

What's important in measuring quality of life? Reflections by autistic adults in four countries.

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Abstract

Relevant and valid measurement is crucial in determining whether interventions and supports have improved the quality of life (QoL) of autistic people. However, it is possible that researchers' and services' use of general population QoL tools may overlook issues of specific importance. In order to advance methodology, we conducted a preliminary exploration of the need and basis for cross-cultural development of additional autism-specific QoL questions.

Nine consultation groups with autistic adults (n=38) were held in Argentina, Australia, Singapore and UK to examine the items of the World Health Organisation QoL questionnaire (WHOQOL-BREF) and the WHOQOL Disabilities add-on module. Each group discussion was transcribed and analysed thematically to identify missing issues and nuances of particular significance to autistic people. Themes seen as important and particularly relevant to QoL of autistic people included: a positive autistic identity, other people's lack of understanding of autism, sensory issues, and autistic people's contributions to society. There were notable similarities across sites indicating that creation of cross-cultural autism-specific items is likely to be possible; the themes identified could inform the focus of items for measurement of QoL. This project represents an initial step towards fuller international consultation, and subsequent development of an autism-specific module for addition to the core WHOQOL model.

205 words

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Introduction

'Quality of Life' (QoL) refers to a person's satisfaction about how their life is going now, taking into account their experiences and environment. QoL is a multi-dimensional construct which an individual judges subjectively, in relation to their experiences and environment.¹ Studies of QoL in autistic adults have almost always found lower QoL compared to the general population, particularly in social relationships.^{2,3}

Ayres and colleagues' systematic review of 14 QoL studies² in autistic adults (total n=959) found seven different measures used but only one specifically designed for autistic people (QOL2) which essentially consisted of one rating.⁴ The most frequently used measure was the World Health Organisation (WHO) QoL measure (WHOQOL-BREF)⁵ which was developed to exacting cross-cultural standards, as a global subjective measure that could complement 'objective' indices (e.g. income, housing or life expectancy).⁶ Recent analyses show that the WHOQOL-BREF is a sensitive measure of change, and can be used to evaluate interventions for a range of physical health and psychological conditions.⁷ Add-on WHOQOL modules of items on Spirituality, Religiousness and Personal Beliefs⁸ and for specific groups such as people with intellectual or physical disabilities (WHOQOL Disabilities module), have also been developed.⁹

What is the problem?

Despite the potential benefit of providing comparative data, general population QoL tools might not be as valid or relevant in measurement with autistic people, for several reasons. Firstly, the intense, sometimes atypical, sensory processing experiences that affect many autistic people¹⁰ are not captured in traditional QoL measures. Secondly, many autistic

people experience high anxiety for a range of reasons, including difficulties in coping with change, and with some social interactions^{11,12} which may not be captured in existing QoL tools. Thirdly, some autistic people say they do not feel a need to socialise, or have negative perceptions of socialising based on past experiences (such as having been bullied), or may socialise in ways that others do not recognise or understand; therefore frequency of socialisation may not identify what is important and infrequent social engagement may not necessarily be experienced as lower QoL.^{13,14} Finally, in terms of experiences, autistic adults are often unemployed or under-employed for their abilities and qualifications;^{15,16} those in employment have benefits from an income and status, but nevertheless the cost may be high in terms of coping with external demands, social anxiety and other stressors.¹⁷ Such complexities are not explored in traditional QoL measures.

Therefore, our UK research group set out to explore whether the items of the WHOQOL-BREF are seen as important and relevant by autistic adults, and what issues and concerns might be missing. Furthermore, given that a significant proportion (up to 80%¹⁸) of autistic people do not have associated intellectual disabilities, we wanted also to explore the relevance of the WHOQOL Disabilities module items. Looking to the future, we also questioned whether the perceptions of autistic adults in the UK might largely be echoed in other cultures; if so, our findings along with any new themes and issues raised could potentially inform development of an internationally-valid autism-specific module of items.

Aims

- 1) To try out a method of enabling group discussion with autistic adults concerning the WHO QoL measures.
- 2) To explore in several countries autistic adults' reflections on the QoL items.
- 3) To explore the need and basis for developing potential autism-specific QoL items.

