# The Social Care Needs of People Affected by Cancer

## A Qualitative Study in Lincolnshire

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**Executive Summary**

## Background

People affected by cancer (PABC) can have a range of social care needs at different stages of the patient pathway. These may include emotional, practical, personal, as well as information and financial needs.

The UK charity, Macmillan Cancer Support want to refocus their current social care provision and, (where need is evidenced) develop new services to better address the social care needs of PABC in Lincolnshire. In order to do this effectively Macmillan together with the Bromhead Medical Charity has commissioned the University of Lincoln to undertake this research, with a view to developing a thorough understanding of the needs of PABC in Lincolnshire to ensure that service developments are acceptable, appropriate and accessible, and in line with the specific requirements of the local population.

## Aim

❖ To examine the social care needs of PABC in Lincolnshire.

❖ To provide recommendations regarding future service development and delivery.

## Methods

❖ A qualitative study utilising in-depth interviews (n=10).

❖ Interviews were analysed using the Framework method of qualitative data analysis (Ritchie and Spencer, 1994).

## Results

❖ All reported the need for emotional support (in particular around the initial diagnosis and surrounding period). This was fulfilled by friends, family, support groups and Macmillan health professionals.
❖ The need for practical and personal care support varied amongst those we interviewed with this often being dependent on the type and frequency of treatment. For most, family and friends shouldered the burden of this as opposed to social services.
❖ Some participants relied on personal income to pay for treatment and fund additional costs associated with their illness. Furthermore, expenses were also attributed to friends and family of the patient. In addition we received reports of negative experiences when dealing with the Department of Work and Pensions (DWP) and claiming for Employment Support Allowance (ESA).
❖ Information and advice was important throughout the cancer journey; the preferred format (physical or online) was influenced by personal preference. For some, they felt well informed whilst others would have liked more information.

## Conclusion

In line with national research (Macmillan, 2015), this study shows similarities in that respondents reported a range of supportive care needs in relation to emotional, practical and personal, financial and information support. Our study offers an in-depth analysis of the social care needs of PABC in a local setting.

The small sample and failure to recruit across all stages of the cancer journey would limit the extent to which the findings could be extrapolated to the wider population. At the same time, it is hoped that the recommendations offer valuable insight into areas that could further be developed to meet the needs of PABC throughout the county.

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## 1.0 INTRODUCTION

### 1.1 Background

Social care is the help and support that people receive both personally and practically to enable them to lead as independent a life as possible. Local authorities have a duty to assess those in need, and to signpost to support and provide funding if the individual is eligible. However, there have been a number of recent changes to social care budgets at national level and these have the potential to impact on individual eligibility to funding for care.

Given the current ageing population in the UK Hope and Wehner (2013) estimate that the total expenditure on social services for this demographic is expected to rise to over £20 billion by 2031. In a time of austerity and economic downturn, concerns have been raised among policy makers and government about the future increase in public expenditure within adult social care (Lloyd, 2010).

Putting People First (HM Government, 2007) set out a new way to provide funding for care through the implementation of personalisation. This involves greater focus upon reablement, prevention and early intervention as well as greater choice and control via personal budgets.

The Annual Budget Survey found that all councils had to make a cut of 26% in their social care budgets in 2010/11, and in 2015 these were expected to fall by a further 10% (Gardam, 2014). According to Charlesworth and Thorlby (2012) these recent cuts to social care have created a underlying disparity between funding, which has resulted in an increasing number of people on low incomes no longer entitled to state support.

These changes to social care can be seen within Lincolnshire County Council (LCC) which was required to make £9 million efficiency savings from its adult social care budget. This was achieved by restricting eligibility threshold for publicity funded social care to 'substantial' or 'critical' levels of need, which resulted in a significant reduction in the services provided. Lincolnshire Council has also reduced its in-house directly provided services budget from £27m to £8.10m in 2011/14. From 2015/16 a further saving is expected of £12.8m in adult social care (Lincolnshire County Council, 2012).

The restricted eligibility threshold and the increasing focus on efficiency savings are potentially problematic for older people and cancer sufferers within Lincolnshire; Lincolnshire has an ageing population and therefore it is expected to see an increasing number of people diagnosed with cancer each year (Ellis and Smith, 2013). Moreover, Lincolnshire is a predominantly rural county and can present significant challenges when it comes to accessing appropriate health and social care services.

### 1.2 Social care needs and people affected by cancer

It is known that people affected by cancer (PABC) have a range of social care needs at different stages of the patient pathway – emotional, practical, personal, as well as information and financial needs (Macmillan Cancer Support, 2009; 2013; 2015). Most are directly related to the person's condition and the impact of treatment and often apply to

both carers and people living with and beyond cancer. The type and extent of these needs will depend on a number of factors such as age, location, support from family and friends, and financial circumstances.

Having cancer can cause distressing emotional issues such as fear, anxiety, loneliness, depression or anger. The Macmillan report *Worried Sick* (2006) identifies that emotional needs and support are key, with 45% of PABC reporting that the emotional aspects are the most difficult to cope with. 49% want information and advice about the emotional aspects of a cancer diagnosis but 41% are unable to get this help. PABC can find it difficult to turn to their family and friends for emotional support and can feel isolated as a result.

Practical support can be both short and long term. The frequency and type of treatment (especially surgery and chemotherapy) itself limits what people can do practically as well as the effect of the condition on their physical strength. Practical needs relate to activities of daily living: for example, ability to prepare and eat food or to do grocery shopping or housework. This can also include issues with mobility around the home or assistance with getting to hospital appointments.

PABC can have difficulty carrying out personal care such as bathing, dressing or going to the toilet. Moreover, almost half of those living with cancer have at least one other long-term condition and nearly a quarter have at least two (Macmillan Cancer Support, 2009). As a result, maintaining personal care can be problematic.

PABC tend not to think about the financial impact of a cancer diagnosis and focus on fighting the disease (Macmillan Cancer Support, 2009). However, having cancer can significantly affect household income. PABC can find it difficult or impossible to work during treatment and beyond because they feel tired, weak, in pain, and ill. This can result in disputes with employers about access to sick pay or extended sick leave with some people losing their job or feeling compelled to leave as a result.

Information can be an effective coping strategy for PABC and it is likely that information needs will change over time and vary depending on the patient's circumstances. Existing research (Van der Molen, 2000) has shown that individuals are less likely to express their need for information relating to their social and supportive needs as opposed to medical information needs. However, that does not mean that such needs do not exist. The Macmillan *Social Care for Cancer* (2009) report highlighted that being referred for tests and waiting for results was a particularly anxious time, when little or no information, advice and support was perceived as available. Information needs can include wanting support on how to tell people about a diagnosis, how treatment will affect a person with cancer and what to expect when treatment finishes. Further information needs may involve wanting to know what support is available emotionally, practically and financially.

Often, PABC are not identified as having social needs, are not signposted or referred to appropriate services, and are unaware of the support that is available. Resources are limited and patients rarely identify themselves as meeting the requirements for social care services. Therefore much social care is provided informally by family and friends.

Patients who have recently been diagnosed commonly report a range of social care needs including psychological distress, a need for information and concerns regarding

their ability to take care of their home and maintain relationships (Whelan et al, 1997). Other research (Harrison et al, 2009; Sanson-Fisher et al, 2000) has shown that social care needs are notably evident with patients undergoing treatment. It is known that people living with and beyond cancer can have a range of unmet needs after treatment has finished (Boyes et al, 2012; Hodgkinson et al, 2007; Pauwels et al, 2013) however, they are often not likely to report these (Armes et al, 2009).

Despite a recent quantitative national study (Macmillan Cancer Support, 2015) there is little evidence, or in-depth analysis, as to what cancer sufferers most value in terms of social care support and how this might change over the course of the cancer journey. Particularly, much is still unknown regarding the needs of cancer sufferers in rural areas (Butow et al, 2012) such as Lincolnshire. Patients from rural areas appear to have higher needs in the domains of physical/daily living and the need to travel for treatment can result in practical, emotional and financial problems.

