Controversies in e-health

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Summary

E-health is a politically charged environment in which strategy, investments and solutions often seem to disappoint. The field is full of tensions in which different stakeholder groups compete to control the priorities and functional characteristics of e-health solutions. This paper explores three key examples that illustrate the controversies in e-health: the development of hospital and GP information systems, the development of health informatics standards, and the priorities of national e-health programmes. In all three cases there is a lack of engagement with the stakeholders who are the principal end users of the systems, and with the stakeholders who are most expected to benefit (i.e. clinicians and patients). There is a need for e-health investments to be better directed by evidence, more clearly and transparently targeted at specified benefits, and more formally evaluated. The discipline of health informatics itself needs to be guided towards prioritising innovations that can be translated into scalable solutions.

Introduction

Controversies exist in every aspect of life: health informatics and health IT are no exceptions. Controversies, and sometimes conflicts, might arise from sound differences of intellectual opinion – alternative approaches to solving a problem each of which has some qualities and some limitations – or might come from conflicting priorities and needs for which, ideally, different solutions are needed but where reality can permit – or afford – only one. Others arise from conflicts of power and control, and the desire for persons or organisations to dominate a strategic area whether they have the best solutions or not. Controversies and conflicts are quite different from competition, in which a free market can choose between multiple products or approaches which meet similar needs and which compete on the basis of unique merits including (but not only) price.

The author has observed these tensions within the discipline of health informatics and in e-health projects and programmes over the past twenty years. This paper, perhaps more accurately an essay, presents a few examples of such controversies, discusses why these issues might arise, and suggests some basic principles that might be adopted in the future to guide e-health programmes.

Hospital and GP information systems

Health IT has been likened to a cottage industry, with many many vendors making very specific systems for niche purposes, which might vary from hospital resource and billing to cancer chemotherapy administration, sophisticated radiology information systems, cardic investigations, simple chronic disease monitoring applications running on mobile devices, new generation genetic analyses, advanced 3D modelling tools, and many more. An average hospital can have 40–60 such systems, few of which are connected to the main hospital management information system (or to each other) and so result in much fragmentation of what is known about each patient and also about the care activities undertaken at the hospital. Equally surprising is the inability of most hospitals to share electronic health information with each other. Consequently institutional paper medical records remain the primary source of patient information in hospitals across the globe, and paper letters and reports (and occasionally e-mail) are the principal basis for shared care between clinical teams.

General practice in many countries has fared better, with the growth of systems over the past thirty years that capture, store and analyse electronic clinical information to support chronic disease management, safe prescribing backed by alerting systems, screening programmes, billing, clinical audit etc. General practices are progressively becoming paperless. However, despite their sophistication GP systems can also rarely communicate with each other. The ability to send basic clinical letters and test results between hospitals and the local GPs is relatively new in most countries, and patchy. If a patient moves address and changes GP, a computer dump on paper is usually the best we can offer the new GP to support continuity of care.

So, why are hospital clinicians so much worse off than their GP colleagues when it comes to the electronic health record, and why is communication between systems so poor? Although the answer to these questions is often presented as a technology issue, or the lack of standards, the
real answer is the priority of investments: i.e., we have poor quality EHRs and poorly inter-operating systems because we have not chosen to put our money into those features of the systems we procure. I was first asked publicly in 1992 why GP systems could not communicate patient data - even between two installations of the same vendor's product. My answer, then, regrettably still true, is: "Because you have not prioritised this requirement." GPs have been in the fortunate position, usually being direct purchasers of their systems, of being able to drive the functional characteristics of their systems in a market oriented way. Many features and functions that support the efficient management of the practice, individual patients, populations of patients and quality improvement have progressively been incorporated by vendors at the direction of their user groups and GP professional bodies. GPs do not have a strong business driver to enable practice-to-practice communications, and have never prioritised this requirement - so vendors have had no strong driver to build in this capability. Even without international standards, exporting and importing a patient record between each vendor's own product could easily have been implemented - twenty years ago - if it had been asked and paid for.

