50 Years of Informatics Research on Decision Support: What’s Next

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Summary
Objectives: To reflect on the history, status, and future trends of decision support in health and biomedical informatics. To highlight the new challenges posed by the complexity and diversity of genomic and clinical domains. To examine the emerging paradigms for supporting cost-effective, personalized decision making.

Methods: A group of international experts in health and biomedical informatics presented their views and discussed the challenges and issues on decision support at the Methods of Information in Medicine 50th anniversary symposium. The experts were invited to write short articles summarizing their thoughts and positions after the symposium.

Results and Conclusions: The challenges posed by the complexity and diversity of the domain knowledge, system infrastructure, and usage pattern are highlighted. New requirements and computational paradigms for representing, using, and acquiring biomedical knowledge and healthcare protocols are proposed. The underlying common themes identified for developing next-generation decision support include incorporating lessons from history, uniform vocabularies, integrative interfaces, contextualized decisions, personalized recommendations, and adaptive solutions.

1. Introduction
This publication is focused on decision support at the cross-roads, a set of talks that were given at the 50th anniversary symposium of the journal, Methods of Information in Medicine. The considerations of history, status and future dimensions of decision support paradigms due to new computer science methodologies and complex problems including genomics are all reflected in these thoughts of a group of international leaders in the field of Biomedical Informatics. The result is a rare view into these issues.

The paper begins with a review of the history of decision support and the pioneering work of early informaticians in creating systems for assisting in decision making in healthcare. This motivates an analysis of successes and shortfalls, especially the recognition that the future of decision support lay with integration into clinical workflow and with shared standards for clinical concept recognition. Issues considered include the evolving science of decision support and the tools and techniques that will be important for the future. In short, the path forward builds on the early work in the field and an understanding of its successes and failures.

The next four sections focus on the complexity of the scientific situation paralleled with the demands of the healthcare settings. The common theme asserts that the biomedical informatics profession needs to step up to the plate of more complex and demanding needs, going far beyond the simple rule-based systems that were given at the 50th anniversary symposium of the journal, Methods of Information in Medicine. The result is a rare view into these issues.

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sues of coping with the complexity of the human genome. The educational system for all health professionals will also need to be revamped to work in a transformed world.

The challenges of the human genome project and how to build an infrastructure that would be needed for genomics clinical decision support are carefully examined. Several methods by which genomic decision support is already being accomplished with traditional approaches are highlighted. The solution to the overall genomic decision support problem, however, will take new paradigms and national or international coordination for representation of the genomic knowledge.

The importance of terminology as a foundation for clinical decision support is also emphasized. Many challenges are imposed by the use of multiple terminology and concept representation systems. The lack of controlled terminology has a negative impact on all health care systems. Drawing from the example of Sweden and its use of SNOMED CT as the terminology standard for the whole country the international standards organizations are urged to work together to provide a common terminology to be used in health care.

The last three sections consider important dimensions of decision support that are needed for successful implementations. Institutional and leadership dimensions both locally and globally are vital. Considerations on how to bridge decision support systems with other knowledge bases to create a whole that is larger than the parts are needed for a complete solution.

Decision support in healthcare institutions suffers from fragmentation, little context to the recommendations, and unequal access for the multiple of people who need assistance with making decisions. A new global approach for decision support in healthcare would help to create a world vision and could allow for the various fields of expertise and methodologists needed to create the future could all be involved in making the vision a reality.

The myths of Icarus and Phaeton are apt analogies for institutional wisdom associated with the implementation of clinical information systems and especially decision support tools. Institutional leaders must value pioneering clinical informatics faculty as strategic resources for their institution so that the lessons of the past are remembered as future systems are created.

Finally, viewing decision making and decision support more generally, the important work that is involved in the decision journals make on what to publish and what not to publish should not be neglected. Many difficulties have been encountered with misleading scientific communications, and special considerations should be given to creating smart systems that can bridge between journal articles and all of the other knowledge sources in medicine to help bridge gaps in the knowledge for decision support.

2. Decision Support as an Evolving Science

The notion that computational methods could be used to assist clinicians in their decisions regarding a patient’s diagnosis, therapy, or other management has intrigued both scientists and the public from the early days of our field. In fact, in the English-speaking world the seminal article that began the field of biomedical informatics is arguably the discussion of statistical foundations for medical diagnosis and the potential of computers to assist in the process, published by Ledley and Lusted in 1959 [1]. With subsequent important work on Bayesian diagnostic systems by Warner [2], Gorry and Barnett [3], and de Dombal [4], among others, the history of clinical decision support systems is roughly the same age as Methods of Information in Medicine, which has also published many important articles in this area.

