

Comprehension of Feedback by Patients within a Delphi Survey

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Method Article

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Abstract

Background: Delphi studies, used to develop consensus, allow participants to change their responses to a questionnaire after reviewing the summarised responses of other participants. Different methods for presenting feedback within a Delphi are employed in core outcome set (COS) development, including a summary statistic (e.g. median) and histograms. It is not known how well these feedback methods are understood by patient participants. The aim of this study was to examine patient preferences for style of feedback and to determine whether different feedback methods could be accurately interpreted by patients.

Methods: Participants were patients who had been interviewed for development of the CORMAC COS for anal cancer. In a separate one-to-one interview, participants completed a simulated 2-round Delphi whilst being asked to 'think out loud'. Feedback was presented first as a single summary statistic (a median) then simultaneously as two different forms of graph, a histogram and a pie chart. Participants were asked to explain their understanding of the terms used, e.g. "median" and "average" and give an overall preference.

Results: Eight patients were interviewed. No participant fully understood median; six described median average as the mean and two could not accurately explain any average. All participants understood both types of graph, although two required additional explanation of the graph axes. All valued seeing the spread of scores provided by the graphs and the concept of distribution was well understood. Seven out of eight participants preferred the histogram overall.

Discussion and conclusions: This small study provides the first evidence for patient understanding of feedback within a Delphi. Participants understood and valued seeing the spread of scores as a histogram. Median was not well understood and may be an inappropriate choice for Delphi surveys involving patients. Larger studies are needed to validate these findings.

Background

Core outcome sets (COS) are increasingly being advocated as a means to ensure relevance of research outcomes to stakeholders, reduce outcome heterogeneity and minimise reporting bias.[1-4] Trial funding bodies, regulatory authorities and guideline development groups, such as the (UK) National Institute for Health Research, the European Medicines Agency and the (UK) National Institute for Health and Care Excellence, now actively endorse the use of COS.[5] The COMET Initiative promotes rigorous consensus methods involving key stakeholders for the development of COS[6] and the consensus derived COS-STAD (core outcome set standards for development) recommendations[7] describe a set of minimum standards for COS development projects. However no specific consensus methodology is yet advocated. Despite this, a 2015 systematic review of COS studies[8] identified an emerging consistency of methodological approach, with 31% of all COS studies published between 2013-2015 including a Delphi survey, increased from 15% in an earlier systematic review (1981-2013). At the time of writing, the COMET database[9] lists

20 COS studies published so far in 2018, of which 17 (85%) included a Delphi (search run 13th August 2018). Patient involvement in COS development is also increasing. Biggane et al surveyed developers of COS published between 2013 and 2017 and found that patient participants were reported as being included in 87% of projects (141/162), of which 85% utilised a Delphi survey.[10] Of the 20 COS studies published in 2018, 85% (17/20) involved patients, and 14 of these involved patients in a Delphi survey.

Controlled feedback, whereby the results from the previous round are shown to participants completing subsequent rounds, is a defining property of the Delphi technique.[11] Several different methods for presenting feedback within a Delphi have been employed, including a summary statistic (e.g. median) and graphs showing the full distribution of scores, such as a histogram. Whilst health care professionals may be familiar with simple descriptive statistics and graphs, patient participants may not be. Graphs are used to make complex information visually striking and can make quantitative data easier to understand. [12] Graphs are therefore an appealing method for the display of feedback data within a Delphi. However, accurate interpretation requires a degree of graphical literacy and therefore can be prone to error.[13]

Determining which presentation method is most useful and easily interpreted by participants is a research priority specified in the COMET Handbook. Survey-based feedback has been used in some COS development projects to evaluate aspects of Delphi methodology, however none has so far assessed understanding of score feedback methods.[14, 15] The aim of this study was to generate preliminary data on patient preferences for commonly used styles of feedback within a Delphi and to ascertain whether such feedback could be understood and accurately interpreted.

