

Health Information Technology Standards
Series Editor: Tim Benson

Tim Benson
Grahame Grieve



Principles of Health Interoperability

SNOMED CT, HL7 and FHIR

Third Edition

 Springer

Health Information Technology Standards

Series Editor

Tim Benson, R-Outcomes Ltd, Newbury, UK

Health information technology is one of the fastest growing industry sectors. The purpose of this book series is to provide monographs covering the rationale, content and use of these and other standards to help bridge the gap between the need for and availability of qualified and knowledgeable staff. This series will be focused on health informatics technology standards and the technology driving change in health IT. It will appeal to the traditional informatics market, but also cross over into more technical disciplines, but without leaving the remit that this is to expand knowledge in healthcare IT. It will comprise a set of single-author, practically focused, academically driven concise reference monographs on the leading standards and their application. Each volume will focus on one or more specific standards and explain how to use each one individually or in combination. This provides a tight focus for each book. The aim is to offer a set of “must have” references on the widely used standards, and in particular those mandated by the ONC.

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Tim Benson • Grahame Grieve

Principles of Health Interoperability

SNOMED CT, HL7 and FHIR

Third Edition

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*Tim Benson dedicates this book to his sons
Laurence, Oliver, Alex and Jamie.*

*Grahame Grieve dedicates this book to his
family, who lit the fire in the first place.*

Foreword to the Third Edition

Recent US Government reports have included statements such as:

The apparent inability of the private sector to achieve interoperable systems suggests the need for national leadership to support their creation.

Information blocking occurs when persons or entities knowingly and unreasonably interfere with the exchange or use of electronic health information.

Health lacks a common language to share data.

Each of these points oversimplifies the real issues facing healthcare information exchange. A combination of technology, policy and alignment of incentives has worked in every industry to enable data liquidity. If stakeholders understand all the issues, the same thing will happen in healthcare.

Unfortunately, domain expertise in interoperability is rare. The standards are esoteric and detailed. Politics and emotion can cloud the objective evaluation of standards that are suitable for purpose, well documented and mature enough for adoption.

Principles of Health Interoperability: SNOMED CT, HL7 and FHIR (3rd edition) by Tim Benson and Grahame Grieve provides an accessible, well-organized primer that is objective and clear. It clarifies that interoperability is not just as simple as pushing HL7 transactions from point to point.

When I was 2 years old in 1964, my mother gave me ampicillin and I developed two red dots on my stomach. She declared me allergic to penicillin. For 50 years my medical record has said “penicillin allergy” and not:

Substance: Pencillins and Cephalosporins

Reaction: Urticaria

Observer: Mother

Level of Certainty: Very Uncertain

Date of observation: January 1, 1964

If we are to share data among stakeholders, we need easy to implement technologies that provide a structure for the information (such as the five components of an

allergy above), appropriate vocabularies (how do we describe the nature of the reaction in a uniform fashion) and a secure means of transmitting that information over the wire. If I was diagnosed with a live threatening strep infection, for which Penicillin is the most effective drug, would a clinician make a different decision on treatment knowing that my allergy is uncertain and minor? Certainly.

Principles of Health Interoperability is a must read for policymakers, technology leaders and industry implementers. The book distills thousands of pages of standards into the essential information you need to know. The addition of the *Fast Healthcare Interoperability Resources* (FHIR) makes the 3rd edition even better than the 2nd edition. FHIR will enable an ecosystem of apps, which layer on top of existing EHRs, reduce the cost of interfacing and accelerate innovation.

If you are looking for the definitive resources on the latest techniques to implement content, transport and vocabulary interoperability, look no further than this book. It will be a centerpiece of my own bookshelf.

Beth Israel Deaconess Health System
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Boston, MA, USA

John D. Halamka

Foreword to the First Edition

Health data standards are a necessary component of interoperability in healthcare. Aggregation of health-related data mandates the use of standards, and aggregation is necessary to support safe and quality care. The American Recovery and Reinvestment Act (ARRA) includes \$19 billion dollars in direct funding and an additional \$18.5 billion in returned savings tagged to the use of health information technology (HIT). The resulting expanding use of HIT has engaged a growing number of stakeholders, many of whom now realize the value of standards.

All aspects of creating and “meaningful use” of electronic health records (EHRs) require standards. With the increasing demand for individuals knowledgeable in what standards are available and how and when to use those standards, this book is most welcome. The author, Tim Benson, has been engaged in the creation of standards since the beginning. His experiences span organizations – including HL7, CEN and ISO and terminologies such as SNOMED and LOINC. He has engaged the global community and understands similarities as well as differences among the global community. He has a top reputation as a teacher and writer within the international community. I know no other individual more qualified to write this book than Tim Benson.

In *Principles of Health Interoperability HL7 and SNOMED*, Tim focuses on major contributors to the set of required standards. In the first section, he lays out a framework for why interoperability is important and what is needed to accomplish that interoperability. Health Level Seven (HL7) is pre-eminent among the several contributing Standards Developing Organizations (SDOs) in the global community. HL7 standards are widely used and cover the full spectrum of applications. Its membership is international (currently including over 35 countries) and includes the major HIT vendors and representatives of the full set of stakeholders. The International Healthcare Technology Standards Developing Organization (IHTSDO) is rapidly promoting SNOMED CT as the preferred terminology in healthcare. While focusing on HL7 and SNOMED CT, Tim has included much useful information on other standards and other organizations.

Readers will find this book easy to read, even if it is their first exposure to standards. In this rapidly changing field, this book is a must for anyone who is involved or has interest in the use of health information technology – and who isn't.

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W. Ed Hammond

Foreword to the Second Edition

The success of this book validates the above remarks. Interoperability and the focus of the broad community on this topic and the implementation of systems and standards that support interoperability have grown at an exponential rate. As the implementation of Health Information Interchange systems grows, more and more people join the workforce to support this growth. They need to be taught and learn about standards supporting interoperability. A number of colleagues and I use this book as a text. The students love it – it is clear and easy to read and understand. Technology and the ensuing standards to support standards change rapidly. In this second addition, Tim has astutely addressed this challenge. In some sections, he expanded the material; in others, he reorganized the material; and, most importantly, he added new sections to increase the comprehension and coverage of the topic. The second edition is even better than the first.

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W. Ed Hammond

Preface

Interoperability is one of the hottest topics in healthcare, yet one of the least well understood. Successful interoperability offers great opportunities to improve quality and outcomes while reducing waste and costs. The task of interoperability is to deliver the right information at the right time to the right place. Everybody (patient, clinician, manager and payer) stands to benefit from more soundly based decisions, safer care and less waste, errors, delays and duplication.

Interoperability needs appropriate standards to link computer systems, and to share information in a way that meets security and privacy needs. SNOMED CT and HL7 (including FHIR) provide key standards that underpin efforts to improve healthcare interoperability. HL7 provides the structure, rather like English grammar, while SNOMED CT provides the words that computers understand.

This book gives a broad introduction to healthcare interoperability in general, and the main standards, setting out the core principles in a clear readable way for analysts, students and clinicians.

The third edition of this book is fully revised, reorganized and extended. There are five new chapters on FHIR (Fast Healthcare Interoperability Resources), written by Grahame Grieve, the father of FHIR. This is the first comprehensive introduction to FHIR in any book.

FHIR APIs are likely to have a massive disruptive impact on healthcare interoperability, being an order of magnitude less expensive to implement than previous standards. FHIR will also support an explosion of patient-centric apps that can interoperate with legacy systems.

To accommodate these changes, we have changed the order of the chapters, so that clinical terminology and SNOMED CT come before HL7 interchange formats, v2, v3, CDA and FHIR. The introductory chapters have also been revised and updated.

The book is organized in four parts. The first part covers the principles of health-care interoperability, why it matters, why it is hard and why modeling is an important part of the solution. The second part covers clinical terminology and SNOMED CT. The third part covers the longer established HL7 standards, v2, v3, CDA and IHE XDS. The final part covers FHIR.

Newbury, UK
Melbourne, Australia
January 2016

Tim Benson
Grahame Grieve

Principles of Health Interoperability: SNOMED CT, HL7 and FHIR (3rd Edition)

Healthcare interoperability delivers information when and where it is needed. Everybody stands to gain from safer more soundly based decisions and less duplication, delays, waste and errors. This book provides an introduction to healthcare interoperability and the main standards used.

The third edition includes a new part on FHIR (Fast Healthcare Interoperability Resources), the most important new health interoperability standard for a generation. FHIR combines the best features of HL7's v2, v3 and CDA, while leveraging the latest web standards and a tight focus on implementation. FHIR can be implemented at a fraction of the price of existing alternatives and is well suited for mobile phone apps, cloud communications and EHRs.

The book is organized into four parts. The first part covers the principles of health interoperability, why it matters, why it is hard and why models are an important part of the solution. The second part covers clinical terminology and SNOMED CT. The third part covers the main HL7 standards: v2, v3, CDA and IHE XDS. The new fourth part covers FHIR and has been contributed by Grahame Grieve, the original FHIR chief.

Newbury, UK
Melbourne, Australia

Tim Benson
Grahame Grieve

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Tim Benson: Many people have contributed to my understanding of this healthcare interoperability. In particular, I want to thank Ed Hammond, David Markwell, Roddy Neame, Abdul-Malik Shakir, Alan Rector, Bob Dolin, Charlie McCay, Charlie Mead, Clem McDonald, David Ingram, Ed Cheetham, Ed Conley, Georges de Moor, Jack Harrington, James Read, Kent Spackman, Larry Weed, Leo Fogarty, Mark Schafarman, Mike Henderson, René Spronk, Sigurd From, Tom Marley and Woody Beeler. Finally, I wish to thank my family for their forbearance and all the great people who have created SNOMED, HL7 and FHIR.

Grahame Grieve: FHIR is a community, a collective accomplishment, and many people have contributed, too many to list. But a few deserve mention: Ewout Kramer, Lloyd McKenzie, Josh Mandel, James Agnew, Brian Postlethwaite and David Hay for contributing the most to the community and the specification. More personally, Kevin Moynihan, David Rowlands, Thomas Beale, Kim Clohessy, Chuck Jaffe, Gunther Schadow, Charlie McCay, Andy Bond and Woody Beeler have contributed enormously to my understanding of healthcare, integration and the business environment in which it thrives. Also thanks to Mel Grieve for editing the FHIR part, and to my family for sharing their holidays with this book.

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About the Authors



Tim Benson graduated from the University of Nottingham as a mechanical engineer. He was introduced to healthcare computing at the Charing Cross Hospital, London, where he evaluated the socio-economic benefits of medical computing systems. He founded one of the first GP computer suppliers (Abies Informatics Ltd). There, with James Read and David Markwell, he helped develop the Read Codes, which became the national standard for NHS primary care and one of the two sources of SNOMED CT. Tim led the first European project team on open standards for health interoperability, which led to CEN/TC251 and collaboration with HL7, where he was a co-chair of the

Education Committee for several years. He has also developed a family of short generic patient-reported outcome measures (<http://www.r-outcomes.com>).



Grahame Grieve graduated from the University of Auckland as a biochemist and worked as a clinical diagnostic scientist at St Vincent's Hospital, Melbourne, before spending 4 years performing medical research in diabetes, lipid metabolism and oxidation. He then switched focus and joined Kestral Computing P/L, a Laboratory and Imaging Information Systems vendor, where he ended up as Chief Technology Officer, before leaving to establish his own consulting business (<http://www.healthintersections.com.au>). A growing involvement in integration, and interoperability, lead him to the HL7 community where he has led committees and edited standards for HL7 v2, v3 and CDA. The out-

come of this was the recognition that something new was needed, and this led to the creation of the FHIR specification, which now consumes his life.

Part I

Principles of Health Interoperability

Chapter 1

The Health Information Revolution

Abstract This chapter sets out some of the core problems and opportunities facing the digital healthcare sector. Healthcare is all about communication. Large investments in digital health have failed to live up to expectations, partly due to poor interoperability. Patient centered care requires a new approach, organized primarily for patient benefit, not just for provider organizations. What matters most is the point of care, which is inevitably complex. Many lessons can be learnt from past experience, successes and failures.

Keywords EHR • Communication • Information • Patient-centered care • Outcomes • Key performance indicators • Quality • Waste • Clinical decisions • Clinical specialty • El Camino hospital • POMR • GP computing • Prescription form • NHS National Programme for IT • Summary care record • Detailed care record • Infoway standards collaborative • MedCom • Meaningful use

Healthcare is Communication

Modern healthcare depends on teamwork and communication. Interoperability is needed to provide information when and where required, facilitate quicker and more soundly based decision making, reduce waste by cutting out repeated work and improve safety with fewer errors.

Convergence of digital health interoperability, wireless sensors, imaging technology and genomics will transform the way that healthcare is practiced, its efficiency and effectiveness. Patients using their own mobile devices are leading this revolution. Patients won't wait, even if it takes years for physicians to adopt new medical advances [1].

Most healthcare processes involve communication within the system. Billions of documents are generated mostly using pen and paper. Healthcare remains the largest remaining market for pens, paper and fax-machines. The long-promised digital health revolution has been slow to arrive and is still characterized by “hope, hype and harm” [2]. Large initiatives such as the \$30Bn *Meaningful Use* scheme have failed to improve efficiency as much as was hoped, in large part due to failure to address interoperability at the clinical level.

Paper-based patient records are widely recognised as unfit for purpose. What Bleich complained of more than 20 years ago is still common:

The medical record is an abomination ... it is a disgrace to the profession that created it. More often than not the chart is thick, tattered, disorganized and illegible; progress notes, consultants notes, radiology reports and nurses notes are all co-mingled in accession sequence. The charts confuse rather than enlighten; they provide a forbidding challenge to anyone who tries to understand what is happening to the patient (Bleich 1993) [3].

Paper records can only be used by one person at a time, and are often not where they are needed. Once to hand, it is hard to find what you want in a disorganized, illegible, inconsistent, incomplete, badly sorted collection. The user has to work hard just to glean any useful information. An enormous amount of staff time is spent locating, transporting and reviewing these paper repositories.

