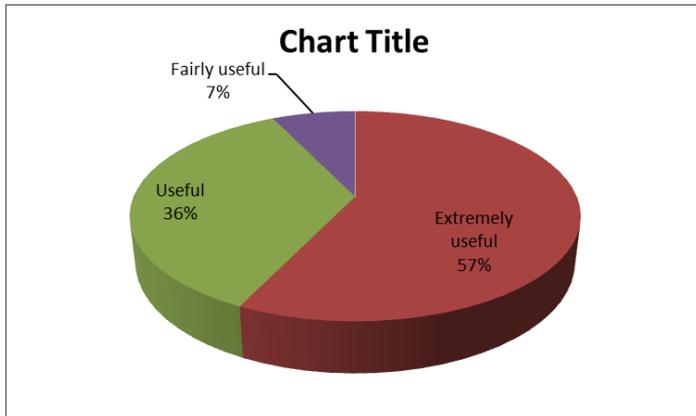


Muscle channelopathy patient information day May 9th 2015

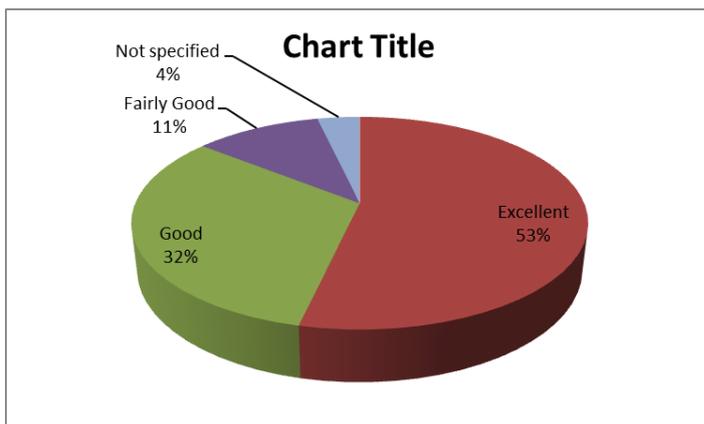
Quantitative evaluation

Question 1: How useful did you find this event?

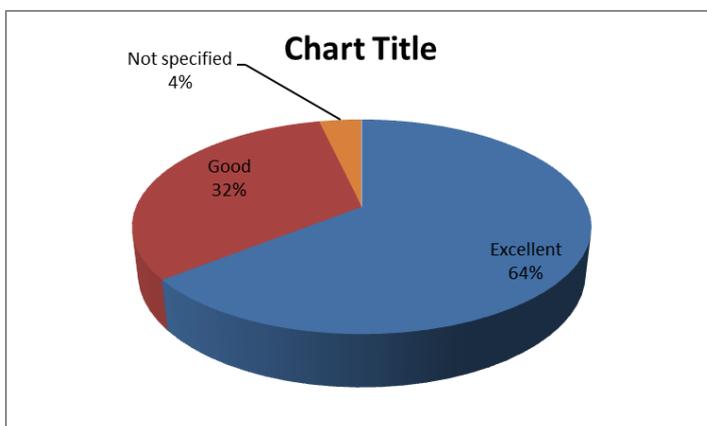


Question 2: What was your overall impression of this event?

