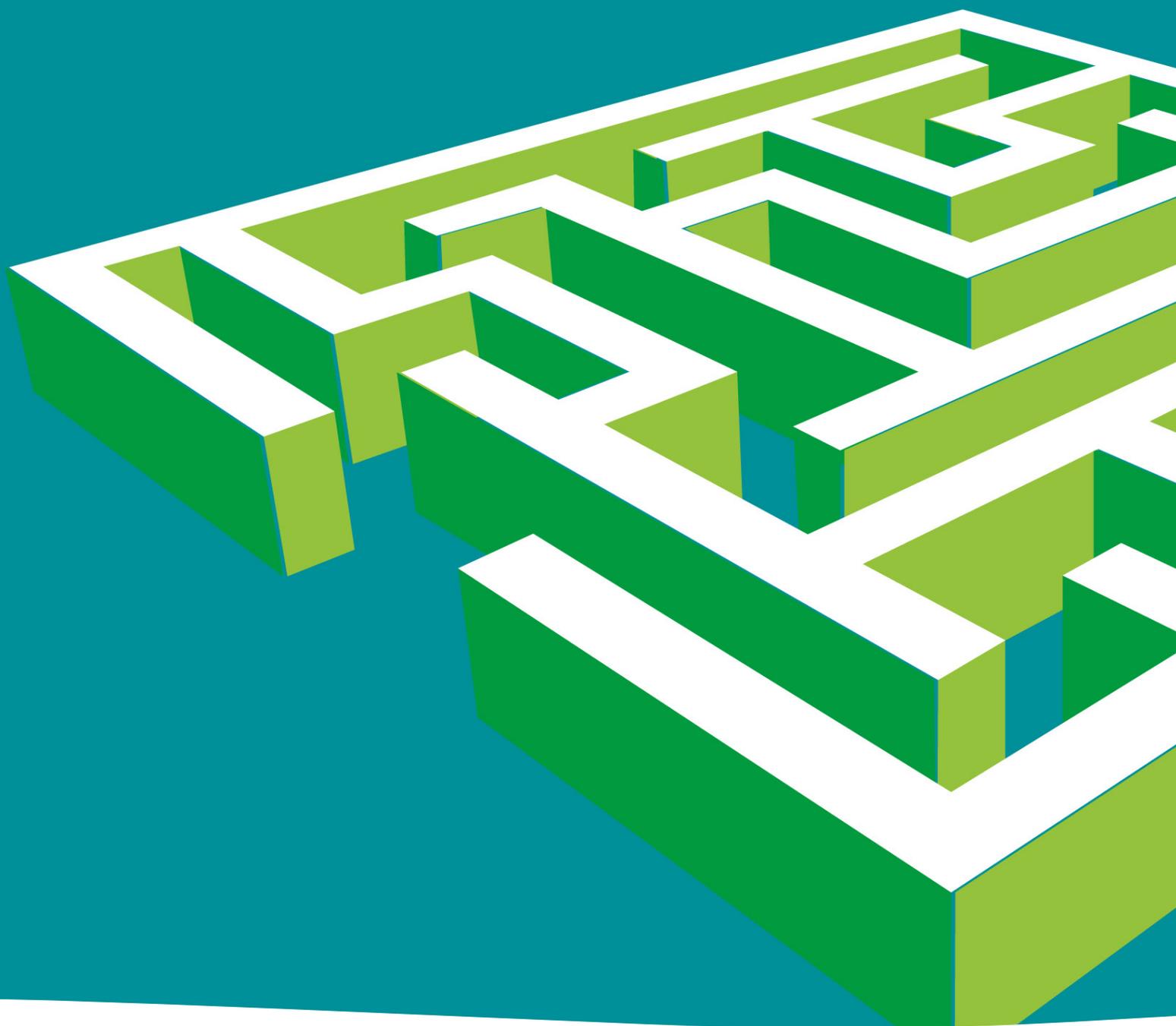


CAUGHT IN THE MAZE



Delivering personalised, integrated
care for people with cancer

MACMILLAN
CANCER SUPPORT

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Foreword

Steven McIntosh, Executive Director of Advocacy & Communications



We are at a crossroads for cancer care. After a year of devastating disruption to diagnosis and treatment caused by the Covid-19 pandemic, no one can be under any illusion about the scale of the challenge cancer services face to get back on track and ensure everyone has access to timely care. Our incredible workforce is exhausted and over-stretched.

Resources are depleted. At risk too, is the progress health systems across the UK have made in recent years with ambitious plans to deliver personalised care for everyone living with cancer. Despite the best efforts of the workforce, Covid-19 risks having a long-lasting and traumatic impact on patients' experience of cancer care. We need to do whatever it takes to address this.

But whilst Covid-19 has brought delays, disruptions and immense challenge, system leaders and people living with cancer have also told us about the opportunities that have emerged. Deep-rooted structural barriers to collaboration between health and social care organisations dissolved overnight. The drive and determination of health and care professionals to work together to support people with cancer through this difficult time has been awe-inspiring. We have seen tests and treatment carried out in community settings, challenging the concept that cancer always needs to be managed in specialist acute centres.

Despite this progress, Macmillan's new research reveals that the care people with cancer receive is not always seamless. People are still 'caught in the maze' – whether that's being left in the dark about their care plan, stuck between different teams and hospitals waiting for appointments or scans, or feeling like they are on a 'cliff edge' after their treatment ends. We are grateful for the many examples of professionals and services delivering incredible workarounds to join up care. They now need support to enable this to be the norm.

We cannot wind the clock back to before the pandemic. Instead, we should be embracing the best of the innovation and collaboration that the response to Covid-19 provoked. This is a timely moment to 'reset' cancer services in all parts of the UK, and take the opportunity to review how the services which people with cancer need, not just in hospitals but in all parts of the system, work together to deliver personalised care for people with cancer. That includes primary care, social care, mental health and end of life care: all vital parts of the 'cancer jigsaw'. We need to think bold and look at the way funding flows to cancer alliances and within systems, how service providers are incentivised to deliver personalised cancer care and at the workforce models which underpin this 'whole systems' approach.

As discussions accelerate about the role of integrated care systems in England and new cancer plans and strategies in Scotland, Wales and Northern Ireland take shape, now is the moment to act to make personalised care the heart of every ambition for people living with cancer.

Introduction

The term ‘integration’ has become a buzzword in health and care services and is often used interchangeably with partnership working and/or to reference care that is well-managed. Integration in cancer is particularly complex because care is often provided across multiple settings: acute, primary, community and social care – and people experience a range of physical, emotional and practical needs as a result of having cancer, which vary over time. This report takes stock of how far the UK’s health and care services still need to go on integration for high-quality, personalised cancer care to be a reality for everyone.

Our health and care services have a mixed record on delivering integration in cancer care. There is much to celebrate. Most people with cancer rate their overall care highly, and in many areas they are more likely to feel well-supported than people with other conditions¹.

Personalised care, meaning **“care which is designed in collaboration with the person who needs it, or with someone who knows them well, so that it is tailored to meet individual needs”**², now plays a prominent role in the UK nations’ cancer plans and strategies, bringing much-needed resources.

However, too many people are still diagnosed with cancer late and experience long waits to start treatment. More people are surviving or living longer with cancer, but many experience long-term physical and mental health effects. People from more deprived areas and BAME communities have worse experiences and outcomes from cancer services³. Major gaps in the cancer workforce limit people’s access to personalised support⁴.

