

The Role of ISABEL and Clinical Decision Support Systems in the 21st Century NHS

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March 2004

RECOMMENDATIONS

1. The objectives for ISABEL must be more closely specified
2. ISABEL must be part of the NHS Quality programme.
3. An organisation in the NHS must be made responsible for Decision Support.
4. Service provision models should be investigated and an appropriate supply arrangement for ISABEL put in place.
5. A methodology for evaluating the performance of decision support systems should be developed.
6. The capabilities of Autonomy's pattern matching software should be researched further.
7. The potential of ISABEL as an educational tool and the implications of early adoption of technology during training and continuous education should be carefully analysed.

Abstract

The seemingly simple task of identifying options for promoting the wider use of ISABEL in the NHS has required a wide ranging study of ISABEL itself, clinical decision support systems in general and the issues surrounding the introduction of IT based innovations into the healthcare system. This is because the *functionality* of ISABEL can be tested in isolation but its *performance* is dictated by the *confidence* that its *users* have in it.

There are numerous issues that will have to be addressed if ISABEL is to be made widely available and the report has tried to identify them all. They range from the technical to the cultural. Practically though, the most important issue is establishing and retaining user's confidence in ISABEL. Confidence can be lost for a variety of reasons but the most likely is if ISABEL contained poor quality information. An equally difficult issue to resolve is that, in common with other ICT-based healthcare initiatives, the benefits to one set of stakeholders are achieved at a cost to another.

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1. Introduction to the Report and Study Methodology

In August 2002 Lord Hunt requested the Department of Health to "...examine [ISABEL's] potential effectiveness in the wider clinical context and to explore options for promoting its wider use in the NHS". A study was designed that covered a wide range of issues that would need to be researched and these are given in Appendix 1. The approach adopted by the authors was to commission two domain experts to prepare short reports addressing one or more of the evaluation questions listed in Appendix 1. Dr Jim Briggs, Department of Information Science and Computer Applications, University of Portsmouth undertook an evaluation of ISABEL usage and usability and Dr. Puay Tang, Science and Technology Policy Research (SPRU), University of Sussex commented on the more general issues surrounding its operation. Their full reports are appended.

In addition, Dr. Jeremy Wyatt was interviewed on the general subject of decision support systems. Mr. Robert Gann provided information on the development costs of an Internet based health information system, NHS Direct Online. The service it provides has been evaluated by the Centre for Healthcare Improvement (CHI) and the criteria they have applied are reported.

In preparing this report it became clear that ISABEL in particular and Clinical Decision Support Systems (CDSS) in general, do not exist in isolation but as part of a healthcare system. Their *functionality* can be measured in isolation but their *performance* can only be determined as part of a system. Furthermore, factors such as the culture of the organisation in which the CDSS is being used can affect its performance and its perceived *value* to the user.

So, in order to meet the objective of this study which is to provide information to support the Department in reaching a decision on how to take ISABEL forward we:

- Describe existing CDSS and compare them with ISABEL
- Discuss the drivers for the use of CDSS in the NHS
- Report the specific findings for ISABEL
- Discuss the barriers to the implementation of ISABEL (and other CDSS) and how they might be overcome
- Make general recommendations.

2. Description of CDSS and comparison with ISABEL

2.1 What is a Clinical Decision Support System?

Clinical Decision Support Systems (CDSS) are

"active knowledge systems which use two or more items of patient data to generate case-specific advice" (Wyatt, 1991)

CDSS are typically designed to integrate a medical knowledge base, patient data and an inference engine to generate case specific advice.

CDSS have been developed in an attempt to make available to clinicians, in time to influence decisions, small amounts of knowledge relevant to the patient and the current dilemma. They save the clinician from the need to formulate and carry out a search for medical knowledge and are usually able not only to provide, but also explain, advice. (Wyatt, 2001)

Systems have been developed using many different techniques for representing medical knowledge, each of which is associated with an appropriate reasoning method. The different approaches, listed below, vary in the extent to which the knowledge is derived by the system from data or explicitly represented by the knowledge base author.

- Bayesian model (causal probabilistic network)
- Prognostic rule or model
- Neural Network
- Reminding or alerting system (guideline-based system)
- Knowledge based system (expert system)

(Wyatt, 2001)

Among the most common forms of support systems are drug-dosing calculators, computer-based programs that calculate appropriate doses of medications after clinicians input key data (e.g. patient weight, indication for drug, serum creatinine). These calculators are especially useful in managing the administration of medications with a narrow therapeutic index. Other systems, both simple and complex, may be integrated into the point-of-care and provide accessible reminders to clinicians regarding appropriate management based on previously entered data.

The output of the CDSS is a combination of the adequacy of the CDSS knowledge base, its inference engine, how the user interacts with the system and the specific data that is entered. Therefore the user can affect the performance of the CDSS.

2.2 What is ISABEL?

ISABEL is an online clinical decision support system for healthcare professionals, initially covering the whole spectrum of paediatrics, but with a full adult version scheduled for release in 2004. ISABEL is a diagnostic system, which acts as a safety net, or reminder system for clinicians prompting them to consider relevant probable diagnoses. It uses powerful pattern recognition software donated by a specialist company to interrogate text supplied by a medical publishing company.

ISABEL has taken three years to develop and since it was made available has attracted registration by approximately 15,000 healthcare professionals in UK. However, not all users have to register to make use of the ISABEL site: there is an automatic login for anyone accessing ISABEL from an NHS address or from an academic institution and therefore, the actual number of users (as estimated by the ISABEL team) is close to up to 25,000. (Britto, 2004)

The concept behind ISABEL is that by equipping clinicians at DGH's with a sophisticated decision support tool, clinical decision making could be enhanced and delays in starting the correct treatment will be avoided which in turn will reduce the need for patient transfers to specialist centres.

In the current model of healthcare delivery within the NHS, care is provided in the form of an inverted pyramid of knowledge. Clinical wisdom and knowledge are concentrated at the top among senior staff, in many cases distant from the patient who is first seen by a junior doctor at the bottom of the pyramid (Fisher et al, 2003). It has long been acknowledged that this is the "wrong way round" and at their first encounter patients should be seen by people most able to make decisions about their treatment. Organisationally it is difficult to do this, though. It is hoped that ISABEL would make an important contribution in redistributing knowledge across the NHS and 'reshaping' the pyramid.

