EHTEL

EUROPEAN HEALTH TELEMATICS ASSOCIATION

Policy lessons from a decade of eHealth – bringing a new direction into focus

A Briefing Paper

Prepared by the Board of Directors of EHTEL

Foreword

EHTEL is a multi-stakeholder platform, bringing together eHealth and healthcare leaders. While actively working on consensus building mechanisms, EHTEL may also be perceived as a ship on which interconnected leaders and stakeholders can develop leadership by exchanging experiences with navigators from across all Europe. It was a wise choice by the EHTEL founders, to use a lighthouse for EHTEL's logo. This emphasises our role as enabler for safe and successful navigation through all kinds of riffs and dangers in healthcare.

With this Briefing Paper, EHTEL aims at reframing current policy approaches, by analysing how deployment of eHealth evolved and why not all goals have been reached until now. One key insight is that eHealth stakeholders and policy makers are disconnected from the realities "in the field". Having identified a gap and by relying on EHTEL's core competencies, we will bring solutions to all actors in order to successfully bridge this gap together.

Of course, this is also a position paper, addressing internal organisational goals:
1. EHTEL delivers an account of a twelve years long eHealth journey across healthcare.
2. The EHTEL Board of Directors in charge from 2009 to 2011, who initiated and worked on this briefing paper, is setting up the present position of EHTEL.
3. By this we pass the ball to the new EHTEL Board of Directors, handing them over not only food for thoughts, but suggestions and recommendations for action in the coming years.

EHTEL is determined to contribute for pragmatic and reality-based solutions, which means to build upon practical and well grounded experience. It is our understanding that all actors and participants in healthcare – whether using an "e", "m" or "Tele" for their communities – need to communicate, to exchange experiences in personal networks. And we are confident in the raise of a new breed of younger and elder leaders who understand the needs in healthcare.

Martin D. Denz, EHTEL President

Abstract

The challenges facing healthcare and eHealth are well documented but confronting them has proved more difficult than anyone realised. EHTEL has come out strongly about the interdependence of healthcare stakeholders and the role of eHealth in supporting this. Now 2011 brings a new dimension, not just the recognition of an economic crisis that threatens to destroy the European Union, but the realisation that healthcare will have to fight for resources just to stand still and that the current healthcare model is unsustainable both in Europe and in the USA.

The impact for eHealth and eHealth policy is dramatic – a new healthcare model has to be constructed bottom up based on myriad local efforts and successes; this will take time and there will be huge conflicts in the evolving process. Health policy will have to reinvent itself to encourage this new process (and eHealth policy will have to follow and find its part in the mainstream). This spells the already predicted end for “e”, for “tele” and other labels overtaken by events as the focus moves to health and care and the contribution that can be made to new models of healthcare

New ways of thinking, of working together, of sharing experience, information and knowledge will generate a “for the patient, with the patient” focus for all stakeholders.

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1 Introduction

The huge challenges that healthcare faces under pressure from all sides are well known and documented (resources, skills, continual change, demography, rising costs, growing and more articulate expectations and demand, increasing and encouraged societal and geographic mobility, the public health consequences of all this, unemployment, the European economic scenario ...).

In addition, there are more questions than answers depending on individual and group perceptions and positions. Many of the answers are in conflict or at least are less than complementary; many of these are driven by other factors than the quality, convenience and access to care (though much time and effort is taken to obfuscate this).

1.1 Three fundamental lessons from a decade of eHealth (1999-2009)

The EHTEL Decade paper[1] highlights three fundamental lessons:

- ⇨ eHealth in Europe is no longer just about the Research and Technological Development (RTD) Programmes – there are many other ways of moving this forward, but as yet, the potential for connecting to care episodes, consultations, patient and citizens remains far from fulfilment
- ⇨ Health is a complex joint working collaboration between many stakeholders which is only effective when underpinned by active commitment and involvement
- ⇨ Industry, despite its investment, does not yet have the capability to apply itself effectively in eHealth, as it has done in other industries, nor indeed to turn a reasonable profit from it.

At the time that the briefing paper was written, the conclusions were that as yet there is no truly scalable collaboration model or any clear unequivocal set of business cases. Nor is there a pragmatic information base within the operational units of healthcare which could enable policies to balance the demands of quality, access and convenience of care.

1.2 In 2011, things have moved on

In 2011, while these points remain valid, things have moved on: there are serious global economic and financial issues and the direction of travel is moving against healthcare. Where resources were a challenge, now they are undermined by job cutbacks. Where finances were stretched, now they are being reduced. Where there was serious shortage of healthcare professionals, there are significant increases in chronic disease and societal inadequacy which cannot be supported by traditional methods or stretched levels of care.

