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Reducing the Zone of Confusion

A publication based on a
Nuffield Trust Policy Review Seminar

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FOREWORD

The first publication in the Nuffield Trust series - *Redesigning Health Services: Reducing the Zone of Delusion* - highlighted the need to redesign our health services to meet the needs of the 21st Century, rather than merely reorganising them yet again. This proposition was based on the reflection that we are on the verge of a major technological change in health care which has been made inevitable by a number of developments, particularly progress in genetics, information and communication technology and the worldwide web. These developments will have huge implications for clinical practice, ethics and the expectations of patients. Public interest - repositioning individuals within the health system - was very much the theme of the Nicholas Timmins article in the *Financial Times* of 14th October, "Patient, heal thyself online".

The importance of Information Technology was also highlighted by the Prime Minister at the "All Our Tomorrows" conference on the occasion of the 50th Anniversary of the NHS, when he said that "the challenge is for the NHS to harness the information revolution and use it to benefit patients". He went on to say that cardiac patients are already having their heartbeat monitored by telephone and that the day is not far off when the internet and interactive television will give us the convenience of home visits done through technology.

Information technology has the power to help us transform situations and a national information infrastructure can be an essential tool and resource in promoting the nation's health. The health sector has not applied or been resourced to apply information and communication technology as effectively as other sectors. The recently-published *Information for Health. An Information Strategy for the Modern NHS 1998-2005* ' outlines how the benefits of the information age will be applied to the NHS in England: we await with interest the parallel documents for Scotland, Wales and Northern Ireland.

The Trust welcomes the key thrusts of the Information for Health strategy, refocusing towards individuals, population health and support for clinical practice. These are not new emphases and were part of the Information Technology for the NHS in Wales (1991) which included an electronic patient record research and development project. Experience reminds us to ensure adequate investment funds and also to be prepared to reorganise working practices if benefits are to be realised in patients and communities.

Information and Information policy has a crucial place in the Trust's programme of work. Our theme of the changing role of the state in health policy sees information as a driver for change, resulting from and contributing to both globalisation and devolution. The World Trade Organisation already has a remit for electronic commerce and may extend it to look at the impact of electronic communication in health. *Information for Health* recognises this and says "the new information communications technologies represent a major vehicle for modernisation in rapidly transforming the way we do business, receive services and lead our lives. They are global and pervasive. Their speed and power is such that most sectors of the economy now have virtually no choice about whether and when to adopt them" [2]. Furthermore the Amsterdam Treaty and the revision of Article 1.29 is an indication of the development of public health in Europe with its focus on improving information for the development of public health, the capacity to react rapidly to threats to health and through tackling health determinants through promotion and disease prevention.

Information policy and arrangements for its administration are also highlighted in the Trust's publication *Devolution and Health.* ' In my introduction I commented that administrative devices such as Commonwealth and state agreements in Australia for health information will need to be considered in our rapidly-devolving UK to ensure the limitation of wasted effort and to ensure a common approach. The recently-revised information policy agreements in Australia were agreed in July 1998 [4].

More specifically in information for health the Trust recognises that telemedicine will provide ethical challenges and this was the topic of a Trust-supported conference, "Taking Health Telematics Safely into the Twenty-First Century: Balancing Opportunities and Ethics", held at the Royal Society of Medicine in December 1998. The Trust also supported a meeting to explore a potential collaborative project between the University of Newcastle-upon-Tyne and UCLA to exploit the potential of the worldwide web for economising on curriculum development for medical education. A number of other academic centres have expressed an interest in this initiative.

Furthermore the Trust considers that there is still a need for a regular Health Information Policy Forum, despite the establishment of new institutions such as the UK National Institute for Health Informatics and the DTI stakeholder Foresight and IT Committee. The need is for a forum that will assess UK developments in the light of the various territorial health department approaches, the emerging role of the EU in public health and the priority to be afforded to information, ethical, international regulation and classification issues as well as the UK's international obligations for data and national statistics for OECD. The global nature of the IT industry should inform UK implementation of its health information policy, particularly in the area of international standards for data transmission and communications.

This latest Nuffield Trust publication realises the fundamental role of information in health care delivery and management and the need to reduce the zone of confusion through common vision - collaboration, sharing and trusting as a way forward.

John Wyn Owen
January 1999

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1 Information for Health. An Information Strategy for the modern NHS 1998-2005. NHS Executive. September 1998.

