Improving data quality in English healthcare. From Case Studies to an applied Framework.

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This Thesis demonstrates the problems of data in English healthcare with direct consequences for developing, managing and delivering services for all. Despite recent opportunities of a New Labour Government and several strategies for Information Management & Technology, little has changed over the course of the research.

Moreover, the general conclusions have much in common with observations from eminent people, more than sixty years ago, referring to inequalities in society and wasted resources:

"The more lucid thinkers... are revolutionaries not because the present way of living is a hard and tyrannous way of living, but because it is from top to bottom exasperatingly stupid".

HG Wells.
The New World Order,
Secker and Warburg, London, 1940.

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(February 2004).

Abstract

This Thesis argues that the quality of data for professionals and information for patients may be limiting healthcare in England. Data are required for individual care, for monitoring servicess for populations and as part of broader research and development. Similarly, informed patient consent and real involvement in their own care depend on information. Failings in these areas can lead to a fragmented National Health Service which is slow to change.

A Data Quality Framework (DQF) is therefore the main product of the Thesis. Prominent Themes which should be addressed have been identified through four representative Case Studies. From national data collection in Intensive Care to Visual Impairment Notification, the Studies span the range from quantity to quality of life and related healthcare services.

Datasets in the Studies are found to be poorly researched; lacking support for collection and management; and unlinked to information for patients. Assistance from technology is under developed, while overall costs and benefits of both data collection and provision of patient information are poorly documented.

These Prominent Themes are augmented by National Constraints derived from a review of healthcare policies and strategies for Information Management & Technology (IM&T). Demands for data and information are increasing and the delivery structures of care are changing through policy pledges. At the same time, healthcare is officially described as "largely based on manual systems". Problems with the introduction of technology are demonstrated by three IM&T strategies from 1998 to 2002. Culture and change management in the NHS have only recently been identified as major research issues. The necessary "information infrastructure" for data collection and information provision is still not in place at 2004.

The full Data Quality Framework has separate components for assessing an existing or proposed system (Step 1. Appraisal Tool) and introducing managed change (Step 2. Implementation Programme). It draws in particular on recent central initiatives paralleling the Prominent Themes with adjustments for the National Constraints.

The central initiatives cover: evolving mechanisms for appraising and approving all national healthcare datasets; care process modelling to highlight sources of data and points for information provision to patients; principles for accrediting information providers, paralleling those for organisations involved in NHS research; and standards for labelling information resources for indexing and easier retrieval (meta-data) as part of the eGovernment Interoperability Framework for the whole public sector.

Benefits are assessed by applying the DQF to the Visual Impairment Notification process and comparing a review of the same process by the Department of Health (still ongoing at late 2003).

Application of the DQF produces formal evidence to justify and direct change. Recommendations include a new visual impairment identification form linked to information sources and monitoring mechanisms, with pilots in both electronic and paper formats. In contrast, interim proposals from the official review has provided only anecdotal evidence and three new forms without a clear logic to support content or completion practices. The official approach contradicts the Department of Health's own policies on broad consultation and standards for developing national datasets. Moreover, alternative approaches derived from the DQF cannot be developed without prior Department of Health approval.

The DQF has not been fully applied and needs for refinement are acknowledged. Nevertheless, it is possibly the only example of its kind in English healthcare with general principles supported by evidence from the real world Case Studies.

Chapter 1

Introduction and overview

1.1. Introduction.

Medical provision and social support in the community are combined in the term healthcare. Services in the UK are provided predominantly by the NHS and Local Authorities, complemented by the voluntary and private sectors. The Department of Health has ultimate responsibility in England with Concordats covering health and social care in other UK countries (DoH, 2001a).

Healthcare depends on data at all levels. Observations, measurements and substantive records direct care for the individual, often initiated or supplemented by feedback from patients themselves. Subsets are shared to coordinate services for the patient across specialities or sectors. Aggregated and summarised, data also inform local and national managers.

Equally, research relies on data from individuals, organisations or regions. Appropriately combined with other data on health and services for populations, it influences policy making, planning, and identification of areas for special action.

Support information for professionals and patients highlights an important sub-set related to data collection and use. Instructions guide staff, while less formal but equally structured material directs patients to additional information and support. Fundamentally, it is the basis for informed patient consent to care procedures or data disclosures.

This Thesis argues that the importance of data and support information in theory is not matched by activities in practice. The preliminary conclusion is based on four research programmes from 1988 to 2002, brought up to date in all cases. They ranged from Intensive Care to Visual Impairment Notification (registration); covered individual care, monitoring within organisations, and performance by national processes; and included GP surgeries, hospitals, and Social Services Departments. All examples were limited by the "quality" of available data and support information.

Visual Impairment Notification (VIN) is given prominence in later sections. It was the broadest and most recent research programme and, since 2001, the subject of an ongoing review by the Department of Health.

Assistance with issues of data and support information was examined as part of the VIN project. Policies and IT strategies were assumed to provide guidance for projects generally.

In fact, a Data Quality Initiative from the Department of Health was found to be potentially biased. Dimensions of completeness, timeliness and accuracy were being judged against use by national managers, with little reference to ease of collection or local relevance.

Considerable information was available on diagnoses, treatment and sources of support. However the information, primarily from charities and professional bodies, lacked coordination. There were few quality measures beyond a general notion of future "kite marking" and limited provision as part of direct patient care.

Moreover, problems were likely to increase. Reorganisation of healthcare over a 10 year period from 2000 (The NHS Plan) was changing dataflows through new structures (Primary Care Trusts and Strategic Health Authorities). Demands for data were also rising from requirements to monitor new standards for diagnostic and demographic groups (National Service Frameworks) and performance more generally (Performance

Assessment Frameworks). In parallel, the Government's modernising agenda required greater public information from all sectors and coordinated services tailored to the individual.

Data quality was the common concern from the 4 research examples and has not been fully addressed at national level. It is a logical, practical and timely feature for formal attention.

1.2. Hypothesis and Objectives.

Hypothesis.

Inadequacies in data quality, including information for patients, at local and national level inhibit the delivery and management of care, and the capacity for research to introduce change. Closer examination of particular problems from real world examples provides sufficient evidence to identify generic areas for improvement. Data quality improvements in turn increase the quality of care for individuals and groups as well as the pace of change.

Objectives.

O1. Problem identification through Case Studies. Use the 4 previous research programmes as a representative sample to identify the particular problems of data quality that impede achievement of health, social care, political or research targets.

O2. Extraction of Prominent Themes. Define the nature of common or significant problems of data quality by analysing results from the Case Studies.

O3. Comparison with National Policies. Review recent Government policies and IT strategies affecting data in healthcare to highlight current problems at the top level, and to illustrate connections and parallels at local level as represented by the Prominent Themes.

O4. Generic Data Quality Framework. Propose a Framework to remedy the Prominent Themes, covering: explicit constraints; mandatory Government requirements; good practices; products and technologies; and measures of performance.

O5. Framework application. Apply the Framework to an earlier Case Study (Visual Impairment Notification) and demonstrate that attention to data in the review and re-design of a care process has potential to bring improvements for all parties.

1.3. Organisation of the Thesis.

Part 1. From Case Studies to Prominent Themes.

Chapter 2 justifies the selection of Case Studies. Each study is presented as an individual critique. Common criteria introduced in this chapter are adopted to organise material within Studies and as the basis for discussion and extracting Prominent Themes in chapter 7.

Studies in the intervening chapters cover:

- National data collection from individual Intensive Care Units.
- Data collection by patients with Diabetes Melitus as a direct part of care (home data collection).
- Monitoring the hospital admissions process in an Accident & Emergency department.

- The Visual Impairment Notification process in England.

The five Prominent Themes emphasise:

- **Datasets** - unclear roles, limited design and links with other data sources.
- **Data collection and management** - little attention to source and formats, limited staff support, failure to keep data up to date.
- **Information for patients** - largely ignored despite moral and legal obligations, and practical benefits for care coordination.
- **Technology** - unfulfilled potential without reasonable access, system compatibility and staff support.
- **Costs** - real costs and benefits of general data management and information provision are rarely specified.

Part 2. From Prominent Themes and National Considerations to a Data Quality Framework.

The focus now moves from real problems to potential solutions. Chapter 8 introduces the approach to development and assessment of a Data Quality Framework over 3 chapters.

Chapter 9 considers the support available from recent Government policies and related strategies for Information Management & Technology in English healthcare. It identifies responsible organisations, specific technologies and the Government's aims for public services with "Britain online" in the "information age". A special Annex covers the official Accreditation Process for data quality in the NHS.

Chapter 9 concludes, however, that key components of the Information Infrastructure are not yet in place. Notably, collection costs and demonstrable benefits for mandatory national datasets in the NHS remain unknown at mid 2003.

Chapter 10 develops the formal Data Quality Framework. Separate Parts address appraisal of existing data collection processes, and support for programmes introducing change.

The Framework adjusts and combines four recent central initiatives paralleling issues raised by the Prominent Themes:

- Appraisal and approval mechanisms for significant datasets in healthcare from the NHS Information Standards Board, addressing the business case as well as practicalities and costs of collection.

- Related programmes of care process and data modelling from the NHS Information Authority, identifying sources of data and points for patient information.

- Formal assessment of organisations involved at all stages of research in the NHS, comprising part of the Research Governance Framework for Health and Social Care and logically extending to providers of patient information.

- Public sector standards for description and retrieval of information resources, developing under the Office of the eEnvoy within the Cabinet Office and appropriate for developments in healthcare

Chapter 11 applies the Framework to Visual Impairment Notification in England. The key to this national process is the "certification" form (BD8) linking medical assessments in the hospital to community support from Social Services.

Recommendations are made for pilots of a new electronic form and information for patients in the old Camden & Islington Health Authority. Equivalent forms in paper and electronic formats allow comparable pilots in geographic areas with varying IT support.

Detailed modelling and pilots themselves have not been conducted because of the ongoing national review by the Department of Health. Nevertheless, the chapter concludes that the Data Quality Framework is an improvement on DoH's approach to change. Primarily, the chapter argues that the appraisal and approval process for significant datasets in healthcare, recently introduced by the NHS Information Standards Board, should logically apply to substantive forms involved in individual care and contributing to national process monitoring.

The Department has not provided objective evidence to justify and direct changes to either the Notification process or the BD8 form. It is therefore unlikely to pass its own approval mechanism for national datasets as applied to the relevant form.

In contrast, the appraisal and approval mechanism is adjusted and incorporated into the Framework. The DQF also contains explicit requirements for information to support patients and acknowledges Government intentions for modernisation.

Assessment of the Thesis.

Chapter 12 reviews the collective work against the original hypothesis and objectives. Data quality is accepted as a significant problem in English healthcare. Generic themes and solutions are acknowledged, but are not necessarily comprehensive and have not been shown to work in practice beyond a theoretical case for change.

The Data Quality Framework is found to be based on justified principles. Developments depend on wider acceptance of those principles and refinements through application in the field.

1.4. Assistance for the reader.

1.4.1. Appendices to the main Thesis.

Five appendices provide technical material relevant to several chapters.

Appendix 1 – *Bayesian time Series analysis (BATS)* - details the methods used to analyse home data from diabetics (chapter 4) and daily attendance rates at an A&E department (chapter 5). An extended account is provided as the methods can be applied to continuous and discrete data with several ordering schemes in addition to time, and used to monitor features of data quality in parallel with "signals" derived from the main measurement series.

Appendix 2 - *Properties of psychometric questionnaires* - principles behind the design and assessment of questionnaires targeting patient (or staff) opinions and perceptions. Questionnaires could have been used in any of the Case Studies, but demonstration was limited to patient perceptions of treatment and data collection among diabetics in chapter 4.

Appendix 3 – *Technological specifications for the electronic Visual Impairment Notification System (eVINS) including Entrust's Public Key Infrastructure (PKI)* – provides details relevant to chapters 6 & 11, and drawn up with the NHS Information Authority and a major digital security company.

Appendix 4 - *Web languages referenced in the Thesis* – gives summaries and references with particular relevance to the electronic Visual Impairment Notification System in chapters 6 & 11, and mandatory national requirements in chapter 9.

Appendix 5 - *Basic conventions of the Unified Modeling Language (UML)* - a de facto standard in IT, adopted by the Government and NHS as a diagramming language for

presenting the structure of processes and data specifications, as stated in chapter 9. Online examples of data specifications from the NHS and Government generally, obtained during development of the Data Quality Framework in chapter 10, use this language without reference to an Appendix like this for explanation of principles and symbols.

1.4.2. Acronyms and references.

Acronyms relevant to several chapters, or used several times in the same chapter, are defined on the first occurrence and also listed in a separate section (p439).

References are given in the last section of the Thesis (p442). They are listed using the Harvard formulation, eg. (Smith, 1999). Abbreviations are used for some organisations, eg. DoH for the Department of Health. A code or acronym is also added to distinguish multiple references from the same author or organisation, eg. (DoH, 2000/nhsp) for the NHS Plan.

Part 1

From Case Studies to Prominent Themes

Chapter 2

Introduction to Part 1

2.1. Introduction.

The main Thesis begins with an examination of particular problems with data quality in the field through 4 Case Studies. Each Study is self contained and a critique of an existing healthcare process or research programme in its own right. The broader aim is to extract Prominent Themes from real life examples as the initial basis for a general Quality Framework

2.2. Selection of Studies.

The Studies cover the majority of HJL's academic work from 1988 to 2002. They include topics addressed as a research student, specific projects related to Fellowships, and requests from collaborating organisations.

The domains are therefore self-selecting. However, they span extremes from Intensive Care to Visual Impairment, and were linked retrospectively by issues of poor data quality including provision of information for patients.

2.3. Common structure for the Studies and criteria for Prominent Themes

A common structure promotes comparisons between Studies. Three main headings and sub-categories identify relevant material. Prominent Themes are then suggested by comparable problems or isolated examples with wider significance.

1). Background and wider context.

Material in this section provides a national perspective for the Study with local details where appropriate.

Patient group and management process. The general area of investigation is established by diagnostic categories for patients and the broad issues behind the targeted care process.

Origins. Historic review considers whether the "problems" are recent or long standing and why the area has received special attention.

Stakeholders. Professions and organisations involved in the care process or affected by change. The specified patient group is automatically a stakeholder.

Related initiatives. Areas of healthcare policy or professional developments logically related to the specified care process.

2). Specification of the process or research programme.

A sequence of major sections address the existing care process followed by details on particular data collection components or changes introduced by a research programme.

Structure. Organisations and staff involved and division of activities.

Scale. Measures of activity appropriate to the level of the Study.

Datasets, dataflows and support information. Specific data content, exchanges and points for support information mapped onto the structure of the process or research programme.

3). Particular problems with data quality.

Key problems identified by the Study are expanded.

Consequences. Impact of the specified problems or recommended changes on process management or individual stakeholders.

Causes. Action, inaction or design factors contributing to the problem(s).

Chapter 3

General critical care for adults in England and Wales: national data collection from individual hospitals.

3.1. Introduction.

Critical Care is an American term increasingly adopted in the UK to describe the more familiar area of Intensive Care. It identifies prolonged hospital treatment for actual or potentially life threatening conditions. It is not a recognised speciality in Britain, so the Department of Health also use the term Augmented Care as a category for assigning component activities to other specialities.

General and specialised Intensive Care Units (ICUs) provide assistance for the most severely ill patients. Care for less severe cases is now delivered, in principle, in High Dependency Units (HDUs).

Research specifically into Intensive Care was the starting point for this Thesis. It began in 1988 with intentions to develop models for physiological prediction. However, visits to units in London demonstrated that few data were pre-computerised. The problem led to a review of national data collection in general adult critical care in recent times forming this first Case Study.

Organisation of the Case Study.

Section 3.2 describes historic problems with data collection in the UK. Performance and requirements for improved data in 1997/8 are presented from a review of England and Wales by the Audit Commission. An introduction to current national initiatives follows, including a review of requirements by the Critical Care Information Advisory Group (CCIAG) which was on-going at late 2002.

Section 3.3. Care processes in units and hospitals are then summarised to illustrate the environment in which data are generated. The section shows the wide range of staff and services in a modern unit, and necessary channels of communication across the hospital.

Sections 3.4 & 3.5. The 2 main national data collection programmes are then examined. The Augmented Care Period (ACP) dataset is a mandatory Department of Health data requirement on all acute hospitals. It is a deliberately short dataset covering basic critical care activity anywhere in the hospital, according to formal definitions. .

In contrast, the casemix programme (CMP) focuses on illness severity before treatment specifically in general ICUs. This complex dataset is part of a voluntary scheme run by the Intensive Care National Audit and Research Centre (ICNARC).

CMP is analysed in detail. Together with summaries of ACP, results show differences in approach and achievements from 2 official programmes.

Section 3.6 considers the ability to collect data across critical care units generally. Data provided by the Audit Commission, specifically for this Thesis, demonstrate that better collection for local or national monitoring is only weakly associated with computerised management of patient data, and collection across all units for national use is poor.

General findings

Overall, the Case Study shows that data quality problems extend beyond basic computerisation. Definitions of care, physical availability of data, the skills and motivation of collection staff, and limited integration of collection with national electronic systems are also part of the problem. Moreover, widespread data collection to high national and international standards is expensive.

3.2. Background and wider context.

3.2.1. Patient group and the management problem.

Most admissions to a modern unit involve planned stages of major surgery or unexpected emergencies from the A&E department and deteriorating patients from medical wards. Major recipients of critical care services across all ages are the newborn, very young children and the older population.

Costs of care are substantial. They have not been defined and standardised for all units, but high nursing levels are the primary factor with accepted estimates around 42% of unit budgets (Edbrooke et al, 1999). Provision, and therefore costs, are projected to rise with the aging population. Regional organisation of services is a regular academic debate while the media highlight bed shortages in individual hospitals (unmet need and premature discharges).

Within units, there are concerns about the range of patients who benefit from care, reflected in risk adjusted survival rates (casemix), and variation in treatment for comparable cases (clinical practice). Moreover, the research process itself is limited by the ethics of randomised controlled trials (RCTs). Views are changing (Rowan, 1994a)

but the general problem highlights the importance of systematic observation and data collection in complex areas of medical practice.

3.2.2. Historic review.

Adult critical care became a part of medical research in the 1840s (see eg. Wiel & von Plantar, 1989). Scientific advances in infection control and pain relief began an expansion in surgery and related care. Developments in the logistics and technology of care have been particularly associated with wars, epidemics and natural disasters.

As a major example, outbreaks of polio in Denmark and California in the 1950s required breathing support for large numbers, leading to ventilators and the modern life support machines (Lassen, 1953). Indeed, the 1950s are often taken as the start of modern critical care.

Care units emerged in the early 20th century with the professional specialties of individual doctors and hospitals. They tended to merge as similarities between medical and surgical cases, and benefits of centralised resources, were realised.

Britain established the first professional association in the field in 1970. The Intensive Care Society (ICS) has since promoted research and training as the only UK organisation with a "sole interest" in the subject. The Critical Care Society, formed in 1973, is the American equivalent.

Critical care and related disciplines became an established specialty in America, France and Russia in the early 1990s. In 2002, it is still not specifically recognised in the UK.

3.2.3. Recent history of data problems in the UK.

America was also the first country to attempt a national plan for future development. In 1983, the National Institutes of Health convened a consensus forum to review practices and make recommendations (NIH, 1983). Proposals were very general and not necessarily applicable to the UK as British ICUs tended to admit more severe cases. Nevertheless, the initiative prompted a UK review in 1988 by the King's Fund (1989).

The Fund concluded that there was insufficient evidence on activities, outcomes or costs on which to base any recommendations on policy or practice. Instead, it called for an immediate and comprehensive programme of research.

The research that followed was neither comprehensive nor coordinated. Different organisations had different criteria for care. Intensive care was the established term at the time, but a lesser category (high dependency) was also emerging. Studies of organisation and cost were inconsistent (see, in particular, a review for the King's Fund, Shiel, 1991).

After this period of activity, DoH established a Working Group to review progress (DoH, 1996a,b). Its subsequent guidelines were acknowledged as "not evidence-based" and it proposed programmes of further research. Essentially, it had reached the same conclusions as the King's Fund almost 10 years earlier.

3.2.4. Critical care services in England and Wales at 1997/8.

The Audit Commission targeted "critical care" with aims to assist individual Trusts with service planning and configuration for general adult units. However, its final report acknowledged that "there has been no national plan for adult intensive care services"

(Audit Commission, 1999). The opportunity was also taken to bridge part of the "information gap" by addressing national unit and bed numbers in all varieties of critical care.

Study design took account of various stakeholders (Table 3.1). Postal questionnaires were sent to all acute Trusts in England and Wales in late 1997. More complete questionnaires were then sent to all identified units providing general critical care primarily for adults in the year to March 1998 (Audit Commission, 1998a,b). All Trusts and around 85% of units replied.

Provision and performance.

The geographic distribution of general adult services showed unequal access (Figure 3.1) consistent with consultant reports of "haphazard" development. Across all varieties of critical care, 712 units with 4,609 beds were identified in 227 Trusts (Table 3.2).

Provision for general adult care accounted for only 295 units and 1,730 beds (41% and 38% respectively). A fifth of units catered exclusively for newborn babies and children while a third of beds were set aside in speciality units (eg. renal, liver, burns and spinal injury units).

Considerable variations were reported in the size, casemix and organisation of general adult units. The Commission therefore adopted the simplifying concept of an "average ICU" to report findings.

Most statistical assessments were in fact based on ICNARC's databases rather then questionnaire returns with more data available on ICUs compared to HDUs. Performance statistics derived from ICNARC publications (Table 3.3) are broader than the Commission's figures and in some cases, notably mortality rates, are in direct conflict. Their sample, though, is potentially biased (see 3.5.4 for details).

According to the Commission, 75% of admissions were planned (surgical cases) and 25% were unexpected emergencies. However, the proportion was reversed in some units. From a few cases to 44% were admitted from A&E, depending on the hospital location. Circulatory problems were the most common reason for admission but pneumonia accounted for the longest stays. Significantly, most patients had multiple problems on arrival. A small number of admissions to adult units were children (up to 10 per unit per year).

On average, 16% of cases died on the unit rising to 21+% within the hospital. Mortality was higher for units where consultants worked fixed periods each week rather than a full week in the unit followed by 2-3 weeks on other duties. A cause and effect relationship was not examined but the finding would not have emerged without collaboration between the Commission and ICNARC.

Requirements for data.

The Commission emphasised 5 data areas to support local monitoring, management, service delivery and expansion.

- **Patient flows.** Regular monitoring of patient movements within a hospital may illustrate where resources are used and where treatment has been witheld or ended prematurely because of shortages. It may also consider the extent to which peaks and troughs in activity are predictable, with implications for staffing.

- **Casemix.** Management and performance measures (eg. beds, survival rates, lengths of stay) should be supported by formal information on the mix of cases and, where appropriate, adjusted for illness severity (see 3.5.1).

- **Clinical practice.** The Commission re-emphasised the shortage of local and national data in this area and highlighted evidence of marked variations between doctors.

- **Information provision.** Leaflets and directories explaining illnesses, equipment, sources of support and organ donation were relevant to recovering patients and grieving relatives but rarely provided (with notable exceptions).
- **Follow-up.** Nationally, there were limited data on long term survival and few units which routinely followed former patients. Mechanisms for feedback from patients on quality of life, healing rates and unit recollections were identified for improving local practices.

Good practice guidance made considerable demands for data and stated that "Trust board's need to put in place an information and audit system". However, there were no recommendations on specific datasets, methods of collection or lines of responsibility.

3.2.5. Significant developments in national data collection.

There have been 3 important initiatives since the King's Fund report, in addition to the detailed programmes presented in 3.4 and 3.5. DoH's 1996 review led to a National Intensive Care Bed Register for England. Units of all varieties are now contacted several times a day and information is available to other units at all times. DoH has also established a census of general and specialist critical care beds in all English Trusts. Conducted twice a year (January and July), it is reported to DoH via paper form KH03A.

The Critical Care Information Advisory Group (CCIAG) has been established since 1999 and is identified in (NHSIA, 2002/acpdscn). It is believed to be a special interest

group working under the NHS Information Standards Board and contributing to the national review of all official healthcare datasets (see chapter 9 on national policies, and chapter 10 for details on the Information Standards Board).

Table 3.1. Organisations involved in the Audit Commission's 1997/8 survey of critical care (the stakeholders).

Association of Anaesthetists.
British Association of Critical Care Nurses.
Intensive Care National Audit and Research Centre (ICNARC).
Intensive Care Society.
NHS Executive (part of the Department of Health).
Welsh Office (NHS in Wales).
Paediatric Intensive Care Society.
Royal College of Anaesthetists.
Royal College of Nursing Critical Care Forum.
Royal College of Physicians.
Royal College of Surgeons.

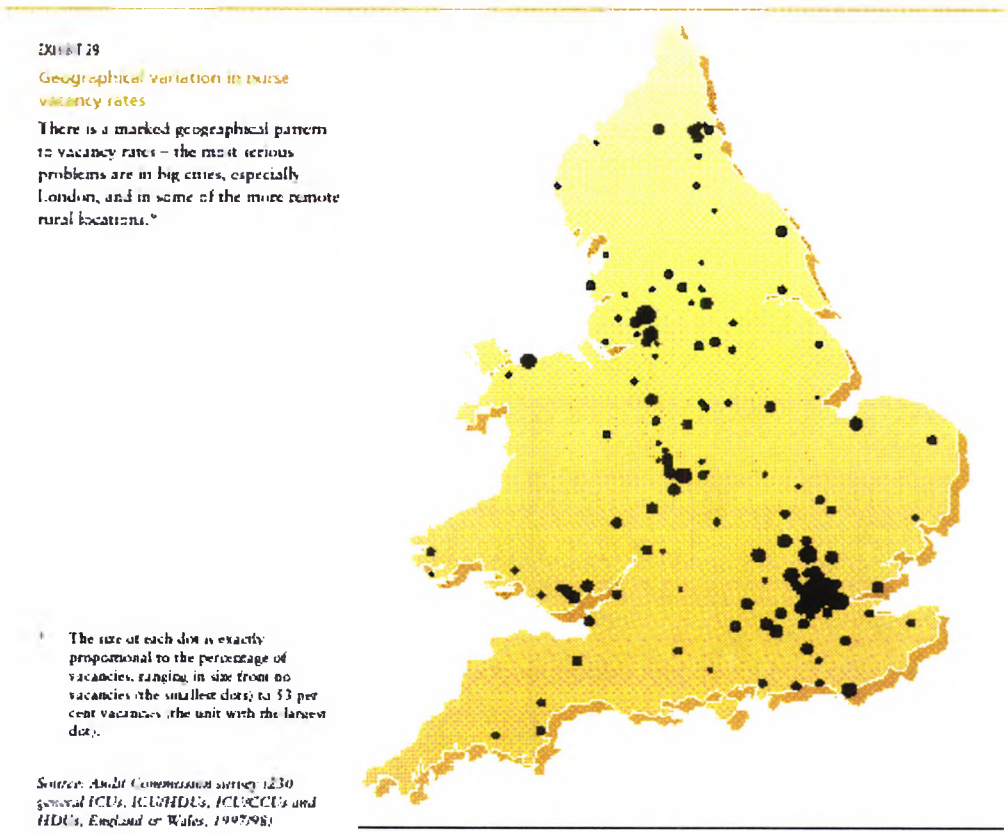


Figure 3.1. Geographic distribution of critical care units in England and Wales in 1997/8 (from Audit Commission, 1999).

Table 3.2. Critical care services in England & Wales at 31st March 1998 (computed from Audit Commission, 1998b).

A. Summary of units and beds by major categories of critical care.

	Units	Available beds	% of all units	% of all beds
General critical care	295	1,730	41.4	37.5
Neonatal & paediatrics	146	1,304	20.5	28.3
Other sub-specialties[1] & off-unit beds	271	1,575	38.1	34.2
Grand total	712	4,609		

[1]Sub-specialties: dedicated coronary care, cardiothoracic, neurological/surgical, burns/plastics, liver, renal and spinal injuries.

B. Distribution of general critical care units by ICU and HDU status.

Care type	ICUs	Combined	HDUs
General/mixed	128	83	25
Surgical	2	3	26
Medical	0	1	8
Combined general & coroonary care	8	10	1
Totals	138	97	60

Table 3.3. Summary of general adult critical care unit performance in the UK, according to analyses of ICNARC's potentially biased Casemix Database at 1998/9 (ICNARC, 1999).

Patient sample.

59,855 patient datasets received from 118 units. 34,333 datasets from 82 units validated.

22,059 datasets from 62 units in the Case Mix Database.

NB. Sub-groupings do not sum to 22,059 except for university/non university totals.

Admission type	N patient datasets	Mean age (SD)	Mean age excluding paediatric cases	% female cases	Length of unit stay in fractional days, median (range)	Unit survival (%)	Hospital survival (%)
All	22,059	57.3 (20.2)	59.1 (18.0)	39.4	1.6 (0-169.1)	79.3	70.1
Non urgent	12,313	53.9 (20.8)	55. (18.6)	41.2	1.8 (0-169.1)	72.3	62.8
Surgical	9,728	61.7 (18.5)	63.1(16.4)	37.3	1.2 (0-110.9)	88.2	79.4
Following emergency/urgent surgery	4,136	60.4 (20.3)	62 (20.3)	30.5	1.9 (0-110.9)	78.6	66.3
Following elective/scheduled surgery	5,527	62.7 (17.0)	64 (14.7)	35.6	1.0 (0-73.3)	95.5	89.4
Paediatric (<16 years OLD)	763	6.5 (5.4)		43.1	0.9 (0-36.7)	91.9	90.3
University/affiliated	12,242	56.7 (20.0)	58.6 (17.8)	38.6	1.5 (0-107.1)	79.0	69.0
Non University	9,817	58.1 (20.3)	59.9 (18.2)	40.5	1.7 (0-169.1)	79.7	71.5

3.3. The critical care process in units and hospitals.

Modern critical care units for adults involve a wide mix of professional skills and technical support (Figure 3.2). The Audit Commission's statistically "average ICU" has 6 beds staffed by 47 nurses and 3 consultants with fixed commitments, 3 more covering on-call rotas and a trainee doctor on 24h duty. The unit has a dedicated ward clerk and shares a business manager, technician, audit clerk and ancillary services with other departments.

Critical units are part of the network of services within an acute Trust (Figure 3.3). Consultants elsewhere in the hospital are responsible for coordinating admission and discharge of their own patients while managers oversee bed availability in other wards and discharge from hospital. Transfers between hospitals use the new National Intensive Care Bed Register and require risk assessments of medical state and journey conditions for individual patients.

Principles of care are comparable in most cases. Where appropriate, immediate resuscitation involves interventions to ensure adequate breathing and circulation. Patients are then stabilised, often sedated and administered with pain relieving drugs. Detailed cause(s) of the presenting problem is determined with x-rays and pathological tests. The most severely ill may require invasive monitoring and therapy. Other patients receive basic support and close observation (one working definition of High Dependency).

Treatment aims to provide the best circumstances for natural recovery mechanisms to take their course. Improvement is shown when immediate cause(s) of the problem is relieved and reflexes progressively return (eg. pupil responses to light, coughing). Conversely, patients have no chance of recovery once the brainstem is clinically inactive.

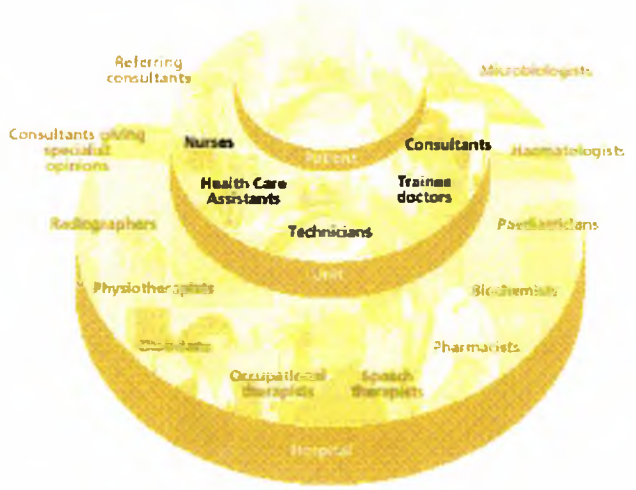
Survivors require preparation for transfers to other parts of the hospital and discharge home. This may involve adjustments to lower levels of treatment and personal support as well as rehabilitation (training to recover old skills). Comprehensive units also provide follow-up visits to patients on general wards and clinics for those discharged from hospital.

A substantial proportion of staff time is spent informing and counselling relatives. The extent depends on the casemix of patients and the physical facilities available (explanatory leaflets, accommodation). Topics range from explanations about the unit to decisions on organ donation. Staff also require emotional support and tend to develop informal coping mechanisms where formal hospital support is limited.

EXHIBIT 3

The main hospital clinical staff involved in caring for critical care patients

The delivery of critical care services to patients involves a complex network of interactions between many people working within the hospital.



Source: Audit Commission

Beds and units

11. Nine out of every ten acute trusts have a 'general ICU', sometimes including high dependency or coronary care as well as intensive care beds. Some have separate high dependency units (HDUs) or specialty-specific units [EXHIBIT 4]. Most critical care beds are in general, mixed specialty units. On average, 1 per cent of acute hospital beds are designated for general critical care, but this varies widely, with the top quarter of trusts having more than twice the percentage of the bottom quarter. The same wide variation is found if specialist beds are included, with the average rising to just over 2 per cent. There are no significant differences in provision between trusts of different types [EXHIBIT 5, overleaf].

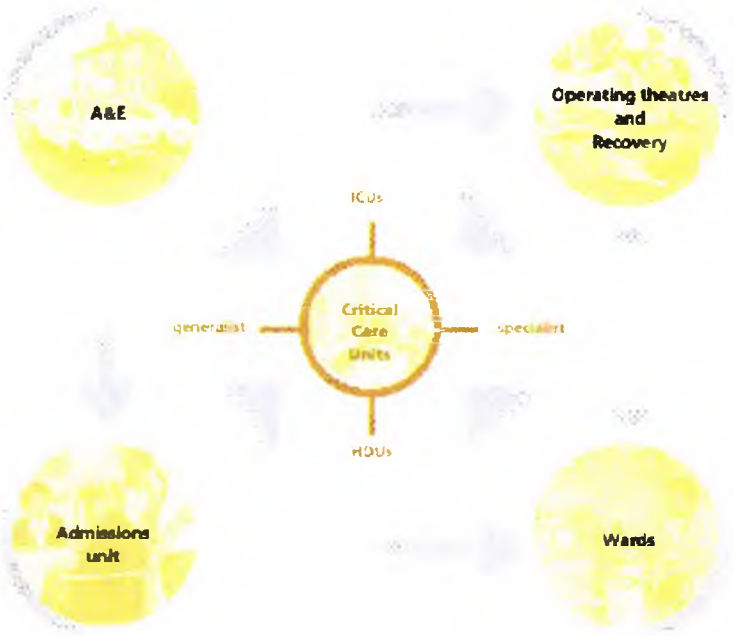
12. There is also no consistency in whether trusts have created few or many, small or large units. Some trusts have a large number of specialist units, managed by different clinical directorates. By contrast, other trusts bring these specialties into general units. For example, one teaching trust provides acute services from two hospitals containing eighteen separate critical care units. By contrast, a slightly larger teaching trust, despite operating from three hospitals, has two large, mixed-specialty, ICU/HDUs, with only a further five specialist units. Although this variation will partly reflect differences in the medical and surgical services offered by the two trusts, it also reflects different degrees of centralisation.

Figure 3.2. Components of the modern critical care unit (from Audit Commission, 1999).

EXHIBIT 33

Critical care as part of the network of care delivered by an acute hospital

Critical care forms an essential part of a network of care that makes up an acute hospital.



Source: Audit Commission

121. Given what is known about the history of directorate development and relationships across the hospital, trusts need to consider how likely it is that this whole network of critical care resources is being well used. Differences of opinion and judgement are likely and will affect how well the whole resource is used, and the board will need to clarify these, involving working doctors and nurses in their discussions. And, as described in Chapter 3, trusts must also make sure that they are managing demand and using current beds appropriately and efficiently, before considering supply-side increases [EXHIBIT 34, overleaf]. This means both improving care on ordinary wards and the management of critical care units to reduce the unnecessary spiralling of costs and pressures. The hallmarks of trusts that do not do this contrast with those that reduce bed pressures by planning [BOX E, overleaf].

Figure 3.3. Communications channels supporting critical care within the acute hospital (from Audit Commission, 1999).

3.4. Augmented Care Period dataset (ACP).

ACP originated with work by John Morris (consultant anaesthetist, William Harvey Hospital, Ashford, Kent), partly through his role as chair of the intensive care working group within the former National Casemix Office (see eg. NHS Executive, 1996). His surveys and discussions with colleagues across Kent concluded that there were insufficient national data on activity but only a relatively simple dataset was practical for collection. Proposals were adopted by DoH and refined by a committee of stakeholders into the ACP dataset.

ACP became a mandatory addition to the Commissioning Dataset on all in-patient cases involving critical care in England and Wales in Autumn 1997. Specifications were first circulated to hospitals in 1996, with minor modification for compatibility with ICNARC in 2002 (NHSIA, 2002/acpdscn). Integration with the full specifications for commissioning datasets (NHSIA, 2002/cmds) awaits CCIAG recommendations within the national review of healthcare datasets. The user's manual provides operational details and is also due for an update. (NHSIA, 1997).

3.4.1. Purpose and content of the dataset.

ACP aims to provide standardised data on intensive and high dependency care activity to support contracting, internal management, national statistical analysis and policy development. Within definitions, it covers critical care anywhere in a hospital, inside and outside designated units, and is intended to complement other programmes.

Definitions and exclusions.

ACP covers both Intensive and High Dependency Care and is defined as:

"a period of time within a Consultant Episode during which a patient requires close observation and intervention by additional, specially trained staff using medical equipment not routinely available on general hospital wards".

An ACP begins when treatment is initiated, but a new period can occur with a change of location (from ICU to HDU) or change of admitting consultant (new consultant episode). Locations and activities outside a critical care unit are explicitly excluded unless they conform to ACP definitions and are an unplanned part of care. Resuscitation in an A&E unit or special support on a maternity ward or emergency care for any out-patient are, for example, excluded.

The 13 data items.

1. ACP Number - a sequential number identifying the case and each period within a Consultant Episode.

2. Local Identifier - optional code for cross-reference with other local or national programmes.

3. Start Date.

4. Source - patient location immediately before the ACP (10 options).

5. Intensive Care Level Days - number of days where any form of IC is delivered for any part of a calendar day.

6. High Dependency Care Level Days - number of days where any form of HD is delivered for any part of a calendar day without administering any higher level care (ie. IC takes priority on days of mixed care provision).

7. Location of care - descriptions of various common care locations without strict definitions (17 options).

8. Number of organ systems supported (for intensive care level only) - according to official definitions of systems and support (Table 3.4).

9. Specialty Function Code - specialty code for the consultant whose patient is receiving an ACP (8 common options with full list in the NHS Data Manual).

10. Planned Indicator - flag for any part of the ACP that was a planned part of care (options Yes/No).

11. Outcome Indicator - codes recording survival/death at the end of the ACP and whether organs were donated (4 options).

12. Disposal - destination of a patient following ACP (9 options).

13. End Date.

3.4.2. Collection procedures.

Decisions on collection are left to local managers. Ward clerks are identified as the main collectors, with medical support on technical categorisations. Data collection is expected at source, in paper or electronic formats. The IT department is involved in issuing ACP numbers and data transfers to the hospital's Patient Administration System (PAS) for linkage with other commissioning data.

3.4.3. Collection performance.

Collection problems were reported in the ICS newsletter before ACP was formally introduced (Morris, 1997):

"There is some scepticism regarding the feasibility of the project among intensivists nationally. This largely stems from difficulties in collecting even a small dataset in their intensive care units, poor provision of electronic data collection systems and data personnel by Trusts because of financial constraints".

The usual transfer of commissioning data over NHSnet (the NHS Wide Clearing Service) includes mechanisms to derive data quality reports and Health Episode Statistics for DoH. Since ACP is not fully integrated with this system, figures on collection performance since 1997 have not been identified (see chapter 9 for details on the clearing service).

Table 3.4. Summary of organ systems, monitoring and support relevant to national data collection in critical care.

A. Body systems identified within the ICNARC coding system (ICNARC, 1997,Section 5).

Respiratory
Cardiovascular
Gastrointestinal
Neurological (including eyes)
Trauma
Poisoning
Genito-urinary
Endocrine, Metabolic, Thermoregulation and Poisoning
Haematological/Immunological
Musculoskeletal
Dermatological
Psychiatric

Table 3.4. Continued...

B. Organ Systems Support Definitions for the ACP dataset (NHSIA, 1997, Appendix C).

System monitoring/support	Indicators (any combination)
1. Basic respiratory	· More than 50% oxygen by fixed performance mask. · Potential for deterioration to the point of needing advanced respiratory support. · Physiotherapy to clear secretions at least two hourly, whether via a tracheostomy[1], minitracheostomy, or in the absence of an artificial airway. · Patients recently extubated[2] after a prolonged period of intubation[2] and mechanical ventilation. · Mask CPAP[3] or non-invasive ventilation. · Patients who are intubated to protect the airway but needing no ventilatory support and who are otherwise stable.
2. Advanced respiratory system monitoring/support	· Mechanical ventilatory support, excluding mask (CPAP) or non-invasive methods, e.g. mask ventilation. · Extracorporeal respiratory support.
3. Circulatory	· Vasoactive drugs used to support arterial pressure or cardiac output. · Circulatory instability due to hypovolaemia from any cause. · Patients resuscitated after cardiac arrest where intensive care is considered clinically appropriate. · Intra aortic balloon pumping.
4. Neurological	· Central nervous system depression, from whatever cause, sufficient to prejudice the airway and protective reflexes. · Invasive neurological monitoring, e.g. ICP[4], jugular bulb sampling.
5. Renal	· Acute renal replacement therapy (haemodialysis, haemofiltration etc.).

[1]Use of breathing tube in trachea.

[2]Insertion/removal of breathing tube.

[3]Continuous Positive Airways Pressure.

[4]Intra Cranial Pressure.

3.5. Casemix programme (CMP) from the Intensive Care National Audit and Research Centre.

ICNARC evolved from a relatively large study of unit mortality rates in Britain and Eire by ICS (Rowan, 1992; Rowan et al, 1993a,b; Rowan et al, 1994; Rowan, 1994a,b). It was formally launched in 1995 with funding from DoH and the Welsh Common Services Health Authority and is now a self funded not-for-profit company/charity. Programme fees are set at "cost recovery" levels and units join voluntarily.

The centre aims to provide a forum for professional discussion and a point of coordination for research findings, as well as data and information for providers, purchasers and the media (ICNARC, 1994a). Sub-committees are addressing the costs of care and standard scoring systems for organ dysfunction and clinical/nursing activity. The casemix programme (CMP) is at the centre of all this work and intends to provide a large High Quality Clinical Database (HQCD). The initial focus for the data is on measuring casemix and deriving risks of mortality as tools for audit and clinical research (ICNARC, 1994b).

3.5.1. Principles of casemix and risk adjustment in critical care.

Mortality rates are a "crude" measure of performance, taking no account of patients' depth of illness or natural recovery mechanisms. Techniques are developing to identify and measure these casemix factors before major treatment begins, and then to calculate statistical risks of hospital mortality (Ruttimann, 1989).

The principle for performance measurement is to adjust actual death rates using the statistical predictions as a standardising factor, similar in concept to age adjustment in other areas of epidemiology:

Standardised Mortality Ratio (SMR) = actual deaths/predicted deaths [Eqn 3.1]

Good unit/hospital performance, or benefits of new treatments, are shown by ratios below 1. There is, however, no fully accepted method and no current approach that also includes unit/hospital organisational factors with widespread applicability.

Depth of illness and reduced potential for recovery.

Depth, or severity, of the presenting illness is assessed via physiological and pathological tests which are normally taken as part of care and covering the major organ systems (Table 3.4). Degrees of abnormality are the important factor. Measurement intends to represent the patient's condition on admission. In practice, the worst values over the first 24h of care are often used.

Severity is put into context by the nature of referral to the unit. In general, cases following elective (planned) surgery are expected to have extremely abnormal clinical measurements immediately after the operation but are also anticipated to recover over relatively short periods. In contrast, emergency surgery and medical cases are believed to have deeper presenting conditions. Specific categories and diagnoses are commonly used in these circumstances to describe casemix in more detail.

Reduced ability to recover has been logically related to 3 main factors. Age and emergency treatment immediately before admission are readily available data. Presence of other conditions (chronic health or co-morbidity) is considered, usually restricted to the vital organ systems within the previous 6 months.

The casemix factors are measured by assigning points to particular ranges of continuous clinical variables at time of admission, with additional points for the presence of the chronic and mitigating conditions. Components and points may be combined and summed in different ways. A generic equation for an illness score is:

Illness score = Presenting physiological points + [Eqn 3.2]
Mode of referral points +
Specific diagnosis points +
Chronic health points +
Age points

Statistical risk of mortality.

Illness scores are converted to risk probabilities using logistic regression models. These define a logistic curve (or S-shaped relationship) between illness scores and proportion of deaths on the range [0,1] which is interpreted for the individual as risk of death.

Model parameters depend on the choice of variables comprising the illness score. They are fitted to the model, producing a risk prediction equation. An example for the generic illness score above is (with a linearised form of the logistic equation):

Mortality Risk = b_1(Presenting physiological points) + [Eqn 3.3]
b_2(Mode of referral points) + b_3(Specific diagnosis points) +
b_4(Chronic health points) + b_5(Age points) + Constant

where parameters b_1-b_5 and the constant are determined by the statistical fit to a sample of development data from past patients.

Eqn 3.3 computes the mortality probability for each case in a sample of new cases. Patients with values >0.5 are statistically predicted to die. System performance can be measured by a range of statistics based on tabulated true and false outcomes (see

Appendices to Rowan et al, 1993a,b). A common general method is the Receiver/Operator Curve (ROC) which plots the expected relationship between probabilities and actual numbers/proportions of deaths. The relationship should give a straight line from bottom left to top right and encloses 50% of the graph's area. Experimental plots that cover a significantly different area, overall or in localised pockets, show that the system is unreliable.

The prominent scoring and predictive systems.

Five systems dominate the literature in adult and paediatric critical care, primarily because they have been developed and subsequently tested on large samples. (See Table 3.5 for variables).

(1). Acute Physiology and Chronic Health Evaluation (APACHE) II (Knaus et al, 1985).

The international de facto standard for general adult patients.

(2). Acute Physiology and Chronic Health Evaluation (APACHE) III (Knaus et al, 1991).

APACHE II updated with parameters for more diagnostic categories and facilities to track and adjust predictions over time.

(3). Simplified Acute Physiology Score (SAPS) II (Le Gall, 1993).

A European approach substantially based on APACHE.

(4). Mortality probability models (MPM II) (Lemeshow et al, 1993).

Two models with relatively small datasets covering risks on admission and after 24h ($MPMII_0$, $MPMII_{24}$).

(5). Pediatric risk of mortality (PRISM) score (Pollack et al, 1988).

The only identified paediatric system with large scale evaluation.

3.5.2. Purpose and content of the CMP dataset.

The main purpose of CMP is to test the 5 prominent scoring and risk systems in the UK setting and, as data accumulate, to compute new parameters. The longer term aim is to refine the content and parameters of models in optimal systems for the UK.

The CMP dataset.

The dataset extends beyond the five outcome prediction models. It also includes the ACP items; activities, dates and times immediately before admission and after unit and hospital discharge; as well as organ donation rates. Official details are given in the ICNARC Case Mix Programme Dataset Specification (ICMPDS - ICNARC, 1997).

The full dataset contains 70 items but the number required for each patient varies with answers to branching questions (eg. location before admission). Items used in ICNARC's public analyses are listed in Table 3.5. A summary of sub-sets in order of collection is:

- Admission 1&2. Administrative codes (including ACP), demographics, source of admission and immediate prior care.

- Past medical history. Structured record of key chronic conditions based on presence/absence of evidence.

- Reason for admission. Up to 2 reasons (conditions) for admission.

- Mortality Prediction Model at admission (MPM II0). Model items not already covered.

- Physiology. Clinical tests (physiological, biochemical, histological) and clinical states (eg. sedation, paralysis) used in the 5 prediction models.

- Mortality Prediction model at 24h (MPM II24). Model items not already covered.

- Other conditions. Up to 2 relevant conditions that may have been identified since admission.

- Unit outcome. Ultimate reason (condition) for admission with classifications; codes for sub-periods of care and number of organ systems involved (ACP); dates, times, actions and destinations dependent on vital status and including organ donation.

- Hospital outcome. Vital status, dates and destinations at hospital discharge.

The CMP coding mechanism for medical conditions.

Arguably the most difficult items to record for critical care datasets are the patients' conditions (covered by "reason for admission" and "other conditions"). ICNARC provides a 5 level hierarchy, or cascading tree of choices, to build up a sequence of selections as the final code. The levels cover:

(1). Type of code (surgical/non-surgical).
(2). Body/organ system.
(3). Anatomical site.
(4). Physiological/pathological process.
(5). Condition.

3.5.3. Collection procedures.

Broad aims and requirements.

ICNARC's aim for a High Quality Clinical Database (Black, 1999) encourages involvement of clinicians, pooling of resources and data. it also emphasises 4 fundamental requirements:

- **Standardisation.** All data should be consistent within and across units and with international practices.

- **Incorporation of valid casemix methods.** It is noted that the methods are still developing. Nevertheless, contemporary approaches should be scientifically sound and have consensus support to encourage unit participation.

- **Collection of raw data.** Collection of raw data at source, rather than direct coding and classification, removes immediate problems from collectors and allows checks and alternative codings to be applied later.

- **Confidentiality.** In addition to legal constraints, results of analyses from individual units are open to interpretation. Publications and analyses shared with all participants have identifiers for patients, units and hospitals removed.

Process and procedures.

The process for each unit of data collection, validation and submission to the CMP database is shown in Figure 3.4. Up to 3 members from each unit are formally instructed by ICNARC and provided with material to train colleagues.
Data are collected by an audit clerk using a paper booklet for each patient with subsequent transcription to computers. Direct computer entry is applied if the system stores raw data before assigning codes and complies generally with the dataset specifications (ICMPDS). Data are transferred to ICNARC on floppies, CD or via a modem link.

A senior staff member is given responsibility for data quality and a 6 week pilot is performed. Recruitment to the programme also entitles the unit to regular newsletters and an annual meeting of all programme participants.

Once established, the unit transfers data on consecutive patients over a 6 month period (formally termed a "cycle" of data). It joins a queue for checking by ICNARC. A Data Validation Report (DVR) is returned to the unit confirming good quality data or highlighting items for local checking.

DVRs and revised dataset (cycle) are transferred between ICNARC and the unit until the cycle is declared "clean". A Data Analysis Report (DAR) is then sent to the unit and

patient records with sufficient entries or explanations for missing values are added to the programme database.

3.5.4. Collection performance from 1995 to 1998/9.

Performance statistics have been derived from various ICNARC publications including: the 1999 annual CMP database report (ICNARC, 1999); summary sheets released with the report; and information on costs from an earlier project proposal (ICNARC, 1996). Figures on unit sizes and clinical specialties were not included; and unit numbers vary between publications and within ICNARC's own analyses for the same periods.

Unit coverage (Table 3.6).

134 units were officially identified including 118 in England and Wales (118/295=40%). There was complete coverage in some old NHS regions (English regions changed in 1998) but no participants from Scotland. Despite a bias towards non-university units, university and affiliated sites have contributed more patient records to the CMP database.

Time to validate data cycles (Table 3.7).

Units joined the programme at different stages. 118 units had submitted at least 1 cycle of data with 82 fully cleaned, while 42 had reached the 3rd cycle with 24 cleaned. The mean times for validation at the 1st and 3rd cycles had fallen from 30.1 to 25.6 weeks. Most units required up to 3 DVRs (interchanges with ICNARC) to validate data. Delay at the units was the main constraint.

An interpretation of these figures is complicated by units joining and sending data at different times. Nevertheless it is clear that, on average, it was taking longer to validate the 6 monthly data cycles than they took to collect in the first place. In some cases, it took over 1.5 years.

Computer use in local collection (Table 3.8).

All 134 units were using commercial or locally developed computer packages. Computerisation removes additional transcription and was an ICNARC requirement for data transfer. There was no evidence, however, that computers assisted data collection at source or at an initial transcription. Indeed, ICNARC's co-ordinator for the North West reported that data collection practices varied markedly and quality was more closely related to consultant motivation than to computers (O'Connor, 1998).

Item completeness in the CMP database (Table 3.5).

The number of patient records in the validation process was reported as 59,855, of which 344,333 had been validated and 22,059 were in the database. Timescales and priorities for validation were unclear and criteria for inclusion in the database were also uncertain. Nonetheless, the figures may suggest substantial delays in the process and a reduction of up to a third in the number of patient records contributing to analyses after validation.

Completeness in the programme database showed high levels for most variables except biochemical and histological tests. Serum bilirubin, for example, was only 40% complete in some variable groupings for evaluating particular risk models.

ICNARC do not force collection procedures in unjustified circumstances. Nevertheless, missing data rates imply that full datasets for prediction models may be unavailable for a significant minority of patients under realistic conditions.

Costs of collection.

Annual costs to a unit charged by ICNARC are quoted at 1996 prices:

Administration, co-ordination, data processing and reporting (cost per bed)	£326.00
Training in data collection/Annual meeting	£326.00
ICMPDS + data collection support (cost per unit)	£54.34
Maximum cost to each unit in the first year (reductions for units >6 beds)	£2,336.34 + VAT

These figures give an annual fee of £366,291 over the 134 identified units; and £16.61 for each of the 22,059 patient records in the CMP database assuming figures can be applied to a single year (£6.12 for each of the 59,855 record sets in the collection process).

Additional local costs, indicated by ICNARC and estimated by HJL, are required to participate in the programme:

Personnel for data collection and entry (1 full time clerk equivalent)	£20,000.00
Computer hardware and general software	£500.00
Specific software development from the ICMPDS	£1,000.00

Overhead and administration costs are inexact but the main component is data collection staff. A further £3m should be added to annual costs for the 134 units, assuming each

unit has a clerk dedicated to the programme, and almost £6m if all 295 units in England and Wales were involved.

Table 3.5. The ICNARC casemix programme dataset and levels of completeness in the database AT 1998/9 (from ICNARC, 1999).

Explanatory notes

Data items	Items are a subset of the whole CMP dataset as grouped and presented in ICNARC's report on database completeness.
Completeness measurement	Tables include a column for % completeness. Items at or close to 100% are left blank. Those with significant missing rates have been taken from ICNARC's tables or estimated from by HJL graphs.

1. Admission.

22,059 patient cases 15 data items.

Postcode	
Date of birth	
Sex	
Date of admission to hospital	
Date of admission to unit	
Time of admission to unit	
Managed by unit team prior to admission	
Date/time managed by unit team	90
Planned admission to unit	
Admission for pre surgical preparation	
Source of admission to unit	
Location immediately prior to source	
CPR within 24h prior to admission to unit	w
Date/time of original admission to unit[1]	
Date of original admission to hospital[1]	95

[1]If internal/external patient transfers involved.

2. Unit outcome.

22,059 patient cases 12 data items.

Treatment withdrawn	95
Status at discharge	
Date of discharge from unit	
Time of discharge from unit	
Reason for discharge from unit	
Destination following discharge	
Brainstem death declared	
Date/time of removal of body	80
Organ donor	90
Death outside unit	95
Date of death	
Time of death	

3. Hospital outcome.

17,491 patient cases 5 data items.

Date of discharge from hospital	
Status at discharge from hospital	
Destination following discharge from hospital	
Ultimate date of discharge from hospital[2]	90
Status at ultimate discharge from hospital	90

[2]If patient has several episodes in a unit or delays in hospital discharge.

4. Paediatric Risk of Mortality (PRISM) model.

736 patient cases 15 data items.

Age	
Systolic BP	80
Diastolic BP	80
Heart rate	90
Respiratory rate	90
Oxygenation[3]	70
[4]$PaCO_2$	70
Serum bicarbonate	50
Serum potassium	80
Serum calcium	50
Serum glucose	80
Serum bilirubin	40
PT/PTT[5] times)	50
Glasgow Coma Score	80
Pupillary reactions	90

[3]% of O_2 in air mix if breathing assistance provided.

[4]Partial pressure (content) of CO_2 in blood.

[5]Prothrombin (blood clotting) times.

5. Acute Physiology and Chronic Health Evaluation (APACHE) II model.

19,554 patient cases 15 data items.

Type of admission	90
Age	
Chronic disease	
Temperature	90
Systolic BP	90
Heart rate	90
Oxygenation	90
Serum bicarbonate	60
Serum sodium	85
Serum potassium	85
Urine output	90
Serum urea	80
White blood cell count	85
Serum bilirubin	60
Glasgow Coma Score	90

6. Acute Physiology and Chronic Health Evaluation (APACHE) III model.

19,427 patient cases 15 data items.

Age	
Chronic health history	
Temperature	95
Mean arterial BP	95
Heart rate	95
Respiratory rate	95
Oxygenation	85
Serum bicarbonate	45
Arterial pH	80
Serum sodium	90
Serum potassium	90
Serum creatinine	90
Haematocrit/haemoglobin	90
White bloodcell count	90
Glasgow Coma Score	85

7. Simplified Acute Physiology Score (SAPS) II model.

19,554 patient cases 15 data items.

Type of admission	95
Age	
Chronic disease	
Temperature	90
Systolic BP	95
Heart rate	95
Oxygenation	95
Serum bicarbonate	60
Serum sodium	90
Serum potassium	90
Urine output	90
Serum urea	85
White blood cell count	85
Serum bilirubin	60
Glasgow Coma Score	90

8. Mortality Prediction Model at admission (MPM II_0.

16,758 patient cases 9 data items.

CPR within 24h prior to admission	
Medical/unscheduled surgery	
Mechanical ventilation	
Chronic diagnoses	
Systolic BP	90
Heart rate	90
Coma or deep stupor	90
Acute diagnoses	
Intracranial mass effect	85

9. Mortality Prediction Model after 24h (MPM II_{24}.

10,916 patient cases 12 data items.

Medical/unschedules surgery	
Age	
Mechanical ventilation	
Chronic diagnoses	
[6]PaO_2	90
Serum creatinine	95
Urine output	95
PT[5]	80
Coma or deep stupor	90
Intracranial mass effect	90
Confirmed infection	90
Vasoactive drugs	90

[6]Partial pressure (content) of O_2 in the blood.

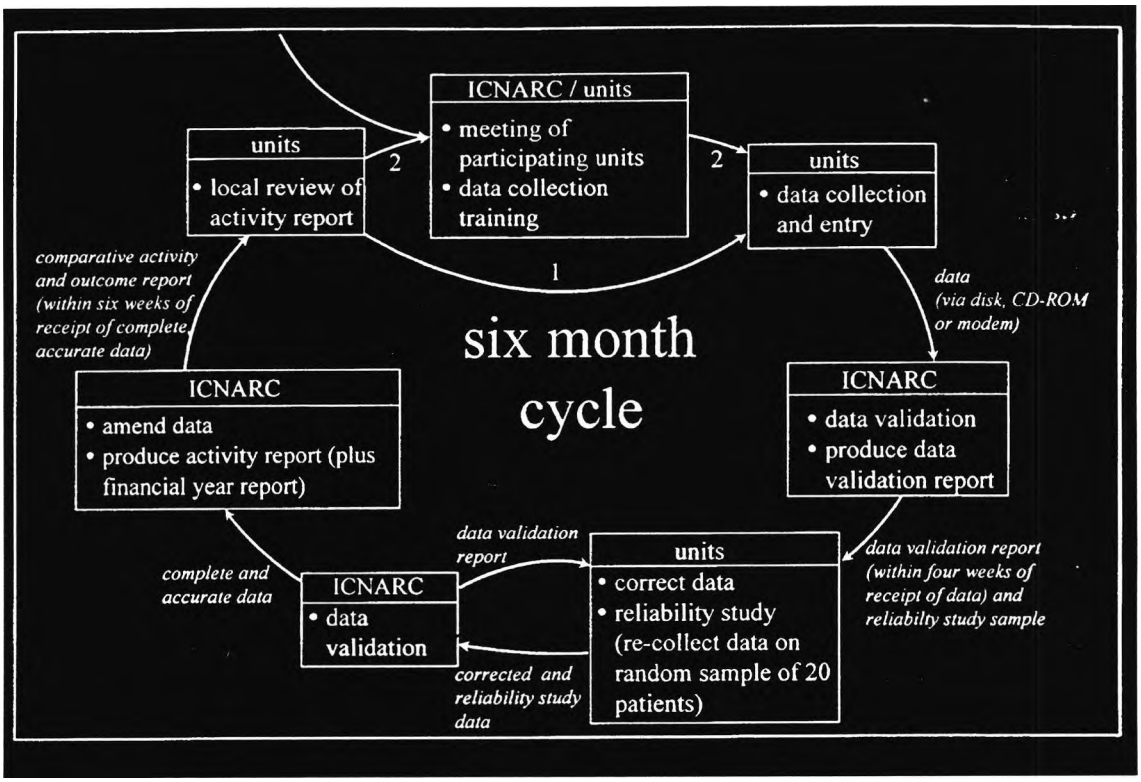


Figure 3.4. Schematic summary of the Case Mix Programme (CMP) data management process (from ICNARC, 1996).

Table 3.6. Recruitment of units by ICNARC at 1998/9 (from sheets accompanying ICNARC, 1999).

NB. The reported 119/203 (53%) coverage of general adult units in England/Wales/N. Ireland is inconsistent with Audit Commission figures of 295 units in England alone (see Table 3.2).

A. Recruitment by old NHS region or country.

Region	Units involved with ICNARC /units in region	% coverage
West Midlands	27/27	100
North West	35/35	100
South West	18/30	60
Anglia & Oxford	9/21	42.9
Trend	9/25	36
Northern & Yoorkshire	12/35	34.3
North Thames	10/34	29.4
South Thames	7/38	18.4
Northern Ireland	3/12	25
Wales	4/19	21
Total	134	

B. Recruitment by hospital type.

Type	N units	% of total recruitment (134)
University	26	19.4
University affiliated	21	15.7
Non university	87	64.9
Total	134	

Table 3.7. The data cleaning process on ICNARC's casemix programme (figures from sheets accompanying ICNARC, 1999).

The process of data collection, transfer to ICNARC and resolution of possible errors was summarised in Figure 3.4.

Cycles. Data from each unit are sent in batches (or "cycles") covering the last 6 months and join the queue for validation.

Data Validation Reports (DVRs). Anomalous data are checked and rechecked by sending DVRs between ICNARC and the unit.

A. Number of cycles received and cleaned by ICNARC (total dataset).

Cycle	Received	Cleaned
First	118	82
Second	79	46
Third	42	24
Fourth	27	6

B. Number of steps (DVRs) to clean each cycle (total dataset).

1 DVR	1	2
2 DVRs	30	9
3 DVRs	31	8
4 DVRs	17	5
5 DVRs	3	

C. Comparison of "time to clean" at 1st and 3rd cycles.

Time to clean a cycle (weeks).

	Cycle 1	Cycle 3
Mean (range)	30.1 (6-81)	25.6 (2-46)

Break down of times to clean a cycle (weeks).

	Cycle 1	Cycle 3
ICNARC: cycle received to DVR1 sent to unit	2.75	3.8
Unit: DVR1 returned	10.1	5.24
ICNARC: DVR1 received to DVR2 sent to unit	3.78	4.45
Unit: DVR2 returned	5.01	3.03
ICNARC: DVR2 received to DVR3 sent to unit	3.77	4.48
Unit: DVR3 returned	4.5	2.74
ICNARC: DVR3 received to DVR4 sent to unit	3.94	4.03
Unit: DVR4 returned	3.42	2.57
ICNARC: DVR4 received to DVR5 sent to unit	4.36	9.86
Unit: DVR5 returned	1.74	4.43

Table 3.8. Use of computers by units in 1998/9 for collection of ICNARC's casemix dataset (data from sheets accompanying ICNARC, 1999, contact details for system developers in ICNaRC, 1996).

System/developer	N units in use
Accubase	32
Auditbase	17
MIDAS	16
StopGap	15
Riyadh	6
WardWatcher	6
InforMed	5
ITUBASE	5
Dr Wilson (York)	5
ENACT	4
Ms Bracey (Devon)	4
PICIS	1
Quorum	1
Dr Winter (Nottngham)	1
"Home grown"	16
Total	134

3.6. Analysis of potential for local and national collection using Audit Commission data.

The Audit Commission, ACP project and ICNARC programme had all demonstrated problems with collection of national data but none had examined factors improving quality from individual units. The issues were raised with the Commission who agreed to release a sub-set of data from their postal questionnaire of units for independent analysis. The dataset had 85% unit coverage across England and Wales and had been officially supported by major stakeholders in critical care.

The aims of analysis were to examine the:

- Consistency of data collection in individual units as the basis for local monitoring and management, and separate from national requirements.
- Amount collected to common standards from all units for national use.
- Amount collected to common national standards with data split into logical groups (Collection Categories).
- Effects of unit type, size and computerisation on national collection.

3.6.1. Methods: dataset, Collection Categories and analytical concepts.

Section E (Activity) from the questionnaire was provided by the Commission. It contained an isolated question (item) on use of computers in patient data management, and 52 main items summarising patients, nursing and clinical activities over 1997/8.

Most items required counts over the period of collection; a minority needed basic derivations or calculations. The set of main items is listed in Table 3.9 grouped by Collection Categories described below.

Qualifiers on collection - quality criteria.

Each main item was accompanied by boxes to record the period and accuracy of collection with the following response classes:

Period of collection. 1 - Financial year 1997/8 (the Commission's preferred period).
2 - Calendar year 1997.
3 - Any identified period of under 1 year.

Accuracy of count or calculation. 1 - Accurate..
2 - Approximate.

Data reduction and Collection Categories.

Some items were ambiguous or did not fit easily into any group. They were assigned to a Category excluded from analyses. Other items were effectively multiple responses to a common question dividing the total number of admissions into different sets. For example:

Total admissions	=	Patient numbers by age categories
	=	Live unit discharges + Deaths on unit

There were unexplained differences between some of the sub-group totals and the number of admissions reported by units. Sub-groups within +/-10% of admissions were maintained in the database and the others re-classed as missing.

Removal of exclusions and merger of multiple responses reduced the total number of items for analysis. The resulting 26 items were grouped into 7 Collection Categories:

1. Admissions - 2 items. Broad patient referral sources.

2. Patient age structure - 1 item.

3. Occupancy - 9 items. General data on lengths of stay and consequences of limited bed availability within the unit and the hospital.

4. Nursing/patient dependency levels - interpreted as patient numbers - 1 item. Nursing requirements and indicator of a major cost component.

5. Clinical practice - 4 items. Broad treatment classes applied to the patient population.

6. Outcomes - 3 items. Discharge destinations and survival rates in the unit and hospital.

7. National datasets (ACP, CMP and related) - 6 items. Data specifically related to the 2 detailed collection programmes but not covered by other Categories.

Analytical concepts.

Collection Categories allowed total data collection to be examined by logical groups. The data collection qualifiers provided 6 recording methods, or "qualities". The following definitions were used for analysis:

Collection to national standards. Items from all units should have the same standard, recorded for the financial year (Audit Commission's preferred method) with accurate rather than approximate data (period=1, accuracy=1).

Local consistency. Items from an individual unit should be collected to the same local standard, whether or not it meets the national requirement.

3.6.2. General adult critical care units providing data: type, size and computerisation.

The 252 responding units divided into 3 broad types with corresponding bed availabilities:

Code	Unit type	N units	N beds	Median bed size	Range of beds
	All	252	1573	6	2-22
1	ICUs	116	705	5	2-14
2	Mixed	101	708	6	2-22
3	HDUs	35	160	4	2-10

The median unit size was 6 beds, allowing 2 size categories for subsequent analysis:

Code	Size (beds>	N units
1	<=6	164
2	7+	88

Computerisation within individual units was addressed by the isolated item on the Commission's questionnaire to identify:

"the statement that best describes how patient data are managed.":

Class identifier	Description	n units	% of 252 units
	No response.	7	2.8
1	Cmputer system with automatic recording of all patient data.	5	1.9
2	Computer system with automatic recording for some data and paper records for other data.	42	16.8
3	Manual recording of patient data, with some data entry into a computer system.	180	71.4
4	Manual recording only.	18	7.1

In analyses, management classes 1&2 were grouped as 1 = Computerised, and 2 = Manual.

Statistical relationships within the sample of units.

Different unit types had different mean sizes. But use of computers for managing patient data was spread proportionately between the 3 unit types. (Chi^2=0.08, p=0.96).

3.6.3. Results.

Local consistency.

In general, a variety of different collection qualities was used within each unit with the range increasing with the number of items collected (Table 3.10). At the top level, only 4 units collected 20+ items with a single common quality in the individual unit. The unit that collected all 26 items used 3 different qualities.

Global data collection to national standards.

Table 3.11 reports data collection across all units, covering all items and divisions by Collection Categories and using all 6 quality combinations. The national requirement (financial year & accurate record) was the most common recorded format but only 30% of the total national dataset was collected to this standard.

