

Rarer Cancers

Contents

1. Executive Summary
2. Background
 - 2.1 Rarer Cancers
 - 2.2 Specialised Cancer Services
3. Main Themes
 - 3.1 Diagnosis
 - 3.2 Research
 - 3.3 Choice
 - 3.4 Outcomes

1. Executive Summary

This report is one in a series produced by the Specialised Healthcare Alliance looking at various services, including rarer cancers, which have been prioritised by the National Specialised Commissioning Group. This report was particularly informed by a stakeholder workshop on rarer cancers organised by the Alliance and the National Cancer Action Team on 31st March 2011.

A wide range of stakeholders including patients, commissioners, clinicians and representatives from patient organisations attended the workshop.

The report sets out some background information on rarer cancers and specialised cancer services before seeking to distil the major themes explored during the workshop in relation to diagnosis, research, choice and outcomes. For each theme, some context and background with regard to the key issues is given, as well as an overview of the discussion at the event.

Among the most important points to emerge, attention is drawn to:

- **The development and dissemination of a suite of generic symptoms often linked with rarer cancers could assist in promoting early referrals from primary to secondary care;**
- **Learning from current collaborations between industry and the NCRN (National Cancer Research Network) and encouraging partnership funding could help to address the current lack of funding for research on rarer cancers;**
- **All patients should be provided with a personalised care plan and a Key Worker to ensure their care is integrated, coordinated and effective;**
- **Local healthcare teams should be trained and supported to provide care at the end of life for people with rarer cancers;**
- **A one-stop shop on the NCIN (National Cancer Intelligence Network) website should be established that could act as a signpost for healthcare professionals and the public to the range of data currently available on rarer cancers.**

2. Background

2.1 Rarer Cancers

Rarer cancers are often defined as all cancers excluding the 'big four': breast, bowel, lung and prostate, and are estimated to account for 53% of all incidents of cancer in the UK.

The 2010 National Cancer Patient Experience Survey¹ was the first to cover all cancer groups. This showed that there were significant differences in the experience of treatment and care that patients in different cancer groups reported to have received. On the whole, patients with rarer cancers recounted a poorer experience of their treatment and care than people with more common forms of cancer. In particular, people with sarcoma, brain/central nervous system cancers, urological cancers (excluding prostate) and 'other cancers' most frequently reported poor experiences.

In addition, the Rarer Cancers Foundation highlights that access to tailored information and to Clinical Nurse Specialists for rarer cancers is still patchy.² Indeed, the Patient Experience Survey underlines this point, with 89% of people with a 'big four' cancer being given the name of a Clinical Nurse Specialist, compared to 79% of people with a rarer cancer.

¹ Full report:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_122520.pdf

² Rarer Cancers Foundation website:

http://www.rarercancers.org.uk/news/current/the_rarer_cancers_forum_publishes_its_new_manifesto

In recent years, various policy documents have been published setting out the current government's strategy for cancer. For example, the *Cancer Reform Strategy* (December 2007) was a five-year strategy designed to ensure better care and treatment for people with cancer.³ These documents have obvious relevance for rarer cancers, but do not address the particular issues associated with the diagnosis, care and treatment of people with rarer cancers.

Improving Outcomes: a Strategy for Cancer (Jan 2011) is the most recent government strategy.⁴ The overall aim of the *Strategy* is to set out the steps required to drive improvements in cancer outcomes, in line with the ambitions of the government's current proposed NHS reforms. The strategy focuses on putting patients and the public first by promoting the use of patient information and patient choice; improving outcomes by promoting prevention and earlier diagnosis, by improving quality of life and patient experience for people living with and beyond cancer, by providing better treatment and by reducing inequalities; and improving the commissioning of cancer services.