Methods

The study employed a simulated 2-round Delphi survey, using mocked-up feedback for round 2. 'Think-aloud' interviews were used to explore patient understanding and preferences of different feedback formats. Such interviews ask participants to talk as they go through a given task, such as responding to questions on a questionnaire, using digital innovations, or interpreting information.[16]

Participants

This study was nested within the development of a core outcome set for trials of chemoradiotherapy for treatment of anal cancer (The CORMAC project). Participants were individuals who had taken part in semi-structured interviews to identify priority outcomes as part of outcome long-list generation in the CORMAC project,[17] but who were not going to take part in the CORMAC Delphi (interview participants were a priori excluded from participation in the CORMAC Delphi). All interview participants gave consent to be contacted again about work to assist in the design of a Delphi survey for the CORMAC project. Research ethics committee approval for the interviews was granted on 22nd December 2015 by the Greater Manchester East Research Ethics Committee (REC reference 15/NW/0971).

Outcomes used and source of feedback scores

The scores used to generate the mocked-up feedback were taken from real-world scores given by patient and HCP participants in the first round of a Delphi for a COS for surgical trials in colorectal cancer.[18] This previously published study was selected as many outcomes relevant to treatment for colorectal cancer are also relevant to treatment for anal cancer, and we had access to the data. Outcomes in the CORMAC long-list also present in the colorectal cancer Delphi were selected, to represent three different result scenarios: (i) patient and HCP participants both scoring highly (overall survival), (ii) HCP participants scoring more highly than patients (anaemia) and (iii) patients scoring more highly than HCPs (fatigue).

Types of feedback

Of the 17 COS studies on the COMET database published so far in 2018 including a Delphi, 29% (5/17) provided feedback of the summarised scores using a summary statistic (4 median; 1 mean) and 24% (4/17) provided the full distribution of scores (2 described feedback as “numerical and graphical”; 1 stated that the “full distribution of scores” was fed back and 1 stated that the number of participants selecting each score from 1-9 was fed back). One study specified that scores from the previous round were not shown. The remaining 41% (7/17) did not report the method of feedback. We therefore elected to assess comprehension of Delphi feedback displayed as a summary statistic (median) and as a histogram to represent the styles of feedback in use in COS studies. Median rather than mean was selected as responses on a Likert scale in this context are often heavily skewed towards one end of the scale. There is some evidence that health care professionals may more accurately interpret pie charts than histograms when comparing patient reported outcomes data.[19] We therefore also assessed the comprehension of a pie chart as an alternative graphical format.

Interview content

Interview participants were invited by phone or e-mail to take part in a 20-30-minute interview undertaken by RF, to explore their understanding of different styles of feedback used within a Delphi. Participants who did not respond to the initial invitation were followed up with one further e-mail or telephone call. A minimum of one week before the interview, participants were sent a paper copy of the round 1 CORMAC Delphi survey with a covering letter asking them to look at the outcomes listed and consider how they might answer.

Participants were then taken through a simulated Delphi survey and asked to ‘think out loud’ during a one-to-one interview. First, the participant was asked to score the outcome as in round 1. Using the same language as used in the CORMAC online Delphi, they were asked to score an outcome for importance of inclusion in a COS on a 1-9 Likert scale (figure 1A). Participants were then shown mocked-up feedback summarising other participants’ scores (patients and health professionals separately) and asked to look

at the feedback and re-score the outcome, whilst 'thinking out loud', simulating round 2. The different ways of displaying the summarised scores were shown sequentially, starting with the median (figure 1B), followed by the pie chart and histogram (shown together; Figure 1C), and the participant asked to re-score at each stage whilst thinking-aloud. This approach was selected to limit potential sequencing bias as the histogram and pie chart introduce additional information that is not provided by the median. The histogram and pie chart were shown together as they displayed the same information in different formats (figure 1C). Participants were also asked specifically to explain what they thought the feedback showed, and to explain their understanding of the terms used, for example "median" and "average". This process was repeated for the three different outcomes (survival, anaemia and fatigue). At the end of the exercise, participants were asked which style of feedback they preferred and why.

