



## UKCRC Board Subgroup on Public Awareness

12.00 – 14.00pm, Thursday 5 March 2009  
Fletcher, MRC Head Office  
20 Park Crescent, London W1B 1AL

### Minutes

---

#### Meeting attendees:

Professor John G Williams  
Dr Helen Munn  
Dr Richard Tiner  
Simon Denegri  
Kate Law  
Sir Nick Partridge  
Peter Knight

Chris Long  
Dr Louise Wood  
Katherine Cowan  
Danielle Horton-Taylor  
Dominique Capostagno  
Dr Matthew Hallsworth  
Dr Rebecca Hodges  
Dr David Lynn

Chair  
Academy of Medical Sciences  
ABPI  
AMRC  
Cancer Research UK  
INVOLVE  
NHS CfH Research Capability  
Programme  
DH/NIHR  
DH/NIHR  
Patient/Public Member  
Patient/Public Member  
UKCRC Secretariat  
UKCRC Secretariat  
UKCRC Secretariat  
Wellcome Trust

#### Invited guests:

Philippa Cowley-Thwaites

Straight talking communications

#### Apologies:

Simon Wilde  
Nick Samuels  
  
Max Prangnell  
Dr Sue Denman  
Professor Bernie Hannigan  
Craig Gilbert

MRC  
Imperial College Healthcare NHS Trusts  
(on behalf of NHS Confederation)  
AoMRC  
Welsh Assembly Government  
Northern Ireland HSC R&D Office  
Scottish Government Chief Scientist  
Office

---

## **1. Welcome and introductions**

**1.1** The Chair welcomed the members to the third meeting of the UKCRC Board Subgroup on Public Awareness and introduced members who were attending for the first time.

## **2. Minutes of the last meeting 4<sup>th</sup> August 2008**

**BSG-PA-05**

**2.1** The UKCRC Board has agreed that Board and Board Subgroup minutes should be made publicly available on the UKCRC Website. The Chair asked the Subgroup if there were any objections to putting minutes of the previous meetings, as well as the current set, on the website to link the discussions taken place at each meeting. No objections were raised.

**Action: Secretariat to circulate minutes of previous meetings to members. Members to confirm that the minutes are suitable for publication on the website**

## **3. Matters Arising**

Progress on matters arising:

**3.1** The Chair and Peter Knight recently attended a meeting of the BMA Electronic Health Record Group. Although no decision was made at the meeting, the discussions were positive and encouraging. The Subgroup also noted that the recent publication of the Coroner's and Justice Bill had prompted some negative press comments from the Academic Staff Committee and other stakeholders on the impact of the Bill on the confidentiality of personal medical records.

**3.2** Simon Denegri reported that, as part of the launch of their recent publication "A very public benefit: Twenty-one years of charity support for medical and health research and innovation", the AMRC highlighted the findings of their recent Ipsos MORI survey on public attitudes to medical research charities. The top-line finding was that there are huge gaps in the public's knowledge about medical research charities, even though these now top the list of charitable causes to which the public gives money.

**3.3** David Lynn updated the Subgroup on the Government response to the Walport/Thomas report. The Research Capability Programme has found the response and the safe haven modelling helpful. Louise Wood reported that text in the recently published Handbook to the NHS Constitution acknowledges the proposal for "approved" researchers to take forward consent for consent. The exact details of how this will be made operational are still under discussion.

**3.4** David Lynn updated the Subgroup that the Best Practice Guidance for GPs was close to being published in the next few weeks.

**3.5** David Lynn reported that of the 17 Wellcome Trust/EPSRC/ESRC/MRC electronic patient records and databases in research funded projects, 4 or 5 had a very strong focus on public awareness. The Principle Investigators of all the projects are attending a Trust meeting in April and David will update the Subgroup at the next meeting.

**3.6** Kate Law gave an update on the use of Cancer Research UK's BLOG. Common discussion topics are symptoms testing, diagnosis, life with cancer and dying. Its primary function is that of a chat room where people can support each other. There is a moderator who ensures that any topics/discussions that, for example, involve inappropriate treatment recommendations are responded to with accurate, evidence-based information. The BLOG is not currently being used to actively raise the profile of research.

