Generativity for Infrastructuring eHealth

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Abstract. The theoretical notion of e-infrastructure is explored and compared to the ambitions and status of eHealth as advocated in Europe and Norway. The Internet's quality of generativity is seen as central to its evolution. This evolution has brought it close to a digital equivalent of such canonical infrastructures as railways or electricity. Thus, to enable a true infrastructure, both eHealth's strategies and its backbone technologies should enable generativity, allowing a leveraging of third parties for its evolution. The answers from a simple survey given 60 professionals taking a university introductory course in Health Informatics demonstrates that the practical motivation is there, for inclusive, middle out development strategies.

1 Introduction

As of 2014, it is just about twenty years since the Internet and email were made accessible for commercial use, although its early history runs back to the 1950'ies. What is now in our affluent parts of the world considered a global infrastructure has actually been more than 60 years in the making. Starting out as a failure resistant military communications network technology for the US military, its further development was reinforced by making it accessible first to some research universities, more universities and even CERN in Switzerland. Commercial use came in the nineties when functionality and usability had evolved to a stage where public use was deemed desirable and feasible. Both the timespan, and its sheltered circumstances in the early years, lends perspective to the practice of infrastructure building.

The use of information technologies to improve and promote better health and healthcare systems has of course a similar historical timespan to look back on. Moreover, with the Internet's success, the ambitions for and expectations to eHealth are large and growing in all corners: with public administration and politicians, with citizens, with both healthcare and technology employees, as well as investors and researchers. What began as local and standalone systems and artefacts now number several thousand different, more or less disconnected, electronic type systems in a single Norwegian hospital. The idea of eHealth, as its latest denomination, represents a vision of an e-infrastructure for health [1] where the technologies should remain largely in the background while citizens and professionals strive for good health and satisfactory healthcare services. What we want is seamless functionality with correct and accessible (i.e. shared) information on the patient, as well as computer assisted harnessing of up to date medical know how. We seek workflow control and quality

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assuring functionality that facilitates fluent patient trajectories, with effective treatment and empowered patients.

This article goes on to describe aspects of the ICT domain infrastructures as found in the research literature, and what theoretical descriptions of such e- or Information Infrastructures [2] may suggest towards accomplishing these ambitions for eHealth. This is offset and discussed against the answers from a simple survey given 60 professionals taking the university course: Health Informatics Introduction. They were asked about their motivation and expectations towards taking the course. Their answers and eHealth ambitions reflect the notion of a way forward which corresponds to middle out strategies [3] involving a broad spectre of actors and activities for making eHealth a reality. This demonstrates an expectation to participate in leveraging the efforts of, or as, third parties in the comprehensive infrastructuring activities needed.

2 What would make eHealth an infrastructure?

As pointed out by Moen et al. [4], eHealth is the latest term in use on the European scene following a row of terms regarding the use of ICT within the health arena, such as: telemedicine, medical informatics, biomedical informatics, health informatics, nursing informatics etc. The sequence mirrors the general evolutionary trend of ICTs as one of successively expanding scope and reach effecting changing roles and expectations to the technologies in use [5]. The early ICTs were local *tools* of single standalone machinery and programs (medical technology) for medical and healthcare activity. Subsequent development gave us networked technologies of multiuser and multiple systems of ever increasing reach (EPR, RIS, PACS, Telemedicine, Core Patient Journals, message based services etc.) filling also the role of *medium* for communication and interaction. The present eHealth visions resonate with the ideas of 'the Internet of things' and 'Cloud Computing' where everything, - perhaps even everyone, is connected and to some degree computerized as invisible parts of an *e-infrastructure*. We now want supportive technologies with distribution of knowledge for citizen-centred preventive health measures, in addition to the reparative, post damage healthcare services for when we are patients. The goal is technology that supports healthcare providers, as well as a citizen-managed choice of services or providers. Choice can be seen either as a natural personal freedom, or as a regulatory measure of competition, providing a driver for improving the quality of healthcare.

