

# LET'S TALK ABOUT IT

WE ARE  
MACMILLAN.  
CANCER SUPPORT

Improving information  
and support for people  
affected by cancer



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# 1. FOREWORD

I have always been interested in how information is delivered to people affected by cancer and, as Macmillan's Chief Medical Editor, I help to produce a wide range of patient information. Over many years working in medical oncology, specialising in the chemotherapy treatment of gastro-intestinal cancers, I have seen the importance of excellent information and support directly.

I strongly believe that every person affected by cancer should be offered the information and support they need to understand: the type of cancer they have; their treatment options; the potential consequences of treatment; and any medical procedures they will have. People diagnosed with cancer, and their carers, should be supported to make decisions about their medical care and treatment, as well as the non-medical aspects of their cancer and its impact. To do this, they must be informed about the wider impacts of cancer on their life and what support is available. Their information needs change at different times through their cancer journey. We have to recognise how these needs change and ensure they have the information they require at an appropriate time.

To ensure patients are empowered in this way, I believe health and social care professionals have a key responsibility to play in facilitating the necessary culture change. To do this, we must be able to engage with patients and carers and ensure their diverse needs are fully understood. Some patients do not want to be in control of decision-making, but do want to enjoy parity of esteem in the relationship with professionals. Others want to fully understand all their options so they can exert their right to choose. Patients and health professionals

need to be given time to develop and sustain such relationships. Services must be sufficiently flexible and innovative to enable them to meet these needs.

As professionals, we are working within ever changing structures, with services and resources in constant flux. Professionals can be prevented from delivering excellent information and support if they do not work in cultures with the right resources available to them, including time, technology, knowledge and skills. Removing these barriers together is our responsibility to people affected by cancer and I welcome the ideas set out in this report for how we may do this together.



Dr Tim Iveson, Consultant Medical Oncologist and Macmillan Chief Medical Editor

## 2. INTRODUCTION

This report begins a dialogue with decision-makers about how excellent information and support can improve the lives of people affected by cancer. It contains fresh ideas for discussion and starts the conversation about what could be possible in future. We identify issues and barriers currently impacting the universal provision of excellent information and support. We detail service solutions and suggest ideas to improve the information and support landscape together.

This discussion takes place at a time of unprecedented change in organising and delivering national health services, with tightening financial constraints, growing demographic pressures and rising consumer expectations. To enjoy longer-term savings, we believe local level spending decisions and plans for service transformation must recognise the importance of information and support to improved cancer outcomes.

With over two million people living with or beyond cancer in the UK,<sup>1</sup> the need for high-quality information and support and services has never been greater. Furthermore, the number of people living with cancer in the UK is increasing by 3.2% every year. If this rate continues there will be four million people living with cancer by 2030.<sup>2</sup>

Many people affected by cancer benefit from Macmillan's growing network of information and support services. However, we know that many still do not receive the right information at the right time, in the right place or in the right way. The following are some of the key issues faced by people affected by cancer and the health system as a whole:

- The Cancer Patient Experience Survey (CPES) for 2013 shows that 18–30% of all people affected by cancer do not receive sufficient information that they can easily understand about the type of cancer they have,<sup>3</sup> their treatment's side effects,<sup>4</sup> their operation<sup>5</sup> or the potential impact of their condition or treatment on their work life or education.<sup>6</sup> The CPES results of people's experience of written and verbal information vary substantially between trusts.



**18–30%** of all people affected by cancer do not receive sufficient information that they can easily understand

- From CPES 2013, we estimate that 49,500 people receiving their first treatment for cancer within the past year did not receive written information about the type of cancer they had.<sup>7</sup> An estimated 65,500 did not receive any information about financial help or benefits, although they would have liked to.<sup>8</sup>
- A poll of over 3,000 people living with cancer found that more than half would like more information about the long-term effects of treatment at diagnosis.<sup>9</sup> We also found variations in results between different cancer types.<sup>10</sup> For example, people diagnosed with kidney, cervical, lung and womb cancer types are less likely to receive any information on long-term treatment effects than those diagnosed with prostate or breast cancer.<sup>11</sup>

- Regarding the information and support they received, 1 in 10 people were dissatisfied,<sup>12</sup> and nearly 1 in 5 recall receiving conflicting information from more than one source.<sup>13</sup>
- A total of 16% of people feel they have little control over decisions about their treatment and care and 8% feel they have no control at all. One third of people affected by cancer would like to talk more with health professionals after diagnosis.<sup>14</sup>
- A quarter are not told at the time of diagnosis who to contact to discuss things further. Those with cervical, uterine and ovarian cancer are significantly more likely than other cancer types to report not being told who to contact.<sup>15</sup>

We want to work together with the government, the NHS, providers and commissioners, to address these problems and ensure the availability of high-quality information and support for people affected by cancer. That way, we can ensure that they can make the best decisions about their treatment and lives.

# 3. RECOMMENDATIONS

Macmillan is committed to working in partnership with those who share our vision for improving information and support. We aim to fully explore the best ways to achieve our vision for improved information and support, as outlined in the *Cancer in the UK 2014: State of the nation report*.<sup>16</sup> This report suggests some ideas to consider further so that people affected by cancer can experience:

- better information
- more local services
- improved communication.

## 1. Better information

Everyone affected by cancer should be offered high-quality, personalised information about the condition and their support and treatment options, including the short-term and long-term consequences of treatment.

*Cancer in the UK 2014: State of the nation report*

We want to see national resources and guidance in place that support local approaches to improving the quality, format and accessibility of holistic information for people affected by cancer.

