

UK Clinical Research Collaboration: Patient and Public Involvement Strategic Plan 2008 - 2011

In addition to their own organisational approaches to patient and public involvement, the UK Clinical Research Collaboration Partners are jointly committed to the following three-year strategic plan.

Our vision

What we aspire to

Patients and the public, actively involved in developing and sustaining a thriving clinical research environment in the UK, to improve the health and well-being of all.

Our objectives

What we will do to achieve our vision

We will encourage and facilitate the development of patient and public involvement in clinical research, offering leadership in areas that will most benefit from our collaborative approach.

We will establish partnerships with others to deliver three key strategic objectives:

- ▶ To ensure that patients and the public influence and support the development of UK clinical research at a strategic level.
- ▶ To improve public confidence in, and understanding of, clinical research through greater patient and public involvement.
- ▶ To develop sustainable solutions to the barriers that can prevent or impede public involvement in research.

How we will work

We will:

- ▶ Involve patients and the public in the work of the UK Clinical Research Collaboration, paying particular attention to the need for greater diversity amongst the wide range of communities, groups and individuals that could be involved
- ▶ Advocate the value of patient and public involvement to UK clinical research at local, regional, national and international level
- ▶ Recognise the importance and value of patient and public involvement by offering people appropriate and continued support and reward for their involvement

- ▶ work closely with organisations that have a specific remit to support patient and public involvement in clinical research (such as INVOLVE and Involving People: Cynnwys Pobl), to ensure that we make the best use of available resources, share knowledge and avoid unnecessary duplication of effort
- ▶ monitor and evaluate our work both to improve our own practice and to add to the developing knowledge base describing the processes and impact of public involvement in research

Activities within the three key strategic objectives:

Ensure that patients and the public influence and support the development of UK clinical research at a strategic level

Over the next three years we intend to:

- ▶ Support opportunities for the development of patient and public involvement membership in structures and processes of organisations that have a strategic remit in clinical research
- ▶ Develop and support a network of patients / public with experience of patient and public involvement in research to act as broader reference group for a range of UK Clinical Research Collaboration activities

Improve public confidence in, and understanding of, clinical research through greater patient and public involvement

Over the next three years we intend to collaborate in:

- ▶ Developing resources for patients / public to inform them about the broad spectrum of research-related activities in which they can get involved
- ▶ Exploring the role of patient and public involvement in improving public confidence in, and understanding of, clinical research
- ▶ Influencing researchers' attitudes towards, and understanding of, the value of patient and public involvement in research
- ▶ Exploring, with relevant trade associations and other industry stakeholders, how to support patient and public involvement in industry

Develop sustainable solutions to the barriers that can prevent or impede public involvement in research

Over the next three years we intend to:

- ▶ Support the development of the evidence base for the impact of patient and public involvement in research through collaborating with others in reviews, mapping, monitoring, evaluation and related activities
- ▶ Work closely with the UK Clinical Research Network Coordinating Centre to support it in embedding patient and public involvement in the clinical research networks
- ▶ Collaborate with other organisations to facilitate seminars, workshops and other events, to share knowledge and learning



igniting our potential

UKCRC Patient and Public Involvement: Background Report (April 2008)

Introduction

The UK Clinical Research Collaboration (UKCRC) is a partnership of organisations working to establish the UK as a world leader in clinical research, by harnessing the power of the NHS. The UKCRC Partner organisations are collaborating on a broad programme of work designed to re-engineer the clinical research environment in the UK, to benefit the public and patients by improving national health and increasing national wealth.

Since its inception in 2004, the UKCRC has recognised the importance of patient and public involvement¹ to the delivery of its overall mission and has worked closely with one of its Partners, INVOLVE. Through both its Patient and Public Involvement and Public Awareness groups a number of projects have been developed and delivered including: the recruitment of patient / public members to key UKCRC Boards and Advisory Groups; materials aimed at raising public awareness and understanding of clinical research; and People in Research (www.peopleinresearch.org), a web-based resource which helps patients and members of the public make contact with organisations that have opportunities for patient and public involvement.

In March 2007, the UKCRC Partners recognised the need to build further upon this project-based approach by developing a more coherent strategy on patient and public involvement in support of UKCRC activities. Accordingly, the development of a patient and public involvement strategy became part of the UKCRC's Workplan for 2007/08.

