

Older people with learning disabilities affected by cancer: Involvement and engagement work to inform a research agenda

Final Report

September 2007



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Older people with learning disabilities affected by cancer: Involvement and engagement work to inform a research agenda

Lisa McCann

Dr Liz Forbat (Principal Investigator)

Funded by COPA (Centre for the Older Person's Agenda).

September 2007



**UNIVERSITY OF
STIRLING**

DEPARTMENT OF
NURSING AND MIDWIFERY

ACKNOWLEDGEMENTS

The Cancer Care Research Centre team would like to thank the people who contributed to this piece of advisory work for speaking about their experiences of cancer. Their willingness to share their experiences with the research team means that future research projects with adults with learning disabilities affected by cancer will be informed by what they felt was most important.

We would also like to extend a thank you to the health care professionals, advocacy, support and charitable organisations we contacted to ask for assistance in distributing information about the project to service users. Without these networks, it would have been impossible to speak to people with learning disabilities affected by cancer for this piece of work.

Finally, thanks to Heather Wilkinson from the Centre for the Older Person's Agenda for her support of this project



Centre for the
Older Person's Agenda



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Table of Contents

CONTENTS

SECTION 1	7
1.1 INTRODUCTION	7
1.2 BACKGROUND	8
 SECTION 2	 16
2.1 Methods	16
2.2 Ethical Statement	16
2.3 Aims and Objectives	16
2.4 Recruitment procedure	17
2.5 Establishing Contact	18
2.6 Sample	19
2.7 One-to-one Conversations	20
2.8 Methodological Challenges	21
2.9 Data Analysis	21
 SECTION 3	 23
3.1 Findings	23
3.2 Knowledge and awareness of cancer	23
3.3 The wider impact of cancer	24
3.4 Communication with health professionals	25
3.5 Screening and Healthy Behaviour	27
3.6 Support provided to participants during their experience of cancer	29
3.7 Views of gatekeepers	30
 SECTION 4	 31
4.1 Discussion	31
 SECTION 5	 33
5.1 Limitations	33

SECTION 6	34
6.1 Recommendations for potential research proposals	34
6.2 Conclusion	36
 References	 37
Appendix 1 – Full search terms and databases searched	40
Appendix 2 – Accessible flyer for group advisory work	43
Appendix 3 – Accessible flyer for one-to-one advisory work	44

EXECUTIVE SUMMARY

- i The Cancer Care Research Centre worked in collaboration with the Centre for the Older Person's Agenda, at Queen Margaret University, Edinburgh, to engage with older adults with learning disabilities affected by cancer and identify research priorities.
- ii Twenty three organisations across Central Scotland who support people with learning disabilities were contacted by the research team. These organisations distributed information about the project to services users, and invite them to participate in advisory groups to talk about their experiences of cancer.
- iii Four people with learning disabilities contacted the research team to participate in the advisory work.
- iv As the number of interested individuals was low, people participated in one-to-one conversations with a researcher to talk about some of their experiences of cancer, rather than joining a group. Three people spoke from the perspective of having a family member with cancer. One person spoke about her own experience for breast cancer.
- v The research team faced a number of challenges when recruiting people to the project, as on a number of occasions it was found that people with learning disabilities were not told their diagnosis or the diagnosis of their family member or friends.
- vi Participants shared many of their experiences of cancer during the one-to-one

conversations with the researchers. Researchers made detailed notes of the conversations, including verbatim quotes

- vii Individuals spoke about a wide range of experiences related to cancer and cancer care, including their knowledge and awareness of cancer, the wider impact of cancer, communicating with health professionals, healthy living and screenings and the support they received from family/friends/support workers.
- viii Participants were asked about research priorities based on their experiences; this was framed as “what could be done better?” “what should people know more about?”
- ix A number of priorities for future research have been identified based on what participants told the researchers and through interpretative analysis of the conversations.
- x Key areas for research include:
 - (i) communication between health care professionals and people with learning disabilities when someone develops cancer;
 - (ii) the effectiveness of supportive measures for families when someone gets cancer;
 - (iii) appropriate support mechanisms for people with learning disabilities, their families and staff when someone is very ill or dies from cancer;
 - (iv) incidence and prevalence profiles for people affected by learning disabilities.
- xi An accessible summary of the project is available and has been disseminated to the individuals who participated as advisors and to organisations that support adults with learning disabilities.

SUMMARY (PLAIN ENGLISH)

The Cancer Care Research Centre (CCRC) works with people affected by cancer to find out about their experiences of cancer and what they think about the treatment and care they have had. The CCRC has 16 Advisory Groups of people affected by cancer across Scotland. These groups help the Centre develop research plans by discussing their experiences and views of cancer services.

This project worked with adults with learning disabilities affected by cancer. Four people with learning disabilities met with the researchers to talk about their experiences of cancer. Three people had a family member with cancer. One person had breast cancer and talked about her care.

By speaking to the researchers, these people advised the researchers on the important issues to research for people with learning disabilities affected by cancer. The project found that new research should focus on:

- » communication in hospitals between professionals and people with learning disabilities
- » how families cope when someone gets cancer
- » how to support people with learning disabilities, their families and staff when someone is very ill or dies from cancer
- » how many people with learning disabilities develop cancer

SECTION 1

1.1 INTRODUCTION

The Cancer Care Research Centre (CCRC) engages in research which informs cancer service development, by working in partnership with people affected by cancer and people working in cancer care. A key part of this research is working with people affected by cancer in advisory groups across Scotland. These advisory groups bring together a range of people to talk about their experiences of cancer, cancer care and treatment. The groups work with Centre staff to determine the priorities for research (Worth et al, 2005).

At the CCRC, members of the advisory groups are viewed as co-researchers rather than research 'subjects'. There are currently 16 advisory groups comprised of people affected by cancer guiding the Centre. These meet approximately quarterly with CCRC staff to discuss key issues and concerns regarding cancer care, focusing on service developments, research priorities and policy drivers.

Running in parallel to this is work with individuals who prefer to engage with the Centre on their own, rather than in groups. Around 50 people have chosen to have individual contact with Centre staff and have taken on roles such as: reviewing draft reports, interviewing Health Board Chief Executives, commenting on the readability of the website and newsletters, and informing researchers of research topics important to them.

These groups and the ethos of engagement, involvement and patient experiences all underpin the work of the Centre to create change based on the unique experience of patients and carers. These approaches provide a sound research base to underpin developing policy and practice in cancer care, with patients' and carers' experiences as a core driver.

¹ "people affected by cancer" is a term adopted by the CCRC which refers to people who have/had cancer, informal carers of people with cancer, family members of people with cancer.

This report describes the process and outcomes of engaging with older people affected by cancer who have learning disabilities, as advisors on key research topics. A collaborative relationship was established between the Cancer Care Research Centre and The Centre for the Older Person's Agenda (COPA) to develop advisory groups of people with learning disabilities affected by cancer. COPA aims to improve the quality of life of older people and their carers through multidisciplinary programmes of linked research education and practice development.

1.2 BACKGROUND

In this section, literature is presented offering a contextual backdrop to the empirical work discussed later in the report.

A literature search was conducted, with parameters to include English language documents, published between 1980-2007. Peer reviewed papers were included, as were grey literature and conference abstracts. Table 1 outlines the search terms and databases searched during the literature review. Appendix 1 provides a detailed table of the keyword search terms used and includes the expansion of keywords as necessary. The tables do not include the number of hits generated, as this is difficult to succinctly represent due to the number of searches conducted; however, it was clear that there is a paucity of published literature relevant within the domain and focus of this project. In particular, hits generated related to older people with learning disabilities affected by cancer revealed very limited information, save for papers focused on epidemiology. Research exploring, theorising and documenting the experiences of older adults with learning disabilities affected by cancer was not identified and reveals a significant gap in the field.

