Journal of the American Medical Informatics Association, 2024, **31(11)**, 2423–2428
https://doi.org/10.1093/jamia/ocae249
Editorial

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Reflections on interactive visualization of electronic health records: past, present, future

Introduction

In the early 2000s, the transition to paperless documentation of patients' health data begun at large scale, with the introduction of *Electronic Health* and *Medical Records* (EHR and EMR, respectively). This constituted a paradigm shift in how patient data was stored and exchanged among institutions. The impact of the so-called "Electronic Health Revolution"[1] was significant. Standardization of personal health data allowed for a more uniform definition of diagnoses and their ensuing clinical process, with fewer mistakes in diagnosis and treatment, and a more reliable application of medical guidelines.[2] For instance, in the United States (US), patients now have control over their information, with more mandated electronic access.[3] Recent studies showed that online medical records by US adults doubled over the last 8 years.[4] Simultaneously, a new generation of smart, affordable, and wearable devices, such as smartwatches, has emerged. These devices generate fine-grained and continuous data about the health status of their users, with minimal discomfort, eliminating the need for specialized equipment. The rapid evolution of Artificial Intelligence (AI) technologies is about to significantly impact healthcare as well. AI technologies present opportunities and challenges for both physicians and patients.[5] AI models recognize patterns in complex datasets, potentially identifying a broader range of disease progression patterns that might not be immediately apparent to clinicians or patients. However, the inherent "black-box" nature of AI has slowed its adoption, as healthcare professionals often struggle to evaluate the underlying process that led to the AI recommendations. In essence, while it can be impressive *what* AI models predict, concerns remain about *why* the AI produces a particular output, and *how*. The considerable lack of transparency impedes trust-building, such that "the doctor just won't accept that,"[6] calling for explainable AI output.

Visualization and Visual Analytics (VA) research has a well-established history of success stories and impactful applications in the healthcare domain.[7–9] The potential of visualization and VA techniques in healthcare is multifaceted: they can support patients in becoming more self-conscious about their health data, assist physicians in effectively exploring large volumes of EHRs, and enhance trust by explaining AI methods used in clinical practice. The core philosophy of VA is keeping the *human in the [analysis] loop*, in analysis and decision-making scenarios where replacing people through automation would create serious harm. Making users a fundamental part of the analysis process and leveraging the strengths of both humans and machines improves the confidence, quality, and relevance of results. Moreover, a particular asset of many visualization and VA techniques is their ability to make AI recommendations more explainable and transparent, effectively "opening" the box. Common themes of the "*Workshop on Visual Analytics in Healthcare*," with more than a decade of annual events include COVID-19 visualization and analysis,[10,11] healthcare data exploration and hypothesis discovery,[12,13] support for medical research and decision-making,[14–17] VA for clinical and health records,[18–20] and Human-AI collaboration in healthcare.[21,22]

In this Focus Issue on "*Interactive Visualization of Health Data for Digital and Personal Health*," we sought submissions that investigate the intersection of digital and personal health and interactive visualization and VA. The overarching goal was to advance the state-of-the-art at the crossroads of health informatics and data visualization. By fostering this interdisciplinary collaboration, we aim to address critical challenges in healthcare, such as improving patient engagement, supporting clinical decision-making, and increasing the interpretability of AI-driven insights. The contributions in this issue highlight innovative approaches that push the boundaries of what is possible in the visualization of health data, setting new standards for future research in this vital area.

The Focus Issue received a total of 44 submissions, of which 12 (27%) were ultimately accepted. Among these, 9 (75%) belong to the "Research and Applications" paper category. These articles describe the design and development of prototypes that provide support for physicians and researchers in their analytical workflow,[23–28] and/or enhance personal healthcare data accessibility and interpretability.[29–31] In addition, the issue includes one paper each in the "Perspective," "Case Report," and "Brief Communication" categories. These contributions address important themes: the investigation of equity in patient portal access,[32] the utilization of visual hierarchies for effective communication of health data,[30] and an analysis of the impact of animated graphics on communicating probability and risk in medical contexts.[33] Collectively, these papers represent a diverse range of approaches and innovations at the intersection of health informatics and visualization, setting new directions for research and application.

