Reflections on a decade of eHealth – the second stage in Healthcare Transformation

A Briefing Paper

Prepared by the Board of Directors of EHTEL

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European Health Telematics Association (EHTEL)

Abstract: This article provides some background from the early days before there were any convenient labels for this segment, looks at where we are today with eHealth (successes and failures, gaps in understanding and in the value business case, strategic acceptance and lessons learnt) and then takes a view forward for the next decade looking at how we can expect eHealth to evolve in the real world, why it is important, what are the critical success factors, and a brief view of the world of eHealth at the end of the decade.

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Introduction

This paper is inspired by the 10th anniversary of EHTEL (European Health Telematics Association) an organisation that has been active in eHealth from the beginning, providing a unique forum for all eHealth stakeholders across the European Union (and beyond).

eHealth is the current label used to describe interaction between healthcare and information technology. We can already identify three clear stages of eHealth evolution as discovery, acceptance and deployment – and also postulate a fourth stage when all labels become redundant, and what we now call information technology is accepted as an integral part of the care process - just like telephones, scanners and bedpans. But this would be to run before we can walk (a not infrequent characteristic of eHealth and its precursors).

The underlying theme of this address is to derive some practical conclusions to support the process of 'making eHealth happen', to look at some of the aspirations and in particular to consider how to make progress towards the fourth stage. To do this we have to go back and paint a picture of how we got to where we are (and where we are not) with eHealth, looking at the interrelationship between health and information technology. Then we need to take a realistic look at the status quo, what is already on the table, what evidence already exists and what are the gaps, the areas which have as yet not received a great deal of attention. Finally we need to build on existing templates for the next decade and consider the factors that will create a constructive obsolescence roadmap for eHealth.

The first age of Discovery (1989-1999)

The first stage of discovery (1989-1999) was heralded by the European Commission's recognition that their Research and Technology Development (RTD) programme should also tackle issues within vertical sectors despite the difficulties involved in interpreting the governing rules which were predicated purely on a research and technology base. This eventually led to the AIM programme specifically designed for health. The major achievement here was to enable and support a community across the European Union of people committed to working together, exchanging ideas, information and experience. This did not exist in the health IT world, only within the clinical community but with increasing access through email, this new community developed around EC projects and associated conferences, workshops and other 'European' activities. Even then the governing rules made it extremely difficult to avoid the 5 year research model which often meant that, by the time the project was complete, any useful results had often been overtaken by events. Despite the difficulties this was the baseline for eHealth and by the end of the decade, this was a vibrant and active community (though still rather introspective and technology oriented).

These were the days of "magic solutions", "silver bullets" and "paradigm shifts" – not to mention a somewhat impractical commitment to the imposition of wide ranging standards. Like many similar new communities, it spent huge amounts of time and money talking only to itself, with little direct connection to healthcare professionals and not enough contact with the real world of clinical practice. The constraints of the EC RTD programme, the disconnect between Health ministries and IT, wide ranging ignorance of eHealth and its potential, and the enthusiastic pursuit of interesting technologies all made this a frustrating time. Pilots were everywhere and achieved things locally but almost none of it was consolidated, and most of it was lost in silos, conference proceedings and budgetary inflexibilities. There was also a significant reluctance, sometimes downright opposition, to change - quite apart from the transformation that was becoming an evident necessity. The paternalistic model has a proven track record all the way back to Hippocrates. But there were (and still are) conflicting interests involved.

There have been some important signposts along the way. With the AIM programme - a turning point for what we now call eHealth – which ran between 1988 and 1994 under the direction of Niels Rossing, Health Informatics had come to be viewed as Health Telematics. Also, one of the first major gatherings of this community was in Geneva at MEDINFO in 1992. A foreword from the Chairman of the Scientific Programme Committee, Salah Mandil, was entitled - "From EDP in Health to Health Informatics" and the first keynote speech was by Roger Penrose of Oxford University entitled – "What computers can and cannot do!!" In the same year, the European Commission, at the highest level, was considering a proposal to establish common base networks for open health information systems in Europe.

