

Conference report

Comprehensive computerised primary care records are an essential component of any national health information strategy: report from an international consensus conference

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SUMMARY

In many countries, primary care informatics has developed to the point that it is recognised as an important enabler of quality improvement; this has not occurred to date in the United States.

With this conference, we aimed to build an international consensus as to whether primary care has unique characteristics that require an informatics subspecialty; and, if so, to establish the role of

primary care informatics in improving patient care, and to enable its recognition in the national strategy.

The conference was organised by the primary care informatics working groups of AMIA, EFMI, IMIA and Wonca and took place at Medinfo 2004 in San Francisco. It consisted of two plenary lectures, two small-group work sessions and a panel discussion to summarise the day. It was attended by

an international audience of 53 health informaticians, mostly working in primary care.

There was consensus among the participants that primary care has many unique characteristics that justify the existence of an informatics subspecialty: primary care informatics (PCI). The conference identified principles and practical examples of: (1) the effective deployment of information technology to underpin the provision of records, communication and access to information; (2) the need to harness the extensive knowledge base about the practice of PCI; and (3) the contribution of the

experimental work and theory that underpins the science of PCI. These principles and examples of their practical application were largely derived from the extensive knowledge base which has been built up in countries that have developed PCI over the last one to two decades.

Keywords (MeSH terms): consensus development conferences, family practice, health policy, medical informatics, medical records systems – computerised, primary care

Introduction

In the United States of America (USA), primary care faces the challenge of the announcement of a new national health information strategy (National Health Information Infrastructure – NHII), within which its role is not clearly defined.¹ The international recognition of the importance of primary care can be traced back to the World Health Organization's Alma-Ata declaration of 1978, which saw primary care as key to attaining 'health for all'.² At the time definitions of primary care focused on the attributes of primary care services. For example, the Institute of Medicine defined five: accessibility, comprehensiveness, coordination, continuity and accountability.³ More recently definitions have come to focus on the types of patients and their problems, and that they are seeing specially trained primary care professionals (see Box 1).⁴

The Primary Care Informatics Working Group (PCIWG) of the American Informatics Medical

Association (AMIA) has promoted the development of a national strategy, but one within which the primary care computer record has a more pivotal role.⁵ They have done this through the development of a vision statement, within which the central position of the computerised medical record (the 'electronic ambulatory information system') should be noted (see Box 2).⁶ They have also developed a strategic plan for developing primary care and have been instrumental in setting up the National Alliance for Primary Care Informatics (NAPCI).^{6,7} The former sets out the unique information needs of primary care, and the latter provides a forum for stakeholders with an interest in seeing that primary care is able to implement effective and comprehensive clinical records.

Elsewhere in the world the technical infrastructure, practice and science of primary care informatics have developed greatly over the last two decades. Many countries have comprehensive primary care computer systems; these are all quite distinct from those used in secondary care. *De facto* primary care informatics (PCI) has evolved as a subspecialty of health informatics. PCI has its own journal, and within many national and international informatics organisations has its own working groups that help promulgate best

Box 1 Starfield's definition of primary care⁴

'Primary care ... is the basic level of health care provided equally to everyone. It addresses the most common problems in the community by providing preventive, curative, and rehabilitative services to maximize health and well-being. It integrates care ... and deals with the context ...

Primary care is distinguished from other types of care by clinical characteristics of patients and their problems ...

Primary care practitioners are ... distinguished from their secondary and tertiary counterparts by the variety of problems encountered ... primary care is the first point of contact with the health system.'

Box 2 Vision statement of the AMIA Primary Care Informatics Working Group⁶

'In order to provide all US citizens with high quality, affordable healthcare, every primary care provider must be given the opportunity of using an electronic ambulatory information system, including a fully functional electronic medical record, and the ability to access needed clinical information at the time and place of care.'

practice in PCI.^{5,8-11} It is widely accepted that medical informatics is a science: it studies how data, information and knowledge can promote health and improve medical care.¹² PCI has also been defined as a science (see Box 3).^{13,14} The implication of this is that the knowledge base within primary care informatics should be based on experimental work, with hypotheses that can be challenged and defended, as well as on the experience of practitioners. It is also increasingly accepted that PCI is an enabler of quality in primary care.¹⁵

Box 3 Definition of primary care informatics

'The scientific study of data, information and knowledge, and how they can be modelled, processed or harnessed to promote health and develop patient-centred primary medical care.

