# QORU | quality and outcomes of person-centred care policy research unit

# Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT) - Appendix

Agnes Turnpenny, James Caiels, Tanya Crowther, Lisa Richardson, Beckie Whelton, Julie Beadle-Brown, Julien Forder, Joanna Apps, Stacey Rand

January 2015

University of Kent

THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

UNIVERSITY OF OXFORD

The Policy Research Unit in Quality and Outcomes of person-centred care (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics (LSE) funded by the Department of Health.

Our aim is to improve the quality of health and social care of people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

**CONTACT**

QORU
Personal Social Services Research Unit
University of Kent
Canterbury
CT2 7NF

Email: c.l.heath@kent.ac.uk

www.qoru.ac.uk

## APPENDICES

## APPENDIX 1   THE STAGGERED REVEAL METHOD

The staggered reveal method was designed by the research team to provide a structured approach to facilitate group discussion. It helps to explore in a systematic way the adequacy of the pictures, the clarity of questions and answers, any difficulties in understanding or responding, and how well questions reflect the content of the domains. It also provides an insight into how participants interpret and answer the questions, and how their personal experiences match the answer options. The method was used in the working group and focus groups. The staggered reveal approach consists of the following steps:

1. Picture(s) that accompany the domain are shown to participants and they are asked what the picture(s) show and what they think the question will be about.

2. Another sheet with the same picture(s) and the question stem (the main question without the response categories) is handed to the participants. The question is read out and participants are asked if there are any words that need explaining. The facilitator then checks whether participants understand all the words, particularly those we anticipated to be potentially difficult or complex. Once the facilitator is confident that participants understand the question, they are asked to answer in their own words. Answers are probed and discussed in the group.

3. Participants are shown a third sheet with the full item – picture, question stem and responses. Each response is read out and participants are asked if any words need explanation. Participants' understanding of words is confirmed as in the previous step. Participants are then asked to choose the answer that best describes how they feel and explain why they have chosen that particular option. If necessary, answers are read out more than once.

Initially there was an additional step whereby participants were shown the main picture(s), the question stem and the pictures accompanying the answers (without the answers themselves) before the full question was revealed. Participants were asked to pick an answer based only on the pictures. However, this step was dropped as it did not add much information but it was relatively time consuming.

In the focus groups, participants were shown an additional (fourth) sheet with alternative "short" answer options in addition to the full answer options on the third sheet.

The same procedure is repeated for each domain. The facilitator uses plain language and repeats the same questions for each domain in a consistent manner. The repetition of the questions was found to be helpful as the discussion was predictable for participants and they became increasingly confident in answering and commenting on the questions.

This exercise aimed to explore whether participants were able to use four-item scales adequately. In the focus groups, participants were asked to order two sets of four show cards starting from "best" to "worst" (Figure A2.1) and "most frequent" to "least frequent" (Figure A2.2). All show cards had smiley/sad faces and text. If necessary, participants were given help to read the show cards and move them, but no other support was provided.

**Figure A2.1    Best-worst showcards**



| It is very good | It is quite good | It is quite bad | It is very bad |

**Figure A2.2    Frequency showcards**



| Always | Most of the time | Some of the time | Never |
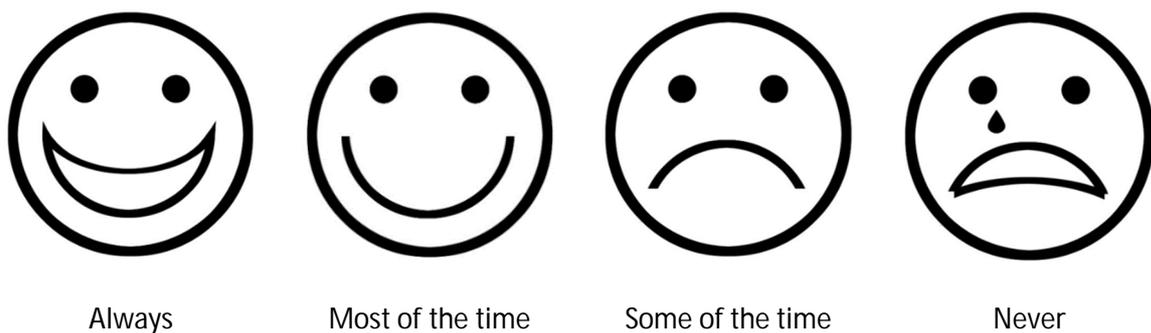
**Introduction**

Thank you for agreeing to talk to us.  My name is _____ and I work at the University of Kent in Canterbury.

