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A FRAMEWORK FOR THE DEVELOPMENT OF A
MINIMUM BASIC DATA SET
FOR AMBULATORY CARE
IN EUROPE

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1. Introduction

Information about the health of communities in member states of the European Community is extraordinarily difficult to collect at any level more sophisticated than mortality rates. Until the rapid growth of information technology over the past decade, the concept that it might be possible to share data within and between health systems remained a far-off ideal. Since that era has arrived the experience of many clinicians and health managers has been to find their hopes of data exchange and evaluating the effect of different health systems tarnished by the inability to obtain comparative data.

The critical problem is that compatibility is lacking in both the clinical and information technology fields. Some attempts have been made to solve the problem of agreement over the classification to disease. In addition to the standard World Health Organization International Classification of Disease (now in its ninth revision) there also exist classifications with a primary care orientation by WONCA¹. Thus the International Classification of Primary Care (Lamberts, 1987) links through the International Classification of Health Problems in Primary Care to ICD-9. A new release of the International Classification (10th revision) is due in 1993. However, different countries use different international classification systems and there is evidence of even greater variation in the use of coding systems for procedures and operations (Rodrigues, 1987). Variability in the basic data set collected by each system and different methodologies for collecting resource use data further contribute by the lack of established standards for the information technology industry, resulting in data collection and computing systems which are incompatible with one another.

Recognition of these problems has occurred within the wider agenda - common to all developed countries - which relates to controlling health care costs while assuring quality. Costs have escalated in parallel with demands for more high technology medicine. At the same time, changes in both the demography of the population of Western Europe and in the causation of ill health have increased the need for investment in chronic illness management and prevention. Given the finite limits to health care funding it is clear that there is a need to develop information systems which can underpin the effectiveness and efficiency of different health systems.

Any attempts to evaluate such aspects of the quality of care within and between health systems in the European Community are to be frustrated until agreed minimum basic data sets and common computing systems and standards are developed. A natural division of this task falls at the interface between inpatient and ambulatory care. Problems of achieving compatibility within

¹ WONCA: World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians.

individual hospitals are severe enough, although these at least have the advantage of usually being discrete organizations with more easily measurable inputs, outputs and simple resource use data.

Outside of hospital units, the problem of collecting compatible health data is much more severe: on one hand there is the vast array of size and types of sites from which care is delivered, on the other hand ambulatory care by its very nature is difficult to measure. Both elements present major obstacles to assuring the quality and cost-effectiveness of the delivery of ambulatory care, at a moment that in most western industrialized countries in the last 15 years a shift of hospital inpatient care towards ambulatory care has been realized.

Central to the solution of the aspects of incompatibility is the definition of, and Community-wide agreement on, a minimum basic data set (MBDS) for ambulatory care. Such an undertaking presents a formidable task given the variety of site types, communities, health professionals and health systems in which the data set must be accepted. We should therefore in this project define ambulatory care in the European context (see section 2) and identify its actors and activities (see section 3 resp. 4).

While acceptability of any proposed data model is clearly a major issue to be addressed, there also is the issue of the feasibility of collecting valid and usable data based on the model.

To allow for valid comparability yet achieve a data set which is not overburdensome in its collection - with the result that data collection might be incomplete - there is a fine balance to be drawn. Models proposed by researchers in this field have taken two approaches - either to create a theoretical model and then determine what data is needed and how it might be captured, or to start from an empirical base of existing data and build towards a more complete structure.

As agreed with the Commission of the European Community, McAce will follow the first (=top-down) approach. The initial framework therefore has been laid down in section 6 of this deliverable.

To address the questions why and for whom we are setting up a MBDS for ambulatory care, in the perspective of the many problems and dilemmas we will face in doing so, we created a separate section 5 in the deliverable, called the need for a MBDS.

In section 7, finally, we will elaborate more on where we are and what intentions the McAce-consortium has in mind for the development of the MBDS for ambulatory care.

This first deliverable of McAce is the initial outcome of intense discussions about the development of a MBDS for ambulatory care in Europe: 'a pathway is appearing'.