Its methods reflect the biopsychosocial model of primary health care and the longitudinal relationships between patients and professionals.

Its context is one in which patients present with unstructured problems to specially trained primary care professionals who adopt a heuristic approach to decision making within the consultation.'

This conference was held in order to learn from the extensive international experience and knowledge of how PCI might improve the quality of primary medical care.

Conference organisation

The meeting was jointly organised by a committee drawn from the PCI working groups of AMIA, the European Federation for Medical Informatics (EFMI), the World Organisation of Family Doctors (Wonca) and the International Medical Informatics Association (IMIA).^{5,9,10,16} The AMIA Primary Care Informatics Working Group has a ten-year long tradition of organising such meetings.

The meeting was planned over the preceding year, via a series of email exchanges, conference calls and planning meetings. It was arranged for the day prior to the triennial Medinfo (IMIA) conference to facilitate attendance. There was no charge for attendance.

The first third of the meeting focused on exploring the extent to which there is an international consensus

about the nature of primary care; and if so what are the unique features that justify the existence of its own informatics subspecialty.

The second part of the conference attempted to define the core elements of PCI and the practice of PCI; and how it improves the quality of primary medical care. Attendees chose which group they went into. The groups examined different elements of primary care informatics: one group took an academic stance, setting out to identify the core content and boundaries of PCI; one evaluated the technical infrastructure that was needed to underpin PCI; another discussed the potential for PCI to provide population data to inform public health needs. Members of the organising committee participated in each group.

The conference lasted for a full day and consisted of two one-hour plenary sessions; two and a half hours of small-group work; one and a half hours of feedback and discussion from the small group work; and a one-hour panel discussion at the end.

Participants were invited to leave their email address and country of origin if they wished to participate in a post-conference email discussion on the findings of the consensus conference and/or receive a copy of the post-conference report.

The plenary session slides, flip charts and computer notes made during the small-group sessions and feedback sessions were all collected. Observers reported on the narrative and dynamic of each small group. Notes were taken throughout the meeting. All these records were collected and collated. The findings in this report, which focus on the primary care computerised medical record, are reported below.

Outcomes

Attendees

There were 53 delegates of whom 43 provided information about their country of origin. Delegates came from ten countries, spread across four continents. Only Africa was not represented in the group (see Figure 1). The majority, 32/47 (68%), came from the USA, the location of the conference. The delegates from the USA included family and general medical specialists, internal medicine specialists, paediatricians and nurse practitioners working in primary care. Other countries represented were Holland with four delegates; United Kingdom (UK), Japan, Australia and Thailand with two each; and Canada, Norway, China and New Zealand with one each. Most of these practitioners were working as generalists, without the subspecialisation as in the USA.¹⁷ Two UK

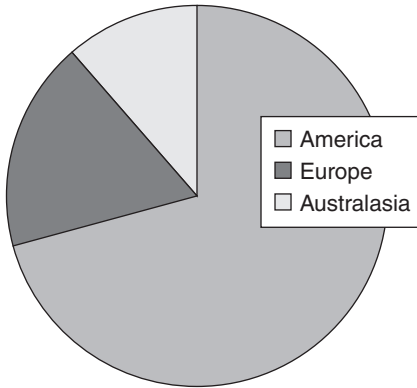


Figure 1 Pie chart of continent of origin of the delegates, $n=53$

potential participants and one from the USA sent preconference contributions by email; we received 22 post-meeting email contributions.

Consensus about the unique characteristics of primary care

There was a high degree of agreement between delegates about the definition of primary care. All the groups saw primary care as a unique patient-centred specialty that is about health promotion as well as curative medicine and chronic disease management. It is practised in the context of longitudinal relationships with patients and families; it requires information from a number of sources to be aggregated. There is multidisciplinary teamworking in the care of the patient. The nature of problems presented in primary care is that many are vague and hard to define; they often have a social and psychological basis as well as a medical one. Management of patients reflects this. For example, the start and end of episodes of disease and their associated care are frequently hard to define. The lists produced by the groups are provided in Table 1. Three themes were listed by all four groups: continuity of care, comprehensiveness, and the need for a community or public health focus. The need to deliver patient-centred care was listed by three out of four.

Many delegates commented on an additional and evolving feature of primary care, that of increasing administrative burden. This applied whatever type of health service delegates belonged to. Later in the day's discussions many delegates returned to the issue of the imprecise nature of primary care diagnosis and management. This created difficulties when the information recording requirements associated with the consultation presumed greater certainty than was really the case. Treatment in these circumstances was often appropriate symptomatic treatment (heuristics) while the nature of the problem emerged or resolved.

