

What do we know about visualisation of group-level PRO data from cancer clinical trials for patients? Results from a systematic literature review

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1. INTRODUCTION & AIMS

SISAQOL-IMI ([Setting International Standards in Analyzing Patient-Reported Outcomes and Quality of Life Endpoints - Innovative Medicines Initiative](#)) is an international consortium currently developing standards for the use, analysis and interpretation of patient-reported outcome (PRO) data in cancer clinical trials.

As part of this project, work package 4 (WP4) performed systematic literature searches to gather existing knowledge on how PRO trial data should be visually presented to different stakeholder groups. This poster reports findings for patients.

2. METHODS

Web of Science, EBSCOhost and the Cochrane Library were searched applying a two-step approach.

SEARCH 1 identified trials investigating graphical presentation formats of PRO data in oncology.

SEARCH 2 identified more broadly visualization advice for PRO data irrespective of the medical field.

Two independent reviewers performed title/abstract and full text screening for each reference. One researcher performed data extraction subjected to quality control. Disagreements were resolved through discussion. According to the aim of WP4, only references addressing the visualization of group-level PRO data were included in the qualitative synthesis.

3. RESULTS

The selection process resulted in 32 references, of which 19 provided information on the visualization of group-level PRO data. 16 of those references relate to oncology. Seven references are reviews, another seven are mixed-methods studies, three are qualitative studies, one is a quantitative study and one reports a modified Delphi process.

All references included in search 1 were also covered by search 2. Figure 1 presents the PRISMA flow chart of references.

Main findings for patients are reported in Figure 2 in box 3.1.

3.1 MAIN FINDINGS

There is no "one-size-fits-all" solution!

- GRAPH TYPE:** no consensus on preferred graph type; reasonable: line graphs, pie charts, bar charts, mixed-format: color arrays, 3D critical: Kaplan-Meier, curves, categorical plots, funnel plots
- EXPLANATIONS:** "how-to-read-a-graph" explanations and textual explanations aiding comprehension appreciated
- STATISTICAL DETAILS:** found rather confusing; keep level of statistical information low; but highlighting of statistically significant differences and numerical indicators of numbers or percentages (e.g., in pie charts) appreciated
- DIRECTIONALITY:** directional labels or descriptive labels indicating betweenness; results and interpretation; no consensus on preferred directionality of scores; don't mix directionality within one graph
- SCALING:** scaling of axes should be consistent and not distort data
- COLORS:** color coding between groups appreciated; traffic light colors well understood; use colors with strong contrast; consider needs of color vision impaired population

4. DISCUSSION & CONCLUSIONS

One main challenge in the review process was the methodological heterogeneity between studies, which complicated both extraction and synthesis of data and may have led to a lack of rigor.

Literature provides some specific recommendations on the graphical presentation of PRO trial data to patients. Nevertheless, further in-depth research is needed to address patients' particular needs.

Patients' numerical, graphical and health data literacy influence how well graphs are understood. Therefore, such differences among patients need to be taken into account.

The work of SISAQOL-IMI WP4 will help to advance knowledge in this regard in order to pave the way to understandable and useful presentation formats.

SUMMARY

On behalf of SISAQOL-IMI, WP4 conducted systematic literature searches to gather evidence on how to best present PRO trial data graphically to different stakeholder groups.

19 references were included in the qualitative synthesis of the review.

Main findings for patients:

No "one-size-fits-all" solution!

- no consensus on preferred graph type
- simple graphs generally preferred

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ABSTRACT

Aims: As part of the SISAQOL-IMI project, currently developing standards for the use, analysis and interpretation of patient-reported outcome (PRO) data in cancer clinical trials, work package 4 (WP4) performed systematic literature searches to gather existing knowledge on how PRO trial data should be visually presented to different stakeholder groups. This abstract reports findings for patients.

Methods: A two-step approach was applied for searching Web of Science, EBSCOhost and the Cochrane Library: Search 1 identified trials investigating graphical presentation formats of PRO data in oncology and search 2 identified more broadly visualisation advice for PRO data irrespective of the medical field. Two independent reviewers screened each reference (title/abstract, full text; FG, RP, and/or LW) and one researcher (FG or RP) performed data extraction (subjected to quality control; LW). Disagreements were resolved through discussion. According to the aim of WP4, only references with group-level PRO data visualisations were included in the qualitative synthesis.

