

NCRI Consumer Forum Steering Group meeting

Minutes for Meeting Held in Room 2.22, Angel Building, 407 St John Street, London EC1V 4AD
Tuesday 2 March 2016, 10.45 – 14.30



Present

Matthew Baker (MB)	- Consumer Forum
Margaret Grayson (MG)	- Northern Ireland
Nicola Keat (NK)	- NCRI Head of Clinical Research Groups
Zena Jones (ZJ)	- NIHR PPI Lead
Natalie Salhov (NSa)	- NCRI Consumer Administrator
Natalie Simon (NS)	- Wales
Richard Stephens (RS) (Chair)	- NCRI Consumer Lead; Chair, Consumer Forum

John Rouse (JR) (Invited) - Consumer Representative Conference Committee

Apologies

Helen Bulbeck (HB)	- Consumer Forum
Stuart Griffiths (SG)	- NCRI Partners
Peter Rainey (PR)	- Scotland

1. Welcomes, Introductions, Overview of Day

- 1.1 Minutes of Previous meeting
- 1.1.1 Minor corrections given to previous minutes.
- 1.1.2 **Action (NSa):** amend and publish previous meeting minutes on website.
- 1.1.3 Action point 7 to address outreach to underrepresented groups, such as teenage and young adults and the recruitment of such patient representatives to CSGs. ZJ highlighted opportunities to network with teenagers in Leicester and North London local groups (e.g. local imam groups). In the North West of England, there are groups that focus on women in science (underrepresented groups in Eastern Europe and Afro Caribbean groups). The North East of England has programmes promoting the interaction of young people (e.g. Durham University). These present channels for advertising the TYA role.
 - 1.1.3.1 **Action:** ZJ will circulate websites.
 - 1.1.3.2 NS: There are programmes addressing the inclusion/engagement of young people in research in Cardiff, such as the ALPHA young people's research advisory group, and young people with cancer.
 - 1.1.3.3 **Action:** NS to circulate the details.
 - 1.1.3.4 **Action:** RS/NK to speak to James Adam at the Consumer Forum meeting about recruitment and to consider how to pitch recruitment.
- 1.1.4 The future pitch for conference workshops was raised, and RS discussed resubmitting workshop pitches for 2017. NK suggested the spotlight theatre planned for the 2016 Conference to be a potential opportunity for consumer involvement.

2 Updates from 4 Nations

- 2.1 Scotland
 - 2.1.1 No update given.
- 2.2 Northern Ireland (MG)
 - 2.2.1 ECMC Network PPI Working Group – forum member, Geoff Hill, to chair this group.
 - 2.2.2 World Cancer Day – forum members linked arms with researchers, scientists and oncologists at the Belfast CRUK Centre and the Cancer Centre, wearing the CRUK unity bands. The event received local television coverage and the television report covered the role of research.
 - 2.2.3 The NI Cancer Patient Experience Survey was sent to 5000 and had a reply rate of 62% (for the period December 2013 to May 2014). When asked if they have seen information about cancer, 86% said yes and 14% no. And when asked if they have discussed taking part in research, since diagnosis, 18% said yes and 82% said no. A group has been set up to look at the results and discuss the way forward, such as what needs to be looked at and the differences between the health trusts. In particular, RS asked if the low rate of patients being offered research opportunities was being



considered as part of wider discussions of the survey outcomes, given that this issue has arisen in the English networks too. MG will ask.