2. Definition ambulatory care

As the boundaries of ambulatory care differ widely in the countries of the European Community it is the more important for this project to define ambulatory care and in such a way that it will be a workable, in all relevant countries recognizable concept.

We would then define ambulatory care as personal health services provided by health professionals for people not currently admitted.

There are 3 important elements in this definition:

- * personal health services
- * provided by health professionals
- * for people not currently admitted

Around these elements we have to draw a line as well:

Personal health services: is defined as all health services, preventive and curative provided to an individual, whether he/she has requested for these services or not. This definition excludes all health services provided at community/population/group-level.

Health professionals: are qualified persons who render (personal) health services. This group includes medical and non-medical disciplines, people who provide direct care to the patient and people who have a more supportive function in this care.

In designing upon our MBDS we will surely face the dilemma of including or excluding certain groups.

Should, for example, social workers or clinical psychologists or family be called health professionals? Yes, if they are qualified and are (assisting in) solving a health problem, no if otherwise.

Should administrative staff be incorporated as health professionals? Looking around the Community a wide variety of administrative functions appears within and between countries. In some countries these administrative staff are carrying out curative/preventive services in combination with administrative duties, in other countries only administrative duties. We should then carefully look at all these functions in all countries of the Community, keep our definition of health professional in mind and decide on these functions so far our MBDS is concerned.

Is all health/medical staff and personnel relevant for the development of the MBDS? As we are restricting ourselves - for ambulatory care - to personal health services, we leave out all health professionals working in community health services, as long as they are not dealing with individual patients (e.g. community physician/public health nurse).

To ease our choice for the appropriate groups of health professionals for the development of a MBDS for ambulatory care we propose to create a core group of health professionals, who obligatory provides ambulatory health care services (e.g. general practitioner/consultant/trainee/nurse/physiotherapist/dentist/-pharmacist/midwife/nurse practitioner/dietician), and other groups of health professionals who may provide such services (e.g. psychologist/social worker/ administrative staff/ health visitor/home help).

People not currently admitted: we are forced to keep this part of our definition of ambulatory care rather vague as we are confronted with an extreme variety of systems and structures in this field in the different countries of the European Community. The rather popular institutions of day hospital care and short stay admission belong in some countries, for financing and planning regulations, to ambulatory care, while in other countries due to historical developments to hospital care. Nursing homes, in all their variety put us also for dilemma's, for sometimes you may find an infirmary inside. Similar problems are present with home based care for the terminally ill, for people in need of haemodialysis, for people suffering from AIDS. They all receive specialist care, originally provided in hospitals, but now available through the ambulant care sector.

The question raises whether all these types of care belong to ambulant care and if we are putting it this way, does it influence international comparison within the Community in a positive or negative way? In general, we must be aware that in many countries of the European Community the health systems are in transition not only through the implementation of structural changes, but also through the implementation of changes in ideology. It is an impossible and not desirable task to control all dynamics going on in the different health systems, for bringing these health systems on line just for the sake of the development of a MBDS.

In our discussion we therefore concluded that we only can do justice to all diversity within and between health systems of the Community, if we make this section of the definition just opposite to hospital inpatient care i.e. not currently admitted.

3. Identification of actors within ambulatory care

The definition of ambulatory care, as given in the section 2, indicates that a number of people are directly or indirectly involved. We call them actors. Roughly we distinguish three major (groups of) actors within ambulatory care.

1. **patients/users:** people, who have a health problem for which they receive or contract for professional advice or services from a health care provider.
2. **providers:** people and organizations responsible for the direct management of a health problem or illness. The description of their functional status is usually laid down in law or contractual agreement within professional groups or organizations.

Related to ambulatory care we can identify a number of providers, which are identical in the different health systems of the countries of the European Community (e.g. physician/nurse/ general practice/hospital). However beside these providers there exists an enormous variety within and between countries of other providers involved in ambulatory care. For the development of our MBDS we will look at both groups (the identicals and non-identicals) and set criteria, on which we will decide whether to include them or not as people in need for information.

