

# NCRI Consumer Forum Steering Group Meeting

Room 2.22 Angel Building, 407 St John Street, London EC1V 4AD

Thursday 12<sup>th</sup> January, 2017; 10.45 – 14.30

Followed by Key Consumers' meeting; 14.45 – 16:00.

Attendees: Helen Bulbeck (HB) - Consumer Forum  
Matthew Baker (MB) - Consumer Forum  
Margaret Grayson (MG) - Northern Ireland  
Stuart Griffiths (SG) - NCRI Partners  
Ian Lewis (IL) - NCRI Head of Clinical Research Groups  
Vee Mapunde (VM) - NCRI Associate Consumer Lead  
Barbara Moore (BM) (TC) - Wales  
Natalie Salhov (NSa) - NCRI Consumer Administrator  
Richard Stephens (RS) - NCRI Consumer Lead; Chair, Consumer Forum

Apologies: Natalie Simon (NS) - Wales  
Karen Inns - NIHR PPI Lead  
John Rouse (JR) - Consumer Conference Rep.  
Peter Rainey (PR) - Scotland

## 1. Welcome

1.1. Minutes of previous meeting approved. **Action:** NSa to publish on website.

### 1.2. Actions update

- 1.2.1. Previous action "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." **Action:** HB to put a piece together, identifying linkages on how the metrics are assessed in recruitment, training and in the role description. This is to be addressed at the next Consumer Forum meeting.
- 1.2.2. Previous action "VM to bring as agenda item at CSG Chairs Meeting: how to gauge insight into how they are ensuring consumer input." CSG Chairs suggested that new Mentoring and Annual report processes ensure that there are areas for ensuring patient involvement and how to use consumers effectively.
- 1.2.3. Previous action: "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." **Action:** NSa to request explicit consent from the Consumer Forum, to share contact details. This will also be introduced at the Consumer Induction. **Action:** Collating non-NCRI patients contact details on Sales Force will be considered.
- 1.2.4. Previous action: "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." **Action:** IL is to speak to SG as to whether the NCRI joins the Shared Learning Group. (BM considered that this membership is more appropriately suited for the NIHR, rather than the NCRI.)
- 1.2.5. Previous action: "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)." The holding name is "Triangulation Survey".
- 1.2.6. Previous action: "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." This work is on hold pending PR's resumption of full activity.

- 1.2.7. Previous action: “NS to report back on how Wales Cancer Bank is linked to CMPATH”. Action: BM is not aware of this and will see if there are links with the Wales Cancer Bank.
  - 1.2.8. Previous action: “NSa/NK to review and circulate ToR to CFSG.” In May, the ToR will be reviewed to ensure they reflect the new NCRI Strategy.  
**Action:** NSa to send ToR of Consumer Forum Steering Group and Consumer Forum to the Steering Group
  - 1.2.9. **Action:** NSa to visit LIFT, in order for it to be considered for Consumer Forum meetings.
2. Nation Updates
- 2.1. Wales update – BM spoke to a previously circulated written report
    - 2.1.1.
    - 2.1.2. A need has been identified to clarify how patient research partners report back on their impact.
    - 2.1.3. Wales Cancer Bank: Action: BM will see if it possible for consumers to deliver training. Action: MG to consult with Northern Ireland’s bank to see if they deliver a similar type of training to volunteers on informed consent, and if they can share their current practice.
  - 2.2. NI update – MG spoke to a previously circulated written report
    - 2.2.1. **Action:** MG to send the Control of Data Processing Bill link to IL, to see if it is relevant for Rupesh’s data work.
  - 2.3. Scotland update: no written report received; PR had sent apologies
    - 2.3.1.
    - 2.3.2. HB attended the Scottish Clinical Trials Conference, hosted by Cancer Clinical Trials Unit, Scotland (CaCTUS), in November, 2016, Edinburgh.  
Action: HB is to send out a document on this attendance.
  - 2.4. NIHR update – KI had sent a written update, which had been circulated
    - 2.4.1. Regular meetings between KI, IL and RS are being arranged.
    - 2.4.2. NIHR reporting is to feed into the NCRI Consumer impact metrics (see 3.1).
    - 2.4.3. VM identified current medical technology initiatives currently run by the NIHR, which are looking into how PPI is involved in the development of technology.
3. Impact and Value Added
- 3.1. NIHR Metrics (IL): It was highlighted that the NIHR funds NCRI consumer activities (a 3-year agreement, which runs up until April 2018). As part of this agreement, the NCRI is to report on specific areas of PPI activity. This reporting is done in 2 ways: what we are currently doing and what we will be doing.
  - 3.2. NCRI Metrics (HB): the metrics were developed from the impact activities at the Consumer Forum NCRI Conference welcome dinner. RS aligned the responses with the NIHR objectives, combining the NCRI and NIHR metrics.
    - 3.2.1. Data collection was considered. IL suggested the possibility to introduce online diaries (Google docs) as a measure to report back on meetings.  
Action: RS to ensure metrics tables show who collects data (and/or how).It was noted that the NIHR metrics capture activity not impact. However that gives the opportunity to NCRI to define “impact”. RS suggested that in the NCRI context, “value-added” is a better description than “impact” both for consumers and for funders. This was agreed.
    - 3.2.2. SG highlighted that a measure of impact/added value could be to gauge if there is more recruitment to trials when there is consumer involvement. RS agreed but suggested that at this stage, the process of recording impact or capturing value has to be manageable and as undemanding on resources as possible. Nevertheless part of the process of developing metrics has to be the identification and sharing of good practice.
4. NCRI Conference and Consumer Involvement