In response to these issues and to the particular demographic challenges faced by cancer sufferers in Lincolnshire, Macmillan Cancer Support now want to refocus their current social care provision and, where need is evidenced, develop new services to address better the social care needs of PABC in Lincolnshire. In order to do this effectively Macmillan want to develop a thorough understanding of the needs of PABC within the county to ensure that service developments are acceptable, appropriate and accessible, and in line with the specific requirements of the local population.

Awareness of social care needs is vital for the planning of future services and as such, Macmillan together with the Bromhead Medical Charity has commissioned the University of Lincoln to undertake this research to understand further the needs of PABC. Future interventions need to be proactive and targeted to meet social care needs at different stages of the cancer journey (Janda et al, 2006) as unmet needs can result in unnecessary hospital admissions.

## 2.0 METHODOLOGY

### 2.1 Ethical approval

An application was made on 25th April 2014 to the Health Research Authority/NRES Committee: West Midlands (14/WM/0154). This was approved on 20th May 2014. A copy of the approval letter is included at Appendix 1.

Approval was also sought from the Lincolnshire Community Health Services (LCHS) NHS Trust Research and Development office via a formal application submitted on the 2nd May 2014. This was approved on 30th July 2014 and the approval letter is included at Appendix 2.

Furthermore, an application was made on 12th May 2014 to the Research Ethics board at the University of Lincoln. This was approved on 21st May 2014. The approval letter can be found at Appendix 3.

Finally, a Participant Identification Centre (PIC) application was submitted to the United Lincolnshire Hospitals Trust (ULHT) Research and Development department on the 12th June 2014. This was approved on the 8th August. A copy of the approval letter is included at Appendix 4.

### 2.2 Aims and objectives

The aims of the study were:

❖ To examine the social care needs of PABC in Lincolnshire.

❖ To provide recommendations regarding future service development and delivery.

The specific objectives were:

❖ To conduct twenty interviews with PABC at different stages of the cancer journey
- 5 x recently diagnosed
- 5 x currently undergoing treatment
- 5 x living with and beyond cancer
- 5 x in receipt of palliative care
❖ To analyse and collate the findings from the qualitative interviews, to identify emerging themes about social care needs and provision in Lincolnshire.

## 2.3 Methods

### 2.3.1 Design

Given the exploratory nature of the research a qualitative approach was considered appropriate to allow for open discussion about participants' experiences. This research adhered to the consolidated criteria for reporting qualitative research (COREQ, 2007) guidelines.

### 2.3.2 In-depth interviews

The objective of the interviews was to explore the views of a sample of PABC in relation to social support and identify the strengths and weaknesses of current social care provision within the county.

### 2.3.3 Designing the topic guides

An in-depth topic guide developed specifically for the qualitative interviews with PABC in this study. The topic guide was designed to explore in depth their experiences of social support services. Participants were also encouraged to elaborate on any issues of particular importance or relevance to themselves.

A copy of this is included at Appendix 5.

### 2.3.4 Collecting the qualitative data

Participants were recruited (on behalf of the research team) via Macmillan Clinical Nurse Specialists (CNS) who already had an established relationship with the patient.

They were sent (by post) a cover letter introducing the study (included at Appendix 6), an invitation (included at Appendix 7), and an information sheet (included at Appendix 8). Those who expressed an interest in taking part were asked to register their interest with the research team, who contacted the participants on a one to one basis to arrange a convenient time and location for the interview. The research team conducted ten interviews between 18th November 2014 and 10th June 2015 at various locations across Lincolnshire.

Prior to the interview, participants were reassured that participation was voluntary and would not affect their support in anyway and that they could withdraw at any stage, should they wish to do so. Each participant was asked to read and sign a consent form (included at Appendix 9).

All the interviews took place in the participant's home with the exception of three interviews that were held at a private location at the University of Lincoln, Brayford Campus. Interviews lasted between 40 and 75 minutes and all were digitally recorded and transcribed verbatim. No personal information appeared on any of the transcripts: only unique ID codes were used. The digital transcriptions were stored on a password

protected computer at the University of Lincoln and printed versions were stored in a locked filing cabinet on the university premises.

### 2.3.5 Analysis

Qualitative interview data were transcribed and anonymised. Data were processed using the qualitative data analysis (QDA) software package NVivo (Ver. 10) and analysed based on the Framework Method of qualitative data analysis (Ritchie and Spencer, 1994). Transcripts were independently read by three members of the research team (D.N., R.K. and H.D) then independently open coded and discussed until they reached agreement. Transcripts were reviewed multiple times, and new codes added as appropriate and others were grouped together into broader categories. Next, themes were deduced and interpreted. Regular review and discussion by the research team contributed to data synthesis and interpretations.

## 3.0 RESULTS

### 3.1 Description of sample

The sample consisted of ten participants, six female and four male. The majority (70%) of those interviewed were aged 55-74. Six participants resided in an urban area, with four living in a rural area; participants from six of Lincolnshire's nine districts were interviewed. The majority (70%) were currently married and most (60%) were retired. Whilst the aim was to recruit participants at all stages of the cancer journey, the majority (80%) of the sample were people living with and beyond cancer (LWAB), with 1 participant currently undergoing treatment (CUT) and 1 participant recently diagnosed (RD). For further details of the sample, see table 1 below.

**Table 1: Participant details**

| ID | Gender | Age | Living area | District | Marital status | Employment status | Stage |
|----|--------|-----|-------------|----------|----------------|-------------------|-------|
| 01 | Female | 55-64 | Rural | West Lindsey | Married | Employed, part-time | LWAB |
| 02 | Female | 45-54 | Urban | North Kesteven | Married | Employed, full-time | LWAB |
| 03 | Female | 75+ | Urban | Lincoln | Widowed | Retired | LWAB |
| 04 | Female | 55-64 | Urban | Lincoln | Married | Retired | LWAB |
| 05 | Female | 65-74 | Urban | East Lindsey | Widowed | Retired | LWAB |
| 06 | Female | 65-74 | Urban | North Kesteven | Divorced | Retired | CUT |
| 07 | Male | 55-64 | Rural | South Holland | Married | Unable to work | LWAB |
| 08 | Male | 55-64 | Rural | East Lindsey | Married | Unable to work | LWAB |
| 09* | Male | 65-74 | Urban | Boston | Married | Retired | RD |
| 10* | Male | 75+ | Rural | North Kesteven | Married | Retired | LWAB |

*Note: Participant's partner was also interviewed*

### 3.2 Report on the qualitative interviews

The results of the Framework analysis are presented within the following four categories:

- ❖ Emotional Support

- ❖ Practical and Personal Support

- ❖ Financial Support

- ❖ Information and Advice

#### 3.2.1 Emotional Support

All ten participants reported the need (to varying degrees) for emotional support throughout the cancer journey. This was primarily fulfilled by friends, family, peers and Macmillan health professionals. For some, emotional support over the phone was satisfactory whilst others preferred to meet someone face-to-face.