An interview guide was used to ensure instructions on how to complete the questionnaire corresponded to those given to participants in the live CORMAC Delphi. The axis and segments of charts were labelled as shown in figure 1C, but no further explanation of the charts was offered until participants had been asked to explain their understanding of the charts. If this explanation was incorrect, a short further explanation was given by the interviewer, describing the chart components:

"The numbers [demonstrating x-axis/segment label] represent each score from 1-9, and this is the percentage of people answering the question [demonstrating y-axis]. So this bar/segment shows the percentage of people that scored it a nine, an eight, a seven [etc. demonstrating individual bars/segments]."

Analysis

Interviews were audio recorded and due to time constraints transcribed by an approved professional transcription service (www.1stclass.uk.com). Analysis followed an applied framework approach. Codes were derived from the objectives of the study, the interview guide and the interview content, and then reviewed in a coding matrix cross-tabulating codes in columns against participants in rows. Criteria for what could be considered accurate interpretation of each style of feedback by participants was set out a priori (Table 1).

Table 1: Criteria for demonstrating adequate understanding of different styles of feedback

Feedback method	Accurate interpretation
Average (median) score	The middle score The mid-point of all the scores
Pie chart or histogram	Percentage/proportion of people that chose each score How many people chose each score <i>Additional information that might be identified:</i> Score chosen by most people Score chosen by fewest people Lots of people chose different scores Most people chose the same score

Where quotations from the interviews are used for illustrative purposes, these are attributed to the participant's unique identifier in the format 'P[number].

Results

Ten out of nineteen participants responded to the invitation to participate. Two participants cancelled for personal reasons. Eight interviews were conducted (4 male: 4 female). The median age of participants was 62 (range 42-71). Interviews lasted 18-50 minutes (median 32 minutes). The results are summarised in Figure 2.

Understanding of median and average

Many participants had not heard the term median before and when asked, none felt able to describe what it meant.

Researcher: And what do you understand by what this says here [Average (median)]?

P7: What does median mean? Does it mean average....?

Researcher: Is that [median] something that you've come across before?

P7: Median, no.

However, two participants described the term average as 'the middle'.

The average is the sort of norm, the middle ground (P3)

Four participants understood the term average as the mean, providing an accurate description of how this is calculated.

Researcher: This word, median, does that mean anything to you?

P6: Well, I would just imagine that that's the average score. Some people have scored seven, some people have scored nine, on that, and that's what's come out as the overall outcomes, the strongest number.

Researcher: Okay, and if I asked you to explain what you understand by average...

P6: Average would be...again, it's normally the amount divided by the amount of people that have taken the test or answered the questions.

One participant was aware of the three different types of average but could not describe what they were.

Yes, I'm trying to remember. Because there was the mean, the median and something else and I can't remember what the difference was. (P3)

Two participants could not explain average at all.

Understanding of graphs

Six out of the eight participants accurately interpreted both the pie chart and histogram as presented (Figure 1C).

So, this [histogram] is saying that 6 per cent of people, of patients, scored one, when asked the question about overall survival. (P3)

[Pointing at the pie chart] "You've got 39 per cent quoted number 9, 15 per cent 8s, 20 per cent 7 and so on" (P7)

The two remaining participants were able to correctly interpret the charts after a short additional explanation of the components. All eight participants said that they felt the charts provided more information than the summary statistic (median), and that they found the extra information useful and interesting. When describing what extra information was provided by the charts, almost universally participants cited the distribution of scores, using terms such as 'spread of scores' and 'range of scores'. Several participants were cautious of being misled by a summary statistic and felt seeing the distribution was essential for accurate interpretation.

"There might be 100 people but only 50 have chosen 9, so I was already thinking, when I looked at that [median] what the spread was" (P7)

Others were initially less aware of the potential for a wide spread of scores and were surprised by seeing this on the charts.