On the other hand, it is easy to overlook just how flexible and durable paper-based patient records are in spite of these deficiencies. EHRs need to become just as flexible, reliable and easy to use.

Traditionally, healthcare information systems have been organised hierarchically on the basis of the flow of money and authority, flowing from payer to provider organizations and down to departments, clinicians and finally patients. This model is way out of alignment with the natural flow of information needed to care for individual patients, which is more like a social network, with each patient at the center of his or her own net.

All people want the same things from health and social care. They want to feel better physically and mentally, to do more and be independent. They want this now and in the future, with a long healthy life followed by a quick peaceful death, not a slow demise. Every patient also wants excellent care and service, to be treated kindly, to be listened to and have issues fully explained, be seen promptly and for systems to perform reliably and safely.

More confident and engaged patients tend to report better outcomes and experience and have lower costs. These patients are typically more empowered, knowledgeable, confident to manage their own health, able to get help when they need it and participate in shared decision-making,

Given that patients are the sole reason for healthcare activity, health services increasingly need to focus on the outcomes that matter to patients. Great organizations have always used a small number of key performance indicators (KPIs).

What matters is ... settling upon a consistent and intelligent method of assessing your outcome results and then tracking your trajectory with rigor (Collins 2006) [4].

Efforts to improve quality often lead to lower costs, while efforts to cut costs invariably lead to lower quality. The primary focus needs to be on quality improvement not cost cutting.

In a person-centered model, care is based on continuous clinical relationships, customized to individual patient needs, with the patient ultimately in control. Knowledge is shared, information flows freely and decisions are based on evidence. Transparency and collaboration are virtues, patient needs are anticipated and effort

is devoted to eliminating waste, which is any activity that costs money but delivers no benefit to patients.

However, today’s healthcare information systems were designed mainly to support the traditional medical model, based around discrete conditions, visits and episodes. Each clinician decides independently on what investigations and treatment to order based on their training and experience. This has led to large variation in treatment, much of which is unwarranted (Wennberg 2010) [5]. The patient record is often just a log of what happened, incentivized to maximize fee income and kept secret from the patient. The system defends professional demarcation and reacts to patient needs only as and when they arise.

However, when so much of what we do is performed over the Internet, there are no technical barriers to sharing information and providing joined-up patient-centered care, yet good interoperability remains a rarity.

Back in 2001 the Institute of Medicine in *Crossing the Quality Chasm* set out rules for a person-centered healthcare system [6] (see also Table 1.1).

1. Care should be based on continuous healing relationships, not based on payment for discrete episodes. This means continuous access, taking full advantage of modern information technology, 24-h a day, 7 days a week and 365 days a year.
2. Customization based on patients’ needs and values. Variation should be based on patients’ informed needs and wishes, not professional autonomy.
3. The patient should be in control over decisions, access and information sharing – “no decision about me without me”.
4. Knowledge and information should be shared with patients as a right, without restriction, delay or the need for anyone else’s permission.
5. The best care results come from the conscientious explicit and judicious use of current best evidence and knowledge of patient values by well-trained experienced clinicians.
6. Safety should be a system property, not be regarded as an individual responsibility. Systems should prevent error when possible, detect any errors that occur and mitigate the harm done if an error does reach the patient.

Table 1.1 Contrast between traditional and patient-centered healthcare models (Based on Institute of Medicine 2001)

Aspect	Traditional	Patient-centered
Focus of care	Discrete visits/episodes	On-going care relationship
Variation mainly due to	Professional autonomy	Patient needs and values
Control	Professionals in control	Patient in control
Decisions based on	Training and experience	Evidence
Safety	Individual responsibility	A system property
Openness	Secrecy	Transparency subject to patient privacy
Reactivity	React to patient needs	Anticipate patient needs
Economic focus	Cut costs	Eliminate waste
Collaboration	Demarcation	Cooperation
Information technology	Silos	Interoperability

7. Use knowledge of individual patients, local conditions, and the natural history of illness to predict and anticipate needs not simply react to events.
8. Economies by reducing all types of waste, not by cutting costs. Improving quality can save money, but cutting costs reduces quality. Examples of waste in the US health system include [7]:
 - Service overuse (\$210 billion)
 - Inefficiency (\$130 billion)
 - Excess administrative costs (\$190 billion)
 - Prices that are too high (\$105 billion)
 - Missed prevention opportunities (\$55 billion)
 - Fraud (\$75 billion)
9. Teamwork, cooperation, collaboration, communication and coordination are more important than professional prerogatives and roles.

Information Handling

Information handling has evolved over several thousand years through the four stages originally set out by Marshall McLuhan (1962) [8].

In the first stage, information and knowledge was held only in the human brain and transferred from one person to another by speech. Oral tribe culture provides an example. Access depends on the person with the knowledge being present and this is lost forever when they die. Much of medicine still relies on this model of communication and the clinician's memory.

The second stage began with the invention of handwriting. Hand-written records are formatted at the time of writing, cannot be replicated without transcription and may be hard to read. However, modern healthcare, involving teams of doctors and nurses, each doing a specialised task, would be impossible without written records. Hospital medical records are still largely hand-written.

Gutenberg

The third stage was triggered by the invention of printing by Johannes Gutenberg around 1455, which provided the means to replicate and broadcast information widely. This led to the Renaissance, the Age of Enlightenment, the Industrial Revolution and the Information Society. The impact of top-down broadcasting and dissemination of knowledge on medical education has been massive, but there has been little impact on how people perform routine consultations or maintain records.

The fourth and last stage, the electronic age, has its origins in the electronic computers and information science developed during the Second World War and has gathered pace exponentially ever since. The digital revolution has led to explosive

development of the Internet, the Web, mobile phones and social networking, following Moore's and Metcalfe's laws.

Moore's Law is the prediction made in 1965 that the power of computer devices would continue to double every 2 years; this has held good for 50 years and shows few signs of stopping yet. Two to the power 25 is over 33 million. Metcalfe's Law says that as networks grow, the value to each user increases linearly but the total value of the network increases exponentially.

Topol has drawn close parallels between the transformative effects of Gutenberg's press and those of the smartphone. These include explosion of knowledge, spurring innovation, promoting individualization, promoting revolution and wars, fostering social networks, reducing interpersonal interaction, spreading ideas and creativity, promoting do-it-yourself, flattening the Earth, reducing costs, archiving and reducing boredom. He suggests that just as Gutenberg democratized reading, smartphones will democratize medicine by giving individuals unfettered direct access to all of their health data and information [9].

We are moving towards new relationships between patients and citizens, their clinicians and smartphone apps and supporting algorithms, sharing the same health and care information. This co-production triangle can reduce data-action latency, the delay between information being available and its being acted upon [10].

Use of Information

Healthcare is the quintessential information-based industry, yet has singularly failed to harness these forces. The electronic health record (EHR) lies at the heart of digital health. The wide range of uses, clinical and non-clinical, are shown in Fig. 1.1.

Clinical care is task-oriented. At any moment a clinician is performing one of a number of well-defined tasks, but every clinical microsystem is different. Clinical care is made up of thousands of discrete tasks, each with its own information and communication needs and requiring systems, terms and classifications tailored to the needs of the task.

These tasks are ultimately determined by the complexity and variety of the natural history of disease processes and their corresponding diagnostic, treatment and administrative procedures. Automating these tasks, which include everything needed to support clinical decision-making, to order tests and treatment, to correspond with all those involved in the care of individuals (patients, hospital specialists, GPs, community and social care services), is the core task of digital health.

Managers cannot and do not need to understand every detail of clinical care; their focus is to provide a safe, efficient and courteous service, smooth administration of each patient's visit, and to ensure that everything is done in order to get paid.

Their focus is on service management. These tasks are far more homogeneous than clinical uses, focused on meeting the contractual obligations imposed by regulators and payers. However, such regulations and contracts change frequently and are ultimately determined politically.

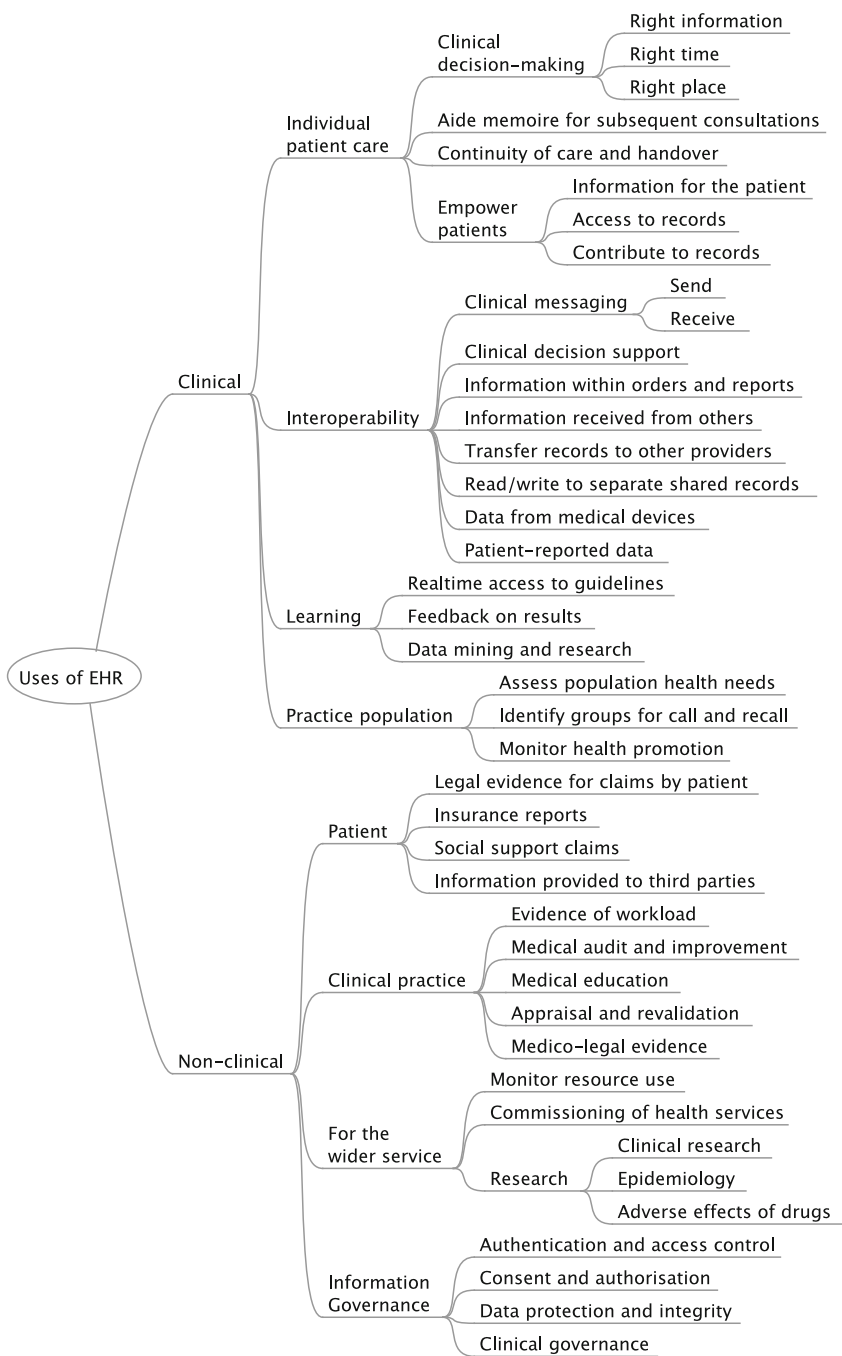


Fig. 1.1 Uses of electronic health records

One of the problems is that health professionals can be overwhelmed by information and by demands for information. Herbert Simon noted that:

Information consumes the attention of its recipients; a wealth of information creates a poverty of attention and a need to allocate that attention amongst the overabundance of information sources that might consume it (Simon 1971) [11].

In medicine, as in art, the value of information is often related to its rarity. The key to medical decision-making is Bayes law, which is based on how much a new piece of information changes the prior probabilities.

A combination of EHR features, such as auto-population, templates and cut-and-paste, which were conceived to save data entry effort and maximize income, often generate voluminous notes where it is hard to find what you are seeking.

Clinical Decisions

Differences in treatment and investigation patterns of individual doctors lead directly to different costs and outcomes. Doctors spend the money. It is always important to do tests efficiently, but if a test or procedure is inappropriate, it is waste irrespective of how efficiently it is done. Don Berwick has written:

The ultimate measure by which to judge the quality of a medical effort is whether it helps patients (and their families) as they see it. Anything done in healthcare that does not help a patient or family is, by definition, waste whether or not the professions and their associations traditionally hallow it (Berwick 1997) [12].

What principally determines cost is doing the right things. Only a small proportion of cost variance is down to service efficiency – doing things right.

Electronic patient records are key to improved clinical decision-making. Computer-based records are legible and, in theory, information can be displayed in the best way for the task at hand. Several people can work on the same record at the same time in different places, saving the delays and effort required to locate, retrieve and transport paper. Prompts can improve quality and safety, prevent key data being omitted, and save time by not needing to record the same data time and again.

Healthcare communication and information flow patterns involve large numbers of people over a wide geographical area and diverse subject matter. For example, each primary care doctor refers patients to many specialists and each specialist receives referrals from many referrers. Each doctor communicates with a multitude of specialised investigation and treatment services, community care agencies, administrative and funding bodies. These highly complex many-to-many communication patterns are found throughout the health and social care services (Fig. 1.2).

The half-life of information (how long a piece of information has much value) differs enormously between contexts, such as outpatient clinics, wards, intensive care units and operating theatres. There is little benefit in showing information well after its half-life is over, even if it has to be preserved for medical legal purposes.

