

Feedback Summary Report

London School of Hygiene and Tropical Medicine Cancer Survival Group and NCRI Consumer Forum Joint Meeting, Monday 13 February, 2017

This is a summary report of the feedback given by NCRI consumer representatives of the London School of Tropical Medicine (LSHTM) Cancer Survival Group and NCRI Consumer Forum joint meeting on Monday 13th February, 2017 at the LSHTM, London. The meeting consisted of 2 parts: the Cancer Survival Group and NCRI Consumer Forum joint meeting, which included the Dragons' Den session and the NCRI Consumer Forum. 45 NCRI consumers attended the meeting, along with 44 Cancer Survival Group and LSHTM representatives. Following the meeting, the NCRI Consumer Forum were requested to complete 2 online feedback surveys: one for the joint meeting, and the second on the Consumer Forum meeting. This report includes feedback on both surveys and responses from 29 consumers for the joint meeting survey and 27 for the Consumer Forum meeting survey (some replies were anonymous).

1. Joint Meeting Feedback

The first survey included questions for feedback on the sessions during the joint meeting, as described in the agenda.

Thinking of your personal development as a consumer in cancer research, how informative did you find each session?

According to the results below, the session with the combined highest score of informative and extremely informative was "Data and cancer epidemiology" presented by Bernard Rachet (21) and then "Successes so far and future plans" presented by Claudia Allemani (20). The Dragons' Den sessions received the highest score for "extremely informative" (13 for each session). The topics that "supplied no new information" was "Questions and comments on the day" by Lynn Faulds Wood (4).

	Topic supplied no new information to me	Topic reinforced existing information	Slightly informative - some new information	Informative - new information and/or new understanding	Extremely informative
Successes so far and future plans (Claudia Allemani)	0	4	5	13	7
Data and cancer epidemiology (Bernard Rachet)	0	4	4	15	6
Where consumers can help re: wider issues (Margaret Grayson)	0	6	9	7	6
Cancer survival statistics: use and mis-use (Michel Coleman)	0	2	3	13	11
Examples of consumers using cancer data (John Reeve)	0	3	10	9	7
Q&A on the morning's learning (Expert Panel)	0	6	6	13	4
Dragons' Den table session	0	4	8	4	13
Dragons' Den plenary feedback session	0	4	6	6	13
Questions and comments on the day (Lynn Faulds Wood)	4	6	6	8	5

Additional comments

This open text box question included following the topics/themes:

- A useful overview of the activities of this group
- Not all sessions demonstrating awareness for the collective knowledge and understanding of the Consumer Forum.

Thinking about all your roles as a consumer in cancer research, but principally as an NCRI Consumer (if appropriate), how useful did you find the sessions?

According to the results below, the session with the combined highest score of extremely useful and useful was “Cancer survival statistics: use and mis-use” presented by Michel Coleman (26).

	Topic not relevant to me	Relevant but not useful	Slightly useful	Useful	Extremely Useful
Successes so far and future plans (Claudia Allemani)	0	2	10	13	3
Data and cancer epidemiology (Bernard Rchet)	0	3	7	12	6
Where consumers can help re: wider issues (Margaret Grayson)	0	4	11	8	4
Cancer survival statistics: use and mis-use (Michel Coleman)	0	1	1	17	9
Examples of consumers using cancer data (John Reeve)	0	1	8	14	5
Q&A on the morning's learning (Expert Panel)	0	4	12	7	4
Dragons' Den table session	1	6	5	6	10
Dragons' Den plenary feedback session	1	4	7	7	9
Questions and comments on the day (Lynn Faulds Wood)	2	8	10	5	3

Additional comments

This open text box question included following the topics/themes:

- An excellent, interesting and informative day
- Very high quality information and good debate
- A good range of topics
- Useful when information is placed into contest
- Handouts with key messages for each session would be useful

What part of the meeting did you find most helpful and why?