Notably, the initial diagnosis and surrounding period were traumatic for several of the respondents when asked how they felt during this time. They stated:

*"Absolutely devastated, I just couldn't believe it."* (Participant 05)

*"I just felt lost; gutted."* (Participant 08)

*"Frightened to bloody death."* (Participant 09)

One of the participants suggested that they would have liked a private area in the hospital to help them adjust to the emotional impact of a cancer diagnosis. She states below:

*"I think when I was told; maybe it would have been nice to have gone somewhere afterwards where you can get yourself together again. Obviously it is upsetting, I'm not being blasé, you come out of a consultant's room and you have to walk through outpatients, where it's really busy. Maybe if you could have gone somewhere where you could have composed yourself and walked out that would have been nicer…because it is quite embarrassing."* (Participant 02)

Another respondent explained that they would have struggled to cope with their situation without emotional support, in particular when they had been recently diagnosed:

*"Like I say if you didn't have that (emotional) support especially in the beginning then it would have been a completely different story."* (Participant 01)

Several of the participants reported negative experiences of communicating with health professionals at the point of diagnosis, as evident below:

*"Well I was a bit dumbfounded because the doctor was very outright, outspoken about it, not beating around the bush."* (Participant 03)

*"And quite frankly it was rather blunt the way the doctor told me, he said, well Mr (removed), you've got prostate cancer…he needs a different approach as to how he deals with patients who are first diagnosed…if it was phrased slightly differently…but no it was just straight."* (Participant 10)

Another participant explains the difficulties of coping with a cancer diagnosis and having trouble sharing this information with friends and family:

*"You're hit with so much to begin with; you've got to cope with a life threatening illness, you've got to cope with telling your friends and family, knowing that it's a horrible battle and it's not pleasant."* (Participant 04)

For some, it was important to have someone to talk to, outside friends and family. For example, the following participant reported on how Macmillan fulfilled that role. He stated that:

*"I think you want somebody to talk to. Your family is there…but I think you want somebody outwith that who doesn't really know you and can talk to you properly. And like I say with Macmillan they did that, just for a chat and stuff like that."* (Participant 07)

Another participant reported positively on the emotional support they received from Macmillan, specifically from one of their Information and Advice Centres:

> (Macmillan Information and Support Facilitator's name), she was our first point of contact after I received the news, I was virtually devastated. I don't know what I would have done had she not been there, but she was there and she consoled me and reassured me that it wasn't the end of the world and they were there to support me in whatever way they can." (Participant 10)

For others, they had difficulty sharing their cancer diagnosis with fellow employees. For example they stated:

> "…the nature of my job, you have to plan for cover, so I had almost two weeks where I had to carry on at work. Obviously it was traumatic because I couldn't be myself, I still couldn't share, and that was the difficult part. I couldn't bring myself to tell everyone around me...the only person I could share with was the personnel manager…if I'd been able to discuss it with my co-workers maybe I could have handled it better." (Participant 01)

> "Obviously I had to tell my line manager what was going on but that week that I had to wait (for results), it was particularly difficult because I didn't want to tell anyone else at work, so that was quite a strain." (Participant 04)

It was evident that peer support assisted with the emotional support needs of several of the participants interviewed. For example, the following participant stated that:

> "I've been very fortunate that I've made quite a few friends that were also having chemotherapy and we are also still in contact. It was a real source of support…During our treatment times I would meet up for lunch or evening meals with these other girls that were all going through the same thing as me…About two weeks after our chemo we'd all be feeling a lot better and we'd all go out and hit the town somewhere!" (Participant 04)

Additionally, the participant below explains how they benefited from using online support groups as a form of mutual support. He stated that:

> "…When you talk to people on the online support group, a lot of them have been through the same trouble…people come on and say I've just been diagnosed and we all talk to each other and help each other." (Participant 07)

Interestingly, the following participant explains how initially he did not want to attend a support group and how upon going has reported a positive experience of this. They stated:

> "Well I said I'm not interested in going and talking to a load of other people about my situation…I'll go once but I won't be going back. And we've only missed one in the last 9 months. Fantastic group of people. All sorts of different people, from recently diagnosed to living with cancer that are in remission at the moment…and they have a great social aspect to it as well." (Participant 08)

A further area that some of the respondents identified with regards to emotional support was that the partner or carer of the patient should also have someone to talk to. For example, the participant below explains:

> "From outside, I think it maybe would have been nicer for my husband to have had someone to talk to…I think it's always worse for other people than for the person that is ill." (Participant 02)

In addition the following participant reiterates the importance of support for those supporting the patient and explains a situation where his partner became upset and he felt unable to help. He stated that:

> "I think it's more important for the carer or the supporter to receive support. You know, she (patient's partner) sat here one night and I just noticed a tear. I said, what's wrong? She said, 'I've got nobody to talk to.' Of course, when the tears happen, I'm lost, I'm no good, and I'm a man after all! (Participant 08)

Finally, the same participant went on to say that his partner attends a local support group which she enjoys, however, he felt that there was a need for age specific carer support in that she was the youngest attendee and would have benefited further from meeting others closer to her age.


### 3.2.2 Practical and Personal Support

The need for practical and personal care support varied amongst those interviewed with this often being dependent on the type and frequency of treatment. For some, practical and personal support was a significant concern when they were undergoing treatment such as surgery and chemotherapy. Several participants reported feeling fatigued as a result of treatment, for example, the respondent below stated:

> "It's draining, physically; I just suddenly lost all my energy." (Participant 01)

For some they were happy with their treatment, it was the side effects that meant they needed assistance with daily living. For example, the following participant explains how the British Red Cross assisted with personal care. She stated:

> "I think they were Red Cross volunteers, yes, they were, who brought you drinks whenever you wanted and sandwiches at lunchtime. They were good." (Participant 05)

Furthermore the same participant also received practical support from the local hospice (St Barnabas) who assisted with the provision of a blue badge, wheelchair, cushion and a rollator. She goes on to explain how she recently received help with her shopping from a Macmillan Volunteer service also.

Several of those interviewed reported the need for assistance with household tasks such as shopping, cleaning, cooking and gardening. For the majority, family and friends shouldered the burden of this as opposed to social services. For some, they had family in close proximity and as such, could rely on them to help during their treatment. For example, the respondents below stated:

> *"…my mum and dad live next door, more or less, so they would come round everyday to do my hoovering and ironing and I could manage the rest."* (Participant 02)

> *"I was lucky my husband helped around the house…but I'm sure some people wouldn't be able to if they were on their own, I don't know how they would cope with running a home, doing the washing, ironing, and the cooking."* (Participant 04)

In addition, several respondents reported the importance of home help for those who do not have family or friends available and those who are geographically isolated, as can be the case in a predominantly rural county such as Lincolnshire.

Also worth noting is that several of those interviewed were suffering from a range of comorbidities, with many reporting that the effects of other illnesses were often worse than the cancer treatment. Not surprisingly, these participants tended to have a higher level of need when it came to practical and personal support. For example, the following respondents stated:

> *"I could hardly walk or anything, it was the pneumonia that made me more ill than the cancer."* (Participant 03)

> *"That was worse than the actual cancer treatment because the cancer treatment you got the injection and the blood test and that was it, virtually. But the eczema, you had to bathe and put the ointment on."* (Participant 10)

One of the participants reported positively on how their employer accommodated them returning to work after their treatment. She stated:

> *"They couldn't have done more for me. I even have my own toilet and wash basin, because I've got a tube in my throat, I can't go into communal toilets and sort my plumbing out. That was the only drawback, so they just gave me a toilet with a lock on the door. They couldn't have helped me more."* (Participant 02)

Several of the participants reported having to travel significant distances to receive treatment. This was due to their treatment not being available at their local hospital. Consequently, this meant relying on family and friends as well as hospital transport. The following participant lived in close proximity to their place of treatment; however, they recall how their friends travelled a significant distance to receive radiotherapy therapy treatment. She stated:

> *"I was very fortunate that I live quite close to the hospital [NAME OF HOSPITAL] so the journeys weren't too bad but I did have two friends that used to have to come for radiotherapy all the way from Grantham. One of them didn't drive and so she literally left at half past 7 in the morning, she got picked up and didn't get home until 3 in the afternoon…she was utterly exhausted. She had to do that for 15 days. It's such a big county; you'd think she could have had treatment at a different hospital, a closer hospital."* (Participant 04)

Furthermore, the participant below reported a positive experience of utilising hospital transport to travel to Nottingham for treatment. They stated:

> *"A few times I went with hospital cars which were very good…I was given a phone number and I could phone up and book the car. Sometimes it was just me and a couple of times they picked up someone else…They were excellent. When you go and see the specialist afterwards sometimes you can be in the queue, the driver said 'you don't do that if you are with a hospital car, tell them and they will put you to the front of the queue and you won't have to wait so long.' It worked."*
> *(Participant 03)*

Finally, there was evidence of Macmillan assisting with personal care needs of patients. For example, the following participant recalls how a Macmillan Information and Support Facilitator provided him with a toilet card that was designed to give urgent access to a toilet. He stated:

> *"She gave me a Macmillan card, it's like a credit card. It says on it due to your medical treatment you need to use the loo and you can show it to anyone; a shop, a pub, a restaurant or anything." (Participant 10)*

### 3.2.3 Financial Support

Most participants reported that finances were a significant worry throughout the cancer journey. For example the following respondent stated:

> *"Definitely, you can't be worrying about money when you are worrying about your health; I think that would be an added burden." (Participant 01)*

Many of those interviewed did not receive any financial assistance and had to rely on personal income to fund additional costs, such as, getting to and from hospital. One participant felt that hospital transport should be easily accessible for all those on lower incomes. Furthermore, several of the participants chose to pay privately for treatment and as a result have had to manage their finances more carefully.