- 2.2.4 MG presented the 4th Year Report by the NI Cancer Research Consumer Forum, which covers September 2014 to August 2015 and was published on February 26th, 2016.
 - 2.2.4.1 **Action:** MG to circulate link to report.
 - 2.2.5 The NI Forum is hosting a public information evening on Breast and Ovarian Cancer Research. The event is taking place on April 13th, 2016, at the Centre for Cancer Research and Cell Biology.
 - 2.2.6 The Bowel Advisory Group have the S-Cort event for PPI links planned for the trial meeting in June, and this will include a visit to Almac Pharmaceutical. This will be followed by a stratified medicine public event in the evening
 - 2.2.7 Medical students at Queens University, as part of the Clinical Academic Module, have an afternoon session with MG, highlighting the importance of involvement in research.
 - 2.2.8 NI Forum working groups will look at training and evaluation, communication and awareness.
 - 2.2.9 CTRad has a new NI consumer, Sonia Patton.
- 2.3 Wales (NS)
- 2.3.1 The Annual Network Group meeting, on February 1st, 2016, was well received. There were pre-meeting activities on engagement in public research, which worked well.
 - 2.3.2 Work includes a planning review to evaluate processes and work remit (expenses, recruitment and involvement of stakeholders)
 - 2.3.3 There is a new e-introduction source by NHS Wales, which is not fully tested yet but looks good. NS is happy to talk to anyone about it.
 - 2.3.4 The engaging population programme by National Population Study in Wales, Healthwise Wales, was launched on February 29th, 2016, and has an ambitious goal to have 260,000 register their interest to be on future research studies.
 - 2.3.5 Wales Cancer Research Centre has open events and is engaging well with the public. The results of the recent PPI scoping exercise which was undertaken by WCRC were summarised and further information is available from NS.
- 2.4 NIHR (ZJ)
- 2.4.1 The NIHR PPI strategy's visions and values were signed off by the Department of Health.
 - 2.4.1.1 **Action:** ZJ to circulate when appropriate.
 - 2.4.2 The MOOC online course will include a section on 'building research'. There is a move towards a learning and development framework, which MOOC and its partnerships will sit under.
 - 2.4.2.1 MOOC will be re-advertised in June, 2016.
 - 2.4.3 Patient Research Ambassadors Initiative (PRAI) is to expand to help support pushing out research in the NHS.
 - 2.4.4 The Join Dementia Research (JDR) project transferred to the NIHR on February 8th, 2016. There is a request to publicise JDR.
 - 2.4.5 'NIHR at 10' conference is on May 18th 2016 and invitations are starting to go out.
 - 2.4.6 In April, ZJ will be working on a feasibility project with pharmaceutical companies.
 - 2.4.6.1 RS suggested that more Consumer Forum members should be engaged with the PRAI. There is involvement in research but not as ambassadors. RS asked how the NIHR CRN suggests we deal with this.
 - 2.4.6.2 ZJ: those involved need to be mapped out and identified, such as those within hospital trusts, and convince people they are ambassadors, given they are involved in research. The NIHR CRN is pushing out a registration form, and there is work in progress to broaden and deepen the focus. Stage 1 of the national directorate plan is complete, and stage 2 now is the implementation.
 - 2.4.6.3 ZJ identified that registration information is sensitive data. RS suggested taking 2/3 laptops to the Consumer Forum meeting, to get people to register. RS to consult NK and Karen.
 - Action:** NSa to arrange laptops at Consumer Forum meeting.
 - 2.4.6.4 ZJ suggested that everyone should have the opportunity to know about research, as it should be part of our daily understanding of research and an explicit link should be made between research involvement and being a patient ambassador.
 - Action:** NK and RS to discuss incorporating the role of patient ambassadors into the future role description of NCRI consumers.



