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Older Carers and Involvement in Research

Why, what and when?



Older Carers Involvement in Research

This briefing paper describes the views, experiences, motivations and plans of six older carers who decided to stay involved in research following their participation in a one year project at the University of Nottingham funded by Macmillan Cancer Support. The project was set up to study the experiences and main support needs of older carers looking after someone with advanced cancer and was designed to also encourage and facilitate the active involvement of carers in the research process (the support needs of older carers identified in the project are outlined in another briefing paper, 'Improving support for older people looking after someone with advanced cancer').

34 older carers were recruited into the research project, with five taking part in an individual interview and 29 in one of five group discussion meetings conducted by a team of experienced researchers from the university. The interviews and meetings took place between early June and late July 2010. The 29 carers who came to a group meeting were asked if they would like to stay involved in the project and invited to attend an introductory course about research and public involvement. The two day course was run in October 2010, and attended by eight carers.

Carers getting involved in research Why...?

There are many reasons why people get involved in research

The research about older carers looking after someone as they approach the end of their life found that many of the experiences and support needs are similar, but there are also many differences. The findings suggest that some of the different end of life care experiences identified relate to the contrasting experiences of support provided to the older carers by health and social care services.

Many of the carers participating in the study were saddened and angered by this finding and wanted reasons behind the different experiences of support to be examined fully so that services can be improved and delivered in ways that ensure all older carers with support needs are supported equally well.

These feelings and ambitions were what prompted the carers to consider staying involved in research. The carers got involved in research...

...to use their personal experiences to make a difference and influence change

...to help improve support services for other older carers



Getting involved in research

What does involvement mean?

Involvement in research means many different things, from minimal, one-off or occasional engagement to a range of more formal, authoritative and ongoing activities

Involvement in research projects can be:

Consultative This is where researchers consult members of the public about the research e.g. through individual contacts, one-off meetings

Collaborative This involves active, on-going partnerships between researchers and members of the public e.g. involvement of members of the public on the project steering / advisory group, or as research partners on a project

User led / user controlled This is where members of the public lead the research and are in control of the research. This is often through a community or voluntary led by service users

...Carers can be involved in research as leaders, as partners or as consultants

...Carers can get involved in research at various stages

...Carers can get involved in various different types of research activities

Involvement when...?

Doing what...?

In addition to the 34 carers participating in one of the group meetings or interviews, carers were involved in a range of other research activities throughout the research process. Carers were involved:

1. Before the project

- contributing to initial discussions about the proposed project
- reviewing draft versions of the funding application
- sitting on the selection panel that decided which funding applications Macmillan Cancer Support would fund

2. During the project

- sitting on the project advisory group
- assisting with recruitment
- assisting at group discussion meetings
- participating in a group discussion meeting or an individual interview
- attending a two-day research awareness training course
- contributing to and commenting on the final report of the project

3. Since the project ended

- making the findings of the study known through various types of 'dissemination' activities
- undertaking further research training
- getting involved in various local and national research development activities
- contributing to the design and content of this briefing paper

The types of involvement in research described in this paper are examples of consultative and collaborative involvement.



Carers getting involved in research

Why did I get involved...? What it's really like...?

Contributing ideas about the focus of the research and commenting on the funding application

"I was asked to get involved in the older carers research project in early 2008, some while after I got interested in influencing cancer research. I'm a member of the Consumer Liaison Group of the National Cancer Research Institute, a group that promotes the involvement of patients and carers in cancer research. A university researcher (Sheila) had asked the group's chairperson to recommend someone to be a lay advisor on the project. He suggested me as he knew I am especially keen on research about carers.

I was happy to get involved as 'carers needs' is an issue dear to my heart - I know from my own experiences of looking after my late husband how complex care can become as cancer progresses, and that older people can be less informed or assertive.

Sheila and I discussed ideas for the project over the phone and by email and later I was asked to comment on the funding application being prepared by the research team. The following spring Macmillan Cancer Support awarded a grant to fund the project, and I was delighted that my input to the application and the 'user' involvement aspect of the project had helped secure the grant" (DiR)

"Researchers and the research actually benefit from my presence and contributions."

"Making the case for carers is an issue dear to my heart."

Being on the project advisory group

"I was pleased to accept the invitation to be a member of the project advisory group (PAG) and we met three times during the project. As I see it, the group had the role of ensuring the project was sensitive to both the practical and emotional needs of the carers involved and monitoring the project in relation to its aims and timescale. The PAG was made up of 6 academic researchers and 3 non-academics -- one of whom used to be a nurse and another who works for an organisation that co-ordinates and supports 'self help' groups, and me!

