Shaping the future healthcare experience for people with cancer

July 2023

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1 What matters most to people with cancer

At Macmillan Cancer Support we do whatever it takes to support people with cancer to live life as fully as they can. Douglas Macmillan stood for 'betterness' when he founded the organisation in 1911, and we believe his ethos is as important and relevant today as it was over 110 years ago.

In the spirit of betterness, we are aiming to start a conversation about what it will take to ensure the best possible healthcare experience for people with cancer by 2035. Through the work that is summarised in this document, we want to catalyse everyone working in healthcare, as well as people who have been or who are impacted by cancer, to take action, now; so that we can work together to ensure that everyone diagnosed with cancer in 10 to 15 years' time has the best possible experience of healthcare and the best possible outcomes.

To do this, it is essential that we begin with what matters most to people with cancer, as they are the experts, who know what they need and how the system works for them.

At Macmillan we have developed a rich understanding of the needs of people with cancer from our wide-ranging research and work alongside people with cancer over the years. To provide additional insight to help inform this project, over 25 people with lived experience of cancer generously contributed their time, knowledge and experiences to our discussions. We are hugely grateful to the people involved for bringing the voice of lived experience into the work, informing the questions that need to be asked and the decisions that need to be made.

Clear priorities came out of these conversations with people with lived experience of cancer at a top-line level, which broadly align with what we have heard through our previous work. We have outlined these priorities in this section of this summary report. Our ambition is to accurately report the experiences of people with lived experience of cancer and we include people's own words where relevant to support this. We also recognise that there will still be some people with lived experience of cancer whose needs and experiences are not yet fully represented when we carry out projects such as this one and we are committed to addressing this.

While the fundamental needs of people with cancer are unlikely to change in the future, the changing cancer experience will mean that people have new needs, and we will need to think differently about how best to respond to them.

On thinking ahead...

As a starting point, people with lived experience of cancer told us why it is so important that we – the various individuals and organisations involved in delivering care for people with cancer – work together now to bring about a better future when it comes to cancer care.

We at Macmillan are keen to work in partnership with other organisations and communities – especially those representing marginalised groups of people with cancer – to build on these findings to shape solutions that can transform cancer care.

On clinical care...

People with cancer will always need excellent clinical care.

This starts before people are diagnosed with cancer – ensuring people have the right support to understand and manage their risk of cancer where possible.

> **"If you are telling people to get fit and lose weight, you need to give them the support to do that... There are barriers and people need support."**

To diagnose cancer and ensure people get the best treatment for their individual cancer, they want equitable access to quick and accurate tests.

> **"[I would like to see] a more seamless journey through investigation and diagnosis and rapid access to up to date treatment options. [I] would also like equity of access to the treatment options available in other parts of the UK."**

> **"Quick and accurate diagnostics are so, so important."**

People want to be supported to manage their cancer symptoms, alongside their other health conditions and needs, and to be able to re-access specialist care if they need it.

"I want to know what my drug pathway looks like – what's next. I would also like my family to know about the side effects of that treatment."

Finally, people want support to live well with the consequences of cancer and cancer treatment.

"When you're in the thick of it, the MDT (Multi-Disciplinary Team of professionals coordinating someone's cancer treatment) works very well but that's a tiny bit in the middle and the bit before and afterwards is chaos. Wouldn't it be amazing if there was an MDT overlooking care pre- and post- treatment."

"The ongoing support is crucial especially in the first five years as your body changes and you have the odd niggle, it's good to have someone to speak to."

On cancer care and support...

Alongside excellent clinical care, people with cancer will always need efficient, effective and accessible cancer care that is tailored to them and their individual needs.

People want to be able to navigate all stages of their cancer care easily and efficiently.

"I would like a much clearer roadmap of the process from the point of diagnosis, through treatment, through post-treatment."

"[I would like to see] that patients are able to get joined-up cancer care around the country and that great variations in care around the country are reduced."

People want clear, timely information from trusted sources, delivered in a format and language that is easy to understand and use.

"You get a lot of leaflets, a lot of information, but it's not in plain English."

"[What's most important is] information about what to expect during treatment."

Wherever possible, people want care to be delivered in convenient and accessible locations, with support for people who need it to travel to more specialist settings.

"My local hospital now has a [specialist] hub so I have my follow-up appointments there. It's really convenient. That's a good thing."

"[I would like] more help for disadvantaged people to travel to receive the best possible treatment they can have."

Alongside face-to-face support, people also want to be enabled by technology to have better care and they want to be supported to use digital tools to manage and personalise their care.

"I would like to see better use of technology to support people having cancer care[....]"

"[Digital versus face-to-face care] – it needs to be an 'and/and', not an 'either/or'."

On living life as fully as possible…

Finally, people with cancer should always be able to live life to the full – whatever that means to them.

People want what matters to them, as well as to the people closest to them, to be prioritised throughout their treatment and care and, if relevant, towards the end of their life.

"We need to look at people as people and not just diseases. We are people with our own attitudes and beliefs with complicated health needs."

"We should be talking about personalised experience, not just personalised treatment."

Through shared decision-making and supportive conversations, people want to understand their choices and to access support which meets all their needs – physical, emotional, practical, spiritual and financial.

"People with a lived cancer experience should be afforded all the help and assistance to live life to the full after diagnosis. This includes access to services including counselling and mental health and wellbeing."

2 An introduction to this work

At Macmillan, we understand how cancer can impact every aspect of a person's life, so the scope of this work is necessarily vast. The insight we have summarised in this report focuses on the future of cancer care, touching on everything from prevention and early diagnosis to living with and beyond cancer and end of life care.

It is estimated that one in two people in the UK will be diagnosed with cancer in their lifetime by 2030[1] – through this work, we have looked even further ahead to 2035. Reflecting on the changes we have seen in cancer care over the past fifteen years – including safer surgery and perioperative care, the introduction of immunotherapies and digital healthcare – shows us what progress could be possible in the same timeframe as we move forwards.

A brief reflection on the changes in cancer care over the past 15 years

1990s
57 new drugs approved

- Introduction of targeted chemotherapy
- Mortality rate starts to decline despite aging population

2000s
57 new drugs approved

- **2003:** Tomotherapy system developed using CT-guided intensity-modulated radiation therapy
- **2008:** HPV vaccine offered to girls aged 12-13 at schools across UK

2010s
143 new drugs approved

- **2011:** Immunotherapy drug ipilimumab approved in UK for melanoma, followed by pembrolizumab and nivolumab in 2015
- **2016:** Minimally invasive and robotic surgery
- **2018:** CAR-T therapy approved in UK
- **2018:** UK's first proton beam centre opened
- **2019:** Histology independent treatments

2020-2022
76 new drugs approved

- **2020:** International Pan-Cancer analysis of whole genomes – analysed 2,600 whole genomes from 38 cancer types
- **2021:** record number of drugs approved for cancer (30)
- **2021:** Liquid biopsy – cfDNA under trial for clinical use in UK
- **2022:** National Screening Committee recommends targeted lung cancer screening is made available across the UK

Source: Deloitte Analysis, [2] Memorial Sloan Kettering Cancer Centre – A decade of progress in cancer care www.mskcc.org/news/decade-progress-cancer-care-and-what-s-next

[3] Sharing good practice – Electronic Holistic Needs Assessment and care planning (macmillan.org.uk)

[4] Arruebo M, Vilaboa N, Sáez-Guiterrez B, Lambea J, Tres A, Valladares M, González-Fernández A. Assessment of the evolution of cancer treatment therapies. Cancers (Basel). 2011 Aug 12;3(3):3279-330. doi: 10.3390/cancers3033279. PMID: 24212956; PMC3759197

2 An introduction to this work

Creating the space and optimism in the here-and-now to look ahead can be difficult, given the enormous challenges we see in cancer care today. Current problems – including rising cancer incidence and prevalence, severe workforce shortages and ongoing recovery from the impact of the Covid pandemic – need urgent solutions.