Relevant policy documents are also reviewed in this section of the report, indicating the connections with national health and social care frameworks.

Table 1 : Themes and sub-themes

	Keyword Search Terms	Databases searched
Search 1	Learning Disability / Intellectual Disability AND Cancer AND Ageing / Gerontology	Medline Assia
Search 2	Methodology AND Learning Disability AND Creativity	Assia Web of Science
Search 3	Involvement in research AND Learning Disability	Assia Medline

Cancer and learning disability: incidence and prevalence

Cancer incidence among people with learning disabilities is poorly documented (Patja et al, 2001a). Studies that have focused on cancer in the learning disability population have primarily been conducted in institutional settings (Hogg et al, 2001), and tend to indicate a lower incidence of cancer among people with learning disabilities. However, the epidemiological methods used in studies of cancer in people with learning disabilities have been felt to be unsound, particularly when considered in relation to studies conducted about cancer in the general population (Hogg et al, 2001). The paucity of consistent and reliable learning disability and cancer epidemiological data means drawing conclusions of the incidence and prevalence of cancer in people with learning disabilities can be problematic. The lack of consistent data problematises meaningful comparisons with the general population.

However, as with the general population, many people with learning disabilities will be affected by cancer, either through personal experience of having cancer or through the diagnosis of cancer in a family member or friend (Tuffrey-Wijne et al, 2006). The number of people with learning disabilities developing cancer is likely to increase as demographic trends feed into changing patterns of morbidity and mortality. Research suggests this may include prolonged periods of dying from illnesses such as cancer (Tuffrey-Wijne et al, 2007a). Although increased longevity and changes in lifestyle (Jancar, 1990) suggest increases in cases of cancer deaths in the learning disability population, comparatively, the

levels of death from the disease are still reported to be lower than for the general population (Turner and Moss, 1996).

A potential relationship between levels of learning disability, i.e. mild, moderate, severe and profound, and deaths caused by cancer have been investigated (Turner & Moss, 1996). Within an institutional population, the prevalence of deaths caused by cancer was higher among people with learning disabilities typically classified as mild, moderate or severe, when compared to people with profound learning disabilities (Turner and Moss, 1996).

Evidence suggests that increases in deaths from cancer among people with learning disabilities living in the community are attributable to people following lifestyles that place higher risks on their health (Dupont et al, 1987), such as increased levels of obesity and smoking. Both of these are known risk factors for cancer (Turner & Moss, 1996), and are considered to equally apply to the general population and individuals with learning disabilities (Burkhart et al, 1985).

Cancer and learning disability: Age and aetiologies

The life-expectancy of people with learning disabilities is increasingly regarded as reaching that of the general population (Hogg, 1997). Some sub-groups of individuals with a learning disability, such as people with Down's syndrome, however, still have a significantly lower life-expectancy (Hogg, 1997). The reduced life-expectancy of people with Down's syndrome was cited as a possible explanation for prevalence of cancer within this particular sub-group (Cooke, 1997). Cooke's (1997) 10-year study from 1986-1995, reporting on a 60-year survey on the rate of deaths from cancer in a learning disabled cohort, identified only one case of cancer in a person with Down's syndrome. Furthermore, when the average age of death from cancer considered within this study was compared to the average of death of the total population, people were dying younger from cancer; 62.0 years for males and 69.9 years for females, compared to 66.4 years and 71.2 years respectively (Cooke, 1997).

More recently, Patja et al (2001a) published the first population-based cohort study of intellectual disability and cancer, reporting the incidence of cancer in the Finnish population of people with learning disabilities. In this study, it was observed that people with intellectual disabilities had an increased risk of cancer between 15 – 29 years of age, with a significantly reduced risk of cancer noted in males aged 60 years and above and although

a few exceptions were noted, the authors found indications that the risk of cancer among people with intellectual disabilities was similar to the risk in the general population.

One of the exceptions for the risk of cancer in people with learning disabilities discussed by Patja et al (2001a) was neoplasms of the gallbladder – a significant increase was noted among people with severe and profound intellectual disabilities. However, no difference was detected between women with intellectual disabilities and women in the general population in relation to the incidence of breast cancer (Patja et al, 2001a). Nonetheless, it is considered difficult to make comparisons between cancer incidence in people with learning disabilities and the general population for reasons that are threefold: (i) people with learning disabilities have a lower life expectancy than the general population, (ii) there are differences in aetiology and factors which predispose particular syndromes to cancer and (iii) there are often difficulties in accounting for lifestyle factors, as there are challenges in comparing the effects of diet, stress, smoking and alcohol between people with learning disabilities and the general population (SHS Trust, 2003).

Patja et al (2001b) studied cause-specific mortality in the Finnish population and identified neoplasms as the third most common cause of death (behind cardiovascular and respiratory diseases); there was reduced mortality of neoplasms when compared with the general population (with exception to older people with mild learning disability): “out of all causes of death, cancer accounted for 4% of all deaths in subjects with profound ID, 11% in moderate ID and 16% in subjects with mild ID” (Patja et al, 2001b:34). The mean age at death was 63.6 years.

Adults with learning disabilities in Scotland

In September 2006, there were an estimated 22,859 adults with learning disabilities known to local authorities in Scotland; 4,869 were aged 50-64 and 2,160 were aged 65+ (Scottish Executive, 2006).

Following the closure of institutional organisations, the care for people with learning disabilities has been relocated within community settings. The number of people with learning disabilities living in their own tenancies has increased over the years, with 6,448 people living in their own tenancy in 2006, an increase of 130 people from the level recorded in 2005 (Scottish Executive, 2006).

With the increases in people living in community settings, either independently or in supported accommodation, the relevance of a recent Scottish Executive document, *Delivering for Health* should be highlighted. This document outlined the need for a shift in the balance of care in Scotland, with a focus on delivering care as locally as possible and within communities to reflect the changes in the health care needs of Scotland's population (Scottish Executive Health Department, 2005a). An ageing population and an increase in long-term conditions were outlined as challenges for the NHS in Scotland has also been set out in Scottish Executive policy (Scottish Executive Health Department, 2005b). The challenge of tackling changing needs such as these applies to the learning disability population, perhaps with greater saliency than the general population, as the demographic and social profile has changed for this group so dramatically in recent years.

Involving people with learning disabilities in research

In the past, people with learning disabilities were largely excluded from participating in research and expressing their views on issues that affect their lives, including healthcare and service provision (Tuffrey-Wijne et al, 2007a). In particular, there appears to be a paucity of research exploring the views of people with learning disabilities on issues such as death, dying and care at the end of life. However, there have been some developments in relation to this recently, and it has been shown that people with learning disabilities are both willing and able to provide their opinions on these matters (Tuffrey-Wijne et al, 2007a).

The importance of involving people with learning disabilities fully in research has been noted on previous occasions (Tuffrey-Wijne et al, 2006; Walmsley and Johnson, 2003) particularly if the research is concerned with their experiences. Research of this nature will benefit from the advice of people with learning disabilities, with recommendations for people with learning disabilities to be involved in all stages of the research process if possible (Tuffrey-Wijne et al, 2006). To help inform best practice guidelines for cancer services there is a strong belief that the experiences of people with learning disabilities affected by cancer should be further explored to ensure their voices are being heard (Tuffrey-Wijne et al, 2006) and that service delivery is based on their experiences.

