

HealthConnect
Interim Research Report

VOLUME **2** **Research Reports**

HEALTHCONNECT: A HEALTH INFORMATION
NETWORK FOR ALL AUSTRALIANS



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FOREWORD

The *HealthConnect* Interim Research Report is an important landmark in the area of electronic health record systems development. Bringing together the findings of the first 20 months of the *HealthConnect* Project being undertaken jointly by the Commonwealth, state and territory governments, this report represents a substantial contribution to the body of knowledge in this area, both nationally and internationally.

As a two-year research and development project, the *HealthConnect* Project has been framed by a set of seven high level research questions aimed at testing the value, technical feasibility, preferred implementation model, costs and sustainability of *HealthConnect* as a national approach to electronic health records. The research questions have also sought to answer what privacy and governance arrangements would be needed to oversee an undertaking on the scale of *HealthConnect*, and what the role of the private sector might be in its delivery and operations.

Another major area of work undertaken under the *HealthConnect* Project has involved the development of the key building blocks, needed not only for *HealthConnect*, but for the broader e-health agenda — such as consent, privacy, and technical and information standards.

This volume is the second of the three-volume *HealthConnect* Interim Research Report. As such, it contains seven separate research reports responding to each of the high level research questions, together with a report on e-health building block progress. While the individual reports can be read as stand-alone documents, read together as a whole they provide a comprehensive picture for taking *HealthConnect* forward beyond the first two-year phase. They also provide the background research material for volume 1 of this report, which provides an overarching view of the Project's achievements and findings to date and recommends a way forward for this important national project.

The material contained in this volume (and volumes 1 and 3) goes a long way to answering the research questions. Notwithstanding this achievement, there is still further work required to finalise the design for *HealthConnect* and test it in a range of settings before health ministers will be in a position to make a decision on proceeding with *HealthConnect* nationally. Accordingly, health ministers have agreed to undertake a second, two-year phase of development work on *HealthConnect*, up until June 2005.

I look forward to this next phase of the Project which will continue to be managed through the joint Commonwealth, state and territory *HealthConnect* Program Office, building on the substantial achievements to date.



Paul Fitzgerald
Manager
HealthConnect Program Office

July 2003

GLOSSARY

Access control	A process that determines who is given access to a local or remote computer system or network, as well as what and how much information someone can receive.
ADSL	Asymmetrical Digital Subscriber Line uses an existing phone line to deliver a broadband internet connection. Depending on the service, ADSL can be up to 20 times faster than a standard 56.6kbps (kilobits per second) connection to the internet.
Authentication	A process verifying that users are who they say they are. An example of authentication is requiring users to identify themselves with a password.
Authorisation	The process that grants access to a local or remote computer system, network or to online information.
Bandwidth	The amount of data that can pass through a given communications channel in a standard amount of time (usually per second). An indication of the capacity of the network's 'pipes'.
Bespoke	A product built from raw materials to specific customer requirements. This compares to the development approach which takes an existing product and makes alterations to fit the customer requirements. The Community Health Information Management Enterprise (CHIME) project based in NSW is an example of a bespoke development.
Business Architecture	The Business Architecture documents the functional requirements for <i>HealthConnect</i> .
CD/CD – ROMs	CD-ROM stands for Compact Disk – Read Only Memory (CD-ROM) which has been abbreviated further to Compact Disk (CD). CDs are designed to store computer data in the form of text and graphics, as well as hi-fi stereo sound. CDs are composed of a polycarbonate plastic substrate, a thin reflective metal coating, and a protective outer coating.
Client master index	<p>A client master index can be summarised as being a dynamic, secured directory of uniquely identifiable clients/patients, and 'pointers' to where relevant records reside. Each client represented in a PMI may be identified in more than one information system, across multiple services or organisation in a wide variety of settings, over a period of time.</p> <p>A client master index itself is not a repository for client information itself. However, it may also provide pointers to such repositories, for example providing summarised event histories or 'alerts'.</p>
Coding	The process of assigning an alphanumeric code to a concept in accordance with an agreed classification system e.g. ICD10AM (International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification).