The public has long associated “computers in medicine” with the notion of computer-supported diagnosis, imagining systems that would allow a user to “punch in” a patient’s signs and symptoms and to receive advice through this special, stand-alone process. The result was systems that were seldom used by busy clinicians and tended to be the basis for educational programs. The methods that they demonstrated and refined, however, became part of the science of our field, and continue to be drawn on to this day (e.g., Bayesian diagnosis, leading to belief networks and influence diagrams as computational power increased; rule-based systems, adopted broadly outside of biomedicine and now increasingly evident in clinical systems as well; algorithm-based advice, reincarnated in the last two decades as clinical guidelines, with substantial work to implement these in order-entry and other clinical data management environments). After the introduction of personal computers and local area networking in the early 1980s, with recognition that there was now a model for system integration evolving that would
allow decision support tools to gather information from other data sources, rather than directly from clinicians, the delivery model for decision support began to shift. By 1990 the consultation model for DSS (dubbed the “Greek oracle” model by R. Miller [8]) had been cast aside, with growing recognition that the future of DSS lay with their integration into clinical workflow, with shared standards for clinical concept representation and tight coupling to order-entry and EHR systems.

With the 1990s came the popularization of the Internet through the creation of the World Wide Web, which began to change the ways in which decision support could be delivered, including to the public. Early lay tools for diagnosis began to appear on the Web, as did consumer health sites that provided a variety of educational materials for the public that assisted them with decision making about their own health issues. At the same time, the commercial clinical systems companies saw a growing demand for their products. Early adopters began to demonstrate a formal commitment to EHRs, seeking elimination of paper records. As EHRs were integrated with CPOE, reminder systems began to be incorporated into commercial products, typically leveraging the Arden Syntax which had been devised by the informatics community as a standard for representing basic rules regarding reminders/alerts and the underlying criteria for triggering them [9]. The commercial inclusion of decision support functionality was complicated by concerns about legal exposures (in case of error, outdated advice, or liability generated for physicians and provider organizations), the potential role of regulation [10], and institutional resistance to providing generic advice that had not been created and vetted locally.

Today there are decision support capabilities in many commercial systems, although they often require the client organization to refine or provide the knowledge that will trigger the warnings and alerts that are provided. Computers are used routinely to read EKGs, to monitor devices in intensive care settings, and to assist with therapeutic planning in settings such as radiation oncology. But the notion of a full-fledged diagnostic or therapeutic decision support tool, integrated with workflow, tied to the EHR, and assisting clinicians routinely in the assessment of patient data or the generation of management advice remains elusive. Some tools, such as DXplain [11], have had a significant role in medical education environments and continue to be used via the Internet to this day. Others, such as the well-known Internist/QMR program [12], have not been maintained and are no longer available. These stand-alone systems did not integrate with modern systems and hence were not responsive to our growing understanding of the crucial role that integration and workflow make in assuring the utility and acceptance of decision support tools.

Yet these and other systems from the early years have had a dramatic influence on informatics from a methodological perspective and in increasing our understanding of the social and human factors that are crucial to the effective deployment of decision support. It is accordingly erroneous to characterize the DSS research of the last several decades as having “failed” (a comment which is occasionally made). The work is, rather, a key element in an evolving science that would be much less mature if it were not for the pioneering work of the past. It is important to view the early work in that light and for today’s students of decision support to study the past work and to understand how the lessons that were learned define the path for the decade ahead.


Early clinical decision support systems have led to techniques that generated new research and applications in knowledge based systems and other information management and analytic frameworks. With the grand objective of helping clinicians make better and well-informed diagnostic, therapeutic, and prognostic decisions, many important computational and information management techniques in complex environments were first proposed, examined, and demonstrated in the clinical settings. In practice, however, clinical decision support has largely been limited to information visualization, smart alerts, reminders, and references, and some limited automation of clinical protocols and practice guidelines [13].

New computing technologies are increasingly being recognized as instrumental in preventing medical errors, especially diagnostic errors, reducing cost, and improving patient safety [14]. There is, however, three major types of challenges that the next-generation clinical decision support systems must address: 1) Domain challenges: A large number of interacting and complicating conditions or factors is usually involved in clinical decisions; relevant information and available options are incomplete, uncertain, and often changing with the progression of the disease(s), the genetic makeup of the patients, and the outcome of the actions; 2) System challenges: The constantly varying clinical workflows, rapidly changing information technology platforms, and exponentially accumulating information and data of various forms render many subsystems or processes incompatible or obsolete very quickly. These in turn complicate the proper encoding, maintenance, and integration of the information and knowledge needed to support cost-effective decision making; and 3) Usage challenges: The same clinical decision support systems may support different users with vastly different backgrounds, different objectives, and even different preferences in their decision making approaches. Different ways of encoding and access to the relevant information are needed to fulfill the information needs and enhance the cognitive capabilities of different decision makers.

