

Integrating Health and Social Care Informatics to Enable Holistic Health Care

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Abstract. Personalization of healthcare has a number of claimants, including pHealth. However, to the citizen real personalization is the delivery of integrated support services to maintain their health and well-being, particularly in times of chronic illness and frailty. The integration of health and social care support has been identified a key but challenging step in this. The pHealth community faces the choice either of reinforcing the isolation of silos of care and thus fragmentation of service, or of seeking to become a unifying agent though thoughtful and considered development of sharing of monitoring from pHealth devices.

Keywords. Personalization; integrated care; monitoring; choice; social care.

Introduction

‘Health’ and ‘health care’ for centuries have been the subject of tension and distancing in a discord or power imbalance between professionalism and personalization. Health is a personal state of an individual citizen, created by a personal combination of biology, behavior and social and employment environment. Healthcare is a service, normally focused on addressing health problems and ill-health, delivered by professionals with a high level of expert knowledge. While the health professional has delivered a confidential service unique to each individual patient, the service has been based increasingly on scientifically optimized standard responses to diagnosis-based needs. This distancing between patient and professional has been based very much on a knowledge imbalance, with the patient being dependent on, and trusting of, the professional’s significantly superior and generally inaccessible knowledge base.

Furthermore, healthcare has traditionally been delivered at the health professional’s location of practice, be it consulting room, clinic, or hospital. Thus the patient has been further disadvantaged by being in strange surroundings, while the professional is in his or her professional context, with all their familiar support.

In the last couple of decades, though, there has been a radical reshaping of this scenario triggered primarily by the information revolution created by new information and communication technologies (ICTs), coinciding with societal and consumer changes. Three aspects are significant – radical reduction of the power imbalance between patient and professional based on the information imbalance being significantly reduced by Internet technologies and information modalities; a shift to a consumerist society with greater citizen choice and service expectations; and new

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health technologies enabling more care to be delivered outside hospitals, concurrent with recognition that individual citizens can use available general and personal information to optimize their own health through lifestyle and preventive actions.

Into this reshaped landscape has come a further and more recent entrant – the vision of integrating all responses in support of health into one holistic coordinated package. Broadly speaking, this seeks to bring together health care delivery with social care delivery, linked also to services such as supported housing. But this linkage brings yet further clashes of philosophy, practice and organizational traditions.

Into this changing and confusing scenario comes the potential of p-Health, with its opportunities to contribute timely data from a range of key signal monitoring methods, but with the risks of data swamping, and of further fragmentation. But alternatively, given its freedom from long-established inherent traditions, it has the potential to be a unifying agent crossing the traditional care delivery domain barriers. The key lies in being citizen-focused, and facilitation choice and change simultaneously.

1. Personalization and Health

Health is a very personal experience, unique to each individual. It is not the product or prerogative of health professionals or other outsiders, though these will play vital roles on occasions. As the World Health Organization defines it, health is “A state of physical, mental, and social wellbeing, and not merely the absence of disease” related to an individual [1]. Thus health is far more than the product of healthcare services - it is a state personal to the individual, in their own circumstances, and a range of activities and enabling factors are essential for its maintenance. It is citizen based – and ‘personal’ in that fundamental sense.

1.1. The Ownership Claims for Personalization

However, while the rise of service quality standards and consumer expectations is raising pressures for health support to be tailored to personal needs, three different technological development trajectories are laying claim to the concept of ‘personalization’. These are:

- **Personalized Medicine:** This is based on the rapid development of proteomic, genetic and genomic science, and postulates the adjustment of treatments, and of proactive preventive actions, on the genomic profile of the individual. This is indeed personalized, but in a very biological way.
- **Personalized Care:** This recognizes that care should not be delivered in an impersonal standardized way, but that the core interventions should be personalized according to choice and preference, both for moral reasons and to aid effectiveness as well as efficiency. This is particularly far reaching for domiciliary care, where delivery should meet the patient’s circumstances, including their overall activities and family support.
- **pHealth Mobile Monitoring Personalization:** Thirdly, the pHealth movement has claimed its role in personalization, in that wearable micro and nano technologies enable personalized monitoring.

