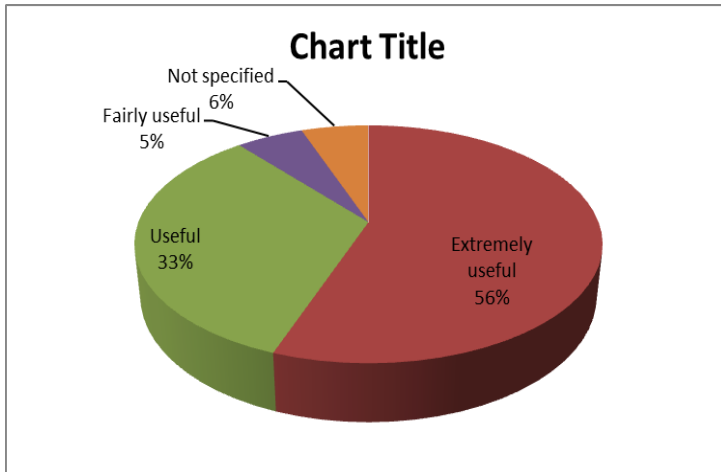


Mitochondrial patient information day June 20th 2015

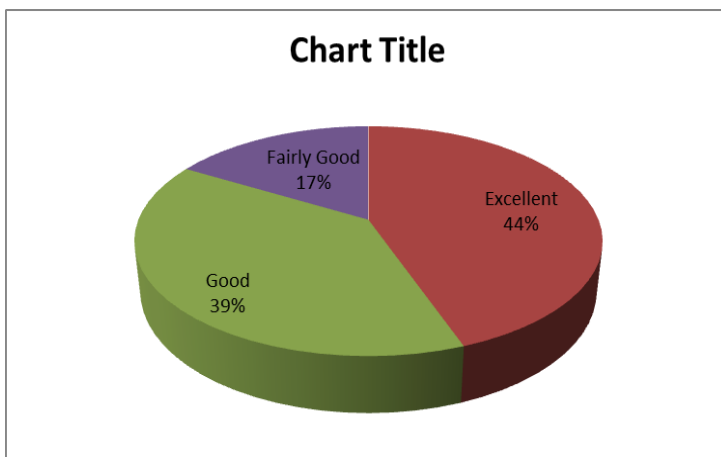
Quantitative evaluation

Question 1: How useful did you find this event?

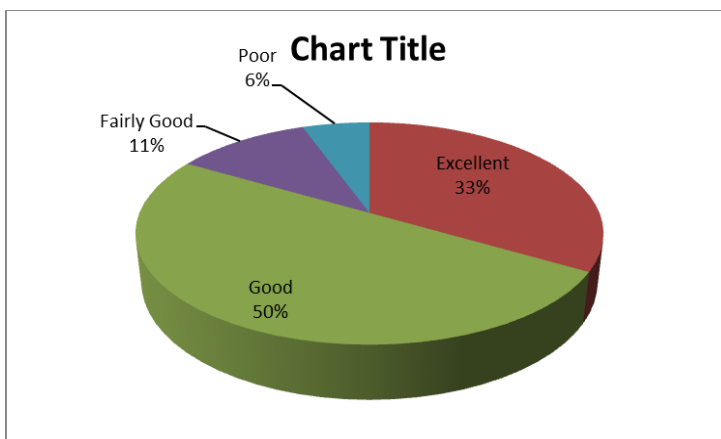


Question 2: What was your overall impression of this event?

