



## The Role of Data Visualization Tools in Presenting Medical and Record Information Effectively

Bader Qaryan Ghabn Alruwaili<sup>1</sup>, Amal Mohammed Hendi<sup>2</sup>, Tahani Muhammad Al-Anazi<sup>3</sup>, Amerah Mohammed Alsubaie<sup>4</sup>, Mubarak Abdullah Aldawaseri<sup>5</sup>, Ahmed Mohammed R Alotaibi<sup>6</sup>, Sultan Nahis Duaibl Alanazi<sup>7</sup>, Abdullah Saeed Abdullah Alghamdi<sup>8</sup>, Bader Hamad Khalaf Almohawish<sup>9</sup>, Yasser Rashed Ahmed Alzahrani<sup>10</sup>, Abdulrahman Muayjil Tali Almutairi<sup>11</sup>, Hind Mohammad Zin Aldein<sup>12</sup>, Yahia Mohammed Aziabi<sup>13</sup>, Ali Hussain Jarbin<sup>14</sup>, Marwa Saad Althalabi<sup>15</sup>

<sup>1\*,2,3,4,5,6,7,8,9,10,11,12,13,14,15</sup>Ksa , ministry of health

\*Corresponding Author: Ayed Rahil Muhji Alfuhaymani

\*Ksa , ministry of health

### Abstract

As patients are receiving their own health data more often and in larger amounts, visualizations are generating enthusiasm for their ability to help patients understand the information. It is crucial to assess these representations to guarantee that patients can comprehend and, when suitable, take action based on health data in a secure and efficient way. The aim of this systematic study was to assess and analyze the current status of patient-facing representations of personal health data. We conducted a thorough search on five reputable academic databases, namely PubMed, Embase, Scopus, ACM Digital Library (Association for Computing Machinery Digital Library), and IEEE Computational Index (Institute of Electrical and Electronics Engineers Computational Index). We included English-language papers that created or examined patient-oriented visual representations for personal health information. The results of the article indicated that a greater proportion of patients were able to comprehend number lines and bar graphs as opposed to line graphs. Additionally, it was shown that the use of color was useful in conveying danger, enhancing understanding, and boosting confidence in interpretation. This review provides a concise overview of the many kinds and components of visuals that are directly accessible to patients. Additionally, it outlines the different approaches used in the production and assessment of these visualizations, as described in the examined publications. In addition, we provide suggestions for future research on the collection and presentation of data, exploration of clinically significant thresholds for various kinds of data, and use of data science techniques. This effort will be crucially significant as the use of patient portals and mobile devices for accessing personal health data continues to increase.

**Keywords:** data visualization, understanding, patient involvement, health literacy, consumer health information

### 1. Introduction

The number of efforts to provide people access to their own health data is increasing. Due to the implementation of meaningful use stage-2, patient portals now enable patients and caregivers to directly obtain medical findings electronically. Previously, these data were only provided to patients in print format following a burdensome request procedure.[2] Additional endeavors have advocated for enhanced visibility of all individual medical data, such as OpenNotes, and have received favorable reactions from patients.[3] Simultaneously, patients are becoming more proficient in producing their own health data via mobile health technology and questionnaires that collect patient-reported outcomes (PROs).The user's text is enclosed in tags. [5] Patients may promptly and easily access their patient-reported outcomes (PROs) and other health data provided by patients (PGHD) using the same electronic systems, such as smartphone apps and wearable devices. [6,7].

Returning health data to the patient has the potential to bring about many advantages, such as enhancing the patient's understanding of their health condition, increasing their involvement in their own healthcare, and encouraging the adoption of beneficial health practices [8], [9], [10]. Therefore, it gives a chance for the patient to actively engage in their own health and wellness. However, there is hesitation in giving patients unrestricted access to their health data without the guidance of a doctor. This is because of worries around their limited understanding, perception of risk, and the potential for engaging in harmful or unhealthy behaviors as a result of the data [7,11]. Personal health information may be complex, particularly when including many data points and medical terminology. Additionally, it may need contextualization taking into account factors such as age, gender, baseline status, and other individual characteristics. A significant number of professionals have a preference for personally conveying medical findings and information to patients, enabling them to provide essential interpretation and contextualization [12,13,14]. Nevertheless, the vast amount

of patient data that can be collected and sent to patients in the current digital era makes this impractical in several situations.

Data visualizations provide a potential approach to assist patients in comprehending and placing their health information in perspective [15,16,17]. Data visualization utilizes the human visual perception of variations in item sizes, forms, colors, and spatial placements to depict data and communicate information effectively [18]. Information visualizations are particularly attractive since they do not depend on the patient possessing advanced reading or numeracy skills. For instance, some design elements, such as colors, may aid in understanding just as well as explanatory language [19]. Furthermore, information visualizations may be conveniently sent to patients using the technologies they are already extensively utilizing, such as smartphone apps and web sites. [15].