The situation in hospitals is more complex, because the functional capability of hospital systems has usually been driven by the organisation's business needs - efficiency of care, resource management and robust billing - and regrettably not quality of patient care [1]. Migrating clinical information from paper to electronic systems has not until recently had a financial business case, and even now only in a few countries such as the US [2]. Core hospital IT therefore serves managers more than clinicians, and money more than health. Those pockets of a hospital that do often have good IT, such as laboratories and radiology, have done so primarily because of the efficiency savings these provide. There are isolated examples of hospital systems that do deliver significant clinical value, such as the University Hospital of Geneva (Switzerland) and the Royal Marsden Hospital (UK). These systems have been developed in-house, have engaged multiple stakeholders in gathering and meeting their requirements, and have been successfully used by all staff. In-house developments are no longer fashionable, as their maintenance and evolution is considered to be too high risk by the present generation of senior managers and health policy advisers. Certainly buying an off-the-shelf product from a large vendor might seem to be a more reliable way of sourcing and supporting a mainstream IT product, but what good is that if it fails to meet user needs?

Many countries are now recognising the importance of, and gains to be made from, electronic health records that can integrate access across care organisations. But with procurement specifications still being directed by those far from the clinical coalface, what hope do we have that the right requirements will be recognised and met? Individual clinical teams are too small and not vocal enough to influence such procurements. There is now an urgent need for national clinical professional bodies to come together and drive the requirements, priorities and acceptance of hospital and GP systems, and for them to include the communication of patient records between care teams and systems as a top priority.

In parallel, research organisations and public bodies should invest in better evaluations of well-adopted in-house hospital IT systems and small vendor products, to understand their success factors and returns on investment. Otherwise we risk propagating the myth of the robustness of large scale public procurements of monolithic systems from monolithic providers, which might only assure us of mediocre systems that are clinically limited, whilst dampening innovation and competitiveness in evolving the best of breed in clinical systems.

The development of health informatics standards

Health informatics standards are not only vital for the interoperability between health IT systems, but often influence their internal information and knowledge representations, structure and functions. Good standards can therefore have an important impact on the e-health landscape. However, standards development organisations (SDOs) do not necessarily have sound mechanisms in place to ensure that the standards they develop and eventually publish are well suited to user and market needs, tackle the right problems at the right level of detail, and are of good quality. This is because of some fundamental flaws in the standards development organisations and their processes. A further complication is that the bodies themselves are each reputation-hungry, and in many cases that reputation maps to business success, and so potentially drives a competitive model rather than a collaborative one between SDOs.

To start with, though, we should recognise that health informatics standardisation, especially encouraging adoption, is a tough challenge. As indicated earlier, health care is a low-budget and fragmented market, in which some vendors rely to some extent on "lock-in" to retain their customer base. Sharing information, e.g. at a regional or national level, benefits patients, but not the internal budget of any one health care enterprise, and most users and purchasers care more about functions, screens and report generation than interoperability. It is little wonder that few market developers exist to persuade industry to adopt health informatics standards, and a tough non-receptive marketplace risks unhealthy and antagonistic standards!

The initiative to develop a new standard is often triggered by an enthusiastic individual or a single public body that believes the standard will be useful to it and proposes a roadmap for its development. A national specification is sometimes offered as a valid starting point, with the hope from that country that their way to tackling a problem can readily be accepted as the international standard. The choice of which SDO should develop a standard is entirely based on which SDO that proposing individual or body knows about rather than the one with related prior standards or relevant expertise. In over a decade of (multiple) SDO participation I have never come across a situation in which one SDO refers a new proposal to another SDO.
Very few proposals are turned down: since development is a volunteer activity an SDO can run with any proposal and allow it to sink or swim downstream to no disadvantage: there is no need to be selective or diligent at the start. The multi-national ballot process often seems impressive to outsiders, but in practice the specialist expertise required to appraise a proposal for a new standard, or to review and comment on a draft standard, is so narrow that within the small pool of each national standards body only a couple of people can usually provide a response. There is no obligation for the proposer or indeed a subsequent development team to review the research or standards landscape to identify similar or overlapping work on which this standard should draw or with which it should interface. No student would be permitted to undertake research without first reviewing the literature! None of the SDOs require a market assessment or gap analysis to demonstrate that the need really exists for a new standard. Only recently have several SDOs joined together to align their ballot processes and to share knowledge of active standards developments in order to avoid obvious clashes, but in rather an ad hoc way.

