

**Intricacies of Professional Learning in Health Care**  
**The Case of Supporting Self-Management in Paediatric Diabetes**

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## **Declaration**

I declare that I have composed this thesis myself and that it embodies the results of my own research. Where appropriate, I have acknowledged the nature and extent of work carried out in collaboration with others included in the thesis.

Sarah Doyle

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## **Abstract**

This thesis offers a rethinking of the role for education as critical workplace pedagogy in complex problems of health care. Taking the case of paediatric diabetes, the study explored how health-care professionals learn the work of supporting children, and their parents, to self-manage the condition. By reconceptualising work problems as sociomaterial learning struggles, this research contributes new understandings of informal professional learning in everyday health-care provision.

Data were generated through fieldwork in an outpatient clinic. Particular challenges of supporting self-management in this case were the difficulties of balancing policy aspirations for empowerment with biomedical knowledge about risks to immediate and long-term health. Tracing the materialisation of learning as it unfolded in moments of health-care practice showed professionals handling multiple and contradictory flows of information. Particular challenges were posed by insulin-pump technologies, which have specific implications for professional roles and responsibilities, and introduce new risks.

A key insight is that professionals were concerned primarily with the highly complicated perpetual discernment of safe parameters within which children and their parents might reasonably be allowed to contribute to self-management. Such discernment does not readily correspond to the notion of empowerment circulating in the policies and guidelines intended to enable professionals to accomplish this work. As a result, this thesis argues that the work of discernment is obscured.

Learning strategies evolve, but could be supported and extended by explicit recognition of the important work of learning as it unfolds in everyday practices of supporting self-management in paediatric diabetes. Most importantly, workplace pedagogies could be developed in ways that attune to the profound challenges and uncertainties that are at stake in these practices.



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# 1 Working and learning in paediatric diabetes

## Introducing the study

### Lauren

A diabetic Fife teenager who died during a school trip was laughing with her friends moments before she suddenly collapsed, an inquest has heard. Lauren, 14, had been diagnosed with type 1, insulin-dependent diabetes in 2000.

The inquest heard readings from her electronic testing machine indicated that her blood glucose levels had fluctuated wildly in the months before her death and the last reading she took, at about midnight, showed it was unusually high at 28.9 millimoles per litre. A mark on her thigh suggested she had injected herself with insulin as a result.

Recording a verdict of death by natural causes, coroner Dr Andrew Reid said: "It appears that it was with some difficulty that she (Lauren) controlled these blood sugar levels and that is a reflection of the nature of the disease and no criticism of her or those who cared for her."

(‘Diabetes Caused Fife Teenager’s Death’, BBC News, 2010)

I begin with this BBC News report because it is a powerful insight into the challenges that children, parents and health-care professionals face as they try to manage diabetes. The risks are frightening and as the coroner recognised, the condition is difficult. Reading about the death of this young person is harrowing, and it is especially poignant for me because I am a parent of a child with type 1 diabetes. That there was no reason to lay blame for what happened to Lauren is not sufficient basis for assuming that all is well in the provision of support for those who are self-managing diabetes. Rather, the nature of the condition and

the potential for devastating outcomes underscores the need for highly skilled health care. And yet, the year after Lauren's death the Health Foundation (2011) acknowledged that still very little is known about how to help clinicians learn to provide the support that best enables people to self-manage long-term health conditions.

My research makes a contribution by examining what I call the intricacies of professional learning as clinicians encounter and respond to the problems and challenges of supporting self-management in paediatric diabetes. My focus is not on formal programmes of education and training but instead on the informal learning that emerges in the hospital clinic settings of everyday work.

Before turning to introduce my study more generally, I want to mention Lauren once more. I chose to open my thesis with Lauren because although this educational research focuses on health-care professionals, I am always mindful that the well-being of children and their parents is also entangled in these questions of professional learning. Lauren and others like her are important stakeholders in such research, even if they are not central in this particular empirical investigation.

### **The challenges facing health-care professionals**

Health-care workforces across the UK and globally are facing a series of seismic transformations in the coming years. In the recently published *National Clinical Strategy for Scotland* (Scottish Government, 2016), for example, these transformations include radical redistribution of hospital and community health services, increasing integration of provision for health and social care, and growing development and uptake of digital technologies in both the organisation and in the delivery of health care. Alongside and as part of such transformations, individual and community responsibility for health continues to be a key priority (Health Foundation, 2011). Self-management, defined as 'a concept where a person takes ownership and is central ... a process of becoming empowered to manage life with long-term conditions' (Long Term Conditions Alliance Scotland,



2008, p. 5), is set to become a pillar of sustainable health care (Department of Health, 2014; Scottish Government, 2016).

Both the proliferation of digital technologies and the emphasis on positioning patients as autonomous and active decision makers have particular implications for health-care professionals. Digital technologies, as others have shown (see, for example, Pols and Willems, 2010; Oudshoorn, 2011; Halford et al., 2015), do not slip unnoticed into existing arrangements but instead require considerable adaptation of associated work practices. Similarly, efforts at privileging patients' autonomy sometimes alter professional roles and responsibilities in significant ways: as Morden et al. (2012) have shown, balancing patients' preferences with predefined optimal biomedical outcomes is not a straightforward accomplishment for the clinicians involved.

Of particular note in my own study is the way in which digital technologies and the emphasis on self-management combine to produce particular effects. Digital technologies expand the possibilities for patients to monitor and respond to bodily functioning, and increase the expectations that they do so (Lupton, 2013a; 2013b), thereby augmenting the effects of self-management policy directives. However, digital technologies can also introduce particular new risks (Webster, 2013; Petrakaki et al. 2014). Such new risks prompt the emergence of corresponding new roles and responsibilities as professionals learn to respond.

### **Professional learning**

My study focuses on the ways in which health-care professionals learn to work with and within such reconfigured arrangements for health care. Following Fenwick (2008), I am interested in the learning struggles of health-care professionals, or in other words, the informal learning that unfolds in everyday work. Such a focus on learning struggles draws attention to the challenges that health-care professionals encounter, consider, explore and (temporarily) resolve. This is not to suggest that there is a smooth, linear process of learning. Instead,

tracing these learning struggles helps to illuminate myriad fine-grained intricacies.