However there is still an important assumption behind the design and operation of ISABEL and that is that a "knowledgeable intermediary" will use it and be responsible for acting on its advice.

2.3 Evidence for the Effectiveness of CDSS

The majority of the systematic reviews portray clinical decision support systems in a positive light. A seminal systematic review of computer-based decision support systems, for example, found that 43 of the 65 investigated studies showed at least some benefit in either the process of care or patient outcomes. (Trowbridge, 2000). It will be important to be able to evaluate the benefits of ISABEL (and other CDSS) over time. There is a need for an agreed methodology to do this.

From the results and analysis presented in Section 4, which includes the results of user surveys and a system performance evaluation, it can be seen that ISABEL has proved to be a useful tool for health professionals

2.4 Comparison of ISABEL with other CDSS

The following table describes some of the other CDSS in use in the NHS at the moment and allows a comparison to be made to ISABEL.

Name	Description	Size of database	Ranked list
Dxplain	Uses a set of clinical findings (signs, symptoms, laboratory data) to produce a ranked list of diagnoses which might explain (or be associated with) the clinical manifestations. DXplain provides justification for why each of these diseases might be considered, it suggests what further clinical information would be useful to collect for each disease, and lists what clinical manifestations, if any, would be unusual or atypical for each of the specific diseases. DXplain also provides appropriate reference material for each specific disease. DXplain is owned by Massachusetts General Hospital and access is provided only after executing a license with MGH. Access is limited to hospitals, medical organizations, and medical schools. (http://www.lcs.mgh.harvard.edu/). Uses non-Bayesian algorithms	Database contains the basic probabilities of over 5,000 clinical manifestations associated with over 2,000 different diseases.	Yes
Diagnosis Pro	By entering findings such as signs, symptoms, lab values, X-ray or EKG results, DiagnosisPro generates a hierarchical list of diseases. The system provides a detailed review of each disease, including clinical presentations, abnormal lab values, rule-outs, complications, treatments. DiagnosisPro can be installed on stand-alone Windows computers, most network servers and handheld Windows CE/Pocket PC devices. (http://www.firstsoftware.com/diagnosis_pro.htm)	Database of 10,000 diseases, 20,000 findings and 250,000 relationships.	Yes
Iliad	Medical expert software that provides expert diagnostic consultations and patient simulations. Library of approximately 1,400 photos including dermatology, radiology, cutaneous manifestations of diseases and photo microscopy. Fields include Pediatrics, Internal Medicine, Oncology, Infectious Diseases, Gynaecology. Uses Bayesian logic in formulating a differential diagnosis	> 930 diseases; 1500 syndromes. provides treatment protocols for each. 13,900 disease manifestations	Yes
Quick Medical Reference (QMR)	QMR is a diagnostic decision-support system with a knowledge base of diseases, diagnoses, findings, disease associations and lab information. The user enters clinical findings describing the patient's case which are used by the system to create hypotheses. Database undergoes constant revision and expansion. Uses non-Bayesian algorithms.	c. 700 diseases and more than 5,000 symptoms, signs, etc.	Yes.
ISABEL	ISABEL comprises a differential diagnostic tool, treatment algorithms, APLS guidelines, an image library and experience section. ISABEL also includes treatment algorithms. It provides peer-reviewed national and internationally approved treatment plans in an algorithmic format. Also contains an image section. ISABEL is specifically a paediatric system. (www.isabel.org.uk)	3,500 disease descriptions	No. It acts more as a reminder of potential diagnoses.

2.5 Other types of Decision Support Systems

The application of Decision Support Systems is not limited to the process of diagnosis. Various healthcare activities from primary care to specialist surgery can be supported by the use of a diversity of quantitative or qualitative DSS applications. The need for systems that support decision making on resource allocation is one of the main issues driving the creation of such systems.

The most notable example in the primary care area is PRODIGY, the result of a collaboration between the Sowerby Centre for Health Informatics at Newcastle (SCHIN), the Department of Health and the suppliers of clinical computing software to general practice. In summary, PRODIGY is a computer-based decision support system for General Practice, offering a series of up-to-date evidence-based recommendations for the management of a condition. One of the most interesting features of PRODIGY is that it integrates with the electronic patient record (EPR), so the advice that is offered is specific to the patient. Used during the consultation, the GP enters a diagnosis or problem, in response to which PRODIGY can suggest a range of management options including prescribing and non-drug advice, doctor/patient shared screens, patient information leaflets or referral advice (www.prodigy.nhs.uk).

Some other decision support systems have been developed to support surgeons when deciding on the likelihood of success of a surgical procedure. Such tools aim to support surgeons' decisions by calculating the risk of complications or mortality associated with surgery. The results are based on the patient's specific circumstances. The Dendrite Clinical System, for example, is a computer program capable of giving predictions of individual patients' chances of surviving heart surgery. It gives an overall risk of death and also predicts details such as the amount of blood likely to be needed for transfusion, the length of stay in intensive care and likely post-operative complications. (It is already being used in more than 30 heart surgery centres). This type of technology has been endorsed by the Association of Surgeons of Great Britain and Ireland, but it is considered to be a back-up for a decision that *has already been reached on the basis of clinical judgement*.

Other systems such as POSSUM (Physiological and Operative Severity Score for the enumeration of Mortality and Morbidity) focus on the need for an accurate measure of surgical outcomes so that hospital and surgeons can be compared properly. The system, developed by Portsmouth University, uses a physiological score and an operative severity score to calculate risks of mortality and morbidity.

Other tools have been created to exclusively facilitate the access of health professionals to up-to-date evidence based information.

As an example, Best BETS (Best Evidence Topics), provides access to the best current evidence on advanced clinical topics to provide answers to real-life clinical questions. It was developed on the premise of outdated textbooks

and the need to perform literature reviews during a consultation. BETs, an online tool, was developed in the Emergency Department of Manchester Royal Infirmary. BETs uses a systematic approach to reviewing the literature and relies on the users publishing 'BETS' of their own (www.bestbets.org).

