Special article

Information technology for quality health care: a summary of United Kingdom and United States experiences

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"What is new and significant must always be connected with old roots, the truly vital roots that are chosen with great care from the ones that merely survive." Bela Bartok

Introduction

The explicit use of health information technology (HIT) to enable threshold improvements in the delivery of health care services is beginning to emerge as a serious objective for health care organisations and systems. Many readers who are very knowledgeable of quality measurement are relatively uninformed about health informatics and the converse is also true. It is for these readers that this paper is written. Specifically, the objective of this review of HIT in the UK and USA will focus upon salient features, deployment, and related policy issues. Particular attention will be given to areas in which threshold improvements in quality now exist or are likely to be forthcoming. Comments are organised to relate at the level of the individual, teams or microsystems, organisations, and larger systems, including national information infrastructures.

Health care information technology is a broader phenomenon than it is deep. Over the past 30 years the information technology revolution developed slowly from roots in Turing's military intelligence machines of World War II to DARPA and the present day Internet when the pace picked up. While the telephone took 40 years to reach 10 million people, it only took 4–5 years for the Internet to reach 100 million. Despite successes being clouded by hype and hope, the Internet consumer health market is projected to reach \$1.7 billion by 2003.

Randomised trials now confirm the early evidence that health care quality can be significantly improved through health informatics.¹ Evidence of improved access and cost effectiveness should soon follow.² Over the next two decades e-health could deliver patient, provider, and planner/manager interactions for all aspects of health care. A positive impact on quality, access, and cost effectiveness is likely and this should lead to better evaluation of health status and outcomes. The focus for action can change from detection of errors and

problems to information systems whose processes prevent many adverse outcomes.

National differences in the health care systems of the USA and UK have resulted in complementary strengths with respect to HIT. Most early major deployments of information technology in health care were for financial accounting of medical transactions. Only now is HIT being regarded as an essential investment for enhancing quality, and the UK is currently leading the way.³ Despite being at the onset of a phenomenon, so many examples of computer-based quality orientated efforts now exist that this paper can list only a few as illustrations.

The UK⁴ and the Netherlands⁵ have offered world leadership in primary care HIT deployment and privacy policy, while the USA has strengths in information systems for hospitals and health systems.⁶ Correspondingly, joint leadership in standards and terminology have complemented these priorities.^{7–10} Australia¹¹ and Canada¹² may well have the best records for combining national strategies with deployment.

Both the UK and the USA have policy documents and legislation that favour the deployment of HIT for simplification of patient care and administration. Clearly, the most dramatic is England's *Information for Health* strategy that was developed in 1998 and runs to 2005.^{3, 13} It has the following objectives: lifelong electronic health records for everybody in the country; round the clock online access to patient records and information about best clinical practice for all NHS clinicians; genuinely seamless care for patients through GPs, hospitals, and community services sharing information across the NHS information highway; and fast and convenient public access to information and care through online information services and telemedicine. It was announced as a £1 billion initiative but, to date, less than £100 million has been allocated for local implementation. This agenda fits within the broad policies emphasising "modernisation",¹⁴ e-government,¹⁵ and the National Information Partnership.¹⁶ This has been confirmed in *The NHS Plan* of July 2000 with its £200 million investment over the next

Prepared as a background discussion paper for Ditchley Park Conference, co-sponsored by The Commonwealth Fund and the Nuffield Trust, Oxfordshire, UK, June 2000.

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Accepted 6 July 2000

three years in HIT and a further £250 million in the year 2003/4.

In the USA a 1991 report from the Institute of Medicine, *The Computer-based Patient Record*, mentioned the quality enhancing aspects of HIT.⁶ The report was followed by additional reports from the Institute of Medicine and National Academy of Sciences dealing with related cogent subjects such as data management,¹⁷ privacy, confidentiality¹⁸ and security,¹⁹ telemedicine,²⁰ and systems considerations for networking health through the Internet.²¹ Much of this work was supported by the National Library of Medicine, a part of the US Public Health Service located at the National Institutes of Health in Bethesda, Maryland. US government reports and early legislation focused on telehealth and related developments.

The US Health Insurance Portability and Accountability Act of 1996 creates regulations for all electronic health transmissions whether related to government programmes or not.²² In February 2002 regulations are due to be published governing coding sets, security and privacy regulations, a universal patient identifier, and standards and transaction formats for electronic transfer of clinical records.²³ The goal is to reduce administrative costs that approach a quarter of the total national health budget and the first two listed above are well underway, with some aspects completed.

