Good European Health Record

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The Good European Health Record

Requirements for Clinical Comprehensiveness

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1 Introduction: The Context of Clinical Records Development

This document lays out the set of clinical requirements which it is proposed must be met by a computerised patient record if it is to be comprehensive, communicating and portable whilst supportive of a high standard of clinical care, in line with the goals of the Good European Health Record project. The document has been structured so as to assist the definition of a medical record architecture in the next phase of the project.

An important strength of the project methodology has been the pre-existence of a multilingual prototype exhibiting some of the features which will be required of the record architecture. In addition to literature reviews and the collation of functional requirements from a variety of sources, the work of the project places a strong emphasis on the evaluation of successive generations of such prototypes in field test sites. The prototype currently being tested will be referred to as the Current Health Record Architecture. The project will seek whenever possible to anchor evaluation and quality assessment to the practical implementation of draft architectures and supporting software tools.

The proposed set of clinical requirements rests on the results of the first-year workplan as described in workpackages 1 to 4 of the Project: the requirements for clinical comprehensiveness in primary and secondary care, across specialities and data types, and prototype testing of the Current Health Record Architecture in these settings. Further requirements identified here are based on previous work, liaison with other AIM projects and national initiatives in the field.

The context of the medical record is described in this introduction (fig. 1); the thinking behind this document has developed from here. It is to this view that the document will return in the final chapter, which includes a summary of the clinical requirements for comprehensiveness directly linked to the context within which the clinical record is created.

It is important that the set of requirements embracing such a large field of reference be assigned relative priorities so that any compromises which prove necessary when specifying an architecture to meet them are consistent with the real world in which the record will be used. The priorities of the GEHR Project reflect the belief that the medical record is most necessary, and should be most available, when a clinical member of staff is offering care or recording the care they have given in a consultation. Thus compromise should always be directed towards offering the fastest, most precise and most complete information to an individual carer when attending a patient.

The recording of medical information is selective and will always involve a compromise, largely because of time and space constraints. We need to be aware of the danger that the growing enthusiasm for a better organised and more statistically useful document may presume too greatly on the human factors involved in delivering it.

The requirements set out here are not the requirements of a computer system, for it is not envisaged that any one system can be used in all settings. They relate specifically to the record itself.

The clinical record will be used by staff trained in different disciplines, working in different settings, on different sites, and in different languages. The architecture must facilitate record storage on different sites and provide a common interchange format between heterogeneous systems.

Throughout this document a variety of terms have been used to describe the computerised medical record. These rightly reflect the origins of the document: they have been employed to stimulate a debate which is expected to lead to a uniform language in the future. The preferred term used here is 'computerised clinical record', which is intended to imply a record created and used by all healthcare professionals who consult with patients. This definition subsumes medical and nursing records, although there are occasions when these terms are used. The term health record implies a desirable approach to health care, and the term patient record implies patient ownership. Both of these concepts are embraced within the clinical requirements which follow.

The record architecture must accommodate the current growth towards the systemisation of medical knowledge. This involves issues of terminology, classification and a fundamental understanding of the basic sciences of medicine and their clinical correlates. Given the use of the record in the individual doctor/patient consultation, it is clear that it must be ordered around a realistic support of the processes of clinical care and the requirements for access to information. It must take account of the wider needs for communication of the record which must traverse to a greater or lesser extent all aspects of the health care services, and in the global village we inhabit, across regional and national boundaries.

The medical record must accept three areas of change; in time, place and clinical perspective. A record evolves gradually over a person's lifetime, and family records over generations. We know that people's health care needs change and evolve in time, as does the practice of medicine, and the economic and social framework within which medicine is practised.

It is recognised that a computerised medical record will be developed within the

context of current technology and systems. The development has to be efficiently managed, and has to be responsive to public needs and priorities, which go beyond personal health care, and which must be debated within an epidemiological and public health context. These domains of technology, economy, management and public health largely influence the decisions as to how best, and to what extent, the clinical requirements of a well-ordered medical record can be met. They provide a framework and tools, but they do not provide solutions. Solutions must evolve, from the central point of need which is the individual consultation and clinical record. The evolution of solutions will require work in all areas covered in the diagram (Figure 1), and within an over-view of the whole, which recognises the strengths and limitations of what has been achieved, and the opportunities which arise from new developments.

There is a consensus that current computerised medical records do not fully provide the resource we require in clinical practice for the provision of care. Whilst it is generally accepted that the automation of certain processes, and improved accessibility of a shared medical record are already tangible benefits of computerisation, there is a need for the development of a record which can faithfully record and support the provision of clinical care, in a way that the health worker finds appealing, and which encourages and demonstrates clinical competence.

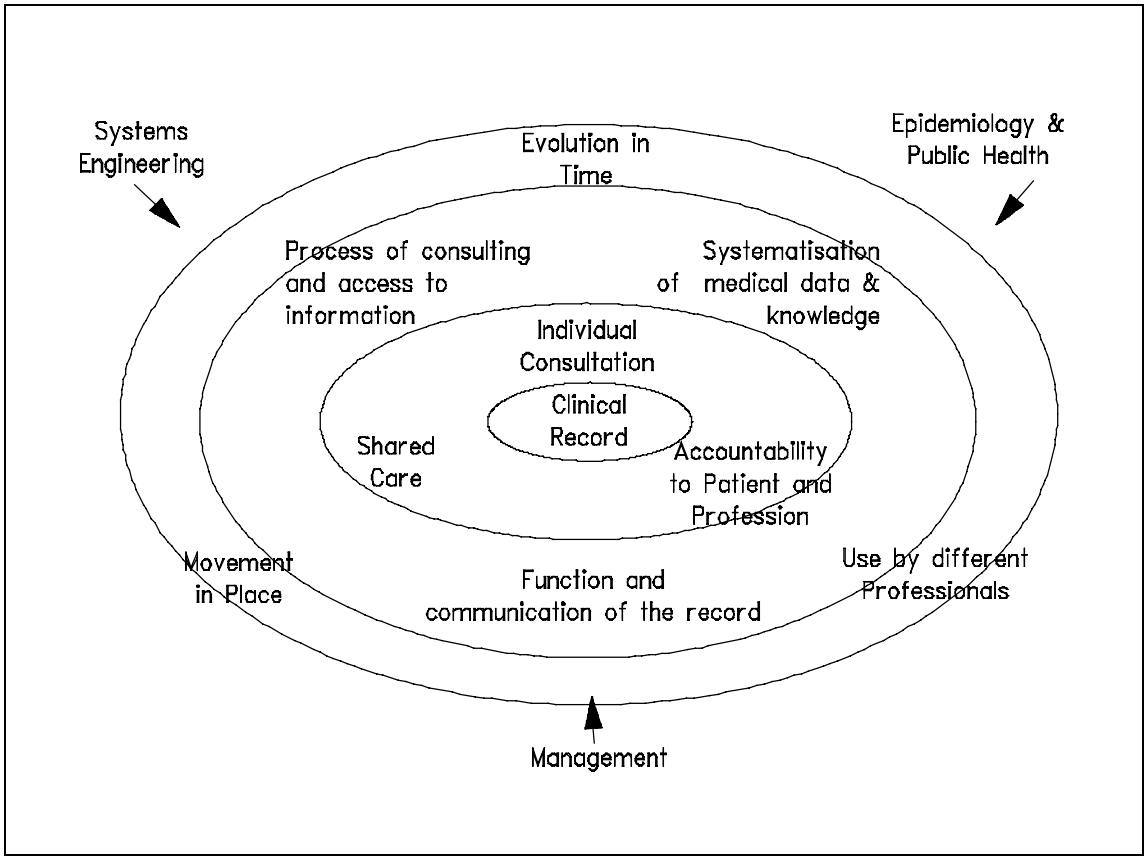


Figure 1 The context of medical record development

2 The Historical Background of Clinical Records

Some of the oldest surviving examples of medical recording are papyri from ancient Egypt which contain details of surgery and prescriptions. There has always been a recognised need for those involved in healing or treatment to pass on details of successful procedures or potions either by written methods or through an oral tradition. It is also likely that individual practitioners attempted to describe what they saw and what they did but this was not a widespread practice. The earliest surviving records that describe individual patients in the United Kingdom belong to St Bartholomew's Hospital and date from its foundation in 1123 AD[1]. This was in the reign of Henry I who established the first public records office in England. By the mid nineteenth century individual physicians often kept some notes about their patients but these were usually kept in books according to physician, one book for each year, with the patients filed in alphabetical order. This chronological method of recording meant episodes of illness were considered in isolation. As people became more interested in the cause of illness, the importance of reviewing past events was realised. In 1907 St Mary's Hospital started a system of unit notes where the patient and not the disease episode became the unit for record compilation. The unit record received extensive development and evaluation at the Presbyterian Hospital in New York where it was implemented in 1916[2]. However, the ideal situation whereby an individual patient only has one record has never been fully realised and each patient still has a set of notes for each institution he or she attends[3].

Institutions have often attempted to influence the data collected within their walls but there has always been resistance to standardisation on the grounds that the freedom of individual clinicians must be protected. A 1923 textbook noted that " From the stand point of scientific record taking, case histories are most glaringly defective in what they fail to record about a patient[4]." However attempts to introduce pro-forma to increase the amount of information collected were widely rejected. In the last decade there has been renewed interest in the value of establishing "core data" sets which can help junior staff learn from others' experience of what data is most helpful to specific situations. An International research programme exploring computer-assisted diagnosis of acute abdominal pain has shown that the introduction of a structured data collection sheet improved the inexperienced doctor's ability to make the correct diagnosis. Guidelines about which data to collect out of the myriad possible symptoms and signs was achieved by examining thousands of cases and learning which symptoms and signs were the most important indicators of pathology[5]. A study of three methods of taking an antenatal history showed that structured questionnaires (computerised or paper) provided more and better information than unstructured

methods and that their use improved clinical response to risk factors[6].

It could however be argued that if pro-forma had been widely introduced in 1923 they might have hindered the development of new ideas in medicine by discouraging new observations and thoughts. In 1957 Balint published his book "The doctor, his patient and the illness" which recognised the psychological basis of many problems[7]. This book has had a huge impact on medical practice and therefore on the content of medical notes which now need to contain information relevant to an individual's psychological well-being such as sources of stress, social interactions and perceptions of illness.

In Britain a system of primary and secondary care was instituted with the foundation of the NHS in 1948. The primary care physician (general practitioner) was likely to be looking after many members of the same family and the need to document family relationships became important[8].

As the United States of America and many European countries became more affluent in the second half of the twentieth century: better education led to higher expectations of health care than previously. In order to provide a fuller range of services both primary care and secondary care organisations became more complex and instead of the notes acting as an aide memoire for an individual physician they became important as a means of communication between physicians. The availability of continuous rather than episodic health care, the involvement of different professionals in care and the recognition of the inter-relationship of physical, psychological and social factors led to notes becoming vast repositories of data with little structure to facilitate the processing of this data.[9]

In 1969 Weed published a book "Medical records, medical education and patient care" which introduced a method of structuring a record, the Problem Orientated Medical Record (POMR)[10]. This was a format for clinical recording consisting of a problem list, a data base (that is, the history, physical examination and laboratory findings), and then, written out separately for each problem, a plan (diagnostic, therapeutic and educational) and a daily SOAP (subjective, objective, assessment and plan) progress note. The problem list was kept at the front of the medical record and served as an index for the reader so that each problem could be followed through until it was resolved. This system widely influenced note keeping by recognising the four distinct phases of the clinical decision making process: data collection; formulation of problems (not necessarily diagnoses); devising a management plan; reviewing the situation and revising the plan if necessary. However the POMR was not widely adopted exactly as Weed proposed because it proved to be too time consuming. The individual note entries were classified according to problem but were still entered sequentially in date order, making it a time consuming process to acquire a retrospective picture of events within one problem[11].

With an expansion of education and greater awareness of individual civil liberties the medical profession and their records have come under greater scrutiny. Medical records are now used in claims for negligence and in some countries are read by the patient. These two developments, and the fact that records are used for audit of medical practice have led to a situation where records need to be understandable to a non-medical reader and the rationale behind any action clearly stated[12].

A further development in medical records has been the patient-held record, first used in the fields of obstetrics and child health, but used increasingly in the management of chronic disease. This involves the doctor recording care on a record which is carried by the patient. A transition from doctor owned to institutionally held to patient-held records is becoming apparent. Recently there have been many successful experiments in patient-held records and the effects of patients carrying their medical information has been assessed.[13]

As the process of human reasoning has become better understood, it has become apparent that logical thinking coexists with less well understood "intuitive" processes; both modes of thinking and reasoning are important in medical decision making[14]. This insight into cognitive processes has led to the current situation where there is an apparent paradox between the need for more "structured data" which is used in a logical way to derive a conclusion and the need for "narrative data". This need to value and listen to the story as told by the patient is explored in "Doctors Stories" by Kathryn Montgomery Hunter[15]. She suggests that when physicians have a working knowledge of life histories and a sense of medical narrative that can accommodate the experience of illness, they are better able to provide good medical care, especially for those they cannot quickly cure. This tension may only be an apparent paradox as both types of data are important and can coexist. A structured approach will ensure all the necessary information is acquired to arrive at the right decision. However within any structure there must always be the facility to record events as described by the patient (not in a processed form) and the ability to record data that does not immediately seem significant.

Nursing Records

It is only relatively recently that nurses have been seen as professionals in their own right. Modern Professional Nursing[16] published in 1949 identifies information which the nurse will need to collect in order to aid physicians in their work. It suggests that "What the doctor wants is not the *opinion* of the nurse, but a clear-cut, exact statement of the facts observed by her during her period of duty, and these facts should neither be embellished nor belittled by language stimulated by the idea or the imagination of the person making the report." It goes on to list information which will be valuable to the nurse:

"The personal effects, keepsakes, valuables etc., brought by the patient; The address of the next of kin; The full name, address, age, occupation of the patient; the history of the case, including family history, the personal history (noting the previous illnesses, kind of work, habits, etc.), and the present illness, with details of the symptoms in series. The nurse should try to get as many details as possible about the case which will help the doctors in their diagnosis. In many cases the writing down of the details is not insisted on, except for the making out of a case sheet and temperature chart."

Since the late seventies nursing care in Britain has moved away from a task-centred approach, and basing care on a medical model, to patient- centred care. When planning patient care nurses increasingly use a problem solving approach, based on a model of nursing. A model is a conceptual framework to aid the nurse in her assessment of the total needs of her patient; it may be created by a group of nurses to meet the needs of their client group[17] or, more commonly, a well established and widely used model is adopted or adapted. The model chosen will depend on the philosophy of the unit and the level of dependency of patients. The most commonly used model in British hospitals, developed by Roper, Logan and Tierney, is based on the activities of daily living[18] (see Appendix 1). These are identified as:

* Maintaining a safe environment
* Breathing
* Communicating
* Eliminating
* Working and playing
* Mobilizing
* Eating and drinking
* Sleeping
* Personal cleansing and dressing
* Expressing sexuality
* Controlling body temperature
* Dying

Once the initial assessment has been made the stages of care planning are:

1. Identifying problems
2. Stating aims of care
3. Listing nursing actions required
4. Review / Evaluation of care given

Within the nursing record there is usually also a multi disciplinary communication section to facilitate information sharing with other health care professionals.

The nursing care plan is, as far as possible evolving in partnership with the patient

and/or carer and in language understandable to them. Patients have access to part or all of their nursing record so entries must be unambiguous and objective so that the patient can understand their content[19]. Information collected is recorded on pre - printed sheets which have a number of headings with spaces for details to be entered.

This individualised approach to planning care is sometimes supplemented by a 'standard care plan', these pre - printed plans address the problems of a group of patients with common needs eg. the early post operative care of patients who have undergone coronary artery bypass grafts. If based on research and regularly updated this approach encourages a uniformly high quality of care. For audit purposes pre-printed care plans have been shown to improve documentation of patient teaching[20]. This approach conflicts with the philosophy of individualising care but can provide consistency of care over time, as well as cutting down on unnecessary paper work. There should always be room within the 'standard' care plan for the nurse to add problems specific to the individual needs of the patient[21].

Rector and colleagues state:[22]

> "*The goal of developing analyses and models for the medical record is to create an architecture for structured information which is both faithful to the process of care and adequate for the other uses of the information collected. As the number of information systems increases, the demands to use the same information in many different ways also increases. The greater the demands to make multiple use of the information, the more important it is that the underlying models reflect accurately the nature and structure of the information. Many of the difficulties experienced in attempting to generalise existing systems stem from the fact that they have pre-selected and distorted information in order to fit into particular applications, usually clinical research and epidemiology. The models omit much of the information actually used in clinical care and do not accurately reflect the real status of the data they record.*"

2.1 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

The Historical Background of Clinical Records

1. Structured data collection can improve clinical performance.

2. Health records must contain psychological, social and family information.

3. Health records should facilitate communication between agencies.

4. Some health professionals will wish to use a formal method of recording such as a problem orientated structure but others will not.
   Health records must be able to accommodate both groups.

5. Health records should be comprehensible to the non medical reader eg: patient, lawyer, audit department.

6. The rationale for clinical decisions needs to be apparent from the health record (what was done and why).

7. Health records should support a narrative structure and documentation of the patients' own words.

3 Clinical Competence and the Clinical Record

Introduction

Clinical competence is at the heart of all medical practice; a fundamental requirement for the medical record is therefore, that it should enable and reflect the competence of the clinician who creates it. Definitions of clinical competence form the basis from which acceptable standards for independent practice are derived (ref) and should therefore bear a close relationship to the principles underlying the clinical requirements for a medical record. The purpose of this section is to explore the roots of our thinking about clinical requirements for the medical record from a perspective and research literature that is not always included in discussions of the structure of the medical record. This is a conceptual test site and the record must be robust in this area if it is to be accepted, particularly as many within the field of assessment expect the medical record to be a reliable tool for examining clinical competence.[23]

A Definition of Clinical Competence

Considerable effort has been expended in attempting to define the professional skills and knowledge required for the demonstration of competence. [24] [25] The definition which follows also includes the moral and personality attributes which are important components of competence but which have received less attention to date. They are however highly valued by society although they are infrequently assessed. [26] Groups which have attempted to name the humanistic qualities that characterize competence have invariably reported difficulty in their precise definition.[27] Nevertheless there has long been widespread agreement that it is important to try. The American Board of Internal Medicine has stated that:

> *"Moral behaviour is an overriding professional consideration in caring for patients. A major responsibility of those training residents in internal medicine is to stress the importance of the humanistic qualities in the relationship between patient and physician throughout the residency."*

We have selected a comprehensive definition because it has implications for the medical record which will be explored later.[28] We also assert that the definition of clinical competence is highly context bound and the role of physicians in the societies in which they will ultimately practice should determine the professional behaviour that they will be expected to demonstrate.[29]

Competence is composed of cognitive and interpersonal skills, moral and personality attributes. It is in part the ability, in part the will, to consistently select and perform relevant tasks in the context of the social environment, in order to resolve health problems of individuals and groups in an efficient, effective, economic and humane manner.

Components of Competence

The specific components of competence include:

1. The consistent ability to select and perform tasks employing intellectual, psycho-motor and interpersonal
skills.

The tasks from which a competent physician will select are subsumed by the list of functions which follows. The importance of each function varies with the context but each has a direct relationship to the structure of a comprehensive medical record which must facilitate each one.

to deliver curative and rehabilitative care
to promote health
to organize preventive activities
to plan, organize and evaluate health education activities
to collaborate with other agents of community development
to participate in research
to manage his or her services /resources
to train other members of the health care team
to participate in and sometimes to lead the health care team
to engage in self directed learning
to engage in self evaluation and quality assurance.

2.The consistent demonstration of appropriate moral and
personality attributes.

Each attribute should be locally defined and be culturally sensitive. The absence of any one of the following attributes will compromise competence:

1. as a person a physician should exhibit:

honesty.

2. as a doctor a physician should exhibit:

self awareness.

3. in the doctor patient relationship a physician should exhibit:

empathy
respect for patient autonomy
confidentiality

These attributes, which are an essential part of competence, were defined after consideration of the following concepts.(ref)

accepting feedback	authenticity	
availability		discretion
flexibility		integrity
perseverance		reliability
responsibility		sensitivity
stamina		tolerance

They are parts, but not the whole, of honesty, self awareness, empathy and respect: they inform the more detailed consideration of the clinical requirements for a medical record which will enable and reflect honesty, self awareness, empathy and respect for patient autonomy and confidentiality in the clinician who creates it.

How can a medical record promote and support honesty in the clinician? If it is too rigorous and unforgiving it will be avoided. If it allows lies it will not be trusted. Clinicians need the ability to modify the record by explaining, reinterpreting and commenting on their actions without altering their initial record. Patient autonomy is promoted by ensuring that as far as possible patients are informed. In particular the record must be accessible to patients and avoid unnecessary jargon. Confidentiality and the question of who has access to the record must be defined. Perhaps the patient should decide the level of access to sensitive information that is afforded to any given health professional.

Can a medical record enhance, reflect or impair empathy? Is this more to do with the human machine interface and its effect on the consultation or can the way in which information is arranged within the record affect empathy. Is the quality solely a property of the physician or dependent on the doctor patient machine information

dynamic. How do classifications of information enable the doctor to be 'as if' the patient for at least some of their relationship? These questions will be the subject of research but it seems likely that approaches which enable the patient's 'story' to be told with the timing and pacing dictated by health care needs will enhance empathy.[30] If the use of a medical record forces premature revelation of information in the name of efficiency or epidemiology it may impair clinical competence by undermining empathy.