Patient age structure was relatively well recorded (74%) while only 16% of data on nursing levels (the major cost component) was reported to the national standard. Notably, standard data on outcomes was also less than half the total requested (43%).

Effects of unit size, type and computerisation on data collection to national standards.

Table 3.12 presents the amount collected within Collection Categories for comparison across unit sizes, types and levels of computerisation.

There was no statistical difference in the % of total data collected between the 2 unit size groups. In contrast, differences in total collection between type and computerisation groupings were statistically significant with improvements of 10% and 8% respectively:

Groups for comparison	Mean % total collection	T value	Signif. of T
ICUs	33.3	2.55	0.01
HDUs	23.3		
Computerised management of patient data	36.0	2.34	0.02
Manual management of patient data	28.4		

The relationships were also shown at the level of individual units. The top 25 units included 17 which were ICUs and/or computerised (13 computerised, 4 manual) compared to 7 in the bottom 25 units:

	Top 25 units	**Bottom 25 units**
Range of total data collected (%)	61.5-80.8	0-7.7
N units: ICU or Computerised	17	7
N units: ICU and Computerised	2	1
N units: Computerised non ICU	11	4
N units: ICU not Computerised	4	2

3.6.4. Conclusion from the analysis.

The Audit Commission's questionnaire was an official example of large scale data collection. The amount collected to national standards increased in ICUs and units generally which applied computerised patient data management. However, the overall amount collected for national use was low and, in general, units were using too many different "qualities" or methods of collection to support efficient local monitoring.

Table 3.9. Data items from Section E (Activity) of the Audit Commission's postal questionnaire of individual units (Audit Commission, 1998a) grouped into Collection Categories by HJL.

Key to superscripts.

[1,2]Sub-groups that should sum to total number of admissions.

[3]Should not exceed total number of admissions.

[4]Should not exceed length of monitored period.

Note on number of items. Superscripts 1 & 2 effectively identify single items with multiple responses, reducing the effective number of items in some Collection Categories. Together with "exclusions", this reduces the total number of items for analysis from 52 to 26.

0. Exclusions (no simple Category assignment).

Number of admissions who received a period of intensive care.
Number of admissions who received a period of high dependency care.
Number of admissions ventilated for more than 24 hrs.
Number of ventilated bed days.
Number of re-admissions before discharge from hospital.

1. Admissions - 2 items.

Total number of admissions.
[1]Number of emergency admissions.
[1]Number of elective admissions.
[1]Number of patients transferred in from another trust.

2. Patient age structure - 1 item.

[1]Number of babies (admissions) less than 1 month of age.
[1]Number aged 1 month to 12 months old.
[1]Number age 1 to 5 years (ie. after 1st birthday).
[1]Number aged 6-10 years.
[1]Number aged 11-15 years.
[1]Number aged 16-17 years.
[1]Number aged 18-65 years.
[1]Number aged 66-85 years.
[1]Number aged 86+ years.

3. Occupancy - 9 items.

Number of occupied bed days (sum of daily count of midnight bedstate).
Per cent of patients who stayed 24 hours or less in the unit.
Average occupancy (%)
Median length of stay (days).
[4]Number of days when unit was full (ie. no spare beds with available staffing).
[3]Number of patients discharged early from the unit due to pressure on beds.
[3]Number of patients whose discharge was delayed due to shortage of beds to discharge to
Number of patients refused admission because the unit was full.
Number of cancelled operations.

4. Nursing/patient dependency levels - interpreted as patient numbers - 1 item.

[1]Number of patients/patient days of low nursing dependency (ie. needing 1 nurse to every 2 patients).
[1]Number of medium dependency (1:1).
[1]Number of high dependency (1.5:1).
[1]Number of very high dependency (2+:1).

5. Clinical practice - 4 items.

[3]Number of admissions ventilated for any period.
[3]Number of admissions receiving tracheostomy.
[3]Number of admissions receiving pulmonary artery catheterisation.
[3]Number of admissions receiving haemogiltration.

6. Outcomes - 3 items.

[1]Number of patients discharged alive.
[1]Number of patient deaths on the unit.
[3]Number of discharged patients who died in the hospital.
[3]Number of patients transferred out from this unit to a unit in another trust.

7. National datasets (ACP, CMP and related) - 6 items.

ACP number of days of intensive care.
ACP number of days of high dependency care.
Mean APACHE II score for admissions.
Median APACHE II probability for admissions.
[1]Number of admissions with primary diagnosis: Medical.
[1]Number of admissions with primary diagnosis: Trauma.
[1]Number of admissions with primary diagnosis: Surgical.
[1]Number of admissions with primary diagnosis: Paediatrics.
[1]Number of admissions with primary diagnosis: Any other specialty.
[2]Number of patients with 0 organs failing.
[2]Number with 1 organ failure.
[2]Number with 2 organs failing.
[2]Number with 3 or more organs failing.

Table 3.10. Number of different "qualities" of data collection by individual critical care units.

The Table overleaf shows the range of different standards (or "qualities") for collecting the Audit Commission's requested dataset across all studied units. It demonstrates that individual units are using different standards for their own, local data collection as well as for national use.

Explanatory notes

Data. The dataset contained 26 items (see Table 3.9). 246 of the 252 studied units provided data. There were 6 different standards for collecting each item (3 collection periods and 2 levels of accuracy).

Interpreting the Table. Column 2 shows the number of items collected (from 1 to 26). Column 1 shows the number of units collecting that number of items. The 6 columns to the right split the number of units according to the number of collection standards used (ie. 1-6).

In summary, each row indicates the number of items collected, the number of units collecting those items and the range of collection standards used by the identified units.

N units	N items	N qualities of collection					
		1	2	3	4	5	6
1	1	1					
3	2	2	1				
0	3						
4	4	2	1	1			
0	5						
4	6	3		1			
4	7	2	1	1			
9	8	2	3	3			1
5	9		3	2			
8	10	1	6	1			
6	11		3	2	1		
11	12	2	3	6			
8	13		3	3	2		
10	14		2	4	4		
15	15	3	3	6	3		
13	16	6	2	3	2		
22	17	4	5	9	4		
17	18	1	5	2	8	1	
20	19		4	10	6		
16	20	1	8	4	2	1	
22	21	2	4	13	2	1	
23	22		5	5	10	3	
12	23	1	3	5	3		
9	24		1	1	5	2	
3	25				1	2	
1	26			1			

Table 3.11. % total data collection from 252 study units for the 6 reporting "qualities" for all 26 data items and for each Collection Category.

Collection Category	N items	N total items (units*items)	Financial year/ Accurate	Financial year/ Approximate	Calendar year/ Accurate	Calendar year/ Approx.	Part year/ Accurate	Part year/ Approx.
All	26	6,552	29.9	4.9	5.1	2.2	8.8	2.5
Admissions	2	504	58.5	0.8	11.3	0.2	4.0	0.0
Patient age structure	1	252	73.8	0.0	0.0	0.0	0.0	0.0
Unit Occupancy	9	2,268	21.4	8.4	5.5	3.7	8.7	3.5
Nursing levels	1	252	16.3	0.0	0.0	0.0	0.0	0.0
Clinical practice	4	1,008	29.3	9.7	8.4	3.9	9.3	2.8
Outcomes	3	756	42.5	1.9	4.0	0.9	15.3	4.9
National datasets	6	1,512	22.2	1.2	2.6	0.7	9.9	1.3

Table 3.12. Percent total data collected to national standards (financial year & accurate report) for the different Collection Categories compared across size, type and computerisation classes as unit groupings.

Collection Categories	All	Admissions	Patient age structure	Unit occupancy	Nursing levels	Clinical practice	Outcomes	National datasets
Unit groupings								
All units	29.9	58.5	73.8	21.4	16.3	29.3	42.5	22.2
Size <=6 beds	29.1	58.8	80.5	19.9	17.1	28.0	41.9	20.8
Size 7+ beds	32.2	57.3	62.7	25.3	14.7	32.7	43.1	26.2
ICUs	33.3	59.5	81.0	25.0	15.5	33.0	47.4	25.0
Mixed	28.3	60.4	70.3	20.2	12.9	26.5	39.9	20.8
HDUs	23.3	50.0	60.0	13.0	28.6	25.0	33.3	16.7
Patient data management classes 1&2 (Computerised)	36.0	58.5	76.6	32.6	10.6	33.0	48.2	27.0
Patient data management classes 3&4 (Manual)	28.4	58.8	73.7	18.7	17.7	28.7	40.9	20.8

3.7. Particular problems with data quality.

Definitions of care, units and beds.

There is still no clear distinction between intensive and high dependency care, with further complications introduced by the terms "critical" and "augmented care" which are new to the UK. This problem explains difficulties in reports from the Audit Commission and ICNARC in clearly identifying unit numbers and patient groups. In addition, monitoring of national bed numbers is a recent English initiative. Given this situation, it is not surprising that national data on the details of care have been absent for some time and are proving difficult to collect.

Use of computers.

Computerisation removes the costs and potential errors of repeated paper transcription and simplifies data transfer. In contrast, there is little evidence beyond a statistical link identified in 3.6 to show that computers improve direct data collection. The amount collected to local or national standards by "computerised" units was still relatively poor. Moreover, full benefits of computers are limited if raw data are in physically different locations and stored on paper or incompatible electronic formats.

Data collection depends on clerks.

Collection for local and national audit is delegated to clerks. One of ICNARC's regional co-ordinators in the North West has observed that data quality may be most closely related to the motivation of consultants. While the observation may reflect local decisions on resources, it also suggests that special support and knowledge based skills might be targeted at the staff who have responsibility for direct data collection.

Data collection practices in general.

ICNARC have stated that "there is no evidence to support the hypothesis that training in data collection will improve the accuracy of the data collected at individual units" (eg. ICNARC, 1999). However, their North West co-ordinator has also observed a very wide range in collection practices across the 34 units in her region. This suggests that studies to test ICNARC's hypothesis, and collection practices generally may be difficult to design and implement.

Missing values and broader content for datasets.

There has been no formal feedback on quality of the short ACP dataset since introduction but consultants were sceptical in advance. The much longer CMP database does provide evidence that variables for the prediction models, particularly biochemical and histological tests, are routinely incomplete for a significant minority of patients.

Information on unit organisation is not included in any of the 5 mainstream prediction models or in ACP. The Audit Commission, however, identified a statistical link between higher mortality rates and consultant shift patterns. It should be noted that this finding was only possible through collaboration with ICNARC. If the models or raw datasets cannot be enlarged, then audits should take more advantage of collaborative monitoring approaches.

The cost of quality.

ICNARC's own figures show that achieving a High Quality Clinical Database (HQCD) is expensive. Data collection staff account for most of the cost but most of the time is spent validating collected data. Given the additional concerns from the ACP project and

the findings from 3.6 that most units are unable to collect audit data to recognised standards, a fully national approach along ICNARC lines is unlikely in the near future.

3.8. Conclusion to the Case Study.

General adult critical care in England and Wales has had no coordinated approach to data collection for audit or research. There is now, at least, a national bed monitoring programme in England. A basic dataset introduced across England and Wales (ACP) was initially discounted by consultants as unfeasible and has provided little further feedback. A much more complicated dataset (ICNARC's CMP) is running nationally on a voluntary basis. It is arguably the most important development in the field in this country, but it is also expensive and time consuming.

The Critical Care Information Advisory Group is re-considering datasets and standards as part of the 2002/3 national review across healthcare. In addition to requirements of top level managers and researchers, it should consider basic staff skills and computer requirements which may make large scale data collection quicker and more cost-effective.

Chapter 4

Home data collection by patients suffering from Diabetes Melitus

4.1. Introduction.

The second Case Study addresses the role of data collection by patients themselves as an integral part of clinical care (home data collection). Diabetes Melitus (DM) is the example.

DM is a disorder of carbohydrate metabolism predominantly managed by careful diet, daily injections of insulin or tablets enhancing the effects of hormonal control systems. Regular collection of home blood sugar tests is the minimal requirement for personal monitoring and for specialists to assess the details of therapy.

The disorder affects several organ systems and can lead to premature death. Prevalence is reputedly increasing in the West. There is no cure but, in principle, DM can be managed following early detection.

In marked contrast, specialist services are relatively rare and tend to be concentrated in a few centres. The situation has prompted research into computing as a method for spreading skills and knowledge to more healthcare professionals and to patients themselves.

An example computing initiative is reported in this chapter. The project was a collaboration with a major London diabetes centre over 1994-7 and funded by the Engineering and Physical Sciences Research Council (EPSRC). It aimed to develop

algorithms advising on insulin regimes for individual patients (Leicester et al, 1997/esrc).

Organisation of the Case Study

Section 4.2 defines the types of Diabetes Melitus, their broader medical consequences and the principles of care. scale and costs are addressed with information from Diabetes UK (formerly the British Diabetic Association). Historic developments and recent research into individual care and service management are considered; along with more direct implementation of initiatives at national and international level.

Section 4.3 introduces practices at the major hospital collaborating with the reported research.

Section 4.4 describes the computer system developed as part of the research programme - *UTilities for OPtimising Insulin Adjustment* - UTOPIA.

Section 4.5 tests assumptions about data quality required to use the UTOPIA system. Thirty-seven patients using data collection technology are followed over 2 years in the *Meter Study*.

Technical details are largely confined to Appendices to the main Thesis.

Appendix 1 details methods of Time Series Analysis based on Bayesian methods (BATS) incorporated in the UTOPIA system to extract daily patterns of control from blood sugar data, and used in the Meter Study to track disease control and data quality for individuals over longer periods.

Appendix 2 Summarises principles of questionnaires targeting opinions and perceptions of patients used on the Meter Study.

General findings

The Case Study shows the contradiction between the importance of home data in manual and computer approaches to care, while the quality of such data is receiving relatively little academic attention.

4.2. Background and wider context.

4.2.1. Patient group and management problem.

Medical explanation of Diabetes Melitus.

Sugars are a major source of energy in the human body. They are extracted from the diet, stored as long chain carbohydrates primarily in the liver (glycogen), and released back into the circulation in response to demand. When energy supplies are low, fats and proteins are also naturally converted to raw sugars. Glucose is presented as the important sugar because it is a component of other sugar compounds and measurement techniques are relatively well developed.

In broad terms, relevant metabolic processes are controlled by 2 hormones secreted by the pancreas (from Islet cells). Glucagon promotes release of sugars from the liver while insulin controls cellular uptake.

Abnormalities in the processes result in at least 2 categories of Diabetes Melitus. The insulin dependent form (IDDM or Type 1) is attributed to progressive under production of insulin and commonly diagnosed under the age of 40. The non-insulin dependent form (NIDDM or Type 2) is currently linked to normal insulin production but with reduced effect. It is more commonly diagnosed in people over 40 and associated with increased weight. More general risk factors, beyond family inheritance, are uncertain.

Treatment and consequences of poor disease control.

IDDM is treated by advice on diet, exercise and daily insulin injections. NIDDM patients receive similar advice but the injections are replaced by tablets to increase (potentiate) the effects of naturally produced insulin. Increasingly, injections are the clinical recommendation for both IDDM and severe cases of NIDDM.

The aim of advice and medication is to achieve normal and stable blood glucose levels over time. High or low levels should be balanced by corresponding peaks and troughs in blood insulin activity. If the balance is wrong, blood glucose can fall too low (hypoglycaemia) with immediate risks of coma. Long periods of abnormally high blood glucose (hyperglycaemia) can disrupt other metabolic processes and damage small and large blood vessels.

Symptoms of thirst and tiredness are common. Long term "complications" due to circulatory damage include, reduced sensitivity in the hands and feet with possible gangrene; coronary and kidney diseases; impotence; sight loss; and secondary damage to the central nervous system causing persistent mental confusion.

Insulin "regimes" are defined by the number of daily injections, the activity period of each insulin type (short, medium or long acting) and the strength or volume of the injected insulin measured in Units (U). The normal range for blood glucose varies with professional opinion but is commonly cited at 4-10mmol/l. An adult patient's weight is assess by the Body Mass Index (weight in kg/(height in m)^2 in m) giving an accepted range of 19-24. Broad clinical control is measured by glucose attaching to haemoglobin (HbA1c, measured in %) or with other sugar-protein compounds (eg. fructosamine) reflecting glucose levels over the past 3 months and 6 weeks respectively.

Patients are expected to monitor their own blood sugars, administer injections and keep records for inspection by professionals at clinical visits. However, records may be falsified to please clinicians. Repeated use of the same injection sites damages tissues and reduces insulin absorption. Control may be particularly difficult during

illness or stress. In addition, low blood sugar can trigger large and automatic release of stored sugar (rebound effect) hiding the true control problem.

4.2.2. Scale and stakeholders.

According to Diabetes UK (see www.diabetes.org.uk), 1.4 million people nationally suffer from DM. A further million are unaware that they have the problem while each known case also affects a family or carer. Costs of chronic care are considerable but it is widely argued that personal costs to families and national losses through reduced ability to work are greater still.

Cases of NIDDM are projected to rise with the aging population. Medical consequences from both types of DM are also expected to rise with social trends in reduced exercise and poor diet.

The human and economic figures highligh DM as a concern beyond patient groups and specific charities. It is a target area for the Department of Health. Numbers of endocrinologists specialising in diabetes (diabetologists) are limited and there are relatively few nurses in hospitals or GP surgeries with appropriate qualifications. In addition, the multi-system nature of DM extends the stakeholder group to other branches of medicine, particularly ophthalmology and coronary care.

4.2.3. Historic developments and research.

The hormonal controls over DM were first identified by Banting and Best in the 1920s. More recent research is concentrating on genetic causes of the disorder and transplantation of islet cells as a long term cure. The interim initiatives have been addressing external factors of treatment and service organisation which are more immediately open to development and implementation.

Improvements in personal treatment.

Insulin for patients was manufactured by extraction from tissues from different animal species. Genetic engineering changed the situation during the 1980s (particularly the US company GenenTech). Human and animal varieties of the hormon are now produced directly from related genes (ie. direct from the genetic code), in bulk and to high quality.

Pharmacologists have developed methods to adjust the periods and peaks of insulin activity in the blood (formulations and preparations). A choice of insulin types is now available for tailored therapy (very short, short, medium and long acting). Dietary supplements have also been identified for patients with special circumstances, notably during pregnancy.

Bioengineers have updated the technology for delivering injections and personal monitoring of control. Needles have become smaller and often attached to calibrated "pens" delivering specified combinations of insulins in single injections. Blood glucose measurement still uses pinprick samples applied to special paper strips, but the strips can now be photochemically analysed and the results stored by the same handheld device for patient use (glucometers). A range of devices is available from pharmaceutical companies with increasing support for data downloads to computers.

Major IT initiatives.

Broader IT applications were promoted in the late 1980s by the European Union's Artificial Intelligence in Medicine Programme (AIME). The scale of the problem, and overlaps between best medical practice and engineering concepts, established DM as a flagship application domain.

The subsequent Diabetes Optimisation through IT initiative (DOIT) brought together projects on electronic clinical records, home monitoring, physiological simulation

and patient education. DM projects are also prominent in more recent European programmes promoting electronic networks (telematics).

Diabetes remains a productive area for technological research. Arguably, though, it lacks the necessary agreements on concepts, standards and direction on transition from manual approaches for systems to be adopted on any scale.

Large clinical trials and international targets

Clinical practice has been more directly influence by large scale treatment trials. The World Health Organisation compared intensified insulin injections with insulin infusion pumps in centres across Europe (Staehr Johanson, 1989; Thibult, 1990). In America, the Diabetes Control and Complications Trial compared normal practices with intensified injections and support over the longer term (DCCT Research Group, 1986, 1987 - studies continued until 1994). Bothe found essentially that more "aggressive" conventional therapy improved outcomes while external pumps were cumbersome and risked infection.

Such trials, coupled to poor mortality and morbidity statistics for the diabetic population, prompted a revised approach from the World Health Organisation. Its St Vincent Declaration set guidelines and new targets for individual care and organisation of services across Europe (Krans et al, 1992).

Patient perceptions as an additional measure of care

The clinical trials also encouraged development of psychometric questionnaires and scales to include patient perceptions as part of assessments. The more established scales (see Bradley, 1994) are now being widely adopted and developed not only in large trials but also in local clinical audits (Williams et al, 1992) and as part of datasets to monitor continuing care (Wilson et al, 1993).

4.2.4. Related initiatives.

International guidelines and targets have been updated and tailored to the UK in a recent National Service Framework. Services across sectors are supported by Quality Indicators for Diabetes Services (QUIDS) and patient information pilots from Diabetes UK. Patient registers based at GP surgeries are proposed to monitor progress for individuals and developments for demographic and geographic populations.

4.3. Clinical practice at a hospital with a major Diabetes Centre.

Research reportted in the next 2 sections was based on clinical practice at a Diabetes Day Centre. Professionals were organised into teams led by diabetologists. Care staff included specialist nurses, dieticians, chiropodists, ophthalmologists and counsellors. Laboratory staff provided support with analyses of blood samples and biochemical composition of whole body tissues (eg. fat and protein ratios).

Patients were normally recommended to attend the clinic at 3-6 month intervals and to receive an annual review. They were advised on most aspects of self care in addition to medical and social issues of diabetes.

Insulin regimes were set by diabetologists and adjusted as appropriate by nurses and patients. Regimes were judged on the stage of disease and patient preferences. Advice also covered recovery strategies following hypoglycaemic crises.

Home blood glucose testing was recommended 4 times a day - before the 3 main meals and at bedtime. Paper log-books were provided to collect results. Similar log-books for food were available if required.

At each clinical visit, professionals examined log-books, measured height and weight and took a blood sample for glucose, HbA1c and fructosamine results to clinical standards. These data, coupled with patient consultation, were the bases for adjusting therapy.

4.4. The UTOPIA computer system.

Utilities for Optimising Insulin Adjustment (UTOPIA) aimed to mimic clinical practice through a combination of statistics, mathematical models and simplifying assumptions. This summary complements the theory and design provided by Deutsch et al (1996).

The key principles were:

- Blood glucose data collected under a given insulin regime yield a characteristic daily pattern - the "Modal Day".
- A change to the insulin regime changes the Modal Day.
- This "dose-response" relationship allows the change in Modal Day to be predicted for any change in insulin and thus provides a basis for ranking and selecting regime adjustments.

4.4.1. Mathematical formulation.

Landmark measurement times and Modal Day extraction

The 4 daily blood glucose measurement times required assumptions of equal spacing for subsequent use as a Time Series (TS). Time periods on the 24h clock were adopted with nominal times for the main measurement points (the "over night" period was added for monitoring data collection only):

Period label	From	To	Nominal time for TS analysis
0. Overnight	2:00	5:00	
1. Breakfast	5:00	11:00	6:00
2. Lunch	11:00	15:00	12:00
3. Dinner	15:00	22:00	18:00
4. Bedtime	22:00	2:00	00:00

The Modal Day was extracted using Bayesian Times Series Analysis (BATS) and the model:

$$G_i = \text{level} + \text{season}_i + \text{noise} \qquad \text{[Eqn. 4.1]}$$

where,

i counter for the 4 blood glucose measurements over the day (1,...,4 in repeating sequence through the data);

G combined blood glucose pattern (ie. Modal Day);

level mean across the day;

season cyclical departures around the mean at the landmark measurement times;

noise spread of measurements about the Modal Day pattern.

Global parameters were required to yield the Modal Day using all available data between clinical visits with equal weighting. These conditions reduce Eqn. 5.1 to a standard seasonal curve fit for 4 measurement points (i=1,..,4) using the data relevant at each point. (eg. all breakfast data for I=1).

The fit is equivalent to computing the mean for each of the I points ($\sum x_i$/n days data). The level is then the mean of means ([$\sum x_i$/n days data)]/4); and the seasonal deviations are the differences at each of the i ([$\sum x_i$/n days data)] - level).

Insulin Profiles

Insulin regimes were converted to 24h Insulin Profiles in the blood using a model of subcutaneous insulin absorption and system elimination (Berger & Rodbard, 1989).

The model contained adsorption and degradation constants for different insulin types. A small fraction of the insulin in the blood was allocated to a compartment for "interstitial fluid" where it was considered to be active.

Injection timings were assumed to correspond to the nominal blood glucose measurement times. Each insulin injection and type was computed separately. The final profile was then the sum of these "sub-profiles".

Dose-response relationship

Modal Days and Insulin Profiles were computed at consecutive clinical visits. Changes compared the current with the previous visit. In principle, changes in Modal Days at any point i were attributed to cumulative changes in Insulin Profiles over the previous 24h (i-24) and weighted by time from i. Figure 4.1 illustrates with example Modal Days and Insulin Profiles graphed on the same time axis.

This dose-response relationship for the changes was expressed as a convolution integral:

$$dG_i = \int_{t=I-24}^{i} S.dI_t.r_t.\left(1-e^{-K}\right)/K.e^{t-24} \qquad \text{[Eqn. 4.2]}$$

where,

i	times of patient's blood glucose measurements;
t	integration variable running from i-24h to i;
dG	change in blood glucose Modal Day;
dI	change in Insulin Profile;
r	a fixed daily rhythm in insulin sensitivity drawn from pharmaceutical literature (BoeHringer Mannheim);
S	insulin sensitivity parameter,

K glucose self control parameter.

Solution for parameters S and K over all landmark measurements (dGi) then predicted the change in the Modal Day at any given point via:

$$dG_i = S.D(I_{i)} + K.G_i \qquad \text{[Eqn. 4.3]}$$

where D indicates an integration over the interval i-24 to i, and other symbols are drawn from Eqn. 5.2.

Advice generation

The final step assumed that the dose-response relationship for changes could be applied to the current Modal Day and Insulin Profiles to predict the effect of any insulin adjustment. Predictions for any new Modal Day were given by:

$$G_i\text{predicted} = G_i\text{current} + dG_i \qquad \text{[Eqn. 4.4]}$$

4.4.2. Computer design and implementation.

UTOPIA was implemented for WINDOWS in Borland C++ 5.0. Figure 4.2 summarises the 4 module design and links to the clinical database at the collaborating hospital. Modules and their functions were:

Data Viewer. Allowed patient selection and display of results from all modules. Descriptive statistics for blood glucose data covered period of day, day of week or within specified dates.

Interpreter. Extracted the Modal Days from blood glucose data.

Learner. Computed the Insulin Profiles and solved the convolution integral.

Adviser. Used results from the Adviser to predict new Modal Days for a range of relatively small insulin adjustments; ranked the results according to qualitative rules; and selected the advice predicting the most stable (flat) Modal Day within target ranges.

4.4.3. Summary of underlying assumptions for using UTOPIA.

Although there were logical and mathematical abnormalities in the system implementation, the fundamental assumptions relating to home data were:

- A patient followed consistent injection and measurement regimes between clinical visits.
- Home blood glucose data were statistically stable over time (stationary) with implications that the disease itself was relatively stable over the collection period.
- Missing data were rare and evenly spread across the 4 measurement times of the day.
- Dietary changes, illness and other occasional events added only random noise to the data.

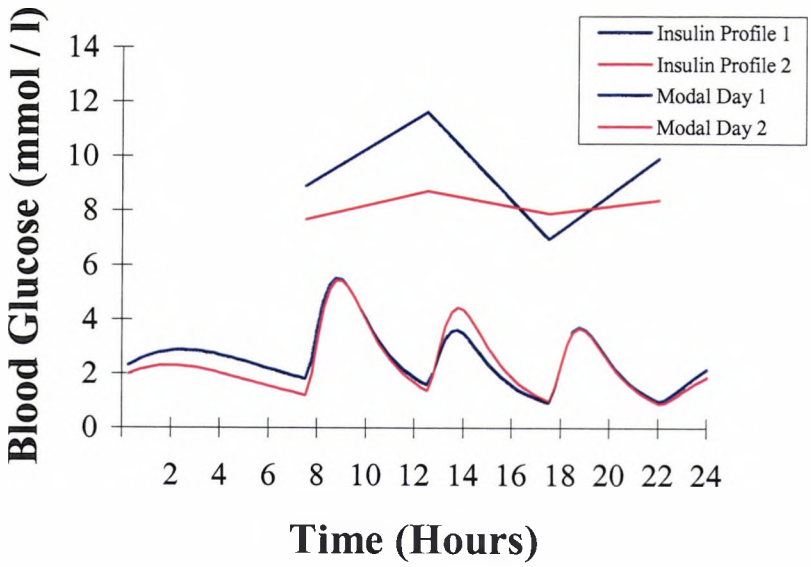


Figure 4.1. Graphical view of blood sugar Modal Days and blood Insulin Profiles at successive clinical visits. Changes in Modal Days at a given landmark point I are attributed to cumulative and weighted changes in Insulin Profiles over the period I-24h to i.

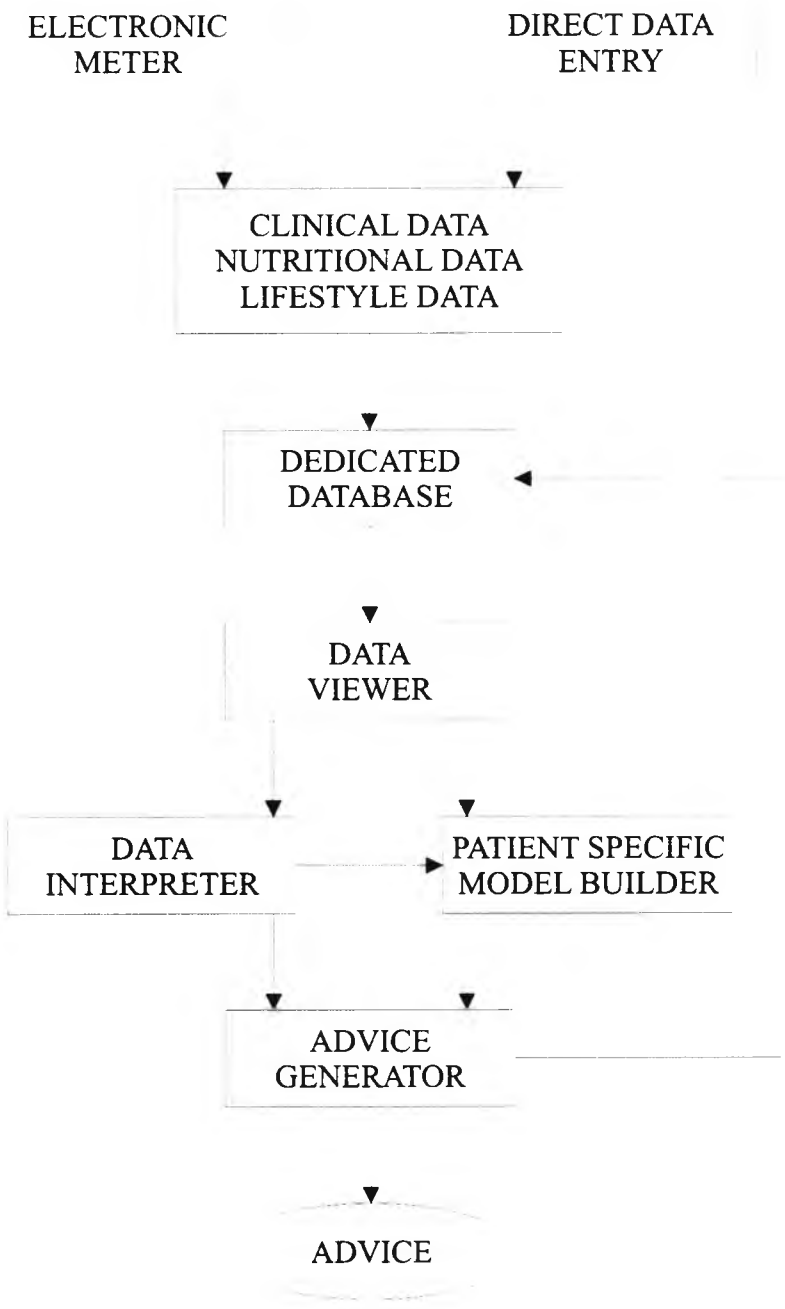


Figure 4.2. Schematic overview of the UTOPIA system implementation.

4.5. The Meter Study.

This programme aimed to test UTOPIA's assumptions on real patients and to explore the use of technology for home data collection. It followed a patient sample over 2 years, allowing individuals to adopt their own collection preferences (influenced by official recommendations) rather than the strict requirements of a clinical trial.

4.5.1. Meter Study design.

Patient cohort.

Thirty-seven patients diagnosed with IDDM were selected by diabetologists. The sample was predominantly white, covering both sexes, a range of ages and occupations (engineers, barmaids, doctors, housewives). A significant number suffered from other disorders in addition to medical and psychological complications of diabetes. Table 4.1 gives a clinical summary.

Home data collection technology.

Collection was facilitated by the Accutrend DM meter (Boehringer Mannheim GmbH). It measured 15.5*8.1*2.6cm, weighed 240g, and stored up to 500 blood tests in a rolling memory. Insulin doses and other coded information could be added via a keypad. All entries were automatically date-time stamped with facilities for display on a small screen and manual adjustment of stored measurements. Blood sugar tests by patients using the meter correlated with laboratory results ($r=0.95$, based on data from 167 clinical visits).

A card of codes to record special events was prepared to fit inside the meter case. Codes covered natural events, including menstruation, change of circumstances, such as shift working or holidays, and periods of notably increased/decreased exercise,

food or alcohol intake since the last blood test. The card was not widely introduced (though see Figure 4.8). All patients were requested to code sugar tests involving too little blood or meter malfunctions (known faulty results).

Past paper log-books were requested for comparison with meter results. Few patients reported regular use of a log-book and no paper records were provided.

Measuring patient perceptions of data collection and treatment

No recognised questionnaires were available to assess the burdens of data collection. The Diabetes Treatment Satisfaction Questionnaire (DTSQ, Bradley, 1994b) was adopted as the closest approximation and self administered by patients at recruitment and at 4 to 6 month intervals. Table 4.2 (Panels A&B) define the scale. Appendix 2 - an introduction to expected properties of scales - is included for reference.

Questions were added to address practicalities of self-care and data collection explicitly (Table 4.3). These were an exploratory feature and self administered by patients at recruitment only.

Patient training and clinical visit coordination

A specialist nurse coordinated all training and visits to the clinic. Patients were encouraged to record all injections and blood test at the usual 4 times of the day, but it was not an absolute requirement. They returned at 2-4 month intervals to download data, re-test meters, and monitor control through HbA1c, fructosamine and body weight. Patients' comments on circumstances and control since the last visit were recorded along with the nurse's advice on therapy.

Time Series Analysis of home data.

Bayesian methods from Appendix 1 were used on individual patient records to track the frequency of missing data; timing of measurements within periods of the day; and the evolution of Modal Day patterns in blood glucose between clinical visits.

Table 4.1. Clinical summary of Meter Study patients at recruitment.

A. Demographics, disease history and current control.

Males	17	**Females**	20

Category	Sub-category	Mean	SD	Min.	Max.	Missing cases
Age (yrs)		35.8	10	21	62	
Disease duration (yrs)		20.4	10	0	46	6
Metabolism	Body Mass Index	24.9	2.9	19.0	33.2[a]	1
	HbA1c (%)	7.8	1.3	4.8	10.8	

[a]Body builder.

B. Insulin regimens.

2 injections/day 19 **3+ injections/day** 18

	Mean	SD	Min.	Max.
Insulin dose/day (U)	45	14	18	78

C. Diabetic and other complications (n patients).

Category	Sub-category	Diagnosed	Warning signs
Diabetic	1 "classic" microvascular complication	2	12
	2 "classic" microvascular complications	3	3
	Other microvascular complications (eg. erectile dysfunction)	6	
	Hypoglycaemic unawareness	10	
Non-diabetic or non-specific	Chronic illness (eg. multiple sclerosis)	4	
	Psychological symptoms (eg. depression)	9	

Table 4.2. Diabetes Treatment Satisfaction Questionnaire: specification and results from the Meter Study.

DTSQ was self administered at recruitment and at clinical visits 4 and 8 (3 times at roughly 4-6 month intervals). Appendix 2 explains the principles of psychometric properties (structure, reliability, validity).

A. Substance of questions.

"I am satisfied with..."

1	Current treatment
2	Convenience
3	Flexibility
4	Understanding of disease and management
5	Recommend to others
6	Continue with current treatment
7[a]	Blood sugars too high
8[a]	Blood sugars too low

[a]Additional questions to aid interpretation - not part of main scale.

B. Scoring system.

Response scale	Integer range: 0 (-ve opinion) to 6 (+ve opinion)
Total score	Sum of 6 main items (range: 0-36)

C. Scores from administrations.

	Mean	**SD**	**Min.**	**Max.**	**N cases**
Recruitment	28.5	4.2	19	34	35
Visit 4	27.1	6.4	13	36	29
Visit 8	28.2	5.9	13	36	14

D. Statistical structure at administrations.

Factor analyses identified 1 main factor loading strongly and consistently with the scale questions and a 2nd factor without a clear and repeatable pattern.

The Table indicates loadings of >=0.4 ("+") and <= -0.4 ("-") for the 6 scale questions at each administration.

		1	2	3	4	5	6
Factor 1	**Recruitment**	+	+	+	+	+	+
	Visit 4	+	+	+	+	+	+
	Visit 8	+	+	+	+		+
Factor 2	**Recruitment**			-	+		
	Visit 4						
	Visit 8					+	

E. Reliability at administrations.

Cronbach's alpha values (average of correlations between questions – internal consistency).

Recruitment	Visit 4	Visit 8
0.75	0.90	0.85

Correlation of DTSQ scores with independent items
(variables which might logically be correlated, p values in brackets).

	N cases	HbA1c clinical measurement	Perception of high blood sugars (scale question 7)	Perception of low blood sugars (scale question 8)
Recruitment	35		-0.46 (0.005)	
Visit 4	29		-0.5 (0.006)	
Visit 8	14	-0.54 (0.06)	-0.67 (0.009)	

Table 4.3. Additional questionnaire items on self care and data collection: specifications and results from the Meter Study.

2 sets of questions were self administered by patients at recruitment.

A. Practicalities of self care and data collection.

Format of questions	"I do/feel X ..."
Response scale	Integer range: 1 (never) to 5 (always).

Question	N cases	Mean (to nearest integer)	Min.	Max.
1. Adjust own injections	35	4	1	5
2. Vary injection sites	34	4	1	5
3. Worry about complications	34	3	2	5
4. Embarrassed by treatment in public	35	2	1	4
5. Feel physically ill	35	2	1	4
6. Feel pain from treatment	35	2	1	4
7. Worry about passing out	34	2	1	4
8. Take unrecorded blood tests	34	3	1	5

B. Convenience of data collection.

Format of questions	"I feelthat X is..."
Response scale	Integer range: 0 (very inconvenient) to 3 (acceptable).

Question	N cases	Mean (to nearest integer)	Min.	Max.
1. Taking extra blood tests	35	3	1	3
2. Recording extra blood tests	35	3	0	3
3. Recording injection details	35	3	0	3
4. Recording dietary details	34	2	0	3
5. Recording details of exercise	34	2	0	3

4.5.2. Results from the Meter Study.

1). Effects of the study on disease control.

Group mean HBbA1c values showed no statistical improvements when compared between clinical visits (Table 4.4). Thus use of meters and closer medical attention had no impact on broad indicators of control. However, the group were relatively well controlled at recruitment, and HbA1c does not reflect the detail of individual disease control or personal experience (see 4) below).

2). Patient perceptions.

Diabetes Treatment Satisfaction.

DTSQ provided a score over the range 0-36 with higher values showing higher satisfaction. To avoid complications with official scale properties, questions and rubric were not changed from the published version, Despite the context of the Study, it was not clear that patients considered the use of meters when answering questions.

Results for the cohort are given in Table 4.2 (Panels C-E). Good reliability and scale structure were found at each administration. Scores tended to cluster markedly towards the upper limit of the scale. They did not correlate with the physical measures of HbA1c at all clinical visits. Instead, they related consistently to perceptions of hyperglycaemia (-ve correlations with the separate question about "blood sugars too high").

Additional questions on self care and data collection.

Results of individual questions added to DTSQ at the first administration (Table 4.3) suggest that the pain and embarrassment of self care were not major concerns for this sample. Most reported collection of blood test and injection details to be convenient. Collection of diet and exercise data did not form a formal part of the study. However, collection of these data was perceived as "marginally" more inconvenient. Of particular relevance to UTOPIA, most patients reported that they adjusted their own insulin regimens.

3). Data collection.

Data completeness.

Completeness was computed for each patient based on data from individual days and summed over all days on the study. The target number of injections per day was given by each patient's regime. For blood sugar monitoring, at least 1 test per day was expected at the 4 landmark times identified by applying the 24h time grid (in 5.2.1). Missing days were calculated separately for injections and blood tests. Adjustments were made when meters were known to be faulty.

Results for the cohort are combined in Table 4.5. Neither the frequency of blood tests nor of recorded insulin doses was statistically related to the number of injections in individual regimens. The mean for recorded insulin doses was 68.9% but the distribution showed no obvious pattern. In contrast, blood test collection showed prominent clustering towards high frequencies at breakfast and suppertime, and low frequencies at lunch and bedtime.

This pattern of results was broadly reproduced when data were sub-divided into six monthly periods, and when compared to multiple tests by period of the day. Behind the stability of group patterns appears to be the tendency for individuals to persist with their own, personal measurement and recording schedules.

Timing of measurements.

Among patients with high blood glucose completeness (>75% of tests recorded), there was marked regularity in the timing of measurements across the day. Figure 4.3 provides an illustration of measurement regularity with a clear and natural change in behaviour at weekends. Such conscientious data collectors are likely to follow a stricter measurement regimen than most. Nevertheless, many patients demonstrated a low degree of timing variability over the measurements they did collect.

Table 4.4. Group changes in disease control over the Meter Study measured by HbA1c.

Group HbA1c means are compared at 6 monthly intervals. Data for individual patients were obtained at the clinical visits closest to the "target dates.

A. Raw data.

		Recruitment	6 months	12 months	18 months
N cases		37	36	26	11
HbA1c (%)	**Mean**	7.8	7.6	7.4	7.5
	SD	1.3	1.2	1.2	0.9
Timing of measurement (days since recruitment)	**Mean**	177	355	533	
	SD	32	27	32	

B. Group differences in HbA1c at 6 month intervals (with paired t-tests).

	(6 months) - (Recruitment)	(12 months) - (6 months)	(18 months) - (12 months)
Mean difference	0.18	0.07	-0.12
SD	0.79	0.69	0.98
95% Confidence Interval	-0.09 - 0.45	-0.2 - 0.35	-0.78 - 0.54

Table 4.5. Completeness of home data collection over the Meter Study.

The number of insulin njections relative to the regimen and the number of landmark blood sugar tests (at breakfast, lunch, supper, bedtime) have been computed for all 37 patients over their time on the Study, and presented as group results.

A. Amount collected.

Component		Mean	SD	Min.	Max
Time on Study (days)		371	161	120	632
[a]Missing (% days)		12.0	15.6	0	65
Insulin injections (%)		68.6	27.8	10.7	119.6[b]
At least 1 blood sugar in period of day (% days)	**Over night**	5.2	4.8	0	19.6
	Breakfast	76.1	24.0	14.5	99.7
	Lunch	41.3	25.5	0.8	89.3
	Supper	69.3	26.2	13.4	99.4
	Bedtime	33.6	22.6	4.1	88.3
Multiple blood sugar tests in periods of day (% days)	**Over night**	0.2	0.8	0	4.4
	Breakfast	10.2	12.8	0	57.3
	Lunch	5.1	9.7	0	48.0
	Supper	27.2	25.3	0.9	87.7
	Bedtime	4.9	6.3	0	23.3

[a]Days when meters were faulty or unavailable.

[b]Some patients adjust their own number of injections so % collected can exceed 100.

B. Analyses.

Test	Test statistic	Interpretation
Correlation between % of injections and blood tests recorded	r=0.8, p=0.001	The significant correlation suggests a consistent level of collection (good or bad) for injections and blood sugars by individuals.
Difference in amount of landmark blood sugars recorded between people with 2 injections/day and those with >2 (one-way analysis of variance)	F=2.41, p=0.13	The ratio of variances is not significant, suggesting that the amout of landmark blood tests recorded is not related to the number of injections in the regimens.

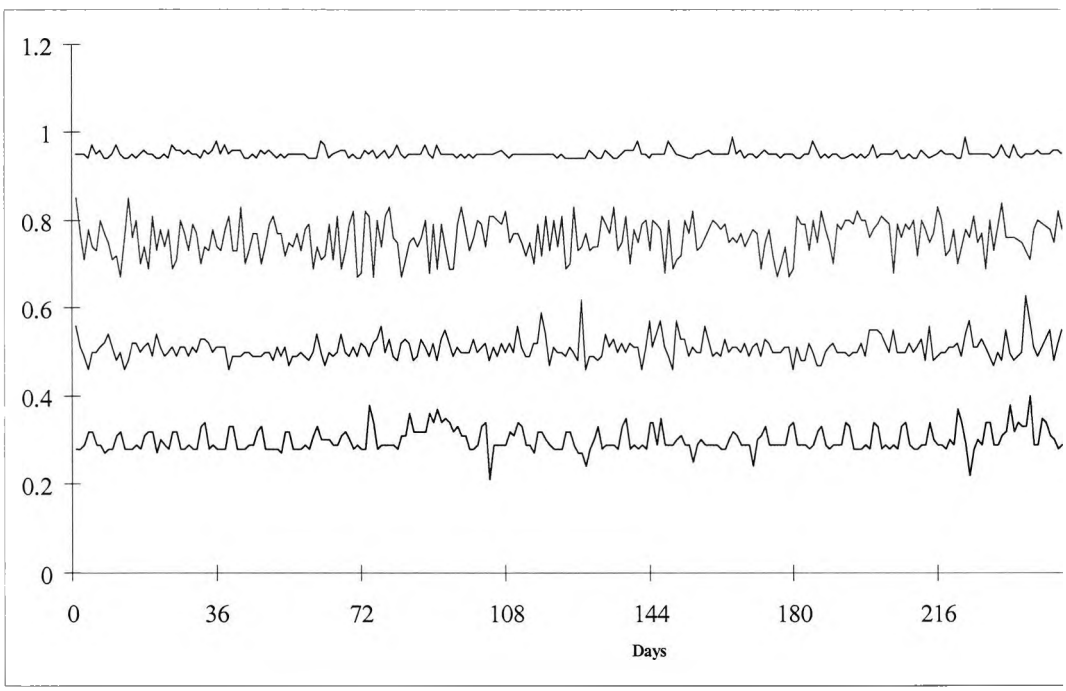


Figure 4.3. Timing of blood sugar measurements at the nominal "landmark" times of the day from a conscientious diabetic patient, tracked with a Time Series model over a 10 week period. (Time series principles given in Appendix 1).

4). Individual patterns of data collection and control during the Meter Study.

Patients selected in this section had good data completeness or illustrated particular issues. Time Series models were used to track statistical patterns through the data, including: blood glucose control, measurement timings, and missing value frequencies. Technical details on the Bayesian time series method are given in Appendix 1.

Examples of stability and instability between clinical visits.

Figure 4.4. illustrates the instability of blood glucose control over relatively short periods, common among established patients. Data are from a 38 year old male, diagnosed as a teenager and currently injecting 46U a day.

In contrast, Figure 4.5 shows the greater stability associated with early stages after diagnosis. This recently diagnosed 26 year old woman was injecting 14U a day; her blood tests and hbA1c measurements were within narrow ranges over time.

Special events affecting control and data collection

The most common "special events" reported by patients at clinical visits were illness, stress and response to episodes of hypoglycaemia. Figure 4.6 annotates control for a young woman with such events reported at clinical visits superimposed. Figure 4.7 shows another patient's response to early pregnancy. Her frequency of measurement improved dramatically; blood sugar levels and HbA1c's improved in parallel.

Figure 4.8 presents results from a woman Who used her meter to record blood tests as well as information about meal size (larger/smaller than usual) and exercise (particularly active/quiet) since the last blood test. The patient was diagnosed aged 3

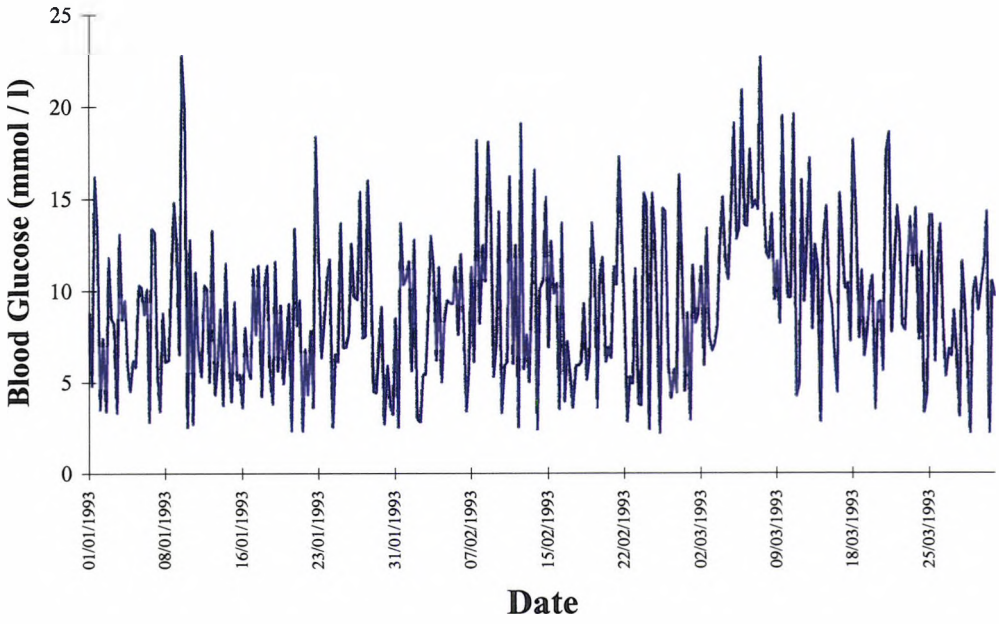
and was 34 at the time of analysis. Her HbA1c's were good and improving, yet the patient complained of being "unable to control my diabetes". The stress led her to take fewer blood tests for fear of "seeing the abnormal values".

Fluctuations in the raw blood sugar values, variety of meal size and alternation between periods of activity and inactivity, all suggest that the standard clinical measures of control (eg. HbA1c) hide considerable individual variation in details of control between hospital visits.

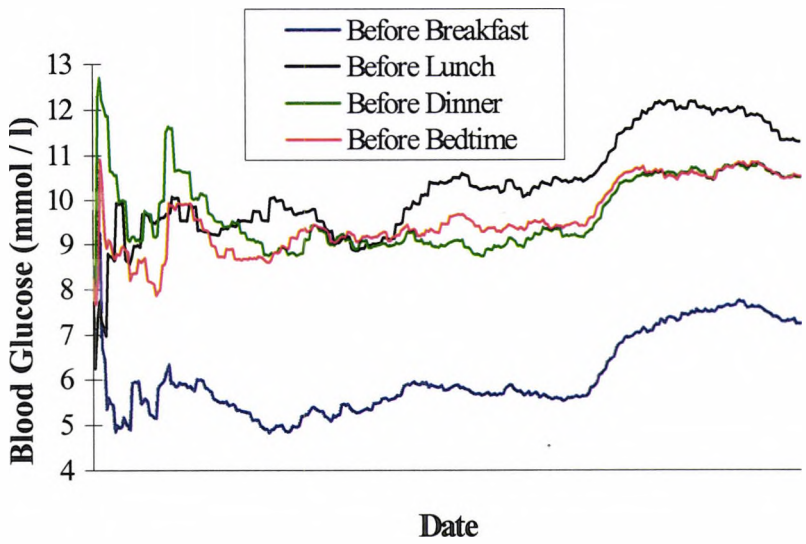
Specific response to actual or perceived hypoglycaemia

The fear of hypoglycaemic crises, reported by patients at clinical visits, was shown in blood test data from several patients. A recent hypoglycaemic crisis, or perceptions of risk, was associated with blood sugar means at the upper end of the normal range (9-10mmol/l) and individual measurements commonly around 20mmoll.

Figure 4.9 illustrates with a histogram of data from Figure 4.4 showing a Male patient's response to a recent hypoglycaemic event. The high glucose values towards the end of the plot may have been a natural physiological response. Equally they may have resulted from deliberate behaviour to maintain high blood glucose levels with reduced hypoglycaemic risks but increased chances of long term complications.

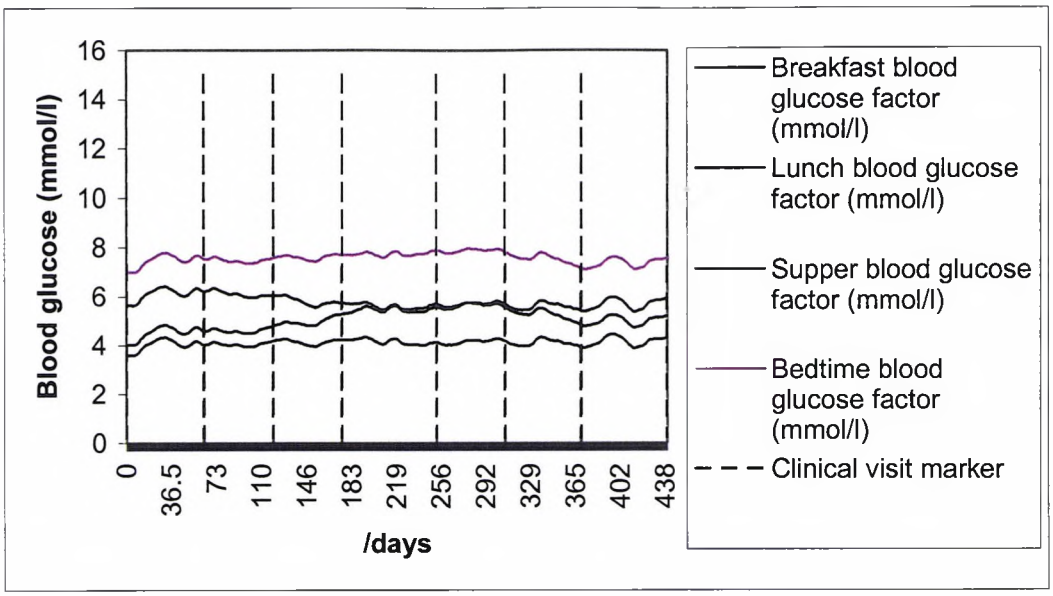


a).Raw blood sugar data collected over 6 months by an established diabetic.

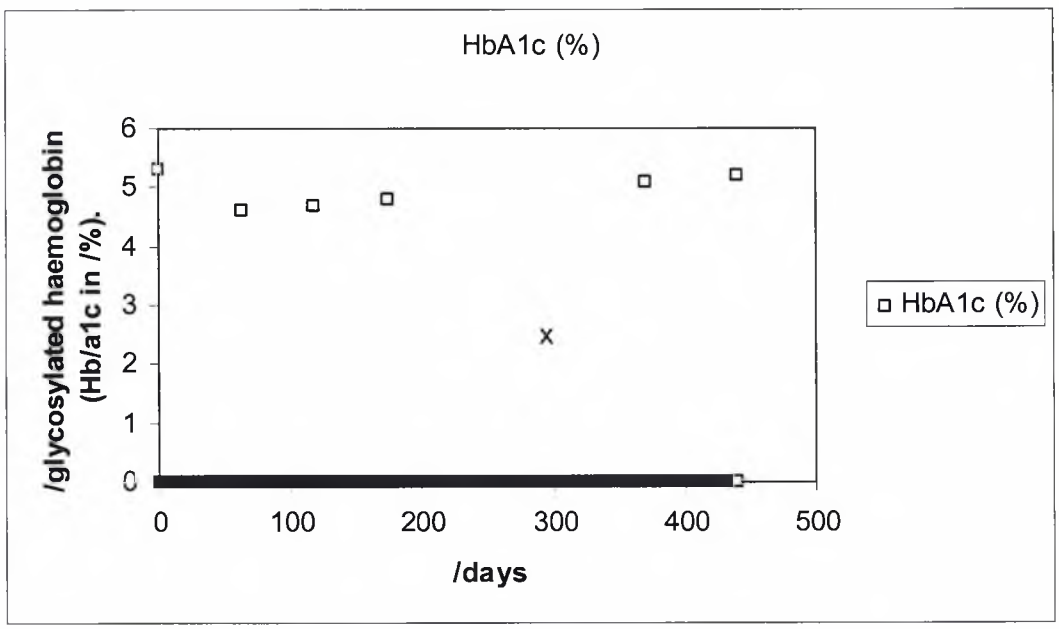


b). Statistical estimate of blood sugar values at landmark times of the day tracked by a Time Series model in data from Panel a.

Figure 4.4. Comparison of home blood sugar data presented as raw values (Panel A) and after applying a Time Series model to track the Modal Day pattern (Panel B).



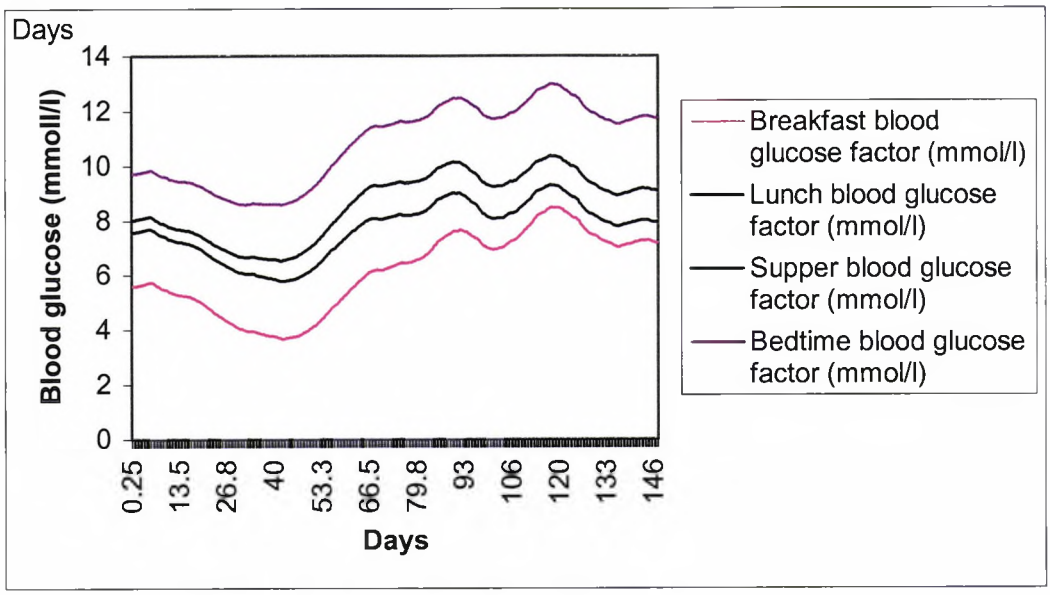
a). Patterns in daily blood glucose control with clinical visits superimposed.



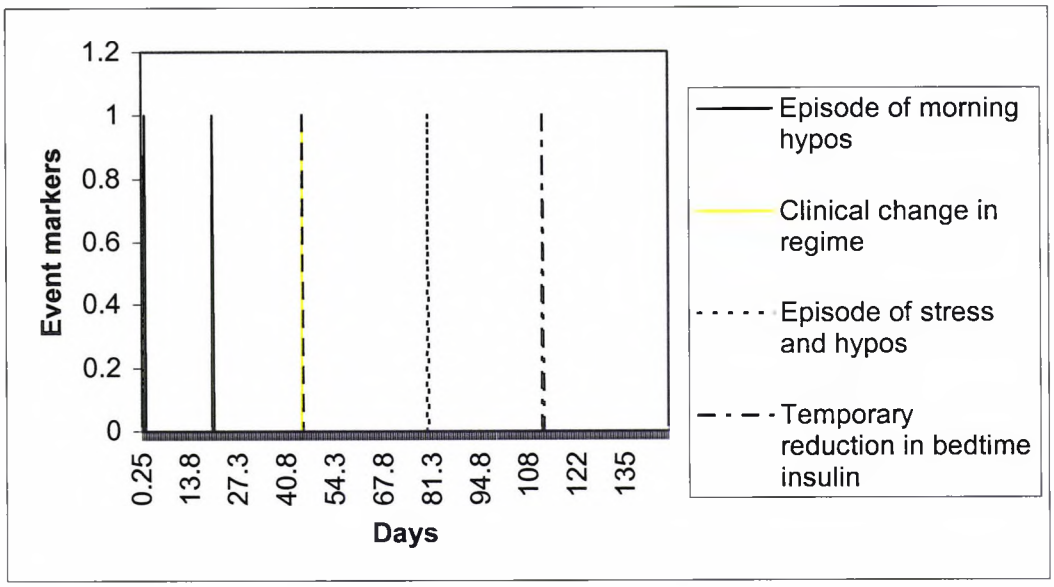
b). Glycosylylated haemoglobin (HbA1c) att clinical visits.

Figure 4.5. Stability of diabetic control in the early stages after diagnosis.

This recently diagnosed 26 year old woman was injecting 14U of insulin a day. Relative stability of her disease is shown by patterns in blood glucose measurements (tracked with a time series model with a mean and 4 daily factors and a discount factor of 0.95) and clinical measures of control (glycosylated haemoglobin) at visits to the hospital.

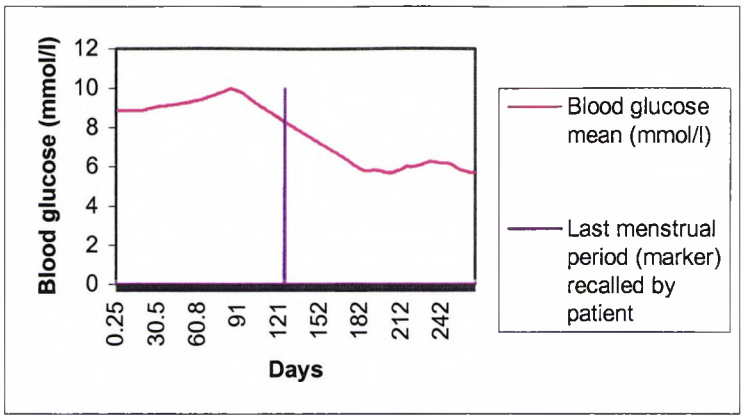


a). Daily blood glucose control.

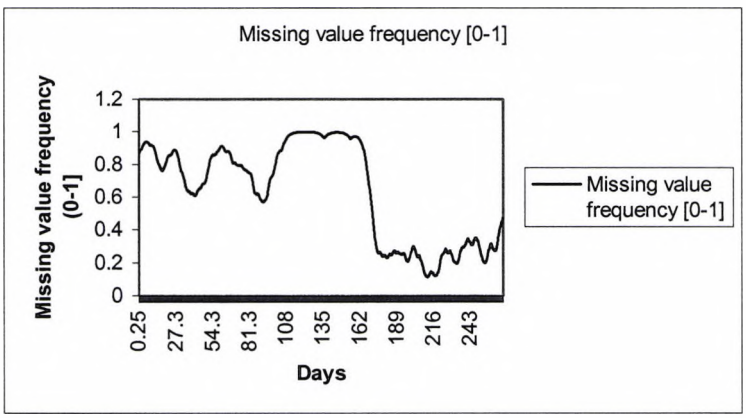


b). Significant events recalled by patient at hospital visits.

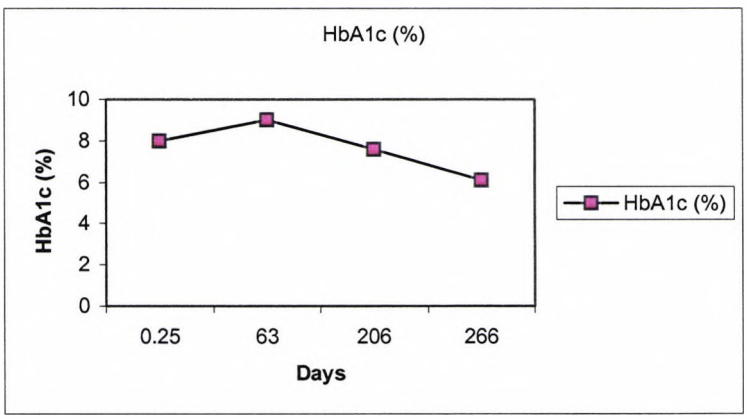
Figure 4.6. Diabetic control over time annotated with events recalled by the patient at hospital visits.



a). Daily blood glucose control (tracked mean) with patient's last menstrual period superimposed.



b). Missing values frequency (based on 4 measurements per day).

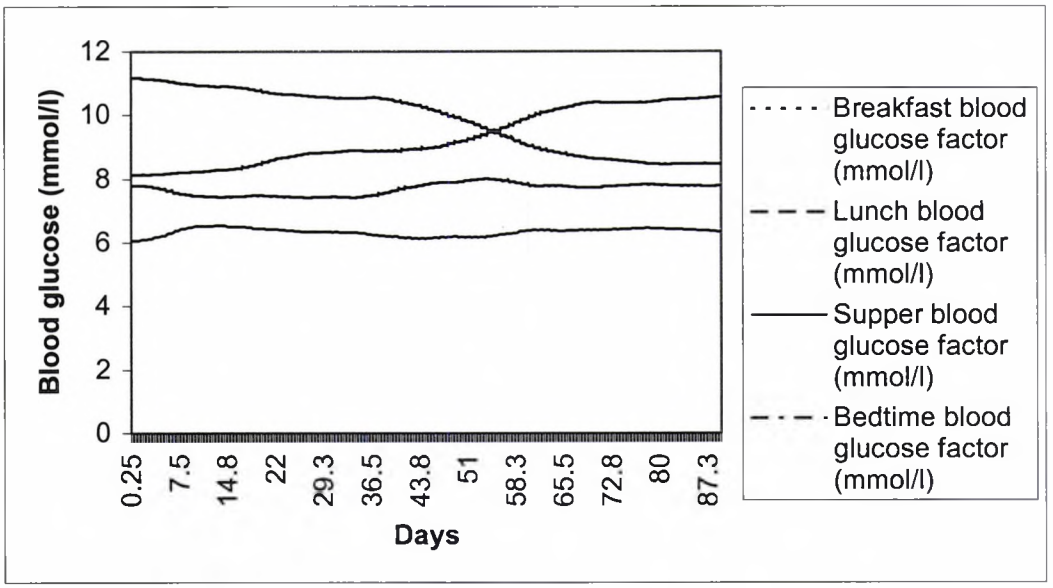


c). Clinical measure of control (glycosylated haemoglobin – HbA1c).

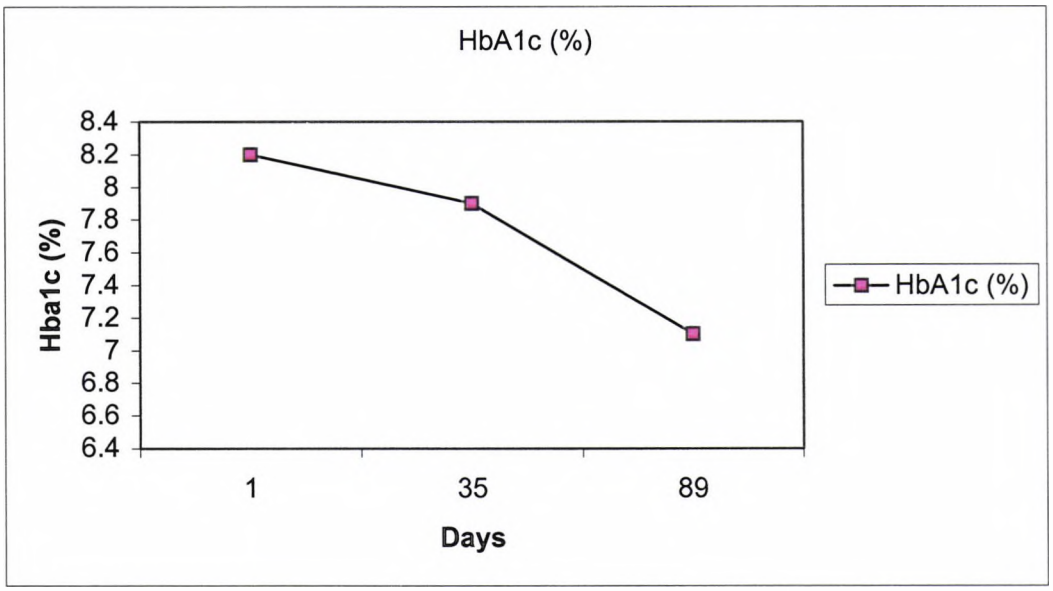
Figure 4.7. Effects of a pregnancy on self care with consequences for diabetic control.

Figure 4.8..Diabetic control, data quality, meal size and physical activity monitored over time by an individual.

