

NSW Health

**An Evaluation of the Healthelink Electronic
Health Record Pilot**

Summary Report

Prepared by KPMG for NSW Health

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1 Overview

This report presents the results of an evaluation of the New South Wales (NSW) Health Healthelink electronic health record (EHR) pilot. It focuses on the implementation, functioning and performance of the Healthelink EHR pilot from the time of its commencement in March 2006 to September 2008.

Healthelink is an information technology system that brings together a selection of a patient's health information from participating health service providers – general practitioners, hospitals and community health centres – into a single electronic health record.

NSW Health developed a system-wide electronic health record in response to a need to improve information flow across the health care system. A shared EHR enables clinicians across the health sector to have more timely access to patient information and is regarded as critical to improving patient care, and as a facilitator to other health care reforms being pursued by NSW Health and the Australian Government.

The Healthelink pilot is the largest shared electronic health record pilot to occur in Australia in terms of the breadth of application, and its period of operation, and has been the first to use an opt-out approach to patient involvement (for consent). Healthelink is therefore a significant contributor to informing national reforms in electronic health systems.

The Healthelink pilot commenced in March 2006 and initially eligibility was restricted to patients 65 years and over residing in selected Maitland (Hunter Valley) postcodes, and patients aged 15 years and under residing in selected Western Sydney postcodes. NSW Health expanded the eligibility criteria in February 2008 to include both age cohorts in the selected postcodes, and added four postcodes to the Western Sydney pilot site to include patients that resided and accessed service providers involved in Healthelink. Healthelink has involved over 800 clinicians of which 165 have used Healthelink in the last 90 days and has over 40,000 patients with a shared EHR.

The purpose of the Healthelink evaluation has been to inform the NSW Health state-wide rollout of Healthelink by assessing the acceptability, useability and viability of the Healthelink model. The evaluation involved both quantitative and qualitative activities, including interviewing patients and clinicians, analysing Healthelink data, and assessing technology and operational features.

Overall, the evaluation found that:

- NSW Health has succeeded in establishing and maintaining the technology to sustain an EHR in an environment where it has to contend with multiple health information system vendors, multiple versions of the same vendor product, variations in local set up configurations of the same system as well as different local approaches to data management.

- Strong support exists amongst clinicians and patients participating in Healthelink; very few patients have opted out of Healthelink and the opt-out rate has remained relatively low for the entire pilot.
- There is strong support for the consent model amongst patients and clinicians.
- There is confidence amongst clinicians and patients in the privacy and security arrangements.
- Compared to the underlying health care system, patients participating in Healthelink have more informed choices about their health information, have greater transparency as to the management of their health information and have direct access to their health information (in summary form).
- There is confidence that the EHR will deliver benefits to clinicians, patients and to the service system more broadly.

The evaluation found that clinicians are supportive and confident that Healthelink will deliver the expected benefits. The use of Healthelink has been lower than anticipated, an observation that has been monitored and reported by NSW Health during the pilot. The evaluation assessed the reasons for this pattern of use, and has concluded that the contained nature of the pilot and the characteristics of the model employed, has led to a slower than expected take up of Healthelink into every day clinical practice.

The lower than expected level of use of the EHR can be attributed to:

- Healthelink has not yet reached a critical mass of patients, and does not yet contain sufficient information for its potential to be realised. Both of these factors are important for the EHR to be beneficial, and therefore to provide the incentive to clinicians to use Healthelink routinely. This is a consequence of the contained scope of the pilot and that it takes time to build up the content of the EHR.
- The process of accessing and using Healthelink is not yet seamlessly integrated into clinicians' routine system processes. This reflects the decision of NSW Health to contain the degree of sophisticated functionality as part of its pilot risk management strategy.
- Healthelink has experienced difficulties with some independent vendor software products that were not originally designed to accommodate a shared EHR. This will remain an issue until the software products used by GPs are able to accommodate the requirements to transmit information to a shared EHR.

The evaluation has identified a number of cases where Healthelink has been of benefit to clinicians, patients and more broadly to the service system, where:

- clinicians are not having to waste time to obtain patient information;

- clinicians are able to make more timely decisions and reduce the risk of a poor outcome for the patient; and
- patients access their own EHR enabling them to take more control over their care management.

The evaluation identified a number of areas that need to be addressed to realise the full potential of an EHR, and which have implications for the rollout strategy and Healthelink model. These are as follows:

- NSW Health should consider an incremental approach to the next stage of development focusing on extending the pilot to all patients in the existing two sites and enlisting the participation of more GPs and other community health care providers including specialist medical services and community pharmacists.
- The concept and role of the EHR should be broadened from being just a database to the health information exchange that links the public and private health care sectors. For example, it is envisaged that the EHR:
 - would include capability for active messaging between clinicians;
 - have functionality to pro-actively alert clinicians to new information about a patient or a patient's condition; and
 - enable patients and clinicians to directly and interactively share responsibility for on-going management of the patient's health.
- The EHR should include a health summary for each patient that is maintained by the patient's health care provider; the content of the summary needs to be developed by NSW Health in consultation with clinicians and patients.
- Healthelink needs to be interfaced with clinicians' routine clinical management processes, and thus into their primary clinical system, to improve the efficient use of Healthelink.
- NSW Health needs to actively engage the Australian Government on a number of key issues that will require a national approach, including national information standards and national technical standards that independent software vendors will need to comply with to ensure inter-operability and effectiveness of EHR operations.
- Finally, NSW Health needs to have in place a governance framework through which important issues such as privacy and confidentiality policies and provisions can be managed transparently and through which on-going development of Healthelink can be channelled.

2 Evaluation terms of reference and methodology

This evaluation was designed to provide information to NSW Health on the experiences and opinions of patients, service providers and stakeholders involved in the pilot and to advise on the implementation, functioning and performance of the Healthelink EHR¹. In particular, the evaluation provides advice in relation to:

- **Acceptability:** To what extent do participants and stakeholders accept the Healthelink EHR, particularly in relation to issues of consent, privacy, and security?
- **Usability:** How 'user-friendly' is the Healthelink EHR and to what extent is its current use contributing to the achievement of benefits for clinicians, patients and the health system?
- **Viability:** How viable and appropriate is the current Healthelink EHR model for broader implementation across NSW, including the suitability of the technical, operational and governance models?

