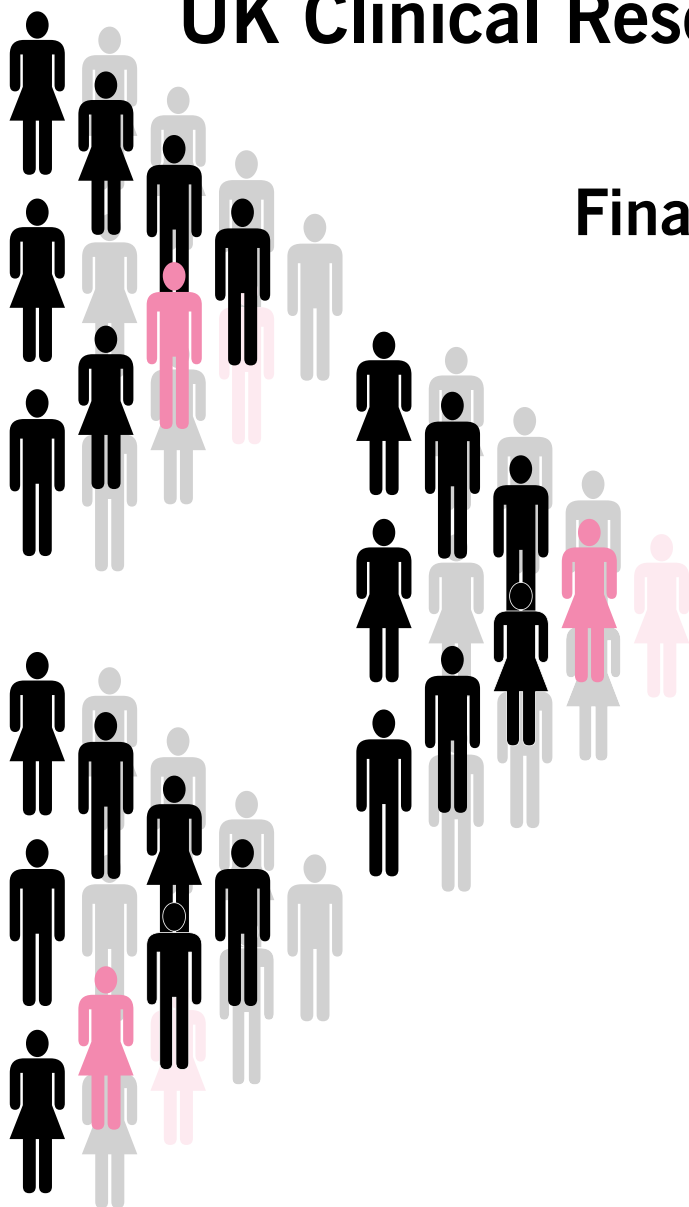


# An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration

Final Report



# Contents

	<b>Page</b>
<b>Thanks</b>	3
<b>Executive summary</b>	4
<b>1. Introduction</b>	8
<b>2. Background</b>	10
<b>3. How we carried out this evaluation</b>	12
<b>4. Development of patient and public involvement in UKCRC advisory groups</b>	15
<b>5. Assessment of the process of patient and public involvement in UKCRC advisory groups</b>	20
<b>6. Impact of patient and public involvement in UKCRC advisory groups</b>	26
<b>7. Conclusions</b>	31
<b>8. Recommendations</b>	32
<b>Appendices</b>	
Appendix 1: More about the UK Clinical Research Collaboration	36
Appendix 2: Acronyms used in this report	37
Appendix 3: Further information about:	38
a) recruitment, selection and induction of patient / public members	
b) continued evaluation of meetings	

# Thanks

We are very grateful to the people who agreed to be interviewed for this project:

## **Patient / public members of UKCRC groups**

Katherine Cowan  
Cathy Hamer  
Danielle Horton-Taylor  
John Hughes  
Jenny McKibben  
Diana Robinson  
Andrew Russell  
Tony Sergeant  
Christine Vial

## **Chairs of UKCRC groups**

Sarah Buckland, *Chair of the UKCRC Board Subgroup for Patient and Public Involvement*  
Sally Davies, *Chair of the UKCRC Board*  
Simon Denegri, *Chair of the UKCRN / UKCRC Joint Communications Advisory Group*  
Russell Hamilton, *Chair of the UKCRC Board Subgroup for the UK Clinical Research Networks (UKCRN)*  
Nick Partridge, *Deputy Chair of the UKCRC Board and Chair of the UKCRC Budget Committee*

## **UKCRC staff**

Hannah Brown, *Administrator*  
Liam O'Toole, *Chief Executive*  
Philippa Yeeles, *Programme Manager*

We are also grateful to those members of the UKCRC Board Subgroup for Patient and Public Involvement who took part in the Advisory Group for this project:

Cathy Hamer  
David Rea (*Chair of the Advisory Group*)  
Victoria Thomas  
Philippa Yeeles

## Executive summary

This is a report of a project to evaluate patient and public involvement (PPI) in some of the groups which form part of the UK Clinical Research Collaboration (UKCRC). In September 2006 the UKCRC Board agreed to pilot PPI within some of its advisory groups and subgroups. An evaluation of this pilot project was carried out by TwoCan Associates. TwoCan Associates carry out research, development and training to support patient and public involvement. The evaluation sought different stakeholder perspectives on:

- ▶ The process of involvement
- ▶ The contributions made by patient / public members of advisory groups
- ▶ The impact of those contributions
- ▶ What could be done in future to improve PPI in UKCRC advisory groups.

We used the following methods to carry out this evaluation:

- ▶ A review of relevant papers
- ▶ Interviews with patient / public members, UKCRC group chairs and UKCRC staff
- ▶ A workshop with patient / public members to review our initial findings and to begin to think about recommendations
- ▶ Interviews with key stakeholders (including the chair and vice-chair of the UKCRC Board) to test out our recommendations.

The full report summarises our findings and makes recommendations about how PPI in UKCRC advisory groups could be taken forward.

Recruitment of patient / public members of UKCRC groups took place in early 2007. These roles were advertised nationally. 220 information packs were sent out and 46 applications were returned. Twelve people were interviewed and eight patient / public members were appointed. A ninth patient / public member was appointed in March 2008.<sup>1</sup> Four UKCRC groups were initially identified to be part of the pilot, but given the fast moving nature of the UKCRC's work, these changed. During the pilot period, there has been patient / public membership of the following UKCRC groups:

- ▶ The UKCRC Board
- ▶ The UKCRC Board Subgroup for the UK Clinical Research Network (UKCRN)
- ▶ The UKCRC Board Subgroup on Public Awareness
- ▶ The UKCRC Board Subgroup for PPI
- ▶ The UKCRN / UKCRC Joint Communications Advisory Group
- ▶ The Research and Development Advisory Group to Connecting for Health.

### **Assessment of the process of patient and public involvement in UKCRC advisory groups**

Overall, the process of PPI in UKCRC groups seems to be working well. The recruitment process was effective and fit for purpose. Although some patient / public members were concerned that the process was challenging, this was felt to be appropriate, given the nature of the involvement of patient / public members. Patient / public members are well supported – they receive high quality support from a

---

1 The ninth patient / public member was recruited by invitation.

Programme Manager, and very good practical help (e.g. through prompt sending out of papers and payment of expenses and fees). Opportunities for training have been welcomed. Chairs of UKCRC groups are thought to have a key role in ensuring that patient / public members can participate in meetings. In this context, induction meetings and pre-meetings with chairs were seen to be very useful.

The only aspect of the process of PPI which would benefit from more thought relates to the clarity of the role(s) and purpose of patient / public members within UKCRC groups. When the pilot was developed, all patient / public members were given a role description which outlined the key *tasks* they should undertake. But it was not clear what *role* they should have. There are two broad roles patient / public members could take, which are:

- ▶ To offer a patient (or carer) perspective, bringing their own views and possibly the views of a wider patient group in order to ensure that the UKCRC's activities bring the maximum benefit to patients
- ▶ To act in a role similar to that of a non-executive, enhancing accountability for public spending.

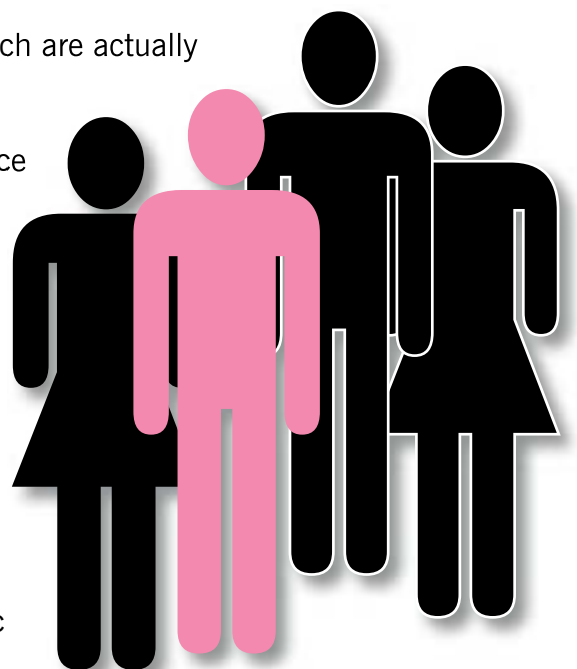
It may be that different UKCRC groups need patient / public members to take on either or both of these roles – this needs to be made clear.

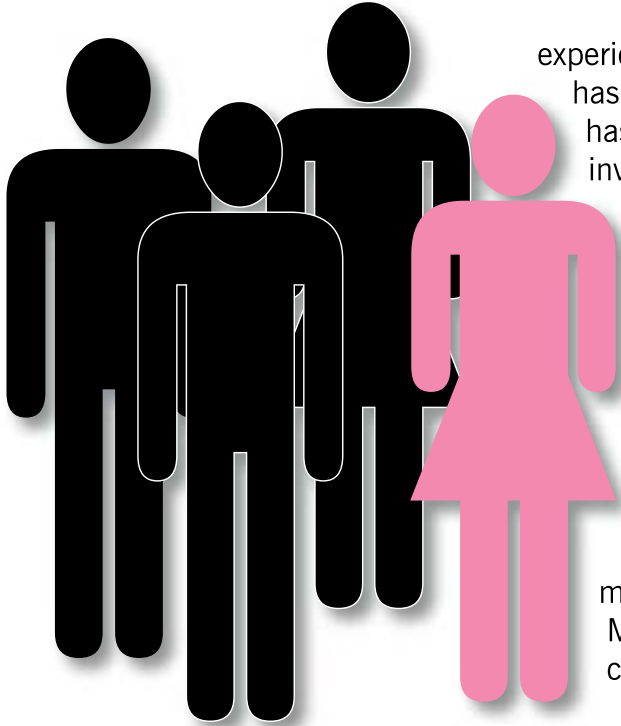
### **Impact of patient and public involvement in UKCRC advisory groups**

It has been difficult to measure the impact of PPI within UKCRC groups. This is partly because PPI has not been in place for very long. It is also hard to judge the precise impact that one or two people have had on the outcomes of group discussions. However, it is clear that patient / public members have made a difference. Impact has been varied, and includes:

- ▶ Asking what may appear to be simple questions, but which are actually questions fundamental to the debate
- ▶ Keeping a discussion grounded
- ▶ Monitoring performance and recognising good performance
- ▶ Promoting issues or questions which members believe would be important to patients and / or the public
- ▶ Acting as a reminder of patient / public accountability
- ▶ Bringing in knowledge from other related experiences
- ▶ Contributing to practical decisions
- ▶ Promoting the use of plain English
- ▶ Lobbying for more PPI within particular activities.

Involvement has also had an impact on patient / public members. In some cases they have become involved in other activities which they would not have done otherwise. There has also been a more personal impact – patient / public members have felt they have been valued and their skills and





experience have been recognised. For others, the main impact has been demands on their time – membership of some groups has proved very demanding in terms of the amount of time involved.

There have also been factors which have limited the impact of patient / public members. One has been the lack of clarity about their role. Others relate to the environment in which patient / public members are operating: the work of the UKCRC is fast-moving, highly strategic and often extremely complex. Patient / public members are involved for brief periods of time. Along with the fact that decisions are sometimes made outside of meetings, this makes it difficult for patient / public members to have a meaningful role in decision-making. Membership of the UKCRC Board presents a particular challenge in this respect.

However, other members of UKCRC groups are convinced that patient / public members have had an influence on discussions and decisions, even when patient / public members themselves feel that their presence has not made any impact.

### **What should 'successful' patient and public involvement in UKCRC groups look like?**

The interviewees had clear views about what successful PPI in UKCRC groups should look like:

- ▶ It should happen across all of the UK Clinical Research Network and in all geographical areas
- ▶ It would be a part of the UKCRC's core business – not an add-on
- ▶ The patient / public perspective and role would be understood and valued by other members and UKCRC Partner organisations
- ▶ There would be networks for patient / public members to consult, if they wished to test out their opinions on a particular issue
- ▶ It would involve a diverse range of people.

PPI should also add value – to the UKCRC and to the individuals who are involved. It should be developed in partnership with patients and the public.

## Recommendations

The full report contains 11 recommendations. We suggest that the first five of these are implemented during 2009. The remaining six recommendations are less urgent and could be taken forward in 2010 if necessary. Our recommendations are summarised below:

1. Continue the involvement of patient / public members in UKCRC advisory groups, and maintain the level of support provided for PPI activity.
2. Capitalise on the expertise and knowledge that have been gained within UKCRC advisory groups and use the learning to plan for the future.
3. Review and define the purpose of PPI and the role of patient / public members within the UKCRC.
4. Explore and clarify how support for PPI will be provided beyond December 2009.
5. Review how PPI is put into practice at Board level, and explore how this can be done more effectively.
6. Bring together patient / public members who are involved in strategic decision making in health research at a national level, to share experience and promote learning, identify opportunities for collaboration and shared goals, and / or identify any common needs for training and development.
7. Support patient / public members to access networks of patients or the public to enable them to access the views of others, if patient / public members feel this would help them to fulfil their role.
8. Offer informal de-briefing and support to patient / public members after all UKCRC group meetings to help them to review their performance.
9. Ensure greater diversity amongst new patient / public members.
10. Explore how technical expertise might be made available to patient / public members, when they are dealing with complex issues and are uncertain about how best to consider specific questions or concerns.
11. Continue to develop methods to capture and where possible measure the impact of PPI across the UKCRC.

