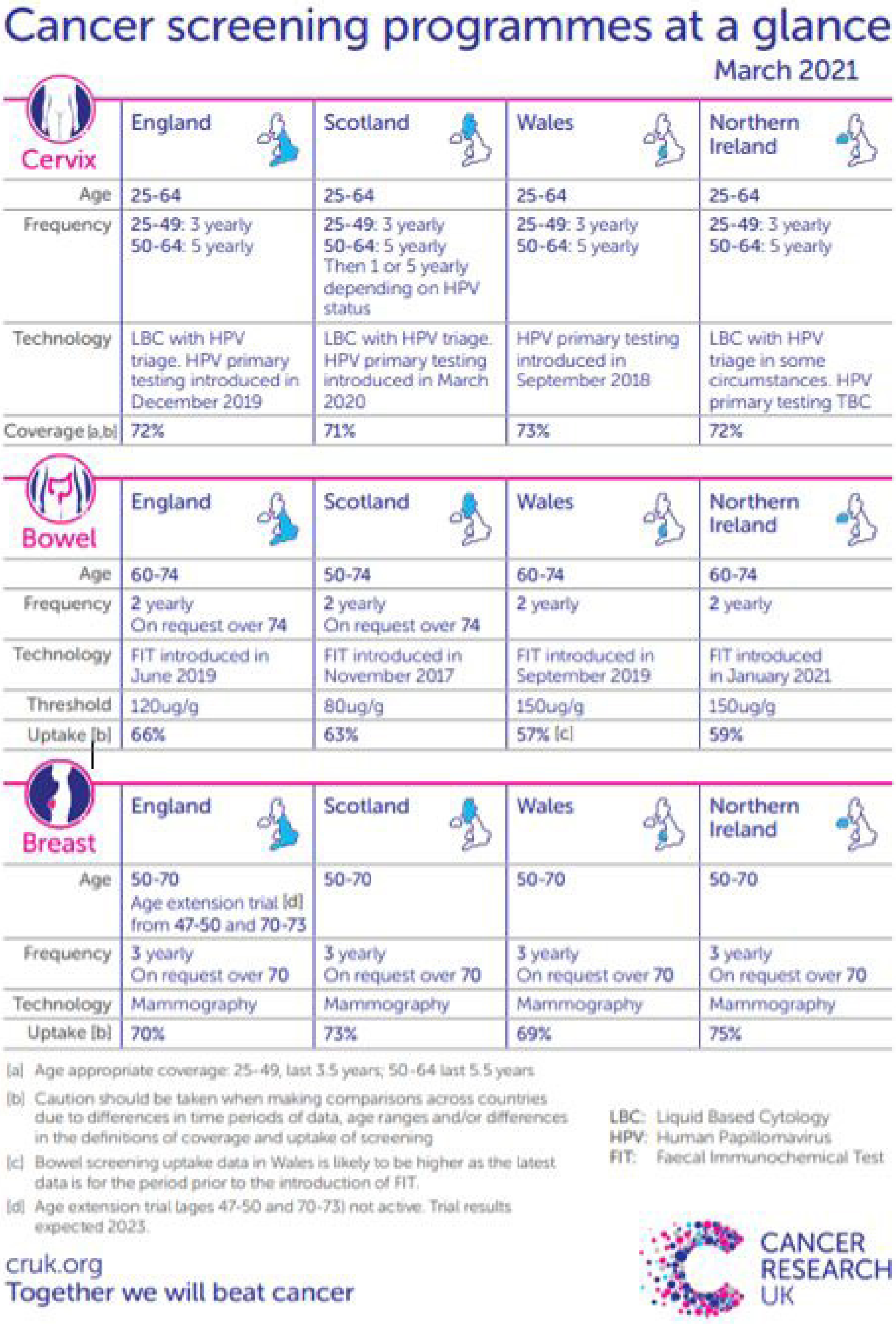


Cancer screening programmes at a glance

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

cruk.org
Together we will beat cancer

CANCER RESEARCH UK

---

[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

---

[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.

---

[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.

---

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

Reducing late stage diagnosis

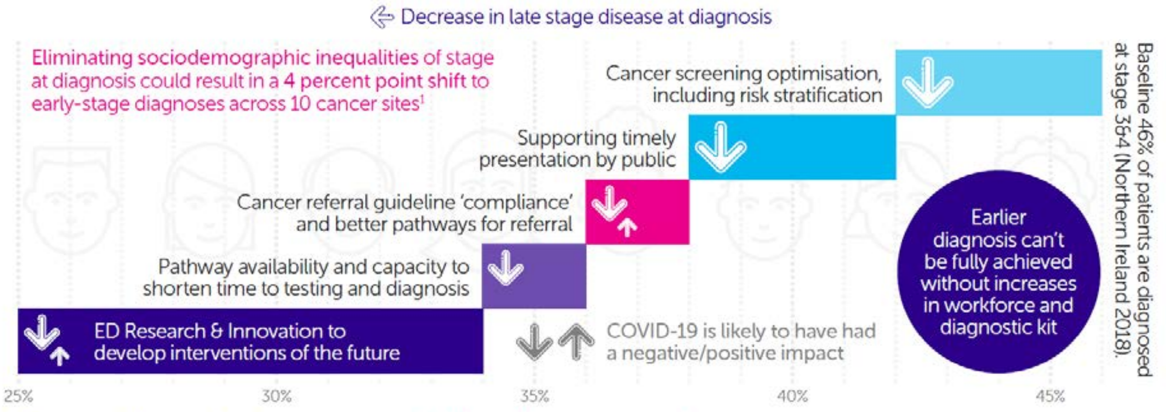
There is no one thing that will achieve a reduction in late-stage cancer diagnoses; we need to act together across a range of different interventions, and across the diagnostic pathway, in a coordinated and considered way.

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.

---

[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.

---

[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.

---

[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.

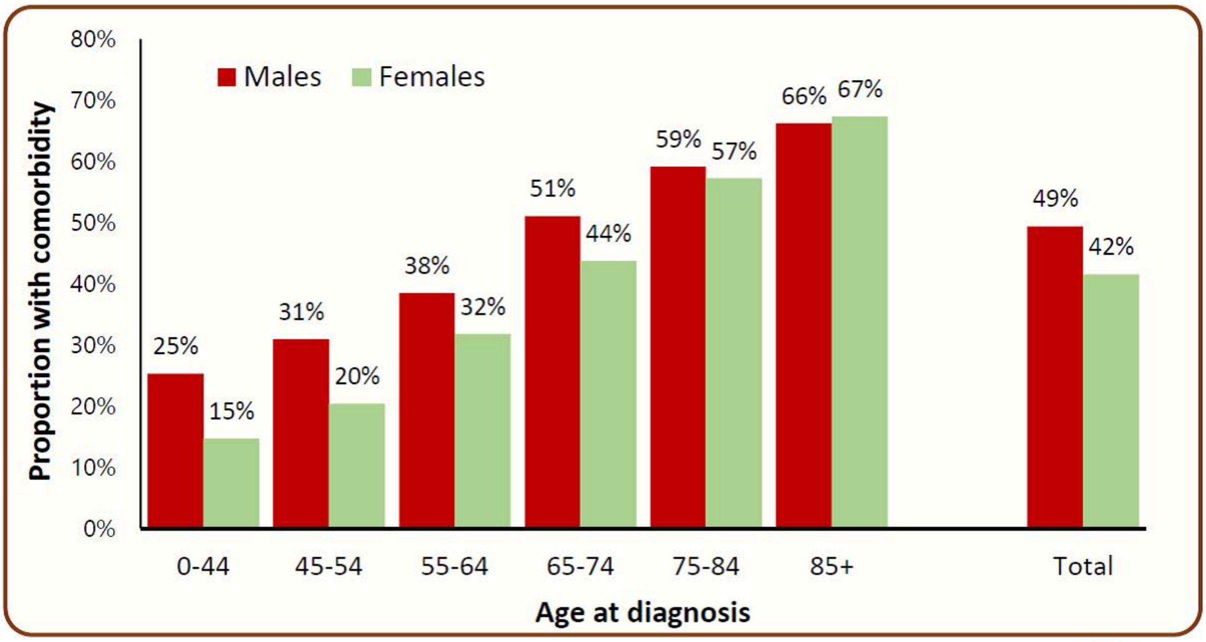
We will consider the development of CAR-T services for NI.

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

---

[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.

[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.

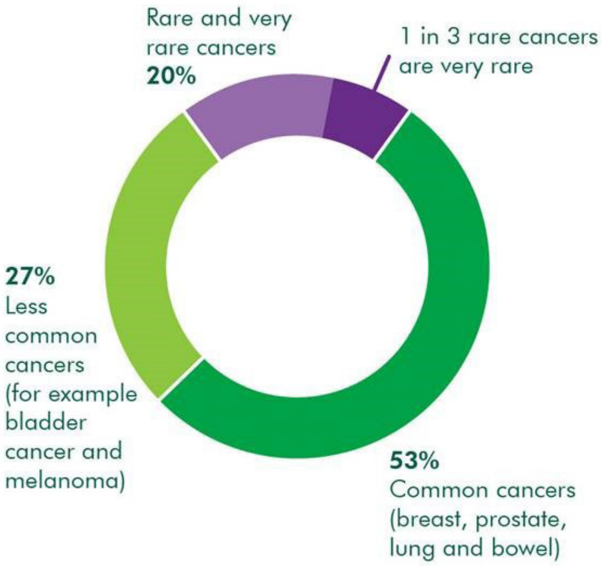
---

[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.

---

[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

---

[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)**
> ”

> “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.”

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 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.”**

---

[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.

---

[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

---

[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

---

[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 to live well and die well

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.**

---

[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]

---

[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

> 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.

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.

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.

---

[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.

---

[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

---

[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.

> **“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.”**

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

---

[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

[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]

---

[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.

---

[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.

---

[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.

---

[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

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.

> “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.”

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.

---

[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.

Implementing the strategy

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.

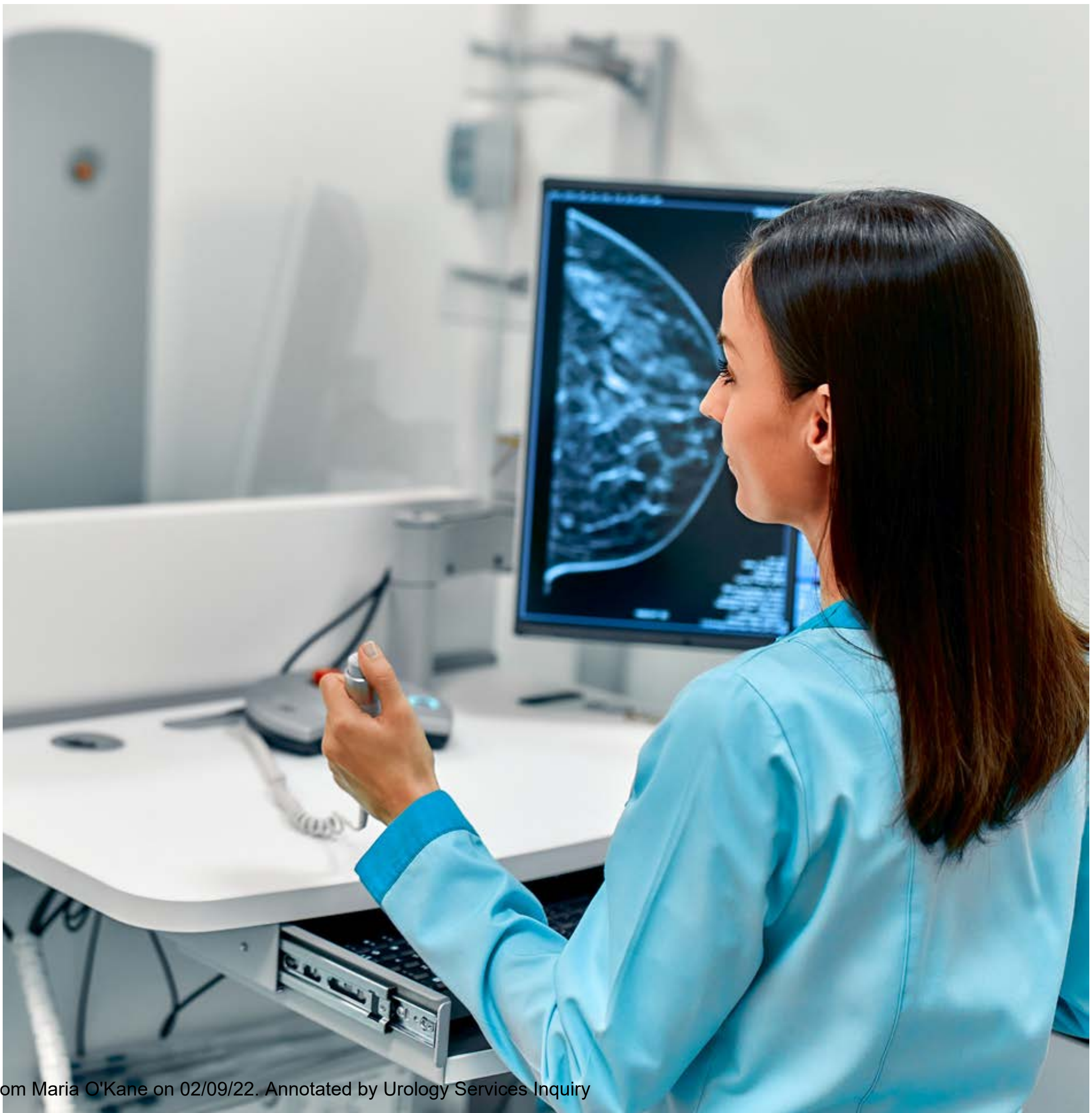
Allied health professionals have a key role across the cancer pathway including diagnostics, the provision of prehabilitation and rehabilitation services, providing palliative care and support for people at the end of life.

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.

---

[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.

---

[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.

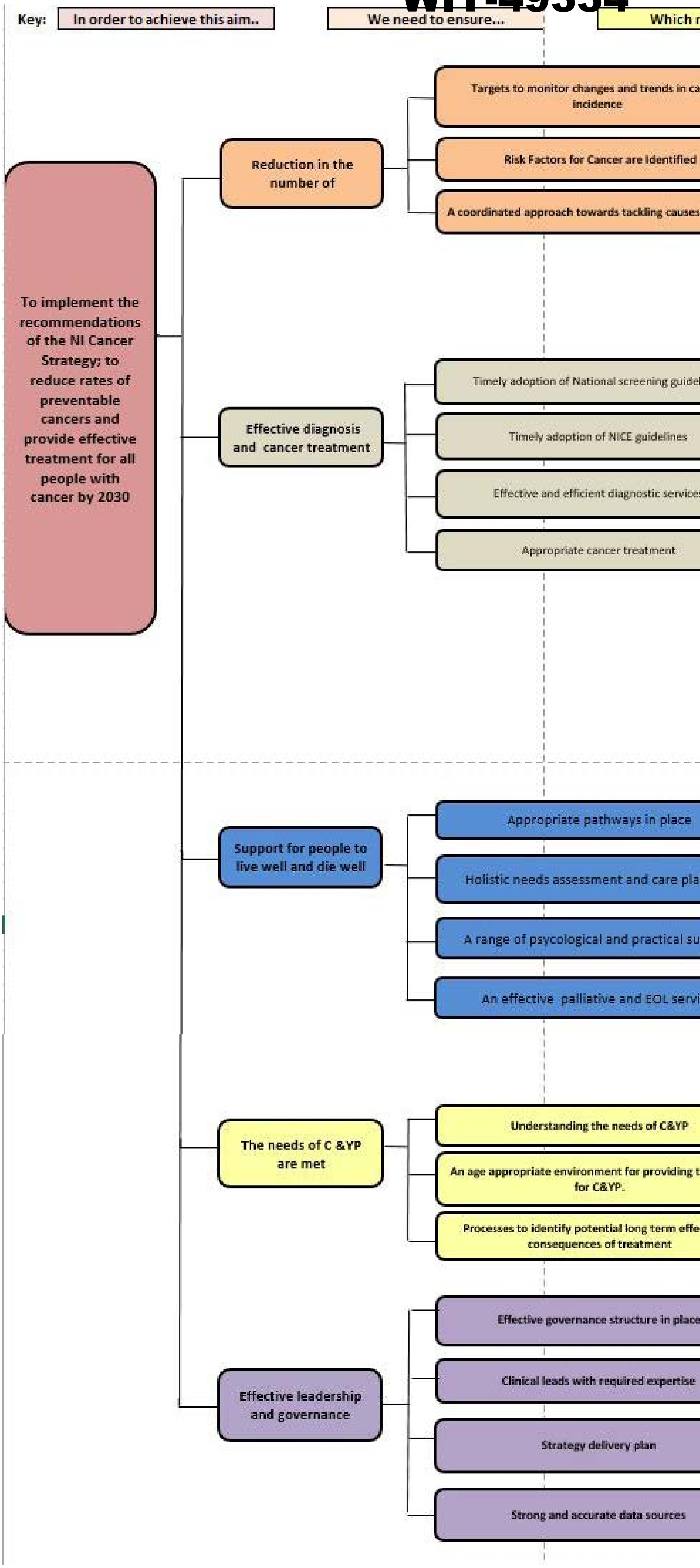
Data – our review of cancer service data requirements has highlighted that provision of accurate and timely information is a central requirement for any effective strategy of cancer control. Such information underpins evidence-based and informed decision making by policy makers, researchers, health professionals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

equires...

Ideas to ensure this happens

ncer

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

lines

s

- 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

nning

pport

ce

- 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.

Appendix 2 References

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)

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

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-

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)

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

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

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

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

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

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)

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

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

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

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

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.

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

28. Rare Cancers, Macmillan Cancer Support, Website

29.‘National Institute for Health and Clinical Excellence, Improving Outcomes in Children and Young People with Cancer -The Manual’ pdf

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

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

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)

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

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 - Draft v0.3 (hscni.net)

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

43.The Recovery Package Copyright © Macmillan Cancer Support 2013 RecoveryPackageDiagramJPG.jpg (2268×2489) (macmillan.org.uk)

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

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

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

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. 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

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

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

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.

61.ESMO Consensus Guidelines 2020 Management of cardiac disease in cancer patients throughout oncological treatment: ESMO consensus recommendations - ScienceDirect

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

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

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)

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

69. Marie Curie (2020). The vicious cycle of fuel poverty and terminal illness. pdf (mariecurie.org.uk)

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? - PubMed (nih.gov) BMJ Support Palliat Care, 8 (4).

72. DHSSPSNI (2003) Breaking Bad News Guidelines. DHSSPSNI, Belfast 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

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

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

HSC Southern Health and Social Care Trust

WHISTLEBLOWING POLICY

Policy Checklist

Name of Policy:	Whistleblowing Policy and Procedure for Raising Concerns at Work
Purpose of Policy:	The Public Interest Disclosure (Northern Ireland) Order 1998 was introduced to safeguard anyone who raises concerns, and this policy encompasses the requirements of that Order. The policy provides a mechanism for staff to raise concerns about a range of matters at an early stage and in the right way thereby developing a culture of responsible openness and constructive criticism regarding all aspects of the Trust's activities including clinical care.
Directorate responsible for Policy	Directorate of Human Resources & Organisational Development
Name & Title of Author:	Vivienne Toal - Head of Employee Engagement & Relations
Does this meet criteria of a Policy?	Yes
Staff side consultation?	Yes
Equality Screened by:	Vivienne Toal – Head of Employee Engagement & Relations
Date Policy submitted to Policy Scrutiny Committee:	30th March 2015
Policy Approved/Rejected/ Amended	Approved subject to amendments
Communication / Implementation Plan required?	Yes
Any other comments:	
Date presented to SMT	April 2015
Director Responsible	Mr Kieran Donaghy
SMT / Trust Board Approved/Rejected/Amended	Approved
Date returned to Directorate Lead for implementation (DHR& OD)	30th March 2015
Date received by Employee Engagement & Relations for database/Intranet/Internet	30th March 2015
Date for further review	March 2017

POLICY DOCUMENT – VERSION CONTROL SHEET	
Title	Title: Whistleblowing Policy Version: 2_0 Reference number/document name:
Supersedes	Supersedes: Whistleblowing Policy version 1
Originator	Name of Author: Vivienne Toal Title: Head of Employee Engagement & Relations
Policy Scrutiny Committee & SMT approval	Referred for approval by: Vivienne Toal Date of Referral: Policy Scrutiny Committee Approval SMT approval: As Above
Circulation	Issue Date: September 2017 Circulated By: Vivienne Toal Issued To: Directors, Assistant Directors, Heads of Service for onward distribution to staff.
Review	Review Date: March 2017 Responsibility of (Name): Vivienne Toal Title: Head of Employee Engagement & Relations

Southern Health
and Social Care Trust

Quality Care - for you, with you

WHISTLEBLOWING POLICY

AND

PROCEDURE FOR RAISING ISSUES OF CONCERN AT WORK

Author	Vivienne Toal, Head of Employee Engagement & Relations
Directorate responsible	Human Resources & Organisational Development
Date	March 2015
Review date	March 2017

Contents *Page No.*

1.0 Introduction to Policy 5

2.0 Public Interest Disclosure (NI) Order 1998 5

3.0 Purpose and aims 5

4.0 Policy statement 6

5.0 Scope of Policy 7

6.0 How we will handle your concern 7

7.0 Responsibilities 7

8.0 Equality & Human Rights Considerations 9

9.0 Alternative Formats 9

10.0 Copyright 9

11.0 Procedure for Raising Issues of Concern at Work 9

12.0 Sources of Independent Advice and Further Information 13

Appendices

Appendix 1 – External Contacts 14
Appendix 2 – List of Non-Executive Directors 15
Appendix 3 – Flowchart – Options for raising concerns 16

1.0 INTRODUCTION TO POLICY

The Southern Health & Social Care Trust is committed to promoting a culture of openness in which staff are encouraged to raise concerns without fear of reprisal and victimisation; and to ensuring that health and social care services are provided with the highest standards of integrity and honesty. The Trust expects all employees to maintain high standards in all areas of practice. All employees are therefore strongly encouraged to report any perceived wrongdoing by the organisation, its employees or workers that fall short of these principles.

Each of us at one time or another has concerns about what is happening at work. Usually these concerns are easily resolved. However, when they are about dangers to or ill treatment of service users, staff or the public, issues relating to the quality of care provided, patient safety, professional misconduct, unlawful conduct, financial malpractice, fraud, health and safety, or dangers to the environment, it can be difficult to know what to do.

You may be worried about raising such issues. You may want to keep the concerns to yourself, perhaps feeling it's none of your business or that it's only a suspicion. You may feel that raising the matter would be disloyal to colleagues, managers or the organisation. You may decide to say something but find you have spoken to the wrong person or raised the issue in the wrong way and are not sure what to do next. You may also not be clear how your own professional code of conduct relates to Trust procedures.

2.0 PUBLIC INTEREST DISCLOSURE (NORTHERN IRELAND) ORDER 1998

The Public Interest Disclosure (Northern Ireland) Order 1998 was introduced to protect anyone who raises concerns from detriment and / or dismissal, and this policy encompasses the requirements of that Order. The Order protects employees or workers who make “protected disclosures”, i.e. who reports wrongdoing within the workplace. This policy provides a process to enable employees or workers to inform the organisation about any wrongdoing in the workplace which they believe has occurred, or is likely to occur. Protection is against victimisation, disciplinary action or dismissal for employees who raise genuine concerns.

The Order 1998 has a tiered approach to disclosures which most easily gives workers protection for raising a concern internally. It is intended that this policy and associated procedure provide reassurance to staff who wish to raise such matters internally. Guidance from a range of regulatory / professional bodies encourages registrants to raise their concerns internally to ensure maximum level of protection under the Public Interest Disclosure Act.

Further details of the Order can be found using the following web address: http://www.pcaw.co.uk/law/pida.htm.

3.0 PURPOSE AND AIMS

Purpose

The Senior Management Team of the Trust is committed to running the organisation in the best way possible and to do so we need the help of those who work for us. We have this policy is place to reassure those who work for us that it is safe and acceptable to speak up and to enable all workers to raise any concerns that they may have at an early stage and in the right way.

There may be times when, after staff have raised a concern under this policy, it is deemed to be more appropriate to be dealt with differently. However this should not stop staff raising concerns under this Policy.

This policy aims to:

- Provide an avenue for you to raise a concern internally as a matter of course, and receive feedback on any action taken;
- Provide for matters to be dealt with quickly and appropriately and ensure that they are taken seriously;
- Reassure you that you will be protected from reprisals or victimisation for raising the concern in good faith;
- Allow you to take the matter further if you are dissatisfied with the Trust's response.

4.0 POLICY STATEMENT

The Trust would rather that you raised the matter when it is just a concern rather than waiting for proof. It is important to raise any concerns at an early stage, on the basis of any level of concern or relevant information. Indeed, if you have serious suspicions that an offence has been committed, you have a responsibility to report them as soon as possible. We all have a responsibility to protect the Trust, its service users, staff and public. **If in doubt – raise it!**

If something is troubling you that you think the Trust should know about or look into, please use the Procedure for Raising Concerns at Work – see section 10.0. You should never accuse individuals directly, and telling the wrong persons may jeopardise an investigation.

What we do ask is that in order to qualify for protection under this policy, you must:

- Act in good faith (effectively this means honestly) and

- Genuinely believe the information you are going to impart is accurate and
- Not act maliciously.

Our assurances to you

Your safety

The Chair, Chief Executive & Trust Board are committed to this Policy. If you raise a genuine concern under this Policy, you will not be at risk of losing your job or suffering any form of retribution as a result. Provided you are acting in good faith, it does not matter if you are mistaken. Of course, this same assurance is not extended to someone who maliciously raises a matter they know is untrue, and in such cases disciplinary action will be considered.

Your confidence

Confidentiality
The Trust will not tolerate the harassment or victimisation of anyone raising a genuine concern under this Policy. However, we recognise that you may nonetheless want to raise a concern in confidence. If you ask us to protect your identity by keeping your confidence, we will respect your request and it will not be disclosed without your consent. However a situation may arise where we are not able to resolve the concern without revealing your identity (for instance because evidence is needed in court, or the Trust has to act on the information), and this will be discussed with you in advance of any disclosure.

Anonymous allegations
Remember that if you do not tell us who you are, it will be much more difficult for us to look into the matter or to protect your position or to give you feedback. You are encouraged to put your name to any issue of concern you are raising. Allegations expressed anonymously and/or with little detail or information are much less powerful and more difficult to address but may be considered at the discretion of the Trust. Whilst we will give due consideration to anonymous reports, we cannot follow the procedure set out in Section 11.0 for any concerns raised anonymously. The Trust endeavours to promote a supportive environment in which you are able to express your concerns in confidence, thereby hopefully negating the need for raising concerns anonymously.

5.0 SCOPE OF POLICY

This Policy applies to you whether you are a permanent, temporary or bank employee. The Trust is also very dependent on a wide range of contractors, suppliers, and others not directly employed by the Trust such as agency staff, trainees, volunteers, secondees, or a student or anyone on a work experience placement – the policy applies to all individuals in these categories where there are concerns about the activities of the Trust.

6.0 HOW WE WILL HANDLE YOUR CONCERN

Members of staff, including students, can seek support and guidance from their Trade Union or professional organisation when raising a concern. Staff may be represented at any stage of the procedure by a trade union representative or colleague where appropriate.

Once you have told us of your concern, we will look into it to assess initially what action should be taken. This may involve an internal enquiry or a more formal investigation. We will tell you who is handling the matter, how you can contact him/her, the timescale for action and whether your further assistance may be needed.

All staff who raise a concern will be automatically allocated support from the Head of Employee Engagement & Relations or a nominated deputy throughout the investigation process in line with section 8.0.

When you raise the concern you may be asked how you think the matter might best be resolved. If you do have any personal interest in the matter, we do ask that you tell us at the outset. If your concern falls more properly within the Grievance Procedure we will tell you.

While the purpose of this policy is to enable us to investigate possible malpractice and take appropriate steps to deal with it, we will give you as much feedback as we properly can and confirm our response in writing. Please note that we may not be able to tell you the precise action we take where this would infringe a duty of confidence owed by us to someone else.

7.0 RESPONSIBILITIES

7.1 Your responsibilities

The Trust wishes to encourage you to highlight areas where you are aware of inadequacies in the provision of services. In doing so concerns can be addressed at the earliest opportunity thus ensuring an overall improvement in the level of services provided to service users.

In particular you have a responsibility to:

- report any genuine concern of wrongdoing or malpractice preferably to your line manager or alternatively via one of the other options set out in the procedure in section 10.0. Proof of wrongdoing is not required, merely a genuine and reasonable concern. At the same time, you have an equal responsibility not to raise issues maliciously, where no potential evidence or indication or malpractice or danger exists; and

- familiarise yourself with and to understand the procedure for raising concerns outlined in section 11.0.

- be aware that information given unjustifiably to the media may unreasonably undermine public confidence in the Trust and Health and Social Care generally.

7.2 Our Responsibilities

All **managers** contacted by a member of staff, are responsible for:

- ensuring at the earliest opportunity that the appropriate action is taken in line with section 10, considering the nature and seriousness of the concern raised, including informing others, responding to concerns quickly and in confidence, taking all concerns seriously. This action will include deciding how any person, against whom an allegation is made, is informed of the matter, ensuring that the investigation is not jeopardised by the disclosure.

- supporting and reassuring those raising concerns – it is recognised that raising concerns can be difficult and stressful

- responding to all concerns without pre-judging

- recording all concerns, including the date the concern was raised, dates of interviews with employees, who was present at each interview and the action agreed

- keeping all records safely and securely

The **Trust's Senior Management Team,** through the Director of Human Resources & Organisational Development is responsible for:

- ensuring that these procedures are explained to all new staff, as part of Trust Induction

- protecting the interests and confidentiality of staff, for treating any concerns raised seriously, and for investigating them fairly and thoroughly

- ensuring that an investigation report relating to each Whistleblowing concern raised is considered as part of the Trust's Corporate / Clincial & Social Care Governance arrangements.

8.0 SUPPORT FOR EMPLOYEES

It is recognised that raising concerns can be difficult and stressful. Advice and support is available from the Head of Employee Engagement & Relations or a nominated deputy throughout any investigation process. The Head of Employee Engagement & Relations will not undertake an investigation role in any whistleblowing case but will oversee any investigation undertaken and provide support to the individual raising the concern throughout the process, ensuring that feedback is provided at appropriate stages of the investigation.

The Trust also provides Carecall services to all employees through its Employee Assistance Programme; this service is free to all employees and is available 24/7. Contact details are: 0808 800 0002.

The Trust will take steps to minimise any difficulties which you may experience as a result of raising a concern. For example if you are required to give evidence at disciplinary proceedings, the Head of Employee Engagement & Relations will arrange for you to receive advice about the process.

If you are dissatisfied with the resolution of the concern you have raised or you consider you have suffered a detriment for having raised a concern, this should be raised initially with the Head of Employee Engagement & Relations.

9.0 EQUALITY AND HUMAN RIGHTS CONSIDERATIONS

This policy has been screened for equality implications as required by Section 75 and Schedule 9 of the Northern Ireland Act 1998. Equality Commission guidance states that the purpose of screening is to identify those policies which are likely to have a significant impact on equality of opportunity so that greatest resources can be devoted to these.

Using the Equality Commission's screening criteria, no significant equality implications have been identified. The policy will therefore not be subject to an equality impact assessment.

Similarly, this policy has been considered under the terms of the Human Rights Act 1998, and was deemed compatible with the European Convention Rights contained in the Act.

10.0 ALTERNATIVE FORMATS

This document can be made available on request in alternative formats, e.g. plain English, Braille, disc, audiocassette and in other languages to meet the needs of those who are not fluent in English.

11.0 COPYRIGHT

The supply of information under the Freedom of Information does not give the recipient or organisation that receives it the automatic right to re-use it in any way that would infringe copyright. This includes, for example, making multiple copies, publishing and issuing copies to the public. Permission to re-use the information must be obtained in advance from the Trust.

12.0 PROCEDURE FOR RAISING CONCERNS AT WORK

There are a range of options from which you can choose if you wish to raise a concern.

Concerns are best raised in writing. You should set out the background and history of the concerns, giving where possible:

- names,
- dates,
- places, and
- the reasons why you are particularly concerned about the situation.

If you do not feel able to put the concern in writing, you can of course raise your concern via telephone or in person. A statement can be taken of your concern which can be recorded for you to verify and sign.

12.1 How to raise a concern internally

Staff should raise any concern internally using one of the options listed below:

- **Option 1**

Managers have a vital role to play in ensuring that you and your colleagues are able to make constructive contributions and to feel that your ideas are welcomed, appreciated and where appropriate, acted upon in a positive manner.

You are therefore encouraged in the first instance to raise concerns with your line manager. You may wish to involve a Trade Union representative or colleague to advise or assist you. As soon as you have a concern, you should make an immediate note of it. You should write down all the relevant details – what was said or done, date, time, names etc.

- **Option 2**

If, for any reason, you feel unable to raise the concern with your line manager, please raise the matter with another senior person you can trust. This might be another manager or a Senior HR representative and again you may wish to involve a Trade Union representative or colleague.

- ***Option 3***

If you feel that the concern is so serious that it cannot be discussed with any of the above you can contact:-

- Director of Human Resources & OD direct line [redacted]
- Chief Executive direct line [redacted]
- Non –Executive Director contacted through the Chair's office
  (See Appendix 2 for names) direct line [redacted]

The contact address for any of the above is: -

Southern HSC Trust Headquarters, Craigavon Area Hospital, Lurgan Road, PORTADOWN, BT63 5QQ

12.2 Response required from internal managers / Director to whom concerns are reported

Stage 1

ALL whistleblowing concerns MUST be notified by internal managers to the Director of Human Resources & Organisational Development for logging and investigation. The Director of Human Resources & Organisational Development will ensure that the Head of Employee Engagement & Relations is notified of the concern to ensure support can be provided to the employee.

The manager / Director should be clear on the range of other Trust policies and procedures in the event that the concern raised might be more appropriately dealt with under another policy / procedure e.g. Grievance Procedure, Working Well Together Procedure, Maintaining High Professional Standards (Medical & Dental staff). Advice from Employee Engagement & Relations may help to clarify this at any early stage.

Any internal manager / Director to whom a concern is raised must then arrange to meet with the employee to discuss the concern without delay along with a representative from the Employee Engagement & Relations team.

The manager / Director and HR representative should establish the background and history of the concerns, including names, dates, places, where possible, along with any other relevant information. The manager should also explore the reason why the employee is particularly concerned about the matter.

A record should be made of all discussions at this stage by the manager and Employee Engagement & Relations.

It may be necessary with anonymous allegations to consider whether it is possible, based on limited information provided in the complaint, to take any further action. Where it is decided that further action cannot be justified, the reasons for this decision should be documented and retained by the Employee Engagement & Relations Department.

Stage 2

Once the preliminary facts / issues of concern have been established, the approach to investigating the concern must be discussed and agreed. A record should be made of the decisions and/or agreed actions which should be signed and dated.

Stage 3

Within 10 working days of the concern being received, the manager receiving the concern must write to the employee:

- Acknowledging that the concern has been received;
- Indicating how the matter will be dealt with;
- Providing an estimate as to how long it will take to provide a final response; and/or
- Telling the employee whether any initial enquiries have been made; and
- Telling the employee whether further investigations will take place and if not why not; and /or
- Letting the employee know when s/he will receive further details if the situation is not yet resolved; and
- Providing the employee with details of whom to contact should s/he be dissatisfied with this response (see 10.4 below)

Advice from Employee Engagement & Relations should be sought when drafting the letter of response.

11.3 How to raise a concern <u>externally</u>

If you are unable to raise the matter internally as outlined above in Options 1 to 3, or if you feel it has not been dealt with properly, we would rather you raise it with an appropriate external agency, detailed in Option 4 below, than not at all.

- **Option 4*.***

Provided that you are acting in good faith and have evidence to back up the concern, your concern may also be raised with: -

  - Relevant Professional / Regulatory Bodies (e.g. Nursing & Midwifery Council, General Medical Council, Northern Ireland Social Care Council, Health Care Professions Council etc.)

  - Statutory Bodies (e.g., Mental Health Commission, Regulation & Quality Improvement Authority (RQIA))

  - The Health and Safety Executive for N. Ireland

  - Department of Health, Social Services and Public Safety.

Contact addresses and telephone numbers are included in Appendix 1.

11.4 If You Remain Dissatisfied

If you are unhappy with the response you receive when you use this procedure, remember you can go to the other levels and bodies detailed in Section 10.3. While we cannot guarantee that we will always respond to all matters in the manner you might wish, we will do our best to handle the matter fairly and properly. By using this procedure, you will help us to achieve this.

12.0 SOURCES OF INDEPENDENT ADVICE AND FURTHER INFORMATION

You may also wish to access independent advice for example,

- A Trust JNCF Trade Union representative or any other recognised Trade Union official*;*

  or

- The independent charity *Public Concern at Work*
  - telephone 0207 404 6609 where lawyers can give free confidential advice at any stage about how to raise a serious concern.

Appendix 1

Northern Ireland Social Care Council
7th Floor Millennium House
Great Victoria Street
BELFAST
BT2 7AQ
028 90 417600

Nursing & Midwifery Council
23 Portland Place
LONDON
W1B 1PZ
020 76377181

Regulation & Quality Improvement Authority (RQIA)
9th Floor Riverside Tower
5 Lanyon Place
BELFAST
BT1 3BT
028 90 517500

General Medical Council
20 Adelaide Street
BELFAST
BT2 8GD
028 90 517022

Health Professions Council
184 Kennington Park Road
LONDON
SE11 4BU
020 78409814

Department of Health, Social Services & Public Safety (DHSSPSNI)
Castle Buildings
Stormont
BELFAST
BT4 3SJ
028 90 520500

Health & Safety Executive for Northern Ireland
83 Ladas Drive
BELFAST
BT6 9FR
028 90243249 (Free phone 0800 0320 121)

Mental Health Commission for Northern Ireland
4th Floor – Lombard House
10-20 Lombard Street
BELFAST
BT1 1RD

DHSSPS Fraud Hotline
Tel 08000 963396

Appendix 2

List of Non-Executive Directors with whom a concern can be raised

Mrs Deirdre Blakely

Mr Edwin Graham

Mrs Siobhan Rooney

Mrs Hester Kelly

Mrs Elizabeth Mahood

Mr Raymond Mullan

Mr Roger Alexander

Contact can be made with any of the above Non-Executive Directors through the Office of the Chair on 028 38 613962.

Southern Health
and Social Care Trust

Quality Care - for you, with you

Nursing and Midwifery Accountability and Assurance Framework

Heather Trouton
Interim Executive Director of Nursing, Midwifery & AHPs
August 2019
Version 4

1. PURPOSE 3
2. STRATEGIC CONTEXT 4
3. PROFESSIONAL REQUIREMENTS 5
4. FRAMEWORK INTERVENTIONS 6
5. GOVERNANCE STRUCTURES, ROLES AND RESPONSIBILITIES 7
6. AUDIT, ASSURANCE AND COMPLIANCE ARRANGEMENTS 14
7. LEARNING, DEVELOPMENT AND SUPPORT 17
8. WORKFORCE 20
9. REGISTRATION / REVALIDATION...21
10. RAISING & HANDLING CONCERNS 22
11. NURSING QUALITY IN THE INDEPENDENT SECTOR 24
12. REFERENCES 25

APPENDIX 1 – FRAMEWORK LOGIC MODELS

1. PURPOSE

The Accountability and Assurance Framework for Nursing and Midwifery (hereafter referred to as the 'Framework') has been developed to ensure there are clear and effective lines of accountability and assurance for the professional governance of the Nursing and Midwifery workforce in the Southern Health and Social Care Trust (hereafter referred to as the 'Trust').

The Framework sets out the arrangements which assure the standards of practice, conduct and professionalism of the workforce. It enables the Trust, through the Executive Director of Nursing, Midwifery and AHPs (EDoN) to assure itself that effective governance systems are in place to enable the achievement of the professional standards and regulation requirements that nurses and midwives must uphold in order to be registered to practice (NMC, 2015; NMC 2016) and that services provided by the Nursing and Midwifery workforce are safe and of a high quality.

The Framework creates an environment which enables nurses and midwives to:

- Practice in accordance with The Code (NMC, 2015), the organisational vision and corporate objectives to ensure the best possible care and treatment experience for service users and families.
- Maintain the standards of conduct of practice and to provide high-quality services and promote public trust and confidence in Nursing and Midwifery services.
- Be responsible for their continuous learning and development.
- Highlight and address areas of concern and risk if required.

The Framework details the professional nursing structure and supporting mechanisms essential to the governance of the Nursing and Midwifery workforce. It may evolve in light of experience, learning and service reconfiguration or development.

2. STRATEGIC CONTEXT

HSC Trusts have corporate accountability for maintaining and improving the quality of services in the form of Clinical and Social Care Governance. The responsibility of oversight and assurance for the quality of Nursing and Midwifery is devolved to the Executive Directors of Nursing and Midwifery. Individually, nurses and midwives are professionally accountable to the Nursing and Midwifery Council (NMC) but they also have a contractual accountability to their employer and are accountable, in law, for their actions.

