

Review of the Cancer Reform Strategy: Macmillan's response

Executive Summary

People living with and beyond cancer continue to have serious physical, emotional, social, practical and financial problems that need addressing. We want the new CRS to focus on the following outcomes for people living with and beyond cancer:

- Every patient to have access to the best treatment and care for their cancer
- Everyone to understand information about their cancer and treatment, so they are able to make good decisions
- Everyone who has finished treatment to be supported with their ongoing needs
- Every patient to receive care in high-quality cancer environments
- Every person nearing the end of their life able to die at home if they wish
- Every person to have fair access to treatments and services, regardless of gender, age, race, disability, sexual orientation, socio-economic status or type of cancer.

To deliver these outcomes the revised strategy needs to address the following challenges:

Access to treatment: implementing the Cancer Drugs Fund

England continues to lag behind Europe in giving cancer patients access to most effective treatments. Therefore we welcome the Government's commitment to develop a Cancer Drugs Fund.

We want:

A Cancer Drugs Fund that:

- Includes drugs for rarer cancers
- Is implemented to ensure that those with rarer cancers benefit
- Is efficient and transparent in order to reduce stress for patients
- Is measured by an audit of all applications that records the demographic and equality dimensions of those receiving the drugs, where they live and the reasons for their application.

Provision of information: rolling out Information Prescriptions (IPs)

The principle of 'no decision about me without me', a key strand of the Health White Paper, can only be adhered to if patients have access to high-quality, relevant information about their condition and the various treatment and support options available to them.

We want:

- Clear commitment to the roll out of IPs over the next two years
- Information and support provision, including delivery of IPs, to be included in the NICE Quality Standards for cancer
- The delivery of IPs to be included in the commissioning guidance provided to GP commissioning consortia.

Ongoing support: survivorship

Macmillan supports the National Cancer Survivorship Initiative (NCSI) vision. We want everyone reaching the end of treatment to work with their health care professional to develop a written, personalised care plan and to be able to access services to meet their needs.

We want:

- The Government to give its public support to the NCSI as it continues to pilot and disseminate new models of care
- NICE to incorporate standards for post-treatment care in all NICE Quality Standards for cancer, including provision of an assessment and care plan
- The development of a payment by results tariff which rewards provision of assessments and care plans, treatment summary records from consultant to GP, patient education events, supported self-management programmes and physical activity packages
- The new NHS Commissioning Board to include provision of an assessment and care plan as part of the commissioning framework for GP commissioners
- The development of a robust reporting procedure to ensure that providers of care collect information on the incidence of the consequences of treatments. This data should be collated on a national level in order to inform the development of cancer services
- The national cancer survivorship survey to be repeated every two years.

Work and cancer

Back to work support for people with cancer is inadequate. Most people with cancer of working age want to remain in, or return to work, during or after their treatment. However, more than four in ten people who are working when diagnosed have to make changes to

their working lives after cancer, with almost half of those changing jobs or leaving work altogether.¹

We want:

- Information and advice on working through treatment for cancer, or returning to work afterwards, to be routinely provided by the NHS
- Vocational Rehabilitation (VR), to support people with health conditions to remain in, or return to work, offered to every cancer patient that needs it.

High quality environments

We believe that cancer patients deserve to be treated and supported in high quality cancer environments, which are designed around their needs and help to improve their outcomes, no matter where they are in the cancer journey.

We want:

- A renewed commitment in the CRS to the continued improvement of cancer environments
- All cancer facilities to aim and be encouraged to achieve the Macmillan Quality Environment Measure (QEM)
- The inclusion of a patient experience indicator for cancer environments within domain four of the NHS outcomes framework
- NICE to establish a single cross-cutting quality standard for cancer environments that recognises the QEM as best practice in the delivery of excellent cancer environments
- The QEM to be recognised as best practice in guidance for commissioners.

Choice about place of death

We believe that people should be able to die at home if they wish.

We want:

- The NICE Quality Standard on end of life care to include non-clinical as well as clinical needs
- The end of life tariff, to be developed as part of the end of life funding review, should accurately reflect the cost of providing care in different settings and actively incentivise good practice
- An indicator on end of life care, which measures the quality of end of life care and whether people are able to die in their place of choice, included in the NHS Outcomes Framework.

Equalities in cancer care

We believe that every single person who is diagnosed with cancer should have access to high-quality treatments and services that are appropriate and responsive to their needs at

¹ YouGov online survey of 1,740 UK adults living with cancer. Fieldwork took place between 26 July-9 August 2010. Survey results are unweighted.

every stage of their cancer journey, no matter who they are, what part of the country they live in, or what type of cancer they have.

We want:

- Ongoing DH commitment to implement the National Cancer Equality Initiative (NCEI) vision and projects
- The NHS Outcomes Framework to measure the progress being made to tackle inequalities in care and treatment²
- NICE and the NHS Commissioning Board to use learning from NCEI projects in the development of cancer Quality Standards and commissioning guidance respectively.

Delivery that meets the needs of people living with and beyond cancer

We believe that effective service delivery for people affected by cancer requires that:

- GP consortia ensure they commission services to meet the clinical and non-clinical needs of cancer patients along the whole of the cancer pathway, except where those services are specialised
- GP commissioners are likely to require access to specialist advice when commissioning cancer services. We think mechanisms need to be put in place, whether on the current network model or a new form, to provide coordination and cancer commissioning expertise
- Indicators in the NHS Outcomes Framework must reflect the needs of people living with and beyond cancer and include:
 - Disaggregation by disease, including cancer, and equality dimension
 - Indicators that measure people's health status at key points (domain two)
 - Cancer included in the indicator for emergency admissions (domain three)
 - Indicators relating to information and support, the provision of equitable care, whether people are able to die where they wish and whether people are satisfied with the clinical environment (domain four)
- NICE Quality Standards for cancer must cover the whole patient journey, include non-clinical as well as clinical needs and must be mandatory
- There needs to be a strategic approach to workforce development and investment in the workforce, including additional Clinical Nurse Specialist and Allied Health Professionals, and the development of new roles to deliver post-treatment services.