All of these recommendations should be taken forward in partnership with patients and the public.

# Introduction

# 1

## 1.1. What did this evaluation aim to do?

The aim of this project was to evaluate a pilot scheme to recruit and support patient and public involvement (PPI) in the advisory groups of the UK Clinical Research Collaboration (UKCRC). The role and work of the UKCRC is summarised in Appendix 1 of this report. The evaluation sought different stakeholder and patient / public members' perspectives on:

- ▶ The quality of the processes of involvement
- ▶ The contributions made by patient / public members of advisory groups
- ▶ The impact of those contributions
- ▶ What could be done in future to improve PPI in UKCRC advisory groups.

The UKCRC groups which formed this pilot scheme were:

- ▶ The UKCRC Board
- ▶ The UKCRC Board Subgroup for the UK Clinical Research Network (UKCRN)
- ▶ UKCRC Board Subgroup on Public Awareness
- ▶ The UKCRC Board Subgroup for PPI (formerly the PPI Project Group)
- ▶ The UKCRN / UKCRC Joint Communications Advisory Group
- ▶ The R&D Advisory Group to Connecting for Health (this group has been superseded by the Joint OSCHR E-Health Records Research Board & Research Capability Programme External Reference Group).

It is anticipated that the UKCRC will use the findings from this evaluation to:

- ▶ Share the learning with a wider audience
- ▶ Shape the future development of PPI in UKCRC activities
- ▶ Add to current evidence / knowledge of PPI in research
- ▶ Demonstrate accountability to the funders of the UKCRC.

## 1.2. About the authors of this report

This evaluation was carried out by Bec Hanley, Carolyn Morris and Kristina Staley from TwoCan Associates. TwoCan Associates carry out research and evaluations, and provide training and support to help voluntary and statutory organisations involve people who use services in their work. Almost all of our work is undertaken in partnership with service users or carers. For further information please see:

[www.twocanassociates.co.uk](http://www.twocanassociates.co.uk).

### 1.3. About the structure of this report

The remainder of this report is structured as follows:

*Section 2:* Background

*Section 3:* How we carried out this evaluation

*Section 4:* Development of PPI in UKCRC advisory groups

*Section 5:* Assessment of the process of PPI in UKCRC advisory groups

*Section 6:* Impact of PPI in UKCRC advisory groups

*Section 7:* Conclusions

*Section 8:* Recommendations

In this report, quotations from interviewees or from reports and papers are in *italic text*.

We have tried to ensure that quotes cannot be attributed to particular individuals. However, we recognise that it is often helpful to know if a comment has been made by a patient / public member or by a chair of one of the UKCRC's groups or by member of staff. For this reason, we have attributed quotes either to 'patient / public members' (this refers to the nine patient / public members of UKCRC groups); 'UKCRC group chairs' (this refers to the chairs of Board subgroups and advisory groups), or 'UKCRC staff' – this refers to members of the UKCRC Secretariat.

A list of the acronyms used can be found in Appendix 2.

# Background

# 2

In this section, we look at what is meant by PPI and some of the challenges of evaluating PPI. To do this, we have drawn on some of the publications that we used to help us to plan and carry out this evaluation.

## 2.1. What do we mean by patient and public involvement?

In 2007 the House of Commons Health Committee published a report on PPI in the NHS. In this, the Committee described the distinct roles of *patient* involvement as opposed to *public* involvement. Patient involvement is about involving people who have used health services in the planning, management or review of health services (or health research). Public involvement is about involving people as citizens, to ensure public accountability for decision-making and the spending of public money. Professor Celia Davies summarised this for the Committee:

*For me, one of the fundamental distinctions is between involving people as citizens in hard choice decisions, maybe in commissioning, in the policy process of government and, at the other end, involving them as service users who have had the experience and can feed something back.<sup>2</sup>*

However, the Committee noted that patient involvement and public involvement have been conflated, and that this has led to confusion about the purpose of involvement and how it should best be achieved:

*The confusion about the purpose of involvement has led to muddled initiatives and uncertainty about what should be done to achieve effective patient and public involvement.... [T]he overall aim of patient and public involvement often seems elusive, with patient and public involvement often used to serve several different purposes simultaneously. These can broadly be divided into two headings:*

- i. improving the quality of services; and*
- ii. enhancing accountability for public spending<sup>3</sup>*

In this report we use the term 'patient / public member' to describe the patients and members of the public who were recruited to become members of UKCRC groups. In section 5.1 of this report we discuss how the conflation of patient involvement and public involvement has led to some confusion about the role of patient / public members in the UKCRC.

## 2.2. Evaluating patient and public involvement

This evaluation aimed to assess both the process and impact of PPI in UKCRC advisory groups. In terms of evaluating *process*, there are many different publications describing 'good practice' in PPI. We found the following references particularly useful:

- ▶ R. Telford, J. Boote and C. Cooper. (2004) What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations* vol 7, pp209-220.

2 House of Commons Health Committee 2007 *Patient and Public Involvement in the NHS*, page 10

3 House of Commons Health Committee 2007 *Patient and Public Involvement in the NHS*, pages 3 & 13

- ▶ InterAct. Working Paper: *Evaluating participatory, deliberative and co-operative ways of working* (2001).
- ▶ INVOLVE: **Involving the public in NHS, public health, and social care research: Briefing Notes for Researchers** (2004).

The Telford paper describes a consensus study, undertaken in 2002, to identify what successful PPI in NHS research would look like. Although some of the criteria Telford and her colleagues identified are specific to research *projects*, the following are also relevant to involvement in research at a strategic level:

- ▶ Roles of patients and the public are agreed
- ▶ There is an appropriate budget for involvement
- ▶ Patients and the public are offered training and support
- ▶ ‘Professionals’ ensure they have the necessary skills to involve patients and the public, and there is respect for the differing skills, knowledge and experience of patients and the public.

There have been many more evaluations that looked at the *process* of involvement than evaluations of the *impact* of involvement. Our experience of evaluating a number of PPI projects in both voluntary and statutory organisations has led us to conclude that evaluation of impact can be much more of a challenge. There are many reasons for this including<sup>4,5</sup>:

- ▶ It is not always easy to show clear causal connections between a complex social activity like PPI and the practical or the less tangible outcomes
- ▶ Patients / members of the public and professionals may have different views of the impact that PPI has made. This means all stakeholders need to be asked for their views
- ▶ The impact of PPI is very varied depending on the context. This means there is no standard way of measuring impact that can be applied in all situations
- ▶ Patients / members of the public and professionals can find it difficult to recognise and be clear about the impact that PPI has made
- ▶ After a period of continuous involvement, individuals may find it hard to remember or be certain at which key points PPI made a significant and observable difference.

Consideration of these challenges led us to structure our evaluation of PPI within UKCRC groups in the way we describe in the next section.

---

4 Doel M. et al. (2007) *Participation: Finding out what difference it makes*. London: SCIE.

5 Hanley B, Morris C and Staley K. (2005) Report to the Steering Group. Macmillan Cancer Support Success Measures project.

# How we carried out this evaluation

# 3

## 3. How we carried out this evaluation

This evaluation was undertaken between August and December 2008. It consisted of the following stages:

- ▶ A review of relevant papers
- ▶ Semi-structured interviews to understand more about the process and impact of PPI
- ▶ A workshop for stakeholders
- ▶ Further semi-structured interviews to test out provisional recommendations
- ▶ Production of a final report.

Each of these stages is discussed in more detail below.

### 3.1 Review of papers

After an initial meeting with Philippa Yeeles, the Programme Manager with responsibility for supporting the development of PPI in UKCRC activities, we reviewed all the relevant papers on PPI in UKCRC groups in order to:

- ▶ Draw out key lessons / reflections for this report
- ▶ Prioritise who we wanted to interview
- ▶ Help shape the interview schedules – including general questions for all interviewees and specific questions about particular PPI activities
- ▶ Ensure we were fully informed of the context prior to conducting interviews.

### 3.2 Initial interviews

We drew up a list of people we would like to interview, and drafted interview schedules for use with the different groups (UKCRC patient / public members, group chairs and staff). We drew on our reading (see section 2.2) to develop these interview schedules. These schedules included questions about both the process and impact of PPI, and sought views about how PPI activity might be improved in future. The topics covered included:

- ▶ Recruitment and induction of patient / public members
- ▶ Training and support for patient / public members
- ▶ Roles and remit of UKCRC groups and their members
- ▶ The purpose and expectations of PPI in the groups
- ▶ The work the groups have done and how PPI influenced this
- ▶ The impact of PPI on individual group members, the group as a whole and the UKCRC as an organisation
- ▶ Factors that that have enabled and / or inhibited PPI
- ▶ The added value of PPI
- ▶ What could be done to improve the process of PPI
- ▶ What would help PPI to have a greater impact.

The Project Advisory Group considered these interview schedules and our proposed list of interviewees. We amended the schedules in response to feedback from the Project Advisory Group and undertook 13 interviews in September and October 2008. These included:

- ▶ Nine patient / public members
- ▶ Two UKCRC group chairs
- ▶ Two members of UKCRC staff.

We conducted the majority of interviews face-to-face. Where permission was given, we tape recorded interviews. Each tape was transcribed by the interviewer. The interviewer then reviewed the transcript and highlighted key themes. All of the interviewers read all of the transcripts. We then met to discuss the analysis of the transcripts, agree common themes and the main points for the final report. All tapes and notes will be destroyed at the end of the project.

### 3.3 Workshop

We produced a summary of our findings and our initial thinking about recommendations. We discussed these with patient / public members and the Project Advisory Group at a workshop on 31<sup>st</sup> October 2008. This workshop was facilitated by Derek Stewart, a TwoCan Associate. He brought fresh eyes to the evaluation, having had no previous involvement. In order to promote constructive reflection and to provide an opportunity to make comparisons with other relevant PPI activities, we invited a PPI specialist to act as a 'critical friend' at the workshop. The role of a critical friend is to ask provocative questions and offer a constructive critique *as a friend*.<sup>6</sup> In this project, this role was undertaken by Rachel Purtell, Director of the Folk.us project.<sup>7</sup>

After the workshop we produced a revised draft of the key findings and drew up a list of provisional recommendations, incorporating the views of workshop participants.

### 3.4 Interviews to test out the recommendations

In November and December 2008 we interviewed a small number of key stakeholders, to test out our recommendations. Again we developed draft interview schedules, an invitation letter and a prioritised list of interviewees, which we agreed with members of the Project Advisory Group. At this stage we interviewed:

- ▶ The Chair of the UKCRC Board
- ▶ The Deputy Chair of the UKCRC Board
- ▶ The Chief Executive of the UKCRC
- ▶ The Chair of the Board Subgroup for PPI.

6 Costa A & Kallick B (1993) Through the lens of a critical friend *Educational Leadership* 51 (2) 49-51 and Swaffield S (2002) *Contextualising the work of the critical friend* Paper for 15<sup>th</sup> International Congress for School Effectiveness and Improvement January 2002.

7 Folk.us brings the world of research and researching to people who use health or social care services across Devon. See [www.folkus.org.uk](http://www.folkus.org.uk)

We asked the interviewees for their views on:

- ▶ Findings from the evaluation
- ▶ Recommendations for the future development of PPI in UKCRC activity
- ▶ Factors which might enable and / or inhibit acting on the recommendations.

We conducted these interviews face-to-face or by telephone, depending on the preference of the interviewees. We took detailed notes during all of these interviews, which were again transcribed and analysed to identify key themes. All interviewers read all notes and discussed the implications for the final report.

### **3.5 Producing a final report**

A draft of our final report was discussed with the critical friend. It was also sent to all interviewees and all Project Advisory Group members with an invitation to comment. The final report was delivered to David Rea, the Chair of the Project Advisory Group and Philippa Yeeles, UKCRC Programme Manager.

# Development of patient and public involvement in UKCRC advisory groups

# 4

## 4.1. Background to the appointment of patient / public members to UKCRC groups

When the UKCRC was first established, work to promote PPI was relatively slow in starting, although some of the Partner organisations (for example INVOLVE, the National Institute of Health Research in England and the Chief Scientist Office in Scotland) had been promoting and supporting PPI for a number of years.

In December 2005 a UKCRC PPI Project Group was established. The aim of this group was to develop a shared agenda for PPI, with a view to engineering long-term change<sup>8</sup>. Membership consisted of staff with responsibility for PPI from some of the UKCRC Partner organisations, who were joined by a small number of other stakeholders with an interest in PPI. The group discussed how they might promote PPI within the UKCRC and its Partner organisations. It took some time to develop consensus about what this should involve.

In May 2006 the group agreed to identify a small number of different activities through which patients and the public could contribute in a meaningful way to the work of the UKCRC. The group hoped that these activities would achieve some quick wins around PPI and gain momentum for this area of work. Four activities were identified. They were:

- ▶ People in Research, a web-based resource to promote PPI and provide links for interested members of the public (see [www.peopleinresearch.org](http://www.peopleinresearch.org))
- ▶ Exploring the use of standard criteria for assessing PPI in research funding applications
- ▶ Exploring opportunities for ensuring that research contracts encourage appropriate PPI
- ▶ Developing the evidence base for PPI in research.

