



White Paper

Chronic Care at the Crossroads

Exploring Solutions for Chronic Care Management



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Exploring Solutions for Chronic Care Management

The World Health Organization reports that chronic disease is responsible for 60% of all deaths worldwide.¹ In the UK, 17.5 million people are living with chronic illness, and among people over 75 years of age, three-quarters have at least one chronic disease.² Chronic illness is challenging for patients because they often have to make significant changes in their social and family relationships while dealing with physical pain, prolonged medical treatment, psychological distress and growing restrictions on their daily activities.³ As a result, their quality of life is significantly reduced.

Quality of life among people who provide care to chronically ill family members is also affected. Carers face an increased financial, physical and emotional responsibility. Some carers who are employed report missing work, taking personal days off, or even retiring early to provide care.⁴ Since many patients are also faced with stopping work, chronic illness frequently leads to economic hardship for patients and their families.

The economic burden to healthcare systems is also significant; in the UK 80% of GP consultations relate to chronic illness and 60% of hospital bed days result from chronic illness and related complications. As the population ages and the number of people affected by chronic disease grows, the demand for healthcare resources will escalate. The number of people aged 50 years and over in the UK is projected to increase by 36% by 2031, while the number of people over 85 years will increase by 44%.⁵ These demands will have important implications for governments as they address the challenge of sustaining an equitable healthcare system.

The Chronic Care at the Crossroads summit, hosted by Intel Corporation in July 2007, was convened to debate these issues. Jeremy Vine, the BBC broadcaster, moderated three panel discussions that brought together 10 healthcare experts, including representatives from NHS Connecting for Health, The Research Institute for the Care of the Elderly (RICE), and the UK eHealth Association. The summit gave participants a forum to discuss ways of improving patient care and easing the strain on healthcare professionals, families and the NHS.

Executive summary

The prevalence of chronic illness is escalating as the population ages and the burden for patients, families and the healthcare system continues to increase. Patients prefer to receive care in their own homes, and the healthcare system must evolve to deliver treatment in the home and provide the support that both patients and carers require. Current initiatives, such as the Map of Medicine and National Service Frameworks, are helping to ensure that patients with chronic illness receive the best possible treatment to maximise their quality of life. User-friendly technologies that connect patients with their healthcare team will facilitate these initiatives by providing tools to help them be more active and engaged in their own care. Pilot eHealth programmes are also underway at local, national and international levels and should now be superseded by new, fully implemented programmes. The implementation will depend on cooperation between healthcare and social care networks to provide economic support and deliver care. Patients are vital to the success of eHealth and must be encouraged to take a central role in directing their own care.

Definitions

eHealth	<ul style="list-style-type: none"> Health services, information and education delivered or enhanced through the internet and related technologies. eHealth encompasses all of the methods listed below.
Telecare	<ul style="list-style-type: none"> The continuous, automatic and remote monitoring of real-time emergencies and lifestyle changes over time in order to manage the risks associated with independent living.
Telehealth	<ul style="list-style-type: none"> Using communications networks to provide, access, and manage any type of health information or service.
Telemedicine	<ul style="list-style-type: none"> Telemedicine is a type of telehealth. The term describes the activity performed specifically by a physician who uses IT and the internet for the diagnosis and/or treatment of a patient in another location.

Panel 1: The burden of chronic care and ageing in the next generation

Louis Burns, Vice President and General Manager, Intel Digital Health Group

Mark Duman, Honorary President, Patient Information Forum

Dr Ric Fordham, Associate Dean, School of Medicine, Health Policy & Practice, University of East Anglia (UAE)

Professor Roy Jones, Director, The Research Institute for the Care of the Elderly (RICE) and Professor of Clinical Gerontology, University of Bath

The cost of chronic care

As people grow older, they develop chronic conditions that may not be immediately life-threatening, but cause considerable suffering and likely reduce their lifespan. The panel discussed the challenge of providing care that addresses the needs of patients, families and carers, but is also economically viable. "If a person is over 80 they will almost certainly have one chronic disease, probably two," said Roy Jones. "Only about 15% of people over the age of 80 do NOT have a chronic disease."

