

Responding to the challenge of chronic diseases: ideas from Europe

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ABSTRACT – Health systems everywhere face increasing challenges in responding to chronic disease. This paper explores the nature of these challenges, including the increasing burden of chronic disease and the weak evidence that informs clinical and policy responses. It then describes a series of innovations in different parts of Europe that seek to address these challenges: nurse-led clinics; mechanisms to bridge health and social care; and two more comprehensive programmes, Disease Management Programmes in Germany and national service frameworks in England. Finally it discusses how to overcome the barriers to change and the scope for learning from international experience.

KEY WORDS: chronic disease, disease management, Europe, integrated care, skillmix

Objectively, the provision of healthcare in Europe over the past two decades has been an enormous success. All countries have achieved virtually universal coverage of their populations. Deaths from causes that are amenable to healthcare have fallen markedly.¹ And in most countries the per capita costs of healthcare, as a proportion of national income, have remained stable. These achievements are especially notable when contrasted with the situation in the USA where the probability of dying prematurely from a range of common, treatable conditions is much higher than in Europe (Fig 1) and the gap is widening, even though the cost of American health-

care is now almost 40% higher than in France, which currently has the dubious honour of providing one of the most expensive healthcare systems in Europe. The European situation does not, however, provide grounds for complacency. While the problems may seem minor compared with those in, for example, the USA, they can seem equally intractable.

The challenges

One set of challenges faced by all industrialised countries arises from a series of interlinked factors involving the rise in chronic disease and the quest for evidence of effectiveness.

Advances in healthcare – particularly keeping people alive and controlling but not curing their conditions – mean that there are growing numbers of people with multiple disease processes. These have become vastly more complex to manage as new, more potent but also often potentially more hazardous drugs become available. But these drugs are often being administered to people whose characteristics, in particular their age, would have excluded them from the trials that demonstrated their effectiveness,² with many of them consuming a complex combination of pharmaceutical preparations whose combined efficacy and scope for interactions have never been adequately tested. As one recent contributor to this journal showed, citing examples relating to many common conditions, the disparities between results reported in trials and those obtained in routine clinical practice mean that much of the reputed evidence base for clinical decisions is of limited value in routine practice.³

However, an even greater gap in the evidence base relates to the organisation and delivery of health systems, rarely a priority for funders whose interests are more likely to be focused on, for example, the arguably illusory promises of genomics. Ironically, the prospects of conducting such research are often reduced even further by increased scrutiny of research conducted in publicly funded universities, as in the UK Research Assessment Exercise, where the quest for ‘high quality’ research tends to drive out capacity to undertake work that is more practical and possibly locally orientated.

There is growing recognition of the multi-system

Key Points

The delivery of healthcare is becoming increasingly complex, as ageing populations have multiple chronic disorders

Growing evidence of effectiveness often overlooks those with the most complex problems

The way in which healthcare is provided must change to meet the challenge of complexity

New ways of working include bridging the interface between hospital and primary and social care and changing skillmix

Tax funded systems may find it easier than those funded by social insurance to implement necessary changes

nature of many chronic diseases, as well as the diverse needs that they create. Yet while it is clear that the traditional relationship between the patient and a single doctor is inappropriate, it is much more difficult to define what is the best model, as each package is highly dependent on context, with terminology used in one setting having a quite different meaning in another one. Thus many organisational interventions, such as stroke units, are evaluated as 'black boxes', in which the intervention is defined by the name given to it, often with little understanding about the critical factors for success or failure.

At the same time, expectations are changing. The growth of the consumer society, coupled with the explosion in information available via the Internet, is creating a more empowered group of patients who are no longer willing to accept uncritically the model of care provided for them. Yet these developments may have unintended consequences. On the one hand, they may increase the responsiveness of health services, as individuals demand packages of care that are more suited to their perceived needs. However, they may also compromise equitable access to care, as the digital divide enables those who are most privileged to take greatest advantage of the new opportunities provided, while those in most need are left behind.⁴ The situation is exacerbated as populations change, with increased global migration creating groups in the population who, despite the goal of universal coverage, may fall between the cracks, especially if their migration has been illegal.⁵ Unfortunately, our understanding of the scale and nature of any impact of these changes on access to care remains limited.

