3.3.4.	Electronic databases are used to capture recommendations during the meeting (including the rationale for the decision and any uncertainties or disagreements about the recommendations) – a standard pro-forma is used where such a database is not available.	P CAPPs system is an electronic database which is used to collect data on patients and document MDT decisions. Investigation plans and treatment recommendations are formulated	F	F	F	F	F	F	F

		during the meeting and recorded in narrative format by the MDT Co-ordinator. .							
3.3.5.	Core data items are collected during the meeting and cancer datasets completed in real time (where feasible) – training may be required to ensure accurate recording of real-time information to minimise the impact on (i.e. slowing down) the MDT discussion. Some MDTs will wish to collect as much of the core data items before the meeting to save time – the function of the MDT is then to check these are correct. It is important that any data items collected locally that are in existing national datasets or are within the NHS Data Dictionary are in line with these data	Not in place Further discussion/work required to explore how to streamline process.	F	F	F	F	F	F	F

	definitions and codes when collected.								
3.3.6.	Mobile phones are off or on silent during the meeting and if phone calls have to be taken during the meeting the person taking the call leaves the room.	F	P Mobile phones are not turned off	F	F	F	F	P	P
3.3.7.	There is effective chairing and co-ordination throughout the meeting.	F	F	F	F	F	F	F	F

Post MDT meeting/co-ordination of services

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
3.4.1.	Processes are in place: • for communicating MDT recommendations to patients, GPs and clinical teams within locally agreed timeframes e.g. patient clinics on the same or next day as MDT meetings where feasible; • for ensuring that patients' information needs are assessed	P Some of the consultant clinics take place the week after the MDT	P F F	P F F NIP	F	F	P F F	P	P

	and met; • to ensure actions agreed at the meeting are implemented; • to ensure the MDT is notified of significant changes made to their recommended treatment/care plan; • to manage referral of patient cases between MDTs (including to MDTs in a different Provider); • to track patients through the system to ensure that any tests, appointments, treatments are carried out in a timely manner e.g. Within cancer waits standards where applicable.	NIP NIP F F Patients are tracked from diagnosis up until the 1st definitive treatment (31 day & 62 day pathways).	NIP F Re-discussed if there is a change F F F	NIP F P			F NIP F F	NIP	
3.4.2.	Relevant items from cancer datasets are completed (if this has	F	F	F	F	F	F	F	F

	not been done in real time at the meeting).								

4. Patient Centered Clinical Decision-Making

Who to discuss?

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
4.1.1.	There are local mechanisms in place to identify all patients where discussion at MDT is needed.	Not sure? Red flag referrals from GPs and other consultants are triaged and depending on outcome are put on 31 day and 62 day pathways which are tracked.	F	F	NIP	F	F	F	F
4.1.2	There are referral criteria in place so it is clear when to send a case to the MDT for consideration i.e. clarity on: • which patients should be discussed by the MDT; • the clinical questions	F	P Some patients are added and at times it is not clear what the question is – a MDT proforma would help to standardize	F	F	F	F	F	F

	that need to be addressed by the MDT; - what information has to be available for the MDT discussion to be productive; - when to refer a patient on to another MDT (e.g. from a local to a specialist MDT).		this						
4.1.3	There is local agreement about if/when patients with advanced/recurrent disease should be discussed at MDT meetings.	P	P Metastatic patients are not always brought back to the MDT and is based on the consultant's decision	F	F	F	F	F	F
4.1.4	A clinician can bring the case of a private patient to the MDT for discussion provided there is time on the agenda - any reimbursement arrangements are for	NIP	F	F	N/A	F	F	F	F

	local determination.								

Patient-centered care

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
4.2.1.	Patients are aware of the MDT, its purpose, membership, when it meets and that their case is being/has been discussed and are given the outcome within a locally agreed timeframe.	F	F	F	F	F	F	F	F
4.2.2	A patient's views/preferences/holistic needs are presented by someone who has met the patient whenever possible.	F	F	F	F	F	F	P	F
4.2.3	A named individual at the MDT has responsibility for identifying a key worker for the patient.	NIP Key worker not identified at the MDT meeting – this may happen afterwards	F	NIP	F	F	F	NIP	P
4.2.4	A named individual at the MDT has responsibility for ensuring that the patient's information needs have been (or will be) assessed and	F	F	F	F	F	F	NIP	F

	addressed.								
4.2.5	Patients are given information consistent with their wishes, on their cancer, their diagnosis and treatment options including therapies which may be available by referral to other MDTs, sufficient to make a well informed choice/decision on their treatment and care.	F	F	F	F	F	F	F	F

Clinical Decision-Making Process

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
4.3.1	A locally agreed minimum dataset of information is provided at the meeting i.e. the information the MDT needs to make informed recommendations including diagnostic information (pathology and radiology), clinical information (including co-morbidities, psychosocial and specialist palliative care needs) and patient	NIP An MDT Proforma would help with this	P Not all of the information is provided (e.g. co-morbidities)- an MDT Proforma would help with this	NIP	F	P	F	F	F

	history, views and preferences. It is important that any data items collected locally that are in existing national datasets or are within the NHS Data Dictionary are in line with these data definitions and codes when collected.								
4.3.2	MDTs consider all clinically appropriate treatment options for a patient even those they cannot offer/provide locally.	F	F	F	F	F	F	F	F
4.3.3.	MDTs have access to a list of all current and relevant clinical trials (including eligibility criteria) particularly those in the NCRN portfolio and consider patients' suitability for appropriate clinical trials as part of the decision-making process - the relevant trial coordinator/ research nurse attends MDT	P Patients who are referred to the Specialist MDT will have access to clinical trials as they are usually regional trials	P The MDT does have access to relevant trials though the Clinical Trial nurse does not attend MDT meeting	P	P	NIP	F	P	F

	meetings where feasible.								
4.3.4.	Standard treatment protocols are in place and used whenever appropriate	F	Nip There is individual case discussion. The MDT does not use treatment protocols.	F	F	F	F	F	F
4.3.5	A patient's demographic profile and co-morbidities are always considered - age does not in itself act as a barrier to active treatment.	F	F	F	F	F	F	F	F
4.3.6	A patient's psychosocial and supportive & palliative care issues are always considered (e.g. via holistic needs assessment).	F	F	F	F	F	F	F	F
4.3.7	A patient's views, preferences and needs inform the decision-making process when relevant/possible	F	F	F	F	F	F	F	F
4.3.8	The clinical–decision making process results in clear recommendations	F	F	F	F	F	F	F	F

	on the treatment/care plan resulting from the meeting. These recommendations are: • evidence-based (eg. in line with NICE and/or cancer network guidelines); • patient-centered (in line with patient views & preferences when known and taking into account co-morbidities); • in line with standard treatment protocols unless there is a good reason against this, which should then be documented.								
4.3.9	MDT recommendations are only as good as the information they are based on – if there are concerns that key data is missing this should be documented.	F	F	F	F	F	F	F	F
4.3.10	Where a recommendation cannot be made because of incomplete data or where new data becomes	F	F	F	F	F	F	F	F

	available at a later stage it should be possible to bring the patient case back to the MDT for further discussion.								
4.3.11	It is clear who will communicate the MDT recommendation(s) to the patient, GP and clinical team, how and by when and this is minuted.	F	P This is not minuted but each consultant is responsible for review/sign off on CAPPS for their own patients	F	P	F	F	F	F
4.3.12	MDTs collect social demographic data (on age, ethnicity and gender as a minimum) and consider that data periodically to reflect on equality of access to active treatments and to other aspects of treatment, care and experience – Information relating to these issues will/should be on PAS / NIECR / CAPPS (based on NHS Data Dictionary	P Not sure if ethnicity is collected?	P ethnicity is not collected – this would be important particularly in relation to impact on appointment time if interpreters are required	P	P	P	P	P	P

	definitions) and MDTs should link up to the source of these data rather than create separate data capture processes.								

5. Team Governance

Organisational support

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
5.1.1.	There is Organisational (employer) support for MDT meetings and MDT membership demonstrated via: • recognition that MDTs are the accepted model by which to deliver safe and high quality cancer care; • adequate funding/resources in terms of people, time, equipment and facilities for MDT meetings to operate effectively (as set	F P Issues with cover for Radiology and Oncology Need more	F P Room space does not accommodate all members present in	F P	F P	F P	F P	F P	F P

	out in this document).	resource for audit and tracking	room -Issues with V/C and sound at times -Need more resource for audit						
5.1.2.	Trusts consider their MDTs' annual assessments and act on issues of concern (see 5.3.10).	NIP	P The screening part of the Breast service is reviewed annually by the Trust SMT but not the full service	F	P	F	F	NIP	F

Data collection, analysis and audit of outcomes

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
5.2.1.	Data collection resource (i.e. the ability to capture relevant information in a timely manner etc) is available to the MDT.	P Histology, stage and grade are captured Radiological info	P Data collection resource is limited and would require	F	P	F	F	F	F

		All treatment options captured – free text is used to generate an outcome	further resourcing in terms of staff and setting up an independent database for research / audit purposes						
5.2.2.	Key information that directly affects treatment decisions (e.g. staging, performance status and co-morbidity) is collected by the MDT.	P Performance & co-morbidity is recorded in the free text box, there is no structured data fields to capture this	P Staging is recorded, co-morbidities may be recorded if it is something significant, performance status is not recorded	P	F	P	F	P	P
5.2.3.	Mandated national datasets are populated prior to or during MDT meetings where possible and appropriate – if this is not possible this takes place shortly after the meetings.	P CAPPs datasets are populated after MDT Under current legislation regarding the use of secondary data, the	F	P	F	F	P	P	F

		MDT is not able to provide data for national datasets							
5.2.4.	Data collected during MDT meetings (including social demographic data extracted from PAS) is analyzed and fed back to MDTs to support learning.	NIP This is not currently happening and would require further resource to support this. It would support the MDT with forward planning, and provide assurance in relation to meeting standards / guidelines by providing a systematic review of MDT activity		NIP	P	P	NIP	NIP	P
5.2.5.	The MDT takes part in internal and external audits of processes and outcomes and reviews audit data (eg. to confirm that treatment recommendations match current best practice and to consider trial recruitment) taking action to change practice etc where necessary.	P Limited audits due to lack of resource available to support	P Limited audits due to lack of resource available to support	P	P	P	F	F	F
5.2.6.	MDTs consider and act on clinical outcomes data as they become available eg. through peer review, NCIN	NIP Clinical outcomes data not	F	P	F	F	F	F	F

	clinical reference groups etc.	available through peer review							
5.2.7.	Patient experience surveys include questions relevant to MDT working and action is taken by MDTs to implement improvements needed in response to patient feedback.	P CPES & local surveys don't ask specific questions on MDT working	P As per urology	NIP	P	F	F	P	F

Clinical governance

No.	Statement	Urology	Breast	Gynae	Lung	LGI	UGI	Skin	Thyroid
5.3.1	Data collection resource (i.e. the ability to capture relevant information in a timely manner etc) is available to the MDT.	P Very limited due to lack of support available	NIP As per urology	P	P	F	F	F	F
5.3.2	There are agreed policies, guidelines or protocols for: • how the MDT operates; • who the core and extended members are; • the roles of members; • how members should work together; • how changes in clinical practice are to be managed;	F	P ? not sure Perhaps needs to be	F	F	F	F	F	F

	• communications post meetings eg. To patients, GPs and other clinical colleagues.		a policy for this – usually agreed & disseminated through CRG for surgery but unsure of process for other modalities						
5.3.3	User Partnership Groups are given the opportunity to advise on the development of MDT policy and practice – they are given feedback in response to their advice including actions taken in response to their recommendations.	NIP There is a Trust Cancer Service User Group who have acted as a readers panel in relation to the MDT patient information leaflet. This group is currently being re-established and the terms of reference reviewed. There is scope to explore how the group can support the development of the MDT.							
5.3.4	MDT policies, guidelines and protocols are reviewed at least annually	F	F	F	F	P	F	P	P
5.3.5	There are mechanisms in place to: • record the MDT recommendation(s) versus the actual treatment given and to alert the MDT if their treatment recommendation(s) are not adopted and the reason for this – the MDT has regular opportunities	NIP will required dedicated support in relation to ongoing audit of MDT outcomes. Reinforces importance of role of CNS at clinics.	NIP Needs to be considered but will required dedicated support in relation to ongoing audit of MDT outcomes	P F	P F	P		NIP F	F

	to review and act on learning from such cases; - ensure that the MDT is alerted to serious treatment complications and adverse or unexpected events/death in treatment - the MDT has regular opportunities to review and act on learning from such cases.	Department of Health Patient Safety regulations does not overlap with cancer services							
5.3.6	There are strategies in place to monitor: - the proportion of patients discussed without sufficient information to make recommendations/ take action at that meeting; - the proportion of patients offered and/or receiving information recommended by the MDT.	NIP Needs to be considered but will required dedicated support to ensure regular auditing	NIP Needs to be considered but will required dedicated support in relation to ongoing audit of MDT outcomes	NIP	P NIP	NIP	NIP	NIP	NIP
5.3.7	The MDT shares good practice and discusses local problem areas with MDTs within its own trust/Network.	P There is no formal mechanism locally for MDTs to do this but	P At network level, there is an opportunity through the regional	P	P	F	F	F	F

		should be considered.	Clinical Reference Group to share good practice and highlight areas of concern						
5.3.8	The MDT has representation on the Clinical Reference Group (CRG) for its cancer site and that representative attends the meetings or sends a deputy.	F	F	F	F	F	F	F	F
5.3.9	Significant discrepancies in pathology, radiology or clinical findings between local and specialist MDTs should be recorded and be subject to audit.	NIP Discrepancies may be recorded but are not audited	NIP There is no specialist Breast MDT unlike some of the other tumour sites e.g. Gynae	P	P	P	F	F	P
5.3.10	MDTs reflect, at least annually, on equality issues, for example, that there is equality of access to active treatments and other aspects of treatment, care and experience for all patients.	NIP Needs to be considered but will required dedicated support	P MDT has completed an audit to review the age stratified management of women with breast cancer in the	NIP	NIP	NIP	F	F	F

			trust compared to the National audit The Screening service has implemented programmes to promote uptake of screening in particular groups of people.						
5.3.11	The MDT assesses (at least annually) its own effectiveness/performance and where possible benchmarks itself against similar MDTs making use of cancer peer review processes and other national tools as they become available – results of the assessment are acted on by the MDT or employing organisation.	P The MDT was peer reviewed in September 2015 and submitted self-assessments in 2016 and 2017	F	P	F	F	F	F	P

SOUTHERN HEALTH & SOCIAL CARE TRUST

Title	**Cancer MDT Improvement Plan**
Version control date	**1st November 2021**
Executive Leads	Barry Conway, Assistant Director Cancer & Clincial Services; Dr Shahid Tariq, AMD Cancer; David McCaul Clinical Lead for Cancer Services
Report Author	**Mary Haughey; Macmillan Cancer Service Improvement Lead**
Timeframe	1st November 2021 - 31st March 2022

Introduction

The Southern Trust is undertaking work to strengthen approaches to cancer multidisciplinary team (MDT) processes. This improvement work will include a review of how MDTs currently function and consider any potential additonal assurance measures that may be required. The NCAT tool - Characteristics of an Effective Multidisciplinary Team (MDT), self-assessment and feedback questionnaire (Feb 2010) was adapted by the Trust and amended into a fillable audit proforma to assist with obtaining a baseline of the holistic MDT attributes and help form the basis for quality improvement. The MDT audit is designed to target and drive patient safety and quality improvement by identifying areas for strengthening systems and processes. Between June-August 2021, the x8 local MDTs completed the NCAT self-assessment tool to reflect the views of their own MDT, these were then circulated to the wider MDTs for review and comment. During September-October 2021, the Cancer Services Management Team met with all of the MDT Leads to review the baselines, identify common areas/themes , identify tumour-site specific areas and prioritise areas for improvement. This action plan is a product from those meetings to capture all of the issues identified and agree actions to address. The action plan has been cross-referenced against the Urology SAI recommendations. The initial time frame for this action plan is from 1st November 2021 - 31st March 2022.

NCAT Section / Characteristic	Generic issue	Action/s to address	Action Product	Action owner	Action start date	Action End date	Status update	Cross-reference to Urology SAI recommendation/s
Section 1: The Multidisciplinary Team								
1.1.1 / 1.1.3	All relevant specialities are represented in the team, cross cover for some specialities	Audits of attendance at MDM should be more regular (?quarterly) rather than review at annual business meeting - this will also assure on quoracy and allow for issues to be addressed earlier	Audit of MDT Attendance on quarterly basis	MDT Co-ordinator / MDT Leads	Jan-22	Will be on-going quarterly	Dr Tariq to write to all MDT Leads to ensure that attendance is being accurately recorded at MDT meetings. Audits of attendance to take place on a quarterly basis when MDT co-ordinator is in post.	Recommendation 1
1.2.1	Dedicated time in job plans for preparation & attendance at MDT	Ensure job plans of all MDT members has dedicated time included to prepare and attend the MDT meeting	Review of MDT Job plans	Dr Tariq	Nov-21	Dec-21	Dr Tariq will write to surgical & medical directors to clarify that MDT time is included in job plans of MDT members and how much time is allocated	Recommendation 1; Recommendation 4
1.2.6	Extended members / non-members attend for cases relevant to them	To develop a MDT Principles/Protocol and detail this in it including the operational policy	MDT Principles document	Cancer SIL/ MDT Leads/ OSL /	1st Nov 2021	30th Nov 2021	1st draft to be presented to MDT Leads at Cancer checkpoint meeting 5/11 and to the Urology Task & Finish Group meeting 08/11/21	Recommendation 1
1.3.5	MDT Leader has a broader remit not confined to MDT meetings	Develop role description of the MDT Lead and ensure adequate time is alocated in their job plan	Job description for MDT Lead role	Dr Tariq; Stephen Wallace	1st Nov 2021	30th Nov 2021	Dr Tariq to liaise with Stephen Wallace in relation to MDT Lead role description. M.Haughey to check with colleagues if a role description has been developed in other trusts.	Recommendation 7
1.4.1	Each member has clearly defined roles / responsibilities in the team which they have signed up and included in their job plans	Define and detail the roles and responsibilities of all members involved in the MDM meetings	Review of MDT operational policies to ensure all MDT members roles are clearly defined; Review of MDT job plans	MDT Co-ordinator / MDT Lead ; Medical Speciality, AMD/ CD for Cancer	Nov-21	Mar-22	As per 1.2.1. MDT Co-ordinator to review all MDT Operational policies with MDT Lead to ensure roles and responsibilities are included.	Recommendation 1
1.5.2	Networking opportunities to share learning & experiences with other MDTs locally	Provide opportunity for MDTs to meet locally, at least once per year, to share learning and experiences	Set up an Annual networking meeting for all MDTs	Dr Tariq; AD for cancer services; MDT Leads	1st Nov 2021	Mar-22	Dr Tariq to contact MDTs Leads for feedback on the format and content of an annual networking event and to seek a date early 2022	Recommendation 6
Section 2: Infrastructure for meetings								
3.2.5	Locally agreed minimum dataset of information about patients for discussion collated and summarised prior to meeting (pathology, radiology, clinical, co-morbidities, psychosocial & spec palliative care needs	To develop MDT Proforma per tumour site with locally agreed minimum dataset	MDT Proforma	Cancer Services Co-ordinator/OSL / MDT Co-ordinator	1st Nov-21	Nov-21	Draft proforma for Urology MDT developed and shared with MDT Lead for review	Recommendation 1
3.2.6	Members know what info from locally agreed minimum dataset of info they will be expected to present	To be detailed in the MDT Proforma	MDT Proforma	Cancer Services Co-ordinator/OSL / MDT Co-ordinator	1st Nov	Mar-22	To be developed in a phased approach for all MDTs, beginning with Urology MDT	Recommendation 1
3.3.1/3.3.2	It is clear who wants to discuss a patient & why being discussed / a locally agreed dataset of information is presented on each patient including diagnostic information	To develop MDT Proforma per tumour site with locally agreed minimum dataset, clear reason for discussion and sign off from the presenting clinician	MDT Proforma	Cancer Services Co-ordinator/OSL / MDT Co-ordinator	1st Nov	Mar-22	To be developed in a phased approach for all MDTs, beginning with Urology MDT	Recommendation 5
3.3.5	Core data items are collected during meetings and datasets completed in real time	Review and agreement of which data fields should be completed during MDT discussion and by whom, this should be detailed in MDT Principles/Protocol	Completion of core data fields during MDT meeting & agree process to check compliance	MDT Co-ordinator /MDT Trackers / SIL	1st Nov	Mar-22	Draft MDT Principles document to be developed and shared with MDT Leads for review	Recommendation 5
3.4.1	Processes in place to ensure patients info needs are assessed and met; to ensure actions agreed are implemented;	CNS to use the Cancer Information Recording form to record the information provided by the clinical team to the patient and file in the patient notes: All patients receive a written record of their management plan with diagnosis and contact details before they leave clinic	Audits to check completion of Cancer information recording form & permanent record of consultation	MDT Co-ordinator /Tumour site CNS's / HOS /	1st Nov	Mar-22	Audits to take place when MDT Co-ordinator is in post	Recommendation 2
	ensure MDT is notified of significant changes made to recommended treatment/care-plan	Any variation from recommended treatment/careplan should be documented at a MDT meeting. Ensure there is a clear pathway on whose role it is to capture , record and document and how this will be done for any patients that have declined further treatment.	Included in MDT Principle's document; agree audit process to check compliance	SIL / OSL / MDT Co-ordinator	1st Nov	Mar-22	Draft Principles document developed fro review/sign off. Audit process to be agreed when MDT Co-ordinator takes up post	Recommendation 5
Section 4: Patient Centred Clinical Decision-making								
4.1.1	Local mechanisms to identify all patients where discussion at MDT is needed	Define and detail what failsafe mechanisms are in place to ensure that there is a safety net to identify all patients who require MDT discussion	Failsafe mechanism agreed with Pathology	Cellular Pathology; Labs HoS; AD; OSL	1st Nov	Dec-21	A plan to address is being developed by Cellular Pathology & Lab service	Recommendation 5
4.1.3	Local agreement about if/when patients with advanced/recurrent disease should be discussed	MDT site specific agreement if/when patients with advanced or recurrent disease are listed for discussion and detailed in operational policy	MDT agreement and detailed in operational policy - audit compliance	MDT Co-ordinator / MDT Leads	1st Nov-21	Mar-22		Recommendation 4
4.2.3	Named individual at MDT has responsibility for identifying a key worker for the patient	To be detailed in MDT Principles doc - cross-referenced in the Operational Policy	MDT Principles document	SIL /MDT Leads	1st Nov	30th Nov 21	1st draft to be presented to MDT Leads at Cancer checkpoint meeting 5/11 and to the Urology Task & Finish Group meeting 08/11/21	Recommendation 5 & Recommendation 2
4.2.4	Named individual at MDT ensures patients information needs are assessed and addressed	To be detailed in MDT Principles doc - cross-referenced in the Operational Policy	MDT Principles document	SIL/MDT Leads/CNS	1st Nov	30th Nov 21	1st draft to be presented to MDT Leads at Cancer checkpoint meeting 5/11 and to the Urology Task & Finish Group meeting 08/11/21	Recommendation 2

4.3.1	A locally agreed minimum dataset of info is provided at the MDT meeting	To develop MDT Proforma per tumour site with locally agreed minimum dataset	MDT Proforma	MDT Co-ordinator / MDT Leads	1st Nov	Mar-22	Draft proforma for Urology MDT developed and shared with MDT Lead for review	Recommendation 1; Recommendation 5; Recommendation 8
4.3.3	MDTs have access to all current clinical trials, consider patients suitability, relevant research nurses attends MDT where feasible	Ensure that all MDTs have access to clinical trials and recruitment is considered as appropriate	MDT Principles document	Clinical research Nurses / MDT Leads / MDT Audit or Clinical Trials rep	1st Nov	30th Nov 21	1st draft to be presented to MDT Leads at Cancer checkpoint meeting 5/11 and to the Urology Task & Finish Group meeting 08/11/21	Recommendation 1;
4.3.12	MDTs collect social demographic data (age, ethnicity & gender) & consider data periodically to reflect on equality of access to active treatments	To review systems to identify how this information can be collected and agree a clear process on how this info is captured, whose role it is to do this and when this will be considered by the MDTs	Data collection	MDT Co-ordinator / MDT Leads	1st Nov	Mar-22	Review to take place when MDT Co-ordinator is in post	Recommendation 6
Section 5: Team Governance								
5.1.1	Organisational support demonstrated via adequate funding/resources in terms of people, time, equipment for MDT meetings to operate effectively	Clear process in place to enable MDT Leads to meet with Cancer Services management team and to escalate any issues that may impact negatively on the effectiveness of the MDT meeting	Set up meetings between MDT Leads and Cancer Management team	Cancer services management Team	1st Nov			Recommendation 9
5.1.2	Trusts consider their MDTs annual assessments and act on issues of concern	Cancer Services team attend MDT annual meetings and process in place to enable escalation of MDT areas of concern	Attendance at MDT annual business meeting	Cancer services management Team	1st Nov		Schedule of MDT business meetings to be agreed at start of each year and communicated to management team	Recommendation 3
5.2.1	Data collection resource is available to the MDT	Identify what data support is required by MDTs and explore funding sources with Trust SMT and commisioners	Data resource calculated	AD / HOS / OSL	1st Nov	Dec-21		Recommendation 6
5.2.2	Key info that directly affects treatment decisions is collected by MDT (staging, performance status, co-morbidity)	To review systems to identify how this information can be collected and agree a clear process on how this info is captured, whose role it is to do this and when this will be considered by the MDTs	Sytems review	MDT Co-ordinator / MDT Leads / OSL	1st Nov			Recommendation 5
5.2.3	Mandated national datasets are populated prior to or during MDT meetings or shortly afterwards	Detailed in MDT Principles doc and clear process detailed on what info is collected and by whom	MDT Principles document	MDT Leads/ MDT Co-ordinator	1st Nov	30th Nov	1st draft to be presented to MDT Leads at Cancer checkpoint meeting 5/11 and to the Urology Task & Finish Group meeting 08/11/21	Recommendation 6
5.2.4	Data collected during MDT meetings (including social demographic data) is analysed and fed back to MDT to support learning	Agree the data, who will collect & analyse it and when this will be shared with the MDTs for consideration	Data collection process agreed per MDT	MDT Leads / MDT Co-ordinator	1st Nov	Mar-22	M.Haughey to liaise with Sinead Lee to clarify what social demographic data is collected during MDT and how	Recommendation 6
5.2.5	MDT takes part in internal and external audits of processes & outcomes, reviews audit data and takes action to change practice where necessary	MDTs to identify and agree their audits at the annual business meeting including whi will lead and what support is required	Participation and log of audits	Dr Tariq / MDT Leads	1st Nov	Mar-22	Dr Tariq to write to MDT Leads to seek input on completion and review of future audits and the process for this to be discussed and agreed	Recommendation 6
5.2.7	Patient experience surveys include questions relevant to MDT working and action is taken to implement improvements in response to pt feedback	Local patient experience surveys per MDT should be rolled out at least once every two years.	Patient experience surveys	CNS's / SIL	1st Nov	Mar-22	Scope what patient experience surveys have been undertaken and identify any gaps across MDT teams	Recommendation 6
5.3.1	Data collection resource is available to the MDT	Identify what data is required for the MDTs and by whom and how often	Data resource calculated	OSL /MDT Leads / MDT Co-ordinator	1st Nov	Dec-21		Recommendation 6
5.3.3	User Partnership Groups are given the opportunity to advise on the development of MDT policy and practice	Re-establish the Cancer Service User Group and agree the process for involvement in MDT policy and practice	Establishment of Cancer Service User Group	SIL / HoS Cancer / Macmillan HWB Manager	1st Nov	Feb-22	Draft terms of reference developed; recruitment process underway	Recommendation 6
5.3.5	Mechanisms in place to record MDT recommendation v actual treatment given and alert MDT if these are not adopted and reason for this; ensure MDT is alerted to serious treatment complications and adverse/unexpected events/death in treatment	Develop a safety cross-check process to ensure that there is a safety net for all patients in ensuring the actions agreed from MDM are completed; define how MDT is advised of adverse complications/unexpected deaths etc. These should be detailed and monitored.	Safety cross-check process established for all MDTs	Cellular Pathology / Labs service / AD / OSL	1st Nov	Dec-21	A plan to address is being developed by Cellular Pathology & Lab service. Dr Tariq to contact all MDT Leads to seek feedback and agreement on the process if recommendations are not adopted.	Recommendation 8
5.3.6	Strategies in place to monitor: proportion of pts discussed without sufficient information to make recommendations & proportion of patients offered and/or receiving information recommended by MDT	Agree how this data is collected & analysed for MDTs, by whom and when this will be shared with the MDTs for consideration	Data collection & analysis - AUDITS	MDT Co-ordinator/MDT Lead	1st Nov	Jan-22	To be agreed when MDT Co-ordinator takes up post	Recommendation 1; Recommendation 2
5.3.7	MDT shares good practice & discusses local problem areas with MDTs in own trust/network	Provide opportunity for MDTs to meet locally to share learning and experiences (see 1.5.2)	MDT networking event	Cancer Management Team	1stNov	Mar-22		Recommendation 3
5.3.9	Significant discrepancies in pathology, radiology or clinical findings between local and specialist MDTs should be recorded and subject to audit	This is currently done on a one-to-one basis, a process needs to be developed and implemented	Audit	Dr Tariq / MDT Leads	1st Nov	Mar-22	Dr Tariq to liaise with MDT Leads to discuss process. M.Haughey to contact Ciara Toal, BT, to query addition to the MDT communications protocol in relation to communication back to local MDTs	Recommendation 6
5.3.10	MDTs reflect annually on equality issues	Data to be agreed and collected for MDT annual reports for review & reflection by the MDT members	Data collection	MDT Co-ordinator / MDT Leads	1st Nov	Mar-22		Recommendation 1; Recommendation 6
Additional areas	Overall governance of MDT and decisions arising from MDTs	Review of JDs for ADs, CDs and AMDs – both for cancer and specialties.	Process set up to review JDs	Medical Directorate/ Specialities	1st Nov	TBA		Recommendation 6; Recommendation 7
	The Southern Health and Social Care Trust must provide high quality urological cancer care for all patients	Undertake a demand/capacity review of all cancer services beginning with the Urology cancer service	Demand & capacity analysis	MDT Coordinator / OSL / AD's	1st Nov	Mar-22		Recommendation 1

MDT	NCAT Characteristic	Issue/s	Action/s to address	Action Product	Action owner	Action Start Date	Action End Date	Status update	Sign Off
GYNAE	1.2.2 Core members are present for the discussion of all cases where their input is needed	Pathology input at times	Review MDT attendance on quarterly basis	MDT attendance audit	MDT Co-ordinator	1st Nov-21	Mar-22		
	1.2.3 Clinician who has met the patient whose case is being discussed is present at the meeting	Patient may be seen by different HCP until confirmation of cancer & management plan agreed	Following confirmation of diagnosis, it will be the same clinician who sees the patient	MDT Principles Document	SIL / MDT Leads	1st Nov-21	30th nov		
	1.5.4 MDTs have a teaching & training role within team and beyond	Due to COVID, there have been less medical students / clinicians-in-training at the MDT	Include in MDT Principles document	MDT Principles dcoument	SIL / MDT Leads	1st Nov-21	30th Nov		
	3.2.3 Cases are organised in a way that is logical for tumour area being considered and sufficient time given to more complex cases	Cases are alphabetical for main part of meeting. Small number are set aside for regional meeting	Review of case listing	MDT List	MDT Lead / MDT Tracker / MDT Co-ordinator	1st Nov-21	Mar-22		
LUNG	1.2.7 Anyone observing should be introduced to team members and their details included on the attendance list	Medical student/registrars are not always recorded. SAS Drs would like their attendance recorded	To consider this going forward	MDT attendance list	MDT Tracker / MDT Lead	1st Nov-21	Dec-21		
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	Consideration of MDT training for new consultants/nurses/other specialities through their training route/professional bodies	MDT Principles document shared with all new members	MDT Principles document	SIL / MDT Lead	1st Nov-21	30th Nov		
	4.3.11 It is clear who will communicate the MDT recommendations to the patient, GP and clinical team, how and by when and this is minuted	This is not minuted but each consultant is responsible for communicating with other clinical teams, the patient and their GP	To develop MDT Communication doc	MDT Communication doc	OSL / MDT Co-ordinator	1st Nov-21	Dec-21	Review / amend BT Communication protocol	
BREAST	1.4.2 Team has agreed what is acceptable team behaviour/etiquette	Not in place	Include in MDT Principles document; consider 360 questionnaire to audit / measure	MDT Principles document	SIL /MDT Leads	1st Nov-21	30th Nov		
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	Consideration of MDT training for new consultants/nurses/other specialities through their training route/professional bodies	Consider bespoke course for MDTs - mandatory training for new appointees to MDT	MDT Principles Document	SIL / MDT Leads	1st Nov-21	30th Nov		
	4.1.2 There are referral criteria in place so it is clear when to send a case to MDT for consideration	Some patients are added and at times it is not clear what the question is for the MDT	MDT Proforma would help to standardise this	MDT Proforma	Cancer Services Co-ordinator / OSL / mdt Co-ordinator	1st Nov-21	Dec-21		
	4.3.4 Standard treatment protocols are in place and used whenever appropriate	Not in place - there is individual case discussion, the MDT does not use treatment protocols							
	4.3.11 It is clear who will communicate the MDT recommendations to the patient, GP and clinical team, how and by when and this is minuted	This is not minuted but each consultant is responsible for communicating with other clinical teams, the patient and their GP	Include in the MDT Principles / protocol doc for sign off	MDT Principles document	SIL /MDT Leads	1st Nov-21	30th Nov		
	5.3.2 There are agreed policies, guidelines or protocols how changes in clinical practice are to be managed; communications post meetings	Not sure of process for other modalities / specialities. For Surgery, this is agreed and disseminated through the Breast CRG	To be clearly documented for all specialities	MDT Principles Document	SIL/MDT Leads	1st Nov-21	30th Nov		
SKIN	1.4.2 Team has agreed what is acceptable team behaviour/etiquette	Not in place	Include in MDT Principles document	MDT Principles document	SIL /MDT Leads	1ST Nov	30th Nov		
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	Through different routes: appraisals, revalidation, training courses completed by members	No specifc training course in relation to the MDT						
	3.2.2 Locally agreed cut-off time for inclusion of a case on the MDT list	Not in place - there is no cut-off time for cases to be brought back	Potenial to filter out cases that are not suitable and to ensure availability of MDT list earlier in week.	Agree cut-off time for cases	MDT / MDT Co-ordinator	1st Nov-21	Dec-21		

UROLOGY	1.2.7 Anyone observing should be introduced to team members and their details included on the attendance list	Medical student attendees are not recorded	Consider recording all attendees for future MDT meetings	MDT attendance list	MDT Tracker / MDT Lead	1st Nov-21	Dec-21		
	3.2.3 Cases are organised in a way that is logical for tumour area being considered and sufficient time given to more complex cases		This could be improved by implementing protocolised pathways for more straight forward cases which are registered and signedd off by the MDT Chair. The more complex cases would be listed for discussion.	MDT Proforma	Cancer Services Co-ordinator / MDT Lead	1st Nov-21	Dec-21		
	4.1.4 A clinician can bring the case of a private patient to the MDT for discussion provided there is time on the agenda	Not in place							
	5.2.6 MDTs consider and act on clinical outcomes data as they become available e.g. through peer review	Clinical outcomes not available through peer review	Agree what clinical data will be collected, by whom, & when this will be reviewed by the MDT	Data collection	MDT Co-ordinator / MDT Lead	1st Nov	Mar-22		
	5.3.11 The MDT assesses at least annually its own effectiveness/performance & benchmarks against similar MDTs	The MDT was peer reviewed in 2015, and submitted self-assessments in 2016 and 2017	Set up a process / ensure mechanism is in place for this to happen outside of peer review programme	Annual business meeting	MDT Co-ordinator / MDT Lead	1st Nov	Mar-22		
LGI	1.2.2 Core members are present for discussion of all cases where their input is needed	Issue with pathology input at times	Review MDT attendance on quarterly basis	MDT Attendance list	MDT Co-ordinator	1st Nov	Mar-22		
	1.2.5 A register of attendance is maintained, members sign in and out with times	Untimed weekly register is maintained by MDT Co-ordinator							
	1.2.7 Anyone observing should be introduced to team members and their details included on the attendance list	Medical students are introduced but not listed on the attendance sheet	MDT Attendance sheet	MDT Attendance sheet	MDT Tracker / MDT Lead	1st Nov	Mar-22		
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	More access to ACST is required	Need an update in relation to future ACST courses		HOS Cancer	1st Nov	Dec-21		
UGI	5.3.4 MDT policies, guidelines and protocols are reviewed at least annually	MDT operational policy reviewed, and annual report and workplan updated. This has fallen behind over past couple of years.	To review all MDT docs and arrange a MDT meeting to sign off	MDT Docs updated for 2019	SIL /MDT Lead/ MDT Co-ordinator	1st Nov	Mar-22		
THYROID	5.3.4 MDT policies, guidelines and protocols are reviewed at least annually	MDT operational policy reviewed, and annual report and workplan updated. This has fallen behind over past couple of years.	To review all MDT docs and arrange a MDT meeting to sign off	MDT Docs updated for 2019	SIL / MDT Lead /MDT Co-ordinator	1st Nov	Mar-22		
	5.3.11 the MDT assesses at least annually its own effectiveness/performance & benchmarks against similar MDTs	The MDT was peer reviewed in 2016, and submitted a self-assessment in 2017	Set up a process / ensure a mechanism is in place for this to happen outside of peer review	Annual business meeting	MDT Lead / MDT Co-ordinator	1st Nov	Mar-22		

SOUTHERN HEALTH & SOCIAL CARE TRUST

Title	**Cancer MDT Improvement Plan**
Version control date	**1st November 2021**
Executive Leads	Barry Conway, Assistant Director Cancer & Clincial Services; Dr Shahid Tariq, AMD Cancer; David McCaul Clinical Lead for Cancer Services
Report Author	**Mary Haughey; Macmillan Cancer Service Improvement Lead**
Timeframe	1st November 2021 - 31st March 2022

Introduction

The Southern Trust is undertaking work to strengthen approaches to cancer multidisciplinary team (MDT) processes. This improvement work will include a review of how MDTs currently function and consider any potential additonal assurance measures that may be required. The NCAT tool - Characteristics of an Effective Multidisciplinary Team (MDT), self-assessment and feedback questionnaire (Feb 2010) was adapted by the Trust and amended into a fillable audit proforma to assist with obtaining a baseline of the holistic MDT attributes and help form the basis for quality improvement. The MDT audit is designed to target and drive patient safety and quality improvement by identifying areas for strengthening systems and processes. Between June-August 2021, the x8 local MDTs completed the NCAT self-assessment tool to reflect the views of their own MDT, these were then circulated to the wider MDTs for review and comment. During September-October 2021, the Cancer Services Management Team met with all of the MDT Leads to review the baselines, identify common areas/themes , identify tumour-site specific areas and prioritise areas for improvement. This action plan is a product from those meetings to capture all of the issues identified and agree actions to address. The action plan has been cross-referenced against the Urology SAI recommendations. The initial time frame for this action plan is from 1st November 2021 - 31st March 2022.