Many standards become the cherished work of one individual or team, and at times standardisation seems to be regarded as a way to enshrine such work rather than a well chosen route to effecting a vitally needed consistency of information systems behaviour. Tensions can easily mount if more than one expert or country has prior work or an approach they want to become incorporated. Since so few people, even globally, will understand the subtle differences between two choices in fine detail, the discussions and ballots regarding the specifications risk being left to only a small number of persons, or risk that others with influence but not insight side-track a standard into unwise design compromises that mask the issues and will cause adoption problems later.

A good critique of a draft standard ought to come from industry; those responsible for implementing it should be able to tell if it is complete and unambiguous enough to be correctly adopted, and those involved in buying and selling the systems should be able to confirm if the standard is affordable to put into products, and is prescriptive enough to bring consistency where it is needed and yet permissive enough to cater for diverse use cases. However, industry participation in standard development is weak. Small and medium size companies often have a lot to gain, as interoperability often adds to their credibility (since they often make only parts of an enterprise-wide solution). They therefore need a “good standard” but one which is not too expensive to implement or interface with. Small companies often have a good understanding of user requirements and of usage challenges. But their participation is at a high cost: the time invested is coming out of a small budget. Re-engineering to conform to new standards may be a significant proportion of the total development budget of a small company. Large companies have a lot at stake: their market success might rely on interoperability within their product set, not on inter-vendor interoperability. They sometimes expect a unique position of influence on a standard, based on an existing product. However, large companies have a lot to offer standards developments: they can bring valuable multi-national market experience, and often have access to wide and rich expertise. They have tremendous potential to help endorse and to validate a good candidate standard. All sizes of industry are underrepresented within standards development teams, and as a consequence many of our standards are too theoretically sound, but impractical.

SDOs have too few processes in place to prevent standards from being poorly attuned to user and market priorities, from being driven by a few enthusiasts, or from being published and then largely ignored. New standards proposers should be required to review the standards and research landscape as a preliminary step, and to produce a clear business case for the eventual standard. Development teams should be required to be multi-stakeholder, at minimum including users (standards implementers and end users of those products), industry and academia, rather than determined purely by size and country spread as at present. First generation outputs should only be published as specifications, not full standards, until validated in real products and used. SDOs must not be permitted to publish and forget, but need a means of retaining links with adopting communities, mechanisms to support that adoption and any issues that arise, collecting feedback and using this to inform a future definitive standard. A roadmap for the future of European health informatics standardisation has recently been published by the Calliope project [3]. All of this has funding implications, which it is easy to make into a reason for not doing these things, but at present we are wasting much more money on poor quality standards and products that as a consequence fail to meet user expectations. We also need to radically rethink whether SDO competition and battles for supremacy can somehow be overcome.