However, while our visions truly resonate with conceptions of an apparent ease and practiced use of technologies in other walks of life, reports from within healthcare tell a mixed story. We perceive ICT to be an integrated and close to invisible element in banking, oil, aviation, or for that matter the operating theatre and advanced medicine. However, neither employees nor actual patients experience that ICTs have become a seamless infrastructural part of healthcare provision [6]. Seamless - as in unnoticeable and naturalized, except when it in seldom cases breaks down. The ICT use – or lack of fluent use, which is regularly remarked upon in media, by politicians, and in patient stories indicates that in reality eHealth has some way yet to go. Indicative are the EPR system updates sent on discs by post, patient journals urgently

forwarded by taxi, new fax machines for coordinating patient transfers to nursing homes etc. [7]. Compared to expectations on how technology could be used, the lived experience within public organized healthcare often falls short. Yet we know of incredible medical advances taking place, being used or researched that rely on working technology – at least on a local scale. The challenge being large scale use in regular and 'available for all'-settings, everywhere, as part of quality services across organizational and professional boundaries – both now and the next time we need healthcare. We envision technology for improved medicine and health services, but also for wellbeing in the hands of citizens themselves.

While we have notions of how infrastructural ICTs have become elsewhere, Edwards et al. [1] point out that what we have is more like an infrastructure-in-waiting. They define genuine infrastructures as: "*.. robust, reliable, widely accessible systems and services that are beginning to look in form and centrality like the digital equivalents of the canonical infrastructures of telephony, electricity, and the rail network"* [1, p.366]. Two features of IC technology change in the past two decades are indicative of the evolution taking place: 1) *Information handling* has moved from the individual computers and local networks to more distributed computing in grids or the cloud with ubiquitous links to and through the global internet. 2) *Digital convergence* of media (data processing and text editing melding with audio, video and images). *"Yet despite all this, in many respects and settings, localized information systems and individual computers remain the norm. .. But perhaps e-infrastructure is emerging first on smaller scales of time, space, and service on top of and around the Internet and other information networks"* [ibid.]. As we have seen, this resonates with the status of eHealth in Europe [4].

From studies of such smaller scale infrastructures Edwards et al.[ibid.] identify three central practical problems: 1) how to integrate with or replace existing infrastructures (new features and innovation is desirable), 2) how to handle divergence from the existing norm, including how or whether to allow workarounds, 3) what is gained and lost in transition to new e-infrastructure. Somehow any new infrastructure must integrate with an installed base that includes not only artefacts but also human habits, norms, and roles. This may prove especially difficult because new infrastructure often shifts the power relationships within the actor groups involved in its use as tasks are rearranged. This engenders resistance [8], due to lost or missing mandates or resources for performing expected tasks, as well as feelings of power lost or in question.

In order to understand, and thus with more success build infrastructures, Edwards et al. [1] sum up their edited Special Issue on e-infrastructures, with infrastructures as relying on ongoing efforts of negotiations in two senses – process and outcomes. Firstly, *process* – while there is no 'correct way', those involved must grapple to make appropriate trade-offs between the local needs and larger community goals to find practicable workable solutions. Secondly, *outcomes* – an understanding that conflict is an ever present feature of infrastructural life as infrastructuring is about changing organizational routine, practice and capacity. In effect infrastructuring has a powerfully redistributive function by constraining or enabling the scope of action for various actors. *"This means that questions of distribution, power, and justice needs to be addressed urgently and systematically in [research on e-infrastructures] .."* [ibid. p.372.]

Essentially, the work of infrastructuring is an issue of both technology design/-procurement, as well as the establishment or rearrangement/revision of the (work) practices it supports. Pipek and Wulf [9] suggest that the distinction of *technology designers* versus *technology users* is unhelpful in this setting and suggest a retake by adopting the notion and concept *work infrastructure.* This consists of the full set of systems and practices employed in a given group. Note - the *work infrastructure* only includes the features in actual use, rather than the full set of features technically available. Such a retake puts focus on the co-development of work practices and its evolving socio-technical circumstances.