The shifting balance of care

Taken together, these developments can be seen as evidence of the growing complexity of healthcare. They are also influencing profoundly the way that healthcare is being delivered. These influences can be considered under at least seven headings.⁶

- 1 *The growing opportunities for early intervention*, coupled with a greater recognition in some countries of the benefits of reducing the burden of disease as a means of relieving pressure on health systems, are shifting the balance between treatment and prevention. In the UK, for example, a Treasury study on future needs for healthcare constructed a variety of scenarios differing largely in the extent to which the health of the population improves. The difference in costs in 2022 between the most optimistic and pessimistic scenarios was approximately £30 billion (€44 billion), about half of current National Health Service expenditure.⁷ Yet the issue is not one of shifting resources from treatment to prevention; rather it is finding ways to integrate the two, with prevention strategies that take full advantage of developments in healthcare while reorienting healthcare to embed prevention at all stages.
- 2 *There is a changing balance between hospitals and alternative settings for care.*⁸ Hospitals have the advantage of confining the patient in one place, waiting for a series of investigations or a sequence of treatments to be undertaken. The patient is

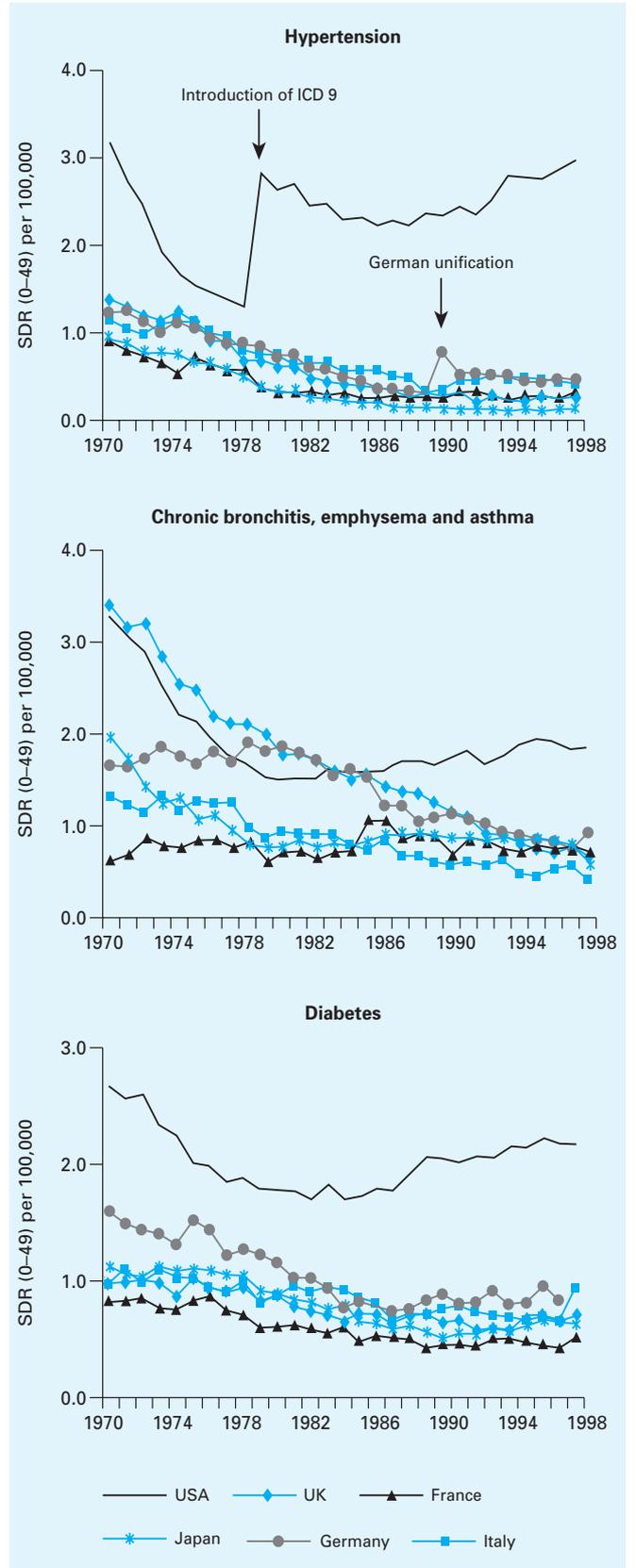


Fig 1. Age standardised death rates (SDRs) (age 0–49) from common diseases in the USA and selected industrialised countries. ICD 9 = International Classification of Diseases, Vol 9. Source: authors' calculations from WHO Mortality Data.

seen when it is convenient for the healthcare providers. Organisationally, this makes it easy to deliver complex packages of care but it creates major disadvantages for the patient, whose liberty is restricted. Even for those people requiring continuing care, hospitals may not be the most appropriate setting to receive it. Patients with advanced cancer may be better placed in a hospice; those with moderate disabilities may be able to manage in their own homes but with enhanced nursing or other support. Again, this introduces a degree of complexity, as the needs of the patient are assessed and alternative modes of care provided.

- 3 *The balance between professional and patient involvement in care is changing.* In a less deferential society, patients are less willing to accept instructions without explanations. At the same time health professionals are realising that, for many chronic conditions where the course of the disease may be labile, such as asthma or diabetes, the informed patient can control his or her disease process far better than any health professional.