The use of Decision Support Systems within the healthcare sector is not necessarily restricted to health professionals. Recently, the concept of shared decision-making and patient choice have attracted much attention in the UK, and various types of DSS have a potential role in the pursuit of these activities. Work conducted at Harvard Medical School and the Foundation for Informed Medical Decision Making, led by Professor Albert Mulley, has shown that the use of tools that support clinicians and patients in their decision-making roles, decrease utilisation of high cost medical and surgical interventions while improving measures of decision quality.

3. Drivers for the use of CDSS in the NHS

Currently the NHS is undergoing a massive programme of modernisation to create a service fit for the 21st Century. A cornerstone of this modernisation is the use of ICT to deliver services. Developments like ISABEL support the vision of the National Programme for Information Technology (NPfIT) which is to provide "The right information in the right place whenever health decisions are made and acted on".

A lack of information contributes to errors being made. Mostly these errors go unnoticed or cause only non life-threatening problems (such as bed-blocking) but some have disastrous consequences that can also result in costly litigation. Most of these situations are avoidable and there is a considerable literature around avoidable errors (AE).

The culture of the organisation also has a bearing on how one learns from errors. More open organisations acknowledge that staff will inevitably make errors, but use this as a "teaching and learning" moment and a way of improving practice. This is what is envisioned for the NHS in the document "Organisation with a Memory" (Department of Health, 2000) and in the NHS Quality Programme. (NHSE, 1999). The rest of this section discusses how ISABEL, and CDSS in general, can make a contribution to meeting both of these agendas.

3.1 Medical errors in the UK

Medical error has been the subject of major pieces of academic research in Australia and the USA, but work in the UK is in its infancy. The best research-based estimates suggest that in NHS hospitals alone, adverse events in which harm is caused to patients:

- occur in around 10% of admissions - or at a rate in excess of 850,000 a year;

- cost the service an estimated £2 billion a year in additional hospital stays alone, without taking any account of human or wider economic costs. (reference)

According to the NHS Executive, currently, NHS reporting and information systems provide only a patchy and incomplete picture of the scale and nature of the problem of serious failures in health care.

The increasing trend towards litigation and the blame culture in the UK has led to comparisons with the USA where the practice of defensive medicine is the norm. There is a highly adversarial climate, with rising settlement costs and doctors' insurance premiums becoming unaffordable, especially in obstetrics and gynaecology (Department of Health, 2003).

The National Audit Office accounts for 2001/2 predict that the NHS faces a total bill of £5.25bn for clinical negligence claims, if all known and anticipated claims are settled. This is a rise of £850 million in 1 year. Five years ago the figure was £2.3bn. Last year the NHS paid out £4.46bn towards clinical negligence claims. This is a significant rise of £31 million, since 2001 (MPS, in Scott, 2003). There are many reasons for this rise. The 'blame culture' continues unabated and the public have become increasingly educated and demanding, prompted by media reporting.

On average, claims took more than five years to settle and in almost half the cases the legal costs exceeded the actual damages paid. This figure increases to two thirds where the settlement was £50,000 or less. There are 23,000 claims outstanding as of March 2003 (NAO,2003)

An accurate assessment of the total bill for claims related to adverse events is complex and has been debated intensely. However, it is very clear that the likelihood of a decrease in the number of claims is low. This means that the implementation of *any* tool that can contribute to prevention and detection of avoidable errors and provide the capability to learn from avoidable errors can potentially have a major financial impact. For instance, the reduction in litigation costs could go some way to offsetting its development costs.

3.2 The role for ISABEL in Avoidable Errors (A.E.)

As has been stated above, patients are the recipients of a number of interventions in each of which an error can be made. The severity of the consequences of such errors is variable, and can occur anywhere throughout the healthcare process (e.g. errors can occur in the primary or secondary sector, and during diagnosis or surgery etc) This feature makes the detection and therefore the prevention of errors in healthcare extremely complex.

ISABEL supports diagnosis and as the following table shows there are different types of diagnostic errors:

Types of diagnostic error	
No-fault errors	Illness, silent, masked, atypical
System errors	Organisational and technical failures
Cognitive errors	Inadequate knowledge, faulty data gathering, inaccurate clinical reasoning, faulty verification

Graber et al, 2002 as quoted by Vincent (2003)

Of the three areas of diagnostic error, ISABEL can address “cognitive errors” as shown in Figure 1.

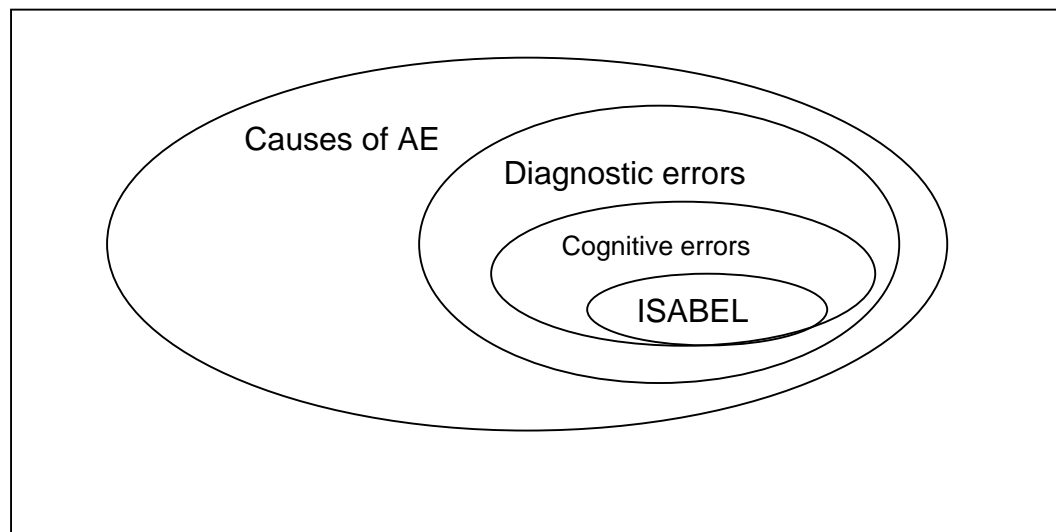


Figure 1. Where can ISABEL make a difference?