NCAT Section / Characteristic	Generic issue	Action/s to address	Action Product	Action owner	Action start date	Action End date	Status update	Cross-reference to Urology SAI recommendation/s
Section 1: The Multidisciplinary Team								
1.1.1 / 1.1.3	All relevant specialities are represented in the team, cross cover for some specialities	Audits of attendance at MDM should be more regular (?quarterly) rather than review at annual business meeting - this will also assure on quoracy and allow for issues to be addressed earlier	Audit of MDT Attendance on quarterly basis	MDT Administrator & Project Officer / MDT Leads	Jan-22	Will be on-going quarterly	Dr Tariq has written to all MDT Leads to ensure that attendance is being accurately recorded at MDT meetings. Audits of attendance to take place on a quarterly basis when MDT co-ordinator is in post.	Recommendation 1
1.2.1	Dedicated time in job plans for preparation & attendance at MDT	Ensure job plans of all MDT members has dedicated time included to prepare and attend the MDT meeting	Review of MDT Job plans	Dr Tariq	Nov-21	Dec-21	COMPLETED. Dr Tariq has written to the surgical & medical directors to clarify that MDT time is included in the job plans of all MDT members. Attendance at the MDT meeting has been confirmed for all tumour sites. Preparation time is not included and falls under the time allocated for general patient admin time.	Recommendation 1; Recommendation 4
1.2.6	Extended members / non-members attend for cases relevant to them	To include in the MDT Principles document and detail in the operational policy	MDT Principles document	Cancer SIL/MDT Leads	1st Nov 2021	30th Nov 2021	Draft principles document presented to MDT Leads at Cancer checkpoint meetings 5/11 and 03/12 and feedback requested. Also circulated to members at Urology Task & Finish Group meeting 08/11/21.	Recommendation 1
1.3.5	MDT Leader has a broader remit not confined to MDT meetings	Develop role description of the MDT Lead and ensure adequate time is alocated in their job plan	Job description for MDT Lead role	Dr Tariq; Stephen Wallace	1st Nov 2021	30th Nov 2021	Dr Tariq has liaised with Stephen Wallace in relation to MDT Lead role description. A draft has been circulated to all MDT Leads for review / comment.	Recommendation 7
1.4.1	Each member has clearly defined roles / responsibilities in the team which they have signed up and included in their job plans	Define and detail the roles and responsibilities of all members involved in the MDM meetings	Review of MDT operational policies to ensure all MDT members roles are clearly defined; Review of MDT job plans	MDT Co-ordinator / MDT Lead ; Medical Speciality, AMD/ CD for Cancer	Nov-21	Mar-22	As per 1.2.1. MDT Co-ordinator to review all MDT Operational policies with MDT Lead to ensure roles and responsibilities are included.	Recommendation 1
1.5.2	Networking opportunities to share learning & experiences with other MDTs locally	Provide opportunity for MDTs to meet locally, at least once per year, to share learning and experiences	Set up an Annual networking meeting for all MDTs	Dr Tariq; AD for cancer services; MDT Leads	1st Nov 2021	Mar-22	Dr Tariq to contact MDTs Leads for feedback on the format and content of an annual networking event and to seek a date early 2022	Recommendation 6
Section 2: Infrastructure for meetings								
3.2.5	Locally agreed minimum dataset of information about patients for discussion collated and summarised prior to meeting (pathology, radiology, clinical, co-morbidities, psychosocial & spec palliative care needs	To develop MDT Proforma per tumour site with locally agreed minimum dataset	MDT Proforma	Cancer Services Co-ordinator/OSL / MDT Administrator / MDT Leads	1st Nov-21	Nov-21	MDT proforma for Urology MDT agreed and will be rolled out from 4 Jan 22. Proformas for Lung, UGI and LGI to be considered next.	Recommendation 1
3.2.6	Members know what info from locally agreed minimum dataset of info they will be expected to present	To be detailed in the MDT Proforma	MDT Proforma	Cancer Services Co-ordinator/OSL / MDT Administrator	1st Nov	Mar-22	To be developed in a phased approach for all MDTs, beginning with Urology MDT (Jan 22)	Recommendation 1
3.3.1/3.3.2	It is clear who wants to discuss a patient & why being discussed / a locally agreed dataset of information is presented on each patient including diagnostic information	To develop MDT Proforma per tumour site with locally agreed minimum dataset, clear reason for discussion and sign off from the presenting clinician	MDT Proforma	Cancer Services Co-ordinator/OSL / MDT Administrator	1st Nov	Mar-22	To be developed in a phased approach for all MDTs, beginning with Urology MDT	Recommendation 5
3.3.5	Core data items are collected during meetings and datasets completed in real time	Review and agreement of which data fields should be completed during MDT discussion and by whom, this should be detailed in MDT Principles/Protocol	Completion of core data fields during MDT meeting & agree process to check compliance	MDT Administrator /MDT Trackers / OSL	1st Nov	Mar-22	To be considered when MDT Administrator is in post	Recommendation 5
3.4.1	Processes in place to ensure patients info needs are assessed and met; to ensure actions agreed are implemented;	CNS to use the Cancer Information Recording form to record the information provided by the clinical team to the patient and file in the patient notes: All patients receive a written record of their management plan with diagnosis and contact details before they leave clinic	Audits to check completion of Cancer information recording form & permanent record of consultation	MDT Administrator /Tumour site CNS's / HOS /	1st Nov	Jan-22	Audits to take place when MDT Administrator is in post	Recommendation 2
	ensure MDT is notified of significant changes made to recommended treatment/care-plan	Any variation from recommended treatment/careplan should be documented at a MDT meeting. Ensure there is a clear pathway on whose role it is to capture , record and document and how this will be done for any patients that have declined further treatment.	Included in MDT Principle's document; agree audit process to check compliance	MDT Leads /OSL / MDT Administrator	1st Nov	Mar-22	Draft Principles document developed for review by MDT Leads. Audit process to be agreed when MDT Administrator takes up post.	Recommendation 5
Section 4: Patient Centred Clinical Decision-making								
4.1.1	Local mechanisms to identify all patients where discussion at MDT is needed	Define and detail what failsafe mechanisms are in place to ensure that there is a safety net to identify all patients who require MDT discussion	Failsafe mechanism agreed with Pathology	Cellular Pathology; Labs HoS; Pathology Clinical Lead	1st Nov	Dec-21	A plan to address is being developed by Cellular Pathology & Lab service in Belfast. B.Conway to link with Geoff & Claire for an update.	Recommendation 5
4.1.3	Local agreement about if/when patients with advanced/recurrent disease should be discussed	MDT site specific agreement if/when patients with advanced or recurrent disease are listed for discussion and this is detailed in operational policy	MDT agreement and detailed in operational policy	MDT Leads / MDT Administrator	1st Nov-21	Mar-22	Work is ongoing to streamline presentation of patients at the MDTs	Recommendation 4

4.2.3	Named individual at MDT has responsibility for identifying a key worker for the patient	To be detailed in MDT Principles doc - cross-referenced in the Operational Policy	MDT Principles document	MDT Leads / SIL	1st Nov	30th Nov 21	Draft document presented to MDT Leads for review and comment.	Recommendation 5 & Recommendation 2
4.2.4	Named individual at MDT ensures patients information needs are assessed and addressed	To be detailed in MDT Principles doc - cross-referenced in the Operational Policy	MDT Principles document - audit of compliance to be agreed	MDT Leads/CNS's / HoS Cancer / SIL	1st Nov	30th Nov 21	Draft principles document shared with MDT Leads for review / agreement. Work ongoing with CNS's to ensure that patient info needs are assessed and this is documented.	Recommendation 2
4.3.1	A locally agreed minimum dataset of info is provided at the MDT meeting	To develop MDT Proforma per tumour site with locally agreed minimum dataset	MDT Proforma	MDT Administrator / MDT Leads	1st Nov	Mar-22	Proforma for Urology MDT developed and agreed, this will be used from 4 Jan 2022. Next tumour sites for consideration are Lung, LGI and UGI.	Recommendation 1; Recommendation 5; Recommendation 8
4.3.3	MDTs have access to all current clinical trials, consider patients suitability, relevant research nurses attends MDT where feasible	Ensure that all MDTs have access to clinical trials and recruitment is considered as appropriate	MDT Principles document	Clinical research Nurses / MDT Leads / MDT Audit or Clinical Trials rep	1st Nov	Ongoing	When Principles doc is agreed by MDT Leads, process will be agreed to ensure that MDTs are aware of clinical trials and consider patients suitability	Recommendation 1;
4.3.12	MDTs collect social demographic data (age, ethnicity & gender) & consider data periodically to reflect on equality of access to active treatments	To review systems to identify how this information can be collected and agree a clear process on how this info is captured, whose role it is to do this and when this will be considered by the MDTs	Data collection	OSL /MDT Administrator	1st Nov	Jan-22	OSL to raise at next regional CAPPS meeting	Recommendation 6
Section 5: Team Governance								
5.1.1	Organisational support demonstrated via adequate funding/resources in terms of people, time, equipment for MDT meetings to operate effectively	Review of MDT Leads job plans, clear process in place to escalate any issues that may impact negatively on the effectiveness of the MDT meeting,	MDT job plans; MDT room for meetings; regular meetings with Cancer Management Team	Cancer services management Team	1st Nov	Jan-22	MDT Leads job plans all reviewed; room allocated for MDT meetings; MDT Administrator post; regular meetings set up to escalate issues / concerns	Recommendation 9
5.1.2	Trusts consider their MDTs annual assessments and act on issues of concern	Cancer Services team attend MDT annual meetings and process in place to enable escalation of MDT areas of concern	Attendance at MDT annual business meeting	Cancer services management Team	1st Nov	Jan-22	Schedule of MDT business meetings to be agreed at start of each year and communicated to management team to ensure representation	Recommendation 3
5.2.1	Data collection resource is available to the MDT	Identify what data support is required by MDTs and explore funding sources with Trust SMT and commisioners	Data resource calculated	AD / HOS / OSL	1st Nov	Dec-21	This will be considered further once the MDT Administrator is in post	Recommendation 6
5.2.2	Key info that directly affects treatment decisions is collected by MDT (staging, performance status, co-morbidity)	To review systems to identify how this information can be collected and agree a clear process on how this info is captured, whose role it is to do this and when this will be considered by the MDTs	Sytems review	MDT Administrator / MDT Leads / OSL	1st Nov	Feb-22	This will be considered further once the MDT Administrator is in post	Recommendation 5
5.2.3	Mandated national datasets are populated prior to or during MDT meetings or shortly afterwards	Detailed in MDT Principles doc and clear process detailed on what info is collected and by whom	MDT Principles document	MDT Leads/ MDT Co-ordinator	1st Nov	30th Nov	1st draft to be presented to MDT Leads at Cancer checkpoint meeting 5/11 and to the Urology Task & Finish Group meeting 08/11/21	Recommendation 6
5.2.4	Data collected during MDT meetings (including social demographic data) is analysed and fed back to MDT to support learning	Agree the data, who will collect & analyse it and when this will be shared with the MDTs for consideration	Data collection process agreed per MDT	MDT Leads / MDT Co-ordinator	1st Nov	Mar-22	M.Haughey to liaise with Sinead Lee to clarify what social demographic data is collected during MDT and how	Recommendation 6
5.2.5	MDT takes part in internal and external audits of processes & outcomes, reviews audit data and takes action to change practice where necessary	MDTs to identify and agree their audits at the annual business meeting including whi will lead and what support is required	Participation and log of audits	Dr Tariq / MDT Leads	1st Nov	Mar-22	Dr Tariq to write to MDT Leads to seek input on completion and review of future audits and the process for this to be discussed and agreed	Recommendation 6
5.2.7	Patient experience surveys include questions relevant to MDT working and action is taken to implement improvements in response to pt feedback	Local patient experience surveys per MDT should be rolled out at least once every two years.	Patient experience surveys	CNS's / SIL	1st Nov	Mar-22	Scope what patient experience surveys have been undertaken and identify any gaps across MDT teams	Recommendation 6
5.3.1	Data collection resource is available to the MDT	Identify what data is required for the MDTs and by whom and how often	Data resource calculated	OSL /MDT Leads / MDT Administrator	1st Nov	Jan-21	This will be considered further once the MDT Administrator is in post	Recommendation 6
5.3.3	User Partnership Groups are given the opportunity to advise on the development of MDT policy and practice	Re-establish the Cancer Service User Group and agree the process for involvement in MDT policy and practice	Establishment of Cancer Service User Group	SIL / HoS Cancer / Macmillan HWB Manager	1st Nov	Feb-22	Draft terms of reference developed; recruitment process underway	Recommendation 6
5.3.5	Mechanisms in place to record MDT recommendation v actual treatment given and alert MDT if these are not adopted and reason for this; ensure MDT is alerted to serious treatment complications and adverse/unexpected events/death in treatment	To be detailed in MDT Principles document including quality indicator to audit	MDT Principles Document	MDT Leads / SIL / MDT Administrator	1st Nov	Dec-21	Once Principles document is signed off, audits will be agreed	Recommendation 8
5.3.6	Strategies in place to monitor: proportion of pts discussed without sufficient information to make recommendations & proportion of patients offered and/or receiving information recommended by MDT	Agree how this data is collected & analysed for MDTs, by whom and when this will be shared with the MDTs for consideration	Data collection & analysis - AUDITS	MDT Co-ordinator/MDT Lead	1st Nov	Jan-22	To be agreed when MDT Administrator takes up post	Recommendation 1; Recommendation 2
5.3.7	MDT shares good practice & discusses local problem areas with MDTs in own trust/network	Provide opportunity for MDTs to meet locally to share learning and experiences (see 1.5.2)	MDT networking event	Cancer Management Team	1stNov	Jan-22	Dr Tariq has contacted MDT Leads to seek feedback on timing and format of event	Recommendation 3

5.3.9	Significant discrepancies in pathology, radiology or clinical findings between local and specialist MDTs should be recorded and subject to audit	This is currently done on a one-to-one basis, a process needs to be developed and implemented	Audit	Dr Tariq / MDT Leads	1st Nov	Mar-22	Dr Tariq to liaise with MDT Leads to discuss process. M.Haughey to contact Ciara Toal, BT, to query addition to the MDT communications protocol in relation to communication back to local MDTs	Recommendation 6
5.3.10	MDTs reflect annually on equality issues	Data to be agreed and collected for MDT annual reports for review & reflection by the MDT members	Data collection	MDT Administrator / MDT Leads	1st Nov	Mar-22	To be agreed when MDT Administrator takes up post	Recommendation 1; Recommendation 6
Additional areas	Overall governance of MDT and decisions arising from MDTs	Review of JDs for ADs, CDs and AMDs – both for cancer and specialties.	Process set up to review JDs	Medical Directorate/ Specialities	1st Nov	TBA	This is ongoing via the Medical Directorate	Recommendation 6; Recommendation 7
	The Southern Health and Social Care Trust must provide high quality urological cancer care for all patients	Undertake a demand/capacity review of all cancer services beginning with the Urology cancer service	Demand & capacity analysis	MDT Administrator / OSL / AD's	1st Nov	Jan-22	Analysis has been completed for Urology and to be reviewed by wider Task & Finish Group	Recommendation 1
	Process for receipt of red flag referrals from ED	Establish a formal process ; staff awareness regard NICE RF referrals criteria	Referral process; staff education	SIL / HOS ED / AD's	1st Dec	Jan-22	Issues and proposed actions to address to be discussed at ED Speciality meeting; Formal process to be developed and compliance monitored	

MDT	NCAT Characteristic	Issue/s	Action/s to address	Action Product	Action owner	Action Start Date	Action End Date	Status update	Sign Off
GYNAE	1.2.2 Core members are present for the discussion of all cases where their input is needed	Pathology input at times	Review MDT attendance on quarterly basis	MDT attendance audit	MDT Administrator	1st Nov-21	Mar-22	Regular reports to be run when MDT Administrator is in post	
	1.2.3 Clinician who has met the patient whose case is being discussed is present at the meeting	Patient may be seen by different HCP until confirmation of cancer & management plan agreed	Following confirmation of diagnosis, it will be the same clinician who sees the patient	MDT Principles Document	SIL / MDT Leads	1st Nov-21	30th nov	This is detailed in the Principles document which has been circulated to MDT Leads for approval	
	1.5.4 MDTs have a teaching & training role within team and beyond	Due to COVID, there have been less medical students / clinicians-in-training at the MDT	Include in MDT Principles document	MDT Principles dcoument	SIL / MDT Leads	1st Nov-21	30th Nov	This is detailed in the Principles document which has been circulated to MDT Leads for approval	
	3.2.3 Cases are organised in a way that is logical for tumour area being considered and sufficient time given to more complex cases	Cases are alphabetical for main part of meeting. Small number are set aside for regional meeting	Review of case listing	MDT List	MDT Lead / MDT Tracker / MDT Administrator	1st Nov-21	Mar-22	To be reviewed when MDT Administrator is in post	
LUNG	1.2.7 Anyone observing should be introduced to team members and their details included on the attendance list	Medical student/registrars are not always recorded. SAS Drs would like their attendance recorded	To consider this going forward	MDT attendance list	MDT Tracker / MDT Lead	1st Nov-21	Dec-21	To be agreed with MDT Leads / MDT Co-ordinator	
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	Consideration of MDT training for new consultants/nurses/other specialities through their training route/professional bodies	MDT Principles document shared with all new members	MDT Principles document	SIL / MDT Lead	1st Nov-21	30th Nov	Draft document shared with MDT Leds for sign off	
	4.3.11 It is clear who will communicate the MDT recommendations to the patient, GP and clinical team, how and by when and this is minuted	This is not minuted but each consultant is responsible for communicating with other clinical teams, the patient and their GP	To develop MDT Communication doc	MDT Communication doc	OSL / MDT Co-ordinator	1st Nov-21	Dec-21	Review / amend BT Communication protocol	
BREAST	1.4.2 Team has agreed what is acceptable team behaviour/etiquette	Not in place	Include in MDT Principles document; consider 360 questionnaire to audit / measure	MDT Principles document	SIL /MDT Leads	1st Nov-21	30th Nov	Detailed in MDT Principles document	
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	Consideration of MDT training for new consultants/nurses/other specialities through their training route/professional bodies	Consider bespoke course for MDTs - mandatory training for new appointees to MDT	MDT Principles Document	Dr Tariq / SIL / MDT Leads	1st Nov-21	30th Dec	Dr Tariq has written to colleagues in Liverpool and they will share their training course with us for consideration	
	4.1.2 There are referral criteria in place so it is clear when to send a case to MDT for consideration	Some patients are added and at times it is not clear what the question is for the MDT	MDT Proforma would help to standardise this	MDT Proforma	Cancer Services Co-ordinator / OSL / mdt Administrator	1st Nov-21	Dec-21	MDT Proforma developed for Urology and this will be rolled out in a phased approach	
	4.3.11 It is clear who will communicate the MDT recommendations to the patient, GP and clinical team, how and by when and this is minuted	This is not minuted but each consultant is responsible for communicating with other clinical teams, the patient and their GP	Develop a MDT communications doc	MDT Communication document	OSL /MDT Administrator / MDT Leads	1st Nov-21	30th Jan 22	BT Communications document to be reviewed and adopted	
	5.3.2 There are agreed policies, guidelines or protocols how changes in clinical practice are to be managed; communications post meetings	Not sure of process for other modalities / specialities. For Surgery, this is agreed and disseminated through the Breast CRG	To be clearly documented for all specialities	MDT Communications Document	OSL / MDT ADMINISTRATOR/MDT Leads	1st Nov-21	30th Jan-22	BT Communications document to be reviewed and adopted	
SKIN	1.4.2 Team has agreed what is acceptable team behaviour/etiquette	Not in place	Include in MDT Principles document	MDT Principles document	SIL /MDT Leads	1ST Nov	30th Nov	Draft document shared with MDT Leads for sign off	
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	Through different routes: appraisals, revalidation, training courses completed by members	No specifc training course in relation to the MDT	Explore what training is available	Dr Tariq / MDT Leads	1st Dec	Jan-22	Dr Tariq has written to colleagues in Liverpool and they will share their training course with us for consideration	
	3.2.2 Locally agreed cut-off time for inclusion of a case on the MDT list	Not in place - there is no cut-off time for cases to be brought back	Potenial to filter out cases that are not suitable and to ensure availability of MDT list earlier in week.	Agree cut-off time for cases	MDT / MDT Co-ordinator	1st Nov-21	Dec-21	MDT Lead to take forward with Pathology	

UROLOGY	1.2.7 Anyone observing should be introduced to team members and their details included on the attendance list	Medical student attendees are not recorded	Consider recording all attendees for future MDT meetings	MDT attendance list	MDT Tracker / MDT Lead	1st Nov-21	Dec-21	Ensure all attendees are recorded - this will be picked up through the quarterly attendance audits	
	3.2.3 Cases are organised in a way that is logical for tumour area being considered and sufficient time given to more complex cases		This could be improved by implementing protocolised pathways for more straight forward cases which are registered and signedd off by the MDT Chair. The more complex cases would be listed for discussion.	MDT Proforma	Cancer Services Co-ordinator / MDT Lead	1st Nov-21	Dec-21	MDT Proforma developed for Urology and this will be rolled out in a phased approach	
	4.1.4 A clinician can bring the case of a private patient to the MDT for discussion provided there is time on the agenda	Not in place	Process to be detailed in MDT Principles dcoument	MDT Principles document	SIL / MDT Leads / Cancer Managemetn team	1st-Nov	Dec-21	MDT Principles document developed and shared with MDT Lead for sign off	
	5.2.6 MDTs consider and act on clinical outcomes data as they become available e.g. through peer review	Clinical outcomes not available through peer review	Agree what clinical data will be collected, by whom, & when this will be reviewed by the MDT	Data collection	MDT Administrator / MDT Lead	1st Nov	Mar-22	To be considerd with MDT Leads when MDT Administrator is in post	
	5.3.11 The MDT assesses at least annually its own effectiveness/performance & benchmarks against similar MDTs	The MDT was peer reviewed in 2015, and submitted self-assessments in 2016 and 2017	Set up a process / ensure mechanism is in place for this to happen outside of peer review programme	Annual business meeting	MDT Administrator / MDT Lead	1st Nov	Mar-22	To be part of all future business meetings	
LGI	1.2.2 Core members are present for discussion of all cases where their input is needed	Issue with pathology input at times	Review MDT attendance on quarterly basis	MDT Attendance list	MDT Co-ordinator	1st Nov	Mar-22	Attendance audit to be conducted on a quarterly basis when MDT Administrator is in post	
	1.2.5 A register of attendance is maintained, members sign in and out with times	Untimed weekly register is maintained by MDT Co-ordinator	To be documented in MDT Principles document	MDT Principles document	SIL / MDT Leads	1st Nov	Dec-21	MDT Principles document developed and shared with MDT Lead for sign off	
	1.2.7 Anyone observing should be introduced to team members and their details included on the attendance list	Medical students are introduced but not listed on the attendance sheet	MDT Attendance sheet	MDT Attendance sheet	MDT Tracker / MDT Lead	1st Nov	Mar-22	Attendance audit to be conducted on a quarterly basis when MDT Administrator is in post	
	1.5.3 Access to training opportunities as required to support an individuals role in the MDT	More access to ACST is required	Need an update in relation to future ACST courses	ACST Courses provided	HOS Cancer / SIL	1st Nov	Dec-21	Regional meeting convend Dec 21 to discuss a virtual course	
UGI	5.3.4 MDT policies, guidelines and protocols are reviewed at least annually	MDT operational policy reviewed, and annual report and workplan updated. This has fallen behind over past couple of years.	To review all MDT docs and arrange a MDT meeting to sign off	MDT Docs updated for 2019	SIL /MDT Lead/ MDT Co-ordinator	1st Nov	Mar-22	All MDT documents to be updated on an annual basis	
THYROID	5.3.4 MDT policies, guidelines and protocols are reviewed at least annually	MDT operational policy reviewed, and annual report and workplan updated. This has fallen behind over past couple of years.	To review all MDT docs and arrange a MDT meeting to sign off	MDT Docs updated for 2019	SIL / MDT Lead /MDT Co-ordinator	1st Nov	Mar-22	All MDT documents to be updated on an annual basis	
	5.3.11 the MDT assesses at least annually its own effectiveness/performance & benchmarks against similar MDTs	The MDT was peer reviewed in 2016, and submitted a self-assessment in 2017	Set up a process / ensure a mechanism is in place for this to happen outside of peer review	Annual business meeting	MDT Lead / MDT Co-ordinator	1st Nov	Mar-22	All MDT documents to be updated on an annual basis and presented for review at an annual MDT meeting	

CPES Report – SHSCT

451 patients (total sample 3217) from SHSCT

77 respondents were treated for urological cancer (17% of total sample)

Highest scores:

Q1.Saw GP once/twice before being told had to go to hospital ***(NI-74%, ST-82%)***

Q2.Patient thought they were seen as soon as possible ***(NI-86%; ST – 87%)***

Q6.Staff gave complete explanation of purpose of test ***(NI-84%; ST – 86%)***

Q7.Staff explained completely what would be done during test ***(NI-88%; ST – 89%)***

Q14.Patient given written info about type of cancer they had ***(NI-48%; ST – 54%)***

Q17.Possible side effects explained in understandable way ***(NI-75%; ST – 77%)***

Q22.Patient finds it easy to contact CNS ***(NI – 82%; ST – 88%)***

Q24.Get understandable answers to imp questions all/most of time ***(NI-89%;ST-90%)***

Q28.Patient has seen info about cancer research in hospital ***(NI-79%; ST-90%)***

Q37.Patient had confidence & trust in all Drs treating them ***(NI-86%; ST-90%)***

Q38.Drs didn’t talk in front of patient as if they were not there ***(NI-80%; ST-86%)***

Q52.Given clear written info about what should/should not do post-discharge ***(NI-78%; ST – 84%)***

Q54.Family given all info needed to help care at home ***(NI-59%; ST-68%)***

Q61.Dr had right notes & documentation with them ***(NI-97%; ST-98%)***

Q69.Patient’s rating of care excellent / very good ***(NI-90%; ST-90%)***

Lower scores:

Q8.Given easy to understand written information about test ***(NI-88%; ST-83%)***

Q11.Patient told they could bring a friend when first told they had cancer ***(NI-76%; ST-71%)***

Q15.Patient given a choice of different types of treatment ***(NI-81%; ST-67%)***

Q18.Patient given written information about side effects ***(NI-64%; ST-61%)***

Q20.Patients definitely involved in decisions about care and treatment ***(NI-75%; ST-71%)***

Q21.Patient given the name of the CNS in charge of their care ***(NI-53%; ST-48%)***

Q25.Hospital staff gave info about support groups **(NI-67%; ST – 47%)**, Q26. impact cancer could have on work/education **(NI-60%; ST-55%),** Q27. info on getting financial help **(NI-41%; ST-33%)**

Q29.Taking part in research discussed with patient ***(NI-9%; ST-1%)***

Q36.Got understandable answers to important questions all/most of time ***(NI-74%; ST-72%)***

Q39.Patients family def had opportunity to talk to doctor ***(NI-58%; ST – 56%)***

Q49.Patient was able to discuss worries or fears with staff during visits ***(NI-69%; ST-67%)***

Q59.Hospital staff definitely gave patient enough emotional support ***(NI-75%; ST-71%)***

Q67.Patient offered written assessment and care plan ***(NI-11%; ST-9%)***

Q68.Patient did not feel that they were treated as a ‘set of cancer symptoms’ ***(NI-84%; ST-78%)***

NICaN

Northern Ireland Cancer Network

Title	Guidance for HSC staff on the provision of information to people affected by cancer	
Developed by	HSC Trust Cancer Information Leads – see Appendix 3	NICaN Service Improvement Lead for Patient Information – see Appendix 4
Version Control	Final version 1.0 issued May 2017	
Implementation	All Trusts	
Contact Person (s)	HSC Trust Cancer Information Leads	NICaN Office Tel: [redacted]
Review Date	June 2019	
Group Responsible	HSC Trust Cancer Information Leads	

Table of Contents

Section 1: General Information

1. Purpose

This Guidance has been developed to support the implementation of generic information packs across cancer health and social care (HSC) services.

2. Scope

This Guidance relates to all HSC staff. It is not limited to specialist cancer services and staff.

People receive health and social care services, directly related to their cancer investigations, diagnosis or otherwise, in various settings and from a wide range of HSC staff. Staff could be asked directly for cancer-related information or could identify a need for cancer-related information in their patient/client.

In this Guidance, 'information' means both clinical and non-clinical information. It is used to describe 'permanent' information for example, leaflets, booklets, web-based material, and audio-visual material.

This Guidance should be read and implemented in conjunction with the Trust policy on informed consent.

3. Aims/objectives

- To improve patient safety and patient/carer experience
- ? To help HSC Trusts achieve and evidence their delivery of patient information-related elements of patient safety alerts e.g. National Patient Safety Agency (NPSA)
- To help HSC Trusts achieve and evidence their delivery of the patient information standard in the Service Framework for Cancer Prevention, Treatment and Care
- To help HSC Trusts achieve and evidence their delivery of the patient information-related measures in Peer Review
- To help Service managers understand their responsibility in supporting the implementation of generic cancer information packs
- To help staff understand their responsibilities to provide information to people affected by cancer
- To help staff use generic information packs as a tool to do so.

4. Roles and responsibilities:

4a. HSC Trust leads for cancer patient information
Each HSC Trust has nominated a lead for cancer patient information.

The main role of the Cancer Information Lead is to provide advice to Trust managers on the implementation of network-agreed generic information packs in the Trust.

The role crosses several boundaries, notably between specialist and non-specialist cancer services, and between primary, secondary and tertiary care. The Cancer Information Lead is a resource and guide who communicates with those who have service responsibility to people affected by cancer.

Each Trust's Cancer Information Lead nomination is outlined in Appendix 2.

4b. NICaN role for Patient Information
The NICaN role for patient information is the coordination of the work of groups developing generic information packs and support to the work of Trust Cancer Information Leads.

4c. Staff providing specialist and non-specialist cancer care
The main roles of staff relevant to this Guidance are to provide appropriate information to patients in line with cancer information pathways and to record such provision as evidence for audit.

5. Context
Patients and carers cannot express preferences about care and make choices on involvement in decision making unless they have access to appropriate and timely information. Furthermore informed consent for investigations or treatment for example cannot be obtained if patients do not have the appropriate information.

The DHSSPS report on its Regional Audit of Consent in 2007 states that,

"Seeking consent is a process of providing information, discussion and decision making. Consent for a (procedure or) treatment must be based on the patient having the information they need to make a valid decision. They can be given the information to read, and have time to discuss it with their family, carers or healthcare professionals before giving consent to the treatment.

As patients and staff move between different Health & Social Care (HSC) organisations throughout Northern Ireland it is important that the information used across the HSC is standardised".

Staff must adhere to their Trust's policy on seeking informed consent and should consult NICaN to see if regional information for investigations or treatment has been agreed.

Many patients report that they receive inadequate information from health and social care professionals. The Northern Ireland Cancer Patient Experience Survey, 2015 showed that only 64%

of patients reported having received information on the type of cancer they had at diagnosis comparted to 72% in England. It also showed that only 65% of patients reported having received information on the type of operation they were having compared to 76% in England (i).

Information materials of high quality should be available in places where patients can access them readily, with patients being offered them at key stages in the patient pathway (ii).

While good face to face communication skills are vital, patients also need access to other sources of information. Studies have shown that some patients only remember one tenth of what they were told during a consultation. Face to face communication needs to be backed up with high quality, accurate information that the patient can return to in their own time (iii).

Surveys have consistently shown nine out of ten people diagnosed with cancer want to receive information about their disease, its diagnosis, treatment options, side effects, and clinical outcome. It can enable them to feel informed and subsequently empowered to make their own choices, rather than having these imposed on them.

Studies have revealed that patients who are well-informed, experience less anxiety, and are more likely to cope with their illness than those who are ill-informed or uninformed (iv, v, vi).

There is evidence that leaflets specific to a condition are read by patients (vii) and evidence that patients receiving written information are more satisfied with the information they are given (viii).

Cancer has become a chronic disease that people live with for a number of years. Many of these people have an on-going need for care, rehabilitation, information and support. This might include information about the long-term side-effects of treatment and other 'survivorship issues' that can help an individual regain a sense of normality in their lives e.g. sexuality, fertility, financial issues, employment, and sources of support such as counselling and support groups.

The Service Framework for Cancer Prevention, Treatment and Care (DHSSPS, 2010)(ix) includes standards that aim to improve the patient experience. It builds on several other regional policy documents that address patient information, including Cancer Services: Investing in the future (Campbell Report, 1996)(x) and The Cancer Control Programme (DHSSPS 2006) (xi).

This Framework is currently under review however Health and Social Care (HSC) Trusts are still required to actively monitor performance against framework standards. This includes a specific standard on the provision of information.

> All people affected by cancer should be offered good information to support them throughout their cancer journey. This information should be tailored to their needs both in content and the way in which it is given (DHSSPS, 2010).

In recent years, there has been development work undertaken by Cancer Services within Northern Ireland to regionally agree high quality information for people affected by cancer. This guidance aims to help HSC staff understand how they can improve patient experience through making use of such work.

Section 2: Generic Information Packs

6. What is a generic information pack?

A generic information pack is an agreed core set of information given at or close to diagnosis of cancer. The current pack contains:

1. The Cancer Guide (Macmillan)
2. Information for you booklet (NICAN)
3. Benefits advice service leaflet (Macmillan CAB)
4. Living with and beyond cancer, survivorship website flyer (NICAN)
5. Macmillan support and information centre/service information (Local Trust)

The information resources have been identified as offering clear, accurate and well written information likely to be relevant to everyone diagnosed with cancer. This core generic pack can be added to throughout the cancer journey, to reflect the information needs of individuals e.g. Cancer Specific or treatment information, advice on talking to children etc.

Staff with any queries about tumour-specific information should direct them to Trust specialist staff for those cancer types in the first instance. The Cancer Information Manager/ Health and Wellbeing Coordinator within each trust may also be able to help (see Appendix 3 for list of managers).

7. Where can staff find information packs?

Generic information packs are available from Cancer Information Managers / Health and Wellbeing Coordinators or Clinical Nurse Specialists within each trust.

(See Appendix 3 for list of cancer information managers/health and wellbeing coordinators)

Section 3: Providing information

8. The interaction between information provider and recipient

There are a number of steps involved in a basic interaction between an information provider and the patient/carer. This includes selecting or sourcing information in alternative formats as needed.

These steps are outlined in Appendix 1.

See section 9 below for reference to complex interactions.

9. Skills development in information provision

Communication is a core competency within the Knowledge and Skills Framework (KSF). Each staff member's training needs on information provision, particularly complex interactions, should be assessed and addressed at their KSF appraisal.

10. Recording information provision

It is important that the Trust is able to evidence that information has been offered.

All staff providing information should record that the generic information pack has been offered and should file this in the patient's/client's case note. This could be achieved by using the keyworker sticker for example. Cancer Information Leads or Information Mangers within each trust should be contacted to determine the documentation method agreed locally.

Section 4: Monitoring and review

11. Monitoring:

The Trust will regularly and robustly monitor their implementation of this Guidance.

12. Review:

This Guidance will be reviewed in June 2019

References

i. Northern Ireland Cancer Patient Experience Survey, 2015

ii. Improving Supportive and Palliative Care for Adults with Cancer, National Institute for Clinical Excellence, 2004

iii. NHS Cancer Plan, 2000

iv. The Quality of Life. Fallowfield L. London Human Horizons Series Souvenir Press 1990

v. Information needs of cancer patients in the west of Scotland Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, Fallowfield L. BMJ 1996 313 724-726

vi. How much truth and to whom? Respecting the autonomy of cancer patients when talking with their families-ethical theory and patients' view. Benson J, Britten N. BMJ 1996 313 729-731

vii. Edwards, M. (1990) "Satisfying Patients' Needs for Surgical Information". British Journal of Surgery vol. 77. pp 463-5

viii. Mayberry, J. (1988) "Information Booklets for Patients with Inflammatory Bowel Disease" International Disability Studies. Vol. 10 pp 179-80

ix. The Service Framework for Cancer Prevention, Treatment and Care, DHSSPS, 2010

x. Campbell Report, 1996

xi. The Cancer Control Programme, DHSSPS 2006

Appendices

Appendix 1 - The information interaction

(Based on Macmillan Cancer Support, Managing Cancer Information Materials 3rd edition)

Appendix 2 - Cancer Information Leads as at January 2017

Appendix 3 - HSC Information post holders as at January 2017

NICaN
Northern Ireland Cancer Network

Appendix 1: The information interaction

(Based on Macmillan Cancer Support, Managing Cancer Information Materials 3rd edition)

Beginning	1.Be approachable 2.Use open body language and eye contact 3.Listen to the person's concerns 4.Try not to interrupt, but be ready to speak when they are finished
Explore the content of the enquiry	1.Use open questions to tease out information needs 2.Consider topics included on the information pathway 3.The person's real Issue of concern may not always be their opening question 4.Establish any information they have previously received on the topic 5.Reflect back what they have said
Clarify and summarise	1.Clarify the question to ensure you have interpreted their needs correctly 2.Describe and agree together what they need 3.If there are a range of issues, consider prioritising some– do this with the person and check that they are happy to do so
Guide enquirer through range of options appropriate to them and their query These options may be you providing information yourself, or you signposting them somewhere else	1. Consider resources listed in the information pathway. -Published leaflets -Non-print resources, e.g. CD -Guided internet search -Listening support -Counselling -Signposting to specialist services 2. Consider the person's information capacity. Do they need information in another language, an 'alternative format' or at a higher/lower literacy level? Remember you may have a statutory duty here (you can ask your Equality Manager for more information about this) 3.Go through the benefits and limitations of the options 4.Do not overwhelm the person 5.Agree and provide the information materials 6. If you don't know the answer to their question, signpost the person to an appropriate source. Do not risk giving wrong information 7.Offer the person written details of any websites or organisations and any resources you do not have to hand
Identify how to end and clarify enquirer's choices	1. Consider putting a timeframe on the end of the enquiry, e.g. "During the next five minutes or so, we'll go through what we've just discussed, and then I'll leave you to look through the information". 2.Check you have answered their question(s) 3.Confirm options and close the enquiry, e.g. "I think I have given you all of the information you have asked for, but let me know if there is anything else you need" 4.Ensure the person knows how they can get more information 5.Record the information you offered and whether the person took it up

Appendix 2: Cancer Information Leads

Trust	Name	Designation
BHSCT	Margaret McManus	Information Manager, Macmillan Support and Information Centre
NHSCT	Pat McClelland	Clinical Services Manager
SEHSCT	Mary Jo Thompson	Clinical Manager for Cancer Services
SHSCT	Fiona Reddick	Head of Service
WHSCT	Elizabeth England	Lead Cancer Nurse

Appendix 3: HSC Information post holders

Trust	Name	Designation
BHSCT	Margaret McManus(BCH),	Information Manager
	Angela Small (RVH)	Information Manager
	Lindsey Anderson (BCH)	Information and Support Radiographer
SEHSCT	Karen Kelly	Health and Wellbeing Coordinator
NHSCT	Norma Adams	Information and Support Manager
WHSCT	Martha Magee	Information Manager
SHSCT	Sharon Clarke	Health and Wellbeing Coordinator

Appendix 4: NICaN Service Improvement Lead for Patient Information (Oct 14- ? 15)

Organisation	Name	Designation
NICaN	Edel Aughey	Service Improvement Lead for Information (Jan 15- Oct 15)

A Cancer Strategy for Northern Ireland 2021-2031

Department of
Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

Minister's Foreword

My vision is to ensure that everyone in Northern Ireland, wherever they live, has equitable and timely access to the most effective, evidence-based referral, diagnosis, treatment, support and person centred cancer care.