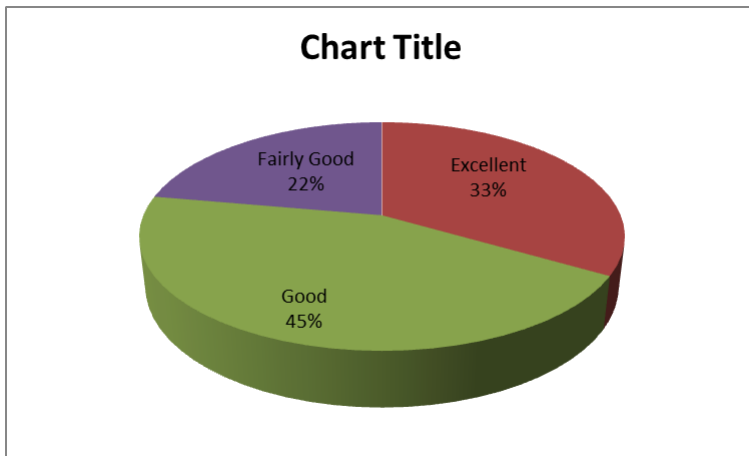
Programme



Organisation

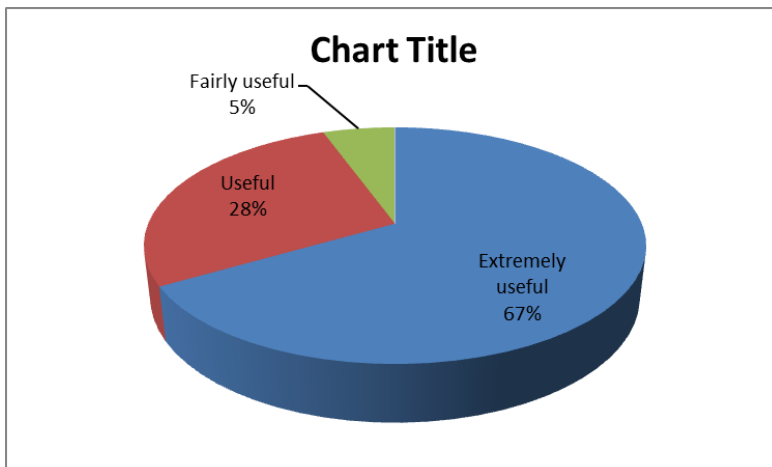


Catering

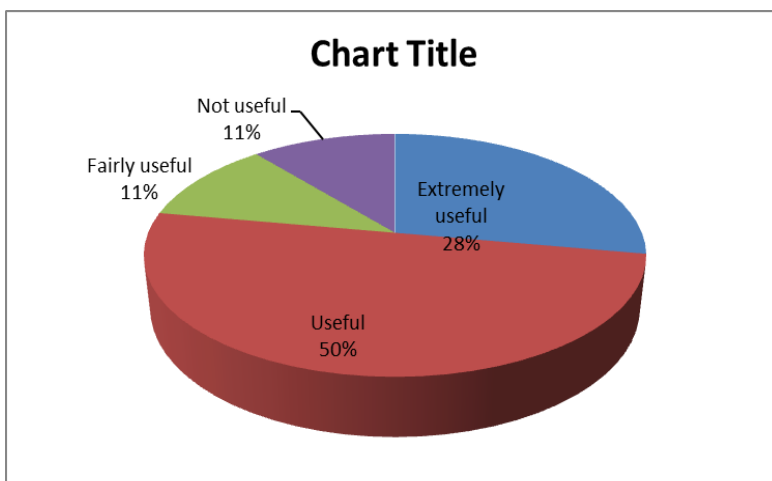


Question 3: How useful to you personally was each session?

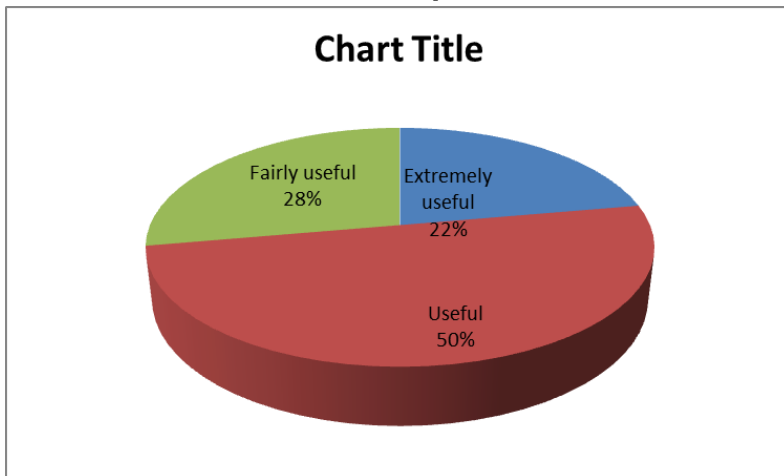
Introduction - Muscle Channelopathies - Professor Mike Hanna