Thus there is almost a conflict developing as to which branch of health care system development is claiming the core contribution to personalization of health care, and the roles of the different technologies. Each is indeed making the formal care process more personal. However, what must remain at the centre is the core definition – that health (and thus health support) should be citizen-centric, delivered for the individual in the way they most prefer (within realistic resource and technical constraints). And it is in this integrated personalization context that this paper seeks take the focus away from solely health clinical interventions to support for well-being and health, which is far wider.

2. Holistic Integrated Care for Health

Since health is a state personal to the individual, a range of activities and enabling factors are essential for its maintenance. Such activities are part of normal living for healthy citizens, and include cooking and eating, exercise (physical and cerebral) and socialization. Additional important enabling factors include safe housing and adequate income or sources of essential supplies. However, when any of these functions are restricted or rendered impossible, such as by illness or frailty, overall health is compromised.

The usual first line of meeting the needs of the disabled or frail dependents is the family, and indeed providing such support is a central part of parenting, and a regular part of household life. But not every citizen has fit family members to support them – particularly in old age, the dependent person may be widowed, or their spouse also may have functional limitations; and younger adult family members may have moved away from home. Thus to meet these needs all countries have a system of social care support to assist vulnerable persons with those activities essential for life and health. But in almost every country this provision is separate from health care not just in delivery, but in legislation, funding and organization. Housing support is usually separate again.

Thus when a dependent citizen has a health-related condition which requires a range of support services this requires efforts of coordination across all these services, but often there is no mechanism. The user viewpoint too often is of services that may be individually technically good, but which are fragmented, each delivered in isolation, and each against its own standards and goals. The citizen is left poorly served, confused when individual services work to different aims and priorities, and frustrated when service delivery clashes and they have to negotiate with schedule-driven providers. And it is the frail citizen, or their extended family carers, who are left to navigate the large provider organizations' procedures, and try to negotiate solutions.

There are of course other definitions for person's needs such as Maslow's hierarchy of needs, Gough and Doyal's Theory of Human Need, or the PIES (Physical, Intellectual, Emotional and Social) needs, considered and not referenced in this paper.

2.1. Tentative First Steps

Thus there are now moves to seek to harmonize, or to integrate at delivery level, health and social care. And in so doing, ICTs may have an important part to play, as they can enable the sharing (with permissions and within ethical controls) of key information, without disturbing core professional roles or revealing the full personal history. For instance, in England it is now government policy to strive for harmonization – though

little has been done to address the practical issues described below. In Finland there is different progress, with the development of harmonized national strategies for e-health and e-social care, and a single agency coordinating this.

2.2. Identification of the Issues

There has also been some structured analysis of the issues. An Exploratory Workshop sponsored by the European Science Foundation drew together a cross-disciplinary group of 23 experts from 15 European countries. This meeting identified the key issues in harmonizing health informatics and social care informatics, and yielded a unanimous declaration, as well as publications [2, 3].

3. The Barriers to Coordination

There are three practical informatics issues identified as forming the main barriers to the desirable goal of harmonization of health and care delivery, and ICT enablement.

3.1. Record-keeping Differences

A central issue is the major differences in record keeping between health care and social care, whether paper-based or electronic [4]. Health records are focused on a single patient, with often considerable technical detail and depth, and confidentiality of the individual is strongly protected. Social care records by contrast place the citizen in their daily living context of family and other informal carers, including the attitudes and effects on each, so as to ensure mutual support and understanding. Social care records contain far less technical material, compared with the high proportion of biophysical and similar data in health records, yet contain proportionately more narrative or subjective material, while each domain uses its own vocabulary of terms.

3.2. Specialism-driven Fragmentation

Secondly, there is increasing specialism within both health and social care services. In each sector, not only is increasing specialism seen as key to quality of service, but regulations and qualifications support this. Intrinsically this may be good, such as special medical and nursing expertise for supporting specific care groups and clinical procedures, and social care skills such as care assistance, lifting procedures when moving patients, and training for those allowed to offer counsel or advice, but this reinforces fragmentation of provision, and creation of more silos of specialist knowledge and records. This specialism may have commenced with justification, but also acts directly counter to the citizen-based aims of holism and service coordination.

3.3. Sector-specific ICTs

While there is increasing investment in ICT applications in health care, and in a different way in social care, it is almost always sector-specific and often problem-specific. This grows out of the drive for specialism, and from the separate

organizational and funding structures, with lack of umbrella coordinating mechanisms or cross-sector investment or standards mechanisms. ICT investment is seldom citizen-centric, nor do many countries have over-arching strategic informatics program coordination.