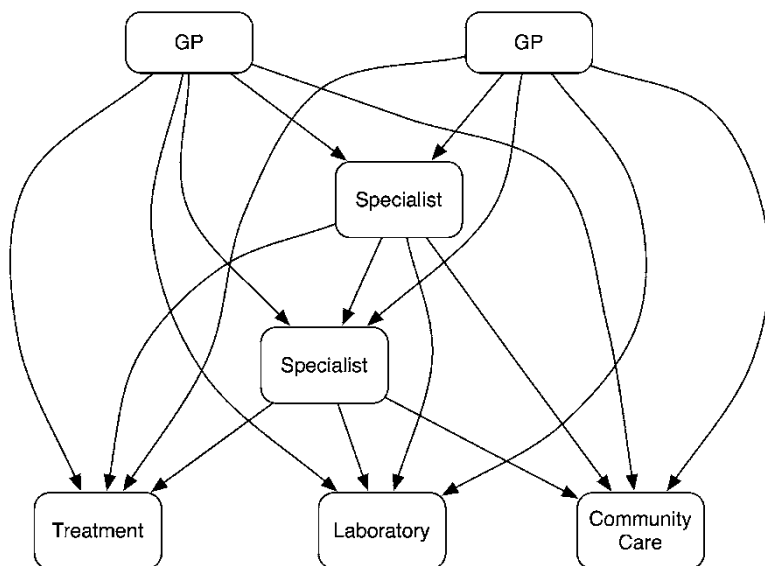


Fig. 1.2 Complex information flow patterns

Every specialty has its own needs. Doctors are organised into 60 or more specialties and there are similar numbers for nursing, treatment and investigation professions. Each specialty has its own governance, education and quality assurance requirements, speaks its own dialect and has its own ways of working. Specialists understand their own specialty very well, but not other specialties.

This helps explain why successful electronic patient record systems are often limited to a single specialty, such as general practice, maternity care or renal medicine, where the needs are relatively homogeneous and well understood.

Clinicians in hospitals are very mobile; they are found on any ward where they have patients, in clinics, at any one of several hospitals, on domiciliary visits in the community, in laboratories or in their own office. Mobility just adds to the problems of computerization.

The concept of the one-size-fits-all patient record has seldom been successful except where enormous efforts and adequate resources have been devoted to tailor the system to individual specialty needs and where management has been able to mandate its use.

Lessons from History

El Camino Hospital

These issues have been well known for at least 40 years. The first hospital to implement a comprehensive EHR was the El Camino Hospital, Mountain View, California, which went live in 1971. This project was subjected to a detailed 6-year evaluation,

which compared its costs and other outcomes with control hospitals. Such detailed long-term evaluations are surprisingly rare and when done are not always published, but almost all other studies have shown similar findings.

The following quotes come from an account of the experience by Melville Hodge, who led the project for the supplier (Hodge 1990) [13]. The project at El Camino was initially met with:

Massive resistance from important segments of the medical staff, spreading quickly to ... national newspaper headlines. This resistance, initially justified in part by early system shortcomings, seemed intractable.

Healthcare is a complex socio-technical system, involving the interaction of both people and technology. You cannot design organizational and technical systems independently of each other, nor expect to re-engineer healthcare systems successfully without a thorough understanding of both the human and technology requirements to make all the parts work smoothly together (Coiera 2004) [14]. Hodge warned:

Never forget that introduction of [EHR] into a hospital impacts a human organization to an unparalleled degree. If the need to manage the change process is ignored, resistance and even rebellion may be reasonably predicted.

The initial resistance was overcome by learning these lessons and:

By effective leadership of the more visionary El Camino physicians.

The outcome was that 10 years later, in 1981, the hospital chief executive could claim a triumph:

The hospital inpatient cost per case is 40% less than the county average for 13 similar community hospitals.

To summarize:

Success has repeatedly been demonstrated to be the consequence of each doctor, one at a time, coming to see how his performance is enhanced by investing his always-scarce time in learning how to use the system efficiently. Similarly, hospital managers must participate in and buy into a carefully designed benefits realization program before they can be reasonably expected to act.

These problems and risks, and the knowledge of how to mitigate them, were first understood almost 40 years ago, yet the same things still happen (Wachter 2015) [2].

Success in GP Surgeries

In the UK all GPs (family physicians) use EHRs in their consulting room and almost all work paper-free – they rely entirely on electronic records while consulting. All primary care prescriptions are printed by computer or sent electronically [15]. This all happened by the mid 1990s, more than 20 years ago.

Leadership and incentives played a big part in why GPs use computers (Benson 2002) [16]. Over a 30-year period, the leaders of the GP profession worked hand-in-hand with the government to encourage and remove barriers to computerizing practices.

The story of the NHS computer-printed prescription form provides a good example of how governments can remove barriers to computerization. Computer-assisted repeat prescribing saves writing out prescriptions by hand and improves legibility and safety. The computer-printed FP10 (comp) form is twice the width of a standard prescription, with a blank area on the right hand side. The original reason for the blank space was that narrow tractor-feed printers were not available when the form was developed in the 1970s. The blank right hand side was used to provide each patient with a record of his or her medication; this was so useful that no one then considered doing away with it.

In spite of reservations that the wider form would be more expensive and computers would make it easier to prescribe more, hence increase the NHS drugs bill, the Department of Health approved the national use of the form in 1981. This single regulatory change was critical in stimulating the spread of GP computing. In other countries computer printed prescriptions remained illegal for decades longer, slowing uptake there.

Failure in Hospitals

The story in hospitals is very different. Attempts to replicate the success of GP computing in hospitals have failed repeatedly. There are several reasons.

You cannot shoehorn a system that works well in one specialty into another, yet the information systems used by different specialties need to work together, which requires interoperability.

GPs work as individuals mainly from a single consulting room, but hospital clinicians work as teams and are very mobile; their work is individually specialised, there are many specialties and each works in a different way. No one understands everything that goes on in a hospital.

Hospital clinicians need excellent communication within their work-group (the clinical micro-system) between doctors, nurses and other professions. An Australian study of hospital doctors found that they spent about 33 % of their time in communicating with other professionals, compared with 15 % of their time in direct care, including communication with the patient and their family. 70 % of the tasks performed by junior hospital doctors were with another member of staff, usually another doctor. Interns spent twice as much time on documenting (22 %) as on direct care (11 %) [17].

Hospital doctors have been offered few incentives or career encouragement to become involved, leading to alienation. Hospital computing has usually been treated as an administration overhead, reporting to the finance director, who is usually concerned with maximizing revenue and cutting costs.

NHS National Programme of IT

The NHS National Programme for IT (NPfIT) was described as the biggest computer programme in the world (Brennan 2005) [18] and turned into one of the biggest failures. It set out to provide detailed electronic health records for everyone in England, but this central objective was abandoned. How did this come about?

Conceived in 2002 during the period between 9/11 and the invasion of Iraq, things went badly wrong from the start. The central recommendation of the report, which led to the creation of the project, was for:

A doubling of spending on ICT to fund ambitious targets of the kind set out in the NHS Information Strategy. To avoid duplication of effort and resources and to ensure that the benefits of ICT integration across health and social services are achieved, the Review recommends that stringent standards are set from the center to ensure that systems across the UK are fully compatible with each other [19].

More detail was provided in a strategy document 3 months later, which stated:

The core of our strategy is to take greater control over the specification, procurement, resource management, performance management and delivery of the information and IT agenda. We will improve the leadership and direction given to IT, and combine it with national and local implementation that are based on ruthless standardization (DH 2002) [20].

Note two important differences between these quotations. The vision of integration across health and social services and cross-UK compatibility was dropped. Then the recommendation to set stringent standards was changed to one of ruthless standardization (an odd term as standards are usually based on consensus). The revised focus was to provide a centrally procured set of one-size-fits-all systems, and to rip-and-replace every system in the country. However, many local managers simply refused to replace working systems with those that were procured, which many did not consider to be fit for purpose.

The Strategy had ten key elements, the final one being to:

Create national standards for data quality and data interchange between systems at local, regional and national levels (paragraph 2.3.2) [20].

From the outset, the challenges of developing and deploying the necessary standards were greatly underestimated. The strategy document published in June 2002 strongly and wrongly implied that the relevant standards were already available.

Work is already underway on a strategy for electronic Clinical Communications and a report is due at the end of March 2002 (sic) (paragraph 4.2.2) [20].

The first phase of the project, between April 2002 and March 2003, was to be used to:

Define the data and data interchange standards we will require in the future (paragraph 1.2.3) [20].

Responsibility for standards development was spread across four separate organizations for strategic direction, defining standards, ratifying standards and

certification testing. No one had overall control of the whole picture. These national functions were eventually brought together April 2005 under NHS Connecting for Health. By then the key decisions on scope, technology and budgets had all been set in stone.

A central team developed specifications for national services using HL7 v3, but the specification and deployment of local services was left to local providers who adopted different releases of HL7 v2.

Two key parts of the program were the summary care record (SCR) and the detailed care records (DCR). The SCR is a nationally stored summary of patient's medical records in England, for use out of hours and emergency care. It contains details of medication, allergies and adverse drug reactions.

The evaluation of the SCR identified damaging conflicts between separate but interacting socio-technical networks [21]:

- The design network – policy makers, advisers, software developers and those involved in the technical infrastructure
- The implementation network – involved in implementation
- The governance network, responsible for privacy and security
- The front-line user network – users
- The evaluation network – evaluators.

Early use of the SCR was lower than expected, although this has now been turned into a success after several more years of effort. DCRs were even less successful.

Canada

In Canada, the Health Infoway project established a centrally funded Infoway Standards Collaborative, to:

Support and sustain health information standards and foster collaboration to accelerate the implementation of pan-Canadian standards-based solutions [22].

The scope of the Infoway Standards Collaborative covers the interoperability standards that are required to meet the needs of the program, including their establishment, promotion, support and maintenance, and liaison with international standards development organizations.

The process used engages all stakeholders, stimulates market demand for these standards and seeks to reduce the risks and barriers to adoption. An open governance structure and long-term funding support it.

Denmark

Denmark has been uniquely successful in linking primary care doctors with laboratories, hospitals and pharmacies. In 1994 the Danish Government established MedCom as a national public project collaborating with public authorities,

healthcare organizations and private firms. A small group of experts developed a set of standards for referrals, discharge letters, laboratory and radiology requests and reports, prescriptions and reimbursement claims, which were based on European standards originally developed by CEN TC251. These specifications were piloted, revised and re-tested in fifteen independent locally managed projects. Finally, the experience gained was brought together in voluminous documentation:

In such detail and so accurately and precisely that the overwhelming opinion is that MedCom's standards can indeed be used from Gedser to Skagen (from one end of Denmark to the other) (MedCom 1996) [23].

Even after this preparation, the information sent was not always displayed or was misinterpreted due to ambiguity in data definitions of data elements, local coding schemes and lack clarity about which elements were mandatory or optional. These issues were tackled in a 3-year consolidation project leading to revised standards and compulsory certification. By the end of 2002, 53 software versions had been certified and the error rate was cut by more than 70 % (Johansen 2003) [24].

Today all Danish GPs receive discharge summaries and lab results electronically; most prescriptions and referrals are also sent electronically. One of the lessons is that success requires long-term persistence and political support (MedCom 2008) [25].

Meaningful Use

The term Meaningful Use of health IT was introduced in Obama's HITECH (Health Information Technology for Economic and Clinical Health) Act, 2009, which encapsulates in its name both the financial and care drivers for digital health. The nominal focus is to deliver the promise of electronic health records (EHR), but the real goal was to improve value for money (Blumenthal 2009) [26].

The US healthcare system started from a low base. In 2008, Tom Daschle, Obama's original nominee as Secretary of Health, summarised the problem as follows:

Our healthcare system is incredibly primitive when it comes to using the information systems that are common in American workplaces. Only 15 to 20 per cent of doctors have computerized patient records and only a small fraction of the billions of medical transactions that take place each year in the United States are conducted electronically. Studies suggest that this weakness compromises the quality of care, leads to medical errors, and costs as much as \$78 billion a year (Daschle 2008) [27].

By January 2014 93 % of eligible hospitals and 82 % of eligible physicians had registered for the program. By March 2015 more than \$30 billion had been paid out.

The government had the good idea that people should be paid for using computers, not just for having them (shelf-ware). To receive incentive payments for being a meaningful user of a certified EHR system, each doctor (or other eligible professional) and hospital has to demonstrate that they are using computers for purposes including e-prescribing with decision support, laboratory results, radiology reports, visit summaries and to exchange coded data and quality reports.

However, physician dissatisfaction has grown. Between 2010 and 2014 satisfaction with EHRs fell from around 61 to 34 % [28]. Almost half of respondents (in a self-selected sample of 940) reported that EHRs reduced efficiency, 72 % stating it was difficult for EHRs to decrease physician workloads and 54 % saying that EHRs increased operating costs. The only positive was that those who have used their system for longer were more satisfied than those who had only recently converted.

The reasons for clinical dissatisfaction are multiple and complex [2]. Many of them have been discussed above; four stand out. First, decisions about what systems to use have usually been made to meet business objectives such as maximizing income rather than to improve clinical quality and patient outcomes which are harder to count. Second, major computer systems are complex to design, build and implement and almost all of the systems in use today were designed in the era before meaningful use. Third, the scheme is seen as overly bureaucratic in its specifications and demands for evidence. Fourth, the regulations failed to incentivize interoperability, which is the subject of this book.

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Chapter 2

Why Interoperability Is Hard

Abstract This chapter explores some of the reasons why healthcare interoperability is hard and why standards are needed. Interoperability can be looked at as layers (technology, data, human and institutional) involving different types of interoperability, technical, semantic, process and clinical. Standards are needed to tame the combinatorial explosion of the number of links required to join up systems, but usually require translation to and from an interchange language. Users and vendors are not always incentivised to interoperate. Apparently simple things such as addresses are more complex than they seem. Clinical information in EHRs is inherently complex, but complexity and ambiguity in specifications creates errors. Any interoperability project involves change management.

Keywords Interoperability definition • Interoperability layers • Technical interoperability • Semantic interoperability • Process interoperability • Clinical interoperability • Interoperability standards • Combinatorial explosion • Electronic health records (EHR) • Translation • Rosetta Stone • Problem-oriented medical records (POMR) • ISO 13606 • Name • Address • Discharge summary • Clinical laboratory reports • GP2GP • Complexity • Errors • Change management

Layers of Interoperability

Few large health IT projects manage to achieve all of their objectives, especially when it comes to interoperability. This chapter looks at some of the reasons why health interoperability is so hard to get right and why standards are essential.

