Do Once and Share

Diabetes

Final report

Dr Mark Smith

Dr Gail Boynton

Amendment History:

Version	Date	Amendment History
0.1	27/10/2005	First draft for comment
0.2	7/11/2005	Second Draft
0.3	5/12/2005	Third Draft
0.4	22/12/2005	Fourth Draft
0.5	27/12/2005	Fifth Draft
0.6	31/12/2005	Sixth Draft
1.0	4/1/2006	Seventh Draft

Key Contributors:

Dr Sue Roberts
Dr Colin Bradshaw
Dr Peter James
Yvonne Storey
Jill Remnant

Business Process Modelling
Dr Mark Smith
Tim Jones
Ian Herbert

Reviewers:

Version	Release Date	Reviewer	Written Comments Received
0.1	29/10/05	DOaS Diabetes Action team	
0.2	7/11/2005	DOaS Diabetic Action Team	

Approvals:
This document requires the following approvals.

Name	Signature	Title	Date of Issue	Version
Dr Mark Smith		Clinical lead and chair		
Dr Stephen Singleton		SHA Lead		

Document Status:

This is a controlled document.

This document version is only valid at the time it is retrieved from controlled file store, after which a new approved version will replace it.

On receipt of a new issue, please destroy all previous issues (unless a specified earlier issue is base lined for use throughout the programme).

Related Documents.

These documents will provide additional information.

Ref no	Doc Reference Number	Title	Version
1	NPFIT-NPO-GEN-IP-0067	Glossary of Terms Consolidated.doc	Latest

Glossary

BME	Black Minority Ethnic
CfH	Connecting for Health
DVT	Deep vein thrombosis
DKA	Diabetic ketoacidosis
DMSP	Disease system management programme
DOaS	Do Once and Share
ICP	Integrated care pathway
LSP	Local service provider
NHSIA	NHS information authority
NICHE	National institute for health and clinical excellence
NPfIT	National Programme for IT
NSF	National Service Framework
PCPI	Patient carer public involvement
PCT	Primary care trust
SHA	Strategic Health Authority

Contents

1. DOaS Diabetes: Executive summary

Aim

The aim of this project was to identify key components of the Electronic Health Record (HER) for people with diabetes and the healthcare professionals they work with, that would enable holistic diabetes care to take place. This requires patient and professional priorities for each intervention to be acknowledged across the domains of Clinical Care, Knowledge and Health beliefs and Social, Emotional and Behavioural dimensions, because together they facilitate the process of shared decision making.

Do One and Share Projects

The DOaS programme was developed in response to two imperatives.
1. To provide Local Service providers (LSPs) with National Standards for the content of the EHR that were agreed by clinicians and users in all the clusters, to replace the fragmented development process previously underway.
2. To further engage clinicians and patients in the national Connecting for Health initiative, ensuring the development of an ongoing Reference Group for each specific condition.

In the first year 42 of the most common clinician conditions were divided between SHAs who were commissioned to identify nationally best practice, fill gaps identified by working locally (Do One) and ensure that the final products had agreed national buy in. (and Share). The process was to be transparent and inclusive and the methodology and end products would be quality assured by the Connecting for Health (CfH) Knowledge, Process and Safety Board.

Routine and continuing Care of people with diabetes was allocated to Northumberland Tyne and Wear Strategic health Authority (NTWSHA).

Scope, deliverables and achievements

The outputs of the project that were specified and achieved were
- A documented map ('national pathway') for the ongoing and 'continuing care' and treatment of adults with Type 2 diabetes.
- Data items to support the development of the EHR and enable diabetes care to take place
- A set of proposals based on the lessons learned, outlining any changes needed to the relevant sections of the OBS for the Care Records Service, in the light of currently accepted best practice.

Specific exclusions
- Patients before their 17th birthday
- Retinal Screening
- Care record requirements for complications of diabetes and specialist interventions, or the related issues of CHD, stroke and renal disease which will form the basis of subsequent DOaS Projects.
- Sharing the products of the local work with national stakeholders. This aspect will be delivered via Diabetes Information Strategy Group. However a local Reference Group was set up, which could form the basis of a National Reference Group in due course

Additional outputs achieved
- Detailed 'maps' of requirements developed in two forms
  - A clinical facing view – to enable patients and clinicians to take part and validate the process

6

      o A supplier facing view – to enabled an LSP to develop the work into a practical and usable system: This approach used BPMN methodology

Additional work identified as necessary but out of scope of this project

- The development of SNOMED definitions for many of the data items

Ways of Working and Methodology

The project was run on a day to day basis by a small multidisciplinary group, the Diabetes Action Team (DAT) with a project manager, and accountability to a Project Board Chaired by the Medical Director of the SHA.

User involvement was assured via the SHA Head of Patient, Care, and Public Involvement as a key member of the team and by the methodology of engagement that was adopted. The products were developed iteratively in workshops, where half the members were service users, and in focus groups for BME individuals where English was not the first language. A majority of those involved volunteered to join the ongoing Reference Group. Clinical engagement was achieved similarly by participation in workshops and an additional workshop for senior diabetes professionals to assure the final product.

The project stages are described below.
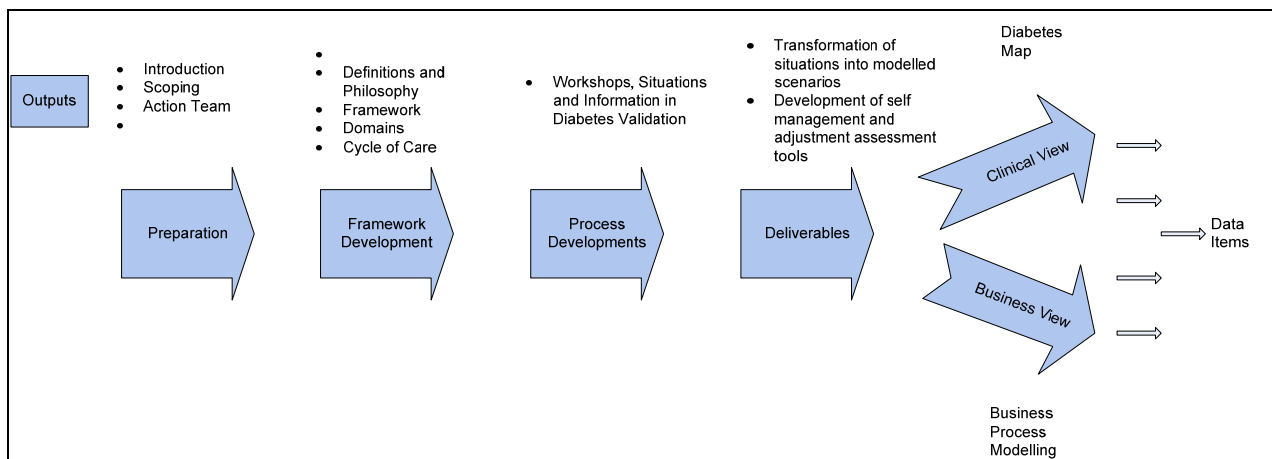
Key stages

1. The DAT action team met fortnightly for two months to review national best practice obtained on line, in visits, or one to one discussions; to clarify taxonomy of 'pathways' and the implication; to scope the domains (clinical, knowledge and health beliefs, social, emotional and behavioural) and cycles of care, drawing heavily on the literature, national work on 'consultation', care planning and single assessment process; and plan the workshops. Two workshops of people with diabetes, carers , clinicians and members working with the DAT and three other DOAS team representatives identified over 140 clinical 'situations'' their vision of a good outcome in each, and the information requirements before , during and after each 'situation'. (Appendices 7,8,9)

2. These situations were then processed in different ways to enable them to become the foundation of the health record. They were crosschecked with the framework and domains originally proposed by the DAT, and this was repeated when the results of the BME focus groups were available. There was a close match. The situations were then converted into 'scenarios' and activities, with associated patient, clinical and 'system' goals and behaviours for each. Finally the scenarios were grouped under the core activities which are part of a healthcare system (e.g. prescribing, diagnosing, reviewing, care planning etc). (Appendix 10)

3. The outputs of this process were then developed in two ways. The *clinical facing view* resulted in a 'map' based around the original NSF structure of diagnosis, initial management and continuing care. The *LSP facing view* used Business Process Modelling Notation (BPMN) to present the outputs in a form that could be built into electronic systems.

4. Simultaneous work included development of self management and adjustment 'maps' to be incorporated into the record and the detailed data items attached. These were added to other data items required to support the scenarios and were then identified either as existing in various data sets or in need of development(Appendices 11,12,13)

5. Finally the existing knowledge support in the form of national guidance, algorithms etc were associated with the appropriate part of the record. Appendix 5)

6. These final products were thus proposed (following national 'sharing') as the essential requirements for the OBS for diabetes (routine and continuing care only).

Key learning of wider significance

1. The Diabetes Action Team identified early on that the interpretation and definition of terms such as 'care pathway' 'patient journey' etc. was unclear and used to mean different things both within and out with Connecting for Health. It became essential to clarify this prior to significant user and clinician involvement. The outcome was
   a. The use of the term 'map' to describe the main output of the team and production of a document which identified a taxonomy of structure and processes of care in the NHS in 4 'levels' (Appendix 6). This is now in use to discuss the planning of diabetes services more widely.
   b. That since the Diabetes NSF provided the highest level map 'level 1' (Appendix 6) the work of the Action Team would be to populate 'level 2'. This addressed the requirement for detailed national data standards for LSPs, but also enables local services to develop local 'models' (level 3') and 'pathways' of care ('level 4') compatible with these. Inevitably different DOaS projects were observed to be working at different levels depending on the state of national standard development in each particular condition.

2. Working with such a large percentage of patients and carers demonstrated that the core structure of the electronic health record must include all the relevant domains (clinical, knowledge and health beliefs, social, emotional and behavioural) if it was to enable shared decision making between the patient and clinician.

3. The DAT identified that the EHR could best support the clinical consultation by providing a framework of domains and a core structure for standard situations (e.g. prescribing, care planning, new problem etc) which would be relatively stable over time. It should *not* have linear, time dependant or algorithmic structures. It could best be expressed as a clinical or technical user map. It was envisaged that ever changing evidence and knowledge/decision support would slot easily onto this formwork. This would allow regular updating without either disrupting the underlying structure of the consultation or the record.

4. The DAT learnt that technical developers are key people in the team, working closely with clinicians and non technical members to help develop and clarify solutions. But it is also essential that they are involved if they are to understand the requirements. The DAT would maintain that it is this dialogue and interaction which is critical and cannot be duplicated within an individual however expert they are at both clinical and technical issues.

Key project deliverables

The Project achieved all the milestones and outputs required (See section on Scope and Deliverables above). Key products appear in the Appendices. Areas out of scope appear in Appendix 1. The team expect that further discussion on the detail of the clinical 'maps' and a more consistent approach to the levels of granularity in these will be part of the next phase 'sharing' the work nationally.

Conclusion

The DAT for the DOaS initiative took the task of developing a patient centred HER right through from aspiration to the development of data items. It was firmly grounded both in previous work and best practice examples from around the country but drew heavily on the vision, commitment and hard work of people with diabetes and clinicians within Northumberland Tyne and Wear SHA. It is a robust and innovative piece of work which has provided lessons for development within Connecting for Heath and the wider NHS in addition to its prime task. It has provided a framework and detailed content that is fit and ready to be shared with the wider diabetes community in England.

While the product is comprehensive we believe that for completion the many data items should be incorporated in the SNOMED dictionary. This detailed piece of work could not be achieved within the timescale of the project but would add considerably to the value of the whole endeavour. It would be sensible to resource this while the local understanding and enthusiasm is available.

2. Introduction

Diabetes – where are we now?

Diabetes is a chronic and progressive disorder that impacts upon almost every aspect of life and organ of the body. It can affect children, young people and adults of all ages, and is becoming more common. The number of people with diabetes continues to grow with an estimated 1.8 million people in the UK diagnosed and a further 1 million undiagnosed. Although there is considerable research into the condition, diabetes remains a long-term condition for which there is no proven cure, only treatment. It can affect every organ in the body, and may lead to complications such as blindness, heart disease kidney failure and amputations, and affect mental health and well being. The increased prevalence of diabetes is caused by a number of factors such as an ageing population, obesity and low levels of activity. Another important factor for diabetes is the changing ethnic mix of the population. People from black and minority ethnic communities are six times more likely to develop the disease, suffer from a 50% increased risk of heart disease and have much higher levels of kidney disorders. The care of people with diabetes can also be complex with 25% of people suffering from three or more other long-term conditions. The end result is that diabetes has a heavy impact on the lives of the people who have it, their family and friends. The impact on the resources of the NHS is significant, with an estimated £5 million a day being spent on treatment (9% NHS spend). Much of this is due to the cost of complications which are now preventable with good professional care and good self management.

Another significant factor that marks diabetes care are the wide disparities in outcomes, with up to sixfold difference in blindness and amputations rates in people with diabetes between different parts of the country and different socioeconomic groups. In December 2001, the Diabetes National Service Framework (NSF) was published. The NSF set out the first ever set of national standards for the treatment of diabetes to raise the quality of NHS services and reduce unacceptable variations between them. When the Diabetes NSF was published it was, and remains, in the vanguard of moving the patient to the heart of their care. It describes a system of care where the person with diabetes is at the centre of decision making. One where healthcare professionals work in true partnership with people with diabetes – jointly designing and delivering individual care to meet individual needs and choices. [1]

Aims of the project

For people with diabetes and the health professionals they work with, this project aimed to identify the key components of the Electronic Health Record that would enable holistic diabetic care to take place. To do this we need to acknowledge and record patient and professional priorities. For each interaction we must consider Clinical Care, Knowledge & Health Beliefs and Social, Emotional and Behavioural dimensions. Together they facilitate the process of shared decision making and patient centred care.

It is difficult to demonstrate that current diabetes information technology systems, despite their sophistication and impact on process, have delivered significant improvements in patient centred outcomes. Whilst knowledge support software for clinicians is important, the electronic health record must give at least equal weight to those factors important to patients. Therefore our project needs to deliver a coherent story for both the diabetic community but also the clinical supplier

---

[1] Dr Sue Roberts in Improving Diabetes Services – The NSF Two Years On.

The diabetes NSF emphasises the importance of true collaborative working, and is very clear throughout, and particularly in standard three, that patient empowerment is a critical feature of diabetes care. Any diabetes system should support the process of shared decision making, taking into account those aspects of care important to patients and health care professionals, leading to true collaborative working.

Background

Do Once and Share (DOaS) is an idea whose time has arrived. Why? Local and National communities were struggling to find a way to deliver valid mandated National Health Service (NHS) user requirements and content to their National programme for IT (NPfIT) Local Service Provider's (LSPs), that would have widespread acceptance by them both.

Also where no natural communities of interest existed outside the traditional existing networks, the Do Once and Share programme can facilitate their creation.

Why it's not NSFs again

The DOaS initiative aims to tackle the top 50 illnesses and is different from the NSFs in that NSFs do not cover all of these areas. NSFs build consensus around standards of care. DOaS aims to build consensus around "what should be in an NPFIT application".
Further the NSFs are concerned with delivering standards of care and although they may include an information strategy, they have not had the aim to provide the level of detail to provide LSP's with the information they need to build suitable systems. Where the NSFs are focused on the delivery of processes and outcomes of care, the DOaS initiatives are focused on delivering the detailed clinical and management information that the LSPs require to ensure that their systems are suitable to be used by clinicians engaged in delivering the NSFs. Each project will work at a different level depending on the maturity of existing networks, communities of interest or existing NSFs.

Localisation

Communities of practice will argue that they are "different" and DOaS will not cover their needs. The argument is dependent on the definition of "different".
If they are applying differing standards of care what have the local clinical governance leads got to say? The National Institute for Clinical Excellence, National Service Frameworks (NSFs) and the new General Medical Services Contract, among others are driving common care standards. Usually what is inferred from "we are different" are system configuration issues around patterns of care delivery rather than the content that DOaS will provide to the LSP, as essentially individual care processes are made up of patient/clinician interactions (that can be highly varied and different), based on activities including referring, receiving discharge letters, prescribing, recording information, viewing pictures and looking at results.

The localisation issues therefore tend to be concerned with issues such as "populating the system with local telephone numbers", "recognizing that we don't have a PET scanner", and "ensuring the system recognizes that orthopaedics see this case rather than the rheumatologists in our area".

Providing Content for the Electronic Health Record to the LSPs

For the LSPs there has been no apparent interface for them to receive these mandated requirements and for them to be convinced that this was an expression of the broader NHS's view on a particular illness. Given contractual constraints LSP's do not have the time frame or the capacity to deal with multiple instances of the same local work on a

particular disease subject (in our case Diabetes) and then arbitrate with the communities to reach a consensus. That process should be considered a NHS role - describing what it wants from the LSP systems and the NHS as a whole should own the output. The NHS has struggled to provide a methodology to provide that content. DOaS is a recognition of that and accepts "we are where we are" and rather than rehearsing the history of what should have happened to move the process forward – hence its timeliness.

In our case a diabetes NSF already exists, giving the standards of care and broad direction of travel, and our challenge is to provide specific content to shape the diabetic electronic health record around Type 2 diabetes rountine and continuing care.

Validation and Assurance

Each DOaS project will be locally managed and carried out within a Strategic Health Authority (SHA). One of its key tasks will then be to network and consult with national stakeholders, communities of interest and clinicians who are working in particular programmes to ensure that their work is incorporated into the DOaS project (whilst ensuring engagement of the local networks and clinicians). In the case of the DOaS diabetes project the aim was to have in depth consultation with local communities. One of the main features of DOaS is to have the work validated and assured by the CfH (Connecting for Health) Knowledge Process and Safety Board who will ensure adequate patient input and that the right stakeholders have been consulted to "peer review" the work.

If for example much of the definitive work on Diabetes has been undertaken in the North West and the DOaS project for that work is located in Newcastle, the role of that project is not to repeat it but to assimilate it into the national Do Once and Share work.
In this way the process mandates the work of the LSP.

Scope

The diabetic action team commenced work in June 2005 and began the task of the scoping the requirements for the project. Review of the initial programme documents suggested that there were some areas which were out of the scope of the project.

DOaS for diabetes was given a specific programme mandate to deliver certain outputs. The mandate is agreed between the Strategic Health Authority (SHA) and the service implementation team. The project was intended to be a bounded discrete piece of work, to be completed within six months, which is not intended to cover the whole domain of diabetes and its relationship to NPfIT.
The specific required outputs within the scope of the project were:

- A documented "pathway"[2] for the routine and continuing care
- care and treatment of adults with type 2 diabetes.
- Data items to support the development of the electronic health record for people with diabetes and enable diabetes care to take place
- A set of proposals concerning the relevant sections of the Output Based Specification for the Care Records Service, outlining any requirements which need to change in the light of currently accepted best practice[3]

Specific exclusions from the scope of the project were considered to be:

---

[2] See section 3.1
[3] These comments are in the form of Business Process Modelling Notation, which describes in detail the system requirements http://www.bpmn.org

- Care pathways and data sets for coronary heart disease, stroke and renal disease (these were to be covered by the Integrated Care Pathway and individual DOaS projects).
- Retinal screening
- Patients aged under 17 i.e. before 17th birthday.
- Complications or specialist input (see Appendix 6 level1 "tadpole diagram")
- Widespread national sharing for this project was agreed to be commenced once the project had concluded (as per agreed scoping document)

The project does not include the implementation of the pathway locally, although the pathway will be made available to local implementstion teams and diabetes networks following the conclusion of this project.

For more detail on areas out of scope with reference to the DOaS Programme Terms of Reference, see Appendix 1

3. Project Governance

As Do Once and Share is a national programme, there was a national programme assurance and governance structure in existence prior to the start of the project, led by Sir Muir Gray, Director of Knowledge, Process and Safety for Connecting for Health. A project board was set up at a local level to provide project assurance and governance. An action team for Do Once and Share diabetes was set up to run the project and carry out the functions of the project. In terms of project governance and assurance, the DOaS diabetes action team reports to the DOaS diabetes project board, who report to the National DOaS programme board and the Service Implementation Team.

