Switched on to Telecare: Providing Health and Care Support through Home-based Telecare Monitoring in the UK and the US,

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Background

This report is a collection of the papers presented at the World Multi-Conference on Systematics, Cybernetics and Informatics, chaired by Jeremy Porteus, National Lead, Housing and Telecare Networks, Care Services Improvement Partnership, Department of Health, London, UK.

1. Overview of all Presentations

Five presentations were given at this session on telecare, and included these titles:

1. “Switched on to Telecare: Increasing Independence and Dignity for Older People,” presented by Jeremy Porteus, Housing and Telecare Network Lead, Care Services Improvement Partnership, Department of Health, London, UK
2. “The Experience of Kent County Council: Telecare as a Preventative Tool, and a Catalyst for Service Integration,” presented by Clare Skidmore, Telecare Project Manager, Kent County Council, UK
3. “Two Telecare Examples from the UK: Lifestyle Reassurance and Chronic Heart Failure,” presented by Simon Brownsell, Research Fellow, Barnsley Hospital Foundation Trust, UK
4. “Comparisons Between the UK and US Home Telecare Delivery Modes to the Elderly,” presented by Audrey Kinsella, Director, Information For Tomorrow Home Telehealthcare Planning Services, Asheville, North Carolina, USA

Four of the five papers focused on issues of home telecare delivery in the UK and the need for targeting services appropriately for the elderly living at home. A fifth paper, by Kinsella, noted the significant differences between the UK and US systems of delivering home care to the elderly.

All papers underscored needs of the elderly for receiving regular and targeted care and support. They are summarized as follows:

- Jeremy Porteus provided an overview of the national policy objectives for telecare planning in England, indicating that telecare was expected to be in all homes that need it by the year 2010. Starting in April 2006, the Department of Health in England has invested 80 million pounds over two years to assist in the implementation of telecare to the elderly, who are the key target of telecare planning and implementation. With telecare tools and systems, these people will be assisted in living independently. The funding is provided in two tranches to 150 local social care authorities and their partners in health and housing services.

To provide a background on the impetus of this planning objective, Porteus noted that studies in England have found that about a quarter of a million elderly people who live in nursing care homes could be supported to live at home or in extra care housing schemes through the use of telecare and other support services. This finding has in fact resulted in significant service redesign in local health and social care economies, coupled with the Department of Health’s funding of 52 extra care housing schemes.
• Clare Skidmore provided details on the focused use of telecare and telehealth in Kent, England, for delivering home-based preventative rather than reactive, crisis-driven services to adults. Noting that Kent’s population of 1.3 million people has a rapidly growing elderly population (65 years plus), the projected problem of very minimal growth of working age populations (ages 16-64 years) to support this elderly population warrants particular attention by Kent County Council. Other challenges of serving older people in Kent were noted, including its large population of people with learning disabilities and of people living with long-term conditions (e.g. heart and respiratory conditions, diabetes). The challenges of taking a preventative approach to caring were noted, such as making it inclusive and addressing issues like quality of life, independence, and control. An important goal of this county council is to move forward in its role as a community leader, so as to enable its residents to reap the benefits of telecare services to support independence, well being, and quality of life, and to facilitate the increased integration and personalization of all health, social, and housing services.

• Audrey Kinsella described the current system in the US of providing home healthcare and telehealthcare to the elderly under the federally funded Medicare Home Health Care benefit. This benefit is routinely made available for a 60-day period to Americans over age 65, and has been in place for four decades as a socialized form of health care in the US. However, apart from its short-term provision of care, other factors limit its availability for elderly people living with long-term conditions. For instance, a prerequisite for receiving this benefit is having a hospital stay related to the primary diagnosis (such as diabetes or heart disease) before being admitted to home care services. It was also noted that there is no payment for telehealthcare equipment or services to home health agencies that use telehealth to help elderly people self manage and avoid subsequent hospitalizations.

Many similarities between elder care in the US and the UK were noted—both countries’ elder populations are booming, and a large segment lives with multiple chronic diseases and conditions over their lifetimes. Differences between the two countries’ care of the elderly were also noted. For instance, no telecare services and social network systems are available in the US as they are in the UK. Another difference is that telehealthcare delivery in the US is only now becoming more common (though it has hardly been introduced in the UK to date) and it is mainly limited to enabling patients’ physiological monitoring of vital signs for the 60-day period that they are admitted to home healthcare services. Details on further types of education-oriented contact with patients that could be useful in patient self-management programs developed for this purpose in the US and in the UK were provided, and are detailed in the Key Lessons segment, below.