Project scope expanded dramatically, as also did the eHealth community itself as ideas about specific applications of information technology to healthcare began to develop across care settings and health communities up to a global level. By the end of 1999 it was clear that to bring together technology and healthcare, the academic and technology emphasis would have to be rethought. Some way of building bridges and achieving active collaboration between the various stakeholders would be a prerequisite for success.

The second stage of Acceptance (1999-2009)

The second stage of acceptance (1999-2009) began with recognition by the eHealth community that nothing was going to happen by osmosis or just because of the enthusiasm of that community alone. There would need to be vision and structure, stakeholder involvement, some high level encouragement and a lot of hard work on the ground. Once again the European Commission took the initiative to support a number of activities to tackle these transformation factors. One of these was the establishment of the European Health Telematics Association (EHTEL) to provide a forum for all key stakeholders. The drive for this came partly from SMEs looking for ways to get connected to EC programmes, and to become involved with the health IT community with other stakeholders. The challenges were evident – there was no main stream credibility for health IT within the technology sector or indeed within healthcare itself; there was no voice for innovation and new ideas; there was no business case, no evidence base and among the major players, there were few who were aware or listening to the health telematics community.

In contrast, the opportunities were beginning to open up. The health IT community was beginning to gain momentum and credibility in some areas. New technologies were maturing which had relevance to healthcare and particularly there were a lot of small companies actively working with innovative local health groups and clinicians. The growing pressures of demography, medical advances and patient empowerment were all in sharp contrast with finite resources available to address a growing demand from citizens and patients for more health attention. The impact of increasing incidence of chronic disease, evidence based medicine, and early glimpses of personalised care, information based management and control, economics of transformation through technology support and development of strategic ideas from European markets were changing perceptions, priorities and the choice of health business models. In addition, as opportunities emerged, stakeholders began to be more aware of the opportunities and threats associated with ongoing change.

During this decade, some forward progress was achieved. But often, time seemed to stand still, and much of the tactical movement was either sideways or even backwards. Key progress centred around consolidation of various IT 'labels' into the term 'eHealth'. Again, it was the European Commission that took the initiative,holding held the first high level conference on eHealth in 2003. This provided official endorsement for eHealth - and since then, the label has stuck. In February 2009, the seventh of these conferences will take place in Prague. The key next step was to increase the level of understanding of the importance and value of eHealth. Today, there are few dissenters, and most stakeholders are happy to acknowledge this state of affairs. In January 2008, the EC launched its Lead Market Initiative programme with eHealth as one of the significant components. In an interview in January 2009, Ilias Iakovidis put forward the proposition that eHealth could be a key to future European industrial growth, with the current economic crisis possibly offering a huge opportunity to invest in eHealth, to stimulate jobs and to drive economic growth.

The European Commission's continuing support for eHealth will be crucial in the next stages of evolution, but one of the things we have learnt is that the Commission alone cannot do all of this on its own. Its key responsibilities and priorities are declared, but eHealth is not just a top down affair. There are some components which can be dealt with at European level but these are rather restricted since there is currently no European market for healthcare or for eHealth. The financial crisis will emphasise this – for all the European and national support for banks and economies, the crisis will hit local communities hardest, and has to be tackled locally on a day to day basis, not just at a macroeconomic or national level. This makes it difficult for politicians who will have to delegate in order to be effective locally (and more so in health than other parts of the public sector).

In this second stage, much attention has been paid to issues of healthcare transformation and to the role of eHealth, but the results have been disappointing, particularly where excessively centralist strategies have tried to impose 'one size fits all' solutions. Issues of scale and complexity in healthcare are only just beginning to be understood in relation to eHealth, although this was highlighted early on in the decade[1]. Even now, it seems evident that working with population groups above 5 million involves a major shift in complexity which is still beyond the practical application of today's IT technology in a healthcare environment. This is not just a European phenomenon. Even the USA Veterans Administration, a world leader in health IT with common systems plus a 'command and control' culture, has experienced problems with multiple different implementations of the same (apparently identical) systems. Experience with the UK National Programme for IT serves to underline this issue and now risks causing of a serious 'disconnect' with the supply side of IT industry, both large and small. The National Care Record service, as originally envisaged, is now regarded as impractical and non-viable. Experience with medical records in France, the demise of GIP-DMP, and the smart card programme in Germany all endorse these difficulties with over ambitious projects. Even in the Netherlands, for so long a pioneer in health IT, the national programme is struggling to deliver against the original objectives.

