

Coping with more people with more illness

Part 1: The nature of the challenge and the implications for safety and quality

Health systems are under more pressure than ever before, and the challenges are multiplying and accelerating. Economic forces, new technology, genomics, AI in medicine, increasing demands for care—all are playing a part, or are predicted to increasingly do so. Above all, ageing populations in many parts of the world are exacerbating the disease burden on the system and intensifying the requirements to provide effective care equitably to citizens. In this first of two companion articles on behalf of the Innovation and Systems Change Working Group of the International Society for Quality in Health Care, in consultation with representatives from over 40 countries, we assess this situation and discuss the implications for safety and quality. Health systems will need to run ahead of the coming changes and learn how to cope better with more people with more chronic and acute illnesses needing care. This will require collective ingenuity, and a deep desire to reconfigure healthcare and reengineer services. Chief amongst the successful strategies, we argue, will be preventative strategies targeting both physical and psychological health, keeping people at home longer, experimenting with new governance and financial models, creating novel incentives, upskilling workforces to fit them for the future, redesigning care teams and transitioning from a system delivering episodic care to one that looks after people across the life-cycle. There are opportunities for the international community to learn together to revitalise their health systems in a time of change and upheaval.

Keywords: Massive ageing, ageing population, health system reform, elderly

Introduction

The growing number of older people living with chronic conditions is a major focus for international organisations such as the World Health Organization,[1] the Organization for Economic Co-operation and Development,[2] United Nations[3] and the World Economic Forum.[4] Multiple books and reports have estimated the escalating size of the ageing population relative to other age cohorts and described a cascade of social and economic consequences. Many have taken a country-specific, and a few, country-comparative approach.[5-7] Only a few nations and organisations have moved beyond providing general warnings, and offered implementable solutions to cope with ageing, frailty, and long-term care needs.

Focusing on ageing alone understates the overall problem. New technologies, genomics, personalised medicine and other advances are also increasing the pressure on healthcare systems. Nevertheless, the ageing population is a core challenge confronting countries and systems. This is why we, the Innovations and Systems Change Working Group (I&SCWG) of the International Society for Quality in Health Care (ISQua) suggested that ISQua use the ageing population as the platform and starting point from which to assess the potential tsunami of consequences for our current approaches to conceptualising, assessing and improving the safety and quality of healthcare. As yet the necessary innovations required—in delivery systems, quality and safety standards, and care provision—are at a very early stage. We believe that the rate of progress is too slow and that current initiatives are too narrow in scope.

The I&SCWG on behalf of ISQua, having consulted over the last four years at each annual conference with some 40 countries, has been grappling with this problem on behalf of the institutional and individual members of its international community. This work has led us to frame the problem thus: nations need to address the growing challenge inherent in the

increasing ageing population with cost-effective solutions, in parallel with confronting the health of children and youth, as chronic diseases accelerate, with a focus on improving quality and safety of health and care.

In this, the first of two companion papers, we outline the implications for safety and quality of an ageing population and share ideas generated from ISQua's international community. We provide an account of the challenges to healthcare systems, the range of potential solutions and the broad implications for patient safety and quality of care. There are multiple difficulties ahead, but our present aim is to address a particular role and mission of ISQua, namely the definition, provision and accreditation of healthcare organisations and standards. In our second paper we provide a more detailed proposal for the new type of standards that will be required, the extension of standards to deal with the entire patient journey, and the challenges for leaders in tackling this issue.

How we got here

In the last 60 years progress in hygiene, improvement in access to clean water and nutritious food, the relative absence of war, preventative strategies in public health, continuous improvement in diagnostic and treatment modalities (especially for infectious diseases and maternal and child mortality) have combined to create huge reductions in premature deaths in the under 50s.[8] Living to over 90 years or age is becoming the norm in Western countries. For several decades now people have, on average, gained three months extra life for each passing year, in many countries.[9] This degree of years of life gain is unprecedented in human history. Although they have previously lagged behind High Income Countries (HICs) this acceleration of increased lifespan can be even greater in low- and middle-income

countries (LMICs).[10] Survival for its own sake is not the goal however: reduction of disabilities, better quality life-years and supporting outcomes which patients favour, are key.