The Covid-19 pandemic has shone a spotlight on many of these issues. Macmillan estimates that 50,000 people in the UK are missing a cancer diagnosis due to disruptions caused by coronavirus, with many people being too scared to seek help for symptoms from their GP⁵. In addition, delayed tests and treatment have significantly affected thousands of people’s emotional and physical health. Poor communication with patients during

the first wave left many anxious about whether they could safely access services.

At the same time Covid-19 is forcing a fundamental re-evaluation of the way that services for people with cancer are provided. Responding to the crisis has brought organisations together and driven improvements in team collaboration, reducing bureaucracy and duplication. It has also shown how care can be delivered in the community through diagnostic hubs and mobile units outside hospital settings⁶. Technology has enabled services to join up in a way that system leaders have long been attempting – for example, primary to secondary care digital interfaces have accelerated the urgent referral process.

The mammoth task now facing cancer services, to restore activity to pre-pandemic levels and eliminate the backlog of people waiting for tests and treatment, raises questions about their capacity to deliver personalised care. As this report highlights, experiences of cancer services are far from seamless. People are caught in the maze of health and care services. They are still falling into the cracks between primary and secondary care, information is not always tailored to individual needs, and support for wider needs, including mental health, is patchy and often delayed. Cancer professionals and the wider workforce are working flat out to support people with cancer, but with the system geared towards rapid measurement of diagnosis and treatment, personalised care is too often an ‘add-on’. Macmillan believes it is time for a rethink⁷.

The strengthening of integration through proposed legislation on Integrated Care Systems (ICSs) in England, a new cancer plan for Scotland and new cancer initiatives on the horizon in Northern Ireland and Wales create a window of opportunity to do this.

Our research highlights that there is more work needed to join up the UK's health and care services to meet the personalised care needs of people with cancer. Addressing these issues requires a national and local system-wide approach. There are clear recommendations for each government in the UK, local system leaders and wider stakeholders:

Recommendations

1. **All UK governments should urgently review the funding, commissioning and targets for cancer services in the light of Covid-19 to ensure that the UK's health and care services are, equipped and committed to delivering personalised, integrated cancer care.** Our research identifies major issues when people leave hospital, and gaps in information and support, particularly during transition points between services. Tackling the backlog from Covid-19 and meeting ongoing demand requires personalised care to be central to each nation's approach, accompanied by dedicated resources.
2. **NHS England and Improvement should ensure that system level reforms (the creation of ICSs) around integration align with cancer alliances and providers to create a whole-systems approach for cancer.** All nations should use opportunities on the horizon to assess how integrated its health and care services are, and use learning from across the UK to ensure cancer care is well-integrated in local systems.
3. **The NHS in each nation should ensure that everyone can access navigation to support them through their cancer journey.** Our research highlights the importance of a 'navigator' role to give people with cancer more control, refer and signpost to support.
4. **Governments and healthcare leaders must deliver on their commitments around personalised cancer care and allocate the resources systems need to implement these.** More work is needed at a local system level to make sure personalised care and support planning (PCSP) is routinely provided and monitored for impact on people's experiences and outcomes.
5. **All national governments should have a fully costed workforce strategy enabling cancer teams to deliver personalised care for everyone with cancer.** This needs to address shortages in many parts of the workforce, including clinical nurse specialists (CNSs), radiologists, GPs and Allied Health Professionals (AHPs) as well as skill sharing with the wider health and care workforce.
6. **Training bodies and cancer stakeholders in each UK nation should take a 'whole systems approach' to the wider cancer workforce.** Greater engagement with and learning from other long-term conditions is needed along with the removal of professional silos and expanding cancer teams to include staff in mental health, end of life and social care.
7. **Cancer organisations and the wider system should ensure that the experiences of people living with cancer shape pathways and service redesign.** There is growing evidence about people's experiences of cancer services across the UK. Locally and in each nation services should learn from people's experiences and include people with cancer consistently as partners in the delivery of personalised, integrated care.

Personalised integrated care and cancer

What does good, integrated care look like for people with cancer?

Because integration in cancer services and structures is complex and multi-dimensional, we use a definition of integration that stresses the impact on the individual.⁸

“I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.”

The term ‘cancer services’, used in the report, covers the whole range of support that people with cancer need to access from diagnostics, all forms of treatment and follow-up care provided by specialists, primary and community care teams, the voluntary sector and social care (see Figure 1).

The findings of this report reflect a comprehensive literature review and interviews with 25 system leaders and people with cancer across the UK between March and May 2020. All the people with cancer interviewed had received a cancer diagnosis in the last six years. Finally, we received additional insight from six system leaders in November 2020 to consider if and how Covid-19 had affected integration in cancer care.

Integration is a term which often refers to the ‘architecture’ of health and care systems. In this report we have taken a broad approach to integration to include the elements of care and service provision that directly affect whether people experience care that is ‘joined up’⁹ – reflecting what really matters to them. Professionals’ communications with patients, teams collaborating with each other, the ability of systems to meet people’s aftercare and wider health and care needs are as much characteristics of personalised, integrated care, as the ‘behind the scenes’ mechanics of healthcare funding, commissioning and delivery.

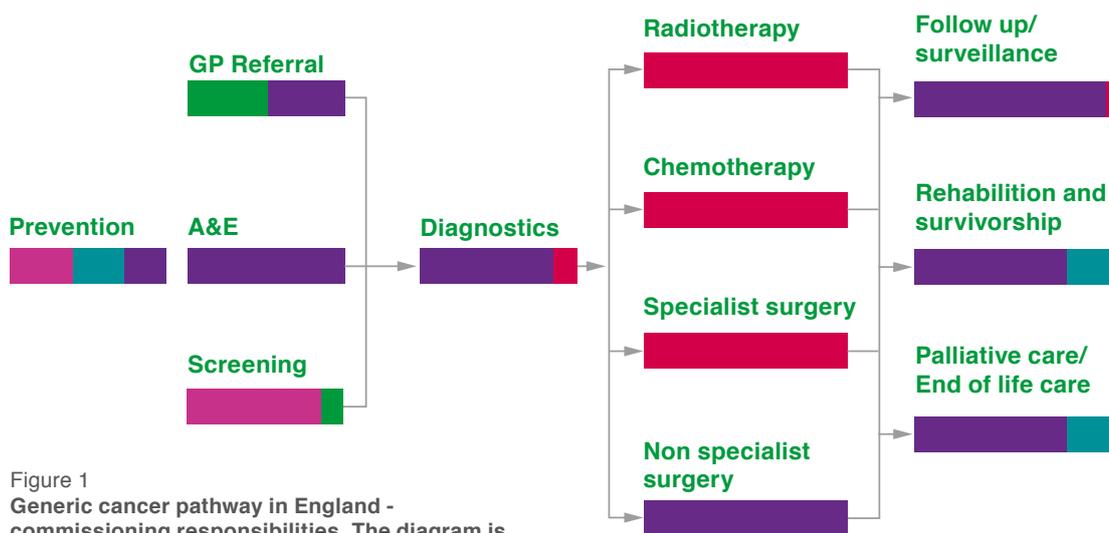


Figure 1
Generic cancer pathway in England - commissioning responsibilities. The diagram is an estimate and is not an exact representation of commissioning responsibilities

Key

- Clinical commissioning group
- Primary care commissioning - NHS England / CCGs
- Public Health England
- NHS England – Specialised commissioning
- Local authority

Our analysis suggests there are four key dimensions to personalised, integrated cancer care.

1. Everyone with cancer can access personalised, joined-up care

Information and communication tailored to people's individual needs is critical. Everyone expects to be included in decisions about their care. There is strong evidence on the effectiveness of a 'care coordinator' or 'navigator' to chase up appointments, results and ensure the system works smoothly for each person.¹⁰

2. People with cancer are supported by health and care professionals consistently working together

People with cancer want professionals and services to 'work together as a team around the patient'.¹¹ Barriers persist around the delivery of cancer services, obstructing whole system working. These are even more acute for people with multiple conditions.