- 4 As already noted, *there is a changing balance between evidence and intuition in the clinical encounter*, with a growing quest for evidence to underpin clinical practice, and for mechanisms to ensure that the evidence is acted upon, that performance is assessed and action taken to improve it. This balance is, however, dynamic as initial enthusiasms for protocol-driven care confront the reality of individual patient characteristics, thus exposing the limits of determinism.⁹
- 5 In the face of evidence of growing inequities in societies, *some services simply respond to demand whereas others proactively seek need*, even when it is not voiced as demand, in the knowledge that those whose needs are greatest may be least able to access the care that they need.
- 6 *There is the unrealised potential of information technology.* Patients accustomed to booking holidays or shopping on the Internet are increasingly puzzled by the continuing reliance of health services on postal communication. In theory, booking an appointment should be easy. Yet there is a crucial difference. The Internet model of holiday booking is analogous to a single episode of care, for example an attendance for a routine medical examination. However, the traveller in search of a tailor-made holiday, visiting a sequence of destinations suited to his or her individual needs, and using a variety of travel modes (a model more analogous to a patient with a multiple chronic diseases) will require the services of travel agent. Given that most patient journeys more closely resemble the bespoke holiday market, it is unsurprising that healthcare information systems, so far, often struggle to deliver what they promise.
- 7 *There is the challenge of developing a workforce to respond to the changing healthcare environment.* This is a vast issue, drawing together many of the previous six issues, with the added problem of how to provide training in the increasingly diverse settings for healthcare.

Potential solutions

Some examples of potential solutions to these challenges being tried in different European countries are presented below, together with the findings from a larger study of how health systems in Europe are responding to changing circumstances. The material provided is based primarily on a search of PubMed using terms ‘chronic disease management’, ‘nurse-led’, ‘integrated care’ and ‘community care’ linked to the names of individual European countries, supplemented by follow-up of cited references and contacts with researchers known to be working in this field. The review cannot claim to be comprehensive, in part because of the limited availability in scientific publications of information on innovation in healthcare in many countries. Furthermore, it does not seek to review the extensive literature about changing clinical practice, in particular enhancing uptake and use of guidelines and protocols. Although this is a key element in improving management of chronic diseases, it is outside the scope of this review which focuses on organisational innovations.