The world had 200 million people over 60 in 1950; this will increase to 1 billion by 2020, and 2 billion in 2050.[12] Many among this population will suffer one or more chronic conditions, such as musculoskeletal problems, heart disease, neurodegeneration, or frailty.[12] By 2050, on the other side of the demographic curve, 1 or 2 billion younger people will be newly diagnosed and treated for a chronic condition such as cancer, cardiovascular disease, back pain or diabetes, due in part to the rapid advances in personalised medicine.[13]

We have tended until now to see these problems in terms of an increasing number of older and sicker people, but case complexity is intensifying as well. Multi-morbidity and polypharmacy are on the rise. However, the reality that healthcare faces is not so much the problems of the very old, but the sheer number of people living with illness on the planet. By the 2050s, more than 50% of the global population will be living with a chronic illness, compared to less than 20% in 2000. Anxiety and depression are very large burdens on individuals and societies, too.[14]

Recent studies have reinforced the challenge and tragedy of loneliness and social isolation in both urban and rural areas, associated with poor health outcomes.[15, 16] In many countries older adults live alone, women in particular, because of the differences in the life expectancy of sexes. It is more difficult to provide health and social care services and resources to this population,[17] particularly in remote areas. This problem needs specific recognition and attention by healthcare providers and should be reflected in prevailing standards.

This represents not just a healthcare and social test of our ingenuity, but a substantial economic one. Governments will find it increasingly hard to allocate sufficient funding for education, transport and security as a proportion of Gross Domestic Product (GDP), alongside the growing demands for more spending on healthcare and social care. In addition, the available funds must be divided across a greater spectrum of healthcare requirements including general practice, acute care, aged care, rehabilitation, and community services, with other specific demands, such as for assistive technologies. Addressing wider social determinants of health, such as income equality, will also be critical.[18]

The present path

The primary goals of transforming the system related to massive ageing are: to preserve the autonomy and physical and psychological wellbeing of the elderly as long as possible, respecting and mitigating against the risks of increasing frailty; and addressing the rapid increase in cognitive disorders (principally Alzheimer's disease and other dementias). Injuries in the elderly, especially the frail elderly, are important too. Simultaneously, we must respond to the health and social needs of the growing population at end of life stages, and the concomitant implications for palliative care.

What can we do to tackle this thorniest of problems? Traditionally, healthcare systems were designed to heal recurring, acute diseases affecting younger citizens, and to treat a few seniors affected by aggressive diseases, in turn by delaying death or simply providing palliative care.[19, 20] Such healthcare systems have simply not been designed for the new reality, our emerging future, and the exponential increase of people with chronic conditions.[21] Sophisticated and costly diagnostics, long-term treatments and needed aged care could, if extrapolated over decades, lead nations to the brink of unaffordability. On the

present path, universal health coverage (UHC) may become increasingly difficult to achieve despite WHO efforts and international support; or UHC may become embedded as part of the solution, as an enabler of population healthiness. We do not yet know which.

But we do know that if we continue on the present path, in which the focus is primarily on acute healthcare, healthcare systems will become progressively unsuited to the populations they need to serve. Health systems will need to be transformed in ways that support more primary and secondary services, preventative health, and integrated care.[22] The current silo-oriented structures, disjunctions between health and social systems, and divisions between acute and community services represent major barriers to progress. The task is to control costs, increase efficiencies, introduce and adapt new organisation structures and initiate new models of care, all supported by relevant policy frameworks, structural alterations, change models, and education of all involved.[13, 23] Reducing the amount of low-value care, including overdiagnosis, over prescription, and unnecessary or poor value clinical practices is a key part of this equation.