An approach in complementary vein is argued by Pagliari [10] on the design and evaluation of eHealth by calling for interdisciplinary research and activity by software developers and health service researchers. With differing languages, cultures, motives, and operational constraints there is a need for developing a mutual awareness and respect for each other's methods, theoretical bases and epistemologies to provide sufficient overlap for transdisciplinary work – if mutual trust is to be developed.

Gauging the mood within the eHealth domain, Moen et al. [4], based on a survey performed by EFMI in 2011, find a shift in focus from the previous ICT-orientation to a more comprehensive approach to developing the entire health system. The survey on the Status and challenges of eHealth, was given to the different national member associations in Europe. Four broad topics were identified in the analyses of the responses: *Strategy & policy, Technological, Professional* and *Organizational.* It is clear that within the research communities, also from the perspective of health care services, there is a practical understanding of the need of a transdisciplinary address – of both organizational and technological issues. However, neither of these exist in a vacuum, as their larger context also comes to bear – as in the identities/roles for involved actors, the goals to be sought, and the legal and practical circumstances of their efforts.

3 Can you plan an infrastructure?

While the above provides useful insights as to the need for broad and ongoing involvement with attention to negotiating the changes of both processes and outcomes, a more nuanced understanding of the nature of desired changes would be useful. To characterize their purpose as beneficial is not enough. In a call to broaden the scope of CSCW research (Computer Supported Cooperative Work) beyond workplace studies to encompass the practical reality of working organizations and individuals as handling a multiple set of systems, Monteiro et al.[2] suggest that some answers lie in research into what they have termed Information Infrastructures (II).

They say that the unfolding of an II is characterised by having two main effects for work. Firstly, *standardisation* in where local use of a technology in constrained by its use in other locations (such as requirements of other user groups for the sake of a desired collaboration through the technology – i.e. global, larger community goals). Secondly, *embeddedness* where the implementation of a system becomes entangled

with other apparently separate systems/IIs (such that the use of the one implicates how the other may be used). As one example of how organizations and technology developers typically deal with these challenges, they point to the typical ERP (Enterprise Resource Systems) which seeks to align the interests of various user groups by choosing amongst a set of templates which makes the centralized support and management of a system manageable [ibid., p.598]. Essentially this is a choice of 'a few sizes fits all'. This is easily a strategy which limits future innovation due to the normal change of circumstances and requirements over time [11]. These two effects on work relate to nr. 2 and nr. 3 of the central practical problems for infrastructuring as described by Edwards et al. (ref). In terms of the first practical problem, they claim the following.

Enabling an infrastructure to grow, is about managing network effects and path dependency [2, 12]. *Network effects* are about how the number of users of a system directly affects the utility for other users. New users are attracted if there are many adopters already, and conversely, the challenge in getting a new system going lies in attracting these early adopters. *Path dependency* is about staying with the system you are already using, which hinders the adoption of new systems. Making a new system as easy and simple to adopt as possible - for the first user and for the last, is a successful way of bootstrapping a new system into being [13]. This may be done by for instance latching onto an installed base. A recent example of this is – Sony subsidised the selling price of each Playstation 3 unit with $100, worldwide [BBC documentary *Secrets of the Superbrands – Technology*, 2013]. The first version Playstation 3 could play both BlueRay discs as well as the, at the time, usual DVH HD. This tactic later supported the new Blue Ray Discs' entry into the market by boosting its ability to compete with the existing standard: DVD HD video & games discs (owned by another consortium).

On the other hand, to overcome path dependency, a useful strategy is to create gateways that enable use across systems, allowing new systems to evolve over time. Another essential quality which supports innovation is - *Generativity* – denoting a "technology's overall capacity to produce unprompted change driven by large, varied, and uncoordinated audiences" [2, p.599, 14, p.1980]. This is a quality attributed to the Internet which, with "the combination of its end-to-end architecture and the programmability of its terminal nodes (i.e the computers linked to the network). End-to-end architecture means that the network's functionality is located in the networks ends" [2p.599-600]. This quality allows decentralized creativity and innovation, by third parties connecting new nodes/features to the 'existing' Internet.