Our recommended ways to achieve this are:

- a) NHS England should explore the extent to which the Information Standard's benefits are recognised by health professionals and people affected by cancer, and promote its use more.
- b) NHS England should issue a framework detailing what information should be produced nationally and locally.
  - We believe there may be merit in NHS England building on the model of the information prescriptions service by commissioning an online central repository of high-quality national information resources on NHS Choices.
  - This should then be promoted to people affected by cancer and professionals.
  - The repository should be accompanied by guidance about its use.
- c) CCGs and hospital trusts should ensure health professionals have access to, and utilise, up-to-date local information directories about the local services and support options available.
  - Macmillan suggests CCGs commission, and hospital trusts appoint, an information lead to collate and maintain a directory of local services for people with cancer and their carers.

## 2. More local services

Local health and social care leaders should ensure that people affected by cancer can access and are offered local, high-quality, face-to-face cancer information and support services.

*Cancer in the UK 2014: State of the nation report*

We want to see commissioning incentives to develop the information and support infrastructure, and ensure people affected by cancer have ongoing support and are signposted to services.

Our recommended ways to achieve this are:

- a) The Department of Health should signal the importance of excellent information and support.
  - We believe there may be merit in also including the NHS Constitution pledge that people receive 'easily accessible, reliable and relevant information and support' in the NHS Mandate.
  - Macmillan suggests the Department of Health investigates options for holding health bodies to account for this through the NHS Outcomes Framework.
- b) NHS England should explore ways to incentivise the commissioning of better information and support pathways so that people affected by cancer have ongoing support throughout their cancer journey.
- c) Local trusts should examine their local Cancer Patient Experience Survey data, publish action plans addressing weaknesses and report annually on progress.
- d) We suggest that there may be merit in NHS England showcasing examples of best practice where the role of information giver is highly valued. This should include service examples and endorsements from local champions, leading clinicians and successful managers.

### 3. Improved communication

Health and social care leaders must make information-needs assessment and communication skills a higher priority in service plans and training. This will ensure professionals identify what information people with cancer need and provide appropriate support.

*Cancer in the UK 2014: State of the nation report*

We want to see new approaches to workforce roles and skills. These would ensure all NHS staff are given access to vital learning and development to support them in delivering care with dignity and respect.

Our recommended ways to achieve this are:

- a) Macmillan suggests Health Education England includes information-needs assessment and associated skills as part of relevant frameworks currently in development.
- b) NHS England should explore who is best placed to act as a 'named contact', and evaluate and consider the potential roll-out of other models for people affected by cancer. These include, for example, the named GP for people over 75.
- c) NHS England should issue guidance for professionals to clarify what is permitted regarding using digital technology when offering people information and support.
- d) Macmillan suggests NHS England should continue to promote tools and resources for use by NHS staff to improve patient experience and care planning, such as:
  - Macmillan's Values Based Standard®
  - the Recovery Package, which includes an electronic Holistic Needs Assessment.

# 4. REPORT METHODOLOGY AND SCOPE

This report collates evidence gathered over the past year including:

- a YouGov poll on the experiences of more than 3,000 people living with cancer across the UK
- policy-scoping interviews with external stakeholders, including NHS England and several voluntary groups, to understand emerging themes
- a focus group with people affected by cancer to identify key issues impacting on their access to better, personalised information and support
- a focus group with healthcare professionals to identify key barriers and explore practical solutions that will enable excellent provision of information and support
- research on the impact of providing, or not providing, high-quality information.

It is important to note that our research is not concerned with the issue of patient data, information governance or access to care records. Instead, our research considers in depth the issue of ‘supported information’ for people affected by cancer as opposed to data about people. This report builds on our recent work on the issue of patient experience.<sup>17</sup> Our recommendations focus predominantly on people affected by cancer in England. Although many of the issues raised – and suggestions made – apply more broadly in other locations and across other conditions. We look forward to future collaboration to ensure far-reaching improvements to information and support.

# 5. THE IMPORTANCE OF INFORMATION AND SUPPORT

The case for providing high-quality information and support is clear. It is crucial for patient engagement and activation, enhances patient experience and leads to clinical benefits.<sup>18</sup> As many as 9 out of 10 people affected by cancer want to know more about their disease, its diagnosis, treatment options, side effects and likely outcome.<sup>19</sup> This allows them to make well-informed choices that reflect their individual priorities.<sup>20</sup>

Information can reduce anxiety, help develop coping skills and enhance recovery.<sup>21</sup> Providing people with high-quality, accessible health information can improve their physical and mental health, and their ability to manage living with cancer. They are more able to understand and participate in their treatment plan, communicate well with healthcare professionals and look after themselves more effectively. This all enhances patient experience and wellbeing.

We believe improved communications between patients and professionals will result in people affected by cancer assuming greater responsibility for actively managing their own health. This will lead to better adherence to treatment regimes,<sup>22</sup> better health outcomes and significantly lower costs. This could be through reduced communication failures, levels of complaints and claims of negligence, as well as through facilitating choices. Evidence suggests that when given the right support and information, people usually choose more cost-effective treatment options.<sup>23</sup>

If we get this right, we will see the impact on people affected by cancer, with increased effectiveness of treatment and reduced risks. We will also witness positive effects on service utilisation, health costs and health inequalities.<sup>24</sup> We believe that better information and support holds the key to unlocking potential in the health system and could lead to:

- people's increased ability to become active partners in their care, and greater confidence in self-management and self-care
- improved patient experience, increased patient safety, decreased levels of concerns and reduced litigation around informed consent
- reduced variation and the avoidance of unnecessary duplication and waste.

### **Becca's story**

'I was in my 20s and working in the media when I was diagnosed with cancer. As strange as it sounds, I consider myself incredibly lucky. When I received my cancer diagnosis from my doctor, he was just brilliant. He asked me if I'd like to bring my boyfriend along. The doctor stayed with me late one Friday evening at the end of his clinic to give me all the time I needed to properly understand my diagnosis and answer all the questions I could think of.

I know not everybody feels the same way though – perhaps because they didn't have the same chances to talk it through and make sure they understood what was going to happen next. When I met other people affected by cancer last year I heard how many of them had a totally different experience. Some people find that the information and support they are offered is disjointed, confusing and not at all relevant to them.

