Optimising Health Informatics Outcomes – Getting Good Evidence to Where it Matters

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Summary
This editorial is part of a For-Discussion-Section of Methods of Information in Medicine about the paper “Evidence-based Health Informatics: How do we know what we know?”, written by Elske Ammenwerth [1]. Health informatics uses and applications have crept up on health systems over half a century, starting as simple automation of large-scale calculations, but now manifesting in many cases as rule- and algorithm-based creation of composite clinical analyses and ‘black box’ computation of clinical aspects, as well as enablement of increasingly complex care delivery modes and consumer health access. In this process health informatics has very largely bypassed the rules of precaution, proof of effectiveness, and assessment of safety applicable to all other health sciences and clinical support systems. Evaluation of informatics applications, compilation and recognition of the importance of evidence, and normalisation of Evidence Based Health Informatics, are now long overdue on grounds of efficiency and safety. Ammenwerth has now produced a rigorous analysis of the current position on evidence, and evaluation as its lifeblood, which demands careful study then active promulgation. Decisions based on political aspirations, ‘modernisation’ hopes, and unsupported commercial claims must cease – poor decisions are wasteful and bad systems can kill. Evidence Based Health Informatics should be promoted, and expected by users, as rigorously as Cochrane promoted Effectiveness and Efficiency, and Sackett promoted Evidence Based Medicine – both of which also were introduced retrospectively to challenge the less robust and partially unsafe traditional ‘wisdom’ in vogue. Ammenwerth’s analysis gives the necessary material to promote that mission.

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Health Informatics and Health Information Technologies (HIT) are enigmatic subjects. Rather like the smile of Lewis Carroll’s Cheshire Cat [2] they are now everywhere within healthcare and consumer health, yet difficult to define or capture. But it was not always thus. Computer applications, expanding into the many forms of health informatics and e-health, have crept up on the health sector surreptitiously, and in response to enthusiastic encouragement they have continued to expand. But in the process the new industry and the new scientific domain of health informatics have evaded the normal controls of the need for proof of effectiveness and safety, and this enthusiasm has often been driven by policy makers or those eager for ‘modernisation.’ Now that integrated informatics systems are becoming the norm, understandably they are often seen as disruptive technologies, and ones which take over aspects of information retrieval and of decision-making from health professionals, yet they are still normally outside the requirement for the scientific validation expected of any other health science or innovation. And by virtue of the fact that informatics systems aim to improve care effectiveness and safety, by definition if they fail to achieve this objective then patient care is compromised.

How has this avoidance of the need for proof happened? In the 1960s computers became affordable enough for widespread commercial use, for undertaking simple processes on a very large scale more efficiently than human driven paper-based processes. In health care the first uses were administrative, such as for billing, then this progressed to keeping track of hospital patients to be billed, and thus patient administration systems (PAS) were born. The same process occurred in primary care, while in community services child registers of new births could be computerised to ensure that all children received immunisation appointments.

It was only natural for functions to extend to other areas of high volumes of simple datasets as capacity and expertise developed, hence computerisation of pathology results, and early messaging systems. Digitisation of X-rays produced radical change in that diagnostic field. Simple telemedicine started as far back as 1967. Each application was simple, transparent, and the benefits or adverse aspects could easily be identified, and indeed often were assessed so as to justify the innovation.

Two trends then happened – computers became more powerful, and could be pro-
grammed to compute clinical data faster and (if programmed appropriately) more effectively than a busy clinician; and applications could be interlinked to transfer data to produce a 'bigger picture' either in richness of content or in geographical reach for source data. This was the crossing of a line – the computer was no longer an automated calculator or file retriever, it was now something more complex, whose workings could not be checked in the daily workplace, and which the user (and thereby the patient) had to trust, as its processes were invisible. The computer as a 'black box' had been born, but the alarm was not raised that this was now a risk technology needing formal testing and evaluation. The transformation for clinicians' daily practice was also under-appreciated, in that recording data electronically in a very structured form is very different from jotting notes on paper, while searching the content of computer files is significantly different from sifting paper charts, yet if something is mis-recorded, mis-calculated, or mis-retrieved it is the patient's health and the clinician's livelihood which are at stake. Grémy (in 1995) was one of the first to argue the need for evaluation of this new construct of informatics applications, and for this to be by class of complexity of application which would require not just health technology assessment skills but also human and psychological sciences, and social science [3]. However, take-up to this call was limited as it diverted effort and development money away from new applications, and hesitancy and doubt were to be avoided.

