

Development of EQ-5D-5L bolt-ons for cognition and vision

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Background

In certain circumstances, the **EQ-5D** is insensitive to changes or differences in **health status**. **'Bolt-on' dimensions** could provide additional information about certain conditions or symptoms. Previous research has highlighted **cognition** and **vision** as good candidates for bolt-ons. Cognition and vision bolt-ons have been used in the past, but with **limited development**. No study has developed bolt-on descriptors in a programme of **qualitative** and **quantitative** research.

Aim

- To identify the **dimensions** of health-related quality of life that are important to people with lived experience of cognitive impairment and visual impairment.
- To develop EQ-5D-5L bolt-on descriptors for cognition and vision, using suitable **terminology**.

Methods

- Recruitment of people with a range of experiences, including carers.
- Focus groups:** two for each bolt-on, 4-9 participants.
- Semi-structured interviews:** three for each bolt-on.
- Thematic analysis of transcriptions.

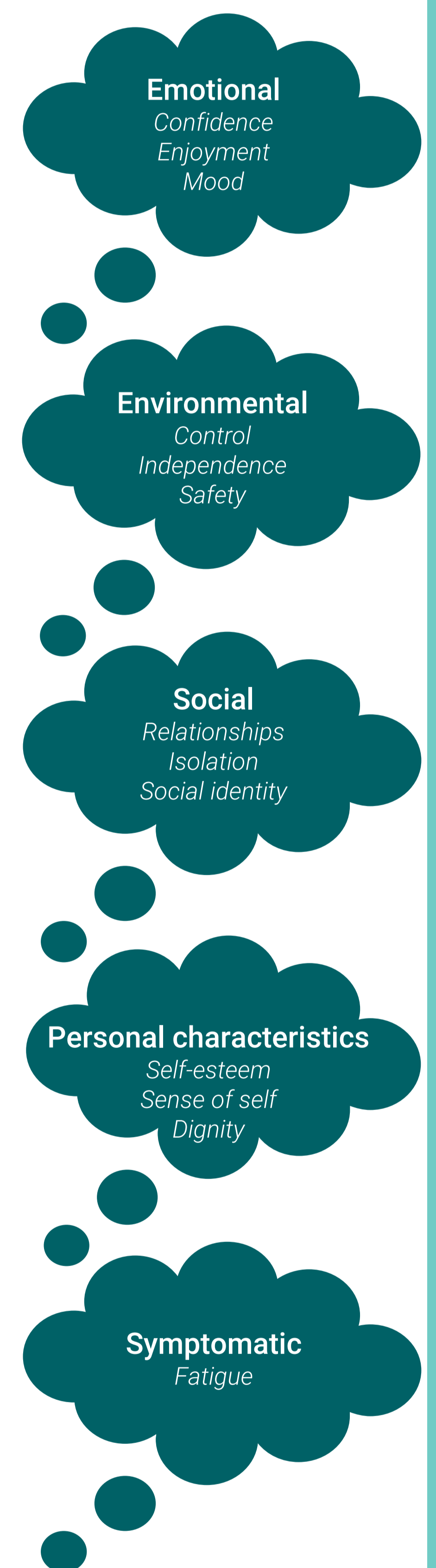
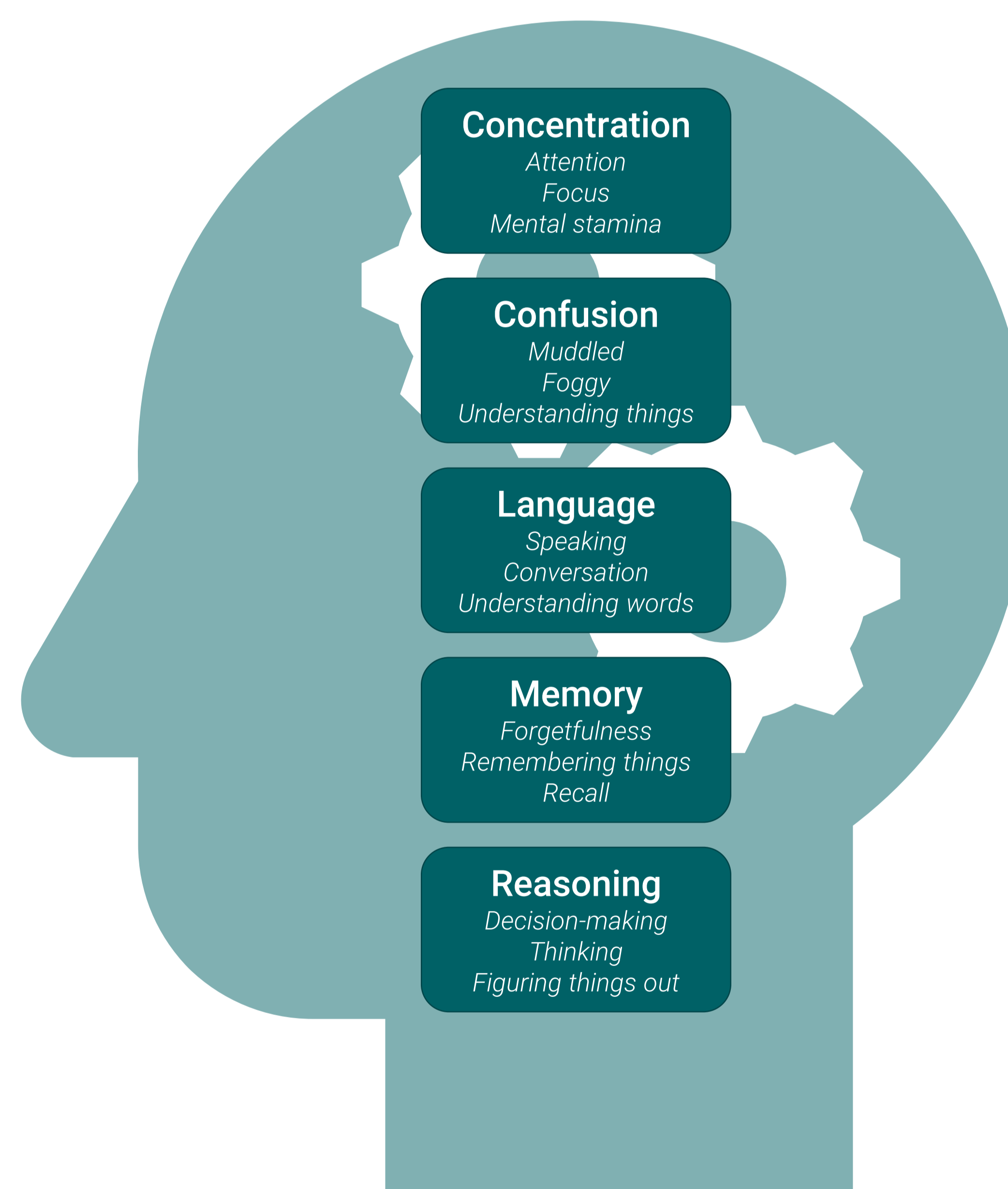
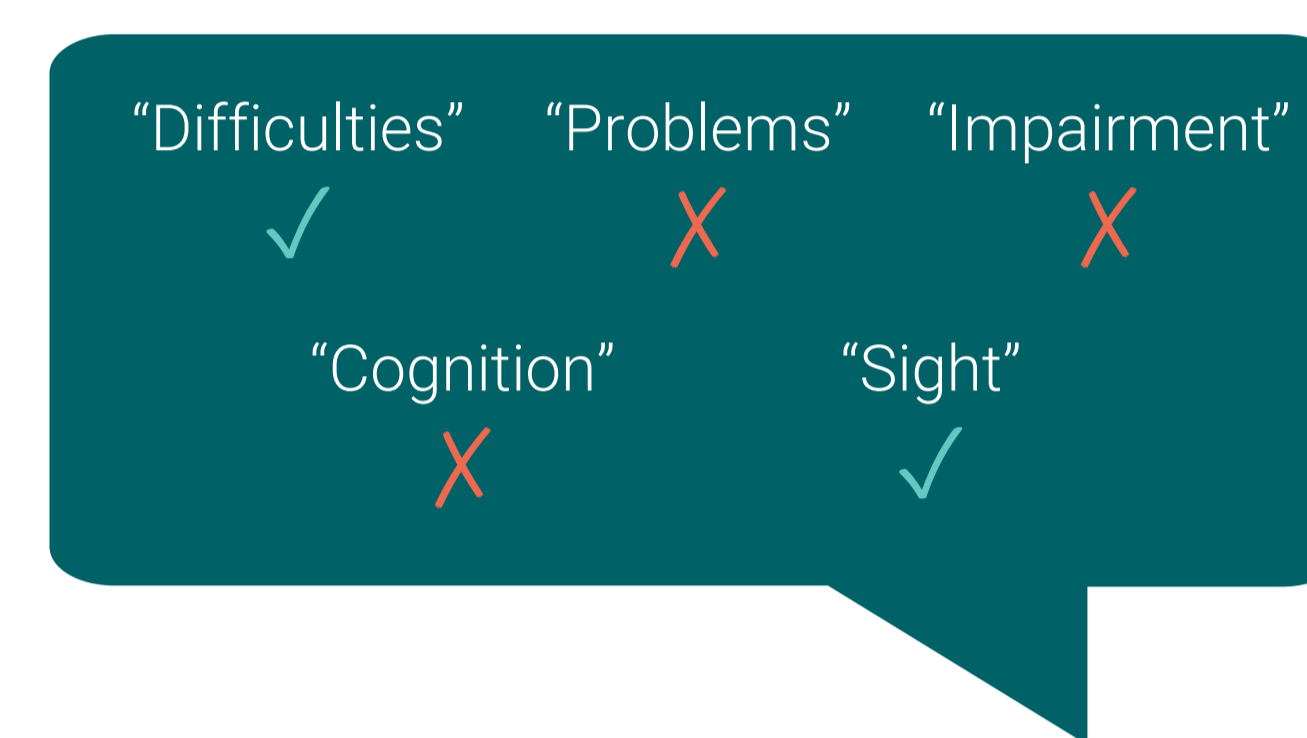
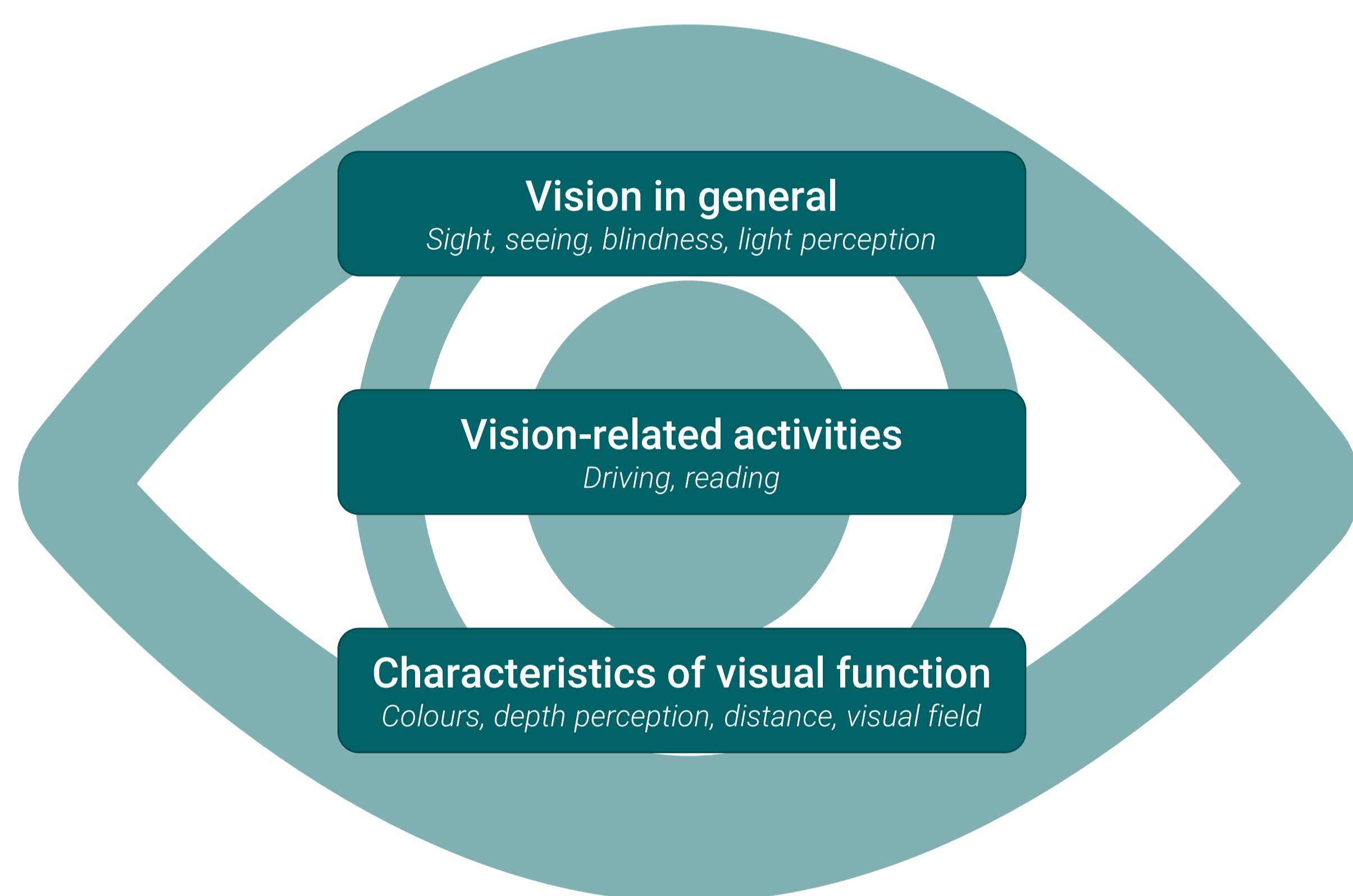
Results

