Developing accessible versions of ASCOT: QORU Engagement programme

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Engagement programme – background

- Research on the impact of social care at PSSRU.

- Personal Social Services Adult Social Care Survey (ASCS).
  - Annual survey of social care service users receiving services funded wholly or partly by Social Services.

- Not everyone can answer for themselves, even with support.

- 14.5% of service users in 2012 receiving the ASCS had a learning disability.

- 71% of service users reported having help to complete the questionnaire.

Engagement programme

- Range of associated problems with any long term condition can make it more difficult for people to take part in research.

- Structured format of surveys can be challenging for people with cognitive or intellectual disabilities which can lead to exclusion.

- For some individuals the risk of exclusion is high.

Engagement programme

- Engagement is one of a number of programmes running under QORU.
  - Application, Measurement, Service Delivery

- Measurement is a core government mechanism to manage accountability.

- If such measurement is to be rigorous, valid and unbiased, it must include the voices of those populations or individuals that are reluctant to take part, hard to include or seldom heard.
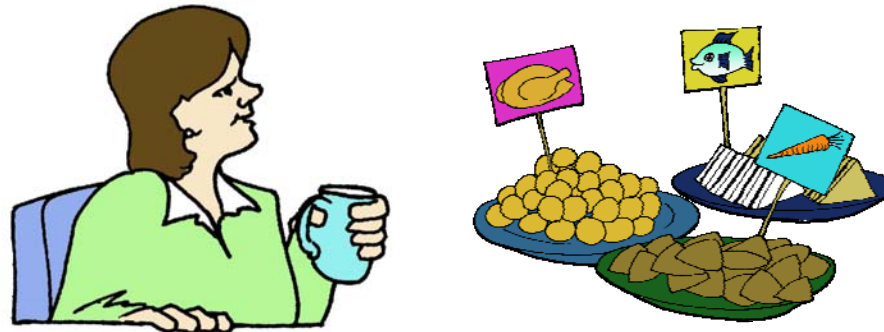
Programme strands and aims

- Easy read version
  - Develop an easy read version of ASCOT

- Proxy version
  - Develop a proxy version of ASCOT for formal and informal Carers

- Semi-structured Interview version
  - Develop a semi-structured interview version of ASCOT

- Community Observation version
  - Explore feasibility of using observation in a community setting

Easy Read Version

- An easy read version was developed as part of the ASCS.

  – Undertaken under tight time pressures with aim of minimizing differences for comparison.

  – Feedback from user groups suggest revision would be beneficial

- More systematic approach to revising:

  – Working group;

  – Change (easy read illustration design);

  – Focus groups;

  – Cognitive interviews.

Easy Read Version

Food and drink domain

Version 1

Revised

Easy Read Version

- Changes thus far:

  – Yellow paper

  – New black and white pictures

  – Amended 'happy' and 'sad' faces for response categories

  – Amended wording for domains

  – Safety domain split

- Next steps

  – Cognitive testing with people with learning disabilities

  – Analysis and final revisions

Proxy Version

- Approach:
  - Contact homecare providers and informal Carer support organisations.

  - Focus groups with paid care workers.

  - Focus groups with informal Carers
    one to one interviews with informal Carers.

  - Examine domains and domain questions
    - Can a proxy answer these questions?
    - How should they be amended for proxy respondents?

Proxy Version

- Issues related to using a proxy:

  - Who's view are we really getting?

  - Identifying the best person to complete a proxy questionnaire.

  - Knowledge of the service user and their preferences.

  - Gaming.

    - Paid Carers 'self-assessment'

    - Informal Carer 'agenda' for improving or increasing service provision

Proxy Version

- Some early findings (formal Carers):

  - Person centred ethos of provision of social care conflicts with the idea of being a proxy.

  - Want to evidence / justify *why* a certain response has been chosen.

  - Need to have supported / worked with individual for a substantial period of time.

  - Two sets of responses? One for 'what I think the service user would say' and one for 'my professional opinion' as a Care worker.

  - Difficulty of commenting on domains that rely heavily on how someone 'feels' e.g. dignity, safety.

- Next steps

  - Analysis, development, cognitive testing

Semi-structured Interview Version

- People unable to complete or take part in a structured questionnaire can comment on the domains.

- Semi-structured interviews can gather data on the domains without asking people to do cognitively difficult tasks.

- People can comment on:

  - how their lunch was that day;

  - what they have done that morning;

  - opportunity to capture information in a less structured way.

Semi-structured Interview Version

- **Food and drink**
  - *What do you think about the food you get here? What is the food like?*
  - *How was lunch/breakfast today?*
  - *Where do you eat your meals?*
  - *Tell me what happens at mealtimes?*
  - *Do you think you are getting enough food and drink?*
  - *Do you get food and drink at times that suit you?*
  - *Are you able to have a snack outside of mealtimes? How would you get a snack outside of mealtimes?*
  - *Are you able to access the kitchen here?*
  - *If you want a drink, how do you get one?*
  - *How much choice do you have over the food and drink here?*

Semi-structured Interview Version

- Provisional semi-structured interview schedule based around ASCOT domains.

  - tested with 36 residents living in six older adult care homes.

  - Interviews often did not cover all eight domains.

  - Some domains more difficult to cover than others: dignity; safety; personal cleanliness and comfort.

- Next steps

  - Amend prompts and re-test.

Community Observation Version

- Derived from observational tool in residential care setting.

- Feasibility stage

  – of using observation in peoples' homes.

  – PIIG review of methodology.

    - Complex multi-layered recruitment process.

Reports

- Work ongoing - most to complete end 2014

  - Easy read, summer 2014

  - Semi-structured, late summer 2014

  - Proxy, winter 2014

  - Observational, provisional start spring 2015

- All reports will be available on the QORU and PSSRU website.

- Dissemination to include: peer reviewed journal articles; conference presentations; social media.

Further information

For more information see QORUwebsite:
http://www.qoru.ac.uk/

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