The success of Internet as a near thing to an e-Infrastructure lends credibility also to the notion that eHealth, through empowered citizens and third party technologies, may prove to be a driver towards making eHealth a genuine infrastructure. Important factors in making that happen, on top of establishing a generative technological backbone, will be the enabling of transdisciplinary development and research, such as Pagliari has argued for – in funding strategies [10] - and in educating those that must collaborate in performing the negotiations of design and adoption processes for both backbone – and third party technologies.

4 Continuing education students' expectations to eHealth studies

The eHealth continuing education master program (120 ECTS) at NTNU is by 2014 in its sixth year. Although with a slow start (as with any infrastructure/new system innovation), the student numbers are now picking up, in part due to the opportunity to sign up for single courses (7,5 ECTS) in addition to the year-modules of 4 courses each. For the second year now, we offer a single Introductory course in Health informatics (7,5 ECTS).

Each class had 30 students which were asked, before attending, to state their expectations and requirements towards the course (non-anonymously, but confidentially - for the benefit of the teaching staff). These data give an indication at least of what this group of individuals deems necessary or interesting about eHealth competence – personally or in terms of their work. The author of this paper is currently, and from its start in 2008, a coordinator of the multidisciplinary HI master program at NTNU.

The curriculum of the master program has been constructed with the basic assumption that there are broadly two student groups to target – those with a background education within ICT, and those with a background in a health related profession. Consequently, the courses aim at introducing a basic knowledge of the other field and its knowledge work, establishing an understanding for embracing the multi-actor context of ICT use and design especially in the health context. Further aims are to teach context sensitive, user centred methods of design and implementation for bridging the diversity of objectives, technical and organizational aspects. See the list of courses in Berntsen, Faxvaag and Mjøen [15]. Learning outcomes for the first introductory course in the program is given in Table 1.

As eHealth is a multidisciplinary field it attracts continuing education students with a diverse range of occupational backgrounds. As it turns out, these are not easily placed in our original two student categories. While our original aim was to attract employees working with eHealth in a professional capacity, and that the employer would pay the course fees, it turns out that not all employers are keen to support their employees' studying. Especially employees in the private ICT companies are slow to join, as well as those working with health/~ICTs outside the hospital setting (i.e. community health). This is in part due to lacking funds for continuing education, the need for temps during teaching hours (2+3=5 full days on campus per 7,5 ECTS course), or simply a lack of understanding for the potential outcomes of eHealth master level studies, for employer as well as employee.

Learning Outcomes - Introduction to Health Informatics S2014 (7,5 ECTS)
Upon completion of the course the student should have:
Knowledge about:
The status of ICT use in the healthsector with an overview of different types of Health Information Systems, information services and infrastructure
Health informatics as practice - roles and actors
The electronic pateint record(EPR) as a system - structure and function
Models and ontologies for health infomation
Standards and terminologies
Process- and decision support
Relevant legislature and some ethical issues on privacy
Requirements engineering for Health information systems (HIS) - gathering and specification
Design and construction of HIS
Architecture for HIS
Evaluation of HIS
Developing trends in ehealth
General competence in order to:
Give an overview of use, opportunities and challenges in terms of ICT use in the healthsector
Skills for:
At a basic level perform design, specification and introducton of HIS
Reading research literature to in order to make independent evaluations of relevance and to summate/use it for specific, individual problems
Navigate the discipline and identify the important sources of documentation, standards, norms and practices
Reading, using and making simple informationsmodels

Table 1. Specified Learning Outcomes for the course Introduction to Health Informatics (HI), spring 2014. *(HIS denotes Health Information Systems)*

In order to identify the student's background and personal motivations and expectations towards the course *Introduction to health informatics*, they were given an online survey questionnaire to answer before arriving on campus. Some of the results from the course survey given autumn 2013 and spring 2014 are presented here. 30 students were signed up for the course each of the semesters, respectively 29 and 26 students responded to the questionnaire. Their answers are of course biased in terms of: 1) their decision to join the course, 2) the fact that they have argued for their decision to join given that this probably both affects their work setting and family life, 3) the objectives the course and master program is marketed as addressing, 4) the learning outcomes specified for the course (see Table 1). The survey specifies their professional and occupational background (more or less formal/practical), education, and expectations to the course. Not related here are questions concerning where they work and how they learned of the program's existence and application date.