What about healthcare users – how do they view eHealth? The simple answer is that they do not yet see it as an immediate priority. The prevailing perspective is rather limited and varies significantly depending on different user categories. On the one hand, many users are clinical professionals across a range of specialties and functions from paramedics and nurses to hospital consultants. In their own private lives, most will be IT users at some level. Yet, when they go to work, corporate IT capabilities often don't extend to supporting and enabling them to do their jobs. Indeed, there is even considerable frustration, centred on the view that medicine is a personal relationship between clinician and patient, which needs to be kept that way. On the other hand, for patients and increasingly citizens, there is a parallel frustration, but reflecting the paradox of a perceived special relationship with GPs and the medical profession which is often at odds with reality.

[1] Report written for UK DTI (Department of Trade & Industry) Understanding the Market for eHealth October 2001

But on the other hand, the work EHTEL has done with patients groups leading up to the publication of the Patient's Charter[2] highlights very real concerns about quality, access, convenience, and confidentiality as well as the sustainability of present prevailing models of care. Choice and empowerment sounds good - but is it any practical help when you are seriously ill or coping with chronic disease? But looking ahead for users, the prognosis is good – they will be better informed, and more notice will be taken more notice of their individual preferences. They are likely to be given more responsibility for their own health, but there is still a large gap in understanding between them and other stakeholders that will have to be addressed at local as well as at national level.

Much of what we have learnt in the past decade is not actually new, but rather a more pragmatic reflection of the difference between popular perception and prevailing reality.

Healthcare is about people and if eHealth is to make a major contribution, as the eHealth community and its stakeholders believe, then it must be more people oriented. Not just for government or politicians; not just for clinical professionals, nor indeed for health managers or civil servants. We have learnt that the paternalistic model of healthcare is breaking apart at the seams under growing pressures of demand, demography, choice, public health and patient safety.

New business models are now required where the citizens are given both choice and responsibility; where this is encouraged and informed; where clinical professionals, as just one part of a strictly finite set of high quality resources, are supported and informed to be more effective, to work as part of broader care teams looking towards more personal and personalised care; where regions, national governments and politicians are confident enough to allow the principle of subsidiarity and delegation to be applied; and for common sense to break out in healthcare. This is not going to happen overnight but more likely over an extended period of time in order to release the full benefit potential of eHealth.

There are already some clear signposts for the way ahead. For example, the progress being made in Sweden based on the national eHealth strategy. There is a bewildering array of different telemedicine projects, mostly small scale and locally focussed, but with the potential to be deployed more widely given the right supporting infrastructure, reimbursement and political will. There is already some genuinely innovative thinking typified by the multi-award winning Virtual Ward Disease Management Project initiated by Croydon Primary Care Trust in the UK. The initial concept is now well proven and accepted, and local community strategic thinking is focused on second phase issues about how eHealth can effectively add value and support new models of care.

We have learnt that eHealth is no longer subject only to RTD, and that support must now come from different funding programmes and initiatives. The Lead Market Initiative (LMI)[3] and the recent ICT Policy Support Programme are both examples that are moving the focus towards local deployment. There are many good initiatives just started, with projects

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[2] The briefing paper "A Patients Charter for eHealth Information System" is available at www.ehtel.org

[3] To read more about the Lead Market Initiative, see http://ec.europa.eu/enterprise/leadmarket/leadmarket.htm

such as Calliope (Call for Interoperability in eHealth)[4], epSOS (Smart Open Services for European Patients)[5] and Commonwell[6] notable leaders. The focus is now on interoperability, telemedicine, personal health systems. But the real potential for connecting to care episodes, consultations, patients and citizens is still far from fulfilled.