The goal of this Focus Issue was also to bridge the 2 research communities of visualization and medical informatics more systematically. Along these lines, 2 accepted papers[24,28] are extended versions of work initially presented

Received: September 10, 2024; **Accepted:** September 11, 2024.

at the Workshop on *Visual Analytics in Healthcare* (VAHC), co-located in the IEEE Conference on Visualization (VIS) held in 2023, the premier forum for advances in theory, methods, and applications of visualization and visual analytics. The VAHC workshop had its 14th appearance, every second year, located at the AMIA Annual Symposium. Notably, the first authors of 4 articles are new to JAMIA, but have strong publication record on visualization journals and conferences. This suggests that the issue was successful in attracting contributions from the visualization community. Next, we discuss 4 main themes that emerged from the Focus Issue submissions, reflecting the interdisciplinary nature and potential of combining these fields.

User-centered design in healthcare

User-centered design is one of the staples of modern visualization, VA,[34,35] and Human-computer interaction research.[36] It entails the identification and the collaboration of stakeholders from the target audience in the design process of the VA system under development. The goal is to deliver a final product that supports users' workflows, addressing their needs and ultimately leading to more significant and trustworthy insights from the data. This approach has been used in countless applications, and the papers in this focus issue apply this method to the analysis and comparison of EHRs.

Warnking et al.[23] investigate the design of interactive visualization for analyzing chronic lung diseases using a user-centered approach. The interpretation of lung function is a complex task that requires to investigate several numerical parameters. Their evolution is monitored and compared to a baseline values according to the person age, gender, and general health condition. However, manually comparing the values is not a scalable solution when multiple exam records are available, and current systems do not provide users with a unified and centralized view that allows to obtain an effective all-round perspective of the patient's lung function. To address these challenges, the paper presents a design study that culminates in the development of a VA prototype evaluated by means of expert interviews. 4 pneumologists from Germany were interviewed as part of the evaluation strategy for the prototype. A curated set of tasks was compiled for the participants to solve using the system, mimicking what practitioners would encounter in their own daily work activities. The evaluation results were mostly positive, with consistent answers throughout the different tasks and positive qualitative comments.

Jeffs et al.[31] set out to explore the design of personal health data visualization aimed at supporting recent transplant recipients in their post-surgery experience. The success of a transplant long-term depends on strict adherence to strict medical regimens that minimize the risk of rejection and benefit both the lifespan and quality of life of the patient. Hence, there is a need for personal health visualizations that can actively support the patients and their caregivers in such a delicate journey—especially in a pediatric context such as the one presented in the paper. Little is known about how visual tools can support patients and caregivers in tracking, understanding, and definitively assessing normalcy in the context of a chronic illness with young and at-risk populations. The paper presents a study where patients and caregivers collaborate in the design of visualization meant to explore their condition and compare to others in search of how "normal" their experience was. The challenge is that, especially in the circumstances of a transplant in young age, the sensation of normalcy is very personal and fluctuates greatly from person to person. The study was conducted as 3 different asynchronous design sessions. These sessions began with the participants describing their own experiences and perception of normalcy using symbolic representations; the representations were then used by the authors to create visual analogies and later, visualizations for the participants to evaluate and discuss. The authors identified commonalities that could be condensed in design principles for the design of future visualization tools: (1) incorporate personal values, (2) facilitate comparisons, (3) and communicate abstract concepts. Despite being limited to participants from 2 urban hospitals, this work presents an important step toward the integration of personal visualizations in standardized clinical workflows for chronic patients.

Scholich et al.[26] describe a 3-phase user-centered design process to develop a VA prototype for the analysis of type-1 diabetes patients' data. In the first phase, expert physicians reviewed commercially available systems to explore diabetes' data, gathering information about practictioners' requirements and daily tasks, plus potential open challenges and chances of improvement. These guided the development of *GlucoGuide*, a mockup design that also integrated algorithmic "insights" presented to the users to highlight specific data occurrences. The goal of the paper is to demonstrate the benefits of a user-oriented design approach in this context, the importance of the requirements and task analysis, improving practice but without requiring radical shifts that would make the adoption of such tools "in the field" more challenging. The addition of the algorithmic insights also proved to be positively received, as long as sufficient context and explanation were given to the experts to properly understand and evaluate them.