By discussing the potential for cancer care by 2035 today, however, we believe we will ultimately achieve more through focusing on sustainable and longer-term change.

At a top-line level, the themes we have identified have resonated in our conversations with peers across the UK. It is important to note however that across England, Northern Ireland, Scotland and Wales, each nation has its own challenges and opportunities – with some systems more integrated than others – and will need to decide the right actions to take with these in mind.

This work demonstrates the value that comes from bringing all of us who are passionate about creating a better future for people with cancer together, to think holistically about the factors influencing it. Too often these factors are considered in isolation or from a specific organisational or clinical perspective – radical change calls for systemic action to be taken forward collectively.

3 A summary of our findings so far

To bring together the insights that are summarised in this document, Macmillan commissioned Deloitte to support us in producing a report that draws on both our expertise and our networks, across the UK and also internationally.

Together, we analysed evidence, conducted interviews and held a series of workshops with people with lived experience of cancer and with people working in cancer care. We have spoken to over one hundred leaders in cancer care, including: policymakers and regulators, healthcare professionals and professional bodies, healthcare organisations and local government, academics and research funders, industry representatives and voluntary and community sector organisations across England, Northern Ireland, Scotland and Wales.

Through the process, we identified 12 factors that are influencing the evolution of cancer care. These are detailed on the next page. Whilst we explored these separately in our work, there are significant relationships between the factors that will determine how they evolve over time.

Alongside these 12 factors, this work has also considered the impact of demographic trends by 2035. The UK's aging and growing population[2] will increase cancer incidence[3], which in turn is a driver for increasing prevalence[4] alongside more people living longer with their cancer. It is important to acknowledge that this work has not considered explicitly the economic context for the UK over the next decade, but this will also be a critical influence both on people's health as well as on the funding available for healthcare.

Our research has identified 12 factors that are shaping and changing the experience of people living with cancer, and that these will continue to evolve over the next 10 – 15 years.

4 The 12 factors shaping the evolution of cancer care

People's understanding and awareness of cancer risks and symptoms

Early diagnosis (including targeting screening)

New and precision treatments

Personalised care (including wellbeing)

Living with and beyond cancer (including with multiple health conditions) and end of life care

Health equity

Location of care

Workforce availability

Workforce skillset

Data and digitalisation of healthcare

Priorisation of cancer in policy (including funding of cancer care)

Collaboration between public, independent and voluntary sector healthcare organisations

4 The 12 factors shaping the evolution of cancer care

This summary report explores the 12 factors grouped into five thematic areas:

- **Advances in science and technology**
  - Early diagnosis (including targeted screening)
  - New and precision treatments
  - Data and digitalisation of healthcare
- **Equity in cancer care**
  - Health equity
  - People's understanding and awareness of cancer risks and symptoms
  - Location of care
- **The future workforce delivering cancer care**
  - Workforce availability
  - Workforce skillset
- **Personalised care**
  - Personalised care (including wellbeing)
  - Living with and beyond care (including multiple health conditions) and end of life care
- **Policy and collaboration**
  - Prioritisation of cancer in policy (including funding of cancer care)
  - Collaboration between public, independent and voluntary sector healthcare organisations

Through the conversations exploring the 12 factors, we heard great optimism about the positive impact that exponential advances in science and technology could have.

- Home-testing for cancer, liquid biopsy technology and genome sequencing bring great potential to diagnose more people with cancer and at an earlier stage.
- Precision treatments will mean that many more people have better outcomes with fewer harmful side effects from their treatment.
- Technological advances should enhance the ability of healthcare professionals to deliver high-quality care, closer to home and enable people to manage their health with their clinical team, if they wish to.

However, we – at Macmillan – also heard significant concerns that healthcare systems and workforces across the UK may not be able to adopt this innovation equitably at scale. Depending on how different areas manage significant funding and workforce pressures, this could both compound and increase variation in people's care, based on their postcode, their income and their self-efficacy. There was most concern that some people may have an even worse experience and outcomes if urgent action is not taken now in four key areas:

- Health inequalities today mean there are stark differences in experience and outcomes amongst different groups. Inequalities could worsen if some people benefit more from advances in science and technology than others.
- The healthcare workforce is already in crisis with demand already outstripping supply. Without more staff supported to work differently and to develop new skills, cancer care will get worse, not better.
- With a workforce under pressure and an increasingly complex care pathway, personalised care could be under threat. Precision medicine means people's experience of treatment will be increasingly individualised, but if care is not tailored to people's individual needs, some people could have a worse experience and quality of life.
- The UK is already falling behind comparable countries on cancer outcomes.[5] This will get worse if UK governments do not invest sustainably with robust, long-term strategies and plans for cancer care including the workforce.

Finally, throughout our conversations, we heard a broad range of examples of how people across the UK are already innovating to realise the opportunities for the future and address the challenges we face today. This brings to mind the well-known quote said to come from the American-Canadian speculative science-fiction writer and essayist, William Gibson:

> **"The future has already arrived. It's just not evenly distributed yet."**

This report includes a selection of the examples we have come across to illustrate how cancer care is already changing and how we – together – can shape it for the future.

4a Advances in science and technology

Three of the 12 factors influencing the evolution of cancer care demonstrate the potential to significantly improve people's experiences of cancer care and their outcomes – early diagnosis; new and precision treatments; and data and digitalisation of healthcare.

We must harness advances in science and technology to make early diagnosis of cancer a reality for everyone.

Diagnosing cancer earlier is a shared ambition across the UK, yet progress towards this has been slow. Less invasive diagnostic techniques combined with molecular advances and advanced data analytics now bring the potential to diagnose people earlier and lead to a better prognosis for many.

Example: The Scottish Capsule Programme (SCOTCAP)[6] using Colon Capsule Endoscopy (CCE) has been integral to the national redesign of outpatient gastroenterology services, enabling early and effective screening in the community and avoiding unnecessary referrals for hospital outpatient appointments. CCE is highly accurate, with the potential to be cost effective, less invasive, and more acceptable to people than existing procedures. The project has also delivered an Innovation Partnership Framework to support innovative procurement for public services in Scotland.

