

# Supporting the shared care of diabetic patients

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## ABSTRACT

This paper reports on a study of clinicians who care for diabetic patients, and on the design of an application to support their work. The clinicians' long-term activity is rooted in a series of private sessions with the patient. Clinicians exchange information but the timeliness, specificity and other salient features of the communication are often unsatisfactory. Problems consequently arise such as the omission or duplication of tests. We describe a conceptual framework to account for the effectiveness of knowledge-sharing in groups such as these, and use it to motivate an application aimed at improving the clinicians' levels of communication and coordination.

## Keywords

Cooperative systems, medical informatics, knowledge sharing.

## INTRODUCTION

This paper reports on a study of clinicians engaged in the care of diabetic patients, and on the design of an application aimed at improving the clinicians' levels of communication and coordination in carrying out their work. The investigation is part of the Mushroom<sup>1</sup> project's development of a model and platform for shared workspaces [8-11]. The project's research goal is to understand enough about the relationship of our workspace model to the collaborative task in order to assess its usability and efficacy in supporting the work.

A diabetic patient may be seeing several clinicians concurrently over a given period. Mostly, a clinician works on the task of patient care just when the patient is present, or immediately before or after the consultation. Consultations involve just the patient and the clinician in a private room for ten to twenty minutes. Much of what occurs in patient care consists of the production, transformation, recording and communication of data and knowledge. Clinicians must acquire good enough data to perform their role, which involves ascertaining the medical state and history of the patient and arranging for a sequence of actions to follow the

consultation.

The clinicians who care for a particular diabetic patient are engaged in what we call a loosely-coupled collaboration. That is, they work largely autonomously, at separate sites. Only in some local cases are they organised into co-located teams. To a certain extent

loose-coupling is a positive reflection of organisational autonomy between different communities of practitioners. However we shall show that it impedes some aspects of the clinicians' work. The manner and frequency of their coordination – in particular, their exchange of knowledge – is of limited efficacy with respect to the requirements of their group task.

We conceive of a shared workspace as a medium for exchanging knowledge<sup>2</sup>. One might be tempted to say that "exchanging knowledge" is communication, but communication can only be said to occur where those involved share sufficient context. In cases such as diabetic care, there is a common purpose but a heterogeneous set of understandings and backgrounds. A workspace achieves knowledge exchange not simply by supplying communication channels, but by storing shared data which form a context for individual and collective problem solving, and by providing the channels in the context of that shared data.

Much knowledge cannot, practically speaking, be represented in a workspace (medical "expert systems" have had little impact on clinical practice). And knowledge is sometimes not readily shared because of the different backgrounds and expertise of the participants. However, Hildreth and Kimble [1] report on how a shared document or other artefact of common interest can act as a stimulus for users who do not share precisely the same knowledge and understanding, but who usefully exchange it as a result of discussing the artefact. Through their discussions, users not only learn particular facts from one another, but they also can usefully learn about one another's capabilities and about one another's need for particular forms of knowledge. It is this aspect of stimulating knowledge-exchange that we aim to exploit in our workspaces.

The paper is structured as follows. In Section 2 we discuss a conceptual framework for understanding the distribution and re-distribution of knowledge in a collaborating group – particularly a loosely-coupled group of collaborators. Section 3 goes on to give an overview of our study of diabetes treatment, illustrating the application of our framework. With the framework and study as background, Section 4 describes and gives the rationale for the design of a workspace to support the clinicians. We conclude in Section 5 with a summary and discussion, including an outline of how we propose to evaluate the efficacy of the workspace design.

## CONCEPTUAL FRAMEWORK

A collaborating group is bound by its common purpose and its need to share knowledge. Clinicians, for

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<sup>1</sup>UK EPSRC grants GR/L14602 (1996-97), and GR/L64300 (1998-2000).

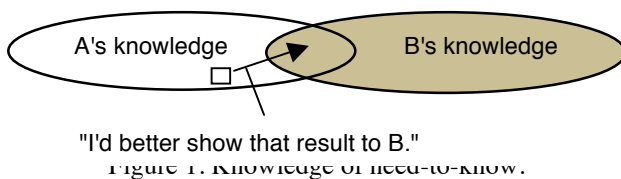
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<sup>2</sup>Unless indicated otherwise we henceforth take the term 'knowledge' to include reasonable belief and understanding.

example, share the treatment of patients and supply test results and other information to one another. A group's work involves the acquisition and transfer of knowledge. We consider there to be a 'knowledge economy' within the group. Knowledge has value. Acquiring and exchanging knowledge (and, sometimes, failing to do so) costs effort. If we are to help support the group, then we need to understand the value of different types of knowledge, and to try to reduce and/or redistribute the costs of acquiring and transferring knowledge in accordance with the group goals and individual goals.

Our conceptual framework for describing a group's knowledge economy is intended to account for the level of coordination in that group and to understand whether there is a shortfall or redundancy of coordination with respect to the group's purpose. The framework has the following four components:

**1. Types of knowledge.** We distinguish three sorts of knowledge: knowledge of data, domain-specific knowledge, and knowledge of others (Table 1). *Data* are simple values, graphs etc. taken without inference or interpretation. Users acquire *domain-specific knowledge* from data by applying their understanding – often using data in the context of other data. Our *knowledge of others* is about what particular facts we believe they know, their expertise (know-how) and what it is they need to know to do their job. In Figure 1 clinician A shows a result to clinician B according to A's knowledge of B's need-to-know, and possibly also knowledge of B's expertise.