In July 2006 a Programme Manager (Philippa Yeeles) was appointed. Her role was to take the lead on PPI and on nursing workforce issues. Within about nine months, when responsibility for nursing workforce issues passed to another member of the UKCRC Secretariat, her time became solely focussed on PPI.

In September 2006 agreement was reached to pilot PPI within UKCRC advisory groups. The UKCRC Secretariat used two criteria to select groups in which to pilot PPI:

- ▶ *Groups where the Chair has experience of and / or is committed to PPI coupled with a willingness to accommodate the needs of patient / public members within their group*
- ▶ *Groups where it is possible to identify among group members someone who is willing to offer patient / public members an agreed amount of 'technical/ scientific' support.*<sup>9</sup>

Initially four groups were identified:

- ▶ The PPI Project Group
- ▶ The Implementation Group for the Nurses in Clinical Research report
- ▶ The R&D Advisory Group to Connecting for Health
- ▶ The UKCRC Board Subgroup for the UK Clinical Research Network.

<sup>8</sup> See *UK Clinical Research Collaboration Progress Report 2004-2006* p41

<sup>9</sup> P Yeeles *Briefing for Liam O'Toole for UKCRC Board Subgroup 23/11/06*

It was agreed that two patient / public members would be invited to join each of these groups.

#### **4.2. Recruitment of patient / public members**

In late 2006 work began to recruit patient / public members. The preparation involved:

- ▶ The development of job descriptions and person specifications
- ▶ Processes for advertising and selecting patient / public members
- ▶ Planning an induction process and mechanisms to offer support to patient / public members
- ▶ The development of guidance materials to support UKCRC groups that were part of the pilot
- ▶ Identifying appropriate training opportunities.

Copies of the documents developed and used in the recruitment process are attached in Appendix 3.

During February 2007 adverts were placed in:

- ▶ The Big Issue
- ▶ New Nation and Eastern Eye (and online on nine associated websites)
- ▶ The Guardian
- ▶ The UKCRC website and by email to Partner organisations
- ▶ The Association of Medical Research Charities newsletter
- ▶ The INVOLVE email alert system and News Board.

A deadline of 12<sup>th</sup> March 2007 was given for the completion of application forms and 220 application packs were sent out. These consisted of:

- ▶ Background information about the UKCRC
- ▶ A role description
- ▶ Role requirements
- ▶ Information about the UKCRC groups seeking PPI
- ▶ Application requirements
- ▶ Information about the selection process
- ▶ An application form
- ▶ A diversity monitoring questionnaire.

Forty six applications were returned. In March 2007 an interview panel, consisting of a UKCRC Board member, the UKCRC's PPI Programme Manager, a patient / public member and a PPI specialist shortlisted and then interviewed 12 people. Eight of them were appointed to become UKCRC patient / public members. A summary of the gender, age, marital, disability and employment status, ethnic origin and where applicants saw the advertisement is included in Appendix 3.

A ninth patient / public member was recruited by invitation in March 2008 to join the UKCRN / UKCRC Joint Communications Advisory Group.

### 4.3. Induction of patient / public members

An induction session was held for new patient / public members in June 2007. This included:

- ▶ An introduction to the UKCRC and its work
- ▶ A patient talking about his experience of being a member of a strategic advisory group
- ▶ One-to-one discussions with UKCRC Secretariat staff about each of the four groups that patient / public members were to join
- ▶ A discussion about training and support needs.

All attendees were sent a biography of those attending, and were asked to complete an evaluation form at the end of the event.

### 4.4. Appointment of patient / public members to UKCRC groups

The eight patient / public members were each allocated to one of the pilot groups. However, the Implementation Group for the Nurses in Clinical Research did not meet, so the two patient / public members who were allocated to this group did not join a UKCRC group for at least one year after their training.

In addition, in June 2007 the R&D Advisory Group to Connecting for Health was dissolved, and a new group called the Joint OSCHR E-Health Records Research Board & Research Capability Programme External Reference Group was established. This group advises Connecting for Health and OSCHR, and is not part of the UKCRC. The UKCRC patient / public members were invited to join the new group when it formed, and continue to attend UKCRC patient / public members' meetings, and have contact with the UKCRC Secretariat.

Two patient / public members have now joined the newly formed UKCRC Board Subgroup on Public Awareness. One patient / public member joined a time-limited UKCRN / UKCRC Joint Communications Advisory Group – it had been planned to have two patient / public members on this Group but one was unable to take part due to other commitments. Two members also joined the UKCRC Board.

A diagram highlighting UKCRC groups which currently have patient / public membership is on page 18.

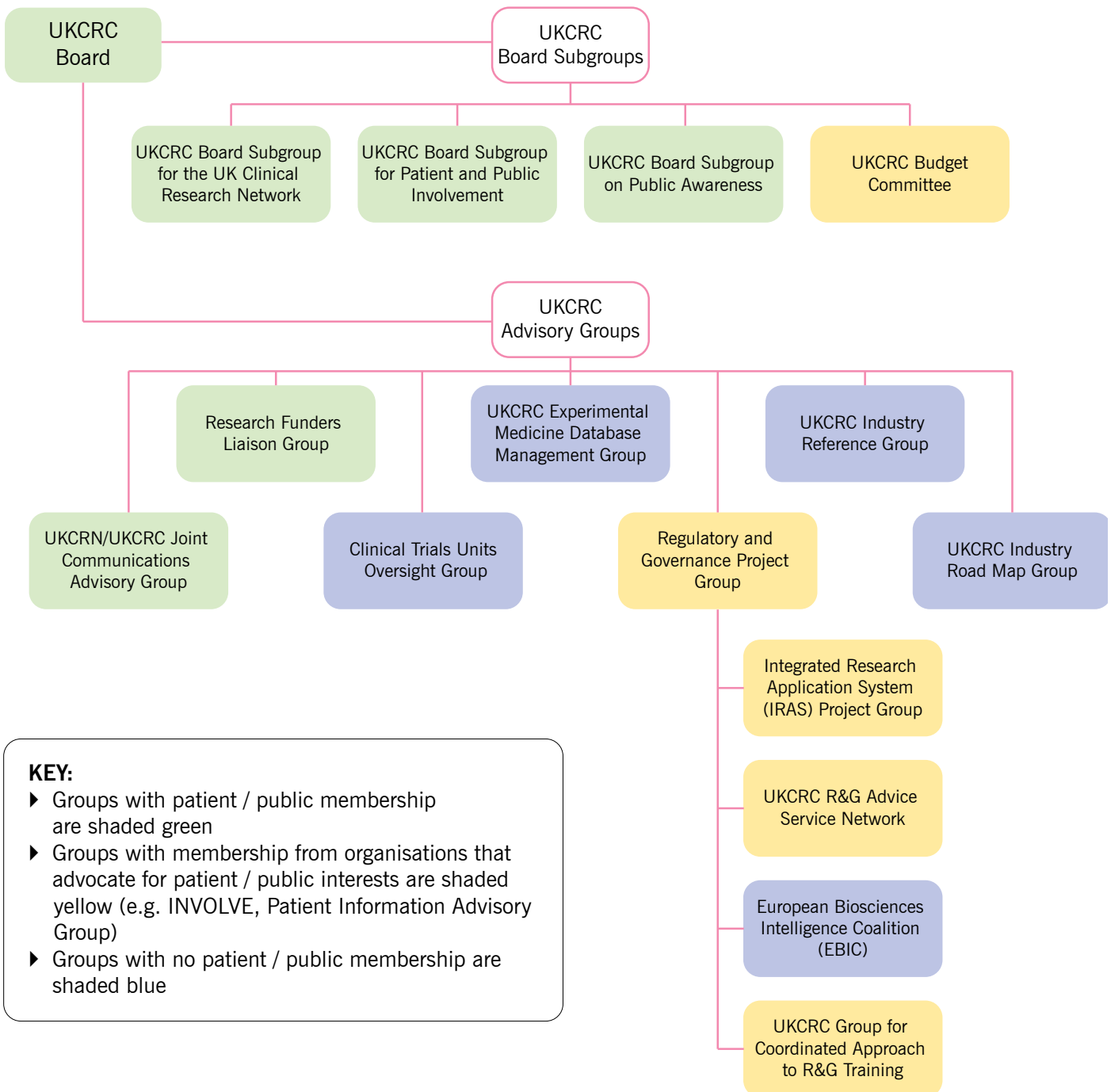
Some of these groups meet frequently, others rarely. This means that patient / public members spend varying degrees of time on UKCRC activity. This ranges from a few hours per month to one or two days per week.

### 4.5. What is the role of patient / public members on UKCRC groups?

The role description for patient / public members on UKCRC groups states that members should:

- ▶ *Regularly attend and participate in group meetings*
- ▶ *Assist the group in understanding some of the perspectives of patients and the public that are relevant to the work of the group*
- ▶ *Contribute to discussions that take place during meetings*

**Figure 1 UK Clinical Research Collaboration Groups: December 2008**



- ▶ *Prepare for group meetings by reading meeting papers and raising any issues for clarification with the UKCRC Secretariat*
- ▶ *Identify with the UKCRC Secretariat any personal needs for training and support*
- ▶ *Participate in appropriate training and support activities*
- ▶ *Participate in any evaluation of this role or the activities of the Group<sup>10</sup>.*

#### **4.6. Other activities**

In addition to their membership of UKCRC groups, patient / public members have taken part in other related activities. For example, they participated in workshops to develop a PPI strategy for the UKCRC, as well as contributing to the strategy in other ways.

#### **4.7. Support and training**

To help prepare the patient / public members for membership in the various UKCRC groups, some took part in an induction meeting with the chair of the group. All met with the member of Secretariat staff who supported each group. Secretariat staff have continued to make themselves available before and after meetings of UKCRC groups.

All patient / public members were offered opportunities to take part in other training and conferences. For example, during 2007, patient / public members:

- ▶ attended the UKCRN national conference
- ▶ attended a seminar organised by the James Lind Alliance
- ▶ attended other R&D events as UKCRC patient / public members, and
- ▶ visited other R&D organisations at local / regional level.

Meetings for patient / public members take place three times per year. The aim of these meetings is to update members on developments within the UKCRC and its Partner organisations and to enable members to update and seek advice / information from each other.

Practical support – for example printing of all meeting papers and arrangements for payment of fees and travel expenses - is provided by UKCRC Secretariat staff.

#### **4.8. The future of patient and public involvement in the UKCRC**

It is not yet clear how PPI will be taken forward by the UKCRC as part of a broader process of reshaping the UKCRC beyond 2009. It is likely that one of the Partner organisations will take a lead on this area of work and assume responsibility for ensuring that UK-wide work to promote effective PPI is taken forward. It is anticipated that this will become clearer following Board discussions about the future of the UKCRC early in 2009.

---

10 UKCRC *Information Pack: Recruiting patient and public members to UK Clinical Research Collaboration (UKCRC) Groups 2007*

## Assessment of the process of PPI in UKCRC advisory groups

# 5

In this section we review how the process of involvement worked in terms of meeting the relevant criteria for successful involvement in NHS research (described in section 2.2). These are:

- ▶ The roles of patients and the public are agreed
- ▶ There is an appropriate budget for involvement
- ▶ Patients and the public are offered training and support
- ▶ 'Professionals' ensure they have the necessary skills to involve patients and the public, and there is respect for the differing skills, knowledge and experience of patients and the public

### 5.1. The roles of patients and the public are agreed

In this section we discuss the recruitment and selection of patient / public members and the role that was identified for them.

#### 5.1.1. The recruitment process

An analysis of the monitoring forms (see Appendix 3) shows that almost all applicants (and all successful applicants) were white. Some of the patient / public members expressed concern about this and about the fact that most of the patient / public members are of a similar age (most were aged between 55 and 64 at the time of applying). It is also of note that 40% of applicants (and 75% of successful applicants) saw the UKCRC's advert in The Guardian newspaper. However, this apparent homogeneity of patient / public members is common to many organisations which seek to involve patients and the public.

Some of the successful applicants found the recruitment process challenging:

*I'm used to making applications – but I found that really challenging. There were too many questions. I can't imagine how underrepresented groups would be able to handle some of those questions.*  
(Patient / public member)

But most found this challenge reassuring:

*I liked the fact that it was very formal. I felt that they were taking the process very seriously.*  
(Patient / public member)

Some people felt that the recruitment process excluded people who would struggle with the length or demands of the application form and interview:

*I was trying quite hard to do some work to make sure that the advertisements went out to the student population, to black and ethnic minority communities... but the basic paper work and the application pack... that was just as it was... I **know** that it excluded some people. So that's the only big thing... that I'd really try to do differently next time round.*  
(UKCRC staff)

However, some people felt that the process was fit for purpose, in that it aimed to recruit people who could operate at a senior level, and take part in strategic decisions. It may not be appropriate to

simplify the recruitment process, if this results in the recruitment of people who are unable to work at this level:

*My view is that you have to have at least the capacity to operate in that environment... If you're going to have an impact then you need to have the skills to work in the system with the people who take the major decisions. And you've got to be able to work in a way that they take you seriously.* (Patient / public member)

### 5.1.2. The role of patient / public members

The general picture that emerged from the interviews is that *patient* and *public* involvement have become conflated within the UKCRC (see section 2.1). This means that the precise role of patient / public members is often unclear. Some patient / public members are offering a patient perspective, focussing on bringing in patients' views, as a way of ensuring that the UKCRC's activities bring the maximum benefit for patients:

*I try and articulate some perspectives that I pick up as a result of the networks I'm involved in, in other areas... I would never claim to represent them in that way... what I would try and do is to articulate a perspective that I think represents the way patient and public would feel about these issues.* (Patient / public member)

Others are acting more as a non-executive – someone who brings a 'disinterested' perspective and enhances accountability for public spending:

*I see it as a critical friend – someone who can look at things from a different perspective because I don't have such a strong vested interest as some of the others there.* (Patient / public member)

*Well I see it as a governance aspect, trying to represent this other point of view, which is the taxpayer... I think we have got a more overall view... is it in the interests of taxpayers for a lot of money to be spent on this because this is a very expensive operation... But when you ask me what my role is, it's to try and bring my experience of life and organisations in an objective way.* (Patient / public member)

However, there is no consensus on what the role ought to be and how it might differ in different contexts. This lack of clarity about roles appears to contrast with other members of the UKCRC groups, who seem to have very defined roles:

*Being the industry representative or the Scottish government representative or the MRC representative. They are all, they've all got a bag, a specific bag, and they have the interest if you like, and probably a mission statement and they can check everything, does this accord with our mission.* (Patient / public member)

However, this perception that other members of UKCRC groups have clearly defined roles may not always be accurate – it may be that these members are also unclear about their precise role, and / or may bring specific qualities which are not related to being a representative of a particular organisation.