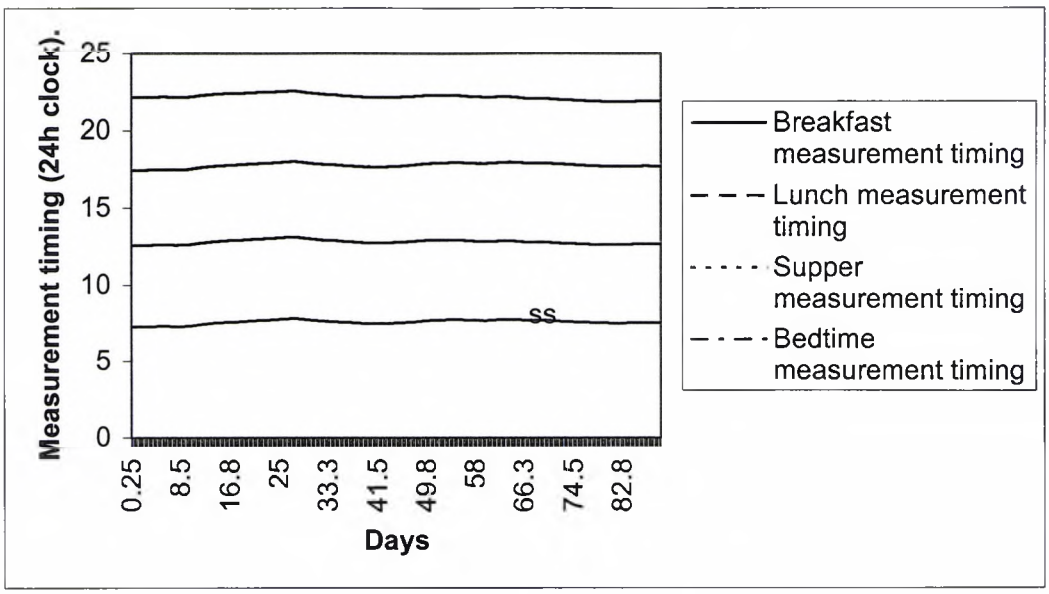
This female patient recorded additional lifestyle information at the time of blood glucose measurements. Despite reasonably good and improving clinical measurements of control (HbA1c), her records show considerable variation in daily activities which is not usually accommodated in clinical assessments. She also complained of stress from perceptions of poor disease control and tended to avoid blood glucose measurement rather than see particularly high values.



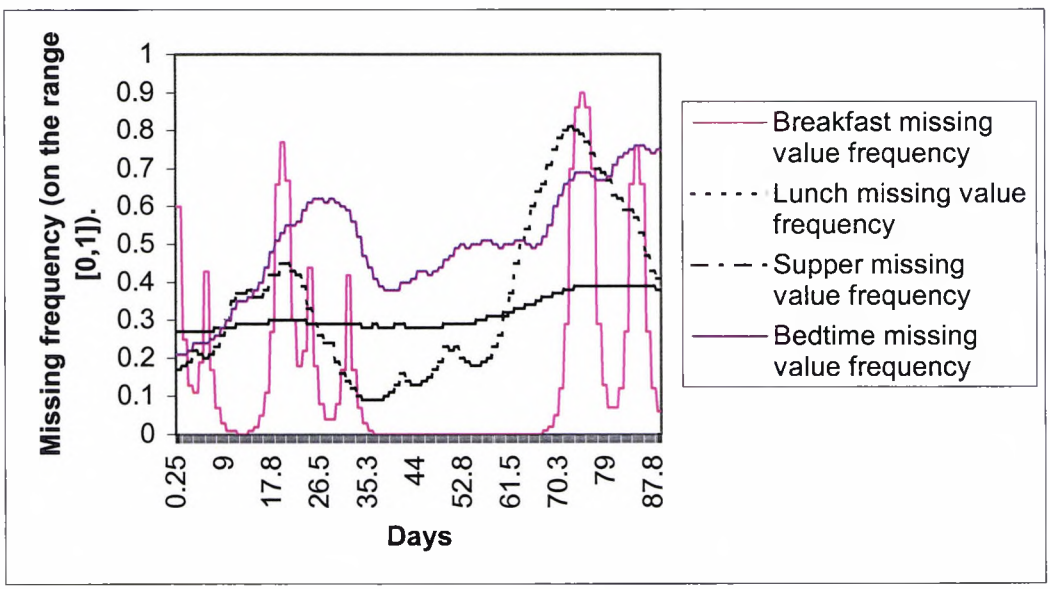
A1). Daily blood glucose control).



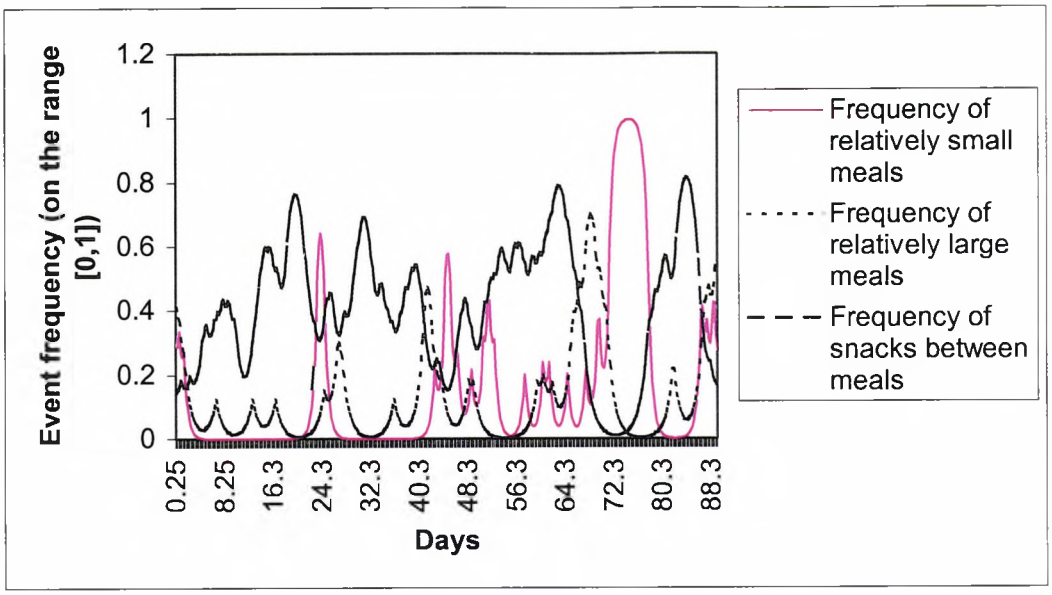
A2). Clinical measure of control (HbA1c).



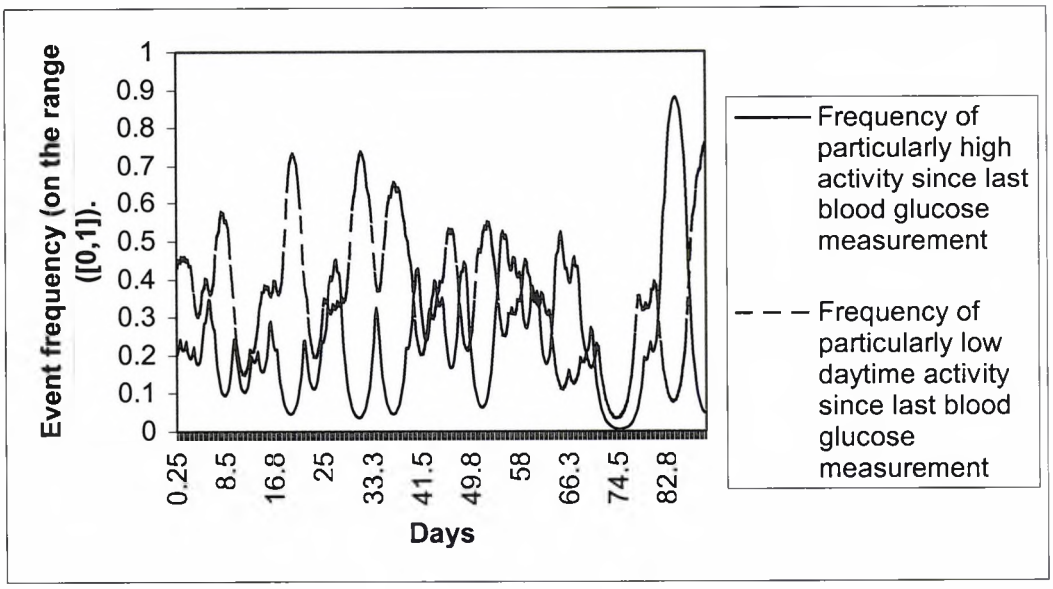
B1). Timing of blood glucose measurements, monitored against the recommended times over the day.



B2). Missing blood glucose measurement frequency computed against the recommended measurement times over the day.



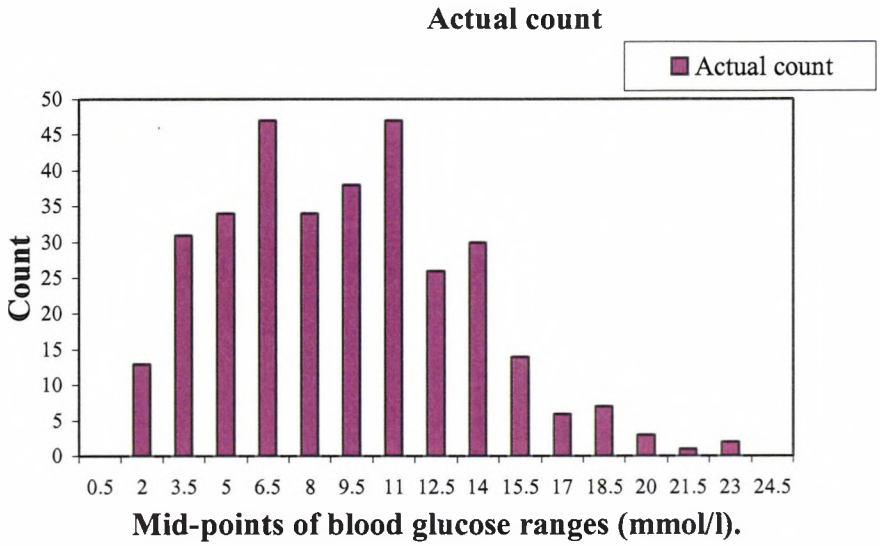
C1). Reported meal sizes and snacks between blood glucose measurements.



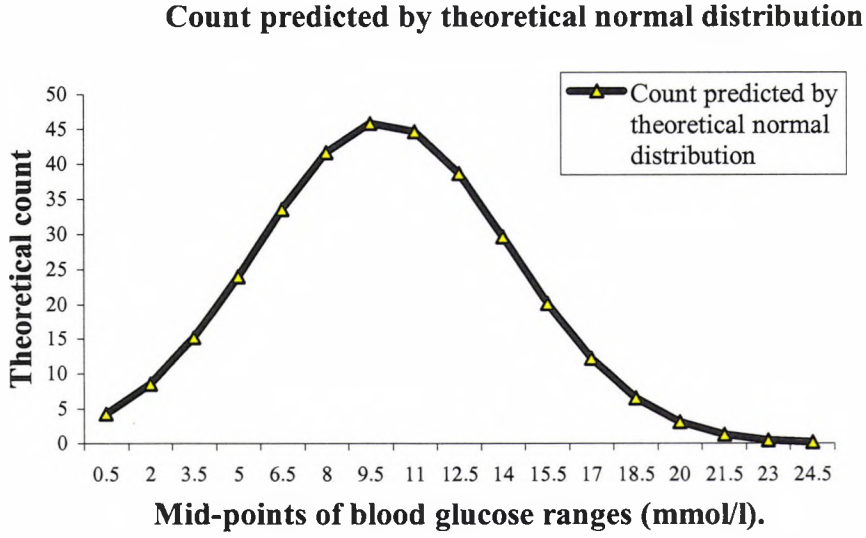
C2). Reported physical activity since the last blood glucose measurement over the normal daytime.

Bayesian time series models

Daily blood glucose patterns, measurement timings and missing value frequencies have been modelled and tracked with a formulation comprising a mean and 4 cyclical factors per day (corresponding to recommended measurement timings). Event frequencies have used a simple mean tracking the presence (1) or absence (0) of a reported event. All models have used discounting to emphasise local data (discounting factor = 0.95).



a). Counts from actual data.



b). Counts predicted by equivalent theoretical normal distribution.

Figure 4.9. Histogram of data within specified ranges for the blood glucose measurements presented in Figure 4.4, along with counts predicted by an equivalent theoretical normal distribution.

The source data contain 333 values (ignoring 27 missing items) with a mean of 9.245 and variance of 4.308.

4.5.3. Meter Study conclusions.

Implications for UTOPIA and comparable systems.

Fundamental assumptions behind UTOPIA were inappropriate in real life. Few patients followed the clinically recommended monitoring and data collection schedule. Most followed their own personal preferences and tended to focus on brekfast and suppertime measurements. The majority also reported changing their own insulin regimes between clinical visits.

Stable control between visits was demonstrated for only 1 patient who had been recently diagnosed. The established patients showed marked variations in control, commonly associated with bouts of illness, stress or hypoglycaemic events. Variations in control were a combination of physiological change and possible adjustments in behaviour to reduce risks of hypoglycaemia.

Treatment satisfaction and use of meters.

The Diabetes Treatment Satisfaction Questionnaire was simple to administer and reproduced good structural and reliability properties. Individual scores were difficult to interpret, but results for this patient sample suggested that higher satisfaction was associated with low perceptions of hyperglycaemia.

All patients used the meters throughout the study. DTSQ indicated broad satisfaction, and results from additional questions on data collection were generally high. In combination, these findings imply that use of meters and requests for more home data are tolerated.

4.6. Particular problems with data quality.

The Meter Study provided examples of particular problems in practice. This section highlights areas where further research appears justified.

Paper transcription.

UTOPIA, and comparable systems in this area, depends on availability of pre-computerised data. A manual approach would require transcription of upto 720 blood tests and 180 daily insulin injection regimes at a 6 monthly clinical visit for each patient (clinically recommended monitoring schedule). With further assumptions of legibility and 10s to transcribe each item, this accounts for at least 2.5h of staff time.

Meters removed this burden. On the other hand, increased data collection and visits to the clinic did not, in general, improve daily or medium term control. The only clear exception was a pregnancy during the study. Meters were not the cause of markedly improved control, but use allowed the improvements to be monitored in detail.

Accuracy, representation and context of blood glucose measurements.

Accuracy of individual measurements (point accuracy) was demonstrated with meters, though values could be manually changed and errors required flagging. Representation of glucose levels over time by recorded samples (process accuracy) was not addressed but is important to both research and clinical practice.

An interim solution to the process accuracy problem is illustrated by the histogram in Figure 4.9 (estimate of the underlying distribution). In principle, representative data at successive clinical visits should show increases/decreases in area of the

distribution corresponding to increases/decreases in HbA1c values and other clinical tests for the same collection periods.

The interpretation of individual measurements and sequences depends on measurement context. An exploratory system of codes was used with some patients. It demonstrated the variety of factors influencing control and allowed periods such as illness to be isolated. However, methods to analyse codes separately or to link them to measureable changes in blood glucose were not developed.

Costs of increased data collection.

Meters removed expenditure on transcription but added costs of equipment and more expensive test strips. Future cost-benefits analysis might consider direct improvements in daily control or indirect effects on patient reassurance.

4.7. Conclusion to the Case Study.

Details of individual diabetic control determine clinical adjustments to therapy and are based on home data collection. Assumptions behind the reported computer research were inappropriate for real world patients. Equally, clinical measures of control (eg. HbA1c) reflected blood sugar levels over too long a period to assist with daily problems.

Although the "quality" of home data varies, patients do tend to follow their own monitoring and collection schedules which might be exploited by clinical staff. Time Series models can track patterns in blood sugar levels as well as timing of measurements and frequency of missing data. However, results from current approaches were not used by staff and therefore had no direct influence on care or individual control.

Further research is required into the content, recording schedules and methods of analysis for home datasets that improve daily control and therefore justify the effort of collection. Use of technology is the most practical approach for home data collection on a large scale. Thus research should also consider technological standards for greater efficiency.

Chapter 5

Monitoring hospital admission via an Accident & Emergency department

5.1. Introduction.

A review of Accident & Emergency care for elderly people was commissioned by a major London NHS Trust from St Bartholomew's School of Nursing and Midwifery (Meyer & Bridges, 1998). The project considered individual care and procedures for hospital admission and discharge via the A&E department. It ran from June 1997 to April 1998.

An Action Research approach was adopted, combining qualitative and quantitative assessments. HJL was requested to analyse waiting times at the Trust (op. cit, Appendix 4). Concerns about the quality of data provided and of additional requested material justify this project as one of the Case Studies.

Organisation of the Case Study

Section 5.2 puts research issues at the Trust into context by characterising the targeted patient population followed by a review of recent background in A&E in England and Wales from the Audit Commission.

Sections 5.3 & 5.4 summarise St Bartholomew's Action Research project (the AR project) and provide details on the analyses of waiting times and requests for additional data.

General findings.

Although the Trust required data to support individual care and plan services, the Study demonstrates a dependence on paper systems and a fragmented approach to collection. These factors contributed to limited care coordination and quality for individual elderly patients. They also precluded statistical assessment of separate care sstages and numeric models of processes across the Trust.

These findings at a single trust in 1997/8 were not isolated examples When judged against the Audit Commission's reports.

5.2. Background and wider context.

5.2.1. Patient group and management problem.

Elderly patients are the sub-set of retired people aged 75+. Their connection with A&E departments was highlighted in a national review of care for patients with hip fractures (Audit Commission, 1995): "most people who fracture ahip are elderly [and] almost all are admitted to hospital via A&E". Delays between injury and hospitalisation and the importance of understanding a patient's domestic and social circumstances were raised as particular concerns.

Broader issues were also highlighted by the Commission and in the literature review by the AR project. Elderly patients are more likely to present with multiple conditions and

to be overwhelmed by busy clinics. Moreover, the effects of ageing may mask important symptoms and increase risks of pressure sores (developing within 30 minutes in some cases). Recommendations included improvements to the assessment and documentation of elderly patients on arrival and routine use of pressure sore risk scores to support individual care and process audit.

5.2.2. General A&E services at 1996.

The Commission followed work on hip fractures with a wider review of A&E services in hospitals across England & Wales (Audit Commission, 1996). Individual A&E departments were presented as the major point of contact between hospitals and all sectors of local communities. Responsibilities ranged from major trauma management to treatment of minor injuries and responses to general enquiries. Services included:

- Immediate resuscitation and stabilisation with coordination of subsequent care for those with life-threatening conditions.
- Diagnostic facilities for all patients.
- Assessment and referral of patients requiring admission (or specialist care) to the appropriate hospital department.
- Definitive care of minor injuries.
- Support for patients seeking urgent medical advice.

Quality of care was a significant factor but emphasis was placed on waiting times. Logically, the medical benefits and improved patient perceptions at individual stages of care were lost if the sequence was uncoordinated and overall timescales were excessive. The implied aims of the Commission's review were to identify good practice and to promote debate on alternative organisation of services.

Service organisation across the country.

The Commission identified 227 departments with size and geographic distribution determined by history rather than recent and formal planning (Figure 5.1). 113 departments were studied with 11 examined in detail.

Basic support for medical staff included pharmacies, pathology and radiology laboratories. However, no department had the "ideal" combination of in-house services and links to other specialities in the hospital or shared with other organisations (Figure 5.2). Costings were unreliable because of differences in allocation of resources and overheads to specific budgets and absence of standard measures for case types and severity (casemix).

The Commission, and its local auditors (District Audit programmes), found considerable variation in performance across A&E departments. It is significant, however, that no national dataset existed to cover all departments in general or to follow all processes in any single hospital. A summary of the partial data from the report for comparison with later sections on the AR project is given in Table 5.1.

Patient arrivals and destinations.

Almost 15 million patients were seen over the year (attendances). Very few had life-threatening conditions. Emergency medical cases had risen by 2% a year since 1981, primarily due to more GP referrals, and represented the greatest single increase in A&E workload. 10 broad categories accounted for 75% of attendances but hip fractures and other age-related conditions were not distinguished. Estimates of unnecessary attendances (3.4-54%) depended on unstated criteria. In practice, such cases also involved poorly defined symptoms requiring attention before judgements could be made (eg. chest or abdominal pains).

Most patients were discharged home or into GP care. 15% were admitted to the relevant hospital while a minority left before treatment. Arrangements for other patients depended on local organisation of community services. A re-attendance rate of 12%+ suggested inadequate initial care or inappropriate use of A&E resources warranting "critical examination"

Sources of delay.

Four potential causes of delay were highlighted within individual departments. Excessive waits for hospital admission with makeshift interim arrangements (trolley waits) were another concern but considered beyond the control of A&E alone.

Congestion. Inability to admit patients to the hospital removed A&E resources from other duties.

Availability of doctors. Although the number of A&E medical staff had increased nationally, there were wide variations between departments and many posts remained unfilled. Explanations were a combination of financial constraints, competition for junior doctors between specialities, and changes in requirements for A&E experience for trainee surgeons. The British Association of Emergency Medicine (BAEM) had proposed a formula for medical staffing based on local patient numbers but the Commission predicted a shortage of A&E doctors at both junior and senior level for the foreseeable future.

Matching nursing and medical staff to demand. Peaks and troughs in hourly and daily patient attendance rates had not been monitored in most departments. Staffing shifts (rosters) tended to follow hospital or historic practices rather than specific A&E demands.

Quality of management information. Management data for coordinating individual care and departmental planning was given high priority by the Commission. However, audits identified deficiencies in manual and computer systems across A&E departments:

- Data were often incomplete with insufficient attention to validation.
- Examinations and decisions made in A&E by doctors from other specialties were the least likely data to be properly recorded.
- Many A&E computer systems were inflexible or inadequate
- Data analysis often had to compete for limited terminal availability and processing time.
- System designs included logical errors such as sequencing problems when the 24h clock was used, automatic data overwrites when patients re-attended, and premature record closures if the final data fields were completed before earlier sections.
- Discrepancies existed between departmental databases and hospitals' main records (Patient Administration Systems).
- Reliability problems occurred with individual systems in departments and links across a hospital.

The choice of management data was presented as a decision for local providers and service commissioners. Responsibilities for collection should be left to those with "greatest operational need for the data". The Commission placed most of the burden on nurses and secretaries supporting doctors.

5.2.3. The 1996/7 winter crisis.

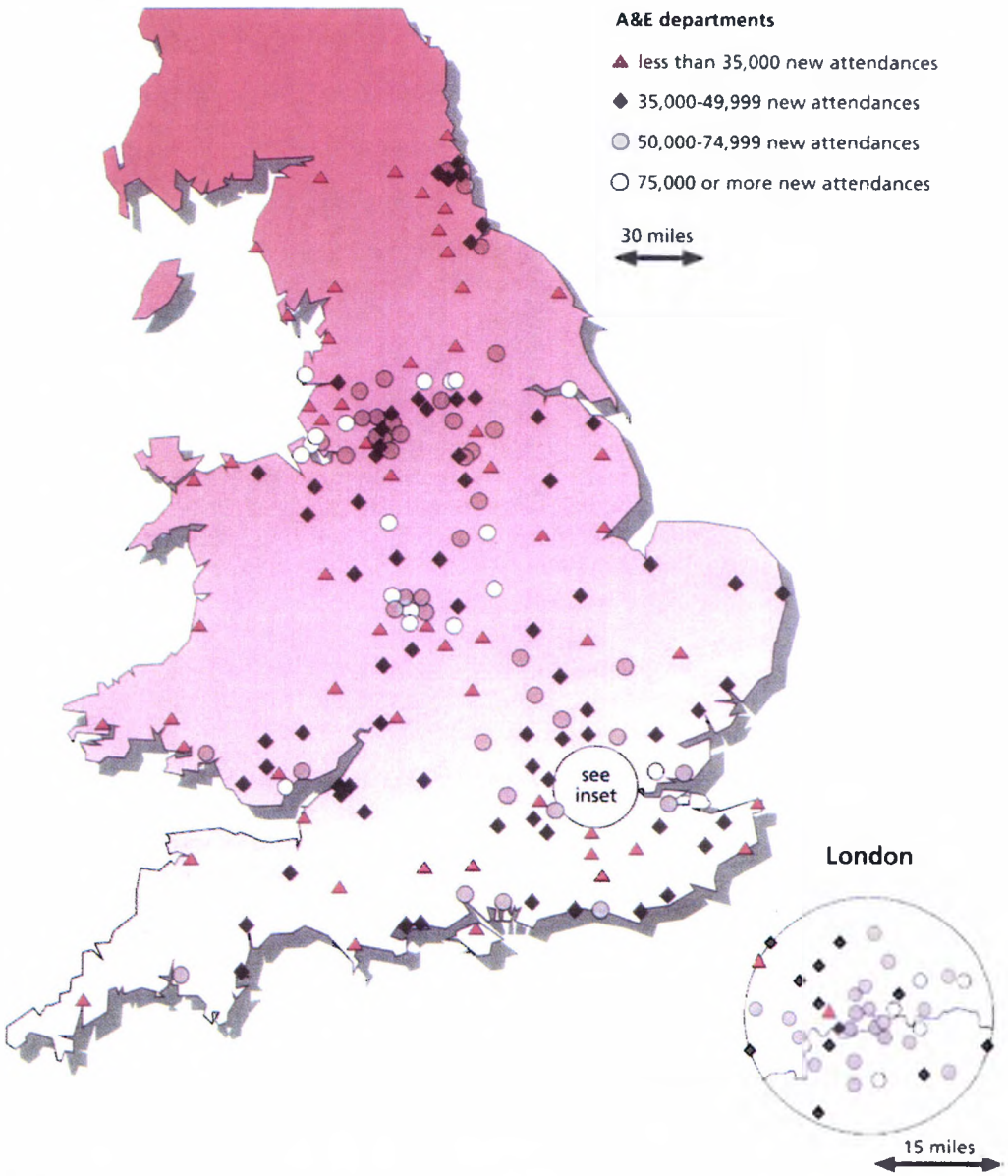
Peaks in activity over winter periods were historically so common to warrant the label "winter pressures" or "winter crises". Existing problems in A&E were compounded over

the winter of 1996/7 by a flu epidemic. Staff and basic resources, including mortuaries, were overwhelmed in several parts of the country.

The Department of Health responded by combining previous crisis planning initiatives under a new Emergency Planning Team (NHS Executive, 1997). Additional intensive care beds were provided and £300m of "emergency monies" were set aside for the following winter. Winter flu injections for people age 75+, along with annual medical assessments by GPs, are now Expected as standard practice under the National Service Framework for older people (since 2002).

Exhibit 23
Geographical distribution of A&E departments

This reflects history as much as current need.



Note: 'Major' departments in England and Wales offering a full A&E service

Source: Audit Commission, from surveys and directories

Figure 5.1. Size and distribution of A&E departments in England and Wales in 1996 (From Audit Commission, 1996).

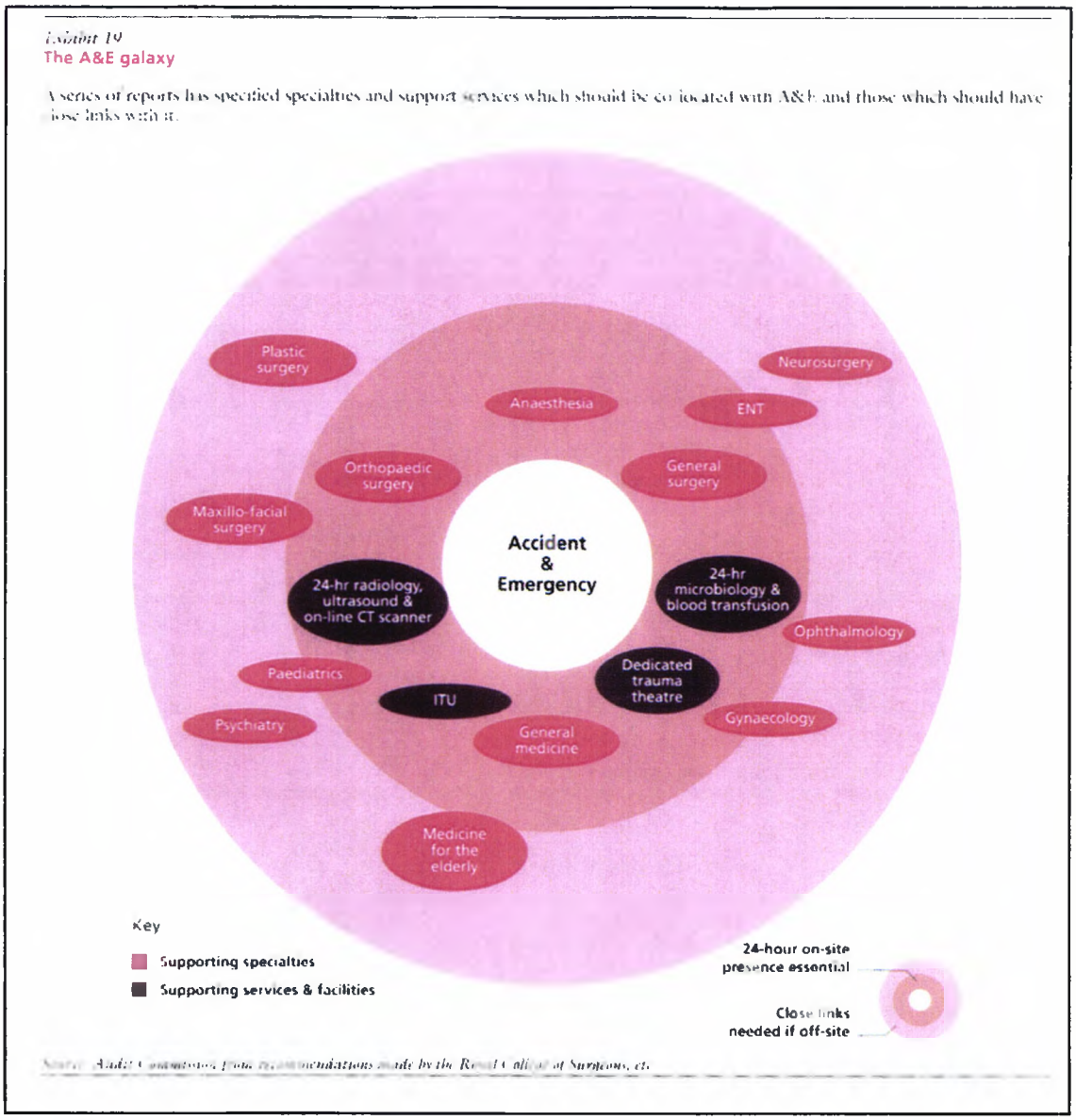


Figure 5.2. The ideal "galaxy" of care and support services associated with an A&E department (from Audit Commission, 1996).

Table 5.1. Statistical summary of A&E departments in England and Wales in 1996. (Derived from Audit Commission, 1996).

A. A&E departments and attendance rates

All departments in England & Wales	227
Total annual attendances	Almost 15 million
Attendances /day	70 - 300+
Attendances per year per 1,000 head of local population	400

B. Source and nature of attendances

Life-threatenng injuries	>0.5%
GP referrals (emergency cases assumed)	17%
Diagnostic categories	10 broad categories account for 75% of attendances
Estimates of numbers attending but not requiring hospital facilities (not standardised)	3.4% - 40%

C. Destinations after arrival

Discharged home or into GP care	The majority
Admitted to in-patient beds	15%
Asked to return to specialist out-patient clinic (elsehwere in the hospital)	10%
Followed up in A&E clinics	10%
Leave before treatment (significant problems assumed)	1 - 8%
A&E re-attendance rates (including return visits to A&E follow-up clinics)	54%

D. Staffing levels

Approx. national medical staffing levels by grade at 1994	A&E consultant 300. Associate specialist/senior registrar 120. Registrar 90. Staff grade/clinical assistant 230. Senior House Officer 1,350.
Nursing levels per department per 10,000 attendances	4 - 8

E. Process in A&E departments

Patient assessed within 5 mins	75% -98%
Seen by doctor within 1h	40% - 95%

5.3. The Action Research (AR) project at the London Trust.

The AR project was prompted by successful bids for emergency monies following the 1996/7 crisis and previously adverse local audits. The main project focused exclusively on elderly patients treated in A&E or subsequently admitted to hospital. According to HJL's interpretation, the quantitative aspects addressed the structures and processes involved, while qualitative features considered the quality or detail of care provided within and between stages as well as overall communications and culture at the Trust.

A general introduction and summary of the qualitative approach are reported here. The statistical analyses and structural modellling aspects follow in the next main section.

5.3.1. Organisation of the Trust for A&E services and care of elderly people.

Figure 5.3 summarises the management structure of the Trust as inferred by the AR project. Below the Chief Executive were 2 operational directorates with responsibility for their own departments, services and budgets. The Acute Directorate included the A&E department. However, acute services for elderly people were managed separately under "Services for Elderly People" (SEP) within the Primary, Community and Mental Health Directorate. Formal mechanisms for collaboration across the 2 directorates existed only at top management level.

The clinical director of A&E was also the sole emergency care consultant. The main acute provider within SEP was the Department of Medicine for Elderly People. Five DMEP consultant geriatricians handled GP referrals via A&E and noormal hospital admissions with standard cover during office hours. They liaised with other medical and surgical specialties with access to 170 beds in 7 in-patient wards (the hospital contained 26 wards in total, including an A&E observation ward and an Intensive Care Unit).

Figure 5.4 summarises the process of care and hospital admission in the Trust's A&E department. Stages and examples of monitoring data (shown in italics) were extended by HJL from the Audit Commission's 1996 report and were appropriate to the Trust.

5.3.2. The main AR project.

Principles of Action Research.

AR aims to study change (action) with the full participation, and where possible ownership, of the programme by those involved in the processes (Reason, 1988; Hart &

Bond, 1995). A facilitator or comparable mechanism is required. In principle, the approach uses all available data and information but emphasis is placed on observation and feedback from individual participants. Results are an interpretation of circumstances and cultures involved in the identification and introduction of change.

An "Action Research cycle" typically includes:

- Negotiation to identify the problem areas and potential interventions.
- Innovation to introduce the changes.
- Post innovation review to assess the outcomes as well as any barriers or promoters to the initiatives.

Methodology and objectives at the Trust.

The AR project was facilitated by an experienced nurse from St Bartholomew's School who established 3 participant groups. The "Key Participants" had overall responsibility with representation from management, professions, patients and carers affected by the whole project. The "Working Group" comprised staff and patients directly affected by specific changes. The "Wider Group" represented managers and staff whose work was likely to be affected if changes were made permanent.

The Key Participants identified 3 areas for Action Research cycles (ie. attention): Care While in A&E; A&E discharge; and Admission to in-patient Bed via the A&E department. Specific changes were already planned and funded by the emergency monies, and introduced in November 1997. Social workers had increased budgets and support from an occupational therapist. A nurse specialising in elderly care assisted with hospital admission and discharge procedures; while a health visitor provided patient follow up at home.

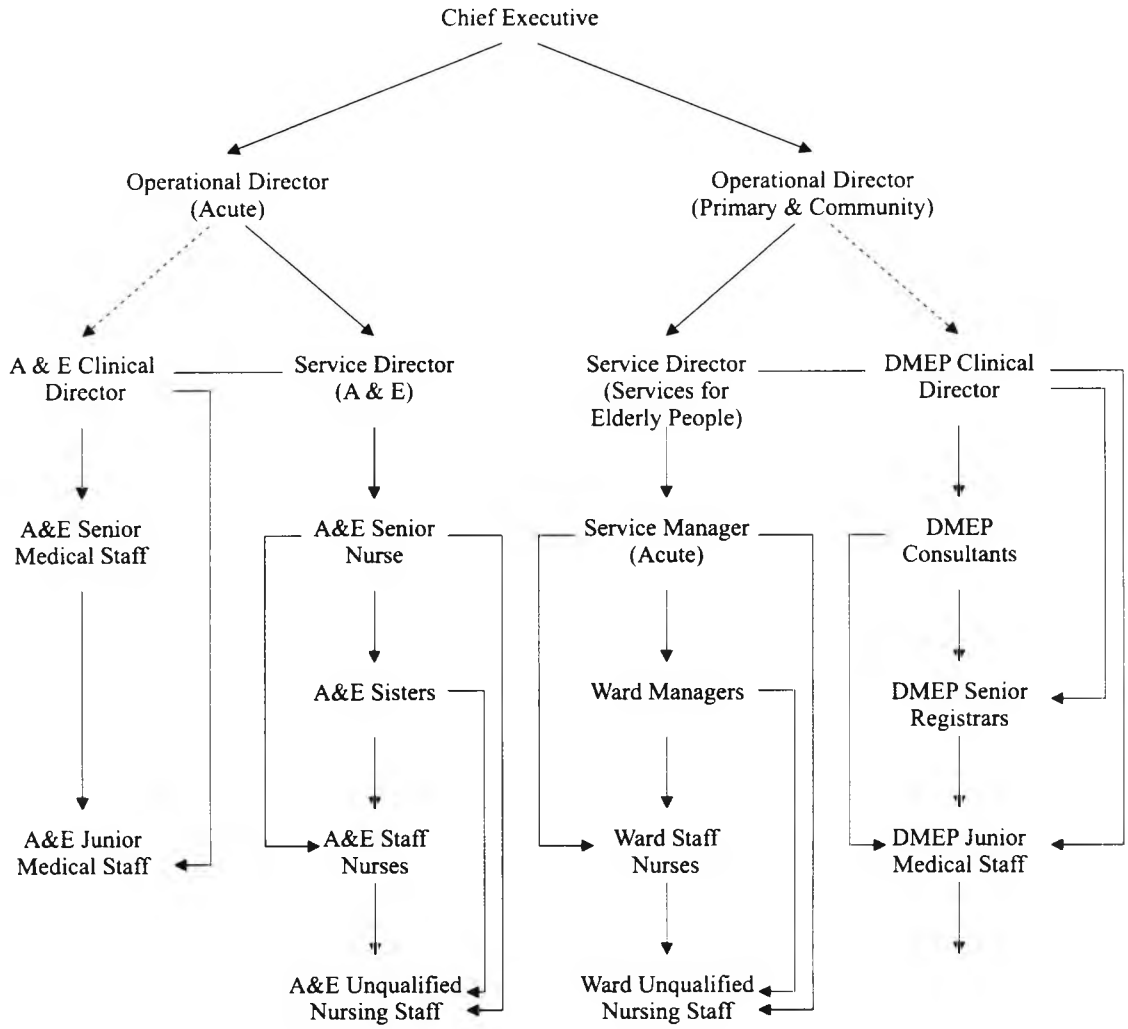
Data collection included field notes, questionnaires, transcribed interviews and meetings; hospital policy documents and official records of patient complaints. Separate databases on hospital admissions and discharges were established in the A&E department. Apart from material in the next main section, quantitative data were not formerly analysed.

Findings and recommendations.

The project's analyses and 51 recommendations described a Trust with management structures and cultures that inhibited change. The Trust was viewed as hierarchical with internal political pressures working against rather than in favour of new initiatives. Responsibilities for elderly people were split between the A&E department and Services for Elderly People (SEP) with reluctance to change without additional resources. Training and equipment to improve care in the A&E department were identified and contact between departments and professions had (apparently) improved. However, sustained progress and development were believed to require further funding.

Needs to improve basic data and information management directly relating to care were also highlighted. The Trust's directory of community services was out of date and not available in A&E. There were no guidelines for recording risks of pressure sores or using pressure relieving equipment. General guidelines for nurses did not include professional standards on care of the elderly or protocols for handling specific events.

Quality of patient social histories taken by A&E doctors and nurses was relatively poor and not audited. Access to old medical notes was slow; and the patient "transfer form" was not used consistently by A&E and ward staff as a template for communicating relevant information.



Please note a) lines of authority and working for service directors are not shown within their own service directorates beyond the first level (as their display will make the diagram too visually complex), and b) lines of professional accountability are nt necessarily reflected here (e.g. relationship of clinical directors to Trust's medical director or chief executive).

Figure 5.3. Administrative structure and lines of authority covering the Accident & Emergency department and care for older people at the NHS Trust collaborating. (From Meyer & Bridges, 1998, Appendix 5, Panel DD0a).

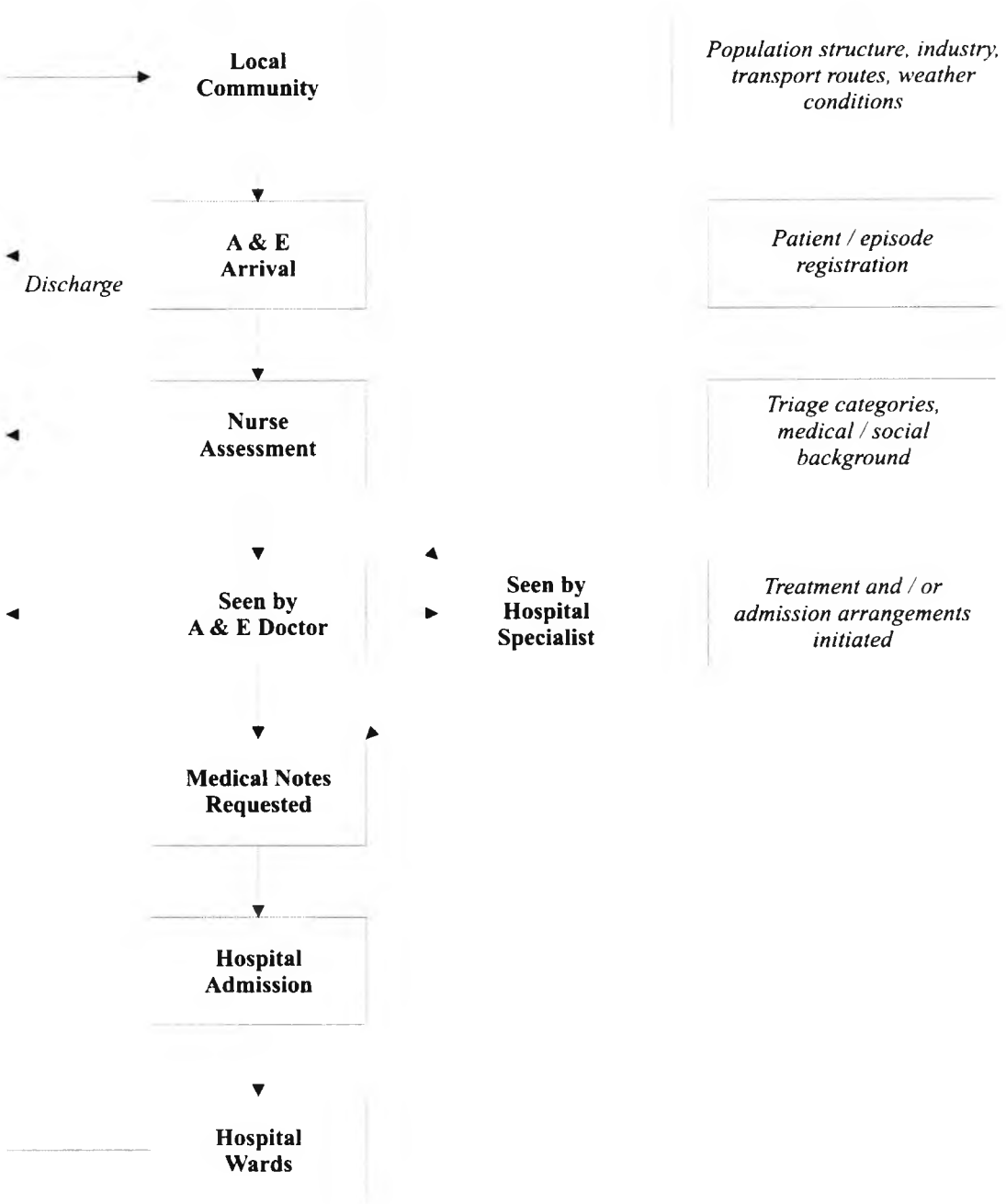


Figure 5.4. Schematic overview of the A&E/hospital admission process, with sources and types of available data..

5.4. A&E waiting times and process modelling at the Trust.

The AR project was interested in times to see a doctor over the whole study period. However, there was scope for more detailed evaluation based on the project's database of hospital admissions, supplemented by other requested data sources. Aims for this sub-project were therefore to:

- Measure the effects of initiatives by the Trust on A&E waiting times over the 1997/8 winter.
- Assess the processes of data collection/provision for continuous monitoring and development of an A&E process model.

5.4.1. Study period and patient numbers.

Data collection ran from 23rd October 1997 to 4th February 1998 (105 days) and was limited to hospital admissions only. The global sample of 4,104 admissions was split into 2 equal halves for assessing change (n1=n2=2,052) at 16th December (day 56).

5.4.2. Data, sources and quality.

Provided and requested sources.

Data requirements were broadly defined by the care process model in Figure 5.4. As listed below, the primary source was the A&E department database established specially

for the AR project. Three other sources were requested to put the patient sample and activity timings into context.

Special A&E database. This was the sole source of pre-computerised data and covered only patients admitted to hospital. Data on these admissions were entered by receptionists and extracted from nurse documentation on individual cases. Variables are listed in Table 5.2.

Local population characteristics - Report from the regional Director of Public Health. The document did not cover the time period or specific catchment area boundaries for the study.

Nurse and medical staffng levels - weekly staff rosters in print and manual formats. Printed medical rosters contained occasional manual changes and no indications of medical grades. Nursing rosters were printed templates with manual entries and corrections reducing legibility.

Hospital bed occupancy - printouts of midnight counts. Manual counts in the 26 wards were made by a touring nurse each night and subsequently computerised. Only sample printouts were provided.

Pre-computerised versions of requested material were not readily available. Basic data on all arrival types was officially stored in the hospital's Patient Administration System but definition of variables was not provided and access was limited by local resources. Moreover, databases within wards (including those connected to A&E) were not cross-referenced with unique patient identifiers.

Assessments by nurses were not timed and triage categories were undefined. Information about medical specialties served by different wards (admission destinations) was available but not provided. In addition, policy on liaison between A&E doctors and

hospital specialists, and responsibilities for medical assessment and initial treatment, were unclear.

In summary, analyses were necessarily limited to the special A&E database with no context on total workload or staff availability. Interpretation of illness severity and significance of waiting times to see a doctor were left to HJL's assumptions.

Completeness of the special A&E database and its implications.

Completeness for the whole sample was measured as the % of case numbers and is summarised in Table 5.2. Basic data on date, age, referral source, triage category and destination for patients were good (Panel A). In contrast, timings of specific steps in the process were relatively poor (Panel B) with similar patterns of missing records across referral sources and triage categories (Panels C&D).

Collection overall was more complete for elderly compared to younger patients. The sub-set for analysing delays before medical assessment (arrival time and time to see a doctor), for example, was twice as likely to be recorded for the elderly group (Odds Ratio = 1.98, 95% confidence interval 1.71-2.29).

Interpretation of missing data was unclear without indications of context (which variables were inappropriate for which patients). Assumptions that missing data conformed to the statistical distributions for available values were also questioned. Clearly missing data could not be tested, but data from elderly and younger patients on times to see a doctor, for example, had different variances (F-test = 5.13, p=0.02).

5.4.3. Statistical results based on the special A&E database.

General patient characteristics.

A third of all admissions were elderly (33.1%). The distribution also showed a marked peak for those aged 0-5 years and increased numbers in the 25-35 age range (see Figure 5.5).

Most admissions followed self referral (82.6%) or emergency referral by a GP (17.2%). Ambulance emergencies and transfers from other organisations accounted for only 0.2% of cases. Most patients were given an "urgent" or "standard" triage category (63.3%, 21.4%) with a significant number rated as "very urgent" (11.5%).

The pattern of patients across both referral source and triage categories, including GP referring practices, are given in Table 5.3. They were comparable over time according to the split half samples; and the proportions of elderly and younger patients in each sub-category were also consistent.

Time to see a doctor: comparison of elderly and younger patients for the whole sample.

Data were complete for only 2,705 cases (66% of the total sample). Timings were assessed by comparing group means (t-test) and rankings showing any tendency for one group to be seen later than the other (Mann-Whitney U test). Interpretation of results requires caution as tendencies do not show the size of any difference while difference in means may be affected by small numbers of extreme waits.

T-tests indicated a longer wait to see a doctor for elderly patients of around 15 minutes (0.233 decimal hours) with a 95% confidence range from 1-30 minutes. Results were significant for the whole sample but not for separate triage categories.

Elderly patients also tended to see doctors later than the younger group, according to average rankings for the whole sample with a statistically significant result (1441.2 compared to 1298.9, $p<0.001$). A significant difference in ranknqs was also found for the large, "urgent" category (867.1 compared to 812.4, $p=0.02$) but not for the other triage categories.

Changes in total A&E waiting time for all patients over the study period.

Data on total A&E waiting times (arrival to discharge to ward) were complete for 85% of cases with comparable levels for the split half samples. Mean waiting time for all patients in the first half was 6.6h (95% confidence range 6.36-6.84); and fell to 5.5h in the second half (confidence range 5.29-5.71). The improvement of over 1h, with reduction in general times and extreme waits, was supported by changes in the split half data distributions (Figure 5.6).

5.4.4. Conclusion to the quantitative assessments at the Trust.

The national problems with data collection, identified by the Audit Commission, were duplicated at this Trust. Apart from the specially introduced database, there were no pre-computerised or readily available sources of data for building a process model. Many

entries in the database were missing without clear explanations. Difficulties with interpreting analytical results was the main consequence

Analyses did show that elderly patients "tended" to be seen later by doctors compared to younger people. This result supported the findings of the main AR project that care of the elderly could be improved. However, overall waiting times to hospital admission for the whole patient population had fallen significantly during the study period , suggesting that initiatives at the Trust had contributed to more general improvements.

Table 5.2. Data completeness for the special database on patients admitted to hospital via the A&E department (total cases = 4,104).

A. Basic data for the whole sample.

Variable	% present
Date Of Episode	100
Age	99.6
Referral Source	100
Triage category	100
Destination (ward)	100

B. Event timings for the whole sample.

Variable	% present
Arrival time	98.9
Seen by A&E doctor	66.2
Referred to specialist	44.8
Seen by specialist	41.4
Medical notes requested	99.6
Medical notes ready	94.9
Departure to ward	85.7

C. % Event timings by referral source.

	Casualty (self referral)	GP referral	From other hospital	Ambulance service (999)	Emergency Bed Service (EBS)
Number of patients	3,388	796	7	2	1
Arrival time	98.8	99	100	100	100
Seen by A&E doctor	74.7	26.1	14.3	100	0
Referred to specialist	49.4	23.5	0	100	0
Seen by specialist	40.9	43.5	42.9	100	0
Medical notes requested	99.6	99.7	100	100	100
Medical notes ready	95.2	93.5	100	50	100
Departure to ward	85.4	87.1	71.4	100	100

D. % Event timings by triage category.

	Standard	Immediate	Urgent	Very urgent	Non urgent
Number of patients	877	155	2,597	471	4
Arrival time	98.5	99.4	98.9	99.2	100
Seen by A&E doctor	66.7	68.4	64.5	73.9	75
Referred to specialist	41.2	46.5	44.6	52.4	75
Seen by specialist	38.4	44.5	41.8	43.9	25
Medical notes requested	99.8	98.7	99.7	99.6	100
Medical notes ready	95.4	94.8	94.8	94.9	100
Departure to ward	85.4	91	86	82.6	100

Table 5.3. Spread of admissions by referral source and triage category as % of patient sample size (4,104).

	Casualty (self referral)	GP referral	Other hospital (transfer)	Ambulance (999)	Emergency Bed Service (EBS)	% patients in triage categories (row totals)
Standard	17.4	3.9	0	0	0	**21.4**
Immediate	3.6	0.1	0	0	0	**3.8**
Urgent	51.1	12.0	0.1	0	0	**63.3**
Very urgent	10.3	1.2	0	0	0	**11.5**
Non urgent	0.1	0	0	0	0	**0.1**
% patients in referral groups (column totals)	**82.6**	**17.2**	**0.2**	**0**	**0**	

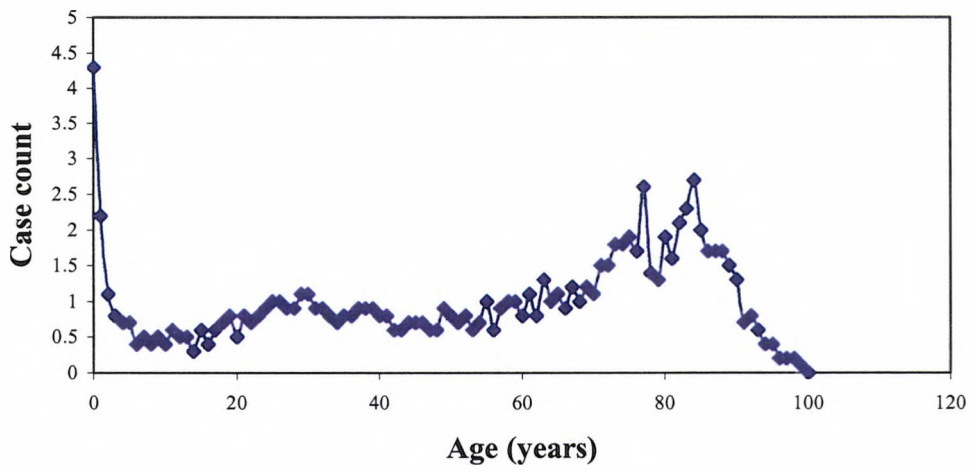


Figure 5.5. Age distribution for patients admitted to hospital via A&E over the monitored period.

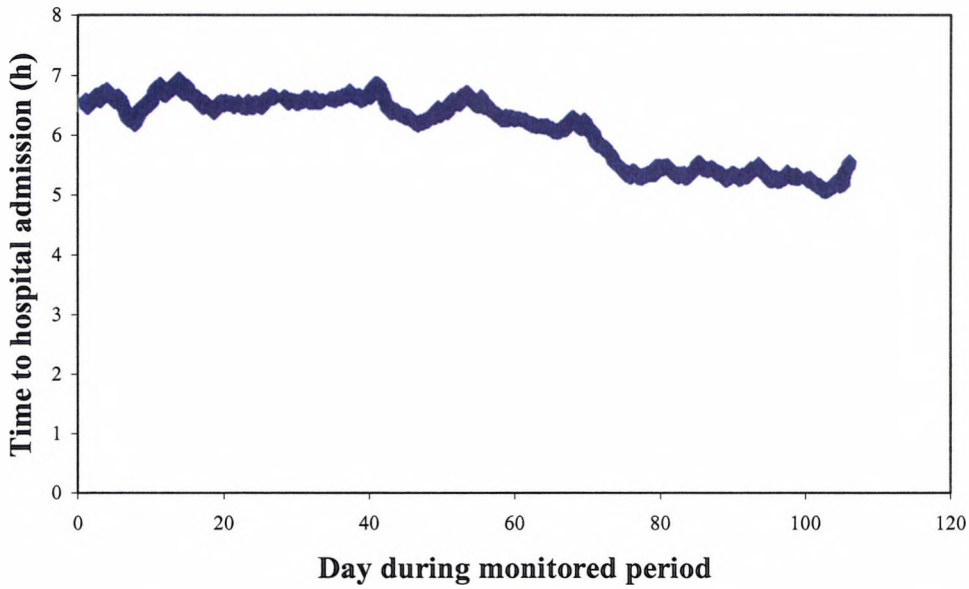


Figure 5.6. Waiting times from arrival at A&E to hospital admission over the monitored period (smoothed with a Time Series window of 1 week). (Time series principles given in Appendix 1.

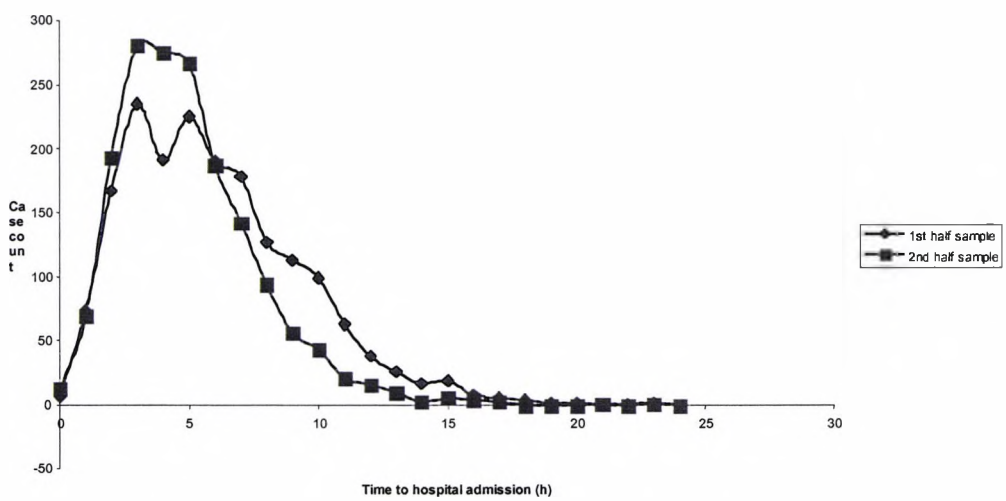


Figure 5.7. Distributions of waiting times from A&E arrival to hospital admission over the monitored period, split for comparison with Figure 5.6 at day 56.

5.5. Particular problems with data quality.

Dataset design and practicalities of collection.

The special A&E database was not supported by clear definitions of referral sources, triage categories or hospital wards to provide indicators of casemix. Indicators of overall workload were also omitted by decisions to restrict entries to hospital admissions. Moreover, there were no pathways or models to show which data were required for which patient groups and which were genuinely missing.

All data were entered retrospectively by extraction from paper records. The study did not examine the additional time and skills required by reception staff or consider the opportunities for direct entry by nurses and other staff involved in patient care.

Importance of complementary data sources.

Interpretation of practices and achievements at the Trust depended on additional information about the local catchment area and national policies affecting staff provision in particular. Such complementary information improves comparisons between Trusts but none of these sources was readily available to this study.

Statistical consideration.

Use of t-tests and other quantitative approaches based on the normal distribution are limited in studies of waiting times. Skewed distributions, such as the Weibull, are more appropriate for detailed analyses. Nevertheless, the problem of high levels of missing data remains.

Overlaps between qualitative and quantitative methods of analysis.

The 2 methodological approaches were not closely integrated on the AR project. In practice, though, the nurses adopted some aspects of information science by highlighting the importance of structured information (eg. care guidelines, patient transition forms and community directories). Equally, statisticians emphasised the relevance of local knowledge and experience to explain missing data in formal records. Closer cooperation between the methodologies would benefit future AR studies.

5.6. Conclusion to the Case Study.

Data collection to monitor hospital admissions via A&E departments was a national problem in 1998. The example of 1 NHS Trust showed a dependence on paper collection and transcription procedures resulting in databases which were not readily accessible, contain significant amounts of missing data, and which were not linked across the hospital. There was no agreement on datasets at national or local level and no policy guidance on staff responsibilities for collection.

Evidence of poor quality management data at the Trust were matched by concerns about the quality of individual care for elderly patients. Qualitative assessments suggested that the organisation was reluctant to change without additional and sustained resources.

The Case Study shows, however, that funded initiatives can make a difference. Changes introduced over the winter of 1997/8 reduced average waiting times for hospital admission via A&E for the general patient population by more than an hour. Significantly, evidence for this improvement required data collection practices and statistical analyses which were not routinely in place at the Trust.

Chapter 6

Visual Impairment Notification in England.

6.1. Introduction.

The final Case Study addresses a national care process linking patient assessments in hospitals to the start of community support from Social Services. Visual Impairment Notification (VIN) is essentially the voluntary mechanism for formal registration with the Local Authority. Until recent changes, it was also the primary route for national epidemiological data.

Comparable systems and problems exist across the UK. Responsibilities in England lie with the Department of Health (DoH) who, in principle, collaborate with equivalent bodies in other constituent UK countries (the "devolved administrations").

A project to develop an electronic Visual Impairment Notification System (eVINS) examined problems with the existing paper process, and ran from 1998 to 2001 (Leicester et al, 2002). Based at Moorfields Eye Hospital, it was supported by sections of DoH, the NHS Information Authority and other relevant national organisations. Plans were made for pilots in Moorfields home area of the old Camden & Islington Health Authority, including provision to assess options for pilot expansion across the country (Leicester, 2001).

Circumstances changed towards the end of the eVINS project. In particular, RNIB (not directly represented on the project) lobbied Government ministers for major changes to the whole Notification process. A DoH Review Group of stakeholders was established in late 2001; preliminary proposals were released for public consultation in Summer

2002. The Review was incomplete at Summer 2003 (but see chapter 11 for subsequent events).

Problems with the existing process and these two initiatives justify VIN as a Case Study in its own right. Moreover, VIN is used as the test case for the Data Quality Framework developed in Part 2 and applied in chapter 11.

The need to modify the Notification process is widely accepted, but the two initiatives represent different approaches. Although eVINS had a remit for introducing technology, it concentrated on features of data and information. The DoH Review, in contrast, has not published any formal evidence to justify and direct change.

Later application of the Data Quality Framework draws heavily on material in this chapter. The academic issue in Part 2 is to determine whether the general work supporting eVINS (and re-formulated under the Data Quality Framework in chapter 11)or the DoH Review offers a potentially more constructive approach to change.

In addition, issues of technology raised by the eVINS project provided the main reason for a national review of policies and related strategies for Information Management & Technology presented in chapter 9. Despite following Government policy and taking advice from relevant agencies, the project's proposals for an electronic system were limited by IT capability in the field. There were clear implications for any proposals based on IT from all the previous Case Studies.

Organisation of the Case Study

Section 6.2 summarises the patient group and the general Notification process. Registration trends are examined, along with the history of problems and recent developments logically related to Notification.

Sections 6.3 & 6.4 specify procedures, forms, annual case numbers, costs and data problems associated with the current process.

Sections 6.5 & 6.6 outline the eVINS project and problems connected to an electronic system on a national scale.

Sections 6.7 & 6.8 introduce the DoH Review, its preliminary proposals and problems linked to both data quality and changes to the structure of the Notification process.

Detailed technical material is largely confined to Appendices to the main Thesis.

Appendix 3 provides eVINS' technological specifications.

Appendix 4 introduces related web languages.

General findings

Visual Impairment Notification in England is not formally monitored and costs almost £2m per year in consultant fees alone. Although registration rates are increasing, there is no concensus on the prevalence of sight loss in the UK as a measure of coverage by the process. There is evidence of register management problems on cases already in "the system", including limited data on numbers with multiple disabilities.

Epidemiological data collection direct from Notification forms has been halted because of poor quality. Social Services are not provided with additional data to prioritise and plan cases; and patients lack the information to make informed decisions.

In 2001, an electronic approach was limited by variation between hospitals on access to computers in clinics and policies on local system security. Few Social Services were

connected to the electronic network for healthcare (NHSnet). However, greater use of IT was Government policy for healthcare and across the public sector,

DoH proposes a greater role for high street opticians and GPs, and 3 new forms. In practice, there is no clear care pathway or new monitoring procedures. The design and number of forms have not been fully addressed. Logical links with other initiatives from DoH, the NHS and independent organisations are not shown in any document to date from the Review.

6.2. Background and wider context.

6.2.1. Patient group and management problem.

Patients with permanent conditions affecting both eyes, and meeting Government criteria (Table 6.1), are eligible to be registered in one of two categories:

Blind. *Cannot do any work for which eyesight is essential.*

Partially Sighted. *Substantially and permanently handicapped by defective vision caused by congenital defect or illness or injury.*

The scheme is voluntary. Patients have the incentives of assessments and care packages from local Social Services and access to statutory benefits and concession schemes following registration. Officially, patients are "certified as registerable" by the consultant and formally offered registration by Social Services. The labels of registration are difficult for some patients but, for most, their is no practical distinction between the 2 stages.

Consultants certify patients by completing form BD8(1990). Dispatch aims to:

- Alert the patient's GP.

- Send epidemiological data to the Office for National Statistics (ONS).

- Initiate community assessments and packages of care coordinated by the Local Authority Social Services Department, including the invitation to be registered.

- Reimburse the consultant with a fee from the patient's Health Authority.

General problems with Notification from the patient's perspective were raised by RNIB (Cox, 2001). The existing process had not changed substantively since the NHS began. There were concerns about patient coverage; tendencies from Local Authorities to ignore unregistered people; complicated access to benefits, and general delays,

The process is also the only national and regular mechanism for data collection on causes of sight loss. However, such data were last analysed for 1990/1 (Evans, 1995a). ONS believed that data were "too poor for cost-effective analysis" (personal communication) and requirements to complete the epidemiological section of BD8 forms (Part 5) have been halted while "alternative methods are considered" (DoH, 2000/bd8).

6.2.2. Origins and recent history of registration.

According to Evans (1995b), counts of blind people in England began in the mid 19th century with declarations on census returns. The 1920 Blind Persons Act established a register of cases identified by any medical practitioner, followed in the mid 1930s by nominations signed by ophthalmologists via the first BD8 form. In 1948, the National

Assistance Act gave formal responsibilities to Local Authorities for registers and community services for all recognised disabilities.

The changes established BD8 as a useful source of epidemiological data. Analyses were pioneered by Arnold Solsby, beginning in the 1950s with causes of blindness and followed by partial sight in the late 1960s.

Procedures were reviewed by DoH in 1983. Forms were reaching Local Authorities by unorganised routes and DoH were receiving only 60% of epidemiological returns. Diagnostic records were not standardised and consultants were making arbitrary distinctions between blindness and partial sight. Requirements for central returns from registers were also reduced to 3 yearly cycles during the 1980s to reduce data collection burdens, though sub-sets on children were still reported annually.

The current Notification process was introduced in 1990. DoH took responsibility and ONS' predecessor (Office of Population Censuses and Surveys - OPCS) was given the contract to collate and analyse epidemiological sections from new forms. Automatic release of diagnoses to Social Services was also stopped.

Forms and channels for data exchange were never piloted. Problems persist despite regular reviews and circulars from DoH (identified in DoH, 2000/bd8) as well as academic reports commission, for example, by Guide Dogs for the Blind Association.

6.2.3. Stakeholders.

Stakeholders involved in the DoH review (Table 6.2) include the Government, Association of Directors of Social Services (ADSS), professional bodies in healthcare, along with national and local charities.

Most of the 15k optometrists operate from high street opticians (figures from General Optical Council – personal communication). The 36k GPs in 10-12k surgeries are not specifically represented on the DoH review (figures from DoH Organisational Codes Service).

There are around 750 eye consultants in 191 main hospitals, often collaborating with other hospitals lacking specific eye departments (monitoring by the Royal College of Ophthalmologists). Moorfields Hospital is effectively the largest eye department in the UK by a factor of over 3:

Eye Dept / Hospital Size	**N Consultants**	**N Eye Departments**
Small	1-2	28
Medium	3-7	136
Large	8-16	26
Moorfields	60 (43 main staff)	1

The 150 Local Authorities with social services responsibilities covering England (identified by DoH's Social Statistics Division and ONS publications) divide into 4 categories by legal status and size of population:

Authority type	**N Authorities**	**General population (000s)**	
		Mean	**Range**
Shire Counties	35	686.9	284.6-1353
Metropolitan Districts	36	309.3	152.7-1010.4
London Boroughs	33	223.5	6.4-345.5
Unitary Authorities	46	181.1	37.8-406.2

6.2.4. Scale and trends in registration.

Data on numbers are available from the last 3 yearly review of registers in 2000 (DoH, 2001) and for the general population from (ONS, 2001). Concerns about quality are raised in 6.4.2. Nevertheless, analyses indicate broad patterns and changes already occuring in the Notification process.

30,440 new cases were registered in England in the year to March. Around 13k cases were "blind" and 17k "partially sighted". Total numbers on registers were estimated at 307k (158k blind, 149k partially sighted). Numbers had almost doubled since 1982 with increasing cases of partial sight as the dominant trend (Figure 6.1).
As Table 6.3 illustrates, most new and existing registrations were pensioners (83% and 79% respectively). Compared with 1992, new registrations had increased above demographic change in all age groups except those aged 65-74 (note the fall in general population for this age category). Most of the change occurred in the 75+ age group.

6.2.5. Logically related initiatives.

A range of initiatives relate directly to issues aroundd registration. Others are developing with changing healthcare policy, considered more closely in chapter 9. None has been referenced explicitly in any publications from the DoH review.

Deaf-Blind consultation. DoH's Social Care Group conduct R&D in relevant areas and are key members of the DoH Review. In the late 1990s, they began a consultation on services for people with dual sensory loss (www.doh.gov.uk/scg/deafblind.htm) which included preliminary assessments of Notification as a means for identifying cases (raised in DoH, 2000/bd8). Note that organisations representing deaf-blindness were not initially included on the DoH Review Group (Table 6.2).

Parallels in Scotland. A review of Notification in Scotland (Scottish Social Work Inspectorate, 1999) led to a report for Scottish ministers. Recommendations would be released by the Scottish Executive following formal ministerial agreement. However, ministers were re-shuffled after the death of the First Minister. No recommendations were formally sanctioned.

Standards for Social Services. In line with a new Quality Strategy for social care in England (DoH, 2000), the Association of Directors of Social Services (ADSS) commissioned draft service standards for visually impaired adults (Sensory Services, 2001a,b). Essentially they covered the existing Notification process with general guidance on categories for patients at risk, basic service delivery timetables, information provision, and process monitoring.

Optometry (opticians). Low Vision Services (assessment, aids and training to maximise residual vision) are known to vary in quality and quantity across the country (Ryan and Culham, 1999; Ryan and McCulloch, 1999). A National Low Vision Consensus Group (NLVCG) has been established to encourage debate between professionals and service planners and to promote local advisory committees lead by users. The launch document in 2000 was reputedly endorsed by the Secretary of State for Health.

