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Summary

Macmillan Cancer Support has been working alongside people living with cancer and our partners in communities and health services for many years to develop models of care that improve the quality of life for people living with cancer through personalised care and support.

This short report outlines why Macmillan strongly believes we need a new approach to supporting people living with cancer in England. It sets out the current context and how integrated personalised cancer care offers a unique opportunity to implement a system-wide, truly joined-up intervention that can transform the experience of people with cancer.

In our accompanying guide 'Elements of Successful Integrated Personalised Care' we share a set of service development principles which have had an enormous impact where they have been implemented.

We invite you to work with us to develop truly integrated transformative cancer care and support across England. Please get in touch if you would like any further information: **personalisedcare@macmillan.org.uk.**

Introduction

The story of cancer has changed and care must adapt. Increasing cancer incidence and an ageing population mean ever more people are living with cancer and its consequences. Many will need support for several years after their initial diagnosis and treatment.¹

Systems across England are facing unprecedented challenges in delivering high quality personalised cancer care and support. People living with cancer are not able to access treatment as quickly as they could in the past and are presenting to the health system with increasingly complex, and often non-clinical needs, exacerbated by the pandemic² and the cost-of-living crisis.³

Everyone with cancer should be able to access the support they need from the moment of diagnosis and throughout their cancer experience. Yet too many people are missing out with devastating impacts for people and their families, and unacceptably poor outcomes for the system as a whole. At best, people are struggling to navigate a complex system and access support to meet their needs. At worst, they are falling into crisis because their needs are not addressed or met at an earlier stage.

Our vision is for improved experiences and outcomes for people with cancer. We know early intervention results in less unplanned crisis care and support, bringing benefits for a system under strain and improvements for people affected by cancer through better agency, reduced distress, and better self-management.

The health system in England does not have the capacity, and is not always best placed, to respond to growing numbers living with the wide-ranging and long-lasting effects of cancer. The system and workforce are stretched to breaking point. But together, we can reduce inequalities in access to care and support and release capacity in the health system. Through whole-system, holistic personalised care and support rooted in local communities, we can transform the experience of care and reach those most under-served.

The introduction of Integrated Care Systems offers a unique opportunity to do things differently and direct energy and resources to where they will have the greatest impact. Partners in the health service, social care, and voluntary and community sector need to do more together. It is time to put people and their experiences at the centre and join up services around them, ensuring they get the right support, in the right place, at the right time.

Whether it is the provision of care across settings, ensuring access to financial help, or information and emotional support, Macmillan's holistic model has the potential to truly embed transformational change. This new approach will finally deliver on the duty to provide personalised care as set out in the NHS Long Term Plan, which made the commitment that everyone with cancer should have access to a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.⁴

Macmillan has been working in Scotland to roll out a programme that will ensure everyone with a diagnosis of cancer will be offered a conversation with a link worker about their needs and given a tailored support package to meet those needs. The Improving the Cancer Journey service has helped to transform the experience and outcomes of those who have accessed it in Scotland, but it has also brought huge benefits for the wider system by freeing up clinical capacity and reducing pressure on hospitals.

Macmillan's ambition is to see the principles of this model of care in every part of the UK. We need to unlock a system-wide approach to supporting people living with cancer. By providing a universal offer with tailored support, we can reduce variation in access to holistic support, increase reach into under-served communities and have a huge impact for people living with cancer and the wider system.

Our vision is for improved experiences and outcomes for people living with cancer through systematic person-centred early intervention.

Why we need a new approach to supporting people living with cancer

The number of people with a cancer diagnosis is increasing. Record level waits for cancer tests and treatment across the UK are leaving tens of thousands in poor health and experiencing worse outcomes.⁵ The effect is reduced opportunities for early holistic intervention, increasing pressure on the broader system both in terms of the number diagnosed and the complexity of needs presenting. Macmillan strongly believes we need a new approach to supporting those with cancer and the following sections explain why:

- Increasingly complex needs require
 Personalised Care and Support Planning.
- Acute care can't do everything and won't reach everyone.
- Integrated, community-based solutions meet non-clinical needs more effectively and reach those who struggle to access support.
- When people have agency they are better able to self-manage and pressure on the broader system is reduced.