Communicating healthcare data

Visualization could be used to improve the communication of healthcare data with patients and laypersons. Marquard et al.[29] conduct an experimental comparison between 4 existing EHR visualization tools, with the goal of assessing which elements had the greatest impact on task performance. Patient portals present documented usability issues (see, eg, Ref. [37–39]). This paper presents a study where lay individuals are asked to complete an immunization form with data to be extracted from 4 different existing EHR visualizations. The participants were asked to consult a medical record of the immunization administered to a fictitious 5-year-old child using one of the 4 visualizations (suggesting a between-subject arrangement) and then to execute various tasks. The individual performance is assessed through time/accuracy and perceived task complexity. Both performance measures showed significant differences between the different tools, and the paper discusses which design features might have contributed to these differences. Numeracy, health literacy and demographics did not show significant differences; workload measures and perceived complexity were also consistent across the visualizations. The paper finally compiles a list of design principles suggested by the study results and the participants' qualitative feedback to support designers in creating these visualizations.

Saw and Gatzke[30] discuss in their Case Report the process and experience of redesigning a hereditary colorectal cancer lab report using visual hierarchies. The authors motivate their work by saying that successful usage of such visual representations in healthcare information technology applications is not widespread, despite being a well-established practice in healthcare information visualization. Design meetings and research were used to identify the targeted user groups of the redefined lab report (ie, general practitioners and counselors), the visualization requirements, and the information hierarchy for each category of users. The presented case report discusses the process of designing visual hierarchy methods in the healthcare information technology context, shares lessons learned, and generally raises awareness on how such known techniques in information visualization could make a difference in this context.

Ancker et al.[33] in their perspective paper discuss recent studies about graphical risk communication in healthcare using interaction and/or animations. The authors sampled different quantitative studies that compared 2 or more formats for communicating numerical data about probabilities and risk assessment related to healthcare data (eg, chances of side effects), directed at lay adults. Out of 181 surveyed papers, 24 also had animation and/or interaction. The first takeaway is that little research has been done in the context of evaluating the use of animation and interaction in the context of risk communication. The second is that these studies have been mostly inconclusive in establishing a positive impact between the use of animation and interaction in the context of healthcare risk communication. The survey excluded novel or sophisticated interactive techniques that were not compared to other static and acknowledged methods in the healthcare domain. While there is enough evidence in visualization literature to hypothesize the efficacy of the use of animation and interaction in risk communication, current evidence is insufficient in proving it, thus advocating the need of further research.

Physician support and clinical research

Papers in this category focus on visualization and VA systems developed to support physicians and empower clinical research through the analysis and comparison of EHRs. Goodwin et al.[24] present the Australian Cancer Atlas (ACA). The Atlas aims to provide small-area estimates of cancer incidence and survival in Australia to help identify and address geographical health disparities. It was originally launched in 2018 with great success, and in 2024 a new design was released. The data comes from Australian cancer registries for 20 types of cancer, and uses Bayesian geostatstical models, developed in parallel to the visualization, for spatial smoothing.[40] The design process included a preliminary literature review and multiple workshops to reach different types of audiences, ranging from the general public, to patients, to health practitioners, up to policy makers. Targeting such a wide spectrum of users poses a significant challenge, in terms of visualization efficacy, accessibility, clarity. Other than the main visualization being a choropleth map like many we saw, for instance, during the Covid-19 pandemic, the paper also discusses different design alternatives for the visualization of uncertainty. The success of the atlas stemmed primarily from the collaboration of research, stakeholders, and healthcare system.

