Improving health and healthcare with interactive visualization methods

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Abstract: Interactive information visualization and visual analytics methods will bring profound changes to personal health programs, clinical healthcare delivery, and public health policy making. This article describes the state of the art within these three domains and gives examples of current efforts that hint at the remarkable transformations that are possible. Then it offers seven challenges for information visualization and visual analytics researchers. The arguments and challenges are aligned with the National Institutes of Health's roadmap for Predictive, Preemptive, Personalized, and Participative medicine. Many technologies need substantial advances to produce reliable, effective, safe, and validated systems, but the potential societal benefits are enormous.

1. Introduction

Evolving health informatics systems promise to revolutionize health and healthcare programs worldwide. However, turning this hope-filled vision into a reality will take enormous effort from thousands of designers, analysts, software engineers, usability specialists, and medical professionals. While there are many challenges to overcome, this paper focuses on the central role of information visualization and visual analytics processes (Kielman & Thomas, 2009; Ward et al., 2010). These algorithms, interactive designs, and analytic processes support exploration, monitoring, insight discovery, professional collaboration, and comprehensible presentations to patients, clinicians, policy makers, and the general public. The US Institute for Medicine's 2011 Report (IOM 2011) focused on improving patient safety through "cross-disciplinary research" on "user-centered design and human factors applied to health IT." The report sharply noted that "Information visualization is not as advanced in parts of clinical medicine as compared with other scientific disciplines."

2. State of the Art

Over much of the past century, medical imagery based on x-rays, and then later technologies such as CT scans and MRIs have transformed medical care by providing accurate 3D volume visualizations that highlight problem areas. Other successes include visualization-supported surgical planning, tele-surgery, pharmaceutical drug discovery, chem-informatics, and genomic expression analyses. In addition, information visualization is amplifying the benefits of health informatics databases and networks by dramatically expanding the capacity of patients, clinicians, and public health policy makers to make better decisions (Shortliffe & Cimino, 2013).

Hesse et al. (2010) provide a useful framework for analyzing health informatics technologies, under the popular term “Health 2.0”. This term suggests contemporary strategies that are web-based, participatory, and mobile. These strategies employ social media, personal sensors, mobile devices, as well as big data visual analytics integrated with advanced statistical methods. These strategies are a far cry from the physician recording blood pressure readings with a pen in a paper record that is unlikely to ever be seen again or used to detect national trends. Hesse et al. envision three domains for Health 2.0 (Figure 1):

1) **Personal Health Information**: Individuals will increasingly collect information about their own health practices, while body monitors and sensors will enable them to better understand their strengths and weaknesses.
2) **Clinical Health Information:** As Electronic Health Record (EHR) systems become pervasive (e.g. allscripts.com or epic.com) patient care could improve and secondary use of these data will provide valuable insights about treatment patterns.
3) **Public Health Information:** Federal and state governments collect large volumes of public health data that can enable policy makers to make more reliable decisions.

