Hewitt Review call for evidence - Cancer Research UK response

Introduction

Cancer Research UK welcomes the opportunity to respond to the call for evidence as part of the Hewitt Review of the oversight and governance of Integrated Care Systems (ICSs). Following the Health and Care Act 2022 formalising the role of ICSs in England's health system, they will play a central role in the planning, commissioning and delivery of cancer services across England, and have important responsibilities to support research and innovation. Given the significant challenges facing cancer, it is vital that ICSs are enabled to succeed within a framework that ensures accountability while allowing for the autonomy to respond to the needs of their populations.

Cancer services span the breadth of the health and care system, from public health, screening and primary care through diagnostic services and acute care, community and palliative care. Given the complexity and breadth of cancer pathways, there is significant potential to improve patient outcomes through **service transformation driven by Integrated Care Systems, and Cancer Alliances acting as their 'cancer arms'**.

As ICSs embed in their geographies, it is vital they ensure that **cancer is considered a population health issue** by the whole health and care system. As cancer incidence rises due to a growing and aging population, the locus of activity must **shift towards preventative interventions** given that 4 in 10 cancers are preventable.[i] **Early diagnosis is key to improving outcomes**, as recognised in the NHS Long Term Plan ambition to diagnose 75% of all cancers at Stage I or II by 2028 and the expectation in planning guidance to make progress against this ambition. Therefore, measures to improve early diagnosis, timely care and management and opportunities to address systemic inequalities relating to awareness and to access must also be a central part of this approach.

It is important that ICSs have sufficient **autonomy to focus on the specific needs of their populations**, which vary significantly across geographies in terms of population size and other demographic factors including age and prevalence of specific health risk factors. This autonomy and flexibility should exist within a robust system of accountability not only to operational standards such as Cancer Waiting Times (which are particularly salient in importance given current service pressures and poor performance) but also to evidence-based quality standards that will make a real difference to outcomes for every patient.

There are also a number of risks that must be mitigated as ICSs establish themselves. For example, there are barriers to effective system leadership, service transformation and innovation – notably **the lack of time for clinical leaders and NHS managers to meaningfully engage in service improvement**, symptomatic of a lack of capacity right across the NHS in England. Within the scope of this report, efforts to address NHS capacity shortfalls must be considered not only improving access to care but also time to innovate and improve services. A move to delegate authority for **specialised commissioning** from NHS England to ICSs must also ensure these vital services for cancer patients do not face reduced funding, disruption to provision, increased barriers to access or an increase in unwarranted variation.

The following response addresses the specific questions set out in the call for evidence. For further questions, please contact Matt Sample (Health Policy Manager) – Matt.Sample@cancer.org.uk.

Transforming services, improving outcomes – barriers and enablers

Please share examples from the health and care system, where local leaders and organisations have created transformational change to improve people's lives.

England's 21 Cancer Alliances offer a number of instructive lessons for Integrated Care Systems – not least given Cancer Alliances will act as the 'cancer arm' for their ICSs.

While there remains variation between geographies, at their best Cancer Alliances have decisively taken forward the cancer transformation agenda by bringing key stakeholders together, providing strategic direction and investment and acting as the leading voice on cancer in their area. High performing Cancer Alliances have also helped embed collaboration in system-wide working and were critical in facilitating collaboration across the NHS to maintain cancer services through the COVID-19 pandemic.

For example, the Innovations Programme established by West Yorkshire and Harrogate Cancer Alliance working closely with the local AHSN, has accelerated the introduction of innovations with the potential to transform cancer diagnostics. This programme has helped triage patients and inform risk assessment by stratifying patients who present and more effectively managing scarce resources. The roll-out of these innovations was accelerated during the pandemic, supporting the system through providing ways to meet patient need if they couldn't be seen through the traditional routes.[ii]

The most effective Cancer Alliances have managed to embed a robust culture of system working through building strong relationships across the system, protect dedicated time for clinical leadership, and have taken a population health approach across the patient pathway. It will be critical to build a framework that fosters these principles across Integrated Care Systems to ensure they can improve outcomes in population health and healthcare.

Do you have examples where policy frameworks, policies and support mechanisms have enabled local leaders and, in particular, ICSs to achieve their goals?

