

Research needs and priorities in Health Informatics – early results of a Delphi Study

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Abstract. A four-phased Delphi study has been performed on the topic of “research needs and priorities to implement the Information Society within Healthcare”. This contribution presents the outcome of the first three phases. The biggest surprises are that ‘Telemedicine’ is relatively lower ranked than expected, and that ‘Business Process Re-engineering’ is the highest ranking topic, as judged from the number of issues and barriers raised by the expert panel.

1. Introduction

Ever increasing options for diagnosis and treatment are available. One can get spare parts for replacement of even unthinkable body parts. The option for personal insight into one’s physical body and its prognosis goes almost infinite with the gene-technology and genomics. The information technology can send a man to the moon and can nurse a nuclear power plant, etc. The Information Society is here and glues it all together for the individual client and/or server (respectively the patient in spe and the health care staff). The political demand for effectiveness and efficiency is increasing, as is the population’s demand for insight, service and influence on one’s own situation. However, as compared with other domains healthcare has not yet exploited the advances of Information Technology and Telecommunication. In view of the revolutionary effect of the photocopying machine from invented to handle a simple duplication task till today’s revolution of administration and case management, the Information Technology may also imply a completely new world, the Information Society.

The Health Informatics¹ literature includes a number of recent contributions by highly esteemed researchers on future research needs and priorities, both for the domain as a whole and for individual sub-domains, see e.g. [1-13]² - just to mention some highlights. The huge technological potential and the fast evolution means that we can not afford (economically, organisationally, ethical) investment failures. So, to support prioritisation of research initiatives one needs to balance individual perspectives on the subject against each other, rather than adopting the (subjective) viewpoints within the literature. Thus, the scope of the present investigation was defined as “the aim is to achieve a ‘kind of’ map (a rich picture) of the needs and priorities within Health Informatics research for the next decade”.

A Delphi approach was selected. Delphi is a consensus method [14-16], at which a central team interrogates with a panel of experts on a predefined topic, and at which the experts

¹⁾ We let this term be synonymous with Health / Medical Informatics & Telecommunication in a broad sense.

²⁾ ... plus all the commentaries on [5].

comment on each other's contributions and/or adjust their own contribution in an iterative process controlled by the core team. The Delphi approach has proven to be effective in exploring future trends and forming a basis for strategic planning. The participants are all experts in a domain and have the ability to extrapolate trends and events within their domain. Brought together in the Delphi phases they adjust and inspire each other.

2. Method

The methodological aspects, options, perils and pitfalls within a Delphi investigation are excellently described in [14-18]. A Delphi investigation is normally starting with an open question, which at some point in the process is converted into a questionnaire to achieve (semi-)quantitative answers on the original qualitative statements. We chose a four-phased approach, as outlined in Table I. When writing this, the study is in the middle of its fourth phase: the questionnaire developed has been distributed to the panel.

Table I: The contents of the selected four phases.

Phase	Phase contents
1	Brainstorming phase: Elicitation of research items from the expert panel on the basis of the open question <i>"What research questions would you intuitively point at as the ones which should be emphasised within the next 5-10 years as the most important in addressing the Information Society in health care?"</i> A small scenario related with the Information Society was used to focus the mind-set of the respondents, but to avoid a bias no example was given.
2	Evaluation phase: Mutual commenting is applied to get constructive and critical feedback, thereby extending the original views and facilitating revision. As our information need is of a qualitative nature there is no need to have everyone comment every other expert's contribution. So, to minimise the burden on the panel and to avoid the effect of duplicates, the contributions were grouped. The grouped material was personalised for each member in a way that he/she received the contributions from Phase 1 only of his/her fellow group members. The material was made anonymous by coding and removal of potential identifiable information, and subsequently harmonised with respect to layout. For each research issue a pre-cooked list of questions (with options for free text commenting) were inserted, related to the respondent's expertise on the specific topic, the relevance/usefulness of the topic, specific constraints and aspects of feasibility of the topic.
3	Feedback phase: Submission of comments received within the second phase to the individual contributors with insertion of all feedback, including insertions into the original text. The main purpose of this phase was to allow for clarification or extension of the original contributions.
4	Questionnaire phase: Submission of a questionnaire prepared on the basis of the original contributions and all the comments. As we are looking for a rich picture of the future rather than a quantitative statement on priorities, it will suffice with one interrogation on the questionnaire.