## 5.2. Budgets for patient and public involvement

Patient / public members are paid a fee for taking part in meetings and other events – this is set at the current National Institute for Health Research (NIHR) recommended rate.<sup>11</sup> Patient / public members felt that this level of payment was appropriate – and payment was seen to be enabling of involvement for most people.

Patient / public members are also very happy with the practical arrangements for payments, as these happen very promptly. However, this is a challenge for the Secretariat as they operate within an administrative framework that takes a different approach to PPI. (The UKCRC Secretariat is hosted by the Medical Research Council (MRC), which provides all support related to procurement, finance and human resources.) Making payments promptly can be difficult:

*I mean I try to make it as easy as possible for them but I am limited by the MRC, I have to go through their finance processes... I find that quite difficult.* (UKCRC staff)

An analysis of costs for patient / public members' attendance at UKCRC groups between April and July 2008 shows that £3,550 was paid in total. An additional £800 was spent to cover the costs of patient / public members attending other meetings (for example visiting the NIHR Clinical Research Network Coordinating Centre). If these figures reflect activity for a year as a whole, then the total cost for expenses and payment is around £17,500 per annum. However, this figure does not represent the full cost of PPI, as it does not cover staff time, nor costs such as venues and refreshments for patient / public members' meetings.

It's not possible to state confidently whether or not this investment represents 'value for money', as there is no figure we can use for comparison. We do not know how much it costs for other people to be involved in UKCRC groups (these costs are usually incurred by Partner organisations rather than by the Secretariat on behalf of Partner organisations), and there are no criteria to determine 'value for money'.

## 5.3. Training and support for patient / public members

This section covers:

- ▶ Induction training
- ▶ Ongoing training and development
- ▶ Support for patient / public members
- ▶ De-briefing after meetings

### 5.3.1. Induction training

Evaluation forms completed at the end of the induction session showed that everyone who attended thought that all aspects of the meeting were at least '*somewhat useful*', with some aspects, particularly the talk on the work of the UKCRC and the one-to-one discussions with Secretariat staff,

11 See *National Institute for Health Research Programmes: Payment and reimbursement rates for public involvement* (July 2008 - 2nd version) - [www.invo.org.uk/Publication\\_Guidelines.asp](http://www.invo.org.uk/Publication_Guidelines.asp)

being seen by most attendees as *very useful*. The session was especially valuable in bringing people together:

*I don't think they could have done a lot better. I think it did its job.... You got to know other people. I think that was really good.* (Patient / public member)

Suggestions for improvement identified in the evaluation forms included:

- ▶ *It would be useful to get to know all other members of this group, have discussions as a whole not just in the pairs and to learn about people's experiences who have already attended an advisory group meeting*
- ▶ *It would be useful to have more time for an update on the UKCRC*
- ▶ *Ensure there is enough time allocated so that all agenda items can be covered fully*
- ▶ *It would be useful if examples of the kinds of issues being considered by the 4 advisory groups and then explore any possible overlaps and common themes*

Patient / public members were grateful for not being overloaded with information at the beginning. It is very hard to understand the UKCRC and what it does, and it took patient / public members a long time to understand what was going on. This is not a reflection on them – but on the UKCRC and the complexity of the world in which it operates. However, relationship diagrams and further explanation of the role of the UKCRC would be helpful for new members in future.

### 5.3.2. Ongoing training and development

Patient / public members felt that they had good access to training if they wished:

*They did make available ways of finding out training that was available... and that is very good. There isn't any shortage of things they're happy to support you in doing.* (Patient / public member)

But some felt they also wanted help with understanding information, or an 'expert' with whom they could test out their ideas.

*It would be useful if you could have somebody who's technically competent but independent of the issues you're looking at that you could phone and say well look, they're talking about this, and I've got some concerns about that, does that make any sense to you...* (Patient / public member)

### 5.3.3. Support

The term 'support' is used to include support provided by the Secretariat, practical support and peer support.

**Support provided by the Secretariat** was thought to be of high quality. For example, without

exception, everyone we interviewed was extremely positive about the support they received from the Programme Manager:

*I wouldn't fault Philippa at all – she's very good at allowing people to shape things – she's got a very good relaxed style. Philippa did a good job of setting the tone really early on and making sure people felt comfortable about saying whatever they wanted and shaping the agenda.* (Patient / public member)

In evaluation forms completed by patient / public members in August 2008 to review experience to date, patient / public members also reported that they had been able to raise any queries they had ahead of meetings. In the majority of cases (90%) these had been fully answered.

Group chairs also recognised the importance of Programme Manager's role in supporting patient / public members to make a contribution to meetings:

*It's the best example [of support from staff] I've seen... Philippa suggested the induction session and made it happen. And she acted as a contact point. I think that's important.* (UKCRC group chair)

There was very positive feedback about the speed in which **practical support** is provided – for example sending out hard copies of meeting papers, dealing with expenses claims and payment. An analysis of a review of experience of patient / public members to August 2008 shows that with only one exception, papers arrived in advance of meetings. Patient / public members were also very appreciative of the fact that the Administrator, Hannah Brown, is willing to act as a contact point:

*The admin is fantastic. I feel well looked after.* (Patient / public member)

**Peer support** was also seen to be important by patient / public members. They value the opportunity to meet with other patient / public members regularly to share their experiences. These meetings help keep patient / public members informed between meetings and enable people to discuss issues in more detail and gain more information.

*It's very helpful that it's small. In an evolving situation that has been really helpful.* (Patient / public member)

Evaluation forms are completed at the end of each patient / public members' meeting. Some of the things that members have identified as helpful include:

- ▶ *Information re progress and outcomes of PPI in the various PPI Groups*
- ▶ *Learning about the different parts members are playing in patient / public representation in the various groups, getting updates on developments, and helping to form a shared view about where we are in progressing PPI*
- ▶ *Opportunity to share ideas in order to make contributions to the respective groups with which members are involved*
- ▶ *Presentations on relevant topics e.g. the presentation on OSCHR*

- ▶ *The opportunity to discuss the key issues re PPI and why it is important. Also the opportunity to engage in more prolonged conversation with my co-Project Group member during the lunch break*
- ▶ *To gain a clearer sense of the direction of PPI within UKCRC and be part of that process. Also to feel part of a group rather than isolated in this work.*

Some members are also linking with (or planning to link with) patient / public members from other organisations who are also working at a national, strategic level within health research.

#### 5.3.4. De-briefing after meetings

Some patient / public members felt that de-briefing after UKCRC meetings would be useful – this is offered at present, but not consistently. There were differing views about the need for such de-briefings, as some patient / public members did not want to feel they were a ‘special case’.

De-briefing could usefully take place after group meetings, and focus on whether people are fulfilling their role(s) effectively. It may be more appropriate to get this feedback from the Secretariat than from the group chair.

*Some feedback would be helpful. Keep it informal – because we don’t want to build too many structures that add to the workload... Normally someone from the [UKCRC Secretariat] team sits on the meetings – so it would be good to get feedback from them – the Chair may have other issues if... you’ve raised something they don’t agree with.*  
(Patient / public member)

#### 5.4. The role of other UKCRC group members in relation to patient / public members

PPI members felt that they were welcomed onto groups by chairs and other members. The role of chairs was seen to be key to whether patient / public members felt able to operate effectively within a group.

*The chair is very accommodating towards the patient / public members and pro-actively makes opportunities for us to air our views – and definitely checks we’re happy with the responses we get in meetings – so is very, very supportive.* (Patient / public member)

*The chair sat next to me and made sure I was comfortable.* (Patient / public member)

Pre-meetings and induction meetings with chairs were found to be very useful.

*I got an opportunity to have a pre-meeting with the chair, Philippa and Matthew. That was really good.* (Patient / public member)

#### 5.5. Conclusion

Overall, the process of PPI in UKCRC groups seems to be working well, in that it has been valued by the wider membership and patient / public members feel able to make a contribution. The support provided by UKCRC Secretariat staff has been universally agreed to be of high quality. The only aspect of the process of PPI which would benefit from more thought relates to gaining more clarity as to the role(s) and purpose of PPI.

# Impact of patient and public involvement in UKCRC advisory groups

# 6

## 6.1. The impact of involvement

It is difficult at this stage to be confident about the impact of PPI in those groups where it has been introduced. There are a number of reasons for this. One is that some people feel it is too early to judge, given the complexity of the UKCRC and its work. Another reason is that it is difficult for any one individual to judge what impact they have had on the outcomes of a discussion:

*I'm not sure you could identify many examples of significant differences that have come from PPI – what you get is confirmation that people are part of a positive process – it's not like the group's going off in one direction and you convince them to completely change it – it's about refining and contributing to the debate. (Patient / public member)*

*I'm not convinced you can do 'this' now and see 'that' happen then. Sometimes it's about sowing a seed... (Patient / public member)*

It is also difficult to assess the impact of patient / public members (or any group member) on strategic level decision-making, where the outputs relate to developing policy or working principles. It is much easier to observe impact in circumstances where there is a more practical or tangible output (for example, input to a patient information sheet or a decision about whether to fund a research grant application).

### 6.1.1. Different types of impact

However, it is possible to identify the different kinds of impact that patient / public members have had in the groups. These are listed below, followed by some illustrative quotes:

- ▶ Asking what may appear to be simple questions, but which are actually questions fundamental to the debate
- ▶ Keeping a discussion grounded
- ▶ Monitoring performance and recognising good performance
- ▶ Promoting issues or questions which members believe would be important to patients and / or the public
- ▶ Acting as reminder of public / patient accountability
- ▶ Bringing in knowledge from other related experiences
- ▶ Contributing to practical decisions
- ▶ Promoting the use of plain English
- ▶ Lobbying for more PPI within particular activities.

*The people I've had on those [advisory] groups have been brilliant. They ask really simple questions – that everyone is too frightened to ask because they don't want to look stupid. (UKCRC group chair)*

*We have both worked to raise the levels of PPI and we have seen some progress on that. (Patient / public member)*

*It's the old situation of lay people being involved in a technical world. I think what you have to do is identify the broad things that concern you and then be prepared to niggle away at the technos and the others either until you feel they've taken it on board, or whatever, and hope that your wit and your persistence will get you there....*

(Patient / public member)

*[We] have raised a lot of questions about the performance management of the networks – I suppose our perspective is that a lot of money is being invested – are we confident they are running well and that investment is achieving the outcomes we want?*

(Patient / public member)

*The only way I think that I or anybody there in my role would make a difference is by being there, if you see what I mean. If that was a closed shop without public representation, over time I tend to think people would behave differently.*

(Patient / public member)

*If nothing else I sit in the room and remind people what they're doing is supposedly for the benefit of people like me... that in itself is a good thing, no matter what else.*

(Patient / public member)

*They have had constructive examples and brought a lot to bear from their own professional lives.*

(UKCRC group chair)

*The impact falls into two quite different baskets. One is... the old style lay member. In other words someone who is a professional in their own right and who has experience of dealing with organisational issues and the way boards work and can perform a non-exec role... Then they do provide the patient and public thing... Both non-exec and patient and public views are valuable, but for different reasons. The first one is very helpful... They [patient / public members] have a perspective that the rest of the group doesn't have. So they're able to say very helpful; or very simple things, like it would be very helpful if you presented the information in this way... They often comment on a report... whether it really does show progress against plan... They've also been helpful on occasions in doing the right thing that a dispassionate observer would do... saying we should recognise good progress...*

(UKCRC group chair)

### 6.1.2. Impact on the patient / public members involved

At the end of the induction training session, patient / public members were asked what they hoped to gain from being part of a UKCRC group. They gave the following responses:

- ▶ *Learn more about the UKCRC, its partners and clinical research*
- ▶ *Intellectual challenge / stimulus / learning something new and building on experiences / knowledge already have*
- ▶ *Doing something significant / actively contributing to an important agenda.*

During the interviews, patient / public members were asked to reflect on whether their expectations had been met and to think about what impact their involvement had had on them - both personally and professionally. For some, their involvement in UKCRC has led to further involvement in other

activities – for example the establishment of a new network of patient / public members with a specific interest, or involvement in another organisation or group. For others there has been a personal impact – that they feel valued or recognised.

*It has affirmed that I can contribute something from my experience. It comes down to self worth.* (Patient / public member)

*I think it's been quite a privilege to do it.* (Patient / public member)

For many the main impact has been the amount of time they spend on work related to the UKCRC. This varies enormously, depending on the time available to members and the demands of the group.

## 6.2. Barriers to impact

There seem to be a number of barriers which prevent patient / public members from having more of an impact. These relate to:

- The complexity of the context in which patient / public members are operating
- The speed at which decisions need to be made
- The fact that PPI is not part of the core business of the UKCRC
- The lack of clarity about the role(s) of patient / public members
- The particular challenges of the UKCRC Board

These barriers will now be discussed in turn.