Confidentiality	<p>Confidentiality protects the privacy of information being exchanged between communicating parties.</p> <p>In computer security, a concept that applies to data that must be held in confidence and that describes the status and degree of protection that must be provided for such data about individuals as well as organisations.</p>
De-identified data	<p>Data are termed ‘de-identified’ when an individual’s identity is not apparent, and cannot reasonably be ascertained by the user, from the record elements. Guidelines for de-identification and the use of de-identified information will be required.</p>
Data model	<p>A depiction of the relationship between data entities and their attributes.</p>
Data store	<p>Repository of data.</p>
Diagnostic	<p>Referring to the process of identifying disease from its signs and symptoms.</p>
Diastolic	<p>The lowest arterial blood pressure during the cardiac cycle, reflecting relaxation and dilation of a heart chamber.</p>
Digital Subscriber Line (DSL)	<p>A technology for bringing high-bandwidth information to homes and small businesses over ordinary copper telephone lines.</p>
Directory store	<p>A repository of directory information e.g. client master index and <i>ProviderConnect</i>.</p>
DOCLE	<p>A system used at the interface level by computerised Australian general practitioners as part of the clinical software—Medical Director. The DOCLE browser operates on over 16 000 medical objects that are related to one another in a linnean hierarchy much like what Carolus Linnaeus did to biological classification. The linnean biological framework comprising phyla, class, order, family and species is a framework for classifying medical objects. DOCLE is different in that it is totally alphabetic and uses primary, secondary and tertiary keys to access ‘objects’ that hold the linnean properties of each medical object. All these objects are linked together in a congruent ‘belief system’. <www.docle.com.au>.</p>
DVD	<p>DVD (digital versatile disc) is an optical disc technology that holds 4.7 gigabyte of information on one of its two sides, or enough for a 133-minute movie. With two layers on each of its two sides, it will hold up to 17 gigabytes of video, audio, or other information. Compared to the current CD-ROM disc of the same physical size, holding 600 megabyte, the DVD can hold more than 28 times as much information.</p>
e-Commerce or electronic commerce	<p>A broad definition of ‘electronic commerce’ is provided by Electronic Commerce Australia (ECA, formerly EDIC) in its 1994 Annual Report as:</p> <p style="padding-left: 40px;">‘The process of electronically conducting all forms of business between entities in order to achieve the organisation’s objectives.’</p> <p>The term ‘electronic commerce’ embraces electronic trading, electronic messaging, EDI, EFT, electronic mail (email), facsimile, computer-to-fax (c-fax), electronic catalogues and bulletin board services (BBS), shared</p>

databases and directories, continuous acquisition and lifecycle support (CALs), electronic news and information services, electronic payroll, electronic forms (e-forms), online access to services such as the internet and any other form of electronic data transmission.

EHR*Net	This is a key component of the New South Wales' Integrated Clinical Information Programme. EHR*Net will be the repository for electronic health records in New South Wales. It is being implemented initially in two areas focussing on chronic and child health.
Encryption	<p>Transformation of data to an unintelligible form in such a way that the original data either cannot be obtained (one-way encryption) or cannot be obtained without using the inverse decryption process (two-way encryption). Process of converting messages, information, or data into a form unreadable by anyone except the intended recipient. Encrypted data must be deciphered, or decrypted, before it can be read by the recipient.</p> <p>The manipulation, or encoding, of information to prevent anyone other than the intended recipient from reading the information. There are many types of encryption, and they are the basis of network security.</p>
G3	<p>G3 is the marketing name used by Apple Computer for the 750 microprocessor that is used in Apple's iMac and Power Macintosh personal computers. Like other PowerPC microprocessors, the G3 uses reduced instruction-set computing (RISC). The G3 and other PowerPC processors were developed jointly by Apple, IBM, and Motorola.</p> <p>Developed at IBM, RISC is based on studies showing that the simpler computer instructions are the ones most frequently performed. Traditionally, processors have been designed to accommodate the more complex instructions as well. RISC performs the more complex instructions using combinations of simple instructions. The timing for the processor can then be based on simpler and faster operations, enabling the microprocessor to perform more instructions for a given clock speed. Typically, the PowerPC can perform one instruction for each clock cycle. The PowerPC architecture handles 32-bit instructions.</p>
Greenfield	A 'greenfield' site is one that has no existing activities that would constrain or distort the proposed development an analogy derived from property development activities.
HeSA	Health eSignature Authority Pty Ltd (HeSA) is a registration authority for the provision of digital keys and certificates required for Public Key Infrastructure (PKI) use within the Australian health care sector. For the health care sector, PKI enables the transfer of sensitive medical information across the internet, without compromising the individual's right to privacy. Both HeSA and SecureNet (the Certification Authority) have successfully completed the Commonwealth Government Gatekeeper process to become an Accredited Provider of PKI within the Australian health care sector. HeSA is a wholly owned subsidiary of the Health Insurance Commission (HIC).

