Health informatics for older people: a review of ICT facilitated integrated care for older people

Growing demands on welfare services, arising from expanding populations of older people in many countries, has led policy makers to consider the use of information and communications technologies (ICTs) as a means to transform the cost-effective delivery of health and social care. The evidence for these claims is examined by reporting the main findings of a review of worldwide published literature documenting the adoption of health informatics applications to improve health and social care for older people. It focuses around two dimensions of the UK government's programme for 'modernising' public services, which emphasise the use of ICTs to facilitate the sharing of health and social services information and its potential to foster person-centred approaches to independent living. Findings suggest that there is little evidence that these dimensions have been realised in practice and the perceived incompatibility between them is more likely to produce expensive and ineffective health informatics outcomes.

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Introduction

Health and social services for older people are unquestionably an information-intensive business (Grimson, Grimson & Hasselbring, 2000; Levy, Bradley & Swanston, 2002) requiring enormous amounts of data to be collected from a complex variety of medical and welfare institutions (hospitals, clinics, laboratories, surgeries) and social and community agents (housing, voluntary and community groups, social services, carers, community nurses). Not surprisingly, information and communications technologies (ICTs) are often regarded as a means to transform both service information processing as well as 'informing' and empowering the service user. Weiner and his colleagues maintain that 'information technology is the structural component of healthcare most likely to improve the process of healthcare delivery, leading to improved health outcomes and thereby increasing the functional independence of older adults' (Weiner, Callahan, Tierney, Overhage, Mamlin, Dexter & McDonald, 2003: 433). What evidence then currently exists in the research literature for improved professional integration and user-centred health and social care services for older people arising from health informatics? This article reports the findings from a review of internationally published sources to find examples of good practice and any evidence to support the high expectations and confidence in ICTs to effectively address the challenges of health and social care of older people. It is thereby intended to inform the decision-making and research activities of policy-makers, practitioners, managers and academics worldwide.

This literature search arises from research we have undertaken to examine an aspect of the UK's policy intention of adopting new ICTs to reorganise health and social care management and practice for older people through its 'modernisation' programme (Department of Health, 2003). It has consequently been designed to review findings that could have a direct bearing upon the implementation of this policy directive. In most of the UK government's proclamations the modernisation programme proposes a radical change in governance between the interested parties by transforming social relations from a vertically integrated, institutional provider-led hierarchical system to more community-based and user-centred informational health networks (Department of Health, 2006; Loader, 1999). Underlying this ambitious organisational and cultural change, and facilitating its

prospective realisation, is the perceived change-management capabilities of new ICTs. Early policy statements demonstrated the importance to the UK government of ICTs for the delivery of health and social care through electronic service delivery (Department of Health, 2001, 2002). A primary focus for the adoption of health informatics applications for older people was the introduction of the Single Assessment Process (SAP) which was set out in the *National Service Framework for Older People* (Department of Health, 2001) and the *Information Strategy for Older People* (Department of Health, 2002). The infrastructure supporting these initiatives is the National Health Service (NHS) national programme for IT (Department of Health, 2002). More recently, the UK has made a commitment to *Building Telecare in England* (Department of Health, 2005) while the White Paper *Our Health, Our Care, Our Say* (Department of Health, 2006) reinforced the central tenets of the modernisation agenda.

The key issues running through these modernisation documents, as they relate to the health and social care of older people, form what we believe can be seen as an emerging policy vision comprising the following objectives:

- To both acknowledge the importance of older people (aged over 65) as the primary users of health and social services in the UK and to recognise that existing health and social services are fragmented, inefficient and potentially may be unable to cope with the rising demands of this population group.
- To provide integrated services whereby health and social service professionals and organisations share user information.
- To enable the independent care of older people, whenever possible within their own homes and communities.
- To provide a positive view of old age and include the service user and their carers in their assessment, diagnosis and care programmes.
- To share appropriate and easy-to-use information with older people and (where applicable) their carers through a variety of communication means.

