

LOST IN TRANSITION

A REVIEW OF CANCER
COMMISSIONING

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CANCER SUPPORT

Contents

Foreword	4
Cancer commissioning has become fragmented, making it harder to commission joined-up pathways of care for people with cancer	6
There is confusion among commissioners as to what their responsibilities are	8
This fragmentation and confusion poses a risk to cancer services and people affected by cancer	9
These issues are further compounded by a lack of knowledge, training and expertise	10
The loss of cancer networks is contributing to these problems	10
No one has filled the void caused by the loss of cancer networks	12
Commissioners are calling for support to effectively commission cancer services	13
Cancer commissioning is working better in areas where commissioners are working together	14
Summary of recommendations	15

Foreword



The 2013 reforms to the NHS in England have resulted in significant changes to the commissioning of cancer services. Some of these changes have been positive and have potential to improve cancer services and outcomes – such as bringing equity to how specialised cancer services are commissioned across the country.

However, Macmillan’s insight in this area shows that some of the changes and the general upheaval of the reforms have resulted in confusion and fragmentation in how cancer services are commissioned. This insight includes large-scale research with commissioners carried out by the consultancy OPM. Based on our findings, we have serious concerns about whether the commissioning system can protect the existing standard of cancer services, patient experience and outcomes, let alone lead to the improvements we feel are urgently needed.

By 2020, almost half of us will have to face cancer at some time during our lives. UK survival rates are among the worst in Europe. Without urgent action not everyone with cancer will get the care that’s right for them.

People with cancer tell us that receiving care and support that is stress free and person-centred is fundamental. We know that this doesn’t just refer to the physical treatment people go through but the social, emotional, financial and ongoing aftercare they receive too. People don’t look at their care according to who commissions or provides it. What they want is a holistic, seamless journey, for example from treatment to rehabilitation, that gives them the care and support they need. So while joined-up commissioning may not be a top priority for people affected by cancer, it’s critical in delivering the holistic, seamless experience of care that is so important to them.

Our research with commissioners shows that:

- ➔ Commissioners feel cancer commissioning is far more fragmented than before. Responsibility for commissioning across various parts of the cancer pathway is divided up but there is no one with overall responsibility to ensure the whole pathway is joined up. This results in disjointed pathways for people with cancer.
- ➔ Cancer commissioning is complex and there is lots of confusion about who is responsible for commissioning what. This means that there is a danger that some services are not being commissioned at all, as each commissioning body assumes the responsibility falls to another. Our regional staff are already seeing examples of some services falling through these gaps.
- ➔ Cancer networks used to oversee the overall cancer pathway to ensure it was joined up, and provided much-needed cancer expertise to commissioners. The diminishing of cancer networks, and the cancer expertise therein, is considered a major setback to many commissioners while they struggle with the new system.
- ➔ We have carried out additional research that shows that strategic clinical networks have not replaced cancer networks. It is unclear what their role is in cancer commissioning, if they have one at all. As a result, there is a void in the oversight and coordination of the cancer pathway, and in expertise around the specifics of cancer commissioning.

We are calling for:

- ➔ the Department of Health and NHS England to urgently clarify cancer commissioning roles and responsibilities
- ➔ the Department of Health and NHS England to ensure that, at a local, regional and national level, they allocate accountability to a person or body to have oversight of the whole cancer pathway, and ensure it is coordinated, joined up and delivering value across the whole pathway
- ➔ NHS England to provide adequate resourcing to ensure cancer commissioning can be carried out to a high standard
- ➔ local commissioners to follow the lead of successful areas and establish strong co-commissioning relationships across geographies and organisational boundaries.

A handwritten signature in blue ink, appearing to read 'Mike Hobday', with a long horizontal stroke extending to the right.

Mike Hobday, Director of Policy
and Research, Macmillan Cancer Support

Cancer commissioning has become fragmented, making it harder to commission joined-up pathways of care for people with cancer

The NHS reforms dramatically changed the way cancer is commissioned, and devolved a great deal of decision-making to local bodies. Cancer commissioning has been split between a number of different organisations. NHS England has taken on responsibility for commissioning specialised services, while clinical commissioning groups (CCGs) will commission all other NHS cancer services.