2 Information for Health, op cit

3 Hazell R and Jervis P. Devolution and Health. Nuffield Trust. 1998.

4 Healthcover. Vol 8. No 5. Healthdata Services, Sydney, Australia.

INTRODUCTION

Information is central to health care delivery, and is essential for health care delivery processes. Whilst information may be regarded as the fundamental basis of health care practice - both from a knowledge perspective and from the point of view of record-keeping and communication - to date there has been little strategic consideration given to the systematic development of applied information science in health care in the United Kingdom, despite the continued demands and policy expectations for specific data sets. Information policy and practice have created a 'zone of confusion' in what should be an area of understanding and informed commitment.

Information in health care has never been properly recognised as an intellectual area; rather, it has been thwarted by custom and practice traditions that have built up around paper records systems, and more recently by technocratic advocacy of advanced electronic systems. The core purpose of records as an information source and communications medium, and policies for the optimal harnessing of proven readily available technology, have been largely overlooked and deplorably underdeveloped. Whilst there have been a number of important health informatics innovations in the UK, and successful policy initiatives, these have not been exploited as effectively as they might have been, particularly through lack of a common evaluative evidence-based and supportive environment. Stakeholder interests have tended to adopt and defend particular positions or interests, including inertia, rather than coming together to create a positive way forward.

Thus, at a time when modern technologies should be giving major impetus to the better use of information to enhance the quality and efficiency of health care delivery, in reality progress is limited, uncoordinated and at times grossly inefficient, with major opportunities being ignored. A radically reshaped strategic approach is needed, based on more effective research and development, evaluation, and enablement programmes, with better overall coordination between key interests in order to lead to firmly based policies and professional principles.

THE ROLE AND SIGNIFICANCE OF INFORMATION

Information can be identified as having five key roles in health care:

in **Patient Care** for

- ***recording the presenting problem*** or health care need
- systematically ***representing the dynamic clinical history***
- ***co-ordinating*** treatment

in **Professional Practice** for

- ***recording activity and findings***
- ***communicating*** between involved clinicians
- enabling ***self-review***
- when necessary ***defending action taken***
- providing the **foundation for evidence-based practice**

in **Management** for

- ***operational management*** purposes
- optimising ***resource management*** and deployment
- enabling ***service improvement***

in **Service Development** for

- ***evaluating*** treatments and services
- ***measuring outcomes*** and thus ***developing knowledge***
- ***planning*** future service patterns and structures

in **Policy Development** for

- ***providing intelligence*** for policy formulation

Thus information can be demonstrated to have a pivotal role in ensuring effective and efficient health care. It is not surprising that the British Medical Association has identified information in clinical practice as 'The Heart of the Matter'', and that there are professional standards and policies on record-keeping. For similar reasons, the Audit Commission has devoted attention to this field, finding on the one hand that health professionals spend 25 % of their time handling information, yet on the other hand that information systems are under-developed, under-resourced and poorly run [W4]

THE UNACCEPTABLE CURRENT SITUATION

The discomforting findings of the Audit Commission, and the poor state of development of information systems compared with what is clearly possible, indicate the unacceptable state of current information policy and understanding. There are a number of contributory factors.

The Low Status of Information

For all its importance, health information has a low status in the British health care sector. This can be demonstrated by the range of core issues that remain unresolved or unaddressed, including in particular:

- lack of cross-disciplinary core principles other than for manual record-keeping
- lack of a common vision on the future priorities and approach to information infrastructure development
- no research focus (for pure or applied research)
- unrealistic policy instructions and expectations
- lack of support to academic and research units

- inadequate validated exploitation of modern techniques and technologies
- uncoordinated application development
- no common education programme
- low academic status

Continued Fragmentation

A principal reason for the failure to make greater progress has been the fragmentation of thinking and development on health information and informatics in the UK:

- the health professional bodies have proved unable to come together to set a common vision or agenda
- each of the four home countries has developed its own strategic approach
- desirable health policy initiatives that are totally dependent upon information have been produced in isolation from information policy development (e.g. audit, outcomes studies, costing and resource management, evidence-based care, primary-led care)
- applied health information systems fall between the divisions of the Research Councils
- there is no deep common agenda-setting between the Department of Trade and Industry and the Health Departments
- there is much to learn from international collaboration, but European health informatics liaison is led from the NHS Executive in Leeds, G7 liaison from the Department of Health in London, and International Medical Informatics Association membership from the British Computer Society
- academic departments have not found a common coordinating vehicle, and are weakened by lack of research funding
- the efforts of individual innovators such as de Dombal and Read

exemplify the difficulty in finding organisational frameworks for early innovation.

