

SOCIAL CARE FOR CANCER

**WE ARE
MACMILLAN.
CANCER SUPPORT**

**Do social care services
meet the needs of people
affected by cancer?**

Report of findings

'There are currently 1.6 million people in England who are living with a diagnosis of cancer. Cancer must move up the agenda of social care so that they are not left to cope with the consequences of cancer alone.'

Ciarán Devane, Chief Executive, Macmillan Cancer Support

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Thank you to everyone who agreed to share their stories for this research.

Social care for cancer

Do social care services
meet the needs of people
affected by cancer?

Bringing the social care needs of people affected by cancer into the spotlight

Cancer should be as much a social care concern as it is a health priority. Yet social care services are currently failing people with cancer.



Macmillan knows that people living with cancer and their carers have social care needs as well as health needs. They tell us they need emotional and practical support and

financial help and advice throughout their cancer journey. Improvements in cancer treatment mean that more people are surviving once they have had a cancer diagnosis but we know that their lives don't return to normal.

People living with cancer and their carers have great difficulty obtaining the social care that meets their needs. Over a third of people (35%) do not feel confident about how and where to access social care support.¹ In the first place, they are often not referred to social care services for assessment. Even if they do receive an assessment, that is no guarantee they will receive the support they require, particularly if they are assessed as having low or moderate needs; pressure on resources means that services are often rationed to those assessed as having the greatest need. When people do access services, they find they are not responsive enough to their specific needs. The lack of high-quality social care for people living with cancer means that carers are required to take on substantial responsibilities, which has a knock-on effect on their health, well-being and financial status. Consequently, people's needs can escalate, resulting in costly and inappropriate hospital admissions.

Macmillan commissioned this research to find out why cancer is not a priority for social care services, to inform both the Government's reform of the adult social care system and the development of Macmillan's own services.

The research found significant barriers preventing people with cancer and their carers from accessing social care, particularly when they have low or moderate needs. Lack of awareness among individuals about social care services is a major obstacle. But there are also major system barriers, which need to be addressed by Government. A shortfall in resources is compounded by commissioners lacking the expertise, information and data to measure the cost-effectiveness of services at delivering better outcomes for people in the long-term. This means that commissioners concentrate on providing short-term solutions for those in crisis and are unable to also provide preventative support services. People who are the recipients of social care are often not involved in the design, development and delivery of services, though health services have found such involvement to be beneficial. Poor integration between health and social care in terms of commissioning and delivering services means that in many areas, appropriate services simply don't exist and people are left to fend for themselves.

The report's findings must be acted upon. The Government must increase the funding of social care and ensure current resources are used most

¹ *Worried Sick*. Macmillan Cancer Support, 2006.

effectively. Health and social care priorities need to be much more closely aligned. Commissioners in both health and social care need to be encouraged to invest in services for people with low or moderate needs. People must be signposted to social care services by both health and social care professionals as a matter of course.

Macmillan wants everyone who has a cancer diagnosis to be able to access the social care services that they need. Our research shows that social care commissioners don't yet recognise that people with cancer have long-term ongoing needs. We would like to work with the Department of Health, Association of Directors of Adult Social Care Services, the Local Government Association and with commissioners and providers of health and social care to develop their understanding about the needs of people affected by cancer.

Macmillan is already working with local authority and health commissioners to test out services that are likely to bring about cost savings for both health and social care, whilst at the same time delivering better outcomes for people with cancer. For example, Macmillan is funding a scheme in Northamptonshire where a social care co-ordinator, based in cancer services, will spot purchase short-term care for people affected by cancer with low or moderate needs. Over the next three years, we are piloting Macmillan Solutions, a project developed in partnership with people affected by cancer and their carers across East Hampshire and Central Manchester. People affected by cancer will talk with volunteers to identify the services and opportunities they want to help them cope with the impact of their cancer diagnosis. Macmillan Solutions will work with existing services in these areas and also offer personal budgets to support

people to manage their own situation and purchase what they need to improve the quality of their life.

There are currently 1.6 million people in England who are living with a diagnosis of cancer. Cancer must move up the agenda of social care so that they are not left to cope with the consequences of cancer alone.



Ciaran Devane
Chief Executive Officer
Macmillan Cancer Support

Executive summary

Background, objectives and methodology

- Against the backdrop of the Government consultation on reform of the adult social care system, Macmillan commissioned this research to explore a range of issues relating to the provision of social care for people with cancer and their carers.
- The objectives of the research are to explore barriers and opportunities around commissioning of social care for people with cancer; consider solutions which ensure that the social care system meets the needs of these people; and provide intelligence for the future development of Macmillan services.
- 15 depth interviews with commissioners of social care and cancer care were conducted: 4 with Primary Care Trusts (PCTs); 11 with local authorities.
- 4 depth interviews with providers of social care were conducted.
- 6 trios (groups of three participants) were conducted among people with cancer (4 trios) and carers (2 trios).

Summary of main findings

The social care needs of people with cancer

- All participants accepted that people with cancer and their carers have social care needs, and that these can vary considerably throughout the cancer journey and from person to person.
- People with cancer and carers do have access to social care services, but the degree to which they are using them, or being made aware of them varies considerably.
- Many people with low to moderate social care needs fall outside of the social care system and rely on friends and family to provide the emotional and practical support that they need.

The process of commissioning social care

- Commissioners nearly all commission social care exclusively for people with critical and substantial (in local authorities) or complex (in PCTs) needs. This is primarily driven by a lack of available funding to commission other services and the statutory requirement to ensure these needs are met.
- While the needs of people with cancer are seen as important, local authorities generally reject the idea of formally commissioning services which are cancer-specific. They feel that this would be inappropriate, and see such services as the domain of either the NHS, private or voluntary sector organisations.
- Most local authorities and PCTs in the sample are moving towards joint commissioning of services, which appears to have the potential to encourage more comprehensive coverage of the needs of people with a range of conditions (including cancer) in commissioning strategies.
- However, the degree to which PCTs and local authorities are implementing joint commissioning in a practical sense varies. Some have started to plan services jointly, but continue to deliver them from separate budgets. Others have started to pool budgets for commissioning of services aimed at some user groups (for example, end of life care).

Levers and incentives for commissioning social care

- According to the local authorities interviewed, the commissioning of social care is driven primarily by the need to provide value for money services for people who need it most.
- Decision-making within PCTs in the sample is based on delivering national government

strategies locally. Commissioners describe placing an increasing importance on national strategies such as the Cancer Reform Strategy and the Government's strategy on end of life care.

- Traditionally, both local authority and PCT commissioners have commissioned by volume and price (ensuring greatest value for money and coverage of services). However, they are both increasingly taking quality criteria into consideration when developing new services and assessing existing ones. They take into account the views of services users, and the degree to which they feel the service has delivered the outcome that they needed and expected.
- Evidence is a key driver for commissioning (or decommissioning) social care services in both PCTs and local authorities. Commissioners say that they increasingly need to prove that a service provides measurable benefits to the service user and/or to the local economy (ie reducing demand for other services).

Opportunities and barriers to providing more social care for people with cancer and their carers

- Some PCTs and local authorities are finding innovative ways to deliver more social care services to people with low to moderate needs. These often include accessing other funding streams through Local Area Agreements (LAA) or encouraging more partnership working between local authorities, NHS departments, service providers or the voluntary sector.
- However, a number of barriers remain which prevent more services (or specific services for people with cancer) being commissioned. These include:

On the part of individuals:

- low awareness of available services
- lack of understanding around eligibility
- lack of willingness to ask for help.

On the part of local authorities, PCTs and Government:

- lack of national policy drivers of debate
- lack of available resources to commission more services
- inflexible provision of existing mainstream services
- lack of adequate signposting to available support
- lack of integration between health and social care
- lack of commitment of some commissioners to expanding services.

What specific services may be required?

- Local authorities and PCTs would consider (and already do) using the voluntary sector to provide emotional support and some low level practical support. However, there are concerns about the viability of delivering more demanding social care services via volunteer organisations or networks. These include concerns regarding the availability and consistency of the volunteer force, potential problems with compliance with statutory regulations and difficulties measuring performance.
- The degree to which local authority commissioners fully understand the role different services, funding arrangements and partnership approaches undertaken by Macmillan varies. Some would not naturally consider Macmillan as a potential partner or provider of social care services, and are not aware of the types of relationships Macmillan has with other authorities.

Recommendations

If people with cancer and their carers are to receive the social care they need, there are a number of issues to address:

Accessing existing provision and encouraging demand

- Government should increase knowledge and understanding among the public of the social care assessment process and what services are available.
- Government should encourage commissioners and providers to raise awareness of locally available support through a range of information sources, including staff.

Improving and influencing supply

- Government should increase social care funding to help meet unmet needs.
- Government should encourage local commissioners to assess the needs of people with cancer and their carers for social care support as part of the Joint Strategic Needs Assessment.
- PCTs and local authorities should continue to develop joint commissioning strategies and agree the use of pooled budgets, in order to meet the needs of specific groups better, including people with cancer and their carers.

Innovation and investing in services

- Service users should be involved as equal partners in the design, commissioning and delivery of services.
- Government should provide commissioners with guidance on managing services aimed at preventing people's needs from escalating and producing long-term cost savings.

Macmillan should:

- Explain the needs of people with cancer and their carers and why they have specific needs (for example, due to the frequency and duration of treatment) to stimulate more

informed debate among commissioners in local authorities and PCTs and persuade them to commission services that meet their needs.

- Provide information, advice and support to generic service providers so their services can better meet the needs of people with cancer.
- Work with PCT and local authority decision-makers who express an interest in invest-to-save programmes or prevention programmes in their commissioning strategies.
- Use evidence from projects that support people with cancer who have low to moderate needs to demonstrate effectiveness at preventing future critical and substantial needs and improved outcomes.
- Explore potential new services which can be delivered by volunteers.
- Explore alternative ways of funding services in addition to the current pump-priming model.
- Raise awareness of the information, advice and support currently available to people with cancer and their carers.
- Along with health and social care professionals, encourage people with cancer and their carers to ask for help and support when eligible.

Further informing the debate

Government and Macmillan should encourage health and social care regulators to look at the quality of social care support (information, emotional and practical support and financial advice) provided to people with cancer.

Government should provide guidance to local authority and PCT commissioners on how best to measure the quality of social care services.

The extent of unmet social care needs is not fully understood. Macmillan should consider measuring the national scale of unmet social care needs quantitatively, among people with cancer and their carers, to help influence the Government's agenda.

Background

The Government announced its six month engagement on reforming the adult social care system in England in May 2008: *The case for change – why England needs a new care and support system* (HM Government, 2008).

The consultation document reaffirms the Government's commitment to ensure high-quality services, and to promote independence, choice, and control. It poses three questions:

- What more do we need to do to make our vision of independence, choice and control a reality?
- What should the balance of responsibility be between the family, the individual and the Government?
- Should the system be the same for everybody or should we consider varying the ways we allocate Government funding according to certain principles?

The Government includes a wide range of activities within the scope of the engagement process:

- Domiciliary care and other independent living/housing support (for example, help with shopping, cooking, laundry, cleaning; help with getting up, getting dressed, undressed and getting to bed; help with caring for others, including children).
- Occupational therapy (for example, help with mobility, dexterity, routine tasks, home adaptations and safety).
- Talking therapies (for example, counselling, clinical psychology, or psychotherapy).
- Respite care to give carers a break (including short-term sitting services and longer-term residential respite).
- Benefits to help with the additional costs of poor health and disability.

It recognises that people need social care because of their old age, long-term health needs, or disability. However, it places particular emphasis on the social care needs of our ageing population. There is no explicit mention of the social care needs of people with cancer.

Macmillan Cancer Support prepared a response to *The case for change*. A range of existing evidence and knowledge was used to do this. During the preparation of Macmillan's response, it was identified that some of the issues covered in the document needed to be explored in more detail in order to better inform the response.

The research was also needed to inform Macmillan regarding the development of social care services for people with cancer and their carers; and inform future dialogue with PCT and local authority commissioning teams around this issue.

Research objectives

The background to this project and intentions for the research findings inform the following three overarching objectives:

To explore the barriers and opportunities around commissioning and providing social care services (daily living, carers and financial support) for people living with cancer and their carers.

To provide intelligence for the development of future Macmillan daily living, financial support and carers services, both directly provided and indirectly provided by funding other organisations.

To consider solutions which help to ensure that the social care system meets the needs of people with cancer and their carers.

'It is time to create a new care and support system that is fit for the 21st century, a system that is personalised to individual needs and gives real control to those needing care and their carers'

Gordon Brown Prime Minister, *The case for change: why England needs a new care and support system, 2008*

Methodology and sample

The research was undertaken using qualitative methods. These methods are designed to provide depth and flexibility, capturing the rationale behind responses in detail.

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Methodology

The following specific methodologies were used:

- individual depth interviews
- trios (groups of three respondents).

Individual depth interviews

Individual depth interviews were conducted among PCT and local authority commissioners and social care providers. This methodology was selected as it delivers practical and methodological benefits:

- Interviews provide a flexible forum through which to discuss issues in detail, and to follow-up on fully-given responses.
- Arranging and booking fieldwork is practically more efficient. Professional people are busy, and finding a convenient time to participate can be challenging, particularly if attempting to convene focus groups. Depth interviews provide greater flexibility in this regard.

Depth interviews were conducted either in person, or by telephone, depending on the availability and location of the participant. Face-to-face interviews lasted approximately one hour, and telephone interviews approximately 45 minutes.

Trios

Trios were conducted with people with cancer and carers of people with cancer. Groups

provide interaction and discussion between participants, which helps to stimulate responses. Groups of three people were used as they retain the group interaction, but provide more time and a more intimate environment within which people are able to talk about their own cancer journey in more depth and detail than would be possible with a larger group.

Trios lasted approximately 1.5 hours and were conducted in central locations such as hotels, recruiters' homes and one of Synovate's dedicated research facilities.

Sample

PCT and local authority commissioners

We conducted 15 depth interviews across a range of PCTs and local authorities. We interviewed people with responsibility for commissioning social care and/or cancer care in each organisation. The exact job title for each participant varied, depending on the structure of commissioning within each organisation. We included some individuals with direct experience of commissioning services, as well as a small number with a more strategic role (for example directors of care).

In total, we interviewed 11 local authorities social care commissioners working in adult or older people's services departments. This comprised:

- A mix of performance levels using Commission for Social Care Inspection (CSCI) Performance Assessment Framework (PAF) reports: eight local authorities who scored higher; three who scored lower.
- Two local authorities which had social care

strategies, commissioning plans or projects for people with cancer in place; nine with no such provision. We aimed to include a more equal mix of authorities according to their strategies and plans for social care services for people with cancer. However, finding councils with such provision was difficult.

- Four local authorities from the North, three from the Midlands, four from London and the South East.
- Three interviews were conducted face-to-face; eight were conducted by telephone.

In total, we interviewed four PCTs involved in the commissioning of cancer care or social care services:

- We aimed to include a mix of performance levels (using Healthcare Commission annual health check assessments): three PCTs were rated as fair; one was rated as weak.
- Three PCTs had social care strategies, commissioning plans or projects for people with cancer; one had no such provision.
- One PCT was based in the North, two were from the Midlands, and there was one based in London and the South East.
- One interview was conducted face-to-face; three were conducted by telephone.

We aimed to include both organisations involved and not engaged in joint commissioning. We were not able to find organisations who classify themselves as not involved in joint commissioning. However, local authorities and PCTs interpret being involved in joint commissioning in different ways (see detailed findings) and a range of different levels of engagement were included in the sample.

Providers

We conducted four interviews with providers of social care to people with cancer. We interviewed individuals in senior roles within each organisation who were able to speak about the commissioning or funding process in detail.

The sample breakdown was as follows:

- One provided services for people with critical and substantial needs; three provided services for people with low to moderate needs.
- One provider offered domiciliary care; one offered talking therapies; one offered occupational therapy; one was a respite care provider.
- Two providers had national coverage, two were local providers.
- Two were private sector providers; two were public or voluntary sector.
- Two were generalist providers, offering services to anyone with a social care need; two were specialists, providing, for example, services targeted at people with cancer.