3 Updates on Forum Activities

3.1 Mentoring Project (NK)

- 3.1.1 Since the last update, all actions have been completed for the Mentoring Report.
- 3.1.2 The report includes the purpose, function, responsibilities of mentoring and a template to record sessions.
- 3.1.3 The report is in its draft form and is open for comment. RS would like to keep it short and simple. NK to bring the process to implement the report forward. The buddying element will be separate and will be distinguished outside of the report, so that the term is not used interchangeably with mentoring.
- 3.1.4 Mentoring will be a structured process.
- 3.1.5 RS considered it has been a long time since this project has been raised, and there is a need to roll this out as soon as possible in the CSG groups and have the guidelines available. It was asked how this would be launched.
- 3.1.6 NK stated that the mentoring programme was being implemented for new consumers, however there isn't an awareness of the document as yet, so it will be passed on to a small number of mentors as a user test.
- 3.1.7 MB considered the user process diagram should be in the report. A tripartite meeting between the chair, mentor and mentee should be considered, whereby a work plan is reviewed as a scoping exercise (outlining what the role involves), which the mentor supports. This would give structure to the mentoring activity. It was agreed this should be included as a future development to the process.
- 3.1.8 ZJ considered it initially important to establish whether the mentee and mentor would want to work together, versus the performance of the mentee in the consumer role.
- 3.1.9 RS considered it is important to take care when recruiting for consumers and pairing with the mentor. The work programme may not be a realistic approach due to the different nature of each CSG and the consumer roles within them. The key aim for mentoring was identified as ensuring the first year for the consumer is not a struggle and that their induction training and handover period is supported, and that the mentoring is relevant for the individual consumer and the specific CSG.
- 3.1.10 NK confirmed that CSG members outline expectations, so they know whether they achieved what they set out to do in their 3-year term.
- 3.1.11 MG considered how the mentoring process is enforceable. NK confirmed that consumers know that they have a scientific mentor and there is not a big shift in expectations. Furthermore new consumers receive a CSG guidebook when they start.
- 3.1.12 NK suggested a case study of mentoring to demonstrate good practice, which should be included in the document in the future.
- 3.1.13 Depending on the feedback of the drafted mentoring report, it will be sent out to individuals for piloting and a draft version circulated at the training. This is CSG specific and the future document needs to include other forms of consumer involvement.
- 3.1.14 MB suggested considering people's experiences of this process to see if it was helpful.
- 3.1.15 NS offered to help with communications, when it is rolled out to the larger audience.
- 3.1.16 **Action:** CFSG to comment on the document by Friday 4th March. NSa subsequently to send to a few mentors. Revised version will be presented to CSG Chairs at their Forum Meeting.

3.2 Recruitment (NK)

- 3.2.1 New consumer members, recruited to the CSGs, CTRad and conference committee, were announced. The CSGs that did not recruit this time round will recruit again at the next round.
- 3.2.2 The CMPath consumer is to be recruited. Dr Karen Oien is the new lead and is now recruiting for the work stream.
- 3.2.3 The interview panel for the Consumer Lead interviews was confirmed.
- 3.2.3.1 A separate consumer forum panel was confirmed to conduct informal interviews with the candidates following the initial interview. Feedback from the consumer panel will be fed back to the interview panel, to help with the decision-making process. The consumer forum has been notified of this plan.
- 3.2.3.2 The interview questions are being planned.
- 3.2.3.3 ZJ and MB considered the expectations of the consumer lead role.

NB: RS left the room for items 3.2.3 - 3.2.3.3

3.3 Training Days (RS)

- 3.3.1 NSa confirmed 13 consumers to attend training.



- 3.3.2 The content for the training days were considered (day 1, day of context; and day 2, what it is like to be consumer member, the job at hand, introduction to clinical trials and the toolkit). Day 1 and day 2 should be attended in that order.
- 3.3.3 RS to invite other partners to future training sessions.

3.4 Forum Meeting (RS)

- 3.4.1 It was confirmed that the agenda is completed and full, and although there is some space for movement there is no room for additional items.
- 3.4.2 Chris and Danielle have a long session. NSa to confirm that it is still needed.

4 **Planning Ahead**

4.1 Conference activity

- 4.1.1 It was confirmed that the Dragons' Den session has been approved, although the date, time and location are not confirmed (the aim is for a larger room).
- 4.1.2 RS raised a new idea for inclusion in the passport competition, involving researchers meeting consumers for a quick conversation and to get a password. NL liked the idea and will attempt to fit it into the conference programme.
- 4.1.3 JR to meet with NL to discuss consumer issues, including approaching industry stands and the Consumer Forum meeting.
- 4.1.4 Consumer bursary application numbers will possibly be greater than the budget will allow, so at the next Consumer Forum Steering Group meeting the application process will require further consideration (such as tweaking applications for filtering purposes or alternative forms of funding).

