# A study of diabetic patient care

**Tim Kindberg**
Department of Computer Science
Queen Mary & Westfield College
University of London.
London E1 4NS, United Kingdom
timk@dcs.qmw.ac.uk

## ABSTRACT

This paper reports on a study of clinicians who care for diabetic patients. The main features of this study are, first, that it concerns work which is loosely coupled for much of the time. This long-term activity is rooted in a series of private sessions between the patient and a clinician. Second, we believe that it is helpful to understand the work from the standpoint of epistemology. Much of what occurs consists of the production, transformation and transmission of information grasped with various levels of certainty and various grounds in evidence. We conclude with a discussion of the extent to which philosophical techniques are relevant to studies of collaborative working.

### Keywords

Cooperative systems, medical informatics, information sharing, epistemology, philosophy.

> Suppose everyone had a box with something in it: we call it a "beetle". No one can look into anyone else's box, and everyone says he knows what a beetle is only by looking at *his* beetle.–Here it would be quite possible for everyone to have something different in his box. One might even imagine such a thing constantly changing.– But suppose the word "beetle" had a use in these people's language?–If so it would not be used as the name of a thing. The thing in the box has no place in the language-game at all; not even as a *something*: for the box might even be empty.–No, one can 'divide through' by the thing in the box; it cancels out, whatever it is.
>
> Ludwig Wittgenstein
>
> *Philosophical Investigations*, Note 293 [1].

## INTRODUCTION

The above quote is taken from Wittgenstein's philosophical enquiry into whether it is possible for a person to have a private language – private words which an individual may use to refer to internal sensations. But his 'beetle in the box' is a striking image for the CSCW practitioner. His question of what is *logically* either shared or private, corresponds to what for us is a set of practical questions. For example, we might ask: What do the users share, and what is private but germane to the collaboration? How should artefacts be disclosed for sharing – what boundary objects [3] do we need to bridge between 'private' representations? What can we 'factor out' of our systems, on the basis of the users' shared understandings?

Philosophical investigation has different goals from methodologies such as ethnography which are normally practised in CSCW. But there are two philosophical techniques which seem relevant to our domain. The first is to ask: "What are the grounds for this – can we doubt it?" – where "this" is some everyday assertion [19]. The answer, Wittgenstein says, can be derived from looking at how the assertion is actually used. It can tell us something about people's shared context for actions and utterances, and the possibilities for dispute and misunderstanding. The second technique is to explore the boundaries of what makes sense. Philosophy often deals in quasi-absurd questions such as "How do I know whether I have a headache?", in order to get at the meaning of words. In the case of CSCW, this translates into a question that pushes at the boundaries of established working: "But what if the nurse changed the doctor's prescription?". In CSCW neither type of question – of the grounds for an assertion or of what makes sense – is required to produce an absolute, logical answer. Rather, we need answers that throws light on the nature of the work which we aim to support. The answers are relative to the user group's epistemological framework, and to their way of conducting their work. For example, we can ask: "How does the doctor know that the patient has been looking after herself? – What counts as evidence here?", and "How does clinician A know to refer the patient to clinician B, without knowing what clinician B knows? – What type of 'knowledge' is that?".

This paper gives a first report on an ongoing study of the work of clinicians engaged in the care of diabetic patients. The study is part of the Mushroom project[1] [4-7], which is currently investigating the application of a shared-workspace system to support the clinicians' work. The research goals are to develop our model of shared workspaces so as to support this work, particularly in

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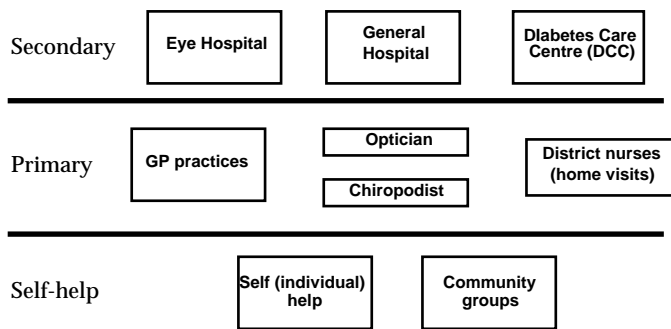| | | | |
|---|---|---|---|
| Secondary | Eye Hospital | General Hospital | Diabetes Care Centre (DCC) |
| Primary | GP practices | Optician / Chiropodist | District nurses (home visits) |
| Self-help | | Self (individual) help | Community groups |

Figure 1. Levels of health care for patients with diabetes.

respect of data security and integrity, and to devise an evaluation framework that will enable us to assess its usability and efficacy.

