Sustainable Information Infrastructures: Insights from a Realist Synthesis

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Abstract. Policy makers and health system managers in many countries are advocating the deployment of inter-operable health information technology systems, spanning organisations in a health economy, believing that they will be clinically effective. The case for investments has not, however, been made to date. This paper presents early results from a systematic review of the effects of inter-operable systems on patient safety. The review uses the realist synthesis method, which focuses on evidence about the decisions and actions that link interventions and outcomes, as well as the evidence about those outcomes. The evidence base is sufficient to identify plausible arguments for investments in inter-operable systems. This said, there is limited empirical evidence about each of the steps in the sequences of events. We comment on implications for the design of sustainable socio-technical solutions. We suggest that current gaps in the evidence base are in areas where informatics field methods can make a valuable contribution to our understanding of the role of inter-operable systems in patient safety.

Keywords. Interoperable, health information technology, patient safety, realist synthesis

1. Introduction

Governments and health system managers in many countries are funding inter-operable health information technology (HIT) systems [1, 2]. They believe that clinicians need access to the whole of a patient's record, particularly when that patient has complex needs and is supported by several professionals. It is therefore necessary, they reason, to deploy inter-operable systems across all organisations in a health economy. While the argument is intuitively reasonable, though, the case for inter-operable HIT systems has not yet been made. This paper seeks to establish whether a case can be made, and if it can, what evidence is available to support it.

If everyone agreed on the way forward, and was convinced of the value of inter-operable HITs, this might not matter. In practice, though, influential clinicians have recently drawn attention to the practical difficulties that they face in the course of their work [3, 4]. The case does, therefore, need to be made.

The need, then, is for a review method that 'opens the black box', and reveals on the sequences of decisions and actions that lie between the use of an inter-operable HIT and substantive outcomes, as well as establishing the nature and value of those outcomes. We present the early findings of a systematic literature review, using the realist synthesis

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method, which focuses on the effects of inter-operable HIT systems on patient safety. The IEEE defines inter-operability as the ability of two or more systems or components to exchange information and to use the information that has been exchanged [5]. In this review we focused on foundational and structural deployments that are more common in practice: more evidence is available about them, and findings will be relevant to the majority of current practitioners [6].

2. Methods

Realist synthesis involves, first, identifying programme theories [7]. These are sequences of decisions and actions that link an intervention to an outcome, and thus capture the *intended* effects of the intervention. Attention is also paid to policy makers, researchers and others' theories about the intervention. The review team use their theories to develop their own accounts both of how *and why* the intervention might work in a particular way. Literature searches are then designed, and empirical evidence identified, assessed and synthesised, to evaluate the extent of evidence for *actual* sequences of decisions and actions. The evidence might lead to a particular programme theory being supported, rejected, or to being refined. Realist syntheses therefore address both components of a business case, empirical evidence and closely reasoned argument.

The five stage of a realist synthesis is described in detail by Pawson in *Evidence-based Policy* [7]. Stage 1 of the review involves developing programme theories (see Figure 1). There were two elements to the research in this Stage. Three literature searches were undertaken, using Medline, Embase and other electronic resources:

(1) Systematic reviews that included insights into the relationships between inter-operable HIT systems and patient safety;
(2) Search for policy documents, opinion pieces (e.g. editorials) and reports describing leading theories about the relationships between HIT systems and patient safety;
(3) Author searches for articles by David Bates, the most cited author in the health informatics literature, and Robert Wachter, the author of an influential 2016 report on IT in the NHS in England.

The search findings were used to develop initial programme theories.

2.1. Nominal Group Meetings

The second element of Stage 1 comprised nominal group meetings with each of two groups of stakeholders, namely senior health and care service IT managers and policy makers. The nominal group technique involves an initial meeting, where initial agreement on a topic of interest is reached. This is followed by one or two rounds of email consultation, to allow participants to reflect on the initial agreement, and if necessary refine it [8]. In this review participants were invited to comment critically on the initial programme theories, on the basis of their knowledge and experience. They were also asked to prioritise theories, and/or particular sequences of events within theories, for further study. Following these meetings, and consultation with the study patient and public involvement group, decisions were made about the focus of the evidence searches in subsequent Stages.