Ophthalmology. R&D in ophthalmology is now covered by a national strategy (Royal College of Ophthalmologists, 2002). It is accompanied by the electronic Ophthalmic Research Network (ORN) supported by a website maintained at Moorfields (www.orn.org.uk or www.site4sight.org.uk). The package sets aims for ophthalmic research with mechanisms for monitoring and improved communication. The same web team has responsibility for the ophthalmic section of the National Electronic Library for Health (see chapter 9 on NeLH and related).

VISION 2020: a potentially integrating approach. The World Health Organisation (WHO) has established VISION 2020 as an international programme to improve

services especially for those with treatable disorders. VISION 2020 UK is represented on the DoH review and has familiar aims (from internal minutes of meeting of VISION 2020 UK in spring 2002):

- Promote communication between professionals, researchers and service providers.
- Improve information provision for users.
- lobby politicians.
- Establish a register of visually impaired people.

Policy and monitoring developments.

National Service Frameworks. NSFs set standards on activities and datasets for particular conditions or patient groups. Those relevant to visual impairment include "Older People", "Diabetes" and a new NSF for "Long Term Conditions" (also see NSFs in chapter 9).

Referrals, Assessments & Packages of care. RAP is a new set of statistics developing under consultation with Local Authorities and known to include the Notification process from the point of formal contact with Social Services.

Online statistical returns. DoH Social Statistics Division requires Local Authorities to return some statistics over the Internet from 2003 (DoH, 2002/pss). The 3 yearly summaries of Local Authority registers (form SSDA902 - see 6.3.1) are covered by this initiative. The technological approach is similar to eVINS without encryption and digital signatures.

Table 6.1. UK criteria for registerable blindness and partial sight (from Bd8(1990) form).

Both eyes must be affected. The better state in either eye with spectacle correction is considered.

Visual function tests

Acuity (eye chart). How close a patient needs to be to recognise letters of standard size compared to the "normal" population, expressed as a ratio.. Reading letters of different size from a fixed point it equivalent to moving the viewing distance. A common test distance is 6m (20ft) hence 20/20 vision is "normal".

Field (Peripheral vision). Ability to recognise objects away from the centre (central fixation). A full field is expressed as 180 degrees in all "planes" or directions. A field of 10-5 degrees or less would be very constricted.

A. Blind

Criteria[I]	Acuity (metres)	Field
1	<=3/60 or	
	><=1/18	Considerable restriction
2[1]	>3/60 -	Very contracted
3[2]	>=6/60	Very contracted, especially if contraction in lower field.

B. Partially Sighted

Criteria[II]	Acuity (metres)	Field
1	>=3/60 - 6/60	Full
2	>=6/24	Moderate contraction, opacities in media or aphakia[b]
3	>=6/18	Gross defect or marked contraction

Additional guidance

[I] Also consider age of patient and how recently eyesight has failed.

[II] Infants and young children with congenital ocular abnormalities leading to visual defects should be certified as partially sighted, unless obviously blind. Children aged 4 or over should be certified as blind or partially sighted according to binocular corrected vision.

Exclusions

[1]Exclude if had a visual defect for a long time and does not have a very contracted field.

[2]Homonymous or bitemporal hemianopia[a] with acuity >=6/18.

Technical terms

[a]Hemianopia. Loss of half field, or field quadrant, through fault with visual pathways (eg. following stroke).

[b]Aphakia. Lens absent.

Table 6.2. Stakeholders involved in the Department of Health review of visual impairment identification and notification.

Organisations are drawn from the January 2002 list released on request by RNIB members. Others have joined subsequently (shown in italics) and numbers have increased generally since the public consultation phase of the review (DoH, personal communication).

For reference, BBC Radio 4's In Touch programme identified over 300 UK organisations directly related to VI issues (charities & self help groups) in the early 1990s. Note also that GPs and dual sensory loss organisations (deaf-blindness) were not explicitly represented on the Review Group.

Area	**Representative(s)**
Department of Health	Social Care Group (Disability Policy sub-section) Optical & Dental Division (medical policy)
Social Services	Association of Directors of Social Services (ADSS) London Sensory Impairment Managers Group Social Care Association (Rehab workers professional body)
Ophthalmology	Royal College of Ophthalmologists
Optometry	College of Optometrists
World Health Organisation	*VISION 2020 Programme UK Branch*
Major National Charities	Royal National Institute for the Blind (RNIB) Guide Dogs for the Blind Association (GDBA) *Action For Blind People (AFBP)*
Local Support Charities	National Association of Local Societies for the Visually Impaired (NALSVI)
Miscellaneous	Independent Users SeeAbility (charity)

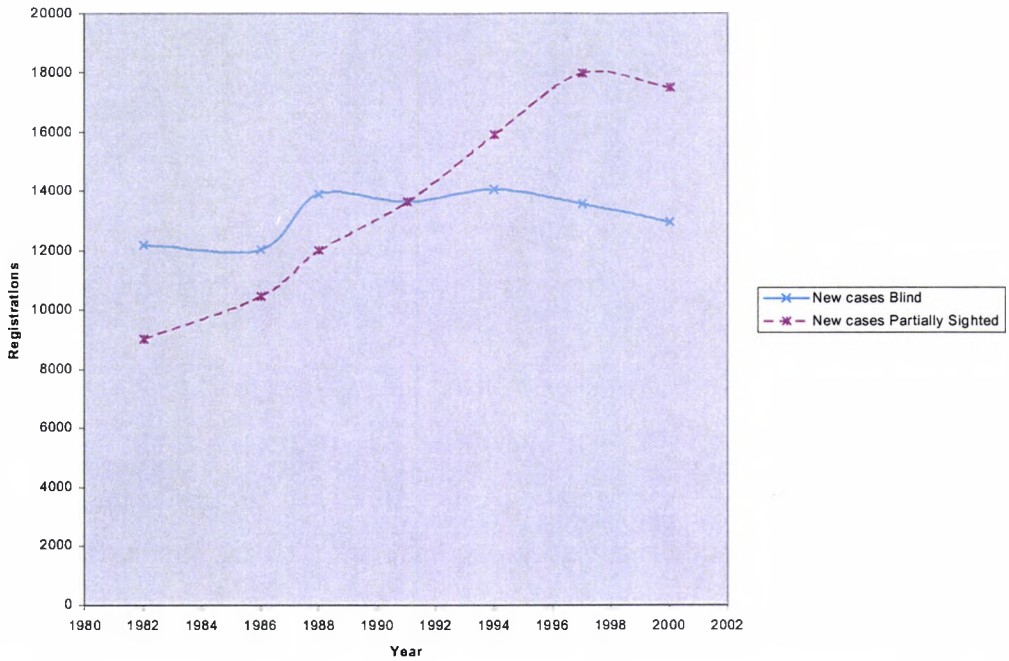


Figure 6.1. Number of New Registrations each year in England by category from 1982 to 2000 (from DoH, 2001).

Table 6.3. Official figures on general population, total and new registrations in England compared at 1991 and 2000 (constructed from ONS, 2001 and DoH, 2001).

Note the different categorisations for children and male/female pensioners between general population and registration data.

A. General population by age groups in 000s.

Year	All ages	0-4	5-15	16-59/64	59/64-74	75+
1991	48,208.1	3,237.9	6,473.0	29,627.0	2,816.1	3,408.6
2000	49,997.1	2,999.7	7,074.8	30,902.0	2,589.7	3,712.2
Change						
Absolute	1,789.0	-238.1	601.8	1,275.0	-226.4	303.6
%	3.7	-7.4	9.3	4.3	-8.0	8.9 (85+: 30.2%)

B. Total numbers on registers by age groups.

Year	All ages	0-4	5-17	18-64	65-74	75+
1991	229,980	1,040	3,670	44,400	31,940	148,940
2000	306,500	1,330	6,800	55,340	31,940	211,070
Change						
Absolute	76,520	290	3,130	10,940	0	62,130
%	33.3	27.9	85.3	24.6	0	41.7

C. New registrations in each year by age groups.

Year	All ages	0-4	5-17	18-64	65-74	75+
1991	27,270	280	350	3,770	4,500	18,370
2000	30,440	370	520	4,070	4,120	21,380
Change						
Absolute	3,170	90	170	300	-380	3,010
%	11.6	32.1	48.6	8.0	-8.0	16.4

6.3. The current Notification process.

Figure 6.2 provides a schematic summary. The main channel of communication is between hospitals and Social Services via the BD8 form. In practice, several Social Services Departments have delegated responsibilities to local charities (Agents). Fee forms, dispatches to ONS and central returns from registers are also included as logical components of the full Notification process until epidemiological returns were formally removed in Autumn 2000.

6.3.1. Procedures and forms.

There is no set route to a hospital's ophthalmology department. Patients may be sent by GPs, high street optometrists or self-referred through Accident & Emergency departments.

Consultants should judge whether a condition is permanent and take account of the patient's social circumstances and ability to cope. Patients are entitled to a second opinion. General advice on Notification and counselling are advocated. Low vision assessment should be performed at the hospital or indicated for action by Social Services.

BD8 and fee forms are substantially completed and dispatched by secrertarial staff. BD8s should be signed and dated by the consultant with signatures from the patient and a witness to confirm information disclosures. In practice, time constraints in the clinic mean that forms are sometimes signed before completion and patients are sent home before providing background information.

BD8(1990) essentially comprises two 8" by 16" pages with sensitive paper producing copies. Detailed specifications of structure and content (Table 6.4) summarise as:

Page	Parts	Content summary
1	1. About the patient.	Patient identifying details, including GP and local Social Services Department.
	2. Consent form - for disclosure of information.	Ticks and signatures (patient/representative and witness) defining understanding of the process and agreements to disclosures.
	3. Aspects of visual function.	Record of visual function assessments (optometry) and general information about the patient.
	4. Certificate of blindness or partial sight.	Category of visual impairment signed and dated by the consultant.
2	5. Details of person examined.	Anonymous summary of patient demographics, sight loss status and ophthalmic diagnoses, signed by the consultant.

Consultant fee forms are not standard and copies are often produced by local photocopying. An example from Camden & Islington Health Authority is included as part of an electronic BD8 in the next section (Figure 6.5, last page). Forms are sent with BD8s to Social Services for counter signing and forwarding to the patient's Health Authority.

BD8s completed in clinic are given to patients and sections for ONS are often sent in bulk. Ignoring these special arrangements, there are potentially 5 postal exchanges involved for each patient:

Form	From	To
BD8 all Parts	Hospital	GP
BD8 Parts 1-4, and fee form	Hospital	Social Services
BD8 Part 5	Hospital	ONS
BD8 all Parts	Hospital	Patient
Fee form	Social Services	Health Authority

SSDA902 form is the 3 yearly central return on registers completed by Local Authority information departments and sent to DoH's Social Statistics Division. Content is defined

in Table 6.5 and includes new and total cases by age group and cases of blindness with additional disabilities.

6.3.2. Annual processing rates and approximate costs.

Patient and professional numbers (from 6.2.4 & 6.2.3) averaged for England imply that:

- A consultant completes 3-4 forms a month.
- Social Services receive 3-4 a week.
- GPs are sent fewer than 1 form a year or 3-4 per surgery.

Costs approach £2m a year in consultant fees alone. They are entitled to around £60 for each new registration and £40 for a re-registration from partial sight to blindness.

The separate costs of data processing are estimated at £83k or around £2.70 per case. Figures and calculations (Table 6.6) are limited to form production and distribution, postal dispatches and subsequent processing. Most of the estimate (£54k) is attributed to paper-electronic transcription of completed forms by ONS and Social Services.

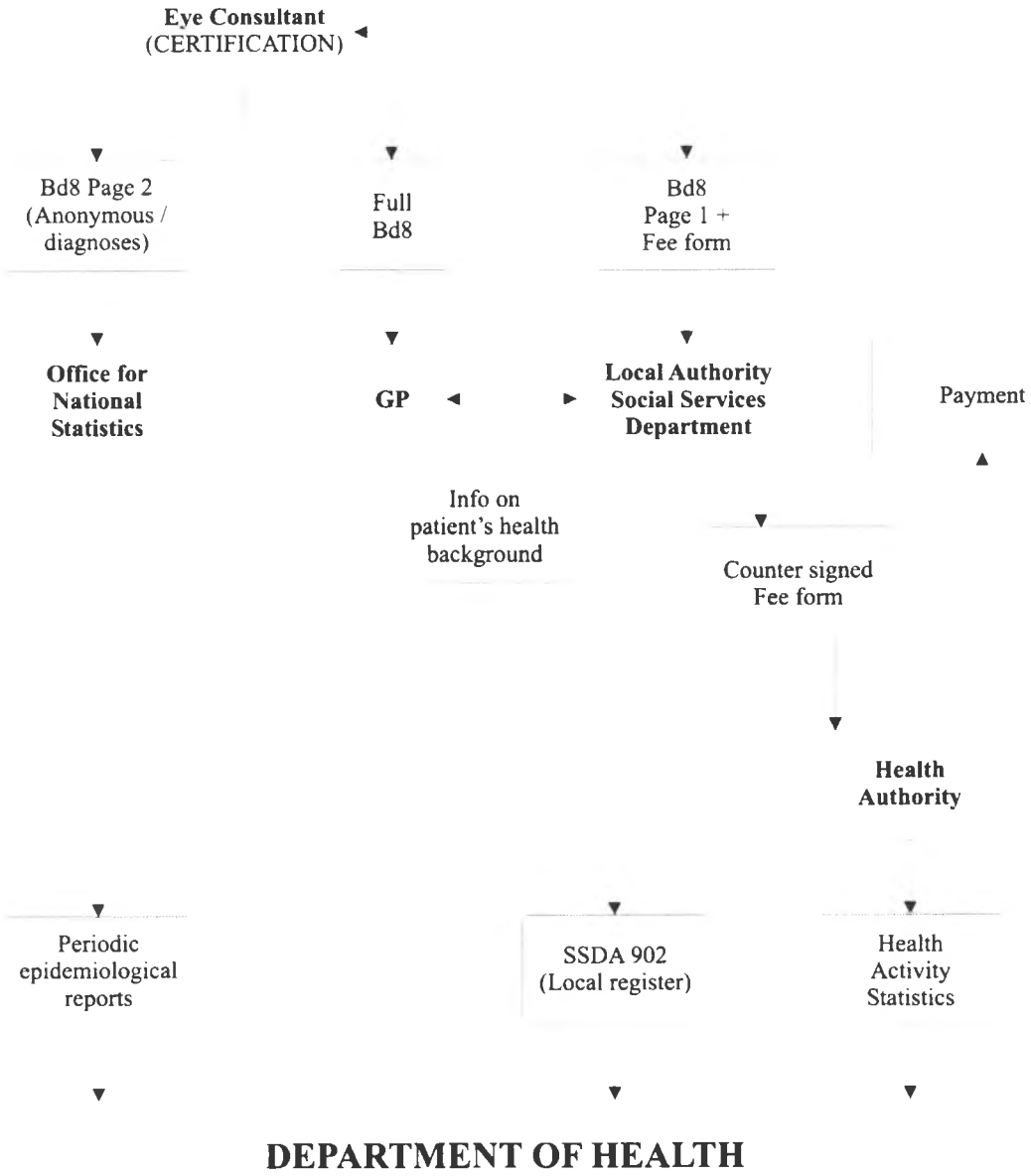


Figure 6.2.. Schematic summary of the paper Notification (or BD8) process.

Table 6.4. Comparison of form BD8(1990) with the NHS Data Dictionary Version 3.2 (performed by the NHS Information Authority) and data fields in an Electronic Patient Record system being developed at Moorfields Eye Hospital (ePatient).

BD8(1990) data item	NHS Dictionary term	Format	Comments	EPatient ("yes" if item in records)
Part 1 – about the patient				
Surname	**Person Name Type 'Preferred name': PERSON NAME WORD TYPE** 'Family Name or Surname'	Format/ length: 35		Yes
Other name	**Person Name Type 'Preferred name': PERSON NAME WORD TYPE** ' Forename or Personal Name'	Format/ length: an35		
Title	**PERSON NAME WORD TYPE:** 'Title'	Format/ length: an35		Yes
Date of birth	**BIRTH DATE**	Format/ length: n8-ccyymmdd		Yes
Address	**ADDRESS FORMAT TYPE** a. Post Office Preferred Format b. Vernacular Format c. Unstructured Format ADDRESS: UNSTRUCTURED A type of ADDRESS. A recognizable postal address comprised of up to five lines of 35 alphanumeric characters. Note: The format relates to the physical layout, and not necessarily to the logical layout of the address.	Patient's Usual Address Format /length: an175 (5 lines each an35)		Yes
Postcode	**POSTCODE** Notes: The **Postcode** associated with the **Address: Unstructured** nominated by the **Patient**, with **Address Association Type** of 'Main Permanent Residence' or 'Other Permanent Residence'.	Format/ length: an8		Yes

BD8(1990) data item	NHS Dictionary term	Format	Comments	EPatient ("yes" if item in records)
Name (of General Practitioner)	**Person Name Text** of a **Person Name: Unstructured**	Format/ length: an70	The NHS Data Dictionary allows for free-format names, as well as structured ones	Yes
Address (of General Practitioner)	See above		Address can be in Post Office preferred format (PAF); structured in some other way (vernacular format) or unstructured. The latter is 5 lines of up to 35 characters in length.	Yes
Name (of Social Services Department)			NHS Organisation Codes do not cover Social Services currently.	
Address (of Social Services Department)				

BD8(1990) data item	NHS Dictionary term	Format	Comments	EPatient ("yes" if item in records)
Part 2 – Consent form				
I am – Patient Parent of patient Patient's guardian Patients' authorised representative	**PERSON RELATIONSHIP TYPE** The classification of the role of the second PERSON in a PERSON RELATIONSHIP. Classification: a. Guardian b. Next Of Kin c. Not the same person		The Dictionary classification does not map, but it was defined for different purposes. Conformance is not required.	
Patient understands form and how it will be used			Nothing equivalent	
Patient agrees to parts being sent to Social Services			Nothing equivalent	
Patient agrees to one part being sent to OPCS			It is now Office for National Statistics (ONS)	
Patient agrees to all parts being sent to the GP			Nothing equivalent	
Date		Format/ length: n8- ccyymmdd		Yes
Signatures			Will there be 'electronic signatures'?	

BD8(1990) data item	NHS Dictionary term	Format	Comments	EPatient ("yes" if item in records)
Part 3 – Aspects of visual function				
Visual acuity, unaided – right eye			Nothing equivalent	Yes
Visual acuity, unaided – left eye				Yes
Visual acuity, with spectacles – right eye				Yes
Visual acuity, with spectacles – right eye				Yes
Visual acuity, best with both eyes open				Yes
Total loss of visual field				
Extensive loss of visual field				
Primarily loss of peripheral field				
Primarily loss of central field				
Duration of sight loss Less than one month Less than one year More than one year			Nothing equivalent	Yes

Low vision aid Prescribed To be assessed Not appropriate			Nothing equivalent	
Sight loss only			Nothing equivalent	
Also poor mobility			Nothing equivalent	
Also significant hearing impairmen t			Nothing equivalent	
Other relevant informatio n (free text)			Cannot standardise free text	

BD8(1990) data item	NHS Dictionary term	Format	Comments	EPatient ("yes" if item in records)
Part 4 – Certificate of blindness or partial sight				
Person is: Blind Partially **sighted**			Nothing equivalent	Yes
Consultant 's name	**Person Name Text** of a **Person Name: Unstructured**	Format/ length: an70		Yes
Consultant 's address			Address can be in Post Office preferred format (PAF); structured in some other way (vernacular format) or unstructured. The latter is 5 lines of up to 35 characters in length	Yes
Signature			Electronic signature?	
Date		Format/ length: n8- ccyymmdd		Yes

BD8(1990) data item	NHS Dictionary term	Format	Comments	EPatient ("yes" if item in records)
Part 5 – details of person examined				
Date of birth	**BIRTH DATE**	Format/ length: n8- ccyymmdd		Yes
Town	**POST TOWN**			Yes
Postcode	POSTCODE	Format/ length: an8		Yes
Main cause of visual disability			Nothing equivalent	Yes
Person is : Male Female	Sex 0 Not known 1 Male 2 Female 9 Not specified Notes: Sex is a **Characteristic Code** - an attribute of **Characteristic** classified by the **Characteristic Type** "Sex".	Format/ length: n1	The classification is an international standard	Yes
Person is: Blind Partially sighted			Nothing equivalent	Yes
Ophthalmic condition causing blindness or partial sight – right eye Up to 5 conditions			Nothing equivalent – we have diagnoses or procedures	Yes
Ophthalmic condition causing blindness or partial sight – left eye Up to 5 conditions			Nothing equivalent – we have diagnoses or procedures	Yes
Disease causing			National statistics are	Yes

ophthalmic conditions Right eye Left eye Both eyes Up to 5 diseases			collected in ICD10. Read Codes (Clinical Terms) can map to ICD10, but I'm not sure how a map from a specialty-specific coding system to Read Codes would work. Additionally, I am not certain that there will be a mapping from Read Codes to SNOMED CT.	
Signature			Electronic signature?	
Date		Format/ length: n8-ccyymmdd		Yes

Table 6.5. Summary of SSDA902 forms for triennial central returns on Local Authority blind and partial sight registers.

Purpose. Statistical summary of all blind and partial sight cases on the register at the year ending 31st March and new cases during the year.

Design problems (from HJL). Age groupings do not match standards (eg. children aged 15-, no sex categories for pensioners). Additional disabilities limited to blind cases. Identified and eligible but unregistered cases ignored.

A. GUIDANCE AND DEFINITIONS.

Identification of cases.

1. Only registered blind or partially sighted persons normally resident in the area should be entered on this return. This includes persons normally resident in but living outside the area (eg in residential homes or hospitals or employed in workshops for the blind, etc) and for whom the local authority is making provision by arrangements under either Section 21 or Section 29 of the National Assistance Act 1948.

2. Additions to the register should not include re-certification or transfers from other areas.

Age categories (years)

Total registrations categorised by age at end of year.
New cases categorised by age at registration.

Age category ranges:
All ages, 0-4, 5-17, 18-49, 50-64, 65-74, 75+.

Definitions of additional disabilities

Mentally ill. Only those suffering from mental illness within the terms of the Mental Health Act 1983, including those in hospital.
Learning disabilities. Only those persons with 'severe mental impairment' or 'mental impairment' as defined in the above Act.
Physical disabilities. Only those blind persons suffering from defects of a permanent and substantial character, eg a person suffering from paralysis, or crippling diseases, etc.
Deaf without speech. Those who have no useful hearing and whose normal method of communication is by signs, finger spelling or writing.
Deaf with speech. Those who (even with a hearing aid) have little or no useful hearing but whose normal method of communication is by speech and lip-reading.
Hard of hearing. Those who (with or without a hearing aid) have some useful hearing and whose normal method of communication is by speech, listening and lip-reading.

B. FORM CONTENTS.

Local Authority Identification

Authority name	Contact name
Authority code	Telephone/extension

SSDA902 Table 1. Blind persons and partially sighted persons

Numbers on the register and new registrations.

All blind cases by age category	All partially sighted cases by age category
All new cases of blindness by age category	All new cases of partial sight by age category

SSDA902 Table 2. Blind persons by age category registered at end of year who have an additional disability:

Mentally ill only Learning disabilities only Physical disabilities only Deaf without speech only Deaf with speech only Hard of hearing only	Mentally ill with other physical, sensory or speech disabilities. Learning disabilities with other physical, sensory or speech disabilities. Physical disabilities with other sensory or speech disabilities.

Table 6.6. Approximate annual costings for the manual Visual Impairment Notification process in England.

A. Assumptions & comparisons.

30,500 cases per year. Re-registrations excluded. Only BD8 and fee form production & distribution, dispatch and transcription are considered. Annual cost in consultant fees for new registrations (£60 per case) is £1.83m.

B. Tabulated cost components and calculation results.

Component	Items	Cost per case (£s)	Annual Cost (£s)
Form production & distribution to hospitals	BD8[a]	0.34	10,370
	Fee form (sup>b	0.02	610
Form dispatches[c]	BD8 & fee forms	0.60	18,300
Transcription	2 clerks at ONS[d]	1.18	36,000
	1 clerk for all SSDs[e]	0.59	18,000
Total		2.73	83,280

[a]Figures from Astron Ltd (formerly part of HMSO).
[b]Produced by local photocopying.
[c]3 dispatches per case at 2nd class mail + envelope.
[d]600-700 forms a week to transcribe.
[e]Equivalent of 1 clerk serving all Social Services Departments.

6.4. Particular problems with data quality: The current Notification process.

6.4.1. Epidemiological estimates for the scale of visual impairment in the general population.

Reliable estimates for the scale of registerable sight loss would provide an important measure of patient coverage by the Notification process. In turn, good coverage would indicate that Notification provided a valid patient sample for addressing causes of sight loss. However, there is no consensus opinion on the prevalence of registerable sight loss in England or the UK.

English data (307k on registers in 2000) extrapolate to 367k for the UK based on relative population sizes (Table 6.7). In marked contrast, RNIB state that there are over 2 million people with significant sight loss in the UK including 1.1-1.2 million who are eligible to be registered (RNIB, 2001b). Registrations have been increasing above population growth (Table 6.3). But the implication from RNIB and ONS data that 70% of registerable people are missed by the current Notification process is not readily explained.

The charity's estimates were based on various sources collectively known as the "Needs Survey" (RNIB, 1989; Bruce et al, 1991; Cole-Hamilton and Vale, 2000). Research was conducted with input from the Office for National Statistics, and estimates were adjusted with survey data on disability in Great Britain from the Department of Social Security in 1996 and most recently in 1999 (DSS, 1999).Concern over the sight loss criteria used and assumptions behind calculations have been accepted (RNIB Research Unit, personal communication; and implied by RNIB comments published in The Lancet (Senior, 2002).

In fact prevalence estimation is an international problem. A recent model for the US population was based on "the best available data" from studies around the world mapped to census figures (NIE, 2002). In addition to concerns about statistical combination of studies, estimation methods were limited to people aged 40+, considered only 4 sight loss diagnoses, and required ethnicity data. The collated data are now the basis for an international collection programme under WHO's VISION 2020 initiative, rather than an immediate source for accurate estimation in any country.

6.4.2. Management of Local Authority registers.

Registers are important to local planners as well as epidemiologists. However, discrepancies suggest data management problems for patients already in "the system".

There is no national mechanism for handling re-locations or deaths. A number of Authorities indicated (personal communications) problems with changing administrative boundaries and communications between Information Departments and staff collecting data in the field. With no additional incentives and few initiatives to link registers, data on cases of multiple disability are particularly limited.

Older people comprise the majority of registrations (see Table 6.3). Comparison of older registrations as a proportion of the oder population across Local Authorities is given in Figure 6.3. There are marked differences between Authorities of similar size. Genuine concerns about the accuracy of general population statistics are not a factor as they are common to all Authorities. Instead, results may reflect natural statistical variation, local differences in registration practices or real problems with data management.

6.4.3. Design of forms.

All forms are paper based. Entries cannot be controlled or forced to be legible, and transcription increases costs. Individual forms raise more specific problems.

Consultant fee forms and the general issue of confidentiality.

Most patients are unaware of consultant fees. There is no common form but most contain essentially the same information as BD8 Parts 1-4 which are sent to Social Services and GPs with direct patient consent. Release of current fee forms to unnamed financial administrators, and the practice of signing BD8s before completion, break the principles established for data sharing in healthcare by the Caldicott Committee Report (The Caldicott Report, 1997 - summarised in Table 6.8).

SSDA902 (3 yearly return on registers).

Design does not allow a full characterisation of the registered population and limits cross references with other data sources. Re-registrations and identified but unregistered cases are ignored. There are no categorisations by sex or ethnicity; age groupings for children and older people are not standard; and additional disabilities are intended to be recorded for blind people only.

BD8 (1990).

The form is an abnormal shape for most filing systems. Content provided at hospitals to help Social Services prioritise and plan cases is limited and often ignored when patients are sent home before form completion.

The epidemiological section (Part 5) covers diagnosis through a complex of 16 boxes on "main cause", "conditions" and "underlying diseases". This has led to ambiguous and incomplete data returns (Evans, 1995a,b). Visual function data are not provided for independent assessment. Anonymity removes the ability to check errors and to monitor total case numbers over time as opposed to new cases (prevalence v. incidence).

6.4.4. Process monitoring.

There are currently no official statistics to monitor the Notification process. Thus there are no formal data on causes and consequences of delay. Waiting time to see a consultant is often cited as the problem area. With a current average of 3-4 cases per month per consultant (see 6.3.2), the burden on consultants and their junior staff is not high. However, improvements at the hospital are of limited use if bottlenecks follow at Social Services.

Referrals, Assessments and Packages of care (RAP) statistics are the likely source of future data. They incorporate recommendations from DoH (2000/bd8) and ADSS (Sensory Services, 2001a) for Social Services to make first contact with patients within two weeks and to initiate assessments within four weeks. DoH's statement is actually confused as it also states that assessments should be completed within four weeks. Moreover, there is no "Day 0" for the process, indicating when the patient is first identified; allowing hospital assessments to be included; and putting the Social Services' timetables in context.

Inaccurate form dispatches are one recognised source of delay. There is no single and regularly maintained set of contact details for Social Services. The Social Services Handbook (identified on BD8 instructions) is out of date on publication; and the relevant NHS directory (DoH's Organisational Codes Service) does not cover the area beyond Local Authority codes.

6.4.5. Patient factors in access to services.

Patients with significant practiccal or emotional problems but who do not meet registration criteria are technically excluded. Moreover, official guidance is ambiguous. Local Authorities with limited resources may ignore this special patient group, using the ambiguities of official advice as a plausible explanation.

DoH (2000/bd8) emphasised that "registration is not a pre-requisite to assistance". However, it did not clarify whether meeting the registration criteria in all other respects would still be a condition. Equally, ADSS recommendations on adult services defined "visual impairment" using broadly the same terms and tests stated on the certification form (see Sensory Services, 2001a, Glossary).

Patients who would meet registration criteria but who refuse or are missed by Notification identify another special category. Numbers are unknown. In addition, there are few studies of patient factors affecting Notification uptake. Such factors are raised as side issues in journal papers and in discussions during eVINS.

Patient factors affecting uptake of notification/registration may include:

- Limited advertising of services and support.
- Unawareness of sight problems (the brain can "hide" the effects, particularly in peripheral loss).
- Belief that sight loss is a natural and unavoidable part of aging.
- Tendency not to check visual function regularly because of opticians' charges.
- Language barriers among ethnic minorities.

- Misunderstanding of the role of Social Services, particularly when children are concerned.

- Personal independence.

6.4.6. Information for patients.

Research for the Association of Directors of Social Services (ADSS) recommended a wide range of information topics to help counsellors and patients (Table 6.9). Together with (DoH, 2000/bd8), it also advocated provision in appropriate formats. Examples of such good practice in the field Were not identified in 2001.

Table 6.7. Number of visually impaired people on English registers at 2000 extrapolated for the UK based on relative populations.

A. Number on English registers (from DoH, 2001).

307,000

B. Populations for the UK and component countries (ONS, 2001).

Country	Mid 2000 population (000s)
England	49,997.1
Wales	2,946.2
Scotland	5,114.6
Northern Ireland	1,697.8
United Kingdom	59,755.7

C. Estimated number on UK registers.

307,000 59,755.7/49,997.1 = 366,921.3

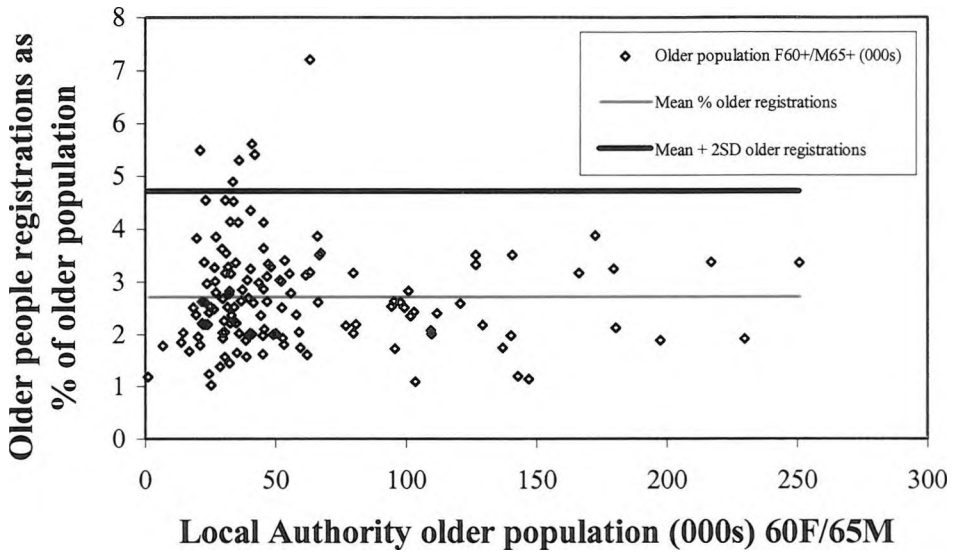


Figure 6.3. Relationship between number of older people in English Local Authority areas with social services responsibilities and the proportion of visual impairment registrations in the comparable age category in 2000. Mean and +2 standard deviations mark out outlying Authorities. (Constructed from DoH, 2001, and ONS, 2001).

NB1. Population figures were computed for females aged 60+ and males aged 65+ (pensionable age) as provided by ONS. The closest category on returns from registers (SSDA902) covers age 65+ with no distinction between sexes.

NB2. 11 out of 150 Local Authorities are absent because of particularly small populations (eg. Scilly Isles), missing central returns and boundary identification problems.

Table 6.8. Summary of Caldicott Principles and Recommendations for collection and use of patient identifiable data. (From The Caldicott Report, 1997).

A. Principles.

1	Justify the purpose(s)
2	Don't use patient-identifiable information unless it is absolutely necessary
3	Use the minimum necessary patient-identifiable information
4	Access to patient-identifiable information should be on a strict need-to-know basis
5	Everyone with access to patient-identifiable information should be aware of their responsibilities
6	Understand and comply with the law

B. Broader recommendations.

1	Every dataflow, current or proposed, should be tested against basic principles of good practice. Continuing flows should be re-tested regularly.
2	A programme of work should be established to reinforce awareness of confidentiality and information security requirements amongst all staff within the NHS.
3	A senior person, preferably a health professional, should be nominated in each health organisation to act as a guardian, responsible for safeguarding the confidentiality of patient information.
4	Clear guidance should be provided for those individuals/bodies responsible for approving uses of patient-identifiable information.
5	Protocols should be developed to protect the exchange of patient-identifiable information between NHS and non-NHS bodies.
6	The identity of those responsible for monitoring the sharing and transfer of information within agreed local protocols should be clearly communicated.
7	An accreditation system which recognises those organisations following good practice with respect to confidentiality should be considered.
8	The NHS number should replace other identifiers wherever practicable, taking account of the consequences of errors and particular requirements for other specific identifiers.
9	Strict protocols should define who is authorised to gain access to patient identity where the NHS number or other coded identifier is used.
10	Where particularly sensitive information is transferred, privacy enhancing technologies (e.g. encrypting identifiers or "patient identifying information") must be explored.
11	Those involved in developing health information systems should ensure that best practice principles are incorporated during the design stage.
12	Where practicable, the internal structure and administration of databases holding patient-identifiable information should reflect the principles developed in this report.
13	The NHS number should replace the patient's name on Items of Service Claims made by General Practitioners as soon as practically possible.
14	The design of new systems for the transfer of prescription data should incorporate the principles developed in this report.
15	Future negotiations on pay and conditions for General Practitioners should, where possible, avoid systems of payment which require patient identifying details to be transmitted.
16	Consideration should be given to procedures for General Practice claims and payments which do not require patient-identifying information to be transferred, which can then be piloted.

Table 6.9. Patient information topics Recommended by the Association of Directors of Social Services (Sensory Services, 2001) grouped by provider.

Common	Hospitals	Social Services
Registration purpose and procedures	Certification purpose and procedures	Community assessment procedures, services and eligibility criteria
Benefits information	Eye conditions (including prognosis and possible treatments)	Any charging systems
General information on social services provision	Medical/research charities related to eye conditions	Local, regional and national voluntary agencies services
Self help groups and peer support	Low vision services	Specialist services for visually impaired people
Local and national help lines	Other health services	Local libraries
Community equipment services		Employment services
Procedures for complaints and compliments		Education services
Service quality and standards		Transport services
Rights under the Disability Discrimination Act		Services from other relevant agencies
Advocacy services (support with claims/disputes)		

6.5. The electronic Visual Impairment Notification System (eVINS).

eVINS developed from a project to explore options for computerising the Notification process. Guide Dogs for the Blind Association (GDBA) provided funding. The Steering Group included DoH, Association of Directors of Social Services (ADSS) and Office for National Statistics (ONS).

The project was based in a former joint department of Moorfields Eye Hospital and the Institute of Ophthalmology (Glaxo Department of Ophthalmic Epidemiology - GDOE). Members were also invited to join a local forum of professionals and patients formed in 2000 in Moorfields' home area (Camden & Islington Low Vision Services Group - C&ILVSG). Running from late 1998 to late 2001, the project formally reported in (Leicester et al, 2002).

Original specifications for a DOS based system for BD8 data collection were met by HJL in 1999. However, consultants expected a more modern approach and greater use of the Web was becoming Government policy.

Adoption of web technology, together with background information on Notification reported in earlier sections, led to broader project aims and system design components:

- New form content addressing concerns of Social Services and epidemiologists.
- Explicit identification on the same form of patients with significant problems but not meeting the strict registration criteria.
- Involvement of nurses and social workers to support consultants in form completion.

- Inclusion of the consultants' fee form.

- Electronic dispatch of form sections to all relevant parties using recognised signing and encryption technologies, and provision for local printing.

- Establishment of a National Low Vision Centre to collate epidemiological returns; manage patient details over time within the NHS on behalf of Local Authorities; and provide a central point for online access to support information.

The revised system was developed by HJL and a technical colleague and demonstrated on Moorfields' network in Autumn 2000. At that last Steering Group meeting, it was the clear interpretation of HJL and the funding organisation (Guide Dogs) that the preparation of pilot proposals for submission to DoH should be the last stage of the project. This was also DoH's position when they were subsequently asked to explain the letter in September which halted epidemiological returns via the existing Notification process before any replacement mechanism was in place (DoH, 2000/bd8).
Pilot plans for Moorfields' home area included evaluations to guide national expansions based on acceptable local performance (Leicester, 2001 – and see later). Start up equipment and wider piloting costs were judged by HJL to be an unwise investment unless DoH showed commitment to both pilots and further development.

Colleagues advised leaving the submission until after the 2001 General Election. The DoH Review followed in September so no submission was actually made.

Nevertheless, the ground work had been laid. Local organisations were supportive and the then head of Information Management & Technology for the London NHS region also agreed to consider proposals if appropriate. In addition, Moorfields R&D Department replaced the former GDOE department and took responsibility for rationalising the system with additional input from an ophthalmologist on the DoH Review.

6.5.1. Technological overview.

Figure 6.4 provides a top level technological summary of the system intended for national use. It was developed with input from the NHS Information Authority (NHSIA - Telecoms Branch for London) and an international digital security company (Entrust Technologies Ltd). Detailed specifications and descriptions of Entrust's products are given in Appendix 3.

Explanations below refer to the Figure. The demonstration system on Moorfields' network applied the principles but was not integrated with Entrust's security products. With reasonable adjustments, the same basic design could be adopted on the national scale, within an individual hospital, or on an isolated machine linking periodically to a network or running scaled down products as a self contained system.

General architecture.

The eVINS form completion and dispatch site was hosted on central servers on NHSnet connected via Moorfields' hub. Access was therefore available to all hospital eye departments and GPs with local NHSnet connections. Form data were stored on the site database until formally submitted for dispatch. Validated forms were then encrypted and sent electronically to the appropriate Social Services and GP. They could also be printed locally. Forms and dispatch details were transferred to the Backend Server as an audit trail. Server software linked to backup tapes supported system monitoring and crash recovery mechanisms.

Forms and completion.

eVINS was developed using web languages identified in Appendix 4 (excluding XML which was not Government policy at the time). Forms were essentially web pages displaying on a user's browser, linked to databases on servers hosting the system. Access to patient data and rights to make or change entries were controlled by user names and passwords for each hospital, consultant and consultant support team.

Organisational addresses were automatically completed from database entries mapped to the patient's postcode. Selection lists for forced choice fields were also populated from databases. Duplicate information was copied between form sections. Items were validated with webpage checks (scripting) and test criteria set within databases before accepting submissions.

Signatures, encryption and dispatch: Public Key Infrastructure (PKI).

Discussions to incorporate digital signatures and encryption began in Autum 2000. Entrust was identified as a collaborating partner as its recent work in the NHS (Chadwick et al, 2000) led to contracts for a national development programme for secure pathology messaging as part of the national Information Management & Technology strategy (see chapter 9).

Entrust products supported subsequent NHS requirements for the emerging international security architecture. Public Key Infrastructure (PKI) allows document exchanges to be coordinated for a community of users on the same network. The products would integrate with components on the main eVINS site with additional "plug-ins" for user browsers.

The PKI approach had three main features. Public-private key pairs supported encryption and decryption. Digital certificates contained encrypted details issued to each user; and a public database provided identity and contact information for all users on the system.

Key pairs allowed material to be encrypted for users with their public keys which could then only be decrypted with the corresponding private keys. Equally, material encrypted by a user with his private key could be decrypted by others with the public key. Thus there was no practical distinction between the keys. But once one of a pair was nominated, it had to remain private.

A certificate was issued after vetting the corresponding user. It contained identifying details and digital signature (or unique code) encrypted with the user's private key. The digital signature could be added to documents, and other details were available for inspection by the intended recipient of a document using the browser plug-ins.

The public database of user details allowed digital signatures and certificates to be verified online. It also contained the public keys for use by other users or for automated encryption and dispatch by the main eVINS site.

Entrust proposed a range of certificate types for special requirements. Social Services, GP surgeries and Health Authority finance departments would use site certificates shared by local teams. Hospital support staff would be issued with standard, individual credentials. Consultants working in several hospitals would have special certificates for "roaming users".

Epidemiological data and information for patients: The National Low Vision Centre.

Decisions on epidemiological datasets were not finalised. The simplest mechanism (shown in the Figure) used manual transfer of completed forms on the eVINS site to a Safehaven Computer for deletion of unnecessary entries and long term storage.

The Office for National Statistics (ONS) agreed in principle to check data against national death registers. Indeed, they accepted arguments to computerise the whole process and reduce costs (currently at least 80p per case) as a national service for all Local Authorities.

The eVINS architecture allowed access to Internet sites via NHSnet protected gateways. Web editors at RNIB and Guide Dogs (GDBA) agreed to provide special material on their sites.

6.5.2. New form designs.

Figure 6.5 reproduces a new BD8 form as printed from the eVINS system. The structure and design of the old BD8 was maintained for user familiarity. All pages were adjusted to A4 size for local printing with possible enlargement from A4 to A3 pages by photocopying.

Main changes to content covered:

- Inclusion of sex, ethnic group and NHS numbers for monitoring by Social Services and epidemiologists (Parts 1&5).

- More entries covering patient background (Part 3).

- A new patient category of "Notifiable" for those who did not meet registration criteria (Part 4).

- A revised epidemiological section (Part 5).

- a consultant fee form based on a paper example from Camden & Islington Health Authority (last page).

NHS numbers.

Despite Caldicott guidelines (Table 6.8), there was actually no policy on use of these numbers outside the NHS. Government lawyers subsequently considered the position in 2003 using information sharing on mental health patients as the test case.

Data coding with Read Codes Version 3.

Read Codes provided a system of terms and codes for use in electronic clinical systems. They were maintained by NHSIA and mandated within the NHS. The most recent version at the time was also compatible with developments to merge the UK system with the US equivalent (becoming the Systematized Nomenclature of Medicine - Clinical Terms [SCT]).

Diagnostic terms and codes mapped to the WHO's International Classification (ICD-10 - NHSIA, 1993). The Read section on "Ophthalmological Disorders" was adopted for BD8's epidemiological entries. Visual function categories and ethnic groups were also drawn from Read Codes.

Items covering patient background were selected to highlight patients at risk and to illustrate likely consequences of the diagnosis in daily life. A final set was not agreed. Nevertheless, Read Codes had a range of items available (Table 6.10) and a mechanism to request additions from NHSIA.

6.5.3. Pilot proposals for Camden & Islington Health Authority.

C&I was the home area for the eVINS project as well as several significant national organisations (Table 6.11). Parallel programmes were anticipated to assess the technology and implementation details for an electronic Notification process, and to evaluate options for pilot expansion.

1). Collaborating organisations and eVINS users.

The two Social Services Departments agreed to participate. IT departments were contacted from the six relevant hospitals serving patients in C&I. The Health Authority was consulted. All GP surgeries were identified but not contacted.

Table 6.13 lists professional sites, staff and patient numbers by types of digital certificates agreed with Entrust.

Several organisations outside the pilot area would be affected and warned before the pilot. Calculations based on relative numbers of consultants and Social Services Departments suggested that only 10% of eligible patients seen by the identified hospitals would actually live in C&I (72/720 cases over 3 months' live operation). This was due to

Moorfields' national catchment area and the policy of all the hospitals to run "outreach clinics" at other locations.

2). Pilot programme.

An 8 month programme was split into four stages:

I. eVINS NHS website development (2 months).

The website would be set up on NHSnet, integrated with Entrust products and formally registered.

II. User enrolement and risk assessment (2 months).

All sites would be visited and enroled on the system. Local contacts would be appointed and a help line would be established to support individual users. Certificates would be issued to sites and staff members using Entrust's online registration and dispatch mechanism.

Dummy data would be used to assess a range of potential risk (Table 6.14, Panel A) including system reliability, authorised and unauthorised access, and accuracy of form dispatches. The NHSIA were particularly interested in management of user credentials at all stages of a pilot.

III. Live Pilot (3 months).

Risk factors would continue to be monitored. Additional assessment factors (Table 6.14, Panel B) would cover frrequency of lost or corrupted user certificates, data quality, patient and staff acceptance. Changes to BD8 content would also allow monitoring of

eligible patients declining registration and those needing help but missed by current criteria.

IV. Evaluation (nominally 1 month).

Detailed in 4) below, this stage would run throughout the programme and consider the practicalities and costs of expanding the pilot into other areas of the country.

3). Special pilot constraints.

Organisations outside NHSnet required additional security technology to link two networks (NHSnet and Internet) for access to full services on the eVINS site. The additional expense was judged by Entrust to be unnecessary at the pilot stage. Social Services were therefore able to receive and decrypt material but not to sign and re-encrypt documents. Print copies of electronic fee forms would therefore be posted from Social Services to the Health Authority, but fully electronic demonstrations would be included. Similarly, facilities to return erroneous electronic BD8s to the eVINS site would be shown but not fully implemented.

The number of GP surgeries in the pilot area (115) was also prohibitive when judged against BD8 processing rates (<4 per surgery per year). Thus, only two sites would be used for demonstration.

ONS death register and NHS patient tracing services would not be employed. Instead, contents of the safehaven database would be judged against the organisations' required standards.

4). Evaluation for expansion.

National monitoring with the NHS Information Authority.

Levels of NHSnet connections around the country, as well as changes and delivery on national IT strategies, would be monitored with NHSIA assistance. Local details would be provided by direct contact with individual organisations.

A Camden & Islington process model for national comparisons.

Models of local service organisation, representing both the manual and electronic approaches to Notification, would allow other areas to compare current practices and options for computerisation.

The models would be circulated for particular comment from: neighbouring Health Authorities; other areas with large eye hospitals (Manchester, Birmingham); a region with recognised remote communities (Cornwall); and locations with a reputation for teamwork across services (Newcastle, Rotherham).

An economic model.

The current costs of Notification (6.3.2) set the targets for any future electronic approach. £85k, or around £2.70 per case, was the upper limit for basic system costs.

The model would use pilot results to estimate equipment costs, staffing requirements and the likely rise in patient numbers. Table 6.15 identifies areas of cost and potential savings for an established system. The case for using a small proportion of the annual

£2m expenditure on consultant fees to support a system like eVINS was privately acknowledged by ophthalmologists.

5). Project management.

NHSIA recommended PRINCE 2 (PRojects IN Controlled Environments) as the preferred methodology (see 10.3.2 for further details). The eVINS project Steering Group were anticipated to continue as the pilot's Management Board. A Technical Board would include NHSIA, Entrust and local user representatives. The local forum of professionals and patients (C&ILVSG) were invited to be an External Reference Group of stakeholders and direct system users.

6). Resources and costs.

Budgets for the project (Table 6.16) were estimated to total £111k over eight months. The two staff members, at relatively senior level (£51k), had responsibilities for project coordination and system management respectively. A standard overhead of 40% of staff salaries contributed a further £16k. Hardware and software setup costs were £39k. Entrust offered its products and installation engineers at a special rate (£7k).

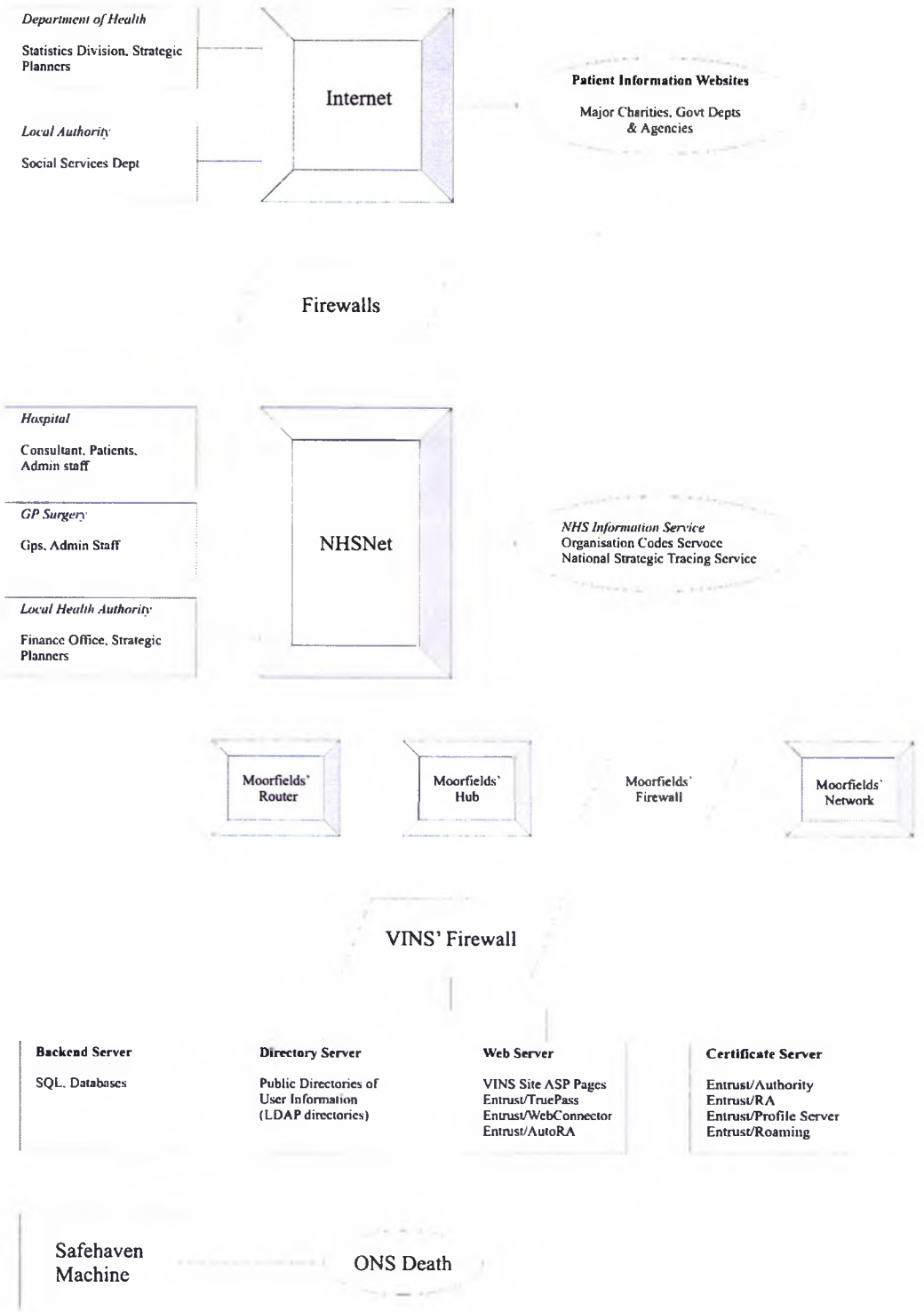
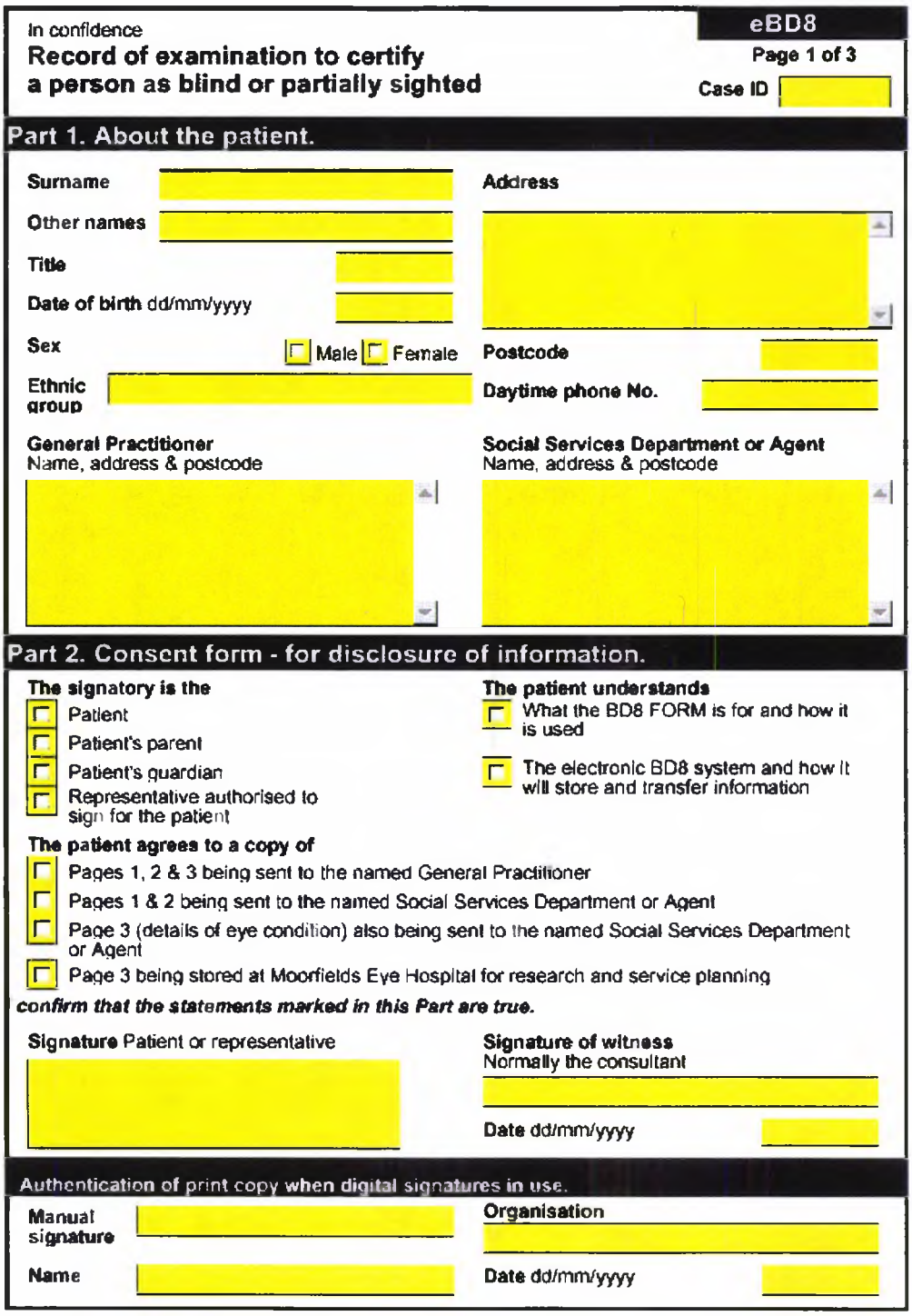


Figure 6.4..Top level network diagram of the electronic Visual Impairment Notification System (eVINS) for pilots.

Figure 6.5. New BD8 and consultant fee forms from the electronic VINS system.

Presented over this page the next 3 pages.



In confidence

Record of examination to certify a person as blind or partially sighted

eBD8

Page 1 of 3

Case ID

Part 1. About the patient.

Surname

Other names

Title

Date of birth dd/mm/yyyy

Sex ☐ Male ☐ Female

Ethnic group

Address

Postcode

Daytime phone No.

General Practitioner
Name, address & postcode

Social Services Department or Agent
Name, address & postcode

Part 2. Consent form - for disclosure of information.

The signatory is the

- ☐ Patient
- ☐ Patient's parent
- ☐ Patient's guardian
- ☐ Representative authorised to sign for the patient

The patient understands

- ☐ What the BD8 FORM is for and how it is used
- ☐ The electronic BD8 system and how it will store and transfer information

The patient agrees to a copy of

- ☐ Pages 1, 2 & 3 being sent to the named General Practitioner
- ☐ Pages 1 & 2 being sent to the named Social Services Department or Agent
- ☐ Page 3 (details of eye condition) also being sent to the named Social Services Department or Agent
- ☐ Page 3 being stored at Moorfields Eye Hospital for research and service planning

confirm that the statements marked in this Part are true.

Signature Patient or representative

Signature of witness
Normally the consultant

Date dd/mm/yyyy

Authentication of print copy when digital signatures in use.

Manual signature

Name

Organisation

Date dd/mm/yyyy

In confidence

eBD8

Continued record of examination to certify a person as blind or partially sighted

Page 2 of 3

Case ID

Part 3. Aspects of visual function and patient circumstances.(Multiple entries under headings are appropriate).

	Right	Left
Unaided		
Corrected		
Best with both		

☐ Total or ☐ central loss
Within ☐ 10° or ☐ 5° of centre
Patchy ☐ centre ☐ periphery
☐ Sector loss (eg. hemianopia)
☐ Night/dim light blindness

☐ Blur ☐ glare
☐ Contrast ☐ colour
☐ Image stability
☐ Eye/image coordination
☐ System noise eg.
☐ System fatigue

Progress of sight loss

☐ Total loss at birth
☐ Progressive since birth
Over recent ☐ months ☐ years
☐ Sudden loss/deterioration

Low Vision Aids

☐ Not appropriate
☐ Prescribed
☐ To be assessed

Other medical problems

☐ None recorded. ☐ Routine medication.
☐ Hearing loss. ☐ Poor physical mobility.
☐ Sight loss part of syndrome.
☐ Sight loss part of systemic disorder.
Other disorder(s) ☐ known ☐ suspected.

General information

☐ None recorded
☐ Lives alone
☐ Little/no home support
☐ Poor/no English
☐ Has dependent family
☐ Job/education at risk
☐ Recent driver

Preferred medium for information

Not recorded

Other relevant information

Part 4. Certificate of visual impairment.

I consider that the person is

☐ **Blind.** They cannot do any work for which eyesight is essential.

☐ **Partially Sighted.** They are substantially and permanently handicapped by defective vision caused by congenital defect or illness or injury.

☐ **Blind and previously Partially Sighted.** They were previously certified as Partially Sighted and now meet the criteria for Blindness.

☐ **Notifiable.** NOT IN USE. They do not meet the criteria for Blindness or Partial Sight but may benefit from assistance because their sight loss is made worse by other medical or social circumstances.

Consultant's name

Signature

Date of signature dd/mm/yyyy

Date of patient eligibility (if different) dd/mm/yyyy

Hospital/clinic address & postcode

Authentication of print copy when digital signatures in use.

Manual signature

Name

Organisation

Date dd/mm/yyyy

In confidence

Case summary for analysis of causes of blindness and partial sight

eBD8

Case ID

Part 5. Details of person examined.

Birth date

Form date

Eligibility date

Postcode 1st half

NHS number

Ethnic group

The person has

- Hearing loss
- Poor physical mobility
- Other known disorder(s)
- Other suspected disorder(s)

GP code Not in use

The person is

- Male
- Female
- Blind
- Partially
- Blind & previously P. Sighted
- NOT IN USE (Notifiable)

Ophthalmic conditions. (Click underlined words to select from standard terms).

Main Condition The sole or dominant condition affecting both eyes.

Other Conditions Conditions affecting one eye, or non-dominant conditions affecting both eyes.

Condition	Eye(s)

Visual function.

Visual acuity WHO categories

	Right	Left
Unaided		
Corrected		
Best with both		

Field of vision

- Total or central loss
- Within 10° or 5° of centre
- Patchy centre periphery
- Sector loss (eg. hemianopia)
- Night/dim light blindness

Vision problems with

- Blur glare
- Contrast colour
- Image stability
- Eye/image coordination
- System noise eg.
- System fatigue

Authentication of print copy when digital signatures in use.

Manual signature

Organisation

Name

Date dd/mm/yyyy

In confidence

eBD8

Case summary for analysis of causes of blindness and partial sight

Page 3 of 3

Case ID

Part 5. Details of person examined.

Birth date

Form date

Eligibility date

Postcode 1st half

NHS number

GP code Not in use

Ethnic group

The person has

- ☐ Hearing loss
- ☐ Poor physical mobility
- ☐ Other known disorder(s)
- ☐ Other suspected disorder(s)

The person is

- ☐ Male
- ☐ Female
- ☐ Blind
- ☐ Partially
- ☐ [illegible] & previously P. Sighted
- ☐ NOT IN USE (Notifiable)

Ophthalmic conditions. (Click underlined words to select from standard terms).

Main Condition The sole or dominant condition affecting both eyes.

Other Conditions Conditions affecting one eye, or non-dominant conditions affecting both eyes.

Condition	Eye(s)

Visual function.

Visual acuity WHO categories

	Right	Left
Unaided		
Corrected		
Best with both		

Field of vision

- ☐ Total or ☐ central loss
- Within ☐ 10° or ☐ 5° of centre
- Patchy ☐ centre ☐ periphery
- ☐ Sector loss (eg. hemianopia)
- ☐ Night/dim light blindness

Vision problems with

- ☐ Blur ☐ glare
- ☐ Contrast ☐ colour
- ☐ Image stability
- ☐ Eye/image coordination
- ☐ System noise eg.
- ☐ System fatigue

Authentication of print copy when digital signatures in use.

Manual signature

Organisation

Name

Date dd/mm/yyyy

Table 6.10. Electronic records: example terms and codes for administration, visual symptoms, recording additional patient background, and monitoring ethnicity.

Terms and codes drawn from Read Codes Clinical Terms Version 3 (compatible with SNOMED-CT). NI indicates that a code has not been identified.

A. Administration.

Topic	Term	Code
Form	BD8 form	XaEJp
	BD8 completion	XaEJq
Certification categories	Blindness	1B75.
	Partial sight	Xa1Ih

B. Ophthalmic diagnosis in context.

Topic	Term	Code
Rate of sight loss	Sudden visual loss	F4811
Symptoms	Colour perception deficiencies	F485.
	Contrast perception deficiencies	NI
	Sensitive to glare	NI
	Night blindness	F486.
	Nystagmus (jerking eye movements)	XE176
	Disordered binocular eye movements	Xa9Bh
	Anomalous image convergence (from the 2 eyes)	X00fo
	Subjective visual disturbances (misinterpretations by the brain)	NI

C. Patient background.

Topic	Term	Code
Awareness of diagnosis	Patient aware of diagnosis	1H0..
	Family aware of diagnosis	1H2..
Additional disability	Multiple sensory disability	Ua2BN
	Intellectual functioning disability	Ub0ih
	Behavioural disability	Xa1ai
	Hand function disability	Ub0ir
	Walking disability	Ub0ip
	Chronic physical disability	13VC3
	Personal care disability	Ub0ib
Household composition	Lives alone	XM0Ct
	Lives with family	Ua0IV
	Lives with relatives	13FH.
	Lives in a community	Ua0Ik
Care & support	Patient themselves providing care	Ua0VL
	Help from lay carer	Ua0VC
	Help by relatives	13WJ.
	Needs assistance at home	Xa87Q
	Domiciliary services available	13G..
Life events	Bereavement	Ua1q5

D. Ethnicity

Office for National Statistics	**Read Codes V3**
Categories from the 2001 census form to "indicate your cultural background".	**From the "Race" sub-tree with top level code "Xa8Es".**
A. White British Irish Any other white background (specify)	Caucasian
B. Mixed White and black caribbean White and Black African White and Asian Any other mixed background (specify)	Afro-caucasian Mixed
C.Asian or Asian British Indian Pakistani Bangladeshi Any other Asian background(specify)	Pakistani Bangladeshi
D. Black or Black British Caribbean African Any other Black background (specify)	Afro-Caribbean
E. Chinese or other ethnic group Chinese Any other (specify)	Oriental Chinese Japanese Korean Arab
Left blank	Not stated Unknown

Table 6.11. National organisations and programmes relevant to Visual Impairment Notification and based in the old Camden & Islington Health Authority.

Influential hospitals	Moorfields Eye Hospital Great Ormond Street Children's Hospital
Major charities	Royal National Institute for the Blind (RNIB) Royal National Institute for the Deaf (RNID) Help The Aged
Social Services	Social Care Institute for Excellence (SCIE)
Universities	London School of Hygiene and Tropical Medicine (LSHTM) - UK's major centre for Public Health; base for the former Department of Ophthalmic Epidemiology from the Institute of Ophthalmology; and coorinating centre for NHS sponsored research into cultural and organisational change (from 2002/3). City University - recognised School of Informatics, including programmes in healthcare and research into web accessibility sponsored by the Disability Rights Commission. Centre for Health Informatics and Multi-disciplinary Educatioon (CHIME) as University College London - specialising in electronic records and represented on the NHS' Modernisation Board.

Table 6.12. Hospitals and consultant numbers serving visually impaired people from the old Camden & Islington Health Authority.

NB. Consultant numbers required further checks. Statements from individual hospitals did not match figures from the Department of Health Organisational Codes Service (list of consultants by speciality and hospital Trust). Trusts also had complicated and changing arrangements for sharing consultants.

Hospital	Estimated number of consultants	Comments
Moorfields Eye Hospital	43	Also involved in 9 outreach clinics; and some consultants "shared" with other university hospitals.
Royal Free Hospital (RFH)	3	Figure seems low. Also involved with outreach clinics and other hospitals.
Whittington Hospital	?	Known to be linked to RFH.
University College Hospital	?	Believed linked with RFH.
Great Ormond Street Children's Hospital	4	
Western Eye Hospital	7	Serves C&I patients but outside the Health Authority area.
Approx. total	**60**	

Table 6.13. Sites, users and digital certificates involved in electronic pilots of a Visual Impairment Notification System in Camden & Islington Health Authority.

Summary of process

BD8 and fee forms are completed in hospitals and dispatched to Social Services. Fee forms are then forwarded to the Health Authority. Types of digital certificate provide identity and different rights for form signing and encryption/decryption.

A. Sites, users & certificates

User type	Activities	Type of digital certificate	N users
Hospital consultants	Form completion & signing	Individual	60
Hospital secretaries, nurses & counsellors.	Form completion & dispatch	Site/multiple user	6
GP users	2 demonstration surgeries	Site/multiple users	2
Patients & witnesses	Signing	Temporary (24h) certificates	800
Heads of Sensory Needs Teams (Social Services)	Decryption, signing, re-encryption & dispatch	Individual	2
Social Services support staff	Decryption	Site/multiple user	2
Health Authority finance officer	Decryption, signing, re-encryption & storage	Individual	1
Health Authority finance office support staff	Decryption	Site/multiple user	1

B. Hospitals & consultants.

Hospital	N Consultants	Comments
Moorfields	43	Also involved in 9 outreach clinics.
Royal Free	3[a]	Figure seems low. Also involved with outreach clinics.
Whittington	3[a]	Linked to Royal Free.
University College	4[a]	Believed linked with Royal Free.
Gt Ormond St	4	
Western Eye	7	Serves C&I patients but outside the HA.
Total	**60[a]**	

[a]Approximate.

Table 6.14. Risk and performance factors for monitoring during pilots of the electronic Visual Impairment Notification System (eVINS).

A. Risk factors for initial testing and continuous monitoring.

Site downtime. Unauthorised access. Denials to authorised users. Data storage, retrieval or deletion failures. Secure Sockets Layer (protected link to site) failures.	Public Key Infrastructure (PKI - signing and encryption) component failures. Consistency of dispatches with patient consent entries. Accuracy of organisation contact details. Inconsistent site log files or backup tapes. Virus warnings.

B. Performance monitoring during live system use (in addition to routine user feedback).

Administration	Time to issue certificates and encryption keys. Number of certificates/keys requiring cancellation and new issue.
Technology acceptance	Number of consultants regularly using eVINS. Number of patients agreeing to use eVINS (form completion).
Notification process	Time for BD8 form completion. Number of staff and sessions involved in BD8 completion. Average time before forms moved to the safehaven computer (process completion). Number of patients accepting long term data storage. Number of patients certified but not registered. Number of patients with sight related problems but not meeting criteria. Number and characteristics of patients prioritised by social services. Length and waiting times on social services lists before and after pilots.
Data quality	Number of BD8 or fee forms returned with errors. Number of diagnoses without Read Codes. Completeness of safehaven database and compatibility with data format standards from death register and patient tracing services. Use of online patient information.