3. People with cancer receive personalised, integrated care across services provided by different parts of the system

Care is still organised around hospitals, not always around the needs of the individual. Integrated care often breaks down during transitions between services and needs are overlooked – for example around follow-up care after discharge¹² and mental health support.

4. Services are designed, commissioned and funded around the goal of personalised, integrated cancer care

The fragmentation of cancer funding, commissioning and provision mean that services are not always aligned around the needs of the individual.

How do the UK nations' health and care systems compare?

England

In England, the Department of Health and Social Care sets the direction for health policy – though in practice, considerable decision-making is devolved to NHS England and Improvement (NHSEI). In 2019, NHSEI established seven regional offices to further devolve service coordination.

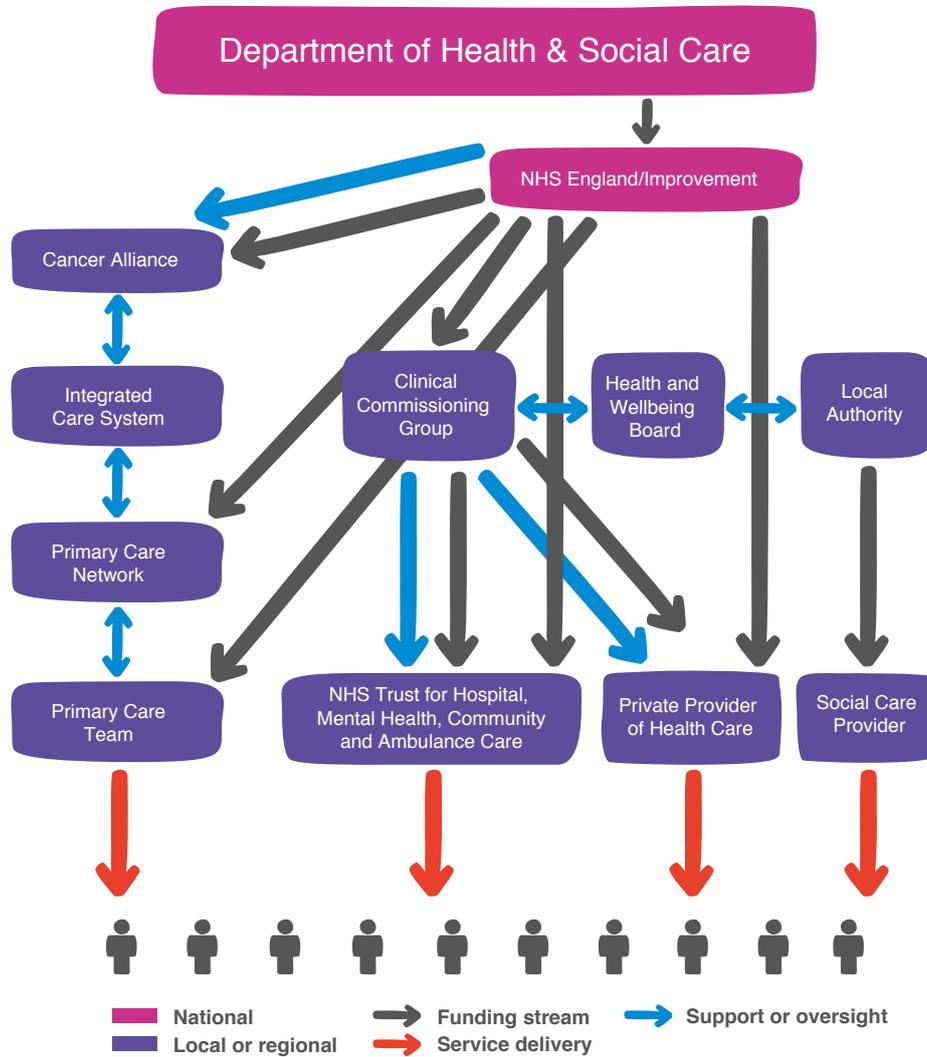
Despite the Department of Health rebranding itself to include social care in 2018, the funding and commissioning arrangements in health and social care have always been separate, unlike other UK nations. There has been a recent focus on integrating health and social care at system level by bringing them together with other stakeholders including Voluntary, Charity and Social Enterprise (VSCE) organisations in Sustainability and Transformation Partnerships (STPs)¹³.

The 2019 NHS Long Term Plan committed that every STP would transition into an integrated care system (ICS), advanced local partnerships sharing responsibility for their population's health, by April 2021. NHSEI proposals to strengthen ICSs as statutory organisations and streamline or remove Clinical Commissioning Groups (CCGs) at system level promise to strengthen integration further. The move to 'system by default' removes competition between different providers. It also blurs the split between purchasers and providers – ICSs bring together providers as well as commissioners.

New primary care networks allow primary care teams to provide a wider range of support at 'neighbourhood' level – including early cancer diagnosis and enhanced care in care homes, and in the future, a specific remit around personalised care.

21 cancer alliances bring together the organisations that plan and deliver cancer services on a sub-regional level. They receive annual allocations directly from NHSEI to deliver nationally set priorities as well as meeting local population needs. Cancer screening is currently overseen by Public Health England (though commissioned by NHSEI), with end of life, mental health and primary care largely commissioned by CCGs.

The structure in England



Northern Ireland

The Health and Social Care Board currently commissions health and social care services in Northern Ireland.

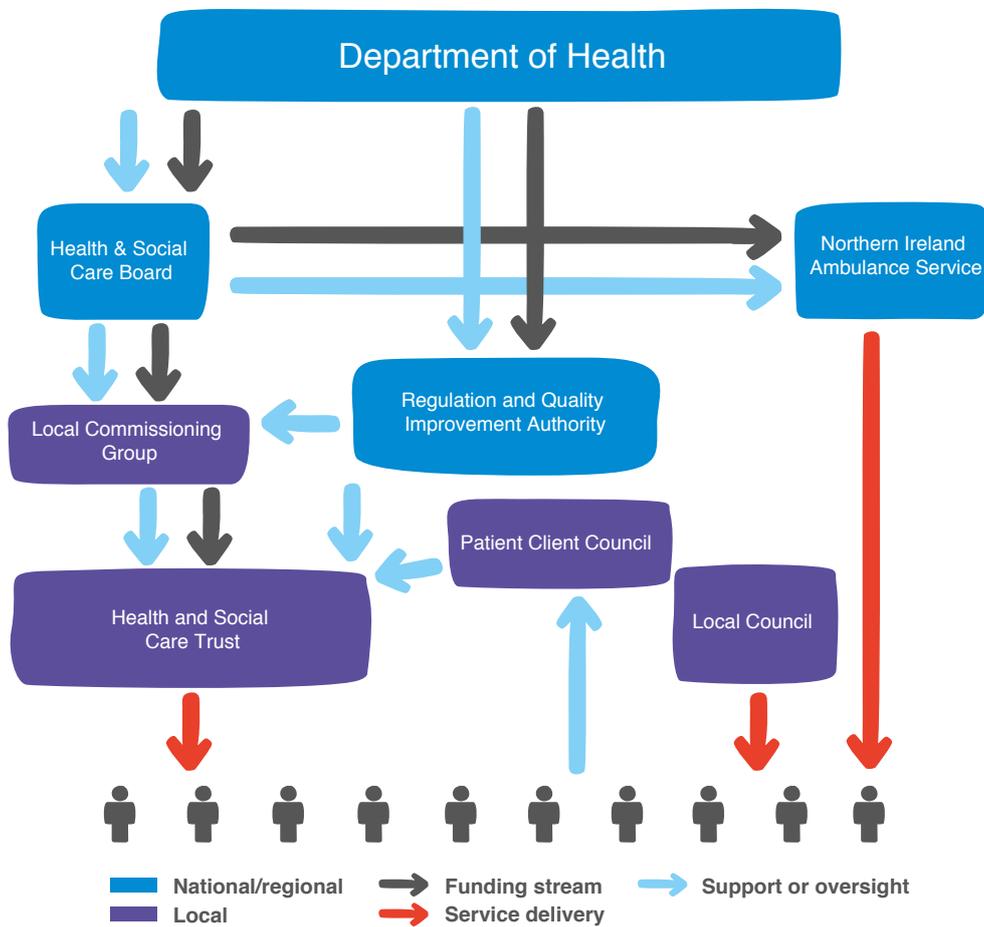
Northern Ireland has six health and care trusts. Five Trusts provide integrated health and social care services across Northern Ireland and are responsible for the running of hospitals, health centres, and other facilities, including residential homes. The sixth Trust is the Northern Ireland Ambulance Service, which operates a single nation-wide service.

