Co-Designing a digital solution using Patient Reported Outcome Measures for People with Dementia
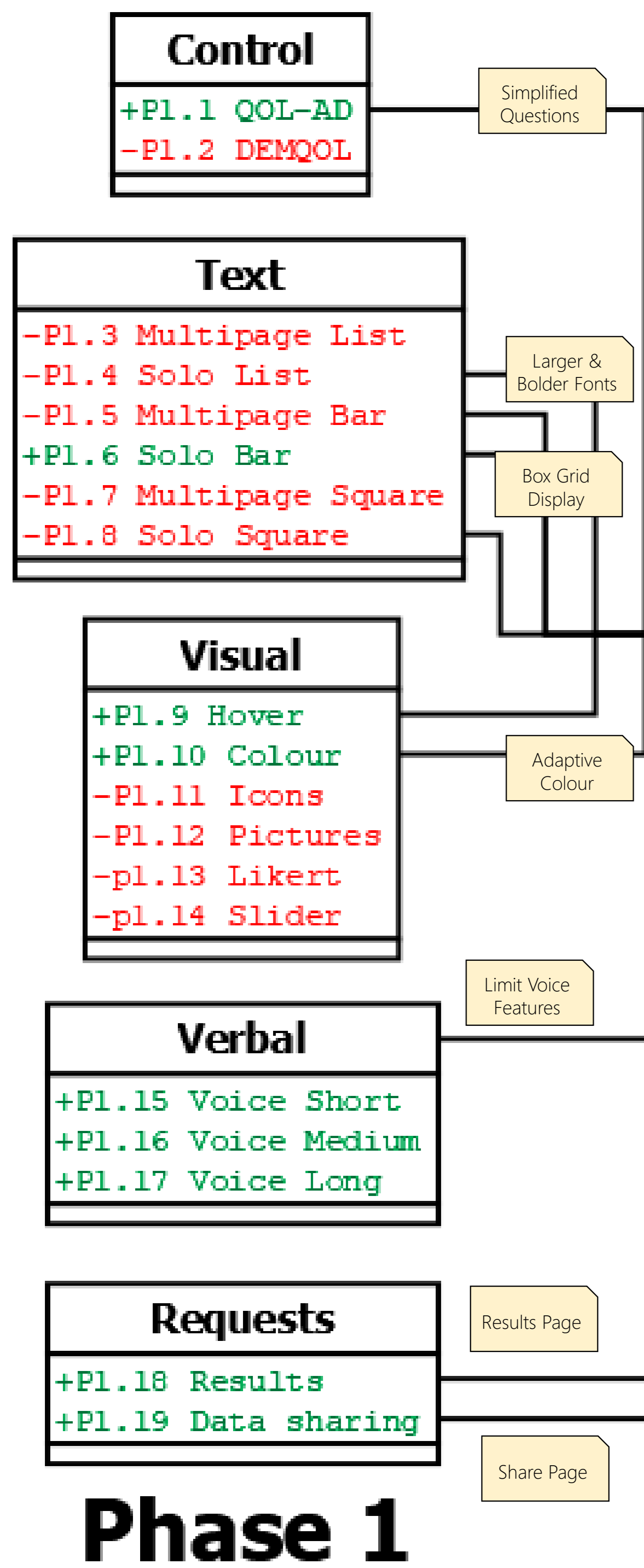
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CAPITA

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Background

Patient Reported Outcome Measures (PROMs) are tools used to routinely measure subjective outcomes directly from patients during health care or treatment and are an effective way of determining an individual's changing needs.