We need a set of new informatics paradigms for developing cost-effective clinical decision support systems in a changing environment with uncertain and incomplete information. These paradigms should support context-aware, situation-specific representation, reasoning, and learning, not as separate but as interacting and integrated processes. These processes would allow semi-automated configuration of the underlying computation and communication structures and systems as new infor-
mation becomes available, in the form of expert knowledge or learned models from observational data. The motivations and objectives of this approach arise from recent advancements in cognitive psychology, neuroscience, decision theory, probabilistic modeling, and machine learning—a true confluence of multiple disciplines to support biomedical informatics.

3.1 Context-sensitive Reasoning: Focusing to Optimize Resources

In general context-aware computing, the system and the reasoning process adjust to focus on the important tasks, using only the right information at the right level of abstraction, thereby cutting down on the time and space resource requirements. At the domain level, context-sensitive reasoning allows the system to focus on the relevant conditions, based on the available evidence, and gather more information on the fly. At the user level, context-sensitive reasoning allows the users to better focus and reduces the chance that the relevant recommendations are ignored or sidelined. A new class of generative representation models that can generate decision “policies” in different situations is needed to enable context-sensitive reasoning in the clinical settings.

3.2 Transformation Modeling: Inducing Representation Change

The current assumption of (and reliance on) a complete knowledge base or model in clinical decision support systems makes it very difficult to ensure that all the knowledge is encoded consistently in the knowledge base, and that the relevant information can be derived when needed. Inspired by recent advances in cognitive science on concept formation [15], knowledge encoding systems and models should be able to transform based on observing or learning emerging patterns to support different types or stages of reasoning for different decision makers, e.g., from first principles through available, general knowledge, to “fast-and-frugal rules” [16] at the expert level, when sufficient patterns have been detected or learned.

3.3 Transfer Learning: Adapting Knowledge to New Situation

As it is infeasible to assume or work toward a complete knowledge base, clinical decision support systems should aim at incorporating a set of transfer learning techniques that would facilitate model adaptation, especially in the presence of similar or reusable contextual, structural, and/or parametric constraints. By dynamically adapting part of the decision model as new data and evidence arrive over time, focused reasoning and learning can be supported, even with incomplete and changing information.

3.4 Human-centered Interfacing: Personalized Support in a Changing World

Recent advances in and lessons learned from situated awareness research [17] have illuminated the scenarios where different cognitive biases may arise. Clinical decision support systems should provide human-centered interfaces to steer the clinicians away from biases that would lead to diagnostic errors [18]. Studies and findings from cognitive psychology should be incorporated; user engagement should also be integrated into the development process. Decision support recommendations should change according to the case at hand, the background and experience of the clinicians attending, and evaluation feedback.

We can now better understand the constraints and limitations of the past and current generations of clinical decision support systems. We also accept that we cannot capture all the information needed to make all the potentially relevant recommendations in the complex clinical settings. We need a new generation of systems that can effectively deal with change, uncertainty, and incompleteness, and yet provide useful and practical support in a wide range of clinical decision tasks. This is a crucial time when we should rethink our approaches and methodologies.

4. Dealing with Complexity for Decision Making in Genomic Medicine

“In short the science of complexity can help all of us address the challenges and opportunities we face in a new epoch of human history.” – David J. Snowden and Mary E. Boone

We are witnessing a sharp increase of complexity within health care, public health and biomedical research. This increased complexity can be seen not only in the available knowledge about diseases, diagnostic and therapeutic procedures, but also in the environment in which we work (health care levels, jurisdictions, management models), under multiple stressing forces (aging population, increasing number of chronic patients, sustainability of the system, legal regulation). All these elements are also reflected in the complexity of the information space in which we have to carry out our work as well as in the systems that we have to design and develop [19].

Our discipline is in a privileged position to address these challenges from their current central role in the processing of information and knowledge management. This perspective can certainly affect the design of educational programs, as well as how we define, develop, implement and evaluate our projects.

4.1 The Challenge of Dealing with Complexity

Complexity has been defined as: “that property of a model which makes it difficult to formulate its overall behaviour in a given language, even when there is reasonably complete information about its atomic components and their inter-relations” [20]. The use of the term complex is often confused with the term complicated. Complex is the opposite of independent, while complicated would be the opposite of simple.

Many scientific fields have dealt with complexity although complexity is a science in itself [21]. It can also be measured, compared, increased or reduced.
within a system. Modularity is key to deciphering complexity. The science of complexity comprises several theories that are familiar to many experts in health and biomedical informatics. The pioneering work of cybernetics, general systems theory, chaos theory, games theory, artificial life and some aspects of artificial intelligence represent a good part of the theoretical arsenal with which we can face the challenges posed by complexity.