Financial costs should not just be attributed to the patient as some of those interviewed reported added financial pressure on family and friends. For example, one participant who had their treatment in Nottingham explains below how her partner saved money with accommodation being provided at the hospital, she stated that:

> *"The nursing staff in [NAME OF HOSPTIAL] had a relatives' room and so he stayed ten days in the relatives' room which they didn't have to do that. Obviously, he (partner) saved a lot of money." (Participant 02)*

Furthermore, the following participant explains how it was a costly period for her children when traveling to see her, they stated:

> *"It was a strain; it had been a bit of a strain on the daughters, traveling, the cost of petrol, having to have time off work…none of them could say it's only just half an hour or twenty minutes down the road. So it was bad for them." (Participant 03)*

Several of those interviewed had been in employment when they were diagnosed. The following participant (at the time of interview) was about to return to her job as a

pharmacist and reported a positive experience of being supported financially, she stated that:

> *"I'm still off work. It's at the end now. I had the official support to be off because I've been with the company for a long time. The absence support has been great." (Participant 01)*

Another participant explained that they were given 6 months on full pay and 6 months on half pay when off work. In addition to this they were entitled to a small sum of financial support when on half pay but had to do a 45 minute telephone assessment in one sitting and found this process tiring as they were receiving treatment at the same time. They were then later told that this money would be reclaimed when they returned to work and explain below their frustration with this:

> *"And you just think, I have struggled to get through cancer and struggled to get back to work and now you are penalising me for it. So yes that made me feel very cross." (Participant 04)*

Additionally, the same participant explains that after having lymph nodes removed they found returning to their previous job as a classroom teacher exhausting and consequently had to take early retirement. She stated:

> *"I was told I had to go back to my job as a classroom teacher because the budget wasn't there for an intervention teacher, I did it for a short while but it was too exhausting…unfortunately they wouldn't let me take early retirement, I had to take quite a loss on my pension." (Participant 04)*

Furthermore, the following participants also had to give up work prematurely as a result of their illness. They stated:

> *"Well you see I had to pack up work because I couldn't do a day's work." (Participant 07)*

> *"I was made to give up my job through the company I was with which was rather hard for me, I had no intention of ever retiring because I can't afford it but that's beside the point." (Participant 08)*

Some respondents reported negative experiences when dealing with the Department of Work and Pensions (DWP). For example, the following participant had lost their skills of communication as a result of treatment and found corresponding with the DWP problematic.  She stated:

> *"…very strangely the DWP spoke to my husband when they wanted their £588 paid by debit card over the phone and so they made an exception there. Unfortunately, for anything else it's the Data Protection Act. You would think they wouldn't take my bank details from someone else, so it was a bit convenient. I don't think the people that work there have the skills that are required." (Participant 02)*

The same participant goes on to suggest that there should be someone who is legally recognised to help with paper work and financial matters, especially for older people or those who don't have any family in close proximity.

Again another participant outlines issues they had with the DWP and receiving Employment Support Allowance (ESA). He stated:

> *"The only thing really was the DWP. According to them I went through 6 months of chemo for the love of it, they said there's nothing wrong with you! Like I say, I go for a medical and I'm not fit to work. My immune system is virtually shot, that's part of leukaemia…so I have to be careful with what I do…I was on ESA but its due for renewal next year and I think they'll want to get me back to work. To me it's all government figures, make it look good, get him off that!" (Participant 07)*

Conversely one of the retired participants reported a positive experience of dealing with the DWP, when receiving Attendance Allowance to assist in paying with their personal care. They explained how the local hospice (St Barnabas Lincolnshire Hospice) assisted with the paperwork and that the payments were made promptly after submission. Further to this, they remarked on how they were unaware they would be eligible for such a payment had the hospice not suggested it. She stated:

> *"Then one day, I got this envelope full of information from St Barnabas, fill all these forms in and I ended up getting Attendance Allowance which I knew nothing about." (Participant 05)*

Some of the interviews revealed that participants were reluctant to apply for benefits or funding to meet their social care needs because they felt that they wouldn't receive it. One participant reported how her past experience when her husband was ill had influenced her decision not to ask for social care support. She stated:

> *"I knew that when my husband was ill, he never got anything socially, he wasn't eligible because you've got money in the bank." (Participant 03)*

Moreover, others felt they didn't need this help and so wouldn't seek it but recognised the importance of financial assistance being available to those worse off than them.

There were several positive reports of Macmillan introducing benefits and financial support. For example, the following participant explains how a Macmillan Benefits Advisor assisted him. He stated:

> *"Macmillan they helped with benefits and stuff like that and they did what I wanted, they helped a lot. I've managed, money has been a bit tight but we live to our means… I tried to get some extra benefits, through Macmillan, they helped me 100%. I do get council tax relief and bits and pieces." (Participant 07)*

Finally, the following participant explained how Macmillan assisted financially with utility bills. He stated:

> *"We were struggling with electricity and gas bills and we got a grant from Macmillan, £250, which helped with the bills. But then a benefits officer from Macmillan contacted us, because we are with [NAME OF ENERGY SUPPLIER],*

*they do a system where they work in conjunction with Macmillan and we now actually pay £10 a month for gas and £10 for electric, for a two year period and anything else is written off which is excellent." (Participant 08)*

### 3.2.4 Information and Advice

Whilst information and advice was important throughout the cancer journey, some of the patients reported that they felt it was essential around their initial diagnosis. The preferred format of information varied amongst those interviewed as did the frequency with which this was accessed, and was often influenced by the patient's personal preference. For some, they felt well informed throughout the journey whilst others felt they could have been informed better.

Many participants utilised Macmillan literature that was available at the hospital where they were receiving treatment. In addition to this, others made use of Macmillan's online materials, although some preferred physical hard copies of literature, particularly the older participants interviewed. Both physical and online materials served as a way of further informing patients about their condition and its side effects, with most reporting positive experiences of using these and that they were easily accessible. However, one participant acknowledged that other approaches should also be considered, such as delivering information orally to groups of patients, she stated:

> *"Information is key. Like I said, all the resources are there but it's not like everybody has the flair to read. So maybe like classes." (Participant 01)*

Furthermore, the following participant felt Macmillan literature was lacking in detail, she stated that:

> *"They give the basics. They are pretty basic, if you want a little bit more you can go elsewhere." (Participant 06)*

Some participants relied only on the information they were given and felt overwhelmed with the wealth of material online. For others, they proactively sought material online to read up about their condition. Interestingly, one respondent felt the information online was often out of date and that reading up on statistics was distressing. However, the following individual reported a positive experience of using the internet, in particular the CLLSA (Chronic Lymphocytic Leukaemia Support Association), he stated:

> *"So I started looking on the internet, I'm not very computer savvy but I found this other support group which I joined…I clicked on it and they said we'll send you an envelope and all the details…they do these meeting all round the country and we go and talk to other CLL patients and we go and tell each other the good, the bad and the ugly of it. There's one or two of them and they must be computer brilliant because they find stuff out, new research, I don't know where it is? They put it on there and you can read it that gives you a comfort." (Participant 07)*

Another respondent explained how they would read as much as possible online because they felt poorly informed from health professionals. In addition, another participant reported that they would often have to ask for information when seeing health

professionals, in that they felt they weren't always fully informed about the extent of their illness. Furthermore, some participants explained that consideration needs to be given to the terminology and language that health professionals use when discussing their condition.