In my experience, when it comes to information and support, it's not just the clinical information that matters – you need to find out how cancer will affect other aspects of your life too, whether that's work and money or family issues. I want to make sure that the quality of information is consistent and, most importantly, that communication from professionals inspires trust.'

# 6. A SHARED VISION FOR INFORMATION AND SUPPORT

## Macmillan's vision

Macmillan provides supported information for people affected by cancer, tailored to their needs. People affected by cancer are supported to understand this information, consider its consequences and make the decisions that are best for them.<sup>25</sup>

For more than 20 years, we have developed and improved a large range of information and support services reflecting what people affected by cancer want. For us, information and support involves dialogue, trust, confidence and consistency of relationships. To support this, the system needs standard information, leadership, commissioning incentives and well-resourced staff.

Based on our experience, we have identified that good information and support should:

- be delivered as a service in its own right and not be divided into separate components of 'information' and 'support'
- adhere to quality standards
- be available in different formats and channels, taking account of health literacy needs
- be effectively communicated and tailored to the needs, values and circumstances of the person receiving it
- be provided throughout the cancer pathway in a well-paced way.

## About Macmillan Cancer Support

We produce free, up-to-date, quality-assured information materials in printed and digital formats. Many are available in other languages, as easy-read resources or in audio, with more than 3,500 pages of online information.<sup>26</sup> We also review information materials produced by other organisations and refer to their resources.

Our information services (of which there are more than 180) take many forms including:

- information and support centres and info-pods<sup>27</sup> in hospitals and community settings such as libraries, and financial support services including benefits advice<sup>28</sup>
- outreach staff, Macmillan mobile information services and Boots Macmillan Information Pharmacists on the high street
- phone service of cancer support specialists (Macmillan Support Line),<sup>29</sup> Macmillan digital information services, an online community, Macmillan Connected (online buddy service), and self-help and support groups.

In 2013, people visited our information and support services and our mobile information support services 462,816 times, and 213,435 people were helped by our Macmillan Support Line.<sup>30</sup>

## The government's vision

We welcome the ambition set out in the Department of Health's strategy and 10-year framework for transforming information, *The Power of Information*.<sup>31</sup> In particular, we agree that information be regarded as a health and care service in its own right for us all. Appropriate support in using information should be available for those who need it, so that information benefits everyone and helps to reduce inequalities.

We are also encouraged that there are a number of goals that the Department expects to see for individuals if the strategy is effectively implemented, including:

- 'I will get the information I need when I need it in a form I can use and, if I need help, I will be signposted to people who can help me.'
- 'My doctors, nurses and other professionals will be even better at communicating.'
- 'I will be able to make informed decisions about my care and about the treatment.'
- As set out in the NHS Constitution: 'I will have easily accessible, reliable and relevant information enabling and supporting me to participate fully in my own health and care decisions and to support me in making the right choices for me'.
- 'I will understand better what I can do to improve my own health or cope better with any long-term condition or disability'.

However, we are concerned that these ambitions are not yet sufficiently visible in practice, with detrimental results for people affected by cancer and the wider health and social care system. As the following section makes clear, our research has found a number of barriers hindering these goals. By setting out our ideas for improving information and support, we hope to help realise our shared vision.

# 7. BETTER INFORMATION



## 7.1 What is the problem?

### Confusion and inconsistent quality of information

- As many as 1 in 10 people living with cancer say they are dissatisfied with the information and support they receive.<sup>32</sup>
- Nearly 1 in 5 recall receiving conflicting information from more than one source.<sup>33</sup>

Some NHS trusts produce their own information which means that they are unnecessarily duplicating resources, resulting in costly inefficiency and diversity in quality. Too often, we are told that people affected by cancer are offered poor quality information that doesn't meet professional standards or is out of date. The Information Standard aims to help people quickly identify reliable sources of quality, evidence-based health and care information through an easily recognisable quality mark.

There are still some concerns that the Information Standard ([england.nhs.uk/tis](http://england.nhs.uk/tis)) is not as widely used by professionals and members of the public as it could be. We welcome steps by NHS England to ensure the new version of the Information Standard focuses more on user-tested end products than editorial processes. However, as the Information Standard is not mandatory we fear that, if it is not widely recognised, there may be little incentive for its use.

**'Unpicking inaccurate information that has been given by other clinicians is often more time-consuming than giving the information in the first place.'**

Clinical nurse specialist

Without accurate and consistent supported information, people affected by cancer can be left confused, unable to fully understand or trust what they access. Many different forms of information and support are available from different sources, and many professionals and organisations are involved in cancer care.

### Lack of information at all stages of the cancer journey

A common complaint from many people living with cancer and their carers is that they do not receive timely information about what is happening. For example, they do not receive well-timed information about when procedures are likely to take place and when they are likely to hear results or outcomes. If people affected by cancer are not offered information at the optimum time there can be significant implications for their longer-term quality of life and wellbeing. For example, they may decide not to take up treatment.

There is an evident gap between the point in people's cancer journey when they would have liked to receive information versus when it was actually provided. In the worst cases, people receive little or no information about their cancer diagnosis, treatment options or living with the disease. Others find themselves overloaded with complex medical information – often solely focused on their physical condition – around the time of diagnosis, when they are least equipped to process it. This is coupled with an under-supply of information at later points.