The cost of chronic illness to the NHS is substantial. Figures provided by Ric Fordham suggest that common chronic diseases such as heart disease, stroke, hypertension, diabetes, and chronic obstructive pulmonary disease are responsible for NHS costs of approximately £12 billion per year. However, NHS costs represent only a portion of the total cost. "Much of the cost of illness is 'out of pocket' cost for the patient, and another major cost is from lost productivity," said Louis Burns.

The cost of lost productivity is often examined in cost-of-illness studies that take a societal perspective. These costs include income and benefits lost to both patients and carers who have had to take days off work, or stop working, as a result of the patient's condition. For example, lost productivity due to coronary heart disease in the UK has been estimated at approximately £3 billion per year.⁶ As the population becomes older, this burden will escalate.

From the patient's perspective, however, intangible costs may represent the most substantial burden. These include the pain, suffering, emotional distress and reduced quality of life associated with chronic illness, none of which can be assigned a monetary value. The key to reducing these costs will be to maximise the healthy years and prevent people from entering a period of decline in their later years. "What we are really talking about," said Roy Jones, "is squaring the survival curve, so that people live a long time and have a relatively short period of disability and illness before they die, rather than having these years and years of deterioration." The challenge is to pinpoint where money should be spent to maximize quality of life as much as possible.

Home care

For many patients with chronic illness, remaining in their own home is a key concern. Roy Jones explained: "We're trying to help people to stay at home, to cope with chronic illness, and to continue to live independently with a bit of support." It has therefore become important to look at practical ways of facilitating home care. "We have to expand the boundaries of how healthcare is designed and defined."

Successful treatment in the home will require improved communication between patients and their healthcare team, and better access to adequate and appropriate health information. "If information is not communicated well and the patient does not receive support, changes are not going to happen," said Mark Duman. "We need to understand better how people live their lives and what can be done to improve their coping skills and their information and communication issues."

Placing patients at the centre of the healthcare discussion and ensuring that they are fully engaged in their own care is vital. People need to remain connected, active and involved, but many need help to overcome challenges like visual and hearing loss, literacy or numeracy problems, or memory and cognitive deficits. Solutions are needed that can help preserve their dignity and allow them to continue to live independently.

Home care cannot focus on the patient alone. There are approximately 6 million people in the UK who provide unpaid care to patients.⁷ These carers will have to be integrated into a healthcare team that also includes the patient, nurses, clinicians and possibly other healthcare professionals. When patients are visiting his memory clinic, Roy Jones has found that it is almost mandatory for a carer to accompany them. Currently, however, there is little support for carers and the impact of their contribution to chronic care cannot easily be measured.

The role of technology

Isolation is a serious problem for older people living with chronic disease and can lead to withdrawal and declining health. Simple technologies that can keep patients connected, active and involved in the late stages of life could help preserve quality of life. “The technology industry often tries to show its brilliance through the sophistication of their products,” said Louis Burns. “In fact, the brilliance has to show up in the simplicity.” For example, a telephone that displays simple information about callers may encourage patients with cognitive problems to use the phone more often and thus maintain their social network.

It has been suggested that technology may be difficult for older people to use. However, recent European figures suggest that ‘silver surfers’ – internet users over 55 years old – have higher broadband adoption rates than other age groups and that their internet use is growing at a higher rate.⁸

The cost of technology also may be a concern, but the panel agreed that patients should not be bound by economic strata. Technology is likely to be one important part of the chronic care solution, and it needs to be available and workable for everyone.

The crossroads

Having reached a crossroads in the treatment of chronic care, the panel were asked which path should be followed in the future. “We could actually go backwards,” said Ric Fordham. “We are in real danger if we keep treating and treating and lurching from crisis to crisis. We really need to look at the way we engage with people to prevent and palliate chronic illness.”

Moving forward will require cooperation between patients, carers, healthcare professionals and technologists to come up with solutions that are user-friendly and practical. “There are a lot of solutions out there,” said Marc Duman. “We need to ask patients, patients groups and third party groups what works and what doesn’t. We really have to put patients at the centre of the discussion.”

Summary

The prevalence of chronic illness is escalating as the population ages and the burden for patients, families and the healthcare system continues to increase. Patients prefer to receive care in their own homes and the healthcare model must evolve to provide that care. The new model must provide support for patients and carers, encourage patient engagement, and explore user-friendly technologies that connect patients with their healthcare team.