A number of advisory bodies and ad hoc groups do exist, but the great majority are uni-disciplinary, and almost all are specific to their own home country of the United Kingdom, creating more likelihood of fragmentation than of co-ordinated progress and vision related to what should be an integrated approach to health care delivery and its appropriate information support. Thus, overall there is neither cohesion nor leadership[5], and no forum within which to develop truly shared innovation and policy[6].

Entanglement with Efficiency and Administration

This situation is no doubt exacerbated by attitudes that do not look at the strategic payback of an effective approach to information. These negative factors include:

- political drives against management costs even when these support clinical processes
- pressures for short-term results rather than sound developments, often linked to Governmental cycles
- the difficulty of obtaining capital investment, or educational funding, for other than explicitly clinical purposes
- medical and other professional antipathy to supposedly administrative and managerial activity
- the lack of an integrated research or dissemination focus
- reluctance to invest in evaluation and experiential learning.

A further compounding factor is that much investment in information technology has been focused on administrative and business systems, where they are of proven effect and the returns are visible to those who allocate the investment. However, if there were more evaluated innovation and proven realised benefits related to clinical activities, these would enable clinical representatives to put forward or support investment proposals in terms of benefit to care delivery, and thus there would be more incentive to invest in clinical systems and for clinicians to adapt to using them.

A Lost Impetus

This unsatisfactory situation need not have come about. The UK had early successes with electronic applications to health care records, but the stimuli were different in different sectors. In primary care the drive came largely from technological and pharmaceutical interests, and in community care from local government's wish to improve uptake of preventive services; only in the hospital sector was there a major lead from central research initiatives. Moreover, seldom was the potential for improved health care delivery adequately exploited by health professional interests, thereby amplifying the focus on administrative processes, business efficiency, and management of large organisations.

Thus the current state of health information science, investment and education does not reflect in any adequate way the core role of information as an essential tool in health care practice. Indeed, even generally welcomed policy developments in health care design and delivery are currently being jeopardised by the lack of attention to the information aspects[7,8]. If the quality of care sought by clinicians, the efficiency sought by policy makers, and the effectiveness sought by society are to be achieved, a rediscovery and recognition of the importance of information to health care, and the systematic application of known innovation, are needed in a far more cohesive environment.

A NEW BEGINNING

It is necessary, therefore, to think in terms of a new beginning for British healthcare informatics - both for policy and for techniques. This will require:

- a new commonality of vision
- a proper Research and Development (R&D) programme
- a focal part of the R&D programme to be on methods, tools, and products
- evaluation and impact analyses of systems to be a core part of R&D
- implementation enablement to be put on a sound footing
- support for new informatics functions, and formulation of ethical and quality control standards, to be developed hand-in-hand
- an objective-based approach, with proven effects on health care a principal yardstick
- longer overall time horizons, giving stability against short-term pressures
- above all, a forum where key interests can meet to agree core principles, review evidence and coordinate technological and policy innovation

This should lead to a longer-term, integrated and robust view, largely separated from the transient nature of central politics and from the special interests of individual clinical or commercial groups. A shared common vision stands far more likelihood of successful implementation in the long term. In moving in this direction of integrated vision, it is important to recognise and build upon those initiatives and infrastructures that are effective and robust - all four countries of the UK can contribute in this respect. The key issues and opportunities are explored in the following sections:

THE FULL PARADIGM SHIFT

The importance of moving from business systems to clinical systems has been well emphasised of late in policy settings, and is beginning to have significant effect. However, this paradigm shift - from Administrative Business Systems to Clinical Systems - is only a beginning; most clinical systems still focus upon a business approach, albeit now related to clinical business.

Patient Focused Systems

The full paradigm shift must be to move beyond the current goal of patient-based systems (where patients are the recording units for clinical business systems) to Patient Focused Systems, where the individual system would underpin the delivery of reliable, good quality care to the individual patient. This should take place within a strategic context in which relevant sections of record created to a common format and content would pass from one responsible clinician to the next.

