

Consumer Report to the NCRI's Sarcoma CSG

Consumer Representative: Michael Maguire

Date of Meeting: 18/12/15

Date of Report: 02/12/15

Consumer members of CSGs are members of the NCRI Consumer Forum, whose purpose is:

To create a professional, focused and committed constituency of consumer research partners for NCRI, who can help NCRI achieve its aims.

The Guiding Principle of Consumer Involvement is that we are:

Working together to build a community with the common purpose of providing patient and public perspectives throughout the research process, to deliver research with better outcomes and experiences for all.

The report below shows the activities of one of the consumer members of this CSG. It aims:

To show the activities of the CSG consumer

To show how these activities have contributed to the work of the CSG

To show how these activities have contributed to the work of the Consumer Forum

1.0 Membership of subgroup/trial groups/committees/forums/support groups:

- Member of Online Carers Support Group.
- NCRI Consumer Forum - Astra Zeneca Patient Panel, including Patient Review Group for the PROACT study (to be published January/February).

2.0 Engagement with CSG activities and members since the last report:

3.0 Major activities since the last report:

- Attended the NCRI Conference in Liverpool in November. Including Consumer Forum meeting and a Forum-NCIN-CRUK Data sharing workshop.
- Also at Conference took part in the successful Dragon's Den 50-hour challenge collaboration to develop patient led applications to enable patients access to their information and to report real-time problems and side-effects when on a clinical trial. (This is a collaboration between The NCRI Consumer Forum, AstraZeneca, and the Christie Hospital.)
- Attended NCIN conference in Belfast in August.
- Assisted in delivering an MRC CTU patient-led plain English training session for academic and clinical researchers and patient reps patients for the Northern Ireland Cancer Forum in Belfast.
- Completed the 4 week online NIRH CRN Introduction to Clinical Studies course, with 7,000 other patients and researchers in the UK.
- Sarcoma UK Talking Research event in June.

- National Sarcoma Survey - Expert Panel in December.

4.0 Forthcoming involvement/events:

- BSG conference in February.
- Consumer Forum meeting in March

5.0 Messages for the CSG:

- How will we or can we utilise the 100,000 genome project, biobanking and NCRI's Cellular Molecular Pathology initiative in our strategy?

6.0 Collaboration, Advice, Views or Support (if any at this time) required from fellow CSG members:

- There will be at least one consumer involvement showcase at the 2016 NCRI conference. Are there any trials that the group has been involved in or that has received funding that has had patient involvement that has added considerable value?
- Please take a look at the results of the Sarcoma Patient experience survey. Especially relating to the potential age related bias in physiotherapy. Please let me know of other areas/opportunities related to CSG that I can get involved in.