² *Transparency in Outcomes – a Framework for the NHS*, Department of Health 2010

Introduction

- 1.1. Macmillan welcomes the decision to review the 2007 Cancer Reform Strategy (CRS). Despite good progress since the publication of the CRS, local implementation is losing momentum. A report conducted by Consulting Inplace on behalf of Macmillan found that there has been progress developing Information Prescriptions, providing information and support and benefits advice, and growing provision of cancer rehabilitation and Clinical Nurse Specialists but that, at a PCT level, the CRS had now been superseded by other priorities and strategies.³
- 1.2. Macmillan welcomes the new focus on outcomes that the NHS needs to deliver but we are concerned the scale of the fundamental changes proposed to the NHS may put at risk standards of care for people living with cancer. Cancer policy needs to adjust to take account of the proposed changes to ensure that the needs of people with cancer are not ignored, deprioritised or misunderstood. People with cancer continue to have serious physical, emotional, social, practical and financial problems that need addressing. We now know that there are 1.6 million people living with and beyond cancer in England and this figure is rising by three per cent each year.⁴
- 1.3. We want the new CRS to focus on the following outcomes for people living with and beyond cancer:
 - Every patient to have access to the best treatment and care for their cancer
 - Everyone to understand information about their cancer and treatment, so they are able to make good decisions
 - Everyone who has finished treatment to be supported with their ongoing needs
 - Every patient to receive care in high-quality cancer environments
 - Every person nearing the end of their life able to die at home if they wish
 - Every person to have fair access to treatments and services, regardless of gender, age, race, disability, sexual orientation, socio-economic status or type of cancer.
- 1.4. To deliver these outcomes the following challenges need to be addressed:
 - Implementation of the Cancer Drugs Fund
 - Roll out of Information Prescriptions (IPs)
 - Development of better post-treatment support services, including the provision of assessment and care plans
 - Embedding vocational rehabilitation in cancer care
 - Tackling cancer inequalities
 - Ensuring cancer environments are high quality
 - Ensuring new commissioning structures meet the needs of people living with and beyond cancer

³ Consulting Inplace (2010) Strategic Review of NHS Primary Care Trust Plans for Cancer, 2010.

⁴ Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009. 101: 541-547.

- Ensuring indicators in the NHS Outcomes Framework reflect the needs of people living with and beyond cancer
- Developing new NICE Quality Standards for cancer that cover the whole cancer pathway and include non-clinical as well as clinical needs
- Investment in the workforce, including additional Clinical Nurse Specialist and Allied Health Professionals, and the development of new roles to deliver post-treatment services.

'I had extremely aggressive chemo for lymphoma which left me with damage to my legs and hand. I asked for help and advice for ages but by the time anyone listened I was badly damaged and needed walking sticks. It's left me feeling alone and rejected by a system which seems to have departments which do not speak to each other.'

David, Essex

1.5. We want the revised CRS to set the strategic direction of cancer services for the lifetime of this parliament, with a commitment to a new strategy being developed in 2015. We want the National Director for Cancer to continue to report on the progress of the CRS every year.

How we prepared our response

1.6. In preparing our response Macmillan consulted people affected by cancer and Macmillan doctors and nurses. We conducted four focus groups with people affected by cancer, the findings of which reflect the challenges we have identified above.

Access to treatments

- 2.1. Cancer treatment is constantly evolving and people with cancer should be able to benefit from innovations. We agree with the Secretary of State that patients should be able to access treatments that are readily available in Europe.⁵ As a recent report by Professor Sir Mike Richards showed, at present we lag behind the rest of Europe in terms of access.⁶ Better access to cancer drugs will also positively impact upon the one and five year survival indicators included in the NHS Outcomes Framework.
- 2.2. We believe that people should be able to access clinically effective treatments whatever kind of cancer they have, something that is not happening at present. We remain seriously concerned that in recent years NICE has rejected a number of treatments for rarer cancers or approved them only for very limited population groups.⁷ The public agrees with Macmillan that cancer patients should get the treatment they need regardless of what type of cancer they have. In our research, 90% said people with rarer cancers should have the same access to cancer drugs that might benefit them, as people with more common cancers do.⁸
- 2.3. At the moment, if a treatment is rejected for funding on the NHS by NICE, people can try to obtain funding through their PCT's exceptional funding request process. Despite new guidelines in April 2009, this process is still highly variable across the country and a source of stress for many cancer patients, as the quote below demonstrates.⁹

*"I would like to see the application that was made on my behalf to the PCT ... You don't see it so you don't even know what's been put down on your behalf."
(Female, 60s, non Hodgkin's lymphoma, applying for rituximab)*

- 2.4. A report by the Rarer Cancers Foundation found that almost half (46%) of patients described the guidelines as being 'fairly hard' or 'hard' to find.¹⁰ If patients are denied access through the exceptional funding process, the only option left is to co-pay for their treatment, an option that can force people to take extreme financial measures, eg remortgaging their homes, in an attempt pay for treatment.

⁵ DH Press Release, 27.07.10

⁶ DH Press Release, 27.07.10. Specifically, it showed that the UK ranks relatively low for access to cancer drugs at number 10 out of 14 countries, highlighted by the fact that for cancer drugs launched within the last 5 years, usage is less than 50% of the all-country average.

⁷ Examples of rejections in the last year include temsirolimus, sorafenib and most recently everomimus for renal cell carcinoma (kidney cancer) and sorafenib for hepatocellular carcinoma (advanced liver cancer). In terms of treatments that have only been approved for very limited patient groups Topotecan for cervical cancer is a recent example.

⁸ Macmillan Cancer Support commissioned survey. All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 1740 adults. Fieldwork was undertaken between 26 July and 9 August 2010. The survey was carried out online. The figures are unweighted.

⁹ Report prepared by RS consulting, Access to treatments summary of focus group findings, 20 September 2010.

¹⁰ Rarer Cancers Foundation, Exceptional progress? Assessing the progress made in improving access to treatment for people with rarer cancers, 2010.

What further action is required?

- 2.5. We are very pleased the Government has announced that a £200 million Cancer Drugs Fund (CDF) is to be introduced in April 2011, with an interim fund of £50 million to commence in October 2011. We would like to see these funds, and the longer term solution of value based pricing, implemented so that people can access clinically effective drugs whatever their kind of cancer, an objective that will improve outcomes.¹¹ The funds and value based pricing must 'help patients get the cancer drugs their doctor has recommended' whatever type of cancer a person is diagnosed with.¹²
- 2.6. However, we are concerned by recent suggestions that the total amount allocated to the full CDF may be less than £200 million.¹³ We urge the Government not to renege on its financial commitment; a recent report released by the Rarer Cancers Foundation suggested £200 million is the minimum required to cover demand.¹⁴
- 2.7. It is important that the fund reimburses drugs that are prescribed off-label for extremely rare cancers. At present, access to this funding is very variable.¹⁵ If the CDF does not include off-label drugs, then another solution needs to be found, for instance a separate fund for this purpose.
- 2.8. It is essential that an effective way is found to disseminate information on new treatments to clinicians, to ensure that patients can access treatments regardless of where they live. This could be undertaken at a regional level by groups such as the London Cancer New Drugs Group. It is also essential that if decisions about the fund are to be made above the level of individual clinician, as proposed with the interim £50 million fund, that expertise in terms of rarer cancers is represented on decision making panels. Creating information on new drugs that is accessible to patients is also crucial if they are to exercise informed choice over their treatment.
- 2.9. It is important that the mechanism for implementing the fund is efficient and transparent so that the anxiety experienced by patients is kept to a minimum as they go through the process. It is important to avoid the pitfalls of the current exceptional funding process, with many patients waiting long periods of time for a decision. Patients should be able to access treatments recommended by their clinicians quickly and without uncertainty as to how the process works, leading to improved outcomes in terms of patient experience of the access to drugs process. Key aspects of this would include:

¹¹ Value based pricing would see the prices paid by the NHS for medicines reflect their therapeutic value to patients

¹² Department of Health (2010), Equity and excellence: Liberating the NHS.