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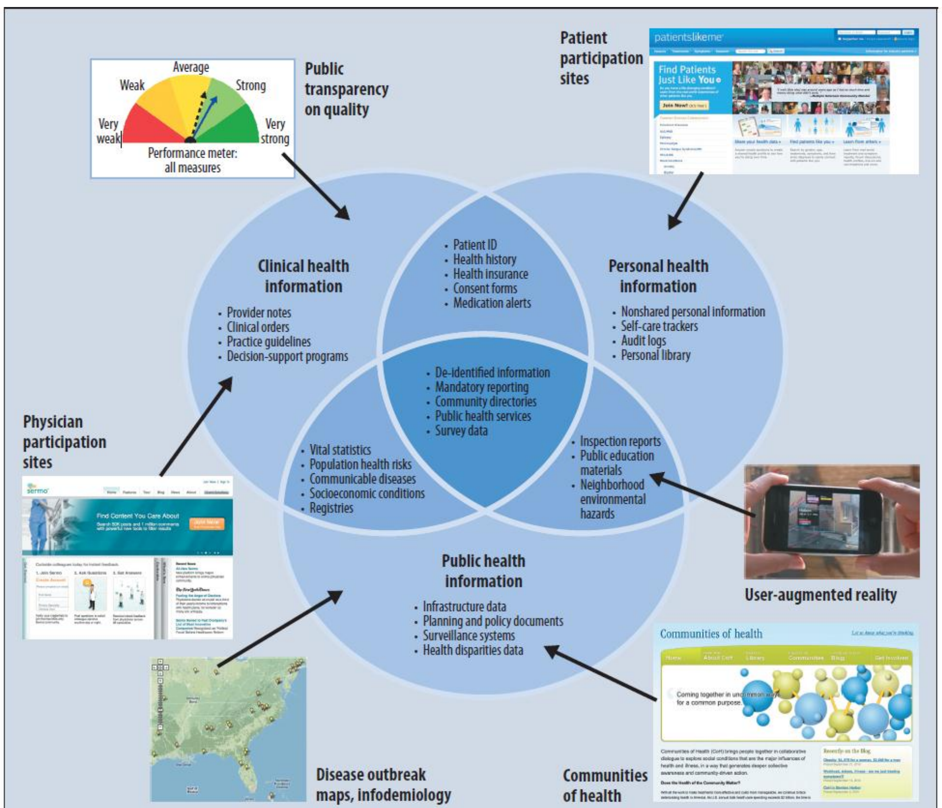

Figure 1. Research opportunities in developing the national health information infrastructure. Technology-mediated social participation systems have applications within the spheres of personal, clinical, and population health information.

Figure 1: The three overlapping domains for Health 2.0. These three domains provide vastly different challenges for designers of interactive visualization tools. Personal health information users may have little training, work with small mobile devices, and may be

intermittent users. Clinical health information users are likely to be professionals who are frequent users with substantial training, but must make rapid life-critical decisions in busy distracting environments. Public health information users may be experienced statisticians, who process voluminous data to test complex hypotheses that could lead to massive national changes in public guidance or medical care (Hesse et al. 2010)

2.1 Personal Health Information

Increases in online information and personal sensors have started to increase patient knowledge and responsibility for their health. This is a huge shift from the paternalistic view of medical care in which patients entrust their health to their physicians, whom they visit for an annual checkup or when faced with an injury or illness. Patient-led health programs include diets, exercise programs, lifestyle changes, non-prescription medications, and nutritional supplements. Health informatics services empower patients by allowing them to monitor their evolving health so as to assess their treatment plans or to understand their struggles to adhere to diet or exercise plans (e.g., carepass.com, healthvault.com). As devices improve and designers come to understand motivational structures and persuasive strategies, more patients can successfully monitor their diabetes, control obesity, or stop smoking. Applying social media through mobile applications enriches the possibilities for engaging users to understand the common practices of people like them.

Encouraging success stories such as the PatientsLikeMe web site (Figure 2) suggest that fresh approaches can be transformative. The site initially focused on a small number of chronic diseases, but it has expanded to cover more than a thousand conditions. Instead of the usual privacy policy PatientsLikeMe has an Openness Philosophy which encourages members to report in great detail on their treatments and side effects. Presenting visual patient histories that have sufficient detail, yet remain comprehensible to patients and physicians remains a challenge. Then visual search strategies to find patients with certain sequences of events such as suffering a stroke, receiving Coumadin (blood thinner), and then having severe headaches within 72 hours requires advanced visual analytics tools for search and to display the search results of exact matches and near misses.

Personal sensors are also gaining adherents among those devoted to the Quantified Self movement (quantifiedself.com), who advocate detailed data collection on health, exercise, diet, etc. Products such as Fitbit (fitbit.com) collect movement data and the associated website shows retrospective temporal patterns, which help users change their behaviors. Some patients are satisfied with simple timelines, while others prefer more playful metaphoric imagery with sound and animation (Figure 3).