Cancer Alliances have been instrumental in driving local implementation of important transformation and innovations. For example, the NHSE Targeted Lung Health Check (TLHC) programme, which offers low dose CT scans to people who are at increased risk of lung cancer, is now live in 33 locations and has invited over 500,000 people for a check. NHS England has also indicated the programme has seen a significant shift toward early diagnosis which is critical to improving cancer outcomes.[iii]

The NHSE TLHC programme has benefitted from dedicated implementation funding at a system and national level, and importantly this funding has been on a multi-year basis. This has allowed Alliances to plan appropriately for the programme's scale and complexity, and is an important illustration of how the NHS nationally can support systems to implement transformational change.

In contrast, reliance on non-recurrent revenue funding to support recovery and transformation activity limits systems' ability to invest in the areas of greatest impact, where service transformation may take a number of years.

Furthermore, to date funding has been tied to nationally-led planning guidance, with limited flexibility to recognise variation between different systems' populations and their health needs, operating models, system maturity or current local activity or priorities.

Looking forwards, it will be important to ensure that there is both a multi-year funding model to give systems greater certainty, alongside sufficient flexibility to allow for localised approaches to implementation of improvements or innovations. This flexibility should apply both to nationally-directed transformational projects, and innovative local priorities.

Do you have examples where policy frameworks, policies, and support mechanisms that made it difficult for local leaders and, in particular, ICSs to achieve their goals?

Around 4 in 10 cancers are preventable.[iv] This is also an issue of inequality: smoking is the single biggest driver in inequality in life expectancy in the UK,[v] and remains the biggest cause of cancer and premature death in the UK.[vi,vii]

ICSs are uniquely positioned to ensure that population health is a focus across local authority, NHS, and voluntary sector activity, but it is important that roles, responsibilities and funding streams are clearly defined to facilitate collaborative working across both Integrated Care Boards (ICBs) and Integrated Care Partnerships (ICPs).

Prevention is critical to reducing the burden of cancer in the population, but there is significant regional variation and underinvestment. There are significant opportunities to better align and join up activities – for example, through robust planning for smoking cessation services to be embedded within TLHCs.

It is vital that a population health approach is embedded right across the pathway, encompassing cancer prevention, supporting informed cancer screening uptake, improving symptom awareness and supporting people to seek help when they develop symptoms that may be cancer.

Harnessing the wealth of expertise within ICSs will be necessary for success. There must be a clear expectation for each ICP and ICB to develop their integrated care strategies and 5-year forward plan for healthcare in tandem and ensure that efforts to reduce cancer incidence and improve early diagnosis are a clear focus in both as they develop.

What do you think would be needed for ICSs and the organisations and partnerships within them to increase innovation and go further and faster in pursuing their goals?

ICSs having access to high quality data and analysis is a key enabler for local leaders to proactively identify the priorities for their population, and rapidly identify impactful evidence-based solutions. These issues are explored further below.

Alongside funding issues described earlier, ICSs need the capacity and capabilities to lead complex change processes across systems. As well as clinical leadership, this requires sufficient resource and capacity within ICS central teams for programme management, delivery, analysis and evaluation.

Despite being pivotal to improving outcomes for cancer patients, clinical research is often seen as lower priority add-on to standard care[viii]. Consequently, research often suffers first when the NHS is under immense pressure.

The 2022 Health and Care Act provided the pre-requisite statutory footing for a stronger research culture, enhancing ICB's and NHSE's duties to report on how they are promoting and facilitating research[ix]. However, to achieve meaningful culture change, DHSC needs to give greater priority to delivering the Clinical Research Vision, including plans to help ICBs understand and fulfil their new research mandate[x]. Enhancing the role of AHSNs and research-focussed organisations within ICSs will also be important.

Although the arrangements across areas may differ, ICSs should implement system-wide innovation that best serves their populations. The benefits of a co-ordinated approach include breaking down barriers between settings of care to enable whole-pathway transformations, strategic use of innovation and research funding and resources, and enabling measures such as system-wide information governance and data sharing policies.

What policy frameworks, regulations or support mechanisms do you think could best support the active involvement of partners in integrated care systems?

Charities can provide deep expertise to support ICSs on investment decisions to improve outcomes. CRUK works with NHS England to provide insight and evidence to inform policy-making; support Cancer Alliances to respond to national policy through networks with local leaders; and brief on emerging innovations and the wider evidence base. Additionally, we have insight into public health measures to reduce cancer incidence, such as junk food advertising restrictions and tobacco control measures.

Further opportunities to support ICSs to develop locally-specific data-driven population health strategies could arise from increased access to integrated, system-level datasets enabling insights into factors such as experience and outcomes of care, risk factors, or addressing inequalities.