At the first meeting I commented on the content and design of the recruitment leaflet and volunteered to help recruit carers to take part in the group interviews. I also got involved in the discussion about the need for 2 researchers and some separate, private space at the meeting venues in case any of the carers became upset and needed support or a break.

At the second meeting, the research team reported that 19 of the carers who took part in the discussions had said they would like to stay involved in the project. Unfortunately this number was more than could be offered a place on the research awareness course. We agreed we had to find an appropriate way to select a cross-section of 10 carers. I was pleased that my comments and suggestions about how to select from the pool of volunteers were accepted as constructive. I was also instrumental in the decision for the course to be run over two days rather than as a series of six short sessions. As someone with experience of providing end of life care and as an older person who goes to various meetings, I knew the practical arrangements involved in attending for lots of short trips would be difficult for some and generally unpopular.



Overall, I feel my voice was taken note of as the group was small enough to listen and the researchers recognised the value of what they heard: it's good to think that the researchers, and the research, actually benefit from my presence and contributions". (DiR)

"As leader of the Nottingham cancer patient and carers support group for over 25years I was delighted to accept the invitation along to the steering group and offer my knowledge, experience and skills. At the meetings I felt encouraged by Sheila's commitment and her interest in what we all had to say". (Fl)

Helping with recruitment

"I thought my local knowledge and existing relationships with carers' groups and organisations in the York area would be valuable to the recruitment of carers to the discussion meetings. I gave Sheila the names and contact details of various people and places in my area and took a number of recruitment leaflets and posters about the study to the local carer groups and organisations and asked the organisers to display and distribute them in their centres. I also asked for details about the study to be put in their newsletters. I told Sheila about the annual Carers Week event and she came along to boost our chances of getting carers to sign up to be interviewed or attend a group discussion meeting.

However, despite my local knowledge and efforts, for several weeks no-one came forward. I felt increasing apprehension about whether anyone would actually take part even though there had been considerable interest in the topic. Fortunately, in the end, a number of older carers did come forward and I joined them for the group discussion that was held in the same building as the York Carers' Centre. (DiR)

"I was asked to identify people or places where carers might be recruited from so I suggested our group to Sheila and asked her to come along to explain the project and ask some of the members to get involved".





Carers getting involved in research

What it's really like...?

Taking part in a focus group meeting (a group discussion)

"I was at a meeting for bereaved carers at my local hospice and was asked if I would like to be involved in a project about the experiences and support needs of older carers. It sounded good so I said yes. I was worried about going but by the time three or four people had spoken I felt less nervous and I wanted to say lots of things which could help others later. Things that mattered. Listening to other people's stories there was a lot of good and a lot of bad. We said that it should be better - the standard should be good and improving to very good. Also it gave me thoughts about doing more to try to help people worse off than myself. Afterwards I felt like I had done my best and hoped it might help others in the future." (DonR)

"I was happy to be asked to join in the meeting. I found the day very interesting, upsetting sometimes but very interesting. At first it was difficult for some people to talk ... Because I have taken part in another study about end of life care issues and advance care planning I'm more used to talking about my personal experiences. I said to the group that if I got upset - which I did to start with - they should ignore it. I think it broke the ice and helped others to join in. People seemed to want to talk but were not sure how to, or where to start". (SL)

"Being involved in the meeting gave me the opportunity to talk and to hear about others experiences, both good and bad. I found the involvement very helpful as my experience is very limited and was for a short period only... It seems carers are somewhat reluctant to talk about their experiences and difficulties at the time as their priority is the person for whom they are caring". (JA)

"We were both very apprehensive when we were asked to contribute to the research. We wanted to do it but it felt like sailing into uncharted waters. We were able to talk freely and there was a lot of shared emotions but we could go for a breather or opt out of the meeting at any time. Our hearts went out to many as we took it in turns to share our stories, but talking together we felt united in our experiences. When the opportunity to stay involved in the research was mentioned we both felt we wanted to, to contribute, to make a difference for future carers". (HR & PH)

Taking part in the research awareness course

A two day introductory research awareness training course was organised and delivered to eight of the older carers who had attended the group discussion meetings. The course aimed to give the participants an introduction to different types of health and social care research, and some of the ethical issues and dilemmas in research involving palliative and end of life care. It also provided them with information about a range of research activities for 'lay researchers', across all stages of the research process.