The number of cancer cases diagnosed in Northern Ireland has increased by 54% over the past 25 years and is projected to double by 2040. Cancer services were challenged before the pandemic and there continues to be significant capacity and workforce challenges across a range of areas. There is a need to move forward urgently to implement the recommendations outlined in this strategy to rebuild and transform our services in the short, medium and longer term. I have recently published a cancer recovery plan 'Building Back; Rebuilding better' which will focus on dealing with the current backlogs and immediate pressures, however there is a much bigger task to transform cancer services for the decade ahead. The Cancer Strategy affords us the opportunity to look forward 10 years to identify and implement what will really make a difference for people living with cancer.

Reducing health inequalities is integral to the implementation of this strategy. Social deprivation and health inequalities are a major contributory factor in the development of the majority of cancers. This means that there are potentially avoidable variations in outcomes, patient experience and survival across NI. Tackling inequalities goes far beyond the remit of the Department of Health and will require a concerted, co-ordinated focus across government departments. Improving cancer services for the people of Northern Ireland must be a major priority for the whole Executive in the years ahead.

At the heart of the many successes of cancer services is the hard work and dedication of our staff, in every grade and role, who are delivering care at higher levels than ever before. In addition to maintaining oncology services throughout the pandemic many staff from a wide range of professions have been involved in the development of this strategy

The successful delivery of this strategy will require collaboration. This will involve maintaining and building on the many successful developments which happened over the past year in response to the pandemic, and learning from what could have been done better. Collaboration between HSC organisations, across sectors and with patients, families and carers will be a key enabler to effecting meaningful change.

People living with cancer and staff providing treatment and care have been at the heart of the development of this strategy. As we move towards implementation we will ensure that this collaborative working continues.

This 10 year strategy is ambitious and is currently unfunded as the costs cannot be met from within the Department's financial allocation. Significant recurrent funding is therefore required, if we are to deliver these recommendations to improve diagnosis, treatment and care for all those who need it now and in the years ahead.

Personal information redacted by USI [redacted]

Co Chairs Foreword

Over time cancer impacts on the lives of all of us. While there have been many advances in the diagnosis, treatment and care of people over recent years we know that, with many more people surviving cancer combined with a rapidly ageing population, our current system is unsustainable. Transformational change is needed if we are to provide evidence-based, high quality care for all those who need it in the future.

We are pleased to present this strategy which has been developed by co-production and has brought together people with lived experience of cancer, cancer charities, healthcare professionals from across all Health and Social Care Trusts, the Public Health Agency (PHA), the Health and Social Care Board (HSCB), Primary Care, and policy makers.

The strategy has been developed using a quality improvement approach called quadruple aim which focuses on;

- Improving the health of our people
- Improving the quality and experience of care
- Supporting and empowering staff
- Ensuring sustainability of our services

We believe we can do better for people who have cancer and that we should have the ambition to have a world class service which is based on improving outcomes for everyone diagnosed with cancer. We are committed to ensuring that the voice of people who use and work in cancer services are threaded through the recommendations and that our services are efficient and effective and respond in a timely way to the needs of all who use it. There is much more we can do to support our workforce to deliver the best care. This requires change, working and thinking in different ways and seeing things from different perspectives. The strategy has drawn on the best available evidence and 67 recommendations have been developed which will move us closer to the world class service we all aspire to.

We strongly believe that all of us have responsibilities for our own health and there is much each of us can do to reduce our risk of developing cancer. There is undeniable evidence of the impact of smoking, poor diet and obesity on cancer rates. The use of sun beds and exposure to sunlight are the major contributing factors to the very significant increase in skin cancer which is the most common type of cancer in NI. Not everyone is aware of the risks associated with developing cancer or is in a position to change their lifestyle. Strenuous efforts must be made to support people to lead healthy lifestyles, participate in screening programmes and to come forward with health concerns, particularly those from less heard groups and in more deprived populations.

Finally we would like to thank the co-chairs and members of the seven subgroups who continued their work on this strategy during the pandemic and the small team at the Department of Health, in particular Heather Monteverde and Gay Ireland. Special thanks must go the many people living with cancer, who so generously shared their experiences and insights which have shaped the strategy.

Personal information redacted by USI

[redacted]

Contents

Why we need a cancer strategy

Cancer is a common condition. In Northern Ireland one in two people born since 1960 will be diagnosed with some form of cancer in their lifetime. Survival has improved for many cancers over recent years and now over half of people will live ten years or longer following diagnosis and treatment. This is largely due to earlier detection, improvements in treatments and changes in exposure to risk factors. The number of people diagnosed is however expected to continue to rise, largely due to our ageing population.

More than 26 people in NI are diagnosed with cancer every day, and almost 10,000 people are diagnosed with cancer annually. The number of cancer cases diagnosed increased by 54% over the past 25 years and is projected to double by 2040 (45% for males and 58% for females). Large increases are predicted for many cancers with poor survival including pancreatic and liver cancers and lung cancer in females with only stomach and cervical cancer numbers projected to decrease.

This brings considerable challenges to health services in meeting the ever growing demand for diagnostic services, screening programmes, treatment, follow-up surveillance, supportive and palliative care. Increased demands will be felt across the entire health and social care system as many people diagnosed with cancer are also living with multiple other long term conditions.

Despite efforts being made to reduce the growth in the incidence of preventable cancers in Northern Ireland (NI), there is evidence to suggest that the pace of change in reducing the risk factors underpinning these cancers is not sufficient. Largely preventable cancers predicted to increase include melanoma and lung cancer. Ultimately, this highlights the real need to maintain focus on tackling preventable cancers, and the urgency for accelerating change.

Although cancer survival in Northern Ireland has improved over the years it still lags behind other comparable countries both in Europe and internationally. The International Cancer Benchmarking Project (ICBP) Module 1 report showed cancer survival in Northern Ireland (NI) to be behind other parts of the UK, Australia, Canada, Denmark, Republic of Ireland, New Zealand and Norway. Northern Ireland consistently ranked between 8th and 10th out of the 12 jurisdictions involved.

Recently published ICBP Module 2[1] evidence shows that the UK as a whole had the lowest 1- and 5-year survival rates between 2010-2014 for 4 of the 7 cancer types reviewed.

Cancer has accounted for over 20% of all deaths in Northern Ireland every year since 1987. In 2018, the most recent year for which detailed statistics are available, cancer was the leading cause of death in Northern Ireland – accounting for 28% of all deaths. Unsurprisingly, death rates from cancer are usually higher among those aged 85+ than any other age group among both men and women. [2]

England, Scotland and Wales and the Republic of Ireland have in recent years produced new cancer strategies for their respective jurisdictions designed to further improve the outcomes for people affected by cancer. These strategies have all identified new approaches to service planning and delivery as well as prevention.

The New Decade, New Approach Agreement gave a commitment that the NI Executive would develop a new cancer strategy by the end of December 2020, however this deadline had to be pushed back due to the COVID-19 pandemic.

The Cancer Strategy affords us the opportunity to look forward 10 years to identify and implement what will really make a difference for cancer patients in Northern Ireland. This will require a comprehensive approach to prioritisation – making rapid change early where possible and laying the groundwork for truly revolutionary evidence-based interventions where we know this could transform outcomes.

Strategy Development

The development of the strategy, has been led by the Chief Nursing Officer, Professor Charlotte McArdle. It is based on co-production methodology which has brought together people with lived experience of cancer and healthcare professionals from across all Health and Social Care Trusts (HSC), Public Health Agency (PHA), Health and Social Care Board (HSCB), Primary Care, policy makers and cancer charities to develop the 10 year strategy. The strategy aims to place Northern Ireland at the forefront of world class cancer prevention, treatment and patient experience.

A Steering Group was established, supported by seven sub-groups: prevention; diagnosis and screening; treatment; care and support; living well; palliative and end of life care, children and young people.

The aims of the strategy are threefold;

- to reduce the number of people diagnosed with preventable cancers,
- to improve survival and
- to improve the experience of people diagnosed with cancer. This is illustrated in the Driver Diagram (Figure x) in the following page.

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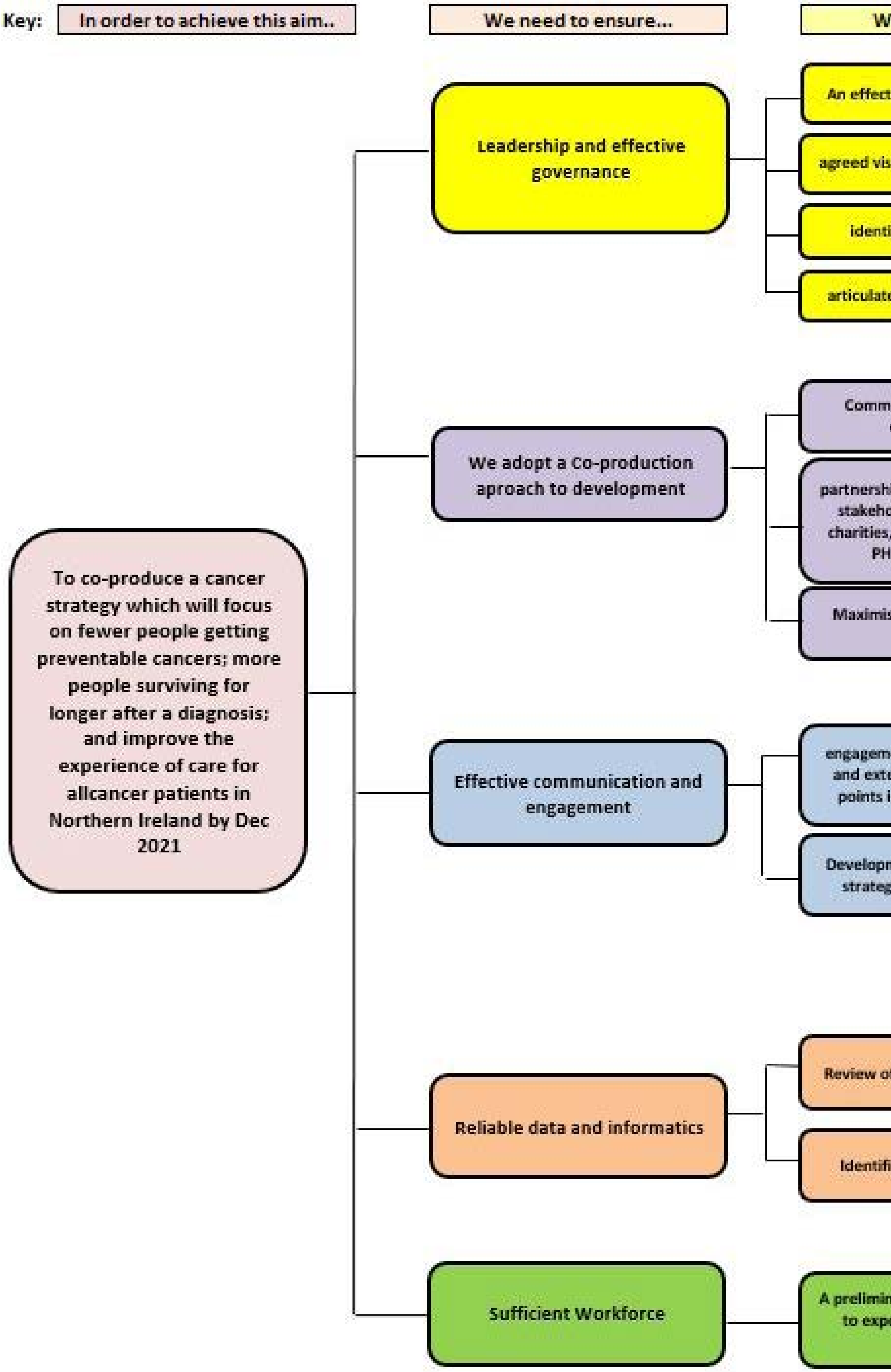
[1] Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study - The Lancet Oncology

[2] Statistics fact sheet (macmillan.org.uk)



Key: In order to achieve this aim.. | We need to ensure... | W

To co-produce a cancer strategy which will focus on fewer people getting preventable cancers; more people surviving for longer after a diagnosis; and improve the experience of care for allcancer patients in Northern Ireland by Dec 2021

Leadership and effective governance

- An effect
- agreed vis
- identi
- articulate

We adopt a Co-production aproach to development

- Comm
- partnersh stakeho charities, PH
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Effective communication and engagement

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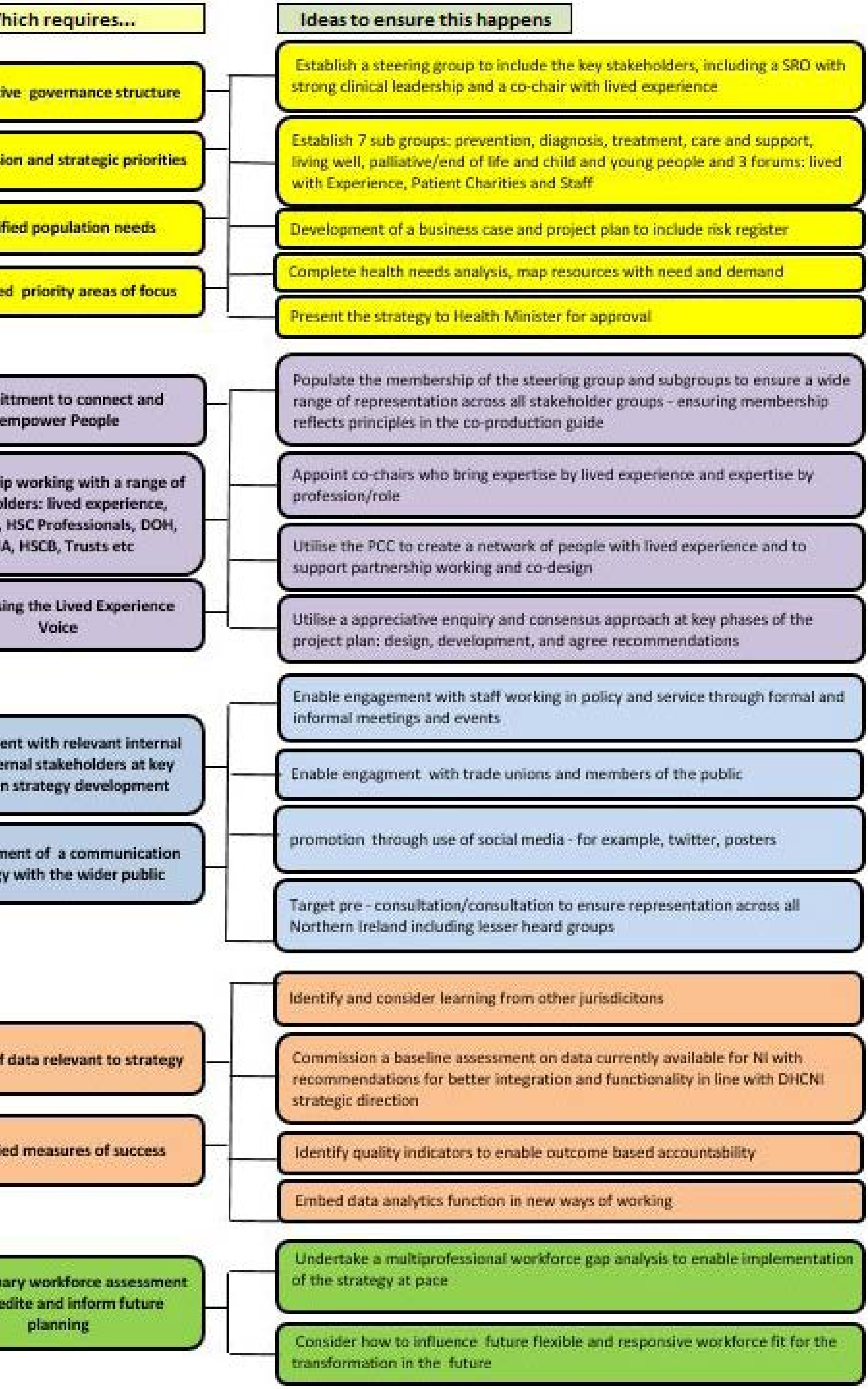


hich requires...

Ideas to ensure this happens

ive governance structure

ion and strategic priorities

fied population needs

ed priority areas of focus

Establish a steering group to include the key stakeholders, including a SRO with strong clinical leadership and a co-chair with lived experience

Establish 7 sub groups: prevention, diagnosis, treatment, care and support, living well, palliative/end of life and child and young people and 3 forums: lived with Experience, Patient Charities and Staff

Development of a business case and project plan to include risk register

Complete health needs analysis, map resources with need and demand

Present the strategy to Health Minister for approval

ittment to connect and empower People

ip working with a range of olders: lived experience, , HSC Professionals, DOH, A, HSCB, Trusts etc

sing the Lived Experience Voice

Populate the membership of the steering group and subgroups to ensure a wide range of representation across all stakeholder groups - ensuring membership reflects principles in the co-production guide

Appoint co-chairs who bring expertise by lived experience and expertise by profession/role

Utilise the PCC to create a network of people with lived experience and to support partnership working and co-design

Utilise a appreciative enquiry and consensus approach at key phases of the project plan: design, development, and agree recommendations

ent with relevant internal ernal stakeholders at key n strategy development

nent of a communication y with the wider public

Enable engagement with staff working in policy and service through formal and informal meetings and events

Enable engagment with trade unions and members of the public

promotion through use of social media - for example, twitter, posters

Target pre - consultation/consultation to ensure representation across all Northern Ireland including lesser heard groups

f data relevant to strategy

ed measures of success

Identify and consider learning from other jurisdicitons

Commission a baseline assessment on data currently available for NI with recommendations for better integration and functionality in line with DHCNI strategic direction

Identify quality indicators to enable outcome based accountability

Embed data analytics function in new ways of working

ary workforce assessment edite and inform future planning

Undertake a multiprofessional workforce gap analysis to enable implementation of the strategy at pace

Consider how to influence future flexible and responsive workforce fit for the transformation in the future

Cancer services were challenged before the pandemic with unacceptable waiting times and significant capacity and workforce challenges across a range of areas. COVID-19 has led to a worsening waiting times position, resulting in considerable anxiety for patients. A Cancer Recovery Plan, Building Back; Rebuilding Better has been developed to address the immediate issues in adult cancer services with the aim of getting us to a place where services are stronger than before, providing a solid foundation for the world class service envisaged in the strategy. Building Back; Rebuilding Better was published by the Minister for Health on 24th June 2021 and is fully aligned with the short term recommendations in the Cancer Strategy and will focus on a 3 year timescale.

Key Aims of Building Back; Rebuilding Better

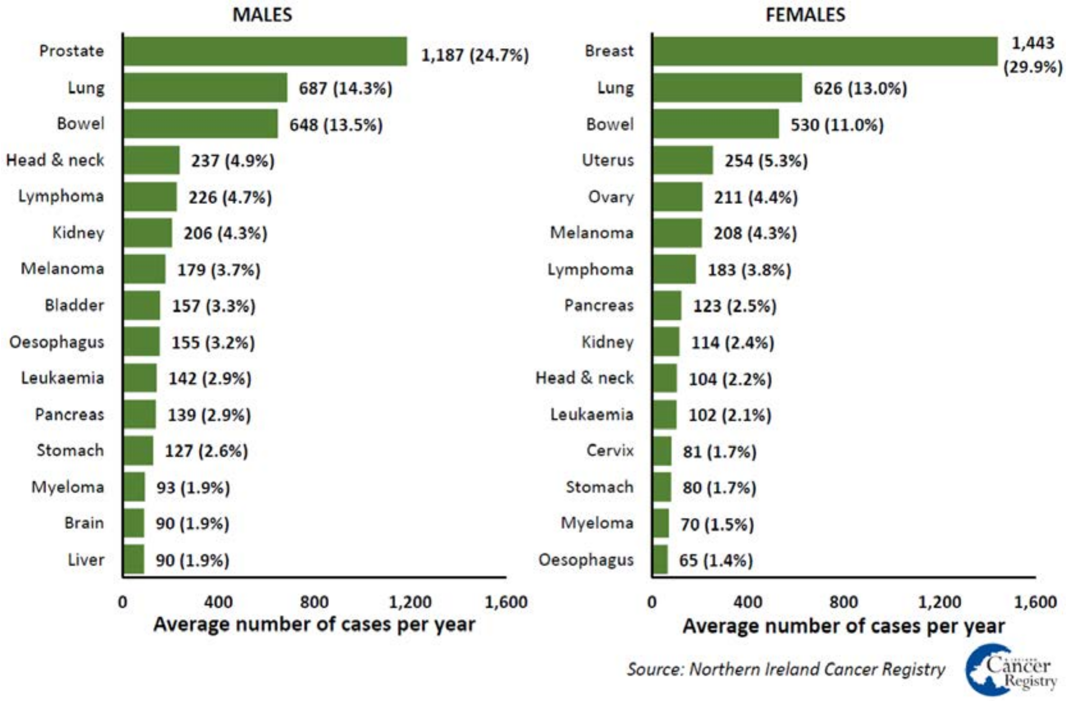
1. Adopt a regional approach for Northern Ireland, where appropriate, to ensure patients receive equitable access to diagnostics, care, treatment and support.
2. Create smoother and more efficient patient pathways from initial referral, through diagnosis and treatment encompassing the appropriate care and support during and after treatment with the aim of improving cancer waiting times and patient outcomes and patient experience.
3. Invest in cancer services and enable new, more sustainable, models of care that will be resilient to potential future surges of COVID-19 and to the projected increase in cases of cancer.
4. Learn from the impact of COVID-19 on cancer services and the wider HSC and adopt the successful innovations for the future.

Prior to the pandemic many core services were fragile and struggling to deliver in a timely manner, with escalating waiting lists. We fully recognise the immense pressures the HSC, including all those involved in cancer services, has been put under over the past year as a result of COVID-19. Creating a sustainable workforce to care for those with a cancer diagnosis is an integral part of this recovery plan and for the Cancer Strategy.

Cases

In 2018 cancer was diagnosed in 13452 people from NI, 3823 of these were Non Melanoma Skin Cancer (NMSC), a disease that is easily treated and causes few deaths but which use health service resources and also cause a lot of concern and trauma to patients. This strategy takes account of these conditions but focuses on the more serious, almost 10,000 per year, cancers which are a major cause of cancer deaths. The most common cancer in men (excluding NMSC) was prostate (1,187 cases per year, 25%), and in women was breast cancer (1,443 cases per year, 30%). Lung (1,313 cases per year) and colorectal cancers (1,178 cases per year) were common in both genders (see figure 1).

Figure 1: Average number of cancers diagnosed per year by sex and cancer type: All cancers (ex. NMSC), 2014-2018



Source: Northern Ireland Cancer Registry

The risk of developing cancer increases with age, with two thirds (67%) of cases in men, and over half (58%) in women diagnosed over age 65. This compares to 11% of cases (ex. NMSC) diagnosed in those under 50 years. Those living in socio-economically deprived areas had overall cancer levels 15% higher than the NI average, with especially higher rates for lung (70% higher per year), liver, head and neck, cervical and stomach cancers. Those living in higher socio-economic areas had levels 6% lower than the NI average overall, but higher levels of prostate cancer and melanoma.

Almost half (49%) of male and 42% of female cancer (ex. NMSC) patients had a comorbidity recorded up to one year prior to their diagnosis. Comorbidities (other medical conditions) are more common with age, can affect treatment options and affect survival, ranging at one year from 83.5% if no comorbidity, to 48.3% among those with at least four comorbidities recorded prior to diagnosis.

The number of cancer cases diagnosed has increased by 54% over the past 25 years and is projected to double by 2040 (45% for males and 58% for females). This projected rise to 6,788 male and 7,450 female cases (excluding NMSC) is due primarily to population ageing. Large increases are predicted for the cancers with poor survival, (pancreas, liver and especially in women lung cancers), with only stomach and cervical cancer numbers projected to decrease. Cancers which are largely preventable and predicted to increase include melanoma and lung cancer.

Every year in Northern Ireland, around 60 children under 16 years of age and 80 teenagers and young adults aged 16 -24 years are diagnosed with cancer. While there is variation year to year, these numbers have remained stable over the past 20 years.

The most common types of cancer diagnosed in the 0-15 age group are blood cancers and brain tumours.

Teenager and Young Adult refers to people aged 16 up to their 25th birthday. The numbers of cancers diagnosed are low and the most common cancers in this age group are lymphoma and leukaemia, testicular, ovarian, brain and colorectal cancers.

Deaths

Cancer was the largest cause of death in Northern Ireland during 2018, with 2,326 male (30%) and 2,122 female (26%) deaths per year. The most common causes of cancer death among men were lung (554, 24%), prostate (276, 12%) and bowel (232, 10%), and among women were lung (469, 22%), breast (314, 15%) and bowel (207, 10%).

Prevalence

The number of people living at the end of 2018 after a diagnosis of cancer (prevalence) is estimated at 97,807 (including 37,894 with NMSC) with 12% of these diagnosed in the previous year. The most common cancer types prevalent (ex. NMSC) in men were prostate (10,938) and bowel (4,713), with breast (16,462) and bowel (4,048) the most common among female survivors.

By 2033 the number of cancer survivors in the population is projected to increase by over 40%, with increases among men for all cancer types except bladder cancer, and among women for all cancer types except cervical cancer. In particular 10-year prevalence is expected to more than double among males for liver cancer, with significant increases for melanoma, kidney cancer and pancreatic cancer. Among females the number of survivors is expected to almost double for lung, pancreatic, liver and kidney cancer. Many patients will be cured, others will live for many years with cancer as a long term condition and for others the disease will progress.

Although many more people will be cured from their cancer not all continue to live well and for many the late effects and consequences of treatment will present lifelong problems. Cardiac problems due to some chemotherapy drugs, bowel problems post pelvic radiotherapy and osteoporosis due to hormonal therapies and prolonged use of steroids are some of the many ongoing problems survivors have to deal with.

Survival

Cancer survival is a key measure of the effectiveness of cancer services reflecting preventive initiatives such as vaccinations (HPV), screening, early detection, access to timely diagnostics and rapid and effective treatment by specialists. Stage at diagnosis is important. Currently 48% of pancreatic, 44% of lung and a fifth of cancers overall are diagnosed at a late stage when the treatment options are limited and survival is poor.

Five-year survival for patients diagnosed with cancer (ex. NMSC) in 2009-2013 was 54.3% for men and 58.5% for women. Five-year survival varies considerably by cancer site. In addition to poor survival for lung cancer (12%), survival is very low for other tobacco related cancers (e.g. pancreatic, stomach and oesophageal cancers). Changes in tobacco use could have the greatest impact on cancer incidence and survival. Cancer survival rates in NI, like the rest of the UK, fall short when compared internationally. While year on year improvements in survival have been documented, the COVID-19 pandemic is likely to reduce survival.

Improvements in treatment seen in the past five decades mean that around 80% of children 0-16 years diagnosed with cancer in the UK will survive their cancer for at least five years. This means that there is a growing population of children and young adults who have experienced cancer and treatment as children. Most will require ongoing follow up and support and some will require this for life.

Preventing Cancer

Background

The proportion of cancer incidence in NI attributable to modifiable lifestyle and environmental factors is estimated to be in the 30% to 40% range. A population approach, supported by policy and legislative measures, is required to encourage and support people to live healthier lives and reduce the prevalence of cancer risk factors such as tobacco and alcohol consumption, obesity, lack of physical activity and UV radiation exposure.

Like other European countries, the number of cancers in NI is increasing driven by an ageing population, changes in exposure to risk factors and improved survival as a result of earlier detection and better treatments. There is evidence to suggest that the pace of change in reducing the risk factors underpinning these cancers is not sufficient. Ultimately, this highlights the real need to maintain focus on tackling preventable cancers, and the urgency for accelerating change. Although death rates for cancer are falling, the total number of cancer deaths continue to rise due to an increase in the numbers of older people in the age range when the cancer typically occurs. This brings considerable challenges to health services in meeting the demand for care as well as the impact on the individuals affected. Treatment services alone cannot address the burden of cancer care. Prevention must be a key focus of this cancer strategy as it offers the most long-term, cost effective approach, however it will take time before the impact can be realised.

By implementing robust prevention strategies not only can we reduce the risk of cancer by up to 40% but also up to 75% of new cases of heart disease, stroke and type 2 diabetes, and significantly reduce the risk of dementia.

Health Inequalities

Reducing health inequalities must be a key focus of this strategy.

Inequalities in health arise because of inequalities in the conditions in which people are born, grow, live, work and age. These conditions influence the ability of individuals, families and communities to take control over their lives and choices, and whether they are enabled and supported to lead, long, healthy, active lives.

Health inequalities are associated with lower symptom awareness, later presentation and lower uptake of services including screening. Inequality across NI means there are potentially avoidable variations in outcomes, patient experience and survival. The majority of cancer types have much higher incidence in more deprived areas. There is strong evidence linking risk factors which are more common in areas of deprivation with higher incidence of cancer including smoking, obesity and poor diet. Addressing health inequalities cannot be achieved by the recommendations of this strategy alone and will require a concerted cross departmental approach.

We also need to embed health literacy. Low levels of health literacy are associated with poorer access to health services, poorer communication with health-care professionals, lower adherence to treatment and poorer self-management of health conditions. Better health literacy could therefore contribute to reducing health inequalities, strengthen health and improve health-care efficiency.

Major strides have been made in the development of relationships with many community and voluntary sector organisations as a result of the pandemic. We need to learn from the COVID-19 experience and continue engagement with lesser heard communities including BAME groups, people with learning disabilities, those for whom English is not their first language to ensure equality of access to cancer services across the pathway and to information and support services.

CANCER IS A PREVENTABLE DISEASE –

WHAT ARE THE MAIN KNOWN MODIFIABLE RISK FACTORS?

SMOKING

Tobacco is the single greatest modifiable risk factor for cancer prevention.

ENERGY IMBALANCE & DIET

Being active lowers the risk of colon, breast, prostate & endometrial cancers.

Excess weight raises the risk of gallbladder, liver & kidney cancers.

Heavy consumption of processed meats & high GI foods increase the risk of cancer. Low GI foods decrease it.

ALCOHOL USE

Heavy alcohol intake is a risk factor for oral cavity, pharynx, larynx, liver, bowel & breast cancers.

ENVIRONMENTAL POLLUTION

Air pollution increases the risk of lung cancer.

INFECTIONS

Papilloma viruses increase the risk of cancers of the cervix, penis, vagina, anus & oropharynx.

Hep B & Hep C increase the risk of liver cancer.

H pylori increases the risk of stomach cancer.

RADIATION & OCCUPATIONS

UV radiation is the main cause of skin cancer.

Overexposure to radon gas increases the risk of lung cancer.

Some occupations are linked with a higher risk of cancer, eg mining, construction, manufacture.

30-50% of all cancers are PREVENTABLE (World Health Organisation)

HSC	Public Health Agency Health Intelligence	Pocket Briefings August 2019	CANCER PREVENTION CANCERS CAUSED BY MODIFIABLE RISK FACTORS

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[3] Public Health Agency Health Intelligence, Pocket Briefings, August 2019, Cancer Prevention- Cancers caused by modifiable risk factors

ESTIMATION OF PREVENTABLE CANCER CASES IN NI

- Nearly 4 in 10 cancer cases in NI could be prevented.
- Not all modifiable risk factors have the same impact on cancer risk.
- It can take years for the cancers caused by modifiable risk factors to exhibit. The impact of current/new prevention measures may not be seen in the short-term.

About 3,500 cancer cases In N Ireland could have been prevented in 2015.

BJC (2018) 118:1130-1141; https://doi.org/10.1038/s41416-018-0029-6
Excluding non-melanoma skin cancer, age 16+, hormonal covers post-menopausal hormones & oral contraceptives.
Cancer cases for Individual risk factors do not sum to the total due to the method used to combine attributable fractions.

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[4] Public Health Agency Health Intelligence, Pocket Briefings, August 2019, Cancer Prevention- Cancers caused by modifiable risk factors

[5] Brown, K.F., Rumgay, H., Dunlop, C. et al. The fraction of cancer attributable to modifiable risk factors in England, Wales, Scotland, Northern Ireland, and the United Kingdom in 2015. Br J Cancer 118, 1130–1141 (2018). https://doi.org/10.1038/s41416-018-0029-

Cancer Risk factors

Smoking

The numbers of new cases of lung cancer are falling as a result of the decrease in smoking prevalence over several decades. Tobacco use, however, continues to be a significant factor in many cancers and cancer deaths across NI. There are over 1300 cancer deaths per year caused by smoking. It is the main cause of preventable death from cancer in NI. Smoking prevalence for 2020 is estimated to be nearly 30% for the most deprived communities compared to 10% for the least deprived.

The vast majority of lung cancers and over half of all head and neck cancers (oral cavity, oesophageal, laryngeal and pharyngeal) can be attributed to smoking. Smoking is also a contributory factor in many other cancers including kidney, bladder, liver, pancreas and cervix. Public awareness of the links between smoking and lung cancer are strong but there are low levels of awareness of the wide range of other preventable cancers caused by smoking.

Ambitions of achieving a ‘smoke free’ target of 5% average adult smoking prevalence have been set in some UK nations but, to date, not in Northern Ireland.

We will take account of the learning and progress made through the implementation of the Tobacco Control Strategy and, when required will support the need for the development of a new Tobacco Control Strategy. We will raise public awareness of the links between tobacco and cancer.

Smoking prevalence has fallen;

24% in **2010/11**

17% in **2019/20**

Obesity

Obesity is responsible for almost 600 cases of cancer each year in NI. It is a key contributory factor associated with cancer risk and mortality, including breast, uterus, liver, gall bladder, colorectal and kidney.

Obesity is the second biggest preventable cause of cancer in Northern Ireland .

65% of adults in NI are overweight or obese with around a quarter (27%) of children aged 2-5 either overweight (19%) or obese (8%). Trend analysis shows that rates of overweight or obesity have remained relatively static and there are no indications of a long-term decrease. There is a low level of understanding amongst the general public of the links between obesity and cancer.

There is no single action that will solve Northern Ireland's high obesity and overweight prevalence; a combination of actions is required to address the food environment and ensure that people are supported to live healthier lives.

The intended impact of this recommendation is for people in Northern Ireland to be supported to make healthier food choices, removing triggers to purchase unhealthy food, and ultimately reduce prevalence of overweight and obesity. This in turn will lead to fewer obesity related cancers.

We will take account of the learning and progress made through the implementation of the existing obesity strategy and when required will support the development of a new obesity strategy. We will raise public awareness of the links between obesity and cancer.

65% of adults in 2019/20 were either; **overweight (38%)** or **obese (27%)**
(up from 62% in 2018/19)

Diet and Physical Activity

The importance of lifestyle factors including physical activity, sedentary behaviour, and diet and their association with cancer has been recognised in recent years.

Breast feeding is the best start for baby and has a protective effect for the mother. Breastfeeding for 12 months reduces the risk of developing breast cancer in the future by over 4%.From Health Intelligence Data NI it is encouraging to note that the number of mothers attempting to breastfeed increased from 54.1% to 61.2% between 2012 and 2018 .There is however a deprivation gap with 46.8% of mothers living in the most deprived areas reporting as attempting to breastfeed compared to 74.9% from the least deprived areas. Efforts to increase breastfeeding must be supported across a range of programmes both in midwifery units and in the community.

High consumption of processed meats is a major contributory factor to bowel cancer but conversely a diet high in fruit and vegetables reduces the risk of many cancers including bowel, stomach and oesophagus.

Health Survey data 2017/18 shows that 17% of adults ate processed meats most days of the week. This is an increase from 2010/11. There is a gender differential with more men than women eating processed meats (23% v 12%) and a deprivation gap between the most and least deprived (24% v 12%).

In 2019/2020 56% of adults ate less than the recommended 5 portions of fruit and vegetables per day. This is down from 68% in 2010/11, with lower rates for men and for the most deprived.

Less than two-fifths (39%) of those living in the **most deprived areas** reported eating **5 or more** portions of fruit and vegetables compared with over half of those in the **least deprived areas** (56%)

Sedentary behaviour is associated a higher risk of many cancers but most notably colon, endometrial and breast cancers.

Health Survey NI data for 2016/17 shows that 45% of adults did not meet the recommended levels for physical activity. There is a gender differential with more women than men inactive (49% v 39%) and a deprivation gap between the most and least deprived (56% v 37%).

Ultraviolet Radiation

Skin cancer is the most common form of cancer in N Ireland. The figures for skin cancer in NI are stark with incidence rising year on year. Incidence has trebled since the mid-1980's. By 2040 a further 82-149% increase in malignant melanoma cases and a further 99-132% increase in non-melanoma skin cancer cases are predicted.

The main cause of skin cancer is over exposure to UV radiation from the sun or artificial tanning devices. Health survey results (2016/17) indicate that 4% of females and 1% of males currently use sunbeds, and 31% of females and 11% of males have used sunbeds in the past. This level of use is equivalent to or slightly higher than reported use in 2012/13. The number of sunbed premises in N Ireland has more than doubled in 10 years, to 19.6 sunbed businesses per 100,000 population in 2019.

The Health Survey 2016/17 reported that 33% of adults in NI never check for any changes in their skin which could indicate skin cancer and 21% reported having had sunburn in the previous year.