The Common Core of Practice

The essence of clinical competence is reflected in the common core of practice which comprises that component of practice that distinguishes an individual as a member of the medical profession.[31] It contains knowledge, attitudes, and skills which any doctor who engages in independent practice in any branch of the profession, including the non-clinical branches, should exhibit. These include moral and ethical behaviour in the practice setting, humanistic skills and the skills necessary to maintain competence within their chosen field. A critical approach to their own work, a willingness to engage in medical audit, a commitment to independent learning and an awareness of the legal, ethical and societal issues relevant to medicine are therefore all characteristics to be expected of any competent physician who in turn will expect to use a medical record which itself derives from these principles. Some of the content of this core of practice may well be defined by society from time to time and be reflected in legislation and judgments in courts or findings within other disciplinary fora, the medical record must be capable of simultaneous evolution.

Although these themes apply throughout clinical practice they are in a dynamic relationship to the context of practice as well as its content. Physicians must be aware of the legal, ethical and societal issues current as they use the medical record. Hence the record itself must be dynamic, a true record of each encounter made within the prevailing context but which allows this context to map directly onto a different context as changes within society and the profession are translated into legislation. Examples might be changing definitions of who can have access to the record, the age for giving informed consent, allowing death in certain circumstances using certain drug regimes. This requirement is further complicated by changing contexts due to cultural differences particularly when different languages determine perspectives.

The Medical Record and the Assessment of Competence

Most developed societies are taking an increased interest in the activities of the

professions within them. Medicine is no exception and the modern clinician is expected to be accountable for clinical decisions and the use of resources to the patient and the wider community. The requirement to engage in medical audit is now part of the UK general practice contract, and several countries have introduced or are actively considering reaccreditation for established clinicians in most of the major specialties.[32] Current and proposed programmes to assess the competence of practising clinicians, for whatever purpose, usually include scrutiny of the medical records of a representative group of patients. While these developments may be accompanied by debate about confidentiality and access to the record by third parties, including lay assessors, it is clear that they are likely to be widely implemented throughout the European Community within the next decade. The medical profession and the public have a right to expect that when a competent clinician uses The Good European Health Record, its structure
will allow a fair assessment of patient care in its widest sense.

3.1 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

Clinical Competence and the Clinical Record

1. The medical record must enable and reflect clinical competence
2. The medical record must be capable of supporting practice in all of the areas defined as components of clinical competence.
   - to deliver curative and rehabilitative care
   - to promote health
   - to organize preventive activities
   - to plan, organize and evaluate health education activities
   - to collaborate with other agents of community development
   - to participate in research
   - to manage his or her services /resources
   - to train other members of the health care team
   - to participate in and sometimes to lead the health care team
   - to engage in self directed learning
   - to engage in self evaluation and quality assurance.
3. Some components of clinical competence are closely related to the role of physicians in the societies in which they practice. The medical record must not impose the values of one society on the clinical practice of another, although it should promote ways of learning about different styles of clinical practice.
4. The medical record must be capable of evolution as society develops and defines some aspects of the common core of practice. The record must be dynamic,a true contemporary record of each encounter which maps directly onto a different context as changes within society and the profession are translated into legislation
5. The medical record must support moral and ethical behaviour in the clinical setting.
6. If required to do so for assessment purposes, the medical record should demonstrate the clinical competence of the clinician who made it.

4 The Role of the Clinical Record

The medical record is an important tool supporting quality in clinical care. Just as there will be many different situations in which it is accessed, the record can play many roles in the provision of care to individuals and to populations.

Rector and colleagues state[33]:

> "*We maintain that the principal purpose of the medical record is to support individual patient care. The design of many existing electronic medical records derives, implicitly or explicitly, from support for the use of aggregated data for research, audit, finance, or planning. We maintain that such designs are inappropriate for a record for clinical use and, ultimately, inadequate.*"

The following structure for the roles fulfilled by the record is based on a list from Shortliffe et al.[34]

4.1 Forms the basis of a historical account

The clinical record has always had a special place at the heart of clinical practice. It is used to maintain an ongoing account of the clinical care provided by an individual doctor, for an individual patient, and finds its principal clinical use and value at the time of individual consultations as part of an ongoing patient/doctor relationship. As such it is a very human document, concerned with a private and confidential world. As well as what might be termed objective measures such as blood pressure, it will contain prompts, reminders, impressions, hunches, recognitions of uncertainties and dilemmas.

4.2 Supports communication

Clinical care, in an increasingly specialised profession, involves sharing of responsibility among health care professionals. Inevitably parts of the medical record must be shared, and this must be effective and germane to the issues involved, such that different areas of medical expertise can be brought to bear on clinical need.

People, doctors and patients, move and the clinical record must be able to move with them if effective and efficient care is to be maintained. This is one area where current record-keeping and transfer systems are often challenged to the point of ineffectiveness.

Different professionals, working within quite different professional contexts will work with the patient at different times and places. In looking at the training needs for continuing care in the community, a case was recorded of a family in great stress being looked after by twenty-eight different social, medical and other agencies, none of which had any formal means of communication with each other. This extreme example demonstrates the diversity of contributions to individual patient care and the need for well-ordered appropriately communicated records.

The medical record is also an important aide-memoire for any one clinician involved in the continuing care of the patient. It may at times need to store ideas or notes which are not specifically related to the patient's medical case, but which are reminders for the next encounter. Sometimes these will need to be shared, but there are occasions when clinicians wish to have a place to temporarily store personal thoughts which are not for sharing. The role of the medical record formally in this function will need further debate.

As patients acquire increasing rights of access to information held on them, it is possible that much of the record will be able to be read by them, or by their appointed carers. This creates further opportunities for the record to be used as a means of communication with the patient personally, for treatment instructions or health information.

4.3 Anticipates future health problems and actions

Computer systems have always been at an advantage in storing and retrieving data relating to future health care needs. While local systems can anticipate future health requirements through structured data entered in the past, there is an urgent need to draw attention to medical actions that require attention at a future date when the medical files are transferred from one site to another. The paper record has not been very successfully developed to warn the attending clinician of actions required in the future, and it is possible for the computer record to greatly develop this function.

4.4 Describes preventative measures

There is an increasing need to demonstrate clinical competence by drawing attention to preventative measures, possibly recording them in a separate part of the record. Screening procedures are often performed at the initiation of the clinician rather than the patient, and prompting mechanisms from within the record structure greatly enhance the likelihood of this being carried out.

Patient-completed questionnaires and charts have found a growing place within the medical record, and their role is being developed further for domiciliary recording of symptoms, and for clinical measurements such as peak flows as well as the time-honoured urine glucose testing performed by diabetic patients. The ability for patients to enter information into the record themselves is a potentially exciting, although probably very controversial area.

4.5 Identifies deviations from expected trends

Many serial measurements are made in all fields of medicine. Trends in serial measurements are difficult to ascertain without graphical representation. Examples include hourly blood gases in ITU, blood pressures in general practice, the growth of a child, and haemoglobin levels in a patient treated with penicillamine. Displaying these serial measurements and relating them to 'normal' expected levels in a diagrammatic form must play an increasing part in supporting good clinical management.

4.6 Provides a legal account

The medical record should help the clinicians to provide a standard of care which is seen to be accountable both to the patient and to the wider medical profession. It is therefore at the heart of medico-legal responsibility, and the ethics of good clinical practice.

The record must demonstrate competence through faithfulness to the coherent mental processes undertaken by the doctor, and the narrative of care provision.

4.7 Supports clinical research

Clinical research will have varied and evolving requirements on a medical record. The tools for retrospective data collection from a computerised medical record can be developed to a high degree if there is a standard architecture. Local innovations in medical records will be

required for prospective clinical research. Recording consent within the record will also be desirable.

Llewelyn[35] proposed a novel way of meeting the clinical and research needs in their hospital by providing standard descriptions of the process of care for diseases and allowing computerised alteration of these to fit the patients problem. This improved the classification of the disease (as the summary was more likely to be appropriate), the quality and frequency of discharge summaries, and can be linked with data collection protocols for research.

4.8 Enhances the efficiency of health professionals

Many repetitive processes can be automated. Prescription orders, billing and reporting are examples.

The organisation of the information as presented to the clinician can be controlled and altered. This should improve efficiency of both locating and recording. The ability to view information at various levels of detail will also mean that information can be retained in the record without overwhelming the clinician providing care. For example, a blood test result may need to be viewed in great detail on its initial return, though may be scanned as "normal" in future, though its individual values may be accessed for purposes of a graphic display for assessing trends.

If computerising the record does not enhance the productivity of professionals either economically or through efficiency or satisfaction, then the enterprise will not be successful.

4.9 Supports continuing professional assessment

Chart review is established practice in the US, and likely to be adopted in other countries. Continuing assessment, as part of an overall strategy of evaluating clinical competence has been discussed earlier.

4.10 Supports medical education

Medical records have always been used by students for learning and by teachers for demonstrations, or assessing competence. The work in this

area will be published in a separate document in November 1993.

4.11 Accommodates decision support

Considerable finance and effort have been invested in the development of decision support systems. It is clear that any approach to a generic system must operate on a generalised medical record. Current projects working in this field, such as the AIM project DILEMMA have proposed draft data models [24] which must be considered further. Future progress is likely to be accelerated should a common record architecture be available.

4.12 Accesses medical knowledge bases

Accessing knowledge bases directly from the medical record is another major requirement for future medical record systems. It is not entirely separable from decision support, and ideally both should be accessed in a similar way. Both decision support and knowledge base access will require a term based record, as the number of accessible terms will be limited.

4.13 Assists with audit

Medical audit is a major growth area within the in health care provision of many countries. The retrospective data collection used in the past is fast changing to prospective protocol based recording, with flow diagrams and standard forms. Clinicians will increasingly wish to study the factors influencing their management decisions, and outcomes. Future record developments should seek to make this process more inviting than the current chronological history sheets are able to.

4.14 Facilitates management tasks

Benjamin begins his assessment of the use of statistics in health administration and medical practice with the following[36];

> "*An organisation is a group of functional components brought together to bear on a stated objective. It needs management to*

hold it together as an organisation; to ensure that the functional components can work together with maximum efficiency and with the best allocation of resources. In turn, management needs information. There must be communication between components about their respective activities and about the action which one component desires to generate in another, so that objectives can be clarified and their attainment assessed. There must be information of the likely consequences of actions by any one component, so that optimum overall strategy may be chosen."

4.15 Accommodates future developments

The growth of national health services throughout the world has placed new demands on the medical record beyond that of the initiating doctor-patient consultation to include use by many interested parties.

These include:

the patients themselves and their appointed carers

the clinician, in preventive or anticipatory care roles

groups of clinicians working in primary or secondary care

paramedical colleagues working with the patient

clinicians and clerical or research staff for clinical audit, personal or department quality assurance

hospital managers and health care purchasers (health authorities or insurers) for quality assurance

health care planners at hospital, practice, district region or national level

legal advisors for the patient or clinician

clinical researchers

medical students and medical teachers

commercial product developers for market research (eg. pharmaceutical industry)

insurance companies for determining payment, or assessing risk

politicians and health economists (and journalists!)

Health care technologies are growing in number and sophistication, the medical record must accommodate these developments. Policy and financial considerations may have implications on the record which must be considered.

4.16 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

The Role of the Clinical Record

The medical record must:

- Form the basis of a historical account
- Support communication
- Anticipate future health problems and actions
- Record preventative measures
- Identify deviations from expected trends
- Provide a legal account
- Support clinical research
- Enhance efficiency of health professionals
- Support continuing professional assessment
- Support medical education
- Accommodate decision support
- Access medical knowledge bases
- Assist with audit
- Facilitate management tasks
- Accommodate future developments

5 The Nature of Clinical Data

5.1 Complexity

The complexity arising in practice from simple recordings of attributes can be quite overwhelming. Consider the example of the measurement of blood pressure. For many purposes in clinical care a compound record of systolic and diastolic (e.g. 120/80) will be adequate. For reviewing of repeated measurements graphical representation will be helpful, but it will necessitate the separation of the readings into systolic and diastolic pressures. To add to complications a blood pressure entry may have the value "Unrecordable" or a combination of a numeric entry and a text entry:

"Systolic : 60, Diastolic : unrecordable".

Blood pressures may be measured once every five years, monthly, a number of times a day and continuously. The datum may then have associated "modifiers". Blood pressure may be measured in different positions (lying, sitting or standing), at different sites (e.g. arm or leg) and by different methods (sphygmomanometer, intra-arterial) which may themselves be further specified (e.g. large cuff).

The problems are more apparent when more complex data is recorded. Blois describes the problems in recording clinical information, and differentiates between the "low-level processes" of chemistry and physics (e.g. weight, height: attributes generally appear sharp and clear) and the "higher-level processes" (e.g. understanding, behaviour: attributes tend to be soft and fuzzy) carried out in more complex organisms.[37] Blois and Shortliffe argue that:

"*Computers are used routinely in commercial applications in which humans and situations concerning them are involved, and relevant computations are carried out successfully ..... in these commercial applications, the descriptions of humans and their activities have been so highly abstracted that the events or processes have been reduced to low-level objects. In medicine, abstractions carried to this degree would be clinically worthless.*"[38]

5.2 Certainty and precision

Data of all types when recorded carry with them degrees of uncertainty. This relates to all information, but especially to clinical findings and interpretations. Uncertainties will be dealt with in a way appropriate to the specialities, generally by further information gathering and use of time. Use of language in describing uncertainties is often ambiguous, and Bryant and Norman (Figure 2)[39] have demonstrated the wide disagreement about the meaning of common terms.

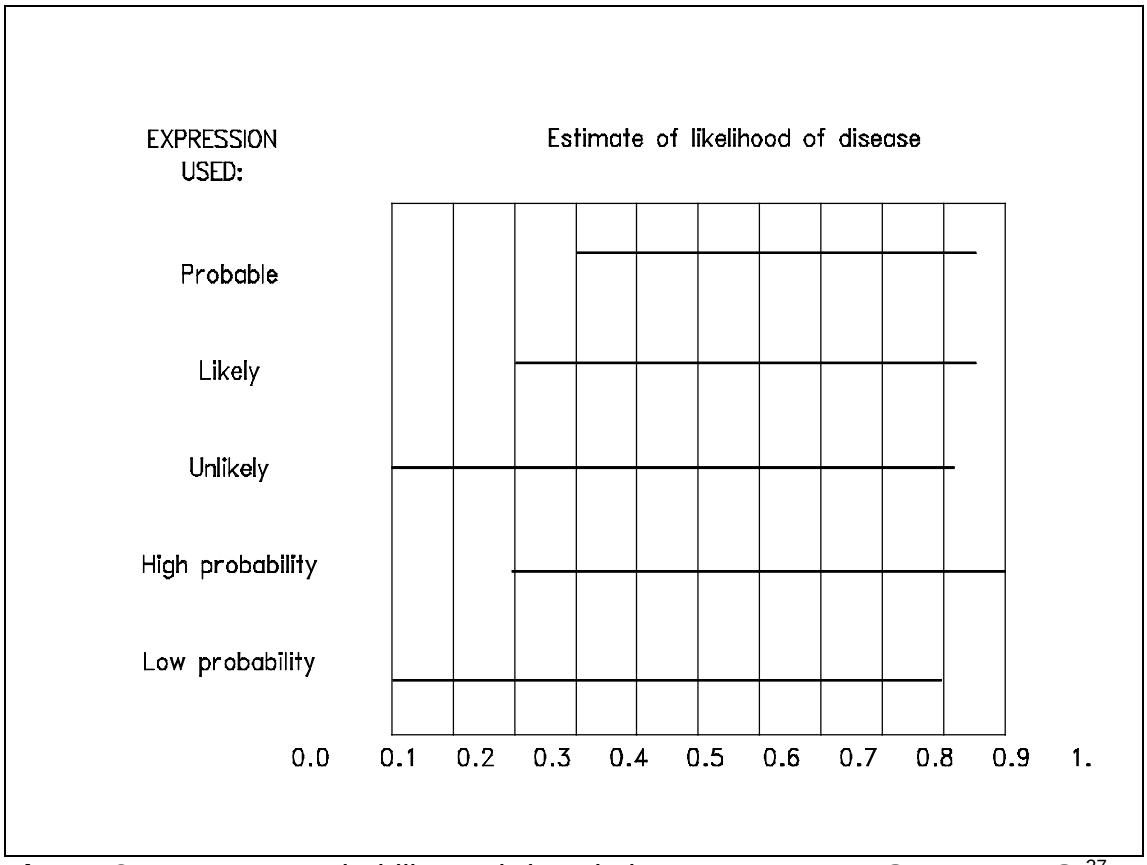


Figure 2 Probability and descriptive terms. Bryant G, Norman G.[27]

Owens and Sox[40] state:

> "*The use of probability or odds as an expression of uncertainty avoids the ambiguities inherent in common descriptive terms.*"

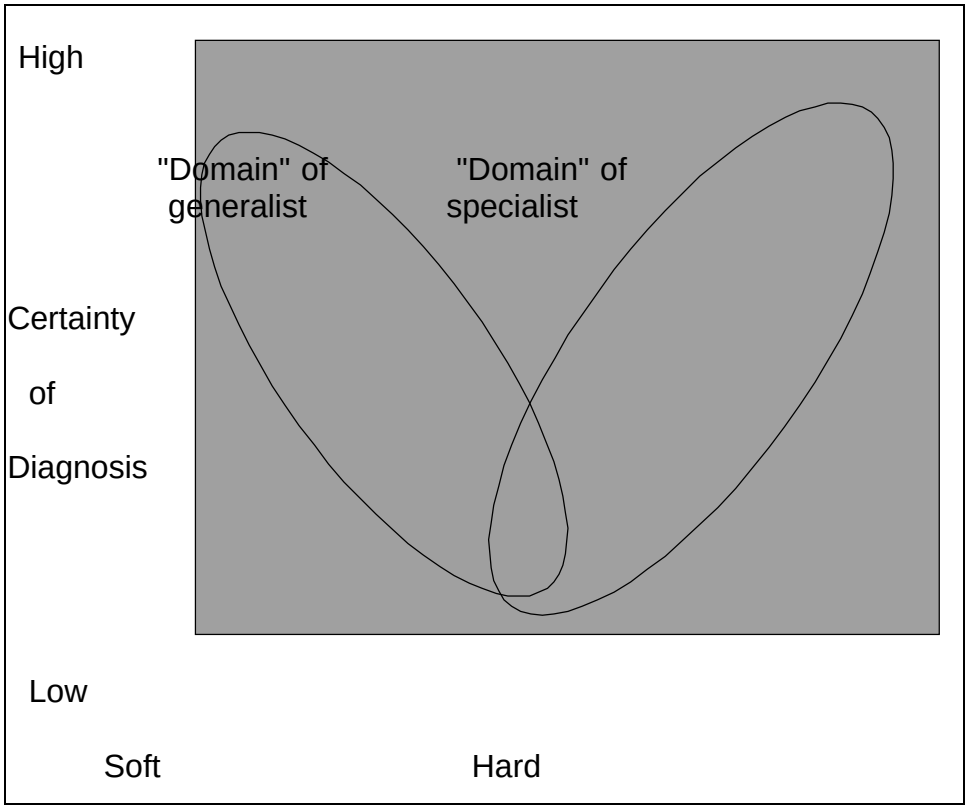
The Royal College of GPs (UK) Computer Group recognise in their report the tentative nature of many diagnoses. They state in their recommendations for computer systems[41] that;

> "*Any diagnosis needs to be given a level of certainty; to be changeable if proved wrong but not lost from the database*."

It is widely recognised that all medical diagnoses and problem statements have a certain degree of "hardness" or "softness". The usual aim in a series of consultations is to "firm up" the hardness of the diagnosis to a point where treatment and prognosis are optimal. Thus in general practice we may start with a very soft statement such as "dry cough", and this may then progress through "tracheitis" to "Haem. Infl. tracheitis". As a rule the generalist's diagnoses will cluster in the softer area because of lack of investigative procedures, and as a rule the specialist will tend to seek for more specific diagnoses.

Likewise there is a dimension to the diagnosis concerned with the degree of certainty with which the diagnosis is made. This may range from an educated guess ("I think this is a tension headache"), to a post-mortem certainty ("Parietal lobe meningioma present").

If these two parameters are projected graphically it can be observed that the generalist tends to work more in the area of soft data and diagnoses, and attempts to move the diagnoses to a higher level of certainty, but usually requires the specialist to take over to produce diagnoses with both a high level of certainty and precision.



The domains of certainty of diagnosis illustrated between the specialist and the generalist

The assessment of severity or risk in a situation is often as important as the recording of findings and, especially in primary care, may be the sole basis for management decisions. Bolens and colleagues have attempted to alter the balance of recordings towards accurate assessment of severity.[42] They used a combination of three scores in their paediatric practice as shown below.

Index	**Score**
Risk to life	**0**: no illness **1**: symptoms that worsen & threaten life in > 24 hrs **2**: symptoms that may worsen in < 24 hrs **3**: symptoms that may worsen in < 12 hrs **4**: symptoms that may worsen in < 2 hrs
Functional risk	**0**: no illness **1**: risk of temporary partial loss of a physiological function of an organ **2**: risk of permanent partial loss of function **3**: risk of temporary total loss of function **4**: risk of permanent total loss of function
Seriousness	**0**: no illness **1**: dysfunction of an organ that does not interfere with normal activity **2**: dysfunction of an organ that moderately restricts activity but does not cause dysfunction of other organs **3:** dysfunction of an organ that causes secondary dysfunction of other organs **4**: impairment of one or more organs beyond our therapeutic capacities

They state in their description of their unique medical record keeping approach:

> "*We reason that the presence of a symptom, irrespective of its intensity, indicates the presence of an abnormal process. Therefore, only the presence or absence of a symptom is recorded; its intensity is not specified. However, the severity of*

> *the clinical situation is assessed for the patient as a whole....instead of using an adjective such as 'light', 'moderate', or 'serious' to describe this symptom, one can enter a score for overall severity.*"

Measures which can be used to evaluate the reliability of ratings in clinical settings have been described and validated[43]. Moves towards the progressive computerisation of the medical record will require a recognition of these aspects of the clinical information to be expressed.