¹³ Earl Howe at a press conference, widely reported in the press e.g.

<http://www.telegraph.co.uk/health/healthnews/7912228/Banned-cancer-drugs-to-be-paid-for-with-50m-government-fund.html>

¹⁴ Rarer Cancers Foundation (2010), Exceptional funding: recommendations for improving access to cancer medicines and delivering better value for money for the NHS.

¹⁵ Rarer Cancers Forum (2009), Off limits.

- A strict limit on the time it takes from a doctor requesting the drug to the funding being authorised/denied
- Clear information for patients so they can fully understand how the process works
- Support provided to patients by, for example, a specialist cancer nurse, to ensure they fully understand not just how the process works, but the implications of having the treatment and all possible alternatives. This will enable individuals to make the choices which are best for them.

2.10. The implementation of the CDF should be measured by an audit of all applications. We believe this audit should record who, in terms of demographic and equality dimensions, is receiving the drugs, where they live, their diagnosis and the reasons for their application. We support the suggestion by the Rarer Cancers Foundation that this audit should be hosted by either the National Cancer Intelligence Network or the National Cancer Research Initiative. The purpose of this audit would be to:

- Determine whether people affected by rarer cancers have the same access to drugs as those affected by more common cancers
- If access is refused, determine whether the decision is based on strong clinical grounds, for example denial of Herceptin on the grounds that the patient is HER2 negative
- Determine whether there are geographical disparities in treatment access
- Build up the evidence base for the use of treatments to support future NICE applications, or license applications in the case of off-label drugs, so that in future patients with extremely rare cancers can access proven treatments.

Recommendations

2.11. We want to see a system for approving cancer drugs that:

- Includes drugs for rarer cancers
- Is implemented to ensure access to all, including people with rarer cancers and regardless of patient's equality characteristics and
- Is efficient and transparent in order to reduce stress for patients.

Information and support

- 3.1. Information, and support to understand that information, are integral to a patient's experience of care and affects their health outcomes. However, currently not all cancer patients are getting the information and support that they need to inform them about their own condition and treatment, and so are not empowered to make informed decisions about their care. In a recent Macmillan survey of cancer patients, 35% of respondents told us they had received no written information at all from any healthcare professional.¹⁶ This suggests little progress has been made since a 2005 National Audit Office report, which showed that 40% of patients were given no written information.¹⁷
- 3.2. Even those given written information on their diagnosis, treatment or support options may still need additional support to help them understand that information. Research has shown that:
- Over half of cancer patients are unlikely to understand cancer information brochures routinely used in hospital settings¹⁸
 - At least 50% of cancer patients forget most of the information provided to them within minutes of their consultation.¹⁹
- 3.3. The support needed by patients will vary from individual to individual. We believe information provision should include face-to-face consultation with a professional, telephone and/or email support, as well as written information.
- 3.4. Having the right information at the right time with the right support means patients:
- Have improved quality of life through improved physical and mental health²⁰
 - Are able to manage their long-term conditions more effectively^{21 22}
 - Use NHS services less often than patients who have not been given information²³
 - Choose less invasive (and less expensive) treatment options.²⁴

¹⁶ Total sample size was 1740 adults. Fieldwork was undertaken between 26 July and 9 August 2010. The survey was carried out online. The figures are unweighted.

¹⁷ NAO 2005. Tackling Cancer: Improving the patient journey.

¹⁸ Manning, D, Dickens C. (2006) Health Literacy: more choice, but do cancer patients have the skills to decide.

European Journal of Cancer Care.

¹⁹ Manning, D, Dickens C. (2006) Health Literacy: more choice, but do cancer patients have the skills to decide.

European Journal of Cancer Care.

²⁰ Unreliable information can lead to incorrect self diagnosis and/or increased feelings of anxiety and stress. Half (52%) of patients and service users who said that they had received information agreed that it had helped to improve their care: Department of Health (2008) Evaluation of Information Prescriptions

²¹ Department of Health (2008) Evaluation of Information Prescriptions (Two-thirds (66%) agreed that they now felt more in control of what was happening with their condition.)

²² Bupa (2010) Stronger Together (Informed patients choose less care but achieve better satisfaction from the care they receive.)

²³ Bupa (2010) Stronger Together (Information leads to greater patient empowerment and reduces unnecessary invasive treatments.)

The future for information and support

3.5. We welcome the vision set out by the new Government in its Health White Paper for a more patient-centred NHS, where the individual is at the heart of decisions about their care and can make the choices that are right for them. We believe the principle of *'no decision about me without me'*, a key strand of the Health White Paper, can only be adhered to if patients have access to high-quality, relevant information about their condition and the various treatment and support options available to them.²⁵ The proposed 'information revolution' will help to achieve this, by increasing the amount and type of information available to patients, including on the quality of services in their area. Macmillan looks forward to working with the Government in implementing the 'information revolution' and engaging closely with Government on their proposed Information Strategy.

3.6. In implementing a 'revolution', we should not lose innovative developments in information that have been achieved since the publication of the CRS three years ago. Introducing Information Prescriptions (IPs), for example, will be a huge step towards adherence to the principle of *'no decision about me without me'* for cancer patients.

3.7. IPs are now ready to be rolled out across the country and we want to see their effective and successful roll out completed in the next two years. Macmillan has committed around £5 million to professional posts and training programmes to support implementation over the next couple of years. We are currently awaiting the two-year implementation plan from the National Cancer Action Team.

Recommendations

3.8. In the revised CRS we want to see:

- Clear commitment to the roll out of IPs over the next two years, and recognition of their role, as part of the 'information revolution', in helping to embed the principle of *'no decision about me without me'*, in information provision. This will require an implementation post within the National Cancer Action Team to support the co-ordination of local level implementation of IPs, and ministerial support in the form of a foreword/letter to PCTs/GP consortia accompanying the IP implementation plan
- Information and support provision to be measured in the NHS Outcomes Framework
- Information and support provision, including delivery of IPs, to be included in the Quality Standards on cancer produced by NICE
- Delivery of IPs to be included in the commissioning guidance offered to GP commissioning consortia by the NHS Commissioning Board.

²⁴ O'Connor A et al (2004) Health Affairs. Modifying Unwarranted Variations In Health Care: Shared Decision Making Using Patient Decision Aids

²⁵ Department of Health, Equity and excellence: Liberating the NHS, 2010

3.9. We believe implementation of these recommendations will help produce better experiences and outcomes for cancer patients, and also help the NHS to operate more effectively and efficiently.