Figure 2: A PatientsLikeMe report on Rheumatoid Arthritis based on more than 3000 participants.
[http://www.patientslikeme.com/conditions/52-ra]

Figure 3: UbiFit Garden's Glanceable Display: a) at the beginning of the week, b) after one cardio workout, c) a full garden with variety, and a full garden on the background screen of a mobile phone. Butterflies indicate met goals (Consolvo 2008).

2.2 Clinical Health Information

Physician training continues to improve but the vast knowledge of specialized conditions, numerous medications, and professional guidelines emerging from research make it very difficult for physicians to know all that they need to know. Furthermore the increasing data recorded by patients, stored in EHRs, and captured from medical lab tests challenge the capacity of physicians to grasp an overview of the patient history while seeing specific data values that alert them to potential problems. Designers who learn enough about medical decision-making have the potential to enable clinicians to make more accurate and rapid decisions.

Designs for single patient visual histories have been explored, but no strategy has emerged to be widely accepted (Rind et al., 2013). Temporal histories with various forms of timelines are becoming common (Figure 4), as are body maps showing the location of previous and current conditions, surgeries, or injuries (. Some innovative designs have been made to present lab test results so as to steer user attention to abnormal readings or to changes from previous tests, but there are no widely used or authoritatively validated practices for highlighting or comparative presentations (e.g., mscui.net). A long-time visualization success story is the use of growth charts to compare a child's trajectory with relevant populations (http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5909a1.htm).

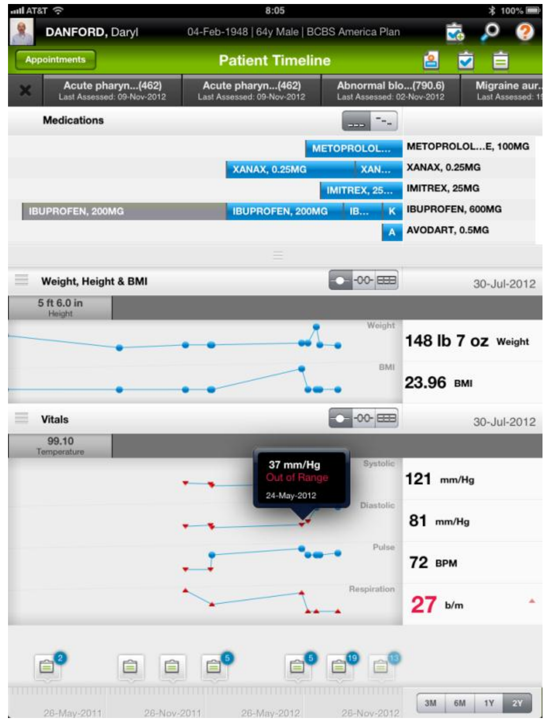

Figure 4: The Wand Timeline view of a patient record in Allscript's ambulatory EHR iPad application.

Used with permission of Allscripts. www.allscripts.com

Organizations are under pressure to demonstrate adherence to clinical guidelines and need to analyze their own performance data. For example, a large health organization may want to investigate patterns in re-admission rates in patients with asthma who are prescribed long-acting beta-agonist asthma medication according to new guidelines (Figure 5). Interactive visualizations are starting to help clinicians and patient safety managers query EHR databases to understand the patterns of use. They soon will be able to study medication adherence rates by examining patient refill patterns or study switching rates and dose reductions after FDA warnings about drug interactions.

While clinical trials remain the work horse of clinical research there is now a shift toward the use of existing clinical data for discovery research, leading researchers to analyze large warehouses of patient histories (e.g., btris.nih.gov). Visualization can reveal data quality problems, which are common when repurposing clinical data for secondary analysis. Temporal patterns are critical to this research, so interactive visualizations are beginning to support powerful temporal queries, present rich result summaries, and offer fluid interactions to identify the clinically relevant temporal patterns hidden in the data (Wongsuphasawat et al., 2011). Visualizations help clinicians identify cohorts of patients who match selection criteria for clinical trials (e.g. www.i2b2.org). .