Privacy, confidentiality, and security considerations remain a central concern but they are treated differently in the two nations. In my opinion the UK leads in policy while the USA has the edge in practice behaviour. The UK has developed the Caldicott work programme for this purpose²⁴ and the EU has its policy directives.²⁵ The UK also has unique personal identifiers for patients although they are not used typically by hospitals. While the recent UK Government decision to access all e-mail traffic made headlines in the USA, it was scarcely reported in the UK. However, the entire HIT strategy for communications in patient care in the UK is planned around a private network, *NHS Net*,²⁶ rather than the Internet in the hope of securing privacy.

Privacy considerations may well offer the greatest capability to both foster and limit future prospects of HIT.²⁷ Regulation is clearly needed and striking the right balance will be a challenge for both nations, particularly for that sector of the population who are very concerned about their privacy. This is illustrated in the USA by the 50 000 plus comments across a wide spectrum of views that followed the publication of proposed rule making for the HIPAA mandated privacy regulations.²³ There is widespread agreement that federal privacy legislation is preferred, but consensus has not been achievable. It seems unlikely that fully amicable compromises will be reached or that legislation will be passed during this session of Congress. Key questions are how much security is enough, who owns the record(s), and who gets to use the data. The management of trust and risk are becoming the crucial information technology policy issues for 2000–

2005. Today it is rather easy technically to achieve “pretty good privacy” through encryption,²⁸ and virtually impossible reliably to assure privacy by “anonymising the data”.

Assuring all citizens access to HIT today is an impossibility, but virtual universal access in the UK and USA to the Internet is expected by 2005–2010. The goals for health orientated communications should include universal accessibility and sensitivity to language, culture, and educational level. Voice recognition will help as will inclusion of personal narratives in computer-based patient records. These emerging capabilities offer great promise for making care more patient-centred.

Qualities of information technology

To understand aspects of using HIT for quality improvement, some of its features deserve elaboration. Information technology has inherent transactional and transformational capabilities. The typical initial goal for computer systems is simply to automate earlier paper- or telephone-based interactions considered to be essential. Once done, users notice that clusters of transactions can be amalgamated so new procedures and features are designed. When this is accomplished, users consider transformational steps where key processes are redesigned to secure previously unimagined improvements.²⁹ For the present, this means that quality improvement must take a more biological approach to growth and development, since no other strategy works.

Information technology can be transformational through its machine-human interface. For example, e-mail seems to offer simultaneously distancing and intimacy. This feature may eventually result in global access to effective low cost programmes for conditions such as depression. Mental health patients may prefer telehealth care to face to face encounters with a therapist, and patients entering care are reported to confide sensitive personal information more quickly through an IT interface than in person.³⁰ Depending upon the uses of such findings, this can result in both highly desirable or undesirable innovations. Powerful “virtual” communities who can plan actions for peace³¹ or disruption³² are created in Seattle, Washington or London. Whether caveat emptor or caveat venditor will ultimately prevail is not yet clear.

Information technology exhibits ongoing threshold level improvements in power and capability. As the speed of processors increases, the size of components decreases and software capabilities improve. Greater portability, speech recognition, and voice synthesis is at hand. Bob Kahn, one of the developers of the Internet, has noted all those bytes and bits add up to quite a bit. The human-machine interface will become smoother and, except for those instances where the psychic distance proves useful, we may see it disappear.³³

These compounding features of IT can accelerate the pace of discovery, both within a field and in aggregate, since data from one field potentiate cascades of insights with other domains of knowledge. Probably no fields

illustrate this feature more than human genome mapping and its emerging relationship with genetic counselling.³⁴ The degree to which change occurs reflects our priorities. When quality becomes more important for HIT systems, higher performance programmes will appear and these will cascade as well.