The figures for AEs provided above are from all sources including the results of the three types of diagnostic error contained in the table. Because of the nature of ISABEL, as a supportive tool for the diagnostic process, its potential impact is concentrated mainly on cognitive errors. It is impossible to say what fraction of the total number of AEs occurring in the NHS are due to cognitive errors. However, even if ISABEL only has an effect on a tiny fraction of the NHS litigation bill for AEs, that is still likely to represent a large sum of money.

However, if widely available and used (as discussed in subsequent sections), ISABEL could have an indirect effect on the second category (system errors) creating even greater savings from the NHS litigation bill.

3.3 Clinical Decision Support Systems and the NHS Quality Programme

In recent years, the pursuit of service quality has been one of the main drivers for NHS modernisation. Achieving quality in the NHS is now being seen as a priority and several policy documents have focused directly or indirectly on the strategies required to transform the existing service into a ‘quality one’. The NHS Quality Programme creates a framework for this activity.

In this section we will discuss some of the underpinning principles of the NHS Quality Programme and how information, knowledge management and information technology are critical in achieving the objectives of the programme – as highlighted in *Building a Safer NHS for Patients* (2001). Many avoidable shortcomings in the health sector that result in poor quality are due to inaccessible data, information and knowledge and poor co-ordination (Scott, 2003).

The potential role of Clinical Decision Support Systems in the development of quality in the NHS will be described.

3.3.1 Quality in the NHS

The NHS Quality Programme is built upon several principles, including the following:

- Accountability for service quality in every NHS organisation through clinical governance.
- Effective systems of adverse event recognition and analysis and subsequent effective learning and risk management to enhance patient safety (*An Organisation With a Memory*, National Patient Safety Agency).
- Strong mechanisms to spread and learn from research evidence (NHS Modernisation Agency - Service improvement)

Figure 2, illustrates the overall Quality Framework and how the roles of the various initiatives and agencies contribute.

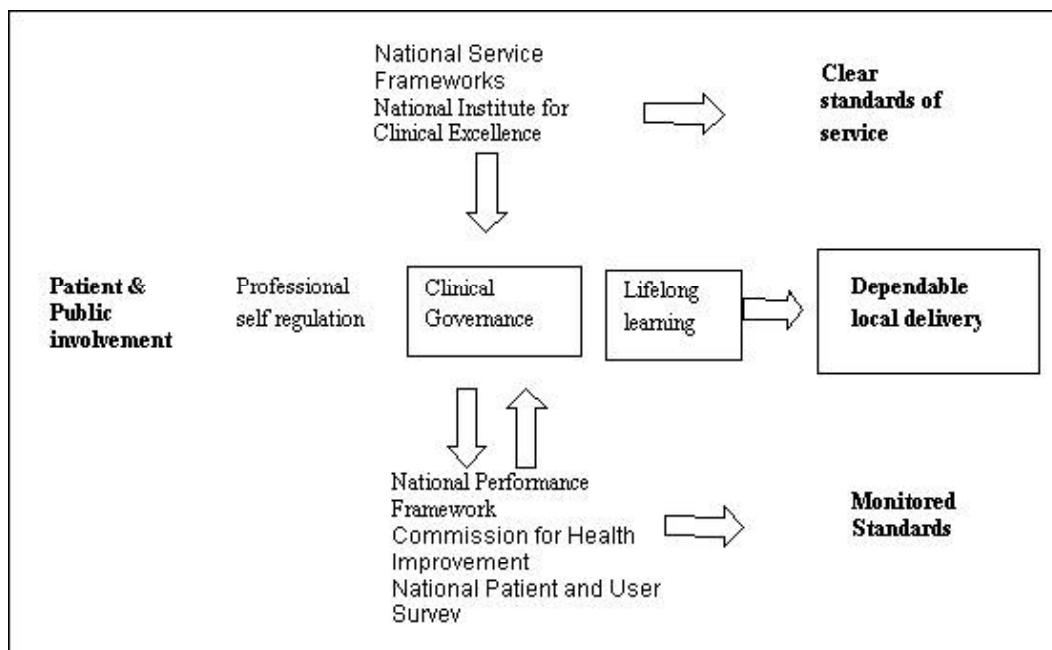


Figure 2. The Quality Framework (From Fisher et al, 2003)

Clinical Governance

Over time, local NHS organisations will need to ensure that their clinical governance plans are underpinned by comprehensive information on quality. Present NHS information systems are not of an adequate standard to meet these needs for information on quality. Amongst other strategies, it has been suggested that computer based information systems should be encouraged as part of the infrastructure of local clinical governance.

A crucial element of clinical governance, and indeed of any good quality improvement system, is the ability to detect, analyse and learn from relevant experiences, including adverse events and service failures. It is important to ensure that where adverse events do happen the lessons are learned and put into practice to help prevent recurrence. That brings us to our following point.

Adverse event recognition and risk management

The culture of the NHS still errs too much towards a blame culture that can encourage people to cover up error for fear of retribution. The existing focus on individual actions can conceal the true causes of failure which in many cases are rather the result of system-related features.

There has been much debate about the way other industries have managed to implement safe systems in which error is neither tolerated nor unreported. The experience of these sectors provide valuable lessons to the NHS for the following reasons:

- Organisational culture is central to every stage of the learning process - from ensuring that incidents are identified and reported through to embedding the necessary changes deeply into practice.

- The value of systematic approaches to recording and reporting adverse events and the merits of quarrying information on ‘near misses’ as well as events which actually result in harm has been identified. (reference)

The NHS does not compare well with best practice in either of these areas.

Methods that have been effective at reducing error rates in other industries and appear applicable to medicine include (Bates and Gawande, 2000):

- Simplifying
- Standardising
- Reducing unnecessary reliance on memory
- Implementing forcing functions (reengineering a process to prevent a specific error, such as requiring a foot on the brake pedal to put a car in reverse)
- Improving information access

Research evidence

In 1999, the NHS Executive highlighted the fact that health professionals need knowledge from research to support their clinical decisions with the following statement:

(Knowledge) must be (...) tailored to the needs of health professionals taking clinical decisions. This means focusing on the means by which evidence is made accessible and equipping staff with the skills to know how to evaluate and apply it in individual clinical situations. (NHSE, 1999)

The NHS Research and Development Programme ensures that relevant primary research is carried out to generate new knowledge. A comprehensive and sound R&D programme that produces a constant knowledge flow is considered to be the first building block in evidence-based clinical decision making.