Strategy Development

In June 2007, a Strategy Development Group was established, sponsored by Professor Sally Davies (Chair of the UKCRC), chaired by Simon Denegri (UKCRC Board member and Chief Executive of the Association of Medical Research Charities) and actively supported by the broader UKCRC Patient and Public Involvement Project Group. The Group was tasked with identifying and managing the process for developing the strategy.

The Group recognised that the UKCRC is one organisation of many across the UK that share an interest in contributing to the development of patient and public involvement in clinical research. It would therefore be important to focus the UKCRC's strategy and activities on issues where it could add value and that could not otherwise easily be tackled by a single organisation.

¹ The definition of 'patient and public involvement' used by the Strategy Development Group can be viewed on the UKCRC website <http://www.ukcrc.org/patientsandpublic/whatisppi.aspx>. The Group noted that 'patient and public' is often used loosely as an umbrella term referring to a spectrum of potentially differing and heterogeneous perspectives and interests.

Consideration was also given to the continued and rapid development of patient and public involvement in other aspects of UK healthcare such as in the development and delivery of services. The strategy therefore needed to be flexible enough to respond to a dynamic environment whilst focusing on key areas where a collaborative approach amongst organisations would be most effective in supporting the delivery of the UKCRC's aims.

Initial scoping was conducted through interviews with UKCRC Board members, all of whom positively endorsed the value of patient and public involvement to clinical research. All interviewees also expressed the view that there is a valuable role for the UKCRC to perform in supporting the future development of patient and public involvement in clinical research, particularly where its collaborative approach can be used to embed patient and public involvement into the UK clinical research culture. Board members were asked which of the UKCRC's activities would benefit from greater patient and public involvement. The UK Clinical Research Networks were most frequently identified as the area of UKCRC activity where patient and public involvement could make a significant difference.

Board members broadly identified potential strategic roles for the UKCRC as a:

- ▶ Pathway for increasing patient and public involvement at a strategic level
- ▶ Catalyst for improving public understanding of, and confidence in, clinical research
- ▶ Supportive influence, developing the sustainability of patient and public involvement in the UK.

In October 2007, two patient / public workshops were organised². The aim of the workshops was to bring together people with a broad range of experiences of public involvement in research to elicit their views on both how the UKCRC could support and develop patient and public involvement in research and how patients and the public could help the UKCRC to achieve its aims.

A number of cross-cutting themes emerged as priorities across the two workshops and these broadly corresponded to similar issues that had been raised by other groups of patients and members of the public in developing patient and public involvement strategies. They included the need to:

- ▶ Involve patients and the public throughout the research cycle and at all levels of research management and governance (as a requirement – not an option)
- ▶ Recognise, support and resource involvement – including funding appropriate patient and public involvement support posts, offering payment for people's time and expertise and reimbursing expenses
- ▶ Bring together information about what research is currently taking place, the results of research that has already taken place and making it accessible to patients / public and in plain English
- ▶ Do more to demonstrate the impact of patient and public involvement in research.

In addition to undertaking interviews and workshops, the Strategy Development Group reviewed the patient and public involvement strategies of UKCRC Partners and other key organisations and also reviewed further relevant literature. The final draft of the strategy was developed through a process of consultation with the UKCRC Patient and Public

² A copy of the Workshops' Report can be obtained from the UKCRC.

Involvement Project Group, UKCRC Board members, patients / public who were workshop participants and patient / public members of UKCRC advisory groups.

Next steps

In April 2008, the UKCRC Board approved the Strategic Plan and established a UKCRC Board Subgroup for Patient and Public Involvement to oversee its implementation.

The Board Subgroup is chaired by Sarah Buckland (Director of INVOLVE). The Subgroup is taking on the role and broad membership of the UKCRC Patient and Public Involvement Project Group, which will cease to function. Membership of the Subgroup includes organisations with a specific remit to support patient and public involvement in clinical research, such as INVOLVE, the UK Clinical Research Network Coordinating Centre, Involving People: Cynnwys Pobl and the James Lind Alliance. This will help to ensure that the UKCRC's patient and public involvement resources are used most effectively and that any unnecessary duplication of effort is avoided.

Working with the UKCRC Patient and Public Involvement Project Group, the Strategy Development Group developed a draft implementation plan for 2008/09 and this will be finalised by the Board Subgroup at its first meeting. The Board Subgroup is charged with regularly reporting to the UKCRC Board on progress with the implementation of the Strategic Plan.

For further information about the UKCRC's patient and public involvement activities contact:

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