What did we do?

Consultation groups with autistic adults were held. The adults acted as ‘consultees’, i.e. they were consulted about what changes might be needed in QoL measurement with autistic adults prior to future clinical research, and gave advice on the questionnaire items. In all, nine groups were held with a total of 38 consultees (24 males; 18 years or older, with a self-reported professional diagnosis of an autism spectrum condition), four in the UK (n=20) in 2016, and subsequently in 2017/8 three in Singapore (n=11), and one each in Argentina (n=4) and Australia (n=3) (see Table 1, characteristics of consultees and facilitators). Of the eight group facilitators (4 male), one is an autistic advocate, one the parent of an autistic young adult, and six are researchers (of whom 3 are also clinicians) working with autistic individuals.

[Insert Table 1 about here]

The groups examined the items of the WHOQOL-BREF and the WHOQOL Disabilities module. The WHOQOL-BREF¹⁹ is a self-report measure of subjective QoL containing 26 items. Two global questions provide an overarching concept of general quality of life and health; 24 items represent different facets of QoL, scored in four domains: Physical (7 items, e.g. ‘*How well are you able to get around?*’), Psychological (6 items, e.g. ‘*To what extent do you feel your life to be meaningful?*’), Social (3 items, e.g. ‘*How satisfied are you with the support you get from your friends?*’), and Environment (8 items, e.g. ‘*How satisfied are you with your transport?*’). Items are scored on 5-point Likert rating scales (e.g. ‘*very dissatisfied*’ to ‘*very satisfied*’). For autistic adults, internal consistency has been found good for the Physical, Psychological and Environment domains (Cronbach’s alpha .84-.87) and marginally acceptable for the Social domain (.68).²⁰

The WHOQOL Disabilities add-on module⁹ includes one global question and 12 additional items scored in three domains: Discrimination (3-items, e.g. ‘*Do you need someone to stand up for you when you have problems?*’), Autonomy (3-items, e.g. ‘*Do you feel in control of your life?*’), and Inclusion (6-items, e.g. ‘*Do you feel that your dreams, hopes, and wishes will happen?*’). Items have additional text in explanation (e.g. for the last example about ‘dreams’, ‘*For example, do you feel you will get the chance to do the things you want, or get the things you wish for, in your life?*’) and the verbal rating scale points are enhanced by ‘smiley faces’. Internal consistency of domains and total score has been shown acceptable to good (.69 to .85) for people with physical or intellectual disability⁹ and in an autism sample.²⁰

In both questionnaires, some items are reversed so that higher scores always indicate greater (better) subjective QoL. Domain scores are transformed onto a scale from 0 to 100, to allow for comparisons.

How were the groups run?

Invitations to the consultation groups^a were issued via social media and local community and advocacy contacts in each country. No selection was applied other than consultees being aged 18 years or over. In the UK, one of the four discussions was hosted by a drama group for people with (mild/moderate) intellectual disability, with a support worker well known to those attending.

Group facilitators in Argentina, Australia and Singapore were known to the UK research team, and expressed willingness to run similar consultations. As the autistic adults were acting as consultants, an Ethics opinion was not required except in Singapore (National University of Singapore, IRB approval N-17-041).

In most cases, consultees did not know each other when they came to the group. The autism advocate and parent of a young autistic adult who acted as facilitators in the UK devised a group structure which aimed at enabling participation by all and a broad discussion of themes, breaking down the task of examining the questionnaire items into manageable steps. Consultees were invited to discuss the clarity, relevance and importance of the WHOQOL items²¹. The semi-structured process was that consultees as a group completed a sorting task adapted from Q-sort methodology²² for the 36 combined BREF and Disability items (i.e. excluding the three global questions). First, each of the facilitators would model taking an item written on a card, reading it out and then discussing how important s/he thought the topic was to their own and autistic people's QoL. Then, two or three items were handed to each consultee, and they were invited in turn to say why they thought the item was important or not, and other consultees were also encouraged to give their views. The items written on cards were gradually laid down within a pyramid-shaped structure on paper, with a rating scale along the bottom of the columns (from -5 to +5 on 'importance'). (See example in Supplementary material Figure.) Consultees moved items between columns during discussion. It was emphasized that what was important was the discussion and reasons consultees each gave, rather than the rankings *per se*; also that they did not need to agree in their views or ratings. Near the end of the group, consultees were asked to write down areas of QoL that they thought were not captured by the items they had just discussed.