4.2 Conference Feedback

- 4.2.1 NSa presented the NCRI Consumer Bursary Feedback report.
- 4.2.2 Moving forward, guidelines will be given to consumers on how to complete the feedback form (e.g. compulsory to fill in name and comments have to be open for publication). Further questions to encapsulate their experience will be constructed.
- 4.2.3 MB considered that consumers need to consider their bursary as a privilege and that accountability needs to be taken, in representing the NCRI at the conference.
- 4.2.4 ZJ suggests new consumers should be given priority to attend, and then subsequent consumers should apply to attend.
- 4.2.5 JR to feed this back to the consumers at the next Consumer Forum meeting, including raising awareness over the budget for the conference and that the consumers need to consider what they give back, given their bursary.
- 4.2.6 **Action:** time will be allocated to discuss the conference and consumers further at the next Consumer Forum Steering Group meeting.

4.3 Annual Survey

- 4.3.1 The next survey was previously agreed to be in autumn 2017, and then to assess if it should be every 2 or 3 years after.
- 4.3.2 RS considered this time frame too far away in view of the turnover of membership on CSGs and the new developments in Induction and Mentoring, , and suggested it should be every 18 months, starting spring 2017.
- 4.3.3 It was agreed that the next survey will be conducted in spring 2017, subject to CSG Chairs' approval, and to see how much work is involved before committing to a schedule for future surveys.
- 4.3.4 **Action:** NK/MB to streamline the surveys and investigate technologies to use to run the surveys, e.g. survey monkey.

4.4 Other Forms of Membership

- 4.4.1 NK is currently collating contacts from the recruitment spreadsheet.
- 4.4.2 **Action:** NSa to collate contacts from earlier recruitment rounds and will put together as part of a larger "contact list".
- 4.4.3 RS remarked that he hoped for something stronger, e.g. collating contacts from local research groups and patient research ambassadors, with the aim of circulating notifications of the website, NCRI newsletters, news flashes from the NCRI website and opportunities. This topic can be discussed in more detail at a future CFSG meeting.



4.5 Publishing Other Papers

4.5.1 The following were recommended to be placed on the NCRI website:

- Reports to NCRI partners and CSG Chairs forum
- Annual reports and minutes and commentaries of meetings, including Consumer Forum meetings.

4.5.2 Website changes

4.5.2.1 There is a need to manage expectations of what we can do in-house.

4.5.2.2 Need for sections/organisation of information

4.5.2.3 **Action:** MB volunteered to work with a new consumer, as a new pair of eyes, to update the website. RS to identify new consumer at the Consumer Forum meeting to volunteer.

4.6 Budget Information (NK)

4.6.1 NK presents the break down on where the NCRI Consumer Forum budget has been allocated for the financial year 2015/16.

4.6.2 There may be financial capacity to hold a third Consumer Forum meeting in the summer.

4.6.3 There have been no extra projects this year, except the mentoring report, which will require budget allocation/consideration.

4.6.4 Future training costs should be considered.

4.6.5 MB considered the need to know figures at the end of the year and what we need to accommodate for the next year and if we are able to rollover any leftover budget, should there be any.

4.7 Summer Forum Meeting

4.7.1 A summer meeting was proposed

4.7.2 There is work with consumers over showcases for the conference, and to develop topics, e.g. forum working with industry (possibly to have a company to host and sponsor the meeting), data sharing, how recruitment to trials is carried out in the new Network structure.

4.7.3 NK and ZJ to discuss the financing of a Consumer Forum meeting in July.

4.7.4 MB considered it a good idea in principle, whereby there is a common vision amongst the consumers and this vision can only be shared when meeting face to face.

4.7.5 NK to consider possible venues and agenda.

4.8 Annual Report

4.8.1 RS considered what it should look like (structure), what it should include, and the potential for it to reach a wider audience.

4.8.2 ZJ suggested including the following headings:

- i. Demonstrate key achievements,
- ii. Challenges that were faced and how they were overcome;
- iii. Three areas of impact (to demonstrate value for money).

Furthermore, case studies and stories should be incorporated under these headings, to illustrate the nature of involvement we engage in. For example, a matrix illustrating the Consumer Forum involvement with X no. of pharmaceutical companies and X no. of research studies that went through the research pathway, change in delivery and ethics.