Two clear dimensions to the modernisation process can be discerned from these objectives, both of which represent significant loci for contestations between professional boundaries and discourses of empowerment. The first is focused around the concerns of 'joined-up' government whereby greater efficiency is achieved through improved integration between health and social care service providers and professionals. ICTs are seen in this context to have the potential to develop electronic networks enabling communication and information sharing across organisations and professional boundaries. They also provide the possibility for linking back-office administrative functions with front-line staff and street-level bureaucrats. This supply-side application of electronic service delivery addresses the first two modernisation objectives outlined above.

The second dimension arises from the even more ambitious directive underlying these objectives, which is a commitment to make health and social services person-centred. The vision here is for a lifelong digital health record for every citizen. Such a model in its ideal form places the older person at the centre of a communications network dedicated to the assessment, planning and delivery of health and social care arrangements. *The National Service Framework for Older People* (Department of Health, 2001) stated that 'older people and their carers should receive person-centred care and services which respect them as individuals and which are arranged around their needs' (Department of Health 2002: Chapter 2). This would be achieved at the outset through the implementation of the SAP alongside the adoption of the *Information Strategy for Older People* which was 'intended to provide the information infrastructure, systems and services required to deliver these programmes' (Department of Health, 2002: ii). The role of ICTs is clearly also important for the realisation of this user-centred policy directive. A variety of networked applications could both improve 'the delivery of clinical and educational services' (Norris, 2001: 80) and also 'promote and enable independent care in the community and home setting' (Emery, Hayes & Cowan, 2002: 29). However, attempts to establish a system of non-clinical shared information have largely failed to achieve their aims and have recently given rise to a joint venture under the National Shared Business Service.

A range of hardware and software resources have been seen as suitable for employment in realising electronic service delivery including: electronic patient records designed to enable the sharing of information between practitioners and agencies; the use of interactive TV, internet websites and help-lines to enable users to access information; electronic networks to provide easier on-line appointments booking; electronic messaging for reminders; the adoption of mobile technologies; and remote consultations and assessments through video conferencing. The potential resources that may be used reflect both the complexity of user-centred integrated service delivery and the diversity of 'solutions' that have been used both in the UK and globally.

Search strategy

The literature search was designed to provide a comprehensive listing of primary research findings from studies which focused upon ICTs and the health and social care of older people. Literature specifically devoted to ICTs and the implementation of the SAP for integrated and user-centred healthcare for older people was unsurprisingly limited. Consequently, it was decided to include dimensions of care as they were seen to

relate to the modernising of adult social care objectives. This required a diverse search and covered a number of different subject disciplines including clinical evaluations, social science disciplines and computer sciences. One of the significant consequences of this multidisciplinarity was the difficulty it posed for robust comparisons of findings between different disciplines. Contrasting methodologies from different disciplinary perspectives were also reported as a significant feature of many of the multidisciplinary research projects reviewed.

A growing demand for health informatics?

The anticipated rising pressures upon contemporary health systems provide the backdrop against which the modernisation agenda and the role of health informatics initiatives for older people should be understood (Newman, 2001; Wistow, 2001). These include socioeconomic trends such as the growing population of older people, the fragmented nature of services which are uncoordinated and the rising costs of healthcare. Described by Alan Walker as a 'demography of despair' (1999), many of the articles discussed in our own present article open their accounts by referring to the likely increasing demands upon health and social services by older people (especially the over-80s) as a consequence of increasing chronic and long-standing illnesses. Together with other wider environmental factors these developments are regarded as the death knell for the traditional bureaucratic modes of service delivery which characterised the British NHS and European Welfare States. Consequently perhaps, the most significant reason, identified in the search, for looking to health informatics for the modernisation of health and social care for older people is the prospect it offers of providing cost-efficient services. Such an approach has in part been supported by the use of ICTs in the private service sector where impressive increases in productivity have been achieved by transferring 'transaction costs' to the service user (Loader, 1998).

It must be remembered, however, that the rhetoric of modernisation is not solely characterised by the 'managerial' discourse of cost efficiency. A strong appeal is also made to the social inclusion and empowerment of older people by making services person-centred. This might be seen as a significant response to a consistent argument in social gerontology (Phillipson, 1982; Townsend 1981; Walker, 1982), that dependency in old age is 'socially constructed' by labour market and welfare state institutions. According to this perspective, welfare professionals and staff can facilitate dependency in older people by how they undertake assessments of need and deliver services. 'They can', argues Walker, 'play a large part in determining whether older people are either dependent or independent adults, whether they are empowered or powerless' (Walker, 1999: 159–160).