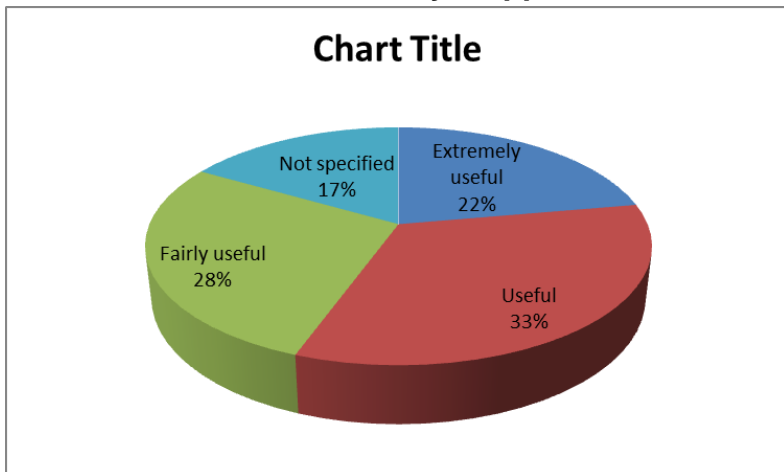
The Neuromuscular Complex Care Centre (NMCCC) & Transition - Dr Ros Quinlivan



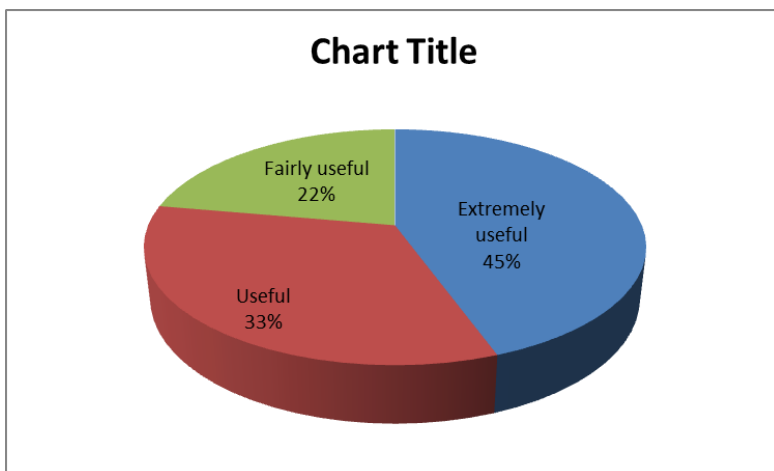
Exercise and service development ideas - Sarah Holmes + Natalie James



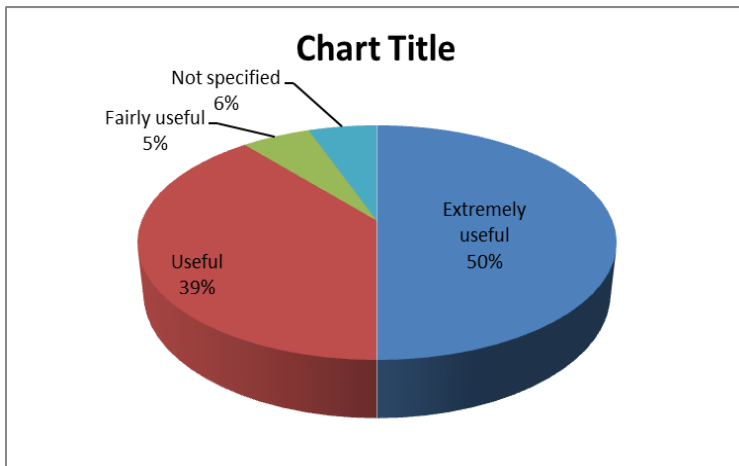
Patient involvement, sensory support in mitochondrial disease