Where finances were stretched, now they are being reduced. Where there was serious shortage of healthcare professionals …

[1] Reflections on a decade of eHealth – the second stage in Healthcare Transformation. EHTEL, 2009. The briefing paper is available at http://www.ehtel.org/publications/ehtel-briefing-papers/10-anniversary-briefing-paper. It has also been published by ePractice in 2010

In 2011 as well, it is evident that there are more fundamental problems with healthcare. The existing business model is unsustainable in every European country – even more seriously the same increasingly applies in the US which has been the driver of much of the innovation and new thinking in healthcare. In the rest of the world, there are working health business models only in certain specific places, but for most of the world's population, the issue is not sustainability but the very existence of any business model which can relate to the general population's health and care.

The challenge that faces European policy in healthcare is mirrored starkly in the current economic trauma facing both Europe and the US. Politicians are ready to acknowledge the problems, but seem unable to construct escape plans within the overall confusion of ideological bickering and the spectre of "unmanageability".

For 20 years, Europe has tried hard to move things forward through technology and the RTD programme but whilst there are pockets of brilliant results, overall it has been a tale of limited success in moving forward the effectiveness of care on the ground across Europe.

2 Policy must change course

Now policy must change course through learning reality-based what works, what delivers and what does not, by better articulating a bottom up rather with the current top down one.

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If one had to take an example of this catalogue of failure, then UK would be a surprising choice yet is one that has much to be learnt from. In UK, the business model of healthcare is overtly broken and the policy initiatives of the last twenty years are at least a significant part of that breakdown**.** Top down eHealth approaches have been a disaster; money has been poured into healthcare (up from 10% to 18% of Gross Domestic Product (GDP)) over the last three decades with little if any increase in productivity). The UK faces a crisis and is struggling to utilise one of the most effective primary care systems as the basis for a new paradigm.

If a top down approach can be a disaster, then a bottom-up only approach has little impact. This is clearly illustrated indeed by the statement often heard that there is more pilots in telemedicine than… in the Royal Air Force (or Air France or Lufthansa depending from the origin of the person making the statement). Typically, each “pilot” in healthcare tends to implement his own pilot project, fostering epidemics of isolated and non-sustainable activities. As this relates to medicine, one could name it the “Pilotitis syndrome”…

The challenge is therefore for policy makers to find the right balance between both approaches, i.e. with a top down approach to set the frame, create the infostructure and the necessary conditions for scale-up and a top down approach to pragmatically meet the real needs of the users in the field.

European policy also has had little impact here but on the positive side, the RTD programmes have generated a vital set of people networks across Europe and beyond, which offer some hope through appropriate scaling, targeting and focussed management.

The fundamental issue is that the model is broken and can only continue to be sustained for a short while (which is getting shorter as Europe faces a series of economic and societal crises). Ways must be found to invert the model, working from the ground up, to find ways of delivering better care which are part of a broadly based set of initiatives at local levels, to build a better model.

If scale makes the current model too complex, then turn to the advice from those who work with complexity and start to decompose the issues to levels where they can be resourced, where people can work with people and where results can be measured and value secured for cared and carer, for patient and professional alike.

3 What does this mean for eHealth and for eHealth policy?

A number of other observations have emerged within EHTEL activities which may provide some clues for future policy making to be more effective in healthcare.

3.1 eHealth to become a mainstream player

The paradigm shift for eHealth will need to take account of the primacy of working towards a sustainable health and care model and looking for ways and means whereby eHealth can be an effective partner in this drive. eHealth has to take the first steps to removing its 'e' by becoming a mainstream player rather than a technology/ academic/corporate niche. The drive is coming from cultural and societal movement as well as from patients expectations, clinical frustration and political vacuums.

… a model that truly brings together strategic objectives for healthcare and enablers such as new processes, people-based change and, at the right point, supportive technology

One answer might lie in a model that truly brings together strategic objectives for healthcare and enablers such as new processes, people-based change and, at the right point, supportive technology.

eHealth has, in the main, been technology driven with the focus on implementation rather than on achieving specific benefits. There is a mind-set that believes new technology will always result in improvements to healthcare delivery rather than determining what improvements are sought, what organisational, cultural and other changes are required to achieve those improvements and what is the most appropriate, supportive combination of technology.