Muniyappa et al.[32] introduce a novel approach to patient portal activation data to support equity improvements. Differences and disparities in patient portal access and usage have persisted since their first inception and introduction. To address this problem and improve equity in patient portal access, the paper introduces 2 dashboards that collect and visualize different metrics clinics use to identify disparities in portal activations and equity-related variables (ie, age group, language, ethnicity, insurance). The target audience is high-level officials of clinics, departments, and hospital service lines. From a visualization perspective, the dashboards provide a compact and concurrent representation of several types of information, allowing for easy comparison, trend recognition, and correlation discovery.[41,42] By using the dashboards, the paper reports several cases of patient portal access disparities in 2022. Individual clinics also used the ambulatory patient portal dashboard to track the impact of interventions to address disparities in their specific patient population. The paper reports that the interventions to mitigate disparities identified with the support of the 2 developed dashboards led to overall improvements in patient portal activations.

Ondov et al.[25] describe a design study where multilayer epidemiological data is visualized with animated glyphs named *geocircles*. This type of epidemiological data is made up of multiple, time-varying, geospatial variables—making the problem significantly complex, both from a visualization and interaction design standpoint. In the wake of the Covid-19 pandemic, VA has shown how it can support policy makers and governments for both putting in place disaster recovery measures and informing the general public.[43] The paper introduces a VA system named CoronaViz, where a combination of different variables are encoded as glyphs represented as animated, hollow circles. The geographical facet is used to place the glyphs onto a map. The efficacy of the proposed method is shown through case studies and 2 user studies. The first study entailed interviewing epidemiologists in the context of comparing different tools for visualization of epidemiology data—including the one developed within the paper. Overall, comments were positive: they expressed the necessity of visualizing different variables in compact glyphs but also expressed concerns on the cognitive load. In particular, experts were not completely convinced by the use of animations, which could have been misleading: for this reason, a further study was conducted, this time comparing the animated approach with a faceted, static visualization represented by 2 of the most popular dashboards developed during the Covid pandemic. This time, participants were non-experts. Study did not highlight significant differences in performance, but a higher engagement with the animated approach, which could make a difference during a public health crisis.

The role of AI in clinical support

Papers in this category tackle in some form the use of AI within VA software in the healthcare domain to assess disease progression and support the treatment process. Li et al.[44] introduce *TrajVis*, a VA system designed to support clinicians assisting patients with chronic kidney disease. TrajVis adopts AI models on EHRs to manage and monitor the progress of the patients' conditions. The paper is organized as a visualization design study, and begins with a requirement analysis with domain and Machine Learning (ML) experts. AI is integrated by projecting the input features to build a disease progression trajectory using the DEPOT model.[45] The result is a complex VA system with multiple views, whose efficacy is demonstrated by means of a case study and a survey to evaluate the users' experience. The participants, both physicians and data scientists, ultimately found the tool "intuitive, helpful, and easy." The visualization of the clinical trajectories in latent space is novel, and Trajvis provides a VA solution tackling clinical information. Moreover, the discovered trajectories were compared to the progression predicted by the *Kidney Failure Risk Equations* (KFRE), showing consistent conclusions. This is worth mentioning as KFRE is commonly used in clinical practice to estimate risk for patients with different levels of kidney failure.[46]

Morgenshtern et al.[28] introduce *MS Pattern Explorer*, a VA system that integrates ML to analyze wearable fitness tracker data. The proposed system is applied to clinical studies aimed and monitoring the conditions of multiple sclerosis patients, with the ultimate goal of enhancing the understanding of the disease symptomatology and supporting clinicians in exploratory medical sensor data analysis. The system is developed and presented as a design study, starting with a requirement and task analysis. At its core, the system couples a ML algorithm, leveraging the Self-organizing maps approach,[47] for the sequence retrieval of the chosen time series. The final outcome of this design process is an interactive VA system with multiple coordinated views, meant to support expert users in exploring these time series, searching for specific patterns, and contextualizing them within auxiliary metadata. The evaluation is conducted as user study with 15 participants uniformly sampled from the intended target audience (clinicians, data scientist, non-experts). Participants were asked to use the system to respond to a series of both open and closed questions, and their performance was measured based on how accurately such tasks were completed. Overall, the results indicate that participants could interpret high-level patterns with relative ease, but were, in some instances, overwhelmed by the parametrization-dependent analysis. Ms Pattern Explorer provides a step forward in making wearables' data more usable in these contexts. Scalability remains a limiting factor, but this tool showed potential for the analysis of personal healthcare data in such a delicate context.