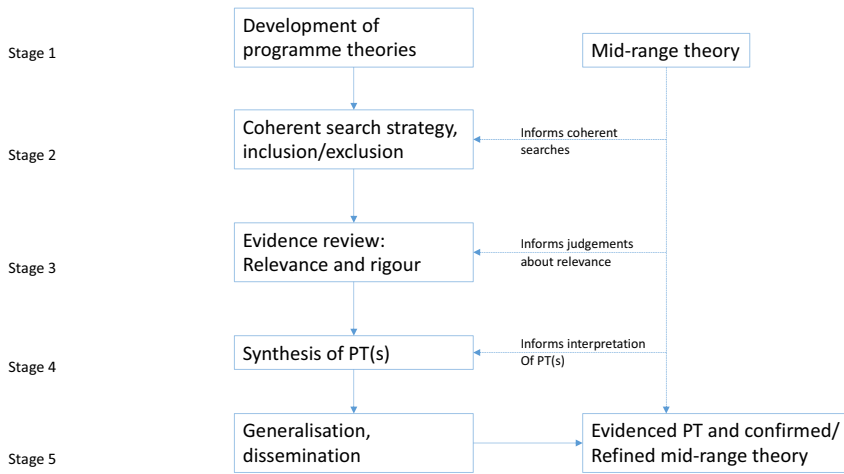Realist synthesis: modified method

Figure 1. Stages of the realist synthesis (PT = programme theory).

2.2. Mid-Range Theory

Mid-range theories are more general forms of programme theories, which typically capture the way in which an intervention works across a number of settings, e.g. how a telehealth application works in a range of specialties, for different groups of patients, and in different countries [9]. They perform an integrating function in the course of a realist synthesis. As Figure 1 shows, they provide an explicit basis for methodological judgements in Stages 2-4. By their nature, realist syntheses deal mainly with observational evidence, typically drawn from studies undertaken in a number of different academic traditions (e.g. ethnography, cognitive psychology, organization studies). A mid-range theory was identified, which provided a broad theoretical framework for interpretation of evidence from the traditions covered in the review.

2.3. Evidence Search, Selection and Synthesis

Stages 2, 3 and 4 are designed to establish the sequence of events that lead to *actual* effects of inter-operable HIT systems: evidence is identified in literature searches, and used to evaluate the intended effects. Stage 2 comprises the main literature searches. Search PICOS – populations, interventions, comparators, outcomes and settings – were determined. Inclusion and exclusion criteria were agreed within the team, the searches undertaken, and included papers identified on the basis of titles and abstracts. Stage 3 involved close reading of the included papers, which were assessed for rigour and relevance. Papers were excluded at this Stage if it became clear that they were not relevant. In Stage 4 the findings from the included/relevant papers were synthesised, drawing on the mid-range theory as the theoretical basis for interpretation. The syntheses led to refinement of the initial programme theory.

Two sets of searches were undertaken, one focusing on the co-ordination of health and care services in general, and the other on a specific co-ordination challenge, medicine

reconciliation, where a patient is prescribed by more than one professional. Each set involved a number of literature searches, which together were designed to evaluate key steps in the programme theory, and reveal both how and why inter-operable HIT systems were effective (or ineffective). For care co-ordination, reported here, the searches were designed to address three questions:

(1) What is the nature of the care co-ordination problem? Are the problems of a kind that inter-operable HIT systems can help to solve – or not?
(2) What are the experiences of health and care professionals searching for information about patients in one anothers' systems?
(3) What are the effects of inter-operable HIT systems on patients' clinical risks?

3. Results

In Stage 1, we did not find any published, plausible, sequence of events linking the use of inter-operable HITs to patient outcomes. The searches did, though, yield a number of theory fragments, and we used these to construct three initial programme theories. Consultation with the nominal groups led us to focus on a specific domain, namely the treatment and care for frail older people living in their own homes. The consultation also prompted us to focus on evidence about functional HIT systems. The argument was two-fold. First, we should find relevant evidence about current systems, but relatively little about semantically inter-operable systems. Second, policy makers' and practitioners' immediate need was to identify convincing business cases for their current systems. The battle for hearts and minds in the broader health and care system was not yet won.