• Simon Brownsell reported on his group’s research work at Barnsley Hospital on defining where telecare service delivery can provide the greatest returns for the elderly, and noted that two of the most important areas are telecare service in the forms of lifestyle reassurance and in chronic disease management. Findings at interim periods of these studies have so far noted that people equipped with telecare services feel safer at home, have improved social functioning and have maintained or improved their ability to stay living at home. Details on these studies are provided in the Practice Development segment, below.

• Paul Gee described the immediate market priorities for serving elderly people living at home in the UK using telecare and he identified some likely future developments within the telecare field. The immediate focus ought to be to address the remarkably large and rapid growth of the elderly population in the UK
(which will increase 47% in the next 20 years, to number 11.6 million people by 2026). In addition to the 80 million pounds in England, planned demonstration projects in England are aimed at robustly evaluating telecare for a resident population of one million people over three sites to establish how assistive technology and service design:

- promotes long-term independence
- improves individuals' and carers' quality of life
- improves working life of staff
- is more cost effective
- is more clinically effective and
- provides an evidence base for future care and business models

Details on Gee’s views on means to develop and meet these needs for telecare are provided in the Practice Development and the Futurescope segments below.

2. Policy Drivers in the UK and the US

The significantly growing population of people over age 65 is a key factor driving national health and social policies in the UK and, to a much lesser extent, in the US (though its elderly population is growing just as considerably). In the UK, for instance, there is a projected 47% increase in this group to 11.6 million by the year 2026. Similar numbers are noted in the US. In both countries, the majority of aging people say that they want to stay in their own homes, and in the UK, some policies are already addressing this stated preference.

An important step in new policy development for the elderly in the UK is to help people who live at home be supported there, through telecare and other support services. The Department of Health’s recent White Paper, Our Health, our care, our say: a new direction for community services (2006) provides a new focus in providing care to the elderly in their own homes has resulted in a significant redesign in local health and social care economies, and the development of innovative extra care housing schemes for older people. Expectations of success of these first steps are high: Through a combination of policy initiatives there will be closer integration of primary and social care, and expected improvement in long condition management including a reduction in 1.6 million emergency hospital admissions by people over age 65, as well as significant reductions of falls at home.

As Gee noted, telecare can help the government and elderly people who live at home to achieve these expectation but what is needed is to turn this promise (of helping people to stay at home assisted by telecare) into a reality. Currently, the Government in England is trying to build a knowledge base about telecare delivery to the elderly. This focus on telecare is intended to provide the elderly with a new dimension of care outside of hospital and into the home, as well as offer preventative care and an early warning dimension to enable older and disabled people to live at home independently and with dignity. The Preventative Technology Grant (£80m GBP), an allocation to 150 local authority social care authorities with their partners, is focused on financially supporting local initiatives.

In the US, there are no or very few policies that are focused on assisting elderly people to age in place safely. A current move toward helping the elderly return to their homes from nursing homes and other residential settings is represented by
several federal initiatives. These include the “Money Follows the Person” rebalancing initiative that is part of the Federal Deficit Reduction Act of 2005 as well as part of the New Freedom Initiative (2001). However, there are not yet a focused means in place of ensuring that care is delivered as needed. Creations of social networks of care that are becoming typical in the UK are nonexistent in the US, and frail and sometimes needy elders may very well be on their own.

3. Research in Practice

The UK Setting
According to Paul Gee, today’s UK telecare research landscape can best be summarized as a series of pilot programs. Most do not have clear objectives or are large enough and as such, the evidence base is not robust. He noted that a business case for telecare will continue to be elusive because it is based on determining and calculating cost savings. He notes, however, that cost savings will not really be noted if in fact telecare is “successful” and care needs are prevented and care services are not actually used. (There will be no costs to count.)