Such a model adopts a different orientation from the standard planning process, but is powerful in that it enables all stakeholders to be clear about what they are seeking to achieve before they initiate new projects. It also impacts upon and helps industry in that companies can work with other stakeholders to develop more relevant products and services, confident that there is a sustainable market for them. It has the potential to present evaluation criteria that can be used by funders at all levels to require that positive outcomes and benefits have been identified as measurable targets and plans in place for ensuring they are delivered.

3.2 The need for change management methods

This drive has to be 'professional' not just in clinical terms but also in terms of such elements as deployment methods, programme and project management, complexity and scale management as well as basic elements such as real value based, benefit driven business cases. It needs cooperation from all the stakeholders; working together has to become the norm, not the exception, and the vision has to be oriented "for the patient, with the patient" or based upon some tangible day to day value based measure of success.

Not everyone sees it in such terms – not just self-interests, complacency, status, remuneration, power, votes but the evident difficulty of taking this approach will, and indeed has, make progress fraught. But there remains the unsustainability of the current model (at all sorts of different levels) from money through skills, to demography, and societal demand which has to be addressed. There is no choice. There are no simple answers, no panaceas, no smoking guns. It is like building a dry stone wall – selecting each piece to fit in and to be part of a satisfying, functional whole that works to protect in both directions.

3.3 The added value of European policy

To play its part in this transformation, European policy has to be more constructive. There will still be some need for blue sky initiatives but the focus has to be on supporting, encouraging and enabling local initiatives (this is already being recognised by the European Commission in its plans for 2012-2020). Such actions will need to include those to provide sharing of information and results as a matter of course, and taking these into education and CPD (Continuous Professional Development) for a new generation of care receivers and providers.

… the policy has to be deployed indirectly by people and for people who do not necessary agree with (or even understand) the rationale or details of the policy.

There are a number of things that should *not* be done – it is no good creating European strategic policies and assuming compliance; the policy has to be deployed indirectly by people and for people who do not necessarily agree with (or even understand) the rationale or details of the policy. Changing organisational structures does little to solve real problems – often it creates more than it solves – yet it is the standard way of moving the goalposts to blur the challenges to be faced.

What is needed is cultural change not organisational disruption, new ways of working and communicating, new flexibilities within existing structures. In terms of education and skills development, the focus must be brought back to the basic elements of effective care, starting with the consultation, information skills, team and community working, people management and inter personal skills as well as the fundamental clinical elements.

Forums and vehicles which improve access to deployment methods and good practice, to clinical and organisation teams, to specialist skills, to local communities, social care teams.... will be crucial – policy can help build and encourage these. Above all, there is a need for leaders at local level who can take responsibility, make things happen and then ensure that this is utilised as widely as possible. This means finding and encouraging thought leaders, putting together programmes to reward and replicate success, to educate and harness industry into a win / win scenario. Ways and means of making communication easy and effective for busy people (including patients and citizens) at their convenience have to be developed, built and grown.

At the European level, the role might be to identify, motivate and champion the champions, although in a way that does not obstruct good work on the ground.

As a set of basic drivers for European policy, there will need to be rules for deployment – unless initiatives or policies can be shown to produce real benefits with a shared understanding across all stakeholders in these areas, they should not go ahead whatever the political or organisational mandates. This is hard, will be difficult to police but unless these priorities are simple and understandable across the spectrum of care and carers, and get all the stakeholders to think not just about their own priorities but all about the broader ones, then good money (which is no longer affordable) will continue to be thrown after bad in the headlong rush to the implosion of healthcare.

4 The role of EHTEL and other groups in this change process

This is all fine but what can EHTEL and other groups concerned with repairing the broken model of healthcare do now and for the next year to get this going?

4.1 Narrowing the gap between the European level and the ground

One of the first tasks is to ensure that the Commission opens its mind to the messages outlined in the paragraphs above. This is essential in narrowing the gap between the European level organisations and the good practice that is happening on the ground. Furthermore, it is a message that has to be sold to national authorities and to those who fund academic research in the "traditional" activities in eHealth. While this message is put to the top levels, there needs to be communication with other levels (particularly with operational clinical staff) to empower them to force the message from the bottom up.

… focusing on communicating (not about technology or information) but about the business priorities of the various groups to improve understanding of relative positions.

Good strategic words and commitment are vital but most of all, there needs to be people on the ground that have the enthusiasm and the confidence to work together. The aim should be to build a parallel set of models for the new healthcare, bit by bit, success by success locally, team by team, with groups of teams sharing and complementing each other, building synergy. The resources available will not be able to cope with more than the unavoidable duplications – communications is the key here. This means focussing on communicating not about technology or information but about the business priorities of the various groups to improve understanding of relative positions.