Evidence must be easily available to clinicians and its use encouraged to support high quality clinical decision-making. There needs to be a systematic approach to the collection and dissemination of evidence, within an organisation, to ensure that clinicians are able to access the most up-to-date information deriving from research.

3.3.2 Quality Improvement Systems and CDSS

Various organisations outside the NHS have demonstrated that quality can be substantially improved if appropriate IT use is increased. Computerisation of processes that are error-prone and computerised decision support systems, may substantially improve both efficiency and quality, as well as dramatically *facilitate quality measurement* (Bates, 2002).

ISABEL, and CDSS in general, can contribute to the Quality programme by supporting clinical governance strategies, continuous education (including learning lessons from near-misses and actual errors) and ultimately, the

optimisation of local delivery. These three areas are the ones shown outlined in Figure 2.

4. Evaluation of ISABEL

A summary of the results of the evaluation of ISABEL carried out by University of Portsmouth and their implications for the development of ISABEL is reported in this section.

4.1 Technology and Operation

The software underpinning ISABEL is supplied by Autonomy, a large US company (www.autonomy.com). Essentially the system is in two parts, a database and a search tool based on pattern recognition. Firstly, medical text is entered into the database and then in operation this text is searched for matches with the clinician's typed input describing the patient's symptoms. Matches are identified and a list of up to 15 possible diagnoses is presented. There is no attempt to rank these diagnoses in terms of likelihood.

This pattern matching technique is claimed to be much more powerful method of searching databases. Other searchable databases require data entries to be identified with a simple code or "tag" and in operation the search engine seeks matches between the input data and the tags. Pattern recognition removes this step in the process. However, operational details on the search tool are limited as they are commercially confidential.

At the same time as providing likely diagnoses, ISABEL provides other decision support to the clinician by making available text, annotated images, and practice guidelines specific to each diagnosis. A section entitled "experience" attempts to capture and highlight common clinical lessons learnt at various steps within the guidelines and at relevant points in the diagnostic process.

The user's access to ISABEL is via a website (www.isabel.org.uk). The website itself exhibits some good properties: there is little evidence of broken links or changing structure. Most output is dynamically generated using Java Server Pages. Portsmouth University's criticism of the site is its use of frames. Most web page experts deprecate frames, and their adoption on this site made some of their analysis of its usage (e.g. how users proceed through the site) impossible.

4.2 Usage and Usability

Usage and usability was determined from a study of the web logs and through a questionnaire sent by e-mail to the 4436 UK-based registered users of ISABEL. 518 replies were received (11.7%) that were completed sufficiently for analysis.

4.2.1 Summary of the web survey

The web survey shows that the ISABEL website is used by a core of regular users, 50 or so of whom use it on average once a week, another 150 who use it every 2 to 3 weeks and a further 600 or so who have used it more than a handful of times. However, 90% of its registered users have used it 5 or fewer times, and 46% of its users only once.

This suggests strongly that there is a small community of devotees, including those who are involved in the development of the site, but that the website is either not sufficiently useful or not sufficiently convenient for the vast majority of users who have tried it out. Patterns of usage show that it is most used during the normal working day, with reduced usage out of normal hours and at weekends.

Most usage (where identifiable) is from the UK, with at least a quarter of accesses coming from somewhere within the NHS, but there is also a significant amount of access via Internet service providers. Detailed breakdown of where in the NHS access is coming from is frustrated by the anonymisation of sources by the NHSnet to Internet gateways.

4.2.2 Summary of the user survey

The survey achieved an 11% response rate from those to whom it was sent, but, it is suspected that this includes a very high proportion of the regular users of ISABEL. 58% of respondents were paediatric specialists, but the fact that 42% were not, indicates that people in a wide variety of health service roles use ISABEL. Around 90% of users are doctors of one grade or another, with over half of the paediatric specialist doctors being consultants.

As one might expect, paediatric specialists use ISABEL slightly more frequently than non-specialists, but very few people use it more often than weekly. Three-quarters say they would use it more but for time constraints and lack of access to information technology. For those who would not use ISABEL more often, the main reason is that they use ISABEL as much as they require. However, one-third of paediatric consultants and one-fifth of General Practitioners say ISABEL is unsatisfactory in its present form and improvements are needed.

Half the respondents use ISABEL "in some cases", with one-third of respondents only using ISABEL in difficult cases. Only about 2% use ISABEL in all cases presented. The aspects of ISABEL that are particularly liked are the differential diagnostic tool and the guidelines, and approximately two-thirds are of the opinion that ISABEL assists in clinical management. Half of respondents found ISABEL easy to use most of the time, with one-quarter finding it always easy to use. Over 80% of respondents said that they do not share registration and password information.

Access to computers is slightly easier for the non-paediatric respondents and if there are computer problems, these are fixed sooner. However, the paediatric respondents have a slightly higher access to the Internet. Only 18% of paediatric staff, but 56% of non-specialists, have a computer next to or in the same room as the patient.

4.2.3 Overall conclusions on Usage and Usability

It is clear from both the web survey and the questionnaire results that ISABEL has a small number of very devoted users, who think very highly of it. The site is effortless to navigate, and lends itself well to the medical practitioner who may not be very knowledgeable about computer and Internet language. However, only 2% of users claimed to use it in every case. Nevertheless, it obviously has an important role in allowing both specialists and non-specialists to confirm or assist the diagnosis in a minority of cases.

Much of the analysis distinguished between paediatric specialists and non-specialists. It is interesting to note from the user survey that nearly one in four respondents works in the primary care sector, indicating that ISABEL is not just a tool for secondary care specialists. It is also not solely a tool for doctors – approximately 10% of users are nurses or therapists.

The web survey showed that only about a quarter of accesses apparently came from within NHSnet, yet the user survey revealed that 94% of paediatric specialists and 92% of other healthcare professionals use ISABEL in their normal workplace. Some professional access could be made via academic networks (the .ac.uk domain), and overseas users would of course not use NHSnet, but there is a significant disparity between these two statistics. Resolving it is difficult without a detailed analysis of every Internet address that has accessed ISABEL, and there have been over 4,000 of them.

