

Leading article

Exploiting the information revolution: call for independent evaluation of the latest English national experiment

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ABSTRACT

Background The English National Health Service (NHS) has a long history of national experiments with information technology; some successful, others less so. The NHS England Five Year Forward View aspires to ‘Exploit the information revolution’ through the transformational work of the National Information Board (NIB). NIB has published a ‘Framework for Action’ that promotes citizen empowerment, information availability, transparency, public trust, innovation, informatics skills and societal value.

Issue The framework sets out many laudable and common sense ambitions, but is light on evidence to support its aspirations, or plans for its evaluation. Considerable resource was invested in evaluation studies in the later stages of the National Programme for IT in England, but the analyses do not seem to have been included. Most of the cited evidence is from an unpublished report by management consultants rather than independent peer-reviewed work.

Recommendation National experiments of this importance should be evidence-based and properly evaluated so that each iteration of ‘information revolution’ produces an evidence base to inform subsequent generations of care provision models and technology innovation. Evaluation should be planned from the very start rather than added in as an afterthought. Like any good business plan there should be defined critical success factors for health and social care, and a declaration of how they might be measured. Unintended consequences should be qualitatively explored. Evaluation should also consider critical-interpretive social perspectives to understand the human factors in technology deployment and should seek a theoretically informed insight into the mechanisms of change.

Conclusions The NHS Five Year Forward View and the NIB framework set out challenging ambitions based on transformative use of information technology and collaborative partnerships with commissioners and providers. Whilst the framework stands up very well against the Hayes principles, but the learning opportunities associated with this programme should not be missed.

Keywords: evidence-based practice, health policy, medical informatics, programme evaluation

INTRODUCTION

The NHS England Five Year Forward View¹ aspires to 'Exploit the information revolution' through the transformational work of the National Information Board (NIB). The NIB has commendably brought together a broad spectrum of public and patient bodies and published a Framework for Action² that sets out proposals based around citizen empowerment, information availability, transparency, public trust, innovation, informatics skills and societal value. These are all good aims, if not entirely new ones.

The NIB framework is keen to say that it is 'not a strategy' and 'not a national plan', but represents 'core and immediate priorities' that will be developed in a series of forthcoming 'roadmaps'. The framework and the associated NHS planning guidance³ do seem to reflect a genuine attempt at a more joined-up approach at the national level (in England) and a desire to build relationships with local commissioners and providers that are more open, collaborative and partnership based than previous central planning regimes have achieved. The framework also promises a published evidence base to support its proposals – one of the main points that this article addresses.

The framework is the latest in a long line of information strategies for the NHS in England (which it is, despite its protestations to the contrary) such as 'Implementing the infrastructure'⁴ in 1994, the seminal 'Information for Health'⁵ in 1998, the well intentioned but ultimately doomed 'Delivering 21st Century Support for the NHS'⁶ in 2002 and the 'information Revolution'⁷ consultation that led to the 2012 (but already archived) 'Power of Information'.⁸ Each iteration has contributed something, but information strategies are transient by nature and have recurrently fallen short of their grander aims.

ISSUE

The framework sets out many laudable and common sense ambitions, but is light on evidence to support its aspirations, or plans for evaluating the results of its experimental interventions.

Considerable resource was invested in evaluation studies in the later stages of the National Programme for IT in England, but the analyses⁹ are not cited in the framework's reference lists. Most of the cited evidence is from an unpublished report by management consultants¹⁰ rather than independent peer-reviewed work. The consultancy report was 'commissioned to support this framework', which inevitably raises questions about its objectivity. There is an 'Additional reference material' section that does give a bibliography of academic and grey literature relevant to each proposal heading, but it is not integrated into a coherent evidence-based justification. The only genuine evidence directly cited is the collection of research summaries produced by National Voices about person-centred care.¹¹ However, the actual text of these digests is more nuanced than the rather sweeping generalisations offered by the framework and, curiously, this one good piece of evidence only merits a single incomplete sentence of comment.¹² Regrettably, the text of the framework does invite the suspicion of a selective use of knowledge from previously attempted 'revolutions'.

The foreword promises that an evidence base will be published, but this only reinforces the inference that the proposals are primarily derived ideologically rather than evidentially.

Of course, there is a significant literature reporting various benefits of health information technology to clinicians, patients and management in a wide variety of settings, but systematic reviews have questioned the strength and sufficiency of the evidence base.¹²⁻¹⁴ Information technology can have negative impacts on care provision and patient outcomes,¹⁵⁻¹⁷ and there is a lack of mature measurement science in health informatics.¹⁸ The European Federation for Medical Informatics and International Medical Informatics Association working groups have provided sustained leadership to address these weaknesses and develop health informatics into a properly evidence-based discipline,¹⁹ but this is a long journey from where we are now.

RECOMMENDATION

We first offer a brief critique of the main ideas of the framework, based around the questions.

- What is the evidence for the central assertions of the framework?
- What is planned for evaluation?
- How well does the framework apply the Hayes principles²⁰?