Other methods which involve people with learning disabilities in research have included the use of the Nominal Group Technique (NGT). This approach was adopted by Tuffrey-Wijne et al (2007b) to investigate the views of people with intellectual disabilities on end

of life-care provision. The NGT approach involves 4 stages and combines both quantitative and qualitative data collection activities, typically in small groups of stakeholders. The four stages are:

“(i) silent generation of ideas by each individual; (ii) round-robin recording of ideas; (iii) structured and time-limited discussion of ideas; (iv) selection and ranking of ideas (voting)”

(Tuffrey-Wijne et al, 2007b:81)

A single question is used in this approach; the success in this approach is reliant upon the clarity of a question, so that a range of responses can be generated from this one question (Tuffrey-Wijne et al, 2007b). The researchers in this study found that people with learning disabilities who participated in this process were able to provide their opinions and thoughts about a wide variety of issues surrounding end of life care provision with both authority and enjoyment.

As noted above, people with learning disabilities are increasingly becoming more involved in research as participants. Increasingly this has shifted to working more collaboratively with people with learning disabilities too, often based on principles of emancipatory research. Participative research involves working with people as co-investigators rather than research subjects to observe, interview and reflect on a shared enquiry with the aim of improving the nature of practice in an arena (Patton, 2002). This form of research is growing in interest and recognition with people with learning disabilities (Tuffrey-Wijne et al, 2007a). Views are expressed clearly and authoritatively through such methodologies. Action research (the aim of which is to solve specific problems within any one organisation, community or programme, Patton, 2002) may also be a fruitful methodology. However, although action research and participatory research appear to be common approaches when conducting research with people with learning disabilities, studies have shown that the use of this type of model, combined with the advocacy model, is perhaps incompatible with demands of working in academic settings (Stalker, 1998). Thus, while ideologically sound, the pragmatics of conducting collaborative research may be troubled.

Involving people with learning disabilities in setting the research agenda

Despite the growing involvement of people with learning disabilities in research this has largely been as participants rather than engaging with them as co-researchers or people

who will inform the research agenda. Thus, there appears to have been limited uptake or evidence of uptake of Patient Focus and Public Involvement (Scottish Executive, 2003) or adoption of the ideas promoted by organisations such as INVOLVE (an NHS funded organisation which promotes public and patient involvement in health research) around engagement in service design/delivery and engaging in research.

This is in line with the general population where engagement in research, particularly in Scotland, and to a slightly lesser extent the rest of the UK, is limited (Hubbard et al, 2005). Furthermore, large scale research projects which tend to attract the attention of policy makers, are still within the traditional realm of noninclusive research centres. Therefore, inclusive approaches to research tend still to be marginalised (Walmsley, 2004).

There are limited accounts of including people with learning disabilities in setting whole research programmes/agendas (Young & Chesson, 2007), despite the promotion of the need for engagement in the processes as previously described. Young & Chesson (2007) have, however, highlighted successful collaboration between people with learning disabilities, their carers and researchers to identify research questions specific to health. They report that by adopting a participatory model, robust research findings were produced.

Policy frameworks in public and patient involvement

People with learning disabilities have traditionally been excluded from involvement in decision making about services that affect their lives, with general presumptions made around inability to form opinions about their needs (Tuffrey-Wijne et al, 2007b). However, partnership with patients and the public is embedded in current Scottish health care policy (Scottish Executive, 2003) and has been identified as a key driver for change in future NHS developments (Delivering for Health, Scottish Executive, 2005a). The Patient Focus and Public Involvement agenda has driven forward the commitment to this within health boards and Community Health Partnerships (Scottish Executive, 2003) leading to considerable attention to ensuring that health care users voices are sought, listened to and acted upon.

Part five of the Adults with Incapacity (Scotland) Act (2000) lays out guidelines for obtaining consent for people who are deemed not to have capacity to provide informed consent for medical treatments, procedures and research. This may apply to people with learning disabilities if they are deemed to be unable to give informed consent and is of relevance

in oncology since the procedures and treatments invoke a need for consent. A recent research study indicates that understanding of the Act is limited amongst clinical staff, raising concerns about the implementation of it and the rights of people with learning disabilities receiving medical services (Ramsey, 2005). A further study identified significant training gaps in clinical staff (Davidson et al, 2004) indicating concerns about how people with learning disabilities in need of health care may have their treatment negotiated with them, their families and between health care staff.

Recent government initiatives in relation to cancer services (DoH 2000, Scottish Executive, 2001) have placed emphasis on a patient focused approach to care, with the Cancer Plans in both Scotland and England clearly identifying the importance of planning services around patient needs:

"We are aiming for a future where patients and their relatives and carers are at the heart of the healthcare and support services - involved not just in receiving care but in planning and developing that care."

(Cancer in Scotland: Action for Change, p8).

Underpinning this policy is the belief that effective patient involvement will make services more responsive to patients' needs, more acceptable, accountable, equitable and accessible and improve quality and outcomes of care (NHS Executive 1999, Department of Health 2003).

There is a need to create a patient-focused culture of involvement, listening and feedback, where the patient's experience is the catalyst for improving services (Department of Health 2003). Collating information on patient experience and ensuring it is fed back to service providers is a major impetus to the improvements in cancer care proposed in Government policy and is the sine qua non for developing partnerships with patients and carers at practice and policy levels (Kearney et al. 2003).

Therefore, the establishment of advisory groups of people with learning disabilities affected by cancer will ensure that the Cancer Care Research Centre and the Centre for the Older Person's Agenda continue to be led by the experiences of people affected by cancer in the development of research projects and grant applications. Indeed, it has been recognised that further research studies are required to explore the subjective experiences of people with learning disabilities affected by cancer (Tuffrey-Wijne et al, 2006).

SECTION 2

2.1 Methods

The CCRC is experienced in establishing and developing Advisory Groups of people affected by cancer, and centralises flexibility in its approach to participants. This ensures that groups are reactive to the needs of its members.

2.2 Ethical Statement

The ethical position of CCRC advisory groups was clarified with the Central Organisation for Research Ethics Committee (COREC). COREC advised that advisory groups did not require ethical approval, as groups or individuals acting in an advisory capacity do not constitute research and thereby do not require NHS ethical clearance.

However, the research team adhered to formal ethical guidelines and conduct, referring to those laid out by the British Sociological Association and British Psychological Association.

The researchers have experience in working with people who are traditionally considered vulnerable, and were attentive to participants' needs and wishes throughout. Involvement in this project was clearly framed as voluntary, and participants were informed that they were free to withdraw at any stage. Notes from conversations were anonymised and stored securely. No audio recordings were made, as participants expressed their dislike of this media. No individuals are identifiable from any of the details below.

2.3 Aims and Objectives

The aim of the work was to establish advisory groups of adults with learning disabilities affected by cancer to inform the research agenda of The Centre for the Older Person's Agenda (COPA). People contributing to the advisory groups should themselves be considered 'older' or refer to the experience of a family members who is 'older'. 'Older' was defined in collaboration with the commissioner of the work from COPA, Dr Heather Wilkinson, as people aged 50 and over. However, it was agreed that some younger people, whose experience related to someone over the age of 50 would also be appropriate.

The objectives of the project were to:

- Develop at least one advisory group comprised of older people with learning disabilities affected by cancer, to focus on setting a research agenda.
- Establish connections and networks with local advocacy organisations and service providers, ensuring local buy-in and networks for knowledge transfer.
- Conduct a literature review to inform the development of future research proposals in order to complement the research agenda established by the advisory group.