Table 6.15. Potential areas of cost and savings from an electronic Visual Impairment Notification System (eVINS).

Costs	Savings/Benefits
NHSnet access	Form production and distribution.
Public Key Infrastructure (PKI) services	Postage.
Site running costs	Consultant/staff time.
Hardware and software upgrading programme	Data quality.
User technology and support	Epidemiological analysis time.
R&D component	Patient/representative access to support information.
ONS death register and NHS patient tracing services	Local Authority register management & epidemiological research.

Table 6.16. Budgets for an 8 month pilot of an electronic Visual Impairment Notification System in Camden & Islington Health Authority.

Component	Description	Cost (£s)
1. Personnel	Academic staff spine point 16	
Project Manager		25,512
System Administrator		25,512
2. Administration Overhead	40% of basic salaries	15,532
3. Hardware & Software		
Firewall	Machine + software	10,000
4 servers		21,200
Safehaven machine		500
Software licences	500	
4. Entrust Technologies Ltd consultancy	5 days setup (@ 1,200 /day + expenses)	7,000
5. Consumables and miscellaneous	Running materials, site visits, software for performance assessment & system/project management.	5,000
Total		110,756

6.6. Particular problems with data quality: Electronic approaches represented by eVINS.

6.6.1. Electronic forms in general and BD8 in particular.

BD8, like other substantive forms, is not an official dataset, Compared with central returns and commissioning datasets, which have largely been computerised, such forms involved in direct individual care have been ignored by Government modernisation plans.

Official specifications for Electronic Patient Records (DoH, 2000/epr) did not cover form completion. Even systems developed especially for eye departments had ignored BD8 (including the system at Moorfields). As Table 6.4 illustrated, important concepts for form completion had not been addressed for electronic systems (eg. relationship of a witness/representative signatory to the patient).

Despite instructions to anonymise patient data by using NHS numbers (Caldicott principle - Table 6.8), there is no established policy on use of these numbers outside the NHS. For reader information, the issue is being considered in 2003 by Government lawyers to support shared care for mentally ill patients. There is also no policy on the transition of systems from paper to electronic formats. In particular, facilities to produce the same form in either format has not been addressed. (Note the dual approach to signatures and use of an independent patient identifying code alongside NHS numbers in the eVINS BD8 form reproduced in Figure 6.5).

6.6.2. Diagnoses and classification for epidemiological comparisons.

Official UK statistics are mandated to use WHO's ICD-10 classification system which maps to Read Codes for easier data collection from electronic records. In fact, both systems have limitations for ophthalmic epidemiology. ICD-10 is arguably too general, while Read Codes provide many terms for essentially the same concept where the detail is important to clinicians but not necessarily to epidemiologists.

Age-related macular degeneration (central vision loss in older age) is a good example as the commonest cause of sight loss in the West. Extracts below demonstrate that ICD-10 has no distinct code, while Read Codes Version 3 indicate several potential factors causing or contributing to the disease.

ICD-10 code, category title and disorders/clinical signs for inclusion	**CTV3 (Read Codes v3) Sub-tree of terms and codes**
H35.3 Degeneration of macula and posterior pole Angioid streaks Cyst Drusen (degenerative) of macula Hole Puckering Kuhnt-Junius degeneration Senile macular degeneration (atrophic)(exudative) Toxic maculopathy	Age-related macular degeneration [XE18j] Drusen [F4257] Drusen plus pigment change stage macular degeneration [XaF41] Atrophic age-related macular degeneration [F4251] Fibrovascular macular scar [XaE5N]

A structured sub-set of Read Code terms mapped to ICD-10 is a likely solution for the eVINS application. Further expert advice is still required to balance:

- Ease of navigation in a tree of diagnoses.
- Appropriate coverage, including rare and multi-system disorders.
- Consultants' knowledge outside their sub-specialties.
- Detail required for genuine contributions to epidemiological monitoring and service planning.

6.6.3. Security and NHSnet connection.

There was no official policy on encryption and digital signatures in the NHS until January 2001 (NHSIA, 2001/crypto,a,b). Discussion for eVINS began before the publication. It complied because advice and clarification were sought at each stage. There was also unresolved debate on the project over the need for site firewalls. Entrust maintained that there was no written NHS requirement but Moorfields, and many other hospitals, had installed them. (Note the potentially unnecessary £10k+ eVINS budget component for firewalls in Table 6.16).

NHSnet connection rates were monitored with NHSIA to assess effects on the eVINS project. Trust connection to NHSnet rose from 20% to almost 100% between Autumn 1999 and April 2001. Following a Government decision on direct funding (GP Connect programme), GP connections were also predicted to reach 95% by 2001. However there remained no policy on large scale connection of Social Services.

Local details were considered in an informal telephone survey of major English eye departments/hospitals ahead of pilot planning. Trusts had varying levels of computer provision in the clinic and different approaches to NHSnet access from machines holding personal records. Together with the problems of Electronic Patient Records, this finding confirmed the decision to establish eVINS as a separate and centralised system with minimal costs and technological burdens on user organisations.

6.5.4. Web Information for patients and supporters.

Web editors from RNIB and GDBA supported principles behind the eVINS project. In contrast, Action For Blind People (AFBP) claim not to understand initial requests to identify the main aims of their organisation and provide webpages illustrating key areas of their work.

Traning and access to the Internet for counsellors and staffed involved with patients completing BD8 forms was not policy at Moorfields. The situation changed because of eVINS.

Since the project, the National Library for the Blind has established an information website with lottery funding and support from VISION 2020 UK Branch:

http://www.visugate.org

Though at early stages, this initiative highlighted the potential problems at 2002. The website did not contain a clear policy on cooperation between contribnutors. Specific topics were difficult to find. Material was not provided for use away from computers. Moreover, the target audience was (de facto) the sub-set of counsellors and patients with relatively advanced IT skills.

6.7. Department of Health review and proposals for public consultation.

The DoH review was an unexpected development towards the end of the eVINS project. RNIB were not directly involved with eVINS and independently raised concerns about the whole Notification process through questions to Government ministers on BBC Radio 4's "In Touch" and "Today" programmes.

A Review Group was established in September 2001 with stakeholders from England (Table 6.2) and observers from other UK countries. Cox (2001) layed out RNIB's original concerns. An approach taking account of all viewpoints was anticipated, but Bairstow (2001) noted marked differences on objectives between stakeholders at the first meeting.

The Group released proposals for public consultation in summer 2002 (Cox 2002, and www.doh.gov.uk/sensoryimpairment). Recommendations from ministers were due after the Autumn Parliamentary recess but the programme of consultation and action was incomplete at Summer 2003 (see chapter 11 for further details).

By the time of the public consultation, proposed aims for a revised Notification process had become:

- Early identification of social care needs.
- Provision for patients who were not technically registerable but whose lives were affected by persistent sight problems.
- Collection of more accurate data on the scale and type of eye diseases.
- Increased take-up of registration.

- Improved clarity to patients and others about the process and benefits of registration.

- Use of terminology reflecting the presence of residual low vision in patients technically registrable as blind.

6.7.1. Changes to procedures and forms.

The governing law (National Assistance Act 1948) would not change, so the registration categories and criteria of blindness and partial sight would remain. A greater role for high street optometrists and GPs was suggested to increase patient identification; and BD8 would be replaced by 3 new forms with nominal labels (Figure 6.6).

According to Cox:

Form A. An "identification" letter or leaflet for optometrists, GPs and other community providers to give to customers found to have significant problems with their vision. The letter is addressed to the local Social Services Department (or Agent) and customers can use it as a self-referral to get information about support services without waiting for further diagnosis or treatment.

Form B. Similar to form A, this would be completed by eye clinic staff and sent direct to Social Services (or Agent) formally requesting an assessment of social care needs. It would be used (with patient consent) where registration is not immediately planned, or the patient has refused it, but there are concerns about emotional or practical difficulties in relation to serious visual loss.

Form C. A simplified version of form BD8 focusing on formal registration specifically to establish eligibility for benefits and concessions.

Figure 6.6. Draft forms A, B and C from the Department of Health review (identified in Cox, 2002).

Forms, presented over the next 6 pages, were reconstructed with minor modifications from paper copies provided by RNIB.

Form A. Optometrist: patient identification.

For the attention of:
[contact details for Local Social Services Department or Agent, to

include a website or referral e-mail address]

Date [ ]

I have recently seen my optometrist

[name, address or stamp].

I have been advised to contact you because poor eyesight is making daily life more difficult. I understand that your organisation will be able to inform me of the specialist information or help which is available in this area.

Full name [ ]

Please contact me or my friend / relative / representative as follows:

[Name, address, telephone number, e-mail address]

Now tick any of these statements which apply:

Please contact me in the first instance by [] telephone [] letter.
I would prefer information: [] in large print [] on computer disk [] by e-mail.
[] I would prefer information in [language].
[] I live alone
[] I have the following disabilities (e.g. poor hearing, difficulty getting about, etc.) Please specify.

[

]

[] I am especially concerned about (e.g. cooking on my own, crossing roads safely, becoming isolated etc.) Please specify.

[

]

My age is [] Under 18 [] Between 18 and 60 [] Between 61 and 75 [] Over 75.

Form B. Hospital Eye Service: referral for social needs assessment.

From [Nominated eye clinic staff member and clinic contact details].

To [Local Social Services contact details].

cc: Patient & GP. Date [ ]

This patient has been seen in our clinic. With the patient's consent, I am referring them to you because difficulties with their eyesight are making daily life more difficult. I am requesting an assessment of their social support needs. Please also inform the patient of the range of specialist information or help which is available in their area.

Patient contact (and supporting) details.

[Name, address, telephone number, e-mail address, date of birth). GP details].

Statements which apply

[] This patient lives alone.
The patient also has the following disabilities: [] poor hearing [] difficulty getting about,other (please specify):

[

]

In discussion with the patient, we have agreed to alert you to the following information:
[] Concerns about (e.g. cooking unaided, crossing roads safely, becoming isolated etc).
Please specify:

[

]

[] Concerns about the emotional impact of sight impairment.

In my view these concerns require contact with the patient to be made:
[] Immediately (risk factors present) [] Within the next 2 weeks [] Not urgent.

Please contact the patient in the first instance by:
[] telephone [] letter [] visit.
[] large print [] computer disk [] e-mail, in [Language].

Continued over leaf

The patient has been given a copy of this referral letter for their information. It is their understanding that they will be contacted by your organisation without further action on their part.

Consent section.

I have seen / been advised of the contents of this form. I consent to a copy of this form being sent to my local authority and my GP.

Patient's signature [ ] Date [ ]

I have advised the patient of the contents of this form.

Name of staff member [ ]
Signature [ ] Date [ ]

Form C. Hospital Eye Service: Notification of `Blindness' or `Partial sight'.

To [Local authority or Primary Care Trust, name & contact details.]
[ ]
[ ]

cc Patient, GP, Hospital notes

Part 1. (To be completed by a consultant ophthalmologist).

A. Patient details

Surname
Other names
Title
Date of birth

Address

Daytime telephone number

Details of General Practitioner.

Name
Address

Telephone number

Details of Local Social Services/Agent

Name
Address

Telephone Number

B. Visual function.

Visual acuity (Snellen or functional assessment, e.g. hand movement or finger counting).

	Right eye	Left eye
Unaided		
With spectacle correction		
Best with both eyes		

Field of vision

[] Total loss. [] Extensive loss. [] Primarily peripheral loss. [] Primarily central loss.

Low Vision Services: [] Has been assessed, [] To be assessed.

Continued...

C. Diagnosis.

This section will contain the names of the commonest eye conditions, as tick boxesplus an `other' space for alternatives

D. Certificate of eligibility to be registered as `Blind' or `Partially Sighted'.

I consider
[] That this person is `severely visually impaired or blind'.
[] That this person is `moderately visually impaired or partially sighted'.

Reason[?]

Consultant's name [ ]
Address [
]
Signature [ ]
Date of examination [ ]

This date is to be taken as the date from which any benefits are calculated.

Continued...

Part 2 (To be completed by eye clinic staff).

E. Other relevant factors about the patient.

[] The patient lives alone.
[] The patient also has a hearing impairment
[] The patient has poor mobility.

Other relevant factors (Please specify):

[

]

F. Ethnic origin.

List of standard categories as tick boxes.

G. Patient format preferences

The patient prefers future information to be provided:
[] in large print [] on computer disk [] by e-mail. In [Language].

Part 3. to be completed by the patient or their representative

I consent to the information on this form being passed to the local authority or Primary Care Trust and my GP, with a copy being kept by the hospital. I have also been given a copy.

Patient/Representative's signature [

]

Date [ ]

6.8. Particular problems with data quality: The DoH Review.

6.8.1. Connections with the eVINS project.

The DoH Review had potential to change the Notification process and invalidate design work behind the eVINS system. Clarification on the future of eVINS was sought from DoH in Spring 2002. In the event, DoH requested a special meeting where eVINS was demonstrated.

Notably, the meeting took place after DoH had released material for public consultation. Information for patients was not discussed, though the importance of diagnoses as pointers to sources was raised by HJL. Epidemiological data and consultant fees were to be treated as special issues.

6.8.2. Form designs and completion procedures.

Data on patient background and personalised requests for information.

Broadly similar sections covering these areas are included in the 3 proposed forms (A-C). They are slanted towards the older population. Needs of parents with affected children or people of working age with risks to employment or education are not covered. Large print has been proposed, but a substantial proportion of current registrations are blind with central loss and may require greater assistance.

The letter making a formal request for information from Social Services on the patient's behalf (Form A) is patronising and possibly illegal (Disability Discrimination Act 1995, Section 22). Local Authorities are funded by the public and therefore morally obliged to advertise their services, and logically required to make particular arrangements for services targeted at people with special communication needs.

Greater coordination between Social Services and the NHS is also Government policy. As an example of developing practice, Camden & Islington Low Vision Services Group has prepared a directory of local organisations and national contacts (C&ILVSG, 2002). There are plans to place it on the web for general access (at HJL's request).

Activities and forms at the hospital.

Forms B & C are completed in the hospital respectively for those who do not meet the formal criteria or decline registration and for those who accept registration immediately. The principle that there is no practical difference between certification by the consultant and registration by Social Services is now acknowledged. However, DoH's concern is with speed of form completion. Form C, as the formal certification document, is assumed to require greater input from the consultant and is, in fact, not substantially different from the current BD8 and the equivalent from VINS (accepted by DoH).

Arguably only one form is required in the hospital. Consultants must go through the same assessment procedures to determine patients official categories and contribute a maximum of six ticks and one signature to necessary sections of a form. Completion with secretarial support is already common practice. Moreover, DoH and the eVINS project are both advocating greater involvement of nurses and hospital social workers to complete sections on patient background.

A single form is suggested with additional boxes to identify non registerable but significant problems and those who initially decline registration. A consistent dataset is

then available to Social Services and (potentially) to epidemiologists. Moreover, eligible blind patients who subsequently decide on registration do not need another appointment and form completion.

Access to benefits.

Statutory benefits are one of the prime incentives behind registration. Complicated access was an original concern from RNIB and the review has emphasise dates on new forms as dates of eligibility for registration. However, simplified access to benefits did not appear as one of the aims of a new process as released for public consultation.

In fact, there is no immediate link between registration and benefits. Tax concessions require cooperation and assistance from employers (Inland Revenue forms), while general benefits (eg. Disability Living Allowance) entail more forms and assessments often requiring advice (RNIB, 2001a).

Although registration dates are important, the date of first contact with the Benefits Agency is more significant in practical terms. This is the point for paying benefits used by the Agency regardless of registration status. The same principle covers carers applying for financial support.

The DoH Review should recommend that patients are advised to contact the Benefits Agency at the earliest opportunity. Well organised practice would ensure that the issue is discussed with patients and the contact made on their behalf. The paper application forms that follow also imply additional and confidential support with completion.

6.8.3. Patient pathway (referral procedures).

From the Cox (2002) description, there are still no formal plans for process monitoring. Greater involvement of GPs and opticians in patient identification is sensible. However, it raises serious concerns about their current practices. There are also no formal data indicating that high risk patients visit surgeries or opticians with sufficient frequency to make a difference.

There is no direct hospital referral for patients at risk of further deterioration. Equally, there is no clear statement on responsibilities for providing low vision services, particularly to overcome immediate problems.

6.8.4. Epidemiological issues with implications for patient information.

Epidemiological monitoring has been left open by DoH and is unlikely to be covered by initial recommendations to ministers. There is a split view on the Review Group but a general opinion that data collection on causes of sight loss and community care are separate processes and should be developed independently.

Aside from broader epidemiological concerns, this view ignores the benefits of a clear diagnosis as a guide to information and possible characteristics of sight loss for patients and social workers. Indeed, access to diagnoses is a common request from social care staff. Currently, clear diagnoses do not appear on the BD8 form or on any forms proposed by DoH.

6.9. Conclusion to the Case Study.

Visual Impairment Notification in England is a failing process currently under scrutiny from the Department of Health. Most of the problems are long term and have been raised by successive process reviews, without any tangible improvements.

The existing Notification process was examined as part of a project to develop an electronic Visual Impairment Notification System (eVINS). It highlighted a lack of agreement on the true scale of registerable sight loss. There were no process monitoring data; and little formal information to help patients make informed decisions.

Costed pilot proposals included a new certification form. Completion by hospital consultants supported by other staff was advocated alon with electronic dispatches to relevant organisations and facilities for local printing. A National Low Vision Centre was included to manage epidemiological data on behalf of Local Authorities, and to provide online patient information. In addition, proposals recommended a centralised system to remove costs and burdens of technology from user organisations.

A Department of Health Review of the whole Notification process was launched independently towards the end of the eVINS project. Proposals covered thre new forms and a greater role for GPs and high street opticians. Problem areas were not supported by data, and results from a public consultation were also not published. The number and design of forms were not clearly justified; a care pathway for patients was not recommended; and process monitoring was not introduced.

Issues are revisited in chapter 11 where Visual Impairment Notification is the test case for application of the Data Quality Framework. Need for change is not disputed. Equally, a policy is not advocated for full dependence on technology. Rather, the question is whether an approach based on quality of data for professionals and

information for patients (eVINS' principles), or one adopting committees and anecdotal evidence (the DoH Review), offers the better opportunities for real change.

Before these academic points are considered, the Thesis continues with a review of all the Case Studies. Development of the Data Quality Framework follows in Part 2, including assessments in chapter 9 of national policies on IT in healthcare and putting some concerns raised by eVINS into the broader context.

Chapter 7

Prominent Themes from the Case Studies

7.1. Introduction.

Part 1 of the Thesis concludes by extracting common problems with data quality or isolated examples with wider significance from the previous Case Studies. Particular points from each Study are summarised (section 7.2) and a general discussion follows (7.3). Finally (7.4), five Prominent Themes are presented as major topics to guide development of the Data Quality Framework in Part 2 of the Thesis.

7.2. Summary of Studies (the particular problems).

Intensive Care (IC). General data collection by individual ICUs for national use was poor. Specific initiatives either lacked integration with comparable national programmes or were time cconsuming and relatively expensive.

Diabetes Mellitus (DM). Assumptions about stability of the disease and collection of self-monitored data (home data) by patients were inappropriate in real life.

Accident & Emergency (A&E). Data on hospital admissions via an A&E department were insufficiently coordinated for whole process monitoring; and did not link quantitative and qualitative measures of performance to aid interpretation.

Visual Impairment Notification (VIN). The national process was unmonitored; had no concensus agreement on potential case numbers in the general population; and produced poor quality data for all parties including information for patients. An electronic approach was limited primarily by varying access to computers and policies on system security in ophthalmology clinics across the country.

7.3. Discussion.

Common ground between Studies.

Separate Studies were in fact linked as recognisable stages in care sequences for paticular groups. A&E is the dominant route for unplanned IC admissions; and diabetes is 1 of the major causes of visual impairment in the West. In addition, most of the patient groups considered were predominantly from the older age range.

General findings.

Several identified problems had existed for some time or demonstrated missed opportunities. Studies covering care processes (A&E and VIN) had repeatedly been reviewed by the Department of Health with no appreciable difference. Home data collection technology (eg. in DM) has been improving over the last 15 years, butstandards for datasets and compatibility between devices from different manufacturers are still unavailable.

Data collection and information provision which did not form a direct or traditional part of patient care were, in general, poorly handled in all Studies. Every identified stage for data collection or dispatch was potentially a point for providing staff and patients with

support information. However, no standards and systems for information provision were identified in the major Study where "informed consent" was an explicit requirement (VIN).

Paper based data collection systems gave no direct assistance to users or restrictions on valid entries. They added stages for both collation of source material and subsequent transcription of completed forms.

There was no formal evidence of improvement through computerisation except where technology was the only practical means of collection (eg. regular or continuous monitoring). Problems with both data management and information provision were compounded by the absence of baseline figures specifically covering data quality issues from existing processes

Four broad data types.

Data involved in direct patient care were the focus in DM, and used to derive monitoring summaries or content for official forms in the other examples.

Background data on individuals, collected for example by ophthalmologists to help Social Services, were an important feature in VIN. There was no shared understanding of the role of such data and no recognised datasets or standards.

Epidemiological data on case numbers and causes are relevant to both service planning and medical research. VIN and DM highlighted the distinction between data on patients already identified (in "the system") and data used for prevalence estimation for the general population (potentially undetected cases). Assumptions and problems can be different in each case. Moreover, VIN demonstrated limitations with the internationally recognised coding system (ICD-10).

Research data highlight problems with existing collection processes while introducing additional problems with new or multiple datasets. A&E and DM, in particular, showed the importance of a common understanding about the role of different data types (quantitative v. qualitative) and allocation of resources for efficient collection.

Collection procedures.

Data collection outside direct patient care is commonly delegated to relatively junior staff, with or without supervision. Considerable skills are required to locate sources, decypher hand writing, and to match clinical summaries to collection standards. Form completion in VIN suggested that these skills require clearer instructions and reinforcement at consultant as well as junior level.

Design of Forms deserves particular attention. All examples from the Studies contained anomalies affecting ease of completion, interpretation of results, or compatibility of datasets with other data sources.

Data management

Confidentiality concerns were common to data on organisational performance and personal information shared between professions in individual care. Agreement to participate in casemix adjusted mortality analyses, for example, depended on anonymity of individual ICUs. DoH proposals for a new VIN registration process emphasised consent before releasing data to Social Services. However, current practices allowing main forms to be signed before completion and sending significant personal details to financial administrators without patient knowledge were not questioned.

VIN also showed that Local Authority disability registers were not cross-referenced or kept up to date. Field staff with the most recent information were not routinely contacted before central returns were completed, and a national mechanism to handle deaths and re-locations was not in place.

The A&E Study illustrated the importance of coordinating different data sources in local process monitoring. Quantitative data were not linked and not available to the Action Research programme to put timings and staffing levels in context. Comparable problems were observed in IC, involving the Audit Commission on the national scale.

A context for measurements and observations was equally important for individual care. DM illustrated that individual blood tests were of little value to the specific research without a time stamp, and difficult to interpret clinically without further information on general health and recent activities.

Technology

Computerisation was a necessary data collection component in DM, home data collection for clinical use depended on technology for efficiency. Hospital equipment for continuous monitoring are also electronic. Data from devices for patient or professional use are unavailable to subsequent anlyses without compatible capture, exchange and storage systems.

Examples of technology applied to more general data collection showed further limitations. Although specific programmes in Intensive Care depended on electronic data exchange, original data sources were usually not computerised, contributing to delays in both initial preparation and subsequent cleaning.

VIN showed that completion of official and substantive forms direct from electronic records was not practicable because it was not covered by NHS specifications for such

systems. A compromise solution to complete forms online was limited by varying policies on computer access in clinics and system security in eye departments across the country.

Social Services connection to NHSnet was not an absolute requirement for electronic exchanges. However, there was no policy for widespread connection, and a fully operational system linking two networks (NHSnet and the Internet) would require additional technology, management and costs.

Parallels with information provision

Points for staff and patient information support map directly onto any care process with similar stages for data collection. Moreover, comparable quality standards should logically apply.

In practice, A&E showed that directories of local services were neither up to date nor available in relevant parts of the NHS Trust. In VIN, national NHS directories omitted contact details for Social Services and information about the registration process was not routinely available.

Costs

Expenditure on data collection and information provision, compared to achievements, are logical measures of performance. Costs can be estimated from assumptions about scale and division of tasks, and were calculated for illustration in the IC and VIN Studies. However, staff and equipment are often shared with other local operations. None of the Case Studies identified official data sources with sufficient detail for full analysis.

7.4. The Prominent Themes (the generic problems).

Five Prominent Themes summarise the generic problems of data quality from all the Case Studies and previous discussion.

PT1. Datasets.

Items and sets are not always well researched, designed or linked to other data sources.

PT2. Collection and management.

Practices may rely on unsupported staff and procedures.

PT3. Information for patients.

Provision is part of the broader care process. Logical and practical links to data collection and coordination of care may not be fully appreciated. Direction to further sources of support for patients and families also tends to be a low priority.

PT4. Technology.

IT can support both data collection and information provision. In addition to basic access, achieving full potential may require closer attention to issues of system compatibility and user support.

PT5. Costs.

Expenditure directly relating to data management and information provision are receiving insufficient attention in both manual and electronic processes.

Part 2

From Prominent Themes and National Considerations to a Data Quality Framework

Chapter 8

Introduction to Part 2

8.1. Introduction.

Prominent Themes affecting data quality in specific Case Studies have been stated (7.4). Part 2 now aims to develop methods for identifying and avoiding such Themes in similar areas of English healthcare. The methods are developed over the next 3 chapters and summarised as a Data Quality Framework (DQF) which is then applied to an earlier Case Study.

8.2. National considerations (chapter 9).

As chapter 6 indicated in reviews of the national Visual Impairment Notification process, it is Government policy for greater use of IT in healthcare. Chapter 9 identifies relevant infrastructure programmes, and considers the practical role for IT in a DQF under circumstances at 2002/3.

The healthcare system is officially described as "largely manually based". Moreover, the third Information Management & Technology strategy in four years has recently been introduced (2002) with timetables moving backwards and other delays with national training programmes and important research initiatives. The DQF should therefore follow NHS policy but acknowledge that paper is the primary format for patient data collection in hospitals and the necessary electronic "information infrastructure" is not yet in place.

8.3. Data Quality Framework development and presentation (chapter 10).

The DQF combines separate central initiatives with issues in common with the Prominent Themes from Part 1. The four overlapping initiatives have arisen since 2000 and are first identified in chapter 9. Adjustments remove unjustified assumptions that data sources are primarily electronic, and allow applications on both national and local scales.

Appraisal and approval mechanisms from the NHS Information Standards Board (ISB). Significant datasets must now conform to standards for data recording and transfer (data outputs) as well as tests of practicalities and costs of collection. Recognised NHS standards should be adopted and general principles logically apply on any scale.

National Datasets Development Programme from the NHS Information Authority. NHSIA are supporting particular projects to deliver ISB approval. They emphasise modelling of care processes and data as first steps in all projects, together with a common project structure. Models can be extended to accommodate data in different locations and formats, and to make practical comparisons between organisations.

Accreditation of organisations providing patient information. It is now central policy to accredit organisations involved in all stages of research within the NHS (part of the Research Governance Framework for Health and Social Care). Principles may be extended to the provision of patient information.

Information description and retrieval mechanisms from the Office of the eEnvoy. IT policy implementation spanning Government and the public sector is lead by OeE. At the centre is the "eGovernment Interoperability Framework" which includes standardised terms for describing information resources and simplifying searches (meta-data). Principles apply to patient information sources as well as

datasets exchanged between public organisations. Mechanisms are electronic but identified sources can be stored or delivered in various formats. Furthermore, care process modelling from the earlier initiative suggests points for information provision.

The initiatives are developed individually in chapter 10. At the end of the chapter, the DQF provides a unifying summary with two sections for initial assessments followed by a development and implementation plan.

8.4. Application of the DQF to Visual Impairment Notification in England (chapter 11).

VIN is selected as a test case for the Data Quality Framework for two reasons. Firstly, much relevant background material has already been presented in chapter 6. More importantly, the chapter included a review of the national process and proposals for change from the Department of Health. An existing care process and changes derived from the Framework may therefore be assessed in the same step, using DoH's review for comparison.

Chapter 11 concludes that use of the DQF offers improvements. In contrast to the DoH approach, the Framework provides the evidence to justify change as well as specific modifications to the VIN process introduced through a managed programme.

Chapter 9

Review of policies and IM&T strategies affecting data and information in English healthcare

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9.1. Introduction.

Since the first election of New Labour in 1997, data for professionals and information for patients have been promoted by modernisation programmes in healthcare and the public sector generally. Improvements in service quality and performance are specific pledges. Delivery will involve new ways of working based substantially on Information Management and Technology (IM&T) with supporting strategies for IM&T implementation.

This chapter reviews those modernising initiatives and considers their implications for the Data Quality Framework (DQF) developed in the next chapter. One aim is to establish the level of current delivery and timetables for developments. A second is to identify good practices, specific technologies and particular central initiatives relevant to any DQF targeting healthcare in England.

The review may also be considered as a large scale Case Study in its own right. It was originally motivated by plans for an electronic Visual Impairment Notification System (chapter 6). Despite following Government policy and taking advice from the NHS Information Authority, progress was limited by IT capability in the field. Comparable situations existed in all the previous Studies.

For completeness, the official Data Quality Initiative and Accreditation Process for the NHS is acknowledged and examined in an Annex to this chapter. Though referenced in the main sections (9.4.3), these developments are relatively new and focus primarily on central returns for regional and national managers (outputs). Arguably, they highlight the problems rather than providing a flexible structure to address the broader issues of data quality raised by this Thesis.

Organisation of the main chapter.

Section 9.2 – *Background and wider context* - introduces the Government's wider modernisation programme, the healthcare system which New Labour inherited, as well as the organisations and structures behind policies and IM&T strategies.

Section 9.3 – *Broad specifications of policies in healthcare.* - looks at the policies in more detail to consider their impact on data and information and states the targets and budgets for healthcare improvements set by politicians.

Section 9.4 – *Broad specifications of IM&T strategies relating to policies* - maps the policies to strategies for healthcare and the broader public sector.

Section 9.5 – *Particular problems with data quality* - addresses some of the strategic issues before looking at details under headings provided by the Prominent Themes affecting data quality from Part 1 of the Thesis.

Section 9.6 – *Contribution from the review to the Data Quality Framework* - identifies features of national policies and IM&T strategies taken forward in the next chapter.

General findings.

New Labour inherited a healthcare system with chronic under funding and growing inequalities among geographic areas and population sub-groups. As with other sectors of the economy, policies in healthcare promised radical changes within ten years.

In practice, the national information infrastructure is not in place and timetables are moving backwards. IM&T is competing for funds with staff recruitment, hospital building programmes and shortage of modern equipment in direct care. There have been three main strategies for healthcare in four years. A national staff training programme has been re-launched; and scoping studies into cultural and organisational change related to eHealth have only recently been introduced.

The healthcare system is officially described as "largely manually based" (dependent on paper). Despite this collection of problems, demands for data and information are increasing through a combination of policy pledges and legal requirements.

Given this position, the Data Quality Framework should monitor developments on IM&T strategies. Potential contributions are currently limited to good practices laid down in guidelines and the law, and technologies specified for the whole public sector;

Separate central initiatives may address practicalities and costs of data collection; modelling care processes to identify data sources and points for information provision; and developing approaches for classifying information resources with accreditation of information providers.

9.2. Background and wider context.

New Labour was first elected in 1997 with a manifesto for change. Quality and performance would be achieved through re-structuring, new ways of working and widespread adoption of Information Technology throughout Government and the public sector.

Various documents were released for consultation within and across sectors. Those affecting healthcare were moving towards firmer policies by 2000 (Table 9.1).

Change was also coupled to investment, negotiated through the "Comprehensive Spending Review" (HM Treasury, 1998). It aimed to increase both funding and timescales for planning. In addition, it included Public Service Agreements (PSAs - pledges and targets) for individual Departments and Government as a whole.

9.2.1. The wider modernising agenda.

Drivers for change.

According to the "Modernising Government" white paper (Cabinet Office, 1999/modgov), western societies had growing expectations as a result of changing lifestyles, increased recognition of minority groups, and trends in IT. Citizens might reasonably expect bbetter integrated services, more information and greater involvement in local and national decisions. Specific principles and pledges were laid down as the foundation for further developments (Table 9.2).

Those interested in social care summarised some of the "Drivers For Change" in the healthcare sector led specifically by IM&T issues (DoH, 2001/ifsc, Appendix 2 - Figure

9.1). Demands for change were a complex mix of national policies and strategies, local initiatives and external pressures from special interest groups and the general public with Internet access and other sources of information.

Changing laws.

Laws were among the first features of society to change under New Labour, though some adjustments were under way before 1997 (Table 9.3). The commercial sector lobbied for new regulations to support eBusiness and electronic documents with eSignatures. The Data Protection Act required updating to bring consistency to data management and use in both paper and electronic formats. The remit of the Race Relations Commission were strengthened and a Disability Rights Commission was established.

British law also had to take account of international trends. The Cabinet Office website in early 2003 indicated that almost half UK laws had been affected by EU Directives. Further pressures within and beyond Europe brought the Human Rights and Freedom Of Information Acts.
Specifically in healthcare, GP terms and conditions changed to permit electronic records. Legal barriers to closer working between health and social care were removed; and new care standards with enforcing organisations were established in law.

9.2.2. The healthcare system inherited by New Labour.

Health and healthcare inequalities.

At an early stage, the Government commissioned an independent review of inequalities in health and healthcare (Atcheson, 1998). It found growing differences between sectors of society, related primarily but not exclusively to income; significantly worse mortality figures for the "major killers" compared to other western countries; and variations between geographic regions in available resources to deliver improvements.

Seventy-four recommendations were made to ministers, presented individually and in various combinations addressing particular issues. The four general recommendations called for all Government policies to be assessed for impact on health; a review of data requirements and monitoring mechanisms; and a special focus on actual or potential mothers with secondary consequences for the health of the next generation.

Under investment.

Opening sections of DoH's investment strategy highlighted chronic under funding in many areas (DoH, 2000/dis). There were insufficient frontline staff and premises (capacity). Many buildings were poorly maintained and inappropriately design for modern services. There were also marked shortages in up to date equipment for diagnoses and treatment compared to other parts of Europe.

Information Management and Technology.

IM&T was clearly competing with other, fundamental components of the system for modernisation funds. The area inherited a considerable amount of healthcare modelling

from academics in the NHS, a mandatory system of clinical and health-related terms (Read Codes); and a directory of NHS organisations and regions managed by the Department of Health (Organisational Codes Service). A secure electronic network was in place (NHSnet) as well as mechanisms for bulk electronic transfer of financial and activity data (commissioning datasets and derived Hospital Episode Statistics - HES).

Healthcare also inherited guidelines on information sharing and a developing network of local advisors (The Caldicott Report and subsequent Caldicott Guardians - see Table 6.8). Support for all these features was limited by a shortage of trained IT staff which continues to be reported in annual surveys (eg. NHSIA, 2001/recruit).

9.2.3. Organisations and structures behind policies and IM&T strategies affecting healthcare.

The challenges facing healthcare and the broader public sector were addressed by various modernisation programmes. Organisations and lines of responsibility are introduced below, with a reference summary in Table 9.4.

Cross Government initiatives.

Pan government modernisation activities are led by the Cabinet Office. Units cover issues such as strategy, policy and delivery. They link to programmes in the Prime Minister's Office specifically addressing public sector reform, public consultation, and rules for public servants and services.

Programmes in technology are managed in the Cabinet Office by the Office of the eEnvoy. OeE liaises across central and local government and public services, with other governments (particularly the European Union) and with national and international IT

standards organisations. In theory, all initiatives affecting several organisations or sectors should have OeE approval.

A management forum of senior public and industry sector members (eGovernment eChampions Group) has "ownership" of the general direction and specific initiatives. It is supported by sub-committees covering technology trends; government processes and supporting data; general and special interest groups. Combined developments in particular technological areas are termed "Frameworks".

Healthcare.

Modernisation in this area is led by the Department of Health. Closer links with front line services were encouraged by merging the positions of DoH's principal civil servant (Permanent Secretary) and NHS Chief Executive in 2002 (see also "Shifting The Balance Of Power" – 9.3.2).

A Modernisation Board is chaired by the Secretary of State, with policy implementation supported by DoH's Modernisation Agency, supplemented by a wide range of specialist committees, expert groups and Directorates for research and statistical data collection. Priority issues are covered by Task Forces overseen by individual ministers.

IM&T issues are now managed at the top level by the National Information Policy Board. NIPB members are drawn from across central and sector organisations, and oversee the various IM&T strategies directly and indirectly affecting healthcare. Detailed direction is given by the NHS Executive's Information Policy Unit (IPU) which was the lead on such areas before NIPB.

The NHS Information Standards Board (ISB) replaced the Committee for Regulating Information Requirements. Sub boards cover clinical, management and technological issues. ISB has authority over the NHS and areas of overlap with Social Services. All

national or significant datasets must pass an official appraisal and approval process (see chapter 10). Note also that major ISB programmes are subject to approval by the Office of the eEnvoy.

DoH and NHS central organisations involved with IT are supported with administration and management of major projects by the NHS Information Authority. NHSIA was renamed from the Information Management Group and is now technically a Special Health Authority (SHA) aiming to bring IM&T issues closer to the mainstream NHS.

Developments in the social field are led by DoH's Social Care Group. SCG works closely with the Association of Directors of Social Services (ADSS) and the Association's Information Management Group (SSIMG). It also contains separate Health and Social Services Inspectorates which are progressively merging. In addition, a Health and Social Care Joint Unit was established to promote greater cross departmental collaboration.

Additional monitoring organisations.

Since 1990, the Audit Commission has been responsible for monitoring use of funds and general good practice in both local government and local healthcare organisations. Equivalent scrutiny of spending by central government and individual departments is performed by the National Audit Office (NAO) and the Parliamentary Public Accounts Committee.

These organisations have been joined in local healthcare service monitoring by the Centre for Health Improvement. CHI is responsible for improving clinical and service standards, and works closely with the National Institute for Clinical Excellence (NICE) and the developing Social Services Institute for Excellence (SSIE) which effectively set the main clinical and procedural standards.

Table 9.1. Key consultation/direction documents, policies and IM&T strategies affecting data and information in English healthcare (1997-2002).

A. Consultation/direction documents.

Sector	Title	Reference
Government	Modernising Government.	(Cabinet Office, 1999/modgov).
Health	The new NHS - modern and dependable.	(DoH, 1997/newnhs).
	A first class service: quality in the new NHS.	(DoH, 1998/first).
	Our healthier nation: a contract for health.	(DoH, 1998/ohn1).
	Clinical governance: quality in the new NHS.	(DoH, 1999/cgov).
	An Organisation with a Memory - Report of an expert group on learning from adverse events in the NHS.	(DoH, 2000/memory).
Social Care	Modernising social services: promoting independence, improving protection, raising standards.	(DoH, 1998/modss).

B. Policy documents.

Sector	Title	Reference
Health	Saving lives: our healthier nation.	(DoH, 1999/ohn2).
	The NHS Plan - a plan for investment, a plan for reform.	(DoH, 2000/nhsp).
	Shifting The Balance Of Power.	(DoH, 2001/stbop).
Social Care	A Quality Strategy for Social Care.	(DoH, 2000/qssc).
	Quality Protects. A quality strategy for children's services.	(DoH, 2000/qp).
Research	Research Governance Framework for Health and Social Care.	(DoH, 2001/rgf).

C. IM&T Strategies.

Sector	Title	Reference
Government	eGovernment: a strategic framework for public services in the information age.	(Cabinet Office, 2000/egov).
Health	Information for Health. An Information Strategy for the modern NHS 1998-2005.	(DoH, 1998/ifh).
	Building the Information Core - Implementing the NHS Plan.	(DoH, 2000/bic).
	Delivering 21 st Century IT Support for the NHS. National Strategic Programme.	(DoH, 2002/nsp).
Social Care	Information for Social Care. A framework for improving quality in social care through better use of information and information technology.	(DoH, 2001ifsc).

Table 9.2. Principles of modern government and public services in the UK.(From Cabinet Office, 1999/modgov).

Quotations from the *Modernising Government* white paper signed by the Prime Minister and Minister for the Cabinet Office.

A. A new package of reforms:

A commitment to public services available 24 hours a day, seven days a week where there is a demand.
Joined-up government in action including a clear commitment for people to be able to notify different parts of government of details such as a change of address simply and electronically in one transaction.
A new drive to remove unnecessary regulation.
A new target of all dealings with government being deliverable electronically by 2008.
New 'Learning Labs' to encourage new ways of front-line working by suspending rules that stifle innovation.
Taking a more creative approach to financial and other incentives for public service staff.
Within Whitehall, a new focus on delivery - asking every Permanent Secretary to ensure that their Department has the capacity to drive through achievement of the key government targets.

B. To ensure that government is both inclusive and integrated:

Ensuring that policy making is more joined up and strategic.
Making sure that public service users, not providers, are the focus, by matching services more closely to people's lives.
Delivering public services that are high quality and efficient.

C. Centring the programme on five key commitments:

Policy making. We will be forward looking in developing policies to deliver outcomes that matter, not simply reacting to short-term pressures.

Responsive public services. We will deliver public services to meet the needs of citizens, not the convenience of service providers.

Quality public services. We will deliver efficient, high quality public services and will not tolerate mediocrity.

Information age government. We will use new technology to meet the needs of citizens and business, and not trail behind technological developments.

Public service. We will value public service, not denigrate it.

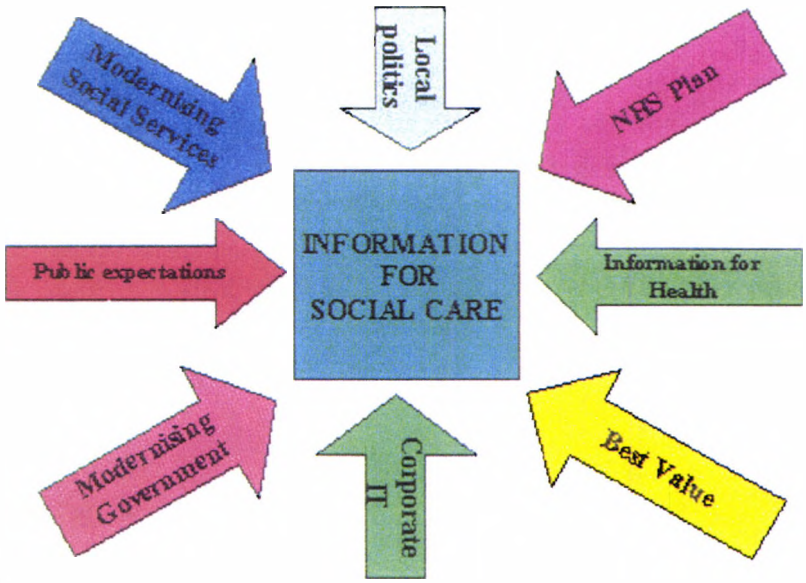


Figure 9.1. Summary of information "Drivers For Change" identified in *Information For Social Care* (DoH, 2001/ifsc).

"There are a number of drivers behind the need for a more co-ordinated and coherent approach to information development and use... These drivers do not always appear to work in the same direction and there will on occasions be tensions between these agendas".

A. Schematic summary of interacting drivers on local healthcare organisations.

B. Drivers by category.

	Category	Description	Examples
Central (top down).	National policies and strategies which must be incorporated into local IM&T strategies.	Health policy agendas. Social Care policy agendas. Information Age Government agenda. Other National Agendas (eg. on crime and community regeneration).	
Local (bottom up).	Factors arising from developments and initiatives at the local authority or area level.	Local political agendas. Local demographic and geographic factors. Social welfare issues. Process changes to improve efficiencies. Partnership arrangements with other services and agencies.	
External/social change.	Changing expectations from the public.	Growing public access to technology recognised by the Information Age Government agenda. Specialist technologies for particular health and social groups. Alternative sources of information (charities, self-help groups). Legal changes. Academic research as a continuous driver.	

Table 9.3. New and changed laws affecting healthcare modernisation (primarily since 1997).

NB1. Bills and final Acts of Parliament are available via the website of The Stationery Office. (www.hmso.gov.uk).

NB2. Acts may be amended through secondary legislation.

A. Social Inclusion.

Disability Discrimination Act 1995.

B. Healthcare.

Health Act 1999.

Care Standards Bill 1999
(nursing & residential homes).

The Children (Leaving Care) Bill 2000
(Local Government responsibilities).

C. Data and Electronic Communications.

Computer Misuse Act 1990.

Data Protection Act 1998
(replaced the 1984 Act).

Electronic Communications Bill/Act 2000.

Regulation of Investigatory Powers Bill/Act 2000.

D. Data Protection Principles

from Schedules 1-3 of the 1998 Act.

(See also the Caldicott Principles - Table 6.8).

Table 9.4. Reference summary of structures and organisations behind policies and IM&T strategies affecting English healthcare at 2002/3.

	Policies	IM&T Strategies
Cross-Government /public sector	**Cabinet Office and Prime Minister's Office** (Coordination).	**Office of the eEnvoy [OeE]** (Coordination). **eGovernment eChampions Group** (Strategy "owners").
Healthcare (Department of Health)	**Modernisation Board** (Broad policy). **Modernisation Agency** (promote implementation). **Social Care Group [SCG] and Association of Directors of Social Services [ADSS]** (lead on social issues **Health and Social Care Joint Unit** (cross-department coordination).	**National Information Policy Board (NIPB]** (top level coordination). **Information Policy Unit [IPU]** (strategy development and control of implementation). **Information Standards Board [ISB]** (sets and monitors data collection standards). **NHS Information Authority [NHSIA]** (general administration and daily responsibilities for major programmes/services). **Social Services Information Management Group [SSIMG]** (IT arm of ADSS, much smalller but equivalent to NHSIA).

9.3. Broad specifications of policies in healthcare.

This section identifies the major policy statements under New Labour in chronological order. It emphasises the pledges affecting data and information, including consequences of service re-organisation and special initiatives with particular demands. It closes with the targets and budgets for healthcare service improvements set by politicians.

9.3.1. The essential policies.

1). Health.

The NHS Plan - a plan for investment; a plan for reform. (DoH, 2000/nhsplan).

The NHS Plan was the key policy statement on healthcare services. It expanded on previous documents with sector and public consultations and the political motivation of a new Secretary of State in 1999. The Plan promised a redesigned service fit for the 21st century and delivered in 10 years. (Another Secretary of State took over in 2003 - the third in six years).

General principles were adopted to reinforce traditional values and introduce modern ideas (Table 9.5). Support came from a range of professional and patient organisations potentially involved in implementation and adding their names to the document.

A political case was made for increasing "capacity" through more staff, independent sector "concordats", and use of overseas providers establishing UK centres. Change was also related to new pay structures, working hours and greater financial freedoms for

organisations performing well against official targets (foundation hospitals). All these goals are progressing but have proved controversial.

More practical cases were made for less strict demarcations between professions and ranks (eg. nurse practitioners) coupled to training and continuous learning (eg. NHS University and Leadership programmes). Service delivery would be supported by basic guidelines and rapid spread of new practices (Knowledge Management).

Older people, vulnerable children and the mentally ill, together with disease groups with high mortality, were targeted with new standards for care and use of resources (National Service Frameworks - see also 9.3.3). Closer working between health and social care was encouraged to deliver "seamless care". Individuals would be supported in all hospitals through a new Patient Advice and Liaison Service (PALS).

2). Social Care.

A Quality Strategy for Social Care. (DoH, 2000/qssc).

The strategy had principles in common with the NHS Plan (eg. overlapping care in the community) as well as features specific to the sector (eg. youth offender teams). Sub-programmes addressed leadership, reduced violence towards staff, improved training, new qualifications and monitoring of performance.

A range of parallel initiatives contributed to the main strategy and addressed particularly vulnerable groups. "Quality Protects" (DoH, 2000) was a major sub-strategy for children in care or foster homes. Others are listed in (DoH, 2001/ifsc, Appendix 2).

3). Public Health.

Saving Lives: Our Healthier Nation (OHN). (DoH, 1999/ohn).

As the Government's initial response to public health issues, "Our Healthier Nation" (DoH, 1998/ohn) was among a number of central initiatives considered by the "Independent Inquiry into Inequalities in Health Report" (Atcheson, 1998). A website was set up (www.ohn.gov.uk). *Saving Lives: Our Healthier Nation* followed as the official strategy in public health, joined in 2001 by an R&D programme (DoH, 2001/rdph).

Health Action Zones (HAZs) were introduced in 1997/8; local Directors of Public Health were required to draw up Health Improvement Programmes (HIMPs). Public Health Observatories (PHOs) followed with the developing strategy as a broader monitoring mechanism across the regions. Coordination was provided by the Health Development Agency, formed from previous organisations involved in public education, monitoring and analyses.

4). Research.

Research governance framework for health and social care. (DoH, 2001/rgf).

A variety of actual and potential abuses of patient consent in health related research produced public scandals. This framework was the response, with a re-statement of general principles and links to the broader concept and monitoring mechanisms of "clinical governance".

A national research register and online information source were also established to avoid duplication and focus on official priorities. All organisations involved in funding, sponsoring or conducting research in the NHS or social care settings were now subject to formal assessment and accreditation.
The framework was supported by an Implementation Plan and is due for updating in late 2003. Areas where the framework should be applied are illustrated in the R&D Strategy for Public Health, covering an extremely broad range of topics for populations and sub-groups.

9.3.2. Changing the structure of healthcare.

Shifting the balance of power (STBOP). (DoH, 2002/stbop).

STBOB targeted delivery through re-organised services and new ways of working. It complemented the NHS Plan with implementation in the field supported by DoH's Modernisation Agency. The underlying model for devolving decision-making to a more local level was reported in the NHS Plan to be widely accepted nationally and internationally.

Primary Care Trusts (PCTs) are now at the centre of English healthcare. In principle, GP surgeries, Social Services and community care planners have re-organised by local area with responsibility for decisions on care delivery and budgets. Hospital Trusts remain as separate units, though mergers and arrangements to share specialised resources (outreach clinics) occur regularly. Particularly close cooperation between PCTs and local hospitals is intended to be formalised in Care Trusts (CTs).

Some responsibilities from ninety-nine old Health Authorities have passed to PCTs. Other duties have been taken over by twenty-eight Strategic Health Authorities (StHAs).

Coordination and support roles have transferred to StHAs with the addition of some budget and performance monitoring components from a reduced Department of Health.

Special Health Authorities (SHAs) provide new and existing services best coordinated at the national level. Traditional areas of support (eg. transplantation and public health education) have been augmented with organisations for Information Management & Technology (NHS Information Authority - NHSIA) and for assessing cost-effective treatments (National Institute for Clinical Excellence - NICE). Similar organisations are emerging in Social Care (Social Services Institute for Excellence - SSIE).

9.3.3. Special initiatives with demands for data: monitoring and performance management.

National Service Frameworks (NSFs).

NSFs set service standards for particular disease or demographic groups (Table 9.6). The NHS Plan targeted cancer, coronary heart disease and mental health in special programmes, while Social Services focused on children and older people. All became NSFs and have been joined by diabetes, long-term conditions, renal services and paediatric intensive care. Each framework is accompanied by a developing "information strategy" to collect monitoring data.

A new NSF was expected each year on average. However, the initial pace of the programme has since slowed.

Performance Assessment Framework (PAF).

In contrast to the specific frameworks, PAF aims to assess local and national NHS performance "in the round" and against factors that "matter most to patients" (DoH, 1999/nhspaf). Figure 9.2 provides a schematic summary with example performance indicators and broad links to other developing datasets.

A cycle of six components has been adopted (population health improvement - fair access - effective delivery - efficiency - patient experience - outcome - back to population health). Indicators are evolving through a process of consultation and piloting. Bench marking clubs and local information networks (LINS) are supporting data interpretation and geographic comparisons. Chief Executives of individual organisations have responsibility for raw data collection and "quality"

Comparable frameworks are developing in personal social services, human resources and public health. Analysed data contribute to annual league tables and star ratings.

An integrated approach.

PAF and NSFs are part of a broader approach incorporating the National Institute for Clinical Excellence and the Centre for Health Improvement (Figure 9.3). It was quoted in the NHS Plan but originated in earlier documents (DoH, 1997). Application of the overall process is described as "Continuous Quality Improvement" (CQI). Local and national adjustments to information feedback are termed "Performance Management".

9.3.4. Political targets and budgets for improved health and healthcare services.

The NHS Plan set specific targets for health and social care to be achieved at various stages up to 2010 (Table 9.7). Key areas were cancer mortality rates, suicides, drug rehabilitation and educational performance of children in care.

Additional funds from the Comprehensive Spending Review were allocated according to DoH's investment strategy (Table 9.8). Almost #13bn was available from 2000 to 2004. Contributions were also expected from the commercial sector for major building programmes and local service projects via the Private Finance Initiative (PFI) and Public Private Partnership (PPP). A special Trust was established for improvements to individual GP premises (Local Investment Finance Trust - LIFT).

Approximately £2bn was alotted to clinical priorities and waiting times. The majority (£6.3bn) was left to local investment decisions. Note that almost £1bn was assigned to IM&T (7.1% of total funds over the four years).

Table 9.5. Updated Core Principles for a modern NHS. From the Preface to the NHS Plan (DoH, 2000/nhsp). (cf. principles for modernising Government - Table 9.2 – particularly those marked here with an *).

"Underpinning the Plan are a set of core principles... [which] represent the common ground between the Government and the NHS as the task of modernising and rebuilding the health service begins. Some of the principles restate the founding values of the NHS, others reflect issues that are important today".

1	The NHS will provide a universal service for all based on clinical need, not ability to pay.
2	The NHS will provide a comprehensive range of services.
3*	The NHS will shape its services around the needs and preferences of individual patients, their families and their carers.
4*	The NHS will respond to different needs of different populations.
5*	The NHS will work continuously to improve quality services and to minimise errors.
6*	The NHS will support and value its staff.
7	Public funds for healthcare will be devoted solely to NHS patients.
8*	The NHS will work together with others to ensure a seamless service for patients.
9	The NHS will help keep people healthy and work to reduce health inequalities.
10*	The NHS will respect the confidentiality of individual patients and provide open access to information about services, treatment and performance.

Table 9.6. Information sources on current and developing National Service Frameworks at 2002/3.

NSFs set standards and recommended care pathways for particular disease or population groups. They should be monitored by data collection (information strategies). Developments are supported by an External Reference Group of stakeholders; and process modelling within the Datasets DevelopmentProgramme (NHSIA, 2002/ddp1).

A. Central information source.

Department of Health base page

www.doh.gov.uk/nsf/nsfhome.htm

B. NSF by broad categories.

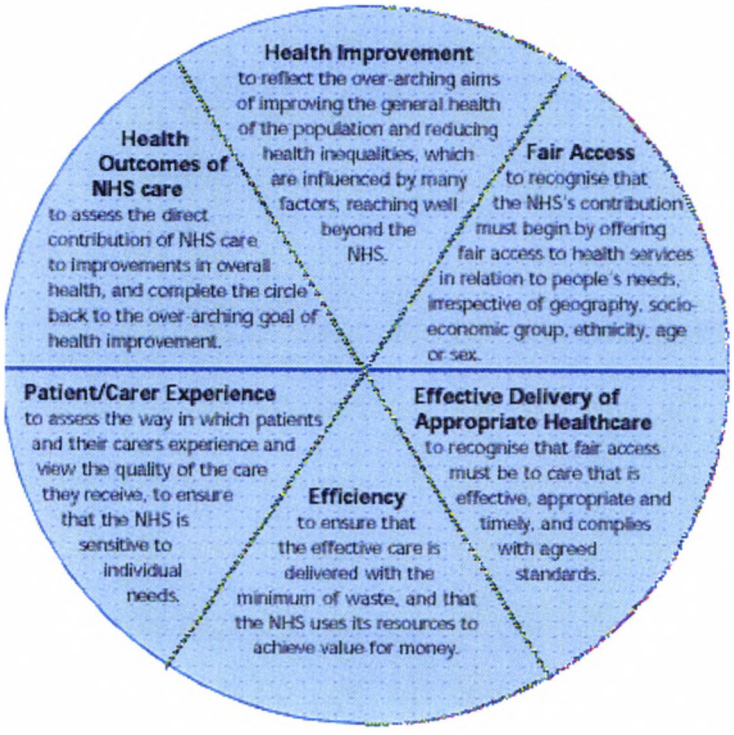
Category	NSF	Information source
Medical conditions and services	Cancer	www.doh.gov.uk/nsf/cancer.htm
	Coronary Heart Disease	www.doh.gov.uk/nsf/coronary.htm
	Mental Health	www.doh.gov.uk/nsf/mentalhealth.htm
	Diabetes	www.doh.gov.uk/nsf/diabetes/index.htm
	Paediatric Intensive Care	www.doh.gov.uk/nsf/paediatri.htm
	Renal Services	www.doh.gov.uk/nsf/renal.htm
Community care	Children	www.doh.gov.uk/nsf/children.htm
	Older People	www.doh.gov.uk/nsf/olderpeople.htm
	Long-term conditions	www.doh.gov.uk/nsf/longterm.htm

Figure 9.2. Summary of the NHS Performance Assessment Framework at 1999. (From DoH, 1999/nhspaf).

A. Verbal description of the "cycle" of 6 dimensions.

*"From an initial view of the health of the diverse communities of the local population under consideration (**Health Improvement**), we need to ensure that everyone with health care needs (**Fair Access**) receives appropriate and effective health care (**Effective Delivery**) offering good value for money for services (**Efficiency**) as sensitively and conveniently as possible (**User/Carer Experience**) so that good clinical outcomes are achieved (**Health Outcome of NHS Care**), to maximise the contribution to improved health (**back to Health Improvement**)".*

B. PAF schematic summary.



C. PAF structure: working definitions, example interpretations and high level performance indicators (HLPIs).

NB. PSS Interface indicators – cover areas of overlap with Personal Social Services and a parallel performance framework developing in PSS (see www.doh.gov.uk/scg/pssperform/joint.htm).

1. Health Improvement.

Description	Sample dimensions for interpretation
Overall health of populations, reflecting social and environmental factors and individual behaviour as well as care provided by the NHS and other Agencies.	

Performance Indicators.

Deaths from all causes (people aged 15-64)	Deaths from all causes (people aged 65-74)
Cancer registrations	Deaths from malignant neoplasms
Deaths from all circulatory diseases	Suicide rates
Deaths from accidents	

2. Fair access

Description	Sample dimensions for interpretation
Fairness of provision of services in relation to need and availability.	Geographic provision. Socio-economic group. Demographics (age, ethnicity, sex). Care groups (eg. people with learning difficulties).

Performance Indicators.

Surgery rates	Size of inpatient waiting list per head of population (weighted)
Adults registered with an NHS dentist	Children registered with an NHS dentist
Early detection of cancer	

3. Effective delivery of appropriate health care.

Description	Sample dimensions for interpretation
Extent to which services meet relevant criteria.	Clinically effective (interventions or care packages are evidence-based). Appropriate to need. Timely In line with agreed standards. Provided according to best practice service organisation. Delivered by appropriately trained and educated staff.

Performance Indicators.

Disease prevention and health promotion	Early detection of cancer
Inappropriately used surgery	Surgery rates
Acute care management	Chronic care management
Mental health in primary care	Cost effective prescribing
Discharge from hospital[PSS]	

4. Efficiency

Description	Sample dimensions for interpretation
Extent to which NHS services may be judged against recognised efficiency criteria.	Cost per unit of care/outcome. Productivity of capital estate. Labour productivity.

Performance Indicators.

Day case rate	Length of stay in hospital (case-mix adjusted)
Unit cost of maternity (adjusted)	Unit cost of caring for patients in receipt of specialist mental health services (adjusted)
Generic prescribing	

5. Patient/carer experience

Description	Sample dimensions for interpretation
Patient/carer perceptions on the delivery of services.	Responsiveness to individual needs and preferences. Skill, care and continuity of service. Patient involvement, good information and choice. Waiting times and accessibility. Physical environment; the organisation and courtesy of staff.

Performance Indicators.

Patients who wait less than 2 hours for emergency admission (through A&E)	Patients with operation cancelled for non-medical reasons
Delayed discharge from hospital for people aged 75 or over[PSS]	First outpatient appointments for which patient did not attend
Outpatients seen within 13 weeks of GP referral	% of those on waiting list waiting 12 months or more

6. Health outcomes of NHS care

Description	Sample dimensions for interpretation
NHS success in using its resources.	Reduce levels of risk factors. Reduce levels of disease, impairment and complications of treatment. Improve quality of life for patients and carers. Reduce premature deaths.

Performance Indicators.

Conceptions below age 16	Decayed, missing and filled teeth in five year old children
Adverse events/complications of treatment	Emergency admissions to hospital for people aged 75+[PSS]
Emergency psychiatric re-admission rate[PSS]	Infant deaths
Survival rates for breast and cervical cancer	Avoidable deaths
In-hospital premature deaths	

D. PAF: links to other performance indicators.

"The development of the [Performance Assessment Framework – PAF] and its high level indicator set has been complemented by work ... to develop a range of indicators ... [PAF] will provide the overall structure for the development of all such performance indicator sets ...".

Other indicators

A set of clinical indicators.

Clinical effectiveness indicators.

NHS Trust reference costs.

Primary care effectiveness indicators.

Results of the first survey of NHS patients (in due course).

An equivalent framework under development for Personal Social Services (PSS).

Figure 1 A simple illustration of the key elements of the NHS quality strategy (from *A First Class Service*)

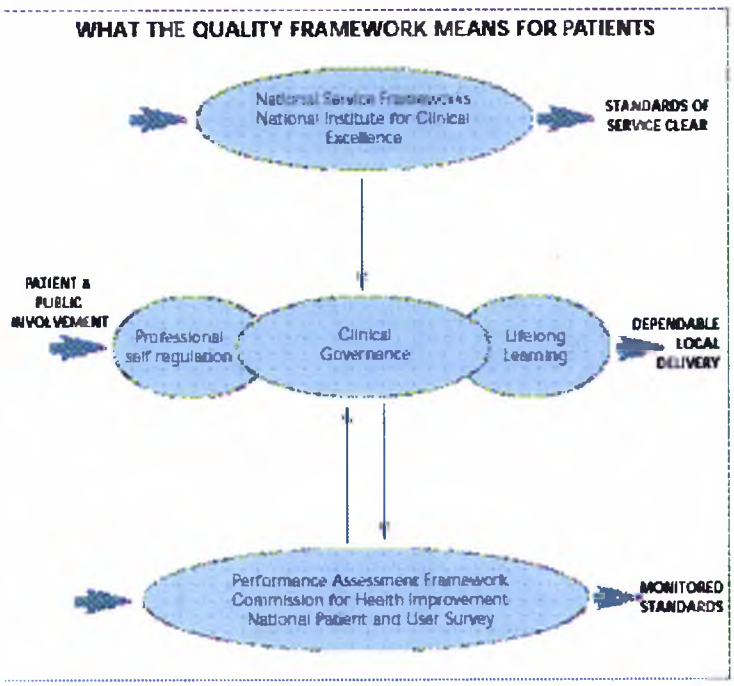


Figure 9.3. Schematic summary of central initiatives contributing to continuous quality improvement (CQI) in English healthcare. (From DoH, 1999/nhspaf).

Table 9.7. Summary of pledges and targets for the NHS set by the NHS Plan and duplicated in the Department of Health's Public Service Agreement. (From DoH, 2000/nhsp, chapter 16, with the PSA as Appendix 3).

A. General pledges.

A system of inspection and accountability for all parts of the NHS.
A consultant contract that gives most money to the doctors working hardest in the NHS.
Nurses and other health professions will be given the bigger roles that their qualifications and expertise deserve.
Local health and social services will be brought together in 1 organisation.
The NHS and private sector will work more closely together.
Patients will have an advocate in every hospital.

B. Capacity growth.

B1. Likely net staff increases by 2008.

15k more GPs and consultants.
30k more therapists and scientists.
35k more nurses, midwives and health visitors.

B2. Hospital beds and investment for growth.

10k more general and acute hospital beds.

NB. More of the spending on training, capital infrastructure and modernised information technology.

C. Specific targets (for year on year review and expansion).

C1. For the NHS.

Primary care access	Access to primary care professional within 24h and a primary care doctor within 48h by 2004.
Hospital waiting times	Maximum waiting for outpatient appointment 3 months by 2005.
	Maximum wait for inpatient treatment 6 months by 2005
Hospital appointment pre-booking	66% of outpatient appointments and inpatient elective admissions pre-booked to suit patient and level of clinical need by 2003/4.
	100% by 2005.
Patient satisfaction with hospital care	Year on year improvements measured by independently audited surveys.
Decreases in mortality from major killers by 2010	At least 40% from heart disease in people under 75.
	At least 20% from cancer in people under 75.
	At least 20% from suicide and undetermined injury.
Narrowing health inequalities	Targets for reduced inequalities covering children, socio-economic groups and geographic areas to be set with stakeholders and experts in 2001.
Costs of care	Benchmarked with agreed milestones to be set for 2003/4.

C2. For the NHS in partnership with Social Services.

Pre and post hospital admission care for people aged 75+	Reduced preventable hospitalisation and discharge delays monitored via the Performance Assessment Framework.
Problem drug use	55% increase in support programme participation by 2004.
	100% by 2008.

C3. For Social Services.

Life chances for children in care by 2004	Levels of education, training and employnment for care leavers at 19 years at 75% of achievements for peer groups.
	At least 15% of children in care with 5 GCSE grades A-C.
	Reduced cautions and convictions compared with peer groups.
	Improved use of adoption system, with targets following the Prime Minister's review.

Table 9.8. Summary of the Department of Health Investment Strategy for England, 2000-2004. (Derived from DoH, 2000/dis, Table 4 - see also Crisp, 2001, Appendix).

A. Annual and total additional investment (£m).

Year	Investment
2000/1	2,615
2001/2	3,056
2002/3	3,483
2003/4	3,741
Total	12,895

B. Annual and total additional investment by components (£m).

Component	2000/1	2001/2	2002/3	2003/4	Contribution of component to total investment over 2000-2004.
Clinical priorities and waiting times	524	432	415	469	1,840
IM&T	65	215	317	319	916
Private Finance Initiative (PFI) hospital investment programme	632	788	811	832	3,063
Local investment decisions	1,335	1,405	1,750	1,819	6,309
Other	59	66	65	65	255
Unallocated	150	125	238		513

C. Annual and total additional investment by components (figures from B as %).

Component	2000/1	2001/2	2002/3	2003/4	Contribution of component to total investment over 2000-2004.
Clinical priorities and waiting times	20.0	14.1	11.9	12.5	14.3
IM&T	2.5	7.0	9.1	8.5	7.1
Private Finance Initiative (PFI) hospital investment programme	24.2	25.8	23.3	22.2	23.8
Local investment decisions:	51.1	46.0	50.2	48.6	48.9
Other	2.3	2.2	1.9	1.7	2.0
Unallocated	5.7	4.1	6.8		4.0

9.4. Broad specifications of IM&T strategies relating to healthcare policies.

The previous section illustrated the range of policies and special initiatives placing demands on data and information. Now, 9.4 considers the strategies intended to support delivery through Information Management and Technology (IM&T).

The section begins with a review of the public sector in general, followed by details for healthcare. It concludes by highlighting particular IM&T initiatives and stating the central IM&T targets and required actions from 2002/3.

9.4.1. The overarching eGovernment strategy.

The GovTalk mechanism.

The Office of the eEnvoy (OeE) have adopted Internet and web technologies in a strategic decision intended to reduce costs, risks and development time through integration within organisations and across sectors. The choice covers industry-wide standards developed and maintained through international processes and available for public inspection ("open standards").

Selected standards are periodically updated as more features of government or society are addressed and technology changes. OeE's GovTalk.gov.uk site provides technical information, guidance, and a change management process supporting developments "at internet speed" (www.govtalk.gov.uk).

eGovernment Interoperability Framework (eGIF).

eGIF is the cornerstone of the public sector strategy for service integration, data exchange and provision of information. It links with other, more specific Frameworks including security and authentication, IT skills, websites, web portals and emerging "channels" for delivering information (eg. kiosks and digital TV).

Version 1 was released in April 2000 (available via the GovTalk website). Version 4 (April 2002) split eGIF into two sections. Strategy updates are now released annually while additions to technological standards are available every six months.

Version 3 introduced "transcoder" technologies for information provision to people with special communication needs (the disabled and ethnic minorities with English as a second language). No details were provided – but see chapter 10 for details on possible technical approaches).

Version 4 (and later) incorporated the Government's Meta-data Standards Framework for information description and retrieval via tailored search engines - the eGovernment Meta-data Framework (eGMF) - (see chapter 10 for HJL's proposals in healthcare).

eGIF sets absolute requirements on systems within government departments and the public sector to adopt:

- Browsers as the main mechanism for information access.

- Extensible markup language (XML) for data exchange and integration (see Appendix 4 and chapter 10).

- The Government Data Standards (GDS) to describe information for the public, or shared with other organisations (the first step in eGMF - see chapter 10).

- The Unified Modeling Language (UML) for presenting system and dataset functions and design in a common visual format (see Appendix 5 and chapter 10).