The evaluation methodology included the following key activities:

- an analysis of quantitative Healthelink data relating to trends in patient enrolment, the richness of data on the record, opt-out rates and system use by clinicians and patients;
- qualitative research to explore clinician, stakeholder and patient experiences of Healthelink, including: interviews with more than 50 clinicians involved in Healthelink; interviews with a range of facility health service administrators, patient advocacy groups; and 174 patient² interviews, including patients that had decided to opt-out of Healthelink; and
- an assessment of technical operational and governance issues.

The results of these analyses were used to address the three evaluation terms of reference.

¹ The evaluation was not required to assess the cost of establishing and operating Healthelink.

² The term "patient" is used to refer to patients 65 years of age and older and to the guardians of patients who were 15 years or younger at the time of enrolment.

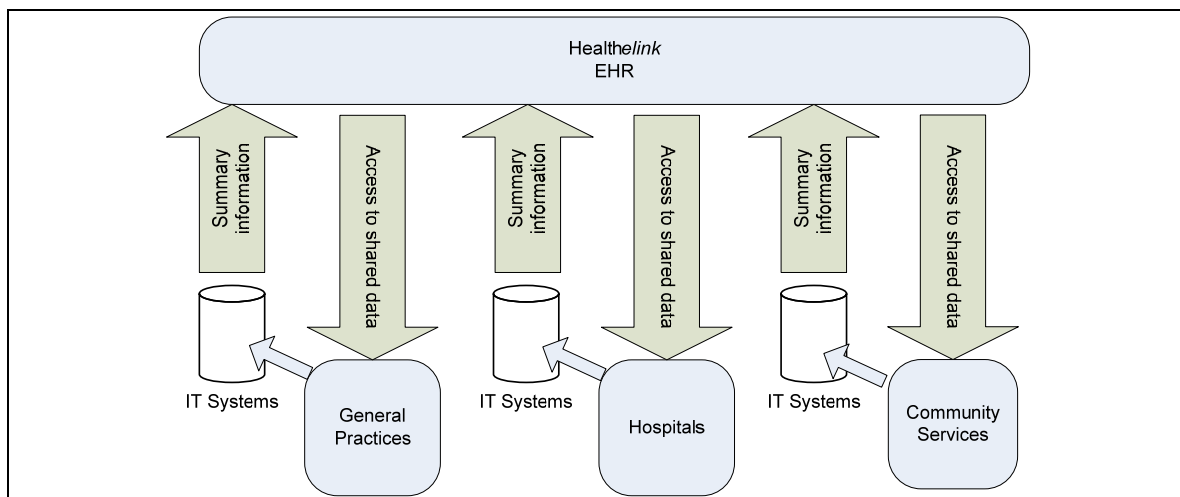
3 The Healthelink pilot

3.1 Purpose of the pilot

The purpose of the Healthelink pilot was to provide the opportunity to identify and assess the issues that would be critical to the long term viability of a state-wide EHR, to inform the business case for a state-wide EHR and to inform the rollout strategy.

Healthelink is an information technology system that brings together a selection of an eligible patient's health information from participating providers – general practitioners, hospitals and community health centres – into a single electronic health record. The following figure provides an overview of the Healthelink EHR process.

Figure 3-1: Overview of the Healthelink process



NSW Health made certain decisions regarding the technology and operational model for Healthelink, to ensure that the pilot was sustainable and to minimise the risks associated with taking too much on too soon. These decisions included:

- limiting the functionality of the EHR to being a data storage and retrieval system (and thereby excluding a range of functions that, for example, could have actively supported clinical decision making);
- limiting patient eligibility to children and the aged from selected residential postcodes;
- limiting the range of health service providers that could contribute patient data to the EHR to those with selected patient information systems;

- advocating an opt-out approach to ensure the confidentiality of sensitive health information; and
- collecting episodic health data from the date of the patient's enrolment with Healthelink (i.e. not collecting historical patient data).

Healthelink may not necessarily assume the same functional, operational and data content characteristics in a state-wide rollout of the EHR. The evaluation has assessed the extent to which these decisions have impacted on the Healthelink pilot and on stakeholder experiences of Healthelink.

3.2 Scope of the pilot

The Healthelink pilot is the largest shared electronic health record pilot to occur in Australia in terms of its breadth of application, its period of operation, and it was the first to use an opt-out approach to consent. Healthelink is therefore a significant contributor to informing national reforms in electronic health systems.

The Healthelink pilot is operating over two sites in NSW – Maitland and Greater Western Sydney (GWS), with eligibility for participation in each pilot site determined by residential address postcode and the age of presenting patients. Initially, the Maitland pilot site involved patients 65 years of age and over living in designated postcodes, and the GWS site involved patients 15 years and under living in designated postcodes. Since February 2008, both pilot sites involved patients from both age groups. In addition, the GWS site was expanded to include a number of additional residential postcodes (2142, 2146, 2147 and 2153) to accommodate the catchment of the Westmead Hospital and location of service providers that serves this catchment.

This has resulted in a considerable increase in the number of patients enrolled in Healthelink, namely from 7,265 in the Maitland pilot site and 16,916 in GWS at end of February, to over 12,378 patients and nearly 27,923 patients respectively at the end of June 2008.

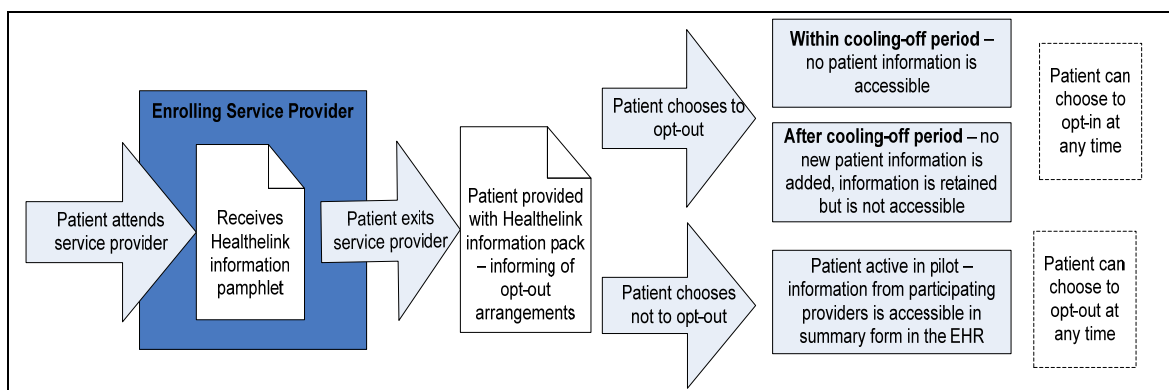
3.3 Enrolment of patients into the pilot

Patient involvement in Healthelink commences when they attend an enrolling health service. Patients are provided with initial information on Healthelink by the service provider, which is followed by an information pack being posted to their home. The information pack explains Healthelink and what involvement in the pilot means for the patient; this includes information on how to opt-out of Healthelink if they so choose.