The Triple Function of the Record

The effecting of this major paradigm shift would reflect recognition of the three functions of the health record, which are inextricably linked in paper systems but can be differentiated in electronic systems. These three functions are:

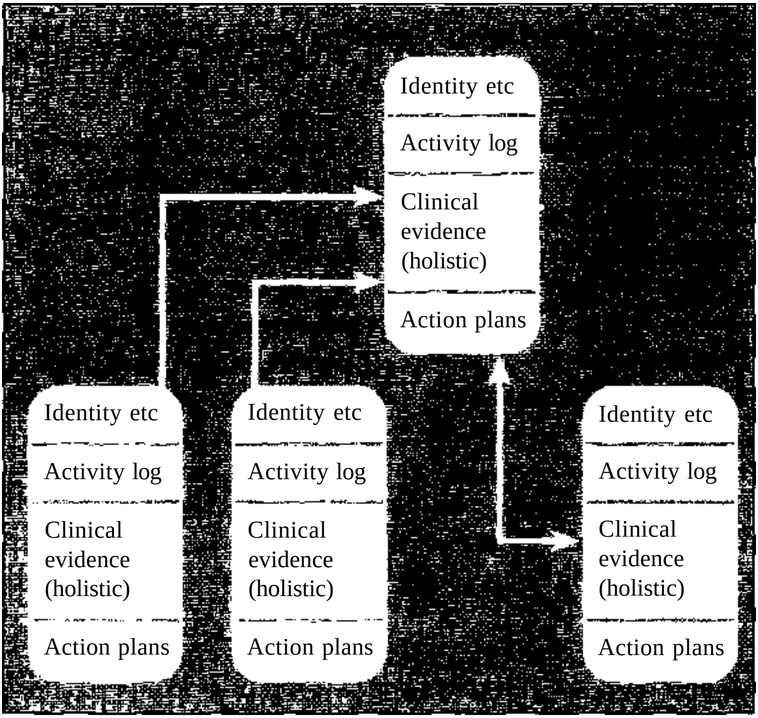
1. **The Activity Log:** An up-to-date sequential record of contacts, activities, and interventions with and for the patient, essential for many purposes but poorly structured as a clinical picture.

2. **Folder of Clinical Evidence:** The clinical history can be built up from transaction data in a structured way, including health problems, diagnostic results, social and family settings, and clinical characteristics.

3. Plan of Action: Care should be delivered in a coordinated way to achieve set objectives, with health professionals working to a common view and integrated schedule, shared with the patient.

Given this structured approach to records, and with common terminology and technical compatibility, each provider's record for a patient could be used to contribute to the creation of a patient-focused record for the patient relevant to a new setting or as a new health care need arose, as shown in Figure 1.

Figure 1



A HOLISTIC VIEW OF PATIENTS

The full paradigm shift would also enable the patient to be viewed - and supported - holistically. Social environment, care preferences, carer responsibilities and concurrent conditions would be seen as being as important as current diagnosis and prescription. Nursing brings this wider view of patients, but there is a constant struggle (and also in the paramedical professions) to get recognition of the need to further within health informatics the information tools used in holistic clinical assessments as an essential part of multidisciplinary care.

THE NURSE'S TALE

Ruth Roberts

For almost two millennia, health has been perceived as 'a state of reasonable functioning and freedom from pain''. This concept of the functioning person was taken further in the World Health Organisation's founding definition of health as 'a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity'[10]. At this time, over 50 years ago, it was widely believed that there was a clear distinction between health and ill-health; however, it has now been accepted that there is not such a clear-cut differentiation, and that there is also a subjective judgement on the part of the individual as to whether he or she is feeling well or unwell. Health is now defined in relation to the individual and his or her expectations, and to his or her optimum level of functioning in everyday living ''.

In subscribing to, and taking the lead for delivering, this performance - and perception - based approach to health, nursing seeks to promote a holistic approach. A principal focus is the measurement of three aspects of functioning: physical, psychological, and social. In so doing, it seeks objectivity and empiricism wherever possible, ranging from assessment of the risks of developing pressure sores, to the use of anxiety and depression scales. These assessments are not single events, but are repeated to measure progress and changing needs; they seek not to categorise patients into classification boxes, but to accommodate individuality through empirical recording.

Whilst the introduction of nursing information systems was viewed by many nurses as a welcome solution to the challenge of handling the volumes of structured data collected during the assessment of patients, the reality has been disappointing, with inadequate recognition of nurses' information needs. There is the requirement to be able to view and compare original and subsequent assessments in order to determine progress or maintenance of health status, and for those patients who require frequent hospital admission for the same procedure there is the need to be able to check quickly the patient's previous assessment details, and update these if required.