In particular, if studies prove successful, liquid biopsy technology will transform the accessibility and reach of screening, being able to detect multiple cancer types with one blood test. It could also be used in surveillance strategies and as reassurance for people after cancer to guide treatment and detect recurrence at a much earlier stage.

However, people will need personalised information to understand that risk, make decisions to reduce it and be supported through this new aspect of the cancer experience.

Example: The NHS-Galleri Trial[7] is a research trial to see if using the Galleri blood test – which can detect signs of many different cancers in a sample of a person's blood – alongside existing cancer screening in the NHS can help to find cancers earlier.

Screening may, however, be an area of increasing inequity – uptake today is higher in communities where there is a higher awareness of cancer symptoms and risks. Taking action to address this – now – is critical to achieving health equity (explored in the next section).

If the shift to earlier diagnosis of more cancers is successful, healthcare systems will need to design service models with sufficient workforce to assess, diagnose and treat more people at the early stages of cancer. Novel treatments will need different workforce configurations with new training requirements to avoid people experiencing delays waiting for a diagnosis and for treatment.

4a Advances in science and technology

As genomics becomes part of population-level screening and is embedded in cancer care, more people will understand that they and their family have an inherited risk of cancer. This means people with an inherited risk of cancer can be looked after more closely and benefit from preventative or early diagnosis strategies.

Example: A team at the University of Southampton funded by Cancer Research UK has developed a web-based decision support tool to help young women with breast cancer reach an informed decision around BRCA (breast cancer) genetic testing[8]. This has been adopted by the National Institute for Health Research and Breast Cancer Care is funding a project to test its implementation in oncology care across Wessex[9].

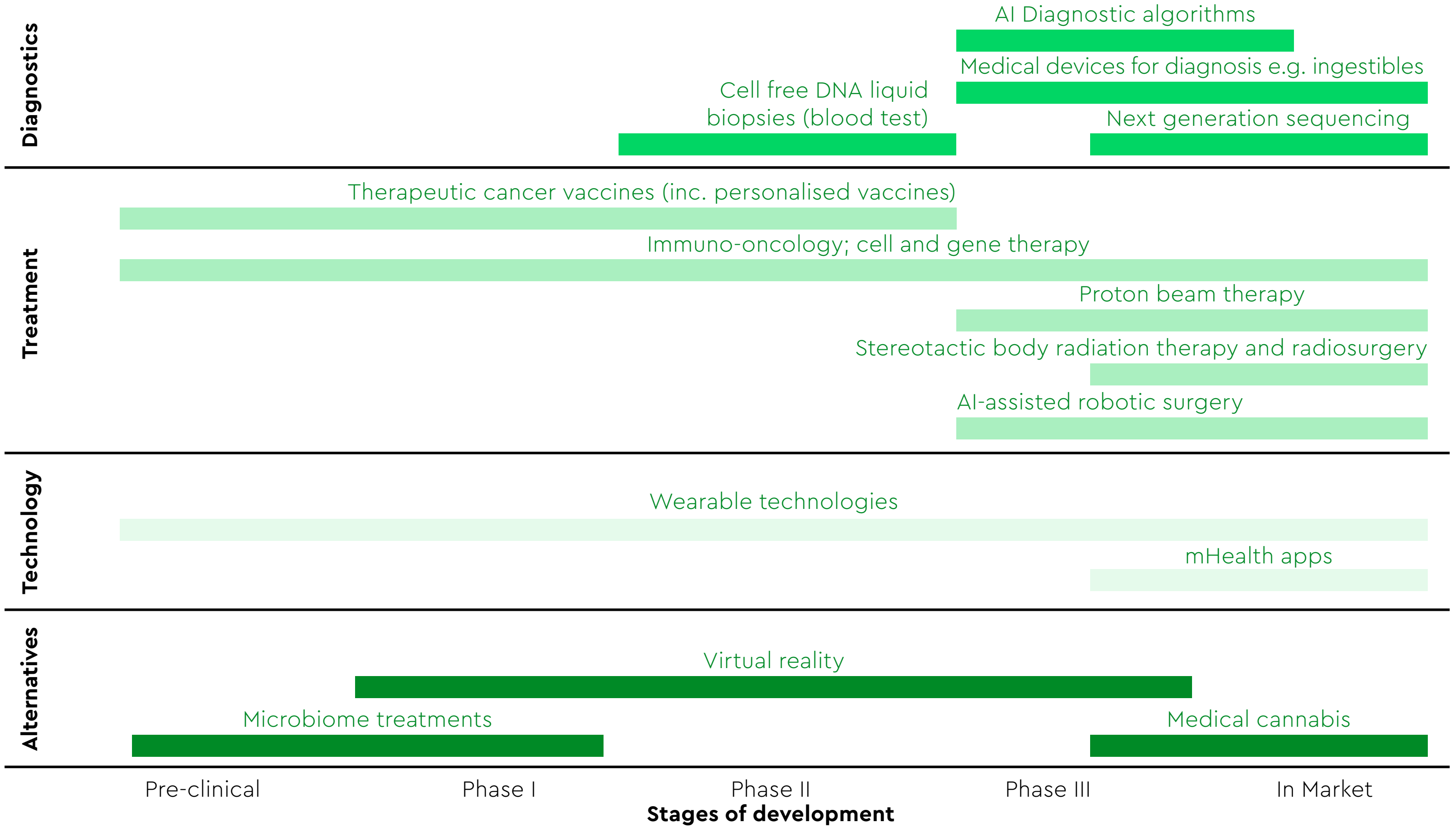
We must adopt advances in medicine to tailor people's treatment to their individual cancer to improve cancer outcomes.

Increasing numbers of precision medicines will become available over the next decade as demonstrated on the next page. By 2035 this could include cancer vaccines, a type of immunotherapy. As these are adopted in clinical practice, alongside genome sequencing and pharmacogenomics, treatment options will fundamentally change. Treatments can be focused on a cancer's genetic make-up, moving away from generic tumour type-based approaches. Advances in high-precision radiotherapy techniques supported by data analytics will predict people's individual responses to treatment. Better risk stratification and prediction will make clearer who will benefit from particular types of surgical intervention and how to minimise the risk of complications. These approaches can reduce harmful side effects from treatment and greatly enhance shared decision making.

Example: The Department of Health for Northern Ireland has introduced routine DPYD testing[10] in 2021 to identify potential DPD (dihydropyrimidine dehydrogenase) deficiency in cancer patients before they are treated with certain types of chemotherapy, to check if they are at risk of severe side effects to the medications, and to help prevent this from happening.

Equitable access to the most effective models of precision treatment for people across the UK requires investment in up-to-date equipment, alongside the skills and knowledge of the workforce to deliver them.

Examples of diagnostics, treatments, technologies, and alternatives in their development stages.



Source: Deloitte Analysis; Current Oncology (2020), Frontiers in Oncology (2021), Cancer Treatment Reviews (2022), Nature Reviews Drug Discovery (2022), BioNTech (2022), The Lancet Digital Health (2022), JMIR (2022), Journal of Geriatric Oncology (2019), Contemporary Clinical Trials Communications (2022), BMC Cancer (2021), Nature Medicine (2019).