3. **policy makers/planners/managers:** people and organizations, whose main role is to set up strategies and operational plans for future development of health services, to implement these plans and to monitor the health services, by control and evaluation. They may function on national, regional and local level, in governmental or private institutions, insurance or advisory bodies.

This group of actors is carrying out a variety of functions, such as policy making strategic planning, programming, management, budgeting, accounting, evaluation.

So both, function and level of functioning, will dictate the requirements for a MBDS, the content as well as the level of detail.

On a little distance a fourth group of actors may be identified, which has mainly a supportive function to the other groups of actors:

4. **Researchers:** people and organizations responsible for using and introducing innovations in current knowledge an scientific methodology, for answering different kind of questions for different purposes.

Researches should play an independent role, serving different groups of actors, which implies specific requirements of information to be incorporated in a MBDS. That is why we have put researchers in a separate group of actors.

Having now identified the four most important groups of actors within ambulatory care, the next step we will make in the development of a MBDS is a description of the relationships between the different groups of actors and consequently what these relationships mean for the requirement of information. In section 6 you may find the first results of this description of relationships.

4. Identification of activities within ambulatory care

The fast development of ambulatory care over the last decade and the wish to control the development, demand more insight into the amount and nature of the services concerned, i.e. which activities are performed by which groups of actors.

As there is an enormous variety of activities performed within ambulatory care, we have to give these a structure. Guiding principle in this exercise should be: who has which needs of information.

First, we therefore have to distinguish the different kind of processes that makes the ambulatory health services functioning. These processes are:

1. Planning

Priority-setting and decisions on patients that will be in care and the resources that will be supplied.

2. Performance

Actual use of planned resources, given an expected demand of care.

3. Monitoring

Analysis and tuning of care provided: efficiency/effectiveness/efficacy/equity are most important concepts.

Second we have to look at the levels on which information is needed to support these processes.

The first level is the professional level. On this level the people in need of information are those directly involved in the primary process of performance and those who support this process. They are usually the providers of care themselves: medical specialists, general practitioners, nursing personnel and so on, as well as administrative assistants in the practices. Individual patients and insurance companies should be included on this level as important people in need of information.

Although for the people working on this level, information supporting the primary process is of paramount importance, most of them will need information supporting the processes of monitoring and planning too.

On the second institutional level the people in need of information are the hospital and primary care managers: general managers as well as the (medical) staff. On this level the process of performance includes the care provided by the outpatients department of the hospital, by general practice, district nursing services. The people on this level will need information on behalf of the internal management of the institutions.

Information will be required to support the operational short-term management, with emphasis on the processes of monitoring and short-term planning, as well as more tactic and strategic long-term management with emphasis on the processes of medium- and long-term planning and policy development.

The third level is supra-institutional. The people in need of information are regional and national authorities, insurance companies, institutes for scientific research, interest groups and so on.

On this level the process of performance concerns outpatient or primary care provided, looked at from different points of view: the outpatient/primary (health) care system as a whole in a country or in a restricted area, outpatient ambulatory care provided by a particular specialty or supplied to a particular group of patients.

As far as the authorities are concerned, information will be required to support the processes of ambulatory care policy development, hospital/primary care planning and financing, and the like. Of course, on this level, financiers of care will be interested in information supporting the process of hospital/primary care financing and monitoring.

Although in certain cases information will be required on the professional or hospital/primary care level, mostly more general information will satisfy, supporting long-term planning processes.

In the matrix below, an overview is given of the possible activities in terms of the three main processes and the people in need of information (levels) described above. This matrix can be used to define the activities on a global level.

LEVELS	supra-institutional (regional, nation-wide)	institutional level (internal hospital/ primary care)	professional level (provider of care)
PROCESSES	external management	internal management	professional management
planning	ambulatory care planning	resource planning	resource planning
	ambulatory care financing system	internal financing system	
	epidemiological research	epidemiological research	clinical research
performance	'health care'	'hospital/ primary health care'	'professional health care'
monitoring	utilization review	utilization review	utilization review
	quality assurance	quality assurance	quality assurance
	hospital monitoring		

In this paragraph we have proposed a framework, based on the processes going on in ambulatory care and different levels in need of information from ambulatory care, from which we can identify activities which may be included in a MBDS.