The benefits of joined-up healthcare depend on safe, secure and reliable interoperability to provide the right information when and where it is needed.

We can think of interoperability as having four layers:

- Technology
- Data
- Human
- Institutional [1].

These are not necessarily listed in sequential order. For example, air traffic control is a good example of successful interoperability, where standardisation was achieved first at the human and institutional layers, and the data and technology layers came much later.

In healthcare interoperability each of these four layers is important. Governments, providers and vendors need to work together to achieve good results, especially at the institutional level, where barriers to interoperability are exacerbated by privacy concerns, technology lock-in and lack of appropriate incentives. The art is to enable diversity while ensuring that systems work together in the ways that matter most. We need to aim for optimum interoperability.

One of the tricks to the creation of interoperable systems is to determine what the optimal level of interoperability is: in what ways should the systems work together, and in what ways should they not [1].

Definitions

The term interoperability means different thing to different people. The *HIMSS Dictionary of Healthcare Information Technology Terms, Acronyms and Organizations* lists 17 definitions from the strictly technical to those that emphasize social, political and organizational factors [2].

The most widely used definition is:

Interoperability is ability of two or more systems or components to exchange information and to use the information that has been exchanged (IEEE 1990) [3].

This includes both the exchange of information, which is *technical* interoperability and the capability of the recipient to use that information, which is *semantic* interoperability. A third concept, pertaining to the actual use of the information, is *process* interoperability to which we would add *clinical* interoperability (Fig. 2.1) [4].

Technical Interoperability

Technical interoperability moves data from system A to system B, neutralizing the effects of distance. Technical interoperability is domain independent. It does not know or care about the meaning of what is exchanged. Information theory, which shows how it is possible to achieve 100 % reliable communication over a noisy channel, is the foundation stone of technical interoperability [5]. Technical interoperability is now taken for granted. This is the technology layer.

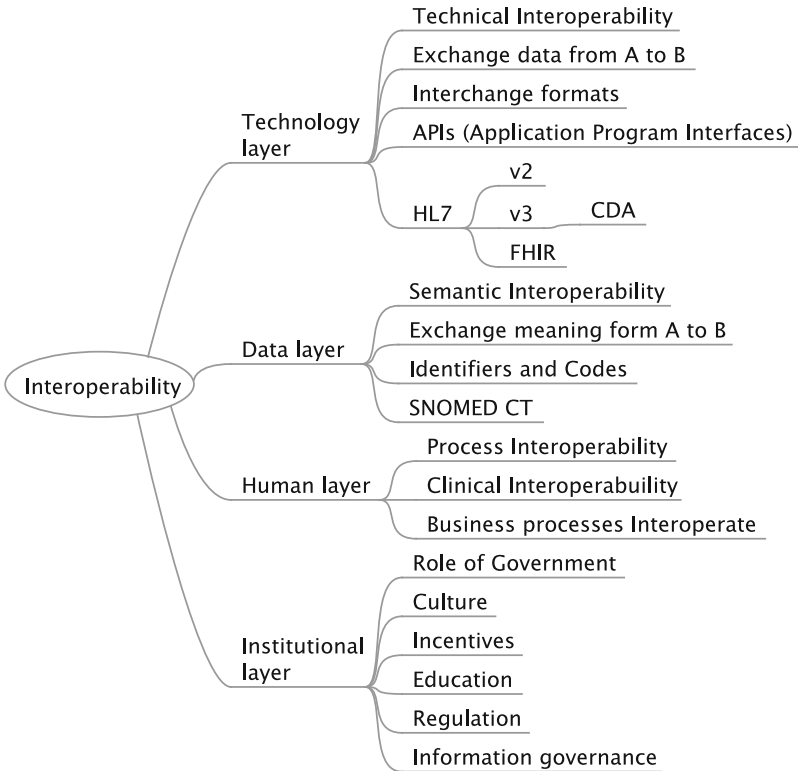


Fig. 2.1 Layers of interoperability

Semantic Interoperability

Dolin and Alschuler define semantic interoperability as “*the ability to import utterances from another computer without prior negotiation and have your decision support, data queries and business rules continue to work reliably against these utterances*” [6]. Both the sender and recipient need to understand the same data in the same way. Semantic interoperability allows computers to share, understand, interpret and use data without ambiguity. Semantic interoperability is specific to domain and context and requires the use of unambiguous codes and identifiers. This is the data layer.

Process Interoperability

Process interoperability is achieved when human beings share a common understanding across a network, business systems interoperate and work processes are coordinated. People obtain benefits when they use information originating

elsewhere in their day-to-day work. The importance of re-engineering work processes to take full advantage of electronic systems has long been recognised, but the lessons have not yet been well learnt in healthcare. This is the human layer.

Clinical Interoperability

In healthcare we need to focus on clinical interoperability, which is a subset of process interoperability. Clinical interoperability can be defined as:

Clinical interoperability is the ability for two or more clinicians in different care teams to transfer patients and provide seamless care to the patient [7].

On its own exchanging data achieves nothing. Only when people use new information in some way that differs from what they would have done without it, can we obtain different results and outcomes. In healthcare clinical interoperability is what matters. This requires changes in workflow and in the way clinicians and clinical microsystems function at a fine level of detail.

The more we understand these different aspects of interoperability, the less likely we are to underestimate the work required to make health systems interoperable. Technical, semantic, process and clinical interoperability are interdependent, and all are needed to deliver significant business benefits.

Interoperability can save an enormous amount of duplication, waste and errors but relatively few of those responsible for commissioning and paying for healthcare know enough about the subject and what is required to achieve the business benefits. This is the institutional layer involving culture, education, regulation and incentives.

Why is interoperability successful in some contexts and not in others? One explanation is to consider the individual and institutional self-interest. It may be in the vendor's financial self-interest to insist on using a proprietary non-standard interface, even though they know well that this will ultimately create an interoperability nightmare. This is technical lock-in. Similarly it can be in a provider's financial self-interest not to share patient information with providers they regard as competitors, thus creating patient lock-in.

In *The Tragedy of the Commons*, it is in each farmer's interest to add an extra cow to the common grazing land, even though that degrades the pasture as a whole [8]. The selfish farmer gains 100% of the benefit from his extra cow, but the downside is shared between everyone.

The traditional solution to this type of problem is for governments to establish an independent regulator, to enforce rules and regulations and impose supervision or oversight for the benefit of the public at large. The regulator would specify what standards should be used within their geographical area, in full and open consultation with all concerned interests, covering interoperability and related security and privacy issues. Many other aspects of healthcare and communications industries have independent regulatory agencies. The case for a regulator to enable healthcare interoperability and related information governance provisions is strong.

Why Standards Are Needed

Part of the problem with standards is not that there are so many to choose from, but that we have failed to adequately incentivise the use of those we have. Often the problem is that there is no one, such as a regulator, with the power to make deployment happen in an ordered way. Standards that are not deployed are a waste of time and effort.

An alternative view is that the standards available have been overly complex and expensive to implement and maintain. This view has led to the development of FHIR (Fast Healthcare Interoperability Resources), see Chap. 18.

The volume of transactions in healthcare is mind-boggling. For example, in 2007 a single EHR system at one large hospital (the Mayo Clinic in Rochester, Minnesota) processed more than 660 million HL7 messages a year, about two million messages a day [9]. This indicates the size of the prize to be won.

Examples of transactions include:

- Requests for tests and investigations.
- Prescriptions for medicines and treatment.
- Orders for nursing care, equipment, meals and transport.
- Test reports.
- Administration notifications for changes in patient details and scheduling.
- Letters from one clinician to another such as referral, clinic and discharge letters.
- Transfer and merging of medical records.
- Aggregate information for management, audit and monitoring.
- Commissioning, billing and accountancy.

Combinatorial Explosion

The number of links needed to connect n different systems increases according to the formula:

$$\text{Number of links} = \frac{n(n-1)}{2} = \binom{n}{2}$$

Linking two nodes needs only a single interface, which can be agreed quite easily by a couple of people sitting round a table. Linking 6 nodes requires 15 interfaces, and linking 100 nodes requires 4950 interfaces. This is known as a combinatorial explosion.

The center of the star at the right of the figure below (Fig. 2.2) indicates a single specification being used for linking six domains. This replaces the 15 separate links, each of which could be different, shown on the left hand side.

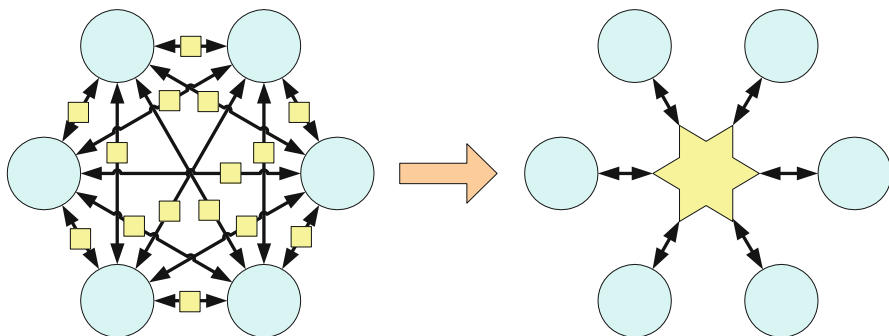


Fig. 2.2 The benefits of one standard

Translations

Every type of computer system stores data internally in a different way. This means that, in order to communicate, data has to be translated from one internal language or format into another. Linkage involves translating to a standard wire format that is understood by each party. This requires two translations, first from the native language of the sender to the wire format and then from the wire format to the native language of the recipient. HL7 provides a common *lingua franca* to do just this.

The Rosetta Stone from ancient Egypt, now in the British Museum, provides an analogy. This contains the same proclamation in three languages, used by the priests (Hieroglyphic), the court (Greek) and the people (Demotic). In our context, the three languages could be those used by a sending system, the receiving system and a common wire format used for information interchange, such as HL7. The meaning of a message is precisely the same in each language but the notation is quite different. The inscribers of the Rosetta Stone only needed to perform their translation once, but in computer interoperability, every message instance has to be translated from one format to another without error.

The choice of interchange language is not sufficient to ensure interoperability. Each transaction must be defined in stringent, unambiguous detail as part of a complete, consistent, coherent and computer-readable set of specifications.

Electronic Health Records

The original vision of an electronic health record (EHR) was a collection of statements, which provide a record of what clinicians have heard, seen, thought, and done [10]. However, the health record is also the key source of information used to support claims for payment, to defend legal actions and for research. This has led to much information being added for bureaucratic financial, legal or research purposes, making it harder to use as a clinical tool.

However, the EHR is not really a collection of facts, but rather a set of observations about a particular patient, made by clinicians, each at a specific time and place and context. It is quite possible for two statements about the same event to disagree with each other. Such disagreements can often be resolved if the context or provenance of each statement is known. This is metadata, typically covering what type of thing it is, who stated it, when and where. As with a work of art, a statement without provenance or context is of doubtful validity.

The ISO 13606 Reference Model for electronic health record communication sets out a hierarchical structure for clinical information [11, 12] (Fig. 2.3).

- **EHR:** The electronic health record for one person.
- **Folder:** High-level organisation of the EHR. Folders may be used as containers for grouping compositions by episode, care team, clinical specialty, condition or time period.
- **Composition:** A composition is a set of information relating to a specific clinical encounter, session or document. Each composition shares common metadata such as the author, subject (patient), date/time and location. Progress notes, laboratory test reports, discharge summaries, clinical assessments and referral letters are all examples of compositions. Once created a composition is immutable (cannot be changed). The EHR is made up of compositions. Compositions may be grouped together into folders, and sub-Folders.
- **Section:** A section is a grouping of related entries within a composition usually under a heading such as history, risk factors, medication, examination findings, diagnoses, investigations and plans, reflecting the workflow and consultation process. Sections may have sub-sections.
- **Entry:** Each entry is a statement about a single observation, evaluation or instruction. Think of it as a single row in a spreadsheet. Examples include the entries about a symptom, test, problem or treatment. Entries may be grouped together in sections. Each composition comprises a number of entries. Entries are also known as clinical statements.
- **Cluster:** Nested multi-part data structures including tables and charts. Related elements may be grouped into clusters. For example, systolic and diastolic blood pressures are separate elements, but are grouped into a cluster (eg 140/90), which represents one item in an entry.
- **Element:** The leaf node of the EHR hierarchy is an Element, which is a single data value, such as systolic blood pressure, a drug name or body weight.
- **Data Value:** Data types for instance values, such as codes, measurements with units etc.

Problem-Oriented Medical Records

Larry Weed's Problem Oriented Medical Record (POMR) was one of the first attempts to structure the patient record [13].