At the outset, however, it should be noted that this is an area that has seen remarkably little comparative research that can either inform policy-makers about what is happening or, as importantly, what works and in what circumstances. There are several reasons for this:

- Perhaps the most important is the difficulty in obtaining comparable data. International data compendiums, such as that collated by the Organisation for Economic Co-operation and Development (OECD), focus almost exclusively on things that can easily be counted. This in part reflects the increasing desire by governments and statutory agencies to monitor health system performance, even though what can be counted may not be what is important. The most extreme example of this can be seen in England (other parts of the UK have been more cautious), where the Department of Health’s NHS Plan has led to the creation of numerous quantitative performance targets. Inevitably, these centrally driven targets, which take no account of local context, have led to opportunistic behaviour. As a consequence, the Audit Commission, in its review of NHS performance,¹⁰ concluded that the large number of piecemeal targets led to short-term, unsustainable responses. However, in the present context, the main importance of this approach is that many of these targets divert attention from the needs of those whose care cannot easily be measured, in particular those with chronic diseases. The above example is symptomatic of the nature of much discourse on international comparisons of health systems which is based on quantitative data that is removed from its context.
- In many cases, responses to the challenge of providing evidence-based care to patients with chronic diseases have been developed as local initiatives and have not been evaluated or systematically described. Where evaluations have been published, it is often unclear whether they have been implemented beyond the pilot settings described. In some cases, responses will have developed through informal

mechanisms, with ‘street-level bureaucrats’¹¹ finding ways to overcome legal and regulatory obstacles. In addition, it is known that there are numerous local initiatives to implement disease management programmes, drawing on growing evidence of the effectiveness of many of their components.¹² What comparative evidence exists tends to compare differences in utilisation of individual interventions and outcomes,¹³ or reported use of treatment guidelines,¹⁴ rather than looking at how the overall package of care is provided.

- Research on health service delivery and organisation in Europe lacks funding, and remains a poor relative of more narrowly defined technology assessment. As a consequence, there is relatively little published material on the diverse pathways that patients in each country follow, and what does exist largely relates to acute care.¹⁵

Of necessity, therefore, the following examples are essentially descriptive, and the few evaluations that have been reported are mostly on a small scale.

National service frameworks in England

Probably the most comprehensive policy in any European country on the management of chronic diseases is the English national service frameworks (NSFs), produced by the National Institute for Clinical Excellence (Table 1).¹⁶

NSFs exemplify the need to take a broad view of health improvement, encompassing primary and secondary prevention, diagnosis and treatment, and rehabilitation. For example, the coronary heart disease NSF identifies as immediate priorities the establishment of smoking cessation clinics, rapid access diagnostic facilities for patients with chest pain, quantified improvements in the speed of thrombolysis for those with myocardial infarctions, and enhanced use of drugs such as beta-blockers and statins for those recovering from an infarction.

The NSFs are relatively recent developments and while the monitoring regime that has been put in place ensures that progress is being made, it is likely to be some years before the results will be apparent. There are, however, numerous accounts of local programmes of implementation that seem to indicate that they are feasible.

Nurse-led clinics

In many countries, the traditional divisions between tasks undertaken by different health professionals are being eroded, with implications for the management of chronic disease. One area being affected is primary care. The nature of primary care varies considerably within Europe. At the risk of generalisation, the model found in the UK also exists in Ireland, the Netherlands, Italy, Spain, Portugal and the Scandinavian countries. In these countries, primary care is based largely on multi-professional teams of physicians, nurses and other health professionals. Patients are registered with a particular primary care facility which acts as a gatekeeper to secondary care. In contrast, in most of the countries funded through social insurance

Table 1. Subjects of English national service frameworks published or in preparation.

Cancer	Paediatric intensive care
Coronary heart disease	Renal services
Diabetes	Long-term conditions (focusing on neurological conditions)
Mental health	Children
Older people	

(the Netherlands is an exception) there is free choice of family practitioners and specialists working in ambulatory care. In this model, physicians are much more likely to work as individual practitioners.