Sunbed use poses a specific risk for melanoma, independent of skin type and of solar exposure. Melanoma risk increases with younger age of first sunbed use and with greater lifetime use of sunbeds. Sunbed use has also been associated with increased risk of non-melanoma skin cancers and ocular melanoma (cancer of the eye), especially for those who started artificial tanning at a younger age.

Development of any new version of the skin cancer prevention strategy should give consideration to including a specific focus on occupational skin cancer. The World Health Organisation (WHO) is expected to introduce a new 1CD-11 code for skin cancer of occupational origin in 2022.

We will take account of the learning and progress made through the implementation of the skin cancer prevention strategy and when required will support the need for the development of a new strategy. We will raise public awareness of the links between skin cancer and cancer.

Alcohol

Drinking alcohol causes over 300 cases of cancer a year in the Northern Ireland. Alcohol causes a variety of types of cancer; mouth, upper throat (pharynx), larynx, oesophageal, breast, bowel, and liver. These encompass some of the most common cancer types and some of the most difficult to treat. The risk of some of these cancer types is increased even at low levels e.g. oesophageal, oral cancers and breast cancer while others are only increased at moderate to heavy consumption e.g. bowel and liver respectively. When combined with smoking the risks are increased significantly. Awareness amongst the public of the relationship between alcohol and cancer is low. There is an opportunity for this to be highlighted in the Substance Abuse Strategy as a significant risk factor.

Introducing a minimum unit price for alcohol products could be an effective way of reducing alcohol related cancers in Northern Ireland.

Three Quarters **(77%)** of adults aged 18 or over **drink alcohol**

We will take account of the learning and progress made through the implementation of the Substance Abuse strategy. We will raise public awareness of the links between substance use and cancer.

Infections

Several specific infections are implicated in the development of some cancers including H pylori, hepatitis B and C and the human papilloma virus (HPV). H pylori is associated with an increased risk of stomach cancer, however it is no longer common in the UK and for most people it is successfully treated with antibiotics and will not cause any further problems.

Chronic infections with hepatitis B and C are associated with an increased risk of developing liver cancer. Laboratory confirmed cases of both hepatitis B and C have increased significantly in the past decade. A hepatitis B immunisation programme for young children was introduced in 2017 which will subsequently reduce the risk of developing cancer in the future.

HPV is one of the most common sexually transmitted infections. Infections with HPV cause the vast majority of cervical cancers, most anal cancers and a significant proportion of oropharyngeal, vaginal, vulval and penile cancers. The HPV vaccination programme for both adolescent girls and more recently boys has been successful in reducing sexually transmitted infections which as a result will reduce the numbers of these cancers in the future. Men having sex with men, aged under 45 and who are attending Genitourinary clinics, can also avail of HPV vaccinations.

Going forward it is crucial that we maintain the high uptake rates for these vaccination programmes.

Comprehensive sex education and awareness programmes must be developed and implemented to reduce the number of sexually transmitted infections which could lead to the development of a preventable cancer.

Oral Health

Cancer of the oral cavity is on the increase, particularly among our younger population. This includes cancers of the lip, tongue and oropharynx. Checking for signs and symptoms of cancer is perhaps the most important role dentists carry out routinely. Attendance for routine examination and care is an ideal time for 'opportunistic' screening. In addition dentists also have a key role to play in supporting many people having treatment for cancer.

The established risk factors for developing mouth cancer are smoking (or using tobacco in other ways for example chewing tobacco), drinking alcohol and infection with the human papilloma virus (HPV). The risk of developing oral cancer for those who use tobacco and drink alcohol is greater than the sum of the separate risks. (i.e. the risk is multiplied not added). Oral cancers caused by HPV tend to affect younger individuals than those associated with alcohol and tobacco.

In 2018, 290 people in Northern Ireland were diagnosed with oral cancer, 188 males and 102 females. The median age at diagnosis was 63 and 62 years respectively, however, 30 (12%) of those diagnosed were aged under 50 years. Over the 25 year period from 1993 to 2018, the number of people diagnosed with oral cancer in Northern Ireland has increased by more than 80% with the relative increase being greater among women than men.

Unfortunately, the majority of oral cancers in Northern Ireland are diagnosed at stage IV which has a significant impact on survival. Five year survival rate for oral cancer in Northern Ireland is approximately 45% overall but is 66% for those diagnosed at stage I and only 25% for those diagnosed at stage IV. Like many other cancers, studies indicate there is a socio-economic gradient with oral cancer - the risk of developing oral cancer is significantly greater among those from deprived communities.

We will raise public awareness of the risk factors and early signs of mouth cancer and the importance of regular dental check-ups for those at increased risk.

Environmental Pollution

In 2013, the International Agency for Research on Cancer (IARC) confirmed that outdoor air pollution is a cause of cancer. In Northern Ireland, around 70 cases of cancer each year are caused by exposure to outdoor air pollution. The smallest particles known as PM10 and PM2.5 are linked to lung cancer.

Northern Ireland is currently the only nation within the UK that does not have a dedicated strategy to reduce air pollution. The Northern Ireland Department of Agriculture, Environment and Rural Affairs is currently consulting on a discussion paper in advance of developing such a strategy.[6]

Air pollution in Northern Ireland comes from a variety of sources. Domestic combustion (burning wood and open fires) is one of the biggest sources of PM10 (27%) and PM2.5 (44%) in the UK.[7] Road transport is responsible for 11% both of PM10 and PM2.5 emissions across the UK,[8] of which 27% to 43% is from vehicle exhaust emissions and the remaining is from tyre and brake pad wear.[9]

We will liaise with the Department of Agriculture, Environment and Rural Affairs and support the development and delivery of Northern Ireland's first Clean Air Strategy.

Radon

Radon is a radioactive gas which is naturally produced in the ground from uranium which is present in small quantities in soil and rocks. Most radiation exposure from radon arises from inhaling its short-lived solid radioactive decay products rather than radon itself. Radon is recognised by the International Agency for Research into Cancer (IARC) as a Class 1 carcinogen (IARC, 2012). In the UK, exposure to indoor radon is responsible for an estimated 1,100 lung cancer deaths each year with smokers and ex-smokers at the greatest individual risk. There is currently no strong evidence to link radon exposure to cancers other than lung cancer or to other diseases (AGIR, 2009). The Department of Agriculture, Environment and Rural Affairs and other agencies are contributing to a UK National Radon Action Plan.

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[6] Northern Ireland Department of Agriculture, Environment and Rural Affairs (2020) Clean Air Strategy for NI – Public Discussion Document (pdf)

[7] UK Department for Environment, Food and Rural Affairs (2020) National Statistics – Emissions of air pollutants in the UK, 1970 to 2018 – Particulate matter (PM10 and PM2.5) (website)

[8] UK Department for Environment, Food and Rural Affairs (2020) National Statistics – Emissions of air pollutants in the UK, 1970 to 2018 – Particulate matter (PM10 and PM2.5) (website)

[9] UK Air Quality Expert Group (2019) Non-Exhaust Emissions from Road Traffic (pdf)

Chemoprevention

Chemoprevention is the use of medication to prevent the development of cancer and is a relatively new approach to cancer prevention. Its use is primarily focused on those known to be at a significantly higher risk of developing cancer, for example those with a strong family history or diagnosis of a premalignant or predisposing condition. Guidelines produced by the National Institute for Health and Care Excellence (NICE) for familial breast cancer recommend that women at an increased risk of breast cancer should be offered medication to reduce their risk. There is also emerging evidence of the protective effect of aspirin in Lynch Syndrome. Going forward, as new evidence emerges, chemoprevention is likely to play a greater role in the prevention of more cancers.

We will develop a co-ordinated approach towards chemoprevention and implement NICE guidance within an agreed timeframe.

Targeted Surveillance

Significant research developments are happening at present which will bring changes to the organisation and delivery of services so that patients at higher risk of a condition can be “targeted” for additional surveillance so that an early diagnosis of cancer can be made for these conditions.

Many precancerous lesions, if detected, can be adequately treated preventing progression to cancer. Progression from precancerous disease to cancer varies by site and there has been limited research following patients with precancerous conditions on a population basis.

In Northern Ireland research teams at Queen’s University Belfast have established the following precancerous databases:

- Barrett’s Oesophagus Register – The Northern Ireland Barrett’s oesophagus Register is one of the largest population-based registers of Barrett’s oesophagus worldwide.
- Colorectal Polyp Register.
- Endometrial Hyperplasia Register
- Monoclonal Gammopathy of Undetermined Significance (MGUS) Register

These databases are enabling researchers to identify clinical and molecular characteristics that predict progression to cancer that can facilitate service planning and healthcare provision. Expansion of the precancerous databases would enable Northern Ireland to lead the way in population based research on precancerous conditions.

We will make sure that Trusts have surveillance systems in place for conditions where there is clear evidence regarding the pre malignant potential of a particular condition to ensure people are not lost to follow up.

Secondary Prevention

There is a long-established evidence base showing that certain behaviours are linked to the development of cancer (smoking, being overweight/obese, drinking at harmful levels, exposure to UV without protection). People who have developed cancers arising from these factors may worry about the cancers returning, and could be at an increased risk of recurrence without behavioural changes. Multiple studies have demonstrated strong evidence for the benefits of physical activity in reducing the risks of both cancer recurrence and death from cancer for a variety of tumour types. We know from feedback from patients and health professionals that people who have been diagnosed with cancer would like more information, tailored to their individual needs on how to make lifestyle changes.

HSC providers should ensure that all people treated for cancer are given advice, tailored to their individual circumstances and risk level, on how to improve their lifestyle. Advice should include healthy eating, weight control, physical activity, smoking cessation and alcohol consumption, to help prevent secondary cancers and reduce the risk of recurrence. This advice should be recorded in their medical notes. All people treated for cancer should be signposted to local services in their community where they can be supported in making their lifestyle changes.

We will ensure that all people diagnosed with cancer have appropriate and targeted information and support to live well and reduce the risk of long term consequences and developing second cancers.

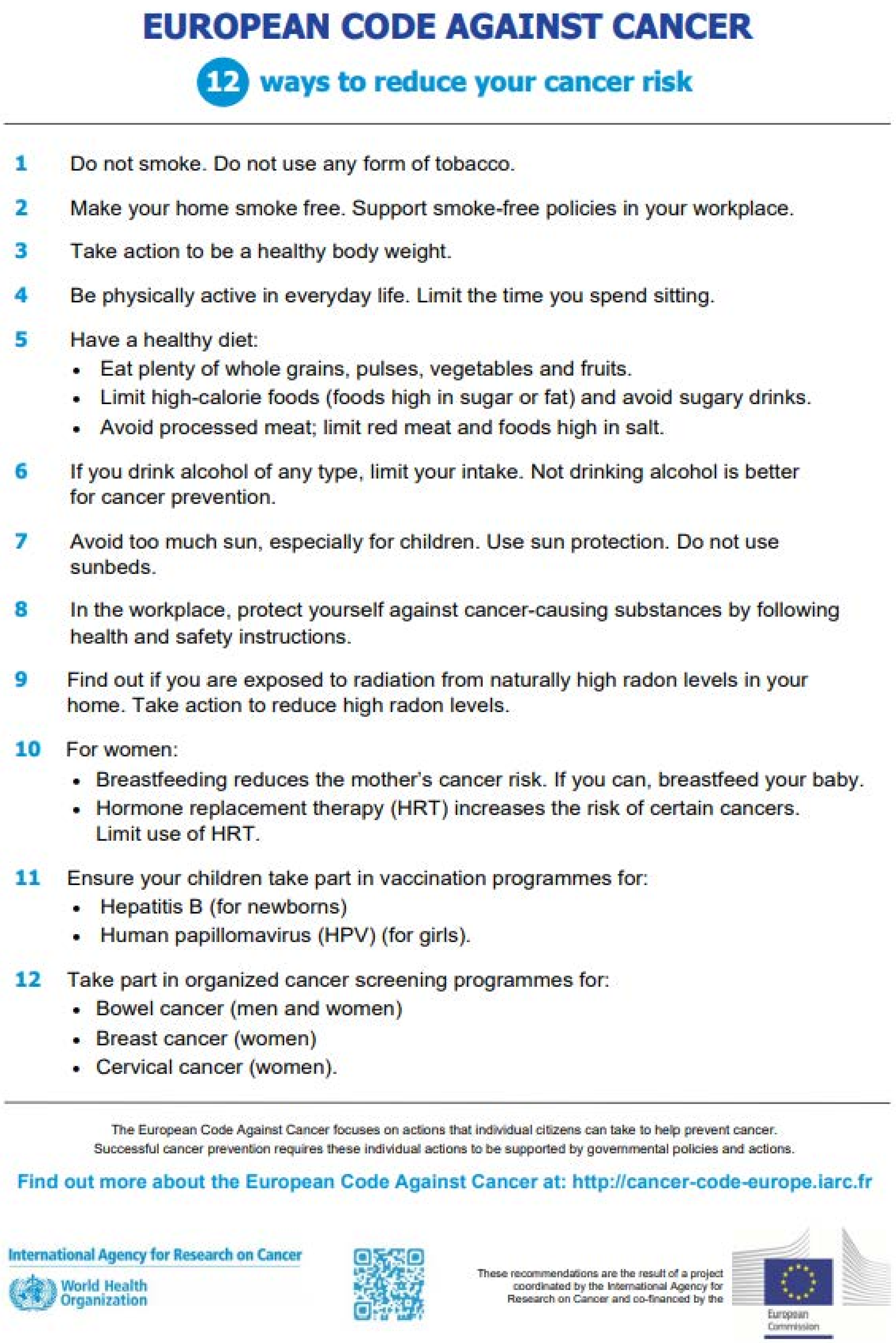
From the evidence it is clear that reducing the number of preventable cancers in NI goes far beyond the remit of the Department of Health and will require a concerted focus across government departments. Social deprivation and health inequalities are a major contributory factor in the development of the majority of cancers. More evidence on carcinogenic chemicals and substances will undoubtedly become available over the coming years. In addition to health measures, legislation will be required and funding made available if the change needed is to be realised.

Making Life Better

Making Life Better (MLB) is the overarching strategic framework for public health through which the Executive committed to creating the conditions for individuals, families and communities to take greater control over their lives, and be enabled and supported to lead healthy lives.

The All Department's Officials Group (ADOG) is a key part of the structures for co-ordinating implementation of MLB. Its key function is to bring together senior officials from all NI Government Departments and to inform and support the Executive's Ministerial Committee for Public Health in carrying out their role of providing strategic leadership and cross-government coherence effectively. ADOG could therefore be used as the mechanism to engage with other Government Department and Agencies in addressing the wider social determinant of cancer, and ensuring the Government policy aligns to prevent cancers developing in the first place.

Alternatively consideration could also be given to the establishment of a sub group of the NI Civil Service board, chaired by the permanent secretary of the Department of Health.



EUROPEAN CODE AGAINST CANCER

12 ways to reduce your cancer risk

1. Do not smoke. Do not use any form of tobacco.
2. Make your home smoke free. Support smoke-free policies in your workplace.
3. Take action to be a healthy body weight.
4. Be physically active in everyday life. Limit the time you spend sitting.
5. Have a healthy diet:
   - Eat plenty of whole grains, pulses, vegetables and fruits.
   - Limit high-calorie foods (foods high in sugar or fat) and avoid sugary drinks.
   - Avoid processed meat; limit red meat and foods high in salt.
6. If you drink alcohol of any type, limit your intake. Not drinking alcohol is better for cancer prevention.
7. Avoid too much sun, especially for children. Use sun protection. Do not use sunbeds.
8. In the workplace, protect yourself against cancer-causing substances by following health and safety instructions.
9. Find out if you are exposed to radiation from naturally high radon levels in your home. Take action to reduce high radon levels.
10. For women:
    - Breastfeeding reduces the mother's cancer risk. If you can, breastfeed your baby.
    - Hormone replacement therapy (HRT) increases the risk of certain cancers. Limit use of HRT.
11. Ensure your children take part in vaccination programmes for:
    - Hepatitis B (for newborns)
    - Human papillomavirus (HPV) (for girls).
12. Take part in organized cancer screening programmes for:
    - Bowel cancer (men and women)
    - Breast cancer (women)
    - Cervical cancer (women).

The European Code Against Cancer focuses on actions that individual citizens can take to help prevent cancer. Successful cancer prevention requires these individual actions to be supported by governmental policies and actions.

Find out more about the European Code Against Cancer at: http://cancer-code-europe.iarc.fr

International Agency for Research on Cancer
World Health Organization

These recommendations are the result of a project coordinated by the International Agency for Research on Cancer and co-financed by the European Commission

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[10] European Code Against Cancer - International Agency for Research on Cancer (IARC). European Commission: 12 ways to reduce your cancer risk.

Diagnosing Cancer

Pathways to diagnosis

People can receive a cancer diagnosis in a variety of places such as screening centres, GP surgeries, hospital settings including outpatient departments, inpatient wards and emergency departments. Increasingly during the COVID-19 pandemic people received their diagnosis in their own homes by phone.

The first ever Pathways to a Cancer Diagnosis report for NI was published in January 2020. This was a research project between the Health Foundation, Queen's University Belfast (QUB) and Business Support Organisation (BSO) which looked at how and where patients with cancer are diagnosed. One of the key findings of this work was to highlight the significant proportion of people being diagnosed in the emergency department, the majority of whom are presenting with late stage disease. This includes 28% of blood and lymph cancers, 42% of digestive tract cancers, 27% of upper gastrointestinal tract, 25% of head, neck, brain and eye cancers and 35% of lung cancer. Other key findings were the significant survival differences dependent on the route to diagnosis, with 3 year survival highest for screen detected cancers at 97% compared to 3 year survival of 21% for those presenting as an emergency.

It is important that this work is repeated regularly in order to understand how improvements in the system and increased public awareness are impacting on how and where people are presenting, being diagnosed and the stage of disease at diagnosis.

Raising Awareness

There is little doubt that early diagnosis of cancer improves survival and reduces mortality. For certain cancers the difference is stark. Bowel cancer diagnosed at stage I or II, has a one-year survival of 90%, if diagnosed at stage IV survival is less than 10%.

Early diagnosis is a complex, multifaceted topic dependent on a range of factors including public awareness of symptoms, access to primary care, access to diagnostic services, referral guidelines and pathways. People who recognise abnormal or persistent symptoms and seek medical advice are much more likely to have earlier stage disease and have better outcomes.

Raising public awareness on the signs and symptoms of cancer has been proven to be successful elsewhere in the UK. England and Scotland run regular campaigns designed to raise awareness of the signs and symptoms of different types of cancer and to encourage patients to visit their GP if they experience symptoms or notice changes in their body.

England's 'Be Clear on Cancer' campaign was particularly successful in increasing the numbers of early stage operable lung cancers.

The Public Health Agency (PHA) developed a cancer awareness programme for Northern Ireland, Be Cancer Aware, in 2015. It has a dedicated website but, largely due to funding constraints, there have been no media campaigns run since 2016.

In addition to financial issues there has been concern that such campaigns will lead to increased visits to already overstretched GPs and an increase in referrals to already overstretched diagnostic services.

Awareness campaigns must be co-designed with General Practice and diagnostic colleagues as any promotional activity will drive increased presentations to general practice and will inevitably result in increased referrals to diagnostic services. This is more important than ever as we emerge from a global pandemic with an expected surge in the numbers of patients presenting with symptoms combined with very significant backlogs.

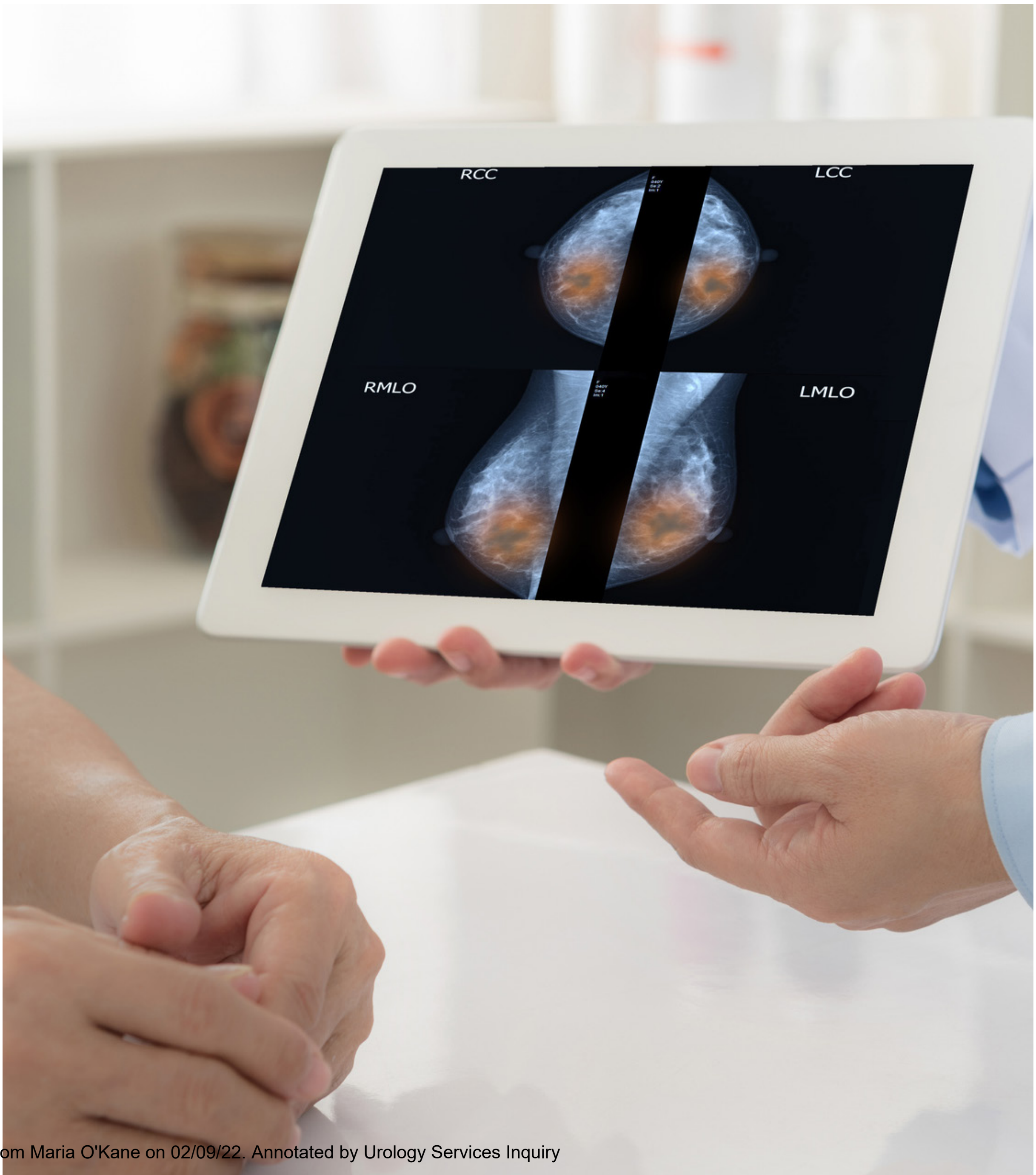
There is evidence that people from lower socio-economic groups often have lower recognition of signs and symptoms of cancer. This is likely to be the case for other seldom-heard and harder to reach groups, particularly those from ethnically diverse backgrounds and those with learning disabilities. Awareness raising campaigns must be co-produced and specifically tailored to be more easily understood. Consideration must also be given to translation of resources into other languages and to the provision of appropriate resources for those people with sensory impairment.

Many cancer charities have a focus on promoting awareness and have developed excellent resources in accessible formats. There is much to be gained in combining efforts and working in partnership with community and voluntary sector organisations who often are more successful in reaching minority populations where the need is greatest.

Data capture and evaluation are essential in order to measure impact and to learn and adapt campaigns for the future.

We will deliver regular, effective, targeted evidence-based ‘Be Cancer Aware’ campaigns.

We will develop measures to increase uptake of all cancer screening programmes, particularly in seldom heard communities.



Screening

Screening programmes are targeted at large groups of the population, the majority of whom will have no symptoms of cancer. Screening offers the opportunity to diagnose many more cancers at a much earlier stage leading to better outcomes for patients. Three programmes currently exist in NI: breast, bowel and cervical. There is however considerable variation in the uptake of all three programmes, with poorer uptake strongly associated with social deprivation.

Effective IT systems for the call/ recall of people for screening are essential for the efficient running of all screening services. The system for cervical screening is particularly vulnerable and an upgrade is urgently required.

The UK National Screening Committee (UK NSC) makes evidence-based recommendations to UK nations regarding population screening programmes. In the past, Northern Ireland has been slower than other nations in adopting some recommendations made by the UK NSC. This must be addressed as a matter of urgency.

Professor Sir Mike Richards recently published his review of adult screening programmes in England. While most of the recommendations were for England specifically, there are a number of things that should be adopted by devolved screening programmes, including Northern Ireland. This should include NI participation in any new UK screening advisory body, annual publication of routine performance data and quality assurance reports for screening programmes, and high priority given to an integrated approach to increasing uptake and coverage.

Going forward cancer screening programmes will continue to evolve and new programmes are likely to develop for people at higher risk. Currently pilot programmes using low dose CT scans to screen for lung cancer, targeting smokers and ex-smokers, are being established across the UK including an innovative pilot in the Southern Health and Social Care Trust.

It must be emphasised that screening is only effective at reducing morbidity and mortality if there is also timely access to diagnostic and treatment services

Bowel Screening

Bowel cancer is the third most prevalent cancer in Northern Ireland and the second leading cause of cancer death. The bowel screening programme is offered to people aged 60-74. The programme detects 8.3% of all bowel cancers. 67% of cancers detected through bowel screening are at an early stage. Removal of early polyps detected through screening can very often prevent cancer from returning or developing any further.

The qFIT test, is a new easier to use home test for bowel screening which only needs 1 sample instead of the current 3 samples. It has been rolled out in all other UK nations and was introduced in NI in January 2021. First confirmed results from Scotland after their introduction of qFIT showed increased uptake of bowel cancer screening from 55.4% to 63.9%.Importantly, this increased uptake was seen in men, areas of higher deprivation, and in difficult to reach audiences. This increase in uptake means more pre-cancerous changes and cancers are likely to be detected - and at an early stage.

An introductory sensitivity rate of 150ug/g has been agreed for NI. This is the same as Wales but considerably higher than England and particularly Scotland. The UK National Screening Committee has recommended that the starting age for bowel screening be reduced to 50. NHS England has agreed a four year phased approach to mobilisation of age extension across England commencing in April 22.

Going forward it is important to have plans in place for NI to reduce sensitivity levels and extend the age range in line with these recommendations.

The success of the bowel screening programme is highly dependent on access to timely endoscopy services. There are very significant challenges with the capacity of endoscopy services across all trusts. These must be addressed as a priority to cope with existing demands and to be able to accommodate reductions in sensitivity levels and widening of age bands in the future.

There are other emerging tests being rolled out at pace elsewhere in the UK, for example CT-capsule endoscopy. Early adoption of such tests may well be key in terms of developing a sustainable response to the ever increasing demand for endoscopy services.

Breast Screening

Breast screening is the most established cancer screening programme in NI. 29% of breast cancers are diagnosed via the screening programme. Mammography for all women aged 50-70 and registered with a GP is carried out every 3 years via mobile and static units. It is available for women aged over 70 on request. Trials have begun in England to explore broadening the age range from 47-73. This is likely to have a significant impact for NI if it is deemed to be successful. The ongoing success of breast screening services is reliant on responsive symptomatic breast cancer services in all Trust areas.

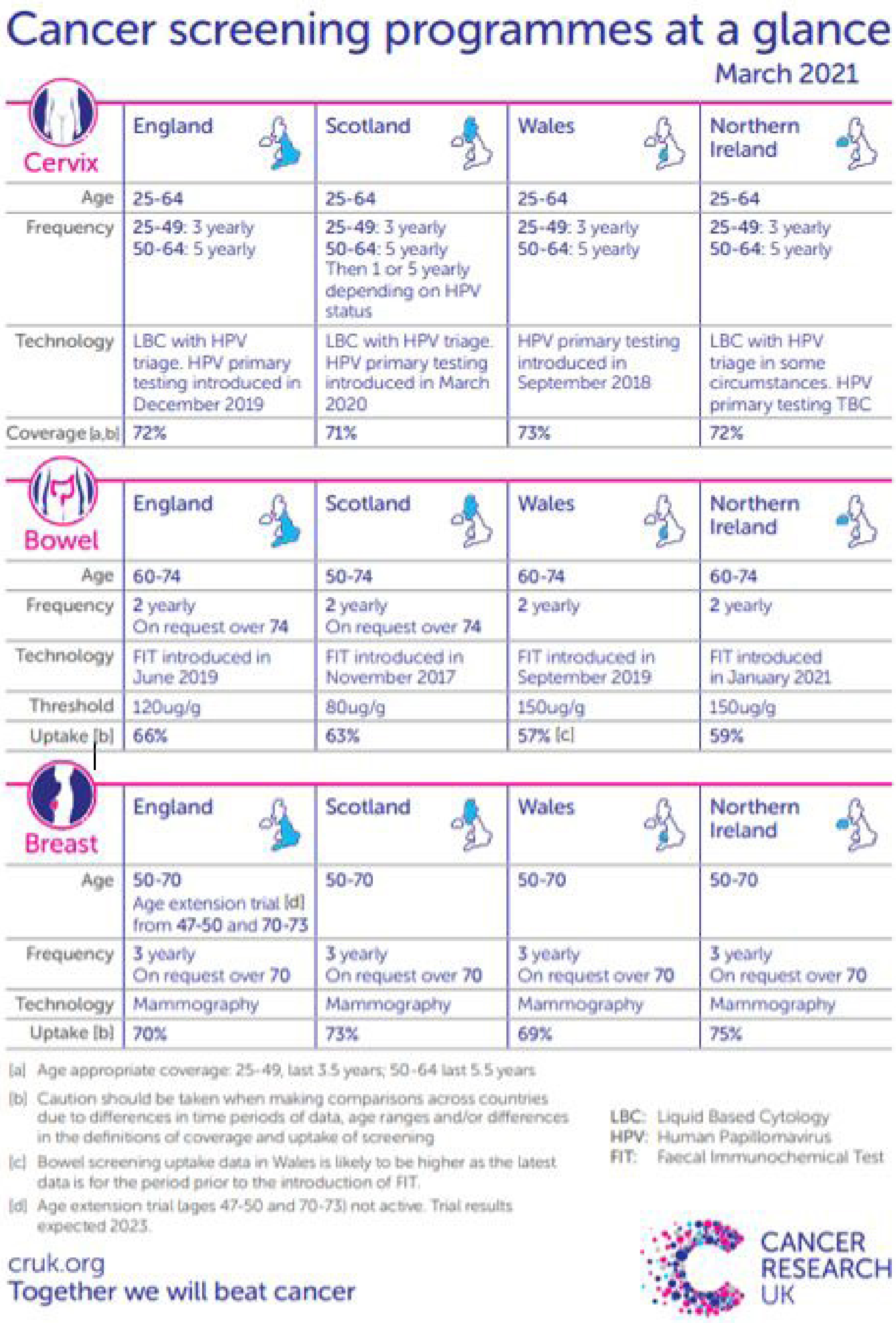
Cervical Screening

Cervical screening is offered to all women aged 25 - 49 every 3 years and every 5 years for those aged 50-64. 24% of cervical cancers are detected via the screening programme.

Samples are taken in a GP surgery and are analysed in a labratory using a process called cytology. If abnormal cells are detected, the sample is then tested for high risk high-risk Human PapillomaVirus (hr-HPV). hr-HPV is the most common cause of cervical cancer.

In 2016 the National Screening Committee recommended that cervical screening programmes switch to testing for hr-HPV as the primary test. Switching to hr-HPV as the primary test does not require anything different at the point of testing, but does require some reconfiguration of laboratory services. In the short term it is expected to increase referrals for colposcopy investigation. In the longer term HPV testing is a more accurate test than cytology and will ultimately be more cost-effective by enabling a longer interval between tests. This change has been agreed in principle for Northern Ireland with the aim of implementation in 2022/23.

Pilot studies on self-sampling are underway across the world and in some parts of the UK. This may well improve uptake and become more mainstream in the future.



Cancer screening programmes at a glance

March 2021

Cervix	England	Scotland	Wales	Northern Ireland
Age	25-64	25-64	25-64	25-64
Frequency	25-49: 3 yearly 50-64: 5 yearly	25-49: 3 yearly 50-64: 5 yearly Then 1 or 5 yearly depending on HPV status	25-49: 3 yearly 50-64: 5 yearly	25-49: 3 yearly 50-64: 5 yearly
Technology	LBC with HPV triage. HPV primary testing introduced in December 2019	LBC with HPV triage. HPV primary testing introduced in March 2020	HPV primary testing introduced in September 2018	LBC with HPV triage in some circumstances. HPV primary testing TBC
Coverage [a,b]	72%	71%	73%	72%

Bowel	England	Scotland	Wales	Northern Ireland
Age	60-74	50-74	60-74	60-74
Frequency	2 yearly On request over 74	2 yearly On request over 74	2 yearly	2 yearly
Technology	FIT introduced in June 2019	FIT introduced in November 2017	FIT introduced in September 2019	FIT introduced in January 2021
Threshold	120ug/g	80ug/g	150ug/g	150ug/g
Uptake [b]	66%	63%	57% [c]	59%

Breast	England	Scotland	Wales	Northern Ireland
Age	50-70 Age extension trial [d] from 47-50 and 70-73	50-70	50-70	50-70
Frequency	3 yearly On request over 70	3 yearly On request over 70	3 yearly On request over 70	3 yearly On request over 70
Technology	Mammography	Mammography	Mammography	Mammography
Uptake [b]	70%	73%	69%	75%

[a] Age appropriate coverage: 25-49, last 3.5 years; 50-64 last 5.5 years

[b] Caution should be taken when making comparisons across countries due to differences in time periods of data, age ranges and/or differences in the definitions of coverage and uptake of screening

[c] Bowel screening uptake data in Wales is likely to be higher as the latest data is for the period prior to the introduction of FIT.

[d] Age extension trial (ages 47-50 and 70-73) not active. Trial results expected 2023.

LBC: Liquid Based Cytology
HPV: Human Papillomavirus
FIT: Faecal Immunochemical Test

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Together we will beat cancer

CANCER RESEARCH UK

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[11] Screening for cancer | Cancer Research UK www.cancerresearchuk.org/about-cancer/screening

Lung Screening

There are over 1300 cases of lung cancer diagnosed in Northern Ireland annually, and over 1000 deaths. Five-year survival is very poor at only 12.1%. In NI, 35% of lung cancers are diagnosed via emergency presentation, with almost 70% of those diagnosed at late stage (III or IV). Patients diagnosed at later stages have fewer treatment options and this leads to the disease having very poor survival rates. Over half of all diagnoses are in the lowest two deprivation areas; incidence is 70% higher in the most socially-economically deprived areas than the NI average.[12]

The UK National Screening Committee (UKNSC) is currently considering the introduction of a targeted lung cancer screening programme which would identify and test those at higher risk of the disease based on an agreed set of criteria including age and smoking status. Those invited for screening would receive a low-dose, non-contrast CT scan, which is better at identifying lung cancer than plain film x-ray.

This type of programme aims to identify people at the early stage of lung cancer, perhaps even before the person has noticed any symptoms, in order to provide potential curative treatment and improve survival.

We will ensure that all UK National Screening Committee recommendations are implemented within an agreed timeframe.

We will review specialist screening IT systems and will allocate funding to upgrade/replace where needed.

In 2015, the National Institute for Health and Care Excellence (NICE) launched their newest ‘Suspected cancer: recognition and referral NG12’ guidance. These are guidelines for GPs when determining whether/how to refer someone with suspect cancer. England and Wales currently use these NG12 guidelines, and Scotland uses their own guidelines, though there are many similarities to NG12. Northern Ireland has not introduced this NICE-recommended cancer referral guidance NG12, and uses guidelines developed by the Northern Ireland Cancer Network, (NICaN) most recently updated in 2019.

NG12 guidance frames how suspected cancer is dealt with by primary care, by organising guidance by symptom and by cancer site and including information on primary care investigations and safety-netting. This design aims to make guidance easier to interpret and utilise. NG12 was developed using a risk threshold where if the risk of symptoms being caused by cancer is above a certain level then action (investigation or referral) is warranted. In 2015 NICE guidance changed which means that more people are referred for tests in an attempt to improve early diagnosis, and

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[12] https://www.qub.ac.uk/research-centres/nicr/FileStore/OfficialStats2018/Factsheets2018/Filetoupload,957488,en.pdf

are a reflection of how non-specific and challenging some cancer symptoms are to detect and manage.

There have been concerns that the introduction of NG12, in NI, would lead to increased referrals to diagnostic services, creating further pressure on already stretched services.

NG12 guidelines also include a significantly increased level of GP direct access to some diagnostic tests for certain cancer types. This includes plain film x-ray, computerized tomography (CT), Magnetic Resonance Imaging (MRI), non-obstetric ultrasound (NOUS) and endoscopy. GPs in NI have a very low level of direct access to diagnostic tests compared to elsewhere, and there is wide variation across NI and by test modality.

Direct access to tests can speed up access to testing, reduce the number of patient appointments and potentially improve timeliness of diagnosis.

Currently Northern Ireland has three measurements for cancer waiting times:

- At least 95% of patients should begin their first treatment for cancer within 62 days following an urgent GP referral for suspected cancer
- At least 98% of patients diagnosed with cancer should begin their first definitive treatment within 31 days of the decision to treat
- All urgent breast cancer referrals should be seen within 14 days

Northern Ireland also measures diagnostic waiting times (75% of patients should wait no longer than 9 weeks for a diagnostic test, with no patient waiting longer than 26 weeks). These diagnostic waiting time measures, while they do include cancer tests, can only provide broad information about diagnostics generally.

NI does not have a metric for measuring diagnostic time specifically for cancer, red flags or staging investigations. The 62-day cancer waiting time target is often used as a proxy for cancer diagnostic waiting time, but it actually measures the time from referral to first definitive treatment which is not exclusively diagnostic time, and only applies to those with a red flag referral via a GP. The 62 days include time for patients to have all diagnostic tests required to make their diagnosis of cancer and, while it doesn't track the diagnosis interval exclusively, can provide general information on the performance of cancer diagnostic services. This target was introduced in 2009 but has never been met.

The long-running poor performance against both 62-day cancer waiting time target and the diagnostic waiting time target would point to a problem with diagnostic services, but the current targets don't allow clear identification of where the key blockages are in the system, and so it has been difficult to identify clear changes that would improve patient diagnostic waiting times.

Both Wales and England have introduced new waiting time measurements which recognise the importance of tracking the diagnostic interval specifically (28 days in the case of both nations).

