

NCRI Consumer Forum Steering Group meeting

Room 2.13, Angel Building, 407 St John Street, London, EC1V 4AD
Thursday 24 September 2015 at 10:30–16:00



MINUTES

Attendance: Matthew Baker (MB) Natalie Simon (NS)
Helen Bulbeck (HB) Richard Stephens (RS) (Chair)
Margaret Grayson (MG)
Stuart Griffiths (SG) **Executive:** Nanita Dalal (ND) (from 12:30)
Nicola Keat (NK) Leanne Murphy (LM) (until 12:30)
Yoshiyuki Majima (YM) (*guest*)
Peter Rainey (PR) **Apologies:** Zena Jones (ZJ)

1. Membership:

- 1.1 RS introduced himself as the Chair of the new Group and welcomed all members.
- 1.2 RS welcomed YM from Japan (PCAN) who presented under item 2.
- 1.3 RS advised that this meeting aims to set “where we are, where we are going and how we can get there,” to determine how the steering group can help make NCRI consumers as a group of individuals to become a more professional and cohesive forum.

2. Update from the 4 nations & Japan:

2.1 Scotland – PR

- 2.1.1 Hard to track PPI activity and what relates to the NCRI because of lack of formal/informal structure
- 2.1.2 3 large institutions including 2 ECMCs that are very active
- 2.1.3 PR would like to map NCRI Partners in Scotland (PPI and research specific) – CRUK did a mapping exercise back in 2013-14
- 2.1.4 *Scotland Against Cancer* Conference (Monday 16th November 2015) is a good catalyst to grow a Scottish consumer community

2.2 N. Ireland – MG

- 2.2.1 24 PPI members at different levels and 23 are on the NI Cancer Research Forum, servicing anything relating to cancer (including biobanking and registries)
- 2.2.2 Remit from HRC - no earmarked PPI funding but get support from N. Ireland Cancer Trials Network
- 2.2.3 Quarterly capture of PPI activity produced by the CRUK senior nurse
- 2.2.4 NI CRF members are currently planning a 3 year strategy

2.3 England – RS

- 2.3.1 Roger Steele has confirmed that the NIHR computer system is to record whether a clinician has talked to a patient about research, so NCRI reps will continue to lobby for this question to be included in NCPES
- 2.3.2 Roger Steele will test some questions on patient experience at the NCRI Conference Dragon’s Den
- 2.3.3 Development of Patient Research Ambassadors role in each network in the NIHR (not disease specific or clinical trial focussed) will be discussed at the NCRI Forum meeting at the NCRI Conference. Jenny Preston is the new NIHR lead for this project.

2.4 Wales – NS

- 2.4.1 Reorganised structure – 5 new research centres and 3 research unit
- 2.4.2 Wales Cancer Research Centre (funded by government) – 4 themes for cancer with an implementation plan for strategy. There will be a consumer place on the Board.
- 2.4.3 2 lay members for the 4 themes and an academic lead for the members
- 2.4.4 Public engagement membership team provides training and financial help for people who wish to get involved
- 2.4.5 NHS host KPIs to monitor performance which is funded by government
- 2.4.6 Advise researchers to put a funding request for consumer involvement into their grant applications
- 2.4.7 Involving People Wales and NISCHR are now both part of Health and Care Research Wales.



2.5 Japan – YM

- 2.5.1 Japan has a population of 124million compared with 63million in the UK yet the UK has 3x more clinical trials. What are Japan doing wrong/UK doing right – reason for YM attending
- 2.5.2 PCAN located in LA and lobby senators for cancer research
- 2.5.3 Members involved in many organisations and has links with CRUK, ASCO, NCRI, ACR, NCCN et al
- 2.5.4 Had a 10 year plan of 34 actions but have only achieved half and spent all the money – is funding perhaps not being spent most appropriately?
- 2.5.5 Created USA Recalcitrant Cancer Research Act in 2013– lung and pancreatic cancer were left out
- 2.5.6 Cancer is the #1 cause of death in Japan (1 in 3 die of cancer)
- 2.5.7 Only \$12m spent on pancreatic cancer in 8 years in Japan – small Asian countries spending more
- 2.5.8 Incidence of Pancreatic cancer almost 2x more than USA
- 2.5.9 Takes a very long time for preapproved drugs to start being used in Japan. New bills have brought it down to 3 years but large percentage of pancreatic patients die in first year, must get drugs to patients more quickly
- 2.5.10 Copying European compassionate use system and should come in April 2016
- 2.5.11 No real single organisation dealing with or coordinating cancer research; government, medical community and patients are separate
- 2.5.12 YM advised that he will report back to the government and medical/cancer society in Japan that they need reform and should take note of what is happening in the UK (training, patient involvement, committees, etc.) to take research forward.
- 2.5.13 YM requested various NCRI documents and information. RS will send.