This Framework sets out how the EDoN provides assurance to the Chief Executive, Trust Board and the Chief Nursing Officer (CNO) on the quality and professionalism of Nursing and Midwifery. When implemented, the Framework provides evidence that structures and processes are in place to provide the right level of support, scrutiny and assurance across all Nursing and Midwifery services.

This Framework reflects the five standards outlined in the Assurance Framework for Professional Nursing and Midwifery Practice in Northern Ireland (2019, draft version 5)

Standard 1: There must be explicit and effective lines of nursing and midwifery accountability from every registrant in every care and service setting to the EDoN and through to CNO.

Standard 2: There must be collective professional leadership across every care and service setting that maximises the unique contribution of Nursing and Midwifery to safe and effective care.

Standard 3: Person-centred practice must be prioritised and embedded across every care and service setting.

Standard 4: Practice environments must be conducive to promoting positive health and well-being in every care and service setting.

Standard 5: The Nursing and midwifery workforce must be supported and equipped for practice across every care and service setting.

3. PROFESSIONAL REQUIREMENTS

As an aid to using the Professional Assurance Framework some of the underlying terminology is clarified below.

3.1 Accountability and Responsibility

The terms ‘responsibility’ and ‘accountability’ should not be used interchangeably.

Responsibility can be defined as a set of tasks or functions that an employer, professional body, court of law or some other recognised body can legitimately demand.

Accountability can be defined as demonstrating an ethos of being answerable for all actions and omissions, whether to service users, peers, employers, standard-setting / regulatory bodies or oneself.

3.2 Scope of Practice

Nurses and midwives must work within the parameters of their designated role and capability. This was formerly known as the Scope of Professional Practice but guidance on this has subsequently been incorporated into the NMC Code.

3.3 Delegation Framework for Nursing & Midwifery Practice (NIPEC 2017)

The purpose of delegation is to ensure the most appropriate use of skills within a health and social care team to achieve **person-centred outcomes**.

Delegation is defined as the process by which a nurse or midwife (delegator) allocates clinical or non-clinical tasks and duties to a competent person (delegatee).
The delegator remains accountable for the overall management of practice (NIPEC, 2019).

4. FRAMEWORK INTERVENTIONS

The Trust has a range of mechanisms in place to support assurance and accountability of the Nursing and Midwifery workforce.

- Governance Structures, Roles and Responsibilities
- Audit, Assurance and Compliance Arrangements
- Learning, Development and Support
- Workforce
- Registration / Revalidation
- Raising and Handling Concerns
- Nursing Quality in the Independent Sector

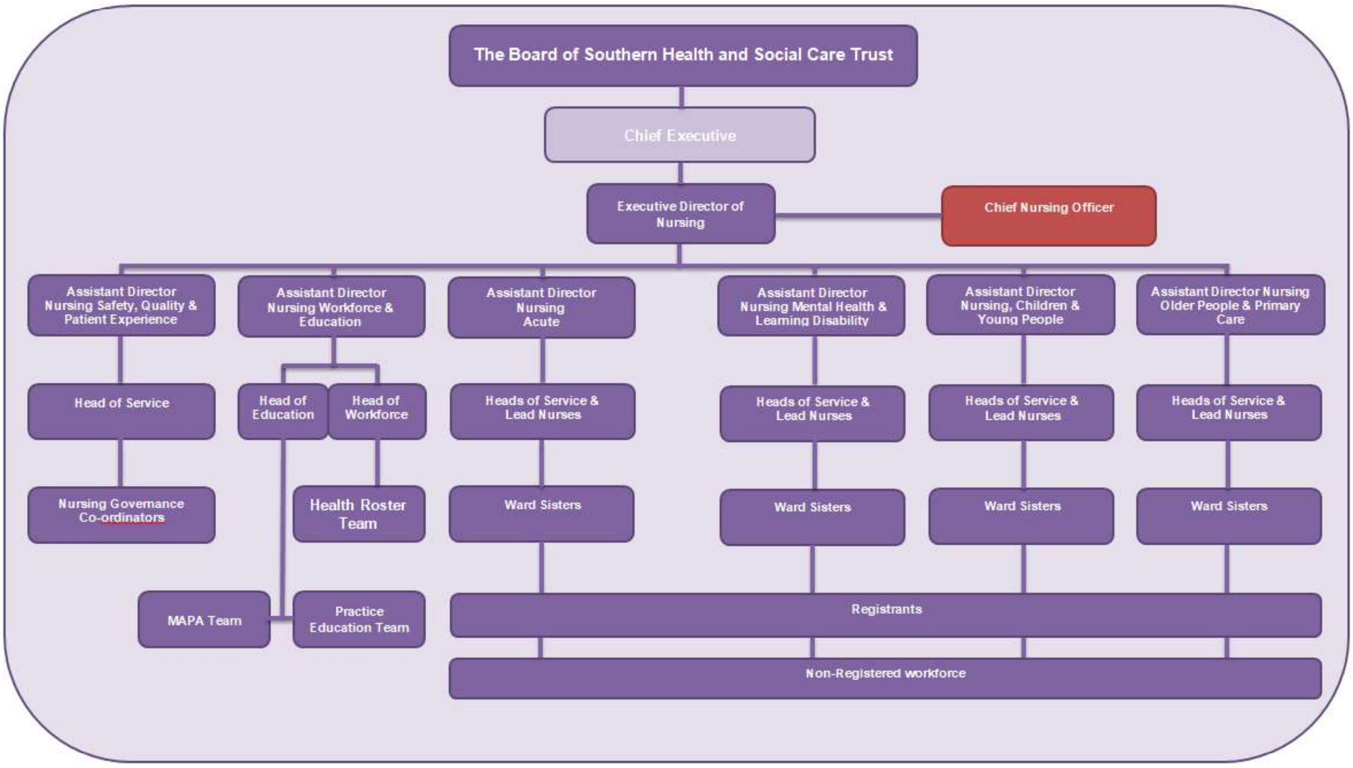
Figure 1: Accountability and Assurance Interventions

Each of the interventions is explored in detail in the following chapters.

5. GOVERNANCE STRUCTURES, ROLES AND RESPONSIBILITIES

The professional Nursing and Midwifery accountability and leadership structures within the SHSCT are as outlined below.

PROFESSIONAL GOVERNANCE MANAGEMENT STRUCTURE



The above configuration has potential for change depending on the agreed Nursing structure in operational directorates

5.1 Professional Accountability Roles and Responsibilities

Trust Board

The Board of the Southern Health and Social Care Trust has a responsibility to ensure that safe, high-quality care is provided and is underpinned by the public service values of accountability, probity and openness (Southern Health and Social Care Trust, 2017).

Chief Executive

The Chief Executive is the accountable officer of the Trust and holds ultimate accountability for the delivery of clinical, care and professional governance and adherence to the guidance issued by the Department of Health (DoH) in respect of governance.

Executive Director of Nursing, Midwifery & AHPs

The EDoN is responsible to Trust Board for providing robust triangulated evidence regarding the quality of professional nursing and midwifery practice, associated workforce issues and patient experience. This is done so that the Trust Board may make informed and sound decisions in fulfilling their joint responsibility regarding quality assurance and patient safety. That evidence should also include issues regarding escalation so that the Trust Board are informed of the risks and challenges the organisation faces. In addition, the EDoN is directly accountable to the CNO in respect of professional nursing and midwifery practice within the Trust.

In order to do this effectively, the EDoN is responsible for ensuring that there are robust and effective assurance structures and processes in place from every care and service setting through to the EDON. These structures and processes should drive improvement in the quality of nursing care and address any identified suboptimal standards of care.

The EDoN is responsible for ensuring that nursing care provided to patients is of a high standard meeting recognised professional standards and statutory requirements.

The EDoN provides professional leadership by ensuring professional issues are considered as part of strategic professional and operational service delivery.

Corporate Nursing Team

Assistant Director of Nursing and Midwifery (Safety, Quality & Patient Experience)

The Assistant Director of Nursing and Midwifery (Safety, Quality & Patient Experience) reports to the EDoN and is responsible for providing assurances that the Trust has robust arrangements in place to achieve high standards of professional governance to support the delivery of quality Nursing and Midwifery care. He / she works closely with the nursing operational Assistant Directors / Directorate Nurses to provide assurances.

The Assistant Director has oversight of established triggers and processes for the escalation of concerns about practitioner conduct, capability and / or fitness to practice and advise on legislation, rules, standards and guidance pertaining to nursing and midwifery. In addition, the Assistant Director develops and reviewing policies, procedures and protocols to ensure that these promote best Nursing and Midwifery practice and the delivery of high quality care.

The Assistant Director is responsible for ensuring that the EDoN is able to fulfil her / his role at Trust Board. This includes ensuring that robust assurance processes are implemented and their effectiveness monitored. He / she is responsible for ensuring that the EDoN is briefed about each clinical area and that issues of concern are escalated accordingly.

The Assistant Director will formulate a quarterly assurance paper that summarises the overall position in relation to Nursing and Midwifery assurance, including any action planned to address risks and areas of concern. This will be submitted to the Performance Committee via SMT.

He / she will ensure that the risk register accurately reflects the risk associated with the challenges nursing and midwifery are currently facing.

The Assistant Director is responsible for ensuring that nursing care provided to patients is of a high quality, meeting national standards and statutory requirements. Where significant quality and safety issues are identified, he / she in conjunction with the operational Nursing Assistant director / Directorate Nurse will initiate a thorough assessment of the clinical / service area and formulation of an improvement plan and ensure that the EDoN is briefed regarding the situation.

The Assistant Director is responsible for leading on the improvement of patient experience in line with regional priorities and in response to patient / client experience feedback.

Head of Nursing (Safety, Quality and Patient Experience)

This Head of Nursing (Safety, Quality and Patient Experience) is responsible for providing professional leadership and has managerial responsibility for the safety and quality of nursing and patient experience across the Trust.

The Head of Nursing (Safety, Quality and Patient Experience) works collaboratively across operational directorates to ensure high standards of patient experience and compassionate care, whilst promoting compliance with relevant standards and indicators of the safety and quality of nursing and midwifery.

He/she supports the Assistant Director of Nursing Safety, Quality and Patient Experience in strategic development of nursing and midwifery standards, policies and procedures, quality initiatives and the development and implementation of key performance indicators.

He/she is responsible for all aspects of the operational management of the Nurse Governance Team, Nurse Revalidation Team, Bereavement Co-ordinator, Head of Research and Development for Nurses, Midwives and AHPs, Patient and Client Experience/10,000 Voices Facilitator and Information Analysist, in addition to any temporary staff aligned to the team to support regional or local initiatives. He/she will provide clear leadership to all staff within their sphere of responsibility and will be responsible for effective financial management and the efficient use of all resources.

Assistant Director of Nursing and Midwifery, Workforce Development and Training

The Assistant Director of Nursing and Midwifery, Workforce Development and Training is responsible for all aspects of the Trust's arrangements for post registration Nursing and Midwifery training and education and for the Nursing and Midwifery pre-registration clinical placement oversight function. This requires the development and maintenance of partnership working with Department of Health (DoH), Public Health Agency (PHA), Health and Social Care Board (HSCB), universities, colleges and other training providers. They have a commissioning, performance management and quality assurance role for training which will be provided both internally and externally to the Trust.

The Assistant Director of Nursing and Midwifery Workforce Development and Training contributes to the Trust's corporate workforce planning and development. This involves engaging with colleagues from human resources and other disciplines in designing and putting in place various training programmes and arrangements including Qualifications and Credit Framework (QCF).

Head of Nursing and Midwifery Education and Workforce Development

The Head of Nursing and Midwifery Education and Workforce Development is responsible for the development of a learning and assessment education governance framework to ensure the NMC requirements are met; providing strong professional leadership, and facilitating learning and development through effective education strategies. This includes leading on Trust-wide training needs analyses; coordinating post registration education requirements, pre-registration education requirements and the education and development of Nursing and Midwifery support staff with all internal and external stakeholders.

They are also responsible for leading and coordinating workforce development initiatives related to the Nursing and Midwifery workforce.

Head of Nursing and Midwifery Workforce Planning and Utilisation

The Head of Workforce Planning and Utilisation is responsible for the planning and utilisation of the Nursing and Midwifery Workforce across the Trust. He / she leads workforce planning and utilisation of the nursing and midwifery workforce using appropriate and relevant strategies for workforce measurement and appropriate use of skill mix, as well as contribute to the Trust’s corporate workforce planning and development agenda. They provide support and leadership to Directorates in changing working practices in nursing roles to ensure the nursing and midwifery workforce is dynamic, responsive and adaptive to the needs of patients / clients and the public and will help to build capacity and capability to support workforce innovation and new role development. Working with a wide range of stakeholders key actions as outlined in the Trust’s Nursing and Midwifery Workforce Action Plan (SHSCT 2019) will be completed through the implementation of effective workforce strategies.

Operational Nursing Teams

Nursing Operational Assistant Directors / Directorate Nurses

Operational Assistant Directors who are registered nurses / midwives are directly accountable and responsible for the professional nursing and midwifery practice within their Division / Directorate. They will report directly to the EDoN and work in conjunction with the Assistant Director of Nursing (Safety, Quality and Patient Experience) to provide assurances regarding nursing and midwifery practice within their areas of responsibility.

Nursing Heads of Service

Heads of Service who are registered nurses / midwives are accountable and responsible for the professional nursing and midwifery practice within their service areas. They will report directly to the Operational Assistant Directors within their Division / Directorate and work in conjunction with the Directorate Nurse if applicable and the Assistant Director of Nursing (Safety, Quality and Patient Experience) and Head of Nursing (Safety, Quality and Patient Experience) to provide assurances regarding nursing and midwifery practice within their areas of responsibility.

Lead Nurses / Nurse Managers / Ward Sisters / Charge Nurses / Team Leads

This group of senior nurses will provide clinical, professional and managerial leadership to ensure the objectives and quality standards of the Framework are met. They will inspire, motivate and empower nurses, midwives and wider health care teams to continually improve the patient experience and provide effective nursing care to enhance patient safety.

They are responsible for the quality of nursing / midwifery care in their area and will deliver on this by ensuring that their staff are inducted and trained to effectively and safely carry out their duties, facilitate supervision and the implementation of staff support policies. They will escalate concerns regarding practitioners' conduct, capability or fitness to practice as required, following discussion, they will progress actions agreed, monitor and feedback.

Nursing and Midwifery Staff

All Nursing and Midwifery registrants are responsible for meeting the regulatory standards of conduct and practice as set out for their profession by the Nursing and Midwifery Council (NMC) professional regulatory body. They are individually responsible to ensure they maintain their professional registration. They must comply with Trust policies and procedures and their on-going professional development designed to support them in the delivery of safe and effective care.

Nursing Assistants

Nursing Assistants are required to meet the Standards for Nursing Assistants (DoH, 2018) and, to comply with Trust policies and procedures designed to support them in delivering safe and effective care.

5.1 Supporting Arrangements

Nursing Governance Team

The Nursing Governance Team support and facilitate teams to achieve improvements in Nursing and Midwifery care through a variety of approaches including quality improvement and practice development.

Practice Education Team

This team consists of Practice Education Facilitators, led by a Practice Education Coordinator. Under the direction of the Assistant Director of Nursing and Midwifery Workforce Development and Training, the team's remit is to develop and sustain an effective learning culture, infrastructure and environment for Nursing and Midwifery students on a Trust-wide basis within a NMC approved governance framework. They also evaluate the effectiveness of pre and post-registration learning and education activities to provide enhanced value added benefits reflected in improved quality of care of patients and clients. Another of the team's remit is to lead on the implementation, monitoring and evaluation of the Trust's new registrant Induction, Rotation and Preceptorship programmes.

Revalidation Team

The Nursing and Midwifery Revalidation Team support operational directorates and the corporate nursing team to provide the EDoN with oversight and assurance with regards to Nursing and Midwifery revalidation. The remit of this team will be extended to provide assurances around other aspects of the framework, including supervision.

5.2 Professional Governance Forums

There are a number of professional fora across directorates which support the EDoN in providing assurances regarding the quality of professional nursing and midwifery practice. These fora promote an ethos of awareness, continuous learning, accountability and improvement. They are essential in supporting corporate governance arrangements, specifically in relation to promoting continuous professional education and development and ensuring professional standards and regulatory requirements are in place and adhered to. They ensure professional processes are monitored and reviewed and that all risks related to the nursing and midwifery workforce are considered and where necessary mitigated against through timely and effective action planning and dissemination of learning.

6. AUDIT, ASSURANCE AND COMPLIANCE ARRANGEMENTS

The Trust monitors Nursing and Midwifery professional governance through a suite of performance and quality indicators designed to ensure that the care, treatment and support are of a consistently high quality throughout the system. These are communicated down through professional nursing and midwifery structures and action plans developed as required to provide assurance.

6.1 Accountability Reporting

The EDoN compiles an Executive Director of Nursing and Midwifery report twice yearly to Trust Board to provide assurances regarding professional nursing and midwifery practice. In addition, the EDoN will table a performance report to the Performance Committee on a quarterly basis.

6.2 Monitoring Arrangements

Nursing and Midwifery practice is reviewed and monitored through a range of processes and fora as outlined in the table below.

Key Performance / Quality Indicator and Reports	Description	Frequency of Review	Reviewed / Monitored through
Executive Director of Nursing, Midwifery and AHPs Reporting	A summary of activity and developments within the Nursing and Midwifery profession.	Twice Yearly reports to Trust Board reports Quarterly reports to the Performance Committee	• Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Senior Management Team • Performance Committee • Trust Board
Induction status reporting	Compliance with Trust Nursing and Midwifery Induction Requirements - New registrants - Registrants - Role specific	Biannual	• Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Performance Committee
Preceptorship requirements reporting	Compliance Nursing and Midwifery preceptorship requirements	Quarterly	• Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Senior Management Team • Performance Committee

Key Performance / Quality Indicator and Reports	Description	Frequency of Review	Reviewed / Monitored through
Audit of Compliance with Mandatory Training	Scorecards of mandatory training performance	Quarterly	• Local and Directorate management meeting • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF)
Nursing and Midwifery Supervision Audit	Audit of supervision practice against Supervision Standards.	Quarterly	• Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Performance Committee
Audit of Compliance with Annual KSF and Personal Development Plans	Sample audit of Personal Development Plan completion	An annual audit of PDP completion	• Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF)
Compliance with Standards for Learning and Assessment in Practice (NMC, 2008)	Mentor register reports Placement evaluation reports Educational Audits	Biannual Biannual Biannual	• Practice Education Team • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Performance committee
Post registration Education service level agreement usage , including DNA rate	Post registration Education service level agreement usage , including DNA rate	Bi annual	• Operational director • SNMGF • Performance committee
Audit of Compliance with Normative Staffing	Monitoring report Phases 1-6	Biannual	• Directorate Nursing and Midwifery Governance Fora. • Office of Chief Executive and Executive Director of Nursing
Revalidation and Registrations Status Reporting	Compliance with NMC registration requirements	Quarterly	• Directorate management and governance Fora • Directorate Nursing and Midwifery Governance Fora • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Performance committee
Fitness to Practice	Summary of Nursing and Midwifery staff referred to NMC	Bi annual	• Performance committee • SNMGF • Operational Directorates
Compliance with regional and locally agreed clinical NQI's and KPIs including PACE and Patient Safety Thermometer data.	Compliance with regional clinical NQI Bundles and other relevant safety / practice indicators	Monthly	• Ward Sisters / Charge Nurses • Lead Nurses
		Quarterly	• Directorate Nursing and Midwifery Governance Fora • Operational Director • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Performance Committee

Key Performance / Quality Indicator and Reports	Description	Frequency of Review	Reviewed / Monitored through
Patient Experience Feedback	Utilise the feedback of service users and / or carers to improve services. Includes 10,000 voices feedback.	Monthly	• Directorate Governance Fora • Operational Director
		Quarterly	• Trust Senior Management Team • Patient and Client Experience Steering Group • Trust Patient and Client Experience Committee
Nursing Quality in the Independent Sector	Monitored via the Trust Independent Sector Governance Forum	Bi annual	• Operational Director • Trust performance committee

6.3 Information Systems

To support the Nursing and Midwifery Accountability and Assurance Framework there are a number of information systems alongside the need to manually collate information:

- HRPTS Workforce Information System
- DATIX Complaints and Incident Management System
- Allocate Health Rostering System
- Easy Information Management System (EIMS) – Mentor Register
- E-CATS – Health Visiting and District Nursing
- Filemaker
- HCAT System
- Revalidation register

7. LEARNING, DEVELOPMENT AND SUPPORT

There are systems in place to monitor workforce volumes, highlight issues and to ensure that the Nursing and Midwifery workforce have the appropriate knowledge, skills and support needed to provide high-quality care.

Corporate Induction

The Trust Induction Policy (SHSCT, 2013a) requires all newly appointed staff to attend a Corporate Induction (in addition to a Departmental Induction / orientation). The programme comprises of information of common interest across all staff groups and contributes to building a commonality of understanding amongst the workforce. New employees are required to attend Corporate Induction ideally within three months of commencement but no longer than six months following appointment.

Nurse Induction for New Registrants

A Nurse Induction programme is delivered biannually to all new Nursing registrants. The programme is delivered in a blended approach by Clinical Education Centre, Practice Education Team and in-house SHSCT staff over a period of 3 days. It combines Corporate and Professional Induction, elements of Mandatory Training, a range of e-learning, and preceptorship training. All new registrants are given the option at recruitment phase to undertake a Rotational Programme to facilitate consolidation of knowledge and skills across a range of care settings.

Currently there is work ongoing to develop a Regional Induction Programme for Nursing Assistants.

Specialty / Departmental Induction

The Trust Induction Policy (2013a) requires all new employees to undertake specialty / departmental induction to ensure they have the information they may need to undertake the requirements of the post and to undertake the requirements of the job / professional role.

Preceptorship Programme

The Practice Education Team delivers a Preceptorship Programme to new registrants.

The duration of the programme is six months and runs concurrently with induction and the probationary period. A Preceptorship procedure (SHSCT, 2018) details the requirements for the Preceptorship Programme. The Trust reports annually to the Chief Nursing Officer (CNO) and quarterly to Trust Board regarding compliance with the Preceptorship Framework (DHSSPS, 2013).

Nursing and Midwifery Supervision & Annual Appraisal

The learning and development requirements of the Nursing and Midwifery workforce are identified through the Trust supervision and appraisal systems. The Trust considers the implementation of supervision and KSF processes as a critical priority in valuing staff and supporting their development to help achieve the key objective of safe, high-quality health and social care. The outcome of supervision activities informs the individual's KSF and Personal Development Plans, including identification of training requirements.

Mandatory Training

The Trust Corporate Mandatory Training Policy (Southern Health and Social Care Trust, 2013) details the Corporate Mandatory Training for Nursing and Midwifery staff groups. The policy denotes the mandatory training requirements for nursing, midwifery and nursing assistant staff groups.

Role Specific Training

All clinical areas ensure Nursing and Midwifery staff undertake role specific training to deliver safe and effective care. This is managed locally by the Ward Sister / Charge Nurse / Team Lead and all registrants.

Continuous Professional Development (CPD) Maintenance

All nursing and midwifery registrants have access to educational programmes provided through the Clinical Education Centre Level Agreement and the Education Commissioning Plan which provides them with opportunities to maintain Post Registration Training and Learning and gain recognition for learning.

Clinical Education Centre (CEC) – Service Level Agreement (SLA)

All nursing and midwifery registrants have access to the CEC which provides them with a range of programmes to maintain continuous professional development. Monitoring and uptake is ongoing throughout the financial year through monthly reports from the CEC. The procedure for the Management of the Nursing and Midwifery SLA with the CEC provides guidance on all courses available and with the CEC (SHSCT, 2016a)

Education Commissioning Cycle – Training Needs Analysis

As part of the Regional Education Commissioning Group chaired by the DoH funds are allocated for education to each HSC Trust. The completion of an annual Training Needs Analysis facilitates Nursing and Midwifery staff to undertake further education including stand-alone modules, short courses and specialist practice to facilitate the development of skills, knowledge and expertise for practitioners. The procedure for the Management of Nursing and Midwifery Post-Registration Education Commissioning provides guidance on all aspects of the Nurse Education Commissioning process (SHSCT, 2016b)

8. WORKFORCE

The Trust recognises that ensuring appropriate nurse staffing is a key element in influencing the quality of care. Given this, a comprehensive Nursing and Midwifery Workforce Action Plan 2019 – 21 has been developed and the action plan is being progressed through 3 work streams. Progress is reported through to SMT and Trust Board.

8.1 Recruitment

Active recruitment of Nursing and Midwifery staff occurs on an ongoing basis via an open advertisement with the Business Services Organisation (BSO). Targeted recruitment via International Nurse Recruitment, UK wide recruitment fairs and local recruitment is managed by the HR Trust's recruitment team and the Corporate Nursing Team in a planned process. Monthly vacancy reports are reviewed by Directorates and escalation processes are in place to address staff shortages.

8.2 Delivering Care Project (Normative Staffing)

The Delivering Care Project continues to be implemented (DHSSPS, 2014). It aims to support the provision of high quality care which is safe and effective in hospital and community settings, through the development of a framework to determine staffing ranges for the Nursing and Midwifery workforce in a range of major specialties. Although funding has only been approved for phase 1, biannual reporting is completed to the HSCB of all agreed phases.

9. REGISTRATION / REVALIDATION

The Trust has developed an infrastructure to support the registration of the Nursing and Midwifery workforce which enhances the professional regulation of the workforce and reinforces the individual’s responsibility to provide quality Nursing and Midwifery services.

Monitoring at Operational Level

While the responsibility to maintain registration lies with the registrant, line managers are responsible for ensuring that registered nurses and midwives have a valid registration and are on the NMC Register (SHSCT, 2017c).

HRPTS Oversight & NMC Registration Employer Centralised Oversight

The Trust has a dedicated Revalidation Team which record and monitor Nursing and Midwifery workforce registration and renewal status. The regional HRPTS system is used for central recording and monitoring of workforce registration and renewal status. Monthly reports are issued to managers on registration and renewal status.

Pre-Employment Checks

The Trust Recruitment and Selection Procedure (SHSCT, 2010) stipulates a pre-recruitment phase which involves the development and approval of personnel specifications and a range of checks to be undertaken pre- employment.

NMC Registration and Renewal Processes

The Trust Policy on the Validation and Monitoring of Registration with a Professional Regulatory Body (SHSCT, 2017d) defines the approach for registration and the maintenance of Nursing and Midwifery professional registration.

10. RAISING AND HANDLING CONCERNS

The Trust has a range of mechanisms for raising and handling concerns which are designed to ensure the Nursing and Midwifery workforce achieve and maintain appropriate standards of conduct, performance and behaviour.

Identification of Poor or Variable Performance

Concerns about poor or variable performance are identified through supervision, probationary reviews, incidents, complaints, patient feedback, whistleblowing and managerial engagement with front-line teams. Depending on the severity and potential impact of the issues identified a line manager may seek to resolve locally through identification of further training and development needs, increased supervision or enact the Trust's management of probationary, capability or disciplinary procedures.

Probationary

All Nursing and Midwifery appointments are subject to a probationary period which is normally 6 months duration, during which time progress is monitored. In the event of unsatisfactory progress, despite appropriate support and / or counselling, employment will be terminated with appropriate notice either during or at the end of the probationary period in accordance with the Trust's procedure for probationary periods (SHSCT, no year).

Management of Capability, Conduct or Health Concerns

The Trust Capability Procedure (SHSCT, 2015a) has been designed for use in situations where there is evidence of '*a genuine lack of capability rather than a deliberate failure on the part of the employee to perform to the standards of which he / she is capable*'.

The Trust Disciplinary Procedure (SHSCT, 2015b) is designed to help and encourage all employees to achieve and maintain appropriate standards of conduct, performance and behavior.

Line managers work very closely with the Trust Occupational Health Department and Attendance Management Team to appropriately manage health concerns related to the Nursing and Midwifery workforce.

Management of Fitness to Practice Referrals to NMC and NMC Investigation Process

Trust Procedures for initiating and managing a referral to a Professional Regulatory Body and the Independent Safeguarding Authority and Requesting the DHSSPS to issue an ALERT (SHSCT, 2015c) outline the processes to be followed should this be required. All referrals to NMC for fitness to practice and requested for an alert to be issued should be discussed with and quality assured by the Assistant Director of Nursing (Safety, Quality and Patient Experience) and approved by the EDoN.

The corporate nursing team will support nurses and midwives involved in NMC investigations and hearings.

Nursing and Midwifery Human Resources Interface Forum

The Trust Nursing and Midwifery Human Resource Interface Forum has formalised interfaces between the Assistant Director of Nursing (Safety, Quality and Patient Experience), Assistant Directors of Human Resources (Directorate) and Head of Employee Relations in relation to conduct, capability or fitness to practice of Nursing and Midwifery staff.

11. NURSING QUALITY IN THE INDEPENDENT SECTOR

There are robust processes in place for assuring the quality and safety of services commissioned from third or independent sector providers.

Contracts

Where externally provided services are commissioned by the Trust, the same high levels of compliance with Trust safety and quality standards are required to be implemented by the Provider through adherence to robust, descriptive contracts. The contracts stipulate clear arrangements for monitoring that these standards are met. Advice and guidance can be sought from the Operational Assistant Directors or Assistant Directors of Nursing as required.

If concerns are identified regarding the conduct, capability or fitness to practice of a registrant not employed by the Trust the Trust Procedures for initiating and managing a referral to a Professional Regulatory Body and the Independent Safeguarding Authority and Requesting the DHSSPS to issue an ALERT (SHSCT, 2015c) should be followed.

Contract Management and Monitoring

There are identified contract managers who undertake both formal and informal contract management and monitoring. At a minimum, an Independent / 3rd Party Contractor is subject to an annual formal Contract Management meeting.

The majority of Independent / 3rd Party Contractors engaged with by the Trust are registered with RQIA and subject to their ongoing monitoring and inspection.

12. REFERENCES

Department of Health Social Services and Public Safety and Northern Ireland Practice Education Council (2013) Preceptorship Framework for Nursing, Midwifery and Specialist Community Public Health Nursing in Northern Ireland, Belfast: NIPEC.

Department of Health, Social Services and Public Safety (2014) Delivering Care: Nurse Staffing in Northern Ireland

Department of Health (2018) *Standards for Nursing Assistants employed in HSC Trusts by Northern Ireland*. Belfast: DoH

NIPEC (2019) *Deciding to delegate: a decision support framework For nursing and midwifery.* http://nipec.hscni.net/download/projects/current_work/provide_adviceguidanceinformation/delegation_in_nursing_and_midwifery/documents/NIPEC-Delegation-Decision-Framework-Jan-2019.pdf

Nursing and Midwifery Council (2008) Standards to Support Learning and Assessment in Practice Retrieved from https://www.nmc.org.uk/globalassets/sitedocuments /standards/nmc-standards-to-support-learning-assessment.pdf

Nursing and Midwifery Council (2015) The Code for Nurses and Midwives Retrieved from www.http//nmc.org.uk/standards/code

Nursing and Midwifery Council (2016) *Revalidation* Retrieved from http://revalidation.nmc.org.uk/welcome-to-revalidation

Southern Health and Social Care Trust (no year) *Management Guidance Note: EER 05, Trust's procedure for probationary periods* (SHSCT).

Southern Health and Social Care Trust (2010) *Recruitment and Selection*

Southern Health and Social Care Trust (2013) *Corporate Mandatory Training Policy*

Southern Health and Social Care Trust (2013a) *Trust Induction Policy*

Southern Health and Social Care Trust (2015) *Policy for the Management of Complaints (Working Draft)*

Southern Health and Social Care Trust (2015a) *Capability Procedure*

Southern Health and Social Care Trust (2015b) *Disciplinary Procedure*

Southern Health and Social Care Trust (2015c) *Trust Procedures for initiating and managing a referral to A Professional Regulatory Body and The Independent Safeguarding Authority and Requesting the DHSSPS to issue an ALERT*

Southern Health and Social Care Trust (2016) *Policy for Supporting Nursing & Midwifery Students in Practice*

Southern Health and Social Care Trust (2016a) *Procedure for the Management of the Nursing and Midwifery Service Level Agreement with the Clinical Education Centre*

Southern Health and Social Care Trust (2016b) *Procedure for the Management of Nursing and Midwifery Post-Registration Education Commissioning*

Southern Health and Social Care Trust (2018) *Preceptorship Procedure for Nurses, Midwives and Specialist Community Public Health Nurses*

Southern Health and Social Care Trust (2017) *Board Assurance Framework*

Southern Health and Social Care Trust (2017a) *Procedure on the Identification, Management and Monitoring of Practice Placements for Students who are undertaking NMC approved programmes.*

Southern Health and Social Care Trust (2017b) *Procedure for Maintaining the Trust Register.*

Southern Health and Social Care Trust (2017c) *Policy on the Validation and Monitoring of Registration with a Regulatory Body*

Southern Health and Social Care Trust (2017d) *Professional Registration Policy*

Southern Health and Social Care Trust (2019) *Nursing and Midwifery Workforce Action Plan 2019-21*

Appendix 1

Southern Health and Social Care Trust

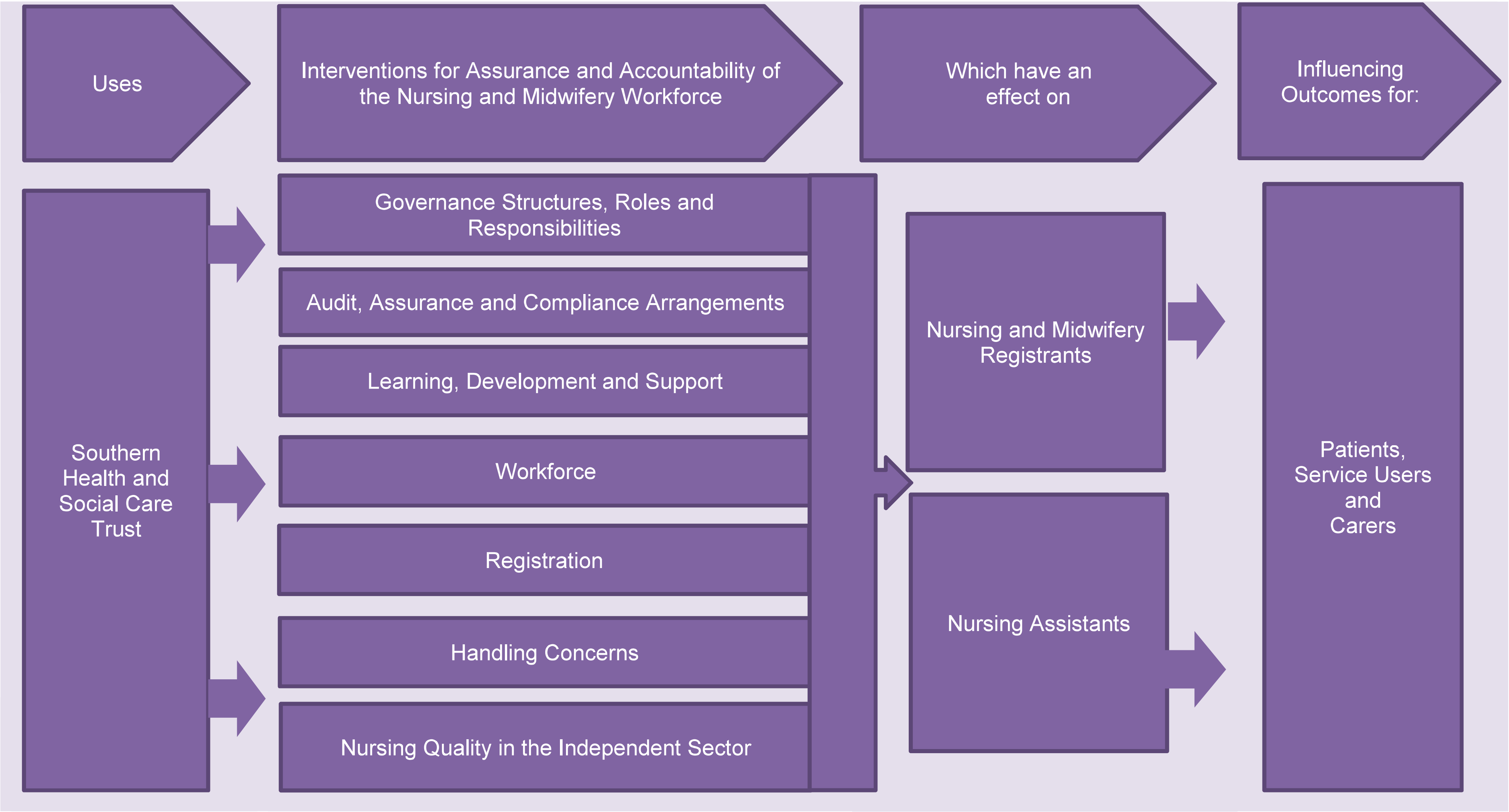
Quality Care - for you, with you

Nursing and Midwifery Accountability and Assurance

Logic Models

Southern Health and Social Care Trust
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery



Uses

Interventions for Assurance and Accountability of the Nursing and Midwifery Workforce

Which have an effect on

Influencing Outcomes for:

Southern Health and Social Care Trust

Governance Structures, Roles and Responsibilities

Audit, Assurance and Compliance Arrangements

Learning, Development and Support

Workforce

Registration

Handling Concerns

Nursing Quality in the Independent Sector

Nursing and Midwifery Registrants

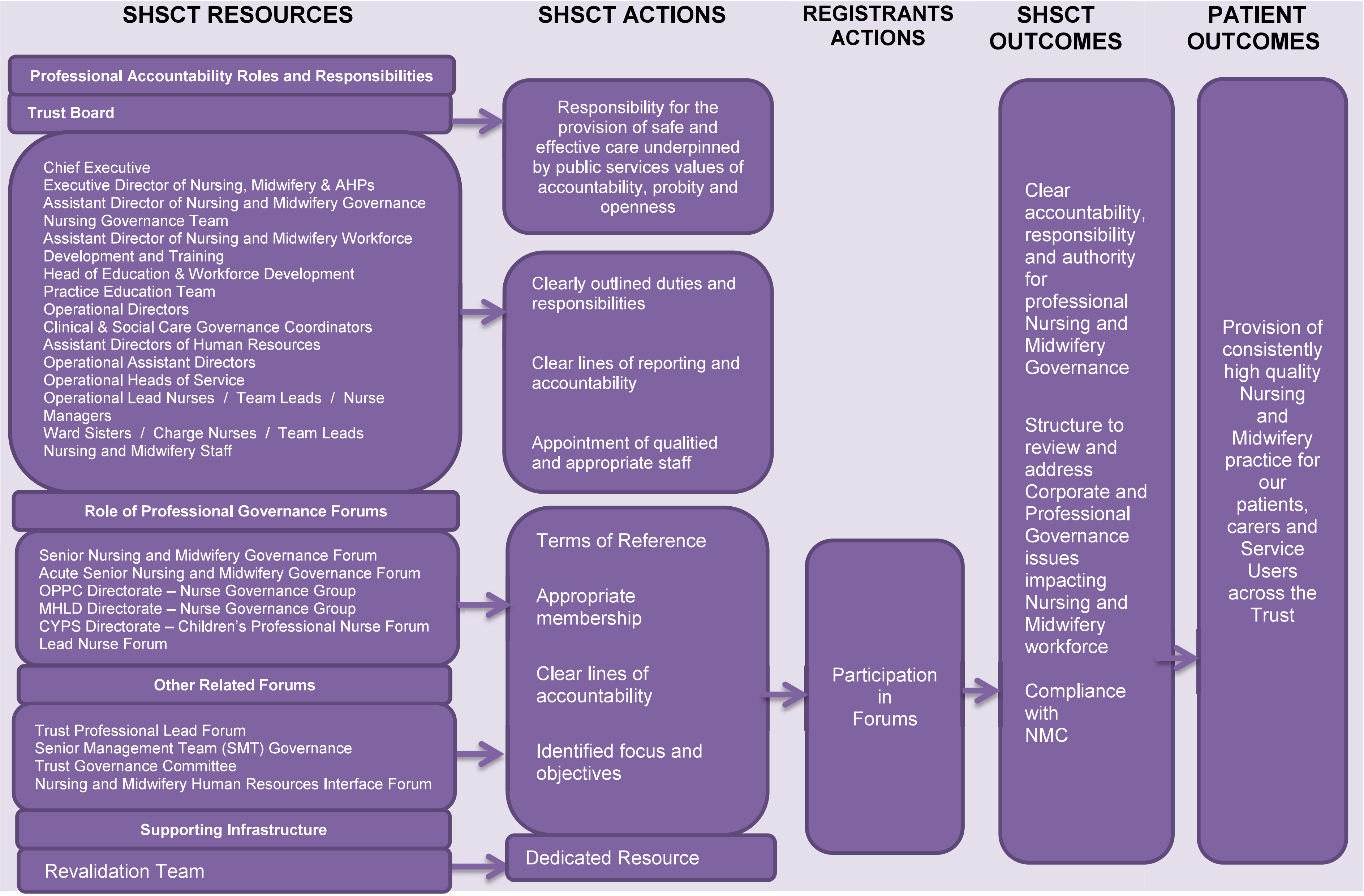
Nursing Assistants

Patients, Service Users and Carers

Southern Health and Social Care Trust
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Governance Structures, Roles and Responsibilities