Wales' new Single Cancer Pathway[13] is unique in that it is the only cancer waiting time measurement which includes all cancer referrals, regardless of source or classification. It includes all suspected cancer referrals from GPs, screening referrals, referrals from emergency departments and other specialty consultants, and combines them all into one single waiting time target of 62 days from point of suspicion of cancer to first definitive treatment. Within this 62-day target, National Optimum Diagnostic Pathways have been outlined for all major cancers which aim to ensure a 28-day diagnosis standard for all patients within the 62-day Single Cancer Pathway. This 28-day diagnostic pathway is tracked separately within the Single Cancer Pathway.

We will work towards the implementation of NG12 or the most current NICE referral guidelines by 2024.

We will implement new diagnostic tests within an agreed timeframe after approval and recommendation.

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[13] http://www.walescanet.wales.nhs.uk/single-cancer-pathway

People with vague but worrying symptoms

Arguably some of the most difficult people to diagnose are those who present with vague but concerning symptoms, sometimes several in combination. Their symptoms are often non-specific and can leave the GP without clear guidance on which specialty to refer these patients to. There is currently no clear pathway for these people and they can often be ‘bounced’ between various consultants, diagnostic tests and general practice in an effort to make a diagnosis. Individuals presenting in this way experience longer times to diagnosis overall and poorer clinical outcomes compared to those with site-specific recognisable symptoms.

The concept of diagnostic hubs for patients with vague but worrying symptoms originated with the Accelerate Coordinate Evaluate (ACE) programme in England, facilitated by Cancer Research UK (CRUK) and Macmillan based on models developed in Denmark. Analysis of data from 5 pilot sites demonstrated a cancer diagnosis for 8% of all people referred. A significant proportion of these would be considered rare or hard-to-diagnose. In addition more than a third of patients were diagnosed with other conditions and referred to the appropriate service.

England, Wales and Scotland have all adopted versions of this specific pathway for patients with vague but worrying symptoms.

> **“The issue of being ‘ping ponged’ back and forth rang bells. I would welcome an all in one diagnostic centre. I have been through tests, and nothing found in that region, and then back to the GP to start again.”**

> **“Frequent delays in getting tests done, results back, waiting for information are an unnecessary waste of time and money”**

Diagnostic centres

Currently in NI, diagnostic tests are done linearly – people are referred for one test which is reported and reviewed before referral for additional tests. We do not currently have the ability to order tests as a cluster – even if the clinician knows in advance that a certain grouping of tests will be required. This results in patients having repeat visits to diagnostic facilities for testing which lengthens their diagnostic interval.

There has been no sustained improvement in cancer or diagnostic waiting times over several years, despite efforts by Trusts and others to increase capacity and access to tests. A new approach is required to improve the diagnostic pathways in NI. If change is not made, waiting times will continue to deteriorate, more people could be diagnosed late, impacting the effectiveness of treatment and even survival. Diagnostic tests are carried out in a wide range of facilities across Northern Ireland. In many sites the equipment for diagnostics is also used for acute and emergency presentations, causing potential scheduling issues. In some areas radiology and endoscopy are not available on the same site. Diagnostic imaging is performed in all acute hospitals across Northern Ireland, though numbers of scanners vary by location. Acute hospitals with only one CT scanner are vulnerable as that scanner must be used for any emergencies. This means diagnostic appointments can be cancelled or delayed.

Across the rest of the UK there is a focus on the reconfiguration and consolidation of diagnostic services into larger diagnostic centres or hubs.

The key to these pilots was the establishment of a single hub location where patients could attend for a range of tests on the same day. Quick movement through the diagnostic hub is maintained by active and ongoing coordination and clinical liaison by the Clinical Nurse Specialist (CNS) and patient navigators who track and support patients throughout the process.

In Wales and Scotland diagnostic hubs are currently focused on patients with 'vague but worrying symptoms.'

Based on results from the ACE pilots in England there is ongoing expansion of their diagnostic hubs to provide the same services for a wider range of patients including all those with red flag referrals. These larger diagnostic hubs will provide a single point of access to a diagnostic pathway for all patients with urgent symptoms that could indicate cancer, and a personalised, accurate and rapid diagnosis of their symptoms by integrating existing diagnostic provision and utilising networked clinical expertise.

NHS England has recently accepted recommendations made by former England National Cancer Director, Sir Mike Richards for the development of 'community diagnostic hubs' in England. His recommendations included the separation of emergency and elective diagnostics to reduce patient delays, consideration of 'alternative' sites for diagnostic hubs (including high streets or out of town retail parks), increased staff in imaging and endoscopy, and purchase of additional CT scanners.

For NI the introduction of centralised diagnostic hubs, initially for patients with vague but concerning symptoms, and then expanded to include all those with a red flag referral for cancer, has the potential to reduce the number of GP, hospital consultant and diagnostic appointments and significantly speed up diagnosis for people.

The development of these diagnostic hubs would mean easier and more flexible staffing and scheduling, opportunity to utilise newer techniques and technology, facilitation of clinical training and supervision and potential for improved waiting times with centralised lists and locations. Most importantly there is the opportunity to diagnose more people early and to improve both patient experience and outcomes.

We will ensure that people who have cancer are diagnosed as quickly as possible, with adequate staffing, infrastructure and equipment in place; this will include the development of diagnostic hubs.

To increase our regional cancer diagnostic capacity and meet increasing demand through innovation, transformation and modernisation we will develop effective working relationships with the Regional Medical Imaging Board, the Pathology Network and Endoscopy Network.

We will introduce a 28-day diagnosis standard which tracks the time for all people from first referral for suspected cancer to confirmation of a cancer diagnosis, and includes all diagnostic and staging investigations.

Triage tools

Triage tools are valuable in being able to stratify people who meet referral criteria.

In addition to being used as a screening tool qFIT offers rapid determination of whether people require a colonoscopy for possible bowel cancer.

There are in excess of 50 000 dermatology referrals annually across Northern Ireland. Approximately half of these are for the diagnosis and management of skin cancer. Currently only 5% of red flag referrals to dermatology convert to a diagnosis of skin cancer. Services have been under extreme pressure for several years as demand markedly outstrips capacity.

In recent years plans have been progressing to develop a Regional Skin Cancer Phototriage Service. This is currently being rolled out across NI and involves GPs submitting images to secondary care for e-triage. This reduces unnecessary appointments and streamlines pathways for the people referred and enables prompt feedback to the referrer.

Cytosponge is a new triage tool which has been developed and undergone testing in England and is now being been rolled out more widely based on successful implementation. These tests have the immediate potential to reduce the very lengthy waiting lists for endoscopy and dermatology. High waiting lists for upper GI endoscopy due to COVID mean that cytosponge has also been quickly adopted in Scotland and Wales. NI is currently planning the introduction of this tool which can identify Barrett's Oesophagus, often a precursor for oesophageal cancer.

Both these tests have the immediate potential to help reduce the very lengthy waiting lists for endoscopy in NI.

Several new diagnostic tests broadly under the heading of 'liquid biopsy' are in development or testing. Liquid biopsy refers to tests of body fluids including blood, saliva, faeces or urine. One major advantage of tests such as these is that they are much less invasive than a traditional biopsy in which a sample of a suspected tumour is removed for analysis in the lab, sometimes requiring a general anaesthetic. It is highly likely that one or more of these tests will be approved for use in the NHS soon.

Grail is a US/UK company whose Galleri multi-cancer blood test will be piloted by the NHS on 165,000 people in England. It claims to be able to diagnose 25 different cancers by checking for molecular changes in cell-free DNA. It is targeted at people aged 50-79 with no symptoms and is designed as a triage test and not a replacement for traditional diagnostic tests. This test is the furthest along the development pathway and is likely to be rolled out quickly by NHS England if the pilot is successful.

It is hoped that some of these tests will be gamechangers for the future in helping to diagnose cancer much earlier using less invasive procedures. Northern Ireland should monitor development of these tests to be ready to implement them whenever evidence shows their effectiveness.

Diagnosis of haematological malignancies – NG47 and NG35

Malignant Haematological diagnoses are based on the analysis of several different specimens (blood and bone marrow) by specialists in multiple laboratory disciplines. Together these results provide an accurate final diagnosis which informs personalized patient management.

NICE guidance NG47, updated in 2016, recommends an accredited Specialized Integrated Haematological Diagnostic Service (SIHMDS) to manage the diagnosis of all haematological malignancies. A SIHMDS for NI would be located on a single site, have a full range of specialist diagnostic staff and be the single point of sample analysis and diagnosis for any suspect haematological malignancy. SIMHDS exist in most other centres across the UK including Leeds, Newcastle, Sheffield and Cardiff as well as the larger centres in London, Manchester and Glasgow.

Without a SIHMIDS and adoption of NG47, NI is unable to get a World Health Organisation (WHO) 2016 classification diagnosis that would allow comparison with clinical/epidemiological/pathological data in other nations and ensure that patients are treated optimally for their disease.

NG35[14] (developed 2016 and updated 2018) recommends full-body MRI scan as the first line of diagnosis for patients with suspected myeloma. The most recent guidance on the diagnosis and management of multiple myeloma recommends CT PET and whole body MRI as the standard of care.

Neither NG47 nor NG35 are currently implemented in Northern Ireland.

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[14] https://www.nice.org.uk/guidance/ng35

Reducing late stage diagnosis

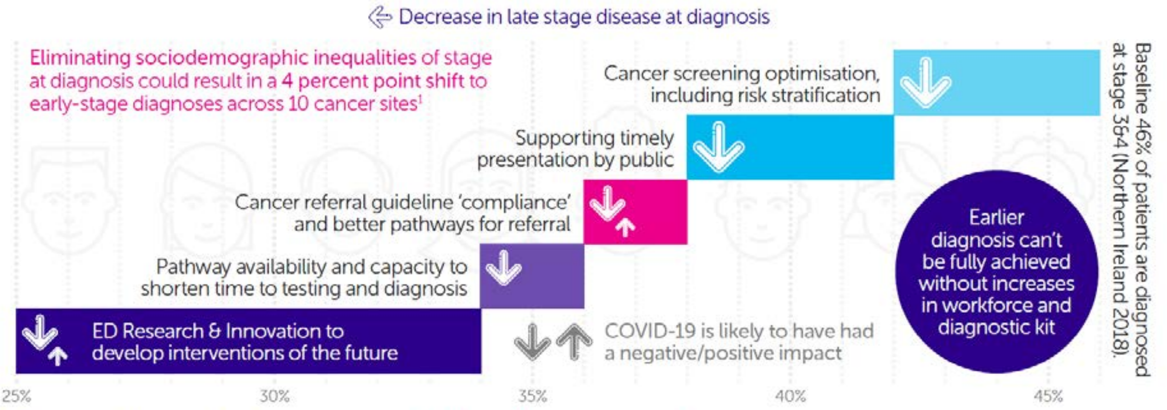
There is no one thing that will achieve a reduction in late-stage cancer diagnoses; we need to act together across a range of different interventions, and across the diagnostic pathway, in a coordinated and considered way.

This includes speedier and more equitable implementation of what we know, and research to identify the innovations and shifts of the future.

This waterfall diagram has been developed by CRUK and estimates the contribution that acting at different parts of the pathway could contribute to the all cancer stage shift. Originally, it was developed in anticipation of a significant national commitment to early diagnosis in England. In January 2019, the NHS England Long Term Plan outlined an ambition that, by 2028, 75% of cancer patients should be diagnosed at stage I or II. In this iteration of the diagram we reframe to focus on reduction in late stage cancer diagnoses for NI. 46% of all cancer cases were diagnosed at stage III & IV (out of those with a known stage at diagnosis) in Northern Ireland in 2018.

No one thing will address late stage cancer – action is needed on all fronts

CANCER RESEARCH UK
Together we will beat cancer



For more information please contact earlydiagnosis@cancer.org.uk

This is an **illustrative diagram**. Data have been used where available and expert input for the remaining areas. It will be updated as more evidence comes to the fore.
(1) Barclay, M. E., Abel, G. A., Greenberg, D. C., Rous, B. and Lyratzopoulos, G. (2021) *Socio-demographic variation in stage at diagnosis of breast, bladder, colon, endometrial, lung, melanoma, prostate, rectal, renal and ovarian cancer in England and its population impact.* British Journal of Cancer.

March 2021

The potential impact of COVID-19 has been reflected in the diagram. We cannot yet be certain of the actual impact of the pandemic but it is reasonable to assume that disruptions to cancer screening, altered patient and health professional behaviour, reduced availability of tests and protracted pathways will have a negative impact which may translate into poorer patient outcomes. The waterfall also highlights the need for significant progress and rapid translation of early detection and diagnosis research, as well as further service improvements, including investment in workforce, equipment and other infrastructure. It also notes the importance of addressing inequalities in stage at diagnosis.

Treating Cancer

Treatment for cancer varies by tumour type, stage of the disease, the person's general health status, age and increasingly genetic and molecular information. Patients may be offered surgery, radiotherapy, hormonal therapy, systemic anticancer treatment which includes chemotherapy, immunotherapy and biologic agents. For many it will be a combination of treatments.

Demographic changes in our population will result in an increased demand for high quality, effective cancer treatments which offer the best possible outcomes.

Certain groups of patients such as children and young adults, the elderly and those with rare cancers require specific attention.

Surgery

Surgery is the cornerstone of treatment in the management of non-haematological cancers and for many cancers it is curative as the sole treatment. In addition surgery may be undertaken as a preventative measure, for diagnostic purposes, reconstruction or for palliation.

Ideally surgery for cancer should be planned in advance but the reality is that many cancers still present as emergencies often requiring emergency interventions. It is therefore difficult to completely separate planned and emergency cancer surgery.

There is evidence that specialisation of services and the centralisation of complex surgery on fewer sites results in better patient outcomes for certain procedures. There is a broad consensus that surgical services should be configured to ensure that patients receive the highest standard of multidisciplinary care. [15]

There is however a balance to be achieved through maximising resources and scarce clinical skills by specialisation and centralisation with the provision for minimally invasive and day case surgery delivered more locally.

Advances in surgical techniques and new technologies have resulted in less invasive procedures which not only reduce length of stay in hospital but also contribute to improved patient recovery and experience. New techniques may continue to replace the role of traditional surgical resection.

Minimally invasive surgery will undoubtedly play an increasing role. This is partly due to improvements in visualisation, endoscopic and minimally invasive technology and the expanding role of robotics and nano-technology. Robotic surgery has been implemented in NI but its use is limited currently to prostate cancer and partial nephrectomy.

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[15] Brown,H., et al An evaluation of cancer surgery services in the UK.2014, Health Services Management Centre, University of Birmingham, and ICF-GHK consulting)

Failure to introduce new surgical technologies will significantly impact on both the ability to deliver training for the next generation of surgeons and on the recruitment of new consultant surgeons. Delays in the implementation of new technology may also result in inequitable access to the best standards of care in the future.

Big data, genomics and artificial intelligence will increasingly drive developments in surgery. Increasingly, precision or personalized medicine will be based on an individual patient's genetic, molecular and/or cellular characteristics and specific attributes of their tumour. These revolutionary changes will impact on, if and when traditional surgery plays a role in treatment. While the role of surgery may diminish in the primary treatment of some cancers, greater understanding of disease biology is likely to increase the surgery in selected patients with more advanced disease.

The role of prehabilitation, with optimisation of patients prior to treatment is now increasingly recognised. This combined with less invasive techniques may increase the proportion of elderly or frail patients suitable for radical treatment.

We will give consideration to the delivery of cancer surgical services alongside any future recommendations for the delivery of emergency and elective surgery.

We will develop a plan for the introduction and implementation of new surgical technology over the next 10 years.

Prehabilitation

Prehabilitation and Enhanced Recovery After Surgery programmes (ERAS) have been developed in a wide range of surgical specialities but are not universally implemented across NI.

Prehabilitation enables people with cancer to prepare for treatment through assessment, needs-based prescribing for healthy behaviour and follow-up.

The key components are exercise, nutritional management and psychological support. Prehabilitation and rehabilitation are core elements of the pathway of care from diagnosis, and focus on enablement and empowerment. Services are led and delivered by a range of Allied Health Professionals (AHPs).

Although prehabilitation guidelines, developed by the Royal College of Anaesthetists and the National Institute for Health Research Cancer and Nutrition Collaboration, in partnership with Macmillan Cancer Support,[16] were launched by the Department of Health in 2019 there is no planned, coordinated or commissioned prehabilitation service available in Northern Ireland. While some ad hoc pathways, pilot initiatives and models are developing for some tumour groups there is minimal provision available for rehabilitation despite strong international evidence about the benefits and cost effectiveness.

Research has shown that in the absence of prehabilitation and rehabilitation programmes, functional recovery is delayed (for older patients in particular) so that 6 months post operatively only 50% have achieved pre-operative functional levels. Prehabilitation and rehabilitation services enable a more proactive and cost-effective care approach, with the potential to reduce length of hospital stay, need for ICU / HDU admissions, medication and post-treatment complications, whilst enhancing recovery and quality of life overall.[17]

Enhanced Recovery After Surgery

Enhanced Recovery After Surgery (ERAS) has been described as a paradigm shift in perioperative care, resulting in substantial improvements in both clinical outcomes and cost savings. Originally programmes were developed for colorectal surgery but have now been shown to be advantageous for almost all major surgery.

Examples of evidence-based modern care include changes from overnight fasting to carbohydrate drinks 2 hours before surgery, minimally invasive approaches instead of large incisions, management of fluids to seek balance rather than large volumes of intravenous fluids, avoidance of, or early removal of drains and tubes, early mobilization, and serving of drinks and food the day of the operation. Enhanced Recovery After Surgery protocols have resulted in shorter length of hospital stay by 30% to 50% and similar reductions in complications, while readmissions and costs are reduced.[18]

ERAS programmes have been implemented in some areas in NI. There is a need to implement programmes regionally and at scale to ensure both enhanced patient outcomes and greater efficiencies.

We will develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit.

We will implement Enhanced Recovery After Surgery programmes on a regional basis for all appropriate major cancer surgery.

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[16] Macmillan (2019) Prehabilitation Guidance for People with cancer www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf

[17] NHS England NHS England. (2018) Quick Guide: the role of allied health professionals in supporting people to live well with and beyond cancer. Transforming health, care and wellbeing with allied health professionals. London. Allied Health Professions team. https://www.england.nhs.uk/wp-content/uploads/2018/10/quick-guide-ahp-cancer.pdf (Accessed 18 May 2019).

[18] Ljungqvist O, Scott M, Fearon KC. Enhanced Recovery After Surgery: A Review. JAMA Surg. 2017 Mar 1;152(3):292-298. doi: 10.1001/jamasurg.2016.4952. PMID: 28097305

Radiotherapy

Radiotherapy is a vital component of the different treatment options for cancer patients and has widespread uses in both curative treatments and for the treatment of symptoms in palliative patients. Different studies over a number of years have indicated that approximately 50% of people with cancer should receive radiotherapy as part of their primary treatment. There is also a recognised increase in the number of people who will require radiotherapy as part of a re-treatment regime. This is estimated to be approximately 25% of cancer patients suggesting that more than 60% of people with cancer will require radiotherapy at some point during their care by 2025.[19]

Radiotherapy in Northern Ireland (NI) is delivered at two centres: the Northern Ireland Cancer Centre (NICC) at the Belfast HSC Trust and the North West Cancer Centre (NWCC) at the Western HSC Trust, based at Altnagelvin. The NWCC additionally provides treatments to patients from parts of the Republic of Ireland under an all-Ireland agreement. The two Centres are independent with people undergoing their whole radiotherapy pathway in one or other of the Centres. Transfer of patients part way through the radiotherapy pathway is not easily achieved and is subject to increased risk.

Some people are currently referred for highly specialist treatments such as proton beam radiotherapy to centres within the UK or internationally. It is unlikely that the population of NI will ever be large enough to sustain these treatments and consideration should be given to exploring all Ireland solutions for these low volume, costly treatments. Access to these treatments is often on a cost per case basis. This can add to delays in the patient's pathway, and adds to the administrative burden for the service. Consideration should be given, where possible, to the development of service led agreements.

Radiotherapy treatments are delivered over differing timeframes ranging from a single dose for palliation to several weeks as part of a fractionated treatment course. Different cancer types, stages and sites will have different overall radiation dose and fractionation schedules associated with them. The capacity requirements on the treatment delivery units (linear accelerators) will be affected by a complex relationship between the number of patients, the number of fractions and the complexity of each treatment. There is a trend towards the use of less fractions per treatment, which reduces demand on the accelerators, but there are growing numbers of more complex treatments which increases demand on the accelerators. The capacity available on the radiotherapy treatment units needs to be able to accommodate changes to this complex balance between reducing number of fractions and increasing complexity of treatment.

Modern treatments can take many hours or days to plan and require highly trained staff and advanced software packages to fully exploit the potential of modern radiotherapy techniques. Each person will require some level of treatment planning. The increasing complexity of treatment impacts directly on the workload of the treatment planning staff.

Recent advances in radiotherapy have ensured more accurate delivery of treatment so reducing long term side effects and improving quality of life. As treatment becomes more advanced there will be a requirement for ongoing investment. Currently there is a clear need for a rolling replacement programme for LINACs combined with investment in both software and staff training. The use of imaging such as Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET) in both treatment planning and delivery must also be considered for the future.

Radiotherapy is a very data intensive treatment modality. These data include multiple pre-imaging data sets, both for diagnosis and treatment planning purposes, multiple treatment verification image data sets and potentially many follow-up image data sets.

To deliver a safe, quality assured and outcome driven radiotherapy service robust and accessible datasets are required. The other UK countries routinely analyse radiotherapy outcomes. Going forward it is important that we contribute to national and international audits in order to provide confidence in our ambition to be a world class provider of cancer services. Commitment to a continual cycle of data review and examination is fundamental in providing learning opportunities which help to reduce cancer relapse, toxicity and improve quality of life.

[19] How many new cancer patients in Europe will require radiotherapy by 2025? An ESTRO-HERO analysis - ScienceDirect pdf

Systemic Anticancer Treatment

Systemic anticancer treatment is a collective term which describes all drugs used to treat cancer and includes chemotherapy, immunotherapy and targeted therapies. It can be given intravenously or orally, in hospital or in other settings. As the incidence of cancer increases and survival continues to improve there is an associated increase in the demand for systemic anticancer therapy. SACT may be given on its own or in combination with other treatments and may be given with the aim of curing the cancer or of prolonging life.

SACT is currently delivered in both cancer centres and in the 3 cancer unit hospitals, Antrim, Craigavon and the Ulster. The cancer unit service depends on visiting oncologists to provide SACT clinics as well as outpatient clinics for new and review patients. SACT services for the more common cancers including lung, colorectal, breast and prostate cancer are provided in the 3 cancer unit hospitals and both cancer centres. SACT for regional specialist services are provided in the Northern Ireland Cancer Centre. This centralisation of SACT services for regional specialised services ensures that people are managed by specialist teams with the appropriate level of clinical expertise and caseload to maintain this. The majority of SACT treatments are given on an outpatient basis but more complex haematology and oncology treatments require admission to a specialist inpatient unit, in some cases for very prolonged periods of time.

The current service model for non- surgical oncology was established over 20 years ago. Since then there have been major developments in many areas of cancer care including imaging, pathology, genetics, surgery and treatment regimes.

For many years there have been ongoing issues with the sustainability and resilience of the service. The Oncology Services Transformation Programme (OST) reported in 2019 and was followed by the Oncology Haematology Stabilisation Plan in October 2020. OST identified a 6% projected annual growth requirement in SACT services until 2026. The project also determined that the way forward was to develop a sustainable medically led and supported service as opposed to the current consultant delivered model. It is essential that these plans are implemented if we are to ensure an efficient, effective and resilient service for the future. Failure to implement will mean that we do not make the most appropriate use of skills within the medical and non-medical workforces. Furthermore the continued use of a consultant led service will be at considerably greater cost than other models in the future.

The COVID-19 pandemic has resulted in some positive changes to the delivery of SACT services, these include the delivery of certain oral SACT treatments to peoples homes, the development of near to home phlebotomy services and the use of remote assessment, all of which have been well received. Learning from these developments must be used to shape services for the future. Oncology services have been maintained throughout the pandemic, but as referrals have started to recover and more people are offered SACT or radiotherapy as alternatives to surgery the pressure is increasing on an already fragile service.

The home delivery of oral SACT developed during the pandemic has reduced footfall in hospitals and provided convenient, safe care for patients. This could be extended to people receiving subcutaneous therapies (given by injection under the skin) who agree to and are competent to self administer their treatment. A significant number of haematology patients are under active surveillance (watch and wait). This includes people with early stage chronic lymphocytic leukaemia and other pre-malignant conditions. Many of these people are suitable for primary care or nurse led follow up.

Over recent years there has been a rapid expansion in the use of oral targeted therapies and immune checkpoint inhibitors in particular. In contrast to the use of intravenous cytotoxic chemotherapy requiring specialist nursing care, many of these new treatments are either oral medications or can be administered as relatively simple intravenous infusions. The use of chemotherapy is likely to continue. However as a proportion of the total number of SACT treatments delivered, its use is proportionately likely to fall over the next 10 years. This will afford the opportunity to explore the development of other models of delivery of this treatment in future, for example delivery of treatments in health and wellbeing centres, or in non-cancer unit hospitals with daycare facilities. Failure to provide SACT at home or close to home for those suitable is adding to the footfall in hospitals and is costly in both time and travel for people living with cancer.

The prescription of chemotherapy depends on results of blood tests taken within 72 hours of planned treatment. Bringing people to one stop clinics for blood tests followed by consultation prolongs the time in the outpatient clinic and has an adverse effect on patient flow through the clinics. The provision of phlebotomy services needs to be reviewed to provide a more efficient and convenient service for the future.

We will implement in full the recommendations of the Oncology Service Transformation Project and the Oncology Haematology stabilisation plan by 2026.

We will agree a person centred model of care, which is effective and efficient, and which is built on learning from COVID 19 with increasing use of telehealth and technology and with standard operating procedures by 2022.

We will put in place service level agreements to ensure timely treatment where services cannot be provided in Northern Ireland due to specialist nature of services, technology constraints and low numbers of patients.

We will develop near to home phlebotomy services by 2023.

Pharmacy

The lynchpin of SACT provision is pharmacy. The OST programme made specific references to modernising pharmacy services. This includes the need to expand and develop the clinical and aseptic pharmacy workforce. Failure to do so may risk the sustainability of current and future services and will restrict the ability to manage both new and complex treatments and the expansion of precision medicine. There is a need to plan for a more integrated and holistic pharmacy service. This includes pharmacists undertaking clinical verification, medicines optimisation, prescribing, monitoring of patients, patient education and community liaison. Pharmacist involvement in these areas has been shown to be effective in identifying treatment and adherence issues, improving the patient experience, improving patient and carer treatment knowledge, and making cost-effective medicines choices.

We will review our model of delivery for Systematic Anti-Cancer Treatment services including the delivery of near/ close to home SACT treatments to patients by 2024 in line with the cancer recovery plan.

Acute Oncology Services

In response to a report in 2008 from the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), which showed serious deficiencies in the care of acutely unwell cancer patients, acute oncology services have been developed across most of the UK. They exist in hospitals that have emergency departments or are specialist cancer hospitals. Their role is to address both the needs of people presenting as emergencies prior to diagnosis, as well as dealing with acute consequences of treatments provided to patients. In many cases people are presenting with life threatening issues such as neutropenic sepsis. Acute Oncology Services (AOS) were implemented across Northern Ireland in 2016. This represents a major step forward in the safe provision of non-surgical oncology services. To date they have demonstrated reduced hospital stay, avoidance of admission, have expedited investigative pathways and have also shown that we can avoid unnecessary investigations where appropriate. There are, however, recognised limitations to the service. Currently the service is provided across all trusts on a 5 day, 9-5 model. Cancer registry data demonstrates that two thirds of people who would benefit are presenting outside this time frame. A National Peer Review visit in 2018 highlighted a number of serious concerns including insufficient staffing. Without expansion, the current AO services are not sustainable given the increasing incidence of cancer and number of people receiving SACT.

Cancer of Unknown Primary

Following on from the NCEPOD Report guidance has been developed by NICE (2010) mandating the provision of a Cancer of Unknown Primary Service. Metastatic cancer of unknown primary (CUP) is a common and well recognised syndrome. It represents 3-5% of all malignancies and is the fourth most common cause of cancer related death. Overall survival at 12 months is around 16%, but only 6% for those who present as an emergency. People diagnosed with Cancer of Unknown Primary are known to have aggressive advanced disease, complex clinical needs, chemotherapy resistant biology and poor clinical outcomes.

A CUP service is a dedicated specialist team aiming for improved survival based outcomes and enhanced quality of life and patient experience. A regional CUP service for NI should be commissioned to ensure timely diagnosis, improved survival and better outcomes for patients.

Metastatic spinal cord compression (MSCC)

Metastatic spinal cord compression (MSCC) occurs when there is pathological vertebral body collapse or direct tumour growth causing compression of the spinal cord. Irreversible neurological damage ensues with resulting permanent paralysis.

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[20] 'Diagnosis and management of adults at risk of and with metastatic spinal cord compression' http://www.nice.org.uk/CG75

The true incidence of MSCC is unknown but post mortem evidence indicates that it is present in 5-10% of people with advanced cancer. In 2008 NICE[20] issued guidance on MSCC which recommends that patients with suspected, impending or confirmed metastatic spinal cord compression should have their care co-ordinated and streamlined to ensure appropriate and timely treatment, the benefits of which are earlier diagnosis and importantly improved outcomes for patients including prevention or delay in the onset of paralysis, timely rehabilitation and significantly reduced length of stay in hospital.

This service should be introduced in Northern Ireland. Without access to regional MSCC coordination service, the pathway for these people is fragmented resulting in potentially delayed diagnosis, poorer survival outcomes and sub optimal quality of care for those with limited life expectancy.

We will develop a robust and coordinated 24/7 metastatic spinal cord compression service with rapid access to gold standard imaging and treatment.

We will develop a fully integrated equitable 7 day acute oncology service across all Trusts.

Precision Medicine

In the last decade molecular pathology and diagnostics has successfully been implemented in health services, resulting in a dramatic change in the access to new targeted drugs for people with cancer. The expansion from the current molecular pathology structure to a more holistic genomic medicine approach is inevitable in the next few years, and it is supported UK-wide through several white papers and more recently through the transformational activities of the 100,000 genomes project led by NHS England. NI has recently become part of this project via recognition as a Genomic Medicine Centre.

Precision Medicine will become increasingly important in determining the most appropriate management plan for people with cancer. Improvements in technology mean that molecular profiling will become available at a relatively low cost and information will be available within clinically relevant timeframes. The long-term vision for Precision Cancer Medicine in NI is for all cancer patients to have access to high-quality, comprehensive and timely molecular characterisation of their tumour to inform therapeutic and clinical management. However NI lags behind other regions of the UK in developing this service.

The systematic application of genomic technologies has the potential to transform lives by:

- enabling a quicker diagnosis for patients with a rare disease
- matching people to the most effective medications and interventions, reducing the likelihood of an adverse drug reaction
- increasing the number of people surviving cancer each year because of more accurate and early diagnosis and more effective use of therapies

Going forward Molecular Tumour Boards should be established to provide advice to multidisciplinary teams (MDTs) in determining appropriate management options and prognosis. These services should be fully incorporated into all aspects of cancer pathways including diagnosis and screening services, therapeutic decisions, monitoring of response, relapse or recurrence. Embedding genomic testing in the routine patient management, including generic consent, would generate an efficient pathway for the implementation of precision cancer medicine.

It is important to ensure that people and their families are well informed of the benefits and consequences of genomic testing, particularly in regards to the risks of pertinent findings (i.e. genetics variants linked to cancer predisposition such as BRCA1/2, MHL1)

We will commit to delivering genetic and genomic testing in cancer pathways in line with NICE recommendations.

Haematological Cancers

Haematological cancers, otherwise known as blood cancer, is a broad term which refers to cancer which primarily affects the blood or blood producing organs. These cancers range in complexity and prognosis with some being low grade chronic conditions to aggressive life threatening conditions. Treatment also varies significantly from surveillance, outpatient chemotherapy and immunotherapy, to intensive and complex including stem cell transplantation.

Haematology services are provided within all trusts. Specialist level 3 care is provided at Belfast City Hospital (BCH). Data demonstrate an increase in new referrals to haematology services in Northern Ireland of 42% between 2013 and 2018. The associated day patient activity has increased by 22.9% over the same time period and inpatient activity has increased by 32%. This regional specialist unit generally runs at 120-130% capacity with outlying patients in the Northern Ireland Cancer Centre.

Currently the BCH site provides autologous haematopoietic stem cell transplantation (auto-HSCT) and sibling allogeneic transplantation (allo-HSCT). Patients undergoing Matched Unrelated Donor (MUD) transplant receive pre-transplant work-up and post-transplant follow-up in BCH but they must travel to another centre such as St James's Dublin or a London based transplant unit to undergo the procedure. The number of people undergoing auto-HSCT is rising year on year. In 2019 the transplant service was unable to meet the demands and as a result patients were transferred to King's College, London for transplantation. In order to meet the ever increasing demand for haematopoietic stem cell transplantation and avoid travel outside of N.I expansion of transplant capabilities at BCH is required.

NICE Guidance (NG 47) clearly defines the facilities required to provide level 3 care. This includes single occupancy rooms with individual bathrooms and clean air systems. Currently there are 6 hepa-filtered rooms available for patients undergoing haematopoietic stem cell transplant. In order to provide safe and timely treatment and reduce the incidence of nosocomial infections single occupancy rooms with ensuite facilities are required for patients in all haematology units.

NG47 also stipulates the need for onsite contiguous access to critical care along with respiratory and cardiology specialities to safely care for patients receiving higher intensity SACT and transplant.

Chimeric Antigen Receptor T cell Therapy (CAR-T) has emerged as a promising new treatment for some blood cancers in both children and adults. Earlier this year further approval in the UK has been given for the treatment of follicular and mantle cell lymphoma. It is expected that by the end of 2021 approval will be granted for multiple myeloma. The clinical indications for this intervention continue to expand and it is likely that it will rival and possibly replace autologous HSCT in some instances.

Some 30% of patients undergoing CAR-T require ICU admission during their inpatient stay. A multiprofessional approach is required for the safe management of these patients including timely input from critical care, renal, neurology, cardiology and allied health care professionals.

At present this treatment is only available at a small number of highly specialised centres in GB. A service is under development in Dublin and is due to be operational later in 2021. Relatively small numbers of adult patients are referred annually for CAR-T but numbers are expected to rise significantly in the coming years. CAR-T is also licensed for use in the treatment of children and young people.

Travel for people can be challenging given their underlying diagnosis and usually involves at least 2-3 visits to a GB site before CAR-T takes place. Following the procedure people spend 3-4 weeks in hospital before returning home.

New models of care for haematology need to be developed including ambulatory and Out of Hours (OOH) facilities. This would enable a reduction in the numbers of people being delayed from hospital at discharge, the timely management of neutropenic sepsis and other life threatening complications and people being inappropriately admitted to hospital.

Electronic prescribing of SACT for haematology patients was highlighted as a major concern during SACT peer review 2019. This limits data collation and comparison of patient outcomes. Standardised electronic prescribing systems have been shown to reduce the risks of SACT related incidents. An electronic prescribing system must be fully implemented for all haematology patients.

We will develop ambulatory care haematology units within each of the five Trusts and establish near to home treatment services for suitable patients.

We will ensure that all people including children and young adults are cared for in an environment appropriate to their needs.

We will ensure that future capital requirements of the level 3 haematology centre at Belfast Trust meets NICE NG 47 guidance.

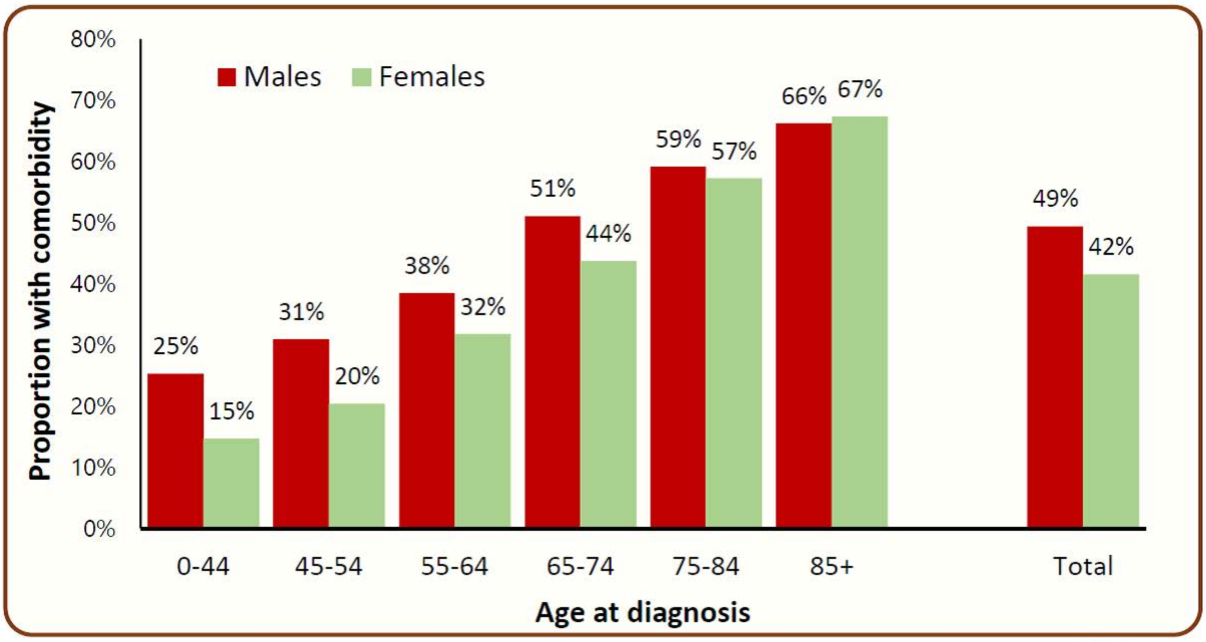
We will consider the development of CAR-T services for NI.

We will ensure that a safe and robust electronic prescribing system is used for all Systemic Anti Cancer Treatment regimes.

Older People with Cancer

Cancer is a disease related to ageing and increases in incidence in older adults. 2015 figures for UK show that 36% of people diagnosed with cancer were over 75 years of age. It is estimated that by 2035, this proportion will rise to 45% and will account for 65% of cancer deaths.[21] The Cancer Research UK report "Advancing Care, Advancing Years: Improving Cancer Treatment and Care For An Ageing Population" notes that age is a proxy measure for complexity as increasing age is associated with increased co-morbidities, cognitive issues and complex social care needs. This is illustrated using data from the NI Cancer Registry in the table below. These issues will require significant consideration in the development of cancer treatment and care plans. Like all other age groups the needs of people vary. Many older people are active and in good health while others are frail with multiple other long term conditions.