Delivery.

Electronic records in all public organisations were due by 2004. New electronic systems (handling data or public information) should be eGIF compliant, and all systems should be updated by 2005.

Online access for citizens to all personal records, public services and information is beginning to be integrated through a central portal (www.ukonline.gov.uk).

9.4.2. IM&T strategies in healthcare.

Three main strategies covered the period from late 1998 to early 2002. In addition to NHS requirements, they addressed areas of obvious overlap with social care and were joined in 2001 by a parallel strategy from Social Services. The current main strategy (the National Strategic Programme – NSP) introduced radical changes binding on both sectors.

Information for Health 1998-2005 (IFH). (NHSE, 1998/ifh).

IFH was the initial strategy for healthcare following election of New Labour and covering seven years. It acknowledged past burdens of management data collection on clinicians, and NHS failings to give IT system developers clear directions. It also advocated efficient collection and use of data for both primary and secondary purposes.

Commitments were made to expand NHSnet and provide online libraries and information for professionals and patients. Electronic records would support individual care with additional mechanisms to extract sub-sets for 24h emergency care and life long records for individual and group monitoring (see also 9.4.3).

Coordinated electronic services would be delivered through Local Implementation Strategies (LIS) organised by Health Authorities with other local agencies. LIS were also intended to link with the local Health Improvement Programmes.

The first strategy was subsequently described as setting the "direction of travel" and updated in line with changing policies.

Building the Information Core - Implementing the NHS Plan. (DoH, 2001/bic).

"Building the Information Core" was the revised strategy though still referred to as IFH. Commitments were expanded to accommodate service re-organisations and the emerging National Service Frameworks.

In parallel with the revised strategy,GP connection to NHSnet was targeted in particular. It would support online prescribing pilots (Electronic Transmission of Prescriptions - ETP). Developments for electronic hospital booking systems were initiated. Exchange of pathology messages between GPs and hospitals on a national scale (Pathology Messaging Programme - PMEP) was also intended to produce an architecture for other sensitive services requiring encryption (an encryption strategy for the NHS was not published until 2001).

A series of demonstrator sites, involving health and social care organisations, were set up to progress the Electronic Records Development and Implementation Programme (ERDIP - see 9.4.3). The existing system of terms and codes for electronic record (Read Codes) began to merge with an equivalent approach from the College of American Pathologists to produce the "Systematized Nomenclature of Medicine - Clinical Terms" (SNOMED-CT or SCT) (CAP, 2000).

A letter from the NHS Chief Executive apologised for late release of guidance and reminded IM&T managers of their strategic targets (Crisp, 2001). no reference was made to the major changes that were to come within a year (NSP).

Information For Social Care (IFSC). (DoH, 2001/ifsc).

IFSC was a notable component of the "Quality Strategy for Social Care". "Owned" by DoH's Social Care Group and the Association of Directors of Social Services, it was an evolving document due for updates in early 2003 and 2005. (HJL could not find an update in late September 2003).

Compared with mainstream medicine and health, IM&T in social care had traditionally been under funded and a low priority for staff training and R&D. Working system examples and developments were limited to a few local enthusiasts and some demonstrator sites in the electronic records programme (ERDIP).

The original IFSC document provided a summary of the position, future intentions and tools to help local managers with broad system specifications. Steps towards electronic records were also considered (see 9.4.3).

The National Strategic Programme (NSP). (DoH, 2002/nsp).

As the third strategy for mainstream healthcare under New Labour, NSP was launched in April 2002 in response to limited national progress. It characterised the position as "locally successful through individual efforts, but not sufficiently supported or funded to promote IT generally or to achieve a national infrastructure".

A strategy Taskforce chaired by a minister was established. The head of DoH's information, statistics and surveys Directorate was given daily responsibility supported by a national programme manager and Chief Information Officers across the Strategic Health Authorities.

The new strategy applied absolutely to the NHS and areas of overlap with social care. Local implementations were intended to run in parallel and to integrate as "local communities are ready".

All aspects of funding, specification, delivery and performance now reverted to central control. System providers and users were advised to adopt "ruthless standardisation". (Also see later comments identifying NPFIT).

9.4.3. IM&T Initiatives with special relevance to data and information.

Work Programmes from the NHS Information Authority.

NHSIA exists to manage national programmes and promote IM&T locally. Formerly the Information Management Group, it was renamed and rationalised in 1999. In fact, it

now has many more projects and areas of responsibility. Table 9.9 provides a summary of work programmes within delivery areas.

NHSIA sets and monitors contracts for NHSnet and network services, including electronic transfer of central returns via ClearNet and other networked applications. It is responsible for terms and codes for electronic records (Read Codes/SNOMED-CT) and manages international classifications for use in the UK. It also develops products for grouping and analysing aggregated clinical data (Casemix, Health Resource Groups, Health Benefit Groups).

NHSIA also supports the National Service Frameworks with a Dataset Development Programme (see Table 9.10 for references). NSF information strategies should pass ISB's appraisal and approval processes, and are assisted with care process modelling to identify data sources and flows (see chapter 10 for details and additional uses in provision of information to patients).

The Data Quality Initiative and Accreditation Process is covered in the Annex to this chapter. It is just one of the programmes run by NHSIA. In fact all of these programmes are contributing in some way to "data quality". They are best considered as linked components – a view which (arguably) is not promoted by NHSIA's publications and website.

Electronic records.

GP systems were a special case covered by the NHSIA's Requirements For Accreditation (RFA) programme. In other sectors, three record classes had been anticipated in original strategy documents:

Electronic Patient Records (EPR) - for recording individual care in provider organisations.

Electronic Social Care Record (ESCR) - an EPR equivalent tailored to Social Services and "agents" (service providers under local contracts).

Electronic Health Record (EHR) - a shared record (or mechanism) with components from EPR and ESCR for individual care, particularly in emergencies, as well as long-term individual and group monitoring.

EPRs for acute care had five development levels (Table 9.11) with the functions of Level 3 required for most hospitals by 2002/3. ESCR was at a very early stage, but types and physical formats of data and a generic structure had been identified (Figure 9.4).

Sixteen demonstrator sites were intended to develop national guidelines and architectures for EHR as part of the electronic records programme (ERDIP). The national evaluation concluded that a "good start" had been made but there was "no clear evidence" of service benefits or a consensus system design (PA Consulting, 2003). Moreover, evaluation was not formally considered until after designs and implementations had begun (UKIHI, 2001a,b).

A change in DoH's approach was indicated by a reference to "Integrated Care Record Services" in the national ERDIP evaluation (PA Consulting, 2003, Appendix 2). A broad description of ICRS was provided (Table 9.12). There were, however, no references to related policies and no obvious relationship to the rest of the document. (Also see later comments on NPFIT).

Information for professionals and patients.

Online libraries and telephone services are part of DoH's Knowledge Management programme (Table 9.13 for web details). The National electronic Library for Health (NeLH), with links to journals and systematic reviews of procedures, is targeted at

professionals. Separate modules, or "library floors", are developing for branches of medicine and a parallel service is emerging in social care (NeLSC).

The NHS.UK programme provides public information on individual orgganisations and performance. More specific enquiries or concerns about a personal medical problem are handled by a nurse led service in 22 call centres across England, assisted by a decision support system and a parallel website. NHS Direct was evaluated by Sheffield and City Universities with details via www,sheffield.ac.uk, according to the annual report (NHS Direct, 2002). Again, an equivalent service in social care is developing with the initial focus on older people (Care Direct).

DoH also maintains a database of contacts and weblinks to complement its Strategy of "Caring about Carers" (DoH, 2003/carers). A decision to use commercial companies to maintain this service was taken in 2003. Negotiations are in progress.

The "Knowledge Network" is an exploratory project to promote coordinated information within central government. Six departments, including DoH, are addressing integrated information sources and flows. They have completed the first stage of feasibility studies and "State Of Readiness" assessments (Cabinet Office, 2000/km). In addition, all departments are linked by a secure network with Internet gateways and paralleling NHSnet (Government Secure Intranet - GSI).

9.4.4. IM&T targets and strategic actions from 2002/3.

Targets and timetables.

The National Strategic Programme has adopted a four phase plan of firm activities until 2005 and tentative proposals to 2010. Social Services have areas of overlap as well as separate programmes. Relevant targets in both areas are summarised in Table 9.14).

The first year of NSP was vital (Phase 0). Mechanisms set with central government (Office for Government Commerce) were required to standardise funding procedures and validate contractors. A major programme was also launched to review data standards and set specifications for exchange compliant with the Office of the eEnvoy and eGovernment strategy (Updated Standards were not available from official online sources until late 2003 - see also chapter 10).

Responsibilities.

Ministers and senior civil servants were now in direct control. Strategic Health Authorities (StHAs) were intended to rationalise the old Local Implementation Strategies, including new support for Primary Care Trusts.

NHSIA would continue with major project management and critical national programmes. It would set criteria for selecting companies to deliver the computer packages for use by individual healthcare providers. In addition, NHSIA would oversee new or renewed contracts for networked services covering network upgrades, email, encryption as well as the information services for professionals and the public.

Likely next steps.

When NSP was launched, decisions had not been made on how to organise and fund future development. Choices range from total provision by the private sector to all arrangements made by individual hospitals and PCTs. Moreover, demonstrator sites considering electronic records had not formally reported and DoH had not identified any private company with sufficient management and product scalability for the whole NHS. Similar observations were made by DoH's Social Care Group (DoH, 2001/ifsc, Appendix 5C).

The most likely option for healthcare was "strategic outsourcing". Key infrastructure components would be delegated to the private sector under NHSIA guidance. An "application portfolio" of packages for use by individual healthcare providers (so far unspecified) would be restricted to products from validated companies or "consortia". StHA would control release of funds and monitor progress against new national standards (also unspecified).

Contacts in the healthcare IT industry suggest that a major new initiative is underway. Five major computer companies may be the key players, delegating some work to smaller, specialist organisations. The initiative is probably linked to the "Integrated Care Record Services" identified in 9.4.3. Additional funding levels and associations with DoH's investment strategy from 2000 to 2004 are unclear. Public announcements and timescales are apparently due in late 2003. (Media announcements about a major £2.3bn Government programme to computerise patient records, at least for emergency care, were made on 8th December 2003).

National Programme For Information Technology (NPFIT).

The "next steps" were formalized in a national programme, developed after release of NSP and explaining some of the unresolved issues raised above. Online details on the programme for England are available via the link given for the NPFIT entry in the Acronyms section (p440).

Table 9.9. Work Programmes within Delivery Areas from the NHS Information Authority. (Summarised from the NHSIA website "Delivery Areas" page in October 2003).

NB. The NHSIA's descriptions of its own work changed from 2002 to 2003, presumably to reflect the new *National Strategic Programme*. There are anomalies in the assignment of Work Programmes to Delivery Areas (adjusted here by HJL and shown by *), and no attempt to indicate broader inter-dependencies.

Main Delivery Areas.

	Title	Description
A.	Access to Information.	Telecommunications infrastructure.
B.	Knowledge Management.	Factual information services for professionals and the public (see also Table 9.13).
C.	Information for Organisations and Business.	Applications and network services for management information (nationally coordinated, locally applied).
D.	Population Health and Service Management Information.	Programmes and services for more detailed and local management information. (See also Figure 9.6 for details on Data Quality Accreditation).
E.	Information for Personal Health.	Programmes and services to manage data exchanged in direct patient care.
F.	National Health Informatics Development.	Recently re-launched programme (late 2002) to promote data management and IT skills.
G.	Standards and Services Support Programme.	National initiatives, general services and information sources to promote standards in a range of areas. (Overlaps with other Delivery Areas).

A. Access to Information.

Work Programme	Summary
Ambulance radio system	Digital upgrade.
NHSnet	Standards, risk management and contracts for the telecommunications infrastructure within UK healthcare known as "NHSnet". Re-branding as the New NHS Network (N3).

B. Knowledge Management.

Work Programme	Summary
National Electronic Library for Health (NeLH)	Information, mainly for professionals, developing with modules/floors for specialisms. Links to clinical guidelines, evidence on particular procedures (systematic reviews) and eJournals.
nhs.uk	Web portal to information about NHS organisations and performance (for public and professionals).

C.Information for Organisations and Business.

Work Programme	Summary
Audit	Services to check breast and Cervical Screening programmes against national standards.
NHAIS (The Exeter System)	Software suite to coordinate eg. commissioning contract payments, patient registration, cancer screening admin. Under re-design, particularly to support GP-hospital connections.
*NHS Strategic Tracing Service (NSTS)	New national database of people, places and organisations for many aspects of service and data coordination. (Close links to the New NHS Number programme).
*NHS-wide Clearing Service (NWCS)	Centrally coordinated electronic service for reporting patient activity data to commissioning organisations (payment system) and to DoH (monitoring). Data quality reports are also produced.

D. Population Health and Service Management Information.

Work Programme	Summary
Dataset Development Programme	Programme to support all nationally collected datasets. Emphasis on clinical data but early examples cover management data.
Data Quality, Accreditation and Classification.	Guidance on national and international coding systems (for epidemiology) with a Data Quality Accreditation process for local organisations.
Cancer	Coordinating portal on cancer initiatives including information strategy, datasets, patient referrals and registries.
Maternity Care Data Project	Portal to the programme including care process model and data dictionary.
Mental Health Information Strategy	Portal to the programme including documents from the national coordinating team, key projects and information sources.
Mental Health Minimum Dataset	Specific programme to introduce a minimum datast into all trusts by March 2003.
NSF Information Strategies	Support and coordination for all NSFs with links to other areas, particularly the Datasets Development Programme.
Casemix, The	Products and services for grouping patients and analysing data according to disease characteristics, resources used or benefits expected.
National Clinical Audit Support Programme (NCASP)	Recent initiative (2001) commissioned by the Centre for Health Improvement (CHI).

E. Information for Personal Health.

Work Programme	Summary
Caldicott and Confidentiality	Site reputedly under re-development (see the DoH site for guidance and toolkits).
Clinical Terminology Service	Support for all versions of the national system of terms and codes for electronic patient-based records (Read Codes) and presumably the new system (SNOMED-CT).
Clinical Communications	Projects aiming to bring up-to-date information on clinical messaging work.
Context of Care Project	Development of terms to put Read-Coded items into context (for interpretation and analysis).
Headings for Communicating Information	Developing a structure for clinical messages.
UK Clinical Products Reference Source (UKCPRS)	Addressing the absence of standards for describing medicines, appliances and medical devices. Coordination of new and comparable work (eg. Read Codes) for use in wider applications.
Electronic Records Development and Implementation Programme (ERDIP)	Central support for all organisations implementing electronic records (including earlier demonstrator sites).
GP to GP Communication Project	To overcome current problems of exchanging complete patient records between GP systems.

F. National Health Informatics Development.

Work Programme	Summary
NHID	Re-launch of various training and research initiatives to equip the whole NHS workforce with the skills to manage information and use IT systems.
*PRIMIS	Training and support services for IT in primary care (GPs).

G. Standards and Services Support Programme.

Work Programme	Summary
· Electronic Government Interoperability Framework (eGIF)	Support team guiding the NHS on compliance with eGovernment requirements for the public sector.
· NHS Information Standards Board (ISB)	NHSIA provides admin. support to the ISB Boards for appraising and approving standards and datasets (see main text and chapter 10).
· Data Standard	Nationally agreed and mandatory standards for patient-based data, published in the NHS Data Dictionary and Manual.
· Data Set Change Notices	Mechanism to inform local organisations of changes to data standards or sets.
· *Requirements For Accreditation (RFA)	Testing and accreditation programme for GP systems.
· RFA99 V1.2	Special changes in RFA to support primary care systems for re-structured healthcare (*Shifting The Balance Of Power*).
· National Accreditation and Procurement Process Service (NAPPS)	Recently established (2002) to accredit IT systems against nationally agreed requirements. (Assumed to focus on trust rather than GP systems).
· NHS Numbers for Babies	Part of a larger programme to introduce a specially designed numbering system across the UK for service and data coordination.
· Standards	Various websites providing information on requirements for system functionality and procurement.
· Tracking Database	Database for monitoring progress of organisations and regions on broad IT development (eg. connection to NHSnet).

Table 9.10. Main references introducing the Datasets Development Programme from the NHS Information Authority.

The references are a source of criticisms of current data collection process in the NHS in addition to providing background to the programme supporting the National Service Frameworks.

Title	Version	Reference
The National Dataset Development Programme. A Strategic Framework.	0.12	NHSIA (2002/ddp1)
Dataset Process Models.	0.2	NHSIA (2002/ddp2)
The National Dataset Development Programme Emerging Dataset Issues. Enabling the Derivation of ' Business' Information from Electronic Records.	0.5	NHSIA (2002/ddp3)
Standardised Clinical Datasets - Pre-Requisites to Successful Data Mining.	N/A	NHSIA (2002/ddp4)
Data Standards Programme. Generic Core Model.	1.0	NHSIA (2002/ddp5)

Table 9.11. Levels for Electronic Patient Records (EPRs) for the acute sector. (Identified in Information For Health and the Electronic Records Development and Implementation Programme (see eg. UK INI/NHSIA, 2001/ini1).

NB. Hospitals were originally expected to reach Level 3 by 2002/3.

Level	Functions
1	Clinical administrative data Patient administration and independent departmental systems
1+	Integrated patient master index, department systems
2	Integrated clinical diagnosis and treatment support
2+	Electronic clinical orders, results reporting, prescribing, multi-professional care pathways
3	Clinical activity support
3+	Electronic access to knowledge bases, embedded guidelines, rules, electronic alerts, expert system support
4	Clinical knowledge and decision support
4+	Special clinical modules, document imaging
5	Specialty specific support
5+	Telemedicine, other multi-media applications (e.g. picture archiving and communications systems)
6	Advanced multi-media and telematics

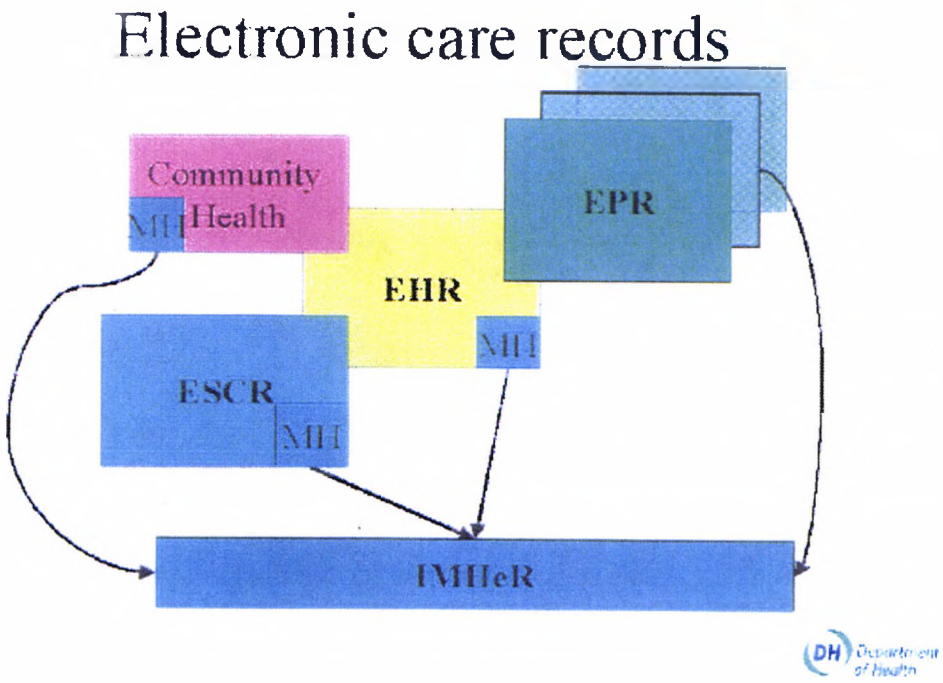


Figure 9.4. Schematic design for an Electronic Social Care Record (ESCR) (from DoH, 2001/ifsc).

Developments on ESCRs were limited in 2001. DoH therefore proposed the above generic scheme to illustrate a possible structure, and to highlight the different types and physical formats of data which should be considered.

Table 9.12. Components of the Integrated Care Record Service (ICRS) and principle of Regional Service Providers (RSP) (from PA Consulting, 2003, Glossary - document passed by NHSIA).

ICRS. *"The service by which a patient's record is to be delivered electronically to care professionals and to patients themselves, under the planned investments announced on 18 March 2001 by ... [the] Minister of State for Health".*

RSP. *"The private sector lead contractor that will be accountable for delivering ICRS in each [Strategic Health Authority - StHA] or cluster of StHAs".*
"The broad composition of [the] services is indicated by the [Table over leaf]".

HJL's comment. The "possible examples" can be assigned to several "components" in the official description below, suggesting problems with definition and identification of services which are apparently ready for implementation.

Service component	**Possible examples**
1. Access services	Basic connectivity
	Access to knowledge
	Access to patient demographics
	Access to clinical records
	Patient access
2. Specialist services	Rules-based decision support
	Telecare and tele-monitoring
	Digital imaging
3. Communication services	Referrals
	Discharge summaries
	Clinical correspondence
	Ordering
	Results reporting
	Prescribing/Dispensing
4. Integrated services	Shared clinical records
	Integrated care pathways
	Care assessment
	Care plans
	Multi-organisational scheduling
	Clinical governance
	Knowledge Management
	Resource management

Table 9.13. Official and recommended sources of online information in English healthcare at 2003.

A. NHS/Government sources.

National electronic Library for Health (NeLH)	Information on procedures, good practice and research primarily aimed at professionals. www.nelh.nhs.uk
National electronic Library for Social Care (NeLSC)	A developing equivalent to NeLH. www.nelsc.gov.uk
NHS.UK programme	Portal to information about organisations and performance for the public and professionals. www.nhs.uk
NHS Direct	Public information and advice on specific diseases, treatments or lifestyle issues. Progressively integrating with NHS.UK and Care Direct. www.nhsdirect.nhs.uk
Care Direct	Equivalent to NHS Direct with the focus on community and general support for older people. www.caredirect.gov.uk
Information for Carers	Database of information sources for family or friends supporting a long-term patient at home. DoH are currently (2003) negotiating commercial contracts to maintain the database. www.doh.gov.uk/carers
Patient Advice and Liaison Services (PALS)	Additional service for all patients in all hospitals. Announced in the *NHS Plan* and coordinated locally. Predominantly paper-based. www.doh.gov.uk/patientadviceandliaisonservices/index.htm (policy information only).

B. Additional, unofficial sources. (Selected from the "useful links" page on the Faculty of Public Health (FPH) website - via www.fph.org.uk).

BBC Health	Articles and advice on topical issues. www.bbc.co.uk/health
Healthsites UK	Portal to many of the UK's largest or frequently used sites. www.healthsites.co.uk/index.php3
Patient UK	General information and online access to some official leaflets. www.healthsites.co.uk/index.php3

NB. The FPH site also links to charities for the commoner diseases and major "killers".

Table 9.14. Timetables for delivering the Information Infrastructure and electronic services: in healthcare generally (from 2002) and social care (from 2001).

A. Timetable from the National Strategic Programme.

(DoH, 2002/nsp).

Phase 0 - April 2002 - March 2003 - Firm Scope	
Infrastructure	Define data standards Define interchange standards 100% Consultants with PCs
Application services	Create first stage National Health Record Service Agree XML based EPR System Specification
Implementation and Support	Work with OGC and e-Envoy to streamline procurement Begin increase of NHS IT capacity and capability
Phase 1 - April 2003 to December 2005 - Firm scope	
Infrastructure	Broadband access <>123kb) to every clinician & support staff in the NHS, increased bandwidth to minimum - 2Mbps between trusts and across NHS Net Gateways. Access and authentication available for all NHS staff
Implementation of National NHS Directory Service	Domain to domain encryption implemented
Application Services	National Bookings Service, implemented National Prescriptions service, 50% implemented All PCTs, NHS Trusts actively implementing elements of EPRs Full National Health Record Service implemented and accessible nationally for out of hours reference National Patient Record Analysis Service established for 100% of NHS transactions aterials through the NHS University
Quality Management	Establishment of a Faculty of Health Informatics in the NHS University Implementation of Gateway procedures for Information and IT projects
Implementation and Support	National IT services portfolio established StHA investment plans accepted (and funding agreed) by National Programme Director

A. Timetable from the National Strategic Programme, continued...

Phase 2 - January 2006 - December 2007 (Tentative scope)	
Infrastructure	Broadband access implemented at recommended access speeds across local and wide area networks in the NHS Secure access mechanisms (e.g Smartcards) for all NHS staff
Application Services	Full National Health Record Service, with core data and reference links to local EPR systems for full record access National Bookings Service, all patient appointments, implemented National Prescriptions Service, with full clinician and patient functionality, 100% implemented EPR (compliant with new National standard, XML-based specification) systems implemented in all PCTs and Hospitals Picture Archiving and Communications Systems for all acute Trusts Telemedicine established in all GP surgeries for ECG and skin disease Patient/Citizen Portal available via Internet, Digital TV, wireless devices Ambulance Telemonitoring implemented in 20% of all emergency response vehicles Ambulance radio replacement Home Telemonitoring available in 20% of homes requiring it Common clinical terms implemented for hospital and primary care National Knowledge Service fully established (???)
Phase 3 - January 2008 - December 2010 (Tentative scope)	
Miscellaneous	Ambulance Telemonitoring implemented in 100% of all emergency response vehicles Home Telemonitoring available in 100% of homes requiring it Unified Health Record (with all appropriate Social care information)

B. Timetable from Information For Social Care.

(DoH, 2001/ifsc) - NSP takes precedence in areas of overlap.

Date – quarter starting	Target	Indicator	Source
April 2001	Local IAG targets established	All targets set	IAG targets
	Information for Social Care demonstrator projects start (end June)		*Information for Social Care*
July 2001	Caldicott Guardians appointed in social services (9/01)	Named person	NHSIPU– Caldicott in Social Care
October 2001	Social Care information and IT strategy developed locally, by 1/10/01	Document produced and agreed at LIS and Council level	*Information for Social Care*
January 2002	Basic Caldicott audit (2/02)	Completed	NHSIPU – Caldicott in Social Care
	Information for Social Care demonstrator projects evaluated, and local impacts identified	Redrafted IT strategy. Checklist for each authority produced and sent to Dept of Health.	*Information for Social Care*
April 2002	Single health and social care assessment process Registration of social care workforce begins	For older people only initially Qualified social workers registered	NHS plan General Social Care Council
July 2002	Full Caldicott audit (8/02)	Completed	NHSIPU – Caldicott in Social Care
October 2002	Front line staff direct access to technology (email; internet; intranet; word processing) Seamless service	% staff, locally set	IAG targets
December 2002	ERDIP projects completedand evaluated		NHS IPU
January 2003	*Information for Social Care*	Revision published	Dept of Health
April 2003			
July 2003			
October 2003			
January 2004			
April 2004			
July 2004			
October 2004	Electronic Records Management	All new records have an electronic version – The ESCR is operational.	ERM guidelines
January 2005	*Information for Social Care*	Revision published	Dept of Health
April 2005			
July 2005			
October 2005	Front line staff direct system Access	100% staff	IAG targets

9.5. Particular problems with data quality.

The two previous sections have demonstrated demands for data and information, and the support available from IM&T strategies. This section now considers their combined consequences for data quality at national and local levels.

The summary begins with the strategies adopted by DoH. The following sub-sections address areas in more detail, using the Prominent Themes from Part 1 as headings to emphasise connections with the Studies from Part 1 of the Thesis.

9.5.1. Strategic issues.

The National Strategic Programme was the third main IM&T strategy for healthcare in four years. That fact, coupled to the new management approach and further announcements which are still awaited (on Integrated Care Records), was clearly a sign of concern at the top level over delivery on pledges and timetables.

Observations about the risks of a new strategy are open to interpretation as criticisms of past performance at all levels (DoH, 2002/nsp, Appendix 3):

- Changing policies and targets was associated with lack of leadership. and reduced interest from NHS organisations.

- Potentially poor prior analysis, consultation and planning were linked to escalating costs, disjointed product delivery and services without support staff or trained users.

Changing healthcare structures and other pressures on data.

Continuous re-organisation in the NHS was identified as a particular problem by DoH's Chief Inspector of Social Services (SSI, 2002). It also had immediate effects on data flows. Priority guidance was issued to IT managers to maintain existing electronic transfers. The payment system using Commissioning datasets was at particular risk during the transition, but several other datasets are transferred by this route or derived from electronic sources (eg. Health Episode Statistics).

At the same time, demands for data and information in electronic and paper formats have been generally increasing through a combination of policy pledges and legal requirements. In summary:

Local and national monitoring.

- Local prioritisation based on identified needs of individuals and groups (Primary Care Trust requirement for population monitoring).
- Local and national monitoring of errors coupled to improvement mechanisms (clinical governance requirement).

- National targeting of multi-disciplinary services for particular age groups or medical conditions (information strategies for National Service Frameworks).

- Reduced inequalities in provision and performance of services across the country (collection of indicator data for the Performance Assessment Frameworks).

Service access and coordination.

- Respect for all cultural and social groups (Modernising Government principle requiring evidence from monitoring).

- Organisation of services around individuals and families (Modernising Government principle requiring evidence from monitoring).

Broader access to data and information.

- Controlled access to personal data by the individual (Modernising Government and legal principle with implications for systems and patient support).

- Respect for individual confidentiality by professionals (Modernising Government and legal principle with implications for system designs).

- Open access to public information (Modernising Government principle with implications for system designs).

Growing demands for data in the mainstream NHS are also felt in the social care sector (DoH, 2001/ifsc, Appendix 2):

"The information agenda is being driven from several directions. It may feel as though local authorities are being swamped by demands for management information from a number of different agencies in response to the many initiatives currently being taken forward. There is a need for better co-ordination of these demands across government".

9.5.2. Prominent Theme 1. Datasets.

Population and public health.

The Inquiry into Inequalities in Health recommended "a review of data needs to improve the capacity to monitor inequalities in health and their determinants at a national and local level" (Atcheson, 1998). There are also several references to use of epidemiological data in official documents on service planning.

However, HJL has not identified a national epidemiological strategy for any condition or group. There are occaisional studies,but national and regular data collection appears to be substantially limited to patients already in "the system".

The interpretation of such data also raises problems. A recent report on casemix groupings in mental health, based on national returns, could be giving a misleading picture (NHSIA, 2003/phsmi). Data using only disease classifications were "poorly correlated with service need".

The R&D Strategy for Public Health highlighted the need for improved data, greater data sharing and new, multi-disciplinary methods for analysis (DoH, 2001/rdph). Consultation on Performance Indicators, by the Association of Public Health Observatories and the Health Development Agency, have only just finished (Jan-Mar 2003).

Service performance data.

There have been similar concerns over the interpretation of general Performance Indicators for individual organisations and related publication of league tables (note the

comments later in 9.5.6). Choice and definition of PIs are still evolving. Moreover, results are linked to future funding, increasing the pressure on managers.

9.5.3. Prominent Theme 2. Support for collection and management.

Characteristics of data in the field.

The NHS is officially described as "largely manually based" (NHSIA, 2002/ddp3). A number of fundamental constraints on existing record systems were also noted, with further implications for collection and limits on use (see references in Table 9.10):

- Many recordings, particularly in acute units, are still on paper only.
- Most clinicians do not record all data to support the care process.
- Many records are coarsely structured and use non-standard terms.
- Many official and nationally collected datasets are incomplete.
- Several versions of national datasets for NSFs have arisen.

Comparable problems were found with case records from a sample of seven Social Services Departments (SSI, 1999). The Social Care Inspectorate observed a "usually untidy mix" of paper and electronic sources and concluded that "there is a substantial management agenda to be tackled around case recording".

Confidentiality.

A major consultation with healthcare sectors and the public in late 2002 had not reported by summer 2003 (NHSIA, 2002/confid1). The Lord Chancellor's Office was still due to rule on use of NHS numbers outside the NHS as part of initiatives on mental health. More widely, the importance of appropriate confidentiality procedures were highlighted by: requirements for monitoring and research (DoH, 2001/rdph); increasing clinical data requests from police against NHS policies (NHSIA, 2003/confid2); and a prominent report into system failures in the care of vulnerable children (DFES, 2003).

Arguably, the basics are already in place through the Caldicott and legal principles (Tables 6.8 & 9.3). Reaching agreements over content, protocols and agencies involved in information sharing appears to be a persistent top level problem.

Staff training.

The NHSIA's programme for widespread preparation of all staff with modern skills began in the mid 1990s with the Education, Training and Development programme (ETD). It was revised as "Working With Information" (WOWI); and revised again in 1999 as "Learning To Manage Health Information" (LTMHI).

The most recent programme has itself been launched twice (NHSIA 1999/ltmhi1, 2002/ltmhi2). he first LTMHI document noted that existing healthcare professionals were the least likely to have modern skills and new trainees were unlikely to have appropriate manual or computer systems in their hospitals to reinforce training. The second document was effectively a relaunch of the programme because management of health information had not been "embedded" in the curricula of most relevant educational organisations.

9.5.4. Prominent Theme 3. Information for patients.

The NHS Performance Assessment Framework has a category for "Patient Experience". This includes information provision but no relevant indicators were involved in the 1999 specifications (Figure 9.2).

"Lessons learned" from the ERDIP demonstrator sites showed the significance of patient information (Table 9.15). A genuine need for information was identified but currently limited by missing standards for content, preparation, coordination and provision.

Early consultation for the NSF targeting long-term conditions also emphasised information for patients and carers (DoH, 2002/nsfltc). They suggested "kite-marked websites to ensure that the information available reflects usual opinion [with] links to voluntary organisations' websites (also kite-marked)". Again, criteria were not specified.

It is Government policy for patients to have greater access to their own medical records. The new SNOMED-CT system of terms and codes for electronic records also acknowledges increased patient involvement in care (CAP, 2002). However, there are no links to layman's descriptions of technical terms. Similarly, the meta-data standard for classifying information resources (eGMS) has yet to be developed and applied widely in healthcare.

9.5.5. Prominent Theme 4. Support from technology.

Data collection and exchange.

Fundamentally, IT systems are not widely used in front line hospital care or in the community by services allied to medicine. They are prominent in GP surgeries, but they use different versions of the mandatory system of terms and codes (Read Codes) and a

new version is now in place (SNOMED-CT). There is also no mechanism for exchanging electronic records when patients re-locate (now an NHSIA project).

System design problems are further compounded by interoperability requirements (eGIF). In autumn 2002, standards for defining exchangeable data using the prescribed language (XML) were limited to household addresses and financial fields for online council and income tax returns.

The area was a priority for the first year of NSP. eGIF version 5 (April 2003) shows that the international system for healthcare messaging (Health Level 7 - HL7) had been recommended for approval by the Office of the eEnvoy. NHSIA circulars also indicate that updates to the NHS Data Dictionary should be in place, behind schedule, by autumn 2003 (see chapter 10 for online addresses).

Moreover, there is no clear strategy for transition from paper to electronic systems. The ERDIP demonstrator sites, for example, talked of the "switch". However, the Visual Impairment Notification project (chapter 6) asked NHSIA how paper and electronic forms might run in parallel with electronic signatures and provision for patients. The answer was "good question" with no further feedback.

In general, targets for the introduction of electronic records and services supported by data standards are subtly moving backwards. Note, as a significant example, that the NHS Plan covers ten years from 2000, while the original "Information For Health" strategy considered only the period to 2007. (The ten year timescale was actually first introduced by the "New NHS" document in 1997).

Information provision.

Websites were widely acknowledged as a potential vehicle for provision in 9.5.4. In addition to lack of general standards, it is noticeable that none of the ERDIP demonstrator sites used or commented on NHS or Care Direct.

Equally, RNIB's campaign for good designs for web and other digital media has targeted online businesses but not healthcare (www.rnib.org.uk/digital). It has also given little publicity to web technologies that allow material to be converted into alternative formats for use at home and away from computers (possibly a relevant consideration for most disabled or older people).

A belated focus on cultural and organisational change.

Such issues are fundamental to the Government's plans for widespread use of IT. They were raised as "formidable challenges" in the first main IM&T strategy. However, the topics have only recently been adopted for direct research in the NHS.

Two scoping studies have been launched by the NHS Service Development and Organisation (SDO) programme coordinated by the London School of Hygiene and Tropical Medicine. The first seeks a "conceptual map" of eHealth technologies and issues surrounding development and adoption (NHSSDO, 2003a).

The second is a consultation with stakeholders addressing more immediately practical barriers to uptake by healthcare providers (NHSSDO, 2003b). Both studies are intended to guide future R&D in the area and have nine months from September 2003 to deliver.

9.5.6. Prominent Theme 5. Costs of data collection and information provision.

Although the NHS Information Standards Board requires evidence of cost-effectiveness for all nationally collected datasets, there are indications that DoH has not followed its own principles. NHSIA reported that an opportunity had arisen to examine the issues for the first time using a subset of the Chronic Heart Disease NSF dataset (NHSIA, 2002/ddp3). The situation probably resulted from medical and public debate over hospital league tables published around 2000 and based on crude mortality figures.

The need for additional staff to collate paper records was acknowledged before NHSIA stated that:

"The Department of Health has committed to the collection and publication of cardiac surgery audit data in 2003. ... it will [then] be possible to provide an estimate of the overall cost to the NHS of adopting, collecting and publishing these data".

Costs of providing information to patients are similarly unclear. Funding for NHS Direct, as an example, appears to be subsumed within other budgets in the DoH investment strategy (DoH, 2000/dis) with no financial details in the annual report (NHS Direct, 2002).

NHS Direct depends heavily on major charities as information sources. Budgets with the relevant detail from these organisations have also not been identified by HJL.

Table 9.15. Lessons learned about patient information from the Electronic Record Development and Implementation Programme (ERDIP) demonstrator sites.

The NHS Information Authority pooled all reports on and from 16 demonstrator sites into a "lessons learned" database for further research. The Table below reproduces an initial, summarising report on Patient Information (NHSIA, 2003/erdipll1, Section 7) with some re-grouping of quotes by HJL.

Note: patient information was not considered by all sites; it was not covered by evaluation standards; evaluation itself was not addressed by ERDIP managers until well after sites had begun (see UKIHI, 2001).

Lesson learned/Issue	Comment from report	Source
Role of information	The quality of information is vitally important.	Wirral cancer literature review
	Information is an essential part of patient care and can enhance patient experience. Receiving the right information, at the right time, in the right way' makes a significant difference to patients and their families.	Wirral cancer literature review
	Patients and carers often want different information at different stages in the patient's care. Research results across studies and countries are consistent. Not all clinicians are aware of these findings.	Wirral closure report
General patient views on patient information.	Large numbers of cancer patients are dissatisfied with the information they are offered. The vast majority of patients want a great deal of specific information at all stages of their care. Patients want to be offered information rather than to ask, and to be directed to other sources of additional information. Information giving should be an ongoing process beginning before diagnosis and continuing well after treatment is complete. Flexible policies should assess/check information needs directly with patients throughout cancer care.	Wirral cancer literature review

Lesson learned/Issue	Comment from report	Source
Research evidence base	Evidence bases for patient information provision do not exist, other than in this project. Evidence bases are appropriate to any/all delivery media. Locally, there is a partial match between the evidence base and information currently available for web publication. An evidence base facilitates gap analysis and future planning.	Wirral closure report
	The NHS should consider funding the development of patient information evidence bases from the international literature, for other clinical conditions. Evidence can be updated and made more specific through local research.	Wirral closure report
Physical format	Written information is the predominant medium for patient information. The research is clear that written information is chaotic, fragmented, uncoordinated and unregulated. Written information is rarely produced to identified and published standards either locally or nationally.	Wirral closure report
	Written information provided to patients should be evaluated or withdrawn. It should be sought/produced and disseminated to agreed standards.	Wirral cancer literature review
	The electronic medium is suited to providing information tailored to an individual's requirement, including their timetable.	Wirral closure report
	Online patient information resources are globally accessible. Demand is increasing. There is vast self- help potential. Patients online want information through interactivity.	Wirral cancer literature review

Lesson learned/Issue	Comment from report	Source
Additional coordination	Implementation of [preparation and distribution to agreed standards] is a huge task. The appointment of an information lead/coordinator has been found helpful.	Wirral cancer literature review
	Bringing together information sources from outside the local area, such as leaflets etc, permissions need to be sought before including them within a web site, this needs to be done earlier on in the gathering of the information rather than at the implementation phase. Web sites need to be advertised, especially when offering specific information on subjects such as cancers , potential users need to be pointed towards these local sources of information.	Wirral closure report
	The Information Support Worker project has confirmed the value of accessible and relevant information to both patients and professionals [in primary care]... ... The evaluation identified the most frequent reasons for patients accessing the service were to receive information or advice about: welfare rights; benefits; social contact and community care. The most frequent users of the service were women living alone over the age of74. This indicates that, within the population served by Bury Knowle Health Centre, this age group needs to be targeted as potential 'under-claimers' of benefits	Bury Knowle Information Support Worker Project
	The NHS should consider introducing a set of standards for production/purchase of patient information (e.g. DISCERN, Plain English, the standards of the Royal National Institute for the Blind, the Flesch readability index, as well as adhering to patient's stated needs).	Wirral closure report

9.6. Contributions from the review to the Data Quality Framework.

The main review closes by highlighting national features which any Data Quality Framework targeting English healthcare should address.

Constraints.

The necessary "information infrastructure" to deliver an electronic healthcare system is not yet in place. Progress on the National Strategic Programme should be monitored along with developments from the national staff training programme (Learning To Manage Health Information - LTMHI) and findings from the scoping studies into eHealth from the System Delivery and Organisation (SDO) initiative.

Good practices.

General principles for data collection and use, in both paper and electronic formats, are set out in the Caldicott Report and the 1998 Data Protection Act (see Tables 6.8 and 9.3). "Reasonable adjustment" for information access by people with special needs is the legal test under the 1995 Disability Discrimination Act. Other good practice standards relating to data are maintain by professional bodies in health and social care (listed in NHSIA, 1999/ltmhi, Appendix).

Toolkits.

Assessment guides for information sharing projects are available from the Caldicott Guardians' website. "Information For Social Care" (DoH, 2001/ifsc) gives an information triangle and information matrices to help system designers identify sources and recipients of both data and public information. In addition, "Recording With Care" contains basic requirements and audit tools for recording individual case notes on social aspects (SSI, 1999).

Specific technologies.

Computers should be used where available and appropriate. The standards are set by the eGovernment Interoperability Framework (eGIF); with compatible data specification for use in any project provided in the NHS Data Dictionary; and whole system specifications set by the NHS Information Authority.

Relevant national initiatives.

1). Assessing practicalities and costs of data collection.

These issues, along with a general Business Case, are stated considerations in the new appraisal and approval process for all significant datasets from the NHS Information Standards Board.

2). Care process modelling.

The NHS Information Authority has a programme in this area, supporting clinical datasets to achieve ISB approval. In principle, process models identify data sources and flows. Logically, points for information provision may also be included.

3). Accredited sources of patient information.

The Department of health now has an accreditation process for all organisations involved in research (part of the Research Governance Framework). Similar principles may be applied to organisations providing patient information.

4). Standards for specifying information.

In addition to standards for general systems and data, eGIF from the Office of the eEnvoy includes developing terms for classifying information resources for storage and retrieval (eGovernment Meta-data Standard - eGMS). Refinements may be developed for healthcare applications.

9.7. Conclusion.

This chapter reviewed policies affecting data and information in English healthcare, and the support delivered by strategies for Information Management and Technology (IM&T). Healthcare is still largely a paper-based system. The necessary information infrastructure of technologies and trained staff is not yet in place to produce widespread improvements in data quality.

Nevertheless, there are good practices in data management set by guidelines and the law. Appropriate technologies are specified for the whole public sector; and some central initiatives are addressing issues paralleling the Prominent Themes identified in Part 1 of the Thesis. All these features are incorporated into the Data Quality Framework developed in the next chapter.

Annex to chapter 9

Accreditation Process for data quality in the NHS

Information sources (2003).

- Data Quality home page from the NHS Information Authority (NHSIA). (www.nhsia.nhs.uk/dataquality/pages/default.asp).
- Accreditation Process (www.nhsia.nhs.uk/dataquality/pages/accredit.asp).
- Data Accreditation Web News (DAWN - newsletter). (www.nhsia.nhs.uk/dataquality/pages/dawn.asp).

Background.

The need to improve data quality was acknowledged in the first two IM&T strategies ("Information For Health" and "Building the Information Core") and in local implementation strategies (LIS). The Accreditation Process was the result.

However, it is limited to contents of the main management databases within care organisations (Patient Administration System - PAS - and Patient Master Index - PMI) and procedures to collate information for those databases.

The process was developed for acute trusts and is being adapted for other sectors. It is administered by the NHS Information Authority (NHSIA) who verify external auditors (individuals) and award levels of Accreditation to organisations.

Required evidence for audit includes: documentation specifying and supporting procedures; staff interviews; and analyses of samples from the databases.

The three stage process.

Stage 1. Checklist review.

A "high level scrutiny of basic activities which every organisation should be able to complete". It is a simplified version of the later stages for internal use.

Stage 2. Review of management processes.

A "more detailed examination of a hospital's [organisation's] main systems and administrative arrangements".

An internal and external review of (7 components):

- Security and confidentiality
- Coverage.
- Validation and quality assurance.
- Training.
- Communications.
- Accountability.
- Health Records Management.

Stage 3. Review of data outputs.

This stage is currently under revision (late 2003). It "looks in detail at the data generated to support particular areas of the provider's operations". Four "data groups" should ultimately be reviewed (admitted patient care, outpatients, waiting list management, and patients' charter [[performance data relating to service pledges in the NHS Plan]).

A sample of one month's data is analysed; other organisations who usually receive "outputs" from the provider are formally contacted.

The internal and external reviews and analyses cover (3 components):

- Timeliness.
- Completeness and validity.
- Accuracy.

Resources required.

- A steering group of senior managers.
- A lead reviewer.
- An internal review team.
- Funding for expert assistance and external audits.

- Approx. 300 hours of staff time for Stage 1 and the internal review phases of Stages 2 and 3.
- Approx. 12 days for external audit of a single data group or 27 days for all 4 data groups.

Timings and costs depend on the size and complexity of the provider organisation; the number of data groups addressed; and corrective actions recommended before Accreditation is granted. Accreditations at given levels last for three years unless there are changes to the structure of the organisation or introduction of new computer systems.

Mandatory requirements and uses of accreditation

Activities towards Accreditation are mandatory; full Accreditation requires successful completion of all three Stages. Level of Accreditation achieved by care providers is increasingly incorporated into commissioning contracts and a developing High Level Performance Indicator (HLPI) for data quality.

All organisations should have achieved Stage 1 by 2001. Acute trusts should have passed Stage 2 by 2002.

Chapter 10
Development and presentation of a Data Quality Framework

10.1. Introduction.

A Data Quality Framework (DQF) aims to diagnose and remedy issues in English healthcare covered by the Prominent Themes from chapter 7. It should also acknowledge the national findings from chapter 9, demonstrating policies for greater use of IT But limited by a care delivery system still largely based on paper records.

The approach to development in this chapter draws on four central initiatives addressing issues comparable to the Prominent Themes. The DQF itself is presented as a unifying summary in the last section.

Organisation of the chapter

Section 10.2. The first central initiative sets appraisal and approval criteria for collection of any significant dataset within the NHS. Mechanisms are overseen by the NHS Information Standards Board (ISB).

Section 10.3. The second, and related initiative is administered by the NHS Information Authority. They support major dataset projects to achieve ISB approval through a common approach to project management, and a focus on modelling healthcare

processes as the source of most raw data. Process modelling may also identify points for providing information to patients.

Section 10.4. Accreditation of organisations providing patient information is an extension of an initiative from a related area. Organisations involved in NHS research at all levels must now be formally assessed under the Research Governance Framework. Similar principles may be applied to information providers.

Section 10.5. The Office of the eEnvoy (OeE) is responsible for the final initiative. It sets the standards which should be adopted across the public sector to make information access easier. Provision for those with special communication needs is an additional goal dependent largely on developing technology and widespread uptake.

Section 10.6. A cross reference summary of previous material from the chapter is followed by the formal Data Quality Framework. DQF Part 1 provides questions for assessing existing datasets, collection procedures and provision of patient information (the Appraisal Tool). DQF Part 2 comprises the stages for introducing change (the Implementation Programme).
Separate Appendices to the main Thesis provide details on two technologies common to all the central initiatives. The technologies are mandated for use in the public sector under the eGovernment Interoperability Framework (eGIF). Explanation of presentation conventions support the Figures in this chapter and online examples from Government and NHS sources.

Appendix 4 Includes details on the eXtensible Markup Language (XML) - a web technology specifically for specifying data (and information) for collection, exchange and presentation in different formats.

Appendix 5 covers the Unified Modeling Language (UML) - a diagramming technique for summarising the structure of processes or components of a dataset.

General comment

The DQF is neither dependent on technology nor tied to any scale for application. These potential constraints of all the central initiatives are explicitly removed. However, the DQF does emphasise technology as a means for validating data and accessing information resources.

10.2. Appraisal and approval mechanisms from the Information Standards Board (ISB).

10.2.1. Background.

ISB has responsibility for information standards in the NHS and areas of overlap with Social Services. It is answerable to DoH's National Information Policy Board as well as boards for information management across the public sector. In 1999, it replaced existing structures for regulating information requirements. Sub boards cover clinical, management and technological standards. References to recent ISB work used in this chapter are given in Table 10.1.

Distinction between Information and Data Standards is arbitrary. ISB is interested in the standards achieved at the end of collection procedures (data outputs) such as diagnostic classifications. However, Information Standards must be used in practice. With the exceptions of large and generic systems of standards (eg. eGIF), most Information Standards are actually examined through application to real datasets.

Material in this section provides the DQF with general principles for evaluating datasets and collection processes. Adjustments allow applications on the local as well as national scale.

10.2.2. Recent changes.

New ISB mechanisms were established and modified in response to further observations from the IT community. Aims of the previous IM&T strategies did not map to Information Standards in all cases. New technological standards for the public sector were also being imposed. Overall, a structure or classification for organising and developing Information Standards in the NHS was not in place.

Consultations began around 2001 proposing a 4 level hierarchy of Standards (Table 10.2). It distinguished overarching structures, specific classes and operational detail. Areas for new or changed Standards might then be mapped and developed consistently at the appropriate level.

All significant datasets should use Standards from the NHS Data Dictionary, or specifically address omissions. Review of existing Information Standards, with updates to the Dictionary, formed part of the third IT strategy for healthcare (National Strategic Programme - Phase 0).

The Dictionary and ISB standards database were taken offline during the review period, and had not been reinstated at early 2003. For reference, specifications will use the diagramming and formulation techniques covered by Appendices 4&5 (XML and UML).

10.2.3. Appraisal and approval procedures.

The ISB consultation process was accompanied by updated appraisal and approval mechanisms. New or changed Standards may follow an "order or command" from ministers or senior DoH/NHS staff. Others may be requested or developed by individual NHS organisations with higher clinical or policy bodies as initial sponsors.

There are requirements to show practicalities and costs of collection. Implications from the ISB literature suggest that updating existing electronic systems is the main concern. This Thesis indicates that implications of existing paper record systems should also be included.

Approval follows four stages. Each has a set of questions (appraisal tool) which must be met before approval is granted at the given stage. Particular features, shown in brackets below, are detailed in Table 10.3.

Requirement Appraisal.

a.If there is no central "order or command", confirm and specify the need for a new or changed Standard (the Business Case).

b. Determine whether any existing or developed Standards exist; and why 1 of them should/should not be implemented (Option Assessment).

c. Provide initial, funded plan to move towards Draft Standard approval (Development/Implementation Plan).

Draft Standard Appraisal.

a. Guidance for local use of a Standard should cover technical sspecifications, human and organisational factors (Implementation Guidance).

b. Provide evidence of successful implementation of the Standard in at least 1 typical setting (Evidence from Field Testing).

c. Provide funded plan to move towards Full Standard approval (Development/Implementation Plan).

Full Standard Appraisal.

a. Provide evidence of successful implementation in at least 3 representative settings (Evidence from Field Testing).

b. Update Guidance and Implementation Plans for widespread adoption (Implementation Guidance).

Reviewed Standard.

a. A Standard will be reviewed when it reaches 75% penetration of the market and/or every 5 years.

b. Earlier reviews may follow strong suggestions of harm to patients, or a request from ministers/Senior NHS/DoH staff (Evidence Sources for Reviewing an Established Standard or Practice).

Table 10.1. References to recent (2001/2) documentation from the NHS Information Standards Board, and online sources on Information/Data standards in the NHS.

A. Appraisal and approval process documents.

NB. Documents are "controlled" versions. More recent editions take precedence.

Source web address (2002/3)

http://www.isb.nhs.uk/pages/process/help.asp

Documents.

Category	Title	Version	Issue date
Background	Strategic Standards. Consultation Document	1.4	4.3.02
	Standards Hierarchy. Discussion Document.	0.3	4.3.02
Appraisal Tools	Requirement Appraisal Tool	3.0	12.01
	Draft Standard Appraisal Tool	3.0	8.02
	Standard Appraisal Tool	3.0	8.02
	Reviewed Standard Appraisal Tool	3.1	8.02
Content guidelines for submissions	Requirement submission - content guidance	1.0	12.01
	Draft Standard - content guidance	2.0	8.02
	Standard - content guidance	2.0	8.02
	Reviewed Standard - content guidance	2.0	8.02

B. Online references to standards specifications for the NHS (in 2003).

ISB Standards Database

http://www.isb.nhs.uk/pages/datbase/indexnew.asp

NHS Data Dictionary & Manual

http://www.nhsia.nhs.uk/datastandards/pages/ddm/index.htm

Table 10.2. Hierarchy of Information Standards for the NHS, proposed by the Information Standards Board (ISB, 2001/ishier).

Level	Title	Outline definition	Examples
1	Framework	High level, overarching structure from which standards at other levels can be derived and developed.	eGovernment Interoperability Framework (eGIF). Health Level 7 (HL7) (developing international standard for clinical communications).
2	Fundamental Standard	A standard that encompasses many distinct areas and may have multiple specific applications (instantiations).	Extensible Markup Language (XML) Version 1.0. ICD 10 (WHO's International Classification of Diseases, Injuries and Health Related Problems). OPCS 4 (former Office of Population Censuses & Surverys' classification of medical and surgical procedures).
3	Specific/Operational Standard	Detailed and precisely defined standard for operational use within specific areas of the NHS and Social Services.	Specific XML implementation (schema) for a clinical message
4	Entity	Component level item contributing to a given (or set of) Specific/Operational standard(s).	Name, address

Notes

1.	There are expected to be a restricted set of frameworks covering · System interoperability · Clinical messages · Security · (Possibly) record structures
2.	Frameworks must be compatible with each other.
3.	Fundamental standards can be derived from Frameworks, but not all standards contained within a Framework are necessarily applicable to the NHS (eg. eGIF). Elements relevant to NHS from such wider Frameworks should be examined and made explicit.
4.	Some Frameworks may be incomplete for deriving Fundamental Standards for the NHS. Judgements are required on adoption of components from other sources while maintaining compatibility with existing NHS Frameworks.
5.	Changes at the Entity level mustt be handled by changes at the Specific/Operational Standard level (structural inheritance).

Table 10.3. Features involved in the 4 stage appraisal and approval process from the Information Standards Bord. (Derived and extended from documents identified in Table 10.1).

NB. Distribution of items between components may vary in practice.

A. The Business Case.

Purpose & scope	**Risks & benefits**
Overview of the current position. Functional description of the proposed standard in use. Number and types of organisations affected.	Benefits/disadvantages to patients, staff, Trusts, the NHS and the Government. Risks of not proceeding with change.
Stakeholder consultation	**Change management**
Level and nature of support from the NHS, Social Services, suppliers and patient groups likely to be affected. Evidence of confirmed support from the sponsors/endorsers.	Review of time pressures. Replacement of existing standards including migration issues. Review of service reorganisations.
Policy compliance	**Costs & funding arrangements**
Strategic fit. Operational fit (eg. service delivery, performance assessment).	Detailed analysis at the local, national and supplier levels.

B. Option Assessment.

Potential standard	**Impact assessments (local and national)**
Candidate from an international organisation with implementation evidence relevant to the UK. Candidate from a UK organisation with implementation evidence.	Person days involved in data collection. Skill mix changes in organisations. Implications for undergraduate / postgraduate education and development. Costs.
Dependence on other standards	**Dependence on other work/projects**
Existing technology standards (eg. eGIF). Professional practice standards. Security and confidentiality policy and practice. British Law. Other UK standards.	Development work required. Connections with similar or related programmes.

Detailed description of selected or required standard

Targeted care process, organisation type or patient group(s).
Technical specifications.
User knowledge and skills required.

C. Development/Implementation Plan.

General administration at the given Appraisal stage	**Local assistance with implementation**
Identified people/organisations with overall responsibility for the Plan. Scale of implementation. Timescales. Funding and budgets.	Technology, training and realtime support. Advice/sraff for service reorganisations.
Communications	**Use of evaluation**
Agent (person/organisation) responsible for communications on each Plan sub-component. Communication with organisations implementing the Standard. Communication with system suppliers. Design and feedback of Conformance and Performance testing.	Incorporation of Conformance and Performance results and academic evaluations into Specifications and Guidance. Continued evaluation and feedback after the Appraisal stage.

D. Implementation Guidance.

Technical setup and support	**Data management**
Integration with existing systems. Provision of supporting staff and services.	Method and frequency of collection. Processing. Quality assurance.
Change management	
Staff training. Staff contractual issues. Organisational changes. Cultural issues.	

E. Evidence from Field Testing.

Conformance	Performance
Compliance of site implementations with specifications (structure & process). Compliance of resulting datasets with standards for content and format (output).	Staff time in collection. Impact on direct and indirect care. Total and component costs

F. Evidence Sources for Reviewing an Established Standard or Practice.

Original Business Cases and Approvals at each stage. Current Conformance and Performance testing. Site/Implementation feedback. Academic evaluations in research journals. Collection of publications and actions resulting directly or indirectly from use of the Standard. Complaints and the Health Ombudsman's Reports. Feedback via the Standards Board website. Direct consultation with users, patients and system suppliers.

10.3. Care and data modelling in the National Datasets Development Programme (NDDP) from the NHS Information Authority (NHSIA).

10.3.1. Background.

NDDP complements the ISB approval process by supporting major clinical datasets. Management and modelling resources are provided for projects covering National Service Frameworks, commissioning subsets and practice based registers. Table 10.4 identifies source references for this section and links to online project illustrations (using UML & XML techniques).

A relatively simple principle has been adopted by NDDP. Items in a dataset should map to raw data available through specific activities that form the healthcare process. The results should be general, with no representation of care organisation or data management systems from any particular NHS site.

This section provides the DQF with methods for modelling healthcare processes and assigning data to care activities. Adjustments remove current constraints on NDDP projects. Consequences of paper records are now also considered (data locations, formats and processing costs), as well as comparison of collection practices between organisations.

10.3.2. Project management.

PRINCE 2 is the recommended methodology - PRojects IN Controlled Environments - (Bentley, 1997). It is a Government standard, widely used by NHSIA. Version 2 removed strict references to IT to make PRINCE applicable to projects generally.

A common project structure from the NDDP (figure 10.1) includes a formal Project Board with one or more Project Teams and Working Groups. An External Reference Group. covering domain experts from all relevant fields and stakeholders encompassed by the project, should also be established.

Project initiation documents comprise the Business Case along with formal role definitions and terms of reference for project groups. Formal and informal lines of progress reporting should be in place. Compliance with the "Framework for research in health and social care" (DoH, 2001/rf) is not stated by NHSIA. However, it highlights rights and responsibilities of all parties including patients.

10.3.3. Healthcare process modelling.

NHSIA and its predecessor (Information Management Group) have been modelling processes and data in healthcare since at least 1990. However, early results such as the "Common Basic Specification" were "not understood by the NHS" and "ignored by industry" (IMG, 1995). There is now greater interest because of national datasets and IT promotion by the Government.

Principles of modelling are common to most projects. Techniques and results from current projects are, in fact, simpllified sub-sets of the current full model specification (the NHS "Health Care Model"). Material is regularly updated and extended, with versions available at:

http://www.standards.nhsia.nhs.uk/hcm

Dataset modelling principles.

Answers to 5 initial questions guide model design and development:

Scope. What part of the world (process) is to be described?

Realisation. Is a recommended (ideal) or existing (actual) process to be modelled?

Breakdown Basis. What principles will be used to decompose the process into activities?

Model Type. What should be related to the activities?

Granularity. How detailed should the process breakdown be?

NDDP models for datasets focus on data sources (Model Type) in the care delivery process for a given condition or population group (Scope). Only ideal cases are considered (Realisation) because of the decision to ignore real life practices.

Model uses.

Several Component Models may be required for a full Process Model representing different views of healthcare delivery. The NDDP gives 3 main uses. Additions, specifically for the DQF, remove constraints of adopting the "ideal" view of a healthcare process.

Validation. Confirming the availability of items from a given dataset in the care process.

Derivation. Identification of data in the care process that may form part of a formal dataset.

Co-development. Parallel development of processes and supporting datasets for new or changed forms of care delivery.

Comparison. Comparing data collection procedures between different organisations (Realisation = actual; Model Types = data locations and formats).

Costing. Assigning costs to components of data collection (Realisation = actual; Model Types = data locations and formats, staff numbers and time).

10.3.4. Identifying and decomposing healthcare activities.

The NDDP advocates combined use of 2 techniques. The first is a generic approach with the focus on general activities as the source of data. The second is specific to healthcare with the emphasis on clinical intentions. It may identify activities missed by the generic approach, and provide more meaningful or clinically related terms for the final model components.

NHS Provide Patient Care model.

Most processes in the service and manufacturing sectors are assumed to divide into activities common to the particular domain. NHSIA's previous work has identified 6 activities/sub-activities relevant to healthcare. The activity sequence may apply once for a single episode of care, or be repeated for patients with chronic disorders. Figure 10.2 shows the top level model, where the 6 activities summarise as:

A. Initiate care.
By a patient, carer, bystander, or clinician.

B. Establish basis for care.
Do any interventions, tests, investigations.

C. Create/revise care plan with patient & carer(s).
Seek and provide information.
Give advice, support, education or training.
Explore the issue with the patient & records, & agree care goals.

D. Organise care activities for patient(s).

Arrange future care, including appointments, referrals & investigations.

E. Perform care activities for patient(s).

F. End care provision.
Because encounter has ended, issue is resolved, patient has died, or no more can be done

The activities A-F define a single model (note the inclusion of "information provision" in the official NHS version). Each activity may be broken down further to form another model with comparable activities at a lower level (sub-activities).

Care Paradigms.

Paradigms provide a conceptual breakdown specifically of healthcare processes. Four major examples are reproduced as model diagrams (Figure 10.3) and summarise as:

Screening. Early identification of pathology/risk factors to reduce adverse events.

Maternity care. A special case of continual screening and resource provision for a natural biological process effectively involving 2 patients.

Management. Repeated actions for conditions with no known cure. Variants include palliative care, and risk reduction even when symptoms are absent.

Resolution. Treatment leading to cure or acceptable improvement, though timescales may vary for given conditions.

Several paradigms may be required to describe all features of a care process. Detail is added to individual paradigms by partition into Phases according to clinical sub-intentions.

10.3.5. Identifying data relating to activities and preparing datasets.

Data assigned to activities depend on the model use. In general, datasets on current NDDP programmes aim to describe clinical states and record professional actions (eg. for National Service Frameworks).

The more direct goal is to map dataset items to source data used or generated by care activities. In turn, the activities provide the contexts for data collection and therefore a means to structure dataset items for presentation and analysis. The dataset and the method of partitioning are combined in the term "logical dataset".

Data may be identified by field studies or expert opinion. The NDDP highlights data and data types of particular importance in dataset work by using "Templates for actions and patient observations" (Figure 10.4).

Some projects have developed their own data specifications to complement and expand the NHS Data Dictionary. Specifications for data location and format would be examples for any project using the DQF from this Thesis.

10.3.6. Data validation.

Validation is not explicitly covered by the NDDP recommendations, but requires technology for large data volumes. Computerised collection can support users with help screens, error checking and additional processing.

XML technology provides a more general approach. It allows datasets and validation criteria to be specified for use in systems with or without XML features. XML applications can use the specifications directly.

"XML-enabled" programs store the collected or source data in plain XML files. Data specifications are provided in XML Schema. Mechanisms allow one to be checked against the other.

Browsers such as Internet Explorer 6.0 and later are XML enabled. It is part of the XML specification that applications should halt and issue error messages if a Schema has been specified and data inconsistencies found.

10.3.7. The resulting steps for model building.

The NDDP recommends a common sequence. Details depend on original project objectives and choices from the 5 model uses. These factors are described in the steps below as decisions based on the "source material", and introduce variations primarily at the Initial Development step.

Step 3, for identifying source data, includes changes specifically for the DQF. Moreover, Step 4 has been added to linke a care process model to information provision for patients. Details follow in a later section on describing information resources (10.5).

1). Initial Development.

a. Formalise project objectives according to the level of detail available from the source material.

b. Establish major clinical states, activities and general features of the care process described by the source material.

c. Determine the initial number, scope and granularity of Component Models required for a full Process Model reflecting the source material.

Repeat stages 2-5 for each Component Model.

2). Initial Model.

a. Build initial model from output of 1 using the NHS Provide Patient Care Model.

b. Refine the activities and activity lables in the model using Care Paradigms.

3). Addition of Source Data.

a. Add source data to activities using the source material, expert opinion and NHS Healthcare Model class templates.

b. Expand and refine the model to achieve the appropriate granularity for mappings between activities/source data and dataset items.

c. Specify the locations of source data.

d. Compare source data and dataset formats using the NHS Data Dictionary and/or other dictionaries prepared by the project.

e. Specify the rules for validating the dataset items.

f. Confirm that the purpose and technical interpretation of shared data are understood by all relevant parties.

4). Patient Information Provision.

a. Identify points in the care process for information provision,

b. Specify the nature, format and source of required information.

c. If appropriate, expand the Component Model with specific activities for information provision and recommended information sources.

5). Quality Assurance.

a. Submit models and datasets for review to informaticians and clinicians working in the field.

b. Submit information specifications and examples for review by patients, patient representative organisations and healthcare professional bodies.

6). Final Process Model Formulation.

a. For each Component Model, confirm the link between each dataset item to the activity that creates/provides it, the validation rules and the level of processing required.

b. For each Component Model, confirm points for information provision and the required information specifications.

c. Collate all models into the final (composite) Process Model.

Table 10.4. Source documents and illustrations from the National Datasets Development Programme.

NB. Material is primarily from the NHS Information Authority.

Documents are "controlled" - newer versions take precedence.

A. Source documents.

Original web source

(From the Public Health and Service Management Information programme).

http://www.nhsia.nhs.uk/phsmi/datasets/files/

Title	Version	Date/Reference
The National Dataset Development Programme. A Strategic Framework.	0.12	NHSIA (2002/nddp1)
Dataset Process Models.	0.2	NHSIA (2002/nddp2)

A. NHS Example: Datasets for older people (posted May 2003).

(Associated with the NSF for Older People, and covering: Single Assessment Process (SAP, stroke, falls, dementia, continence).

http://www.nhsia.nhs.uk/phsmi/datasets/pages/ds_oolder.asp

The UK Government Data Standards Catalogue (GDSC).

(Data Standards for use across the public sector - draft and approved).

http://www.govtalk.gov.uk/gdsc/html/default.htm

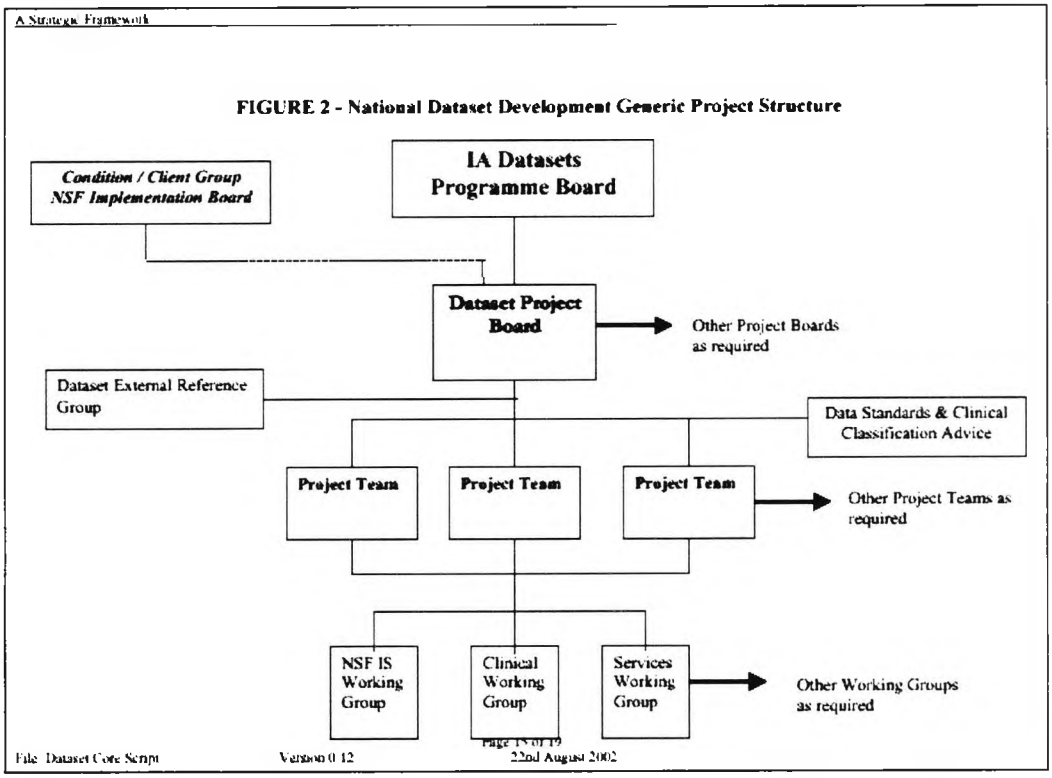


Figure 10.1. A common structure for major dataset development projects based on the PRINCE 2 management methodology. (From NHSIA, 2002/nddp1, Figure 2).