5.3 Diversity

The medical record is made up of a collection of entries, which are at present usually on paper and identified explicitly (by signature) or implicitly (by handwriting). The information entered is usually identified as relating to a particular contact, as summary information, or as information from another source (e.g. laboratory data).

These entries are in the form of **narrative data** in many situations. Mixed with these are many loosely coded **short hand conventions** such as "SOB" (shortness of breath), "SOA" (swelling of ankles) and "PERRLA" (Pupils equal, round and reacting to light and accommodation). **Phrases** such as "failure to thrive" have become standardised in some areas, though "malnutrition" and "severely deprived" may also be used in similar cases in different locations though not synonymously.

Many medical data have **numeric values** (e.g. weight, serum cholesterol), and it is particularly in such data that the notion of precision becomes important.

Clinicians frequently make clinical **drawings** to describe abnormalities detected -this is often the most concise way to make such recordings. Coupled with this is the use of symbolic diagrams to convey concepts. In some cases these have been developed to a high level of sophistication but many remain recognised only at a local level.
ECGs and EEGs are expressed as **analogue data**, usually stored graphically, and many test results are now in **image** form (Xrays, ultrasounds etc).

It is also clear that some specialities, such as Ophthalmology, have

highly stylised symbols and drawings which are for communication within the speciality.

The range of such methods for conveying information is not static and will evolve as medicine itself progresses. The tools for recording and interpreting these forms of data, whether on paper or computer are an equally important part of this process and must be catered for.

5.4 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

The Nature of Medical Data

The electronic record must recognise that medical data has:

complexity
levels of certainty and precision
diversity of data types

6 The Structure of Medical Language

All medical records are at present structured in some way. This may be by source (Nurse, Doctor), by time (Date of contact), by information type (Contact records, letters) or by problem (Problem oriented records). Shortliffe and Barnett[44] are clear on their view of the requirements for improved communication of medical information in the medical record:

> "*Imprecision and the lack of a standardised vocabulary are particularly problematic when we wish to aggregate data recorded by multiple health professionals or to analyze trends over time. Without a controlled, predefined vocabulary, data interpretation is inherently complicated and the automatic summarisation of data may be impossible. .... Regardless of the arguments regarding the 'artistic' elements in medicine, the need for health personnel to communicate effectively is clear, both in acute care settings and when patients are seen over a long period. Both quality and scientific progress depend on some standardisation of terminology.*"

6.1 Classification and coding systems

There are many coding systems used in medicine, and a shared medical record must allow use of any or one of these systems. They are usually designed for a specific purpose and may be used in specific or general settings.

In the UK the government has encouraged the use of the Read Classification system, a large bank of related terms which are not as yet defined. The code associated gives a hierarchical structure allowing 'branches' of related terms to be searched electronically. The difficulty with this system is the number of terms required to be comprehensive (already in excess of 65,000) and the difficulty of accommodating queries that do not fit the hierarchy built into the coding system. Mapping to other classification systems has been attempted but not validated.

Other classifications limit themselves to specific areas of care:

ICPC - the International Classification of Primary Care. This broad classification is designed to classify the reason for encounter, and the process of care. It is validated and has been used widely in research. The Dutch primary care organisation encourage its use in computer systems. It is available in 12 languages.

ICD - the International Classification of Disease, Injuries and Causes of Death. This is still the most commonly used classification, and is produced by the WHO. It is now in its 10th version. It has been used extensively in Hospitals for more than a decade, in filling hospital activity analysis. The OPCS classification of procedures is currently in use in the UK rather than the ICD procedure chapters (first released in revision 9).

SNOMED - Systematised nomenclature of medicine. This has been produced by the American College of Pathologists and is particularly useful in classifying histological diagnoses. Its widest use is in oncology.

All of the different systems developed within the field of medicine have attempted to classify as well as code, to varying degrees.

Regrettably each major coding system, such as ICD, SNOMED, FRAMEMED, MeSH, Read, has been developed independently, often from within a specialist group of the medical field. These systems often attempt to do little more than to accurately classify disease labels, and yet translation between them is fraught with difficulty. Translation softwares, such as MicroMeSH, require considerable interactive user input.

Drs Cimino and Barnett, professors of medicine and informatics in New York, have endeavoured to construct a semantic model which can act as an intermediary language, and facilitate automatic translation. Medical terms are classified into 'frames' (such as diseases, anatomic sites, time descriptors). Each frame has classes and progressive subclasses of terms. "Treatable diseases" and "infectious diseases" would have subclasses "therapeutic agents" and "infectious agents" respectively. Logical associations would allow "treatable infectious diseases" such as malaria to be classified, and restrictions such that "organisms" could only occur as a subset of "infectious agents".

An algorithm for automatic word matching has also been written based on the MUMPS operating structure, and has successfully linked ICD-9 and MeSH terms. Although the compilation of the vocabulary has required the exhaustive

work of skilled translators, the authors suggest that the further development of this single semantic classification would be considerably less than constructing multiple translation networks between coding systems.

The problems with all of these coding systems are readily apparent:

each classification is only primarily valuable to the specialist group that designed it

even users within that group can find it too rigid or need considerable training

limited vocabulary constrains natural expressivity and may artificially skew information

difficult to link terms together meaningfully

insufficient room within codes for expansion of medical knowledge

concepts behind the structure become outdated

The development towards an electronic clinical record needs to explore the possibility of coding systems which avoid the pitfalls of current classifications.

Several key projects are involved in research within the domain of medical language and coding systems. Considerable development within this field is still necessary in order to better accommodate the natural expressivity of clinicians. Devising a comprehensive classification or coding system is not formally the remit of this project, but it will be necessary for the record architecture to interface successfully with the requirements of the newer coding systems as they emerge. The GEHR consortium has made contact with many of these projects in order to ensure that the mechanism for these links to the clinical record are properly represented.

Early work investigating the range of medical word use is described later in this document. The enhancement of the Current Health Record Architecture term list through the requirements of clinical specialists, is also described later, and is an important evaluative facet of the project.

Regular meetings have been held with other AIM projects involved in the field of medical language and coding, including GALEN and DILEMMA. Contacts

have been made in Holland with the ICPC working groups, and the GEHR project now has a working agreement to use and analyse prototype versions of the Read Clinical Classification.

Strong links have been forged in the UK with the Clinical Terms Project: a substantive two-year project involving forty clinical specialities to develop a comprehensive classification and coding system.

A significant part of the work in this project is being directed to this field, with results and is to be published in future deliverables.

6.2 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

The Structure of Clinical Language

There are many coding systems being used in and developed for medicine, and a shared medical record must allow use of any or none of these systems.

7 Evolving from Paper Records

Traditionally medical records were intended to record one specific physician's personal notes on a patient and were not used by other people. Through the past century, medicine has become too complex to be practised in isolation. Modern medicine has grown dependant on a staff of nurses, paramedics, doctors psychologists, physical therapists and others working in association or combining their efforts and knowledge, The need for sharing notes and information and the introduction of the "shared-care" principle has changed the way records are being kept. The amount of notes, reports and technical summaries can be awesome with some chronic patients, thus leading to bulky and unwieldy records.

Good care goes hand in hand with good record-keeping and in order to achieve this and regardless of whether information flows via paper, lines or electrons the medical world has to impose on itself a certain discipline in the way it is recording its observations. By imposing a certain level of excellence, sometimes simply by forcing people to note what they see, the electronic patient record might improve health care, but not without imposing a certain number of standards and not without some controversy.

Achieving a certain discipline and imposing a minimum quality in record-keeping without restricting subtle personal views or refined and detailed observation is a challenge for everybody working with a computer in the medical profession.

Health care has become expensive and certain examinations cannot be unnecessarily duplicated without risk to the patients' health or wastage of health resources. Information has to be circulated in several different ways. Knowing that a certain test has been performed is often as important as the results of that specific test. Where it has been performed and by whom is also of relevance. It is certainly not always sufficient to provide only the interpretations of results. Physicians have the need and the right to derive their own opinions from the raw data from tests which have been performed on their patients. Test contents and not only their reports have to be made available if we want to avoid duplication of examinations.

Patients have become mobile. Not only do they travel on holiday, but they periodically move home and even change their country of residence. Travel of the elderly is increasing, more and more on a seasonal basis and in a north-south direction. But the age group over 65 is responsible for more than half of medical spending. However, patients rarely depart from home with a summary of their paper record, even for long-term stays. The EEC groups twelve different countries with different cultures,

different languages and a different brand name for the same chemical substance in every single European country. This presents a challenge for the computer to excel where paper has failed to.

The ethical and legal environment is changing and imposes certain restraints on medical records. Paper is certainly not the ideal medium for long-term, identifiable and non-erasable storage. Paper cannot be secured or provided with differential security access. With insurance and liability issues arising, the need for indelible and verifiable information is increasing. It becomes essential to know who did what and where and to be able to prove it.

During the first year of the project many groups of clinicians have been consulted to elicit their attitudes to the growing trend towards a paperless consultation. As the medical record continues this process of evolution, a number of core properties were felt important to be retained. Many of these features are applicable to medical records in general, irrespective of whether they are on paper or computer. In addition recurrent problems with the current situation were cited as opportunities for major improvement.

7.1 Locating the record

The current situation with paper medical files, particularly in larger institutions, is that they are not always readily available. Considerable expense and manpower is expended in the administration and movement of medical folders. Despite this, lost or missing notes are a regular feature of every clinician's life and, particularly at nights, the records may not be available because the records department or practice building is locked. Modern trends towards sub-specialisation often mean the patient is under the simultaneous care of two or more departments, any of which might be holding the set of records.

A computer-based record has the potential to overcome many of these problems, but care must be taken to ensure that access to a computer is not inadvertently made as difficult as to the former records department. Scope must be made for the awakening of new demands, such as that for doctors to be able to take a useable record with them on home visits.

7.2 Locating information within the record

Clinicians almost invariably are working in consultation under a pressure of time with sometimes only one or two minutes allocated to updating the record. They have

acquired a considerable skill in assimilating salient points from a medical folder which often is in considerable disorder, and often without summaries. However, the extraction of epidemiological information from these notes is very cumbersome, and even locating a single piece of information during a consultation can sometimes prove frustratingly difficult.

Navigation through a computer record should aim to be as intuitive as possible. The paper record, while often difficult to use effectively, has some inherent advantages that should be remembered. Paper records flow sequentially down each page, then move right and to the top of the next page. This pattern of eye movements down, then to the right is well understood.

A clinician may gain some impressions about the patient from the appearance of the notes. The thickness, the number of letters, the number of results, the wear and tear of the cover will all intimate what has been going on in the past. While this may not always be accurate, it is often a valuable guide to the handling of that consultation.

It is usually very obvious who has made the entries in small institutions by the hand writing. Sometimes colours are used to indicate the nature or importance of certain information. As strange as it may seem, the main problem encountered by physicians when they read a record is deciphering illegible handwriting, including their own calligraphy. Knowing about the importance of very small details, eliminating this hazard also means that one cannot hide uncertainties behind an illegible scrawl.

It is usually easy to distinguish outgoing and incoming correspondence, as the paper quality is quite different. Many institutions have easily recognisable notepaper, and it is often possible to locate a particular letter from a well-known local hospital at a glance. Partitioning of the correspondence by institution within the computer will not necessarily be helpful, as the chronological dialogue is often very useful.

The traditional way is to work with the front and back of one or more partitions of the record, rarely venturing deep into the thick folds heavy with print. What the computerised record must cater for is the occasional foray into the past, either scanning summaries or reading detail, or both.

The structure and use of any new record should be simple and be quick to learn. Commonly used functions like accessing a portion of the record, going to the most recent contact, looking up patient details (administrative or various types of summary) must be available in a way that most doctors will achieve with minimal training.

Automatic functions undertaken by a system must take place at appropriate times, and the speed relationships must reflect the likely time pressures to obtain the answer. For example, if a clinician has just used a set of notes, they will expect to have almost

immediate access to them for re-checking or for adding further information. Analysis of data within a patient's file must be near instantaneous, whilst finding all diabetics in a hospital with an abnormal blood result may take somewhat longer without causing concern.

A screen display which is comfortable to the eye, and adaptable by professional groups or users to suit their needs, will play an important part facilitating the interpretation of the computer record. Colour on the screen could be used to convey messages about sub-sections of the record, or to highlight important facts, just as currently on paper.

Interfaces such as keyboards prove to be a limiting factor for many physicians. Not everybody is willing to give up handwriting to type information. Some might force themselves to do it, but not without abandoning certain detailed information they would have put in writing. On the other hand imposing certain structures to be recorded via data-sets might make medical file more organized and easier to read by a third party. Finding the balance between structuring information collection and leaving enough room for individualities and fine detail is one of the challenges when working on developing an electronic record.

The traditional record has been called source-structured. It is commonly arranged in a set way which includes several sections: administrative, summary sheets, contacts in chronological order, test results and correspondence. Whilst this may not necessarily be retained in a computerised record, many users will continue to think in this manner and the facility to section the record along these lines may still be helpful.

The medical record should ideally be structured in a way that preserves the meaning of the information when it is finally written or saved, so that it can be understood even if it to be read by another person elsewhere.

7.3 Comprehensiveness

The medical record must contain or reference all information thought to be clinically relevant to the care of a patient. The choice of terms requires a very comprehensive approach, and the out-come of the Clinical Terms Project, a £2 million Department of Health funded programme in the UK, will be the first systematic approach to this problem. Cook[45] describes his own collection of terms from various US sources and his associations of manifestations of disease with the diagnoses.

The ability to view information at various levels of detail will also mean that information can be retained in the record without overwhelming the clinician providing care. For example, a blood test result may need to be viewed in great detail on its initial return,

though may be scanned as "normal" in future, though its individual values may be accessed for purposes of a graphic display for assessing trends.

The clinician must be able to update the record in a manner consistent with the requirements for future access. It is very difficult to agree where to record information in paper records so that it is likely to be noticed at some point in the future when the patient may benefit from that information.

7.4 Expressiveness

Many doctors fear that their ability to express themselves in the record will not be met once the record is computerised. This is certainly true for most current systems. Kathryn Hunter in her book "Doctors' Stories"[46] expresses the view that not only are our memories and notes narrative in nature, but the knowledge we hold is of the same quality. It would seem important then to maintain the ability to store narrative data in the record!

While at times, or in some locations there may be an overwhelming need to have a medical record with rigid protocols, decision support and management plans, other clinicians will require expressive narrative to convey their findings. The record itself must cope with all types of data collection, though clearly a system implementing the record may take either or both paths, depending on specific requirements.

7.5 Faithfulness

Rector and colleges identify three aspects of faithfulness[47];

"*1) Faithfulness to the clinicians observations of the patient*

2) Faithfulness to the decision making process
3) Faithfulness to the clinical dialogue."

The first applies to direct observations, the second to interpretation and justification, and the third to the dialogue, communication, plan etc.

There is a growing trend for analytic tools to be available to users during the process of data entry on computer, including classifications and coding systems. It is important that the record when saved or copied should retain the original meanings as far as possible. Where the information has been re-presented, for example by language translation, that the reader should be made aware of this and has access to the original entry.

7.6 Sharing of medical information

The essence of the medical record is its role communicating information to people providing clinical care to patients. Pagano[48] takes great trouble to stress the importance of establishing the audience your record is likely to have, and the purpose of the recording you make. The consequences are a strong leaning to the narrative style of recording. We have listed the likely future audience for the record, and already in the USA records are regularly reviewed by managers to establish that criteria for payment have been met. Transmissibility is a corner stone of the medical record.[49]

As the importance of the record increases, so do the number of persons who would simultaneously wish to have use of it.

> Rector and Nolan[50] summarise the basic requirements for sharing of medical records:
>
> > "*To show the relationship amongst events - causes and effects, evidence and counter evidence.*
> >
> > *To support the full range of information needed for clinical care and knowledge based decision support systems.*
> >
> > *To accept user defined extensions systematically.*
> >
> > *To allow exchange of information between heterogenous information systems.*"
>
> They go on to argue that these requirements "can best be met by an approach based on descriptions rather than classifications or faceted schemes".

A major perceived benefit of computerisation is the ability to have many different views of the same data, allowing different professionals use of the same information, and reducing the need to enter similar data many times in the record.

7.7 Adaptability

The practice of medicine is evolving in many areas at a rapid rate. Attitudes to record

keeping can change dramatically in a short time, and innovations may lead to totally new data being recorded in a few centres. Doctors and other health care workers get pleasure from tailoring their notes to their own needs and interests. Adaptability is a major requirement of any paper or computerised medical record.

7.8 Author responsibility

It is widely recognised that every entry in the record must be attributed to an author. The relationship between the entry and the author of the record may vary (e.g. a houseman clerking someone or recording a ward round decision made with the consultant) but the author should accept the responsibility for drawing attention to that source of information if it is not themselves.

What is displayed in the record should be a true account of events as recorded by the author, in that if changes need to be made, it must be possible to step through and account for those changes individually.

All entries in the record have a status, such that even if they are later found to be incorrect they can be found stored as part of the full record. This view has considerable following in the field of medical informatics[51].

7.9 Security of the record and within the record

Paper can be destroyed by fire, deteriorate with age or by spillage of coffee amongst other environmental hazards. Computer data allows the possibility of backup copies to be held.

A very real danger is that existing notes can be erased or pages lost. Accessing and reading records lying on an office table or even stored in the central store-room is far from being prevented by current practice or hospital security measures. Identification of the author in the notes is not enforced and sometimes based on calligraphical analysis. There is no way of recording that the record has been opened and consulted unless notes or inscriptions have also being made. Any computer record which is even more widely accessible on a computer network will need to have a greater degree of security protecting access. A very sophisticated audit trail will need to be kept, and it may be that the record will be partitioned to tailor access to individual rights.

These issues are part of a complex ethical and legal framework which will need to be discussed in greater detail. A further document: Deliverable number 7 covering this field more extensively will be published in November 1993.

7.10 Storage of the record

Paper records take space, and take a considerable amount of manpower to distribute and process.

The increasing age of patients and chronic care provided means that many medical records hold a very large amount of data. When held on paper they become heavy and very difficult to use. The space and administrative resources required to maintain adequate paper records is considerable.

Many authors cite the redundancy of information with the paper record as a motivation for computerising the record. If the notion of permanence of data is upheld, then redundancy, no matter what format, is inevitable. How the clinician is 'protected' from redundant information is of little interest until they feel that there is something lurking in there!

However, it is also important to remember the long standing history of reliability of the paper record. As a device which can be read quickly without requiring machinery or power, paper may always represent the ultimate in portability! To rely upon a magnetic medium on the only store for all backup copies of the information, however carefully performed, may prove a disadvantage in the event of a catastrophe such as a nuclear explosion.

7.11 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

Evolving From Paper Records

1 The medical record on paper or computer should be as available as soon as possible at the time of need.

2 Navigation through a computer record should aim to be as intuitive as possible.

3 The medical record should be structured in a way that preserves the original meaning of the information.

4 It must be possible to store narrative data in the record.

5 The record must be capable of evolution as medicine and technology change.

6 Every entry in the record must be attributable to its author.

7 There should be automatic translation facilities to allow the clinical record to be read in different languages.

8 Computers and Medical Records

There is a large literature covering the use of computers in medical practice, and medical records in particular. Perhaps the most important document from the USA comes from the "Committee on improving the Patient Record" of the Institute of Medicine. A summary of their recommendations, published in 1991 is given below.

Recommendations of the Institute of Medicine[52].
The computer based patient record (CPR) as the standard for medical records. Health care professionals and organisations adopt the computer based patient record (CPR) as the standard for medical and all other records related to patient care.
The CPR contains a problem list The CPR should contain a problem list which clearly delineates the patient's clinical problems and the current status of each.
The CPR supports measurement of health status. The CPR encourages and supports the systematic measurement and recording of the patient's health status and functional level to promote more precise and routine assessment of the outcomes of patient care.
The CPR states the logical basis for decisions. The CPR states the logical basis for all diagnoses or conclusions as a means of documenting the clinical rationale for decisions about the management of patients' care.
The CPR can provide a lifelong record of events. The CPR can be linked with other clinical records of a patient - from various settings and time periods - to provide a longitudinal record of events that may have influenced a person's health.
The CPR system addresses patient data confidentiality.

Recommendations of the Institute of Medicine[52].
The CPR is accessible for use in a timely way at any and all times by authorised practitioners.
The CPR allows selective retrieval and formatting of information. It can allow different views of the same information.
The CPR system can be linked to both local and remote knowledge, literature, bibliographic or administrative databases.
The CPR can assist the process of clinical problem solving.
The CPR supports structured data collection. Storage of information should be based on a defined vocabulary. It adequately supports direct data entry by practitioners.
The CPR can help individual practitioners and health care providers manage and evaluate the quality and cost of care.
The CPR is sufficiently flexible and expandable not only to support today's basic information but also the evolving needs of each clinical speciality and subspeciality.

8.1 Benefits of computerised medical records

The Institute of Medicine[53], while acknowledging that developing computerised medical records had not progressed as expected despite considerable funding, identified five conditions in the current health care environment that increase the likelihood of success. First, the uses of and legitimate demands for patient data are growing. Second, more powerful affordable technologies are now available. Third, Computers are increasingly accepted as a tool for enhancing efficiency in virtually all facets of life. Fourth, an increasingly aging population requiring more chronic medical care and continued mobility of this population creates greater pressure for patient records that can manage large amounts of information and are easily transferable among health care providers. Fifth, pressures for reform in health care are growing, and automation of patient records is crucial to achievement of such reforms.

