

What Is a Care Pathway?

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Abstract. This paper argues that it is possible to develop useful generic representations of care pathways, drawing on evidence and argument about clinical teams, about the ability of teams to cope with radical uncertainty and about the influence of institutional arrangements on the journeys that patients take through health systems. The arguments are used to identify a mismatch between current practices in the design of large scale digital systems and doctors' and other health professionals' needs for information about patients' risks and outcomes to support their work.

Keywords: health care; care pathways; requirements.

1. Introduction

The rate of innovation and diffusion of digital services in health care is low, relative to other sectors, in developed countries. There are many reasons for this, but one stems from our poor understanding of the fundamental processes in health care, variously termed patient journeys or care pathways, which are broadly equivalent to industrial and commercial production processes.

While some have argued that we are now in a world where requirements are no longer needed – in part because users can configure their own services – this cannot be the case in health care. There is clear evidence that poor requirement and specification processes are still leading to failures in procurement, design and implementation. [1,2]

Further, legacy systems in primary and hospital settings will not, at present, allow users to tailor services to their own needs.

This chapter argues that it is possible to identify flaws in the prevailing assumptions about the role of IT systems in health care, to develop useful generic representations of care pathways, and to use those representations to chart a more productive direction of travel. It is concluded that problems with the design and use of systems are due, at least in part, to a combination of the flawed thinking and lack of attention to identification of hardware and software requirements.

2. Two Ideas

The author Victor Hugo observed that there is nothing as powerful as an idea whose time has come. In the last decade or so, health systems around the world have been exposed to two such ideas. The first is that service delivery is becoming ever more complex, in the sense that it requires more intensive and more frequent co-ordination between different professionals, or across a number of organisations, or both. We need to find ways of managing this complexity, and in practice this means finding new ways for clinicians, managers and others to collaborate with one another. It has always been difficult to link inputs, outputs and outcomes in health care, and the complexity – reflected in highly modularised, but poorly co-ordinated, care – only makes the task harder. In practice professionals have to be involved in the identification and implementation of strategies for designing services that reconcile them, and thus achieving better control of resources. Similarly, safety improvements are most likely to be effective when clinicians work collaboratively, co-ordinating their work with one another.

The second idea is that health systems need to manage risks pro-actively. The argument, in a nutshell, is that no country can afford to run reactive illness services any longer, cost pressures are increasing all the time, and all countries must find ways of managing costs more effectively. In England, for example, 30% of the population has one or more chronic health problems, and consumes about 70% of the budget.

Historically, health services have been reactive, responding to people as they became ill. Today people still get ill, but the policy focus now is on preventing, or at least

delaying, the problems associated with getting older, or with poor lifestyle choices (smoking, lack of exercise, consuming too much salt or refined sugar). This has two notable consequences, namely that health systems have to identify effective strategies for managing risks, and that those risks often arise outside health care systems – lifestyle choices occur out in civil society.

3. The Challenges

These two ideas have major implications for the organisation of health care. Health systems have traditionally been organised along functional lines, with family doctors, community services and hospital departments operating separately from one another. This made sense, at a time when the over-riding need was to ensure that each of these services was as efficient as possible. This organisational model served us reasonably well for a long time, when many problems could be solved by visiting one or two services, when the co-ordination challenge was relatively modest.

It has become clear, though, that traditional organisational forms cannot deliver the co-ordination needed in the new environment. Many people need support from several services, often over months and years. Many of them are older people, and people with chronic health problems such as heart disease, stroke, diabetes, asthma and some cancers. Maximising the efficiency of each service is no longer the primary task. Rather, there is a need to manage patients' clinical risks, arising from their own problems and from the complexity of modern health systems.

Similarly, traditional organisations are not set up to manage demand, and hence control costs – that is, control organisational risks. The idea, the belief, is that this can be achieved by identifying problems early, or before they occur, either by encouraging healthier lifestyles or by screening populations and identifying individuals at risk of developing preventable problems (eg stopping smoking reduces the probability of lung cancer).