4. Further Underlying Challenges in Linking Health and Social Care

Additional to these informatics issues, there are also more fundamental practice issues.

4.1. Service Need Assessment

The first is that the basis for assessing the need for formal support is very different. Though individuals are encouraged to take personal responsibility for their health, once a health problem arises the provision of health care is by a health professional working for or regulated by a professional body. By contrast, daily living is the responsibility of the individual, supported as necessary by their family as part of normal family life. Therefore in social care the degree of need for support from outside the extended family varies according to personal, family and social circumstances, so that for any level of dependence the degree of need for external social care support also varies.

4.2. Market Features

Secondly, social care provision is generally provided from a truly mixed market of public services, private commercial services, unpaid volunteers, and not-for-profit bodies of various kinds which themselves may require full cost reimbursement, voluntary reimbursement, or no reimbursement [5]. Moreover, subject to fairly simple regulation this market is comparatively open, and indeed variety and plurality are welcomed – but are a challenge to orderly informatics systems based around citizens. By contrast, though health care may also be by a market system, there is more heterogeneity of providers and much less market churn. So in social care the processes of governance and regulation are important to provide protection, as are the processes of maximizing support and minimizing cost, and balancing external funding with client co-payments, compared to the health sector's comparatively stable systems.

4.3. Legal and Governance Variation

A final challenge in most countries is the lack of a level of coordination between, and ownership or jurisdiction of, health and social care. The lowest common level of policy responsibility is often not even at Ministry level, but higher within government – with the consequence that it does not get the focus deserved. In most countries the management and funding of health are quite distinct from the management and funding of social care, creating difficulties when seeking harmonization or joint policy decisions. Indeed, there are almost as many combinations of structure as there are countries, and different levels of delegation to local agencies or municipal government. To compound this, in most countries the whole set of political, regulatory, and funding structures is different between health care and social care. Further, within their own separate contexts each is in many cases going through processes of reform.

4.4. *Independent Sector Reform rather than Cohesion*

While reform is in principle neither good nor bad, often it is too frequent or uncoordinated and thus destabilizing or mutually impeding. Also the lack of coordination of reforms further acts against increasing holistic support - particularly when reform involves new governance and funding mechanisms, and when it increases market mix (both often being the case), as this results in lack of counterparts being available with whom to enter into meaningful discussion. It is also a major impediment to informed and effective ICT innovation and investment, as the reform priority has to be changed to existing systems to match new frameworks and organizations, and ensure the supply of revised management data, rather than new delivery innovation.

4.5. *Housing and Other Services*

Housing is usually separate again, even though it can have a key role in ensuring the provision of safe homes for the elderly and disabled, and its increasing use of monitoring technologies. Furthermore, other important services such as social security or pensions and income support, and transport assistance, usually come under yet more ministries and have different funding and eligibility.

Thus not only is care provision and delivery fragmented, but the governance structures are set against coordination. Though they serve the same citizen, and each depends for its efficiency on the other, there is seldom a shared policy structure, and thus there is no means to initiate harmonization of informatics, funding, or governance.

5. The Research Issues for Integrating Health and Social Care

The ESF-funded workshop identified the necessary enabling research agenda if care delivery is to be coordinated to provide holistic support to individuals [2, 3]. Subsequently the OECD and the US National Science Foundation have also acknowledged this agenda for developing 'smarter' health systems [6]. pHealth issues should feature in many aspects. The issues to be addressed can be seen as follows:

1. Planning research to identify and then **define the range of user needs (personal, professional, and organisational)** for an ICT-enabled supporting framework. These will range from finding trusted information sources about services and their providers, through to management of budgets of resources contributed by public or insurance bodies. The need for (and separately the wish for) pHealth solutions should feature within this.
2. Establishing the basis for a **Charter of Subject Rights for Electronic Record and Care Delivery Systems Containing Social Care Data**, recognising constituent rights including subject access; subject recording; and subject-selected rules for information sharing to formal and informal third parties. Data from monitoring is a specific case within this, as to who can and should see what – and what responsibilities for action such viewers have.

