

# National Cancer Research Institute Consumer Involvement Steering Group Meeting

Meeting held from 10.45 – 14.30 on Tuesday 16<sup>th</sup> May, 2017 at Angel Building, Room 2.18, 407 St John Street, London EC1V 4AD. *Followed by Key Consumers' meeting; 14.45 – 16:00.*

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## Draft Minutes

Present :	Matthew Baker (MB)	- Consumer Forum
	Helen Bulbeck (HB)	- Consumer Forum
	Jo Burns (JB)	- Representing Karen Inns, NIHR PPI Lead
	Ian Lewis (IL)	- NCRI Head of Clinical Research Groups
	Michael Maguire (MM)	- Consumer Forum
	Margaret Grayson (MG)	- Northern Ireland
	Vee Mapunde (VM)	- NCRI Associate Consumer Lead
	Barbara Moore (BM)	- Wales
	Natalie Salhov (NS)	- NCRI Consumer Administrator
	Richard Stephens (RS) (Chair)	- NCRI Consumer Lead; Chair, Consumer Forum
Apologies:	John Rouse (JR)	- Consumer Conference Representative (Item 4)
	Peter Rainey (PR)	- Scotland

### 1. Welcomes

- New members to the steering group, MM (from the Consumer Forum) and BM (Wales representative), along with JB, who stood in for KI (NIHR representative).
- The previous actions table was updated and the minutes of the last meeting were approved for publication on the NCRI website.

### 2. Updates from 4 Nations

- Nation representatives, MG and BM spoke to previously circulated written reports.
- It was suggested that at future conferences, there should be an area with a screen showing films demonstrating Consumer involvement.
- HB agreed to represent Scotland in PR's absence for the interim period.
- JB provided an update on NIHR's activities.
  - JB is going to send the "I am research" link to the Consumer Forum. She also discussed the film screening events, held in association with International Clinical Trials Day, which are being organised across England. These screenings aim to highlight local research portfolios and regional opportunities for PPI.
  - Ian Mallet was announced as the new NIHR PPI Lead.

### 3. NCRI Strategy – Consumer Involvement Overview

- To ensure that Consumer activity is delivering the strategy, the Steering Group needed to review consider its ways of working and amend its terms of reference accordingly, as agreed at January's meeting.
- The proposed ToR for the renamed Consumer Involvement Steering Group had already been circulated and amended. Further changes were suggested with the updated document to be circulated for approval.
- It was agreed that the group will be called 'Consumer Involvement Steering Group' as a better reflection of its role and remit.
- The need to recruit a new Partner representative for the Steering Group will be highlighted at the upcoming NCRI Partners meeting. It was suggested that 2 Partners should sit on the Steering Group, and rotated every year amongst the charity Partner members.



- The budget for Consumer involvement was considered as part of a wider discussion around business planning.
  - Consideration will be given to the NCRI's funding agreement with NIHR, with regards to the Consumer budget. JB will pick this up with Ian Mallet.
  - JB highlighted the need for the NCRI's Consumer Involvement work to demonstrate how it reaches into the broad community and primary care settings, as well as having a digital engagement strand of activity.
- NCRI Conference updates were given.
  - Opportunities for Consumer involvement in the 2018 NCRI Conference Committee were discussed following an email contribution from JR. Suggestions included:
    - Consumer involvement better integrated into the conference programme rather than a separate stream.
    - More Consumer involvement when planning the different streams of the conference.
    - Consumer speakers or chairs at the plenary sessions.
    - A bigger presence for the Dragons' Den session on the programme, with the possibility of sessions on multiple days.
  - A Consumer bursary application update was given. All agreed the priorities for allocating bursaries outlined in the call for bursary applications.
  - It was felt that the NCRI Conference is not at present the type of conference for a specific Patient/Public Involvement stream, nor PPI events or workshops, except where they inform or support cancer research (e.g. Dragons' Den).

#### **4. NCRI Strategy – Impact on Consumers**

- The Steering Group approved the role profile for Consumer Membership on CSGs.
- The Consumer Involvement Metrics were presented and positive feedback was received.
  - Changes to the wording were considered and updates will be made.
  - It was agreed that the metrics should be reviewed at the end of every financial year.
- Feedback on the previous Consumer Training event was discussed. The feedback data is going to be reviewed by IL, NS and RS to see if there was a difference in feedback between the NCRI and non-NCRI Consumers who attended the training.
- Application numbers for the current round of recruitment of Consumer members to CSGs was discussed
  - Twitter and direct channels of communication with charities is needed to drive outreach.
- The form for requesting support to attend events was presented to the group.
  - The questions on the application should directly inform the decision-making process for deciding the outcome of requests.
  - It was suggested that the questions on the request form should be re-ordered so that the first question determines what impact attending the course will have for the NCRI.
  - It was agreed that future requests will be circulated to the Steering Group for feedback with the final decision taken by IL as budget holder.

