The Patient - Patient-Centered Outcomes Research

The Parker Model: Applying a Qualitative 3-Step Approach to Optimally Utilize Input from Stakeholders When Introducing New Device Technologies in the Management of Chronic Rheumatic Diseases

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SUPPLEMENTARY MATERIAL

SUPPLEMENTARY METHODS

Summary of Concept Mapping Methodology

The following excerpt from Trochim, W. & Kane M. (2005) Concept Mapping: An introduction to structured conceptualization in health care. *International Journal for Quality in Health Care*;17(3): 187–191, summarises the concept mapping methodology used in this study:

"The concept mapping analysis encompasses the organization and representation phases. The core data for a map come from the unstructured or free sort where each participant groups the generated statements into piles of similar ones. Participants are free to use as few or as many piles as they think necessary to arrange the statement set meaningfully in terms of their similarity. These data are decidedly judgmental and qualitative. To use the data in the subsequent quantitative multivariate analyses, each sort is first converted to a 0,1 co-occurrence matrix that has as many rows and columns as there are statements, where a 1 is entered into a cell if the row and column statement pair were placed by the participant in the same pile and a 0 is entered if the statements were not sorted together in a pile. These matrices are then summed across all participants, yielding a similarity matrix that indicates the number of participants that sorted each pair of statements together. This summed square similarity matrix is the input for multidimensional scaling (MDS) analysis which takes (dis)similarity data and represents them as distances in Euclidean space. In concept

mapping, the MDS solution is typically restricted to two dimensions to allow for the integration of additional information from cluster and rating analyses. Thus, for each statement the MDS analysis yields an x and y value. When plotted in a bivariate plot these constitute the basic point map form of the concept map. The MDS x,y values are the input for hierarchical cluster analysis using Ward's algorithm, which has the effect of partitioning the MDS statement map hierarchically into non-overlapping clusters. Typically the analyst facilitates the discussion of a subgroup of participants who select the number of clusters most useful for the purposes at hand. This cluster arrangement is superimposed on the point map (the cluster map) and the participant group typically names these clusters. If rating data were collected in the project, they can be averaged for all participants and for any subgroups and can be overlaid on a point or cluster concept map to identify meaningful patterns.

In addition to the point and cluster maps (with or without ratings overlaid) several graphics have proven indispensable, especially for comparing multiple patterns of ratings at either the cluster or point level. The pattern match or 'ladder' graph, is a bivariate comparison of the cluster average ratings that shows aggregate patterns and can be used to compare for a single variable the ratings of multiple groups or waves of measurement, or to compare multiple variables. Instead of being arranged in typical x,y axis form, the two axes are set vertically side by side and joined by a separate line for each cluster that indicates average cluster rating. This arrangement makes it much easier than a bivariate plot does to detect visually whether there is overall agreement between patterns and where the patterns may specifically disagree. The 'go-zone' graph is a bivariate plot of two patterns of ratings at the statement level. The bivariate space is divided into quadrants based on the average x and y values. For example, when comparing an importance and feasibility rating of the statements, the go-zone is the quadrant showing the statements simultaneously rated above average in both importance and feasibility. While pattern matching is especially useful for high-level pattern assessment, go-zones are particularly valuable for detailed use of the maps for planning or evaluation at the statement level. The point and cluster concept maps, with various rating data overlaid, the pattern matches and go-zones, and accompanying detailed tabular statistical results constitute the primary analytical results that the participants subsequently interpret and utilize.

To illustrate the use of concept mapping in health care contexts, the basic results from a health planning project are presented briefly here. The project was undertaken because a

state in the USA needed to develop rapidly a comprehensive statewide plan for the use of significant unexpected funds from the tobacco settlement agreement. Concept mapping was especially appropriate because of the complex nature of the task and the political need for both speed and involvement of multiple stakeholders (including all constituencies across the state and a variety of subject-matter expert consultants throughout the USA). Figure 1 shows the point and cluster concept map of the 90 brainstormed ideas, where MDS analysis determined the point location and hierarchical cluster analysis partitioned the point space into seven clusters of issues that were interpreted by participants as a two-dimensional matrix that crosses domain (system versus community factors) by level (structure, infrastructure, or transmission)."