4a Advances in science and technology

In the future, more people will be making decisions about novel treatments with new, complex genomic information. However, a significant proportion of people may still not be treatable with a precision approach, as not all genetic mutations will be targetable despite promising drug development. For certain cancers, disease outcomes are still, sadly, unlikely to improve, leading to disappointment for some people.

People with cancer and professionals will need up-to-date, authoritative information that they can access in a way that is accessible to them. They will also need the knowledge and confidence to discuss these complex treatment choices to make the right decisions for themselves about their treatment and care alongside their healthcare professionals.

Alongside funding for these new technologies and treatments, an early priority must be to plan for their impact in terms of where and how novel care is delivered, and on workforce skills and knowledge to support more people experiencing these new treatments and to signpost them to find peer support from people with shared experiences of treatment.

Full representation of people with cancer of all ethnicities in datasets for clinical trials and genomics will also be essential. Clinical trials have historically underrepresented people from ethnically diverse communities. Collaborating with communities to address cultural and language barriers and mistrust as well as providing researchers with the tools to be more inclusive in trial design is critical so that new treatments are grounded in evidence for all protected characteristics and social determinants of health. Focusing specifically on genomic datasets, there is currently a bias towards people of European ancestry. For people to benefit from genomic advances equally, datasets must be fully representative of people of non-European ancestry.

4a Advances in science and technology

Example: Genomics England's Diverse Data Initiative[11] aims to 'reduce health inequalities and improve patient outcomes in genomic medicine for minoritised communities'. Its intended outcomes are to earn and sustain the trust of diverse communities in genomics, achieve more and better research with diverse communities and improve prognosis, diagnosis, treatment and care involving genomics for diverse populations.

We need to keep pace with advances in technology to improve the way healthcare is delivered and the support for healthcare professionals and people with cancer.

The pandemic accelerated the role of digital tools and technologies in cancer care, but its use is very varied across healthcare systems today. Looking ahead, further change will be driven both by the evolving needs of people with cancer and healthcare systems as well as by advances in technology which will shape the way services are delivered and how people interact with care.

By 2035, digital solutions will be present in every part of cancer care. Digital and robotic tools will increasingly automate administration and repetitive activities, reducing burdens on clinical staff. Increased use of technology coupled with improved data analytics and the use of artificial intelligence will generate new insights to enhance clinical decision-making.

Example: Through a partnership with South Eastern Health and Social Care Trust and Cancer Focus NI, a two year pilot at Ulster Hospital, Dundonald is offering an advanced mole mapping technique[12] for specific patients identified by the clinical team as being at higher risk of developing melanoma skin cancer. It uses a new technology – Automated Total Body Mapping – which detects malignant melanoma earlier when treatment is most effective.

Telemedicine will connect people with cancer to professionals in different settings, bringing some aspects of care closer to home and reducing geographical inequity. Wearables, sensors and apps will increasingly enable some people to monitor and manage their health, with the data generated by these digital health solutions enabling clinical teams to intervene when needed.

Example: Macmillan has piloted schemes using patient-recorded outcome measures platforms to monitor for late effects and treatment side effects and has piloted apps to improve mental health and sleep in people with cancer.[13]

Example: Wales is exploring virtual reality as an intervention to reduce anxiety and improve overall experience for people during treatment.[14]

However, fully realising technology's transformative impact will require investment in an interoperable IT and data infrastructure, in building trust and confidence amongst citizens and patients to share their health data securely and in workforce skills development. For example, clinical teams will need to learn to use and evaluate digital and artificial intelligence tools to work more efficiently and effectively.

Enabling everyone with cancer to benefit from digital healthcare equitably will mean prioritising digital inclusion, supporting people with simple to use digital tools in collaboration with their clinical teams, and providing trusted advice to find and navigate digital solutions within a large and rapidly changing market. There needs to be a focus on building trust amongst citizens to use new, different technologies for their care, as well supporting people to develop the skills and knowledge they need to benefit from them. Digital tools will need to complement rather than replace face-to-face support, with services designed to respond to people's personal preferences and needs and address the variety of experiences that people have today.

Moving the conversation on

A consistent theme of this work has been that people are confident that scientific and technological advances will continue, bringing the promise of major improvements in people's clinical outcomes and experience. However, innovations also have potentially disruptive impacts. The need to develop services to support the toxicities caused by immunotherapies is a significant recent example.

There is significant concern about healthcare systems' ability to adopt these advances equitably and at pace. Innovation in isolation is too common today, with examples of good practice often not taken to scale and continuing unwarranted variation in care. It will have major implications for the workforce as well as for healthcare estates and infrastructure. It will need effective information sharing, collaboration and leadership to scale innovation. People with cancer need to be involved to shape the approach to implementation of innovation so that it takes account of their needs and preferences.

This leads us to ask:

What conditions need to be in place for healthcare systems to adopt all this innovation at pace equitably across the UK?

4b Equity in cancer care

It is essential that preventable differences in cancer care are addressed over the course of the next decade to deliver fair, personalised cancer care for everyone in the future. It will be a grave failure by all of us working in cancer care if we do not achieve this.

While health equity spans all the 12 factors explored in this work, three factors emphasise the importance of shaping the future now, so that everyone benefits from advances in science and technology. These are health equity, people's understanding and awareness of cancer risks and symptoms, and location of care.

We must focus relentlessly on achieving equity in cancer care.

Today, there are stark differences in people's experiences of cancer care and in their outcomes. These differences have multiple, complex and often interconnected causes.

This is further complicated by the underdeveloped nature of the current data and evidence on inequalities. Much of the evidence that exists is about inequalities for people based on their:

- socio-economic status: mortality remains significantly higher and the gap in cancer mortality rates between the least and most deprived groups has worsened..
- ethnicity: people with cancer from ethnically diverse backgrounds often have worse experiences and outcomes.
- location: survival rates vary by cancer type and where the person is treated.
- age: older people may be offered less radical treatment options.

The characteristics highlighted above are not the only relevant factors, but they are some of the most well documented and evidenced. However, there is a lack of up-to-date, accurate and detailed data relating to the prevalence and experiences of cancer even within the data relating to these four characteristics.

Collection of comprehensive data and evidence, in collaboration with diverse communities, is essential to ensure there is a full understanding of existing inequalities. Achieving this will mean ensuring that the healthcare workforce recognise accurate data collection as a priority and that this is enabled by well-designed, secure systems which citizens trust.

It must also be built into the roll-out of new innovations to fully understand their impacts.