#### **5. NCRI Strategy – Annual Business Plan**

- It was suggested the new NCRI strategy provides an opportunity to develop new approaches to Consumer involvement at the NCRI.
  - A need for succession planning and a vision for the future of the Consumer Forum was raised. This needs to be on Agenda for next meeting.
- The last Consumer survey was discussed, ahead of a repeat survey of Consumers, CSG Chairs and Consumer Mentors this year.
  - Changes to the current survey will be made to reflect the current mentoring arrangement for Consumers.



- It was agreed that the next survey will be run in autumn 2017, with its launch at the CSG Chairs Meeting, the date of which is yet to be confirmed. Review of the responses should be completed by January/February 2018.
- Members of the Consumer Forum are attending an immunotherapy learning and working day at Southampton University on May 31<sup>st</sup>.
- A calendar of events, which the NCRI would benefit from having a Consumer presence at, was considered.

## **6. Items and Updates for Information**

- Vee presented the Standard Operating Procedure on recruitment. VM is to feedback on the blanks to NS.
- MB discussed the work involved with updating the toolkit.
  - Maintaining the toolkit is still a laborious task, but it is now up to date and factually correct.
  - More work is required, but he will touch base with Jack Towner when he returns from annual leave.
- Caroline Cross (NCRI Communications Manager) joined the meeting to present the updated NCRI website and Consumer Involvement page.
  - It was suggested that in future we will be able to monitor the traffic to specific areas of the Consumer website and determine how many people are accessing reports and key resources.

## **7. Key Consumer Meeting**

- The group needs to arrange a teleconference to discuss the next steps for Consumer activity and business planning.

THE NEXT MEETING IS SCHEDULED FOR TUESDAY 12<sup>TH</sup> SEPTEMBER, 2017.





## Actions Table

ACTION NO.	ACTION POINT	OWNE R (S)	DEADLINE/ PROGRESS
<i>Outstanding Actions</i>			
1	Report back on how Wales Cancer Bank is linked to CMPath.	IL	September
2	Send NI Consumer Forum's quarterly update to RS, NK and SG in future.	MG	Ongoing
3	Identify how the metrics measures are assessed in recruitment, training and role description.	HB	
4	Collate list of all consumers NCRI roles.	NSa	Summer
5	HB to pull out top level points to inform bursary allocation.	HB	Before 25/5/17
6	MM to look into IT solution for information sharing, e.g. Google Classroom	MM	Prior to Sept meeting
<i>Current Actions</i>			
1. Welcomes	i. Publish minutes of previous CFIG meeting on website	NS	Completed
2. Updates from 4 Nations	i. Invite Ian Mallet to upcoming Steering Group meeting	NS/KI	Prior to Sept meeting
3. NCRI Strategy	i. Update CISG ToR, including version update in name, date reviewed by CISG and date for review by CISG (year ahead) at footer of document.	NS	End of June
	ii. Raise request for partner representation at CISG meetings at upcoming Partners Meeting	IL/RS	
4. NCRI Strategy	i. Update Role Profile with suggested edits same footer as ToR	NS	Prior to Sept meeting
	ii. Next CISG meeting: add agenda item: role description for non-core members	NS	
	iii. Update metrics with suggested edits and put in version no. to name	NS	
	iv. CISG send contacts at charities to NS fir recruitment	All	
	v. Add guiding principles to both templates	NS	
	vi. Update event request form, reordering criteria and decision-making process	NS	

5. NCRI Strategy	<ul style="list-style-type: none"> <li>i. Arrange separate meeting for business planning</li> <li>ii. Succession planning and a vision for the future of the Consumer Forum to be added to agenda of next meeting</li> <li>iii. Send names attending upcoming Immunology meeting</li> </ul>	NS NS NS	July September
6. Items and Updates	<ul style="list-style-type: none"> <li>i. Direct Consumer Forum of new Forum webpage.</li> <li>ii. Present webpage on slide at upcoming Consumer Forum meeting</li> <li>iii. Conduct survey on website feedback in four months</li> <li>iv. Advise CISG on recruitment drive and website visits</li> </ul>	RS NS CC/NS CC	Upcoming months
7. Key meeting	<ul style="list-style-type: none"> <li>i. Send doodle poll for June for next steps for Consumer activity (HB, MB, RS, MM, IL, NS, VM)</li> </ul>	NS	

