DOaS Diabetes: Executive summary Jan 2006

Aim

The aim of this project was to identify key components of the Electronic Health Record (EHR) 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 (LSP's) 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
    - 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
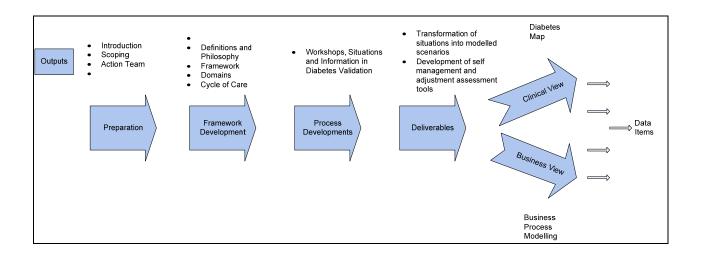- The development of SNOMED definitions for many of the data items

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.

2. 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)

3. 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 a domain 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)

4. 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.

5. 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)

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

7. 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 LSP's, 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.