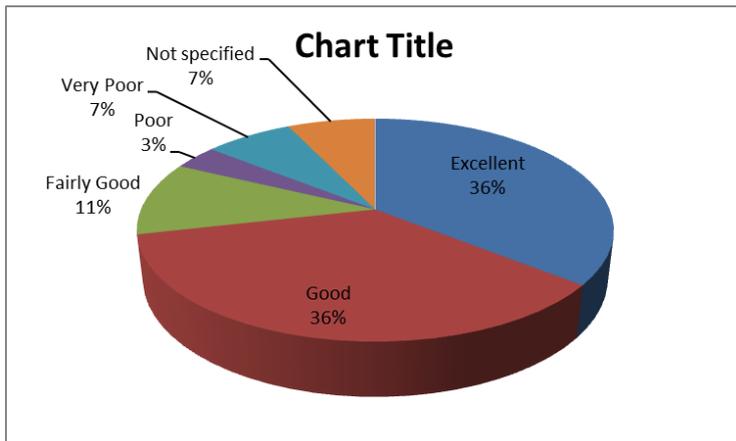
Programme



Organisation

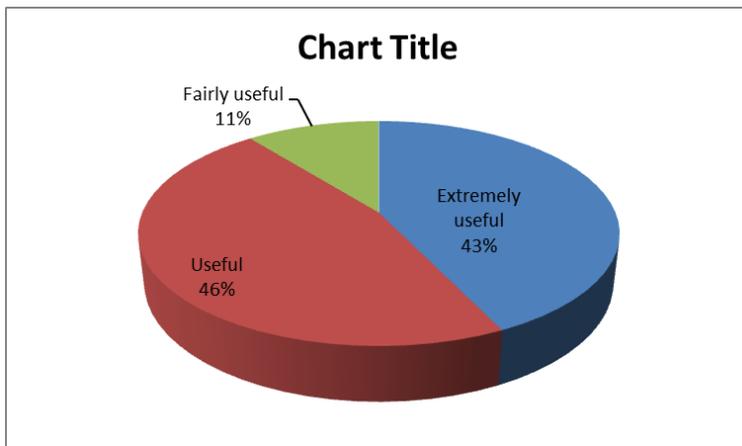


Catering

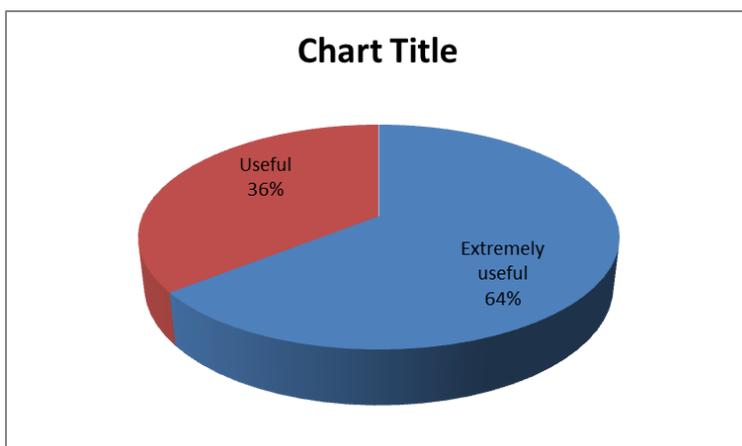


Question 3: How useful to you personally was each session?

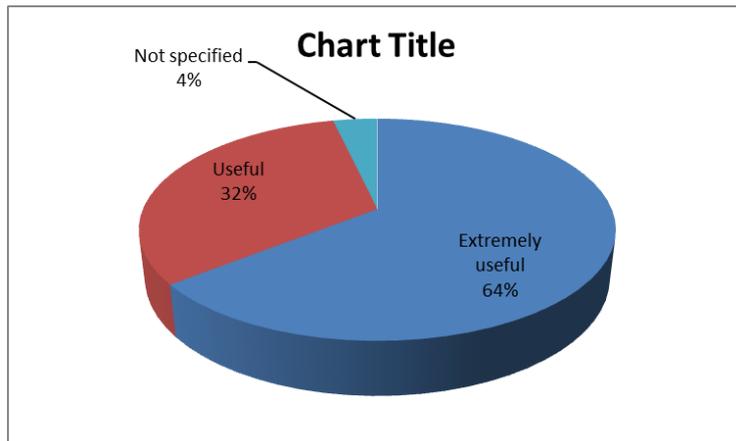
Introduction - Muscle Channelopathies - Professor Mike Hanna