We are making a form that can be used to find out about the life of people who use services.  I would like to talk to you about the form.

I will ask you to look at the form and answer the questions. Think out loud as you go along. This means telling me what you think and why you have answered the way you did.
After each question, I will ask you:
- Why you chose a particular answer, and
- What you thought about the question, for example were there any difficult words, was it easy to understand the question etc.

We are interested in how you understand the questions in the Form and how easy or difficult it is to answer them. There are no wrong answers and this isn't a test. We are not doing this to change your support.

Everything you tell us is "confidential". This means that everything you tell me stays between us and other researchers. We won't tell anyone else, except if we think you are in danger of getting hurt.

Everything you say will be kept anonymous.  This means we won't use your name or any other personal information in the report. The people who read the report won't be able to recognise you. Here is copy of **confidentiality information**.

We will always aim to treat people kindly and politely. We will use the information in our report in a respectful way. If you think we treated you unfairly or we do anything bad (we are rude etc.) you can complain. It is OK to complain and it helps us to know if we did anything bad.  Here is a copy of **complaint information**.

I would like to record the interview so that I don't have to make lots of notes during the interview. Only a small team of researchers will be able to listen to the recording and we will delete it when we no longer need it. Is this OK?

Do you have any questions?

Now we will look at the **consent form** (read it together or let them read it and answer the questions. Check if they understand consent).

Do you have any questions?
Are you ready to start? If you need a break or you would like to stop, please let me know.
[start recording, if consented]

**Control**

Read out or let participant read (out) question and answers.

---

This question is about choice in your daily life. Having choice means that you can decide what to do. Think about what choices you have.

How do you feel about choice in your daily life?

Please tick (✓) 1 box

I have as much choice as I want. It is great.

I have enough choice.  It is OK.

I have some choice. But I would like more.

I have no choice. It is bad.

---

Questions/probes:

- How would you answer this question? Which answer would you choose?
- Why? / What were you thinking about when you chose that answer?
- What choices were you thinking about when you answered the question?
- Were the pictures at the top of the page useful? If not, why not? If yes, how were they useful? Probes: in telling you what the question is about? In helping you choose an answer?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?
- Were there any difficult words in the question or the answers? / Any difficult words that you think others might find difficult?

**Personal cleanliness**

Read out or let participant read (out) question and answers.

---

This question is about being presentable.

Being presentable means being clean, having clean clothes and feeling comfortable in what you are wearing.

How presentable do you feel?

Please tick (✔) 1 box

I feel very presentable.

I feel quite presentable. It is OK.

I do feel a bit presentable. It could be better.

I do not feel presentable at all. It is really bad.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / What were you thinking about when you chose that answer?
- Were there any difficult words in the question or the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?
- Do you get any help with keeping clean, having clean clothes and choosing things to wear?

**Food and drink**

Read out or let participant read (out) question and answers.

---

This question is about what you eat and drink. Think about if:

- You can have the food and drinks you like.

- You have enough food and drinks to keep you healthy.

- You can eat and drink as often as you need to.

What do you think about what you eat and drink?

Please tick (✓) 1 box

I get all the food and drink I like when I want.

I get enough of the food and drink I like when I want.

I get some of the food and drink I like when I want, but not enough.