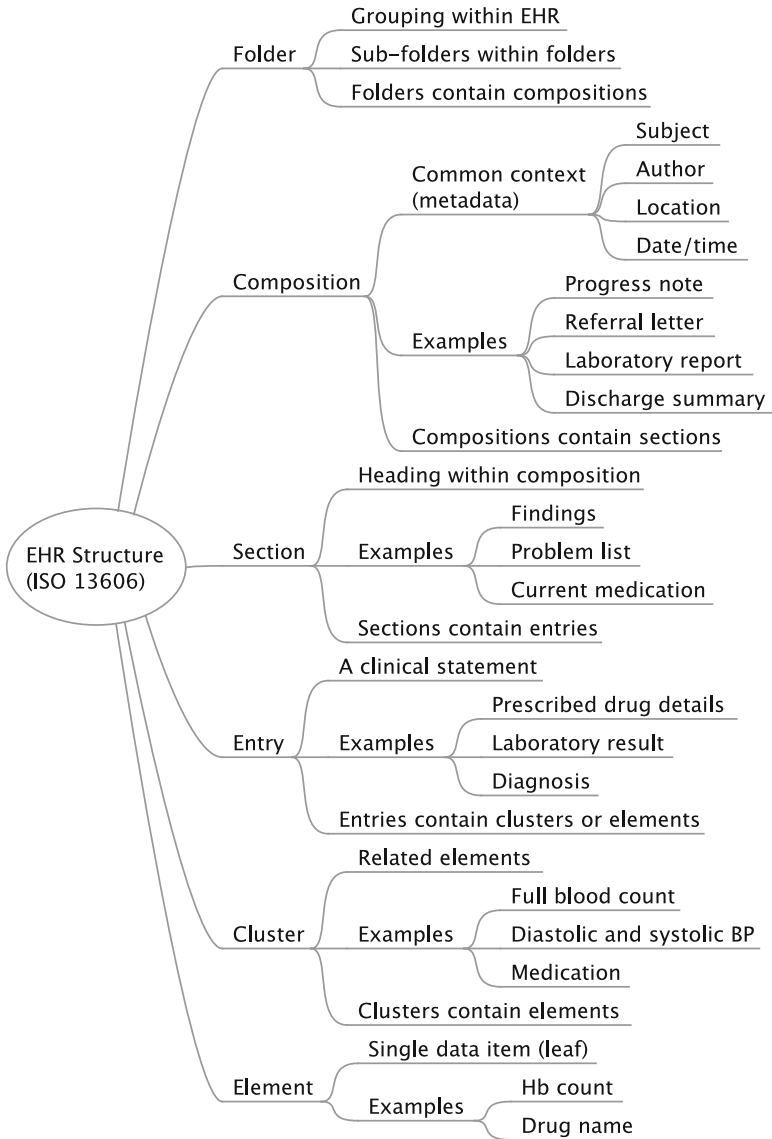


Fig. 2.3 Hierarchical structure of the EHR

The POMR divides the record into two parts, progress notes and database (see Fig. 2.4).

Progress notes are organised under problems. A problem is anything that causes concern, not only a diagnosis. The problem list is a list of all the patient’s problems indicating those that are active and those that have been resolved. Each progress note has a problem heading and four sub-headings, using the acronym SOAP:

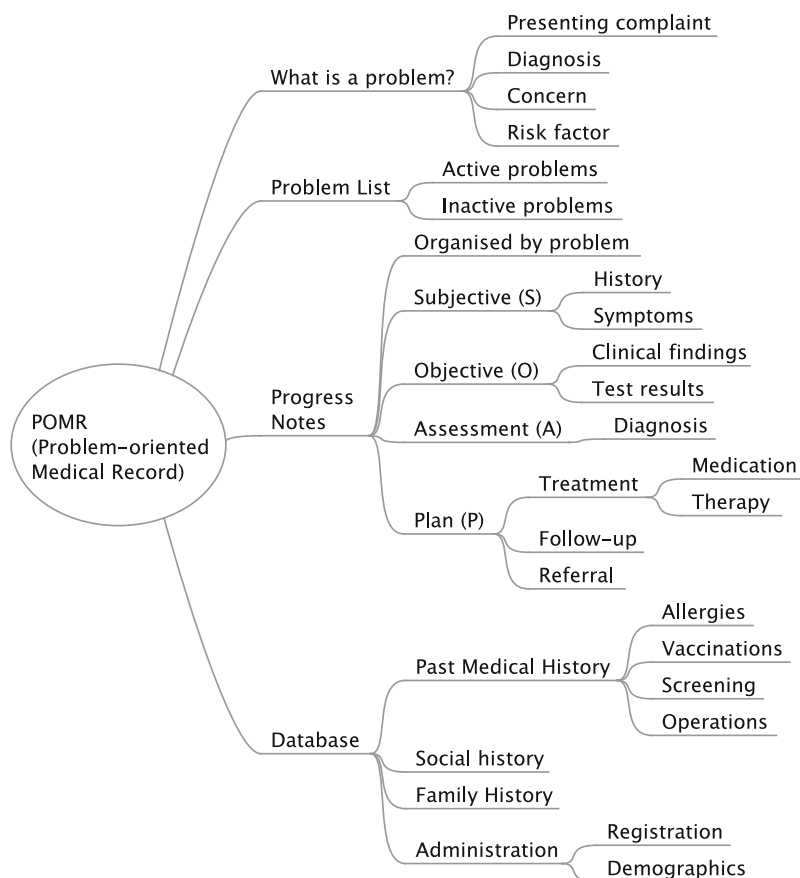


Fig. 2.4 The structure of problem-oriented medical records

- S Subjective**, meaning the information provided about history and symptoms by the patient or relative.
- O Objective**, meaning information obtained by direct examination of the patient or from clinical investigations (laboratory, radiology etc.)
- A Assessment**, meaning the clinician's assessment about what is the matter with the patient (diagnosis), prognosis etc.
- P Plan**, meaning the future plan of action, including investigations and treatment (drug prescriptions, physiotherapy, surgery and so on). Drugs prescribed are also listed in a separate medication list. This section is a problem-specific care plan.

The database covers the patient's social, family and past medical history.

From 1967 to 1982 Weed was funded by the US government to implement a problem-oriented electronic patient record system known as PROMIS, using first-generation touch-screen terminals. This remarkable pioneering project was

implemented for many years on medical and gynecological wards at the University of Vermont, but it was withdrawn after federal funding ceased [14]. Although not a long-term success, PROMIS was one of the most influential systems ever.

Weed went on to develop problem-knowledge couplers (PKC), which match detailed patient information with an extensive medical database to provide guidance tailored to individuals [15, 16].

The Devil is in the Detail

The grand vision of joined-up healthcare is predicated on the notion that patient records can be shared electronically between clinicians across specialties. Historically, this has proven difficult, in part because every clinical specialty has its own way of thinking and working.

It is hard to share information between different computer applications even within the same specialty. Each computer application stores data in a different way. Furthermore, even within one specialty, the information is more heterogeneous than may be expected. For example, data collected at a routine outpatient visit differs greatly from that for an elective surgical operation or an emergency admission.

GP2GP

The GP2GP project in England illustrates this point. All NHS patients have a life-long medical record, which follows them when they move from one GP to another. In an ideal world, each patient's records would be sent electronically from their old practice to the new to avoid the need to re-enter information.

The GP2GP project set out to do just that; although the project's leaders recognized that it could a poisoned chalice [17]. The work was as difficult as predicted and each record has to be checked before transmission and on receipt. Early versions met problems, which took several years to overcome. For example there was a technical size limitation of 5 Mb and 99 attachments, which excluded its use on those patients with the most complex records (about 15%); sending practices were required to print copies of all attachments, which was onerous; and it was difficult to quickly integrate records of patients who live in more than one place, such as students, and move back and forth between practices.

After 15 years of effort these problems have been resolved and it is now a contractual requirement for all GPs to use GP2GP. About two million life-long medical records are being exchanged every year in England.

Much of the hard work of health interoperability and digital health in general lies in teasing out the detail of hundreds and thousands of different use cases. Those who pay for IT services like to focus on high volume transactions and pass over the specific needs of smaller specialties. Yet, the common stuff is often not the most important clinically.

It is helpful to distinguish between information that needs to be processed by computer and what needs to be read and understood by human users. Computer processing is required when data has to be matched, retrieved or counted. This type of information should be structured, complete, unambiguous and validated.

Human readers need information in a form they can understand. This should be easy to read and accompanied by supporting contextual data such as who wrote it, when and where, and for what purpose. Humans are good at judging the significance of small discrepancies, while digital computers are unforgiving of a single unexpected bit.

On first thought, names, addresses, clinical laboratory reports and discharge summaries may each appear to be fairly homogeneous, but this is not so.

Names

A person may have several names and several addresses, which they can change at will. A woman may use her maiden name in one context and her married name in another. One person may use several addresses (home, work, previous, holiday etc.) and each address is likely to be associated with different sets of people, such as family members, friends or colleagues. The order in which names and addresses are written varies substantially between countries.

Addresses

An address is a label used to reference a geographical object such as a property through the use of identifiable real-world objects [18]. The postal address is used for the delivery of mail. This is a routing instruction leading to the property. However, most geographic objects have addresses, some of which are postal addresses, but some never receive mail. These include:

- Domestic, commercial and industrial properties.
- Public buildings (schools, hospitals, prisons, halls, leisure facilities, public toilets).
- Churches and monuments.
- Places where events take place (sports fields, parks).

Locations need to be identified and accessed for a range of purposes, which include:

- Uniquely identify people via their place of residence.
- Identify customers and potential customers.
- Identify where people live and work, for planning public services.
- Delivery points for goods or services.

- Levy taxes on people and organizations.
- Property registration and transactions.

Addresses normally have a structure using a nested set of spatial units:

- Sub-unit within a building or property.
- Building or property within a street.
- Street (but some rural areas do not have street names).
- One or more geographic areas (locality, town, county etc.)
- Country.

Part of an address is often abbreviated by a code (eg a postcode or area code).

The definition of each level varies considerably from country to country. Many buildings, both large and small, may have multiple addressable objects within them. Examples include: bed-sits with shared bathrooms and/or kitchen facilities, shared houses, student and worker accommodation, residential care homes for the aged and disabled, flats with third party access to the inside of the property for delivery purposes, flats where there is a single point of delivery for all residents, business premises with residential owners, managers or staff, shared business properties with no particular differentiation (normally associated companies), businesses each with their own private area but shared reception and toilet facilities, and self-contained businesses with one shared entrance. There are no clear rules about how these types of premises should be recorded.

The life cycle of an address is yet another complication. Addresses are often needed before the building itself is built. For example, temporary addresses are often allocated during the planning or construction phase of new developments. Changes to addresses can occur due to merging of two or more properties, extension, subdivision or demolition of a property, change of property number or name, occupancy or use and the names of areas used in the address (for example due to administrative area reorganization).

Discharge Summaries

There is enormous variety in the letters sent from hospitals to GPs, which are sometimes collectively referred to as discharge summaries [19]. Consider the following:

- An elderly patient discharged home after recovering from a fractured femur after a fall.
- Mother and baby following birth.
- A family at the end of a course of counseling by a clinical psychologist.
- Initial consultation report from an ophthalmologist notifying a proposed operation for cataract.
- Notification that a patient has been diagnosed with cancer and outlining the treatment plan.
- Discharge from hospital following hip replacement.

Clinical Laboratory Reports

Clinical laboratory reports differ greatly according to type of laboratory. Histologists examine cells under a microscope; microbiologists cultivate colonies of bacteria; hematologists count blood cells, and clinical chemists measure the intensity of color changes when chemicals are added. The only commonality is that they all work with specimens extracted from patients. But sometimes the requester supplies the sample, sometimes the sample is taken by the laboratory; sometimes the patient is required to be present in person.

Complexity Creates Errors

Building a single link to exchange data between two computers is relatively straightforward. Everyone sits around a table and works out what to do. This works fine for very small projects, where each person is co-located, but does not scale.

The alternative is to provide rigorous implementation guidelines, but these often grow complex and voluminous. For example, the implementation guidelines for the NHS Pathology Message Implementation Project (a successful national project to send clinical chemistry and hematology laboratory test reports to all GPs in England) comprise almost a million words, about ten times the length of this book. The endeavor to be rigorous creates errors caused by the sheer length and complexity of the specifications.

Another problem arises when the domain experts (such as doctors, nurses and managers) do not understand these specifications due to the complexity of language or the time it takes to read them.

Errors multiply according to:

- The probability of misunderstanding any part of the specification. This depends on difficulty of language and terms used as well as the level of domain and technical knowledge of participants. It is rare to find people with adequate technical knowledge and domain knowledge.
- The length of specification. In a long specification, the same idea may be presented in different ways in two places, but each may be understood differently. If large blocks of similar but not identical information are replicated in different sections, key differences can be missed.
- The number of options permitted. Optionality increases the chance of error. The easiest specifications to implement are those that require precisely one instance of each item, without optionality or multiplicity.
- The number of times different implementations need to be made. Each implementation on another system involves mapping or translating the specification into the local implementation language.

All of these issues lead to error [20]. Errors increase costs and reduce quality, create delays and hit profits and reputation. Successful specifications avoid errors by limiting scope, being easy to understand, relatively short and simple, with few if any options.

Many problems could be avoided by more thought and preparation by those responsible for the specification. As deadlines loom, it is all too easy to be vague or offer the implementers a choice of options depending on the local context. This simply increases errors by pushing the problems further down the road.

Users and Vendors

Often, users and vendors genuinely believe that they are in full agreement until the moment when users try to use the final product. Few users fully understand what they want, let alone what other parties can or cannot provide. They seldom commit enough time or effort up front to fully review written requirements specifications. They then won't commit to these, and insist on new features after the schedule and budget have been fixed.

End users are usually technically unsophisticated, do not understand the software development lifecycle and are unable to perform the sort of scrutiny that is often required of them. To do this users would need a much higher level of education in digital health than has been provided in the past.

Vendors are also guilty. Managers often try to shoehorn the users' requirements to fit their existing systems or patterns, believing that it will be quicker, cheaper and lower risk to re-use what already exists, while failing to grasp that the user really needs something else and will never be happy without it.

Vendors often lack specialized domain knowledge and do not understand the user's business processes at the required level of detail to appreciate that their preferred solution will not fit. They focus attention on high volume aspects of digital health, which they understand well, and cover up their lack of knowledge of the idiosyncrasies of every specialty by requiring users to check and sign off on specifications that neither party fully understands.

Shared meaning between computers requires shared understanding between the human participants. As an analogy consider the purchase of a new kitchen. The kitchen designer prepares a plan of the new kitchen. This plan is checked, reviewed and signed off by the customer and this becomes the basis of the contract. This plan uses a precise technical notation, which also provides a means of communicating precisely the user's needs to the implementer (manufacturer), in a form that can be understood by both customer and manufacturer. Manufacture only begins work after the customer has agreed the specification. The challenge in interoperability is similar but even harder; it is to ensure understanding vertically between users and developers and also horizontally across business and clinical processes in different locations (Fig. 2.5).