Much of what occurs in patient care consists of the production, transformation and transmission of information grasped with various levels of certainty and various bases in evidence. To perform their roles effectively, the clinicians are trained to be sceptical investigators at the same time as being carers. They must acquire good enough information to perform their role, and yet two factors militate against this. First, they often have no access or imperfect access to one another, or to information known by one another. At least, they tend not to have this access at convenient times. Second, the patient sometimes gives misleading accounts of symptoms and the extent to which he or she has been managing her diabetes. We shall try to bring out some of the epistemological framework in which the clinicians (and patient) work in order to throw some light on it. By epistemological framework, we mean the system by which they acquire knowledge from evidence, and the grounds for their actions. This is intended to be part of, not replace, more traditional ethnographic analysis. It is not novel to make the connection with philosophical concerns. Wittgenstein himself addressed Frazer's anthropological research from his philosophical standpoint [2].

The paper is structured as follows. First we discuss the aims and methodology of the study. We give an overview of diabetes and its treatment. Then we give an account of our observations. We begin with consultations between patient and clinicians. We discuss issues concerned with patient records, and then move on to describe the clinicians' cooperation, particularly the act of referral from one clinician to another. We conclude with a summary and discussion.

## THE STUDY
The health care system in the UK is divided into layers that apply different degrees of expertise and specialisation in the treatment they provide (Figure 1). 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." [8].

In shared care, a person with diabetes is treated in the primary sector as far as possible. The stated aims are to improve care for the patient, who often prefers seeing her GP to going to hospital, and who can receive a greater level of monitoring; and to place less strain on secondary resources.

From an early stage, our study raised two points in relation to the definition of shared care. The first is that shared care in fact involves more clinicians with significant roles than the definition mentions – notably the specialist nurses. Second, the "enhanced information exchange" seems hardly to exist. The clinicians we work with feel that their interactions concerning patients could be better supported in terms of the quality of information exchanged. More frequent interactions may sometimes be appropriate. Just as the shared health care group is more diverse than the definition suggests, we have also discovered that interactions between the clinicians are more complex than the inter-layer cooperation it mentions. In particular, intra-layer clinician interactions are part of the same web. And larger administrative influences are brought to bear on how they can conduct their work.

Our aim is to give a systemic characterisation of the work of diabetic care from the points of view of the clinicians involved, including the contexts they work in (their organisations, the structure of their working days, etc.). This is to enable us in the next stage of our research to go on to examine ways to improve on existing support (while recognising that conflicting interests are sometimes involved [9]). We are gathering evidence to formulate and test hypotheses about the work, which will enable us to predict the effects of changes in support.

The study is conducted by interview and observation. Completely 'immersive' ethnography [10] 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. Seeking approval for the various aspects of our study is a slow and tentative business. For example, at the time of writing, we are awaiting consent from the local Ethics Committee to tape-record telephone conversations between clinicians.

Most studies are of work in which people's activities are physically closely coupled – as, for example in air-traffic control rooms [11], or in more distributed situations where there is frequent interaction, e.g. [12]. One of the main points that has quickly emerged from our study so far is how loosely coupled and yet cooperative is much of the clinicians' work. They often work autonomously at separate sites, and only in some local cases are they organised into teams. The diabetic patient serialises the clinicians' concurrent activities. 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.

## 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. In the so-called insulin-dependent form it normally begins when the patient is a child or young adult. In its non-insulin dependent form it begins in adults about forty or over. It is estimated to affect 1-3% of people in the UK [8]. The mortality rate is relatively high for people with diabetes – about twice that of the non-diabetic group in one study of people aged 45-64. 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. One large-scale trial [18] has shown that, in the case of insulin-dependent diabetes, tight blood glucose control leads to a marked decrease in the incidence of complications. The price paid for this regime, which involves administering insulin to keep glucose levels down, is a significant rate of hypoglycaemic attacks. A current UK study aims to establish whether similarly tight glucose control is as beneficial for non-insulin dependent diabetes. In both cases glucose control is applied, but exactly how strict it needs to be is a current research question. This is significant for patients who have to inject themselves several times a day, take drugs and observe a regime of controlled diet and exercise. To quote a handbook on diabetes care for health care professionals [8, p. 15]: "It should always be borne in mind .. that professionals involved in diabetes care are treating patients and not (blood glucose) levels."

The key 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.