Macmillan wants to understand the new commissioning landscape. Ultimately we want to do this so that we're able to support the improvement of cancer commissioning, along with outcomes and experiences for people living with and beyond cancer. So we commissioned the consultancy OPM to find out how the new local commissioners approach cancer.

OPM audited commissioning plans, and carried out 82 interviews with commissioners, including representatives from CCGs, health and wellbeing boards (HWBs), local area teams and commissioning support units (CSUs). In total, the research included interviews with one third of all CCGs, and six of the 10 area teams responsible for specialised commissioning. For the audit, the researchers assessed the commissioning plans of 50 of the 211 CCGs, and the HWB plans* of 150 of the 152 upper-tier local authority areas in England.

We also held an event with the King's Fund and the cancer community in April 2014, which looked at challenges and opportunities in the new NHS, including the new commissioning arrangements.**

Through our research we have found that the reforms have resulted in some opportunities for improving cancer commissioning. For example, it was felt that specialised commissioning has the potential to be more equitable (by improving consistency in access to specialised services) now that it has been standardised across England. However, the results of our research were generally very concerning insofar as they illustrate a confused and fragmented system.

One of the main challenges commissioners discussed was the fragmentation of commissioning responsibilities across different bodies. Commissioners felt that this is particularly an issue for cancer care. The early and end of life stages of the pathway are commissioned by CCGs, specialist services are commissioned by NHS England local area teams, and public health has responsibility for prevention and awareness-raising.

This is further complicated by the fact that in some areas much of the responsibility for commissioning cancer services is devolved from CCGs to CSUs. Additionally, many CCGs commission services from at least two provider trusts, leading to further difficulties when trying to establish single patient pathways.

* Both Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies.

** Attendees included national and local commissioners, Department of Health, NHS England, Strategic Clinical Networks, Academic Health Science Networks, academia, providers, the voluntary sector, and other national and regional health and cancer bodies.

No single body or person at local, national or regional level has overall accountability for the patient pathway, and individual commissioners are struggling to ensure the pathway is joined up. Commissioners reflected that the division of responsibilities makes it difficult to take a 'whole pathway' approach to commissioning. This is because they have only a narrow awareness of the interventions they are responsible for commissioning.

For this reason, we are calling on the Department of Health and NHS England to ensure that, at a local, regional and national level, they allocate accountability to a person or body to have oversight of the whole cancer pathway, and ensure it is coordinated, joined up and delivering value across the whole pathway. Such leadership is required to ensure that fragmentation of commissioning doesn't lead to a fragmentation of care, and subsequent poor experiences and outcomes.

'It's hard to say what's going on. I don't think anyone has an overarching view or overall control of it. Everyone is only seeing only what is in their remit and locality.'

(CCG Cancer Lead, Board Member)



There is confusion among commissioners as to what their responsibilities are

There is also confusion around cancer commissioning responsibilities. Some interviewees in our research, and attendees at our event, felt that there is a lack of clarity over the boundaries between specialised and non-specialised commissioning of cancer services. Others were unclear whether CCGs have any responsibility for prevention and screening, or to what extent screening is the responsibility of public health or NHS England. Commissioners are concerned that prevention and screening drives are being neglected as a result.

There is confusion about whether end of life and palliative care is the responsibility of tertiary care or the charity sector. There are also concerns that a lack of accountability for the social, psychological and emotional aspects of cancer care means more holistic aspects of care are falling through the cracks between different commissioners, or are seen as the responsibility of the voluntary sector. We are concerned that some aspects of cancer care are therefore not being picked up by anyone involved in cancer commissioning.

Some CCG representatives even assumed that all or most cancer treatment would be commissioned by others because it sits with tertiary rather than secondary care.

When some commissioners have tried to clarify their responsibilities they have been unable to find the appropriate guidance.

'Part of what we're struggling with is what bits of cancer services are we actually responsible for commissioning? What is our responsibility? And in all honesty we don't really know.'

(CCG Chief Operating Officer)

This fragmentation and confusion poses a risk to cancer services and people affected by cancer

Commissioners feel that this fragmentation is resulting in a disjointed pathway, and far from encouraging person-centred care, is leading to a tendency to lose sight of the whole person.