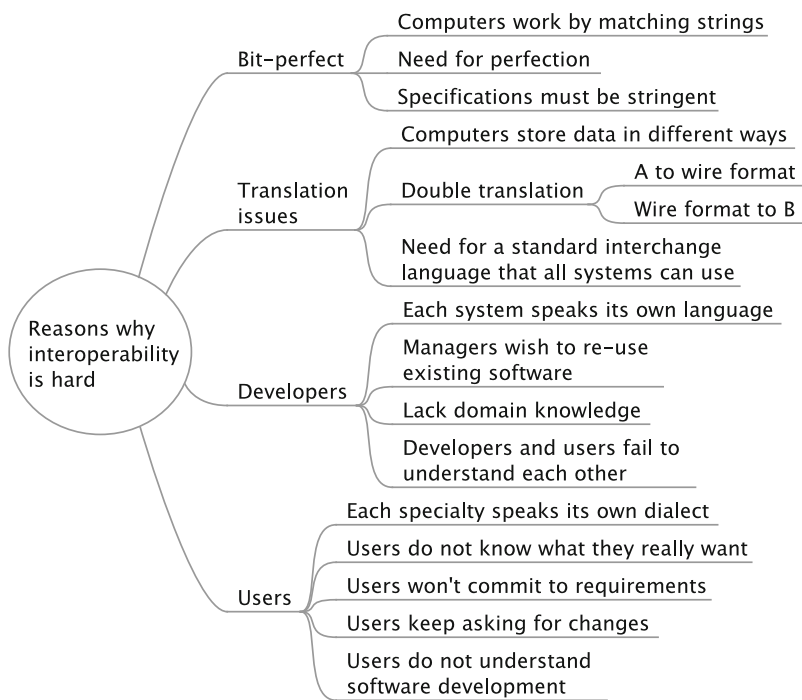


Fig. 2.5 Reasons why interoperability is hard

Change Management

One of the main lessons that come out of studies on health innovation is that change takes time. Progress often comes from modest incremental changes, which accumulate over time to large gains, over the long, not short, term. Change is driven by a combination of technical, policy, economic, clinical or managerial factors often working together on different actors and at different levels within organisations [21].

Common factors include technology developments, such as Wi-Fi and mobile technologies, the culture of how clinicians and managers work together, and detailed design of patient-centered pathways to give better outcomes at lower cost. Data sharing, including appropriate performance metrics, enables feedback, benchmarking and comparisons of performance and variation. Frontline support enables change, such as quality improvement, education and training and dissemination of best practice. Financial carrots and sticks incentivise and focus on the need for change.

Kotter has identified eight common errors and has proposed remedies for managing innovation and change (Table 2.1) [22].

Table 2.1 Errors and remedies in management of change

	Common errors	Proposed remedy
1	Not establish a great enough sense of urgency	Establish a sense of urgency that something really has to be done (it even helps to have a crisis)
2	Fail to create a sufficiently powerful guiding coalition	Form a powerful guiding coalition of key stakeholders with position power, expertise, credibility and leadership
3	Underestimate the power of vision	Create a vision and strategy that is desirable, feasible, focused, flexible and can be communicated in less than five minutes
4	Under-communicate the vision by a factor of 10 (or 100 or even 1000)	Communicate the change vision simply using examples. This needs to be repeated over again in multiple forums; address apparent inconsistencies, listen and be listened to
5	Permit obstacles to block the new vision	Empower employees to modify structures and systems to bring about the changes required. Changes will be needed in process, workflow and information systems
6	Fail to create short-term wins	Generate short-term wins that are visible, clearly related to the change effort and build momentum
7	Declare victory too soon	Consolidate gains, reduce interdependencies and produce more change
8	Neglect to anchor changes firmly in the corporate culture	Anchor new approaches in the culture. This comes last, not first

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Glossary¹

Abstract message The basic level definition of an HL7 V2 message associated with a particular trigger event. It includes the data fields that will be sent within a message, the valid response messages and the treatment of application level errors.

Access control Means of ensuring that the resources of a data processing system can be accessed only by authorized entities in authorized ways

Accountability Property that ensures that the actions of an entity may be traced uniquely to that entity

ACK Acknowledgement message

ACR American College of Radiology

Acronym An abbreviation formed by using the initial components in a phrase or name.

Act Any action of interest. Something that has happened or may happen.

Actor An abstraction for entities outside a system that interact directly with the system. An actor participates in a use case or a coherent set of use cases to accomplish an overall purpose.

ActRelationship A relationship between two Acts

ADT Admission Discharge and Transfer

AMIA American Medical Informatics Association

ANSI American National Standards Institute. ANSI represents US interests on International standards organizations such as ISO.

API Application Program Interface. A set of rules and specifications that enable communication between software programs in much the same way that a user interface facilitates interaction between humans and computers.

Application A software program or set of related programs that provide some useful healthcare capability or functionality.

¹The definitions in this Glossary are derived from the HL7 Glossary, SNOMED CT User Guide, 2008, CEN EN 13606, HIMSS Dictionary of Healthcare Information Technology Terms, Acronyms and Organizations and other sources.

- Application layer** The seventh and highest layer of the OSI model. Provides resources for the interaction that takes place between a user and an application.
- Application role** An abstraction that expresses a portion of the messaging behaviour of an information system.
- ARRA** American Recovery and Reinvestment Act of 2009. It includes the HITECH bill, which provides incentives to providers and hospitals to adopt Health Information Technology.
- Archetype** Reusable, structured models of clinical information concepts that appear in EHRs such as test result, physical examination and medication order, expressed in terms of constraints on a reference model.
- Artefact** Any deliverable resulting from the discovery, analysis and design activities leading to the creation of HL7 message specifications.
- Architecture** A framework from which computer system components can be developed in a coherent manner and in which every part fits together without containing a mass of design detail
- ASCII** American Standard Code for Information Interchange
- Association** A reference from one class to another class or to itself, or a connection between two objects (instances of classes).
- ASTM** American Society for the Testing of Materials
- Attestation** Process of certifying and recording legal responsibility for a particular unit of information.
- Attribute-value pair** The combination of an attribute with a value that is appropriate for that attribute. The attribute name identifies the type of information and the attribute value provides a value. Example: FINDING SITE=Lung structure
- Audit trail** Chronological record of activities of information system users, which enables prior states of the information to be faithfully reconstructed
- Authentication** Process of reliably identifying security subjects by securely associating an identifier and its authenticator.
- Authorization** Authorization is the process of giving someone permission to do or have something. Authorization is sometimes seen as both the preliminary setting up of permissions by a system administrator and the actual checking of the permission values that have been set up when a user is getting access.
- BCS** British Computer Society
- Binding** Indicates how an element content is taken from a value set.
- Browser** A tool for exploring and searching the terminology content. A browser can display hierarchy sections and concept details (relationships between concepts, descriptions and Ids, etc.).
- BSI** British Standards Institute. BSI represents British interests on International standards organizations such as CEN and ISO.
- caBIG** Cancer Biomedical Informatics Grid
- CAP** College of American Pathologists
- Cardinality** A measure of the number of elements in a set.
- Care Plan** A care plan is an ordered assembly of expected or planned activities, including observations, goals, services, appointments and procedures, usually organized in phases or sessions, which have the objective of organizing and man-

aging healthcare activity for the patient, often focused upon one or more of the patient's healthcare problems. Care plans may include order sets as actionable elements, usually supporting a single session or phase. Also known as Treatment Plan.

CCDA Consolidated CDA, an XML-based implementation guide that specifies the encoding, structure, and semantics for a document that summarizes a single patient's clinical information

CCHIT Certification Commission for Health Information Technology

CCITT Comité Consultatif International Télégraphique et Téléphonique

CCOW Clinical Context Object Workgroup; HL7 standard for single sign on.

CCR ASTM E2369 – 05 Standard Specification for Continuity of Care Record. An XML-based standard that specifies a way to create a clinical summary of a patient's information

CD Concept descriptor data type

CDA Clinical Document Architecture

CDC Centers for Disease Control

CDISC Clinical Data Interchange Standards Consortium. CDISC mission is to develop and support global, platform-independent data standards that enable information system interoperability to improve medical research and related areas of healthcare.

CEN Comité Européen de Normalisation (European Committee for Standardization)

CENELEC Comité Européen de Normalisation Electrotechnique

CEN/TC 251 CEN Technical Committee 251 responsible for standards within health informatics in Europe

Certificate Authority (CA) Issues digital certificates in a public key infrastructure environment

Choice A message construct that includes alternative portions of the message. For a choice due to specialization, the sender picks one of the alternatives and sends it along with a flag.

CIM Constrained Information Model

Class An abstraction of a thing or concept in a particular application domain.

Class A class represents a concept within the system being modeled.

Classification The systematic placement of things or concepts into categories, which share some common attribute, quality or property.

Clinical Decision Support (CDS) Clinical Decision Support (CDS) refers broadly to providing clinicians or patients with clinical knowledge and patient-related information, intelligently filtered or presented at appropriate times, to enhance patient care. Clinical knowledge of interest could range from simple facts and relationships to best practices for managing patients with specific disease states, new medical knowledge from clinical research and other types of information.

Clone A class from the Reference Information Model (RIM) that has been used in a specialized context and whose name differs from the RIM class from which it was replicated. This makes it possible to represent specialized uses of more general classes to support the needs of messaging.

CMS Centers for Medicare and Medicaid Services

CNE Coded No Exceptions

CMET Common message element type (CMET) is a specialised message type in a Hierarchical Message Description (HMD) that MAY be included by reference in other HMD's.

Code A fixed sequence of signs or symbols, alphabetic or numeric characters, serving to designate an object or concept.

CodeSystem A FHIR resource that presents information about a coding system.

Coding Scheme A system of classifying objects or entities such as diseases, procedures or symptoms, using a finite set of numeric or alphanumeric identifiers.

Component An identifiable item in the main body of SNOMED CT, or in an authorized Extension. Each component is a uniquely identifiable instance of one of the following: Concept, Description, Relationship, Subset, Subset Member, Cross Map Set, Cross Map Target, History Component.

ComponentID A general term used to refer to the primary identifier of any SNOMED CT Component. All ComponentIDs follow the form of the SCTID specification.

Composite data type A data type assigned to a message element type that contains one or more components, each of which is represented by an assigned data type.

Composition The set of information committed to one EHR by one agent, as a result of a single clinical encounter or record documentation session.

Concept A clinical idea to which a unique ConceptID has been assigned in SNOMED CT.

Concept equivalence When two SNOMED CT concepts or post-coordinated expressions have the same meaning. Concept equivalence can occur when a post-coordinated expression has the same meaning as a pre-coordinated Concept; or when two different post-coordinated expressions have the same meaning.

Concept Model The SNOMED CT Concept Model is the complete set of rules that govern the ways in which concepts are permitted to be modeled using relationships to other concepts.

ConceptID The unique identifier (code) for each SNOMED CT concept. Refer to the SNOMED Technical Reference Guide for a full explanation of how this identifier is structured.

Example: For the concept Pneumonia (disorder), the ConceptID is 233604007

Concepts Table A table that includes all SNOMED CT concepts. Each concept is represented by a row.

Confidentiality Property that information is not made available or disclosed to unauthorized individuals, entities, or processes.

Conformance (FHIR) A set of statements about how the FHIR API and resources are used by a actual or possible system.

Conformance Profile A conformance profile is a constraint to either an underlying standard or another conformance profile. Normally, it specifies a single message or document.

Connectathon (FHIR) A gathering of implementers to test out how well systems can exchange data based on the FHIR specification.

Constraint Narrowing down of the possible values for an attribute; a suggestion of legal values for an attribute (by indicating the data type that applies, by restriction of the data type, or by definition of the domain of an attribute as a subset of the domain of its data type). MAY also include providing restrictions on data types. A constraint imposed on an association MAY limit the cardinality of the association or alter the navigability of the association (direction in which the association can be navigated). A Refined Message Information Model (R-MIM) class MAY be constrained by choosing a subset of its Reference Information Model (RIM) properties (ie, classes and attributes) or by cloning, in which the class' name is changed.

Context Model A model that specifies relationships relating to semantic context that has been defined outside of the SNOMED CT Concept Model.

Continua Alliance Continua Health Alliance is a non-profit, open industry coalition of healthcare and technology companies joining together in collaboration to improve the quality of personal healthcare, such as those used in the home.

Control event wrapper A wrapper that contains domain specific administrative information related to the "controlled event" which is being communicated as a messaging interaction. The control event wrapper is used only in messages that convey status, or in commands for logical operations being coordinated between applications (eg, the coordination of query specification/query response interactions).

CPOE Computerized practitioner order entry

CPT-4 Current Procedural Terminology. Coding system used in the US as a guide to services for which patients may be billed.

CRE Care record element

CRS Care Record Service (NHS)

CTS Common Terminology Services. The CTS defines the minimum set of functions required for terminology interoperability within the scope of HL7's messaging and vocabulary browsing requirements.

CTV3 Clinical Terms Version 3 (Read Codes Version 3)

CTV3ID A five-character code allocated to a concept or term in CTV3. For data compatibility and mapping purposes, SNOMED CT concepts include a record of the corresponding concept codes from the Clinical Terms Version 3 (CTV3, previously known as Read Codes) and SNOMED RT.

CUI Microsoft Health/NHS CFH Common User Interface (CUI) provides user interface design guidance and toolkit controls that address a wide range of patient safety concerns for healthcare organizations worldwide, enabling a new generation of safer, more usable and compelling health applications to be quickly and easily created [<http://www.mscai.net>]

CWE Coded With Exceptions

DAM Domain Analysis Model

Database A collection of stored data typically organized into fields records and files and an associated description (schema)

Data type The structural format of the data carried in an attribute. It MAY constrain the set of values an attribute may assume.

Defining relationship A relationship used to define the meaning of a concept.

Delimit To mark or set off. For example the day, month and year in a string such as 2/5/2009 are delimited by the “/” symbol.

Description Each Description is assigned a unique DescriptionID and connects a Term and a Concept.

DescriptionID An SCTID that uniquely identifies a Description.

Dialect A language modified by the vocabulary and grammatical conventions applied in a particular geographical or cultural environment.

DICOM Digital Imaging and Communications in Medicine

Digital Representation of an entity based on binary (on/off) signals.

DIN Deutsches Institut für Normung – the German national standards organization.

dm+d Dictionary of medicines and devices, containing unique identifiers and associated textual descriptions for medicines and medical devices used in the NHS.