3. Developing suitable robust **models of information system custodianship**, as well as models of Rights to Data Access, clear and citizen-oriented Rules for Urgent Sharing of Information and wider Rights of Access for Specific Purposes including quality assurance and training, with the citizen having informed choice in the matter. Linked rules would allow for deeper sharing in an emergency, but such special use would be reported so as to preclude abuse.
4. Sponsoring **Research and Development of leading edge ICT innovation** and appropriate applications, including controlled forms of information brokerage, cross-viewing, or record sharing between agencies and providers, as well as by citizens and their supporters. The pHealth community is already active here, but there might be more research into intelligent signal analysis, when linked to signals from other domains.
5. Developing a shared **Ontology for Social Care** linked also to Health Care – a structured vocabulary and terms so that information can be shared between professional and support staff without ambiguity or misunderstanding.
6. Facilitating **research into planning- and delivery-enabling technologies** in social care linked to health care, such as technology assisted scheduling, resource management, and decision support tools that assist both citizens and professionals when profiling needs or identifying risks. pHealth data should be able to contribute to this. These technologies largely exist in commerce, but have only just started to be applied in health and social care.
7. Assessing means of **making such informatics support acceptable and non-threatening for citizens**, recognising that many of the most needy and vulnerable will not be informatics literate. This must be trusted and enabling technology, not disempowering. A mix of both innovative design, use of multiple technologies, and other solutions such as designated trusted agents, will be necessary and must be research based. Monitoring can be enabling, but also threatening or intrusive; worn devices can be seen as providing freedom, or as restricting.
8. Thorough and systematic **consideration of the ethical, legal, governance and regulatory issues**. Technologies need to be tested in different settings, cultures, and populations to ensure applicability and acceptability. There are many aspects ranging from professional and organisational accountability to means of quality measurement and quality assurance, including those which look at the totality of inter-agency care, as well as cross-agency care management and coordination.
9. Developing new **methods and paradigms of costing, charging, and budget and resource management**, recognising that in many cases the individual citizen will be operating in a mixed economy. Personal, organisational, and social costs need to be accommodated, as well as budgeting and cross-charging, and management of any user co-payment. Indeed, pHealth has to be paid for, and there may be other beneficiaries than the current payer.

10. Developing **education programs for citizens, professionals, and informaticians** in both social care and health, and for policy makers to enable achievement of this vision of caring. Success will be dependent on understanding, and this will need public awareness, education on overall principles and policies, and training in individual applications.

In general, these are not issues about new technology, and should not in any way depersonalize care. Instead, they are focused on personalizing and integrating care, and achieving the goal of appropriate modern e-Enablement to the standard of other services in society. The European Commission is intent on funding a number of initiatives as research projects, pilots, or learning networks, while the European Science Foundation plans to publish a position paper on the research issues.

6. Issues for pHealth in Integrated Holistic Care

So what are the issues for pHealth in this background move to more closely integrate health care and social care support and delivery? pHealth itself is based on a philosophy of enabling more home care, and less disruption to the citizen by formal care processes in their time of ill-health or frailty, so should feature robustly.

6.1. Silos or Synergy?

The challenge to be faced is that pHealth is generally a supporting technology. Though new means of monitoring and communication are developed, primarily they support a traditional care delivery. In particular, specialist clinical processes are supported by enabling data such as specific vital signs to be monitored, and the results transmitted.

Already the challenge has been identified in that care tends increasingly to be delivered in a compartmentalized way, leading to ‘silos’ of care which deepen fragmentation. Overall, eHealth has a potential to deepen these silos, given the increased clinical specialization, the specialized nature of much monitoring data, and the data protection ethos of not sharing personal data. This runs directly against concepts of integrated care, and of a holistic and shared approach. Indeed, two major European e-health pilot initiatives, CommonWell and INDEPENDENT, sponsored a joint conference to address the very issue of moving beyond the new silos, with the acknowledgement that “... *advanced ICTs provide a major opportunity to realize care integration. At the same time, telecare, telehealth and other ICT applications in this field also remain locked up in segregated silos, mirroring the overall situation.*” [7].

However, the challenge is significant. Overall, pHealth may be a technology innovator, but it works within a wider but specific care need resolution service, for instance supplying data that the clinician sees as important, or which enable a supported housing provider to assess the wellbeing of residents – in other words, it responds to data needs from other services, and facilitates their service delivery. Thus it works within the rules of those individual client services, and their confidentiality frameworks, with an additional overlay of data protection.