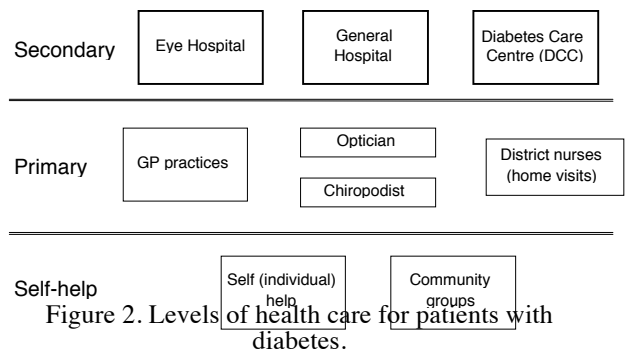


"Knowledge" of others is more likely to be reasonable belief. It may be based on what we know the other person's role to be (e.g. "the GP"), or it may be based on what we know about them individually ("Dr. Gill at Walker St.–whom I often deal with").

**2. The value of knowledge.** Knowledge has value relative to the context of the task at hand – value with respect to the group task, and value with respect to the task of the individual who processes it. For example, a blood-test result may have more or less significance when the overall clinical state of the patient is taken into account. Or it may have less value by itself than when taken in the context of a set of such tests showing a trend.

Knowledge	Description	Examples
Data	Simple values, graphs etc. taken without inference or interpretation	"The patient's glucose level is 18.6."
Domain-specific	Domain-specific expertise or knowledge acquired from data using understanding – often data in the context of other data	"The patient's glucose control is poor."

<sup>3</sup> In this paper we do not address other criteria for evaluating the work, such as the participants' motivation through a sense of involvement.



Knowledge of others (as individuals and/or roles)	Knowledge (more often, belief) as to whether others know particular facts or have/had access to particular data or have certain expertise. Knowledge of another's need to know certain facts or facts of a certain type.	"Nurses do not have the expertise to prescribe insulin." "Let's have a look at that bad glucose result." "I'd better show the result to B."
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Table 1. Types of knowledge.

**3. The effort of acquiring and transferring knowledge.** Many different sorts of effort are required for individuals to acquire knowledge locally and to transfer it to others – via communication channels and shared artefacts such as documents and databases. We concentrate here on generalisations of what we have observed amongst the clinicians: pushing and pulling, interpreting, translating and educating. *Pushing* knowledge involves such effort as questioning another participant or interrogating a database or thumbing through a folder of notes. There is in general a combination of physical effort and the cognitive effort of searching for salient facts. We assume that users will not pull knowledge unless there is some likelihood that the required knowledge exists in the person or artefact concerned. *Pushing* knowledge involves targeting it at another user or group of users – for example, putting it in a database or writing a letter. Effort may be required to get the recipient's attention. We assume that users will not push knowledge unless they know that the recipient needs to know it. There may also be an issue of whether the other party is entitled to know it – e.g. patient data is confidential, sometimes even with respect to other clinicians.

Whether knowledge is pushed or pulled, further effort may be involved in *interpreting* knowledge supplied by another, in *translating* knowledge for the purposes of another, or in *educating* another in, for example, what types of knowledge the recipient needs.

Note that there may be a cost associated with not transferring knowledge, or with processing an exception such as receipt of inaccurate information. For example, a patient may not be seen at all for an annual review if neither of two clinics has informed the other that they have no arrangement to see the patient. And required data may not be gathered at all by rushed or naïve practitioners. Clinicians tend to be able to recover from the absence of data by obtaining it themselves (involving extra effort), but their loose-coupling means that there is no feedback channel to point out the omission.

**4. Trade-offs.** After ascertaining value and effort according to the foregoing analysis in a particular case, we need to go on to understand the trade-offs between value and effort with respect to both group and individual goals. These trade-offs help us to understand why users behave the way they do currently, and will help us to predict the users' response to changes. The following list of questions is not meant to be comprehensive:

- Are users aware of the costs of knowledge transfer and of failure to acquire or transfer knowledge?
- What is the relationship between the value of knowledge and the effort of obtaining it – with respect to the group goals and individual goals?
- What is the apportionment of effort between the users involved in knowledge transfer, and do they perceive their relative effort as being justified?
- What are the relative costs of obtaining knowledge from another and finding it out for oneself?

The above framework can be related to much existing work. Bannon and Bødker [3] use the term 'common information space' to refer to aggregated data which is accessed by users with different work practices and understandings. They discuss the need for interpretation and packaging of data by members of one community for those of another. Boundary objects [4] may also be needed at the interface between communities. They mention but do not address the factors that govern the flow of knowledge between users – such as knowledge of others' needs, and confidentiality.

For participants to know that they share knowledge with another can aid communication and coordination between them. Studies of patient notes [15] show how knowledge of the context in which a point is read can help in how briefly it can be made on the notes. In general, *common ground* is the understanding (knowledge, beliefs, suppositions) accumulated during the course of joint actions, which the parties involved believe that they share. Clark [5] argues that to understand how joint actions proceed we must take common ground to consist of three parts:

- Initial common ground – what the participants share at the inception of the activity.
- What they understand the shared state to be;
- The public events (history) of the activity so far.