Increasingly complex needs require Personalised Care and Support Planning

Recognising varied and complex needs

Alongside urgent medical needs, cancer can affect every aspect of life, bringing practical, physical, emotional and financial problems that can last long after treatment ends.⁶ For too many people, these needs are consistently unmet.⁷

- 31% of people with cancer have practical or personal care needs but do not get enough support or get no support at all.8
- Over 70% of people with cancer report emotional wellbeing concerns.
- 83% of people with cancer in the UK experience some kind of financial impact from their diagnosis. For those affected the average cost can reach £891 a month on top of their usual outgoings.¹⁰

For example, cancer can drastically affect a person's finances, through a combination of factors including loss of income and additional costs related to their diagnosis, such as transport and heating costs. Some people may struggle to pay bills, get into debt or be forced to cut back on essentials such as heating and food.

Cancer care and support is experienced differently by some groups and so a personalised response is vital to ensure the care and support people are offered is relevant to their lives and personal experiences.

During the worst of times,
I couldn't afford to feed me
and my family nutritious food
which is so important for energy
and health, and I couldn't visit
family and friends because of
transport costs.

Sarifa from East London, diagnosed with breast cancer in 2010



The 2021 National Cancer Patient Experience Survey, found that certain groups, such as people living in the **most deprived areas**, those from **ethnic minorities**, people reporting a **mental health condition**, and those with **Learning Disabilities** on average reported poorer experiences of care.¹¹

Patients from a **minority ethnic background** report poorer experiences of cancer services than white patients, including delays in diagnosis and referrals to hospital doctors; provision of information; communication and interactions with healthcare professionals; and access to help and support.¹²

Identifying and addressing needs through personalised care and support planning

If people with cancer are to have their broader health and wellbeing needs met Personalised Care and Support Planning must take place. This approach enables those with cancer to be offered a conversation to discuss their broader needs with the use of a Holistic Needs Assessment (HNA) tool. A Personalised Care and Support Plan will then be created to meet those needs, with the HNA accessed by everyone involved in their care, from hospital to GP, to social care.

Everyone's needs are different; we need to understand what is important to that individual... It is important that people are able to make their own decisions about managing their health. Failing to identify and support people's needs results in poorer outcomes and experience for people living with cancer.

Dinah, Macmillan Community Personalised Care Lead for the West Yorkshire and Harrogate Cancer Alliance

Having a clear, Personalised Care and Support Plan can make a huge difference; but not everyone in England has an assessment of their needs and a plan in place to meet them. Having a meaningful conversation about needs and developing a co-produced Care and Support Plan can be the difference between someone feeling lost and at the mercy of their diagnosis, to feeling empowered and more able to manage what matters to them. For example, for those whose housing or financial concerns are not identified and addressed, the consequence could be crisis situations with significantly worse outcomes and

experiences. This could include housing insecurity, opting out of treatment because of unaffordable travel costs, or people becoming more unwell due to an inability to heat their homes.

Despite the NHS Long Term Plan committing that "every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support" there is currently no clear and systematic way for every person with cancer to know how to access a needs assessment and find appropriate support.

▲ Improving the Cancer Journey – a pioneering model of integrated, personalised care and support planning¹⁴

Improving the Cancer Journey (ICJ) is an innovative, proactive service model that has successfully demonstrated the impact of Personalised Care and Support Planning and early non-clinical intervention. It is now being rolled out across all 31 Health and Social Care Partnerships in Scotland alongside local partners and the Scottish Government as part of the Transforming Cancer Care Partnership. Across Scotland each ICJ model is being designed and built by local system partners to effectively meet local needs and optimise the effectiveness of local resources.

ICJ is a working example of the type of service aspired to by policy makers worldwide – holistic, person-centred, needs-driven, and delivered through collaboration.