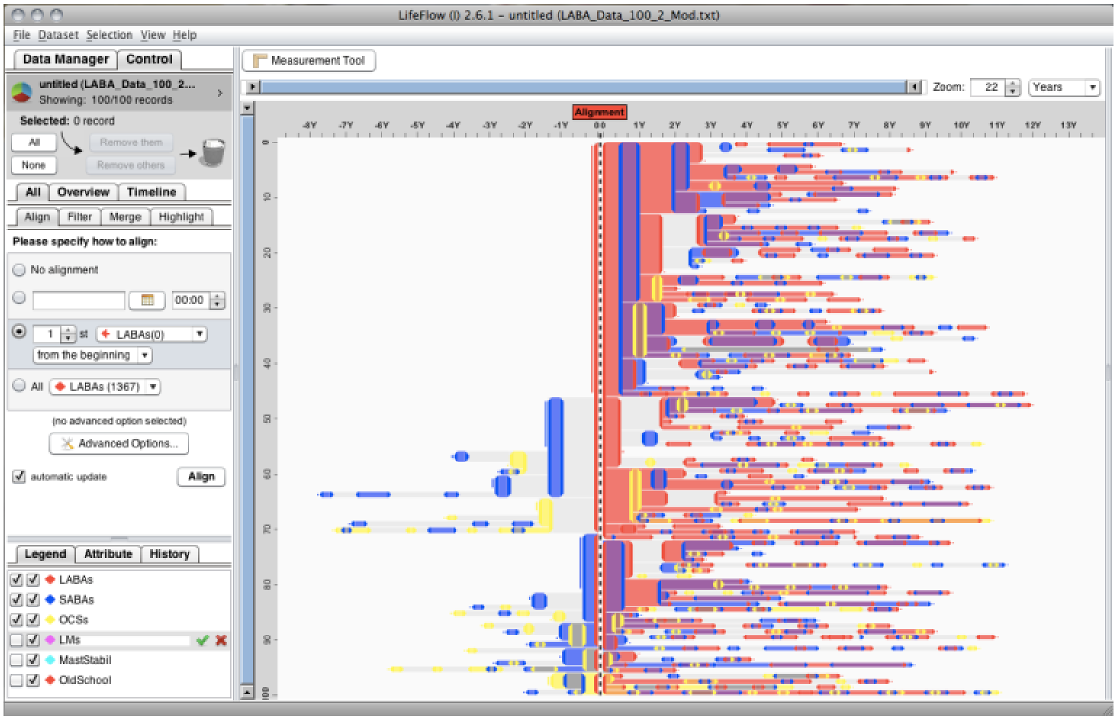

Figure 5: Exploring prescription patterns of 3 drugs (A in red, B and C) for 100 patients in EventFlow (www.cs.umd.edu/hcil/eventflow).Visualization helped reveal that guidelines regarding the use of Drug A were not adequately followed. For example when all records are aligned by the start of Drug A (see the dotted vertical line) about half of the records have no drugs prior to the alignment point) which means that those patients did not receive the other less potent drugs prior to the start of Drug A. The figure also illustrates the chaotic-ness of the temporal patterns and the need for better summaries that combine interval sequences based on similarity, as opposed to exact matches.

2.3 Public Health Information

The huge volume of information collected by the US National Center for Health Statistics, Centers for Disease Control, Census, Health and Human Services, the World Health Organization, and other agencies in the US and elsewhere provides valuable information to guide public policy (e.g., healthdata.gov, data.medicare.gov, seer.cancer.gov, data.euro.who.int.). However, exploring their datasets and correlating between them to derive insights remains a challenge. The data are inherently geo-spatial (ranging from individual households to entire states), and temporal (ranging from minutes to decades), enriching the challenge of finding patterns, relationships, clusters, gaps, and outliers. However, when poor outcomes in a neighborhood or county are identified, they can be presented in compelling ways that influence decisions by policy makers. The Maryland Environmental Public Health Tracking Network, for example, formed an online collaboratory to help public health researchers extract value from visualizations built through geographic information systems (http://ideha.dhmh.maryland.gov/OEHFP/EH/tracking/SitePages/Home.aspx) and to use those data for informing state and community policy.