Figure 2 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
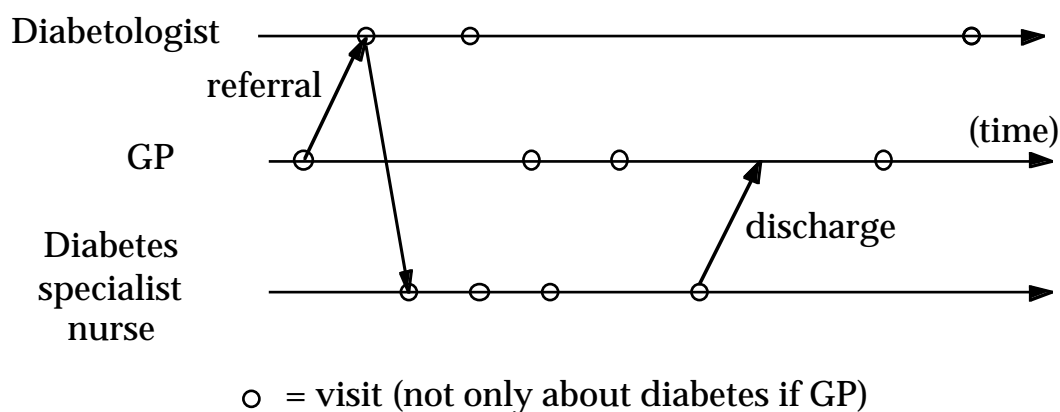
o = visit (not only about diabetes if GP)

Figure 2. A pattern of concurrent treatment by several clinicians

- 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.

Figure 3 shows the main health care sites that were the subject of our study. This is a typical organisation for shared care. A hospital unit called the Diabetes Care Centre (DCC) is shown in the middle of the figure. On either side are the other hospital sites that the DCC works with (shown merged), and the general practices in the area (shown merged). The idea of this organisation is for the DCC to provide a concentration of diabetes-related specialists, including a specialist nurse to liaise with other sites, particularly with the general practices.

The three diabetologists at the DCC provide expert treatment of diabetic out-patients in the area. These clinicians also oversee in-patients on the wards of a local hospital. They are assisted by trainee doctors – the registrars and senior house officers (SHOs) – whom they supervise and advise. The diabetes specialist nurse at the DCC advises patients and other clinicians, in person and by telephone. She has her own list of patients to see. The DCC also has a chiropodist and dietician.

At the other hospital sites patients see specialists in ophthalmology, neurology, vascular surgery and renal medicine, who treat the complications of diabetes. In the general practices diabetic patients see their GPs as well as (in some cases) a practice specialist nurse. Before describing the interactions between clinicians, we first look at individual consultations.

**CONSULTATIONS**
We have observed consultations at a practice and at a DCC. We now provide some illustrations to help characterise the work at these sites.

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 [13]. 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