People with cancer and carers

We conducted six trios with people with cancer and carers of people with cancer. The sample breakdown is shown in the table below.

We also included a mix of respondents according to:

- type and stage of cancer
- previous access to, or use of, social care.

Trio	Type	Location	Gender	Demo-graphics
1	People with cancer	North	Female	ABC1
2	People with cancer	North	Male	C2DE
3	People with cancer	South	Male	C2DE
4	People with cancer	South	Female	ABC1
5	Carers	South	Female	ABC1
6	Carers	Midlands	Mix	C1C2D

Recruitment process

Recruitment of commissioners and providers was managed in-house by our team that specialise in recruiting professionals. Organisations were identified through the performance ratings available from CSCI, the Healthcare Commission, and the Association of Directors of Social Services (ADSS). A small number of potential participants were provided by Macmillan Cancer Support.

We wrote to the most relevant senior professional in each organisation to ask for their support and to invite their team to take part. We then contacted them to determine who they thought was the most relevant person in their organisation to take part in the study.

Once appointments had been made, participants were sent an e-mail confirmation, providing details of the appointment time and an opportunity to contact a member of the project team with any questions.

Recruitment of group discussions with people living with cancer and their carers was conducted by a freelance recruiter network, managed in-house to try to ensure high-quality standards. We recruited people through social networks, cancer support groups and commercial patient research panels. All participants were sent a letter of bona fides to convey the legitimacy of the study.

People with cancer and their carers received £45 to cover any out of pocket expenses incurred (for example travel, subsistence, childcare, etc) and to thank them for their time. Although not usual Macmillan Cancer Support policy, paying such an incentive enables and encourages a wider range of people to attend the group discussion. Given the need to hear from people from diverse backgrounds, paying such an honorarium was considered appropriate in this instance.

Ethical considerations

- All researchers are members of the Market Research Society and bound by its code of conduct.
- All participants were given information about the research to enable them to make an informed choice whether or not to participate.
- Researchers checked before, during and after interviews that people were happy to continue to participate in the study.
- People with cancer were advised that they could take breaks or leave fieldwork sessions whenever they wished.
- All data gathered was anonymised and stored securely.

Approach to research and analysis

All interviews and trios were conducted by experienced qualitative researchers using topic guides developed by Synovate, in close liaison with Macmillan Cancer Support (see appendix A). Although topic guides ensured coverage of all key points across the sample, they were flexible to allow the issues of relevance to participants to be covered. All interviews and groups were recorded and transcribed.

We used Grid Analysis to ensure openness and transparency of analysis. In summary, Grid Analysis plots the response from each interview or group in a specific row and groups the main themes in an individual column on the grid. Findings recorded in the grid are referred back to the transcript to ensure transparency. A summary of the main points raised in each column is generated in a separate row.

The data was interpreted by two researchers separately to ensure credibility and validity of the outputs.

Introduction to the findings

The research method and sample was designed to provide a clear indication of the key issues and themes emerging around the topic. However, the sample sizes do not support extrapolation of findings to the population as a whole. Findings and conclusions are based on majority responses, unless otherwise stated. Particularly atypical responses have largely been excluded, unless they help to support a broader point, where their inclusion has been indicated.

We have divided the research findings into five sections:

Social care needs of people with cancer and their carers

This section looks at awareness of the term 'social care' among people affected by cancer. It also looks at their emotional, practical and financial support needs and information and advice services.

Commissioning social care

This section explores the role of PCTs and local authorities in commissioning social care.

Opportunities and barriers to improving the provision of social care for people with cancer and their carers

This section looks at how innovation in commissioning and service delivery could help meet the needs of people affected by cancer and what the barriers are to achieving this.

Specific services

This section looks at a number of specific areas that participants felt should be improved.

Implications for Macmillan

This section explores the role Macmillan could have in increasing the provision of social care for people affected by cancer.

Research findings

Social care needs of
people with cancer and
their carers

Awareness of the term 'social care'

People with cancer and their carers don't always know what 'social care' is or does.

They do not differentiate between social care needs in the way that social care services do, ie low, moderate, substantial and critical social care needs.

This term was only really meaningful to the commissioners and providers in our sample. However, they generally assume that support will

be means tested and only available to those in greatest need or on the lowest incomes. A few people with cancer and their carers had been assessed for social care support, but had not met the eligibility criteria.

Perceived social care needs and access to appropriate support

Once the meaning of social care is explained, participants agree that people with cancer and their carers have social care needs.

They agree that the level of social care needed can vary greatly, for example, from needing someone in the same position as them to talk to, through to formal psychological support. Commissioners, providers, people with cancer and their carers agree that some social care needs are ad hoc and short-term, while others are long-term or on-going.

All participants agree that people with cancer and their carers need:

- emotional support
- practical support
- financial support.

Some PCT and local authority commissioners believe that these needs are not necessarily

different from those of people with other health conditions. However, some providers acknowledge that people with cancer can have specific and complex social care needs compared with other service users, for example, due to the length of treatment, impact of treatment on mobility, their ability to perform daily tasks, the emotional impact of a cancer diagnosis and treatment, and carer support needs.

'If we come into it quite early on, their needs are not that much different to anybody else receiving services. [But] if we come into it later on when we are looking at end of life, then a lot of the support is with the families as well. You are looking after the individual needs, but also

dealing with them knowing they are imminently dying...it makes it much more intense.'

Domiciliary care provider, South

The extent to which commissioners and providers see information and advice services as social care varies. However, commissioners, providers and people with cancer and their carers agree that people with cancer and their carers need access to information, advice and support throughout the cancer journey.

All participants agree that people with cancer and their carers' specific social care needs can vary depending on:

- age
- gender
- socio-economic group
- carer responsibilities
- access to informal carers such as family and friends
- stage of the cancer journey (diagnosis, treatment, follow up, remission, relapse, or end of life).

The extent to which commissioners actively commissioned support for people with cancer varied. Some commissioners in PCTs and local authorities are funding cancer-specific social care services. Most local authorities are not commissioning social care services specifically for people with cancer. Providers of generic social care services also said they worked with people with cancer in the course of their job.

Social care providers were concerned that local authority social care commissioners see cancer as a health issue and, as such, may leave commissioning of appropriate support to PCT commissioners. Although joint commissioning arrangements are becoming more commonplace, the impact of these does not seem to have been felt yet by some providers.

'The trouble is with cancer, [for example, if a young person has cancer] it is seen very much as a health need. Therefore, you will not get social care funding for it. The health professionals do not provide the social care for somebody that is undergoing treatment. It is a continual fight between health and social care [over] whose budget it comes out of.'

Domiciliary care provider, South

Overall, several PCT and local authority commissioners expressed concern about a lack of integration between health and social care provision, even where joint commissioning was taking place.

'What is missing is somebody who co-ordinates everything...it is that initial referral when they go to the GP, and the GP says, sorry I think this may be cancer and I'm going to refer you to the hospital. The patient is then on their own for that two weeks until they get there, and then they can still be on their own until they get the diagnosis. So that is a big problem because they are panicking, they're frightened, they don't know what to do and they're just waiting.'

PCT, North

Although people with cancer and their carers may need social care, commissioners, providers, people with cancer and their carers agree that: (a) some are more willing than others to accept offers of information, advice and support, while others adopt a more stoical approach; and (b) some are more likely than others to gain access to the social care they need (ie people who have experience of social care before their cancer diagnosis or people who have critical and substantial needs).

We explore access and uptake in more detail below.

Emotional support needs

Commissioners, providers, people with cancer and their carers agree that people with cancer and their carers need emotional support.

Being told that having cancer is a possibility, and actually having it, is both frightening and distressing for the person with the disease and their family and friends. Many people with cancer said they found the cancer journey an emotional roller coaster. Several said being referred for tests and waiting for test results was a particularly anxious time where little or no information, advice and support was perceived to be available.

People with cancer and their carers said getting a cancer diagnosis and the associated prognosis is devastating. However, people acknowledge that once in the system, information, advice and support is more readily available. People with cancer and their carers said telling their family and friends was particularly hard. Few said they had any information, advice and support about how to handle this. Similarly, they said that coping with the physical impact of treatment had a significant impact on their perceptions of self (for example, physical changes like the loss of a breast, but also feeling ill, tired and in pain).

The time after treatment has been completed was also cited as particularly worrying, when contact with healthcare services rapidly diminishes as does any associated information, advice and support from professionals. People with secondary cancers said that being told a cancer has spread or relapsed, or that cancer treatment has been unsuccessful is particularly devastating. The fear of death throughout the cancer journey often has a key impact on emotional well-being. The loss of independence

both during treatment and beyond can also have a particular impact on how someone feels about themselves. Many people with cancer and their carers find the loss of social interaction and connection to their communities particularly difficult to deal with.

Caring for someone along the cancer journey can also have an enormous impact on someone's emotional well-being. Carers said they often neglect their own lives to some extent, for example, losing touch with friends or giving up opportunities. People with cancer and their carers' relationships can also be strained at times. People with cancer and their carers said they can need emotional support with all these aspects of the cancer journey.

People with cancer said they can find it hard to turn to their family and friends for emotional support. They feel they have to be strong for the people around them, especially those with children or elderly dependants. Many can feel isolated as a result. Carers can find it hard to tell the person with cancer how they are feeling because they don't want to upset them. They often feel they have to be strong for them. Consequently, having someone the carer can talk to outside of the immediate family is often considered particularly important.

The level of emotional support a person with cancer or their carer may want can vary greatly. Some people with cancer and their carers said they asked for or sought out emotional support themselves (for example, through an online

search, speaking to other people with cancer who they meet during treatment, or by asking professionals). Others said they took up an offer of support from a professional they encountered along the cancer journey. A few said that the professionals they encountered did not offer any such support. Several said they attended a cancer support group. A few carers said they had access to bereavement counselling after the person they cared for died.

‘My wife...I know she was going through a lot of pain at the time with regard to uncertainty as to what was happening and she didn’t have many people to talk to really...I often went to stuff on my own and talked to the surgeons and the nurses and so on, but my wife...in hindsight didn’t have much support.’

Person with cancer, North, Male

For others, maintaining normal life is the priority. They tend to take a more stoical approach and do not readily engage with the support available. Men appear more likely to adopt a stoical approach than women.

‘Where I live it’s very Cumbrian...you don’t ask for help. Only the weak ask for help...the only way I could get him to access any social help was like go to the pub, don’t come back until you are really drunk, this was his way of coping because he could go and see his friends, and it was somewhere outside cancer.’

Person with cancer, North, female

For those who want emotional support, the level of support they feel they need can range from:

- Having someone to talk to, either informally one-to-one (for example, someone with similar experiences who understands and has insight into what you are going through) or more formally structured support, for example, via a cancer support group; to:
- Formal counselling or clinical psychology services (for example, to help tackle

depression, to help with relationship problems, to help come to terms with end of life diagnosis, to help come to terms with a recent bereavement, etc).

The extent to which people have access to emotional support can vary greatly. Some people do not have ready access to family and friends close by who are able to provide emotional support, for example, more isolated older people. People living in rural areas said they can find it difficult to get to support groups which are often a long drive away. Some said that no such support was offered to them. Carers, in particular, appear to find it harder to gain access to appropriate emotional support. This is often made worse by the fact that they may be isolated and may not have time to connect with their friends for support.

Many people with cancer and their carers think the NHS is better at medical care than emotional support. People are not aware that emotional support services provided locally by voluntary sector organisations can be NHS-funded. It was difficult to determine the extent to which voluntary sector emotional support services were NHS-funded. We interviewed a voluntary sector provider of emotional support for people with cancer, and practice support providers who also provided emotional support as part of their service delivery model, albeit in some cases in an informal manner. Both received NHS funding.

‘[Our staff provide emotional support] by just being there. I am not sure that would necessarily be on the job specification, but being the kind of person that does this job for the wage it commands, yes they do provide emotional support as well.’

Domiciliary care provider, South

The emotional support provided by Macmillan nurses, Marie Curie nurses, local hospice staff and a wide range of local charities is widely

praised by those who have access to such support. However, some people with cancer and their carers said they were not offered or signposted to any emotional support at any stage during the cancer journey by the professionals they came into contact with, and often simply did not think to ask for it.

‘No one gave us anything. Unless I searched for the information myself I wasn’t given a thing.’

Carer, South, female

Local authority commissioners tended to see emotional support as the responsibility of PCT commissioners. PCT commissioners said they funded emotional support services for people with cancer. Some said that support was available via generic talking therapy services (for example, formal counselling or clinical psychological services). Some funded cancer-specific emotional support (for example, from the voluntary sector). However, the extent to which all cancer patients receive a full psychological assessment (as required by the NICE Improving Supportive and Palliative Care for Adults with Cancer guidance) is unclear.

Some PCT commissioners also believed that providers of mainstream emotional support services worked with people with cancer (for example, generic counselling or clinical psychology services). For example, healthcare professionals were able to refer people with cancer and their carers with an emotional support need into such services. However, such support could be time-limited (for example, a six to eight week programme). People with cancer and their carers were not generally able to self-refer to any such NHS support. There could also be some time delay before an appointment to see a counsellor or clinical psychologist was available, due to the high demand for such services.

‘I was depressed [after chemotherapy] and I was referred to a counsellor. But by the time they got round to me I told them to get lost and went and found my own counsellor...I didn’t have anybody else come in aside from my friends now and then.’

Person with cancer, North, female

Commissioners, providers, people in the end stages of cancer and their carers often felt that emotional support was more actively signposted by professionals as part of end of life care. They agreed that more signposting and easier access was needed during the early stages of the cancer journey. Several PCT commissioners said they were striving to meet NICE guidance to implement the Gold Standard Framework and the Liverpool Care Pathway for the Dying Patient.

Overall, commissioners, providers, people with cancer and their carers agreed that the provision of emotional support for people with cancer should be more widespread and more accessible, with better signposting from health professionals to such support along the cancer journey.

‘None of it is automatic really. It seems a lot of people are left [to find out things for themselves], so you’ve been diagnosed with cancer and you’ve been treated for it but the rest is up to you to find out what is available.’

Person with cancer, South, male

Practical support

All participants agree that both having cancer and being treated for cancer (especially surgery and chemotherapy) can leave people feeling tired, weak, in pain, and ill (including nausea and vomiting). This can make maintaining normal life difficult.

The frequency of treatment itself (for example, several hours a day, several days a week for several months) can also limit what people can practically do. Surgery itself can also limit people's physical strength and mobility, either temporarily or permanently (including removal of lymph nodes, muscle damage, or even loss of limbs).

'I have actually crawled across the floor in pain... I couldn't stand up, so I couldn't do anything. I couldn't get any sleep because it was too painful... when you're in very severe pain, you can barely think straight.'

Person with cancer, North, female

As a result, people with cancer say they can find it difficult to do household chores like shopping, cooking, cleaning, ironing, making the bed or changing bed clothes, caring for family, gardening, or other home maintenance. Lifting things or reaching for things on shelves can be challenging – even holding or reading a book or magazine can be a challenge for some. People with cancer said they can find it difficult to drive themselves or to manage alone on public transport, including getting to and from treatment, to and from the shops, dropping off and picking up children from school. Climbing and descending stairs can be difficult or impossible. People can also find it difficult getting up and going to bed, getting dressed and undressed, and maintaining personal hygiene (for example going to the toilet, bathing or showering, shaving, etc).

Some older people with cancer said they had difficulty with such tasks before their diagnosis, but they were nearly impossible after diagnosis. Several said they found their subsequent loss of independence challenging. Older carers often found providing support with such tasks particularly physically challenging, especially lifting and pushing a wheelchair. They also found the impact such changes had on their relationship with the person they cared for difficult.

The level of practical support people with cancer can require can have a significant impact on the lives of their carers. Consequently, carers can also need access to support (or respite care) to give them short or longer-term breaks, ranging from someone to sit for a few hours with the person they care for to allow them to go to the shops, to a longer residential stay to enable them to take a few days' holiday. Some people with cancer said that they find it demeaning when family members and friends have to help them with such tasks. However, some are also reluctant to let strangers do such things for them.

'My mum didn't want anyone else; she didn't want anyone else doing anything [other than me].'