The protocol for conducting the groups was developed in the UK, and instructions along with all materials and forms were sent to leaders to ensure consistency of procedure and presentation^b. Discussion was audio recorded (with signed consent from consultees to the recording and use of selected anonymised quotations) and transcribed verbatim. Groups were conducted in English (UK, Australia & Singapore^c) or Spanish (Argentina, transcript translated into English).

Did the group structure enable discussion?

Each discussion lasted up to two hours. The need for some kind of structure at the start was exemplified by one UK consultee: *'I think you're very optimistic thinking a room full of people with autism are going to have a group discussion.'* However, near the end the same consultee commented: *'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.'* Although the session structure was designed by members of the autism community, some of the discussion transcripts appeared somewhat constrained by the overt purpose of assigning ratings of 'importance' to existing WHOQOL items. In any future consultation, a fully participatory research approach should involve an ongoing relationship between autistic advisors and researchers, with exploration of how to structure tasks and how best to enable trust and communication.

What did we learn from the group discussions?

The UK groups' transcripts were analysed first. A deductive approach was taken to identifying emerging themes, with two main areas of focus²³:

- (i) Nuances in the discussion, either concerning items that autistic people found difficult to interpret, or experiences that seemed to differ from what might be reported in the general population; and
- (ii) QoL topic areas that were identified as missing from the measures.

The transcripts were read through repeatedly and coded by DM and HM, identifying recurrent themes and/or those identified as important. These were then discussed and refined by all UK group leaders (CW and DG reflected viewpoints from the autism community) to test the validity of the themes. Once themes (n=11) were established, coding agreement (i.e.

relative frequency of application of codes throughout one transcript) was calculated ($r_s=.93$, $p<.001$).

For the groups held subsequently in the other three countries, coding of transcripts had the same foci as above, and in addition included whether (1) the UK themes were also evident in the new transcripts, and (2) there were different emphases, perspectives and examples, or any new themes in the other country discussions. One transcript was coded in full by CW, DM and HM and discussed to reach agreement. The remaining transcripts were then coded, with agreement established between DM and HM on samples from each group ($r_s=.77$, $p=.003$). Altogether over 80% of the material was double-coded and agreement reached by consensus. The conclusions were then shared with the group facilitators in each country to comment on and confirm the validity of additional themes identified before finalizing.

Were WHOQOL-BREF and WHOQOL Disabilities module items seen as important?

Across all consultation groups, most of the 36 generic and disability-related WHOQOL items were judged important and relevant for autistic people. Indeed, in several groups it was not possible to allocate every item to a space in the pyramidal Q sort grid, as consultees were reluctant to designate any items as ‘less important’.

Items placed in the highest two levels of ‘importance’ by most groups included two on feelings: ‘*How often do you have negative feelings such as blue mood, despair, anxiety, depression?*’, ‘*How much do you enjoy life?*’, one on financial resources: ‘*Have you enough money to meet your needs?*’ from the WHOQOL-BREF, and one on discrimination: ‘*Do you feel that some people treat you unfairly?*’ from the WHOQOL Disabilities module.

Items placed in the lowest levels of ‘importance’ were more variable, but for most groups included the WHOQOL-BREF items: ‘*Are you able to accept your bodily appearance?*’

and *'How satisfied are you with the support you get from your friends?'*. Comments made by consultees on the first of these included: *'I just stopped caring what people think really, because when I was younger I used to get quite upset by what people thought of me, whereas now I've learned to just accept it.'* The low rating of the 'friends' question was explained in one group as: *'Sometimes people just want their friends there for fun and don't really want them for support as well'*.

What themes emerged as highly relevant for autistic people?