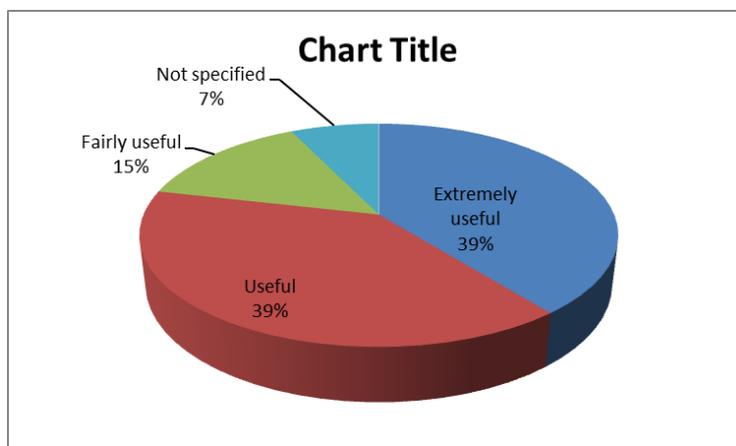
Clinical overview - Dr Emma Matthews



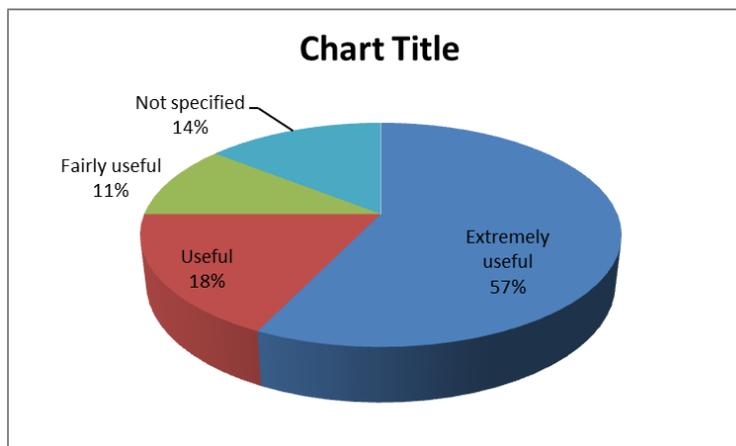
Role of clinical nurse specialist - Natalie James



Research update - Dr Doreen Fialho

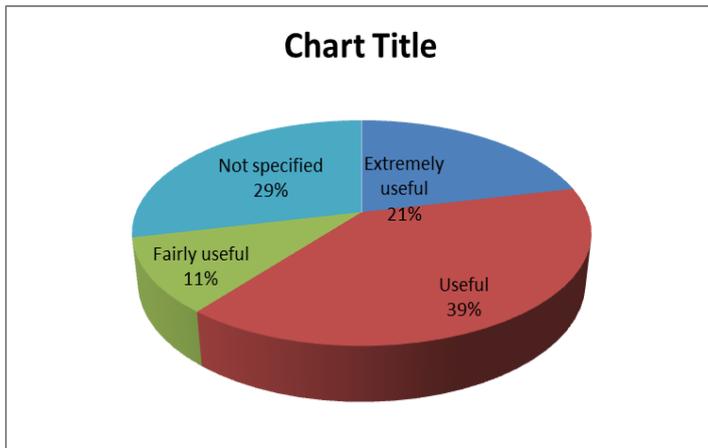


General question and answers session - Professor Mike Hanna

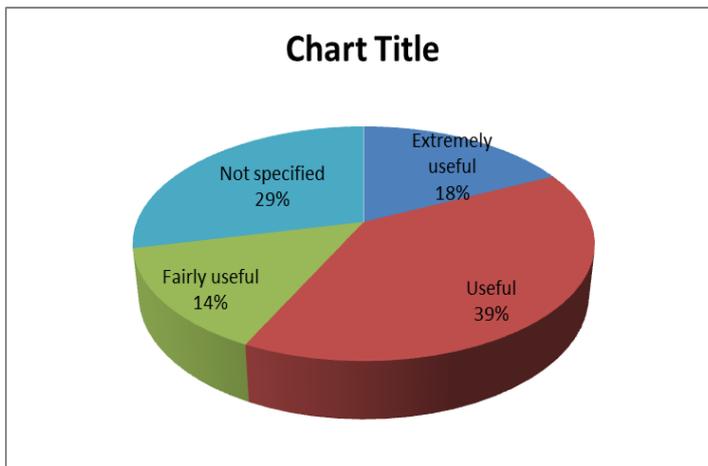


Question 4: How useful to you personally was each information stand?