Access to treatment has always been an important issue for people with rarer cancers. The government has recently consulted on a new system of pricing for medicines - value-based pricing (VBP) - which will be introduced from 2014. The overall aim of this system is to ensure that drugs are available to clinicians and patients at a price that reflects their value, for example the value of a drug may be higher if it helps to meet a previously unmet need. The government has also consulted on a 'Cancer Drugs Fund' which, pending the introduction of VBP, will make available £200 million a year from 2011 to enable clinicians to prescribe cancer treatments which they feel are most appropriate for their patients. It is envisaged that the Fund will cover treatments that are not routinely available on the NHS. These fall into four main categories:

- drugs which have yet to be appraised by NICE;
- drugs which will not be considered by NICE due to the small patient population for which they are licensed, but which are not covered by specialised commissioning arrangements;
- drugs which have not been recommended by NICE, mainly on the grounds of cost effectiveness; and
- drugs which cannot be appraised by NICE, as clinicians wish to use them outside their licensed indication to treat forms of cancer with a similar biology of disease to that for which they are licensed (off-label treatment).⁵

Improving Outcomes recognises that the quality of cancer surgery has improved with more operations being carried out by specialised surgeons with expertise in particular procedures. The document also acknowledges however that there is likely to be an increase in demand for surgical oncology (with improvements in early diagnosis and rising incidence), which must be planned for. The strategy also recognises the importance of ensuring equitable access to radiotherapy for those patients who need it, while noting that variations in activity remain across the country.⁶

2.2 Specialised Cancer Services

'Specialised' cancer services are defined as those with a planning population (catchment area) of more than a million people, meaning that each service would typically be provided by

³ Full document:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf

⁴ Full document:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf

⁵ p. 60. *Improving Outcomes: A Strategy for Cancer*

⁶ p. 55 and 57, *Improving Outcomes: A Strategy for Cancer*

less than 50 hospitals in England. Such services are set out in the Specialised Services National Definitions Set (SSNDS) or are those for extremely rare conditions, which are commissioned at a national level.

At present, the services in the SSNDS should be commissioned by ten regional Specialised Commissioning Groups (SCGs) rather than by individual PCTs. Nationally commissioned specialised services are commissioned by the National Specialised Commissioning Team (NSCT), with a body called AGNSS (the Advisory Group for National Specialised Services) advising Ministers on which services should be commissioned nationally and which centres should provide them.⁷

The term 'specialised cancer service' therefore denotes the method by which the service is commissioned. This allows for certain elements or services within the patient pathway of someone with a rarer cancer (and indeed of a 'common' cancer) to be specialised and others elements to be non-specialised. This can make the commissioning and provision of services for some cancers extremely complex.

Currently, the commissioning of all cancer services is supported by 28 Cancer Networks in England. Cancer Networks work together with commissioners to help them with the discharge of their own strategic planning and commissioning responsibilities, for example by helping commissioners to plan for the whole patient pathway. This is true also for rarer cancers. Cancer Networks serve populations of between one and three million people, meaning that specialised cancer services are those where a Cancer Network supports specialised commissioners in one of the following three ways:

- 1) at usually no more than two NHS trusts in a Cancer Network area;
- 2) at a single NHS Trust in a Cancer Network area;
- 3) at a single NHS Trust serving two or more Cancer Networks.

In the third case – where a Trust providing a particular specialised cancer service does not exist in every Network – several Cancer Networks may form a supra-network group to support commissioners regarding this service.

Under the Government's proposed reforms of the NHS, both regional and national specialised services will be commissioned by the NHS Commissioning Board. *Improving Outcomes: A Strategy for Cancer* suggests that 'it is very likely that GP consortia will wish to purchase support from a new style of cancer network' (p.17). However, during the transition, funding for cancer networks will continue to support the emerging GP consortia.

Specialised cancer services for adults are set out in definition 1 of the SSNDS.⁸ In addition, definition 23 covers services for children with cancer⁹ and definition 2 describes specialised services for blood and marrow transplantation.¹⁰ Further information on definition 1 can be found as an appendix.

