



igniting our potential

UKCRC Board Subgroup on Public Awareness

12.00 – 14.00pm, Wednesday 3 June 2009

Room H, MRC Head Office

20 Park Crescent, London W1B 1AL

Minutes

Meeting attendees:

Professor John G Williams

Dominique Capostagno

Katherine Cowan

Simon Denegri

Dr Sue Denman

Emma Greenwood

Professor Bernie Hannigan

Dr Rebecca Hodges

Danielle Horton-Taylor

Peter Knight

Nicola Perrin

Max Pragnell

Simon Wilde

Dr Louise Wood

Chair

UKCRC Secretariat

Patient/Public Member

Association of Medical Research Charities

Welsh Assembly Government

Cancer Research UK (on behalf of Kate Law)

Northern Ireland HSC R&D Office

UKCRC Secretariat

Patient/Public Member

NHS Connecting for Health Research

Capability Programme

Wellcome Trust (on behalf of David Lynn)

Academy of Medical Royal Colleges

Medical Research Council

Department of Health England

Invited guests:

Philippa Cowley-Thwaites

Steve Palmer

Straight talking communications

Cancer Research UK/National Institute for

Health Research

Apologies:

Craig Gilbert

Dr Allison Jeynes Ellis

Kate Law

Dr David Lynn

Dr Helen Munn

Sir Nick Partridge

Scottish Government Chief Scientist Office

ABPI

Cancer Research UK

Wellcome Trust

Academy of Medical Sciences

INVOLVE

1. Welcome and introductions

1.1 The Chair welcomed the members to the fourth 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 5th March 2009

BSG-PA-10

Changes to be made in the following paragraphs:

2.1 Change the third sentence to read “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”.

2.2 Change the second sentence to read “The Principle Investigators of all the projects are attending a **Trust** meeting in April and David will update the Subgroup at the next meeting”.

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

3. Matters arising

Progress on matters arising:

3.1 Best Practice Guidance for GPs will be published by the Wellcome Trust week commencing 22 June and will be circulated to the Subgroup when it has become available.

4. Phase II of project to raise public awareness on the use of patient data

BSG-PA-11

4.1 Philippa Cowley-Thwaites of Straight talking communications reported on progress with phase II of the project to develop a marketing strategy and supporting materials. She thanked the Subgroup for their input in both the workshop and one to one discussions which helped in the development of four key messages to underpin the marketing strategy.

4.2 Philippa Cowley-Thwaites reported her findings and suggestions to the Subgroup for discussion. It was noted that the four key messages were lengthy, and it was agreed that the messages should be reviewed to make them more concise. Message 3 should become the first message.

4.3 It was agreed that the marketing strategy would be more appropriately described as communications strategy.

4.4 It was agreed that the difference between the use of identifiable and anonymous data should be made clearer in the messages and the communications strategy.

4.5 There was agreement that both primary and secondary care healthcare workers were the primary audience for the communications strategy.

4.6 The following communications products, set out in paper BSG-PA-11, were discussed by the Subgroup:

Product 1. Patient Information Leaflet and **Product 2.** GP Poster

It was agreed these products should be developed together. The leaflet should be available in an electronic format to download from relevant websites, but also in hard copy for GPs to hand out to patients.

Product 3. Patient Information web presence

Peter Knight noted that this could be taken forward as a microsite as part of existing work by the Research Capability Programme (RCP) with the NHS Choices website.

Action: The Chair and Peter Knight to discuss how this could be taken forward with the RCP and NHS Choices

Product 4. Paid for supplement in a broad sheet newspaper

It was noted that this would be an expensive product, and the Subgroup agreed that it should be discussed at a later stage once the other products had been delivered.

Product 5. Press by line and notes to editors

The draft by line and notes to editors will be included in the communications plan.

Product 6. GP e-Brochure

Peter Knight noted that this product could be taken forward as part of existing work by the Research Capability Programme with their preferred website. It was also agreed that the Royal College of General Practitioners could also be a good route to access GPs.