It was also apparent from the discussions that there was a clear assumption that information technology (IT) should be part of the process of primary care. One delegate reported that junior doctors seeking to work in family practice wanted to know if the practice used computerised medical records prior to making an application. They did not want to work in a practice with paper records.

Dilemmas for US primary care

Inevitably, with the overwhelming majority of delegates coming from the USA, and the conference taking place against the background of the proposed development of the USA National Health Information Infrastructure, what emerged from the plenary sessions and small groups were the current dilemmas facing primary care in the USA. These included: the lack of a definition of a primary care provider in the USA (compared with a general practitioner [GP] in the UK or the Netherlands); the fear that primary care could get swallowed up within the medical specialties; and that provision of computerised medical records might benefit the specialist not the generalist. There were strong feelings that NAPCI was the best way of bringing primary care stakeholders together.⁷

The focus of the conference shifted to examine what might be learnt from the experiences of other countries to address these dilemmas. The issues identified are examined under three headings:

1 Technology to support PCI

- What infrastructure models have been found to be successful in other countries, and where is primary care placed within them?
- Which model for computerisation should be used?
- What coding and terminology system should be used?
- Should communication use the internet?
- How should the whole process be resourced?
- How can the risk of purchasing be minimised when there is a plethora (over 1000) of small clinical computer systems suppliers?

2 Practice of PCI

- How are computers best used in the consultation – whether face to face or using other media?
- How is coded and structured data optimally recorded and reused – both in the practice and for population statistics?
- How do we train primary care professionals and disseminate best practice?

3 Science of PCI

- How do we avoid information overload?

Table 1 What makes primary care unique?

Feature	Group number			
	1	2	3	4
1	First contact	Integration of information from many sources	Continuity with the same professional and team	Undifferentiated problems
2	Comprehensive: – any problem – any time – any place	Continuous/ sustained: – 24/7	Triage function: – advocacy for patient – broad spectrum of conditions	Diversity of problems
3	Co-ordinated and co-ordinating	Individual in context of population	Comprehensive cover: – range – over time	Chronic disease care
4	Continuity of care to individuals and families	Synchronised: – in and out of hours	Resource management: – for patient – for community	Longitudinal compared with high contact frequency in secondary care
5	Accessibility: – cultural – language	Accessible: – for all	Performance: – of the clinician – of the team	Dynamics of whole person
6	Patient centred: – family – community	‘Medical home’	Different views: – patient – institutional	Complexity of problems and circumstances
7	Accountability: – professional – to patient	Patient advocacy, including public health	Trust – the primary care physician is the trusted advocate	Multidisciplinary working
8	Population focus	Consultations via all media: – internet – phone – email – letter	Access for all: – not a reality in the US	Patient centred, but also providing a community perspective of disease/health needs
9	Prevention and health promotion	Ubiquitous	Safe and of high quality	Provider accountability (by the practice for resources used)

- How is the coding system or terminology best used for new and emerging diagnoses?
- How is an information system most effectively used within the complexity of primary care where the context of a consultation is so important?

Lessons from the Netherlands, Australia, New Zealand, the UK and US Veterans (Table 2)

The technology to support PCI

The information strategies within all these countries, and within the USA Department of Veterans Affairs (VA), place primary care records at the heart of their strategies.^{18,19}

Distributed database (that is, a computer in each office/practice) is a model that works in the Netherlands, Australia, New Zealand and the UK. It appears to be a robust and reliable approach and free from some of the spectacular failures that have occurred associated with large-scale IT projects.²⁰

Limited projects to pass information from one system to another are reputed to be working effectively in a number of countries, though overall interoperability is still quite limited in most countries. Some successes include: transmitting pathology results from the laboratory, sharing registration data, and emergency information. The UK plans an ambitious programme to link all of its health service together using a national spine; however, this has not yet been developed although contracts for its procurement have been placed.²¹

There is no agreement as to what is the most appropriate coding system for primary care. Countries in mainland Europe as well as Canada largely use the International Classification for Primary Care (ICPC-2) or the International Classification of Disease (ICD); the latter is also used in Australia.^{22,23} The UK and New Zealand use Read Terminology Version 2 effectively, but the UK at least has pledged to migrate to the Systematized Nomenclature for Medicine – Clinical Terms (SNOMED-CT).²⁴

In the UK the National Health Service (NHS) has created NHSnet, its own intranet, but this is only open to health service bodies – not patients. There are no agreed standards for security and confidentiality of electronic messages across the internet or by email. However, many practitioners were using these media.