DMIM Domain Message Information Model

DNS Domain Name System, an Internet system to translate human-readable names into Internet addresses

Domain expert Individual who is knowledgeable about the concepts in a particular problem area within the healthcare arena and/or is experienced with using or providing the functionality of that area.

Domain Message Information Model (D-MIM) A form of Refined Message Information Model (R-MIM) constructed to represent the totality of concepts embodied in the individual R-MIMs needed to support the communication requirements of a particular HL7 domain.

DRG Diagnosis Related Group

DSTU Draft Standard for Trial Use

DTD Document Type Definition (XML)

EAI Enterprise Application Integration

ED Encapsulated Data Type

EDI Electronic Data Interchange – based on electronic sending and receiving of messages

EDIFACT Electronic Data Interchange For Administration, Commerce, and Transport – a set of rules and syntax for EDI maintained by the UN.

EHR Electronic Health Record. A comprehensive, structured set of clinical, demographic, environmental, social, and financial data and information in electronic form, documenting the healthcare given to a single individual.

EHR-S FM EHR System Functional Model—provides a reference list of over 160 functions that may be present in an Electronic Health Record System (EHR-S)

EHR System The set of components that form the mechanism by which patient records are created, used, stored, and retrieved.

Element A FHIR resource is composed of a tree of elements, which are the root type for all other elements.

ElementDefinition The description of an element and its possible content.

EMR Electronic medical record

EN Norme Europeene (European Standard) approved by CEN and which normally takes precedence over local or national standards.

Encounter Encounter serves as a focal point linking clinical, administrative, and financial information. Encounters occur in many different settings – ambulatory care, inpatient care, emergency care, home healthcare, field and virtual (telemedicine).

Entity A person, animal, organization or thing. Something that has separate and distinct existence and objective or conceptual reality. Something that exists as a particular and discrete unit. An organization (as a business or governmental unit) that has an identity separate from those of its members.

ENV Europäische Vornorm (European Pre-standard) – a standard that has yet to be put into a final and definitive form for approval as an EN.

EOM End of Message

Eponym The use of a person's name to describe an entity.

EP Eligible Provider

EPHI Electronic protected health information

EPR Electronic Patient Record (owned by the patient)

ESC Escape

ETP Electronic Transfer of Prescriptions

Expansion A list of the codes in a value set under current conditions.

Expression A collection of references to one or more concepts used to express an instance of a clinical idea. An expression containing a single concept identifier is referred to as a pre-coordinated expression. An expression that contains two or more concept identifiers is a post-coordinated expression. The concept identifiers within a post-coordinated expression are related to one another in accordance with rules expressed in the SNOMED CT Concept Model.

Extension (SNOMED CT) Extensions are complements to a released version of SNOMED CT. Extensions are components that are created in accordance with the data structures and authoring guidelines applicable to SNOMED CT.

Extension (FHIR) Additional data added to an element as a pair of (url, value) as allowed by the FHIR specification.

FDA Food and Drug Administration

FHIR Fast Healthcare Interoperability Resources

Field The smallest named unit of data in a database. Fields are grouped together to form records.

File A collection of electronic data. A file has a name by which it is known to the computer and may contain, for example, data, records, text, image etc.

Folder The high level organisation within an EHR, dividing it into compartments relating to care provided for a single condition, by a clinical team or institution, or over a fixed time period such as an episode of care.

FMM FHIR Maturity Model - an estimate of how far through the development process a resource has progressed.

FTP File Transfer Protocol

Fully defined concept Fully defined concepts can be differentiated from their parent and sibling concepts by virtue of their relationships.

Fully Specified Name (FSN) A phrase that describes a concept uniquely and in a manner that is intended to be unambiguous.

Generalization An association between two classes, referred to as superclass and subclass, in which the subclass is derived from the superclass. The subclass inherits all properties from the superclass, including attributes, relationships, and states, but also adds new ones to extend the capabilities of the parent class. Essentially, a specialization from the point-of-view of the subclass.

GP General Medical Practitioner

GP2GP GP to GP record transfer service (NHS)

Graphical expression A visual representation of a model that uses graphic symbols to represent the components of the model and the relationships that exist between those components.

GUI Graphical user interface

HAI Hospital acquired infection

HCO Healthcare organization

HDF HL7 Development Framework

HES Hospital Episode Statistics (NHS)

Healthcare agent Person, device, or software that performs a role in a healthcare activity

Healthcare organization Organisation involved in the direct or indirect provision of healthcare services to an individual or to a population. NOTE Groupings or subdivisions of an organisation, such as departments, may also be considered as organisations where there is a need to identify them.

HealthCare Party Person involved in the direct or indirect provision of healthcare services to an individual or to a population.

HealthCare Professional. A person who is authorized by a nationally recognized body to be qualified to perform certain health duties.

HealthCare Provider A HealthCare Provider is a person licensed, certified or otherwise authorized or permitted to administer healthcare in the ordinary course of business or practice of a profession, including a healthcare facility.

HealthCare Service Service provided with the intention of directly or indirectly improving the health of the person or populations to whom it is provided.

HIE Health Information Exchange

Hierarchical Message Description A specification of the exact fields of a message and their grouping, sequence, optionality, and cardinality. This specification contains message types for one or more interactions, or that represent one or more common message element types. This is the primary normative structure for HL7 messages.

Hierarchy An ordered organization of concepts. General concepts are at the top of the hierarchy; at each level down the hierarchy, concepts become increasingly specialized.

HIMSS Healthcare Information and Management Systems Society

HIPAA Health Insurance Portability and Accountability Act, 1996

- HIO** Health Information Organization, an organization that holds patient information and/or provides services to allow members of the organization to exchange health information
- HIS** Health (or Hospital) Information System
- HISP** Health Information Service Provider, the entity that is responsible for delivering health information as messages between senders and receivers over the Internet
- HITECH** Health Information Technology for Economic and Clinical Health Act, a bill that, as a part of the American Recovery and Reinvestment Act of 2009, aims to advance the use of health information technology such as electronic health records
- HITPC** Healthcare IT Policy Committee, a federal advisory committee charged with making recommendations to the National Coordinator for Health IT surrounding standards implementation specifications, and certifications criteria in order to shape a nationwide infrastructure for the adoption of healthcare information technology and the exchange of meaningful patient medical information
- HITSC** Healthcare IT Standards Committee, a federal advisory committee charged with providing standards guidance and testing infrastructure to support the recommendations of the HIT Policy Committee
- HITSP** Health Information Technology Standards Panel
- HL7** Health Level Seven is an international standards-development organization, whose mission is to provide standards for the exchange, integration, sharing, and retrieval of electronic health information; support clinical practice; and support the management, delivery and evaluation of health services
- HMD** Hierarchical Message Description
- Homonym** One term having two or more independent meanings
- HTML** Hypertext Markup Language
- HTTP** Hypertext Transfer Protocol
- ICD** International Classification of Diseases
- ICP** Integrated Care Pathway
- ICPC** International Classification of Primary Care
- ICPM** International Classification of Procedures in Medicine
- ICT** Information and Communication Technology
- Identifier** A piece of data that uniquely identifies an item, information, or a person as the subject of this identity within a given context
- IDN** Integrated Delivery Network, a network of healthcare organizations organized under a parent holding company that provides a continuum of healthcare services
- IEC** International Electrotechnical Commission
- IEEE** Institute of Electrical and Electronics Engineers
- IHE** Integrating the Health Environment. IHE (Integrating the Healthcare Enterprise) is an industry-led initiative to improve the way computer systems in healthcare share information. IHE promotes the coordinates use of established standards such as HL7 and DICOM to address specific clinical needs. <http://www.ihe.net/>

IHTSDO International Health Terminology Standards Development Organization

IM&T Information Management and Technology

IMIA International Medical Informatics Association

Implementation Guide A specification that describes how to use a general platform specification (v2, CDA, FHIR) in a particular context to solve a specific problem.

Implementation Technology A technology selected for use in encoding and sending HL7 messages. For example, XML is being used as an implementation technology for Version 3.

Implementation Technology Specification (ITS) A specification that describes how HL7 messages are sent using a specific implementation technology. It includes, but is not limited to, specifications of the method of encoding the messages, rules for the establishment of connections and transmission timing and procedures for dealing with errors.

Information Model A structured specification, expressed graphically and/or in narrative, of the information requirements of a domain. An information model describes the classes of information required and the properties of those classes, including attributes, relationships, and states. Examples in HL7 are the Domain Reference Information Model, Reference Information Model, and Refined Message Information Model.

Integration Profile An integration profile describes the workflow for a specific use case. It combines actors and interactions.

Interaction A single, one-way information flow that supports a communication requirement expressed in a scenario.

Interface A common boundary between two associated systems across which information may flow. The interface may filter or modify data as it passes across the boundary.

Interface Terminology Systematic collections of clinically oriented phrases or terms aggregated to support clinicians' entry of patient information directly into computer programs, such as clinical documentation systems or decision support tools. They may mediate between a user's colloquial conceptualizations of concept descriptions and an underlying reference terminology.

International Release The required international components of the SNOMED CT terminology, along with related works and resources, maintained and distributed by the IHTSDO.

Internet The International network of computers providing support for data exchange, Email and the World-wide Web.

IOM Institute of Medicine

ISB Information Standards Board (NHS)

ISO International Organization for Standardization – the body overseeing endorsement and publication of international standards.

ISO/TC 215 International Standards Organization/Technical Committee 215 (Health Informatics)

ISP International Standardized Profile

ITS Implementation Technology Specification

ITU International Telecommunications Union

IVR Interactive Voice Response

JSON Java Script Object Notation

LAN Local Area Network

Language Subset SNOMED CT can be translated into any language or dialect. These translations use existing SNOMED CT concepts, along with new language-specific descriptions. A language subset is a set of references to the descriptions that are members of a language edition of SNOMED CT. Additionally, this subset specifies the type of description (FSN, Preferred Term or synonym).

LOINC Logical Observation Identifiers Names and Codes

LR Legitimate Relationship

LSP Local Service Provider (NHS)

Mandatory If an attribute is designated as mandatory, all message elements, which make use of this attribute, SHALL contain a non-null value or they SHALL have a default that is not null.

Markup Computer-processable annotations within a document. Markup encodes a description of a document's storage layout and logical structure. In the context of HL7 Version 3, markup syntax is according to the XML Recommendation.

Master file Common lookup table used by one or more application systems.

May The conformance verb MAY is used to indicate a possibility.

MBDS Minimum Basic Data Set

Meaningful Use Often abbreviated as MU, defined in the Final Rule from CMS published in July, 2010 under the ARRA HITECH provisions

MeSH Medical Subject Headings

Message A package of information communicated from one application to another. See also message type and message instance.

Message element A unit of structure within a message type.

Message element type A portion of a message type that describes one of the elements of the message.

Message instance A message, populated with data values, and formatted for a specific transmission based on a particular message type.

Message payload Data carried in a message.

Message type A set of rules for constructing a message given a specific set of instance data. As such, it also serves as a guide for parsing a message to recover the instance data.

Meta-model A model used to specify other models. For example, the meta-model for a relational database system might specify elements of type 'Table', 'Record', and 'Field.'

MIB Medical Information Bus

MIM Message Implementation Manual published by NHS Connecting for Health.

MIME Multipurpose Internet Mail Extensions, an Internet standard that extends e-mail to support content beyond simple ASCII plaintext data.

MPI Master Patient Index

MT Message Type

Model A semantically complete abstraction of a system

Multiplicity In the information model, multiplicity is a specification of the minimum and maximum number of objects from each class that can participate in an association. Multiplicity is specified for each end of the association.

Narrative XHTML in a FHIR resource added to provide human readability.

Nationwide Health Information Network A set of standards, services and policies that enable secure health information exchange over the Internet

Navigability Direction in which an association can be navigated (either one way or both ways).

NCI National Cancer Institute

NCPDC National Council for Prescription Drug Program

NDC National Drug Code

NHS National Health Service

NHSCR NHS Central Register

NIST National Institute for Science and Technology

NLM National Library of Medicine

Nomenclature A set or system of names or terms, as those used in a particular science or art.

NPfIT National Programme for Information Technology (NHS)

Null A value for a data element that indicates the absence of data. A number of “flavors” of null are possible.

Object An instance of a class. A part of an information system containing a collection of related data (in the form of attributes) and procedures (methods) for operating on that data

Object identifier A scheme to provide globally unique identifiers. This object identifier (OID) scheme is an ISO standard (ISO 8824:1990).

ODA Open Document Architecture

ODP Open Distributed Processing (ISO/IEC 10746, used for describing distributed systems)

OHT Open Health Tools is a community of open source developers, health professionals, and an ecosystem that brings together members from the health and IT professions to create a common health interoperability framework, exemplary tools and reference applications to support health information interoperability. The fact that this software framework is available under a commercially friendly open source license means that anyone, any company, and any hospital, whether or not they are a member, can build applications using this framework – without any payment required for the software.

OID Object Identifier

OMG Object Management Group

ONC Office of the National Coordinator for Health Information Technology in the Department of Health and Human Services, the principal Federal entity charged with coordinating nationwide efforts to promote the use of health information technology.

Ontology The hierarchical structuring of knowledge about things by subcategorizing them according to their essential (or at least relevant and/or cognitive) qualities.

OpenEHR OpenEHR is a not-for-profit foundation to make EHRs “adaptable and future-proof” through the use of a technology independent architecture.

OSI Open Systems Interconnection

OWL Web Ontology Language

P2P Peer-to-peer

P4P Pay for performance

PACS Picture Archiving and Communication System

PAP Policy Administration Point creates and manages policies and consent directives.

Participation The involvement of a Role in an Act

PAS Patient Administration System

Patient One who is suffering from any disease or behavioral disorder and is under treatment for it.

PCAST President’s Advisory Council on Science and Technology

PCP Primary Care Provider

PDP Policy Decision Point evaluates and issues authorization decision.

PDS Personal Demographics Service (NHS)

PEP Policy Enforcement Point intercepts user’s access request to a resource and enforces PDP’s decision

PHIN Public health information network

PHR Personal Health Record, an electronic health record managed by a patient. A PHR may be “connected”, opening a patient-friendly portal to information ultimately owned by a healthcare organization, care provider, or insurance company; or it may be “unconnected,” providing a patient-owned space for storing and editing personal medical information.