I'm an energetic person normally but chemotherapy for my bowel cancer knocked all energy out of me. It was depressing to feel that way, but the great support I had from the hospital staff and my employer made all the difference. Because of that support I could work part time and had the confidence to ask colleagues to take tasks off me to lighten the load.'
Jenny, 59, Cambridgeshire

Ongoing support: survivorship

4.1. The CRS acknowledged that people's needs after cancer treatment were not being met. The National Cancer Survivorship Initiative (NCSI) was established in 2008 as a partnership between the Department of Health and Macmillan to address their needs by piloting new models of care, work that is still ongoing. The NCSI Vision, published in 2010, outlines the five key shifts that are needed in the health and care system to help cancer survivors get their lives back on track after treatment.²⁶ By 2012 the NCSI aims to ensure that cancer survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

4.2. The next step is to implement the vision across the NHS. A long-term condition approach is needed for cancer. The new system should be based on assessment, care planning and management of the long-term consequences of cancer and its treatment.

'After my treatment for lymphoma was over, that's when the problems began. I suffered both from psychological and physical effects. Being back at work became increasingly difficult and trying to get an interview with occupational health took six months. I look back now and wish I'd searched out advice from the health professionals as no one asked me what support I may need.'
John, 58, Co Durham

What are the potential benefits of better support for cancer survivors?

4.3. The managed aftercare approach set out in the NCSI Vision has the potential to deliver better outcomes for patients and more efficient use of NHS resources. The benefits include:

- Reduced recurrence of cancer
- Recurrences spotted earlier
- Better cancer survival rates
- Decreases in co-morbidity incidence
- Efficiency savings due to reduced hospital admissions, GP and outpatient consultations
- More cancer survivors returning to, and staying in, work.
- Improved health and well-being outcomes.

Recommendations

4.4. In order to deliver these outcomes, we want:

- Everyone reaching the end of treatment to be offered an assessment by an appropriately trained professional. The assessment should result in the creation of a written, personalised care plan. Every cancer survivor's plan

²⁶ Department of Health, Macmillan Cancer Support and NHS Improvement, National Cancer Survivorship Initiative, 2010

should cover health, social, emotional, financial and work-related needs, where relevant

- Everyone able to re-enter the system swiftly if they think they have a recurrence or need more support.

4.5. We believe the development of post-treatment care plans and support services can be supported by:

- Ongoing Governmental support for NCSI as it continues to pilot and roll-out new models of care
- NICE incorporating standards for post-treatment care in all NICE quality standards for cancer, including a post-treatment care plan
- The development of a survivorship package in the payment by results tariff which would include a range of services including care planning, case management, treatment summary records, self-management programmes, vocational rehabilitation and physical activity packages
- The new NHS Commissioning Board including provision of a care plan as part of the commissioning framework for GP commissioners
- The development of a robust reporting procedure to ensure that providers of care collect information on the incidence of the consequences of treatments. This data should be collated on a national level in order to inform the development of cancer services.
- We welcome the development of a national cancer survivorship survey and want the survey to be repeated every two years.

Case study: The impact of a community Macmillan nurse in curative care

The Birmingham Cancer Network and NHS Birmingham East and North worked together to develop projects testing a Macmillan Primary Care Cancer Nurse (MPCCN) supporting breast cancer patients at Good Hope Hospital. The aims were to provide an expert assessment early in the cancer pathway to address and identify problems faced by people living with breast cancer. The MPCCN role was integrated into multidisciplinary teams where they devised clinical outcomes, measures, a patient evaluation questionnaire and patient information leaflets.

The innovative service provided every patient assessed by the MPCCN with an individualised care plan which was reviewed at each treatment visit. Subsequently, the MPCCN prevented 11 accident and emergency admissions and over 100 outpatient attendances. The evaluation study concluded: 'If complex needs of breast cancer patients are not addressed early this can affect how they cope with their breast cancer treatment but also how they cope with their transition from cancer patient to cancer survivor.'²⁷

²⁷ NHS Improvement, Living with and beyond cancer: the story so far, July 2010

Work and cancer

- 5.1. Back to work support for people with cancer is inadequate. Most people of working age with cancer want to remain in, or return to work, during or after their treatment - many attach a very strong importance to work after a cancer diagnosis.^{28,29} Work represents a return to normality, and can help alleviate financial pressures - 91% of cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer.³⁰ However, more than four in ten people who are working when diagnosed have to make changes to their working lives after cancer, with almost half of those changing jobs or leaving work altogether.³¹ There is strong evidence that good work is good for physical and mental health and wellbeing.³² Therefore support for cancer patients to return to and remain in work may prevent future readmissions.
- 5.2. People with cancer tell us they want information about work but over half of patients in work (56%) say that no health professional talked to them about the impact cancer might have on their working life. Ensuring that patients receive information about work through IPs is an important first step. However, there also needs to be a culture change in the NHS; health professionals need to be having conversations with patients about work issues and need to be equipped to do so.
- 5.3. Patients also need information about their legal rights; less than 40% are aware that cancer is covered by the Disability Discrimination Act 2005 (DDA). The CRS 2007 highlighted the low awareness (18%) amongst employers that cancer is covered by the DDA. In the three years since then, awareness has not increased. With the DDA being superseded by the Equality Act, it is important that DH and DWP work together to raise awareness of disability employment rights.
- 5.4. Many cancer patients need access to specialist vocational rehabilitation services to help them to return to work. However, NHS rehabilitation professionals, such as occupational therapists, have little capacity to do more than hospital discharge planning. Only 3% of cancer patients received support from an occupational therapist after their initial treatment finished and only 2% received support from someone who gave advice about returning to work.³³ It is vital the NHS plays its part in helping patients get their working lives back after cancer treatment.

²⁸ Spelten E, Spragers M and Verbeek J, (2002), 'Factors reported to influence the return to work of cancer survivors: a literature review', *Psycho-Oncology* 11:124-131.

²⁹ Amiz Z, Neary D and Luker KA, (2008) 'Cancer Survivors' views of work 3 years post diagnosis – A UK Perspective', *European Journal of Oncology Nursing*, 12(3):190-197.

³⁰ Macmillan Cancer Support (2006). *Cancer costs*.

³¹ YouGov online survey of 1,740 UK adults living with cancer. Fieldwork took place between 26 July-9 August 2010. Survey results are unweighted.

³² Waddell G, Burton K, *Is Work Good for Your Health and Wellbeing?* 2006.

³³ YouGov online survey of 1,740 UK adults living with cancer. Fieldwork took place between 26 July-9 August 2010. Survey results are unweighted.

Recommendations

5.5. In order to help cancer patients get back to work if they so wish, we want:

- Everyone who needs it to receive information on how their ability to work might be affected, how to manage their condition, when they might expect to be ready to return to work and what legal rights they have
- Everyone who needs it to receive vocational rehabilitation support, which might include physiotherapy, counselling, retraining, and workplace assessments or adjustments.