Through the opt-out model, patients who present to specific health care facilities are automatically involved in the pilot. New patients are automatically enrolled and are subject to a 30 day cooling-off period. During the initial 30 days, the new patient's Healthelink record is not accessible to anyone and patients can choose to opt-out of

Healthelink. Where a patient does not opt-out of Healthelink within 30 days, it is regarded as though the patient is consenting to participate in the pilot, and this approach is accepted as a valid approach to consent that is consistent with privacy principles. The following figure provides an overview of the enrolment and consent process for Healthelink.

Figure 3-2: Enrolment Process



4 The health reform context

The Healthelink EHR pilot is occurring within a broader health reform context, both at state and national levels. These reforms include:

- *State and national initiatives to improve collaboration and coordination of care:* Healthelink is potentially an important mechanism to facilitate collaboration and assist with coordination of health care through the sharing of information amongst clinicians that are involved in the care of the same patient.
- *Quality improvement and best practice initiatives:* Healthelink is a medium through which health information can be provided to assist clinicians with best practice and quality improvement.
- *Other health information system developments in NSW* to improve the collection and sharing of information within the public health system³ will result in potentially more efficient and reliable sources of information for the EHR. The EHR also has the capacity to support the broader application of these reform efforts by being a primary and consistent mechanism for delivery of such health information.
- *National e-health initiatives* being pursued by the National Electronic Health Transitional Authority (NEHTA) will, over time, influence private suppliers of health information systems, drive consistent information standards and set direction for a national EHR strategy, all of which will impact on Healthelink.

These reforms occur at a time when the pressures on the health care system continue to grow and there is an increasing need for approaches that improve the coordination and collaboration of services. Therefore, the EHR has the potential to improve individual patient care as well as support broader reform efforts to improve the efficiency and effectiveness of the health system.

³ Such as NSW Health's strategy to implement an Electronic Medical Record (EMR), and individual Area Health Services interests in implementing Electronic Discharge Referral Systems (EDRS).

5 Findings

The findings of the evaluation are drawn from an analysis of the Healthelink quantitative data, interviews with health service participants, including clinicians and participating patients, and an assessment of the technical and governance issues relating to the pilot. The findings are presented under the key focus areas of the evaluation: the acceptability of the Healthelink EHR; the use and usability of the EHR; and the future viability of the Healthelink system for rollout across the NSW. The evaluation has found that:

- The Healthelink pilot has demonstrated the feasibility of establishing and maintaining a shared EHR spanning the public and private health care sectors and in the complex information and communications systems environment that characterises the Australian health care system. Healthelink has proven its capacity and capability to share information between public and private health care providers in a seamless manner and, for most service providers, without disruption for normal end user operations.
- Healthelink has successfully contended with a highly variable systems environment - multiple patient information system vendors, multiple versions of the same vendor product, variations in local set up configurations of the same system, as well as different local approaches to data management. That it was able to establish and sustain a shared EHR in this environment, often with minimal disruption to normal system operations of health care providers, is a significant outcome.
- The pilot has demonstrated the technical achievements that are possible for an electronic health record and the technical complications that exist. Thus, it has assisted NSW Health in working through appropriate solutions. It tested the technologies readily available and in use by the health care sector and, as a result, NSW Health has a better understanding from which it can design and build the state-wide rollout.
- The Department, rather than prescribing and issuing vendors with a standard installation package, has worked with the GPs and vendors to adapt the installation to individual GPs' system (software, hardware and data collection) environments. Forty-one implementation sites were successfully deployed during the pilot. As a standard deployment model was not utilised, this represents a major implementation success for a pilot program.
- Priority was given to ensuring business continuity for participating GPs. NSW Health's strategy for installing Healthelink onto clinicians' patient management systems ensured that there was no disruption to clinicians' routine use of those systems. Additionally, it meant that on-going maintenance undertaken by NSW Health frequently went unnoticed by clinical users of Healthelink enabling them to continue their work uninterrupted.

5.1 Acceptability of the Healthelink EHR

The key finding from the stakeholder interviews is that the Healthelink EHR has considerable support from a wide range of stakeholders including patients, clinicians and health service administrators. This level of support reflects stakeholders' views of the expected benefits of an EHR that covers a large number of patients and health service providers and holds a sufficient amount of information to be useful. Specifically, their acceptance of Healthelink is based on the following factors:

- that Healthelink will overcome frustrations amongst clinicians that are not able to access information when required. This has been reinforced by positive experiences in the use of Healthelink that has resulted in actual benefits to patients, clinicians and the service system;
- the Healthelink EHR will alleviate frustration amongst patients and/or their carers in having to provide the same information on multiple occasions;
- Healthelink provides a greater level of transparency and empowerment for patients as it gives them access to their own health information that can otherwise be difficult to obtain;
- acceptance that computerisation of health information records is inevitable in the future;
- recognition that the need for and push to improved collaboration will require a more effective approach to information sharing than what currently exists; and
- confidence that government will have in place appropriate and effective arrangements to safeguard privacy and confidentiality of patient information.

5.1.1 The consent model

There was overall support for the opt-out consent model used for Healthelink by clinicians and patients. Clinicians generally supported the use of an opt-out model, with only one respondent reporting a preference for consent through opt-in. There were a number of arguments presented for the adoption of an opt-out model over an opt-in variant, including:

- an opt-in model is impractical to operate because of the level of staff commitment required to manage the opt-in process. There was the belief that an opt-in based model would have ultimately resulted in the demise of the project because of the impost on staff time – a number of respondents cited the experience of the Tasmanian HealthConnect trial as an example of the opt-in experience;
- that an opt-in model would not result in a critical mass of patients within Healthelink and that, as a consequence, the EHR would not be utilised by clinicians; and

- that the opt-out model provided sufficient opportunity for a patient to withdraw their participation in Healthelink, and that this was supported by the operational model which provided a 30-day period prior to information being accessible through the EHR.

