

NCRI Consumer Forum Meeting

Rosebery Room, Sadler's Wells, Rosebery Avenue, London EC1R 4TN
Monday 25 July 2016, 10.30 – 4pm



Minutes

1. Welcome and Introductions

Richard welcomed the Consumer Forum members to the meeting. A moment's silence was held in memory of Allister Murphy.

2. NIHR Cancer and Nutrition Collaboration

- 2.1. Lesley Turner provided a verbal update on the Cancer and Nutrition NIHR infrastructure collaboration. In 2014, the NIHR Southampton Biomedical Research Centre and some other parties commenced establishment of a coordinated framework for cancer and nutrition. The first phase included a patient and clinician survey, and incorporated the theme of trials in nutrition. The report can be found on the website (<http://cancerandnutrition.nihr.ac.uk>). The second phase of work has 5 work streams, one of which is being steered by Lesley (Information provision and communication with cancer patients and the public).
- 2.2. Lesley discussed the involvement of NCRI consumer members in the work stream's workshop, which was held in February 2016. The major objective of the work stream was accomplished due to the involvement of the consumers - Lesley created a set of slides for clinicians and patients to use. In addition, Richard Stephens has offered a letter of support and terms of reference were defined.
- 2.3. A charity day for the project, which will be held on September 2016, will be opened by patients and include a patient panel. Lesley requested feedback from Forum members as to why they feel research into nutrition is an important issue for cancer patients.
Action: Consumer Forum to provide Lesley Turner with feedback on the importance of nutrition for cancer patients.
- 2.4. Lesley thanked all the consumers involved.

3. CPES 2015 – Headlines and Further Research Work

- 3.1. Carolyn Morris presented her slides (NCPES 2015). Carolyn remarked that she is looking at working on slides to take to Clinical Studies Group meetings, based on the set already used by Gillian Murphy and Lesley Roberts at the Haem Onc CSG.
- 3.2. John Lancaster presented his slides and talked about his experience of using CPES stats to spark discussions at and with his local Trust.
- 3.3. Margaret Grayson commented on Northern Ireland's statistics, in comparison to the NCPES results. Richard pointed out that Wales and Scotland both have CPES too, although not all the questions are the same across all four nations. DH (England) is currently working on some UK comparisons.

4. Improving Clinical Trials For Patients - A Consumer Workshop On Challenges In Cancer Clinical Trials

- 4.1. Michael Maguire introduced his session, highlighting that it was developed as an outcome of an MRC CTU workshop he had attended on behalf of the NCRI Consumer Forum, about speeding up trial results for patient benefit, and that it also links with a new JLA project on trial recruitment. At the MRC CTU workshop, a list of barriers to and challenges for changing clinical practice and delivery policy were discussed, based on the views and experiences of clinicians and researchers. The aim of today's workshop was to continue to develop a more comprehensive list based on the views and experiences of the members of the NCRI Consumer Forum.



4.2. At the conclusion of the workshop Michael thanked all participants. The findings will be written up and circulated to all Forum members during August for further comment and additions, and a final version produced in September. This will be passed to MRC CTU for their project, and appropriate sections may also be submitted as the Forum's contribution to the JLA exercise. Other spin-offs may include a poster, and/or a journal papers about the process and/or outcomes.

Action: Michael Maguire to write up and circulate findings from Consumer Forum workshop, for further comment and additions.

5. Adding value - what does our measuring stick look like?

5.1. Helen Bulbeck presented on impact and about changes we can bring to trials (top level quantitative and qualitative measures). Helen invited consumers to identify these measures and highlight those they prioritise.

5.2. At the conclusion of the workshop Helen thanked all participants. The results will be written up in August and used to form a set of consumer-designed metrics and standards that may be used to assess the impact of consumer involvement in NCRI both of individuals and of the Forum as a group, and which can be used by funders to assess value for money.

Action: Helen Bulbeck to write up findings from Consumer Forum workshop.

6. Understanding the impact of key statistical issues in cancer clinical trials

6.1. Presentation by Professor Lucinda Billingham. Professor Billingham delivered an interactive presentation and learning/development session, which she had designed for the Forum members with a view to its potential for use with other patient groups.

6.2. At the conclusion of the session members thanked Professor Billingham. Feedback will be sent to her to help shape future iterations of the presentation and activities.

Action: Professor Billingham to draft a list of questions that consumers can ask about non-inferiority trial designs.

7. Introduction to NCRI Strategic Planning - The Environment in Which We Work and NCRI Strategy – Karen Kennedy, NCRI Director

7.1. Karen's slides are attached, covering the background to and methodology of the NCRI's current consultation to develop its new Strategy from 2017 onwards.

8. Presentation by Susan Kohlhaas, Head of Strategic Planning and Initiatives, on the NCRI Strategy.

8.1. Susan posed the question to the Forum "how would consumers like to be consulted?", for example, whether it is through JISCmail and/or, through a second consultation period, such as at the Consumer Forum meeting at the NCRI conference. Susan also asked the Forum "how can we work with consumers to further NCRI goals?", and requested input from the consumers on the strategy presented. Feedback included:

- Regular meetings with NCRI and the Consumer Forum to discuss issues around research
- Discuss/understand what the top barriers are and to know what we should do to prioritise them
- The words of the strategy are fine, but they are general. They could be applied to any partner organisation and are not unique to the NCRI
- There are no other cross-cutting groups like the Consumer Forum
- No evidence of challenging/scrutinising partner roles
- Improve quality: conception of research needs consumer involvement.
- Great relationship and transparency between stakeholders and organisations.
- Appropriate portfolio: stakeholders and partnership priorities could be the same, so who will take over something? How do they divide areas of interest? Partners say they have a consumer voice, but how do they reconcile those voices?
- Barriers: many of those faced by the NCRI can be unlocked by consumers, therefore there is a need to look at consumer involvement at every level. The Consumer Forum is a unique resource and it should be used to the full extent and supported in the future.



- Portfolios: should be patient-led; not only overall survival but quality of life should be supported.

8.2. Consumers posed questions regarding NCRI's strategy, and in particular as to whether it will be adapted, given the input from consumers. Karen suggested that the strategy will change, whereby the goals maintained at the top level and the objectives will be re-examined year on year. Susan commented that progress will be constantly reviewed.

8.3. Richard thanked Karen and Susan for coming to the Forum meeting. He said that as NCRI's Consumer Lead, he would suggest that NCRI should have Consumer Involvement as one of the explicit main enablers to deliver the objectives of the new Strategy, and that it should take the lead in co-ordinating consumer involvement across UK cancer research as part of a UK-wide cancer research strategy. This view was welcomed by Forum members.

9. Final Remarks and Feedback Reminder

9.1. Richard thanked everyone for working productively during a long and very warm day. He asked all attending to make sure they completed feedback forms, as the feedback received will shape the next meeting.

9.2. The meeting ended on schedule at 4.00pm.