SHSCT RESOURCES

Professional Accountability Roles and Responsibilities

Trust Board

Chief Executive
Executive Director of Nursing, Midwifery & AHPs
Assistant Director of Nursing and Midwifery Governance
Nursing Governance Team
Assistant Director of Nursing and Midwifery Workforce Development and Training
Head of Education & Workforce Development
Practice Education Team
Operational Directors
Clinical & Social Care Governance Coordinators
Assistant Directors of Human Resources
Operational Assistant Directors
Operational Heads of Service
Operational Lead Nurses / Team Leads / Nurse Managers
Ward Sisters / Charge Nurses / Team Leads
Nursing and Midwifery Staff

Role of Professional Governance Forums

Senior Nursing and Midwifery Governance Forum
Acute Senior Nursing and Midwifery Governance Forum
OPPC Directorate – Nurse Governance Group
MHLD Directorate – Nurse Governance Group
CYPS Directorate – Children's Professional Nurse Forum
Lead Nurse Forum

Other Related Forums

Trust Professional Lead Forum
Senior Management Team (SMT) Governance
Trust Governance Committee
Nursing and Midwifery Human Resources Interface Forum

Supporting Infrastructure

Revalidation Team

SHSCT ACTIONS

Responsibility for the provision of safe and effective care underpinned by public services values of accountability, probity and openness

Clearly outlined duties and responsibilities

Clear lines of reporting and accountability

Appointment of qualitied and appropriate staff

Terms of Reference

Appropriate membership

Clear lines of accountability

Identified focus and objectives

Dedicated Resource

REGISTRANTS ACTIONS

Participation in Forums

SHSCT OUTCOMES

Clear accountability, responsibility and authority for professional Nursing and Midwifery Governance

Structure to review and address Corporate and Professional Governance issues impacting Nursing and Midwifery workforce

Compliance with NMC

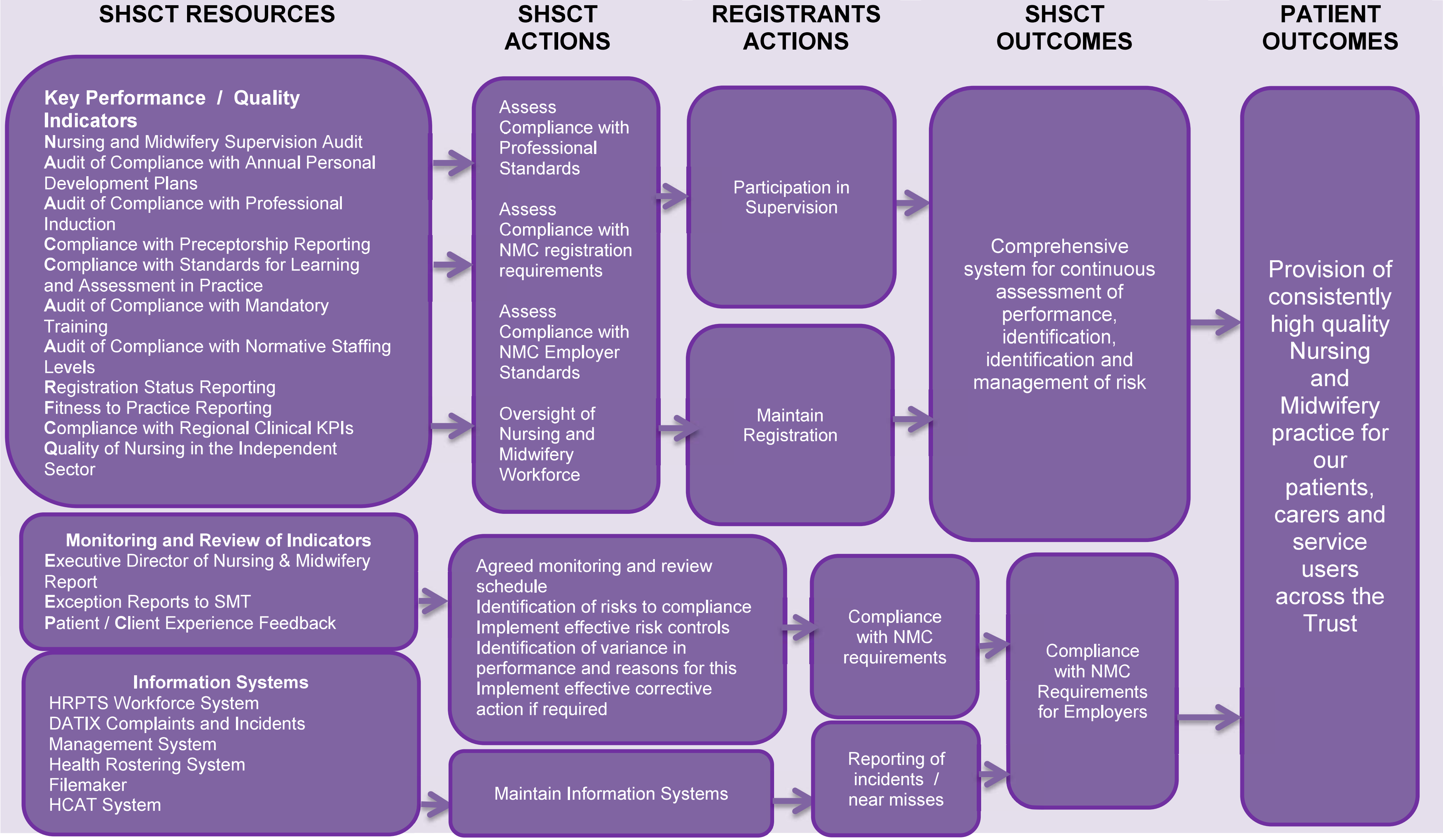
PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery practice for our patients, carers and Service Users across the Trust

Southern Health and Social Care Trust
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Audit, Assurance and Compliance Arrangements



SHSCT RESOURCES

SHSCT ACTIONS

REGISTRANTS ACTIONS

SHSCT OUTCOMES

PATIENT OUTCOMES

Key Performance / Quality Indicators
Nursing and Midwifery Supervision Audit
Audit of Compliance with Annual Personal Development Plans
Audit of Compliance with Professional Induction
Compliance with Preceptorship Reporting
Compliance with Standards for Learning and Assessment in Practice
Audit of Compliance with Mandatory Training
Audit of Compliance with Normative Staffing Levels
Registration Status Reporting
Fitness to Practice Reporting
Compliance with Regional Clinical KPIs
Quality of Nursing in the Independent Sector

Assess Compliance with Professional Standards

Assess Compliance with NMC registration requirements

Assess Compliance with NMC Employer Standards

Oversight of Nursing and Midwifery Workforce

Participation in Supervision

Maintain Registration

Comprehensive system for continuous assessment of performance, identification, identification and management of risk

Provision of consistently high quality Nursing and Midwifery practice for our patients, carers and service users across the Trust

Monitoring and Review of Indicators
Executive Director of Nursing & Midwifery Report
Exception Reports to SMT
Patient / Client Experience Feedback

Information Systems
HRPTS Workforce System
DATIX Complaints and Incidents Management System
Health Rostering System
Filemaker
HCAT System

Agreed monitoring and review schedule
Identification of risks to compliance
Implement effective risk controls
Identification of variance in performance and reasons for this
Implement effective corrective action if required

Maintain Information Systems

Compliance with NMC requirements

Reporting of incidents / near misses

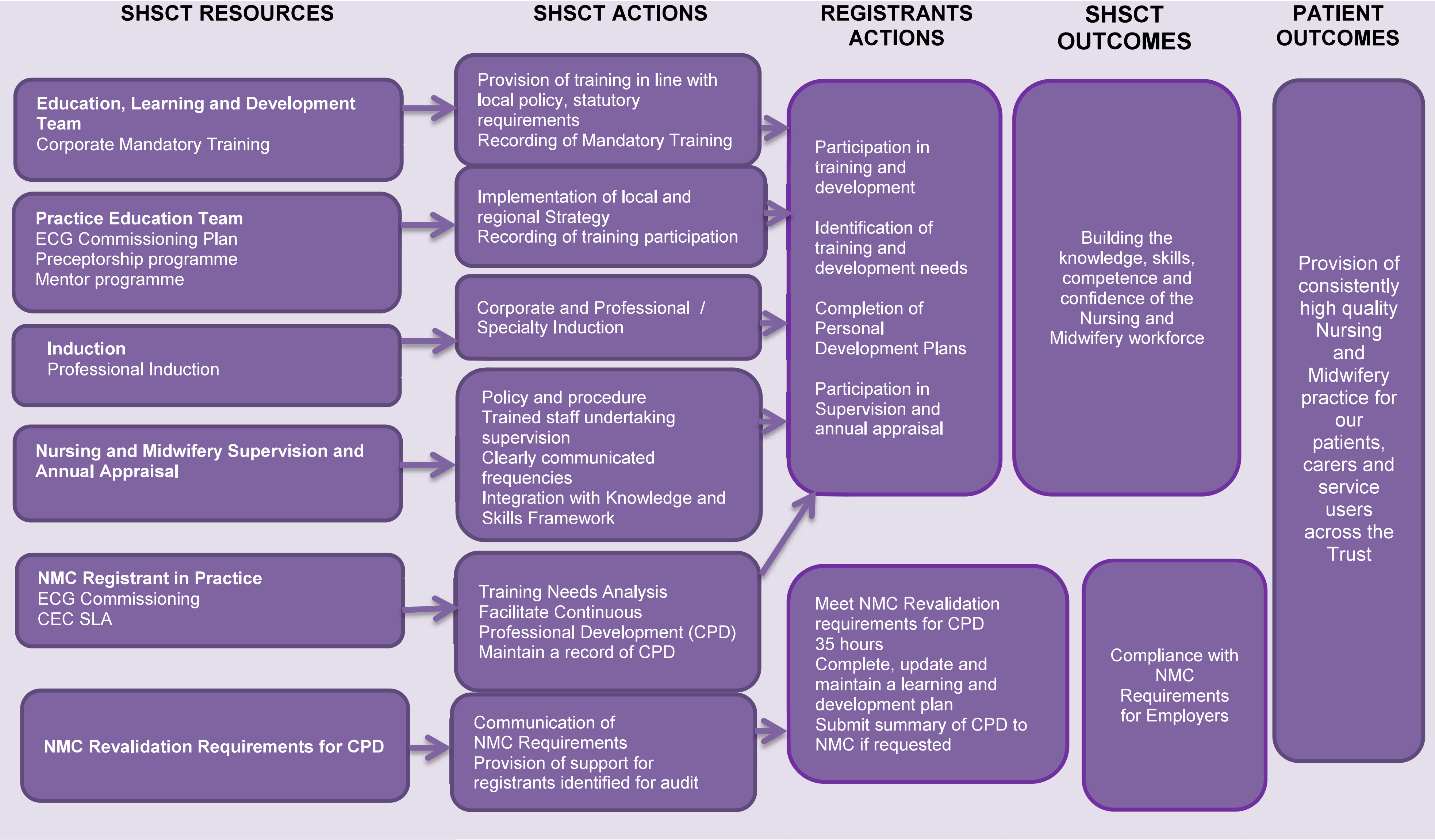
Compliance with NMC Requirements for Employers

Southern Health and Social Care Trust

Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Learning, Development and Support



SHSCT RESOURCES

Education, Learning and Development Team
Corporate Mandatory Training

Practice Education Team
ECG Commissioning Plan
Preceptorship programme
Mentor programme

Induction
Professional Induction

Nursing and Midwifery Supervision and Annual Appraisal

NMC Registrant in Practice
ECG Commissioning
CEC SLA

NMC Revalidation Requirements for CPD

SHSCT ACTIONS

Provision of training in line with local policy, statutory requirements
Recording of Mandatory Training

Implementation of local and regional Strategy
Recording of training participation

Corporate and Professional / Specialty Induction

Policy and procedure
Trained staff undertaking supervision
Clearly communicated frequencies
Integration with Knowledge and Skills Framework

Training Needs Analysis
Facilitate Continuous Professional Development (CPD)
Maintain a record of CPD

Communication of NMC Requirements
Provision of support for registrants identified for audit

REGISTRANTS ACTIONS

Participation in training and development

Identification of training and development needs

Completion of Personal Development Plans

Participation in Supervision and annual appraisal

Meet NMC Revalidation requirements for CPD 35 hours
Complete, update and maintain a learning and development plan
Submit summary of CPD to NMC if requested

SHSCT OUTCOMES

Building the knowledge, skills, competence and confidence of the Nursing and Midwifery workforce

Compliance with NMC Requirements for Employers

PATIENT OUTCOMES

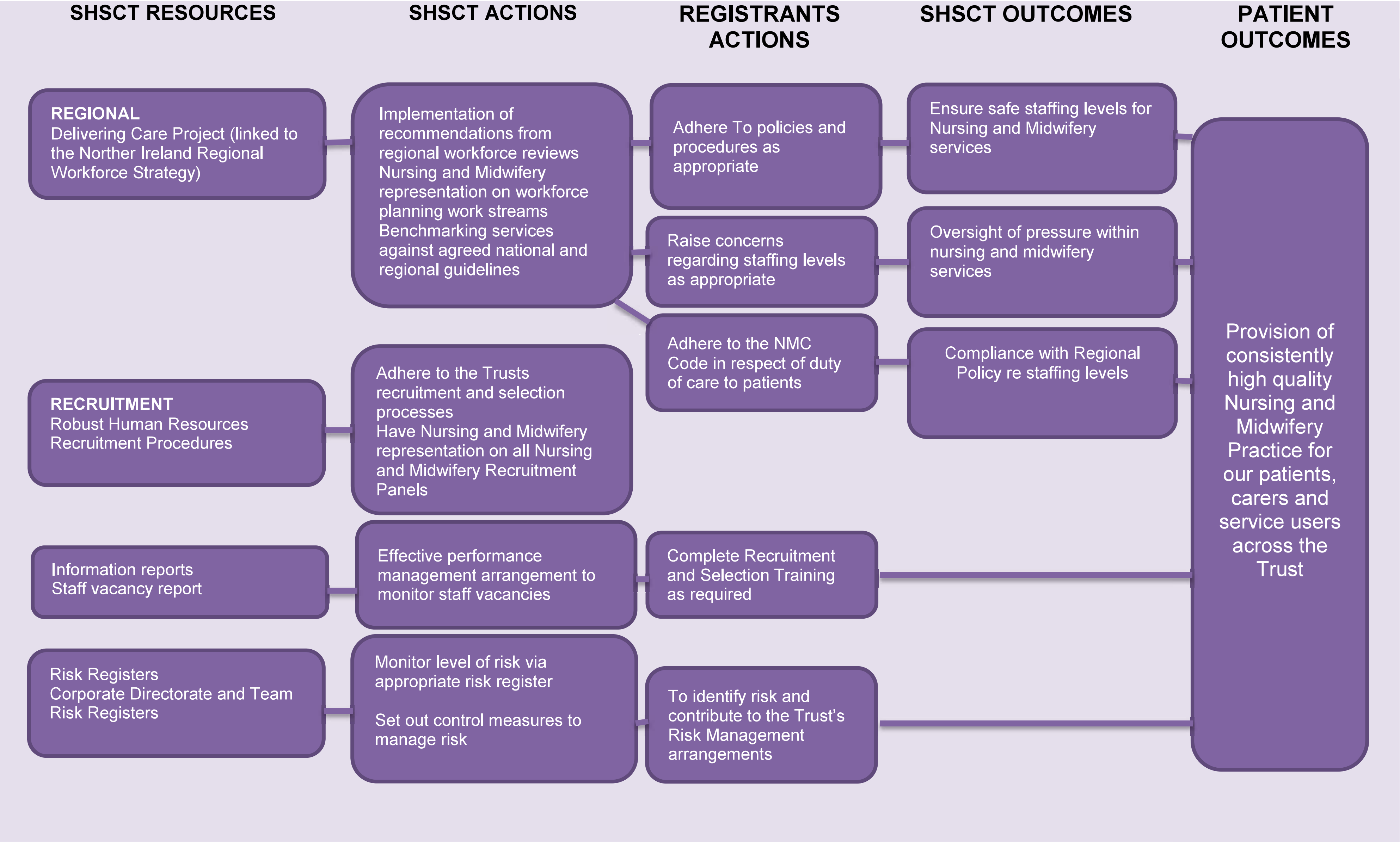
Provision of consistently high quality Nursing and Midwifery practice for our patients, carers and service users across the Trust

Southern Health and Social Care Trust

Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Workforce



SHSCT RESOURCES

REGIONAL
Delivering Care Project (linked to the Northern Ireland Regional Workforce Strategy)

RECRUITMENT
Robust Human Resources Recruitment Procedures

Information reports
Staff vacancy report

Risk Registers
Corporate Directorate and Team Risk Registers

SHSCT ACTIONS

Implementation of recommendations from regional workforce reviews
Nursing and Midwifery representation on workforce planning work streams
Benchmarking services against agreed national and regional guidelines

Adhere to the Trusts recruitment and selection processes
Have Nursing and Midwifery representation on all Nursing and Midwifery Recruitment Panels

Effective performance management arrangement to monitor staff vacancies

Monitor level of risk via appropriate risk register

Set out control measures to manage risk

REGISTRANTS ACTIONS

Adhere To policies and procedures as appropriate

Raise concerns regarding staffing levels as appropriate

Adhere to the NMC Code in respect of duty of care to patients

Complete Recruitment and Selection Training as required

To identify risk and contribute to the Trust's Risk Management arrangements

SHSCT OUTCOMES

Ensure safe staffing levels for Nursing and Midwifery services

Oversight of pressure within nursing and midwifery services

Compliance with Regional Policy re staffing levels

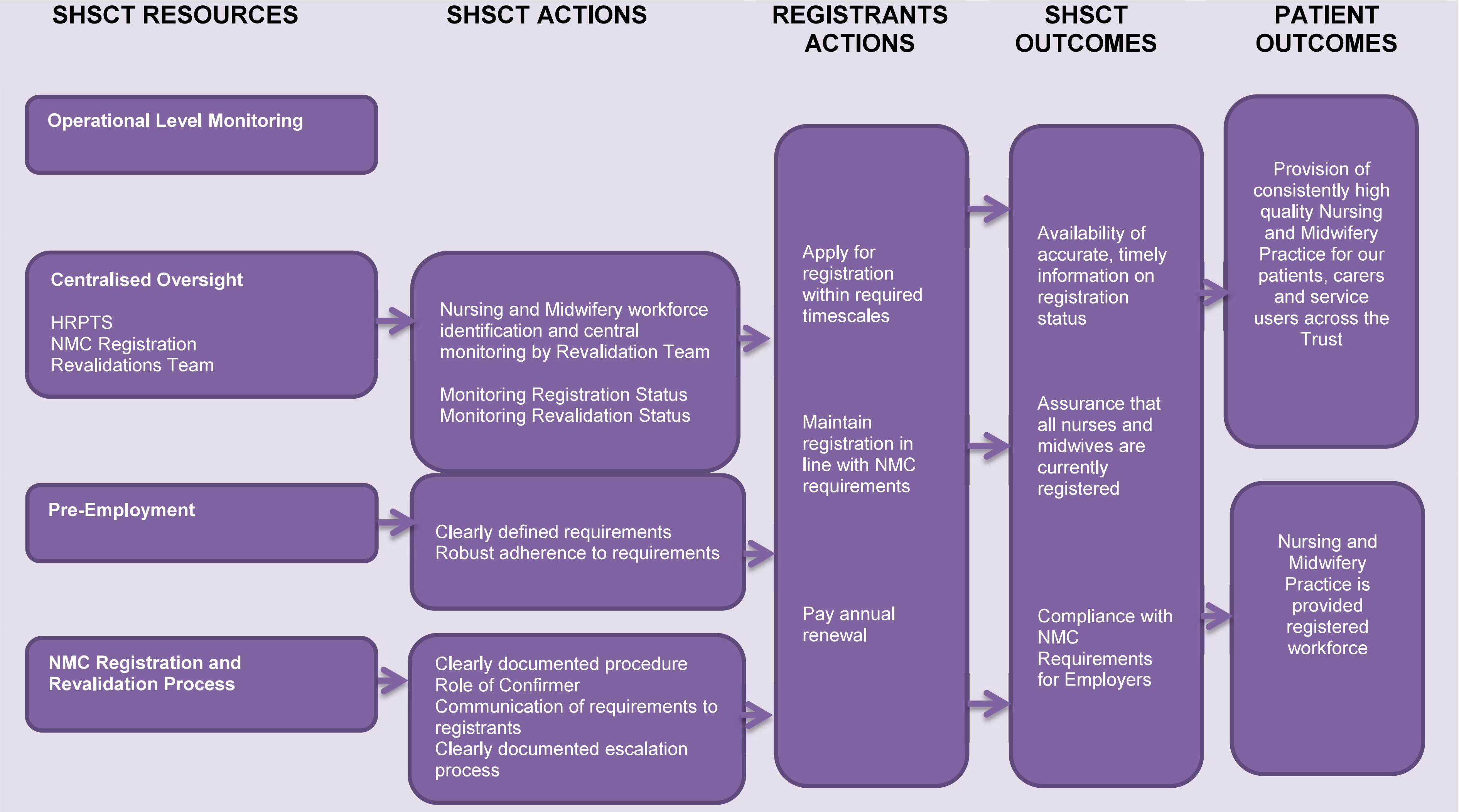
PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

Southern Health
and Social Care Trust
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Registration



SHSCT RESOURCES

Operational Level Monitoring

Centralised Oversight

HRPTS
NMC Registration
Revalidations Team

Pre-Employment

NMC Registration and Revalidation Process

SHSCT ACTIONS

Nursing and Midwifery workforce identification and central monitoring by Revalidation Team

Monitoring Registration Status
Monitoring Revalidation Status

Clearly defined requirements
Robust adherence to requirements

Clearly documented procedure
Role of Confirmer
Communication of requirements to registrants
Clearly documented escalation process

REGISTRANTS ACTIONS

Apply for registration within required timescales

Maintain registration in line with NMC requirements

Pay annual renewal

SHSCT OUTCOMES

Availability of accurate, timely information on registration status

Assurance that all nurses and midwives are currently registered

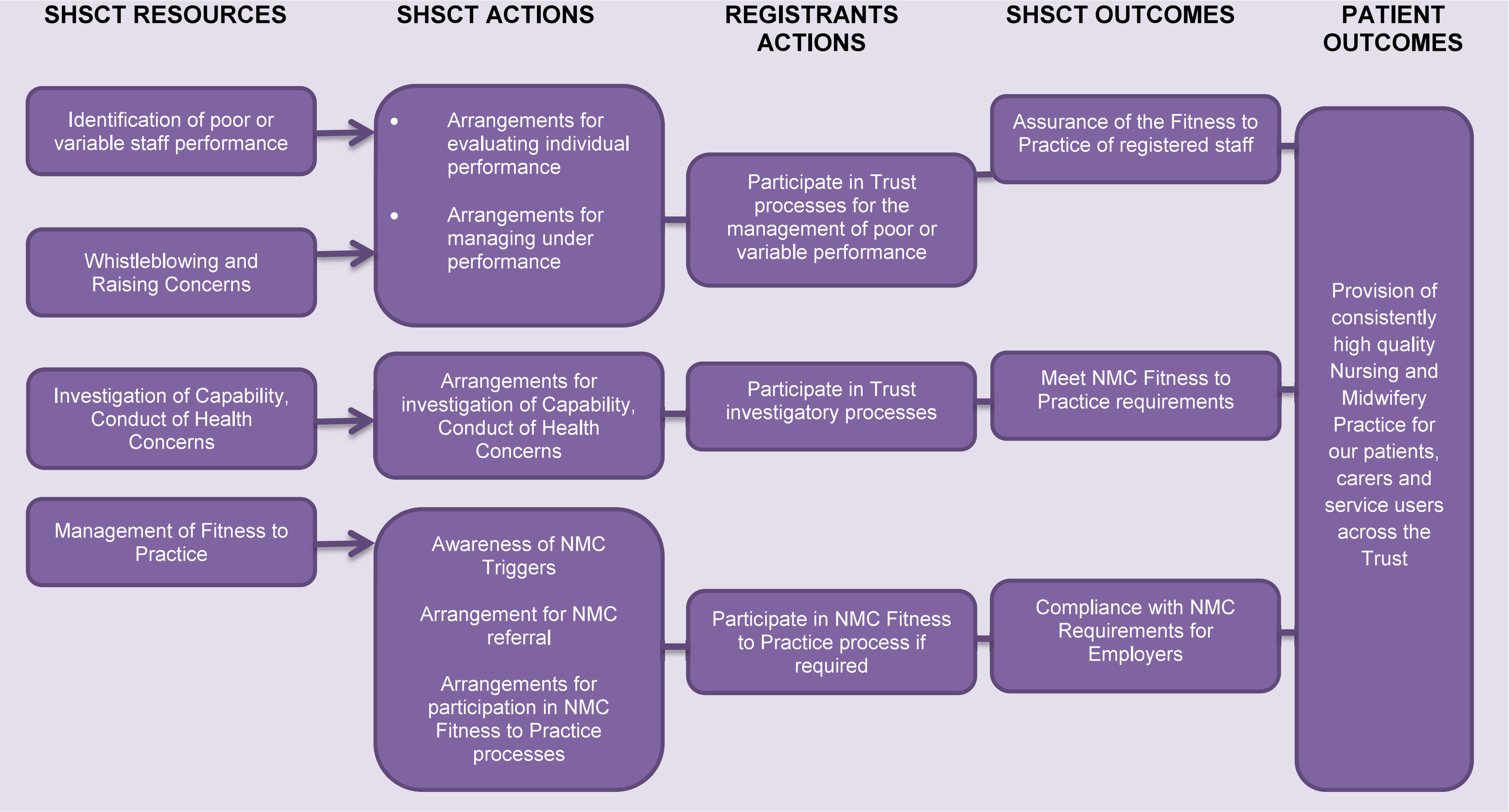
Compliance with NMC Requirements for Employers

PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

Nursing and Midwifery Practice is provided registered workforce

Handling Concerns



SHSCT RESOURCES

- Identification of poor or variable staff performance
- Whistleblowing and Raising Concerns
- Investigation of Capability, Conduct of Health Concerns
- Management of Fitness to Practice

SHSCT ACTIONS

- Arrangements for evaluating individual performance
- Arrangements for managing under performance

Arrangements for investigation of Capability, Conduct of Health Concerns

Awareness of NMC Triggers

Arrangement for NMC referral

Arrangements for participation in NMC Fitness to Practice processes

REGISTRANTS ACTIONS

Participate in Trust processes for the management of poor or variable performance

Participate in Trust investigatory processes

Participate in NMC Fitness to Practice process if required

SHSCT OUTCOMES

Assurance of the Fitness to Practice of registered staff

Meet NMC Fitness to Practice requirements

Compliance with NMC Requirements for Employers

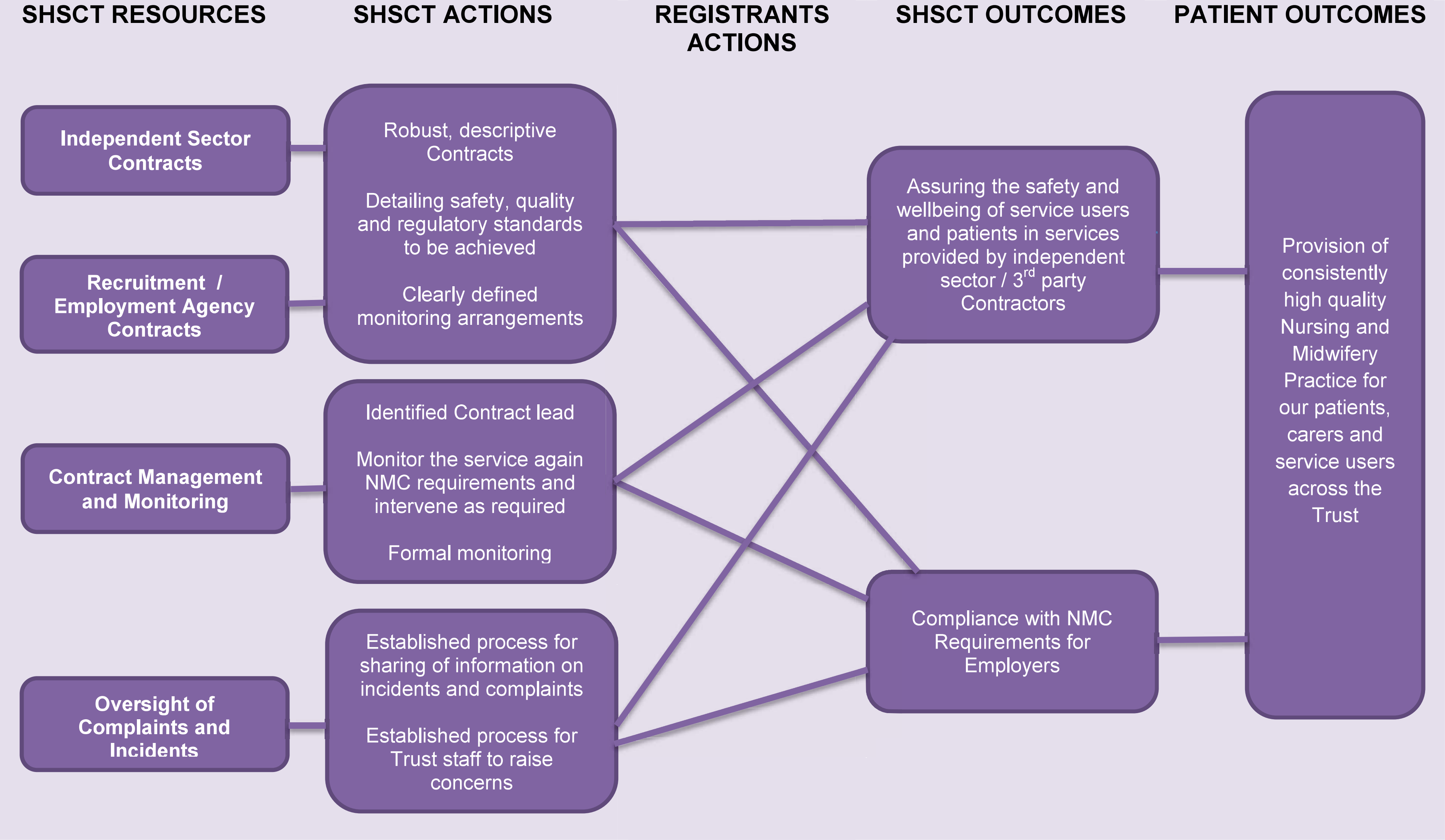
PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

Accountability and Assurance Framework

Nursing and Midwifery

Quality of Nursing in the Independent Sector



SHSCT RESOURCES

SHSCT ACTIONS

REGISTRANTS ACTIONS

SHSCT OUTCOMES

PATIENT OUTCOMES

Independent Sector Contracts

Recruitment / Employment Agency Contracts

Contract Management and Monitoring

Oversight of Complaints and Incidents

Robust, descriptive Contracts

Detailing safety, quality and regulatory standards to be achieved

Clearly defined monitoring arrangements

Identified Contract lead

Monitor the service again NMC requirements and intervene as required

Formal monitoring

Established process for sharing of information on incidents and complaints

Established process for Trust staff to raise concerns

Assuring the safety and wellbeing of service users and patients in services provided by independent sector / 3rd party Contractors

Compliance with NMC Requirements for Employers

Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

Appendix 14- Revalidation NMC & GMC guidelines

Nursing Revalidation SharePoint Tile Nursing & Midwifery Governance - Revalidation

FAQs on NMC Revalidation.pdf

Medical Revalidation SharePoint Tile M&M Resources - Home

Medical Induction & Revalidation.html

NMC REVALIDATION - FREQUENTLY ASKED QUESTION

NMC – Nursing and Midwifery Council.

CPD – Continuous Professional Development

	FAQs	**Information will be updated as arrangements for revalidation are agreed**
GENERAL	***What is Revalidation?***	Revalidation is a legislative requirement of the Nursing and Midwifery (Amendment) Order 2014 which came into force in December 2014. See Appendix 1 for more information. The amended Order allows the NMC to prescribe Fitness to Practise Rules and specific arrangements for revalidation.
	Why do we need it?	- The legislation requires it. Revalidation - - Improves public protection by ensuring that all registrants remain fit to practise throughout their career. - Reinforces individual personal and professional duty to remain fit to practise, incorporating the Code into daily practice. - Builds on existing PREP arrangements by seeking feedback from patients and colleagues, reflecting on the Code and seeking confirmation that requirements have been met. - Enhances employer engagement and awareness of regulatory standards and increases participation in appraisals and professional development.
	Who does it apply to?	To **ALL** Nurses, Midwives and Specialist Community Public Health Nurse who are registered with the NMC.
	When does it take effect from?	October 2015 – NMC is expected to approve the revalidation arrangements at its meeting in October. The arrangements will take effect immediately but in practice will, in the first instance, apply to those registrants due to revalidate in April 2016. Thereafter all registrant must comply with the new arrangements.
	What do I need to do?	Register to access your personal NMC online account. This is the route for submitting information on compliance with revalidation requirements. Go to http://www.nmc.org.uk/registration/nmc-online/. See information on NMC website.
	How will I know when to revalidate?	Once you have registered to access your personal NMC online account – log out and then log in again using your password and you will be able to access your personal information held by the NMC which includes the date you are due to revalidate.
	Is this date the same as the date for annual payment of fees?	Not necessarily. **NB fees are paid annually and usually on the same month each year. Revalidation is every 3 years**. You need to check on your personal NMC online account for your revalidation date. The month for annual payment of fees may be different from that of your revalidation.

PRACTICE HOURS	***How do I know if I have met the required hours of practice?***	***You will be required to declare that you have undertaken 450 practice hours over the previous 3 years.*** The hours of practice can be estimated from your employment contract which specifies the hours/week you are required to work. The minimum is 450 hours over 3 years (150 hours / year or 12.5 hours / month). Those with e.g., 1.0 or 0.5 wte contract will have met these requirements. However, registrants who are 'pure' Bank staff with no fixed hours will need to clearly demonstrate to their confirmer that they have worked for the minimum 450 practice hours over the previous 3 years. Similarly, registrants who have had a career break or a long term sickness period must also evidence that they have practiced for 450 at some point over the previous 3 year period.
	I am a Registered Nurse and a Registered Midwife, how many hours of practice do I need to do?	You will be required to declare that you have met 900 hours of practice over the previous 3 years, 450 in each area. If you are a Registered Nurse and a Registered Specialist Community Public Health Nurse you need only declare that you have met 450 hours of practice over the previous 3 years.
	Does voluntary or unpaid work count?	Yes **but only if the role requires you to be a NMC registrant**. If you are NOT required to be a registrant you cannot count these as practice hours.
	What happens if I don't have the required practice hours?	You must complete an appropriate NMC-approved Return to Practice programme before the date of your revalidation application
CONTINUING PROFESSIONAL DEVELOPMENT	***How will I know if I have the required CPD hours?***	***You will be required to declare that you have undertaken 40 hours of CPD over the previous 3 years.*** Keep a note of all course, conference and learning activity undertaken in the past 3 years. For each **Identify the part of the Code relevant to the learning activity.** In your discussion with your registrant colleague you can agree the learning activity undertaken which supports compliance with the CPD revalidation criteria.
	Does mandatory training count as CPD?	Only if it is relevant to your scope of practice as a nurse or midwife and professional development.
	What does Participatory Learning mean / include?	Participatory Learning includes any learning activity in which you personally interacted with other people.
	How will I evidence the other 20 hours?	The remaining 20 hours does not have to be participatory, i.e., learning with other people, and can include reading journal articles, scoping best practice, project work undertaken as part of a course. As with participatory learning you will need to **Identify the part of the Code relevant to the learning activity.**
	I am a RN (A) and RN (MH) and have a recordable qualification, do I need to demonstrate that I have met CPD requirements for each?	No. The evidence is to support your overall fitness to practise as a registrant and not specific parts of the register. However, the CPD evidence should reflect activity within your current area of practice.

PRACTICE-RELATED FEEDBACK	***How will I gather my evidence on practice-related feedback?***	***You must obtain* at least *five pieces of practice-related feedback over the previous 3 years.*** Feedback can gathered from a variety of sources and can be specifically related to yourself and your individual performance or your team, ward or division/directorate's performance. However, you will need to be clear about the specific impact that the feedback has had on your practice as a registrant. **At your registrant discussion you need to say how this feedback has influenced your practice and your application of the Code.**
	My role is not patient/client facing so how do I obtain the evidence?	You can obtain feedback from a variety of sources relevant to your role such as from students, service users or colleagues who do not have to be nurses or midwives. You can also obtain feedback through reviewing complaints, team performance reports and serious event reviews. You can also use feedback received at your annual appraisal.
	How do I record this feedback?	The NMC has developed a template to support registrants in recording feedback but this can be amended to suit your own individual feedback requirements.
	Does the person feeding back have to sign to say it is correct?	No, however, you should tell patients or colleagues about how you intend to use their feedback and that it will remain confidential and be careful not to include any information that might identify a specific patient or service user in your portfolio.
REFLECTION & DISCUSSION	***How will I gather my evidence of reflective practice?***	***You must record* at least *five written reflections on the Code, your CPD and practice-related feedback over the previous 3 years.*** There are a number of reflective models which can be used to support this activity including the Nurse Supervision model currently in place. You should record all reflections on your CPD and practice including those discussed at supervision.
	How far back can I use examples from?	You can use examples gathered over the past 3 years but it may be useful to more recent reflections to map across to the revised Code.
	How do I record reflective practice?	The NMC has developed a template to support registrants in recording their reflections but this can be amended to suit your own needs. There are other templates that you can use e.g., NIPEC DPF. You should retain these in your portfolio as a record and provide them to the NMC if requested. You must make sure that the NMC registrant with whom you had your professional development discussion signs a form stating their name, NMC PIN, email, address and postcode and date of the discussion.
	Who will I have my registrant discussion with?	If your line manager is also a registrant, your discussion will most likely be with him/her. However, you can also have the discussion with someone you

		frequently work with or e.g., who is in the same learning group.
	What is the purpose of this discussion?	The purpose is to share what you have learned from your CPD activity or feedback with another registrant **and discuss specifically how you have changed or improved your work and how this has impacted on your application of the Code.**
	I am a lone-worker so can I do this over the phone?	The NMC expect the registrant discussion to be a face-to-face conversation. If for some reason this is not possible, then you could arrange a video conference.
	Who will arrange this?	You are expected to arrange the discussion meeting with your registered colleague.
	Can I have my confirmation meeting at the same time?	While the discussion with another registered colleague can form part of your wider confirmation discussion, it is not the same as obtaining confirmation. If your line manager is also a registrant it is likely that these two processes will take place consecutively and will usually form part of your annual appraisal meeting.
HEALTH & CHARACTER	***What does declaring good health and character mean / entail?***	You will need to complete the following declarations as part of your revalidation application. - ***You must provide a health and character declaration*** *and* - ***You must declare if you have been convicted of any criminal offence or issued with a formal caution over the three years prior to the renewal of your registration.*** Further information can be found at http://www.nmc.org.uk/education/becoming-a-nurse-or-midwife/when-studying-to-be-a-nurse-or-midwife/ http://www.nmc-uk.org/Registration/Staying-on-the-register/Declaring-police-charges-cautions-and-convictions/
	Does having a disability or health condition mean I am not of good health?	No, but the NMC expects that you are able to provide safe and effective practice without supervision, after any reasonable adjustments are made by your employer.
	Do I have to declare the time I have been on sick leave in the past 3 years?	No, unless this adversely affects your ability to practice safe and effectively. You should discuss this with your line manager.
	Do I have to declare if I have received a caution or conviction?	Yes. You must declare if you have received any cautions or convictions, or have any police charges pending over the three years prior to the renewal of your registration. A caution or conviction includes those received in the UK for a criminal offence, as well as a conviction received elsewhere for an offence which, if committed in the UK, would constitute a criminal offence.
	Do I have to declare driving offences?	No, you do not need to declare fixed penalty fines for traffic offences unless they have led to a disqualification or motoring offences that you have already notified the NMC about.

