

Report on the 2016 NCRI Cancer Conference Consumer Feedback

1. Background

Following the 2016 NCRI Cancer Conference, all attendees of the conference were invited to provide feedback on the conference, via its online survey. Patient/carer attendance at the conference included NCRI consumer members and non-NCRI patients and carers. This attendance is indicated by 33 respondents who classified themselves as working in 'consumer involvement'. 27 respondents classified themselves as a 'consumer representative' and 6 as a 'patient/carer'. 25 respondents classified themselves as core members of the NCRI Consumer Forum, which includes consumers sitting on NCRI Clinical Research Groups (CRGs). 5 classified themselves as affiliate members of the Consumer Forum, 2 as 'associate members of the NCRI Consumer Forum (e.g. Former CSG member)', and 7 as "other Consumer member (e.g. NIHR, CRUK, NCIN, Tenovus Cancer Care)".

The NCRI offered 40 bursaries to the NCRI Consumer Forum members, of which 38 were allocated and 34 attended. 28 of the 33 respondents attended under an NCRI bursary.

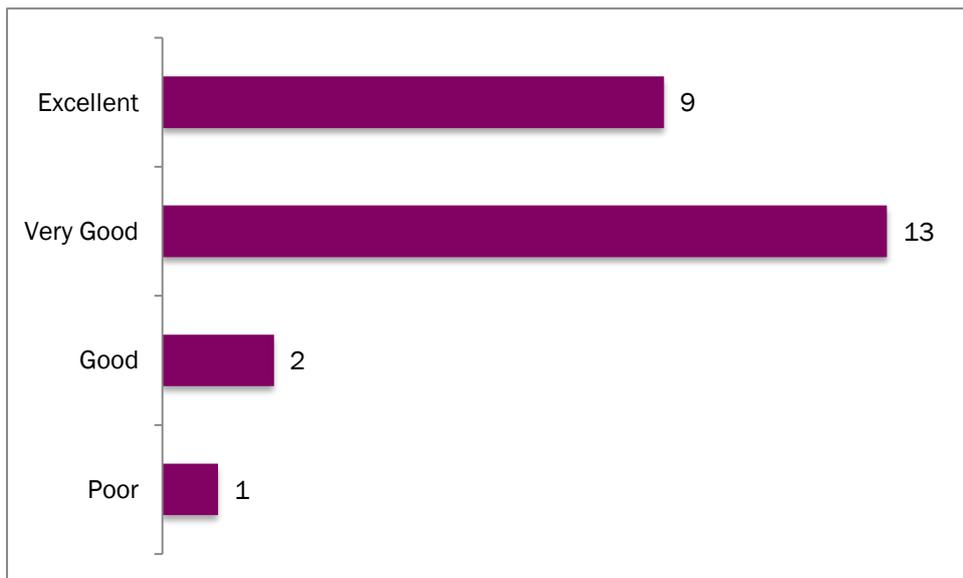
2. This report

This report summarises key consumer feedback data and comments from the post-conference survey, as provided by the NCRI Conference Team. The summary of feedback includes responses from the NCRI Consumer Bursary holders who completed the survey (28)¹. It should be noted that respondents were able to submit their answers without having completed the survey fully. This accounts for any possible variances in the total number of feedback answers summarised in this report.

2.1 Key statistics & comments

¹ Under the terms and conditions of the NCRI Conference Consumer Bursary award, bursary holders were instructed to complete the post-conference online survey.