5. The need of an MBDS

An MBDS has the potential of providing standardized information for decision making in medical- and health care. The basic information needed, depends largely upon the area of decisions attempted: 'what do you want to do?' dictates what one needs to know.

Various areas of decision making tasks can be discriminated:

- clinical research
- epidemiology
- quality assurance
- politics
- economics
- management

Different areas and different responsibilities will probably involve different data of input, process and output. Moreover, political planning and management rely on much more predictable data than for example clinical research.

It is not yet clear whether the various decision making tasks will require the same data or not. The same standard data set applicable for quality assurance may not serve political decision making. It is an open question whether one MBDS can serve all the masters. This raises the question, what is meant by minimum and basic in the definition of MBDS. Are minimum and basic defined if we succeed to create a data set that is serving all the masters or are we able to lay down criteria? This dilemma might probably be solved if we follow a route for the development of our MBDS, which is dictated by the needs of the potential clients and by the technical facilities for the operationalizations of these needs.

Modelling might be helpful to further clarify this route of identification of requirements of a MBDS. It is essential to agree on one model applicable in all the different areas of decision making. It is clear, however, that experience within some of the areas is more developed than in others. In clinical research and economics first hand experience will probably by and large have overtaken the basics of modelling. It is essential to take into account this experience, especially in the complex field of ambulatory care. As this field serves both patient-groups in general medicine care and in sub-specialty care, a divergence in relevant basis data can be expected. The modelling technique might help us identifying similarities, what allows for comparison.

The creation of possibilities to compare (patient groups/providers/health systems) forms the ultimate aim of developing a MBDS.

6. Initial framework for minimum basic data set

6.1. Developing a model

In order to understand the complex requirements and constraints which actors and organizations will place on a MBDS we need a descriptive method which will enable and structure the analysis. Rather than choose an extensive verbal description which may obscure any interrelationship we have chosen to use modelling techniques to represent the MBDS structure and the requirements and constraints upon it.

In this section we describe the modelling technique we are exploring most frequently, although not to the exclusion of simpler methods where these are appropriate. We then go on to exemplify the method in the health field and, further, describe an initial framework which we shall use to analyze the activities and requirements of clinicians.

The value of the proposed modelling lies in the ability of the technique to represent how information about ambulatory care relates to the activities that produce or make use of it, and to the actors or agents who generate or interpret the information. This class of model thus provides a systematic framework for describing, discussing and agreeing the significance of such information in the context of the enterprises which are concerned with it. It is the use of such models as a means to facilitate the necessary consensus-forming process amongst diverse actors and organizations that is of major importance to this project; the definition of a European MBDS which encapsulates an adequate subset of ambulatory care information will clearly be subject to such a process.

6.2. Enterprise modelling - description and application in the health field

The Enterprise Modelling approach on which our model is based was developed in other CEC's RACE program, and is being further developed and applied in other CEC research programmes (e.g. ESPRIT and DELTA). At this stage this approach has not been extensively used in this project and it may turn out that significant modifications need to be made to allow it to be used in the medical field or we may incorporate modelling techniques from the medical field which are not always made explicit e.g. clinical research model (health services research models). It may be more convenient to use simpler more conventional requirements modelling methods in the early stages of the project. Nevertheless the Enterprises modelling approach is presented here to give an indication of our intentions.

The information collected about ambulatory care falls into three basic types: information about the actors in ambulatory care, descriptions of the activities they are involved in and an outline of the data of which they make use. These basic types correspond closely with the three elements used in Enterprise Modelling Notation: agent, activity and resource (see figure 1). Three different symbols are used to represent these. The 'resources' used can be of various types. The three main ones are

information resources, consumable resources (e.g. time and materials), and facility resources. The type of a resource is indicated by an appropriate letter in the corner of its symbol.

