

Are we making a difference?

Consumer designed surveys of the impact of Involvement on the work of the cancer Clinical Studies Groups
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BACKGROUND

Cancer Clinical Studies Groups (CSGs) were set up in 2001 by the National Cancer Research Institute (NCRI) to develop their own trials and to coordinate the UK's portfolio of cancer studies. From the outset consumer members have served on these groups, alongside researchers, clinicians and other health professionals.

Consumer involvement is embedded in UK cancer research through the Consumer Liaison Group (CLG). This is a national network of cancer patients and carers, and the 42 CSG consumers are the Core Members of the CLG.

NIHR CRN: Cancer has undertaken regular but separate surveys of Consumers and of CSG Chairs and scientific mentors to assess consumer impact in the work of the CSGs.

METHOD

Consumer members were asked to play a lead role in the 2013-14 surveys and were involved in the design, analysis and report writing. They decided to survey simultaneously the CSG Chairs, consumers and scientific mentors, to enable for the first time contrasts and comparisons in a triangulated snapshot.

A range and mix of questions were asked covering the type of involvement, communication methods and frequency of contact between Chairs, consumers and mentors, as well as on impact, support needed, training experienced and skills offered.

RESULTS

Results were compiled into a report to inform the NCRI's Review of Consumer Involvement. Survey responses were grouped into three common themes – Contribution, Support and Impact - to examine different aspects of CSG consumer involvement.

Response rates were 68.6% consumers; 52% Chairs; 42% scientific mentors.

Chairs were asked:

'How often do consumers contribute to CSG work?'
91% responded **'often'** or **'always'** and 9% **'sometimes'**

Consumers were asked:

'How often are you asked to comment on trial papers for funding?'
44% consumers responded **'often'** or **'always'** and 46% **'sometimes'**

Consumers were asked:

whether they were able to provide their view at CSG or subgroup meetings?'
93% replied **'always'** or **'usually'**

62.5% of consumers are involved in subgroups, compared to 50% in 2011, demonstrating a deeper consumer involvement in different aspects of research.

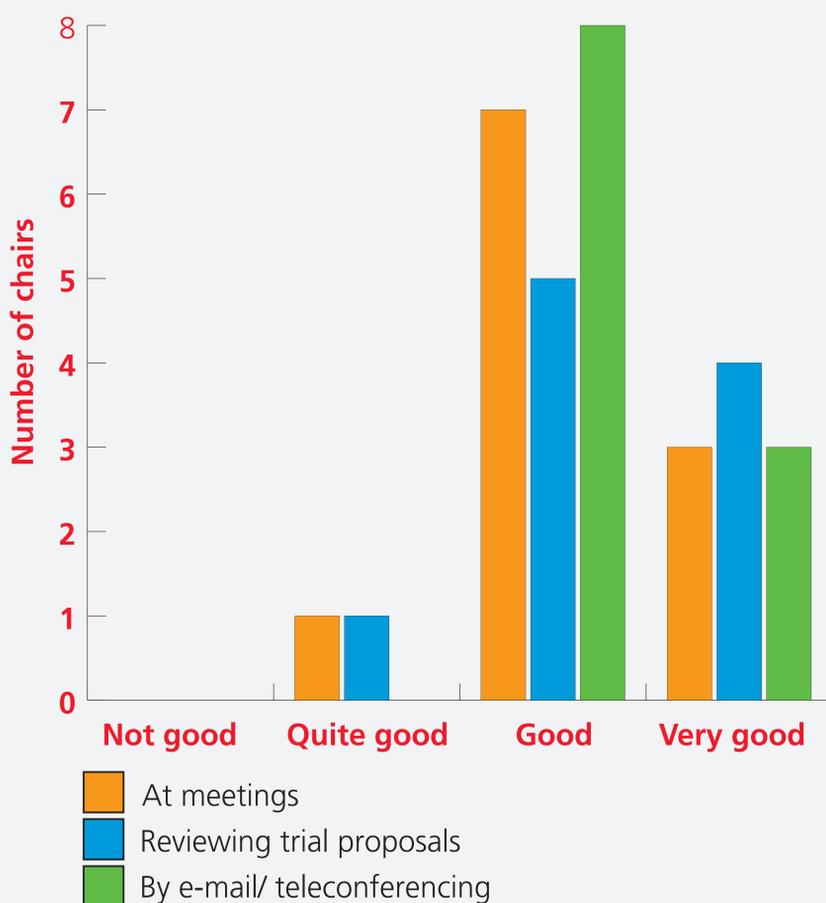
Direct impact examples of consumer impact included:

"Symptom management had not been discussed at the CSG before I raised it. Now we have a very active and successful working party."

Other improvements identified by consumers included:

- The design and implementation of a consumer toolkit
- Tailored induction training for new consumer members – co-designed and delivered with consumers
- A report template for consumers to contribute in a standard format to CSG meetings
- An exit survey to learn from consumers stepping down from their positions at the end of their term.

How would you rate your consumer members' contribution to your CSG's work?



Comments from Chairs and Mentors included:

They are keen to contribute and even when alternative to the main opinion, the contribution is valuable.

Awareness of how the wording of text and talk has an impact on people living with cancer. I have learnt a lot.

Consumers make a valuable contribution to the CSG. I think they are integral to our functioning and make a difference to the development of our research proposals.

CONCLUSION

- The NCRI has a pool of experienced and committed consumers with proven ability to contribute to academic research at a strategic committee level
- Chairs and mentors recognise the increasingly positive impact of consumer involvement in CSG work, as do consumers themselves
- Training and development improve consumer effectiveness, particularly when consumer-designed or led

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References: *Patient and Public Involvement in the NCRI Clinical Studies Groups – A report from three online surveys of consumers, Chairs and scientific mentors.* J. Rawlinson April 2014 (NIHR CRN:Cancer)