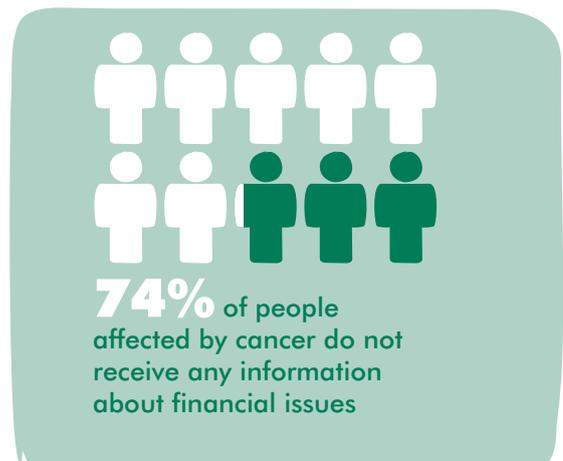
**'We felt overwhelmed by the amount and density of information and almost no time was allocated to going through the various packs and leaflets. We are both very capable of understanding information and asking questions but the shock of the diagnosis and ensuing psychological impact has to be taken into account at these times.'**

Person living with cancer and their carer

### Unmet holistic information and support needs

Our polling found significant differences in the level of provision of different types of information.

- As many as 74% of people affected by cancer do not receive any information about financial issues. More than half have not received any information about emotional issues and half nothing about practical support.



- Although the financial impact of cancer is extremely high – with 4 in 5 people financially impacted<sup>34</sup> – a mere 8% receive information about financial issues at diagnosis. While 10% receive this information during treatment.

Our analysis of the CPES 2013 showed that in England an estimated 65,500 people did not receive any information about financial help or benefits, although they would have liked to.<sup>35</sup>

Other key areas where the CPES 2013 revealed significant shortcomings were:

- Regarding emotional support, 30% of respondents being treated as an outpatient or a day case do not feel that they receive enough emotional support from staff.<sup>36</sup>
- Nearly 40% of people living with cancer do not feel that their family (or someone close to them) receive all the information they need to care for them at home.<sup>37</sup>
- Just over half of people living with cancer (54%) are given information about benefits and financial help by hospital staff.<sup>38</sup>

Many people affected by cancer want to be offered information and support on broader issues beyond just clinical information.

Cancer can impact on almost every aspect of people's lives. So, in addition to information on medical matters, they may have psychological, emotional, financial, and social information and support needs.

Only a small number of people had some contact with financial providers and social workers. Of those who had been in contact, 40% felt this hadn't been enough.<sup>39</sup> Benefits and debt advice is a much-needed service for people affected by cancer who are experiencing financial hardship. We know that, when supported to access financial information, people affected by cancer will be more likely to act on it.

As more people are living with and beyond cancer, more people will have unmet holistic – and not just medical – needs. So we need to make sure there is a wider range of information and support on emotional, practical and financial issues available. More than 80% of people living with cancer tell us that work is important to them. Professionals should be supported to offer information and support about work, so that people affected by cancer can make decisions about their choices.<sup>40</sup>

### **Long-term consequences of treatment**

- While only a third of people affected by cancer are told about the long-term effects of treatment at diagnosis, more than half would like more information at this point.<sup>41</sup>
- We know 59,000 people between one and five years after a cancer diagnosis of breast, colorectal, prostate cancer or non-Hodgkin lymphoma would like more information or advice about diet and lifestyle. Many more would like information about the physical, psychological and emotional aspects of living after cancer.<sup>42</sup>

People living with cancer need to be made aware of the consequences of treatment and supported to make decisions that reflect their individual priorities. A failure to do so can perpetuate unmet needs, undermine the quality of people's care and reduce their ability to self-care. Because many family members continue to have difficulties accessing appropriate

information and support, the holistic information and support needs of partners and family members must also be addressed. They too may experience distress following diagnosis, be physically and emotionally involved in the care of people living with cancer and play a significant role in decision-making. Good information can help cut down this distress and open the door to other sources of appropriate support.

What is more worrying in these times of structural change is the prospect of information and support services being threatened by staff shortages and funding restraints. This could lead to local services being cut, and a corresponding lack of available community services to refer people affected by cancer to.

**'If someone had told me that you can have a stoma this would have been very helpful. In the end I did find it out but it was three or four months later than it should have been and it was my eldest daughter who found it for me on the internet.'**

Male focus group participant

### **Sharing information and signposting**

Health professionals providing information and support may not have the time, tools or resources to engage with or share information about people living with cancer with others involved in their care. They may also feel unclear about when it is appropriate to direct people affected by cancer to local information and support services. Or they may not alert them to other sources of support, such as welfare or benefits advice, sometimes distributing printed materials and little else. In a changing landscape when they are unaware of available services, they may have difficulties signposting back to the community.

### **How one local trust avoided the need to reinvent the wheel**

Producing patient information is a time-consuming activity and the cost of producing information is often hidden in staff time. Across Sheffield Teaching Hospitals' cancer team, consultants and nursing staff had historically produced a whole series of chemotherapy leaflets. These were used and shared electronically with other cancer teams across their local network. These leaflets were heavily used and had involved considerable input from staff over the years. So it was with some reluctance that they agreed to use national information.

As a trust they have consistently promoted the need to check external information sources first to ensure they weren't duplicating existing leaflets. This became more of a focus with the promotion of information prescriptions (IPs) and with a recent drive within the trust to ensure leaflets were updated in a timely manner.

As part of the review of leaflets, the trust wanted to ensure they were focusing their efforts in the right place. Given the large number of cancer-related leaflets the trust was using, the cancer team were faced with an ever-growing backlog of leaflets to update. The trust's new policy of archiving leaflets if they hadn't been reviewed in two years also put pressure on the team to consider other options.

The main sticking point for staff was retaining their own 'Important advice' instructions for patients – local information which is vital should a patient become ill. With the support of the lead cancer nurse and clinical educator, staff agreed on a compromise. They agreed to develop a couple of standard front sheets which could be attached to the nationally produced chemotherapy leaflets. This way, they could retain the important local advice they needed to provide at the same time as using nationally approved content. They were assured that this would be updated for them on a regular basis.

The trust agreed on a switch date and over the course of one weekend they removed the majority of their own chemotherapy resources and replaced them with those from the IP system. Their electronic systems were updated the same weekend, at which time they took more than 80 of their own leaflets out of circulation.