The committee concluded;

> "*Computerisation can help improve patient records and improved patient records and information management of health care data are essential elements of the infrastructure of the nation's health care system*".

Paper records have been in use for a long time and, as such, they are intrinsically linked to everyday clinical practice.

What are the benefits of paper records ?

1) They are familiar and everybody is accustomed to working with them.
2) They are portable and can be carried without any difficulty.
3) They are not subject to technical contingencies such as power failures.
4) They are flexible, they are open to any kind of ' soft' data.
5) They are a proven technology in its glory and in its misery.

On other hand, they have certain problems:

1) There are great problems with the format and framework in which they are implemented.
2) Their content is variable in terms of structure which creates ambiguity.
3) There are great problems in terms of availability, retrieval and storage.
4) Integration with other data is almost impossible.
5) They are extremely slow to use if we consider the speed of knowledge creation available currently.

Computerised medical records will have many more users than the current paper records due to availability and ease of retrieval. It is important that the main beneficiary of such developments is the patient.

8.2 Benefits to teams sharing the record

Early work with computerised medical records has drawn attention to the fact that clerical and nursing staff were more likely to cooperate with and benefit from the implementation.

Campbell and colleagues compared two clinics at the University of Nebraska[54]; one using the COSTAR computerised medical record, the other using the traditional paper record. The residents only used the program infrequently and were the least satisfied, thought the nursing and clerical staff were generally very pleased.

Attitudes of Nursing and Clerical staff to COSTAR medical record system in out-patients:

Benefits consistently attributed to COSTAR

- Access to the record when needed
- Access to the data on the most recent patient encounter
- Readability
- Ability to find current problems
- Less time required to obtain information
- Less time spent answering patients questions
- Better handling of phone calls in the clinic
- Better management of prescription refills

Benefits consistently attributed to the paper record

- Access to the hospitalisation summary

The same study showed that the clinic using COSTAR was less efficient in all areas, though there were more tests performed by the residents (the COSTAR program prompts clinicians to act in certain situations).

Evaluation of PROMIS[55] showed similar findings, the description of which can only lead physicians to sympathise with the 'guinea pigs'. Korpman[56] more recently draws attention to the fact that nurses are the main record keepers in hospital, and the proportion is increasing. He states:

> "*Today, patients are hospitalised more often for nursing surveillance and nursing care than for medical care. In inpatient units, the nurse, not the physician, is the primary integrator and coordinator of information and often the primary deliverer and monitor of care*."

He states how typically the nurse is overlooked in computerised medical record research and how, especially in inpatient care, the nurse and other clerical staff are essential users. He also sees the patient as the centre of health care coordination and makes a plea for a "*unified database*" as the core of the computer-stored medical record.

Spann[57] in his comprehensive review of the literature on the possible benefits of

computerising the medical record cites many examples of specific improvements in patient care, audit and quality control, as well as reduced cost and time due to computerisation, all comprehensively referenced. It is important to recognise that such examples may be the only successful aspect of computerisation in the institution cited, and cannot necessarily be added to other systems, or may require massive maintenance.

In the same journal Rodnick[58] raises many problems associated with computerisation of the medical record. Having expressed the view that voice recognition is beyond modern technology he states that "*the cost of manual data entry is the Achilles' heel of computer stored medical records*". He sees manual data entry as the only option, though states that "*the greatest stumbling block to the successful operation of a computer stored medical record is devising a means of accurate, efficient, and economical data entry*". He acknowledges the benefits of storing some data on computer.

Tang[59] and colleagues make a recent impassioned plea for rapid computerisation of the record. They chronicle the present poor performance in Health Care where computer technologies could support the clinician, especially when aggregated data is required, (an increasing necessity) or records are necessarily dispersed.

Skifjeld and colleagues working in NORA (Norwegian Health Care Record Project) state that the computer based record needs to be "significantly better than today's paper based medical record" and that it must be "easy to learn, flexible, as well as simple and efficient to use"[60]

Bishop presents a simple approach for the format of the Medical Record based on experience in FrameMed[61]. He proposes that the record should be divided into the **administrative** section, the **patient synopsis**, the **chronological medical record** and the **detailed medical record**. Bishop argues that such a format would allow physicians to find their way around the record easily and to enable sharing of information. It is not clear to what extent the format is a view of data held in a general database, or extends to the physical storage. The basis for decisions on storage of data in each section , particularly storing information in the chronological record rather than the detailed record, is also unclear.

8.3 The evolution of the electronic health record: a review of the literature

Introduction

A review of the present state of development of computerised medical records, reveals global trends which reflect the work of many researchers. We can, therefore, begin to accept the definition of the computerised health record as 'an electronic patient record that resides in a system specifically designed to support users by providing accessibility to complete and accurate data, alerts, reminders, clinical decision support systems, links to medical knowledge, and other aids. [62]

Complete and accurate data will also include all the financial information which might be important for the management of the health resources, from the perspective of the providers as well the clients, always recognising the social and cultural context of health care. Indeed the computerisation of health records has become absolutely necessary, not just a question of fashion. The costs of health care in developed countries are reaching unprecedented levels: the USA spent nearly $700 billion dollars in 1991, and [63] future predictions point to nearly 17% of the USA GNP to be spent on health care by the year 2000, with a cost between $100 and $240 Billion directly related to redundancies inherent in the present paper-based system administration.[64]

In Europe the figures reflect the same trends. The pragmatic economic view adopted within the USA has led them to approach these issues openly and directly, while Europe has taken a more conservative view, tackling the question fundamentally from the architectural standpoint, in the context of several European research programmes (AIM, RACE etc). These programmes are trying to influence the scientific community to engage with Health Informatics, and in the process, to negotiate a means for survival with the end-users.

This free-for-all has created an explosion, and at present, hundreds of software packages try to meet the needs of a population of health providers who are still only a small percentage of potential users. It is very curious to observe that in Europe and the USA during the last 10 years, the number of research papers about General Practice and Computerisation of medical records has not increased in the medical press.[65] We might believe that if the potential of the electronic patient record exists everybody will recognise it. The evidence does not support this intuition:[66] many physicians have in fact been reluctant to accept the new ideas because the fact is that the users are just not happy with the present solutions.[67] [68]

Perhaps the way the issue has been dealt with has been less than ideal. It seems that neither a 'just costs' approach, nor the epistemological constructs of new avant-garde solutions from European academics, are the practical answers that the health providers would like to be presented with. They are still waiting for better solutions. Now is the time to try to give them what they really want; the end-user must be an active and central character in the plot.

This review derives from several sources. We have reviewed the medical and computer science literature for the years 1989-92, including references about computerised health records and the logical associations with this topic. We have also discussed with several end-users and experts in computer science. Above all we have tried to integrate the experience of some with the expectations of many together with our own views of this complex problem.

Background

In less than 50 years the evolution within information science and computing has taken us from the mammoth valve machines and hard-wired programs to the personal workstation of today.

Medicine has been defined as a science of 'Information management and real time integration with knowledge'[69]. Indeed, medical practice has been described as being 'dominated' by how well information is processed or reprocessed, retrieved, and communicated. It is therefore logical and inevitable that medicine and information science are synergistic. At present progress, although real, lags behind the real possibilities opened up by the interaction[70]. At the same time the excitement of using new technologies has led to an enthusiastic quest for new ways of addressing the issues of medicine and computers. Against this background what are the current trends? What is being done? What can seriously be expected?[71]

In order to address these questions for the USA the Institute of Medicine has published 'The Computer-Based Patient Record'[72], which proposes answers relevant to the present and important future guidelines for the American scene. In Europe, EC research programmes [ESPRIT, AIM, RACE, DELTA] have been investigating the different issues raised by the Health Record and the relationship with several areas of science, in particular telecommunications.

I Standards

Although various bodies and projects have adopted different methodologies, the objective is the same, namely, the creation of standards[73]. This objectives has been addressed in Europe within the AIM programme by projects like SESAME (Standardization in Europe of Semantical Aspects in Medicine), EUCLIDES (European Standard for Clinical Laboratory data exchange), MASQUES (Medical Applications Quality Enhancement by Standards), QAMS (Quality assurance of Medical software) and SCP-ECG (Standard communication Protocol for Computerized Electrocardiography).

Others have reviewed the work done in these different areas: in our project we have sought to incorporate the ideas suggested. Our approach has always been to avoid re-inventing the wheel. We are paying particular attention to the work of CEN (Comité European de Normalisation)/CENELEC (Comité European de Normalisation Electrotechnique/ETSI (European Telecommunication Standards Institute), which has been examining and summarising procedures in order that, with other international organisations, it will be possible to implement the OSI (Open System Interconnection) reference model in Europe. This would be a major step in bridging asymmetrical and heterogenous architectures from different implementations.[74] . Maybe the ISO will eventually be able to sponsor a common denominator for the health record from this common framework.

The programme of the present AIM phase, continues work in this direction and it seems that a realistic view might be that while we may not need a standard in terms of data structure we will need to develop new models in interconnecting completely different data realities[75] [76]

The HL7 group in the USA has already collected ideas and made proposals for models of common definitions. There are already practical examples of their approach reported in the literature. [77]

Standards imply semantic models with common denominators, among the publications in this field we have been interested in the report by Knut Skifjeld et al whose work has been to abridge the semantic relationships of data in a concept they call 'data carrier', in which they try to encapsulate the holistic nature of health data.[78]

We could argue that the attempt to create semantic standards is a daydream bearing in mind the cultural differences throughout Europe and indeed the rest of the world. While we cannot deny these differences, there are documented common denominators in health care despite the differences. In a study conducted between the Dalby Health Centre in Sweden and the Spili Health Centre in Greece which compared diagnoses and the contents of the medical records, great similarities in the distribution of the most frequent health problems were reported. The study showed that despite the significant difference in the physical climate and the social and ethnic characteristics of the communities, surprising similarities existed.[79] It would seem therefore that standards in the semantic format are possible. The potential and the difficulty of connecting the loose ends resides within our common understanding of the interaction of social context with the individual health needs and problems of a human being. In a sense medicine deals with this duality.

Another important area within the work on standards is the medical/legal one. We do not intend to give, at this point, a comprehensive view of the problem. We must point out that a lot of work has already been produced, with the participation of many groups

and interested parties worldwide. In particular, we are aware of the work of the Council of Europe, which has established a working party (CJ-PD-GT 12 on medical data) with the intention of subjecting the area to intense scrutiny. This organisation concentrates on human rights and does not address technical or managerial issues. The enforcement of common European procedures can only be achieved by proposals from the Commission of the European Communities to the national governments in relation to the implementation of standards. [80] In fact many EC countries have not yet implemented regulations in relation to this matter, although it is essential to have this issue addressed in order that there will be a future common European pathway in health informatics.[81]

In the USA the Institute of Medicine also addressed the matter declaring that "...there should be a review of federal and state laws and regulations for the purpose of proposing and promulgating a model legislation and regulations to facilitate implementation and dissemination of the Computerised Health Record ..."[82] At present individual states have different ways of dealing with these issues and there are no uniform state laws which govern the computerised patient record. [83]

Finally, the third area of standards that we wish to highlight is in relation to language definition. Some AIM projects have addressed the question and have been working hard to define a common vocabulary of medical usage (the Project SESAME produced recommendations for the framework and procedures for the standardisation of medical terminology in Europe). In the American literature the Unified Medical Language System (UMLS), of the National Library of Medicine has been mentioned as a good example within the computer-based medical record - Institute of Medicine Report. In Europe we must go much deeper into the understanding of vocabulary, because we are dealing with a multi-lingual context which must confront not only the difficulty of translation, but also the cultural and societal differences which determine the way in which language is used. Nevertheless good progress has been achieved within this area and there are now proposals to create 'a core formalism' which will enable the production of standard representation semantics of medical expression for computer use.[84]

II The Assessment of Worldwide Implementation

A. Architectural Debate

From a managerial perspective the successful use of computers in health can be considered in three stages:

1. Identify customers
2. Understand their requirements
3. Translate these requirements into functional characteristics of the system

It seems that the real issues vis-à-vis the above are:
1. Speed, availability, convenience of record access
2. Quality
3. Security
4. Flexibility
5. Connectivity
6. Efficiency

These are the requirements proposed by the USA Institute of Medicine as essential components of the process of health informatisation. The fundamental requirements for Europe are the same but at this stage we are confronted with the distinction between the logical entities which embody the clinical health record, comprising such things as clinical observations and diagnoses, and the structure which supports information, dealing with speed, security, flexibility etc. In other words, the tension between the logical inner structure of the model and its implementation in real terms.[85]

Taking into account the proposed requirements the present day responses seem to be within three areas:
1. Distributed processing
2. Object orientation
3. Telematics

At the enterprise level the mainframe computer has been relegated by the network multiserver paradigm in a process called downsizing, or rightsizing. Information systems in the health environment have previously been dominated by central processing which results from the use of large hospital systems with a bias towards large computers containing all of the data flow and storage. Consideration of centralised processing versus distributed processing reveals benefits and disadvantages for both approaches. The user must have the means and the courage to make the right decision. It has already been recognised that no current database management system is capable of optimal storage and retrieval of the full range of patient data[86] It follows therefore that by the use of different specification systems, but with a common channel of communication, we have the capability to process in rather different ways and with existing software, data in completely different logical arrangements. In a manner of speaking we are integrating the object orientation of software development at the user level. The type of architecture chosen as DBMS in a distributed processing environment has mainly been the relational one, with good results. The SQL model (Structured Query Language) in its different incarnations, through the 4GL ORACLE, has been tried and tested in a lot of different situations and against various targets with good results. [87] [88] [89] [90]

Recently object oriented database management systems have emerged, but as a

relatively new technology their use in computerised health records has not been extensive. However the development of accepted Heuristic Rules and new KBS systems will accelerate the advance of these systems. Indeed, within this methodology it is now possible to store data and, most importantly, also store the ontology which surrounds the computerised health record. K. Skifjeld et al have used an object-oriented document architecture by the means of the data carrier concept, in order to reconstruct the multiple relationships which are buried within the raw data file. Within the AIM initiative the HELIOS project has demonstrated that is possible to use a distributed (client-server) architecture with a dynamic implementation where, depending on the context, one of the components can be either a server or a client conditioned by the requested resources queued by messages.[91] A software bus connects intelligently the asymmetry of the client stations and a kernel through which service processes guarantee the information systems, the documentation facilities and the interface manager. The information system includes an object oriented database management system. The Helios structure distinguishes two kinds of structures, the software objects and the medical objects. This project has shown that the object oriented paradigm can be put into action in the practical setting. Although it is still a prototype environment it has demonstrated that with appropriate manpower and expertise this area has a lot of potential.

The AIM project and other programmes within the research conducted within the EEC (ie DELTA, RACE) has focused on the field of telematics. A lot of work has been completed on the definition of communication standards EUCLIDES (European Clinical Laboratory Data Exchange standard), HIPACS (Hospital Integrated Picture Archiving and Communication Systems), SPC-ECG (A standard Communication Protocol for Computerized Electrocardiography), TELEMEDICINE (Requirements, Standards and Applicability to Remote Care Scenarios in Europe). In addition the CEN groups and the SIG (Special Interest Group) in the USA have also produced consistent and important work.

All data communication products must answer to very strict rules on security and confidentiality. In the AIM programme, in the US and at the CEN level, a great deal of work has been done to assure that in future all implementations will enable the safety of medical data to be at least as high as that of financial data. It is no longer acceptable in the ATM's or money wire transfers to assume data is only reasonably secure; the level of protection must be at the highest level. We can only trust our system if data can be transmitted with quality which includes:-[92]

Integrating levels of confidence
Context degradation
Code list granularity
Time zones
Compaction/conversion

Attribution
Defining the level of attribution
Elements of the message
Ownership/copyright
Communications integrity
Assuring data integrity
Non-repudiation of despatch
Non-repudiation of delivery
Responsibility for delivery
Application acknowledgement of receipt
Confidentiality
Access rights
Disclosure
Priority/importance
To guarantee the possibility of prioritisation of data

The use of modern technology in telecommunications has allowed new experiments in transferring images and biosignals as well as text. The use of digital communication networks (ISDN), and in a near future BISND (Broadband ISDN) will broaden the scope further. The CE programs of RACE including TELEMED and MULTIMED have focused principally in wide-band networks in health care and demonstrated their benefits.

In order to develop the distributed architecture it will be essential to be able to process all data in real time. The AIM project, TELEMEDICINE, has emphasised that the impact of telemedicine will have a revolutionary effect in the perceptions of 'the needs and wants of health care users; - the timeliness, accuracy and sufficiency of medical information; - the clinical patient-provider relationships'. However inappropriate use of telemedicine will aggravate many of the problems that clinicians are confronted with, for example, the issue of ownership, confidentiality control and direct implementation costs. These issues may eventually overtake any gain in efficiency.[93] But in any case the potential does exists and the eventual cost is something that must be supported given the advantages of being pioneers in new domains.

B. The Human-Machine Relationship

The emergence and maturing of new technologies within computer science has contributed to a better man-machine interface. The availability of the mouse, pen computing, palm top computers, voice recognition; new techniques such as better retrieval tools, hypermedia links, GUIs Graphical User Interfaces), 4GLs (4th. Generation Languages) and new ways of correlating information like pattern-matching,

hypermedia links or fuzzy logic devices, all help to compensate for the burden of information overdose[94]

Graphical user interfaces are becoming widely available throughout personal computing, but in the health record they offer an unparalleled friendliness for the user, making it a lot easier to communicate with the system. With the emergence of software like Windows 3.x for the MS-DOS environment, it has become possible to utilise solutions which were rather expensive until recently using relatively cheap hardware.[95]. In the intensive processing environment which characterises hospital practice, the X-WINDOWS UNIX base solution has been deployed with success creating the concept of clinical work stations[96]

In the AIM project ADAM (Advanced Architecture in Medicine), the idea of a GP Work station (GP-WS) is presented, and while we cannot currently link X-Terminals with General Practice because of costs, the solutions are not far away, with a principal question being the singularity of medical practice and the need for proper tools to deal with clinical challenges.

X-WINDOWS has been closely connected with the client-server distribution architecture presented[97] and even with object oriented implementations (HELIOS), but its benefits as with any other GUI, derive from the possibility of presenting multiple instances of the data in the same physical dimension. In other words it is possible to look at a medical chart in a window, and at the same time, work on a medical discharge summary in another and conduct a research query in a connected database server in a third. This opens up the possibility of working through event driven actions and multi-tasking procedures[98]

Through the decoupling of physical space from time, the computer based health record has opened up new expectations concerning the quality and assurance of certainty of clinical judgement. This momentum has created a synergy between the study of medical decision making and medical informatics itself. Moreover, 'medicine forced the classical schools of artificial Intelligence to challenge new unconquered worlds where chaos is the common denominator of knowledge and where rule based systems can only be seen as unpolished and crude methods of describing reality'. In medical artificial intelligence systems (AI), uncertainty has been handled by a variety of ad hoc models which simulated probabilistic considerations in a quasi Bayesian approach. These approaches have proved less than satisfactory in reality[99] Of the work completed and in progress in this area we have been interested in the AIM GAMES project (General Architecture for Medical expert Systems) which is developing an understanding of the clinical task as an iterative approximation with reality through an abstraction-abduction-deduction-induction mechanism. This can best be summarised as a fractalisation of knowledge or the discovery of a state through which a generate-test cycle leads to a logical encapsulation of both the epistemological and the

computational levels.[100]

With the advent of such systems, and in conjunction with multimedia and interactive video, we will be confronted more and more with the issue of reliability within artificial intelligence. It is commonly believed that expert systems are reliable in the sense that they are able to reason without being disturbed by the external distractions which affect humans. This leads us to conclude that there is a residual type of intelligence intrinsically incompatible with the machine. It seems to be a better approach to try to integrate the nature of the artificial with the power of ontologic knowledge of the human being, taking the best of both[101]

Conclusions

This review has described a journey and has given some pointers to future directions. The role of medical informatics seems to be as a tool for developments in medical science, where it will be an integrating force, but confronter of misconceptions. Certainly the developments will have many educational and continuing medical educational implications. Work at the University of Groningen and Nijmegen in the Netherlands by W.Beckers, R.Grol et al, uses functional working protocols in general practice with integrated computerised medical audit. Their work is a challenge for the implementation and assessment of the impact of the use of computers in daily clinical practice. It will also examine the usefulness of computerisation as a guarantee of quality of care. Indeed quality must always challenge the exponential growth of the medical sciences. What therefore are the vectors that equate the cyberspace of medical knowledge ?

1. Relational Database Systems with gradual implementation of Object Oriented methodologies
2. Clinical work stations
3. New technologies in data acquisition and retrieval (GUI, pen computers etc.)
4. Image processing and storing
5. Data-exchange, vocabulary and semantic standards
6. System communications (OSI model implementation)
7. Network model
8. Reliability
9. Linkages with secondary databases
10. Multimedia implementation
11. AI support with new frameworks of Structuring medical reasoning
12. Security and compliance with medical ethics
13. Always have the end users as main participants in the active process

This review, though not comprehensive, attempts to be faithful and complete. We end with a quote from Massimo Negrotti from the University of Urbino in Italy who defines

Artificial Intelligence and Informatization as " Learn how people think and how to do it better using computers as tools". We think that we are walking in the right direction.

9 A Study of Paper Records Paper Records in use at St Bartholomew's Hospital

INTRODUCTION

The St Bartholomew's group undertook two reviews of current paper hospital medical records. The first survey was to look at the structure of medical and nursing notes and at the types of headings and subheadings used (Appendix 2). The second survey was carried out in association with the hospital's department of medical audit and compared the notes made by different health professionals to look for common content and common processes (Appendix 3).