Improvements in multivariate data analysis tools are already facilitating the analysis of survey data (Oliveros 2012), and in turn helping decision makers gauge populations' access to health care or eating habits to adjust nutrition guidelines or take action to curb alarming trends such as the rapid increase of obesity.

Retrospective analysis of state and county health patterns is also useful to residents and public health policy makers. The Community Health Map (Sopan, 2012) provides simplified access to health data that supports easy exploration and comprehensible presentations. Current visualizations integrate temporal pattern analyses to enable users to answer many more complex questions such as: which areas are moving in the right direction and which are not? More specific tasks are to understand which areas are making the most rapid progress and why? Such tasks are easy to imagine, but integrating reliable data from multiple sources and supporting complex temporal geo-spatial and multivariate data remains a challenge.

Controlling the spread of new infectious diseases or responding to biological attacks is also an opportunity for visual analytics solutions, helping national or local health organizations rapidly query emergency room records to find patterns that may have been overlooked, track patients that may have been infected, or identify patients at risk who are in need of preventive treatment. Improved syndromic surveillance includes the analysis of over the counter drug sales as well as the ebb and flow of social media discussion topics. Coupled with models of disease spread, visualizations are starting to help decision makers predict the future course of the outbreak, and evaluate strategies which can be applied to control an epidemic (Afzal, 2011).

While temporal and geo-spatial data are already a strong component of health informatics, network data is becoming increasingly valuable in understanding dangerous epidemics and adoption of healthier lifestyles. Christakis & Fowler (2011) launched a lively controversy about the power of social networks to spread health behaviors such as smoking vs smoking cessation or obesity vs. healthy diets and exercise. Their claims offer hope to those who believe that increasing use of social media could be used to trigger healthier lifestyles.

Social media are opening remarkable possibilities for health and healthcare researchers. For the first time in history much of what we do is recorded online, and for the first time in history we have the tools to capture, analyze, and visualize these data. Data from twitter is especially interesting for public health analysts since it is publicly available to enable studies of how medical trends spread. Clustering algorithms can sort out the active communities of discussions and network analysis metrics such as betweenness or eigenvector centrality help to detect the key influencers for each medical topic (Figure 6).