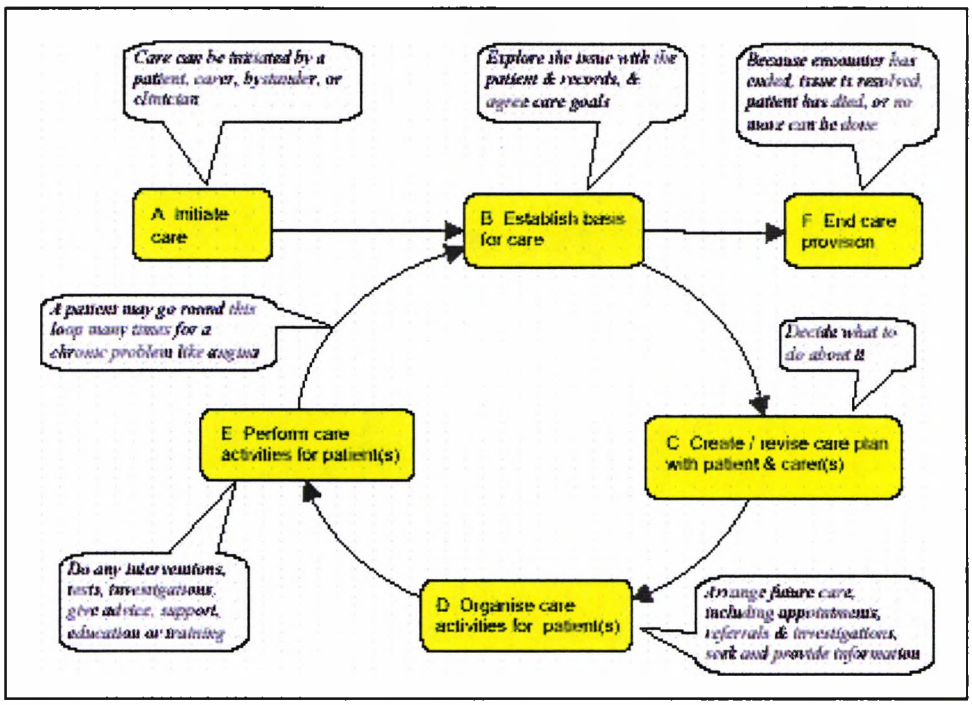


Figure 10.2.Top level NHS "Provide Patient Care Model". (From NHSIA, 2002/nddp2, Figure 2).

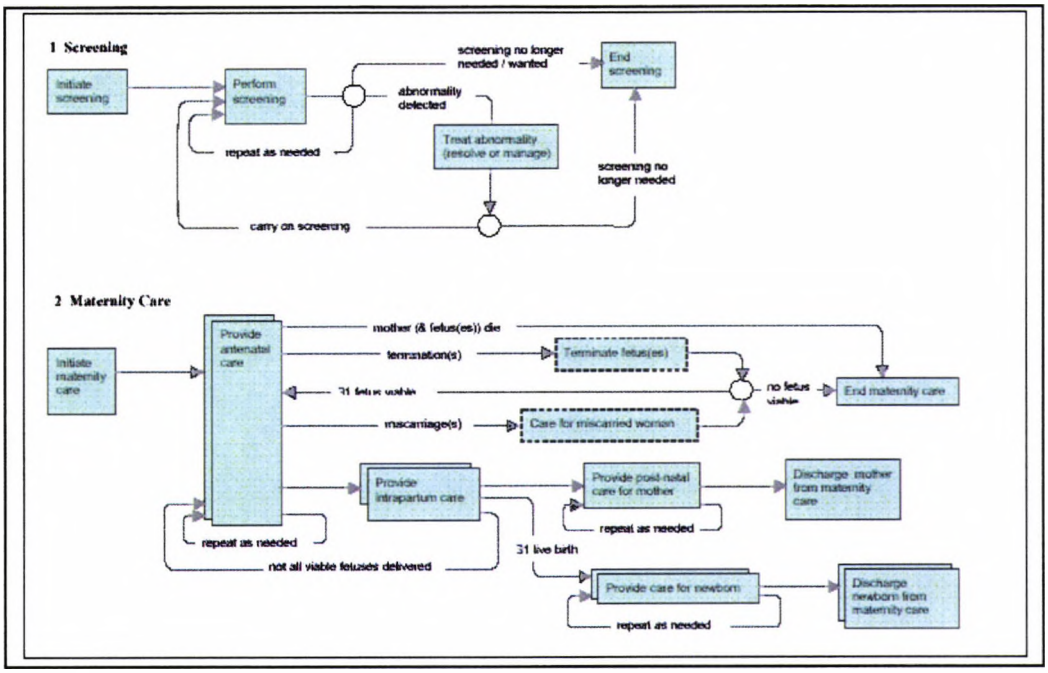


Figure 10.3. Model diagrams of the 4 principal Care Paradigms used in clinical dataset projects.(From NHSIA, 2002/nddp2, Figures 3-6).

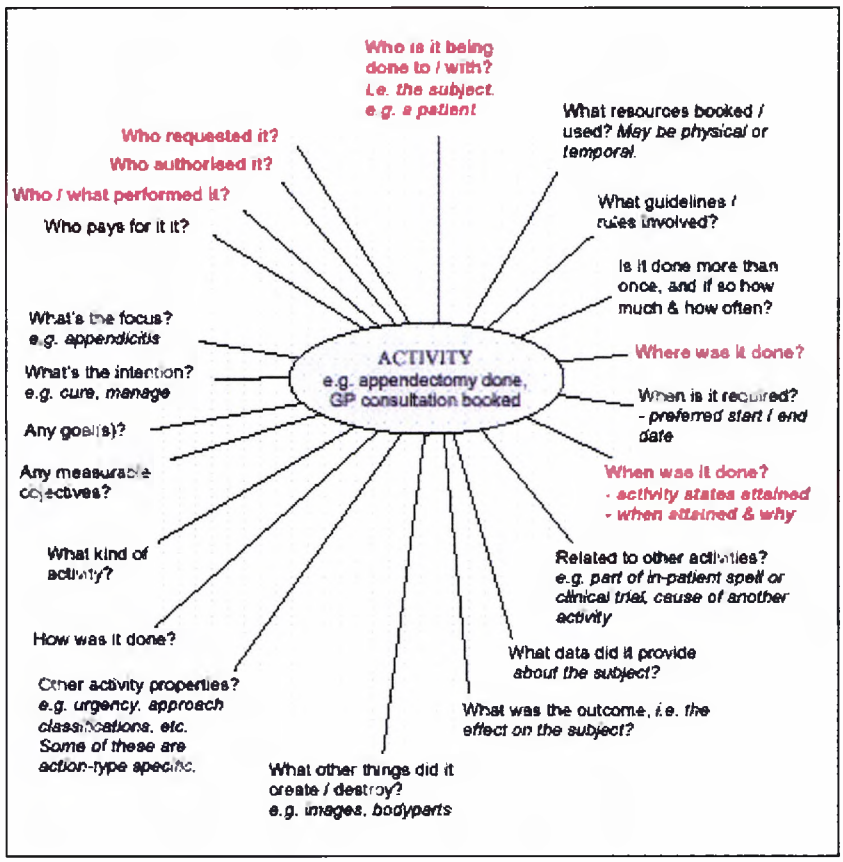


Figure 10.4. Data requirements and types specifically recommended by the NHS Information Authority for clinical dataset projects.

(From NHSIA, 2002/nddp2, Annex Y, "Templates for actions and patient observations", and reproduced from the full NHS "Health Care Model").

10.4. Accreditation of patient information providers based on parallels with research governance.

10.4.1. Background.

The "Research Governance Framework for Health and Social Care" (DoH, 2001/rgf) includes formal assessment of involved organisations. Levels of involvement cover funders, sponsors (organisations confirming the research methods and with broader interests in the work), as well as those conducting the research.

There is no equivalent mechanism to accredit providers of information to patients and supporters. The omission has produced fundamental concerns from patients and professionals reported in 9.5.4. It has not been addressed by relevant national organisations like NHS and Care Direct and the locally developing Patient Advice and Liaison Services (PALS).

Principles from the research framework are adopted here specifically to address information provision. The DQF benefits from this section through proposals for initial criteria and mechanisms for accreditation. These steps at the level of the organisation also link to the next main section on approaches to information indexing and retrieval.

10.4.2. Accreditation criteria.

Relevant organisations.

Targeted organisations fall into two categories. The first covers statutory bodies, such as hospitals and Social Services and their contracted agents, required by law to deliver services and related information.

The second comprises more general charities, national support organisations and self help groups. These organisations tend to focus on particular diseases, demograhic groups or occupations and interests. In addition, the major charities are often supported by medical and other experts with a range of publications already available.

Topics and criteria.

Ideally, organisations would be able to map their potential contributions to different stages identified in care process models (see the earlier section 10.3). It is currently more realistic to request basic "sign post" material usually contained in mission statements, annual reports or registrations with other bodies (eg. the Charities Commission).

Criteria for the "quality" of information provided have been proposed for the Association of Directors of Social Services by Sensory Services (2001a). With minor adjustments from HJL, they include:

- Accuracy, completeness and date of most recent updates.
- Explanation of technical terms.
- General ease of reading and navigation.
- Provision for patients with differing abilities and for relatives/carers.

Broader tests for any formal communication are:

- Is it provided at the appropriate time?
- Is it clear?
- Does it achieve intended goals (a better informed patient or patient actions)?

10.4.3. Accreditation methods.

The original Research Framework was accompanied by online forms for quick, initial assessments of organisations by DoH. Forms were temporarily suspended in 2003 while updates to the whole Framework were considered for a new version.

Appropriately designed online forms linked to databases may also be the most effective method for maintaining a register of information providers. A username and password system would be required. But the onus would be on individual organisations to keep their details up to date. Larger bodies should have the facilities, though assistance is anticipated for smaller groups.

10.5. Information description and retrieval mechanisms from the Office of the eEnvoy (OeE).

10.5.1. Background.

Metadata are the additional items assigned to an information resource as a structured description for information storage and retrieval. Principles are similar to mechanisms

for specifying datasets. There is guidance for choosing description items but, unlike data specifications, currently no strict rules for enforcement or validation.

Libraries have used paper systems for many years. Now, the Office of the eEnvoy (OeE) has adopted an electronic approach, using either HTML or XML technologies. It is formally stated in the eGovernment Metadata Standard (eGMS) which, during 2001/2, was integrated with eGIF. Related documents and websites are given in Table 10.5.

This section provides the DQF with principles for describing information resources (of any physical format), and examples of technology for converting electronic resources into different output formats. Since metadata mechanisms are not widespread in public information provision in English healthcare (at late 2002), recommendations for development are included. Overall, the section adds detail to Stage 4 (Patient Information Provision) in the care modelling sequence (10.3.7).

10.5.2. Essential problems and recent changes.

OeE acknowledges the volume of official information potentially available, and therefore the need for a metadata system. Moreover, existing central websites are not well designed for easy browsing. Site search mechanisms, and general search engines, do not have the additional details (metadata) to tailor searches.

In healthcare, there are no existing examples of advanced metadata in use by NHS public information services at late 2002 (eg. NHS Direct at www.nhsdirect.nhs.uk). Moreover, charities and other significant but independent information providers, are not officially covered by eGMS or any equivalent scheme.

The eGMS approach is substantially based on an international development forum known as the Dublin Core Metadata Initiative (DCMI). Experience has been drawn from comparable initiatives in America and Australia, and from specialist organisations. In

addition, OeE has acknowledged the need for public information services to be equally available to people with limited resources or special communication needs (social inclusion).

Developments are at early stages and rely heavily on the web and XML technology. Nevertheless, there is potential for use by professionals on behalf of patients as virtually all NHS sites and Social Services are connected to the web, while most significant independent information providers also have websites.

10.5.3. Describing information resources.

Metadata descriptions are made up of Elements and Encoding Schemes. Simple examples are shown here along with adjustments for healthcare. Extended examples for application are given in the next chapter.

Elements.

As basic units of description, 25 Elements have been adopted in eGMS (Table 10.6). In principle, they identify areas for full description of any information resource. Only a sub-set is required in most cases.

Elements can be divided into sub-Elements and identified by construction (refinement mechanism). For example, eGMS has the element "Subject" with refinements for "Category" and "keywords". They are identified using:

e-gms.subject.category and e-gms.subject.keyword

Some Elements in eGMS have been specially developed. Most have been adopted from other systems, in particular from the DCMI (Dublin Core). Element names have not been changed for these direct mappings.

Encoding Schemes.

Elements and their refinements are essentially variables. Contents are left to the user, but may be selected from controlled vocabularies (Encoding Schemes). Example schemes recognised by eGMS are given in Table 10.7.

Use of certain Elements has been made "mandatory", "recommended" or "optional". However, at 2003, The only mandatory Encoding Scheme under eGMS is the Government Category List, for use particularly in the subject entry (e-gms.subject.category).

A simple example.

The following defines an HTML webpage (an information resource) with metadata tags showing compliance with the W3C Web Accessibility Initiative and a subject entry from the Government Category List. Web addresses for the related Encoding Schemes are contained, for reference only, in the scheme attributes.

```
<html>
<head>
<meta name="e-GMS.accessibility"
scheme="http://www.w3.org/TR/WAI-WEBCONTENT/"
content="Double-A" />
<meta name="eGMS.subject.category"
scheme="http://www.govtalk.gov.uk/schemasstandards/egif.asp"
content="Information management"/>

</head>
<body>
...Main page content...
</body>
</html>
```

Adjustments for healthcare.

A consistent approach, in paper and/or electronic formats, is required across all recognised information providers targeting patients. eGMS contains Elements for the general Subject and Audience for an information resource as well as its physical Format and Location. Nevertheless, there is significant room for improvement.

A practical step to link information to direct care is incorporation of Read Code/SNOMED terms as Encoding Schemes (controlled vocabularies) for particular disorders or stages of care. It is worth noting that Read/SNOMED is mandated for Electronic Patient Records. More broadly, personal data items collected as part of a

formal dataset may also be useful keywords or conditions for tailored information retrieval (diagnosis, age, etc).

10.5.4. Local information provision in formats for use at home.

Advanced preparation of material is the simplest approach. However, it places storage constraints on paper systems, and transcription costs on organisations attempting to produce material in a full range of formats. The web, coupled to local production devices (eg. printers), is a potential solution to the storage problem. A recent development in XML technology may also address the transcription issue.

Again, this section introduces general principles, simple examples and adjustments for healthcare. More developed examples follow in the next chapter.

The eXtensible Stylesheet Language (XSL).

eGIF version 3 identified "transcoder" technology as a method for transforming information resources into formats for non English speakers and disabled people. By version 5, details were still not provided. XSL was the likely candidate as it is specifically designed for format conversions on the web.

The eXtensible Stylesheet Language became a W3C standard in 2001. In fact, it comprises 3 languages for converting plain XML source files according to rules and procedures. Essentially, tags (or markup) in a source XML file are identified by the stylesheet and matched to corresponding conversion routines.

A variety of conversion procedures are available and rules can be constructed from filtering and sorting methods. The conversion can be performed on a website server or by the user's browser, provided it is "XML-enabled". In principle, the results of conversion (outputs) can be determined by user preferences (inputs).

A simple example.

Table 10.8 lists XML source and style sheet files coded for a catalogue of home monitoring devices for diabetics. If the XML source file is loaded into an XML-enabled browser, it is automatically displayed in HTML format (as a table in a standard webpage).

The example illustrates that information stored in a plain XML file can be converted for local printing with any choice of colors and font sizes specified in the XSL conversion file.

Translations to other human languages and production in speech are achievable "in principle". Example sites on the web purport to translate English web pages into other European languages. Equally, recent Microsoft operating systems (XP) contain a speech synthesizer, and synthesizer markup languages are developing.

Adjustments for healthcare.

There are few, if any, examples of XSL applications fully operational for providing information to patients in English healthcare. Adoption is likely to be slow. There are many online information sources and website updates take time and investment. Similar arguments apply to the adoption of metadata principles for general description of information resources.

There is a solution, at least in limited areas of information provision. A dedicated central website may provide the metadata indexing facilities and the XSL transformation files. Collaborating organisations provide the site managers with raw information in plain XML files using very simple tags, or in HTML itself, (HTML 4.01 and xHTML are XML compliant). Sufficient indexing information is also required. The site may then serve as a central resource for patient counsellors as well as the public.

Table 10.5. Reference material related to descriptions of information resources via the eGovernment Metadata Standard (eGMS).

Most of the material here is produced by or available through the Office of the eEnvoy (OeE) via (www.govtalk.gov.uk). A general introduction to metadata has been prepared for OeE (Hutchison, 2002).

Examples of metadata in webpage headers are available on the OeE site and the Cabinet Office site (www.cabinet-office.gov.uk). The only clear example of eGMS in operation at 2002/3 (with tailored search engines) is the UK Government's official online portal (www.ukonline.gov.uk).

A. Standards Documents.

Title	Version	Reference/Date
e-Government Interoperability Framework (Part 1 - general policies)	5	OeE (2003/egif1)
e-Government Interoperability Framework (Part 2 - technical specifications)	5	OeE (2003/egif2)
e-Government Metadata Standard	2	OeE (2003/egms)

B. The Dublin Core Metadata Initiative (DCMI).

An internation forum for metadata developments at the centre of eGMS.
http://www.dublincore.org

C. Comparable systems to eGMS from other countries.

Australian Government Locator Service (AGLS)
http://www.naa.gov.au/recordkeeping/gov_online/agls/summary.html
(American) Government Information Locator Service (GILS)
http://www.dtic.mil/gils/documents/naradoc

Table 10.6. Summary of the 25 main themes (elements) available to describe information resources under the UK Government Metadata Standard. (From OeE, 2003/egms).

Column headings

A	Of special value for early use in healthcare (HJL's opinion) - Y or blank.
B	Number used in the eGMS document.
C	Element name.
D	Summary.
E	Has refinements (sub-categories) - Y or blank - see Table 10.7.
F	Has recognised Encoding Schemes (entries from controlled vocabularies) - Y or blank - see Table 10.7.

A	B	C	D	E	F
	1	Accessibility	Design features for people with special communication needs, or child access control.		Y
	2	Addressee	Target for dispatched or circulated document (eg. named person).		
	3	Aggregation	Place of the resource in a larger resource or collection (see also "relation").		Y
Y	4	Audience	Categories of intended human users.	Y	Y
Y	5	Contributor	Person/organisation providing part of the resource		Y
Y	6	Coverage	Time periods and geographical areas covered by/relevant to the resource.	Y	Y
Y	7	Creator	Job title (person)/organisation primarily responsible for resource content.		
Y	8	Date	Date in the lifecycle of a resource (preparation, publication, withdrawal, etc). See more detailed uses (eg. refinements of "Disposal", "Preservation", "Status").	Y	Y
Y	9	Description	Outline of resource content (structure and approach etc).	Y	
	10	Digital signature	Use to be considered by National Archives (formerly the Public Records Office).		

Y	11	Disposal	Retention and disposal instructions for the original provider organisation and users with local copies.	Y	Y
Y	12	Format	Physical or digital format.	Y	Y
Y	13	Identifier	Unique identifier (commonly a code number).	Y	Y
Y	14	Language	Human language of main content.		Y
Y	15	Location	Physical location of the resource (generally for paper items or loan systems).	Y	Y
	16	Mandate	Law or formal requirement for producing the resource.	Y	
	17	Preservation	Information on long term storage for historic purposes.	Y	
Y	18	Publisher	Organisation responsible for resource availability.		Y
Y	19	Relation	Cross-references to parts of the same or related resources.	Y	Y
	20	Rights	Who can view, use or redistribute the resource.	Y	Y
Y	21	Source	Origins or derivations of the resource.		Y
Y	22	Status	Position or state of a resource (eg. draft version).		Y
Y	23	Subject	Topic(s) of resource content.	Y	Y
Y	24	Title	Name for the resource, generally for human use (cf. "Identifier').	Y	
Y	25	Type	Nature or genre of the resource content (eg. policy document, minutes of meeting).		Y

Table 10.7. Selected Encoding Schemes for describing information resources, from the UK Government Metadata Standard. (Identified in OeE, 2003/egms).

Encoding Schemes (controlled vocabularies) provide the choice of descriptive terms to enter under particular Elements used by eGMS. Details are provided for Schemes potentially available for implementation in healthcare.

N**B**. The only mandatory Encoding Scheme is the Government Category List (GLC) for entries under the element/refinement "subject.category".

Contents of this Table

A. Recently released Encoding Schemes.

Title	Version	Reference/Date
Government Category List (interactive version via www.govtalk.gov.uk)	1.3	OeE (2002/egms1)
e-GMS AUDIENCE Encoding Scheme (e-GMSTAS) - Draft		OeE (2002/egms2)
e-GMS Type Encoding Scheme (e-GMSTES)	1.0	OeE (2002/egms3)
Crosswalks Between e-GMS, LOM and the Curriculum Online metadata scheme. Learning Object Metadata from the Institute of Electrical and Electronic Engineers - identified for use with the National Curriculum (schools) by the Dept. For Education and Science (DFES).		Cox G, (2002)

B. Selected Encoding Schemes.

B1. Information Resource administration.

Information Resource description type	**Related Elements/refinements**	**Encoding Schemes**
Intended users	audience audience.educationLevel audience.mediator	eGMS Audience Encoding Scheme (e-GMSAES) See Panel A
		IEEE Learning Object Metadata Audience Encoding Scheme See Panel A and ltsc.ieee.org/wg12/
Language	language	ISO 639-2 (coding system) www.loc.gov/standards/iso639-2
Physical/digital format	format format.medium format.extent (size or duration)	Internet Media Type (IMT) www.iana.org/assignments/media-types/index.html
Physical location	location location.home (normal place) location.temporary (borrowed item)	Government Data Standards Catalogue (entry formatting) See Table 10.4
Identifying code	identifier identifier.filePlanId (files in folders) source	Universal Resource Identifier (URI) www.ietf.org/rfc/rfc2396.txt o http://purl.org/dc/terms/URI
		Book numbers (ISBN) www.isbn.org/standards/home/index.asp
Publisher	publisher	Government Data Standards Catalogue (entry formatting) See Table 10.4
Contributors	contributor	Government Data Standards Catalogue (formats for contact details) See Panel A

B1 Continued. Information Resource administration.

Information Resource description type	Related Elements/refinements	Encoding Schemes
Dates (resource management)	date date.issued date.aquired date.modified etc.	W3C/Dublin Core Metadata Initiative (schema for recording dates and times) dublincore.org/2003/03/24/dcq#W3CDTF
Grouping components of the same resource	relation relation.hasFormat relation.HasPart relation.IsPartOf etc.	Dublin Core Metadata Initiative (relation) purl.org/dc/elements/1.1/relation
Grouping similar resources	aggregation	UK National Archives (records management) www.pro.gov.uk/recordsmanagement/erecords/2002reqs/2002metadatafinal.pdf
		ICRA (suitability for children) www.icra.org/
Improved or controlled website access (accreditation systems)	accessibility	W3C (compatibility with access technology under the Web Accessibility Initiative www.w3.org/TR/WAI-WEBCONTENT/)

B2. Information Resource content.

Information Resource description type	Related Elements/refinements	Encoding Schemes
Broad nature of the resource (eg. minutes, policy statement)	type	eGMS TYPE Encoding Scheme (e-GMSTES) See Panel A Dublic Core Metadata Initiative (type) www.dublincore.org/documents/dcmi-type-vocabulary
Subject (category)	subject subject.category	Government Category List See Panel A and www.govtalk.gov.uk
Subject (keywords)	Subject subject.keyword	Medical Subject Headings (MeSH) www.nlm.nih.gov/mesh/meshhome.html Library of Congress Subject Headings (LCSH) www.loc.gov/catdir/cpso
Geographic focus (area)	coverage coverage.spatial	Dublin Core Metadata Initiative - Box (region using geographic coordinates) dublincore.org/documents/dcmi-box ISO 3166 (Codes for country names) www.din.de/gremien/nas/nabd/iso3166ma/codlstp1/index.html Office for National Statistics (SNAC - database of Standard Names and Codes) www.statistics.gov.uk/geography/snac.asp
Time focus (period)	coverage coverage.temporal	Dublin Core Metadata Initiative (specification of a time interval) dublincore.org/documents/dcmi-period

Table 10.8. Illustrating the conversion of a common information resource into different formats using XML technology.

The first listing is a plain XML file containing a catalogue of blood sugar monitoring devices. The second is an XML style sheet written in the extensible stylesheet language (XSL). The source file contains a reference to the style sheet and will be automatically converted for output as an HTML table when loaded into a browser. Results are also shown.

NB. The style sheet has 2 entries for one of the opening lines, depending on whether the browser used is Internet Explorer 5.0 and 5.5 or 6.0 and later. Remove the unwanted line. IE 5.X uses draft standards while 6.0+ uses the official W3C standard (see Appendix 4, Panel C1, for details on XML and Microsoft browsers).

A. Plain XML file - the source information with a link to the style sheet.

(diabetic_meters.xml

```
<?xml version="1.0"?>
<?xml-stylesheet type="text/xsl" href="stylesheet.xsl"?>
        <catalogue>
                <machine>
                <name>Accutrend DM</name>
                <company>Boehringer Mannheim GbH</company>
                <price>39.99</price>
                </machine>
</catalogue>
```

B. XML style sheet (filename: stylesheet.xsl).

```
<?xml version="1.0"?>
<!-- Line for use with IE 5.0 and 5.5 -->
<xsl:stylesheet
xmlns:xsl="http://www.w3.org/TR/WD-xsl">
<-- Line for use with IE 6.0 and later (W3C standard compliant -->
<xsl:stylesheet version="1.0"
xmlns:xsl="http://www.w3.org/1999/XSL/Transform">

<xsl:template match="/">

<html>
<body>
<table border="2" bgcolor="yellow">
<tr>
<th>Name</th>
<th>Company</th>
<th>Cost</th>
</tr>

<xsl:for-each select="catalogue/machine">

<tr>
<td><xsl:value-of select="name"/></td>
<td><xsl:value-of select="company"/></td>
<td><xsl:value-of select="price"/></td>
</tr>

</xsl:for-each>

</table>
</body>
</html>
</xsl:template>
</xsl:stylesheet>
```

C. Out put from the browser.

Name	Company	Price
Accutrend DM	Boehringer Mannheim GbH	39.99

10.6. The Data Quality Framework: an integration of the four central initiatives.

This chapter has provided the DQF with material for reference. The main DQF itself has 2 Parts. An Appraisal Tool (Part 1) lists key questions for reviewing an existing dataset or requirements for a new system. Modifications or a new process are then addressed and introduced with guidance from the Implementation Programme (Part 2).

DQF Reference Material.

- General principles for evaluating datasets and collection processes according to the NHS Information Standards Board (10.2.3).

- Project management structures and steps for healthcare process modelling adjusted from the NHS Information Authority (10.3.2 & 10.3.7).

- Initial criteria for accrediting providers of patient information, based on similar principles for accrediting organisations involved in research (10.4).

- Principles for describing information resources from the Office of the eEnvoy, with an introduction to technologies for conversion into different presentation formats (10.5.3 & 10.5.4).

DQF Part 1. Appraisal Tool.

a. Are the scale, organisations and stakeholders involved in the care process clearly identified?

b. Does the care process have a widely recognised "care pathway" (delivery model)>

c. Does the related dataset have a clear and relevant purpose?

d. Are shared data clearly identified and understood by providing and receiving professions in the care process?

e. Is there evidence that collection has adverse effects on patients or care delivery in the same or other care processes?

f. Is relevant information provided to the patient and/or supporters, in appropriate formats, and from recognised sources?

g. Are all relevant organisations involved in direct care or service management provided with the final dataset or results of further analysis?

h. Are data collection and exchange, as well as information delivery procedures, cost effective?

DQF Part 2. Implementation Programme.

Stage 1. Initiation.

a. Confirm the scale and remit for the programme.

b. Identify the patient groups, professions and sites affected directly or indirectly by the dataset.

c. Establish a representative steering committee and advisory groups within a recognised project structure and management methodology.

Stage 2. Development.

a. Model the care process with full representation of care activities, data sources and points for information provision.

b. Specify the dataset(s), collection process and any special requirements for exchange.

c. Specify requirements for patient information and identify recognised sources.

d. Assess the potential for web technologies to deliver patient information locally.

e. Design and implement a pilot on an appropriate scale. Measure in particular: the volume and final formats of collected datasets; costs and benefits to patients and care delivery organisations.

f. Compile the evidence for change in a format appropriate for consideration by the Information Standards Board or an equivalent local organisation.

Chapter 11

Application of the Data Quality Framework to Visual Impairment Notification in England

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11.1. Introduction.

The previous chapter proposed a generic Data Quality Framework (DQF) with separate Parts for appraising an established dataset and implementing a programme of change. Though motivated by experience of data quality problems in the field, the DQF was largely based on theoretical approaches. Now the focus returns to practical issues. The aim is to test the DQF against a real world example.

Visual Impairment Notification (VIN) in England is the test case. The existing care process was detailed in chapter 6 along with pilot plans for computerisation (electronic Visual Impairment Notification System - eVINS) and an ongoing Review by the Department of Health (DoH). VIN was the broadest and most recent of the Case Studies in Part 1. Moreover, comparisons with the DoH Review allow the Notification process and the Data Quality Framework to be assessed in the same step.

Five questions guide the assessment.

Does use of the DQF:

- Identify substantive problems and/or acceptable performance from the current Notification process?

- Highlight limitations and/or improvements to earlier proposals for computerisation?

- Lead to justified recommendations for change?

- Provide a supported plan for introducing change?

- Compare with the approach and preliminary proposals adopted by the Department of Health?

Organisation of the chapter

Section 11.2 summarises the Notification process and updates developments since chapter 6, including a significant press release from DoH on 17thSeptember 2003 (11.2.4).

Section 11.3 applies the Appraisal Tool (DQF Part 1) to the Notification process and preliminary proposals from DoH. Material cross references details from earlier sections and is structured under key appraisal questions.

Section 11.4 develops an Implementation Programme (DQF Part 2) for introducing change. It is substantially based on the eVINS project, including electronic pilots in Camden & Islington Health Authority with equivalent forms in paper modes for use in other geographic areas (see 6.5). Updates cover a care pathway; identification of information for patients; and contacts with major projects and organisations to improve consistency and avoid duplicated effort. DQF activities are organised and summarised under the Stages for project Initiation and Development.

Section 11.5 draws conclusions on both the DoH Review and use of the DQF as applied to the example domain.

General conclusions

Changes to the Notification process (and to DoH proposals) are justified by formal evidence and logical argument. The Implementation Programme to introduce a new process is guided by local experience in the field; focuses on key issues; and anticipates expansion after pilots without total dependence on IT.

Use of the DQF in this example is incomplete as full application from Appraisal to Implementation would require DoH support. Collection of epidemiological data is also limited to identified patients. A separate or extended pilot programme would be necessary to collect broader data on the prevalence of significant sight loss in the general population.

Despite such practical difficulties, the DQF approach is judged to be an improvement on the DoH Review. Primarily, it incorporates the appraisal and approval process for significant datassets imposed by the NHS Information Standards Board. Forms used nationally for individual care and process monitoring are not explicitly included but, logically, the same principles should apply. Stepts and material consistent with the ISB mechanism are contained in this Thesis (cf. chapter 6 and Tables 11.1 & 11.2).

In contrast, the official DoH Review has not published any evidence to justify and direct change. The Department's approach therefore appears not to follow the spirit (or logic) of its own policies.

11.2. Summary of Visual Impairment Notification and updates since Chapter 6.

Chapter 6 covered reviews and research up to Summer 2002. This section summarises the Notification process, the eVINS project and the DoH Review. A

subsequent meeting between the eVINS team and DoH is described; and wider developments since chapter 6 are updated.

11.2.1. Summaries from Chapter 6.

The current Notification process.

Consultant ophthalmologists judged whether patients meet criteria for registration as blind or partially sighted. Patients are then invited to sign the form BD8(1990). The form is sent to Social Services, leading to further assessments and support, and an invitation to be formally registered with the Local Authority. Consultants are entitled to a fee for form completion alone.

GPs are also informed via BD8 but the epidemiological section sent to the Office for National Statistics was halted in 2000. Statistical summaries of Local Authority registers are returned to DoH every 3 years via form SSDA902.

The computerisation project (eVINS).

Using web technology, eVINS comprised: a re-designed BD8 form; electronic completion and dispatch procedures; and a central site for managing epidemiological data, and providing online access to patient information.

The NHS Information Authority and a digital security company were involved in system design. Pilot plans were made for Camden & Islington Health Authority but not submitted because of the DoH review.

Department of Health preliminary proposals.

The review followed ministerial lobbying by RNIB. GPs and high street opticians would play a greater role in patient identification. Three forms would replace BD8 covering: formal requests for information from Social Services signed by GPs or opticians; requests from hospitals for further patient assistance from Social Services for those who met criteria but did or did not wish to be registered. Language on forms would acknowledge the useful residual sight ignored by the traditional term "blind".

11.2.2. Meeting between the eVINS team and Department of Health.

The eVINS project (late 1998 - late 2001) took account of the DoH Review starting in late 2001, and deliberately targeted its final report to the funding organisation (Guide Dogs) at the Review (GDBA and other interested parties were Review Group members).

There was no response by early Summer 2002 and uncertainty was delaying the eVINS project. Clarification was sought. In the event, senior DoH members requested a meeting with the project at Moorfields Eye Hospital.

The meeting occurred after material had been released for public consultation. The eVINS team presented recent epidemiological findings on patient numbers missed by Notification. The eVINS system was demonstrated and concluded to provide an electronic version of DoH's proposed form C for formal certification/registration. This was not suprising as the project had targeted improvements to the existing BD8 form. DoH reported that discussion with the NHS Information Authority had been inconclusive. They had not spoken to senior or local NHSIA members aware of eVINS.

DoH stated that epidemiological data and fees to ophthalmologists would be treated as special issues. Moorfields and the eVINS project would be "kept in the information loop".

There was no formal or informal feedback to the eVINS project before this Thesis was completed.

11.2.3. Developments since Summer 2002.

Developments directly and indirectly related to Notification have continued to be monitored for this Thesis. They demonstrate a disjointed approach to change, requiring greater coordination between initiatives before they can benefit staff and patients involved in Notification or the visual impairment community generally.

1). Directly related.

Electronic collection of data from visual impairment registers. Local Authority forms sent to DoH, including SSDA902, are due to be electronic from 2003 as part of DoH's programme of "Improvements in Statistical Ccollection" (DoH, 2002/pss). Anomalies in the design of form SDA902 have not been changed. Validation against records held by staff dealing directly with patient data and cross references between registers for different disabilities have also not been addressed. The technical architecture is comparable to previous proposals for form completion using eVINS but without signatures or encryption.

National Service Frameworks (care standards and datasets for particular groups). NSFs for Older People, Diabetes, and Long Term Conditions are relevant to visual impairment. Technical updates are circulated by the NHS Information Authority and posted on its website. Despite the links with visual impairment, and involvement of DoH civil servants from the Notification review on the programme

for long term conditions, there is still no formal recognition of sight loss in documents from any relevant NSF.

Low Vision Services Implementation Group.LVSiG is a national discussion and development forum established largely by specialist optometrists. The coordinator represents RNIB/College of Optometrists on the DoH review group, and the Camden & Islington LVSG (covering Moorfields' home area) is an example of groups which have formed under the national programme to influence local services.

By Winter 2002, 35 local groups were involved in discussion on services (LVSIG, 2002). Work on care pathways and service directories are among local research initiatives (see examples from Camden & Islington in 11.4.2). Notably, the national coordinator stated at a meeting with C&I that these groups were often the first time that local organisations had met andobvious or simple steps had often been ignored in the past. (Recalled by HJL from the July 2003 C&ILVSG meeting, but significantly not minuted).

Online information for patients. The National Library for the Blind established a gateway to general information with lottery funding (www.visugate.org). It was supported by an organisation represented on the DoH review group (the UK branch of the VISION 2020 programme from the World Health Organisation).

Visugate compares with earlier proposals under eVINS for a central coordination and access point for information. At late 2002, however, sub sections were not tailored to the Notification process. Responsibilities of contributing organisations were not stated on the site; and it did not meet developing standards for improving public information retrieval and provision in different formats (see 10.5). Poor coordination between information providers was also demonstrated during 2003 when the VISION 2020 UK branch contributed yet another website (www.vission2020uk.org.uk).

2). Indirectly related.

Legal changes (potential incentive for registration). The 1995 Disability Discrimination Act has been amended to ensure that registered blindness and partial sight are automatically accepted as "disability" in legal disputes involving the Act.

Patient Advice and Liaison Services. PALS were anticipated in the NHS Plan to complement existing patient support services in individual NHS organisations (DoH, 2002/pals). HJL's experience at Moorfields and in his home area (South West Kent Primary Care Trust) suggests that implementation and public awareness are limited to paper leaflets in non prominent places.

European Directive on patient information accompanying medicines. According to the Directive affecting UK law, all dispensed medicines must now be accompanied by an explanatory leaflet (DoH, 2002/patinfo). While DoH has made arrangements to avoid copyright infringements allowing local organisations to photocopy material, there are no standards on the quality of such information (relevance, ease of comprehension) or provision for people with special communication needs.

2003 - European year for disability with notable emphasis on online information. A number of initiatives have been funded by the European Union, including a programme to harmonise web accessibility standards (www.euroaccessibility.org). Comparable but separate projects have also been launched by the Disability Rights Commission with research by the Centre for Human Computer Interaction, City University (www.drc.org.uk); and by the Government's public libraries and galleries service (www.resource.gov.uk and www.museumscomputergroup.org.uk). Details on these and many other initiatives are available via (www.rnib.org.uk/digital).

Multiple national and international initiatives suggest a fragmented approach to accessible online services and information for disabled people. They also ignore other key issues:

- Estimates on numbers with disability are poor (cf. the criticicms of Visual Impairment raised in this Thesis as one of the more prominent disabilities).

- Costs of Access/Assistive Technology are high and in addition to expenditure on mainstream equipment.

- Support from Access/Assistive Technology suppliers is relatively poor.

- All standards on accessibility are fundamentally based on the Web Accessibility Initiative from the World Wide Web Consortium (www.w3.org/wai). Such standards and related guidelines do not cover compatibility of Access/Assistive Technologies as third party products used in conjunction with browsers or on interaction between products from different suppliers.

- The web is not being targeted as a mechanism for organisations to obtain and produce material for people without access to technology (cf. proposals in the eVINS pilots - 6.5.3 - and developed as part of the DQF - 10.5.4).

11.2.4. Unexpected press release from the Department of Health.

A minister announced changes to the VIN process on BBC Radio 4's "In Touch" programme for visually impaired people on Tuesday 16th September 2003. DoH released a press statement the next day (Figure 11.1) confirming the changes outlined above and detailed in chapter 6. Moreover, it clearly stated that the new system would begin in November.

The situation was discussed by Camden & Islington Low Vision Services Group on 13th October (C&ILVSG, 2003a). A member, who had served on DoH's Review,

pointed out that the Review Group had not met or been consulted in over a year. For the first time, C&ILVSG also discussed DoH's call for research proposals to develop "clinical pathways" for a limited number of diseases.

At HJL's suggestion, C&ILVSG decided to write to DoH with its concerns about the new VIN process which might also be shared by other LVSGs around the country, and covering:

- Unclear timetable for actual introduction.
- Logistics of change in large eye departments.
- Lack of information and direction to high street optometrists and GPs.
- Need for links to the developing "clinical pathways" research projects.

The letter was still in preparation by C&ILVSG's Secretary in late October. It was likely to be less critical of DoH (compared to HJL's position) with more emphasis on how the local area was well placed to develop the principles underlying change. Nevertheless, some of HJL's earlier concerns had at last been raised and acknowledged in an open meeting by professionals and patient groups directly affected by DoH's proposals.

Figure 11.1. Press release on the Visual Impairment Notification process, from the Department of Health on 17th September 2003.

(As provided by RNIB).

FASTER ACCESS TO VITAL SERVICES

FOR PEOPLE WITH VISUAL IMPAIRMENTS

Ladyman announces changes to registration, referral and identification process.

People with visual impairments will have quicker access to support from social services thanks to a number of changes to the identification, referral and registration process, Health Minister Stephen Ladyman has announced.

Following extensive consultation with service users and key stakeholders, it was decided that the existing form BD8, which certifies a person as being registerable by social services as 'blind' or 'partially sighted', was trying to do too much and was often leading to long delays in accessing vital support.

The Consultation Group also found that receipt of form BD8 was often the only way that social services learnt of someone in need of help. Consequently, the Group decided that more needed to be done to refer those who could benefit from social services assistance.

From November there will be:

A simpler, more user-friendly form confirming a person's eligibility to be registered. It uses tick boxes to reduce the amount of written information required, speeding up the registration process. The form will be downloadable from the NHSweb and will be available in formats accessible to visually impaired people.

A new referral letter available from high street optometrists providing information on local and national sources of help and advice. It will be given to people who have developed sight problems that cannot be corrected with glasses so they can refer themselves to their local social services team to obtain assistance.

A new letter for hospital eye services to refer someone with serious sight problems to social services.

An amendment of the terminology used to register individuals with social services from 'blind' and 'partially sighted' to 'blind or severely sight impaired' and 'sight impaired or partially sighted' to encourage more people to reap the benefits of registration.

Stephen Ladyman said: "I am pleased to announce the results of the review of the referral and registration system. Visually impaired people need to be put in touch

with those who can help them as soon as possible, whether they choose to register or not.

The changes agreed by the Consultation Group will enable patients to make contact with social services as soon as there is concern about their ability to cope and in advance of certification. I hope these changes will encourage more people to come forward and get the help and support they need."

11.3. Application of DQF Part 1. Appraisal of the current Notification process and Department of Health preliminary proposals.

Table 11.1 applies the Appraisal Tool. None of the questions produces a positive answer or conclusion. Key criticisms of both the existing process and preliminary DoH proposals include:

- Unknown potential scale of Notification (relevant comparative indicator of performance but not a direct part of Notification).

- Data on Local Authority registers for those already in "the system" are still of unknown quality regardless of plans for electronic central returns.

- No recognised "care pathway" or delivery model.

- Datasets (or sub-sets) are not well designed for sharing patient information between different professions.

- No responsibilities or clear actions to ensure patients obtain statutory benefits. (Note from 6.4 that the important date is the day of first contact with the Benefits Agency).

- DoH proposes two forms (B&C) for use in hospitals where one is sufficient (see arguments in 6.4.2).

- Information is not routinely provided to patients or supporters in any accessible and/or permanent format.

- DoH's proposed Form A, signed by GPs or opticians on behalf of patients simply to obtain basic information from Social Services, is morally wrong

and possibly illegal (Disability Discrimination Act, Section 22, requiring "reasonable adjustments" on the provision of information and services - seemingly a minimal requirement for information/services targeted at disabled people).

Table 11.1. Results from application of the Data Quality Framework Part 1 (Appraisal Tool) to the current Visual Impairment Notification process in England and preliminary proposals from the Department of Health at Summer 2002.)

Appraisal question	Summary of findings	Conclusion
a. Are the scale, organisations and stakeholders involved in the care process clearly identified?	No concensus on the prevalence of registerable visual impairment in England. Organisations identified in 6.2.2 Stakeholders involved in DoH review (Table 6.2) with others coming forward since Summer 2002.	Incomplete
b. Does the care process have a widely recognised "care pathway" (delivery model)?	A feature only now being considered by some local professional groups (eg. local committees under the Low Vision Services Consensus Group initiative). Current and future role of GPs and opticians in identifying patients, as proposed by DoH, is based on assumptions without numeric evidence.	No

Table 11.1. Continued...

Appraisal question	Summary of findings	Conclusion
c. Does the related dataset(s) have a clear and relevant purpose?	Role of certification/registration in general is clear. Epidemiological section of BD8 has been cut, leaving no indication of diagnosis anywhere on the form for use by GPs or patients. DoH proposes separate forms used in hospitals - for patient who do or do not wish to be registered - with different datasets. There is no clear logic to this approach for individual care or service monitoring and management for populations. Form SSDA902 (statistical summary of registers) has been computerised without any consideration of form design or management of source data (see 6.5.3)	Inconclusive
d. Are shared data clearly identified and understood by both providing and receiving professions in the care process?	Consultants often omit sections on the BD8 form intended to help Social Services prioritise Cases. Social Services do not necessarily appreciate the technical meaning or functional consequences of diagnoses.	No
e. Is there evidence that collection has adverse effects on patients or care delivery in the same or other care processes?	Delays reported anecdotally in the Notification process, but no formal monitoring data to identify causes or consequences.	Inconclusive

Table 11.1. Continued...

Appraisal question	Summary of findings	Conclusion
f. Is relevant information provided to the patient and/or supporters, and in appropriate formats?	The norm appears to be informal dDiscussions with patients. No examples found of patients provided with information for consideration at home. Information requirements, as sub-sections of forms proposed by DoH, are potentially biased towards older people and incomplete. Requirement for a formal letter requesting information from Social Services (Form A under DoH proposals) is morally and legally inconsistent in the "information age" with "open government".	No
g. Are all relevant organisations involved in direct care or service management provided with the final dataset or results of further analysis?	No record of diagnosis on forms currently sent to GPs or given to patients. Local Authority registers potentially inaccurate for local service managers because of register management problems and incomplete patient coverage by the Notification process.	Inconclusive
h. Are data collection and exchange, as well as information delivery procedures cost effective?	Only known examples of such analyses are by HJL in chapter 6.	No

11.4. Application of DQF Part 2: Change to the Notification process supported by an Implementation Programme.

Changes to the Notification process are largely based on earlier pilot proposals for the eVINS project in the Camden & Islington Health Authority (6.5.3). Ajustments have been made in response to more recent developments (11.2.3) included in the summary from the DQF Appraisal Tool. Account has also been taken of work since 2001/2 by a local forum of professionals and patients (Camden & Islington Low Vision Services Group - C&ILVSG). Finally, contacts with other organisations and programmes made ahead of pilots are identified to promote a consistent approach and avoid duplicated effort.

Table 11.2 summarises the general steps for introducing changes to the Notification process. Sections below explain the main issues.

11.4.1. Continuation with electronic pilots in Camden & Islington.

Greater use of IT in healthcare remains Government policy. Plans for eVINS pilots had support from local organisations and were drawn up with input from the NHS Information Authority among others.

The eight month programme, with initial cost estimates at #111k, are retained. Forms should be equivalent in electronic modes, allowing comparable pilots of basic changes to the Notification process in other areas without IT support, and acknowledging that hospitals in the C&I catchment area also serve patients from outside the strict pilot region.

An electronic approach to information provision may also benefit two broader areas of healthcare policy. Patient Advice and Liaison Services (PALS) as well as information accompanying medicines were both identified in 11.2.3 as limited by paper based procedures.

Project management would follow the PRINCE 2 methodology, as incorporated in previous plans and expanded with technical details in 10.3.2. Two years on, however, the DoH Review Group might provide the top level Management Board.

In addition to technological issues, and with support from professional bodies on the C&ILVSG, measurements of eVINS in live operation would include variables ignored by the current Notification process such as:

- Sources of patient referrals to hospitals.
- Times from first identification to a hospital appointment.
- Provision of social and practical support ahead of the hospital appointment.
- Times in hospitals for form completion and dispatch from the point of patient agreement.
- Number of eligible cases declining registration.
- Numbers judged to have significant but non registerable sight loss.
- Assessments by social workers on the value of patient background information provided by forms.
- Use and value of information provided by staff for patients and supporters to take home.
- Evidence that healthcare staff have made contact with the Benefits Agency on behalf of patients and at the earliest opportunity.
- Quality of long term data (stored on the safehaven database) for cross referencing with patient tracing and death register services.

11.4.2. Developments from Camden & Islington Low Vision Services Group (C&ILVSG) and overlaps with eVINS.

Low Vision Services

LVS covers functional assessments to maximise remaining vision as an addition to medical management. C&ILVSG has promoted a close collaboration between RNIB and the two local Social Services Departments to launch a Low Vision Centre from early 2003. The new facility complements specialist services at Moorfields working alongside City University's Department of Optometry, and to a lesser extent at the Royal Free Hospital,, as a more general service for local residents.

Patient pathway.

C&ILVSG has contributed a patient pathway as a test case for local pilots. Figure 11.2 provides a text and diagrammatic summary. Further refinements required before implementation are acknowledged. Apart from announcements of comparable work in Oxfordshire (LVSIG, 2002), this may be the only working example in the field.

Patient information.

With support from RNIB and local Social Services, C&ILVSG has also developed a directory of local and national contacts (C&ILVSG, 2001). Contents pages are reproduced in Figure 11.3 for illustration. It is being placed on Local Authority websites at HJL's request and would be reformulated in XML for easier retrieval and local production in accessible formats ahead of pilots (see 10.5.4 and Table 10.8 for technical details).

The directory has been distributed around the two Local Authorities and is available from hospital social work departments. It also supports hospital information desks

developing at the Royal Free Hospital Trust and pioneered by patient representative groups on the C&ILVSG.

A much broader range of information topics has been identified (Table 6.9). At this stage, a more realistic set for online provision would include:

- Simple explanation of the Notification process, local procedures and estimated timescales.
- Statutory benefits relevant to the individual patient (and. Carer).
- Explanation of technical terms in layman's language.
- Contact details, such as the C&ILVSG directory, but also tailored to the patient's diagnosis and domestic arrangements/occupation.

The Data Quality Framework includes proposals to validate information providers (paralleling the official policy for validating organisations involved in health and social care research). This application of the DQF would allow proposals to be refined in practice through assessments of relevant local providers in the Camden & Islington area. Principles behind the general idea of "kite marking" might also be developed, along with mechanisms for keeping resources like the C&ILVSG directory up to date.

11.4.3. Contacts with organisations and programmes before applying DQF Part 2.

An electronic approach to Notification risks duplication of effort and inconsistency with other, larger programmes. Accordingly, the following contacts would be made ahead of pilots.

NHS Information Authority Terms and Coding Section - confirmation that all items on forms are covered by the Read/SNOMED system for current data management and future form completion direct from electronic records.

Related National Service Frameworks – for exploitation of overlaps and a consistent approach to data and project management; **and to make explicit links with visual impairment.**

NHS Direct and Care Direct (main NHS organisations/sites with basic information on disorders in general and support for older people) - for a consistent and complementary approach to information resources.

The Royal College of Ophthalmologists and College of Optometrists - for reliable definitions of technical terms in layman's language.

Table 11.2. Summary of steps to improve data for professionals and information for patients in the Visual Impairment Notification process, using Part 2 (Implementation Programme) of the Data Quality Framework.

Stage 1. Initiation.

DQF Item	Response/Activity
a. Confirm the scale and remit for the programme.	Development of a new dataset (form) and processes for Notification in England.
b. Identify the groups, professions and sites affected directly or indirectlyby the dataset.	Organisations and patients (see 6.2.3). Wider stakeholders (see Table 6.2).
c. Establish a representative steering committee and advisory groups within a recognised project structure and management methodology.	PRINCE 2 methodology (see 10.3.2). **Management Board:** Department of Health, Association of Directors of Social Services, Office for National Statistics, professional representation (Colleges of Ophthalmology and Optometry) and related National Service Framework programmes. **Technical Board:** NHS Information Authority, a digital security company, and contacts from participating hospitals, Social Services Departments and corresponding Primary Care Trusts. **External Reference Group:** Camden & Islington Low Vision Services Group (forum of professionals and patients).

Stage 2. Development.

DQF Item	Response/Activity
a. Model the care process with full representation of care activities, data sources and points for information provision.	Current Notification process outlined in Figure 6.2. Electronic approach summarised in Figure 6.4. Possible adjustments acknowledged for GPs and opticians as initial points for patient identification. No recognised "care pathway", particularly for provision of low vision services (assessment & training to use residual vision). Models developing, eg. Camden & Islington Low Vision Centre working in cooperation with hospital eye departments and funded by Social Services. **Nominal care process and points for information provision:** Initial identification and/or diagnosis (GP, optician, hospital); Diagnosis and Prognosis (hospital); Registration and Subsequent Support (Social Services); Low Vision Services (hospital, optician, specialist centre).
b. Specify the dataset(s), collection process and any special requirements for exchange.	Main dataset (BD8 and consultant fee form) illustrated in Figure 6.5. BD8 items mapped to Read/SNOMED terms in all cases - any additions notified to the NHS Information Authority. **Change of work practice:** Forms completed in hospital by consultants with options for completion of relevant sections by nurses, social work and support staff. **Options for completion and dispatch:** Online with digital signatures and encrypted dispatch; Locally online completion (hospital intranet or individual machines) with printing, signatures and postal dispatch; Fully paper process with form designs comparable to electronic equivalents.

Stage 2. Continued...

DQF Item	Response/Activity
c. Specify requirements for patient information.	**Information by stage of process (but available at any stage):** **Identification of significant sight problems:** details of the local Notification process, sources of immediate support, and benefits/national support schemes available on registration. **Diagnosis/prognosis:** layman's description of technical terms, organisations tailored to the condition and/or other individual patient characteristics. **Primary sources of information:** Department of Health; Social Services/Primary Care Trusts/hospitals; Local voluntary organisations; Professional Colleges (Ophthalmology, Optometry); Major charities.
d. Assess the potential for web technologies to deliver patient information locally.	Cooperation across primary sources of information. Indexing of information resources (metadata - see 10.4.3). Preparation of resources in convertible formats (XML technologies - see 10.4.4). Local access to the Web and peripheral devices by care professionals. Tailored search mechanisms based on fields from the BD8 form (postcode, age, sex, ethnicity, diagnosis).

Stage 2. Continued...

DQF Item	Response/Activity
e. Design and implement a pilot on an appropriate scale. Measure in particular: the volume and final formats of collected datasets; costs and benefits to patients and care delivery organisations.	6 month programme in the old Camden & Islington Health Authority. 60 consultants in 6 main hospitals and 2 Social Services Departments/Primary Care Trusts. Estimated 1500 registerable patients but only 150 (10%) from the C&I area - figures based on averages for a consultant and a Social Services Department (see 6.3.2), with C&I area distorted by the large number of consultants.
f. Compile the evidence for change in a format appropriate for consideration by the Information Standards Board, or an equivalent local organisation, as the Business Case for implementation or further development.	Current best summary ahead of pilots (DQF initial appraisal - Table 11.1).

Figure 11.2. Pathways to services for visually impaired people in the Camden & Islington Local Authorities. (Modified from C&ILVSG, 2003b,c).

Three overlapping pathways have been identified, with the Clinical Pathway as the focus of this Figure through a text description (Panel A) and diagrammatic summary (Panel B).

Clinical Pathway	Access to specialist medical examinations and treatment, and advanced optometric assessments (visual function), with referral to other services as appropriate.
Service/Support Pathway	Additional assistance (assessments, equipment, training, finanical benefits, human help) to support daily life.
Financial Pathway	Who pays - controls the other pathways.

A. Explanation of components in a draft Low Vision Clinical Pathway.

Community based referral	
Description	Practice Nurses, Community Groups, Social Services and similar who encounter the public at home or in the community.
Action	Identify functional sight related problem and suggest visit to GP or optician/optometrist.
Deliver patient to	GP or optician/optometrist.
Note	Useful in accessing people with slowly degrading sight and groups who have not access any agency or the system before (eg. those with language difficulties).
Opticians and Optometrists	
Description	People with chronic problem who have been visiting Opticians and Optometrists but whose sight problem now needs medical and/or specialist optometric assessment.
Action	Refer to GP.
Deliver patient to	GP.
Note	Clinical judgment unlikely to be reversed, but no access to clinical funding.
General Practitioner	
Description	Main point of referral to specialist medical services and community assistance.
Action	Assess problem and options with the patient/supporter.
Deliver patient to	Refer to ophthalmologist or Casualty (A&E for relatively minor problems.
Note	Start of funding. Costs determined by speciality of the referral.
Casualty	
Description	Self or GP referral for acute but relatively minor problems.
Action	Assess severity of acute incident.
Deliver patient to	Home or ophthalmologist.
Note	

Accident & Emergency	
Description	Trauma injury.
Action	Receive trauma patients and assess.
Deliver patient to	Hospital admission and/or specialist opthalmologist.
Note	
Ophthalmologist	
Description	Medical specialists.
Action	Treatment, diagnosis and possible certification.
Deliver patient to	Follow up appointments, Low Vision Services, Social Services.
Note	Waiting lists for appointments with no fast tracking mechanisms. Often slow to refer patient to Low Vision Services and/or Social Services.
Certification by consultant ophthalmologist	
Description	Completion of form BD8 to certify patient as blind or partially sighted (or with a significant but non registerable problem).
Action	Completion and dispatch of form (with assistance from support staff).
Deliver patient to	Local counsellor, Low Vision Services, Social Services.
Note	Low Vision Services not necessarily available at the hospital.

Low Vision Services	
Description	Functional assessments, training and equipment to maximise residual vision, provided by specialist optometrists.
Action	Assessments and recommendations.
Deliver patient to	The referring professional (ophthalmologist, Social Services, GP).
Note	
Social Services (Sensory Services Teams)	
Description	Local Authority Social Services Departments are responsible for coordinating community support for disabled people.
Action	Rehabilitation, mobility training and home aids. Invitation to be registered (effectively decided on certification).
Deliver patient to	Low Vision Services and/or other specialist assessment/training organisations.
Note	

B.

Diagram of the Low Vision Clinical Service Pathway

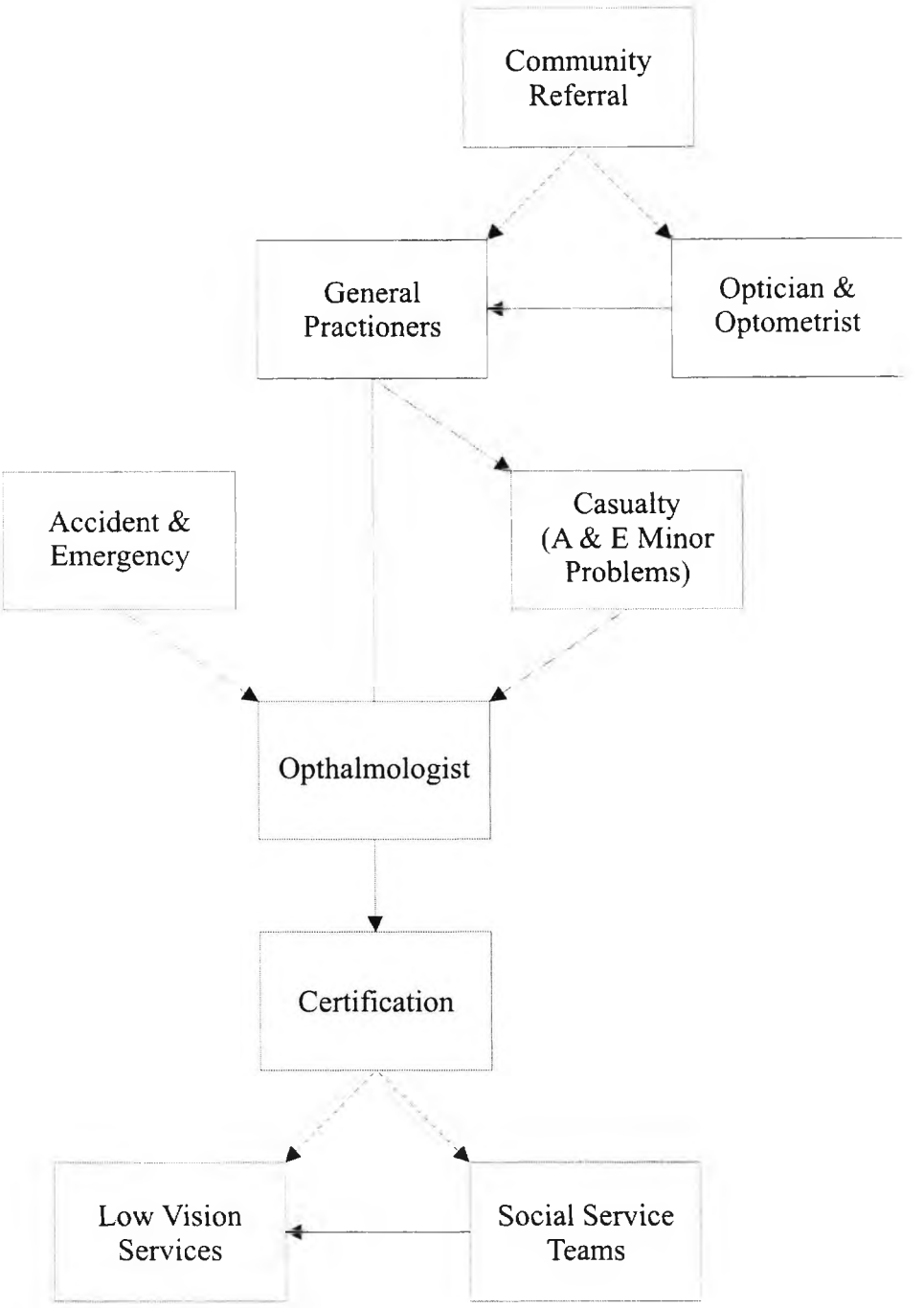


Figure 11.3. Opening pages from draft version of a directory of local and national contacts for visually impaired people in the Camden & Islington Local Authorities. (From C&ILVSG, 2001).

Camden and Islington

Directory of services for people with sight problems

Produced by Low Vision and Prevention Services, Royal National Institute for the Blind (RNIB) on behalf of the Camden and Islington Low Vision Services Group.

Contents

11.5. Summary and conclusions.

This chapter has applied the Data Quality Framework (DQF) formalised in 10.5 to Visual Impairment Notification in England introduced in chapter 6 and updated in 11.2. The aim was to assess the Framework against a real world example using five questions from the Introduction as guidance. The inconsistency of assessing an untested Framework against a currently poorly specified care process is resolved in this last section by comparing the DQF approach to the ongoing Review of Notification by the Department of Health.

Department of Health review.

DoH has not published a formal analysis of the Notification process, or a collation of results from a public consultation. Links have not been made to logically related National Service Frameworks. Furthermore, preliminary proposals do not include recommendations for the general organisation of services; performance monitoring; or plans to test changes before widespread implementation.

According to RNIB, who prompted the review, Notification "has not changed substantively" since 1948 (Cox, 2001). It would be bold to conclude that the mechanisms summarised above will lead to targeted, coordinated and measurable change. These conclusions are also supported by responses to the DoH decision to introduce the new process in November 2003. The official Review Group had not been contacted in over a year; and affected local organisations were given no advanced warning or guidance.

Use of the Data Quality Framework.

In contrast, adoption of the DQF places the emphasis on details of data for professionals and information for patients. It assumes that such steps improve care processes and cost considerations for all parties.

Key information about the prevalence of sight loss in the general population as a measure of performance by the Notification process was not covered. This would involve additional epidemiological data and was logically the subject of a separate collection process. Equally changes to certification forms (BD8) as well as completion and dispatch procedures remain untested.

Nevertheless, use of the DQF has answered four of the five test questions from the Introduction. Detailed research has identified problems with the existing Notification process. Options for computerisation have been considered and related to specific actions. Change, in paper or electronic formats, is justified with potential developments advocated through pilot programmes.

Direct comparisons of the DQF approach with the DoH Review.

Comparisons required by the fifth question from the Introduction suggest that the DQF goes well beyond the DoH review. Anecdotal evidence is replaced by a requirement for supporting data. Information for patients is explicitly addressed. Modelling for a process that has no recognised "care pathway" compares delivery in different geographical areas in preparation for extended pilot programmes.

As the essential difference from the DoH review, the DQF treats forms such as BD8 as national datasets. They are therefore covered by the formal approval process from the Information Standards Board. If this premise is true, principles behind the DQF

for a more structured approach should apply. Moreover, preliminary proposals from DoH would (arguably) fail.

Chapter 12

Conclusion

12.1. Introduction.

The closing chapter concludes a broad programme of work conducted over almost 15 years. The approach focused on improving data quality in English healthcare and is judged against the hypothesis and objectives established in chapter 1 (section 12.2). Contributions to the field are then addressed (12.3). As the main product of research with several dimensions, the Data Quality Framework is considered for future development in the final section (12.4).

12.2. Review of the hypothesis and objectives.

This Thesis proposed that healthcare delivery, management and research were all constrained by limited attention to data quality including information for patients. Four example domains were examined in detail. From Intensive Care to Visual Impairment Notification, they arguably spanned the range of care from quantity to quality of life.

Each Case Study had input from significant organisations in the field, and brought past research up to date. The common feature was indeed poor data quality. In some cases, there had been no improvement over the lifetime of this Thesis, and problems could often be inferred from the literature without special research.

The Thesis also argued that such Case Studies, as a representative sample, provided sufficient information to develop generic solutions to data quality problems. Prominent Themes were extracted to focus further work covering: design of datasets;

practicalities of collection; relevance of supporting information for patients; potential use of technology; and overall costs.

The broader context was provided by reviewing recent Government policies and strategies for Information Management & Technology in healthcare. Demands for data were increasing with new approaches to service monitoring and management. At the same time, basic components of the supporting Information Infrastructure were not in place.

A Data Quality Framework (DQF) was required to address the Prominent Themes from real world examples. Acknowledgement of Government policies was a further condition but, in reality, there was little support from IT delivered under recent NHS modernisation strategies.

Development of the DQF was based on recent central initiatives paralleling issues raised by the Prominent Themes. Separately they covered: formal approval of significant datasets in the NHS; modelling care processes as the source of raw data and points for information provision for patients; accrediting information providers; and standards emerging in the public sector to improve description and retrieval of information resources.

The DQF combined the initiatives and made adjustments for scale and assumptions about available technology. Complementary Parts assessed established datasets and collection procedures (the Appraisal Tool), and provided support for introducing change (the Implementation Programme).

The DQF was applied to Visual Impairment Notification as the broadest and most recent of the earlier Case Studies. Moreover, Notification was also subject to a Department of Health review which began in late 2001, initially promised recommendations by Summer 2002, remained incomplete at Summer 2003; and produced a confusing press release in the Autumn of 2003 introducing a new process by November with no advanced warning or guidance.

Evaluation faced the logical inconsistency of testing the DQF and the Notification process in the same step. This was resolved by comparing the DQF approach with the review and preliminary recommendations adopted by the Department of Health.

The relevant chapter argued that forms involved in Notification were effectively national datasets and therefore covered by the logic of the formal NHS approval process. The Department had not provided any data, beyond anecdotal evidence, to justify and direct change. In short, the official review and proposals contravened the Department's own policies on change management.

In contrast, the DQF incorporated the approval process as well as the three other central initiatives of relevance. It has been used to appraise the current Notification process, and the Department's preliminary proposals, to specify problems and suggest a programme for managed improvement.

Local and national organisations have taken an interest in plans for fully electronic pilots in the old Camden & Islington Health Authority. The principle that forms in electronic and paper formats should be equivalent allows comparable pilots in other areas with less advanced technology in place.

However, use of the DQF to support change management in this example is incomplete. More detailed work at this stage would be misplaced if, as signs indicate, the Department of Health changes the basic structure of the Notification process.

Overall, the collective research for this Thesis supports all components of the hypothesis. Data quality is a demonstrable problem in English healthcare. There are significant common themes from real world examples; and general principles, at least, for introducing change. The specific example of Visual Impairment illustrates that limited attention to data quality in reviews of care processes does indeed lead to confusion and delay.

12.3. Contributions to the field.

Part 1 of the Thesis concentrated on real world problems attributable to data quality and which were receiving unusually limited attention.

As a prime example, long term care of diabetes depends on regular monitoring by patients themselves (home data). Until chapter 4, there were no known studies of home data collection and no methods for monitoring quality over time. Such methods, based on Bayesian time series analysis, were developed and generalised for use in other areas of direct care, management and research (see Appendix 1).

There were no assessments of national data collection in Intensive Care, not even from the Audit Commission, until chapter 3. Before minor changes to data collection and analyses reported in chapter 5, there was no formal evidence of improvements in A&E waiting times from a qualitative study commission by an NHS Trust.

In addition, chapter 6 remains the only contemporary and publicly available assessment of the Visual Impairment Notification process in England. Extensions in chapter 11 provide the only plans for local electronic pilots and wider use of a new notification form which are in line with official Government policy with adjustments supported by evidence. Those chapters highlight the contradictions of limited reported activity from the Department of Health Review, and no official statement on problems and objectives, despite Government commitments to better informed patients and wider public consultation.