Digital technologies have increasingly enabled PROMs to be self-reported by patients and collected remotely though this can be a major barrier to People with Dementia (PwD) who often struggle using electronic devices.
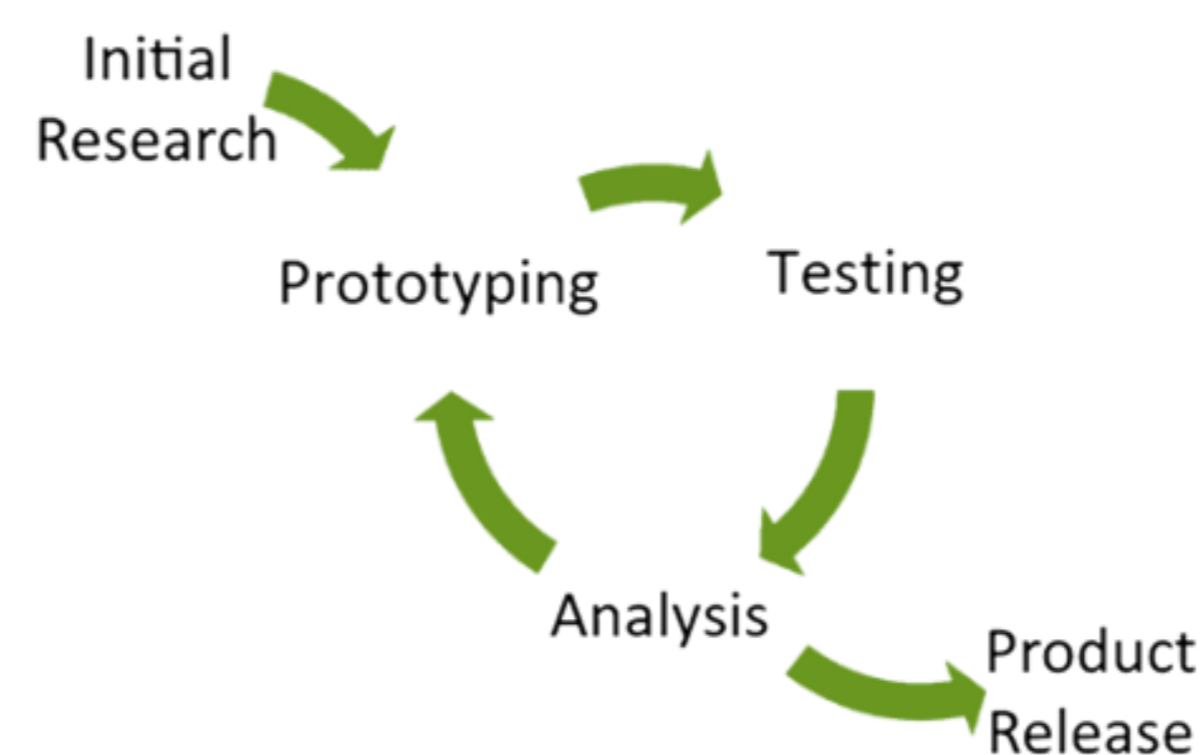
Aim & Methods