Health and biomedical informatics should make dealing with complexity one of its central objectives. The complexity of diagnostic, therapeutic, and preventative decision making grows with each new clinical discovery. Sometimes complexity cannot be reduced, but we can try to hide it from the users of our systems. Decision making in the new field of genomic medicine is a good example [22, 23]. Physicians will have to use information about the patient’s clinical history, his or her personal genome, family medical history, environmental risk factors and have access to knowledge about the molecular basis of the disease. If we adopt here the definition of decision-support systems by Sittig et al. [24] “refer broadly to providing clinicians or patients with computer-generated clinical knowledge and patient-related information, intelligently filtered or presented at appropriate times, to enhance patient care”, there are important barriers to overcome associated to the scale and complexity of genomic medicine, but this also means that in this domain there are numerous opportunities for the design of guidance, workflow and alerting information systems. There are also big challenges associated with the integration of data from multiple sources (clinical records, bioinformatics databases, laboratory tests), but we will only witness clinical applications if we succeed in coping with the immense complexity of human genetic information and in being able to distill useful rules of thumb and basic pieces of information amenable to clinical application by care practitioners. Clinical decision-making systems are also needed to support clinicians in their use of biomarker information to guide disease prevention, diagnosis, prognosis, therapy and follow-up. We must remember that new advances in genomic medicine are producing a major change: instead of applying agreed procedures for all patients with the same disease, the clinician is faced now with new decision matrices, in which, on one axis, we see the different genetic variations that groups of patients may have, on the other, the different molecular entities that are being used to re-classify the disease. This scenario consists of multiple genetic types of patients versus multiple molecular subtypes of disease and will undoubtedly require information systems that support the processes of decision-making for pharmacogenetic, risk prediction and risk reduction [25].

4.2 Impact on Education

The challenges related with dealing with complexity will also have an impact on the design of programs for the education of future scientists in health and biomedical informatics. As Professor Roco wrote: “Formal education will be transformed by a unified but diverse curriculum based on a comprehensive, hierarchical intellectual paradigm for understanding the architecture of the physical world from the nanoscale through the cosmic scale” [26].

With regard to training in skills that are useful to deal with complexity, a great effort should be made in areas such as visualization and knowledge representation, systems design based on modularity, reuse of components and workflows, and promotion of the use of standards.

Complexity can be seen as an opportunity or as a threat for our discipline. If we want to play a central role in the advent of the new era in Medicine, the time is ripe to apply our informational skills. We should also make an effort to raise awareness about these challenges among health professionals and new investigators and contribute to increase their competence in the skills that will be required.

5. Genetics and Genomics: Paradigms for Clinical Decision Support

5.1 Opportunities

The completion of the Human Genome Project in 2003 created the promise of Personalized Medicine. Speculation on its impact on electronic health records followed closely behind [27, 28]. This revolution in healthcare will tailor diagnosis, treatment, and prognosis with the genome information and environmental interactions for each person so as to optimize quality and length of life. Moreover, the promise is to provide predictions of risk for disease from the earliest time so that the healthcare system can focus on prevention of morbidity and mortality instead of focusing on treatment of illness and disability. The advent of Next Generation Sequencing has the promise to make the situation more definitive, but also has added much complexity to an already complex set of issues [29, 30]. Progress is being made on individual elements of this promised future, but the realization of the dream will take not only the full confluence of multiple disciplines but also new decision support paradigms.

5.2 Challenges

Two excellent reviews outline the frameworks for genomics clinical decision support (22, 31). The infrastructure needed is national, or even international, and therefore is more extensive that traditional decision support systems. Needed are 1) standardized representations of genomic data, 2) standardized messaging frameworks for sending data among systems, 3) computer-processable medical knowledge that is maintained by experts, and 4) standard approaches for applying these knowledge resources against patient data. With recent analyses of Next Generation Sequencing, it is now becoming clear that there is a tremendous need to have a complete, curated catalog of human disease variants since there are 3–4.5 million variants per person per genome [29, 32], and the knowledge of which ones are associated with diseases will take ongoing and collaborative analyses.
5.3 Priorities

This is a scientific and medical challenge that will be ongoing, but there are several examples that indicate a variety of solutions to pieces of the problem. Using HL7 and the clinical genomics format with the sequence ontology and GVF file structure, specific methods are being explored to send structured laboratory results from full sequence laboratory test data [33, 34]. This will help with two problems. First, current methods for transferring genetic test report data often result in lost information [35]. Second, data that is transmitted with genomic test results needs to be stored in a standard, structured format within the EMR so that decision support rules can be used. Additionally, regular laboratory reporting methods could be extended to include clinical decision support for molecular laboratories that would include tools for determining if a new variant would likely be benign or pathogenic [36].

Several simple genome alerts now become possible with a standard method to store and transmit the data to the EMR. Examples include the indication that the test was a repeat test, therefore saving time and money; the CFTR test for pregnant women is a case in point. An alert could indicate that a mutation indicates a pharmacogenetic incompatibility [25]. If the results of gene expression profiles such as Allomap™ were to become available, then an alert could indicate that a cardiac biopsy is not needed since no organ rejection is apparent.

