

# UK Clinical Research Collaboration (UKCRC) Board Subgroup for Patient and Public Involvement

10am – 1pm, Wednesday 7 October 2009  
Room H, MRC Head Office, 20 Park Crescent, London W1B 1AL

## Minutes of Fifth Meeting

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### Present:

Lizzie Amis – National Institute for Health & Clinical Excellence (NICE)  
Jo Brett – Warwick University  
Hannah Brown – UK Clinical Research Collaboration (UKCRC)  
Sarah Buckland – INVOLVE (Chair)  
Sally Crowe – James Lind Alliance (JLA)  
Susan Frade – Medicines and Healthcare products Regulatory Agency  
Cathy Hamer – Patient / Public Member  
Bec Hanley – TwoCan Associates  
John Hughes – Patient / Public Member  
Gail Johnston – HSC R&D, Public Health Agency, Northern Ireland  
David Rea – Clinical Research Collaboration – Cymru  
Sophie Staniszewska – Warwick University  
Roger Steel - UK Clinical Research Network Coordinating Centre (NIHR CRN CC)  
Maryrose Tarpey – INVOLVE  
Philippa Yeeles - UK Clinical Research Collaboration (UKCRC)

### Apologies:

Simon Denegri – Association of Medical Research Charities  
Craig Gilbert – Chief Scientist Office, Scotland  
Sandy Herron-Marx – NHS Centre for Involvement  
Emma Radway-Bright – Association of the British Pharmaceutical Industry (ABPI)

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## 1. Welcome and Apologies

- 1.1. The Chair welcomed members to the fifth and final meeting of the UKCRC Board Subgroup for Patient and Public Involvement (PPI).
- 1.2. The Chair welcomed those who were attending the meeting for the first time:
  - 1.2.1. Lizzie Amis attending the meeting as an alternate for Victoria Thomas.
  - 1.2.2. Jo Brett, attending the meeting in relation to the systematic review of PPI evidence, discussed under agenda item 5.

## 2. Minutes of the Meeting & Matters Arising – 7 May 2009

- 2.1. **Minutes of the previous meeting** – Approved as an accurate record of the meeting held on 7 May 2009. It was noted that these minutes will now be published in the UKCRC website.

### 3. A critical assessment of the development of PPI in the UKCRC

3.1. The group welcomed Bec Hanley from TwoCan Associates. Following a formal tender and short-listing process TwoCan Associates had been contracted to undertake a critical assessment of the development of PPI in the UKCRC and produce a report of this project by the end of the year.

3.2. The group noted that TwoCan Associates met with the Advisory Group for this project in order to decide on a series of milestones that the report would follow. The agreed milestones were:

- Planning in the first year
- Development of the UKCRC PPI Project Group
- The provision of a PPI ring-fenced budget
- Recruitment of a UKCRC Programme Manager to focus on PPI
- Scheme to recruit patient/public members for UKCRC Advisory Groups
- Development of the UKCRC PPI Strategy
- Development of work for 2010 onwards

Each of these milestones looks at what PPI is trying to achieve; who has been involved; what has helped/hindered these activities; what has been done/support; and any impact.

3.3. A series of interviews and a brief survey of Board Members was undertaken to inform the report. A range of stakeholders have been interviewed; it was agreed with the Advisory Group who should be interviewed. A lot of information has been gathered from these interviews. The group noted that it will be a challenge to work out how to condense all the information into something meaningful and useful whilst also ensuring that interviewees are not identified.

3.4. The group was invited to comment on the findings presented by TwoCan and more widely on the value of PPI in the UKCRC. Members offered their individual views and the group's discussion focussed on the issue of presenting the data whilst also ensuring the confidentiality of interviewees. It was noted that a small but significant amount of data will not be used due to this issue. It was agreed that the issue itself is significant and it would be useful to raise this in the report.

3.5. The group noted the next steps for this project. The report will be completed by the end of the year and will be distributed to all members of the UKCRC Board Subgroup for PPI. John Hughes will be attending the UKCRC Board meeting in November to present some preliminary findings of the project. The Chair thanked members of the project advisory group and TwoCan Associates for the work that they were doing.

### 4. Activities Update: UKCRC PPI Implementation Plan 09

4.1. **Work with patients and the public to explore the challenges of patient and public involvement in strategic decision making processes (Activity 1.1):** it was noted that following the Workshop in March 2009 and the establishment of a working group, an agenda for future activities is being developed. It has been difficult to develop a consensus on what the next steps should be as this project could potentially go in many different directions. It has been agreed that the first step should be to create an action learning set for those currently involved in strategic decision making. A working group paper will be circulated to the original workshop participants for comment and this will be the final action for the UKCRC as the project will then be handed over to INVOLVE. It is hoped that the action learning set will be established in 2010/11.