Independent Evaluation of ICJ Glasgow 2020

ICJ is a multi-agency service delivering seamless support and unprecedented collaboration across health, social care and the voluntary sector. The first ICJ was launched in 2014 by Glasgow City Council and is now run by Glasgow City Health & Social Care Partnership, with Macmillan its main partner.

Through co-operation with Public Health Scotland, everyone in the Glasgow city area with a confirmed cancer diagnosis received a letter of invitation for ICJ support, successfully reaching those most in need. This included 76% of those accessing the service who were from areas with the highest levels of deprivation and 20% were receiving palliative care who would not typically have received non-clinical support.

The ICJ intervention centred on the Holistic Needs Assessment (HNA), delivered by a dedicated Link Worker. Alongside the person with cancer, the Link Worker built a care plan and played a key role in supporting the person to access support from other services in their community, rather than just signposting on. By being based in the community, link workers had greater awareness of the range of support available within the community, which frontline health professionals may not have been able to build up.

There has been growing recognition that social prescribing and person-centred approaches are critical in promoting health and quality of life. Yet too many people are falling through the cracks in the system and are struggling alone with problems even when support is there for them. They just don't know how to find it.

The answer is proactive, systematic, and universally offered assessment of needs with support tailored to a person's life and accessible in a range of places. This is the model Macmillan have pioneered with partners in Scotland (see Box B) with great success, and one that we are seeking to embed across every system in England. High quality Personalised Care and Support Planning must be available to everyone with cancer and integrated across settings.

As a Primary Care physician I see the complex medical and psycho-social needs my patients living with cancer can have.

Unless we work in an integrated way across settings and have dedicated professionals who have the time, and local experience, to address people with these complex needs, we can't fully support those we care for.

Dr Anthony Cunliffe, Macmillan National Lead Medical Adviser, Macmillan Clinical Adviser for London, Joint Clinical Director, South East London Cancer Alliance and Oncology Lead at ORCHA

2. Acute care can't do everything and won't reach everyone

Hospitals have long been the centre of care for people living with cancer. Now more than ever, the acute workforce is operating under extreme pressure and demand for services is increasing. Even without this growing pressure, 15 the acute system alone would never be able to ensure everyone with cancer could access support that meets all their health and wellbeing needs. This is because true personalised care requires all partners in a system to work together to meet a patient's needs, beyond hospital or even healthcare settings.

Acute pressures require innovative and efficient responses

Providing tailored support means NHS resources and capacity can be directed to where they are needed most, embedding early intervention to enable the broader system to meet a person's needs more efficiently and cost-effectively. The health and care system is facing critical workforce shortages, increased demand and more complex cases. If partners commit to ambitious, collaborative ways of working and design approaches that offer system-wide personalised care for everyone, there is huge potential to improve quality of life and benefit the entire system.

Cancer referrals are rising but workforce supply has not kept up with demand, with staff shortages already felt across key cancer specialisms. ¹⁶ By 2030, 4 million people will be living with cancer across the UK¹⁷ and if staffing levels remain the same our modelling shows we will be 4,000 specialist cancer nurses short. ¹⁸ Integrated personalised care that embeds non-clinical support in community-based settings (see Box B) can address some of these workforce challenges by freeing up capacity and allowing clinical teams to focus on clinical needs.

B Macmillan's Hammersmith and Fulham Links Service²⁰

The Macmillan Hammersmith and Fulham Links Service has been running since January 2020 and is 'about empowering and enabling people to help themselves'. Fourteen link workers based in GP practices work with patients over six sessions and connect them with support for non-clinical issues that impact health and wellbeing. They help patients with a broad range of issues from housing disrepair to benefits, from loneliness and isolation to income maximisation, and from mental health to weight management. The team actively seeks out new ways to fill gaps in patients' needs by working with voluntary and community services including Citizens Advice, Law Centres, Maggie's and the Macmillan Cancer Navigator Service at Imperial College.