The pandemic illustrated the value of the NHS, government, life sciences, third sector and research community working together to access and analyse data rapidly, informing decisions to improve experiences and outcomes. There is untapped potential for all other diseases from creating a secure data environment, accessible to approved users, of national or UK wide timely data to drive quality improvement through analysis. This would allow ICSs to compare their data to other ICSs, and for third sector and researchers conduct analysis to identify inequalities, support innovation and improve experiences and outcomes for patients.

NHSE guidance sets an expectation for ICSs to embed the Voluntary, Community and Social Enterprise sector in governance arrangements[xi], but there is progress still to be made.[xii] It is important there is both support and accountability for ICSs to routinely and meaningfully involve the VCSE sector.

What recommendations would you give national bodies setting national targets or priorities in identifying which issues to include and which to leave to local or system level decision-making?

NHS England is currently preparing to devolve responsibility for many aspects of specialised commissioning from NHS England to ICBs, initially through joint commissioning arrangements. This funding stream covers almost all cancer treatment and some diagnostics and at a minimum, any changes to the way that these services are commissioned should not reduce funding, destabilise provision, limit access, or increase unwarranted variation in the quality and effectiveness of cancer care.

To avoid unwarranted clinical variation, these standards and specifications should continue to be set nationally. NHSE should ensure that it maintains sufficient capacity, capability and engagement with experts to keep service specifications relevant and updated in line with the best and latest evidence and innovations, and that these are effectively disseminated to relevant audiences throughout the health service. The value of this overall change in commissioning arrangements, and readiness of the NHS at all levels (particularly within smaller ICSs) to enact the proposed devolution of commissioning responsibilities should be scrutinised as part of your review.

Devolution of specialised services to ICB's may create challenges in taking difficult decisions required to reconfigure services. There may, for example, be a tendency for ICBs to focus on service improvements within their own geographies, which could impact consolidation of services to develop centres of excellence. The impact of the decreasing role of impartial national-level commissioners on beneficial service configuration should also be considered in this review.

What mechanisms outside of national targets could be used to support performance improvement?

Networking approaches are an important mechanism for performance and quality improvement in the NHS. Cancer Alliances and radiotherapy networks took the lead on improvement activities for services within their networks since their inception. Key factors in their success include the availability of dedicated leadership time, ringfenced transformation budgets, specialist knowledge and expertise (including in improvement techniques), facilitation of spaces for shared learning, consensus-building, collective decision-making, and support from leaders for the role that they play in the wider system. ICSs are developing similar networks for high volume low complexity elective care, diagnostics, and other areas and require further support for national collaboration on common problems.

Success is underpinned by access to data and insightful analysis. At a national level, audits such as the National Lung Cancer Audit and programmes such as GIRFT use data to highlight variation, identify opportunities for improvement, and provide systems with valuable intelligence on which to build improvement programmes. Rapidly available linked national datasets would be more useful for systems to drive quality improvements through comparisons and national analyses, and would provide the evidence for the success of innovations in care.

Cancer Research UK are undertaking work to determine what makes a good cancer service on a cancer-site basis. This will support HQIP's audit work and provide the guidance for trusts to ensure their services are performing. This will only support improvement if national linked datasets are securely and rapidly available for analyses so that comparisons to identify best practice and share learnings are made.

Effectively using health data

How could the collection of data from ICSs, including ICBs and partner organisations, such as trusts, be streamlined and what collections and standards should be set nationally?

It is often not the collection of data, but how accessible these data are for the health service to use, which creates the greatest challenges. Different elements of a patient pathway are stored on different databases or systems, severely limiting the ability to use these data to drive improvements in care and outcomes. When they are brought together nationally, the time taken before these are available for partners to support services is too long and the access mechanisms for these datasets are opaque, time consuming and restrictive. For cancer, data related to referrals, screening programmes, diagnostic tests, diagnoses, treatment and outcomes are all collected but the system is not in place for these data to be available for cross-pathway studies, which would answer important questions on the drivers of variation in outcomes.

Whilst there are many improvements that need to be made to the capture of data, it is the infrastructure and lack of accessibility to these data that urgently needs to be addressed so that the collection of these data can lead to better cancer prevention and improvements in experiences and outcomes for patients.

What standards and support should be provided by national bodies to support effective data use and digital services?

Systemic improvement in the quality of and access to data for care and research has the potential to support development of more streamlined pathways, improved patient experience, and more opportunities for clinical teams to address issues. Prioritising secure access to linked datasets is essential to realise the value of the data held across systems, which the NHS is not doing.