Case study: Blackburn and Darwen Vocational Rehabilitation pilot

Gillian is a science teacher in her 50s, diagnosed with breast cancer. Off work since her diagnosis and surgery, Gillian's medication had made her lethargic and nauseous, and she had a lot of back pain. She had also lost confidence in her ability to manage a physically and mentally demanding job, and did not feel able to return when her sick note was due to expire.

Gillian accessed the Blackburn and Darwen Vocational Rehabilitation pilot, where the case manager helped her with short term goal setting and one-to-one work rebuilding her confidence. The case manager also accompanied Gillian to a meeting with her employer, and helped secure agreement to a phased return to work, a comfortable chair to replace a stool to alleviate back pain, and classroom assistance. Gillian will continue to meet with the case manager, but now feels confident she will be able to return to work shortly when her sick note expires.

Environments

- 6.1. We believe that cancer patients deserve to be treated and supported in high quality cancer environments, which are designed around their needs and help to improve their outcomes, no matter where they are in the cancer journey. Macmillan is leading the way on improving cancer environments and, working in partnership with the Department of Health, has recently rolled out the Macmillan Quality Environment Mark (QEM). The QEM was developed in response to the commitment in the CRS to develop a 'kitemark' for good cancer facilities and works to drive up quality standards by assessing cancer environments against a series of key indicators shaped by people living with and beyond cancer. It acts as a benchmark of excellence for commissioners and supports the patient choice agenda; it will shortly form part of the NHS Choices listings.
- 6.2. Although the QEM is still in the first months of implementation, good progress has been made. However, there is still much work to be done. Too many cancer facilities still fall far below the standard that cancer patients should rightly expect and there is a long way to go before the QEM is embedded within local decision making by service commissioners or providers.
- 6.3. There are a number of studies in the UK and US that support the link between improvements to physical patient environments and improved patient experience and service efficiencies, although more work is still required to understand the direct impact on operating costs in a cancer context. Given this body of evidence it is vital that the commitment to improving cancer environments is renewed.³⁴

Recommendations

- 6.4. In order to encourage healthcare providers to improve their care environments we want to see:
- A renewed commitment in the CRS to the continued improvement of cancer environments
 - All cancer facilities to aim and be encouraged to achieve the QEM
 - The inclusion of a patient experience indicator for cancer environments within domain four of the NHS Outcomes Framework
 - NICE to establish a single cross-cutting quality standard for cancer environments that recognises the QEM as best practice in the delivery of excellent cancer environments

³⁴ The role of hospital design in the recruitment, retention and performance of NHS nurses in England: Price Waterhouse Cooper on behalf of Commission for Architecture and the Built Environment / The Role of the Physical Environment in the Hospital of the 21st Century: A Once-in-a-Lifetime Opportunity, Roger Ulrich*, Xiaobo Quan, Center for Health Systems and Design, College of Architecture, Texas A&M University and Craig Zimring*, Anjali Joseph, Ruchi Choudhary, College of Architecture, Georgia Institute of Technology / The Business Case for Better Buildings, *Frontiers of Health Services Management*, Vol. 21, No. 1, Fall 2004, p. 3-24, Leonard L. Berry, Ph.D., Derek Parker, Russell C. Coile, D. Kirk Hamilton, David D. O'Neill, J.D., and Blair L. Sadler, J.D

- The QEM to be recognised as best practice within guidance for commissioners.

Case study: Leighton Hospital, Crewe

The provision of day and outpatient oncology services at Leighton Hospital, Crewe in 2007/8 was undertaken as a joint development project between the NHS Trust and Macmillan Cancer Support, using the QEM principles and with full service user involvement from the outset. Improvements to the patient pathway increased capacity for local patients. The completed building demonstrates the QEM principles of convenient and easy access, patient comfort, dignity and choice, a supportive physical environment with garden space and art, and easy access to information. It is well liked by its service users and staff and was awarded MQEM accreditation in 2010 by independent assessment.

End of life care

- 7.1. Between 2006 and 2008 Macmillan spent over £10 million on initiatives for people needing palliative care or end of life adult services. Macmillan believes that if someone is nearing the end of their life, they should have a choice over where to spend that time. The NHS Outcomes Framework must include indicators to support that choice.
- 7.2. For the majority of people, home is the place of choice. A recent survey by Macmillan of people who have a cancer diagnosis found that 57% would like to spend the last weeks and days of their life at home. This rose to 73% if all their concerns about dying at home, which included access to round the clock care, were addressed. Only 1% of respondents would choose to die in hospital.³⁵
- 7.3. Yet many people's wishes are not being met as most cancer patients die in hospitals (48%) and less than a quarter (24%) die at home.³⁶ An analysis of patient records in one PCT found that 40% of patients who died in hospital over a one-month period did not have medical needs which required them to be treated in hospital.³⁷

How can care be improved?

- 7.4 Despite the publication of the End of Life Care Strategy in 2008, the most recent progress report shows there is still a long way to go in delivering high quality, consistent end of life care across the country.³⁸
- 7.5 Factors that are preventing people from dying at home include the fact that conversations about place of death preference are not taking place early enough. Evidence obtained from focus groups conducted by Macmillan suggests that conversations about preferences regarding place of death often only happen as a matter of urgency, when death is imminent, instead of some time before decisions need to be made.³⁹
- 7.6 Even where preferences are discussed, they are not recorded. In January 2010, Macmillan conducted a freedom of information (FOI) request of all PCTs. This research found that 42% do not have a process for registering people's wishes regarding where they would like to be cared for as they near the end of their life. Almost half (47%) of PCTs do not collect data on whether patients were able to die in their preferred place.⁴⁰

³⁵ Macmillan Cancer Support, Unpublished survey conducted February 2010 of 1019 people.

³⁶ National Audit Office (2008), End of life care.

³⁷ National Audit Office (2008), End of life care.

³⁸ Department of Health (2010), End of life care strategy: Second annual report.

³⁹ RS Consulting (September 2010) End of Life Care Summary of Focus Group Findings

⁴⁰ Macmillan Cancer Support (2010), Always there? The impact of the End of Life Care Strategy on 24/7 community nursing in England.

Vivienne, 63, Northamptonshire:

'I'd got to the point where I couldn't cope at home. Our GP had requested a district nurse for us but we didn't even get a call, let alone a visit. My husband had asked that I be with him at the end but it didn't happen like that. He died from cancer alone in a hospice before I got there. I suffered terrible guilt that his one wish I'd not been able to keep. If there'd been support for us at home, I'd have been by his side.'

7.7 Community services are lacking: Many PCTs do not have the necessary community services to enable people to die at home if they so wish, with the result that people are dying in hospital. Macmillan's FOI request revealed that 24/7 community nursing is only available in around half of PCTs (56%).⁴¹ This shows little improvement from a survey conducted in 2006-07 by the National Audit Office (NAO) which found that 24/7 community nursing was only available to all patients in their home in around 53% of PCTs.⁴²

Case study: Sheffield PCT Intensive Home Nursing Service

The PCT has both a 24 hour district nursing service, and an Intensive Home Nursing Service (IHNS), which provides up to 24 hour care for terminally ill patients to enable them to die at home. The level of care given is assessed according to need, and takes into account personal and family requirements, by offering tailored care to meet individual needs. The care is provided by a team of support workers, who are co-ordinated, managed, led and developed by a team of senior staff nurses.