However, despite these limitations, the introduction of nursing information systems did stimulate the debate about how to share assessment findings amongst the multi-disciplinary team, and how to build up multi-professional assessments. The challenge of developing information-based nursing tools has led to the International Classification for Nursing Practice [12], and to the Association for Common European Nursing Diagnoses, Interventions, and Outcomes (ACENDIO). The term for the end-point of the nursing assessment - whether 'nursing diagnosis' or 'nursing problem' - continues to stimulate debate, but it must not be allowed to obscure the fact that this conclusion of the nursing assessment is a rich and important part of the holistic view of the patient.

Intended outcome has always been a key concept of the nursing care plan [13] and the tools used for patient assessment also have a role in determining the actual outcome of care. For many patients there will be particular health problems that only require nursing interventions; however, many patient outcomes are achieved by the actions of more than one group of health professionals.

A further key concept that was developed and first applied principally in nursing is that care should be planned and scheduled - to the benefit of the patient, the professional, and overall service efficiency[14]. However, care is seldom planned or delivered in a unidisciplinary setting, and currently patient records tend to hold a variety of pieces of information in single-discipline sections. With such limited information tools, it is difficult to prioritise, evaluate, or adjust the provision of total care. Initiatives have emerged to develop integrated concepts such as collaborative care planning[15] and integrated record systems[16], but they have not received the support for development that their significance merits.

Thus, nursing has always considered the 'whole patient', and has developed processes to achieve holistic health maintenance and health gain. Because the nursing assessment gives the three-dimensional view already described, the assessment at the end of the treatment period gives a holistic outcome statement, and one focused on the patient as a physically and socially functioning person. Information technology raises new opportunities to harness and utilise the information collected and needed, but this raises challenges of structured terminology and data definitions. Nursing has promoted many information innovations, sometimes with disappointing results because too narrow a view has been taken. If the concepts emanating from the nursing approach could be harnessed generically, and seen as a core part of the integrated record rather than as an appendix, then integrated and objective patient-based care delivery would be advanced.

MEDICAL INTERVENTIONS IN CONTEXT

Whilst the health service is seen as medically led, the doctor's role should be seen in context, not least in information terms. Patients come to doctors when they feel they have a problem or health need; the doctor assesses the evidence and in general prescribes or refers. Some secondary care specialists also undertake active therapy such as surgery, but the greatest part of the overall care is given by other professions, who aim to maximise the functioning and social potential of each patient as an individual. The medical record has hitherto been a transaction log, retrospectively studied on occasions for relevant evidence, and supplemented by external evidence, particularly from investigative departments.

Given modern information technology and better understanding of health as a personal attribute, of health-related issues as processes, of healthcare as a set of external interventions into normal life rather than as a good to be collected, and of the need for any clinical practice to be evidence-based and self-reviewed, the need and the opportunity for a new paradigm of health records arise.

THE DOCTOR'S TALE

Ian Purves

The aims of health care are to identify problems (whether presented or asymptomatic), and to understand the impact on the individual; then to resolve or ameliorate the problem to the patient's satisfaction, to the best of clinical capabilities and society's resource limitations, while helping the individual to cope with and manage their illness. This puts tasks upon the patient and the clinician. The task of the patient is to convey his or her health beliefs to the clinician, who will enable this to happen. The task of the clinician is to convey his or her professionally informed beliefs to the patient. The intention of this interactive and mutual process is to assist the patient in making as informed a choice as possible about diagnosis and treatment, and about benefit and risk [17].

The impact of the 'Information Age' on society in general has been to enhance communication, organisation, education, and business. Within health care this has meant realisation of the variability of quality of care, and the challenging of this by an informed society. At the same time medicine has changed through the increase in information, and concomitant changes in the 'science of the art of medicine', but paradoxically without a shift from paternalistic disease-centred medical care.

The paradigm shift required in medicine in an informed society requires exploring both the disease and illness experience; understanding the whole person; finding common ground regarding management; incorporating prevention and health promotion; enhancing the doctor-patient relationship; and at the same time being realistic [18].

Recent studies in England show a lot of activity in computer use in general practice[19], but the distributed nature of general practice personal computer systems, and also their isolation from other health care systems, has lead to difficulties caused by fragmentation. A new and co-ordinated approach is needed to address the opportunities and challenges of the 'Information Age' in medicine.

This approach falls into three aspects, of which the first is understanding human-computer interaction. There must be better understanding of interacting with the computer as a tool, and system ergonomics must understand the new approach to the consultation. Group-working and clinical interlinkage must be developed. Organisational and social issues must adapt to achieve better quality of care through improved interaction with computer systems.