The kinds of workplace problems I have sketched in the preceding sections are often not recognised as learning struggles at all but instead might be addressed as problems of policy implementation or as problems of health-care practice. Informal workplace learning is often rendered invisible in this way (Boud and Middleton, 2003; Fenwick, 2008). However, there is considerable value in examining workplace problems as problems of learning. Such an approach opens up scope to better understand not only the learning that enables professionals to meet challenges but also to better understand the possibilities for enhancing that learning through pedagogical interventions (Boud and Middleton, 2003; Fenwick, 2008; Fenwick and Nerland, 2014). Pedagogy refers not only to instructional techniques but can be considered more widely as a critical educational approach (Zukas, 2006) that also pays attention to the effects and purposes of education and learning.

In this investigation I define professional learning, following Fenwick (2008, p. 19), as ‘expanding human possibilities of flexible and creative action in contexts of work’, and I focus on heterogeneous relations among people and things. In this way, I am drawing from a research tradition that is concerned with both the social world and also with materiality and material effects. In such *sociomaterial* traditions, equivalent attention is paid to social and to material entities, and in fact the focus of attention is on relations rather than on people or things (Barad, 2007; Fenwick and Edwards, 2010; Fenwick et al., 2011). Respecting the commitments of sociomaterial approaches is ‘not simply a matter of adding material objects to the account and stirring’ (Mulcahy, 2012, p. 135) but is instead a carefully nuanced sensibility that takes account of the active participation of human and non-human forces, and pays close attention to the effects produced. I return to discuss the challenges and implications of such commitments many times in the chapters that follow.

A sociomaterial understanding of learning opens the way to studying learning as an enactment (Sørensen, 2009; Fenwick and Edwards, 2010; Mulcahy, 2012) or, to put it differently, to study the ways in which learning materialises. Empirically, one way of proceeding with such an investigation is to examine learning as recursive configurations and reconfigurations of work practices as they unfold in all their mundane detail (Gherardi, 2006; Fenwick, 2010; Gherardi, 2012; Hager et al., 2012). It is this practice-based approach that has informed my own research. In particular, I draw on Gherardi's (2006; 2010; 2012) conceptualisation of knowledge as knowing-in-practice, which offers an approach to studying learning as a practical accomplishment rather than as a purely individual, cognitive process. This approach recognises that professional knowledge is embedded in working practices and also that professional knowledge is situated in particular contexts and arrangements of and for work (Gherardi, 2006). These understandings of work problems as learning struggles, together with recognition of learning as a sociomaterial phenomenon that can be investigated as a practical accomplishment, form the basis for my study of professional learning in the everyday work of health care.

### **Research overview**

Paediatric diabetes is an important locus for this research for several reasons. First, as I show in subsequent chapters, professionals in this field face considerable learning challenges because of the complexity of new policies, changes in arrangements for care provision and the introduction of new technologies. The complexity of new diabetes technologies, particularly insulin pumps and blood glucose monitoring systems, continues to create considerable difficulty for children and their parents (Juvenile Diabetes Research Foundation, 2013) and also for the health-care professionals who provide self-management support. Second, the number of children diagnosed with the condition is rising at an alarming rate every year (International Diabetes Federation, 2015), and so knowledge about pedagogical interventions that might enhance professional learning in this case is highly relevant for health-care services and for health-care

educators. Third, diabetes is a difficult condition to self-manage, with potentially devastating consequences, as the earlier BBC News (2010) report about Lauren shows. Last, as I show in this study, supporting self-management is especially complicated in paediatric settings because of the need to attend not only to the child with diabetes, but also to the parents, who might be undertaking much of the daily management of the condition.

The research questions that were formulated to guide my study are as follows:

- For health-care professionals, what practices and challenges emerge in the work of supporting self-management in paediatric diabetes?
- What related processes and issues of professional learning unfold?
- What in particular are the effects of insulin-pump technologies on professional learning?
- What are the implications of the insights generated by questions (1), (2) and (3) for workplace pedagogies?

The need to trace what professionals actually *do* (Fenwick, 2008) in their everyday responses to workplace problems, and to trace the learning that unfolds, seemed well-suited to a research approach based on ethnographic traditions. Accordingly, this study is based on my fieldwork in an outpatient paediatric diabetes clinic and on the observations, conversations and encounters that in turn generated field notes and interview transcripts. The seven nurses, four doctors and two dieticians who participated in my study allowed me to observe their work in clinic consultations with children and parents, and were endlessly willing to show and explain the details of their work: including me in team meetings and answering my many questions.

The unique contribution this study makes is to argue for a methodology of workplace learning that could help health-care professionals to respond to the problems they encounter when supporting self-management in paediatric diabetes. I present a detailed exploration of the work of supporting self-

management in this case, which shows it to be very much concerned with the highly complicated perpetual discernment of safe parameters within which children, and their parents, might reasonably be allowed to contribute to diabetes management. This focus on safe parameters is not addressed in current approaches to education for health-care professionals supporting self-management, suggesting that a new direction for professional learning is needed. The particular value of such new insights is in the potential for workplace learning to be more carefully aligned to the very specific nature of the work; thus better enabling health-care professionals to support children and their parents.

In the remaining sections of this introductory chapter, I discuss the background and the wider context for my research. Turning first to the broad policy directive of self-management, I explore some of the key debates that generate criticism and controversy. I consider challenges that face the health-care professionals who are tasked with supporting self-management, and relate the current prevailing approaches to education and training, together with brief examples of available educational resources. Moving on to discuss paediatric diabetes, I focus on some of the specific challenges of supporting self-management as a way of introducing this particular empirical case and provide a basic explanation of the nature of the condition. Shifting direction to explain the theoretical and methodological approaches that I have employed, I introduce the particular gathering of sociomaterial ideas that has influenced my study and the ways in which I have investigated professional learning by examining practice and knowledge. The final pages of this chapter detail my own position as the researcher in the study and close with a description of the structure of the thesis.

## **Self-management: the policy directive**

### **The rise of long-term conditions**

In order to understand the challenges professionals face, it is helpful to appreciate the wider policy context. Spiralling numbers of people with long-term conditions such as asthma, diabetes and chronic heart disease are, we are told,

exerting intolerable pressure on health-care services (Wallerstein, 2006; Audit Scotland, 2007; Department of Health, 2012; International Diabetes Federation, 2015; Scottish Government, 2016). A long-term condition is one that cannot, at present, be cured and is instead managed with medications and/or other treatments (Department of Health, 2012). Increasing rates of survival combined with increasing numbers of newly diagnosed cases are creating significant concerns about the proportion of available budgets devoted to those with long-term conditions and about the anticipated rise in costs over the coming years (Department of Health, 2012).