The service provides around 500 shifts a month, and cares for around 600 patients a year. The majority of those patients will have died safely at home, the place of their choice, with high-quality supportive care.

Kathryn Dimelow, whose mother Hazel Smith was recently cared for by the service, said: "In such a difficult time it was a great comfort and reassurance to have the support of the home nursing service. It meant that my sister and I were able to care for mum at home with the help of district nurses and an amazing GP. We felt secure that the nurses were competent and compassionate in their work. Without the service it would have been a struggle."

What needs to be done to deliver improvements and save money in end of life care?

7.8 If conversations about end of life care were held early enough, people's wishes were recorded, and there was better access to community services, more people would be able to die at home and significant cost savings could be delivered. The NAO found that £104 million a year could be used to meet people's preferences for place of care by reducing emergency hospital admissions for cancer patients by 10% and the

⁴¹ Macmillan Cancer Support (2010), Always there? The impact of the End of Life Care Strategy on 24/7 community nursing in England.

⁴² National Audit Office (2008), Results of a census of primary care trusts.

average length of stay following admission by three days.⁴³ This evidence is supported by further research that found that £160 million savings for the NHS could be made if end of life care was delivered in the home.⁴⁴ Much of the real value comes, however, in terms of the quality of patient care. Where the process does work well and the patient has a care plan in place, and their wishes are met, it not only ensures that patients can die where they wish, but that their carer has a less traumatic experience.

Recommendations

7.9 In order to deliver choice in end of life care we want to see:

- The NICE Quality Standard on end of life care to include non-clinical as well as clinical needs
- The end of life tariff, to be developed as part of the end of life funding review, should accurately reflect the cost of providing care in different settings and actively incentivise good practice. Freeing up funding so it follows patients should ensure that if more people want to die at home, the financial resources are available for them to do so
- An indicator on end of life care that measures whether people are able to die in their place of choice included in the NHS Outcomes Framework.

⁴³ National Audit Office. End of Life Care. 2008.

⁴⁴ Dr Foster Intelligence and Healthcare at Home (2010) Hospital care at home.

Equalities in cancer care

8.1 We believe that every single person who is diagnosed with cancer should have access to high-quality treatments and services that are appropriate and responsive to their needs at every stage of their cancer journey, no matter what their equality or demographic characteristics are, what part of the country they live in, or what type of cancer they have.

8.2 We welcomed the emphasis on tackling inequalities in the CRS and the establishment of the National Cancer Equality Initiative (NCEI). However, the NCEI has not made the same progress as other CRS initiatives. Its focus has been on improving prevention and early diagnosis, reflected in the survey of NHS Trusts by the NCEI last year, which found that projects were significantly more likely to be focussed on awareness and early detection, rather than on treatment, patient information or living with and beyond cancer.⁴⁵

8.3 Our recent research produced evidence to show that people with cancer experience inequalities in the care they receive on the grounds of ethnic origin, religion or beliefs, sexual orientation, gender, age, socio-economic background, because of where they live and/or disability.⁴⁶ While Macmillan recognises the importance of improving awareness and early detection to prevent people from getting cancer, we know that major inequalities exist within cancer treatment and services, and that significant action needs to be taken in tackling inequalities in treatment and care, in order to improve outcomes.

The future for tackling inequalities in cancer care

8.4 We believe that the vision paper published by the NCEI earlier this year sets out the key actions that should be taken in cancer care to tackle inequalities.⁴⁷ Macmillan is leading on several of the projects set out in the NCEI vision and is committed to seeing these projects realised.

Recommendations

8.5 In order to tackle cancer inequalities we want to see:

- Ongoing DH commitment to implement the NCEI Vision and related projects.
- A recommendation for the NHS Outcomes Framework to measure the progress being made to tackle inequalities in care and treatment (see Outcomes Framework section)
- A recommendation for NICE and the NHS Commissioning Board to use learning from NCEI projects in the development of Quality Standards and commissioning guidance respectively on cancer.

⁴⁵ NCEI newsletter, July 2009

⁴⁶ Macmillan Cancer Support 2009. Response to the APPG on Cancer's inquiry into cancer inequalities.

⁴⁷ National Cancer Equality Initiative 2010. Reducing cancer inequality: evidence, progress and making it happen

Delivering the revised Cancer Reform Strategy

Commissioning, NICE Guidance, and Payment by Results

- 9.1. The advent of GP commissioning will present opportunities and challenges for commissioning cancer services. GP commissioners will not necessarily have the skills and capabilities to assess the needs of people living with cancer and to commission services to meet those needs.
- 9.2. GP commissioners are likely to require access to specialist advice when commissioning cancer services. Good work has been undertaken by cancer networks across England, coordinating services across and between geographical areas and overseeing compliance with clinical standards. We think there is a strong case for mechanisms to be put in place, whether on the current network model or a new form, to provide cancer commissioning expertise and coordinate services. We believe that networks should remain during the transition from PCT commissioning to GP commissioning to ensure continuity and quality of services. Urgent support is required to maintain cancer networks through the transition period.
- 9.3. Although GPs have clinical expertise, they are not necessarily cancer experts. The average GP will see only eight or nine new cases of cancer a year and may only see patients with rarer cancers once in their working lives.⁴⁸ Therefore, we do not think that all cancer services should be commissioned by GP consortia, particularly treatments for people with rarer cancers and large investment decisions, eg buying new linear accelerators. We think that the following services could potentially be commissioned by GPs: diagnostics; simple chemotherapy and surgery for non-complex cancers; survivorship services and end of life services. GPs will need to commission these services as part of pathway commissioning, seeking advice from specialists.
- 9.4. Though we recognise that the Government wishes to give GP commissioners freedom to commission care, it should consider allowing mandates from the NHS Commissioning Board if serious inequities in provision for either particular conditions, including cancer, or different equality groups are identified.
- 9.5. Embedding the patient voice in the commissioning process is vital to ensure accountability and responsiveness to patients' needs. However, to date, patient involvement in commissioning has often been tokenistic and restricted to surveys and customer feedback, rather than active involvement in decision making. User involvement in the new commissioning consortia needs to go beyond consultation; patients should also be directly represented on governance structures and seen as partners in developing service improvement solutions. We also want the cancer patient voice to be represented on the National Commissioning Board; it should not consist solely of health professionals.