4b Equity in cancer care

Additionally, it is likely that health inequities will increase further over the next decade if we do not take action now. Possibilities include:

- the rising cost of living following the pandemic could have a serious impact on health outcomes for people from lower socio-economic groups. Action must be taken to mitigate the impact of the cost-of-living crisis on access to cancer care and on the overall health of the population.
- as the demographic make-up of the UK becomes more diverse, the healthcare system needs to recognise that diverse communities may engage differently with healthcare. It must actively design services that give everyone an equal voice and provide choice in how their needs are met, irrespective of their cultural identity.
- digital tools used to deliver healthcare may exclude those with a lack of access to digital devices, poor broadband connectivity or a lack of digital literacy. Digital solutions bring opportunities to reduce geographical or other access inequities for some, but they must be accompanied by alternatives for those who cannot or do not choose to engage digitally.
- people who live near or can easily travel to specialist centres will have more opportunity to access the latest treatments, unless there is better support for people who need it most. This could include support with transport and accommodation; more personalised care to support people to access appointments at times that suit them; and different service models which take account of community needs.

Working collectively with partners across local government, education, transport and housing amongst others, there is the opportunity now to set a shared national ambition to achieve health equity in cancer care.

To achieve this, it will be essential to work in partnership with communities to co-create solutions. It will mean building on the strengths, skills and knowledge within communities and focusing investment and action on people who are at risk of worse outcomes or experience. It also means investing in research to understand better how to address inequity, particularly after diagnosis where the current evidence base is weaker. This is essential to avoid a uniform approach and to target resources in communities where inequalities exist.

Example: In England, the NHS Core20Plus5 (adults) initiative[15] has chosen early cancer diagnosis as an area for multi-agency approaches to improve equity with co-ordinated initiatives across the most deprived 20% of the population and 'Plus' groups which include ethnic minorities, inclusion health groups and other groups identified at a local level.

We must increase public understanding and awareness of cancer.

To realise the potential of scientific advances and diagnose people earlier, it is essential that many more people participate in screening and are supported to seek out help to identify possible cancers earlier. This must prioritise health equity given stark differences between communities today, for example black people in England are less likely than white people to have their cancer diagnosed through screening.[16] Improving understanding and awareness of cancer and addressing misconceptions in specific communities must be a priority today.

Example: In London, Macmillan is collaborating with barber shops as safe places to talk about cancer to increase awareness in marginalised communities.[17]

Achieving this will mean co-creating education strategies with communities who currently have less awareness and understanding of cancer risks and symptoms, or who lack trust in healthcare systems. It will also require investment in public health and behaviour change interventions which can reduce harmful behaviours; and to grow the capacity and skills of trusted community sources of support such as experts by experience.

There are also opportunities to develop new referral routes for cancer tests which could be more accessible for marginalised communities, for example, from community pharmacy.

We need to take every opportunity to make cancer care and support more accessible for people.

Bringing cancer care closer to home – into primary and community settings – brings the potential to improve health equity. Whilst this needs sensitive implementation to avoid introducing new inequalities in uptake or adoption, it should improve the accessibility of care for some people by reducing geographical or practical barriers. Opportunities include:

- increasing the accessibility of non-invasive screening methods at home.
- increasing access to community diagnostics.
- delivering treatment at home or in the community for people who are assessed by genomics as being at lower risk of serious side effects.
- promoting prehabilitation (nutrition, exercise and emotional support) before treatment to optimise health and wellbeing using community resources such as local leisure centres and charities.
- using technology to connect people with cancer to specialist centres, for example, with support to use affordable, simple digital tools for remote monitoring.

Example: During the pandemic, the Macmillan Haematology Clinical Nurse Specialist team at the Royal Oldham Hospital pioneered chemotherapy treatment for people with myeloma at home, educating and supporting people to administer treatment themselves. Patients were given access to a 24-hour support line for any issues, and they received nurse-led follow up phone appointments on treatment days which allowed for continued holistic support.[18]

Example: Recognising that some people do not have reliable access to the internet, a digital hub in a local community hospital has been set up in Wales to enable conversations with non-local specialists that builds in support from local care teams.[19]

Moving care into the community wherever possible, alongside greater use of telehealth and telemedicine, brings the potential to create more physical capacity in hospital settings. It must shape healthcare estate strategies, including providing professionals with access to the technology required for confidential care in community settings. It will also require careful planning to put in place increased resource for the community workforce.

Complex care and treatments will continue to require specialist settings. This means putting in place effective support to ensure equity of access to those in more deprived communities or in rural and remote areas. Effective care planning should minimise travel, with better data sharing joining up people's care across settings.

Moving the conversation on

There is widespread concern about the danger of inequalities, but also a firm commitment and determination to address these and to achieve health equity in future.

There is optimism about the potential for care to be delivered in the most accessible location for people to reduce geographical inequity today, alongside concern that some people will be excluded by the greater use of digital.

Today, innovations are often first experienced by more privileged communities, so they need to be designed differently for the future, working with marginalised communities, so that people with cancer benefit equitably.

A key question for everyone involved in delivering cancer care is:

‘How do we partner with communities and with people who have lived experience of inequalities to create robust data and evidence and design the future of cancer care so everyone benefits?'

4c The future workforce delivering cancer care

The best possible future for cancer care cannot be delivered without a healthcare workforce that has the right resources, knowledge, skills and ways of working. This work has focused particularly on healthcare, but across the UK it is important to recognise and consider the vital role the wider care workforce plays in people's cancer care.

Two of the 12 factors focus on workforce: workforce availability and workforce skillset.

We will need more people working in healthcare to deliver cancer care.

Today, the healthcare workforce is in crisis after a decade of under-investment and the unprecedented challenge of delivering care during a global pandemic. This crisis affects most professional groups and is particularly acute in some parts of the UK. People in many areas of the country face long waits for diagnosis and treatment, as a result of staffing shortages. The work pressure this creates on staff today is already causing a vicious spiral of burnout and a retention crisis. Comprehensive, long-term workforce strategies and plans that are appropriately funded are critical to address these problems today and for the future.

These strategies and plans need to exist both nationally and locally, and address recruitment, retention and workforce transformation – including skills, capability and knowledge development. To improve workforce availability today, it is essential that these strategies and plans successfully address the various causes of professionals leaving the NHS today and put in place accessible, effective health and wellbeing support for staff working in emotionally demanding situations. These causes include work pressure as a result of high vacancy rates; issues with pay and terms and conditions; a lack of flexible working; growing demand and complexity of need increasing workloads; poor access to training and continuing professional development; low morale and wellbeing; and bias and discrimination.

To support their implementation, healthcare systems need to collect comprehensive workforce data from local to national level to understand the cancer workforce.

In 2035 there will need to be a larger healthcare workforce to deliver care to the growing number of people with cancer. Whilst digital and robotic tools will automate some activities, such as pharmacy dispensing robots, most innovation will require more staff to deliver it, not less. This will require investment to create the pipeline of people working in both specialist and generalist professional roles as well as in non-clinical roles, including in the growing areas for the future such as data science, genomics and care navigation. It will also require healthcare systems to evaluate and share knowledge of how new roles are introduced, trained and supported.

4c The future workforce delivering cancer care

Example: Wessex Cancer Alliance is trialling the use of physician associates, a relatively new role, to the two-week wait cancer diagnostic pathway for colorectal, breast, urology and gynaecology.[20]

Example: The rapid expansion of support workers to help people with cancer navigate care whilst also freeing valuable time for specialist nurses has already proven valuable and is now supported by a competency framework.[21]

We must support and enable the healthcare workforce to work differently and to have the skills and roles to adopt new technologies and treatments.