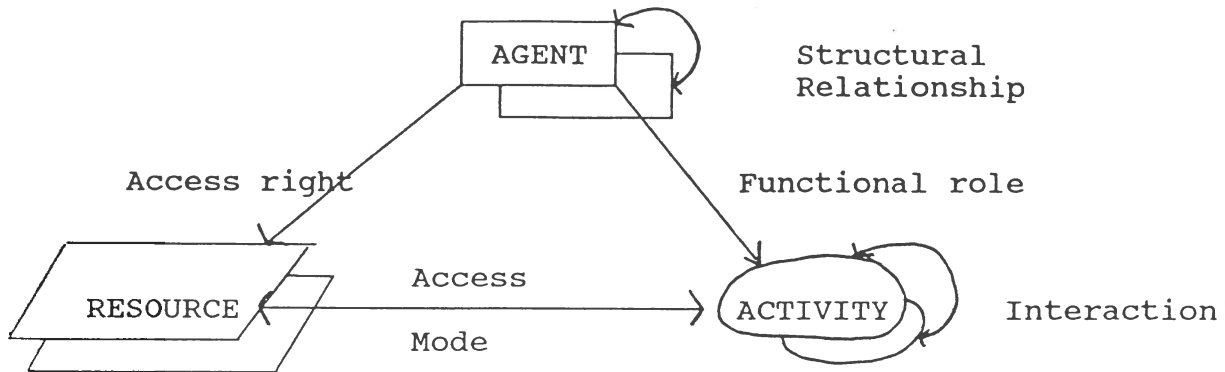


Figure 1. Basic Enterprise Modelling Notation

A model is constructed from these elements using a set of well-defined types of relations represented by labelled lines. Connections between agents represent structural relationships such as client-server, producer-consumer, provider-patient. Agents may be linked to activities by functional relationships, e.g. executor, supervisor. Activities have particular access modes (read, write, make, consume, etc.) to resources, while the relationships of agents to resources are more to do with the access rights (e.g. generate, interpret, allocate, accept). Activities may be linked together by interactions (e.g. verbal communication).

In any particular enterprise environment, there may be specific versions of these types of relations. It is our intention to identify those appropriate to the ambulatory care environment.

With this basic model in hand we are able to work out the requirement of the MBDS. By looking at the different areas of decision making use of already available (scientific) knowledge, in combination with the identified need of information of different people within the health services, we could for example take patient care in general practice; for the sake of information collection. It is important to know that patient care in general practice (=the patient/provider contact) has been operationalized through the so called SOAP notation. The abbreviation SOAP stand for:

- S = Subjective (=presentation of complaints by patients)
- O = objective (=classification of health problem + diagnostic activities)
- A = Assessment (=stating a (working) diagnosis)
- P = Plan (=plan for action)

As this SOAP-notation has been widely accepted and used in general practice we should apply this notation in our basic model. We have worked out such a model in figure 2, although it is important to stress at this point this is merely an example to illustrate the approach and does not represent any definitive model.

