

NCRI Consumer Forum Meeting

Rosebery Room, Sadlers Wells, Rosebery Avenue, London EC1R 4TN
Tuesday 22 March 2016, 10.30am – 4.00pm



Minutes

1 Meeting opens; introductions on tables, icebreakers (Richard Stephens - RS)

- 1.1 RS commented on the impressive turnout at the meeting and thanked the 54 attendees (there were 29 apologies and 8 did not RSVP) (see appendix 1).
- 1.2 RS advised the change to the order of agenda and that the announcement of Consumer Lead/Forum Chair, will be brought forward to the Chair's report item.
- 1.3 The attendees were directed to partake in an exercise, whereby they introduced themselves to their tables (who they are, why they joined the NCRI/why they are here, their NCRI role/what they do and one item on the agenda that interests them). The exercise proceeded.

2 Chair's Report

- 2.1 RS confirmed the Chair's report was circulated in advance, via email to the Consumer Forum. The report is updated and reissued every 2-3 months, and provides the story of change and progress.
 - 2.1.1 Chris Copland, commented on the Chair's report, asking why young people's cancer was left out of activities in the report. RS responded that research into children's cancers were in the report, as an area that needed addressing. He hoped that the outcomes of the workshops at this meeting will kick start activities around children's cancer. There is a need to look at treatment, long-term treatment and late effects of treatment. This will be explored in tables at the workshops. Margaret Johnson, commented that she is glad it came up as it is important to look 20-50 years into the future.
- 2.2 Announcement of Consumer Lead/Forum Chair 2016-2018 (Nicola Keat - NK)
 - 2.2.1 NK announced the appointment of Richard Stephens as the NCRI Consumer Lead and Forum Chair, continuing from his interim role for 75 days per year for a 2-year period. Vee Mapunde was appointed to undertake the remaining 25 days per year, in partnership with Richard. There were several strong candidates that were interviewed, and this arrangement will allow space for new approaches to involvement. Vee provided good answers on diversity and other areas in her interview, and presented an opportunity to represent other areas for consumer activity. NK mentioned that a title for Vee's position was still needed and the NCRI Executive needs to work out who is leading on what areas. There are plans for NK to meet with Richard, Vee and Karen Kennedy, to plan the appointment for early April and to work through how this will work in practice.
 - 2.2.2 Tom Haswell commented on the appointment of Consumer Lead and the need to know the time frame for setting up how the roles will work together. NK responded that the arrangement is to start on the 1st April, and she will be meeting with Richard, Vee and Karen Kennedy on the 4th April to discuss this, and towards the end of April, they will inform the forum on the plans. Tom responded with the query of whether the consumers will be able to offer feedback on the job share arrangement. NK replied they would be happy to hear thoughts and it would be best to present them before April, so they can be considered, when the shaping the job share. This is a new situation and needs to be worked through.
Action: NK to circulate a summary email and role profile to Consumer Forum and will gather the feedback.
- 2.3 Update on Conference (John Rouse - JR)
 - 2.3.1 JR confirmed he had a phone call with the new Head of Conference, Nicole Leida, to discuss the NCRI 2016 Conference, indicating the conference programme was not yet complete and there will be updates on speakers. He had not yet attended a scientific committee meeting, so he had no other updates to give.
 - 2.3.2 RS indicated plans for the 2017 conference and consumer involvement, including workshops and presenting consumer involvement in areas, such as clinical trials, i.e. how consumer involvement has improved, made an impact and made a difference to clinical trials. The consumer forum should plan to make significant impact at the 2017 conference.
 - 2.3.3 Carolyn Morris, commented that it was good to hear of positive discussions on the conference.



2.3.4 Elspeth Banks, commented that Claire Foster, Director of Macmillan Survivorship Research Group, is to present on key aspects of survivorship at the 2016 conference.

2.4 Update on Mentoring Project (Helen Bulbeck - HB)

2.4.1 HB confirmed the mentoring guide has been put together and that currently we are waiting on 3 mentors to provide feedback on the guidelines. The guidelines addressed the request in the Chair's report to provide clear guidance on the mentoring process, to layout a defined process and to manage expectations of mentors and mentees. HB confirmed it is a drafted document and proceeded to quote the principles of the mentorship. It is our responsibility is to drive the mentorship with the CSG mentors.

2.4.2 NK confirmed the guide is to be circulated in the next two weeks, and it will be ready for the next round of CSG meeting in spring.

Action: NK/NS/RS to circulate final guide to Consumer Forum.

3 Workshop: Research Issues in Children's Cancers (Chris Copland & Danielle Horton-Taylor – CC & DHT)

3.1 CC and DHT presented slides (see appendix 2 slides)

3.1.1 CC and DHT commented that they hoped to persuade the Consumer Forum to campaign on children's cancer and involvement in clinical trials, on their behalf. This is CC and DHT's last Consumer Forum meeting and new consumers are Angela Polanco and Nicholas Bird.

3.1.2 The Consumer Forum participated in a table activity, as laid out by CC. The consumers answered questions on how they will address children's involvement in clinical trials in their own Clinical Studies Groups. A table secretary led each table and gathered responses to the questions, to relay to the forum at large.

4 Take 5 - NIHR Cancer and Nutrition Collaboration Consumer Forum Endorsement of Programme

4.1 Elspeth Banks presented the slides (see appendix 3).

4.2 The Consumer Forum meeting voted overwhelmingly to support this initiative (no votes against, 4 abstentions).

Action: Richard to send a letter of support to the Collaboration Lead.

5 Lunch Break

5.1 AstraZeneca presented the patient/carer panel to pilot app to attendees and gathered feedback, during lunch (see item 9 below).