The US Setting
A similar research focus in the US was noted by Kinsella—one in which scores of demonstration projects have focused on cost savings by establishing that use of telehealthcare can reduce costly hospitalizations by patients receiving telehealthcare services at home. Indeed, an enormous number of published literature with case studies of home telehealth use indicates the success of the aim of avoided/reduced hospitalizations. However, few such studies note the short-term view of the typical home healthcare admission period in the US—which is 60 days or less. In all, as documented by these studies, significant numbers of hospitalizations have been avoided during this period of time. Nonetheless, there is no evidence of the longer term effectiveness of home telehealth use for avoiding/reducing hospitalizations after Day 61 for the discharged home care patient.

The home of the average patient setting
‘Who benefits most from telecare at home?’ is a question Simon Brownsell and his research team addressed in their studies of prioritizing users' needs. The group identified 102 factors that affected day-to-day care needs of elders living at home (such as fear of falling or problems managing pressures sores) and followed through with focus groups to define how telecare applications such as lifestyle reassurance and chronic disease management could return the greatest reward for older people. Particular applications of practices are described in the Practice Development segment below.

4. Practice Development

Does telecare and/or telehealthcare work? Some very positive results have been reported. For example, Brownsell’s research group provided unobtrusive lifestyle reassurance sensors to a test group of elders whose houses were wired for an in-home telecare project. Interim results indicated that people in this test group felt safer at home, had an improved degree of social functioning, and had a maintained or improved ability to stay living at home.
In addition, Brownsell presented results of telehealthcare use for chronic disease patient management, with a focus on congestive heart failure (CHF) patients, which used a telehealthcare system with handheld devices to track patients. Findings included avoided emergency care needs as a result of more regular tracking/monitoring of patients and providing earlier interventions. Some benefits of this tracking for the patient may well be prevention of crisis situations and hospitalizations—among these, dehydration and other health incidents. The tracking and interventions were accomplished for these research studies in a very notably short period—on average, the time taken by clinicians to review the telehealthcare data was less than one minute per patient per day. Telecare and telehealth interventions are clearly working in these examples.

Are the telecare/telehealth devices easy to use and correctly targeted for an elderly population? These concerns have long been stated by clinicians and planners and addressed by many developers so that most are simple to operate. However, according to Paul Gee, an even more pressing concern ought to be the need for developing mechanisms that enable interoperability between the range of telecare equipment from different suppliers that is now or will be typically used. A current movement toward this end among telecare equipment manufacturers is occurring, but the end result of a ‘plug and play’ environment is not expected to be reached soon. Attaining this result must be a longer-term goal for telecare and telehealthcare.

Additional factors that prevent targeted and effective telecare use were indicated by Gee. Among these is the need to better understand and use the “R2R” (or referral to response) model of telecare—that is, the technology enables the referral (and provides a response framework to identify and manage the risks). More attention must be paid to the service response—telecare is 90% service after all, only 10% technology. Most planners think that the opposite is true, and that the technology plays the most key role in this developing field of telecare. However, telecare is a service, and the R2R model helps to put this logic into perspective—the technology enables the referral and the referral itself, in which a human communicates with the person in need, provides a framework in which to identify and manage the risks or the caller and his/her needs.

5. Key Lessons

Much attention in the telecare/telehealth field today is focused on development and reportage of pilot or demonstration projects to build the evidence that the use of the technology works, saves money, and reduces the need for institutional care. Some of these projects are extremely broad and long term.

In the United States, more than 30,000 elderly people living with chronic diseases are being tracked through a Medicare-funded 3-year study of, in part, benefits/value of daily telehealth monitoring. It has been suggested that findings from this study may influence the development of a much-needed long-term payment plan for elderly people in the U.S. who live with one or more chronic disease and condition.

In the UK, the Department of Health have recently announced three whole-system assistive technology demonstrator sites to further test the effectiveness of the application and functionality of assistive technology. In particular, to enable people with long-term or more complex health and social care needs maintain their independence and well-being and demonstrate the ability of local health and social care economies to shift hospital care closer to home. In particular, the demonstrators sites will include:
• a strong emphasis on patient education and empowerment, so that people are fully informed about their condition and are better able to manage it;
• comprehensive and integrated packages of personalised health and social care services, including systematic chronic disease management programmes; joint health and social care teams, with dedicated case management through a single expert case manager, 24/7 service contact and an information system that supports a shared health and social care record;
• good local community health and care facilities, offering a better environment for the care of people with complex needs, and greater involvement of specialist nurses in care;
• health and social care commissioners with the right incentives to deliver better care for those with complex needs, mandatory risk stratification so that they can identify those most at risk, and accountability for their performance in improving the lives of those with complex needs;
• intensive use of assistive and home monitoring technologies.