Integrated Care Partnerships are collaborative networks of care providers including healthcare professionals, VSCE organisations, local council representatives, and service users & carers, to design and coordinate the delivery of local health and social care services. The ambition is that delivery is as close to home as possible.

Cancer services vary by Trust area and are delivered by a range of statutory, voluntary and charitable organisations.

The Department of Health is currently developing the first Cancer Strategy for Northern Ireland, scheduled for completion in 2021.

The structure in Northern Ireland



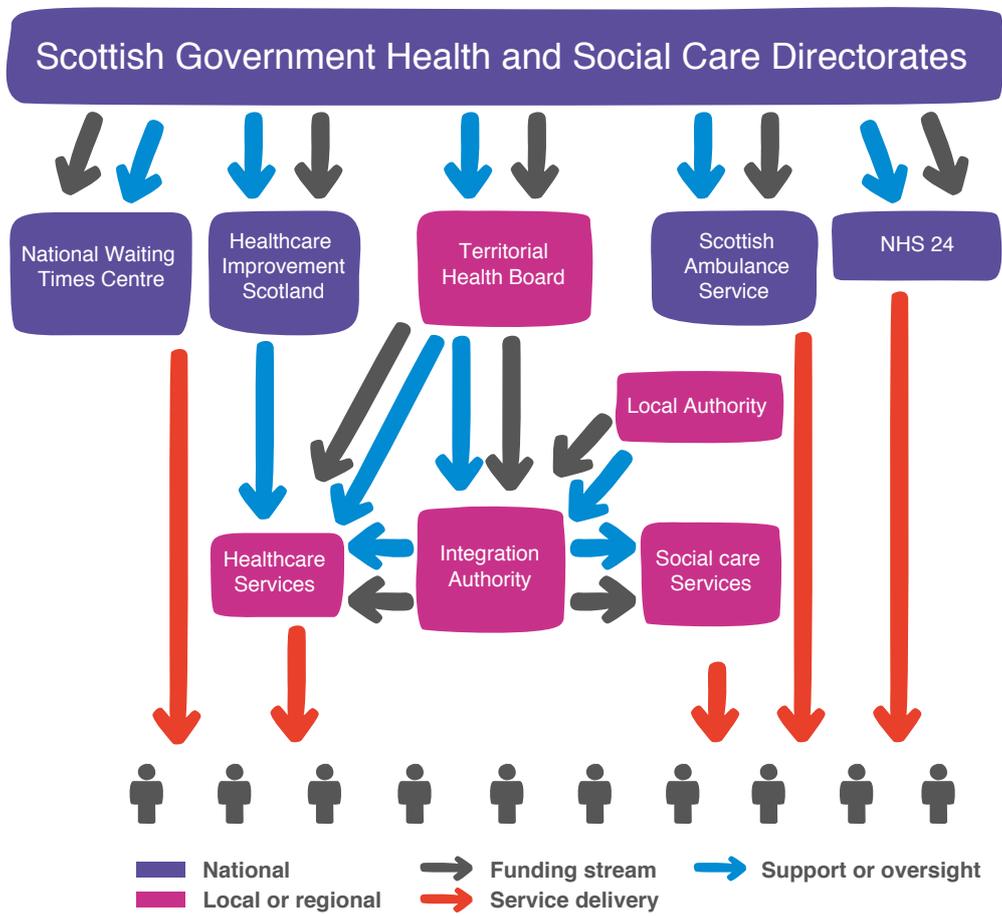
Scotland

14 NHS Health Boards in Scotland plan, commission and deliver hospital and community health services including services provided by GPs and take overall responsibility for the health of their populations. Around three quarters of the total health budget is allocated to the health boards, which determine spending in order to reflect local priorities and/or specific remits including cancer.¹⁴

Since 2014, integration of health and social care has been enshrined in legislation. 31 statutory Integrated Joint Boards (independent of the NHS boards/councils) control more than half of the total NHS and adult social care budget for Scotland. Councils and NHS boards are required to integrate the governance, planning and resourcing of many aspects of NHS care, including palliative care and geriatric medicine¹⁵.

The Scottish Government's 2016 Cancer Plan committed to address unmet need, simplify the system and improve follow-up care for people with cancer. It has invested £9 million to increase support for people during and after their cancer treatment; for example, link workers to provide support in the most deprived communities and Macmillan's pioneering Improving the Cancer Journey programme¹⁶. Following a 2020 update to the plan, a new two-year action plan sets the direction for cancer for the next two years, accompanied by up to £17million of additional funding.

The structure in Scotland



Wales

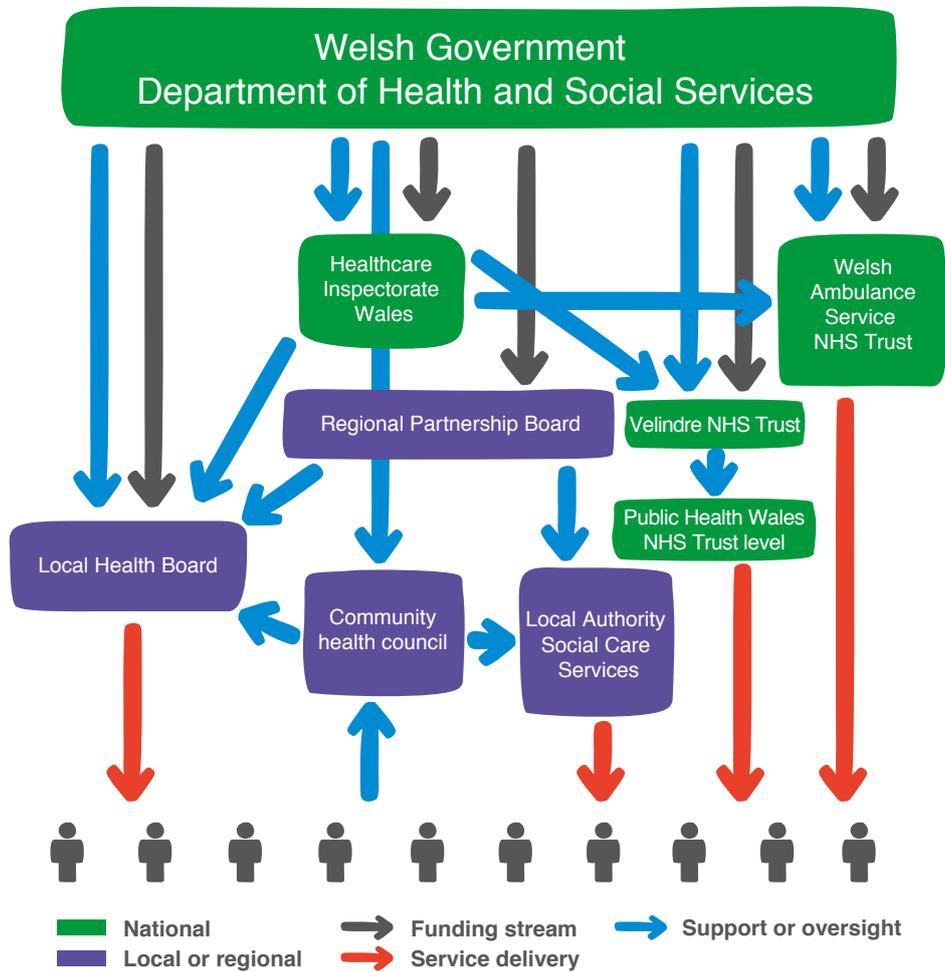
The Welsh Government sets the framework for health and social care through national policy and strategy and the annual requirements in relation to NHS performance.