HTML	HTML (Hypertext Markup Language) is the set of markup symbols or codes inserted in a file intended for display on a World Wide Web browser page, otherwise known as an internet page. The HTML tells the Web browser how to display a Web page's words and images for the user.
HTTP	HTTP (Hypertext Transfer Protocol) is the set of rules for transferring files (text, graphic images, sound, video, and other multimedia files) on the World Wide Web.
ICD10AM	The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification. The International Classification of Diseases has been around since the 1800s. Version 10 came along in the 1990s. It is a statistical classification endorsed and maintained by the World Health Organisation that has grown beyond its early days as a mortality-based classification. Australia modifies the classification for acute care with the inclusion of extra characters on some codes, Australian spelling and the inclusion of the Australian Classification of Health Interventions based on the Commonwealth Medicare Benefits Schedule.
ICPC+2	International Classification of Primary Care Second Edition Plus (ICPC2-Plus) is a primary care classification system using an interface terminology covering terms related to the diagnostic process, therapies, investigations and psychological interventions. A demonstrator version is available at: < http://www.fmrc.org.au/icpc7.htm#2 > or more general background information is available at < http://fmrc.org.au/classifi.htm >.
Identifiable data	Data are termed 'identifiable' when an individual's identity is readily apparent, or can reasonably be ascertained by the user, from the record elements.
Identification of consumers, providers, locations/ facilities and devices	A person identifier is a universal code that uniquely identifies each individual within the health system. Such an identifier can be simply assigned or based on some unique characteristic of the individual (called biometric identification). Similarly providers, facilities, individual devices and the location of the point of care may all have to be capable of unequivocal identification to guarantee the integrity of a system of electronic health records.
IETF	The IETF (Internet Engineering Task Force) is the body that defines standard internet operating protocols such as TCP/IP. The IETF is supervised by the Internet Society Internet Architecture Board (IAB). IETF members are drawn from the Internet Society's individual and organisation membership. Standards are expressed in the form of Requests for Comments (RFCs). < http://www.ietf.org/ >.
Information and communication technologies (ICTs)	Seen as the building blocks of the 'networked world', ICTs include telecommunications technologies (such as telephony, cable, satellite and radio) as well as digital technologies (such as computers, information networks and software).
Information Privacy Principles	The <i>Privacy Act 1988</i> recognises the importance that individuals place on the manner in which federal government agencies treat their personal information and imposes stringent standards to which agencies must comply. Within the

	Act, 11 Information Privacy Principles (IPPs) govern the collection, storage, use and disclosure of personal information by federal government agencies, as well as providing individuals with certain rights to access their personal information and correct errors.
Informed consent	The situation in which agreement to an act is made with a full understanding of the consequences or implications of the act and agreement.
Infostructure	This is a concatenation of the phrase INFOrmation infraSTRUCTURE. It covers both physical (e.g. computers and cables) and abstract (e.g. standards, data sets, terminologies, workforce capacity) infrastructure elements.
Inpatient	An inpatient is a patient who is admitted to hospital for treatment with the intention of discharge after a minimum of one night.
Internet	<p>The internet is behind much of the explosive growth in data communications. Often characterised as a network of networks, the internet is a set of protocols for enabling computers to connect and communicate with each other. Viewed in another way, it is like a communications platform that enables a range of other, internet-specific programs to run. A major stimulus to growth in recent years has been the universal adoption of the hypertext transport protocol (HTTP) and the easy-to-use web browsers that emerged to exploit it. Indeed, so ubiquitous is web-browsing-based internet usage that for many people the internet and the world wide web are synonymous. Indeed, given the ability of web-browsers to emulate a wide range of more function-specific client programs (e.g. email), many other internet programs have, in fact, been absorbed into browser-based functions. (Source: National Bandwidth Inquiry Report (1999), Australian Information Economy Advisory Council (T. Cutler, Chair), Commonwealth of Australia. Document available at <http://www.dcita.gov.au> (pp.10–11).</p> <p>The internet was not originally designed with businesses in mind. It lacks the technology required for secure business communications and transactions.</p> <p>A worldwide system of computer networks. Networks connected through the internet use a particular set of communication standards, known as TCP/IP, to communicate.</p>
LAN	A local area network (LAN) is a group of computers and associated devices that share a common communications line or wireless link and typically share the resources of a single processor or server within a small geographic area (for example, within an office building). Usually, the server has applications and data storage that are shared in common by multiple computer users.
logging	A process of recording information about events that have occurred, often used in audit activities.
LOINC	Logical Observation Identifiers Names and Codes — a vocabulary for pathology test orders and results based on the US LOINC system.
Medicare	Australia's universal public administered health insurance scheme.