Panel 2: Current trends and challenges

Nat Billington, Managing Director, Map of Medicine

Professor Michael Pearson, Professor of Clinical Evaluation, University of Liverpool and Consultant Physician, University Hospital Aintree

Roger Potter, Consultant Clinical Scientist, Lincolnshire Primary Care Trust

Simon Roberts, EMEA Ethnographic Research Manager, Intel Digital Health Group

Barbara Stuttle, National Clinical Lead for Nursing, NHS Connecting for Health and Executive Nurse, South West Essex Primary Care Trust

Home care

The importance of care in the home for chronically ill patients was emphasized by the second group of panellists. Hospitals, it was agreed, should be reserved for intensive, acute medical care. "People with chronic illness can be successfully treated in their own home by skilled healthcare professionals. We should be there to support, facilitate and coordinate," said Barbara Stuttle. "I am a passionate believer that we should give care to people in the home because they are then in the driver's seat, they are in control of what we do."

Although there is a risk that moving care into the home will make the quality more variable, technology may have a role in reducing that variability. In Lincolnshire, technology is being rolled out that allows patients to monitor themselves in their own homes. They can then pass the information on to nursing staff, who can assess if a patient needs intervention and respond appropriately. Roger Potter explained: "This is equipment where patients can make their own measurements, answer questions on a screen and the nurse can set a series of questions that can be answered remotely without having to visit." This allows the nurse to provide care for a wider group of people.

Ensuring equitable treatment with as little variability as possible will also require the adoption of standards to ensure optimal care. For Barbara Stuttle, this means more nurses and more specialist nurses with appropriate training and education. "We have highly skilled nurses in the community who are able to deal with chronic diseases. We have to work with patients as partners. When patients receive skilled care they trust their nurses. Patients do improve and have a good quality of life."

Michael Pearson provided examples of current local and national initiatives that are setting standards for care. National Service Frameworks are long-term strategies for improving specific areas

of care. For patients with chronic conditions, key themes include independent living and care planned around the needs and choices of the individual.⁹ The Quality and Outcomes Framework for general practice is an incentive programme that rewards high quality care in areas including chronic disease management.¹⁰ "If you can get consistency into care, and competence into care, that's something that the public want," he said. "We are not doing this as well as we could be. We have to find ways of putting these initiatives into practice."

Navigating the healthcare system

Ensuring a high standard of care and promoting best practice is the goal of the Map of Medicine, which is an information resource for healthcare providers that visually organises the latest evidence and best practice guidelines into patient pathways.¹¹ The pathways include clinical knowledge across the patient journey from diagnosis to treatment. "If you are diagnosed as a diabetic you are beginning a journey through the healthcare system, which will have various points where key decisions have to be made," said Nat Billington. "We are trying to map out the idealized patient journey for a large number of conditions. What we are trying to avoid is the need for an acute setting which is very expensive and means that something has gone wrong."

It is currently difficult for patients to navigate through the healthcare system; technologies that allow patients to chart their own course may be beneficial. However, there is a concern that some people may not be able to use technology or may not guide their own journey appropriately. "We should not stereotype older people as being unable to use technology. If you are engaged and have a reason to use something, you will do so," added Nat Billington. New systems will have to balance the need of patients to be proactive and involved, while still ensuring that their medical needs are appropriately met.

The role of technology

The panel debated the need for technology and agreed on the importance of maintaining personal contact between patients, carers and healthcare professionals. “Technology is a support and an aid,” said Barbara Stuttle. “You can never replace the human being. Patients want to be given advice and helped to make decisions.”

Technology may also help reduce patient anxiety by allowing them to monitor themselves more regularly than would be possible, even with frequent clinic visits. “When they see the data, they begin to see what is normal for themselves, and they become more competent at managing their own condition. They will get engaged with it and I think that will lead to a sort of cultural change,” said Roger Potter. However, such a cultural change will not be simple. Michael Pearson explained: “For chronic care, the medical profession has to engage with the public and the public have to want to go on that journey.” In fact, everybody through the healthcare chain will have to make adaptations.