'If a patient has cancer today their journey will have followed public health all the way through to my services, all the way through primary care, which I don't commission, all the way to generalist care, which I do commission. But for certain specialist parts of that it'll go to the specialist part which is commissioned by NHS England. So to have a neat pathway for care is a challenge at the moment.'

(CCG Director of Commissioning and Planning)

It is important that people with cancer have person-centred coordinated care – from diagnosis to treatment, recovery, aftercare, and for some, end of life. A joined-up pathway gives them confidence that all the professionals around them are working together to understand their needs and that services are personalised and joined up to improve their outcomes and experience. This includes the sharing of information from care plans at transition points.

Another very real concern is that this confusion over responsibilities, and a lack of joint working to determine who is commissioning what, is leading to duplication of – or gaps in – services. Regional Macmillan staff have already come across examples of this.

Our staff across multiple regions are getting reports that psychological support services for people with cancer are severely stretched, or at risk of being decommissioned. We are currently investigating this further and will be examining the impact this is having on cancer patients.

This may lead to people affected by cancer being unable to access the crucial services and support that they need.

Another risk identified by commissioners is that patients will fall through the cracks because of their referrals not being picked up, or information not being properly shared between professionals.

Therefore, we are calling on the Department of Health and NHS England to urgently clarify cancer commissioning roles and responsibilities.

These issues are further compounded by a lack of knowledge, training and expertise

Commissioners tell us that they have very limited capacity to consider cancer. On top of this, they are concerned about the lack of information and training for those commissioning for cancer. Often, individual commissioners have either extensive clinical knowledge, or broader commissioning experience, but not both. They worry about lacking understanding of either cancer pathways and treatments, or the commissioning process and mechanisms.

'Cancer is an area that was always quite specialist in PCTs – one or two people would lead on it and they held all the knowledge, and that hasn't been passed on to CCGs. I don't have much professional knowledge on how we pay for it, how the data records it, or what the commissioning arrangements are.'

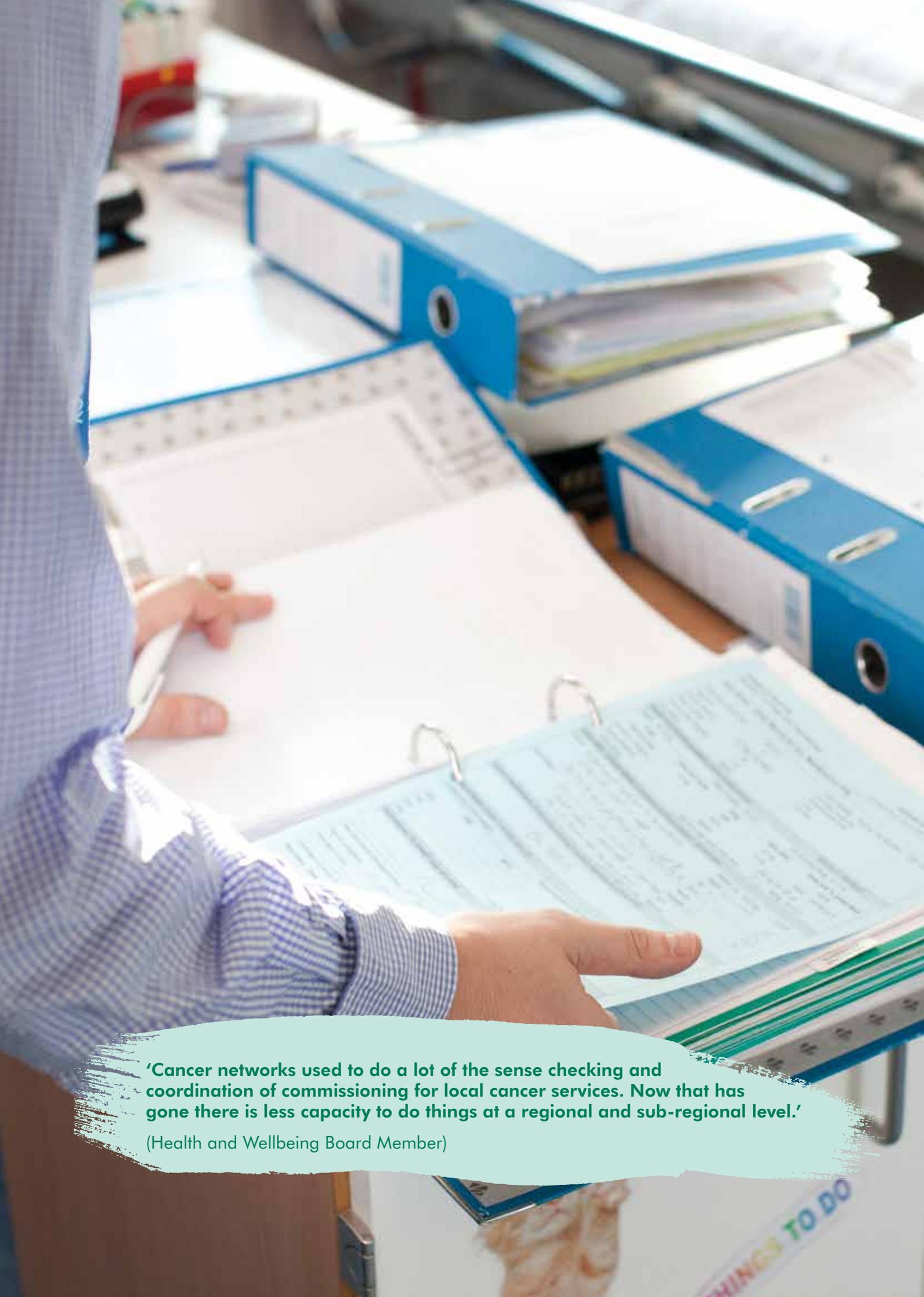
(CCG Senior Commissioning Manager)