Memory stick	Memory sticks are a digital data storage technology with up to 10 times the storage capacity of a 3.5 diskette. Memory sticks are promoted as a new way to share and transfer pictures, sound, and other data between different compact electronic devices such as digital cameras and camcorders. About the size of a flat AA battery, memory sticks are available in 4mb, 8mb, 16mb, 32mb and 64mb sizes. They are smaller in size than comparable data storage devices, including smart media and compact flash memory.
Messaging	The activity and associated processes of sending or receiving a message.
Metadata	Data about data. Metadata describes how and when and by whom a particular set of data was collected, and how the data is formatted. Metadata is essential for understanding information stored in data warehouses.
mmHg	Abbreviation for millimetres of mercury, normally used in measuring blood pressure.
National Health Privacy Code	The proposed National Health Privacy Code is a document that sets out principles for the collection, storage use and disclosure of personal health information. The code has been developed by the Australian Health Ministers' Advisory Council (AHMAC) National Health Privacy Working Group with the aim of achieving national consistency in health privacy protection across jurisdictions and across the public and private sectors. The draft National Health Privacy Code was released for public comment in December 2002. The AHMAC National Health Privacy Working Group recommendations regarding the proposed code and options for implementation will be provided to health ministers later in 2003.
National Privacy Principles (NPPs)	The National Privacy Principles (NPPs) in the <i>Privacy Act 1988</i> set out minimum standard about how business and other private sector organisations should collect personal information, about the use and disclosure of personal information and about ensuring that the personal information they hold is accurate and secure. The NPPs reflect the Organisation for Economic Co-operation and Development (OECD) data protection principles.
Network	In information technology, a network is a series of points or nodes interconnected by communication paths. Networks can interconnect with other networks and contain sub-networks.
Nodes	In a network, a node is a connection point, either a redistribution point or an end point for data transmissions. In general, a node has programmed or engineered capability to recognise and process or forward transmissions to other nodes.
openEHR	<i>OpenEHR</i> , formerly known as the Good Electronic Health Record (GEHR), provides an open architecture and a standard format for electronic health records. The HealthConnect Project has sponsored work at a standards level where convergence of the <i>openEHR</i> approach with the European standards body and key groups in the US has the potential to create a world standard.

In addition, HealthConnect has funded investigations of the practical application of this standard to provide the record architecture for a national HealthConnect.