Clark gives examples of how common ground accumulates during joint actions, and how it is used in the course of those actions as it does so. He argues that common ground can shorten the path to solving a coordination problem, but he mainly considers synchronous joint action between co-located individuals.

Bardram [2] distinguishes between coordination, cooperation and co-constructive collaboration. To coordinate is to take routine actions to inform and synchronise with other workers. To cooperate is to deal with exceptions – difficulties that cannot be handled routinely – and involves reflection on the means of coordination. Co-constructive collaboration is mutual reflection on the objectives of the work, and consequent alterations in the structure of the work itself.

Restrictions on the acquisition and transfer of knowledge (which occur particularly in a loosely-coupled collaboration) mean that coordination may not take place or it may easily break down – sometimes without the parties even being aware of it. We are

seeking to help users such as our clinicians to be more aware of their coordination with others, and to be able to cooperate when they come across a breakdown.

Our assumption is that loosely-coupled collaborations can be supported with workspaces which act as persistent accumulations of data around which joint problem-solving is discussed. With suitable design, a workspace can improve what users know about one another's knowledge needs, their activities and the data they have accessed. And if data in a workspace is repeatedly visited, it may be able to act as a basis for common ground, and thus facilitate problem-solving between them. In particular, the participants can be helped towards an understanding of the salient features each looks for in the data presented to them. This will aid them in supplying appropriate data as part of routine coordination. Before going on to describe the design of such a workspace for our clinicians, we first use our framework to analyse their knowledge-sharing.

### STUDY OF CLINICIANS

The health care system in the UK is divided into layers which apply different degrees of expertise and specialisation in the treatment they provide (Figure 2; see [7] for a more detailed account). At the bottom is the 'self-help' layer, wherein people attempt to manage their own medical problems. This is a crucial layer for a chronic disease such as diabetes. If their diabetes is to be kept under control, people typically need to monitor themselves daily, apply medication at least once a day, adhere to dietary constraints and look after their general fitness. An individual will also be treated for her diabetes and for other medical problems by a variety of clinicians over the course of the disease. Sometimes several clinicians treat the same person concurrently, but not in the same session. In the so-called primary health care layer, GPs and nurses monitor the patient's control, looking for complications and changes from a stable state (for example, weight loss, rises in blood glucose levels). They decide whether they can treat the patient, and whether another clinician's care is required. The secondary layer provides more specialised, hospital-based treatment. Diabetologists – consultants whose speciality is diabetes – and specialist nurses provide monitoring and treatment of the disease as a whole. But diabetes can have complications that require other specialists' attention. Ophthalmologists treat eye complications. Neurologists, vascular surgeons and renal specialists may be needed. In each clinical layer, chiropodists (podiatrists) monitor and treat foot complications. Patients also consult dieticians.

The motivation for the clinicians' involvement in our study is the desire to make shared care work. Shared care has been defined as:

“the joint participation of hospital consultants and general practitioners in the planned delivery of care for patients with a chronic condition, informed by an enhanced information exchange over and above routine discharge and referral notices.” [12].

In particular the clinicians are concerned by the following points which highlight the fact that the “enhanced information exchange” seems hardly to exist:

- Duplication and omission of effort: tests, referrals, patient education, and annual reviews are often duplicated or omitted due to lack of co-ordination.
- Delays in communication (letters can take weeks to travel from one clinician to another) and incomplete information communicated.

- Inconsistency of terminology, patient advice, and knowledge of whether to refer a patient to another clinician.
- The desire for more effective sharing of expertise.

The study was conducted by interview and observation. Completely ‘immersive’ ethnography [13] is not practical: clinicians are hard-pressed for time, and the need for patient confidentiality and consent means that not all situations may be observed. Moreover, seeking approval for the various aspects of our study is a slow and tentative business

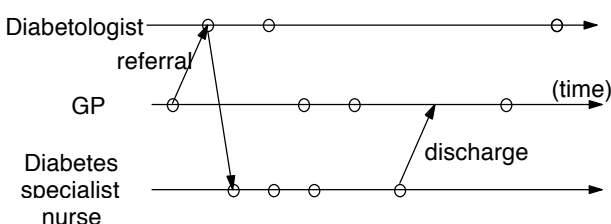
### Diabetes Care

Diabetes mellitus is a chronic disease deriving from the body’s inability to produce or utilise insulin effectively. This leads to an inability to control blood glucose (‘sugar’) levels properly, and problems arise if this level drops too low (hypoglycaemia) or remains too high (hyperglycaemia). The patient may undergo urgent complications of diabetic coma, hypoglycaemic attacks and infection. There can be severe long-term complications: blindness, heart disease, strokes, kidney failure, amputations and nerve damage. Diabetes affects both sexes, all ages and all ethnic groups and is estimated to affect 1-3% of people in the UK [12]. Diabetes has no cure. The goal of diabetes care is to manage the disease so that the patient can lead as near to normal a life as possible.

Treatment of diabetes aims at keeping blood glucose levels within a range that tends to avoid the onset of complications. This is achieved by diet and exercise, insulin injections and oral drugs which help the body utilise insulin.