Consequently, ensuring that people with long-term conditions can rely less on health-care professionals and more on their own personal self-care capacities has become a prominent feature of health-care provision. The frontline implementation of this policy response is termed self-management, and it is defined as ‘a concept where a person takes ownership and is central. It is a process of becoming empowered to manage life with long-term conditions’ (Long Term Conditions Alliance Scotland, 2008, p. 5).

In a corresponding move, health-care professionals are increasingly expected to focus on *supporting* self-management, which is in turn defined as ‘the assistance caregivers give patients with chronic disease in order to encourage daily decisions that improve health-related behaviours and clinical outcomes’ (Bodenheimer et al., 2005, p. 4). However, as pointed out in the opening pages of this chapter, little is known about how best to help health-care professionals learn this work (Health Foundation, 2011; NHS Education for Scotland, 2012).

### **Key debates**

In health policy literature, self-management is clearly identified as an important strategic directive with two broad aims: to improve clinical outcomes in long-term conditions and to reduce reliance on health-care services (Wallerstein, 2006; Scottish Government, 2007; Department of Health, 2010). There are ongoing debates about the extent to which current approaches to supporting self-

management are achieving these aims and even about whether these aims are achievable. One report by the Health Foundation (2011) concludes that while overall, supporting self-management is worthwhile, not all approaches to supporting self-management are equally worthwhile. For example, it is argued that interventions focusing on information provision produce different effects when compared to interventions that focus on changing behaviour (Health Foundation, 2011), yet both types of intervention are considered to be support for self-management. Moreover, it is not at all clear that supporting self-management leads to a simple reduction in the use of health-care services, and instead it is possible that supporting self-management tends to change the ways in which health-care services are used (Health Foundation, 2011).

The notion of empowerment pervades much of the literature and policies that focus on supporting self-management. However, it is not unusual in these writings for empowerment to be conceived as something that can be 'done' to others, or somehow imposed, as a way of producing officially recommended improvements in health (Spencer, 2014). Such conceptions of empowerment differ greatly from the political emancipation anticipated by Freire's (1970) emphasis on critical consciousness-raising, which explicitly recognised the importance of people choosing for themselves.

Sociologists have taken a keen interest in the social implications of devolving health-care responsibilities and in the lived experiences of those engaged in managing their own health. Critiques argue that citizens willingly undertake surveillance of their own health as certain kinds of 'healthy' bodies become more valued by society than others (see in particular Lupton, 2013a; 2013b). Focusing on transitions in the social relations of health care, Bury and Taylor (2008) contend that the role of the patient is being refashioned into a form of 'managed consumerism', which they argue creates and encourages certain patient experiences over others. Further, there are concerns that expecting individuals to rely on their own capacities for self-care does more to promote the aims of neo-liberal government agendas rather than to enhance personal choice about health (Morden et al., 2012).

However, being tasked with self-monitoring of bodily functioning can be burdensome and difficult to incorporate into everyday life (Mol, 2008), and people do not always share the particular aims of their health-care providers: Law and Mol (2004) have shown that people with diabetes express different personal views about whether to make the Herculean efforts required to minimise long-term ill health or whether to prioritise immediate quality of life. Moreover, the proliferation of digital technologies in health care often encourages more complicated and more frequent work on the part of the individual (Oudshoorn, 2011), leading Lupton (2013a, 2013b) to reflect on the mixed blessing of the quantifiable self as more and more bodily data can be generated, recorded and shared.

These debates notwithstanding, health-care services continue to reorganise around self-management and the provision of self-management support. Websites such as [www.nhs.uk](http://www.nhs.uk) offer information and advice about symptoms and management of depression, back pain and diabetes, for example, as one way of reducing reliance on primary care practitioners such as family doctors. Telehealth services have been introduced to enable people to use specialist health technologies at home in order to monitor particular aspects of bodily functioning and to share recorded information with health-care professionals. For example, Oudshoorn (2011) has written in some detail about the introduction of a cardiac telehealth service, and the ways in which patients monitor and measure their own heart function. Rather than attend frequent outpatient appointments, these patients are shown how to select pertinent information to share with health-care professionals, in order that advice might be conveyed by telephone (Oudshoorn, 2011).

### **Implications for health-care professionals**

However, even as the work of supporting self-management continues to be an increasingly important aspect of health care, there is growing recognition that little is known about how best to help health-care professionals learn how to accomplish such work. Patients are repositioned as experts and are expected to



take on roles and responsibilities formerly restricted to health-care professionals, yet the corresponding implications for the health-care professionals themselves have received much less attention. Calls for a fundamental shift in relations between health-care professionals and people with long-term conditions (Wallerstein, 2006; Department of Health, 2010) are not, as yet, accompanied by detailed guidance for the health-care professionals involved. In the interim, health-care professionals are chastised for employing paternalistic models of care (Zoffman and Kirkevold, 2012; Sadler et al., 2014) that undermine patient autonomy and are instead expected to view their roles as facilitative rather than dominant (Wallerstein, 2006).

Some of the available advice about how to help health-care professionals to support self-management emerges from studies that examine the experiences of people who are receiving self-management support. Consequently, that advice tends to focus on making sure health-care professionals acquire a better understanding of what life is like for people living with a long-term condition. For example, Pickard and Rogers (2012) explored the nature of lay expertise in self-care. Although they also considered the role played by health-care professionals and biomedical care regimens, both of those considerations are examined through individual patients' embodied experiences of such professional support and biomedical care regimens. Thus, the conclusions about health-care professional practice and knowledge are formulated solely in terms of the individual patient's everyday practice and experience of self-care, and recommend that detached biomedical intellectualism should not be privileged over lay expertise (Pickard and Rogers, 2012). Similarly, Lawton et al. (2015) examined the challenges parents encounter in their efforts to manage their child's diabetes and included an exploration of parents' experiences of support from health-care professionals. In doing so, the authors' recommendations include further training for health-care professionals to better understand the realities of parenting a child with diabetes (Lawton et al., 2015).

However, the challenges facing health-care professionals as they support self-management cannot always be explained in terms of needing to know more

about the lived experiences of people with long-term conditions. One key difficulty that has been recognised is that health-care professionals sometimes struggle to reconcile the biomedically structured context in which they work with the emphasis on shared decision making (Anderson and Funnell, 2010; Scambler et al., 2014). A focus on improving clinical outcomes can sometimes conflict with ensuring that individual patients' preferences guide health-care provision, leaving health-care professionals with a difficult balance to strike. This balance is especially challenging to negotiate when particular choices are associated with particular risks (Morden et al., 2012).