Age and Co-morbidity. NI Cancer Registry



Note: Includes cancers (ex. NMSC) diagnosed in 2016, with comorbidities up to one year before diagnosis.

Source: Northern Ireland Cancer Registry

Research by the National Cancer Intelligence Network in England (2015) [22] has highlighted the fact that older people are more likely to have their cancer diagnosed late and to present as an emergency.

There is evidence of age-related inequality in cancer outcomes with reduced cancer specific survival in older patients and also evidence of discrepancy between outcomes in older people in the UK compared to the best performing nations. [23] [24] [25] There is no reason to believe the position in Northern Ireland differs from that in any other UK

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[21] Smittenaar CR, et al. (2016) Cancer Incidence and Mortality Projections in the UK Until 2035. Brit J Cancer 115, 1147-1155.

nation. Macmillan Cancer Support raised this as an issue in their 2012 report 'Age Old Excuse: The Undertreatment of Older Patients with Cancer."

There is evidence that older people are less likely to receive different types of treatment which may be a result of individual choice, because they are too unwell for active treatment or because they choose quality over quantity of life. It may be due, at least in part, to them not being offered treatments due to assumptions made about fitness for treatment based on age. The assessment and care of older people with cancer is complex and has given rise to the specialty of Geriatric-oncology supported by its own international association, the International Society of Geriatric Oncology (SIOG).

Methods currently used routinely to assess fitness for treatment are, arguably, not fit for purpose and lead to poor assessment of the needs of older people with cancer. There is also a lack of evidence about the benefit of certain cancer treatments in the elderly who are not adequately represented in clinical trials.

Care of the Elderly Services should be better integrated with oncology and haematology. The identification of frailty is largely based on assessment of performance status, is a visual assessment and does not usually rely on more accurate validated frailty screening tools.

In addition to the risk of under- treatment in older people there is a risk of overtreatment without the use of appropriate geriatric assessment screening tools to identify those older people in need of a more thorough assessment of frailty. Getting the balance right to ensure appropriate treatment, either curative or with palliative intent is difficult, but nonetheless vital.

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[22] NCIN, Older people and cancer (version 3).2015, National Cancer Intelligence Network

[23] Coleman, M.P. et al, ICBP Module 1 Working Group (2011) Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. The Lancet, vol 377, 127–38.

[24] Berrino, F. et al (2007) 'Survival for eight major cancers and all cancers combined for European adults diagnosed 1995–99: results of the Eurocare-4 study'. The Lancet Oncology, 8, 773–83.

[25] Woods LM, et al.(2009). 'Large differences in patterns of breast cancer survival between Australia and England: a comparative study using cancer registry data'. International Journal of Cancer, 124, 2391–9.

Adults with Learning Disabilities/Chronic Mental Health problems

Outcomes for people with cancer who suffer chronic mental ill health are poorly understood. There are data to suggest that they are more likely to present with advanced stage cancer and, stage for stage, have worse cancer specific outcomes than the general population.[26] Similar evidence exists for people with learning difficulties. [27] Furthermore, people with mental ill health problems have higher rates of health behaviours linked with cancer mortality including cigarette smoking and excess alcohol use and may experience bias in the consideration of symptoms they complain of.

For those with learning difficulties and other communication issues including dementia it most often falls to carers, family or other health care professionals to notice changes that require investigation. In order to enable early diagnosis it is important to make these carers and others aware of the signs and symptoms of cancer.

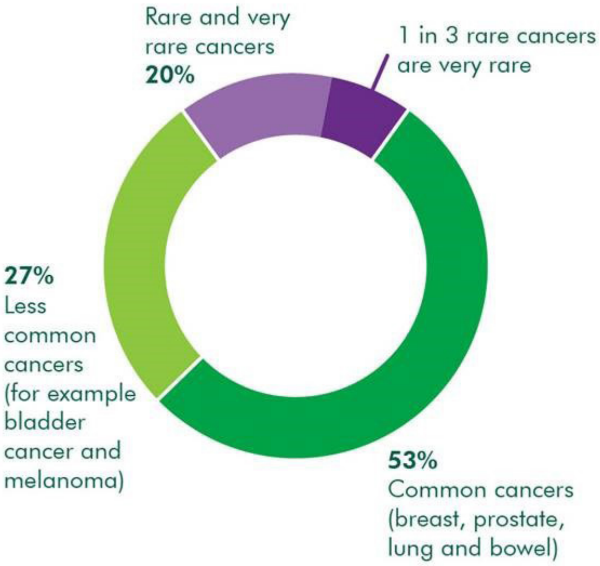
The delivery of cancer treatment for people with learning difficulty or mental ill health is potentially complicated with issues around their capacity to understand and consent to treatment. This may require formal assessment of capacity and careful decision making with the person, supported by their family. There must be better collaborative working between cancer services, learning disability and mental health services to improve outcomes for these groups of people.

[26] Cunningham et al. 2015, Irwin et al. 2014, Cancer survival in the context of mental illness: a national cohort study. General Hospital Psychiatry 37 (2015) 501–506

[27] Hafeez, Singhera and Huddart.. Exploration Of The Treatment Challenges In Men With Intellectual Difficulties AndTesticular Cancer As Seen In Down Syndrome: Single Centre Experience. BMC Medicine (2015) 13:152

Rare Cancers

Four main cancers; breast, bowel, lung and prostate make up 53% of all cancers. Less common cancers such as melanoma and bladder account for 27% with the remaining 20% accounting for rare and very rare cancers. A cancer may be rare because of where it is, if it affects a child, teenager or young adult or it may be a subtype of a more common cancer.



Rare Cancers - Proportions of common, less commmon, rare and very rare cancers. MacMillan Cancer Support[28]

By their nature rare cancers can be harder to diagnose. Treatment tends to be complex and services are usually centralised in highly specialised centres. People may have surgery, SACT or radiotherapy provided in specialist centres outside of NI. There is a need for comprehensive patient pathways for diagnosis, treatment and follow-up care with a particular emphasis on good multidisciplinary team working.

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[28] Rare Cancers, Macmillan Cancer Support, Website

Metastatic Cancer

Cancer which spreads to another part of the body from its initial site is called metastatic cancer. Treatments are available to either slow the progression of the disease or to improve quality of life by treating the symptoms. The treatment offered will depend on many factors including previous treatment, general health status and personal choice. In common with other stages treatment offered may include hormonal therapy, chemotherapy, immunotherapy, radiotherapy and surgery. Unfortunately for many, metastatic cancer will ultimately be terminal but a growing number of people, with the appropriate treatment and care, are living for many years. There is a need to develop regional MDTs for this cohort of people to ensure equitable and optimal care.

Undoubtedly work needs to be done to better understand the needs and experiences of less heard groups with the intention of improving services for the future.

We will ensure the development of appropriate pathways and services for older people with cancer, rarer cancers, teenage and young adults and people seldom heard.

Children and Young People

Childhood is a time of very rapid development and change. What happens in childhood has a life-long impact and affects life chances and outcomes.

Adolescence is a transitional phase of growth and development between childhood and adulthood. Many changes take place in adolescence. Prominent among these are physical changes including puberty and social and psychological changes and a strive for independence.

Spending long periods in hospital or at home feeling ill can seriously affect a child or adolescent's development and outcomes. Special care and resources are needed to support ongoing development and education during this time. The social and emotional needs of children, adolescents and their families must be taken account of and supported during cancer treatment.

The unique cohort of patients aged between 13-25 years old with a cancer diagnosis has complex and specialist needs associated with both their disease and general developmental age. Teenage and Young Adults (TYA) with cancer interact with many services including haematology, oncology, medical and surgical specialities, psychology, psychiatry, palliative care, social work, youth work and education. Their care also transcends professional, organisational and geographical boundaries.

The guideline for children's cancer services NICE CSG 7: Improving Cancer Services for Children and Young People with Cancer was published in 2005 and reviewed in 2015. This guideline recommends that care across the UK should be coordinated from designated centres.[29] Under the auspices of the Childrens' Cancer and

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[29] 'National Institute for Health and Clinical Excellence, Improving Outcomes in Children and Young People with Cancer -The Manual' pdf

Leukaemia Group (CCLG) care is delivered through 19 Principle Treatment Centres (PTCs) led by professional experts in childhood cancer shaping a future where all children survive and live happy, healthy and independent lives.

Children diagnosed with cancer up to the age of 16 will have their care coordinated by the PTC at the Royal Belfast Hospital for Sick Children (RBHSC). A diagnosis after the age of 16 will mean care is provided by the regional Cancer centre in BHSCT and/or one of the regional adult cancer units depending on the diagnosis and treatment.

Built as an eight-bedded unit, capacity in RBHSC was increased to 10 beds in 2018. A separate day care unit was designated in 2013 to meet the increased demand, and in 2020, this facility was further developed. Based on current bed occupancy and predicted need the new children's hospital expected to open in 2027 will have 13 inpatient beds for haematology and oncology and an eight-bedded day unit.

The PTC offers a range of Systemic Anti-Cancer Therapies (SACT) including chemotherapy, radiotherapy, immunotherapy, and Autologous Haemopoietic Stem Cell Transplant (HSCT). The centre also offers a portfolio of clinical trials for a range of haematological and oncological conditions. It also provides acute care 24 hours a day for all the above patient groups. A nurse led telephone triage service is key to this acute service, with SACT trained nurses assessing the need for telephone advice or direct access to the centre for those requiring face-to-face assessment or

> “
> **High levels of expertise but facilities really letting the service down” (RBHSC)**
> ”

> “
> **I don’t think we have coped. I think we survived by taking it one day at a time (parent)**
> ”

admission.

However, it does mean that families from outside Belfast must travel to Belfast for all treatment and care – possibly passing other hospitals with children’s wards and services on the way. There is a definite need to explore options for the development of shared care services for procedures such as blood tests and oral chemotherapy outside of Belfast.

The provision of highly specialist treatments such as allogenic haemopoietic stem cell transplant, proton beam therapy, specialist surgery or early-phase clinical trials is provided in specialist centres outside of NI, primarily in England but sometimes in Glasgow and Dublin. Children will follow an initial treatment plan in Belfast and on return will have step down care and any further treatment. The particular clinical needs of each person are taken into account when a decision is taken about the best centre to refer to. It is essential that appropriate support is provided for both children and parents when receiving care outside of NI. Many parents have highlighted the challenges of being away from home with a seriously ill child for months at a time, in particular the separation from their other children and wider family support. In addition many families struggle financially as one parent often has to leave work to care for the ill child or young person. Restrictions due to COVID-19 have exacerbated these problems for many families. There is a desire to explore the possibility of developing an all-island service for paediatric oncology, similar

> **“Belfast seems far away at 2 am, when your child’s temperature is rising and you have to travel.”**

> **“The fact that it was a drive down the road to Dublin as opposed to an Air Ambulance to Bristol or across the water was a big benefit to us.”**

to that which has been developed for paediatric cardiac surgery.

The treatment and care provided by the health and social care team in RBHSC is supplemented by services provided by a range of charities. These include the funding of core specialist posts and the provision of many therapeutic services for both children, young people and their families.

Play therapists organise a wide range of activities but many of the activities are primarily aimed at pre-school aged children who tend to be the biggest group of children on the ward at any one time. It can be very isolating for older children and young people when they are in hospital for long periods. They are often not able to have visits from siblings or peers their own age because of the risk of infection. Many former patients and parents highlighted a lack of age appropriate activities and environment for older children on the ward.

We will ensure that every child diagnosed with cancer, and their carers, have access to staff with the specialist skills to provide holistic person centred care.

We will explore the potential for greater collaboration between Northern Ireland, Great Britain and the Republic of Ireland in the provision of children's oncology services.

Teenage and Young Adults (TYA)

The most common cancers in this age group are leukaemia, lymphoma, thyroid cancers, brain and spinal cord tumours, testicular cancer, ovarian and sarcoma. Treatment is currently delivered in all trusts with specialist and complex services provided in the NI Cancer Centre, Belfast Trust.

Due to the specific age appropriate needs of teenagers and young adults TYA cancer care is a distinct speciality, which has not only been recognised in NI but across the world. The needs of this age group are specific to people at this time of life as they make the transition from childhood to adulthood. Cancer is a rare disease in this age group and therefore the young people become a rarity amongst their peers. These specific needs are both psychosocial and physical. It is acknowledged that, in some parts of the UK and Ireland, age criteria may vary and there may be some flexibility in age boundaries of services to ensure that patients access the optimum disease and age appropriate services.

TYA cancer patients fall within Paediatric and Adult cancer services. Evidence indicates the care needs of this group of people as being separate from children and adults, requiring a multidisciplinary approach incorporating both disease specific and age specific expertise.

Charitable funding has enabled the provision of TYA Clinicial Nurse Specialists (CNS) in each Trust, who as part of the MDT, ensure young people are supported throughout the treatment pathway, coordinating investigations, fertility preservation prior to treatment and referral on to other services. In addition funding for other key posts is provided by cancer charities. There is no regional TYA Multi Disiplinary Team (MDT) in Northern Ireland, and very few named clinicians with responsibility for TYA.

A paper recently published by the European Society of Medical Oncology (ESMO)[30] explores a number of issues for adolescents and young adults with cancer across

Europe. These include the lack of equitable access to specialised, age-appropriate centres with age-appropriate multidisciplinary care, and the lack of available clinical trials with novel treatments. It states that survival gains have improved only modestly compared with older adults and children with cancer. Other findings from ESMO highlight deficiencies in access to both specialist facilities and to support from a wide range of health care professionals including specialist nurses, AHPs, social workers and psychologists. They go on to advocate a strengthened multidisciplinary approach with greater involvement of both paediatric and adult oncologists and haematologists with expertise in treating adolescents and young adults.

The ESMO working group who have developed this paper specify minimum essential criteria for adolescent and young adult cancer services, which in addition to effective multidisciplinary team working and access to clinical trials, include fertility preservation, age appropriate psychosocial support, age specific environments, access to siblings and peers, age specific palliative care, late effects services, provision of social activities and education.

Services in NI fall short of these recommendations. Current services need to be reviewed against this minimum essential criteria and plans put in place to address the deficits.

> **“Being treated in an adult environment because I was 16, I was neither child nor adult.”**

> **“We never got support. It was all given to our son. We didn’t know about how to budget, how to access services for our other kids. They and we were struggling too.”**

> **“Hospital felt like another world, one that we had not yet learnt the language of.”**

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[30] Adolescents and young adults (AYA) with cancer : a Position Paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) – ESMO Open, 8th April 2021

Transition

Cancer services for teenagers and young people are becoming much more aware of the importance of patient choice while they navigate multifaceted care and treatment pathways.

The term "transition" describes the process of planning, preparing and moving on from children's health care to adult health care. Transition is a gradual process. It gives everyone time to talk about what health care you will need as an adult, chose which adult or hospital services are best for you and make sure you are ready to make the move."[31]

Transition can be a stressful and anxious time for young people and their parents or carers. They may be unsure about what to expect, proposed treatment plans and what help may be available to them in order to plan for their future.

The arrangements for the transition of Teenagers and Young Adults (TYA) vary given the complexity of this age group. Transition may be from the Royal Belfast Hospital for Sick Children (RBHSC) paediatric services to adult services, from a regional hospital to the Northern Ireland Cancer Centre (NICC), from NICC back to a regional hospital. For significant numbers it also involves moving to hospitals outside of NI for specialist treatment and then back again.

Well established transition models exist elsewhere in the UK and Ireland and learning from these will be beneficial in developing an appropriate service in NI.

We will review the provision of services for teenage and young adults in NI including transition arrangements, age appropriate environments, psychosocial support and long term follow up.

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[31] (GOSH 2011). The Adolescents and Young Adults with Cancer.

Multi-disciplinary Teams (MDTs)

Multi-disciplinary Team (MDT) working through Multidisciplinary meetings (MDM) represents the gold standard for treatment planning in cancer patient management, bringing continuity of care and reducing variation in access to treatment – and ultimately improving outcomes for patients. This has been in place in Northern Ireland for the last 20 years. The membership of MDTs in NI is in keeping with NICE/ Improving Outcomes guidance and cancer MDTs have been subject to an ongoing process of MDT Peer Review since 2013 which has been funded by MacMillan Cancer Support.

Teams are under increasing pressure due to the growing numbers of cancer diagnoses, the increased number of treatment options and greater need for a co-ordinated approach to cancer management between specialties. Reform of the current MDT system is required to ensure they remain effective and efficient and that adequate time is available for the discussion of complex cases. Time for MDT meetings requires adequate recognition in the job plans of all MDT members and, where required, preparation time for these meetings.

There has been work to develop referral proforma for MDMs and management protocols however these have not been universally adopted. All discussions at MDMs are captured on the Cancer Patient Pathway System (CaPPS) and outcomes are generally communicated to GPs within 24 hours of the MDT occurring.

Whilst it is expected that all people newly diagnosed with cancer will be discussed at an MDT meeting, there is no formal requirement to discuss people with relapsed or progressing cancer. This could lead to variations in access to treatment and a lack of consideration of all treatment options available. A programme of audit of management decisions for MDTs should be introduced and consideration should be given to the introduction of MDT morbidity and mortality meetings which have been established in England.

We will ensure that an effective Multi-Disciplinary Team meeting is held for all people diagnosed with cancer including cancer of unknown primary and metastatic disease.

Clinical Trials / Clinical Research

Clinical trials are an integral part of high-quality care in the treatment of cancer. Participation in clinical research ensures that patients have access to novel therapeutic agents or techniques, which may otherwise not be accessible to them. It has been demonstrated that people treated in centres with a strong culture of participation in clinical research have improved outcomes, attributable to care from a highly-motivated team, delivering high-quality protocol-driven care.[32] [33] [34] Research also carries benefits for individual clinicians, in terms of developing their professional knowledge and skills, and delivers organisational benefits for healthcare providers, both in terms of reputation and in revenue generation from commercial studies. In addition participation in clinical and translational research will ensure that cancer care will be improved for future generations of patients.

Data from the 2018 Cancer Patient Experience Survey[35] demonstrated a concerning differential between NI and England with only 15% of NI patients reporting that they had been asked about taking part in cancer research/clinical trials compared to 31% for England.

The Northern Ireland Cancer Trials Network (NICTN) exists to promote high quality cancer care by supporting the delivery of clinical research across the Trusts. The NICTN delivers both large, late-phase clinical trials and early-phase studies, as well as supporting the development and delivery of investigator-initiated studies through its Research Management Service. In addition, NICTN provides support for the Belfast Experimental Cancer Medicine Centre (Belfast ECMC) in the delivery of early-phase and biomarker-driven clinical trials. Currently the vast majority of clinical trial activity occurs within the NI Cancer Centre in Belfast Trust.

The complex multidisciplinary nature of clinical trial delivery requires buy-in across Trusts with enhanced access to radiology, pathology and pharmacy services. The opening of trials continues to be challenged due to workforce constraints including research nurses and medical physics experts. In addition we need to ensure reliable funding streams and protected time within job plans to support clinical research across the region.

Participation in clinical trials is considered to be an important factor in the higher survival rates seen in childhood cancers, where around two-thirds of children are recruited onto trials. NICTN supports Teenage and Young Adult trial activity when

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[32] Majumdar SR, Roe MT, Peterson ED, Chen AY, Gibler WB, Armstrong PW. Better outcomes for patients treated at hospitals that participate in clinical trials. Arch Intern Med. 2008;168(6):657-62.

[33] Karjalainen S, Palva I. Do treatment protocols improve end results? A study of survival of patients with multiple myeloma in Finland. Bmj. 1989;299(6707):1069-72.

[34] Downing A, Morris EJ, Corrigan N, Sebag-Montefiore D, Finan PJ, Thomas JD, et al. High hospital research participation and improved colorectal cancer survival outcomes: a population-based study. Gut. 2017;66(1):89-96

[35] Northern Ireland Cancer Patient Experience Survey 2018 | HSC Public Health Agency (hscni.net)

available, but activity in this area is extremely low. Currently TYA trials either sit within paediatric or adult services with few straddling both. Going forward it is important to ensure that trials for TYA are set-up locally in such a way that they can be supported through the transition between paediatric and adult services. In addition stronger links should be developed with trial sites elsewhere in the UK and the Republic of Ireland.

Per capita research spend in NI is considerably lower than in the other UK nations. [36] [37] [38] [39] Numerous charitable organisations provide funding for NICTN activity but in the financial climate "post-COVID" there is little doubt that this funding will reduce over the short to medium term.

We will facilitate as many people as possible; including children and young people to gain access to clinical trials

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[36] https://www.nihr.ac.uk/about-us/our-contribution-to-research/research-performance/12228_NIHR_Annual_Report_18_19.pdf

[37] https://seneddresearch.blog/2020/02/28/explore-the-welsh-governments-final-budget-2020-21/

[38] https://www.cso.scot.nhs.uk/wp-content/uploads/CSO1819OTsummary.pdf

[39] https://www.hrb.ie/fileadmin/2._Plugin_related_files/Publications/2019_Publication_files/Health_Research_Board_Annual_Report_2018.pdf

Supporting people

People affected by cancer includes patients, family members, carers and staff, all of whom will require support at different times, in differing formats and at varying levels. People diagnosed with cancer will require care and support at all stages of their cancer journey from diagnosis, through treatment, living with and beyond cancer and for some into palliative and end of life care.

The HSC is committed to a person-centred approach which aims to put the public, patients, their carers and staff at the heart of cancer services and empower managers and health care professionals to commission, plan, monitor and deliver effective and efficient services of the highest quality. No two people are the same, either in their cancer or their health and care needs. When care is truly person-centred, individuals are treated as individuals, with compassion, dignity and respect. The impact of cancer extends beyond the physical effects of the disease to include psychological, social, economic and spiritual consequences for people living with cancer and their carers. There needs to be a sustained focus in enabling, supporting and empowering people to make informed decisions about their treatment and care and supporting them to self- manage in the longer term.

“person centredness is an approach to practice through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development”.[40]

The approach of focussing on integrated personalised care for people with cancer across health settings has been adopted by Macmillan through the Recovery Package. People with cancer, and particularly those who are also managing other long term conditions, will interact with a multitude of services. Research has shown that one of the strongest predictors of good patient experience is overall coordination of care. In the most recent NI Cancer Patient Experience Survey (2018) only 72% of participants felt that all those involved in their care worked well together to deliver their care.[41]

The European Cancer Patient’s Bill of Rights mandates [42] ‘The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care’. It is well documented that people with cancer require an assessment of their holistic needs and should be active participants in their treatment and care rather than passive recipients. A holistic approach will include all aspects of the persons’ needs such as the physical, psychological, spiritual, social and sexual components.

> **“ I would have “loved” if someone sat down with him and said this is the “rough plan” and what will possibly happen. ”**

> **“ The professionals worked well with the individual patient, but “fell down” in terms of communicating with each other about the patient. ”**

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[40] McCormack, B. and McCance, T (2017) Person-Centred Practice in Nursing and Health Care: Theory and Practice. Oxford. Wiley Blackwell

[41] Northern Ireland Cancer Patient Experience Survey 2018 All Trusts Report - v0.3 (hscni.net)

[42] European Bill of Cancer Patients' Rights - ECPC - European Cancer Patient Coalition

The Recovery Package is a series of key interventions which, when delivered together, greatly improves outcomes for people living with and beyond cancer. The components of the Recovery Package are outlined in table 1 and contain: Holistic Needs Assessment (HNA) and Care Planning, Treatment Summary Records (TSR), Cancer Care Review (CCR), Health & Wellbeing interventions and Risk Stratification. This has been implemented at varying levels across the four nations of the UK and continues to evolve as more data is generated. Implementation of the Recovery Package is a core part of both the English Cancer Strategy (2015) and Long-Term Plan (2019). The subsequent Comprehensive Model of Personalised Care (2019) looks at how person-centred care can be integrated and delivered across four domains: acute, primary, community and digital.

> **“I love the idea of an electronic treatment summary record. At (the minute), I’m the one who seems to (need to) be in control.”**

Components of the Macmillan Recovery Package

Holistic Needs Assessment (eHNA) and Care Planning	A supported conversation using a structured electronic questionnaire to identify needs, facilitate discussion and agree the best way to meet them from the person's perspective. It ensures that physical, practical, emotional, spiritual and social needs are identified in a timely and appropriate way, and that resources are targeted to those who need them most.
Treatment Summary Records (TSR)	A pro forma document which records clear information about a person's treatment, any immediate to longer term consequences of treatment that they need to be aware of, on-going clinical management, any actions they need to take and who to contact with any questions or concerns. It is completed after a significant phase of a person's cancer treatment. A copy is provided to the person living with cancer and their GP.
Cancer Care Review (CCR)	CCRs involve a person with cancer having a holistic conversation with a primary care healthcare professional in order to discuss issues relating to their cancer or treatment.
Health & Wellbeing interventions (H&WB)	The aims of Health and Wellbeing (H&WB) interventions are to: Educate people with cancer on how to live well; Inform people with cancer about where they can access the support they need; Help people with cancer to cope with difficulties (e.g. stress/anxiety, consequences of treatment/late effects); Provide targeted information to people with cancer; Provide opportunities for people with cancer and their carers to access peer support.
Risk Stratification (RS)	An approach to profiling patients following treatment for cancer that is based on their clinical and individual needs. It is appropriate for all people whether they have been treated with curative or palliative intent.

Ultimately, the Recovery Package seeks to provide the support that people living with cancer need to lead their best possible lives. Full implementation of the Recovery Package can ensure that, from diagnosis or soon after, people's needs are identified and addressed.

Data from electronic Holistic Needs Assessment (eHNA) will be a key resource in the development and improvement of cancer services for the future and will enable benchmarking between services, across tumour groups, trusts and the 4 nations of the UK. There are potential benefits for eHNA to be embedded in the ongoing development of Encompass.

With increasing numbers of people surviving their cancer diagnosis, cancer follow-up in primary care is likely to resemble that of other chronic diseases. Healthcare Professionals must be encouraged to provide a TSR and CCR to everyone who has been diagnosed with cancer.

Health and Wellbeing Events should continue to provide a forum by which attendees can receive information on how to self-manage their condition. These events must be offered for all tumour groups.

Risk stratified follow up

The traditional model of oncology follow-up clinics is being challenged like never before. Demand for outpatient appointments is increasing as more people are living with a cancer diagnosis, however many follow up appointments would appear to offer little value to the patient. This is due in part, to traditional oncology follow-up clinics having focused mainly on detection of cancer recurrence and less so on the comprehensive range of health-related quality-of-life (QOL) issues.[44] Many cancer survivors attending these clinics report on-going, unidentified and unmet needs.

In addition recent studies have highlighted a feeling of abandonment from patients during the transition period from cancer patient to survivor.[45] Needs inevitably change as people move along the pathway demanding a more tailored approach to care. Self-management is in place for many breast cancer patients and this should be extended to other cancers where clinically appropriate. This would reduce the need for hospital appointments and would enable resources to be redistributed to diagnosing more new patients and supporting those with metastatic and complex disease.

Appropriate follow up is essential to ensure monitoring of a person's clinical condition and timely investigation of possible disease relapse or progression. A stratification of risk allows the clinical team, and the person living with and beyond cancer, to make a decision about the best form of aftercare. This is based on knowledge of the disease (the type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short and long term) and personal clinical circumstances (whether they have pre-existing illnesses or conditions, and how much support they feel they need).

Models of aftercare include:

- Supported self-management - Individuals are given information about:
    1. self-management support programmes or other types of available support
    2. clinical signs and symptoms to look out for
    3. who to contact if they notice anything of concern
    4. scheduled tests they may need (such as annual mammograms)
    5. how to contact relevant professionals if they have any concerns;
- Shared care – people continue to have face-to-face, phone or email contact with professionals as part of continuing follow-up. Nurse led follow-up is a shared care approach recognising the extended role of the nurse. A systematic review[46]

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[44] Jefford M, Rowland J, Grunfeld E et al (2013) Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA. British Journal of Cancer. 108, 1, 14-20.

[45] Davies N, Batehup L (2011) Towards a personalized approach to aftercare: a review of follow-up in the UK. Journal of Cancer Survivorship.5, 2, 142-151.

[46] Caird J, Rees R, Kavanagh J et al (2010) The Socioeconomic Value of Nursing and Midwifery: A Rapid Systematic Review of Reviews. EPPI Centre, Social Science Research Unit, Institute of Education, University of London

concluded that nurse-led care can be more beneficial than doctor-led care in terms of physical outcomes, psychosocial aspects of care and patient satisfaction, whilst not impairing the long-term survival of patients with cancer. Local evaluations demonstrated effective nurse-led follow-up.[47]

- Hospital based care – people with more complex conditions and needs who remain under the care of the consultant.
- Emerging models which involve new, joint multi-professional clinics such as post radiotherapy for people recovering from head and neck cancer led by the Clinical Site Specialist Radiographer and CNSs. There is potential to further develop these models to include the management of late effects and consequences of treatment.

> **“There are some fabulous things (new following the pandemic). I am having my check ups via Zoom, being sent for scans at the local hospital, so I didn’t have to go to Belfast. There are things that are really working well.”**

Prior to the COVID-19 pandemic some follow-up monitoring was being undertaken by CNSs via telephone. As a direct consequence of the pandemic the use of technology in follow up care has increased significantly. Further work needs to be carried out to establish which modality is best, for which patients and to understand which member of the team is best suited to carry out the review. Training for staff, the development of protocols and agreement on the appropriate technology will be required to develop this further to ensure the optimum experience for both people living with cancer and staff.

We will make sure that all people are offered a holistic needs assessment, an appropriate care plan is developed and they are signposted to relevant sources of help and support.

We will develop a comprehensive treatment summary record for all people diagnosed with cancer. On completion of their treatment, this will be provided to them and their GP.

We will make sure that all people are assessed and risk stratified to appropriate, high quality, follow-up pathways on completion of treatment.

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[47] Semple CJ & Lynas C (2018) Development, integration and evaluation of nurse-led follow-up across five tumour sites at a cancer unit in Northern Ireland. Cancer Nursing Practice. doi: 10.7748/cnp.2018.e1460

Support from Healthcare Professionals

Support from Clinical Nurse Specialists

> There was no clinical nurse specialist within oncology.

Cancer Clinical Nurse Specialists (CNSs) play an important role in the management of individual patients as their key worker.[48] They are a core member of the multidisciplinary team (MDT), and as such each MDT is required to have a Clinical Nurse Specialist in order to meet accepted MDT peer review standards. Data from the NI Cancer Patient Experience Study (2018) clearly demonstrates that the support of a CNS is the single most important factor to a patient's experience of care. However not all patients have access to a CNS and for many the support is limited to the diagnostic and surgical part of the service.

CNSs should be available across the cancer pathway, through diagnosis, treatment for primary and metastatic disease and throughout follow-up. This applies to all children diagnosed with cancer and their parents and includes a dedicated TYA CNS service to support teenagers and young adults throughout their care. CNSs have a key role in: ensuring that all people with cancer have their holistic needs assessed, the development of personalised care plans and facilitating self-management and appropriate longer term follow up.

We will ensure that all patients, including children and young people, diagnosed with cancer have access to a Clinical Nurse Specialist throughout the entire care pathway.

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[48] Quality in Nursing Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Clinical-Nurse-Specialists-in-Cancer-Care_Census-of-the-Nurse-Workforce_Eng-2011.pdf

Support from Allied Health Professionals

Allied Health Professionals (AHPs) are the third largest professional workforce in the NHS, with 13 distinct and unique disciplines. They are integral to the delivery of cancer care across the entire pathway.[49] The AHP workforce is essential in diagnosing cancer, in the delivery of cancer treatment, supporting people through treatment, leading the delivery of prehabilitation and rehabilitation services and providing palliative and end of life care.

Creative Arts Therapies comprise Music Therapists, Art Therapists and Drama Therapists. They are skilled clinical healthcare professionals working with evidenced clinical therapeutic interventions. They can help reduce anxiety, pain, tiredness and increase wellbeing.

These therapists often provide the opportunity for the people and their families to express feelings and emotions which are often unthinkable, unacceptable or impossible to express verbally.

Psychological support

Recognising and treating distress in people living with cancer must be a priority. Research carried out by Macmillan indicates that 21% of people living with cancer experience mental health problems and that 73% of people living with cancer report some type of emotional concern, most commonly worry, fear and anxiety, sadness, depression and loss of confidence. Data shows that circa 70% of people diagnosed with cancer have other long-term conditions to manage alongside their cancer.[50]

A cancer diagnosis often brings a significant change to family dynamics and research shows that family members can often display higher levels of anxiety and depression than patients themselves. [51]

Referrals to Psycho-oncology services have risen sharply in recent years with long waiting lists in several areas. In addition to an increase in referral rates there is the need to prioritise certain groups of people diagnosed with cancer:

- Teenage and Young Adults (TYAs)
- Pregnant women and new mothers

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[49] NHS England. (2018) Quick Guide: the role of allied health professionals in supporting people to live well with and beyond cancer. Transforming health, care and wellbeing with allied health professionals. London. Allied Health Professions team. Available at: https://www.england.nhs.uk/wp-content/uploads/2018/10/quick-guide-ahp-cancer.pdf (Accessed 18 May 2019).

[50] Ref: Macmillan Cancer Support. People living with cancer research (2020).

[51] Mullen, L. & Hanan, T. (2019). National Cancer Survivorship Needs Assessment: Living with and beyond cancer in Ireland. National Cancer Control Programme: Dublin. Available at: https://www.hse.ie/eng/services/list/5/cancer/profinfo/survivorship-programme/living%20with%20and%20 beyond%20cancer%20in%20ireland.pdf

- People awaiting assessment in advance of prophylactic breast surgery in line with NICE guidelines (CG164). People awaiting risk-reducing surgery must be seen within a reasonable timeframe to avoid delays in completing surgery and possible cancer diagnosis in the interim period.
- People receiving palliative care and those at end of life (NICE 2004; 2008). It is essential that palliative people are seen before they become too fatigued or unwell to be able to engage in psychological assessment or therapy.

Counselling supports people dealing with the emotional impacts of cancer. Whilst there is an array of services available across health and social care and in the community and voluntary sector awareness of services and access to services remains a challenge for many.

It is essential that people affected by cancer are able to access different types of support dependent on their level of need in a timely manner.

We will make sure that all people with cancer have equitable access to psychological support which is tailored and specific to their needs.

Information and Therapeutic Support

Staff from all sectors who interact with people and their families play a key role in the provision of information and support. All trusts have designated specialist services which lead on the provision of high quality information and support. In addition both local and national cancer charities have a focus on the provision of information and support services, many providing information via helplines, online fora and via social media channels which Health and Social Care (HSC) is not resourced to do. Collaborative working to maximise resources is essential to ensure all those who need information get it when and where required.
An independent evaluation of Trust Information and Support Services was undertaken in 2019 and the report makes a series of recommendations to ensure that all people are routinely referred to information and support services.[52] These include the increased use of digital applications, integration of social prescribing, improved provision for carers and enhanced partnership working with the community and voluntary sector.

Many people will seek information from pre-diagnosis particularly when they are referred by their GP for further investigations. Specific information resources must be developed and provided to all patients at this early stage specifically for those people who are referred via the 'red flag' route.

Information for people living with cancer goes far beyond the physical implications of cancer. Provision must

> **“I found the period of greatest anxiety to be between receiving the diagnosis and getting into hospital. There was a “period of waiting in between, with millions of questions” i.e. Who do I go to? What's going to happen? What's the process?”**

> **“You still have to pay the bills and support the family. It is hard to juggle commitments with work. There are so many emotions and a lot of pressure.”**

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[52] Macmillan Cancer Support (2020), Evaluation of Macmillan Information and Support Services in Northern Ireland (Rocket Science)

be holistic in nature and encompass financial and benefits advice, employment issues and support for carers.

It is imperative that there is equitable provision of information and support for all sections of society including those who do not have English as their first language, people with a learning or sensory disability and age appropriate information for children, teenagers and young adults. We must also ensure that all people diagnosed and treated in the independent sector have access to the full range of information and support services.

Currently over a third of those living with cancer in NI are of working age. Cancer can have a major impact on a person's ability to work and while most wish to stay in or return to work, many do not receive the information, advice or rehabilitation support they need to help them do so. This results in people falling out of work, having a major impact on individuals, families and employers. Significantly, there is strong evidence to suggest that remaining or returning to work can promote recovery and lead to better clinical and psychosocial outcomes.[53]

Spending long periods in hospital or at home can seriously impact on children and young people's developmental and educational outcomes. Special care and resources are needed to support ongoing development and education during this time. Currently

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[53] Waddell G, Burton AK (2006). Is work good for your health and well-being? London: The Stationery Office.

support for education is variable and there are particular challenges for young people aged 16-18.

The social and emotional needs of children and their families must be taken account of and supported during cancer treatment. The need to invest in and strengthen social and emotional support for children, young people and their families was one of the strongest messages coming from our engagement with people with lived experience.

Benefits advice services, hardship grants to patients and financial guidance are a vital means of supporting people facing the financial hardships caused by cancer. Services are currently available in all trusts but are provided and predominantly funded on an annual basis by voluntary sector organisations with no agreed recurrent funding streams.

Therapeutic services is an umbrella term which represents a wide range of support services. This includes complementary therapies, counselling, self-management programmes and support groups, practical support, creative therapies, pain and symptom control, lifestyle change supports, chaplain service and helplines. Specific services for children and young people include short breaks, peer mentoring, and educational events. The vast majority of these services are provided in the community by the voluntary sector. Post pandemic, many of these services are at risk due to the impact on fundraising for almost all charitable organisations. Better integration and collaboration will be essential to ensure the sustainability of many therapeutic services for the future.

We will make certain that all those with a cancer diagnosis are referred to a Cancer Information and Support Service at diagnosis and advised of the range of services available across their entire cancer pathway.

We will ensure timely and appropriate access to therapeutic and practical support services for people affected by cancer targeting emotional, physical and social needs.

Carers

Support and care provided by families and informal carers is vital to the wellbeing of patients given their assistance in managing medications, treatment regimes, symptom management, personal care, social and psychological support. However, providing informal care is challenging for many and can have a negative impact on both physical and mental health. Evidence has shown that there is a need to deliver improved services for informal carers of patients with cancer in Northern Ireland.[54] [55] [56] [57] Health care professionals have a responsibility to ensure that carers' needs are assessed and that they can obtain information easily across the illness trajectory with adequate signposting to additional support. Cancer Caring Coping[58] is a co-designed, one-stop, online, multi-medium resource (www.cancercaringcoping.com) tailored to support carers in Northern Ireland from diagnosis to possible bereavement. This resource should be made available to all carers.