Project board

Northumberland Tyne and Wear Strategic Health Authority was given responsibility for two DOaS projects – both diabetes and breast cancer. A project board was set up to oversee both of these projects. The project board provides governance for the projects at a Strategic Health Authority level. The board is required to sign off all formal project documents. (See appendix 2 for project board membership).

The main function of the board is to follow PRINCE 2 methodology and ensure the projects deliver their scope and deal appropriately with issues and risks. These are escalated where appropriate.

DOaS Diabetes Action team

The action team was set up at the beginning of the project, and initially included the National Clinical Director for Diabetes, the clinical lead for the NTW SHA/North East CfH, the project manager, the local NPfIT communications manager, Network manager for diabetes and the local head of patient, carer and public involvement (PCPI).
A lead clinical psychologist who is clinical director of diabetes for a local diabetes service joined the team in the role of organizational facilitator. Subsequently two local GPs with a special interest in diabetes also became team members.

The team discussed whether there should be a patient representative on the team. Following lengthy consideration it was decided that having one patient on the action team representing patient views was not the most appropriate way of doing this. The SHA PCPI lead would be part of the team and attend meetings to ensure that structures and processes were in place to access patient and carers views and ensure appropriate patient and carer involvement. (See appendix 3 for diabetes action team membership)

4. Methodology

Project stages

There were several stages involved in developing the final project deliverables:

- Scoping and defining the project
- setting up a project board and action team
- Agreeing project definitions
- Reviewing national pathways and guidelines
- Developing a philosophy of care which the system was to support
- Designing a Patient centred framework
- Researching ways of supporting domains of care and improving shared decision making
- Use of the cycle of care and workshops to develop the detailed content and processes
- Collecting information from workshops
- Validating the methodology and outputs
- Transforming the workshop situations and information into modelled scenarios
- Development of self-management and adjustment assessment tools to be incorporated into the record
- Designing a clinically facing view of diabetes care processes
- Designing a LSP facing view of diabetes care processes
- Developing the data items to support these processes

These stages were carried out as shown in figure 1.

Figure 1: Project stages
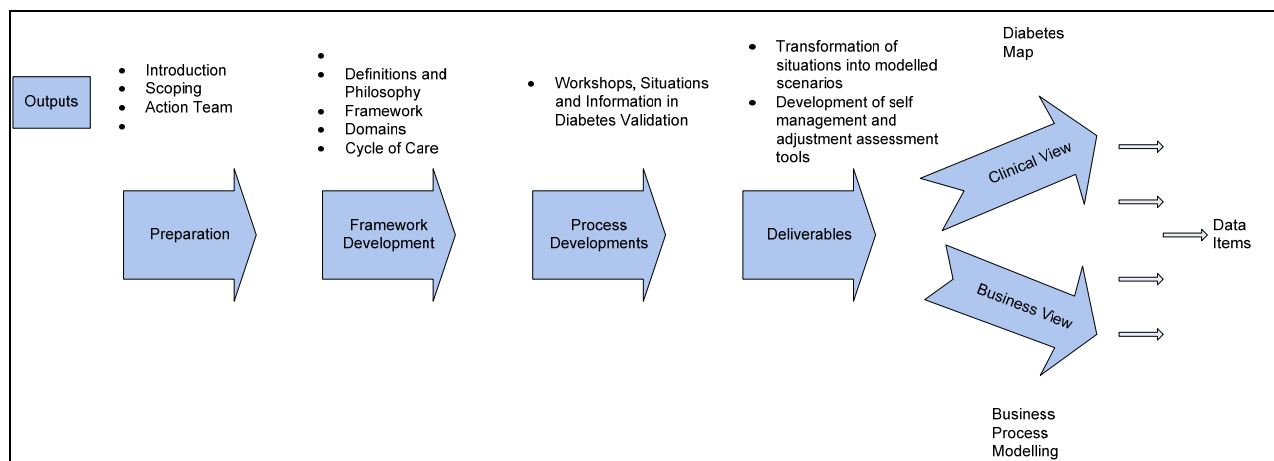
We saw one of the key initial tasks of the action team was to develop a common understanding of what we were trying to achieve particularly around the current terminology which allows for considerable ambiguity and confusion. By this we mean the number of different ways patient journeys, algorithms, patient pathways, integrated care pathways and care planning were used synonymously and interchangeably. All had different semantic definitions to the use of those particular words at a particular instance.

One of the key tasks was first to explore all of these definitions and try to arrive at a common vocabulary which allowed us to discuss and define the project more clearly.

5. Framework Development

Definitions and semantics

At the beginning of the project, the action team reviewed the current use of terminology around "care pathways", and spent considerable time considering and trying to work through existing definitions The team found that a number of definitions of pathways, maps and care plans were in use by NHS Connecting for Health and others. (See appendix 4). The action team examined and discussed these at length, and found that these did not match with the descriptions and definitions within the NSF, and were not helpful in structuring the development of the electronic patient record.

The action team spent considerable time developing a terminology for the diabetic care process to support the methodology which the team would use. Eventually the team decided that best way to describe the process was as a "Map". This could then be used to assist in the development of, in our instance, the diabetic electronic health record. This work was approached in two ways. Firstly, the action team was formed from a unique combination of people of varied backgrounds and disciplines who were able to examine the existing work each from their particular perspective. This combination included representatives from general practice, CfH, clinical psychology, public health, PCPI and communications. Secondly, workshops were held to sense check and validate the terminology and methodology used, and to drive the process of development of the required detailed content. The work developed from this was subsequently validated by local senior diabetes clinicians and by six focus groups from Black and Minority Ethnic communities.

Pathways reviewed

By adopting a solution that focuses on the dynamic interaction between the patient and the clinical system, rather than a linearly defined process of care, we have been able to reflect a very large percentage of this important national work in the DoaS outputs.The work examined includes work done by the London and Southern Best Practice Groups, work on data sets by Professor Philip Home and Dr Nick Vaughan, the DMSP work led in Salford by Dr Bob Young and Colin Gordon and the Leeds Care Pathway work designed by the Leeds Diabetes Modernisation Team. ..

Diabetes Pathways	
Source	**Title**
Salford	Patient journey
London Best Practice Groups	Information flows
Leeds Health Pathways (Leeds Diabetes Modernisation Team, for 5 Leeds PCTs)	Type 2 annual review
	Type 2 behaviour change
	Type 2 defaulters
	Type 2 diagnosis
	Type 2 foot care
	Type 2 initial care
	Type 2 patient education
	Type 2 rolling group education
	Type 2 smoking cessation
	Type 2 triage
	Diabetic emergencies and intercurrent illness (paediatric) (out of scope)
	Diagnosis and referral of childhood diabetes (out of scope)

Queensland	Standard care pathway for the management of diabetes mellitus in adults
Royal Berkshire and Battle Hospitals NHS Trust	DKA (and DVT) pathways(out of scope)
Taunton and Somerset NHS Trust	Diabetes and pregnancy ICP(out of scope)
Isle of Wight Healthcare NHS Trust	Paediatric DKA ICP(out of scope)
Royal Bournemouth and Christchurch Hospitals NHS Trust	Diabetes pathway
East Hampstead Surgery	Diabetes protocol
Airedale NHS Trust	Transfer to s/c insulin – phased care approach DKA – phased care approach(out of scope)
Cheltenham and Tewkesbury Diabetes Review Group	Diabetes ICP
West Sussex PCT	Diabetes pathway
Brighton and Hove PCT	Care pathway for diabetes review in nurse-led clinics
East Lancashire and Blackburn Partnership	Type 2 diabetes care pathway
Lincolnshire Care Pathways Partnership	Patient journey
Tayside Diabetes Managed Clinical Network	ICP adult diabetes
Scottish Diabetes Strategy Group	Outputs from workshops about diabetes care
Gateshead	Map of Medicine diabetes pathway

Diabetes Data Sets

In the field of diabetes, many clinical datasets already exist, and there has been very substantial work carried out developing a common dataset over the last 15 years.

Much of the early work looked at developing a data set to support audit and the annual review process. This work and the resulting data sets have gone through several iterations and name changes, and have evolved into the current nationally approved Diabetes Continuing Care Reference Data Set (DCCRD). More recently, the NHSIA Disease Management Systems Programme (DMSP) worked in collaboration with the NHS Datasets Programme to develop a systematic approach to specifying requirements for the care records systems which support care pathways in major disease management areas covered by National Service Frameworks (NSF). Diabetes was one of these areas, this work being led clinically by Dr Bob Young of Salford NHS Hospitals Trust. This work has been developed locally to produce diabetes IT system which is used across Salford acute and primary care trusts. This has involved detailed work on specifics of the data required to enable this. The primary purpose of the Diabetes Continuing Care Reference Dataset is not the direct clinical care of patients. The Diabetes Continuing Care Reference Dataset identifies:

1. the standard data elements which satisfy the information requirements to support the monitoring of current national diabetes continuing care guidelines;
2. data standards for the recording of each of these data elements; and

17

3. the appropriate coding mechanisms.

It does not constitute the patient record, nor does it constitute an exhaustive record of the care process. This dataset has been well validated and is widely accepted. As its origins were as an audit tool primarily for secondary care services, it naturally has a biomedical focus. Over the years, and with the introduction of the NSF, diabetes care has evolved from being largely secondary care led and focused around the annual review process, to having an increasing focus on self-management and community based services.

The Do Once and Share diabetes team aimed to examine whether there are any additional data items which should be identified for inclusion in the electronic health record in order to support this changing focus. This was done by elaborating user requirements into system processes and deriving data items from these. In order to use these data items in system implementation - a standardised terminology is needed. SNOMED CT is the adopted Connecting for Health standard for this. This allows detailed recording, effective retrieval and interoperable communication of information. Initial examination of SNOMED CT has shown that additional codes will need to be added to support the system requirements elicited by the diabetes DOaS project, particularly in the non-clinical areas.

Guidelines in diabetes care

A diabetes clinical system should be able to provide knowledge support to advise and guide the care process and also improve the quality of shared decisions made in the consultation. This knowledge support may be in the form of local knowledge e.g. local services available, or may be in the form of national guidelines. Over time new guidelines are developed and existing guidelines may be amended, so the provision of guidelines in a system needs to be dynamic or frequently updated. For this project we have taken into account existing NIHCE guidelines, NIHCE technical appraisals, global diabetes guidelines and Diabetes UK care recommendations (A summary of these is shown in appendix 5).

Overview of the Diabetic Map

(Please refer to appendix 6 if needed. It provides more detail that gives context to the narrative below)

It is important that when we plan services, or use technology to support the way we work, that we are clear about what we are describing and that the 'top down' processes do not constrain the local delivery of services that need to be unique to meet the local needs.
In describing the way 'patients' or 'service users' have contact with the service there are four levels at which we feel this relationship can be portrayed, depending on the task the service needs to perform. Currently the nomenclature is confused with words such as 'care pathway' being used to describe different things. It would be helpful if we had taxonomy ('currency') for these descriptions and these levels could help by making clear, for technicians, service planners and commissioners, what is being described.

Care pathways we have examined are often mixed, and incorporate many different levels with it being difficult to ascertain the rationale for all the levels and their purpose. There are, however, some excellent examples nationally and internationally. They are mostly, with few exceptions, based at level four. That should be no surprise because clinicians work day to day at level four (see Appendix 6). However sound planning systems and level three models and level four pathways cannot be built without doing the work at levels one and two. This work is of little immediate interest to clinicians, and may never be visible to clinicians – but cannot be done without them. DOaS projects should be developing levels one and two. Whether the individual project should work at level one or

level two will probably depend on the disease group and the existence or otherwise of an NSF. The main aim of the diabetes DOaS project was therefore to develop levels one and two for diabetes, but also to provide examples of levels three and four which would be used for system development.

Traditional pathways are often in the form of algorithms, which support decision making and/or recording. In this project it has been considered that the development of the care record should provide a framework for recording and displaying information that is important for clinicians, patients and carers. In addition, knowledge support can be provided as an option, allowing the person using the system to access guidance for example from NIHCE, WHO and the National Library for Health. Some of this guidance, but not all, is in the form of algorithms. The optional nature of access avoids presenting the user with a "decision support" algorithm which may be unwanted.

In addition, traditional pathways tend to suggest linearity which does not necessarily reflect working processes.

Ethos and Philosophy

"Medical informatics is as much about computers as cardiology is about stethoscopes… Any attempt to use information technology will fail dramatically when the motivation is the application of technology for its own sake rather than the solution of clinical problems. "
        Enrico Coiera (1995)

Our starting point was therefore the diabetes map, rather than IT system considerations. This was initially considered as a high-level map including diagnosis, initial management and continuing care.

The underlying consideration was for a system which would support collaborative working and shared decision making during each consultation. In order to support this, the consultation should consider patient perspectives throughout all domains of health, rather than relying only on a solely medical model.

It is widely recognised that health care needs to take a "bio psychosocial" model to ensure holistic and comprehensive assessment and intervention. This approach in turn defines different co-existing aspects of people – domains – which help to describe the complexities of human beings. One set of domains in wide use is as follows:

- Emotional
- Knowledge and health beliefs
- Social
- Behavioural
- Clinical

It is with such a conceptual framework, reflected in a wide variety of contemporary theoretical models, that health care professionals can systematically explore critically relevant dimensions that can determine health care use, adherence, self-management and adjustment. The following table gives some examples of potential effects of each of these dimensions on aspects of the life of a person with diabetes... The row headings show the domains of care, and the column headings the area that might be affected.

Positive effect
Negative effect

Domains of Care and Patient Perspectives in the Management of Diabetes				
	Use of Health Services	Use of Treatment	Lifestyle/Self Care	Adjustment/Quality of Life
Behavioural	Regular attendance of routine care	Taking medication as prescribed	Self monitoring and taking exercise	In employment, has a social life
	Inappropriate use of A+E for treatment or reassurance	Inconsistent daily routines	Alcohol/drug use	Avoidance of normal activities
Emotional	Sufficient self esteem to access services	Coping with frustrations of treatment	Confident in leading healthy lifestyle	Content with dealing with diabetes
	Panic causing inappropriate health care seeking	Fear of hypos causing poor control	Too depressed to self care	Grieving for lost health
Knowledge and Health Beliefs	Self management is the key to diabetes	I can improve my outcomes with medication	Exercise is good for me	My life is worth living with diabetes
	My life is in danger – I have to go to A+E	This treatment doesn't work	It wont work for me	My diagnosis must be a mistake
Social	Availability of family to give lifts to clinic	My husband reminds me to take my tablets	My friends lead a healthy lifestyle	We all help each other
	Isolated, poor access to services	My friends don't understand or help me	Stigmatised	My partner says the NHS should do more – I shouldn't have to help myself
Biomedical	Availability of good service to optimise care	Protocols, decision and knowledge support	Clear help in risk assessment and goals	Clear diagnostic messages and criteria
	Inconsistent testing and unstructured care	Inappropriate polypharmacy multiple side effects	Lack of sensitivity of biomedical to changes in lifestyle	"ology-itis" – everything assumed to be related to diabetes

The bio psychosocial aspects were each considered at each stage of the project, in addition to the more traditional clinical aspects. They were incorporated into an overall framework for information flows (Figure 2) which was designed to shape the structure of the diabetes electronic health record. This was used to guide the development of a methodology and the structure of the subsequent workshops and information elicited.

Figure 2: The Framework
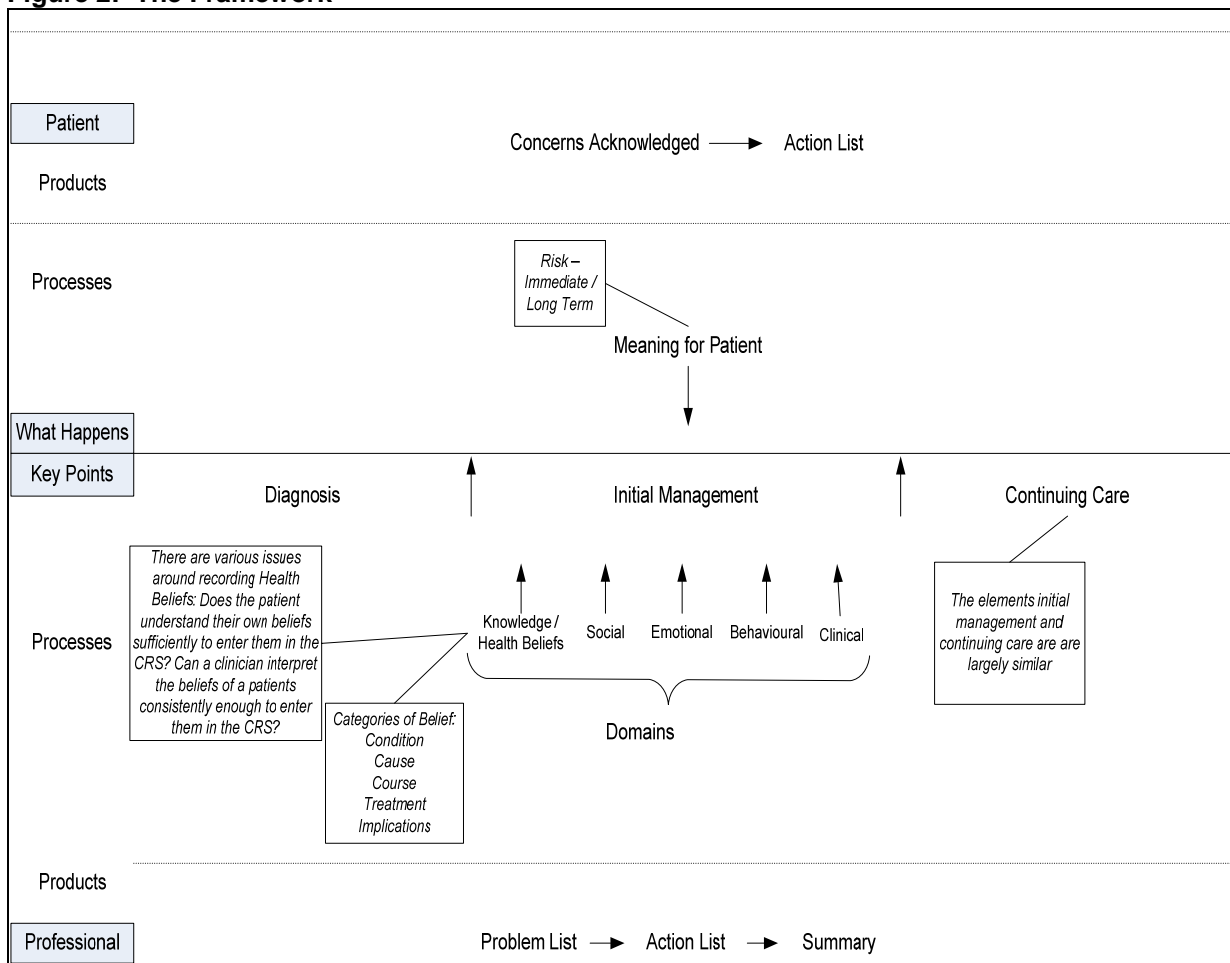
This high level map provided the framework to guide the subsequent process of designing the workshops and elaborating the detail to a sufficient level of granularity that would be useful to design a clinical system around. It is a representation of the high level thinking about level 1 diabetes. It is intended to convey our thoughts around all the key components required by a Diabetic record. It has not tried to represent all the inter-relationships but make enough key linkages to allow the next levels of detail to be elaborated in the next phases of this document. It remained "our guide" to thinking through process for the project.

The diagram should not be taken as left to right or top to bottom. The notion of *linearity is purposefully left out.*

In order to ensure that the diabetic record included the elements needed to support the key processes of diabetic care, we needed to elaborate the information requirements in detail. To drive out that level of granularity of detailed information requirements we used the concept of a "Cycle of Care" (Figure 3).

