

# NCRI Consumer Forum Steering Group Meeting

Minutes for Meeting on Monday 19<sup>th</sup> September, 2016. Angel Building, 407 St John Street, London.

Attendees:	Helen Bulbeck (HB)	- Consumer Forum
	Matthew Baker (MB)	- Consumer Forum
	Margaret Grayson (MG)	- Northern Ireland
	Stuart Griffiths (SG)	- NCRI Partners
	Nicola Keat (NK)	- NCRI Head of Clinical Research Groups
	Vee Mapunde (VM)	- NCRI Associate Consumer Lead
	Peter Rainey (PR)	- Scotland
	Natalie Salhov (NSa)	- NCRI Consumer Administrator
	Richard Stephens (RS) (Chair)	-NCRI Consumer Lead; Chair, Consumer Forum
Apologies:	Natalie Simon (NS)	- Wales
	Zena Jones (ZJ)	- NIHR PPI Lead

## DRAFT MINUTES

### 1. Minutes of previous meeting

1.1. Actions of the previous meeting are run through. All action points were discussed and any outstanding/revised actions have been included in the actions table at the end of these minutes.

1.2. Last meeting minutes approved and NSa to publish on NCRI website.

### 2. Nation Updates

#### 2.1. Update from Scotland

2.1.1. Currently there is no holistic view of consumer involvement in the nation and CSO is considering how this may be determined.

2.1.2. HB commented on her involvement with Scottish Clinical Trials Units and work in developing tools for researchers to engage with consumers.

2.1.3. Consumers, Tom Haswell and Elspeth Banks, have been involved in clinical trials at a local level in Scotland. They have been able to see trial development from an early stage, provide input and work with collaborators. They have also attended the Detect Cancer Early Conference, the Celebration of Excellence and Glasgow University, the ICPV summer school, which was organized by Elspeth and focused on survivorship, and the Primary Research Care Group.

2.1.4. PR gave an update at the CRUK Road Show on patient involvement, and has been involved in CRUK's Grand Challenge Panel. PR is involved in the Scottish Government Cancer Strategy's Working Group, which addresses the lack of universal access to treatment. In addition, a prevention initiative is being started in Scotland, with the Roy Castle Lung Cancer Foundation, which may have a research angle.

2.1.5. There is a need for a PPI initiative in Scotland.

**Action:** HB will work with PR to gather volunteers to help in discussions with David Cameron, on a consumer led initiative to help deliver 2.1.1, after the NCRI Cancer Conference.

#### 2.2. Update from Wales

2.2.1. Written update previously submitted and included in meeting papers. NS was thanked for her informative report. It was questioned how Wales Cancer Bank is linked to CMPath. **Action:** NS to report back.

#### 2.3. Update from NIHR

2.4. It was noted that ZJ's absence from work was likely to continue. NIHR CRN CC has suggested communicating via Karen Inns and colleagues for the time being.

2.4.1. VM raised the point of there being no close connection between NIHR PPI Leeds and NCRI. RS suggested that as the CRN includes 200 professionals with the PPI role in their job description not just the 15 Leads, it is a huge enterprise and perhaps NCRI could innovate e.g. providing patient ambassadors with the messages we need communicated.

**Action:** NK/NSa to share minutes and thoughts with Karen Inns (NIHR).

#### 2.5. Update from Northern Ireland

2.5.1. Written update previously submitted and included in meeting papers. MG was thanked for her informative report.

**Action:** MG to send NI Consumer Forum's quarterly update to RS, NK and SG in future.

#### 2.6.

2.6.1.

2.6.2.MG highlighted the ongoing subgroup activity, which is looking at impact. There is a strategy for involvement in NI produced by HSC Public Health and Research Development Division.

**Action:** MG to send a link to strategy to the Group.

2.6.3.MG drew attention to the 'setting the standards for involvement' leaflet produced in NI.

2.6.4.Queens University medical students, taking the Public Health Cancer Screening module, as part of the course have a session on "The impact of being diagnosed and the importance of patient involvement in research. RS commented that in England, most medical students do not receive this training. MG assumes that the courses in NI are set up, as those involved in patient involvement (CCRCB) have a close link with those setting up the courses at Queens University.