We have learnt that healthcare is not just about politicians, ministries and clinicians or even just patients and citizens. It is a complex joint working collaboration between many stakeholders all of whom are beholden to different pressures, agendas, external dependencies and codes of conduct which conflict at as many points as they converge. We have also learnt that collaboration is only effective when it is underpinned by active commitment and involvement of all the various parties. .

We have learnt that, despite considerable investment, industry does not yet have the capability to apply itself to health as it has done to most other industries; there is no effective global market and still no common solutions. Everything remains bound up with existing interests, politics, resources and essentially insular thinking. But we have seen some progress here too, with Microsoft and Google both taking major initiatives. We have seen Intel come forward to initiate chip level standards, working hard with many other companies in establishing Continua as a practical and down to earth initiative to overcome some of the discrepancies among technology components. We have seen the inexorable rise of Open Source as an alternative model for reducing the constraints of technology 'lock in'. Perhaps most importantly we have now seen the beginnings of convergence between IT, telecoms, medical equipment and medical devices.

What we have still not seen is any truly scalable collaboration model to overcome the silos and protective interests in healthcare. Historical 'legacy' models are still there, as are ongoing turf wars between primary and secondary care, between specialties, against change, and against the citizen-centric service model. Somehow, eHealth is still buried underneath all of this, struggling to extricate itself and prove that it really has the potential to help address the demographic problems that lie ahead.

What we have also not seen any clear and unequivocal business case for eHealth, or even for its component parts; we have not seen clear explanations of what eHealth can do, for whom – and how to go about using it. Where are the good practice examples?, What sort of collaborative models work for which stakeholders and addressing which operational objectives? How can the results and lessons learnt be presented to a wider audience so that people in local communities can understand how they, too, can implement ideas and proposals to deliver better, more effective, more personal care with better value for money. We have known for some time that existing cost savings model are too simplistic for eHealth[7], but we will still need to spend time and effort finding answers which are honest, and clear but also effective in a practical local care environment.

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[4] To read more about CALLIOPE, see http://www.calliope-network.eu/

[5] To read more about epSOS, see http://www.epsos.eu/

[6] To read more about Commonwell, see http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=4589

[7] Presentation given by Tom Jones ACCA at the first high level conference on eHealth organised by the European Commission in Brussels May 2003

The third stage of Deployment (2009 – 2019)

The third stage of deployment (2009 – 2019) will be a challenging one for healthcare. Many of the issues that have been a feature of this sector over the last twenty years will come home to roost. Cost will as ever be the prime one – how will Europe and its Member States cope with the rising cost of healthcare provision (and the financial crisis will not make this any easier). The prognosis from the US is not encouraging with costs already at 14% of GDP and projected to go on rising towards 20%.

Demographic patterns across Europe clearly show an ageing population with more and more people in the age groups associated with higher proportional costs. Widespread increases in the incidence of chronic disease are a testament to our growing ability to avoid premature death – but also an economic millstone that demands changes in the way chronic disease is managed. Diabetes is only one example where there are already insufficient clinical resources to meet current clinical guidelines – incidence is forecast to double over the next decade, but specialist clinical resources are likely to reduce in real terms. New drugs, new procedures, new equipment are emerging to help, but unit costs are rising rapidly. This is only a snapshot of how existing health infrastructures are already struggling to cope.

Beyond this, there are new opportunities and challenges – the concept of personalised medicine, the use of stem cell technology, genomics and proteomics and many others will develop and provide new ways of protecting and preventing disease. But in doing so, we risk radically changing the balance and economics of healthcare. Alongside all of this are ongoing societal developments – the politics of choice and delegation of responsibility; location of management and control; increasing concern about safety and quality; and moves towards self-management (seen by some as the only way to constrain rising cost and meet the expectations of voters). It is a faint hope indeed that the healthcare sector will become less complex, or that there will be simple answers to the demands being made. While much can still be done by organisations like WHO and at European and national level, the hard reality of healthcare will increasingly be evident at personal and community levels - and it is here that information has to be the lubrication for real progress.