It can be concluded that accesses come from a very wide variety of Internet sources, and that those from within the NHS form the majority of those identified. Since at least another quarter of accesses come via Internet Service Providers, Portsmouth's hypothesis is that either user survey respondents actually use ISABEL at home much more than they admit, or, more likely, that many workplace accesses are in fact made via ISPs rather than NHSnet. If the latter is the case, it may signify that many hospitals have not provided their staff with full Internet access, and that other arrangements (whether institutional or private is not known) are being made to achieve this.

An interesting result from the user survey is that not all users wish to use ISABEL more. There is a clear indication that many users feel they do not need to use it in all, or even most, cases. Instead, they use ISABEL occasionally, and feel some security in having it available to back up their judgement.

4.3 Effectiveness

The performance of the system has been evaluated in at least two occasions. During an initial system performance evaluation, ISABEL presented 'clinically accurate' diagnostic reminders more than 90% of the time. A further simulated assessment of the tool's impact indicated that doctors significantly positively modify their diagnostic and management plans in 1 out of every 8 episodes of usage (12.5%) when prompted by ISABEL. The latest multi-centre clinical study assessed the real life impact of the usage of the ISABEL system by junior paediatricians at 4 NHS hospitals and showed that ISABEL reminded the doctor about a 'significant' diagnosis (as judged by an expert panel) in 1 out of 7 times (13.5%) (Ramnarayan and Fisher et al, 2003, Ramnarayan, et al 2003).

4.4 Usefulness as an Education Tool

The survey has shown that ISABEL is not only seen as a useful diagnostic tool, or as a means of checking diagnoses but also as a useful educational tool.

ISABEL's direct educational value falls into two categories. Firstly it is a steadily growing repository of knowledge in the field based on actual experience. Secondly, it is available at "the learning moment". In other words it is available when the practitioner realises that he or she has a gap in their knowledge. In this respect it is superior to other educational tools which do not have that immediacy.

ISABEL also has an indirect educational value. Student contact with ISABEL would help to eliminate the barriers that the introduction of technology in healthcare practice faces nowadays. The use of decision support early on during the students' professional development would be key to ensuring it becomes part of their future working practice.

4.5 Professionals' access to ISABEL

ISABEL's current success relies heavily on health professionals having appropriate IT skills, continuous access to computers and an internet connection. Only just over half of paediatric consultants have access to their own computer, while the rest (and nearly 90% of those below consultant grade) have to share, often with large numbers of people. The user survey shows that 97% of respondents use computers at least several times a day, however an average of 3.29 people share each computer, so one imagines that there must be *some* queuing going on, or opportunities lost because a computer is not available at the right time.

Where the computers are sited is also important. Among paediatric specialists, only 3% have a computer next to the patient and a further 15% have one in the same room. This compares unfavourably with figures of 41%

and 16% among non-specialists (most of whom are GPs). This reveals a glaring difference in technology availability between the secondary and primary care sectors. A few respondents explicitly mentioned wireless networking as a means to resolve this issue in hospitals.

Accordingly, the ISABEL team have been investigating the use of Personal Digital Assistants (PDAs) as a means of accessing ISABEL over wireless networks¹ at three NHS hospitals. The results of the analysis of usage showed a 530% increase in the total number of logins after handheld computers were provided. (Paget and Britto 2003)

An additional factor affecting availability has been highlighted by the current trials. ISABEL is a web-based service so it relies on the Internet for delivery. It is well known that Internet delivery speeds can be quite variable depending on traffic volumes. Using the Internet in the afternoons in UK is always slower because of the traffic generated by users in the US. There has also been one notable instance in the UK when so much traffic was artificially generated that this caused the Internet to be effectively unavailable.

4.6 Discussion of Survey Results

Currently, the ISABEL paediatric decision support service is available on a website on the internet that registered users can visit. Usage is actually quite low. The objective is for usage to grow with the number and complexity of site visits increasing. The survey has highlighted a number of important points from a users perspective that will need to be considered if ISABEL is to develop further. These can be summarised as:

- Access to ISABEL (which would be restricted by lack of IT skills, lack of access to computers, computer faults, lack of support on computer operating problems and lack of Internet connection)
- Availability of the service (which would be restricted by telecommunications faults, no Internet availability, lack of capacity, computer viruses and external hacking)

Three other results from the survey have implications for any further development. These points, and their associated questions are listed below:

1. A significant minority of paediatric consultants and GPs say ISABEL needs modification. So, what exactly are the primary care users' requirements? And what additional features (or modifications) are required by paediatricians for whom ISABEL was designed?
2. ISABEL is used as a teaching resource and it provides real cases for problem-based learning. Then, how should the educational potential of ISABEL be better exploited and managed?

¹ A PDA version of ISABEL can be found at www.isabel.org.uk/pda. Several other hospitals have experimented with PDAs and tablet computers and further information on the work at St. George's Hospital is available at www.sghms.ac.uk/depts/is/pda/pdaresources.htm

3. Only a very small number of people use ISABEL all the time. What exactly are the reasons for the low individual usage?

Three potential reasons have been suggested to account for question 3. a) ISABEL diagnoses seldom differ from the user's, b) the user mistrusts the information on which ISABEL is based or c) the culture of the NHS militates against the use of ISABEL. These three issues affect the implementation and use of all Decision Support Systems not just ISABEL, and are discussed in the next section.

It is interesting to note that issues of security and reliability were largely not mentioned in the survey. One reason for this could be that, as several authors have pointed out, the larger challenge lies in designing convenient, efficient and acceptable interfaces between the clinician and computer for data input and presentation.

5. The wider context for ISABEL and CDSS

In this section we pull together all the ideas developed in previous sections to identify the key issues surrounding the implementation of ISABEL and suggest some options for proceeding.