Summary of the heiQ

The heiQ has 40 items across 8 subscales: "Health-directed activities"; "Positive and active engagement in life"; "Emotional distress", which explores the negative impact of the disease in terms of anxiety, stress, anger and depression; "Self-monitoring and insight"; "Constructive attitudes and approaches"; "Skill and technique acquisition" assesses improvements in knowledge-based skills and health management techniques; "Social integration and support"; and "Health service navigation".

Summary of the SUTAQ

The SUTAQ consists of 22 items divided into 6 different subscales: "Enhanced care" comprises items regarding patients' concerns about health status, their perception of active involvement, recommendations to people in a similar condition, and perceptions of enhanced care; "Increased accessibility" includes questions about patients' perception of time saving, of increased access to care, of health improvement and of easier contact with professionals; "Privacy and discomfort" is composed of items related to patients' concerns about privacy and their perception of discomfort; "Care personnel concerns" includes questions about patients' perception of continuity of care and concerns related to personnel involved; "Kit as substitution" covers patients' concerns about health status and their perception of the e-Device as a substitute for regular care and face-to-face consultations; "Satisfaction" includes questions about patients' satisfaction and their understanding of the e-Device.

Summary of eHLQ

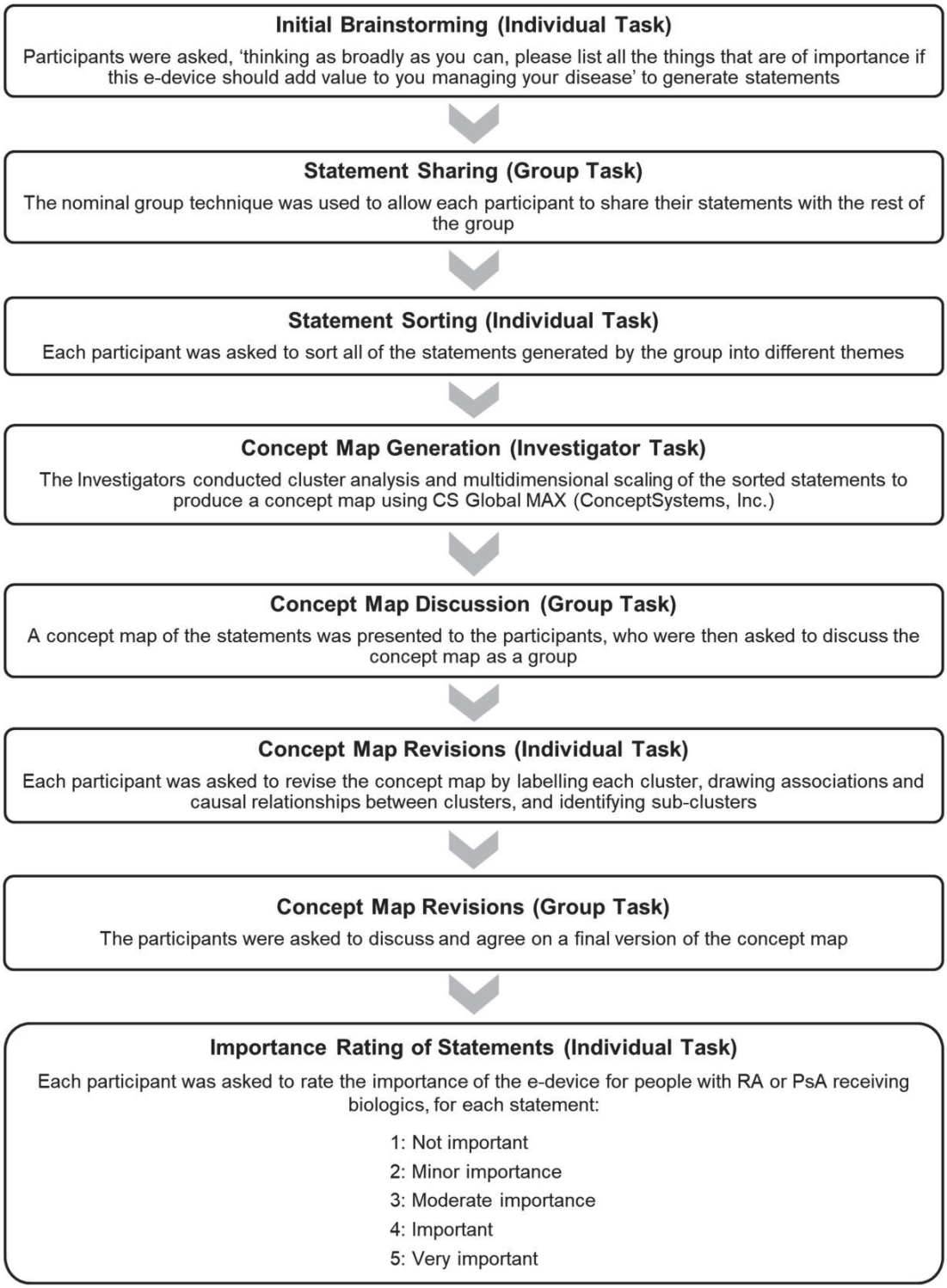
The eHLQ asks participant to score 35 short statements reflecting 7 subscales: "Ability to process information"; "Engagement in own health"; "Ability to actively engage with digital services"; "Feel safe and in control"; "Motivated to engage with digital services"; "Access to digital services that work"; and "Digital services that suit individual needs".