Dimensions

- Participants identified a variety of distinct **cognition-specific** dimensions.
 - These were described using various terms, which we grouped together for coding.
- The vision group mostly described their experiences with reference to their level of **vision in general**.
 - Specific characteristics of visual function were not framed as capturing the impact on quality of life.
- Similar **generic dimensions** arose in both groups, in varying degrees.

Terminology

- Certain terminology used in the study, including **'impairment'**, was identified as problematic.
 - The term **'cognition'** was not recognised as useful.
 - The vision group tended to use the term **'sight'** or 'seeing' rather than 'vision'.
 - Some participants preferred the term **'difficulties'** to **'problems'**.
- In general, the existing **'severity' terminology** of the EQ-5D-5L was acceptable (e.g. slight/moderate/severe).



Discussion

- This is the first study to report on the development of bolt-ons using focus groups.
- To develop a generic descriptor, it is necessary to recruit people with a range of different experiences. It was very difficult to coordinate focus groups with such a group, which meant that we needed to conduct interviews in lieu of more focus groups.
- People do not conceptualise the impact of impairment on their health-related quality of life in terms of their functioning. Rather, people consider broader impacts on quality of life. This made the identification of specific terminology relating to functioning a challenge.
- Without prompting, the participants identified dimensions (both specific and broad) that are not currently captured by the EQ-5D, implying the legitimacy of the bolt-ons research.
- Cognitive impairment is made up of distinct functional impacts, implying the need for a multi-item bolt-on.
- The functional impact of visual impairment was described in general terms. Some people spoke about characteristics of visual function, but these were too diverse to be useful as bolt-ons.
- Some participants disliked negative framing (e.g. "problems") or 'clinical' terms (e.g. "impairment").

Conclusions

- The development of bolt-on descriptors using focus groups is challenging because of the need to recruit a heterogeneous population.
- A cognition bolt-on will probably require multiple items.
- 'Vision in general' may be a suitable single-item bolt-on.
- The current structure of the EQ-5D-5L is amenable to bolt-ons for cognition and vision.
- Terminology is very important – certain words are not meaningful to people with lived experience.
- It will be necessary to test a range of wordings in qualitative interviews.
- Quantitative research is needed to determine the additional information provided by the candidate bolt-ons.



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