Change strategies to improve quality

INDIVIDUAL (CITIZEN/PATIENT/PROVIDER)

APPROACHES

"What information consumes is rather obvious: it consumes the attention of its recipients. Hence a wealth of information creates a poverty of attention, and a need to allocate that attention efficiently among the overabundance of information sources that might consume it." Herbert A Simon
"Men more often need to be reminded than informed." Samuel Johnson

Part of improving the quality of decisions is having the right information at the right time. This may involve education at the "moment for learning" or for action as well as management of the growing base of knowledge. Critical incidence studies have shown timely relevant information to result in instances of better care and outcomes.³⁵ Computer assisted acquisition of knowledge that helps to allocate attention and decision support to guide thinking and to offer reminders creates opportunities for citizens, patients, and clinicians to improve the quality of care. Interested readers may wish to follow the monthly articles by Wyatt in the *Journal of the Royal Society of Medicine*.³⁶⁻³⁸

While gaps in the knowledge between consumers and providers are substantial, the gaps within each group are also substantial. Not everyone is "data driven". Blendon (personal communication, 1999) has noted that only a third of the total population seek out primary data sources directly when a question arises. The remainder do seek advice, but typically from someone who is "data driven".

The UK and US governments are actively bringing better health information directly to the public, patients, and providers. Public initiatives include the *NHS Direct* that includes telephone access to nurses as well as a national website.³⁹ In the USA the availability of public access to the health literature abstracted in *Medline* and *MedlinePlus* at the National Library of Medicine⁴⁰ as well as *Healthfinder*⁴¹ is a similar threshold enhancing effort for sharing high quality health information. In 1999 over a third of a million searches were made daily on *Medline* with over a third of those searches from consumers (D A Lindberg, personal communication, 2000). The openness of the Internet creates a challenge for assuring validity and reliability of information.⁴²

With the policy and practice of both nations favouring primary care providers as "gatekeepers" to the system, a robust knowledge of delivery systems may be crucial for quality, especially since patients cannot proceed further with their care unless approvals are given at this level. It seems that more knowledgeable patients will result in better informed clinicians. Indirectly, it will probably support rising

standards of medical care and research and result in better management of the knowledge base. Decision aids to support evidence-based patient choice⁴³ and partnerships with patients⁴⁴ are a rapidly growing valuable area of research.

Common sources of dissatisfaction for patients relate to poor time and data management by care organisations and the quality of communications with caregivers. Electronic connections between doctors, nurses, and patients seem uncommon today, but this will change.⁴⁵

Meanwhile, although the offices of primary care doctors in both the UK and USA have a computer(s), using it at work is uncommon. For example, 62% of Californian doctors rarely or never used computers at work and only 27% of offices were connected to the Internet (A Milstein, personal communication, 1999). A recent survey from Health on the Net reported much higher rates of use at home in both the USA and Europe.⁴⁶ Lack of financial incentives, weak to absent computer skills, impractical yet functioning legacy systems, legal ambiguities, and resistance to change explain most of the low penetration.

Doctors in both nations have been acculturated to see quality as being mainly their own individual responsibility rather than a collective effort encompassing other people, processes, and, especially, systems. Similarly, virtually all categories of health workers have a greater identification with their own category of professional than they do with how well the care team does as a collective.

Knowledge brokering via a variety of "intermediaries" such as *Ovid*⁴⁷ or *UpToDate*⁴⁸ is likely to become a major enterprise. Indeed, an entire growth industry of knowledge managers may emerge over the next two decades. The massive growth of the base of knowledge will be the most important stimulus. Future prospects include friendly viruses, or gnobots, that roam around inside one's computer-based patient records gathering relevant MESH terms, performing searches behind the scenes, and delivering "just in time" knowledge advice for immediate review and implementation if desired (R E Kahn, personal communication, 1993).

Over the years exceptional clinicians and software engineers have built software programs to assist a wide range of health care quality applications. These have encompassed health education,⁴⁹ data capture and storage, reminders for preventive care, or disease management (such as avoiding risk in drug doses, drug-drug interactions, appropriateness, and/or administration).⁵⁰⁻⁵² Hence, the best are characterised as offering valuable but narrow utility. Examples range from the early work of deDombal in the UK to improve surgeon's decision making under uncertainty⁵³ to Warner Slack's research on capturing the patient's clinical history.⁵⁴

GROUP/TEAM/"MICROSYSTEM" (SMALL PRACTICE/CARE UNIT)

"We don't need expert systems. We need mediocre systems to keep us from doing stupid things." Dean Settg

When in harmony, teams offer real promise for significantly improving care. Information systems can augment this by defect-free and timely performance of critical processes, including integration of activities across other relevant microsystems. For example, chronic disease management strategies with computer-based health records incorporating embedded evidence-based protocols for care and alerts can tie patients, teams of clinicians, and managers together.⁵⁵ A recent web linked home management program has been developed for neonatal monitoring.⁵⁶

Some of the best software available today supports applications that manage data and support decision making for those working as a group. For years the computer-based APACHE scoring system has offered prognostic information for the management of seriously ill hospitalised adults in critical care units.^{57, 58} Other programs track the flow of patients through emergency rooms and trauma centres, thereby improving quality, cost, and satisfaction while reducing stress. IT applications for special teams will always be crucial since the work of some teams can be very sophisticated and, of course, technology changes over time. With sufficient standardisation of language and codes, coordination is possible within the broader system and valid comparisons can be made with similar units elsewhere. Done well, this could allow comparison of system performance across populations located in other parts of the world.