SUPPLEMENTARY RESULTS

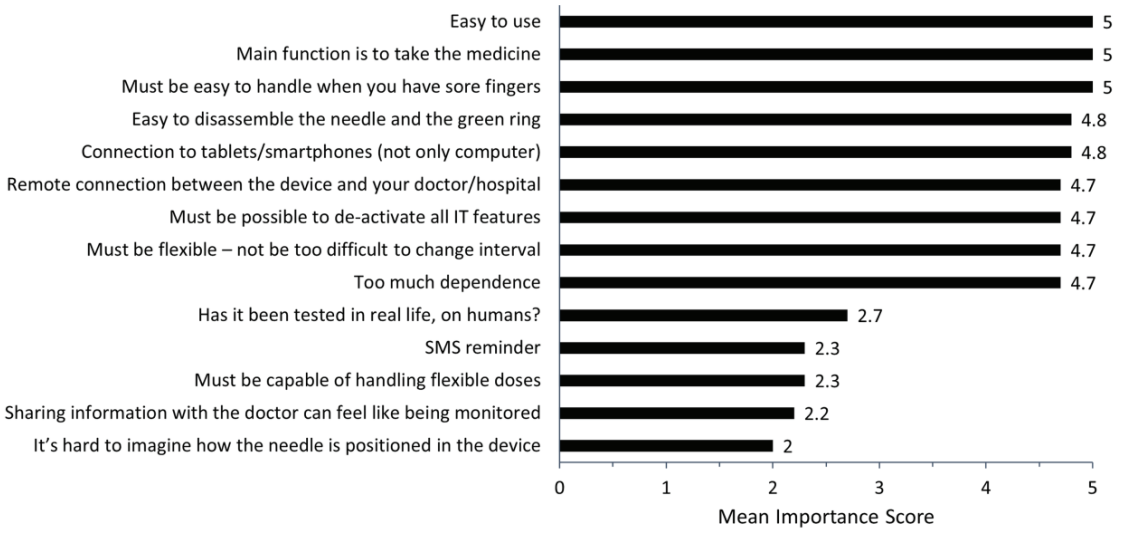
Supplementary Table 1. Demographic characteristics of patients responding to the questionnaire

Demographic characteristic, % (n) unless stated otherwise	Male Patients (n=7)	Female Patients (n=5)	Overall (n=12)
Mean age (years)	63.7	60.8	62.5
Disease			
Rheumatoid arthritis	71 (5)	60 (3)	67 (8)
Ankylosing spondylitis	0 (0)	20 (1)	8 (1)
Psoriatic arthritis	29 (2)	20 (1)	25 (3)
Disease duration			
< 5 years	14 (1)	0 (0)	8 (1)
5–10 years	28 (2)	60 (3)	42 (5)
> 10 years	57 (4)	40 (2)	50 (6)
Duration of treatment with certolizumab pegol			
≤ 2 years	71 (5)	20 (1)	50 (6)
> 2 years and ≤ 4 years	29 (2)	80 (4)	50 (6)
Education level			
Elementary school	14 (1)	0 (0)	8 (1)
Craftsman	57 (4)	20 (1)	42 (5)
Higher education (≤ 9 years)	0 (0)	0 (0)	0 (0)
Higher education (> 9 years and ≤ 12 years)	29 (2)	40 (2)	33 (4)
Higher education (> 12 years)	0 (0)	20 (1)	8 (1)
Other	0 (0)	20 (1)	8 (1)
Employment status			
Employed	29 (2)	40 (2)	33 (4)
Unemployed	0 (0)	0 (0)	0 (0)
Retired	71 (5)	60 (3)	67 (8)
Not stated	0 (0)	0 (0)	0 (0)