Each contact between a patient, a carer or a professional carer is underpinned by a simple cycle of activities. The cycle of care constrains what kind of information is used and collected during that contact, whether the contact is with, for example, a social worker, practice nurse or a diabetologist. Each activity in the cycle of care should take into account each of the domains of health outlined above.

Figure 3: The Cycle of Care
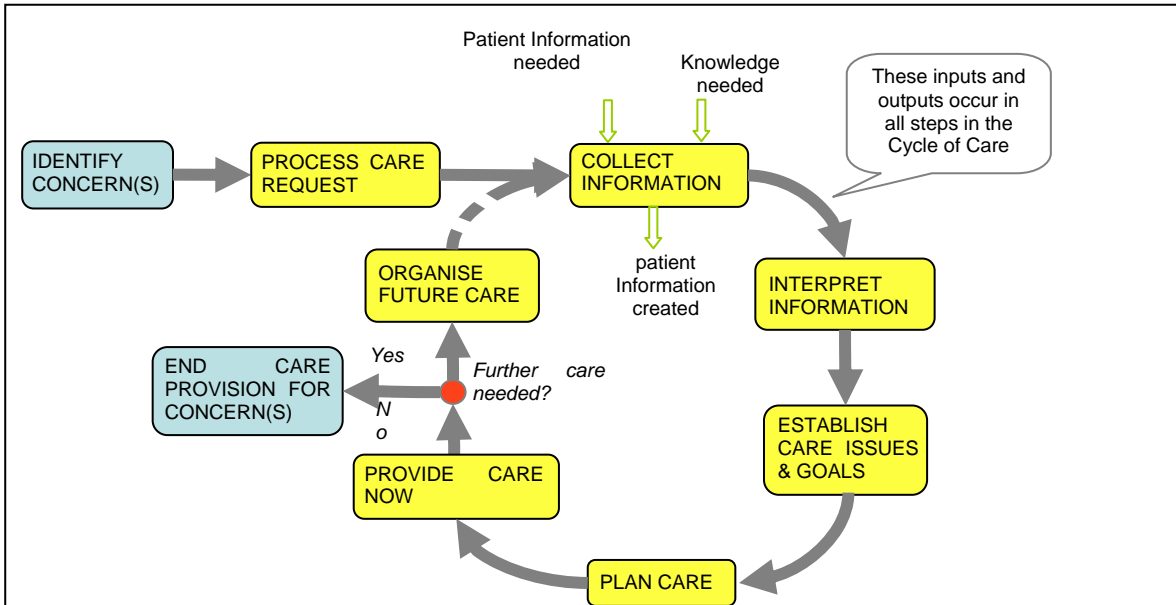
A patient may go round this loop many times over many years for diabetic care, and have several different care providers concurrently &/or sequentially. The cycle of care may occur in any part of the system, and may relate entirely too self management.

Figure 4: Multiple Cycles of Care
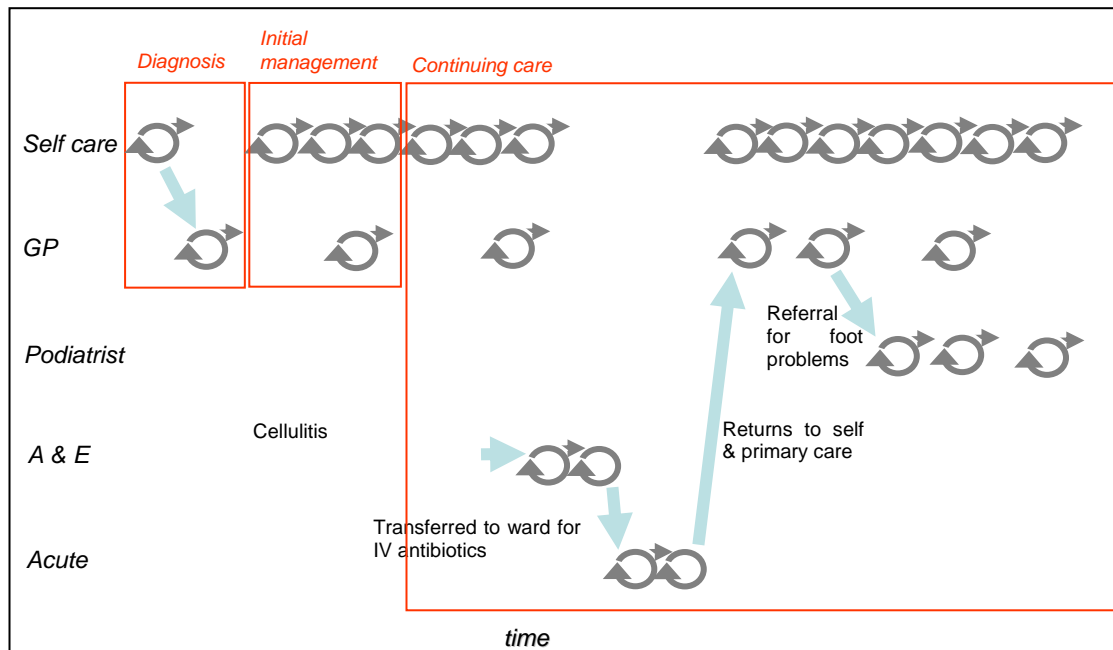
⟳ Represents an individual cycle of care

Support for the consultation and the care planning process

In order to support shared decision making in the diabetes care planning process, at each stage the perspectives of both the patient and the health care professional need to be considered as follows:

Figure 5: The Consultation and Care Planning Process

The Care Planning Process (Diabetes)

- What does the patient want to happen?
- What information does the patient want?
- What does the patient want recorded?

- What does the HCP want to happen?
- What information does the HCP want?
- What does the HCP want recorded?

Information Gathering → Information Sharing → Consultation & Joint Decision Making → Care Plan

Lifestyle Change · Self Management · Further Education · Specific Problem Solving · Telephone Review · Specialist Assignment

We used this methodology to help to structure the workshops (including our framework and cycle of care) to design the question setting and design the information collection templates. It was found to be very helpful way of appropriately prompting attendees for the "right" information as well as efficiently structuring the outputs. This process was not only about producing a more patient centred approach to developing the electronic health record but also valuable as to how the consultation should be supported by the record.

The electronic patient record should support better shared decision making in consultations and support the domains of care alluded to in our framework. We were also tried to move away from the existing state to an approved process that would allow some of the deficiencies of current systems to be corrected to support consultation models even more appropriately. The approach we have taken has a sound theoretical basis in the theory of consultation models, which are being widely adopted in the NHS, for example the Cambridge Calgary Model (reference 6), from which the following descriptive diagram is adapted.

In diabetes this concept of consultation and care is being developed into the care planning approach.

Figure 6: The Consultation Framework

The Expanded Consultation Framework

Initiating the session
-preparation
- establishing initial rapport
identifying reason for consultation

Gathering information
- exploration of the patient's problems to discover the:
☐ biomedical perspective ☐ patient perspective
☐ background information

Physical examination

Explanation and planning
- providing the correct amount and type of information
- aiding accurate recall and understanding
- achieving a shared understanding incorporating the patient's illness framework
- planning/shared decision making

Closing the session
- ensuring appropriate point of closure
- forward planning

Provide structure

making organisation overt

attending to flow

Build the relationship

use appropriate non-verbal behaviour

developing rapport

involving the patient

The function of the clinician

As part of defining the diabetic health record we also thought it worthwhile exploring the role of the clinician interacting with patients and new "clinical system". We recognise a lot of work has been conducted in that area but felt it worth including the following:

"The job of the human clinician is to relate the generalisable evidence[4] to that individual patient by taking a formal history, examining the patient and then discussing the options with a patient allowing that patients values to shape the decision. This new technology does not change the core responsibilities and skills required of the clinician but it dramatically changes the context in which they can be exercised".

The function of the summary (see figure 2)

The electronic health record summary should provide a distillation of the key events and actions from the consultation action points, and should show the priorities for the patient and the health care professional. The summary must be able to be to referenced at any time during the consultation and act as a key planning tool in organising and agreeing further care planning, treatments options and shared decisions.

---

[4] Sir JA Muir Gray

6. Workshops

"Helping service users believe that what they say is going to influence service provision is the single greatest challenge we face in delivering the NSF: patients and carers are still suspicious; getting them involved in the planning process, and showing them the effect they can have, is vital to producing a patient-centred service based around informed choice."   David Coates, Chair of Leeds User Forum[5]

In order to elicit the detailed information required to support diabetes care processes, a series of workshops were designed. The information framework and cycle of care were used to structure the workshops and design templates for eliciting detail which carefully reflected the views of patients and health care professionals. The aim of the workshops was to extract information to inform the map of diabetes care, and define what patients, carers and clinicians want and need in terms of support from the electronic health record to support each situation that presents in diabetic care.

A fundamental principle in designing the workshops was the inclusion of significant numbers of people with diabetes or those who care for those with diabetes. The genuine voice of patients and carers is essential to avoid health professionals making well intentioned but inaccurate assumptions about their motivations, needs and wishes. Our aim was to have equal numbers of patients and carers with health professionals. This was to both ensure that it was not the voice of a token individual patient or two and to give a very clear message about the equal importance being attached to the views of patients and carers. The workshops were facilitated by Peter James, a consultant psychologist and experienced organisational facilitator

The first workshop was held on 27th September 2005 at the Centre for Life, Newcastle. It was attended by 41 people including 15 patients and carers and 18 health care professionals. Clinicians included GPs, practice nurses, consultant physicians, diabetic specialist nurse, dieticians and podiatrists

The second workshop was held on 5th October at the Regus Centre, Gateshead. It was attended by 36 people, including 15 patients and carers and 14 health care professionals (all of whom are clinicians currently working directly in clinical diabetes care).

The events were also attended by the diabetes DOaS action team and other national DOaS team leads. There was representation from Accenture (as North East cluster LSP), business process analysts and North East cluster leads. The events were then structured around group discussions in facilitated small groups, the make-up and size of which were varied throughout the day. A formal evaluation was carried out after the workshop. This was generally very positive. The project team used the evaluation from the first workshop to further shape the following workshop. In particular, the way the information was collected was re-structured, to avoid duplication and to address the issue of getting sufficiently specific information.

There was a lot of enthusiasm from all participants for having this type of input into service development, with patients involved commenting that it was "different" form other events they had attended.   All participated in the difficult tasks of dealing with things that are conceptual in nature and making them practical.   There was no difference between patients, carers and health care professionals in these respects.

---

[5] Quoted in DoH (2005) Improving Diabetes Services – the NSF Two Years On

The feedback given by workshop participants via the formal evaluation forms was collated, analysed and sent to all workshop participants for comments and further feedback (Appendices 6 and 7). The workshop participants were all invited to be part of an ongoing reference group.

Workshop outputs

This generated a large amount of information. The way the workshops were structured allowed us to develop clearly described and articulated information resulting from interactions between patients and health care professionals.

This included records of the discussions of 113 individual situations relating to people with diabetes. The discussions included information on:

- What the patient and the clinician would want to happen in each situation
- What the patient and clinician would consider to be a good outcome
- What information would be wanted by the patient and clinician prior to (discussing) the situation
- What information the patient and the clinician would want recording (in the patient record)

In addition to this, a large amount of specific information was also captured in the following areas, by asking specific questions of groups of patients and clinicians:

- What information a clinician would want to have when seeing a patient for the first time
- Automatic reminders:
    - o What patients would like to or need to be reminded of
    - o What health care staff need to be reminded of when with a patient
    - o What "back office" reminders are needed by health care staff
- Summary information:
    - o What would patients and clinicians want to see in a summary list of current problems
    - o What should be in a summary list of intended actions for a patient
    - o What should be in a summary list of intended actions for a health care professional
- What patients think (or their family/carers think) about:
    - o The name and symptoms of the condition they have
    - o The symptoms they experience
    - o How they expect diabetes to develop over time, and perceptions of risk
    - o The screening, treatment and lifestyle changes that make up optimal care and best outcomes
    - o The implications for the way they live their lives
    - o Their intentions to manage their diabetes
    - o Their action plan to carry out their intentions
- Emotions:
    - o Emotions about having diabetes
    - o Anxieties that may affect care or self management
    - o Frustrations that reduce satisfaction with services
    - o Any other emotional issues
- Behaviour – what people have done:
    - o What a patient had actually done that might influence their diabetes
    - o The behaviour of carers
    - o The behaviour of a health care professional

- o Behaviour that had been anticipated as done but in fact was not done
- Social circumstances – friends, family and community:
    - o How social circumstances may impact on ability to adjust to diabetes
    - o How social circumstances may impact on ability to self manage diabetes
    - o How certain social contacts may be important to include in the planning of yearly care
    - o How the environment someone lives in could be relevant to their diabetes
    - o Who might be a positive influence on patients or carers

Consultations with minority groups

During the course of recruiting patients and carers for the workshop we recognised that there were some people who would find it difficult to attend and contribute to the workshop but who had extremely valuable perspectives to add.

This was felt to be particularly important because of the higher rate of diabetes in some black and minority ethnic (BME) groups. In the Access Report (2003), BME communities identified a gap in practical support to access services. In addition, previous work has suggested that people with diabetes from some BME communities may have a limited understanding of diabetes in relation to its causes, implications for lifestyle and longer term effects

We therefore arranged to do some separate work with groups of diabetes patients whose first language is not English, to gain their perspectives on important aspects of diabetes care, information requirements and the patient record. This work was carried out by Newcastle Health Development team, in partnership with Community Action on health, led by Lucy Hall.

This work was carried out by bilingual health development workers working with community groups in their "mother tongue".

The groups participating were:
- Chinese community
- Pakistani and Indian older women's group
- Bangladeshi men
- Pakistani men
- Middle Eastern Community - Arabic speaking Muslim women

The consultations highlighted that the issues important to people from the BME community reflected those in the general population.
However, there are some key areas where there may be particular needs or preferences, in particular:

- Name and naming system
- Hygiene and appearance
- Food and diet
- Religion
- Death and bereavement
- Procedures and treatments

Issues around faith and religion were explored in more detail by asking the question "What would you like your health care professional to know about your faith?" Particular issues mentioned included:

27

- Patterns of fasting
- Diet issues
- Appointment times to avoid
- Naming issues
- Dress issues for HCPs (e.g. removing shoes to keep carpet clean for prayer)

The consultation also highlighted the importance of knowing about a patient's health beliefs. For example, beliefs regarding the cause of diabetes included:
- Transmitted from another person e.g. caught it from husband
- Transmitted via food e.g. got it by eating husband's diabetic food/sharing plate
- Self-blame – diabetes caused by eating too much sugar or too much food
- Medically-centred health beliefs – it's just an illness that you get, you need to take a tablet, so nothing else can be done.
- Faith-centred health beliefs –
  God is in control of the world, he allows illness, so the illness is God's will. However there is a spectrum of effects this may have on their subsequent feelings about the disease and its potential management depending on the perceived locus of control ranging for example from wanting to make improvements in life to useful abilities God has given increasing the amount of time spent in prayer, to feeling "it's God's will, so there's nothing to be done about it". These beliefs don't generally lead to rejection of conventional western medicine, although they potentially could in some cases.

The information gained from these consultations has been used to augment the data from the first workshops, and inform the data and knowledge requirements of the diabetes electronic health record.
The full results of this consultation are outlined in Appendix 9

7. Outputs

Transforming situations into scenarios

The information from the workshops needed some processing in order for it to be useful in the development of the electronic health record. A first step in this process was to convert the situations arising from the workshops into scenarios and activities, with associated patient and clinician behaviours and the required "system" behaviour. The information generated by these questions and from the individual situations was collated, examined and modelled into scenarios relating to processes in diabetes care. Then applied against existing best practice and the pathways/work discussed in section 3.

Each situation was examined to work out:

- In which activity (ies) of diabetes care would or could this situation occur?
- What is the goal in the situation - what is the aimed for good outcome of the situation?
- What would be the benefit of achieving the goal?
- What is the patient behaviour in the situation – how does the patient participate and what do they do?
- What is the health care professional behaviour in the situation – how does the health care professional participate and what do they do?
- What does the system need to do to support and enable these things to happen?

These scenarios were then used as described in the following sections to develop the required outputs.

Developing Clinical and Technical views

Initial work on processing the information showed that presenting information in a sufficiently detailed technical format to inform system development by the LSPs was not a useful way for clinicians to view the information. Similarly, presenting the information in a clinical format did not allow the detail about processes required by the LSPs

It became clear that two views of the same content were required – a clinically facing view and a technically facing view. These are described below. These views do not show generic areas such as demographics or information requirements. Guidelines will feed into these – some examples of this are given, however guidelines are constantly being developed and updates, so at any time the system must make use of the most up to date guidance.

The Map of Diabetes Care: A clinically facing view.

The map of diabetes care shows the activities and processes occurring around the patient encounter, bounded by diagnosis, initial management and continuing care.

The map of diabetes care was developed as a clinically facing view of the project outputs. It is a functional representation of the components of diabetes care. The top level map (figure 7) shows the key processes and activities of diabetes care at a high level. This map describes the processes at levels one and two (as described in section 3.3).

Each circle represents an activity or process occurring during the routine and continuing care of an adult with type 2 diabetes.

Figure 7: The DOaS Map of Diabetes Care
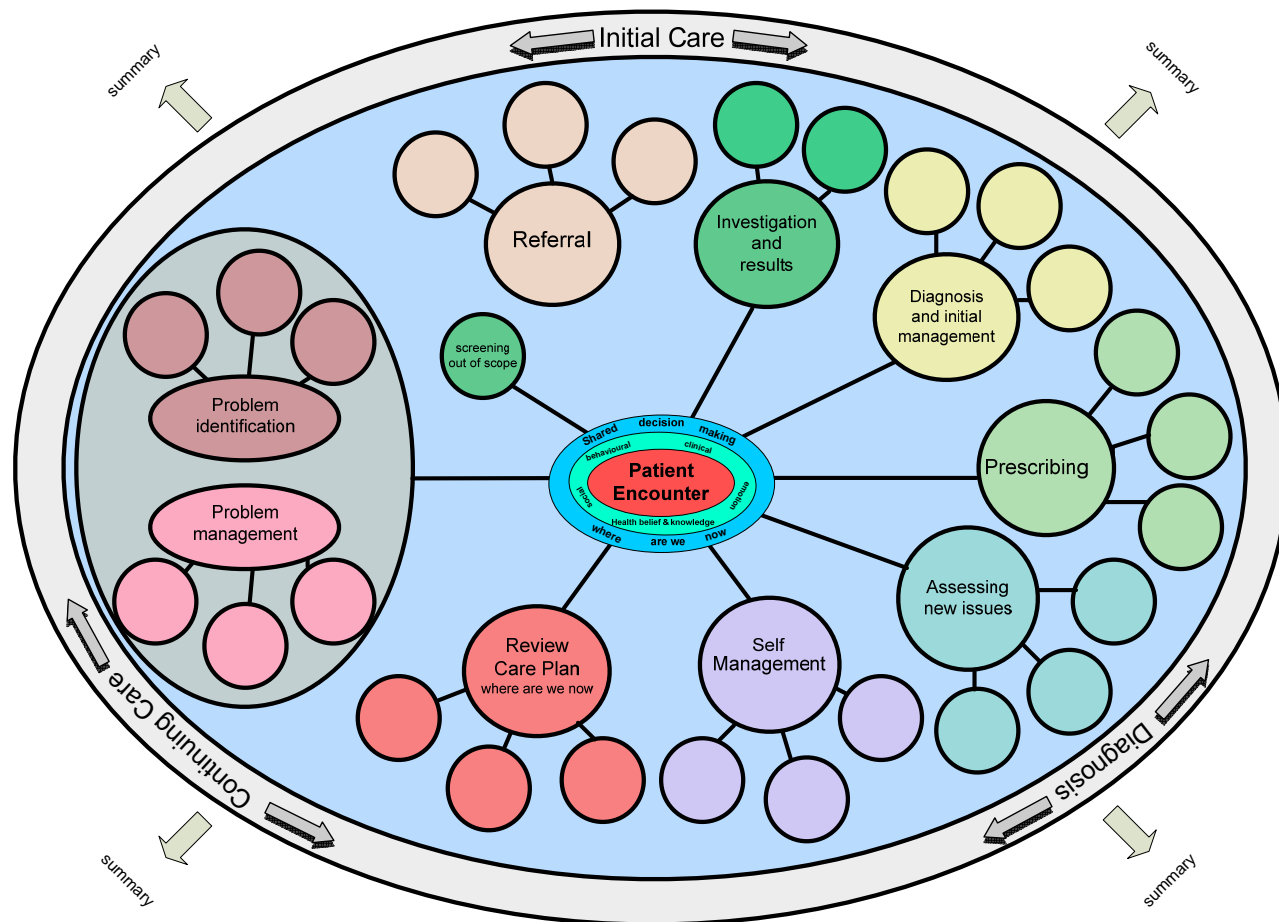
The map was developed from the preceding stages of the project, from the framework through to modelled scenarios derived from the workshop outputs. In order to identify the key encounters occurring in diabetes care, the scenarios were taken and grouped, so identifying common encounters. These were then organised into functional groupings, in discussion with clinicians and within the action team. This was an iterative process, and culminated in the final map showing the key events and processes occurring in diabetes care. The map centres on the consultation, which is the patient's encounter with services. The surrounding bubbles show activities or processes relating to a consultation. These in turn have sub-processes – each bubble was expanded to derive lower level maps as shown below.