9.1 The structure of written medical and nursing notes

METHODS

Eight large volumes of medical notes were randomly selected from the shelves of the medical records department. They were read by a nurse and a doctor together (one nurse and two doctors took part) and all headings and subheadings were extracted. It was easy to extract headings and subheadings from preprinted sheets as their status was clearly defined either by underlining or the presence of a subsequent space to fill in information. In our survey of purely written notes we picked out as "headings" words or phrases that were underlined or which made no statement on their own unless seen as an introduction to subsequent information.

RESULTS

Nursing notes

The nurses in St Bartholomew's hospital used a series of preprinted sheets to enter their information. This meant that there was a very clearly defined process documented which consisted of patient identification, assessment, problem identification, goal setting and regular review of goals. (This process was contained on a series of sheets labelled information about patient, assessment, subsequent assessment, patient problem/ need index, nursing care plan, communication sheet and observation charts). The headings on these sheets were all preprinted and therefore

uniform although the hand written information under these was in free format. A list of these "fields" is contained in appendix 2.

Doctors notes

The administrative section at the beginning of the notes was structured, this was filled in by administrative staff not doctors. Some of the clinical information was contained in a structured format with agreed headings, examples of this found in this survey were a diabetic clinic summary and operation notes.
However the majority of medical notes were made on blank paper in what ever format suited the doctor or the medical problem.
Most entries contained an opening statement which had a variety of names ("presenting complaint", "problems", "complains of", "now..") which was followed by a description of the opening statement which was variously named as "history of the presenting complaint", "HPC", "HOPC", "history" or "progress". This description was subdivided in a number of ways as appropriate to the problem. These subheadings could be different problems, different symptoms, anatomical regions, systems or different temporal points eg. "today", "yesterday", "one week ago", "last year". The important point about this section was the variety of structures used for different problems; for example, a problem such as "chest pain" was subdivided according to its evolution over time. A case of multiple trauma was assessed according to symptoms in different anatomical areas. However the relationship between subheadings was not fixed eg. "chest pain" could be a subheading with further subheadings "last week", "yesterday" , "today" or "chest pain" could be a content of temporal subheadings eg. "18 months ago - MI, 12 months ago - CABG, today - chest pain".

Most notes contained a past history which was referred to in a number of ways ("past medical history", "past surgical history", "PH", "PMH"). They also contained a drug history which was also headed in a variety of ways ("Rx", "medication", "drugs", "present Rx", "on", "current Rx", "current therapy", "pills", "DH"). This was followed by a record of allergies ("drug allergies", "adverse reactions to medication"). There was a section recording family and social history ("personal", "SH", "FH", "FMH"). The section systemic enquiry ("S/E", "enquiry", "ROS") resembled the history of the presenting complaint in that it contained subheadings which were often a mixture of anatomical and systems descriptors (eg. "gastrointestinal", "abdominal", "GIT"). The findings on general examination had similar headings to those found in the systemic enquiry (eg. "CNS", "NS", "peripheral nervous system", "fundi").

At the end of the history and examination the synthesis of this information took a multiple of forms this was called an "impression", a "conclusion", a "list of differential diagnoses" or a "list of problems". The degree of certainty attached to diagnoses was indicated by their ordering in the case of differential diagnoses or the use of symbols

such as "?" or "??".

This formulation resulted in plans which had a huge variety of headings ("watch for", "things outstanding", "remember", "do now", "for", "investigations", "NB", "refer", "start", "Rx", "continue", "admit", "discharge" etc)

The follow up notes also contained headings to do with information given to the patient and his/her relatives and discussions had with other members of staff.

CONCLUSIONS

1. Nursing notes were more structured than doctors notes with common headings and a common process in all of them (this probably reflects the fact they were made on preprinted forms).

2. There was duplication of information between the nursing notes and the doctors notes.

3. The doctors notes adhered to a basic structure and process though this was less obvious than in the nursing notes. This structure was along the lines of
   - Presenting complaint
   - History of presenting complaint
   - Past history
   - Drug history
   - Allergies
   - Systemic enquiry
   - Family. social and personal history
   - Examination
   - Formulation
   - Plan
   - Information given to patient and relatives
   - Follow up notes

4. Many of the headings and subheadings were synonyms but were probably the preferred terms of individual users which would make it difficult for them to use a system which imposed different synonyms.

5. Headings, subheadings and contents were often interchangeable eg;
   - Past medical history (heading)
   - Past surgical history (subheading)
   - Appendicectomy (content)

but appendicectomy might include more contents such as:
date/ surgeon/ place/ complication

6. There were conventions in use for indicating certainty, eg. the ordering of a differential diagnosis with the most likely diagnosis coming first or the use of ? or ??.

9.2 Comparison of hospital notes made by different health professionals

METHODS

The initial comparison was done by a doctor, a nurse, an occupational therapist and a member of the medical audit department. Work is in progress to extend this method to look at notes created by physiotherapists, speech therapists, social workers, dieticians and chiropodists. The aim of the exercise was to see if there were similarities in process between the professions, what parts of the recording were unique to each profession and what parts were duplicated.

RESULTS

There was a core set of administrative information that was duplicated in all notes ("first name", "surname", "address", "age", "date of admission" etc). The doctors and nurses both independently recorded past medical history, drug history and allergies. All three professional groups recorded information about social circumstances but it was appreciated the different groups had different approaches to this and extracted information which was complementary.
The three groups all had a similar process which can be described as collecting basic essential information, an assessment of the patient, a formulation, a plan and an ongoing process of evaluation which entailed further repetitions of the process of assessment, formulation and plan. The nurses and occupational therapists had a more structured approach to the initial assessment which involved filling in preprinted sheets and setting goals. The attainment of these goals or failure to attain these goals was then used to evaluate progress. The setting of goals and reviewing of goals was not part of the doctors process.
There was a lot of duplication in the background information collected about the patient and the process of looking after the patient was also shared. However each profession had a unique content to its assessment, formulation, plan and evaluation.

CONCLUSIONS

1. There was unnecessary duplication of information collected by all three professions. This could be studied further and the most appropriate agency given responsibility for certain types of information.

2. All three professions shared a basic approach which can be summarised as collecting information, assessment, formulation, plan and evaluation of progress.

3. The content of the assessment, formulation, plan and follow up was substantially different for each profession.

9.3 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

A Study of Paper Records in use at St Bartholomew's Hospital

1. Reduction in the current duplication of information which occurs because the different professions keep separate notes.

2. Support of the shared process which already occurs in the way different professionals perform their professional role.

3. Recognition that each profession does within a certain shared process have a unique approach and different needs.

4. Recognition that there are a lot of synonyms in use in doctors notes and the availability of these is necessary to make any system acceptable to individual users.

5. Headings, subheadings and contents need to be interchangeable.

6. Clinical notes need to be able to express uncertainty.

10 A Study of the Use of Computerised Health Records

INTRODUCTION

This section includes a survey of current suppliers of computer software offering a medical record system and a brief comment on the limitations observed in the use of current medical record architectures. This is followed by a review of fields offered by different medical record softwares and a brief comment on how and why these differ. The final part of this section consists of a survey of users of computerised medical records in Luxembourg to establish their views on the requirements for a successful computerised medical record system.

Survey of Computer Softwares in use within Europe

METHODS

A participant from each country represented within the project has assembled a national list of the major computer software suppliers offering a medical record system for clinical use. For some it has been possible to obtain the approximate number of users.

RESULTS

Appendix 4

CONCLUSIONS

It is clear that in each country a diversity of systems exists, and that it is rare for any one system to radically outstrip any of its local competitors. This situation would suggest that real excellence has not yet been achieved by the computer industry in the field of medical recording. Anecdotal experience confirms that many of these systems are either very comprehensive but clumsy to use, or are user-friendly at the price of comprehensiveness. There is little or no standardisation of the record structure between systems; indeed incompatibility has in some instances been deliberately sought to protect a share of the market. The lists of suppliers will be used as a potential mailing list for future discussion papers produced within the project, for feedback from within the industry.

Review of fields offered in medical record software

Almost all current computerised medical record systems rely on the database model in which information is stored in tables. Vertical columns or "fields" represent the description or category of each piece of information, such as Surname, Date of Birth, Weight, Height or Blood Pressure.

METHODS

In the case of five current medical recording systems, it was possible to obtain the list of fields offered to the user for data input. Some of these were headings for free text, others for a specific range of responses. In view of the commercial sensitivity attached to this information, only a simple qualitative comparison has been possible. The aim has not been to attempt to generate a fully comprehensive list of medical record fields, but to demonstrate the kinds of fields available to the users, and the diversity of approaches.

RESULTS

Appendices 5-9

CONCLUSIONS

Three primary care computer software systems were examined, one in Luxembourg and the others in the UK. Two of these are included in the appendices. It is interesting to note that one system offers a large number of free text fields in addition to a modest set of clinical standard data sets, and another has almost no free text but a wide variety of fields many of which are administrative.
The hospital field lists are, perhaps not surprisingly, very exhaustive, but the use of different hierarchies and field names make it very difficult to directly compare them. It would similarly be difficult to envisage the transfer of medical information between these systems without a very complex mapping process which would be vulnerable to any future changes in the systems.

Review of Requirements of Current Medical Computer Users in Luxembourg

INTRODUCTION

In general, both specialists and general practitioners in Luxembourg have a working day which averages 10 hours/day, 5 days/week. This does not include any emergency service duty or being on call. The majority of the work is carried out in

small "practices". Most specialists work on the "Belegarzt"-principle, which means they spend about 50% of their time in the hospital and the rest in their private practice. Lately there has been a shift towards transferring all of their activities to the hospital. General Practitioners work in practices and about 10% of their activity consists of making house-calls. On average 25-30 patients are seen per day by each GP. In general most of them work without a secretary or any other administrative staff. In a lot of cases partners are what we call "helping-spouses" and help with administrative tasks. An average of 15-20 minutes is spent with each patient. Consultation rate per patient and per year is low (less than 1x/year/patient). The average number of patients on file per doctor is about 3500. As patients don't have to register and have free access to all levels of care there is a lot of duplication of care. Specialists spend less time with their patients (5-10 minutes, depending on the specialty), see more patients/day and are assisted by administrative staff. In a survey conducted among a representative sample of doctors including GPs and specialists in both rural and city areas in Luxembourg several points of interest to this project have emerged.

RESULTS

- administrative work is perceived as taking up too much time, especially in general practice, and is the incentive for most doctors to start computerisation of their practice. In some cases computers are only used for administrative functions and are not used at all for clinical care. (1992 figures show 35% of practices have computers but only 25% of these are used for clinical work).

- Doctors were concerned that computers would interfere with the doctor patient relationship and a maximum of 2-3 minutes spent on data input in the presence of the patient was perceived as the limit for acceptability of a computer system.

- if asked what features seemed most important for them to justify computerisation of their clinical records, doctors most often asked for automated integration of laboratory results and reports. Integration of images and voice-controlled data input came second. Coding issues and exportability of data were seldom cited as being important features. There was no spontaneous mention of epidemiological and statistical issues, although when asked specifically about these issues doctors responded favourably to the idea of collecting data for these purposes. The fact that a computerised record may be more structured and better organized than a paper record had to be suggested to be cited.

CONCLUSIONS

If we want to engage in the demanding task of computerising medical records, we have to reconsider the essence of the record itself. We have to keep the possibilities of the electronic medium in mind when we try to transpose paper records onto a

computer screen. This implies a total rethinking of the record itself and imposing a minimum degree of common structure to guarantee exportability and transportability. This integration process can only be carried out by doctors themselves in close cooperation with computer and software technicians. We have to specify what doctors need and not limit ourselves to those features technicians are ready to offer.

10.1 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

A study of the Use of Computerised Health Records

1. Computerised clinical records should be both comprehensive and user friendly

2. Medical data should be structured in such a way that it is transferable between different systems.

3. Computerised medical records should facilitate the performance of routine administrative tasks

4. A computerised medical record will not become widely used unless the time for data input is acceptable for general practice consultations.

5. A computerised medical record should be able to automatically integrate test results.

11 A Study of the Initial Prototype Record Architecture (CHRA)

INTRODUCTION

In order to ensure a scientific and practical approach to the development of computerised records it is one of the objectives of the project to continually test and develop the ideas for a common health record architecture using a succession of prototypes. The prototype currently being tested will be referred to as the Current Health Record Architecture. In order to understand the following work it is necessary to have an understanding of the structure of the current prototype.
All the information relating to one patient is contained within a single file. This file is split up into an administrative section and a medical section. Each documented interaction with a patient is called a "contact". A contact is made up of a series of "items" which each contain "contents". An item is a word or phrase which requires further words or phrases in order to make sense.

EXAMPLES

Item	Content
Blood Pressure	120/80
Subjective symptoms	Tiredness and lethargy
Abdominal examination	Enlarged liver

Items can be arranged in predetermined sequences to enhance the entering of data eg: Subjective symptoms, Objective findings, Appraisal, Plan or can be used in any order to tailor the consultation to the patient. In order to enable the system to perform a number of analyses the list of items is limited to 2000 and the list of contents to 5000. As there are a large number of synonyms used in medicine it takes a considerable amount of time to become familiar with the vocabulary used by the system eg: there is no item called "drug allergies" but there is an item called "adverse reactions to medication" which expresses this concept.

11.1 Questionnaire on the utilisation of the Current Health Record Architecture in Belgium

METHODS
A questionnaire was devised by the scientific committee of the Etudes et Recherche en Informatique Medicale (see appendix 10). This document also included some questions devised by the French Red Cross team. The questionnaire was then tested on some ten respondents who were not considered a representative sample and were therefore not included in the final analysis.
The questionnaire was sent to 33 French speaking General Practitioners in Belgium and 23 were completed and included in the analysis. One respondent did not answer all the questions so sometimes there are only 22 replies for analysis.

RESULTS
The General Practitioners who responded to the questionnaire showed the following demographic features
18 practised in urban areas
5 practised in rural or semi rural areas
22 male, 1 female
The age range was 30 - 59, with an average age of 49
51% consultations were in the surgery / 49% represented home visits

Usage of different functions of the programme
1 .

File Analysis

	Regularly	Occasionally	Never
Micro-analysis	17	5	1
POMR analysis	3	10	10
SOAPT	2	8	13
Multi-criteria	10	8	5

2. **General Tools**

	Always	Often	Never
Sequences of items	16	6	1

Lists of contents	17	6	0
Fixed lists	13	5	5

3. Document Templates

	Regularly	Occasionally	Never
Prescriptions	14	1	8
Certificates	16	6	1
Investigation requests	17	4	2
Referral letters	16	6	1

4 .

Would the inclusion of drawings and images be useful?

	Yes	Possibly	No
X-rays	7	8	8
ECG	15	5	3
Drawings	5	5	13

5.

Assessment of the Dictionary

	Items	Contents
Complete	70%	70%
Precise	80%	80%
Easy access	80%	80%
Scientifically adequate	80%	80%
Synonyms	70%	70%

6. **Do you find yourself not recording information in the file because the coded term does not exist?**

Regularly	Sometimes	Never
2	***14***	6

7. 21 out of 23 respondents were happy with the present structure

8. 17 out of 23 respondents considered the keyboard was a good method of entering the data, only 5 wanted to use a mouse.

CONCLUSIONS

1. File Analysis

The respondents preferred the microanalysis and the multicriteria analysis to the other options. There was a high uptake of the facility to perform analysis of the data.

2. General Tools

This demonstrated that users were very likely to use the sequences and contents already set up by the manufacturers. This has two implications, one is that more training is required to enable users to adapt the software to their own needs, the second is that the enthusiasm for predefined sequences should enable a system to become a tool used to improve data recording.

3. Document Templates

The templates were the most often used function of the software. It is therefore important that the structure of the recording of the consultation facilitates the extraction of data for the purpose of generating documents.

4. Inclusion of images and drawings

The respondents were most enthusiastic about the possibility of including ECG recordings. There was some interest in the possibility of storing images. Only 25% of this sample thought there was a need to include drawings made by the physician.

5. Assessment of the dictionary

This sample thought that the items and contents contained within the Current Health Record Architecture were 70% complete, 80% precise, 80% accessible, 80% scientifically adequate and 70% of synonyms were present. This however represents a significant (20-30%) gap in the dictionary.

6. Loss of information

This survey showed that 16 out of 22 respondents sometimes did not record information because the coded term did not exist. There are several possible causes

for this loss of information. It could be that the required term did not exist, the required term might not have been easy to access, the number of synonyms may have been insufficient or the information may have been such that it could only realistically be recorded by the use of free text.

7. Satisfaction with present structure

There was a high rate of satisfaction among the users with the system. This fact must be interpreted with caution as the group surveyed represented a group who had chosen to purchase and operate this particular software and therefore cannot be seen to represent practitioners in general.

8. Keyboard versus mouse

The majority of users were happy with the keyboard. This again has to be interpreted with caution as this sample was a group who had chosen a keyboard operated piece of software. Most of this group of practitioners had more than one year of experience of data of data input by this method.

DISCUSSION

The most important result of this study is the problem experienced by the users using a limited number of codes. This seems to lead to a loss of quantity of data and quality of data recorded in the file. The causes for this are probably the insufficiency of synonyms in the dictionary of contents, the absence of a whole range of common terms, the absence of linking words and qualifying terms that can be accessed easily and the impossibility of mixing codes and free text.

Future studies should compare recordings made with the CHRA and those made on paper to compare the information content of the two methods. The problem should also be studied by more detailed questioning of the respondents to find out exactly why they had difficulties recording information.

11.2 Results of a questionnaire on the use of the Current Health Record Architecture in French General Practices and French Hospitals

INTRODUCTION

Informatics has now been applied to the management of hospital patient records for about 40 years.[102] The sophistication of data management has improved over this time.[103] During the past twenty years most hospital care management systems have concentrated on administrative applications especially the management of admissions and billing. Attempts to extend these systems to include clinical information have been disappointing on two counts; the quality of the data collected has been poor and the cost of the systems has been high.[104]

Over the last five to six years a two pronged approach is emerging. The first is to develop sophisticated administrative systems in charge of hospital stays and billings, the second is to develop clinical systems designed to contain clinical data. It is very important to establish close links and communications between these two systems as this will be the only way to achieve a cost evaluation for patients and for groups of diseases.[105]

There have been very few ventures into computerised medical record systems for hospital care. Where change has been attempted it has been achieved by adopting a common minimum medical file. This has been seen as restrictive on practice and frustrating to practitioners participating in test sites.

To conclude, even though hospital practitioners are convinced of the obsolescence of paper recording, they are not willing to use a computerised solution which would hinder their freedom of expression and performance. The challenge to medical informatics and future architectures is to protect this freedom by providing links between a diversity of software to encompass the different practices in hospital care.

METHODS

This questionnaire was completed by 38 hospital practitioners from 9 French Red Cross hospitals which used computerised medical records based on the CHRA. All respondents had been using the CHRA for at least a year. The questionnaire is included in (Appendix 11).

RESULTS

All respondents used the CHRA for all contacts. All users were content with the division of the file into two sections, Administrative and Medical. All users agreed that there was no need at present to add further sections to embrace nursing care, summaries etc.
The respondents also said they were happy with the current concept of a "contact" and that the contact header contained the necessary information.
Only 50% of this sample were satisfied with keyboard entry. Those who were dissatisfied with keyboard entry were asked to rank alternative methods of data entry. The most popular method of data entry was voice recognition, followed by handwriting recognition followed by use of a mouse, use of a touch screen and then use of pedals.
The next part of the questionnaire dealt with what other information the surveyed doctors would like to include in their medical records. They were asked about laboratory tests, biosignals and X rays. For each of these tests they were asked whether they would like to enter this additional information themselves manually or whether they would prefer the data to be entered automatically into the notes without being first viewed by the physician in charge. The third alternative was that the physician should view the results on a screen and decide whether or not they should be entered into the record.

The respondents were split into two groups over laboratory tests 50%: wanted them to automatically enter the correct notes, the other 50% wanted to view them first before deciding whether to store them in the notes or not. It was not a surprise to find that no one wanted to transcribe laboratory results manually into the notes!
The issue of biosignals (ECG, EMG, Spirometry and Doppler studies) produced different results. 100% of surveyed doctors said they would wish to view these before deciding whether to include the data in the medical notes. 50% said they would only wish to store the report and 50% wished to store the graph and the report. The question of Radiographs yielded the same results with all doctors wishing to view the image before deciding whether to store it or not. 50% wished to store only the report and 50% the image and the report.
This survey then went on to tackle the issue of items. The respondents felt that the current list of administrative items was adequate for French practice. They also felt that the list of medical items was sufficient for everyday requirements in hospital and general practice. However the current list of items was inadequate for specialist practice. The French doctors felt that the terminology of the items was familiar to them.
Finally the participants were asked what were there top 5 requirements for a computerised medical record. These were:

1. Rapidity of access
2. Support of better follow up of the patient
3. Saving time
4. Clearer prescription sheets

5. A safer storage system for data

CONCLUSIONS

All practitioners were convinced of the benefits of computerised data management. Their reasons for this were stated as easier storage, instant sharing of information, easy access to data and easier analysis of data. The following three issues were also considered in this study, the status of the medical file, the structure within a medical file and specific adaptations according to speciality.

a) STATUS OF MEDICAL FILE

The medical file must have adequate links with the hospital administrative system in particular data concerned with the management of available free beds, charging and billing, cost evaluation, study of cost by disease, study of DRG. There must also be good communication with biosignal and laboratory results management software, so that the user of the medical record has access to laboratory results, X-rays, functional tests and ECGs. In considering the medical file itself there is a choice to be made between a single file held by the patient himself (or herself) with a chronological updating made by different practitioners and as often happens in hospital care several different files for the same patient because each department keeps its own records. The option of a single medical file does seem the most logical, least expensive and most comprehensive solution.

b) STRUCTURE WITHIN A FILE

The set up of the screen and input devices must enable the operator to use the system quickly and easily. There must be automatic transfer of a great deal of data but the practitioner must have control over which parts of this data should be included in the medical file.