This has saved the trust's cancer team a huge amount of time in reviewing and updating information, which is now spent on other areas of patient care. Nearly two years on, the team now has a much more manageable range of leaflets to update and say they have no regrets about making the switch.

## 7.2 What needs to be done?

All people affected by cancer should be offered high-quality, personalised information about the condition and their support and treatment options, including the short-term and long-term consequences of treatment.

*Cancer in the UK 2014: State of the nation report*

We believe a standardised national framework of information resources should remain in place to offer consistency. We also see the value in allowing sufficient flexibility for local approaches where appropriate, so that guided access to local resources can be offered to people affected by cancer as appropriate. To provide excellent information and support, professionals require fast, compatible IT systems, including single sign-on access to patient portals containing NHS and charity information.

Since 2007, we have been actively involved in developing the cancer information prescriptions service ([nhs.uk/ips](https://www.nhs.uk/ips)), editing content and supporting change in the NHS to facilitate the use of tailored information. Information prescriptions are an individualised way of providing information that relates to an individual's specific needs.<sup>43</sup> They are currently being developed across all long-term health conditions, with an online system bringing high-quality information, including that about financial and work matters, together from a range of providers via one resource. A repository needs to be developed that builds on the existing service within NHS Choices.

### Recommendations

NHS England should issue a framework detailing what information should be produced nationally and locally.

- We believe there may be merit in NHS England building on the model of the information prescriptions service by commissioning an online central repository of high-quality national information resources on NHS Choices.
- This should then be promoted to people affected by cancer and professionals.
- The repository should be accompanied by guidance about its use.

We want to make sure information is available in different formats and through different channels. But it is critical that this is accurate and consistent and adheres to content-related quality standards. In the first instance, we believe promoting the Information Standard to people affected by cancer more would empower them to expect certain standards of information from professionals and services.

An organisation can achieve certification under the Information Standard by producing clear, accurate, balanced, evidence-based, up-to-date information.<sup>44</sup> The proposed Accessible Information Standard aims to make sure people are given information in the best format for their needs.<sup>45</sup> We welcome NHS England's work to improve standards. However, we feel there is a need to communicate more widely, and with greater clarity, the roles of the Information Standard and proposed Accessible Information Standard.

### Recommendations

NHS England should explore the extent to which the Information Standard's benefits are recognised by health professionals and people affected by cancer, and promote its use more.

While avoiding the development of local information resources that duplicate national materials, we would like to see better referrals of people affected by cancer to services and support. That way, they can play a more active role in managing their condition and emotional and financial wellbeing.

### Recommendations

CCGs and hospital trusts should ensure health professionals have access to, and utilise, up-to-date local information directories about the local services and support options available.

→ Macmillan suggests CCGs commission, and hospital trusts appoint, an information lead to collate and maintain a local services directory for people with cancer and their carers.

# 8. MORE LOCAL SERVICES



## 8.1 What is the problem?

### Importance of information and support

Researchers have detailed a strong case for information and support, and a succession of policy initiatives and strategies underline its importance. Despite this, we are concerned the value and significance of information and support for people affected by cancer is not fully recognised and does not receive the resources it deserves. Patchy provision of information and support services leads to fragmented and inconsistent experiences.

The NHS Constitution – published in 2009 and strengthened in 2013 – pledges that the NHS commits ‘to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices.’ However, our analysis suggests a level of unmet need and variation that exists between localities and tumour type.

The NHS Mandate outlines the benefits of empowering service users to self-manage their condition. It also highlights the role information can play in encouraging competition and enabling people to make decisions. However, the broad principle of ‘easily accessible, reliable and relevant information in a form you can understand, and support to use it’ has not been translated into specific indicators in the NHS Outcomes Framework. Nor has it been implemented at every level. This means key issues that are important to people affected by cancer, such as communication and information, are not being adequately addressed.

### Incentivising an information and support infrastructure

**‘The culture now is all about what brings in income. When you commission pathways rather than individual episodes, then you have a massive incentive to prioritise information.’**

Doctor

Professionals tell us there is a perception in the current system that information and support does not raise money for hospitals, especially from those people who are post-treatment. In a tariff-based system, professionals note that seeing new referrals, discharging quickly and reducing follow-up are prioritised, leaving many people affected by cancer feeling ‘abandoned’.

Without incentive to sustain the information and support infrastructure, hard-pressed trusts struggling for resources, and professionals under pressure, may not consider information and support key. Yet, poor information and support can result in costs elsewhere in the system. We need national-level efforts to signal the importance of information and support and make the economic case for investment. At the same time, we must promote best-practice examples of services and staff and hold local trusts to account for poor performance.

### **A workforce fit for future challenges**

As the UK's population grows and its health needs change, our health and social care systems have to support more people, with more varied and complex needs. The number of people living with and beyond cancer is expected to rise from two million today to four million by 2030.<sup>46</sup> We are concerned that without addressing the accompanying increasing information and support needs, a significantly detrimental impact will be felt by people affected by cancer. The straining system will also suffer. Information and support needs must be included in ongoing discussions about funding, recruiting and retaining the right professionals for a sustainable workforce.

### **Glasgow Life – an alternative step in the right direction**

The Macmillan Cancer Information and Support Services @ Glasgow Libraries project provides assistance on all aspects of living with cancer at Glasgow's 32 libraries. There have been 3,140 attendances by people at their local libraries in just under two years, where they have received crucial support thanks to the groundbreaking initiative.

The service reaches beyond those diagnosed with cancer as family, carers and friends, whose lives are also affected by the illness, are offered support in numerous areas.

A wide range of services, from benefits and financial advice to counselling and complementary therapies, are delivered within local communities by teams of dedicated volunteers and local partners.

The project wants to make sure everyone in Glasgow can access cancer information and support in their local community.