⁷ For more information, please visit the NHS Specialised Services website:
<http://www.specialisedservices.nhs.uk/>

⁸ Full document:
http://www.specialisedservices.nhs.uk/library/26/Specialised_cancer_services_adult.pdf

⁹ Full document:
http://www.specialisedservices.nhs.uk/library/21/Specialised_Services_for_Children.pdf

¹⁰ Full document:
<http://www.specialisedservices.nhs.uk/doc/specialised-services-blood-marrow-transplantation-all-ages>

3. Main Themes

3.1 Diagnosis

While the importance of early diagnosis of all cancers is a central theme of *Improving Outcomes: a Strategy for Cancer*, the document also highlights the particular challenges inherent in achieving the early diagnosis of rarer cancers. For example, GPs may only see one or two instances of a particular rare cancer in their career, or perhaps none at all. The document also gives information about a recent survey by the Rarer Cancers Foundation of nearly 400 patients which found that nearly one third of respondents had been reassured by their GP and not asked to return when they had first presented with symptoms. In addition, of those who responded to the survey, more than one quarter reported that their cancer was diagnosed at an advanced stage (p. 46).

The 2010 National Cancer Patient Experience Survey also reveals that people with haematological cancers, sarcoma and 'other' cancers reported that they made a particularly high number of visits to their GP before referral to hospital.

The purpose of this workshop session was therefore to explore the ways in which early diagnosis of rarer cancers can be encouraged.

The main conclusions from this session were:

- **A suite of symptoms common to all or most rarer cancers could be developed and communicated to the range of healthcare professionals that may play a part in the diagnosis of a person with a rarer cancer;**
- **A one-stop shop of accredited, evidence-based, clear and accessible information would help to raise awareness of both healthcare professionals and the public;**
- **A shift is required in the GP-patient relationship, which would help to ensure that patients felt able to discuss all of their symptoms with GPs;**
- **Encouraging early referral to secondary care of people suspected of having a rarer cancer is vital;**
- **Risk assessment tools may in the future be a useful resource in diagnosing rarer cancers.**

Awareness

The importance of raising awareness of rarer cancers among GPs and the public was widely acknowledged at the workshop. However, some qualifying points were also made, for example the need also to prioritise prevention alongside early diagnosis and the importance of raising the knowledge and awareness of other healthcare professionals too, for example physiotherapists. Indeed, 20% of people who responded to the 2010 National Cancer Patient Experience Survey did not see their GP at all before going to hospital.

There was also general agreement at the event that it would not be sensible to expect GPs to recognise the symptoms of specific rarer cancers. A potential alternative to this would be raising GPs' awareness of generic symptoms which are common to all, or the majority of, rarer cancers. Stakeholders heard about a Cancer 52 survey that found that the four most common generic symptoms of people with rarer cancers are: fatigue and tiredness, lumps, persistent pain and unexplained weight loss. As a result of the survey, Cancer 52 drew up some key messages for the public which included encouraging people to see their GP if their symptoms were 'unexplained, persistent, severe and recurrent' (the acronym 'SUPR' to represent these descriptions was suggested as a counterpart to 'FAST' for stroke). It was also noted, however, that for some cancers, such as melanoma, these generic symptoms or descriptions are not relevant and could be counterproductive. There was, however, general support at the workshop for developing a suite of symptoms that could indicate cancer and communicating this to healthcare professionals.

Examples were given of various initiatives which have aimed to raise the awareness of healthcare professionals of the symptoms of rarer cancers. For example, NHS Scotland has put together a desktop guide on the symptoms of cancer which has been sent, individually named, to every GP in the country, while a BMJ continuing professional development tool has been produced which teaches healthcare professionals about the early symptoms of ovarian cancer. Stakeholders recognised the merits of this tool and also suggested working with the Royal Colleges in raising awareness of the symptoms of particular cancers.

The importance of GPs and other healthcare professionals having a known resource from which to gain more specialist advice and knowledge was also recognised. Stakeholders also suggested that specialists should be encouraged to share their knowledge with generalists. The merits of an online, one-stop shop which both professionals and the public could access giving information on all cancers were therefore recognised. The importance of this information being accredited, evidence-based, clear and accessible was emphasised.

GP-patient relationship

Cancer 52, as a result of the survey referred to above, also drew up some key messages for GPs. These include always considering that cancer may be a possibility and, where possible, ruling it out at an early stage, and recognising that patients know their own bodies.