Every consultation has phases of assessment and planning, the extent of which will vary depending on the type of consultation. The assessment phase asks "where are we now"? It involves information gathering, from the patient story and the professional story. The patient story is their account of their experiences, for example their history, symptoms, experiences in the psychosocial domains. The professional story is the information gathered by the health care professional, for example previous knowledge, review of records, results of investigations. The assessment stage results in problem identification.
This then leads on to problem definition and priority setting. Guidelines and protocols may be used to inform and guide this process. The domains of care – social, emotional, behavioural, cognitive and biomedical – may be used to explore reasons behind the problem and any barriers to its resolution, leading to priority setting via shared decision making.
The planning phase of a consultation leads to actions to address agreed priorities and problems.

Actions may include for example:
- Solving specific problems
- Lifestyle change
- Self management
- Further education
- Review
- Specialist referral

Developing the data items

The Diabetes Continuing Care Reference Data Set has been extensively validated and is widely accepted. As its origins were as an audit tool primarily for secondary care services, it naturally has a biomedical focus. Over the years, and with the introduction of the NSF, diabetes care has evolved from being largely secondary care led and focused around the annual review process, to having an increasing focus on self-management and community based services. The Do Once and Share diabetes team aimed to examine whether there are any additional data items which should be identified for inclusion in the electronic health record in order to support this changing focus. The framework of dimensions of care described earlier was used to frame questions to elicit further information which patients, clinicians and carers.

The data items required to support the electronic health record were derived using this framework via the situations, scenarios, maps and process models. The situations identified information needed by the patient, carer and clinician, and the information that each thought should be included in the electronic health record. Existing data sets were examined to identify any gaps in the data derived from the situations and scenarios, and to identify items required for the electronic health record in addition to the items in the existing data sets, and to identify how and where these could fit in the existing data set

To present the data in a format which would enable clinicians to validate the map of diabetes care, data items were associated with each headline activity on the map.
In order to do this, for each headline activity, the scenarios associated with that activity were identified, and the information specified in the system behaviour for that scenario identified. The information from all the appropriate scenarios was then aggregated to identify the data requirements for the activity.

Each of the activities from the high level map has been expanded to derive the more detailed low level maps as follows, which show the data requirements for each activity. The detail in the following maps increases from left to right; that is, the left side is a high level representation which becomes more finely granular towards the right hand side of the diagram (The data items related to these maps are shown in detail in the tables in appendix 11).

Care Planning – High Level Overview (figure 8)

Within diabetes care, care planning is a specific type of patient consultation. The NSF states that **"**All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.**"**

Care planning is a scheduled activity, aimed at developing a personal care plan for the patient. Here the assessment and planning stages may be more extensive than in the general consultation.

Every consultation has phases of assessment and planning, the extent of which will vary depending on the type of consultation. The assessment phase asks "where are we now"? It involves information gathering, from the patient story and the professional story. The assessment stage results in problem identification. This then leads on to problem definition and priority setting. Guidelines and protocols may be used to inform and guide this process. The domains of care – social, emotional, behavioural, cognitive and biomedical – may be used to explore reasons behind the problem and any barriers to its resolution, leading to priority setting via shared decision making.

The assessment phase has two areas – the patient story and the professional story.
.

The Domains (figure 9)

This covers our core domains – as discussed above and elaborated in further diagrams below.

The Professional's Story (figure 10 + 11)

The professional story is the information gathered by the health care professional, for example previous knowledge, review of records, results of investigations. This will include assessment of risk factors, outcomes and complications, and a metabolic review.

The planning phase of a consultation leads to actions to address agreed priorities and problems. These actions may then include any of the activities and processes as described in the following maps.

Standards and guidelines (The current evidence base underlying the 'content' of the maps)
NSF standards:
- Standard 3: Empowering people with diabetes
- Standard 4: Clinical care of adults with diabetes
- Standards 10, 11 and 12: Detection and management of long term complications
NSF interventions:
- Initial care of adults with diabetes
- Continuing care of adults with diabetes
NIHCE Compilation Evidence[6]
Management of type 2 diabetes: management of blood glucose:
- Measurement p. 258 – 259
- Targets (HbA1C) p. 259 2
- Self monitoring p.259
- Lifestyle interventions p.259 – 60
- Patient education p.260

---

[6] National Institute of Health and Clinical Excellence (March 2005) Compilation: Summary of Guidance Issued to the NHS in England and Wales. Pages 250 – 350

Knowledge and Health Belief (figure 12)

Behavioural Domain (figure 13)

Emotional Domain (figure 14)

Social Domain (figure 15)
Note these three 13+14+15+21 also align with self management

Diagnosis and initial management (figure 16)
Diagnosis may follow screening, presentation with symptoms or complications of diabetes, or may be an incidental finding. Initial management includes explaining the diagnosis and exploring the patient's view of it. It will include management of any emergency, initial screening for complications, any necessary referrals, and prescriptions.

Standards and guidelines
The World Health Organisation diagnostic guidelines (1999): Definition, Diagnosis and Classification of Diabetes Mellitus and its Complications

Investigations (figure 17)
There are several aspects to investigations – the administration, protocols, planning and preparation, and the investigation results themselves.
The data required relates to biomedical tests and investigations and the linkages to requesting protocols and results reporting.

Prescribing (figure 18)
Prescribing data will be linked to the NHS Dictionary of Medicines and Devices (dm+d). The dm+d provides a unique code for each medicine or device plus a textual description and is integrated with SNOMED Clinical Terms. Knowledge support from for example the BNF, NPSA and NIHCE guidance can be linked in here.

Guidance and standards
NIHCE Compilation Evidence[7]
Management of type 2 diabetes: management of blood glucose:
Insulin secretagogues p.261
PPAR-gamma agonists p.261 – 262
Alpha-gluosidase inhibitors p.262
Insulins p.262
Anti-obesity drugs p.263

Referral (figure 19)
Referral to specialist services. Data needed includes potential services that the patient can be referred to, the patient's demographic data and the contents of the patient referral letter.

Standards and guidelines
NSF Interventions:
- Care of people with diabetes during hospital admission
- Care of women with diabetes during pregnancy
- Diabetic eye complications

---

[7] National Institute of Health and Clinical Excellence (March 2005) Compilation: Summary of Guidance Issued to the NHS in England and Wales. Pages 250 – 350

- Diabetic renal complications
- Lower limb complications
- CHD and stroke

New Issues (figure 20)
These could represent a myriad of issues that a patient with diabetes could develop. New issues may be clinical issues, for example new symptoms, new complications or new procedures. However, new issues are not restricted to purely medical issues such as these , but could encompass any new issues relating to our domains such as depression or moving to an area with the diabetic service is configured differently.

Education (figure 21)
Supporting self-care is a crucial aspect of any high-quality diabetes service, and the Diabetes NSF recommends structured patient education as an important part of this.
NIHCE has recommended that all people with diabetes should be offered structured education, provided by a trained specialist team of health professionals. NIHCE considers the team should include a diabetes specialist nurse (or a GP practice nurse who has experience in diabetes) and a dietician (someone who can give specialist advice on diet). Other health professionals should join the team if needed. Education about diabetes should start when people are first told they have the condition and should then become part of their long-term routine care. NIHCE concluded that there was not enough evidence available to make recommendations about specific types of education. But NIHCE does offer the following general advice.
• People with diabetes generally should be taught in groups, although one-to-one teaching should also be available.
• Teaching sessions should use a variety of different methods to help people learn.
• Educational programmes should meet the needs of the broadest possible range of people with diabetes.

People from different cultures and ethnic groups, and those who have disabilities or who live in more remote areas, all need to be considered. Sessions could take place either in the community or at a local diabetes centre. The Dose Adjustment for Normal Eating (DAFNE) course may be one suitable education programme for people with type 1 diabetes.

High-quality structured education can have a profound effect on biomedical outcomes, and can significantly improve quality of life and satisfaction. The aim of patient education is for people with diabetes to improve their knowledge, skills and confidence, enabling them to take increasing control of their own condition and integrate effective self-management into their daily lives.

Quality standards
In order to encourage consistently high standards across local and national education programmes, key criteria have been developed that a structured education programme should meet to fulfil the requirements of the NIHCE Health Technology Appraisal on patient education2. The nationally accepted standard scheme for type 2 diabetes is the DESMOND programme.

Guidance and standards

NICE Health Technology Appraisal (Number 60) Patient Education Models in diabetes 2003

Structured Patient Education in Diabetes. Report of the Patient Education Working Group.
June 2005

Adjustment (figure 22)

Figure 8 Care Planning – high level overview

Care Planning

- Starting summary
  - Critical issues from domains
    - Health beliefs
    - Knowledge
    - Emotional
    - Social
    - Behavioural
    - Clinical
  - Medical history
    - Diabetes type - current
    - Diabetes type - previous
    - Date of diabetes diagnosis - current
    - Date of diabetes diagnosis - previous
    - Other diagnoses
    - Procedures
  - Current medication
  - Professionals involved in patient's care
    - GP
    - Diabetologist
    - Diabetes Specialist Nurse
    - Dietician
    - Podiatrist
    - Ophthalmologist
    - Psychologist
    - other

- Assessment
  - Where are we now?
    - The patient's view
      - Concerns
        - How are they (holistic)
        - Diagnosis
        - Symptoms
        - Outcomes/complications
        - Other health concerns
      - Significant events since last review
        - Bereavement
        - Marriage
        - Holiday
        - Childbirth
        - Started driving
        - Change of employment status
        - Change of employment type
        - Change of working pattern
        - Other
        - Change of home circumstances
      - review of last care plan
        - date
        - outcome of each action
        - barriers to each action
    - The professional's view (see separate ,map)
    - Joint Review of domains
    - Self management (see behavioural domain)
    - Adjustment
    - Motivation
    - Carers view

- Shared decision making
  - Problem identification
    - details for summary
  - Priority setting
    - detail for summary

- Planning
  - Specific Needs
    - Information
    - Training/education
    - Social Support
    - Equipment
    - Respite for patient who is a carer
    - other
  - Patient actions
    - Self management (see behavioural domain)
    - Specific education
    - Follow up via - all channels
  - Carer actions
  - Professional actions
    - Referrals
    - Investigations
    - Supporting self management
    - Prescribing
    - Follow up

Figure 9 The Domains

Figure 10 Clinical Care Domain

Figure 11 Care Planning – Assessment – The Professional View

Care Planning - Assessment - Where Are We Now?- The Professional View

- Risk factors and Mediating variables
  - Age
  - Ethnic origin
  - Sex
  - Duration of diabetes
  - Other diagnoses
  - Systolic blood pressure
  - Diastolic blood pressure
  - Cholesterol
    - Total
    - HDL
    - LDL
    - Ratio
  - HbA1C
  - Fructosamine
  - BMI
  - Waist/hip ratio
  - Serum creatinine
  - Creatinine clearance
  - Urinary albumin
    - quantity
  - Urinary protein
  - smoking

- Foot Assessment
  - Symptoms
    - Neuropathic pain
  - Examination
    - Foot colour
    - Foot deformity
    - Sensory loss
    - Pulses
    - Ulceration
    - Procedure
  - Risk status

- Clinical Outcomes
  - Renal
    - Albuminuria stage
    - Creatinine clearance
    - Diagnosis of renal failure
    - Renal dialysis
    - Renal failure
    - Under care of renal specialist
  - Eyes
    - Retinopathy screening
    - Specialist eye observation
    - Right and left eye examination
    - Under care of eye care specialist
  - Feet
    - Diagnosis
    - Referral
  - Vascular
    - Cardiovascular
      - new symptom
      - Diagnosis of hypertension
      - Diagnosis of heart failure
      - Diagnosis of angina
      - Diagnosis of MI
      - Diagnosis of Stroke
      - Coronary angioplasty
      - CABG
      - Under care of cardiology
    - Cerebrovascular
    - Peripheral vascular

38

Figure 12 Knowledge and Health Beliefs

** Checklist appropriate to diabetes to be developed

Knowledge And Health Beliefs

Illness representation (understanding of condition)
- Identities — Appropriate attribution of symptoms** — Yes / No — Detail
- Cause — Appropriate attribution** — Yes / No — Detail
- Course — Appropriate attribution** — Yes / No — Detail
- Understanding implications — Appropriate attribution** — Yes / No — Detail
- Understanding treatment — Appropriate attribution** — Yes / No — Detail

Intentions to self manage
- Perception of risk** — Yes / No — Detail
- Perception of gain** — Yes / No — Detail
- Perception of barriers** — Yes / No — Detail
- Perception of self efficacy** — Yes / No — Detail
- Perception of norm** — Yes / No — Detail

Action Plan(SMART)
- Present — Yes — Detail / No
- Behavioural triggers — Yes — Detail / No
- Relapse Plan — Yes — Detail / No

Figure 13 Behavioural Domain

Behavioural Domain — Self management

- Life style /risk factors
  - Physical activity
    - Details
    - Intention
    - Action
    - Summary/readiness cycle
      - Pre contemplation
      - Contemplation
      - Determination
      - Action
      - Maintenance
      - Lapse/relapse
  - Smoking
    - Details
    - Intention
    - Action
    - Summary/readiness cycle
      - Pre contemplation
      - Contemplation
      - Determination
      - Action
      - Maintenance
      - Lapse/relapse
  - Diet
    - Details
    - Intention
    - Action
    - Summary/readiness cycle
      - Pre contemplation
      - Contemplation
      - Determination
      - Action
      - Maintenance
      - Lapse/relapse
  - Alcohol
    - Details
    - Intention
    - Action
    - Summary/readiness cycle
      - Pre contemplation
      - Contemplation
      - Determination
      - Action
      - Maintenance
      - Lapse/relapse
  - Recreational drugs
    - Details
    - Intention
    - Action
    - Summary/readiness cycle
      - Pre contemplation
      - Contemplation
      - Determination
      - Action
      - Maintenance
      - Lapse/relapse
- Foot care
  - Details
  - Intention
  - Action
  - Summary/readiness cycle
    - Pre contemplation
    - Contemplation
    - Determination
    - Action
    - Maintenance
    - Lapse/relapse
- Daily living
  - Driving
  - Holidays
  - Work
  - Education
- Optimising treatment
  - Taking medication
  - Attending screening
  - Attending clinics
  - Self monitoring
    - Glucose
      - Blood
      - Urine
      - Continuous
    - BP
    - Others
      - Details

Figure 14 Emotional

Figure 15 Social Domain

Figure 15 Social Domain

Figure 16 Diagnosis and Initial Management

Diagnosis And Initial Management

- Clinical domain
  - History
    - Current symptoms - general
    - symptoms of hyperglycaemia
      - None
      - Polydipsia
      - Polyuria
      - Weight loss
      - Lethargy
      - Recurring infection
      - skin itch/rash
      - Blurred vision
      - Tingling, pain, numbness
  - Physical Examination
    - Height
    - Weight
    - Waist circumference
    - Hip circumference
    - Waist/hip ratio
    - BMI
    - Temperature
    - Respiration rate
    - Peak flow
    - Foot examination+
    - CVS examination+
    - Eye examination+
  - Investigations
    - Fasting blood sugar
    - Blood glucose 2 hour post glucose load
    - Random blood glucose
    - HbA1C
    - Fructosamine
    - FBC
    - TFT
    - Cholesterol
      - HDL
      - LDL
      - Ratio
    - Eyes+
    - Feet+
    - kidneys
      - UE
      - Creatinine
      - Creatinine clearance rate
      - Urine albumin
      - Urinalysis
      - others
    - Vascular+
  - Family History
    - CHD
    - Diabetes
    - Thyroid
    - Coeliac Disease
    - other
- Diagnosis
  - Diagnosis date
  - Diagnosis clear
    - Type 1
    - Type 2
    - Others
  - Diagnosis unclear
    - Provisional diagnosis
    - Plan further tests
- Review of Other Domains
  - Emotional
  - Social
  - Behavioural
  - Knowledge/Health beliefs
- Adjustment
- Initial Management
  - Diagnosis
  - Initial management plan
  - Specific education and information
  - Plan for review date/location
  - Plan for structured education
  - Initial screening done - foot
  - Initial screening done - eye
  - Initial screening done - kidney
  - Initial screening done - vascular disease
  - Referrals made
    - Dietician
    - Podiatrist
    - Psychologist
    - Diabetician
    - DSN
    - Others

Figure 17 Investigations

Investigations
- Administration and organisation
  - Date requested
  - Reason for request
  - Investigation type
    - Laboratory
    - Radiology
    - ECG
    - Other
    - Electro physiological
  - Prior preparation required
  - Appointment date and time
  - Appointment location
  - Departmental information
- Results
  - Receiving results
    - Notification of result availability
    - Who result is given to
    - What it is
    - What it means
    - Follow up required
    - Calendar event triggered
    - Acted upon
  - Result value

Figure 18 Prescribing

Prescribing
- Current medication
  - Medication name
  - Dose
  - Unit of measurement
  - Format
  - Dose form indicator
  - Dose form size
  - Dose form units
  - Frequency
  - Instructions
  - Route of administration
  - Supplier
  - Cost
  - Duration of prescription
  - Prescription date
  - Amount prescribed
  - Duration of treatment
  - Repeat
- Other medication
  - OTC medication
  - Alternative medication e.g. herbal
  - Allergies
  - Side effects
  - Contraindications
  - Vaccination history
- Patient medication preferences
  - Preferred medication format/type
  - Preferred medications
  - Disliked medications
  - Disliked formats
  - Medication concerns in the following areas
    - emotion
    - social
    - Behavioural
    - knowledge/health beliefs
    - clinical
- Patient's needs
- Medication options
  - Medication type
  - Format e.g. liquid
  - Other treatment/self-management/lifestyle options
  - Risks of medication
  - Benefits of medication
  - Patient medication preferences
- Medication started
  - Medication name
  - Dose
  - Unit of measurement
  - Format
  - Dose form indicator
  - Dose form size
  - Dose form units
  - Frequency
  - Instructions
  - Route of administration
  - Duration of prescription
  - Repeat yes/no, number of repeats
- Medication discontinued
  - Reason for discontinuing
- Modification
  - Dose
  - Route
  - Format
  - Frequency
- Patient's views on medication prescribed
  - Format
  - Labelling e.g. font,language,braille
  - Equipment - e.g. mediset box
  - Collection

Figure 19 Referral

Referral
- Demographic data
- Diabetes care by
- Potential services and referees
- Referred to:
- Referred from:
- Date
  - Date referral sent
  - Date referral received
  - Date of appointment
- Requirements for appointment
  - Ambulance
  - Interpreter
  - Advocate
  - Long appointment
  - Other
- New patient?
- Past Medical History
- Patient information
  - Diabetes type
  - Date of diabetes diagnosis
  - Reason for referral
  - History
  - Clinical observations
  - key self management issues
  - Critical issues from domains
- Medication
  - Prescribing
- Investigations