Part 2 of the Thesis developed the Data Quality Framework as a generic solution to the collective evidence of data quality problems. It began, in chapter 9, by highlighting inconsistencies of Government policies and IT strategies for healthcare. Despite the evidence of problems in the field, demands for national data and information for patients were increasing as political objectives. Three IT strategies between 1998 and 2002 suggested management problems at the top level; and key issues of cultural and organisational change did not become mainstream research topics for the NHS until 2003.

Chapter 10 accommodated evidence from the real world (the Prominent Themes) as well as the inconsistencies of policy (the National Considerations). Four central initiatives were deliberately selected as the basis for the DQF. Parallels with the Prominent Themes were clear, but the connections had to be made and adjustments were required to remove assumptions about widespread availability of technology.

Links to central initiatives provided evidence that issues of quality data in healthcare and information for the public generally were, despite direct experience from the Visual Impairment programme, becoming more important to politicians. They also directed the DQF towards existing areas of research.

In summary, this Thesis has contributed a combination of constructive criticism, specific research results, and a logical basis for a new methodology.

The Case Studies were wide ranging, detailed and presented with a common structure. The DQF addressed the empirical evidence and was consistent with the broad direction of Government policy.

Above all, the Thesis confronted practical problems attributable to data quality which other researchers appear to have consistently overlooked.

12.4. Recommendations for the Data Quality Framework.

The DQF represents a principle rather than a fully developed methodology. Details may change between areas of application, and contributions from IT are likely to increase. However, the DQF is possibly the only example of its kind in English healthcare, extending beyond the data quality Accreditation Process for the NHS reviewed in the annex to chapter 9.

The logic of underlying concepts suggests that approaches like the DQF should improve care delivery and the pace of change, with implications for all branches of healthcare. New medicines or care processes, when accompanied by practical and technical specifications for data collection, are likely to be introduced more quickly. Better information for patients may promote trust, more realistic expectations and greater cooperation with care planning, appointment keeping and recommendations on treatment.

A consistent approach to the quality of data and patient information is required for organisations with the size and complex structure of the NHS. Recent Government policies and IT strategies have not been supportive. Equally, organisations outside formal healthcare have not made constructive contributions. Recommendations to support approaches like the DQF on a national scale therefore include:

- A more consistent and open approach to IT strategies, with more advanced warnings of change and clearer links between the many sub-initiatives.

- Replacement of parallel programmes in health and social care with a more explicit and integrated policy on issues of data for professionals and information for patients.
- More frequent and reliable evidence on the state of data collection and access to technology in individual organisations.
- Greater cooperation between organisations providing patient information - notably charities.
- Replacement of lumped budgets on IT investment with public accounts that clearly show the costs and benefits of national data collection and patient information provision.

The approach in this Thesis has combined real world experience with official policy and practical adjustments. Limitations have been acknowledged, but an empirical and logical case for a Data Quality Framework has been made. Direct use in the field, coupled to the above recommendations, may now be the best route for refining the Framework and promoting wider acceptance.

Appendices, Acronyms and References

Appendix 1

Bayesian Time Series Analysis (BATS).

Time series analysis aims to extract and monitor patterns in regularly collected data. Examples were given in chapter 4 (data collection and disease control among diabetics – Figures 4.4-4.8) and chapter 5 (hospital admission rates via an A&E department – Figure 5.6).

The method was based on Bayes' Theorem and implemented the BATS framework from Pole, West and Harrison (1994) which was in turn based on the mathematical theory from West and Harrison (1989). Subsets of the relevant matrix algebra were programmed in Turbo Pascal 6.0 (Borland Inc.) as part of the diabetes project and as a research tool.

This Appendix presents:

- Time series and Bayesian principles, including parallels with standard statistics and criticisms of Bayesian approaches.

- The top level BATS framework with the main Observation and Signal Evolution Equations.

- The statistical formulation and related matrix algebra behind the Bayesian updating cycle (the main feature of the Pascal version).

- The structure of signals, as individual components contributing to an overall parametric equation; along with recommended starting conditions and special treatment of periodic (or cyclical) features in data.

- Performance of the Pascal version compared with the official BATS framework (using software accompanying Pole's publication) and illustrating principles raised earlier in the Appendix.

- Additional applications for monitoring features of data quality and investigating alternative aspects of the same data series; and highlighting parallels between BATS and statistics used in clinical trials.

Tables and figures are grouped at the end of the Appendix.

A. Introduction.

Time series.

A time series is a sequence of measurements on a single variable ordered by time. Measurements are made at roughly equal intervals and time can therefore be replaced by a counting integer (typically t). Data may be assumed to have a constant variance (a stationary series) or a varying spread (non-stationarity).

Variables are usually measured on a continuous scale (large or real values as opposed to small integer counts). This reflects the influence of economics as the major domain behind time series developments, with a focus on aggregate data covering activities and costs. BATS shares this bias, but methods tailored to qualitative data (with two or more response categories) are also emerging (eg. Collette, 1996). (See also parallels between the normal and qualitative distributions raised later in this section).

Analyses (signal and noise).

Analysis aims to identify systematic patterns which explain the data variance and relate to the measurement sequence. Patterns might also be called "signals", with the data variance as the "noise". Both terms are common in engineering and have an important relationship and use in all methods of time series analyses (signal:noise ratios for parameter adjustment).

ARIMA modelling is the traditional approach (Box and Jenkins, 1976). Successive measurements may be directly related (Auto Regression) with systematic growth or decline (Integration) and random effects (Moving Average).

More recent approaches compare with ARIMA modelling, but the concept of "signals" is perhaps easier to appreciate. Representations use combinations of growth

curves (trend) periodic patterns (cycles) and influences from other variables measured along with the main series (explanatories). Components are formulated as parametric equations (parameters have statistical distributions).

Bayesian approach.

Bayes' Theorem (after Thomas Bayes, 1702-61) is a mechanism for adjusting two probability statements to yield an updated statement. Statistical distributions for parameters and individual measurements are example statements from the field of time series. Pole et al. have therefore adopted the Theorem because it is an inherently sequential mechanism for adjusting signal parameter estimates with each new time series data item.

BATS is restricted to probability statements using the normal distribution. This is not necessarily a limitation because (see Tietjen 1986, chapter 3): many natural variables are normally distributed; means and variances from other distributions also tend to be normally distributed; and the normal is the limiting case for some qualitative (or categorical) distributions when sample sizes are high (eg. the binomial and multinomial distributions).

Specific probability values are computed with the normal probability density function (PDF). Table A1.1 gives the symbols and formulations for PDFs and corresponding distributions. Note the formulations for a standardised normal distribution and an alternative standardised form used in BATS.

Note also the important concept of a "conditional probability". The example of $p(x \mid y)$ means the probability of the value x computed under the distribution y (ie. where x falls in the distribution y).

Bayes' Theorem itself, with signal parameters and a new data item at time t (θ_t, y_t) and Y_t denoting the whole series up to t, may be stated:

$p(\theta_t \mid Y_t=y_t) = p(y_t \mid \theta_t).p(\theta_t)/p(Y_t=y_t)$

Terms and interpretations are:

$p(Y_t=y_t)$	A **Scaling Factor** – the distribution for the time series in which the current value gives a probability maximum (ie. yt is adopted as the current mean of the series Yt).
$p(Y_t=y_t \mid \theta_t)$	T**he Likelihood** – the probability that yt comes from the distribution for the current parameter set (appropriately combined, θ_t defines the mean for the signal predicted at t).
$p(\theta_t)$	TT**he Prior** – the distribution for the parameter set in which the current unadjusted values give a probability maximum.
$p(\theta_t \mid Y_t=y_t)$ new data value.	T**he Posterior** – the adjusted parameter set in response to the

The Likelihood may be interpreted as an error term (difference between the current time series value and the signal mean predicted by current parameters). In BATS, the corresponding value is called the Forecast Error, and a multiple is added to the parameters as part of the adjustment process.

The multiplier is determined by the ratio of parameter to time series variances - $p(\theta_t)/p(Y_t=y_t)$ - which may be different for each parameter in the set (ie. a vector of multipliers with the time series variance as a common denominator). The parameter variance falls with each data point (in theory, point values become more accurate) and so the multiplier itself also adjusts with each data item.

Pole uses the term "Adaptive Factor" for this multiplier. It compares with the "signal:noise ratio" raised earlier. The larger the ratio (the closer the parameter and data variances) the greater the adjustment.

BATS'Adaptive Factor actually uses the combination of parameter and data variances (the Forecast Variance) as the "noise" denominator. Logically, this indicates that parameters have a range of possible values in addition to the data variance around any particular value set. Mathematically, it reduces the degree of adjustment at each time point t. Comparisons with standard statistics (see below) show that the adjustment expected at the next time point (t+1) is instead performed at t. (ie. The predicted sequence of adjustments moves forward by one position).

Note also that Bayesian updating may be expressed in proportional form (Posterior α Likelihood.Prior). Here, ignoring the Scaling Factor - p(B) - is equivalent to setting the time series data variance to 1 (recommended below when the actual value is unknown).

Global versus local parameters (discounting).

Parameters may be estimated on the whole series up to t (Y_t) with each item treated equally (global parameters). This shows how individual items contribute to final results when a complete dataset of known size is already available.

Alternatively, contributions from the most recent data may be emphasised to generate local parameters. This is useful in a continuous monitoring programme when the ultimate sample size has no practical meaning (is effectively irrelevant) and details of changes in a specified signal are the important feature.

Global parameter estimation follows a set sequence of signal:noise ratios which fall as t increases (see the next sub-section). In contrast, local estimation makes special adjustments to the ratios.

The special method in BATS is known as Discounting. It effectively fixes the signal:noise ratios (Adaptive Factor) at a set level by following the reduction of parameter variances (as for global estimation) with the addition of the same

proportion from the data at time t. Similarly, an Adaptive Factor set initially to a higher value will fall until it reaches the set level.

The balance of reductions and additions to variances has a further consequence. Contributions from data at any point t falls exponentially as t increases and other data items are considered. The effect may be interpreted as a time window in which adjustments at any t are still contributing to the updating process (the size of the window is determined by the size of the discount factor).

Parallels with standard statistics for global parameters.

global parameter estimation in BATS and statistics are equivalent. The connection is again the signal:noise ratio. In standard statistics, it is found in its inverted form (noise:signal) in texts on sample size calculations (eg. Armitage and Berry, 1987, pp179-85). With t as the sample size (more usually denoted by n), the relationship is given by:

t = Variance of the data/Variance of the mean

and equivalently,

t = (standard deviation)^2/(standard error)^2.

This shows how variance relationships, under statistical assumptions, are totally predicted by t. The parameter variance (usually represented by the standard error - SE) is also used to express confidence intervals for parameters (eg. mean +/- 2SE for the 95% interval).

BATS analyses may assume a constant time series variance. This predicts that parameter variances must fall correspondingly to give the correct value for t. Equivalently, parameter variance can be determined from t. When the time series variance is nominally set to 1, parameter variances become fractions Results can be

scaled later when an accurate time series variance is available. (Note the link with Bayesian updating in the proportional form).

The sample size equation in its inverted form predicts the sequence of signal:noise ratios as 1/t. BATS reproduces this sequence when set to compute a global mean (though note use of parameter and data variances as the noise component in the Adaptive Factor actually gives a sequence of 1/(t+1)). Local parameter estimation (discounting with a set signal:noise) also reproduces aset ratio appropriate for the degree of discounting. (See later Figures).

Potential criticisms of the Bayesian approach.

Bayesian approaches have been criticised by economists and mainstream statisticians. For example, Harvey (1989) prefers the apparent rigor of parameter re-estimation using the Kalman filter from engineering. Armitage and Berry (1987) dismiss computations involving researchers' own opinions (adjustments to parameter means and variances to reflect alternative assumptions).

In fact, the Kalman Filter is an application of Bayes' Theorem (see Tietjen, 1986, p142) and Harrison (of Pole, West and Harrison) is attributed with bringing the Filter into statistics. In addition, and as illustrated above, Bayesian global parameter estimation based solely on data (with items t=1 to t=sample size n) reproduce results from standard statistics using calculations based on n.

B. The top level BATS framework.

Two top level equations show BATS as a system, linking current parameter estimates and signal predictions to parameter re-organisations as the focus moves from time t to t+1. Bayesian updating uses both equations but introduces some aditional steps and symbols (detailed in the next section).

Statistical assumptions and practical decisions about the form of signals are also raised below. They place some constraints on the nature of time series which may legitimately be analysed as well as the interpretation of results. Further constraints on analyses in earlier chapters are shown by advanced features of BATS omitted from the version programmed in Pascal.

B1. BATS' top level equations.

Observation Equation.

This describes the signal estimated at t. The right hand side is a prediction or forecast based on data up to t-1.

$y_t = F' \theta_t + \eta_t$ $\eta_t \sim N[0,V]$

y_t - the observed value from the time series at t.

θ_t - the parameter set or signal vector.

F - signal reconstruction vector of known constants defining how parameters are

combined to form the full signal.

V - variance of the observed time series.

η_t - random error term for the observation, drawn from the specified normal distribution

(representing the spread of the time series around the predicted signal).

Signal Evolution Equation.

This specifies parameter subsets and how they are combined specifically when moving from t to t+1 (different from combination to form the signal). It completes the Bayesian updating process ready for the next measurement (see D2, step 4). As an example, a signal represented by a straight line fit (level+slope) requires Bayesian updates to parameters as well as the combination of level+slope to give the level at the next t.

$\theta_{t+1} = G.\theta_t + \Omega_t \; \Omega_t \sim N[0,W_t]$

G - signal evolution matrix of known coefficients defining the parameter re-combinations

after updating.

W_t - signal parameter covariance matrix.

Ω_t - random error term for the signal parameters, drawn from the specified normal

distribution.

B2. Practical decisions and statistical assumptions.

In a basic BATS application, statistical calculations and interpretation of results are simplified by:

- Assumption that the time series variance is constant (stationary series) - though this may be partially addressed by discounting (local parameter estimation).

- The linear formulation of the model with additive components.

- Use of a constant signal format with a fixed reconstruction vector (F) and evolution matrix (G) - ie. the signal "template" is fixed but parameter estimates can vary.

- Probability statements using only the normal distribution.

- Assumptions that random error terms for the time series data and signal parameters (η_t and Ω_t)) are independent.

B3. Omissions from the Pascal version of BATS.

Two advanced features were considered unnecessary for the analyses cited in earlier chapters and were therefore omitted from the Pascal programs.

Variance learning. BATS allows the time series variance to be monitored along with signal parameters. Estimates are based on t and the cumulative error - (Forecast Error)^2. There is also an option to relate variance to the expected signal mean through a variance power law ($V=V^{*k}$). These additions explicitly support non-stationary series.

Backward smoothing. The Pascal programs consider data items in their original order (forward smoothing). However, BATS also allows estimates at t to be re-adjusted after results for t+1 are available through an additional application of Bayes' Theorem. The approach is equivalent to running the analysis forward (with t = 1 to n) and then reversing the process (with t = n back to 1).

C. The Bayesian updating cycle.

C1. Relation to the top level equations.

Bayesian updating adjusts parameters from current values (the Prior) to new values (the Posterior) in response to a data item, all at time t. The Observation Equation provides the estimated signal, allowing the Forecast Error to be derived and used in updates.

The Signal Evolution Equation may be seen as the last updating step - moving from the Posterior at t to the next Prior at t+1. It is also the step where local parameter estimation may be introduced (through discounting - see C3).

Note that Pole's description of BATS uses one set of symbols for the top level equations, and another for the statistical quantifications and matrix manipulations. This is assumed to be a teaching device, separating probability statements from formulations in matrix algebra. The matrix algebra in C2 can be used without any additional statements because the underlying probability aspects are implied.

In practical terms, the following mappings apply (from top level equations to the updating matrix algebra):

θ_t t to a_t - for the parameter point estimates.

W_t to R_t - for the parameter covariance matrix.

D_{t-1} - the historic information up to time t-1 (a shorthand or conceptual term used with θ_t

to summarise past statistical information about parameters and adjustments).

C2. Steps in the cycle.

1). The Prior.

θ_t contains the prior point parameter estimates based on the historic information (D_{t-1}) and before considering the current time series value. The two quantities are presented as a conditional statement with a specified normal distribution (ie. The theoretical estimates based on past data).

Eqn A1.1. Prior information about the signal parameters.

$\theta_t \mid D_{t-1} \sim N[a_t, R_t]$

2). Forecast.

A forecast is generated from the Observation Equation using the Prior parameter information. The forecast has a normal distribution where the variance is a function of both the parameter and time series values.

Eqn A1.2a. Forecast point estimate (signal mean).

$f_t = F_t'.a_t$

Eqn A1.2b. Forecast variance.

$Q_t = F_t'.R_t.F_t + V$

Eqn A1.2c. Forecast distribution.

$y_t \mid D_{t-1} \sim N[f_t, Q_t]$

3). The Posterior.

In terms of matrix algebra.

The posterior mean is adjusted from the prior value by a multiple of the one step ahead Forecast Error. Covariances are adjusted by a multiple of the forecast variance. The multiple or Adaptive Factor (A_t) is determined by the relative size of the prior signal parameter and forecast variances (version of signal:noise).

Eqn A1.3a. Forecast error.

$e_t = y_t - f_t$

Eqn A1.3b. Adaptive Factor.

$A_t = R_t.F_t/Q_t$

Eqn A1.3c. Posterior mean.

$m_t = a_t + A_t.e_t$

Eqn A1.3d. Posterior covariance.

$C_t = R_t - A_t.A_t'.Q_t$

In terms of probabilities.

The matrix algebra implements calculations which effectively multiply two probability density functions (PDFs) and then scale the result. The main PDFs cover the Likelihood and the Prior. The Scaling Factor is the distribution for the time series with the current value adopted as the mean. (Note the simplified PDF formulation used by BATS and introduced for comparison with other formulations in Table A1.1).

The Likelihood is the PDF for the forecast distribution evaluated at the actual time series measurement. The difference between this value and the maximum given by the current parameters as the signal mean is related to the Forecast Error.

$$p(y_t \mid \theta_t, V) = \exp(-(1/2)V^{-1}(y_t - F.\theta_t)^2)$$

The Prior gives a maximum probability at current parameter values ($\theta_{t(}$.

$$p(\theta_t \mid D_{t-1}) = \exp(-(1/2)(\theta_t - a_t)'R_t^{-1}(\theta_t - a_t))$$

The Scaling Factor gives a probability maximum for the current time series value. The ratio of PDFs for the Prior and Scaling Factor reduces to the relationship between parameter and data variances. When parameter variances are added to the data variance, this ratio becomes BATS' Adaptive Factor.

4). Posterior to Next Prior.

The Next Prior (for t+1 based on updating at t) is given by applying the Signal Evolution Equation. Parameter means and variances are re-organised (using G) to give the starting conditions at the next t. Updating is reflected in the historic information term (D) by incrementing its subscript. The term W_t included in covariance adjustments (Eqn A1.4b) is addressed in the next section under "discounting".

Eqn A1.4a. Next prior set of signal parameter point estimates.

$a_{t+1} = G.m_t$

Eqn A1.4b. Next prior signal parameter covariance matrix.

$R_{t+1} = G.C_t.G' + W_t$

Eqn A1.4c. Next Prior Information set as a normal distribution.

$\theta_{t+1} \mid D_t \sim N[a_{t+1}, R_{t+1}]$

C3. Discounting and missing data.

Parameter variances fall with each data item as predicted by standard statistics (and incorporated in Eqn A1.3d). However, the last updating step in BATS includes a special addition to the parameter variances (W_t) in Eqn A1.4b). The balance between these operations determines the Adaptive Factor at the next t and is controlled by a Discount Factor ($0<\delta<=1$). (Separate factors may be specified for each signal component).

Eqn A1.5. Next Prior covariance matrix with discounting (replacing Eqn A1.4b).

$W_t = ((1/\delta)-1)\, GC_tG'$

and

$R_{t+1} = G.C_t.G' + W_t$

When $\delta=1$, no additional parameter variance is contributed and updating reduces to global parameter estimation. Lower values contribute a set proportion at each t, but their influence at subsequent t diminishes because of the variance reduction at later updating cycles. The effect of any contribution at a given t decays exponentially over a time or window size determined by δ (for $\delta=0.95$, the window size is around 20).

Missing time series values leave parameter means unaffected, but corresponding variances are increased to reflect greater uncertainty. The variance subtraction in Eqn

A1.3d changes to an addition. Parameter confidence intervals increase as a direct consequence and the Adaptive Factor (signal:noise) is greater at the next t (more "sensitive" to change).

D. Signal formulation and starting conditions.

Typical components with full parametric formulations (trend,, cycle, explanatories) are given separately in Table A1.2. Cyclical components must be rotated at each t to keep the focus on the correct point in the period. Table A1.3 shows the rotation scheme for cyclical parameter means and variances.

D1. Block structuring.

Signals are a linear combination of individual components. Table A1.4 illustrates how signal components are organised using block structuring. Each component may be individually manipulated before all are re-combined into the overall signal.

The signal parameter vector (a_t) stacks the individual component parameter means. The Signal Reconstruction vector defining combination of parameters in the full signal (F) stacks the individual reconstruction vectors. The parameter covariance matrix (R_t) as well as the signal evolution matrix (G) are structured block diagonally. The order must be the same across all components.

D2. Starting conditions.

Recommendations below are appropriate for global estimation or exploratory analysis. BATS provides a "reference" option to obtain representative starting conditions based on an early segment of the data. Table A1.5 provides example starting conditions for a signal with a simple mean (trend component) and a cycle

with period 4 (4 cyclical effects or periodic departures from the mean over each set of 4 measurements).

The choice of starting conditions should, ideally, be based on statistical information derived from raw data or from justified assumptions (the link with standard statistics at least for global parameters). Researchers can adopt alternative starting conditions to explore assumptions about the relative importance of different signal components and variations in the "environment" for forecasts beyond available data (these are the practices disputed by standard statisticians).

Variances.

All variances must be >0 to support adjustments based on signal:noise ratios. The time series value is best set to 1 if unknown in advance (V=1). Parameter variances should initially sum to V with equal spread across all parameters.

Parameter means.

Initial values should give a signal equal to the first time series value ($F'a_1=y_1$). This setting for a simple mean and global estimation is consistent with standard statistics. More complex signals should set the trend component equal to y_1 and other parameters to 0. Starting conditions may be revised after an exploratory pass through the data.

Discount factors.

Values for δ, with or without different values for each signal component, is a matter of judgement. Pole recommends initial experiments and selections reflecting theory. The purpose of analysis is also relevant. Features to consider include the relative

importance and interpretation of components (eg. cycles v. trend) and the rate of change required to identify significant deviations from expected patterns (appropriate window size).

D3. Cyclical components as a special case.

Periodic components not only require matrix manipulations to keep the focus on the correct point in the period (matrix cycling – see Table A1.3), they also introduce special mathematical and statistical features.

The condition for a cycle that departures from the mean must sum to 0 implies that changes to any given parameter should be balanced by an equal and opposite change spread over the other periodic parameters. The covariance matrix is therefore structured to have a sum of 0 across all rows and columns. The main diagonal should contain a choice of variance X with all other cells containing -X/3.

It is also not absolutely necessary for cyclical parameter variances, in combination with other parameters, to sum to the time series variance (V) at initiation. A cycle is, after all, a set of deviations about a simple mean or trend and may be considered as an additional detail based on the same variance information. (Note also that, in standard statistics, data variance and parameter ranges cannot be computed without first calculating the mean (or expected value)).

HJL's recommendations.

These mathematical and statistical concerns may introduce artifacts into analyses using the official BATS' cyclical formulations. The following additional analyses may be performed for comparison with BATS and to aid interpretation of results.

- Extract the simple mean or trend from the raw data before applying the cyclical model to the residual data series.

- Isolate data corresponding to each point in the series as sets of individual time series. Then apply a simple mean model to each new series.

Time series data with a genuine cyclical component should give comparable results from BATS' cyclical formulations and the above two checking methods.

E. Performance of BATS and the Pascal version.

The BATS publication (Pole et al, 1994) was accompanied by software implementing the framework. Figures introduced below (and presented at the end of the Appendix) compare BATS with a subset of the framework programmed independently in Pascal. They also highlight important features relating to the Adaptive Factor (signal:noise) from earlier sections.

The raw time series data used in the tests were first presented in Figure 4.4 (p118). They are blood sugar measurements made by a diabetic over a three month period. Measurement was recommended four times a day, at the "landmark" times (breakfast, lunch, supper and bedtime). In total, there are 360 measurement points with 27 missing values. The dataset has a variance close to 18.

Global and local parameters.

Figure A1.1a,b compares BATS and the Pascal version using a model with a simple mean and a daily cycle (period 4). Global parameters are generated at each time t (no discounting).

Figure A1.2a,b compares the same model with a discount factor for both trend and cycle (δ=0.95).

Results from the BATS and Pascal programs are equivalent.

Signal:noise ratios (the Adaptive Factor).

Figure A1.3a,b presents the Adaptive Factors from the Pascal version tracking a simple mean. Plots for global and local parameters are given (δ=1 and δ=0.95 respectively).

Figure A1.4a,b provides the Adaptive Factors for global and local parameters for a model with a mean and cycle of period 4.

Note that, in both Figures, the Adaptive Factors are presented as inverses, highlighting the "time window " size when data at any given t are contributing to adjustments.

F. Wider BAT's applications.

Uses of BATS have focused on available time series data in the original collection sequence. There are additional analyses which could be applied to aid interpretation or extract other useful information from the same series. There are also parallels between BATS and statistical methods applied to clinical trials which might be exploited if data are collected online.

Data quality.

The main analyses depend on assumptions about availability of sufficient data and regularity of measurements. Both issues were examined using BATS in assessments

of home data collection by diabetics (chapter 4). Thus it is possible to monitor and test assumptions about data ahead of main signal extraction.

Mathematical simulations of processes generating source data.

Simulation of such mechanisms provide a special class of explanatory variables. BATS' parameters showing a relationship with the series would be both a test of the simulation model and an interpretation of statistical patterns in the series. Time series might also feedback information to the simulation model. Note, for example, that a time series model with an explanatory will track the correlation coefficient after standardising both variables (see eg. relations between blood pressure measurements at various sites during a liver transplant operation - Leicester et al, 1997).

Data re-ordering.

A series may be re-ordered to highlight other information contained in the same data. Distance from a geographic reference point is one scheme which may be valid in some cases. As another example, Figure 6.4 shows the number of visually impaired older people in Local Authorities re-ordered by the size of the local older population. It demonstrates increasing variability with size of population, potentially modelled in BATS by a variance law linked to population level.

Links with methods from specialized areas of medical statistics.

BATS adjusts parameters in an inherently sequential process. It can also accommodate adjustments in response to a data distribution as well as individual

measurements (note that a distribution – or set of measurements – is equivalent to a collection of individual measurements considered one at a time). BATS, formulated for global estimation, therefore has features in common with Sequential Analysis (repeated statistical testing as data accumulate to halt clinical trials at the earliest opportunity) and Systematic Reviews (combination of data from multiple trials to give an overall result).

Table A1.1. Formulation of normal distributions and related probability density functions (PDFs).

The normal distribution.

A time series dataset with n measurements has a specified normal distribution shown by $Y_t \sim N[\mu,\sigma^2]$, with mean ($\mu = \sum y_t/n$), variance ($\sigma^2 = \sum(y_t - \mu)^2/n$)) and the square root of the variance termed the standard deviation and denoted by σ.

A standardised normal distribution has mean=0 and variance=1 (denoted N' $\mu=0,\sigma^2=1$]). It is obtained from any normally distributed dataset by subtracting the mean from each item and dividing by the standard deviation.

Probability density functions.

When individual measurements are identified by y_t, and drawn from the full series denoted by Y_t, the normal probability density function (pdf) for Y_t computes the probability for any particular $y_{t.\,It}$ reproduces the familiar bell-shaped probability curve for a range of y_t values (typically mean +/- 4 standard deviations).

$$p(y_t) = 1/(\sigma.\sqrt{(2\pi)}) \,.\, \exp(-(1/2)(y_t - \mu)^2/(2\sigma^2))$$

BATS uses a special form of the PDF where the scaling element (outside the exponent) is omitted.

$$p(y_t) = \exp(-(1/2)(y_t - \mu)^2/(2\sigma^2))$$

Table A1.2. Formulation of individual signal components.

General Descriptions.

Component	Example model(s)	Description
Trend	1st order polynomial: level model. 2nd order polynomial: level+slope model.	The mean of the time series follows a random walk. The trend shows systematic growth/decline.
Seasonal /periodic	Periodic factors. Periodic effects.	A repeating feature or cycle over a set number of data points (the period). A seasonal has 4 seasons (period=4). Factor model: different parameter for each point in the cycle. Mean of factors over the period = the trend. Effects model: isolates an underlying trend from periodic movement about the trend. Sum of effects at each point and over the period = 0.
Explanatories	Standard statistical regression model. Logistic regression and fits to other transformed functions.	A set of explanatory variables measured along with the time series is incorporated as a set of independent parameters. The general method is equivalent to stantard statistical regression. Data can also be fitted to other important analytical functions in their linearised transformation. (Also true for time series data fitted to trends using high order polynomials in their linearised form).

Component Formulations.

Notes on models

The periodic model uses period=4 (a seasonal model) and is an Effects model with inclusion of a trend=level component. Note the cycling requirements for periodic components in Table A1.3.

The explanatories component uses 2 explanatory variables as an example.

Special symbols

Var(p) = variance of example parameter p or covariance of 2 parameters.

Row vectors are shown as transposed column vectors – "[…]'".Rows of a matrix are shown by "[…]".

Component model	**Parameters**	**Parameter point estimates (stacked in a_t)**	**Parameter covariance matrix (R_t)**	**Signal reconstruction vector (F)**	**Signal evolution matrix (G)**
1st order polynomial trend	μ_t - current level	μ_t	Var(μ_t)	1	1
2nd order polynomial trend	μ_t - current level β_t - current rate of change of level	μ_t β_t]	[Var(μ_t) 0] [0 Var(β_t)]	[1 0]'	[1 1] [0 1]

Component Formulations continued...

Seasonal effects with level only trend	μ_t - current level. $p1_t$ - effect at 1st point in the period. $p2_t$ - effect at 2nd point. $p3_t$ - effect at 3rd point. $p4_t$ - effect at 4th point.	μ_t $p1_t$ $p2_t$ $p3_t$ $p4_t$	[Var(æ$_t$) 0 0 0 0] [0 Var($p1_tP1_t$) Var($p1_tp2_t$) Var($p1_tp3_t$) Var($p1_tp4_t$)] [0 Var($p2_tP1_t$) Var($p2_tp2_t$) Var($p2_tp3_t$) Var($p2_tp4_t$)] [0 Var ($p3_tP1_t$) Var($p3_tp2_t$) Var($p3_tp3_t$) Var($p3_tp4_t$)] [0 Var ($p4_tP1_t$) Var($p4_tp2_t$) Var($p4_tp3_t$) Var($p4_tp4_t$)]	[1 1 0 0 0]'	[1 0 0 0 0] [0 1 0 0 0] [0 0 1 0 0] [0 0 0 1 0] [0 0 0 0 1]
Explanatories	$b1_t$ - contribution from 1st explanatory variable. $b2_t$ - contribution from 2nd.	$b1_t$ $b2_t$	[Var($b1_{t)}$ 0] [0 Var($b2_{t)}$]	[1 1]'	[1 0] [0 1]

Table A1.3. Vector and matrix cycling for periodic components.

Consider a component with period 4 and time counter t. t modulo 4 gives the point in the cycle (4 mod 4 = 0 is the last position). The Signal Reconstruction Vector and the Signal Evolution Matrix remain fixed and "pick off" the relevant point in the period while the parameter point and variance estimates (a_t and R_t) are cycled.

Point in cycle	**Parameter point estimates**	**Parameter covariance estimates**
At point 1 out of 4	$a_{t \bmod 4 = 1}$ =	$R_{t \bmod 4 = 1}$ =
	a1	R1,1 R1,2 R1,3 R1,4
	a2	R2,1 R2,2 R2,3 R2,4
	a3	R3,1 R3,2 R3,3 R3,4
	a4	R4,1 R4,2 R4,3 R4,4
At point 2 out of 4	$a_{t \bmod 4 = 2}$ =	$R_{t \bmod 4 = 2}$ =
	a2	R2,2 R2,3 R2,4 R2,1
	a3	R3,2 R3,3 R3,4 R3,1
	a4	R4,2 R4,3 R4,4 F4,1
	a1	R1,2 R1,3 R1,4 R1,1

Table A1.4. Block structuring of signal components.

A model is illustrated with components for trend (T), season (S) and explanatories (E) all at time point t.

Parameter point estimates	a_t =	[a(T)t a(S)t a(E)t]
Signal Reconstruction Vector	F =	F(T) F(S) F(E)
Parameter Covariance Matrix	R_t =	$R(T)_t$ 0 0 0 $R(S)_t$ 0 0 0 $R(E)_t$
Signal Evolution Matrix	G =	G(T) 0 0 0 G(S) 0 0 0 G(E)

Table A1.5. Example starting conditions for a Level + Four Seasonal Effects model.

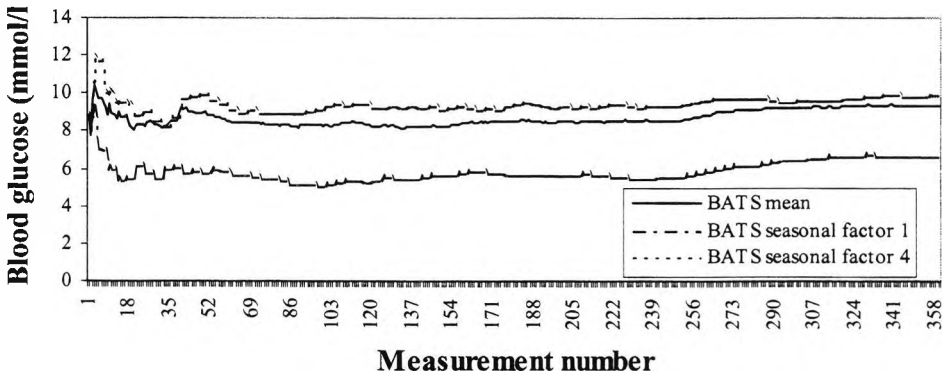
Initial parameter point estimates are set to 0 (a_t=[0 0 0 0 0]'). The parameter covariance matrix ($R_{t=0}$) has a standardised total value of 1 spread over the components.

$$R_{t=0} = \begin{matrix} 1 & 0 & 0 & 0 & 0 \\ 0 & 0.75 & -0.25 & -0.25 & -0.25 \\ 0 & -0.25 & 0.75 & -0.25 & -0.25 \\ 0 & -0.25 & -0.25 & 0.75 & -0.25 \\ 0 & -0.25 & -0.25 & -0.25 & 0.75 \end{matrix}$$

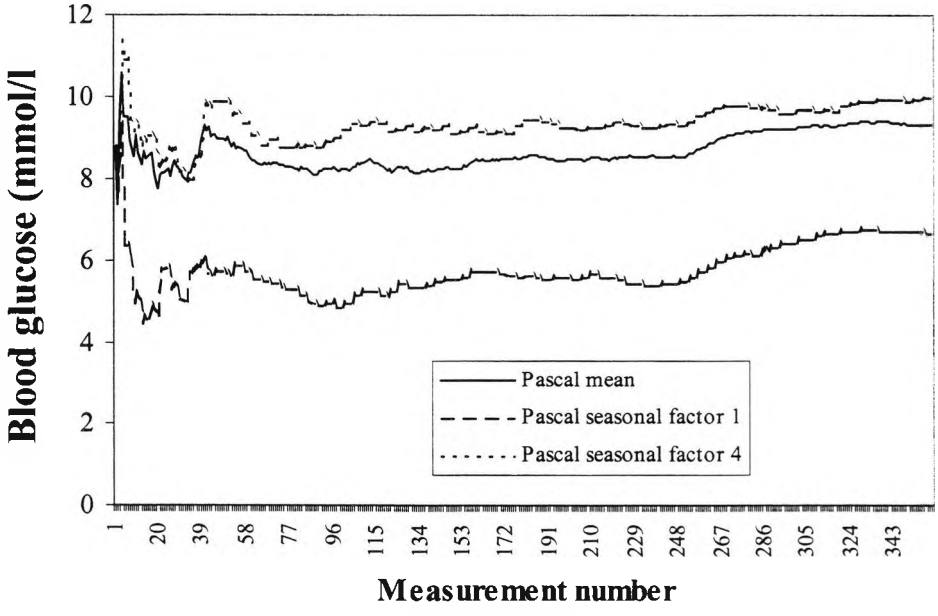
Figure A1.1. Over leaf. Comparison of BATS software and the Pascal version fitting global parameters.

A model with a simple mean (trend) and 4 seasonal factors has been fitted to 360 consecutive blood glucose measurements from a diabetic originally presented in Figure 4.4 (p118). Estimates at each measurement point are based on all data treated equally up to that point (global parameters).

Results from BATS software and the Pascal version are compared. For clarity in the panels, only values for the mean and seasonal factors 1 and 4 are presented.



A1.1. a). BATS results.

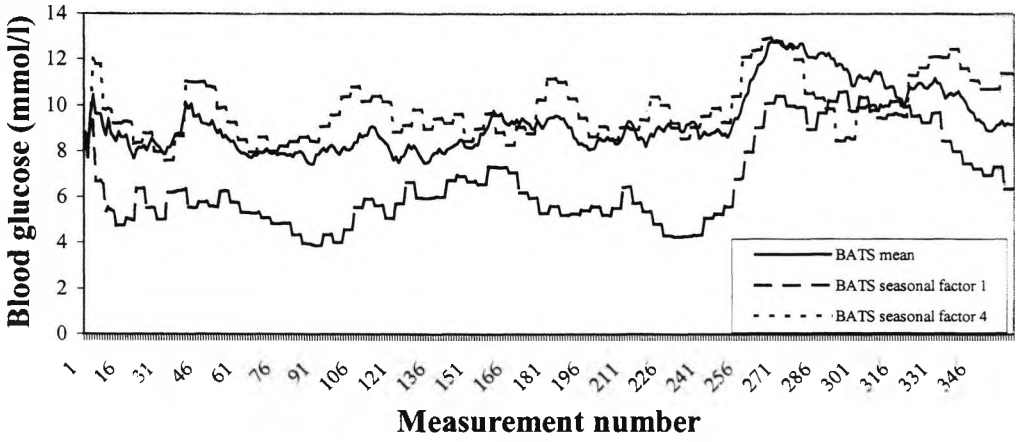


A1.1. b). Pascal version results.

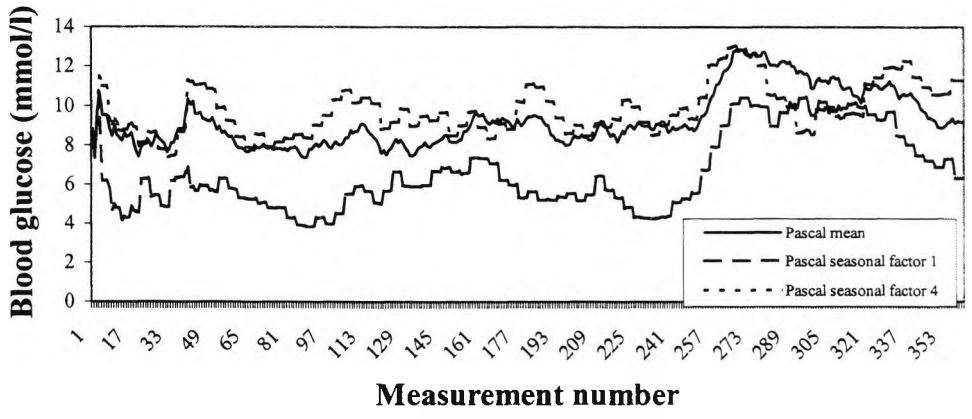
Figure A1.2. Over leaf. Comparison of BATS software and the Pascal version fitting parameters with discounting.

A model with a simple mean (trend) and 4 seasonal factors has been fitted to 360 consecutive blood glucose measurements from a diabetic originally presented in Figure 4.4 (p118). Estimates at each measurement point use the discounting mechanism with a discount factor of 0.95 for both trend and cyclical components (local parameters).

Results from BATS software and the Pascal version are compared. For clarity in the panels, only values for the mean and seasonal factors 1 and 4 are presented.



A1.2. a). BATS results.



A1.2. b). Pascal version results.

Figure A1.3. Over leaf. Following the Adaptive Factor used to estimate the blood glucose mean in data collected by a diabetic.

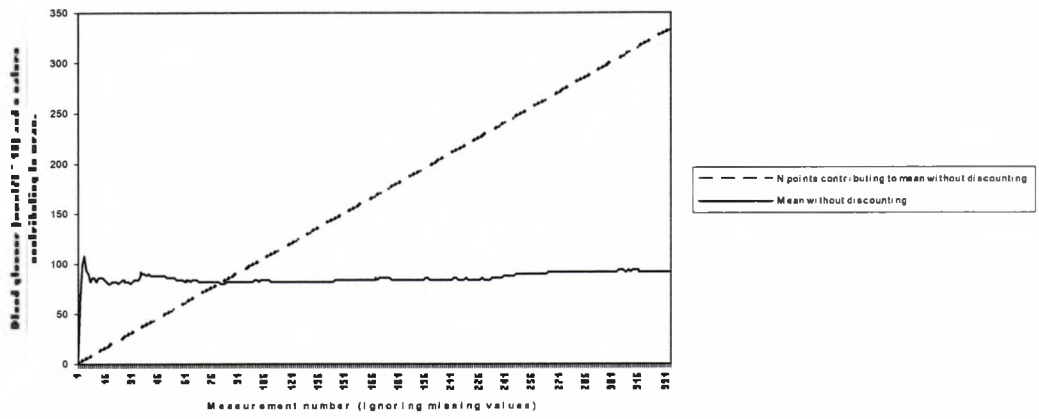
The two plots (panels a and b) estimate the blood glucose mean from data originally presented in Figure 4.4 (p118). Missing values (27 items) have been ignored, giving 333 source data values in total.

The Adaptive Factor is the signal:noise ratio (ratio of the parameter to raw data variances) used to adjust estimates at each point. Both variances have been initially standardised to 1.

The reciprocal of the Adaptive Factor is plotted along with the blood glucose mean. It effectively gives the number of previous data points contributing to the parameter estimate at any point.

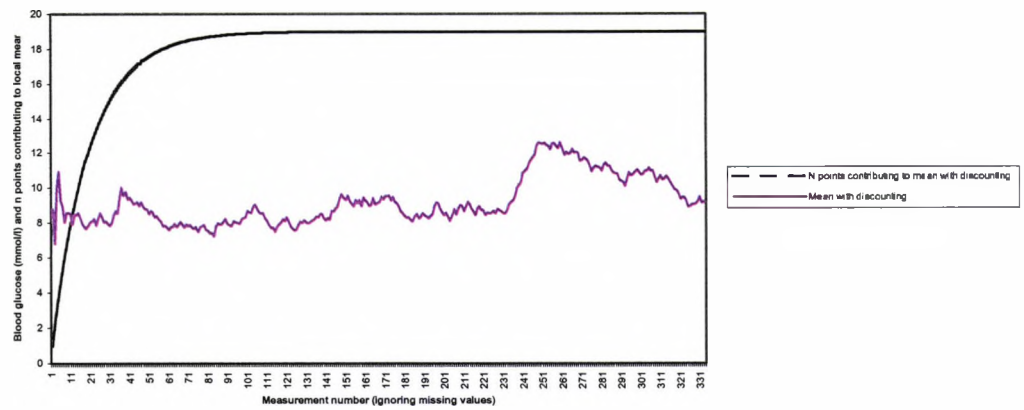
Panel a – shows global parameter estimates (no discounting involved). The number of values contributing at any given point is equal to the number of values considered up to that point – hence the linear relationship for 1/(Adaptive Factor).

Panel b – uses a discount factor of 0.95. The Adaptive Factor will fall until it reaches ((1/0.95)-1=0.0526). The reciprocal is 19, and the plot shows the number of previous values contributing to each estimate increasing until it levels and persists at 19.



A1.3. a). Blood glucose mean tracked without discounting, ie. global parameters estimated at each measurement point.

Note that blood glucose values are mmol/l *10 for ease of presentation).



A1.3. b). Blood glucose mean tracked with a discount factor of 0.95, ie. local parameter estimates.

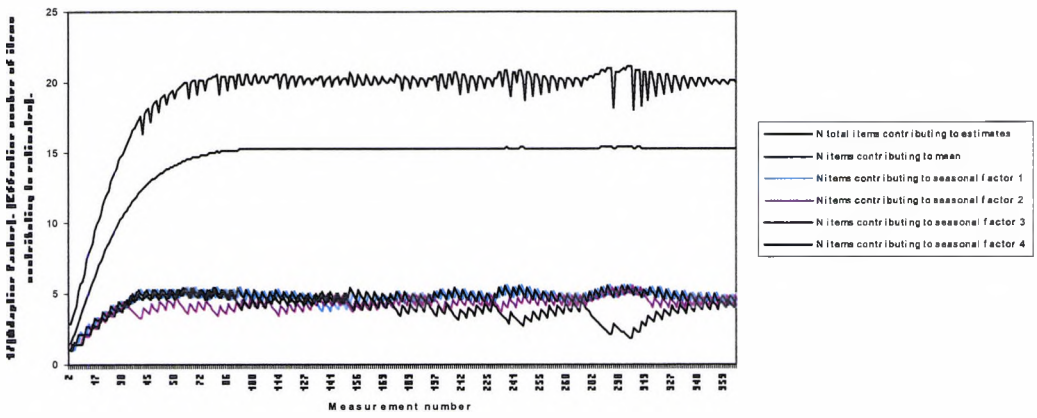


Figure A1.4. Adaptive factors for a model with mean and seasonal factors tracked with discounting.

Results relate to the model and estimates presented in Figures A1.2a,b (a simple mean and a cycle of period 4 tracked in blood glucose data with a discount factor of 0.95 for both the trend and seasonal components).

Lines are presented as the reciprocal of the Adaptive Factor for each parameter (5 in total). They may be interpreted as the effective number of previous raw measurements contributing to the estimates at any given point. The discount factor (0.95) predicts an equivalent window size of 19 to 20 previous data items.

The mean has running contributions (or effective window size) from 15-16 items. Each seasonal factor has contributions from 5-6 items. Total points contributing to estimates at any point is around 19-20.

Appendix 2

Properties of psychometric questionnaires

Reference. Bradley (1994).

Purpose of a questionnaire. A relatively short, structured and numeric approach for recording perceptions of individual patients or professionals, with group results amenable to statistical analyses.

Scales and sub-scales of questions. Questions (or items) may relate to the same "theme" or be grouped to reflect different aspects of the overall theme (sub-scales).

Separate questions. Questions may be added as a separate component to aid interpretation of the main scale.

Response scales and scoring. A small and odd number of labelled response categories are assigned integer values. Generally, categories are ordered (eg. good to bad) and points awarded incrementally (ordinal data). Sometimes a mark is required on a continuous line between extremes of opinion (rational data on a visual analogue scale).

Items negatively related to the "theme" (eg. "I worry that X") are reverse scored (eg. 5 becomes 1 on a 1-5 response scale). Key items may be additionally weighted. The total score for a scale (or sub-scale) is generally the sum of scores from component questions, and mapped onto other intervals (eg. % values)..

Structure. Considers the n questions in a scale as n dimensions of a "response space" and looks for statistical clustering (factor analysis). Questions in a sub-scale are expected to associate (or load) with a single common factor, with each sub-scale

forming its own relatively distinct factor. Loadings >= 0.4 are considered acceptable. Sub-scales are also expected to correlate with total scores, but not with each other.

Reliability. Ability of a scale (or sub-scale) to give consistent results under different study conditions. Commonly measured by an average of correlations between questions in the sub-scale (Cronbach's alpha). Values >=0.7 are acceptable for a scale or sub-scale with 10 questions.

Validity. Accumulated evidence that the scale measures its central "theme" under a range of practical conditions (eg. discriminates between groups, adjusts after intervention). Combines review of the relevance and phrasing of questions with correlations of the scale with similar scales and other measurements which are logically related.

Limitations. Understanding and honesty of respondents. Potentially large changes to properties after small changes to the design of a scale. Consistency across cultures and languages.

Appendix 3

Technical specifications for the electronic Visual Impairment Notification System (eVINS) including Entrust's Public Key Infrastructure (PKI).

System architecture and specifications (except firewall, virus and backup protection, were drawn up with recommendations from the NHS Information Authority and Entrust Technologies Ltd and relate to chapters 6 & 11 (specifically Figure 6.4).

A. Basic site hardware and software.

A1. Firewall.

Checkpoint Firewall 1 (Checkpoint Technologies Ltd))

A2. Main site servers (4 in total).

DELL machines with:

Windows NT 4.0 Server operating system (Intel-based U.S. version) and Service Pack 5, 6, 6a. Do not install NT 4.0 Workstation
Dr Solomon's virus protection software (Network Associates)
MS Internet Information Server
128 Mbytes of RAM
Pentium III 500 or faster
One 24X or faster CD-ROM drive
TCP/IP stack installed
Disc space requirements 2Gb+

A3. Backup system.

DAT tapes controlled by Windows NT 4.0 server operating system

A4. Safehaven computer.

Standard Dell PC with virus protection and backup tapes

B. VINS application software.

Forms and links to databases written in Microsoft Active Server Pages (ASP) integrating with:

MS Internet Information Server (IIS)
MS SQL Server 7.0 (databases)
MS Exchange Server (Email)
Dr Solomon's virus protection software (Network Associates)

C. Public Key Infrastructure: Entrust/PKI 5.X.

C1. Broad compliance with international standards.

Encryption algorithm	128 bit DES (Data Encryption Standard)
Certificates	X509 v3 compliant

C2. Core products.

Entrust/Authority	A store and management system for certificates and keys.
Entrust/RA	Administrator's module for registering users and direct management of certificates and keys.
Third-party LDAP-compliant Directory	A database, in Lightweight Directory Access Protocol, of Email addresses and public encryption keys for the community of users (the "public directory").
Entrust/Entelligence	Interface allowing other Entrust PKI products and specially written applications to link with the core PKI components.

C3. Additional products for PKI customisation.

Entrust/Web Connector (4.0a)	A Common Gateway Interface (CGI) application that runs on a Web server between the PKI and clients. It distributes Web certificates to Standard Web browsers and Web servers.
Entrust/AutoRA	An alternative to Entrust/RA for remote issue and management of certificates and keys. Users are enroled online by answering questions on "shared secrets".
Entrust/Roaming and Entrust/Profile Server	Allow user access from various machines ("roaming users") via a central store of user "profiles".
Entrust/Truepass	Once a secure link is made between a user and the VINS site (using Secure Socket Layer protocol), the Truepass application makes the links to the other PKI components. It provides the website and users with persistent digital signatures and certificate-based authentication and transaction encryption. A secure, provable record of each transaction is generated and stored in the backend server.
Entrust/Express	A security extension to the Microsoft Outlook and Microsoft Exchange email applications, allowing users to encrypt and sign outgoing messages and to decrypt their own incoming messages.
Entrust/Ice	A file protection utility integrated into the site's operating system,. It decrypts/encrypts specified files as they are accessed or at system startup/shutdown.

Appendix 4

Web languages referenced in the Thesis

Material on general languages supports technological descriptions of the electronic Visual Impairment Notification System (chapters 6&11 and Appendix 3). Details on XML expand on methods to formalise data specifications for collection and exchange on networks and conversion of information resources between different physical formats (chapter 10, sections 10.3.5 and 10.4.4).

All cited languages are mandated for use in the UK's public sector under the electronic Government Interoperability Framework (eGIF - see chapter 9). Most can be generated using commercial packages or written in plain text word processors. They may be used on individual machines, networks simulated on individual machines (eg. via Microsofts Personal Web Server programs - PWS) and on full networks.

A. References.

Source	Description
www.w3schools.com	Introductions, examples and links to proprietary and World Wide Web Consortium (W3C) standards for a range of languages.
Wille & Koller (1999)	Programming instructions and examples for Active Server Pages.
www.nhsia.nhs.uk/egif/pages/xml_bpg.asp	Developments from the recently formed (July 2003) XML Best Practice Group in the NHS.

B. Description of general languages.

Abbreviation	Name	Description
HTML	HyperText Markup Language	The W3C standard for webpages. Predominantly a language for onscreen presentation.
PDF	Portable Document File	A proprietary technology from Adobe Systems for onscreen and print presentation of documents with facilities to convert from most word processing and graphics packages. Reputedly the 2nd most common file format on the Web after HTML.
XML	eXtensible Markup Language	A developing suite of languages for collection, exchange and integration of data over networks. XML focuses on content and manipulation of data while HTML covers data presentation.
SQL	Structured Query Language	An industry standard for database interactions. Not specifically a web standard but combines with other standards on "objects" for sharing resources over networks (eg. Open DataBase Connectivity - ODBC - and Active Data Objects - ADO).
JS and VB	Scripting languages	HTML pages allow insertion of small programs (scripts) to respond to machine events or user inputs. Scripts are interpreted and executed on the user's "script enabled" browser. The 2 most common languages are Java Script (from Sun Microsystems) and Visual Basic Script (from Microsoft).
ASP	Active Server Pages	A proprietary technology from Microsoft allowing scripts to be specified for execution on the website server (server-side scripting) or the user's browser (client-side scripting). ASP supports interactions between a site and a browser (eg. recognition of browser type and user preferences before serving pages); direct interaction between webpages and the server (eg. incorporation of XML, SQL and other interactivity standards); and logging of site visitors over time (site statistics and individual sessions).

C. Details on the eXtensible Markup Language (XML).

XML is a system of tags (or markup) which has spawned a number of other languages to manage data over networks and between applications (C1). Unlike HTML, XML tags can be defined by individuals and shared by a community of users.

Implementation requires "XML enabled" browsers but products from different manufacturers have different levels of compliance to official standards (C2). Plain XML files can be loaded into browsers for content viewing only. Scripts are generally required to load the file into a browser's "XML parser" for full manipulation (C3).

C1. The XML suite of languages.

On the next page are the core components and file types of XML. They can be combined, and adjusted with new tag names and definitions, to produce new languages. The following examples are all new languages based on XML: HTML 4.01 and xHTML (HTML reformulated in XML); Wireless Markup Language (WML) for mobile phones; various multimedia integration languages; a developing language for speech based systems (SABL). New languages intended for widespread use in the UK's public sector must first be approved by the Office of the eEnvoy (see chapter 9).

Abbreviation (file extension)	Component name	Description
XML (*.xml)	Plain XML file.	Contains raw data within tags defined and manipulated by the other languages/browser components.
XSD (*.xsd)	XML Schema Definition.	File defining tags and valid content for plain XML files. Progressively replacing Document Type Definitions (DTD) currently used to define file formats such as HTML webpages.
XSL (*.xsl)	XML Stylesheet Language.	File of commands for presenting and/or processing data from plain XML files. Has 3 component languages: **XMLT** - for transforming/manipulating plain XML files. **XPath** - for defining and identifying XML parts and patterns used in the plain XML transformation. **XML formatting object** - combination of XMLT and xPath, with additions, for formating resulting outputs from plain XML files.

C2. Timetable of W3C approvals with implications for browser compliance.

Microsoft anticipated XML before it became a formal standard. It originally proposed XML Schemas and contributed to stylesheet specifications, but developed products based on W3C working drafts. MS Internet Explorer 6.0 and Netscape Navigator 6.0 reputedly have full compliance, but W3Schools work only with Microsoft's browsers for online demonstrations as Netscape were slow to incorporate the technology.

W3C Standards

XML Component	Version	Year of W3C standard
XML (plain file)	1.0	1999
XSD	1.0	2001
XMLT	1.0	1999
XPath	1.0	1999
Full XSL recommendation (including XML formatting object)	1.0	2001

Microsoft's Internet Explorer XML parsers.

IE version	Year of release	XML Parser version	Compliance
5.0	1999	MSXML 2.0	Support for plain XML but non standard for other components.
5.5 (and Windows 2000)	2000	MSXML 2.5	Support for plain XML but non standard for other components.
6.0 (and Windows XP)	2001	MSXML 3.0	Reputedly fully compliant.

C3. Loading and transforming plain XML files using scripts and XSL.

Table 10.8 provided source code for an XML file of meters for diabetic patients (diabetic_meters.xml) and a transformation rules for presentation in HTML (stylesheet.xsl). Remove the reference to the stylesheet in the XML file to make them 2 independent documents.

The following code examples will load the source files into the browser, perform the transformation and present the resulting XML document in HTML format.

1). Locally on the user's own browser (client side): using an HTML file containing a Java Script loaded into MS Internet Explorer.

```
<html>
<body>

<script type="text/javascript">

// Load XML
var xml = new ActiveXObject("Microsoft.XMLDOM")
xml.async = false
xml.load("diabetic_meters.xml")

// Load the XSL
var xsl = new ActiveXObject("Microsoft.XMLDOM")
xsl.async = false
xsl.load("stylesheet.xsl")

// Transform
document.write(xml.transformNode(xsl))

</script>

</body>
</html>
```

2). On the server before sending to the user's browser (server side with potential to adjust for browser type and user preferences): using an Active Server Page (*.asp) containing a Visual Basic Script coordinated by Internet Explorer on the server.

```
<%

'Load the XML!* set xml = Server.CreateObject("Microsoft.XMLDOM")
xml.async = false
xml.load(Server.MapPath("diabetic_meters.xml"))

'Load the XSL!* set xsl = Server.CreateObject("Microsoft.XMLDOM")
xsl.async = false
xsl.load(Server.MapPath("stylesheet.xsl"))

'Transform the file
Response.Write(xml.transformNode(xsl))
%>
```

Appendix 5

Basic notation from the Unified Modelling Language (UML)

UML is a diagramming language for representing the results of modelling work in areas such as system specifications or data definitions. This summary is derived from (NHSIA, 2002/uml and references therein) released as an introduction for the NHS. It supports references to Government material in UML format made in chapters 9 & 10.

UML developed as a combination of competing methodologies in the late 1990s and was formulated by Booch et al (1999/uml). It has become the *de facto* standard in IT, mandated for use under the UK's eGovernment Interoperability Framework (eGIF). Though targeted at IT, UML can be used in any field.

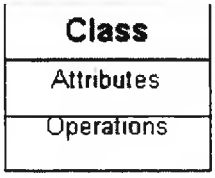
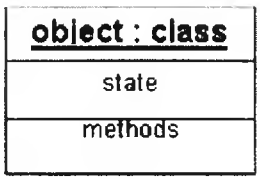
A5.1. Classes and objects.

Classes and their relationships are the primary modelling elements in UML generally. In the area of data specifications, they define the structure of data items and complete datasets.

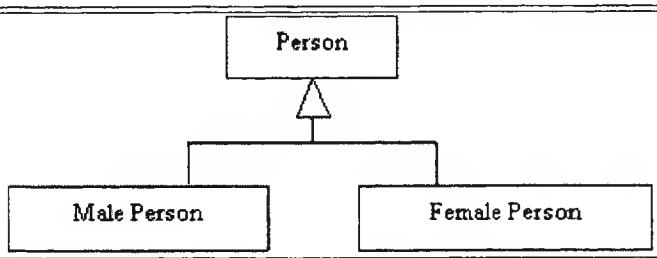
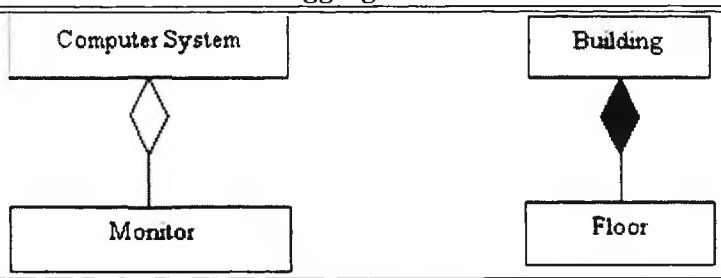
An object is a particular example of a class (instance) in practice (eg. Class = shape; Objects = square, triangle).

A class has common kinds of:

attributes (properties)
operations (behaviour)
relationships to other classes (associations, aggregations)
meaning or understanding in the context (semantics).

	**Class**	Rectangle with up to 3 compartments for the name, attributes and operations	Names should be a singular noun. Attributes describe the characteristics of the class. Operations describe what the class can do or what services it offers.
	**Object**	Rectangle with up to 3 compartments for name, properties and methods.	The object name is conventionally underlined and combined with the class name. Attributes and operations of objects are termed properties and methods.
	A class/object diagram		Collection of some or all of the classes/objects in a model
	**Package**		Group of model elements (commonly classes) that are closely related and have minimal dependencies with other packages. Use to divide models into manageable units.

A5.2. Relationships within and between classes (or objects).

Generalisation

Line with a large triangular arrow head pointing at the superclass.
Relationship between a general element and a more specific element. Superclasses encapsulate the structure and behaviour common to several child classes.
Male and female to person
Aggregation

Line with hollow diamond at the aggregate end
Relationship between a whole and its parts, expressing constituents but not dependence.
Monitor as part of computer system
Composition

Line with solid diamond at the aggregate end
Aggregation where all parts must exist (dependence).
Walls as parts of building

Cardinality of an association.

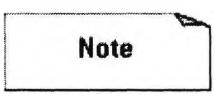
Number of potential units involved.

Association	Symbol
zero-to-one	(0..1)
zero-to-many	(0..* or just *)
one-to-five	(1..5)
one-to-many	(1..*)

The multiplicity is shown near the end of the association, at the class where it is applicable.

The following example shows that each employee is associated with one employer, while each employer has one-to-many employees.

A5.3. Miscellaneous.

	**Note**	Rectangle with turned up corner	Contains comments and may be attached to any diagram component.

Acronyms

AC. Audit Commission - public body responsible for monitoring efficient practices and use of public money in local government and healthcare organisations in England and Wales. See chapter 9 for further background; and chapters 3 and 5 for specific healthcare investigations.

ACP. Augmented Care Period - a term used in England and Wales to describe an episode of Intensive or High Dependency Care anywhere in a hospital; also identifies the mandatory dataset collected on such episodes. See chapter 3.

ADSS. Association of Directors of Social Services - organisation representing heads of social services, primarily in England, and working with the Department of Health to develop policy. See chapter 9 for further background; and chapters 6 and 11 for a specific role in healthcare.

AR. Action Research - method for identifying and studying change in specified settings. Involves continuous feedback from those directly and indirectly involved in the changes; and combines qualitative and quantitative analyses to give complementary and overall results. See chapter 5.

BATS. Bayesian Time Series - methods for analysing how statistical patterns develop from regularly collected data and how such patterns change over time. See appendix 1 for technical details; and chapters 4 and 5 for applications.

BD8(1990). The official form completed by consultant ophthalmologists in England to certify patients as eligible to be registered with their Local Authority as blind or partially

sighted. Introduced in 1990 and changing to three new forms from November 2003. See chapters 6 and 11.

C&ILVSG. Camden & Islington Low Vision Services Group - forum of healthcare professionals, managers and patient groups from the old Camden & Islington Health Authority. Formed in 2000 to advise on local services as part of a developing national network of similar local groups under a Low Vision Implementation Programme led primarily by opticians (optometrists) with a special interest in Low Vision Services. See chapters 6 and 11.

CMP. Case Mix Programme - voluntary national programme and related dataset developed as the basis for monitoring general outcomes and specific trials in Intensive and High Dependency Care. Operating in England, Wales and Ireland and run by ICNARC. See chapter 3.

DoH. Department of Health - Government Department responsible for the health and well-being of people in England. Also commonly abbreviated to DH. See chapter 9, in particular, for details on general structures and roles.

e-GIF. electronic-Government Interoperability Framework - umbrella framework of policies and technical standards, maintained by the OeE to harmonise electronic systems across central and local government and the public sector. See chapter 9.

e-GMS. electronic-Government Meta-data Standard - standards for identifying and describing information resources for easier indexing and retrieval, and forming part of e-GIF. See chapter 9 for further background; and chapter 10 for implementation details.

ICD10. International Classification of Diseases and health related problems, 10th edition - released in 1993 and maintained by WHO. See chapter 6 for specific use in an English healthcare programme.

ICNARC. Intensive Care National Audit and Research Centre - medical charity, serving as a centre for coordinating professional research and discussion, and media enquiries in Intensive and High Dependency Care primarily in England. See chapter 3.

ICRS. Integrateed Care Record Service - a major component of NPFIT focusing on patient and organisational records and services which store, manage and share them. Intended to be delivered by Local Service Providers (LSPs). See chapter 9.

ICS. Intensive Care Society - the sole body formally representing medical professionals, training or directly involved in Intensive and High Dependency Care in the UK. See chapter 3.

ISB. Information Standards Board - organisation within the NHS with responsibility for approving standards and datasets operating on a major or national level. See chapter 9 for further background; and chapter 10 for details on the Board's recent work.

NeLH. National electronic Library for Health - information for professionals and patients, developing as "floors" for each speciality, with coordination and contracts awarded by NHSIA. See chapter 9 for further background; and chapters 6 and 11 for a direct role in a healthcare programme.

NeLSC. National electronic Library for Social Care - complementing NeLH with information on social care. See chapter 9.

NHS. National Health Service - British network of hospitals, GP surgeries, professions "allied to medicine" and support organisations providing and managing healthcare predominantly through public funding. Divided between constituent countries in the UK; answerable to DoH in England, and elsewhere tothe "devolved administrations". See chapter 9 for structures and recent changes relevant to broad data quality issues in England.

NHSIA. NHS Information Authority - SHA in England with responsibilities for managing critical IT programmes, supporting other NHS agencies and programmes influenced by IT, and bringing IT issues closer to the mainstream NHS. See chapter 9 for further background; and chapters 6 and 11 for involvement in a specific healthcare programme.

NICE. National Institute for Clinical Excellence - SHA responsible for identifying cost effective treatments and practices. See chapter 9.

NPFIT. National Programme For Information Technology - a centrally coordinated IT programme for English healthcare, targeting a limited set of national applications and an infrastructure supporting developments, in principle, at all levels.See chapter 9 and online details at 2004 at www.DH.Gov.UK/PolicyAndGuidance/InformationTechnology/fs/en.

NSP. National Strategic Programme - a revised strategy for IT in English healthcare, launched in April 2002 without key details but leading to the NPFIT. See chapter 9.

OeE. Office of the e-Envoy - division of the UK's Cabinet Office led by a nominated official. Responsible for coordinating major and national data requirements across central and local government and the public sector, as well as the electronic systems supporting such requirements. See chapter 9.

ONS. Office for National Statistics - part of the Government Statistical Service concentrating on population structure, health and living conditions, employment levels and costs of living. Formed, around 1996, from the Office for Population Censuses and Surveys (then answerable to DoH) and the Central Statistics Office (then answerable to The Treasury). See chapter 6 for a specific role in healthcare.

PCT. Primary Care Trusts - formed in 2002 by combining responsibilities for the health of the public then spread across individual GP surgeries and separate Social Services Departments. Given evolving responsibilities for decisions and budgets at a relatively local level. See chapter 9.

SCT or SNOMED-CT. "Systematized Nomenclature of Medicine - Clinical Terms" - mandatory system of codes and terms for all electronic records relating to individual patient care in England. Formed in 2000 by the merger of equivalent systems in the UK and US. See chapter 9 for further background; and chapter 6 for an application in healthcare.

SHA. Special Health Authorities - NHS agencies focusing on topics best coordinated at the national level. See chapter 9.

StHA. Strategic Health Authorities - formed in 2002 by merging old Health Authorities into larger organisations with greater coordinating and monitoring roles at local and national levels. See chapter 9.

SSDA902. The official three yearly returns from Local Authorities to DoH's Personal Social Services Statistics Division on blind and partial sight registers. See chapters 6 and 11.

SSIE. Social Services Institute for Excellence - agency identifying good and cost effective practices in social care, and equivalent to NICE in the NHS. See chapter 9.

SSIMG. Social Services Information Management Group - branch of ADSS concentrating on IT issues and equivalent to NHSIA in the NHS. See chapter 9.

UML. Unified Modeling Language – a diagramming language for describing and defining processes and datasets recommended under the e-GIF. See chapter 9 for further background; and appendix 5 for application details.

WHO. World Health Organisation - large collaboration of countries, affiliated to the United Nations, with responsibilities for monitoring and advising on health issues and maintaining classification systems for international comparisons and research. See chapter 6 for classifications and specific initiatives relevant to an English healthcare programme.

XML. eXtensible Markup Language - basis for developing web languages for data manipulation and exchange between systems. Mandated under the e-GIF. See chapter 9 for further background; chapter 10 for an application; and appendix 4 for sources of technical information.

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A. Online document sources.

Many references were obtained from official websites. The sites below are alternative sources of the material if the cited addresses have changed.

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http://www.doh.gov.uk/publications/pointh.html

Department of Health Publications On The Internet (POINT)
http://www.info.doh.gov.uk/doh/point.nsf/Publications?ReadForm

Department of Health Circulars On The Internet (COIN).
http://www.info.doh.gov.uk/doh/coin4.nsf/Circulars?ReadForm

Official documents database.
http://www.official-documents.co.uk

NHS Information Authority.
http://www.nhsia.nhs.uk

NHS Information Standards Board.
http://www.isb.nhsia.nhs.uk

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