**3.7** Matthew Hallsworth updated the Subgroup on the progress of development of the NHS Gateway (a portal where patients are able to find what clinical trials are available and appropriate to them). Currently a detailed technical specification document is being put together to see how much can be delivered within existing IT systems and what would be required through new procurement. The Department of Health is planning to procure and pay for the Gateway but is keen to work with a wider group of partners across the UK to ensure that the Gateway can achieve its full potential. Marc Taylor has proposed that a project board be established to take this forward and is keen to use the UKCRC Public Awareness Board Subgroup as a sounding board and forum for UK-wide engagement where appropriate.

**3.8** Matthew Hallsworth reported that the recently launched education materials on clinical trials were promoted at the Association of Science Education Conference in January and are also being used as classroom support materials for a play on Clinical Trials supported by the AMRC and Wellcome Trust.

#### **4. Development of a portfolio of research success stories**

**4.1** The Chair summarised what had been discussed at the previous meeting in regards to this project and introduced Philippa Cowley-Thwaites, of Straight talking communications. Philippa had been commissioned to complete phase 1 of the project to examine the feasibility of developing and using research success stories on the use of patient data to engage journalists and the media and to raise public awareness.

**4.2** Philippa Cowley-Thwaites gave a detailed presentation on the work she had carried out on behalf of the Subgroup, in particular on her interviews with experts/stakeholders and journalists. The main findings highlighted that:

- ▶ More clarity is needed on how patient data is used in research
- ▶ The success stories are not news in themselves, unless they are about 'new' research, however they are important as background information to any media activity
- ▶ There is a need to be more proactive in approaches to the media, offering and promoting opinion pieces by key commentators
- ▶ More use should be made of experts/champions in this area (e.g. local or in government)
- ▶ There is a need to look at targeted ways to disseminate the information to the public using other options than the media

## **5. Update on Research Capability Programme and public consultation**

**BSG-PA-06**

**5.1** Peter Knight updated the Subgroup on the progress of the Research Capability Programme consultation on the wider use of patient information.

**5.2** There was a large response from the public consultation. Three of the main findings from the consultation were:

- ▶ The messages on the importance of the use of patient data in research need to be clearer, written in plain English and include the correct level of detail to improve public understanding of the issue.
- ▶ The Town Meetings highlighted that a more positive response was received from the public when it was possible to better articulate the issues and clarify any questions raised during the process.
- ▶ The consultation highlighted the need to publish what patient data will not be used for, ie insurance purposes, in addition to what it would be used for.

**5.3** The report is going through the final stages of approval and should be published towards the end of March

## **6. AOB**

**6.1** Matthew Hallsworth updated the Subgroup on the discussions that took place at the UKCRC Board meeting about the future of the UKCRC:

- ▶ All areas of activity will be Partner-led from January 2010 onwards
- ▶ The UKCRC Board will become a forum for bring issues for discussion, agreeing on action and leadership, and engagement/identification of priority issues
- ▶ The UKCRC will be supported by a Secretary in place of a secretariat
- ▶ The UKCRC Board will be looking to move activity to time limited, project based groups unless there is a clear justification to have a standing group for a particular area of focus
- ▶ Areas of activity will be following a Partner-led model during 2009 if it is not yet in place
- ▶ At the June 2009 UKCRC meeting, the Board will discuss and agree which areas of activity will continue 2010 onwards. To inform this discussion, Subgroups will be invited to:
  - Outline issues they consider will continue through 2010
  - Make recommendations for how these issues should be addressed
- ▶ Sue Bourne (UKCRC Secretariat) will write to the Chairs and Secretariats of all UKCRC groups shortly to invite them on behalf of the UKCRC Board to commence these discussions with a view to put together a paper for the June 2009 UKCRC Board

## **7. Summary of actions and next steps**

**7.1** The Chair outlined the actions/outcomes to take forward before, and to discuss at, the next meeting:

- ▶ The Chair to write to the Academy of Medical Royal Colleges to update on the progress of the Subgroup and how the Subgroup can facilitate engagement from the Royal Colleges
- ▶ The Subgroup will commission Philippa Cowley-Thwaites to do further work before the next meeting in May 2009, including:
  - Develop, in consultation with Subgroup members, the main key messages to underpin this area of work
  - Produce more detailed product descriptions for the materials that should be produced in the short term. First drafts could also be produced where appropriate.
  - Set out the longer term vision for the 'marketing campaign' and basic measures of success.
- ▶ The Chair to develop a draft proposal for the long term vision for the Subgroup. This will be based on moving towards the Partner-led model of UKCRC working and will identify further work to be done and the lead Partner(s).

**8. Date for future meetings: 3 June 2009 12:00 – 14:00**