⁴⁸ DH (2000) *The NHS Cancer Plan*

- 9.6. Whether GP commissioning will be responsive to the needs of people with cancer will partly depend on the levers that underpin it, including NICE Quality Standards; the NHS Outcomes Framework; the payment by results tariff; the Quality and Outcomes Framework; commissioning guidance and contracts developed by the NHS Commissioning Board; the revised GP contract and patient involvement mechanisms. We are concerned that the health white paper states that GP commissioners may only need to 'have regard' to NICE Quality Standards and commissioning contracts; as a marker of quality we believe that NICE Quality Standards should be 'must dos', with GP commissioners given the scope to add value to these standards if they wish when commissioning services.⁴⁹
- 9.7. Macmillan would like to be involved in the development of the new Quality Standards for cancer and wants them to be developed swiftly, especially given much of the work that has already gone into developing the Improving Outcomes Guidance (IOGs), on which they should be based. We want the Quality Standards to reflect the full range of psychosocial support a person with cancer requires throughout the cancer journey. Quality Standards in cancer must not water down existing cancer standards. The new standards should build on the existing cancer IOGs and extend these to reflect new service developments, eg survivorship programmes and vocational rehabilitation services.
- 9.8. The peer review process measures the implementation of the IOGs and we believe a similar compliance mechanism will be required to audit the implementation of the NICE Quality Standards, so that commissioners and patients know the standards are being delivered. Any poor providers identified by audits should trigger an inspection by the Care Quality Commission.
- 9.9. Many cancer services need to be redesigned. DH strategy documents, including the revised CRS and cancer commissioning guidance, should strongly set out the case for change and include both economic arguments and evidence that redesign improves patient outcomes. We believe the role of the National Cancer Director will continue to be important in leading change in cancer services.
- 9.10. We want to see the development of a tariff that incentivises the delivery of high quality patient experience. This could be based on annual National Patient Experience Survey data as a cost effective source of quality data. Payments for quality need to be sufficient to incentivise trusts to provide the services and roles that improve experiences and outcomes for patients, for example, access to a CNS and information services. In the meantime we want PCT and GP commissioners to use bonuses or penalties linked to quality outcomes.

Recommendations

- 9.11. In order for effective delivery of cancer services, Macmillan wants:

⁴⁹ Department of Health, Equity and Excellence: Liberating the NHS, July 2010

- Mechanisms to provide specialist advice on cancer, plan and commission cancer pathways across consortia boundaries, ensure access to specialist tertiary services, and oversee compliance with clinical standards
- Networks to be sustained during the transition from PCTs to GP consortia to maintain the continuity in cancer commissioning
- Specialist cancer services to be commissioned by the NHS Commissioning Board
- GP commissioners to involve patients in designing, procuring and evaluating services and user involvement needs to be properly resourced
- NICE Quality Standards to be 'must dos'
- A process similar to peer review to be developed to ensure compliance with the NICE Quality Standards.
- The development of a tariff that incentivises the delivery of high quality patient experience.

The NHS Outcomes Framework

9.12. We welcome the proposal to improve outcomes for patients by using new outcomes frameworks, including one for the NHS. Many of the proposed indicators in the NHS Outcomes Framework will be influenced by the experience and treatment of people living with and beyond cancer.

9.13. Cancer is, for many patients, more akin to a long-term condition, but this may not be well understood by either PCT or GP commissioners; people can oscillate between needing acute care in hospital and needing support to manage their condition after they have finished treatment. If the NHS Outcomes Framework is to show what the NHS is achieving for cancer patients, then it must include indicators measuring the outcomes and experiences of cancer survivors, as well as those of people who are currently cancer patients. We believe that the success of the framework in improving outcomes for cancer patients will depend upon capturing and reporting the right data (including disaggregation by disease and equality dimension) and including appropriate indicator measures for cancer. We also want to see outcomes indicator measures reported by each provider and commissioning consortia, as well as aggregated nationally.

9.14. However, we strongly believe that some alternative measures may be necessary to drive delivery of the Outcomes Framework, because it is difficult to measure some outcomes and some targets are essential to patient care, for example, cancer waiting time targets. Clear NICE Quality Standards (which should be 'must dos'), NHS Board commissioning guidance and appropriate payments in the payment by results tariff and the Quality and Outcomes Framework should all be used to drive delivery.

Disaggregation by disease and equality dimension

9.15. Macmillan believes it is imperative that outcome measures are disaggregated by both disease area, including cancer, and for all equality dimensions (gender, age, socio-economic status, sexual orientation, disability, race).

- 9.16. Many of the proposed outcome indicators refer to long-term conditions. Incidence of long-term conditions varies from disease to disease and the outcome measure figure will need to be weighted to take this into account. We are concerned that if data is not disaggregated by disease area, then poor outcomes for a particular disease area, including cancer, may not be noticeable.
- 9.17. We welcome the ambition to disaggregate all outcome measures by equalities and geography. If this was achieved, we would be able to see how the NHS serves different populations of the country, and it would strongly incentivise commissioners and providers to improve services in areas where it was obvious inequalities existed. However, as the NHS Outcomes Framework consultation document itself notes, it is not currently possible to disaggregate all of the proposed indicators. We want to see a timetable and specific actions that will be taken to ensure all outcome indicators are disaggregated.
- 9.18. There are a number of difficulties associated with using patient reported outcome measures (PROMS) and patient experience surveys. For example, literacy levels are barriers to some people reporting their experiences and outcomes and some groups may report positive experience where this has not been the case. For these reasons it is particularly important that data is disaggregated by equality dimensions so that any unusually poor or good outcomes can be investigated and poor survey response rates can be addressed.

Additional indicators

Domain One: Preventing people from dying prematurely

- 9.19. We welcome the inclusion of the one and five year cancer survival indicators and that they will include people of all ages, not just those under 74. We believe this will help to address the discrimination experienced by some older people.

Domain Two: Enhancing Quality of life for people with long-term conditions

- 9.20. For many people, cancer is more akin to a long-term condition. The indicators for people with long-term conditions need to measure people's health and well-being at key points after treatment. We know that the needs and health status of people who have had a cancer diagnosis can fluctuate and change over time and they may be at particular risk of other conditions. We believe it is important that the Outcomes Framework includes indicators that report the health and wellbeing of cancer survivors at one year and five years post treatment. We welcome the development of a national cancer survivorship survey and want the survey to be repeated every two years.
- 9.21. The NHS Outcomes Framework should include indicators that measure the numbers of people with cancer who are in work, the numbers who say they can work, and the numbers who feel supported to return to or remain in work.

Domain Three: Helping people to recover from episodes of illness or following injury

9.22. Cancer-related emergency readmissions are currently not classified as emergency readmissions as they are often considered to be a necessary part of patient care.⁵⁰ Emergency readmission should not be routinely viewed as a necessary part of the patient's care pathway. Some of these readmissions could be avoidable. Data on cancer-related emergency readmission should be made publicly available as part of the proposed indicators on emergency readmissions.

Domain Four: Ensuring people have a positive experience of care Information and Support

9.23. Provision of timely, appropriate and personalised information and support should be measured in Domain four. Having the right information at the right time with the right support can improve a patient's experience and health outcomes yet there is currently no proposal to include the provision of information in the Framework. We want the following indicators included:

- Percentage of people who say they were involved in decisions about their treatment and care
- Percentage of people who felt they had access to the information and support they needed

9.24. These indicators would need to be aggregated up from a series of questions posed to patients in patient experience surveys. We believe the National Cancer Patient Experience Survey provides the vehicle by which these questions can be posed to cancer patients, and feel strongly that the survey should continue.