Although not necessarily unique to autistic people, eleven themes emerged which were coded as especially relevant. These included, for example, other people's autism-related knowledge, particularly professionals' knowledge or lack of it; access and barriers to external support; family support (and whether this was helpful or constraining); awareness of their own autistic strengths and difficulties; sensory issues; and 'autistic' identity (see Table 2 for definitions of all eleven themes). Where themes overlap with domains or facets covered in the WHOQOL-BREF or Disabilities module, this is mentioned below.

[Insert Table 2 about here]

1. Difficulties due to **other people's lack of knowledge about autism and acceptance of difference** were discussed frequently in all groups.

For a lot of years while I worked there, I wasn't diagnosed. But then I did get diagnosed and my boss and the owner then knew about it, but nothing changed.

(Singapore)

Throughout my entire life, because I was undiagnosed I would go to the doctors with things and they would go 'don't be stupid, it's not that' and... and that's been a pattern, so now I'm recognising the pattern and actually they do far more harm to me than good. (UK)

2. **External support and services** is an existing facet of the WHOQOL model, i.e. access to health and social care (Environment domain). However, this theme was discussed in a nuanced way both in terms of barriers to access (bureaucratic, interpersonal, or procedural, such as having to make first contact by telephoning a stranger) and also some autism-specific support that consultees had received.

I'm self-employed but I can't do any of the business side myself. Because it's just impossible to do paperwork and all that stuff. I've got [W] who's my mentor and I'm getting access to work fund, hopefully to do all that kind of thing. So I need people to do all that kind of thing for me. (UK)

3. Fear of **loss of resources**, especially financial, was a related theme, especially in UK.

I'm on the highest benefits you can think of and I, what happens if I go to that interview and I'm going to lose it when I want to keep it for the rest of my life? (UK)

4. **Family support** from parents or partners was important to many, both emotionally/socially and practically/financially.

Like before we go to social situations, we practice what I'm expected to do and he [husband] says 'you know you'll need to say this' and we practise meeting his relatives every time. (UK)

5. **Sensory issues** were described by some as having a large effect, sometimes leading to restriction in activities or extra costs.

'I have a friend I shall not name and he's on the spectrum - he lives in front of the car park entrance and the lights really hurt him. So his living condition is hell on earth.' (Singapore)

6. Other **characteristics of autism** were discussed by all groups, e.g. how daily hassles and barriers can be detrimental to individuals' needs for structure and routine.

I can get metros and buses but I have significant difficulties with them if they're not timetabled, if they stop unexpectedly, if they change. (UK)

7. **Autistic identity** was discussed in most groups, in terms of pride and awareness of difference. This theme relates to the WHOQOL facet of spirituality, religion and personal beliefs (Psychological domain) but in quite specific ways for autistic people.

I think it's because we are different and I do feel that these questions are asking us 'how do we make sure that you actually conform to our society?' (Australia)

Autism is a strength, which I believe it is; autism is so much as a strength that it is a sense of being. (Singapore)

8. **Self-determination/autonomy** was also a frequent topic.

If I had to live in a place I do not choose, with someone I do not choose, I would feel very bad. For me it would affect my quality of life in a radical way. (Argentina)

For university I didn't want to study the specific degree that they {parents} wanted me to, but since they were paying for it... so I, you know, I went along with it, but in the end, um, I didn't do well. I ended up suffering for two years (Singapore)

The emphasis of comments relating to self-determination/autonomy differed from the WHOQOL Disabilities module Autonomy domain, in that most consultees were not in supported accommodation. At the same time, several reported they could find responsibility and decision-making stressful and overwhelming.

Like I get to make the big decisions in my life but I don't feel in control because of the... there's, there's just too much to do. It's like overwhelming... feeling, so there's too much to be in control of. (UK)

9. The issue of **mental health** was raised by most groups; experiences of anxiety, stress and depression were mentioned openly by several consultees. Although negative feelings are a facet of the WHOQOL Psychological domain, and not exclusive to people on the autism spectrum, the minimal coverage (one item) in the WHOQOL-BREF led to the theme being coded as particularly relevant and important for autistic people.