The initial aims of the service were to reduce clinical time spent on non-clinical needs, reduce pressures on existing services and improve their quality, as well as decrease inappropriate and unnecessary unplanned care through increasing uptake of services meeting non-clinical needs in the community. The team set out to ensure people affected by cancer experienced proactive and improved coordination and support that was personalised and managed in the wider context of their lives. The aim was for people living with cancer to feel better supported across transitions of care, know how to access the right support in their community, feel better able to manage their own health and care, feel more in control of their financial situations and have reduced anxiety and worry about their cancer.

When we had to deal with the social issues, it was very time-consuming and took us away from clinical work. We didn't have the knowledge, so patients were getting a really raw, a really bad deal...

Clinical Nurse Specialist, Glasgow¹⁴

[Improving the Cancer Journey]
has allowed me to refer patients
for advice and support during a
very anxious and stressful time
for them...[it] allowed patients to
access help that they may
not otherwise have had

Clinical Nurse Specialist, Glasgow¹⁴

With integrated personalised care in place, our evidence shows that clinicians feel more confident their patients will be able to navigate systems more effectively, will receive holistic support from appropriate providers and will be more likely to have a positive experience of care and support. 14 Clinicians' trust increases when they see a referral to integrated personalised care services improves patient experience and their patients do not get lost in the system or miss out on clinical expertise. 19

Building on progress and ensuring no one is left behind

Acute-based care and support ensures that first and foremost people receive the clinical treatment they desperately need. However, the focus on delivering personalised cancer care in acute settings has meant non-clinical needs are sometimes left unmet due to lack of capacity and expertise. People living with cancer may be reluctant to burden clinical staff with non-clinical concerns.

There was a Macmillan nurse at the time who... did a Holistic Needs Assessment but data would not be reliable from this, as I didn't tell the truth, I wasn't ready to. I had to be fine. I couldn't tell the truth about how I was feeling. I didn't want to go there, didn't want to open the floodgates...

Gina from Cheltenham, diagnosed with breast cancer in Oct 2021

It's quite difficult working at the hospital because there are lots of things going on for patients. They are really unwell, hence them being in hospital, so it can be really hard to have proper conversations with people when they are feeling that way. Trying to do HNA for some people can be very exhausting...

Link worker from ICJ Glasgow¹⁴

Non-clinical professionals have different knowledge, skill sets and expertise which allow them to identify and engage patients on non-clinical issues they might not otherwise raise with clinical professionals. Furthermore, many from underserved communities face barriers to accessing care and support in healthcare settings and require specialist and culturally appropriate personalised care in out-of-hospital settings to meet their needs.

Many hospital-based teams have been working hard to embed holistic personalised care, increasing the numbers accessing HNAs and Personalised Care and Support Plans and linking people up with the support they need. This has included embedding non-clinical staff alongside