Before they can adapt to new technologies, some patients will need reassurance that their privacy will be closely guarded. Barbara Stuttle pointed out that a great deal of work has been done to ensure that all health electronic records remain private. “People assume that no one else can look at paper records, but you can go anywhere in a GP’s surgery or hospital and see charts everywhere. Electronic records are more instant, but they are also more auditable.”

Many patients, however, have already adapted to technology and expect all of their healthcare providers to have access to their health records. “Patients are actually astonished that we can’t call up all of their records,” said Michael Pearson. “They are surprised that hospitals can’t pull up GP records and access the latest blood test. They are expecting it to happen.” Although there is currently no connectivity between the NHS electronic clinical records and the technologies that are placed in homes, the NHS is a member of the Continua Health Alliance, which is working to establish standards that will ensure interoperability of personal health devices with other technologies.¹²

Panellists also discussed the perception that technology may allow patients to be passively monitored instead of allowing them to be active participants in their own care. Simon Roberts pointed out the fallacy of this perception. “These are not technologies of surveillance; they are technologies of inclusion and integration. They allow patients to monitor themselves and share information with others around them.”

Summary

Current initiatives, including the Map of Medicine and the National Service Frameworks, are helping to ensure that patients with chronic illness receive the best possible treatment. New technologies will facilitate these initiatives and allow patients to monitor their own conditions. With the help of skilled nurses and carers, technology will also allow patients to remain in their own homes while navigating through the healthcare system.

Panel 3: Innovation and possibilities for the future of chronic care and ageing

Dr **Simon Eccles**, Clinical Director, NHS Connecting for Health and Consultant in Emergency Medicine, Homerton Hospital, London

David Kelly, Director, West Lothian Community Health and Care Partnership

Professor Ricky Richardson, Consultant Paediatrician, Visiting Professor of eHealth, Imperial College and Life President, UK eHealth Association

Mariah Scott, Director, Sales and Marketing, Intel Digital Health Group

Patient empowerment

The final group of panellists agreed that patient empowerment was key to the future of chronic care. "We need to put patients at the centre of the healthcare model," said Mariah Scott. One of the most important ways of gaining control for patients lies in access to their health records. Simon Eccles believes that the patient should have full control over their own record, including the right to keep all or part of their record private.

"We should stop seeing them as records that belong to the health service. Actually it is the patient's health record to which clinicians contribute. Patients should be able to stop old things that are no longer relevant from being shared. As the doctor, I may want to know these things, but I don't have a right to know. I hope I could gain the trust of the patient so they wished to tell me," he explained. "Only by giving patients full access to their records and empowering them to control who can see it, do we make it the patient's health record." This will become particularly important as eHealth computer systems become compatible, enabling sharing of records across a wider network.

NHS National Programme for IT

According to Ricky Richardson, we are living through a huge eHealth implementation programme. "Connecting for Health may be the largest civilian IT project on the planet," he said. Connecting for Health is an agency of the Department of Health that supports the NHS to deliver better, safer care to patients, via new computer systems and services that link GPs and community services to hospitals.¹³ It oversees the National Programme for IT, a multi-million pound initiative consisting of several streams of activity designed both to support specific health service reforms and upgrade the underlying information technology infrastructure. The key elements include the NHS Care Records, Choose & Book (which streamlines outpatient appointments) and the Picture Archiving and Communications System.

The National Programme for IT is also about changing the process of healthcare delivery and using information technology to improve both

the patient's experience of healthcare and the outcomes achieved. Simon Eccles said: "It won't work if it just continues what we are doing now using better electronic means. We need to make providing best care the easiest, most obvious thing to do. And then measure outcomes delivered as a result."

Connecting healthcare and social care

In West Lothian, Scotland, 3000 homes are currently connected with telecare. At no cost to patients, the homes have been equipped with detectors linked to a call centre that can be alerted if, for example, an elderly patient falls. The programme aims to promote independence and support patients remaining in their own homes as long as possible.¹⁴ "The average length of stay in a nursing home 4 years ago was 38 months, now it's about 14 months. In Scotland if you have a fall, the average length of time spent on the floor is 4 hours – if you're part of a telecare package, it's 22 minutes," said David Kelly.

The programme was made possible in West Lothian through financial contributions from a variety of different budgets. "You have to look across the board at the patient journey and understand that the budget is in the social care, primary care and acute care systems," explained David Kelly. Spreading the cost is key to implementing these technologies since the immediate capital cost may be beyond any single budget. Downstream savings, however, are likely to be seen across multiple budgets.