2.4 Recruitment procedure

In order to engage with older people with learning disabilities affected by cancer, an accessible flyer (Appendix 2) about the advisory group work was developed. This flyer was distributed to a variety of advocacy organisations and service providers. Distribution of the flyers occurred between June and August 2007 to lead staff, with instructions to pass the information on to their service users/project members. All organisations approached agreed to distribute the leaflet.

Overall, 23 organisations or individuals who have direct contact with people with learning disabilities who may have been affected by cancer were approached. To preserve anonymity the organisations that agreed to distribute leaflets are outlined in broad detail below:

- a. Two heads of learning disability services in Central Scotland

- b. Four learning disability advocacy organisations across Central Scotland
- c. Three learning disability charitable service provider organisations
- d. Eight Learning Disability Nurse Teams in Lothian
- e. Three Learning Disability Nurses in Forth Valley
- f. One Social Worker in Central Scotland
- g. Two lecturers based in a Nursing and Midwifery Department; one in Central Scotland and one in the Highlands

Each of these organisations/individuals was contacted several times to encourage discussion of the project, offer clarification and support. Despite interest from the people spoken to, all these contacts elicited only very small numbers of contacts from people with learning disabilities.

Conversations also took place with the co-ordinator of a national advocacy committee, run by an umbrella campaigning and support charity. A date was arranged with this committee for the research team to visit the group prior to their next scheduled committee meeting to conduct a group advisory session with members of this committee affected by cancer. Initially, interest in this group appeared strong, with the co-ordinator confident that people would be interested in participating in this group. Sixteen people were invited to participate in an advisory group; however, no individuals showed interest in participating. The co-ordinator cited reasons for the lack of interest as: possible over-consultation, time of year (end of summer), and busy committee business near the suggested meeting, alongside an idea that people may not want to speak about their experiences.

In order to further provide individuals from this organisation with the opportunity to participate in this project, the option of meeting with the researcher for a one-to-one conversation was provided; the advisory group flyer was re-worded (Appendix 3) and distributed to various project managers across Central Scotland for dissemination to their project members. However, no participants were identified from this organisation through this method.

As a result of distribution of the advisory group flyer within these networks, four people were recruited to the project.

2.5 Establishing Contact

Individuals interested in participating in the project expressed a desire to do so individually, or via their advocacy organisation or service provider, who then contacted the research team on behalf of the person. The research team then made further telephone contact with the interested individuals to provide more information on the project and make arrangements for an initial meeting.

As previously highlighted, the project information was widely distributed to a wide network of advocacy organisations and various service providers. However, the number of individuals who expressed an interest in participating in an advisory group was limited; only four individuals made contact with the research team over a three month period. Therefore, the research team adopted an alternative approach of involvement than was originally envisaged.

The alternative approach encouraged individuals to participate in a one-to-one conversation with a researcher. This was to ensure that individuals were given the opportunity to take part as soon as possible after their initial interest was expressed and address any potential concerns about discussing sensitive issues in a group setting.

Participants were advised that if sufficient people were identified then the researchers would be in touch to advise them of potential group meeting dates. However, due to the paucity of interest in group meetings, individuals were solely contacted, and met with, on a one-to-one basis.

2.6 Sample

Four people with learning disabilities shared their experiences with researchers. Participants are outlined in Table 2. Specific details are not available in all instances, meaning some data is approximate, reflecting the participant's recall difficulties.

Staff at three organisations who acted as gatekeepers within the work also shared their experiences and thoughts. These are outlined in Table 3.

Table 2: Participants with learning disabilities

Reference	No. of meetings	Gender	Age	Summary of experiences
Person 1	1	Female	22	Aunt (circa 40+ years) had leukaemia. Grandmother died of cancer when she was a child.
Person 2	1	Male	47	Dad died from stomach cancer in 1989; His mum died in 1993. His uncle died from cancer in 1984. He also knows a neighbour who had cancer.
Person 3	2	Male	46	Mother and grandmother both died of cancer. He lived with his mum at the time of her illness.
Person 4	1	Female	53	Had breast cancer a few years ago. Her mother also had breast cancer.

Table 3: Staff from gate-keeping organisations

Reference	Organisation	Summary of conversation
Org 1	Residential support service	Staff have supported around a dozen people with learning disabilities and cancer. Many people had not been told their diagnosis; their peers were unaware of the diagnosis too.
Org 2	Campaigning and support charity	Staff were aware of some individuals who have been affected by cancer, particularly members of one of their national committees. However, those people did not come forward to participate.
Org 3	Learning Disability Nurse Team	Nursing staff have experience of supporting people with learning disabilities with cancer, but were unable to suggest anyone for participation due to high mortality rate of people with learning disabilities, and concerns about the cognitive abilities of people they support.

2.7 One-to-one Conversations

During the one-to-one conversations, the researchers listened to the experiences of four adults with learning disabilities affected by cancer. Conversations were guided by the person's own experiences as someone with cancer or whose family member had been affected by cancer. Clarification and expansion were sought by the researcher throughout, where appropriate. The conversations were not audio recorded but notes were taken by the researcher, with verbatim quotes noted as often as possible. The notes were subsequently written up in detail to provide an accurate reflection of the discussion. In the section below, direct quotes from field notes are used, indicated by the use of speech marks. Where the notes include verbatim quotes this is indicated in the accompanying text.

Conversations with participants were guided by their experience of being affected by cancer – three of the four participants spoke from the perspective of having a family member, either a parent and/or an aunt, uncle or grandparent, affected by cancer. One participant spoke about her own treatment for breast cancer.

In line with the extensive advisory work conducted by the CCRC, discussions focused initially on the person's own experiences and views of cancer. Where appropriate, respondents were asked to reflect on their views of 'things that needed making better' or 'what should people know' in order to elucidate ideas on potential research and practice developments.

In order to assist engaging with individuals in conversations about their experiences, the researchers took an accessible book about cancer to the meetings. The book "Getting on with Cancer" (Donaghey et al, 2002), illustrates through the use of accessible format drawings, the experiences of a woman with learning disabilities through her diagnosis and treatment for breast cancer. The researcher and the individual with learning disabilities reviewed this book together. The individual would often tell their own version of the story depicted in the book to the researcher and sought help or clarification on any pictures if they needed to. This book was often useful in confirming or reiterating an experience the individual had shared with the researcher and for sharing their knowledge about a specific element of cancer and cancer care – for example, a picture in the chemotherapy section of the book shows a woman with no hair, and many of the participants explained this was "because of the drugs".

2.8 Methodological Challenges

As previously illustrated, a wide network of service providers were contacted to invite people with learning disabilities affected by cancer to participate in this piece of advisory work. However, it proved problematic to identify people to take part.

The CCRC has experience in setting up similar groups in the general population, and adopts similar approaches to recruitment, such as attending cancer support groups and asking their members for advice on research. With the general population print and broadcast media are also used to establish new groups (for example, short articles in local papers asking for people to attend meetings). With the general population, these approaches have elicited considerable interest from people affected by cancer who wish to attend meetings. It was felt that approaching pre-existing organisations for people with learning disabilities would have a similar effect. However, the outcomes for this population was considerably different and informal conversations held with gatekeepers revealed insights into the restricted interest in meetings. One of the key issues that impacted on recruitment, which is not experienced with the general population, is that on numerous occasions people were not told their diagnosis or the diagnosis of their family member, relative or friend. A further barrier was gatekeepers' understanding of cancer as a taboo topic. The need to approach people via gatekeepers highlighted paternalistic attitudes that prevented people from becoming involved. It was felt that discussing experiences of cancer would be too upsetting for the service users. Whether a similar pattern of paternalism would be discovered in the general population if they were subject to the same gate-keeping by relatives/friends is uncertain. However, it remains clear that people with learning disabilities' opportunities to participate are significantly affected by the social circumstances of their homes, workplaces and supporters in a way that is not true of the general population.