3. **Consumer involvement in NCRI and beyond:**

3.1 Outline of consumer involvement in NCRI activities

- 3.1.1 New Remit for NCRI Consumer Forum and Consumer Forum Steering Group
- 3.1.2 New guiding principle in place and has been well received by the consumers
- 3.1.3 NCRI is very supportive of appropriate patient involvement in all NCRI activities and keen for this not only to continue but to progress, as envisaged by the Review of Consumer Involvement
- 3.1.4 Updated template for CSG consumer report reflects the guiding principle and clarifies expectations
- 3.1.5 HB and RS will attend one meeting of each CSG by the end of 2016 to update members on the role of the NCRI consumer and what is going on in the consumer community, to support the CSG consumers, and to identify and share good practice and good ideas
- 3.1.6 NCRI CFSG will report its activities to the Partners at the January partners meeting
- 3.1.7 It was agreed that the devolved nation representatives will ask their host organisations to set up formal processes for reporting back outcomes of the CFSG meetings

3.2 Mentoring project

- 3.2.1 Consumer Mentoring Survey circulated by SPADE in February 2015
- 3.2.2 Feb-April - NCRI survey to CSG Chairs & scientific mentors of the consumer members
- 3.2.3 Key points from both surveys:
 - 32% of consumers advised that they did not have a scientific mentor – higher than expected
 - Scientific mentors being used for a variety of different activities – work to be done to make sure mentors are well informed to give the help needed
 - No measure of how effective a scientific mentor is – something to consider
 - Little consumer buddying – experienced consumers should be helping new consumers
 - Clear theme; consumers & mentors all wanting guidelines of what is expected of them
- 3.2.4 HB volunteered to provide guidelines/documentation to take this forward. RS suggested that the project needs to move forward quickly, as another group of new consumers has recently been trained, and we recruit again in early 2016.

3.3 CSG annual reports and CSG Chairs' Forum

- 3.3.1 NK explained the annual report process and advised that the review panel included 3 consumers
- 3.3.2 Key points:
 - Proposal to merge the Bladder and Renal CSG
 - Haem Onc CSG good recruitment (40% patients are in trials) – model of each subgroup having a pragmatic trial in their portfolio