The key diabetes-related medical events in the life of a diabetic patient are:

- Diagnosis – which may occur when the patient attends a general practice or hospital.
- Reviews – these are annual, or at six-monthly or three-monthly intervals, depending on the patient’s condition.
- ‘Referral’ and ‘follow-up’ – where clinician A arranges for the patient to see clinician B (or A again).
- Discharge – where a clinician discontinues a phase of seeing the patient.
- Eye, feet, blood and urine tests, sometimes at hospital.
- Hypoglycaemic attacks and other emergency conditions.
- New symptoms such as eye or foot complications, or worrisome deviations of glucose, protein or other levels which may indicate an underlying change in the disease.
- New treatments – in particular, the onset of insulin treatment or marked changes in dosage.



○ = visit (not only about diabetes if GP)  
Figure 3. A pattern of concurrent treatment by several clinicians

Figure 3 shows an example of a schedule of consultations for an individual patient over a few months. She goes to her GP, who identifies a complication connected to her diabetes which is or may be beyond the GP’s competence. The GP *refers* the patient to the hospital consultant who specialises in diabetes: the diabetologist. This means that the consultant will see the patient, within a period that matches the severity of the complication. The figure shows that this particular patient sees the diabetologist twice at first. The diabetologist decides, in turn, to arrange for the patient a series of follow-up consultations with the specialist nurse. Eventually, the specialist nurse discharges the patient from her care, and notifies the GP. As a result of the original referral, however, it is arranged for the patient to see the diabetologist instead of the GP for annual review from now on (the first such review is shown some months later). In the meantime, the patient continues to see her GP about other problems as well as her diabetes.

In this study we are mainly concerned with the clinicians who exercise some judgement over a diabetic patient’s treatment. This judgement is either applied directly, to the patient, or indirectly, in advising another clinician. The clinicians have several general responsibilities:

- To treat diabetes or an aspect or complication of it, according to the clinician’s allotted role.
- To arrange or carry out tests and measurements on the patient in order to ascertain the state of the disease – blood glucose and cholesterol levels, blood pressure, urine glucose, protein and toxin levels, weight, the conditions of the eyes and feet.
- To educate the patient about the disease and the steps requires to control it.
- To provide the patient with encouragement and moral support.
- To recognise when another clinician’s skills and judgement need to be applied, and to refer the patient on to such a clinician as necessary on an appropriate time scale.
- To advise other clinicians about treatment and about whether there is a need for referral.

### Consultations

We have observed consultations at a practice and at a Diabetes Care Centre (DCC). We now provide some illustrations to help characterise the work at these sites. These are followed by examples of problems with the current support for group work characterised in terms of our conceptual framework.

At the practice, diabetic patients are seen for review, which may be annual, or at three- or six-month intervals, depending on the patient’s condition. The practice specialist nurse sees the patient first, and the patient sees the GP shortly afterwards on the same morning.

The nurse enters measurements and comments into a database which the doctor also accesses when he or she sees the same patient subsequently. Normally, each also refers to the same folder of patient notes on paper. The notes contain test results from outside laboratories and correspondence with other clinicians or outside agencies, arranged in chronological order.

The collective task of the nurse and doctor – and this is true of every clinical consultation we observed – is to take body measurements, observations and statements

from the patient and 'work them up' into a tractable form. This is analogous to the notion of taking raw economic statistics and producing an agreed statement on the state of a country's economy [14]. The output in the clinical case includes actions as well as statements, and the statements are liable to be tentative. The data are worked up in order to end the current session in its allotted 10-20 minutes (an important consideration in a busy health care system), by explaining his or her state to the patient and arranging that *something appropriate happens next*. The processes that take place in the session are:

- Recording measurements and comparing them with previous ones.
- Questioning the patient and filtering what the patient says for its relevance, accuracy and significance.
- Recording information that is or may be relevant to the patient's overall condition.
- In the case of a doctor or consultant, making a diagnosis; most consultations in diabetes care are less categorical than this.
- Informing and reassuring the patient.
- Applying expertise to decide on what is appropriate to happen next. This may be:
  - Prescribing or changing a prescription.
  - Arranging more tests and/or a follow-up visit.
  - Referring the patient to one or more other clinicians.

On the whole, diagnosis is the doctor's preserve; prescription is done by some nurses as well as doctors. Much of the remainder occurs in one form or another in consultations with all the clinicians we studied.

The practice nurse takes measurements (weight, blood pressure etc.), compares the readings with those of the last review, discusses their levels and any changes in them with the patient, and brings significant items to the doctor's attention. Only certain clinicians are recognised as being able to change the patient's medication. Interestingly, this is not strictly a nurse/doctor dichotomy: some GPs will consult the specialist nurse at the secondary (hospital) health care level for advice about medication.

### Problems with the Current Situation

The emphasis in this section is placed on typical problems with the current support for shared care of patients. These problems affect the efficiency and quality of the group work. Often the problems result in the duplication of effort by clinicians; tests are repeated unnecessarily, and patients are asked similar questions by different clinicians. Also, procedures are sometimes omitted altogether. The following sections illustrate these problems through the use of examples extracted from observations of clinicians working with real patients and explained in terms of our conceptual framework.

An interesting aspect of the situation is that there is a diverse set of members in the group working to care for the patient. Typically each member directly collaborates with one other member at a time. This means that each pair of members develops its own set of knowledge which reflects the particular aspect of the patient's case they are working on. Difficulties arise when members need to transfer knowledge to and from different contexts i.e. for different collaborations.