The data from both of these studies in the England and the US will enable both countries to make informed decisions on the further development and deployment of telecare/telehealthcare projects/policies. However, as many researchers have pointed out, protocols for telehealth use or interpretation in both countries are still emerging. As more interest develops and more funding is targeted to telecare and telehealthcare service delivery, we must, as Porteus notes for development in England, begin a “national evaluation of services”. In addition, the recent introduction of the NHS Purchasing and Supplies Agency national procurement scheme in the UK is beginning to streamline community alarm, telecare, telehealthcare equipment selection and purchase (http://www.pasa.nhs.uk/PASAWeb/Productsandservices/Telecare/Telecarenationalframeworkagreementreview.htm).

It is clear that neither telecare nor telehealthcare service planning or delivery happen productively in isolation. The telecare system as widely practiced in the UK, largely driven by local government and voluntary organizations, is all but unknown in the US. Smoke detectors, one piece of the UK’s home telecare system, are widely available in the US but none connect to a social network which delivers information and support to elderly residents. The US would do well to learn from and follow this social-networked system of care for the elderly at home as used in the UK.

On the other hand, the US model of home telehealthcare is not used in the same way and is therefore relatively unknown (at the time of this conference) in the UK. Small pockets of pilot studies have been undertaken in the UK, with the view by researchers that the US is decidedly well developed in telehealthcare use and success and therefore they are following the lead of the published case studies of successful results of telehealthcare use. However, everyone (worldwide) needs to look at the limitations of the “success stories” that appear in published studies of telehealthcare use in the US. They need to recognize that the successful results are short term (most following patients for an average of 60 days only) and the providers are typically not reimbursed for using the technology. At this stage, every country which is interested in telehealthcare needs to decide whether or not to emulate the US model of home telehealthcare delivery or develop a whole-system approach where telecare/telehealth is placed within a context of existing health, housing and social care.
Other uses of telehealthcare service delivery also need to be explored. As Kinsella notes, more focus needs to be placed on educating elderly patients in self management routines during the 23+ hours of the day when they are not collecting and transmitting their vital sign data. Resources to assist in menu planning for persons living with chronic disease such as diabetes and congestive heart failure are becoming very widely available and affordable. In England, there is the Expert Patient Programme for empowering people to monitor their conditions.

There is also a need to look at additional educational opportunities to help elderly patients learn how to take care of themselves and in effect provide preventative care through telephone reminders, targeted web sites/pages, multicultural/multilingual menu planning tools, and a range of other telecommunications-ready resources.

6. Futurescope and Areas of Further Work – based on this conference...

Much work needs to be accomplished before telecare and telehealth is really “ready” and working for the general populace in the UK and the US. Progress needs to be made with equipment connectivity and interoperability coupled with effective design to deal with alerts. Paul Gee, for instance, noted that there is scope for improvements to be made in the useability, ergonomic and external design features to improve uptake by users. The devices are only effective if they are worn and useable— currently, he said, alarm pendants, for example, are a badge of infirmity for some elders who need to wear them. There is a need for development of more discreet wearables that are embedded into fabrics and everyday clothes, even implanted under the skin.

Another deficit Gee noted was this: Some social alarm networks really are not good enough for ensuring optimal care. Many respondents act like a good and caring neighbor; however, as telecare moves into the mainstream, clear standards of response and transparent measurements of performance must be embedded in the service offering. Response should not be hit or miss nor untracked. In a related issue of consistent tracking of patients, he suggested that we use a development model based on the pervasive use of cell phones among teenagers to get at an ‘always-there, always turned on’ device or mechanism to supply to all UK citizens. This mechanism would be equipped with a healthcare package that has a phone-like device that stores associated medical history and records that travel with the phone owner (who may have more than one home and/or may travel frequently).

In the US, as in the UK, much needs to be done to accommodate the burgeoning numbers of elder people needing care whose numbers are growing as the numbers of professional caregivers are shrinking. Telehealthcare will become a ‘need to have’ rather than a ‘nice to have’, according to Kinsella. The need for customized and targeted devices to assist elder persons in future is clear, and there is not now and probably won’t be a packaged kit for all elderly residents at home. The new ‘western medicine’ isn’t just more and new technology for this population; rather, the concern must be in developing part high-tech telehealthcare provision and part safekeeping telecare alarm devices to keep the elderly safe and well at home.