- Survivorship key theme in several CSGs – NCRI to start exploratory work into defining and exploring survivorship
- 3.3.3 RS reported back on consumer activity at the CSG Chairs' Forum. He contributes a written report to each meeting as a Standing Item on the Agenda. The group meets twice yearly.
- 3.4 AstraZeneca Panel
- 3.4.1 Consists of 4 distinct panels with their own projects including consumers
 - 3.4.2 AZ global patients charter –ongoing project with the US
 - 3.4.3 AZ is the only pharma company with which Forum consumers work on a close level
 - 3.4.4 AZ also use RS as a consultant in a personal capacity
- 3.5 Relationship between NCRI and NCIN consumers
- 3.5.1 New NCRI consumer administrator in place to start 1st October
 - 3.5.2 NCIN keen to have the NCRI help with recruitment of consumers and this may now work as a shared role across the 2 organisations – discussing funding but looks promising
 - 3.5.3 HB advised that that she is working with the NCIN on a project on how they can be more creative about sharing data as it is currently very researcher driven
 - 3.5.4 RS advised that over half of NCIN's consumers come from the NCRI Consumer Forum – already sharing expertise and obtaining extra value for Forum's funding, as recommended by the Partners in their adoption of the recommendations of the Consumer Review
4. Consumer representatives on subgroups
- 4.1 Where appropriate it would be good for CSG subgroup membership to include a consumer representative, given that the majority of trial development is initiated from the subgroups.
 - 4.2 Currently there are approx 70 subgroups, of which 16 have consumer representatives at present, most but not all as one of the 10 core NCRI-funded members.
 - 4.3 Consumer representatives on subgroups need to be included as one of the ten core members in order to claim their travel expenses. An honorarium is also then payable, and for this reason increasing the formal consumer involvement on subgroups will be associated with an increase in costs.
 - 4.4 Currently, there is no budget available to support an increase in the number of consumer representatives as core members of subgroups so it will be necessary to consider possible income streams to support this.
 - 4.5 It was emphasised that consumers may still join subgroups if they and the subgroup Chair wish, but the consumers will not be funded by the NCRI unless they are one of the 10 core members.
5. Affiliate members
- 5.1 RS explained that affiliate members are those who are actively involved with NCRI activities. Currently, there is no formal process for appointing affiliate members. Under the Consumer Liaison Group, anyone who was interested in joining as an affiliate member was added to the Group, but they were not necessarily active. Affiliate membership is reviewed after 2 years and there needs to be active involvement in NCRI activities to remain an affiliate member of the Consumer Forum.
 - 5.2 A mechanism to involve affiliate members in NCRI activities and to measure the impact of this, needs to be considered.
 - 5.3 Affiliate members are added to JISCMail and can attend consumer forum meetings, if they are able to fund their travel expenses.
 - 5.4 RS proposed introducing associate membership for 12 months as a “test” prior to setting up a formal process for associate members and doing a survey. Associate membership will be offered to selected candidates who applied to become a CSG consumer representative, but did not pass the interview, and people attending the NCRI Cancer Conference as consumers but not as NCRI Consumers (eg via CRUK or Tenovus).
 - 5.5 SG suggested doing a survey when members join the Consumer Forum as an associate member as well as when they leave.
6. NCRI Cancer Conference
- 6.1 Forum Flyers will include key messages, including brief information on Dragon's Den. Business cards will be available but handed out only to people who are really interested in the work of the Forum.



- 6.2 The documentation provided to the bursary holders at this years' Conference will be similar to previous years but with significant editing. For other people, there will be flyers, adverts, information on Dragon's Den and the Consumer Forum meeting on Monday evening.
- 6.3 The Dragon's Den and Consumer Forum meetings are open events; there are currently no restrictions on the number of people that can attend. This may change going forward.
- 6.4 The format of the Consumer Forum meeting will involve an introduction, a presentation on where the consumer forum sits in the NCRI, then a 1 hour break-out session. The following were suggested as possible topics for breakout session on Monday:
 - o how we measure impact,
 - o the role of the affiliate members
 - o a question from the NIHR, which is yet to be confirmed.
- 6.5 The following activities may take place at the conference for consumers:
 - o A follow up session to one of the Dragon's Den activities on Tuesday or Wednesday
 - o An NCIN event on "donate your data."
- 6.6 There will be a Forum poster at the Conference, the 4th and final poster in the NCPES triptych.

7. Consumer involvement and how to demonstrate impact and value added

7.1 Demonstrating impact

- 7.1.1 HB suggested building a database of clinicians involved with Forum members. RS highlighted that this could be obtained from consumers at the Consumer Forum Dinner on 1 November.
- 7.1.2 It was agreed that at next years' Conference there would be a session/showcase on consumer impact/value. This will involve joint presentations by the researcher and consumer, who would provide examples of consumer involvement/impact. A prize could be given for the best consumer involvement in clinical trials.

7.2 Position statements

- 7.2.1 The Committee supported the idea of position statements. The process is as follows:
 - o Consumer representative volunteers to takes a topic, comes up with a position statement (taking into account the guiding principle), sends/presents it to CFSG for approval and then circulates it to the consumer forum to see if they would support the statement.

7.3 Voice for underrepresented groups

- 7.3.1 RS highlighted that one of the roles of the Consumer Forum is to support the NCRI in encouraging and hearing the voice of underrepresented groups i.e. childhood cancer and ethnic minorities.
- 7.3.2 The "voice" does not necessarily need to be someone who is from one of the underrepresented groups, but someone who is able to speak on behalf of them.
- 7.3.3 Key notes:
 - o Look at the make-up of the CSGs, recruitment to them and the message conveyed about the post, to ensure it targets a diverse population.
 - o Promote the CSGs/Consumer Forum's image, which is diverse and accessible to all groups. This could be achieved via the website and would link with the broader strategy of the NCRI.
 - o Recruiting consumer representatives to the CSGs is challenging as a requirement to join is that they must have experience of being part of an academic /large committee, which rules out a significant population. If consumers are recruited through the subgroup structure, it may help address this issue.
 - o Maybe the affiliate members of the Consumer Forum could be the voices of some of the under-represented groups, subject to suitable training or experience.