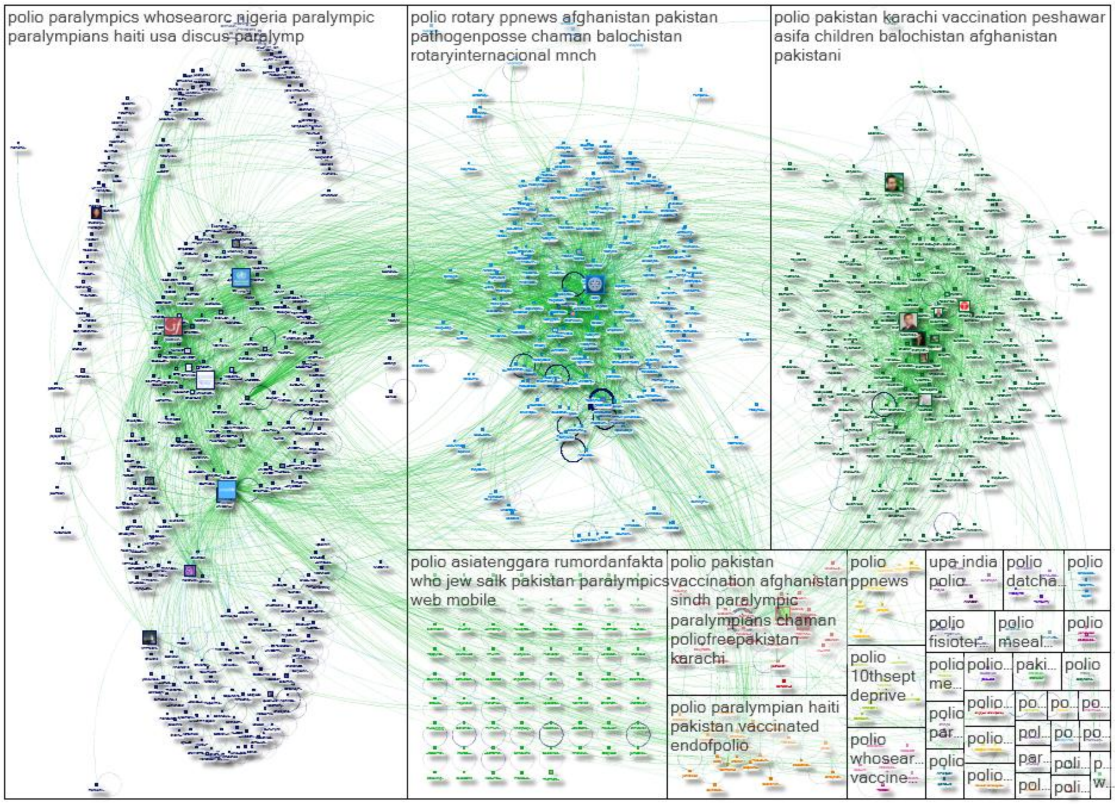

Figure 6: NodeXL (www.codeplex.com/nodexl) graph of tweets with the hashtag #polio. The links represent follower networks which are then clustered to reveal the regional interests (e.g. Nigeria, Pakistan, Afghanistan) in containing polio with topics such as children and vaccinations. Hub participants are dramatically more connected than other participants suggesting a "broadcast" pattern of discussion. Comparing this map to others maps reveals that polio lacks the pattern found in more controversial or polarizing topics (in which separate clusters have few if any interconnections). The small number of isolates shows a well-connected community. (Hansen et al., 2010) (Courtesy of Marc Smith)

3. Trends, Opportunities and Challenges for Information Visualization

Over the past ten years, directors at the National Institutes of Health have argued that in order to save healthcare costs while improving health and healthcare, medicine must move away from its industrial-age roots in providing "one size fits all" therapies to become more **predictive, preemptive, personalized, and participative** over time (www.nih.gov/strategicvision.htm). Each of these attributes is an information-age concept, and depends on advances in networking and information technology to be realized. Needless to say, data within this new 21st Century system will become the new currency. Understanding how to best visualize those data to each community of participants, is a central challenge to improving healthcare.

Consider the case of cancer. Cancer occurs when transcription errors from genetic code alter the control mechanism of a cell in such a way as to spur unregulated cellular growth. The good news is that new advances in high throughput computing, whole genome sequencing, and powerful genome browsers enable clinicians to identify specific transcription errors. Researchers predict that future healthcare professionals will take advantage of these same high throughput computer technologies to improve the predictive accuracy of disease models, to improve care, and to accelerate basic discovery. This is the essence of the "Learning Healthcare System" as described by the Institute of Medicine (IOM). In the IOM's vision, health information technology will enable potent visual data analyses that can improve care, inform decision making, and accelerate discovery.

In November 2011, the American Society of Clinical Oncology (ASCO) described how a new visual-analytics-infused healthcare system might serve to spur the development of a rapid learning system for cancer care. ASCO depicted an idealized system in which data collected through the process of care are stored and made available for the personal, clinical, and public health foci articulated throughout this paper. Patients would gain access to the data for monitoring their own conditions, for reviewing and implementing treatment plans, for gaining social support, for reporting symptoms, and for communicating asynchronously with their care team. These challenges require research on sensors, mobile devices, social media, peak-load network performance, privacy protection, - as well as visualization. Clinicians would be able to access the data as the foundation for their treatment plans, for monitoring the progress of individual patients, to meet quality improvement goals, and for ensuring that all of their patients are getting prompt, high quality care. All of these data could then be cycled back into the public health research enterprise to improve the comparative effectiveness of therapies, to enable population-wide studies, and to generate new evidence. The palette of opportunities is broad for bringing information visualization tools to the task of improving care and accelerating science in cancer and other disease areas.