ORGANISATIONAL LEVEL (HOSPITAL OR AGENCY)

Most complex HIT systems applications today came from hospitals where champions built teams working alone or in collaboration with vendors.⁵⁹ Today a number of vendors are creating web-based products that transcend single organisations to allow systems of care management across primary and secondary care.⁶⁰⁻⁶² Noteworthy organisations in both nations serve as beacons for quality HIT. These include Beth Israel,⁶³ Brigham,⁶⁴ Columbia,⁵² Duke Medical Center,⁵¹ Latter Day Saints Hospital,³⁰ Kaiser, Reigenstreiff,⁶⁵ Stanford,¹³ and Wirral.⁶⁶ Replacing working legacy systems or linking them to successors that are more robust is a major contemporary challenge but web-based “front ends” are becoming more common. Early efforts to implement programs in some NHS trusts and US hospitals were so unsuccessful that subsequent initiatives have been daunting. The relatively small size of the NHS market has also limited its ability to set and receive deliverable features from vendors. The NHS has an uneven record of using its size to manage its supply chain.

Primary care physicians in the UK are now coming together into group trusts with financial responsibility for both primary and secondary care. More robust information management systems are certain to follow. Similar groups are characteristic of practice in the USA. The GPASS system used in 855 primary care practices in Scotland includes scheduling that improves patient satisfaction.⁶⁷

Virtually all hospitals in the UK and USA have automated reporting systems for laboratory results and improvements in timeliness and accuracy are achieved. Far fewer organisations have order entry systems for doctors, nurses, and other clinicians implemented across the entire hospital.

LARGER SYSTEM (REGION)

Regional information systems with robust HIT may offer the greatest promise for optimising care of individuals and populations. Connectivity and scalability (plug-and-play to anywhere) are the by-words for the future but are far from reality today. For example, routine electronic communications between primary and secondary care clinicians on consultations, tests, or summaries of hospital admissions are uncommon in both nations.

An example of what could be is the Intermountain Health Care (IHC) system.⁶⁸ It has hospitals and clinics scattered across a large area in the western USA. They show that HIT using process control and decision support improves outcomes and reduces costs. Axioms gathered from their experience include the following (R Gardner, personal communication, 1995):

- The focus should be on risk assessment and avoiding problems rather than on systems for detection.
- The orientation should be getting the system right rather than focusing on the individual caregiver.
- The patient's experiences are central.
- Variation in practice is endemic.
- Quality can be constantly improved.

The controlling variables for system design are patient volumes, costs per case, perceptions of likelihood of risk, and damage to health if things are not done right. Initially they identified 600 distinct processes of which 62 (10%) accounted for 92% of all inpatient care delivery. Fifteen acute and 15 chronic disease processes accounted for almost 80% of all outpatient disease specific care delivery processes. Examples include adverse drug events (medication errors); hospital acquired (iatrogenic) infections; deep venous thrombosis with risk of pulmonary embolism; decubitus ulcer prevention and treatment; patient strength, agility, and cognition; and blood product transfusions. Sentinel events were also highlighted such as wrong side surgery or assaults. Drug orders tracked type of dose, timing, dose ceilings, checks for allergies, patient characteristics, drug-drug interactions, laboratory values, and genetic sensitivity (B James, personal communication, 1999).

As systems improve, networking of care processes even in rather isolated environments can bring physically isolated practitioners into “virtual” group practices. Both the average level of care may shift upwards and the few “rotten apples” may be identified before serious problems develop. Further, the use of automated data will allow a number of population-based speculations to be generated and conclusions to be reached, particularly as data become more valid and reliable.⁶⁹

Health care institutions have not typically organised themselves to assure optimal care for entire populations within their regions by working together in explicit partnerships. Models that do exist may point to the future of health care.^{59–70}

ENVIRONMENT/NATION

National health information infrastructures must receive sufficient financial support to ensure that this public good becomes widely available.⁷¹ Compared with other information intensive industries, HIT is underinvested by a factor of two or more. This limits the ability to transform the health care system to a much more effective chassis for the delivery of health care to individuals and populations.