Quite unlike the status of telecare/telehealthcare in the US, the UK is on the verge of taking telecare/telehealthcare into the mainstream. To this end: Porteus reviewed the UK’s national procurement scheme for telehealth/telecare, with details on the time and cost savings options inherent in these delivery options. However, he
stressed the need for taking a holistic approach to providing service delivery to an elderly population. Currently, in the UK, social care and not health care services are currently funding telecare developments. However, ideally, any telecare service should be an integrated service between health, social care, and housing. Hopefully, it will be in future.

Porteus also delineated implementation challenges of telehealthcare/telecare in future. These challenges are:

1. Avoiding risk of isolation—planners have to insure that elderly people are not socially isolated as a result of using telecare at home. It should not be a substitute but a complement for traditional care.
2. Building an evidence base—though telecare has been used for over 25 years in England, it still is not well known, nor is the effectiveness of the technology known.
3. Getting the 'right mix' to deliver effective services—that mix includes the equipment, the monitoring and the response for the telecare package.
4. Designing and implementing a national evaluation of services.

This evaluation does not have to only focus on funding concerns, however. As Brownsell pointed out, the majority of people who have not yet adopted a new technology need to be convinced by clinical and economic research of its value. To date, in regard to telecare, there is an 'evidence chasm' that defines the current state of telecare activity. His group's own telecare trials, he says, add to the evidence base but they are only a stepping-stone to more robust evaluations.

However, in addition, Brownsell notes that such trials in telecare are not without setbacks: they are complicated by long training periods, much work that is involved in designing delivery systems and still other problematic issues. This circumstance often results in telecare trials that seek to trial the equipment rather than to quantify the impact of the intervention when compared to other forms of service delivery.

Clearly, therefore, there is much need for standardized protocols for setting up telecare trials and for training to ensure that the impact of the equipment’s use is measured and meets the protocols/codes of practice of agencies such as the Telecare Services Association. In this regard and many others, developers and planners in the UK and the US can learn much from each other to address the very comparable and pressing service needs of the burgeoning elderly populations living in their homes in both countries.
Other Housing LIN publications available in this format:

Housing LIN Reports available at www.icn.csip.org.uk/housing:

- Extra Care Housing Training & Workforce Competencies (Report and Executive Summary)
- Yorkshire & the Humber Region - Extra Care Housing Regional Assessment Study (Report and Executive Summary)
- Preventative Care: the Role of Sheltered/Retirement Housing
- Developing Extra Care Housing for BME Elders
- New Initiatives for People with Learning Disabilities: extra care housing models and similar provision
- Dignity in Housing
- Enhancing Housing Choices for People with a Learning Disability

Factsheet no.1: Extra Care Housing - What is it?
Factsheet no.2: Commissioning and Funding Extra Care Housing
Factsheet no.3: New Provisions for Older People with Learning Disabilities
Factsheet no.4: Models of Extra Care Housing and Retirement Communities
Factsheet no.5: Assistive Technology in Extra Care Housing
Factsheet no.6: Design Principles for Extra Care
Factsheet no.7: Private Sector Provision of Extra Care Housing
Factsheet no.8: User Involvement in Extra Care Housing
Factsheet no.9: Refurbishing or remodelling sheltered housing: a checklist for developing Extra Care
Factsheet no.10: An Introduction to Extra Care Housing and Intermediate Care
Factsheet no.11: An Introduction to Extra Care Housing in Rural Areas
Factsheet no.12: Eco Housing: Taking Extra Care with environmentally friendly design
Factsheet no.13: Supporting People with Dementia in Extra Care Housing: an introduction to the issues
Factsheet no.14: Extra Care Housing Options for Older People with Functional Mental Health Problems
Factsheet no.15: Extra Care Housing Models and Older Homeless people
Factsheet no.16: The Potential for Independent Care Home Providers to develop Extra Care Housing
Factsheet no.17: Delivering End of Life Care in Housing with Care Setting

Case Study Report: Achieving Success in the Development of Extra Care Schemes for Older People

Technical Brief no.1: Care in Extra Care Housing
Technical Brief no.2: Funding Extra Care Housing
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