- 4.1. Bursaries (NSa): clarity is required over subsistence and what the bursary covers. Involvement with the Conference Team, leading up to the next Conference, would help in fine-tuning administration of bursaries.
  - 4.1.1. Bursary allocation should include a selection process. Ideas for the bursary application include: a question on the consumers' level of engagement over the last 12 months and what this looks like; and, asking the CSG Chair for a reference on their consumers' activity in the group.
 

Action: RS to ask Forum members how they would decide priorities.
- 4.2. Feedback from Bursary Holders on Conference (NSa)
  - 4.2.1. **Action:** NSa to send HB conference feedback for impact reporting.
  - 4.2.2. **Action:** NSa to publish NCRI Consumer Bursary Feedback Report on the NCRI website.
- 4.3. Update on 2017 Conference (RS in the absence of JR)
  - 4.3.1. 2017 programme is nearly finished and we need to see where consumer involvement can be brought in as a joint session. Ideas already proposed by RS to Conference Committee include: a workshop co-produced by consumers and researchers on "How to do involvement" for new researchers; to showcase sessions, Dragons' Den. A workshop on grantsmanship and the influence of consumer involvement in trial design had also been suggested.
    - 4.3.2. Action: RS to liaise with Conference (Exec) team.
    - 4.3.3. HB suggested asking the Consumer Forum to see who has had involvement in submission of an idea for the 2017 Conference. Action: RS to raise with Consumer Forum via jiscmail.
5. Recruitment and Roles of CSG Consumers
  - 5.1. Outcomes from Autumn (NSa)
    - 5.1.1. The outcome of the winter recruitment round for consumer members to CSGs was detailed. There is a concern around the limited amount of applications/interest garnered in response to the advertisement. RS identified the grounds for rejecting candidates, mostly (a) those who do not mention 'research' in their written application, and (b) at interview, those who show no grasp of what CSGs do.
    - 5.1.2. SG suggested he would discuss with relevant partners over whom to contact. Other suggestions included: an approach by the NCRI; consideration around the language of the advert; bringing together different groups prior to advertisement and engaging with them, and having current members support this engagement. Extending from this approach for positive action included the possibility for an open day and having NCRI 'ambassadors' visit local group events, to speak on behalf of the NCRI and circulate information (slides, fliers). Action: VM and NSa to complete the SOP to improve the recruitment process. It was noted that the ToR and information will need to show a commitment to the NIHR's PRAI.
  - 5.2. Training (NSa)
    - 5.2.1. Feedback on the previous Consumer training event was presented, and the overall response was positive. RS suggested for KI (NIHR) to present at the training event and AQaction: RS to contact KI for NIHR CRN input to training.
    - 5.2.2. There are currently spaces on the upcoming training in March. Action: IL to consider how these might be used. (RS suggested offering to CRUK, ICPV, NIHR PRAI)
  - 5.3. Toolkit (MB): The volunteer working for NCRI Exce last autumn had produced a working PowerPoint document of the Toolkit, but future development of the document should be on Word, so that it can be easily updated. Action: MB and NSa to consider next steps and schedule.
6. NCRI Website update