One approach could use an Infobuttons to refer a clinician to a resource that would help to explain genetic test results or a genetic disorder [37]. A genomic information prescription for patients could direct them to trusted, online information resources [38]. Genomic risk profiles similar to those used by direct to consumer genetic test sites could be linked within an EMR or PHR to assist with preventive care.

In conclusion, multiple decision support tools are being actively explored to assist with the structuring, interpretation, and presentation of genomic variants that might be associated with health problems. Easy clinical decision support has started and progress is being made. But this domain is much more complex that many of the tried-and-true clinical decision support domains of the past few decades. Much more work is ahead that will undoubtedly explore new paradigms.

6. The Importance of Terminology

Health care is a domain with an unknown number of terminologies. Each discipline and each group of clinicians uses a terminology that is effective for its purposes. There are two major purposes with decision support systems in health care: best practice to every patient and controlled data to feed other systems. Patient security and data quality are two key words for health care and one of the prerequisites to achieve these is a controlled terminology.

The International Standardisation Organisation offers a number of different definitions in the domain of terminology e.g. terminology is a set of designators belonging to one special language (ISO 22128:2008), a designator is a representation of a concept by a sign which denotes it (ISO 1087-1:2000), and a special language is a language used in a subject field and characterized by the use of specific linguistic means of expressions (ISO 1087-1:2000)[39].

Clinical decisions are based upon information. Decision support is based on knowledge of the subject, the processes and the concepts with their relations. Clinical decision support systems are used locally but both the systems and the outcome data have a national and international interest. Identified challenges from a terminology perspective are:

- Terminology awareness by all interested parties.
- Transparency between the special languages used by involved disciplines and clinicians.
- Concept translation between countries and cultures.
- Communication between systems without losing content and context.

In clinical practice, the designator with which the concept is communicated can be a recommended term. But it can also be one or more synonyms to the recommended term or an abbreviation or an acronym. Many information systems have added so called interface terminology to the other possibilities of expressing a meaning in a special language.

The lack of a controlled terminology has a negative impact on the use of health care information systems on all levels. The users have very different background and the clinicians (e.g. physicians, nurses, physiotherapists) are just one of these groups. Others are teachers, researchers, statisticians, health care leaders and politicians. Other parties involved are system developers and health care economists. Using data from a clinical decision support system assumes understanding of used concepts and its descriptors.

The clinical user of a specific system is a professional, well informed of the used special language. Other users of clinical data must be given the opportunity to control the meaning of the concepts behind the data they are using. The opportunities with a controlled terminology are:

- Data is comparable now and over time.
- Patients can also find the meaning of a used concept.
- The terminology can be re-used with the same content and meaning.
- It is possible to maintain the terminology.

6.1 Lessons Learned in Sweden

The Swedish government decided in 2007 that Snomed CT (Systematized Nomenclature of Medicine-Clinical Terms [40]) should be the terminology standard in health care and social care. The government decided at the same time on development of a national information structure for health care and social care. A number of stakeholders were identified and are still participating in the work on regional, national and international levels. The Snomed CT concepts (280 000) have been translated into Swedish and applicable concepts are together with the national information structure model applied in a number of tests. The major aim is to add to patient security, however also to add data quality to follow up, to research, and to de-
Development of knowledge in both health care and social care. The Swedish government has decided that for statistical purposes the WHO-classifications shall be used in health information systems.

The lessons learned so far are that new knowledge and new supporting techniques are needed in order to reach the goals:
- Snomed CT lacks a number of concepts used in Sweden and medical knowledge represented by the relations in Snomed CT has to be validated by clinicians before being used. Snomed CT also lack a greater part of the concepts used in social care.
- Translation of Snomed CT to and from Swedish will continue to be vital.
- Methods for terminology work must be common knowledge in the organisations of health care and social care. On national level methods and terminology of ISO 704 and ISO 1087 are used for terminology work.
- Local governments who are responsible for health care and social care must be supported in order to start using the national terminology. Universities and other teaching institutions must include the national terminology in there curricula.
- Mapping between concepts in a locally used terminology and Snomed CT is important to make sure that the meaning of a concept is fully understood and that the correspondent term in either source is recognised by the parties.

The information structure model and the terminology model are depending on each other in the information systems and in a number of cases information can be stored according to any of the models. A prerequisite is therefore that it is decided in which model a certain part of the information is described.