Clinicians particularly supported the opt-out model, although those clinicians who tend to work with patients where there is a heightened awareness of sensitive patient issues expressed some concern regarding patient confidentiality.

The majority of patients who were involved in Healthelink that were interviewed (62 per cent) favoured the opt-out model, 35 per cent of people were in favour of the opt-in model and 5 per cent did not provide an opinion.

The support for the opt-out model was partly based on a view that it is the more practical approach to consent and partly because of patient and clinician confidence that there were appropriate arrangements to safeguard patient confidentiality.

5.1.2 Enrolment process

Overall, patients and health service participants were satisfied with the level of information provided to support the decision to participate in the EHR, although there were some inconsistencies in how the initial information was provided to patients and some concerns about the appropriateness of the information for people of certain backgrounds, eg different cultural and socio-economic backgrounds.

The experience of the health service respondents suggested that there appeared to be variation in the consenting process within, and between, facilities. The responsibility for providing information to patients was reported as being primarily the role of administrative staff, and there were concerns that processes were not being consistently applied; eg, one respondent reported that their understanding was that only some eligible patients were being provided with the Healthelink information pamphlet. There were a number of reasons provided to explain the inconsistencies, including the high turnover of administrative staff (and casual staff), the failure to appropriately train Healthelink processes, and workload pressures where Healthelink was not a top priority.

With respect to patients, the majority of patients interviewed (66 per cent) reported that they first found out about being involved in Healthelink from the information pack that arrived in the mail. Twenty-five per cent indicated that they were advised when attending a health care facility such as a hospital or general practitioner; 6 per cent could not recall and 3 per cent indicated that the information came from another source. Fifty-one per cent of interviewed patients indicated that they had read all of the information pack, 41 per cent indicated they had read some of it and the remaining 8 per cent had not read the information pack.

In terms of the information pack, the general view of health service participants was that the information was sufficient for the majority of people. There were however

exceptions, and this included the suitability for people with lower cognitive and literacy skills, or for people from culturally and linguistically diverse backgrounds. For a number of respondents, this highlighted the need to ensure Healthelink information is available in various languages and is comprehensible to a diverse range of people.

The majority of patient survey participants found the information pack to be useful and stated it was sufficient for them to understand what taking part in Healthelink meant. These responses indicate that patients understood and supported their involvement in Healthelink which suggests that their decision to remain in Healthelink was a conscious, not a default, decision.

Those that found the information 'somewhat' or 'not useful' indicated that some aspects of Healthelink were difficult to understand or that the benefits of involvement in Healthelink were unclear.

5.1.3 Opting-out

The opt-out rates for the Healthelink pilot were at similar levels in both the pilot sites. Generally, the reasons provided for opting out related to concerns about information security and the manner in which they were informed about the Healthelink system.

The Maitland pilot site had an opt-out rate of 6.5 per cent (5.9 per cent excluding procedural opt-outs) and GWS 4.4 per cent (3.1 per cent excluding procedural opt-outs); for the pilot overall, this equated to an opt-out rate of 5.1 per cent (four per cent excluding procedural opt-outs). The reasons for opting out were varied and, in the majority of cases, was 'not stated' or for 'other reasons'.

Where a reason was expressed by patients for opting out, the most frequent were for 'privacy/security concerns' (28 per cent) and 'insufficient benefits for consumers' (12 per cent). The majority of patients opted-out during the 30-day cooling-off period; 77 per cent at the Maitland pilot site and 81 per cent at GWS. This supports the notion that the cooling off period is a sufficient approach to providing patient choice with regard to involvement in the pilot.

5.1.4 Privacy and information security

Patients and health service participants interviewed had confidence in the security of the system and felt assured that appropriate safeguards were in place to protect their personal information.

Of the patients interviewed, 48 per cent indicated that they were moderately confident in the security of their information, 40 per cent said they were very confident and 8 per cent were not confident. Some interviewees expressed reservations that information cannot be completely secure in an internet-based environment. Despite this, many indicated that the perceived benefits outweigh this concern. The majority of respondents (74 per cent) were in favour of providing health professionals involved in

their care with access to all of their health information as opposed to deciding to which information they should have access.

With respect to health system participants, overall information was regarded as secure as could be expected, and that the Healthelink EHR was an improvement compared to existing information exchange systems; e.g. the Healthelink EHR provided increased security of information over previously faxed copies of documentation. In addition, the ability to audit access to the EHR was regarded as being superior to the existing system. While some health service participants felt that the level of access by health professionals was too broad, and sensitive information should be able to be concealed, other health service practitioners were concerned that this could lead to an incomplete health record.

All clinicians were aware of the importance of patient confidentiality, with many suggesting that a more considered approach will need to be developed to patient confidentiality that limits who accesses sensitive patient information. Clinicians considered that the current approach to patient confidentiality, whereby a patient has to opt-out to prevent sensitive information being transmitted to Healthelink, is not the preferred approach as it is not practical and prevents potentially critical information from being captured. A preferred approach is to have a policy governing access to information that could vary according to the nature of the information, the nature of the service event that requires access to the EHR, and the role of the service provider. Many clinicians noted that patients already withhold information when the patient considers that such information is sensitive and does not want the information to be revealed to or shared with a third party. A transparent policy and associated procedures are required to give confidence to patients that sensitive information will be appropriately protected as otherwise there is a risk that patients could withhold more information if they do not have confidence of the EHR protecting their confidentiality.

5.2 Usability of the Healthelink EHR

The use of Healthelink by clinicians and patients remains lower than what was generally anticipated by stakeholders, but is expected to increase as the number of patients with an EHR increases, as the content of the EHR expands to include information from multiple health care providers and the system functionality is improved.

At the Maitland pilot site, 95 per cent of records were not accessed during the pilot and, at the GWS site, 98 per cent of records were not accessed. This is not surprising given the current status of Healthelink. The EHR for many patients contains information from only one clinical service provider which in many cases is the main provider for those patients. The potential benefits of and therefore use of Healthelink, are expected to materialise once a patient's EHR contains rich information from multiple clinical service providers which will take time for many patients. Hospital

clerical staff⁴ have made above average use of the EHR when compared to other users, while clinical users ranged consistently between one and four log-ons per month. Up to 26 individual users in the private, community or hospital clinician categories, and up to 37 individual users in the GWS pilot site used Healthelink in any given month.

