Social Care Informatics –
The Missing Partner in eHealth

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Abstract. To the individual, social care can be an essential part of maintaining health, as is reflected by the WHO definition of health as being one of wellbeing. However, health informatics currently narrowly restricts itself to health organizations' activities. Digital records in social care are increasing, raising the need to recognize the area of social care informatics. This new domain needs support and nurture, whilst the delivery of social and related care needs to be harmonized with healthcare delivery. In turn, this raises important new issues as to how to best support the citizen, especially when they are dependent, including issues of information sharing, service co-ordination, sharing of meaning and objectives, and of respect for autonomy.

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1. Introduction

Health informatics – as information technology to support healthcare – is clearly well-established and increasingly important. However, given that "health" is defined as being a state of physical, mental, and social wellbeing and not merely the absence of disease or infirmity [1], it is important to appreciate that maintaining health involves far more than the services of formal health agencies. Particularly where a person suffers from a long-term or chronic illness, or where aspects of impaired daily living affect health, social care services are needed to complement health agencies in maintaining the health of the individual. Indeed, it is often the case that hospital stay is prolonged because of restrictions or delays in providing social care support at home.

Thus it is illogical, and both disadvantageous for individual citizens and inefficient for services, to consider healthcare as the only service domain to support health. The logical extension to this is that where other agencies are also keeping electronic records or using other automated information processing support such as automated monitoring, then social care informatics must be recognised as a branch of or complement to health informatics as a part of citizen-orientated informatics to support health.

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2. The Differences of Social and Other Care

The first problem is that social care is usually organised and managed separately from healthcare. The nature of the services is very different, and whilst healthcare is increasingly centralised for many reasons, social care is provided in the home or in the nearby locality. In most European countries social care management is the responsibility of municipal authorities; in some others it is provided by the same organisations as provide healthcare – but even in these latter the management and record keeping are largely separate, often not least due to legal regulations. By contrast, in most countries healthcare is provided by specialist health organisations. This means that at the level of the individual citizen, responsibility for organising services for a health condition falls to two legal entities (or in some countries different units of one agency), though the patient seeks and requires a seamless service.

Thus at the citizen level, for a person with a condition such as a stroke, or early dementia, multiple agencies and operational units are involved in support of their health. Personal circumstances affect the patterns of care required for any specific clinical condition, and these include whether the person lives alone, their type of housing, and their mobility. The same applies, for instance, to a child at risk of poor parenting or abuse; or to a teenager with a disabling condition. These multiple agencies are organised quite separately, and the recipients themselves (or their formal and informal carers) have to be proactive in seeking coordination and harmonisation, even though by definition they are already disadvantaged. This is over and above the problems of coordination within agencies, such as between primary and secondary care delivery, or between domestic meals services and assistance with skills of daily living.

These conundrums will steadily increase in the context of the ageing society, and of the survival for increasing years of persons with enduring or chronic illness. But the current focus of health informatics to look solely at health service delivery is to deepen the insularity and fragmentation that is the enemy of person-centred holistic care.

Agencies of Delivery

Adding to this complexity is the fact that social care is often delivered by many independent bodies, ranging from self-employed individuals to large specialist organisations [2]. All will have different forms of ethos, records, management, quality assurance, and reimbursement and thus of activity reporting. This increase in care delivery agencies is also occurring in health, with specialist personalised supplies management such as home oxygen or dialysis services, through to disease management contracts. However, in social care the degree of commonality in information principles and practice which crosses organisation boundaries is far less than in health. Far fewer of the social care workforce are subject to professional registration and practice standards, training levels required are often less, and other initiatives such as national professional vocabularies are less developed than in health.

3. The Differences of Health and Social Care Records

Though it is important to start considering the role of informatics more holistically in supporting health, it also must be recognised that health and social care records are very different, as are the attitudes to sharing information from the record [2, 3].

3.1. Healthcare Records

Healthcare records are deep but narrow [2, 3]. There is a wealth of technical detail on the history of the individual – investigations, physiological and laboratory data, genetic history, diagnoses, prescribing and other treatment plans, creating the depth. However, intentionally there is little information about third parties, creating the narrowness of the record. The healthcare record is very much about the individual, making it difficult to record the impact of an illness or treatment regime on a third party such as a spouse.

3.2. Social Care Records

In contrast, social care records contain information on context as well as conditions [2, 3]. Planning and delivery of social care require an understanding – and thus a recording – of the citizen's personal circumstances, including their interactions with and contributions from the patients themselves, family and neighbours. Equally it is important to note the effects on carers as individuals, hence family and professional commitments, and stresses or potential adverse effects of caring on employment, are an essential part of the record. Some of these facts are highly sensitive and personal. This leads to a challenging subset of confidentiality and sharing issues within social care delivery, balancing the effective delivery for the core client with the need to avoid harm or distress to others. Further, to a greater extent than in healthcare as by definition so much support is in the areas of daily living and social interaction, disclosure of specific facts to or about others actively involved, including informal carers, may be essential for ensuring effective support.