8. Additional points to note:

- 8.1 Scottish Trial Unit have got funding to work on a cross-nation collaboration on patient engagement (CACTUS) – 4 day course
- 8.2 The vacancy for the consumer forum steering committee will be discussed at the next meeting.
- 8.3 It was suggested that perhaps a Theory of Change might be developed, tailored to the Forum's specific circumstances, if time and resources allow.
- 8.4 The next meeting will be held on 16 December 2015



ACTIONS:

| <u>ACTION NUMBER</u> | <u>Minute and ACTION POINT</u> | <u>OWNER</u> | <u>BY WHEN</u> |
|----------------------|---|--------------|----------------|
| 1. | 2.1.3 Speak with Sara Osborne re: CRUK PPI mapping | PR | 15/11/15 |
| 2. | 2.1.4 Assess <i>Scotland Against Cancer</i> for PPI opportunities | PR | 16.11.15 |
| 3 | 2.3.1 NCPES to include Research Conversation Question | RS | Completed |
| 4. | 2.3.2 Patient Experience questionnaire to come to Dragon's Den | RS | Completed |
| 5 | 2.3.3 PRA Initiative to come to Forum meeting | RS | Completed |
| 6. | 2.5.13 Send requested documents etc to YM. | RS | Completed |
| 7. | 3.1.5 Plan visits to CSGs during 2016 | RS/HB | 31.12.15 |
| 8. | 3.1.5 Attend CSG meetings. The PPT presentation should include how the Consumer Forum is different from the CLG | RS & HB | End of 2016 |
| 9. | 3.1.5 PPT slides that RS used to present in a previous meeting on what the Consumer Forum does, to be emailed to HB | RS | 27/11/15 |
| 10. | 3.1.7 Put in place a formal process for the devolved nation reps to report back to their host organisations | PR/MG/NS | 27/11/15 |
| 11. | 3.2.4 Mentoring report to be edited and circulated | NK | 31/10/15 |
| 12. | 3.2.4 Guidelines to be set for consumer and mentor relationship and what is expected from them | HB | 27/11/15 |
| 13. | 4.4 A costing model for consumer representation on subgroups to be prepared. | NK | 27/11/15 |
| 14. | 5.3 To speak with new consumer administrator re: the JISCMail guidelines which is to include a section on how to use JISCMail/"Do's and Don'ts | NK | Complete |
| 15. | 5.3 Feedback on JISCMail guidelines to be sent to NK by 8 Oct 2015. | ALL | Complete |
| 16. | 5.3 JISCMail guidelines to be circulated to Consumer Forum when approved. | NK | 27/11/15 |
| 17. | 5.4 The associate membership initiative to be discussed in more detail at next Steering Group meeting | ALL | 27/11/15 |
| 18. | 5.5 Surveys for the affiliate and associate membership to be discussed in more detail at next Steering Group meeting. | ALL | 27/11/15 |
| 19. | 7.1 Ideas on topics for the breakout sessions for the Consumer Forum meeting (at the NCRI Cancer Conference) to be sent to RS | ALL | Complete |
| 20. | 7.1 A speed dating session to be organised for the evening dinner. | HB | Complete |
| 21. | 7.1.1 To formulate a question for the consumer forum dinner at conference re database of clinicians/associates. | MB | 20/10/15 |
| 22. | 7.1.2 NCRI Cancer Conference team to be contacted for a slot on next year's Conference, for the "Consumer Impact" session. | RS | 27/11/15 |
| 23. | 7.1.2 Information on COMPASS to be emailed to committee with regards to the consumer showcase at the 2016 NCRI Conference. | PR | 27/11/15 |
| 24. | 7.1.2 Theory of change principle to be completed by the end of November, if time and resources allow. | SG | 27/11/15 |
| 25. | 7.2.1 The position statement process to be trialled on tissue banking, draft to be circulated to this committee for approval at next meeting. | HB | 27/11/15 |
| 26. | 7.3 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. | RS | 27/11/15 |
| 27. | 8.2 Consumer advert to be sent to SG | NK | Complete |
| 28. | 8.3 Mr John Reeve's work on theory of change to be emailed to SG. | PR | 27/11/15 |