The Swedish priorities for the continuing work are:
- Distribution and maintenance of the Swedish version of Snomed CT.
- Development, dissemination and maintenance of teaching material.
- Dissemination and maintenance of methods.
- Providing courses in the use of methods and structure of Snomed CT.
- Identification of and decisions about bindings between the information structure model and the terminology model.
- Fragmentation. Most decision support systems in medicine are fragmented. So, for example, an electronic patient record will display abnormal values in red in the laboratory section; patient allergies in the documentation section and drug-drug interactions in the order entry section. There is no, or rarely, a kind of cockpit that will aggregate all decision support.
- No context. Most systems are not, or little, contextualized. So, for example, the blood creatin will appear as abnormal as it will be elevated, even if the patient is in chronic renal failure and that this is a normal situation.
- Low positive predictive value. The absence of context leads to low specificity, especially for alerts. This is one of the major problems discussed around alerts currently in the literature. Too many alerts kill alerts, how is it possible to keep only pertinent alerts.
- Reserved for selected users. Only some users have decision support. For example, physician do, but nurses don’t. However, nurses do represent high workload in hospitals. Usually, patients do not have any access to decision support.
- Exclusive understanding of decision support. There is a very limited vision of which decision support is for whom. For example, the management will have access to global key performance indicators and white boards about the activity and the business; the prescribers will get support for guidelines and care; the admission about scheduling and capacity.

Overall, decision support in healthcare is in its infancy. Converging needs, understandings, knowledge and semantics is required in order to bring truly pertinent and effective tools to all stakeholders.

7. Confluence of Multiple Disciplines: Decision Support

Decision support in healthcare information technologies is in all mouths, and in all hands. When looking at decision support in general, such as finance, there are some constants supporting decisions: experience, leadership, evidence, cost-benefit, outcomes, etc. The same constants apply in medicine, to all stakeholders facing decisions: care providers, policy makers, public health services, payers or patients to quote some. However, there is one struggling aspect in decision support systems in medicine:

6.2 The Global Terminology Perspective

In Europe are more than forty languages spoken. People travel for many different reasons and both professionals and individuals request transfer of health and social information, without losing of content and context.

The project epSOS – Smart Open Services for European Patients, is the main European electronic health interoperability project. The project is co-funded by the European Commission and the partners representing 27 countries. It focuses on improving medical treatment of citizens while abroad by providing health professionals with the necessary patient data [41]. The terminology work is a vital part of the epSOS project.

It is not enough with national and interdisciplinary terminologies to be able to communicate globally in a secure way. International co-operation bringing stakeholders together are necessary. The international standards organisations: WHO [42], IHTSDO(40) and HL7 [43] must provide a common terminology to be used in health care and social care.
port in the computerized patient record should merge decision support about laboratory, radiology, order entry, but also all type of alerts, for example time to write a progress note, to take care about discharge. The same should apply to all decision takers. The CEO’s should be able to see patient satisfaction, length of stay, overall cost, rate of reimbursement, etc. … in aggregated cockpits.

7.2 Contextualizing Decision Support – Positive Predictive Value

The most evident feature of decision support is also the most difficult to achieve: providing the good decision support, when appropriate. In a recent paper, alerts in some systems tested had a global positive predictive value of 20%. That is, only one alert of five was pertinent to the context. Nobody could imagine that 80% of alerts in a plane cockpit would be false alerts. However, this is frequent in medical environments, including CPOE or monitoring in intensive care departments. Such a low rate of positive predictive value has very negative effects: when in CPOE, this leads to the now very well documented phenomenon of ignoring alerts. In other settings, such as ICU, this leads to considerable cognitive overloads.

7.3 Unequal Access to Decision Support

Decision support tools are unequally distributed in healthcare. In Geneva, during a six month period in the children hospital, using a complete HER, we measured 7,000 encounters, 100,000 order entry by physicians and 3,000,000 nursing care interventions. This kind of figures emphasizes the very high workload on nurses. However, this professional group, while using computers for all their activities, does not have any type of decision support. Looking at workload, it appears however that better management of their autonomous work could lead to substantial improvements in efficiency. The same conclusions can be drawn with numerous other situations.

A new global approach has to be taken for decision support in healthcare. This approach should emphasize a global vision of the decision-taking situation, within a global context and be measured by global effects and impacts, rather than the intrinsic value of the decision support. The better drug-drug interaction system is worth nothing if it does not lead to a significant decrease of this type of incident. In this case, this requires the collaborative work of many different fields, pharmacologists being only one of them. Human-factors, ergonomics, cognitive sciences are essential. Moving to the ideal target of providing a global, aggregated and contextualized vision of the record of a patient with decision-support is even a greater challenge, as it will not be possible without a global approach of all fields together. This understanding should help to stop having each specialty, such as laboratory, pharmacology, radiology, etc. managing their own knowledge and own decision-support systems without taking into account the needs of the final users.