The following individual reported positively on their relationship with health professionals and how they appreciated a direct approach when discussing their illness, she stated that:

> "They're so straightforward with what they're telling you and they're not afraid for me to ask them things and give me proper answers that I've wanted...I can ask them anything." (Participant 05)

The majority of those reported that Macmillan professionals were a positive source of information and advice. However, one participant explained that they did not have a Macmillan nurse when they were initially diagnosed and as a result felt ill informed about their treatment. In particular, those who used one of Macmillan's Information and Advice Centres found these to be an excellent source of support and reassurance. For some knowing this was there and having the contact details (even if they were not used) offered a sense of security to the patient. It should be noted that satisfaction with these centres was heavily influenced by the personal attributes and skills of the Macmillan Information and Support Facilitators that worked there. For example, the following participant explains:

> "I know we have kept on about Macmillan but they have been really good to us. We can't fault them at all and through the (MISF's name) because she's our main contact, they've always been great and told us what we need to know." (Participant 10)

Of additional interest, several respondents reported that health professionals would rarely discuss their social or supportive care needs and that they would have liked this. For many, they felt they would have been ineligible for formal social care support; however, some of them still would have liked to have discussed their social care needs and been signposted to appropriate information regardless of eligibility.

With regards to information on employment and cancer, one participant reported that they felt there was a lack of accessible information regarding this and they had to do a lot of searching themselves which they found tiring. A further gap that participants identified was a lack of information for the carer or partner of the patient. It was evident from the interviews that several respondents felt it was important for the carer to be offered information and advice as they are often not inclined to ask for help themselves.

Some of the participants talked about the importance of peer support and how this served as a useful source of information. For some, support groups were a useful source of mutual support and information whilst others felt these were not for them. One of the participants interviewed had decided to volunteer at Macmillan's Information and Advice Centre at his local Hospital. He would use his own experiences to offer advice to other patients. Aside from this being a positive experience for him and as a means of keeping active, he explained that it had taught him to share his own experiences also.

Furthermore, the same participant volunteers for Macmillan in a local library and has raised awareness on Lymphoma via fundraising at his local Hospital, he explained below:

> *"I did a week outside the restaurant fundraising in [NAME OF HOSPITAL] where I had a stall set up with all the Lymphoma information…I managed to raise £350 odd pounds and they sent me a lovely certificate saying thank you for it. I thought that was nice…" (Participant 08)*

Furthermore, another participant felt inspired to help others with cancer by starting up a support group in their local area, she states below:

> *"I would like to start a support group myself because after my treatment, after my surgery, I went to see if there was a support group in Lincoln but they don't have any for the form of cancer that I was diagnosed with, so that shows there is a gap there…I would like to help others. I don't want everyone to go through thinking they are on their own." (Participant 01)*

Finally, a further area of peer support that a participant explained is a 'buddy up' system where two individuals are connected together. The following participant reported how she was approached to help someone with the same form of cancer, she states:

> *"Yeah I mean I will help anyone else…They've just had a girl of 26 who has had this. They had nobody, I know I am twice her age but they had nobody to advise or talk or whatever, that had the same thing done. And so they asked me last week if in future if they had someone of a younger age would I be willing to answer questions and I said yes." (Participant 02)*

# 4.0 CONCLUSION

## 4.1 Limitations

### 4.1.1 Ethics

- ❖ The research was subject to considerable delay with regards to obtaining ethical approval from several bodies (NRES West Midlands; LCHS R and D; ULHT R and D). This involved several amendments to ensure continuity between applications.

### 4.1.2 Sample size and participant bias

- ❖ The response rate was lower than originally anticipated and failed to deliver the target sample of twenty participants across all four stages of the cancer journey.

- ❖ The sample was therefore inevitably biased predominantly consisting of people living with and beyond cancer and did not contain any patients who were in receipt of palliative care.

### 4.1.3 Recruitment

- ❖ As a result of winter pressure demands, many of the CNSs who were recruiting to the study had an increased workload and did not have time to assist with recruitment.

- ❖ Several of the CNSs did not report back whether they had sent out any invites.

- ❖ Several interviews had to be cancelled due to the participant being too ill to take part.

- ❖ The above delays were documented with senior staff at Macmillan (18/12/14; 12/01/15; 04/02/15; 04/03/15) and it was agreed that going forward other recruitment options would be explored, most notably utilising the services of the Macmillan Information and Support Facilitators throughout the county.

### 4.1.4 Timeframe

- ❖ As a result of the above limitations, the study has been over a longer time-frame than initially anticipated.

## 4.2 Good Practice

This research has highlighted several examples where existing services are working effectively to meet the supportive care needs of PABC.

- ❖ Several respondents reported how utilising Macmillan services (telephone and face-to-face) had helped them emotionally. Furthermore, online and face to face support groups were effective in responding to some people's emotional needs.

- ❖ Services provided by other organisations, notably St Barnabas Hospice, the British Red Cross and Macmillan were effective in meeting some of the personal and practical care needs of the participants interviewed.

- ❖ Participants reported positive reports of Macmillan assisting with financial help, for example, with accessing benefits and paying utility bills.

- ❖ Macmillan literature (physical and online) and Macmillan professionals were a positive source of information and advice. In addition those who had used Macmillan's Information and Advice Centres found these particularly beneficial. Furthermore, support groups and peer support were also utilised as a way of informing some of the participant's about their condition.

## 4.3 Poor Practice

The results also drew attention to a number of areas that were not effective in meeting the participant's social care needs.

- ❖ The manner in which doctors communicated the news of a cancer diagnosis to some of the participants was seen as insensitive and lacking in empathy.

- ❖ There was a perceived shortage of accessible information around cancer and employment. Furthermore, there was a lack of government support surrounding employment and finances, in particular around dealing with the DWP and accessing benefits such as ESA.

- ❖ Several of the participants reported that there was a perceived lack of information and emotional support for carers and partners of people with cancer.

- ❖ Health professionals would rarely discuss social or supportive care needs with patients. Consequently, there was a lack of signposting to social support.

## 4.4 Recommendations

As a result of the findings in this research, several recommendations in relation to social support of PABC in Lincolnshire have been formulated.

### 4.4.1 Clinical empathy

❖ It is recommended that doctors as well as other health professionals who come into direct contact with PABC are trained in advanced communication skills, in particular at the point of diagnosis, as this proved to be a distressing time for several of the participants.

❖ Given that there was a perceived lack of compassion from doctors it is important that future communication training emphasises skills in clinical empathy.

### 4.4.2 Support at diagnosis

❖ At the point of diagnosis, it is recommended that PABC are given a comfortable environment in which they can gather themselves before leaving the building.

❖ Where possible a Macmillan nurse should be available at diagnosis to assist with emotional and information needs. If not available, health professionals should signpost the patient to a Macmillan Information and Advice Centre or relevant support elsewhere.

### 4.4.3 Information support

❖ In order for cancer patients and those who support them to get the appropriate information they need, it is suggested that future information and advice continues to be available in a variety of formats, both hard copies and digitally.

❖ Information resources should be widely publicised and made accessible to all throughout the county in a range of health and community settings.

### 4.4.4 Age-specific needs

❖ It is important to consider the different needs of cancer patients and their carers as this can be age-specific.

❖ A variety of support is needed for example, support groups for younger carers as evidenced by this research.

❖ Support groups will not be for everyone but it is important for patients and their carers to know they exist.