Carer, South, female

Consequently, people with cancer and their carers' practical support needs could be:

- More informal practical support on a short-term and ad hoc basis (for example, help

with daily chores during treatment, someone to sit in while a carer goes shopping, etc).

- Formal domiciliary care (where the level of support required is beyond the level that family and friends can deliver, for example, if a carer themselves is a frail older person, or where no family or friends are sufficiently close to provide the support needed). Formal respite care (for example, to give carers a longer break); physiotherapy to build strength, or occupational therapy to enable people to return to normal life (including relearning how to do basic tasks, or home adaptations like hand rails, and equipment like wheel chairs and walking sticks).

Family and friends will often shoulder much of the practical support needs of people with cancer. People with cancer can find it demeaning when family members and friends have to help them dressing or bathing. They would prefer professional support. However, they are not always clear whether or not they would be eligible for such support or how to gain access to it.

Some people with cancer said they do not have access to family and friends who are able to provide such practical support. They tend to struggle on alone. They are not always aware that professional support may be available. Providers of such services said they do work with people with cancer. However, few people with cancer said that they were offered or signposted to formal domiciliary care (unless already receiving such support before the cancer diagnosis) or respite care. Providers think more people with cancer may be eligible for their support but are either: (a) not being identified, assessed and referred by relevant professionals for support; or (b) not aware of, or asking for, the kind of help that may be available to them.

‘I am wondering if people with cancer struggle on for a long time and think they can only have health treatment. I wonder if they even think about asking for social care, they might just be focused on the medical side.’

Provider of domiciliary care

Some are also reluctant to let strangers do such things for them. They would prefer to preserve their independence regardless of the level of difficulty they encounter with daily tasks and household chores.

Carers can be reluctant to ask for short or long-term respite care. They can see this as letting down the person they care for.

‘When I got back from the hospital I just wanted to sit on the sofa but I had to come in and start all over again...I went from Jo looking after Mike in hospital, to coming home and just being a mum, and I found it really difficult to switch from one to the other. And he would come in and say, why are you quiet? and you have to still try and be jolly and normal for them to keep everything going.’

Carer, South, female

Some people with cancer and their carers had some access to formal physiotherapy and occupational therapy through the NHS. However, others did not (or had to wait a considerable time for it), either because such support was not offered or because they did not think to seek out or ask for such support.

‘I did get some social care services because I needed walking frames when I got back home. I got those sorts of things [home adaptations] as well...I could hardly get up the stairs...I got some dual banisters fitted...it was really helpful.’

Person with cancer, North, male

'It does take a long time...the waiting list is so long...I applied for a rail and it took them five months...I think a walk in shower is something like two and a half years' waiting list.'

Carer, Midlands, male

PCT commissioners believe that people with cancer who needed physiotherapy or occupational therapy would have access to services they commissioned, for example, in hospital to prepare patients for a return home. PCT commissioners generally say domiciliary care is the responsibility of local authority commissioners. Local authority commissioners believed that some people with cancer would be eligible for domiciliary care if they had critical and substantial needs. However, several also acknowledge that there may be a lack of clarity for both service users and staff about the available support and how to gain access to it (including information about relevant eligibility criteria).

'For people who are suffering from cancer, [the main gap in service is] insufficient information to direct them to a support mechanism. I would say there is insufficient understanding within our team [frontline staff] as to which services they can and cannot provide.'

Local authority, South

Financial support (including information, advice and support over employment rights)

People with cancer and their carers said they tend not to think about the financial impact of a cancer diagnosis.

They tend to focus on fighting the disease. When asked, however, people with cancer, carers, commissioners and providers agree that having cancer can have an impact on household income. People are aware that the level of impact can range from having to go without treats associated with normal life (for example, eating out, holidays, etc) to significant loss (for example, loss of homes).

People with cancer said they can find it hard or impossible to work during their treatment and beyond because they feel tired, weak, in pain, and ill. Depending on the extent of carer duties, carers can also find it hard to work. For some, this can result in disputes with employers about access to sickness pay or extended sick leave. Some have lost (or felt compelled to leave) their jobs as a result.

For people who are self-employed or not working, cancer can have a serious and prolonged impact on household income. People with cancer and their carers said they can encounter unexpected expenses, for example, the increased cost of travel to and from treatment, hospital parking fees, etc. This can be especially hard for people living on low incomes, for example, households dependent on state benefits or pensions. Consequently, both having cancer and caring for someone with cancer can have a significant impact on household finances.

Some people with cancer also said they fear their future access to financial services, for example, insurance or mortgages.

'I wasn't entitled to income support because my husband worked too many hours and because I'd been a student I wasn't entitled to benefits. I wasn't sick enough to get the disability living allowance. It is really fortunate I spoke to my bank manager because they managed to suspend my repayments for a year...if it wasn't for the fact his dad had had cancer [that may not have happened]...they could repossess your house.'

Person with cancer, North, female

Financial support for people with cancer might mean:

- Ad hoc and short-term financial information, advice and support. The level of financial support can vary greatly from help with travel and parking fees to help with mortgage payments.
- Long-term financial support, for example, state benefits if a return to work is not possible, or access to other financial services (for example, mortgages, life assurance, pensions, travel insurance, etc).

People are largely unaware of any financial support available other than state benefits. People with cancer and their carers often said

they had not thought to ask for information, advice or support with financial matters. Few said they were offered information, advice or support with financial issues by nurses, doctors or other NHS professionals they came into contact with.

People with a regular income often assumed they would not be eligible for state benefits which they assumed would be means tested. People were also reluctant to ask for state support, due to the perceived stigma attached to claiming benefits. People were sometimes reluctant to disclose their health status to financial institutions for fear of affecting their future access to financial services. Asking for financial help was also considered a sign that they and their family were not coping.

For those with no experience of the benefits system, gaining access to information, advice and support about such matters can be difficult. People don't always know where to turn for such support. Overall, few seem to be gaining access to any form of information, advice and support about the financial impact of a cancer diagnosis.

'I think a lot depends on your financial situation. My financial situation is such that I need to earn money so I go on virtually as if nothing happened, and if I am so wiped out, I do put the day back a bit. Probably there is financial help available but I haven't particularly gone into that.'

Person with cancer, South, male

Service providers were aware that access to information, advice and support on financial matters was extremely limited. They believed few people with cancer and their carers would have access to relevant professionals, for example, social workers and welfare rights advisors. They thought it was unlikely that NHS professionals would signpost the availability of such support. However, they were aware that some local

authorities include a benefits assessment as part of their needs assessment process and will signpost eligible people to formal financial support information.

PCT commissioners generally saw social work and welfare rights as the responsibility of local authority commissioners. Local authority commissioners were aware that the council provided welfare rights advice services, but that these were not targeted at people with cancer or their carers. As such, local authority commissioners accepted that services may need to be developed to better meet the needs of people with cancer and their carers. Either way, people with cancer and their carers were not generally gaining access to the information, advice and support they needed.

'What should happen is the mainstream services, which are funded, should be delivering for these specialist areas... but I can understand why Macmillan are saying they want to promote it [specialist services for people with cancer], because it's more likely not actually happening.'

Local authority, South

Information and advice services

Commissioners, providers, people with cancer and their carers agree that people with cancer and their carers need information, advice and support throughout the cancer journey and beyond.

People with cancer and their carers said they do have access to information and advice from the health professionals they come into contact with. They tend to look for and pay greatest attention to information and advice about medical care (including their cancer diagnosis and prognosis, their treatment options and associated benefits and risks, follow up and after care). However, many said that with hindsight they would have benefited from information, advice and support about financial, emotional and practical support. Several thought that health care professionals should raise such topics with them at an early stage. They thought this would have helped them to anticipate and plan for the future more effectively.

Carers also want to know how to provide more effective care themselves, for example, how to encourage eating and how to help with physical movement. Carers stress the need for more information and signposting to sources of emotional, practical and financial support (as detailed above).

‘I think there is a lack of information all the way through...they give you loads of leaflets, it’s leaflet overload really...[it would be better] if you could sit just for 15 mins and talk to someone one on one ... leaflets, a lot of them say one thing and another says just the opposite.

Person with cancer, North, male

PCT and local authority commissioners say they provide information services in-house (for example, local authority welfare rights services,

Patient Advice and Liaison Services). Some PCT commissioners highlighted their responsibilities to do so as part of NICE guidance. Local authority commissioners are aware they also act as an important gateway to further information, including information about the range of social care support. Some local authority commissioners acknowledge that their services may not fully meet the needs of people with cancer, in terms of easy access to the information and its accuracy in terms of the available support for people with cancer. Few said they were in the process of planning or developing a universal information service (a recommendation in *Putting People First*).

Many local authority commissioners think mainstream services are well-placed to assess the social care needs of people with cancer. However, a few are concerned that frontline staff may not fully understand the social care needs of someone with cancer and may have difficulty assessing and referring them to appropriate support because they tend to deal with different service users groups, for example, vulnerable older people.

‘I think if someone phoned up and gave that example [person with cancer who had recently had surgery and needed frequent chemotherapy], they’d most likely hit a brick wall, they wouldn’t know where to go, and they wouldn’t be able to get an answer, being perfectly honest. I think if someone explained that position, the contact centre wouldn’t be able to answer, and they’d have to get someone else

to come back to her, I guess a social worker or someone in the health team to come back and talk to her. She wouldn't get a good response I think, the response you would expect to receive initially.'

Local authority, South

Local authorities do provide a range of information and advice services for the population as a whole, and in some cases for specific user groups, for example, older people. Some say that they are expecting to improve these services in the future to provide a more comprehensive service. In particular, there appears to be efforts being made to consolidate existing information about the range of services available to people into comprehensive directories.

'We also invest in a service which specialises in maintaining lists of service providers which are given to people according to the kind of needs that they've got. They're accredited providers of services which they probably have to pay for but they're vetted by the local authority.'

Local authority, North

Some PCT commissioners are exploring the value of enabling effective self-care as part of their future commissioning. They recognise that better information and advice on self-care could greatly help to fill gaps in services available for people with low to moderate needs. Some PCT commissioners suggest that information prescription programmes may provide additional insights on providing better information for people with cancer and their cancer diagnosis. However, any such considerations are generally in their infancy.

Overall, many people with cancer and their carers feel they could be getting more and better information and advice throughout the cancer journey.

Research findings

Commissioning social care

Understanding the commissioning process

What is a commissioner?

PCT or local authority commissioners described a range of roles and responsibilities:

- To assess the needs of their population.
- To commission services to meet needs of the population.
- To monitor and develop performance of those services.
- To develop commissioning strategies to shape the future supply or provision of care (and contribute to effective demand management).
- To ensure effective use of taxpayers money and value-for-money service delivery.

What is commissioning?

Commissioning is the process by which services are bought for a community. Commissioning decisions are expected to be evidence-based. Processes like the recently introduced Joint Strategic Needs Assessment (JNSA) are expected to inform commissioning decisions. Local strategic partnerships (involving local authorities, primary care trusts, and other public, voluntary and private sector organisations) are expected to agree with Government how they will commission services to meet national and local priorities through LAAs. Commissioners are increasingly expected to engage and involve service users to inform their commissioning strategy and decisions. The quality of services provided and the use of resources are both reviewed as part of the regulatory assessment.

How well established is commissioning in local authorities and PCTs?

Commissioning is a well-established function within local authorities. Social care commissioners often commission a wide range

of services from both private and voluntary sector providers, especially in relation to domiciliary care services. Different teams usually commission children and young people's services, adult services, learning disabilities services, and older people's services.

Formal commissioning appears to be a newer function within the NHS, although it has a long history of funding support from the voluntary sector. Commissioning is usually separated by condition (eg cancer services, mental health, long-term conditions, etc) or the type of care (eg community services, mental health, planned and unplanned care, and end of life). Some PCTs had no cancer services commissioner. Others had no social care commissioner. Cancer care commissioning can also be managed within both planned and unplanned care.

'There is a process for commissioning social care services as an element alongside health care but I suppose I would see social care services as being much broader than that and I am not sure that there is as such a process for commissioning across a range of social care services. I don't have a sense of an overall commissioning strategy.'

PCT, North

Who is commissioned to provide social care services?

Services can be commissioned within the public sector (for example, through public sector provider services). For example, PCT services will often provide physiotherapy and occupational therapy services in-house. However, many PCTs are separating out their commissioning function and provider services to ensure good

governance and to enable the local voluntary and private sector to compete for contracts in the future, ie to give service users a choice of provider and develop a mixed care economy locally. Services are commissioned through formal contracts and service level agreements.

What is the difference between commissioning and funding?

Local authority and PCT commissioners seem to draw a distinction between formal commissioning and project funding. Mainstreamed services tend to be formally commissioned (for example, physiotherapy, occupational therapy, psychological support, counselling support, domiciliary care and respite care).

The extent to which there is a real local competition for such provision seems to vary depending on the extent to which there is a mixed care economy locally (ie with a range of suppliers for any one service from across public, voluntary and private sector to ensure competition in terms of future commissioning and tendering processes). Both PCT and local authority commissioners appear to be keen to develop such a market place to ensure the best quality care for local service users.

Other services tend to get funded as special projects or programmes through discretionary budgets (eg social marketing to promote bowel cancer screening, Age Concern befriending support for isolated older people). Consequently, their funding is less secure. The extent to which such projects or programmes become mainstreamed varies greatly. It is difficult to say what encourages PCTs to adopt a special project as part of mainstream provision.

The extent to which funding of special projects is linked to outcome measures or key performance indicators varies (for example, number of people supported, service user satisfaction). Some have no such measures. Consequently, commissioners

do not always know what quality of care was delivered.

‘There is a service that we set up, and we set it up on a wing and a prayer with a little bit of money from different things, and we knew that it was reducing admissions and demand for district nursing and GP’s times...but there was no evidence base to show that, and so the performance monitoring has recorded that, it’s also recording how satisfied patients are with the service...and it’s shown a huge decrease in visits to A&E, to GPs...so if we want to extend the service and make it permanent, you’ve got your evidence.’

PCT, North

Providers themselves say that commissioning processes can differ between local authorities, in terms of specification, terms and conditions, levels and nature of support commissioned, and commissioning mechanism (for example, fixed price contract, framework agreement or call-off contract).

What is joint commissioning?

Local authority and PCT joint commissioning of social care appears to be widespread. All local authorities and PCTs had developed, or were developing some form of a joint working. However, joint commissioning encompassed a wide range of activities.

For some PCTs and local authorities, joint commissioning meant that they had completed the required JSNA and developed a joint strategy. However, health and social care commissioning activity remained separated.

‘We have a joint commissioning unit...we have two teams at the moment, and there are two leads, and we work closely together, they report to the joint commissioning boards and we’ve got two commissioning strategies. We have agreed within there that there will be some key priorities for each individual organisation...and there will be

some joint ones. We have limited the joint ones so they are achievable, and people are slowly biting them off and having a look at those issues.'

Local authority, South

Other PCTs and local authorities had pooled budgets for some services (for example, learning disability services), but not others (for example, older people's services). This was sometimes as a trial to see whether or not budget pooling delivered benefits. Some say pooling of budgets has led to far more integrated service provision (for example, in relation to end of life care and increasing the number of people who are supported to die at home). Most believe joint commissioning and budget pooling could provide a more seamless service provision between health and social care providers. However, they felt it was too early to say the extent to which pooled budgets would be rolled out to other service areas.

'At the moment we are commissioning a joint service with social care...we've met jointly and have identified the need for it, we've jointly identified funding for it, and we're working together to design services around the specifications.'

PCT, North

Some PCTs feel that they have been the driving force behind a more joined-up approach to commissioning of certain services (for example, integrated end-of-life health and social care). Several thought that national initiatives and Government guidelines had prompted such action, for example the *End of Life Care Strategy* (DH 2008).

'I am linked very closely to the end of life programme, and that links with the end of life strategy that was published in June...that has been a key driver...[before the end of life strategy] we have never had a national lever saying this is what we should be doing.'

PCT, North

PCT and local authority commissioners generally accept that both commissioning and service provision needs to become more integrated to ensure that service users get a seamless service. They recognise the need to work with a range of local strategic partners to ensure fully integrated public service provision (for example, linking up with local Housing Services, Jobcentre Plus, etc). Similarly, PCTs recognise the need to integrate their commissioning with each other.