### 6.2.1. The complexity of the environment

Most of the work of the UKCRC is highly strategic and far removed from the patient experience. Patient / public members have joined groups which in most instances have been meeting for a while. They are being asked to operate within a very complex, fast moving and changing environment. This can mean that people can struggle to keep up:

*It's such a huge remit... There's a lot of specialist areas so that if you don't have any form of contact with these areas in your normal working life then it's difficult to be up to speed.* (Patient / public member)

*I found it hard to understand at first what it was that UKCRC did. Each time I thought I'd understood what it was about, another complicated layer appeared and it baffled me again.* (Patient / public member)

In a review of patient / public members' experience to date in August 2008, members reported that they could only understand about 60% of meeting papers. These papers are often seen to be highly technical and there is little time to absorb them and consider the issues.

*Before each meeting you actually have two pages of acronyms... That's just one indication of how complicated it is.* (Patient / public member)

The complexity of issues means that patient / public members feel they are able to participate fully around 60% of the time.

### 6.2.2. The speed at which decisions are made

Many people commented that it is very hard to have an impact because of the speed at which decisions need to be made:

*We're rushing at such breakneck speed it's very difficult to make a difference in that kind of context... You can ask little questions around the periphery, but what you've got is this tremendous boulder rolling along at speed and nothing that we say is really going to make much difference.* (Patient / public member)

The pace at which things move mean that sometimes patient / public members can feel they have had an impact on a particular policy, only to find that the policy is then re-drafted and the issue of importance to the patient/public member has been removed.

The time available to patient / public members also presents a barrier for some:

*I don't have a lot of time for it. But it really isn't the kind of thing where you can read the papers on the train and arrive briefed for the meeting. You have to do work in between.* (Patient / public member)

### 6.2.3. PPI is not part of the core business of the UKCRC

PPI is largely seen as an add-on to the main business of the UKCRC.

*The government want to see clinical research really developed in the UK and they're determined that all these stakeholders should work together and PPI to some extent so far has been nailed on to that process.* (Patient / public member)

The 'ownership' of PPI within UKCRC seems to sit with the Secretariat, and not with UKCRC Partners.

*They [patient / public members] weren't Board appointments – they were UKCRC Secretariat appointments.* (UKCRC group chair)

*I have a sense that there's no real investment at the end of the day in PPI. That's not from UKCRC people – but I am not sure it's top of the Board's agenda.* (Patient / public member)

### 6.2.4. The lack of clarity about the role of patient/public members

The lack of clarity around the role (or roles) of patient / public members has also been a barrier to them having more of an impact (see section 5.1.2). For example, some patient / public members found it hard to be the sole spokesperson on what is the 'public interest' in group discussions:

*It's hard to see where the public input would be as it's such a high level discussion. For example, there would be an item on brain banking – there's a public interest in that. Nick Partridge is able to cite research on the public's attitudes to that so Nick is able to speak for a lot members of the public – but all I can do is say 'I think this'. So there's a bit of a mismatch – everyone round the table is able to say HEFCE think this or in industry we think this but I can only say I think this.* (Patient / public member)

*You're trying to say well why am I here and what have I got to say, whereas if you come from the Wales Assembly Government, you come with maybe two questions that meeting about how certain criteria of decisions affect them in their office in Wales, and you go away having ticked a couple of boxes.* (Patient / public member)

Some patient / public members felt that without a 'constituency' to consult, it is difficult for them to contribute a meaningful input based on public opinion. This means that they do not feel they can have the same impact as other UKCRC group members, who often have a clearer constituency:

*The lines of information to me or whoever that member is are very hit and miss and I would prefer it if I had more of a constituency, like every other bag holder around that table has. They are coming with their particular constituency. Even the chair... And I just don't have that...legitimacy... and I think this has been a struggle for all of us....* (Patient / public member)

If patient / public members are only able to contribute their personal opinion, this may limit the impact of what they say:

*If I am discussing patient data issues – I have less energy for what [an individual]... might say to me than I would if someone put in front of me the views of our panel of 30 – from different backgrounds – that would really make me sit up.* (UKCRC group chair)

### 6.2.5. The UKCRC Board

It was seen to be particularly difficult for patient / public members to have an impact at Board level. There is a perception that much of the business of Board meetings is carried out elsewhere and that there is little opportunity for patient / public members to make a contribution:

*It's more difficult for the PPI people because they are dropped in at the committee meeting stage – so their ability to influence discussions is more limited than for other people.* (UKCRC group chair)

However in the context of the UKCRC this way of making decisions is thought to be appropriate. Often a particular piece of work needs to be taken forward by a small group of the Partner organisations and other stakeholders. This group then needs to take decisions on its own, while remaining accountable to the rest of the Board.

### 6.3. Conclusion

It is hard to measure the impact of involvement (which in itself is a complex social activity) within a context as complex as the UKCRC. However, it is clear that patient / public members are making a difference – although the chairs are often more aware of this impact than patient / public members are themselves.

# Conclusions

# 7

It is clear that many aspects of this pilot project to introduce PPI into UKCRC groups have been successful. For example, the process of recruitment and selection worked well and was seen to be fit for purpose. Patient / public members are well supported both practically and in terms of training, development and peer support. Their input is valued. Impact has been hard to measure, and patient / public members have not always been convinced of the difference they have made to advisory groups. But other group members value their input and are convinced that PPI has had an influence on the groups and the work that they have done.

The main challenges relate to the complexity of the work undertaken by the UKCRC and the speed at which it must make decisions, and perhaps most importantly the lack of clarity around the role (or roles) of patient / public members.

In order to get a sense of how PPI could be improved, we asked people we interviewed about what successful PPI in UKCRC groups would look like. People had clear views about this:

- ▶ It should happen across all of the UK Clinical Research Network and in all geographical areas
- ▶ It would be a part of the UKCRC's core business – not an add-on
- ▶ The patient / public perspective and role would be understood and valued by other members and partner organisations
- ▶ There would be networks for patient / public members to consult with if they wished to test out their opinions on a particular issue
- ▶ It would involve a diverse range of people.

*I think it would be an integral element of the way of working – across the whole organisation, so it wouldn't be seen as something new, innovative, special, different... It would be so you don't have to think about it, it's automatic.* (Patient / public member)

*I just think it would be better to have more connections, more roots down the system, and channels of communication through the system, about what the concerns of patients and the public are.* (Patient / public member)

*We need to be more of a funnel – for other PPI members who can raise issues with us – so we can say my colleagues are concerned about this or that.* (Patient / public member)

*I think that the stakeholders, these people with their bags from the different organisations would perhaps be... understanding of the role that PPI might play... I think success would be for them as corporately to realise that PPI actually is quite important in terms of the issues we were talking about like value for money for taxpayers and about asking awkward questions sometimes, but not being awkward, but actually being a part of the team the same as everybody else.* (Patient / public member)

We are clear from our own experience that 'successful' PPI needs to add value – most importantly to the organisation (in this case the UKCRC), but also where possible to the people who become involved as patient / public members. Therefore PPI is best developed in partnership with patients and carers.

# Recommendations

# 8

We have developed a series of recommendations, based on the views of the interviewees and our own experience. These recommendations can only be provisional at this stage, as the future direction of the UKCRC is unclear. Where we feel this is appropriate, we have made suggestions about how some of these recommendations might be taken forward.

We understand that there are two phases proposed for the remainder of the work to be carried out by the UKCRC:

1. Until the end of 2009, the UKCRC will continue to operate as it does now
2. Beyond December 2009, the UKCRC Secretariat will be much reduced in size, and will probably consist of one or two people who will support continued meetings of UKCRC Partners. Individual Partner organisations will be responsible for taking forward future activity under the umbrella of the UKCRC, as and when required.

## 8.1. Recommendations to be taken forward before the end of 2009

There are five key recommendations for the UKCRC in relation to PPI. These recommendations are all suggested for phase one – January to December 2009. They are:

### Recommendation 1

**Continue the involvement of patient / public members in UKCRC advisory groups, and maintain the level of support provided for PPI activity.**

### Recommendation 2

**Capitalise on the expertise and knowledge that have been gained within UKCRC advisory groups and use the learning to plan for the future.**

#### *How could this recommendation be taken forward?*

One very practical step would be to develop guidance for chairs to help ensure PPI is effective, as the chair plays a crucial role in facilitating the input of patient / public members. We recognise that some of this guidance may be generic across all R&D groups, so there would be value in INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)) developing guidance for all research organisations. However, there will also be issues that are specific to the UKCRC. Chairs of UKCRC groups which currently involve patient / public members could work with patient / public members to identify what has been helpful, drawing on the findings of this evaluation. In addition, related work that has already been carried out by other organisations such as the Public Involvement Unit at NICE ([www.nice.org.uk](http://www.nice.org.uk)) could also be drawn upon.

### Recommendation 3

**Review and define the purpose of patient and public involvement and the role of patient / public members within the UKCRC.**

***How could this recommendation be taken forward?***

The UKCRC Board will need to discuss and agree how PPI can best add value to all future UKCRC structures / groups. This work will need to follow agreement as to the future direction of the UKCRC. Given the positive findings of this evaluation, we suggest that PPI becomes the norm rather than the exception, and that a case should have to be made for *excluding* PPI from any future UKCRC structures / groups / initiatives.

Accurate role descriptions should ensure that patient / public members on the Board and other UKCRC structures have realistic expectations about what it is possible to achieve within a large and complex group.

These role descriptions should make it clear whether the patient / public member is there as a member of the public or as a service user/ carer. If there is an expectation that patient / public members will draw on other people's opinions to develop their views on specific topics, this consultation will need to be resourced.

If a Board away-day or development day is planned, it would be helpful to include some discussion about the role and purpose of PPI as part of the day's business.

Clarity about the purpose and role(s) of PPI would make it easier to identify the impact of PPI in the future.

### Recommendation 4

**Explore and clarify how support for patient and public involvement will be provided beyond December 2009.**

### Recommendation 5

**Review how patient and public involvement is put into practice at Board level, and explore how this can be done more effectively.**

***How could this recommendation be taken forward?***

Some practical improvements that could be made include:

- ▶ The patient / public Board member(s) should be encouraged and resourced to meet with other Board members outside of meetings to build relationships and gain an understanding of the role of the other members.
- ▶ Patient / public members should be briefed before each Board meeting, and the chair made aware of any agenda items where patient / public input is felt to be particularly helpful or important.

Some thought will also need to be given as to how patient / public members will be trained and supported beyond December 2009.

### **8.2. Recommendations which could be taken forward after December 2009**

We have additional recommendations, which we suggest could be taken forward after December 2009, if there is no time beforehand:

#### **Recommendation 6**

**Bring together patient / public members who are involved in strategic decision making in health research at a national level, to share experience and promote learning, identify opportunities for collaboration and shared goals, and / or identify any common needs for training and development.**

#### ***How could this recommendation be taken forward?***

Some work on this has already been included within UKCRC plans for 2009, and an exploratory workshop will take place early in 2009.

#### **Recommendation 7**

**Support patient / public members to access networks of patients or the public to enable them to access the views of others, where patient / public members feel this would help them to fulfil their role.**

#### **Recommendation 8**

**Offer informal de-briefing and support to patient / public members after all UKCRC group meetings to help them to review their performance.**

Whilst some patient / public members do not feel the need for this, the complexity of both the UKCRC's business and the role of the patient / public member means that it is important to offer this de-briefing to people who would like this opportunity – particularly at Board and Board Subgroup level meetings.

## Recommendation 9

**Ensure greater diversity amongst new patient / public members.**

***How could this recommendation be taken forward?***

It would be helpful to draw on learning from other sectors about how they have promoted and supported the involvement of a wide range of people. We suggest that a more concerted effort is made to link with a range of community and voluntary organisations to ensure that patient / public membership reflects a broader range of backgrounds. Application forms should also be reviewed, to ensure they are fit for purpose. The concern that patient / public members are often fairly homogenous is shared by a number of organisations and patient / public members within these organisations – so there would be value in INVOLVE addressing this issue and issuing guidance for the whole sector.

## Recommendation 10

**Explore how technical expertise might be made available to patient / public members, when they are dealing with complex issues and are uncertain about how best to consider specific questions or concerns.**

***How could this recommendation be taken forward?***

This recommendation is not about 'professionalising' patient / public members. Rather, it aims to ensure that patient / public members have the confidence to question and where appropriate challenge discussions and decisions. There is a need for this kind of input in a very small number of circumstances. We recognise that there may be concerns around confidentiality and/or conflict of interest, as well as difficulties with finding a truly 'independent' expert. However, there would be value in the Secretariat helping to identify and provide access to technical experts when required.

## Recommendation 11

**Continue to develop methods to capture and where possible measure the impact of patient and public involvement across the UKCRC.**

***How could this recommendation be taken forward?***

This might include mapping where PPI is happening now, setting targets for PPI and ensuring that progress is monitored. Once recommendation 3 has been implemented, it will be possible to measure the success of future PPI in terms of whether it has achieved its stated aims and objectives.

## Appendix 1: More about the UK Clinical Research Collaboration

The UK Clinical Research Collaboration ([www.ukcrc.org](http://www.ukcrc.org)) is a partnership of organisations working to establish the UK as a world leader in clinical research. It was set up by the government in 2004. The UKCRC aims to re-engineer the environment in which clinical research is conducted in the UK to benefit the public and patients, by improving national health and increasing national wealth.