### 4.4.5 Accessibility

❖ Given the rurality of Lincolnshire, it is vital that PABC who are socially or geographically isolated can access home and social care. Efforts should be made to ensure that homes have appropriate access to communication equipment such as a phone line and/or the internet.

❖ Macmillan along with other voluntary organisations and charities need to maintain and continue to build on existing links with the NHS and other social support services to ensure their services are well recognised and readily accessible throughout the county.

❖ Given that some of the participants had to travel significant distances when receiving treatment, it is recommended that where possible, treatment days could be shortened by reducing the number of patient drop offs.

### 4.4.6 Financial Support

❖ There is a need for up-to-date information on maximising income (benefits, help to stay in work) and minimising expenditure (utility bills, council tax etc.) to be available to PABC, their carers and those coming into contact with them.

❖ There is a need for information about Power of Attorney for both financial and welfare affairs.

❖ Where possible financial assistant should be made applicable to family members and carers to assist with the burden of a cancer diagnosis.

### 4.4.7 Employment

❖ There is a need for information leaflets with good practice examples for employees and employers about reasonable adjustments when PABC are returning to work.

❖ This information needs to be widely distributed amongst all employers and co-workers and where appropriate relevant training provided.

### 4.4.8 Carer Support

❖ People supporting cancer patients have social needs too and these need to be acknowledged by health and social care services.

❖ Health professionals should establish a directory of appropriate carer support services and signpost carers to support should they require it.

### 4.4.6 Social Care Assessment

❖ Doctors and nurses have a duty to discuss social and supportive care with patients and their carers.

❖ There is a need for all PABC to be signposted to social care for a holistic assessment of their needs, even if they are not likely to be eligible for funding.

## 4.5 Conclusion

In line with national research (Macmillan, 2015), this study has shown that PABC have a range of supportive care needs in relation to emotional, practical and personal, financial and information support. However, this research offers an in-depth analysis of the social care needs of PABC in a local setting.

Emotional support was important to those interviewed and there were difficulties around the initial diagnosis, most notably with being told the news and then sharing it with friends, family and co-workers. Secondly, the need for practical and personal support was most significant when the participant was undergoing treatment (especially surgery and chemotherapy) and was also dependent on the type and frequency of treatment. Finances were another salient concern; in particular problems around dealing with government agencies were uncovered. Finally, participants mostly felt well informed throughout the cancer journey and relied on a range of information resources but some reported a perceived lack of information on employment and support for carers.

The small sample and failure to recruit across all stages of the cancer journey would limit the extent to which the findings could be extrapolated to the wider population. At the same time, it is hoped that the recommendations offer valuable insight into areas that could further be developed to meet the needs of PABC throughout the county.

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**APPENDIX 1**

**NRES Committee West Midlands - Coventry & Warwickshire**

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839521

20 May 2014

Dr Roslyn Kane
Principal Lecturer
University of Lincoln
Think Tank Building
Ruston Way
University of Lincoln
LN6 7FL

Dear Dr Kane

| Study title: | To examine the social care needs of people affected by cancer (PABC) and to assess the effectiveness of a local support service to carers of people at end-of-life in Lincolnshire. |
|---|---|
| REC reference: | 14/WM/0154 |
| Protocol number: | N/A |
| IRAS project ID: | 146687 |

Thank you for your letter of 19<sup>th</sup> May 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Rebecca Morledge, NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.   The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment.  We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

**Approved documents**

The documents reviewed and approved by the Committee are:

| Document | Version | Date |
|---|---|---|
| Covering letter on headed paper | | 23 April 2014 |
| REC Application Form | 146687/599990/1/238 | 25 April 2014 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | AON | 29 July 2013 |
| Other [Interview Topic Guide Study A] | 1.2 | 23 April 2014 |
| Other [Invitation Letter Study A (Interviews)] | 1.3 | 13 May 2014 |
| Other [Interview Topic Guide Study B] | 1.2 | 23 April 2014 |
| Other [Invitation Letter Study B (Interviews)] | 1.3 | 13 May 2014 |
| Other [Invitation Letter Study A (Foucus Groups)] | 1.3 | 13 May 2014 |
| Other [Revised REC form] | | 13 May 2014 |
| Participant consent form [Study B] | 1.2 | 23 April 2014 |
| Participant consent form [Study A] | 1.2 | 23 April 2014 |
| Participant information sheet (PIS) [Study A (Focus Groups) Group B1] | 1.4 | 19 May 2014 |
| Participant information sheet (PIS) [Study A (Focus Groups) Group B2] | 1.4 | 19 May 2014 |
| Participant information sheet (PIS) [Study A] | 1.2 | 23 April 2014 |
| Participant information sheet (PIS) [Study A (Focus Groups) Group C1] | 1.4 | 19 May 2014 |
| Participant information sheet (PIS) [Study A (Focus Groups) Group A2] | 1.4 | 19 May 2014 |
| Participant information sheet (PIS) [Study B (Interviews) ] | 1.4 | 19 May 2014 |
| Participant information sheet (PIS) [Study B] | 1.2 | 23 April 2014 |
| Participant information sheet (PIS) [Study A (Focus Groups) Group C2] | 1.4 | 19 May 2014 |
| Participant information sheet (PIS) [Study A (Focus Groups) Group A] | 1.4 | 19 May 2014 |
| Participant information sheet (PIS) [Study A (Interviews) Group D1] | 1.4 | 19 May 2014 |
| Research protocol or project proposal | 1.2 | 11 April 2014 |
| Research protocol or project proposal | 1.3 | 12 May 2014 |
| Response to Request for Further Information | | 15 May 2014 |
| Summary CV for Chief Investigator (CI) | | 23 April 2014 |

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance
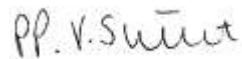
We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

| 14/WM/0154 | Please quote this number on all correspondence |
|---|---|

With the Committee's best wishes for the success of this project.

Yours sincerely

PP. V.Sutut

**Helen Brittain**
**Chair**

Email:          NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net

Enclosures:          *"After ethical review – guidance for researchers"*

*Copy to:*          *Mr Nigel Horner*
                    *David Nelson*

**APPENDIX 2**

Our Ref: Organisational approval PABC
Your Ref:
Please ask for: Janice Wiseman
Telephone: 01522 502023 ext 233
E-Mail address:  research.team@lincs-chs.nhs.uk
Date:   30<sup>th</sup> July 2014

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Fax: 01522 502021
Website: www.lincolnshirecommunityhealthservices.nhs.uk

Dear Dr Kane

**Study title:**       **Meeting Social Care Needs of People Affected by Cancer and their
                        Carers in Lincolnshire**
**REC reference:**     **14/WM/0154**

I am pleased to inform you that your project has gained assurance on behalf of the Lincolnshire
Community Health Services on the 30<sup>th</sup> July 2014.

Please note that this approval does not cover other health organisations within Lincolnshire and
therefore if your research is being conducted elsewhere, then you will also need to apply to that
relevant Research & Development Department for approval.

Conditions of organisational approval include ensuring that the following are adhered to:

- Consent procedures
- The Data Protection Act 1998, NHS Caldicott Principles and NHS approved information
  security standards (Information Governance Standards)
- Health and Safety issues
- Participation with research monitoring

As part of the research governance process all active research projects are routinely monitored;
the level of monitoring will depend on the degree of risk associated with the research project.
Please note that the monitoring form will request certain information regarding accrual figures.

At least 10% of research projects will be audited; this means that the Research Governance
Administrator may visit you and check the procedures you have in place.  We would inform you in
writing prior to any visit and arrange a suitable date and time with you or your representative.

All lead researchers **must** submit details of any amendments in their research in accordance with
IRAS guidance e.g. change of protocol, substantial amendments, change of personnel, any
adverse incidents etc.

We would also like to remind researchers they must declare any conflict of interest that they may
have including commercial interests/income, other research grants etc.