Public/private partnerships work as evidenced by the GPASS national primary care system used in Scotland.⁶⁷ Some US health care organisations believe that major investments are cost effective. Kaiser in Northern California estimated in 1996 that it would break even on its \$1.2 billion investment in HIT in 6.5 years with a 200% benefit payback on investment achieved in 10 years. Return on investment calculations for a robust computer-based office management system that includes patient records is estimated to be 1.5 years for primary care practices in the USA (B Middleton, personal communication, 1999).

No high profile commitment to a plan of action for a national information infrastructure for health like that in the UK has been made in the USA. The investment of a £1 billion is about right for the UK, and \$7–10 billion are needed in the USA. Timely widespread deployment is unlikely without strong federal support. Indeed, in the USA the Balanced Budget Amendment and continued price competition are restricting the capacity of health systems to invest in information systems. Vendors of software systems are all relatively small players compared with the scale of the health care industry. In both nations the qual-

ity of product becoming available is improving. A variety of incentives could be useful.⁷¹

Incentives were used in the UK and the Netherlands to get computers into primary care doctor's surgeries. In addition to purchasing the equipment, financial incentives support transmission of data electronically, much like payments that assure immunisations are kept up to date. Such approaches work.

In the USA depreciation allowances and investment credits would help. More research funds are needed in both countries, including grants and contracts on a variety of topics such as quality enhancing aspects of computer-based health records. For example, research funds could assure development of a set of simulation methods that keep critical skills of clinicians up to date, such as those encountered in cardiac resuscitation. Those programs that work could be assured wide distribution. Similar programs could be very useful for training families who have a member with a specific medical condition that may require prompt attention to avoid serious outcomes. A number of monitoring technologies for use in the home deserve independent evaluation and then distribution. In the USA even simple changes in regulations would be helpful. Telecommunications companies would agree to pass health related messages across local jurisdictions and also support an adequate two way bandwidth for transmission of health information if all of them were required to meet these performance characteristics. Without a regulatory requirement, none will take the first step.

Standards should ideally be available for all to use without paying fees on a regular basis for proprietary reasons. Governments could "buy out" good standards from the developer so that the developer is treated fairly and the standard becomes openly available to any users needing it. These are a few examples of how public funds and/or policies could assure performance capabilities to serve the public good. Other issues are identified in fig 1. The relationship with quality measures and electronic medical systems was recently commented upon by McDonald⁷² who pointed out the crucial relationship between standards and the future of quality management.

Today both nations have an inadequate telecommunications and information technology infrastructure for quality in health care. The limitations are manifold. A strong focus on quality of care was not a primary consideration of most legacy systems and tight capital limited deployment of more robust systems. Support systems including trained personnel, educators, and researchers are needed to overcome cultural resistance and to manage change. Computer-based health records of three types (personal, patient, and population) as part of a national health infrastructure are essential for health care within our nations.^{73–74} While this is conceptually illustrated in *Information for Health*, it is not a clear part of the national system implementation plan. Computer-based records of these three types must be both interoperable and scalable. The challenge for the UK is to assure that the local implementation

Figure 1 Information objectives supporting the key groups. Reproduced with permission from "Information for Health: An Information Strategy for the Modern NHS 1998–2005".¹³

plans allow for connectivity to happen. The current structure does not appear to have balance across the various relevant domains.

There is scant evidence in the UK or USA that quality supported by information systems confers clear advantages in terms of success as measured in economic terms or in the eyes of the public. For example, the University of Pennsylvania committed heavily to a health information system specifically orientated to improving quality and, despite impressive success and national recognition, including three or more national awards, they have struggled recently to maintain their economic performance and have had to back off on this investment (W Kelley, personal communication, 1999).

A recent draft document from the NHS Information Authority specifies a vision for implementation at the local level and includes a specific section explicitly focused on improving quality with HIT.³ This, together with the concept paper on a national health information infrastructure from the National Committee on Vital and Health Statistics (NCVHS)⁷³ (<http://www.ncvhs.hhs.gov/hii-nii.htm>) from the USA, describe the importance of being able to gather data on populations from computer-based records. Both documents mention knowledge management, decision support, and telemedicine. Standards and measures are included as are the importance of research, education, and development. Support for standards work remains acute if proprietary systems are not to dominate and reduce accessibility. Universal access to health information resources are mentioned and this is well under way, but still deserves the attention of government.