This open text box question included the following the comments:

- “Cancer survival statistics: use and mis-use (Michel Coleman) - help me to interpret stats in future
- “Dragons Den - good to see new work being done or proposed
- “I thought the focus on epidemiology was really useful. It is an area that we need to come back to every so often in the Forum as we have done here ...
- “Chatting with colleagues at breaks
- “All sessions were really helpful
- “Positive ideas and constructive suggestions from colleagues

- “The link up between the survival team and the forum was a great idea - very engaging in general
- “Really enjoyable and interesting discussions in Dragons' Den, but perhaps more focus on data and less on individuals' personal stories
- “Data and research. A very important topic, put into context well“

How could we improve the meeting next time?

This open text box question included following the topics/themes:

- The Dragons' Den requires a larger room, the provision of information about the presentations in advance of meeting, and a longer session
- A Q&A session for the Consumer Forum
- More time to view posters
- Cloakroom and space for to sit for lunch
- More space at lunch to sit and talk with others
- Key messages for each speaker

To ensure the meeting ran smoothly, how effective were the following arrangements?

As the results show below, most found the arrangements to ensure the meeting ran smoothly as “very effective”.

	Ineffective	Neither effective nor ineffective	Slightly effective	Very effective	Exceptional
Chairing	0	0	4	17	8
Table hosting for Dragons' Den	2	1	13	9	4
Pre-event communications	0	0	4	18	7

How satisfactory were the following arrangements?

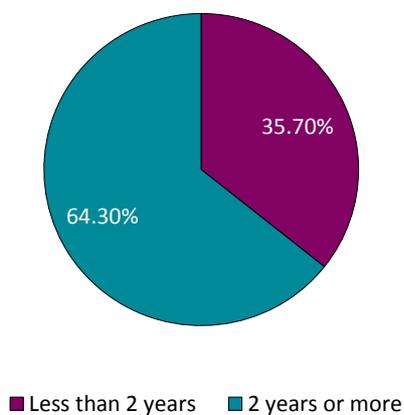
As the results show below, most found the arrangements listed below as “very satisfactory”.

	Unsatisfactory	Neither satisfactory or unsatisfactory	Slightly Satisfactory	Very satisfactory	Exceptional
Event organisation and on-the-day administration	0	1	1	21	6
Venue (building and location)	0	0	2	20	6
Venue (room and comfort)	1	2	9	12	5
Catering	0	1	1	17	9

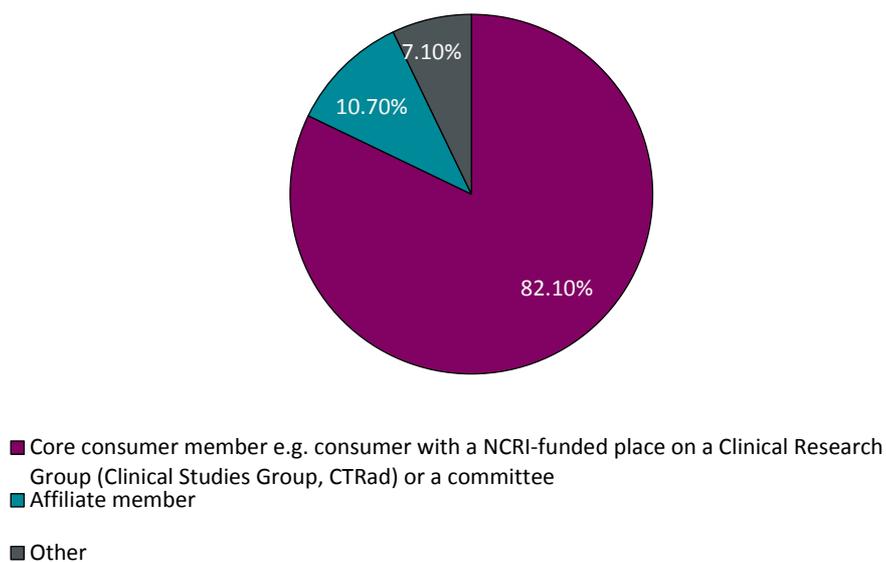
An open text box question included the following topics and themes:

- Main room slightly crowded
- A professionally-run meeting
- An excellent day
- Papers and meeting notes to be available beforehand
- Clearer directions should be given to Dragons' Den presenters
- A more accessible room

How long have you been a consumer member of the NCRI Consumer Forum (previously Consumer Liaison Group)?