	Who confirms that I am in good health and of good character?	You are personally and professionally responsible for making the declaration.
INDEMNITY ARRANGEMENTS	***How will I know if I have professional indemnity?***	***You must declare that you have, or will have when practising, appropriate cover under an indemnity arrangement.*** By law, you must have in place an appropriate indemnity arrangement in order to practise and provide care. NHS bodies are vicariously liable for the negligent acts and omissions of their employees and should have arrangements for meeting this liability. As an employee of a public body the Trust will provide you with appropriate indemnity cover. Trust professional indemnity cover does not apply to self-employed health care professionals such as independent midwives or those undertaking a role or work (voluntary or unpaid) outside the Trust which requires the person to be a registrant.
	Is this different for midwives?	No, registered midwives, employed by and within the Trust are covered. Those registered midwives who also work in a private / independent capacity must arrange appropriate indemnity for when they are working outside the Trust.
	What if I have a private practice as well as a Trust contract?	As above, those registrants who work in a private / independent capacity must arrange appropriate indemnity for when they are working outside the Trust.
CONFIRMATION FROM A THIRD PARTY	***What does confirmation from a third party mean?***	**You must ask a third party to confirm that you have complied with all NMC revalidation requirements.** You must provide the name, NMC PIN or other professional identification number (where relevant), email, professional address and postcode of the confirmer / third party.
	Who will be / who will choose my confirmer?	If your line manager is also a registrant it is likely that the registrant discussion and confirmation will take place consecutively and will usually form part of your annual appraisal meeting. If your confirmer is an NMC registrant, s/he must have an effective registration with the NMC and must not be subject to any kind of suspension, removal or striking-off order at the time of making the confirmation.
	If my line manager is not a registered nurse who will my third party confirmer be?	To be agreed If there is any conflict of interest or perception of bias both you and your confirmer will need to exercise judgement to ensure that the confirmation process remains credible and objective.
	What is the role of the confirmer?	The role is to confirm that you have complied with the NMC's revalidation requirements.

	How long before my registration is due will I need to meet with my confirmer?	To be agreed You can meet with your confirmer once you have complied with all the NMC's revalidation requirements. The NMC recommend that you obtain your confirmation during the final 12 months of the three-year registration period to ensure that it is recent. If your confirmation was obtained earlier, the NMC may ask you to explain why.
	Who will arrange this meeting?	You are expected to arrange the meeting with your third party confirmer.
	How often will have to meet my confirmer?	Ideally, and if you have complied with all the NMC's revalidation requirements, you will only have to meet with your third party confirmer once every three years. However, if your confirmer is also your line manager you will most likely meet with him / her on an annual basis to complete your appraisal and Personal Development Plan (PDP). Progress on the completing your portfolio can be discussed at your annual appraisal and any actions needed to ensure your compliance with the revalidation requirements can be discussed and agreed.
	Will I be a confirmer?	To be agreed – If you are a line manager of registered nurses, midwives and / or Specialist Community Public Health Nurses you will most likely be a confirmer.
APPLYING FOR REVALIDATION	***How do I apply for revalidation?***	The NMC will notify registrants at least 60 days before revalidation is due. Please make sure that the NMC has your most up-to-date contact details by checking your personal account online. You will have 60 days to log into NMC Online and complete the revalidation application form and the NMC has published a step by step guide to registering. If you are also a **registered midwife** practising in the UK, you will need to file your intention to practise notification form. This should be submitted annually to your named supervisor of midwives.
	How do I advise the NMC that I have met the revalidation requirements?	By completing the online revalidation form. You will need to have all the supporting evidence from your revalidation portfolio to hand when you start your online application. You must submit your application on or before the date we specify. **Failure to submit your application on time will put your registration at risk**
	What information do I need to submit?	You will be asked to provide the name, NMC PIN or other professional identification number (where relevant), email, professional address and postcode of the third party that provided your confirmation. You need only complete the online verification details requested as part of the NMC's revalidation process. You do not need to upload any supporting documentation unless specifically asked to do so. If you are selected to provide further information to verify your

		application, the NMC will ask you to provide the signed confirmation form in order to check with your confirmer that he/she provided your confirmation.
		As part of your revalidation application, you will need to pay your renewal fee.
OTHERS QUERIES	***What if I don't revalidate on time?***	The NMC will not usually consider any requests for extensions to submit a revalidation application. The requirements should be met within the three years prior to the renewal of your registration. However, if you believe that you have exceptional circumstances, please contact the NMC directly to discuss you situation.
	Can I still revalidate if I am the subject of an NMC investigation?	Yes, if you are subject to an NMC investigation, a condition of practice order or a caution, you will be able to apply to renew your registration as long as you fulfil all the requirements for renewal. However, you will remain subject to NMC fitness to practise processes and the outcome of those processes. If your renewal is due while you are subject to suspension from the register, **you can only apply once your suspension has been lifted** after which you will have three months to apply for and obtain your renewal. If you fail to do this, you will have to apply for re-admission to the register via an NMC-approved Return to Practice programme. If you have been struck-off or suspended from the register, you will not be permitted to renew your registration because you are no longer on the register.

Appendix 1

Brief summary points / timeline on the Fitness to Practice Rule changes

- In July 2012, the Professional Standards Authority's (PSA) (then Council for Healthcare Regulatory Excellence CHRE) Strategic Review of the NMC identified problems with the NMC's fitness to practise process and recommended these should be addressed at the earliest opportunity.

- In 2013, in its response to the final report of the Mid Staffordshire Trust Public Inquiry, the Government acknowledged that outdated legislation and Rules hampered the NMC's ability to provide assurance on registrants' fitness to practise.

- In March 2013, to support the NMC in amending its fitness to practise arrangements, the Department of Health agreed that a section 60 Health Act 1999 Order should be made to amend the Nursing and Midwifery 2001 Order.

- On 11 December 2014 the section 60 Order came into force making a number of amendments to the Nursing and Midwifery 2001 Order – now the Nursing and Midwifery (Amendment) Order 2014. The amendments allow the NMC prescribe specific fitness to practice including revalidation arrangements, thereby carrying out its registration functions more effectively, improving public protection and increasing the public's confidence in the regulation of nurses and midwives.

- Specifically the Nursing and Midwifery (Amendment) Order 2014 empowers the NMC to make changes to the Rules on Fitness to Practise and Education, Registration and Registration Appeals.

- In April 2014 the Law Commission published its review of 150 years of complex health and care legislation relating to 11 regulated professional groups, including the NMC, and made recommendations for legislative changes. The Government's response will be published in during the next Parliament.

- An associated amendment to the Health Care and Associated Professions (Indemnity Order) 2014 (S.I. 2014/1887) makes it a condition of registration to have in place an indemnity arrangement providing appropriate cover. This enables the NMC to make rules which require registrants to have appropriate indemnity arrangements in place. These rules also enable the NMC to disclose to a third party information that it has received in respect of a person's indemnity arrangement for the purposes only of verifying that information.

- The amendments also introduce provisions to the Registration Rules which will allow registrants to pay the registration, retention, renewal, readmission or restoration fee by instalments and thereby help registrants meet these costs over a period of time.

- Between April and June 2014 the NMC conducted two consultations in respect of the proposed rule changes. The first was an online survey which ran in parallel to the Department of Health's Section 60 consultation from 17th April to 12th June 2014. This consultation received broad support from respondents. Outcomes available on the NMC website.

- Between August and October 2014 the NMC consulted on the ability to pay the annual registration fee in instalments in order to enable nurses and midwives to meet the payment of their registration fees in a more manageable way. This consultation received a very high level of support. Outcomes available on the NMC website.

- Both sets of Rule changes are to be introduced as a single instrument to maximise efficiency and the use of parliamentary time.

- Following consultation the NMC developed a model for the revalidation and, following a pilot in a range of facilities and across professional groups in the four countries, will approve the model at its NMC Council meeting in October 2015 with immediate effect.

- As the notice of revalidation to registrants has been proposed as 45 days, those who are due to revalidate in April 2016 will be the first to provide evidence of compliance with the new arrangements.
- The NMC will issue supportive information on their website which will be updated along with other information leaflets and media releases and the implementation progresses.

- A Northern Ireland Programme Board for Revalidation was convened in November 2014. Chaired by the CNO and with links to the NMC. It will oversee implementation of revalidation within NI. The WHSCT has been identified as the pilot site and will be represented on the NI Revalidation Programme Board.

- A Working Group reporting to the Programme Board has now been set up. During the lifetime of the project it is envisaged that the Working Group will meet monthly.

For further information see Explanatory Memorandum to the Nursing and Midwifery Council (Fitness to Practise) (Education, Registration and Registration Appeals (Amendment) Rules Order of Council 2015, 2015 No. 52 at http://www.legislation.gov.uk/uksi/2015/52/pdfs/uksiem_20150052_en.pdf

Appendix 15- Supervision Policy

Nursing Supervision Policy.pdf

Southern Health and Social Care Trust

Quality Care - for you, with you

Policy Checklist

Name of Policy:	**Nursing Supervision Policy**
Purpose of Policy:	To ensure that a culture of Nursing Supervision is embedded in the Southern Health and Social Care Trust and that the processes through which Supervision is carried out are integral to the organisational arrangements for the delivery of safe and effective care.
Directorate responsible for Policy	Executive Director of Nursing
Name & Title of Author:	Margaret Marshall, Assistant Director of Nursing Governance Paula Fearon, Nursing Governance Co-ordinator
Does this meet criteria of a Policy?	Yes
Trade Union consultation?	Yes
Equality Screened by:	NA
Date Policy submitted to Policy Scrutiny Committee:	9th July 2018

Members of Policy Scrutiny Committee in Attendance:

Electronically by membership of Policy Scrutiny Committee

Policy Approved/Rejected/ Amended	19th July 2018
Policy Implementation Plan included?	N/A – reviewed policy
Any other comments:	
Date presented to SMT	N/A – reviewed policy
Director Responsible	Director of Nursing and AHP's
SMT Approved/Rejected/Amended	N/A
SMT Comments	

POLICY DOCUMENT – VERSION CONTROL SHEET	
Title	Nursing Supervision Policy Version 3 July 2018
Supersedes	Version 2_0_August 2011
Originator	Margaret Marshall, Assistant Director of Nursing Governance
Scrutiny Committee & SMT approval	Referred for approval by: Margaret Marshall Date of Referral:10th July 2018 Scrutiny Policy Committee Approval 9th July 2018 SMT approval (Date)
Circulation	Issue Date: 20th July 2018 Circulated By: Assistant Director of Nursing Governance
Review	Review Date: September 2019 Responsibility Margaret Marshall, Assistant Director of Nursing Governance

Southern Health
and Social Care Trust

Quality Care - for you, with you

POLICY TITLE:	**Nursing Supervision Policy**
ACCOUNTABLE DIRECTOR:	Heather Trouton, Interim Executive Director of Nursing
POLICY AUTHOR:	Margaret Marshall, Assistant Director of Nursing Governance
CO-ORDINATOR FOR IMPLEMENTATION PLAN:	Heather Trouton, Interim Executive Director of Nursing
DATE APPROVED BY POLICY SCRUTINY COMMITTEE:	9th July 2018
DATE APPROVED BY SMT:	N/A – Policy Review

Contents ***Page No.***

1.0 Introduction 5

2.0 Aim of the Policy 6

3.0 Policy Statement 7

4.0 Definition and Scope of the Policy 7

5.0 Supervision and Appraisal 9

6.0 Responsibilities 9

7.0 Legislative Compliance, Relevant Policies, Procedures 11

8.0 Equality and Human Rights Considerations 11

Appendices

Appendix 1 - Guidance on Nursing Supervision 13
Appendix 2 – Range of Supportive Activities 16
Appendix 3 – Ground Rules for Supervision 18
Appendix 4 – Preparation for Supervision Form 20
Appendix 5 – Record of Supervision Forms 21

1.0 Introduction

The importance of effective Supervision has been highlighted in regional critical incident inquiries such as the Lewis Review (2003)[1], Murtagh Review (2005)[2], and McCleery Report (2006)[3]. The Quality Standards for Health and Social Care (DHSSPS 2007)[4] recommend an effective system for Supervision across Health and Social Care (HSC) to help organisations meet each of the Clinical and Social Care Governance Standards.

It is recognised that effective Supervision processes improve: recruitment and retention of nursing staff; job satisfaction; professional autonomy; and reduces absenteeism[5].

1.1 This revised policy and "*Guidance on Nursing Supervision*" (Appendix 1) have been produced to support the continuing development and maintenance of a robust system of Supervision for nursing staff who work within the Southern Health and Social Care Trust (SHSCT).

1.2 The Review of Clinical Supervision for Nursing in the Health and Personal Social Services (Ireland and UK) (HPSS) (2007)[6] recommended action to enhance and promote professional Supervision for Nursing in Trusts throughout Northern Ireland.

The report defined Supervision as:
'a process of professional support and learning, undertaken through a range of activities, which enables individual registrant nurses to develop knowledge and competence, assume responsibility for their own practice and enhance service-user protection, quality and safety'.

Following this the Chief Nursing Officer (CNO) published Standards for Supervision for Nursing[7] which contained 2 Regional Standards.

---

[1] Lewis, RJ, Cole, D, Williamson, A (2003). Review of Health and Social Services in the case of David and Samuel Briggs. Belfast, DHSSPS

[2] Regional Quality Improvement Authority (2005). Review of the lessons arising from the death of the Late Janine Murtagh, Belfast, RQIA

[3] McCleery Inquiry Panel (2006). Executive Summary and Recommendations from the report of the Inquiry Panel (McCleery) to the Eastern Health and Social Services Board, Belfast, DHSSPS

[4] Department of Health, Social Services and Public Safety (2007). The Quality Standards for Health and Social Care. Belfast, DHSSPS

Hyrkäs, K., Appelqvist-Schmidlechner, K. and Haataja, R. (2006). Efficacy of clinical Supervision: Influence on job satisfaction, burnout and quality of care. *Journal of Advanced Nursing*.55(4), 521-535

http://www.nipec.hscni.net/download/projects/current_work/highstandards_practice/framework_for_Supervision_in_nursing_and_miwifery/documents/Supervision-in-Nursing-in-NI-Review-of-Current-Processes.pdf

Chief Nursing Officer for Northern Ireland (2007) *Standards for Supervision for Nursing*. Belfast, DHSSPS

1.3 Other outcomes were : a Regional Policy and Procedure document, a *Frequently Asked Questions Leaflet* ; standardised record keeping resources including contracts for supervisors and supervisees; a regional approach to the preparation of supervisors and supervisees.

A Supervision Regional Forum was charged with directing and supporting the implementation of the Standards. This was facilitated by Northern Ireland Practice and Education Council for Nursing and Midwifery (NIPEC). The Standard Statements were revised as follows:-

Standard Statement 1 *Supervision will contribute to the delivery of safe and effective care when practitioners have access to appropriate systems that facilitate the development of knowledge and competence through a culture of learning by reflection.*

Standard Statement 2 *An organisational framework supporting effective leadership and performance management will ensure that Supervision will become an effective tool to improve the safety and quality of care.*

1.4 NIPEC annually evaluates Supervision process and perceived impact on practice. Each Trust receives a confidential report. The Chief Nursing Officer (CNO) monitors Trust compliance with the Standards through annual reports from each HSC Trust's Executive Director of Nursing (EDoN).

1.5 In June 2016 the CNO and Central Nursing and Midwifery Advisory Committee (CNMAC) agreed to the development of a single regional overarching Nursing and Midwifery Supervision Framework. The new model must provide professional accountability assurances to the CNO, Executive Directors of Nursing and the public. NIPEC is facilitating this development and has reviewed the current Supervision processes. It had been hoped the Framework would be completed by 2017, however work, although near completion, is ongoing. Progress can be tracked via the following link:
http://www.nipec.hscni.net/download/projects/current_work/highstandards_practice/framework_for_Supervision_in_nursing_and_miwifery/documents/Supervision-in-Nursing-in-NI-Review-of-Current-Processes.pdf

As an interim measure, the previously agreed Regional Nursing Supervision Policy (SHSCT) has been reviewed and revised here-in.

2.0 Aim of the Policy

This policy identifies Supervision in Nursing as a key organisational objective for all Health and Social Care (HCS) Trusts in Northern Ireland. The aim of this policy is to ensure that a culture of Nursing Supervision is embedded in the SHSCT and that the processes through which Supervision is carried out are integral to the organisational arrangements for delivery of safe and effective care in the Trust.

2.1 The implementation of an effective system of Supervision for Nursing will help ensure:-

- The promotion and maintenance of Nursing Care Standards,
- A competent and skilled workforce,
- Delivery of safe and effective care; and
- A supportive professional environment for nursing staff.

2.2 Senior management teams in the SHSCT must ensure that appropriate measures are in place to enable Supervision activities for both clinical and non-clinical teams.

3.0 Policy Statement

The SHSCT acknowledges the importance of Nursing Supervision in ensuring the delivery of safe and effective nursing care and the essential role it plays in protecting the public.

The SHSCT stipulates that all nurses it employs should have access to and avail of, a minimum of two Supervision sessions per year. The Trust must ensure there are effective systems in place to support Supervision processes. All supervisors must be supported to acquire the appropriate knowledge and skills to competently undertake this role.

4.0 Definition and Scope of the Policy

The Department of Health, Social Services and Public Safety (DHSSPS) adopted the following definition of Supervision for Nursing following *The Review of Clinical Supervision for Nursing in the HPSS* undertaken by NIPEC in 2006:

'Supervision is defined as a process of professional support and learning, undertaken through a range of activities, which enables individual registrant nurses to develop knowledge and competence, assume responsibility for their own practice and enhance service-user protection, quality and safety', NIPEC 2006[8]

4.1 The SHSCT requires all registered nurses to have a minimum of two formal Supervision sessions per year. Registrants are likely to engage in other activities which could also support the Supervision process. The Regional Forum acknowledged that a variety of diverse approaches and activities could be employed in implementing Supervision. Some examples are included in Appendix 2.

---

[8] Northern Ireland Practice and Education Council (2007) The Review of Clinical Supervision for Nursing in the HPSS 2006 on Behalf of the DHSSPS. Belfast, NIPEC.

4.2 It should be noted that the scope of Safeguarding Children Supervision differs from Supervision referred to in this Policy. Safeguarding Children is separate from, but complimentary to, other forms of Supervision. Safeguarding Children Supervision provides specialist professional advice, case management and support to staff in their safeguarding of children. This includes children in need of protection; children in need; looked after children and families of concern.

The **Safeguarding Children Nursing Supervision** process includes the assessment of staff performance, professional development in relation to safeguarding children and families and quality assurance of practice to ensure compliance with best practice guidelines.

Further information is available via:

- DHSSPS Safeguarding Children Supervision Policy for Nurses (2011).
- https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/safeguarding-children-supervision-policy.pdf
- *The SHSCT Policy, Procedures and Guidance for Registered Nurses, Midwives and Specialist Community Public Health Nurses on Safeguarding Children and Young People (Revised May 2018).* This is available on the Trust Intranet and SharePoint http://sharepoint/gov/home/Policies%20and%20Procedures/Forms/AllItems.aspx?RootFolder=%2Fgov%2Fhome%2FPolicies%20and%20Procedures%2FPolicies&FolderCTID=0x0120002BE1109E37E47349B3DE6A07F51171ED&View=%7B39B022B7%2DEAF5%2D4CE3%2D8BC9%2D6EE55B567DC4%7D

4.3 Midwifery Supervision in Northern Ireland

The awaited Framework for the overarching Supervision of Midwifery, Nursing and Safeguarding Children will be introduced on the completion of the CNO-commissioned NIPEC work. Whilst this work is ongoing, Midwifery (as well as Nursing and Safeguarding) Supervision will continue in Northern Ireland.

Northern Ireland has taken forward legislative changes to the Nursing and Midwifery Order 2001 effective from 31st March 2017. Northern Ireland has taken forward legislative changes to the Nursing and Midwifery Order 2001 effective from 31st March 2017. This removed Supervision from its statutory regulation components. Until the review of supervision is completed by NIPEC midwifery supervision will continue in the agreed format as determined by the Midwifery Working group September 2016.

Details of the arrangements from April 2017 until the overarching Supervision of Midwifery, Nursing and Safeguarding Children can be found via the following link: https://www.health-ni.gov.uk/articles/changes-midwife-Supervision-uk

5.0 Supervision and Appraisal

It is important that Supervisors and Supervisees in the SHSCT recognise and differentiate Supervision activity from other processes such as appraisal. Whilst Supervision activity informs and is informed by the Agenda for Change Knowledge and Skills Framework Annual Review Process, neither activity should be substituted for the other, each activity having a different purpose.

6.0 Responsibilities

In the SHSCT there are key individuals in posts with responsibility for ensuring Nursing Supervision is implemented. They are: -

6.1 Chief Executive

The Chief Executive of the SHSCT accepts responsibility and accountability for quality service provision at Trust Board level which includes systems, such as Supervision in Nursing, which support clinical and social care governance.

6.2 Executive Director of Nursing

The Executive Director of Nursing, in conjunction with the Operational Directors in the SHSCT is accountable to the Chief Executive for the implementation and maintenance of Supervision in Nursing. The Executive Director of Nursing presents the Trust Report to both the Trust Board and the Chief Nursing Officer for Northern Ireland on an annual basis. In addition, s/he may act as a supervisor for Assistant Directors and other senior professional roles when appropriate.

6.3 Directors

All Directors have responsibility for ensuring that arrangements are in place within their directorate to evidence compliance with this policy and that resources are available to support Nursing Supervision, monitoring and reporting processes.

6.4 Assistant Director of Nursing Governance

The Assistant Director of Nursing Governance has responsibility to co-ordinate, facilitate, evaluate and maintain a system of Supervision in the Nursing workforce. S/he is accountable to the Executive Director of Nursing and for presenting information relevant to the quantity and quality of SHSCT Supervision activity in governance reports or accountability reviews.

6.5 Operational Assistant Directors

Operational Assistant Directors have responsibility to co-ordinate and facilitate implementation and maintenance of Supervision for nurses within their individual directorates. They are responsible for agreeing the models of Supervision to be employed within the division/directorate and must ensure appropriate resources are in place to enable nurses to undertake at least two formalised sessions of Supervision annually. They are responsible for monitoring the ongoing level of Supervision activity within individual directorates and will facilitate the Assistant Director of Nursing Governance in collation of reports

6.6 Heads of Service/Nurse Managers/Lead Nurses

Heads of Service/Nurse Managers/Lead Nurses have a responsibility to promote, co-ordinate and facilitate implementation and maintenance of Supervision for nurses within their individual directorates/divisions. They are accountable to the Operational Assistant Director and can act as supervisors for Ward Managers/Team Leaders within their own division/directorate.

6.7 Ward Managers/Team Leaders

Ward Managers/Team Leaders have a responsibility to role-model and facilitate implementation and maintenance of Supervision for nurses within their staff teams. They are accountable to the Heads of Service. They can act as supervisors for other members of staff, either within or outside their own team.

6.8 Supervisors

Supervisors have a responsibility to maintain and develop their own skills and competencies relative to Supervision activity, contribute to the models of learning and to the approaches used. They must seek and undertake Supervision themselves, maintaining records for both their personal Supervision and professional Supervision of others. They must provide at least two formal sessions of Supervision annually for each supervisee, whether group or individual. They must adhere to ground rules identified and conduct Supervision sessions within the principles and process identified in these procedures. They are accountable to their line managers for this activity.

6.9 Supervisees

Supervisees have a responsibility to engage fully in the nursing supervision process, adhering to identified ground rules. They have a responsibility to prepare for, and participate in, a minimum of two formal Supervision sessions per year, keeping accurate records of relevant actions. Activities undertaken between sessions should be used to inform formal Supervision sessions. Supervisees are accountable to their line manager to engage in a minimum of two formal supervision sessions annually.

7.0 Legislative Compliance, Relevant Policies, Procedures

This policy should be read in conjunction with the:-

- Southern Trust Policy, Procedure and Guidance on Record Keeping as outlined in the content and appendices of this document.
- Safeguarding Board for Northern Ireland (SBNI) Regional Core Child Protection Policy and Procedures (2017).
- DHSSPS Safeguarding Children Supervision Policy for Nurses and Midwives (2011) - currently under Regional review

http://vsrintranet.southerntrust.local/SHSCT/HTML/PandP/documents/RecordsManagementProcedures_001.pdf

https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf

http://sharepoint/gov/home/NMC1/NMC%20Standards%20for%20Competence/NMC%20Standards%20for%20competence%20for%20Registered%20Nurses.pdf

http://sharepoint/gov/home/NMC1/NMC%20Standards%20for%20Competence/NMC%20Standards%20for%20Competence%20for%20Registered%20Midwives.pdf

http://revalidation.nmc.org.uk/

https://www.health-ni.gov.uk/articles/changes-midwife-Supervision-uk

https://www.ombudsman.org.uk/publications/midwifery-Supervision-and-regulation-recommendations-change/current-midwifery-Supervision-and-regulation-nursing-and-midwifery-councils-role

8.0 Equality and Human Rights Considerations

This policy has been screened for equality implications as required by Section 75, Schedule 9, of the Northern Ireland Act, 1998. Equality Commission for Northern Ireland Guidance states that the purpose of screening is to identify those policies which are likely to have a significant impact on equality of opportunity so that greatest resources can be targeted at them.

Using the Equality Commission's screening criteria, no significant equality implications have been identified. This policy will therefore not be subject to an Equality Impact Assessment.

This policy has been considered under the terms of the Human Rights Act 1998, and was deemed to be compatible with the European Convention Rights contained in that Act.

9.0 This policy will be included in the Trust's Register of Screening Documentation and maintained for inspection whilst it remains in force.

This document can be made available on request in alternative formats, e.g. Braille, disc, audio cassette, and in other languages to meet the needs of those who are not fluent in English.

The SHSCT audit this Policy every two years and make appropriate changes where necessary.

GUIDANCE ON NURSING SUPERVISION

Purpose of Nursing Supervision

The main purpose of Nursing Supervision is to support: -

- Nurses to develop the necessary knowledge, competencies and skills within a role or clinical area, to enhance safe and effective practice and person centeredness;
- Nurses in both clinical and non-clinical roles by providing an opportunity to discuss issues pertinent to the delivery of safe and effective care and / or professional issues;
- Nurses through difficult circumstances such as challenging patient caseloads or difficult interpersonal contact with other team members;
- Nurses to realise personal and professional growth through reflection and facilitation.

Supervision Processes

Frequency of Supervision

Formalised Supervision sessions for nursing staff should take place at least twice per year.

Nursing and Midwifery Mandatory Requirements

The Nursing and Midwifery Council (NMC) has recognised the importance of reflection and subsequent discussion as integral to professional development of nurses and midwives. It has included reflective discussion as a mandatory requirement for Revalidation. http://revalidation.nmc.org.uk/

Nurses can access guidance on reflection and keeping a portfolio with corresponding templates:-
https://www.nmc.org.uk/globalassets/sitedocuments/revalidation/reflective-discussion-guidance.pdf

The pre-requisite Reflective Template can be completed by staff in preparation for Supervision:-
http://revalidation.nmc.org.uk/download-resources/forms-and-templates/

Preparation for Supervision

Registered nurses should reflect on their own practices as they engage in ongoing learning and development activities in their working environment. This experience should be used to inform the Supervision sessions. There are many ways to reflect on practice and approach supervision-some examples are included in Appendix 2.

In order to benefit from Supervision, nurses should prepare appropriately. Preparation will include becoming familiar with and agreeing to, the Ground Rules for the Supervision session. (Appendix 3) Preparation will also include a review of the current Supervision action plan and reflection on the learning activities that have been undertaken between sessions. A Supervision Preparation template to help structure this process can be found at Appendix 4.

General information and guidance on Nursing Supervision is available in the Health and Social Care Trust (HSC) *'Nursing Supervision Information Leaflet - Frequently Asked Questions (updated 2016).*

Issues of Concern

Where an issue of unsafe, unethical or illegal practice is identified, it should be dealt with supportively via appropriate procedures. All parties must be informed of the intention to disclose, before revealing confidential information.

Use of Patient /Client Records

If necessary, patient/client records maybe used for the purposes of Supervision activity. The NMC states that where this happens, principles of access and confidentiality apply, namely:-

- Patients'/clients' health records should only be accessed where necessary;
- The patient/client reserves the right to refuse access to, or limit the information from his/her records; this should be respected.

The SHSCT Records Management Policy[10] and associate procedures should be adhered to. http://vsrintranet.southerntrust.local/SHSCT/HTML/PandP/documents/RecordsManagementProcedures_001.pdf

The NMC no longer have standalone guidance on record keeping, this has been incorporated into the NMC Code.
https://www.nmc.org.uk/standards/code/record-keeping

Recording Supervision

It is essential that written notes of individual sessions are taken, remain confidential and record clearly any agreed actions. Individual sessional notes are the responsibility of the supervisee. The supervisor should, however, keep brief notes and maintain quarterly Sessional Records information which is submitted to the Ward Manager/Team Leader or the appropriate line manager. Copies of the Record of Supervision form can be found in Appendix 5.

Each formalised Supervision session must have a written record signed by both supervisor and supervisee(s).

Storage of Records

The SHSCT Policy for the safe storage of records must be adhered to however, each registrant should also be mindful of his/her professional accountability with regard to the principle of confidentiality of information. Nurses must, therefore, take responsibility for making sure that the system used is managed in such a way that it is appropriately protected to ensure the security of confidential information.

Monitoring and Evaluation

Monitoring and evaluation of Supervision activity are essential to ensure that resources required for professional Supervision are managed effectively. It is also necessary to monitor the benefit to individual registrants, as the quality of Supervision activities can influence professional and clinical effectiveness.

The SHSCT may seek qualitative information periodically from individual registrants to assist in the ongoing evaluation of Supervision processes.

Individual supervisors must record quarterly the number of sessions they engage in and make these returns available to line managers for collation. This information will, in turn, be collated by directorate managers and communicated to the Assistant Director of Nursing Governance, who is responsible for monitoring Nursing Supervision within the Trust.

Formal Supervision sessions (2 per year) must be recorded on the *“KSF Form for use by NMC Registrants – Part B*” and forwarded to the SHSCT Nursing Revalidation Team at the time of yearly appraisal

Part B of the Annual Personal Development Plan can be found on the Trust Intranet under Knowledge and Skills Framework section – *KSF Form for use of NMC Registrants Only*
http://vsrintranet.southerntrust.local/SHSCT/HTML/KSF/documents/KSFFormforNMCRegistrants_001.docx

Range of Supportive Activities

A range of activities can support Supervision in the Nursing workforce. Whichever activity is used each registrant must ensure he/she has the appropriate skills and competencies required to engage in the activity.

Nurses should use the many learning opportunities within their work environments to reflect on their own practice. These *informal* experiences can be used to inform *formal* Supervision sessions.

Examples of activities which support Supervision can be found in Table 1 – overleaf.

Many activities inform Supervision processes; it should, therefore, be noted that this is not a definitive list of activities, merely examples to guide professional teams.

Table 1: Range of Supportive Activities

Reflective Practice Reflective practice is the process of thinking about your own practice and that of others in a structured way; this leads to new and better ways of working and helps you develop new levels of knowledge and competence. You will learn to think critically about your practice and about what you need to do to improve it and the care you provide. Reflection allows you to describe your experience, think about it, and evaluate the outcomes. This should help you to have new understandings and insights. Reflection is what turns experience into meaningful learning, making sense of the world around you, and building on what is happening. You may also find it helpful to use one of the many reflective tools that have been developed.	**Work-Based Learning** A work-based learning programme is provided by an education institution, using a negotiated, project-led approach; this is managed by you and provides the best opportunities for learning and professional development in the workplace. Work-based learning acknowledges that everyone learns in different ways. It gives you control over how and when you learn and takes learning out of the classroom into the workplace. The learning is gained through work-related projects. Work-based learning opens your eyes to the fact that you can learn from anything. Work-based learning in multi-professional teams, making full use of modern technology, can produce benefits to you, the organisation and the profession. Successful completion of the programme will provide you with accredited learning and lead to an academic qualification. It is concerned with helping you to bridge the practice/theory gap.	**Post Incident Review** This happens when an incident has occurred in the workplace that has caused you and/or other members of the healthcare team a level of distress. The incident has usually resulted in a miss or near-miss, where there has or could have been damage to a patient or client. A post-incident review involves the reviewing of specific incidents, either individually or as a team, within a setting that provides emotional support to each person. The incident is analysed with your involvement and the involvement of all team members, using reflection, self-evaluation and/or facilitated learning to establish how the incident happened and how it could be avoided in the future. If you are involved in a post-incident review, it should result in good support from your team members and outcomes and actions for yourself and the team, with possible organisational implications. The final outcome must provide a clear description of risk factors and required action. You should also use the review process to identify personal action plans and required development. This is a learning event for all involved, with the objective of learning to improve practice.
Learning Sets The term refers to a group of people who meet regularly to work and learn together, using a structured format. The learning set can comprise of uni- or multi-professional groups and the focus is on self-directed learning; the participants decide the particular issues to be addressed. This provides you with a confidential forum in which to test issues that concern you, discuss new ideas and help you and the others to challenge working practices in new and creative ways. It is important to set ground rules to deal with issues such as confidentiality. Each member of the group is facilitated and supported by the others in the solving of issues and problems.	**Critical Incident Review** A critical incident is a significant event or experience that has occurred in your workplace and that you feel has had an impact on you or the people you work with. This could be negative or positive; it could be a personal experience or it could result from observing how other people work. You need to examine the incident through a process of reflection, using an evidence-based approach, to identify lessons to be learned. This could also take place with a group of practitioners working together. This should result in new learning for you and/or the group you are working with and result in a short action plan to bring about improvement in practice.	**Group Supervision** This is a valuable learning activity as it helps to develop critical thinking and collaborative working and brings about improvements in Nursing practice. Group Supervision needs to be set up within a structured format to ensure that nurses have the required skills and are supported by experienced colleagues.
Supervised Practice for Competency Development This is a negotiated period of supervised practice, with agreed learning and competency outcomes and may be provided for you if you require to develop specific, identified competencies. It is also likely to be arranged for you if you have poor or failing clinical competence in an area of practice. This is a period of practice where you are supervised and monitored by an experienced practitioner. The length of the supervised practice and the required outcome are set before the exercise begins. You are required to work closely with your supervisor throughout the entire period of practice. You will also be assessed at the end of the supervised practice to demonstrate that you have the necessary knowledge and competence.	**Preceptorship / Mentoring** A mentor is someone who has skills of working with individuals who can provide guidance and support to help you achieve your potential. Your mentor may not be from your own field of practice but should be a person with mentoring experience. Mentoring is achieved through a process of relationship building between yourself and your mentor and takes place over a period of time. The purpose of the mentoring process is to enable you to recognise your own skills and capabilities and maximise the development opportunities available to you.	**Opportunistic Experiences** Often in the course of a working day there is the opportunity to learn from other people or situations in which you might find yourself participating. These experiences are not planned but provide us with a rich learning ground. Examples of these could be: a medicine round where you learn about a new drug regimen; a community patient visit with a tissue viability nurse; discussing the difficulties a palliative patient in your care is experiencing with a colleague; supporting a colleague who has experienced challenging behaviour from a client. All of these situations provide learning which we often reflect on without recording. It is important to make a brief note of the learning provided by these experiences as it can inform other more formal processes in the future.

APPENDIX 3

GROUND RULES FOR 1:1 SUPERVISION

Prior to Supervision session the SUPERVISEE will have: -

- Read all relevant/associated policies, procedures and guidance
- Prepared for the session and will have considered and identified practice areas for open discussion
- Undertaken relevant action(s) as agreed at previous Supervision session(s)

During each Supervision session both **SUPERVISOR** and **SUPERVISEE** will: -

- Maintain mutual respect
- Have an attitude of open learning
- Maintain strict confidentiality
- Be open to constructive feedback
- Engage in reflective practice
- Deal appropriately with areas of disagreement according to the Ground Rules
- Ensure that identified unsafe, unethical or illegal practice is dealt with supportively via appropriate procedures
- All parties must be informed of the intention to disclose, before revealing confidential information
- Explore the supervisee's expectations appropriately using appropriate knowledge, skills and experience

At the end of the Supervision session both **SUPERVISOR** and **SUPERVISEE** will: -

Agree a suitable time and venue for the next session

After the session the **SUPERVISEE** will: -

- Engage in learning and development activities that will inform subsequent Supervision sessions
- Record and reflect on significant activities using a portfolio approach
- Evaluate the perceived benefit of the session
- Maintain and store records in line with Trust Policy

After the session the **SUPERVISOR** will: -

- Complete the Trust's Sessional form(s)
- Maintain and store records in line with Trust policy
- Provide the supervisee with a copy of the session if not already provided
- Evaluate the perceived benefit of the session to the supervise

GROUND RULES FOR GROUP SUPERVISION

Prior to Supervision session the SUPERVISEES will have: -

- Read all relevant/associated policies, procedures and guidance
- Prepared for the session and will have considered and identified practice areas for open discussion
- Undertaken relevant action(s) as agreed at previous Supervision session(s)

During each Supervision session both **SUPERVISOR** and **SUPERVISEES** will: -

- Be sensitive to the needs of individuals and the overall dynamics within the group
- Maintain strict confidentiality by not disclosing or discussing information provided by any other members of a group
- Be supportive of other members of the group
- Listen to and allow other members of the group to speak
- Maintain mutual respect
- Have an attitude of open learning
- Be open to constructive feedback
- Engage in reflective practice
- Deal appropriately with areas of disagreement according to the ground rules
- Ensure that identified unsafe, unethical or illegal practice is dealt with supportively via appropriate procedures
- All parties must be informed of the intention to disclose, before revealing confidential information
- Explore the supervisee's expectations appropriately using appropriate knowledge, skills and experience

At the end of the Supervision session both **SUPERVISOR** and **SUPERVISEES** will: -

Agree a suitable time and venue for the next session

After the session the **SUPERVISEES** will: -

- Engage in learning and development activities that will inform subsequent Supervision sessions
- Record and reflect on significant activities using a portfolio approach
- Evaluate the perceived benefit of the session
- Maintain and store records in line with Trust policy

After the session the **SUPERVISOR** will: -

- Complete the Trust's Sessional form(s)
- Maintain and store records in line with Trust policy
- Provide the supervisees with a copy of the session if not already provided
- Evaluate the perceived benefit of the session to the supervisees

APPENDIX 1

PREPARATION FOR SUPERVISION

NAME ____

DATE ____ / ____ / ____ **VENUE** __________________ **TIME from** ______ **to** ______

Agreed actions from previous session	Progress on action points

Reflection on Learning from previous session

Issues to be brought forward and discussed at the next meeting

APPENDIX 5

RECORD OF 1:1 SUPERVISON

Date ____/______/______ Venue ___________________ Time from ______ to _______

SUPERVISEE
PRINT NAME: **SIGNATURE**
SUPERVISOR
PRINT NAME: **SIGNATURE**
Review of Action Points from Previous Supervision Session
Issues / Topics for Discussion
Key Points from Discussion
Agreed Action Plan for Supervisee

Actions	**Timescale**

APPENDIX 5

RECORD OF GROUP SUPERVISION

Date ____ /____/_____ Venue _______________ Time from _____ to _____

SUPERVISEES	**SIGNATURE**
SUPERVISOR(S)	**SIGNATURE**

Review of Action Points from Previous Supervision Session

Issue / Topic for Discussion

APPENDIX 5

Agreed Action Plan for Supervisor (if applicable)		
Actions		**Timescale**
If a significant issue requires onward reporting, record below outline of issues for onward reporting, to who and when it will be reported		
Issue	**Report to**	**Timescale**

Issues / areas of disagreement			
Date and Time of Next Session			
Date		**Time**	
Session Evaluation			

Copy to supervisee ☐ **Date ____/____/_____**

APPENDIX 5

Agreed Action Plan for Supervisees		
Actions		**Timescale**
Agreed Action Plan for Supervisor (if applicable)		
Actions		**Timescale**
If a significant issue requires onward reporting, record below outline of issues for onward reporting, to who and when it will be reported Issues / area of disagreement		
Issue	**Report to**	**Timescale**
Issues / areas of disagreement		
Date and Time of Next Session		
Date		**Time**
Session Evaluation		

Copy to supervisees ☐ **Date ____/____/_____**

Southern Health and Social Care Trust

Quality Care - for you, with you

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

CODE OF CONDUCT FOR HSC EMPLOYEES

SEPTEMBER 2016

HSC Code of Conduct for Employees

This Code of Conduct is about the values for which we, as HSC staff, stand. The Code sets out the core standards of conduct expected of all HSC Staff. It has been written to complement existing professional codes of practice.

Professional staff are expected to follow the code of conduct for their own professions as well as this code.

The code aims:

- To guide staff, managers and employers in the work that they do and the decisions and choices they have to make; and
- To reassure the public that these important decisions are being made against a background of professional standards and accountability.

Adherence to the Code is mandatory for all employees, regardless of their status and breaches of the Code will be regarded as serious.

HSC staff are highly principled and value-driven people who will welcome this Code and exemplify the expected behaviours. All staff within HSC are responsible for, and have a duty of care, to ensure their conduct does not fall below the standards detailed in this Code and that no act or omission, within the sphere of their role, harms the safety and well-being of patients/clients and service users and their families. The Code is a set of values which should inform development programmes and training for all staff. It should make us all think exactly how we are going to work, how we make the care and safety of patients our first concern and how we respect the public, patients, clients, service users relatives and carers. If, however, the conduct and behaviours of staff falls short of the public's expectations this reflects poorly on the HSC as seriously as failures by clinical and care staff.