Two central assertions of the framework for health and social care in England are that:

1. information technology can reduce service consumption and operational costs; and
2. the desired 'information revolution' is feasible by 2020.

Given the massive funding gap²¹ facing care services, acknowledged in the forward view, it is understandably tempting to assume that information technology can make it all better and cheaper. However, previous generations of health service information strategies have had similar hopes.

What is the evidence for the central assertions of the framework?

Reducing utilisation and costs

The first fundamental assertion underpinning the whole argument of the framework is given in its foreword and repeated verbatim in the NHS England planning guidance:

'Technology can help people use care services less by supporting healthier lives and it can transform the cost of services when they are needed'.

What evidence supports this claim?

Under the heading: 'There is good evidence that better use of data and technology improves patient outcomes and the value of services', the document refers (twice) to:

1. unpublished management consultancy report - about *potential* benefits, according to its reported title;
2. anecdotal data from an US hospital; and
3. the national voices evidence summaries.

The latter sources cite systematic review evidence of reduced service consumption (in surgery) from improved pre-operative and pre-discharge information, conflicting results about telemonitoring and some evidence of the cost-effectiveness of home-based self-management (but with questions about its economic sustainability).²²

Against this must be weighed other findings. For example the European Commission funded a study of the economic impact of interoperable electronic health records (EHRs) and electronic prescriptions (the 'EHR IMPACT' study). This 2010 report evaluated the costs and socio-economic benefits of EHRs in nine implementations in various European countries (including local, regional and national project of different kinds) and concluded that:

'EHRs and ePrescribing are beneficial socio-economic investments in better healthcare, but, except in very specific circumstances, need net cash injections'.²³

So simply put, information technology makes things better but not cheaper.

Another obvious example is the large scale trial of telehealth in England, known as the whole system demonstrator (WSD).²⁴ The WSD examined effects on mortality and secondary care utilisation,²⁵ organisational issues,²⁶ cost-effectiveness^{27, 28} and the perceptions of healthcare professionals.²⁹ The flagrant political spin on the findings of the WSD, as selectively exploited by the Department of Health, is well known.³⁰ However, the plain fact is that the studies showed that telehealth was not cost effective, based on a realistic estimate of acceptable cost per quality-adjusted life year. Again, perhaps better but not cheaper.

In addition, there are sometimes new inefficiencies introduced by EHRs. The 2013 RAND Corporation report on physician satisfaction^{31,32} found that clinicians in thirty US practices agreed that EHRs improved communications, data access and some aspects of care quality. However, they mostly reported worsened satisfaction arising from time-consuming data entry, poorly designed user interfaces that did not match clinical workflow, interference with direct patient care, insufficient interoperability, information overload, cost, document templates and increased administrative tasks. These various inefficiencies (in some cases requiring work re-design to introduce a 'scribe' to support physician use of the EHR) are all tractable issues, but perhaps suggest that the current generation of off-the-shelf products may not pose a ready-made solution to health service transformation.

In another example, the effect of patient portals to promote self-management on service utilisation and efficiency is unclear; systematic reviews have reported mixed findings, whilst noting that a pronounced social and ethnic digital divide exists.¹⁴

There is no doubt that information technology has the *potential* to reduce transactional operating costs in many areas of health and social care, as in other industries, but the important questions are what will work in what circumstances and how well the transitional costs and operational changes will be managed. In many cases, the financial benefits are not

likely to arise in the same organisational budget as the costs, so judicious whole-system management will be required.

Feasibility by 2020

The framework's second basic proposition is that an 'information revolution' by 2020 is feasible for health and social care in England. To support this, the framework uses the time-honoured analogies with simple transactional services like flight booking and online banking. While there are certainly 'customer transaction' elements in the administration of care (predominantly when it is elective), the long slog to make progress with even the easiest 'service channel' like hospital outpatient booking^{33,34} surely shows that even changing administrative transaction processes in the NHS is far from a trivial piece of business change – however, tantalisingly simple the technology may seem to be.

There are serious flaws in the banking and airline analogies. First, the inherent richness and density of patient information in all its forms is orders of magnitude more complex³⁵ than the simple data used in financial transactions or the instrumentation and logistics data used in aviation. Second, the finance and aviation companies have straightforward hierarchical management structures, unlike the fairly loose 'system' of autonomous professions and organisations that deliver health and social care in England. Third, both of the cited industries have had decades of sustained and substantial investment in their information technology capabilities.^{36,37}

Of course, Wanless³⁸ identified back in 2002 the very low proportionate spending on information technology in health as compared to other sectors of the UK economy. The most recent update³⁹ on NHS spending on information technology (not reported since 2009) did not show a significant improvement in revenue expenditure. It is unknown whether the selective capital financing provided through the NHS England technology funds⁴⁰ has stimulated sustained increases in revenue expenditure. The successes of general practice computing in comparison to hospital EHRs had much to do with the incentives provided.⁴¹

No doubt many of the ambitions of the framework are eminently achievable. However, the briefly stated 2020 ambitions ('all care records digital, real-time, interoperable and using SNOMED CT') seem rather far-fetched. By way of comparison, using a relatively straightforward information requirement, the 'new' NHS number was introduced in 1995⁴ yet is still not universally used after nearly 20 years (as acknowledged by the latest attempt to make it mandatory in the current planning guidance³). Of course, '*stretch goals*' are sometimes useful and no one would suggest an unnecessarily pessimistic or unambitious target. Perhaps the forthcoming 'roadmaps' will build confidence that the five year vision is achievable.