## 8.2 What needs to be done?

Local health and social care leaders should ensure that people affected by cancer can access and are offered local, high-quality, face-to-face cancer information and support services.

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To achieve our vision that people have information and support throughout their cancer journey, we require leaders within and outside the health and social care system. We need them to work together and take responsibility for the information and support agenda at all levels.

**'Leaders need to be pushing the importance of information and support from the centre.'**

Nurse

### Recommendations

The Department of Health should signal the importance of excellent information and support.

- We believe there could be merit in also including the NHS Constitution pledge that people receive 'easily accessible, reliable and relevant information and support' in the NHS Mandate.
- Macmillan suggests the Department of Health investigates options for holding health bodies to account for this through the NHS Outcomes Framework.

We want to see better incentives in place to sustain an integrated information and support infrastructure. We need to see a better understanding of the impact information and support can have on reducing costs elsewhere in the system. This would help ensure that people affected by cancer have ongoing support and are signposted to appropriate services throughout their cancer journey.

We have already heard about some innovative examples that deserve further exploration – for example, one trust offers longer appointments with clinicians at the beginning of the cancer journey. This means individuals can be fully supported to better manage their condition on a longer-term basis. We would like more to be done to understand potential incentives for commissioners to redesign their services in such ways.

**'We have always offered all patients a consultation with their clinical nurse specialist between diagnosis and treatment for pre-treatment counselling and holistic needs assessment. Investing in that time involves patients in their treatment decision-making and helps to reduce levels of anxiety. It is a holistic concerns-led consultation which puts the patient at the centre of their care. It is feasible that investing time at that point saves time in the long run.'**

Macmillan clinical nurse specialist  
– breast care

## Recommendations

NHS England should explore ways to incentivise the commissioning of better information and support pathways so that people affected by cancer have ongoing support throughout their cancer journey.

To enhance accountability, we would also like local trusts to review their Cancer Patient Experience Survey (CPES) data. We would like them to ensure people affected by cancer receive high-quality information, are supported to understand their condition and are offered a written care plan.

## Recommendations

Local trusts should examine their local Cancer Patient Experience Survey data, publish action plans addressing weaknesses and report annually on progress.

We want to meet the changing needs of people affected by cancer and deliver the highest standard of care and treatment. To do so, we need to develop an efficient, effective and flexible workforce that places people with cancer and their carers at the heart of decision-making and service provision. We know the substantial and positive difference a named clinical nurse specialist has on a cancer patients' experience and their perceived quality of care. However, not everybody has access to one.

This means all professionals who play a part in providing cancer care must be supported to provide excellent information and support as a fundamental part of their role. That is whether they are GPs, key workers, community pharmacists, occupational therapists and other allied health professionals, volunteers or people affected by cancer themselves. There is an increasing necessity to meet holistic needs, and a shift towards long-term condition management as survival rates improve. As a result, information and support is increasingly likely to be an issue that must also be addressed in primary care.

We have heard about many examples of innovative practice including:

- the information support role framework in Scotland – we have a network of information and support professionals throughout Scotland in various locations including inside health centres, local government buildings and libraries
- clinical nurse specialists offering phone calls with the advance practice radiographer for test results if that is what a patient prefers
- patient-triggered follow-up and self-management in some local areas to improve patient experience and free up the time of clinical nurse specialists
- Macmillan one-to-one support pilots enabling support workers at Band 4 to undertake Holistic Needs Assessments and signpost patients to tailored information.

## Recommendations

We suggest that there may be merit in NHS England showcasing examples of best practice where the role of information giver is highly valued. This would include service examples and endorsements from local champions, leading clinicians and successful managers.

## Macmillan one-to-one support pilots – cost-effective ways to improve quality

We have committed to investing £300m over the next 7–10 years in a major project piloting new ways of providing one-to-one support for people with cancer UK-wide.

Phase one of the project involves piloting the new approach in 16 sites across England, Wales, Scotland and Northern Ireland. It also includes introducing four new roles across health and social care settings:

- Macmillan cancer support worker
- Macmillan nurse primary care
- Macmillan nurse community care
- Macmillan complex case manager

One-to-one support for people living with a diagnosis of cancer may best be understood as a service that supports their journey across the whole cancer pathway. It is based on the intensity and nature of the individual's needs and will improve quality of care and patient experience and outcomes in a more cost-effective way.

# 9. IMPROVED COMMUNICATION



- As many as 16% of people feel they have little control over decisions about their treatment and care, while 8% feel they have no control at all.<sup>47</sup>
- One third would like to talk more with health professionals after diagnosis.<sup>48</sup>
- At the time of diagnosis, a quarter are not told who to contact to discuss things further. Those with cervical, uterine and ovarian cancer are significantly more likely than other cancer types to say they do not know who to contact.<sup>49</sup>

To achieve the best results and enhance experience, people affected by cancer should be listened to and engaged as full partners in a collaborative relationship of shared decision-making.<sup>50</sup> Good information is a vital step on the way towards creating a culture of shared decision-making. Without support to interpret information, there is a risk that people affected by cancer will not understand the information they are given or find it overwhelming and unhelpful. People affected by cancer need to understand any implications for themselves and family or friends, as well as any choices they could or could not make as a result. This is particularly important for cancer patients who need to make complex and difficult treatment decisions and, potentially, give informed consent for their participation in clinical trials.

**'You start hearing words that you have never heard before and, from that moment, you begin going into shock.'**

Male focus group participant

### Health literacy and patient activation

Poor reading and comprehension skills are not always taken into account when providing accessible information and support, with serious implications for health inequalities and outcomes. While the problem of functional literacy remains a huge challenge, it is possible to be fully literate and yet health illiterate. Health literacy concerns the ability to read, understand and act on health information, as well as navigate the health and social care system.