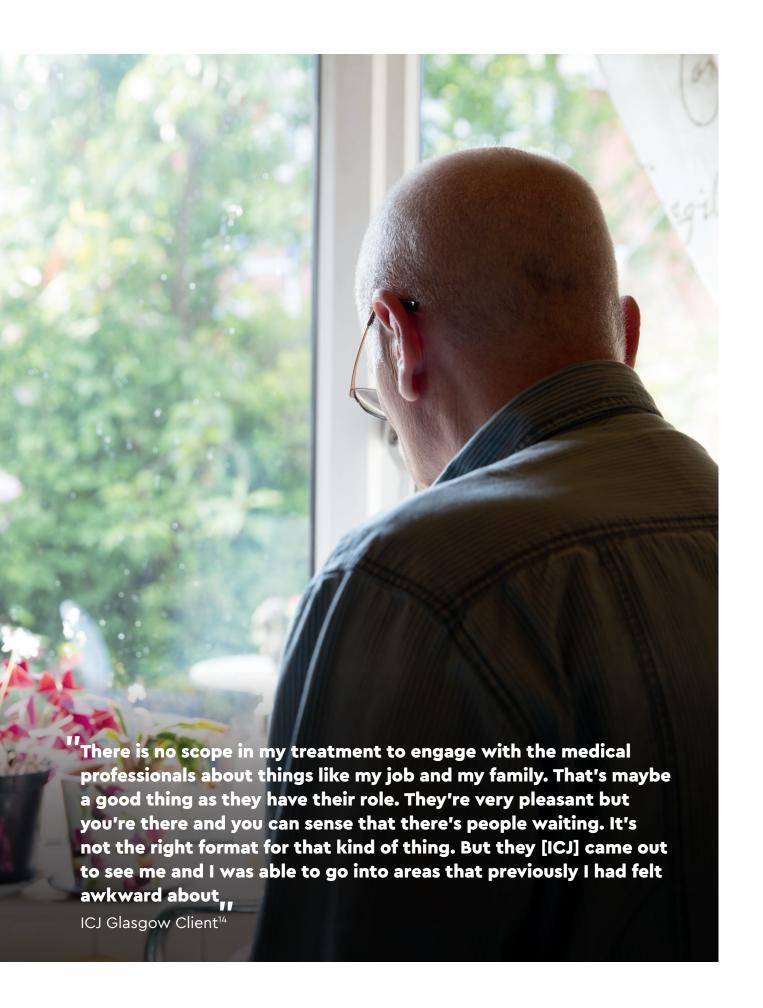
clinicians in acute settings and bringing in roles like Care Coordinators and Support Workers.

Despite this progress, not everyone living with cancer is offered a needs assessment and given a care plan. In fact, only 71% of people said that before their treatment started, they definitely had a discussion about their needs or concerns.²¹ There is also variation in the quality of conversations, plans, and follow up. For example, of those diagnosed with cancer in London in the previous 5 years, just 53% reported being given a care plan and only 40% said they were asked about all their key support needs including emotional, financial and practical needs.²²

We know from Macmillan's own eHNA data that when assessments are completed in a non-clinical setting, where people have more time and space to make their own decisions, they are more likely to raise broader, non-clinical concerns, including housing, money and finance.²³

Personalised care should not be a one-off conversation or tick-box tool used in a clinical environment. People living with cancer have needs that change over time, so regular updates to HNAs are needed to ensure concerns can be identified and addressed. While performance monitoring of tools such as HNAs provides vital insight, it is not clear whether all personalised care conversations and HNAs are high-quality, accessible and are having the maximum impact for people living with cancer. We must not be limited in our ambitions to achieving high-quality personalised care by processes of data reporting and measuring targets in the acute setting when designing models of support, particularly if we know that some out of hospital services are better placed to deliver the right support.

The acute sector has done much to improve the experience for people living with cancer, but alone it is not enough. The acute sector cannot



be expected to provide holistic personalised care to everyone and is not best placed to deal with complex non-clinical needs such as homelessness and financial need. An integrated and collaborative approach that extends care and support out from acute settings and links into the expertise and resources within local communities and neighbourhoods has been shown to significantly improve the experience of people with cancer and bring benefits for the wider system (see Box D).

3. Integrated, community-based solutions meet non-clinical needs more effectively and reach those who struggle to access support

The way cancer care and support is delivered in England needs to change. We need to move away from a primarily acute-based model to one that integrates services from all sectors, and ensures people are helped to access the support they need in their local community. Integrated, personalised, place-based cancer care must be rooted in the context of local systems but it should be a whole-system, cross-sector approach.

