

This is a summary report of the feedback given by attendees of the NCRI Consumer Forum meeting on March 22, 2016 at, Sadlers Well, London. 47 consumers attended the meeting and 35 provided feedback to the online survey.

#### **Session Feedback**

The first part to the survey included questions for feedback on each session, as described in the agenda.

#### How Informative did you find each session?

According to the results (see table below), most attendees identified the sessions, "Workshop: Research Issues in Children's Cancers", as by hosted Chris Copland and Danielle Horton Taylor, (12 responses) and "Chairing, Q&A sessions, explanations etc., as hosted by Richard Stephens, (11 responses) as "extremely informative". Most attendees identified the sessions, "Update on conference" (10 responses) and AstraZeneca and a pilot of a new app" (7 responses) as "Topic supplied no new information to me".

	Response				
Session Title	Topic supplied no new information to me	Topic reinforced existing information	Slightly informative - some new information	Informative - new information /understan ding	Extremely informative
Just A Minute! Introductions on tables, icebreakers	1	2	12	10	8
New Consumer Lead and future plans (Nicola Keat)	1	1	8	17	3
Update on conference (John Rouse)	10	3	10	7	1
Update on mentoring (Helen Bulbeck)	1	7	14	8	3
Workshop: Research Issues in Children's Cancers (Chris Copland and Danielle Horton Taylor)	0	4	4	12	12



NIHR Cancer and Nutrition Collaboration (Elspeth Banks)	1	1	7	16	5
AstraZeneca and a pilot of a new app (Karen Murphy, AZ)	7	18	7	0	0
Setting Up A Local Research Group (Paul Charlton)	2	0	11	12	7
Supporting NIHR: Patient Research Ambassadors (Karen Inns, NIHR CRN)	1	5	7	13	4
Supporting NIHR: MOOC (Karen Inns, NIHR CRN)	0	5	8	16	3
Supporting NIHR: Join Dementia Research Project (Andrew Rutherford, NIHR CRN)	2	2	11	11	5
Macmillan HORIZONS programme (Lynn Calman, Macmillan)	0	0	10	18	5
How Do We Measure Our Own Impact and Value? (Helen Bulbeck)	0	3	8	15	3
Chairing, Q&A sessions, explanations etc. (Richard Stephens)	0	0	7	12	11

#### How Useful did you find each session?

According to the results (see table below), most attendees identified the session "Chairing, Q&A sessions, explanations etc.", as hosted by Richard Stephens, (14 responses), as "extremely useful".

	Response				
Session Title	Topic not relevant to me	Relevant but not useful	Slightly useful	Useful	Extremely useful
Just A Minute! Introductions on tables, icebreakers	0	2	6	19	6
New Consumer Lead and future plans (Nicola Keat)	0	2	5	18	7
Update on conference (John Rouse)	1	8	9	12	1



Update on mentoring (Helen Bulbeck)	0	2	14	13	3
Workshop: Research Issues in Children's Cancers (Chris Copland and Danielle Horton Taylor)	1	3	4	16	8
NIHR Cancer and Nutrition Collaboration (Elspeth Banks)	0	2	5	15	8
AstraZeneca and a pilot of a new app (Karen Murphy, AZ)	1	1	10	15	4
Setting Up A Local Research Group (Paul Charlton)	1	1	10	15	4
Supporting NIHR: Patient Research Ambassadors (Karen Inns, NIHR CRN)	0	1	17	12	1
Supporting NIHR: MOOC (Karen Inns, NIHR CRN)	0	4	9	17	1
Supporting NIHR: Join Dementia Research Project (Andrew Rutherford, NIHR CRN)	3	3	14	7	4
Macmillan HORIZONS programme (Lynn Calman, Macmillan)	0	0	13	14	4
How Do We Measure Our Own Impact and Value? (Helen Bulbeck)	0	0	12	14	5
Chairing, Q&A sessions, explanations etc. (Richard Stephens)	0	0	5	12	14

#### Any further comments on the sessions?

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

- Relevancy of topics to the Consumer Forum
- Seating of consumers from various CSGs, in order to share knowledge and encourage networking
- Announcement of the appointments of the Consumer Lead and Associate Consumer Lead requiring greater thought, including a clearer presentation on their roles and responsibilities
- Agenda too long/ambitious and too much information presented.



 More agenda items, which are relevant to the Consumer Forum, such as "How Do We Measure Our Own Impact and Value?" session

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

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

- Networking amongst consumers
- More sessions in line with "How Do We Measure Our Own Impact and Value?" and Research Issues in Children's Cancers" sessions, which were popular
- Richard's presentations were considered clear and concise

#### How could we improve the meeting next time?

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

- Length of presentations
- Forward planning of NCRI Consumer activities
- Transparency around the NCRI Board
- Too many Power Point presentations
- More time on bigger and relevant topics
- Greater interaction
- More time to network
- Pace of meeting
- Up-to-date information

#### **Meeting Arrangements**

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

#### How satisfactory were the following arrangements?

According to the results (see table below), most attendees considered the arrangements of the meeting as "very satisfactory".



	Response					
Arrangement	Unsatisfactory	Satisfactory	Very Satisfactory	Exceptional		
Pre-event organisation and administration	1	5	25	2		
Venue (building and location)	0	8	21	3		
Venue (room and comfort)	0	11	19	3		
Catering	1	12	15	0		

#### Any further comments, questions, or concerns regarding arrangements?

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

- Longer breaks
- · Lunch and breaks on same floor as meeting
- More variety around catering

#### **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".

Core consumer member e.g. consumer with a NCRI-funded place on a Clinical Research	31
Group (Clinical Studies Group, CTRad, sub-group) or a committee	
Affiliate member	4

The feedback does not account for non-NCRI participants, given there were no responses to "Non-NCRI participation".



### 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 more than 21 years.

2 years or more	21
Less than 2 years	14