In addition people providing unpaid care for loved ones with non-curative cancer and at end of life should have access to support services to meet their own health and wellbeing needs. This includes regular breaks from caring and reliable respite care. There is a wealth of evidence demonstrating that these requirements are not currently being met for many carers.[59]

Whilst carers in all situations face challenges there is a particular need to ensure appropriate support for parents of children and young people with cancer. Services and facilities including overnight accommodation are predominantly funded and provided by charities. There is a clear need for much better partnership working and integration with statutory services to ensure that all families get the support they need across the entire pathway.

Support for staff working in cancer services must also be considered. Research has shown that good staff experience contributes to better patient care. Emphasis should be placed on readily accessible up to date information, support and advice.[60]

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[54] Santin, O. Murray, L. Prue, G. Gavin, A. Gormley, G. Donnelly, M. (2015) Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors. European Journal of Oncology Nursing, 24, 121-129.

[55] Santin, O. Mills, M. C, Treanor. Donnelly, M. (2012) A comparative analysis of the health and wellbeing of cancer survivors to the general population. Journal of Supportive Cancer Care.20.10. 2545-2552

[56] Treanor, C. Santin, O. Mills, M. Donnelly, M. (2012). Cancer survivors with self-reported late effects: their health status, care needs and service utilisation. Psycho-oncology. 22. 2428-35. (Grant*)

[57] Santin, O. Treanor, C. Mills, M. Donnelly, M. (2014) The health status and health service needs of primary caregivers of cancer survivors: a mixed methods approach. European Journal Cancer. Volume 23, Issue 3, pages 333–339

[58] Santin O, McShane T, Hudson P, Prue G. Using a six-step co-design model to develop and test a peer-led web-based resource (PLWR) to support informal carers of cancer patients. Psycho-oncology. 2018 Dec 29. https://doi.org/10.1002/pon.4969

[59] Marie Curie (2018). Lost retirement: The impact on older people of caring for someone with a terminal illness.

[60] Picker/Macmillan, The relationship between cancer patient experience and staff survey results, 2013, Picker Institute Europe.

Supporting People to live well

Whilst more people than ever in Northern Ireland are surviving after a cancer diagnosis not everyone who has survived is living well. Over half of those diagnosed with cancer today will live for at least 10 years and for some types of cancer the figure is much higher. Contributions from people living with cancer to the development of this strategy has consistently demonstrated that surviving is very different from living well. Research carried out by Macmillan in 2013 found that at least one in four people living with cancer face poor health or disability following treatment for cancer. Many people will make a good recovery following treatment but a significant proportion will continue to live with a wide range of problems. People who have had curative treatment can be left with disabling, chronic long term conditions as a result. As there are no agreed pathways in place their treatment and care is often poorly managed, disjointed and uncoordinated.

A significant proportion also live with the increased risk of developing cardiac, bone and bowel problems as a direct consequence of their treatment, some of which will not become apparent until many years later. Up to 75% of children and young people who have been treated for cancer will have long term consequences of cancer including a greatly increased risk of developing a second cancer. As more people survive cancer the problems associated with late effects, consequences of treatment and long term follow up will grow. This comes at a high cost to both the individual and to health and social care. Not only is this an issue for the quality of life of those affected, it is

> “I feel that at the end of treatment we were just left.”

> “I feel I am managing well, but the management of my health has been all consuming and has taken over my life due to the severe impact of surgeries and treatments. I had to take early retirement.”

> “I want to live life, I want to have fun. Still have the craic. This is my view and it has been for the last while.”

also a major challenge for Health and Social Care in the timely provision of long term, tailored care and support. Currently services either do not exist or are not resourced to meet the growing demand.

There are many treatments used to manage a diagnosis of cancer including surgery, radiotherapy, chemotherapy, immunotherapy and hormonal therapy. These can be used alone or in combination, often over a prolonged period of time. Side effects are part of any treatment regime but for the purposes of this section the focus is on the longer term, chronic effects of treatment.

A dearth of data to quantify the size and scale of existing barriers to living well with cancer is a serious concern. There is a gap in the knowledge and understanding of late effects and consequences of treatment, particularly in light of an ageing population. Many people live with their problems, often struggling to get the right treatment and support, and many are unaware that help is available assuming that the symptoms are the cost of a cure.

Any data available is likely to be a gross underestimation. Data collection on co-morbidities and consequences of cancer treatment must be mandated as part of any new development on data collection for cancer services.

Whilst we have focused on the most common consequences and late effects of treatment this is by no means an exhaustive list.

Cardiovascular

The European Society of Medical Oncology (ESMO) consensus paper of 2020[61] states ‘with increasing numbers of cancer survivors living longer, oncologists and other health care providers are faced with challenges in managing long-term and late toxicities of therapy, recognizing that cardiovascular issues are significant causes of morbidity and mortality in this population.’

There is robust, compelling international evidence about the growing impact of cancer treatments on cardiovascular health. Next to cancer recurrence, progression and second malignancies the leading cause of death in cancer survivors is cardiovascular diseases (CVDs) due to the intense oncological treatment which many people receive. A significant number of anticancer therapies are associated with some level of cardiovascular toxicity, ranging from asymptomatic and transient to long-term permanent life threatening problems.

In a recent report the American Society of Cardiology[62] states that ‘the management of cancer can no longer be limited solely to the active treatment of malignancy….. we must invest in additional research and foster multidisciplinary collaboration to tackle gaps in our knowledge and ultimately improve both cancer- and cardiovascular-related health outcomes in this growing population.’

[61] ESMO Consensus Guidelines 2020

[62] American College of Cardiology Cardiovascular Toxicity in Cancer Survivors: Current Guidelines and Future Directions, Jun 29, 2018 | Carlyn Tan, MD; Crystal Denlinger, MDExpert Analysis

Children and young people, in particular, are at serious risk of premature death in later life from cardiovascular and respiratory failure as a consequence of treatment.[63] Some pathways are currently in place for this cohort but this is not a commissioned service.

Cardiovascular oncology is an emerging specialism with dedicated services developing in other parts of the UK.

In NI increasing numbers of people living with cancer who are at risk of developing cardiovascular disease due to treatment are being referred to cardiology services, which is having a major impact on waiting lists and access to services such as echocardiograms. It is estimated that circa 3000 echocardiograms are done for oncology patients per annum.

Bone health

Hormonal therapy is a main stay of treatment for both breast and prostate cancers, often resulting in inevitable osteoporosis. This is also the case for people who have prolonged treatment with steroids. Pathways are in place for monitoring bone density for people living with breast cancer but there are no existing pathways for men living with prostate cancer or others at high risk.

Significant numbers of people develop metastatic bone disease which, for many, can be managed over a period of years. Over recent years there has been a steady increase in referrals to orthopaedic services combined with a significant workload managing long bone fractures and spinal cord compression. Access to appropriate palliative care can be an issue for people with long bone fractures who are initially managed in acute orthopaedic wards. There is no commissioned service in place for the management of metastatic spinal cord compression.

GI consequences of pelvic radiotherapy

Although more people are surviving cancer, problems associated with pelvic radiotherapy are presenting many years (up to 5-10 years) post treatment which has obvious consequences for individuals who have had treatment and for service provision. Many people report severe and distressing symptoms such as faecal incontinence, urgency, bleeding, flatulence and pain. Given the time from initial treatment often neither the person nor primary care teams are aware that this is a likely late effect of radiotherapy treatment.

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[63] Mulrooney DA et al Cardiac Outcomes in a cohort of adult survivors of childhood and adolescent cancer: retrospective analysis of the Childhood Cancer Survivor Study cohort. 2009, BMJ 339;b4606

A regional task and finish group was established to develop guidelines and pathways for the management of the consequences of pelvic radiotherapy. The NICAN GI Consequences of Pelvic Radiotherapy Task and Finish Group Report was published in 2017 but to date has not been implemented in all Trust areas.

Elsewhere in the UK Centres of Excellence for the management of pelvic radiation disease are being established to manage the most complex cases. In addition to the establishment of Trust pathways consideration should be given to the development of a regional service for those with complex problems.

Sexual Health and Fertility

Cancer treatment can have devastating physical and psychological consequences on sexuality and fertility for many people. There may be a wide range of issues including erectile dysfunction, early menopause, body image issues due to disfiguring surgery, loss of libido, reduced fertility and for some infertility.[64]

No formal, coordinated services or pathways exist and undoubtedly the impact of cancer treatment on sexual health is unreported.

There are particular issues for children and young people diagnosed with cancer. Established pathways to the regional fertility centre are in place which are very responsive when time is of the essence to start cancer treatment. For pre-pubescent children research based interventions are becoming available in Oxford and Edinburgh. Consideration should be given as to how children in NI can avail of these in a timely manner.

> **“Did you want to have any more children?” That was the only communication I had regarding fertility.**

At present, as for all cases in NI, people who are infertile because of their cancer are entitled to one cycle of IVF. The recent commitment within New Decade, New Approach to fund 3 cycles of IVF treatment will have a positive impact in this area.

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[64] Belfast Health and Social Care Trust (2017) Has Cancer affected your sexuality, sex life and relationships. Belfast: Belfast Health and Social Care Trust; Katz A. (2005) The Sounds of Salience: Sexuality Information for Cancer Patients. Journal of Clinical Oncology, 23(1), 238-241

Lymphoedema

Lymphoedema can develop when lymph nodes or lymph vessels are removed or damaged. It is a permanent, often disabling condition and cannot be cured. With appropriate support many people are able to manage their condition with a regimen of meticulous skin care, exercise and wearing compression garments. It is commonly associated with breast, head and neck, and gynaecological cancers. There has been a commissioned lymphoedema service in place since 2008 across NI. Referral numbers have increased year on year resulting in long waiting lists. Evidence from the National Cancer Action Team in England shows that investment in lymphoedema services is extremely cost effective and significantly reduces the number of hospital admissions.[65]

Neuropathy

Surgery and radiotherapy for cancer can damage nerve tissue in the targeted treatment areas, and chemotherapy may affect systems throughout the whole body. Nerve damage may be central - with brain effects of loss of cognition and memory, reduced hearing, vision, taste and smell; and/or autonomic - with changes in heart and blood pressure regulation, poor gut function: and/or peripheral - with reduction of normal sensation and motor function of the limbs, increased abnormal sensation and pain, and increased fatigue from loss of function or difficulties in coping with the burden of altered sensation. Many of these effects of treatment reverse or decrease over time, but many are permanent, causing significant disability. Nerve damage from cancer treatment is enhanced by pre-existing nerve dysfunction due to stroke, injury, diabetes, and other conditions.

Studies show that following chemotherapy, 60% of people experience peripheral neuropathic pain 3 months after treatment, and persists for 30% at 6 months. Overall, between 33% and 40% of cancer survivors suffer from chronic pain.[66]

Specialist palliative care clinicians have an invaluable role to play in the management of cancer pain, not limited to end of life care. There is a need for better integration and collaboration between palliative care, oncology, haematology and pain management teams.

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[64] Belfast Health and Social Care Trust (2017) Has Cancer affected your sexuality, sex life and relationships. Belfast: Belfast Health and Social Care Trust; Katz A. (2005) The Sounds of Salience: Sexuality Information for Cancer Patients. Journal of Clinical Oncology, 23(1), 238-241

[65] National Cancer Action Team, Cancer Rehabilitation, Making Excellent Cancer Care Possible 2013

[66] Paice JA. Chronic treatment-related pain in cancer survivors. Pain 2011;152(Supplement):S84– S89.

Seretny M, Currie G L, Sena ES, Ramnarine S, Grant R, MacLeod MR, Colvin L, Fallon M. Incidence, prevalence, and predictors of chemotherapy-induced peripheral neuropathy: A systematic review and meta-analysis. Pain 2014;155(12):2461–2470.

[67] Faculty of pain medicine of the Royal College of Anaesthetists. Framework for pain services cancer and life limiting disease 2019.pdf (fpm.ac.uk)

The Faculty of Pain Medicine of the Royal College of Anaesthetists published 'A Framework for Provision of Pain Services for Adults Across the UK with Cancer or Life-limiting Disease' in 2019. This presents a framework and operational guidance for improving pain services for adults across the UK with cancer or life-limiting disease and should be used to develop services across NI.[67]

Respiratory

Breathlessness can have many causes including damage to the lung by cancer treatments (radiation pneumonitis, chemotherapy fibrosis and surgical scarring), loss of physical fitness/de-conditioning, disease progression, end of life symptoms and other co-morbidities. There are no formal pathways for treating breathlessness as a consequence of cancer treatment or disease progression. Traditionally, referrals are made later in the patient journey when patients are short of breath at rest. Earlier referrals would improve quality of life and maintain independence for many.

Mental ill health

Mental ill health cross cuts the entire cancer pathway. Some services are offered by the voluntary sector but outside of this provision, formalised pathways do not exist for cancer patients. A mental health strategy has been developed to address existing inequalities, however we know that psychiatry and psychology in each of the Trusts is overwhelmed, waiting lists are infinite, no clear pathways from cancer services exist and this has a significant impact on primary care workload. Preventing mental health conditions from developing amongst those living with cancer, as well as ensuring adequate management of conditions should they occur are important in the provision of holistic cancer care. The numbers of people needing help with their mental health is likely to grow as more people are living longer following a cancer diagnosis. There are significant gains to be realised both in patient quality of life and savings in health care costs. [68]

The breadth of services needed to help people with a cancer diagnosis adjust to a new normal do not currently exist.

[68] Sharpe M, Walker J, Holm Hansen C, et al., SMaRT (Symptom Management Research Trials) Oncology-2 Team Integrated collaborative care for comorbid major depression in patients with cancer (SMaRT Oncology-2): a multicentre randomised controlled effectiveness trial. Lancet2014;384:1099-108

Chronic Fatigue

Cancer related fatigue (CRF) is the most commonly reported symptom affecting quality of life and ability to function. Fatigue affects large numbers of people after cancer treatment but for some it persists as a chronic long term condition. Due to difficulties with identification, problems can often go unreported and as a result, unaddressed. No formal commissioned services exist - where support exists it is often an add-on to other services, tumour dependant or provided by charities. Simple interventions such as physical activity have been shown to significantly reduce levels of fatigue.

Continence

Surgery, radiotherapy or disease progression can result in bladder and bowel incontinence, affecting both male and female, and can be seriously life changing. Conservative services (e.g. lifestyle advice, pads etc.) are available but do not actively treat the condition. BHSCT successfully piloted the physiotherapy management of continence due to prostate cancer, and is now an award-winning service. Similar charity sponsored pilots are ongoing for the therapeutic management of incontinence related to colorectal and gynaecological causes; these are not yet commissioned.

We will make sure that all people starting cancer treatment have their health status assessed and recorded and a plan developed to mitigate potential late effects and consequences of their treatment.

We will develop an agreed regional, multidisciplinary approach to the identification and management of all people at risk of late effects and consequences of their cancer treatment.

We will identify people deemed to be at highest risk for late cardiovascular effects and enrol them in a follow up programme with appropriate imaging and with access to cardiology intervention as necessary.

We will regularly screen children to detect early, subtle cardiac abnormalities that might be treated, or may be reversible. In addition, where children are treated with anthracyclines or cardiac radiation they will have lifelong screening every 3 to 5 years.

Caring when Cancer can't be cured

Cancer is the largest cause of death in Northern Ireland. The most up to date figures are circa 4,500 deaths per year with slightly more men than women dying from cancer. The most common causes of cancer death for men are lung, prostate and bowel and for women are lung, breast and bowel.

Findings from the Northern Ireland Health Inequalities report for the period 2017-2019 show that among people aged under-75, the death rate from cancer in the most deprived areas was greater than the least deprived areas by a factor of 1.7.

Numbers of children and young people are small, with on average 9 children and 7 young adults dying annually.

Average Number of Cancer Deaths in Children & Young Adults recorded in NI by Age Band for the period: 2014 – 2018

	Age Band		
	0 - 15	**16 – 24**	**TOTAL**
Average Cases per Year	9	7	16
TOTAL	43	33	76

NOTE:- Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.

Living Matters, Dying Matters a Palliative and End of Life Care Strategy for Northern Ireland was published in March 2010. The vision of this strategy is that any person with an advanced non-curative condition, lives well and dies well irrespective of their condition or care setting.

This requires a philosophy of palliative and end of life care that is person-centred and which takes a holistic approach to planning, co-ordinating and delivering high quality reliable care, enabling people to retain control, dignity and crucially, choice in how and where their care is delivered to the end of their life.

> **“Everyone has a right to palliative care and a dignified passing, both for them and their family…”**

It means being sensitive to the personal beliefs, cultures and practices of individuals and their families and carers and recognising the contribution good palliative and end of life care can make to the quality of their lives.

It means that where the person's preference is to receive care, and where possible to die at home, that the infrastructure and opportunities are in place to make such a choice real and viable. In Living Matters Dying Matters palliative care is defined as: 'the active, holistic care of patients with advanced progressive illness.' Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. More recently the importance of 'early identification and impeccable assessment' has been added to this definition as it is thought that problems at the end of life can have their origins at an earlier time in the progression of the illness and should therefore be recognised and dealt with sooner.

Palliative care can in some cases mean a shift from a curative focus towards an approach which seeks to alleviate and prevent the escalation of symptoms. The transition between curative and palliative care is often blurred, which emphasises the importance of communication between the individual and the health care professional with regards to the intention of treatment. Identifying this transition informs thoughtful decision-making about the appropriateness of proposed treatment options and explores the provision of further social and spiritual support to address emotional, psychological and practical needs, invaluable to the individual, their family and carers in managing the condition.

End of life is described as the period of time during which an individual's condition deteriorates to the point where death is either probable or would not be an unexpected event within the ensuing 12 months, however a specific timescale cannot always be applied. This point will be different for each individual and will often depend on an assessment of their condition by health and social care professionals, carers and/or the patient themselves. Identifying the point at which illness becomes advanced or reaches the end of life phase allows health and social care providers to

Number of Cancer Deaths in Children & Young Adults recorded in NI by Place of Death for the period: 2014 – 2018

	Age Band		
	0 - 15	**16 – 24**	**TOTAL**
HOME	19	12	31
HOSPITAL	19	15	34
HOSPICE	5	6	11
TOTAL	43	33	76

NOTE:- Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.

plan best care with people in order to meet their needs and those of their families and carers throughout the last phase of life and the experience of bereavement. As with palliative care, end of life care also includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Palliative and end of life care is provided in many settings: at home, in hospitals, in care homes and hospices. Whilst much of the formalised care is provided by multidisciplinary teams of health and social care professionals, families, carers and volunteers continue to be the crucial cornerstone of this care. The majority of children and young people die either at home or in hospital.

Within this strategy we refer to people with ‘non-curative cancer’. By this we do not mean every patient whose cancer cannot be fully treated, but those with a non-curative diagnosis who have been identified as potentially benefiting from a palliative care approach. Increasingly people are living with non-curative cancer for prolonged periods of time. This has been termed ‘treatable but not curable cancer,’ and includes many blood cancers, metastatic cancers including breast, bowel and prostate cancer. Growing numbers of people will receive life prolonging treatment over many years and may require palliative care input on an episodic basis over a more prolonged period of time. Existing pathways and criteria are not always flexible enough to ensure people can access palliative care services when and where they need them. If alternative services were available this could avoid unnecessary attendance at hospital and admission for some people.

COVID-19 has significantly disrupted key cancer services which is resulting in more people presenting with advanced disease. This raises challenges for the provision of palliative care service delivery in the short to medium term.

Identification of palliative care needs

There are a number of benefits from the early introduction of palliative care for people living with cancer, including integration alongside active treatment. Timely access to palliative cancer care can result in better quality of life, lower rates of depression, longer survival and higher satisfaction with care among patients. Access to palliative care is, however dependent on both clinicians and patients and carers recognising and accepting that they could benefit from this approach. It also requires close, integrated working between key HSC disciplines, for example oncology and palliative medicine.

In practice it would appear that both cultural and structural barriers are stopping this from happening for some patients, namely:

- the emphasis of many clinicians may be on treatment or survivorship, with a reluctance to refer to palliative care or acknowledge the severity of a patient's prognosis, as this would represent 'giving up'. This may foster an attitude where palliative services are only considered once all active treatment options have been exhausted. Misconceptions about palliative care also exists among patients and their loved ones
- late identification of palliative care needs often means those people, who are still deemed as curative, no matter how small the likelihood, may miss out on receiving palliative care and support services. As a result, some people and those important to them are often shocked by rapid deteriorations and feel unprepared for the end of life.
- late identification also decreases opportunities for advance care planning and steps to facilitate the person's preferred place of care, as well as leading to complex grief in those left behind.

Recent retrospective audits (2019, pre-COVID-19) of people presenting to emergency departments have found between 20-30% of people being admitted to hospital following an attendance at ED have unidentified or unmet palliative care needs. Of those admitted on average 40% of them had advanced cancer.

We will deliver integrated, coordinated and personalised palliative and end of life care to people with non-curative cancer when and where they need it.

Access to palliative care keyworkers

People are likely to receive care and support from a range of professionals including district nurses, GPs, Allied Health Professionals, social care workers, community pharmacy, specialist palliative care professionals. Care may also be provided from a range of organisations including hospices and charities. Patients and families report that it is often confusing having so many different people involved and that communication between services can be fragmented. Living Matters Dying Matters recommended that palliative care patients should be allocated a key worker to co-ordinate care, support and information. To date this has not been implemented uniformly across all Trusts and for all patients.

We will arrange a palliative care keyworker for all people with non-curative cancer when required.

Access to generalist and specialist palliative care services

> This is my dying wish - that I get to have my final days and hours spent in comfort in my own home with my loved ones.

The NISRA Place of Death statistics for 2019 show that 47% of all deaths in NI occur in hospitals, 19% in Care Homes and 34% in all other places. The 'all other places' for 2019 isn't broken down in the official statistics but we know from previous breakdowns that around 3% of those deaths will have been in hospice and circa 27% in the person's own home.

Socioeconomic factors may have a particular impact on the end of life experience of people in their own homes. Marie Curie's research has shown that people with terminal conditions – including cancer – may be more likely to live in fuel poverty and suffer the damaging consequences of living in cold housing.[69] Elsewhere, wider UK studies have found that people in the most deprived areas are more likely to die in hospital than those in the least deprived.[70] [71]

As a result of the pandemic and the associated restrictions for visiting in care homes, hospitals and hospices, it would appear that in 2020 more palliative patients have been cared for in their own homes. Not only has there been an increase in the number of patients but also a significant increase in the complexity of care required. We need to build on the lessons of the past year to enable all those who wish to die at home to be able to do so.

The delivery of high quality palliative and end of life care requires multidisciplinary input. Specialist palliative care professionals will play an important role, but much of the care that people will receive, including at the end of life, will also be provided by wider 'generalists' – including GPs, district nurses, Allied Health Professionals and social care workers.

The need for education and training for staff, from basic understanding of what palliative care is and when it is appropriate, identifying need, advance care planning, local referral processes and integration with oncology services through to care in the last days of life and bereavement is vital if care and co-ordination is to be improved.

Rounds 1 (2018) and 2(2019) of the National Audit for the Care at the End of Life NI reports recommend increased mandatory/ priority palliative care training for all health care professionals. Despite these drivers, no regional palliative care educational framework has ever been developed or funded in NI.

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[69] Marie Curie (2020). The vicious cycle of fuel poverty and terminal illness.

[70] National End of Life Care Intelligence Network (2012). Deprivation and death: Variation in place and cause of death.

[71] Macfarlane, M and Carduff, E (2018). Does place of death vary by deprivation for patients known to specialist palliative care services? BMJ Support Palliat Care, 8 (4).

Out of Hours (OOH) advice and support from specialist palliative care professionals and palliative care pharmacy is not routinely available to all health and social care teams in all locations across Northern Ireland. Where advice is available, this is usually done on an ad hoc, historical or good will basis. Specialist palliative care provision is currently only available on a Monday- Friday 9-5pm basis with no formalised out of hours provision.

In addition there are challenges in ensuring equitable access for all sections of the population, particularly seldom-heard and underrepresented sectors e.g. LGBTQ+ people, those from ethnically diverse backgrounds, people with cognitive impairment such as those with dementia, those experiencing homelessness, people in long-term institutional care including prison care, the ageing and frail population, and those living in rural and remote areas.

We will arrange equitable access to palliative and end of life support and continuity of care for all people with non-curative cancer 24 /7.

Advance care planning (ACP)

In Northern Ireland, there remains a significant taboo around discussing death and dying. This inevitably can result in conversations about palliative care being put off until the advanced stages of a person's condition, because of the association with the end of life stage. This can foster an attitude where palliative services are only considered once all active treatment options have been exhausted.

Advance Care Planning is an important part of routine health and social care practice, to ensure that people have the opportunity to have realistic and practical discussions about where and how they would like to be cared for at the end of their life. It gives a person the chance to think about what matters to them and to consider and record their wishes and preferences for end of life care including decisions in relation to Advance Decisions to Refuse Treatment (ADRT) and Cardiopulmonary Resuscitation (DNACPR). Advance care planning (ACP) plays an important role in ensuring that a person is given the opportunity to be involved in shared decision making and to state preferences and wishes which can be recorded and communicated to those involved in their care. The development of Regional Advance Care Planning Policy for adults in NI is to be welcomed.

Education and training should equip health and social care staff to have regular, meaningful, timely, realistic and practical conversations with people about their diagnosis, prognosis, treatment options and planning for the future. It is particularly important that communication with patients and loved ones is carried out in a sensitive and compassionate manner.

We will support people and their carers to discuss their wishes and preferences for care at the end of life and ensure that this is recorded in a shareable format with the relevant people.

Pre-bereavement and bereavement support

Most bereavement services in Northern Ireland are provided by the community and voluntary sector. Capacity is an issue, with long waiting lists in many areas. Capacity issues are also preventing Trust social work teams from offering greater levels of bereavement support, including follow-up services with carers and loved ones. Patients and their loved ones may have access to chaplaincy support in the hospital setting, but these services will normally cease after discharge, so continuity of care does not continue into the community. Day-to-day support is likely to have been provided via the services delivered to their loved one but these are withdrawn after death. The loss of this support network can compound feelings of loneliness and isolation among recently bereaved carers.

Access to pre-bereavement and bereavement support is crucial to meeting the holistic needs of carers and loved ones. It is vital that we adopt a wider approach and ensure that those important to the person living with cancer, including children, are not forgotten. This type of early intervention and support can be helpful in preventing mental health issues connected to early/traumatic loss and complex grief reactions.

We will arrange timely access for all people living with non-curative cancer, and those important to them, to the bereavement/psychosocial/counselling/chaplaincy services appropriate to their needs and preferences before and after death, across all care settings.

The recommendations outlined for palliative and end of life care align closely with the regional priorities of the Palliative Care in Partnership (PCiP) programme and many are already included in the regional palliative care work plan. The PCiP programme is well established and would be well placed to oversee the implementation and delivery of these recommendations. The recently re-established bereavement group will be taking forward the development of bereavement services for NI and our expectation is that this will include services for cancer.

Governance

The Cancer pathway is complex and interfaces with all aspects of health and social care. Effective governance arrangements, combined with a focus on prevention, early diagnosis, evidenced based treatment and support services are crucial, to ensure that the recommendations of the strategy are implemented.

The strategy provides the strategic direction and key steps to achieving the overall vision for a world class cancer service for NI. It presents a comprehensive and challenging programme of service stabilisation and improvement, reliant on collaborative working and new and innovative approaches to the delivery of care. Many of these require coordinated regional approaches and are likely to be challenging to achieve within the current service commissioning and Trust-based delivery structures.

In order to meet these challenges a NI Cancer Programme Board, with strong clinical leadership, will be established which will include people with lived experience of cancer. The Board will align all parts of the existing structure and oversee the delivery of the strategy. A robust suite of regional key performance indicators is necessary to monitor the implementation of the strategy as part of ongoing evaluation arrangements. In addition consideration will be given to linking funding to the delivery of outcomes and achievement of KPI's. This strategy will be a live document which will evolve as new evidence, technologies and information emerges. Formal evaluation and review of progress will be integral to the implementation of the strategy, with reporting required at the end of year 3 and at subsequent intervals, in addition to a formal annual report.

In order for the delivery of the strategy to be realised over the next decade collaboration will be crucial. This will involve maintaining and building on the many successful developments implemented over the past year in response to the pandemic, and learning from what could have been done better. Collaboration between HSC organisations, across sectors and with people affected by cancer including families and carers will be a key enabler to effecting meaningful change.

Delivery at this scale and speed will require investment in planning and project support infrastructures both within Trusts and across Clinical Networks, in particular The Northern Ireland Cancer Network (NICaN).

NICaN is a regional clinical network that links together the organisations that provide care for people with cancer across the five Health and Social Care Trust areas. NICaN is a partnership of Health and Social Care organisations, academics, charities, cancer specialists and service users, working in collaboration to deliver safe and effective care, improve cancer clinical outcomes and to enhance patient's and carer's experience and quality of life. NICaN, however is currently under resourced with key posts sitting vacant, which has an impact on its ability to provide an effective service. The dissolution of the HSCB planned for 2022 also creates difficulties in filling posts.

There is also a compelling need for NICaN to have access to an enhanced data analysis function. This would support evidence based decision making for both performance management and strategic decisions regarding service provision.

We will set up a clinically led, managerially supported NI Cancer Programme with sufficient resources to oversee the implementation and delivery of the cancer strategy implementation plan. This will be data driven and will include commissioning of cancer services and further policy development.

We will restructure the NI Cancer Network and ensure it is supported and resourced to implement the strategy and to deliver a world class cancer service.

Workforce and Training

Many cancer services are struggling to deliver in a timely manner, with escalating waiting lists in many areas including diagnostics and surgery. The immense pressures the HSC, including all those involved in cancer services, have been put under over the past year as a result of COVID-19 is fully recognised, which has served to increase pressure on an already stretched workforce. Creating a sustainable workforce to care for those with a cancer diagnosis must be an integral part of the Cancer Strategy.

Oncology and haematology services were fragile pre-COVID-19 with services often dependent on small teams and in some instances single-handed consultant practice. Multidisciplinary team work is an essential component of cancer care involving a wide range of health and social care professionals across both primary and secondary care. There is, however unequal provision across tumour sites and across Trusts.

Diagnostic services are the first step in confirming a cancer diagnosis. There is currently a UK wide shortage of radiologists which has an impact on the timeliness of investigations and results. Endoscopy services are under extreme pressure across all trusts and are struggling to meet the growing demand. Likewise pathology services continue to struggle with increasing demand which has been compounded by the COVID-19 pandemic. Our ambition to improve diagnostic services and to diagnose more cancers earlier cannot happen without significant investment to modernise and develop the diagnostic workforce.

Oncology services workforce planning and modelling was undertaken as part of the Oncology Services Transformation work in 2019. A blueprint was developed for a range of roles including nursing, pharmacy, allied health professionals and doctors. The implementation of this plan is not progressing as planned due to funding constraints and as a priority must be implemented in full. If we are to ensure sustainability of services for the future a similar workforce plan must be developed for haematology as a matter of urgency.

Looking forward, the role of genomic medicine will have a significant impact on how we deliver cancer care. This will require a substantial increase in clinical scientist expertise.

In order to provide the optimum care and support for people living with cancer we must ensure that all those diagnosed with cancer have the support of a clinical nurse specialist (CNS) across the entire cancer pathway. Currently not all people have a CNS and for many others the support stops after surgery. In particular there is a recognised deficit for those diagnosed with metastatic disease.

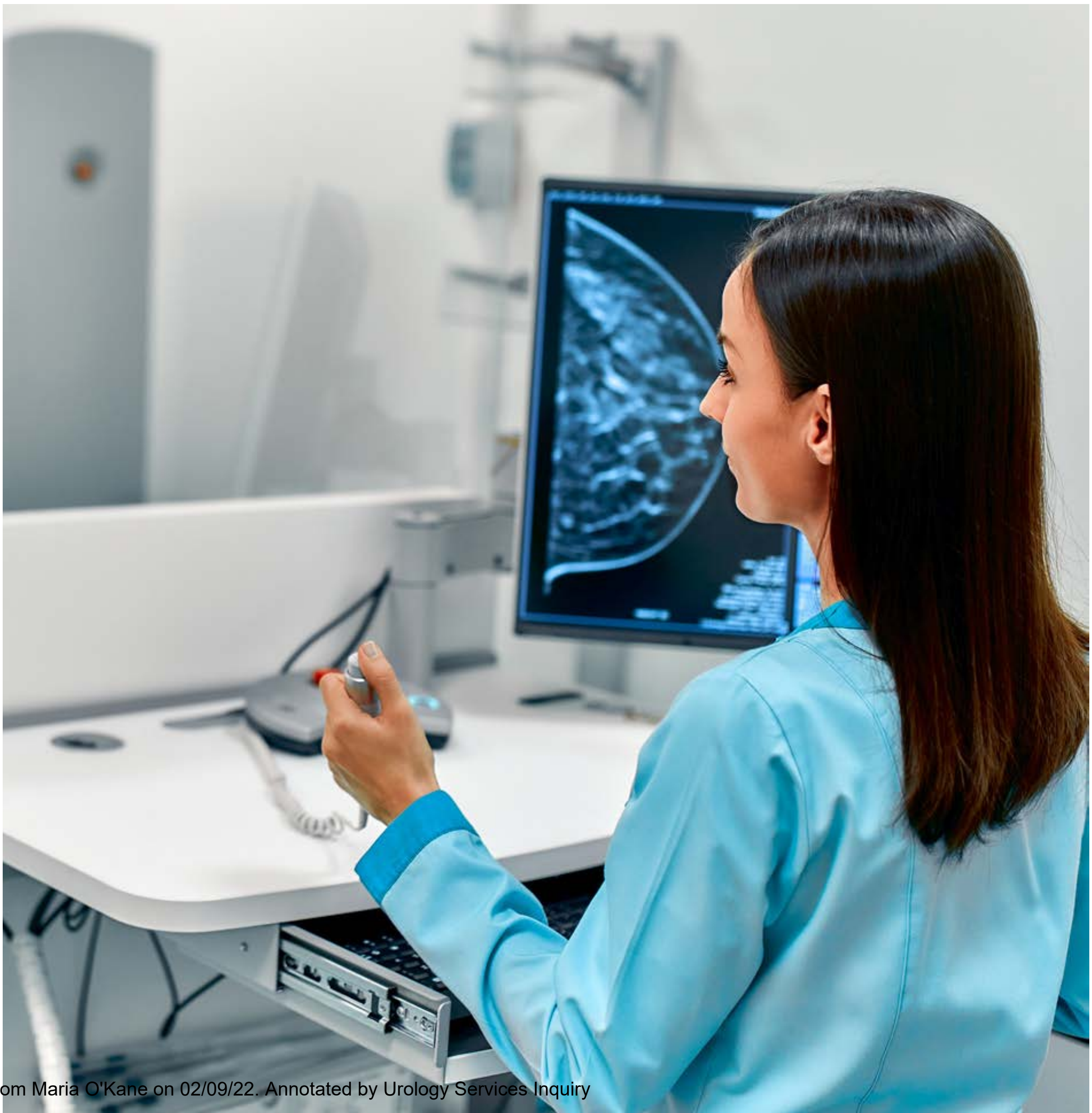
Allied health professionals have a key role across the cancer pathway including diagnostics, the provision of prehabilitation and rehabilitation services, providing palliative care and support for people at the end of life.

Psychology services are vastly oversubscribed with waiting lists across NI. A new model of service provision is required to ensure that all those who need psychological support have access to appropriate services.

The challenge that lies ahead cannot be underestimated. While workforce planning has been undertaken or is underway in some specialties or professional groups, there is a compelling need to review the multidisciplinary cancer workforce as a matter of urgency. The workforce has grown in recent years but growth has not kept pace with the exponential rise in demand for diagnosis, treatment and ongoing care.

Over the past decade there have been many major new developments in diagnosing and treating cancer including PET scanning; cytosponge, proton beam radiotherapy, immunotherapy and robotic surgery. Changes in the provision of care, type of treatments and procedures all have an impact on the workforce required to deliver the service.

In addition to an anticipated increase in numbers of staff required, we must address the appropriate skill mix, career pathways, training and retention of staff across the wide range of professions essential for the delivery of effective and efficient cancer services. The current service model for oncology is largely delivered by medical consultants supported by a wide range of other health professionals. The Oncology Services Transformation Plan (2019) clearly demonstrated the need to move towards a consultant led service, with more services delivered by advanced nurse and AHP



practitioners, in line with best practice internationally. As we move towards the new model we need to be mindful of the lead in time required to train and develop staff. It should also be noted that increasing the numbers of non-medical prescribers and advanced nurse and AHP practitioners is associated with a knock on effect on medical consultants who will be tasked with providing training, mentorship and supervision.

Multiprofessional education and training for staff at all levels and in all settings will be an essential enabler for the successful delivery of this plan. A comprehensive training programme must be developed and must be aligned with the new workforce plan adopting a regional approach to training. Our expectation is that multiprofessional training should be the norm going forward.

We will develop and implement a regional, multiprofessional workforce plan to ensure we have the appropriately skilled staff available to deliver cancer services for the future.

We will develop a regional, co-ordinated approach to training aligned with the workforce plan.

Communicating with people affected by cancer

Communication lies at the heart of health care delivery. What people value most highly are good patient–professional interactions and being treated as a person. There is little doubt that communication between cancer patients and staff could be improved.

Breaking Bad News Regional Guidance For NI was published in 2003.[72] This guidance outlines a pathway for medical and other professional staff to deliver bad news to patients, clients, their families and carers. Studies have consistently shown that the way a doctor or other health or social care professional delivers bad news places an indelible mark on the doctor/professional-patient relationship.

Communication skills training is a requirement set out in NICE Guidance from 2004. Staff working in cancer care have access to various approaches and tiers of communication skills training matched to their role and facilitated through a range of providers. The current Advanced Communication Skills Training model has been in place in NI since 2009 and on-going evaluations demonstrate it has been positively received and had a significant impact on patient care and clinical experience. To date, the majority of this training has been provided by charitable funding. There are ongoing issues with releasing staff to attend training and having adequate trainers to deliver the training across the service.

There is a specific challenge for parents who have been diagnosed with cancer in how best to communicate their diagnosis to dependent children,[73] with evidence highlighting a lack of support and guidance from health care professionals (HCPs). Most HCPs (90%) have had no training in initiating and facilitating this parent-child communication.[74] This is also an issue for parents of children who have been diagnosed with cancer in how to communicate the information to siblings.

We will ensure that all health care professionals who are expected to carry out sensitive communication complete an advanced communication skills training programme.

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[72] breaking_bad_news.pdf (headandnecktrauma.org)

[73] Semple & McCance Semple CJ & McCance T. (2010) Parents' experience with cancer who have young children: a literature review. Cancer Nursing 33 (2) 110 –118

[74] Semple CJ, McCaughan E & Smith R. (2017) How education on managing parental cancer can improve family communication. Cancer Nursing Practice 16, 34 – 40

Understanding the experience of people living with cancer

The ambition must be to put people's experience and quality of life on a par with other clinical outcomes such as survival.

