

CONSUMER INVOLVEMENT IN CECO Guidelines 1st September 2006

1. Who are 'consumers'?

We are talking about people affected by cancer – people who've had cancer themselves, as well as those who have cared for someone with cancer - and people working for organisations that support people affected by cancer. Within the wider context of palliative and supportive care this may also extend beyond cancer to other chronic illnesses which have a terminal phase (eg stroke, heart disease).

The term consumer is widely disliked. However no realistic single word has met any greater acceptance. Service user, an alternative used in some quarters, has specific connotations which are inappropriate in supportive and palliative care.

For CECO I am proposing we use the term Research Partners, rather than consumers, for those who work with us. This has been used successfully by the MRC Clinical Trials Unit. The phrase uses the term partner which sums up the kind of relationship we want to see evolving.

2. Why involve consumers?

Experience has shown that the involvement of consumers in research has a number of benefits as well as being a moral and ethical imperative. The wider perspective brought to a research opportunity can ensure that the question being answered is relevant to patient benefit, not solely valuable within a researcher's view of the issues, or indeed to a career. In a treatment study a patient may be more worried about side-effects, or the on-going quality-of-life, or the costs of participating, while a researcher may be more interested in alleviating symptoms. By ensuring that a rounded view of the research is addressed the most relevant project can be defined.

When it comes to clinical research Research Partners can help to:

- Ensure that studies and trials address questions that are important and relevant to patients and carers
- Refine the research question
- Develop patient centred outcome measures
- Improve the quality of patient information
- Gain approval for a trial or study
- Recruit participants to a trial or study
- Disseminate the results of the research, especially to other consumers

3. Involving Research Partners in research studies

Before you start recruiting Research Partners, you need to develop a role description, outlining exactly what you'd like Research Partners to do, how much time this will involve, what skills or experience they need and whether they will be paid for their time. An template role description which can be used as the core of a standard CECO description is attached.

You should also state that training may be available (see section 7) and what support is in place to help them take on the role.

Research Partners can be involved in a number of ways. The following table can be used to help identify approaches and to help understand how a partnership can be created which develops increasing value from long-term involvement.

Co-option	Compliance	Consultation	Co-learning	Collective action
Token	For patients	For and with patients	With and by patients	Led by patients
Representation	Tasks assigned	Opinions considered	Sharing knowledge	Users' agenda
Researchers cede no roles	Researchers direct	Researchers decide	Researchers facilitate	Researchers may be absent

At the left hand side of the model we can identify activities such as working one-to-one with researchers reviewing a potential area for research, reviewing discussion documents and joining debate about research ideas, then commenting on draft protocols. These offer an effective starting point but it leaves researchers in the driving seat and committed Research Partners will be seeking to move to the right-hand side over time.

The medium term aim must be to move beyond the central column and have an increasing number of activities located on the right-hand side of the model. This should be the open aim of involvement, expressed by the research team, and they should be looking to encourage their Research Partners to think in this way.

4. Finding Research Partners

Once you've developed a role description you can begin to recruit Research Partners. There is a body of opinion that you should, in principle, have two or more Research Partners involved in any activity. It is less easy for their views to be marginalised (even by accident) and it allows shared learning to

develop. It also allows for the occasions when one may be unable to come to a meeting.

There are several different methods for recruiting Research Partners. Some of them are listed below. Whichever method you use, and we would anticipate that you will use several, ensure you use the role description to check that the people who are interested in being involved have the skills and experience you need – or if they haven't, that you can help them to access this.

Your own local contacts and networks. Activities at the University, support centres at the cancer hospital, contacts through clinicians, people engaged in the past – all are routes to potential involved Research Partners. Such people have the advantage of being local.

The National Cancer Research Institute Consumer Liaison Group (NCRI CLG). There are over 50 members of the NCRI CLG and all are familiar with research. The group is national and members come from as far apart as Aberdeen and Plymouth.

Cancer Research Network Consumer Panels (CRPs). This is a development which is starting in 2007, building on a base of seven CRPs which have evolved in different networks over recent years. It is anticipated that every major cancer research centre will have a group in due course and the experience of the first few is that membership will be anything from 10-12 to 40+. Adding CECo to their area of interest will have value to them as well as to CECo.

The Cancer Network Partnership Groups. These are now all established, though poorly resourced. Initial funding came from DH and Macmillan Cancer Support. Macmillan promotes the active involvement of people affected by cancer in a variety of activities and the partnership groups are a major source for involvement.

Cancer Voices is a Macmillan activity, encouraging involvement in national activity through Macmillan. Cancer Voices website has an 'opportunities exchange' which can be used to advertise for patients/consumers.
http://opportunities.macmillan.org.uk/p_homePage.aspx

Cancer support charities. National, regional and local charities have a particular value when you wish to involve patients/carers with a specific experience. There are likely to be several charities supporting people with any specific type of cancer but not all have an interest in research.

5. When to involve Research Partners

Involve Research Partners as early as possible. This may present some issues with funding if there is no core budget for Research Partner activity. To

help with this situation CECo has a central budget and support can be applied for to enable involvement activity to start early.