Recent configuration of PCTs appears to have had an impact on joint commissioning in some areas. Some PCT commissioners cite the configuration as a driver for change, saying that it has promoted joint strategic planning, and made it simpler to undertake. However, the configuration also seems to have delayed, or complicated planned joint commissioning strategies in some areas. For example, some local authorities have had to build relationships with new commissioners, with new outlooks.

'What they are now still doing, almost two years on, is trying to consolidate and rationalise what they've inherited, so we've still got four different intermediate care teams.'

Local authority, Midlands

Some providers are more aware of joint commissioning arrangements than others. Some are aware that local strategic partners work together to assess need and to work out how best to meet it.

What criteria do commissioners use to make decisions on commissions?

Local authorities tend to commission social care in terms of age groups: for example, children and young people, adults, and older people. Few have thought specifically about the social care needs of people with cancer in the course of their commissioning. PCTs tend to commission in disease/condition groups (for example, cancer, mental health, etc) or type of service (for example, planned and unplanned care).

However, few have thought about the specific social care needs of people with cancer. In relation to cancer, most tend to focus on end of life care needs rather than social care needs during the earlier stages of the cancer journey (for example, diagnosis, treatment, follow up, etc).

There is consensus that resources for social care support are limited. Local authority commissioners restrict access to social care (for example, with eligibility criteria or time limits on the level of support available). Most say that services are often restricted to people with critical and substantial need, for example, domiciliary or respite care. Fair Access to Care Services (FACS) criteria are universally used (critical, substantial, moderate, and low).

Guidance around FACS encourages commissioners to consider commissioning to prevent the needs of those currently with low to moderate needs escalating to critical or substantial needs over time. Commissioners did not say that they use FACS criteria specifically to commission services. However, most said that they focus their commissioning on services which are most likely to benefit people with critical or substantial needs.

PCT commissioners similarly say that their resources are limited. Many have to restrict access to patients with specific clinical needs.

A few local authority commissioners say that they have recently lowered the level at which people become eligible for support to include those with a moderate social care need. Their motivation for doing so is to prevent social care needs escalating, for example, due to a fall at home.

‘We have a range of volunteers that we commission so people on low and moderate needs can get support from our volunteers who would do a range of things like a bit of gardening, driving to their hospital appointments

or somebody just sitting with the person while the carer goes out, sometimes just shopping or looking after somebody who is unwell.’

Local authority, Midlands

Providers generally believe that most social care commissioning targets people with critical or substantial needs. However, one provider was delivering commissioned domiciliary care for people with low to moderate needs. This was a preventive measure to stop care needs escalating and to maintain independent living.

‘We probably provide about 60% low to moderate and 40% complex. Low to moderate would be basic personal care, a bit of domestic support, perhaps a bit of shopping, pension collection.’

Domiciliary care provider

Providers agree that provision of care to people with low to moderate needs would deliver benefits to the whole community in the long-term. They were aware that PCTs and local authorities were starting to focus more on prevention in terms of strategy. However, they believe that this had not yet resulted in subsequent commissioning to achieve any such strategic goals.

‘Within xxx [borough] they are quite proactive in looking at different ways of keeping people in the community...We have got a new extra care housing scheme where we are trying to put people into flats and accommodation and bringing services to them...I think people are really moving towards that.’

Occupational therapy provider, North

Local authority commissioners are often aware that family, friends, and the voluntary sector are expected to meet the care needs of people who are not eligible for social care provided by the statutory sector. However, they also say they work with the voluntary sector to secure funding from them and other sources to enable the

provision of support, for example, for people with low to moderate needs.

‘We use the third sector a lot, and they will deliver those low to moderate services. It could be a befriending service, it could be just providing support to the carer who’s looking after the person who’s got cancer...but they’re not specialist services directed at people suffering from cancer.’

Local authority, South

PCT commissioners also fund (or part fund) services to meet the needs of people with low to moderate social care needs, for example, sitting services. Even where no formal commissioning is taking place, PCT commissioners often have strong links with voluntary sector organisations that provide information, advice and support to people with cancer and their carers with low to moderate needs.

‘We do commission and pay for some Macmillan nurses, so we do pay for the health care input... You get some purely voluntary sector services such as night sit-ins provided purely from the voluntary sector. A lot of social care provided by the voluntary sector is managed through social services, so they may commission, but in health we don’t commission those services as much.’

PCT, North

Are PCTs and local authorities commissioning generic or specific services?

Local authority commissioners tend to fund social care services aimed at anyone who meets their eligibility criteria, regardless of any medical condition. Many say that it would be problematic for them to fund cancer-specific support. Given the wide range of disease groups, they would find it difficult to commission specific care for each one. However, they stress that good social care focuses on the need of the individual using

a social rather than a medical model of need. As such, they believe that generic services are well-placed to support people with cancer who meet their eligibility criteria.

‘I think it would be quite difficult to have a cancer specialist per se because at the end of the day you can imagine that if you had somebody in that role and somebody came along with equal needs but happened to have Chronic Obstructed Airways Disease or something then it would be difficult to say, well I’m the cancer specialist. And in terms of flexibility I think we need to keep that in built flexibility with all our staff really. So we would respond more to kind of functional need if you like and how the disease was actually affecting people rather than any specific disease group as such.’

Local authority, North

‘It is whatever the outcome for that particular client. It is not specifically saying we will provide this service for cancer patients. In the health area yes but in social care no. I know it seems quite stark but we are working here to provide outcomes for people regardless of their condition.’

Local authority, Midlands

PCT commissioners commission or fund a mix of both generic services (for example, occupational therapy, physiotherapy, generic end-of-life care) and cancer-specific social care support (for example, cancer support groups, cancer bereavement counselling, etc). They say their decisions are based on the specific needs of the local community.

Providers also say that most social care support is mainstream and not disease specific. However, some think that people with cancer would benefit from a dedicated service. They think people with cancer have specific support needs, for example,

due to the length of the cancer journey. They think staff need to be aware of the specific emotional, financial and practical support needs of people with cancer.

‘I think specialism is the way forward. From both the worker’s point of view and the patient’s point of view it would be much better for them to have a carer who knew that illness inside out, who can help allay the fears to a certain extent.’

Domiciliary care provider

Most local authority commissioners say that people with cancer are not specifically mentioned in their LAAs. Some local authorities strongly focus on the fact that their commissioning strategies should be, and are, fair and inclusive. There is a sense that this means that there is an active decision to avoid services which are labelled as specific. That said, they do accept that one of the purposes of LAAs and JSNAs is to provide a holistic approach to providing services for a wide range of people with different needs, and that people with cancer should be taken into consideration. Others say that other groups of people targeted within their LAA would include people with cancer, and therefore it is not necessary to target them specifically. Some say that LAAs are subject to national guidelines, and that they are not aware of any requirement to specifically include people with cancer within them.

‘Specifically within xxx[borough] there isn’t a reference to cancer [in the Local Area Agreement], but there are half a dozen key social care and health indicators under which I would say cancer would fall.’

Local authority, South

‘We have got a more generic target in the local area agreement around carers. If there was somebody who was caring for somebody with cancer that would be considered, but specifically around cancer there is very little.’

Local authority, Midlands

Levers and incentives for commissioning social care

In order to understand the over-arching levers and incentives to commissioning social care for people in general, we will describe the commissioning criteria used and the degree to which this is changing, and might change in the future.

What criteria do commissioners use to decide who to commission?

Local authority and PCT commissioners admit that they traditionally tended to commission on price and volume. However, they say that they are increasingly looking at quality-based commissioning. This can include a range of approaches including:

- Undertaking contract monitoring visits with providers and service users at regular intervals (local authorities).
- Asking providers to demonstrate and describe their processes for supporting staff and carers as well as service users (PCT).
- Involving the Healthcare Commission and CSCI in planning commissioning (PCT).
- Measuring customer satisfaction and customer experience (National Patient Experience Programme, Place Surveys, other customer satisfaction surveys, monitoring the number of complaints and assessing complaints resolution) (PCT).
- Measuring the impact of services on the user's quality of life through follow-up monitoring and interviews (local authorities).

'Achieving economic well-being would be one of our categories, and the outcome there would be that income is maximised and benefits are maximised, debts are reduced, and that the

person has been informed about it, has taken up individual budgets or direct payments.'

Local authority, North

However, many stress that quality-based commissioning is a relatively new phenomenon in public sector commissioning. They admit that the quality of services commissioned previously was sometimes poor. Many appear to be only just starting to consider how to incorporate quality criteria into commissioning contracts and service level agreements.

The criteria service providers are expected to meet are usually set out in tender documents and service level agreements. How contracts for social care provision are tendered varies on the size of the contract, but operate within European Union procurement rules, with contracts over a certain value tendered through the Official Journal of the European Union.

Providers acknowledge a recent shift to quality-based commissioning. However, providers who are commissioned by more than one local authority describe an inconsistency in the relative importance placed on quality of service versus cost in service level agreements.

'Our service level agreements at the minute,

within the social work service, are more around quantity. But they are now starting to move that, to look at other performance indicators that are coming in around quality, around dignity and whether the public perceive that they are achieving the outcomes that they set out to achieve in the first place.'

Occupational therapy provider, North

'We are firstly measured on price and our ability to take on the work, and then complaints and how we deal with them, then our inspections... they are very budget-driven; one agreement is 70% price and 30% quality, another is 60% price and 40% quality and the other is more weighted towards quality.'

Domiciliary care provider, Midlands

To what extent do commissioners involve service users in designing services?

As joint commissioning of services becomes more prevalent, some local authorities say they are including service users in planning social care at a broad level, helping them to understand unmet needs and gaining feedback on draft service plans. They do this through:

- using Local Involvement Networks, where stakeholders and the public come together on a regular basis
- consulting with user groups
- running individual events for stakeholders and users.

'We have had two stakeholder days which have included service users and carers, to lay before them our thoughts and see what they thought about them. We have had health involved in that, although the actual strategy is primarily to look at social care provision, and from that we've evolved a draft strategy.'

Local authority, South

What is driving change in commissioning decision-making?

Change in social care commissioning appears to be driven by an increased focus on the quality of services provided. This, in turn, is driven by various different factors:

Government initiatives, cited by local authorities:

- Fair Access to Care Services criteria encourages preventive commissioning and discourages discrimination based on age.
- The introduction of direct payments (and the recent positive outcomes for the evaluation of individual budget pilots).
- Local Area Agreements which set out how strategic partners will meet national and local objectives (albeit the content of LAAs tends to be relatively high-level and only one local authority commissioner believed that their LAA made direct reference to people with cancer, with a number unsure of whether theirs did or not – see above).

Government initiatives, cited by PCTs:

- World Class Commissioning in the NHS and associated guidance.
- Our NHS, Our Future (the Darzi Review) and its emphasis on more personalised, safer, more efficient and more effective health care.
- The Cancer Reform Strategy, for example, in terms of prevention, screening, access to services, survivorship. However, several say that it is too early for changes in commissioning strategy to have affected subsequent commissioning decisions and service provision. Some say they are prioritising the implementation of the CRS, and that some aspects which may be relevant to social care provision (for example, the living beyond cancer agenda) have not been addressed fully yet in their strategies.

Other drivers, cited by both PCTs and local authorities, include:

- Arms' length regulatory assessments (ie CSCI, Healthcare Commission, Audit Commission, etc) which assess:
 - Quality of care, including the inclusion of customer experience survey results.
 - Effective use of resources and value for money delivered
- Local commissioning strategies, which can include:
 - A greater focus on meeting local needs, for example, with more effective assessments of local need through the JSNA; many commissioners stress the emphasis in such documents on the impact of an aging population on local service commissioning and the increase in conditions associated with ageing, including cancer, heart disease, dementia.
 - A greater focus on efficiency within public services, for example, with greater emphasis on prevention and self-care in PCT commissioning strategies (albeit such debates are considered relatively recent and associated action appears to be relatively recent and limited in scale).
- Charismatic individuals within local authorities or PCTs who strive to affect change locally and influence local commissioning strategies (for example, commissioning directors, chief executives or chairs, elected members in local government, strategic health authority commissioning leads, or other strategic partners).

Are commissioners considering funding social care services for people with low to moderate needs?

Commissioners tend to focus their social care commissioning on people with critical and substantial (local authorities) or complex needs (PCTs). Some local authority commissioners admit they sometimes struggle to commission high quality social care support for people with

critical or substantial social care needs. Some say that they do not have sufficient funding to commission high-quality care. Consequently, they think it is unlikely they will fund support for people with low to moderate social care needs in the near future.

Our focus is mainly substantial and critical needs but there is a recognition within the authority that we somehow need to get back to low to moderate because that's where we've got more of a chance of radically changing people's cultures and views of what services they should receive and when they should receive them.'

Local authority, South

Similarly, PCT commissioners felt it was important to ensure effective provision for people with complex needs before considering the needs of others.

'You can prevent admissions to hospital, and improve people's quality of life [by providing care at an earlier stage] but the difficulty is we are fire fighting with the complex needs a lot of the time rather than doing the more proactive work at an earlier stage.'

PCT, North

A few PCTs and local authorities feel they have achieved an adequate level of support for people with critical or substantial needs. They are starting to look at commissioning and funding services to support people with moderate social care needs more actively. However, the number of commissioners who said they were doing this is too small to generalise about the factors driving such developments. Any such support is generally funded as special projects or programmes rather than as mainstreamed services. Two reasons were cited for funding such support: (a) ensuring identified local needs are met and ensuring a good service user's experience; and (b) preventing moderate needs escalating in to critical or substantial needs. For example, an occupational therapy

service was commissioned to assess whether older people with moderate needs required adaptations and equipment for older people as part of a local falls prevention strategy. Such funding is not necessarily specifically for people with cancer (although they would be able to benefit from it).

‘We have actually sought additional investment to increase those services [voluntary] so that you know we can then look at people on low and moderate needs.’

Local authority, South

Providers confirm that some local authorities and PCTs are beginning to discuss the provision of services for people with moderate needs, and one was being commissioned to deliver them.

What return on investment do commissioners expect to see on funding of special projects?

As commissioners have to ensure effective use of public funds, funding would be linked to key performance indicators. Commissioners often ask organisations seeking funding to specify the performance indicators for a special project and programme in advance. They expect them to monitor performance against these themselves. If commissioning to meet identified local need, to see the number of people helped, the nature of help provided and the quality of services provided.

‘Well if we’re supporting them financially we need to make sure they meet the statutory and mandatory requirements, that they’re safe and they’re offering good quality care, and then it’s just making sure that patients have got access to them.’

PCT, North

Local authority commissioners say that it is important that they are able to demonstrate that services they commission have a positive impact on the population. This can include specific

groups within the population which are already identified and recognised as having specific needs, for example, older people, people with learning difficulties, younger people.

‘I wish we could do everything, but we can’t, and therefore we have to have some analysis to say, if we develop these types of services for this group, (and it doesn’t have to be the whole population, it could be a specialist area), that would have a beneficial effect for those individuals, and we can quantify it.’

Local authority, South

If commissioning to prevent needs escalating, commissioners want to see evidence that a project or programme reduced demand for more expensive services to meet critical and substantial need and reduced overall spend.

‘[Evidence] would need to be based on the demographics, county, deprivation statistics, evidence of an input that gives a proper outcome possibly from somewhere else in the country. What savings it would make for the local economy to actually make it beneficial to invest in...it has to be evidence based, if it is not it won’t get there. I wouldn’t look at it.’

Local authority, Midlands

Commissioners are aware that such benefits can take a long time to measure and can be difficult to attribute to any one project or programme. Commissioning ‘invest to save’ projects and programmes (ie investing in services aimed at those with low to moderate needs to prevent their needs escalating to critical or substantial, and therefore requiring more expensive care) is believed to be a relatively new phenomenon. Commissioners would welcome information, advice, and support on how to determine effectiveness, for example, about key performance indicators to monitor and how to calculate return on investment. Most look to Government, CSCI, or the Healthcare Commission for such information, advice and

support.

Local authority and primary care trust commissioners appear to see a good fit between the public and voluntary sector in terms of commissioning services and funding projects and programmes. They believe they share similar values and motives, for example, motivation to contribute to the public good.