What is planned for evaluation?

With the notable exception of the experimental patient-controlled mobile care record^{2p.25}, there is a lack of any evaluative framework that might identify either beneficial or harmful unintended consequences of this plan. Evaluation and prospective outcome measurement is only mentioned with reference to care data^{2p.34} and in a passing reference to producing evidence of impact 'using experimental and quasi-experimental methods' ^{2p.54}. The digital maturity index^{2p.30}, a 'census of

digital progress', seems to be the principal measure of adoption and benefit. The planning guidance indicates that NHS England proposes to establish 'a new operational research and evaluation capability' ^{3p.8}, but this is for the new models of care not for the revolutionary information changes.

Policy makers and commissioners should want to ensure that national experiments of this scale and importance are properly evaluated so that each iteration of 'information revolution' produces an evidence base to inform subsequent generations of care provision models and technology innovation. Evaluation should be planned from the very start rather than added in as an afterthought. Like any good business plan there should be defined critical success factors for health and social care, and a declaration of how they might be measured. Unintended consequences should be qualitatively explored. Evaluation should

consider critical-interpretive social perspectives⁴² to understand the human factors in technology deployment and should seek a theoretically informed insight into the mechanisms of change.⁴³

How well does the Framework apply the Hayes principles?

This journal distilled the 2009 Hayes review⁴⁴ into a set of ten guiding principles²⁰ and proposed they could be used to evaluate plans for new information technology projects. Table 1 offers a high-level assessment of the framework using these 10 principles.

The framework stands up very well against the Hayes principles. Especially, in its patient-centric theme and its stated principles of subsidiarity, the approach is encouraging. On these criteria, as argued earlier, its notable weakness is on evaluation

Table 1 Assessing the framework against the Hayes principles

Principles	Assessment	Comment
<i>Patient-centred principles</i>		
The patient must be at the centre of all information systems.	Excellent	The framework is strongly patient-centric and its theme is 'personalised care' for patients and citizens.
The provision of patient-level operational data should form the foundation – avoid the dataset mentality.	Good	The objective (page 32) is 'collecting all the information required to support direct clinical care and the analytic needs of health and care, once and once only at the point of care', but datasets are needed until that is feasible.
Store health data as close to the patient as possible.	Less relevant	This principle set out how trust was key in sharing data. The closer physically data are held to the patient, the greater the willingness to share. Maybe less relevant in the age of the 'cloud'.
Enable the patient to take a more active role with their health data within a trusted doctor–patient relationship.	Excellent	The self-management aim is fundamental to the framework.
<i>Subsidiarity principles</i>		
Standardise centrally – patients must be able to benefit from interoperability.	Good	Adopts the forward view idea of 'central standards, with explicit and extensive permissions to unleash local energy and enterprise' (page 13).
Provide a standard procurement package and an approved process that ensures safety standards and provision of interoperable systems.	Good	The framework leaves procurement to local decisions: 'we will be tight on standards and definitions, and clear on expectations regarding interoperability, but we will support local decision-making on systems, programmes, interfaces and applications...[local health and care communities will] decide upon and procure their own solutions, provided they meet nationally specified technical and professional standards' (page 17).
Authorise a range of local suppliers so that health providers can select the system best meeting local needs.	Good	Proposes 'local buying consortia' and raises the possibility of replacing GPSoc with direct funding to allow greater freedom of choice of supplier (page 52).
Allow local migration from legacy systems, as and when improved functionality for patients is available.	Good	This is implicit in the previous point.
<i>Strategic principles</i>		
Evaluate health IT systems in terms of measureable benefits to patients.	Weak	The concept of evaluation is acknowledged but insufficiently developed, as argued above.
Strategic planning of systems should reflect strategic goals for the health of patients/the population.	Good	In the context of transparency, the framework says it will take account of work by the Department of Health, NHS England, Public Health England and the Local Government Association to 'develop and align the outcomes frameworks for the NHS, public health and social care' (page 38).

(and using the evidence from previous evaluations). It is to be hoped that the forthcoming 'roadmaps' will address these issues.

SUMMARY

The NIB framework is a political programme, and therefore by its nature primarily a vehicle of ideology, but the NIB should

seek guidance from published evidence and lessons from previous attempts. The NIB should positively welcome the idea of independent holistic evaluation so that success can be rightly commended and failure (inevitable in any innovation) can be learned from.

Once again we have an excellent opportunity to improve the evidence-base for health and social care informatics. Let us hope the opportunity is not missed.

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