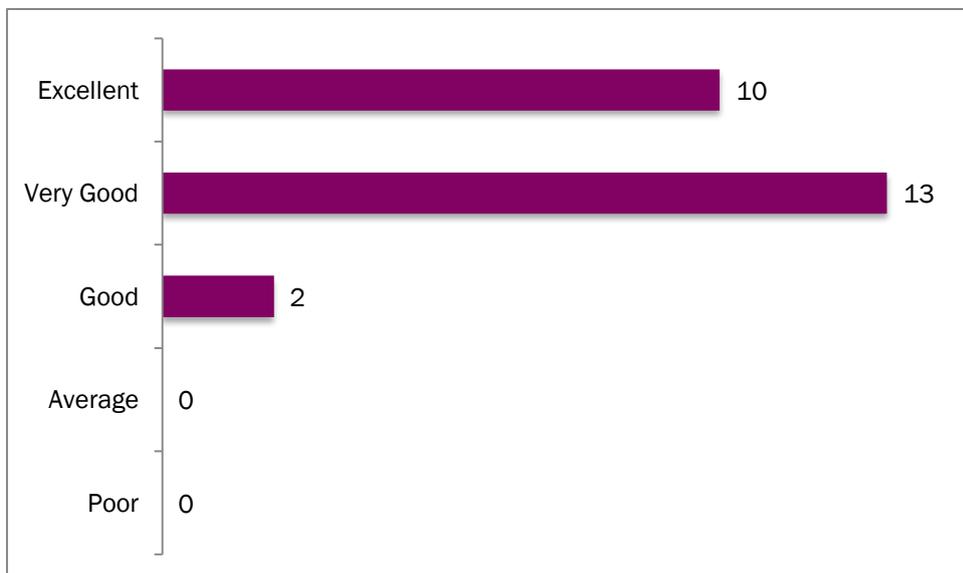
How useful did you find the bursary information pack?



25 out of the 28 NCRI consumer bursary-holder respondents answered this question. 96% of these respondents considered the bursary information pack positively, with 36% answering ‘excellent’, 52% “very good” and 8% “good”.

Respondents were given the opportunity to provide a free-text reply to this question. The replies were largely positive, with the bursary pack provided considered clear and comprehensive, and feedback included that it allowed for preparation for sessions and consumer activities. The respondent replying ‘poor’ was not aware of the bursary pack that had been circulated.

Support at the Conference Was....

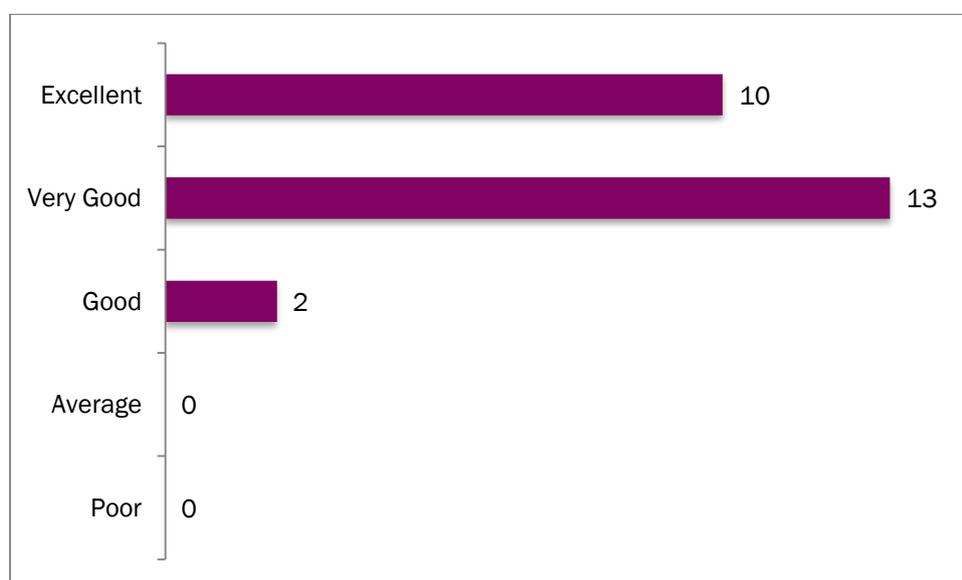


Of the 25 out of the 28 NCRI consumer bursary-holder respondents that answered this question, 92% considered the bursary information pack positively, with 40% answering ‘excellent’, 36% “very good” and 16% “good”.