Indeed, the GP-patient relationship was discussed by many stakeholders, who recognised that a short consultation, where people are encouraged to focus on only one symptom, can hinder the diagnosis of rarer cancers. It was suggested that GP practices could actively encourage patients to list their symptoms before attending their consultation, so as to ensure that the GP is given all the information they need. While this may make the initial consultation slightly longer, it could prevent future repeat consultations.

In addition, stakeholders underlined the importance of working to give people the courage to ask their GP if their symptoms could be cancer. Similarly, it was suggested that there is a need to allay people's fear of cancer, thus encouraging them to go to their GP at an early stage.

Decision aids and referrals

Improving Outcomes suggests that 'providing high quality decision aids and promoting early referral to secondary care' will be two key ways to improve the diagnosis of rarer cancers.

Indeed, stakeholders recognised that an important element of the alternative to GPs having knowledge of all rarer cancers is encouraging them to refer people suspected of having a rarer cancer to secondary care at an early stage. It is vital, however, that GPs have a basic level of awareness (as discussed above) to ensure that people are referred to the right place. There was some suggestion that a level of ambition with regard to referrals should be created, for example three visits to a GP could be set as the maximum, after which an automatic referral would be triggered.

Stakeholders recognised that, should GPs take on the majority of commissioning budgets, it would be imperative to ensure that they, through incentives or disincentives, were aware of the costs which had been prevented later on in the patient pathway as a result of early referral and ultimately earlier diagnosis.

Stakeholders flagged up that the National Awareness and Early Diagnosis Initiative (NAEDI), working with seven cancer networks, is currently trialling a cancer risk assessment tool for

primary care. The tool is based on work done in the CAPER studies¹¹ which identified symptoms of a small number of cancers that are presented to primary care and quantified the risk of cancer associated with them. While this is currently being trialled for lung and bowel cancer only, it is possible that such methods could be used for rarer cancers in the future.

3.2 Research

Organisations such as the National Cancer Research Institute (NCRI)¹² and the National Cancer Research Network (NCRN), which provides support to England's 32 Cancer Research Networks, work to promote cancer research. Multidisciplinary site-specific Clinical Studies Groups have also been established (some of which cover rarer cancers) that work to develop national cancer clinical trials. Yet research into the prevention, diagnosis, management and treatment of rarer cancers is still under-funded and under-prioritised (brain tumours, for example, receive only 1-2% of NCRI partner research funding).

The purpose of this session was to explore the challenges faced in undertaking research on rarer cancers and the potential solutions to these issues.

The main conclusions from this session were:

- **A number of challenges are faced in undertaking research on rarer cancers. These include small patient populations, a lack of funding, a lack of commercial interest, legacies of under-funding and a lack of academic interest and collaboration;**
- **International collaboration, the use of observational trials, encouraging an increase in the numbers of registries/biobanks and sharing outcomes and data between researchers were suggested as means to overcome the challenges connected with small patient populations;**
- **Learning from current collaborations between industry and the NCRN and encouraging partnership funding could help to address the current lack of funding;**
- **It is vital that a new generation of researchers is trained before older researchers retire and a shift in attitudes is required so that research is regarded as a prestigious option for clinicians.**

Challenges

One of the key challenges identified by stakeholders at the workshop was the small and geographically spread patient populations of many rarer cancers. These present difficulties with regard to data collection, availability of biological samples and the ability to undertake randomised clinical trials for treatments for rarer cancers.

Stakeholders also recognised that securing funding for research on rarer cancers can be a challenge, partly because there may be little or no commercial interest in the development of novel therapies for rarer cancers. It is possible that grant proposals may be out-competed by those for more common and 'high profile' cancers. Some stakeholders also pointed out that funding may be secured and provided without a focus on long-term strategy, for example funding may be made available for only the early phases of a clinical trial. A lack of funding in a particular area may lead to a lack of academic interest in this area and, with this, a legacy of under-funding. A lack of robust data collection, through registries or other means, can unfortunately also form part of this legacy.

Indeed, the recruitment of academics is also regarded as a problem, since research may be seen as a less attractive option and the retirement of key researchers can lead to a loss of

¹¹ More information: <http://www.ncbi.nlm.nih.gov/pubmed/19956169>.