The point I make is not to undermine the importance of the experiences of those with long-term conditions, nor to undermine calls for health-care professionals to better understand those experiences. The point is that teaching health-care professionals about the lived experience of people with long-term conditions might not necessarily be the best or the only way to address preoccupations and constraints that are related to biomedical risks and organisational priorities, for example. Health-care professionals face considerable challenges in their work of supporting self-management, and there is, as yet, inadequate understanding of what those specific challenges are, how professionals learn to respond and to meet those challenges and what kinds of workplace pedagogies might be most helpful.

### **Current arrangements for education, training and support**

In an effort to establish a sense of what education, training and support is available for health-care professionals supporting self-management, a relatively recent review by NHS Education for Scotland (2012) examined resources and initiatives across Scotland. The review explored recommendations relating to subject material and also investigated the ways in which education, training and support are organised, delivered and accessed.

Health-care professionals are advised to have skills, for example, in goal setting, team working, assessment of health risk factors, cultural awareness and

collaborative problem definition (Battersby et al., 2008) One of the challenges with these kinds of lists is that the skills and areas identified are highly generic; as Hager (2013) has argued, such generic approaches tend to exaggerate similarities and underestimate difference. For example, although a capacity for collaborative problem definition might indeed be useful, there is no inclusion of nuanced guidance about how health-care professionals might engage in collaborative problem definition with older adults with diabetes, or younger adults with heart disease or children with asthma. There is certainly recognition that the particular health-care context matters, and that it should be taken into consideration in the development of educational resources and initiatives (NHS Education for Scotland, 2012). However, specificity is not a feature of the resources and initiatives that were reviewed.

The national workforce development initiative emerging from NHS Education for Scotland (2012) is a clear example of the current approach to education for supporting self-management. Divided into four sections, the national online learning module focuses on 'Building Partnerships', 'Sharing Decision-Making', 'Enthusiasing and Empowering', and 'Facilitating Enablement'. Each section lists the knowledge and skills required, so, for example, at the section 'Enthuse and Empower', health-care professionals 'need to have knowledge of how to use behaviour change theories and strategies, understand how to use health facilitation and coaching techniques, and have knowledge of how to tap into the person's existing skills, coping strategies and strengths'. This brief example shows that in this online learning module, the emphasis is on knowledge as something to be acquired, or something to 'have', and the focus is generic rather than attuned to a particular health-care context.

Such educational initiatives do not seem to be producing the desired effects. According to recent reports, health-care professionals remain generally slow to embrace working in partnership with people who have long-term conditions (Health and Social Care Alliance Scotland, 2015). Rather than embracing partnership working, there are concerns that health-care professionals persist in emphasising the importance of compliance with expert medical advice (Sadler et

al., 2014). Health-care professionals are considered to have very different understandings of the nature of self-management and of the nature of self-management support, when compared to lay views (Sadler et al., 2014).

Clearly, there is a problem. In fact, what I show in this study is that there are multiple, complex problems. Assumptions about the simple transfer of policies and information into everyday clinical work practice are highly problematic. As Wenger (1998) has argued, the ways in which work practices evolve are not always dependent on intentional pedagogical instruction, nor necessarily solely reliant on individual professionals' capacities for information storage and behaviour change. Without a rich understanding of the particular challenges that health-care professionals encounter, and the complex problems that they are trying to address, educational interventions are highly likely to continue to miss the mark. This study contributes just such an understanding of the work practice of health-care professionals supporting self-management. In the next section, I introduce the particular case selected for the research: paediatric diabetes.

### **Introducing the case: paediatric diabetes**

Perhaps nowhere are the kinds of tensions described above more problematic than in the case of paediatric diabetes. Supporting self-management of long-term conditions presents especially formidable challenges in paediatric settings (Modi et al., 2012), not least because health-care professionals must find ways of balancing obligations to parents and parental authority with obligations to children and their developing autonomy (Silverman, 1987; Hawthorne et al., 2011). Moreover, supporting self-management in paediatric diabetes is not only especially challenging, it is also especially important. The stakes are particularly high because children without access to a regular supply of insulin will die quickly (International Diabetes Federation, 2015). In addition, care regimens are very complex (Coffen and Dahlquist, 2009) and place enormous demands on children (Hawthorne et al., 2011) and on their parents (Sullivan-Bolyai et al., 2003; 2006; Rankin et al., 2015).

## **An introduction to paediatric diabetes**

This research takes paediatric diabetes as a case study. Diabetes is one of the fastest rising long-term conditions globally (Department of Health, 2012) and the numbers of new cases are increasing especially quickly in children (International Diabetes Federation, 2015), making it an important focus for research. This study focuses on the professional work of supporting self-management only in type 1 diabetes because almost all children who have diabetes have type 1 (International Diabetes Foundation, 2015).

The information in the following section is based closely on that provided by the charity Diabetes UK ([www.diabetes.org.uk](http://www.diabetes.org.uk)). It is important to take the time to explain the nature of diabetes care in this section, because without a basic understanding of the role of insulin and the effects of blood glucose levels, readers might find it difficult to engage with some of the nuances of the data presented later in the thesis.

Type 1 diabetes develops when the insulin producing cells in the body have been destroyed and the body is unable to produce any insulin. Without insulin, the body is unable to use the glucose in food that would normally be converted to energy. As a result, the glucose builds up in the blood stream. Over time, high blood glucose levels cause severe health problems, for example, damaging the heart, kidneys, eyes and feet. There are significantly increased risks of heart attack, stroke, loss of vision and amputation. Consequently, caring for diabetes focuses on controlling blood glucose levels as much as possible by taking insulin that allows the body to convert glucose into energy. This process gets the glucose out of the blood stream and into other body cells, where it is needed.

If there is too much insulin, blood glucose levels will become too low and what is often called 'a hypo' (hypoglycaemia) will result. Hypos can develop very suddenly and cause shaking, blurred vision, difficulty concentrating and sometimes drowsiness. Hypos must be treated immediately otherwise loss of consciousness is likely to follow. On occasion, children with untreated hypos can

have seizures. The treatment for a hypo is to eat or drink something sugary, such as a glass of Lucozade, three dextrose tablets, or sweets such as jelly babies. Once blood glucose levels have returned to normal, children will eat a source of carbohydrate such as a small apple, a slice of toast or some biscuits and milk.