What becomes clear from the policy literature is that the role of health informatics or telecare is not only to address both dimensions of the modernisation process identified above, but to do so in conditions which assume that they are mutually achievable. That is to say, ICTs cannot only provide integrated joined-up services, they can also empower the older person vis-à-vis service providers. A view which believes not only that traditionally impervious organisational and professional barriers can be breached, but also that a high degree of shared access to health records and joint decision-making by professionals, carers and users alike can be achieved with the help of ICTs. In contrast to this policy rhetoric, however, what clearly emerges from the research literature is the question whether these two dimensions are indeed compatible (Klecun-Dabrowska & Cornford, 2000); in particular, whether the managerial discourses of efficiency and effectiveness which address the financial demands upon welfare services may come to 'exert a dominant influence on developments in telehealth' (Klecun-Dabrowska & Cornford, 2000: 59). The compatibility of these two dimensions is explored through the literature on health informatics for older people, beginning first with findings reporting upon the electronic integration of care services and followed by evidence for the use of informatics to empower users.

The electronic integration dimension

The advocacy of 'joined-up' government and 'integration' as components of the modernisation agenda foreground the well documented compartmentalisation of service provision and the use of health informatics as a means to foster an integrated user-centred approach. Hardey, Payne, Hawker and Kerr (2001), in an earlier review of information sharing between care services for older people, highlight the existence of professional territories which often prevent the integration of services between health and social service professionals and organisations (Payne, Kerr, Hawker, Hardey & Powell, 2002). A number of other articles point to the challenges of achieving integration across institutional and professional boundaries (Brown, Tucker & Domokos, 2003; Cameron & Lart, 2003; Dowling, Powell & Glendenning, 2004; Glendenning, 2003; Lloyd, 2000). Penetrating such boundaries is central to the introduction of the SAP, which requires professionals to contribute to one care assessment and share the information collected (with informed consent) as effectively as possible. How can health informatics applications help to tackle some of these barriers?

Typically within the health informatics literature the model of effective health and social care integration focuses upon the electronic management of clinical information (Levy et al., 2002; Nicholson, Jackson, Tweeddale & Holliday, 2003). Levy, for example quotes Coiera to describe healthcare informatics as '[T]he

rational study of the way we think about patients, and the way that treatments are defined, selected and evolved. It is the study of how medical knowledge is created, shaped, shared and applied' (2002: 90). This rationalistic understanding is compatible with an informations systems (IS) approach which outlines a clear sequential process underlying a health informatics model. First, the health problem is identified (providing data); second, the problem is classified (creating information); this further enables an understanding of the impact of the problems upon the individual (therefore gaining knowledge); the problem is then resolved or ameliorated to the patient's satisfaction; and this health informatics process is undertaken within the context of medical capabilities and the socio-economic resources available.

A number of articles point to examples of informatics-enhanced clinical encounters that raise the prospect of improved patient care through electronic integration. In the USA, for example, Weiner et al. (2003: 430) describe the Regenstrief medical record system (RMRS) 'as one of the oldest, largest and most comprehensive computerized medical record systems in the world'. RMRS continues to grow in scope and has been robustly evaluated for a number of its capabilities. Aside from providing an informed data profile of the individual patient, the RMRS can also assist timely clinical decision-making by 'pushing' information to 'providers who do not know that they do not know' (Weiner et al., 2003: 430). Trials have demonstrated that these automatic reminders can be very effective in managing long-term complex and multiple conditions. For example, physicians who received reminders were found to order influenza vaccine for twice as many of their patients, who in turn were less likely to either be hospitalised or visit emergency departments. Further benefits have been identified following computer-generated reports and patient summaries for clinical decision-making. Whilst the RMRS has provided some impressive indicators of the potential benefits of a clinical electronic healthcare system, it does not yet provide evidence of a comprehensive community-based information system that might include GP clinics, hospital rehabilitation, home and a wide range of social care settings used by older people. Thus, Weiner and his colleagues maintain that whilst 'information technology can help clinicians meet the challenges of complexity of care for older adults, . . . moving this science forward will require the development of gero-informatics units that include a cadre of geriatricians working with primary care physicians, informatics specialists, and health services researchers' (Weiner et al., 2003: 433).