- 4.2. Support the further development of patient and public involvement membership in UKCRC advisory groups, based on the recommendations of the evaluation undertaken in 2008-09 (Activity 1.2):** it was noted that this activity will continue until the end of 2009 when the UKCRC changes its way of working to the Partner-led model. The UKCRC has recruited a Partnership Manager who is starting work in mid-November; she will continue to support the two PPI members on the UKCRC Board. It is also known that patient/public members will continue to be members of the Clinical Research Funders' Group and the UKCRC Board Subgroup on Public Awareness and that they will be supported by the Partner organisations leading on this work.
- 4.3. Capture key learning from the experience of developing patient and public involvement in the UKCRC (Activity 1.3):** it was noted that this activity was discussed under agenda item 3.
- 4.4. Contribute to the work of the UKCRC Board Subgroup for Public Awareness, the UKCRN, UKCRC Partners and other stakeholders on improving patient and public access to information on clinical research and awareness of the use of patient data for research purposes (Activity 2.1):** it was noted that this work will continue as there will continue to be patient/public members on the UKCRC Board Subgroup for Public Awareness. The Clinical Trials Gateway project is continuing. Andrew Russell has been involved in this project and in the work on Portfolio 2 for the NIHR Clinical Research Network.
- 4.5. Support the further development of the web resource, People in Research ([www.peopleinresearch.org](http://www.peopleinresearch.org)), based on the recommendations of the evaluation undertaken in 2008-09 (Activity 3.1):** the group noted that the redevelopment of the People in Research website is underway. An advisory group and a user group have been established to help with this project. The 'new' site is due to be active from early 2010.
- Complete work with INVOLVE, the Association of Medical Research Charities and the James Lind Alliance to support PPI in research funding and commissioning process (Activity 3.2):** the group noted that a half day 'think tank' event will take place on 9 February 2010. The event will be co-chaired by Russell Hamilton (DH) and Simon Denegri (AMRC). It will bring together representatives from large and small research funding organisations, research commissioning organisations and other groups/individuals that have experience in patient and public involvement in research prioritisation and commissioning.
- 4.6. Support the development of the evidence base for the impact of patient and public involvement in research working with INVOLVE and drawing on the findings of the systematic review begun in 2008-09 (Activity 3.3):** it was noted that this activity would be discussed under agenda item 5.
- 4.7. Project to develop guidance for chairs of research groups and committees that include patient and public members (Activity 4.1):** the group noted that this was an additional project. The evaluation of PPI in UKCRC Advisory Groups had identified this project and the National Cancer Research Network is collaborating on the project. A workshop was held in September and a long list of potential top tips for effective PPI within meetings for chairs was drawn up. Attendees at the workshop identified their top ten. However, the guideline developers felt that on reflection, providing a short list of tips might not be the best approach. Two members of the Group – Sally Crowe & Lizzie Amis on behalf of colleagues at NICE - offered to look at this work with fresh eyes and discuss the best way forward.

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## 5. Systematic Review of Conceptualisation, Measurement, Impact and Outcomes of PPI in Health Research

- 5.1. The group welcomed Jo Brett and Sophie Staniszewska from Warwick University. The group noted the presentation that Jo gave which summarised the focus of the review and some of its initial findings.
- 5.2. The group discussed this issue of assessing the quality of the articles that were included in the study. It was noted that there is currently no quality checklist for PPI so the report of quality related to the studies themselves rather than the PPI in the studies. It was noted that it would be helpful to clearly identify studies rated as being of high quality.

## 6. UKCRC PPI agenda beyond 2009

- 6.1. The group noted the paper of Proposals from the UKCRC Board Subgroup for PPI – 2010 onwards that had been circulated to the UKCRC Board and that the Board had approved these proposals at its meeting in June 2009.
- 6.2. It was noted that from January 2010 the following projects would be taken forward by INVOLVE:
  - People in Research website
  - Strategic Decision Making project
  - Annual Survey / Consultation
- 6.3. It was agreed that this is the end of an important phase in the work of PPI in the UKCRC but recognised that it was the responsibility of all members to ensure that links continue. The group noted the value of the work of the UKCRC Secretariat.
- 6.4. It was noted that there will still be PPI work in the UKCRC Secretariat as the Partnership Manager will continue to support the two patient/public members on the UKCRC Board

## 7. Any other business

### 7.1. James Lind Alliance:

- The JLA have received three more years of funding
- The first priorities from Partnerships are starting to translate into research bids and studies
- The JLA are investing in links with other networks/funders and over the next three years they will be mainstreaming their approach priority setting – for example through providing an online tool / resource.

### 7.2. Medicines and Healthcare products Regulatory Agency:

- Susan Frade is new in post as the Patient and Public Engagement Manager. A two-year action plan began this year to strategically and systematically engage patients and the public in the work of MHRA

### 7.3. Sophie Staniszewska:

- HTA International Organisation – Sophie has joined the PPI Steering Group and suggested it links with INVOLVE.

### 7.4. Clinical Research Collaboration, Cymru:

- There are big structural changes in Wales. CRC Cymru will become incorporated into the National Institute for Social Care and Health Research (NISCHR) which is the operational arm of the Wales Office of Research & Development for Health and Social Care (WORD) and this should happen by the end of March 2010
- The thematic networks will remain but they will be called something else

**7.5. NICE:**

- NICE is expanding to include two new work programmes: i) Medical Devices; ii) Diagnostic Techniques and Tools

**7.6. INVOLVE:**

- The Impact Study – a review of literature should be out in the next few weeks.

The Chair thanked all the members of the UKCRC PPI Subgroup and the Secretariat for their work over the past five years.