I do not get any of the food and drink I like so I might get ill.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / What were you thinking about when you chose that answer? / What food and drinks were you thinking about? Are there any foods that you can't eat?)
- Do you get any help with your food shopping? If yes, what help do you get? Who helps you?
- Do you get any help with preparing food? If yes, what help do you get? Who helps you?
- Were there any difficult words in the question or the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?

**Accommodation cleanliness and comfort**

Read out or let participant read (out) question and answers.

---

This question is about how clean and comfortable your home is.

Having a clean home means that the kitchen, bathroom, bedrooms and all other rooms are clean and tidy.

Having a comfortable home means that you like how your home looks and feels.

How clean and comfortable is your home?

Please tick (✓) 1 box

My home is as clean and comfortable as I want.

My home is quite clean and comfortable.

My home is not clean and comfortable enough.

My home is not clean and comfortable at all.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / What were you thinking about when you chose that answer? / Which rooms were you thinking about?
- Do you live with others or on your own? If sharing, who are you sharing with?
- Do you get any help with cleaning your home? If yes, what help do you get? Who helps you?
- Were there any difficult words in the question or the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?

**Safety at home**

Read out or let participant read (out) question and answers.

---

This question is about how safe you feel in your home. Feeling safe means that you are not worried about:

- Being bullied or abused.

- Falling or getting hurt.

- Being attacked or robbed.


How safe do you feel in your home?

Please tick (✓) 1 box


I feel very safe in my home.

I feel quite safe in my home.

I do not feel safe enough in my home.

I do not feel safe at all in my home.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / What were you thinking about when you chose that answer? / What things around feeling safe were you thinking when you answered the question?
- Were there any difficult words in the question or in the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?

**Safety outside the home**

Read out or let participant read (out) question and answers.

---

This question is about feeling safe when you go out in your local area.

Feeling safe means that you are not worried about:

- Being bullied or abused.

- Falling or getting hurt.

- Being attacked or robbed.


How safe do you feel when you go out?

Please tick (✓) 1 box


I feel very safe when I go out.

I feel quite safe when I go out.

I do not feel safe enough when I go out.

I do not feel safe at all when I go out.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / What were you thinking about when you chose that answer? / What things around feeling safe were you thinking when you answered the question?
- Were there any difficult words in the question or in the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?

## Social participation

Read out or let participant read (out) question and answers.

---

This question is about your social life.

Social life means spending time with people you like.

This could be friends, family or people in your community.


How do you feel about your social life?

Please tick (✔) 1 box


I see the people I like as much as I want. It is great.

I see the people I like sometimes. It is OK.

I see the people I like but not enough. It could be better.

I do not see the people I like at all. And I feel lonely.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / Who were you thinking about when you chose that answer? (Check if they think about family or friends?)
- When was the last time you saw them? When do you think you will see them again? Is this OK for you? Would you like to see them more?
- Were there any difficult words in the question or in the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?

**Occupation**

Read out or let participant read (out) question and answers.

---

This question is about how you spend your time.

Think about all the things you do during the day. You could think about:

- Your free time.

- Going to work, college or volunteering.

- Housework.


Think about if:

You can choose the things you do.

You enjoy the things you do.

You have enough things to do.


How do you feel about the way you spend your time?

Please tick (✓) 1 box


I spend my time how I want. It is great.

I do enough of the things I like. It is OK.

I do some of the things I like. But I would like to do more.

I do not do the things I like. It is really bad.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / What were you thinking about when you chose that answer?
- Check if they think of all three aspects of the occupation domain: What do you do in your free time? Do you work/go to college? What do you do? Do you like it?
- Is there anything you would like to do more of? What is it? Why you are not doing more of this?
- Were there any difficult words in the question or in the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?

**Dignity**

Do you have any paid support?

If participant has paid support:

Read out or let participant read (out) question and answers.

---

This question is about dignity.

Dignity means being treated nicely and kindly.

How do you feel about the way your paid support treat you?

Please tick (✓) 1 box

I am very happy with the way my paid support treat me.

I am quite happy with the way my paid support treat me.

I am a bit unhappy with the way my paid support treat me.