There is a second important effect of not being able to use glucose for energy, and that is that the body tries to get energy from stores of fat and protein instead. Ketones are toxic chemicals produced as a by-product of this process. A build-up of ketones causes diabetic ketoacidosis (DKA), which is a life-threatening emergency. DKA can develop in as little as twenty-four hours, or sometimes more quickly. Hospital admission is essential because DKA can be fatal if not treated. Children with diabetes will check their ketones levels as part of their management of the condition.

Children with diabetes, with their parents, must balance their intake of insulin with both their intake of food and their activity levels. This balance must be monitored throughout the day, every day, because otherwise blood glucose levels might become too high (hyperglycaemia) or too low (hypoglycaemia). For example, more exercise usually means either taking less insulin or eating more food, or perhaps a combination of the two.

Children with diabetes, perhaps with the help of their parents, must also test their own blood glucose levels, using a blood glucose meter. A tool containing a small lancet is used to prick one finger, and a drop of blood is squeezed on to a testing strip already inserted into the meter. In the paediatric clinic I spent time in, the ideal target was usually a result between 4.0 and 8.0. The number of blood glucose tests each day can vary. It can occasionally be as little as two or three times per day, but is more usually four or five times each day and can easily rise to eight or more times each day if many insulin adjustments are being made.

The results of each blood glucose test are usually stored in the memory of most blood glucose meters, but children (or their parents) are also expected to record blood glucose results in a diary or using a computer software package. This

record helps to identify any need for insulin adjustments. For example, a pattern of low blood glucose results each morning after walking to school might suggest less insulin is needed at breakfast.

Children with diabetes, or their parents, must administer insulin in order to survive. Insulin can be injected or delivered by an insulin pump (also known as Continuous Subcutaneous Insulin Infusion). Insulin injections can be taken in different ways: either as fixed amounts, usually twice each day, or more flexibly four or five times each day. With fixed amounts of insulin, children must eat fixed amounts of food at regular intervals. Using a flexible regimen of four or five injections each day, both insulin doses and food amounts can be varied and there is more scope to vary meal times. Insulin pumps deliver precise amounts of insulin throughout the day, and doses are given by pressing buttons on the digital pump unit rather than by injection.

### **The work of supporting self-management in paediatric diabetes**

For children and their parents, managing the condition is extremely challenging: one study estimates that some six hundred discrete tasks must be mastered in order to implement care regimens (Coffen and Dahlquist, 2009). Sustaining all of these activities in balance with other commitments at home and at school is not easy; even with the support of health care professionals, self-management is a formidable challenge for many children and parents (Modi et al., 2011). In this context, the role of professional support is important, and the educational interventions and resources that help professionals to accomplish the provision of such support are also important.

Few studies focus specifically on the work of supporting self-management in paediatric diabetes. Much of the literature employed thus far to explain the background for my research is focused on a range of long-term conditions other than diabetes, sometimes with adults rather than children, and usually with an emphasis on the perspectives of and health outcomes for children and/or their parents. One notable exception is Nidel et al.'s (2012; 2013) study, which

investigates the development of parental expertise by observing and audio recording clinic consultations between health-care professionals and the parents of children with diabetes. Although the focus is on lay expertise, the researchers are also interested in the strategies that health-care professionals employ in their efforts to establish what parents already know and what else they might require in terms of support. The study identifies four strategies of supporting self-management: setting expectations about self-management; trial and error to make sense of insulin doses and blood glucose results; pattern recognition to enable insulin dose adjustment; and proactive management to enable reduced reliance on the clinic. In relation to my own research, this study is particularly interesting because of its exploration of the fine-grained details of what health-care professionals do in clinical consultations, and because it shows the affordances of close inquiry into these situations of knowing-in-practice.

### **Key challenges in paediatric diabetes**

In the case of paediatric diabetes, there are particular work challenges that are important for professional learning and yet, as I have argued, these particularities are rarely considered in existing educational initiatives for health-care professionals. One notable example of a particular challenge is the narrow therapeutic range of insulin; it is very easy to give too much or too little, with potentially harmful consequences (Lamont et al., 2010). As a result, insulin is deemed one of the top-ten high-alert medicines in the world, defined as a medicine that has the highest risk of causing patient injury when misused (National Patient Safety Administration, 2010). Supporting children and parents to self-manage the calculation of insulin doses assumes special importance given such considerations.

Another key challenge for professional learning is the proliferation of new technologies; insulin pumps and sophisticated blood glucose testing devices promise exciting potential for improved health outcomes (Lieberman et al., 2014), but as others have argued (Pols and Willems, 2010; Oudshoorn, 2011;), technologies do not slip smoothly into existing arrangements. On the contrary,



the introduction of new technologies often prompts considerable work for professionals. Such work is not simply about more obvious tasks such as teaching how to use new devices; rather it also entails ongoing ‘articulation’ work (Star and Strauss, 1999), which is the fine-tuning and modifications to existing practice required to accommodate new arrangements. Moreover, showing the associations among technologies, practices and context, Petrakaki et al. (2014) argue that technologies afford possibilities for new risks by reordering relations of power and responsibility. Further, specific devices can be associated with specific outcomes. As Halford et al. (2015) have shown, the affordances of *particular* devices matter. All of these examples have special resonance in, and very particular implications for, paediatric diabetes settings, where potent medicines mean that the stakes are high and where responsibility for health care is devolved not only to adults but also to children.

Tracing professional learning as it unfolds in the work of supporting self-management in paediatric diabetes entails paying attention to these specific challenges as well as others that arise in everyday clinical practice. I turn now to explain the theoretical and methodological resources that have informed my approach to this research.

## **Theoretical and methodological resources**

### **Studying practice and knowledge as a way of examining learning**

In order to examine the enactment, or materialisation, of professional learning, I draw on Gherardi’s (2006; 2010; 2012) concept of knowing-in-practice. By focusing on knowing-in-practice, I am focusing on knowledge as something that people do rather than something that people possess (Gherardi, 2006). By focusing on knowing-in-practice, I am also attending to the sociomaterial nature of knowledge; in this way, knowledge is construed as an effect of relations among, for example, people, tools, technologies and policies (Gherardi, 2006; Fenwick and Edwards, 2010). Such approaches to examining knowing-in-practice recognise that knowledge is not simply in the minds of health-care professionals;

on the contrary, knowledge is situated in particular contexts and embedded in specific arrangements for particular work practices (Gherardi, 2006).