The entire communication with the experts was performed through e-mail as recommended by [18]. It was accomplished in a bilateral fashion to maintain anonymity within the panel of experts. There has been no explicit deadline, but the response was pushed implicitly through the accompanying letter and reminders. The philosophy was that for busy people it is in general not a matter of 'deadlines', but of priority.

To get a broad representation, we defined the following characteristics of the candidates:

- the experts' should possess a visionary capability and insight into the Health Informatics domain as a whole, as well as a broad research-profile,
- the panel as a whole should cover the main elements within a model of factors that forms or influences the future research (market forces, the political arena, application research, basic research and meta-assessments),

- the panel of experts should cover a broad range of sub-domains within Health Informatics³,

Candidate panel experts were identified on the basis of literature reviews on the topic or on our personal knowledge. The list was supplemented with experts from domains outside our personal area of expertise by recommendation according to the same criteria. Fulfilment of all combinations within the above list of criteria would require a huge expert panel. We therefore made the best compromise realistic to accomplish the study scope. The handicap with these criteria is that only V.I.P.s are candidate members of the panel, which may make it difficult to get fast and efficient feedback, or even to get feedback.

The leading principle for grouping of experts within Phase 2 was (1) to separate 'similars' (e.g. 2 experts contributing with the issue 'telemedicine') to minimise a bias in the prioritisation and commenting, (2) to keep all contributions of a given expert in one group to ease the processing, and (3) to make the groups as homogeneous (parallel in contents) as possible.

3. Results

Out of 55 calls for participation, 25 submitted contributions. These experts represent Australia (1), Brazil (1), Canada (1), Europe (Scandinavia 3, Anglo-Saxon/Celtic countries 5, Central-Europe 6, Southern Europe 2), South Africa (1) and USA (5).

The experts were grouped during Phase 2 into 5 groups according to the above mentioned principles. Eighteen responded on the call for comments. This input was fed back individually to the contributor with an option to make corrections accordingly. Three contributors were explicitly addressed with specific questions for clarification, like non-common abbreviations or concepts.

On the basis of the original contributions and all comments, a list of research needs was prepared by cumulating the individual contributions, sorting into main topics and then by cutting and pasting the original texts, followed by a merge of duplicates or almost duplicates. Compound contributions were separated into singular issues and integrated. Depending on the nature of the individual comments from Phase 2, these were incorporated either as new independent research issues or integrated within or extending the existing issues. Subsequently, the entire material was edited and harmonised with respect to appearance and language, but not the semantics. Finally, the text was structured into the following parts for each main topic: a) a short description of a scenario or vision of what might come, based on contributions of a more argumenting or descriptive type of the issues and questions raised, b) a list of research items, and c) a list of potential barriers.

The outcome was a total of 110 research items and 58 supplementary barriers divided on 14 topics, see Table II, of which one is concerned only with the nature of Health Informatics. None of the contributions received a unanimous opinion of "already existing/has been solved" or "not particularly relevant or useful" by the group members, and hence, none of the contributions was cut. Some of the comments received within the second phase also addressed the issue of whether this or that belongs to the core of Health Informatics; however, no contribution was deleted for that reason - again because of lack of unanimity.

The mere distribution on these main topics constitutes a simple measure of priorities, as it reflects the main concerns present in the expert panel.

³) The nursing (informatics) area is rather extensively dealt with within the literature of Delphi investigations on priorities and needs, and hence this area is downsized as an explicit target within the present study.

Table II: The distribution of research issues and potential barriers on the identified main topics.