We also settled on a mid-range theory, which located the synthesis in the literature on information infrastructures [10]. The first statement of the mid-range theory was:

> *Older people with complex needs are supported by care professionals who have different backgrounds and training, and who often work in different organisations. Networked IT systems in health and care settings are embryonic information infrastructures, which over time are likely to become more inter-operable (in the sense that an engineer would use that term). Information infrastructures span a number of professionals and organisations. The long-run intention is that professionals will integrate the use of the IT systems into their work, so that they effectively become invisible. When infrastructures become invisible, they contribute to overcoming co-ordination challenges that naturally arise in these institutional arrangements. The resulting improvements in the effectiveness of co-ordination will, in turn, lead to reductions in patients' risks.*

At the time of writing we have completed three searches on each of two topics, care co-ordination and medication reconciliation, for older people living at home. The full search results, and synthesis, will be presented at CSHI 2019.

We comment here on the three care co-ordination searches. In the first search we found substantive evidence about the nature and extent of care co-ordination problems. Most of the problems were essentially social or cultural in nature. For example, there were several evidenced-based reports of difficulties due to different healthcare professionals having incompatible working assumptions about the kinds of support that older people needed. There was no obvious role for any HIT solution in most of these problems [11].

One problem, though, might be addressed using inter-operable HIT systems. This concerned difficulties associated with information seeking and retrieval, and the second set of searches focused on this question. A number of observational studies were identified, which reported a range of problems with information search and retrieval. The problems were attributed to inter-professional issues – not directly related to technology – as well characteristics of the technologies (such as multiple log-ons) and locating patient information held on other organisations' servers. We did not find any countervailing studies, which reported 'seamless' use of inter-operable HITs [12].

The third search focused on evidence of effectiveness – in this study, in measurable changes in risks to patient safety. We found very limited evidence relating to services for older people, and little more for services for adults more generally [13,14].

4. Discussion

The findings of the first Stage of the review indicate that no complete sequences of events have been published, that might plausibly represent the link between the use of inter-operable HIT systems and effects on patient safety. It is always difficult to 'prove a negative', but we conducted a number of different searches, using different databases, search themes and methods.

This said, we believe that it is possible to identify the outline structure of cases for inter-operable systems in health economies. Our main finding is that, currently, there is limited empirical evidence to support programme theories, particularly in relation to the effects of using HITs on patient level changes in risks. We suggest that this opens up a significant research and development agenda.

The early findings enable us to identify three broad strategic outcomes of current policies. One is the ideal sustainable outcome, where inter-operable systems are deeply embedded in everyday working practices. We have not found evidence for this outcome. The second might be termed 'sustainable but ineffective', or 'frustration with technology': systems fit poorly with working practices, but clinicians have little choice but to use them. There is empirical support for this outcome. A third outcome is failure to deploy, which we have not investigated in this review, but which other studies remind us is a possibility.

The question that follows is: can we explain the current evidence? Wachter, Gawande and others argue that current technology solutions are simply not very good. Our findings offer indirect support for this position. We favour a slightly different explanation, though, which has two related components. The first concerns the design and deployment of systems. Inter-operable systems are, by definition, developed on the basis that can help to solve a systemic co-ordination – or collective action – problem. If the ways in which HITs will help to solve these problems are not addressed in the course of the design and deployment, the scope for an inter-operable system to contribute to safer care must be limited. If experiences in England are at all representative, information technology policy making tends to focus on defining data and communication standards, and on the broad direction of IT developments. They do not consider, in any detail, the ways in which those technologies might produce safer care (or any other desirable outcome).

The second component concerns the need to address social and cultural issues in parallel with design and deployment. If, for example, responsibilities for the reconciliation of medication lists, and of medication lists with patients' symptoms, are

not clear in the first place, the extent to which any inter-operable solution can – by itself - lead to safer care will again be limited.

Finally, we suggest that the gaps in the evidence base are in areas where informatics methods can make a valuable contribution. The most obvious need is to understand the roles and responsibilities of health and care professionals, and the information flows involved. A research programme could draw on responsibility modelling, ethnographic studies of information flows and other methods to characterize these important socio-technical challenges.

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