Update on the Mitochondrial Disease patient Cohort Study UK

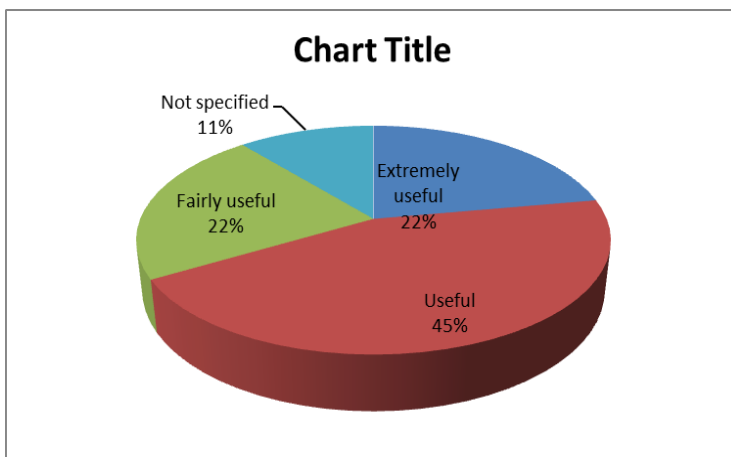


General question and answers session - Professor Mike Hanna

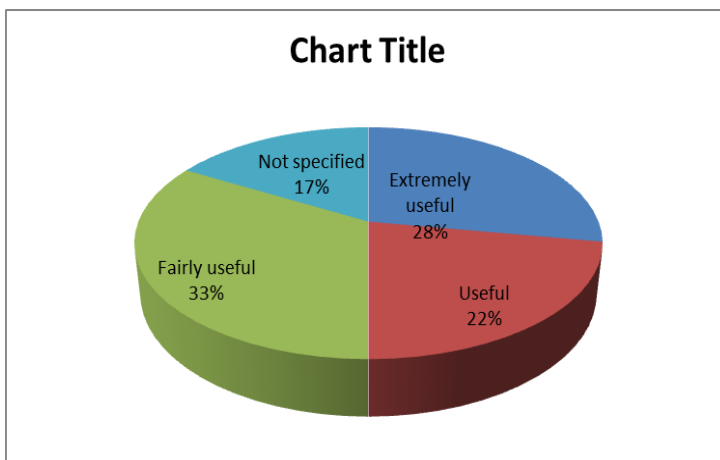


Question 4: How useful to you personally was each information stand?