Despite the significant amount of time clinicians spend finding, storing and using information and the increasingly central role played by computers in this process, there is little evidence for a more general awareness of the value of ICTs in health consultation.

Levy and associates suggest that this may be a consequence of clinicians feeling that 'they have been excluded from the design stages of a system that is supposed to address their clinical information needs' (Levy et al., 2002: 90). More typically, information continues to be distributed across many isolated sources that are not integrated in a common format such as paper records belonging to different organisations, journals and books.

Although frequently advocated, the actual existence of electronic records systems that traversed health, social, community and domestic territories was difficult to detect. In a well received book by Christopher Foote and Christine Stanners, the authors made a specific argument for introducing a 'systems approach' to integrating care for older people. Documenting a UK project, they outline the challenges of sharing information across agencies: 'The sharing of information was seen as an enormous threat by virtually all the professionals involved. The implication was that if somebody else had the information they could undertake that particular role and the original owner of the information would be redundant to the system' (Foote & Stanners, 2002: 177). Moreover, the institutional barriers 'centred on the accountability that each professional had to their own parent organisation, enshrined in their contracts'. Whilst documenting some very effective outcomes of a multidisciplinary health and social care approach to older people, it is perhaps most revealing that Foote and Stanners conclude their chapter on information systems by acknowledging defeat in gaining agreement for the introduction of an electronic information system.

Mouratidis, Manson and Philp (2003: 149), in an exploratory article, focus specifically on the prospects for an integrated health and social care information system to deliver the SAP. They begin their analysis by acknowledging that 'most of the current information systems do not adequately provide the functionality that is required by health and social care professionals'. In the UK a number of software companies (liquidlogic, EASY-Care) are already using web technology and databases to develop systems for delivering the SAP. Mouratidis and colleagues (2003), however, suggest an alternative approach through the adoption of agent technology which they argue could be a more effective means of facilitating information sharing between professionals. Its potential advantage is as a software programme that exhibits intelligence, autonomy and mobility which enable the agent to aid assessment by performing tasks without the intervention of the human professional. At this point in time, however, the adoption of agent technology is still at the early stages of development.

Whilst the majority of articles are positive about the potential of clinical information systems, some point out the limitations of ICTs for the patient consultation. For example, Postle (2002) found that IT-forms often

constrained professionals in their assessments. She argues that assessments are reduced to a linear 'tick box' process, rejecting any idea of exchange of information and knowledge between professionals and limiting opportunities to share information between the client and the worker. Postle (2002) argues that such a procedural model locates information and expertise with the professional. The findings from the research demonstrated the tensions between completing paperwork and doing direct work with service users and their carers and networks. Marc Berg and Pieter Toussaint (2003) want to question the whole directive of electronic health information systems. They suggest that the drivers for integration identified above lead to the development of process-orientated electronic records which are predicated upon:

> an overly positivist, atomistic conception of knowledge . . . In professional work contexts, 'knowledge' and 'information' should rather be conceptualised as highly dynamic and context-dependent entities; as 'flow' rather than 'stock', and as 'tacit' and 'embodied' rather than 'explicit' and instantly codifiable (Berg & Toussaint, 2003: 228).

This work again points to the manner in which electronic assessments and records can be encoded by the discourse of efficiency rather than the situated and interactive nature of user-centred empowerment.

The user-centred dimension

The use of health informatics to provide a user-centred service for older people and carers is focused primarily on using ICTs to provide support for older people living in the community. It is thus related to implementing the second dimension of the policy vision set out above and needs also to be considered within the dual context of being intended to both provide greater independence and address the rising costs of residential and hospital care. Increasingly, such applications are termed telecare. Emery and associates define telecare as 'the application of information and communication technology to promote and enable independent care in the community and home setting' (Emery et al., 2002: 29). As Barlow observes, a distinction can be made between telecare systems that are designed for risk management and those primarily designed for assessment and information sharing. Typically, the former focus upon sensors used to take measurements for an individual's body or surrounding environment and are associated with adaptive technologies and social alarm systems (Barlow, Bayer & Curry, 2005: 443; Fisk, 2003). Our concern here is with the latter form of telecare, associated with assessment and information sharing.