Ongoing information from patient groups, third sector organisations and data from service user feedback systems such as Care Opinion and 10,000 Voices is invaluable in highlighting the experience of people living with cancer. There is, however a recognised lack of information on the impact of treatment and long term effects on people's lives. This reflects the lack of simple mechanisms by which patient related outcomes and experience measures can be digitally gleaned and added to clinical records. Reliance on questionnaires, delivered separately or not directly linked to care delivery is inadequate.

At a population level in NI the only tool currently used to measure patient experience is the Cancer Patient Experience Survey (CPES). This has been carried out twice over recent years and both surveys have reported high levels of satisfaction with over 90% of people reporting their care as excellent or very good but has been postponed for 2021 due to the pandemic. CPES provides insight into the experience of people living with cancer locally and can be benchmarked with similar studies elsewhere in the UK. The methodology is reliant on participants being willing and able to take part, and as a result people with less survivable cancers, and those from more marginalised communities tend to be poorly represented. To date, the inclusion criteria is for those over 18 years of age. Consideration must therefore be given as to how the experience of younger people can be measured.

Patient Reported Outcome Measures (PROMs) represent a more person centred approach to capture and address unmet supportive care needs. While interest exists in PROMS within clinical practice, there is no consistency in the tools or approach taken. The Scottish Cancer Recovery Plan (2020)[75] has committed to provide national support to assessing the potential and value of digital PROMs. Learning from this will be invaluable going forward. In addition NHS England has committed to the introduction of an innovative quality of life metric to track and respond to the long-term impact of cancer. When available, consideration should be given to adopting this for use in NI.

A key outcome of this strategy must be improved experience for all people living with cancer in NI and in order to achieve this we need effective means of gathering the information.

We will undertake a Cancer Patient Experience Survey every 2 years to measure the experience of people living with cancer across NI.

We will ensure a regional approach to the implementation and measurement of Patient Reported Outcome Measures.

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[75] Recovery and redesign: cancer services - action plan - gov.scot (www.gov.scot)

Data

Cancer can affect all aspects of a person's life, therefore the information we collect is crucial to understanding how the delivery of services can be improved for the future.

While HSC currently collects a huge amount of data using a myriad of both manual and electronic formats COVID-19 highlighted difficulties in using this data. Northern Ireland lags behind other UK nations in the range of cancer data it collects, ease of access to and use of the data that is collected, and linking of data which may be collected in different ways. This has led to widespread frustration and dissatisfaction with the inability to link this information and to access routinely collected information from all of the information technology systems.

Accurate data is vital to underpin all decisions including: commissioning; service improvement and development; performance management and future planning. It is vital that common data sets are developed, agreed and used uniformly across the service.

The collection of data on cancer treatment in England was a cornerstone of their first cancer strategy in 2000, initially with the development of the National Cancer Intelligence Network, and more recently, the implementation of the mandatory COSSD reporting system for cancer. This provides "real-time" data to inform cancer commissioning and results in the annual publication of National Cancer Audits.

The lack of routine prospective data collection of cancer treatments and outcomes in Northern Ireland makes assessment of the organisation and effectiveness of cancer services difficult. This highlights the need for Northern Ireland to routinely collect data against the defined minimum datasets for cancer and to submit to National Cancer Audits, to allow, not only benchmarking against cancer outcomes elsewhere in the UK, but also interpretation of local data on service provision required to inform and deliver service improvements.

Whilst primary legislation to allow the secondary use of data is in place, the subsequent establishment of a regulatory and legislative framework has not been completed. These regulations are necessary to allow the legal submission of NI data to National Cancer Audits. Work to progress this legislation is currently underway and is expected to be presented to the Executive in due course.

Developing a method of collecting information once, and making it easily accessible to all stakeholders is paramount. There are multiple stakeholders who need better information in order to provide safe and effective care. The current systems in place are often old, technologically separated and poorly suited to the task, with significant challenges in the extraction of data and visualisation of trends.

Paper records remain dominant, and records are rarely formally linked from primary care through to secondary care and vice versa. Additionally, we need effective integration of data from services provided in the independent sector. This often goes unrecorded unless patient care reverts to HSC organisations.

Data security and privacy are of critical importance; however, fears about the use of data should not limit our ambition. Good data governance allows data to be used for the benefit of both patients and the service.

The NI Cancer Registry (NICR) is located in the Centre for Public Health, Queen's University Belfast and is funded by the Public Health Agency for Northern Ireland. The registry was established in 1994 and a key function is the production of annual official statistics on cancer incidence, prevalence and survival in NI. This includes data on screening, incidence and survival by age, sex, cancer type, variations due to deprivation, stage of disease, treatment and support services received.

The registry has a wealth of expertise in the coding and analysis of healthcare data in cancerous and precancerous conditions. The level of knowledge within NICR is world leading, and with correct technology support and access to the live working systems of HSCNI their impact could be even greater.

Encompass/IT Systems

The new Encompass IT system (see page 80) is a critical part of the digital future of HSC. It will be transformational in its scope and will deliver a paper-less system in secondary care and enable much greater integration across acute and community services and social care. Encompass will replace many of the disparate systems in place currently and will add greater functionality.

It will also provide safe and protected individual data on the care provided with every clinical interaction coded in real-time by the care provider. A central component of Encompass is a patient portal, which will bring citizens closer to the care providers and will enable great transparency and communication between everyone involved in the care pathway.

The programme will start in South Eastern Trust in 2022 and roll out across NI over the following 2 years. In the interim there is a compelling need to develop and improve data systems which will be compatible with Encompass going forward.

We will carry out a review of the use of data and alignment with Encompass in cancer healthcare, at a minimum:

a. We will carry out a formal review of the NI Cancer Registry's role and responsibilities and will expand their remit if required.

b. We will fully engage with our stakeholders regarding the optimum use of data in cancer care and ensure that the data we collect is used to ensure that we can provide better care for every patient.

c. We will establish a cancer data coordination function to facilitate a better strategic approach to cancer data in Northern Ireland.

Research

Within the Health and Social Care sector the provision of high-quality cancer care is a priority. Among all providers, there is a clear focus on the provision of person-centred services and on improving the experience of care. We also know that participation in cancer research improves outcomes for people across all parts of the patient pathway. Research is not an add-on to the delivery of normal care, but it is foundational in the delivery of excellence. There are decades of data demonstrating the link between active research and better outcomes in care delivery.

Northern Ireland has a rich heritage in cancer research. The work of HSC Research and Development (R&D) is based on the principle that the best health and social care must be underpinned by knowledge; based on well-conducted research, which can then be applied to the delivery of care. Cancer research in NI is conducted across a wide range of organisations including the NI Cancer Registry; HSC trusts; universities; cancer charities; private sector, and not for profit organisations. It is funded from a variety of sources, but there is potential for better co-ordination across organisations and an opportunity to influence research priorities for the future.

Challenges exist due to the lack of recurrent funding, fixed term contracts and no career structure for staff. Many consultants do not have protected time in their job plans to develop research interests. Barriers can also exist in implementing research findings into clinical practice.

The All Ireland Cancer Consortium (AICC) was set up in 1999 with the core aim of reducing cancer incidence and mortality on the Island of Ireland through cross-border and transatlantic collaborations in cancer research and education. This is a collaborative partnership between the Department of Health NI, Department of Health Ireland and the National Cancer Institute in the United States. Going forward the AICC has a crucial role to play in the development and implementation of evidence based outcomes for people affected by cancer in NI and beyond.

It is inevitable that there will be many significant advances in technology and new treatments over the life of this strategy. The pace of change in all aspects of cancer means that we must have more agile systems in place to adopt new innovations in a timely manner.

For the successful delivery of this strategy we must embed a culture in which data, research and intelligence are seen as core components for increasing public awareness, an improved uptake in screening, more efficient and timely diagnosis services, better treatment and care, and ultimately better outcomes for people living with cancer. It is therefore paramount that we optimise the involvement of people affected by cancer in formulating and developing research proposals.

We will develop an appropriate infrastructure to deliver a robust research function.

We will engage with universities and industry to ensure our workforce can deliver a world class cancer service and improve the outcomes for people affected by cancer.

Quality and Innovation

The Cancer Strategy aligns with the approach taken by the DoH 10-year Quality 2020 strategy and defines quality under three main headings:

- Safety – avoiding and preventing harm to patients and clients from the care, treatment and support that is intended to help them.
- Effectiveness – the degree to which each patient and client receives the right care (according to scientific knowledge and evidence-based assessment), at the right time in the right place, with the best outcome.
- Patient and Client Focus – all patients and clients are entitled to be treated with dignity and respect and should be fully involved in decisions affecting their treatment, care and support.

These themes cut across a number of key recommendations in the strategy, and in delivering the strategy we will enable a whole system quality assurance approach regarding the performance and quality of cancer care services and associated programmes across NI.

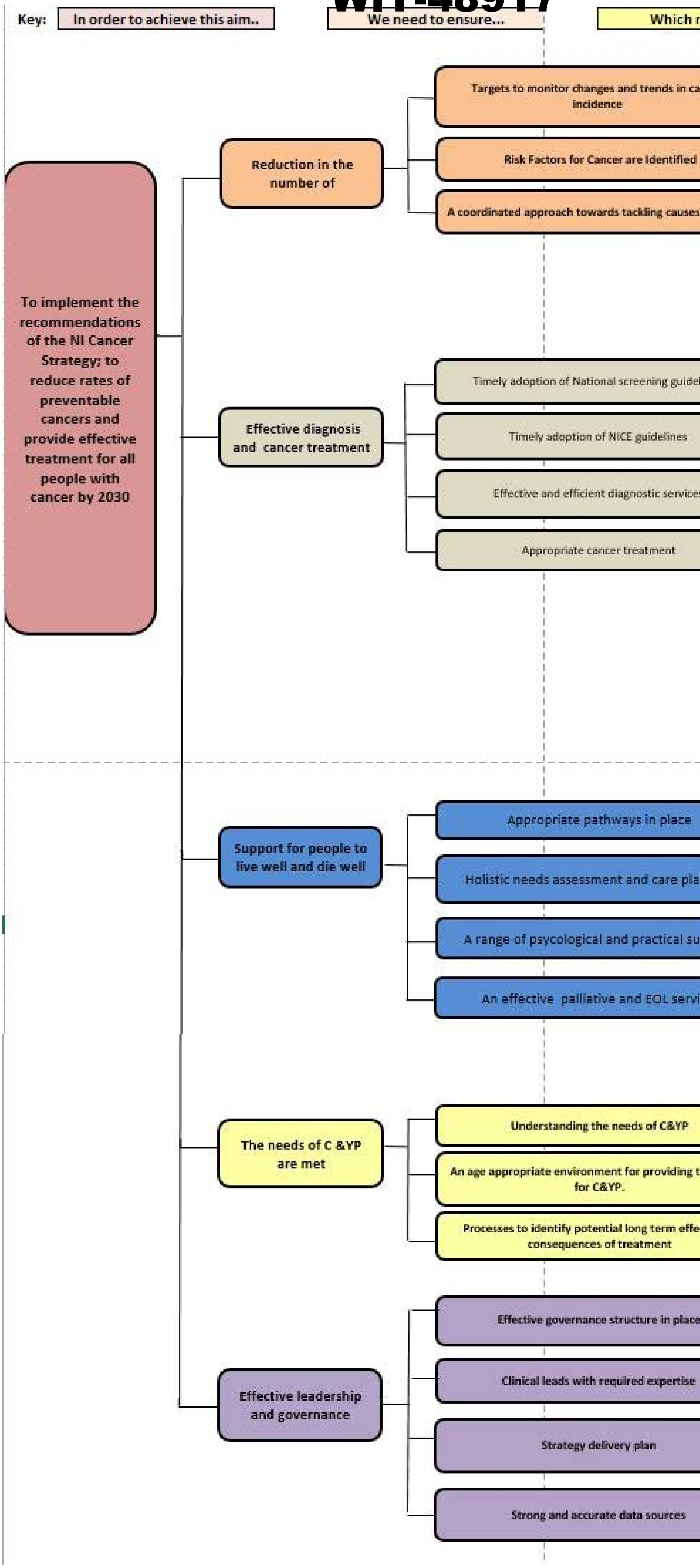
Data – our review of cancer service data requirements has highlighted that provision of accurate and timely information is a central requirement for any effective strategy of cancer control. Such information underpins evidence-based and informed decision making by policy makers, researchers, health professionals and patients.

Workforce – our development of a regional, multiprofessional workforce plan to deliver cancer services together with an aligned comprehensive training programme will ensure that appropriate skill mix and safe levels of staffing are maintained across all specialisms.

Governance – the setting up of effective assurance and accountability arrangements across the HSC system will ensure that regular monitoring and reporting of the implementation of the strategy will take place and that the aims and direction continue to be appropriate to deliver optimum outcomes for patients.

Key Performance Indicators (KPIs) will be deceloped to measure how the health system is delivering on the objective for improvements in cancer care outlined in this strategy. They are essential to monitor the impact of the various elements of cancer control across the patient pathway and direct focus on improvement. Moreover quality indicators, including measuring patient experience and those focused on process and activity, are critical to provide systematic governance oversight of performance and capacity.

KPIs will also be used to focus attention on reducing unwarranted variation in performance and patient outcomes across organisations. The information gatheed will inform decision making in areas such as policy and resource allocation. Therefore, information must be collected, collated, analysed and reported to inform evidence based decision making.



Key: In order to achieve this aim.. | We need to ensure… | Which r

To implement the recommendations of the NI Cancer Strategy; to reduce rates of preventable cancers and provide effective treatment for all people with cancer by 2030

- Reduction in the number of
  - Targets to monitor changes and trends in ca incidence
  - Risk Factors for Cancer are Identified
  - A coordinated approach towards tackling causes
- Effective diagnosis and cancer treatment
  - Timely adoption of National screening guidel
  - Timely adoption of NICE guidelines
  - Effective and efficient diagnostic services
  - Appropriate cancer treatment
- Support for people to live well and die well
  - Appropriate pathways in place
  - Holistic needs assessment and care pla
  - A range of psycological and practical su
  - An effective palliative and EOL servi
- The needs of C &YP are met
  - Understanding the needs of C&YP
  - An age appropriate environment for providing t for C&YP.
  - Processes to identify potential long term effe consequences of treatment
- Effective leadership and governance
  - Effective governance structure in place
  - Clinical leads with required expertise
  - Strategy delivery plan
  - Strong and accurate data sources

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Ideas to ensure this happens

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of cancer

- Implement the recommendations in other relevant strategies eg the sun prevention and obsesity strategy and ensure alignment with other strategies eg mental health
- Support people living with cancer to live healthily to prevent cancer reoccuring
- Develop a coordinated approach towards genetics and chemo prevention
- Highlight the importance of good oral health and check ups
- Raise awareness within the population regarding causes of cancer and warning signs

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- Adopt measures to raise the numbers of people being screened
- Ensure patients receive effective communication from Primary Care through the system
- Ensure all patients have access to CNS and make specialist staff accessible to all patients, including MDT and MTM when required
- Develop process to ensure that all people are diagnosed as quickly as possible
- Ensure all patients are discussed at MDM to ensure the effective planning and delivery of treatment supported by electronic prescribing
- Develop an integrated person centred model of care
- Develop processes to ensure all patients are considered for participation in clinical trials
- Develop a fully integrated 7 day acute oncology service across all Trusts
- Develop processes to support the delivery of treatment close to the patient's home

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- Ensure that effective prehabilitation and rehabilitation services are in place for all patients who would benefit from it
- Implement a process of risk stratified follow up care
- Ensure that all patients and their GP are provided with an electronic treatment summary record
- Ensure all patients have access to therapeutic and practical support services
- Ensure equitable access to psychological support at all parts of the cancer journey
- Ensure timely palliative care services and advanced care planning are available for those that need it

reatment

cts and

- **Support children and their families to transition to adult services**
- **Ensure all C&YP are treated in an age appropriate environment**
- **Provide person and family centred care and support to include parents and siblings**

- **Set up an Advisory Board with required authority and strong clinical leads**
- **Ensure effective Cancer network(s) are in place**
- **Develop and implement a robust system of monitoring and reporting**
- **Implement effective project management processes**
- **Ensure alignment of all HSC data and IT systems and Encompass**

Appendices

Appendix 1 Cancer Strategy Recommendations

Preventing Cancer

1. We will take account of the learning and progress made through the implementation of the Tobacco Control Strategy and, when required will support the need for the development of a new Tobacco Control Strategy. We will raise public awareness of the links between tobacco and cancer.

2. We will take account of the learning and progress made through the implementation of the existing obesity strategy and when required will support the development of a new obesity strategy. We will raise public awareness of the links between obesity and cancer.

3. We will take account of the learning and progress made through the implementation of the skin cancer prevention strategy and when required will support the need for the development of a new strategy. We will raise public awareness of the links between skin cancer and cancer.

4. We will take account of the learning and progress made through the implementation of the substance use strategy. We will raise public awareness of the links between substance use and cancer.

5. We will raise public awareness of the risk factors and early signs of mouth cancer and the importance of regular dental check-ups for those at increased risk.

6. We will liaise with the Department of Agriculture, Environment and Rural Affairs and support the development and delivery of Northern Ireland's first Clean Air Strategy.

7. We will develop a co-ordinated approach towards chemoprevention and implement NICE guidance within an agreed timeframe.

8. We will make sure that Trusts have surveillance systems in place for conditions where there is clear evidence regarding the pre malignant potential of a particular condition to ensure people are not lost to follow up.

9. We will ensure that all people diagnosed with cancer have appropriate and targeted information and support to live well and reduce the risk of long term consequences and developing second cancers.

Diagnosing and Treating Cancer

10. We will deliver regular, effective, targeted evidence-based ‘Be Cancer Aware’ campaigns.

11. We will develop measures to increase uptake of all cancer screening programmes, particularly in seldom heard communities.

12. We will ensure that all UK National Screening Committee recommendations are implemented within an agreed timeframe.

13. We will review specialist screening IT systems and will allocate funding to upgrade/replace where needed.

14. We will work towards the implementation of NG12 or the most current NICE referral guidelines by 2024.

15. We will implement new diagnostic tests within an agreed timeframe after approval and recommendation.

16. We will ensure that people who have cancer are diagnosed as quickly as possible, with adequate staffing, infrastructure and equipment in place; this will include the development of diagnostic hubs.

17. To increase our regional cancer diagnostic capacity and meet increasing demand through innovation, transformation and modernisation we will develop effective working relationships with the Regional Medical Imaging Board, the Pathology Network and Endoscopy Network.

18. We will introduce a 28-day diagnosis standard which tracks the time for all people from first referral for suspected cancer to confirmation of a cancer diagnosis, and includes all diagnostic and staging investigations.

19. We will give consideration to the delivery of cancer surgical services alongside any future recommendations for the delivery of emergency and elective surgery.

20. We will develop a plan for the introduction and implementation of new surgical technology over the next 10 years.

21. We will develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit.

22. We will implement Enhanced Recovery After Surgery programmes on a regional basis for all appropriate major cancer surgery.

23. We will implement in full the recommendations of the Oncology Service Transformation Project and the Oncology Haematology stabilisation plan by 2026.

24. We will agree a person centred model of care, which is effective and efficient, and which is built on learning from COVID 19 with increasing use of telehealth and technology and with standard operating procedures by 2022.

25. We will put in place service level agreements to ensure timely treatment where services cannot be provided in Northern Ireland due to specialist nature of services, technology constraints and low numbers of patients.

26. We will develop near to home phlebotomy services by 2023

27. We will review our model of delivery for Systematic Anti-Cancer Treatment services including the delivery of near/ close to home SACT treatments to patients by 2024 in line with the cancer recovery plan.

28. We will ensure that a safe and robust electronic prescribing system is used for all Systemic Anti Cancer Treatment regimes.

29. We will develop a robust and coordinated 24/7 metastatic spinal cord compression service with rapid access to gold standard imaging and treatment.

30. We will develop a fully integrated equitable 7 day acute oncology service across all Trusts.

31. We will commit to delivering genetic and genomic testing in cancer pathways in line with NICE recommendations

32. We will develop ambulatory care haematology units within each of the five Trusts and establish near to home treatment services for suitable patients.

33. We will ensure that all people including children and young adults are cared for in an environment appropriate to their needs.

34. We will ensure that future capital requirements of the level 3 haematology centre at Belfast Trust meets NICE NG 47 guidance.

35. We will consider the development of CAR-T services for NI.

36. We will ensure the development of appropriate pathways and services for older people with cancer, rarer cancers, teenage and young adults and people seldom heard.

37. We will ensure that every child diagnosed with cancer, and their carers, have access to staff with the specialist skills to provide holistic person centred care.

38. We will explore the potential for greater collaboration between Northern Ireland, Great Britain and the Republic of Ireland in the provision of children's oncology services.

39. We will review the provision of services for teenage and young adults in NI including transition arrangements, age appropriate environments, psychosocial support and long term follow up.

40. We will ensure that an effective Multi-Disciplinary Team meeting is held for all people diagnosed with cancer including cancer of unknown primary and metastatic disease.

41. We will facilitate as many people as possible; including children and young people to gain access to clinical trials

Supporting People to Live Well and Die Well

42. We will make sure that all people are offered a holistic needs assessment, an appropriate care plan is developed and they are signposted to relevant sources of help and support.

43. We will develop a comprehensive treatment summary record for all people diagnosed with cancer. On completion of their treatment, this will be provided to them and their GP.

44. We will make sure that all people are assessed and risk stratified to appropriate, high quality, follow-up pathways on completion of treatment.

45. We will ensure that all patients, including children and young people, diagnosed with cancer have access to a Clinical Nurse Specialist throughout the entire care pathway.

46. We will make sure that all people with cancer have equitable access to psychological support which is tailored and specific to their needs.

47. We will make certain that all those with a cancer diagnosis are referred to a Cancer Information and Support Service at diagnosis and advised of the range of services available across their entire cancer pathway.

48. We will ensure timely and appropriate access to therapeutic and practical support services for people affected by cancer targeting emotional, physical and social needs

49. We will make sure that all people starting cancer treatment have their health status assessed and recorded and a plan developed to mitigate potential late effects and consequences of their treatment.

50. We will develop an agreed regional, multidisciplinary approach to the identification and management of all people at risk of late effects and consequences of their cancer treatment.

51. We will identify people deemed to be at highest risk for late cardiovascular effects and enrol them in a follow up programme with appropriate imaging and with access to cardiology intervention as necessary.

52. We will regularly screen children to detect early, subtle cardiac abnormalities that might be treated, or may be reversible. In addition, where children are treated with anthracyclines or cardiac radiation they will have lifelong screening every 3 to 5 years.

53. We will deliver integrated, coordinated and personalised palliative and end of life care to people with non-curative cancer when and where they need it.

54. We will arrange a palliative care keyworker for all people with non-curative cancer when required.

55. We will arrange equitable access to palliative and end of life support and continuity of care for all people with non-curative cancer 24 /7.

56. We will support people and their carers to discuss their wishes and preferences for care at the end of life and ensure that this is recorded in a shareable format with the relevant people.

57. We will arrange timely access for all people living with non-curative cancer, and those important to them, to the bereavement/psychosocial/counselling/chaplaincy services appropriate to their needs and preferences before and after death, across all care settings.

Implementing the Strategy

58. We will set up a clinically led, managerially supported NI Cancer Programme with sufficient resources to oversee the implementation and delivery of the cancer strategy implementation plan. This will be data driven and will include commissioning of cancer services and further policy development.

59. We will restructure the NI Cancer Network and ensure it is supported and resourced to implement the strategy and to deliver a world class cancer service.

60. We will develop and implement a regional, multiprofessional workforce plan to ensure we have the appropriately skilled staff available to deliver cancer services for the future.

61. We will develop a regional, co-ordinated approach to training aligned with the workforce plan.

62. We will ensure that all health care professionals who are expected to carry out sensitive communication complete an advanced communication skills training programme.

63. We will undertake a Cancer Patient Experience Survey every 2 years to measure the experience of people living with cancer across NI.

64. We will ensure a regional approach to the implementation and measurement of Patient Reported Outcome Measures.

65. We will carry out a review of the use of data and alignment with Encompass in cancer healthcare, at a minimum:

    a. We will carry out a formal review of the NI Cancer Registry's role and responsibilities and will expand their remit if required.

b. We will fully engage with our stakeholders regarding the optimum use of data in cancer care and ensure that the data we collect is used to ensure that we can provide better care for every patient.

c. We will establish a cancer data coordination function to facilitate a better strategic approach to cancer data in Northern Ireland.

66. We will develop an appropriate infrastructure to deliver a robust research function.

67. We will engage with universities and industry to ensure our workforce can deliver a world class cancer service and improve the outcomes for people affected by cancer.

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Appendix 3 Glossary of terms

Age standardised

The rates are calculated by applying the age-specific rates for the location being studied to a theoretical world-wide standard population, usually expressed per 100,000 persons per year.

Adjuvant Therapy

Another treatment used together with the primary treatment. Its purpose is to assist the primary treatment. Also called adjunctive or adjunct therapy.

Benign

Not cancerous. Benign tumours may grow larger but do not spread to other parts of the body.

Brachytherapy

A type of radiation therapy where a radioactive source is placed in or near a cancerous tissue.

Cancer Incidence Rate

The number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population.

Cancer Prevalence

The number of people now living who have ever been diagnosed with cancer. It includes people diagnosed with cancer in the past as well those who were recently diagnosed.

Clinical Nurse Specialist or CNS

A clinical nurse specialist (CNS) is a nurse specially trained to provide expert advice on treatment and care for a particular type of cancer.

Colposcopy

A procedure that allows a physician to take a closer look at a woman’s cervix and vagina. It is used to check for precancerous or abnormal areas.

Cytosponge

A single-use device used to collect cells from the lining of the oesophagus. It is known as a ‘sponge on a string’ pill test. Cytosponge consists of a spherical sponge in a dissolvable capsule, which is attached to a thread.

Digital pathology

Means that pathology samples can be shared and interpreted in digital environment. This means that samples such as biopsies can be reviewed anywhere and allows greater flexibility in how we utilise our pathology staffing.

Endoscopy

A nonsurgical procedure used to examine a person's digestive tract using a long, thin, flexible tube called an endoscope.

Genomics

A discipline in genetics that applies recombinant DNA, DNA sequencing methods, and bioinformatics to sequence, assemble, and analyse the function and structure of genomes (the complete set of DNA within a single cell of an organism,

qFIT or the Faecal Immunochemical Test

A stool test designed to identify possible signs of bowel disease. It detects minute amounts of blood in the faeces and can help to identifying patient who may be at risk of bowel cancer.

Haematological malignancies

Types of blood cancers

Health and Social Care Board (HSCB)

A statutory organisation that arranges or 'commission' health and social care services for the population of Northern Ireland.

Holistic Needs Assessment (HNA)

A questionnaire that enables professionals involved in supporting patients to understand all of the care and support needs a patient might have from concerns about their physical health through to issues around emotional, spiritual and social support.

HPV or Human papillomavirus

A virus that can cause cervical and other cancers.

Immunotherapy

A treatment which uses the immune system to fight cancer. It works by helping the immune system recognise and attack cancer cells.

Invasive cancer

Cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues.

KPI or Key Performance Indicator

A quantifiable measure used to evaluate the success of an organization, employee, etc. in meeting objectives for performance.

Metastatic Cancer

The spread of cancer from the primary site to other places in the body.

Molecular Diagnostics

A technique used to analyse biological markers in the individual's genetic code in order to diagnose and monitor disease, detect risk, and decide which therapies will work best for individual patients.

Mortality rate

The number of deaths occurring in a specified population during a year, usually expressed as the number of deaths per 100,000 population.

Multidisciplinary teams

A group of health care workers who are members of different disciplines or professions each providing specific services to the patient.

Northern Ireland Cancer Network (NICaN)

Brings together Health and Social Care organisations, charities, cancer specialists and service users, to improve cancer outcomes and experiences for patients.

Prehabilitation

The process of supporting patients to enhance their functional capacity or fitness ahead of treatment to enable them to cope with the treatment and to improve their outcomes after treatment.

Public Health Agency (PHA)

The major regional organisation for health protection and health and social wellbeing improvement.

Rapid diagnostic centres/hubs

Are designed to provide earlier and faster cancer diagnosis by providing a single point of access to diagnostic tests for all patients with symptoms that might suggest cancer.

Safety netting

Is about ensuring that there is a management system in place to ensure that patients receive the appropriate diagnostics and treatment in a timely way.

Stage of presentation

The stage at presentation describes the severity of a person’s cancer based on the size and/or extent of the primary tumour and whether or not cancer has spread in the body.

Survival rate

The percentage of people in a study or treatment group who are alive for a given period of time after diagnosis

Systemic Anti-Cancer Treatment (SACT)

The two main types of systemic therapy are chemotherapy (which uses drugs) and hormone therapy (which uses hormones). It can be given to increase long-term survival, control tumour growth and sometimes manage symptoms arising from the cancer.

Appendix 4 Abbreviations

ACE programme
Accelerate Coordinate Evaluate programme

ACP
Advance Care Planning

ADRT
Advance Decisions to Refuse Treatment

ADOG
All Department's Officials Group

AHP
Allied Health Professionals

AICC
The All Ireland Cancer Consortium

AOS
Acute Oncology Service

BAME
Black, Asian and minority ethnic

CAR-T
Chimeric Antigen Receptor T cell Therapy

CaPPS
Cancer Patient Pathway System

CCR
Cancer Care Review

COSD
Cancer Outcomes and Services Dataset

CPES
2018 Cancer Patient Experience Survey

CRUK
Cancer Research UK

DNACPR
Do not attempt Cardiopulmonary Resuscitation

CT scans
Computerized tomography scans

ERAS
Enhanced Recovery After Surgery

HDU
High dependency units

HNA
Holistic Needs Assessment

ICU
Intensive Care Unit

JCVI
Joint Committee on Vaccination and Immunisation

KPI or Key Performance Indicator
A quantifiable measure used to evaluate the success of an organization, employee, etc. in meeting objectives for performance.

LINAC
A medical linear accelerator

LGBTQ+
Lesbian, gay, bisexual, and transgender queer and questioning

MRI Scan
Magnetic Resonance Imaging scan

MSCC
Malignant spinal cord compression

MDMs
Multidisciplinary meetings

NCEPOD
National Confidential Enquiry into Patient Outcome and Death

NICaN
Northern Ireland Cancer Network

NCIN
National Cancer Intelligence Network

NICTN
Northern Ireland Cancer Trials Network

NMSC
non-melanoma skin cancer

OST
Oncology Services Transformation Programme

PCiP
Palliative Care in Partnership programme

PET
Positron emission tomography

PROMs
Patient Reported Outcome Measures

PREMs
Patient Reported Experience Measures

PTC
Principle treatment centres

q-FIT
Faecal Immunochemical Test

TSR
Treatment Summary Records

WHO
World Health Organisation

Appendix 5 Steering Group Members

Name	Organisation / job Title
Charlotte McArdle	Chief Nursing Officer, Department of Health Chair
Brid Farrell	Public Health Agency, Public Health
Cathy Harrison	Chief Pharmacist, Department of Health
Dr Anna Gavin	Northern Ireland Cancer Registry
Dr Anne Kilgallen	Chief Executive Representative, Western Health & Social Care Trust
Dr Martin Eatock	Oncology, Belfast Health & Social Care Trust
Dr Miriam McCarthy/ Cara Anderson	Public Health Agency, Commissioning
Dr Naresh Chada	Deputy Chief Medical Officer, Department of Health
Dr Paul Molloy	General Practitioner Representative
Gay Ireland	Head of Cancer Policy/Cancer Strategy Project Manager, Department of Health
Heather Monteverde	Macmillan Cancer support/Chief Nursing Adviser, Department of Health
Ivan McMinn	Lived with experience/ Co-chair
Joan McEwan	Marie Curie
Joanne McClean	Public Health Agency, Paediatrics
Loretta Gribben	Public Health Agency, Nursing
Margaret Carr	Cancer Research UK
Mary Jo Thompson	Nurse Manager, South Eastern Health & Social Care Trust
Michael Bloomfield	Chair of Northern Ireland Cancer Network Board
Vivian McConvey	Patient Client Council

Pre-consultation Zoom Meeting with Parents of Children with Cancer. Artwork by Lucy aged 8.

Department of
Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

NATIONAL COUNCIL
FOR HOSPICE
AND SPECIALIST
PALLIATIVE CARE
SERVICES

Breaking Bad News
...Regional Guidelines

Developed from
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contents

Section 1 Breaking Bad News - Regional Guidelines

Department of Health, Social Services and Public Safety. Northern Ireland Group of the National Council for Hospice and Specialist Palliative Care.

These guidelines have been developed to assist clinical staff break bad news to patients, relatives and carers. While many of the themes are of a general nature, the emphasis of these guidelines are on breaking bad news to adults. The development of this document has drawn on the work of the Scottish Intercollegiate Guidelines Network (SIGN) and "A Guideline Developers' Handbook".

Scope and Purpose

"Breaking Bad News", outlines a pathway for medical and other professional staff to deliver bad news to patients, clients, their families and carers.

Stakeholder Involvement

This document has been developed as one part of the recommendations identified in the Regional Review of Palliative Care Services, 'Partnerships in Caring'.[1] The development of the "Breaking Bad News" guidelines was led by the Northern Ireland Group of the National Council for Hospice and Specialist Palliative Care, guidelines subgroup, whose membership is detailed in Appendix A.

Consultation on the detail of the guidelines involved the stakeholders outlined in Appendix D.

Rigour of Development

These guidelines for Breaking Bad News have been developed using the best research evidence available and have been externally reviewed by Professor Peter Maguire, Christie Hospital, Manchester.

The guidelines will be reviewed and updated in two years by the Northern Ireland Group of the National Council for Hospice and Specialist Palliative Care.

Applicability

These guidelines are applicable to all Health and Social Care Staff who are involved in breaking bad news to adult patients and clients.

Implementation

Local ownership of the implementation process is crucial to success in changing practice. For this reason the guidelines group is responsible for the development of the guidelines but not for implementation.

Implementation of the Regional Guidelines for Breaking Bad News is the responsibility of each HPSS Trust, HPSS and Voluntary Providers, in partnership with education providers and individual professionals.

A chart summarising the steps to take in breaking bad news is attached at Appendix B.

Section 2 Breaking Bad News
Guidelines for the Health and Personal Social Services

Background

No one likes breaking bad news. Although doctors and other professionals have always broken bad news the increase in chronic illness and the issues related to quality of life, heighten the importance of understanding how the delivery of bad news affects patients, their family /carers and doctors/other professionals.[2]

What is bad news?

Bad news can mean different things to different people. There have been numerous definitions of bad news including, "any information, which adversely and seriously affects an individuals view of his or her future"[3] or, in situations where there is either a feeling of no hope, a threat to a person's mental or physical well-being, risk of upsetting an established lifestyle, or where a message is given which conveys to an individual fewer choices in his or her life'.[4]

Examples include:
- A patient who is told they are HIV positive.
- The man who is told his partner has Alzheimer's disease.
- The patient who is told the lump has been diagnosed as cancer.
- The couple who are told they cannot have children.

The common denominator is that bad news is a message, which has the potential to shatter hopes and dreams leading to very different lifestyles and futures.

Bad news situations can include, disease recurrence, spread of disease, or failure of treatment to affect disease progression, the presence of irreversible side effects, results of genetic tests, or raising the issue of palliative care and resuscitation. Studies have consistently shown that the way a doctor or other health or social care professional delivers bad news places an indelible mark on the doctor/professional-patient relationship.

Whose information is it?

The issue of who to tell bad news to has been debated for many years. This has been given greater emphasis more recently with the Data Protection Act[5] and the European Convention on Human Rights, Article 8, the respect for private and family life.

There is some evidence that doctors are failing to inform patients when they diagnose cancer, particularly in older patients.[6,7,8] This is despite evidence that some patients with malignancy want to know if their illness is cancer, and others want to know as much as possible about their illness, often more than a doctor assume they want to know.[9,10,11,12]

At the same time it has been common practice in some areas to give relatives large amounts of confidential information without the expressed permission of the patient, and often before the patient themselves are aware of their condition. This practice ought to stop. While the ramifications of the Human Rights Act are not entirely clear, practitioners must make sure they respect the private and family lives of patients. While each case is different, clinicians must be careful to fully consider the needs of the patient and their family when they are disclosing information.

What are the skills required?

Breaking bad news is a complex communication task that requires expert verbal and non-verbal skills. This complexity can create serious miscommunications, such as the patient misunderstanding the prognosis of the illness or purpose of care.[13,14] When bad news is delivered poorly the experience may stay in a patient's or family's mind long after the initial shock of the news has been dealt with.[15] Where English is not a first language staff should avail of interpreting services. When patients have other special needs such as sensory impairment, learning or physical disabilities staff should ensure that the appropriate support mechanisms are available.

What do patients want?

The debate about the levels of truth given to patients about their diagnosis has developed significantly over the last few years. While doctors and professionals now increasingly share information it has been the practice to withhold information because it was believed to be in the best interests of the patient.[16]

The evidence indicates that patients increasingly want additional information regarding their diagnosis, their chances of cure, the side effects of therapy and a realistic estimate of how long they have to live.[17,18,19] Patients want their doctor to be honest, compassionate, caring, hopeful and informative. They want to be told in person, in a private setting, at their pace, with time for discussion and if they wish, with a supportive person present.[20]

What is the impact on you as a health care professional?

Breaking bad news can be extremely stressful for the doctor or professional involved. The evidence suggests that the bearer of bad news experiences strong emotions such as anxiety, a burden of responsibility for the news and fear of a negative response. This stress can result in a reluctance to deliver bad news.[21] When staff are uncomfortable breaking bad news they can avoid discussing distressing information, such as poor prognosis or convey unwarranted optimism to the patient that may predispose to depression.[22]

The process of breaking bad news can also have an adverse effect on those delivering the news. This is particularly evident when the doctor or professional is inexperienced, the patient is young, or there are limited options for treatment.[23]

Clinicians are often uncomfortable discussing prognosis and possible treatment options if the information is unfavourable. The evidence suggests that this is due to a number of reasons including:

- Uncertainty about the patient's expectations
- Fear of destroying the patient's hope.
- Fear of their own inadequacy in the face of uncontrollable disease.
- Not feeling prepared to manage the patients anticipated emotional reactions.
- Embarrassment at having previously painted too optimistic a picture for the patient.[24,25,26,27]

Patients and their relatives rely on professional staff breaking bad news as well and as effectively as they can. It is not always possible to get this very complex and emotional exchange of information right.

It is important to recognise the potential stresses that breaking bad news can cause. It is important, for all staff, including senior staff, to reflect on the experience as appropriate with their clinical supervisors, mentors or education facilitators as soon as possible after the event.

Communicating bad news to patients well is not an optional skill; it is an essential part of professional practice.