Figure 20 New Issues

New Issues
- Non-Clinical
  - Social
  - Emotional
  - Behavioural
  - Cognitive
    - Knowledge
    - Beliefs
    - Ability
- Clinical
  - New symptom
  - New complication
    - Eye
    - Renal
    - Cardiovascular
    - Foot
    - Skin
    - Infection
    - Hypoglycaemic episode
    - Hyperglycaemic episode
    - Other
  - New procedure
  - New diagnosis
  - Hospital Admission
- Review of domains

Figure 21 Specific Education

Specific Education (knowledge/ Skills/ Attitudes To Enable Self Management)

- Structured Education knowledge, skills, attitudes
  - Education requirements reviewed
  - Areas where further education is required
  - Structured education programme offered - date
  - Structured education programme refused - date
  - Previously completed structured education programme - date
  - Currently involved in structured education programme
    - Type
      - Group on off
      - Group on going
      - one to one
    - Programme name
    - other details

- Information /knowledge (for each media used and date)
  - What is diabetes - explanation
  - Blood sugar monitoring
    - Technique
    - Recording results
    - Action to be taken
  - Oral medication
    - Preparation and dosage
    - Mode of action
    - Possible side effects
  - Self care during minor illness
    - What to do
    - Sick day rules
    - How to contact services
  - Hyperglycaemia
    - Causes
    - Symptoms and signs
    - Complications
    - Treatment
    - Prevention
  - Alcohol
  - Smoking
  - Recreational drug use
  - Sports
  - Exercise/activity
  - Holidays
    - Diet
    - Travelling with medication and equipment
    - Dealing with time differences
  - Work
    - Coping with shift work
  - Religious festivals
    - Diet
    - Fasting
    - Taking medication
  - Self help groups and voluntary organisations
  - Foot care
  - Driving and DVLA issues
  - Insurance issues
    - Life insurance
    - Health insurance
    - Travel insurance
  - Pre-conception and pregnancy
  - Benefits
  - Organisation of local care including Annual review /care planning

Figure 22 Adjustment

- Accepts Diagnosis (beliefs 1)
  - No denial with family and friends
  - Clear about cause
  - Accepts label (no denial)
  - No misattributed symptom
  - Identifies with appropriate symptom

- Understands Implications (beliefs 2)
  - Realistic about treatment options
  - Realistic about impact on life
    - Need for self management
    - Losses
  - Understands risks to future health
  - Perceived need for more information
  - Realistic time course

- Excessively restricted by condition

- Emotional well being (anxiety/depression vs. optimism)
  - Barrier to self management
    - Anxious avoidance of Self Management
    - Phobic avoidance (e.g. hypo's)
    - Depressed mood
  - Reducing quality of life

- Social factors (2)
  - Has health beliefs disrupted by social contacts
  - Evidence of good examples to motivate
  - Disrupts daily self management
  - Support available
  - Dependant on others to self manage (carer analysis)

- Past experiences (a good/neutral influence) (Behaviour 2)
  - Life evenly disrupt self management
  - Negative outcomes from previous interventions
  - Low satisfaction with service (low trust)
  - State of "readiness" to self manage

Business Process Modelling Notation: A technical LSP facing view.

The LSP requires sufficiently detailed information to develop a system that supports the processes of diabetes care. Discussions with the Connecting for Health Design Authority and the LSP suggested that this could best be done using a process mapping technique, and Business Process Modelling Notation. Each scenario was examined to identify in detail the individual processes performed by patients, health care professionals and the "system" and the interactions between these. These were used as the substrate/content of the Business Process Modelling Notation to develop detailed process maps. Business Process Modelling Notation (BPMN) was selected as a technique for this as it provides the necessary content needed by LSP's, whilst being more easily understandable by "lay people" than alternative techniques such as Riva. BPMN is a graphical notation that depicts the steps in a business process. It does not imply workflow or linearity, but depicts flows of actions, events and triggers, which come together as processes. It provides a notation that is readily understandable by all users, from the business analysts that create the initial drafts of the processes, to the technical developers responsible for implementing the technology that will perform those processes, and to the "lay person" who will manage and monitor those processes. Thus, BPMN creates a standardized bridge between the LSP, CfH and the diabetes community. Whilst the BPMN was developed primarily for the LSP, to inform system development, it is a method that is amenable to understanding to people without any specialist knowledge of it, and so clinicians are able to read and check the processes described.

It uses a concept of "swim lanes" to represent participants in a system. The DOaS diabetes BPMN has swim lanes for the patient (and/or carer), the clinician and the clinical system. Each lane shows the behaviour of the participant at any point in the process. It also has a joint swim lane shared by the patient (and/or carer) and the clinician. These could include for example patient, clinician and the clinical IT system. These swim lanes The BPMN developed in DOaS diabetes uses functional hierarchies of processes and sub-processes to reflect different levels of granularity of detail, through its ability to allow the user to "drill down" from any level to the next level of detail. This means that complex processes can be broken down into sub-processes containing further detail, so combining the need for a readable top level view and the provision of sufficient detail. Some common sub-processes were identified which are used by several other processes. For example each planning process. This also enables guidelines and algorithms to be linked to any point in the care process. The models take account of, but do not model in detail, the clinical guidance included in the Diabetes National Service Framework and relevant NIHCE guidelines.

Data Items and Processes

The Business Process Modelling Notation and associated data items provides the structure and content to the electronic health record. The LSP needs data requirements at a level which describes where the data is generated and where it is used. For each process model, every system process was examined in detail, to define and specify for that process:

- What data is needed?
- What data should be displayed?
- What data should be recorded?

This is presented as a spread sheet with a sheet for each process model, each sheet detailing the data requirements for each system process in that model.

Data may be required or generated by more than one process, and if this is the case will appear multiple times on the spreadsheet. In addition here is some data that is generic, rather than relating to a specific process. This includes:

- Demographic data
- Social data
- Educational data
- Adjustment data
- Self management data

The Business Process Modelling Notation and associated data items provides the structure and content to the electronic health record. This also acts as a commentary on the OBS, by describing system requirements in detail.

Business Process Modelling Notation Examples

The following is an example of a set of Business Process Modelling Notation diagrams for a Care Planning scenario. Although developed for the diabetes electronic health record, some of the models 'Plan aspect of care', 'Explore aspect of care' and 'Plan medication' are generic and are likely to be applicable to any kind of chronic care, and in the case of 'Plan medication' any authorisation of medication for any purpose. It should be noted that the term 'care plan' refers to all the care activities planned for a patient, not just those focused on diabetes. It was not practical within the time constraints of the project to use BPMN to model the processes of the whole of diabetes.

Detailed illustrative examples are given below showing BPMN diagrams which have been derived from the scenarios/diabetic map/workshops. They are:
- Prescribing
- The Review & Plan Diabetic Care process hierarchy
- The Diagnose diabetes & Plan Initial Care hierarchy is as follows
-

The examples illustrate the method used and level of detail required to describe the diabetic care processes in order to provide logical content for the diabetic health record. We have discussed with the North East LSP – Accenture – who found this method of documenting the care processes to be very helpful and found that it reduced the ambiguity normally associated with other less well defined techniques. They have recommended that others adopt the notation. In addition to the scenarios shown in the BPMN diagrams, the rest of the scenarios are included showing their transformation from the situations into scenarios and their functional groupings (see appendix 10). It is assumed these will be modelled in the same way by the LSP/CfH.

It must again be emphasised that the BPMN is not intended to dictate workflows but only the processes that need to occur to deliver that aspect care. The workflow and "how it's done" is part of the localisation of care process that occurs when any health community delivers care – being informed by local service configuration. The "how we do it here" principle.

Modelled Scenarios

Below are the modelled scenarios. The first two (prescribing, review and plan care) show how the initial situations have been transformed from situation->scenario->BPMN. The third and fourth show the BPMN relating to corresponding scenarios which are located in our attached appendices.

Prescribing
1. Start new or change medication
    1.1. Discuss proposed prescribing options with patient
    1.2. Record patients input and preferences into prescribing option
    1.3. Prescribing information and Patient preferences (existing/new) displayed
    1.4. Record prescribing changes

The Review & Plan Diabetic Care process hierarchy:
1. Top level review and plan diabetic care process
2. Provide history of current care plan
3. Clinician examines patient
4. Agree concerns & needs
5. Agree next care plan
    5.1. Re-plan removal of barriers to care
    5.2. Re-plan aspect of care
    5.3. Explore option for care aspect
    5.4. Re-plan lifestyle
    5.5. Re-plan medication
    5.6. Re-plan self care
    5.7. Re-plan management of emergencies & complications

The Diagnose diabetes & Plan Initial Care hierarchy is as follows:
1. Top level diagnosis and plan initial care
    1.1. Take diabetes-related history
    1.2. Clinician examines patient
    1.3. Confirm / exclude diabetes diagnosis
    1.4. Agree initial concerns & needs
    1.5. Agree initial diabetic care plan
    1.6. Plan removal of barriers to care
    1.7. Plan aspect of care
    1.8. Explore option for care aspect
        1.8.1. Plan lifestyle
        1.8.2. Plan medication
        1.8.3. lan self care1
        1.8.4. Plan management of emergencies & complications

Moving Home and Record Transfer
1. Move House
2. GP and patient review record

Example modelled scenario – prescribing

Issue no	Situation	Good Outcome	Information needed by situation & who for(if given: patient, family, healthcare worker, service)	Information created by situation
6	New prescription (Doctor wants to start a new medication)	Patient involved in decision about medication. Reasons for change explained and patient understands	Previous adverse reactions Current medications (non-diabetic) Doctor should know all medications all the time Reasons for all medications Possible side effects	What new prescription is given Advice given to patient regarding instructions / timing / tests needed / S/E Whose responsibility it is to follow up on this
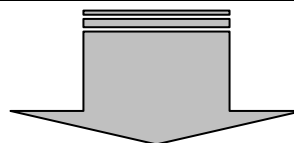
Tranformation

Issue No.	Scenario	Activity	Goal	Patient Behaviour	Clinician Behaviour	System Behaviour	Benefits
6	Start new medication	Prescribing	Patient involved in decision making	• Reports previous adverse reactions. • Confirms current prescribed medication and reports non-prescribed medication • Honestly expresses views therapeutic/medication options • Jointly makes decision	• Discusses medication options with patient • Records new previous adverse reactions/medication • Records reason for prescription • Goes through patient leaflet with patient	Displays information: • Communications difficulties • Language • Current and previous medication • Previous adverse effects • Allergies • Contraindications and interactions with current medication • Previously stated medication preferences Displays knowledge: • Professional education resources available • Local out of hours service – contact numbers • Prescribing/drug information Records: • Medication preferences • Patient's decision regarding medication • Patient's concerns re new medication Prompts: to ask how things are with new medication at next consultation ("you started drug x on 12/2/2006….") • Prints: drug information sheets	• Patient more likely to accept medication • Less waste of unused medication • Safer prescribing

Start new medication or change medication (modelled scenario)

Patient Behaviour

Patient input into decision [+]

Patient prescribing preferences recorded

E.g. fear of medication

Patient information leaflet

Clinical Behaviour

Change medication

Consultation

Review existing medication

Yes

Discuss proposed Diabetic Prescribing options [+]

No

System Behaviour

Medication review

Prescribing information [+]

Record prescribing change [+]

Update patient summary

Patient Behaviour

Patient input into decision

Check patient understanding

Clinical Behaviour

Discuss proposed change and benefits to diabetic medication

Explains leaflet on new medication

System behaviour

Record reason for medication change

Issue prescription

Prints leaflet

Diabetes	author:	Dr Mark Smith	created:	30/10/2005 09:02:13	
	version:	1.0	modified:	25/11/2005 16:14:20	© 2003-2005
Discuss proposed Diabetic Prescribing options (1)	status:	created			**BPMN** powered by
	Prescribe.vsd				itp commerce

55

Patient Behaviour

Patient input into prescribing decision

Honest expression of views on medication options

Jointly makes decision

Discuss proposed prescribing options

Diabetes		author:		created:	30/10/2005 09:02:13	
		version:	1.0	modified:	25/11/2005 16:14:20	
Patient input into decision (1)		status:	created			
		Drawing in CfH DOaS Diabetes Final 0.7.doc.vsd				

© 2005-2005
BPMN powered by
itp
commerce

System behaviour

Diabetic Prescribing Information

- Display patient preferences
- Allergies
- Hierarchy of diabetic medication choices
- Current medication Previous medication attributed to event/ illness and reason discontinued
- Display of diabetic drug information, side effects, contraindications, interactions
- Dosage advice

System application formulary

LINK TO PROPOSED PRESCRIBING OPTIONS

Prescribing Resources

- BNF
- NICE
- NPSA
- NSF

Diabetes	author:	Dr Mark Smith	created:	30/10/2005 09:02:13	
Prescribing information (1)	version:	1.0	modified:	25/11/2005 16:14:20	© 2008-2005 BPMN powered by itp commerce
	status:	created			
	Prescribe.vsd				

Patient Behaviour

Confirm date

Clinical Behaviour

Prompt for medication review date

Has date

Prompt patient for date

System behaviour

Record prescribing behaviour

Record patient preferences to request (change/+new diabetic medication)

Add diabetic medicine to patient medication and update

Record any new side effects, interactions

Add information to summary screen (drug, dose, patient preferences, review date)

Diabetes	author:		created:	30/10/2005 09:02:13
	version:	1.0	modified:	25/11/2005 16:14:20
Record prescribing change (1)	status:	created		
	Drawing in CfH DOaS Diabetes Final 0.7.doc.vsd			

© 2008-2005
BPMN powered by
itp commerce

Another Modelled Scenario – this time by Care Planning

Issue no	Situation	Good Outcome	Information needed by situation & who for(if given: patient, family, healthcare worker, service)	Information created by situation
2	To plan the next year of care in an 'annual review'	Calculated risks and chosen 'do-able' targets with an action plan	Have had all risk information before the meeting presented in a simple way for patient. Information about previous years plans and successes & difficulties for staff	Chosen plan and potential barriers that could cause problems When and how it should be followed up email reminder personal follow up by telephone / email another meeting

Issue No.	Scenario	Activity	Goal	Patient Behaviour	Clinician Behaviour	System Behaviour	Benefits

2	Long-term diabetic management	Care planning and carrying out annual review	Agree shared action plan appropriately balancing risks and quality of life factors	Willing to engage in honest dialog about all dimensions. Desire to take increased control of decisions around action plan. Express preferences around mode of follow-up	Discuss risk/benefit trade off of behaviours (e.g. increased dietary control/exercise) and interventions (e.g. move to insulin). Understand and take into account all dimensions of consultation amending these where indicated. Review plan with patient	Present last year's care plan. Present current biomedical data. Present all dimensions of consultation.Present risk scores on rough timeline Lay out behaviours/interventions Display for the patient and clinician how risks are modulated by the above. Facilitate setting up of
						  o Patient reminders
						  o Scheduled telephone call/email
						  o Appointment
						• Print patient plan
							• Patient better able to make informed decision
							• Action plan more realistic
							• Compliance enhanced

DIABETIC CARE TEAM

PATIENT &/OR CARER

SYSTEM

This process could be entered because:
- Encounter triggered by evidence from another provider that suggests diabetes
- Discovery during encounter for other purposes that patient in several diabetes risk groups
- Diabetes symptoms become apparent during encounter for other purposes
- Encounter triggered by patient suspecting he/she has diabetes
- Encounter triggered as part of diabetes, etc, screening programme. This is not routine yet, but being considered by national Screening Committee. However people known to have impaired glucose regulation should be screened for diabetes regularly

Patient <30

Patient has diabetic emergency

Add information to patient record

Add information to patient record

Add information to patient record

Add information to patient record

CLINICIAN

Enter explanation given

It may be that the initial diabetic consultation is completed before patient care is transferred: check

Enter details of the transfer, and why

Enter details of urgent transfer, and why

Enter contact details

CLINICIAN AND PATIENT &/OR CARER

Explain the diabetes diagnosis process

Take diabetes-related history +

Clinician examines patient +

Is patient obviously ill, or under 30? ◇ >30

Transfer patient to care of adult specialist team

Confirm or refute diab diagnosis +

Arrange contact to initiate diabetes management

Agree initial concerns & needs +

If not ill, just under 30, refer within 24 hrs.to adult diabetes team

if DKA or HONK, urgent transfer to Emergency Medicine or Adult Diabetes Team

Source: NSF Supplementary Part 1 page 17

ill

Admit patient as a diabetic emergency

Could be done during same contact that includes all of this process if enough information available to confirm diagnosis of diabetes

Agree initial diabetic care plan +

Enable diabetic care plan

Patient enters diabetes continuing care process

no

PATIENT &/OR CARER

SYSTEM

DIABETIC CARE TEAM

CLINICIAN

CLINICIAN AND PATIENT &/OR CARER

Display details of most recent consultations

Display current problem list

Display history taking template & any current data

'Current data' means data that can reasonably confidently be assumed to still be true now. It cannot therefore be assumed that any existing data is current data. It is displayed to avoid unnecessary duplication of data collection

Display lifestyle data template

Display family history template & existing data

Display special communication needs template & existing data data

Add information to patient record

Add information to patient record

Add information to patient record

Add information to patient record

Enter patient history

Enter lifestyle information updates

Enter family history updates

Enter special communication reqs. updates

Take patient (diabetic) history

Collect lifestyle updates

Collect family history updates

Collect special communication req. updates

With special reference to diabetes symptoms, see NSF Supplementary Part 1 page 6 Box 1

This covers diet, activity (work & leisure), smoking, recreational drug use, achohol consumption, etc

With particular reference to relatives who have or had diabetes

This information may be needed about the patient &/or any carer

Diagnose Diabetes & Plan Initial Care v01	author:		created:	04/12/2005 22:41:57
Take diabetes-related history	version:	1.0	modified:	30/12/2005 15:15:25
	status:	created		
	Diagnose Diabetes & Plan Initial Care v1_0.vsd			

© 2003-2005
BPMN powered by
itp commerce

61

Diagram: "Diagnose Diabetes & Plan Initial Care v01" — Clinician examines patient (1)

Swimlanes (top to bottom):
- PATIENT &/ OR CARER
- DIABETIC CARE TEAM — SYSTEM
- DIABETIC CARE TEAM — CLINICIAN
- CLINICIAN AND PATIENT &/OR CARER

SYSTEM lane:
- Display template for examination findings
- Populate template with any current data
- Display last findings & date alongside
- Display & store BMI

Note: Current data is displayed in order to avoid unnecessary duplication of data collection. Recent data is that existing data that can reasonably be assumed to be still true of the patient.

CLINICIAN lane (Add information to patient record / Enter steps):
- Add information to patient record → Enter blood pressure
- Add information to patient record → Enter weight
- Add information to patient record → Enter waist circumference / WHR
- Add information to patient record → Enter test results
- Add information to patient record → Enter blood samples taken
- Add information to patient record → Enter urine sample taken
- Add information to patient record → Enter result of check
- Add information to patient record → Enter foot examination results
- Add information to patient record → Enter other current signs

CLINICIAN AND PATIENT &/OR CARER lane:
- Take blood pressure
- Weigh patient
- Measure waist circumference / WHR
- Do near-patient blood & urine tests (Note: For ketones & protein in urine, blood glucose)
- Take blood sample for fasting blood glucose
  - Take blood sample for HbA1c analysis
  - Take blood samples for lipids, LFT and U & E
- Take urine sample for sugar, albumen & creatinine
- Check if retinal screening done
- Do foot examination
- Note any other signs (Note: E.g. evidence of DKA, evidence of other neuropathy / skin problems, chest pain, lipidaemia, etc)

Title block:
Diagnose Diabetes & Plan Initial Care v01
Clinician examines patient (1)
author:
version: 1.0
status: created
created: 04/12/2005 22:41:57
modified: 30/12/2005 15:15:25
Diagnose Diabetes & Plan Initial Care v1_0.vsd
© 2004-2005 BPMN powered by itp commerce

62

Swimlanes (Diabetic Care Team):
- PATIENT &/OR CARER
- SYSTEM
- DIABETIC CARE TEAM — CLINICIAN
- CLINICIAN AND PATIENT &/OR CARER

Process elements:

Any sufficiently recent blood glucose results available?

yes

no

Display diagnostic criteria & any blood glucose results

Add information to patient record

Add information to patient record

Add information to patient record

Add information to patient record

Add information to patient record

Record arrangements

Record blood sample taken

Record /transfer result to system

Assess blood glucose results

Record diagnosis & told to patient

Record patient told it's not diabetes

Arrange provision of blood sample

Take blood sample & send to lab

Clinician receives sample results

Clinician tells patient / carer that it's impaired glucose

Clinician tells patient /carer that it's not diabetes

Further test required

Diabetes

Impaired glucose regulation

Not diabetes or impaired glucose tolerance

Diagnosis is diabetes. Return to parent diagram

Treatment of impaired glucose regulation is out of scope

End of story, or clinician investigates non-diabetic causes of signs / symptoms – which is out of scope

Note:
If patient has diabetic signs &/or symptoms, one diagnostic blood glucose result (random / fasting / 2hr oral tolerance) is sufficient.