The future healthcare workforce will need to work differently in future to accommodate growth in the number of people with cancer, increasing complexity of need, new technologies and delivery of care closer to home. Workforce transformation will need to accelerate to achieve this. This includes making the best use of clinical and non-clinical skills in existing and new roles; realising the potential of technology to communicate and collaborate effectively and reduce administrative burdens; and creating new ways of working which bring together multi-professional teams across healthcare settings and beyond.

Example: The Velindre Cancer Centre in Cardiff has introduced a joint Cancer Nurse Specialist and Allied Health Professional led one-stop neuro-oncology virtual clinic[22] to enhance quality of life and extend survival for people. People have access to holistic support, in a single session, from a neuro-oncology clinical nurse specialist, an occupational therapist, a physiotherapist, a dietitian and a speech and language therapist.

Example: A project funded by the former Health Education England and led by Wessex Cancer Alliance is exploring the role of boundary-spanning clinical nurse specialists,[23] working across primary and secondary care to improve knowledge transfer, develop primary care skills and reduce pressures on GPs.

4c The future workforce delivering cancer care

For all staff involved in delivering cancer care, the complexity of new treatments will require an increase in specialist skills, whilst delivering personalised care for an aging population living with multiple health conditions will simultaneously increase the importance of generalist skills. To support the balance of professionals in specialist and generalist roles, it will be essential that foundational knowledge about cancer – alongside an understanding that this may be one of a number of health conditions people may be living with - is included as a core component of undergraduate and postgraduate education for all healthcare professionals.

Attractive, flexible career and education pathways with funding to deliver them will be critical to support the healthcare workforce to develop the knowledge, skills and capabilities to deliver cancer care of the future.

The exponential growth of innovation will mean that the need for education and training is greater than ever before. Some innovations, for example CAR-T cell therapies, will require specific, seismic shifts in training and recruitment to meet possible demand. Today professional education is often not accessible because of the time or cost involved, or because it lacks direct relevance.[24] Professional accreditation often involves broad curricula that meet the needs of regulators but not of staff and patients.

Looking ahead, the pace of change will demand an agile approach to modular, accredited education and training to support the continual upskilling of an increasingly flexible workforce. Training and education can be delivered by a variety of providers but requires coordination and accreditation for clinical roles to be most effective in any part of the UK, with non-accredited provision for non-clinical roles working in healthcare.

Example: The West Suffolk NHS Foundation Trust identified that Cancer Nurse Specialists (CNS) in five specialities were due to retire in the next few years. As a proactive response, they developed a bespoke 18-month development programme for Band 5 nurses wanting to progress to CNS positions. Nurses who took part in the programme went on to get CNS posts.[25]

Moving the conversation on

First, the twin issues of increased numbers of people retiring and recruitment challenges mean thinking differently about workforce planning. This includes attracting more people to consider careers in healthcare; finding new ways to enable experienced professionals nearing retirement to work flexibly; and supporting people in the workforce today to develop new skills and pursue fulfilling careers. Across the UK there has been a growing focus on establishing competency frameworks to support this. The frameworks need to be aligned to appropriate educational resources for those wishing or needing to enhance specific knowledge and skills.

Example: The Aspirant Cancer Career and Education Development (ACCEND) programme[26] in England will support aspirant cancer nurses and allied health professionals to increase their knowledge, skills and capability, and provide the existing cancer workforce with access to the education and training needed to match the competencies required for their role.

A key question for everyone involved in delivering cancer care is:

'How do we attract people into healthcare careers, enable them to develop those careers in the way which best suits them and make best use of the skills, knowledge and capabilities of older, more experienced staff?'

In addition, despite ongoing efforts, it is very unlikely that current workforce supply will match the demand for healthcare that we will see over the next decade. All professional groups are facing shortages and some, for example therapeutic radiography, need significant expansion to meet predicted demand.[27]

There are many opportunities to transform the workforce. These include using technology and automation differently; clinical and non-clinical roles working differently within multi-disciplinary teams; developing new roles such as physician associates and introducing new models of care for people with cancer. This relies on exceptional clinical leadership to move forward. It will also be essential to engage people with cancer in the design of new models of care to ensure they are confident in and accept support from them.

The challenge is creating the time for the healthcare workforce to design and implement new, safe models of care given the immense pressures today, as well as to take advantage of educational offers that need to be affordable, accessible and agile to support the workforce to deliver optimal care.

Another key question for everyone involved in delivering cancer care is:

'How can we effectively develop workforce skills, roles and ways of working now to deliver the pace and scale of workforce transformation which will be needed over the next decade?'

4d Personalised care

Alongside improving people's clinical outcomes with advances in precision medicine, personalised care must be a high priority because cancer affects everyone differently and people need tailored support to meet their different physical, emotional, spiritual, financial and practical needs. Evidence demonstrates personalised care improves people's quality of life and their experience of care.[28] Two of the 12 factors focus on this: personalised care and living with and beyond cancer, including with multiple long-term health conditions as well as end of life care.

We must maintain our focus on the holistic needs of people with cancer, so that everyone experiences personalised care.

Advances in treatment will often be based on specific molecular, genomic or anatomic features of an individual cancer. These precision approaches are very valuable but should not be confused with personalised cancer care.

Excitement about precision medicine is justified but must not take attention away from the equal importance of understanding people's wider needs and priorities, so that their experience of care and support is focused on what matters to them. After all, genomics are an exceptionally accurate way of defining what is the matter with a person, but can only shed light on some of the things that matter to them.

The increasing complexity of cancer care, as it is delivered in different settings over a longer period, may threaten the delivery of high-quality personalised care because of siloed working by an overstretched workforce.

Prioritising proven tools and interventions like personalised care and support planning (including holistic needs assessments) remain critical. In some parts of the UK where systems are more integrated, the use of holistic needs assessments to identify and support non-clinical needs is already becoming mainstream care. These tools enable healthcare teams to understand what matters most to individuals throughout their cancer care and how to signpost people to support.

4d Personalised care

Example: In Renfrewshire the Improving the Cancer Journey Service (ICJ)[29] delivered by Renfrewshire Council in partnership with Macmillan uses a holistic needs assessment tool to identify support needs and signpost to sources of support for people with cancer as well as other long-term health conditions. The ICJ service is being rolled-out across Scotland as part of the Transforming Cancer Care (TCC) partnership with the Scottish Government.

Example: The Scottish Government is piloting different models of providing a single point of contact to meet its ambition that people will receive dedicated person-centred support throughout the pathway. Across 12 different projects, roles such as pathway coordinators, navigators and support workers are being tested at different points in the pathway. Learning from these pilot projects will feed into the development of a framework to support best practice so that the concept can be adopted by other Health Boards.[30]

Example: In Swansea, a dental therapist is a core member of the head and neck cancer team to improve the quality of care for people with cancer, ensuring treatment focuses on quality of life and holistic wellbeing.[31]

Whilst this work is focused on people's healthcare experience, we at Macmillan know how people with cancer have many different needs and priorities: for example financial, employment and practical concerns. Healthcare teams will continue to need to know where people can find support to meet all their needs. Signposting to carefully co-designed digital solutions can help some people with cancer navigate towards personalised care independently.