Most patients have yet to register to access their EHR - one in 492 patients having registered for internet access at the Maitland pilot site in June 2008, and one in 1,078 patients at the GWS site. Patients indicated two main reasons for this: either they do not have ready access to the internet or they currently have little interest in doing so as they have a single health service provider.

Clinicians generally recognised or believe that Healthelink in its current form has limitations by virtue of it being a pilot. Many clinicians therefore, stated that they expect Healthelink to evolve in terms of its capacity to facilitate information exchange and will improve in terms of its functionality and operational performance. There was a high degree of convergence of views amongst clinicians regarding priorities for the evolution of Healthelink. For clinicians, the main factors are:

- Healthelink has not attained a critical mass of patients. Thus, for many clinicians, only a small proportion of their patients have a Healthelink EHR. The expansion of eligible patients for both pilot sites from February 2008 will slowly improve this situation.
- Many patients may not have attended a health service since their enrolment in Healthelink. The EHR will also continue to have little information for those patients who are relatively healthy or who choose not to attend a health service.
- The EHR contains only information from one clinician for the majority of patients, and therefore there is no additional information available for that clinician. Thus there is little benefit to be gained from using the EHR until patients attend other health services that are also contributing data to Healthelink. Some clinicians also believed that Healthelink should include a summarised health history of the patient and that it should be periodically updated.
- Healthelink in some cases operates as a separate system outside of the clinician's operating systems environment. In these cases, not only is the process of accessing Healthelink disjointed from the natural operational processes undertaken by clinicians but also, it takes time to log onto Healthelink and then to identify whether or not a patient has an EHR which is proving to be a disincentive to use Healthelink. While it may only take a minute or so to access a patient's Healthelink record, in the context that a GP's average consult time is only 10 to 15 minutes, this additional time is significant.

⁴ Note that some clerical staff only have access that enables them to identify that an EHR exists for the patient but not access to the content of the EHR.

- There have been technical issues with vendor products, which in some cases resulted in delays for GPs to connect to Healthelink. This has resulted in some GPs deferring a decision to participate in Healthelink and others to disable Healthelink and has proven to be a disincentive for GPs to use Healthelink.
- Some clinicians believed that Healthelink should enable them to communicate with each other electronically as does an electronic discharge referral system. They would prefer Healthelink to have active messaging that alerts clinicians of events or new information that warrants the clinician to explore the EHR for a patient.⁵

For patients, the main factors impacting on their use of Healthelink are:

- Many patients do not have an interest in their EHR, particularly where they attend only one health service (which is the case for the majority of participating patients).
- Of those who had accessed the EHR via the internet, the majority of older people and guardians indicated that they found the website easy to use. Some reported that it was difficult to find what they were looking for and there could have been easier navigation between pages.

5.2.1 Benefits of Healthelink for users

Clinicians, and in some cases patients, have reported actual benefits from using Healthelink. Furthermore, clinicians remain confident of the EHR being more beneficial as Healthelink expands the number of patients and the number and range of clinicians participating in Healthelink, as richness of information on the EHR improves, and as the system is made more user-friendly.

The evaluation identified some examples of where actual benefits had been experienced by clinicians and patients through the existence of the EHR. These benefits included the following.

1 *Reduced effort to obtain information* – examples include:

- Clinicians in Emergency Departments using Healthelink when attending a patient who is not able to communicate vital information or where direct access to the patient's health history is critical.
- Community nurses undertaking home assessments who otherwise would have had to contact the GP for health history.
- Reduced time taken by clinicians to find historical patient information, particularly for clinicians involved in care planning such as post acute care or assessment.

⁵ This function is only available on Healthelink via subscription.

- General Practice nurses who use Healthelink to prepare a health history summary for the GP for new patients or for patients who have experienced an acute event that will require on-going management by the GP.
- Reduced frustration by avoiding the need to obtain patient information from third parties – clinicians reported that, when the EHR contained the relevant information, the frustration experienced by each clinician and the patient is reduced.

2 *Reduced risk of adverse clinical outcome* - examples include:

- Emergency Department clinicians who were able to initiate appropriate intervention for a patient with an acute myocardial event within the prescribed best practice time by establishing the patient's normal heart function more quickly than what otherwise would have been the case.
- Reduced likelihood of a drug interaction as the EHR enabled a hospital pharmacist to identify a medication that the patient had not communicated at time of admission.

3 *Reduced patient burden* - examples include:

- A patient who had difficulty attending their GP accessed the EHR to view diagnostic results; the results indicated there was no need to attend a GP appointment and they telephoned the GP for confirmation.
- A patient's family did not need to gain access to the patient's home in order to retrieve the medication as the Emergency Department clinician was able to identify the medication history from the Healthelink EHR. The patient had their house keys with them in the ED which would have required the family to travel to the hospital to retrieve the keys and then travel to the patient's home to obtain the medication (round trip of 60km).
- *Reduced frustration* – all of the above examples were accompanied by reduced frustration of the time and effort that otherwise would have been spent to contact health care providers to gain access to relevant information.

5.3 Viability of the Healthelink EHR

The evaluation considered the viability and appropriateness of the current Healthelink EHR for broader implementation across NSW. This was analysed in terms of Healthelink's operational performance and emerging issues that should be addressed to maintain stakeholder support and to realise its potential benefits. Consideration was also given to governance arrangements that would be appropriate for a state-wide

electronic health record to ensure that its implementation is effective and that community confidence is maintained.

It was evident from the interviews with Healthelink participants that there is considerable support for, and confidence in, the EHR in terms of the likelihood of it delivering benefits, that confidentiality can be safeguarded, and that issues impacting on its useability will be addressed over time. These issues have implications for any state-wide rollout of an EHR and have implications for how Healthelink evolves from a technological and operational perspective.