“Okay. It surprises me how spread it is across...and that anybody...so, only 39 per cent actually scored nine. Because, looking at that [median], doesn't give you this overall spread at all. I mean that makes you think that most people scored eight or nine.” (P3)

Figure 2: Summary of patient participants' preferences and comprehension of methods of feedback in a Delphi

Overall preference

Seven out of eight participants specified the histogram when asked which format they preferred overall. One of these seven liked the median displayed alongside a histogram, but notably this participant could not give an accurate description of median or average. The other participant preferred the pie chart format, stating that although she found the histogram 'easier' she felt the pie chart made more of an impact because she had to study it more. Favourable characteristics of the histogram described by participants included finding it easier to see small differences in scores and easier identification of scores with 0% response, and visual mirroring of the 1-9 scoring scale.

“That just makes it very, very immediately obvious to me and you've got the scoring from one to nine, which you tend to think of in a lateral way... as opposed to circular.” (P3)

Improvements

Participants were asked to suggest any ways in which the feedback methods could be improved. Most participants did not have specific suggestions and in general described the feedback as clear and easy to follow. One participant felt that the histogram should be accompanied by more explanation of what the axes were representing.

Discussion

Summary of findings

This small study provides the first evidence for patients' understanding of methods of feedback within a Delphi for a COS. Participants expressed a preference for the histogram format over a pie chart or a summary statistic. The term median was unfamiliar to participants and poorly understood, with many participants understanding average only as the mean. Participants demonstrated good understanding of the concept of distribution of scores and valued this extra information compared to the median alone.

Context of other literature

We have not identified any other studies exploring patient understanding of the display of statistical information within a Delphi survey. Two COS studies have used post-Delphi participant feedback questionnaires to evaluate participants' views on taking part in a Delphi. Hall et al[14] investigated factors influencing participant recruitment and retention in Delphi surveys including participant satisfaction with interpreting the graphical display of feedback. Most respondents (76%; 281/368) reported some degree of satisfaction however patient and HCP responses were pooled, and participant satisfaction does not evaluate comprehension. Turnbull et al[15] reported that 67% of patient and caregivers considered prior voting results from other stakeholder groups when scoring, but did not address interpretation or comprehension of the methods used to display score feedback.

The use of graphs to communicate patient-reported-outcomes (PROs) to patients has been more widely explored. A 2015 review[20] identified nine studies of patient understanding of graphical representation of PRO data. Accurate interpretation of simple line graphs by patients in the included studies was high, ranging from 88%[21] to 95%.[22] There are important differences between PRO data and the feedback within a Delphi, limiting the relevance in this context. PRO data is usually displayed over time and is often used to compare different treatment options requiring more complex representation of multiple variables on the same axes. Although not directly comparable, the high level of patient understanding of PRO line graphs demonstrated in these studies may indicate that the simple histogram could be well understood by patients in the context of a Delphi survey. Researchers have not described the rationale for their choice of method to display feedback in a Delphi in COS studies, so it is unclear why some studies have chosen to use a summary statistic over a graphical display. It is possible that researchers perceive that compared to a histogram, a single summary statistic is simpler and will therefore be easier for patients to understand. However, this study suggests that patient understanding of what the summary statistic represents, especially the median, is limited. Furthermore, participants in this study demonstrated good understanding of the importance of seeing the distribution of scores and valued this information in the context of re-evaluating their own score.

Strengths and limitations

This study provides a unique insight into patients' understanding of the different styles of feedback used within a Delphi. We took care to authentically simulate a Delphi survey by involving patients with experience relevant to the scope of the outcomes used and by using real-world patient and health care professional scores for the feedback. However, there are some limitations. This study included only eight participants and therefore the results may not be representative more generally. The small number of participants in this study precludes generalizable quantitative interpretation therefore no conclusions about which feedback style is 'best' were made. We did not collect data on the educational background, literacy or numeracy of participants, which may affect ability to interpret feedback.

