Digital Health Care: Cementing Centralisation?

Introduction

This paper pursues two arguments about digital health care, using the development of digital services in the National Health Service (NHS) in England as a case study. The first argument is that there is a mismatch between the principal digital and service delivery models of health care organisations. Many digital services are still being designed along bureaucratic – or data processing - lines, at a time when there is a marked trend towards a more networked model of service delivery. Current thinking about health services emphasises the need to manage risks proactively and to co-ordinate services effectively. The second argument is that Open Data and other recent developments encourage centralisation of data collection and analysis, suggesting that the mismatch may if anything be reinforced.

The paper draws on historical institutional approaches [1,2], and takes the view that the digital infrastructure is an institution, which has been shaped over a long period, and which in turn has shaped the thinking and practices of health professionals, managers and system suppliers. The next section briefly outlines the development of digital health services in England over the last 30 years, emphasising the extent to which the NHS is reliant on large numbers of functional systems, many developed in isolation from one another. The following section describes the shift in thinking and practices about service delivery and in the governance of health services that has taken place in the last decade. Then, the emerging effects of three current developments – Open Data, genomics and telehealth – are noted. The paper concludes that there is a tension between two digital objectives, one supporting frontline services and the other centralising data collection, as envisaged in Open Data policies. The latter seems likely to influence frontline data collection, and hence the systems available to health professionals, for the foreseeable future.

The Development of the Digital Landscape: An Outline

The focus of this paper is on the large scale patterns of development of digital health services. This raises two issues, concerning evidence and theory. The evidential issue is that the great majority of high quality studies report on smaller scale systems. Most experimental, and many observational, studies report on the use of individual systems [3]. Many articles talk up the potential of large scale developments in electronic patient records, telehealth and other

technologies, but in general those papers present limited evidence to support their claims [4,5]. Accordingly, the paper draws on national policy documents and policy analyses, which summarise progress and the direction of developments at particular points in time, as well as on academic reviews of evidence about telehealth and other technologies. The theoretical issue concerns the relationship between technology and people. Many social researchers currently favour approaches which emphasise the inter-dependence of the two, for example in theories of practice studies [6] and in computer supported co-operative work [7]. It is not practical to observe the people-technology relationship at large scales, though, and in any case those relationships are likely to be shaped by much broader forces, including government policies, the behaviour of suppliers, and laws and regulations relating to privacy and confidentiality of personal information. The method used here is to trace developments in technology and in the governance of services separately, and then comment on the extent to which the two are, in practice, inter-related. This approach is similar to that used by Dunleavy and colleagues in their study of large scale digital public service programmes [8].

The history of computing in health care stretches back to the 1960's, when early mainframe systems used for 'back office' functions such as managing staff payrolls, and for the aggregation of basic data about hospital activity. There were important developments in the 1970's, including the introduction of patient administration systems, which allowed hospitals to manage appointments and admissions, and systems for recording activity in operating theatres and other departments. To use an old phrase, early systems were developed on 'islands of automation', and were not linked to one another. These were essentially data processing systems, designed to record discrete units of activity, such as hospital appointments or operations performed. They captured and stored large volumes of discrete – mainly numerical - data items, performed relatively limited computational operations, and then produced summarised outputs. As Bowker and Star [9] have pointed out, inherently fuzzy phenomena such as clinical diagnoses were standardised, making it easier to record them in early systems.

UK general practice usefully illustrates patterns of development and diffusion. A number of small, specialist IT firms worked closely with GPs throughout the 1980's, and developed early commercial systems. They had two main objectives. One was to support GPs in their work, and IT systems have been commonplace on GPs' desktops across England since the late 1990's. The other was to automate the remuneration of GPs, who are independent

contractors and have always been paid through a complicated mix of flat fees and tariffs for specific activities (such as providing health screening services or minor surgical procedures). The (then) Department of Health and Social Security developed the Exeter System, which received submissions from the thousands of GPs across England, and processed them for payment. During the 1990s, more and more GPs purchased systems, so that by the end of the decade the great majority of GPs had them on their desks and used them in consultations with patients [10]. Similar patterns of development, and then diffusion across the NHS over a 10-20 year period, occurred for hospital departmental systems.