The need to respond to the two new ideas prompts a question about IT systems. How are health care IT managers, suppliers and policy makers responding to them? The answer seems to be – barely at all. This point will be discussed once care pathways have been examined.

4. Care Pathways

A single idea, the care pathway, appears to make sense of the challenges set out in the last section. A care pathway is really an idea, a high level representation, of the journeys that people take through health systems. People should be encouraged to avoid getting too far down any pathway (through health promotion and prevention). They should take responsibility for decisions about their own care where possible, and make others in consultation with professionals. Professionals need to co-ordinate effectively with one another to ensure that the journey goes smoothly from a clinical perspective. Note here that the focus is on patients – a major shift from the focus on services in traditional models.

In formal guidance, and in the research literature, care pathways are typically represented as sequences of discrete decisions and actions, where recommendations are based on the best available evidence from experimental studies. [3,4] Sometimes flow diagrams are included in guidance, which show how assessments, diagnostic tests and decisions should be linked chronologically. This focus on decisions and actions, and on patients ‘flowing’ between decision-makers, will seem intuitively reasonable to many software engineers.

This said, an obvious question arises: how are the many discrete events actually linked to one another? The short answer is: we don’t know. Leading commentators point out that we are in the early stages of understanding care pathways. [5-7] We know that dynamics of patient journeys are clearly different from industrial production processes such as car assembly or bottling plants [8]. Patients do not travel down pre-determined ‘assembly lines’. There is, rather, substantial unexplained variation in access to, and utilisation of, health care in all countries. The flow diagrams in official guidance are ideals, and do not represent actual processes on the ground. One important consequence is that clinicians and managers are not in a position to help software engineers to identify requirements that will improve the quality and safety of patients’ journeys.

Further, it is at best unclear how to include patients into thinking about pathways. Prevention and health promotion cannot be imposed – people cannot be ordered to

change their lifestyles - and citizens have to be properly involved in decisions about their lives. So, rather than being consumers, citizens need to be active collaborators in their health and health care.

We can make some progress, though, and start by identifying two important problems. The first, which could be called the process problem, stems from the point just made. We need to work out how patients actually move through health systems, and why. The second problem concerns governance – what management infrastructure will help to improve co-ordination along pathways. Even short journeys involve co-ordination between teams, and there is good evidence that the organisation of services can affect both the quality and the outcomes of care.

5. Teams that Expect the Unexpected

In many areas of a health system, specialist knowledge is concentrated in teams – general practice teams, emergency department teams, community-based mental health teams and so on. This starting point – the clinical team - resonates with the thinking behind total quality management, where each team involved in a production process manages its own affairs, co-ordinates its work with other teams locally, and is subject to ‘light touch’ regulation by a senior management team.[9] It is also reminiscent of Piore and Sabel’s concept of flexible specialisation, where teams work relatively independently of one another, each specialising in a particular activity, and building up a deep understanding of that activity over time.[10] This arrangement has important long-run advantages for organisations, because individual teams can change the way they work without significantly disrupting the work of other teams. At the same time, the specialised nature of a team’s work can make it difficult for outsiders – often managers, in practice – to intervene or to co-ordinate the activities of different teams with one another.

One of the keys to understanding patient journeys lies in appreciating the capacity of clinical teams to cope with uncertainty. This is what distinguishes health care from car production and processing insurance claims. Let us consider an example of an elderly woman, Mrs B., who is living in her own home, who feels unwell and makes an emergency call. An ambulance is dispatched, the paramedics assess her, and drive her

to the emergency department at the local hospital. The process can be conceptualised as occurring in discrete phases, with different teams taking primary responsibility at different points in time. It turns out that there is nothing that needs immediate attention, but the episode has taken place in the context of her on-going health problems, including some heart problems and a recent history of falls. Hospital doctors recommend assessments when Mrs B. gets home.