¹² The National Cancer Research Institute is a UK-wide partnership between the government, charity and industry which promotes co-operation in cancer research among the 21 member organisations.

expertise and interest in a particular area. Collaboration between researchers, both within the UK and internationally, may also be lacking.

Possible solutions

Stakeholders discussed a number of possible solutions to the challenges identified. There was much support for international collaboration as a way of overcoming the hurdle of small patient populations. It was recognised, however, that a number of barriers to international trials currently exist, for example obtaining regulatory or ethics approvals, different interpretations of the EU Clinical Trials Directive by member states and various models of sponsorship in different countries.

The need to be flexible regarding the methodology used in trials was also highlighted. For example observational studies, while these do not meet the same criteria as clinical trials, are one way in which research can be coordinated for conditions with small patient populations. At the same time, it was recognised that it can be more difficult for commissioners to use the results of such studies, compared with the outcomes of clinical trials. The importance of registries and biobanks in research was also recognised and thus their wider use across more rarer cancers was seen as a key way to encourage research.

Stakeholders also stressed the importance of ensuring that trials are publicised among healthcare professionals more generally, and particularly among other researchers working on cancer. This is because research into one type of cancer can have relevance for the broader category within which the cancer falls and for other types of cancer. Stakeholders also emphasised the importance of not neglecting other types of research, for example psycho-social research, and there was a recognition of the need to examine where research can be of most benefit.

Turning to funding, stakeholders heard about a collaboration that already exists between the NCRN and Astra-Zeneca, the aim of which is to use novel agents from the Astra-Zeneca pipeline that would not otherwise be pursued by the company in these indications. In addition, stakeholders suggested that more partnership funding of research should be encouraged and that fundraising campaigns run by patient organisations could be joined up.

Regarding recruitment of academics, stakeholders recognised the importance of ensuring that a new generation of researchers are trained before older academics retire. Other countries have a greater emphasis on the merits of research and thus a larger clinical community engaged in research. Ultimately, the aim for the UK would be to bring about a cultural shift whereby academic research was viewed as an equally legitimate and highly respected option for clinicians.

Finally, in areas where the recruitment of patients to take part in trials is low, stakeholders suggested publicising more widely that trials are happening and highlighting the benefits to patients in terms of outcomes of being on a trial.

3.3 Choice

Patient choice is a cornerstone of the government's proposed reforms of the NHS. The aim of this session was to explore what 'choice' really means for people with rarer cancers under three key headings:

1. Settings of care
2. Survivorship
3. End of life

The main conclusions from this session were:

- **People with rarer cancers are faced with a lack of choice of providers of tertiary care, however this is offset by the provision of high quality, safe care in a small number of centres;**
- **Choice can more readily be exercised with regard to care outside a tertiary setting, but patients should be supported in making this choice by their Key Worker and other healthcare professionals and through the provision of high-quality information;**
- **A shift towards personalised methods of follow-up care, informed by work on risk assessment and the patient's own wishes, is required;**
- **All patients should be provided with a personalised care plan and a Key Worker to ensure their care is integrated, coordinated and effective;**
- **Local healthcare teams should be trained and supported to provide care at the end of life for people with rarer cancers;**
- **Early conversations with patients and appropriately trained professionals would help to allow patients to make an informed choice between continued treatment and palliative care at the end of life.**

1. Settings of care

Background

The *Cancer Reform Strategy* (2007) includes a section on 'delivering care in the most appropriate setting'. This recognises that there has typically been an emphasis on ensuring that patients have access to specialist, hospital-based services that are safe and of a high quality. This led to a focus on the benefits of MDTs and is also associated with the concentration of services for people with specialised conditions in a relatively small number of centres.

While access to safe, high quality, specialist treatment is vital for people with rarer cancers, there is also a general recognition of the importance of reducing the need for patients to be admitted to hospital. *Improving Outcomes* explains that the large majority of cancer patients do not want to be admitted to hospital unless it is absolutely necessary and wish to be in hospital for as short a time as possible. Reducing inpatient admissions also saves the NHS money. The roles of primary and community care, and of supported self-management, are therefore seen as increasingly important in providing care to all cancer patients in today's NHS.