Education	#	health	technical	both	+other
	55	35	14	6	26
		64 %	25 %	11 %	47 %

Worked with ICT in a health context	#	recently	many yrs	no, want to	blank
	55	23	13	11	8
		42 %	24 %	20 %	15 %

Practical experience in -- capacity	#	health	ICT	HI	all
	104	37	23	36	8
		67 %	42 %	65 %	15 %

Expectations to the course			
Checklist	# 55	Desired/expected Skills or Competence for: [freq. in 29 statements]	
Insight	80 %	Health Information Technology insight	9
Career move/ECTS	73 %	Design and other challenges for eHealth	7
Work relevant	62 %	Implementation strategies for HI services	5
Personal networking	42 %	Career advancement/MSc	5
Motivating	49 %	Improved dialogue health vs technology	4
Bridging	36 %	Identify requirements and improve systems/use	3
Learn some ICT	64 %	Understand ICT in clinical practice	2
Learn some health	39 %	Improve information quality in community health	1
Skills	18 %	as defined in Learning outcomes	1
		Health domain knowledge	1

Table 2: Results from pre-start survey on background and expectations, given 60 students in the course Introduction to Health Informatics in 2013 & 2014.

Expectations were given in response to a short checklist and a free text option. My analysis of the results is given in Table 2. The answers of the two groups are added together in this presentation – in all 55 respondents out of 60. Excepting the first two questions listed below, more than one answer was allowed. The categorization of the free text replies are based on my interpretation of the response seen together with their answers to all the questions (a mix of checklists and free text fields). The numbers in the far right column indicate the frequency of replies fitting into that category. Some students made several statements, while others made none.

In summation – About two thirds of the students have some form of health education. A quarter have a technical background, while one tenth have a dual background – having 'switched sides' mostly halfway, or longer, through one education. In addition half of them have taken other kinds of additional education. We can deduct that one third of the students (11% *No but want to* + 15% *blank*) do not presently work with ICT in a health context, but desire a career move.

Many, 42 %, have only recently moved into working with HI, indicating that there is a growth in activity and a need for more knowledge of the particularities of HI. This contrasts with my personal experience on the questions and backgrounds of those previously asking for information about the program by phone or e-mail. I used to get questions from individuals with fairly little or no formal education. Although this communication has been intermittently documented, I can safely say that for the last year no such requests have reached me. The numbers are however so small that the safe conclusion to be drawn is a general increase in interest for eHealth. Also, the past

year has seen the start-up of bachelor programs addressing welfare technologies at several University Colleges in Norway (for instance Høgskolen i Østfold).

The responses as to expectations largely follow the premises that are lain out in the profiling of the Health Informatics master program – as in a need for a transdisciplinary building of mutual understandings, common language and knowledge in aid of a better and trusting dialog. This is a practical approach that acknowledges the need for trust through dialogue and network building across disciplines. In addition however, specific practical issues are identified, indicating an interest in doing and participating. A considerable portion of the students came from private companies.

The backdrop is that there is much practical work to be done, as identified with mundane issues such as getting rid of the fax machines [7], the government's recent agendas ("The Coordination reform [16] ", "One citizen - one journal [17]"), and the necessary legislation is finally coming into place. The issues at stake are apparently viewed as complex and different enough to warrant extra education for the work ahead. Let alone in addressing the opportunities and challenges to be faced in order to achieve patient empowerment and the introduction of welfare technology.