Several forms of communication are used in the current situation including:

- **Face to face conversations.** For example, a clinician may briefly mention to a colleague that they will send a patient to see them later for a particular reason.
- **Telephone conversations.**
- **Letters.** Letters are used in the referral process and contain information about the patient's current state as well as reasons for them being referred.
- **Paper-based notes.** These essentially embody a subset of the clinical events so far, e.g. a patient being referred to another clinician or details of previous blood tests.
- **Shared databases.** As with paper-based notes, these reflect public events to date. They may also be used to signal to other clinicians that activities should take place, e.g. a nurse may add a comment that the GP who sees the patient next should pay particular attention to the patient's diet.

### Transferring domain-specific knowledge

The timely transfer of knowledge between clinicians in the shared care of diabetic patients is a *hit-and-miss* affair; some knowledge may be transferred, others may not. Furthermore the clinicians have no way of knowing whether they have missed knowledge that has been pushed for them, or whether the knowledge was not pushed in the first place. In our studies we have found that clinicians are well aware of this problem, indeed, they do not even expect acknowledgements of attempts to push knowledge. In this section we briefly outline some examples of knowledge being successfully and unsuccessfully transferred, and the *ad hoc* tactics clinicians use to signal that knowledge is being pushed.

A striking example of unsuccessful transfer of knowledge occurs when a nurse arranges an appointment for a patient at an eye clinic which the GP is later unaware of. The following extract from the transcript relates to the nurse deciding to refer the patient to the eye clinic.

Nurse: Have you got another appointment at the L. [eye clinic]?

Patient: No, I'm under Dr. X. [the GP the patient sees next] and nurses here.

N: Right... in that case, we need to make an appointment for the next time the camera is available... 6 weeks.

P: I didn't like the L. - they had wrong address for me and blamed me for not turning up. I was under Dr. whatever-her-name-was in G.

Nurse looks at paper notes.

N: Yes

*The patient then proceeds to air more grievances about the L. whilst the nurse types at the computer.*

N: You need to make an appointment.

At this point the nurse has written a letter to arrange an appointment for the patient at the eye clinic and noted the arrangement in the shared database. This letter is printed out at the end of the session and handed to the patient for them to arrange the appointment.

The problem of interest occurs when the patient sees the GP, as illustrated in the following transcript extract.

Patient: I hung on [for an eye examination] because I had it done at the L.... I

explained to Y. [the nurse] that I can't remember when.

*The GP (Dr. X.) then looks through both the paper and computer based patient notes*

GP.: Has Y. given you opticians things?

P: Gave me this letter to tell me to go 'round there.

*The patient then shows the letter prepared by the nurse to the GP.*

GP: That's fine.

P: Y. said go in a month's time.

GP: He'll send us the result.

Although the nurse has noted that he wrote an appointment letter for the patient and informed her when to visit the eye clinic the GP appears to have failed to pull the information from the shared database. The GP spends some time looking through the computer-based and paper-based notes (presumably in an attempt to find out what the nurse has done with respect to arranging for the patient to visit the eye clinic) before asking the patient what the nurse has done. The patient therefore serves as an indirect communication channel between the nurse and the GP. This is unsatisfactory as the channel may be unreliable (the patient may not remember or understand the data being communicated) and moreover, the patient may become worried about the lack of communication between the nurse and the GP which resulted in them acting as a communication channel.

One of the nurses addressed this problem by handing the paper notes to the GP in order to draw the GP's attention to problems he felt were important. This, however, is an *ad hoc* solution which involves extra time and effort for the nurse and relies on both the nurse and the GP being co-located.

Conversely we have observed situations in which no attempt has been made to push knowledge. A typical example of this problem occurs when patients attend eye clinics where tests performed by the eye specialists inform their diagnoses. However, the results of such tests are also of interest to the referring clinician as indicators of the patient's diabetic condition. Typically such results and information about what the eye specialist intends to do for the patient are not returned to the referring clinician. The following extract of transcript highlights one such situation. First the nurse does not know whether the patient has attended an eye clinic (a problem of lack of knowledge transfer from the eye specialist). This results in the nurse expending effort pulling this information from the patient (after failing to find any relevant information). Second, at the end of the extract the nurse states that he will have to 'follow that up' which clearly will involve the nurse in extra work acquiring the knowledge

Nurse: How are your eyes? Have you had them checked?

Patient: I didn't 'cos I had them done, but I didn't know when I had them done.

*At this point the nurse picks up the paper notes - any information from eye clinics will be in the form of a letter.*

P: Do they photograph them?

N: Yes

P: I had them done at the L.

N: They never told us.

*The nurse looks through the notes whilst talking to the patient.*

N: No correspondence. At the L.?

P: Yes.

N: Need to follow that up.

*At this point the nurse stops looking through the notes.*

N: Have you got another appointment?

The hit-and-miss nature of knowledge-sharing means that we have observed several examples of successes; the point is that members of the group cannot be certain about others' attempts to share knowledge.

The following is an example of a situation in which the nurse communicates a concern about the patient which he expects will be met by the GP when she sees the patient. This illustrates effective pushing of knowledge.

In this example the nurse finds it particularly difficult to ascertain the patient's diet and its suitability for his diabetic condition. She communicates her concerns about the diet at the end of the session by typing the following comments into the shared database:

I found it difficult to ascertain what he was eating etc.