Discussion

Stakeholders acknowledged that choice of provider (in particular of tertiary provider) cannot be exercised to the same extent by people with rarer cancers, who require specialised services, than by those requiring non-specialised services. Cancer networks, for example, have prescriptive pathways and accredited centres within each network. It was also noted that a patient referred from one tertiary setting to another might find that the new centre has different links with local services and as a result the patient pathway could lack integration.

Yet, it was recognised that a limited choice of providers of specialised care for people with rarer cancers is off-set by the maintenance of requisite levels of patient numbers and clinical experience in a small number of centres, which ensures a safe and high-quality service. On a related point, stakeholders heard about a survey conducted in 2008 by AMEND showing that 80% of respondents were willing to travel as far as necessary to receive the best specialist surgery for their condition.

There is perhaps, however, more scope for people with rarer cancers to exercise choice regarding how their care is provided outside a tertiary setting and it was felt that ideally this should be provided closer to the patient's home (although the AMEND survey referenced above showed that 50% of respondents were willing to travel as far as necessary for outpatient

appointments). It was highlighted however, that it is essential that patients understand the way in which their care is being delivered, for example through a 'hub and spoke' model. Patients should also be given the option to play an active role in choosing the type of follow-up care they might receive (discussed further below), which would impact upon the level of involvement of local healthcare professionals, such as GPs, in their care.

Where choice of provider is available, stakeholders emphasised that patients must be given high-quality information in order to make an informed choice. The information must be used in a meaningful way; survival rates at a particular centre do not tell the whole story. It is vital that clear information is coupled with conversations with healthcare professionals. This is one way in which a Key Worker's role is central since they can support patients to make informed choices where appropriate and help to ensure the provision of coordinated care and a seamless patient pathway.

Indeed, providing tailored information and engaging in meaningful discussion with patients may help to ensure that the various factors, such as the patient's wishes, their medical and psychological needs and the needs of the NHS as a whole, are balanced appropriately.

2. Survivorship

Background

Improving Outcomes: A Strategy for Cancer focuses on the importance of ensuring that people living with and beyond cancer receive the support they require. Although this focuses on cancer in general, it is equally relevant for people living with and beyond rarer cancers. The document suggests that the needs of people living with and beyond cancer include 'information about treatment and care options, psychological support, access to advice on financial assistance and support in self-managing their condition.' The importance of supporting carers is also underlined. (p. 47)

The National Cancer Survivorship Initiative (NCSI) published a document in January 2010 which set out a range of evidence suggesting that current follow up arrangements (which usually involve outpatient appointments at cancer centres) are not meeting the 'medical, psychological, social, spiritual, financial and information needs that people may have following cancer treatment and do not provide value for money for the NHS.' The documents sets out five 'shifts' necessary to achieve improved care and support for cancer survivors, including a cultural shift (towards a greater focus on recovery, health and well-being after cancer treatment) and a shift towards assessment, information provision and personalised care planning.¹³

Discussion

Stakeholders agreed with the notion that a 'shift' in care is required, suggesting in particular that a tailored approach to individual needs is crucial, thus making the role of personal care plans vitally important. A personalised approach in part means that, when the person is well, they are monitored appropriately, but also have a clear route back into the system where necessary. It was noted that some people who were diagnosed late might not put much faith in re-entering the system through primary care. Stakeholders also recognised the importance of supported self management, noting that the health system sometimes has a tendency of 'holding on' to people unnecessarily, but also highlighted that 'self management' as a concept needs to be more clearly explained to patients.

¹³ p. 51, *Improving Outcomes: A Strategy for Cancer*

It was recognised that there is a lot of pressure at present to reduce follow-up clinics. This could potentially have benefits for patients, who may be able to be monitored less frequently and closer to home, but, as mentioned above, follow-up must be tailored to the person's needs and wishes, not driven solely by policy changes. Stakeholders noted that predictable risk must be monitored and that the National Cancer Survivorship Initiative (NCSI) has worked on risk stratification and different models of follow-up. The importance of patient organisations was also highlighted, with the suggestion that they could play a more formal role in follow-up.