The concept of knowing-in-practice has its roots in organisation studies and is therefore often employed to show how particular practices, or particular ways of doing things, become established. Gherardi (2006), for example, focuses on the ordering processes that enable a practice to be produced and reproduced over time, such that it becomes recognisable as the established way of doing things. In this way, it is possible to show the ways in which novice practitioners become inducted, or socialised, into the work practices of an organisation (Gherardi, 2006). Studying knowing-in-practice is a way of studying how practitioners come to know.

Paying attention to knowing-in-practice also opens up the possibility of tracing the ways in which particular knowledge resources are marshalled. For example, knowledge resources such as tools, technologies, professional expertise and policy guidelines might be employed at particular points, and in particular ways, in order to establish and/or to maintain a particular practice. Importantly, however, a sociomaterial sensibility recognises that such knowledge resources are not simply employed in brute fashion but are instead active participants and exert force (Fenwick et al., 2011; Mulcahy, 2012). For my own research, the key point in this aspect of examining knowing-in-practice is that such an approach can illuminate not just the ordered nature of practices but also the moment-by-moment enactment of learning as practitioners come to accomplish work practice in unfamiliar and changeable contexts.

In order to study knowing-in-practice in such ways, I have also drawn on the work of Mol (2002; 2008), who offers a particular slant on foregrounding practices in ethnographic approaches. In her seminal study on the enactment of disease, Mol (2002) revises the term 'ethnography' to better capture her own specific emphasis on practices rather than on human sense making. Denoting her particular approach as 'praxiography', Mol (2002) makes a deliberate move away from investigating the culture and understandings of human participants and

instead allows such concerns to recede from view somewhat. In this way, it is practices and the effects of practices, including the particular realities that are enacted through the accomplishment of particular practices, which are of central interest.

In such considerations of knowledge and practice, sociomaterial sensibilities assert that what connects knowledge and practice are relations of *mutual constitution* (Gherardi, 2006; Hager et al., 2012). Knowledge and practice are understood to be constitutive of one another and so emerge together. Knowledge and practice are entangled. This brings me to another key theorist, whose work has helped me to better appreciate both the nature and also the implications of such entanglements. Because her work has been so central for my own research, I use her full name: Karen Barad.

### **Entanglements and indeterminacy**

Grappling with sociomaterial approaches to research entails grappling, somehow, with notions of indeterminate relations among social concerns and material entities. In the words of Orlikowski (2007, p. 1437), 'there is no social that is not also material, and no material that is not also social'. As a novice researcher, I found that if I kept such commitments in 'soft focus', they worked perfectly well. However, as I moved to explore their use in empirical work, I struggled with questions of how to manage such indeterminacy. For example, how is it possible to select focal points for investigation, and to even construe oneself as a researcher, with/in methodologies that refute conventional categories and structures and instead engage in perpetual disassembly of hitherto assumed boundaries? These kinds of concerns have been recounted before, both by those new to research (see, for example, Fenwick et al., 2016) and also by those researchers who are more experienced (see, for example, Leonardi, 2013).

In my efforts to engage seriously with such sociomaterial commitments, I found that the work of Karen Barad was especially helpful. Although Barad (2007) shares many of her sociomaterial ideas with others, her particular contributions

for my own thinking were her attention to the specificities of entanglements; the explicit shift to considering phenomena rather than objects as the unit of analysis; and the heuristic of diffraction as a way of examining difference. I devote chapter three to an extended discussion of these ideas and the associated implications for my own research. However, at this point I emphasise that Barad's (2007) particular approach helped me to unravel my tendency towards 'soft focus' by drawing my attention to details and differences. Her approach enabled me to recognise provisional boundaries that helped delineate my study without obscuring my own part in the production of such provisional boundaries.

### **Researcher positioning**

My interest in this study grew from my experiences as a health-care professional, as an educator and also as a parent of a child with diabetes. The demands of the page make it difficult to convey the non-linear nature of these influences; inevitably, particular events and circumstances were important at different times and in different ways, and not always in ways that were immediately apparent. This section introduces and discusses my own positioning(s) as a researcher in this study, although I leave the detailed consideration of how such positioning(s) mattered in the generation, analysis and interpretation of data until chapter four.

As a nurse, working with children and parents made me realise that sometimes the best way to support a child is by supporting the parent. Sometimes, for example, I found that a child recovers from illness or trauma more quickly than his or her parent recovers from the experience of parenting an ill or traumatised child. In such instances, enabling the child's return to health might require little child-focused help but might instead require substantial support to help the parent help the child. Teaching professionals to engage with children and parents made me curious about how knowledge for this kind of work develops, and about how best I might help professionals attune to families' needs.

Exposure to literature that questioned the nature and purpose of education, knowledge and learning, and their connections with professional practice, helped

me to formulate and to ask my own questions. Some hitherto rather uncritical assumptions about the provision of training leading in simple ways to the acquisition of skills became impossible to sustain. My curiosity found a new voice.

Just as I was poised to begin a full-time scholarship towards a Master's degree in Research, my daughter was diagnosed with diabetes. For a short while life changed beyond recognition. However, the process of adjusting and adapting, combined with a timely Master's module on public-health research, sparked an interest in self-management literature and in the enormous challenges anticipated as health services respond to the rapidly growing numbers of people with long-term conditions. I was drawn too to the literature that problematised the policy emphasis on prioritising personal responsibility for health. Turning to the educational resources developed for professionals working in this area of health care, the focus on interpersonal relationships, and on training professionals to relinquish power to people with long-term conditions, seemed at odds with the work my own family was engaged in as we coped with diabetes. Much of our attention was focused on lancets and needles, blood tests, injection syringes and on the insulin that was keeping our daughter alive.

Around the same time I was introduced to sociomaterial writings. Such writings trouble tendencies to attend only to the human influences exerting force and instead argue that equivalent attention might be paid to materiality. Such writings did not necessarily undermine the importance of interpersonal concerns but instead opened up the possibility that the needles, blood testing and insulin syringes might also *matter*; that is, that the needles, blood testing and insulin syringes might exert material influence and create effects beyond their immediate apparent uses. Moreover, such writings offered a way of exploring just *how* such materialities might matter. And here, really, is where my doctoral research began.

## Thesis structure

Chapter two reviews a range of ways of conceptualising and investigating learning, practice and knowledge, drawing primarily from educational literature. This chapter also takes a detour into writings from the field of science and technology studies (STS), focusing on studies that have produced detailed understandings of health-care work. Highlighting the concepts that informed my own research, this chapter pays special attention to sociomaterial approaches, which offer particular ways of examining learning.