Action: Peter Knight to discuss how this could be taken forward with the RCP and their preferred website.

Product 7. Researcher mailing

The Subgroup agreed this could be taken forward through the relevant UKCRC Partners.

Product 8. Newspaper features

Max Pragnell suggested an additional product to place features about the issue with press contacts.

Action: Max Pragnell and Philippa Cowley-Thwaites to discuss future media work

4.7 The Subgroup discussed the order in which the products should be delivered to different audiences, it was agreed that GPs and healthcare professionals should be the initial target audience to enable clearer subsequent messaging to be communicated to the public and patients.

4.8 The need to undertake an Omnibus survey to establish a benchmark in the public's current understanding of, and attitudes towards, the use of patient data was discussed. It was agreed that existing information from the Research

Capability Programme's public consultation (see item 5) may be sufficient. Peter Knight agreed to circulate a paper summarising the findings of the Research Capability Programme consultation, including key themes and benchmarking, following its publication.

Action: Peter Knight to provide Subgroup with summary paper

4.9 The Chair thanked Philippa Cowley-Thwaites, of Straight talking communications for all her efforts in the second phase of the project.

5. Update on Research Capability Programme and public consultation

5.1 Peter Knight noted that the publication of the Research Capability Programme consultation on the wider use of patient information had been delayed in due to the European Elections but would be published as soon as possible.

5.2 The Pilot Programme will start its services in November 2009 and an output report of learning will be published in May 2010.

6. Future of the Board Subgroup

BSG-PA-12

6.1 The Chair introduced the paper setting out the proposals for the future of the Board Subgroup to go to the UKCRC Board at its meeting in June. From 2010 UKCRC activities will be taken forward in a new Partner-led model.

6.2 The paper set out the proposal that the AMRC would host the secretariat support for the work of the Board Subgroup and this was welcomed by the members.

6.3 Support 'in principle' for the funding of the activities from 2010, dependent on the agreed workplan, was offered by the Wellcome Trust, MRC, WORD, HSC R&D, Department of Health England and Cancer Research UK.

6.4 A business case for the ongoing work of the Subgroup will be produced and discussed at the next meeting of the Subgroup in September. This will include a medium term plan, revised terms of reference for the Subgroup and a clear leadership model for the Subgroup beyond 2009. The membership of the Subgroup should also be examined to see if all relevant stakeholders were involved. The business case will then be discussed by the UKCRC Board at the meeting in November 2009.

Action: Simon Denegri to work with the Chair to develop a draft of the business case to be discussed at the next meeting.

6.5 Louise Wood highlighted that the use of patient data is a key interest to industry and that she would be happy to work with the chair and the ABPI to increase the profile of the work of the Subgroup with industry.

Action: Louise Wood to meet with the ABPI to discuss the issue.

7. Summary of actions and next steps

7.1 The Chair outlined the actions/outcomes to take forward:

- ▶ Philippa Cowley-Thwaites to make amendments to the Communications Plan to:
 - Clarify the use of identifiable and anonymous data in the plan
 - Shorten and rearrange the order of the key messages
- ▶ The Subgroup will commission Philippa Cowley-Thwaites to do further work on the following products, and report back to the meeting in September 2009:
 - Product 1 – Patient Information Leaflet
 - Product 2 – GP Poster
 - Product 4 – Press by line
 - Product 7 – Researcher mailing. Philippa to contact and work with Partners to find communication routes to wider audience
- ▶ Peter Knight to investigate whether product 3 (Patient information web presence) and product 6 (GP e-Brochure) can be included in existing work commissioned by the Research Capability Programme with NHS Choices and their preferred website respectively.
- ▶ Max Pragnell to investigate Product 8 (newspaper feature) with journalists and update the group in September on costs and timings.
- ▶ Louise Wood to discuss with the ABPI how to raise the profile of the work of the group with industry.

8 Any other business

No other business was raised.

9 Date for future meetings: 28 September 2009 June 2009 14:00 – 16:00