In the late 1980's some hospitals began to invest in larger, more integrated systems, initially referred to as Hospital Information Support Systems. These typically allowed staff on wards to access the patient administration system, order pathology tests and radiology images, and order pharmaceuticals, and linked some departmental systems together to facilitate retrospective reporting and audit. Diffusion of these systems, which proved difficult to implement, was slow and fewer than a quarter of hospitals had working systems by the mid-1990's [11].

Looking back, there were two notable features of the early digital landscape. First, a supplier market developed, with a mix of UK and international companies, each offering one or more systems. Informatics and health professionals found themselves selecting from what was available. The nature of the supplier market influenced what was procured and implemented. Second, from the late 1980's onwards, the NHS was required to collect larger volumes of data for central administrative purposes. Finance managers also encouraged the collection of more data, to allow them to link activity and cost information. It was finance managers who, in many instances, were prepared to fund investments in departmental systems. The early central requirement was for routine reporting of a few hundred data items, but the number of items grew substantially in the intervening years. The centralising, data processing, model has been further bolstered by an increase in the volume of mandated data to be collected. In the 2000's a number of new initiatives, including disease registers for diabetes and other clinical conditions, were introduced. Some of these, including the Quality and Outcomes Framework dataset for GPs, were introduced relatively smoothly, while others appear to have been viewed, rightly or wrongly, as burdensome additional tasks, and the resulting datasets have been incomplete and error-laden [12].

If we had taken a snapshot of the digital landscape at the turn of the Millenium, we would have captured many islands of automation, and HISS systems in some hospitals, but also many gaps where services continued to rely principally on paper systems. It is not clear how far the functional capabilities of early IT systems, the Department of Health's data requirements, the views of finance managers and the participation – or lack of it – of health professionals in the design of systems influenced the development path taken. It seems reasonable to observe that all played a role in shaping today's systems.

It is possible to comment with greater confidence on what happened next. Frustrated with – as they saw it – the slow rate of implementation, and believing that digital solutions would transform NHS productivity, the Labour Government launched the National Programme for IT in 2002 [13]. The fate of this ill-starred venture has been written about extensively elsewhere [14, 11]. The key point for this paper is that, whatever the intended objectives of the National Programme, the effect was centralising. The NHS Summary Care Record programme, for example, was (and still is) intended to provide – central, national – summary data about all NHS patients [15]. The legacy is a suite of systems which are, in effect, a central repository for a large subset of NHS data, passed upwards from operational systems.

Following the failures of the National Programme, in the last five years there have been two striking trends, which we might be termed colonisation and linkage via portals. There is now extensive digital coverage of NHS services, filling in a number of 'gaps'. The majority of acute hospitals are now heavily computerised, in the sense that there are systems in most wards and departments, and increasingly also links with primary and community care services. All acute hospitals have patient administration systems, and a majority now have order communications systems. IT systems are indispensible for back office functions including finance and workforce planning. Outside the hospital, computerisation of general practice is essentially complete. A majority of GPs are able to 'view' pathology results remotely. In some places community nurses also have access to patients' hospital records, including records of recent pathology tests. Less positively, nurses are the largest single group of health professionals, and yet many hospital and community nurses are still reliant on paper. It remains difficult, in many localities, to access hospital systems remotely. And, very few NHS patients have access to any part of their GP or other records [13].

The second trend has been in the creation of portals, which leave existing systems in place, and provide middleware which allows clinicians in one part of a hospital to view data from systems in other services. Thus they can view information about surgery on a rehabilitation ward, about treatment in accident and emergency in a clinic a week later, and so on. There are some important exceptions to this general trend, notably in the relatively small numbers of hospital Trusts which have successfully implemented integrated hospital-wide National Programme systems. It is still reasonable to say, though, that the data processing legacy is still shaping digital developments today in most NHS organisations.