LCHS NHS Trust follows the requirements of the Freedom of Information Act and the details of
each active and completed research study will be published on LCHS NHS Trust website unless

you specify, in writing to us, otherwise.

Please contact us if you would like any information about the research governance arrangements and direct any information governance concerns to Information Governance Services on 01522 515 404 or email: infogov@lpct.nhs.uk.

We wish you every success with your research.

Yours sincerely

Janice Wiseman
Research Manager

CC –   Mr Nigel Horner, Head of School, The University of Lincoln

Miss A Thomson, Research Assistant, The University of Lincoln

Mr D Nelson, Research Assistant, The University of Lincoln

LCHS Research Team inbox

**Approved documents**

The final list of documents reviewed and approved by LCHS  NHS Trust is as follows:

| Document | Version | Date |
|---|---|---|
| R&D application form | 146687/600836/14/548 | |
| SSI form | 146687/608541/6/907/231927/299545 | |
| REC approval letter – further Information Favourable Opinion | | 20 May 2014 |
| Protocol | 1.3 | 12 May 2014 |
| Participant Information Sheet for Focus Groups (A1, A2, B1, B2, C1 and C2) | 1.6 | 10 June 2014 |
| Focus Group Consent Forms (A1, A2, B1, B2, C1 and C2) | 1.6 | 10 June 2014 |
| Participant Information Sheet for interviews with Carers (Study B) | 1.6 | 10 June 2014 |
| Participant Information Sheet for interviews (D1) | 1.6 | 10 June 2014 |
| Interviews Consent Form for Carers (Study B) | 1.6 | 10 June 2014 |

| Interviews Consent Form (D1) | 1.6 | 10 June 2014 |
|---|---|---|
| Patient Interview Topic Guide | 1.2 | 23 April 2014 |
| Carer Interview Topic Guide | 1.2 | 23 April 2014 |
| Study A Invitation Focus Groups | 1.3 | 13 May 2014 |
| Study A Invitation Interviews | 1.3 | 13 May 2014 |
| Study B Invitation Interviews | 1.3 | 13 May 2014 |
| Minor Amendment approval | | 8 July 2014 |

**APPENDIX 3**

School of Health and Social Care Ethics Committee
College of Social Science
Bridge House
Brayford Pool
Lincoln
LN6 7TS

Telephone 01522 882000
21 May 2014


**RE: To examine the social care needs of people affected by cancer (PABC) and to assess the effectiveness of a local support service to carers of people at end-of-life in Lincolnshire**

Dear Dr Ros Kane

Ethical approval and permission is hereby given for the above study, on the basis described in the EA2 Ethics Approval Form dated 2014-05-21 on one condition:

- Within the Participnt Information Sheet (Focus Groups) under the heading 'What will happen to me if I take part,' we would like you to remove the statement: if you do not want it to be recorded the interviewer will just take written notes.

We feel that if one person refuses the recording it would be difficult to take sufficient notes with so many people in the focus group. The Consent form is sufficiently detailed to overcome this potential issue.

Any changes to the study may require additional approval and must be submitted to the Ethics Committee.

Dr Zowie Davy
Chair Ethics Committee

**APPENDIX 4**

## RESEARCH & DEVELOPMENT DEPARTMENT

**Contact: Helen Ayre**
**(Research Governance & Quality Manager)**
**T: 01522 512512 Ext 2552**
**F: 01522 597845 Email: Helen.Ayre@ULH.NHS.UK**

**Lincoln County Hospital**
**Greetwell Road**
**Lincoln**
**LN2 5QY**

Dr Roslyn Kane
University of Lincoln
Think Tank Building
Ruston Way
LN6 7FL

Date: 08th August 2014
R&D Ref: 060614Nelson
REC Ref: 14/WM/0154

Dear Dr Kane,

**Re: Meeting Social Care Needs of People Affected by Cancer and their Carers in Lincolnshire**

Thank you for submitting the above project for Participation Identification Centre (PIC) consideration. I am pleased to inform you that you have approval from United Lincolnshire Hospitals NHS Trust to use the following sites as a PIC;

- **United Lincolnshire Hospital NHS Trust**

The final list of documents reviewed and approved are as follows:

| Document | Version | Date |
|---|---|---|
| Protocol | 1.3 | 12/05/2014 |
| NHS R&D Form | 146687/623582/14/280 | - |
| Invitation Letter [Study A – Focus Groups] | 1.3 | 13/05/2014 |
| Invitation Letter [Study A – Interviews] | 1.3 | 13/05/2014 |
| Covering Letter [Study A] | 1.0 | 03/07/2014 |
| Participant Information Sheet [Study A – Focus groups; A1, A2, B1, B2, C1 and C2] | 1.6 | 10/06/2014 |
| Participant Information Sheet [Study A – Interviews; Group D1] | 1.6 | 10/06/2014 |

Please notify the R&D department of any future amendments to the approved study and/or documents along with a copy of any Research Ethics Committee correspondence/approval.

**Conditions of Approval:**
- All researchers involved in Clinical Research must have up to date GCP training – See LCRF Training SOP09 for further details. Available at http://www.ulh.nhs.uk/for_staff/lincolnshire_crf/documents/sop/SOP09_Training_Record.pdf
- You must ensure that any reports on the progress and/or outcome of your research requested by R&D are produced on time and to an acceptable standard, in accordance with your responsibilities under section 3.6.3 of the Research Governance Framework, 2nd

Edition (DOH, 2005). As a minimum, this will include completion of the ULHT R&D annual progress report.

- Please note that the Trust audits 10% of ULH non sponsor studies and we anticipate auditing 100% of ULHT sponsored projects approved, on an annual basis.
- Please note that should a Suspected Unexpected Serious Adverse Reaction (SUSAR) or complaint arise from this research, the Research & Development department must be informed within 24 hours of identification.
- Please Note that should a Serious Adverse Event (SAE) arise from this research, the Research Sponsor must be informed within 24 hours of identification. In the case of ULHT Sponsored studies, the Research & Development department must be informed as the Sponsors representative.
- The project is subject to the Research Governance Framework for Health and Social Care, 2$^{nd}$ Edition (DOH 2005) and if a CTIMP trial, The Clinical Trials Regulations and its subsequent amendments.
- Please ensure that you are familiar with all ULHT Lincolnshire Clinical Research Facility SOP's and comply with those relevant to your project. All current SOP's are available at: http://www.ulh.nhs.uk/for_staff/lincolnshire_crf/sop.asp

Please note that this Trust approval applies only to the documents listed above. Any changes to the protocol and/or study documents can only be initiated following notification to and approval by all relevant parties, such as the MHRA, Research Ethics Committee, R&D. All correspondence to the Ethics committee must be copied to Research & Development in order to maintain your Trusts Research & Development approval and indemnity status.

Please contact Dr. T Ahmed, Head of R&D & IP Lead/Director of LCRF, if you require any further information.

On behalf of the Trust, I wish you every success with the study.

Yours sincerely

PP

**Professor O. Eremin**
**Director of Research & Development**

CC.    Mr David Nelson (Research Assistant)
       Mr Nigel Horner (Sponsor Representative)
       Claire Fowler (Local Collaborator)

**APPENDIX 5**

STUDY A: Exploring the social care needs of PABC in Lincolnshire

**Interview Topic Guide**

Introduction; the study; consent; anonymity; confidentiality; timing

Outline structure of interview

Give the participant time to ask any questions. Re-iterate that participant can refuse to answer any questions and is free to terminate the interview at any time.