The UKCRC brings together key organisations that shape the clinical research environment in the UK. These include:

- ▶ the main research funding bodies (e.g. the four Health Departments, the Medical Research Council and the Wellcome Trust);
- ▶ academia (e.g. the Higher Education Funding Councils for England and Wales);
- ▶ the NHS regulatory bodies (e.g. the Medicines and Healthcare products Regulatory Agency);
- ▶ industry (e.g. the Association of the British Pharmaceutical Industry), and
- ▶ patients and the public (e.g. INVOLVE)

The UKCRC has a Board which provides strategic direction and oversight, and a small Secretariat. Some of the UKCRC's work is led and administered by this Secretariat. Other work is led by Partner organisations and administered by the UKCRC Secretariat, or led and administered by individual Partners on behalf of the UKCRC. Work is undertaken within five key themes. These are:

- ▶ Developing a comprehensive infrastructure to underpin clinical research
- ▶ Building an expert research workforce to support clinical research
- ▶ Developing incentives for research in the NHS
- ▶ Streamlining regulatory and governance processes
- ▶ Developing a coordinated approach to research funding

Almost all of the UKCRC's work is led and overseen by groups, made up of representatives from the Partner organisations and other stakeholders. These might be Board Subgroups, advisory groups or task and finish groups.

A diagram showing the groups in the UKCRC, as at December 2008, is shown on page 19.

The structure and role of the UKCRC is likely to change in 2009. The current Workplan and budget run to the end of 2009, and all staff contracts are due to expire by the end of 2009. The UKCRC Board will be discussing the new structure and way of working in February 2009. It is likely that the size of the Secretariat will shrink to one or two staff, who will be employed to organise meetings of Partners. There is an expectation that Partner organisations will take on greater responsibility for leading on particular workstreams, although how this will be done is not yet clear.

Further information about the UKCRC: [www.ukcrc.org](http://www.ukcrc.org).

## Appendix 2: Acronyms used in this report

HEFCE	Higher Education Funding Council for England
MRC	Medical Research Council
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
PPI	Patient and Public Involvement
OSCHR	Office for Strategic Co-ordination of Health Research
R&D	Research and Development
UKCRC	United Kingdom Clinical Research Collaboration
UKCRN	United Kingdom Clinical Research Network

## **Appendix 3: Further information about recruitment, selection and induction of patient / public members and continued evaluation of meetings**

All the documents in this appendix have been developed and used as part of the process of involving patient / public members in UKCRC advisory groups.

Many of these documents have drawn upon the previous work of Partner organisations and other stakeholders who also have processes for recruiting and supporting patient / public members in their organisations. By publicly sharing these documents the UKCRC intends to extend this practice further.

### **3.1 Information about recruitment, selection and induction of patient / public members**

- 3.1.1 Advertisement
- 3.1.2 Information Pack
- 3.1.3 Application Form
- 3.1.4 Diversity Monitoring Questionnaire
- 3.1.5 Summary of Diversity Monitoring Information
- 3.1.6 Interview Schedule
- 3.1.7 Induction Event Programme

### **3.2 Information about continued evaluation of meetings**

- 3.2.1 Evaluation Form – UKCRC Advisory Group Meeting
- 3.2.2 Evaluation Form – Patient / Public Members' Meeting

### 3.1.1 Advertisement

## Do you want to get involved in helping to influence health research in the UK?



We are the UK Clinical Research Collaboration and our task is to make the UK one of the best places in the world to carry out health research for the benefit of patients and the public. An important part of this is making sure that the NHS is actively involved in research. For more information about what we do, visit our website: [www.ukcrc.org](http://www.ukcrc.org).

We are looking for members of the public to join some of our advisory groups and help us understand the views and interests of patients and the public on a range of research related issues.

- ▶ Are you interested in health research?
- ▶ Do you have excellent communication skills?
- ▶ Do you have experience of working in committees/groups?
- ▶ Would you enjoy the challenge of applying your knowledge and skills to new areas?
- ▶ Do you have time to participate in 2 – 6 meetings a year?

We offer an attendance fee for meetings (unless you are in full time employment in the public sector), expenses, and training and support to get you up to speed with the issues being discussed.

To receive an application pack please email [devfocus@devfocus.org.uk](mailto:devfocus@devfocus.org.uk), or write to: **UKCRC Applications, Unit 120, Regency House, 91 Western Road, Brighton BN1 2NW**

Deadline for return of applications: **12th March 2007.**

Interviews will be held in London on **28th & 29th March 2007.**

### 3.1.2 Information Pack



## INFORMATION PACK

### RECRUITING PATIENT AND PUBLIC MEMBERS TO UK CLINICAL RESEARCH COLLABORATION (UKCRC) GROUPS

The information in this pack should help you decide if you would like to apply to be a member of a UKCRC group. It includes:

- A. Background information on the UKCRC
- B. Role description
- C. Role requirements
- D. Information about the groups
- E. Application requirements
- F. Selection process

#### A. Background

##### What is the UK Clinical Research Collaboration?

The UKCRC is a partnership of the key organisations that help to influence and shape health research in the UK. These organisations include the funding bodies, academic organisations, the NHS, regulatory bodies, industry, patients and the public.

The work of the UKCRC is overseen by a Board and its activities are coordinated and facilitated by a Secretariat team.

The shared vision of the UKCRC is to establish the UK as a world leader in clinical research by harnessing and building on the huge research potential of the NHS. The ultimate aim is to benefit patients and the public by both improving the health and increasing the wealth of the UK.

For more information about the UKCRC's work please visit [www.ukcrc.org](http://www.ukcrc.org)

## Information Pack

### **What difference does patient and the public involvement make?**

The UKCRC is working to engage with patients and the public throughout its activities as a key part of changing the clinical research environment. The work of the UKCRC needs to be relevant to patients and the public as they are the intended and ultimate beneficiaries of its programme.

It is important for the success of clinical research that the UKCRC develops a number of different ways through which patients and the public can meaningfully contribute to its work. One of these ways is to actively involve patients and the public as members of UKCRC advisory groups.

Involving patients and the public can improve the effectiveness of the work of the UKCRC through:

- raising and maintaining a focus on issues of importance to patients and the public which might otherwise be overlooked
- making the work of the UKCRC more accessible to patients and the public
- helping the UKCRC to communicate more effectively with patients and the public
- helping to build greater trust and to promote the credibility of clinical research amongst patients and the public

For more information about the UKCRC's patient and public involvement work please visit <http://www.ukcrc.org/patientsandpublic.aspx>

### **The work of the UKCRC**

The UKCRC was established in 2004 to effect the changes necessary to make the UK a world leader in clinical research for the benefit of patients and the public. The strength of the UKCRC is that it brings together key organisations that work in partnership to tackle complex and long-standing issues that cannot easily be addressed by individual organisations alone.

In two years the UKCRC Partners have developed effective new ways of working together and have agreed a broad joint agenda and undertaken an ambitious programme of work.

Working in partnership to develop coordinated solutions to shared problems avoids fragmented responses and/or duplication of effort and ensures that limited resources are used more effectively.

The UKCRC focuses on five main areas of activity:

- Building up the infrastructure for research in the NHS
- Building up the research workforce
- Streamlining the regulatory and governance framework
- Developing incentives for research in the NHS
- Coordinating research funding

## Information Pack

Many of the initiatives and programmes of work require the support and scrutiny of an advisory or management group. For example, the UKCRC has a Patient and Public Involvement Project Group. This provides an arena for Partner organisations and other stakeholders with an interest in patient and public involvement in research to work on a shared agenda for action.

### **Patient and Public Involvement in the UKCRC**

The UKCRC wants to engage patients and the public in the clinical research agenda and one of the ways of doing this is by including patients and members of the public in its advisory and management groups.

The UKCRC has identified four of its groups as a pilot scheme for involving patients and members of the public. They are:

- UKCRC Patient & Public Involvement Project Group
- UKCRC Board Subgroup for the UK Clinical Research Network
- Implementation Group - Nurses in Clinical Research
- Research & Development Advisory Group to Connecting for Health

The aim is to appoint a minimum of 2 patients or members of the public as members of these groups.

An evaluation of this pilot will be carried out before the scheme is expanded to include other UKCRC groups.

For information about the groups that are taking part in the pilot please read Section D.

## **B. Role description**

Patient/public members of all UKCRC groups are required to:

- regularly attend and participate in group meetings
- assist the group in understanding some of the perspectives of patients and the public that are relevant to the work of the group
- contribute to discussions that take place during meetings
- prepare for group meetings by reading meeting papers and raising any issues for clarification with the UKCRC Secretariat
- identify with the UKCRC Secretariat, any personal needs for training or support
- participate in appropriate training and support activities
- participate in any evaluation of this role or the activities of the Group

## Information Pack

### **Term of office**

Generally, UKCRC groups are formed to provide advice and guidance whilst a specific piece of work is being carried out. The group no longer meets once the work has been completed.

### **Time commitment**

Section D gives more information about the frequency, dates and location of meetings for each of the groups.

Members are expected to read meeting papers and when requested, to provide feedback on draft documents. In addition, sometimes members may be invited to work on specific tasks that emerge from the work of the group. Payment will be offered for any increase in time commitments beyond the normal activities of group meetings.

### **Attendance fee**

The UKCRC offers an attendance fee of £150 (a daily rate) to patients and members of the public for preparation and participation in group meetings. This is offered to people who are not working in the public sector and whose time would otherwise not be paid for.

Income Tax at basic rate will be deducted. Individuals are responsible for informing HM Revenue and Customs if this income is taxable at a different rate or if they wish to reclaim the tax payment. Please be aware that people in receipt of state benefits and allowances are required to declare changes in their circumstances to their local Jobcentre Plus office. If you are concerned about the possible impact of accepting payment on your benefits and allowances please contact your local Jobcentre Plus office and/or your local benefits advice agency.

Payment will be made directly into your bank account. More detailed information about the process of claiming an attendance fee will be provided by the UKCRC Secretariat.

### **Expenses**

All reasonable expenses that arise from involvement in group meetings will be reimbursed. This includes: travel, food and drink, accommodation, childcare, carer costs, personal assistant costs, office costs, training and conference fees. More detailed information about the process of reclaiming expenses will be provided by the UKCRC Secretariat.

## Information Pack

### **Training and support**

You will be expected to attend an induction meeting at the UKCRC before you attend your first group meeting. This will include the opportunity to discuss and identify any needs for training and ongoing support. You will be offered the support of a mentor/buddy from the group. You will also be offered support from the UKCRC Secretariat with all the practical issues of group membership such as help with claiming expenses.

### **Declaration of interests**

All group members are required to declare if they have any interests that might be in conflict with the work of the group that they are in. A conflict of interest does not stop you from being a member of a group. However it does mean that you cannot take part in any discussions or decisions made on a project/issue where you have a conflict of interests.

### **Confidentiality**

Members of the group must not communicate any confidential information that they learn as a result of being a member of the group. However, there may well be occasions on which group members are specifically asked to share information within their own communities or seek the opinions and views of others. If you are unclear about whether or not information that you have access to is confidential or not, please seek clarification from the UKCRC Secretariat or the Chair of the group.

## **C. Role requirements**

Patient/public members of the group are required to have:

- Experience of health services or research as a patient or as a carer or as an advocate or representative of patients and carers
- An ability to raise relevant personal experience and knowledge of health services to inform the work of the group
- An ability to raise a broader range of patient/public perspectives beyond their own personal experience
- An understanding of the relevance of patient and public involvement in the work of the UKCRC
- An understanding of the importance of and need for clinical research
- An understanding of and interest in the broad objectives of the UKCRC
- An ability to work and communicate effectively and appropriately as part of a team

## Information Pack

It is also desirable for patient/public members of the group to have:

- Experience of participating in formal meetings where there is a routine expectation for group members to prepare, by reading meeting papers that may be complex
- Experience of patient and public involvement in research
- A basic understanding of or interest in clinical research processes

Please read Section D for any additional role requirements for each of the groups.

Patient/public members of the group are appointed on the basis of their ability to provide knowledge and experience that will be valuable in moving forward the work of the group and the UKCRC. Appointment to the group is made on an individual basis and not as representatives of a particular group or organisation.

## D. Information about the groups

Details of the four groups selected for this pilot are as follows:

### 1. UKCRC Patient & Public Involvement Project Group

#### Background:

The UK Clinical Research Collaboration (UKCRC) is a partnership organisation. All 23 of the UKCRC Partners have their own approaches to patient and public involvement. Collectively they are committed to engaging patients and the public in the health research agenda.

The UKCRC's Patient and Public Involvement Project Group provides an arena for Partner organisations and other stakeholders with an interest in patient and public involvement in research to work on an agenda for action. The group acts as a forum for leadership, advice and support. The areas that the group is currently working in include:

- Developing a web-based resource for the public – [www.peopleinresearch.org](http://www.peopleinresearch.org)
- Exploring the use of public involvement criteria in research applications
- Exploring opportunities for public involvement in research contracts
- Developing the evidence base for public involvement in research

For more information about these projects visit the UKCRC website:  
<http://www.ukcrc.org/patientsandpublic/patientandpublicinvolvement/currentprojects.aspx>.

We are looking for 2 patient / public members for this group.

## Information Pack

### Frequency of meetings:

The group currently meets 3 or 4 times a year.  
Scheduled meetings to date in 2007 are:

- Tuesday 19 June (10:00-12:00)
- Wednesday 19 September (14:00-16:00)

For some projects extra meetings are arranged. Involvement in these extra meetings is optional.

### Additional role requirements:

Desirable attributes:

- Experience of patient and public involvement in research

## 2. UKCRC Board Subgroup for the UK Clinical Research Network

### Background:

The task of the UK Clinical Research Network (UKCRN) is to create a UK-wide infrastructure to support the conduct and delivery of excellent clinical research studies. Much of this is being achieved through the work of a number of Clinical Research Networks which coordinate and support research in: cancer, dementia and neurodegenerative diseases, diabetes, medicines for children, mental health, primary care and stroke.