Secondly, on computer issues, there must be a focus on four things. The **Electronic Patient Record,** and **Decision and Information Support,** are clear concepts that need further development in an integrated way. **Groupware**[20] is an approach that needs much greater understanding and practical development to support known concepts:

- ***Communication*** - patient-based records, e-mail, image sharing, telemedicine.
- ***Collaboration*** - clinical governance, group guidance, education resources.
- ***Co-ordination*** - monitoring and scheduling of tasks and resources.

Finally, **Resource Management and Planning** need facilitating in a positive way, both at the micro level through the planning and delivery of objective care, and at the macro level to optimise use of finite resources.

The third aspect is clinicians' issues. The 'Information Revolution' needs to be channelled into medicine in a constructive way, and as part of that planned programmes are needed to change clinicians in the following ways, to match the new tools that should be made available:

- ***Attitudes*** - clinicians need to mould and embrace clinical information systems, and to value medical records; they need to be non-paternalistic and to value external knowledge; they should want to use the new information to implement quality assurance of their practice; and they need to identify and direct the changing of professional roles.
- ***Knowledge*** - adoption is needed of asynchronous communication, new medical record philosophies and architectures, group working, and new conceptual and ethical constructs - in each case only after informed development of appropriate instruments.
- ***Skills*** - doctors will need to be able to handle information input and output, to evaluate the information and knowledge presented, and to operate continuous quality assurance.

This vision of information-based clinical practice can be summed up by stating that the clinician needs to be part of the same story as the patient, experiencing the illness, and sharing the facts and the underpinning scientific knowledge. However, to achieve this there needs to be a paradigm shift in the organisation and development of information systems. The priority must be to focus on records - at present there is no consistent definition of what a record is, or of how the new-style inter-communicating electronic record can be introduced.

To achieve that requires stakeholder agreement, for which there is currently no process. Such consensus needs to cover the definition of a record, the terms, coding, and narrative used, models of care delivery, and a patient-based focus incorporating multi-disciplinary views [21]. This policy development needs to be iterative, to be realistic about costs, and to understand clinical, organisational, and patient dimensions. From such stakeholder consensus would flow not only development and implementation, but directly related education and training programmes [22].

However, this requires a simple but apparently radical step - the coming together of policy, professional, and other funding bodies to resource and enable the sequence of developments. Without this, entry to the 'Information Age' in medicine will not meet the criteria of being scientific, evidence-based, efficient and effective.

MARKET ASSISTANCE

It is often assumed that once key policy objectives and needs are defined, the health informatics market will ensure development and implementation of suitable products. This position is fatally flawed for the following reasons:

- individual health care organisations are likely (for sound intrinsic reasons) to avoid the risk of commissioning innovation

- system purchasers are unlikely to have full technical competence to specify or evaluate non-production-line systems
- the primary medical care system market is highly fragmented yet severely cost constrained, and the rest of the market is small and also cost constrained, thus overall market suppliers are not able to support significant basic research or product development
- except for highly technical areas such as image handling, systems from other countries have to be tailored - because of the language used, style of practice, health sector funding models, and user expectations, before they can be transferred.

It is conspicuous that many large as well as small information technology companies have left the health sector in recent years, some having been pioneers at an earlier stage. This must raise questions about market returns, as well as causing system users concern at their vulnerability if even multi-national companies cannot be seen as stable suppliers.

THE PIONEER'S TALE

Sally Robins

Development of innovative information concepts in health care, and their pioneering implementation, must be firmly rooted in normal health care practice if they are to be relevant and effective. Unfortunately, mechanisms for ensuring that this occurs do not yet seem to exist in the UK.

By definition, NHS organisations (and indeed private health care providers as well) are charged with making best and prudent use of their funds for the provision of patient care. Risk taking through seeking, commissioning, and piloting new information systems is not compatible with this fiduciary control of public money. At the same time, large suppliers are becoming rare within the health informatics market, whilst smaller innovators cannot muster speculative funds of the magnitude required. Hence some central research and development (R&D), or 'seed corn', activity is essential. Unfortunately, this does not fit comfortably within the commercial philosophies of recent governments, whilst health research bodies do not see information concept or system research as a high priority.