Based on our personal experience we highlight 7 practical challenges which we hope will receive enhanced attention:

1- Offering busy clinicians timely information in the right format

Summarization of large amounts of information into tailored overviews of patient histories remains a challenge. As data are collected over a life span, visual analytics tools will be needed to help users quickly browse the general contours of health functions, look for anomalies, and then drill for details to catch predictable risks early. Visual workflow design and presentation tools can help clinic managers adapt their EHR systems to their practices, while well-designed medical order management displays can steer physicians' attention to late or lost results and help ensure timely follow-up even in busy environments. The improvements in data visualizations can also be critical in improving general clinical practice. Hospitals, healthcare organizations and even individual practitioners will benefit from feedback on their own practices. Commercial systems that integrate visual dashboards of emergency room activity, staff workload, or equipment utilization, will increase situation awareness that leads to more efficient use of resources.

2- Moving toward an ecosystem of visual tools

As more signals are produced, the need to view those data in diverse forms will rise. The patient-centered medical home is a good example. The idea of a patient-centered medical home, which is gaining popularity under the Affordable Care Act of 2010, is to provide patients with a primary care clinician for monitoring general progress across all aspects of care. For the medical home to succeed, tools will be needed to help clinical professionals account for status across multiple conditions over time. Family care doctors have traditionally provided medical care for patients at home. Estimates are that there will not be enough family care doctors to meet the needs in the future. Paraprofessionals, such as physician assistants or family members, will likely take that role, but they will need easy-to-understand visual tools. There are some indications that a new ecosystem of these visual tools are emerging as developers innovate at each point of access to the underlying medical data stream. The Veteran's Administration home care services combine personal health monitoring with telemedicine to dramatically reduce hospitalizations and recovery times (telehealth.va.gov). Well-designed user interfaces with visual presentations for patients and their caregivers are improving the quality of life for patients of all ages. Visualization might address the challenges of dealing with low-literacy populations and speakers of diverse languages. Conversion to multiple languages, use on small screens, and implementation on diverse platforms are further research challenges.

3- Facilitating team decision-making

A change that is triggered by movement toward interoperable data systems is a shift from individual decision-making to team decision-making. Lessons learned from Computer Supported Cooperative Work are relevant here. However, research is needed to apply those lessons to enhance situation awareness among multiple members of care teams, including the primary care physician, specialty care physicians, nursing staff, laboratory technicians, nurse navigators, social workers, behavioral medicine specialists, the patient, and the patient's own care givers. Team-oriented medical decision-making is also challenging since legal liability is involved so all team members must signal their concurrence.

4- Characterizing and understanding similarity

Visualization will be instrumental in helping clinicians solve difficult cases or deal with rare diseases. Further refinement in the visualization of structured and unstructured textual information will guide physicians searching for evidence to support treatment decisions in PubMed and other medical literature sources. Interfaces to query EHR databases can help find similar cases that have been encountered before. For example clinicians might select sequences of problems and treatments they believe are most significant in a patient record, then set similarity tolerances and narrow the search to a set of similar patients, then study their treatments and outcomes, or identify colleagues who treated those patients.

5- Visualizing comparative-effectiveness and cause and effect relationships

A workhorse of health research is comparing cohorts of patients. Visualizations will help characterize differences and facilitate comparative-effectiveness studies to enable researchers and patient safety managers to evaluate methods and treatments. In particular the elusive goal of discovering cause-and-effect phenomena might be aided by combining appropriate statistical analysis and compact visual arrays summarizing the relationships between multiple events.

6- Presenting risk and uncertainty

Complex data with uncertainty and incomplete entries are difficult enough for professionals to analyze, as was demonstrated in the VAST2010 challenge on pandemic prediction (http://hcil.cs.umd.edu/localphp/hcil/vast10). Presenting uncertain sources to personal health data users presents exceptional challenges. In addition, the presentation of risks of treatments, medications, or failure to act is a well-known problem in medical communications for which interactive visualizations could be especially helpful. Showing forecasts with uncertainty is accepted with weather data, but still novel with medical data. Research on design of persuasive visualization for patients who must decide about elective surgeries or be convinced to stop smoking would bring large benefits. Adequate representation of uncertainty during pandemics is a related challenge for public health applications.