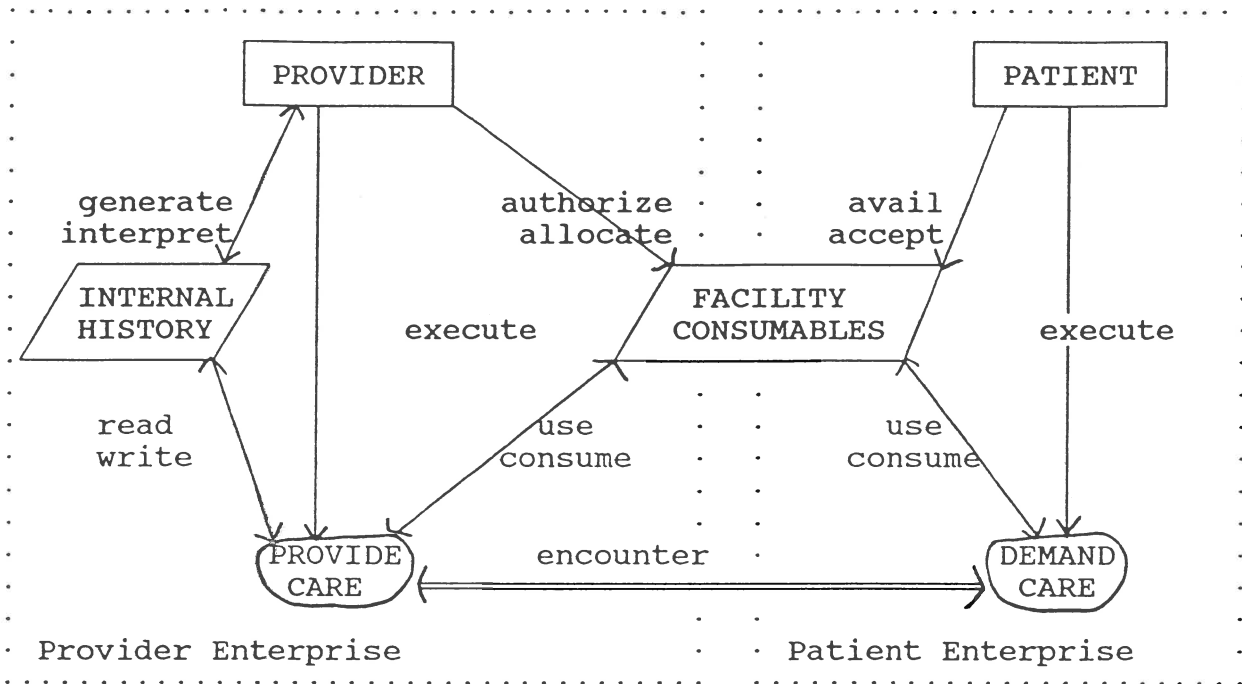


Figure 2. Example of an Enterprise model.

Two agents are included: the care provider and the patient. These two agents have a general relationship ('provider-patient') both within and outside of the general practice environment. This is represented by the thick, double headed arrow which connects them. The details of their articular relation in the general practice environment is shown by the rest of the diagram. Each agent executes an activity which furthers the objectives of the enterprise the agent is part of. Thus the patient executes the 'demand care' activity, and the provider executes the activity 'provide care'. These two activities clearly interact, and this is shown by a thin, double-headed arrow, which generally represents the informal, verbal and even physical communication between the two activities. Interaction between the two activities is enabled by some facility (e.g. clinic, telephone), and there is some allocation and consumption of consumable medical resources by the activities.

During the 'provide care' activity medical and other information is generated which is written to the medical history which forms part of the formal internal state of the provider's enterprise. At later stages of treatment, of course, the activity may need to read this information resource. However the data read is interpreted by the provider agent in the context of the activity and the provider's enterprise.

Note that the model represents the relationship between two enterprises: the provider enterprise (which may be of a corporate nature) and the patient's enterprise (of a personal nature). There are three aspects to this relationship: a structural aspect (i.e. provider-patient), an informal interaction (e.g. verbal interchange). and a formal interaction through the medium of some resource (e.g. attendance at a clinic, transfer of medication).

It is envisaged that a series of such models would be of use in defining the limits and modes of use of a MBDS. However it would be quite an extensive task to produce all possible models and it may be necessary to look at only a limited set of them. Anyhow, the primary purpose of the modelling is not to attempt to describe a highly diverse reality, but more to enable meaningful discourse as an aid to understanding complex requirements, and as a precursor to consensus building.

6.3. Ambulatory care - an initial model

We consider that the point at which information will be generated for a Minimum Basic Data Set will be the patients/provider contact, however that information is actually generated. In concert with a number of other experts groups (the European Union of General Practitioners [UEMO] and the Royal College of Surgeons of England) we have been unable to define Ambulatory Care in absolute terms. Principally this difficulty has arisen because of the various definitions of 'inpatient' to be found in the European Health Enterprise. Thus we have agreed that each country's definition of 'inpatient' should apply to Ambulatory Care in that country, leaving the definition of Ambulatory Care to be made by exclusion rather than inclusion. Thus we have generated a very simple initial model of entry into sectors of the health system (figure 3).