Main Topic	Research issues identified		Potential barriers suggested	
	No.	Example	No.	Example
Business Process Re-engineering ⁴	17	Research on the extent to which injection of Information Technology into the environment actually changes the way that health care is delivered (and not just automate what is currently being done).	13	... or are the health professionals motivated to become part of such a change?
Electronic Patient Record and connected inter-operating systems	15	Research on the infrastructural support to share the contexts of the care episodes among clinicians.	5	... or are the 'people issues' (like motivation and compliance with common definitions, etc.) vital to the success of such an electronic patient record project, and does the success have little to do with the technical implementation?
Management, policy and financial aspects	7	Development of methods and tools of information processing for up-to-date and comprehensive reporting on public health aspects.	9	... or is it a question of pragmatic decisions rather than a core Health Informatics research area?
Quality of life & compensating physical handicaps & bioengineering	11	Research on measures of well being.	3	... or is the economics of compensation of physical handicaps by informatics and bio-engineering completely out of range?
Evidence-based Medicine & Clinical Guidelines	9	Research on medical decision-making and representation of medical treatment plans	4	... or is it a matter of seeking ISO certification or accreditation, and to take this from the macro level to the micro level of care given to individual patients?
Utility of Decision Support / Knowledge-based Systems	10	Research on the context for application of decision-support systems, i.e. how to integrate knowledge-based decision support into the clinical process, so that it turns into clinically useful and operational systems, - i.e. the whole field of <u>decision support</u> .	2	... or are knowledge-based systems mainly relevant for continuous education rather than as clinical (etc.) decision support?
Knowledge extraction from clinical data and free text	7	Development of system wide intelligent systems that are self learning, i.e. research regarding data warehousing and data mining (machine learning from clinical data and information).	4	... or is data dredging as a "re-search" method a basic fallacy, because of the quality of data in Electronic Patient Record Systems?
Education	7	Research on how to obtain a virtual world for consultancy at diagnosis and treatment in general. We can not all be super-experts and as the volume of knowledge and technological options for diagnosis and treatment increase ongoing we need ongoing support.	4	... or is the distance learning simply a matter of using the web technology as it is now?
Telemedicine	5	Research on operational costs	5	... or is it a matter of the remuneration issues?
The Informed Patient	7	Research on issues within patients' access to their own patient record in particular and to medical knowledge in general, such as how to overcome the many legal, cultural, linguistic and ethical challenges?	1	... or is this perspective simply economically unreachable?

⁴) This concept is used here (and below) in its broadest sense as covering all types of approaches and methods for managing organisational change.

Legal, ethical and security issues	4	Research on the trade-off between the harms of security breaches vs. harms of security measures, ... among others also balanced against the need to obtain timely access to data for treatment purposes and to do research on patient outcomes and epidemiology	3	... or are the mentioned legal / ethical issues of a size that will hamper exploitation of the involved technological options?
Information and cognition	6	Research on how alternative formats for clinical information (text, structured text, tables, graphs, time lines, pictograms...) on paper or computer screen influence the ease with which clinicians find and interpret it.	1	... or can image analysis improve clinical decisions or are images just pretty pictures for software demos/journal articles?
Point-of-Care technology	5	Research on a standard for informatics around POC ('Point Of Care') analysers.	1	... or is this something we can expect solved by the suppliers of laboratory equipment?
Nature of Medical/Health Informatics	0	(none)	3	... or will people originating from the 'computing' and the 'healthcare' sides develop the same skills and knowledge after a while?

4. Discussion

The sorting of research issues into main topics and the 'how and what to merge' are based on a judgement of contents and relations, which inevitably are subjective by nature. Nevertheless, the contrast on number of issues raised for the different main topics is marked. Let's point out a couple of interesting aspects.

The biggest surprise was the relatively low ranking of 'Telemedicine' as compared to the explosion of activities in this field (see [12,13]) and a political interest on the subject as e.g. emphasised within the past EU 4th Framework Programme for R&D in Europe.

Another big surprise was the top ranking of 'Business Process Re-engineering' issues (BPR). Except from [2,6] and partly [9,11] - the papers cited in the Introduction ([1-13]) only emphasise this topic marginally, and many of them don't even mention the need for basic organisational change to accompany the application of IT-systems within healthcare. To some extent, this may be explained by differences in the perception of what Health Informatics is, as also reflected in the discussions by e.g. [3-5,9]. We agree with [3] and numerous others that Health Informatics is a multidisciplinary domain, and it must be self-contained in the sense that skills needed to accomplish the process of IT development/application has to be an integrated part of the Health Informatics domain. Insertion of any new technology into an organisation imposes significant changes into its structure or work processes (or other aspects) [19], so the active management of change has to be on the list of issues within Health Informatics.

It was no surprise when counting conference headings during the last couple of years that Electronic Patient Records (or similar advanced connected inter-operating systems) would be high ranked.

Moreover, Evidence-based Medicine (and clinical protocols) is on the same level as the issue of decision-support systems & knowledge-based systems in ranking (when knowledge elicitation is kept separate), in agreement with the main line within the literature cited above. The lack of success of decision support was reflected within the needs raised, as the development of such systems was not raised, whereas the integration of decision support within the clinical processes was, i.e. a BPR issue.

We would say - as [2,6] - that the organisational (and hence Business-Process Re-engineering) aspects are the most important new aspects on the agenda of tomorrow, and

recognised as such by interpretation of the early Delphi study results. This conclusion is in contrast to the conclusion of [1] that the challenges identified are the ones already under way. The outcome of the last phase of this study, however, will show whether the preliminary conclusions are in agreement with the general opinion of the experts.

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