Oacis	Open Architecture Clinical Information System, installed by South Australia in their metropolitan hospitals.
Personal information	The <i>Privacy Act 1988</i> defines ‘personal information’ as: ‘Information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in material form or not, about an individual whose identity is apparent, or can be reasonably ascertained, from the information or opinion.’
Privacy	The interest an individual has in determining how information about that person is collected, maintained, used and disclosed.
<i>Privacy Act 1988</i>	The Act protects the privacy of individuals with respect to personal information about themselves held by other persons or institutions. The Act provides for eleven Information Privacy Principles (IPPs) found in section 14 of the Act. The Act initially applied only to Commonwealth agencies. However, private sector amendments to the Act became operative from 21 December 2001, which provide for ten National Privacy Principles (NPPs), found in Schedule 3 of the Act.
Public Key Infrastructure (PKI)	Public Key Infrastructure (PKI) is a set of procedures and technology that enables users of a network such as the internet to authenticate identity, and to securely and privately exchange information through the use of public key cryptography. To achieve this, public and private keys and a digital certificate can be obtained through a trusted third party authority, known as a certification authority (CA). The CA links the public key to the digital certificate and vouches for the identity of the key holder. In order for the system to operate, a process must be established to accurately identify a person via something like a 100 point test. Registration authorities (RAs) undertake this role by collecting and managing the appropriate levels of evidence of identity (EOI) from applicants for digital certificates. Dependent upon the PKI business model employed, appropriately accredited RAs may also create keys and certificates. The use of PKI ensures authentication, integrity, non-repudiation and confidentiality for e-commerce applications.
Secondary uses of data	This refers to the use of data other than for the primary, or main, purpose for which the information was collected from an individual. In the HIC context, secondary use refers to the use of data for research and statistical purposes.
SMS	SMS (Short Message Service) is a service for sending messages of up to 160 characters (224 characters if using a 5-bit mode) to mobile phones that use Global System for Mobile (GSM) communication.
SNOMED	Systematized Nomenclature of Medicine, known as SNOMED®, is a clinical terminology system for encoding medical records using scientifically

validated terminology and infrastructure that enables clinicians, researchers and patients to share health care knowledge worldwide, across clinical specialties and sites of care. SNOMED International is a division of the College of American Pathologists (CAP). <<http://www.snomed.org/>>.

SSL	The Secure Sockets Layer (SSL) is a commonly-used protocol for managing the security of a message transmission on the internet. SSL uses a program layer located between the internet's Hypertext Transfer Protocol (HTTP) and Transmission Control Protocol (TCP) layers.
Systems Architecture	Describes how the business process models defined in the Business Architecture can be implemented from a systems (data, applications and technology) perspective.
TCP/IP	TCP (Transmission Control Protocol) is a set of rules (protocol) used along with the Internet Protocol (IP) to send data in the form of message units between computers over the internet. While IP takes care of handling the actual delivery of the data, TCP takes care of keeping track of the individual units of data (called packets) that a message is divided into for efficient routing.
Telehealth	Health services, audiovisual communication for educational, administrative or research purposes, and clinical and administrative data processing performed over a distance by means of electronic communication.
Telemedicine	Refers to consultant services provided by off-site physicians over a distance by electronic means of communication.
User interfacing	User interfacing is used in this document to describe the complete local information system through which the user interacts with <i>HealthConnect</i> . Not to be confused with a Graphical User Interface (GUI) which refers simply to the keyboard, mouse, menus of a computer system.
Virtual private network (VPN)	<p>A VPN is a data network that adds certain quality-of-service features, at least privacy and security, to the internet.</p> <p>An internet-based system for information communication and enterprise interaction, a VPN uses the internet for network connections between people and information sites. However, it includes stringent security mechanisms so that sending private and confidential information is as secure as in a traditional closed system.</p>
W3C	The World Wide Web Consortium (W3C) is an industry consortium which seeks to promote standards for the evolution of the web and interoperability between WWW products by producing specifications and reference software. The consortium is international; jointly hosted by the MIT Laboratory for Computer Science in the US and in Europe by INRIA. The W3C was initially established in collaboration with CERN, where the web originated, and with support from DARPA and the European Commission.
WAP	WAP (Wireless Application Protocol) is a specification for a set of communication protocols to standardise the way that wireless devices,

such as cellular telephones and radio transceivers, can be used for internet access, including email, the world wide web, newsgroups, and Internet Relay Chat (IRC).

XML

XML (Extensible Markup Language) is a flexible way to create common information formats and share both the format and the data. Using agreed standards and standardising the way of describing data, enables users to send an intelligent agent (a program) to each computer maker's Web site, gather data, and then make a valid comparison. XML can be used by any individual or group of individuals or companies that wants to share information in a consistent way.

XML describes the content in terms of what data is being described. XML is 'extensible' because, unlike HTML, the markup symbols are unlimited and self-defining. XML is actually a simpler and easier-to-use subset of the Standard Generalized Markup Language (SGML), the standard for how to create a document structure. It is expected that HTML and XML will be used together in many Web applications. XML markup, for example, may appear within an HTML page.