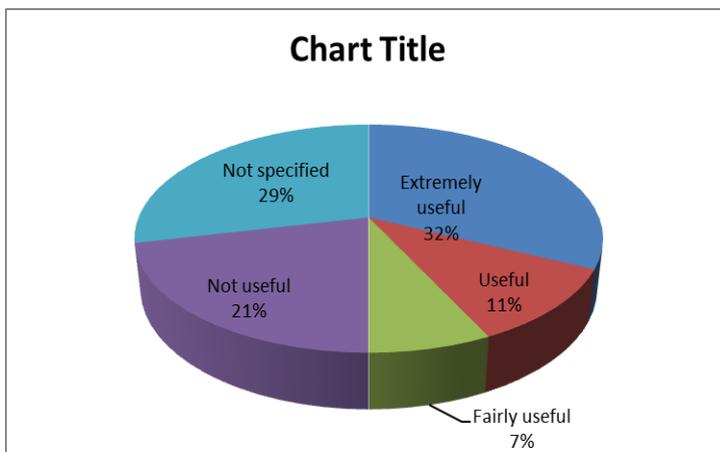
Genetic analysis of Ion Channelopathies –



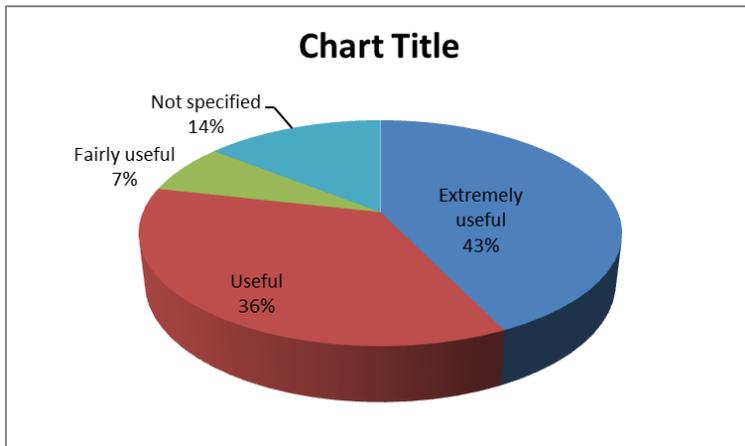
Neurophysiological evaluation and muscle channel trials