4.2 Intermediators and translators

This means that industry must invest in understanding healthcare and the role that technology solutions can play in improving care, not just in terms of savings and people, but to quantify and explain "value" in terms of outcomes, life style, self-care, communities. One vehicle for this would be to establish a group / network of intermediators / disintermediators to facilitate the intercommunications programme and to look at how to improve the flows of information and knowledge, using the intermediators group to link with innovations initiatives and other innovators across Europe. Following on from this, to build a group / network of translators (in the change management rather than language sense) who can help directly build bridges between stakeholders and develop a discipline of translation specifically for healthcare and eHealth. This is crucial as many of the problems of communication are caused by lack of knowledge about the role and importance of others in the care process with whom it will now be vital to work. This activity has to happen in parallel with the gathering and sharing of good practice otherwise valuable years will be lost if this becomes a serial process – "now we know what's good, what should we do with the information?"

4.3 Building on what already exist: epSOS, RENEWING HeALTH and other projects

Some of these programmes will have to be established from Europe or from Member States but then driven through local communities – encouraging a pragmatic point of care information base across Europe, based on an agreed minimum dataset and a preferred superset. At the moment, the basic information from the ground is not available outside the point of collection and cannot be used effectively even with the local communities.

> Now we know what's good, what should we do with the information?

epSOS (www.epsos.eu) is a forerunner on this issue and has recently achieved some significant progress on a minimum data set for a patient summary and a transfer of prescription. RENEWING HeALTH (www.renewinghealth.eu) is another one which has engaged regional communities to test and validate a common methodology for assessing eHealth services outcomes.

This is to be seen as an encouragement, a source of hope that this is achievable. The point however is now to make it part of daily routine care.

Key strands of technology, applications and infrastructure will need to be found which can enable information sharing and find ways of encouraging, supporting joint developments / deployments as identified by CALLIOPE (www.calliope-network.eu) and to be taken up by the eHealth Governance Initiative (www.ehgi.eu).

EHTEL and other concerned groups need help from technology and industry to make caring easier, quicker, better, taking advantage of things which are already helping at home and with e-interactions with government, as well as new ideas to broaden the inclusion of useful information across the healthcare continuum. Innovators and innovation will need help from clear leads on the major areas which need attention, with encouragement and vehicles for getting to market much quicker than at present. Programmes for healthcare leader development such as the "Future eHealth Leaders" (www.futureehealthleaders.org) initiative (although recognising a much wider audience) and for healthcare education for technology people and technology education for healthcare people will be an essential factor.

The overriding need is to find ways to improve the links between policy and deployment (what is wanted and doing it) along with the bi- (and often multi-) lateral understanding of the consequences. For professional involvement, this means local, patient related and of direct benefit (in terms of outcomes or effectiveness). The trick is to find ways of encouraging multiple ground level deployments with local (varying) value but making sure that the feedback loops enable the value to be reused in multiple different locations. Finding ways to harness industry (large and small, multinational and local) is vital to ensure making the most of the resources available, but this means enabling flexibility locally so that investment cases can be evident with a path to returns. The most serious issue is a lack of understanding about the business of healthcare as a whole and the interrelationships between the various parts – no paradigm shift or progress towards building a sustainable business model has, or will, emerge until this is tackled.

5 Conclusion

The key message for eHealth and for health policy makers and influencers is that eHealth cannot help if healthcare does not understand what it can do and while eHealth people cannot explain this in healthcare terms.

The context for this has moved on – it is no longer just cost, effectiveness and access but what eHealth can do to support the building and sharing of components for sustainable healthcare.

The critical elements for action fall into three areas:

- ⇨ **Communicatin**g: using the vehicles that are in place and building new ones e.g via EHTELconnect (www.ehtelconnect.eu), the resources of the European Commission (DG INFSO & DG SANCO in particular), industry and the stakeholders.
- ⇨ **Leadership**, management, motivation and change management skills: encouraged from the top and working on the ground.
- ⇨ **Building networks:** which transcend the silos, the cultures and the hierarchies, providing practical professional help and support on the ground which can be linked at community, regional, national, European and global levels where this adds value.

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Today there are conflicts of interest; differences of opinion, protection, denial, but all of these groups are facing crisis and chaos – a comparison with the current economic situation is a salutary one. The overriding message is that all the constituents of healthcare are in this together – patients / citizens, clinical professionals, providers, insurers, governments, industry.

Who will be the leaders to stand up and be counted to accelerate working together to transform the face and the impact of healthcare for all?

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