The national strategy needs to include a useful computer-based information infrastructure with privacy, data integrity (curation), and access control. The amount of business-to-business and business-to-consumer traffic on the Internet will be such that security through public key encryption should be adequate for personal health data. If the Internet lacks sufficient levels of security, establishing regional intranets appears to be a feasible and possibly a sensible alternative. Key questions remain about how much security will prove to be enough and who owns the record(s) and its data. However, these issues can only be sorted out over time through experience and research. A credible certification authority is needed to assure authentication and honest practices on the Internet.

Information systems may offer the greatest promise for achieving high quality care for both *individuals* and *populations*. A high performing health sector should possess 10 critical features⁷⁵:

- defect-free processes and delivery;
- accelerated cycle time;
- information technology;
- transfer of knowledge;
- aligned incentives;
- encouragement of innovation;
- organised systems of care;
- community-based interventions;

- purchaser and consumer education;
- accountability.

Those within and outside government who are concerned with quality need to support the development and implementation of robust health information systems currently being advocated by the health informatics community. This should include an international information infrastructure geared to quality performance for nations with varying levels of economic development. Without such active support, at least seven of the features outlined above will be weakened.

The use of information technology as one key to threshold levels of quality improvement is just now coming to the foreground in government reports relating to quality. The recent interest in the USA may be in part a response to the report by Kohn *et al* entitled *To Err Is Human*.⁷⁶ This report, together with other activities of the Institute of Medicine Quality Initiative, adds to the strong, well reasoned argument for a robust national information infrastructure advanced by the 1998 President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry,⁷⁷ numerous reports from the Institute of Medicine, and two papers from the work group on the National Health Information Infrastructure of the NCVHS.^{73 74}

The educational challenge that informatics represents is substantial at virtually all levels. The UK could be said to have a bigger challenge than the USA since the USA has a well developed health informatics community with solid roots in both medicine and nursing. There is a national academic organisation (American Medical Informatics Association), a computer-based patient record organisation that recently joined forces with vendors so practical issues get attention (CPRI-HOST), a recent computer-based national medical curricular archive at the Association for American Medical Colleges,⁷⁸ and the National Library of Medicine that funds a number of valuable initiatives. In the UK there is no strongly supported national organisation(s) to focus upon policy, practical deployment, research, and educational initiatives. A recent meeting of UK academics, government officials, and others did show great enthusiasm for building an organisational presence outside government. The UK Institute for Health Informatics will most probably become the non-government organisation to lead education and research efforts.⁷⁹ It will most likely need some initial public financing support to assure its future success. A Foresight Taskforce on Health Informatics has also made relevant recommendations on this topic.⁸⁰

Obviously, generally available computer literacy will help and having self-teaching programs on the Internet is useful. When major clinical initiatives such as mandatory order entry are implemented in hospitals, there must be substantial educational efforts before, during, and after the start of implementation. Teams must be willing to work with users to smooth some of the rough areas in the software that are just too hard on the underlying culture.

As a rule, one cannot simply put a new system into any organisation without making some adjustments to make it fit. In short, education and change management are opposite sides of the same coin when HIT is implemented.

Today the UK Information Authority offers both visibility and leadership that is not clear in the current US governmental structure. No agency today in the US has a clear mandate or the support needed to assure a comprehensive approach to the opportunity that HIT offers quality of care. As a result, the HIT/quality agenda in the USA seems disjointed and weakened despite the best efforts of excellent people throughout government. In summary, modernisation of the HII gets far less attention and support in the USA than it receives in the UK. While *Information for Health* has some significant weaknesses in its implementation plans, it is committed to action. There is great need for more "joining up" of the various players inside and outside the NHS for the objectives of *Information for Health* to be realised, but the agenda is there and work is underway. Australia and Canada are also organised with respect to directing their national strategies for health information for quality care. Today the USA is leaving it to chance. An agency needs to be specifically charged with this mission with adequate funding (as already mentioned) and a timeline for implementation. The initiative should report directly to the Under-Secretary of the Department of Health and Human Services within the Secretary's office.