2.6.5.RS suggested an impact report on the work undertaken in 2015 at the researcher/patient workshop on Plain English in relation to patient information in clinical trials.

**Action:** MG to investigate.

### 3. NCRI Consumer Involvement

#### 3.1. NCRI Strategy 2017-2022 Update (NK)

3.1.1.NCRI's draft strategy went to the Trustees and comments were received. The revised version went to all NCRI Partners and the NCRI Executive for feedback. A wider consultation is being planned for the NCRI Conference. The final version will be published to commence on April 1, 2017.

3.1.2.RS commented that the new draft Strategy sees patient involvement as an enabler, not an objective or a goal, as requested by Consumers at the last Forum Meeting. PR sees the strategy as a collaborative exercise. The strategy group is very receptive to the ideas from RS and PR.

3.1.3.NK commented the strategy is top line for executive and for its partners; it is a framework that will have annual business plans containing more detailed objectives and measurables.

#### 3.2. CFSG ToR

3.2.1.NK is happy with amendments but would want some operational objectives included. RS commented that the CFSG has oversight, not delivery, of those objectives. Queries were raised over the reference to 'associate consumer lead' and its reference in reimbursement. In addition, the need for a nominated individual to stand in to lead the meeting should be included in the ToR, in the case of the Chair not being present.

**Action:** NSa/NK to review and circulate ToR to CFSG.

#### 3.3. Budget information (NK)

3.3.1.At the end of the last financial year (2015/16), there was an approximate £4.5k underspend, which has been carried over into this year (2016/17). Approx. £30k of the £84k budget has been spent this year so far.

3.3.2.RS would like to determine the cost to run a Consumer Forum Meeting (travel and venue), to see if this underspend covers the cost of a meeting. The spending profile determines the next Consumer Forum meeting, so there needs to be a push for expenses to come in before the end of the financial year.

**Action:** NSa to put together figures of venue and travel as separated costs.

3.3.3.The option to hold the Consumer Forum meeting in another city was considered, The geographical spread of the consumers is something that requires attention, given its change over the years, as well as consumers travelling with carers. In terms of cost however, travel costs balance out wherever the venue is (at least in England); the main cost is in venue hire. Moreover London is as easy if not easier to reach as other destinations. NK to liaise with NCRAS to see if they have a suitable venue in London that we may be able to use for a reduced charge/free of charge.

**Action:** NK to contact NCRAS regarding venue options.

#### 3.4. Proposal for Capturing Impact (HB)

3.4.1.We need to lay down the key principles of consumer involvement, if we are going to understand impact. The feedback from the Consumer Forum meeting was collated and HB would like approval as to what to take forward. RS suggested to start with what we can do reasonably quickly from/with information already collected/known.

3.4.2.HB discussed the feedback on impact received at the Summer Consumer Forum meeting. HB identified her expectations of the report, which is to include around 20 items for the Consumer Forum to consider and what the CFSG would like to see in the review. Some items will be harder, such as accounting for every interaction of PPI activity, which consumers can log.

**Actions:** HB needs collective input on the following: a. CFSG review and sign off document (2 week deadline); b. NK and RS to look at the appendix and review together, to see what should be included, and PR to provide thorough review; c. NK, RS and HB to have face-2-face meeting. NK to send date.