Hospital departments

consultant

Opthalmology,
Neurology,
Vascular surgery,
Renal unit

consultant educates/advises registrar/SHO

specialist nurse

seek information, liaise

Diabetes Care Centre

chiropo-dist

dietician

seek advice

refer

refer

consultant (x3), registrar, SHO

seek advice

refer on to

specialist nurse

respond after referral

seek information, respond to referral

Practices

inform

GP

discussion, database sharing
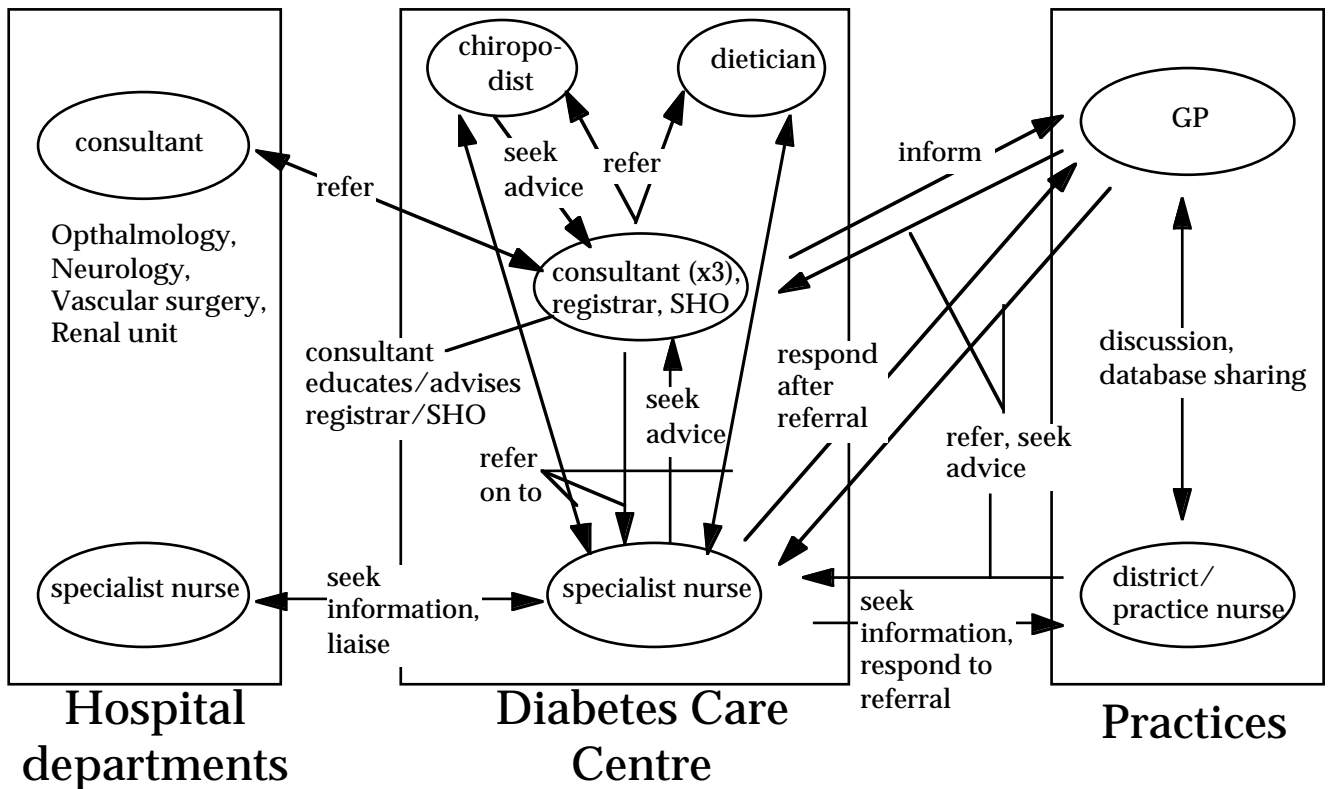
refer, seek advice

district/ practice nurse

Figure 3. Clinicians and their interactions. District nurses, who see patients at home, are shown based at practices. Some other points of care, such as opticians and self-help groups, are not shown.

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 disease is dynamic, information is limited and conclusions, in the sense of 'final remarks', are not what are sought. The matter is not being ended: it is being monitored and subjected to controls. Evidence is being gathered. Not everything, as we shall see, is necessarily what it seems to be. Not everything that comes to light is relevant to caring for the patient's diabetes – although it may be of some medical concern. If the patient is there specifically for diabetes, then other – non-urgent – conditions will be ignored.

An epistemological account of diabetes care has to recognise that the different participants have different bodies of knowledge – both in the sense of knowing *that* certain things are true, and knowing *how* certain things are done (expertise). How does what they do relate to what they know? How do they deal with lack of knowledge? Do they know when they lack knowledge? To what extent do they scrutinise and doubt what is presented to them? Doctors have to be sceptical to a certain extent. They are trained not to jump to conclusions. They are also trained not to take at face value what the patient, who has a subjective view of his or her condition, says. The patient 'knows' exactly what he or she feels, but the phenomena may map entirely differently into the clinician's domain. We shall see a striking example of this shortly.

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. Here is a typical statement to the patient:

Your blood sugar is going up. It might be a natural progression (your insulin-producing cells are not replaced when they die). I'd like to check your results in three months. And we'll see if the doctor would like to change your medicine today.

Note that the nurse has exercised judgement in deciding that a review in three months is necessary – another patient, with a stable condition, might not be seen for a year. But the limits to where the nurse may exercise her judgement are shown by her deferral to the doctor over whether the patient's medicine needs changing. Whether the nurse in fact knows enough and is capable of making such a judgement is irrelevant to this process. 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.

The first proposition in the nurse's statement 'Your blood sugar is going up' is an empirical fact revealed by objective

(although fallible) measures. It wasn't derived from anything the patient said. But the patient in this case immediately accepts it, and cooperates with the nurse in discussing possible dietary causes. In fact, the patient subsequently seized upon the statement that all may not be objectively well and began to talk about her feelings of depression.

The nurse's statement derives from comparing blood test results between this and the last review. There are two types of test for measuring blood glucose levels, which we shall refer to as the 'finger-prick test' and the 'lab' blood test[2]. The chief differences between them are:

- the finger-prick test records an instantaneous blood glucose level, whereas the lab blood test records a value that is averaged over about a two-month period

- patients can administer the finger-prick test themselves (by jabbing themselves on the finger and absorbing the blood on a sensitive strip); the lab blood test has to be performed at a laboratory, and scheduled two weeks before the patient's review so that the result is available.