If patient has no diabetic signs or symptoms, >=2 diagnostic results, each done on a different day, are recommended. If the second result is not diagnostic, the patient should be given a 2hr oral glucose tolerance test.

Source: Diabetes NSF Supplementary Part 1, quoting WHO 1999

Diagnose Diabetes & Plan Initial Care v01	author:		created:	04/12/2005 22:41:57
	version:	1.0	modified:	30/12/2005 15:15:25
Confirm or refute diab diagnosis	status:	created		
	Diagnose Diabetes & Plan Initial Care v1_0.vsd			

63

PATIENT &/OR CARER

DIABETIC CARE TEAM

SYSTEM

Care plan is for all patient issues other than diabetes

The output summarises the history of the current care plan and the information entered in this subprocess itself

Display current care plan

Display diabetic symptoms, signs & test results

Display CHD & other risk information available

Display attitudes & beliefs template

Add information to patient record

Display success factors for self care template

Add information to patient record

Add information to patient record

no

Display carer(s) template & any existing data

Display concerns and needs identified so far

Add information to patient record

Display & print summary of concerns & needs

Add information to patient record

CLINICIAN

Enter educational needs & info. given

Enter attitude to diagnosis & beliefs concerns

Enter self-care ability & motivation concerns

yes

Enter carer(s) concerns & needs updates

Enter prioritised needs & concerns

CLINICIAN AND PATIENT &/OR CARER

Explain the diagnosis, & then what diabetes is

Introduce concept of blood glucose management

Introduce main management options & their rationale

Agree initial educational needs

Discuss patient's knowledge of diabetes & its management

Explore attitude to diagnosis and health beliefs

Agree concerns related to attitude & health beliefs

Explore ability & motivation to self care

Agree any self-care ability & motivation concerns

This covers diet & weight control, activity level, smoking if relevant, monitoring and where relevant medication dosage & concordance

Carer likely to be involved In self-management?

These are in relation to the patient 's needs only

Discuss carer's role

Agree specific carer's needs re patient's needs

Agree priority of concerns

Agree needs for concerns

For both patient & carer(s)

Give output to patient

Must cover emotional, lifestyle, counselling, educational, training, & clinical needs, especially those that mightimpede good self-care

Diagnose Diabetes & Plan Initial Care v01	author:		created:	04/12/2005 22:41:57
	version:	1.0	modified:	30/12/2005 15:15:25
Agree initial concerns & needs (1)	status:	created		
	Diagnose Diabetes & Plan Initial Care v1_0.vsd			

© 2004-2005
BPMN powered by
itp commerce

64

DIABETIC CARE TEAM

PATIENT &/OR CARER

SYSTEM

Plan to clearly discriminate between self-management and professional sections. It includes goals & activities, (including the provision of any future information), and must clearly identify who does what, when and where

Print whole plan for patient / carer → Display whole plan

Add information to patient record

Add information to patient record

CLINICIAN

This includes dealing with any fears, beliefs, attitudes, lack of knowledge and capabilities that are barriers to good self-care,

Covers activity levels (work and leisure), diet, weight & smoking

There may be no medication for someone diagnosed with type 2 diabetes

Covers biochemical self-monitoring (urine & blood), and checking & dealing with incipient emergencies & complications (including when to seek professional help

This includes making any specialist referrals & requesting any services necessary, agreeing professional review schedules, etc,

Enter dates of next review, prior sampling & history recording

Record joint review of plan

CLINICIAN AND PATIENT &/OR CARER

Plan removal of barriers to care [+] → Plan lifestyle → Plan medication [+] → Plan self-care → Plan management of emergencies & complications → Agree dates of next review, prior sampling & history recording → Go thru' whole plan with patient &/or carer

Medication needed? — yes — no

Any current complications or exacerbations? — no — no

These all use the generic planning sub-process 'Plan aspect of care'. Diagramming limitations mean that only 'Plan removal of barriers of care' contains the normal '+' link

This is done to verify that the patient understands the overall plan, and the relationship between its components

This includes agreeing the next diabetic review date, and making sure the lab blood & urine sample results & care plan history are available in time for the next review

Diagnose Diabetes & Plan Initial Care v01	author:		created:	04/12/2005 22:41:57
	version:	1.0	modified:	30/12/2005 15:15:25
Agree initial diabetic care plan (1)	status:	created		
			Diagnose Diabetes & Plan Initial Care v1_0.vsd	

DIABETIC CARE TEAM

PATIENT &/ OR CARER

This is a generic process model that applies to the planning of the following aspects of care:
- removing barriers to care
- lifestylemanagement
- clinical self-management
- managing complications & exacerbations

SYSTEM

Display management options for aspect

Display relevant guideline / pathway

Display agreed prioritised needs for care aspect

Add information to patient record

Display any patient preferences re providers

Display provider directory & waiting times

Add information patient record

Add information to patient record

CLINICIAN

Enter goals for aspect

no

Self-care Activity? yes

Enter updates to care plan

Enter information provided

CLINICIAN AND PATIENT &/OR CARER

Agree any goals for aspect

Select option to explore

Explore option for care aspect +

Specify relevant activity(s) & add them to care plan

Modify any other elements of care plan as agreed

Provide any immediate info. & instructions needed

Another management option to explore? no

Option to be used? yes   no

yes

Thes goals could be to achieve / maintain / avoid something

This may be selected from any relevant guideline / care pathway, or suggested by the clinician / patient / carer

Do we need to log the management options turned down by the patient &/or clinician?

Includes how to do it, it's duration and any repetition, where and when to perform, who / which organisation is to perform it, and any associated training / education activities necessary

Diagnose Diabetes & Plan Initial Care v01	author:		created:	04/12/2005 22:41:57
	version:	1.0	modified:	30/12/2005 15:15:25
Plan aspect of care (1)	status:	created		
			Diagnose Diabetes & Plan Initial Care v1_0.vsd	

© 2001-2005
BPMN powered by
itp commerce

66

Diagram labels and text:

Swimlanes (left side, top to bottom):
- PATIENT &/ OR CARER
- DIABETIC CARE TEAM
  - SYSTEM
  - CLINICIAN
  - CLINICIAN **AND** PATIENT &/OR CARER

Annotations (blue):
- This includes likely outcomes, known side-effects, special precautions, warnings, etc
- This will not be possible for the system unless decision support is enabled
- The modifications will involve modifying &/or replacing &/or rescheduling &/or disposing of other activity(s) in the care plan. These activities may or may not be directed towards diabetes.

Process boxes and labels:
- Option used before, but not in use now
- Display previous use of option, and why ended
- Display knowledge about the option
- Display any interactions with other planned activity(s)
- Display any interaction(s) with patient's state
- Option rejected
- Add information to patient record
- Enter that option rejected & why
- Consider re-use of option
- Re-use of option rejected?
- Discuss net benefit of option in the abstract
- Disbenefit enough to rule option out?
- Consider interactions with other ongoing / planned activities
- Interaction serious enough to rule option out?
- Consider interaction with patient's state
- Interaction serious enough to rule option out?
- Interaction implies mods. to other ongoing / planned activities?
- Agree modification to other activitiy(s)
- Display patient / carer preferences For options
- Discuss patient / carer preferences for options
- Ensure patient & / or carer understands option
- Patient / carer agrees to option?
- Option to be used

Flow labels: no, yes (multiple)

Title block:

Diagnose Diabetes & Plan Initial Care v01	author:		created:	04/12/2005 22:41:57	
	version:	1.0	modified:	30/12/2005 15:15:25	BPMN powered by itp commerce
Explore option for care aspect (1)	status:	created			
	Diagnose Diabetes & Plan Initial Care v1_0.vsd				

67

Swimlanes (top to bottom):

- **PATIENT &/OR CARER**
- **DIABETIC CARE TEAM**
  - **SYSTEM**
  - **CLINICIAN**
- **CLINICIAN AND PATIENT &/OR CARER**

SYSTEM lane:
- Display allergies & adverse drug reactions
- Display patient medication preferences
- Display current & past medication & why discontinued
- Display medication-related needs
- Displays drug information
- Displays drugs as GP / user preferences
- Displays patient friendly view of prescribing options
- Add information to patient record
- No current diabetic medication

CLINICIAN lane:
- Selects diabetes medication as topic
- Selects prescribing options
- Select patient friendly view of prescribing options
- Enter new / stopped / modified medication

CLINICIAN AND PATIENT &/OR CARER lane:
- Discuss needs for medication
- Discuss benefits & trade offs of medication options
- Check patient / carer understanding of options
- Agree prescribing option(s) to use & those to stop / modify

Annotations:
- Includes agreement of patient / carer with medication updates, and reason for new / stopped / modified medication(s)
- Modification only caters for way an existing medication should be taken. Any other change involves stopping one medication & starting another

Diagnose Diabetes & Plan Initial Care v01	author:		created:	04/12/2005 22:41:57	
	version:	1.0	modified:	30/12/2005 15:15:25	BPMN powered by itp commerce
Plan medication (1)	status:	created			
	Diagnose Diabetes & Plan Initial Care v1_0.vsd				

68

DIABETIC CARE TEAM

PATIENT &/OR CARER

Patient triggered   Review due   Clinician triggered

For patient with existing
diabetes care plan who (or whose
carers) are happy to use the computer

Extended
consultation starts

Provide history of
current care plan
+

In this case the history is being provided before the review with the
clinician starts, and is probably being performed by the patient or carer.
It could take place where the patient lives, or anywhere else with access
to the system

SYSTEM

This diagram does not consider
which system this is, e.g.
whether it is My HealthSpace
or nor, or how the patient's
identity is confirmed for the
system. It also assumes that
whatever is entered by the
patient / carer is available to
the clinician(s) involved in
planning diabetic care

For more detail on system behaviour during the diabetic review consultation with
the clinician, please consult the sub-process diagrams. To do this in Visio, click on
the + signs in the processes below

CLINICIAN

CLINICIAN AND PATIENT &/OR CARER

In this case the history is
being provided immediately
before or as part of the
review, probably with
professional assistance.

Provide history of
current care plan
+

Clicking on this will not go to the
expanded Provide history of
current care plan, as it can only
be attached to a single parent.
Click on the instance at the top
of the page instead

Includes verifying their
understanding of it

Go thru review
purpose &
content with
patient &/or carer

Clinician
examines patient
+

Agree concerns &
needs
+

Agree next care
plan
+

Includes preparing & despatching
any prescriptions, making any
referrals & service requests,
sending samples for analysis,

Enable care plan
elements

End of care
planning

This may not be the end
of the consultation
concerned – there may
be immediate care to
provide & other problems
to deal with

Review & Plan Diabetic Care	author:		created:	22/11/2005 13:19:31	
	version:	1.0	modified:	05/01/2006 23:42:13	© 2000-2005
Top Level	status:	created			BPMN powered by
			Review & Plan Diabetes Care v1_0.vsd		itp commerce

69

This model shows an order in which the various facets of the history are collected. If this is felt inappropriate, it can be changed or more or less relaxed by remodelling using the BPMN parallel forking gateway. All tasks should be performed, even if only to say 'nothing to repot'

Some patients will enter the data themselves, in which case it can be done anywhere that with access to the system and before the review with the clinician takes place. Others may require professional assistance, so it is likely be done on the clinician's premises, maybe as part of the clinical review consultation. Many – probably most – patients / carers are likely to require training before they can provide it on their own.

PROVIDE HISTORY OF CURRENT CARE PLAN

PATIENT &/OR CARER

For each activity whether it was done as planned or not, any difficulties experienced, and if not done as planned, why. Should cover all/any of diet, activity, weight control, smoking, monitoring, medication, education, training & counselling

For each goal whether it was achieved or not, reasons why, any difficulties experienced, and for non-achieved goals whether they are now seem realistic

I.e. any DKA, HONK, hypoglycemia and hyperglycaemia events, foot, sight, kidney, mood, tiredness symptoms, etc.

E.g. social aspects (including family & carer), diet, work, leisure activity

For good or ill, and views as to why

Include changes in mood, motivation & beliefs, esp. to self-management, experience of services used,

E.g. about equipment, information, training, understanding, additional support and their priorities

- Consider the contents of the previous consultation
- Were activities done as planned?
- Were any goals present achieved?
- Any new/changed symptoms or emergencies?
- Any significant life events occurred?
- What diabetes impact on quality of life?
- Any change in attitude to diabetic treatment & its outcome?
- Any current concerns &/or needs?

PATIENT / CARER / CARE PROFESSIONAL

- Enter information about activities
- Enter information about goals
- Enter info about any symptoms / emergencies
- Enter information about life events
- Enter information about impact on quality of life
- Enter information about attitudes
- Enter information about concerns and needs

SYSTEM

- Display previous diabetes-related consultation details
- Display current care plan and goals
- Display template for new/changed symptoms & emergencies
- Display template for non-diabetes-related life events
- Display template for impact on quality of life
- Display template for attitudes to diabetes treatment
- Display template for concerns & needs

- Add information to patient record
- Add information to patient record
- Add information to patient record
- Add information to patient record
- Add information to patient record
- Add information to patient record
- Add information to patient record

This diagram does not consider which system this is, e.g. whether it is the patient's own system, My HealthSpace or a clinician's system, or how the patient's identity is confirmed for the system. It also assumes that whatever information entered is available to the diabetic care planning clinician

Review & Plan Diabetic Care	author:		created:	22/11/2005 13:19:31	
Provide history of current care plan (1)	version: status:	1.0 created	modified:	05/01/2006 23:42:13	© 2006-2006 BPMN powered by itp commerce
	Review & Plan Diabetes Care v1_0.vsd				

70

Swimlanes (left labels):
- PATIENT &/OR CARER
- DIABETIC CARE TEAM
  - SYSTEM
  - CLINICIAN
  - CLINICIAN AND PATIENT &/OR CARER

SYSTEM lane:
- Display info re previous diabetic review
- Display current care plan and clinical outcomes
- Display biochemical data, emergencies & trends
- Display CHD & other risk information available
- Display barriers to & difficulties with current plan
- Display impact on quality of life
- Display carer template & existing concerns & needs
- Display & print summary of current care plan concerns & needs
- Add information to patient record (×6)

Annotations (blue):
- These displays are derived from the history of the current care plan entered by the patient / carer, and the results of the patient examination conducted by the clinician
- Carer involved? yes / no
- The output summarises the history of the current care plan and the information entered in this subprocess itself

CLINICIAN lane:
- Enter reason for diabetic review
- Enter agreed conclusions on outcome of plan
- Enter agreed successes & concerns re plan & goals
- Enter agreed successes & concerns re QoL & attitudes
- Enter updates to carer's needs
- Enter prioritised patient's concerns & needs

CLINICIAN AND PATIENT &/OR CARER lane:
- Establish reason for non-scheduled diabetic review
- Refresh on what happened at last diabetic review
- Discuss clinical outcomes of current plan
- Discuss successes & concerns about current plan
- Discuss impact on quality of life & attitudes
- Discuss carer's concerns → Agree carer's needs
- Agree priority of concerns → Agree needs for concerns
- Give output to patient

Bottom annotations (blue):
- Includes quality of glycaemic control, and any new / changed or ongoing symptoms & signs
- What went well & what was difficult to do and why, Were any goals realistic, Any motivation & attitude concerns?
- How did the plan and its outcomes affect the patient's quality of life & attitude – good & bad
- These are in relation to the patient 's needs only
- For patient & any carer(s)
- Must cover emotional, lifestyle, counselling, educational, training, & clinical needs, especially those impeding good self-care

Review & Plan Diabetic Care	author:		created:	22/11/2005 13:19:31	
Agree concerns & needs (1)	version:	1.0	modified:	05/01/2006 23:42:13	BPMN powered by
	status:	created			itp commerce
			Review & Plan Diabetes Care v1_0.vsd		©2000-2005

71

DIABETIC CARE TEAM

PATIENT &/ OR CARER

SYSTEM

Display template for examination findings

Current data is displayed in order to avoid unnecessary duplication of data collection. It may come from any care provider treating the patient. Recent data is that existing data that can reasonably be assumed to be still true of the patient.

Populate template with any usable recent data

Display last findings & date alongside

Display & store BMI

Current blood & urine results available

Ideally all test results for scheduled reviews should be available at the review consultation, the samples having been taken sufficiently in advance. This will probably not be possible for ad-hoc reviews requested explicitly by the patient, carer or clinician.

Add information to patient record

Add information to patient record

No current blood & urine results

Add information to patient record

Add information to patient record

Add information to patient record

Add information to patient record

Add information to patient record

CLINICIAN

Enter blood pressure

Enter weight

Enter blood samples taken

Enter urine sample taken

Enter screening check result

Enter foot examination results

Enter other current signs

CLINICIAN AND PATIENT &/ OR CARER

Take blood pressure

Weigh patient

Take blood samples for lipids, LFT and U & E

Take blood sample for fasting blood glucose

Take urine sample for sugar, albumen & creatinine

Check retinal screening done

Do foot examination

Note any other signs

Take blood sample for HbA1c analysis

E.g. evidence of DKA, evidence of other neuropathy / skin problems, chest pain, lipidaemia, etc

Review & Plan Diabetic Care	author:		created:	22/11/2005 13:19:31	
	version:	1.0	modified:	05/01/2006 23:42:13	
Clinician examines patient (1)	status:	created			
			Review & Plan Diabetes Care v1_0.vsd		

© 2008-2005 BPMN powered by itp commerce

72

DIABETIC CARE TEAM

PATIENT &/OR CARER

SYSTEM

Plan to clearly discriminate between self-management and professional sections. It includes goals & activities, (including the provision of any future information), and must clearly identify who does what, when and where

Print whole plan for patient / carer → Display whole plan

Add information to patient record

Add information to patient record

CLINICIAN

This includes dealing with any fears, beliefs, attitudes, lack of knowledge and capabilities that are barriers to good self-care,

Covers activity levels (work and leisure), diet, weight & smoking The goals may be the same as last time

This includes starting a patient on his / her first diabetic-related medication

Covers biochemical self-monitoring (urine & blood), and checking for incipient emergencies & complications

This includes making any specialist referrals necessary, and providing / arranging education & training in how to handle emergencies (including when to seek professional help)

Enter dates of next review, prior sampling & history recording

Record joint review of plan

CLINICIAN AND PATIENT &/OR CARER

Replan removal of barriers to care [+] → Replan lifestyle → (Re)Plan medication [+] → Replan self-care → Replan management of emergencies & complications → Agree dates of next review, prior sampling & history recording → Go thru' whole plan with patient &/or carer

These all use the generic planning sub-process 'Replan aspect of care'. Diagramming limitations mean that only 'Plan removal of barriers of care' contains the normal '+' link

Medication needed? — yes / no

Any current complications or exacerbations? — yes / no

This includes agreeing the next diabetic review date, and making sure the lab blood & urine sample results & care plan history are available in time for the next review

This is done to verify that the patient understands the overall plan, and the relationship between its components

Review & Plan Diabetic Care	author:		created:	22/11/2005 13:19:31
Agree next care plan (1)	version:	1.0	modified:	05/01/2006 23:42:13
	status:	created		
	Review & Plan Diabetes Care v1_0.vsd			

© 2008-2005 BPMN powered by itp commerce

73

Swimlane: DIABETIC CARE TEAM

- PATIENT &/OR CARER
- SYSTEM
- CLINICIAN
- CLINICIAN AND PATIENT &/OR CARER

SYSTEM lane:
- Display allergies & adverse drug reactions
- Display patient medication preferences
- Display current & past medication & why discontinued
- No current diabetic medication
- Display medication-related needs
- Displays drug information
- Displays drugs as GP / user preferences
- Displays patient friendly view of prescribing options
- Add information to patient record

CLINICIAN lane:
- Selects diabetes medication as topic
- Selects prescribing options
- Select patient friendly view of prescribing options
- Enter new / stopped / modified medication
- Includes agreement of patient / carer with medication updates, and reason for new / stopped / modified medication(s)

CLINICIAN AND PATIENT &/OR CARER lane:
- Discuss needs for medication
- Discuss benefits & trade offs of medication options
- Check patient / carer understanding of options
- Agree prescribing option(s) to use & those to stop / modify
- Modification only caters for way an existing medication should be taken. Any other change involves stopping one medication & starting another

DIABETIC CARE TEAM

PATIENT &/ OR CARER

This is a generic process model that applies to the planning of the following aspects of care:
- removing barriers to care
- lifestylemanagement
- clinical self-management
- managing complications & exacerbations
and possibly medication.

