



UKCRC Board Subgroup on Public Awareness

2.00 – 4.00pm, Monday 28 September 2009

Room J, MRC Head Office

20 Park Crescent, London W1B 1AL

Minutes

Meeting attendees:

John G Williams

Hannah Brown

Simon Denegri

Craig Gilbert

Emma Greenwood

Peter Knight

Katherine Cowan

Danielle Horton Taylor

Rebecca Hodges

Nicola Perrin

Sophie Petit-Zeman

Max Prangnell

Louise Wren

Chair

UKCRC Secretariat

Association of Medical Research
Charities (AMRC)

Scottish Government Chief Scientist
Office

Cancer Research UK

NHS CfH Research Capability
Programme

Patient/Public Member

Patient/Public Member

UKCRC Secretariat

Wellcome Trust

AMRC

Academy of Medical Royal Colleges
Medical Research Council

Invited guests:

Philippa Cowley-Thwaites

Straight talking communications

Apologies:

Robin Banerji

National Institute for Health Research
(NIHR)

Sue Denman

Welsh Assembly Government

Bernie Hannigan

Northern Ireland HSC R&D Office

Allison Jeynes-Ellis

Association of the British

Pharmaceutical Industry

Helen Munn

Academy of Medical Sciences

Nick Partridge

INVOLVE

1. Welcome and introductions

1.1 The Chair welcomed members to the fifth 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 3 June 2009

BSG-PA-13

Changes to be made to the following paragraphs:

4.6 Change to the first sentence under Product 6. GP e-Brochure to read "Peter Knight noted that this product could be taken forward as part of existing work by the Research Capability Programme with their preferred website."

4.6 Change the second action to read "Action: Peter Knight to discuss how this could be taken forward with the RCP and their preferred website."

Action: Secretariat to make amendments to the minutes and publish them on the web

3. Matters Arising

Progress on matters arising:

The minutes of the first three meetings of the Board Subgroup are now available on the UKCRC website.

3.1 The Wellcome Trust published their report *Towards Consensus for Best Practice: Use of Patient Records from General Practice for Research* in June and copies were circulated to members.

4.6 Media work will be covered under agenda item 4.

5 The Research Capability Programme consultation on the wider use of patient information will hopefully receive approval to be published this week. It will then need to be made ready for Gateway review and media slots so it should be published in 3-4 weeks.

6.5 The group discussed other relevant groups within the ABPI and OSCHR with a remit to raise the awareness of the use of patent data with industry. The Chair agreed to follow this up with Louise Wood.

4. Communications Plan – Implementation of plan

BSG-PA-14

4.1 Philippa Cowley-Thwaites of Straight talking communications presented the Implementation Plan for the agreed communication plan for the use of patient records in research to the group. Five activities are described in the implementation plan: i) Finalise messaging and media products and disseminate to UKCRC partner organisations and other interested groups; ii) Development of Patient and GP information; iii) Dissemination/roll out of patient information through GPs, Primary Care Trusts and hospitals; iv) Development of patient and doctor web presence; v) Researcher mailing.

4.2 It was agreed that all five activities should be taken forward. The group felt that the development and the dissemination of the patient and GP information were the two most important activities and should therefore be prioritised. The text from these two activities can then be used for the development of a web presence and the researcher mailing. Once the materials have been developed the media products can be disseminated to UKCRC partner organisations and other stakeholders.

4.3 The group discussed the quotes from the three designers who were invited to tender for the work. It was noted that there was a range in the quotes given, there may be room for negotiation, and that all three would be suitable for the work. Further areas where potential costs savings could be made were identified by the group.

4.4 The group agreed that this work would need suitable governance. A steering group will be set-up to oversee the development of the patient and GP information. This will include representatives from those organisations funding the work. Final sign-off for the work would be the responsibility of the Board Subgroup.

4.5 The group began to discuss the issue of sustainability and agreed that this should become a standing agenda item.

Communications Plan – Monitoring and evaluation of plan

4.6 It was agreed that partners will let the group know of any information that can be used for baseline figures which help to show patients' and GPs' opinions on the use of patient records in research, and any ongoing methods for monitoring success. This will be collated as a paper for the next meeting. The group was also reminded to think about what success would look like.

Action: Members to provide the secretariat with information on how the work can be monitored before the next meeting of the Subgroup.

4.7 It was agreed that the AMRC will monitor the distribution of the information products that are produced by the group.

4.8 Katherine Cowan gave the group some background information on Omnibus Surveys and different ways they can be done, the kind of information that can be gathered and the way the demographics can be broken down.

Action: Katherine Cowan to provide more detailed options for Omnibus Surveys at the next meeting

5. Business case for future work of the Board Subgroup in 2010 BSG-PA-15

5.1 AMRC will project manage this work on behalf of the group and Philippa Cowley-Thwaites will be retained as a consultant. The group agreed the Business Case that was presented however it will be amended slightly to cover costs for the two patient / public members to remain on the group and to include some nominal costs for any future work.

5.2 The timetable for the work was from September 2009 through to March 2011. The group agreed that the review of the group should be brought forward to October 2010.

5.3 The maximum cost for the work described in the Implementation Plan has been budgeted as £110.5k however the costs could be reduced in certain areas (see 4.3). AMRC's costs described in the Business Case are £12,075. Therefore the total funds needed to complete this work is £122,575. The remaining ring-fenced budget for the work of the Subgroup is £49,600 and therefore a maximum of a further £73k is needed to complete all the planned work. Members agreed to go back to their organisation to discuss possible financial contributions to the work.

Action: Simon Denegri to write to funders to see what contributions they can make to this work

6. AOB

No other business was raised.

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:

- ▶ Katherine Cowan to provide more detailed options for Omnibus Surveys at the next meeting
- ▶ Simon Denegri to write to funders to see what contributions they can make to this work
- ▶ Once the additional funding has been agreed Philippa Cowley-Thwaites to re-cost and revise the implementation plan
- ▶ A further meeting of the group to be arranged for early December 2009. At this meeting discussions will include:
 - A revised implementation plan
 - Governance to be clarified
 - Feedback from the November UKCRC Board meeting
 - Further information on monitoring, evaluation and sustainability
- ▶ Members to provide the secretariat with information on how the work can be monitored before the next meeting of the Subgroup.

8. Dates for future meetings

8.1 A date in early December to be identified for the next meeting of the group.