**'How do you provide the right service to the spectrum of understanding and desire for knowledge?'**

Practice nurse

Practically, low health literacy can impact on patients in a number of ways. These include their ability to follow treatment plans, seek support, participate in consultations, understand performance data, understand the implications of provided information, and communicate their own values and needs. Individuals vary in their level of patient activation – the measure of a person's skills, confidence and knowledge to manage their own health.<sup>51</sup> Without understanding health literacy and patient activation, it will be impossible for professionals to offer effective, tailored information and support.

## Tailored information

**'It is important that healthcare professionals tell you what you need to know in a way that makes you feel important and not just like another number. It is also important not to be patronising in giving information: if you are not medical and have not come across cancer before of course you are going to have lots of questions and areas that you are not necessarily going to understand or know about.'**

Female focus group participant

**'Healthcare professionals know that each cancer is individual and they also know that we as people are also individuals. However, they seem to just want to blink, put you on a production line and force you down a certain path. I found they often aren't open minded to alternatives that they could offer you, ranging from 'do nothing' to a severe intervention. And also don't explain what each option entails, what it would mean to you and how it would or would not fit into your lifestyle and future expectations.'**

Focus group participant

The cancer journey can feel like a standardised process or 'conveyor belt' to people affected by cancer. Patients need information that is often very different from the information doctors think they need.<sup>52</sup> Not surprisingly, those people who received tailored information were more content that it met their requirements than those who received standardised material. Yet only 4 in 10 of those who received written information say it was tailored in some way.<sup>53</sup>

In 2004, NICE guidance explicitly recognised the importance of providing people affected by cancer with up-to-date, tailored, high-quality information and support. It also stated that 'poor inter-professional communication and coordination can lead to suboptimal care.'<sup>54</sup> People affected by cancer report inconsistency in professionals' interpersonal skills, as well as their ability to assess information needs and communicate accessible information sensitively. However, when we spoke to professionals many felt that training in this support was seen as a luxury in times of austerity. One of the biggest barriers professionals face is limited time in 'pressurised environments'. They can be required to see patients in 10-minute slots.

## Time to talk

**'It all boils down to time. Any healthcare professional I have come across can be good if they have the time. But they are all so busy and under so much pressure now in the NHS that they don't normally have the time. And that is when you get really rushed diagnosis and feedback. When they do have the time they are amazing.'**

Female focus group participant

According to our survey of people living with cancer, many rate the discussions they have with health professionals highly but would have appreciated more time to talk. As many as 78% of those who felt in control of decisions believed it was because of communication from health professionals. Yet, professionals are busy and under pressure to carry out consultations during short appointments and often do not have the right environments to do so.

## Technology

Just as using the internet for general searching can sometimes feel overwhelming for patients, the use of digital technology to communicate with patients can be a huge frustration for professionals. It is encouraging that the Power of Information Strategy sets out an ambition for the widespread use of modern technology to make health and care services more convenient,

accessible and efficient. However, the fact remains that some professionals are still uncertain and unsupported in terms of accessing digital technology. We still hear exasperated pleas from NHS staff for better access to information dispensers, printer booths, portable tablets, wireless internet and IT support.

**'It takes my computer 10 minutes to warm up! We have to think of innovative solutions. Culturally, I can do this, but I need you to invest.'**

Allied health professional

A lack of inter-operable systems able to exchange and make use of information, equipment, and internet access can reduce the time spent actually discussing what is important to patients. There also seems to be confusion about what is permitted with regards to the use of digital technology to offer people information and support. The fact that different trusts adopt different approaches to this uncertainty suggests that clarification would be appreciated.

## 9.2 What needs to be done?

Health and social care leaders must make information-needs assessment and communication skills a higher priority in service plans and training, to ensure professionals identify what information people with cancer need and provide appropriate support.

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We know that every person with cancer is an individual and every cancer journey is unique. As far as possible, and to be most effective, information and support needs to be tailored to match the particular needs, preferences and circumstances of each person affected by cancer. Patient information and education materials must be written at an appropriate level. Healthcare professionals and information specialists should make use of different methods and modes of communication and support. That way, we can ensure adequate comprehension. We want health and social care professionals to have the resources available to them to provide person-centred information and support, with further training available as required.

People affected by cancer want more time with health and social care professionals. These professionals need suitable environments, as well as the sufficient resources, knowledge,

skills and behaviours to be able to listen and address questions. They should also take into account the individual's health literacy and information and support needs. Tellingly, the most important aspect in information and support provision raised by people affected by cancer was 'being listened to' and being able to discuss their condition and treatment with expert professionals. When asked how satisfied they were with the sources of information used, respondents rated discussions with health professions such as consultants and surgeons highest.

Through good two-way communication involving conversations as well as leaflets, patients will be more empowered to share decision-making with professionals and together achieve better outcomes. Good communication by healthcare professionals is essential for a positive experience of care and participation in decision-making, and is key to achieving optimal health outcomes. Clinicians who are unable to provide good information or communicate well with their patients may find them unable to comply with their treatment plan. Or they may be unable to cope well with their illness, treatment or recovery.

All patient-facing NHS staff must be given access to vital learning and development to support them in delivering care with dignity and respect. Information-needs assessment, communication skills, health literacy and emotional support should be part of every healthcare professional's training. These skills should be appraised regularly and ongoing training given as required. There is an opportunity to consider this as Health Education England develops two relevant frameworks: the 15-year workforce framework and the 15-year Library and Knowledge Services Strategy.

## Recommendations

Macmillan suggests Health Education England includes information-needs assessment and associated skills as part of relevant frameworks currently in development.

With patient-centred care and shared decision-making, patients can be empowered to take more responsibility for their health and care decisions, working in partnership with health professionals. People affected by cancer must be supported to navigate the health and social care system and take control of any complex decisions they may face. People affected by cancer need professionals within the workforce who can work as 'infomediaries' to signpost them towards, and help them acquire, high-quality information and support.