2.9 Data Analysis

None of the one-to-one advisory conversations were recorded during this project, but detailed notes were written up following each conversation. Thematic, interpretative analysis was conducted on these notes (Braun & Clarke, 2006). These are presented below, illustrating issues that were salient within and between participants. Interpretative analysis lies at the heart of working from people's personal accounts of health and wellbeing, and is used to move toward identifying research topics and areas for service improvement.

SECTION 3

3.1 Findings

A number of consistent themes emerged during the one-to-one conversations with the four individuals who participated as advisors in this piece of work. These are presented below, with verbatim quotes used where possible to aid in the illustration of these themes. As highlighted in Table 2, the participants were not all 50 years old or above, though many of the people they spoke of were. Where possible, any issues which are associated with age, ageism or gerontology are discussed. However, the knowledge, views and experiences of cancer of these individuals did not appear to differ significantly when compared across the younger and older ages.

3.2 Knowledge and awareness of cancer

Participants shared their knowledge and awareness of cancer but were often unsure about the causes of cancer, and didn't understand its aetiology. One person thought his mother's cancer may have been caused by the "batterings my Dad gave her" (Person 3). The idea that cancer is caused by violence raises further questions regarding how this impacts on the individual and their lifestyle choices. Person 3, who articulated the idea that domestic abuse resulted in cancer, reveals the potential to explore with this person his own relationship to violence, and those around him.

One person spoke about her knowledge of cancer prior her own diagnosis, and explained that she thought cancer was "one of those things woman got" (Person 4) but knew that "some people even die from cancer if it's not treated". Some participants had heard the words 'cancer' and 'tumour' before their own experience. One individual explained that he

used to go to Red Cross classes and had first heard the terms cancer and tumour there, but when he was asked to expand on his understanding of the term tumour, he replied:

“like what my Dad had in his stomach”

(Person 2)

Therefore, it seems that some people’s understanding of cancer is limited to the context in which they have been affected by it. For example, for Person 2, awareness that his Dad had a tumour in his stomach did not lead to any further understandings, and he was unable to expand any further upon what a tumour is.

One participant (Person 1) explained that she didn’t know that young people could get bowel cancer but she had recently been watching some television programmes about young people with cancer. This comment on age and risk of cancer reflects demographic trends (ISD, 2007), but also highlights unease about how attentive younger people may be to the disease’s signs and symptoms. Constructing cancer as an older person’s concern effectively neutralises health promotion messages and screening programmes.

3.3 The wider impact of cancer

The impact of cancer on the person with the diagnosis and their family was intimated by many of the individuals during their conversations with the research team. Individuals articulated their understanding of the impact of cancer very well, particularly regarding the wider impact on the family of the person with the diagnosis of cancer.

One person made contact with the research team and talked about her aunt who has been diagnosed with leukaemia. During the conversation, an easy format booklet for people with learning disabilities “Someone I know has cancer. What does it mean for me?” (FAIR, 2005) was used as an aid. The researcher used pages that illustrated facial expressions people may show when they hear about a diagnosis of cancer, and prompted the individual to talk about how she felt when she heard that her aunt had leukaemia. Rather than identifying a particular facial expression, the individual told the researcher she:

“Felt sorry for her as she has two young children and knew that cancer would affect everybody in the family.”

(Person 1)

This individual clearly demonstrated a sophisticated understanding of the wider impact of cancer, despite later saying she doesn't know much about the disease. This revelation indicates a dynamic between the respondent and family/support staff who have not reinforced messages that she does indeed have a good understanding of at least some elements of the disease and its impact.

Another individual (Person 2) explained how his father's illness affected his mother. He explained that his mother couldn't cope and she "went wandering", which perhaps implies that she had mental health problems. (The explanation he gave for his use of this term was that she was taken to the Bellsdyke Hospital, the former Royal Scottish National Hospital which has been closed down, following community re-housing policies). Although he did not articulate this, it is possible that his mother's mental health problems were exacerbated by his father's diagnosis and illness.

3.4 Communication with health professionals

Communication with health professionals was raised by three of the four participants. Positive and negative communication experiences with health professionals were shared, with one person reporting a positive experience and two individuals reporting negative experiences of communicating with health professionals. The fourth individual did not discuss any experiences of communicating with health professionals, as she did not appear to have had any contact with health professionals in the context of the experience of which she spoke. Her communication was primarily with her mother and aunt, as she had overheard them speaking about the aunt's diagnosis of cancer. As this participant learnt of her aunt's diagnosis in this manner, it is appropriate to question whether she would have ever been directly informed of the diagnosis, either from her family members or health professionals, had she not overheard the conversation. Thus, although she did not directly identify communication as a direct area of concern, her experiences reveal fissures in communication practices.

3.4.1 Positive experiences of communication

One individual shared her experiences of being diagnosed with breast cancer. During her experiences of both surgery (lumpectomy) and treatment (radiotherapy), she had contact with a range of different health professionals, including her Community Learning Disability Nurse, GP, and doctors and nurses at the local Cancer Centre. The oncologist recommended radiotherapy following her surgery and although she reported that she did not ask many questions about the treatment, she was provided with the opportunity to go into hospital to see the radiotherapy machine before her first session, which she reported was helpful as it made her feel “less nervous” (Person 4). During her stay in hospital and for her visits for radiotherapy treatment, she felt that all the staff were friendly towards her; she felt that they all explained things clearly for her. She told the researcher that she wouldn’t have liked any more information from the health professionals.

3.4.2 Negative experiences of communication

Two participants shared their experiences of having a family member diagnosed with cancer. Both of these people reported negative experiences of communication with health professionals, as they often received little information directly from health professionals about their family member’s diagnosis, illness or treatment. Information was often relayed to these individuals from other family members who had been in direct contact with the doctors and nurses.

One person described how he did not get any information from the doctor about his father’s illness, as all information was relayed to his mother and she decided what to tell him. This resulted in him being provided with few details from his mother about his father’s illness. He said that his mother was concerned that if he knew everything, it would make him too upset. He said he thought “she was right to do that” (Person 2), and reported that he was told:

“He [his father] was dying from cancer and there wasn’t anything they could do”
(Person 2).

Despite saying his mother was right to withhold information, this respondent also expressed

that he would have liked to have been told more about his father's illness and treatments, in case there was anything that could have helped him. Thus, he acknowledges that it would have been difficult to hear as it would have made him upset, but nevertheless did want to know. It seems that while the communication may have been appropriate between the parents, this man felt that they did not manage to supply the appropriate amount and type of information. It appeared that no-one was available to answer his questions. His position as interested/concerned relative was therefore not taken up by the health care professionals or family members. Furthermore, as he was not provided with any information about treatment options available to his father, he was unable to contribute to any discussions the family may have had about the course of treatment his father may have been able to receive or likely side-effects.

Person 3 spoke of his experiences during his mother's illness and described poor communication between him and medical staff. He reported that information on his mother's illness was relayed to him through a sibling. His mother died seven years ago and it was evident that he was still angry and upset about his experiences with the medical staff during his mother's illness. The following are verbatim quotes from the conversation and illustrate how articulate and thoughtful he is about his experience with his mother:

"The doctors didn't even try to tell me...I found out through my sister...they [doctors] think I'm stupid, I'm not stupid."

"I hate Doctors, I can't trust anybody."

"People didn't tell me what was going on."