Results: Figure 1 presents the reference flow. The selection process resulted in 32 references, of which 19 provided information on the visualisation of group-level PRO data. Literature does not indicate a clear preference of any type of visualisation for patients. Line graphs, pie charts and bar charts are considered reasonable options and longitudinal data presentation is favoured. Statistical details tend to be found confusing by patients, though numerical reporting of numbers or percentages and highlighting of statistically significant results is appreciated. Labels indicating the direction of better and worse scores are considered helpful for interpretation. Patients value textual explanations that help them understand the graph. Literature generally suggests to keep visualisations simple for patients, but educational differences can affect both preferences and understanding.

Conclusion: Although literature provides some specific recommendations on the graphical presentation of PRO trial data to patients, further research is needed to address their particular needs, which might vary even within this stakeholder group. The work of SISAQOL-IMI WP4 will help to advance knowledge in this regard.

Disclaimer: The content of this abstract MUST NOT be taken as recommendations of the SISAQOL-IMI consortium. Findings for health care professionals and other stakeholders are reported in a separate abstract.

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As part of this project, work package 4 (WP4) performed systematic literature searches to **gather existing knowledge on how PRO trial data should be visually presented to different stakeholder groups**. This poster reports **findings for patients**.

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Web of Science, EBSCOhost and the Cochrane Library were searched applying a two-step approach. **SEARCH 1** identified trials investigating graphical presentation formats of PRO data in oncology. **SEARCH 2** identified more broadly visualization advice for PRO data irrespective of the medical field.

Two independent reviewers performed title/abstract and full text screening for each reference. One researcher performed data extraction subjected to quality control. Disagreements were resolved through discussion. According to the aim of WP4, only references addressing the visualization of group-level PRO data were included in the qualitative synthesis.

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The selection process resulted in 32 references, of which **19 provided information on the visualization of group-level PRO data**. 16 of those references relate to oncology. Seven references are reviews, another seven are mixed-methods studies, three are qualitative studies, one is a quantitative study and one reports a modified Delphi process.

All references included in search 1 were also covered by search 2. *Figure 1* presents the PRISMA flow chart of references. Main findings for patients are reported in *Figure 2* in box 3.1.

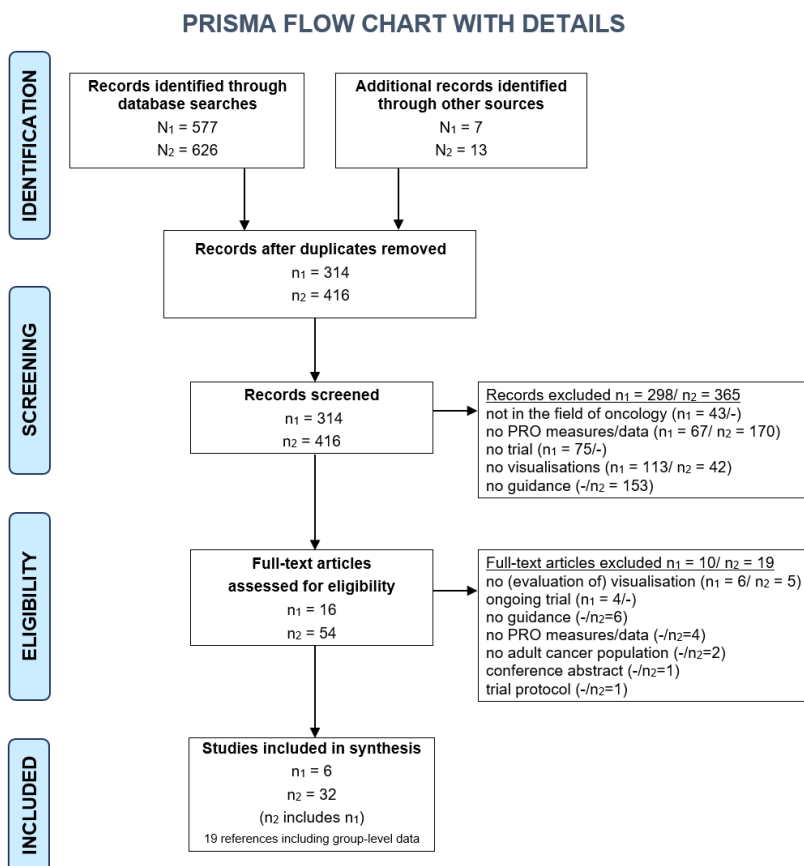


Figure 1 PRISMA flow chart of references from both searches with details (n₁ refers to search 1, n₂ refers to search 2)