The drive for personalisation

Numerous policy documents place particular emphasis on the need for greater personalisation of health and social care services by allowing, for example, choice of provider or flexibility in timing of care. Direct payments and personal budgets are thought to have potential to stimulate greater personalisation of social care provision.

Direct payments have been in operation for almost a decade. Service users or carers get a cash payment to fund services to meet their assessed social care needs. In so doing, the recipient is responsible for employing and paying people to meet their care needs.

We found a greater degree of engagement, understanding and opinion regarding direct payments and personal budgets among local authority commissioners than PCT commissioners, who were aware of the issue, but had less experience and subsequently less to say.

Many councils have commissioned support organisations to help service users handle these responsibilities. However, uptake of direct payments remains comparatively low. Local authority commissioners cite a range of barriers to uptake of direct payments. Service users and carers are unaware of them and how they work (none of the people with cancer or their carers interviewed had heard of them or knew how they worked), what the benefits are and what support is available to help manage them. Some commissioners think their staff have concerns about the ability of service users and carers to make sound judgements about how to use

money available through direct payments. Some commissioners have concerns about the quality of advocacy support available to local people who take up direct payments.

‘At the moment they have a choice, but the plan is that all patients should move onto direct payments, which I don’t think a large proportion of the population would be able to manage, and if they take the money and they spend it on things other than their care, and then they still need care, who should be responsible?’

PCT, North

Providers have some experience of direct payments. Some welcome the flexibility and control they give service users. However, others are concerned about the pressure service users can experience in terms of managing direct payments. The quality of information, advice and support available to service users who receive direct payments is said to be variable. One provider said they had to instruct a social services direct payments office to make house calls to a service user, to help them rectify mistakes and deal with problems they were having with the administration of direct payments.

Personal budgets were recently piloted and are an allocation of funding given to users after an assessment, which should be sufficient to meet their assessed needs. Users can either take their personal budget as a direct payment, or - while still choosing how their care needs are met and by whom - leave councils with the responsibility to commission the services. Or they can have some combination of the two. As a result, they provide a potentially good option for people who do not want to take on the responsibilities of a direct payment. Local authority commissioners believe that personal budgets have the potential to promote independence, choice and control for service users. They think this will mean that services will have to adapt to better meet the needs of service users. To work, they are aware

that there needs to be a mixed care economy locally to give people a choice of provider. Many see their role as stimulating a mixed care economy within their boundaries and facilitating the personal budgets process.

PCT commissioners are also concerned about the efficacy of personal budgets and the quality of support available to service users to manage their personal budget. They are concerned that the reported benefits may not be realised as a result.

Despite a general acceptance of the potential benefits of personal budgets in local authorities, PCT and local authority commissioners say they do not know at this stage:

- Who will qualify for personal budgets (they assume it will remain people with critical or substantial needs).
- How many people will take up personal budgets (based on direct payments they often suspect uptake will be slow and low).
- The level and nature of care people will want as a result (for example, will they pay a family member to drive them to hospital or pay for a taxi?).
- Whether people will want and choose appropriate support and who will ensure that people still get the care that they need. This was particularly important to PCT commissioners.
- The impact their decisions will have on mainstream commissioning (for example, formal domiciliary care, respite care). They do not know if personal budgets will result in less formal care being commissioned or not).

‘...it sets up all sorts of challenges in terms of whether you can influence the market to provide a very flexible type of service, and indeed we are working with our domiciliary care providers... making them really aware that individuals will be coming to them in the future asking them to provide not only what we’ve got on our specification but things outside of that.’

Local authority, South

‘We’re trying to get our heads around how it’s going to work...it’s very early stages at the moment. It is going to turn upside down how we have commissioned and contracted in the past, and I think we won’t be providing some of the traditional services that we have provided in the past.’

Local authority, South

Many commissioners think people will need considerable help to enable them to make informed choices about their care. Some think this presents an opportunity for the voluntary sector. Others think social workers are better placed to provide such advocacy support.

Service providers have mixed feelings about personal budgets. Most share the view of local authority commissioners, ie that some services would benefit more than others. Some providers are aware that they could provide information, advice and support to service users to help them manage their budgets. However, some remain unconvinced that the proposed system will be successful.

Research findings

Opportunities and barriers to improving the provision of social care for people with cancer and their carers

Opportunities

How might innovation in commissioning and service delivery help in meeting the needs of people with cancer?

The issue of resources is a key barrier to providing better social care for people living with cancer. If more money were available in local authority budgets, some of the gaps in service previously discussed could be filled. However, all commissioners and providers feel that there is little or no chance of additional funding being made available, at least in the short-term, or in any significant volume. Therefore, local authorities, PCTs and those with an ambition to provide improved or enhanced services have to consider new and innovative ways of doing so.

One local authority social care commissioner was considering different ways of working with their providers locally to help encourage early intervention and prevention. For example, they were in discussions about the viability of establishing a social enterprise provider to deliver such information, advice and support. Some felt that social enterprise (ie encouraging small providers to set up and charge nominal amounts to users) could be a useful complement to existing voluntary sector activity.

‘We want to encourage early intervention and prevention and so we have to look at it in a different way in terms of working with providers. Not necessarily providing funding but looking at alternative ways of them being able to get involved such as encouraging social enterprise for instance, or assisting with the application of grant funding from other sources other than ourselves.’

Local authority, North

There is a need to deliver efficiency savings in order to make the commissioning or funding of additional services for people with low to moderate needs more viable. One local authority is trying to achieve this by combining existing services into one location. This has the benefit of lower overhead costs and also added convenience for people using the services. There may be an opportunity to encourage local authorities to look at smarter ways of aligning services, and hence demonstrate efficiency.

‘What seemed to be working if you like was a little pilot in...where a number of services had combined together to provide a bit of a one-stop shop. So we’ve started to think maybe it’s not so much about more services, new services, but the way in which they’re configured really.’

Local authority, North

Some local authorities and PCTs say that they are starting to cross-train people working within their existing service providers to meet a wider range of more specialist needs. For example, through a joint commissioning arrangement some home carers are receiving training to provide simple health tasks such as applying dressings. Such a model suggests a potential opportunity for service providers to be given more suitable training around how to support people with cancer or the people who care for them.

Joint commissioning provides opportunities for some local authorities and PCTs to enhance the level and quality of care provided to people with cancer. For example:

- A PCT has developed a system where social workers receive additional training in a specific specialist area including palliative care. These people are then posted in

hospices, or to cover home visits to people with these particular needs.

- A PCT has introduced a new cancer liaison officer role, which is designed to direct people with cancer to the most appropriate care and support from the earliest stages of their cancer journey. Services signposted to include both health and social care, and the role goes some way to address gaps in social care provision for people with cancer.

Partnerships between voluntary sector organisations, such as Age Concern and PCTs, are helping to improve social care for people with moderate, critical or substantial needs by enhancing or improving existing services to better meet the needs of specific groups.

Some commissioners in local authorities describe how they are accessing other funding streams to provide services for people with low or moderate needs. They are engaging other departments, such as housing, on the broad issue of prevention by raising the profile of the issue on the local authority's agenda. It is important that these more forward-thinking approaches are publicised and encouraged across the country.

'From a social care point of view [it is about] making it a corporate responsibility...it's not just social care that can address low and moderate needs, it could be the council as a whole in terms of its leisure and parks and any other facility out there, I think that is a key motivator from our point of view, it's to make it a wider responsibility as such.

Local authority, South

Barriers

There are a number of barriers which limit the potential to improve the commissioning and delivery of social care services for people with cancer.

Lack of national policy drivers of debate

There seems to be little debate about whether and how to meet the needs of people with low to moderate social care needs altogether, at a national or local level. Instead the focus appears to be on improving the commissioning of existing services within existing eligibility criteria. Commissioners can feel that they have very limited 'room to manoeuvre' within the context of the regulatory framework within which they operate.

'I think it comes around to the issue [of] why do we have eligibility criteria, if we're about providing support, health and social care? Health is free access, social care isn't, and therefore if we're going to provide the proper support for people suffering from cancer we have to somehow address that issue.'

Local authority, South

Lack of resources

Commissioners often explain that demand for social care outstrips supply of the available resources (both funds and staff), so access has to be restricted to those most in need (ie people with critical or substantial needs). Many commissioners cite the problem of finding suitably qualified staff as a barrier to commissioning formal services and filling posts in social care within the local authority or PCT.

'I think the difficulty is that, in reality, local authorities work within a strategy context; people are entitled to an assessment of need and to have services, so the difficulty is that if you

commission more services for people with low or moderate needs, you still need to be confident you can cover the other. Local authorities do need to operate within their budgets.'

Local authority, North

'Well I mean we have to meet the needs of everyone who is substantial or critical. It is statutory, we have to do that...It is when we have competing needs further down the eligibility criteria that we have to set about doing a business case to say which services can be developed that will have the greater effect for a group of the population, because there is a limited amount of money that we can put into preventative services.'

Local authority, South

Insufficiently flexible provision

Some commissioners admit that local providers are better at meeting on-going needs compared to the short-term ad hoc needs that people with cancer sometimes have.

Lack of (adequate) signposting to available support

Many people with cancer and their carers said that the professionals they come into contact with (mainly healthcare) do not signpost them to any available social care support. This is confirmed by some local authority commissioners who have doubts about the quality of their own information services and by providers who sometimes say that they do not feel they get as many referrals for people with cancer as they might expect.

Lack of integration between health and social care

Even though more joint commissioning is happening, many local authorities and PCTs still struggle to take an integrated approach to the commissioning of services. They describe how some services (for example, emotional support) can be seen by both parties as the other's responsibility, leading to the possibility that members of the public may 'fall between the gaps' in service. In addition, commissioners confirm that local authorities tend to view cancer primarily as a health issue and that PCTs have traditionally not seen social care as a core service in relation to cancer care in general (although this might be beginning to change with the implementation of the CRS).

'I think if people have got labelled with a disease, social services will automatically try and pass them back over to health, and I think we need to move away from that.'

PCT, North

'[There is a] debate about what is a health responsibility and what is a care responsibility, and I would hope health and social care together would have done the joint assessment, and would have reached a conclusion that, because of the individual's income, some support would be given to get him to his chemo treatment, but I am saying I would hope, I'm not saying that it happens all of the time or it's consistent'

Local authority, South

Attitudes of commissioners

Some commissioners think the family and the voluntary sector should meet low to moderate needs, and that the state should focus its limited resources on those most in need. Local authority commissioners say it is unlikely that they will commission cancer-specific social care support and believe that generic user-focused services can meet the needs of anyone who needs their help.

'I firmly believe we need to create a system which works for the majority, and then for the minority, and it has to work well, and then for the minority we need to be able to respond to their needs, and that's how we should be generating a system. Most people should fall within the majority case, there will be people needing some specialist services, and we adapt systems to. Rather than creating a system for the specialist, we create a system for the majority, and then meet the needs of the specialist later.'

Local authority, South

Difficulty in providing sufficient evidence of benefits of services

Providing evidence of meeting a previously unmet need, or of financial savings, by reducing demand on other services, is considered difficult. Commissioners say that pump-priming is the only viable model to allow useful monitoring at a later stage. They simply had not come across other models which allowed monitoring in this way. However, there appears to be some concerns with the pump-priming model. Some commissioners are now reluctant to pick-up services after feeling that a pump-primed service which was not performing well became difficult to cancel, or that negative relations with the provider were problematic in terms of bad press. They say that in the past they did not effectively monitor the performance of services which they had fully funded.

'We were held to blackmail. If the service fails and you haven't anything else to put into place.'

Local authority, Midlands

'We need to continue supportive services that we have already commissioned, like hospices... evidence based services tend to get the highest priority because it is easier to commission around them. It is quite difficult to commission things like complementary therapies because of the evidence base.'

PCT, North

Some local authorities have adjusted their approach to pump-prime funding in order to avoid the challenges described above. They have moved to more stringent service level agreements at the point when funding is picked up. Others say that they actively avoid pump-prime funding as a model to commission new services and tend to look for evidence of the success of similar services in other locations instead.

Some PCTs have previously found it difficult to put pump-primed services in place due to the unpredictability of their own funding arrangements. They explain that there is little point in allowing a new service to be set up when funding may simply not be available after the initial pump-primed period, regardless of the measured outcomes. One had overcome this issue through work with Macmillan around providing training and support for fully funded staff.

‘The problem is with short-term funding is that we can’t predict the future. Macmillan tends to fund things for two or three years at a time, but we don’t know what’s going to be in the budget in three years time, so it’s very difficult for them to go and see people and talk about funding with the onus that the PCT picks the funding up in three years time...that can actually be more difficult than finding the money now. In the past, we took their expertise and used them to support the nurses and to train them, but we’ve actually funded them from the word go, Macmillan have just supported them, and they’ve held the Macmillan badge.’

PCT, North

Some local authority and PCT commissioners say that they are starting to think about commissioning based on the outcome of a service on the user’s quality of life (does it give people more choice and control? does it improve people’s economic well-being?), rather than on more quantitative measures, such as numbers of assessments made. Although some say that this approach will provide benefits to the end user, they also suggest that until a firm and agreed framework of measures is developed for the new approach, it will be difficult to define with certainty what constitutes a ‘successful’ service. This may make the commissioning of new services difficult to justify.

Research findings

Specific services

Specific services

Participants suggested a number of specific areas where services should be improved.

Information

Information both in relation to their condition, or the broader situation as it relates to it, and in terms of where to access other types of social care which may be relevant. People with cancer say that they would prefer this information to be proactively provided, rather than them having to seek it out.

People with cancer, their carers, commissioners and providers feel that there is not adequate low level emotional support for people with cancer, and in particular their carers, during the early stages of the cancer journey. A more consistent and accessible service providing emotional support during the final stages of the journey (after being discharged from treatment or after losing someone to cancer) was also spontaneously mentioned by PCT and local authority commissioners and providers.

How do commissioners think the needs of people with low to moderate social care needs could be met in the future?

Both local authority and PCT commissioners think that services for people with low to moderate needs might be commissioned in the future, if there was strong evidence that such support prevented needs escalating to critical and substantial support. However, they recognised that existing provision for people with immediate critical and substantial social care needs would have to continue in the meantime.

Other potential services

We asked commissioners if they would consider commissioning or funding additional volunteer

support (such as help with practical support) or networks as a cost-effective way of meeting the needs of people with low to moderate needs.

Most PCTs and local authorities were already supporting or funding the voluntary sector to some extent, and all used it to provide social care to people with low to moderate needs, although local authorities had more experience of dealing with the voluntary sector, specifically around social care. Therefore, they accepted that this could be a cost-effective route to securing support for people with low to moderate needs. However, some questioned the need for any further services of this nature, especially if they were targeted specifically at people with cancer.

Practical support

Several commissioners had concerns about formally commissioning volunteer-based services for practical support. Their main concerns were:

- Whether sufficient numbers would volunteer to provide support (a few cited the difficulty they had had recruiting volunteer patient and public involvement forum members). Some providers also note that for many younger people, volunteering is seen solely as a route to paid employment, making the pool of volunteering resource somewhat transient.
- Difficulty retaining volunteers, leading to a lack of continuity of carers for service users, and a lack of overall sustainability of the service.
- Quality of vetting and training of volunteers (especially those going into people's homes or looking after children).
- Compliance with statutory regulations, for

example, in relation to child-minding.

- Performance management of volunteers and quality assurance processes overall, including reliability and quality of care.

‘I wouldn’t have thought people would want to be reliant on volunteer support. We would actually want them to receive direct payments so they could be in control of the support. That’s going to enable them to have a greater say.’

Local authority, Midlands

Some commissioners thought it was impossible to separate out practical from emotional support. They thought any volunteer should ideally be trained to provide both. People with cancer and their carers shared commissioners’ concerns about using volunteers to deliver practical support. Consequently, commissioners thought it was unlikely that they would ever commission practical support from a volunteer network.