Please select your role at the NCRI Consumer Forum Meeting



The 2 respondents that identified themselves as “other” indicated their role as being on the NCRI Consumer Forum Steering Group and a NCRI CSG Subgroup.

2. NCRI Consumer Forum Meeting Feedback

The second survey included questions for feedback on the sessions during the joint meeting, as described in the agenda.

Thinking of your personal development as a consumer in cancer research, how informative did you find each session?

	Topic supplied no new information to me	Topic reinforced existing information	Slightly informative - some new information	Informative - new information and/or new understanding	Extremely informative
Meet the Manager (Ian Lewis)	0	2	9	9	7
NCRI Consumer Conference Update (John Rouse)	5	2	11	8	1
Engagement, Involvement and Under-Represented Groups (Vee Mapunde)	0	6	10	7	4
Barriers Preventing Trials Benefitting Patients (Michael Maguire)	0	0	5	10	11
Input Sought for Article on Prevention in Scotland (Peter Rainey)	5	2	12	3	1

An open text box question included the following topics and themes:

- Michael's presentation was considered well-prepared and well-delivered.
- Variable in quality and content
- Unnecessary content for a meeting presentation

Thinking about all your roles as a consumer in cancer research, but principally as an NCRI Consumer (if appropriate), how useful did you find the sessions?

	Topic not relevant to me	Relevant but not useful	Slightly useful	Useful	Extremely Useful
Meet the Manager (Ian Lewis)	1	1	8	10	7
NCRI Consumer Conference Update (John Rouse)	4	3	12	6	2
Engagement, Involvement and Under-Represented Groups (Vee Mapunde)	4	4	9	7	3
Barriers Preventing Trials Benefitting Patients (Michael Maguire)	0	0	5	11	10
Input Sought for Article on Prevention in Scotland (Peter Rainey)	5	2	11	3	1
Metrics for Consumer Involvement (Richard Stephen)	2	3	1	7	9

An open text box question included the following topics and themes:

- Metrics useful for all attendees
- Good format
- Need for the metrics to be provided
- Provision of a short summary of the key points of each presentation
- Interesting hearing from other consumers
- Provided a better and wider understanding on being an NCRI Consumer
- Sessions were a little rushed due to time constraint.
- Good to meet put faces to names

What part of the meeting did you find most helpful and why?

An open text box question included the following topics and themes:

- Michael Maguire’s presentation was found most helpful by the majority of respondents, including those that considered it very informative, sparking good post-meeting discussion and seeing how it has developed
- Met the manager: there was positive feedback on hearing Ian’s thoughts and what he would like to achieve
- Networking opportunities
- The range of speakers
- Understanding wider NCRI projects within the consumer forum
- NCRI Chair’s summaries and explanations

How could we improve the meeting next time?

An open text box question included the following topics and themes:

- Understanding the role of the Consumer Forum at large and with the strategy
- Time keeping and more time for speakers and networking
- Repeat similar format
- Identify key messages of each session
- Providing papers in advance
- Vision for the future for the Consumer Forum outlined

To ensure the meeting ran smoothly, how effective were the following arrangements?

As the results show below, most found the arrangements listed below as “very effective”.

	Ineffective	Neither effective nor ineffective	Slightly effective	Very effective	Exceptional
Chairing	0	1	4	14	8
Pre-event communications	0	0	7	15	4

An open text box question included the following topics and themes:

- The second part of the meeting seemed rushed and ambitious
- Difficulties in meeting room space
- Venue and arrangements all excellent