When the GP sees the patient (shortly after the patient has seen the nurse) she first acquires knowledge of the patient's dietary situation by reading the nurse's comments in the shared database. The initial part of the following transcript shows that the GP is taking note of the nurse's concern (also indicated by the unusually large amount of time she spends discussing the patient's diet with him).

GP: How are you getting on with your diabetes? When I visited you at home there wasn't much in your house and we discussed meals on wheels or going to the shop.

Patient: Prefer shop.

GP: What are you buying?

P: Anything.

GP: Do you know what you should be buying for your diabetes?

P: No.

GP: Do you know about things with sugar in them?

P: Don't use sugar.

Essentially the comment in the database affects the GP's perception of the patient's condition, that the patient needs to be further questioned about his diet, and that the patient's diet needs to be carefully monitored in the future (not just by the GP). As a result of the comment work is co-ordinated, and an appointment to see the dietician is arranged.

#### *Knowledge of others*

Often clinicians construct expectations that their colleagues will perform certain tasks or impart certain information to the patient. These expectations are formed from beliefs about the other's roles and knowledge. In the studies such expectations are readily observable when they are conveyed to the patient. The following extract of a transcript illustrates a nurse conveying an expectation to the patient that the GP will advise him about the use of leggings to relieve leg cramps.

Nurse: Anything else?

Patient: My leg is playing up. Cramp-like pains.

N: Ask Dr. X. He may be able to help you with leggings.

However, when the patient sees the GP she has no idea that this expectation has been conveyed and starts enquiries on the theme of legs as follows.

GP: How are your legs?

GP: How far can you walk?

GP: You should try and walk up to and beyond the limits of pain.

Note that the GP does not mention leggings. The patient has to mention the subject himself, to which the GP replies that they wouldn't be of any use as they are for varicose veins (in contrast to the nurse's suggestion). This indicates poor communication about the expectation, and the nurse's incorrect knowledge of the use of leggings. This should be remedied through feedback from the GP, but there was no evidence of this happening in the studies. The example does, however, illustrate the clinicians' clear understandings of their, and others' roles with respect to the patient's care. The nurse knows that it is the GP's responsibility to make decisions about items such as leggings.

In interviews, several clinicians indicated that to a certain extent they arrive at judgements of one another's actual, as opposed to role-attributed, skills. When clinician A telephones clinician B about the prospect of referring on a patient, B may use his or her judgement of what A is capable of, to decide whether the referral is necessary. The referral is more likely to be encouraged by B, if B has doubts about A's capacity to cope.

Knowledge of others' need-to-know is hard to identify from observations. However, we have identified several problems with such knowledge from interviews with clinicians. An example of this is that knowledge of a patient's impotence is useful in the treatment of diabetes, but such information is often not conveyed during referral as GPs are typically not aware of its significance, or may have reservations on the grounds of confidentiality.

#### *The value of knowledge*

Our studies have included preliminary investigations into the clinicians' perceived value of knowledge. One such value judgement arises in the use of blood test values. Two kinds of tests of blood sugar levels are used: 'finger-prick' tests and 'lab' tests. Finger tests yield an immediate result but only reflect the patient's current blood sugar levels whereas the lab test takes around two weeks to be processed and gives a result which indicates levels averaged over a two month period. The clinicians value the lab tests more than the finger tests as patients are often 'good' before attending clinics (e.g. eating, exercising appropriately) which may give a misleading finger test result.

#### *Trade-offs*

Our initial investigations of clinicians' perceptions of trade-offs between value and effort in group work have highlighted one of the reasons for the prevalent duplication of effort. Often tests (e.g. blood tests) and enquiries (e.g. details of a patient's diabetic history) are duplicated by clinicians because the information is valuable to the task at hand, but the effort required to obtain the knowledge from other clinicians is higher than finding it out by themselves.

#### *Summary of problems*

We have presented several examples from our studies which highlight the hit-and-miss nature of sharing of knowledge, and the problems of developing knowledge of others. These problems lead to poor coordination, and motivate us to design new support for shared patient care which can improve the quality and utility of the clinicians' knowledge-sharing. These designs are presented in the next section.

## DESIGN

We have designed a shared workspace in order to address the issues of efficiency and quality of group work in terms of duplication and omission of effort, delays in communication, inconsistencies, and effectiveness of expertise-sharing highlighted in the previous section. This section describes our design and its relation to the conceptual framework of section 2.

From the holistic view of shared diabetic patient care our design addresses the problems of collaboration and sharing of data and knowledge in unusual cases. These are cases where clinicians need to seek advice, or collaborate over and above the usual sharing of data – which may be automated for a core set of data. The clinicians therefore need to understand and determine which information is needed, or should be made available.

In order to address the problem of lack of basic data sharing we have used the Mushroom platform [8-11] to provide secure workspaces which are organised on a *per* patient basis. This means that data and applications relating to a particular patient are stored persistently in an area to which certain users have access. Security constraints must be taken into account when designing systems to support shared clinical work as clinicians will not accept a system with poor security. The Mushroom platform provides flexible role-based access control for workspaces which we are using to implement Anderson's policy model for the security of clinical information [6].