In many countries where strong primary care teams exist, there has been a progressive shift in the management of many chronic diseases to nurse-led clinics in primary care. There is now considerable evidence from various countries and for different diseases that this approach yields better results than traditional physician-led care,¹⁷ although the model cannot be generalised universally: a Cochrane Review found improved outcome with nurse-led community-based management of chronic airways disease when the disease is moderate but not when it is severe.¹⁸

At present, a substantial amount of routine care of people with diabetes in the UK is provided by nurses in primary care settings,¹⁹ and research from Sweden, the Netherlands and the UK has found nurse-led clinics to be effective in the management of chronic obstructive airways disease and asthma,²⁰ heart failure,²¹ diabetes²² and for those on anticoagulant therapy.²³ Looking to the future, as western Europe faces growing shortages of physicians, it seems inevitable that this approach will become increasingly common.

Bridging the divide between hospital and social care

A common problem facing all countries in Europe is how best to manage the interface between acute hospital care and the alternatives for those who are not able to return to a fully independent life.

Numerous studies, in different countries, have shown that many people are inappropriately occupying acute hospital beds, with more recent research using a validated European version of the Appropriateness Evaluation Protocol.²⁴ However, the assumption that often flows from such observations – that all these individuals can be discharged to their own homes – is incorrect. Instead, many will require either a different form of residential care or enhanced community support to enable them to lead as normal lives as possible in their own homes.

Ensuring that these various alternatives exist, and in adequate numbers, has been a major challenge for health systems across Europe,²⁵ particularly in northern Europe where the breakdown of traditional extended families began in the 1960s. By contrast, this kind of change is only now becoming significant in some southern European countries:²⁶ for example, as recently as 1994,

42% of Spaniards aged over 65 lived with their children, while the corresponding figure in Denmark was 3%.²⁷ In consequence, the countries of southern Europe have both the challenge and the opportunity to begin developing services that draw on the lessons learnt elsewhere. There is now a growing number of examples of innovative care models, such as the regional community-based care programmes for patients with respiratory disease that have been established in France,²⁸ as well as projects using telemedicine in increasingly innovative ways.^{29,30}

The growth in discharge destinations has placed much greater emphasis on discharge planning, along with the recognition that, to be effective, this must begin almost as soon as the patient is admitted to hospital. Several countries are examining the 'hospital at home' concept, where patients are discharged earlier than would otherwise have been the case, with greatly enhanced home support. The results are, however, mixed, with evidence that reductions in hospital stay are offset by the costs incurred in the community, and while patient satisfaction may be increased, carer satisfaction may be decreased.³¹

Another attempt to bridge the gap between hospital and community care for patients with chronic diseases is the model of Transmural Care, developed in the Netherlands. As in other systems funded by social insurance, hospital and community care are provided by different organisations. Regular care by medical specialists is complemented by Transmural Nurse Clinics. The outcomes of this approach are, however, still uncertain and it appears that careful selection of clinical areas is necessary to ensure that there is true additional benefit. For example, an evaluation of such a model in rheumatology found that attendance at a Transmural Clinic led to increased attendances with specialists and therapists but no significant improvement in functioning or use of appliances.³² By contrast, a study of Transmural Clinics for children with asthma found an improvement in the information gained by parents.³³ At present, however, research on the value of this model is inconclusive.

Disease Management Programmes in Germany

The organisation of the German healthcare system reflects that of German society more generally, with policies arising from structures that bring together the main interest groups, in this case the sickness funds, hospital associations and physicians organisations. As each participating organisation seeks to promote the interests of its members, the delivery system has tended to institutionalise many of the common divisions that exist everywhere. For example, until recently, there was a strict separation between physicians providing hospital care and those providing ambulatory care. In addition, the system of payment, based on activity, has created a powerful incentive against cooperation. The principle of consensus that underlies these relations has, at times, made it difficult to agree and implement change.