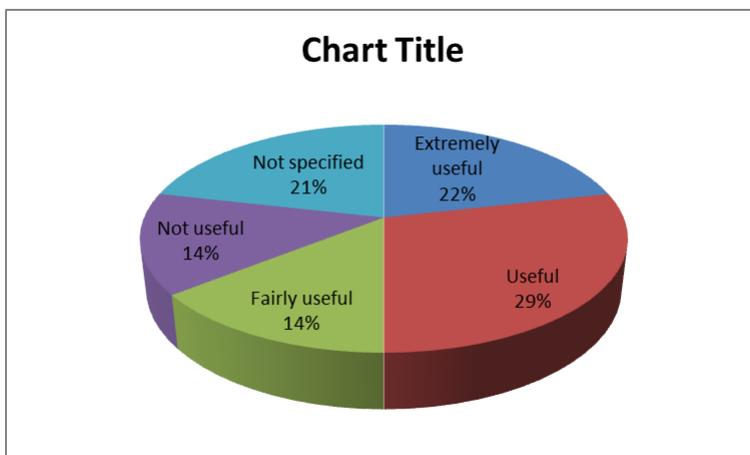
Muscular Dystrophy UK –



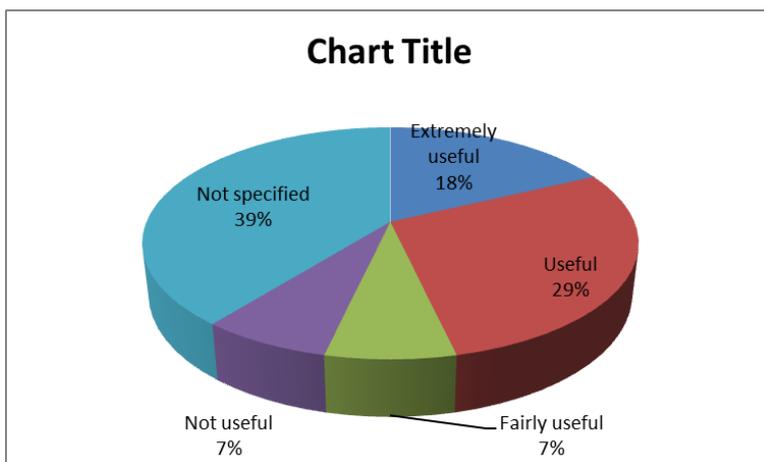
Service development and patient participation



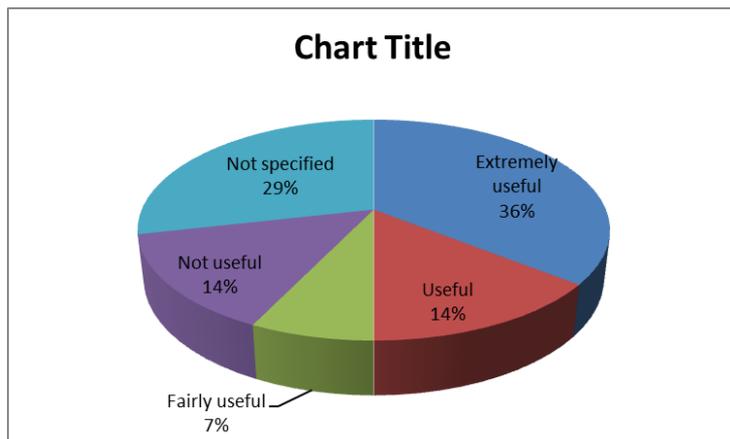
Disease specific stands – ATS



Myotonia/paramyotonia



Periodic paralysis



Qualitative evaluation

Question 5: What would you like to see at our next muscle channel patient day?

- Contact list for people to fill if they wish so that other patients can contact them
- Real life stories of patients could be prepared beforehand. Life events they have experienced and resources they found useful
- Name tags with conditions written on them
- Slower clearer speech
- would like to know more about how ATS is connected to muscular dystrophy and how the muscular dystrophy society can help people with ATS
- List of websites for the conditions
- Diet, food guide. Info leaflet. Exercise info
- Copies of power point presentation. Info leaflets to take away
- Physiotherapist
- good to know who is suffering from what condition so patients can pair up and compare experiences
- copy of list of whole team to take away
- diet plan for PP patients to manage good healthy lifestyle which helps from having an attack regularly
- Age specific groups of patients. The means to contact other patients with same condition. Box with peoples contact info
- Diet and exercise section. Group sessions where people with similar conditions can talk to each other instead of having to have the "what do you have!?" conversation with every person

- More detailed info about diet and exercise. Stickers with peoples condition on them

Question 6: Please add any further comments or suggestions

- Name tags and condition for people to wear to make networking easier
- Please continue the study days, they are invaluable
- Low carb option please
- A tad cold
- The various information stands were very useful and helpful
- physiotherapy ?visit to home would be useful to increase motivation and safe mobility
- Might help if questions are asked (written) on arrival and answered at the end to avoid repeat questions
- Refreshment/display area was very congested and hard to get to. Could this be spread out somehow?
- These events are very useful as my partner has ATS. I learnt a lot about help and support available
- Thank you for refreshments
- research put into more laymen's language
- Hour break is too long. Less use of the pointer as it is distracting
- Shorter break. Badges with condition.