Integration of key datasets, including between primary and secondary care, is essential, enabling opportunities to improve prevention and early diagnosis, and to identify and develop plans to address inequalities and unwarranted variation. Such datasets are also a powerful tool to understand the causes and symptoms of diseases, patient pathways, and patient outcomes. Therefore, prioritising the necessary investment and support for ICSs developing the infrastructure and protocols that underpin these ambitions is imperative.

This will, however, be ineffective if data completeness and quality is poor, or if it cannot be accessed by clinicians, managers or researchers. For example, poor recording of smoking history in GP records reduces the potential for targeted lung health checks, with people missing out. Variability in the completeness of cancer stage at diagnosis submitted nationally hampers our understanding of sub-national variation and progress towards the NHS Long Term Plan 75% early diagnosis target. Programmes such as GIRFT that identify unwarranted variation between services offer a model for how benchmarking can be used to drive improvement. We recommend that the quality and completeness of key clinical and outcomes datasets is given equal weighting with operational data.

What do think are the most important things for NHS England, the CQC and DHSC to monitor, to allow them to identify performance or capability issues and variation within an ICS that require support?

The 2022 Clinical Review of Standards for Cancer led the way on prioritising key national targets for cancer, simplifying the current 9 targets down to 3 covering the whole cancer pathway. CRUK supported these proposals, while emphasising these targets alone are insufficient and ICBs should also focus on quality and outcomes measures – not least because many cancer patients are not captured within current cancer waiting time targets.[xiii] We are initiating a project to map quality standards across cancer with a view to ensuring actionable metrics that allow services to track progress towards better outcomes. We would be happy to share further details of this work.

NICE Guideline 12 provides guidance to GPs to support early identification and appropriate referral of patients with suspected cancer. Urgent suspected cancer referrals now represent the largest patient cohort receiving new referrals into secondary care, but while there are some relevant datasets there is no framework for routinely monitoring how this referral route is being used. This means we have limited evidence to assess whether the NHS is maximising the opportunity for earlier diagnosis through good referral practice or making optimal use of diagnostic resources.

CRUK has played a major role in implementing the National Cancer Diagnosis Audit. While funding constraints are a barrier to further audit rounds, there remains value in this approach which has significantly increased our understanding of referral practices. It is also important to make better use of existing datasets and ensuring they are effectively used for quality improvement.

Is there any additional evidence you would like the review to consider?

Workforce shortages across the NHS impact all aspects of cancer care. The most recent data showed the NHS in England has 132,139 vacancies,[1][xiv] and within specialties key to cancer these shortages are acutely felt. For example, the Royal College of Radiologists found in 2021 there was a 17% shortfall in consultant oncologists in England.[xv]

While current poor cancer service performance reflects the gap between workforce capacity and demand, we must also recognise the negative impact this has on service improvement, transformation and innovation. The importance of ensuring that clinicians have time to engage meaningfully in clinical leadership at a system level, support cross-pathway collaboration and can implement new service models and innovations has been a consistent theme in our work to understand the effectiveness of Cancer Alliances.[xvi]

The same is true for ICSs, and it is vital that clinicians are enabled to commit dedicated time to clinical leadership and support implementation of service improvement, engage in research and understand new innovations to improve implementation. This will depend on addressing the current NHS workforce shortages, highlighting the importance of the Government's upcoming NHS long term workforce plan being published in full and matched with the necessary funding to deliver workforce growth in shortage areas.

Finally, cuts to the public health grant have compromised local authorities' ability to provide preventative services like stop smoking services.[xvii] Sustainable and sufficient funding for these is critical if ICSs are to ensure that population health is a focus across local authority and NHS activity.[xviii,xix]

About Cancer Research UK

Cancer Research UK (CRUK) is the world's largest cancer charity dedicated to saving lives through research. We support research into over 200 types of cancer, and our vision is to bring forward the day when all cancers are cured. Our long-term investment in state-of-the-art facilities has helped to create a thriving network of research at 90 laboratories and institutions in more than 40 towns and cities across the UK, supporting the work of over 4,000 scientists, doctors and nurses. In 2021/22, Cancer Research UK spent £388 million on new and ongoing research projects into the causes and treatments for cancer.

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[1] Total workforce vacancy FTE in NHS England, April-June 2022. Please note, due to the complex nature of how NHS vacancy data is defined and collected, all data sources should be treated with a degree of caution. These data do not indicate how much of the reported substantive gap is filled by temporary staff.

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