Providing equitable care

9.25. As well as disaggregation by equality dimension, we believe there should be specific indicators which measure whether people are treated with dignity and respect and whether they had control over decisions about their treatment and care. Although there is already a question in the National Cancer Patient Experience survey about whether people are treated with dignity and respect, we believe that this indicator would need to be an aggregation of a series of questions examining a patient's treatment, rather than simply asking whether they feel they were treated with dignity and respect.

End of life care

9.26. While we are pleased to see that there is a proposed indicator on end of life care under the patient experience domain (a survey of those 'closest to the bereaved'), we think that it needs to measure whether people experience choice and high quality care at the end of life.

9.27. The indicator should reflect whether people's wishes at the end of life are being met, fitting in with the aim included in the health white paper of moving towards a

⁵⁰ <http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=927>

national choice offer to support people's preferences.⁵¹ It would need to take into account not just where people die, but whether their wishes were met. Given the discrepancy that exists at present between those who wish to die at home and those that actually do, it should over time show a movement towards increasing numbers of people dying in the place of their choosing.

9.28. Statistics are available from the Office of National Statistics on place of death, but data on whether people are able to die in their preferred place is not routinely collected. It should be mandatory for all PCTs/GP consortia to record preferred place of death and whether it has been met, something that may be achieved by the further roll out of locality registers.⁵² We would welcome the opportunity to work with the Department of Health on designing this indicator.

Environments

9.29. The proposed Outcomes Framework suggests that outcome measures for patient environments should fall within domain five, which deals primarily with patient safety. We believe this approach is too narrow and fails to capture the wider effects that environments have on patient experience, such as the design and use of space, access to and around the facility, the availability of emotional and other non-clinical support and user involvement, which are all considered as part of the QEM assessment.

9.30. We believe that domain four of the outcomes framework must include a patient experience indicator that relates directly to patient environments. We suggest the following indicator: Proportion of service users who reported that they were satisfied with the environment where they received treatment, care or support.

9.31. The suggested indicator should not be based on a single question in a patient experience survey. In order to get a comprehensive understanding of patient's experience of environments we would suggest using a series of questions that focus of the following key areas:

- Accessibility
- Privacy and dignity
- Comfort and wellbeing
- Patient choice and control over environment.
- Information
- Patient feedback

9.1 From our experience of developing the QEM, Macmillan has expertise in this area and would welcome the opportunity to work with the Department of Health to develop an indicator for cancer environments.

⁵¹ Department of Health (2010), Equity and excellence: liberating the NHS.

⁵² 'locality registers' – information portals about the end of life care being provided to patients in a given area, so that essential information can be shared more easily between agencies.

Recommendations:

9.32. Indicators in the NHS Outcomes Framework must reflect the needs of people living with and beyond cancer and include

- Disaggregation by disease, including cancer, and equality dimension
- Indicators that measure people's experiences and health status at key points (domain two)
- Cancer included in the indicator for emergency admissions (domain three)
- Indicators relating to information and support, the provision of equitable care, whether people are able to die where they wish and whether people are satisfied with the clinical environment (domain four).

The cancer workforce

- 10.1 A high-quality cancer workforce will lead to better health and social outcomes for people affected by cancer. The cancer workforce will have an impact on many of the indicators underpinning the five domains set out in the NHS outcomes framework. In order for the cancer workforce to be high-quality it must have the right skills and capabilities to meet the needs of patients, be easily accessible to them, and operate in a coordinated way.
- 10.2 The development of the cancer workforce must be a priority and occur in tandem with redesign of services. At the moment:
- There are gaps in coverage, particularly in allied health professional roles, clinical psychologists and in providing one to one support for people with some tumour types, for example lung cancer
 - Professionals sometimes act in an uncoordinated way and often have limited understanding of how things work outside their own sector, for example, secondary care practitioners may not understand how primary care operates
 - Current roles and services do not support people affected by cancer across the whole cancer journey effectively or efficiently, particularly post-treatment
 - People's health, social and information needs are not necessarily met in a co-ordinated way, making exercising choice difficult for people.
- 10.3 Macmillan wants everyone to have access to the right person at the right time, be that a specialist nurse, doctor, allied health professional or other health and social care professional. In addition, people need access to personalised, one-to-one support from a trained professional, who co-ordinates care and communicates with and provides information to the patient. The trained professional may not be the same person across the whole care pathway but will be the most appropriate person at any one time in the pathway.
- 10.4 The cancer workforce therefore needs to comprise of generalist and specialist nurses, doctors, pharmacists, allied health professionals, information and support advisers, psychologists, social workers, benefit advisers and care coordinators and people should have access to these individuals when they need them.
- 10.5 We believe that multi-disciplinary teams (MDTs) are the right model for the cancer workforce but they need to include, or have access to, the correct skill mix. The development of MDTs has led to improved ways of working and better care for patients but often MDTs have not included, or had access to, all the roles required to fully support people with cancer; they have tended to include clinical roles only. This needs to change. MDTs must be able to meet the full range of needs of people with cancer, wherever they are on the pathway by including roles, or having links to, skilled health and social care professionals.
- 10.6 Macmillan is concerned that the devolution of education and training provision to employers will lead to gaps in the workforce. There are already problems filling roles in cancer care because of a lack of skilled professionals, eg radiographers, and

demographic changes in the next decade means that many professionals in palliative care will reach retirement age. Risks inherent in leaving planning to the market include deliberate under-investment in types of role funded, rates of pay and provision of education and training. Successful coordination of education and training places requires an oversight of demographics. A strategic approach to workforce development is needed.

Recommendations:

10.7 In order to deliver improved outcomes for people with cancer, we want investment in the cancer workforce:

- The NHS Commissioning Board should co-ordinate workforce planning, using intelligence gathered by the Centre for Workforce Intelligence.
- MDTs must be able to meet the full range of needs of people with cancer, wherever they are on the pathway by including roles, or having links to, skilled health and social care professionals.
- Commissioners to procure services that offer the full range of roles that people affected by cancer might need access to, including providing personalised support throughout the cancer journey, in tandem with service redesign.
- Commissioners need to invest in the following:
 - Additional tumour site specific CNSs
 - Additional specialist palliative care CNSs
 - New survivorship roles including nurses, allied health professionals and coordinators, along with establishing new services
 - Expanding community nursing, in particular to ensure people are able to die at home if they wish to do so
 - Allied health professionals, to improve rehabilitation services, possibly on a sessional basis.
 - Invest in education and training provision to ensure that skilled professionals are available in the future.
 - Work closely with education providers to ensure training provision recognises the skills required to deliver new services.

Macmillan Cancer Support
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