Chapter three explicates the theoretical work of Karen Barad, whose ideas are central to the way I have undertaken my study. In particular, I focus on Barad's (2007) concept of diffraction as a means of attending to difference, her way of thinking about/with entangled phenomena rather than determinate objects and her overall framework of agential realism as an ontological-ethical-epistemological framework. The theoretical commitments are explained and then discussed in terms of their implications for my research.

Chapter four is in two parts. The first part details the research design and describes the outpatient clinic and the team of health-care professionals who participated as well as relating the commitments and challenges entailed in ethnographic research. I show how Mol's (2002) development of a praxiographic approach helped me to better sustain attention to the enactment of practices. In the second part of this chapter I show the ways in which I generated and handled data that helped answer the research questions as well as considering the particular challenges I encountered in my efforts to engage Barad's (2007) diffractive methodology in my study.

Chapters five, six and seven present the empirical data from the research, organised into three broad areas of interest. Chapter five examines the ways in which technological change influences the emergence of professional knowledge, with a specific focus on insulin-pump technologies. Chapter six takes diabetes care regimens and explores their capacities as always-unfolding epistemic

phenomena, by drawing on the work of Knorr-Cetina (2001; 2006; 2007) and Barad (2007). Chapter seven examines the notion of empowerment as it features in the work of supporting self-management. Following Gherardi (2010), this chapter explores the practical accomplishment of supporting self-management and considers the extent to which the rhetoric of empowerment corresponds to such work.

Chapter eight examines the role for education in the question of how best to help health-care professionals learn to support self-management in paediatric diabetes. Reading across the new insights generated in chapters five, six and seven, chapter eight argues for a methodology of workplace learning, which would entail taking critical account of the nature of the work of self-management in this case.

Chapter nine draws together the various strands of exploration and argument across the thesis. Reflecting on the particular insights generated, this chapter suggests a number of possible directions for further research and offers certain recommendations for policy and practice. Finally, the thesis ends by returning to my own role as doctoral researcher and considers my own learning and development throughout this process.

## 2 Investigating professional learning

If I am to make explicit how *this* text departs from the others around it, if I want to show how it both differs from them *and* is made possible by them, I will have to *relate to the literature*. But how to do this? How to relate to the literature?

(Mol, 2002, p. 3, italics in original)

In the previous chapter, I indicated that the basis for my study is an understanding of work problems as learning struggles, together with recognition of learning as a sociomaterial phenomenon that can be investigated as a practical accomplishment. This chapter presents a much more detailed examination of the particular literature that informs my study. Because the overall aim of the research is to examine learning, and to contribute to the education of health-care professionals, much of the scholarly work included here is from the field of education. However, I also draw on a small number of carefully selected writings from the field of science and technology studies (STS), which are being increasingly used in educational research, and which provide important and detailed investigations of health-care practices.

I begin with an extended discussion of different approaches to conceptualising learning, knowledge and practice, before taking a detour to note that a particular challenge of researching such educational concerns in health-care practice is the need to engage with technical and biomedical details. I show that a number of key scholars in STS have contributed unique insights through their studies of health-care practice. In particular, I focus on the work of STS scholars who have investigated the enactment of disease and the effects of technologies in health care.

I return to the work of educational researchers, focusing in particular on those employing sociomaterial sensibilities in their work. Finally, I bring into this



conversation the concepts of informal learning in work, including the notion of work problems as learning struggles and show the ways in which such concepts are especially suited to my study of health-care professionals learning to support self-management.

### **Learning, practice and knowledge**

In this section I bring together and discuss a selection of key approaches to examining learning, with a particular focus on approaches that have been employed to investigate professional learning. Learning has been, and continues to be, construed in a wide variety of ways according to the interests and academic influences of particular scholars. In fact, tongue firmly in cheek, Fenwick (2010, p. 80) bemoans: 'One is tempted sometimes to abandon the word [learning] as utterly hollowed out of any meaning worth discussing'. Attention to personal reflection, work practices, knowledge acquisition, knowledge production and social participation are all examples of different points of emphasis, which I consider in the following pages. Of special significance in my own study are sociomaterial understandings of learning, which explore learning as enactment. In these sociomaterial understandings, learning is construed as an effect, which emerges in and through heterogeneous gatherings of human and non-human actors (Sørensen, 2009; Fenwick and Edwards, 2010; Fenwick et al., 2011). Before turning to sociomaterial traditions, I focus first on some influential and very different approaches, as a way of clarifying the particular nature of sociomaterial research in educational studies.

#### **Learning as individual process**

Learning has often been investigated through psychological and cognitive understandings (see, for example, Billett, 2002; Eraut, 2000; 2004). In such approaches, the emphasis tends to revolve around, for example, individual sense making (Billett, 2002) or individual learners' acquisition and application of knowledge (Eraut, 2000). Social and workplace factors might also be recognised, but the individual learner's *mind* is held to be the locus of learning.

One particularly prevalent way of conceptualising learning is through Schön's (1983; 1987) work on reflection. Individual reflectiveness has been considered a highly significant means of grappling with the everyday indeterminacies of professional practice (Schön, 1983), particularly in the field of health care. Teasing out the 'artistry' of professional practice, Schön (1987, p. 13) recognises that coping with unique problems, which are not always amenable to generic solutions, involves considerable improvisation. The departure point is that professionals generally know more about this improvisation than they can say, and 'exhibit a kind of knowing-in-practice, most of which is tacit' (Schön, 1983, p. viii). Tacit knowledge refers to that which is known yet cannot be easily articulated, and is sometimes contrasted with explicit knowledge, which is construed as more formal or codified.

Highlighting the processes of reflecting in and on practice, this perspective emphasises the importance of thoughtfulness in professional practice. This thoughtfulness, according to Schön (1983), is one of the ways in which professionals respond to and deal with the unexpected and unpredictable difficulties that often arise in everyday professional work.

However, despite its widespread appeal and its useful recognition of professional artistry, the concept of reflective practice has been roundly critiqued (Fenwick et al., 2012). Schön (1987) might contribute a strikingly prescient account of the many challenges facing professional education, calling for research methods and educational responses better tuned to the complexities and tensions of professional practice and learning, but there are problems. Many of these emanate from the ways in which Schön's discussions of reflection-in-action have been taken up in educational practice (Fenwick et al., 2012). With his focus on the ways in which individual professionals process experiences, Schön's studies have been used to support models of learning that separate thought and action, that assume individuals can discern all of the dynamics that influence their practice and that suggest knowledge is formed retrospectively from experience (Fenwick, 2003; Fenwick et al., 2012). Further, Schön's (1987) concept of reflective practice, particularly as it has been implemented in professional education, does

not fully account for the ways in which colleagues, materialities or the working environment might actively influence professional learning. When the individual professional is the locus of attention and intervention, questions about the wider context for professional learning can easily remain unaddressed.