The establishment of Integrated Care Systems (ICSs) across England provides an opportunity for innovation in how we embed integration, with flexible legislative reforms designed to remove barriers, enable pragmatism and improve collaboration.²⁴ ICS reforms offer the chance to think and work differently, to come together to create more joined-up, more effective and more sustainable support closer to where people live their lives. The flexible organisation of ICSs, which are establishing integrated structures at 'system', 'place' and 'neighbourhood' level, mean that partners working across different parts of a system can align towards providing the best care

© Macmillan's North West Community Holistic Needs Assessment programme²⁵

Between 2017 and 2020, Macmillan invested in six pilots across North West England to enable Holistic Needs Assessments (HNAs) to be carried out in community settings. We found that by embedding HNAs in the service design, particularly ensuring these could take place in the community and not just in clinical settings, people living with cancer were empowered to access the support they needed. We found strong evidence to show that people living with cancer across pilot areas:

- Gained a greater ability to self-manage and voice their concerns, boosting confidence and enabling people with cancer to understand what resources were available to them and;
- Could access more non-clinical support, with 50% of HNAs completed resulting in onward referrals to other specialist support services.

Survey respondents' average mental wellbeing scores increased across the period after they received their HNA, and 94% of service users reported the service had a positive impact on their quality of life.

The programme also benefitted health and care professionals, resulting in improved communications between community HNA providers and secondary care, and increased clinicians' knowledge about the range of services that were available across the system to people living with cancer.

and support in the most appropriate places to reflect the needs of their diverse populations.

Macmillan has a strong track record of developing and delivering innovative services that bridge the gaps between health, care and broader wellbeing. By piloting models with partners across sectors in England (see Boxes B and C), and through our flagship, and independently evaluated service Improving the Cancer Journey (ICJ) in Scotland (see Box A), we can evidence the impact of early holistic, community-based interventions and increased reach into typically underserved communities. For example, in Glasgow 76% of those accessing the ICJ service were from areas with the highest levels of deprivation and 20% of those supported by ICJ were receiving palliative care and would not typically have been referred for non-clinical support.14

4. When people have agency they are better able to self-manage and pressure on the broader system is reduced

Macmillan's experience shows that Personalised Care and Support Planning allows people greater control and agency over their health and wellbeing and empowers them to tap in to and use their own resources more effectively to self-manage (Box D). In fact, evidence has shown that people who are more confident and able to manage their health conditions (that is, people with higher levels of activation) have 18% fewer GP contacts and 38% fewer emergency admissions than people with the least confidence.²⁶ Proactive and universal support, guided by non-clinical experts who can harness contributions from partners in local communities, can ensure individuals are better able to access the support that is right for them (see Box C).

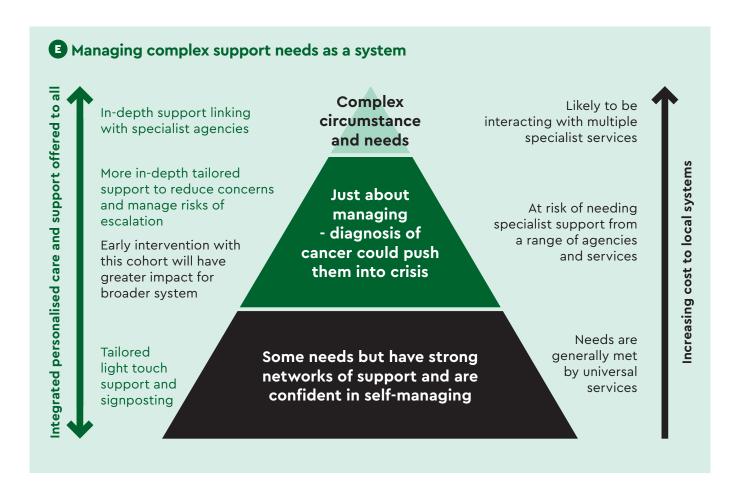
The independent evaluation from Improving the Cancer Journey Glasgow¹⁴ shows proactive and systematic Personalised Care and Support Planning can:

- Help people to get the right support
 when, and where, they need it. Over 90%
 of patients who accessed ICJ Glasgow said
 assistance from link officers ensured they
 felt supported through their cancer journey
 and their concerns were reduced.
- Help people to gain confidence and increase their ability to self-manage.
 66% of patients agreed that ICJ Glasgow provides the mechanisms to help support self-management.
- Improve the financial, emotional and practical resilience of people living with cancer by intervening early to prevent crisis. ICJ Glasgow unlocked over £18 million in benefits and grants and prevented 50 people with cancer from becoming homeless.
- Free up valuable clinician time and resources by doing more in non-medical and community settings. 70% of clinicians agreed that referring patients to ICJ Glasgow saves them time, and thereby has a positive impact on clinical time and efficiency.