**INTERVIEW BEGINS**

1. **INDIVIDUAL INTRODUCTION (10 mins)**
   - When you were diagnosed?
   - What health and social care professionals have you been involved with?
2. **SOCIAL CARE NEEDS (20 mins)**
   - What do you think people with cancer need?
     - o Practical and personal needs
     - o Emotional needs
     - o Financial needs
     - o Information and advice – have you felt well informed?
   - Additional care needs – other health conditions
   - Have your needs changed over time?
   - Do you feel your needs are being met? By whom?
3. **SOCIAL CARE SUPPORT (20 min)**
   - Support from friends/partner/family/carers/charities/social services etc.
   - What do you most value in terms of support?
   - What types of support do you frequently use?
   - Can you identify any gaps in social care provision?
4. **OPPORTUNITIES/BARRIERS TO IMPROVING SOCIAL CARE SUPPORT (15 min)**
   - Have you had an assessment of your needs?
   - Access to social support services
   - Awareness of social support services – have you discussed with healthcare professionals?
   - Have you been referred for social care support? By whom? What for? Means tested?
   - Anything that prevents you doing something you'd like to? Location/Finances etc.

Ask participant to provide a summary of their experiences.

Is there anything that we haven't discussed that you would like to add?

Many thanks for your time.

**INTERVIEW ENDS**

**APPENDIX 6**

Dear

We are supporting a research study that is being carried out by a team of researchers from the School of Health & Social Care at the University of Lincoln.

The study is interested in the social care needs of people affected by cancer in Lincolnshire.

We have attached an invitation from the research team as well as a participant information sheet should you wish to find out more, or be interested in participating.

If you have any queries, please do not hesitate to get in touch with us or the research team directly (contact details overleaf).

Yours sincerely

[Care Team at ULHT; contact details of lead collaborator]

**APPENDIX 7**

Dear

**Meeting the Social Care Needs of People Affected by Cancer in Lincolnshire**

We are a team of researchers from the School of Health and Social Care at the University of Lincoln. We are very interested in the social care needs of people affected by cancer (PABC) in Lincolnshire, and are contacting you to invite you to take part in a research study.

The social care needs of people affected by cancer will vary greatly from person to person. They will be influenced by the cancer journey stage, demographic and socio-economic status, and the level of caring support provided.

The study aims to gain insights into what the social care needs of PABC in Lincolnshire are and the extent to which these are being met. We hope to use the information from this research to identify gaps in service provision and to assist in the reconfiguration and redevelopment of social support services at the local level.

We are inviting people at different stages of the cancer journey who live in Lincolnshire to take part in this study. You have been identified as a potential participant from an existing case load of patients of a Macmillan Clinical Nurse Specialist (CNS).

If you decide to take part in this study, you would be asked to take part in an in-depth interview. With your consent we would like to conduct this in the comfort of your home. A researcher would visit you at a convenient time and the interview would last approximately 60-90 minutes.

We have enclosed a Participant Information Sheet which includes more details about the study. Should you wish to register your interest, you can contact the research team via the contact details overleaf. Furthermore, if you would like some independent advice on taking part in a research study, you can contact the local NHS Research & Development office, details also found overleaf.

Thank you.

Yours sincerely,


Dr Roslyn Kane

On behalf of the research team

1

STUDY A (Interviews): Invitation Letter
Version 1.3
13/05/14

RESEARCH TEAM CONTACT DETAILS

Should you wish to register your interest in this study or simply seek further information about this specific project, you can contact a member of the research team.

Contact details are below:

| | |
|---|---|
| Mr David Nelson | Dr Roslyn Kane |
| Research Assistant | Principal Lecturer |
| University of Lincoln | University of Lincoln |
| School of Health & Social Care | School of Health & Social Care |
| Think Tank | Think Tank |
| Ruston Way | Ruston Way |
| Lincoln | Lincoln |
| LN6 7FL | LN6 7FL |
| T: 01522 83 7343 | T: 01522 83 7326 |
| E: dnelson@lincoln.ac.uk | E: rkane@lincoln.ac.uk |

Alternatively, you can fill in the enclosed reply slip and post back to the research team in the pre paid envelope provided. A member of the research team will then contact you via your preferred method of contact (post/telephone/email).

FURTHER INFORMATION

If you require independent advice about taking part in research you can contact the local NHS Research & Development (R&D) Office.

Contact details are below:

Lincolnshire Community Health Services NHS Trust
Research & Development
Fen House
Fen Lane
North Hykeham
Lincoln
LN6 8UZ
T: 01522 502023
E: Research.Team@lincs-chs.nhs.uk

STUDY A (Interviews): Invitation Letter
Version 1.3
13/05/14

**APPENDIX 8**

## Participant Information Sheet

**Study A (Interviews): Meeting the social care needs of people affected by cancer (PABC) in Lincolnshire**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take approximately 5-10 minutes.

This study is being funded by Macmillan Cancer Support, Bromhead Medical Charity and the University of Lincoln. The study has been reviewed internally by an expert advisory group within the College of Social Science at the University of Lincoln, as well as externally, by the Coventry and Warwickshire, NHS Research Ethics Committee (REC).

You are being invited to take part in an individual interview with one researcher. During the interview you will be asked to discuss your social care needs.

**What is the purpose of the study?**

We would like to establish how well the social care needs of particular groups of people with cancer are being met as well as identifying any potential gaps in social care provision.

**Why have I been invited?**

You have been identified as a potential participant from an existing case load of patients of a Macmillan Clinical Nurse Specialist (CNS).

**Do I have to take part?**

Participation is entirely voluntary. There will be no effect on future care should you decide not to take part.

If you agree to take part, we will then ask you to read and complete a consent form. A note will be made on your patient records that you have consented to participate in this study.

You are free to withdraw at any time, without giving a reason. Withdrawal will not affect the support you currently receive in any way. However, if you decide to withdraw the information you have provided up to the point of withdrawal may still be used in the research.

**What will happen to me if I take part?**

You will be invited to attend one interview, which will last approximately 60 minutes. It will take place in a private and convenient location with one researcher. If you do not wish to answer any of the questions then you do not have to.

With your permission the interview will be tape recorded and later typed up.

**What are the possible benefits of taking part?**

The results of this research will inform the reconfiguration and redevelopment of existing support services and hopes to have significant implications for the health and well-being of PABC at both the local and national level.

**Will my taking part in the study be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you, or that you contribute, will be anonymised and handled in confidence.

Your name will not be recorded in the study. The study will be listed on the University of Lincoln website.

All recordings will be made using digital media files and transcriptions will also be held on electronic files. All files will be held on an encrypted computer for seven years and then be destroyed.

**What will happen to the results?**

The key outputs of the study will be in the form of written reports to the funders which will also be widely disseminated using the University of Lincoln Research Repository.

Participants will be invited to comment on the extent to which the research findings have been interpreted accurately by being given the opportunity to comment on drafts of the research outputs.

In addition, participants will be kept fully informed of all final outputs from the research. Academic papers will be published in relative academic and professional journals. The researchers will seek appropriate national and local conferences through which to disseminate the findings either by poster, or oral presentation.

**What if there is a problem or something goes wrong?**

If you have a concern or a complaint about any aspect of this study, you should ask to speak to the chair of the service users group at the University of Lincoln, who will do their best to answer your questions. Details are below:

Ms. Helen Laws
Care of, Paul Mansfield
University of Lincoln
Bridge House
Brayford Pool
Lincoln
LN6 7TS
T: 01522 886385
E: pmansfield@lincoln.ac.uk

**APPENDIX 9**

![University of Lincoln logo]

# Study A (Interviews): Meeting the social care needs of people affected by cancer in Lincolnshire

# PARTICIPANT CONSENT FORM

**Please initial box**

1. I have read and understand the information sheet, Ver 1.6, 10.06.14, for the above study and have had the opportunity to ask questions.  ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my current support being affected.  ☐

3. I understand that all the information I give will be STRICTLY CONFIDENTIAL.  ☐

4. I understand that the results from this study will only be presented in anonymous form.  ☐

5. I agree to the interview being tape-recorded and/or transcribed.  ☐

6. I agree to take part in this study.  ☐

Signature (participant):  _____ *(please sign)*

Print Name:  _____

Date:  _____

Signature (researcher):  _____ *(please sign)*

Date:  _____