The programme was designed to include opportunities for the participants to 'have a go' at some of the research activities in a structured, safe and supportive environment and to discuss their own ideas for future research. In addition, Derek Stewart OBE, a nationally respected member of the Nottingham Cancer Patients and Carers Support Group and renowned activist in the National Cancer Research Institute Consumer Liaison Group, came to speak to the carers about his involvement in research in a session entitled 'Using your story to effect change'.

"Before I went to the course I was worried as I didn't know what was expected... but I wanted to help any way I could. I found it very interesting and enlightening, very different to what I thought it would be. It gave me insight into what other people thought about older carers and the system and the ways support for carers could improve. The researchers and speakers came across very well. They explained things and it was easy to understand, and made it flow more better. If doing research helps to get more support for carers and makes the service better for patients as well, it will have been well worthwhile. The new information I received at the workshop gave me a lot more to think about the ways in which carers could get involved in research. Now I think getting involved in this project was the best thing I've ever done and it is going to help other people". (DonR)

"My enthusiasm for research and the possibility of using research to make a difference for other carers was fuelled when I attended the research awareness course in Nottingham. I was unsure what exactly to expect but the support from the qualified researchers and the other carers at the time and since has been very helpful and encouraging". (PH)

Carers staying involved in research

What's it really like being a research partner...?

Contributing to the project report

Writing about our experiences

"A few weeks after going to the research awareness course, Sheila asked us to "reflect" on and write about our participation in the workshops and the research course. She wanted our thoughts and experiences of being involved in the project to be included in the final report. Six of us readily agreed to have a go at doing this. I saw that recording and reporting our reflections could be useful for others considering getting involved in research and also it would have value for myself now and in the future.

At first we were unsure about the process of doing it, but four of us arranged to meet together and eventually decided that one of us would write notes of our individual reflections, and record who in the group said what. The notes were then typed up and checked for accuracy by the group. The two who couldn't join us kept in touch by phone and contributed their reflections by email.

The two sets of individual comments on the workshops and the course were all then crafted into combined pieces of "text" by Deb as she is the research partner with experience and skills in writing and editing. She then sent them on to the researchers to put in the report. The experience was enjoyable and we all valued the opportunity particularly as our contribution would add to the influence of the report and the projects findings". (GW)

Commenting on the report

"When we were sent a draft copy of the final report and asked to review it, it felt like we were being taken seriously, as proper partners in the research. Four of us attended a meeting to discuss our opinions with three of the research team and the carer from the advisory group; the others sent their views and suggestions by email or by post.

Several of us said that we thought the project title needed changing as it didn't seem to fit the content of the report, and in the end the title was changed. We also felt it was important that abbreviations and research language should be explained or avoided as they might present a barrier to understanding for people who weren't professional researchers.

We were asked if we thought the report reflected our experiences of the project well and whether our views had been represented accurately. I said I was pleased to find the way real life stories and narrative were brought together in the report - it was so powerful. Reading the report took me back to personal experiences and I suggested that by being so vivid the report might have a greater impact on those in charge of support services when they read it. I also found that I quickly and easily related to the list of 5 Support Priorities highlighted in the report.

When I saw the revised final version I felt our comments had been taken account of - I felt valued and it was good to be listened to it particularly as it reinforced my feelings concerning the strength and importance of the recommendations. We now depend on decision makers to implement them if we are to see real progress for carers". (GW)

Joining a research development group

"Taking part in this project - and the research awareness course - was a brilliant way of building up my knowledge and confidence. And it opened the door to more research opportunities - I'm now a lay member of a group looking into improving ways of researching and evaluating palliative and end of life care. I admit sometimes stuff goes over my head, but the rest of the group are really helpful and supportive, and I feel they value my input". (DA-P)



Carers staying involved in research

Other research activities

Publicising the project findings

"After going to the research course I decided to contact a cancer patients and carers support group in my area to see if they would like me to tell them about the results from the research about older carers experiences and support needs from looking after someone with cancer. Despite some practical problems (the room wasn't large enough to be comfortable and initially the slide projector wouldn't work) I enjoyed telling the group about the research findings and felt it was valuable for the group. Hearing about other older carers' experiences and about my new involvement in research prompted lots of the group to speak about their own experiences and this led on to a discussion about inequalities in care provision.