Analyses of this (relatively simple) sequence of events, and others like it, typically focus on strategies for reducing clinical uncertainty – on arriving at a diagnosis and making decisions about the appropriate course of treatment. But it seems more realistic to argue that there are two distinct types of team, with the difference between the two highlighted by their responses to uncertainty.

There are two distinct types of uncertainty in any patient journey. First, there is task uncertainty – uncertainty about the appropriate course of action for the patient. Second, there is environmental uncertainty.[11] This occurs, in part, because teams are specialized – they do not know, in any detail, how other teams do what they do. More generally, teams cannot anticipate developments in their wider environments, which in the case of health care might include epidemics or a major incident leading to many injuries. Suppose, for the sake of making the arguments clear, that uncertainty can be either high or low, so that there are four possible combinations of high and low task and environmental uncertainty. In the first case there is high certainty about both the specific clinical actions and the best way of co-ordinating them over the next few days or weeks. This is found, for example, in care following the diagnosis of some cancers, or following a suspected heart attack. It may be that our elderly patient, Mrs B., is able to go home the same day, with no need to change any of the support she receives in her own home. The main co-ordination challenge is to get her home safely.

Second, there can be certainty about the treatment that is needed now, but not about the environment that a patient will have to cope with later on in a journey. Mrs B. might be able to go home, but it may not be clear to hospital staff whether she will be able to cope without additional help when she gets there. Third, there can be low certainty about the necessary treatment, but high certainty about the general environment. This situation might occur with many of us, where there is clearly

something wrong, but it is difficult to pin down what it is. While we and our doctors are working out what is wrong, though, at least we know we have our friends and family to support us. Fourth and finally, there are many circumstances where both task and environmental uncertainty are high. It is necessary to rely on local discretion – of both clinicians and patients - about the combinations of clinical inputs needed to help navigate care journeys. In this context it may well be appropriate for individuals with similar medical needs, but who differ in other respects (such as the extent of family support), to receive different services.[12] This diversity should not be confused with the unwarranted variations observed in studies of practice variations.[13] Finally, there is a fourth combination, of high task uncertainty and low environmental uncertainty.

Drawing on these arguments, we can sketch out two theoretical ideals, one based on teams optimizing efficiency and the other on them maximizing the capacity to respond flexibly – to expect the unexpected. The first is, in essence, total quality management. Total quality thinking is based on the relative certainty of industrial production, where there are always major challenges, not least in continuously reducing costs and improving quality, and in ensuring that quality improvements in one part of a process do not disrupt processes elsewhere. This type of thinking is entirely appropriate in many services, where there is high certainty about most patients and there are well established routines, for example in maternity services or high volume elective surgery.

The second ideal is based on a capacity to expect the unexpected, and on having knowledge of the referral options available for each patient. When Mrs B. arrives at the emergency department, the clinicians do not know what is wrong with her. They should be able to assess her and take the appropriate actions, whatever is wrong with her – whether she has a nasty cold coming on, or needs cardiac surgery in the next few hours. That is, the emergency team should be able to mobilize whatever resources they need. These will vary from patient to patient, so that the system as a whole needs to be designed to provide resources in different combinations at any one point in time. The emergency team should, further, be able to ensure that Mrs B. is referred to the right teams – in her case, back to her GP, nursing and therapist teams near her home.

More generally, we can say that this second type of team exhibits, (i) the ability to respond to each patient individually, mobilizing different combinations of services for each one as necessary, and, (ii) an ability to refer patients to the right team or teams, which requires knowledge of the options that are available, and an ability to make the right decision even when it is not clear what the problem is. This is qualitatively different from total quality initiatives, and from the concept of flexible specialization described earlier. The second model is not concerned with continuous improvement, or at least with continuous improvement alone. Rather, the key qualities are flexibility of response and robustness – teams can cope with a very wide range of problems that come through their doors.

6. Institutions Shape Journeys

We have some useful sketches, but they are only part of our story. During Mrs B's hospital visit, her care needed to be co-ordinated. The ambulance needed to arrive quickly, and warn the emergency department about Mrs B's problems. Doctors in the emergency department needed to order tests and get results in a reasonable period of time. And so on.