Breaches of the Code must be investigated fairly and employers should adopt a proportionate approach. Just as the Code sets out how all staff should behave and their responsibilities, you also have rights. You have the right to be treated with respect, evaluated consistently and fairly, encouraged to maintain and improve your knowledge and skills and to be helped to balance your work and home lives properly. HSC Employers must provide and promote an organisational culture which values and supports staff and teams.

This Code of Conduct applies to **all** HSC Staff, across all HSC Trusts and HSC Arms Length Bodies. This code incorporates the principles contained within the Code of Conduct for HPSS Managers 2003 and supersedes it.

This Code is also consistent with the 7 principles of public life, ('the Nolan Principles') which applies to everyone working as a public office-holder and therefore should govern the conduct of all health and social care staff.[1]

---

[1] https://www.gov.uk/government/publications/the-7-principles-of-public-life

1. INTRODUCTION

This Code of Conduct (the Code) sets out the standards of conduct expected of all staff in the Southern Health and Social Care Trust.

It presents the standards of conduct and behaviours required of all staff and informs employers, colleagues, patients/clients service users and the public about these.

The Code refers to "employees", however, for the purposes of this document, this definition also applies to all workers (Agency & Bank), volunteers and work placements.

Adherence to the Code is an integral part of employees' contractual responsibilities during their employment with the Southern HSC Trust.

- The behaviour of employees should reflect the organisation's mission and values at all times.
- Employees must not use their privileged position to neglect, harm, abuse or exploit patients/clients/service users or their families.
- Employees should familiarise themselves with the contents of the Code and should act in accordance with the principles set out in it.

1.1 Overall principles & undertakings

As an HSC employee, I will observe the following principles:

- make the **care and safety of patients and clients** my first concern and act to protect them from risk;
- contribute to improving and protecting the health of the population as appropriate to my role;
- maintain **confidentiality,** respecting and protecting, at all times patients/clients, service users and their families' right to confidentiality, privacy and dignity;
- **communicate openly and honestly** to promote the health and well-being of patients/clients, service users and their families.

- **respect** the public, patients, clients, relatives, carers, HSC employees and teams and partners in other agencies. I will also **show my commitment** to working constructively as a team member by working collaboratively with all my colleagues in the HSC and the wider community;

- **be accountable** and accept **responsibility** for my own work and be **honest and act with integrity**;

- sharing **responsibility for my own learning and development** in order to improve the quality of care to patients/ clients/service users and their families

Managers' Responsibilities

I will also endeavour to ensure that;

- HSC staff in my team are:
  - valued as individuals, colleagues and are treated with dignity and respect;
  - appropriately informed about the management of the HSC;
  - given appropriate opportunities to take part in continuous design, review and improvement of services;
  - have their ideas and realistic ambitions taken seriously;
  - given protection from harassment and bullying;
  - provided with a safe working environment;
  - helped to maintain and improve their knowledge and skills and developed to achieve their potential; and
  - helped to achieve a reasonable balance between their working and personal lives.

These principles are described in more detail in *Section* **2** below.

2. DESCRIPTION OF PRINCIPLES

2.1 Care & safety of patients & clients

I will;

- use the resources available to me in an effective, efficient and timely manner having proper regard to the best interests of the public, patients and clients;
- be guided by the interests of patients and clients;
- ensure a safe working environment;
- act to protect patients and clients from risk by adhering to relevant legislation and putting into practice appropriate policies and procedures;
- work collaboratively with colleagues across all disciplines to support person-centred care/services.

2.2 Confidentiality

I will;

- respect patient, client and staff confidentiality;
- not, except in the performance my job role and duties with the organisation, divulge to any person in any manner whatsoever, any confidential information covering the business or transactions of the organisation and its activities and/or its patients, clients or employees[2], unless ordered to do so by a Court or Tribunal. I will make every effort to prevent disclosure of such information. I will not use social media to share information about the environment I work in or the patients/clients/service users for whom I care.
- comply with all relevant organisation policies in relation to the use of information associated with my role and in particular with reference to the personal use of social networking sites[3].

---

[2] Code of Practice on Protecting the Confidentiality of Service User Information
[3] Social Media Policy

- comply with my obligations under the Data Protection Act (1998) and Freedom of Information Act (2000) through the Organisation's information governance training. [4]

2.3 Respect for others & working as a team

I will;

- respect and treat with dignity and fairness, the public, patients and clients, relatives, carers, HSC employees and partners in other agencies. I will not unlawfully discriminate against, victimise or harass against anyone on grounds of their gender, marital/civil partnership status, sexual orientation, community background, political opinion, religious belief, race, age disability, family status, whether or not they have dependents or are persons who have undergone, are undergoing or intend to undergo gender reassignment.

- seek to ensure that anyone with a genuine concern is treated reasonably and fairly

- show my commitment to working as part of the department and Organisation team

I will show my commitment to team working by working constructively with all my colleagues across the HSC and in the wider community, contributing to an environment in which:

- teams of staff are able to work together in the best interests of service users; and

- leadership is encouraged and developed at all levels and in all staff groups

2.4 Accountability, Responsibility, Honesty & Integrity

I will;

- establish and maintain clear and appropriate boundaries at all times in my relationships with patients/clients/service users and their families, and with colleagues, always behaving in a professional manner;

---

[4] Data Protection Policy

- accept responsibility for my own work and ensure that I am responsible for answering any questions and complaints in an open, honest way.

- be honest and act with integrity and probity at all times and ensure that HSC resources are protected from fraud, bribery and other forms of corruption[5]

- not use my official position to receive, agree to accept or attempt to obtain any financial or other advantage for doing, or not doing, anything or showing favour, or disfavour, to any person[6].

- not receive benefits of any kind from a third party which might reasonably be seen to compromise my personal judgment and integrity.

- not deceive or mislead my employer, or any other organisation it deals with, or the public during the course of my employment with the HSC.

- abide by the rules adopted by my employer in relation to private interest and possible conflict with public duty, the disclosure of official information and in any political activities.

- not misuse my official position or information acquired in my official duties to further my private interests or those of others.

I will ensure proper management of the performance of my team and I will seek to ensure that those I manage accept that they are responsible for their actions to both;

- the public and their representatives; and

- service users, relatives and carers by answering questions and complaints in an open and honest manner.

I will also;

- accept responsibility for the management of the performance of the people I manage;

- seek to ensure that judgements about colleagues (including appraisals and references) are consistent, fair and unbiased and include all information which

---

[5] Fraud Policy

[6] Gifts, Hospitality & Sponsorship Policy, Conflicts of Interest Policy, Fraud Policy, Bribery Policy

affects a colleague's performance, eligibility for advancement/reward and conduct; and

- play my part in making sure that no-one is unlawfully discriminated against and that policies on equality, diversity and human rights are promoted and adhered to at all times.

2.6. Responsibility for my own learning and development

I will seek to;

- Participate in training and personal development required by my employer and take responsibility for the achievement of the competence essential for your role, in line with KSF and organisational requirements

- Keep up to date with best practice and maintain an up-to-date record of your own learning and development

- Share my learning as appropriate and contribute to the learning and development of others

3. Employee concerns about improper conduct

If you believe you are being required to act in a way which:

- is illegal, improper, or unethical;
- is in breach of a professional code;
- may involve possible maladministration, fraud or misuse of public funds; or
- is otherwise inconsistent with this Code

you should either raise the matter through your line management or alternatively, approach in confidence, a nominated officer under the Trust's Whistleblowing Policy[7].

You should make yourself aware of the provisions of the Trust's Whistleblowing Policy.
The Chief Executive, who is the designated accounting officer for the Trust, has overall responsibility for propriety in a broad sense, including conduct and discipline.

---

[7] Whistleblowing Policy

I will;

- act to protect service users from harm, injury or loss by identifying and reducing risk by putting into practice the appropriate support, supervisory and disciplinary procedures for staff;

- seek to ensure that anyone with a concern is taken seriously and treated fairly in accordance with relevant procedures; and

- contribute to the creation of an open and learning organisation where concerns about individuals perceived to be breaking the Code of Conduct can be raised without fear

4. AFTER LEAVING EMPLOYMENT

You should continue to observe your duty of confidentiality after you have left your employment with the HSC.

Nursing &
Midwifery
Council

The Code

Professional standards of practice and behaviour for nurses, midwives and nursing associates

prioritise people

practise effectively

preserve safety

promote professionalism and trust

About us

The Nursing and Midwifery Council exists to protect the public. We do this by making sure that only those who meet our requirements are allowed to practise as a nurse or midwife in the UK, or a nursing associate in England. We take action if concerns are raised about whether a nurse, midwife or nursing associate is fit to practise.

It is against the law to claim to be, or to practise as, a nurse or midwife in the UK, or as a nursing associate in England, if you are not on the relevant part of our register.

It is also a criminal offence for anyone who, with intent to deceive, causes or permits someone else to falsely represent them as being on the register, or makes a false representation about them being on the NMC register.

Publication date: 29 January 2015
Effective from: 31 March 2015

Updated to reflect the regulation of nursing associates:
10 October 2018

A note on this version of the Code

All regulators review their Codes from time to time to make sure they continue to reflect public expectations. This new version of the Code is substantially similar to the 2015 version, but it has been updated to reflect our new responsibilities for the regulation of nursing associates. In joining the register, nursing associates will uphold the Code.

The current versions of our Code, standards and guidance can always be found on our website. Those on our register should make sure they are using the most up to date version of the Code.

For more information about the Code, please visit:
www.nmc.org.uk/code

Introduction

The Code contains the professional standards that registered nurses, midwives and nursing associates[1] must uphold. Nurses, midwives and nursing associates must act in line with the Code, whether they are providing direct care to individuals, groups or communities or bringing their professional knowledge to bear on nursing[2] and midwifery practice in other roles, such as leadership, education, or research. The values and principles set out in the Code can be applied in a range of different practice settings, but they are not negotiable or discretionary.

Our role is to set the standards in the Code, but these are not just our standards. They are the standards that patients and members of the public tell us they expect from health professionals. They are the standards shown every day by those on our register.

When joining our register, and then renewing their registration, nurses, midwives and nursing associates commit to upholding these standards. This commitment to professional standards is fundamental to being part of a profession. We can take action if those on our register fail to uphold the Code. In serious cases, this can include removing them from the register.

---

1. *Anyone practising as a registered nurse or midwife in the UK, or a nursing associate in England, has to be registered with us. The nursing associate role is being used only in England.*
2. *We have used the word 'nursing' in this document to apply to the work of nurses and nursing associates. Nursing associates are a distinct profession with their own part of our register, but they are part of the nursing team.*

The Code sets out common standards of conduct and behaviour for those on our register. This provides a clear, consistent and positive message to patients, service users and colleagues about what they can expect of those who provide nursing or midwifery care.

The professions we regulate have different knowledge and skills, set out in three distinct standards of proficiency. They can work in diverse contexts and have different levels of autonomy and responsibility. However, all of the professions we regulate exercise professional judgement and are accountable for their work.

Nurses, midwives and nursing associates uphold the Code within the limits of their competence. This means, for example, that while a nurse and nursing associate will play different roles in an aspect of care, they will both uphold the standards in the Code within the contribution they make to overall care. The professional commitment to work within one's competence is a key underpinning principle of the Code (see section 13) which, given the significance of its impact on public protection, should be upheld at all times.

In addition, nurses, midwives and nursing associates are expected to work within the limits of their competence, which may extend beyond the standards they demonstrated in order to join the register.

The Code should be useful for everyone who cares about good nursing and midwifery.

- Patients and service users, and those who care for them, can use it to provide feedback to nurses, midwives and nursing associates about the care they receive.
- Those on our register can use it to promote safe and effective practice in their place of work.
- Employer organisations should support their staff in upholding the standards in their professional Code as part of providing the quality and safety expected by service users and regulators.
- Educators can use the Code to help students understand what it means to be a registered professional and how keeping to the Code helps to achieve that.

For the many committed and expert practitioners on our register, this Code should be seen as a way of reinforcing professionalism. Through revalidation, nurses, midwives and nursing associates provide evidence of their continued ability to practise safely and effectively. The Code is central to the revalidation process as a focus for professional reflection. This gives the Code significance in the professional life of those on our register, and raises its status and importance for employers.

The Code contains a series of statements that taken together signify what good practice by nurses, midwives and nursing associates looks like. It puts the interests of patients and service users first, is safe and effective, and promotes trust through professionalism.

Prioritise people

You put the interests of people using or needing nursing or midwifery services first. You make their care and safety your main concern and make sure that their dignity is preserved and their needs are recognised, assessed and responded to. You make sure that those receiving care are treated with respect, that their rights are upheld and that any discriminatory attitudes and behaviours towards those receiving care are challenged.

1 Treat people as individuals and uphold their dignity

To achieve this, you must:

1.1 treat people with kindness, respect and compassion

1.2 make sure you deliver the fundamentals of care effectively

1.3 avoid making assumptions and recognise diversity and individual choice

1.4 make sure that any treatment, assistance or care for which you are responsible is delivered without undue delay

1.5 respect and uphold people's human rights

2 Listen to people and respond to their preferences and concerns

To achieve this, you must:

2.1 work in partnership with people to make sure you deliver care effectively

2.2 recognise and respect the contribution that people can make to their own health and wellbeing

The fundamentals of care include, but are not limited to, nutrition, hydration, bladder and bowel care, physical handling and making sure that those receiving care are kept in clean and hygienic conditions. It includes making sure that those receiving care have adequate access to nutrition and hydration, and making sure that you provide help to those who are not able to feed themselves or drink fluid unaided.

2.3 encourage and empower people to share in decisions about their treatment and care

2.4 respect the level to which people receiving care want to be involved in decisions about their own health, wellbeing and care

2.5 respect, support and document a person's right to accept or refuse care and treatment

2.6 recognise when people are anxious or in distress and respond compassionately and politely

3 Make sure that people's physical, social and psychological needs are assessed and responded to

To achieve this, you must:

3.1 pay special attention to promoting wellbeing, preventing ill-health and meeting the changing health and care needs of people during all life stages

3.2 recognise and respond compassionately to the needs of those who are in the last few days and hours of life

3.3 act in partnership with those receiving care, helping them to access relevant health and social care, information and support when they need it

3.4 act as an advocate for the vulnerable, challenging poor practice and discriminatory attitudes and behaviour relating to their care

4 Act in the best interests of people at all times

To achieve this, you must:

4.1 balance the need to act in the best interests of people at all times with the requirement to respect a person's right to accept or refuse treatment

4.2 make sure that you get properly informed consent and document it before carrying out any action

4.3 keep to all relevant laws about mental capacity that apply in the country in which you are practising, and make sure that the rights and best interests of those who lack capacity are still at the centre of the decision-making process

4.4 tell colleagues, your manager and the person receiving care if you have a conscientious objection to a particular procedure and arrange for a suitably qualified colleague to take over responsibility for that person's care

5 Respect people's right to privacy and confidentiality

As a nurse, midwife or nursing associate, you owe a duty of confidentiality to all those who are receiving care. This includes making sure that they are informed about their care and that information about them is shared appropriately.

To achieve this, you must:

5.1 respect a person's right to privacy in all aspects of their care

5.2 make sure that people are informed about how and why information is used and shared by those who will be providing care

5.3 respect that a person's right to privacy and confidentiality continues after they have died

5.4 share necessary information with other health and care professionals and agencies only when the interests of patient safety and public protection override the need for confidentiality

5.5 share with people, their families and their carers, as far as the law allows, the information they want or need to know about their health, care and ongoing treatment sensitively and in a way they can understand

You can only make a 'conscientious objection' in limited circumstances. For more information, please visit our website at www.nmc.org.uk/standards.

Practise effectively

You assess need and deliver or advise on treatment, or give help (including preventative or rehabilitative care) without too much delay, to the best of your abilities, on the basis of best available evidence. You communicate effectively, keeping clear and accurate records and sharing skills, knowledge and experience where appropriate. You reflect and act on any feedback you receive to improve your practice.

6 Always practise in line with the best available evidence

To achieve this, you must:

6.1 make sure that any information or advice given is evidence-based including information relating to using any health and care products or services

6.2 maintain the knowledge and skills you need for safe and effective practice

7 Communicate clearly

To achieve this, you must:

7.1 use terms that people in your care, colleagues and the public can understand

7.2 take reasonable steps to meet people's language and communication needs, providing, wherever possible, assistance to those who need help to communicate their own or other people's needs

7.3 use a range of verbal and non-verbal communication methods, and consider cultural sensitivities, to better understand and respond to people's personal and health needs

7.4 check people's understanding from time to time to keep misunderstanding or mistakes to a minimum

7.5 be able to communicate clearly and effectively in English

8 Work co-operatively

To achieve this, you must:

8.1 respect the skills, expertise and contributions of your colleagues, referring matters to them when appropriate

8.2 maintain effective communication with colleagues

8.3 keep colleagues informed when you are sharing the care of individuals with other health and care professionals and staff

8.4 work with colleagues to evaluate the quality of your work and that of the team

8.5 work with colleagues to preserve the safety of those receiving care

8.6 share information to identify and reduce risk

8.7 be supportive of colleagues who are encountering health or performance problems. However, this support must never compromise or be at the expense of patient or public safety

9 Share your skills, knowledge and experience for the benefit of people receiving care and your colleagues

To achieve this, you must:

9.1 provide honest, accurate and constructive feedback to colleagues

9.2 gather and reflect on feedback from a variety of sources, using it to improve your practice and performance

9.3 deal with differences of professional opinion with colleagues by discussion and informed debate, respecting their views and opinions and behaving in a professional way at all times

9.4 support students' and colleagues' learning to help them develop their professional competence and confidence

10 Keep clear and accurate records relevant to your practice

This applies to the records that are relevant to your scope of practice. It includes but is not limited to patient records.

To achieve this, you must:

10.1 complete records at the time or as soon as possible after an event, recording if the notes are written some time after the event

10.2 identify any risks or problems that have arisen and the steps taken to deal with them, so that colleagues who use the records have all the information they need

10.3 complete records accurately and without any falsification, taking immediate and appropriate action if you become aware that someone has not kept to these requirements

10.4 attribute any entries you make in any paper or electronic records to yourself, making sure they are clearly written, dated and timed, and do not include unnecessary abbreviations, jargon or speculation

10.5 take all steps to make sure that records are kept securely

10.6 collect, treat and store all data and research findings appropriately

11 Be accountable for your decisions to delegate tasks and duties to other people

To achieve this, you must:

11.1 only delegate tasks and duties that are within the other person's scope of competence, making sure that they fully understand your instructions

11.2 make sure that everyone you delegate tasks to is adequately supervised and supported so they can provide safe and compassionate care

11.3 confirm that the outcome of any task you have delegated to someone else meets the required standard

12 Have in place an indemnity arrangement which provides appropriate cover for any practice you take on as a nurse, midwife or nursing associate in the United Kingdom

To achieve this, you must:

12.1 make sure that you have an appropriate indemnity arrangement in place relevant to your scope of practice

For more information, please visit our website at www.nmc.org.uk/indemnity.

Preserve safety

You make sure that patient and public safety is not affected. You work within the limits of your competence, exercising your professional 'duty of candour' and raising concerns immediately whenever you come across situations that put patients or public safety at risk. You take necessary action to deal with any concerns where appropriate.

13 Recognise and work within the limits of your competence

To achieve this, you must, as appropriate:

13.1 accurately identify, observe and assess signs of normal or worsening physical and mental health in the person receiving care

13.2 make a timely referral to another practitioner when any action, care or treatment is required

13.3 ask for help from a suitably qualified and experienced professional to carry out any action or procedure that is beyond the limits of your competence

13.4 take account of your own personal safety as well as the safety of people in your care

13.5 complete the necessary training before carrying out a new role

14 Be open and candid with all service users about all aspects of care and treatment, including when any mistakes or harm have taken place

To achieve this, you must:

14.1 act immediately to put right the situation if someone has suffered actual harm for any reason or an incident has happened which had the potential for harm.

14.2 explain fully and promptly what has happened, including the likely effects, and apologise to the person affected and, where appropriate, their advocate, family or carers

14.3 document all these events formally and take further action (escalate) if appropriate so they can be dealt with quickly

15 Always offer help if an emergency arises in your practice setting or anywhere else

To achieve this, you must:

15.1 only act in an emergency within the limits of your knowledge and competence

15.2 arrange, wherever possible, for emergency care to be accessed and provided promptly

15.3 take account of your own safety, the safety of others and the availability of other options for providing care

16 Act without delay if you believe that there is a risk to patient safety or public protection

To achieve this, you must:

16.1 raise and, if necessary, escalate any concerns you may have about patient or public safety, or the level of care people are receiving in your workplace or any other health and care setting and use the channels available to you in line with our guidance and your local working practices

16.2 raise your concerns immediately if you are being asked to practise beyond your role, experience and training

The professional duty of candour is about openness and honesty when things go wrong. "Every healthcare professional must be open and honest with patients when something goes wrong with their treatment or care which causes, or has the potential to cause, harm or distress." Joint statement from the Chief Executives of statutory regulators of healthcare professionals

16.3 tell someone in authority at the first reasonable opportunity if you experience problems that may prevent you working within the Code or other national standards, taking prompt action to tackle the causes of concern if you can

16.4 acknowledge and act on all concerns raised to you, investigating, escalating or dealing with those concerns where it is appropriate for you to do so

16.5 not obstruct, intimidate, victimise or in any way hinder a colleague, member of staff, person you care for or member of the public who wants to raise a concern

16.6 protect anyone you have management responsibility for from any harm, detriment, victimisation or unwarranted treatment after a concern is raised

For more information, please visit our website at www.nmc.org.uk/raisingconcerns.

17 Raise concerns immediately if you believe a person is vulnerable or at risk and needs extra support and protection

To achieve this, you must:

17.1 take all reasonable steps to protect people who are vulnerable or at risk from harm, neglect or abuse

17.2 share information if you believe someone may be at risk of harm, in line with the laws relating to the disclosure of information

17.3 have knowledge of and keep to the relevant laws and policies about protecting and caring for vulnerable people

18 Advise on, prescribe, supply, dispense or administer medicines within the limits of your training and competence, the law, our guidance and other relevant policies, guidance and regulations

To achieve this, you must:

18.1 prescribe, advise on, or provide medicines or treatment, including repeat prescriptions (only if you are suitably qualified) if you have enough knowledge of that person's health and are satisfied that the medicines or treatment serve that person's health needs

18.2 keep to appropriate guidelines when giving advice on using controlled drugs and recording the prescribing, supply, dispensing or administration of controlled drugs

18.3 make sure that the care or treatment you advise on, prescribe, supply, dispense or administer for each person is compatible with any other care or treatment they are receiving, including (where possible) over-the-counter medicines

18.4 take all steps to keep medicines stored securely

18.5 wherever possible, avoid prescribing for yourself or for anyone with whom you have a close personal relationship

Prescribing is not within the scope of practice of everyone on our register. Nursing associates don't prescribe, but they may supply, dispense and administer medicines. Nurses and midwives who have successfully completed a further qualification in prescribing and recorded it on our register are the only people on our register that can prescribe.

For more information, please visit our website at www.nmc.org.uk/standards.

19 Be aware of, and reduce as far as possible, any potential for harm associated with your practice

To achieve this, you must:

19.1 take measures to reduce as far as possible, the likelihood of mistakes, near misses, harm and the effect of harm if it takes place

19.2 take account of current evidence, knowledge and developments in reducing mistakes and the effect of them and the impact of human factors and system failures (see the note below)

19.3 keep to and promote recommended practice in relation to controlling and preventing infection

19.4 take all reasonable personal precautions necessary to avoid any potential health risks to colleagues, people receiving care and the public

---

Human factors refer to environmental, organisational and job factors, and human and individual characteristics, which influence behaviour at work in a way which can affect health and safety – Health and Safety Executive. You can find more information at www.hse.gov.uk.

Promote professionalism and trust

You uphold the reputation of your profession at all times. You should display a personal commitment to the standards of practice and behaviour set out in the Code. You should be a model of integrity and leadership for others to aspire to. This should lead to trust and confidence in the professions from patients, people receiving care, other health and care professionals and the public.

20 Uphold the reputation of your profession at all times

To achieve this, you must:

20.1 keep to and uphold the standards and values set out in the Code

20.2 act with honesty and integrity at all times, treating people fairly and without discrimination, bullying or harassment

20.3 be aware at all times of how your behaviour can affect and influence the behaviour of other people

20.4 keep to the laws of the country in which you are practising

20.5 treat people in a way that does not take advantage of their vulnerability or cause them upset or distress

20.6 stay objective and have clear professional boundaries at all times with people in your care (including those who have been in your care in the past), their families and carers

20.7 make sure you do not express your personal beliefs (including political, religious or moral beliefs) to people in an inappropriate way

20.8 act as a role model of professional behaviour for students and newly qualified nurses, midwives and nursing associates to aspire to

20.9 maintain the level of health you need to carry out your professional role

20.10 use all forms of spoken, written and digital communication (including social media and networking sites) responsibly, respecting the right to privacy of others at all times

For more guidance on using social media and networking sites, please visit our website at www.nmc.org.uk/standards.

21 Uphold your position as a registered nurse, midwife or nursing associate

To achieve this, you must:

21.1 refuse all but the most trivial gifts, favours or hospitality as accepting them could be interpreted as an attempt to gain preferential treatment

21.2 never ask for or accept loans from anyone in your care or anyone close to them

21.3 act with honesty and integrity in any financial dealings you have with everyone you have a professional relationship with, including people in your care

21.4 make sure that any advertisements, publications or published material you produce or have produced for your professional services are accurate, responsible, ethical, do not mislead or exploit vulnerabilities and accurately reflect your relevant skills, experience and qualifications

21.5 never use your status as a registered professional to promote causes that are not related to health

21.6 cooperate with the media only when it is appropriate to do so, and then always protecting the confidentiality and dignity of people receiving treatment or care

22 Fulfil all registration requirements

To achieve this, you must:

22.1 keep to any reasonable requests so we can oversee the registration process

22.2 keep to our prescribed hours of practice and carry out continuing professional development activities

22.3 keep your knowledge and skills up to date, taking part in appropriate and regular learning and professional development activities that aim to maintain and develop your competence and improve your performance

For more information, please visit our website at www.nmc.org.uk/standards.

23 Cooperate with all investigations and audits

This includes investigations or audits either against you or relating to others, whether individuals or organisations. It also includes cooperating with requests to act as a witness in any hearing that forms part of an investigation, even after you have left the register.

To achieve this, you must:

23.1 cooperate with any audits of training records, registration records or other relevant audits that we may want to carry out to make sure you are still fit to practise

23.2 tell both us and any employers as soon as you can about any caution or charge against you, or if you have received a conditional discharge in relation to, or have been found guilty of, a criminal offence (other than a protected caution or conviction)

23.3 tell any employers you work for if you have had your practice restricted or had any other conditions imposed on you by us or any other relevant body.

23.4 tell us and your employers at the first reasonable opportunity if you are or have been disciplined by any regulatory or licensing organisation, including those who operate outside of the professional health and care environment

23.5 give your NMC Pin when any reasonable request for it is made

For more information, please visit our website at www.nmc.org.uk.

24 Respond to any complaints made against you professionally

To achieve this, you must:

24.1 never allow someone's complaint to affect the care that is provided to them

24.2 use all complaints as a form of feedback and an opportunity for reflection and learning to improve practice

When telling your employers, this includes telling (i) any person, body or organisation you are employed by, or intend to be employed by, as a nurse, midwife or nursing associate; and (ii) any person, body or organisation with whom you have an arrangement to provide services as a nurse, midwife or nursing associate.

25 Provide leadership to make sure people's wellbeing is protected and to improve their experiences of the health and care system

To achieve this, you must:

25.1 identify priorities, manage time, staff and resources effectively and deal with risk to make sure that the quality of care or service you deliver is maintained and improved, putting the needs of those receiving care or services first

25.2 support any staff you may be responsible for to follow the Code at all times. They must have the knowledge, skills and competence for safe practice; and understand how to raise any concerns linked to any circumstances where the Code has, or could be, broken

Throughout their career, all our registrants will have opportunities to demonstrate leadership qualities, regardless of whether or not they occupy formal leadership positions.

23 Portland Place, London W1B 1PZ
T +44 20 7637 7181 **F** +44 20 7436 2924
www.nmc.org.uk

The nursing and midwifery regulator for England, Wales, Scotland and Northern Ireland

Registered charity in England and Wales (1091434) and in Scotland (SC038362)

Appendix 19-

Code of conduct - GMC (gmc-uk.org)

Appendix 20- Cancer Tracking Guidelines for Urology

Urology-Care-Pathway.pdf

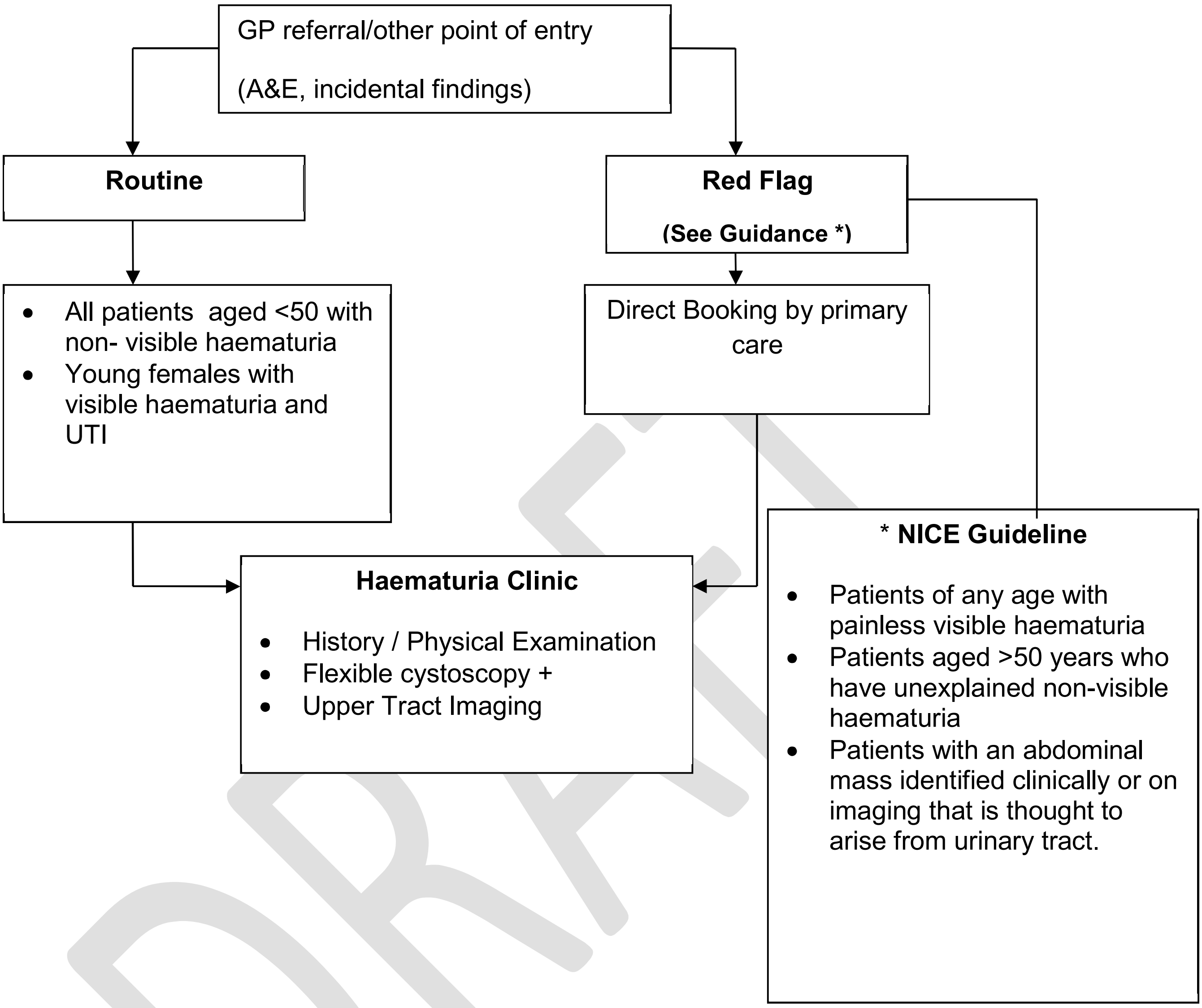
NICaN
Northern Ireland
Cancer Network

Urology Care Pathways

Cancer Care Pathways outline the steps and stages in the patient journey from referral through to diagnostics, staging, treatment, follow up, rehabilitation and if applicable onto palliative care.

Timed effective care pathways are central to delivering quality and timely care to patients throughout their cancer journey and to the delivery of an equitable service. These pathways have been developed following with reference to available best practice guidance. They represent an 'ideal' pathway that can be adapted for local use. The timelines on the pathway are intended to facilitate the proactive management of patients within the access standards and it is to be noted that for some urological tumours, the patient will move much quicker through the pathway (e.g. testicular cancer).

Haematuria Referral Guideline



GP referral/other point of entry

(A&E, incidental findings)

Routine

- All patients aged <50 with non- visible haematuria
- Young females with visible haematuria and UTI

Red Flag

(See Guidance *)

Direct Booking by primary care

Haematuria Clinic

- History / Physical Examination
- Flexible cystoscopy +
- Upper Tract Imaging

*** NICE Guideline**

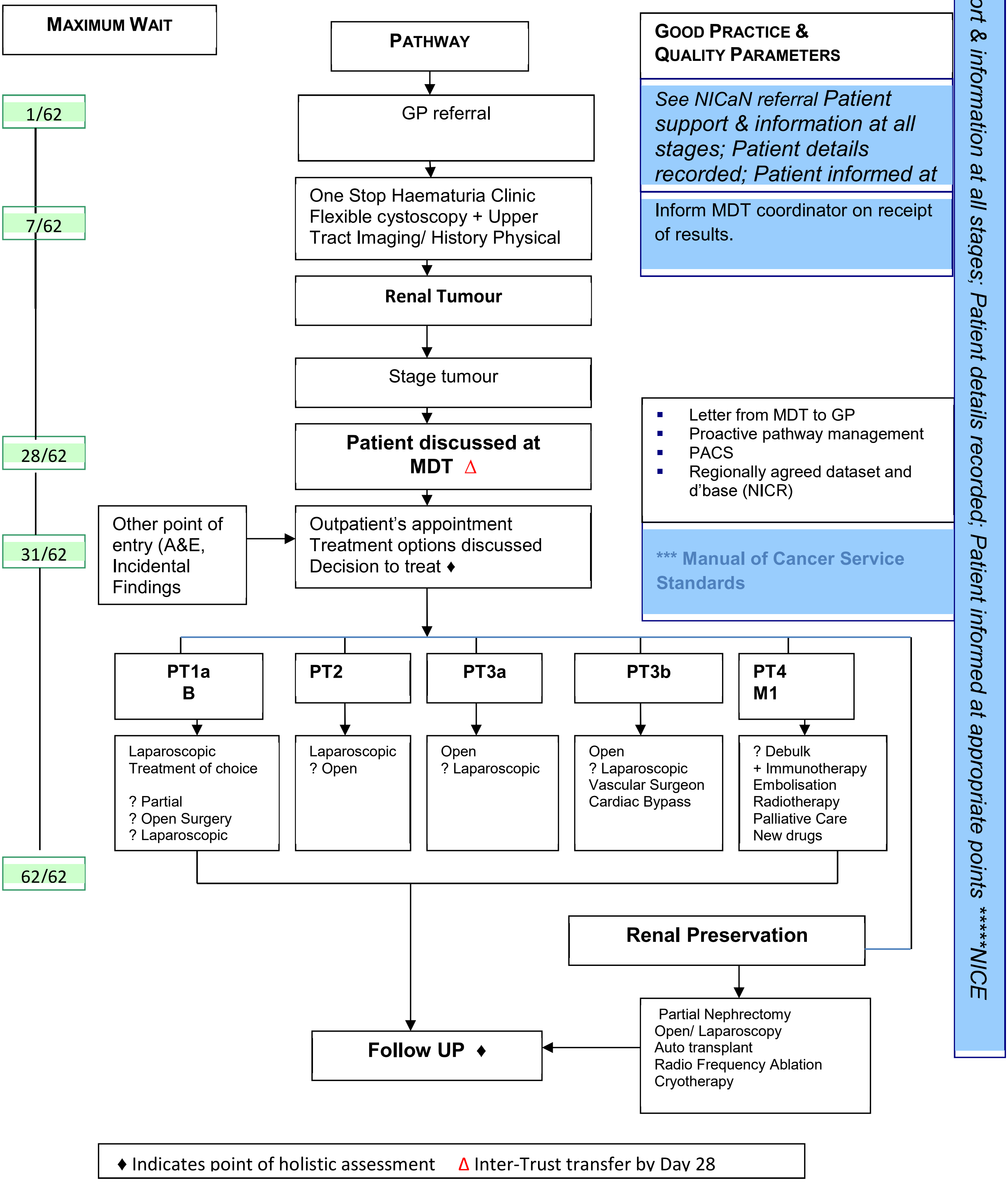
- Patients of any age with painless visible haematuria
- Patients aged >50 years who have unexplained non-visible haematuria
- Patients with an abdominal mass identified clinically or on imaging that is thought to arise from urinary tract.

NOTE: Please Consider Nephrology referral as well as referral to haematuria clinic if the patient has any of the following:

- Diabetes
- Proteinuria
- Hypertension

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Renal Tumour



MAXIMUM WAIT

1/62

7/62

28/62

31/62

62/62

PATHWAY

GP referral

One Stop Haematuria Clinic
Flexible cystoscopy + Upper Tract Imaging/ History Physical

Renal Tumour

Stage tumour

Patient discussed at MDT Δ

Other point of entry (A&E, Incidental Findings

Outpatient's appointment
Treatment options discussed
Decision to treat ♦

PT1a B
Laparoscopic
Treatment of choice

? Partial
? Open Surgery
? Laparoscopic

PT2
Laparoscopic
? Open

PT3a
Open
? Laparoscopic

PT3b
Open
? Laparoscopic
Vascular Surgeon
Cardiac Bypass

PT4 M1
? Debulk
+ Immunotherapy
Embolisation
Radiotherapy
Palliative Care
New drugs

Renal Preservation

Partial Nephrectomy
Open/ Laparoscopy
Auto transplant
Radio Frequency Ablation
Cryotherapy

Follow UP ♦

GOOD PRACTICE & QUALITY PARAMETERS

See NICaN referral Patient support & information at all stages; Patient details recorded; Patient informed at

Inform MDT coordinator on receipt of results.