6 Conclusion

The context of health informatics or eHealth in Norway, Europe and elsewhere is changing. This is reflected both at the strategic levels (government policies, legislative efforts), in new eHealth projects and the increased expectations from media and the public. We do not expect or accept that information transfer between hospitals need transport by taxi. The acknowledgement of the advent of eHealth as a genuine e-Infrastructure for health requires broad and transdisciplinary approaches is growing. However, we are still in the early stages of developing these infrastructures. There is little evidence that *Generativity* [2] as "*end-to-end architecture and the programmability of its terminal nodes*" (see pg.6 here) that characterizes the technical setup of the Internet, is widely acknowledged as a strategy for boosting e-infrastructuring in health. However *work infrastructuring* (see pg.3 here), as a process that gainfully involves employees/users seems to be acknowledged in the sign up for health informatics education. Work infrastructuring addresses both the large and small scales of infrastructuring.

However, perhaps the general interest for personal eHealth technology may contribute to third party involvement, furthering establishment of the technical infrastructures that also will support industry involvement in creating eHealth in large.

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References

1. Edwards, P.N., Bowker, G.C., Jackson, S.J., Williams, R.: Introduction: An Agenda for Infrastructure Studies. Journal of the Association for Information Ssytems. suppl. Special Issue on e-Infrastructure 10, 364-374 (2009)
2. Monteiro, E., Pollock, N., Hanseth, O., Williams, R.: From Artefacts to Infrastructures. Computer Supported Cooperative Work (CSCW) 22, 575-607 (2013)
3. Coiera, E.: Building a National Health IT System from the Middle Out. Journal of the American Informatics Association 16, 271-273 (2009)
4. Moen, A., Hackl, W.O., Hofdijk, j., Van Gemert-Pinjen, L., Ammenwerth, E., Nykannen, P., Hoerbst, A.: eHealth in Europe - Status and challenges. EJBI 8, 6 (2012)
5. Friedman, A.: Computer systems development. History, organization and implementation. John Wiley (1989)
6. Aanestad, M., Olaussen, I. (eds.): IKT og samhandling i helsesektoren - Digitale lappetepper eller sømløs integrasjon? Tapir Akademisk Forlag, Trondheim (2010)
7. adressa.no: Støre vil ha slutt på disketter og faks på norske sykehus (Støre [Minister of Health] wants an end to minidiscs and fax machines in norwegian hospitals) Adresseavisen. Polaris Media, adressa.no (2013, May 6th)
8. Timmons, S.: Nurses resisting information technology. Nursing Inquiry10, 257-269 (2003)
9. Pipek, V., Wulf, V.: Infrastructuring: Toward an Integrated Perspective on the Design and Use of Information Technology. Journal of the Association for Information Systems 10, 447-473 (2009)
10. Pagliari, C.: Design and Evaluation in eHealth: Challenges and Implications for an Interdisciplinary Field. J Med Internet Res 9, (2007)
11. Ciborra, C.A.: From Control to Drift. The dynamics of Corporate Information Infrastructures. Oxford University Press, New York (2000)
12. Shapiro, Varian, H.R.: Information Rules: A Strategic Guide to the Network Economy. Harvard University Press, Cambridge, Massachusetts (1999)
13. Hanseth, O., Aanestad, M.: Bootstrapping networks, infrastructures and communities. Methods of Information in Medicine 42, 384-397 (2003)
14. Zittrain, J.L.: The generative Internet. Harv. Law Rev. 119, 1974-2040 (2006)
15. Berntsen, K.E., Faxvaag, A., Mjøen, S.-L.: Reaching out-A Multidisciplinary Master's Program in Health Informatics (Poster). In: Moen, A., Andersen, S.K., Aarts, J., Hurlen, P. (eds.) 23rd International Conference of the European Federation for Medical Informatics. User Centred Networked Health Care, MIE2011.org, Oslo,Norway (2011)
16. HOD: Samhandlingsreformen: Rett behandling – på rett sted – til rett tid. Helse- og omsorgsdepartementet (2009)
17. HOD: Stortingsmelding 9. (2012-2013) Én innbygger – én journal. Digitale tjenester i helse- og omsorgssektoren (One citizen - One journal). In: Health (ed.). Norwegian Government, Oslo (2012)