Emotional support

We found less resistance to funding volunteer networks for emotional support. Many were aware of successful volunteer-led services in the voluntary sector (for example, Terence Higgins Trust’s buddy programme). They recognise that voluntary sector self-help groups and services can prove particularly helpful and put people in touch with others with shared experiences and insights, including cancer support groups. Several had direct experiences of funding such voluntary sector support. Those working in rural areas, however, stressed the challenge of ensuring that such groups were sustainable over time, because for a population as dispersed as theirs, getting to meetings was difficult.

Providers think such support would be welcomed by people with cancer and their carers, as long as the person providing support was appropriately trained. They think it could be a way of cost-effectively providing a service, especially where needs are currently unmet (for

example, during the early stages of a cancer diagnosis). They are aware that people can have to wait some time for an appointment with an NHS counsellor or clinical psychologist.

Voluntary sector organisations as a source of financial support

We found considerable interest among people with cancer and their carers in gaining access to information and advice about financial support. Most thought helpline services were appropriate, especially if they come from a voluntary sector organisation (with no risk of being sold a product over the phone). However, some people from less affluent backgrounds said they would prefer face to face support, for example, help to fill out forms.

Most local authority commissioners thought such advice was best coming from professionals with a financial background given the complexity of state benefits, charitable grants, and financial services information, advice and support (which is regulated under the Financial Services and Markets Act 2000). Both PCT and local authority commissioners and providers were aware that voluntary sector organisations like Citizens Advice Bureaus (CABs) already offered such information, advice and support. They assume some of the advisers from CABs are volunteers.

PCT and local authority commissioners were aware that demand for such services was very high and people may have to wait to be seen. Several think people with cancer may require more rapid access to support than is currently available via CAB services.

Some PCTs say that voluntary sector organisations already play an important role in the delivery of financial advice and support (for example, CAB). However, they are concerned that relatively few people with cancer and their carers are gaining access to the information, advice and support they need. They are also concerned that local voluntary sector services

would lack the capacity to meet a significant increase in demand for their support.

Providers of emotional support for people with cancer acknowledge that they sometimes need to deal with financial enquiries. They say that people with cancer and their carers will call their services as they do not know where else to go.

Other providers question the possibility of providing welfare advice via a telephone helpline. They place considerable importance on a face-to-face approach, as those looking for advice may need a more in-depth discussion than a telephone call would allow.

Voluntary sector organisations as a source of information support

People with cancer and their carers also wanted access to more and better information throughout their cancer journey, 24 hours a day, seven days a week, 52 weeks a year. Many think a helpline service would be relevant. Similarly, online information is widely valued. However, some older people and people from less affluent backgrounds say they would need printed literature, as they have limited access to or experience of the internet. Many considered voluntary sector organisations as a credible and trusted source of information about cancer, medical care, and social care.

Several PCT commissioners say they are currently striving to improve their own online provision. Some are aware of the Government's information prescription pilots for people with long-term conditions. However, few are aware of the nature of the pilots or of any evidence of their effectiveness. Local authority commissioners were largely unaware of the pilots.

Local authority commissioners thought that charities should provide information through their own funds and did not think they would ever commission or fund such support themselves, as it might duplicate their own

provision. However, they would signpost patients to available provision in the voluntary sector.

How might social capital support the provision of social care?

Social capital is a term used to describe the value of connections between different social networks or between individuals in a community. Social capital has the potential to function best when people feel they are strongly connected into a network of inter-dependence, or a community. People with cancer in our sample generally only have an immediate family network nearby, rather than an extended family network, a community, a strong friendship network or a neighbourhood network. While participants described loose networks of friends, the only strong social networks evident are Church-based, which seem to provide a degree of both practical and emotional support.

'I am a committed Christian, I still am a member of a church and that was helpful from the social point of view as well because there was a community there...they would ring in and ask how I was getting on and if I needed any help in terms of shopping and so on ... that was really helpful.'

Person with cancer, North, male

Most participants felt uncomfortable burdening their friends with their emotional situation, sometimes stating they didn't want to seem too 'needy' or didn't feel it would help the friendship, or that they wouldn't have anything to offer the friendship. Friendships by and large seemed to hold an expectation of equality, of both friends doing roughly equal work and receiving roughly equal reward. There did not seem to be a tradition of supporting friends in very difficult times. Some people appeared to not want to ask because they believed they would be refused, or force their friend into doing something they didn't feel comfortable with. People were also concerned with maintaining privacy barriers, and not wanting to look weak to others.

Research findings

Implications for Macmillan

Implications for Macmillan

One of the main implications for Macmillan Cancer Support in terms of encouraging and potentially delivering social care for people with cancer and their carers is the need to address the fact that local authorities are reluctant to commission social care services specifically for people with cancer.

Commissioners, providers, people with cancer and their carers agree that the Macmillan brand is extremely well-known and all have considerable respect for the work and support it delivers. However, the brand is clearly inextricably linked with a specific disease. It may be challenging to enter into dialogue with local authority commissioners around the question of better social care provision without a clear message that the organisation is able and willing to support services aimed at a wider group of people.

When thinking about the provision of specialist social care specifically for people with cancer, some local authority commissioners see Macmillan as a service provider, operating in the third sector, who they may well signpost people to. They do not tend to think in terms of working with Macmillan to develop or deliver services which may be provided to eligible individuals via mainstream commissioning.

Some local authority commissioners are unaware of the fact that Macmillan provides pump-primed funding for projects and would not think to link the organisation with the provision of social care in their area. They link Macmillan with health, and the provision of high-quality nursing care. Some question why Macmillan is interested in diversifying into the social care market and are unaware of the range of information, advice and support provided by Macmillan. One PCT commissioner was aware that Macmillan provided welfare rights advice

services and other social care support to people living with cancer.

Some local authority and PCT commissioners and service providers think Macmillan should build partnerships with commissioners and service providers across the public, voluntary and private sectors. They think this would help Macmillan to have a greater impact on the social care agenda at a local level.

‘Macmillan are out there, they have got a big name, but there has been no contact with us.’

Provider of emotional support, North

While there is a question in the minds of some commissioners as to why Macmillan might want to offer financial, emotional and practical support beyond what they perceive to be its core service offering, they do not question the ability of Macmillan to deliver quality across this range of services, were they to work with it.

What providers say Macmillan could do

Local authorities, PCTs and service providers describe a number of ways that Macmillan Cancer Support can help to improve the social care of people living with cancer:

As a training provider

Local authorities, PCTs and service providers accept that Macmillan specialists could provide valuable palliative care training to district nurses, social workers or other staff. However, some local authority commissioners believe that they

are not able to use Macmillan for this purpose as they cannot focus on a specific disease group.

‘I did look at one time at my social work team becoming Macmillan social workers but we’re going end of life and I think Macmillan deals just with cancer rather than all end of life, which is a pity really, because I think the services they offer would be absolutely superb.’

Local authority, North

As a provider of support or guidance for mainstream social care services

One PCT commissioner is investigating the possibility of using Macmillan to provide specialist helpline services for their staff to call for advice about palliative care when required

‘If district nurses have a cancer patient with certain symptoms they are concerned about how to manage, they would know to phone the specialist Macmillan nurse and say, well actually I’ve got a patient here, how do I deal with that? Because we acknowledge that the Macmillan nurses are specialist and they don’t have enough to cover the whole patch, but the majority of cases are provided by the district nurse and its about them accessing that specialist advice and care when required.’

PCT, North

As a consultant or partner in planning

Local authorities and PCT commissioners would welcome closer working with an organisation like Macmillan, which might be able to help shape the way in which mainstream social care services are delivered, to ensure that they meet the needs of as many people as possible, including those with cancer. Some feel that they could learn from Macmillan and develop a greater level of understanding of the needs of people with cancer. However, this is not always necessarily something that they would be willing to pay for.

As an influencer of Government policy

Providers and commissioners feel that Macmillan has a strong, positive reputation which should be used to influence Government thinking as much as possible. They feel that organisations with a broad understanding of specific types of people (for example, those with cancer and their carers) should be invited to contribute to the ongoing debate about social care provision.

‘I think [I would like to see] them lobbying national government to say, this is a base service [provision of advice relevant to people with cancer and their carers] which should be provided by all local authorities as part of their own advice and assistant services. I think that’s the role, they need to influence national government to instruct local government to ensure that happens.’

Local authority, South

As an advocate or lobbyist for the caring profession

Providers of domiciliary care also feel that Macmillan has a role to play as an influencer at different levels. They would welcome the support of Macmillan in encouraging local authorities and PCTs to commission more preventative care, or work to find other ways of getting people into social care programmes at an earlier stage. They also feel that pressure needs to be applied at a national level to raise the status of people working in caring professions. They argue that the role of professional carers is often undervalued and this contributes to difficulties with recruiting into the field.

Conclusions and recommendations

Conclusions

1 Commissioners, providers, people with cancer and their carers agree that people with cancer and their carers need social care support (practical, emotional, and financial) as well as information. However, few appear to gain access to any such information, advice or support from public or voluntary sector services, unless they have critical or substantial social care needs, such as end of life care. Even then, people with cancer and their carers are still not getting access to the social care they need and for which they may be eligible. There is a need to make sure that those who need social care the most are aware of and/or are offered appropriate services.

2 There appears to be limited debate about whether and how to meet the needs of people with low to moderate social care needs. There appears to be limited debate about how to meet the social care needs of people with cancer per se.

3 Many people with cancer and their carers say that they have unmet social care needs. However, there is no evidence to suggest that local authorities and PCTs have a clear understanding of how many people have unmet needs. This may hinder the potential to make a case for greater funding from central government.

4 The main reasons why people with cancer and their carers with low to moderate needs don't have access to the social care support they need are:

On the part of individuals

- low awareness of available services
- lack of understanding around eligibility
- lack of willingness to ask for help.

On the part of local authorities, PCTs and Government

- lack of national policy drivers of debate
- lack of available resources to commission more services
- inflexible provision of existing mainstream services
- lack of adequate signposting to available support
- lack of integration between health and social care
- lack of commitment of some commissioners to expanding services.

5 People with cancer and their carers with low to moderate social care needs, in particular, tend to rely on the family to provide such support. Therefore, there is a case for local authority and PCT commissioners to consider lowering the bar on their eligibility criteria and investing in services to support people with cancer and their carers who have low to moderate social care needs.

6 There is some doubt that local authority commissioners would fund cancer-specific social care support. Local authorities aim to commission based on the needs of individuals, rather than by disease groups. They say however, that the needs of people with cancer should be met through the generic services that they commission.

7 There appear to be relatively few clear opportunities for organisations like Macmillan Cancer Support to secure funding from PCTs and local authority commissioners, to provide social care support for people with low to moderate needs, beyond the individual interest of PCT and local authority decision-makers.

8 There are a number of policy initiatives which are set nationally and implemented locally that have the potential to influence social care provision for people with cancer and their carers:

- **The Case for Change:** gives stakeholders and the public the opportunity to influence the agenda.
- **Joint Strategic Needs Assessment (JSNA) and LAA:** encourage local authorities to develop an effective evidence base of needs. Local Area Agreements (LAA) set out a local strategic partnership's (LSP's) priorities and how they propose to meet them (usually based on the JSNAs). However, there is currently no guarantee that the low to moderate social care needs of people with cancer will be considered in JSNAs, or that LAAs will be flexible enough to implement the necessary policies.
- **Cancer Reform Strategy:** in particular, its increased emphasis on survivorship. However, the strategy is too new to assess its potential impact on commissioning decisions.
- **Our NHS, Our Future:** although not directly related to social care provision, it has encouraged PCTs to think differently about some aspects which may affect the future commission and provision of social care services which fall within the PCT's responsibility. For example, emotional support, respite care, and aspects of occupational therapy services.
- **Individual budgets:** the introduction of individual budgets is thought to give people who have access to them greater control over the care they receive, but it is assumed that only people with critical and substantial social care needs will qualify for them.
- **Self-care and prevention:** a greater focus on prevention and self-care may have the potential to prevent people with low to moderate social care needs from needing critical and substantial social care services in the future. However, there is no evidence as yet that funding low to moderate social care

support for people with cancer will prevent them from doing so.

- **Joint commissioning (especially where budgets are pooled):** is believed to be leading to more integrated provision. But without more resources to meet the low to moderate needs of people, the emphasis is likely to remain on those with critical and substantial needs.
- **NICE Guidance on Cancer Services (Improving supportive and palliative care for adults with cancer):** is also encouraging PCTs to consider a wider range of provision (including psychological support, information provision, and end of life care).

9 World Class Commissioning and regulatory assessments (by the Healthcare Commission and CSCI and soon the Care Quality Commission) looking at quality of care and effective user of resources, are both helping to ensure that the quality of commissioning improves and that quality criteria are built into commissioning within the health sector. Again, this may affect the future commission and provision of social care services which fall within PCT responsibility, for example, emotional support, respite care, and aspects of occupational therapy services. However, both PCT and local authority commissioners would welcome more guidance on how to build quality criteria into service level agreements and contracts. Again, neither World Class Commissioning nor regulatory assessments will ensure that the low to moderate social care needs of people with cancer are considered.

10 Higher performing PCTs and local authorities where there is a clear focus on preventing future critical and substantial needs may be more open to discussions about services for people with moderate needs. In the absence of any evidence of effectiveness, such activities would be most likely to be funded as projects or programmes.

11 Local authorities are involving service users more in planning social care provision at a broad level. For example, Local Involvement Networks and long-term user groups contribute to the process of understanding unmet needs. The further involvement of service users in the commissioning process would appear to be likely, and may encourage greater continuity between health and social services.

12 Any new initiatives or services which Macmillan may wish to encourage will need to be supported by evidence of their effectiveness. In the absence of such evidence, such activities are most likely to be funded under the pump-priming model. However, some commissioners are reluctant to use pump-priming. Negative experiences implementing schemes in the past have led to a sense of caution. This is likely to make implementation all the more challenging in the future.

13 Commissioners have little concern about commissioning support from voluntary sector organisations, but expect voluntary sector organisations to be clear about:

- the level of service they will provide
- the quality of service they will provide
- the outcome the service will achieve (ie key performance indicators and outcome measures that will help them show how they are achieving their priorities).

Additional guidance from central government on indicators and measures to consider would be welcomed.

14 There is some interest in commissioning social care support to meet low to moderate needs from a volunteer network (as a cost effective approach that would minimise impact on available resources), including such support for people with cancer. However, to commission a volunteer-based service commissioners want reassurance about:

- sustainability
- continuity of carer
- vetting and training of the volunteer
- performance development of the volunteer.

15 The concept of improving delivery of social care services by increasing social capital and encouraging greater community-based support does not appear to be very common at the current time. We have seen no evidence of formal schemes being implemented to encourage increased social capital. However, support provided by the voluntary sector through support groups is clearly available and being used.

Recommendations

If people with cancer and their carers are to receive the social care they need, there are a number of issues to address.

Accessing existing provision and encouraging demand

1 Government should increase knowledge and understanding among the public of the social care assessment process and what services are available.

2 Government should encourage commissioners and providers to raise awareness of locally available support through a range of information sources, including staff.

Improving and influencing supply

3 Government should increase social care funding to help meet unmet needs.

4 Government should encourage local commissioners to assess the needs of people with cancer and their carers for social care support as part of the Joint Strategic Needs Assessment.

5 PCTs and local authorities should continue to develop joint commissioning strategies and agree the use of pooled budgets, in order to meet the needs of specific groups better, including people with cancer and their carers.

Innovation and investing in services

6 Service users should be involved as equal partners in the design, commissioning and delivery of services.

7 Government should provide commissioners with guidance on managing services aimed at preventing people's needs from escalating and producing long-term cost savings.

Macmillan should

8 Explain the needs of people with cancer and their carers and why they have specific needs (for example, due to the frequency and duration of treatment) to stimulate more informed debate among commissioners in local authorities and PCTs and persuade them to commission services that meet their needs.

9 Provide information, advice and support to generic service providers so their services can better meet the needs of people with cancer.

10 Work with PCT and local authority decision-makers who express an interest in invest-to-save programmes or prevention programmes in their commissioning strategies.

11 Use evidence from projects that support people with cancer who have low to moderate needs to demonstrate effectiveness at preventing future critical and substantial needs and improved outcomes.

12 Explore potential new services which can be delivered by volunteers.

13 Explore alternative ways of funding services in addition to the current pump-priming model.

14 Raise awareness of the information, advice and support currently available to people with cancer and their carers.

15 Along with health and social care professionals, encourage people with cancer and their carers to ask for help and support when eligible.