PICS Protocol Implementation Conformance Statement

PIM Platform Independent Model

PIN Personal Identification Number

PKI Public Key Infrastructure

PN Person Name data type

POC Point of Care

POMR Problem oriented medical record, originally developed by Dr Larry Weed.

Post-coordination Representation of a clinical idea using a combination of two or more concept identifiers. A combination of concept identifiers used to represent a single clinical idea is referred to as a post-coordinated expression (see expression). Many clinical ideas can also be represented using a single SNOMED CT concept identifier (see pre-coordination). Some clinical ideas may be represented in several different ways. SNOMED CT technical specifications include guidance of logical transformations that reduce equivalent expressions to a common canonical form.

PQRI Physician Qualify Reporting Initiative

Pre-coordination Representation of a clinical idea using a single concept identifier. A single concept identifier used to represent a specific meaning is referred to as a pre-coordinated expression (see expression). SNOMED CT also allows the use of post-coordinated expressions (see post-coordination) to represent a meaning using a combination of two or more concept identifiers. However, including commonly used concepts in a pre-coordinated form makes the terminology easier to use.

Preferred Term The Term that is deemed to be the most clinically appropriate way of expressing a SNOMED CT Concept in a clinical record.

Primitive Concept A concept is primitive when its modeling (attributes and parents) does not fully express its meaning. A concept definition is the list of its relationships to other concepts. Primitive concepts do not have the unique relationships needed to distinguish them from their parent or sibling concepts.

Privacy Freedom from intrusion into the private life or affairs of an individual when that intrusion results from undue or illegal gathering and use of data about that individual.

PRP Policy Retrieval Point where consent policy is stored.

Problem List The problem list of a given individual can be described by formal diagnosis coding systems (such as ICD-10) or by other professional descriptions of healthcare issues affecting an individual. Problems can be short or long term in nature, chronic or acute, and have a status. In a longitudinal record, all problems may be of importance in the overall long term care of an individual, and may undergo changes in status repeatedly. Problems are identified during patient visits, and may span multiple visits, encounters, or episodes of care.

Profile A set of functions required in a particular setting or available as part of a particular system or component

Profile (FHIR) A set of rules about how a resource is used in a particular context (e.g. part of an Implementation Guide).

PSIS Personal Spine Information Service (NHS)

PSM Platform Specific Model

QMAS Quality Management and Analysis System (NHS)

QMR Quick Medical Reference

QOF Quality and Outcomes Framework (NHS)

QoS Quality of Service

Realization The relationship between a specification and its implementation.

Realm A sphere of authority, expertise, or preference that influences the range of Components required, or the frequency with which they are used. A Realm may be a nation, an organization, a professional discipline, a specialty, or an individual user.

Receiver The application fulfilling the Receiving Application role in an interaction

Receiver responsibility An obligation on an application role that receives an interaction as defined in the interaction model.

Record A writing by which some act or event, or a number of acts or events are recorded.

Recursion An association that leads from a class directly or indirectly back to that class.

Reference A url that links from one resource to another.

Reference Implementation A software library or application that implements FHIR functionality, suitable for re-use in production systems.

Reference Information Model (RIM) The HL7 information model from which all other V3 information models (eg, R-MIMs) and messages are derived.

Reference Terminology A reference terminology is a terminology in which every concept designation has a formal, machine-usable definition supporting data aggregation and retrieval. Reference terminologies are designed to provide exact and complete representations of a given domain's knowledge, including its entities and ideas, and their interrelationships, and are typically optimized to support the storage, retrieval, and classification of clinical data.

Refined Message Information Model (R-MIM) An information structure that represents the requirements for a set of messages. A constrained subset of the Reference Information Model (RIM), which MAY contain additional classes that are cloned from RIM classes. Contains those classes, attributes, associations, and data types that are needed to support one or more Hierarchical Message Descriptions (HMD). A single message can be shown as a particular pathway through the classes within an R-MIM.

Relationship An association between two Concepts. A Relationship Type indicates the nature of the association.

Relationship Type The nature of a Relationship between two Concepts. The RelationshipType field indicates the ConceptID for the concept in SNOMED that forms the relationship between two other concepts (ConceptID1 and ConceptID2)

RelationshipID A SCTID that uniquely identifies a Relationship between three concepts: a source concept (ConceptID1), a target concept (ConceptID2), and a relationship type.

Each row in the Relationships Table represents a relationship “triplet” (ConceptID1–RelationshipType–ConceptID2) identified by a RelationshipID.

Relationships Table A table consisting of rows, each of which represents a Relationship.

Release Version A version of SNOMED CT released on a particular date. Except for the initial release of SNOMED CT that was called “SNOMED CT First Release,” subsequent releases use the release data. Example: “SNOMED CT July 2008 Release”

Required One of the allowed values in conformance requirements, it means that the message elements SHALL appear every time that particular message type is used for an interaction. If the data is available, the element SHALL carry the data, otherwise a null value MAY be sent.

Requirement A desired feature, property or behaviour of a system.

Resource An package of data with a known location (URL), of one of the types defined in the FHIR specification.

REST REpresentational State Transfer - see http://www.ics.uci.edu/~fielding/pubs/dissertation/rest_arch_style.htm.

RESTful A style of interaction that follows the approach defined as “REST”.

RFID Radio frequency identification (RFID) is a generic term that is used to describe a system that transmits the identity (in the form of a unique serial number) of an object or person wirelessly, using radio waves.

RIM HL7 Reference Information Model

RHIO Regional Health Information Organization

RMIM HL7 Refined Message Information Model

Role A part played by or the responsibility of an Entity

RoleLink A relationship between two Roles.

Root Concept The single Concept “SNOMED CT Concept” that is at the top of the entire SNOMED CT hierarchy of concepts.

Rubric The title or name of a class or category.

SaaS Software as a service

SAEAF Services Aware Enterprise Architecture Framework. HL7’s SAEAF defines the artefacts and specification semantics needed to support interoperability in healthcare, life sciences, and clinical research.

Sanctioned relationships Relationships between SNOMED CT concepts that are sanctioned by the SNOMED CT Concept Model. Sanctioned relationships are specified in a row in the SNOMED CT Relationships table, as opposed to ‘Allowable’ relationships, which are a pattern in the Concept Model.

Scenario A sequence of actions that illustrates behaviour. A scenario may be used to illustrate an interaction or the execution of a use case instance.

Schematron Schematron is an XML structure validation language for making assertions about the presence or absence of patterns in trees. It is a simple and powerful structural schema language.

SCR Summary Care Record

SCT SNOMED Clinical Terms

SCT Enabled Application A software application designed to support the use of SNOMED CT.

SCTID SNOMED Clinical Terms Identifier

SDO Standards Development Organization

SDS Spine Directory Service (NHS)

Section EHR data within a composition that belongs under one clinical heading, usually reflecting the flow of information gathering during a clinical encounter, or structured for the benefit of future human readership.

Semantics Meaning of symbols and codes

Semantic interoperability Ability for data shared by systems to be understood at the level of fully defined domain concepts.

Sender The application fulfilling the Sending Application role in an interaction.

Service A consultation, diagnosis, treatment or intervention performed for a person and/or other activity performed for a person. Includes health, goods and support services.

Set A form of collection, which contains an unordered list of unique elements of a single type.

SGML Standardized General Markup Language

Shall The conformance verb SHALL is used to indicate a requirement.

Should The conformance verb SHOULD is used to indicate a recommendation.

SIG Special Interest Group

S/MIME Secure/Multipurpose Internet Mail Extensions, an Internet standard for securing MIME data. S/MIME provides privacy and data security through encryption; and authentication, integrity assurance, and non-repudiation of origin through signing.

SMTP Simple Mail Transport Protocol, an industry standard for transporting e-mail.

SNOMED An acronym for the Systematized Nomenclature of Human and Veterinary Medicine originally developed by the College of American Pathologists.

SNOMED Clinical Terms (SNOMED CT) The clinical terminology maintained and distributed by the IHTSDO. The First Release of SNOMED Clinical Terms was the result of the merger of the CTV3 and SNOMED RT.

SNOMED Clinical Terms Identifier (SCTID) A unique identifier applied to each SNOMED CT component (Concept, Description, Relationship, Subset, etc.).

SOA Service Oriented Architecture provides methods for systems development and integration where systems package functionality as interoperable services. A SOA infrastructure allows different applications to exchange data with one another. Service-orientation aims at a loose coupling of services with operating systems, programming languages and other technologies that underlie applications. SOA separates functions into distinct units, or services, which developers make accessible over a network in order that users can combine and reuse them in the production of applications. These services communicate with each other by passing data from one service to another, or by coordinating an activity between two or more services.

SOAP Simple object access protocol

Specialization An association between two classes (designated superclass and subclass), in which the subclass is derived from the superclass. The subclass inherits all properties from the superclass, including attributes, relationships, and states, but also adds new ones to extend the capabilities of the superclass.

Specification A detailed description of the required characteristics of a product.

SQL Structured query language

Standard A document, established by consensus and approved by a recognized body, that provides, for common and repeated use, rules, guidelines or characteristics for activities or their results, aimed at the achievement of the optimum degree of order in a given context.

Storyboard Defines what happens from the users point of view. A narrative of relevant events defined using interaction or activity diagrams or use cases. The storyboard provides one set of interactions that will typically occur in the domain.

String A sequence of text characters.

StructureDefinition A definition of a structure in FHIR - either an underlying resource or data type, or a Profile.

Stylesheet A file that describes how to display an XML document of a given type.

Subclass A class that is the specialization of another class (superclass).

Subset A group of Components (eg Concepts, Descriptions or Relationships) that share a specified common characteristic or common type of characteristic.
Example: UK English Subset

Superclass A class that is the generalization of one or more other classes (subclasses).

Swimlane A partition on activity graphs for organizing responsibilities for activities, often corresponding to the organizational units in a business model.

Synonym A term that is an acceptable alternative to the preferred term as a way of expressing a concept. Synonyms allow representations of the various ways a concept may be described.

Syntax Rules for structuring words into sentences or computer commands or electronic messages.

System A collection of connected units organized to accomplish a purpose.

Table view An expression of the Hierarchical Message Description (HMD) common and message type definition condensed in size to fit on a printed page.

TAG Technical advisory group

Taxonomy The science or technique of classification

TC Technical Committee

TCP/IP Transmission Control; Protocol / Internet Protocol. A protocol for communication between computers, used as a standard for transmitting data over networks and as the basis for standard Internet protocols.

Template A template is an RMIM, which is used to constrain another model

Term A text string that represents a concept. The Term is part of the Description. There are multiple descriptions per Concept.

Terminology A set of concepts designated by terms belonging to a special domain of knowledge, or subject field.

Terminology Binding An instance of a link between a terminology component and an information model artefact.

Terminology server Software that provides access to SNOMED CT (and/or to other terminologies). A Terminology server typically supports searches and Navigation through Concepts. A server may provide a user interface (eg a browser or set of screen controls) or may provide low-level software services to support access to the terminology by other applications.

Transaction A complete set of messages for a particular trigger event, eg a message and a response.

Transitive closure table A table that lists all of the ancestor codes of each concept, used in fast subsumption testing

Transport wrapper A wrapper that contains information needed by a sending application or message handling service to route the message payload to the

designated receiver. All HL7 Version 3 messages require an appropriately configured transport wrapper.

Trigger Event Defines what causes a message to be sent. An event which, when recorded or recognized by an application, indicates the need for an information flow to one or more other applications, resulting in one or more interactions.

TRUD Terminology Reference Data Update Distribution Service (NHS)

TSC Technical Steering Committee (HL7)

TTP Trusted third party

UMDNS Universal medical device nomenclature system

UML Unified Modeling Language

UMLS Unified Medical Language System

UN/CEFACT United Nations Centre for Trade Facilitation and Electronic Business

UKTC UK Terminology Centre (NHS)

UPI Unique Patient Identifier

URL Uniform resource locator

Use case The specification of sequences of actions, including variant sequences and error sequences, which a system can perform by interacting with outside actors.

VA Veterans Administration

Valid document A document that meets all of the validity constraints in the XML specification.

ValueSet A FHIR Resource that defines a set of codes selected from one of more Coding Systems.

Value set A vocabulary domain that has been constrained to a particular realm and coding system.

View Specific information displayed on a computer monitor after it has been filtered for a different user or purpose.

Vocabulary The set of all concepts that can be taken as valid values in an instance of a coded attribute or field.

W3C World Wide Web Consortium

WAN Wide Area Network

WEDI Workgroup on Electronic data Interchange

WHO World Health Organization

Wrapper The control or envelope information in which the message payload resides.

WWW World Wide Web

X.509 Digital Certificate A standard for asserting that an entity is who it purports to be.

XDM The IHE Cross-Enterprise Document Media Interchange integration profile, a specification for the exchange of electronic health record documents on portable media. XDM provides an option for zipped file transfer over e-mail.

XDR The IHE Cross-Enterprise Document Reliable Interchange integration profile, a specification for the interchange of electronic health record documents through reliable point-to-point network communication, based on a push of information.

XDS The IHE Cross-Enterprise Documenting Sharing integration profile, a specification for managing the sharing, finding, and retrieval of electronic health record documents among a defined group of healthcare enterprises.

XML Extensible Mark-up Language

XSL Extensible Style sheet Language. The XSL family comprises three languages:

- XSL Transformations (XSLT): an XML language for transforming XML documents
- XSL Formatting Objects (XSL-FO): an XML language for specifying the visual formatting of an XML document
- XML Path Language (XPath): used to address the parts of an XML document.

XSLT Extensible Stylesheet Language Transformations (XSLT) is an XML-based language used for the transformation of XML documents into other XML or “human-readable” documents. The original document is not changed; rather, a new document is created based on the content of an existing one. The new document may be serialized (output) by the processor in standard XML syntax or in another format, such as HTML or plain text. XSLT is most often used to convert data between different XML schemas or to convert XML data into HTML or XHTML documents for web pages, creating a dynamic web page, or into an intermediate XML format that can be converted to PDF documents.

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