The response to date from healthcare and society

By way of response to date, academic and community medicine, healthcare organisations, government and selected healthcare leaders have begun the task of moving in four complementary directions:

- *An increase in awareness, training and competence* in the care of older and frail people in all specialties, including preventive and personalised medicine, support for the role of caregivers, and innovations that specifically apply to the long-term care of the elderly, including rehabilitation [1, 2]

- *System-wide reform initiatives are underway* to improve the quality of care while concurrently attempting to reduce and control costs; this has been progressing for several decades, leading to decreased hospital length of stay, with savings ideally reallocated to rehabilitation, primary, preventative, mental health, community and home care [5, 6]
- *Increased utilisation of information technology.* Electronic health records, practice networks, telehealth, low cost mobiles and widespread data applications can provide healthcare remotely, bolster physician-patient co-decision making, enhance communication amongst the health and social care providers, and support people at home for longer [7]
- *Reconsider the concept of retirement.* Many governments have made changes to retirement ages, pensions, medical coverage and insurance programmes, to reflect the reality of an ageing population and the increased responsibilities of carers [24-26] Some have in addition put long-term economic drivers in place to prioritise the support for an ageing population [27-29]

Priorities for system transformation: the perspective of the ISQua community

To date, the actions taken are important and necessary, but are not yet sufficient. They represent the beginnings of the journey rather than the destination. Providing integrated care to all citizens, for any age, requires radical changes to health and social care systems. The challenge is to redefine, rethink and re-orientate the vision of healthcare; health, not defined by a series of episodes, but, in terms of a person's health journey, an all-encompassing lifespan solution. To support this, needs-based research conducted in close collaboration with knowledge users becomes important.

We took the opportunity at the 2017 ISQua London conference to ask a panel of 50 world leaders in quality and safety to consider the implications of an ageing population for healthcare systems and in particular for our current approach to safety and quality standards and principles. Members of the group ranged from policymakers and managers, to quality improvement and patient safety officers, to clinicians and patients, and their representative groups. We asked them to prioritise potential initiatives to guide us in developing these twin positioning articles and to ensure that the issues addressed were genuine priorities in an international context (Table 1).

<Insert Table 1 here>

The rise in digital capacities was seen as an essential part of the solution but is not without its challenges. Standardisation and integration of e-health platforms were seen as major issues. The workshop considered that, although harnessing technology is critical, emphasis should also be placed on education and developing new standards for primary care professionals, patients and families. The roles of patients and families are central to the delivery of many forms of healthcare. Widespread consultation about the proposed and the co-creation of new forms of care was seen as critical.

The London experts made further points in relation to systems governance. Countries have not signaled a willingness to increase the proportion of GDP currently spent on health and social care. So, there is a need for substantial reallocation of resources within health and social care systems, with a consequential risk of creating ‘winners’ and ‘losers’ while the realignment of funding takes place. Finally, the group emphasised the interlinked nature of all these priorities and the need to consider these developments in a holistic manner.

A reconfigured health and social care system

The London priorities fall into two broad categories. First, the growing desirability of keeping people mentally and physically well for as long as possible in the home setting, and anticipating the reforms needed to all parts of the health and social care systems. Second, the need for new systems of governance to monitor the evolving health and social care systems over the next 30 years. These two priorities echo other international consensus groups and are supported by data from WHO[1] and OECD,[2] among others. The ISQua group further developed a number of additional points which broadened our perspectives on these issues.

With respect to home care, professional roles and related disciplines (particularly in the psychological and social areas) need to be enhanced. Expert teams providing care in the community will incorporate a wider range of disciplines. Care teams may include specialist focus such as psychologists, behavioural therapists and consultant psychiatrists, to handle the assessment and treatment of the growing number of cognitively impaired patients. Nurses, other therapists, families and carers will take on new responsibilities. Carers, whether paid or unpaid, will need to be sufficiently skilled; otherwise, we will promote a cycle of insufficient care and continual readmission.

Governance of health and social care systems resides at national levels, regional levels, and at local levels. Local governance, close to the frontlines of care, will be a particularly critical guarantor of safety and quality standards, both during and after the transformation of services. Although the whole system needs to be transformed, this does not mean that all changes will occur through large-scale top-down reorganisation.[30] The changes are more likely to occur initially at a local level, and increase in scale, such as a regional healthcare initiative that broadens out to the national level [5]. We can only move

the agenda forward if we truly engage local communities, patients, families and all relevant stakeholders.