Once homes are connected to combined telehealth and telecare systems, a major challenge will be giving patients the tools to understand what data means and what they should do with it. Clinicians will need decision support tools so that they can start to manage by exception. Instead of receiving a flood of normal data, the GP will receive alerts and data that require action. In some cases, the system can be set up to alert the carer first, as in West Lothian where carers can be alerted by mobile phone that the patient has fallen. "Ideally care should be tripartite – patient, carer and services," said David Kelly. "Technology makes it easier for all of us"

International eHealth

A number of other eHealth pilot studies are currently operating across the UK, Europe and the US. But Ricky Richardson believes that the time for pilot studies to prove the effectiveness of eHealth is over, and he identified major changes that are underway. "The interface with healthcare services is going to be mobile and that will be rapidly implemented over the next few years. We will also see personalized health care management, which will be about you and your risks, not a specific disease."

One of the larger initiatives is the linking of countries via the Commonwealth eHealth programme, which includes 53 countries and 1.8 billion people with a need to have access to equitable medical knowledge and skills. In partnership with the World Health

Organization, the programme would make the best use of the long-standing relations among member countries to develop and deploy technology to support health system functions.¹⁵ This programme would be particularly beneficial for countries with limited financial resources. The goal is to make personalized healthcare delivery and improved outcomes available to all.

Summary

eHealth programmes are underway at local, national and international levels – pilot programmes should now be superseded with new, integrated systems. Widespread implementation will depend on cooperation between healthcare and social care networks to provide economic support and deliver care. Patient empowerment is vital to the success of eHealth.

Moving forward

All three groups of panellists agreed that technology will have an important role in the eHealth revolution. In summarizing the discussion, Louis Burns described the contribution that Intel can make to eHealth. "Digital Health at Intel is really about how a technology company can listen closely to patients and healthcare professionals and see where we can add our expertise. We would like to add a piece to the puzzle and hopefully help solve it." Mariah Scott explained: "In less than 5 years you will see some next generation capabilities in the home. Intel intends to focus on products for the ageing and those with chronic diseases. We see the importance of extending care into the home and making a difference."

Although the discussion focused on the management of chronic care for older people, it is vital that young people with chronic disease are included in healthcare planning. "Having a device that doesn't brand you as having a condition is important for young people – something that fits in with your lifestyle and belongs in your home and wherever you go," said Mariah Scott. "Technology must be designed with the user in mind."

The audience and the panellists were challenged by Sir Muir Gray, Director of National Knowledge Service and Chief Knowledge Officer for the NHS, to decide what they are going to do next to support the revolution in healthcare for chronic illness. "We need to change the process of healthcare delivery and everybody has to say this to 10 people," said Simon Eccles. This will require champions across the healthcare sector – nurses, GPs, Primary Care Trust commissioners and more. It must be matched by government targets to provide the structure and there must be a clear way of measuring the outcome.

Conclusion

The prevalence of chronic disease will increase dramatically in the coming years in the UK and worldwide. The three panels discussed how the healthcare system is coping with this challenge now and how it must evolve to cope better in the future. Currently, the exchange of information between hospitals, nurses and general practitioners is inadequate, there is inequality in levels of care, and tools are needed to help patients become more involved in managing their own care. Pilot studies in several UK regions have shown that technology will be an important part of the solution.

Technology will help to empower patients, giving them the ability to navigate through the healthcare system, monitor their own conditions and share results with their healthcare

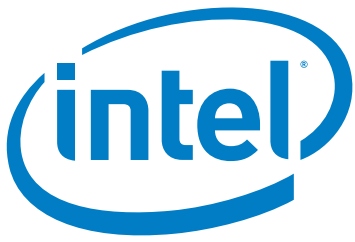
team. Support from specialist nurses in the community will ensure that patients receive support and care while living independent lives.

Implementation of eHealth technologies will require support from patients and healthcare professionals, financial contributions from social, primary and acute care budgets and innovation from technology companies. Meeting the challenges for chronic care will require action from nurses and physicians, support from governments and pressure for change from patients and patient groups. Working together, these groups have the potential to transform the healthcare system.

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