- 6.1. Jack Towner presented the latest update of the patient and public involvement/Consumer Forum page on the NCRI website.
- 6.2. Consumer involvement pages
  - 6.2.1. MB identified that the resources for consumers is a de-contextualized list when taken out of context of the Toolkit. Instead, the resources should be embedded into the Toolkit.
  - 6.2.2. Subdivisions for the content list were considered. Jack will apply subdivisions, taking the categories from the Toolkit.
  - 6.2.3. The naming of the portal was considered, i.e. 'Consumer Forum portal' or 'Public and Patient Involvement' portal, and as to what is engaging with the wider audience. A definition of 'consumer' is required, in order that the non-NCRI patient and public involvement community is to understand the term and engage with the platform. Jack is to put this together.
  - 6.2.4. **Action:** MB is to coordinate feedback on the Website and Portal, following completion of their development.
7. Shared learning group (SG): this was covered earlier in the meeting.
8. Meetings for 2017
  - 8.1. Upcoming CFSG meeting dates were reconfirmed and there was an additional date set for Wednesday 29<sup>th</sup> November. **Action:** NSa to send doodle poll for 2018 dates.
  - 8.2. There is funding for 2 Consumer Forum meetings a year, 1 at conference. Consumers wish a 3<sup>rd</sup> meeting each year, which will need external funding or support in kind (e.g. hosting). This is why February Forum meeting (3<sup>rd</sup> in current financial year) is being hosted by LSHTM and is a shared event. Clarity over NCRI budgets and current spending is needed. **Action:** NSa to add to the CFSG agenda: Budgets and Spending.
9. Key Consumer Meeting:
  - 9.1. Annual ("Triangulation") survey (RS):
    - 9.1.1. The previous survey results indicated gaps in support, which led to the Mentoring report and relaunch. NCRI approves of the survey and the underlying aim of it is to demonstrate impact/value added. However, a lot of work is required and, therefore, requires a budget. Consumer projects require funding.
    - 9.1.2. Questions included in the survey require consideration and should enable year-on-year comparisons.
    - 9.1.3. IL confirmed that for the next survey, NCRI is to collate the data and compile it into table and themes. A consumer should then make recommendations and conclusions of the survey results.
    - 9.1.4. **Action:** IL will consider what the Annual Survey will look at and what it should be like, and to discuss this at the May Consumer Forum Steering Group meeting. The finalised survey will then be circulated in June, with a deadline of July/August. A draft of the survey report will be set a deadline of September, with the aim for reporting back in January.
    - 9.1.5. **Action:** NSa to send IL the previous survey.
  - 9.2. Expenses Policy
    - 9.2.1. Clarity over the Expenses policy is required, so that there are no gaps or loopholes.
    - 9.2.2. There is an upcoming review of the policy and RS would like to know when that is, so that consumer opinions can be included. **Action:** NSa to establish when NCRI Exec is reviewing Expenses Policy.
    - 9.2.3. Timelines for booking travel should be included in the invitation to a meeting (13 weeks prior to event, communication to include "cheap tickets can be purchased 12 weeks in advance). With regards to subsistence before and after meetings, exceptions should be made for some consumers (e.g. if they are undergoing treatment). Saving money should be driving

decisions over mode of transport and accommodation used. Action: IL to send clarifications/good practice/tips as part of NCRI Review process. (NB To/for all claimants, not only consumers)

### 9.3. Operational Matters

#### 9.3.1. Matrix work

9.3.1.1. **Action:** HB to produce a template to reflect the matrix and to share at the Consumer Forum meeting in April.

9.3.1.2. IL confirmed that this can be part of the NCRI strategy in April, as an enabler of the matrix work.

9.3.1.3. **Action:** RS will go through the template reports and apply the matrix.

9.3.2. There is a need to speak to CTRad consumers, so see who needs to go to the conference.

9.3.3. (MB) The toolkit conversion is completed as a power point.

Retrospectively it should have been made into a Word document, but making such changes now would be laborious. Further changes are for a wider task. Currently, it is regarded as a project, and this work should be resourced and for consumers undertake it, so that can be done properly.

**Action:** NSa to circulate the Toolkit.

### Actions

No.	Minutes and Action	Owner	Deadline/Progress
Outstanding Actions			
2.2.1	Report back on how Wales Cancer Bank is linked to CMPath.	IL	End of Day
2.5.1	Send NI Consumer Forum's quarterly update to RS, NK and SG in future.	MG	Ongoing
1.2.1	Identify linkages on how the matrix measures are assessed in recruitment, training and role description.	HB	
Updated actions			
1	Collate list of roles of all consumers.	NSa	Summer
2	HB to pull out top level points to inform bursary allocation.	HB	Before 25/5/17
3	IT solution for information sharing, e.g. Google Classroom	N/A	Future