Seven Local Health Boards (LHBs) are responsible for planning and delivering healthcare services, and aim to integrate specialist, secondary, community and primary care and health improvements. Three NHS trusts cover specialist cancer services; the Velindre NHS Trust, the Welsh Ambulance Service and public health. LHBs and Welsh NHS Trusts receive core funding allocations based primarily on the size and make-up of their local population.

Local authorities have a statutory duty to promote the integration of health and social care whilst public bodies additionally also have a legal responsibility for long term collaboration to better plan for the wellbeing of Welsh citizens through Public Service Boards. The Integrated Care Fund was created in 2014 to facilitate collaboration across social services, health, housing, the third and independent sectors. Seven Regional Partnership Boards (RPBs) drive regional delivery of social services working closely with LHBs. RPBs usually include health, housing, education, and VSCE organisations.

A dedicated leadership structure is in place to oversee cancer services. The Cancer Implementation Group (CIG) has strategic oversight of the cancer delivery plan (CDP) implementation; the National Specialist Advisory Group for Cancer provides clinical input and LHBs plan and deliver services at the local level. A single cancer network, the Wales Cancer Network, advises the CIG on priorities and is responsible for implementing the CDP. The Welsh Government's 2016-2020 CDP is due to be replaced in 2021.

The structure in Wales



DIMENSION 1:

Everyone with cancer can access personalised, joined-up cancer care

Personalised care is essential to meet the diverse needs that people with cancer experience along their journey. It is not a one-off intervention, but an approach that improves people's experiences and outcomes¹⁷.

People's ability to navigate the health and care system affects their care

Macmillan's research points to a two-tiered system – those who know how the system works (for example, because they are confident, articulate and/or have worked in health and care) are able to challenge clinicians and get their views across. For example, Paula, from Northern Ireland, who had a very rare (phyllodes) tumour, and was a health service manager, said *"I don't find the system confusing because I understand it from the inside out."*

In contrast, those less 'in the know' about how the system works and what they should expect, feel less able to question health professionals. More vulnerable and excluded groups are at even greater risk of delayed hospital appointments and their needs not being met¹⁸.

Cathy, who cared for her husband Ray during his prostate cancer, contrasted their situation with an older family member's experience of prostate cancer treatment: *"they wouldn't know what questions to ask, and they would feel as if they were questioning doctors, old school kind of, "We can't ask questions", and they had a terrible time. They were in the dark. That's an example I think of somebody*

that was absolutely in need of somebody medically putting all of that together for that man and saying, "Here's what's happening".

People expect to be involved in key decisions about their treatment¹⁹. Tony from Wales felt that this should also apply to national performance targets for cancer. *"The 62-day national guideline from diagnosis to treatment was not made clear to me. If I had of known about it, I would have felt more empowered to challenge my practitioners."* Educating and empowering patients about how cancer services work can also increase people's control over their care and ability to advocate for their needs.

This patient empowerment role is one which 'cancer navigators' so effectively support. They also refer and signpost to support, chase up appointments and make sure people are updated about their care. This often works best in a non-clinical role, for example a cancer support worker or social prescriber²⁰. The Wales Cancer Delivery Plan commits that everyone with cancer should have access to a key worker, whilst Scotland's new Action Plan for Cancer Services commits to a single point of contact to help navigate services. Many areas across the UK have already invested in this model; however, it is still not accessible to everyone with cancer²¹.

Communication and information needs to be tailored to each person's specific needs

Communication with patients goes to the heart of good personalised care, and ensuring people have a seamless experience. Our research identified a big variation in personalised communication and information provision.

Diagnosis continues to be a key test of effective communication with some people still experiencing a less personal approach. Ruth from East of England said *“My surgeon was brilliant at giving me all the technical stuff but I had to keep stopping him to say, “hold on, you’ve just told me I’ve got breast cancer, can you please hold the breast information until I’ve absorbed that?” They’re firing information at me because it’s stuff they’re used to doing. But if I talked about anything emotional, he would look over my left shoulder.”*

The missing ingredient is that information is not consistently tailored to people's needs. Signposting to further support still appears to be quite random with people stumbling upon information at support meetings rather than it being systematically provided.

Holistic Needs Assessments and care planning

Macmillan believes that information provision and signposting should be at the heart of personalised care. Personalised care and support planning (PSCP) should include a Holistic Needs Assessment (HNA), a personalised care plan and health and wellbeing information. There are national commitments around this approach in England and Wales. However, very few of the people with cancer we interviewed were familiar with an HNA and no-one said that they had received a care plan, reflecting low reported levels in national surveys²². There was a marked difference between what the system leaders and people with cancer described, suggesting that there is still work to do to make the elements of personalised care recognisable and meaningful to every person with cancer.

Good practice:

Belfast's Connected Community Care for Cancer service enables CNSs, GPs and other healthcare professionals to refer people into the service. Once referred, each person is assessed by a Macmillan Link Worker to agree an individual tailored plan and connect them to a wide range of local support services and resources in their community. This helps empower people with cancer to be more in control and have improved quality of life.

Many of the people interviewed had joined local patient forums or groups – keen to use their experiences to improve care for other people with cancer. Some suggestions they have made around communication tools to increase patient understanding and engagement in care include:

- Checklists of useful questions to ask with pictures and diagrams to help people understand what is happening
- Tumour specific starter packs covering issues around pain relief and patient-friendly information on radiotherapy and other treatments
- Recording conversations with health professionals – particularly if during Covid-19, people are unable to be accompanied to appointments

Whilst this feedback is being used constructively in many systems, the expertise of people who have gone through cancer services should be incorporated into all parts of cancer care to shape services going forward.



Impact of Covid-19

Innovations and adaptations to ways of working brought about by Covid-19 will not have a uniform impact and may lead to some people experiencing a reduced quality of care. With so much face-to-face consultation moving to phone and digital interfaces during Covid-19, system leaders took the view that online platforms enable services to continue providing some support to people with cancer and they point to high levels of patient satisfaction.

However, moving to a 'virtual care by default' system disproportionately affects people who are less health literate. A clinical lead in Wales warned that "those who can't "frame their problem in a way that highlights it as something that needs to be urgently addressed" therefore "don't jump through the hoops and they might slip through". It is therefore important that people who need or prefer to access face-to-face cancer care can still continue to do so.

Good practice:

Leeds commissioners have developed a virtual prehabilitation offer, and virtual patient support sessions with a CNS. They are working with communities and general practice in more deprived areas of Leeds. A targeted Facebook live session with BAME communities is planned around 'cancer facts and fiction'.