7- Evaluation

Designers have to validate and refine their prototypes by testing in realistic environments with troubled patients and overloaded clinicians. While errors with mobile device applications for entertainment or social engagement are usually annoyances that are easily reversed, errors in medical situations can prove deadly. Some adventurous designers are taking on these challenges, but the medical context is especially difficult because of the life-critical nature of many decisions. Visual interface designers will need to learn a great deal more about health and healthcare. Designs that provide evidence-based explanations on demand and interfaces that prevent errors will be required to ensure quality treatment. Since poor visual designs could result in misunderstandings and ill-advised choices, simple usability testing is insufficient. Repeated testing in diverse environments and feedback mechanisms from every use can produce continuous improvement for these life-critical applications. Medical visualizations are sometimes integrated into medical devices, thereby requiring US Food & Drug Administration certification. For EHR systems and personal medical monitoring the law is still unclear, so guidelines for proper testing are still emerging (Schumacher & Lowry, 2012) and clinical trials may become necessary to validate the efficacy and safety of visualizations in realistic environments with troubled patients and overloaded clinicians. In addition, effective anonymization and de-identification algorithms are needed so benchmark data sets can be made widely available for research and testing while protecting patient privacy.

Many other general challenges are also critical to health and healthcare applications (Kielman & Thomas, 2009), for example:

- Thorough **data preparation** to cope with missing values, duplicated records, incorrect data entry, patient name entity resolution, and proper date-time stamps. **Scaling** visualization techniques to billions of records by filtering and dynamically forming aggregated values. This supports retrospective analyses by researchers who may seek to compare across patients, physicians, hospitals, time periods, and geographic regions.
- **Systematic yet flexible visual analytics processes** that promote complete coverage, while preserving the option of exploration in depth when novel insights are found. These reliable processes are necessary for repeating analyses as new data sets become available.
- **Logging** of complex sequences of visual analytics operations so users have audit trails of what they have done, allowing them to reapply these workflows to new datasets and share the workflows with clinical colleagues.
- **Moving research prototypes into commercial systems - from Beta to Bedside**
  Some tools already exist but are unequally applied. Working more closely with the conservative and competitive health informatics industry will encourage more rapid adoption of innovation.

4. Conclusions

The rapid growth of information visualization, visual analytics, and health informatics already shows promising results, but their further integration could produce large benefits in improved personal health monitoring, clinician treatment decisions, and public health policy. These three Health 2.0 domains will inspire researchers for many decades to come, producing spin-offs that will be relevant for financial, economic, legal, and other application areas. The eight research challenges are just the beginning. The remarkable wealth of possibilities for information visualization methods to substantially improve health and healthcare will trigger new conferences, journals, courses, curricula, and profound changes to many professions.

Patient understanding of their health and medical conditions will be improved by interactive visual presentations that allow drilling down to gain background information, show comparisons, and highlight anomalies. Developing these personal health visualizations requires considerable research and validation, especially for patients with visual impairments, but research on screen readers and sonification would respond to their needs.

Errors in clinical care remain a severe problem, but many could be avoided or detected by improved visual feedback to **clinicians** about patients, their medical conditions, and the contexts of treatment. Improved EHRs will apply visual techniques to reduce common errors of mistaken patient identification, mode mismatches, flawed interpretations, incorrect recall, or incomplete visibility of system states.

Public health data analysts will benefit from more integrated systems that provide comprehensible access to diverse data sets, establish systematic yet flexible visual analytics workflows, and accepted formats for presenting results to policy makers and the general public.

The call for disciplinary excellence and public service are likely to attract many information visualization and visual analytics designers, implementers, and evaluators. They face substantial challenges, but there are also grand opportunities for societal benefit.

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