Trends In Health Services: Risk and Co-ordination

In the 1980's, in health systems in developed countries, it became increasingly apparent that the dominant mass production model, where services were organised along 'production lines', analogous to car or computer chip production lines, was not able to cope with changing demands. The reasons why have been much debated [16], but similar changes were observed in many industries, suggesting that deep structural changes occurred in western economies. In health systems, including the NHS, there were a number of clear symptoms. It became much more difficult to control costs, and to improve productivity as costs increased. Evidence of the alarming safety records of many hospitals mounted from the early 1990's onwards, culminating in the landmark Institute of Medicine report [17].

Some of the causes are relatively easy to identify. An ageing population and new technologies increased cost pressures. The NHS has historically been reactive, treating people as they become ill: it has not been designed to cope with public health challenges, including those associated with poor lifestyle choices about diet and exercise. At the same time, there are ever-greater public expectations about the safety and quality of services [18]. The challenge has been – and still is – to find a coherent organisational response to these problems and trends.

The policy responses, in many countries, stress the importance of actively managing chronic health problems such as diabetes, asthma, heart failure and some mental health problems, and broader public health problems associated with 'Western' lifestyles, including poor diets and lack of exercise. Chronic health care is expensive. In England, for example, the diagnosis and treatment of the 30% of the population with chronic health problems consumes some 70% of the National Health Service (NHS) budget. The realisation has dawned on policy

makers that this is a systems challenge, with two main components. The first is that services should be focused on the active management of patients' clinical risks, and should provide effective co-ordination of the many different services that people use [19]. The belief is that this will, in turn, make it possible for managers to control the demand for services and their costs. This echoes some Lean thinking about health care. Rather than organising activities by individual functions, as in mass production, resources are organised to ensure the smooth 'flow' of patients through services. Self-contained teams are created, which have all of the resources they need to manage a process from start to finish [20]. The second component comprises the governance of services: over and above effective co-ordination, service managers need to be able to balance the cost, volume and quality of services. Simultaneous reductions in costs and improvements in quality have been the norm in many other industries for a long time (eg the changes in your car or mobile phone in the last decade), but this has not been the case in health care. Trends in both components can be discerned in national health policies, in the changing focus of research, and to some extent on the ground, but the transition is on-going, and will take many more years.

This brings us to the information systems and technology requirements for the new service model. Any solution will have three general features. First, it should support the active management of risk, for example by supporting care planning and on-going monitoring of clinical risks (for example, the risk that a patient will develop an infection, or a pressure ulcer). The second general feature is co-ordination of services. Clinical teams need real time information about patients' risks as they move through a health system, and information that enable clinicians in one team to co-ordinate with others – often in other organisations - to ensure that journeys are as smooth and safe as possible. The third feature is that service managers need to be able to balance cost, volume and quality, and also to understand and manage the demand for their services.

There is a broader context for these requirements. The people with the best understanding of services, who are therefore in the best position to interpret and act upon information, are local health professionals and managers. If we assume, for a moment, that they are responsible for their service, then the reporting lines change significantly. Rather than reporting upwards, as in a bureaucracy, service managers are supported by finance and other departments: it is as if the bureaucratic model is turned upside down. Because the transition to the new model has

already been under way – albeit slowly – for some time, the local management model is familiar, for example in Foundation Trusts [21]. Local managers take exception reporting seriously. For example, they monitor expenditure on expensive drugs, identifying who has prescribed them and talking to the consultants concerned if it is deemed necessary.

It is important to stress that this model of care has been implemented in some places but remains an aspiration in many others. But, if it is the future, it seems reasonable to design information systems to support the new model.   The problem is that there appears to be a substantial mismatch between data processing systems and the requirement for systems that support the management of risk and co-ordination of services. This implies the need for substantial changes in the information that is collected about health care processes, and in the ways in which it is aggregated and used. An institutional view of this problem encourages the observation that digitally mediated practices are long established, as are relationships between suppliers, policy makers, health professionals, informatics managers. It is not, perhaps, surprising that digital services have followed a different trajectory to developments in services and their governance, subject as they are to different sets of institutional relationships.

This assertion prompts a question: does the mismatch matter?   There is some direct and some suggestive evidence that it does. The direct evidence lies in the often-reported observation that health professionals and administrative staff spend a great deal of time keying in data, and receive relatively little back, at least that is timely and in a form that can be used to assure or improve services. It seems reasonable to say that the situation has been improving steadily in relation to test results and other key clinical information, used to treat individual patients, but the 'much in, little out' problem still seems to hold true for the information needed to manage services on a weekly or monthly basis.

