

Feedback Summary

Consumer Forum Summer Meeting 2016



This is a summary report of the feedback given by attendees of the NCRI Consumer Forum meeting on Monday 25th July, 2016 at Sadler’s Well, London. 36 consumers attended the meeting and 34 provided feedback to the online survey (some replies were anonymous).

Session Feedback

The first part to the survey included questions for feedback on each session, 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 (see table below), the sessions with combined highest scores of *informative* and *extremely informative* were from Cindy Billingham on *Understanding the Impact of Key Statistical Issues in Cancer Clinical Trials* (29), and Michael Maguire on *Challenges in Clinical Trial Benefitting Patients More Quickly* (25). Other well-scoring sessions were *Introduction to NCRI Strategic Planning - The Environment in Which We Work* from Karen Kennedy, and *NCRI Strategy* from Susan Kohlass, each scoring 24, i.e. 66%.

Five sessions were identified as including *topics (that) supplied no new information*, however each of these sessions were scored by no more than three attendees (i.e. less than 10% of all consumers attending) per session.

Four sessions, which were intended as updates or continuations of existing work - *NIHR Cancer and Nutrition Collaboration* by Lesley Turner, *CPES 2015 – Headlines and Further Research Work* by Carolyn Morris and John Lancaster, and *Adding Value - What Does Our Measuring Stick Look Like?* by Helen Bulbeck, were identified as *reinforcing existing information* and/or *supplying some new information* by 18, 13, 15 and 15 attendees respectively, i.e. between 33% (12) and 50% (18) of all consumers attending.

Session Titles	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
NIHR Cancer and Nutrition Collaboration (Lesley Turner)	1	11	7	11	2
CPES 2015 – Headlines and Further Research Work (Carolyn Morris)	1	5	8	13	6

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CPES 2015 – Headlines and Further Research Work (John Lancaster)	3	6	9	13	2
Improving Clinical Trials For Patients - A Consumer Workshop On Challenges In Cancer Clinical Trials (Michael Maguire)	0	3	6	15	10
Adding Value - What Does Our Measuring Stick Look Like? (Helen Bulbeck)	0	6	9	12	7
Understanding the Impact of Key Statistical Issues in Cancer Clinical Trials (Cindy Billingham)	2	1	2	14	15
Introduction to NCRI Strategic Planning - The Environment in Which We Work (Karen Kennedy)	0	3	7	18	6
NCRI Strategy (Susan Kohlhaas)	1	4	5	19	5

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 (see table below), the sessions with the highest combined scores for being *extremely useful* and *very useful* were from Michael Maguire on *Challenges in Clinical Trial Benefitting Patients More Quickly* (30), Cindy Billingham on *Understanding the Impact of Key Statistical Issues in Cancer Clinical Trials* (29), and Carolyn Morris on *CPES 2015 – Headlines and Further Research Work* (29). These sessions were also the highest scorers for being *extremely useful*. Attendees marked sessions with scores, in general, higher for *usefulness* than for *interesting*.

Two attendees identified a topic as not relevant, both for the topic *NCRI Strategy*.

One of the four sessions intended as an update/ continuation of existing work, as outlined previously, was identified as either *relevant but not useful* or *slightly useful* by around 40% (14) of all attendees, notwithstanding their low scores for being not especially *interesting*.

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Session Titles	Topic not relevant to me	Relevant but not useful	Slightly useful	Useful	Extremely useful
NIHR Cancer and Nutrition Collaboration (Lesley Turner)	0	6	4	16	6
CPES 2015 - Headlines and Further Research Work (Carolyn Morris)	0	1	3	19	10
CPES 2015 - Headlines and Further Research Work (John Lancaster)	0	4	10	13	6
Improving Clinical Trials For Patients - A Consumer Workshop On Challenges In Cancer Clinical Trials (Michael Maguire)	0	0	3	17	13
Adding Value - What Does Our Measuring Stick Look Like? (Helen Bulbeck)	0	4	3	20	7
Understanding the Impact of Key Statistical Issues in Cancer Clinical Trials (Cindy Billingham)	0	3	1	11	19
Introduction to NCRI Strategic Planning - The Environment in Which We Work (Karen Kennedy)	0	1	9	17	7
NCRI Strategy (Susan Kohlhaas)	2	0	7	17	8