5.1 Confidence in ISABEL

In the previous section we reported the results of the user survey which highlighted some of the (mainly technical) barriers clinicians could encounter in using ISABEL. However, the survey also revealed a number of systemic issues that could affect usage. These can be restated as usefulness, quality and culture. All of these technical and systemic issues will affect the performance of ISABEL (and of any other CDSS). If the *performance* is poor there will be a resulting loss of *confidence* by users in the decision support system. How confidence can be lost can be illustrated with the following example on information liability taken from Dr. Tang's report:

"This is about a German case, which involves a medical book in which a decimal point was missing from a drug dosage. Instead of prescribing a 2.5 per cent sodium chloride (NaCl) infusion, the text read a "25 per cent NaCl infusion." The insurance company of the victim of the incorrect dosage who nearly died sued the book publisher. The hospital paid compensation to the patient, but in turn sued the publisher for partial compensation. The court ruled that a book can never be completely absent of misprints, although the publisher is expected to exert extreme care in the production of the book and undertake due diligence before publication. On the other hand, the court found that in this case, the medical professional should also have used his judgement and knowledge and therefore should have picked up the misprint. The court rejected the hospital's claim."

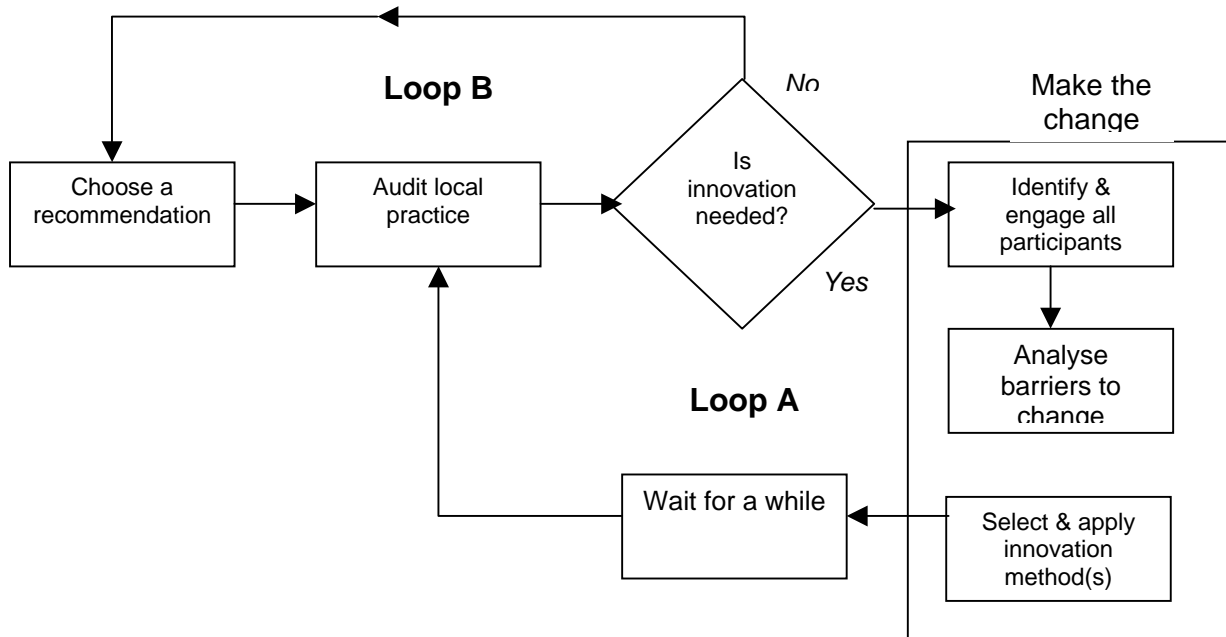
If the text book had been part of ISABEL's database then such an incident would dent confidence in ISABEL which could in turn reduce usage. This could come about because of a failure in the search routine, because the medical text was incorrect or had not been updated to reflect current medical

thinking or because the correct text had been incorrectly entered. The bigger the service grows the greater could be the loss of confidence if something like this occurs.

The *performance* of ISABEL (or any other CDSS) is determined by the *confidence* the users have in it. In the next part of this section we will identify the users in the widest sense by analysing the introduction of an innovation such as CDSS into the complex healthcare system.

5.2 The Users of ISABEL

Much has been written about the process of introducing innovation into a complex environment in such a way that it is sustainable (May et al, 2002). We reproduce below a diagram developed by Jeremy Wyatt to demonstrate the process of new technology introduction. Wyatt suggests that local agreement should be sought for the innovation process and he emphasises the importance of the analysis of individual and organisational barriers to change.



The key task in making the change is to identify the stakeholders (or users) to the process and to describe the benefits it will bring them and the difficulties they might encounter realising those benefits. For ISABEL, and CDSS, in general this is set out in the table below:

Stakeholder	Benefits	Difficulties
Patient and Relatives	<ol style="list-style-type: none"> 1. Reassurance that proposed treatment is optimal 2. Involvement in the care process 3. Knowledge that following an adverse outcome lessons will be learnt 	<ol style="list-style-type: none"> 1. Understanding new ways of working. 2. Changing attitudes towards healthcare professionals' knowledge.
Junior Clinician	<ol style="list-style-type: none"> 1. Availability of support in absence of senior staff 2. Teaching and learning moment 	<ol style="list-style-type: none"> 1. Decision support service not available quickly or easily 2. Information not current
Senior Clinician	<ol style="list-style-type: none"> 1. Confirmation of diagnosis in complex cases 	<ol style="list-style-type: none"> 1. Decision support service not available quickly or easily 2. Information not current 3. Willingness to embrace new technology
Service	<ol style="list-style-type: none"> 1. Audit trail for individual treatments 2. Automatic skilling and reskilling of clinical workforce 3. Use of best practice and minimisation of avoidable errors <p>Minimisation of litigation costs</p>	<ol style="list-style-type: none"> 1. Loss of confidence in system by users 2. Decision support service not used

From an analysis of the stakeholder benefits it is clear that patients and their relatives and the service as a whole have much to gain from the implementation of decision support systems as the advantages outweigh the disadvantages. However, for clinicians themselves the benefits of decision support are much more finely balanced. But if clinicians do not use clinical decision support systems then the other two stakeholders will not realise the benefits that they can see. Clinicians will have to see a value in using the service and the simplest way is to make the service easy to use, readily available and up to date.