They don't understand yet that there is autism, that there is depression... it definitely shapes you a lot cos you feel alone, you feel not accepted. (Australia)

10 and 11. **Social engagement** and **friendships** were generally discussed in terms of individuals' reluctance or difficulty in joining in socially; in relation to social acceptance; and in terms of impact on work opportunities.

[At work] people form little social networks and bonds between each other, don't they? So if you're an outsider, you know; I don't give off the right signals and social strokes to people so they think 'ooh she's aloof'. (UK)

Going through progression in your work is due to a lot of things that are sometimes out of our reach, because it's about things like getting on with people, you know, a lot of stuff that is just really hard for us to do because ... we like to think its meritocracy but it's not. (UK)

This emphasis on social engagement was different in its nuances from the WHOQOL facet of social support (Social domain). For example, as mentioned above, one WHOQOL-BREF item asks about '*...the support you get from your friends*' not about social activities. It was clear

that normative expectations about **friendships**, and negative impact on QoL, may not hold for some autistic people.

The truth is that in high school I had no interest in having friends. And they used to ask me: "don't you feel sad for not having friends?" No, I was fine, I felt good.

(Argentina)

Were perceptions similar across countries?

Overall, there were striking similarities in themes across countries, with five of the themes discussed in all the groups: others' knowledge about autism; characteristics of autism; self-determination/ autonomy; the nature of friendship; and social engagement (see Supplementary Table 1 for the frequency with which each theme was discussed in each of the groups).

We also identified some topics which were discussed more or in different ways in the other country groups, once all the transcripts were considered together.

Economic uncertainty and work. The WHOQOL-BREF item '*Have you enough money to meet your needs?*' was rated as important in most groups. Discussions in other countries added to the UK theme of heightened financial vulnerability/loss of resources; consultees emphasized the need to work to get money in countries where there are few unemployment or disability benefits, or where a diagnosis of autism might affect eligibility for health insurance cover.

Some consultees also described difficult childhoods in poverty, particularly in Argentina. That perspective informed how people view QoL as adults: '*The biggest problem was the low predictability in this country, which makes you lack the capacity to save money, and you always live to the limit. It affects the quality of life, because of unpredictability.*'

The WHOQOL-BREF item on work focuses on ‘*capacity*’. However, discussions in other countries emphasised how autistic people may become underemployed (or unemployed).

We have to be realistic, like we can't always follow our special interests and we can't be too picky about job and careers and things. We have the condition and it's way harder to be employed. (Singapore)

Contributions to others. A striking issue, not covered in the existing WHOQOL items, was the role autistic individuals play as carers or contributors to others and society. Several adult consultees were parents, or caring for elderly relatives. These experiences were central to their perceptions of themselves and their QoL.

I do worry quite a lot; my son is an only child and he is profoundly autistic. My brother lives [abroad], my parents are quite old, so if I wasn't able to care for him what on earth would he do? (UK)

If I didn't feel that what I was doing was helping people I wouldn't bother doing anything. (UK)

Is there a need to develop additional autism-specific QoL items?

In general, consultees judged the existing WHOQOL-BREF and Disabilities module items as relevant and important. Quantitative research has suggested that the WHOQOL-BREF has reasonable structural validity when used with autistic adults.²⁰ However, analysis of the consultation group transcripts revealed themes concerning QoL that seemed subtly or overtly different for autistic people. In summary, topics discussed frequently in most groups included the effect on autistic individuals of other people's autism-related knowledge, particularly professionals' knowledge or lack of it. This could create barriers to accessing support and services, negatively influencing QoL. Families often are the main source of

support, but dependence on families or partners could at times be complex rather than positive. Consultees identified their own autistic strengths and difficulties, such as being honest and direct or finding unexpected change difficult to deal with, as factors influencing their QoL. The discussion also evidenced a positive sense of ‘autistic’ identity, being part of a wider autistic community, and the need for autonomy and self-determination as important aspects determining QoL. The eleven initial themes had many similarities to those identified by Hwang et al²⁴ in open-ended interviews about ‘aging well’ with autistic adults of all ages in Australia.

Considering all data from the four countries together, further themes were emphasised, over and above those derived in the UK, including aspects of economic vulnerability, and the contribution made to society by autistic people.

