Supplemental material

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**Supplementary Material: Acceptability of PROMs in a Cystic Fibrosis Data Registry**

**Interview Guide (Patient version)**

1. First focusing on the CFQ-R, how did you find completing the questionnaire?
   a. Did you time how long it took you to complete the survey? What did you think of the length of the survey?
   b. Could you understand the questions? Did you need someone else's help to complete it?
   c. Was there any ambiguity in the questions?
   d. Thinking about the response options, were these difficult to choose between? Could you suggest a better way of wording the responses?
   e. Were there any problems you encountered while completing the questionnaire?
2. Did you think the CFQ-R questions captured the most important and difficult parts of your experience with CF?
   a. How precisely do these statements relate to your everyday life?
   b. Are there any questions you thought were irrelevant e.g. any symptoms you haven't had trouble with at all?
   c. Are there any questions you could add?
3. Now let's talk about the CFQoL, how did you find completing the questionnaire?
   a. Did you time how long it took you to complete the survey? What did you think of the length of the survey?
   b. Could you understand the questions? Did you need someone else's help to complete it?
   c. Was there any ambiguity in the questions?
   d. Thinking about the response options, were these difficult to choose between? Could you suggest a better way of wording the responses?
   e. Were there any problems or difficulties you encountered while completing the questionnaire?
4. Did you think the CFQoL questions captured the most important and difficult parts of your experience with CF?
   a. How precisely do these statements relate to your everyday life?
   b. Are there any questions you thought were irrelevant e.g. any symptoms you haven't had trouble with at all?
   c. Are there any questions you could add?
5. When you compare the CFQ-R and the CFQoL can you name any advantages one has over the other?

6. How much do you know about the Australian cystic fibrosis registry and how it collects data?

7. Now that you've read these two questionnaires, do you think the information they collect would be useful to include in the registry?

8. If these questionnaires are incorporated in the registry, how often would you be happy to fill out the questionnaire?

    a. What would be a barrier to filling out the questionnaire?

    b. Where would you want to fill out the survey; e.g. at home or at clinic

    c. How would you want the survey to be administered; e.g. electronically, on paper

9. For young children, do you think that they should fill out the survey themselves or do you think we would get the same information if their parents filled it out for them?

    a. How well do parents understand the experiences of their children?

    b. What age do you think children should start filling it out for themselves?

10. A possible future use for the questionnaires is that they are made available to your doctors, who can talk to you about the results.

    a. Would you be happy with your doctor having access to these results?

    b. Do you think there are any possible advantages or disadvantages of being able to use these results in consultations with your doctor?

**Initial Inductive Codes and Resulting Categories**

| Category | Subcategory | Inductive codes |
|---|---|---|
| **Clinical utility** | Barriers clinical utility | Age when useful in consultation |
| | | Interpretation difficulty |
| | | Linkage services |
| | | Mental health benefits only |
| | | Only useful when problem |
| | | Time barrier use consultation |
| | | Unnecessary during consult |
| | Potential use consultation | Identify red flags |
| | | Enable specificity |
| | | Use in team meeting |
| | | Useful when uncomfortable speaking |
| | - | Processes for clinical use |
| | - | Support consultation clinician |
| | - | Support consultation patient |
| **Usefulness within registry data** | - | Historical registry data |
| | - | Use registry trends in consultation |
| | - | Need explanation in registry data |
| **Implementation benefits** | Population level use | Benchmarking use |
| | | Potential drug monitoring |
| | | Research potential |
| | | Policy development potential |
| | | Population trends |
| | Background | CF experience changing |
| | | CF mental health importance |
| | Importance information capture | Lack information |
| | | Lack QOL data capture |
| | | Individual trends |
| | | Investigate impact CF on life |
| | Individual benefit | Correlate medical and psychosocial |
| | | Mental health benefits |
| | | Patient learning experiences others |
| | Potential clinician education | CF team agreement |
| | | Mismatch doctors patient |
| | - | Support implementation |
| **Method of administration** | Clinic administration | Clinic admin variable |
| | | Clinic administration barriers |
| | | Clinic administration benefits |
| | Electronic administration | Electronic benefits |
| | | Electronic resources variable |
| | Home Administration | Home benefits |
| | Paper administration | Paper preference and feasibility |
| | - | Admin patient option importance |
| **Frequency of administration** | Annual review | Annual review admin |
| | | Annual review barriers |
| | | Lack of compliance annually |
| | - | Administration vary based on aim |
| | - | Benefits increased frequency |
| | - | Compliance varies between people |
| | - | Disadvantages increased frequency |
| | - | Need for external recommendation |

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| Category | Subcategory | Inductive codes |
|---|---|---|
| | - | Preference frequency admin clinician |
| | - | Preference frequency admin patient |
| | - | Administration different age groups |
| | - | Adult admin only |
| **Barriers to administration** | Resources | Lack resourcing interview and follow up |
| | | Lack staff data entry |
| | | Follow up staff available |
| | | Resources available |
| | Compliance | Barrier patient burden |
| | | Loss registry participants |
| | - | Artificial changes recorded |
| | - | Barrier literacy |
| | - | Barrier newly diagnosed |
| | - | Inability questionnaire capture diversity |
| **Considerations for implementation** | Follow up processes | Difficulty identifying red flags |
| | | Follow up lack resources |
| | | Follow up necessity |
| | | Methods identify red flags |
| | | Red flag rarity |
| | - | Confidentiality |
| | - | Importance clear aim |
| | - | Reminder process |
| **Parent proxy use** | Assistance for young children | Requirement interviewer |
| | | Reword younger children |
| | Inability young children self- report | Varied ability of children to self-report |
| | | Confronting for young children |
| | Barriers to proxy use | Bringing up conflict |
| | | Different parent completion |
| | | Proxy difficulty emotional |
| | | Proxy difficulty separating |
| | | Proxy mismatch parents children |
| | | Proxy unclear |
| | - | Child involvement |
| | - | Encourage child participation |
| | - | Parent version |
| | - | Proxy variables |