All the countries have gone through the process of change from a large to a small number of suppliers. This has happened as a result of central creation of standards that vendors of computer systems must meet and professional pressure that guidelines and clinical functionality should be provided. Primary

care representative organisations, despite varying political agendas, have by and large worked together over primary care computing and been effective forces for change.

UK primary care computerisation took a big leap forward (1987) as a result of a 'Free computers for GPs' scheme funded by the pharmaceutical industry, and a subsequent one driven by the need to manage certain aspects of payment for performance (1990); this has been consolidated by the 2004 new contract for family doctors, where one-third of doctors' pay will be directly determined using clinical data extracted from their clinical computer system.²⁵ In Australia about 80% of GPs use computer systems that have been funded by the pharmaceutical industry, with diagnosis-specific drug advertising presented to the GP during consultations. The UK has evolved to subsidised computer purchase and now is to move to central NHS purchasing.

Evolution and development of computer systems are slow. Implementation of computer systems (or changes in functionality) often has unpredicted organisational consequences. Long-term partnerships (over five years) are needed for development.

The practice of PCI

Experience from the UK and the Netherlands shows that using the computer in the consultation takes longer, but the amount of additional time required is small and offset by other efficiency gains. Only computerised repeat prescribing (refills of drugs) has been shown to save time, and offer improved safety and accuracy.²⁶

Electronic templates and guidelines integrated into the clinical computer systems are an established part of clinical practice in all the countries outside the USA. These work best in the context of chronic disease management where recording defined clinical activity is useful in the management of the patient (for example in heart disease, asthma, etc.). They have been demonstrated to be a useful component in attempts to improve the quality of care.^{27–29} Some are provided by computer systems vendors, some are created by practices, and many are also developed by colleges and academies of general practice. User groups are highly influential in getting them included into clinical computer systems.

There is considerable experience in all countries of using the data collected for public health and for feedback to practices about the quality of their computer data and quality of care, though the shortcomings of sharing data collected in one context to use in another are recognised.³⁰

There is no real experience of billing to the degree that happens in the USA system. The only similar process was the creation of so-called 'fund-holding'

Table 2 Summary of dilemmas for US primary care and lessons from other countries

Issue	US need	Experience in other countries
<i>Technology to support PCI</i>		
National health information strategy	No central place for primary care information	Central role of primary care information systems
Architecture of system	Distributed, central or hybrid	Long experience of distributed systems (i.e. computer in each practice)
Coding/classification system	SNOMED-CT due to become standard	Netherlands – ICPC-2/ICD* UK + New Zealand – Read UK due transition to SNOMED-CT Australia – ICD
Communication with patients and providers	No system defined; no standards/data not transferable	UK – NHSnet All – no standards for security/confidentiality
Risk of purchase	>1000 suppliers/vendors	System standards from health service professional groups has led to small number of suppliers
Subsidy for purchase	No current plans	Models: pharmaceutical funding, state subsidy, state purchase
<i>Practice of PCI</i>		
Computer in the consultation	What will have minimal impact/save time	Small time penalty
Recording structured and coded data	How to integrate in the consultation	1–2 decades of experience
Reuse of routinely collected data	Data quality such to be usable for public health and biosurveillance	All countries have programmes associated with this work but usability is variable
Design meets clinicians' needs	Current systems are weak	Role of user groups Improvement is a slow iterative process
Professionalism (i.e. recognised PCI professionals)	No plans	First steps towards the registration of professional informaticians in the UK (www.ukchip.org)
<i>Science of PCI</i>		
How much extra time does the computer take	Wants a time-neutral or time-saving solution	Small amount of additional time but offset by efficiency gains
What balance of free-text and narrative	Wants the optimum	It is known there is marked variation between practices
Optimum size of a primary care coding system	Wants the best option	No defining experimental work about the appropriate granularity – but complexity and context complicate
Decision support	Wants the best model	No model that works in all circumstances

*ICD = International Classification of Disease, ICPC = International Classification of Primary Care

software, which was attached to UK computer systems for practices that took on managing their own budget. This experiment only lasted for a few years, but illustrates that it is possible to link finance and clinical systems.