It became evident to me that in a presentation you need to be prepared to deal with a range of reactions from audiences, perhaps especially with a group of both patients and carers dealing with a difficult situation about a topic of direct relevance. On reflection, I think it may have helped to have brought someone with me in a support role - not only for me but also available for people in the group. Having someone with me would also have meant we could have gone over the good and the difficult bits together afterwards which would have been helpful. Instead I sent an email to Sheila who replied offering praise, encouragement and suggestions for the future.

So by doing this presentation, I have learned a lot about reporting research findings to a mixed group. Despite some difficulties, I enjoyed the experience and my part in publicising the research findings - overall I found it a very positive experience and I am confident that next time it will be easier". (JM)

Attending conferences

"At the end of the research course we were offered a number of opportunities to do on our own or together with the other research partners. Three of us went with the researchers to the final meeting of the Cancer Experiences Collaborative (CECo) which took place over two days in Manchester. CECo is a pioneering initiative, set up in 2006 to improve the quality and quantity of palliative and supportive care research. There was a fascinating and wide-ranging programme of presentations and discussions and poster display, which covered subjects as diverse as dying in residential care homes, the effects of acupuncture on managing cancer-related fatigue, ethnicity and cancer and methods of researching end of life care.

It was a great opportunity to meet and talk to a number of experts in the field of palliative care and we also met other research partners from other parts of the country and compared notes with them. It was very interesting and motivating to do something useful. All in all, an unmissable experience". (DA-P)

"I was amazed how much work goes into research and how important research evidence is in trying to improve palliative and end of life care, and how important it is that patient and carers make the right choices with help from the professionals.

I am now getting involved in other projects because this has given me an interest in the power of research. And because of all this involvement in research I have become a more confident person". (PH)

Doing further research training

"The researchers offered us the opportunity to attend the International Research Summer School at the University of Lancaster. I went each day with trepidation and each evening felt some relief at having got through the day! But I got a lot from the course - we covered many aspects of research and not only have I gained more knowledge but I also feel my confidence has improved. I enjoy doing something useful and would encourage others to take part in research activities". (HR)

"I was contacted about taking part in the older carers project because I had put myself on the Cancer Voices part of the Macmillan Cancer Support website. I must say, I never expected getting involved to lead to so many interesting opportunities. It provided me with a springboard into research. I've done courses in research methods and ethics - sometimes scarily challenging, but rewarding!" (DA-P)

Co-writing this briefing paper

"For me this was the most difficult part of my experiences in the research. At first I was unable to visualise the completed document and understand the importance of colour, size etc. However with support from the other partners and the researcher I was able to contribute to the overall document and could see that this was a vital part of the drive to encourage older carers to become involved in research". (JM)

"I enjoyed meeting up with everyone again and even though we meet infrequently we worked as a team: we have always seemed to be on a similar wavelength. It was quite hard work but enjoyable, but by the last afternoon we were getting bogged down and not listening to each other as well as usual". (PH)

"There is a real "bond" in the group - we have varying experiences but a common motivation. In contributing to this briefing paper it felt like it was a key part of us telling the story - a key part of the legacy." (GW)

"I'm so proud to have contributed to this briefing paper. I have never done anything like this before and I would encourage others to get involved - if I can do it anyone can! The sense of achievement is great knowing one's voice and comments can help to make a difference to future carers". (HR)

Benefits of involvement of carers in research

Benefits to carers as research partners

Meet people in the same situation
Share experiences
Make new friends and enjoy yourself
Build your confidence
Learn some new skills
Have your views listened to
Make something good come out of something difficult
Feel proud for influencing the development of better carer support services - making a difference

Benefits to research, to other carers and to patients

'Time and again the evidence shows that service user involvement results in outcomes that are more relevant and useful. It often increases the likelihood of research findings being used by others, as service users often have a much stronger commitment to bringing about change'. (S. Denegri, Association of Medical Research Charities, 2)

The National Cancer Research Institute and National Cancer Research Network believe that by working with consumers the quality of research can be enhanced for the benefit of patients and the public (Consumer Liaison Group, 3).