Sharing patient data

People with cancer have consultations with a range of professionals and often have to repeat their story multiple times. We heard about instances of missing data. Frequently treatment summaries are not received by GPs. Generally, people said that they and their health professionals had good access to digital records and data. However, we know this is not always the case, for example at end of life care, where poor access to integrated data still leads to people's end of life wishes not being met²³.

People with cancer spoke positively about examples of patient-led systems enhancing their care:

- Addenbrooke's in Cambridge uses a system called MyChart which allows patients to see copies of all the correspondence and all the reports that are written about them.
- Leeds health and care organisations all use the 'Leeds Care Record which is a joined-up digital care record that allows clinical and care staff to view real-time health and care information across care providers and between different systems, and helps patients to understand what's happening to them and be involved in decisions.

Recommendations

Everyone with cancer should be able to access care coordination from diagnosis right through to end of life whether through a specific 'navigator' post, a cancer support worker, or a social prescriber.

Personalised care and support must be available to everyone with cancer at every stage of their cancer journey. This includes all aspects of care, from communication at diagnosis and beyond, information provision, involvement in decisions about their treatment and care, identification of people's needs. Personalised care and support planning is a key mechanism, however HNAs and care plans are not ends in themselves – they must be meaningful to patients and trigger support to meet their identified needs.

People's experiences should be used to improve services. Services have a huge amount of data about patients' priorities and needs – from patient participation groups, forums and surveys. It is important that this knowledge is incorporated in designing services and pathways.

Integrated data and systems should be consistently in place to involve and empower patients, and help clinicians pass on information to other teams. Whilst there are good examples of systems integrating to facilitate access across the patient pathway, this is not always accessible to patients and clinicians in all settings.

DIMENSION 2:

Health and care professionals working together

Cancer professionals provide exceptional dedicated support for people with cancer. However, sometimes coordination across settings falls down, affecting people's care.

Professionals delivering personalised care

Workforce pressures often prevent people from seeing the same professionals every time. However, people naturally build relationships with teams over months of treatment such as chemotherapy and radiotherapy, making it easier to get through a difficult time. CNSs are singled out because they make such a personal difference for the people they care for.

Roger from the East of England underwent hormone therapy for prostate cancer which left him unable to sleep: *"this wonderful nurse realised [I needed medication], got me some drugs. I'm not keen on drugs, but I took it and it made a real difference. And I'm eternally grateful to her because she got the local Sainsbury's to stock it. That was just beyond the call of duty. I could talk to her about anything."*

Primary care

Outside the hospital, experiences of personalised care are mixed. Dylan from Wales said that his GP went out of his way to support him following bladder cancer treatment: *"He would check up on me, he was exceptional, he really was"*.

However, GPs are still less involved in follow-up care: Tony said that *"the GP felt I wasn't in his in-tray anymore because I was in secondary care. The GP has never contacted me about my cancer care, it has always been me approaching him – I've never had a cancer care review."*

The pressure facing GPs and primary care is widely acknowledged. A commissioning lead in South East England described 170 professionals responding enthusiastically to a Cancer Care Review training event but only 20 were able to attend because of workload pressures. The reality is that cancer is competing against many other priorities on GPs' long to-do list.

What works

Involving GPs in cancer care often means tapping into their agenda, recognising the valuable contribution many make through cancer care reviews, and emphasising the win-win position.

Good practice:

In Essex the commissioning lead provided funding for Cancer Care Reviews and offered free Macmillan training. This encouraged practices to be more proactive around cancer care and to appoint clinical and non-clinical champions.

The non-clinical champions are already having impact through streamlining the referral process.

Specialists v generalists

“Integrated care shouldn’t really be about specialists” Commissioning lead, North of England

There is still a divide between general practice and hospital-based specialists: teams don’t consistently work closely together. While specialist roles are critical to cancer treatment, there is scope for greater utilisation of the wider cancer team. Conditions such as diabetes and heart disease are very effective at bringing in certificated level training for nurses, AHPs and support staff in areas such as advanced communication and psychological training. A CNS in the North East said that in cancer care, “everybody does their own little bit in each individual silo, and actually it almost needs to be a much “broader brush”.

This siloed working impacts on patient care. Mike in the East of England said: *“although my scan had taken place, they hadn’t reported on it, nothing was happening, and my prostate cancer specialist, said, “Look, I’m not going to do the prostate treatment until I know from the liver scan that [it] was okay”. It was as if the two departments didn’t actually talk to each other, although they were both looking after cancer, but the multi-disciplinary meetings didn’t seem to cross boundaries between the two cancers.”*

The gap between specialist and generic roles is hindered by the relative inflexibility of NHS career pathways and professional development opportunities. However, PCNs (GP federations in Northern Ireland and primary care clusters in Wales) offer opportunities to bring AHPs and new social prescriber roles into primary care teams.

There has been a lot of targeted work to bring primary and secondary care teams together.

Good practice:

South Tees has put in place a nurse cancer educator in primary care. “When we started off over 18 months ago, the practice nurse said: “Cancer, what’s that got to do with us?”, and we changed that a lot. 70 to 95% of our patients have two or more long term conditions, so I think it’s bringing clinicians together – it is a massive culture change.”



Impact of Covid-19

Adapting to new ways of working during Covid-19 has broken down professional barriers amongst teams in different settings. A system lead in the North East described how, faced with redeployments in the first wave, “the cancer nurses are now emailing me to say, ‘I really think we should be having a system wide approach to this’, which is brilliant because that’s what we should be doing. You share the workload, there’s so much duplication”.

However, a practical consequence of the Covid-19 response is that many of the cancer-specific workforce development activities have had to be cancelled and services have come under increasing pressure to tackle waiting lists for diagnosis and treatment.

Recommendations:

National policy makers must maintain national commitments around personalised care – they should improve opportunities to deliver personalised, integrated, cancer care and address workforce gaps through implementation of the NHS Plan and People Plan in England, the cancer plans in Scotland and Wales, and the forthcoming strategy in Northern Ireland. In the longer term, these plans should be supported by comprehensive workforce strategies to build the cancer workforce of the future. This should include more flexible personalised care and navigator roles.

Local commissioners/system leaders should continue to raise awareness of learning and good practice around multidisciplinary team (MDT) working in and with primary care using policy levers such as the GP contract and primary care networks, federations and clusters, and models such as Macmillan GPs and the new Personalised Care Institute (in England).

Training bodies and stakeholders should explore learning from other long-term conditions. Forums such as the Richmond Group's Taskforce on Multiple Conditions, National Voices and other policy networks can share learning around whole system working.

DIMENSION 3:

People with cancer receive personalised, integrated care across services provided by different parts of the system

Cancer patients have to move between primary and secondary care or between different providers of care frequently before, during and after treatment. This often involves interruptions and delays. Our research revealed that for many people with cancer their care is not organised around them but still the hospital(s).

Acute care still organised around hospital(s) not the patient

Roger's care was provided by two different hospitals.

"The relationship between the two hospitals about fixing the appointment was sloppy, it just didn't seem to work... Hospital 1 said you'll have to go to Hospital 2 for this. I used to run a reasonable sized company and I thought it isn't a problem, they'll just ring up [Hospital 2]. Hospital 1 said to me, "Why don't you try ringing them", and I said, "You've got to be joking. It can't be how it works". That's my big criticism, I just cannot understand why someone in that hospital can't ring up someone in Hospital 2 and just say, "We've got this bloke, pleomorphic sarcoma on his right forearm, when does he come? And we'll tell him, and he'll arrive". That's not difficult. You're in the middle of it and you're worried."