Despite the UK government's aspirations that telecare is vital to unlocking 'a future where [older

people] have greater control over their own lives including being able to manage their own risks' (Department of Health, 2005: 3), it is perhaps surprising to learn, as Barlow et al. (2005: 442) observe, that '. . . there is almost no research on the processes underlying the introduction of telecare'. The literature, where it exists, is characterised by relatively small-scale pilot telecare projects. In addition to the challenges presented by the integration of clinical and other information discussed above, a user-centred approach to telecare is also affected by the extent of adoption and use of new ICTs by older people and their carers.

In the UK, studies by Neil Selwyn and associates (2003) and the Oxford Internet Institute (Dutton, di Gennaro & Millwood Hargrave, 2005) have maintained that age is an important determinant of people's use of ICTs. Only a small minority of older people use computers and those that do tend to use them for basic activities. Thus, as Selwyn, Gorard, Furlong and Madden (2003: 576) remark, 'the stereotypical notion of the silver surfer using the internet for banking and finances, shopping and dealings with government agencies was not evinced'. However, the low take-up of internet access among older people cannot simply be seen as a resistance to new technologies on their part since the adoption of mobile telephony, for example, is much more widespread. Instead, the most commonly cited suggestion for non-use of ICTs is the perceived irrelevance of computers to the lived experience of older people (Loader & Keeble, 2004; Selwyn et al., 2003: 577). Richardson, Weaver and Zorn (2005: 240) also point to the 'very wide gap between the New Zealand Government's understanding and promotion of the benefits of computer use and older computer users' perceptions of its benefits'. Telecare can comprise an assortment of different electronic channels, but how they are perceived by older people may have a significant impact upon their potential to enable user-centred assessment and independence. If the increased adoption of ICTs by older people (as an essential component of telecare) is to be achieved, the literature suggests that users need to be directly involved in the design and development of telecare applications.

Where computers are used by older people for electronic communication, they are to be found primarily in the home and, in contrast to the e-commerce and e-government rhetoric, appear to be valued more for 'social, emotional and information benefits to individuals and communities' (Richardson et al., 2005: 240). Whilst it seems reasonable to assume that the number of newly retired 'younger' older people who are more familiar with the commercial search capabilities of the internet will increase during the next few years, the need to match older people's experiential needs with the design of ICTs is likely to remain an important issue. The UK government alludes to this in its acknowledgement of

the need to 'create the best possible atmosphere for the new telecare industry to flourish' (Department of Health, 2005: 6), but as Selwyn and associates (2003: 578) point out, 'the practical barrier to the development of ICT-based services tailored to the needs and interests of older adults is that few, if any, companies would be willing to provide them until a ready online consumer base exists'.

A major EU-funded study that adopted a user-centred approach to developing telecare applications to provide information, education, increased communication and support for family carers was the Assisting Carers using Telematics Interventions to meet Older persons Needs (ACTION) project. As the somewhat contrived title suggests, the projects were not focused directly on the users, but rather on the support for their carers. It comprised a number of European partners and was completed in 2000. A number of technologies including video conferencing, interactive communication and web-base systems were developed and evaluated. The findings themselves were typically favourable. Chambers and Connor (2002), for example, examined the potential of the system to provide carers with advice, information and psychological support to increase their coping capacity. They found that 'family carers felt the software provided reassurance and emotional support, and enabled them to assess their own coping capacity, and provided useful information regarding how to enhance their coping skills'.

The importance of usability and software tailored to the specific needs of the end user were highlighted by Emery and associates (2001, 2002) who focused upon the importance of the user interface for effective take-up of the technology by older people and carers. Barlow also argues that 'inadequate understanding of user needs has been shown to be a major barrier in the implementation of smart homes technologies' (2005). Levy et al. (2002) suggest that a 'technology prescription' could be introduced as an aspect of the assessment process to foster a needs-led diffusion of ICTs.

