

Measuring Quality of Life

We wanted to know if the World Health Organisation's Quality of Life questionnaire (the WHOQoL-BREF) accurately measures Quality of Life. This questionnaire asks about 4 aspects of life: Physical, Psychological, Social, and Environmental.

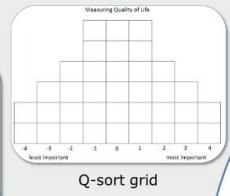


To do this we carried out 4 focus groups with autistic people, in the North East of England.

We asked each group to prioritise the questions using a 'Q-sort' and to tell us the pro's and con's about the questions.

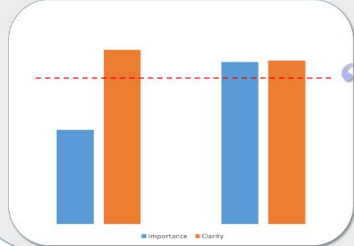
"I'd never met any autistic people before. I've thought, actually it's been really nice to talk with someone that actually understands what I'm saying"

Quote from a consultee



We used a survey to ask people how important and clear the new questions were; revising questions based on the feedback we received.

Questions that were not rated important or clear enough (the red line on the graph) were excluded. Two of the 11 questions were eliminated.



"I was extremely ill at ease with myself before diagnosis. Now I am very happy being me."

Quote about the Autistic Identity question

Consultation



Physical

... includes if pain affects your life, how happy you are with your sleep, if medication affects your life, and if you are happy with your ability to work – amongst others

"It's about opportunities more than capacity"

Quote about 'capacity to work'

... includes your satisfaction with transport or access to health services, how safe you feel, and if you have enough money for your needs

"Not all health services I think are very accessible to people with autism"

Quote about 'access to health services'



Environmental

"Sometimes people just want their friends there for fun and don't really want them for support as well"

Quote about 'support from friends'

... includes how satisfied you are with your friends, personal relationships, and your sex life

Analysis



Psychological

... includes a meaningful life, enjoying life, ability to concentrate, and personal identity – amongst others

"Feeling your life is meaningful is tough because you know, I've always said you give your life meaning you don't look for it from somewhere else"

Quote about 'a meaningful life'

"I interpreted that one, 'how able are you to get around?' as more a physical thing about walking... or does it mean transport?"

Different interpretation

"My concentration can go off on many things. For example loud music and I get distracted that way, or loud noises and I may just tend to shut my ears off."

Quote about sensory issues

We looked at what people had said from each discussion group to see what was good, and not so good, about the questions.

Some questions were interpreted differently and there were some 'missing' areas (such as sensory issues) – see quotes above.

We identified key *themes* from what people said in the discussion group.

Some of the themes were about friendship, finances, and the knowledge other people in society have about autism.

We used these themes to create 11 Quality of Life questions that can be used with the WHOQoL-BREF.



Social

Testing

Item creation



Thank you to Research Autism and Autistica for funding this study and to Northumberland, Tyne and Wear NHS Foundation Trust for being the study sponsor.

Northumberland, Tyne and Wear NHS Foundation Trust



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If you would like to read a more detailed summary of this study please visit either:
The Adult Autism Spectrum Cohort-UK website <http://research.ncl.ac.uk/adultautismspectrum/cohortprojects/>
Or
Research Autism's website <http://researchautism.net/research-autism-our-research/research-autism-projects-completed>

The new Autism Specific Quality of Life questions can be downloaded from:

<https://research.ncl.ac.uk/neurodisability/leafletsandmeasures/autismqualityoflifemeasure/asqolmeasure/>