In the UK, based on the consultation with autistic adults, a proposed set of add-on autism-specific QoL items has been developed and refined through cognitive interviewing and Delphi survey concerning their importance and clarity. A quantitative validation study was then conducted of nine new autism-specific items to be used alongside the WHOQOL questionnaires.²⁰ Proposed items included, for example, *‘Do sensory issues in the environment make it difficult to do things you want to do?’*. Thus the rationale for developing additional autism-specific QoL items seems established.

However, one initial much-discussed theme proved difficult to frame in a clear question - others’ autism related knowledge and acceptance of difference. This was because item phrasing would depend on whether the individual had already made their autism diagnosis known to other people and whether this knowledge was available to those who provide services. This important theme therefore would need further consideration if it is to be addressed in a future international add-on module.

The theme of mental health difficulties also requires further consideration. The one WHOQOL-BREF item concerning negative feelings: *'How often do you have negative feelings such as blue mood, despair, anxiety, depression?'* was criticised by consultees as trying to cover too many aspects of their emotional experiences at once²⁵. Mental health difficulties are common in autism^{26,27} suggesting that their relation to QoL requires more detailed validated measurement to capture the complexity of autistic adults' emotional experiences in relation to their QoL.

What future work is required to establish an internationally valid add-on module?

The themes identified in the UK consultation groups were echoed in the groups run in the three diverse countries. However, future consultation would require expansion to a wider range of consultees, including 'hard to reach' groups in terms of geography, income and ability. This would require establishment of participatory research groups of autistic adults and researchers in several countries. Consultation across a wide range of languages and contexts, following WHOQOL protocol procedures²⁸ in around 20 countries, would enable international qualitative analysis of themes. An international team could then propose new items which capture novel themes (including editing the proposed UK items), before further survey consultation and field testing of important autism-specific QoL items representing relevant outcomes.

The proposed UK items include one on autistic identity (*'Are you at ease (OK) with 'Autism' as an aspect of your identity?'*). This would need further linguistic and cultural exploration, particularly in relation to societal views prevailing in different settings. Cooper and colleagues²⁹ have suggested that a positive autistic identity can be a protective mechanism against anxiety and depression. However, in countries where there is stigma

concerning autism as a disability, the opportunity for a positive group identity may be limited and how to ask a question about ‘autistic identity’ is likely to require adaptation.

Another area to consider would be an item enquiring about how making a positive contribution to society impacts one’s QoL; the public discourse about autism is often about needs and disability, ‘being a burden to others’. One reason that autistic people’s satisfaction in looking after others might go unnoticed could reside in assumptions about empathy. Although some autistic people may have difficulties in perspective-taking which might seem to hinder ‘cognitive empathy’, it is also clear that autistic people do feel ‘emotional empathy’, indeed for some to an overwhelming degree.³⁰⁻³²

Our consultation suggests that some consideration would be needed of how to ask about work in the measurement of autistic adults’ QoL. Employment brings benefits of earning money but is accompanied by high levels of stress for many autistic people.¹⁷ Many are underemployed for their qualifications, by discrimination or by choice.³³ Furthermore, some may gain satisfaction in pursuing work-related interests as ‘leisure’, especially if it relates to highly focused interests,³⁴ whereas existing questions separate work and leisure. Therefore the impact of work on QoL may be more nuanced and complex in autism, and further thought is required about how to appropriately measure its contribution (and that of voluntary work) to QoL of autistic people.

Limitations of this consultation

This study took place across four continents but the reach was limited. That is, there was only one small group in two of the four countries, and all except one discussions were conducted in English. The involvement of some people with intellectual disability was a strength of the consultation, but occurred in only one country. Although a range of ages and current employment status were represented, only the groups in Singapore and Australia included

individuals diagnosed with autism in childhood, and the majority were aged in their 20s or 30s. Consultees were those known to university-based researchers or users of social media in contact with advocacy organisations, mainly living in large cities. Thus the emerging themes of the discussion might have been constrained by these restrictions in range of experience; for example, there was little discussion of safety or social vulnerability³⁵. Other than for the UK discussions, the group leaders were researchers though all were very familiar with working alongside autistic people. The coding was done only by the UK team, though members of the autism community were included and codes were reviewed with all countries' group leaders before being finalised. Future consultation should therefore consider perspectives from a broader range in terms of class, culture, ages and ability, as well as across diverse languages and societies, in order to derive a rounded view of what is of particular importance in measurement of QoL of autistic people. The methodology designed by the WHOQOL Group, whereby all participating countries conduct field work contemporaneously, allows pooling of results for an international analysis.