This helps address needs more effectively and can also bring huge benefits for a system by supporting people to resolve their problems before they escalate in complexity and require more costly and specialist support further down the line (Box D). For example, making sure that someone has financial support in place for their heating and housing, particularly in the higher-pressure period of winter, can reduce the harmful health impacts of fuel poverty and housing insecurity. This can also allow people the emotional space to focus on better managing their health. Together this can reduce potential health episodes that require clinical support thereby reducing pressure on the health system.

Whilst we know that integrated personalised care and support brings benefits to all,

increasing the take up of tailored support to those who are 'just about managing', but whose concerns are most at risk of escalating in complexity, increases their ability to self-manage. This also brings greater benefits for the whole system as fewer system resources are required to deal with crisis situations (Box E). Personalised care can be beneficial at all points in someone's cancer experience, whether they are diagnosed early or later on in an emergency setting. Personalised care and support planning is vital at critical points of intervention, including when people are reaching end of life, as it can support people to better manage their health and wellbeing, reducing the likelihood of unplanned care admissions and other crisis situations.



Conclusion

We need a new approach to supporting people living with cancer that works for the whole system. One that is built around the lives of the communities that the system serves, that is not solely dependent on the health service but adopts a co-ordinated and sustainable approach to the provision of Personalised Care and Support Planning.

We are calling for a system-wide recommitment to integrated personalised care that looks beyond just treating the cancer and instead treats the whole person. A new service delivery approach rooted in local communities is desperately needed.

Macmillan wants to share our learning, build on progress already made and renew our collective efforts to embed integrated personalised cancer care across England. Our accompanying **'Elements of Successful Integrated Personalised Care'** report sets out our model and guide for how to unlock this transformational change.

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- 5 Macmillan Cancer Support/YouGov surveys of 4,096 adults in the UK who have had a cancer diagnosis. Fieldwork was undertaken between 4th - 28th November 2022 (2,020 adults) and 20th March - 8th April 2023 (2,076 adults). The surveys were carried out online. The figures have been weighted and are representative of people living with cancer in the UK (aged 18+). Surveys included 556 people who've been diagnosed within the last ten years and experienced delays to their NHS cancer care (i.e. they've either had to 'wait several weeks to see a specialist after their first GP referral for suspected cancer' or they've had to' wait several months to start cancer treatment after diagnosis'). Question wording in relation to people facing worse cancer outcomes was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. What, if anything, has been the impact of this? Please select all that apply". 23 per cent selected at least one of the following options: My cancer has progressed and/or spread, My cancer symptoms have got worse, My cancer is now incurable, I have fewer treatment options, Surgery is no longer an option for my cancer.
- The NHS Quality of Life Metric has shown that even 18 months after diagnosis, people are still experiencing unmet needs as a result of their cancer. Almost half (48%) of respondents had problems carrying out their usual activities (work, study, housework, family and leisure activities) compared with around one in five of the general population. NHS England, Cancer Quality of Life Survey. Cancer-quality-of-life-survey-summary-report-first-data-release.pdf (england.nhs.uk)
- 7 Throwing light on the consequences of cancer and its treatment (macmillan.org.uk)
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- adults who have received a cancer diagnosis.
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 - 92% of clinicians (nurses and doctors) agreed that referral to ICJ improves the patient experience.
 - 70% agreed that referral to ICJ saves them time.93% agreed that losing ICJ would have a negative impact on cancer care in Glasgow.
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- 25 Macmillan North West Community HNA Programme Final Report
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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. We're doing whatever it takes. But without your help we can't support everyone who needs us.

To donate, volunteer, raise money or campaign with us, call **0300 1000 200** or visit **macmillan.org.uk**