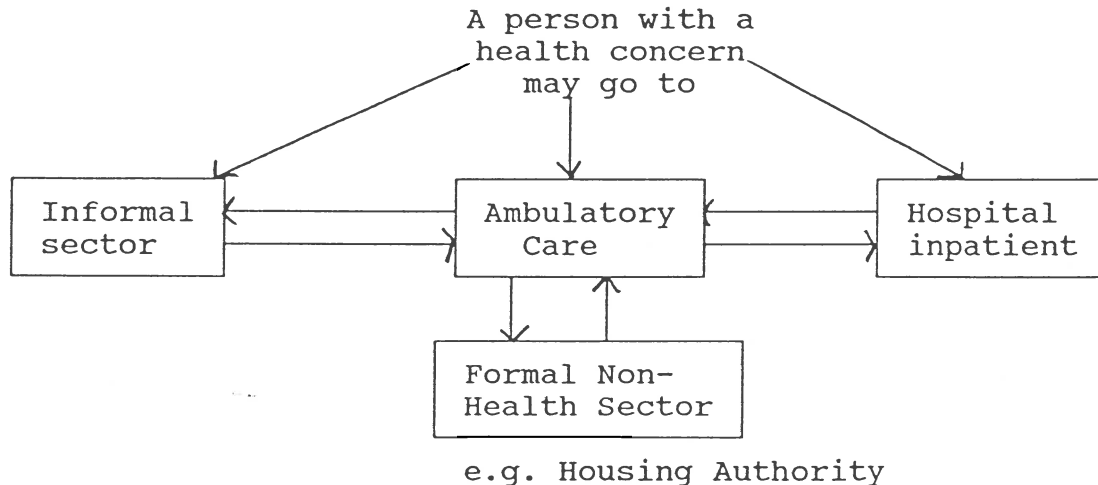


Figure 3. Ambulatory Care Model

This simple model helps to identify the bounds within which actors and organizations in ambulatory care operate and with whom actors interface.

Within Ambulatory Care we have taken the patient/provider contact as the point of information generation. We must therefore understand what the (finer-grained) activities take place in the encounter in order to understand what resources, informational or otherwise, are used and what information is generated and written as history data and hence might be a candidate for abstraction into the MBDS.

Using the notation we describe earlier our encounter model is outlined in figure 4. To reduce complexity relationship labels have been omitted except where essential for understanding, This model takes into account the possibility of both formal and informal interactions with other providers. The 'external history' represents an information resource received from a previous provider (e.g. referral letter or case notes), while the 'decision' is some formal output from the analysis carried out by the provider (e.g. referral or prescription). Informal contact with another provider is represented as an interaction with another 'provide care' activity.