At each consultation for diabetes, the clinician takes a finger-prick test. This result is a piece of evidence of known origin: the test was administered by the trained clinician, who can ask the patient when he or she last ate to make sense of the value. The finger-prick result helps detect clinically significant swings in glucose levels – particularly if a poor finger-prick result coincides with a good lab result. A patient, on the other hand, may err in testing himself inaccurately, not recording the results systematically, or forgetting to note when (in relation to meals) he tested himself.

For all the advantages of finger-prick tests, the nurse has compared the *lab* test results to produce her statement. The status of the finger-prick result is in part an interesting testament to the clinicians' awareness of the frailty of their patients' human nature. Patients are sometimes 'good' just before their annual review, even though they have been careless of their control prior to that. For example, they may have stopped drinking alcohol and started eating sensibly a week or so before the review, in order to appear to the clinician – or to themselves – to be managing their diabetes effectively. In other words, these patients have learned some of the grounds for the clinician to say 'your diabetes is stable'. But they do not grasp the wider theoretical picture behind such a statement. Indeed, it can be argued that even the clinicians' operational picture is open to scientific doubt. The correlation between the *degree* of glucose control and the incidence of each particular type of complication is not wholly understood. But the system operates as though it were. This cautious approach is exercised with respect to the clinician's objective description of the disease – as we pointed out above, this may sometimes conflict unnecessarily with the patient's need for quality of life.

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[2]Clinicians refer to the finger-prick test as a 'BM' or 'HBGM' test; the lab test is an 'HbA1C' test.

Another discrepancy that may occur between one sort of evidence and another is illustrated by the following exchange between a patient (P1) and the diabetologist (D) at the DCC. P1, who has been attending the DCC regularly, is known to D as a conscientious patient. P1 produces sheets containing daily blood-glucose results, which she has obtained herself. They discuss the notation she has used, but D quickly interprets the figures to his satisfaction.

D: How have you felt in yourself?

P1: Not well at all – sugary.

D: You've been far from sugary!

P1: Sometimes, yes.

D: Generally it's been quite good, to be honest. If anything you've been a little low.

The patient's subjective observation belies what D sees as the reality. On the one hand it is this reality that he must treat – and he goes on to weaken the medication she is taking. On the other hand, his responsibility is to try to assuage this patient's genuine feelings of illness. The dialogue continues:

D: (*looking at the computer screen and finding the readings recorded from the patient's last visit*) Your control has been OK. You've put on a tiny bit of weight. Have you had hypos (*hypoglycaemic attacks*)?

P1: I had two yesterday.

D: You're on Mixtard 50 – I wonder if you'd be better on the Mixtard 30 – what you used to be on. When did you change?

P1: In hospital last time. Dr X changed it.

D: I think you may be better controlled on the Mixtard 30.

P1: What do you think has caused all this? (*goes on to describe stressful personal circumstances*).

D: I'm sure it's that rather than the diabetes (that has been making you feel unwell).

Sometimes even the medications, let alone the clinicians' view of the disease, are beyond the patient's practical grasp. This same patient, like several others we observed, arrived with a bag containing all her medication. It was simpler to produce it for the clinician to look at, than to try to remember it all. Several patients did not seem to know what all of their medication was for. For the clinician D, the presentation of the medicines is a good opportunity to establish some facts that may be germane to his or her treatment, or to that of another clinician. He is often starting from scratch since he last saw the patient, because, as in the last example, another clinician may have altered a dose, or prescribed something new. Even with the medicine bottles in front of him, D sometimes confirms the level of the dose with the patient. Even if he has the background training that the other clinician will have applied, he does not know the exact circumstances or line of reasoning or knowledge that the other clinician availed herself of. The patient, in almost all cases, cannot tell him.

## PATIENT RECORDS

Clinicians keep electronic and/or paper records which they consult during their sessions with the patient. At the practice we observed, records were only taken electronically. But the clinicians also read folders of paper notes (letters etc.). Even a practice such as this whose stated aim is to 'go paperless' has to exist in a world which largely uses paper to pass information between clinicians. At the DCC, the diabetologist uses paper as well as a database to record his case notes. This is in part because he travels between sites, and can carry paper with him while the data is transferred electronically (which happens once a day).