If the patient is followed up in a chronological way it must also be possible to view events in an alternative way such as by providing the facilities to enable the data from events occurring within one department to be aggregated.This concept of "different views" of the data is very important both in allowing different professional groups to access their own parts of the record and in allowing practitioners to search by problem in order to look for related events. For example a practitioner may want to view all references to cardiovascular disease or only those references to cardiovascular disease made by himself (or herself). At times a health worker may wish to see only laboratory results. What is becoming apparent is the notion of a medical file structured by chapters within which are chronological recordings.

The architecture should have the ability to integrate X-rays with the capacity for the user to call back immediately one or more digital or vectorised images onto the screen. The user must be able to have more than one image on the same screen at the same time in order to compare details. A zoom function and pointers would be useful. As well as radiology images it would be useful to incorporate biosignals, photographs and sounds (heart sounds, doppler).

Predefined drawings and diagrams should be available. The user should be able to add to these in order to show his (her) findings. Many specialities wish to display their data in chart form (ie anaesthetics, intensive care).

It must be possible to extract and import certain predefined datasets. Recording data must include official classifications or allow personal classifications. It should be possible to perform a wide variety of statistical analyses using a simple request language.

Any architecture must preserve the original meaning of a statement.
i.e. recording:

ankylosis: knee, ankle, elbow

does not have the same meaning as:

knee: ankylosed
ankle: ankylosed
elbow: ankylosed

There must be logical links between items asking for action and the results of a request (ie laboratory tests, X-rays, biosignals etc)

The final point is that any system must contain a high level of security in order to protect the data from loss and misuse.

c) SPECIFIC ADAPTATIONS TO SPECIALITIES

The discussion of structure within a file applies to all specialities, however there are issues which are unique to a particular speciality. These are issues of use of terminology, diseases encountered, chosen treatment plans and specialised examinations (Holter recordings and coronary angiography for cardiologists, colposcopy for gynaecologists). It must be possible to expand any system to cater for specialist requirements.

11.3 Analysis of the frequency of use of items included in the Current Health Record Architecture (Belgium)

METHODS

This research was carried out by Etudes et Recherche en Informatique Medicale. 33 French speaking doctors who had been using the Current Health Record Architecture for at least 18 months were sent a disc which contained an extraction programme. The programme was able to extract the frequency of use of the CHRA items and contents. 24 discs were returned for analysis. These contained 30,078 patient files which contained 26,919 contacts which took place during the test period.

RESULTS

These include frequencies of all items, frequencies of coded contents and the volume of free text contents. Appendix 12 contains tables of frequency and an accompanying letter.

CONCLUSION

No item was unused which demonstrates the need for a very diverse selection of items. It was not possible to draw conclusions from the analysis of contents without considering how these were used to express concepts (ie as phrases rather than individual words). This work will lead onto further studies to further analyze the coded contents and the free text contents.

11.4 An appraisal of comprehensive use in clinical specialities

INTRODUCTION

The GEHR project aims at developing a widely applicable common data structure for computerised health records in Europe. It is based on the assumption that, in electronic health records, *all clinical information will be held in a structured representation which can be manipulated by the system*.[106] In addition to the classical requirements of data structures used in any medical record system, the GEHR architecture must meet three major new requirements: it must be comprehensive, it must communicate, and it must be portable.

Why should GEHR be comprehensive? As long as medical management systems

were essentially local, the data structure they were based upon could remain limited to a specific application and be tailored to local needs. With more and more complex standard messages being transferred to local data bases; or required from them, the data structures will have to be upgraded to an ever increasing level of comprehensiveness. The same will be true when the need arises to transfer partial or complete computerized patient files between different medical disciplines: unless each local data structure has the potential to incorporate the complexities of data coming from other care areas, losses of machine-readable information will inevitably occur at each of the transfers.

The objective of this contribution is therefore to issue recommendations aimed at ensuring that the Good European Health Record will eventually be capable of incorporating any patient information which may be relevant in hospital practice, as well as in any of the specialized fields of medicine.

It is important to remember here that GEHR is concerned only with the structure of the record, not with the information itself it may contain, or, in other words, with the categories of information, and not the values themselves. Thus, *drug history* or the *list of problems* can be important sections in a medical record; *weight*, *date of onset of symptoms*, *reason for encounter*, or *glycaemia* can be important terms. They must all find specific representations in the GEHR architecture. But the values of these record items and their optimal expression (e.g. ICPC, ICD9 ..) is not the responsibility of GEHR, which must propose ways to integrate present and future coding schemes relevant to medical information. The same is true when the content of these items is more complex: free text reports and comments, images, biosignals, etc.

The specific objective of this contribution will therefore be to identify and list these health record items which can be required in the various disciplines of medicine and in the specific domain of hospital care, and to illustrate the way they are usually integrated into existing health record structures. This should then form a solid basis upon which to design the semantic and syntactic basis of the GEHR architecture, which will be the next step in our project.

METHODS

The structure of the health record is shown, on paper records, by the *headings*, either pre-printed, or added manually. In computer records, this structure is represented by headings or *questions* shown on the screen during data entry, or displayed on the screen or on printouts. In several computerized data models, the meaning of values is related to the position they occupy in tables, hence the terms *fields*, *records*, *tables*. While no standard term exists at this date to express this concept, we will use here the term "health record item", or "item" for this purpose.

The lists of items produced here have been collected from different sources.

The first source is the **CHRA** (Current Health Record Architecture), which is the data structure used in the medical management software adopted by GEHR as a first prototype for testing and discussion. In the CHRA, items have been progressively added during the past 6 years, in order to satisfy a progressively larger number of users and medical specialties.

The second source is the input from the **test sites** of the GEHR project, mainly the Croix-Rouge Française and the Medical College of St Bartholomew's Hospital in London. This includes not only specific requests for additional items, but also several technical discussions on the best ways to represent various specialized categories of information. Also included is the enquiry made by Kalamazoo on items required in hospital management systems.

The third source is a **special enquiry** HDMP made amongst current users of the CHRA as well as medical experts in domains less well covered by the test sites (such as, for instance, gynaecology and obstetrics, dermatology, nursing,..).

The fourth source is a collection of **examples of paper records** in several medical disciplines.

The fifth source is represented by **existing or proposed standards** in Europe (the German BDT)[107] or in the USA (ASTM E 1384 - 91)[108]

RESULTS AND DISCUSSION

Items required for comprehensiveness in hospital care and across specialties

The items collected as part of the present work are listed in (Appendix 15), grouped by domains as follows:

demographic / administrative information
cardiology and vascular diseases
gastroenterology
rheumatology - orthopaedics - rehabilitation
haematology
pneumology
nephrology
hormones - metabolism - nutrition
infections and immune diseases
surgery - anaesthesiology

obstetrics - gynaecology
genitourinary tract
ophthalmology
ears nose and throat
dermatology
radiotherapy - oncology
neurology
psychology
paediatrics
stomatology - dentistry
occupational medicine
nursing
general physical examination
social aspects
health record
clinical pathology

They are presented in French, English and German (when available), and listed in alphabetical order of the French translations. These languages are used here since much of the work was performed in these three languages.

There is of course some overlapping, with for instance items found in pneumology and in cardiology, or in haematology and in clinical pathology. We have therefore created a "neutral" section called "general physical examination", in which these general items have been grouped independently from the specialized domains. Another "neutral" section is the one on the "health record", in which the items are rather general health record structures or parameters, common to most or all specialties (such as: *consultation*, *diagnostic criteria*, *prognosis*...).

They represent a total of about 2600 items. This list is still largely incomplete, but nevertheless represents a significant and representative group, from which we can learn about the diversity and extent of the medical parameters which will need to be somehow represented in the GEHR architecture. At this stage, the following requirement can probably be proposed: it is required that the GEHR architecture can integrate any of these items, and that their number and categories can be expanded in an evolutive and coherent way.

Presentation and use of items in the health records.

The items found in medical records are not only extremely numerous and diverse, but their use and presentation can also vary to a very large extent, as illustrated in the paper record examples displayed in Appendix 16. To be comprehensive, the GEHR architecture therefore will have to offer not only the items themselves, but structures

that allow for the various uses and combinations which reflect the many approaches and specialties in the health care sector. We will thus illustrate here the most common such variations.

a) Level of detail

The same information can be presented in a very structured way in some files, and in a less detailed way in other files. For instance, "History" can be a single heading in which any history information will be entered, or it can be the title of a section in which detailed subheadings will be distinguished:

History:.....

vs

History

family history
medical: .....
surgical: .....
obstetrical: .....

personal history
medical: .....
surgical: .....
obstetrical: .....

b) Narrative versus structured presentation:

The same information will be represented in some health records by a complex sentence, while in others, its constituents will be fragmented into several elements, each requiring a short and specific answer:

History of current illness: this patient presented with severe pain in the right flank,..

vs

History of current illness:
Presenting symptom: .....
date/time of onset: .....
location: .....
duration: .....
intensity: .....
etc.

c) Implicit vs explicit item definitions

A heading can have very different implicit definitions from one file to the other, depending on the context. For instance, the heading "reflexes" will probably refer to different parameters in paediatric medicine, in general medicine, or else in a specialized department of neurology. Thus, the information "reflexes: normal" will have a very different meaning according to the context.

It is likely that users will require that their normal way of representing data will be respected as much as possible in GEHR, while the data structure will have to incorporate the context -dependency of each information.

d) Open questions, vs answers to be confirmed

This represents a small but important difference in the way headings are used in medical records. We can illustrate this in the following example. In most patient files used in the field of gynaecology, "dysmenorrhoea" is presented as a heading, for which answers such as no, yes, +, ++, +++, may be requested. In fact, "dysmenorrhoea" is not a question, but an answer that needs confirmation or denial; the implicit item is, for instance, "gynaecological symptoms", and dysmenorrhoea is one such symptom.

The difficulty is that, while the users will want to keep this pragmatic approach, it does not fit very well with the additional requirement of analyzing the data for analyses or statistics. Indeed, searching the records for the term "dysmenorrhoea" might list not only the patients actually suffering from this condition, but also patient with a positive family history.

e) Questionnaires

The above problem is fully expressed in the "questionnaire" type of record entry. If, for instance, one looks at the "systems review" section of the example files displayed for surgery (Appendix 16, page 90) and internal medicine (Appendix 16, page 85), one sees that the latter lists a series of symptoms to be confirmed or refuted, while the former only presents the general heading:

Etat général:.....

vs

Etat général:
Perte de poids: .....
Gain pondéral: .....
Appétit: .....

Fatigue: .....
Fièvre: .....
Frissons: .....
Transpiration: .....

In fact, in the above example, there is a combination of answers to be confirmed (e.g. "Fatigue", and open questions (e.g. "Appétit"): "fatigue" is a symptom, "appétit" is not.

Again, because of the convenience and frequent use of these questionnaires (see for instance the specialized questionnaires designed for rheumatoid arthritis patients, Appendix 16, page 95 and Appendix 16, page 98), it is to be taken as an important requirement in GEHR that questionnaires can be handled in the file structure, taking into account the data input facility, and the data coherence for further analyses.

We have not added such symptoms to the list of items presented below, as they are not considered here as explicit elements of the health record structures.

f) tables

In many situations, entries in a medical record are not defined by one heading, but by their position in a specific table, which therefore is a combination of the definition of the column with that of the row in which they are located. This can be shown in examples of electromyography reports, as well as in joint or muscle testing reports. Some tables can in fact combine more than one definition. In the joint testing report shown (Appendix 16, page 100) for instance, each entry is defined by 4 combined criteria: the date of examination, the joint (shoulder, elbow..), the movement being tested (flexion, extension..), and the side (right/left).
The table format appears to be widely used for medical data (see Appendix 16, pages 99-102, 109) and should therefore be considered as an important requirement for the GEHR architecture. But, at the same time, any such parameter must be exploitable as a single entry. Indeed, instances will also occur when isolated measurements only will be taken, and then compared with the corresponding parameter extracted from a full table. The identification of these parameters in the data structure will therefore need to be straightforward and unambiguous. It might perhaps necessitate the combination of several terms into single data definitions, but only to the extent that this does not create so much freedom as to make further data transfer, conversion, or translation totally impossible.

It is interesting to note here that the BDT format uses specific single codes to represent each of the combinations that can be relevant in a particular field [2]. The BDT offers this approach in the field of ophthalmology, where, for instance, each of the vision test parameters has a specific code combining the information of the test,

the type of correction, and the side (see Appendix 16, page 112-113).

g) Diagrams and clinical drawings

While images and clinical drawings are not the specific concern of this report, we wish to stress here again how frequently drawings are used in the health records to represent important information (see Appendix 16, pages 87,89,91,94,105,106). The example shown in Appendix 16, page 94 , which describes a gastrectomy specimen, shows that the drawing can illustrate very specific concepts.

It is therefore a requirement for the GEHR architecture, that clinical drawings can be incorporated into its data structure, in a way such that the information they contain can be submitted to analyses comparable to those allowed for numeric or coded values.

Similarly, diagrams displaying groups of numeric values are very useful for exploitation of the data (Appendix 16, page 103); the data structure must therefore allow for this type of representation.

h) Relations between items

As a result of the way entries are organized in a medical record, relations between them can be built, either in an implicit or explicit way.[109]

- proximity: information listed together, at the same place in the file, usually refer to data that were collected during the same interview or examination, or that belong to the same test or object. In structured files, the place of the information also indicates that this information belongs to the file segment in which it is physically written. File segments can be organized in many different ways; ASTM has proposed a standard segmentation [103] which should be represented in the GEHR architecture.

- combinations: as seen above, item definitions can be combined, for instance under the format of tables, to create more precise parameters.

- logical groupings: several parameters always belong to the same logical group: an audiogram always describes several frequencies, "p" and "QRS" waves always belong to the cardiogram, etc.. Others can be linked in single tables to display the time trends in groups of data (Appendix 16, pages 96, 109,110).

- events: items can be grouped by events ("contacts"), organized in a chronological way.

- problem linkage: several items, even from different events or record segment, can

belong to a given clinical problem.[110]

- episodes: the items from several contacts can form, together, a specific episode in the health history of the patient (such as an acute onset of lung infection having required two consultations and one hospital stay).

- institutional status: items can also be grouped according to the situation of the patient in a given health care institution: patients can be ambulatory or staying in health care institutions; each hospital stay can in turn be fragmented in the various departments in which the patient has been admitted or transferred.

It is a requirement that the GEHR architecture represents and exploits all of the above-mentioned relationships which may exist between items, with a potential to add new such relations as required in the future.

i) Relationship between items and the record context.

Items are also dependent on the context in which they are presented to the persons responsible for encoding data. Thus, forms can combine items to be filled in, and comments indicating how to answer the questions (see for example Appendix 16, page 98). As far as possible, this context-dependency will have to be taken into consideration in the GEHR architecture.

11.5 Hackney callaborative guideline project and the development of asthma data sets

INTRODUCTION

Collaboration between pairs of consultants and general practitioners in Hackney has produced guidelines for the management of 11 chronic illnesses. The guidelines, which draw on national standards[111], describe minimum agreed standards of care, and provide guidance on patient management, referral and primary/secondary care communication. Two of these guidelines, asthma and diabetes are being evaluated in detail in a cross section of Hackney general practices in an attempt to define an effective, acceptable and practical model of guideline use. To date the 'North of England' study[112] is the only rigorous evaluation of guideline effectiveness in primary care in the UK, showing that guideline writing improved both medical process and patient outcome. While they showed improvement in practices involved in writing guidelines, they found no change in process or outcome measures in practices which were simply given external guidelines.

METHODS

The Hackney project builds on the North of England conclusions, targeting a wide cross section of practices and developing an educational package for practices to help them to 'internalise' the guidelines. If a positive effect can be demonstrated a more realistic model for the development of primary care management than the *de novo* creation of guidelines. Because of the shortage of studies on guideline effectiveness, this study is still testing the null hypothesis that this type of guideline implementation has no effect on the process or outcome of care.

27 practices have been recruited into the study involving a total of 46 principles. 13 practices are single handed, 11 are two handed and two are group practices of 4 and 6 principles each. Six of the practices are computerised against a national average of 80%

Practices have been stratified according to Jarman deprivation score, list size, employment of a practice nurse, and FHSA approval for asthma/diabetes clinics. Each practice will be provided with one guideline and the accompanying educational package, but will provide data for both conditions. During a two month run in phase study patients will be identified through the development of practice disease registers and from hospital identification of out -patient attenders. Baseline data will be collected and the relevant guideline introduced. Further data will be gathered at six months and one year. At meetings between educators and practice staff 'ownership'

of the guidelines by GPs and practice nurses will be encouraged by adapting them to practice needs.

Planned evaluation consists of:

* Disease register - size and growth
* Data extraction from patient clinical record
* Practice profile
* Doctor/staff attitude interviews
* Asthma patient outcome questionnaires and interviews
* Diabetes patient postal outcome questionnaires
* Prescribing analysis
* Taping and analysis of educational meetings
* Hospital outpatient clinic letter analysis
* Qualitative record of communication with practices and hospital departments

DATA EXTRACTION FROM CLINICAL RECORDS

A framework has been developed for extracting data from clinical records; this is currently being validated. Data will be coded and entered by a research assistant onto a database. Proposed measures are as follows:

Asthma

From medical records:

Peak flow measurement in last year
Smoking habit
Occupation or dust/fume exposure
Review in last year including:
Symptom review - nocturnal/exercise
inhaler technique
Beta agonist/prophylactic use

From North East Thames Regional Health Authority Prescribing Analysis and Cost (PACT) data:

Peak flow meters
Beta agonist/prophylactic ratio

Diabetes

From medical records:

Smoking status
Blood pressure within last two years
Examination of feet, acuity and fundi
Blood glucose/BM stick within last year
HBA1c within last year

From PACT data:

Urine/blood monitoring test strips

As part of the educational package and in order to facilitate organised care, practices are being offered an asthma card or a rubber stamp containing the key items identified from the guidelines as a 'minimum data set'(see Appendices 17 and 18). The card has been piloted by a small group of local doctors and nurses. Computer templates have not been considered as only a small minority of practices are computerised.

In addition to these measures the following information will be obtained:

Practice profiles will be built up comprising:
Practice description including practice structure and function.
Doctor and nurse profiles.
Staff attitude interviews.
Patient questionnaires and, in the case of asthma, interviews. These will assess guideline specific changes such as educational issues and perceptions of delivery of care.

Appendix 19 compares requirements for an asthma clinic consultation with available Items from the CHRA. Work is being done on creating a minimum data set for a respiratory medicine hospital outpatient clinic where a wide variety of respiratory problems are seen. In order to rapidly encompass a wider variety of problems a more general SOAPT approach ie. subjective symptoms, objective findings, assessment, reason for encounter, plan of action and treatment seems to be more appropriate. This has also been found in relation to a rheumatology clinic, Appendix 20 shows requirements for a back pain consultation and compares it to the CHRA vocabulary. Appendix 21 lists information collected during the follow up of patients with rheumatoid arthritis

11.6 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

A Study of the Initial Prototype Record Architecture

1. The ability to analyze data at the time the patient is consulting is a useful and popular function.

2. The ability to automatically generate commonly required documents is a popular function.

3. It should be possible to include ECG recordings, images and drawings in the electronic record.

4. There should be no loss of word accuracy if an electronic record is used instead of pen and paper.

5. All electronic record systems should be rigorously tested to ensure all users are able to record all the information they would want to record.

6. In order to make an electronic record a practical proposition there needs to be alternative methods for data entry to the conventional keyboard.

7. It must be possible to vet all results of investigations before they are entered into the electronic record.

8. Access to the electronic record must be rapid.

9. The electronic record should enhance the follow up of the patient.

10. The electronic record should speed up tasks of administration and data entry.

11. The electronic record should allow users to create clear and comprehensible documents.

12. Patient data must never be lost.

13. There needs to be further expansion of the vocabulary: the current CHRA lists are not sufficient.

14. There must be communications and links with other information systems

15. There must be a single medical file per patient.

16. A medical file should be structured by chapters.

17. There must be sophisticated methods of statistical analyses both within an individual file and within populations.

18. There must be logical links between a medical request (test) and its answer (result).

19. Each professional group looking after a patient will wish to have a "view" of the patient's record which enables them to read subsections of the notes in a meaningful way. However they will at times wish to consult notes made by another professional group.

20. Computerised records must integrate a large number of terms and their number and categories must be expanded in an evolving and coherent way.

21. Computerised records must offer not just terms but structures that allow for the various uses and combinations which reflect the many approaches and specialities in health care.

22. Clinical drawings should be incorporated into the data structure in such a way that the information they contain can be submitted to analyses comparable to those allowed for numeric or coded values.

23. Computerised records should support protocols.

24. Some clinicians will wish to use a structured format for their consultations, others will require a much more open format for their consultations

12 An Investigation of the Range of Medical Vocabulary in Use

12.1 Word content of UK referral letters

INTRODUCTION

This section presents an analysis of the medical words used in referral letters, from within General Practice and from Hospital Departments. The letters were all written by dictation and taken from recent chronological archives. The overall frequency of occurrence of individual words was counted using a computer programme. The frequency tables reflect an interesting perspective on the clinical vocabulary, which is discussed. This section is an interim presentation of work currently in progress, to be formally published later in 1993.

The clinical medical record is an essential tool for the storage and communication of ideas influencing the care of individual patients. Despite the increasing use of images, drawings and graphics, the written text remains the primary vehicle for recording medical data. This has previously been confined to the paper record: either hand-written notes by the clinician or typed letters and summaries. The increasing role of computers in clinical record-keeping has generated a need for a fresh appraisal of the way medical language is used to record information. This study is part of that analysis of the medical vocabulary.