We did not include health care professionals in this study. Studies evaluating comprehension of graphical feedback amongst health care professionals assume a level of graphical literacy adequate for

interpretation of the simple graphical formats used in the current study, instead focusing on improving ways of presenting more complex data[20, 23] However, future studies could to provide evidence on the optimal format and labelling of graphical feedback in the context of a Delphi survey.

Implications and future research

Graphical display of feedback between rounds in a Delphi appear to be well understood by patients, and in this small sample, a histogram was the preferred format. The concept of a median, and an average more generally, were less well understood than the graphical representations of feedback and therefore may be an inappropriate choice for Delphi surveys involving patients. Larger studies including a diverse sample of participants are needed to validate these findings and should include patients from a range of educational and socioeconomic backgrounds. Collaborative work with patient partners should also be undertaken to determine the optimal format, labelling and accompanying description for graphical feedback.

Conclusion

This study provides the first data on patient comprehension of feedback methods used within Delphi studies. The results support the use of histograms although larger studies are needed to validate the results.

Declarations

Ethics approval and consent to participate

All interview participants gave consent to participate, including audio recording and transcription of interviews and publication of anonymised quotations. Research ethics committee approval for the interviews was granted on 22nd December 2015 by the Greater Manchester East Research Ethics Committee (REC reference 15/NW/0971).

Consent for publication

Not applicable

Availability of data and material

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

PRW is a member of the COMET management group. All other authors declare they have no competing interests.

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Authors' contributions

RF and PRW conceived of the project. RF, SB, CS and PRW designed methodology. RF conducted the interviews and performed the analysis. RF wrote the first draft of the manuscript. All authors read, critically appraised and agreed the final manuscript.

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Figures

A.

OVERALL SURVIVAL

Overall survival	How long someone lives	Not particularly important			Important			Critically important			Unable to score
		1	2	3	4	5	6	7	8	9	

B.

OVERALL SURVIVAL

Overall survival	How long someone lives	Not particularly important			Important			Critically important			Unable to score
		1	2	3	4	5	6	7	8	9	
								8			

PATIENTS Average Score (median) = 8	HEALTH PROFESSIONALS Average Score (median) = 9
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C.

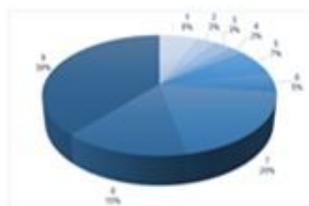
OVERALL SURVIVAL

Overall survival	How long someone lives	Not particularly important			Important			Critically important			Unable to score
		1	2	3	4	5	6	7	8	9	

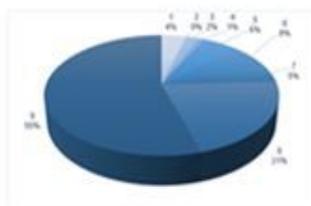
OVERALL SURVIVAL

Overall survival	How long someone lives	Not particularly important			Important			Critically important			Unable to score
		1	2	3	4	5	6	7	8	9	
								8			

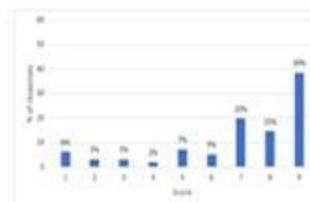
PATIENTS



HEALTH PROFESSIONALS



PATIENTS



HEALTH PROFESSIONALS

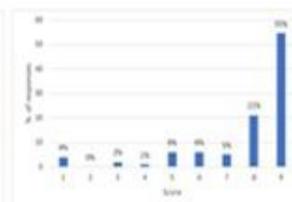


Figure 1

Materials shown to participants during the simulated Delphi. A: Outcome with scoring scale; B. Score feedback as a median; C. Score feedback as a pie chart and histogram. The participants own 'round 1' score was highlighted in subsequent rounds (yellow box)