The subject of paper versus electronic patient records has been studied elsewhere (e.g. [14], [15]). Our preliminary impression is that the paper notes can *not* be entirely replaced by the software that these clinicians use. It seems that paper folders are easier for the clinician to navigate than the screens of their database. They do not cause the clinician to face away from the patient. They are portable between any medical sites. Hand-written records can utilise "defeasibility" [14] for the sake of conciseness, and other clinicians can recognise the identity of their author. Of course, these are not arguments against all conceivable forms of electronic patient record; and electronic records have important advantages.

But there are philosophical difficulties with electronic records. That is, there are questions which seem to lie at the borders of our understanding of everyday things. First, the diabetologist gave us another reason for recording case notes on paper as well as in electronic form. He prefers to have a signed piece of paper to attest to what he has done, should he ever be sued for negligence. The alternative for him would be for the notes to be recorded electronically and unsigned. It is however possible to 'sign' data digitally – would this be a solution? First, there are technical and legal matters here. Digital signing raises several issues, such as the problem of inadvertently exposing the signing key to a third party. We could rely on the judgement of the courts to guide the clinician and his colleagues, taking technical matters into account. But that would be to beg the question of how the courts should reach a resolution. Wittgenstein argues [1] that the meaning of a word or gesture can be equated with how it is used. So what does it mean to sign a document? The answer is not simply technological. Consider that an 'X' mark can count as a signature. Or that a clinician could just as easily substitute rewritten case notes as he could alter electronic records. If meaning is a convention of usage on which people agree, how does the meaning of acts such as signing evolve as we change the conditions of people's work, and agreement lags behind?

The second difficulty with electronic records also concerns meaning and use. One of the doctors we spoke to was unhappy that the screens she had to fill in did not have a 'margin'. On a paper record, she records tentative observations in the margin, with the understanding that another clinician will by this fact realise the remark is tentative. Again, if meaning equates to use, how is she supposed to 'mean' her remark tentatively, when placing it in an electronic form? We can think of ways to create 'virtual margins'. But this is to introduce an artefact whose 'meaning' precedes its use: its meaning is *de jure*, not *de facto*.

## COORDINATION

Despite the loosely coupled nature of much of the clinicians' work, it is of course coordinated: patients are treated, by and large, by appropriate clinicians. We have seen how they are sometimes treated concurrently by several clinicians. But there is no single locus of day-to-day control.

Clinicians sometimes communicate directly by letter or telephone, and sometimes they become aware of one another's actions indirectly through the patient as a 'communication channel'. In the example above involving a diabetologist D and his patient P1, we saw that another doctor had changed the patient's prescription, and that D discovered the change during the consultation (he asks of her medication: "when did you change?"). For a peer to make a minor change to the patient's prescription is not considered a significant enough event to warrant direct communication. But communication can be surprisingly absent (or ineffective) at times. On another occasion with a different patient P2, D has just established that the patient is taking aspirin. The connection with heart disease prompts the patient:

P2: I went to (a different hospital).

D: What happened there?

P2: I was admitted for a week. They told me the pain starts from the heart. They sent me to (this hospital).

D: Have you got another appointment?

P2: Yes, for the Cardiac clinic in January.

D did not know about this episode. The patient is seeing him for the first time, but even with a familiar patient it is not unusual for other such problems to have begun between reviews. It is another aspect of needing to start from scratch in some respects whenever the clinician sees the patient. Note that D might conceivably never have learned about this recent episode. He is, after all, a diabetologist and the patient is not presenting him with the cardiac problem (although D had asked about chest pains). D duly notes what the patient has told him:

Admitted (a hospital) for ?angina

appn (another hospital) cardiac clinic January 98.

Compare this situation with one involving a shared document which several users can edit. In some respects it is as though we discover that someone else has edited a section we have been working on. But, in the clinical setting, clinicians assume that normally no other clinician will make an inconsistent change. Furthermore, they assume that if some other section requires changes, then the appropriate person will edit it. Usually, a patient with a significant medical problem will present it somewhere in the health care system, and they will as a result be referred on until an appropriate person treats it.

Figure 3 shows direct clinician interactions, marked by arrows. These are referrals, or advice-taking, or information-giving between clinicians. The reader should not be misled by the number of arrows in this figure: many of the interactions shown are infrequent and they are often minimal in information content. Referral from clinician A to clinician B occurs when:

(1) an aspect of the disease is beyond, or may be beyond, clinician A's expertise. For example, a GP may refer the patient to the diabetologist for this reason.

(2) while the symptom is not necessarily beyond clinician A's expertise, it is deemed more appropriate, on grounds of role, for clinician B to treat or advise or educate the patient about it. For example, both GPs and diabetologists examine patients' feet for signs of severe complications, but they may refer the patient to a chiropodist for basic help with foot care.