METHOD

The word-counting of referral letters presents two main advantages. Firstly dictated letters reflect a natural use of medical language unconstrained by database entry fields, as explained below. Secondly, as many General Practices and Hospitals now use word-processors, analysis of the letter contents is relatively straightforward.

Four City & Hackney General Practices were selected. All are group practices and reflect a wide age range of doctors of both sexes, and a cosmopolitan mix of patients. None currently offer Consultant Specialist services 'in-house', and all outpatient referrals are normally made by letter. Letters were copied from the archive of word-processed referrals, in reverse chronological order, leaving only a few early letters from each practice. This amounted to 5000 letters from the largest practice and 2500

each from the other three.

St Bartholomews Hospital was selected for the comparison site. Six Departments have been chosen: Gastroenterology, Rheumatology, Chest Medicine, Geriatrics, Obs & Gynae and Paediatrics. 2500 letters have so far been collected from Rheumatology, again starting from the most recent in the archive.

A programming language known as "Awk" was chosen for writing the counting software. Resembling "C", this system is particularly efficient at counting within files. Each letter file was scanned, all control and non-letter characters stripped out. Each string of words was extracted and added to a cumulative frequency table in a Paradox database. Separate frequencies were collected for General Practice and for each Hospital Department.

All words elicited from both sources to date were categorised by the author into Medical, natural English, Abbreviations and Drugs. This division must necessarily be subjective, since the field of medicine is part of the natural language of ordinary people. Words like "pain", "sprain" , "headache" and "rash" are part of normal conversation in use to describe health, and are not exclusively in the domain of clinicians. As a general rule, anatomic descriptions, disease names and uncommon symptoms have been labelled as Medical, whilst common illness descriptions have been labelled as English. The four sample words above are therefore counted as English.

WordPerfect version 5.1 was chosen as the "conventional word-processing dictionary". This product is one of the two most widely used in Europe, and has a wide use within medical institutions. All added or user defined dictionaries were deleted, leaving only the standard dictionary set for comparison purposes.

RESULTS

The raw data from these tables has not been presented in full. These words constitute an important component of this deliverable, since they represent the actual language of doctors in recording their synopsis of the patient consultation. However, the volume of this material has not been felt appropriate to be reproduced fully on paper with this document. They are, however, available from the author on request. Any medical record should be capable at the very least of accommodating this current language of the profession.

ANALYSIS

At this stage only an interim analysis has been prepared. The comparisons made should not be taken to be of statistical significance, but trends and qualitative interpretations have been proposed at this stage, derived through observation of patters during the word-counting process. The questions listed below are to be addressed once data collection is complete. Some interim results have been included below.

What proportion of the words used are from a non-medical vocabulary?
What proportion would be found in a conventional Word-Processing dictionary?

The tables below show the frequencies of word occurrence within the categories described above. The actual number of different words is shown in brackets below each frequency.

Category	WordPerfect	
General Practice (12,000 letters)	Yes	No
English	1,307,507 (12,985)	521 (172)
Medical	77,010 (3,414)	2,608 (757)
Abbreviations	14,571 (135)	66,306 (429)

Category	WordPerfect	
Rheumatology (2,500 letters)	Yes	No
English	251,527 (5,185)	59 (30)
Medical	24,706 (1,603)	1,258 (281)
Abbreviations	1,463 (77)	8,775 (192)

The total number of letters counted is not identical between the two sources. The vast majority of English words (but not all) are present in WordPerfect, but so are over 80% of Medical words. Abbreviations are not usually found in the word-processor dictionary, and although these make up just over 3% of words found, their high relative frequency make these the commonest category of words not found by the word-processor. These proportions are approximately the same for the two sources.

Most frequently used words **not** found in the Word Processor	
English (used > 50 times)	Medical (used > 25 times)
ANYMORE BEDROOMED CHILDMINDER HEALTHCARE KURDISH LONGTERM O'CLOCK	AMENORRHOEA ARTHROSCOPY COLPOSCOPY DYSKARYOSIS FRUCTOSAMINE HAYFEVER INTERMENSTRUAL NOCTE OESOPHAGITIS POLYCYSTIC SPONDYLOSIS

Is there a difference in the range of non-medical vocabulary between Hospital and General Practice?

Category	Words occurred in letters from		
Category	GP only	Rheum. only	both
English	8,294	350	9,725
Medical	2,613	322	3,118
Abbreviations	322	27	484
Abbreviations	601	108	497

These results, whilst reflecting 12,000 GP letters and only 2,500 Rheumatology ones, do tend to suggest that a hospital speciality may generate a limited number of new

medical or English words not often used by a generalist. This analysis will be repeated after further speciality letters have been examined.

Are long words, which we would not normally write longhand, used very often?

A detailed analysis of word length against frequency has yet to be completed. However, a list of the longest words encountered are shown below: word-length >=19

ADENO-TONSILLECTOMY
ANTI-INFLAMMATORIES
COLPOPERINEORRHAPHY
DACRIOCYSTORHINOSTOMY
GASTROENTEROLOGICAL
GASTROENTEROLOGISTS
HYPERCHOLESTEROLAEMIA
HYPERPROLACTINAEMIA
HYPERPROLACTINAEMIC
HYSTEROSALPINGOGRAM
LYMPHOPROLIFERATIVE
METACARPOPHALANGEAL
METATARSOPHALANGEAL
PSYCHOGERIATRICIANS
PSYCHONEUROIMMUNOLOGY
SALPINGO-OOPHORECTOMY
SHARCOT-MARIE-TOOTH
STERNOCLEIDOMASTOID
UVULOPALATOPHARYNGOPLASTY

How often are words misspelt?

The manual correction of spelling errors for this analysis drew attention to the relatively high occurrence of these, despite the availability of a spell-checking device on all of the word-processors in use in the institutions visited. The Hospital departments all use WordPerfect, and the earlier results show that most words could have been identified and corrected.

Category	WP 5.1	Word freq.	Misspelt freq.	Error rate per 1000
English	Y	1,307,507	4,507	3.45
English	N	521	6	11.52
Medical	Y	77,010	2,147	27.88
Medical	N	2,608	171	65.57
Abbrev.	Y	14,571	19	1.30
Abbrev.	N	66,306	172	2.59

The most commonly misspelt words (in proportion to their actual occurrence) is shown below. Each of these words were incorrectly spelt more than 80% of the time they were used.

ACCESSABILITY
ANAESTHETISED
COMMITMENT
COMMITMENTS
CONTRALATERALLY
DISAPPEARANCE
EPIDIDYMAL
EXISTENT
EXTREMITIES
GLICAZIDE
MALLEOLUS
OOPHORECTOMY
PERSPECTIVES
PRECEDING
SELECT
STASIS
WITHDRAWAL

DISCUSSION

The Clinical Case-Notes

Both in Primary and Secondary care, the clinical notes have traditionally been an aide memoire for the patient's doctor and a sequential account for the benefit of subsequent doctors managing that patient. These have generally been handwritten in a free text style. They contain a rich use of idiosyncratic abbreviations and symbols which reflect more the time pressure under which they were written than any attempt to impose structure.

There is a rich and varied vocabulary, constructed into a staccato narrative with a strong bias towards shorter words or those which have an accepted medical shorthand. For example the traditional medical term 'pyrexia' is rarely used in contrast to 'fever' or 'hot' which are quicker to write and easier to spell!

Synonyms are widely used, sometimes to act as an indication of the term a patient has initiated, and sometimes to reflect the expression that has been used in explanation to the patient. These terms are often not placed in quotes since they are rarely an exact verbatim phrase from or to the patient, but rather a shorthand version of it. Other synonyms will reflect the personal vocabulary of the clinician, and of the speciality.

There is an increasing pressure from medical law for the record to accurately reflect the material facts of the medical encounter, including particularly the clinical findings of the doctor. This bias over the last decade has resulted in a greater recording of negative information and normal examination details, with a consequential reduction in the time spent on recording the personal details, impressions and more casual information.

The less personal style of contemporary medicine has increased the likelihood of the notes being used by different clinicians, and has encouraged doctors to write a more full account of the decisive clinical findings for the same of others.

These pressures, together with the limitations of time, on the doctor writing up the notes after a consultation create a considerable constraint on the natural expressivity of the author and have coerced the record into a very telegraphic and legalistic document.

Referral Letters

In contrast, clinicians have for many years been dictating referral letters and case-note summaries for typing by a secretary. Speech is considerably quicker than writing, and medical secretaries generally have a good knowledge of medical terms.

The medical information contained in referral letters is consequently a much richer description of the consultation. They will contain small details and fuller explanations omitted from the case-notes, including personal particulars of the patient. Longer words can be used without constraint and spelling is also not a problem for the dictator. Hunches, summary statements and background information may be included, which would not have been needed to be recorded in the current consultation record.

Typed documents are more commonly seen as shared medical information, and clinicians tend to feel a greater sense of peer appraisal through their letters. The quality of such letters probably represents the author better than their note-keeping.

Referral letters are therefore likely to reflect more accurately a clinical summary and the thought processes of the doctor. They may reflect a more precise use of medical terms and may not always include a complete synopsis of that consultation.

Further areas for consideration in future studies, but which cannot be addressed from within the current methodology include:-

1 Is there a difference in either medical or non-medical use of words between specialities, and are the relative frequencies of word use very different?

2 How are these words grouped together as phrases?

3 Do doctors use a formal set of definitions for terms they use, and is this also communicated with the information?

4 How are the existing or emerging classification systems incorporated into the letters?

5 How often do Doctors use general rather than explicit terms?

6 Is it possible to draw conclusions about "good" practice behaviour from the way medical language is used?

CONCLUSION

It is not possible to draw firm conclusions at this stage, as many more speciality letters from within the Hospital are still to be examined. It is becoming apparent already, though, that the number of new words (both medical and English) encountered through

each successive speciality is likely to be small once an initial General Practice dictionary has been compiled.

The vast majority of words used by doctors in their letters are English rather than medical (although even the latter are usually present in the WordPerfect dictionary). It is not possible to suggest from this work the composition of whole medical **terms**, but it does appear from scanning the word lists that the clinical vocabulary is a rich and expressive form of communication.

12.2 Word content of Luxembourg referral letters

INTRODUCTION

This study aims to realize the scope of currently used medical language and to be able to discuss and compare this with the list of terms available in the CHRA. Frequency range gives an idea about which items are important in GP practice and need specific care for detail.

METHODS

A list of words has been complied from existing files in GP systems. As all files in the Luxembourg systems were in free text form, extraction of words used reflected the actual need and scope of medical language in use by Luxembourg GPs in everyday work. Several sections of the record have been analyzed: medical summary, medical history, clinical observation, comments and prescriptions. By elimination of all non-alphanumeric symbols a list of words was derived which then have been ordered alphabetically. This list contain a large number of words with typing and spelling errors, and an exhaustive list of brand names of medication prescribed. By eliminative extraction all commercial drug names and products were removed, in order to keep only those words felt to be relevant for inclusion in a medical record dictionary. The time period covered by the collection of words spans 8 years. In the first instance evident typing errors were eliminated manually (55600 original words reduced to about 10000 by this process). The resulting list was then fed into a word-processor (Microsoft Word) and checked for spelling mistakes and matched with an existing dictionary. This took the list down to a final number of 6286 words which have been manually checked and compiled on a printed list and downloaded as ASCII file on a data disk.

A similar process was applied to a commonly used French dictionary, and a comparison was with the medical words previously extracted. The dictionary now contains current french words completed by 8 years of medical record words. An additional body of words, not occurring in the records sampled, was therefore available to be used as an additional list. It is possible that a combination of these two word list sources will generate a very comprehensive and valuable potential vocabulary list.

RESULTS

The list of words generated is included in the appendices.

Further analysis of the raw data is still pending, and will be published later.

CONCLUSION

By visually scanning the list it became evident that the medical language used in records is not substantially different from normal language, and mainly differs through the use of a special vocabulary which is different by speciality. Two major problems have attracted our attention: the number of spelling mistakes and the number of abbreviations. Spelling mistakes appear mostly to be not the product of incompetence but the result of typing errors. Another factor is that as doctors are not secretaries, the opposite is just as true; secretaries are not always familiar with complex medical terminology. Some computer software developers solve this problem by suggesting a certain number of predefined "expressions". However the fact that you have to choose from a limited list can be time-consuming and may result in a loss of accuracy if a change of words is the result.

Abbreviations are found in every medical file and are as diverse as the doctors themselves. Many are locally agreed, within the same hospital, university, country or specialty. They may not always be understood outside that arena. Abbreviations are personal and perhaps in a shared record should always refer to an existing agreed set within a medical vocabulary.

Synonyms are another problem. To describe the same fact doctors might use different words to convey the same meaning. Synonyms misunderstanding can arise across specialties and across
different languages and are probably inevitable unless the whole of medical language can be explicitly defined in an agreed way. This is unlikely in the foreseeable future.

12.3 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

An Investigation of the Range of Medical Vocabulary in Use

1 Clinicians must continue to be abe to use a rich and varied vocabulary.

2 Facilities must be provided in a user-friendly manner to minimise the risk of spelling and typing errors.

3 It should be recognised that proper nouns will represent a substantial proportion of the medical text.

13 An Investigation of the Use of Drawings in the Clinical Record

INTRODUCTION

Medical notes often contain sketches and diagrams done by doctors. They are included either because they are a quicker way of recording information or a clearer way of recording information. They are particularly useful when recording the location of something. It is quite hard to accurately describe the location and extent of something like a jagged wound in words and so a sketch is used instead. Language always carries the risk of being misunderstood, two people might mean something slightly different when using the same word. A drawing contains less ambiguity. Sight and visual perception are our best developed senses, we all understand the world through visual images before we learn to speak and some people continue to think in a visual not word orientated way.

Many people in the survey made the point they liked to explain things to patients using sketches, this is useful because it helps to establish a common language (this is the liver, this is the gallbladder....) and helps to convey spatial relationships (the gallbladder rests under the liver on the upper right hand side of the abdomen). They also enable dynamic explanation (if a gallstone obstructs the common bile duct this happens.....). Frequently they are given to the patient to take away so they can remember what was said and use themselves to explain their condition to others.

This survey was set up to find out what drawings were used in practice and to see whether there were any conventions in use as to how to depict particular situations. This information will then be used to provide a facility for making drawings as part of a computerised record that will closely reflect what is already done and not impose new conventions.

METHODS

UK

Questionnaires were given to any doctors this research team came into regular contact with. The rationale was that this would provide a reasonably representative mix and would mean that by targeting the people asked to fill in the questionnaires we would get a high uptake rate. The questionnaire contained 12 questions asking what types of drawings were frequently used and then the participants were asked to draw a series of well defined situations to see if there was any similarity in their approach.

52 questionnaires were analyzed. The sample of doctors was from different age groups 27 -63, 30 were female and 22 were male. 21 were completed by general practitioners and 31 were completed by hospital doctors representing a large number of different specialities. The majority were UK graduates but three had graduated overseas. (questionnaire is contained in appendix 13).

FRANCE

The questionnaire was translated into French and distributed along side the questionnaire on the CHRA. This was completed by 38 practitioners from 9 French Red Cross Hospitals.

RESULTS

25% of the UK doctors and 44% of the French doctors said that their department used stamps or standard printed material to record things in a diagrammatic way. 84% of the UK doctors and 89% of the French doctors said they would use illustrative material to explain things to patients.

The next part of the questionnaire consisted of a list of situations where drawings are sometimes used, the doctors surveyed had to choose from three possible answers for each situation to indicate what best represented their use of drawings.

UK

Area	Nearly always	Sometimes	Never
Do you depict dermatological findings as a drawing/diagram?	13%	64%	23%
Would you record a breast lump as a diagram/drawing?	65%	25%	10%
Do you depict respiratory system findings as a diagram/drawing?	6%	33%	61%
Do you depict abdominal findings as a diagram/drawing?	63%	31%	6%
Would you record the presence or absence of peripheral pulses as a diagram?	27%	31%	42%
Would you record sensory abnormalities as a drawing/diagram?	23%	62%	15%
Would you record findings on fundoscopy as a drawing/diagram?	12%	40%	48%
Do you use drawings/diagrams to record injuries?	46%	50%	4%
Do you use a diagram to record antenatal findings (ie presentation of the foetus)	23%	28%	49%

FRANCE

Area	Nearly always	Sometimes	Never
Do you depict dermatological findings as a drawing/diagram?	0%	44%	56%
Would you record a breast lump as a diagram/drawing?	11%	11%	78%
Do you depict respiratory system findings as a diagram/drawing?	11%	0%	89%
Do you depict abdominal findings as a diagram/drawing?	0%	11%	89%
Would you record the presence or absence of peripheral pulses as a diagram?	33%	22%	45%
Would you record sensory abnormalities as a drawing/diagram?	56%	11%	33%
Would you record findings on fundoscopy as a drawing/diagram?	11%	22%	67%
Do you use drawings/diagrams to record injuries?	0%	44%	56%
Do you use a diagram to record antenatal findings (ie presentation of the foetus)	0%	0%	100%

The results in the tables are from small samples (52 respondents from the UK and 38 from France) and therefore it is not possible to extrapolate to the general population. However a few interesting trends should be noted. In the UK there were particularly high rates of using drawings (nearly always or sometimes) for breast lumps 90%, abdominal findings 94% and recording injuries 96%. In France these rates were breast lump 22%, abdominal findings 11% and injuries 44%. The most frequently used drawings (nearly always or sometimes) in France were sensory abnormalities 67% and presence or absence of peripheral pulses 55%. The overall use of drawings was found to be lower in France than the UK.

The respondents were then asked if there were any drawings or diagrams not mentioned that they used. Drawings of the cervix and vulva were mentioned most frequently. The full list of additional drawings mentioned are:
UK:

Vulva
Cervix
Reflexes
Diagram of an X-ray
Tympanic membrane
Minor operations
Hands
Heart sounds
Throat

Major operations
Endoscopy and colonoscopy
Arthroscopy
Lymphadenopathy
Varicose veins
Family tree
External eye
External ear
Teeth
Menstrual cycle
Site and radiation of back pain
Haemorrhoids
Neck lumps
Larynx
Tests of constructional apraxia
Hirsutism
Joint involvement in arthritis

FRANCE:

Cerebral arteries (Circle of Willis)
Abdominal aorta and its branches
Vascular tree (upper and lower limbs)
Upper and lower limb veins
Foot (top, side and sole)
Vertebral column to show flexibility
Vertebral column to show a scoliosis
Percentage burns
Vertebral column to show degree of pain on flexion
Diagram to show a sitting corset with a tilting angle
Diagrams for reflexes and peripheral pulses
Charts to show heights and weights
Head circumference chart
Verbal capacities chart
Scoliosis follow up
Follow up of neurological parameters

The final part of the work involved looking at how doctors would depict four situations, hepatosplenomegaly and an abdominal scar, tenderness, guarding and rebound in the right iliac fossa, facial injuries and abnormal findings on respiratory system examination. There was a very standard approach to these situations with a consistent way of using symbols and labelling.

CONCLUSIONS

Drawings are widely used in a variety of situations to enhance clinical recording. They are sometimes the only recording made. Two examples were found where people felt limited by using a computer which did not have this facility. One was a colposcopy clinic where doctors annotated the computer print out with drawings of the cervical findings. The second was a computerised general practice which retained paper records for drawings only. Drawings are often seen as the quickest way to record information and therefore any computerised method must be easy and fast to use. Drawings are already fairly standard so it should be possible to provide a library of drawings and tools acceptable to the majority of users.

13.1 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

An Investigation of the Use of Drawings in the Clinical Record

1. Drawings are commonly used to depict clinical information

2. There is a wide variety of drawings in use

3. Drawings are fairly standard in their style and the way information is depicted

4. Drawings are seen as a "quick" way of recording information and any computerised method must be quick and easy to use

5. Drawings are often used in communication between doctors and patients

6. Drawings are sometimes the only record of a transaction between a doctor and a patient and must therefore be stored securely and be transferable

14 An Appraisal of the Incorporation of Images in the Clinical Record

INTRODUCTION AND METHODS

Surveys among French doctors and UK doctors have shown that both groups wish to see X-rays, ECGs and parts of other biological recordings as appropriate. Both the French and UK doctors wished to have the benefit of a specialist's report when viewing images or complex biosignals.
A survey was done of one large UK hospital (St Bartholomew's Hospital, London) to collect a comprehensive list of all images in use in current UK hospital practice, to discover which ones were already available in digital format and to discover how many megabytes they would each take to store electronically. This was achieved by first writing to and then visiting the departments to collect the information required.
Once we had information about the likely size of some of the images we asked a small sample of UK general practitioners what implications this might have for general practice computer systems.

RESULTS (APPENDIX 14)

CONCLUSIONS

There was great interest in viewing as many of the investigations done as possible. Most doctors were most interested in X-rays and ECGs but felt that access to edited parts of more specialised investigations such as EMG and EEG would educate them and increase their job satisfaction. The UK and French doctors expressed reservations about X-rays being widely available without first having been looked at by a Radiologist and would prefer to have the X-rays and report together. The present situation in the UK is that most general practitioners receive the report and no X-ray. It was appreciated that investigations such as X-rays occupied a large amount of disc space and some general practitioners would wish to receive them, view them and then only chose to store a single image or the report. The general practitioners consulted envisaged there might be a central storing system probably at the place the images were generated for retaining a permanent copy of the image.
Both UK hospital doctors and general practitioners agreed that no investigation should ever be entered directly into patients notes. All results of investigations should arrive at some designated point ("Mailbox") and be checked by the responsible clinician before being entered into the patients notes.

14.1 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

An Appraisal of the Incorporation of Images in the Clinical Record

1. General practitioners and hospital doctors wished to view images as often as possible

2. UK general practitioners and hospital doctors would like these to be accompanied by a specialists report as often as possible.