Further informing the debate

16 Government and Macmillan should encourage health and social care regulators to look at the quality of social care support (information, emotional and practical support and financial advice) provided to people with cancer.

17 Government should provide guidance to local authority and PCT commissioners on how best to measure the quality of social care services.

18 The extent of unmet social care needs is not fully understood. Macmillan should consider measuring the national scale of unmet social care needs quantitatively, among people with cancer and their carers, to help influence the Government's agenda.

Glossary and appendices

Glossary

Some of the key terminology used in this report is defined as follows:

Fair Access to Care Services (FACS)

Fair Access to Care Services (FACS) provides guidance to councils with social services responsibilities using a framework for determining eligibility for adult social care. It sets out four levels of eligibility as follows:

Critical – when

- life is, or will be, threatened; and/or
- significant health problems have developed or will develop; and/or
- there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- serious abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- vital involvement in work, education or learning cannot or will not be sustained; and/or
- vital social support systems and relationships cannot or will not be sustained; and/or
- vital family and other social roles and responsibilities cannot or will not be undertaken.

Substantial – when

- there is, or will be, only partial choice and control over the immediate environment; and/or
- abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or

- involvement in many aspects of work, education or learning cannot or will not be sustained; and/or
- the majority of social support systems and relationships cannot or will not be sustained; and/or
- the majority of family and other social roles and responsibilities cannot or will not be undertaken.

Moderate – when

- There is, or will be, an inability to carry out several personal care or domestic routines; and/or
- involvement in several aspects of work, education or learning cannot or will not be sustained; and/or
- several social support systems and relationships cannot or will not be sustained; and/or
- several family and other social roles and responsibilities cannot or will not be undertaken.

Low – when

- There is, or will be, an inability to carry out one or two personal care or domestic routines; and/or
- involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
- one or two social support systems and relationships cannot or will not be sustained; and/or
- one or two family and other social roles and responsibilities cannot or will not be undertaken.

Direct Payments

Direct payments are defined by the Government as follows:

Direct payments are cash payments made to individuals who have been assessed as needing services, in lieu of social service provisions.

Who can receive a direct payment?

They can be made to disabled people aged 16 or over, to people with parental responsibility for disabled children, and to carers aged 16 or over in respect of carer services. A person must be able to consent to have a direct payment and have the capacity to manage one, although they can have assistance to manage their payment on a day-to-day basis.

Giving people choice and control over their own care

The aim of a direct payment is to give more flexibility in how services are provided. By giving individuals money in lieu of social care services, people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered.

The duty to provide direct payments

The law has been changed so that it is a duty to make direct payments. This means that councils must make a direct payment to eligible individuals who are able to provide consent. Direct payments should be discussed as a first option at each assessment and each review.

The latest community care statistics indicate that the changes are having a positive effect. From 1 April 2005 to 31 March 2006, 37,000 adults received direct payments during the year, a rise of over 50% from 24,000 in 2004-05. This figure does not include children or carers.

Individual Budgets

Individual budgets are defined by the Government as follows:

Individual Budgets are designed to bring about independence and choice for people receiving care or support. It gives them a full understanding of the finance that is available, in order to empower them to take control and make decisions about the care that they receive.

The Individual Budgets pilot programme

The Individual Budgets pilot programme was a cross-government initiative led by the Department of Health working closely with the Department for Work and Pensions, and Communities and Local Government. The pilot was conducted over two years 2006-2007 involving 13 local authorities. The full independent evaluation reports were published on 21 October 2008.

Framework agreement

Agreement between one or more contracting authorities and one or more economic operators, the purpose of which is to establish the terms governing contracts to be awarded during a given period, in particular with regard to price and, where appropriate, the quantity envisaged.

Call-off contract

An enabling agreement with one or more suppliers for a defined range of works, goods or services, covering terms and conditions which users 'call off' to meet their requirements.

Fixed price contract

A contract in which a customer and a contractor agree on a price that will not change no matter how much the project actually costs the contractor.

Appendix A – discussion guide for carers

Research objective Understand how people who are living with cancer’s needs for, access to and experience of social care affects those who are caring from them. Understand carer’s own needs for social care, and experiences of receiving this.

Total time 1.5 hours

1. Introduction (10 mins)

Objective To ensure the respondent feels at ease and understands what will happen for the next 90 mins. Gain informed consent for research.

- Thank respondent for their participation
- Introduce self and research background
- Explain purpose of research: explain wanting to understand their experience of caring for someone with cancer in the context of what social care was needed and what was available. Research is conducted on behalf of Macmillan Cancer Support to inform their strategy on social care. There is a Government consultation process that Macmillan wants to feed into, and use the research to inform their recommendations
- Terminology used is ‘carer’ – check people are comfortable with this expression, and use alternative if needed. Check terminology for person affected by cancer (PAC) and use their language throughout
- Please only speak on behalf of yourself, we don’t want to know about the experiences of other people who care for people with cancer, but about your own experiences
- We want to know about your needs as a carer, not just about the needs of the person with cancer
- Your input is critical, no right or wrong answers, we want your honest opinions, ok to disagree but please do sensitively and don’t talk over each other
- Reassure on confidentiality, MRS Code of Conduct, explain audio recording and transcription of responses etc – all used within the remit of this research only
- Go through informed consent process, answer any questions raised, once respondents are comfortable get them to sign and continue
- Respondent introductions; name, age, family, job (past/current), hobbies (past/current)

2. Cancer journey overview (15 mins)

Objective To gain background on the person they care for’s cancer journey, and the care they provide to ground more specific detail gathered later

I would like to understand briefly from each of you a little bit about your experience of the ‘cancer journey’ so far. I appreciate this could be answered in hours, but I would like 5 mins max from each person, just so we get a little bit of an idea of where everyone is at, before we start talking in more depth. What I would like to know is (put up list for people to refer to if needed)

Go around each person individually

- Relationship to the person they are caring for
- What kind of cancer they have
- When it was diagnosed
- What stage of cancer they have now
- Treatment(s) they have gone through
- When/if they stopped working
- Whether they have remained living at home throughout
- What things they can and can't do now (either effect of cancer or treatment)

Go around each person individually.

- What kind of care they are providing
- How many hours a week they are providing care
- Whether any other family members or close friends provide care, how much/frequency
- Whether they work or not, and if this has changed since starting caring
- Effects on other aspects of their life (friends, hobbies, health, time to yourself, finances etc)
- If you were going to give the cancer journey steps/phases, what would these be? (Elicit very briefly)
- If necessary show respondents the Macmillan model of the cancer journey as reference:
 - Something's wrong
 - Going for tests
 - Finding out what is wrong
 - Going through treatment
 - Going home/follow up treatment
 - What if the cancer comes back
 - Living with cancer
 - Cancer survival
 - Dying

Thanks for telling me about your journey.

For the rest of the discussion we won't speak in turns, everyone can join in at any time.

3. Social care needs and experience (20 mins)

Objective To understand the social care needs of respondents. What kind of help and support do they need? To develop an understanding of social care services that are available to them and any barriers encountered to accessing them

Thinking about your experiences since your PAC's diagnosis, let's talk about the main challenges and difficulties that you/they have had to deal with.

- Generate a spontaneous list of issues and challenges
- Encourage respondents to think about all the different stages in their/their PAC's journey

What kind of help or support (other than your PAC's treatment) have you/your PAC needed, need or expect to need in the future? This does not necessarily mean help and support that you/your PAC have received

Generate a spontaneous list of types of help or specific services which would be useful and make life easier. Explore the rationale for these choices.

- Introduce pre-prepared list of different 'types' of care:
 - Practical help (eg help with shopping, dressing, cleaning, laundry etc)
 - Occupational therapy
 - Emotional support
 - Support for people who provide care for someone with cancer (friends, family etc)
 - Information and advice
 - Financial advice and support
- Use this list as a starting point to develop a full list including any spontaneous types already mentioned. Explain that we will be discussing their needs and experiences of these different types of care.

- In addition explain that the care we will be discussing will be care provided by professionals or volunteers, as opposed to family members or friends. For the purposes of this discussion, we will refer to these types of care as 'social care'.

We are going to go through each type of care in turn, but I have a few general questions about this general type of care to ask first...

- Have you heard of the term 'social care' before? Where?
- What does 'social care' mean to you? Where did you get this information?
- Are you aware of any 'social care' which is available to you/your PAC in your local area?
 - Brief description
 - Are they specifically for people with cancer?
 - To what extent is this important to you? How come?
- (if aware, or used any) How did you/your loved one find out about what social care is available?
 - Where did you find this information?
 - How easy or difficult was it to find out about this?
 - How could this information be improved?
- What is your understanding of how you qualify to receive social care where you live?
 - Do you have a sense of who takes priority?
 - How fair, or not, do you believe this is?
 - What care does your loved one qualify for? How was this assessed?
- Have you paid for any private social care? Or had to contribute to the costs of the social care being provided to you?
 - If so, please describe the circumstances.
 - What was the financial impact of this?

4. Social care: needs vs reality (25 mins)

Objective To explore social care needs and social care provision throughout the cancer journey, with a focus on the carer's needs in relation to the person they are caring for

Next we are going to discuss your needs and experiences of social care in a little more detail. Note to probe on their needs for social care, as well as their PAC's.

Go through each type of social care (keeping in mind the different stages of the cancer 'journey' and ask:

What specifically are/were your/your PAC's needs in this area?

- Explore both practical/rational and emotional needs
- How do these vary depending on the circumstances (ie where they are along the cancer journey)?
- Probe for any needs for services/types of social care which were consistent across the cancer journey, and which varied most
- Discuss when overall social care needs are greatest/lowest by phase
- What social care services are/were available to you/your PAC?
- Who provides them?
- Where can you access them?
- How are they funded?
- Which have you used?

If there is a gap between your needs and services available, what is the result of this? What do you do about it?

What are your impressions of the care of this type that is available in your local area? Probe on strengths and weaknesses in terms of...

- The scope and breadth of what is available
- The quality of the services provided

How could the provision of care of this type be improved?

- Probe for specific examples and suggestions

5. Impressions of new ideas and propositions (15 mins)

Objective To understand opinions about personal budgets and to test out proposed Macmillan solutions

Personal budgets

The Government announced a six month consultation on reforming the adult social care system in England in May this year. There are a few questions they want to address in the consultation and we would like your opinions on. Please remember at this point its ok to disagree, but please don't talk over each other. There is a focus in ensuring solutions promote independence, choice and control, so I will be asking you about these aspects.

One measure the Government is planning to introduce is personal budgets. These is how they work (*read and display card*) :

After agreeing with social care services about what support and care an individual like your loved one is entitled to, they are given control of the corresponding sum of money. They can either receive a direct payment, ask social services to manage their budget, use a broker, or a mixture.

- Initial reactions
- *Check for understanding and clarity of solution*
- Likes, positives
- Dislikes, concerns
- How relevant is this to someone like your loved one? How far would this go to meeting their needs? Who would this help most? Can you foresee any difficulties with this for you/them? (Probe on changing needs across time/flexibility of persona budget)

- How do you think they/you would manage their personal budget (ie themselves, social services, broker, mix)? How come? Probe for if carer would manage it or loved one, or combination, and reasons for this
- How would you want to choose what social care they/you used? Would you want to do this? What resources or tools would they/you need to do this? How could these be provided?
- How would you expect their/your needs to be assessed for social care? Who do you think should do this? How often would you want their/your needs to be re-assessed?
- To what extent do personal budgets provide:
 - Independence
 - Choice
 - Control
- Suggested improvements
- How could this best be implemented to achieve a successful outcome?

Potential propositions

We have a few ideas about social care for people living with cancer that we would like to get your views on. Remember, these are just ideas, and we would like your honest opinion of them. Expose statement for each solution and read aloud. Rotate solutions. Repeat questions for each statement.

- Initial reactions
- *Check for understanding and clarity of solution*
- Likes, positives
- Dislikes, concerns
- How relevant is this to someone like your loved one and yourself? How far would this go to meeting their/your needs? Who would this help most?
- To what extent does this provide:
 - Independence
 - Choice
 - Control
- Suggested improvements

After showing all solutions:

- Let's rank these from best to worst.
- Now let's discuss the reasons for the rankings.
- How could these solutions be improved?
- Is there anything missing from this set of solutions?
- What else could the Government/the voluntary sector do to support people who care for people with cancer?
- What else could the Government/the voluntary sector do to support people with cancer?

6. Summary (5 mins)

Objective To allow respondent to summarise key thoughts, and add any extra suggestions

- Is there anything you have mentioned so far that you would like to emphasize?
- If you could sum up your thoughts in one sentence about what we have been talking about today, what would it be?
- What is the one thing that is the most challenging thing about caring for someone with cancer? How could this be addressed?
- Is there any advice you would like to give to Macmillan about providing social care for people with cancer and their carers?
- Or is there anything you think they don't know about people living with cancer and their carers?
- Is there anything else you would like to add?

Thank and close

Appendix B – discussion guide for commissioners and local authorities

Research objective Explore barriers and opportunities to commissioning and providing social care services for people with cancer and their carers, and consider solutions.

Total time 1 hours (40 mins by phone)

1. Introduction (5 mins)

Objective To ensure the respondent feels at ease and understands what will happen for the next 60 mins. Gain informed consent for research.

- Thank respondent for their participation
- Introduce self and research background
- Explain purpose of research: explain wanting to understand their experience of providing social care services to people with cancer. Research is conducted on behalf of Macmillan Cancer Support to inform their strategy on social care. This is both for Macmillan social care service development and to feed into their policy recommendations to the Government.
- Their input is critical, no right or wrong answers, we want their honest opinions
- Reassure on confidentiality, MRS Code of Conduct, explain audio recording and transcription of responses etc – all used within the remit of this research only

2. Background (5-10 mins)

Objective To establish the role and responsibilities of the respondent and how their organisation works

- Could you please describe your role within the organisation?
 - Length of time in role
 - Key areas of responsibility
- Could you give me some background into your organisation
 - Size, number of employees
 - Location(s)
 - Social Care/Cancer Service(s) you provide and/or commission
 - Type of people who are end users of the services you commission and/or provide
- Are you aware of the CRS? Could you explain what this means to you?
- How many people with cancer are there approximately in your local authority?

3. Social care commissioning: general (20 mins)

Objective To understand how social commissioning works locally, and the effect on people with cancer and their carers. To understand the impact of current Government policy on people with cancer and their carers.

What is the process to commission social care/cancer services?

- How do you define social care services (note and explore any services not mentioned, eg domiciliary care, occupational therapy, financial support, talking therapies/emotional support, information support, respite care, etc)
 - Note: we are particularly interested in low to moderate needs here**
- How do you assess need for social care services (eg as part of the Joint Strategic Needs Assessment)?
 - Do you differentiate between low to moderate, and substantial and critical need?
 - Do you map who needs services? How many have a need? Where they are? Who are they?
- To what extent do LAA (Local Area Agreements) take into account the social care needs of people affected by cancer? If not adequately addressed, why not? What needs to change to ensure their ideas are included?
- How do you prioritise between competing needs for social care services (probe: what kinds of qualifying criteria are set? Who gets a service)?
 - Do you differentiate between low to moderate, and substantial and critical need?
 - Which needs/services take priority and why, eg if your budget was cut, what services would get cut first and why? Explore the degree to which low to moderate needs are considered a priority. How is this affected by current Government policy?
- What might be the benefits of commissioning more services for people with low to moderate needs?
 - Look out for mentions of relieving pressure on other services (eg GPs)**
- How do you map/develop the care economy locally (eg statutory, voluntary, private sector providers/quality of care provided)?
- How do you develop the social care strategy (what is the process? What model? Who is involved (eg PCT and local authority))?
- How do you go about commissioning a provider (ie what does the contract/service level agreement cover, eg price, volume, quality criteria)? How does current Government policy impact on this? What changes would you like to see?
 - What services do you currently commission to meet low to moderate needs? And substantial and critical?
 - Who do you actually commission across the statutory, voluntary and private sectors?
 - What do you think you currently do well and less well locally, including meeting low to moderate need, and substantial and critical need?
- How do you ensure performance improvement within the services you commission and why? (eg KPI's built into contracts)
- How, if at all, do you involve service users and carers in the design, delivery, and performance assessment of services commissioned?