However, developers of patient-facing visualizations have many challenges in effectively communicating the significance of personal health data. Patients exhibit significant diversity in terms of health literacy, cultural background, and cognitive level, all of which have an impact on their understanding [20]. Previous studies have conducted comprehensive investigations on visualizations and assessment techniques for health-related information, but none have particularly evaluated visualizations and procedures connected to patients' personal health data. The cognitive processes used by patients when analyzing personal health data vary from those utilized by researchers and physicians with sophisticated statistical and medical expertise.[25,26]. Thus, it is necessary to conduct a thorough examination of the distinct requirements and preferences of patients who access their personal health information. This will enable the development of tools that provide personal health data in a manner that is suitable for use in clinical practice and aligns with patients' cognitive processes. Individuals involved in the development, implementation, and assessment of visual aids for patients need up-to-date evidence to guarantee that patients can comprehend and, when necessary, take appropriate action based on health information in a secure and efficient way.

The primary goal of this systematic review was to provide a concise summary of the current state of knowledge about patient-facing information visualizations of personal health data. Our objective was to analyze existing literature in several scientific disciplines that focus on the development and implementation of tools for displaying personal health data. These disciplines include informatics, medicine, nursing, computer science, and engineering, among others. Our objective was to provide a preliminary set of suggestions for anyone interested in creating visualizations that help patients comprehend and analyze their specific health data. We achieved this by explaining and combining these results.

## **2. Methods**

We conducted a comprehensive search in five reputable academic databases, namely PubMed, Embase, Scopus, ACM Digital Library (Association for Computing Machinery Digital Library), and IEEE computation index (Institute of Electrical and Electronics Engineers Computational Index), with the assistance of a biological librarian. The databases were chosen to include relevant literature from many disciplines such as medicine, nursing, biomedical informatics, computer science, and engineering. The search strategy included the following terms: (patient OR patients OR consumer\* OR user\*) AND (“Computer Graphics” OR visualiz\* OR graph\*) AND (“Health Records, Personal” OR “Electronic Health Records” OR “Telemedicine” OR “electronic health record” OR “test results”). The search phrases were established by collaboration with a biological librarian and content specialists, as well as by iteratively reviewing keywords found in retrieved publications [27].

## **3. The kinds and elements of visualization**

The articles varied in terms of the kinds and elements of visualization used. However, the majority of articles used color and numerical components, with line graphs being the most prevalent form of visualization. The evaluation methods employed in the 27 articles that conducted research on visualizations involving human patients exhibited significant variation, lacking standardization in terms of instruments, methodologies, and measurement of patient characteristics that could potentially impact interpretation, such as health literacy or numeracy. Consequently, comparisons of data are challenging, and it is hard to determine the most effective methods.

Our research indicates that there is a need for more focus on the development of visualizations that are accessible to patients. Our investigation revealed a much greater quantity of papers including visuals intended for health-care providers or researchers (n = 834), in contrast to visualizations intended for patients. This indicates a disparity in the development of health data visualization systems for patients compared to systems for healthcare providers, even though more than half of the population presently has access to patient portals [28]. Here, we outline three important possibilities that might enhance future research on patient-facing visualizations and facilitate the identification of best practices.

Initially, in studies focused on visualizations that patients interact with, there are possibilities for enhancing the process of gathering and presenting data in a more comprehensive manner. Approximately 50% of the studies analyzed in this analysis either lacked human patient research on the established technological system or failed to provide results particularly relevant to the visualizations. We rejected several articles that were otherwise qualified for inclusion due to their lack of real graphics. Furthermore, several papers failed to provide any details about the patient sample, or simply provided a very restricted amount of information (such as age and gender alone). The stated patient characteristics suggest that the samples used in the study were not representative of the general population.

The majorities of participants were middle-aged, female, White, and had a high level of education. This implies that the results could be skewed towards a certain group of patients and may not be as relevant for disadvantaged populations, as well as extremely young and very elderly persons. Significantly, the assessment or reporting of patients' health literacy,

graph literacy, and numeracy was seldom conducted. It is crucial to quantify these patient features since they have an impact on understanding and risk perception. This will enable the customization of visualizations to suit individual needs. Color blindness also affects the understanding of certain colored visual aspects, such the "traffic-light" color scheme mentioned in the articles. Considering the prevalence of this issue among around 8% of males, it is advisable to include color-blindness screening in future study endeavors. Furthermore, it is crucial to examine how the intended patient group perceives color when assessing visualizations that use color encodings, since colors and symbols might have varying significance based on the patient's cultural heritage [19] [29]. Overall, the use of strategies to gather and present more comprehensive sample data will enhance the ability to identify the most effective visual representations for certain groups of patients.