- Letter from MDT to GP
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

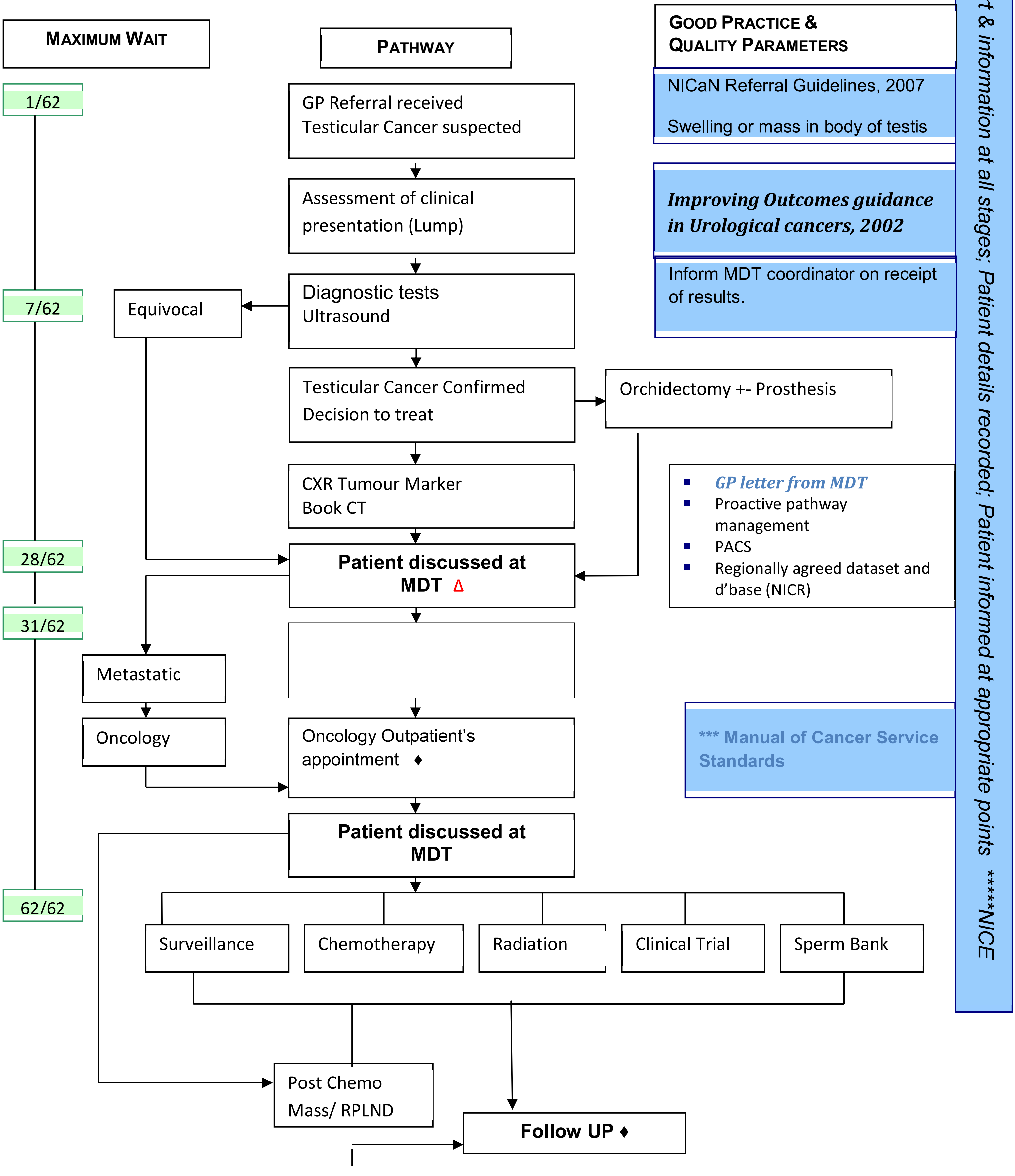
***** Manual of Cancer Service Standards**

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE*

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Testicular Cancer Pathway



MAXIMUM WAIT

1/62

7/62

28/62

31/62

62/62

PATHWAY

GP Referral received
Testicular Cancer suspected

Assessment of clinical presentation (Lump)

Diagnostic tests
Ultrasound

Equivocal

Testicular Cancer Confirmed
Decision to treat

Orchidectomy +- Prosthesis

CXR Tumour Marker
Book CT

Patient discussed at MDT ∆

Metastatic

Oncology

Oncology Outpatient's appointment ♦

Patient discussed at MDT

Surveillance

Chemotherapy

Radiation

Clinical Trial

Sperm Bank

Post Chemo Mass/ RPLND

Follow UP ♦

GOOD PRACTICE & QUALITY PARAMETERS

NICaN Referral Guidelines, 2007

Swelling or mass in body of testis

Improving Outcomes guidance in Urological cancers, 2002

Inform MDT coordinator on receipt of results.

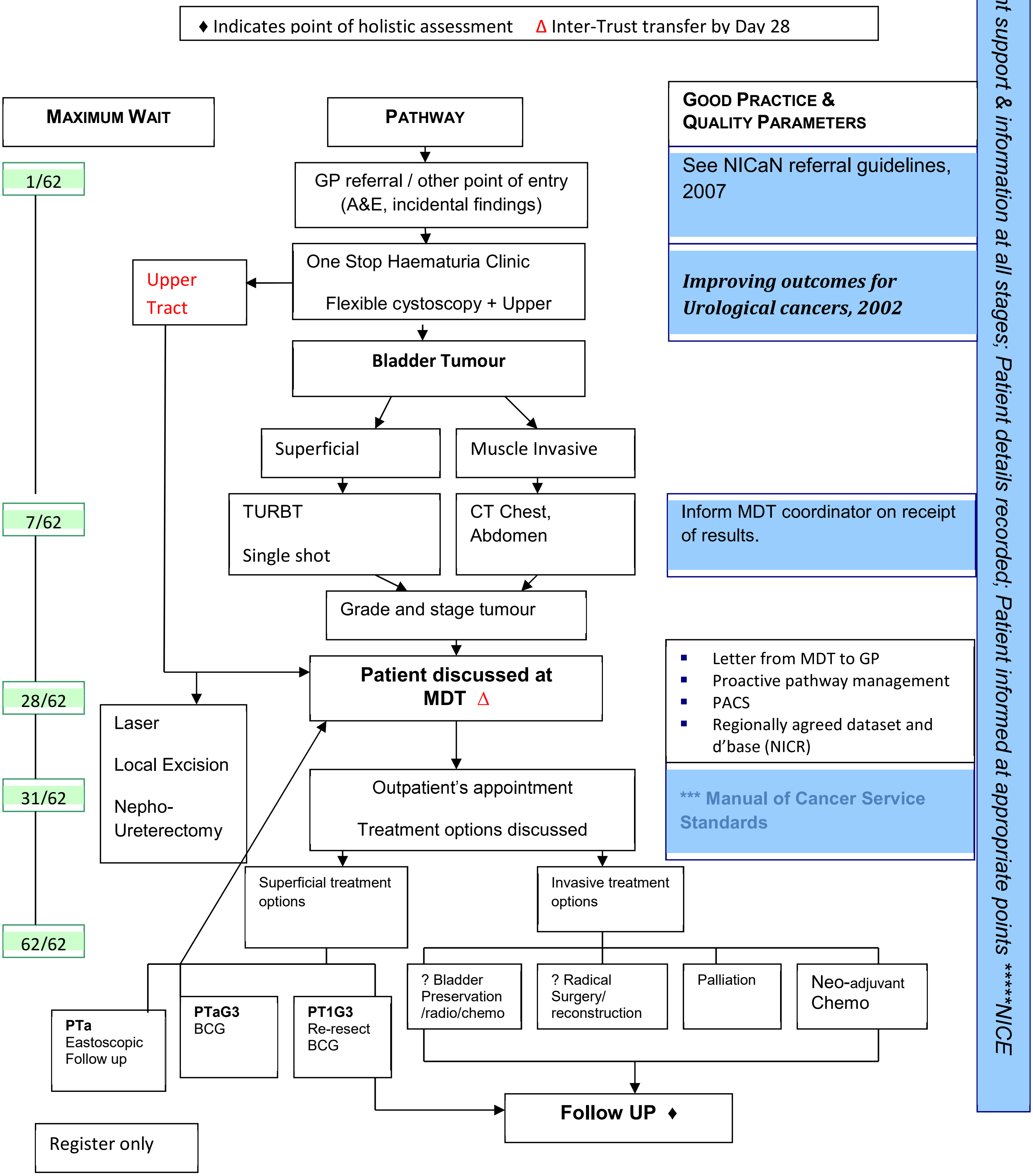
- *GP letter from MDT*
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

***** Manual of Cancer Service Standards**

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE*

♦ Indicates point of holistic assessment ∆ Inter-Trust transfer by Day 28

Appendix 3 of NICaN Urology Cancer Clinical Guidelines



♦ Indicates point of holistic assessment   Δ Inter-Trust transfer by Day 28

MAXIMUM WAIT

1/62

7/62

28/62

31/62

62/62

PATHWAY

GP referral / other point of entry (A&E, incidental findings)

One Stop Haematuria Clinic

Flexible cystoscopy + Upper

Upper Tract

Bladder Tumour

Superficial

Muscle Invasive

TURBT

Single shot

CT Chest, Abdomen

Grade and stage tumour

Patient discussed at MDT Δ

Laser

Local Excision

Nepho-Ureterectomy

Outpatient's appointment

Treatment options discussed

Superficial treatment options

Invasive treatment options

PTa Eastoscopic Follow up

PTaG3 BCG

PT1G3 Re-resect BCG

? Bladder Preservation /radio/chemo

? Radical Surgery/ reconstruction

Palliation

Neo-adjuvant Chemo

Follow UP ♦

Register only

GOOD PRACTICE & QUALITY PARAMETERS

See NICaN referral guidelines, 2007

Improving outcomes for Urological cancers, 2002

Inform MDT coordinator on receipt of results.

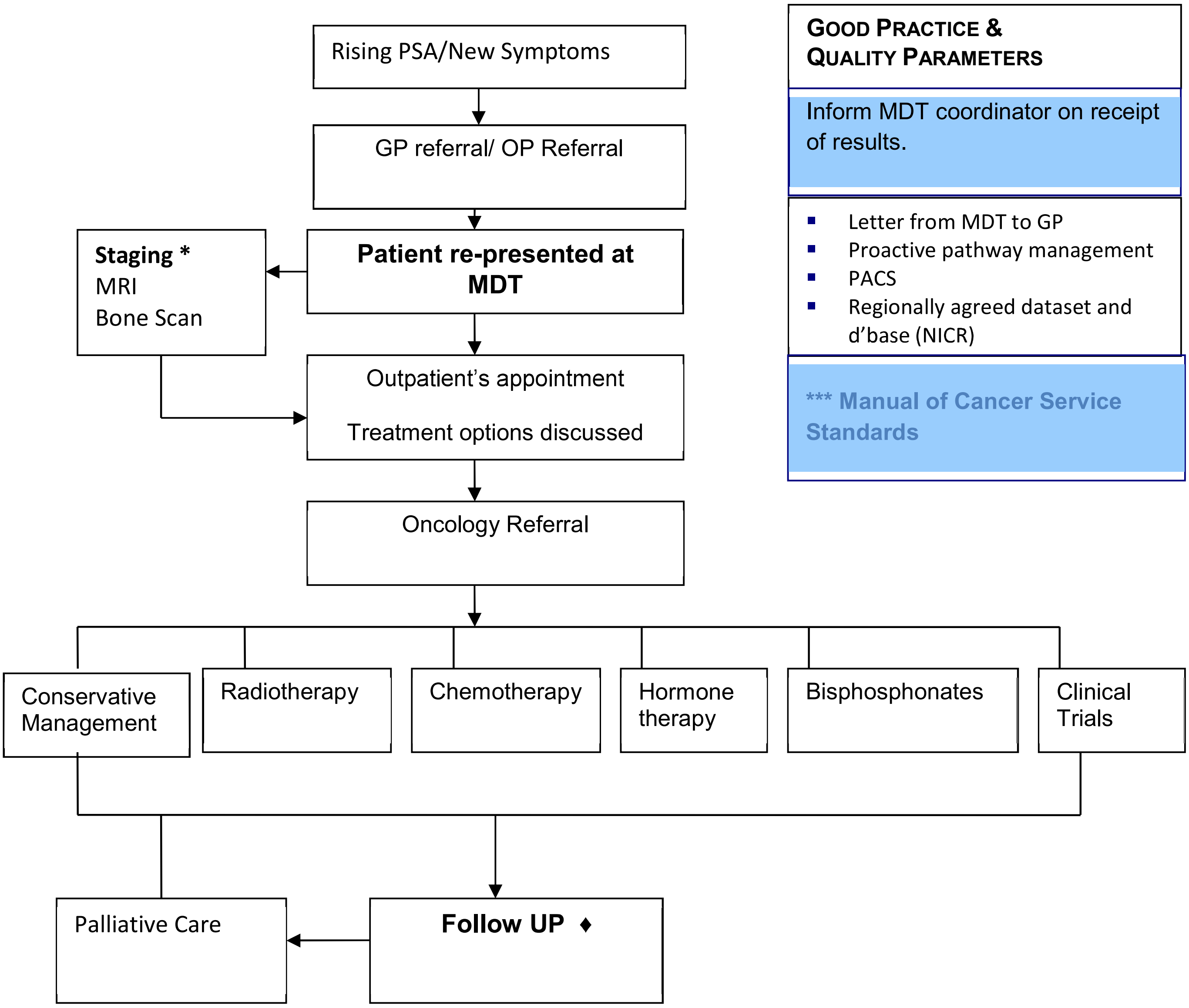
- Letter from MDT to GP
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

***** Manual of Cancer Service Standards**

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE*

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Castration Resistant Prostate Cancer



GOOD PRACTICE & QUALITY PARAMETERS

Inform MDT coordinator on receipt of results.

- Letter from MDT to GP
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

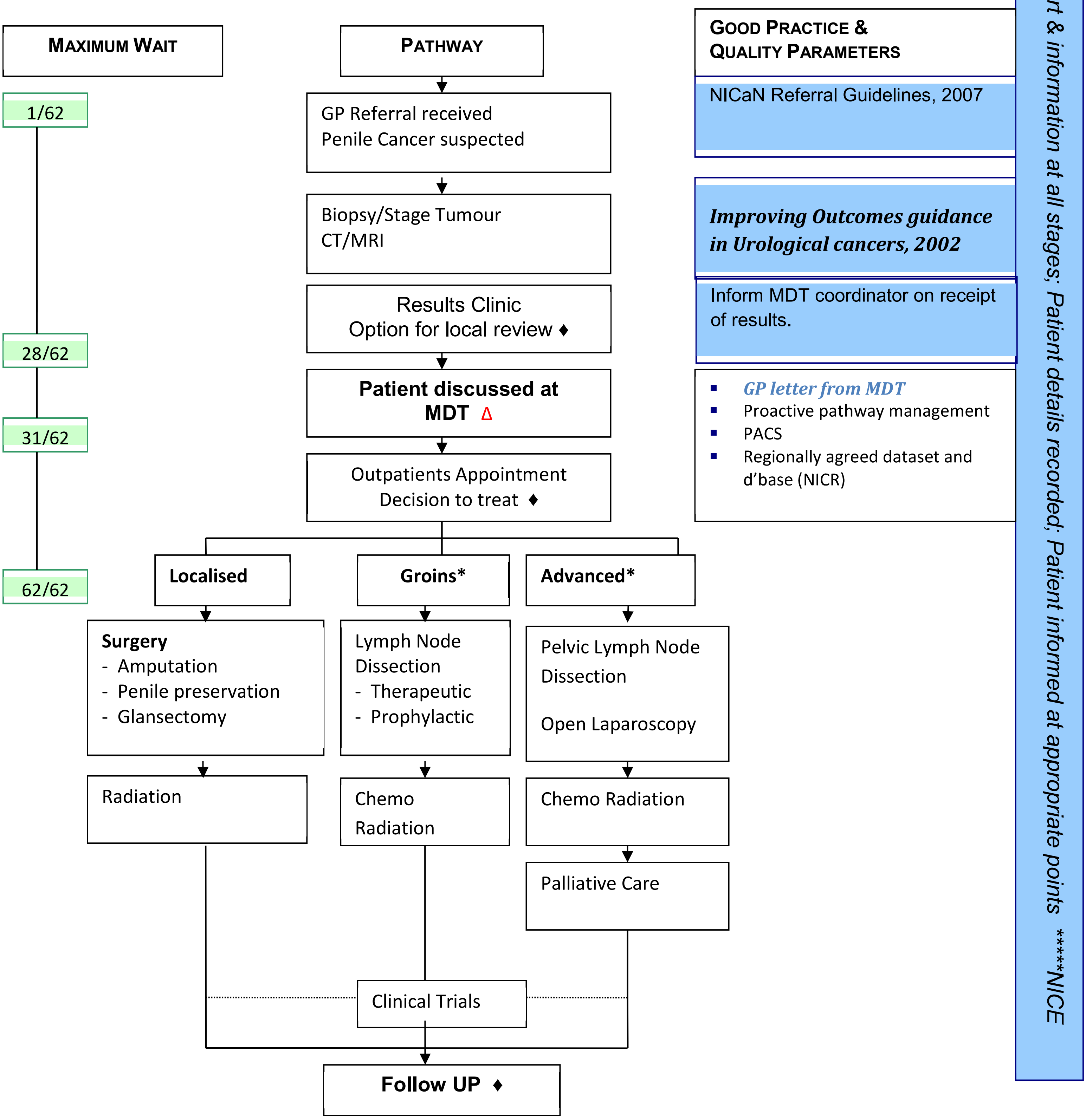
***** Manual of Cancer Service Standards**

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE*

* MRI/Bone Scan as clinically indicated

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Penile Cancer Pathway (Currently Under Review as part of development of local penile service 2019)



♦ Indicates point of holistic assessment   Δ Inter-Trust transfer by Day 28

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

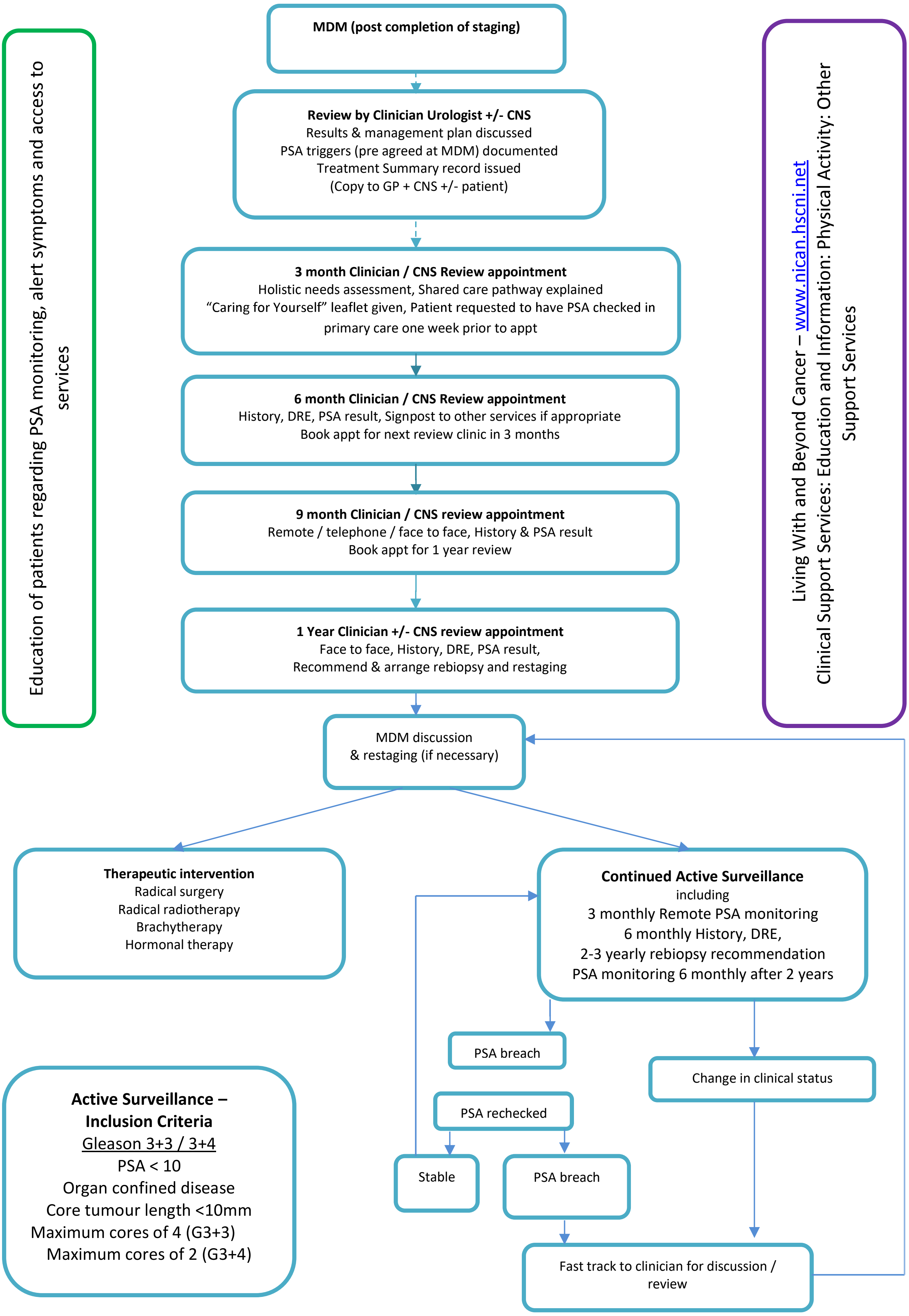
Policy Code / Reference No:

Trust Logo

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 2

Prostate Cancer: Active Surveillance



Education of patients regarding PSA monitoring, alert symptoms and access to services

MDM (post completion of staging)

Review by Clinician Urologist +/- CNS
Results & management plan discussed
PSA triggers (pre agreed at MDM) documented
Treatment Summary record issued
(Copy to GP + CNS +/- patient)

3 month Clinician / CNS Review appointment
Holistic needs assessment, Shared care pathway explained
"Caring for Yourself" leaflet given, Patient requested to have PSA checked in primary care one week prior to appt

6 month Clinician / CNS Review appointment
History, DRE, PSA result, Signpost to other services if appropriate
Book appt for next review clinic in 3 months

9 month Clinician / CNS review appointment
Remote / telephone / face to face, History & PSA result
Book appt for 1 year review

1 Year Clinician +/- CNS review appointment
Face to face, History, DRE, PSA result,
Recommend & arrange rebiopsy and restaging

MDM discussion
& restaging (if necessary)

Therapeutic intervention
Radical surgery
Radical radiotherapy
Brachytherapy
Hormonal therapy

Continued Active Surveillance
including
3 monthly Remote PSA monitoring
6 monthly History, DRE,
2-3 yearly rebiopsy recommendation
PSA monitoring 6 monthly after 2 years

PSA breach

Change in clinical status

PSA rechecked

Stable

PSA breach

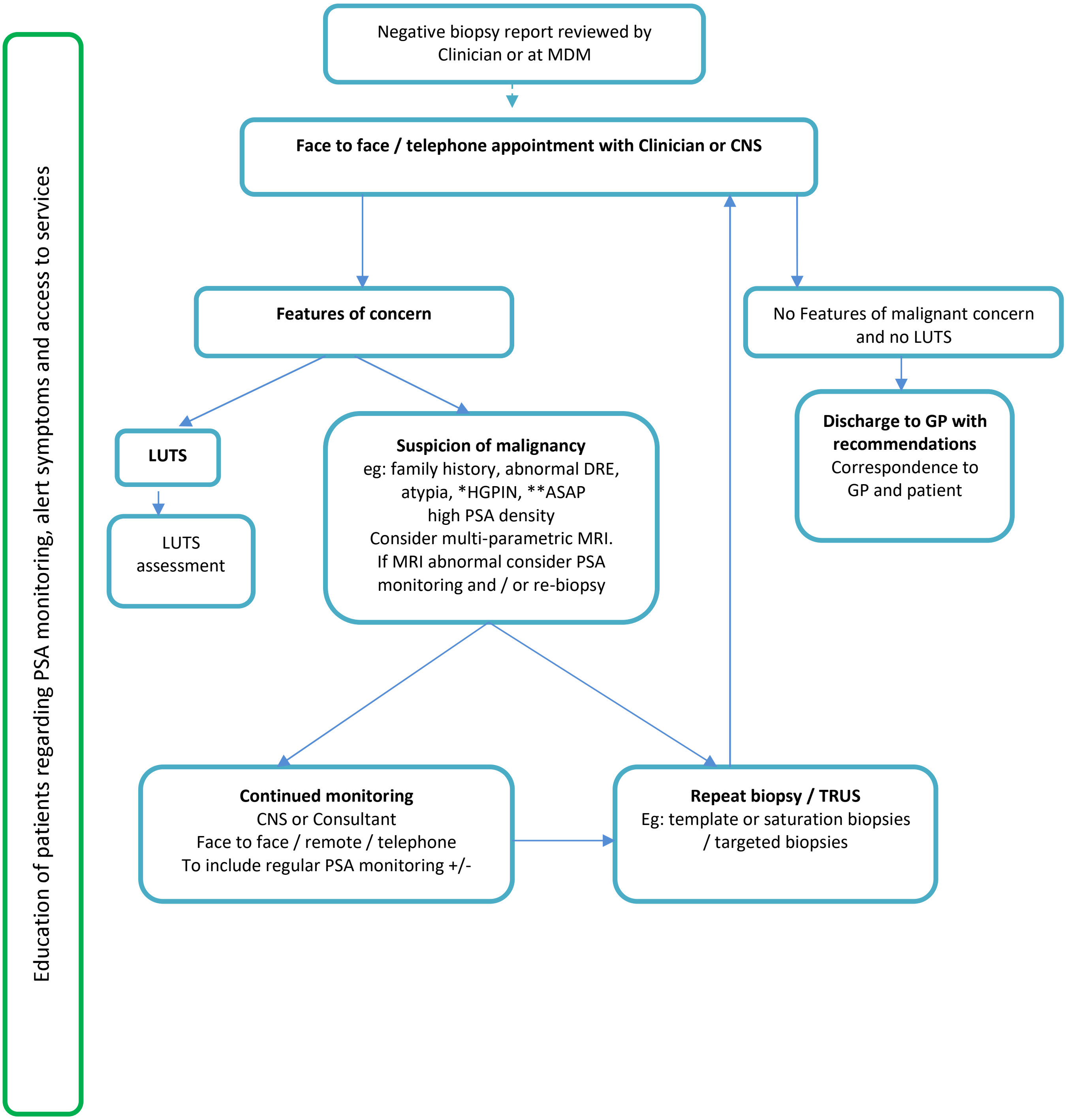
Fast track to clinician for discussion / review

Living With and Beyond Cancer – www.nican.hscni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Active Surveillance – Inclusion Criteria
Gleason 3+3 / 3+4
PSA < 10
Organ confined disease
Core tumour length <10mm
Maximum cores of 4 (G3+3)
Maximum cores of 2 (G3+4)

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

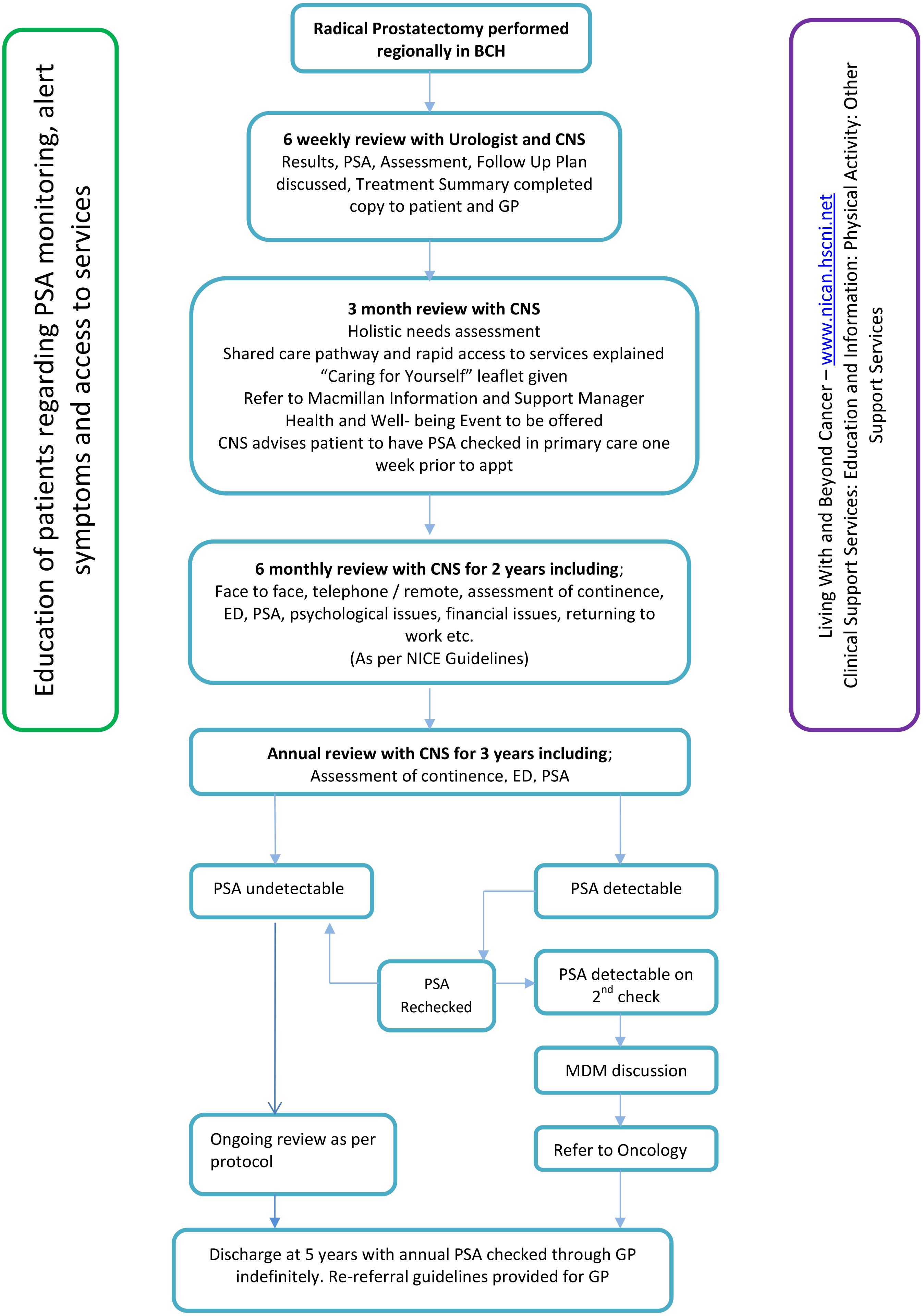
Pathway 3 Raised PSA & Negative Biopsy



*HGPIN – High grade prostatic intra-epithelial neoplasia
**ASAP – Atypical small acinar proliferation

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 4 Prostate Cancer: Radical Surgery – Negative margins



Education of patients regarding PSA monitoring, alert symptoms and access to services

Living With and Beyond Cancer – www.nican.hscni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Radical Prostatectomy performed regionally in BCH

6 weekly review with Urologist and CNS
Results, PSA, Assessment, Follow Up Plan discussed, Treatment Summary completed copy to patient and GP

3 month review with CNS
Holistic needs assessment
Shared care pathway and rapid access to services explained
“Caring for Yourself” leaflet given
Refer to Macmillan Information and Support Manager
Health and Well- being Event to be offered
CNS advises patient to have PSA checked in primary care one week prior to appt

6 monthly review with CNS for 2 years including;
Face to face, telephone / remote, assessment of continence, ED, PSA, psychological issues, financial issues, returning to work etc.
(As per NICE Guidelines)

Annual review with CNS for 3 years including;
Assessment of continence, ED, PSA

PSA undetectable

PSA detectable

PSA Rechecked

PSA detectable on 2nd check

MDM discussion

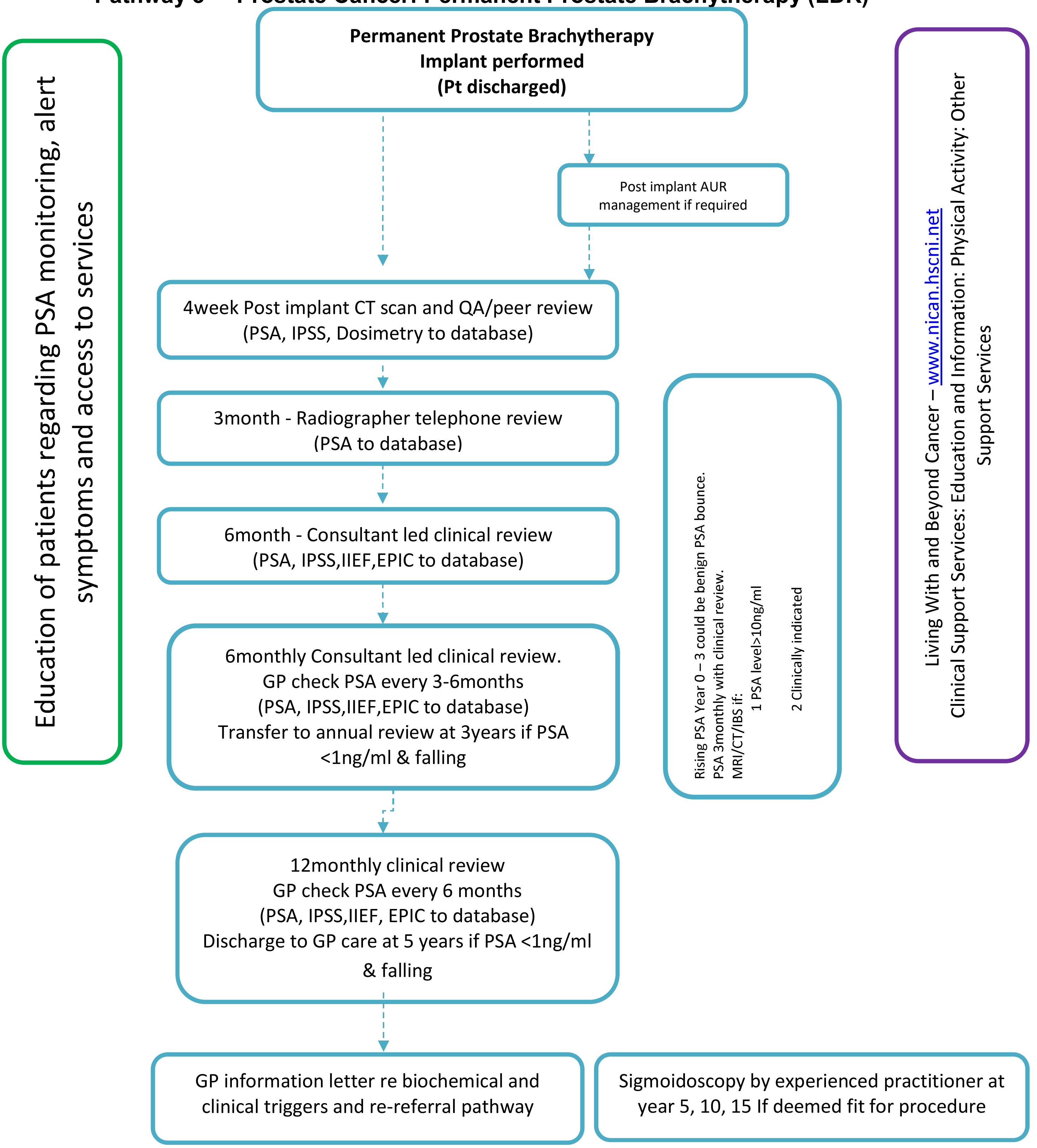
Refer to Oncology

Ongoing review as per protocol

Discharge at 5 years with annual PSA checked through GP indefinitely. Re-referral guidelines provided for GP

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 5 Prostate Cancer: Permanent Prostate Brachytherapy (LDR)



Education of patients regarding PSA monitoring, alert symptoms and access to services

Permanent Prostate Brachytherapy Implant performed (Pt discharged)

Post implant AUR management if required

4week Post implant CT scan and QA/peer review (PSA, IPSS, Dosimetry to database)

3month - Radiographer telephone review (PSA to database)

6month - Consultant led clinical review (PSA, IPSS,IIEF,EPIC to database)

6monthly Consultant led clinical review.
GP check PSA every 3-6months
(PSA, IPSS,IIEF,EPIC to database)
Transfer to annual review at 3years if PSA <1ng/ml & falling

12monthly clinical review
GP check PSA every 6 months
(PSA, IPSS,IIEF, EPIC to database)
Discharge to GP care at 5 years if PSA <1ng/ml & falling

GP information letter re biochemical and clinical triggers and re-referral pathway

Rising PSA Year 0 – 3 could be benign PSA bounce.
PSA 3monthly with clinical review.
MRI/CT/IBS if:
1 PSA level>10ng/ml
2 Clinically indicated

Living With and Beyond Cancer – www.nican.hscni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Sigmoidoscopy by experienced practitioner at year 5, 10, 15 If deemed fit for procedure

Selection criteria for Permanent Prostate Brachytherapy

Clinical inclusion criteria:
Organ confined prostate cancer T1 or T2
Estimated life expectancy >10yrs
Gleason 6 and PSA <15ng/ml
Gleason 7 and PSA <15ng/ml

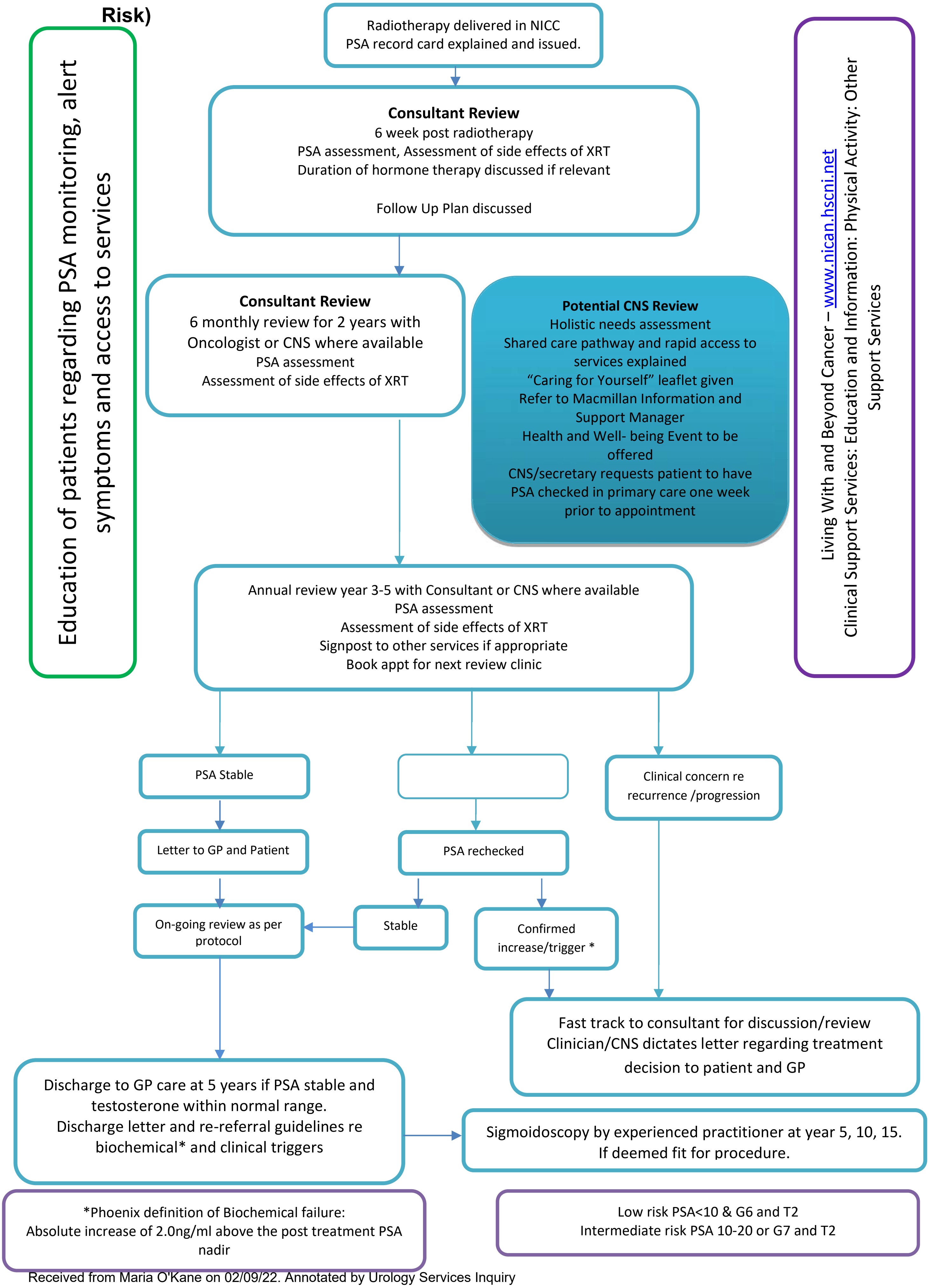
Clinical exclusion criteria for brachytherapy:
Prostate volume >50ml (> 65ml prior to hormonal cytoreduction)
IPSS >9. (Would consider for implant is <15 & Qmax >12ml/sec)
Life expectancy <5years
Large or poorly healed TURP defect
Unacceptable operative risk
Relative contraindications for brachytherapy:
Large median lobe

Selection criteria for combined Permanent Prostate Brachytherapy + EBRT

Selected men with:
High volume Gleason 7 or
Low volume Gleason >7 or
Early T3a disease
May be suitable for dose escalation with combination therapy and should be referred for discussion to central

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 6: Prostate Cancer: Radiotherapy+/-Hormones (Low Intermediate Risk)



Education of patients regarding PSA monitoring, alert symptoms and access to services

Radiotherapy delivered in NICC
PSA record card explained and issued.

Consultant Review
6 week post radiotherapy
PSA assessment, Assessment of side effects of XRT
Duration of hormone therapy discussed if relevant

Follow Up Plan discussed

Consultant Review
6 monthly review for 2 years with Oncologist or CNS where available
PSA assessment
Assessment of side effects of XRT

Potential CNS Review
Holistic needs assessment
Shared care pathway and rapid access to services explained
"Caring for Yourself" leaflet given
Refer to Macmillan Information and Support Manager
Health and Well- being Event to be offered
CNS/secretary requests patient to have PSA checked in primary care one week prior to appointment

Living With and Beyond Cancer – www.nican.hscni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Annual review year 3-5 with Consultant or CNS where available
PSA assessment
Assessment of side effects of XRT
Signpost to other services if appropriate
Book appt for next review clinic

PSA Stable

Letter to GP and Patient

On-going review as per protocol

PSA rechecked

Stable

Confirmed increase/trigger *

Clinical concern re recurrence /progression

Fast track to consultant for discussion/review
Clinician/CNS dictates letter regarding treatment decision to patient and GP

Discharge to GP care at 5 years if PSA stable and testosterone within normal range.
Discharge letter and re-referral guidelines re biochemical* and clinical triggers

Sigmoidoscopy by experienced practitioner at year 5, 10, 15.
If deemed fit for procedure.