Some central initiatives have occurred in order to further the English Information Management and Technology strategy, but personal experience has not been good despite the creative success of the initiative. Involvement in leading a large centrally funded applied R&D project in electronic patient records outside the acute sector afforded experience of arrangements and attitudes that militated against effective progress within and beyond the funded phase. A significant sum of money was to be spent in a 10-month period, with little subsequent activity to exploit the ideas and dynamism created. At the same time, the culture at senior manager level within the parent body was not wholly supportive, with non-operational tasks seen as diversionary from the core business rather than as being beneficial to the organisation and to ongoing NHS development. Above all, lack of follow through after the successful completion of the deliverables (for instance, failure to fund piloting) ensured that the results never progressed to implementation: national interest ceased with receipt of the project results, whilst locally one single Trust could not be expected to fund the creation of full applications systems. Predictions at the time of this effect[23], which falsely were seen as unconstructive, have proved to be accurate.

Thus the NHS seems faced with an impasse. First, information is still viewed generally as an add-on rather than as part of the core business (note the scarcity of dedicated Information Directorates in NHS organisations)[24]. Second, systems that exist (both paper-based and electronic) are perceived to be unsatisfactory for their modern purpose. Yet third, there is an aversion to any form of local risk-taking to address this using what is perceived as money allocated for direct patient care activities. Indeed, there is a tendency to consider innovators as pursuing a policy of personal self-aggrandisement. But the NHS cannot afford not to move forward, and inertia (broken only to implement new central policy business system directives) is not an acceptable option. A way must be found to protect the individual NHS organisation in taking necessary qualified risks, without which no progress can be made (and indeed, to protect the individual risk-takers too, provided they have acted reasonably and professionally).

This impasse needs to be broken, and this shows the contrast with the private sector. In other service industries, the taking of controlled risks is seen to be necessary and healthy, and may indeed raise corporate morale and attract staff. Few successful developments are risk-free in their early stages. This necessitates a culture change in the NHS, together with the introduction of risk management concepts. Risks are not just financial, but should include the impact on patient care and the expectations of health professionals. An essential ingredient is a risk management methodology, which in turn necessitates use of empirical measures of benefit and disbenefit[25].

Linked to this, the NHS also needs to recognise that evaluation is not a process of looking unnecessarily for problems, but rather one of continuous learning. Important new knowledge comes from the evaluation process. Such learning then needs to be shared sensitively with the NHS family to avoid unnecessary relearning, but there seems to be neither the culture nor the mechanism for this within the Information field (itself a somewhat ironic paradox).

So what can the NHS learn from the private sector? First, that information activities are a core part of the business, and need appropriate investment, development, and management. Second that clarity of vision and purposefulness are needed. Third, that solutions are required appropriate to need, but should not be simply available and under-resourced compromises. Finally, that there should be a corporate commitment, at the highest levels, to support innovation and prudent risk-taking against set assessed objectives.

From outside, the private sector sees the NHS as unlikely to generate successful partnership, and thus there are few major companies seeking to work in it - a worrying situation. This is not just because of the unrewarding trading conditions, but more because of the risk aversion, the lack of stability in policy and underlying politics, and the lack of structured follow-through of innovation into proof-in-use and resultant evidence-based adoption. Further, the individualistic autonomy of provider units, and the lack of central leadership, produces a fragmentation of approach that jeopardises the likelihood of investment to create systems for which there can be no guarantee of wide take-up. Without a serious change in attitude, the NHS will not get the information systems which it and its patients need and deserve.

Thus, despite the general principles of market freedom, and of prudent public spending rules eschewing investment in system development (or in applied research), the supplier side of the health informatics market is unlikely to be the driver of development of new integration paradigms. At the same time, principles of financial prudence with public funds, as well as the difficulties of widespread organisational collaboration, render purchaser funding of research or innovation equally unlikely. Without active planning and stakeholder co-ordination, and judicious strategic research and development investment, the harnessing of the information age in the health sector is likely to be uncoordinated and incremental, and thus inadequate and inefficient - directly jeopardising quality of care and service efficiency and effectiveness.

THE NEED FOR A NEW APPROACH TO STRATEGIC DEVELOPMENT OF HEALTH INFORMATION

Information should no longer be seen as an add-on to health systems, and a means of collecting statistics. Information pervades modern daily life, and new technologies are giving rise to recognition of the importance of the 'Information Society'. In health care, evidence - both for practice approaches and for treatment of the individual - is promulgated as of the highest priority. The Audit Commission reports that 25 % of clinical time is spent handling information[2], yet also that clinicians often have to proceed with treatment without essential information[4].