We would like to ensure people affected by cancer have somebody they can turn to from the point of diagnosis onwards. This key contact can provide continuity throughout the cancer journey. How this is done may depend on the local health and social care economy, and commissioners may want to be flexible about how to use appropriate resources.

We do know that use of, and satisfaction with, information is profoundly affected by whether people affected by cancer are given a specific point of contact at diagnosis. This should be someone who they can discuss matters with, and ask or raise questions. Those who feel in control are able to do so because they've been given information about their condition and treatment and communicated with health professionals. Of those who didn't feel in control of their

decisions, 4 in 10 told us it would have helped to have 'one key person you could go to with any questions'.

## Recommendations

NHS England should explore who is best placed to act as a 'named contact', and evaluate and consider the potential roll-out of other models for people affected by cancer. These include, for example, the named GP for people over 75.

We are mindful that face-to-face support and verbal communication will remain key for many individuals, and technology must enhance rather than replace face-to-face support where preferable. However, we also see its potential in the context of information and support. We note the Department of Health's ambition to become a 'Digital First' department of state, with digital tools and techniques embedded throughout its work. We also welcome efforts to 'work with the health and care system to bring together the best information and services from across the NHS, public health and adult social care into a single customer service platform for citizens'.<sup>55</sup>

We would like to see health and social care professionals supported and empowered to use digital technology where it could improve patient experience. This is because we are concerned that this can serve as a barrier to offering tailored information.

## Recommendations

NHS England should issue guidance for professionals to clarify what is permitted regarding using digital technology when offering people information and support.

Many tools and resources have been developed to support professionals in providing flexible, person-centred information and support. We do this by assessing the needs of people affected by cancer, and empowering people to actively participate in decisions where desired and appropriate. Other resources outline behaviours that staff should adopt to offer an optimum care experience.

For example, at Macmillan we developed the use of electronic Holistic Needs Assessments (eHNAs). We would like to see eHNAs rolled out across the health and social care system as part of the Recovery Package.<sup>56</sup> We have also developed the Macmillan Values Based Standard<sup>®</sup> which identifies eight moments that matter to people receiving cancer services, and the associated behaviours from NHS staff and leaders.<sup>57</sup>

## Recommendations

Macmillan suggests NHS England should continue to promote tools and resources for use by NHS staff to improve patient experience and care planning, such as:

- Macmillan's Values Based Standard<sup>®</sup>
- the Recovery Package, which includes an eHNA.

# 10. CONCLUSION

Building on our experience as a service provider and patient organisation, we are perfectly placed to offer this analysis of the barriers and solutions to achieving universally excellent cancer information and support. We believe it is a critical time for us to join forces with the government and NHS, along with providers and local commissioners.

We need to act together to tackle these barriers and work towards better information, more local services and improved communication for people affected by cancer. This would mean people living with and beyond cancer have better access to personalised information and support, variations in provision are tackled and shared decision-making becomes a reality.

We now look forward to exploring the report's ideas and recommendations with all those who share our vision for better information and support.

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  52. KPMG. *Creating new value with patients*. [www.kpmg.com/Global/en/IssuesAndInsights/ArticlesPublications/what-works/creating-new-value-with-patients/Documents/creating-new-value-with-patients.pdf](http://www.kpmg.com/Global/en/IssuesAndInsights/ArticlesPublications/what-works/creating-new-value-with-patients/Documents/creating-new-value-with-patients.pdf) (accessed August 2014).
  53. Macmillan Cancer Support/YouGov online survey of 3,007 UK adults aged 16+ living with cancer. Fieldwork undertaken December 2013. Survey results have been weighted by gender, age, nation and cancer type to ensure they are representative of the wider cancer population.
  54. NICE. *Supportive and palliative care the manual 2*. [www.nice.org.uk/guidance/csgsp/resources/supportive-and-palliative-care-the-manual-2](http://www.nice.org.uk/guidance/csgsp/resources/supportive-and-palliative-care-the-manual-2) (accessed July 2014).
  55. Department of Health. *Digital Strategy*. [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/127317/final-report1.pdf.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127317/final-report1.pdf.pdf) (accessed September 2014).

56. Recovery Package: To better support people with cancer after treatment ends, everyone diagnosed with cancer in the UK should receive a cancer Recovery Package. This should include:

- Holistic Needs Assessments (identifying their physical, emotional, financial and other needs) and care plans at key points during treatment and recovery
- a treatment summary, completed at the end of treatment and sent to the person with cancer and their GP
- a Cancer Care Review to discuss their needs, possible long-term consequences of treatment and what they can do to help themselves, completed six months after treatment by the person's GP or practice nurse
- an education and support event such as a health and wellbeing clinic, to help people work towards supported self-management and a healthy lifestyle, including physical activity and directing them to support available in their local community.

57. Macmillan co-designed the Macmillan Values Based Standard® with more than 300 patients, staff, carers and family members, to provide a practical and innovative solution to improving patient and staff experience. This is based on eight moments that patients and staff said matter most to them, a number of which are underpinned by good information and communication. Currently, there are more than 30 sites across England and Scotland that are using the Macmillan Values Based Standard®. The eight behavioural domains are:

- naming patients – 'I am the expert on me'
- private communication – 'my business is my business'
- communicating with more sensitivity – 'I'm more than my condition'
- clinical treatment and decision-making – 'I'd like to understand what will happen to me'
- acknowledge me if I'm in urgent need of support – 'I'd like not to be ignored'
- control over my personal space and environment – 'I'd like to feel comfortable'
- managing on my own – 'I don't want to feel alone in this'
- getting care right – 'my concerns can be acted upon'.

The Macmillan Values Based Standard® is used as a framework where the underpinning values drive the behaviours of staff at the front line and leaders throughout the organisation. The emphasis is on co-productive behaviours between staff and patients, empowering them to improve the way care is delivered.

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

No one should face cancer alone.  
We are all Macmillan Cancer Support.  
**macmillan.org.uk**