The loss of cancer networks is contributing to these problems

These problems are made worse by a communication breakdown between commissioning bodies, particularly CCGs and local area teams. Commissioners identify the diminishing of cancer networks as part of the problem. Networks previously held a whole pathway focus and so facilitated joint working, coordination and communication around

cancer commissioning. They also held much of the specialist knowledge and expertise on cancer commissioning. Many commissioners describe the loss of cancer networks as a major setback for cancer commissioning. They feel the gaps left by cancer networks have not been satisfactorily filled by other bodies.*

* Note that a few northern CCGs have managed to retain their cancer networks, and are still finding them useful. They are a minority and an exception.

A person wearing a blue checkered shirt is sitting at a desk, looking at a document in a blue binder. The desk is cluttered with several other blue binders and papers. The person's hands are visible, holding a pen and pointing at the document. The background is slightly blurred, showing more of the desk and office environment.

'Cancer networks used to do a lot of the sense checking and coordination of commissioning for local cancer services. Now that has gone there is less capacity to do things at a regional and sub-regional level.'

(Health and Wellbeing Board Member)

No one has filled the void caused by the loss of cancer networks

Commissioners feel that while certain functions previously carried out by the cancer networks have been taken on by the new strategic clinical networks (SCNs), the new networks have less time and clinical expertise, and fewer resources, to devote to cancer. This is due to the different remit of SCNs, and the massive disparity between resources made available to cancer networks and those allocated to cancer in SCNs.

The overall funding for SCNs (and clinical senates) in their first year was £42 million – more than the £18.5 allocated to cancer networks in 2012-13. However, this resource is to be used across all four SCN conditions: cancer; cardiovascular; mental health, dementia and neurological conditions; and maternity and children services. Therefore cancer in the new SCN structure has significantly less funding available than previously.

In addition to a significant reduction in funding, the transition away from cancer networks has seen dramatic reductions in staff. This has reduced the organisational memory, expertise, and capacity available to drive cancer commissioning.

Also, SCNs differ from cancer networks in that they're intended to provide strategic insight for the other SCN conditions alongside cancer. Subsequently, there is a risk that nobody is driving the improvement of cancer services as a standalone condition, in the way cancer networks did. This threatens to undermine the ability of cancer leads within SCNs to apply a patient-centred, whole pathway approach specifically to cancer. This was a strength of cancer networks and is a major loss for commissioners.

The transition from cancer networks to SCNs has also resulted in the loss of some of the operational aspects of the former cancer networks' role. For example, it's not clear what role SCNs have in driving the integration of pathways and services. On their introduction, many SCNs didn't feel it was within their remit to drive integration, yet no other body is accountable or responsible for doing this.