Direction

CECo themes and CECo centres have management groups on which it would be valuable to include local Research Partners. Selecting the right people is important. The role is non-executive and those undertaking it must be aware of the distinction between their role and that of executive members of the team.

Planning research projects

At this stage it's easier to involve Research Partners by phone or email – unless you have funds available to bring them to meetings. Include them in refining the research question, the study design, developing the protocol and commenting on applications for funding.

Once a project is funded

Ask Research Partners to help to develop or to comment on patient information sheets, testing questionnaires, get them to think about study recruitment plans, can they help gain ethical approval etc.

Launching the project

If there is a launch, involve Research Partners in planning this. It may be appropriate to include a quote from a Research Partner in any press releases – they could talk about why this research is important.

During the project

Research Partners should be seen as equal members of a study steering group, and should be involved as you would involve any other member. In projects where Research Partners are taking an active role as co-researchers their time and costs will have been budgeted and professional researchers providing support will build close relationships with them.

Analysing the results

Ensure you involve Research Partners in any discussions about analysis. There may be occasions when a partner-authored section in a report may be appropriate. If they have made a practical contribution do not forget to include them in the list of authors for any publications.

Results

At this stage Research Partners can help to disseminate the results of the trial to their peers. Get them to think about presenting the results at conferences or workshops, either on their own or together with a researcher. You can also consider including a quote from them in any press releases, especially if the press release is coming from a study sponsor or funder.

6. Paying Research Partners

As a very minimum, you need to ensure that Research Partners are not out of pocket as a result of getting involved. So you should budget for travel expenses for two Research Partners to:

- Have an initial meeting with you to learn more about the project and what is involved
- Attend meetings
- Attend launch events or dissemination events
- You should include a notional sum to cover care costs (e.g. costs for a childminder, or to pay someone to care for an elderly relative). If you haven't already recruited Research Partners when you're putting your budget together, we suggest you add £50 per meeting to cover these costs. If you involve Research Partners early enough, you can work out what to budget by asking the Research Partners whether they need to pay a carer, and if so, how much
- Take part in at least one training course – so budget for a training fee of £75 (it may be free) plus travel expenses and carer costs

You should also budget to pay Research Partners in research projects. CECo central funding cannot help with that. Your funding application should include payment of £150 per Research Partner per meeting attended if it is an all day commitment (including travel time) with the need for preparation/reading beforehand, and proportionately less for a lesser commitment. A project steering group meeting lasting 2/3 hours and with papers to read should probably be £80. This is in line with Department of Health guidance.

Please note: the UK Clinical Research Network (UKCRN) is developing guidance on payment practice and we will review our recommendations in line with their conclusions.

7. Supporting Research Partners

When you recruit Research Partners, ask them about any training needs and any support they might find helpful.

It's good practice to phone or email Research Partners before meetings to check whether they understand the papers you've sent them, and to ask if they need any additional information. After meetings, it's useful to contact them to ask them how they found the meeting, and whether they have any suggestions for improving how they are involved.

Consumers on NCRI Clinical Studies Groups have a nominated mentor from among the medical/scientific members of the group. They are encouraged to discuss any issues and questions prior to the meeting, will sit together during the meeting and have short de-briefing afterwards. This seems to work well and should be considered in those cases where a close working relationship

between a Research Partner and a researcher is not routinely in place. In this way we can continue to improve our practice.

Research Partners can access training provided by the UK Clinical Research Network (UKCRN) and the NCRN. See www.ukcrn.org.uk/index/training/

The NCRI CLG is working with NCRN, Macmillan and UKCRN to develop a web-based communications structure to support consumers involved in research and to facilitate the interactions between consumers and professionals. It's likely that this will become available in summer 2007 and we will keep everyone informed.

8. Research Partners and CECo

CECo is developing central involvement of Research Partners to complement what is going on in the CECo Centres and with the CECo Themes and projects.

All Research Partners will be invited to an annual meeting to hear how CECo is developing and to share experiences. We will probably hold this meeting twice – north and south, to minimise travelling. We anticipate that, in time, this would become a good 'introductory' event for new Research Partners.

In addition there will be an annual Partnership Group meeting where Theme leads, management team and invited researchers would meet with Research Partners so they can have a voice in the direction it is taking. The first meeting of this group will be planned for 2007 to coincide with a meeting of the collaborative.

It has also been agreed that there will be a formal annual 'peer review' of CECo by a panel which will include at least one Research Partner.

Roger Wilson
1st September 2006

Appendix one: Example role description for Research Partners working with CECo.

Research Partners: terms of reference

The Terms of Reference act as a guide for Research Partners. Research Partners are lay people who have agreed to become involved in working with our researchers and research centres. They will most probably have a background as a patient or carer, but that is not essential.

The Terms of Reference will give you a better idea about your role in the CECo Collaborative and with the (name of theme) theme if you become a Research Partner. They explain what we expect from you if you became a Research Partner, as well as what you can expect from us. The Terms of Reference can be modified in response to your feedback.