Properly resourced training and sharing experiences of using systems with colleagues and through user groups are essential if primary care computer systems are to be used well.³¹

Professionalism and specialisation are emerging in health informatics as an important component of maintaining standards and ensuring the ethical design and use of clinical information systems and the data contained within them.³²

The science of PCI

All of the countries contributing to the conference had academic departments of medical or health informatics. There are not as yet definitive answers to the research questions raised.

There is no 'optimum' coding system or evidence of what level of granularity of coding systems is best for primary care. ICPC has a much smaller number of terms and a far coarser level of granularity than Read or SNOMED-CT. This is useful for analysis purposes, but less helpful in recording detail about symptoms, results and care plans.

Very little is known about what makes an appropriate balance between coded and free text (narrative) data in a record; we only know that clinicians vary.³³

Understanding context, the complexity of human interaction and belief, and the need to step back and take a holistic – or systems – view are all necessary skills for the primary care informatician. The context within which data were entered into computer systems is critical. People's problems are complex and the underlying reasons for consulting might not emerge until a relationship is established; patients could be helped most by a clinician's interest and support.³⁴ Systems thinking provides a useful approach to understanding complex problems in primary care.³⁵

Recommendations

The recommendations of the meeting were that:

- 1 Primary care computerised medical records should be at the heart of any health service information strategy.
- 2 Stakeholders need to acknowledge their political agendas and then work together. The various stakeholders must understand how their needs fit within the entire healthcare delivery process and work together on solutions.
- 3 The health market can only support a limited number of suppliers. We therefore recommend that the number of vendors should be restricted. This

may be best done through the imposition of quality standards and conformance testing.

- 4 Long-term partnerships are needed to learn how best to integrate computerised medical records into clinical practice; and to set up programmes that will raise data quality to the standard where it can be used for public health purposes.³⁶
- 5 Primary care computing should be subsidised or fully funded. This is a model that is successful, with benefits of computerisation accruing to other parts of the health system when electronic systems replace paper.
- 6 Primary care is best served by computer systems specifically developed for this purpose.
- 7 A strong scientific base is required to allow primary care informaticians to answer the research questions that have been identified.

Discussion

The principal outcome of this consensus conference has been the international agreement about the unique nature of primary care; and hence the justification for its own subspecialty of health informatics: primary care informatics. PCI improves prescribing safety and the quality of disease management, and produces data that can be used to improve public health and monitor preventive and screening programmes as well as to help in the provision of direct patient care. PCI enables recall programmes and the instantaneous transmission of information from hospital laboratory to the primary care clinical computer system. PCI needs to be at the heart of any national health information strategy.

Many of the questions that arose about the practice of PCI had to be answered based on the experience gained through the use of computer systems in practice over the last two decades. The science of PCI needs to be developed so that there is a greater volume of high-quality experimental work that can be drawn on to enable evidence-based decisions to be made about the practice of PCI.

All stakeholders in the health system should recognise the importance for patient care of a complete and accurate primary care record. Computerisation of primary care enables quality improvement and increased efficiency within the health service and should be subsidised; the need for adequate funding has been recognised by the American Academy of Family Physicians (AAFP) who are actively campaigning to advance this issue.³⁷

The limitations of the outcomes from this conference are that its participants are drawn from the health informatics community and largely drawn from one

country, the USA; the voice of the patient was not included in the discussion; and the technology provider, the payer and government were also not represented.

Further research is needed to answer with greater certainty the questions that arose during this conference.

Conclusions

There is worldwide recognition that primary care has unique characteristics with specific data and information needs that require suitable informatics solutions. Existing studies suggest that high-quality primary care is enabled through computerised health records. A comprehensive primary care computerised medical record, along with the necessary supporting technical, human and academic resources, should be an essential part of all national health information strategies.

ACKNOWLEDGEMENTS

The authors acknowledge the help and support given by a number of people over many months: Moon Mullins, who along with John Zapp had the original idea for the conference; Michael Kidd and Jeff Suzewits, who were on the conference organising committee along with the other authors; David Bates and Alan Zuckerman, who were our keynote speakers; Melinda Jenkins, who shared her own notes of the meeting; Tim Cook, who helped organise and structure the ideas for this paper after the conference; and the AMIA staff, who worked so hard in the background to make sure we had everything we needed to run a successful day. We also acknowledge the support of the British Computer Society Health Informatics Committee (BCS-HIC) in contributing part of S de L and ST's attendance costs at the conference.

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CONFLICTS OF INTEREST

None.

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Accepted September 2004