The breakdown in communications between hospitals can even lead to people missing out on treatment. Chrissy missed the window to have chemotherapy following her operation to remove her lung cancer because of a mix-up when she was discharged from one hospital and readmitted into another hospital.

Problems between different departments of the same hospital are also still common. After being discharged from hospital after treatment for bone cancer, Ruth received no follow-up details and so went down to

oncology outpatients and made her own appointment. *"There's no joined up linkage between being an inpatient and an outpatient and if I hadn't have followed it up, I don't know who would have"*.

People still being let down after hospital discharge

The most frequent breakdown in care occurs when people are discharged from hospital.

"I could have just had a visit or an invite to have an appointment at the local GPs or something, just to review and say, "My god, you've just gone through all of this, how are you doing?"... I felt a bit that we were out of hospital, they'd done their important bit and then you're just sort of left to sink or swim and then, when the oncology was finished, everything goes absolutely radio silent and if you're not proactive in finding help for yourself, then there's absolutely nothing, there's no follow up, there's no holistic care, there's no emphasis on diet or exercise or mental wellbeing, you're just cut off from the hospital and that's it, it's gone" (Chrissy, East of England)

Issues with referrals back into primary care are common, and treatment summaries are not always received by GPs. As a result, GPs often don't know that their patients have been discharged or their ongoing care needs.

Designing aftercare

The system leaders we spoke to were extremely conscious of avoiding people being left at a cliff edge following treatment, suggesting that there may be a disconnect between what the system looks like on paper and the reality for individuals.

Good practice:

In redesigning their aftercare support, commissioners in Leeds looked at two different populations: one which was a more affluent population where people lived quite a long time with cancer, and the other was a more deprived community with people experiencing very practical needs around finances and childcare. The lead commissioner reflected that “The only way to do integrated care is to actually understand the home circumstances of your different patient cohorts – it’s not about a pretty pathway with a flowchart, it’s about actually understanding what it looks like from the other side”.

Links to other services and pathways

Integrating with social care:

Access to social care services is vital for many people with cancer²⁴. Local authorities are responsible for community and home care packages (except in Northern Ireland where social care is integrated with health), so it is vital they are involved in discharge planning. However, the lack of health and social care integration in England still impacts on people’s access to care²⁵.

The system leaders we spoke to said local authorities are more involved in boards and meetings however this is a long way from working in an integrated way. A commissioning lead in the North East said: “There are links for signposting to, but I don’t see that level of integration. It would be nice to see more social care staff either based in the hospital with clinical teams, or perhaps a closer working for clinical teams with local government.”

The huge pressure facing social care and successive cuts to local authorities’ budgets was widely acknowledged. There are still major organisational and cultural barriers with social care representatives not being invited to and/or present at key MDT discussions. Where NHS commissioners had come from a local authority background or had a history of close working with social care, they had managed to bridge the divide more successfully.



Impact of Covid-19

The urgent response to Covid-19 has transformed working between the sectors, and in many cases dramatically reduced bureaucracy and institutional constraints. Sustaining these will be critical. The pandemic has also exposed the impact of national differences in the way services are integrated. For example, in Scotland, health and social care partnerships bring together staff in one organisation and building, making it much easier to share information.

Mental health support

“Last year before I was re-diagnosed... I was losing my temper over stupid little things; I’d knock myself on the table and I’d kick the table. I had to go and see the doctor – he said “you’ve got depression...” one thing that stood out with your treatment is your attitude to it and you’ve been positive all the way through, your body has just run out of fuel”, he said “I can refer you to psychological services”, but I had to wait two months”.

- Clint, Wales

People with cancer and system leaders all place huge importance on access to mental health support, whether that’s hospital-based psychological support, or talking therapies/cognitive behavioural therapies in the community.

Some cancer services have developed good links with mental health pathways – most commonly Improving Access to Psychological Therapies (England). Some acute teams have access to a psychologist.

However, mental health services are also overstretched and getting access to support for people with cancer when they need it is difficult. The two clinical areas have not historically worked together closely – and this is reflected in segregated service provision across the UK. In Northern Ireland, the development of the first Cancer Strategy is coinciding with a new Mental Health Strategy, providing a potentially timely opportunity to link mental health and cancer service provision.



Impact of Covid-19

Mental health services have seen a huge increase in demand as a result of Covid-19²⁶, and this is likely to escalate further. A system lead in the North of England highlighted a local analysis of HNA concerns. This showed a dramatic increase in people registering distress as a concern as oppose to anxiety, following delayed hospital treatment during the pandemic. This is triggering unprecedented requests for early mental health support.

End of life care

The very separate processes around the commissioning of palliative and end of life services also leads to fragmented care. Sarah from Wales who cared for her father during his cancer said that *“district nursing staff who administer palliative care... didn't have the resources to do this on a level I think most families would expect”*.

Good practice:

Cancer services in the North East are working with the local Mind to raise awareness of mental health. They have access to a psychology team and through their partnership with the Trinity Holistic Centre they have employed a counsellor to support people with cancer.

Good practice:

Cheshire and Merseyside Cancer Alliance have developed dedicated navigators, employed by GP practices to carry out HNAs and develop care plans, which inform consultations and cancer care reviews. They plan to develop a dedicated end of life navigator role. In the interim, commissioners have built a close relationship with the palliative care team: if someone has a treatable but not curable cancer, the navigator works with the nurse and picks up the more practical aspects of care (such as organising stair lifts, parking badges) to allow the nurse to focus on clinical care.

The relative low priority of end of life care at system level in many areas is reflected in the lack of dedicated resource. One commissioner said he only had a few hours a week with two clinical leads. “There is a clear steer from the ICS that end of life isn't one of the priority workstreams... which means it's not been something which has been agreed by all of the chief exec partners or all the stakeholders that says, “This is something we need to work on now”.

While there are examples of good advanced care planning (which records people's wishes around their care at the end of their lives, for example where they would like to die) being incorporated into cancer services, this is far from consistent²⁷. NHSEI's new regional network system for end of life care, with a clinical lead in each of the seven NHS regions should provide much needed profile and funding for joined-up end of life care.



Impact of Covid-19

The Covid-19 response has put end of life and palliative care services under huge strain. System leaders described how palliative care teams had significantly reduced capacity because of Covid-19 pressures and have been unable to attend most joint planning meetings.

Recommendations

Guidance from national policy makers must reflect the importance of personalised care across the cancer journey. MDT working across primary and secondary care must be prioritised to join up care. The presence of a 'navigator' can increase the effectiveness of team-working across different settings, conditions and tumour sites and helps keep patients informed.

Local systems should build on cross-team collaboration that Covid-19 has fuelled and continue to break down siloed working in primary and acute care through skills sharing and learning opportunities.

Social Care

The underfunding and workforce crisis in social care in England must be urgently addressed. Social care must be included as an essential part of the MDT care of many people with cancer. There is key learning from the ways that teams in different parts of the UK have built partnerships and close collaboration between the sectors.

Mental health

People with cancer must be able to access timely mental health support across their cancer journey. This is particularly important to support people who have experienced extended delays and disruptions from Covid-19.

End of life care

End of life care must be better integrated with cancer services through a whole systems approach by ICSs and local systems across the UK. Investment in community end of life and specialist palliative care is critical.

DIMENSION 4:

Services are designed, commissioned and funded around the objective of personalised, integrated cancer care.