Note that referrals occur within the health care levels, and not just from primary to secondary levels. For example, the diabetologist will refer a patient with eye complications to the ophthalmologist. In all cases of referral, clinician B is expected to exercise independent judgement over an aspect of the treatment, within the bounds of his or her competence and responsibilities. In case (1), clinician A may contact clinician B to discuss and take advice on whether referral is necessary (thick arrows). Otherwise, clinician A simply makes the referral. In case (2), referral is made as a matter of course.

Type 1 referral is an act that must involve communication between clinicians in order to be recognised as such. Patient P2 above claimed that another hospital had 'sent' him to see the diabetologist, but the latter was unaware that a *referral* had taken place. Let us return to our diabetologist, this time with patient P1, whose dose was changed:

P1: Has Dr. A been in touch with you? I saw him on Friday.

D: No. I'll see if there is anything in the notes.

P1. He said he'd get in touch with you about my hands.

D leafs through the notes while they are discussing more tests for P1, but the subject of Dr A's referral never comes up again.

At this point, something appropriate has been arranged (the change from Mixtard 50 to Mixtard 30) and the session is near its close. Everything else is 'future', to be handled as it arises. The 'Dr. A' incident effectively does not yet exist – the referral letter must first be received. If it were an urgent matter, the referring doctor would be responsible for ensuring that the referral happened quickly. Clinicians in the primary sector are issued with guidelines giving criteria for referral of diabetic patients to the secondary sector [16]. Alongside the criteria are instructions on whether the referral is 'urgent'. One case, involving children, specifies 'a same-day telephone referral'.

The guidelines suggest that the referral criteria should be:

"agreed locally and should take account of the level of skill and interest in the management of diabetes amongst primary health care teams".

This description – especially the notions of skill and interest – covers a large amount of ground that we have yet to cover thoroughly in our study. Every clinician has, formally and conventionally, certain skills by virtue of his or her role ('GP', 'ophthalmologist' etc.). This organisational association of role and expertise is supposed to assist clinicians in routing patients through the system to the appropriate health-care giver. But it raises two issues: first, there is the question of whether those involved agree with this division of labour. Second, there is the question of grey areas where the mapping between expertise and roles is not clear.

Clinicians, of course, are well aware of these grey areas. For example, one GP, whose views may or may not be representative, felt that the secondary sector was trying to hold onto certain skills which could be transferred to the primary sector – where he wanted to practice them. But he was obliged to refer his patients to the secondary sector. 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, in deciding 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.

The guidelines do not attempt to advise about the form in which a referral should take place. Should it be negotiated with the secondary clinician? What information should be supplied? For example, it may be relevant that a patient is impotent, but the patient won't necessarily wish to talk to the secondary clinician about this. GPs and hospital consultants are extremely difficult to get hold of by telephone. Referrers quickly learn not to attempt telephone contact, except in an emergency. They resort to writing letters. Some time later they may receive a letter informing them of any actions that have been taken or diagnoses made. Figure 3 shows that the DCC's specialist nurse sometimes gives feedback to GPs about the referrals they make. Often, however, referrals do not receive responses to the act of referral itself: was it necessary or unnecessary? Was sufficient information supplied? What should and could the referrer do differently next time in similar circumstances?

**On-site cooperation**
Clinicians work to some extent as teams on-site. In particular, the diabetologist and GP each work with their specialist nurses at the DCC and general practice respectively. In each case, the nurse and doctor share a database. At the DCC, the nurse made relatively little use of the database, but often came into the diabetologist's consulting room to ask for advice. At the practice, there is much database-sharing but relatively little person-to-person discussion. The DCC's nurse is a highly experienced worker entrusted with a degree of freedom to vary patients' insulin doses. This critical matter is considered beyond the

practice nurse's remit: in fact she and, sometimes, the GPs consult the DCC's nurse about insulin dosage. The difference in criticality of their jobs is reflected in their access to the doctor's precious time. At the practice, the nurse enters data and the doctor peruses the patient record at the subsequent consultation. Neither updates the data in the folder of paper notes. The nurse at the practice told us that sometimes, if she wanted to bring something to the doctor's attention, she would personally hand the folder to the doctor just before the patient saw the doctor. This exchange of the notes is an opportunity to remark about the nurse's concern. She is thus able to synchronise her communication non-disruptively into the doctor's work, and lend personal impact to her message.