### Tabling Data and Clinical Emails

The shared workspace provides access to, and storage of the shared data around which collaboration takes place. Data needs to be transferred from clinicians' own local sources to the shared space. The sources include images from video cameras, scanned letters and photographs, and data from their local computerised clinical information systems (CISs). A clinician may *table* data for others. In tabling data they transfer data with commentary about what they perceive to be the salient points to the shared workspace. These data and related commentaries can then be accessed by others. Our intention is that the commentaries provide a context for the data which others can use to develop an understanding of the originator's knowledge of the data. The effect is to support the pushing of knowledge for others in a more timely and reliable way than was previously possible.

Clinicians can also send *clinical emails* to one another. These are securely delivered and arrive in a separate mailbox from the clinicians' general emails, so that recipients know they are only from their clinical colleagues. They also bear structured references to the workspace for the patient they concern. In particular, tabled data can be referenced in clinical emails, e.g. if the tabling clinician wishes to draw another's attention to the data they can reference the tabled data in their email. This provides a means of getting the recipients' attention (as opposed to the *ad hoc* solutions discussed in the previous section).

Although some core data may be transferred automatically, clinicians retain control over transfers to the shared workspace. For instance, another clinician may ask for a recent image of the patient's foot. If the clinician feels it is appropriate they transfer the data of interest. This raises the issue of what knowledge other clinicians have of the content of each others' CISs. As discussed previously, security is an important issue in the design of shared care support systems. As such it is



not desirable to allow clinicians access to the content of each others' CISs. This presents an interesting design problem of providing an impression of the data that is held privately whilst not divulging too much and so compromising security and confidentiality. We have developed a shared overview of the clinical process, in the form of a *timeline*, to address this issue.

### Timeline View

Figure 4 shows an example of the timeline design. Each clinician involved with the patient has their own *track* (represented as a horizontal line – in this example there are three clinicians involved) on which their actions relating to the patient are represented. The track shows past actions and actions scheduled in the future (indicated by the dotted parts of the tracks). The timeline has an *episodic* time scale; each time the clinician sees the patient is represented as an event on the timeline with the date vertically aligned below it. The actions and data accrued in the episode are summarised on the timeline to provide an overview of the situation. Similarly there are indications of forms of communication used in an episode e.g. clinicians may make available a clinical email. The timeline is designed to give enough information for other clinicians to grasp what has happened and is going to happen without compromising security of sensitive information. This relies on clinicians having a suitable understanding of the processes involved in shared care of diabetic patients e.g. to know that during an annual review blood samples will be taken, and diet may be discussed.

Five events are displayed in the example in Figure 4. The first is an annual review performed by the GP, Gwen, which has been read by the specialist, Simon (read action indicated by the tick on the timeline), but not the dietician, Dorothy who also has access to the data from the annual review (no tick shown). Next some data relating to blood tests has been tabled by Simon, who also sent a clinical email about blood tests on the same day. Gwen has read both these items. Finally Gwen has scanned in a letter about an eye test which no-one else has read, and which, moreover, Dorothy does not currently have access to (indicated by the no-entry sign indicating no access to the contents). In addition an appointment has been made for the patient to see Dorothy for a dietary review.

The timeline was designed to improve the efficiency and quality of several aspects of the shared care process. First, as mentioned previously it can be used in the negotiation of transfer of data from CISs to the workspace. For example, a dietician concerned about the patient's diet may notice that the patient recently had an annual review and ask the clinician who performed the annual review whether they noted any dietary problems. This information could then be relayed to the

dietician (e.g. by clinical email), or it may be transferred from the clinician's CIS to the workspace for use by the dietician (along with any other data the clinician may feel is pertinent). In terms of our conceptual framework this provides knowledge of other group members in the form of a rough outline of their actions.

Second, the timeline presents information about whether clinical emails or other documents have been read (indicated by ticks on the tracks). This is intended to support clinicians in making suppositions about the knowledge of others. For example, a clinician may table information for another. The timeline indicates if this tabled data has been accessed; the fact that the data has been accessed provides grounds for supposing that the other clinician has read and interpreted the data in some way. In a similar fashion the timeline indicates who currently has access to information

Third, during collaboration the timeline provides a focus around which discussion of the ongoing process can be oriented. Clinicians can make assumptions about the other's knowledge of the processes that the patient has been through and is scheduled for. For example, clinicians discussing a problem case could remark that 'this last annual review was the turning point', and be fairly confident that they shared an understanding of which annual review they referred to. As the store is persistent, such data can be returned to at a later date.

Finally the timeline provides a means for individual clinicians grasping the context of the patient's care. For example, the timeline can be configured to indicate which events have occurred since the clinician last saw the patient. This contributes to clinicians' knowledge of the overall care of the patient and the kinds of knowledge other clinicians have of the patient. As discussed previously, only non-confidential summaries are presented to those without full access to the underlying data. The timeline also helps reduce duplication of effort and helps avoid omissions as clinicians become aware of one another's actions.

### Scenario of Use

A scenario of the designed system's use is presented here to illustrate its impact on the efficiency of the group work. In this scenario Gwen (a GP) is concerned about the recent deterioration of her patient Peter's diabetic control. Peter has seen Gwen on a regular basis for several years in connection with his diabetes as well as with other non-related medical problems. He usually has good diabetic control; he eats a suitable diet, takes regular exercise, and administers appropriate medicines to himself.