1. Membership

We are setting up a group of Research Partners to be involved in the CECo (name of theme). The requirements that we think Research Partners need are:

1. Experience of relevant health issue
2. (Experience of working on health/partnership groups)(optional)
3. Interest and enthusiasm about being involved in this project

You do not need to have any previous experience of research. You are free to leave at any time, although we hope that our Research Partners will want to be involved over a period of time and contribute to a number of research projects.

2. What we can provide to Research Partners

If you decide to become a Research Partner, we are committed to providing you with:

- An opportunity to learn about, actively contribute to and influence research
- Flexibility and choice in your level of involvement in the project
- A safe and supportive research environment
- Appropriate and relevant training
- A mentor, to act as your first point of contact for queries or difficulties
- Opportunities to meet other Research Partners to discuss the project
- Payment for attending meetings where needed

We will work with you to:

- Help you to learn about and understand the research project you work with us on
- Identify research and/or administrative tasks that you can help with
- Provide access to appropriate training, where it might be helpful
- Support you in the activities that you undertake

We will provide a safe and supportive environment for your involvement, but working with us is not an alternative to membership of a support group. We are not able to give information or advice on treatments that you might have been given or may be receiving.

3. Key Responsibilities and Aims

As a Research Partner, you will work with each other and with members of the professional research team to develop and carry out one or more of our research projects. You will also be asked to feedback your thoughts and experiences of being involved to the CECo management team. We may ask you to work with other Research Partners on CECo review and direction consultations.

There are many aspects to running a research project. Some of these are administrative or creative and not necessarily scientific or technical. We can discuss the possibilities with you to help you to find things that interest you and that you might like to be involved with. For example there may be opportunities to:

- Read and comment on the design of research projects, and contribute to the development of the research protocol, funding bids etc
- Read and comment on the information that we produce about a project for those who will participate
- Help us to organise small local meetings which involve people contributing to the research
- Discuss the project at a Collaborators' meeting, during its progress or at the end of the research project
- Write short articles for the CECo website or newsletter
- Help to produce and disseminate the results of the project

You can be involved in one or more of the many aspects of a research project. What you do might change as the project progresses. For example, once you have a clearer understanding of the project is doing, and have maybe taken up opportunities for training, you might take on different tasks or suggest other areas where your skills could put to good use. We will work with you to develop these opportunities.

4. Meetings and Communications

We can arrange to visit you or have a telephone conversation with you so that you can find out more about the project before you decide whether or not to become a Research Partner. We will then arrange a meeting at an appropriate time, which may be at a CECo/theme workshop day so you can get a flavour for the team and the topic. We will try to keep meetings very informal and we will try our best not to use technical language or jargon.

This meeting will give you:

- Chance to meet other Research Partners
- Chance to meet the research team members who are running this CECo theme

- Opportunity to find out more about research projects in the theme and decide if you would like to be involved in it

After this first meeting, we will contact you in the way you prefer, and we can send you information in whichever format suits you best (e.g. on paper, email, large print etc). If you need to ask any questions or if you want us to explain something, you can contact us during our working hours to ask. We will do our best to answer all enquiries promptly and clearly. There will be other meetings of the Research Partners but we would like to keep the number of meetings to a minimum so each one will have a clear objective and an agenda announced in advance. We will try to arrange them on dates which suit the needs of the individuals.

5. Payment

We can reimburse you for travel or other expenses for attending meetings and where needed these might include overnight accommodation or carer costs, for example. We will aim to reimburse expenses as quickly as possible and if necessary can book tickets etc in advance on your behalf. In addition, we are able to pay Research Partners for their time spent at meetings at a rate in line with the Department of Health recommended rate for that kind and duration of meeting.

6. Person Specification

To help you understand the key attributes we need in our Research Partners we have compiled this table.

Attributes	Essential	Desirable	Not important
Enthusiastic about research into supportive and palliative care	X		
Some experience of representing patient views		X	
Understanding of medical/research language			X
Good communicator /able to express own views in a mixed group of professionals and consumers		X	

7. Complaints or Disputes

While we hope that our relationship with our Research Partners will work well for all of us all the time, we recognise the need for a system to resolve any differences which may arise.

In the first instance we would expect any problems to be discussed openly, and where possible resolved, with the researchers and Theme Leads with whom you work. If a resolution cannot be reached the CECo Centre Lead, who is a member of the CECo Management Group, should be asked to review the situation and propose a resolution. He/she will consult with other Research Partners, with members of the CECo team as appropriate and these will include Roger Wilson who is the Involvement Co-ordinator for

CECo. In the event that a resolution still cannot be found the CECo Management Team will review the situation and decide on the action to be taken.

8. Updating these terms of Reference

These Terms of Reference may be updated at any time in consultation. Your feedback can help ensure that we keep them relevant to the evolving nature of the work that CECo is undertaking and the changing role(s) which you will take on.

It is our hope that by being open and clear about what we expect from our relationship with you, we can help you gain satisfaction and enjoyment from working with us. We know that is the best way for us to maximise the benefits for our research, and ultimately for patients, which we believe will come from having committed consumers working with us.

Thank you.

Cancer Experiences Collaborative
4th September 2006