Re-conceptualising safety and quality for personal health journeys within the new health and social care systems

Healthcare systems will clearly need to transition from a primarily event-focused, acute system to a longitudinal, life-course perspective including the measurement of improvement. The central aim of health and social care will shift towards preventing disease and illness, and extending the quality of life of people over the long term rather than resolving short-term acute crises. Different solutions will be needed for low-, middle- and high-income settings, based on need and resource availability.

These changes will have profound consequences for how we conceptualise safety and quality. For instance, safety will no longer be described in terms of episodic risk suppression, but in terms of controlling acceptable risk over time in both the short and long term. The calculation of the risks and benefits of care will need to move from an assessment of a single episode to an evaluation reflecting multiple episodes alongside their interactions and social consequences. This long-term perspective also has consequences for the analysis of safety and adverse events.[31] Patient and family inputs and perspectives are increasingly required to identify adverse events and enhance analysis and inclusion of extensive patient information across the entire health and social system with which the person has interacted.

We must also incorporate the lessons of resilient healthcare, giving weight to how safety is achieved, both by individuals and systems, and to how it is lost.[32-35] This suggests enhanced capacities in learning from the successes of everyday care and of rapid detection of problems, including in the home. The evolution of safety risk suppression to risk

management, with a parallel focus on learning and success, has multiple downstream consequences for adverse event analysis, evaluation of risk, regulation, and the accreditation processes.

Existing standards, which tend to be disease or sector based, will need to be gradually revised to reflect a much longer term health and social care perspective. We will also need to develop standards in areas where regulation and accreditation have previously been weak or absent. There are thousands of quality and safety standards for acute care; in contrast very few standards apply to population health, or home and community care. These standards will need to be more flexible than institutional standards, reflecting the needs of those living independently and autonomously at home, managing their conditions with multiple variables impacting their health. This in turn means we have to develop new indicators for safety and quality across settings which more closely reflect the lives and healthcare of those ageing well, or frail people with complex health problems.

Leaders of regulatory organisations and related bodies will have to adapt to new approaches and potentially to the problems of setting standards in a time of rapid change and considerable systems turbulence. In a time of transformative change, it may not be feasible for organisations to meet all newly established standards, and therefore allowance may need to be made for individuals and organisations while they adapt to and embed new standards. Rapid innovation with new technology and techniques can create better care, but can lead to new adverse events; what was acceptable five years ago may be an adverse event today. In healthcare, more-so than many other industries, patient safety is a moving target.[36]

Conclusion

We need therefore to develop systems that reflect quality of care following the person's health journey throughout life. This necessitates a fundamental re-conceptualisation of quality and safety to reflect this new reality, with many implications for standards and accreditation.

We have outlined the scope of the challenge and proposed broad-based systems changes. In the second article in this two-part contribution, we will move to examine in more depth the kinds of standards needed in the future, and the consequences a changing health system poses for the design of new, more flexible standards—and vice versa.

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Table 1: Seven quality and safety priorities, ranked from the most to least urgent as seen by 50 world leaders at ISQua’s 2017 Pre-conference *Workshop on Massive Ageing* in London, England

Priority 1	Write standards and principles to reflect the health trajectory with the emphasis on home and community as the primary location for receiving care.
Priority 2	Develop new governance and leadership structures to reflect the transformed health and social care system, including measures of effectiveness and external evaluation.
Priority 3	Adapt quality and safety principles to reflect the growing number of people with cognitive impairment living at home.
Priority 4	Design quality and safety standards relevant to those living alone and smaller health care organisations located in isolated regions.
Priority 5	Develop quality and safety standards and principles for information technology to reflect and anticipate the digital revolution.
Priority 6	Conceptualise safety and quality differently to reflect the vision of health across the continuum and throughout the health journey. Orient standards toward living longer and healthier.
Priority 7	Adapt quality and safety principles within hospitals to reflect their responsibility for effective transitions and support for later care in community settings.