Many researchers, including those working in the field of computer supported co-operative work (CSCW), would focus quite properly on the role of communication in the co-ordination of Mrs B's care. But sociologists and political scientists point out that institutional arrangements substantially influence the decisions and actions of clinicians working in any given environment. These arrangements have been established over years, or even decades. Individuals within teams have established ways of working with one another, and also established ways of managing their relationships with other teams, so that those teams are able to co-ordinate their work with one another. Much of the time, teams do not need to communicate with one another directly, or can communicate using brief messages – a referral form, a brief telephone conversation. That is, these norms can help to increase efficiency.

The point here is that institutional relationships shape patient journeys. That is, patient journeys are not simply sequences of rational decisions, taken in the face of greater or lesser uncertainty. Decisions taken by both clinicians and patients are influenced by

the prevailing institutional arrangements. In the context of our arguments here, there are two useful indicators of the importance of this point, and key weaknesses in many health systems around the world, namely the extent to which patient journeys are the journeys that patients want and need to take, and the safety of patients in the course of their journeys.

Taking the patterns of patient journeys first we can say, on the positive side, that there is good evidence that patients are often satisfied or very satisfied with the services they receive. The level of satisfaction varies from country to country, and over time, but it seems reasonable to infer that many patients receive the services they need. Their expectations are met and their health problems are successfully addressed. Less positively, as noted earlier, there is evidence of systematic variation in many areas of health care, for example in referrals by family doctors to hospitals, in prescribing practices and in access to mental health, physiotherapy and other services. There is also evidence that people with multiple problems – typical of many older people – receive fragmented and incomplete services.[14] The variation can be attributed, at least in part, to differences between professionals. If some GPs refer more than others, and issue more prescriptions than others, then it is likely that their own behavioural norms are influencing the services that patients receive.

The second indicator is the safety of patients. Adverse events are a reasonable, if general, indicator of the integrity of a health system, covering both events that occur within teams and between them. The Institute of Medicine's report, *To Err Is Human*, stressed the importance of designing safe systems of care – or safe patient journeys in the context of this discussion.[15] There have been very substantial efforts, in many countries, to improve the safety of services since the publication of that report, and other reports conveying similar alarming messages. There have undoubtedly been improvements in many services. Consider the following passage by Leape and colleagues:

“Too many healthcare organisations fit James Reason's definition of the “sick system syndrome.” They are hierarchical and deficient in mutual respect, teamwork and transparency. Blame is still a mainstay solution. Mechanisms for ensuring accountability are weak and ambiguous. Few have the capacity to learn and change

that is characteristic of the so-called high reliability industries. Most do not recognise that safety should be a precondition, not a priority... Many physicians do not know how to be team players and regard other health workers as assistants ... Too many practitioners—doctors, nurses, pharmacists, therapists, technicians—function in “silos,” focusing on their own performance and communicating with others in fragmented and inefficient ways that inhibit teamwork. Patients are seldom included in organisational planning or in the analysis of adverse events that have harmed them.” [16]

The ‘safety movement’ in health care has grown substantially in the last ten years, but there is clearly still a long way to go. The main implication, for this paper, is that improving patients’ journeys requires the proactive management of those journeys, taking into account their preferences, so that they go on appropriate journeys. This point is reinforced by another trend, around the world, away from the provision of reactive illness services to the management of long-term conditions (such as asthma, diabetes or neurological conditions such as Parkinson’s Disease). There is also a trend towards the management of a range of known risks, such as the risk of developing pressure ulcers, of experiencing a fall (and breaking a hip or other bone), or of a heart attack or stroke if one smokes, has a poor diet or fails to exercise. In short, when patient journeys are inherently uncertain – or open-ended - in nature, and there are concerns about the governance of services, the best strategy is to proactively manage those journeys.

