UK CLINICAL RESEARCH COLLABORATION

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A critical assessment of the development of patient and public involvement in the UK Clinical Research Collaboration: Lessons learned

Executive Summary

Report by TwoCan Associates
November 2009

Introduction

This is a report of a critical assessment of the development of patient and public involvement (PPI) in the UK Clinical Research Collaboration (UKCRC). The aim of the assessment was primarily to draw out lessons learned for people who have a responsibility for taking forward PPI within a research organisation.

The assessment focused on the work that was undertaken to promote and support PPI both internally within the UKCRC and externally amongst its Partner organisations. It does not provide an evaluation of the many PPI projects that have been carried out. Nor does it provide an assessment of the impact that patients and members of the public have had on the organisation. It is a commentary on a complex journey to develop PPI within the environment of the UKCRC – a strategic partnership of many different national research organisations.

The work was carried out by TwoCan Associates between August and November 2009. The methods used included:

- A review of relevant internal documents
- Development of a timeline of activity linked to the development of PPI
- Interviews with key stakeholders
- A survey of UKCRC Board members

Carrying out this assessment proved challenging because of the nature of the UKCRC's PPI-related activity. There were a number of different individuals involved over time, either working alone or within various groups and committees. It is widely acknowledged that assessing the impact of any such complex social intervention can be difficult. We therefore aimed to understand the context to each step along the way and to identify the factors that either hindered or facilitated taking PPI forward. We also assessed the outcomes at each stage and the overall impact on the UKCRC and its Partners[1].

Findings

The key milestones in the development of PPI within the UKCRC were:

1. First year plans for PPI
2. Establishing a UKCRC PPI Project Group and the successor Board Subgroup
3. Provision of a ring-fenced budget for PPI
4. Creation of a development and support post in the UKCRC Secretariat
5. Development of a pilot scheme to recruit patient / public members to UKCRC groups
6. Development and implementation of a three-year strategic plan for PPI
7. Development of proposals for PPI in 2010 and beyond

In this summary, we provide a brief overview of what happened at each milestone, what assisted the development of PPI, what were the challenges and where appropriate, what were the outcomes.

1. First year plans for PPI

For the first year PPI was not given a high priority and very little work was taken forward. However, a plan for PPI was developed and approved by the Board in the second year. The factors that **assisted** this development were:

- The knowledge and experience of the staff and members of Partner organisations who worked on the plan
- Careful briefing of Board members so that they were fully informed of the plan before it was discussed at a Board meeting
- A growing acceptance of a patient / public member on the UKCRC Board

1 We based our approach on the model of realistic evaluation developed by Pawson and Tilley – see R. Pawson and N. Tilley (1997) Realistic Evaluation. London: Sage Publications.

The **challenges** were:

- PPI was not seen as a priority for the Board, given its demanding and crowded agenda
- Partner organisations had different objectives for PPI
- Those who were seen as potential champions of PPI did not always agree on the way forward
- There was often a failure to recognise a distinct PPI agenda

2. Establishing a UKCRC PPI Project Group and the successor Board Subgroup

The PPI plan called for the establishment of a PPI Project Group. This group worked collaboratively on a number of PPI activities under the UKCRC umbrella. It became a Board Subgroup in 2008.

The factors that **assisted** the work of this group were the knowledge and expertise of its members and support from a dedicated member of staff.

The **challenges** were:

- Getting the 'right people' involved in the group
- A perceived lack of interest and commitment from some members
- A lack of clarity about the group's aims
- Concerns about the UKCRC's role in relation to PPI
- The challenging nature of the projects the groups agreed to take forward
- The initial lack of resources available
- Differences in opinion as to how best to proceed and on priorities for action

The **positive outcomes** from this group not only included successful PPI projects, but also opportunities for group members to undertake joint projects and to share learning and ideas. This led to changes in people's attitudes and gave more credibility and legitimacy to PPI within Partner organisations.

3. Provision of a ring-fenced budget for PPI

The provision of a ring-fenced budget from 2006/07 onwards made a big difference to the development of PPI across the UKCRC. However Partner organisations could have decided to increase funding for PPI through further pooling of their resources. Such opportunities were either not identified or ignored or missed.

4. Creation of a development and support post in the UKCRC Secretariat

A Programme Manager for PPI was appointed in 2006. This greatly accelerated the work to promote PPI as there was a dedicated member of staff to carry out tasks for the PPI Project Group.

Identified as crucial factors to the postholder's **success** were:

- Good networking skills
- A willingness to lead from behind
- An ability to collect relevant information and to disseminate this to the right people in an accessible and useful form
- An ability to be 'professional'
- A commitment to involvement, but with an ability to make decisions alone where this is necessary

Openness and honesty, sensitivity, approachability, enthusiasm and warmth were also seen to be key attributes to the success of an individual in such a post along with good skills in facilitation and administration. Some people expressed frustration that this post had not been established earlier.