3. General practitioners would not wish to be responsible for the permanent storage of these images.

4. No data should automatically enter clinical notes without being checked by the responsible clinician.

15 The Importance of Data Security

This is the subject of another deliverable to be published later in the year and so will only be touched on briefly in this document. It is important to emphasise that security must be a major requirement and is indeed the foremost concern in most patients minds when the subject of computerised patient records arises. "Computerised patient record systems have two requirements. First patient and provider privacy must be protected. Second, data and software must be safeguarded against tampering and unintentional destruction. These requirements demand both system and data security measures. **System security** refers to the measures taken to keep computer based information systems safe from unauthorised access and other harm. **Data security** involves protection of data from accidental or intentional disclosure to unauthorised persons and from unauthorised alteration."[113] Some of the issues for future consideration include:

1. There must be a watertight method to identify the author of the record (electronic signature)
2. It must be possible to update the record but it must be impossible to alter or erase previous entries completely.
3. If the record is to be used by a large number of professionals for different purposes it must be possible to withhold certain information from general viewing. The patient should be a participant in deciding what information should be withheld from general viewing eg: the patient may not want the fact they were sexually abused in childhood to form part of a hospital medical record but they may wish to discuss this issue with their general practitioner.
4. Electronic health records must be secured against illegitimate use.
5. There should be an internationally agreed set of information recorded every time information enters the electronic record. This might include definition of time and date, definition of time zone, identification of provider (personal ID, name, position, level of competence, physical location, telematic address), identification of coding system used, definition of ownership of the information and who is permitted to view it and determination of the importance of the information.

Another major area of ethical debate is the content of the patient record itself. At present each institution holds only its own data, but with the possibility of amalgamating health information from several sources a vast patient file comprising their whole medical life becomes a reality. Whilst many professionals may see this as an exciting prospect, there are many fears particularly from patients, about such a "Big Brother" approach to their private health information.

16 Drug Prescription and Its Incorporation Within the Clinical Record

INTRODUCTION

In reviewing the topic of computerised prescribing Tallis states that 'writing a prescription must be the most frequently performed medical act'. [114] It has also been suggested that between 55% and 95% of patient visits to a general practitioner's surgery are concluded by the writing of a prescription.[115] The majority of these prescriptions are for therapeutic drugs rather than devices, surgical or nutritional products as it is estimated that a per capita figure of between £20-50 is spent annually on drugs in the UK alone.[116]

With this background, the ability to store drug information in the patient record is a key requirement for the GEHR Project. In addition, the prescription is not an isolated communication of instructions between the doctor and the pharmacist who is expected to dispense the drug, or others directly involved with the core of the patient, it increasingly involves health administrators, epidemiologists and other medical professionals who wish to have access to the anonymised information for their own purpose.

Thus the ability to interchange drug data must also be a feature of the Good European Health Record.

16.1 General issues

There are a number of issues which must be considered when deciding on a standard medication record.

16.1.1 Prescribing Guidelines

Medical practice and tradition varies significantly across Europe. This is exemplified in the area of prescribing guidelines amongst others. Several individual countries have specific guidelines or requirements on the issuing and preparation of prescriptions. In the UK, for example, specific guidelines are published in the British National Formulary with supplementary guidelines for

computer-issued prescriptions. These latter instructions limit the use of computer printer prepared prescriptions to drugs not on the UK controlled list (i.e. not narcotics and related compounds).

In Belgium, following a decree in January 1992, all prescriptions must be handwritten by the physician responsible for the patient.

Other countries such as Italy have no specific guidelines for prescription writing.

Therefore the GEHR architecture has to be sufficiently flexible to cope with these variations and must be able to receive data from a prescription printing program or allow data to be entered manually in appropriate situations.

16.1.2 Automation

Computerisation of the patient record largely post-dates the computerisation of prescribing. This is particularly true in primary care where repeat prescribing occurs frequently on computer (91% of installed systems in the UK) compared with only 26% which keep full medical records.[117]

Computerised prescribing allows the listing of medication for viewing, for automatic notification of prescription orders or printing of prescription forms. Viewing of summaries is useful in many clinical settings, and recording summary information (e.g. discharge summary). Semi-automatic ordering of take home medication at the time of writing the discharge letter and repeat prescribing in primary care.

In addition, the linkage of the automated prescribing systems to other systems can be used to check for potential drug interactions, contra-indications or to assist in general clinical decision making. However, the databases providing this information would reside outside GEHR, although appropriate links would be necessary to record the information sources in GEHR used to support decision making.

16.1.3 Prescribing and Drug administration records.

Prescribing and administration records are closely related, the former includes instructions and total dose, the latter may require a second signature. Only a subset of key information from these records needs to be included in GEHR

but local preferences may dictate precisely the information chosen.

16.1.4 Specific Information

In particular clinical settings specific information will need to be captured by the GEHR architecture in a specialised manner to ensure that vital data is not lost or diluted. For example, maximum lifetime doses for cytotoxics, and such drugs require careful noting in a shared medical record so that the total administered dose must be stored.

16.2 Implementation issues.

16.2.1 Administrative Procedures

Administration protocols for the interaction of the GEHR architecture record with computerised prescribing will need to be developed. Particular areas that need addressing are:

(a) Training in the use of the GEHR architecture within the context of an appropriate software implementation.

(b) Correct safeguards and checks on data input or modification by locums.

(c) Scheduling of back-ups and down time for both the GEHR architecture database and the prescribing database to ensure that optimal access to both datasets is provided to the users. Clearly in a hospital environment, computer systems need to be on-line if possible, throughout every day. However, in a general practice situation much more flexibility in the choice of down time is possible.

(d) Implementation of upgrades to software will need to be standardised, particularly in the hospital environment to ensure that data is being recorded consistently in the GEHR architecture.

16.2.2 System Access

Data entry must be controlled allowing **data concurrency** in a large institution. In primary care the requirements will be of a lower order unless pooling of information is sought.

In a ward situation **mobility of terminals** is a major issue. Bedside terminals is another option. At the Royal Marsden Hospital during a three month trial it was found that:

> terminals in bays were not used but they were used in sister's office where doctors sat or in the room with the drug trolley.[118]

However, the development of more medical applications for 'notebook' and 'palmtop' computers should overcome some of these problems in the foreseeable future.[119]

16.2.3 Interaction with the Pharmacy

Automatic feedback of prescribing information could be formalised for drug data contained in the GEHR architecture, as this would automate the replacement of drugs for an individual ward thus facilitating the drug ordering process within the institution. In addition, such linkage could provide rapid access to drug usage data for auditing and costing purposes, if required. However, appropriate security levels would need to be identified in order to prevent access to a patient's confidential data.

16.2.4 Local Formularies

It is estimated that about 20% of the general practices in the UK have their own formularies, but this number is increasing (Ref.3) as cost pressures mount on GPs.

In hospitals formularies are now an established part of the environment, therefore from both areas it will be essential to reference these formularies and also to provide links to national and international drug coding systems.

The development of disease related treatment protocols is a new and potentially growing area of influence upon drug prescribing in hospitals. These protocols specify the administration of particular subsets of drugs selected from the hospital formulary thus adding another layer of complexity to the linking of

the patient record with the local formulary.

16.2.5 Nursing requirements.

In a hospital situation access to drug data contained in the GEHR architecture must be provided for nursing staff. This must be available to enable them to review the current information on the patient and their medication schedule, to check prescription sheets during drug administration and to add any specific notes or observations on the patient's reaction to the administered drug. Specific instructions on the method of administration of IV drugs and their timings needs to be communicated to nursing staff. The extent of this information that is stored in the GEHR architecture with the primary details of the drug prescription will need exploration as the GEHR architecture develops.

16.3 The Prescription

The prescription is the key document which initiates a chain of events that should culminate in a patient using a particular drug therapy. For the prescription to accomplish its purpose it must possess the attributes summarised below:

16.3.1 Drug description.

(a) Drug Name

This may either be a generic or trade name. The generic name is usually an internationally approved name (INN) whilst the trade name is supplied by the drug manufacturer and may be specific for an individual country.

(b) Form

This may be used synonymously with presentation but describes the physical characteristics of the drug as presented (EG DRY POWDER).

(c) Presentation

Details of the presentation may be required to add further clarity to the description of the drug as presented by the manufacturer (EG DISKHALER)

(d) Strength

The strength of a drug is the amount of the active ingredients in an administered dose.

(e) Pack size

This describes the presentation in further detail if necessary.

16.3.2 Dose

The dose is a concept that may be qualified by descriptors such as maximum, total, total daily, or administered. The default should be administered dose though the other qualifiers may be necessary at times. The important aspect of the dose is that it should contain a number and a unit, whether it is 1 tablet or 250mg. In the case of applications or bandages a dose is not applicable so the dose should not be compulsory.

16.3.3 Instructions.

(a) Frequency (EG 3 HOURLY)

The number of administrations per time unit

Specific times for the administration, continuous or intermittent for infusions may also be required for example 0200, 0500, 0800, etc.

(b) Route

Describes the route of administration (EG INHALED)

(c) Method of administration

This may include information on route though may add more specific information (EG VIA NEBULISER)

(d) Quantity

The total quantity of drug to be administered

(e) Duration

For drugs administered in a hospital situation a dosing duration will be specified. However, in primary care this is dependent on patient compliance.

(f) Date/Time, Name and address of prescriber, other information relevant to prescribing.

- Number of repeats
- Review
- Date/time of review

(g) Signature

This must be of an approved person.

17 The Role of the Clinical Record in Education

(This is based on "Educational Implications of the Development of a Common Health Record Architecture for Europe" written by D. Ingram, J.Murphy, S. Griffith, L. Southgate, presented at a conference, "Medical Education and Training in Europe : the Future", at the Royal College of Physicians of London; October 1 and 2 1992.)

A major requirement for a standard architecture of a health record is that it should support developments in medical education. Rapid increases in the range and amount of knowledge relevant to clinical care have led to changes in medical studies with greater emphasis on self-directed learning and problem-based approaches. The goal of integrating basic medical science with clinical studies presupposes information systems which enable students to move flexibly between the particular and the general, between the problem-at-hand and the knowledge which underpins clinical practice.[120]

The aim of the new curricula in medical schools is to equip doctors so they are capable of continuously updating their knowledge and skills. Rapid and flexible access to information has become an increasing priority. Sophisticated information retrieval skills are essential, both with respect to the literature and also on-going records of clinical care which will provide learning resources in the form of case-studies of special interest.

The adoption of standard approaches to computerised record-keeping creates new opportunities to support medical teaching using real clinical data from collections of patient records, protected to preserve confidentiality. At the same time, economic imperatives make it ever more essential for health professionals to know how to operate clinical information systems and maintain records for themselves. As doctors become more involved in designing and using systems, this should also improve the quality of data. As a general principle, a higher quality of recording is achieved if data is captured by professionals, close to source, with as few intermediaries as possible in the chain.

But of course, for most professionals (and doctors are no exception), the task of recording the vast quantity of information encountered in the course of a working day is regarded as an irksome duty which tends to be given low priority. Those who believe that well structured medical records are an essential element in the practice of high quality medical care need to convince doctors that it is in their interest to improve the quality of medical records.[121]

Our expectation is that in the process of demonstrating the value of recording well

structured patient data to students at an early stage in their studies, we will help to promote attitudes and practices which will carry over into later professional lives.[122] [123]

It is generally agreed that for teaching purposes, traditional medical records are very rich in material, but difficult to access. It has proved hard to exploit this material because much of the practice and knowledge of professionals is recorded haphazardly, if at all. In the absence of documentation, much of professional practice is implicit rather than explicit. A lack of systematic records makes it difficult to distil knowledge from practice for the next generation of clinicians. Poor quality information also has consequences for epidemiological research, for clinical audit, and for shared care/ teamwork.[124]

If the educational requirements outlined above are to be fulfilled, a common architecture for computerised records must be designed so it enables students to exploit the potential of the records. It must be possible for students to organise and structure a simulated practice and to maintain duties of accountability to patient and profession. The system must support routine administrative tasks of summarising and reporting; it must guide clinical decisions through access to relevant literature, graphic, pictorial and film archives, standard data sets and advisory software; it must assist research and critical analysis of care through access to standard protocols and software which supports the methodologies of clinical trials and statistical data analysis.

The common architecture should liberate the full potential of much existing educational software, currently of limited application, by enabling it to be rewritten and represented in a way which builds new links with patient care. It should be possible to access background information and demonstrate particular disease states or functions in an optimal manner and relate these to details of individual patients under consideration. One spin off of the architecture could be that future educational software will be written within the standards set for health care records to display graphic, pictorial and film images which illustrate the structure and function of organs and systems in health and disease. An ability to relate these visual representations to diagrams and images collected for the purpose of clinical care would be another important advance.

17.1 Requirements

IMPLICATIONS FOR THE CLINICAL REQUIREMENTS

The Role of the Clinical Record in Education

1. Computerised records should support developments in medical education, in particular self-directed learning and problem based learning.

2. Computerised medical records should be accessible to students at an early stage in their medical education. The user interface should be designed so as to make it easy for the inexperienced user to find his/her way around the system.

3. Adequate safeguards need to be established to ensure privacy, confidentiality, and data protection. For instance, there may need to be methods of stripping records of personal identifiers.

4. Computerised records should be viewed as a rich resource for analysis and study by students. Clinicians, epidemiologists and medical educators will need to design activities which encourage students to use records as a learning resource. There will need to be easy access to statistical support tools.

5. The relationship between data quality and patient care should be obvious so as to encourage students to take responsibility for patient data.

6. It must be feasible to directly access decision support tools and bibliographic databases.

6. Computerised medical records should interact with educational software so the latter is seen as relevant and supportive of good clinical care.

18 List of Requirements

This list of requirements is a distillation of the requirements which are contained within this large document. This is not a comprehensive list but will indicate in which chapter of this document more detailed information can be found.

* The medical record must be capable of supporting practice in all of the areas defined as components of clinical competence (Chapter 3).

  to deliver curative and rehabilitative care
  to promote health
  to organize preventive activities
  to plan, organize and evaluate health education activities
  to collaborate with other agents of community development
  to participate in research
  to manage his or her services /resources
  to train other members of the health care team
  to participate in and sometimes to lead the health care team
  to engage in self directed learning
  to engage in self evaluation and quality assurance.

INDIVIDUAL CONSULTATION

* Health records must accommodate both highly structured methods of recording information and very informal methods of recording information (Chapters 2, 7, 9, 15).
* Clinicians must continue to be abe to use a rich and varied vocabulary (Chapters 2, 9, 11, 12).
* Clinicians must be able to record information in the form of drawings and diagrams (Chapters 11, 13).

SHARED CARE

* There must be only one health record for each patient (Chapter 11).
* Health records must facilitate communication between agencies (Chapters 2, 9, 15).

ACCOUNTABILITY TO PATIENT AND PROFESSION

* Health records must be comprehensible to the non-medical reader eg: patient,

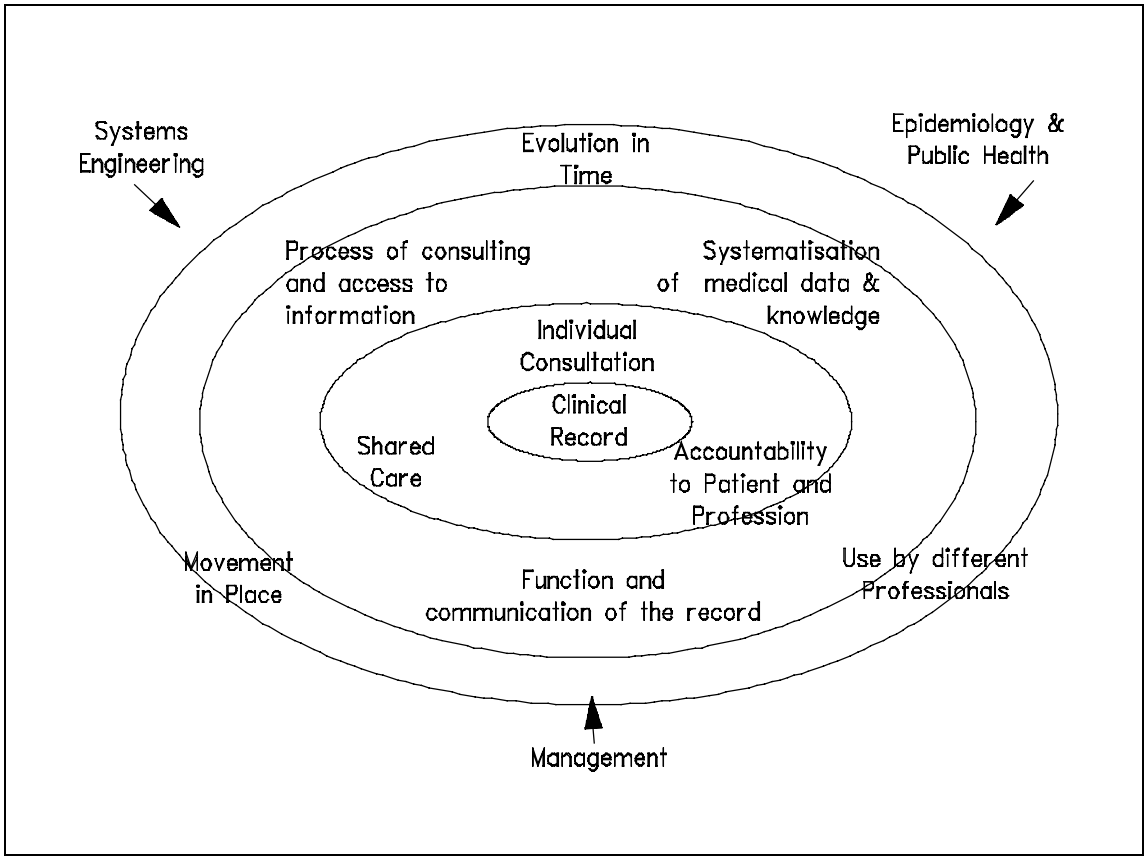


Figure 5 The context of medical record development

lawyer, audit department (Chapter 2).

* The rationale for clinical decisions must be apparent from the health record (what was done and why) (Chapter 2).
* The medical record must enable and reflect clinical competence (Chapter 3).
* Every entry in the record must be attributable to an author (Chapter 7).
* Clinical notes must be able to express uncertainty (Chapter 9).
* The medical record must support moral and ethical behaviour in the clinical setting (Chapter 3).
* Computerised patient records must ensure privacy, confidentiality and data protection (Chapters 16, 18)
* Patient data must never be lost (Chapter 11).

PROCESS OF CONSULTING AND ACCESS TO INFORMATION

A) PROCESS OF CONSULTING

* Computerised clinical records must be both comprehensive and user friendly

(Chapters 7, 10, 11, 12, 18).

* The time for data input into a medical record must be an acceptable proportion of the total consultation time (Chapters 10, 11).
* There must be no loss of information when an electronic record is used (Chapter 11).
* The results of investigations must be checked by the clinician in charge before they are entered into the electronic record (Chapters 10, 11, 14).

ACCESS TO INFORMATION

* Health records must contain psychological, social and family information. (Chapter 2)
* Computerised records must include ECG recordings, images, photographs, sound recordings and drawings (Chapters 11, 13, 14).
* It must be feasible to directly access decision support tools and bibliographic databases from the computerised patient record (Chapter 18).

SYSTEMATISATION OF MEDICAL DATA AND KNOWLEDGE

* Computerised records must integrate a large number of terms and their number and categories must be expanded in an evolving and coherent way (Chapter 15).
* Computerised records must offer not just terms but structures that allow for the various uses and combinations which reflect the many approaches and specialities in health care (Chapter 15).
* The electronic record must recognise that medical data has:

  complexity
  levels of certainty and precision
  severity
  diversity of data types (Chapter 5)

* There are many coding systems used in medicine, and a shared medical record must allow use of any or none of these systems (Chapter 6).
* The medical record should be structured in a way that preserves the original meaning of the information (Chapter 7).
* Clinical drawings should be incorporated into the data structure in such a way that the information they contain can be submitted to analyses comparable to those allowed for numeric or coded values (Chapters 13, 15).

FUNCTION AND COMMUNICATION OF THE RECORD

* Medical data should be structured in such a way that it is transferable between different systems (Chapter 10).
* It must be possible to communicate with other information systems either in administration or ancillary support outside the building in which the computerised medical record is being accessed (Chapter 11).

MOVEMENT IN PLACE

* Some components of clinical competence are closely related to the role of physicians in the societies in which they practice. The medical record must not impose the values of one society on the clinical practice of another, although it should promote ways of learning about different styles of clinical practice (Chapter 3).
* There should be automatic translation facilities to allow the clinical record to be read in different languages (Chapter 7).

EVOLUTION IN TIME

* The record must be capable of evolution as medicine and technology change (Chapter 7).
* The medical record must be capable of evolution as society develops and defines some aspects of the common core of practice. The record must be dynamic,a true contemporary record of each encounter which maps directly onto a different context as changes within society and the profession are translated into legislation (Chapter 3).

MANAGEMENT

* Computerised medical records should facilitate the performance of routine administrative tasks (Chapters 10, 11).
* Computerised records should facilitate management tasks (Chapter 4).

USE BY DIFFERENT PROFESSIONALS

* Each professional group looking after a patient will wish to have a "view" of the patient’s record which enables them to read just their own notes in a meaningful way. However they will at times wish to consult notes made by another professional group (Chapter 11).

EPIDEMIOLOGY AND PUBLIC HEALTH

* Computerised records should be viewed as a rich resource for analysis and

study by students. Clinicians, epidemiologists and medical educators will need to design activities which encourage students to use records as a learning resource. There will need to be easy access to statistical support tools (Chapter 18).

* It must be possible to perform both analyses within an individual patient's file and on a population of patients for epidemiological purposes. The request language for this should be easy to use (Chapter 11).

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