SYSTEM

- Display management options for aspect
- Display relevant guideline / pathway
- Display agreed prioritised needs for care aspect
- Any current care plan elements for diabetes?
- yes
- Display current care plan & goals
- Add information to patient record
- Add information to patient record
- Add information to patient record
- Display any patient preferences re providers
- Display provider directory & waiting times
- no
- Self-care Activity?
- yes
- Add information patient record
- Add information to patient record

CLINICIAN

- Enter continuation of current plan & goals for aspect
- Enter goals for aspect
- Enter updates to existing plan
- Enter updates to care plan
- Enter information provided

CLINICIAN AND PATIENT &/OR CARER

- Agree current plan for aspect OK? — yes / no
- no
- Agree any goals for aspect
- Agree existing plan activities to stop / modify / suspend
- Select option to explore
- Explore option for care aspect [+]
- Option to be used? — yes
- Specify relevant activity(s) & add them to care plan
- Modify any other elements of care plan as agreed
- Provide any immediate info. & instructions needed
- Another management option to explore? — no
- no
- yes

Thes goals could be to achieve / maintain / avoid something

The existing plan activities being updated may have already been started, or have yet to start. They may even be unscheduled as yet

This may be selected from any relevant guideline / care pathway, or suggested by the clinician / patient / carer

Do we need to log the management options turned down by the patient &/or clinician

Includes how to do it, it's duration and any repetition, where and when to perform, who / which organisation is to perform it, and any associated training / education activities necessary

This may be as the information itself, or as references to it. It may include the addresses of service providers, contact details, etc and may be produced by the system or provided from stock. It must be in a format suitable for the intended reader, e.g. big print, audio, etc

Review & Plan Diabetic Care	author:		created:	22/11/2005 13:19:31	
	version:	1.0	modified:	05/01/2006 23:42:13	
Replan aspect of care (1)	status:	created			
			Review & Plan Diabetes Care v1_0.vsd		

© 2004-2005 BPMN powered by itp commerce

75

Swimlanes (top to bottom): PATIENT &/ OR CARER · DIABETIC CARE TEAM (containing SYSTEM, CLINICIAN, CLINICIAN **AND** PATIENT &/OR CARER)

PATIENT &/ OR CARER

Patient / carer agrees to option? — yes → Option to be used

SYSTEM

Option used before, but not in use now? — no → Display knowledge about the option

This includes likely outcomes, known side-effects, special precautions, warnings, etc

This will not be possible for the system unless decision support is enabled

Display any interactions with other planned activity(s)

Display any interaction(s) with patient's state

yes → Display previous use of option, and why ended

Option rejected — Add information to patient record

Option rejected — Add information to patient record

Option rejected — Add information to patient record

Option rejected — Add information to patient record

Display patient / carer preferences For options

Option rejected — Add information to patient record

CLINICIAN

Enter that option rejected & why

Enter that option rejected & why

Enter that option rejected & why

Enter that option rejected & why

Interaction implies mods. to other ongoing / planned activities? — no → Display patient / carer preferences For options

Enter that option rejected & why

CLINICIAN AND PATIENT &/OR CARER

Consider re-use of option → Re-use of option rejected? — yes / no

Discuss net benefit of option in the abstract → Disbenefit enough to rule option out? — yes / no

Consider interactions with other ongoing / planned activities → Interaction serious enough to rule option out? — yes / no

Consider interaction with patient's state → Interaction serious enough to rule option out? — yes / no

yes → Agree modification to other activitiy(s) — no

The modifications will involve modifying &/or replacing &/or rescheduling &/or disposing of other activity(s) in the care plan. These activities may or may not be directed towards diabetes.

Discuss patient / carer preferences for options → Ensure patient & / or carer understands option

no (to Patient / carer agrees to option?)

76

PRIMARY CARE

Lane	Content
PATIENT/ CARER	○ → Patient authorises record transfer
OLD GP	GP authorises record transfer
OLD GP SYSTEM	Record sent to new system
NEW GP SYSTEM	Stores old record • Stores appointment details • Displays old record • Stores patient's views in current record
NEW GP	GP enters views
NEW GP & PATIENT/ CARER	GP arranges appointment with patient • Appointment starts • GP checks that record is for patient • Review / update old record [+] • GP elicits patient's views re move & services • Conclude consultation [+] → ◉

Issue 4 - Moving house	author:		created:	14/11/2005 09:04:26
	version:	1.0	modified:	30/12/2005 15:16:03
Issue 4 - Moving House	status:	created		
	Issue 4 - Moving House v1_0.vsd			

© 2003-2005
BPMN powered by
itp commerce

77

Data should include:
- Emergency contact number
- Current treatment
- Special info, e.g. what if hypo at night
- Previous medication
- Adverse reactions
- Personal concerns, e.g. blood sugar control, driving
- Current condition in all five dimensions of care

PRIMARY CARE

NEW SYSTEM
- Old record displayed
- Store corrections & unchanged old data in current record
- Display local diabetic services & old care plan
- Print details of local srevices
- Store (changed) care plan as current plan
- Print current record (incl. current care plan)

NEW GP
- Corrects old record as necessary
- Enter any revisions to care plan

PATIENT/ CARER

GP & PATIENT/ CARER
- Verify contents of old record
- Introduce patient &/or carer to local diabetic services
- Give local service details to patient / carer
- Agree any changes to care plan to fit local services
- Give printout to patient / carer

Issue 4 - Moving house	author:		created:	14/11/2005 09:04:26	
	version:	1.0	modified:	30/12/2005 15:16:03	
GP & patient review old record (1)	status:	created			
			Issue 4 - Moving House v1_0.vsd		

© 2003-2005
BPMN powered by
itp commerce

78

Appendix 1: Further detail on scope of the project

With reference to the National DOaS Terms of Reference document, the following are out of scope:

- Screening is out of scope, although there will be liaison with the National Screening Committee, who will be represented on the external reference group.
- The integrated care pathway work. This is a separate project which will be led nationally by Dr Sue Roberts.
- A national community of practice sustained and sustainable via community web space. There will be an external reference group led by Dr Sue Roberts, who will lead the national sharing and communications. However the sustainability of this group following this project is not within the scope of this project.
- National Care Pathway templates both approved by NIHCE and modified for local implementation with guidance to facilitate localisation of care pathways. The pathway will be made available to NIHCE, for submission through the "big 50" committee, but approval will not be expected during the timescale of this project.
- A clear specification for Common User Interface;
- A specification of the NPfIT contribution to safety;
- A definition of Research and Design needs and opportunities; and
- A definition of new models of clinical practice and care enabled by NPfIT for recommendation or further piloting and evaluation by NPfIT eHealth transformation

Appendix 2: The Project Board

Name	Title	Role
Dr Stephen Singleton	Medical Director, NTW SHA	Chair / Executive
Dr Mark Smith	NPFIT Clinical Lead, NECluster/NTW SHA & General Practitioner	Senior User
Kevin Allan	Chief Information Officer, NTW SHA	Senior Supplier
Clive Griffith	Cancer Services Collaborative national clinical lead for breast cancer	Senior User
Dr Sue Roberts	Dept of Health National Clinical Director for Diabetes	Senior User

Appendix 3: The Action Team

Dr Mark Smith GP Clinical Lead NPfIT North East Cluster & Northumberland, Tyne Wear Strategic Health Authority	Action team lead and Chair representing SHA
Dr Sue Roberts National Clinical Director for Diabetes	Lead Clinician
Dr Gail Boynton DOAS Diabetes Project Manager.	Project management
Lisa Eisan/Adam Bell SHA NPfIT Project Support Officer	Providing administrative support and organisational skills. Arranging meetings, events and venues.
Yvonne Storey SHA Head of Communications for NPfIT	Ensuring that the public, NHS staff and any other specified groups are appropriately informed about the project. Providing a channel for answering public queries about the project. Providing input into patient information arising from the project.
Jill Remnant SHA Head of Patient, Carer and Public Involvement	Representing patients, carers and public. Ensuring that the views of patients, carers, community and voluntary groups are adequately taken into account. Facilitating this at events.
Peter James Organisational Facilitator	Facilitating at stakeholder events. Providing input into the organisation of stakeholder events.
Professor Colin Bradshaw	GP with special interest in diabetes

Other attendees to action team meetings included:
Anne Cooper, National Diabetes Support Team Regional Manager
Bev Bookless, National Diabetes Support Team National Programme Director
Linda Wood, Diabetes UK Regional Manager
Dr Niel Soulsby, GP
Sarah Cherrill, representing local diabetes networks
Simon Stone, Accenture
Ian Herbert, Independent Business Analyst

Appendix 4: Definitions

Pathways, maps and care plans, and the relationship between them	
Care Pathways NPfIT - (Updated March 2005)	Definitions are proposed …. To reduce confusion created by the same terms being used in different ways (homonyms) and the same concept having multiple names (synonyms).
Care Pathways NPfIT - (Updated March 2005) author Tim Benson, programme director Tim Jones	**Care Pathway** maps out a pre-defined set of activities and/or choices within a specified scope, which may be applied to one or more issues or problems. It defines what should be recorded about the care delivered in such a way that variance between proposed and actual care can be audited and local practice refined accordingly. A care pathway may specify the goal and/or expected outcome, the data required, decisions and choices that may be appropriate (with supporting arguments) and actions to be carried out, when and by whom. A care pathway may reference guidance or protocols. In this paper the term "care plan" is not used. This is because the term is used in different contexts to mean different things and also because the definition of care pathway is sufficiently broad to cover most uses of the term.

Clinical Lock-in 5; Structured planning of care	**Care pathway:**
	• A care pathway maps out a consistent set of decisions and activities relating to one or more issues or problems. The aim is to define a structured process of care in order to achieve specified goals. Care pathways present current best practices supported by an evidence base. A care pathway enables the variance between proposed and actual care to be audited, and best practice to be refined accordingly.
	• Includes template and in-use (see later)
	• Templates have a tightly controlled authoring and versioning process
	
	Care plan:
	• Care Plan
	  – When a care plan template is applied/personalised for a patient it leads to a group of planned activities - a care plan; which becomes a subset of the care programme.
	  – It may be designed from scratch with a patient for that patient only, or refined from an existing care plan template.
	• Care Plan Template
	  – The combination of a need, goal and a set of activities including decision making - a (possibly) reusable chunk of a pathway. Often locally defined to agreed policy, may be personally defined but reusable.

	– Examples: Pre-operative preparation, broken neck of femur, patient does not speak English
	
	Care component:
	• Atomic concepts used to construct pathways and care plans
	    – Goals
	    – Needs
	    – Activities/Interventions
	    – Decisions/choices between options
	• Can be stored or created 'on-the-fly'

Muir Gray report to Knowledge Support and Decision Support meeting may 2004	• *Pathways* are forms which set out the protocol or guideline if there is no localised protocol, for clinicians to follow to minimise the risk of errors of omission or commission, and to ensure that the necessary data are collected for audit. Pathways, sometimes called care pathways, describe the patient journey, and the term patient journey is sometimes used as a synonym for pathway. They may also be called integrated care pathways if they cut across primary and secondary care. Pathways may be made available in either paper or electronic form.
Care Pathways NPfIT - author Tim Benson, programme director Tim Jones (Updated March 2005)	(In 4 Architecture -> 4.1 Integrating Patient Records and Knowledge) A care pathway *in use* is logically part of an identified patient record, while a care pathway *template* is not linked to any individual patient - it is general clinical knowledge. This implies two logical repositories – patient care record and knowledge library (Smith's Internet). The user interface provides views into these repositories.

Appendix 5: Guidelines in diabetes care

The following is a summary of guidelines taken into account during this project.

Diabetes guidelines

World Health Organisation (1999) Definition, Diagnosis and Classification of Diabetes Mellitus and its Complications

NIHCE guidelines

**Clinical guidelines for type 2 diabetes – management of blood glucose
1st September 2002. 235 pages**
This guideline is aimed at all health care professionals involved in the management of Type 2 diabetes in primary and secondary care, irrespective of location of care facilities. The guideline is not primarily aimed at health care professionals involved in the management of blood glucose working in the tertiary care sector, although it may be useful to them. The recommendations are specifically linked to available evidence and are informed by the consensus views of the guideline development group. This section of the national guideline deals with the management of blood glucose in adults with diagnosed Type 2 diabetes. It does not address the care of children, nor the identification of undiagnosed diabetes.
http://www.NIHCE.org.uk/pdf/NIHCE_full_blood_glucose.pdf

Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults
28th July 2004
This guideline is concerned only with Type 1 diabetes, a condition that is a pure hormone-deficiency disease. The guidance is divided into three parts, addressing the care of children (people younger than 11 years), the care of young people (older than 11 but younger than 18) and adults (those aged 18 and above). For children and young people the guideline recommends an integrated care package by a multidisciplinary paediatric care team.
http://www.NIHCE.org.uk/pdf/CG015NIHCEguideline.pdf

**Compilation – Endocrine and metabolic review
October 2005**
A compilation of diabetes guidelines and technology appraisals

**Type 2 diabetes: prevention and management of foot problems
28th January 2004**

Type 2 Diabetes is a complex metabolic disorder which is becoming increasingly common in the UK. The serious complications that can arise can have a considerable impact on the individual and also on health services. Serious complications can, however, be delayed, and in some instances even be prevented from occurring, with appropriate and careful management.

http://www.NIHCE.org.uk/pdf/CG010NIHCEguideline.pdf

Inherited Clinical Guideline E management of type 2 diabetes retinopathy - screening and early management

1st February 2002
The key issue in screening for diabetic retinopathy is to identify those people with sight-threatening retinopathy who may require preventative treatment. This guideline is aimed primarily at healthcare professionals providing retinopathy care to people with diagnosed Type 2 diabetes in primary and secondary care.

http://www.NIHCE.org.uk/page.aspx?o=27967

Inherited Clinical Guideline F management of type 2 diabetes - renal disease - prevention and early management
1st February 2002

This guideline on type 2 diabetes is aimed primarily at all healthcare professionals providing renal care to people with diagnosed type 2 diabetes in primary and secondary care. Dependent on the type, stage and severity of the clinical problem, the guideline may also be valuable to those who work in diabetes care in the tertiary sector. The guideline has been developed to advise on the care of adults with type 2 diabetes, but it may also help to inform the care of those with type 1 diabetes. Patient information is given at Appendix C.

http://www.NIHCE.org.uk/page.aspx?o=27964

Inherited Clinical Guideline H management of type 2 diabetes - management of blood pressure and blood lipids

Type 2 Diabetes affects increasing numbers of people in the UK and the burden of serious complications can be considerable for both the individual and the health service. Many aspects of these complications can be limited, and even prevented, with good management of the condition. Steps include monitoring blood lipid levels and blood pressure and providing appropriate therapy.

1st Inherited Clinical Guideline H management of type 2 diabetes - management of blood pressure and blood lipids

1st October 2002
Type 2 Diabetes affects increasing numbers of people in the UK and the burden of serious complications can be considerable for both the individual and the health service. Many aspects of these complications can be limited, and even prevented, with good management of the condition. Steps include monitoring blood lipid levels and blood pressure and providing appropriate therapy.
http://www.NIHCE.org.uk/pdf/NIHCE_INHERITEd_Hv8.pdf

NIHCE Technology Appraisals

Guidance on the Use of Patient Education Models in Diabetes
April 2003 (to be reviewed in February 2006)
http://www.NIHCE.org.uk/pdf/60Patienteducationmodelsfullguidance.pdf
NIHCE has recommended that all people with diabetes should be offered structured education, provided by a trained specialist team of health professionals. NIHCE considers the team should include a diabetes specialist nurse (or a GP practice nurse who has

experience in diabetes) and a dietician (someone who can give specialist advice on diet). Other health professionals should join the team if needed. Education about diabetes should start when people are first told they have the condition and should then become part of their long-term routine care. NIHCE concluded that there was not enough evidence available to make recommendations about specific types of education. But NIHCE does offer the following general advice.

• People with diabetes generally should be taught in groups, although one-to-one teaching should also be available.

• Teaching sessions should use a variety of different methods to help people learn.

• Educational programmes should meet the needs of the broadest possible range of people with diabetes. People from different cultures and ethnic groups, and those who have disabilities or who live in more remote areas, all need to be considered. Sessions could take place either in the community or at a local diabetes centre. The Dose Adjustment for Normal Eating (DAFNE) course may be one suitable education programme for people with type 1 diabetes.

Guidance on the use of continuous subcutaneous insulin infusion for diabetes TA 6th February 2003

Continuous subcutaneous insulin infusion (CSII or 'insulin pump therapy') is recommended as an option for people with type 1 diabetes provided that: multiple-Dose insulin (MDI) therapy, (including, where appropriate, the use of insulin glargine) has failed; and those receiving the treatment have the commitment and competence to use the therapy effectively. CSII therapy should only be initiated by a trained specialist team, and all individuals beginning CSII therapy should be provided with specific training in its use.
http://www.NIHCE.org.uk/pdf/57_Insulin_pumps_fullguidance.pdf

Guidance on the use of glitazones for the treatment of type 2 diabetes TA 27th August 2003

This document updates guidance issued in August 2000 and March 2001, in which NIHCE recommended that people with Type 2 Diabetes who are unable to take metformin and sulphonylurea combination therapy, or whose blood glucose concentration remains high despite an adequate trial of this treatment, may be offered rosiglitazone or pioglitazone combination therapy as an alternative to insulin.
http://www.NIHCE.org.uk/pdf/TA63_Glitazones_Review_Guidance.pdf

Guidance on the use of long-acting insulin analogues for the treatment of diabetes - insulin glargine TA

6th December 2002

Insulin glargine is recommended as a treatment option for people with type 1 diabetes. It is not recommended for routine use for people with type 2 diabetes who require insulin therapy. Insulin glargine treatment should be considered only for those people with type 2 diabetes who require insulin therapy and who fall into one of the following categories: those who require assistance from a carer or a healthcare professional to administer their insulin injections; those whose lifestyle is significantly restricted by frequent hypoglycaemic episodes; those who would otherwise need twice-daily basal insulin injections in combination with oral antidiabetic drugs. Patient information is provided at Appendix C.
http://www.NIHCE.org.uk/pdf/53_Insulin_analogues_full_guidance.pdf

Pancreatic Island Cell Transplantation
22nd October 2003
Guidance from the NIHCE Interventional Procedures Programme. This document addresses the following aspects of pancreatic islet cell transplantation: guidance; the procedure (indications, outline of the procedure, efficacy, safety, and other comments); further information
http://www.NIHCE.org.uk/pdf/ip/IPG013guidance.pdf

NIHCE Technology Appraisals under Development
Diabetes (type 1 and 2) – Inhaled Insulin
Expected date of issue October 2006

Diabetes UK Care Recommendations
(See Diabetes UK website)

Diabetes Services - The NSF Two Years On
Published:
23 March 2005

The Diabetes National Service Framework set out the first ever set of national standards for the treatment of diabetes to raise the quality of NHS services and reduce unacceptable variations between them. This report highlights progress over the two years following the publication of the NSF Delivery Strategy.
Improving Diabetes Services - The NSF Two Years On

National service framework for diabetes: One year on
Published:
08/04/2004

This report describes the progress made in the first year on the NSF for diabetes.
National service framework for diabetes: One year on

National service framework for diabetes: standards
Published:
14/12/2001 (supplementary material published 15 March 2002)

This document sets out twelve new standards and the key interventions necessary to raise the standards of diabetes care.
National service framework for diabetes: standards

National Service Framework for Diabetes: Delivery Strategy
Published:
09/01/2003

This strategy sets out national targets against which local NHS performance on the standards in the National Service Framework for Diabetes can be judged.