5. Development of a pilot scheme to recruit patient / public members to UKCRC groups

In 2006 the Board agreed to pilot PPI in the UKCRC's advisory groups. The recruitment process was rigorous and eight PPI members were appointed in June 2007. The impact of this PPI has been evaluated and reported elsewhere[2].

The factors that **assisted** the development of this pilot scheme were:

- An effective recruitment process
- Patient / public members were assigned clear tasks
- Effective administrative systems were put in place to support patient / public members
- Effective mechanisms were put in place to enable information sharing and peer support

2 See *An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration*, TwoCan Associates 2009'. http://www.ukcrc.org/patients-and-public/ppi/ppiinukcrcgroups/

The key **challenge** was recruiting people from a range of backgrounds, particularly people from black and minority ethnic communities – the UKCRC was not able to achieve this.

An important **positive outcome** is that the UKCRC has gained credibility in terms of its PPI activity.

6. Development and implementation of a three-year strategic plan for PPI

The PPI Project Group set up a working group to develop a PPI strategy as they recognised that their work needed a clearer focus and direction. Over a year, a wide range of stakeholders were involved in developing the strategy, which was presented to the Board in 2008.

The factors that **assisted** the development and implementation of the PPI strategy were the creation of an effective working group, senior level support from the Chair of the Board and a sense of ownership from relevant stakeholders.

The main **challenge** was developing a strategy that everyone could sign up to at the same time as developing a strategy that would actually direct change.

A **positive outcome** was that the strategy provided greater clarity and transparency for the UKCRC's PPI work. Some people felt it also provided the impetus to drive PPI forward, although others questioned whether this opportunity had been fully realised.

7. Development of proposals for PPI in 2010 and beyond

From January 2010 the UKCRC will operate through a Partner-led model with all future activities led and supported by UKCRC Partners. The size and function of the Secretariat will be much reduced. As part of this process, it was agreed that INVOLVE would be the lead Partner for PPI, and would provide continued support for a number of key activities. The Board Subgroup for PPI was formally disbanded in October 2009.

The factors that might **assist** further development of PPI are the commitments that have been made to taking forward PPI across the Partner organisations, and the efforts that have been made to learn from the UKCRC's recent experience.

The **challenges** will be:

- The onus is now on INVOLVE as the lead organisation working with Partners to take forward PPI
- There are many other competing priorities for action
- The reduction in dedicated resources for PPI within the UKCRC Secretariat

Impact of the development of patient and public involvement

The work that has been undertaken to promote and support PPI has led to changes within the UKCRC itself. There have been changes in organisational culture, especially at Board level, which have meant that PPI has become more of an integral part of Board activities. There is also much more PPI activity in UKCRC working groups and committees.

The factors that have **assisted** these changes include:

- Senior level support
- Board and other advisory group members having had direct experience of PPI
- An increase in the number of PPI champions
- The appointment of a patient / public member as a deputy chair of the UKCRC Board

The **challenges** to taking this work forward were:

- The pace and complexity of the UKCRC's agenda
- The difficulty of turning commitment to PPI into action
- The different attitudes of Partner organisations to PPI
- The time it can take to bring about culture change

A **positive outcome** has been that the development of PPI has also had an impact on Partner organisations. It has created an opportunity to:

- Learn from others
- Take the learning about PPI into their own organisations
- Work with other organisations to take forward projects of shared interest

Lessons learned

The lessons for people with responsibility for taking forward PPI in research organisations are summarised below:

What to think about when developing PPI:

- Make PPI a priority early on
- Identify clear aims and develop a shared understanding of PPI
- Ensure you have dedicated resources and the right staff as early as possible
- Develop a strategy that has broad ownership, but also directs and coordinates action
- Develop a programme of work that allows for quick wins and for long-term projects
- Ensure that all PPI-related activity is visible and adds value to other activities
- Demonstrate good practice, model high quality PPI and report what you have done, so that others are encouraged to do likewise
- Consider how you will measure any impact of PPI when you are at the planning stages

Building relationships:

- Ensure you have senior level commitment
- Build strategic alliances
- Keep sight of the bigger picture and don't consider PPI to be the only issue of importance
- Develop positive strategies to challenge sceptics:
  a. Demonstrate how PPI can help research organisations to achieve their goals
  b. Introduce change at an appropriate pace

Being realistic:

- About what can be achieved
- About the time it takes to achieve a culture change

> **PPI as part of the UKCRC is a real example of the politics and tactics of involving patients and the public in high level strategic decision making in clinical research. In this context PPI had to be flexible enough to cope with a constantly evolving clinical research landscape and complex partnerships. This critical assessment maps the journey of a collaboration of interested and not so interested parties. It has a start and a finish, but also some challenging twists and turns, so in this sense it is a realistic account of PPI, both the challenges and the achievements, and gradual change of attitudes over time.**

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Report and executive summary can be downloaded from the UKCRC website
http://www.ukcrc.org/publications/reports/