The indirect evidence comes principally from Tjora, a Norwegian emergency physician and researcher, who has reflected on the value of the systems in his hospital [22]. He has access to a number of departmental systems at a single terminal. He observes that he needs information that helps him to manage processes – moving patients efficiently and safely through his service – and that his hospital's systems do not provide what he needs.   Dr Tjora's experiences may result in part from poorly design (unrelated to available data), or to efforts to standardise operational processes which are not succeeding for some reason. But, it

seems reasonable to suggest that a mismatch between the information he needs and what is available contributes to his problems.

Looking Ahead: Open Data, Genomics and Telehealth

Three further developments are already under way, each of which could – if there is extensive diffusion– reinforce the tensions set out above, by providing new incentives to centralise data collection and linkage. Under the Open Data banner, health systems are beginning to publish datasets that have until now been held within health care organisations, and used by planners and public health specialists who need information (in principle, at least) to direct resources to the right services. External interested parties include academics, pharmaceutical firms and others, who want access to routine datasets for research and development purposes [23]. One way to provide data to all of them is via a single route – the consolidated electronic patient record – with extractions being made from those records, and subject to data protection and other legislation.

The second development is in genomics. It is now possible to analyse an individual's DNA and other genetic material at relatively low cost, and in a matter of hours. The prospects for identifying susceptibility to diseases, and for identifying new strategies for treating diseases with a genetic component, have been hyped for at least the last decade. As Topol points out, however, there have been few breakthroughs that can be used to improve diagnosis and treatment [24]. In spite of this, there is government support for sequencing for people with cancer in the UK, prompting the thought that data may be more valuable in aggregated form, for research and development, than for treating individuals [25]. Similar thinking informs government policies in the third area, telehealth, where the computing and medical devices industries are gradually integrating with one another. Free-standing medical devices that monitor blood sugar levels, oxygen and other variables are increasingly being promoted for use in peoples' homes, linked to computer networks, such that individuals' health status can be monitored remotely. As with genome data, there has been considerable hype surrounding telehealth, though in this instance there is also empirical evidence that it is not cost-effective [26]. Again, the perceived value of telehealth may, as things stand, lie more in centralisation of the data derived from monitoring devices than in clinical applications. While predicting future trends is fraught with danger, it seems reasonable to observe that each of the three developments has the potential to reinforce the desire for centralisation, and if anything also reinforce the need for demographic and other data in existing systems to be mined, so that

existing clinical data can be combined with these new data. There may be value, for service planning or for research and development, in these activities. Equally, though, they may displace other developments, designed to improve the quality and safety of services. The costs and benefits of each strategy might usefully be compared.

Concluding Comments

This paper is based on the observation that it is possible to identify an 'internal logic' driving the development of digital health services. It is entirely reasonable to implement systems to support 'counting and accounting' in a tax-funded health care system. But the discrete data about activity favoured in data processing models are not well suited to the very different challenges facing clinicians and managers today. They need real time information that helps them to manage risks and to co-ordinate many services, tailored to the needs of individual patients. There is, in short, a marked mismatch between the logic of digital services and of modern care processes.

Looking forward, the mismatch may not be as sharply drawn as it has been here in years to come. The large volumes of data must, if they can be successfully linked, contain valuable information. Trends in pathology test results, or combinations of data from different datasets, may provide leading indicators of risk, eg of increasing risk of diabetes or heart disease. This points to a significant research and development agenda. The arguments suggest, though, that policy makers still face a choice between two objectives, encouraging digital services that support the frontline (and pursuing the idea that digital services can transform health services), and the collection of large datasets for secondary uses. Open Data policies, and developments in genomics and telehealth, are creating a new nexus of interests for the secondary uses of data. In England researchers, politicians and commercial firms, including pharmaceutical firms, all believe that large volumes of detailed data should be published [27]. So, current thinking favours secondary uses. This may not stop suppliers and health professionals building new features into their systems to support service improvements, but these features will have to compete for space with centrally determined information requirements.

Acknowledgement

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