There is clearly a feeling of being uninformed due to his learning disability and is one of the few instances in the data corpus where individuals referenced this identity as relevant to people's responses to them. Being considered 'stupid' is a feature of this man's experience which has remained with him, and was a core component to how he framed his overall experience of relating to health care professionals.

This same individual felt particularly strongly about the communication skills of health professional staff at the hospital his mother attended. The following verbatim quotations express very clearly his views:

“(health care professionals) haven’t got any patience for people like me”

“They are not concerned about the person’s feelings; I’ve got feeling as well.”

“They didn’t respect my feelings so why should they be involved.”

“They should listen to people like us. They don’t even talk to me. They have bad attitudes to people with disabilities.”

“They should communicate more with people, so how you meant to know things. If you can’t communicate, you shouldn’t be in a job like that.”

This participant was very clear in articulating the need for better communication and expressly told the researchers that this was something that required remedying in the health service.

3.5 Screening and Healthy Behaviour

During conversations it emerged that individuals rarely engaged in self-examination and screening procedures as part of their health care routines. Person 4 appeared to be the most knowledgeable about screening practices, and this may be explained by her recent experience of breast cancer. However, prior to her illness, she said that she didn’t know the word mammogram and hadn’t had one before she was ill, but now she knows the word and has a mammogram every year. When asked what she understood about mammograms, she told the researcher that she thinks they are a bit sore and she knows:

“Your breast has to be squeezed in just to check it.”

(Person 4)

She now has some knowledge and experience of mammograms, but this followed a diagnosis and treatment for breast cancer. This participant happened to find a lump in her breast when she was getting dressed. She had not been doing regular self-examinations. This individual’s experience seems to suggest that her knowledge and understanding of

screenings developed as a result of her illness. This may differ from women in the general population as they are likely to be familiar (via mass media) with the terms mammogram and self examination and understand the purpose and importance in engaging in these procedures.

Both of the women who participated in one-to-one conversations were asked if they had ever had a cervical smear test. Person 4, who had experience of mammograms said she had never had a smear test. Person 1 explained that she had only had one smear test in the past but she would never get it done again as it was “too horrible and sore”. She did not explain how much information she had been given prior to going for the smear test or how much support was provided for her at the time but she intimated to the researcher that it had not been a pleasant experience for her.

Neither of the men spoke about any tests or self-examination during their conversations with the researchers, but they did speak more of healthy behaviours and healthy living. Person 3 felt that “a lot of folk don’t know how to keep healthy” and spoke of the importance of engaging in exercise and eating the right sorts of food – “not fatty”. Person 2, who had lost both an uncle and his father to cancer, expressed that they both smoked so he knew smoking was bad for people. He explained that he knows “no to smoke”, “no to drink” but he does like to “take a wee beer”.

Alternative medicines were discussed by one individual in relation to her visits to her homeopathic doctor. She explained that she goes to see a homeopathic doctor every Thursday, which is arranged by staff at her support service. She told that she goes to the homeopathic doctor to receive Iscodor injections. When asked what she knew about these injections, she said:

“They prevent you from getting cancer.”

(Person 4)

Although this individual did not explain whose decision it was that she visits the homeopathic doctor, it was clear to the researcher when discussing these injections that they were now an important part of her post-illness self-care. Similar to her experience of now engaging in mammograms, it appears that her experience of her illness has prompted additions to her healthcare routine.

3.6 Support provided to participants during their experience of cancer

Individuals often spoke about the support they received during their experiences of cancer, some in more depth than others. Where family was available, this tended to be the main source of support. However, it was not always the case that they received support from their parent(s), as Person 3 spoke of having to support his father while his mother was ill and after she passed away, rather than his father supporting him. He described how he found this difficult and that he had to go and stay with one of his sisters for “quite a while”. His sister then supported him, as did various friends and colleagues.

Another participant spoke of the support she received from various people during her experience of breast cancer, including her parents, housemates, staff from her support service and her Minister. Although her parents did not visit her in hospital after her surgery as they lived in England, she said she spoke to them a lot during her illness, especially her mum, as “mum had it [breast cancer] as well” (Person 4). However, she did not know a lot about her mum’s experience of having breast cancer, raising questions about how family communication around illness might be supported. She also spoke of receiving support from the staff members from her support service and her housemates, particularly following her surgery, although she couldn’t remember if her housemates visited her in hospital with the support service staff. Support from her Minister and church were very important to this person too, and she told the researcher her Minister “prayed for her” (Person 4).

Bereavement support provided by dedicated counselling services was raised by one participant, as he had spoken to a counsellor following the death of his mother. His support worker had facilitated the referral. He went to see the counsellor once a week for about seven weeks, and said of speaking to the counsellor “it felt strange at the beginning” and he initially thought “what the hell am I doing here?” (Person 3). However, it would appear that this contact with the counsellor had some benefit for him, as he stated to the researcher that “everyone who’s feeling down should see a counsellor”.

3.7 Views of gatekeepers

While not within the explicit objectives of this project, the views of gatekeepers were canvassed as a by-product of negotiating access to people with learning disabilities. These conversations warrant reporting, since they substantially contextualise the above findings and provide further reflections on the process and outcomes of advisory work with people with learning disabilities affected by cancer.

Primarily, gatekeepers felt that people with learning disabilities would not be interested or able to take part. Staff (for example from Organisation 1) called into question their communication skills, interest in taking part and their ability (based on lack of knowledge of the disease). This last point – lack of knowledge of the disease – relates to the revelation that most people with learning disabilities who developed cancer were not informed of their diagnosis; additionally, when a relative from the general population developed cancer the diagnosis was not shared with the person with the learning disability. Compounding this, many peers/co-residents of those with cancer were also not informed of the illness, either during the person's treatment or after their death.

Gatekeepers spoke primarily of their own experiences when someone in their service developed cancer. They discussed the tensions around disclosing the diagnosis to the person, to their peers and negotiating this with the person's relatives. Many staff reported their grief and distress at people developing cancer, and dying of the disease.

These factors around (i) disclosing diagnoses and (ii) ongoing processing of their own position as staff meant that they did not feel able to refer people with learning disabilities to the advisory forums.

SECTION 4

4.1 Discussion

This project was tasked with eliciting the views of older people with learning disabilities affected by cancer, and for the purposes of this project older was defined as 50 years of age and above. Only one of the four people recruited to participate in one-to-one conversations met the criteria for “older” as that defined in this project, though each of them discussed people affected by cancer who were ‘older’.

Though the sample size is small, there were no indications of difference in the experiences of these adults with learning disabilities affected by cancer aligned to age. Thus, age was not the dominant organising principle through which experience was understood – rather, learning disability became the main lens through which cancer was mediated. This is not to advocate an essentialist understanding of disability, but a social constructionist one where cancer’s meaning was interpreted through disability rather than ageing. There was little evidence of the two constructs colliding, though this is noted in the context of limited data from a small sample size.

As with the general population, experiences were also shaped by the individual’s circumstances, their relationship to the person with a diagnosis of cancer, the knowledge and understanding they had of the disease, communication experiences with health professionals and the support they received throughout their experience of cancer.

The findings in this study connect with previous work where public understandings of cancer have been investigated (Kearney et al, 2005). Many members of the general population have very limited understandings of the aetiology and symptoms of cancer. Findings from

the current study indicate that people with learning disabilities may not have substantially lower levels of understanding than members of the general population who have not been affected by cancer (for example, person 1 who did not know that younger people could get bowel cancer).