- 3.4.3. Deadline for final report is for around Christmas. The paper is to be presented to the Consumer Forum at the Conference Dinner, and then the final report is to be presented at the Spring 2017 meeting. **Action:** HB
- 3.4.4. Thanks were expressed to Helen for her hard work to date on this project.
- 3.5. CSG Subgroup report (NK)
- 3.5.1. The report on consumer involvement in subgroups was presented at the CTSG meeting. The outcome of discussions was that it was agreed consumers add value to subgroups and, therefore, we should include them on these groups.
- 3.5.2. NK is to write paper for Trustee meeting in December on honoraria and consumer involvement in subgroups.
- 3.5.3. RS noted that CTSG was asking CSG and subgroup chairs to give up one of their 10 funded places on subgroups for consumers. The question is to how the consumers should be identified and recruited, and the possibility for conducting interviews for this role, as with CSG interviews. However it is achieved, finding and recruiting another 30-40 knowledgeable consumers to sit as equal partners on subgroups should be seen as a task for 3-5 years.
- 3.5.4. Consideration was given to the fact that we have 4 consumers on subgroups, who are funded by the NCRI, but are not members of the NCRI Consumer Forum. According to the rules, they should be core members. This has financial implications on subgroup consumers in future, as identified in 3.5.4. NK suggested that these four should be brought into the Forum as affiliate members. The option to cover their travel to Consumer Forum meetings can be considered on a case-by-case basis, pending budget allowances and training opportunities. Existing subgroup members, who are core, will eventually rotate off and become affiliate members, given invitation and acceptance. All future subgroups members would be affiliate members (unless already core members by virtue of other NCRI consumer roles, e.g. CSG membership). CFSG agreed to these proposals. **Action:** NSa to contact the 4 consumers identified.
- 3.6. Annual Work Plan
- 3.6.1. NSa gave a run-through of the annual calendar and work plan for NCRI consumer events.
- 3.6.2. RS would like to see meetings where we have commitment for NCRI consumer involvement presence, e.g. the conference in Scotland. NSa confirmed there will be space for this on the new NCRI Consumer 'Events' webpage.
- 3.7. Expenses policy queries
- 3.7.1. MG raised the query that taking budget planes is not always the cheapest option for travel. NK confirmed that the NCRI expense policy is for use across all NCRI activities, and so the current policy is a starting point. We will be gathering feedback received for input into a revised version. Each claim will be approached with a case-by-case stance, as there is flexibility, based on individual circumstances. This policy is to make sure everyone thinks about when and with whom they are booking. **Action:** RS to remind Consumer Forum that the NCRI is not looking to discriminate in the application of its policy, and would like feedback if it doesn't work for individuals (e.g. exceptional circumstances or lack of clarity).
- 3.7.2. HB would like clarification over how to submit claims (hard copy or email).
- 3.7.3. *Post meeting note:* The expenses policy is to send a hard copy or scan a copy, with copies of the receipts, and email to [NCRIfinance@ncri.org.uk](mailto:NCRIfinance@ncri.org.uk).
- 3.8. Consumer involvement in the annual review of the CSGs was considered at the start of the meeting. The process had worked well and would be repeated in 2017. RS asked that the consumers involved should provide some form of report or overview for the Forum.
- 3.9. Links with consumers at NCRAS, ECMCs and CTUs (update). RS is reluctant to proceed at present, until budgets and membership of consumers is confirmed at NCRI. However the other organisations/groups are each considering how they wish to proceed with Involvement, and he he is keeping in contact. NK would like to see a draft paper outlining Richard's thoughts about national connections before the end of the calendar year.
- 3.10. CFSG consumer vacancy: The vacancy on the CFSG for an additional consumer member was discussed. It was agreed that it is now timely for this position to be advertised. It was agreed that call should be circulated, specifically looking for a 'new' member of the Consumer Forum, i.e. somebody who joined during or after 2014, to ensure newer recruits are represented on the group. **Action:** NK and NSa to discuss plan and timetable.
4. Headline of Forum activities
- 4.1. NCRI conference
- 4.1.1. Bursaries
- 4.1.1.1. There were 51 applications. In the first instance, only core Forum members on CSGs and other initiatives were allocated a bursary. Since then, 2 out of 5 subgroup members are funding their attendance from outside NCRI, and the other 3 subgroup

members have gained funding from NCRI following drop-outs. 39 consumers have bursaries, along with 2 carers, and 2 consumers are funded from other sources.