One of the major disincentives to using the system is that of entering consultation data. If this could be automated then this barrier could be overcome. Some of the data comes from electronic patient records, laboratory results and formularies. The output of these would need to be compatible with the decision support system so that they could feed straight into it. Then the decision support activity could be activated with the minimum of key strokes or commands. Whilst technically possible this may take some time to achieve so an interim solution must be found.

Another value of ISABEL or clinical decision support systems to clinicians could be the "teaching and learning moment". This is when an individual identifies a gap in their own knowledge. The value of ISABEL is that they then have immediate access to knowledge to fill that gap. Ordinarily, it is very

difficult to engineer a situation where identified knowledge gaps can be filled as they reveal themselves. It has been suggested that use of ISABEL or any other appropriate clinical support system could attract CME points if it was being used in this way or to pass on experience.

A further value that might be perceived by clinicians is that in using ISABEL or some other decision support tool, they are creating an audit trail that can be used to demonstrate that they were working to best practice. In the unlikely event that a clinician's decisions were questioned this audit trail would serve as evidence but there would have to be mechanisms in place to ensure that it could not be retrospectively adjusted.

5.3 Options for the Implementation of ISABEL

To summarise, the four issues for ISABEL (and other CDSS) that must be addressed in any implementation are:

- what is the scope of the service
- what is the best way to provide the service
- how can the service be kept current
- what will make the service widely used

5.3.1 Scope

Currently ISABEL is aimed at hospital doctors but clearly there is a demand from GPs for decision support. As with every IT project, ISABEL would have the best chance of success if the scale and scope were clear and adhered to. A clear specification would also help in making decisions on the following three issues.

5.3.2 Service Provision

The non-availability of the service can have a big impact on user confidence. The way ISABEL is provided at the moment many of the features that could contribute to non-availability are outside its control. If the NHS provided the service on its own infrastructure the technical factors affecting non-availability would be within its control. This would have the effect of restricting university use and stop overseas use of ISABEL. Alternatively, the NHS could procure the service from a third party who would guarantee a certain level of availability.

ISABEL is currently provided by a mixture of third party providers; the ISABEL charity, Elsevier, Autonomy, the website designer and BT. Both Elsevier and Autonomy seem content to allow their products to be used during the development phase but in the future the commercial situation must be regularised both to reward firms for the use of their IPR and to ensure that liability is clear. In the case of the Autonomy software a user licence will have to be negotiated (perhaps on the basis of the number of searches requested) as is the case with other proprietary software

5.3.3 Keeping the Service Current

The biggest impact on user confidence and on performance would be through poor quality of information. If the NHS provided the service then it would have to ensure quality and especially in the updating of information. The NHS is putting the mechanisms in place to do this through organisations such as CHI.

In the past year CHI has reviewed another web-based service, NHS Direct Online. Initially there was some doubt as to whether CHI's evaluation criteria could be applied but the exercise was successful pointing out ways in which the service could be improved. CHI's clinical governance reviews set out to answer three questions:

- what is it like to be a patient/service user?
- how good are the systems for safeguarding and improving quality of care?
- what is the capacity in the organisation for improving the patient/service user's experience?

These questions are equally relevant to a decision support system. NHS Direct Online is the responsibility of one organisation and it would seem sensible that decision support would be identified as a particular responsibility, perhaps that of the National Electronic Library for Health.

Alternatively, if the NHS procured the service from a third party such as a company with the correct mix of technical and clinical skills to provide the service, it could set quality goals and use its quality framework to enforce them.

5.3.4 Widescale Usage

It is clear from the stakeholder analysis that the maximum benefit to the Health Service of ISABEL (and of clinical decision support in general) occurs when it is widely used. There is little use of clinical decision support now and the user survey shows that when ISABEL is made available very few people use it all the time. The cultural issue behind this will have to be addressed if the implementation of ISABEL is to achieve its full potential. This situation is repeated where other innovations have been introduced into healthcare. As we mentioned before, it has been suggested that greater use of decision support tools in medical and nursing education would contribute to changing the culture.

6. Report Summary and Recommendations

This study shows that ISABEL is providing a service to clinicians, can contribute to the NHS Quality programme and that it has the potential to improve outcomes for patients. As it stands, though, ISABEL is not robust. It could be subject to loss of user confidence due to a variety of reasons, the most serious being poor quality information. All these issues must be addressed before ISABEL can be expanded and made available throughout the NHS.

Wider availability can be achieved either as an application running on the NHS communication infrastructure or through a third party supplier. Both have associated costs and operational advantages and disadvantages. The more complex issue is that the benefits of using ISABEL are distributed across a number of stakeholders; whether these benefits are realised depends on the value that one stakeholder group, the clinicians, see in ISABEL.

Recommendations

8. The objectives for ISABEL must be more closely specified
9. ISABEL must be part of the NHS Quality programme.
10. An organisation in the NHS must be made responsible for Decision Support.
11. Service provision models should be investigated and an appropriate supply arrangement for ISABEL put in place.
12. A methodology for evaluating the performance of decision support systems should be developed.
13. The capabilities of Autonomy's pattern matching software should be researched further.
14. The potential of ISABEL as an educational tool and the implications of early adoption of technology during training and continuous education should be carefully analysed.

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Appendix 1

Evaluation Tasks

Some of the areas that need to be investigated are given below:

1. What is its scope – what are the clinical areas of use, what are its objectives (as set by the original developers), are there any other limitations to use
2. How does it work – what algorithm does it use, what search engine does it use, where does it search, what technology is used, how fast is it, can it be used on the existing/planned NHS infrastructure
3. How does it compare - qualitatively with other systems eg NHS Direct, NeLH, where does it sit with other decision support/task support systems
4. Have there been any quantitative evaluations – who uses it, how often, what results do they get, are there any controlled comparisons with other decision making/support systems or against human decision making, what is the meaning of *accuracy* in this context
5. How useable is it – how many key strokes are required to get an answer, how is the answer presented, how much training and support is required to use it, how easily are the results interpreted, could it be used in a consultation setting
6. Operation – who owns it, how would NHS gain access, how would it be maintained, can it be scaled up
7. Effectiveness – is it a useful clinical tool, do patients feel reassured by clinicians using it
8. Cost – what is the cost of ownership both capital cost and long term running cost