3.1 MAIN FINDINGS

There is no "one-size-fits-all" solution!

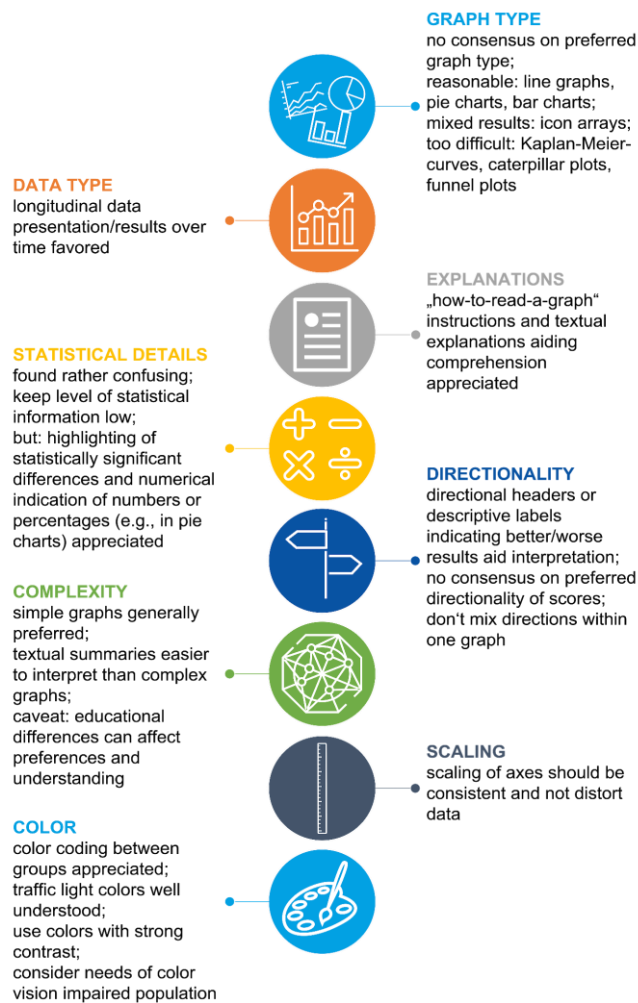


Figure 2 Thematic scheme of main findings for patients

4. DISCUSSION & CONCLUSIONS

One main challenge in the review process was the **methodological heterogeneity between studies**, which complicated both extraction and synthesis of data and may have led to a lack of rigor.

Literature provides **some specific recommendations** on the graphical presentation of PRO trial data to patients. Nevertheless, **further in-depth research is needed** to address patients' particular needs.

Patients' numerical, graphical and health data literacy influence how well graphs are understood. Therefore, such differences among patients need to be taken into account.

The work of SISAQOL-IMI WP4 will help to advance knowledge in this regard in order to pave the way to **understandable and useful presentation formats**.

SUMMARY

On behalf of SISAQOL-IMI, WP4 conducted systematic literature searches to **gather evidence on how to best present PRO trial data graphically to different stakeholder groups.**

19 references were included in the qualitative synthesis of the review.

Main findings for patients:

No "one-size-fits-all" solution!

- no consensus on preferred graph type
- simple graphs generally preferred
- longitudinal data favoured
- additional explanations valued
- labels indicating directionality of scores aid interpretation
- colour coding appreciated
- statistical details found rather confusing

Although literature provides **some specific guidance, further research is needed** to address patients' particular needs.

REFERENCES & DISCLOSURES

References available upon request.

Find more information on the project on the [SISAQOL-IMI homepage](#).

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