As previously discussed, no differences were apparent in these individuals' experiences based on their age. A difference in experience did seem to be apparent, however, related to whether they had personal experience of the disease or had a family member with the disease. The most notable occasion where experiences differed was in reference to the communication individuals had with health professionals during their or their family member's illness. The one individual who spoke from the perspective of having surgery and treatment for breast cancer had positive experiences of communicating with her health professionals, whereas two other individuals with experience of communicating with health professionals during their parents illness had very negative experiences of this contact. Positive experiences of communication appeared to be a result of the individual being provided with adequate information about her illness and treatment. When these examples of good practice are compared with those of the two individuals who reported negative experiences of communication with health professionals, it is clear to see that an underlying cause in the negative experiences is that the people were frequently by-passed when information was being provided to the families from the health professionals. It then became the families' responsibility to relay this information to the individual. Whether a similar pattern of communication would be considered tenable for the relatives of people from the general population is moot.

For one participant communication was particularly unsatisfactory, as he felt the lack of engagement from the health professionals with him was a consequence of his learning disability, as he felt he wasn't being involved in the family consultations as the health professionals thought he was "stupid".

Seeing these concerns in the light of organisations supporting people with learning disabilities, and the apparent frequency with which the person with the learning disability was not told of their diagnosis (documented in Section 2) means that evidence of maladaptive communication from health care professionals is much wider spread than shown in these four interviews.

The importance of the provision of support from family, friends, housemates, colleagues, support workers and a counsellor were often highlighted by the individuals in this study. The combination of these support networks varied for individuals but families were consistently reported as one of the main sources of support. Families appeared to have a dual-role for the individuals in this study, as they were required to not only support the individual but were also required to relay information from health professionals, as previously discussed. This may have meant that on some occasions, families were filtering the information the individual received, thereby in some way unconsciously over protecting them from the details of their relative's illness.

SECTION 5

5.1 Limitations

The small number of people who participated in this work limits the claims that can be made regarding the generalisability of the findings. However, since care was taken in all conversations to ask open and non-leading questions about the person's experiences, the findings should be considered to have good face validity. The second conversation with participant 3 also indicated a good level of reliability, as similar concerns were expressed in the second meeting.

Thus, recruitment difficulties posed significant challenges. As discussed in section 2.8 over 20 contacts were made with people who acted as gatekeepers in this study. Despite this high number (and the number of people with learning disabilities who these individuals are in touch with), only four participants came forward to take part. Many service providers informed the researchers that they were in touch with several people whose lives had been touched by cancer – either as someone who had had cancer themselves or a relative of someone with cancer. Service personnel were reluctant to put the researchers in touch with these people (as discussed in section 3.7).

While originally focused on developing an advisory group of older people with learning disabilities affected by cancer, this particular piece of work liaised with people on an individual basis. This may have resulted in the production of somewhat different, though no less useful, data. Discussing cancer in a group format may have enabled the discussion of group processes and elucidated new views on cancer, as participants would have had the opportunity to share their experiences. Groups tend to allow the expression of public, rather than private, narratives and hence have offered some different views of cancer (Morgan, 1997).

SECTION 6

6.1 Recommendations for potential research proposals

The following section outlines key recommendations for further research around older people with learning disabilities affected by cancer. Interpretative analysis informs the development of research topics. They are presented below in order of importance, as perceived by the research team based on conversations with the participants in this study. Although all of the topics could be viewed as being of equal importance, it is believed that this ranking process will aid in the illustration of the key issues this project has raised. Ideas which emerged directly from conversations with people with learning disabilities have been given priority – and these first research ideas include areas which were explicit in people’s talk, as well as those derived through interpretative analysis.

RECOMMENDATION 1: Communication between health care professionals and people with learning disabilities.

Far removed from normalisation principles, people with learning disabilities continue to be the subject of paternalism. This was evident in conversations with some support staff. Moving to a position where health care professionals and support staff feel able to share the diagnosis and work collaboratively with the person affected by cancer will necessitate additional supports to all involved. The focus of a research project could helpfully focus on facilitating factors in successfully sharing the diagnosis and support structures for best practice in keeping communication loops open and functional.

RECOMMENDATION 2: Communication between relatives and people with learning disabilities.

The focus of this research could focus on supportive factors in enabling families to discuss cancer (whom ever it affects) and the support that families (the person with the learning disability alongside their family) would need to do this.

RECOMMENDATION 3: The impact of cancer on the whole family.

Cancer affects the whole family, and research could helpfully explore the changing dynamics of families where someone has a learning disability. This might include identifying people with learning disabilities who position themselves as carers where someone else has cancer. Families are likely to have older members who themselves may have had cancer, adding complexity to people's reactions and concerns. A key dimension to this research will be whether the person with learning disabilities lives with the family or in supported/ independent accommodation.

RECOMMENDATION 4: Screening and testing.

As the population grows older the likelihood of women being called for mammograms will increase, and drives to increase uptake of cervical screening will continue. Combining this with testing for prostate cancer and other cancers related to older age, will necessitate careful planning and delivery of screening. Research could investigate the development of best practice guidelines for service providers within the public, private and not-for-profit sectors.

RECOMMENDATION 5: Health promotion and self care.

The messages of healthy eating, non-smoking and importance of exercise should be mapped out for the learning disability population, focusing on older adults who may increasingly have co-morbidities which include cancer. This is particularly the case given the limited awareness people have about the incidence of cancers in younger people and appropriate self care.

RECOMMENDATION 6: Loss and bereavement.

As people grow older they are increasingly likely to know peers/friends/relatives who have died from cancer. Given strong associations between cancer and death, the potential for late diagnosis, the social contexts in which people with learning disabilities live, and fear of taking up treatment, identifying bereavement and loss supports will be crucial. This research could helpfully include a prospective or retrospective needs assessment.

RECOMMENDATION 7: Exploring the support needs of staff working with people with learning disabilities who develop cancer.

Given the expressed views and interpretative analysis of conversations with gatekeepers, research could focus on a needs assessment of staff, particularly regarding their information/knowledge of the disease, emotional impact of the cancer, bereavement and relationship building with family members

RECOMMENDATION 8: Age and prevalence/incidence and cancer.

There is a paucity of information regarding the incidence and prevalence of cancer in this population making a study which explored the epidemiology valuable to inform service planning, design and development.

RECOMMENDATION 9: The dimensions of appropriate support to peers/co-residents when a person develops cancer.

Similar to previous proposed research topics, the wider impact of cancer could helpfully be explored focusing on other people with learning disabilities and explore fears, particularly given the paucity of positive communication around the disease, its symptoms and side-effects of treatments. This study could explore the knowledge and awareness of peer groups, and what supports are necessary if the peers are aware of the diagnosis and symptoms. Given the very different social circumstances in which people with learning disabilities live, compared to the general population, a range of different supports will be necessary. An approach which is cognisant of the necessary partnership and systemic working will be necessary to drive this forward.

6.2 Conclusion

This report has outlined the process and outcomes of developing advisory forums for people with learning disabilities who have been affected by cancer. The study, working alongside people with learning disabilities affected by cancer, has identified a rich vein of research ideas.

One of the major barriers to progressing research in this field will be in working alongside support services and health care professionals to facilitate access to people affected by cancer. Challenging the enduring paternalism of services, and opening dialogue about how best to support people with learning disabilities engage as fully as possible in their care, must be a first step.

References

Adults with Incapacity (Scotland) Act (2000)

Braun, V. & Clarke, V. (2006), "Using thematic analysis in psychology". *Qualitative Research in Psychology*, 3, pp. 77-101.

Burkhart, J., Fox, R., & Rotatori, A. (1985). Obesity of mentally retarded individuals: prevalence, characteristics and intervention. *American Journal of Mental Deficiency*, 90, 303-312.