7. Implications for IT Systems

Current IT design practice tends to focus on the collection of detailed activity information. This is reasonable. The recording of clinical information has a long history, stretching back into antiquity. Counting, and aggregating, information for managing services and for accountability to governments or insurers has a shorter history, but it has had a major influence of thinking about information in the last 30 or so years. Data collection on the ground has long had to include data required by others, who are not directly involved in treatment and care. Indeed, in many countries

this ‘machine bureaucracy’ thinking dominates thinking about the design of digital services. The result is that digital services have long been designed and used principally for recording and counting purposes.

In the last decade or so, there have been two significant trends. One involves the progressive linking together of formerly separate IT systems – family doctor systems to hospital systems, hospital systems to one another, and so on. The other is the ‘colonisation’ of people’s personal lives, under the banner of so-called telehealth applications. Most of these applications are designed to gather data from individuals, living in their own homes, purportedly to monitor their health status remotely. It has to be said that there is little evidence that such applications are effective, still less cost-effective. It is also striking that the ethical implications of these two trends have barely been explored. Linking systems together, by its nature, raises concerns about privacy and confidentiality. Colonisation raises questions about the relationship between health care providers and individuals going about their private business. But governments around the world are enthusiastic about telehealth, and suppliers are happy to provide technical solutions.

The important point here is that there is a mismatch between most current practices in designing and implementing digital services and important trends in the management of patient journeys. The implication of the arguments set out in this chapter is that it is difficult to turn ‘machine bureaucracy’ information, that has been collected in silos, into information that can be used to actively manage patient journeys. Indeed, managing risks in the course of patient journeys will often require quite different types of information. The information that helps nurses to monitor Mrs B’s risk of a fall or of developing a pressure ulcer is different in kind to the information that is routinely collected on a ward or in a community setting in most countries.

There is some evidence about this mismatch. One person who has thought hard about this problem is Dr. Aksel Tjora, a Norwegian emergency physician and researcher.[17] He makes a straightforward observation: in his hospital, he has access to a number of departmental systems at a single terminal. And yet, even though he has access to far more information than he used to, it does not help him very much with the management of processes of care.

8. Concluding Comments

We can put the arguments set out in this chapter together. They point to the need to develop information systems for managing clinical and organisational risks. Thinking and practice in this area is still in its infancy. But there are signs that thinking is changing. There has, for example, recently been a great deal of interest in the use of checklists for managing both known risks and to encourage clinical teams to ‘expect the unexpected’, for example by checking that procedures are in place should anything go wrong (conceptually, the equivalent of having fire extinguishers in place in the unlikely, but plausible, event of fire). There has, similarly, been substantial interest in capturing patients’ assessments of the outcomes of the services they receive. By and large the tools and procedures for monitoring risk and outcomes have not been automated: but the existence of valuable research and practice suggests that automation is now possible.

Thinking about the systems that will enable patients – and their carers – to become actively involved in their journeys is for the future. One obvious move is to ensure that patients can access their own records – and this is already possible in several countries. The problem here, of course, is that existing systems are not focused on patients’ risks – on the extent to which they, or their clinicians, are successfully managing risks, as opposed to treating them reactively.

From a patient perspective, there is also an argument for implementing systems to ensure that risks and outcomes are being routinely monitored, and signs of problems acted upon. That is, there are arguments for ensuring that systems are designed in patients’ interests – not just that they are engaged in their own journeys. If patients cannot trust the institutions looking after them, then they need assurance processes to be built in. The results would look very different from much current practice, emphasizing risks and outcomes rather than the recording and counting of activity.

This chapter has argued that it is possible to identify a generic approach to representing health care pathways. The approach is based on three building blocks, namely clinical teams (as opposed to decision-makers or idealized patient ‘flows’), the ability of teams to cope with radical uncertainty, and taking into account the ways in which institutional arrangements influence the journeys that patients take through

health systems. In practice, few suppliers in the sector have begun to incorporate checklists and other risk management tools into their systems. There is, then, a mismatch between much current requirements and design practice and the need on the ground, for information systems that are oriented towards the pro-active management of clinical and organizational risks.

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