



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

Final Report - 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 2008.¹ 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
- ▶ 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 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

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

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members are well supported – they receive high quality support from a 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.

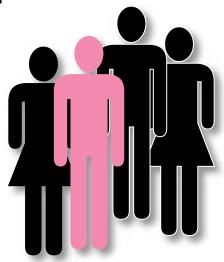
However, other members of UKCRC groups are convinced that patient / public members have had an influence on discussions and decisions, even when patient / public members themselves feel that their presence has not made any impact.

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.



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