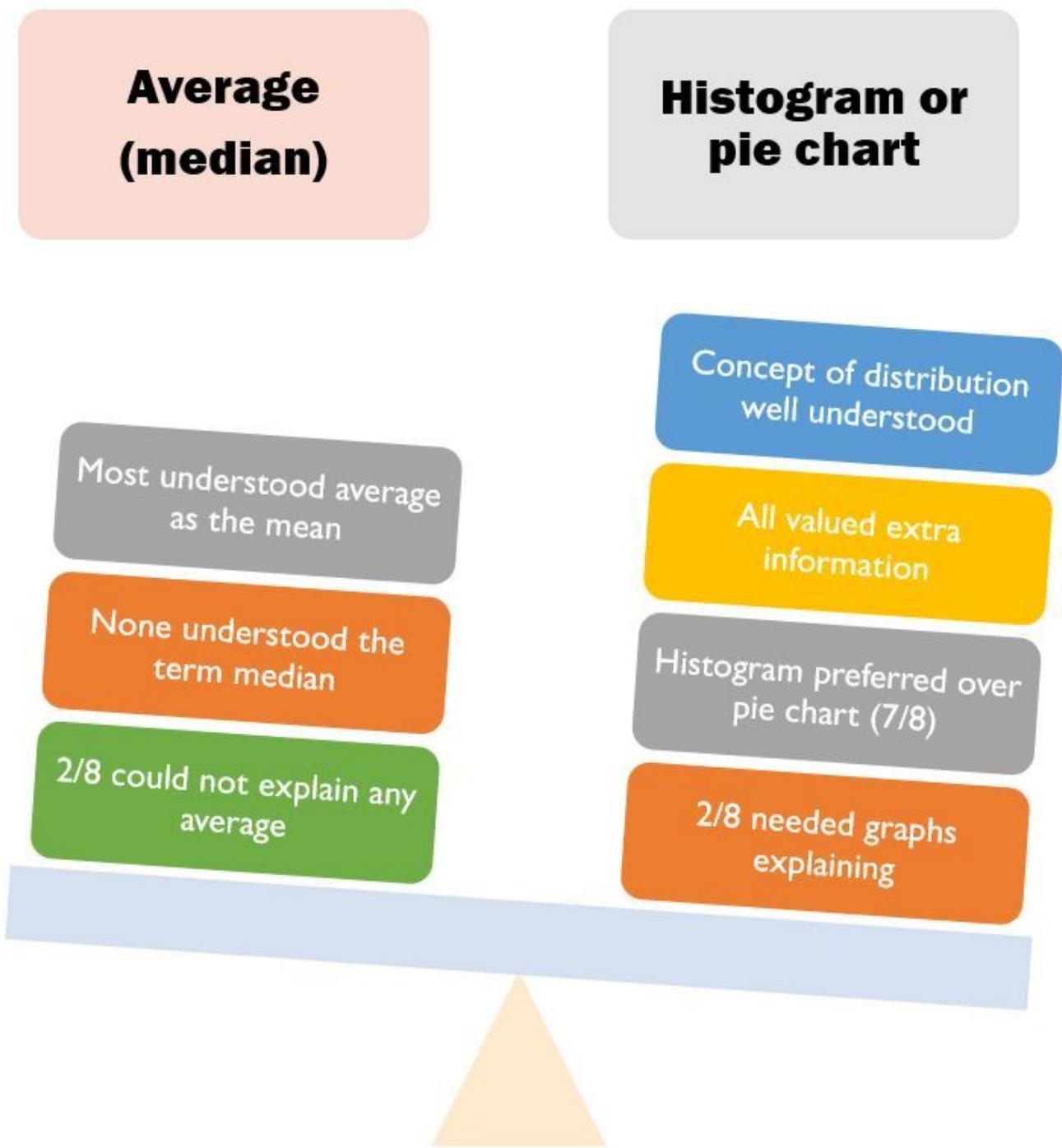


Figure 2

Ten out of nineteen participants responded to the invitation to participate. Two participants cancelled for personal reasons. Eight interviews were conducted (4 male: 4 female). The median age of participants was 62 (range 42-71). Interviews lasted 18-50 minutes (median 32 minutes).