If pHealth is not to get caught firmly in this paradox of being an enabling technology which reduces citizen restrictions yet deepens fragmentation, new thinking is needed. Not least, pHealth advocates might think how they can start to span

traditional divides, and instigate ethical sharing of results and analyses; should they support individual clinical services, or a more citizen focused trusted care agent?

6.2. Advanced Multi-stream Analysis and Added Accountability

In particular, intelligent data analysis algorithms might be seen to have considerable potential. Already clinical professionals work with pHealth developers to devise algorithms which detect adverse or changed patterns in order to trigger alerts. Increasingly, the desirability of these analyses and related alerts being pro-active (identifying a potential impending problem to enable prevention) rather than reactive (advising that a crisis has occurred) is being recognized. Secondly, multi-channel or multi-stream analysis is valued in enabling a more robust analysis.

However, there seems to be an unmet potential to analyse signal streams across disease management divisions, and across domains. This will need challenging discussions and methodologies to devise and validate the algorithms, and clear protocols as to who leads and coordinates service responses. In turn, pHealth providers will have to develop accountability and audit models, as well as ensuring the presence of agreements to share the data streams and the resultant analyses. Accountability for the algorithms will need to lie with those who approve and validate them, while the monitoring provider will be responsible for the data stream veracity and resultant automated responses. Further, social care data, such as delivery (and consumption) of meals, or failure to get out of bed in a morning, may be a valuable input stream.

This creation of a safe space brings new depths of safety and reassurance, but to the subject it may feel threatening or frightening. It also brings new challenges of authentication to protect against abuse, and new forms of subject control to ensure the citizen does not feel loss of autonomy or privacy. Encouragingly, work has been done on setting principles and frameworks for enabling subject-based trust and control of their sensor-created ubiquitous information space [8, 9].

6.3. Professional Support and Proprietary Solutions

A different challenge comes with the advent of an increase in the range of proprietary or retail products. Hitherto most pHealth monitoring has been provided through formal health or housing systems, initiated by the professional service provider. Identification of the pHealth solution is part of the professional service infrastructure. The monitoring of the results is by the professional service, and there are accountability and trust structures. However, there is now an increasing demand for more retail or over-the-counter solutions, and the monitoring agent will not be a professional. Indeed, a family member making a daily Skype call is performing a form of private pHealth monitoring. This scenario is very different in terms of appropriateness of interpretations, and reliability of actions, from professional monitoring – yet totally fits the philosophy of personal and societal responsibility for eHealth.

The right of any citizen, such as a concerned family member, to seek to monitor the health or well-being of another family member is a private situation between two citizens, and whether a pHealth tool is involved does not affect this. This is similar to a person deciding to monitor their own vital signs such as blood pressure, though now two (or more) people are involved and should agree. It is the trust in the equipment, and any inbuilt calculation of normality, deviation, and change, which are crucial

pHealth responsibilities. Medical device regulations and approval, and Health Technology Assessment, must be tailored to this situation.

6.4. Is an App a Phone or a Medical Device?

The explosion of mobile telephone applications software (apps), a number of which now either contain, or are linked to, sensors, which has further changed this situation. Is a mobile phone app a part of a telephone, or a medical device? It would be difficult to think of mobile phones having to seek medical device approval, but equally the public should not be put at risk by apps which would not be approved as stand-alone over the counter devices. Ongoing work at ISO and IEC is addressing those issues. The pace of technology is exciting, but always brings new complications and new potential risks, and balancing benefits availability, risk avoidance, or sensible monitoring, is always difficult – as exemplified by considering whether a hovercraft should comply with aviation, marine, or road traffic regulations as it is domain independent of but impinges on all these domains. And as part of the integration of holistic support for health any device which crosses domains, and / or enables remote carers to be more supportive, should be welcomed.

7. Conclusion – pHealth, Personalization, or Integration

The pHealth community is thus in a strategic position. A current core objective is to harness technology for the benefit of patients, by providing relevant data faster and with reduced inconvenience to normal living. This is seen as an important aspect of personalization, as each person's data is collected in a way and from a location personal to them.

But in this process, it is potentially likely that this may increase fragmentation of care by reinforcing care specialization and thus deepen silos of care provision. But, aware of this problem and with new dimensions of controlled data sharing and of multi-stream predictive algorithms, balanced by user controls, pHealth has the opportunity to be an enabler of integrated holistic care linking health care, social care, housing care, and other supports to personal health.

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