Conclusion

The WHOQOL-BREF and its Disabilities module address many issues that are relevant and important to autistic people, and can capture different aspects of their QoL. At the same time, the themes emerging from discussion in four countries, as presented here, suggest that the methodology can be improved upon, and that there is enough commonality to suggest improvement will be possible. The next step would be to consult further, involving people with a wider range of personal characteristics, from a broader range of situations and cultures, with the process driven by international collaborative groups of autistic people and researchers. Such consultation would form the basis from which to develop, expand and validate internationally an autism-specific QoL module of items to be used alongside the WHOQOL core measures.

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Footnotes

a The invitation text explained: ‘We are holding meetings to ask people their views about what makes your life have quality and meaning. This is important because it may help to inform service development for adults on the Autism Spectrum and their families. We would like to evaluate the current method for assessing quality of life and see if it is suitable for adults on the Autism Spectrum. We hope this information will inform policy, practice and communication in this area.’

b For the discussion in Argentina, the (bilingual) group leader translated the Disability module items and WHO provided the WHOQOL-BREF in Spanish.

c Most Singaporeans are bi- or multi-lingual and fluent in English. Singapore has four official languages (English, Mandarin, Malay, Tamil), with English being the official language of education and administration (Singapore Statistics, 2010; see https://www.singstat.gov.sg/media/files/publications/cop2010/census_2010_release1/indicators.pdf)

Table 1. Characteristics of those who took part in discussion groups

	UK1	UK2	UK3	UK4	Aus.	Sing1	Sing2	Sing3	Argent.
Consultees									
Number and gender	2 F/ 5 M	2 F/ 2 M	3 F/ 1 M	0 F/ 5 M	2 F/ 1M	0 F/ 4 M	0 F/ 2 M	2 F/ 3 M	2 F/ 2 M
Age in years: mean (range)	25.7 (18-45)	29.0 (18-40)	34.5 (30-36)	26.3 (19-41)	31.1 (19-53)	34.0 (29-46)	27 and 34	28.6 (21-51)	35.0 (29-47)
Diagnosis (self-reported)	1 autism, 3 ASD, 3 AS	1 autism, 1 ASD, 2 AS	3 ASD, 1 AS	3 autism, 1 ASD, 1 AS	3 AS	1 ASD, 3 AS	2 ASD	2 ASD, 3 AS	1 ASD, 3 AS
Age at diagnosis (in years)	18, 19, 19, 21, 23, 35, 45	18, 19, 39, 40	30, 36, 36, 36	19, 22, 23, 25, 41	9, 12, 44	3, 10, 22, 42	11, 18	5, 5, 8, 23, 42	28, 30, 30, 43
Employment status:									
Unemployed	2	0	0	2	1	0	0	0	1
In education	2	1	2	1	1	0	1	3	1
Carer	1	0	1	0	0	0	0	0	0
Self-employed	1	1	0	0	0	0	1	1	0
Employed	1	2	1	2	1	4	0	1	2
Group facilitator(s)									
Number and gender	1 female /2 male				1 male	2 female/ 1 male			1 female
Role	1 autistic advocate, 1 parent & voluntary organisation leader, 1 researcher				1 clinician/ researcher	2 clinical psychology trainees, 1 researcher/clinical psychologist			1 clinician/ researcher & voluntary organisation leader

Aus. = Australia; Argent. = Argentina; Sing = Singapore; F = female; M = male; ASD = autism spectrum disorder; AS = Asperger syndrome

Table 2. Definitions of coding for emergent themes with particular relevance for autism