Respondents were given the opportunity to provide a free-text reply to this question. The replies were positive and recurrent topics/themes included:

- Helpful and available staff
- Reception staff and level of understanding of sessions
- Support from NCRI staff and consumers

How useful did you find the opportunities to meet other bursary holders and gain support from them?



Out of the 25 NCRI consumer bursary-holder respondents that answered this question, 100% responded positively to networking opportunities amongst consumer bursary-holders, with 40% answering ‘excellent’, 84% “very good” and 8% “good”.

Respondents were given the opportunity to provide a free-text reply to this question. The recurrent topic was the appreciation for the consumer events, particularly the Welcome Dinner, as opportunities to network with other consumers.

Did you engage with the Conference, e.g. present a poster, a speaker, provided support to other consumers, attended a workshop, asked questions, etc.?

Respondents were given the opportunity to provide a free-text reply to this question. The recurrent topics were as follows:

- Asked questions
- Attended Dragons' Den
- Attended workshops and sessions
- Networking with delegates and presenters, representing the Consumer Forum
- Supported other consumers
- Linked researchers to potential studies
- Poster presentations
- Communicated with workshop speakers
- Invited delegates to the Consumer Forum meeting

8 out of the 33 respondents did not answer the questions.

What experience/knowledge did you gain from attending the Conference?

Respondents were given the opportunity to provide a free-text reply to this question. Most respondents indicated topics of information they obtained at the conference, which included:

- Current cancer research
- Medical practice, treatments and technologies
- Medical language, terminologies and biomedical sciences
- Clinical Research Group (CRG) membership
- Consumer role
- Socio-economic dynamics of medical care provision
- Quality of life, care and survivorship
- Trends in cancer
- NCRI strategy
- NCRI initiatives
- Clinical trials

Experience gained at the conference included networking.

How will you use this experience/knowledge either for your own benefit or to add value to the work of groups or organisations with whom you have links?

This was a free-text question, with respondents providing details on how they will apply their learning and experience at the conference to their roles within their wider consumer activities. Recurrent topics included:

- Renewed interest
- Transferable learning, applied when reviewing research and providing input on committees
- Share information and opportunities for informed discussions with local and national networks, stakeholders and organisations they are involved in
- Increased involvement, given informed opinions, on CRGs
- Report learned information at CRG meetings
- Appreciate links with pharma and academia
- Inform other patient ambassador initiatives
- Pursue patient-led research and posters for future conferences
- Increased appreciation for patient involvement
- Opportunities to share knowledge with patient and carer groups.

Comments included:

- “Renew my interest in addressing inequalities in cancer outcomes, especially those related to cultural differences. Emphasised [further] the importance of the right quality of life measures and will do what I can to push for this.
- “I have already commenced discussions with various people in organisations with the aim of helping to progress the collaboration of progressing research in to patient care further.
- “I will use the information for myself when reviewing research protocols and sitting on funding panels and executive boards.
- “I always collect information from posters/abstracts and bring it back to the CCG for their cancer steering group, for clinical colleagues in lung cancer and other areas, and also to contribute to other committees to help them keep updated.
- “The experience gained from the conference will help mostly with presenting and responding to data collected as part of the CSG, as well as over the role I have as a consumer to provide advice and guidance over clinical trials, studies, and other work undertaken within the group.”

What do you intend to put into action in your consumer role/s as a result of something that you have learned or an interaction you have had at the Conference? Would you require any support from the NCRI to be able to achieve this action?