"to co-design, develop and evaluate a novel digital application to enable People with Dementia to regularly self-report Quality of Life Patient Reported Outcome Measures"
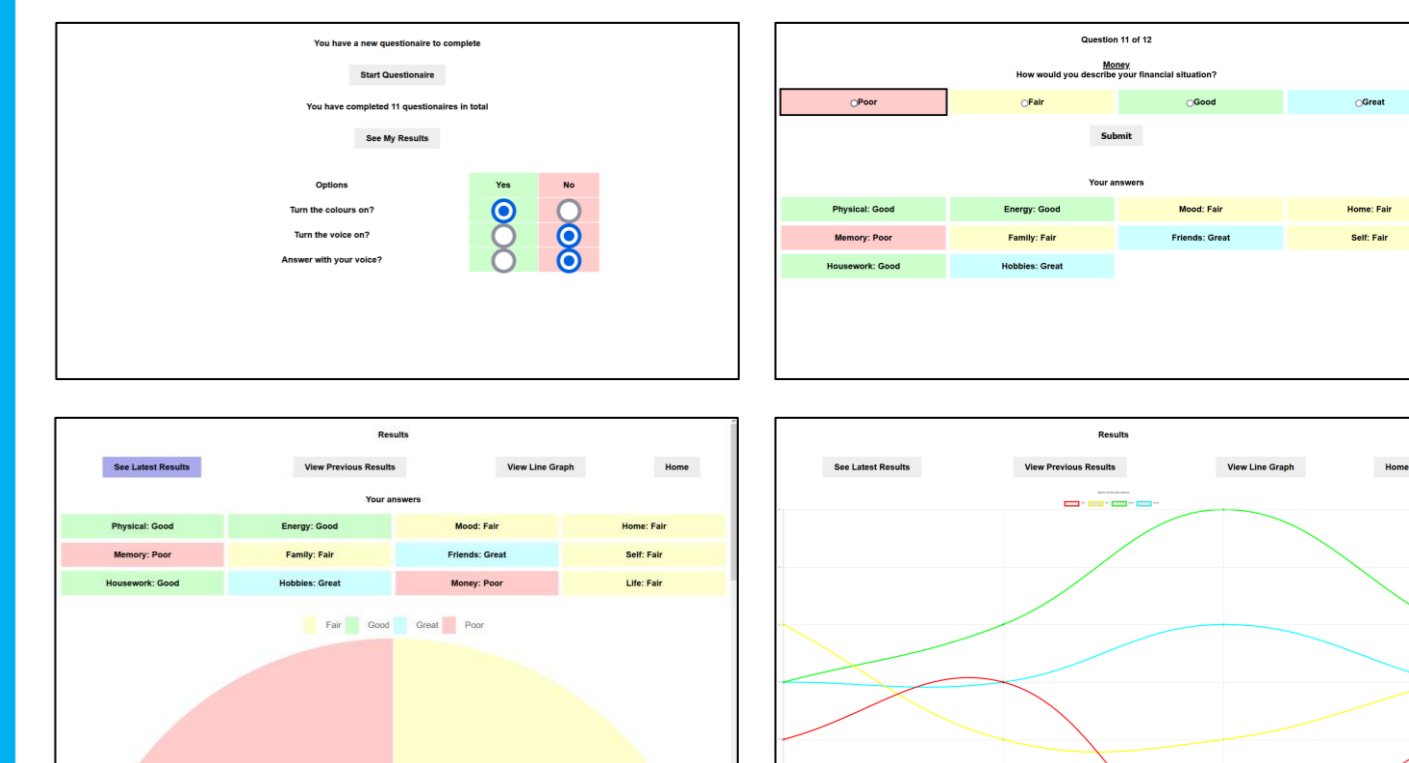
This Qualitative Research Project co-designed, developed and evaluated multi-modal (text, visual, voice) prototypes directly with PwD.

Using an iterative co-design methodology, PwD were directly involved in every stage of the development process, from initial concepts to functional prototypes, voting for each feature included.

Initial Research → Prototyping → Testing → Analysis → Product Release

Results

Control
+P1.1 QOL-AD
−P1.2 DEMQOL

Simplified Questions

Text
−P1.3 Multipage List
−P1.4 Solo List
−P1.5 Multipage Bar
+P1.6 Solo Bar
−P1.7 Multipage Square
−P1.8 Solo Square

Larger & Bolder Fonts

Box Grid Display

Visual
+P1.9 Hover
+P1.10 Colour
−P1.11 Icons
−P1.12 Pictures
−pl.13 Likert
−pl.14 Slider

Adaptive Colour

Verbal
+P1.15 Voice Short
+P1.16 Voice Medium
+P1.17 Voice Long

Limit Voice Features

Requests
+P1.18 Results
+P1.19 Data sharing

Results Page

Share Page

Phase 1

Interactive
+P2.1 Audio Visual
+P2.2 Tracking
−P2.3 Zoom
−P2.4 Pan

Multi-modal Options

Display Responses

Results
−P2.5 Results
−P2.6 Answers
−P2.7 Aggregated
+P2.8 Listed
+P2.9 Chart
+P2.10 Line

Visual charts

Data Sharing
+P2.11 Share

User Autonomy

Phase 2

Words
+P3.1 Questions
+P3.2 Answers

Refine Questions

Voice
−P3.3 Voice

MultiModal
+P3.4 Pre-Production

Refine Questions

Phase 3

Multi Modal
+P4.1 Beta

Final Functional Prototype

Phase 4

Conclusion

A total of 33 prototypes were developed over 4 iterative co-design phases resulting in a final functional prototype

Users highlighted the importance of personalisation with user accessible features to turn colours or voice on/off and skip or exclude questions being key.

Existing dementia PROM terminology was deemed inappropriate and non-inclusive with significant changes needed.

Preferences for text-based modalities with limited visuals. Voice modalities were universally disliked.

Users were keen on being in control of their own data, requesting access rights to their results as well as the ability to choose who and when to share the data.