Stakeholders recognised the vital role played by the Key Worker (ideally a Clinical Nurse Specialist) in providing care to people both living with and beyond cancer. The Key Worker helps to ensure that the patient experiences a seamless pathway of care and is the person's first point of contact if they have any questions or concerns. Finally, stakeholders emphasised the importance of meeting survivors' psychological needs as well as their physical needs. The psychological impact of the person's experience may not become apparent until several years after their treatment, meaning that patients must have ready access to psychological support at any point.

3. End of Life

Background

The previous government's *End of Life Care Strategy* (2008) is still very relevant. The principal aims of the *Strategy* are to improve the quality of care for those approaching the end of their life and to give them greater choice about where they die. *Improving Outcomes* recognises that there have been some successes, with more people being able to choose to die at home. It also highlights that this allows for NHS resources to be freed up and used to treat more patients.

Palliative care is a central element of supporting people at the end of life. Patients with rarer cancers may require, but may not always receive, specialised support at the end of life. The NICE guidance *Improving Supportive and Palliative Care for Adults with Cancer* recommends that 'commissioners and providers, working through Cancer Networks, should ensure they have an appropriate range and volume of specialist palliative care services to meet the needs of the local population, based on local calculations. These services should, as a minimum, include specialist palliative care in-patient facilities and hospital and community teams. Specialist palliative care advice should be available on a 24 hour, seven days a week basis. Community teams should be able to provide support to patients in their own homes, community hospitals and care homes.'¹⁴ However, the document also recognises that access to and availability of specialist palliative care services is variable across the country.

Discussion

Stakeholders heard that a 2010 Macmillan survey of 1019 UK adults living with cancer found that 73% of respondents said that they would prefer to die at home if all their concerns about dying at home (such as access to pain relief, round the clock care, and support for their family and carers) were addressed. It was also noted, however, that for many people with rarer cancers, dying at home is not currently an option. Often people with rarer cancers have complex care requirements at the end of life, meaning that they need to be cared for in a specialised setting away from their home. It was agreed that it is imperative, therefore, to train and support local teams to care for people with rarer cancers. One way in which this could be achieved is for local healthcare professionals to have clear links with specialised centres, from

¹⁴ p. 11, *Improving Supportive and Palliative Care for Adults with Cancer*. Full document: <http://www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf>

where they could obtain advice and guidance on caring for people with rarer cancers at the end of life.

Stakeholders also discussed the ways in which patients can be supported to make a choice between palliative care and continued treatment at the end of life. It was acknowledged that some centres are very focused on continuing treatment, but that appropriately trained professionals who are aware of the relative merits of treatment and palliative care could help to give people the choice they want at the end of life. It was noted that continued treatment could be discussed with patients as just one option and that options for end of life care should be discussed at a relatively early stage to give time for an informed choice. Working towards a shift in attitudes towards death and dying (the Dying Matters Coalition is doing a lot of good work in this area) would also help to redress the balance between continued treatment and palliative care.

3.4 Outcomes

The government's reforms of the NHS focus to a large extent on the importance of outcomes in driving up the quality of services. This is reinforced in *Improving Outcomes: A Strategy for Cancer*, and although the patient populations for rarer cancers are small, the same requirements for outcomes data exist.

DH and NICE guidance, together with the Manual for Cancer Services 2008, which identifies the characteristics of a service that are likely to have a significant impact on health outcomes, provide an excellent basis for developing outcomes for rarer cancers. Commissioners and Cancer Networks have been working to put in place the systems and mechanisms required to record meaningful outcomes. The National Cancer Intelligence Network (NCIN) supports this process by improving the collection and analysis of cancer data.

The purpose of this session was to discuss the progress made in collecting data and developing outcomes for rarer cancers and to think about the use of outcomes for rarer cancers in the future.