	Code:	Description:
1	Autism related knowledge and acceptance of difference	Other people's knowledge about autism - societal views, stigma, individual people encountered, employers, etc. This includes adaptations (e.g. to work environment, clinic processes) that autistic individuals would like or which have been made.
2	External support and services – access and barriers	Reference to gatekeeping / gatekeeping culture. Issues of trust in people providing services. Someone in an official capacity who will stand up for the individual. Need for autism-specific service. This code can also apply to past experiences, e.g. at school.
3	Vulnerability (or loss) of resources that people rely on	Loss of support, either financial or the people / organisations that support the individual. Coping with that uncertainty.
4	Family support	The role family play in the life of an adult with autism. Could be social, monetary, or advocacy support. Could be restricting experience, expectations, etc. This relates to parents, partners, spouses etc.
5	Sensory issues	Issues around distractibility, loud noise etc. (i.e. interaction with the environment) that commonly have impact on autistic individuals.
6	Characteristics of autism	Self-knowledge of one's strengths, limitations or abilities/skills. Ways that people generally do things that may not be adaptive. Issues that may prevent autistic people from holding a job/obtaining resources etc. Impacts on functioning include protracted worrying; straight-talking; difficulty with uncertainty or change.
7	'Autistic' identity	The sense of identity that 'autism' provides and the opportunities for shared experience with other autistic people. Reference to identity politics, e.g. disconnection from 'neurotypical' experience.
8	Self-determination, autonomy	Points related to having a desire (or lack of desire) about decision making, whether decision making is something that is always a good. Choosing how to live; what's important in life; enjoying being on one's own.
9	Mental health issues	Experiences of high anxiety, depression, etc, and the circumstances that may lead to this. Consequences of feeling depressed/anxious. (nb. Discussion of more than everyday stress.)
10	The nature of friendship	What people want friends for; whether they want friends
11	Social engagement	Comments about social interaction being difficult for an autistic adult, or tiring, or not feeling understood in social situations, or issues about safety.

Lay summary

Why was this study done?

Quality of life (QoL) refers to how satisfied a person is with their life now, taking into account their experiences and the conditions in which they live. There are questionnaires for the general public to rate their QoL, but these may ask questions in ways that are not important or relevant for autistic people; for example, some autistic people have few or no friends, but are fine with this. Also questionnaires miss out topics such as sensory overload that impact on QoL for autistic people.

What was the purpose?

We wanted to try to understand if the questions in the World Health Organization Questionnaire (WHOQOL-BREF for short), and in the optional add-on Disabilities questionnaire, were important and relevant to autistic people from different countries and cultures. We also wanted to find out if autistic people thought there were other important topics missing from these questionnaires.

What did the researchers do?

We held nine consultation groups about the WHO questionnaire items, with 38 autistic people in four countries: United Kingdom, Singapore, Australia, and Argentina. Researchers, including members of the autism community, read the typed out discussions a number of times to find common themes, especially what was particularly relevant, or topics and experiences that were missing. First we analysed the four UK groups, and then the other five groups.

What were the results of the study?

Autistic people we consulted thought that most of the existing items of the WHOQOL questionnaires were important. From the discussions, we found thirteen themes that were identified as particularly relevant to QoL, including being positive about one's autistic identity, other people's (lack of) knowledge of autism, sensory issues, mental health difficulties, the nature of friendships, and supporting other people as carers or volunteers.

What do these findings add to what was already known?

The discussions from the four countries were quite similar. The items from the WHO QoL questionnaires were mostly viewed as important and relevant by autistic people, but a number of issues are missing which seem different in autism and should be included in any improved measurement of QoL.

What are potential weaknesses in the study?

The project was a first step in consultation about measuring autistic adults' QoL, involving only four countries, and all except one group conducted in English. Only one group included people with intellectual disability.

How will these findings help autistic adults now or in the future?

Having good QoL is central for everyone. Our consultation found that some topics highly relevant for autistic people are not included in QoL questionnaires developed for the general population. Our findings suggest it will be both important and possible to develop a set of internationally-appropriate items for autistic people to add to the existing WHO QoL questionnaires. This would allow researchers and health workers to measure accurately the QoL of autistic adults and to be able to judge how helpful supports and services are in improving QoL.