The USA and UK also have an international leadership role to play. If health information technology offers clear promise for better quality, access, and cost effectiveness in our nations, tailoring it appropriately for less economically developed nations is another ringing challenge. Information technology for the health of populations and individuals must transcend national borders.⁸¹ A global HIT strategy is needed to assure that the benefits of the Information Age have a global reach. We should work to assure that health is a primary good everywhere.

As Charles Kettering notes: "We should all be concerned about the future because we will have to spend the rest of our lives there". The linking of information technology and quality improvement offers great promise. Indeed, a successful synthesis of the two may prove the defining characteristic of improved health status for humanity in the 21st century.

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Appendix 1: Characteristics of personal, patient and public health records (US)⁷⁴

Personal health record

(A) MAJOR ELEMENT

- Patient identification number
- Emergency contact information
- Lifetime health history: summary of care giver records from all sources of care including immunisations, allergies, family history, occupational history, environmental exposures, social history, medical history, treatments, procedures, medication history, outcomes
- Laboratory results (for example, EKGs) or links to results (for example, MRI results at a radiology department data warehouse, digital images of biopsy slides, or digital video of coronary angiography)
- Emergency care information (for example, allergies, current medications, medical/surgical history summary)
- Provider identification and contact information
- Treatment plans and instructions
- Health risk factor profile, recommended clinical preventive services, and results of those services
- Health insurance coverage information

(B) OTHER ELEMENTS

- Correspondence: records of patient-provider communication, edits made to public health record, or concerns about accuracy of information in health care
- Provide medical records instructions about access by other persons and institutions
- Audit log of individuals/institutions who access electronic records
- Self-care trackers: nutrition, physical activity, medications and dosage schedules
- Personal library of quality health information resources
- Health care proxies, living wills, and durable power of attorney for health care

(C) ELEMENTS FROM THE COMMUNITY HEALTH DIMENSION

- Local public health contact information
- Local health care services (e.g. walk-in clinics)
- Environmental measures and alerts pertinent to an individual's home, neighbourhood, school, and workplace

Patient record

(A) MAJOR ELEMENTS

- Patient identification information
- Sociodemographic identifiers (sex, birthday, age, race/ethnicity, marital status, living arrangements, education level, occupation)
- Health insurance information (including covered benefits)
- Legal consents or permissions
- Referral information
- Correspondence
- Patient history information (may include longitudinal history from public health data, immunisations, allergies, current medications)
- Stated reason for visit
- External causes of injury/illness
- Symptoms
- Physical examinations

- Assessment of patient signs and symptoms
- Diagnoses
- Laboratory, radiology, and pharmacy orders
- Laboratory results
- Radiological images and interpretations
- Record of alerts, warnings, and reminders
- Operative reports
- Vital signs from ICU
- Vital signs from public health data
- Treatment plans and instructions
- Progress notes
- Functional status
- Discharge summaries
- Instructions about access
- Audit log of individuals who accessed the patient record
- Patient amendments to patient record
- Provider notes such as knowledge of patient, patient-provider interactions, patient's access to services

(B) OTHER ELEMENTS THAT SUPPORT CLINICAL PRACTICE

- Protocols, practice guidelines
- Clinical decision support programmes
- Referral history

(C) ELEMENTS FROM COMMUNITY HEALTH DIMENSION

Depending on the patient, the health care provider dimension would include additional contextual information necessary for understanding, treating, and planning the care of the patient:

- Aggregate data on the health care of community members
- Community attributes affecting health (for example, economic status and population age)
- Community health resources (for example, home health services)
- Community health (for example, possible environmental hazards at home, work, school, or in the community at large).

Core content in the community health dimension

(A) PUBLIC HEALTH DATA

- Infant mortality, immunisation levels, and communicable disease rates
- Environmental, social, and economic conditions
- Measures related to public health infrastructure, individual health care providers, and health care institutions
- Other summary measures of community health
- Registries
- Disease surveillance systems
- Survey data
- Data on healthy people objectives and leading health indicators

(B) INFORMATION FROM HEALTH CARE PROVIDER DIMENSION (WITH PERSONALLY IDENTIFIABLE INFORMATION REMOVED EXCEPT UNDER LEGALLY ESTABLISHED PUBLIC HEALTH PROTOCOLS AND STRICT SECURITY)

- Health status and outcomes, health events, health risks, health behaviours, and other individual characteristics
- Health care utilisation and access, health insurance status
- Health care of community members

(C) OTHER ELEMENTS

- Directories of community organisations and services