- 4.1.1.2. The bursary holders dinners is now a Forum dinner, with all NCRI consumers to be invited.
- 4.1.1.3. We should have been tighter on defining priorities applications for bursaries and next year we need clearer priorities or strategic/quota allocation of bursaries. Most specifically, we need to be realistic and consider that funding is unlikely to cover even all the core consumers who apply, let alone affiliates or beyond.
- 4.1.2. Activities and impact
  - 4.1.2.1. Forum members' dinner should be a working dinner and include items, such as HB's matrix on impact.
  - 4.1.2.2. Dragons' Den is a CRUK sponsored event and the administration is being organised by them. There is an aim of 10 applications/tables, making it the biggest event to date. The deadline is October 10, 2016. **Action:** RS is to contact non-NCRI consumers pre-conference re the conference events, and will need their contact details from Conference Team (if possible). **Action:** NSa to obtain all Consumer/Patient/Carer attendees at conference when registration closes.
  - 4.1.2.3. The Consumer Forum meeting will include a CM-Path workshop.
  - 4.1.2.4. 2 posters will be displayed this year. **Action:** NK will see if they can be put next to each other. There is an oral presentation on the CPES poster (RS).
  - 4.1.2.5. There is the CTRad event on Wednesday afternoon at the conference.
  - 4.1.2.6. Elspeth will be co-chairing a session.
  - 4.1.2.7. It is possible for Roger Wilson to present at the Consumer Forum meeting. **Action:** NSa to invite SG to attend the Consumer Forum dinner.
  - 4.1.2.8. Consideration over how to capture impact of the consumers at the conference was given (beyond the feedback). Consumers should be asked "what is the question you ask?", "how many researchers have you engaged with?". PR considered raising this at the Consumer Forum dinner.
    - 4.1.2.8.1. Expectations of the consumers need to be set, e.g. a. drive researchers to posters; b. talk to researcher and PhD students/young researchers (and drive them to Dragons' Den); c. prompts; d. template to fill in impact (HB suggests consumers to initial on the matrix what they will report back on at the Consumer Dinner, and identify who will ask what questions); e. introduce someone to the NCRI stand; f. speak to a non-NCRI consumer and talk about the Consumer; g. ask questions at Q&A.
    - 4.1.2.8.2. Feedback post-conference: survey monkey is to be used as part of the wider conference survey. RS comments that questions need to be specific about activities and events, relating back to the impact matrix.
    - 4.1.2.8.3. **Action:** NSa to circulate questions from last year's survey to the CFSG for input.
    - 4.1.2.8.4. Identifying the completion of feedback by bursary holders and addressing anonymity was addressed: consumers have to complete name and the following will included: "feedback will be kept anonymous and names used only for tracking purposes". Giving feedback is an integral part of the bursary award, and those who do not complete feedback may not be considered for bursaries in future.
- 4.2. Feedback from the July Forum Meeting
  - 4.2.1. Changes were made in light of feedback from March meeting. Comments were favourable and it was recognized that consumers were listened to.
  - 4.2.2. Request for a longer time per agenda item had been acknowledged and the July meeting reflected this approach. Feedback was better.
  - 4.2.3. Consideration was made into cheaper venues, e.g. Friends House (Quaker) or the fire station at Waterloo, or Lift (behind Doubletree). **Action:** NSa to investigate cheaper venues.
5. Key Consumer Meeting
  - 5.1. Toolkit (MB)
    - 5.1.1. NCRI does not have access to a master copy of the toolkit and has recruited a volunteer to reproduce it, in order to have an editable version. The timescale is estimated to be 4-5 days of work and the aim is to complete by end November.
  - 5.2. Website development: NSa gave an overview of the current work, outlining the proposed new architecture and acknowledging the involvement of Jack Towner. The new webpage will be for both NCRI and non-NCRI consumers. Consideration needs to be given regarding how the website can be used as a hook for researchers.

5.3. NCPES (RS)

5.3.1. There is a draft version of a journal paper on the survey, containing links and themes, currently with RS for review. It is an academic paper, which will draw people with interest in specific bits. There are links to improved satisfaction and inequalities in research conversations.