This was a free-text question, with respondents providing details on the following intended actions. Recurrent themes in feedback included:

- Greater involvement with CRGs
- Increase opportunities for involvement in research
- Further learning
- Offer support to other consumers
- Attending patient-led group activities
- Efforts to present poster at the next conference
- Replicating consumer activities in other patient groups, e.g. Dragons' Den
- Pursue patient-led research and involvement
- Training opportunities

Support from the NCRI, indicated in the feedback, included the following:

- Obtaining contact details from the NCRI
- For NCRI to appreciate the link for consumer involvement across all initiatives
- Support in research involvement

Have you any comments on how the bursary application process was dealt with?

Feedback concerning the bursary application process was largely positive, with the process being considered, smooth, fair and efficient. Suggestions included the following:

- Possibility to consider if all consumers need to receive funding for all activities, so that there can be an increase in opportunities to support more consumers
- All NCRI Consumers to be offered bursary
- Tick boxes during registration to be clearer
- Available to consumers who have the experience to learn from the sessions

Is there anything else you would like to suggest to help us improve the Conference for bursary holders?

Respondents were given the opportunity to provide a free-text reply to this question. Recurrent themes included:

- Allowing consumers the opportunity to attend the conference networking event, by not holding any activities during that time

- Making the Dragons' Den event more 'mainstream' at the conference
- Combining delegates at conference dinner tables
- Involve consumers in more talks and planning of sessions
- Avoid clashes of sessions involving patients
- Understanding of website and registration
- Q&A session per session
- Refine priorities of the bursary holders
- More seating in the hall space
- More bursaries for non-core consumers
- Consumer Forum stand

2.2 Conference-related key statistics & comments

This section summarises data and feedback obtained from respondents that classified themselves as consumers.

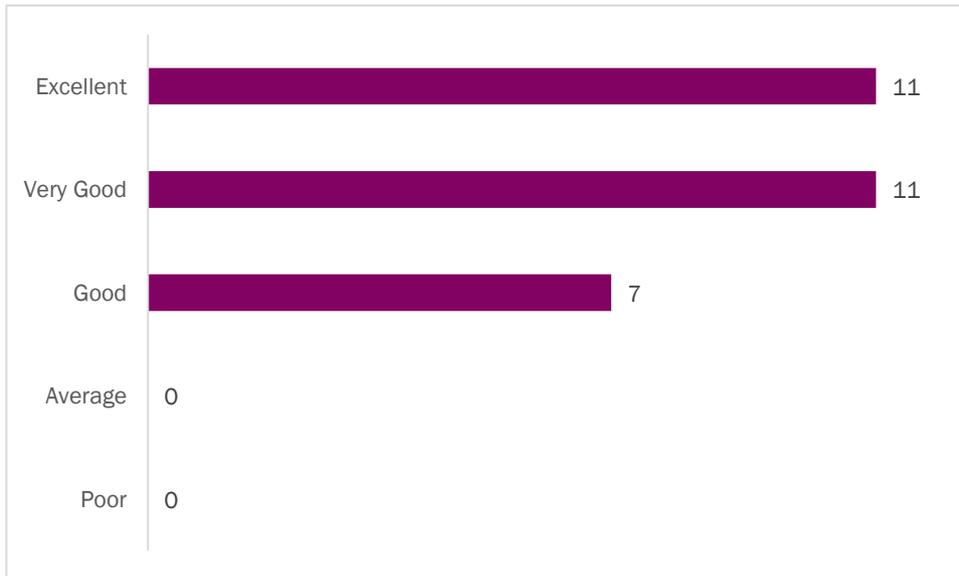
Please rate your overall Conference experience:



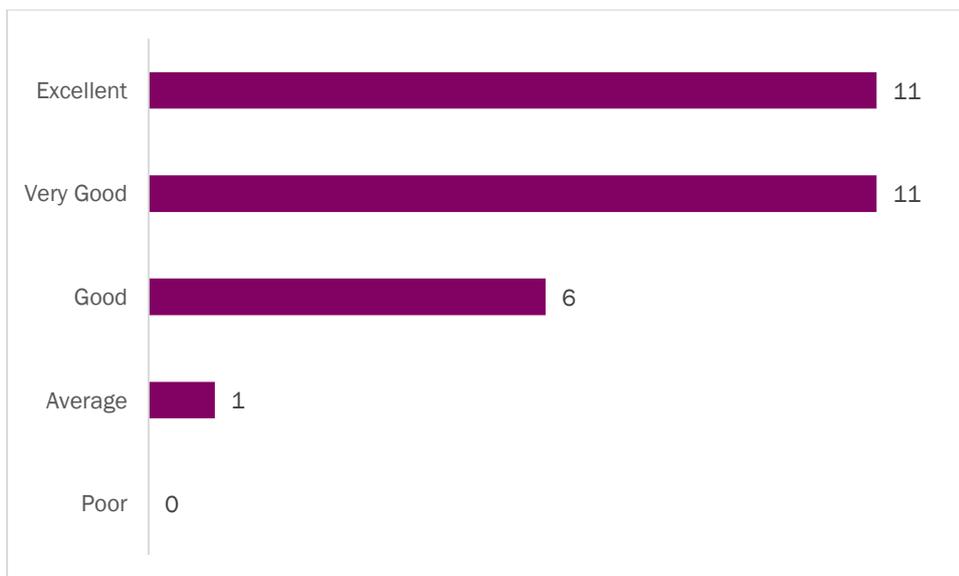
Of the delegates who responded to this question, all (29) respondents had a positive experience at the conference, with 34% responding 'excellent', 34% "very good" and 38% "good".

Further feedback by the respondents on the conference is as follows:

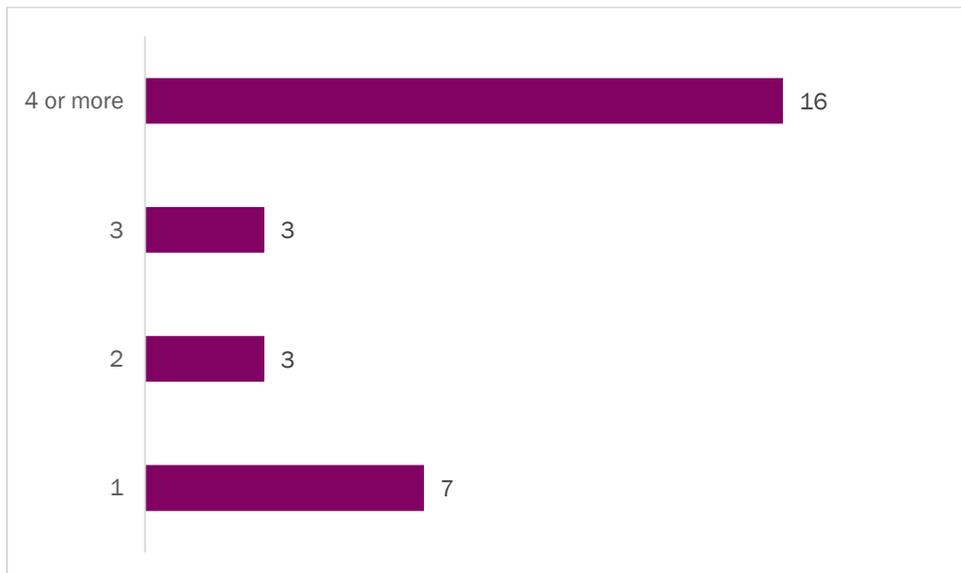
Please rate the Conference in terms of knowledge gained:



Please rate the Conference in terms of networking/contacts gained:



Including this one, how many NCRI Cancer Conferences have you attended?



The NCRI Conference team will be circulating a Feedback Report shortly, which includes further feedback on the Conference at large.

3. Conclusion: Future Consideration for Consumer Involvement at the NCRI Conference

- Extensive learning opportunities
- Opportunities to network amongst other consumers
- Need to allow consumers to conference networking events
- Opportunities to apply learning to consumer roles on CRGs and amongst networks