Do you specifically address the needs of people with cancer as part of your social care planning and commissioning (mapping need, setting priorities, mapping/developing the care economy, setting strategy, commissioning services, performance appraisal, user involvement, etc)?

Who do you commission to provide such support (specialist and mainstream)?

- What are their strengths and weaknesses and why?

Have you assessed the accessibility, appropriateness, and quality of social care specifically for people living with cancer and their carers and why?

I would like to talk through a couple of scenarios relating to the issues we have been discussing... Throughout, probe on how current Government policy affects these individuals

- I am Jane. I'm 45 and I've got my own interior design business. I've just been diagnosed with breast cancer
- I am John. I'm 46 and I'm a self-employed builder. I've just been diagnosed with bowel cancer
 - What can you do for me?
 - Will I/how will I gain access to your support?
 - What priority will I take?
 - How are you going to assess my needs (single assessment)?
 - What do you think you are going to do well and less well for me?
 - How many social care professionals am I going to encounter?
- Okay, I've just had surgery and am having to go for chemotherapy/radio therapy five times a week at a hospital 15 miles away. I'm not currently earning anything as a self-employed person:
 - I care for my frail elderly mother and just can't do this right now (any respite care for me)?
 - I'm feeling increasingly depressed, but feel I just have to soldier on for my family and friends (anyone I can talk to)?
 - I live alone and just don't have the energy to cook or clean up the house for myself at the moment (any help with cooking and cleaning available)?
 - I'm finding it hard to make ends meet as I'm not earning and am concerned about meeting my rent/mortgage payments (any financial advice and support available)?
- I'm aware my girlfriend is getting overwhelmed looking after me (any respite support for her)?
- I'm having difficulty post-surgery, getting in and out of the bath/getting up and down stairs (any home adaptations for me)?
- (if time permits) What if I don't have any one to drive me to the hospital (any help available with travel)?
- (if time permits) The parking is £6 per day (any help with parking fees)?
- Okay, I've completed treatment, but I'm still having difficulty getting around/lifting things – any occupational therapy:
 - What care is available for me?
 - What if I was over 65?
 - What if I was under 16, what support for me and my parents?
 - What if I was already receiving social care, eg as a frail elderly person?
 - What if I was long-term unemployed and dependent on state benefits?
 - What if I was working, but my employer was hassling me to get back to work full-time before I felt ready to do so (any advocacy support)?
 - What if I am caring for someone with cancer?
 - What if I was in the end-stages of cancer?
 - What if my partner/child dies as a result of cancer (any bereavement support)?

So, to sum up what gaps do you think currently exist in your service provision and why?

- Have you formally assessed the gaps?
- What were they and why? Probe for impact of current Government policy
- What do you intend to do to support people who are in need but not eligible for funding?

Have you considered the cost/affordability of providing such services to people living with cancer and their carers and why?

- Low to moderate need?
- Substantial and critical need?

How do you work with other local commissioners/strategic partners to make sure you understand the social care needs of people living with cancer and their carers?

- To what extent are you priorities and plans aligned?
- What could you do to improve joint working locally?
- How would this benefit people living with cancer and why?

What are the links between social services and healthcare like? What links are set at DH level? What is agreed locally? How could these links be improved? What role does current Government policy play in fostering these links?

What role do you see for partner organisations in providing services for people who are

- eligible for social care services?
- not eligible for social care services?

What role do volunteers have in delivering social care?

- Is there scope for this role to increase?
- Advantages and disadvantages of this?

Who (if anyone) has to contribute to the costs of social care provided for them and why?

- Do people living with cancer and their carers have to contribute financially in some circumstances?

4. Future directions: opportunities and barriers for policy and service development (10 mins)

Objective To understand the barriers to commissioning and providing social care, and ways to overcome/capitalise on these, with reference to future potential Government policy direction

- Based on what we have been discussing, what are the key issues for people with cancer and their carers you believe Government policy needs to address? Prioritise and rank top issues (write onto cards)
- Where are the most promising opportunities for change for social care for people with cancer and their carers? Discuss
- What are the areas that are the most difficult to address? What are the barriers to change in your area?
- Draw up list of policy suggestions and identify priorities

5. Solutions (15 mins)

Objective To understand reactions to consultation document and response to Macmillan's suggested solutions.

- How do you think social care services could be made more relevant, accessible, and effective for people living with cancer (using briefing note to outline Macmillan Cancer Support view on specific needs of people living with cancer and their carers?)
- What do you think about the Government consultation's main questions in this context (using briefing note):
 - What do you think independence, choice and control means?
- What needs to be put in place to ensure it exists?
 - Do we need different systems for people with different needs (ie people with cancer and their carers) or the same system for all?

- To what extent should we have local flexibility or a national standard?
- As you know, one measure the Government is planning to introduce is personal budgets for social care. What are your opinions on these?
 - How do you imagine personal budgets might affect your organisation?
 - What do you think would work well? Opportunities?
 - Can you foresee any difficulties with this for your organisation?
 - How will you ensure there are a range of services available for people with personal budgets to choose from?
 - Do you envisage providing or commissioning services that offer practical help, eg shopping, gardening?
 - Do you intend to provide advocacy services to help people navigate personal budgets and why?
 - What funding streams should be included in personal budgets in future?

Solutions to test

- What level of need do you think there is for each of the following types of social care services for people with cancer locally?

Expose statement for each solution and read aloud (See separate document). Rotate solutions. Repeat questions for each statement.

- To what extent are you currently assessing/meeting such needs among people with cancer locally?
- Who, if anyone, is providing such services currently?
- How, if at all, are you commissioning such services?
- If not currently in place, what evidence would you need to support a decision to commissioning such services (eg return on investment/ROI data)?

- What expectations would you have of a voluntary/private sector provider of any such services, were you to commission them and why?
- How do you feel about a charity such as Macmillan developing services which could be incorporated into your long-term strategy?
- In what ways could this benefit their planning and delivery?
- What are the main barriers to this approach?
- Is there anything else missing from this set of solutions?
- What else could the Government/the voluntary sector do to improve the social care commissioned and provided to people with cancer and their carers? What policy/ies could be introduced that would make the most difference to this situation? Probe for reasons.

6. Summary (5 mins)

Objective To allow respondent to summarise key thoughts, and add any extra suggestions.

- If you could sum up your thoughts in one sentence about what we have been talking about today, what would it be?
- Is there any advice you would like to give to Macmillan about commissioning and providing social care for people with cancer?
- Is there anything else you would like to add or emphasize?

Thank and close

Appendix C – discussion guide for people living with cancer

Research objective Explore barriers and opportunities to providing social care services for people with cancer and their carers, and consider solutions.

Total time 1 hours (40 mins on phone)

1. Introduction (5 mins)

Objective To ensure the respondent feels at ease and understands what will happen for the next 60 mins. Gain informed consent for research.

- Thank respondent for their participation
 - Introduce self and research background
 - Explain purpose of research: explain wanting to understand their experience of providing social care services to people with cancer. Research is conducted on behalf of Macmillan Cancer Support to inform their strategy on social care.
 - Their input is critical, no right or wrong answers, we want their honest opinions
 - Reassure on confidentiality, MRS Code of Conduct, explain audio recording and transcription of responses etc – all used within the remit of this research only
- Could you give me some background into your organisation
 - Size, number of employees
 - Location(s)
 - Social Care/Cancer Service(s) you provide
 - Type of people who are end users of the services you provide
 - How would you describe the social care needs of people living with cancer?
 - Probe on the difference between low to moderate, and severe and enduring needs
 - Probe on difference between these and the needs of others, such as frail older people, disabled people, people with other long term conditions (eg HIV, arthritis)
 - What is your understanding of the 'cancer journey' as defined by Macmillan?
 - How does this understanding impact your perspective on the social care needs of people with cancer?
 - What impact do you think stage of the cancer journey can have on social care needs (diagnosis, treatment, aftercare, end of life) and why?
 - What do you consider the main sources of information about the social care needs of people living with cancer and their carers?

2. Background (5-10 mins)

Objective To establish the role and responsibilities of the respondent and how their organisation works.

- Could you please describe your role within the organisation?
 - Length of time in role
 - Key areas of responsibility

3. Social care (20 mins)

Objective To understand how providers are affected by social care commissioning, and the impact this has on the care that they provide.

- How does social care commissioning work locally?
 - What kinds of social care services are commissioned? (note and explore any services not mentioned, eg domiciliary care, occupational therapy, financial support, talking therapies/emotional support, information support, respite care, etc)
 - Are you aware of how social care needs are assessed locally (eg as part of the Joint Strategic Needs Assessment)?
- Probe on the difference between low to moderate, and severe and enduring needs
- Are service needs mapped in any way by local commissioners? How does this work
 - Are you aware of how local commissioning teams prioritise between competing needs for social care services (probe: what kinds of qualifying criteria are set? Who gets a service)?
- Probe on the difference between low to moderate, and severe and enduring needs
- Which needs/services take priority and why, eg if budgets are cut, which types of services tend to get cut first? Do you know why?
 - How do you go about getting commissioned to provide the service(s) that you do (ie what does the contract/ service level agreement cover, eg price, volume, quality criteria)?
- Do you provide services specifically for people with cancer? If so why?
- If not specifically providing services to people with cancer, to what extent do the services you provide meet the needs of people with cancer? How would they need to change to do so more effectively?
- What services do you currently provide to meet low to moderate need? And severe and enduring?
- Are other providers commissioned locally across the statutory, voluntary and private sectors to deliver similar care?
- What do you think is currently done well and less well locally, including meeting low to moderate need, and severe and enduring need?
 - How is your performance assessed by the local commissioning teams?
- What is the impact of such assessments? Explore positive impact on the level of service provided
 - To what extent does the local commissioning team involve you in the design, delivery, and performance assessment of services commissioned?
- Does the local commissioning team specifically address the needs of people with cancer as part of its social care planning and commissioning (mapping need, setting priorities, mapping / developing the care economy, setting strategy, commissioning services, performance appraisal, user involvement, etc)?
- How would you describe the level of service currently available locally to people with cancer?

Use next section if time permits to explore perceptions of social care services in general.

I would like to talk through a couple of scenarios relating to the issues we have been discussing...

- I am Jane. I'm 45 and I've got my own interior design business. I've just been diagnosed with breast cancer
- I am John. I'm 46 and I'm a self-employed builder. I've just been diagnosed with bowel cancer
 - What can be done for me locally?
 - Will I/how will I gain access to support?

- What priority will I take?
 - How will my needs be assessed (single assessment)?
 - What types of things will be readily available and what will be difficult to find?
 - How will your organisation help me?
 - How many social care professionals am I going to encounter?
- Okay, I've just had surgery and am having to go for chemotherapy/radio therapy five times a week at a hospital 15 miles away. I'm not currently earning anything as a self-employed person:
 - What if I don't have any one to drive me to the hospital (any help available with travel)?
 - The parking is £6 per day (any help with parking fees)?
 - I care for my frail elderly mother and just can't do this right now (any respite care for me)?
 - I'm feeling increasingly depressed, but feel I just have to soldier on for my family and friends (anyone I can talk to)?
 - I live alone and just don't have the energy to cook or clean up the house for myself at the moment (any help with cooking and cleaning available)?
 - I'm finding it hard to make ends meet as I'm not earning and am concerned about meeting my rent/mortgage payments (any financial advice and support available)?
 - I'm aware my girlfriend is getting overwhelmed looking after me (any respite support for her)?
 - I'm having difficulty post-surgery, getting in and out of the bath/getting up and down stairs (any home adaptations for me)?
 - Okay, I've completed treatment, but I'm still having difficulty getting around/lifting things – any occupational therapy:
 - What care is available for me?
 - What if I was over 65?
 - What if I was under 16, what support for me and my parents?
 - What if I was already receiving social care, eg as a frail elderly person?
 - What if I was long-term unemployed and dependent on state benefits?
 - What if I was working, but my employer was hassling me to get back to work full-time before I felt ready to do so (any advocacy support)?
 - What if I am caring for someone with cancer?
 - What if I was in the end-stages of cancer?
 - What if my partner/child dies as a result of cancer (any bereavement support)?
 - So, to sum up what gaps do you think currently exist and why?
 - Have you formally assessed the gaps?
 - What were they and why?
 - How does your organisation fit into the local social care 'landscape' for people with cancer?
 - In your view, what are the links between social services and healthcare like? How could these be improved?
 - In your view, to what extent do LAA (local area agreements) take into account the social care needs of people affected by cancer? If not adequately addressed, why not? What needs to change to ensure their ideas are included?
 - What is your relationship like with the Local Authority and PCT?
 - Probe for involvement, influence and frequency and method of communication.
 - What works well, what doesn't work well? How come?

- To what extent are your priorities and plans aligned?
- What could you do to improve your working environment locally? How would this benefit people living with cancer and why?
- How is your organisation linked into the healthcare of the people you provide with social care? How could these links be improved?
- Who (if anyone) has to contribute to the costs of social care provided for them by your organisation and why?
 - Do people living with cancer and their carers have to contribute financially in some circumstances?
- What plans does your organisation have to improve social care provision? How will existing plans improve social care support for people living with cancer and their carers?
- Have you engaged with people with cancer and their carers to inform upcoming organisational plans/changes? Probe for reasons and outcome.

4. Opportunities and barriers (10 mins)

Objective To understand the barriers and opportunities to commissioning and providing social care, and ways to overcome/capitalise on these.

What opportunities do you think there are locally to commissioning social care support for people living with cancer and their carers and why?

- Probe for different types of social care: domiciliary care, respite care, occupational therapy, talking therapies, etc?
 - Low to moderate need?
 - Severe and enduring need?
- Explore impact of stage of cancer journey?
- Explore impact of type of cancer?
- What other factors would have an effect?

What do you think should be done to capitalise on such opportunities and why?

What barriers do you think there are locally to commissioning social care support for people living with cancer and their carers and why?

- Probe for different types of social care: domiciliary care, respite care, occupational therapy, talking therapies, etc?
 - Low to moderate need?
 - Severe and enduring need?
- What impact stage off cancer journey?
- What impact type of cancer?
- What other factors to take account?

What do you think should be done to tackle such barriers and why?

Draw up list of issues and identify priorities (if time permits)?

5. Solutions (15 mins)

Objective To understand reactions to consultation document and response to Macmillan's suggested solutions.

- How do you think social care services could be made more relevant, accessible, and effective for people living with cancer (using briefing note to outline Macmillan Cancer Support view on specific needs of people living with cancer and their carers)?
- What do they think about the Government consultation's main questions in this context (using briefing note):
 - What should the balance be between government, individual and family responsibilities?
 - Do we need different systems for people with different needs (ie people with cancer and their carers) or the same system for all?
 - To what extent should we have local flexibility or a national standard?
 - To what extent should resources be targeted at those least able to pay? Should people be expected to save to fund social care in later life?

- As you may know, one measure the Government is planning to introduce is personal budgets for social care. What are your opinions on these?
 - How do you imagine personal budgets might affect your organisation?
 - What do you think would work well? Opportunities?
 - Can you foresee any difficulties with this for your organisation?

Solutions to test

- What level of need do you think there is for each of the following types of social care services for people with cancer locally?

Expose statement for each solution and read aloud. Rotate solutions. Repeat questions for each statement.

- To what extent are such needs among people with cancer being provided for locally?
- Who, if anyone, is providing such services currently?
- To what extent would you consider providing such services as viable and workable? What would need to change to make it more viable?
- Is there anything else missing from this set of solutions?
- What else could the Government/the voluntary sector do to improve the social care commissioned and provided to people with cancer and their carers?

6. Summary (5 mins)

Objective To allow respondent to summarise key thoughts, and add any extra suggestions.

- If you could sum up your thoughts in one sentence about what we have been talking about today, what would it be?
- Is there any advice you would like to give to Macmillan about commissioning and providing social care for people with cancer?
- Is there anything else you would like to add or emphasize?

Thank and close

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support, and push for better cancer care. One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

For further copies visit
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