5.3.1 Technical and implementation issues for the Healthelink EHR

The evaluation identified some technical and operational aspects of Healthelink that need to be reconsidered in any future expansion of the EHR. These are:

- *Sustainability of operational model:* the limited scope of the pilot has permitted a more hands-on approach to various aspects of Healthelink during the pilot. This level of operational support is unlikely to be sustainable in a state-wide program. Manual support was required for setup, installation, configuration and troubleshooting Independent Software Vendors (ISV) technology at GPs' offices to connect and communicate with Healthelink. Continuing support of the connectivity for some GPs during the pilot period, as well as maintaining data sets (provider directory, user account management), has required manual intervention and additional support. It will be important for NSW Health to consider options for a more automated operational model for the state-wide rollout.
- *Sustainable vendor engagement and accreditation model:* NSW Health did not issue a prescribed installation for vendors to use. Consequently, the installation of Healthelink varied across vendor products and across versions of the same product. Therefore, the effort required by NSW Health to work with vendors and test and accredit vendor systems exceeded expectations. Nor could NSW Health assume that, once the vendor's product was accredited in one location, it could remain accredited for any length of time because of the risk and likelihood of further localised changes being made by the vendor to the operational environment for that product that could put at risk the transmission of data to Healthelink. NSW Health needs to assess the options that, over time, would require the vendor to ensure compliance with Healthelink requirements and to take responsibility for the integrity of transmission of data to Healthelink once its product has been accredited for Healthelink.
- *Variability in impact on source system operations:* NSW Health identified that some, but not all, GPs experienced performance problems with their vendor system once Healthelink functionality had been enabled in their system. Similarly, NSW Health often experience different installation issues for the same vendor product across different GP sites. It is critical for NSW Health to better understand the variables that impact on installation and operational performance prior to extending

Healthelink, and it has the opportunity to do so by undertaking a retrospective review/audit of current installation sites. This will also assist NSW Health to establish minimum requirements for vendors and service providers to provide some confidence to the service providers and NSW Health that the installation impacts will be minimised.

- *Vision for how Healthelink integrates with clinical practice:* a single business imperative and model for how Healthelink could best serve healthcare is evolving but requires much more exploration by clinicians and NSW Health. Healthelink is currently a passive repository of patient and service event information. It is critical to further explore how the EHR is to operate in support of clinical and patient management processes as part of the next phase of Healthelink development and prior to a full state-wide implementation.
- *Standardised data structures and information management practices:* clinicians, from the various GP offices or hospitals, each input their information in their local systems according to local coding customs and procedures. Healthelink frequently displayed similar types of information differently which may, over time, be difficult to comprehend or are confusing to the Healthelink user. Optimising data content, structures and data management need to be further explored as part of the vision for Healthelink.

5.3.2 Governance arrangements for the Healthelink EHR

THE EVALUATION has considered the governance arrangements that will be required for the state-wide rollout of the EHR. Governance has been understood in this context to encompass the institutional arrangements, legal framework, policies, procedures, and supporting programs and practices that are needed to provide accountability and support the efficient and effective operation of a state-wide EHR.

There are a number of issues that need to be considered in relation to developing an effective approach to governance arrangements for the development and administration on an EHR system:

Privacy

Privacy concerns associated with health information are significant and are usually the most contentious issue associated with EHRs. Successful implementation of a state-wide EHR will require a high level of public support and confidence in the privacy and security of the personal information that is held. This largely relates to privacy of personal information about patients and their health; however, concerns can also extend to personal or commercial information about service providers. Governance issues relate to:

- reviewing the appropriateness of the privacy legislation;

- clarifying ownership in the health information that is held on the EHR;
- determining consent procedures in situations where all personal health information is considered to be sensitive and generally be protected from disclosure;
- the use of secondary data given the context of the NSW Privacy Principle 10, that health information can only be used for the primary purpose for which it was collected except in specified circumstances;
- who has access to an EHR and processes for managing sensitive information;
- maintaining the accuracy of data;
- protecting the security of health records;
- systems for handling complaints; and
- establishing effective compliance and auditing arrangements to be in place to detect compliance with access requirements and any security and privacy breaches.

Systems compatibility and inter-operability

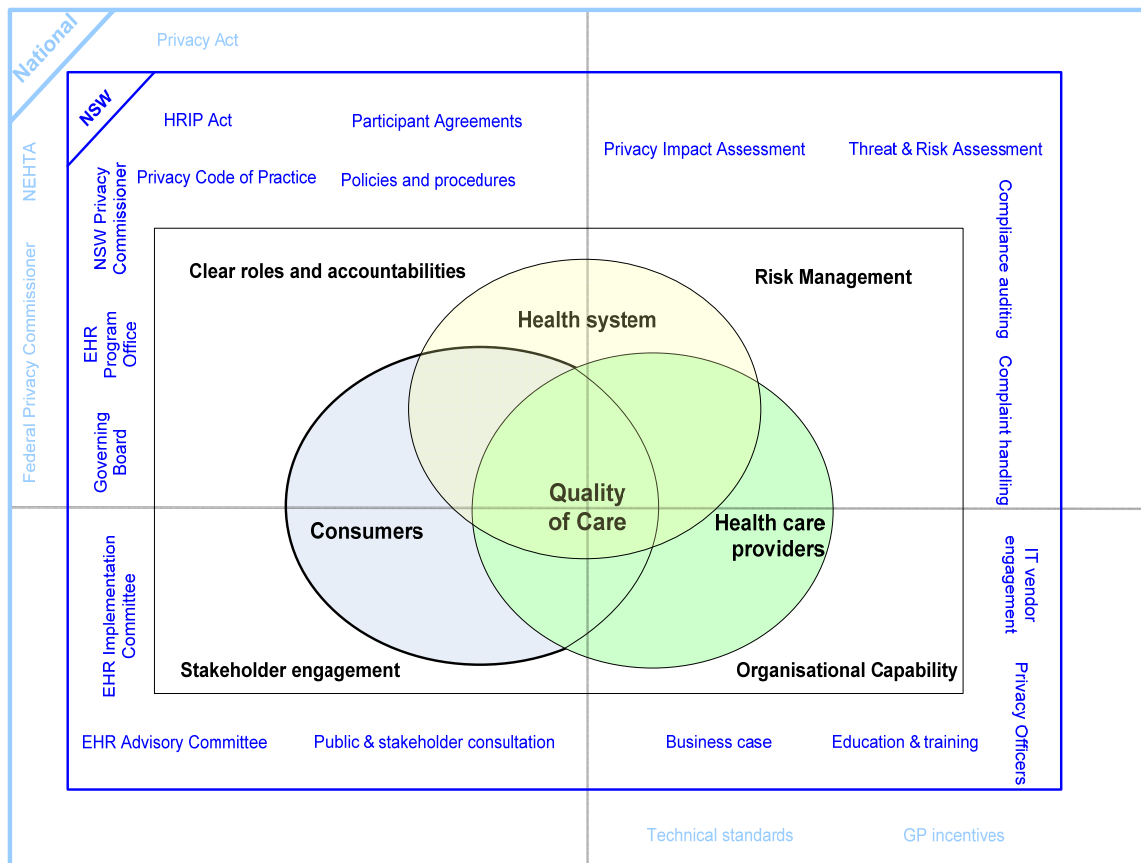
A key governance issue will be ensuring the technical compatibility of the participating health providers' computer systems with the central record, including ensuring there is an effective engagement strategy in place for vendor software to ensure products are compatible with EHR. The issues of consistency and inter-operability with electronic health records in other states or at the national level will also need to be addressed in the future.