“What frustrates me is that there isn’t a system approach to funding”

- System lead, North East England

Cancer funding and commissioning not integrated across the system

Funding for services which people with cancer need in all four UK nations is complex, eclectic and therefore difficult to measure. For example, Cancer Research UK lists 17 funding flows for the delivery of their priority areas including early diagnosis and workforce²⁸. This does not include flows for the delivery of personalised care (Living With and Beyond Cancer) or funding provided by VSCE and local authority partners. The level of funding available for services that people with cancer require is unpredictable and often unsustainable.

In contrast, Scotland’s very different funding mechanisms provide more clarity about available funds. There is no national tariff – health boards are funded on a per capita basis for health and social care services. This includes funding streams covering each disease area and for deprivation as an annual budget which boards must stick to, and out of that, provide integrated care across the pathway, without weighting for volume or activity. This approach presents its own difficulties: for example, staying within the annual allocation is challenging. The ability of integrated authorities to deliver strategic financial planning has been questioned²⁹.

The commissioning of cancer services is also split across multiple organisations in England. NHSEI recently admitted that national specialised commissioning arrangements for vital cancer treatment, including chemotherapy and radiotherapy,

sometimes lead to “fragmented care pathways, misaligned incentives and missed opportunities for upstream investment and preventative intervention”³⁰. There is therefore no consistency across cancer pathways, or indeed with mental health, other clinical areas, or end of life care. This makes it extremely difficult to deliver integrated services for people with cancer, particularly those with multiple health conditions³¹.

Good practice:

In East Kent, a dedicated cancer commissioner with a nursing background advocates for cancer services across the system. The area has a lot of active Macmillan GPs and a prominent lead GP so is well supported in primary care. The cancer commissioner sits within the CCG and has a very good relationship with Kent and Medway Cancer Alliance, the commissioners, and across the system, which ensures frequent meetings, good communication and cooperative learning.

Cancer services are measured against performance targets that apply to parts, not the whole system in all four nations. For example, England, Scotland and Northern Ireland have a target of no more than two months (62 days) wait between the date the hospital receives an urgent referral for suspected cancer and the start of treatment. In Wales the 62-day target also

includes non-urgent referrals. GPs in England, Northern Ireland and Wales are paid for their care of cancer patients via the GP contract. There is no system-wide incentive to collaborate as organisations to deliver personalised care for everyone with cancer across their cancer journey.

Good practice:

The Northern Health and Social Care Trust in Northern Ireland has brought GPs into health and social care commissioning, enabling healthcare professionals to work across primary and acute settings in a 'shared care approach'.

The organisation of services around national funding and central targets for hospital performance gives little scope to flex to local priorities: it's more a case of 'what gets measured gets done'. At the same time, cancer-specific programmes and strategies in all the UK nations provide profile and funding to deliver personalised care. For example, in Wales the 2016 Cancer Delivery Plan includes provision for every Welsh cancer patient to have access to a key worker and receive an electronic Holistic Needs Assessment (eHNA). However national and local priorities also change in response to shifting political agendas, as Covid-19 has highlighted all too clearly.

Good practice:

In Dumfries and Galloway cancer drop-in centres have been established in three parts of the region as part of the Transforming Care After Treatment programme. All parts of the service are working well together to support people holistically outside hospital settings around benefits advice, support back to work and psychological support.

Cancer after Covid-19: A new model of care?

Covid-19 has raised big questions around what the future model for cancer care should look like. "Why would you go to a hospital setting if you don't need to be there?" One system leader asked, suggesting there are lessons that could be applied from the management of other long-term conditions which revolve around out of hospital care.

With chemotherapy provided in some community facilities – including mobile units and even buses during Covid-19, this is already starting to happen³³. A key recommendation of the 2020 Richards diagnostics report was the provision of diagnostic hubs in the community to minimise Covid-19 risks³⁴. The response to Covid-19 has also accelerated new rapid diagnostics centres. However, many system leaders are concerned that there are likely to be hard times ahead. Dealing with the economic fallout of Covid-19 is likely to hit NHS and social care budgets hard. For cancer services, managing the backlog of procedures will be additionally challenging with an exhausted, depleted workforce and VSCE partners also facing cuts. Therefore, where and how cancer treatment is delivered and the workforce that supports it, requires a rethink.

England – Closer integration of health and social care

In England, proposals to strengthen ICSs in legislation by April 2022 are designed to overcome the barriers to integration. Simultaneous changes to commissioning mean that it will be brought into systems – with CCGs either streamlined or disappearing altogether. NHSEI also proposes to take a step back from specialised commissioning, which would come mainly into ICSs. This appears a positive step for cancer services, however it highlights how integral a close and collaborative relationship between cancer alliances and ICSs will need to be, to ensure that the needs of people along their cancer journey are met.

System leaders have a mixed reaction to the impact of closer system integration on cancer services. Whilst some see it removing duplication and formalising pre-existing relationships there is also a strong sense that ‘you cannot write in integration’. It must be underpinned by trust and respect between organisations, which is difficult after years of being asked to compete which still challenges the perception of ‘one system’. “Even [with Covid-19] we’re hearing chief executives say, “I don’t want my x, y and z employees going to work for somebody else, because they work for me”. Well no, they work for health”. (system leader, North East)

Early adopter ICSs may be at an advantage because they are more used to working in this way. However, even strengthened, ICSs may not make a meaningful impact on the issues that really matter to people with cancer.

“I’m not sure that’s the bit that makes the most difference to personalised experience. The bit that really makes the difference... is: Does the receptionist know your name? Does the practice nurse think that your cancer is as important to you as your diabetes? And, I don’t think you can legislate for any of that at an ICS level”,
– System leader, North of England.

It’s important to recognise that integration isn’t the end goal, but a means by which we can improve personalised care for people with cancer – alongside many other efforts. The Long-Term Plan commits to develop a patient integration index. This initiative, being introduced in 2021, will track patients’ experiences of services across their journey³². This data, alongside Cancer Patient Experience Surveys and the Quality of Life metric introduced this year, should mean that systems have a clear picture of patients’ experiences of integration in cancer.

Recommendations

National governments must maintain and increase investment in cancer services over the next few years. Cancer must not become a casualty of cuts. Between 2003 and 2015 cancer services in England received no large-scale central investment and had to compete against other clinical areas for resources³⁵.

NHSEI should look at the financial flows and commissioning of cancer services as a priority. The complex arrangements across the UK lead to confusion, duplication and fragmentation between different clinical pathways. Going forward, arrangements should be simpler, more transparent and promote collaboration between different service areas and teams in all UK nations.

Whole system incentives must be designed for personalised integrated cancer services delivered across the pathway in all UK nations. Having different targets for primary and secondary care fuels a fragmented approach.

Nationally and locally, system wide approaches must ensure that **new models of care are patient-centred** and are informed by the experiences of people living with cancer. There may also be opportunities to learn from different approaches taken across the four nations.

Conclusion

Integration in cancer is messy and multi-dimensional. This means the solutions to many of the challenges, including achieving personalised care for all, are not simple. The picture is further complicated because Covid-19 has put services under so much additional strain.

Responding to the Covid-19 crisis in the short term and dealing with its legacy also raises questions about the current model for cancer services: its financial flows, delivery framework and workforce. Increasingly people can expect to have a cancer diagnosis and treatment in community facilities while GPs can expect to play a bigger role in cancer management.

Modern cancer care for the three million people living with cancer is just as much about services outside the hospital as it is about acute treatment.

Therefore, an effective integrated model must reflect people's frequent transitions between primary and secondary care, services provided by different organisations, and people's health and wellbeing needs throughout their cancer journey. Perhaps this model should more closely resemble other long-term conditions, centred around primary and community support. At the heart of this approach is personalised care, which if it is embedded at the centre of the cancer model, could hugely enhance the experiences and outcomes of everyone with cancer.

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