Commentary on Sessions

In conclusion, new topics are more likely to score high in terms of interest and usefulness, although topics considered of less interest may still be considered useful. Arguably, there is not a noticeable difference in scores given to a session in terms of the format of delivery, i.e. presentations versus table work. However, in general, table discussions are more likely to be informative, in comparison to presentations (although, this is not necessarily so, in terms of usefulness). *Challenges in Clinical Trial Benefitting Patients More Quickly*, as presented by Michael Maguire, *Understanding the Impact of Key Statistical Issues in Cancer Clinical Trials*, by Professor Cindy Billingham, can be considered the two most successful sessions, whereby they were considered of both interest and usefulness. Both sessions covered new topics incorporating explicit links to the roles of consumers

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on Clinical Studies Groups. These sessions also covered subjects as per requests by Forum members. Both sessions have been considered well planned, prepared and executed.

Sessions for this Consumer Forum meeting received higher scores, particularly with regards to usefulness, than for the previous March meeting, which itself was scored very positively. This is supported by the flavour of the comments received (below).

Any further comments on the sessions?

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

- Useful day, organised and good use of time
- Still some sessions lacking sufficient content
- The NCRI strategy session and the opportunity to feed that input is valued
- Compared to the March meeting, there was more time and fewer expert veterans
- More time and information on certain workshops and sessions
- Good mix of information, workshops and learning
- Good interactions
- Enthusiastic speakers

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

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

- Statistics presentation: informative, well explained, fascinating, enables an understanding of the decisions behind trials and well presented
- NCRI strategy presentation: allows consideration for the future role of the consumer forum; encourages ideas of how consumer involvement can be valuable in helping NCRI meets its aims; and important to know
- Group work on tables and networking opportunities
- Clinical trials workshop: useful and relevant to consumer role; interesting

How could we improve the meeting next time?

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

- Larger venue with better ventilation/heat control
- More time for learning opportunities and specific projects
- Suggestion for a Dragon's Den session
- Presentation on understanding the future of the Consumer Forum
- Clearer signing in at registration, clearer roles for table hosts
- Better time keeping amongst presenters
- Use of microphone
- Report from the Consumer Forum Steering Group
- Introduction from Associate Consumer Lead.
- More presentations and less workshops
- Move people around for each workshop

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Meeting Arrangements

The second part to the survey sort feedback on the arrangements of the meeting.

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

According to the results (see table below), most attendees considered the arrangements of the meeting as “Very effective”

Arrangements	Ineffective	Neither effective nor ineffective	Slightly effective	Very effective	Exceptional
Chairing	0	0	1	22	11
Table hosting	0	2	6	23	1
Meeting paper work	0	0	5	27	1
Pre-event communications	0	0	3	27	4

How satisfactory were the following arrangements?

According to the results (see table below), most attendees considered the arrangements of the meeting as “Very satisfactory”.

Arrangements	Unsatisfactory	Neither satisfactory or unsatisfactory	Slightly Satisfactory	Very satisfactory	Exceptional
Event organisation and on-the-day administration	2	2	1	23	5
Venue (building and location)	2	2	4	23	3
Venue (room and comfort)	6	4	10	14	0
Catering	5	1	6	19	3

Any further comments, questions, or concerns regarding arrangements?

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

- Temperature of room and need for air-conditioning
- Variety at lunch
- Circulating the seating plan

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- Biscuits in the morning
- Venue closer to the station and food on same floor

Consumer Membership

The final part of the survey sort to identify the type of memberships of the respondents.

Please select your role at the NCRI Consumer Forum Meeting

According to the results (see tables below), most attendees identified themselves as “Core Consumers”.

	Response Percent	Response Count
Core consumer member e.g. consumer with a NCRI-funded place on a Clinical Research Group (Clinical Studies Group, CTRad) or a committee	79.4%	27
Affiliate member	20.6%	7
Non-NCRI participation (please specify)	0.0%	0

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

According to the results (see table below), most attendees identified themselves as having been a consumer member of the Consumer Forum for 2 years or more.

	Response Percent	Response Count
Less than 2 years	29.4%	10
2 years or more	70.6%	24
Not an NCRI Consumer (see question 9)	0.0%	0