Furthermore, this research highlights the absence of standardized methods in the existing literature for the selection, creation, and assessment of visualizations based on certain data types or objectives. The publications exhibited significant variations in the kinds and components of visualizations, as well as the methodologies and measurements used to assess them. For instance, several publications presented overall subjective preferences, whereas others used randomization techniques to perform quantitative tests on understanding and risk perception. Furthermore, the intentions behind the visualizations were not well articulated in several publications. The potential goals include a broad spectrum, ranging from the interpretation of a singular value, to the interpretation of values within the framework of a desired value or range, to the identification of significant patterns over a period of time. Ultimately, this complicates the process of comparing and identifying visuals that effectively achieve a certain communication objective. Other studies that have explored assessment methodologies for health-related visualizations have similarly identified a lack of consistent tools and procedures for assessing these visualizations. This lack of standardization hampers efforts to determine the most effective visualizations for a certain audience.

Ultimately, there are chances to improve understanding and influence actions by using data science and applying clinically significant thresholds, sometimes referred to as minimum important differences (MIDs) [30]. Less than 25% of the visualizations in the evaluated studies used advanced analytics to provide more profound insights in the data, such as risk ratings and notable patterns. Significant progress has been made in the field of health data science, enabling computers to effectively detect significant trends and make predictions based on personal health data. Therefore, there is a significant possibility to combine sophisticated data analysis with visual representation in order to provide medically relevant and practical information to patients. It will also be crucial to expand this research beyond visual representations of data that have distinct limits for taking action, such as laboratory results, which have defined normal ranges.

The frequency of visual representations illustrating laboratory values in the articles included in this analysis corresponds to a recent study indicating that laboratory test results are the most prevalent kind of information presently provided in patient portals [31]. However, the identification and communication of MIDs for several other categories of personal health data, such as symptoms and health behaviors, are as crucial but pose more difficulties. At now, there is a growing interest in research that aims to find meaningful improvements in patient-reported outcomes (PROs) and other patient-generated health data (PGHD) [30]. Study that focuses on visualization may further this study by determining the most effective ways for communicating the MIDs to patients.

#### 4. Conclusion

This systematic review examines the current status of patient-facing visualizations and presents research results that indicate certain kinds and components of visualizations that might enhance understanding and interpretation. Nevertheless, there is a need for more focus on the development and assessment of visualizations that are accessible to patients. We propose enhancing the research by implementing more rigorous data collection and reporting methods, adopting systematic evaluation techniques, establishing clinically actionable boundaries (MIDs) for various data types, and utilizing data science to empower patients in interpreting and utilizing the data. This study will be crucial as patient use of their personal health data via digital health technologies continues to increase.

#### References

1. Oh H, Rizo C, Enkin M, Jadad A. What is eHealth (3): a systematic review of published definitions. *J Med Internet Res* 2005; 7 (01) e1
2. Mishra VK, Hoyt RE, Wolver SE, Yoshihashi A, Banas C. Qualitative and quantitative analysis of patients' perceptions of the patient portal experience with OpenNotes. *Appl Clin Inform* 2019; 10 (01) 10-18
3. Health IT. Patient-generated health data. Available at: <https://www.healthit.gov/policy-researchers-implementers/patient-generated-health-data> . Accessed August, 26, 2019
4. Baumhauer JF. Patient-reported outcomes - are they living up to their potential?. *N Engl J Med* 2017; 377 (01) 6-9
5. The Office of the National Coordinator for Health Information Technology. Conceptualizing a data infrastructure for the capture, use, and sharing of patient-generated health data in care delivery and research through 2024. Available at: [http://healthit.gov/sites/default/files/onc\\_pghd\\_practical\\_guide.pdf](http://healthit.gov/sites/default/files/onc_pghd_practical_guide.pdf) .
6. Lai AM, Hsueh PS, Choi YK, Austin RR. Present and future trends in consumer health informatics and patient-generated health data. *Yearb Med Inform* 2017; 26 (01) 152-159
7. Baker L, Rideout J, Gertler P, Raube K. Effect of an internet-based system for doctor-patient communication on health care spending. *J Am Med Inform Assoc* 2005; 12 (05) 530-536

8. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. *Health Aff (Millwood)* 2010; 29 (07) 1370-1375
9. McInnes DK, Shimada SL, Midboe AM. , et al. Patient use of electronic prescription refill and secure messaging and its association with undetectable HIV viral load: a retrospective cohort study. *J Med Internet Res* 2017; 19 (02) e34
10. Reading MJ, Merrill JA. Converging and diverging needs between patients and providers who are collecting and using patient-generated health data: an integrative review. *J Am Med Inform Assoc* 2018; 25 (06) 759-771
11. Sanger PC, Hartzler A, Lordon RJ. , et al. A patient-centered system in a provider-centered world: challenges of incorporating post-discharge wound data into practice. *J Am Med Inform Assoc* 2016; 23 (03) 514-525
12. Cohen DJ, Keller SR, Hayes GR, Dorr DA, Ash JS, Sittig DF. Integrating patient-generated health data into clinical care settings or clinical decision-making: lessons learned from project HealthDesign. *JMIR Human Factors* 2016; 3 (02) e26
13. Cheng K, Hayes G, Hirano S, Nagel M, Baker D. Challenges of integrating patient-centered data into clinical workflow for care of high-risk infants. *Pers Ubiquitous Comput* 2015; 19 (01) 45-57
14. Grossman LV, Feiner SK, Mitchell EG, Masterson Creber RM. Leveraging patient-reported outcomes using data visualization. *Appl Clin Inform* 2018; 9 (03) 565-575
15. Woods SS, Evans NC, Frisbee KL. Integrating patient voices into health information for self-care and patient-clinician partnerships: veterans affairs design recommendations for patient-generated data applications. *J Am Med Inform Assoc* 2016; 23 (03) 491-495
16. Few S. Data visualization for human perception. In: Soegaard M, Friis Dam R. , eds. *The Encyclopedia of Human-Computer Interaction*, 2nd ed. Aarhus, Denmark: Interaction Design Foundation; 2013
17. Chen HM. An overview of information visualization. *Libr Technol Rep* 2017 53. (03):
18. Arcia A, Velez M, Bakken S. Style guide: an interdisciplinary communication tool to support the process of generating tailored infographics from electronic health data using EnTICE3. *EGEMS (Wash DC)* 2015; 3 (01) 1120
19. Ancker JS. Delivering patient data to patients themselves. *EGEMS (Wash DC)* 2018; 6 (01) 16
20. Wu DTY, Chen AT, Manning JD. , et al. Evaluating visual analytics for health informatics applications: a systematic review from the American Medical Informatics Association Visual Analytics Working Group Task Force on Evaluation. *J Am Med Inform Assoc* 2019; 26 (04) 314-323
21. Isenberg T, Isenberg P, Chen J, Sedlmair M, Möller T. A systematic review on the practice of evaluating visualization. *IEEE Trans Vis Comput Graph* 2013; 19 (12) 2818-2827
22. Faisal S, Blandford A, Potts HW. Making sense of personal health information: challenges for information visualization. *Health Informatics J* 2013; 19 (03) 198-217
23. Backonja U, Chi N-C, Choi Y. , et al. Visualization approaches to support healthy aging: A systematic review. *J Innov Health Inform* 2016; 23 (03) 860
24. Mamykina L, Heitkemper EM, Smaldone AM. , et al. Structured scaffolding for reflection and problem solving in diabetes self-management: qualitative study of mobile diabetes detective. *J Am Med Inform Assoc* 2016; 23 (01) 129-136
25. Garcia-Retamero R, Cokely ET. Designing visual aids that promote risk literacy: a systematic review of health research and evidence-based design heuristics. *Hum Factors* 2017; 59 (04) 582-627
26. Covidence systematic review software. Melbourne, Australia: Veritas Health Innovation; 2016. . Available at: [www.covidence.org](http://www.covidence.org) . Accessed September 29, 2019
27. Pluye P, Gagnon MP, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *Int J Nurs Stud* 2009; 46 (04) 529-546
28. Patel V, Johnson C. *ONC Data Brief. Individuals' use of online medical records and technology for health needs.* Available at: <https://www.healthit.gov/sites/default/files/page/2018-03/HINTS-2017-Consumer-Data-Brief-3.21.18.pdf> . Accessed August 26, 2019
29. Lor M. Color-encoding visualizations as a tool to assist a nonliterate population in completing health survey responses. *Inform Health Soc Care* 2018 ; (e-pub ahead of print) Doi: 10.1080/17538157.2018.1540422
30. Lapin B, Thompson NR, Schuster A, Katzan IL. Clinical utility of patient-reported outcome measurement information system domain scales. *Circ Cardiovasc Qual Outcomes* 2019; 12 (01) e004753
31. Facts About Color Blindness. *Color Blindness*. 2015 [https://nei.nih.gov/health/color\\_blindness/facts\\_](https://nei.nih.gov/health/color_blindness/facts_)