I am very unhappy with the way my paid support treat me.

---

Questions/probes:

- How would you answer this question? / Which answer would you choose?
- Why? / Who were you thinking about when you chose that answer?
- Were you thinking of one particular staff or everybody? Are you very happy/quite happy/a bit unhappy /very unhappy with the way they all treat you? Has it always been like this?
- Were there any difficult words in the question or in the answers? If yes, which words? Can you think of other words to say it?
- Were the pictures at the top of the page useful? If not, why not?
- Did you look at the smiley faces when you were choosing an answer? Did they help you choose the answer? Why?
- Was it easy or difficult to answer the question?

End of questionnaire.

- What did you think about the Form?
- Is there anything you'd like to change in the form? If yes, what would that be?
- If you got a form like this to fill in, would you ask anybody to help you?
- Who would you ask?
- What would you need help with?

Thank you etc.  [stop recording]

In addition to their integral involvement in developing the tool, members of the working group were also asked about their experiences of this and being part of the research and development process. In part this was to reflect on the approach that had been taken in involving people with learning disabilities and autism, but also to give members of the group an opportunity to express their own views on their involvement and whether they would consider taking part in research in the future. Furthermore, there is potential for data collected as part of this process to form the basis of an 'information for potential participants' document. The purpose of this would be to show others what it is like to take part and work with researchers, and to help people decide whether or not they would like to take part.

Participants were initially asked to explain the work that we had been doing in their own words and describe each of the sessions that had been held. Overall, participants were able to describe the purpose of the working group, with one participant explaining that *"we have been working on the form to make it easier for people to understand"*.

Going through and recalling each of the working group sessions was difficult for some members, and it was agreed by researchers and members that ending each of the sessions with a brief recorded summary that everyone could have then taken away or received separately would have been useful, particularly as a reminder of the previous work before attending the next group.

Despite difficulty for some, participants were able to remember and describe each of the groups. Participants described the first group as *"a welcome one [meeting] and that the researchers had told us about it [the project], what we'll be doing"*. Participants also recalled completing consent forms and being told that *"we didn't have to come if we didn't like the working group or changed our mind about being involved"*, as well as setting ground rules for each of the groups around confidentially and allowing individuals in the group to speak without interruption. Participants described doing the work in the second and third groups as *"looking at the pictures because they weren't very self-explanatory so we had to make some improvements on them"* and subsequently that *"we looked at the writing"*. In addition, participants recalled that *"we used recorders and wrote things down"* and also making improvements to the questionnaire: *"we improved it [the questionnaire] by looking at it again and came up with yellow forms and thought that's okay"*. Lastly, participants remembered that they were each given high street vouchers as a thank you for taking part in the groups and that they enjoyed the lunch that was provided at the groups.

We asked participants to provide feedback about their experience of being part of the working group and the impact that it had on them. Participants all agreed that they would recommend taking part to others and gave a number of reasons for this including: *"being part of a group"* and using it as a good way of *"meeting new people"*. Participants also pointed to more altruistic reasons for being glad to take part such as contributing to something that would help others. One participant commented that it had been: *"very interesting and helpful for me and for other people"*. Some participants also reported a personal impact on them such as improving confidence and learning themselves, commenting that: *"it has helped me to be more confident"* and *"I learn at the same time when working with researchers"*.

Participants reported that they had been given enough support by the core team of researchers and that they were happy with the number of researchers present at each meeting, which varied from three to four. One participant suggested that the timing and frequency of the meetings was slightly sporadic and *"drawn out"*, which sometimes made it difficult to remember what they had done at the previous meeting and, as above, participants agreed that being provided with a summary after each meeting would have been beneficial. The research team agreed that future work would incorporate this.

Many of the major changes that were made to the pictures and wording of the questionnaire were as a result of the working group sessions, with much of the refinement and modifications to fine-tune the questionnaire being made during the subsequent fieldwork (focus groups and cognitive interviews). The value of the working group and the considerable benefit of including users and user groups from the early stages of development were highlighted by this process.