There has been increasing concern about the ability of this system to respond to those whose needs are complex and who require care that criss-crosses these rigid interfaces. In response, the various stakeholders have agreed what are called Disease

Management Programmes.³⁴ The first four conditions to be covered will be diabetes, breast cancer, asthma and coronary heart disease. Despite initial opposition from physicians, the first programmes have now been implemented, for type 2 diabetes and breast cancer. Patients who enrol in these programmes are being managed according to a set of protocols, although the programmes also stress the importance of not interfering with clinical autonomy. They include, for example, regular examinations for the complications of diabetes, such as retinoscopy, as well as patient information on diet and avoidance of risk factors.

One feature of these programmes should be noted. They are funded through a change in the risk adjustment structure which creates incentives to enrol patients in them, and the system of reimbursing the physician responsible is a radical departure from the usual fee-for-service model. In effect, this is a recognition that the traditional model, based on the concept of individual episodes of disease, is poorly suited to delivering the integrated care required by patients with complex chronic disorders.

Conclusion

This brief review reflects some of the available literature on this topic: it is strong on diagnosis but weak on treatment. As in the rest of the developed (and increasingly, developing) world, the countries of Europe are facing a major challenge in implementing evidence-based responses to the increasing burden of chronic diseases.

The difficulties exist at several levels. One is the weakness of the evidence base, as discussed earlier. Others relate to health system characteristics, which determine how easy it will be to introduce new patterns of service delivery. While the explanatory power of financing system is often overstated, it is relevant that there are, broadly speaking, two types of health system in Europe (although this generalisation conceals many intermediate forms):

- The first, which is tax financed with government-owned (or at least tightly regulated) facilities, offers considerable potential scope for integration of care across boundaries, even if this potential is not always realised. In this model, health authorities of various forms and at various levels can exert a planning role.
- The second, funded by social insurance funds, involves the funds taking a more limited role, ensuring that independent providers, both hospitals and ambulatory care facilities, are paid for the patients they treat.

Although any conclusions must be extremely tentative, it does seem that innovations involving coordination across interfaces or changes in skillmix are easier in the tax-based systems. For example, the English national service frameworks require a degree of integration that seems unimaginable in Germany, given their difficulties in implementing Disease Management Programmes. This observation adds to the growing evidence that social insurance systems, so long considered by many as superior to tax-based systems, at least in terms of their ability to provide prompt, high-quality acute care, may have major difficulty responding to the challenges of the future – a finding that

deserves more attention than it has received so far in the debate about how to pay for the British NHS. The difficulty in implementing integrated care where the financial incentives acting on providers encourage individualism and discourage splitting income with other professionals, such as nurses, is becoming apparent at the same time as concerns grow about the wisdom of collecting most healthcare income from those in employment, disregarding the numerous alternative sources of collective income.³⁵

The diversity of European healthcare systems means that there are no universal solutions to the challenges of chronic disease. What may be possible in one healthcare system may be impossible, at least in the short term, in another ostensibly similar system, if the two differ in critical aspects. Although financing regimes do seem to be important, this conventional dividing line obscures many other differences in, for example, the status of family practitioners or the degree of medical autonomy. Each system must find its own solution, although it can also draw on the lessons learned by others. It may also conclude that the necessary changes are not possible in the existing system and instead require fundamental reform.

Although this paper is about Europe, similar issues arise in other parts of the world, as illustrated by a recent examination by British researchers of developments in the USA.³⁶ Indeed, despite its worse performance at a population level, the best American examples provide many lessons for Europe. These include Kaiser,³⁷ the Veteran's Administration, and the Group Health Cooperative of Puget Sound, whose Chronic Care Model³⁸ has been shown to achieve substantially better outcomes than conventional care.³⁹ Importantly for Europe, the more generous research funding in the USA means that the benefits of these programmes are better documented. In a commentary on the applicability of the Chronic Care Model to Europe, one of its leading proponents identifies the importance of exclusive relationships with providers, integration across interfaces, appropriate financial incentives, and explicit models for chronic disease management.⁴⁰ To this might be added the very substantial investment in information technology, far exceeding anything seen in Europe so far.

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