Prior to the current financial crisis, the European context for IT was already moving in the right direction, with increased interest from major players and SMEs alike along with movements to bring IT along side medical equipment on the supply side. However, recently it has started to look as if Europe (traditionally strong in the healthcare technology field) may be beginning to lose its competitive edge. Traditional IT suppliers (many of them now operating as services suppliers) have had a mixed time recently in the UK and elsewhere, while small specialist suppliers have been decimated in some markets. This financial crisis will hopefully help to focus minds within the IT industry. But healthcare does not necessarily offer straightforward options to replace declining financial services revenues. Some of the reasons for this are that health is a difficult market to engage, often not knowing what it wants or what is likely to be realistic. There is no effective hierarchy of decision making, and still considerable suspicion and mistrust between healthcare and IT industries. This is evident in the adversarial procurement and contract management typified by the National Programme for IT in England, where Local Service Providers are struggling with Cerner and iSoft to deliver effective care record solutions. But behind this there is a more serious issue – that of encouraging smaller suppliers with existing healthcare solutions or new technologies and technical innovations. If, as we have said before, successful deployment of eHealth depends on collaboration between stakeholders, then we have to find a way to bring along industry, both large and small, and it has to be a way that provides both opportunity and motivation. Most importantly, it also has to allow them to identify with (and share) wider strategic goals for healthcare service delivery.

Given these contexts and the current economic crisis where we are now with eHealth? We know there are no simple answers or panaceas, no single immutable way forward. We know that eHealth is just one (albeit a key one) enabler for healthcare transformation. We are close to having the technology we need, including interoperability of information and the systems that share it, but not yet the transformational change mentality nor the flexibility of approach to collaborate and share. But we are beginning to see an awakening stakeholder awareness of the true potential value of eHealth. As yet the eHealth community is still too small, too narrow, still talking to the converted, not inclusive enough and not yet identifying with fundamental grass roots of healthcare transformation.

So we are still only at the threshold of the third stage, where healthcare is facing huge challenges from all sides. eHealth is accepted as an idea but not yet as a practical, valuable and essential support tool for facing many of these challenges. Now we have a global financial crisis which will inevitably impact, and exacerbate, many of the problems facing healthcare. For eHealth, the crisis underlines the challenge of investing now to keep our heads above water - and taking bold steps forward towards 21Century care.

The direction of travel is towards information based care, built on evidence and collaboration; towards more informed self-management and responsibility for both patient and citizen. The role of technology will increasingly be to provide and support this information from the lowest level upwards, deriving management, public health and research information gathered at the point of care and as an integral part of the care process. Critical success factors will be based on effective local working, together with mechanisms to share, inform and educate across the wider continuum. Technology has to become the servant of care, delivering eHealth as close as possible to citizens and patients, bringing subsidiarity into healthcare and enabling results that people on the ground want and need rather than what others in the chain think they want, and being able to assess value by outcomes within the care conversation.

We will only begin to make real progress by learning the lessons of the last two decades, putting them into practice wherever they are effective, by understanding the complexity of the healthcare process following good practice by decomposing the complexity into manageable components and managing at that level. We have to work harder to bring stakeholders together looking for synergies and common purpose. We have to find ways to bring initiatives at all levels into a form that makes sense and where conclusions, good practice and advice can be generated and shared. We have to find ways to bring industry on board, and get them involved, in learning where best to invest, with whom and why successful partnerships are so important. We also need an informal infrastructure of collaboration and communication, so that everyone who needs to know can find out who is doing what and where, and with what results.

Our aspirations for 2019 should include a much more common community care model, irrespective of funding sources, where information is an automatic by-product of the care process, eHealth becomes just an integral part of care, and where IT and medical technology converge at the level of usefulness and value. Innovation has to be encouraged, rewarded and deployed, reducing not just ‘time to market’ for products and services but also ‘time to generate value’ in successful user deployments. Most of all, a pragmatic information base is needed to enable an improved balance between quality, access and convenience of care.

We recognise this as “one of the grand challenges facing mankind” as described by the US National Academy of Engineering[8] but we are confident that Europe will rise to the challenge.

[8] News article e-health-insider.com/News/3480 February 2008

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