The UKCRN focuses on improving the coordination of research, maintaining and enhancing the quality of studies, widening participation in studies and speeding up access to results with the ultimate goal of ensuring that patients across the UK are receiving the best treatment available. It is a challenging task that requires working closely with industry, funding bodies, NHS Trusts, clinicians, patients and the public. For more information about the UKCRN: <http://www.ukcrn.org.uk>

The UKCRN is a key part of the UKCRC. The UKCRC Board Subgroup for the UKCRN is responsible for the strategic oversight of the UKCRN. Amongst other activities this includes monitoring performance and progress.

We are looking for 2 patient/public members to join this group.

## Information Pack

### Frequency of meetings:

The group currently meets 4 times a year.  
Scheduled meetings to date in 2007 are:

- 2<sup>nd</sup> May (all day)
- 31<sup>st</sup> July (afternoon)
- 7<sup>th</sup> November (all day)

### Additional role requirements:

Desirable attributes:

- Experience of patient and public involvement in research

## 3. Implementation Group - Nurses in Clinical Research

### Background:

The UK Clinical Research Collaboration (UKCRC) is working to support the development of an expert research workforce by addressing issues such as training and career structures.

In 2005, the UKCRC established a Sub Committee for Nurses in Clinical Research (Workforce). The Sub Committee was asked to examine the current role of nurses as researchers, to investigate the barriers that stand in the way of nurses undertaking research careers, and to make recommendations for a training and support structure for nurses to work as researchers. For more information about this project and a copy of the report visit the UKCRC website:

<http://www.ukcrc.org/publications/news/nursingreport.aspx>

In the summer of 2007, following a period of public consultation the final report will be published and an implementation group will be established to take forward the recommendations in the report.

We are looking for 2 patient / public members to join this group once it is formed.

### Frequency of meetings:

This group has not yet been set up. It is expected that it will meet for the first time in May/June 2007. It is not yet known how often the group will meet but it could be once every 2 months or thereabouts.

## Information Pack

### **Additional role requirements:**

Desirable attributes:

- Knowledge of training pathways and careers structures in academic settings
- Knowledge of the nursing workforce from the perspective of a patient, carer or member of the public.

## **4. Research & Development Advisory Group to Connecting for Health**

### **Background:**

The UK Clinical Research Collaboration (UKCRC) is working with Connecting for Health to ensure that personal data collected via the new NHS Care Records Service (NHS CRS) in England also meets the needs of those conducting research or public health investigations in support of patient health. There is more information about NHS CRS on their website <http://www.nhscarerecords.nhs.uk/>.

In June 2006, the UKCRC established the Research and Development Advisory Group to Connecting for Health to provide advice on the use of the NHS CRS for research purposes. So far, the group has met three times. It has begun a programme of work to establish how best the NHS CRS could be used for research purposes. Please visit the website for more information about what has been done so far: <http://www.ukcrc.org/publications/news/connectingforhealthresearch.aspx>

Further work is planned for 2007/08 that the Advisory Group will need to oversee. The interests of patients and members of the public are key to the work of this group. As a result we are looking for 2 patient / public members to join.

### **Frequency of meetings:**

The group meets quarterly. There may be opportunities to become involved in additional meetings. Involvement in these additional meetings is optional. Scheduled meetings to date for 2007 are:

Wednesday 6<sup>th</sup> June 2007 (10.30-12.30)

Tuesday 2<sup>nd</sup> Oct 2007 (14.00-16.00)

### **Additional role requirements:**

Whilst experience or knowledge of issues around patient records is not essential, desirable attributes are:

- An awareness of issues raised by personal data handling
- An understanding of the issues raised by the transfer of data between domains, for example, the transfer of data between health and social care.

## Information Pack

### **E. Application requirements**

If you wish to apply to join a UKCRC group please complete the application form and the diversity monitoring questionnaire.

Please send the completed application form and diversity monitoring questionnaire either by email to: [devfocus@devfocus.org.uk](mailto:devfocus@devfocus.org.uk), or by post to:

UKCRC Applications  
Unit 120  
Regency House  
91 Western Road  
Brighton BN1 2NW

By 1 p.m. on 12 March 2007

### **F. Selection process**

Selection will be made by a panel of 4 people:

- A member of the public with experience of patient and public involvement
- A UKCRC Board Member
- The UKCRC's Patient and Public Involvement Officer
- A community and public engagement specialist

1. Shortlisted candidates will be invited to attend a 30-40 minute interview on 28 or 29 March in London. Expenses forms to attend the interview will be provided after the interview.

2. Successful candidates will be offered a place on the groups, conditional on a satisfactory reference. Formal offer of a place on a group will be made after receipt of a satisfactory reference.

3. Applicants who are not successful in being shortlisted will be notified after the shortlisting process has been completed.

If you would like any more information before making an application please contact Philippa Yeeles at the UKCRC on 020 7670 5153 or [philippa.yeeles@ukcrc.org](mailto:philippa.yeeles@ukcrc.org)

### 3.1.3 Application Form



## APPLICATION FORM FOR PATIENT & PUBLIC MEMBERS OF UKCRC GROUPS

### To fill in this form:

1. Save the document onto your hard drive.
2. Use the tab key to move between questions.
3. Text boxes will automatically expand to take your response.
4. Tick boxes can be checked/unchecked using the space bar or mouse.

### Personal Details

Title:	Surname:	First name(s):
--------	----------	----------------

### Home Address & Contact Information:

Address line 1:

Address line 2:

Address line 3:

Town/City:

Post Code:

Phone no:

Mobile no:

Email:

### How did you find out about this opportunity (please put a X in the box):

- |                                     |  |
|-------------------------------------|--|
| <input type="checkbox"/> Asian Eye  | <input type="checkbox"/> Association of Medical Research Charities     |
| <input type="checkbox"/> Big Issue  | <input type="checkbox"/> The Guardian <input type="checkbox"/> INVOLVE |
| <input type="checkbox"/> New Nation | <input type="checkbox"/> Other (please specify)                        |
- Other:

### Please indicate your current employment status: (please put a X in the box(es))

- |   |   |  |
|---|---|--|
| <input type="checkbox"/> Carer          | <input type="checkbox"/> Full-time employed     | <input type="checkbox"/> Housewife/husband |
| <input type="checkbox"/> Long-term sick | <input type="checkbox"/> Part-time employed     | <input type="checkbox"/> Retired           |
| <input type="checkbox"/> Self-employed  | <input type="checkbox"/> Volunteer              | <input type="checkbox"/> Student           |
| <input type="checkbox"/> Unemployed     | <input type="checkbox"/> Other (please specify) |  |
- Other:

## Application Form

**Please describe your current employment status (200 words max.)**

**Statement of why you want to become a member of a UKCRC group (200 words max.)**

### **Role requirements - skills and experience**

Please describe your experiences of health services or research as a patient or as a carer or as an advocate or representative of patients and carers (200 words max):

Please provide examples of your ability to draw on your personal experience and knowledge of health services to inform debate and discussion: (200 words max):

Please provide examples of your ability to raise broader health issues beyond that of your personal experience (200 words max):

Please describe your experience that demonstrates your understanding of the relevance of patient and public involvement in the work of the UKCRC (200 words max):

Please describe how your experience demonstrates your understanding of the importance of, and need for, clinical research (200 words max):

Please describe how your experience demonstrates your understanding of and interest in the broad objectives of the UKCRC (200 words max):

Please provide examples that demonstrate your ability to work and communicate effectively and appropriately as part of a team (200 words max):

## Application Form

**Additional Information**

Please provide any additional information about your skills and experience that are relevant to joining the advisory groups (200 words max):

**Please indicate your preferences for Advisory Group to join:**

(Select 1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup> & 4<sup>th</sup> choice from drop down list)

- 1st UKCRC Patient & Public Involvement Project Group
- 1st UKCRC Board Subgroup for the UK Clinical Research Network
- 1st Implementation Group - Nurses in Clinical Research
- 1st Research & Development Advisory Group to Connecting for Health

**Referee**

**(please provide the name and contact details, and the capacity in which they know you, of one referee that we can get in touch with. Preferably, someone who is connected to your experience in patient and public involvement):**

Name:

Address line 1:

Address line 2:

Address line 3:

Town/City:

Post Code:

Phone no:

Email:

Capacity known:

**Do you have any accessibility needs that should be met to ensure that you can participate in the recruitment process (please put a X in the box)?**

Yes  No

**If yes, please specify:**

**In the future, would you like us to contact you should other opportunities for patient and public involvement arise (please put a X in the box)?**

Yes  No

## Application Form

**Declaration**

I agree to this information only being used for legitimate purposes connected with recruitment and selection monitoring.

I declare that the information that I have given is, to the best of my knowledge or belief, true and complete.

If you e-mail your application form you do not need to sign it now, but you will be asked to sign should you be invited to join an advisory group.

Signature:

Date:

### 3.1.4 Diversity Monitoring Questionnaire



## DIVERSITY MONITORING QUESTIONNAIRE

The diversity monitoring questionnaire will not be used in the selection process. The information you provide on it will be used to provide statistics to the UKCRC on the diversity profile of the patients and members of the public who apply to become members of its advisory groups. The data will be anonymised and entered onto a database, after which the questionnaires will be destroyed. The statistics provided to the UKCRC will influence its recruitment policies to ensure that there is diversity of membership of its patient and public members of its advisory groups.

### To fill in this form:

1. Save the document onto your hard drive.
2. Use the tab key to move between questions.
3. Text boxes will automatically expand to take your response.
4. Tick boxes can be checked/unchecked using the space bar or mouse.

**Full name:**

**Gender (please put a X in the appropriate box):**

Male       Female

**Age at present (please put a X in the appropriate box):**

16 – 24     25 – 34     35 – 44     45 – 54     55 – 64     65+

**Marital status (please put a X in the appropriate box):**

Unmarried                       Married                       Same sex civil partnership

**Nationality:**

**Ethnic origin:**

**White:**

British     English     Scottish     Welsh     Irish

Any other white background (please specify):

## Monitoring Questionnaire

**Ethnic origin (continued):****Mixed, Mixed British, Mixed English, Mixed Scottish, Mixed Welsh or Mixed Irish:**

- White & Black Caribbean       White & Black African       White & Asian  
 Any other mixed background (please specify):

**Black, Black British, Black English, Black Scottish, Black Welsh or Black Irish:**

- Black or Black British – Caribbean       Black or Black British – African  
 Black or Black British – Any other Black background (please specify):

**Asian or Asian British, Asian English, Asian Scottish or Asian Welsh:**

- Asian or Asian British – Indian       Asian or Asian British – Pakistani  
 Asian or Asian British – Bangladeshi       Asian or Asian British – Any other Asian background (please specify):

**Chinese, Chinese British, Chinese English, Chinese Scottish, Chinese Welsh or Chinese Irish:**

- Chinese or Chinese British  
 Any other Chinese background (please specify):

**Other Ethnic Group:**

Other ethnic background (please specify):

**Disability:**

**Do you consider that you have a disability (please put a X in the appropriate box)?:**

- Yes       No

If yes, please specify

**How did you find out about this opportunity (please put a X in the box)?:**

- Asian Eye       Association of Medical Research Charities  
 Big Issue       The Guardian       INVOLVE  
 New Nation       Other (please specify)

Other:

### 3.1.5 Summary of Diversity Monitoring Information

#### Summary of Diversity Monitoring Questionnaire

#### Information gained from applicants' monitoring forms

##### Gender

	All		Successful Applicants	
Male	21	47.7%	3	37.5%
Female	23	52.3%	5	62.5%

##### Age

	All		Successful Applicants	
16-24	0	0	0	0
25-34	4	9.1%	1	12.5%
35-44	6	13.6%	1	12.5%
45-54	9	20.5%	1	12.5%
55-64	20	45.5%	4	50%
65+	4	9.1%	0	0
Not Answered	1	2.3%	1	12.5%

##### Marital Status

	All		Successful Applicants	
Unmarried	11	25%	2	25%
Married	30	68.2%	5	62.5%
Same sex civil partnership	0	0	0	0
Widow	3	6.8%	1	12.5%

## Disability

	All		Successful Applicants	
Yes	8	18.2%	2	25%
No	35	79.6%	6	75%
Not Answered	1	2.3%	0	0

## Ethnic Origin

	All		Successful Applicants	
<b>White</b>				
British	27	61.4%	6	75%
English	10	22.7%	2	25%
Scottish	2	4.6%		
Welsh	1	2.3%		
Irish	1	2.3%		
Other	1	2.3%		
<b>Mixed, Mixed British, Mixed English, Mixed Scottish, Mixed Welsh or Mixed Irish</b>				
White & Black Caribbean				
White & Black African				
White & Asian				
Other				
<b>Black, Black British, Black English, Black Scottish, Black Welsh, Black Irish</b>				
Black or Black British – Caribbean				
Black or Black British – African				
Black or Black British – Other				

## Ethnic Origin

	All		Successful Applicants	
<b>Asian or Asian British, Asian English, Asian Scottish or Asian Welsh</b>				
Asian or Asian British – Indian				
Asian or Asian British – Pakistani	1	2.3%		
Asian or Asian British – Bangladeshi				
Asian or Asian British – Other				
<b>Chinese, Chinese British, Chinese English, Chinese Scottish, Chinese Welsh or Chinese Irish</b>				
Chinese or Chinese British	1	2.3%		
Other				
Other Ethnic Group				

## How did you find out about this opportunity?

	All		Successful Applicants	
Asian Eye	0	0	0	0
AMRC	3	6.9%	1	12.5%
Big Issue	3	6.9%	0	0
The Guardian	18	40.9%	6	75%
INVOLVE	4	9.1%	0	0
New Nation	0	0	0	0
Other	16	36.4%	1	12.5%

### 3.1.6 Interview Schedule

---

#### **INTERVIEWS FOR UKCRC ADVISORY GROUPS – Patient / Public Members**

- CHAIR TO INTRODUCE THE PANEL AND EXPLAIN FORMAT OF INTERVIEW:
  - Interviews will last around 30 mins.
  - We will take it in turn to ask a series of 12 questions
  - Why notes will be taken during the interview
  - Invite questions during the interview and there will also be an opportunity to ask Qs at the end of the interview
  