6 Take 5 – Setting Up A Local Research Group (Paul Charlton – PC)

6.1 PC presented slides (see appendices 4-6).

7 Supporting NIHR (Karen Inns and Andrew Rutherford – KI and AR)

7.1 KI and AR presented slides (see appendix 7) on the following three areas:

- Join Dementia Research Project
- Patient Research Ambassadors – Next Steps
- MOOC – feedback from Consumers/PPI reps
 - The next MOOC is scheduled for 6th June for a 4 week period.

8 Macmillan HORIZONS programme (Lynn Calman, Macmillan – LC)

8.1 LC presented slides (see appendix 8).

8.2 LC commented how consumers need to see the questionnaire and to provide feedback on the programme. Alf Oliver, commented that patients need full information. Hilary Stobart, commented how the pathway needs to be examined. Questions for cancer patients who are carers present difficulty.

8.3 Any consumers interested in being involved should contact LC.

9 How Do We Measure Our Own Impact and Value? (Helen Bulbeck – HB)

9.1 HB presented the session and table activity, focussing on how the Consumer Forum can measure their impact on patient involvement and value to CSG activity.

9.2 The Consumer Forum conducted a table activity, listing their impact and value on a spreadsheet.

10 AstraZeneca – Feedback on the work earlier (Karen Murphy – KM)

10.1 KM provided an overview of Consumer feedback on their app and commented on the rich information she was able to gather. The feedback had 3 key messages: 1. How to bring the role of carer and treatment journey into the functions; 2. How to recognise patients on multiple medicines, and the constraints in the technology; 3. The personalisation piece; looking at text sizes, visualisation, sounds, voice control, and the wider communications piece, such as feedback on your progress and how the patient's trial is going.



10.2 The AZ team will keep in touch via Forum Chair on the progress of this work.

11 AOB

11.1 Diana Robinson commented that she would like contact from any consumers interested in helping with a piece of Supportive and Palliative Care research with which she is involved in (email: dianarob@ntlworld.com).

12 Final comments (Richard Stephens - RS)

12.1 RS thanked members for their tributes to Shirley Harrison and Mathew Cooke, and how both families had appreciated them.

12.2 RS thanked members for their support and encouragement, and looked forward to two more years as Consumer Lead and Forum Chair.

12.3 Actions of the meeting

Action: An email confirming the new lead will be circulated to the Consumer Forum JISCMail (NK).

Action: Minutes to be circulated to the Consumer Forum JISCMail (NS). This will include a link to the NIHR patient research ambassador registration [page](#).

Action: A feedback form for the meeting will be circulated to the Consumer Forum.



Consumer Forum Meeting – Attendance

Tuesday 22 March, 2016

Name	Clinical Research Group/Other Attribution
James Adams	Teenage & Young Adults
Christine Allmark	Imaging Advisory Group
Malcolm Babb	Head & Neck Cancer
Elsbeth Banks	Psychosocial Oncology & Survivorship
Matthew Baker	Former Lung Cancer; CFSG consumer
Elizabeth Benns	Breast Advanced Disease Subgroup
Lindy Berkman	Former Colorectal; Screening and Prevention
Nicholas Bird	Children's Cancer and Leukaemia
Helen Bulbeck	Brain Tumour, CFSG consumer
Peter Burchill	Brain
Lynn Calman	Macmillan
Yvonne Carse	Upper GI
Paul Charlton	Former Primary Care; NCIN Consumer Member
Christopher Copland	Children's Cancer & Leukaemia
Beryl Elledge	Gynaecological Cancer
Patricia Fairbrother	Skin Cancer
Jean Gallagher	Bladder Cancer
Margaret Grayson	Chair, Northern Ireland Cancer Research Consumer Forum, NCRI CFSG NI PPI representative
Tom Haswell	CTRad member; CLG/ PPI Steering Group member; Lung
Karen Inns	NIHR
Sandra Irvine	Colorectal Cancer
Monica Jefford	Colorectal
Margaret Johnson	Former Haematological Oncology; Primary Care CSG Early Diagnosis
Rachel Jones	Astra Zeneca
Nicola Keat	NCRI
Debbie Keatley	Brain Tumour
Emma Kinloch	Head & Neck Cancer
John Lancaster	Carer Pancreatic Care
Karin Lovsund	InUse



Michael Maguire	Sarcoma
Angela McCullagh	NCRI Board consumer member lay-trustee
Carolyn Morris	Psychosocial Oncology & Survivorship
Karen Murphy	Astra Zeneca
Allister Murphy	Prostate Cancer
Victoria Nnatuanya	Former Complementary Therapies
Alf Oliver	CTRad; Former Colorectal; Anorectal Subgroup
Angela Polanco	Children's Cancer and Leukaemia
Derek Price	Prostate
Janette Rawlinson	Lung
Lesley Roberts	Haematological Oncology
Diana Robinson	CTRad
Janice Rose	Primary Care
John Rouse	Conference committee representative; Former Skin Cancer
Ann Russell	Former Colorectal Cancer; Currently Primary Care
Andrew Rutherford	NIHR
Natalie Salhov	NCRI
Richard Stephens	NCRI Consumer Lead, Chair NCRI Consumer Forum, Consumer Forum Steering Group
Hilary Stobart	Breast Cancer; Former Gynaecological Cancer
Danielle Taylor	Children's Cancer & Leukaemia
Robert Thurstans	Imaging Expert Advisory Panel
Christy Watson	Renal Cancer
Andrew Winterbottom	Bladder Cancer
Vincent Wolverson	Testis Cancer
Stephen Michael Wood	Lymphoma