By this time computerisation in health care was seen as a desirable logical development, led by computer research, by some clinical innovators, and by promotion of commercial systems. The lay person expects health systems to use more modern technologies, and politicians are keen to promote 'modernisation'. As a result of this evolution, and the apparent simplicity of what are in fact practice-changing systems, health informatics and their technological applications have become able to assume a claim to special treatment, with departure from the Precautionary Principle [4, 5] and deployment only after proof of benefit and safety.

At organisation level implementations are too often based on market forces and vendor promises, not all of which may be achieved in practice, while at policy level the risks and the ignorance are even greater. One of the most obvious cases is the intended creation of a universal electronic health record system for the NHS in England, enthusiastically espoused and promoted by then Prime Minister Tony Blair (who himself ironically never used a computer), a programme now well known for not accomplishing its aspirations. Subsequently released papers show that the decision was taken in a meeting lasting under 2 hours, evidence from health care informatics does not feature in the discussion, and there were no expert health informaticians present other than industry representatives [6]. The literature on the outcome of that policy, and its radical revision, is well known, including recently the proof of patient harm [7]. No other proposed change of health care clinical support processes would be discussed and decided in this type of evidence-free environment.

Sadly, this optimistic (and arguably irresponsible) attitude that informatics implementations can only be good is doing a disservice to the science and industry of informatics, and more importantly to patients and health professionals dependent on effective systems. It facilitates bad decisions leading to waste or even system failure, and it is known to cause patient harm and even death [8]. This situation needs to change, to fit it in with the otherwise universal espousal of evidence-based approaches, in the same way that Archie Cochrane initiated the drive for Efficiency and Effectiveness in Healthcare [9], and David Sackett formulated Evidence Based Medicine [10], both of which should have been 'no brainers' in modern parlance but which in fact themselves each required a major and continuing challenge to question and change established traditional policy and practice.

Pioneer in recent times in the equivalent retrospective promotion of Evidence Based Health Informatics has been Professor Elske Ammenwerth, who has initiated real action in developing methods and practical approaches. This started with the creation of an expert European workshop in Innsbruck in 2004 [11], and has seen a decade of accomplishments against the agenda set there [12], much of it through the EFMI Evaluation Working Group and the IMIA Working Group on Technology Assessment & Quality Development. Not least along the way has been the creation of a database of completed evaluation studies, currently containing 1800 reports [13].

Ammenwerth now presents to us a commanding analysis of the importance, issues and challenges of promoting evidence-based health informatics, and how the methodologies and the subsequent evaluations should be developed [1]. This is a message which needs to be spread widely, not least amongst policy makers and political decision-makers.

Currently we look forward to a paradox – health informatics is increasingly complex and interlinked, with wide inter-operability, yet the basis of decisions is evidence-light when all other sectors of health are bound by evidence. Meanwhile the game has changed – simple system evaluations are less and less the need, and instead components of complex systems need to be studied. As Gordon Lightfoot wrote and sang in 1964, and many others including Bob Dylan and Elvis Presley repeated, You can’t jump a jet plane Like you can a freight train [14]. Health informatics systems are now big, and more like a jet plane with many inter-dependent features rather than a simple rail car, and evaluation, evidence, and decision-making must respond. The analysis and reflections Ammenwerth shares with us are relevant, timely and important. The eight methodological challenges she puts forward are powerful and pertinent. But apart from knowing "What we need to Know" as per her title; using scientific reporting standards as resulted from her Innsbruck workshop in the form of the EQUATOR-endorsed Statement on Reporting of Evaluation Studies in Health Informatics (STARE-HI) [15, 16]; and being aware of evidence sources such as [13], what is imperative is to promulgate the concept and importance of evidence-based decision-making regarding informatics developments and applications in the health sector, and in its related sectors in the context of integrated care.
So we also need to “Know who Needs to Know it”, and to go on to make sure that they are fully informed. The days when policy makers can say ‘evaluation is just a means of keeping academics employed – we know the system works’, as was said to this writer some years ago by a national lead officer for health informatics, must now be banished to history, as must secret political decisions. Evidence Based Policy, and evidence based decision making, should be the norm [17, 18]. Informaticians and their professional bodies, academics, and HIT system users must create awareness and insist on this, for the sake of efficiency and safety. It is up to these groups to study Ammenwerth’s rigorous and clear analysis, from this to adopt the zeal equivalent to that initiated earlier by Cochrane and Sackett, and make sure that those who need to act do act, and those who need to know do know.

References
2. Carroll L. Alice in Wonderland, first published London, 1865