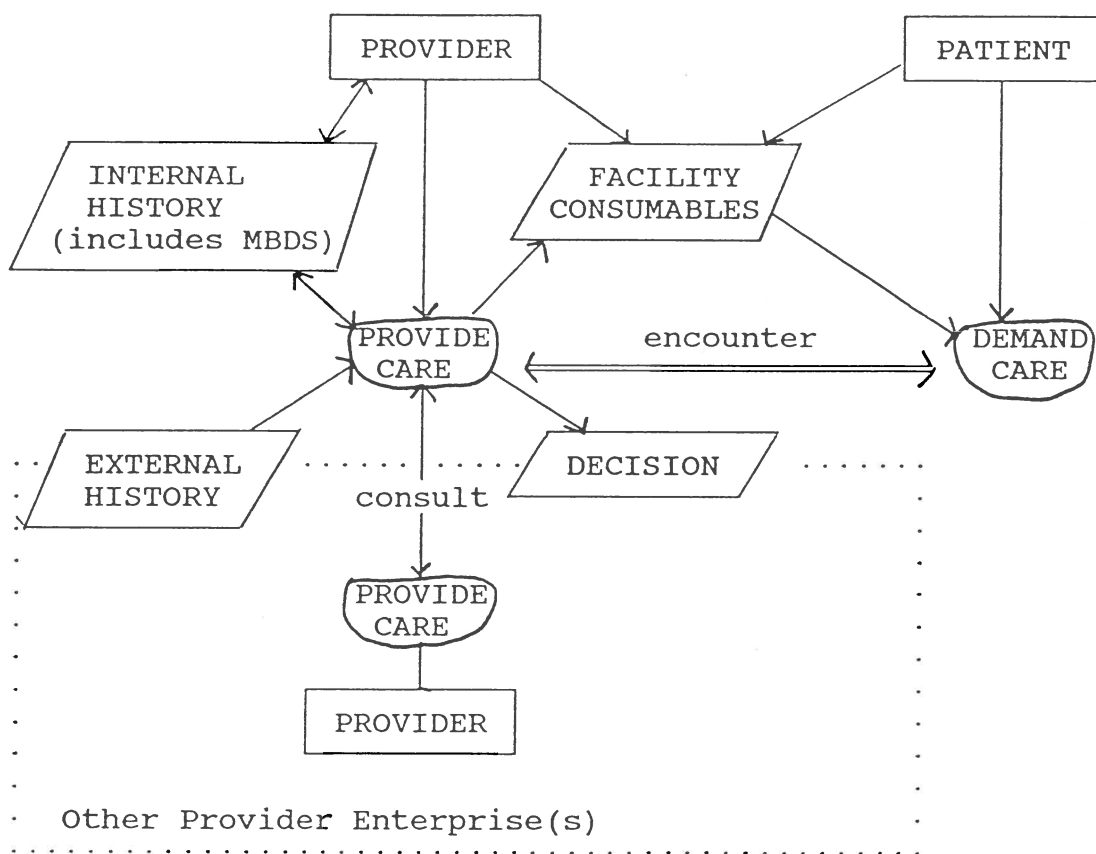


Figure 4. Generic Encounter Model

The initial model of the patient/provider encounter may be developed to provide us with a generic framework for analyzing and describing the finer grained activities which constitute the encounter.

6.4. Future Development

At this early stage we are only able to give a flavour of the technique and the output. However, our initial work on understanding the activities of clinical actors will allow us to develop a series of models which will elucidate the requirements and constraints of the MBDS, in addition to the structure. Although we have commenced with the clinical encounter we shall develop the method in such a way as to understand the needs of other groups of actors. In particular we need to look at the

actors concerned with higher levels of decision and policy making which affect the provision of ambulatory care, therefore, in addition to going down a level of abstraction through modelling finer grained activities and the information they generate, we also need to go up a level. Thus we shall be able to construct a model of structure, requirements and constraints of the MBDS which will be both systematic and comprehensive.

7. Overview

At this stage, three months after the start of the McAce-project and the production of this deliverable we might carefully assess where we are i.e. what progress we have made.

Taking the complete different professional and national background of the participants in this project into consideration and the fact that with this deliverable we took the first steps in structuring the immense complex field of ambulatory care, we could conclude that the intense discussions we had, were fruitful not the least because of available knowledge and pleasant cooperation.

We succeeded in reaching consensus on the definition of ambulatory care, on the actors and activities within ambulatory care and on the need for a MBDS.

We agreed using modelling techniques to developing the MBDS for ambulatory care. Ahead is the formidable task to combine these modelling techniques with already available (scientific) knowledge about the ambulatory care sector. However, this knowledge is not always made explicit and we therefore have to explore some sub-sectors within ambulatory care in more detail. Although we are aware of the similarities between hospital inpatient care and ambulatory care, which will be used in a symbiotic way in our project, we also realized that a MBDS for ambulatory care can't just be a copy of a MBDS for hospital inpatient care. Structure and nature of ambulatory care differ therefore too much from hospital inpatient care, that means, that we have to feed the project with ideas and knowledge from the inside. The experience with the determination of the framework and the route for the identification of requirements for a MBDS demonstrates, we can feel secure about the second deliverable of workpackage 1, what will deal with the requirements and constraints for a MBDS.

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