Payne et al.[27] conduct a user study investigating AI-powered Early Warning Scores (EWS) showing potential deterioration risks in the context of simulated sepsis scenarios. The goal of the paper is to obtain insights and perspectives on the use of EWS, which were presented to the study participants within an EHR VA system. The system showed vital signs, the EWS, visualizations with highlighted abnormal values, and previous clinicians' notes. EWS were calculated using *eCART* score, short for *electronic Cardiac Arrest Risk Triage*. The study was conducted in the form of expert interviews also aimed at assessing participants' prior understanding of AI in the context of clinical support, and to understand if such suggestions were trustworthy or, more general, how they were considered by the clinical experts. In general, the interviewed experts were generally inclined to base their decisions on the provided EWS, but with prior verification ("trust but verify"). Considerations about the visual representation of EWS were also collected during the study, concerning the design of patient(s) views, score information, and interface customization. The participants debate about the usefulness of EWS: these indeed helped identify patients in need of attention, but at the same time not all alerts required action. In general, the study confirmed the need for visual metaphors to explain how EWS were derived, but also the need for closer collaboration of stakeholders in the design, validation, and integration of AI predictions in EHRs. The study, however, also highlights a limited familiarity of clinicians with AI prediction models.

Discussion

From the discussion of the papers included in this issue, some key takeaways emerge. First, there is a need for closer collaboration between stakeholders and researchers in the development of new VA systems for clinical practice, through user-centered design processes. Second, visualization can play a major role in physician-patient communication. This is especially true in delicate contexts, such as pediatric and chronic diseases. Third, interactive VA proved successful in supporting disease incidence monitoring and more generally, in clinical research at a large scale. Finally, while the adoption of AI technologies in supporting diagnosing and treatment has the potential to support physicians in their daily work, it cannot happen without building trust in AI models in healthcare. There is already a growing field of research, within the visualization community, for *Explainable AI* (XAI). The intersection of medical informatics and XAI would significantly contribute to the successful and conscious adoption of AI in the clinical context.

Some themes for future work emerged as well. The adoption of EHRs comes with 3 inherent challenges: *accessibility* for laypersons, *scalability*, and *privacy*. There is a large corpus of research on the use of visualization to improve the readability and accessibility of large data. As the health data available to physicians increases, the results of this issue are further proof of the benefits of VA systems developed with a user-centered approach. Further research on VA for large-scale health data could unlock further insights to benefit patients in terms of care quality and self-consciousness of their own health data, while researchers would be able to process, compare, analyze larger quantities of data more effectively. A conscious approach to the EHR revolution should pass first through increased digital literacy and improved communication of healthcare data. In this, visualization perception research can play a decisive role in developing understandable visual metaphors for the complex processes represented in this context.

Conclusion

We would like to thank the reviewers and the Guest Editorial Committee members for their contributions to this Focus Issue. The included papers present exciting new ideas and insightful and thought-provoking perspectives. While we consider this issue a success, it serves primarily as a starting point for future researchers to address the emerging challenges in the field, that can only be solved applying interdisciplinary approaches. We are pleased to deliver this collection of articles to the JAMIA audience, hoping not only to address analytical challenges, but also inspire curiosity and foster visualization-driven, interdisciplinary research. Addressing these research gaps is our final recommendation for readers of this issue.

Acknowledgments

We thank JAMIA and its EiC Prof. Suzanne Bakken for supporting the idea of the Focus Issue as well as the peer reviewers for their constructive and thoughtful feedback on submissions.

Author contributions

All authors managed the peer-review of the papers in this Focus Issue and made selection decisions. AA drafted the editorial; all authors contributed to the results interpretation, discussion, and proofreading. All authors approved the final version of the manuscript.

Funding

None declared.

Conflict of interest

None declared.

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Journal of the American Medical Informatics Association, 2024, 31, 2423–2428
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