National Service Framework for Diabetes: Delivery Strategy

Other Guidelines

Web Content Accessibility Guidelines

http://www.w3.org/TR/1999/WAI-WEBCONTENT-19990505/

RNIB Clear Print Guidelines

http://ndf.copperstream.co.uk/rvi/clearprint.doc

Appendix 7

Level 1:

Picture a map of a country with all the main cities and towns and motorways. These are essential to recognise the country e.g. the names of cities define the human geography of England and a map of England should have London on it.

This is a small scale map e.g. 1:500,000 so will only contain the biggest and most important features.

For an individual it would be particularly useful for getting an overview of their 'journey' – for the services it describes the essential components.

Experts might be able to suggest the best or quickest route – but individuals might decide to go in other ways

Diabetes:

This 1:500,000 map is equivalent to the 'Tadpole' diagram in the Diabetes NSF
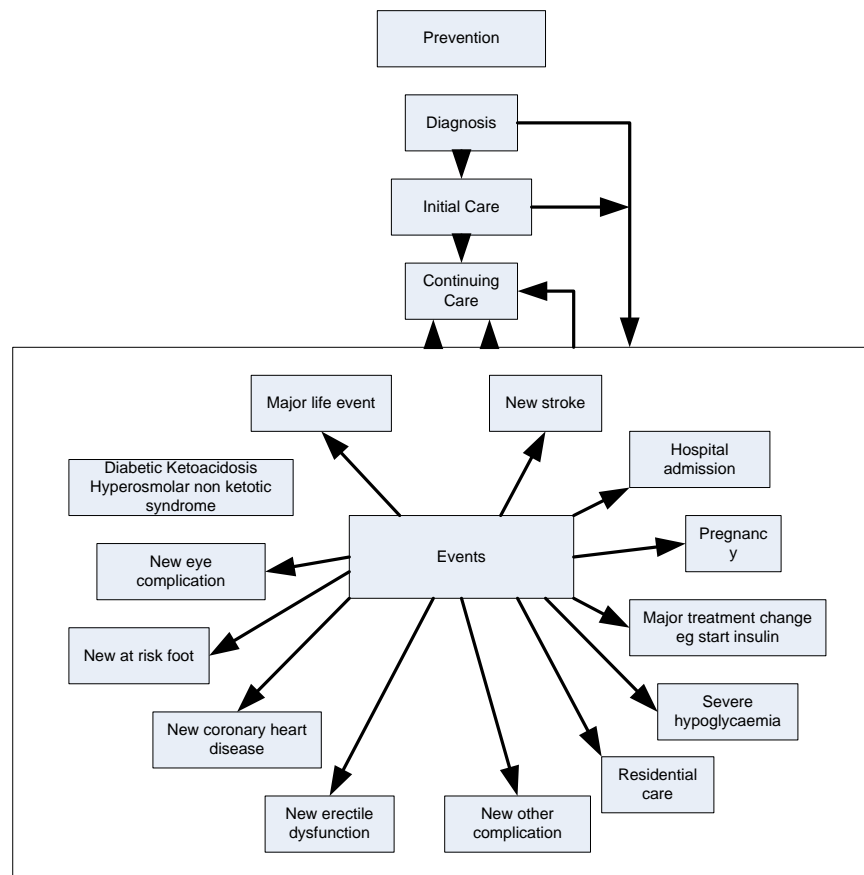
Level 2:

This is a larger scale map e.g. 1:50,000 – imagine a town plan. Just as in the map of the country there are certain main components without which it couldn't really be described as a town. E.g. there needs to be a town hall, a sewage works and a school and various streets and paths to connect them.

A patient can also take a journey through the town – taking their own route – though expertise ('a walk through the town' showing major landmarks) might be the quickest way for a visitor to learn about it.

Diabetes:

The 'town' in diabetes is one segment of the diagram above – it might just show the detail of the 'tail of the tadpole' (below) or one of the arrows going to pregnancy or foot issues. The components of this will also be 'national' i.e. common to everywhere there is a diabetes services.
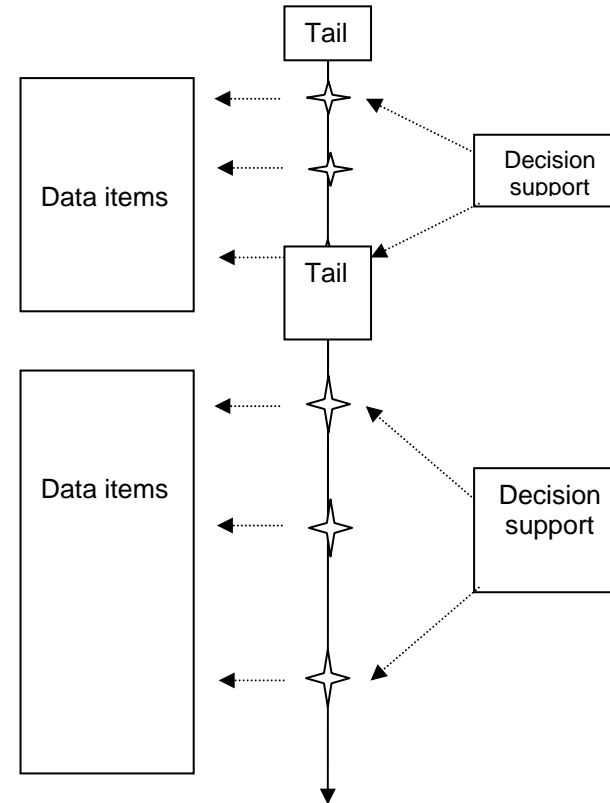
The 'Do one and share' project is concerned with defining the items that go to make up a 'town' anywhere and the symbols that will be used to draw them i.e. the data items.

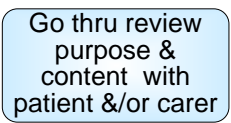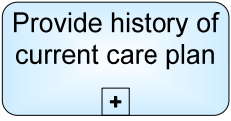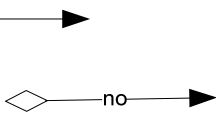| **Level 3:**	**Diabetes:**
Each town can be laid out in a different way, depending for instance of if the terrain is hilly or it is at a confluence of rivers. The 'new town' planners need to decide the relationships of the various essential parts outlined in Level 2 and how they work together. Scale 1:10,000	This is the work of the local diabetes community – ideally the diabetes network - to define the local 'model of care'. This is how all the components at level 2 are put together in their local circumstances. For instance it would define whether there was an intermediate level of care, or just primary, community and specialists, and who did what. *This plan would enable the local town planners to employ architects and builders – in health terms to commission the services needed for the plan from the right people. It allows local flexibility depending on the availability of local resources and to meet special local needs, for example how services are commissioned to meet the needs of prisoners in custody.*
Level 4:	**Diabetes:**
Having got the town built the town council needs to have operational plans to run it. In what order and on what days of the week is the rubbish collected, is schooling in two or three tiers – when does the pupil move from one schools to another etc. There may be more national policies to guide this – just like a national curriculum in schools- but how each town is run is up to the local people as long as it still contains all the elements in levels 1 and 2. Scale : 1000	The operational plans in diabetes are the 'care pathways' being constructed up and down the land, sometimes based on guidelines, sometimes not, but often excluding important parts (especially the patient centred parts) because they have not been built up from Level 1. *The care pathways are the ways the local model works, the referral pathways, who does what etc. They can be audited using chosen data items for the relevant activity – these are datasets. (They can be checked for variance). They may be supported by national and local guidelines.* *Care pathways can also be represented as algorithms, including decision support on how to use them.*

Appendix 7: Evaluation of workshop one

H:\NPfIT\DOS for
Diabetes\Workshop\E

91

Appendix 8: Evaluation of workshop two

H:\NPfIT\DOS for
Diabetes\Workshop\E

Appendix 9: Consultation with Black and Ethnic Minority Communities

H:\NPfIT\DOS for
Diabetes\Workshop\E

Appendix 10: Creating modelled scenarios from workshop situations

H:\NPfIT\DOS for
Diabetes\Workshop\E

Appendix 11: Data items relating to diabetes map (table)

H:\Outputs\Data and
links\Map and Data\D

Appendix 12: Data items relating to business processes

H:\NPfIT\DOS for
Diabetes\Workshop\E
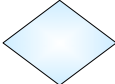
Appendix 13

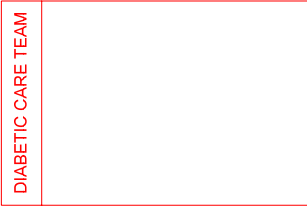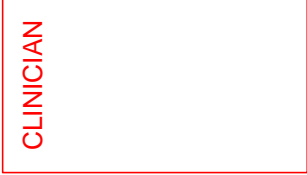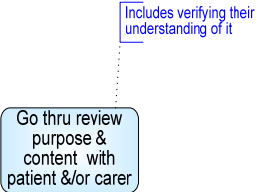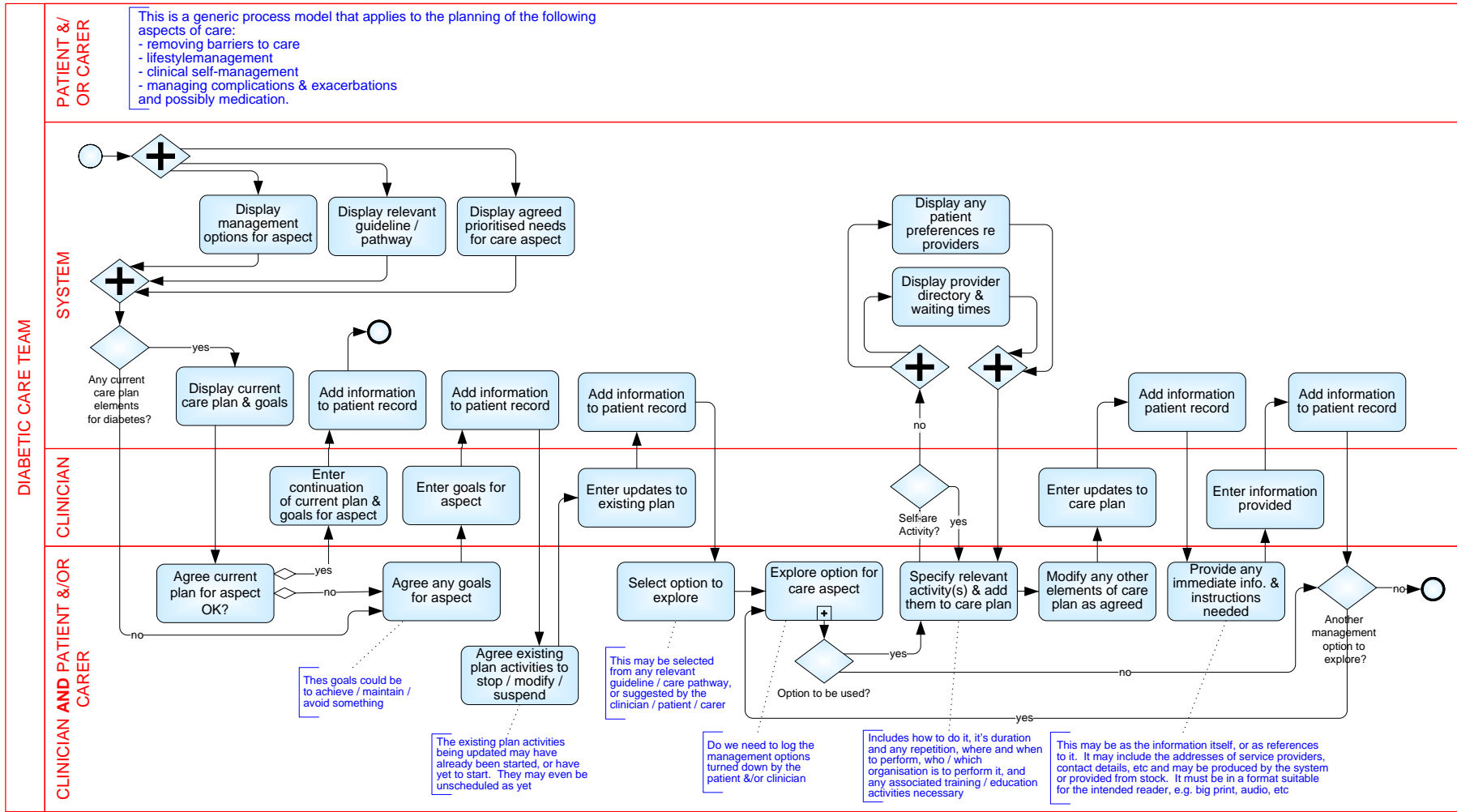## 8. Business Process Modelling Notation (BPMN) used in Diabetes Process Models

S I Herbert 31st December 2005 Version 0.1

The diabetes process models use a small subset of the PMN Release 1.0 elements. They also make novel use of the BPMN pool and lane elements, all the elements used are described below, and a sample model from the diabetes collection is included to assist reader understanding.

Notation element	Symbol	Description
Process		A group of two or more activities that make up a single model diagram. An activity may be a Task or a Sub-Process, both of which are defined below. In the diabetes models a process is contained within a single pool – see the definition of Pool given below.
Task (Atomic)	Go thru review purpose & content with patient &/or carer	A Task is an atomic activity that is included within a Process. A Task is used when the work in the Process is not broken down to a finer level of Process Model detail.
Sub-Process (non-atomic)	Provide history of current care plan [+]	A Sub-Process is a compound activity that is included within a Process. The "plus" sign indicates that this is a Collapsed Sub-Process, and that a more detailed set of activities are available for it but are not visible in this diagram. Clicking on the "plus" will bring up a new diagram – the Expanded Sub-Process - showing the activities making up the sub-process.
Sequence Flow	───▶ ◇──no──▶	A Sequence Flow (see upper symbol to the left) is used to show the order that activities will be performed in a Process. Normal Sequence Flow comes from a Start Event and continues through activities - including any alternative and parallel paths involved - until it finishes at an End Event. A Sequence Flow can have conditional expressions that determine whether or not it will be used. If a conditional flow comes from an activity, then the Sequence Flow has a mini diamond at the beginning of the line (see lower symbol to the left). If the conditional flow comes from a Gateway, then the line will not have a mini-diamond. In either case text describing the condition under which it is used is shown over it.

Notation element	Symbol	Description
Event		An event is something that "happens" during the course of a business process. These events affect the flow of the process and usually have a cause (trigger) or an impact (result). There are three types of Events, based on when they affect the flow - Start, Intermediate, and End. The diabetes models do not use intermediate events. In the diabetes models, start and end events are only shown where there are multiple parallel activities that occur at the start of a process, and/or there are multiple start or end points for a process.
Start event	Patient triggered Review due	The Start Event indicates where a particular process will start. A process can have multiple start points. A start event triggered by time is shown with a clock face in it (see lower symbol to the left).
End event	End of care planning	The End Event indicates where a process will end. A process can have multiple end events.
Gateway	Medication needed?	A Gateway is used to control the branching and merging of Sequence Flows. It must have three or more associated sequence flows, at least one incoming and at least one outgoing. Gateways allow alternative and concurrent sequence flows to be represented. It is the only way BPMN models can represent groups of activities that can be done in any sequence. Gateway Control Type Icons within the diamond shape will indicate the type of flow control behaviour. Only a few of the possible gateways are used in the diabetes models, and these are described below.
Exclusive (XOR) Event-Based		A gateway which is be passed through if any **one** of the incoming sequence flows is true.
Parallel (AND) gateway		A gateway which may be passed through only if **all** the incoming sequence flows are true – there does not have to be more than one – and for which all the outgoing sequence flows must be followed – again there does not have to be more than one. Typically used to bring together concurrent activities that must be started after a preceding activity, or the converse.

Notation element	Symbol	Description
Pool	DIABETIC CARE TEAM	The diabetes models use a Pool to contain the activities for a particular business Process, such as "Plan Care".
Lanes	CLINICIAN	Aka "swim lane". A Lane is a sub-partition within a Pool and will extend the entire length of the Pool. Lanes are used to organize and categorize activities within a Pool. In the diabetes models a lane is used to represent a role played in an activity, e.g. the patient or clinician role. Where a role may be played by more than one kind of actor, e.g. a patient or carer, this is indicated in the lane name shown at the left-hand end of the lane, e.g. "patient &/or carer". The diabetes models also use a single lane to represent role interactions that cannot properly be represented by separate lanes & activities joined by sequence flows, for example a "Clinician & patient/carer" lane contains activities representing discussions and negotiations between them.
Text Annotation	Includes verifying their understanding of it Go thru review purpose & content with patient &/or carer	Text Annotation objects can be used by the modeller to give additional information about a Process or attributes of the objects within the Process. If they apply to a particular feature on the diagram, they are linked to it by a dotted line (known in BPMN as an association).

PATIENT &/OR CARER

This is a generic process model that applies to the planning of the following aspects of care:
- removing barriers to care
- lifestylemanagement
- clinical self-management
- managing complications & exacerbations
and possibly medication.

DIABETIC CARE TEAM

SYSTEM

Display management options for aspect

Display relevant guideline / pathway

Display agreed prioritised needs for care aspect

Any current care plan elements for diabetes?   yes

Display current care plan & goals

Add information to patient record

Add information to patient record

Add information to patient record

Display any patient preferences re providers

Display provider directory & waiting times

no

Self-are Activity?   yes

Add information patient record

Add information to patient record

CLINICIAN

Enter continuation of current plan & goals for aspect

Enter goals for aspect

Enter updates to existing plan

Enter updates to care plan

Enter information provided

CLINICIAN AND PATIENT &/OR CARER

Agree current plan for aspect OK?   yes / no

Agree any goals for aspect

Agree existing plan activities to stop / modify / suspend

Select option to explore

Explore option for care aspect

Specify relevant activity(s) & add them to care plan

Modify any other elements of care plan as agreed

Provide any immediate info. & instructions needed

Another management option to explore?   no

Option to be used?   yes / no

no

yes

Thes goals could be to achieve / maintain / avoid something

The existing plan activities being updated may have already been started, or have yet to start. They may even be unscheduled as yet

This may be selected from any relevant guideline / care pathway, or suggested by the clinician / patient / carer

Do we need to log the management options turned down by the patient &/or clinician

Includes how to do it, it's duration and any repetition, where and when to perform, who / which organisation is to perform it, and any associated training / education activities necessary

This may be as the information itself, or as references to it. It may include the addresses of service providers, contact details, etc and may be produced by the system or provided from stock. It must be in a format suitable for the intended reader, e.g. big print, audio, etc

Review & Plan Diabetic Care	author:	Ian Herbert	created:	22/11/2005 13:19:31	
	version:	1.0	modified:	12/12/2005 18:38:17	BPMN powered by
Replan aspect of care (1)	status:	created			itp commerce
		Review & Plan Diabetes Care v1_0.vsd			© 2006-2005

96