Involving service users in the dissemination of research findings has been shown to help reach a lay audience, to make the findings more accessible and to make the messages more powerful (K. Staley, 5; D. Evans, 6)

Plans for the future - the carers' research plans

1. To present and or send information about the research findings to local hospice, cancer patient and carer groups, older people's forums, GPs, local health and social service commissioners

"The way health services are organised, particularly responsibility for commissioning services, is changing - the changes will also affect local authorities and social care. In the context of research influencing real change it will be very important for us as research partners to have some understanding of the position of services in our local areas and the way they are commissioned and organised. We need to know who the key players are and direct our efforts to engaging with them, to make sure they know about the findings from our project and take them seriously". (GW)

2. To contact local radio, TV and print media for them to report the research findings

3. To contact local radio, TV and print media for them to report their ongoing involvement in research activities to improve support for carers and people with advanced cancer

4. To promote and highlight the value and benefits of user involvement in research - but especially research by carers for carers

5. To contribute to the development of a research proposal about the training and effectiveness of carer mentors for older carers of people approaching the end of life



Top Tips

...for researchers involving carers in research

Treat carers as equal partners - personal experience and ideas can be as valuable as theoretical expert knowledge

Make the involvement meaningful - make it clear what has resulted from the carers' contributions

Ensure the researchers 'host' organisation has sufficient resources to enable an ongoing commitment to support, training and facilitate involvement in further research activities

Offer lots of ongoing support and supervision

Be approachable

Include carers' input in the final document

Encourage carers who have been involved as research partners to keep in touch with each other - to develop an informal support and information network

Monitor and evaluate carers' views and experiences of their research involvement activities and respond as appropriate

...for carers considering getting involved in research

Be positive about your involvement. It may help someone else

Try to draw on your experiences and don't feel embarrassed if this results in tears. Everyone will understand

Listen and learn

Keep in touch with other research partners so you can exchange ideas and concerns

Be willing to learn new skills even if you doubt your abilities: ask what training and support is being given to the role you're undertaking

Request a mentor so you can get guidance and feedback about your contributions

Try to partner with someone who has previous experience of the kind of research involvement you're thinking about undertaking.

Best practice is to have two or more lay representatives on any decision-making group: ask who else is involved if this is what you'll be doing

Put aside anxieties and realise that your involvement is crucial to improving services for others

Feel the fear and do it anyway

The 'value' of involvement in research

"I think getting an allowance for being involved in research as well as travel expenses is a good thing: getting paid shows me that my contribution is really valued. Unfortunately, the payments system used by the university at the start of the older carers project was complicated and slow, with problems and delays relating to whether we were involved as casual employees or as volunteers - this caused me some worry around tax and national insurance issues.

Sheila clarified our position to the university finance department confirming that all those involved in the project (apart from the qualified researchers) were volunteer participants and that we were being given a payment to honour our contributions and expertise. Once the university accepted we were volunteers, the payment process was straightforward and much faster.

This experience has made me realise how important it is for host organisations to have simple and appropriate arrangements for payments of allowances - in any future research projects I might get involved in, I intend to check out first how they get sorted out". (DiR)





Further sources of information and references used about public involvement in research

1. INVOLVE - promoting public involvement in NHS, public health and social care research. www.invo.org.uk
2. User involvement in research: A route map
<http://www.twocanassociates.co.uk/routemap/why-involve-service-users.php> (last updated 10.11.2010)
3. Consumer Liaison Group, National Cancer Research Institute. www.ncrn.org.uk - follow the links to patient and public involvement and the Consumer Liaison Group (last updated 25.11.2010)
4. We're all affected by cancer. We can all help. Macmillan Cancer Support: Cancer Voices
<http://www.macmillan.org.uk/GetInvolved/CancerVoices/CancerVoices.aspx> Head Office telephone 020 7840 7840
5. Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research. Staley, K. (2009) Eastleigh: INVOLVE.
http://www.invo.org.uk/pdfs/Involve_Exploring_Impactfinal28.10.09.pdf
6. Involving the public in research: the emerging evidence base for impact. Evans, D. (2010) CARE Conference. UWE, Bristol. 1.12.2010
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Written and produced by: Sheila Kennedy in association with Jim Allcroft, Deb Allen-Perry, Lydia Bird, Karen Cox, Pat Huteson, Sandra Lingard, Joya Morris, Heather Redshaw, Don Robertson, Diana Robinson, Jane Seymour, George Wood, Natalia Wysocka and Tom Partridge.

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For further information about the research project, contact Professor Jane Seymour at the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of life care, School of Nursing, Midwifery and Physiotherapy, University of Nottingham, Nottingham NG7 2HA. Tel: 01 15 82 31202 Email: jane.seymour@nottingham.ac.uk