4.8.3 NS suggested a summary at the start of the report.

4.8.4 The timing of publication was considered to include the timing to present to the partners in June, the Consumer Forum meeting in July, and for it to be available at the conference.

4.9 AOB

4.9.1 NK presented information on consumer involvement with CSG subgroups, which raised questions about the number of core consumers (travel funded by NCRI) and non-core consumers (expanded membership not funded by the NCRI).

4.9.1.1 ZJ and MB raised that there is a possibility to have core and non-core consumer members sitting on the same subgroup. However, the budget is a significant amount to be allocated to this involvement, and if all CSG sub groups have consumer participation, the budget won't stretch to cover all of them.

4.9.1.2 Moving forward, there is the requirement for stricter guidelines over subgroup involvement and consumer membership, possibly with hosting groups, and there needs to be a decision-making process over involvement.

4.9.1.3 RS considered that it is up to the Chair of the subgroup, as there are 10 spaces to fund.

4.9.1.4 ZJ considered the need to centralise travel bookings.



- 4.9.1.5 **Action:** NK to contact Chairs to gage insight into how they are ensuring consumer input.
- 4.9.1.6 MB considered that the consumer input derives from their CSG involvement, which is an operational relationship through which the subgroup is involved.
- 4.9.2 Next Consumer Forum Steering Group meeting to be held on April 26th, 2016. MG to teleconference in.
- 4.9.3 Appreciation was expressed for RS' efforts, contribution and good work as interim Consumer Lead.



Actions

No.	Minutes and Action	Owner	Deadline
<i>Outstanding Actions</i>			
1	Plan and prioritise visits to CSG strategy days and CSGs with new consumer members during 2016.	RS/HB	Ongoing
3	SG would like to have a mechanism in place to feedback to NCRI Partners about the consumer work. Nicola Harris (NH) to pull together a list of Partner contacts for SG	PR/SG/NS NH	27/11/15 14/03/2016
4	Theory of change principle to be completed by the end of November, if time and resources allow. <u>Outstanding:</u> SG's role has changed, so he will address this during 2016.	SG	During 2016
5	Underrepresented groups to be explored with NK, specifically the possibility of looking at affiliate/ associate membership, who the underrepresented groups are and how to find them Update: NK to redraft advert to address group and to circulate to specific groups over next recruitment round, e.g. Bright Light.	NK/Lorna	During 2016, before next recruitment
<i>Current Actions</i>			
1.1.2	Amend and publish previous meeting minutes on website	NSa	21/03/2016
1.1.3.4	Speak to James Adams at the Consumer Forum meeting about recruitment and to consider how to pitch recruitment.	RS/NK	22/03/2016
1.1.3.2	Circulate organisation websites focused on inclusivity	ZJ	21/03/2016
1.1.3.4	Circulate details on inclusivity programmes in Wales	NS	21/03/2016
2.2.4.1	Circulate link to 4th Year Report by the NI Cancer Research Consumer Forum	MG	21/03/2016
2.4.1.1	Circulate NIHR PPI Strategy's visions and values for comment	ZJ	21/03/2016
2.4.6.3	Arrange laptops at Consumer Forum meeting	NSa	22/03/2016
2.4.6.4	Discuss incorporating the role of patient ambassadors into the future role description of NCRI consumers.	NK/RS	Before next recruitment, September 2016.
3.1.16	CFSG to comment on mentoring guide. NSa to send to several mentors and meets. Revised version to presented at CF meeting	All/NSa	22/03/2016
4.2.6	Allocation of time to discuss conference and consumers in greater detail at next CFSG	NK/RS/NSa	26/04/2016
4.3.5	Streamline the surveys and investigate technologies to use to run the annual surveys	NK/MB	21/03/2016
4.4.2	Collate contacts from earlier recruitment rounds to put together as part of a larger 'contacts' spreadsheet	NSa	21/03/2016
4.5.2.3	Evaluate how to update to website.	MB/volunteer consumer	21/03/2016
4.9.5.1	Contact Chairs to gage insight into how they are ensuring consumer input	NK	21/03/2016