- EACH PANEL MEMBER TO MAKE NOTES IN BOX PROVIDED AND TO SCORE CANDIDATES' ANSWERS ON A SCALE 1 TO 4.  
SCORE:
  - 1 – FULLY ANSWERED QUESTION
  - 2 – ADEQUATELY ANSWERED QUESTION
  - 3 – PARTIALLY ANSWERED QUESTION
  - 4 – DOESN'T ANSWER QUESTION

### 3.1.7 Induction Event Programme

<b>CANDIDATE Name:</b>	
<b>Q.1 - What particularly interests you about this role and led you to apply?</b>	
<b>Q.2 – In your application you mention ..... (an experience to be identified from application) ... please can you tell us about some of the positive and negative aspects of this experience.</b>	1                  2                  3                  4
<i>Criterion: Experiences of health services or research as a patient or as a carer or as an advocate or representative of patients and carers</i>	
<b>Q.3 - Can you give us an example of how your own experience of a health issue has related to a health story that has been in the media?</b>	1                  2                  3                  4
<i>Criterion: Ability to draw on personal experience and knowledge of health services to inform debate and discussion</i>	
<b>Q.4 - What do you think are the differences or the similarities between patient and public involvement in research and patient and public involvement in health services?</b>	1                  2                  3                  4
<i>Criterion: Ability to raise broader health issues beyond that of personal experience</i>	
<b>Q.5 - What do you think we are trying to achieve by having patients and</b>	1                  2                  3                  4

<p><b>members of the public joining UKCRC advisory groups?</b></p> <p><i>Criterion: Understanding of the importance of and need for patient and public involvement in the work of the UKCRC</i></p>									
<p><b>Q.6 - Based on your own experience of health services or research what makes you believe that clinical research is important?</b></p> <p><i>Criterion: Understanding of the importance of clinical research</i></p>	<table border="1"> <tr> <td data-bbox="715 703 874 770">1</td> <td data-bbox="874 703 1034 770">2</td> <td data-bbox="1034 703 1193 770">3</td> <td data-bbox="1193 703 1422 770">4</td> </tr> <tr> <td colspan="4" data-bbox="715 770 1422 1070"></td> </tr> </table>	1	2	3	4				
1	2	3	4						
<p><b>Q.7 - From the information that you have read about the UKCRC, what would you say are its main objectives?</b></p> <p><i>Criterion: Understanding of and interest in the broad objectives of the UKCRC</i></p>	<table border="1"> <tr> <td data-bbox="715 1070 874 1137">1</td> <td data-bbox="874 1070 1034 1137">2</td> <td data-bbox="1034 1070 1193 1137">3</td> <td data-bbox="1193 1070 1422 1137">4</td> </tr> <tr> <td colspan="4" data-bbox="715 1137 1422 1438"></td> </tr> </table>	1	2	3	4				
1	2	3	4						
<p><b>Q.8 - Can you give us an example of when you have used your skills to promote an unpopular viewpoint?</b></p> <p><i>Criterion: Ability to work and communicate effectively and appropriately as part of a team.</i></p>	<table border="1"> <tr> <td data-bbox="715 1438 874 1505">1</td> <td data-bbox="874 1438 1034 1505">2</td> <td data-bbox="1034 1438 1193 1505">3</td> <td data-bbox="1193 1438 1422 1505">4</td> </tr> <tr> <td colspan="4" data-bbox="715 1505 1422 1805"></td> </tr> </table>	1	2	3	4				
1	2	3	4						
<p><b>Q.9 - What do you hope to get from this role?</b></p>									
<p><b>Q.10 – Do you have strong feelings</b></p>									

<b>about joining any of the 4 advisory groups</b>	
<b>Q.11 – Is there anything that you'd like to ask us or anything that you'd like to tell us about that we haven't covered in the interview?</b> (Robert)	
<b>Q.12 – Does anyone have a final question to ask</b> (going back to previous responses)? (Lester)	

## CHAIR –

- Explain what happens next:
  - Hope to invite up to 8 people to join the 4 UKCRC advisory groups
  - Interviewing over 2 days
  - Will inform interviewees of decision on 30<sup>th</sup> (ask if email OK method of contact)
  - Invitation to join groups are SUBJECT to receiving references
  - Final confirmation letters after receiving satisfactory reference
  - Induction meeting to be arranged thereafter
- Check they have been given an expenses claim form and advise to contact UKCRC Secretariat if need any help.
- Thank them for their interest/time/trouble.

<b>Decision:</b>  <b>Offer/Reject</b>  <b>Reason for rejection</b>  <b>Suggestions for groups</b>	
---	--

### 3.2.1 Evaluation Form – UKCRC Advisory Group Meeting

## Patient/Public Members UKCRC Advisory Groups

### Induction event programme

1pm – 4.30/5pm on Friday 1<sup>st</sup> June 2007

Room J, Medical Research Council Head Office,  
20 Park Crescent, London W1B 1AL

1 – 1.30pm	<b>Buffet lunch</b>
1.30 – 2.30pm	<b>An introduction to the work activities of the UKCRC</b> Matthew Hallsworth, Head of Communications
2.30 – 3.00pm	<b>Experience as a patient/public member of a UKCRC advisory group</b> Don Espie, UKCRC Strategic Planning Group on Microbiology and Infectious Diseases Research
3.00 – 3.15pm	<b>Tea break</b>
3.15 – 3.45pm	<b>Small discussion groups:</b> <ul style="list-style-type: none"> <li>• <b>Advisory Group for Connecting for Health</b></li> <li>• <b>UK Clinical Research Network Subgroup</b></li> <li>• <b>Patient &amp; Public Involvement Project Group</b></li> <li>• <b>Nurses in Clinical Research Implementation Group</b></li> </ul>
3.45 – 4.15pm	<b>Identifying/supporting training needs/opportunities</b>
4.15 – 4.30pm	<b>Claiming expenses and attendance allowance</b>
4.30pm	<b>Any other business</b>

### 3.2.2 Evaluation Form – Patient / Public Members' Meeting

## Patient / Public Involvement in UKCRC Advisory Group Meetings Evaluation form



---

### Completing this form:

Please complete and return this form to Philippa Yeeles at the UKCRC

**Philippa Yeeles**  
**UK Clinical Research Collaboration**  
**20 Park Crescent**  
**London**  
**W1B 1AL**

---

### Background information

#### What is the purpose of this form?

- To record the reflections of patient / public members after participating in UKCRC advisory group meetings
- To improve the processes of public involvement in UKCRC advisory groups
- To provide information for an evaluation of patient / public membership of UKCRC advisory groups

#### What will happen to this information?

- UKCRC Secretariat will store the data
- Anonymised comments will be compiled and used to inform the evaluation and to improve the processes of public involvement in UKCRC advisory groups
- Anonymised comments may be included in reports written by the UKCRC on patient and public involvement

---

### A. You & the meeting

Your name:

Name of the advisory group:

Date of the meeting:

---

## B. Before the meeting

1. Did you receive the papers in time for you to prepare for the meeting?

Yes  No

If 'no' please explain:

2. Were you able to understand the papers?

Fully  Partially  Not at all

If 'partially' or 'not at all' please explain:

3. Were you offered an opportunity to raise any queries before the meeting?

Yes  No

4. If 'yes', were your queries answered?

Fully  Partially  Not at all  None raised

---

## C. During the meeting

5. Did you feel able to contribute to the meeting?

Fully  Partially  Not at all

Further comments:

6. Do you feel that the inclusion of patient / public members has any impact on the work of the group?

Yes  No  Not sure

Please give examples from the meeting to illustrate / explain:

7. Were you supported by the group's UKCRC Secretariat? (For example, by explaining acronyms used.)

Fully  Partially  Not at all

Further comments:

8. Were you supported by the group's Chair? (For example, by being encouraged to contribute to discussions.)

Fully       Partially       Not at all

Further comments:

9. Were you supported by other members of the group? (For example, by asking for questions on points of clarification.)

Fully       Partially       Not at all

Further comments:

---

#### **D. After the meeting**

10. How would you describe your input into the meeting?

Sufficient       Insufficient

Further comments:

11. Do you think that your views were valued?

Yes       No       Not sure

Further comments:

12. What might help your input into future meetings?

Suggestions:

13. Were you offered an opportunity to raise any queries after the meeting?

Yes       No

14. If 'yes', were your queries answered?

Fully       Partially       Not at all       None raised

15. Did you identify any training or information needs during the meeting?

Yes  No

If 'yes' please explain:

16. Do you have any other additional comments you would like to share?

Comments:

---

Thank you for completing the form. Please return it to:

Philippa Yeeles  
UKCRC  
20 Park Crescent  
London W1B 1AL  
[philippa.yeeles@ukcrc.org](mailto:philippa.yeeles@ukcrc.org)

Acknowledgement and thanks also to authors of the following documents from which this evaluation form has drawn – National Cancer Research Institute Clinical Studies Group Meeting Evaluation Form, Report on a study to evaluate patient/carer membership of the first NICE Guideline Development Groups, evaluation forms of the Royal College of Physicians Patient and Carer Network.

---

# Patient/Public Members UKCRC Advisory Groups

## Meeting

# Evaluation Form



### A. The meeting:

#### 1. How useful were the following parts of the meeting? *[Please select response]*

##### **Updates: Members' Experiences**

Poor / Not useful / Somewhat useful / Useful / Very useful

##### **Update: Training and Support**

Poor / Not useful / Somewhat useful / Useful / Very useful

##### **Presentation: OSCHR**

Poor / Not useful / Somewhat useful / Useful / Very useful

##### **Update: UKCRC PPI Implementation Plan 08/09**

Poor / Not useful / Somewhat useful / Useful / Very useful

##### **Informal discussions during lunch and breaks**

Poor / Not useful / Somewhat useful / Useful / Very useful

#### 2. Overall, what do you think was the most valuable aspect of the meeting?

#### 3. Overall, what do you think was the least valuable aspect of the meeting?

**4. Is there anything that you intend to do differently as a result of the meeting?**

**5. Do you have any suggestions as to how we could improve our future meetings in 2009, both in terms of the content and/or the format of the meeting?**

**6. If you had any specific support and assistance needs were they met?**

*[Please select response]*

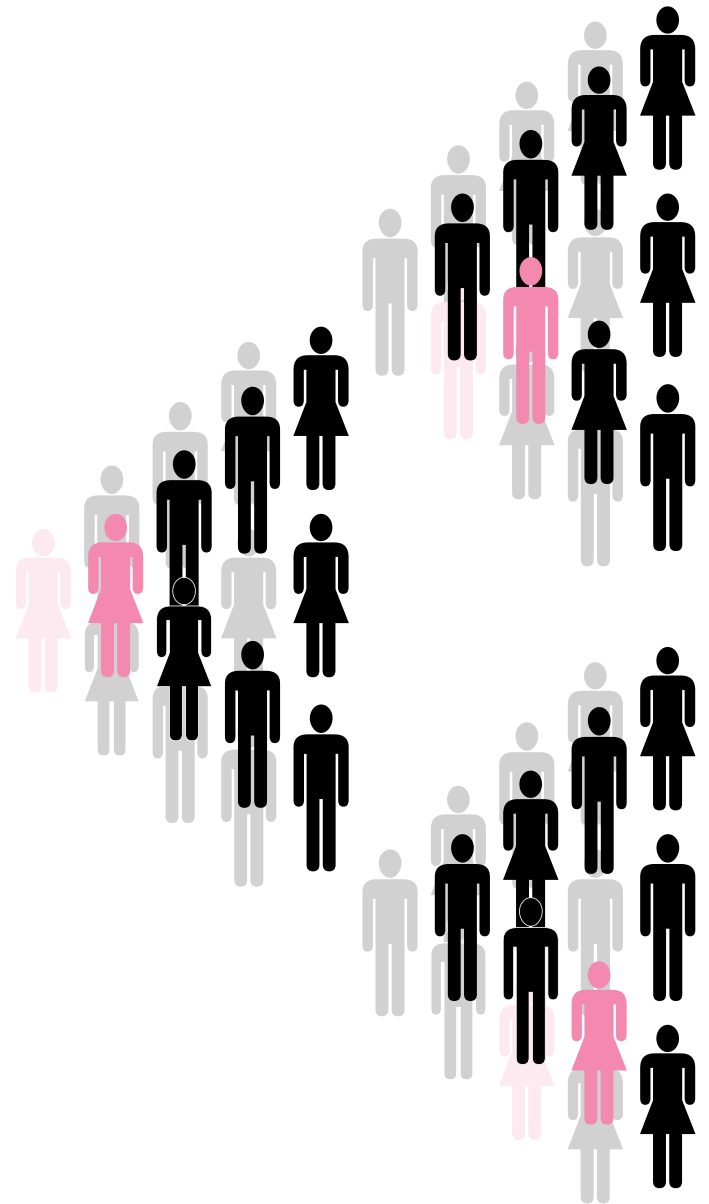
None identified / fully met / partially met / not met

**If they were not met or only partially met please explain further:**

**7. Any other comments?**

---

**Thank you for completing the form.  
Please return it to Philippa Yeeles at the UKCRC  
By email to: [philippa.yeeles@ukcrc.org](mailto:philippa.yeeles@ukcrc.org)  
By mail to:  
UKCRC, 20 Park Crescent, London W1B 1AL**



**UK Clinical Research Collaboration**

20 Park Crescent

London

W1B 1AL

United Kingdom

Tel: +44 (0)207 670 5452

Fax: +44 (0)207 637 6067

[info@ukcrc.org](mailto:info@ukcrc.org)

[www.ukcrc.org](http://www.ukcrc.org)