The main conclusions from this session were:

- **A one-stop shop on the NCIN website should be established that could act as a signpost to the range of data currently available on rarer cancers;**
- **Outcomes specific to rarer cancers should be considered, however, because of the small numbers being managed by individual providers and within defined geographical populations, thought would need to be given to how organisational level data should be grouped;**
- **Patient-reported outcomes are at an early stage of development, but their importance and the possibility to combine them with clinical outcomes are recognised;**
- **Data should be collected at different points along the patient pathway and clinicians should input into the type of data which should be recorded.**

A recommendation arising from the session would be that data for rarer cancers should be captured through existing data processes and managed by the regional cancer registries, rather than be separated up into specific 'isolated' registries.

Data collection and analysis

Stakeholders heard about the range of data that is currently collected on rarer cancers. Data collected can be used to calculate incidence rates, mortality rates, survival rates and routes to diagnosis.

It was recognised that fundamental difficulties are connected with analysing data for small patient populations, for example it can be difficult to analyse data provided from a small sample, while for some very rare cancers, no data at all are collected (these very rare cancers are not easily identified within codes used to classify different cancer types).

Stakeholders were asked whether additional data on rarer cancers should be collected which would be different from that captured for all cancers. It was suggested that it would be very useful if data were mapped to the specific aspects of the patient pathway, which would support the development of a larger number of outcome measures. In addition, stakeholders suggested that there should be more discussion with clinicians regarding what should be measured and collected.

It was suggested that an online, one-stop shop (on the NCIN website) could be established which would allow users to select a particular cancer type and then either access the data available, or learn about what data may be available, as well as find useful links to other websites. This could be accompanied by a briefing that would highlight the main messages from the data, as well as advice on interpreting the data (for example warnings on how to use data from small patient populations and how to interpret confidence intervals).

Outcomes – Clinical and patient-reported

Stakeholders indicated that the development and use of clinical outcomes for rarer cancers (beyond survival and mortality) is still at an early stage. Patient-reported outcomes are at an even earlier stage of development, although patient experience data are starting to be collected (for example through the 2010 National Cancer Patient Experience Survey).

Outcomes are often divided into clinical and patient-reported, but there is an increasing awareness of the importance of regarding clinical and patient-reported outcomes as intrinsically linked.

There was general support for this concept at the workshop, although some stakeholders suggested that the issues that are most important to patients are, for example, parking, how they are spoken to and the food they are given, which have little relation to clinical outcomes. However, it could be argued that these more experiential factors could have a significant bearing on a person's clinical recovery by affecting both their physical and mental condition.

Consideration needs to be given to specific outcomes that relate to rarer cancers, which may not be relevant for all cancers. NCIN can then ensure that either generic analyses for all cancers are extended to include rarer cancers (where numbers permit, or to identify any limitations in analysis), or to work with specific rarer cancer groups to identify their analytical and outcomes needs and to assess whether these are different from the more common cancers.

Appendix

Summary: Definition 1 - Specialised Cancer Services

Guidance published by NICE (and prior to the introduction of NICE, by the Department of Health) informs which cancer services are included within the SSNDS since it sets out the planning populations and optimum number of centres for different tumour sites. NICE guidance for different tumour types also recommends which healthcare professionals should be involved in treatment and care, including the multi-disciplinary team (MDT) composition, and the types of hospital or cancer centre that are best suited to provide that care.

The definition divides specialised cancer service activity into three parts:

- **rare cancers** (NB. in some cases, the definition sets out those elements of the patient pathway for a particular rare cancer which are not specialised), for example anal cancers, brain/central nervous system cancers, children's cancer, teenagers' and young adults' cancers and endocrine cancers.
- **specialised interventions/services** (these include tumour specific; non tumour specific and services used in the treatment of cancer AND other diseases), for example laparoscopic liver resection for people with gastrointestinal cancer and photodynamic therapy.
- **nationally commissioned services** – these include choriocarcinoma services, ocular oncology services, primary malignant bone tumours service and proton beam therapy services.

Definition 1 also explains that although chemotherapy and radiotherapy services (apart from highly specialised interventions) have not been included in the definition it is important to note that two recent Department of Health publications refer to the need for radiotherapy services to be reviewed and organised at SHA/SCG level and for chemotherapy services to be organised at Cancer Network level, which would bring them into the remit of the definition by virtue of the one million planning population criterion.