5.3.2. The research question “did you have a conversation about research”, will be included again in NCPES this year.

5.4. New forum-badged work (RS with Michael Maguire): speedier trials benefit. Proposal to give to MRC-CTU will point towards training needs of people.

5.5. Cancer QoLs: work by Roger Wilson on setting criteria; ABPI has expressed an interest in working on this topic. Roger has asked the NCRI for support, and discussions are ongoing as to how, and indeed if, the NCRI can add value to this project.

5.6. Tracking activity (NSa): consumer activities are accounted for by, first, CSG reports and contributions to the meeting, and second, consumers contributing to other areas of work. NSa asks what should we be capturing with our spreadsheet.

5.6.1. It was suggested that activities undertaken by non-CSG consumers could perhaps be collected twice per year.

5.6.1.1. We will wait feedback on HB’s matrix and then see how to tweak the CSG activities report.

5.7. External events: NHS Expo event was attended by VM, where consumer involvement was presented. People wanted to know what impact there is and how to move research trials forward. These themes link with the work we already have in hand and suggest that there is a leadership/innovation role for the NCRI Consumer Forum at national level.

5.8. RS’ statement, to be given on behalf of the NCRI Consumer Forum, addressed the need for better quality research (Taskforce recommendation 52), and requires the endorsement of the Consumer Forum. He will send his statement to them, to garner whether they agree to it. PR and the CFSG members recommended shortening the statement. **Action:** RS will revise and send to the CFSG for input prior to circulation.

## Actions

No.	Minutes and Action	Owner	Deadline/ Progress
<i>Outstanding Actions</i>			
1	Theory of change principle: SG to be available to Susan Kohlhaas to consult over the consumer position for the NCRI strategy on Theory of Change.	SG	To revisit early 2017
3	Clearer guidelines are needed on what consumers should be doing on CSGs, with input from CSG Chairs. HB and MB are to liaise and look into identifying guidelines.	HB and MB	
4	VM to bring as agenda item at CSG Chairs Meeting: how to gauge insight into how they are ensuring consumer input.	VM	CSG Chairs Mtg
5	Collate contacts from earlier recruitment rounds to put together as part of a larger 'contacts' spreadsheet. Need to build up and look into when/how to use this.	NSa	Ongoing
7	SG to share details of the Shared Learning Group with Consumer Forum Steering Group. In addition, SG to send terms of reference to CFSG. Agenda item for next meeting.	SG	Next meeting
8	Annual Survey needs a name. All to come to up with suggestions. RS suggestion: Triangulation Survey, because it is looking at Involvement on CSGs from three points (Chair, Consumer and Mentor).	All	
<i>Current Actions</i>			
2.1.5	HB will work with PR to gather volunteers to help in discussions with David Cameron, on a consumer led initiative to pull together a PPI strategy for Scotland. HB hoping to meet with PR this month to progress.	HB/PR	In progress
2.2.1	NS to report back on how Wales Cancer Bank is linked to CMPath.	NS	Next meeting
2.4.1	NK/NSa to share CFSG meeting minutes with Karen Inns (NIHR).	NK/NSa	Ongoing
2.5.1	MG to send NI Consumer Forum's monthly update to RS, NK and SG in future.	MG	Ongoing
2.6.5	MG to investigate the Joint Researchers Workshop's report on the use of 'plain English'.	MG	
3.2.1	NSa/NK to review and circulate ToR to CFSG.	NSa/NK	
3.3.3	NK to contact NCRAS regarding venue options.	NK	
3.4.2	HB needs collective input on the following items for the impact proposal: a. CFSG review and sign off document (2 week deadline); b. NK and RS is to look at the appendix and review together, to see what should be included, and PR to provide thorough review; c. NK, RS and HB to have face-2-face meeting. NK to send date.	All	
3.4.3	HB to present the final Impact report at the Spring 2017 meeting. To present at meeting.	HB	Spring 2017
3.10	NK and NSa to discuss plan and timetable for the recruitment of a new CFSG member.	NK and NSa	
4.2.3	NSa to investigate cheaper venues for the Consumer Forum meeting	NSa	Prior to Spring meeting planning