8. Icarus and Phaeton: Myths or Syndromes Afflicting Healthcare Informatics?

Successful clinical informatics (Cl) implementations require multidisciplinary, collaborative efforts that address important clinical problems. Critical CI elements include: psychosocial end-user needs analyses; human factors considerations for interface designs; technical architectures that scale and persist; innovative computer science methods for algorithm development and knowledge representation; ongoing, expert-level clinical knowledge; ability to optimize the processes underlying local healthcare delivery; persistent collection of feedback from end-users with meaningful responses thereto; maintenance processes that address problems identified as well as implementing technical advances; and, periodic systematic evaluations providing additional feedback. In institutions where people commit to ongoing cross-disciplinary collaboration, and where exemplary intellectual, financial, and organizational resources persist, CI systems become tools for end-users at the level of “clinical macro programming languages”. Those CI systems enable practitioners and healthcare managers to change actively how their institutions deliver care. This paper reviews circumstances leading to sub-optimal outcomes in such complex environments.

The myths of Icarus and Phaeton have real-world CI counterparts. In Greek Mythology, Daedalus, a master craftsman, built a maze to contain the Minotaur. Later, he and his son, Icarus, were imprisoned on Crete. Daedalus constructed wax-and-feather wings, enabling them to fly. Daedalus warned Icarus that the sun could melt the wings; nevertheless, Icarus soared too high and subsequently fell into the sea. In another tragic saga, Helios, the sun god, drove through the orb through sky daily on his chariot. At his son Phaeton’s insistence, Helios permitted Phaeton to drive the difficult-to-control vehicle. Phaeton’s erratic course went high and low, scorching the earth and evaporating the sea. Only a fatal lightning bolt from Zeus prevented Phaeton from destroying the earth. Thus, crashing and burning (or burning and crashing) has a fabled, long history.

Academic institutions that pioneer exemplary new CI systems become subject to the Icarus Syndrome. Academia rewards individuals’ creativity and innovation directly through promotion to managerial positions, and indirectly by luring talented faculty to external institutions elsewhere. Through both mechanisms, the “Daedalus” inventors fly away from their former frontline CI roles. Institutional leaders, like Icarus, become overconfident, believing that the original CI systems were fully complete and stable. They replace the originators with less talented, less expensive “maintenance” IT staff, eschewing new faculty innovators. Thereby, the project team loses touch with the intellectual body of reasoning that underpinned the original system. The team does not appreciate the history of institutional social interactions that supported the original system. The Icarus-like administrators fly high but lack insight and understanding. As the original developers depart, the diminished CI team discontinues its previous unbridled innovation. The institutional leadership then replaces...
the original homegrown system with a commercial one – unaware of the institutional costs and consequences of limiting future flexibility. The institution then loses control of its own clinical systems destiny. Thus, Icarus has soared high and fallen into a sea of mediocrity.

The CI Phaeton syndrome afflicts hospitals and clinics lacking the resources to develop CI systems de novo. Inspired by pioneering academic institutions’ examples glowingly described in the literature, such sites naively and imperfectly install commercial versions of major CI systems. The Phaeton syndrome typically occurs when a few high-level administrators or an isolated IT group purchases a large-scale clinical system without requisite institution-wide planning and involvement; lacking collaborative buy-in, the small advocacy group rolls out the system imperiously. Adverse events occur that generate a large hue and cry from irate clinical users. Besieged institutional leadership must then “send a bolt from on high” to turn off or seriously curtail the misguided use of the system. These events engender a great loss of money, personnel, and institutional trust. Pathogenesis of the CI Phaeton syndrome is multifactorial. Whereas pioneering academic CI developmental processes are ongoing and rely on frequent, collegial end-user feedback to drive evolution, commercial vendors purposefully limit the changes possible at each installation site. Vendors’ “one size fits all” approaches depend on regionally or nationally centralized software support teams. This approach discourages significant degrees of local autonomy or customization. The emphasis during vendors’ installation and training is for customers to learn how to use the system “as is” (with minor screen layout or vocabulary customization) rather than to empower users to “flex the system” to meet local needs. Such vendor-dependent CI environments cannot adjust to rapid advances in clinical practice, or respond to significant adverse clinical shortcomings in a timely manner. As local users recognize the cognitive and functional disparities between local practices and system capabilities, they generate “change requests” that are sent to vendors with deaf ears. Vendors have inadequate time or insight to understand and respond to every local need. Over a large nationally installed-base, vendors typically make only several dozen “bug fixes” in each semi-annual system upgrade. This leaves thousands of valid local requests unheeded. End-users become frustrated with lack of responsiveness to local needs. The initial allure of driving the IT chariot results in a scorched end user community that pleads for institutional leaders to alter or turn off the non-responsive system.