Supporting the workforce to develop the knowledge, skills, sensitivities and capabilities to deliver personalised care should be at the heart of future plans. Equally important will be investing in, and putting in place, secure data sharing frameworks so that accurate, holistic and timely information is shared with the individual's consent between healthcare and wider teams to facilitate personalised care and support. Finally, the services to meet people's holistic needs, including equitable access across the UK to prehabilitation, rehabilitation[32] and mental health support, will also need continued, appropriate investment.

Example: In Greater Manchester, Prehab4Cancer is offered to some people with newly diagnosed cancer who will be undergoing either colorectal, lung or oesophago-gastric surgery. The programme includes prescribed physical exercise, nutritional screening and advice, and emotional wellbeing support before, during and after cancer treatment.[33]

We need to be prepared to support more people to live with and beyond cancer, as well as to die well.

Population and treatment changes mean that more people are likely to live with and beyond cancer for a number of years[2,3], meaning their care will need to be managed as a long-term condition. Many people will also be living with one or more other health conditions. This may make it harder for healthcare professionals to assess people's holistic needs, and people with cancer may struggle to know who is leading the delivery of their care.

It will be critical that the primary and community workforce is resourced and skilled to support people to live well with cancer as a long-term condition. This will mean assessing and addressing their holistic needs across multiple health conditions, with the ability to access specialist support rapidly when needed. Closer working between professionals from different specialties through the cluster medicine model will be important as well as mental health support integrated with physical care. Delivering joined up, holistic care will demand new workforce models which bring together specialist and generalist skills, such as geriatric oncology.

Example: Multidisciplinary clinics of oncologists, geriatricians and Allied Health Professionals make comprehensive assessments of older people with cancer, such as at the Macmillan supported GOLD service at Guys and St. Thomas' hospitals and the frailty clinics at The Christie hospital.[34]

With more people living longer with and beyond cancer cared for across a variety of healthcare settings (including primary and community settings and the independent sector), support with navigation and coordination of care will be essential. There are real opportunities to enable people in clinical and non-clinical roles to work differently together and to join up care more effectively through technology.

In the future, changes to cancer demographics will mean the number of people dying from and with cancer, and dying with complex needs and other health conditions, will increase. It is right to be optimistic about novel treatments, but people also need support to plan ahead and consider what matters most to them as they approach the end of their lives.

Growing numbers of people dying will make getting the fundamentals right even more important, including 24/7 access to out-of-hours medicines and funding palliative care services in the community.

More resources will be needed to enhance the services and skills of community care teams to support people to die at home, working alongside specialist palliative care teams focused on people whose needs are more complex.

Example: In Barnsley, an Advanced Specialist Practitioner role was introduced through the Palliative and End of Life Service to provide enhanced care planning to care home residents in the last year of life, reducing unplanned hospital admissions and increasing staff confidence discussing end of life issues.[35]

Moving the conversation on

At Macmillan, we have heard extensively from people with cancer about the challenges they face today navigating and joining up their care, and it is likely that this will become increasingly more complex in future.

Much work is already underway across the UK to explore how best to improve coordination of care including single point of contact models, use of digital portals and the role of the non-clinical workforce as navigators, coordinators and link workers.

The example of a summary health record held digitally and made available securely to all relevant healthcare organisations was often given as a digital solution for optimal care that is technically possible but this has not yet been implemented.

A key question for everyone involved in delivering cancer care is:

'What are the most effective approaches to care coordination and to navigate people to the support they need?'

Understanding this will enable those of us working in cancer care to make more rapid progress towards making these available to everyone.

Another key question for everyone involved in delivering cancer care is:

'How do healthcare services and ways of working need to develop to best meet the needs of the aging population and those living with multiple health conditions?'

Most people with cancer already have at least one other long term health condition (multi-morbidity). As multi-morbidity becomes the norm, teams will have to consider the impact of a cancer diagnosis on the person's other long-term conditions and vice versa. Personalised care needs to consider this holistically for the individual. This question clearly goes beyond cancer care and is a key question for health and care to answer over the next decade.

4e Policy and collaboration

Finally, achieving the best possible future for cancer care is dependent on sufficient funding, effective policy and close collaboration between all organisations involved in cancer care.

This is the focus of the final two of the 12 factors:

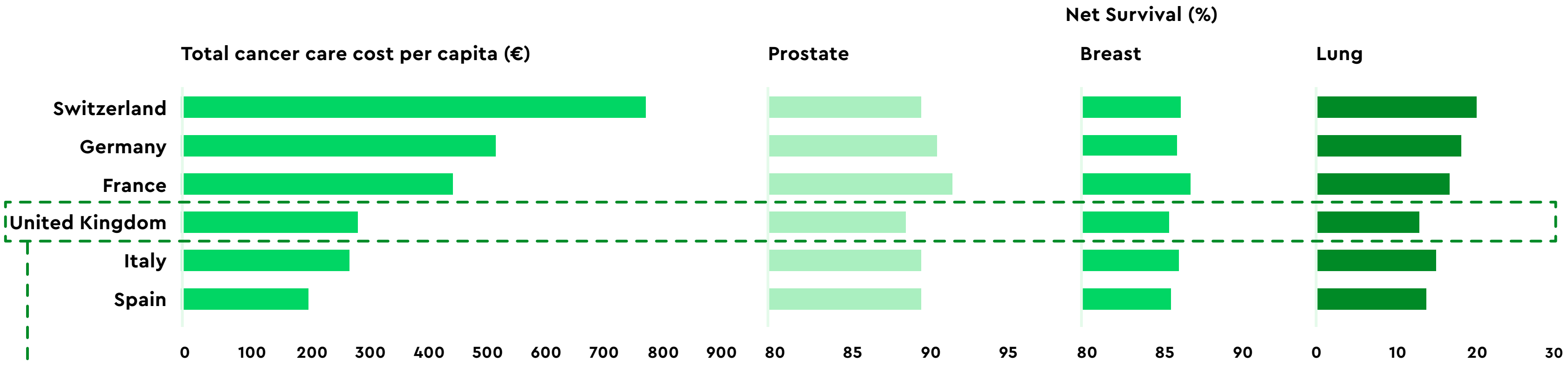
- prioritisation of cancer in policy (including funding of cancer care).
- collaboration between public, independent and voluntary sector healthcare organisations.

We have to invest sustainably to deliver ambitious programmes to improve cancer care across the four UK nations.

Today, the UK is behind the best-performing countries in the world on a number of health measures. In Europe, the UK was 12th for five-year net survival in prostate, 14th for breast and 18th lung cancer.[36] The UK is also lagging behind the best Organisation for Economic Co-operation and Development (OECD) countries on a number of health measures,[37] including overall health and cancer funding,[38] cancer mortality, and the availability and use of diagnostic imaging technologies (computed tomography (CT)), magnetic resonance imaging (MRI) and positron emission tomography (PET) scanners).[39]

Policy – UK funding and outcomes for cancer treatment

Total healthcare cost of cancer per capita (direct and indirect costs) and net survival outcomes (NS%) for prevalent cancers.