4. The Challenges of Holism, Sharing and Confidentiality

The ideal for all those seeking to maintain the optimum health of the individual must be to coordinate to the highest level the care provided by all agencies and informal supporters. Some of this may be achieved by measures such as avoiding clashing scheduling of activities, whilst other issues may be more sensitive such as understanding the caring capacity a next-of-kin carer. Some issues will be sensitive because of professional and organisational boundaries which cut across commonality of care, such as how much about a health condition the warden of a supported housing scheme should know, or a school teacher of a child. Hitherto the tendency has been to minimise sharing, but then be upset when care is sub-optimal or the citizen suffers harm. So as computerisation comes to these services, not only do they have to address their internal issues of governance, but the new sharing potential raises new issues, requirements and choices. Many other industries such as the travel can provide electronically linked packages of services from autonomous providers, so it seems inappropriate to deny citizens this where their health and well-being are concerned.

5. Current Experience – A Formative Stage

Electronic care records seem to be at an early stage across Europe, though in some countries such as parts of the UK they are increasingly being encouraged. In Finland,

where both health and social care are municipal responsibilities, there is increasing awareness of the new issues with active programmes, but still little information transfer. In the Netherlands, with its strong moves to e-health, e-social care appears to be barely lifting over the horizon. In Sweden a small integrated pilot is underway [4] and national information structures are being designed to support this integration [5].

Thus now appears to be a good moment to act within Europe. On the one hand, European recognition of the future Information Society, and experience with health informatics, coupled with awareness of the ageing society, should provide a fertile and supportive environment. At the same time, social care informatics science is young enough to be amenable to new approaches and structures, not least regarding initiatives and creation of evidence bases recording outcomes, issues, and successes.

6. The Need for Care Informatics Professionalism

If these issues are to be addressed, a shared professionalism, governance and evidence base amongst all those involved in all informatics applications to support health and care in the widest sense needs to be developed.

6.1. Informatics Professionalism

Health informatics has shown the way forward, with the development of health informatics as a distinct profession, with national and international professional bodies, education programmes, and conferences and similar exchanges. Means need to be found of recognising and developing social care informatics as a partner discipline which may in due course become a section of a broader care informatics profession. Whether they remain two linked but separate professions, or two branches of one, only time and debate will determine; this may include professional education in social care informatics, through specialist courses, or modules within widened health informatics courses. EFMI should be an important catalyst in this discussion and development.

6.2. Evidence Generation and Promulgation

The traditional health informatics domain has a number of respected scientific conferences and journals, enabling exchange of views and analyses. Social care informatics has yet to achieve this standing. One modest first step was that the 2008 E-Challenges conference ran a dedicated Social Care Informatics workshop, yielding an initial interest group, and this is set to grow in 2009 with a full session of reviewed scientific papers. The future optimum balance between stand-alone social care scientific fora and journals, and streams within health informatics settings, is an issue.

6.3. End User Education

One area where the ground has been prepared is regarding end-user education on using electronic records and e-working. The 'Health' Module of the European Computer Driving Licence is already framed in terms of "health and social care" [6]. Application in the health domain is steadily growing, and this momentum and experience exist to be drawn upon by the social care domain.

6.4. Standards

The health domain has a history of developing standards, terminologies and coding systems, not just for diseases and pharmaceutical products, but increasingly for presenting problems, procedures, and other processes. European and international standards are being developed and adopted, not least though the work of CEN TC251. Social care has significantly less development of such standard terminologies, and they may be less amenable to adoption between countries, as lifestyle and support issues are likely to be culturally and socially sensitive. However, it is important that issues of social care informatics standards, matched to health parallels, start to be addressed.

6.5. Governance and Legislation

Governance (including confidentiality, security, and the careful control of essential data sharing) may be one area where commonality might be achieved more quickly, and this would be a major reassurance to those seeking greater digital harmonisation between the sectors supporting the care of individuals. Most European countries implementing e-health solutions are developing robust protocols. With the anticipated rise of e-social care similar governance issues must be addressed, including advice to citizens, and maybe common approaches can be developed. For instance, this appears possible in England, with the recent adoption of a Social Care Record Guarantee mirroring its health partner, and a framework developing for a comprehensive governance treatment [3]. Legislation needs to enable coordination of care while still maintaining privacy.

7. Conclusion

As Europe becomes an increasingly ageing society, yet one which seeks to ensure modern consumer-orientated services, the need to recognize social care informatics, and to establish an ethical relationship with healthcare so as to support holistic health, will increase. At present only very modest steps are being taken, with little support for addressing the confidentiality and technical issues of digitization of these services' records and processes. Now is the time to consider the development of social care informatics, and its essential partnership with health informatics, to ensure truly holistic and integrated modern support to citizens' health, and EFMI could well initiate action.

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