Organisational capability

Maximising the organisational capability of NSW Health and the participating health care providers is an essential pre-requisite to successful implementation and functioning of an electronic records system. This raises governance issues such as the need to identify appropriate arrangements for operating the system and supporting participants.

In response to these issues, a possible approach to a governance framework has been developed that is summarised in the figure below.

Figure 5-1: Governance Framework



This framework is based on the central premise that EHRs operate for the mutual benefit of patients and health care providers as they promote improvements to the quality of health care. The framework uses four governance priority areas for a state-wide EHR: establishing Clear Roles and Responsibilities, Risk Management, Organisational Capacity and Stakeholder Engagement.

The framework is also based on the identification of four governance priorities for a state-wide EHR: These arrangements include institutional arrangements, legal requirements, policies and procedures, and supporting programs. .

- *Governance Priority 1 – Establish clear roles and accountabilities:* make sure that the roles, responsibilities and accountabilities for the management of the program are clearly defined and understood; this can be achieved through institutional arrangements, legal obligations and policies and procedures.
- *Governance Priority 2 – Effective Risk Management:* establish effective risk management across all aspects of developing and operating the electronic health record; this includes adequately identifying and managing privacy and security risks,

other implementation risks like organisational capability constraints, barriers to participation by health service providers and patients, and financial and project management risks.

- *Governance Priority 3 – Maximising Organisational Capability:* ensure NSW Health and the participating health service providers have adequate capacity to implement an electronic health record, which is vital to its successful implementation and operation.
- *Governance Priority 4 – Stakeholder engagement:* to engage key stakeholders in the process of developing and implementing a state-wide EHR is a high priority; there are a number of options for achieving this engagement that sit along a continuum from ad-hoc stakeholder and public consultation at key decision points through to permanent engagement in making those key policy and operational decisions.

5.4 Implications for and importance of the national EHR agenda

Some of the challenges encountered by Healthelink ultimately require input from, and decisions to be made at, the national level. At the same time, Healthelink presents an important opportunity to inform and influence national decisions.

The issues encountered by Healthelink that require some form of national input/action are:

- *Development and implementation of standards:* This includes standards of health data (terminology and coding conventions such as for pathology information); standards for a health history summary, both in terms of content and structure; and messaging standards for transmission of information between source systems and the EHR. NEHTA has responsibility to develop these and other standards that are important to the EHR. NSW Health needs to actively engage NEHTA to ensure that there is a clear timetable for the development and implementation of these standards.
- *Vendor system compliance:* It is critical that vendor systems, and for the Australian Government, that GP vendor systems are capable of transmitting information to an EHR, include the minimum information required by an EHR and are designed to enable efficient transmission of information to an EHR.
- *Participation of community-based providers in the EHR:* Community-based health care providers need to be encouraged and have incentives to participate in an EHR. This includes GPs, private medical specialists, primary allied health care providers and private hospitals. The Australian Government already has incentives in place for GPs to move from paper based to IT based systems. The focus of this strategy needs to be broadened to ensure that providers have the technology means and collect the relevant information that adhere to appropriate standards in order to

ensure that most, if not all, providers have the capability to transmit data to and access data on an EHR.

- *Development of a national confidentiality and privacy policy:* A national approach to patient confidentiality and privacy will ultimately be required as this will be critical to encourage vendor compliance with a single set of standards and will facilitate the uptake of the EHR.

Healthelink is currently not critically dependent on having in place a national framework that puts in place these standards and strategies, but it will reach a point where NSW Health may be limited in the penetration it achieves with the EHR until these issues are resolved. The Healthelink experience should be used to inform the national debate and development of priorities and should be used as a catalyst to have these issues resolved more quickly than otherwise might be the case.

6 Considerations for future developments

There are a number of important considerations for the development of Healthelink that have arisen from the evaluation. These relate to the approach to rolling out Healthelink, the governance and on-going management of Healthelink (including governing patient confidentiality), strategies to improve its performance and sustainability, and considerations for the national EHR agenda.

6.1 Approach to state-wide rollout of Healthelink

- *NSW Health should pursue an incremental approach to extending Healthelink.* Such an approach would allow time for NSW Health to address some of the issues impacting on the useability of Healthelink. It will also create the opportunity for NSW Health to test those aspects of Healthelink that have not been fully explored, given its current scope and configuration.
- *The extension of Healthelink should be purposeful and strategic.* Given the rationale for an incremental approach, the direction for expansion of Healthelink should be determined in a way that will progressively resolve and overcome barriers to use of the EHR, and assist with testing/exploring those issues which may not have been able to be considered in the current form or configuration of the EHR.
- *Developing the Healthelink model:* There is a need for NSW Health to evolve the current form of the EHR which acts as a passive information repository to one that more purposefully links into clinical and patient management processes and that becomes a means by which clinicians pro-actively exchange information. There may be opportunities to use the current Healthelink technology to expand the role of the EHR. Ultimately, it will require redesign of the EHR and possibly an alternative technology solution.
- *Change management must be an integral part of the rollout strategy:* The EHR is more than just improving access that clinicians have to patient information. Change management should focus on integrating the EHR into routine clinical and patient management practices. While this will also require improvement in functional attributes of the EHR (discussed elsewhere), it also requires a conscious decision on the part of management to ensure that the EHR is integrated into routine processes and for management to invest in change management processes to ensure that the EHR is embraced.

6.2 Effective governance

- *Development of a governance framework is required:* There is a need for a formalised and comprehensive governance framework within which NSW Health, together with relevant stakeholders, develop policies, structures and processes that will govern all aspects of and future decisions regarding Healthelink. Some options for a governance framework have been suggested for further consideration.