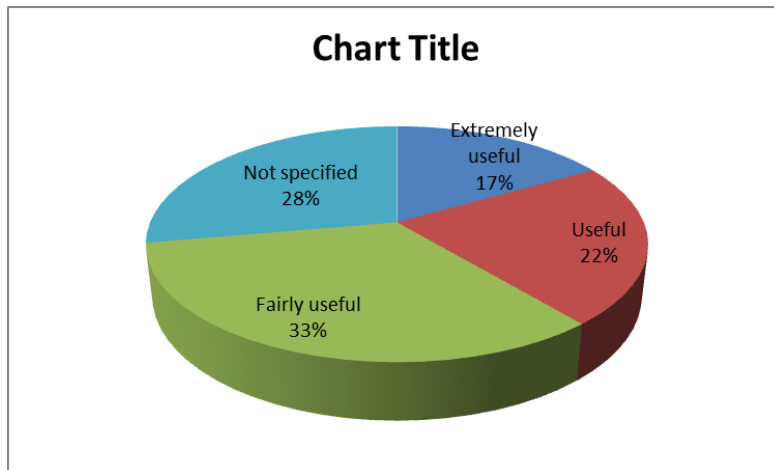
Cohort study-



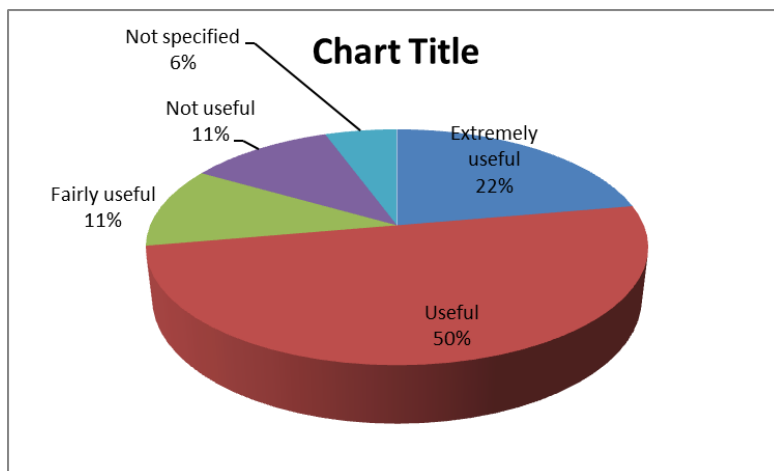
Mitochondrial genetic testing



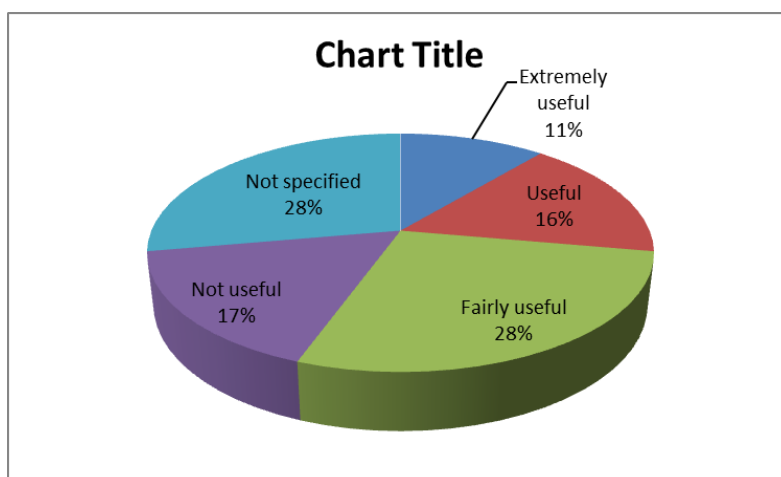
Investigating mitochondria in biochemistry



Service development and patient participation



Muscular Dystrophy UK –



Qualitative evaluation

- **Question 5: What would you like to see at our next mitochondrial patient day?**
- what support is out there to access to newly diagnosed patients and their carers
- Info about muscle cramp, muscle wasting and falls.
- Info on supplements/vitamins to take. Diet, food and nutrients
- The different kinds of fatigue experienced by mito pts.
- a slightly shorter break in the middle
- Hand-outs that explain what mito disease is to friends, family and GP's. These could cover all the different types with a short explanation
- More leaflets to take away as there is not a lot of info about the disease at the local GP or hospital If we had leaflets, we could show them
- Activities for groups of young people
- Update and latest stats from Cohort Study eg how many adults who have the disease onset in infancy survive? New treatments/drug cocktails.
- The Q&A session is excellent so it would be good to have it lengthened. Much can be learnt from other peoples experiences
- More leaflets to take away as there is not enough info about the illness. Local GP & hospital (warwick) do not know much about mito disease. If I had leaflets, I could show people
- Feedback on advances/results from study. Cohort study feedback
- More info about medications and other treatment options. Time to ask questions privately
- more on how to coordinate care for less symptomatic patients

Question 6: Please add any further comments or suggestions

- can we get a copy of the presentations by email
- All the staff involved, well done. You are all very caring and very helpful. Thank you
- more chairs in the lobby
- the choice of fresh fruit, very refreshing
- hour break is too long, maybe 45 minute break would be better
- more on the science/biology/chemistry of diagnosis at the displays might interest some
- very good to be able to talk to the practitioners in the break
- Please have chairs in the foyer for patients with muscle weakness
- Did not need an hours break - would be better to finish early
- Thank you for the palantypist - much appreciated
- We think the 60 min break is too long, 45min would be plenty.
- more chairs in lobby please

- Please could the patient day be arranged earlier and the date found easily on the website. Many phone calls were made to enquire about the date of this year's mito day and was
- Thank you very much for all your hard work.
- Networking seems to be an issue so as a suggestion why not add a sharepoint with discussion threads etc to the website)