Following the ACTION project, Emery et al. developed a web-based system called CarePlus. This project demonstrated that the 'perceived barriers to electronic information delivery are overcome when users access a comprehensive collection of local, relevant and up-to-date information' (2003: 131). To ensure that information was relevant and reflected local service provision, the research team invited older people and their carers to be involved in the collection process: 'As a result local people were consulted as much as possible in the whole process of setting up and delivering CarePlus' (Emery et al., 2003). Such projects, whilst highlighting important issues around implementing user-centred telecare, tend to provide examples of the potential rather than the realised benefits of adoption of ICTs for the health and social care of older people.

Typically, they do not appear to continue beyond the life of the project and there is little or no evidence for any of them becoming mainstreamed into service delivery.

Discussion

The perceived potential of health informatics to facilitate a person-centred approach to health and social care for older people by enabling integrated service provision across organisational and professional boundaries has arguably made a very compelling zeitgeist for policy-makers. If ICTs can be designed to enable more 'joined-up' service provision tailored to the needs of the patient to enable longer independent living, then surely this can go some way to both lessening demands upon expensive healthcare and achieve greater empowerment. Yet, as is manifest in the literature, these two drivers for policy change may not in fact be as compatible as desired. Instead, policy white papers which appeal to both objectives may only be disguising a significant cleavage between two competing models of health and social care. The first is a perspective that emphasises the patient as consumer and is consistent with the tenets of public managerialism, whereby improvements to service delivery are produced by managing performance, targeting quality improvements and enabling easier access to responsive and flexible services. The second, contrasting approach is more associated with the notion of users as citizens, which foregrounds the objective of greater integration between multi-agency service providers from different sectors working in partnership with citizens, primarily at the community level.

Whilst these two approaches may be blurred at the boundaries and do not represent polar opposites, they have significantly influenced debates about the adoption of ICTs as a means to improve health and social care for older people. Electronic service delivery, drawing as it does upon the business sector, would appear to be consistent with the consumer model of public service provision, but may not be of such value to efforts to empower older citizens within their community. A related aspect to this debate is that many of the applications identified in the review focused upon clinicians sharing information for decision-making processes around diagnosis or treatment, but there was far less reference to the potential of technology to help service-users to make decisions or be involved in the process. This would favour the bio-medical model of service delivery which has been well-documented in the medical sociology literature and which points to the user as a subject and passive recipient of healthcare planning. Thus, as Barlow remarks:

> Telemedicine is inherently easier to implement than telecare because it focusses on a single condition (e.g. teledermatology, telepsychiatry) and involves

simpler interactions with fewer stakeholders. Telecare, in contrast, involves services targeted at individuals with a wide variety of conditions and brings together a number of different stakeholders across the care and housing systems (Barlow et al., 2005: 446).

The marginalisation of older people in the design and implementation of technologies intended to provide user-centred support, services or to enhance abilities means that the specific needs of users are likely to be 'added on' rather than integral to the system. The danger here is that ICTs will be 'adapted' to meet perceived usability requirements when there may be better opportunities to develop dedicated systems designed around user needs.

The aspiration of ICTs to reconcile these competing models of care also foregrounds the importance of recognising that ICTs are designed and diffused within a particular social context that can either stimulate its adoption or make it redundant. The fastest broadband network connection will be of little use if health and social care professionals are not prepared to share information with each other, let alone allow access to older people wishing to participate in decisions about their care. Similarly, the most accessible website will be seldom used by older people if its information content is not perceived as relevant to the life experiences of the user. Thus, while ICTs may be regarded as important tools for enabling the 'modernisation' objectives to be achieved, their effectiveness is crucially shaped by the outcome of debates about those objectives themselves.

ICTs cannot be viewed as a means to reconcile such policy contradictions. Such confused rhetoric is only likely to produce expensive and ineffective health informatics outcomes. The contradictions will merely be encoded into the system. Despite the repeated policy claims for health informatics to facilitate integrated person-centred health and social care, there is little evidence in the literature review considered here that it has been realised.

Acknowledgement

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