Supplementary Figure 1. The concept mapping workshop process



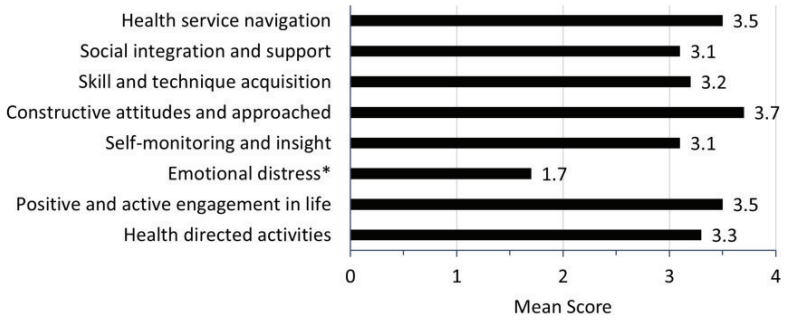
Supplementary Figure 2. The mean patient-assigned importance ratings of a sample of statements generated by patients during the concept mapping workshops



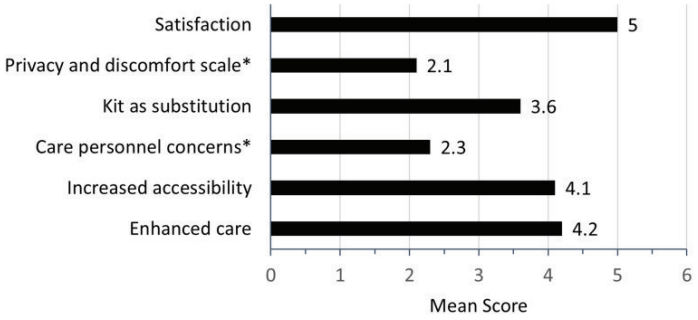
5: Very Important; 4: Important; 3: Moderate Importance; 2: Minor Importance; 1: Not Important. These statements are a randomly selected sample of those with mean importance ratings across the spectrum of importance ratings, where all or almost all participants agreed on the rating they assigned to the statement.

Supplementary Figure 3. Patient reported outcomes for CZP-treated patients who evaluated the e-Device. a) Patient empowerment (heiQ) b) Acceptability of the technology (SUTAQ) c) Health Literacy (eHLQ)

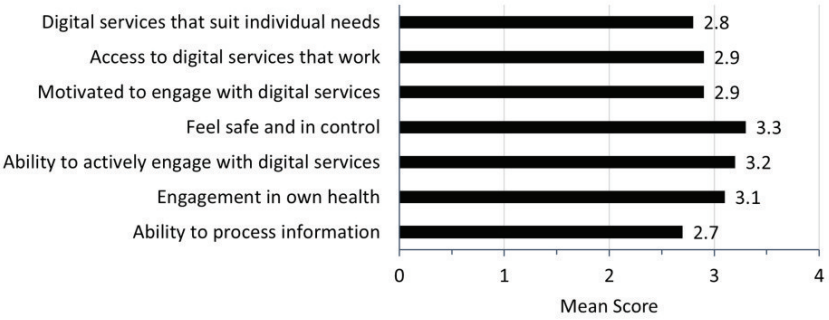
a) heiQ[a]



b) SUTAQ[b]



c) eHLQ[c]



[a]heiQ scores range from 0 to 4. A high score reflects a positive outcome. [b]SUTAQ scores range from 0 to 6. A high score reflects a positive outcome [c]eHQL scores range from 0 to 4. A high score reflects a positive outcome. *Exceptions where a low score reflects a positive outcome.