National e-health programmes

At the time of writing this article several national programmes are in reversal: grand plans have now been recognised to be under-performing and over-budget, for example [4]. Most will be trimmed back rather than stopped, and most will have made some useful contributions to the e-health infrastructure and provided some new or improved services. However, the overstated ambition and assurances of these programmes have done more harm than just consume excess national budget. They have made promises that have stalled local initiatives that might otherwise have made good progress over recent years, and some small software companies have lost business or gone under because purchasers (e.g. hospitals) have put off small scale purchases to await the national grand solution. But why have so many countries over-pitched their programmes? Health services across the world are political footballs. Demand exceeds affordable supply everywhere, and the complexity of health care makes it difficult to introduce changes that truly improve cost effectiveness and efficiency. Yet every new government and health ministry feels pressurised to make changes, usually to meet “brave” electoral prom-
is. As a consequence changes in the way health services are organised, internally funded and reimbursed, services and patient groups prioritised or de-prioritised, are made regularly with limited real conviction amongst grass-roots stakeholders that the fundamental demand-supply gap will be closed. Each wave of change is therefore largely based on ideology or is novel-looking simply to appear innovative and with the potential to make improvement.

E-health services, electronic systems for managing data, information, knowledge and workflows in health care, are innovations that have the capacity to change how clinicians, patients and managers interact and therefore to initiate or to support health service change. E-health is therefore at times used as the change agent of health service reform, which makes it vulnerable to being used politically. Of course some health service changes are driven by a genuine desire for service improvement (quality improvement, better safety, or better optimised resource utilisation), and many e-health innovations are success stories. However, because e-health services are often developed and introduced as innovations, even experiments, they sometimes lack a clear health care objective at the outset. This risks making them solution-driven rather than problem-driven, such as the desire to introduce online outpatient appointment booking in the NHS in England, which seems to have been driven by a desire to modernise the health service to resemble an airline rather than an evidence-based response to problems with the previous booking systems.

It is essential that e-health projects begin with a clear definition of the problem they wish to tackle, what aspects of current health care practice are sub-optimal and what success criteria are aimed for. Projects should be evidence-based: it should be clear that experience from previous work has been taken into account, wheels are not being reinvented. From recent experience of national programmes it should also be clear what dependencies exist on novel solutions, and how the project will be risk-managed from a human factors point of view as well as a technical development point of view. A statement of requirements for the solution should be developed and available for review at an early stage: adequate protected time is required for small scale piloting and testing, lessons to be learned and incorporated as changes before a wider rollout is undertaken. Standards development organisations need to be fed by identified needs, and challenged to be strategic and responsive to bottom up issues rather than being enthusiast led. Procurement processes need to be transparent about the stakeholders who will benefit from the project or system, and include them at an early date – not a token one or two but through a more open consultative process.

**Conclusion**

The often experimental and often political nature of e-health projects has an impact on health informatics as a research discipline. Every good discipline embraces multi-ple approaches to tackle every problem encountered: each approach is adapted and improved, and eventually one approach becomes the one widely adopted. In many sectors the market eventually determines success; what solution is good enough at an affordable enough price, and can easily be integrated into co-existing products and services and user behaviour? For e-health these market forces are not natural but contrived, partly because health systems are usually an odd historic mixture of privately funded and publicly funded components, and partly because of political drivers mentioned earlier. This means that the academic discipline of health informatics itself at times lacks a clear business-like objective to its outputs, so that research threads can wander in scope and complexity without any clear roadmap for translation into widescale use. There has been significant investment in e-health systems, at local levels by hospitals and GPs and regional health authorities, and in recent years nationally by large scale programmes across the globe. Looking back, hospital information systems have been in existence since the early 1970s, GP systems from the late 1970s. Yet the maturity of these to support clinical record keeping and the useful exploitation of longitudinal EHRs to support better quality of care is very disappointing. We seem to launch new e-health projects that repeat mistakes that have been learned long ago, and already repeated countless times. It is now urgent that we change this behaviour before the whole of health informatics and health IT becomes discredited. Small scale academic research projects and pilots are a vital seed for discovery and innovation. They must not be confused with scalable solutions. Scaling up of things that work in a single pilot need their own roadmap including evaluation.

All of this might seem time consuming and expensive – but could it have been more expensive than the waste of public money seen in recent years on large scale public health IT projects? Value for money does not mean spending nearly nothing, it means spending wisely. It is time for evidence-based e-health!

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**References**