The UK currently ranks:
13th in Europe for highest total spend per capita on cancer
13th in direct health expenditure
18th in cancer drug spend

Source: Deloitte Analysis, European Journal of Cancer. Net Survival (%) – Lancet (2018)

Over the next decade, the UK needs to invest in cancer care at the same level as comparable European countries in order to improve outcomes.[38] This means increased day-to-day funding and capital investment to deliver care, to make available advances in diagnostic technologies and treatment and to invest in the workforce to deliver them. This will support more people diagnosed with cancer, treated for cancer, and more people dying with cancer. Funding commitments must be for several years so that evidence-based innovations can be scaled up after piloting.

It will be equally important for governments, regulators and healthcare systems to develop policies that prioritise what matters most to people with cancer, as well as measurement frameworks that hold them to account for delivery. National approaches to evaluating new technologies will also need to evolve to recognise their value, considering what matters to people with cancer. They will also need to take into account the service delivery implications of introducing the new treatment into the NHS, such as additional diagnostic tests or follow-up appointments involved. Investment and workforce planning decisions need to be informed by a robust understanding of the potential impact of new treatments or technologies.

Governments also play a critical role in building the proper infrastructure to support increased used of data. Major investment is required to achieve this alongside creating the governance and accountability frameworks that allow data to be shared securely between organisations with the permission of the person with cancer. This also requires sustained commitment to building and strengthening public confidence in data sharing within the healthcare system – demonstrating the potential benefits, learning from existing best practice, and understanding and addressing causes of mistrust.

We must work more effectively together across the public, independent and voluntary and community sectors to deliver joined up, integrated care and support for people with cancer.

The voluntary and community sector will continue to provide vital support to meet people's holistic needs nationally and locally. The sector also plays an essential role to enable and empower people from all communities to have their voices heard so that the future of cancer care can be designed collaboratively and reduce health inequity. It will be important that the sector increasingly works collaboratively together to have the most impact for people with cancer with the breadth of needs they experience, including other health conditions. Sustainable funding models are also needed to secure these services that are facing growing demand.

4e Policy and collaboration

Example: In Lincolnshire, the Living With Cancer Programme embedded Macmillan Community Cancer Care Coordinators to work with the local authority, mapping over one thousand community assets into a local directory to signpost people to support through Cancer Support Lincolnshire.[40]

The independent sector also plays a growing role in delivering NHS-funded cancer care. This includes life science, data analytics and digital health companies, as well as independent sector providers of screening and diagnostics.

People in the UK are also increasingly choosing to pay for health solutions provided by private companies. This includes purchasing digital health tools including apps and wearables or direct-to-consumer genetic testing. There has also been an increase in people with private medical insurance since the pandemic. Some people with cancer will need support to make the best choices for them about the services they pay for and the personal health data they are willing to share. Not everyone with cancer will have the resources, or the self-efficacy and health literacy to act on or share personal health data proactively, to join up their experience. This risks further health inequity.

Healthcare systems will need to support and incentivise collaboration across the different organisations involved in cancer care. Barriers to address include HR processes, data sharing arrangements and financial allocations and incentives which create siloes today.

Example: Cancer Care Stewardship in Mid and South Essex[41] is bringing together multi-professional, multi-organisation clinicians and managers to take on collective responsibility for managing resources including an integrated budget across their care area to get the best value from shared resources.

Moving the conversation on

It is clear that more investment will be needed, and this needs urgent attention by UK governments. This work has focused on healthcare, but social care is also critically important for people living with cancer. Long term, sustainable, properly funded strategies and plans need to address both health and social care within the different contexts of the four nations.

It will be essential to involve people with cancer in designing and developing policy and measurement frameworks. A key question for everyone involved in delivering cancer care is:

'How can people with cancer be meaningfully involved and participate in developing strategies and accompanying measurement frameworks so that these fully reflect what matters to them?'

Secondly, progress is dependent on seamless data sharing between organisations. It will be particularly important to build people's trust and confidence in data sharing. Individuals choosing to share their data creates better population-level data to improve overall clinical care, as well as joining up their own treatment and care.

Another key question for everyone involved in delivering cancer care is:

'What needs to happen now to build people's trust and confidence to share their personal health data including their genomic data, securely and appropriately to improve their cancer care and the cancer care of others?'

5 Moving the conversation on

This project has demonstrated the significant value of working collaboratively to think holistically about the impact that different factors will have on people's experience of cancer and care in the future, as well as to understand what it will take for us to achieve the best possible experience and outcomes for people with cancer by 2035.

Throughout this summary report, we have highlighted some of the biggest strategic questions that our discussions have highlighted. These questions need answering urgently.

Only by working together can we build momentum to go further faster, sharing and learning from what we each know already and designing the future of cancer care. We – policy makers and regulators, clinicians and professional bodies, healthcare organisations and local governments, academics and research funders, life sciences and technology companies, and voluntary and community sector organisations – must collaborate to create the future we all want to see.

At Macmillan, we are now developing the next chapter of our own strategy. This report and the questions that have been raised on the journey give us invaluable insight into the opportunities and challenges of the future for cancer care. It is a critical input for our strategy development, helping us to determine where we focus our efforts to have the most impact for people in the future.

In parallel, we want to continue to catalyse the conversations we have started. Collectively we – the various individuals and organisations involved in delivering care for people with cancer – must develop our call to action to shape the future healthcare experience for people with cancer.

5a Important questions to answer

Advances in science and technology

- What conditions need to be in place for the healthcare system to adopt all this innovation at pace equitably across the UK?

Equity in cancer care

- How do we partner with communities and people with lived experience of inequalities to create robust data and evidence and design the future of cancer care, so everyone benefits?

The future workforce delivering cancer care

- How do we attract people into healthcare careers, enable them to develop those careers in the way which best suits them and make best use of the skills, knowledge and capabilities of older, more experienced staff?
- How can we be most effective to develop workforce skills, roles and ways of working now to deliver the pace and scale of workforce transformation which will be needed over the next decade?

Personalised care

- What are the most effective approaches to care coordination and to navigate people to the support they need?
- How do healthcare services and ways of working need to develop to best meet the needs of the aging population and those living with multiple health conditions?

Policy and collaboration

- How can people with cancer be meaningfully involved and participate in developing strategies and accompanying measurement frameworks so that these fully reflect what matters to them?
- What needs to happen now to build people's trust and confidence to share their personal health data including their genomic data, securely and appropriately to improve their cancer care and the cancer care of others?

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Vine Health
Western Health and Social Care Trust

At Macmillan, we give people with cancer everything we've got. If you're diagnosed, your worries are our worries. We will move mountains to help you live life as fully as you can.

And we don't stop there. We're going all out to find ever better ways to help people with cancer, helping to bring forward the day when everyone gets life-transforming support from day one.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland.
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