*Phoenix definition of Biochemical failure:
Absolute increase of 2.0ng/ml above the post treatment PSA nadir

Low risk PSA<10 & G6 and T2
Intermediate risk PSA 10-20 or G7 and T2

Appendix 21- NiCan Clinical Management Guidelines

Sharepoint link to all tumour site guidance- Clinical Management Guidelines - Home (hscni.net)

Urology NiCan guidelines- Urology - All Documents (hscni.net)

Appendix 22- Key Performance Indicators for Cancer Nurse Specialists from Macmillan

https://www.macmillan.org.uk/documents/aboutus/commissioners/excellenceincancercarethecontributionoftheclinicalnursespecialist.pdf

Ensuring Better Treatment

National Cancer Action Team
Part of the National Cancer Programme

NHS

Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist

WE ARE MACMILLAN.
CANCER SUPPORT

Contents

Foreword 3

The role of the Clinical Nurse Specialist in cancer care 4

Key contributions that CNSs make to cancer care 5

The cost of managing cancer 5

Reducing the financial burden of cancer – the potential of the CNS 6

CNSs: leading quality and productivity in cancer care 6

Experience from the front line – CNSs transforming cancer care 7

Case Studies 8

Delivering the future for cancer patients 11

Matching workforce planning to patient need 11

Issues for Employers and Managers to consider 12

Further sources of information 13

Acknowledgments 13

References 14

Endorsements 15

Foreword

Together we share an ambition to achieve the best cancer outcomes for patients in the UK, recognising that, at a time of tightened budgets, it is critical that NHS resources are deployed to best effect. Now more than ever, clinical nurse specialists (CNSs) have a vital role to play in delivering high quality and compassionate care, including care closer to home, and supporting a drive for efficiency that improves health outcomes and maximises resources.

Cancer CNSs have played an important role in the successful implementation of initiatives to improve NHS cancer services. Despite an increasing incidence of the disease and an ageing population, death rates from many cancers are dropping, survival rates are improving and many patients' experiences of care have been enhanced. CNSs are at the front line of cancer care; they are the main point of contact for patients and as a result help to shape services for each patient according to need and patient choice, which contributes to wider cancer priorities. For example, CNSs play an important role in enabling care to be delivered closer to home and in improving patients' and their families' ability to self-manage symptoms and side-effects of treatment.

CNSs contribute to increasing the quality of care provided by the NHS; indeed, in the face of rising patient expectations, more patients report being treated with dignity and respect and having trust and confidence in their care team. Increasingly, they have an ongoing role in supporting cancer survivors as well as cancer patients. Overall it is estimated that there are now 2 million people living with cancer and this is set to rise to 4 million by 2030.[1]

For people affected by cancer, the effective management of their care pathway is essential to maintain quality of life. People whose care is unplanned and un-coordinated are more likely to be high users of health and social care services, including emergency care. CNSs work closely with patients and with their clinical colleagues to adapt to patients' emerging needs thus reducing the need for unplanned care.

This short guide is designed to support clinical teams, commissioners, employers and managers to understand and evaluate the contribution of CNSs in cancer as they plan their local workforce and service improvement strategies. With examples drawn from front-line services across a range of cancers, this guide sets out how effective CNS deployment drives innovation, reduces inefficiency and improves the quality of cancer care across the UK.

We still have further to go if we are to improve outcomes for all cancers, with the aim of bringing us in line with the best in Europe. Ensuring provision of CNSs where they are needed, coupled with effective use of their skills and expertise will enable us to move faster towards this goal.

Professor Sir Mike Richards
National Cancer Director

Ciarán Devane
Chief Executive
Macmillan Cancer Support

Ciarán Devane

Dame Christine Beasley DBE
Chief Nursing Officer (England)
Department of Health

CBeasley

The role of the Clinical Nurse Specialist in cancer care

The roles undertaken by Clinical Nurse Specialists (CNSs) are many and varied; however, there are core clinical practice functions and a level of practice that could be reasonably expected of all CNSs in cancer care.

CNSs in cancer care can be described as registered nurses, who have graduate level nursing preparation and who would usually be expected to be prepared at Master's level. They are clinical experts in evidence-based nursing practice within a specialty area. The specialty may be focused on a population (e.g. young people), type of care (e.g. palliative care), type of problem (e.g. lymphoedema), type of treatment (e.g. chemotherapy) or tumour type (e.g. lung cancer).

CNSs treat and manage the health concerns of patients and work to promote health and wellbeing in the patients they care for. CNSs in cancer care practice autonomously and integrate knowledge of cancer and medical treatments into assessment, diagnosis, and treatment of patients' problems and concerns.[2] Whilst many specialist nurses may function at an advanced level, this level of practice is not common to all, thus the title Clinical Nurse Specialist does not in itself indicate that the nurse is an 'advanced practitioner'.

The high-level activities of CNSs can be separated into four main functions.[3] In the context of cancer care these consist of:

1. Using and applying technical knowledge of cancer and treatment to oversee and coordinate services, personalise 'the cancer pathway' for individual patients and to meet the complex information and support needs of patients and their families
2. Acting as the key accessible professional for the multidisciplinary team, undertaking proactive case management and using clinical acumen to reduce the risk to patients from disease or treatments
3. Using empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines as appropriate
4. Using technical knowledge and insight from patient experience to lead service redesign in order to implement improvements and make services responsive to patient need

Furthermore, some cancer CNSs have developed their roles to include technical elements, for example: physical examinations and diagnostic tests; and insertion of central venous lines for the delivery of chemotherapy or for nutritional purposes.

Many cancer CNSs work as part of a tumour specific team, whereas others may work across more than one service or setting. Although many are based within acute trusts, post-holders are also located in primary care and community settings or private and voluntary sector organisations. They may be responsible for whole client groups, or for episodes of care and nursing services more widely. They are also typically core members of a multidisciplinary team.[4]

Key contributions that CNSs make to cancer care

Clinical Nurse Specialist

- Acting as a key worker across the whole care pathway
- Advanced clinical / diagnostic skills
- In depth knowledge of a tumour area
- Ability to assess patients' holistic needs
- Advanced communication and advocacy skills
- Empathy for patients and their families
- Excellent decision making abilities
- Leadership within the MDT and wider cancer team
- Innovation, project management and change management

The cost of managing cancer

The cost to the NHS in England of patient care for cancer in 2007/8 was £5 billion.[5] Department of Health figures for 2007-08 showed that:

- Over half (i.e. over £2 billion) of the total expenditure on cancer in England went on inpatient care[6]
- Inpatient care for cancer patients accounted for 12% of all inpatient beds in England[6]
- The number of emergency admissions for cancer increased by 47% in the past 8 years[6]
- 4.7 million bed days were cancer related[6]

Statistics from 2006-07 for England show:

- 417,646 emergency inpatient admissions for cancer representing 2,963,987 bed days[6]
- 339,038 elective inpatient admissions for cancer representing 1,750,223 bed days[6]

Reducing the financial burden of cancer – the potential of the CNS

The specialist nature of the cancer CNS and their role as key worker to individual patients means that they can quickly identify emerging issues that might require medical attention, enabling care to be planned and emergency admissions averted. CNSs also support enhanced recovery after surgery – equipping patients to manage their recovery at home and reducing the need for lengthy hospital stays. These two important contributions help the NHS to improve patient experience and safety.

There are also sound economic arguments for supporting patients to manage their care at home and helping them through the complex systems of health care provision.

The National Audit Office's End of Life Care report estimated £104m savings by reducing emergency admissions by 10 per cent, and reducing the length of stay by 3 days.[7]

An economic modelling analysis by Macmillan Cancer Support in 2009[8], focusing on the role of the CNS, suggested that service improvements along the cancer pathway could release about 10% of cancer expenditure in the Manchester area. This related only to breast and lung patients admitted through the two week wait system in one health economy. If extrapolated to a national level then the economic benefits could be significant.

CNSs: leading quality and productivity in cancer care

Patients rightly expect high quality, effective healthcare and CNSs have an important role to play in meeting their needs and expectations.

The proposed NHS Outcomes Framework[9] is structured around five high level outcome domains. These are intended to cover everything the NHS is there to do. These five outcome domains are:

- Preventing people from dying prematurely
- Enhancing the quality of life for people with long-term conditions
- Helping people to recover from episodes of ill health or following injury
- Ensuring people have a positive experience of care
- Treating and caring for people in a safe environment and protecting them from avoidable harm

As practitioners and partners at the heart of multidisciplinary teams, CNSs have influence and credibility across the care pathway. They are increasingly taking a leadership role in refining systems and smoothing care pathways, making a demonstrable contribution to effectiveness, patient experience and safety.

Experience from the front line – CNSs transforming cancer care

Impact of key CNS-led activites

Improving quality and experience of care

- Managing complex, individual and changing information and support needs of patients and carers
- Supporting patients in choices around treatment and care
- Enhancing recovery and delivering care flexibly and closer to home
- Facilitating set up of support groups

Reinforcing safety

- Delivering safe, nurse-led services
- Using vigilance of symptoms and drug toxicity to trigger rescue work
- Identifying and taking action to reduce risks
- Facilitating rapid re-entry into acute services, if appropriate

Increasing productivity and efficiency

- Intervening to manage treatment side effects and/or symptom control, preventing unplanned admissions
- Providing nurse-led services that free up consultant resource
- Empowering patients to self-manage their condition

Demonstrating leadership

- Educating the wider healthcare team and acting as a mentor
- Identifying and implementing service improvement and efficiencies
- Determining measurable outcomes, auditing practice, and sharing good practice and innovation

CNSs across the country are already transforming patients' experiences of cancer care. The following case studies provide a flavour of the kinds of initiatives that CNSs are leading – highlighting their pivotal role in maximising resource and benefitting patients.

Case Studies

Innovation, project management, change management

Lesley Barnett, Macmillan Lead Cancer Nurse, Doncaster
Gina Wibberley, Macmillan Lung CNS, Lincoln

CNSs in Doncaster and Lincolnshire have implemented rapid alert systems to ensure that they are immediately informed when one of their patients enters hospital with an unplanned admission. Using mobile technology and integrated IT systems, a text message and email is sent to the CNS who can immediately attend the patient or discuss the case with the treating clinicians.

Using their specialist knowledge in lung cancer, and their understanding of individual patients' needs, CNSs in Lincolnshire use this as an opportunity to re-assess the patient's cancer pathway outside of scheduled patient planning, or identify where a quick specialist intervention can turn around an inappropriate admission. The nurses in Doncaster have identified length-of-stay reductions of one to two days per patient, they work to ensure that the patient is admitted to the correct ward and in some cases prevent admission altogether. Added to these productivity benefits is the increased quality of care experienced by patients who report feeling completely supported, knowing that they are receiving coordinated care.

Empathy for patients and their families

Frances McKay, Macmillan Mesothelioma and Lung CNS, Medway

Frances, and her colleagues Caroline Williams and Pat Cameron, run the only lung cancer and mesothelioma support group in their Cancer Network. Up to 28 people each month attend the group.

The CNSs work in collaboration with a local hospice to facilitate the monthly group meetings with a hospice volunteer managing the meeting practicalities. A successful buddy system has been established for patients and carers who face the challenging and complex issues of a terminal disease.

The group also enables the CNSs to identify emerging health issues, including helping patients to self-manage symptoms such as shortness of breath, reducing anxiety and maintaining quality of life. Importantly, the CNSs are able to mediate between patients and hospital services and quickly address any issues of concern raised by patients and their families.

Advanced clinical and diagnostic skills

Sharon McGeary and Amanda Gerrard, Paediatric Oncology Outreach Network CNSs, Newcastle Upon Tyne

Nurses from the children s oncology outreach service in Newcastle work with children and young people throughout their cancer journeys. Using specialist knowledge of symptom management, palliative and complex care, the nurses work a 24/7 on call system, allowing for timely, effective interventions which maximise care delivery. The nurse team are trained as non medical prescribers, and more than half are practising prescribers.

Working in a large geographical region, the nurses have developed effective collaborative working practices with local primary care service providers. This is particularly important in enabling children and young people with progressive disease to be cared for, and die, in their preferred place of choice, often their home.

The nurses are leading the way in the implementation of new technologies in their hospital trust. Smart Pump technology, considered to be the next generation of ambulatory infusion devices, allows the release of medication over seven days maximising symptom management and minimising hospital attendance. Corresponding drug libraries, managed by the nurses, help to improve safety by reducing drug errors, improving workflow and providing a new source of data for continuous quality improvement.

Acting as key worker across the whole care pathway

Tina Lightfoot, Lead Specialist Nurse for GI services (surgery), Chester

Tina and the colorectal specialist nurses provide quality services to enhance recovery for patients with colorectal cancer at the Countess of Chester Hospital. Through a pre operative counselling initiative, patients and carers have an increased understanding of recovery and discharge expectations, helping them to make plans for managing care at home. In addition, patients who are expected to have a stoma are visited at home by the stoma nurse for a dummy’ teaching session, reducing the time it takes to become self-sufficient in stoma management.

Patients on the enhanced recovery programme are discharged as early as two days after surgery, and there is evidence that this is significantly reducing care costs. The colorectal specialist nurses contact the patient daily after discharge for up to 10 days to assess their progress. This vigilance ensures that complications are picked up early enabling timely intervention, and patients report feeling supported through their recovery.

Excellent decision making abilities

Debbie Fitzgerald, Gynaecology CNS, Torbay

Debbie has developed an innovative early-alert service for women with ovarian cancer who suffer from a painful and distressing build up of fluid in the abdominal area.

Patients are alerted to the possibility of fluid build-up, and encouraged to phone her if they begin to experience symptoms. When contacted, Debbie makes a clinical assessment, organising an abdominal scan if required and booking blood tests pre-admission. The drainage can then be done as a day patient, preventing emergency admission to A&E and lengthy inpatient stays as well as improving patients’ quality of life.

The CNS’s coordinating role ensures that phlebotomists, radiographers, and the medical team are all available at the right time. Debbie has developed this into a protocol - now widely used.

Advanced communication and advocacy skills

Judith Clarke, Surgical Breast Care CNS, Coventry

Judith has developed an innovative system to monitor and best manage anxiety among patients recalled to the breast screening clinic for further assessment following attendance to the NHS breast screening programme. Judith devised a simple tool that encourages patients to reflect on their anxiety and prompt them to seek additional support from the breast care nurse (BCN). It also promotes greater collaboration with radiographers and a more coordinated patient-centred experience.

Designed to look like a thermometer, the assessment tool asks women to score themselves from 0 10 (low to high anxiety) enabling BCNs to triage the more vulnerable women (scoring 5 and above) and ensure they are offered a BCN consultation before being re screened. Radiographers also use the self-assessment to ensure more patient-focused care, taking into account women s concerns. Feedback from patients shows that women find this activity useful and many have commented on how it helped to reduce their anxiety.

Case Studies (continued)

Demonstrating Leadership

Catherine Oakley, Nurse Consultant, London

Catherine and the team of chemotherapy nurse specialists at Guy's and St Thomas' Hospital have been working together to redesign the way chemotherapy is delivered. Nurses in the chemotherapy unit now work in four specialised teams according to tumour types to improve consistency for patients and maximise the nurses' clinical expertise.

Catherine piloted an intervention in urology in which a specialist nurse and pharmacist delivered an improved pre-treatment consultation. The key to its success is structuring the consultation to ensure that patients' educational and supportive care needs are met to optimise safety and empower patients to actively participate in their treatment plan. Additionally, CNSs proactively call patients to monitor their progress during the course of their treatment. Closely monitoring patients in this way ensures that any side-effects can be quickly managed and that patients are supported through this sometimes difficult part of their cancer journey.

In-depth knowledge of tumour area

Tessa Fitzpatrick, Macmillan Lung CNS, North Tees

Analysis of patient experience at University Hospital of North Tees suggests that lung cancer patients and carers can encounter problems following admission to the Emergency Assessment Unit (EAU). These include unnecessary investigations, poor symptom management, lack of recognition of end of life, delays in discharge and inadequate communication. This has a negative impact on patients' confidence in the service and also on the length of stay which has a cost implication.

The CNSs at North Tees use their specialist knowledge of lung cancer to support patients who are admitted as emergency cases, reducing inpatient stays and helping patients and carers to understand and manage symptoms. University Hospital of North Tees examined a total of 94 inpatient episodes resulting in 964 bed days. The average length of stay for those patients not referred to the lung CNS was 10.8 days however there was a reduction in length of stay to 9.7 days for those patients who had lung CNS input during their admission.

Ability to assess patients' holistic needs

Anita Pabla, Sarcoma CNS, Leicester

Anita works with patients throughout their cancer journey but has particularly focussed on supporting survivorship and smoothing the transition from secondary to primary care.

Six to eight weeks post-treatment, she provides patients with detailed and individual end of treatment' summaries within the context of a holistic consultation. This captures their initial diagnosis and treatment history, medication and follow up schedule incorporating the wider services they have accessed, such as limb fitting and support groups. The summary also acts as an important communication tool for their GP, enabling greater integration between different parts of the patient pathway.

The summary and assessment has proved valuable to patients increasing their confidence and ability to self-manage as well as to primary care improving appropriate referral if and when needed.

Delivering the future for cancer patients

The NHS White Paper, Equity and Excellence: Liberating the NHS, puts patients and clinicians at the heart of decision-making in the NHS. The phrase “no decision about me without me” is used in the White Paper to emphasise patients’ involvement in their own care.[10] CNSs are often the main point of contact for cancer patients and their families, and work closely with colleagues throughout the patient’s cancer journey. As a result, they are well placed to support patients at each stage and to promote integration within care teams.

Equity and Excellence proposes a shift away from measuring clinical inputs and processes in favour of achieving improved clinical outcomes and higher quality patient experience. Here too, CNSs already demonstrate their skills in assessing and putting in place interventions to achieve these.

The Cancer Reform Strategy (2007) stated that: “Commissioners and providers should ensure that the critical roles of clinical nurse specialists in information delivery, communication and coordination of care are supported”.[11] This remains essential to achieving safe and high quality cancer care and we expect to see this reflected in the refreshed Cancer Reform Strategy.

Nursing is changing, reflecting and rewarding the skills and expertise of its workforce. Career pathways have been updated and transferable skills identified to enable nurses to shape their careers within and across different care pathways.[12] Embracing new models of care, the CNS role extends beyond the hospital setting into local community and specialist settings and increasingly includes informed individual care planning that enables patients to self-manage their condition where possible.

There is wide variation in the types of tasks that CNSs are carrying out. While some of these make good use of their skills, there is evidence that CNSs are also being diverted into general ward duties and tied up in administrative tasks. This does not represent good value to the NHS. Commissioners, employers and managers therefore need to consider whether CNSs are being deployed to best effect.

Matching workforce planning to patient need

Clinical teams will be considering whether provision of CNSs in their local area is sufficient to meet need. Understanding the patterns of access is fundamental to being able to match the CNS workforce to patients’ needs. Despite the expansion in overall CNS numbers since the 1980s, workforce shortages are still an issue.[13]

The best available data indicates that not every cancer patient has access to a CNS, despite the recommendations made in the Improving Outcomes Guidance. The National Cancer Action Team’s Workforce Review Team 2010 census demonstrates significant variation in provision of cancer CNSs in England, which cannot be accounted for by geographical differences in cancer incidence or in patient flows.[14] Since the last census in 2008,[15] there appears to have been an increase in CNS posts in rarer cancers, but the 2010 census revealed no significant growth in other tumour groups despite increasing cancer prevalence. Inequities remain across England and also between different tumour types. Patient advocacy groups have argued that in some cancers - notably lung and urological cancers - CNS provision falls significantly short of patient need and that CNSs face variable case-loads.

Issues for Employers and Managers to consider

CNSs provide quality care and contribute to improved outcomes for cancer patients. They lead innovation, and can drive efficiency in their teams. They also contribute to the delivery of health strategies and policy guidance including:

- Cancer Reform Strategy
- Improving Outcomes
- Quality, Innovation, Productivity and Prevention Challenge
- High Impact Actions for nursing and midwifery
- Equity and Excellence: Liberating the NHS
- Chemotherapy Services in England
- Vital Signs
- End of Life Care Strategy

Employers and managers may wish to ask the following questions when considering their cancer services and assessing their CNS provision, to identify to what extent cancer services are configured to maximise the safety, quality and productivity of care:

Your community

- What is the all-age, all-cause cancer incidence rate in your PCT?
- What are the demographics of your PCT in terms of: age; socioeconomic and deprivation factors; prevalence of risk factors; ethnicity?
- Are there communities with particular unmet needs?
- What priority issues for cancer have been identified through the Joint Strategic Needs Assessment?
- How have you reflected these in the selection of local priorities and incentives for health care providers e.g CQUINs? QOF?
- How do you plan to measure and improve outcomes in these areas?

Provision and capacity

- How many whole-time equivalent CNSs posts are there in your PCT?
- What is the distribution of these across different cancers?
- How does this compare to patterns in neighbouring areas and to the national picture?
- Does each specialist team dealing with a particular cancer type have at least one CNS member?
- How good is CNS attendance at MDT meetings for each team?
- How many new patients does each CNS see each year?
- Have you considered using the expertise of the Macmillan Cancer Support Service Development Team to redesign CNS roles and services should you have concerns that CNSs may not be working to the best potential of their roles?

Where can CNSs make most impact?

- How many unplanned admissions are there for cancer each year in your PCT? And how does this vary by cancer type?
- Do audited records demonstrate that at least 80% of patients receive information about their diagnosis, treatment and care plan?
- Can it be demonstrated that care is effectively coordinated across boundaries?
- Are CNSs working in roles that reflect and demand their knowledge and skills or are they undertaking general ward duties?

Further sources of information

- Cancer Commissioning Guidance
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110115
- Cancer Commissioning Toolkit
  https://www.cancertoolkit.co.uk
- Cancer Reform Strategy and Annual Reports
  http://www.dh.gov.uk/en/Healthcare/Cancer/ReformStrategy
- National Cancer Intelligence Network
  http://www.ncin.org.uk
- Association of Public Health Observatories
  http://www.apho.org.uk/
- Public Health Observatory Handbook of Health Inequalities Measurement
  http://www.sepho.org.uk/viewResource.aspx?id=9707
- Guidance on Joint Strategic Needs Assessment
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081097
- The Operating Framework for the NHS in England, 2010/11 (December 2009)
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110107
- Specialist nurses. Changing lives, saving money. Royal College of Nursing, London. 2010
  http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf
- Programme Budgeting data for 2007-08
  http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743
- National Audit Office, End of Life Care, November 2008 available here:
  http://www.nao.org.uk/publications/0708/end_of_life_care.aspx
- Department of Health, Equity and excellence: Liberating the NHS, July 2010
  http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf
- To download this publication go to:
  http://ncat.nhs.uk/our-work/ensuring-better-treatment/quality-in-nursing

Acknowledgments

The Department of Health, National Cancer Action Team and Macmillan Cancer Support would like to thank all those who have contributed to the development of this publication, in particular the Clinical Nurse Specialists who provided examples of good practice, and the members of the National Quality in Cancer Nursing Steering Group for their advice and guidance.

References

1 Maddams J, Moller H and Devane C., Cancer prevalence in the UK, 2008, Thames Cancer Registry and Macmillan Cancer Support, July 2008

2 American Nurses Association. Nursing: Scope & standards of practice, 2004

3 Leary A (2011) in Leary A (Ed) Lung cancer a multidisciplinary approach, Wiley-Blackwell Oxford In press

4 National Cancer Peer Review Programme Manual for Cancer Services 2008: Breast Measures

5 Department of Health, Programme Budgeting data for 2007-08

6 NHS Improvement Transforming Care for Cancer Inpatients - Spreading the Winning Principles and Good Practice: July 2009

7 National Audit Office, End of Life Care, November 2008

8 Macmillan Cancer Support, Demonstrating the economic value of co-ordinated cancer services. An examination of resource utilisation in Manchester , March 2010

9 Department of Health , Transparency in outcomes a framework for the NHS, July 2010

10 Department of Health, Equity and excellence: Liberating the NHS, July 2010

11 Department of Health, Cancer Reform Strategy, December 2007

12 Department of Health, Towards a framework for post-registration nursing careers - consultation response report, July 2008

13 National Cancer Action Team, National Cancer Peer Review Programme 2004 – 2007. An overview of the findings from the second national round of peer reviews of cancer services in England, June 2008

14 National Cancer Action Team Workforce Review Team, Census of Cancer Specialist Nurses in English Cancer Networks, 2010

15 Trevatt, P., Leary, A., A Census of the advanced and specialist cancer nursing workforce in England, Northern Ireland and Wales, European Journal of Oncology Nursing (2009) 14:1 (68-73)

Endorsements

The content of this publication is endorsed by the following organisations:

BRAIN TUMOUR UK

BREAKTHROUGH BREAST CANCER

breast cancer care

Kidney Cancer UK
SUPPORTING PATIENTS & CARERS

Blood and Lymphatic cancers
Leukaemia CARE
supporting a quality of life

Ovarian cancer action

PANCREATIC CANCER UK
Striving for Survival

THE PROSTATE CANCER CHARITY

RCF RARER cancers FOUNDATION
incorporating Rarer Cancers Forum

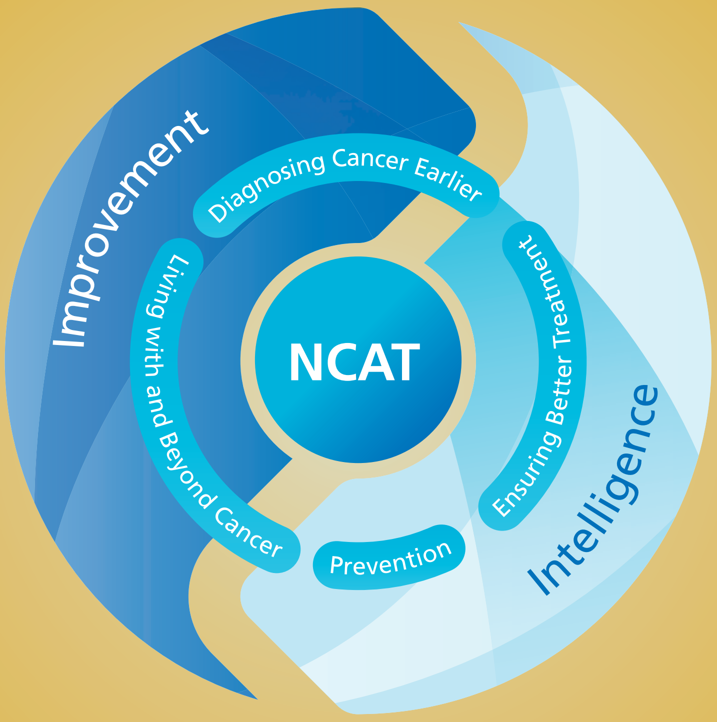
Royal College of Nursing

TARGET OVARIAN CANCER
For every woman. For life.

UKONS
Oncology Nursing Society

DH Department of Health

Gateway Number: 14851



WE ARE MACMILLAN.
CANCER SUPPORT

NHS

Belfast Health and Social Care Trust

caring supporting improving together

JOB DESCRIPTION

POST: Data Officer/MDT Co-ordinator

LOCATION: RVH, BCH and MPH

GRADE: Band 4

REPORTS TO: Business Support Officer, Cancer Services

RESPONSIBLE TO: Assistant Service Manager Cancer Services

JOB SUMMARY / MAIN PURPOSE:

The post holder will play a key role in the production of information to support Cancer Services business objectives in conjunction with the Cancer Services Information Officer. They will undertake processes to ensure the completeness and validity of cancer datasets held in Trust systems. The post holder will collect, record, analyse and report cancer information as requested in order to meet national, regional and local reporting requirements.

The post holder will be responsible for the co-ordination and organisation of Multidisciplinary Team (MDT) meetings. They will attend meetings obtaining and recording relevant information to facilitate the timely provision of care for patients.

The post holder will be required to be flexible with regards to the duties and demands. They will participate in audit collection and production of audit reports.

Main Duties / Responsibilities

DATA OFFICER:

1. Assist in the production of activity information reports both standard and ad-hoc, required to support the Cancer Services Team.
2. Assist in the delivery of a high quality information service to support the business needs of services groups and performance management.
3. Data validation to ensure complete and accurate performance reports, MDT annual reports and operational policies.
4. Use Trust information systems to facilitate collection of data for all cancers and enter this onto CaPPs in conjunction with clinical leads and Information Officer
5. Collect audit data and information for Cancer Services

6. Participate in developing information reports to ensure data quality within the Trust's information systems.

7. Provide accurate and timely data to the Cancer Management Team

8. Assist in the analysis and preparation of information for reports for monitoring waiting times, monthly/quarterly, for Trust Board and Cancer Management Team.

9. Maintain timely and accurate data collection, maintaining Cancer Patient Pathway System (CaPPS) and taking corrective action when data is incomplete or inaccurate.

10. Provide access and training for the Cancer Patient Pathway System (CaPPS)

MDT CO-ORDINATOR:

1. Responsible for the co-ordination, organisation and management of the weekly MDT meetings Trust wide, ensuring all relevant people are notified and all required information, notes, reports and results are available.

2. Generate a list of relevant patient names for the meetings and distributing this to the MDT members prior to meeting.

3. To work with the members of the MDT to ensure that all patients diagnosed with a new primary cancer are discussed at an MDT meeting.

4. Attend weekly MDT meetings. Complete the relevant information on the Cancer Patient Pathway System (CaPPS) for each patient discussed, including ensuring the details are sent to the relevant GP within 24 hours of MDT.

5. Responsible for typing live on CaPPS, noting action points and following up to ensure actions are taken in a timely manner.

6. Ensure all referrals made from MDT are forwarded to relevant professional.

7. Maintain a record of treatment decisions made at multi-disciplinary team meetings and ensure that the MDT proformas are filed in the patient notes.

8. Maintain an accurate record of attendance at MDT meetings ensuring all cancelled meetings are recorded with a cancellation reason. Provide annual MDT attendance figures to MDT members and the cancer services management team.

9. Ensure all documentation is kept in such a manner that any cancer patient tracker is able to take on the work.

10. When required receive telephone calls, communication with patients and/or their relatives.

11. Coordinate MDT business meetings and take minutes as required

12. Act as a point of contact for issues relating to videoconference equipment

General Responsibilities

Employees of the Trust are required to promote and support the mission and vision of the service for which they are responsible and:

- At all times provide a caring service and to treat those with whom they come into contact in a courteous and respectful manner.
- Demonstrate their commitment by their regular attendance and the efficient completion of all tasks allocated to them.
- Comply with the Trust's Smoke Free Policy.
- Carry out their duties and responsibilities in compliance with the Health and Safety Policies and Statutory Regulations.
- Adhere to Equality and Good Relations duties throughout the course of their employment.
- Ensure the ongoing confidence of the public in-service provision.
- Maintain high standards of personal accountability.
- Comply with the HPSS Code of Conduct.

Records Management

All employees of Belfast Health & Social Care Trust are legally responsible for all records held, created or used as part of their business within the Belfast Health and Social Care Trust, including patient/client, corporate and administrative records whether paper based or electronic and also including e-mails. All such records are public records and are accessible to the general public, with limited exceptions, under the Freedom of Information Act 2000, the Environment Regulations 2004 and Data Protection Act 1998. Employees are required to be conversant with the Belfast Health and Social Care Trust policy and procedure on records management and to seek advice if in doubt.

Environmental Cleaning Strategy

The Trusts Environmental Cleaning Strategy recognizes the key principle that "Cleanliness matters is everyone's responsibility, not just the cleaners" Whilst there are staff employed who are responsible for cleaning services, all Trust staff have a responsibility to ensure a clean, comfortable, safe environment for patients, clients, residents, visitors, staff and members of the general public.

Infection Prevention and Control

The Belfast Trust is committed to reducing Healthcare associated infections (HCAIs) and all staff have a part to play in making this happen. Staff must comply with all policies in relation to Infection Prevention and Control and with ongoing reduction strategies. Standard Infection Prevention and Control Precautions must be used at all times to ensure the safety of patients and staff.

This includes:-

- Cleaning hands either with soap and water or a hand sanitiser at the appropriate times (WHO '5 moments');
- Using the correct '7 step' hand hygiene technique;
- Being 'bare below the elbows' when in a clinical environment;
- Following Trust policies and the Regional Infection Control Manual (found on intranet);
- Wearing the correct Personal Protective Equipment (PPE);
- Ensuring correct handling and disposal of waste (including sharps) and laundry;
- Ensuring all medical devices (equipment) are decontaminated appropriately ie. cleaned, disinfected and/or sterilised;
- Ensuring compliance with High Impact Interventions.

Values:

The Belfast Trust aims to recruit staff not only with the right skills but also with the right values to ensure the delivery of excellent patient care and experience. Staff will be expected to be committed to provide safe, effective, compassionate and person centred care by:-

- Treating Everyone with Dignity and Respect
- Displaying Openness and Trust
- Being Accountable
- Being Leading Edge
- Maximising Learning and Development

By embedding the above values we will make a significant contribution to the delivery of the Trust's Vision.

Personal Public Involvement

Staff members are expected to involve patients, clients, carers and the wider community where relevant, in developing, planning and delivering our services in a meaningful and effective way, as part of the Trust's ongoing commitment to Personal Public Involvement (PPI).

Please use the link below to access the PPI standards leaflet for further information.

http://www.publichealth.hscni.net/sites/default/files/PPI_leaflet.pdf

Clause: ***This job description is not meant to be definitive and may be amended to meet the changing needs of the Belfast Health and Social Care Trust.***

Belfast Health and
Social Care Trust

caring supporting improving together

JOB SPECIFICATION

POST: Data Officer/MDT Co-ordinator **Band 4**

LOCATION: RVH, BCH and MPH

ESSENTIAL CRITERIA:

1. 4 GCSEs Grade C or above, to include English (excluding English Literature) and Mathematics or equivalent qualifications and 2 years' administrative experience

OR

HNC/HND or equivalent / higher qualification preferable in an administrative related field and 1 years experience in a clerical /administrative role

OR

Three years' administrative experience

AND

2. Working experience of the Patient Administrative System (PAS) and other Hospital Information Systems
3. Excellent communication skills both orally and in writing
4. Excellant keyboard skills and experience in the use of computerised systems/packages including Microsoft Excel.
5. Experience of medical Terminology or OCR stage 2 text processing (Part 1) and stage 2 word processing
6. Ability to work as part of a team

DESIRABLE CRITERIA

1. Experience of collecting data and running reports

VALUE BASED RECRUITMENT

* Values Based Recruitment is a process adopted by the Belfast Trust to attract and select employees on the basis that their individual values and behaviours align with those of the Trust and incorporating the Healthcare Leadership Model.

It focuses on the 'how' and 'why' people do what they do.

Candidates who are short-listed for interview will need to demonstrate at interview that they have the required knowledge, skills, competencies and values to be effective in this new role.

In answering the value based questions you have the opportunity to share examples of when you have demonstrated values relevant to the Belfast Trust.

Belfast HSC Trust Values

Whilst employees will be expected to portray all the values, particular attention is drawn to the following values for this role.

RESPECT & DIGNITY

- Being respectful to others
- Showing compassion to those who need our care
- Acting fairly and even-handed
- Acknowledging the good work of others
- Supporting others to achieve positive results

OPENNESS & TRUST

- Communicating openly and consistently
- Listening to the opinions of others and acting sensitively
- Being trustworthy & genuine
- Ensuring that appropriate information is shared honestly

ACCOUNTABILITY

- Taking responsibility for your own decisions and actions
- Openly admitting your mistakes and learning from them
- Using all available resources appropriately
- Challenging failures and poor practice courageously

LEADING EDGE

- Actively seeking out innovative practice
- Participate in new approaches & service development opportunities
- Share best practice with others
- Promote the Trust as a centre of excellence

MAXIMISING LEARNING & DEVELOPMENT

- Act as a role model for the development of others
- Continuing to challenge my own practice
- Fulfil my own statutory mandatory training requirements
- Actively support the development of others

PATHWAYS TO A CANCER DIAGNOSIS:

Monitoring variation in the patient journey across Northern Ireland 2012 – 2016

Technical Document

1. Introduction

This document provides a summary of the data sources and methodology used for the first ‘Pathways to Cancer Diagnosis in Northern Ireland’ project. Extracted data covers tumours diagnosed in 2009 to 2016.

The origin of Pathway to Cancer Diagnosis Analysis

The National Cancer Registration and Analysis Service (Public Health England) have produced an award winning Routes to Diagnosis study which defined a methodology to determine the route a patient took through the healthcare system before receiving a cancer diagnosis. It is from this that the Pathways to Cancer Diagnosis project in Northern Ireland has taken its lead.

Routes to diagnosis are an important and often modifiable prognostic indicator in cancer care. Patients who present as an emergency have poorer one year survival than those who present via the ‘red flag’ route or via screening.

Quantifying incidence by route or pathway to diagnosis data has potential to highlight variation across a range of different variables such as age, deprivation, health geography.

The ‘Pathways to Cancer Diagnosis in Northern Ireland’ project adapts the Public Health England methodology to provide the first analysis of this type for cancer patients in Northern Ireland.

2. Overview of the Routes to Diagnosis project

2.1 Project goals

The aim of this project is to produce, for the first time, measures on pathways to diagnoses in Northern Ireland for all cancers and by individual cancer site, as well as by Trust of residence, urban/rural and deprivation category. The diagnosis pathways used are those categorised by the National Cancer Registration and Analysis Service (Public Health England).

The study examines first whether it is feasible to apply the Public Health England Routes to Diagnosis methodology and algorithm to the Northern Ireland setting.

On the basis that this is feasible, for at least some years of data, the project looks to identify whether there is an association between pathways to diagnosis and survival for cancer patients. Also, do age, sex, deprivation, cancer stage and geographical area of residence on diagnosis have any influence on routes?

The study uses funnel plots to explore the variation in pathways to diagnosis in order to aid interpretation and identify areas for follow-up analysis and subsequent development of intervention strategies.

2.2 Technical overview

Data from the Northern Ireland Cancer Registry is combined with Patient Administration System data for Inpatient and Outpatient activity and Cancer Patient Pathway System data. Using these datasets cases of cancer registered in Northern Ireland diagnosed in 2009 to 2016 are categorised into one of 8 principle 'Routes to Diagnosis' as identified by the National Cancer Registration and Analysis Service (Public Health England) Routes to diagnosis study.

2.3 Policy Context

The project forms part of the Health Foundation's Applying Advanced Analytics Project.

The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK. Under its 'Applying Advanced Analytics Project', the charity is funding pilot projects, to be carried out from within the UK health-service, to build up analytical capacity to drive monitoring and improvement of service delivery.

The Pathways to Cancer project proposal was submitted by BSO in partnership with the Centre for Public Health in Queens's University of Belfast and was supported by the Northern Ireland Cancer Registry and the Director of Commissioning for the Health and Social Care Board.

3. Methods

The methodology used to produce the pathways to cancer diagnosis for Northern Ireland is detailed in the sections below.

The original algorithm which assigns a route to diagnosis was produced by the National Cancer Registration and Analysis Service (Public Health England). An overview of the original Routes to Diagnosis algorithm is set out within the PHE technical documentation.

> "The algorithm takes as a starting point the date of cancer diagnosis, as defined by the UK and Ireland Association of Cancer Registries (UKIACR) using European Network of Cancer Registries (ENCR) rules. Routine data immediately prior to this date are examined and a series of rules is used to classify the 'Route to Diagnosis' for each case. The routes are categorised in detail by 3 variables: the end-point, the pathway group, and the start-point. These detailed routes have been aggregated into 8 broader categories to facilitate analysis.
>
> It is important to note that patient records being used to describe the route to diagnosis may not have a cancer code assigned to them, as the episodes and attendances will have taken place before a cancer diagnosis has been coded. It is therefore not possible to be absolutely certain that the episodes and attendances related to the patient prior to diagnosis were directly related to the process of diagnosis of cancer. However, the frequency of hospital attendance and admission in the period immediately before diagnosis greatly exceeds the 'background' rate making the assumption that they are related to the cancer diagnosis reasonable."
>
> **Source: http://www.ncin.org.uk/publications/routes_to_diagnosis**

This PHE methodology has been followed as closely as possible to allow for potential comparisons of data across regions. However, a number of variations have been introduced in order to best fit Northern Ireland's different recording systems.

As with the PHE hospital data extracts, hospital information used to assign routes cannot be matched to cancer diagnoses from the NICR with absolute certainty as, having taken place before diagnosis, they may not have a cancer code assigned to them. As with the PHE project, the decision has been taken that the proximity of the hospital attendance or admission to the cancer diagnosis makes it reasonable to assume that they are related.

4. Data Sources

4.1 Northern Ireland Cancer Registry (NICR)

The NICR is a population based cancer registry collecting data on all malignant and certain non-malignant tumours diagnosed in Northern Ireland.