Gwen is unsure of the reason for Peter's degeneration and the course of action to take so she considers referring Peter to the diabetic specialist at the local hospital (Simon). Conventionally (a scenario developed from our observations and interviews with clinicians) she would write a letter asking whether Peter needs to be referred to Simon, including some information she feels is relevant (e.g. recent blood and urine test results). Simon, a busy specialist, receives the letter some weeks later, but is unable to determine whether a referral is necessary as he needs extra information about the patient. He is unable to immediately contact Gwen to check for the information he needs and so decides to make an appointment to see him, just to be on the safe side. Several weeks later Peter arrives for his appointment with Simon who takes various tests and decides on a revision of Peter's care. Notes on the reviewed care plan are sent to Gwen in a letter.

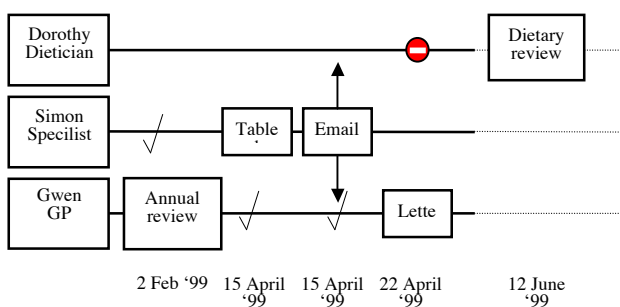


Figure 4 - The timeline view of data



Alternatively, using our system Gwen emails Simon about the patient with a collection of pointers to data she feels are relevant (i.e. she tables the relevant data). At the end of the day Simon checks his clinical email and reads the mail from Gwen. He notices that certain important data are missing for him to assess whether the patient should be referred. Looking at the timeline view of the patient's care, he sees that Peter had an annual review a month ago and was also seen by Gwen three months ago. He replies to Gwen's clinical email asks her to table specific data from these episodes.

The next day, before Gwen starts her surgery, she checks her clinical email and sees that Simon has requested some more data. Although the data is sensitive she feels that it would be acceptable to make it available to Simon, so she tables it without making it accessible to others.

At the end of the day Simon checks his clinical email and sees that the necessary data has been tabled. He decides that a referral is not necessary as Gwen should be able to modify the patient's care appropriately. So he emails Gwen detailing his rationale behind not asking for a referral for Peter, and detailing what actions Gwen should take. He also attaches pointers to relevant data to the email to help illustrate which information was important in his decision making. The following day Gwen reads her clinical email and takes Simon's advice.

We see three main advantages in our new scenario. First, time and effort is saved for both clinicians and the patient. Although Gwen and Simon spend time and effort communicating with each other they save Simon's time in actually seeing the patient and performing relevant tests. They also save Gwen's time in following up the referral. Furthermore they save Peter's time and inconvenience in having to travel to the hospital to see Simon.

The second advantage of the new scenario is that Gwen develops a better understanding of Simon's knowledge needs. When she makes a request for referral to Simon again she will have a better understanding of the data to table. Moreover, Gwen has been educated in part of the shared care of diabetic patients. When this situation arises again she may be able to handle it herself rather than asking Simon for advice. This clearly saves both clinicians' time. Furthermore in such a collaboration Gwen and Simon develop their professional working relationship.

Finally, as data is stored persistently in the workspace it can be referred to at a later date. For example, Simon may have explained his rationale by comparing the case to a similar previous case he dealt with. Similarly, Gwen could refer back to the shared data at a later date to help with her understanding of similar cases.

#### **SUMMARY**

We have presented a conceptual framework for analysing group work in terms of types of knowledge, its value and the effort involved in acquiring and transferring it. Our motivations in constructing such a framework are to inform the design of group work support environments and to provide a framework within which we can evaluate such systems. This paper has described a study of group work in shared diabetic patient care in terms of our framework. Problems raised by considering the work with respect to our framework were then used to motivate the design of new software support.

We anticipate that our design will have advantages over the current system through its support for:

- Sharing data – it can easily be tabled and referred to.
- Sharing knowledge about the patient – clinicians can more easily flag the salient data.
- Developing understandings of each other's knowledge of the patient's situation – the timeline provides a rough overview of the kinds of knowledge other clinicians probably have.

Our current work involves the investigation of the clinicians' different perceptions of the value of knowledge. These notions, together with thorough understandings of the trade-offs between value and effort will help us in the evaluation of our support for group work. We are currently using our conceptual framework to develop an evaluation framework for group work taking into account:

- The effort needed to push knowledge at others (e.g. tabling in our design) and to pull knowledge, including interpretation and translation.
- The extra effort needed to carry out a task in ignorance of useful information, and for processing exceptions (misleading data, or misinterpretations).
- Users' sense of involvement in the group work and awareness of members of the group.
- Trade-offs between knowledge value and effort.
- Overall time costs or savings.

Value and effort trade-offs are particularly pertinent for clinicians. Their motivations in developing and embracing new support tools are to re-appropriate time that is currently wasted on duplication and unnecessary actions, for work they perceive as being most valuable. In particular they are interested in freeing up time for activities such as regular virtual discussion sessions about "problem" patients, which will help educate the clinicians. Moreover the patient will benefit from more thorough clinical attention, reduced duplication of tests and questioning, and more treatment at the local practice, which is preferable to hospital visits.

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