To prevent and manage the Icarus Syndrome, administrative leaders must value pioneering CI faculty as strategic resources for their institutions. Adequate funding for expansion of CI faculty units to handle both ongoing maintenance and new inventions must be ongoing. Aggressive replacement of pioneers with equally talented young faculty members must occur. Largely due to the Phaeton syndrome, no single vendor or product now claims a dominant market share of the multi-billion dollar marketplace for CI systems. The first vendor to develop large-scale CI systems that local institutions can flexibly customize autonomously – while still being supported by a competent vendor – will garner the potential to dominate the industry. Correspondingly, vendor support should intensify persist after systems “go-live”, rather than withering away after go-live.

Our field is early in the process of its understanding of how to best design, develop, install, and maintain the complex interdisciplinary systems that comprise clinical informatics solutions. Journals like Methods have helped to catalyze our advances, and will play a critical role in both describing problems and promoting solutions as we work toward a better future.

9. Fifty Years of Progress

Congratulations to Methods for its 50 years of exemplary leadership! The amazing progress in medicine and in medical informatics poses the question, what now is the role of the scientific journal? I suggest that, like the little girl in the childhood poem, “When she was good, she was very, very good, but when she was bad she was horrid”. Generally our great journals in their traditional functions are essential features of scientific progress, whatever blend of print and electronic communication. These include

- Peer review of scientific claims and conclusions before publication
- Publication of counter-claims, questions, additional findings, letters-to-the-editor, reviews and summary papers
- Publication of well-argued commentaries and policy recommendations
- Editor’s work regarding writing, layout, checking references and documentation
- Editorial assessment of truthfulness of the papers
- Retractions and corrections as needed
- Linking of published articles with electronic appendices.

If this is Good, what behavior of a journal is Horrid? The creation and growth of ClinicalTrials.Gov warrants our attention simply because it highlights the bad experiences some great journals (not Methods) have had: namely in inadvertent printing of deliberately misleading or totally false manufacturers claims for clinical trials of drugs. American Congressional legislation prompted NLM to create this registration system and public and free repository of trial results. There are 115,953 trials registered in ClinicalTrials.Gov from all sources. Of these 49,933 are purely U.S. trials. The remainder are from 178 other countries. The legislation’s fundamental purposes are to eliminate secret trials on humans and to eliminate secret results of such trials. The International Committee of Medical Journal Editors also strongly endorsed and enforced the requirements for clinical trials registration and results reporting. Provision is made for authors to report these results in scientific journals of their own choosing. Thus is restored the traditional obligation of the journals to seek the truth in published claims, as well as to provide whatever peer review, discussion, and rejoinder they feel appropriate.

This new circumstance accentuates an ongoing change in scientific communication. Readers who want the whole truth must now bridge the gaps between traditional publications, public data bases like ClinicalTrials.Gov which now contain...
group results otherwise not publicly available, and other more technical scientific database (not detailed here). Taken together should be truth about the efficacy and/or troubles with the specific drugs in question. How well is this system working?

Registry and results entry are going well. Thus there is reasonable compliance with the legal requirements for trials in the US and related venues. We are surprised that subsequent voluntary publication of results in traditional journals is not happening in many cases, for reasons we do not know yet. What about reporting worldwide? The WHO has established a good widely used description of twenty essential record elements for describing clinical trials (though not their results). There has been substantial progress in efforts properly to align and rationalize ClinicalTrials.gov in the US with registrations in the European Medicines Agency. If it is possible to agree on common linguistics, this would solve the data access problems for much of the world. Logically one would hope for an Asian center, as has been the case for human genome sequence results. WHO has unfortunately encouraged exactly the opposite solution: namely, that all its 93 member nations establish their own trials registries. This outcome would certainly complicate quality control and would make recognition of duplicate entries virtually impossible.

The ultimate “smart” search systems that can bridge between journal articles and all the other Knowledge Sources in medicine to find the information we need to know have not yet fully appeared. Two interesting possible candidates are the Semantic Medline development of Fiszman, Kandilfeisch, and colleagues at NLM, and the famous IBM Watson system that recently won the Jeopardy contest against human experts. Semantic Medline is based on the Unified Medical Language System (originally described in Methods years ago) plus excellent computational linguistic research aimed at (eventually) understanding the actual meaning of published articles. The IBM system (described by Ferrucci) is based in massive parallelization of common workplace computers plus linguistic logic not yet fully described.

10. Conclusions

Overall, 50 years of research into methods and systems to aid in human decision making has only scratched the surface of an important cognitive need. As systems become more integrated and ubiquitous, users will demand assistance in making the varied decisions and choices that is part of their work, whether it is in the healthcare domain or other parts of life. The underlying issues of harmonized vocabularies, structured knowledge, contextualizing the system to the user, bridging across diverse systems, and adapting to new situations to give personalized support will surely be seen in many manuscripts published in Methods of Information in Medicine in future.

Thus we are left with new computing methods, new publishing methods, new bio-medical scientific goals, and uncountable opportunities for decision support – and another 50 years till our Centennial publication!

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