For this project, all cancer registrations across Northern Ireland between 2009 and 2016 inclusive, with ICD-10 diagnosis codes **C00–C97, D00-D09, D13, D15, D27, D29, D32, D33, D35** and **D37-D48** (all neoplasms) were extracted from the NICR.

A subset of this data for tumours with ICD-10 diagnosis codes **C00-C97** excluding **C44** which were diagnosed in calendar years 2009 to 2016 was used for reporting. A number of other exclusions were also made from the NICR extract following validations and based on experience of the PHE research. These are detailed below:

- all D codes with the exception of **D05, D06, D090, D32, D330-D332, D333, D334, D352-D354, D42, D430-D432, D433-D434, D437-D439** and **D443-D445** were excluded from the reporting dataset
- the records for patients with non-melanoma skin cancer
- records where the sex code and cancer site code are incompatible
- records with invalid ages
- duplicate records identified
- records with invalid ICD10 site codes

Routes were derived for all tumours fitting the criteria specified above. This includes incidences where more than one tumour is recorded in the same person.

4.2 Patient Administration System (PAS)

Patient Administration Systems are principally used to manage and record inpatient, day case and outpatient activity within Health and Social Care hospital sites in Northern Ireland.

4.2.1 Hospital Inpatient System (HIS)

The Hospital Inpatient System (HIS) is formed in the HSC Data Warehouse from PAS data and provides information on admitted patient care delivered by health and social care hospitals in Northern Ireland. It is a patient level administrative data source and each record relates to an individual consultant episode.

For the pathways to diagnosis project, an extract containing 2008/09 to 2015/16 records was used to identify patients from the NICR with a hospital admission for any cause during the six months prior to their cancer diagnosis.

4.2.2 Outpatient Universe

The Outpatient Universe is formed in the HSC Data Warehouse from PAS data and provides information on outpatient appointments at Health and Social Care (HSC) hospitals in Northern Ireland. It is a patient level administrative data source and each record relates to an appointment. This can include a change in appointment details.

For the pathways to diagnosis project an extract containing 2008/09 to 2015/16 records was used to identify patients from the NICR with an outpatient attendance for any reason during the six months prior to their cancer diagnosis.

4.3 Cancer Patient Pathway System (CaPPS)

The Cancer Patient Pathway System (CaPPS) is a bespoke data system used to administer cancer treatment services within Health and Social Care (HSC) Trusts in Northern Ireland. This dataset contains patient level information and is used to monitor and report on the number of patients treated for cancer following a decision to treat being taken.

For the pathways to diagnosis project an extract containing 2008/09 to 2015/16 records was used to identify patients from the NICR who received an urgent GP referral for suspect cancer.

5. Data Preparation

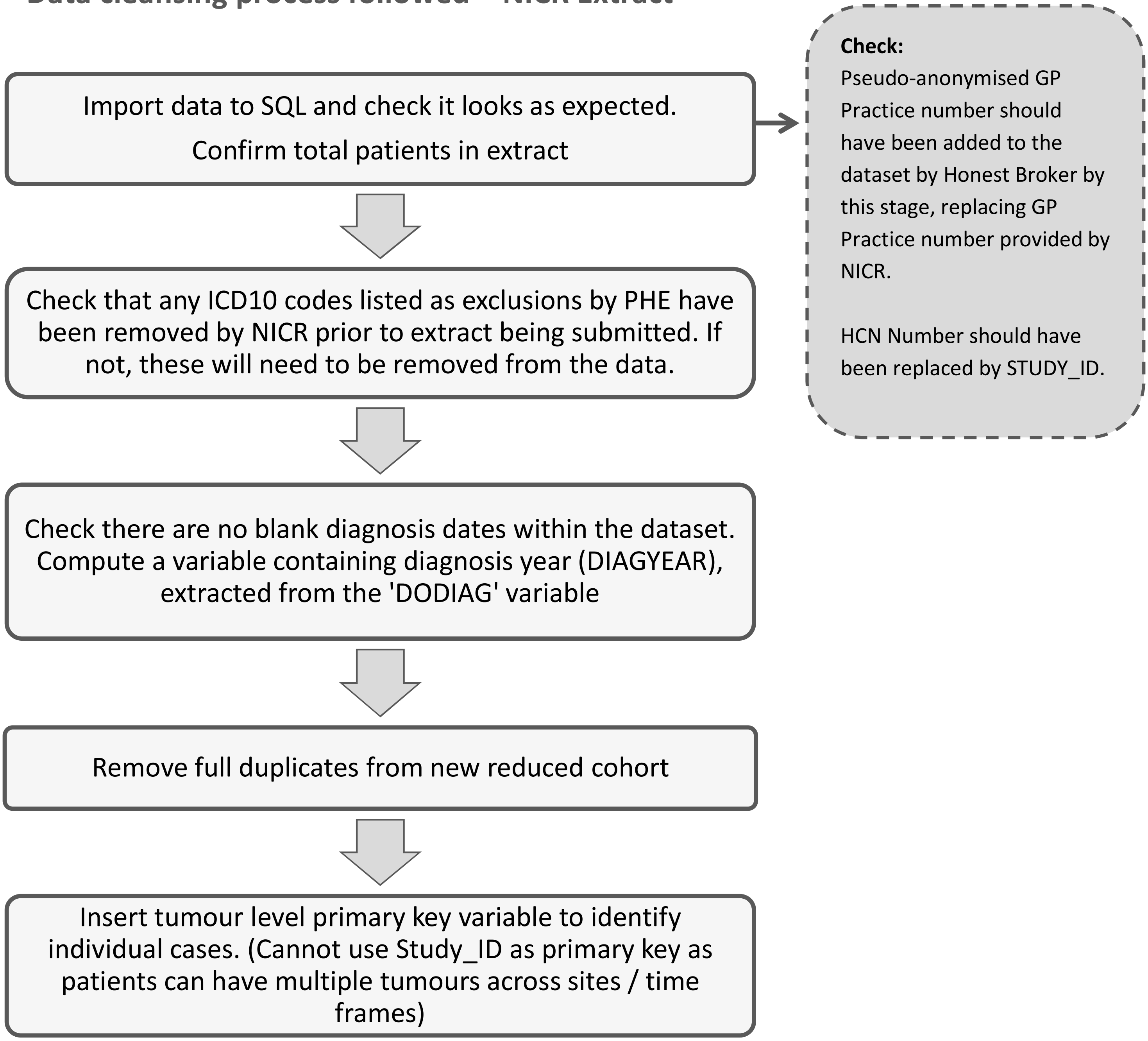
5.1 Northern Ireland Cancer Registry (NICR)

Variables requested from the Data Warehouse were as follows –

HCN – Health and Care Number, replaced by honest broker with **STUDY_ID**
SEX – Sex of patient
AGE – Age of patient
DEPRIV2010 – deprivation quintile, based on patient postcode (2010 values)
URBAN_RURAL – urban/rural indicator, based on patient postcode
LGD2014 – Local Government District, based on patient postcode
TRUST – HSC Trust of residence of the patient
GP_Practice – replaced by **GP_ANON**. Produced by Honest Broker, anonymised GP practice of the patient at time of diagnosis.
DODIAG – Date of diagnosis of tumour
SCREEN – Screen detected flag placed on data by cancer registry
BASIS – Clinical variable relating to tumour
SITE_ICD10 – Site of tumour with 4 character ICD10 code
SITECLASS – Aggregated tumour site grouping
MORPH – Clinical variable relating to tumour
GRADE – Clinical variable relating to tumour
STAGE – Clinical variable relating to tumour
DODEATH – Date of death of patient
CAUSED – Flag to identify patient cause of death (*Cancer / Other*) or if patient is alive (*Alive*)

The above information was extracted for all patients appearing on the Northern Ireland Cancer Registry between the years 2009 and 2016.

Data cleansing process followed – NICR Extract



Import data to SQL and check it looks as expected.

Confirm total patients in extract

Check:
Pseudo-anonymised GP Practice number should have been added to the dataset by Honest Broker by this stage, replacing GP Practice number provided by NICR.

HCN Number should have been replaced by STUDY_ID.

Check that any ICD10 codes listed as exclusions by PHE have been removed by NICR prior to extract being submitted. If not, these will need to be removed from the data.

Check there are no blank diagnosis dates within the dataset. Compute a variable containing diagnosis year (DIAGYEAR), extracted from the 'DODIAG' variable

Remove full duplicates from new reduced cohort

Insert tumour level primary key variable to identify individual cases. (Cannot use Study_ID as primary key as patients can have multiple tumours across sites / time frames)

Preparing the Northern Ireland Cancer Registry (NICR) extract

The NICR extract was submitted to the Honest Broker Service (HBS) where the data was anonymised with each HCN being replaced with a variable which will enable linkage across extracts (**STUDY_ID**) before being made available for use.

A variable was added to identify the year of diagnosis (**DIAG_YEAR**) for each tumour. The pathways have been calculated on individual years of data so this variable was used to filter the data accordingly.

The original data extract included some codes which had been excluded by the PHE and so had to be removed prior to analysis (list can be found in the NICR section above as well as in the SQL code). However in the updated extract these codes were removed by the NICR. It would be good practice in future to check that this have been done in any future extracts, for that reason this portion of code on has purposely been left in.

A check was completed to confirm there were no missing values against the date of diagnosis (any such cases would need removed) and that the number of cases across each year was broadly consistent.

All full duplicates were removed from the file. There were a small number of cases where the only difference was the marital status variable. Since this variable was not of interest it was removed and the remaining duplicate cases deleted. In future extracts there is no need to ask for marital status information and as such have removed it from the list of extract variables above.

Finally a primary key variable (**TUMOUR_ID**) was added for analysis.

The file has been saved as **'HONESTBROKER.E024.NICR_FINAL'**

5.2 Outpatient Universe

Variables requested from the Data Warehouse were as follows –

HCN – Health and Care Number, replaced by Honest Broker with **STUDY_ID**
Appointment_date – date and time of appointment
Attendance_code – denotes whether the appointment took place or not
Attendance_desc – descriptor variable for attendance code
Appointment_type_r – regional variable classifying appointment as first or review
Referral_code – local code identifying the source of the referral
Referral_desc – local descriptor variable for source of referral code
CMDS_value – closest matching value to the PHE referral source mapping

The above information was extracted for all patients appearing on the Northern Ireland Cancer Registry between the years 2009 and 2016. Outpatient appointments were obtained for the years 2008-2016 to enable identification of appointments attended during the 6 month period prior to cancer diagnosis.

Data cleansing process followed – Outpatient Extract

Import data to SQL and check it looks as expected.

Confirm total patients in extract

Remove any appointments which were not attendances.

Retain only **attendance code** - **A** (attendance), **W** (walk-in), **S** (seen - small number of occurrances, only used by Northern Trust)

This step will include removal of any appointments with **blank attendance codes**. Cannot determine whether these appointments were attended or not so decision taken to exclude from analysis.

Remove all dupilicates as specified in Outpatient data prep, from new reduced cohort. Where multiple appointments occur on the same day the earliest is retained. Where multiple appointments occur at exactly the same time, a randomly chosen appointment is retained

Save as final dataset.

Preparing the Outpatient data extract

The outpatient extract was submitted to the Honest Broker Service (HBS) where the data was anonymised with each HCN being replaced with a variable which will enable linkage across extracts (**STUDY_ID**) before being made available for use.

Unnecessary variables were removed, for the next extract we could exclude these from the DAA.

Only appointments that were actually attended were needed for analysis so I have removed any that were cancelled or missed. I also removed any appointments where the attendance code was blank. This left only appointments that were attended (A), seen (S) or walk-ins (W).

I have then looked at the new reduced cohort and carried out a validation of the referral source variable (CMDS Value) using the local descriptions. Any regional codes that looked to be incorrect I have recoded in line with their local code. I have also recoded all action cancer cases to be picked up as screen detected. This recoding will need done manually again with any new extracts.

Using the recoded referral information, I have checked the file for full duplicates and have removed any such cases.

There are a number of other types of duplicates that need to be identified and removed from the file. To help with identifying them I have created an extra variable which only has the date of the appointment and drops the time element (**APP_DATE_ONLY**). This variable will also be used later when calculating proximity of outpatient activity to cancer diagnosis in the NICR extract.

Where there appear to be multiple appointments attended on the same day at exactly the same time but with different referral sources I have selected a random one to retain.

Where a patient attended more than one appointment identical appointment on the same day I have retained the earliest appointment in the day.

Where a patient attended more than one appointment on the same day with different referral sources I have retained the earliest appointment in the day.

Where a patient attended more than one appointment on the same day with different referral sources and different attendances codes I have retained the earliest appointment in the day.

Where a patient attended more than one appointment on the same day at the same time but with different referral sources and different attendances codes I have randomly selected an appointment to retain.

The file has been saved as **'HONESTBROKER.E024.OUTPATIENT_FINAL_FILE'**

5.3 Inpatient Universe

Variables requested from the Data Warehouse were as follows –

HCN – Health and Care Number, replaced by honest broker with **STUDY_ID**
EPS_START_DATE – This field contains the episode start date (without time) on which a patient was under the continuous care of one consultant. For each new episode, which may be due to transfer to another consultant or hospital, there will be a new episode start date.
EPS_END_DATE - This field contains the episode end date (without time) on which a patient finished under the continuous care of one consultant. It may be that the patient was discharged, but also may be due to transfer to another consultant or hospital, for which there will be a new episode start date.
EPS_ORDER - This field contains the order of the episode within the hospital admission.
ADMIT_DATE - Date of admission with time of the first or only episode within a hospital stay. ADMIT_DATE is recorded on all episodes within a hospital admission.
ADMIT_METHOD_CODE - Method of Admission. This is recorded on the first and all subsequent episodes within the admission.

The above information was extracted for all patients appearing on the Northern Ireland Cancer Registry between the years 2009 and 2016. Inpatient admissions were obtained for the years 2008-2016 to enable identification of admissions occurring during the 6 month period prior to cancer diagnosis.

Data cleansing process followed – Inpatient Extract

Import data to SQL and check it looks as expected.

Confirm total patients in extract

Remove full duplicates from the cohort

Remove all dupilicates as specified in Inpatient data prep file, from new reduced cohort.

Save as final dataset. There will be instances where there are still multiple admissions for patients on the same day, the cases will be sorted by the algorithm based on the episode start/end dates.

Preparing the Inpatient data extract

The Inpatient extract was submitted to the Honest Broker Service (HBS) where the data was anonymised with each HCN being replaced with a variable which will enable linkage across extracts (**STUDY_ID**) before being made available for use.

All full duplicates were removed from the file.

Local codes for admission method had been requested in the original extract but they weren't needed for the analysis, regional coding was used which is more consistent and matches the categories used by PHE. Local codes were deleted and any duplicates that were created by doing this were then removed.

There were a number of cases where all information was identical apart from the admission method. In other words it looked as though the patient was admitted via two different methods at exactly the same date/time. In these cases only one record was retained and this was selected at random.

The file has been saved as **'HONESTBROKER.E024.INPATIENT_FINAL_FILE'**

5.4 Cancer Patient Pathway System (CaPPS)

Variables requested from the Data Warehouse were as follows –

HCN – Health and Care Number, replaced by honest broker with **STUDY_ID**
DATEDECISIONTOTREAT – Date of decision to treat
TUMOURSITE – Suspected tumour site code contained in the referral
TUMOURSITE_DESC – Suspected tumour site description contained in the referral
CONFIRMED TUMOUR_SITE – Confirmed tumour site (may differ from suspect)
PRIMARY_REF_TYPE_DESC - Description for the primary referral type, grouped into regional categories

The above information was extracted for all patients appearing on the Northern Ireland Cancer Registry between the years 2009 and 2016. CaPPS records were obtained for the years 2008-2016.

Data cleansing process followed – CaPPS Extract

Import data to SQL and check it looks as expected.
Confirm total patients in extract

Remove full duplicates from the cohort

Remove all dupilicates as specified in CaPPS data prep file, from new reduced cohort.

Save as final dataset. This can be filtered by the type of referral - GP red flag / consultant upgrade / other

Preparing the CaPPS data extract

The CaPPS extract was submitted to the Honest Broker Service (HBS) where the data was anonymised with each HCN being replaced with a variable which will enable linkage across extracts (**STUDY_ID**) before being made available for use.

Any unnecessary variables were removed, for future extract these should be excluded from the DAA.

All full duplicates within the extract were removed to leave only single instances of each.

Where there is only a difference in tumour site these duplicates were removed to leave only one instance. The tumour site is not used for the linkage so a random case has been retained.

The file has been saved as **‘HONESTBROKER.E024.CAPPS_FINAL3’**

6. Calculating the Pathways to Cancer

6.1 Data Matching

All records have been allocated a STUDY_ID by the Honest Broker Service to enable linkage to take place. This anonymised ‘STUDY_ID’ variable was added to all datasets based on the HCN from the original extracts. HCN details have been removed prior to their release by the Honest Broker Service.

Records from the NICR, Inpatient and Outpatient datasets have been matched based on STUDY_ID and their proximity to each other.

Records from NICR and CaPPS have been matched on STUDY_ID. Only CaPPS records with a valid decision to treat date have been matched; where the date of diagnosis lies between 62 days before and 31 days after the decision to treat date.

6.2 Producing the Pathway to Diagnosis

The Pathways to Diagnosis algorithm has been constructed to replicate, as closely as possible, the methodology of the PHE Routes to Diagnosis algorithm. The algorithm assigns a three part code to each tumour within the NICR based on available inpatient and outpatient hospital data. The three part codes are then mapped into broad categories for analysis purposes. Finally, the presence of screening or CaPPS information is checked for. This data will take precedence over assigned route.

Calculating the end point of the pathway to cancer diagnosis

End points have been identified for each tumour based on the proximity of the patient’s inpatient and outpatient hospital interactions to the date of diagnosis. The end point is assumed to be the clinical care event that led most immediately to diagnosis. The following rules have been applied, in line with Public Health England.

- Where both inpatient and outpatient activity occurred on the date of diagnosis the inpatient episode was defined as the end-point of the route.
- Otherwise, if there was an episode within 28 days prior to the date of diagnosis then this was assigned as the end-point of the route, with inpatient episodes taking precedence over outpatient episodes and the most recent episode taking precedence if there were multiple episodes.
- If there was no hospital activity within 28 days of diagnosis then the most recent episode within 6 months (inpatient or outpatient) was used as the end-point of the route.

Based on these rules, the one of five end-point codes were assigned:

Special cases (SC) – patients with a cancer diagnosis date on the same day as an inpatient admission date and an outpatient attendance date, or whose closest hospital interactions to diagnosis are an inpatient and outpatient record occurring on the same date. These are a special case of inpatient diagnosis.

Inpatient diagnosis (IP) – patients with a cancer diagnosis date related to a preceding inpatient episode (excluding patients already defined as special cases). An inpatient diagnosis is defined where the cancer diagnosis date is within the start and end of an episode. In addition, due to the potential for diagnosis to be confirmed following a relevant inpatient episode, a cancer diagnosis date that is within 6 months after the end of an episode and with no outpatient activity between would also be regarded as an inpatient diagnosis.

Outpatient diagnosis (OP) – patients with no inpatient episodes preceding the cancer diagnosis date (as defined above) but with an outpatient attendance preceding the cancer diagnosis date or with an inpatient elective admission, or were emergencies via an outpatient clinic, or were unresolved inpatient transfers.

Unknown (UN) – Unable to match cancer diagnosis date to any informative inpatient episodes or outpatient attendances within the valid timeframe. It is likely that, for these patients, the cancer diagnosis date was obtained from pathology records only, indicating diagnosis or treatment that only took place outside of a hospital setting (eg NHS patients seen in primary care, independent treatment centres or a community setting, and private patients seen and treated only in private hospitals).

Death Certificate Only diagnosis (DCO) - The cancer registry receives a small number of cancer related death notifications, for which they are unable to obtain additional information to register the disease details fully. This registration is regarded as Death Certificate Only (DCO) and the date of diagnosis is the same as that of the date of death.

Calculating the start point of the pathway to cancer diagnosis

The start point has been calculated by working backwards from the end point of each pathway. The start-points have been categorised based on the following rules, in line with Public Health England.

- Routes that originated in an outpatient attendance use the outpatient source of referral of that attendance as the ‘start-point’ code.
- Routes that originated in an inpatient episode use the inpatient method of admission as the ‘start-point’ code.
- Routes where inpatient or outpatient data were unavailable the start-point codes may be assigned as null or unknown (this also includes DCOs).

The start point will determine the initial source of the pathway – ie the outpatient referral source or inpatient admission method of the initial appointment. A breakdown of all possible start codes is provided in the following table.

Available inpatient admission methods
Not known (0, 99)
Elective – Waiting List (11)
Elective – Booked (12)
Elective – Planned (13)
Emergency – A&E Department in the same Board (21)
Emergency – General Practitioner (22)
Emergency – Bed Bureau / Central Bed Bureau (23)
Emergency – Consultant Outpatient Clinic (24)
Emergency – Domiciliary Visit by Consultant (25)
Emergency – Other means (28)
Maternity – Ante Partum (31)
Maternity – Post Partum (32)
Other – Patients from another hospital (81)
Other – Babies born in the hospital (82)
Other – Baby born outside the provider (83)

Available outpatient referral sources
Initiated by consultant responsible for the appointment
Consultant – Following emergency admission (1)
Consultant – Following a domiciliary visit (2)
Consultant - Following A&E Attendance (10)
Consultant – Other (11)
Not initiated by consultant responsible for the appointment
Referral from General Practitioner (GP) (3)
From an A&E Department (4)
From consultant other than in A&E Department (5)
Self-referral (6)
Referral from prosthetist (7)
Referral from GP with special interest (12)
Referral from Specialist Nurse (13)
Referral from allied health professional (14)
Referral from optometrist (15)
Referral from orthoptist (16)
Referral from a national screening programme (17)
Referral from general dental practitioner (92)
Referral from community dental service (93)
Other source of referral (8)
Other (97)
Not known (99)

Pathway grouping of the cancer diagnosis

Each tumour has been assigned one of the following pathway group codes based on the available inpatient and outpatient data.

Pathway Group	Description
A	Inpatient hospital interaction only within 6 months prior to diagnosis
B	Outpatient hospital interaction only within 6 months prior to diagnosis
C	Special case, an inpatient elective or Emergency via outpatient clinic, and there is outpatient interaction within 6 months prior to diagnosis
D	There are no hospital data 6 months prior to diagnosis
E	No hospital data at all prior to diagnosis

Assigning the final route and category for each cancer diagnosis

For each record in the Northern Ireland Cancer Registry, the route end-point, the pathway group and the route start-point are concatenated to produce a final route code. These codes are then aggregated up into eight broad categories. These categories have been classified in line with PHE Routes to Diagnosis. Detail on the categories and how they are mapped is included below.

GP Referral: includes routine and urgent referrals where the patient was not flagged as a suspect cancer referral

Urgent GP Red Flag Referral: urgent GP referrals with a suspicion of cancer (Reported as ‘Two Week Wait’ by

Emergency Presentation: an emergency route via A&E, emergency GP referral, emergency transfer, emergency admission or attendance

Other Outpatient: an elective route starting with an outpatient appointment that is either a self-referral, consultant to consultant referral, other or unknown referral (these referrals would not include patients originally referred under the Two Week Wait referral route)

Screen Detected: flagged by the cancer registry as detected via the breast or cervical screening programmes

Inpatient Elective: where no earlier information can be found prior to admission from a waiting list, booked or planned

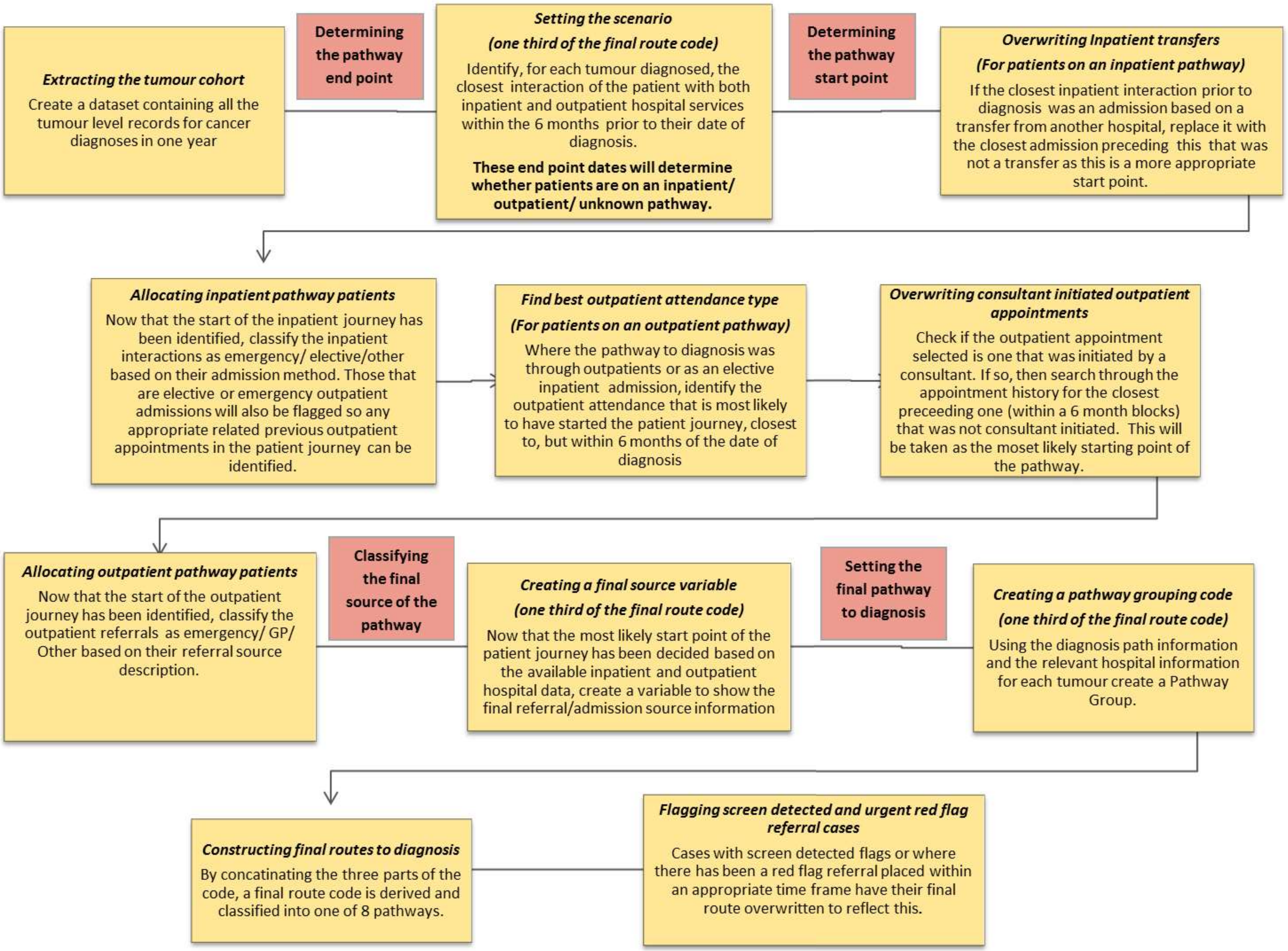
DCO: diagnosis by death certificate only

Unknown: no relevant data available from hospital inpatient or outpatient records, CaPPS or screening information on the Cancer Registry.

Final Route to Category Mapping

No.	Route code	Route group	No.	Route code	Route group
1	DC-D-DCO	DCO	43	OP-B-O3	GP referral
2	DC-E-DCO	DCO	44	OP-B-O4	Emergency presentation
3	IP-A-I0	Unknown	45	OP-B-O5	Other outpatient
4	IP-A-I11	Inpatient Elective	46	OP-B-O6	Other outpatient
5	IP-A-I12	Inpatient Elective	47	OP-B-O7	Other outpatient
6	IP-A-I13	Inpatient Elective	48	OP-B-O8	Other outpatient
7	IP-A-I21	Emergency presentation	49	OP-B-O10	Emergency presentation
8	IP-A-I22	Emergency presentation	50	OP-B-O11	Other outpatient
9	IP-A-I23	Emergency presentation	51	OP-B-O12	GP referral
10	IP-A-I24	Emergency presentation	52	OP-B-O13	Other outpatient
11	IP-A-I25	Emergency presentation	53	OP-B-O14	Other outpatient
12	IP-A-I28	Emergency	54	OP-B-O15	Other outpatient

		presentation			
13	IP-A-I31	Inpatient Elective	**55**	OP-B-O16	Other outpatient
14	IP-A-I32	Inpatient Elective	**56**	OP-B-O17	Screening
15	IP-A-I81	Inpatient Elective	**57**	OP-B-O92	Other outpatient
16	IP-A-I82	Inpatient Elective	**58**	OP-B-O93	Other outpatient
17	IP-A-I83	Inpatient Elective	**59**	OP-B-O97	Other outpatient
18	IP-A-I99	Unknown	**60**	OP-B-O99	Unknown
19	IP-C-O0	Unknown	**61**	SC-C-null	Unknown
20	IP-C-O1	Emergency presentation	**62**	SC-C-O1	Emergency presentation
21	IP-C-O2	Other outpatient	**63**	SC-C-O2	Other outpatient
22	IP-C-O3	GP referral	**64**	SC-C-O3	GP referral
23	IP-C-O4	Emergency presentation	**65**	SC-C-O4	Emergency presentation
24	IP-C-O5	Other outpatient	**66**	SC-C-O5	Other outpatient
25	IP-C-O6	Other outpatient	**67**	SC-C-O6	Other outpatient
26	IP-C-O7	Other outpatient	**68**	SC-C-O7	Other outpatient
27	IP-C-O8	Other outpatient	**69**	SC-C-O8	Other outpatient
28	IP-C-O10	Emergency presentation	**70**	SC-C-O10	Emergency presentation
29	IP-C-O11	Other outpatient	**71**	SC-C-O11	Other outpatient
30	IP-C-O12	GP referral	**72**	SC-C-O12	GP referral
31	IP-C-O13	Other outpatient	**73**	SC-C-O13	Other outpatient
32	IP-C-O14	Other outpatient	**74**	SC-C-O14	Other outpatient
33	IP-C-O15	Other outpatient	**75**	SC-C-O15	Other outpatient
34	IP-C-O16	Other outpatient	**76**	SC-C-O16	Other outpatient
35	IP-C-O17	Screening	**77**	SC-C-O17	Screening
36	IP-C-O92	Other outpatient	**78**	SC-C-O92	Other outpatient
37	IP-C-O93	Other outpatient	**79**	SC-C-O93	Other outpatient
38	IP-C-O97	Other outpatient	**80**	SC-C-O97	Other outpatient
39	OP-B-null	Unknown	**81**	SC-C-O99	Unknown
40	OP-B-O0	Unknown	**82**	UN-D-UNK	Unknown
41	OP-B-O1	Emergency Presentation	**83**	UN-E-UNK	Unknown
42	OP-B-O2	Other outpatient			



Extracting the tumour cohort

Create a dataset containing all the tumour level records for cancer diagnoses in one year

Determining the pathway end point

Setting the scenario

(one third of the final route code)

Identify, for each tumour diagnosed, the closest interaction of the patient with both inpatient and outpatient hospital services within the 6 months prior to their date of diagnosis.

These end point dates will determine whether patients are on an inpatient/ outpatient/ unknown pathway.

Determining the pathway start point

Overwriting Inpatient transfers

(For patients on an inpatient pathway)

If the closest inpatient interaction prior to diagnosis was an admission based on a transfer from another hospital, replace it with the closest admission preceding this that was not a transfer as this is a more appropriate start point.

Allocating inpatient pathway patients

Now that the start of the inpatient journey has been identified, classify the inpatient interactions as emergency/ elective/other based on their admission method. Those that are elective or emergency outpatient admissions will also be flagged so any appropriate related previous outpatient appointments in the patient journey can be identified.

Find best outpatient attendance type

(For patients on an outpatient pathway)

Where the pathway to diagnosis was through outpatients or as an elective inpatient admission, identify the outpatient attendance that is most likely to have started the patient journey, closest to, but within 6 months of the date of diagnosis

Overwriting consultant initiated outpatient appointments

Check if the outpatient appointment selected is one that was initiated by a consultant. If so, then search through the appointment history for the closest preceeding one (within a 6 month blocks) that was not consultant initiated. This will be taken as the moset likely starting point of the pathway.

Allocating outpatient pathway patients

Now that the start of the outpatient journey has been identified, classify the outpatient referrals as emergency/ GP/ Other based on their referral source description.

Classifying the final source of the pathway

Creating a final source variable

(one third of the final route code)

Now that the most likely start point of the patient journey has been decided based on the available inpatient and outpatient hospital data, create a variable to show the final referral/admission source information

Setting the final pathway to diagnosis

Creating a pathway grouping code

(one third of the final route code)

Using the diagnosis path information and the relevant hospital information for each tumour create a Pathway Group.

Constructing final routes to diagnosis

By concatinating the three parts of the code, a final route code is derived and classified into one of 8 pathways.

Flagging screen detected and urgent red flag referral cases

Cases with screen detected flags or where there has been a red flag referral placed within an appropriate time frame have their final route overwritten to reflect this.

Running the Pathways to diagnosis SQL Code

There are 13 files to be run to produce the pathway to diagnosis for each of the tumour level records. Each of these process files will need to be run separately for each applicable year of diagnosis

All the files are stored and numbered in the **Project 024** folder in the subfolder called **'Jen Algorithm Replication'.**

1. Extract Tumour Cohort from NICR dataset

(You need to update the selected year in this section)
This section of code extracts the cohort and variables from the pre-prepared NICR dataset that are required for determining the pathway to diagnosis. These variables are saved into a new table which matches the PHE structure and this can then be updated to produce the finalised Pathways dataset.

2. Set Scenario

(You don't need to update any code in this section)
This file calculates the 'Route Scenario' for each record in the file. The Route Scenario is the end point for each patient that is the final contact point of the patient before they are diagnosed with cancer (based on the NICR date of diagnosis). This will form one third of the final route code.
There are a number of additional variables that will be used for the calculation; these are created in the first section. Once this has been done the code takes the Outpatient and Inpatient extracts and joins them to each tumour record in the NICR based on the STUDY_ID. Next the code selects the dates of the hospital inpatient and outpatient interactions which happened closest in time to the date of diagnosis of each record in the NICR extract. We only check within 180 days prior to the diagnosis date, anything outside this timeframe is not assumed to be connected.

The number of days between the closest Outpatient appointment and Inpatient admission for each tumour diagnosis is calculated. This information is then used to determine the route scenario number. The route scenarios are then aggregated into five different end point categories according to the rules detailed above – Inpatient, Outpatient, Special Case, Death Certificate and Unknown.

3. Inpatient Transfer Overwrite

(You don’t need to update any code in this section)

This file identifies instances where the closest Inpatient admission has an admission method of '81' meaning they were a transfer from another hospital. For these cases we want to look back to the inpatient admission that was closest before this that was not a transfer. In other words we want to try and identify the start point of the patient entering hospital. This change is only needed for patients who have been assigned to an inpatient pathway in the previous section.

There are a number of additional variables that will be used for the calculation; these are created in the first section. Once added, the code then places a flag against all cases where the admission method is ‘81’ and the diagnosis path is classified as inpatient (‘IP’).

For this subset only, the code now identifies the closest admission prior to the one flagged that has an admission method other than ‘81’ (i.e. not a transfer from another hospital). We only check within 180 days prior to the flagged date, anything outside this timeframe is not assumed to be connected. As a patient can have multiple admissions within the six month time period, the code uses the rank function order by clause to sure identify the closest. If there are two admissions on the same day episode end date then episode order are used to rank them.

The relevant information relating to these newly selected admissions is populated into the ‘IP_PreTransfer_Admimeth’,’ IP_PreTransfer_Epistart’ and ‘IP_Elective_Admidate’ variables.

Next this section of code assigns a ‘final’ admission method to each of the cases on the inpatient diagnosis pathway. For the cases above where we identified a non-transfer admission, that admission method is used. Otherwise, the original method is used. There will likely be some of the ‘81’ cases where we weren’t able to override the admission with a more appropriate earlier one, in these cases the ‘81’ is retained.

Finally, the final admission date information is updated for the cases where we now have a different admission to the one originally identified.

We have now identified he start point for all the inpatient pathway cases.

4. Allocate Inpatient Records

(You don’t need to update any code in this section)

Now that we have identified a final admission method for all patients on the inpatient diagnosis pathway, this section of code buckets all the cases into ‘emergency’, ‘elective’ or ‘other’ categories.

Each group is populated based on the final admission method codes. There is some divergence from the PHE code here. For **emergency inpatients** codes 2A 2B 2C 2D have been removed as they don’t exist in NI, all of these methods are included under code 28 instead. Also, code 25 (emergency admission following domiciliary visit by consultant) has been included; this doesn't appear in the English HES codes.

Where the inpatient method was non-elective then we need to remove the ‘IP_Elective_Admidate’ information. The next section of the code performs this step. Admission method code '24' needs to have the ‘IP_Elective_Admidate’ retained; this is an emergency code but is for outpatients so different to the other emergency categories.

Where an inpatient admission was elective (or via and emergency outpatient referral) we will go on to look for preceding outpatient appointments. For this reason these cases are now flagged so they can be identified easily.

Elective inpatients are now identified and flagged, including the emergency outpatients as well as the transfers that we were unable to overwrite before.

Finally, all remaining cases falling into the ‘other’ category are flagged. Again there is some divergence from PHE. Codes 84 and 89 which were in the PHE code have been removed as they don’t apply in NI; these are included under 0 which has been included here instead. These codes are all used to classify 'Unknown' admission method.

5. Find Best Outpatient Attendance Type

(You don’t need to update any code in this section)

Having dealt with those patients on the Inpatient pathway this section is addresses the outpatient initiated cases. This will be those bucketed into the ‘OP’ or ‘SC’ categories of those flagged as elective inpatients in the previous section. The code is used to find the most appropriate outpatient appointment prior to the date of diagnosis (i.e. the one most likely to have initiated the pathway to diagnosis).

There are a number of variables used by this section of code which must be set to null, also the ‘OP_Step_Flag’ must be set to 1 to identify the subset being examined.

It is important to note that some of the emergency outpatient cases were flagged for this in the previous section so it is important not to clear this flag or they will be dropped from the subset.

The code splits the outpatient appointments into first, review and unknown and examines each of these groups in relation to every tumour to find the closest in time to date of diagnosis, within a six month period. The appointments are placed in separate tables.

When selecting final appointments for the NICR extract preference is ranked in the following order; first appointments, then review and finally unknown (our dataset currently has no unknown cases). The appointment details are inserted into the appropriate columns in the main table and the temporary tables dropped as they are no longer required.

6. Outpatient Consultant Overwrite

(You don’t need to update any code in this section)

This section is used to flag outpatient appointments where the appointment identified as the start point closest to the date of diagnosis was initiated by a consultant. For these appointments we will look to see if there is an earlier more appropriate one that wasn't initiated by a consultant.

There are a number of additional variables that will be used for the calculation; these are created and populated as either 0 or null in the first section. Once this has been done the code flags all the selected outpatient appointments where the referral source is consultant initiated.

7. Outpatient Consultant Overwrite

(You don’t need to update any code in this section)

Now that the consultant initiated outpatient appointments have been flagged, this section of code is used to overwrite these, where possible, with the closest non-consultant initiated appointment that preceded it (again within a six month time frame). As before, the appointments are split into type and ranked with first being preferable, followed by review and unknown last.

The cases that are selected for the Outpatient Consultant Overwrite have specific referral source codes and cases are only selected where the outpatient appointment has not been initiated by the consultant responsible for the appointment.

In Northern Ireland we have noticed that there are a number of cases with a final Outpatient Route-to-Diagnosis who have a referral Source of 11.

This equates to “Initiated by consultant responsible for the appointment – Consultant – Other (11)”.

These cases are not selected as part of the consultant overwrite and maintain their “outpatient” route-to-diagnosis status.

The code has been written deliberately this way by PHE however this could be investigated to see if the same rationale in terms of coding applies in Northern Ireland.

Examination of a sample of these cases does show that earlier GP Referrals were present for a number of cases so altering the code to include these cases in the consultant overwrite could potentially lead to a decrease in the outpatient routes and an increase in GP Referrals.

However before making this amendment consultation with PAS Systems managers and clinicians would be required to assess the type of cases that are being assigned this referral source in the outpatient universe.

Finally, the PHE code preforms a looping process to keep looking back in 6 month blocks, at present this has not been automated for NI but was done on a manual basis. There are small numbers of cases involved. Further development is required to introduce a loop to the NI analysis.

8. Allocate Outpatient Records

(You don't need to update any code in this section)

This section of code is used to 'bucket' the final selection of outpatient appointments based on their referral source. Appointments are classified into three groups – 'GP referral', 'Emergency referral' and 'Other source of referral'. This information is not necessary for the pathway definition but is a useful extra insight into the data.

9. Consultant HES Related Route Code

(You need to update the year in the section used to code pathway group 'B')

This portion of code is used to construct the pathway grouping of the route to diagnosis and the final referral source. These are the other two thirds of the