Cooke, L. B. (1997), "Cancer and learning disability", *Journal of Intellectual Disability Research*, vol. 41, no. 4, pp. 312-316.

Davidson, S., Wilkinson, H., Urquhart, G., Wasoff, F., and Mason, A. (2004) Review of the Implementation of Part 5 of the Adults with Incapacity (Scotland) Act 2000: A qualitative study of Implementation and Early Operation. Scottish Executive Research Findings No. 38, Edinburgh.

Department of Health (2000) The NHS Cancer Plan. Department of Health, London.

Department of Health (2003) Strengthening accountability: Involving patients and the public. Department of Health, London.

Donaghey, V., Bernal, J., Turrey-Wijne, I., & Hollins, S. (2007) Getting on with cancer Gaskell/ St George's Hospital Medical School, London.

Dupont, A., Vaeth, M., & Videbach, P. (1987) Mortality, life expectancy and causes of death of mildly mentally retarded in Denmark. *Uppsala Journal of Medical Science Supplement*, 44, 76-82.

FAIR (2005) Keep Yourself Healthy: Living with Cancer. Book 2: Someone I know has cancer. What does it mean for me? FAIR Multimedia, Lothian.

Hogg, J. (1997) "Intellectual disability and ageing: ecological perspectives from recent research", *Journal of Intellectual Disability Research*, vol. 41, no. 2, pp. 136-143.

Hogg, J., Northfield, J., & Turnbull, J. (2001) Cancer and people with learning disabilities BILD, Kidderminster.

Hubbard, G., Kidd, L., Donaghy, E., MacDonald, C., Simpson, M., Haig, A., & Walker, S. (2005) Phase 1 report: Literature Review. Involvement of people affected by cancer in research, policy and planning and practice, Cancer Care Research Centre, Department of Nursing and Midwifery, University of Stirling.

ISD 2007, <http://www.isdscotland.org/isd/1508.html#All%20cancer%20types> viewed September 2007.

Jancar, J. (1990) "Cancer and mental handicap. A further study (1976-85)", British Journal of Psychiatry, vol. 156, pp. 531-533.

Kearney N, Worth A, Paterson G, Kendall M (2003) Patient Experiences Of Cancer Care In Scotland. A review of patient experience and involvement in cancer care.

Kearney, N., Rowa-Dewar, N., Ager, W., Ryan, K., Hargan, I., Gibson, F., Worth, A., Hubbard, G., & Walker, S. (2005) Phase 1 report: Public Involvement, Cancer Care Research Centre, University of Stirling.

Morgan DL (1997) Focus Groups as Qualitative Research. Thousand Oaks, CA: Sage.

NHS Executive (1999) Patient and Public Involvement in the New NHS. Leeds, Department of Health.

O'Brien, K., Tate, K., & Zaharia, E. (1991) Mortality in a large Southeastern facility for persons with mental retardation. American Journal on Mental Retardation, 95, 397-403.

Patja, K., Eero, P., & Iivanainen, M. (2001a), "Cancer incidence among people with intellectual disability", Journal of Intellectual Disability Research, vol. 45, no. 4, pp. 300-307.

Patja, K., Molsa, P., & Iivanainen, M. (2001b), "Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study", Journal of Intellectual Disability Research, vol. 45, no. 1, pp. 30-40.

Appendix 1 – Full search terms and databases searched

Search limits:1980-2007/humans/english language

	Keyword Search Terms	Databases searched
Search 1	Learning Disability /Learning disorders Intellectual Disability /mental retardation/ mentally disabled persons AND Cancer/neoplasms AND Gerontology/Geriatrics/Aged, 80 and over/aged/older people/aging/ ageing	Medline
	Learning disabilities/intellectual disability\$/mentally disabled persons/ mental retardation/ AND Cancer AND elderly people/older people/geriatric/ aged/aging/ gerontology/ageing	Web of Science
Search 2	Methodology/methods/ research design AND Learning Disability/learning disorders/ mental retardation/intellectual disability/ mentally disabled persons AND Creativity/imagination/ art/creativenes	Medline
	Research/methodology AND Learning disability / intellectual disability AND creativity	Web of Science
Search 3	Involvement AND Research/research design/research methods AND Learning Disability/learning disorders/mental retardation/intellectual disability/mentally disabled persons (LIMIT TO OVER 19 YRS OLD)	Medline
	Involvement AND Research/research methods/methodology AND Learning disability/intellectual disability/learning difficult (NOT CHILDREN)	ASSIA

Appendix 2 – Accessible flyer for group advisory work

OLDER PEOPLE WITH LEARNING DISABILITIES AFFECTED BY CANCER

WHAT ARE WE DOING?

I work at the Cancer Care Research Centre at the University of Stirling. I want to do some research with older people with learning disabilities who have had cancer or know someone who has had cancer. We would like you to help us to find out what to research.

WHAT WOULD I HAVE TO DO?

Do you know someone who has had cancer?
What do you know about cancer? What is important for us to know about it?



If you know someone that's had cancer, I would like you to come to a meeting with a small group of people to find out what you think.



We would all have a chat in a small group and you would tell me about some of your experiences of cancer.

There will be tea and coffee and we can pay for your bus/taxi ride.

WHEN WILL THIS HAPPEN?



We would meet as a group about 5 times over the summer.

WHO WILL I SPEAK TO?



My name is
Lisa McCann
and I am a
researcher.

I will be the person running the group. Phone me on 01786 849260 if you want to chat about the work or come to the meeting – it would be great to hear from you!



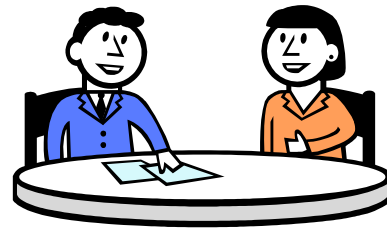
We have been given some money from Heather Wilkinson from Queen Margaret University in Edinburgh to find out what you think.

Appendix 3 – Accessible flyer for one-to-one advisory work

OLDER PEOPLE WITH LEARNING DISABILITIES AFFECTED BY CANCER

WHAT ARE WE DOING?

I work at the Cancer Care Research Centre at the University of Stirling. I want to do some research with older people with learning disabilities who have had cancer or know someone who has had cancer. We would like you to help us to find out what to research.



The two of us would have a chat and you would tell me about some of your experiences of cancer.

WHAT WOULD I HAVE TO DO?

Do you know someone who has had cancer?
What do you know about cancer? What is important for us to know about it?



If you know someone that's had cancer, I would like to chat with you to find out what you think.

I can travel to come and see you in your home or anywhere else you would like me to meet you.

WHEN WILL THIS HAPPEN?

We would meet once for a chat by the middle of September.

WHO WILL I SPEAK TO?



My name is
Lisa McCann
and I am a
researcher.

I will be the person you will speak to. Phone me on 01786 849260 if you want to chat about the work or speak to me – it would be great to hear from you!



We have been given some money from Heather Wilkinson from Queen Margaret University in Edinburgh to find out what you think.

Document Purpose	Involvement and engagement work to inform a research agenda for COPA
Authors	Lisa McCann, Dr Liz Forbat
Publisher	Cancer Care Research Centre, University of Stirling
Publication Date	September 2007
Target Audience	Health and social care professionals; researchers; policy makers
Further Copies From	cancercare@stir.ac.uk
Copyright	This publication is copyright CCRC and may be reproduced free of charge in any format or medium. Any material used must be fully acknowledged, and the title of the publication, authors and date of publication specified
Internet Address	www.cancercare.stir.ac.uk
Price	Free