Equally, it is unclear who is able to, and responsible for, facilitating user and clinical engagement groups in the absence of the former networks. As a consequence, clinical knowledge, best practice, and meaningful patient and user engagement – all of which contribute to an integrated person-centred pathway – have also been lost.

Commissioners are calling for support to effectively commission cancer services

Because of this confusion, and loss of cancer expertise, commissioners are asking for improved guidance and support. They have asked for assistance on the specifics of cancer, and clarity on who has responsibility for commissioning different parts of the cancer pathway. They have said that they are struggling with limited funds and time to consider cancer. Some commissioners feel that they do not have adequate cancer expertise to fully understand the services they need to commission.

The lack of financial resources is particularly acute at certain stages of the cancer pathway. Commissioners reflected that the majority of the cancer budget is concentrated on the treatment stage, while prevention, diagnosis, survivorship* and end of life care are comparatively underfunded. Some interviewees noted that this has the potential to create perverse incentives.

'For example, there is more funding for specialist treatment than for screening and early intervention. So there is almost an incentive to let people get to the stage where they need specialist treatment, rather than deciding to focus on prevention and early intervention.'

(CCG Chief Officer)

Several interviewees felt that there needed to be more freedom to move funding around to the parts of the pathway where it was needed.

Many commissioners also feel that they lack the time to devote to commissioning for cancer. Some think there is a tendency to let existing contracts roll over because they don't have time to revisit commissioning arrangements. They tend to feel more confident in their commissioning role if they have a specialist responsibility for commissioning for cancer, and some protected time to focus on it.

'My other commissioning colleagues struggle to have the time to focus on cancer issues because they need to work across a much wider range of commissioning focuses. So being able to retain that focus is really helpful.'

(CCG Cancer Lead)

Therefore we are also calling on NHS England to ensure cancer commissioning is adequately resourced – with the time, capacity, expertise and funding to commission effectively.

* Ensuring that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

Cancer commissioning is working better in areas where commissioners are working together

Our research found that commissioners with an established network of stakeholders, who they can meet with to discuss cancer, are more positive about the effectiveness of their cancer commissioning. They are also clearer about how they fit into the local health system.

These networks are more evident in larger urban areas, where several CCGs operate across a conurbation. They typically include representatives from multiple CCGs, acute providers, public health and CSUs. Sometimes they include charitable organisations working with cancer patients and their families, as well as the local area team, Macmillan GPs and Macmillan nurses.

These meetings and/or joint working are facilitated by SCNs, London Cancer, cancer networks (where retained under a different name), or sometimes health and wellbeing boards. Some interviewees attribute their successes to these partnerships. However, some of the less successful commented that they did not have these relationships and felt less able to address challenges.

Sometimes these groups exist primarily to share knowledge, information and good practice. But they can also result in partners across a local system jointly commissioning aspects of their cancer support. For example, around rarer cancers, and where it is not necessary or cost effective to provide multiple, similar services across a wider area.

We encourage local health and social care commissioners to follow the lead of successful areas and establish strong co-commissioning relationships across geographies and organisational boundaries.

'We're very lucky that we have these meetings and we think that the fact that these people keep coming back regularly shows that they're working. They help to see across the pathway.'

(CCG Head of Service Improvement)

Summary of recommendations

In summary, we are calling for:

- the Department of Health and NHS England to urgently clarify cancer commissioning roles and responsibilities
- the Department of Health and NHS England to ensure that, at a local, regional and national level, they allocate accountability to a person or body to have oversight of the whole cancer pathway, and ensure it is coordinated, joined up and delivering value across the whole pathway
- NHS England to provide adequate resourcing to ensure cancer commissioning can be carried out to a high standard
- local commissioners to follow the lead of successful areas and establish strong co-commissioning relationships across geographies and organisational boundaries.

We look forward to working with the Department of Health, NHS England and local commissioners to implement the recommendations in this report.

When people have cancer, they don't just worry about what will happen to their body, they worry about what will happen to their life. At Macmillan, we know how a cancer diagnosis can affect everything and we're here to support people through. From help with money worries and advice about work, to someone who'll listen, we'll be there. We'll help people make the choices they need to take back control, so they can start to feel like themselves again. Together, we are all Macmillan Cancer Support.

No one should face cancer alone. For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**