6.2.1 Governing consent and privacy

- *Enabling the continuation of Healthelink:* NSW Health needs to in the short term extend the timeframe for the regulation that has allowed Healthelink to operate with its specific consent model and consider longer-term legislative options.
- *Consent processes to accommodate specific patient characteristics:* NSW Health needs to develop specific policies and procedures to accommodate the circumstances of individuals who have variable capacity and capability to be involved – this includes, for example, patients without a reliable residential address; patients with a guardianship order; and patients under 18 years of age who would want to take individual responsibility for their EHR independent of their parent.
- *Ensuring patient confidentiality and privacy:* Healthelink needs to have a more structured and comprehensive approach to managing patient confidentiality and privacy that allows for the need to have varying levels of access to varying types of data, while ensuring that patients are not at material risk from preventing clinician access to information in critical situations.
- *Impact assessment to be part of overall approach to risk assessment:* NSW should consider including privacy impact testing as part of a formal and transparent decision making framework that will govern the on-going development of Healthelink.
- *Options to manage confidential information.* A component of the next stage of Healthelink development should include consideration of options to better manage confidential information. There is a need to consider specific policies and procedures for managing confidential information within Healthelink, rather than relying on the current practice of a patient opting-out as a means of protecting confidential information. This will be important for the state-wide rollout when there are increased access opportunities across health service providers and thus increased risk of a privacy breach. While it may not be feasible to incorporate the preferred option into the current design of Healthelink, the Healthelink work program needs to include work at least to identify and assess options.

6.3 The value of EHR

- *Expand eligibility criteria to achieve a critical mass of patients:* It is important that sufficient numbers of patients are enrolled into the Healthelink EHR to optimise the benefits for participating health services. Whilst recent changes to the eligibility criteria have gone towards this, NSW Health should, at a minimum, further extend Healthelink in the existing two areas to all patient groups and further extend the catchment areas for participating service providers.
- *Improving the richness of the EHR:* The benefits from an EHR depend on clinicians having access to information from multiple sources that are not readily accessible. This will require NSW Health to encourage more GPs to participate in Healthelink and extend Healthelink to Area Health Services and to specialist medical providers

in hospitals and the community. Critical to enrolling more GPs is the need to resolve the problems NSW Health has faced with the GP vendor systems.

6.4 Functionality of the Healthelink EHR

- *Enhancing the functionality of the EHR:* There are a number of opportunities to improve the functionality of the EHR infrastructure and thus to improve the ease of access and use of the EHR. Most notably, there is a need for the Healthelink EHR to interface with operational systems already used by clinicians. NSW Health has identified this to be an important matter to address where currently Healthelink access and use is not interfaced with clinicians' operating systems. NSW Health has indicated that this will be considered in the program of work for on-going development of Healthelink.

6.5 Effectiveness of Healthelink operations

- *Options to engage third parties in Healthelink operations:* NSW Health needs to consider options for those aspects of Healthelink operations where it is unlikely that the current intensive and hands on role of NSW Health may not be sustainable in the long term. One option is for NSW Health to engage the Divisions of General Practice to undertake those roles that relate directly to supporting GP Healthelink operations, such as the installation of Healthelink components onto GP systems and then the on-going technical support required by GPs.
- *Improving the consistency and sensitivity of the enrolment process:* The current enrolment processes need to be applied more consistently by health services when a patient first becomes involved with Healthelink – this may also reduce the opt-out rate. In addition, the enrolment process and documentation need to be modified to make it more appropriate to the needs of patients with reduced capacities to understand the consent process. NSW Health has improved the information pack provided to patients which will simplify the information for many patients. NSW Health will need to consider options to address the variable information needs of specific patient cohorts, such as adolescents and patients with limited cognitive skills.
- *Ensuring continuity of operations for clinicians:* It is important to ensure continuity of Healthelink operations at the clinical level. NSW Health must ensure it has an effective and proactive strategy to engage software vendors to minimise interruptions to Healthelink; for example, when vendors upgrade products, they need to ensure that they are integrated with Healthelink components.
- *Improving the cost efficiency of Healthelink operations:* Some aspects of Healthelink implementation are costly and may not be viable in relation to a state-wide system. These include the arrangements for the installation of Healthelink software for GPs and training for health service participants. There is a need to consider alternative arrangements for third party delivery of such activities.

6.6 The national EHR agenda

- *Engage NEHTA to inform the national EHR strategy:* Healthelink provides a rich learning environment that can be drawn upon to inform and influence the development of policy, strategies and technical and operational solutions for an EHR.
- *Increasing the compatibility of Healthelink with other clinical software:* NSW Health should advocate and support a leadership role by NEHTA to develop national minimum requirements for source systems and related technologies (hardware and communication technology requirements) that will be necessary for efficient installation of a state-wide EHR and to minimise any subsequent disruptions to other vendor software to:
 - have an effective strategy to engage the software industry; and
 - develop national minimum requirements for source systems and related technologies (hardware and communication technology requirements) that will be necessary for efficient installation of a state-wide EHR and to minimise any subsequent disruptions to other vendor software.
- *Minimum information standards:* Minimum information standards are required for all aspects of core EHR information, such as pathology, medical terminology and patient health history.

7 Concluding comment

The Healthelink pilot has been successful in establishing and maintaining a shared electronic health record. From a technology perspective, it has been successful in providing an effective means of transmitting and storing health related information that has the potential to provide clinicians with improved access to patient health information and result in time savings and improved clinical decision making.

There is considerable support from clinicians and patients for the Healthelink EHR, specifically in relation to its concept and its approach to enrolling patients (i.e. opt-out model). The current use is less than originally expected, which reflects the developmental nature of Healthelink and the time required to build up the content of the EHR. It is clear that clinicians' support for the EHR reflects their current frustration in not being able to readily access all relevant patient information which results in wasted time, delayed clinical decision making and increased risk of adverse patient outcomes. Clinicians in all service settings have expressed a desire for Healthelink to be expanded to include all patients and a greater coverage of health services, and for Healthelink to be more functional. Their overall support for Healthelink reflects their confidence that these issues will be addressed in the future.

It is suggested that NSW Health place a high priority on resolving the key issues identified by this evaluation through pursuing a more incremental approach to rolling out Healthelink. The next stage of the rollout would be usefully directed to further developing and testing various elements of Healthelink. This will also require a formal governance framework to be put in place that includes a more comprehensive approach to managing patient privacy, a strategy to engage the Australian Government to accelerate its EHR efforts, and a strategy that integrates Healthelink into clinical processes supported by an appropriate change management strategy.