This means that information, starting with clinical records and communications, should be treated with the same importance as other practice tools such as pharmaceuticals or developed clinical skills. At the same time, it must be recognised that introduction of information technology in this area has raised past tensions as to purpose and ethics[26], whilst the ability to accumulate, cross-link, analyse, and access large quantities of personal data raise new threats as well as benefits, but concerning which there is no forum for analysis, debate, or the setting of new shared basic principles.

Furthermore, information principles and policies need to be future-proofed, and independent of structural change. This can only be achieved by the sharing of a common vision, its underpinning by shared principles, and its implementation based on research and evidence. Indeed evidence based medicine cannot happen without information, so it is only logical for information policy itself to be evidence-based.

Warner has already emphasised the delusion of assuming that continued reorganisation will produce health services appropriate for the coming century, arguing that redesign matched to societal need is the only satisfactory approach[27]. A similar situation applies to information as one of the key resources of health care - neither incrementalism, automation of existing processes, nor centrally determined policies will be effective; instead a new visionary yet purposeful and collaborative approach is needed.

Together, these issues call for a much more objective, integrated, and research-based approach to the science and application of health information systems, including:

- a funded Research and Development programme
- support for academic units and institutions as repositories for knowledge and expertise in the field
- much enhanced interaction between new information opportunities and practice development
- a highly regarded independent forum to oversee research

developments, and to set key principles such as frameworks to balance new opportunities and related new risks to privacy

- a truly collaborative, needs-led and opportunity-influenced approach between Government departments responsible for health (across the UK), technology, and trade
- stimulation of a holistic approach linking the health professions and professional bodies at fundamental level
- recognition of the importance of ongoing evaluation and review as an essential part of the learning and development processes
- a fundamentally refocused, holistic move towards patient focused health informatics

In contrast to the tension and fragmentation of the United Kingdom situation, collaborative yet scientific approaches are under way in other countries. For instance in Canada a National Task Force on Health Information led to the establishment of the independent Canadian Institute for Health Information, and other national groups that have had a creative influence on creating the vision for an information infrastructure have been the Information Highway Advisory Council and the Prime Minister's National Forum on Health[28]. Meanwhile, in the Netherlands a recent initiative established a national concerted action on electronic patient records to support four fundamental research projects and five application projects, with a total multi-million pound equivalent funding, and a collaborative inter-relationship between the nine projects - some 140 parties responded to the first call for expressions of interest[29]. Denmark has established an Observatory, to monitor and record the local identification of and solutions to key issues in nationally funded EPR pilot sites, based on the fundamental understanding that developments should be research- and evidence-based in the local setting, rather than imposed or based solely on aspiration[30]. A four-nation global collaboration has emphasised the importance of looking at people and organisational factors as much as at the technical ones[31]. Set against these examples of impartial and evidence-based health information development, the British situation does not compare at all favourably.

CONCLUSION

All parties, from professional bodies and the NHS central organisations to individual health professionals, concur that information is pivotal to effective healthcare delivery and management. However, each uses a different language to relate to different visions and understandings. No-one has a leadership role, though many would claim rights to policy determination. Indeed, there is even strong underlying suspicion, which has an impeding effect[26]. There is fragmentation within the NHS and within government, and in general only limited partnership with the supplier industries.

Given the current situation, it is safe to predict that the NHS, its practitioners, and its patients, will be unnecessarily disadvantaged, whilst resources will be wasted. Hence the need for a new realisation of the fundamental role of information in health care delivery and management, which in turn needs common vision and a shared and trusting way of collaboration in moving forward. To achieve this needs a sea change from the current clash between central policy directives, isolationist initiatives, and the general culture of inertia.

Information needs to be recognised as a core resource, and the development of information systems as a key enabling task supporting all interests from clinical to managerial. The research-based visionary service redesign approach of Warner is called for in this domain, and is being created in other countries. Existing tensions are merely disadvantaging patients, wasting resources, and undermining the standing of information systems - thereby perpetuating a harmful 'Zone of Confusion'.

To achieve the vision, it is necessary to return to a realisation of the fundamental role of information in health care delivery, and then to create an impartial but influential forum whereby all stakeholders can meet and establish key principles, backed by levels of research and of developmental resources that recognise the benefits of strategic information solutions acceptable to all. And throughout this new vision, the patient must be at the centre, with evidence based health care, and information based integrated health care delivery, meeting their needs, and with information ethically derived from these processes illuminating the management processes. 'Achievable Vision' must replace 'Avoidable Confusion'.

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