Communication through the database alone is fallible. First, the GP sometimes misses minor matters that the nurse had recorded. Second, not all data is in the database. Consider the following exchange between the GP and patient P3, who has just seen the practice nurse:

> GP: I'll just go through what (*the nurse*) has noted down so far (*looks at screen*). You had a little bit of protein in your urine. Did she mention that to you? (*P3 affirms*) Your cholesterol is good. Did she tell you the results? (*P3 affirms*).

> GP (turns to folder of notes): Your blood sugar is higher. (*P3 expresses surprise.*)

It is unlikely that the nurse forgot (it would be inconsistent with the usual thoroughness we observed). The GP's questions about whether the nurse told the patient these things are rhetorical. They serve to check the patient's understanding. The GP does not doubt the nurse. The most likely explanation for the omission is that the notes folder was not given to the nurse on this occasion. There can be several concurrent demands on the notes within the surgery, and at a busy time they can be temporarily mislaid or may be given straight to the GP instead of the nurse by mistake. On a previous occasion when this happened, the nurse told us 'I feel lost without the notes'.

It is not clear exactly in which respects she was, as opposed to felt, lost. Irrespective of the precise circumstances, this brings us to a general point about empirical knowledge. A subject can only know something empirically if she is presented with evidence for it which she *sees*. The lack of systematisation in the information presented to clinicians means that overlooking is possible, as well as omission. We saw several harmless instances of this. The neglected lab result may in fact have been available in the nurse's computer system (these results are also delivered electronically). But finding it there is time-consuming and inconvenient and normally to be avoided in favour of the notes. This location may not have been in her search path, if she was pressed for time.

## SUMMARY & DISCUSSION
We have reported the initial findings of an ongoing study of the shared care of diabetic patients at a diabetes care centre and general practice. From observation and interviews with clinicians we have arrived at an outline characterisation of aspects of their work, which we have illustrated.

The first observation is that much of the work is loosely coupled. This is especially so between GPs and consultants. The exception is between some doctors and nurses. By loosely coupled, we mean that direct interaction between clinicians is infrequent. And when it does occur, it is often in the form of a 'one-shot' communication. For example, one clinician writes a letter to another to make a referral, or asks the patient to 'go and make an appointment with the chiropodist' (bearing a brief note).

Nonetheless, coordination and cooperation does occur, in a decentralised way. Any ill patient will enter the system at some health care point (whether it be an accident-and-emergency department or at an appointment with a GP), and thereafter must be routed to appropriate specialists and general carers. Between the different clinicians it is essential that there is recognition of one another's domains of knowledge and expertise. The system defaults to a conventional division of knowledge, but there are grey areas and in these areas individual clinicians may make their own judgements about one another's individual expertise.

We have shown that the clinicians inhabit an uncertain world. Far from having a system that keeps them aware [17] of what each is doing, clinicians must at each episode verify and rebuild their picture of the circumstances surrounding each patient. A patient's treatment is realised as a series of consultations (often with little communication concerning the patient with others in between). At each consultation, the clinician assembles evidence from sources of varying reliability and works it up into a statement to the patient and into something appropriate to happen subsequently. The clinician's long-term responsibility is executed in this short-term form.

We have also argued that a complete description of the work involves an account of the epistemological frameworks of those involved. It is not enough to say 'this is what the clinicians do, these are their aims.', if we are to understand the effects of changes in support on their work. We must also discover how they work up evidence into knowledge; and what grounds they have – or believe they have – for what they say and do. If a GP 'knows' that he needs to refer the patient to a certain specialist, what are his grounds for knowing this? Does he, for example, say: "It's what I always do: it seems to work." Or: "Dr X told me always to send her a patient who has these characteristic patterns on her retinas."?

We have suggested that certain philosophical techniques may help us to elucidate the target group's work. These include investigating the grounds for everyday assertions made by the target group, and testing the boundaries of what makes sense as part of their work. This is not to be confused with doing philosophy. It seems clear that, for the purposes of CSCW, there are no boxes that cannot be opened up in order that we may examine what is inside. Indeed, there is perhaps no hard distinction between these techniques and what those who study work already count as

falling under ethnographic analysis. But we feel that the philosophical literature is a source of fresh ideas.

We are led to wonder whether philosophy can throw some light on the process of design. Wittgenstein's beetle-carrying boxes are givens, what he calls the 'outward criteria' for 'inner processes' in our shared 'forms of life' [1]. The CSCW literature is full of *designs* for boxes. We call them 'awareness widgets', 'media spaces' etc. Can an understanding of how the outward criteria work, philosophically speaking, help us produce better designs?

## ACKNOWLEDGEMENTS

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