### **Learning as social participation**

In a deliberate move away from the individual practitioner, and from understanding learning as the acquisition of knowledge, some theorists sought instead to focus on learning as a process of participation (Sfard, 1998). Emphasising the social nature of learning as a kind of participation helps to shift away from purely psychological and cognitive approaches to understanding learning. In this way, learning is conceptualised not as cognitive process but as social practice (Lave and Wenger, 1991).

Recognised as influential scholars in this approach to investigating professional learning, Lave and Wenger (1991) highlight the importance of socially negotiated meaning making as a key aspect of participatory learning. This sociocultural approach holds that learners become gradually inculcated into a field of practice, such as midwifery, by engaging in activities progressively more complicated and specialised. Through the development of their concept of 'communities of practice', Lave and Wenger (1991) draw attention to the relations among people, activities and the wider world as significant conditions for learning. Communities of practice are not understood as tightly defined groups of locally situated participants, and they 'are not a design fad, a new kind of organisational unit or a pedagogical device to be implemented' (Wenger, 1998, p. 228). Instead, tracing communities of practice as sets of relations offers a way of exploring professional knowledge as a social entity.

Perhaps most interesting in this perspective is the contemplation of learning as independent of intentional instruction (Wenger, 1998). Although the approach does seek to inform educational design, there is also an important acknowledgement that learning very often happens without or in spite of

pedagogical intervention. Focusing on the social arrangements for learning introduces a range of different design issues for consideration. From this perspective, factors such as individual professionals' capacities for information storing and behaviour change need not be the central concern (Wenger, 1998). What might be of interest instead, for example, is the layout of the workplace and its suitability for learners to observe, or perhaps the tensions between seasoned practitioners and the newcomers jostling for position (Lave and Wenger, 1991).

### **Learning as practice**

Much like the distinction noted above, between learning and instruction, there is a difference between work processes and work practices. Although work processes can be designed, work practices evolve (Wenger, 1998) in response to the exigencies of professional work (Eraut, 2000) and in response to the need for novel responses to uncertain phenomena. Practice consists of 'the relations among the everyday interactions, routines and material arrangements in particular environments and forms of knowing generated from these' (Hager et al., 2012, p. 3). Examining professional work practices has emerged as a highly useful way of understanding 'seamless know how' (Hager, 2013) and of showing the ways in which practice relates to knowledge and learning (Hager et al., 2012).

One particular concept of knowing-in-practice (Gherardi, 2001) has roots in organisational studies, but the interest in the practical accomplishment of knowing in work settings enables it to resonate in professional education studies too. The concept of knowing-in-practice emphasises that knowledge is an ongoing, situated, collective achievement (Gherardi, 2001; 2010) and encourages attention to the sayings and doings that mobilise knowledge and put it to work in particular settings (Gherardi, 2012). For example, Gherardi (2010; 2012) investigates the practice of telecare consultations between cardiology specialists and general practitioners (GPs), and shows the ways in which professional competence is enacted, how learning and working are entangled and how technological settings participate to shape professional knowing. Hers is a

detailed study of the ways that professionals talk and act, thereby showing the ongoing production and reproduction of professional knowledge.

In such examinations of knowing-in-practice, Gherardi (2010; 2012) shows the ways in which practices become stabilised. With careful attention to the ordering processes at play, Gherardi (2006) argues that it is the ongoing, recursive performance of a practice that makes it recognisable as such. However, practices are also recognised as only *provisionally* stable, because the heterogeneous arrangements for practice are dynamic. Such recognition opens the way to investigate breakdowns in practice, means of repair and the ways in which practices persist even in spite of problems or when there are efforts at organisational change (Gherardi, 2006).

Professional practice has also been theorised as embodied (Hager and Reich, 2014). Investigating anatomy and surgery education, Prentice (2013) draws on traditions of cultural anthropology to examine how physicians, especially surgeons, are 'made'. Focusing on the practices of medical training, Prentice (2013) contributes fascinating insights into the impact of cadaver dissection on students' learning, particularly the effects of bodily engagement with cadavers and the simultaneous recognition of cadavers as persons. Technologies, in the form of sophisticated new surgical instruments and also in the form of simulators, are rapidly becoming integral to medical work and Prentice (2013) shows the intricate relations between surgeons' hands, surgical instruments and patients' bodies. In particular, she makes visible the central importance of haptics, or sensations of touch, and the ways in which technologies change surgical practice, for example, by altering the required techniques in minimally invasive 'keyhole' surgery. Tracing what professionals actually do is a way to explore their learning as it unfolds in work practice.

### **Learning, knowledge and practice in health care**

I make a shift at this point in the chapter to consider some of the very particular nuances of investigating professional learning in health care work. One of the key

challenges, especially when the focus of inquiry is everyday clinical practices, is the need to engage with technical, biomedical details. These details are not the natural habitat of educational research. However, understanding the particular tensions in and the influences on professional learning in this case of paediatric diabetes cannot proceed without these details.

Making sense of the extracts from field notes and interview transcripts that are presented in chapters five, six and seven of this thesis, is impossible, I suspect, without these details. Moreover, the theoretical and methodological commitments of my approach to this research (discussed further in chapters three and four) emphasise the significance of these details. For example, to present medicines and their participation in professional learning in general or abstract terms is to ignore the vast and important differences in the nature of participation of particular medicines. Some medicines are more dangerous, costly or experimental than others and it is important to be clear about these issues.

The point in this example of medicines is not necessarily to reify biomedical preoccupations. Instead, the point is to illustrate that in order to understand how a particular medicine might influence a particular professional practice, the details matter. Insulin, for example, is the key medicine in the care of diabetes. It is also, potentially, a very dangerous medicine (Lamont et al., 2010). To repeat, these details matter, because they have material effects on the phenomena under investigation.

### **A detour into science and technology studies (STS)**

Turning to professional learning, knowledge and practice in health care, increasing attention is paid to the non-human elements of professional work. Medicine and health care are full of such things as tools, technologies, pharmaceutical products and bodily substances, all of which play varyingly significant roles in professional work. Finding ways to account for these material entities in my study is helped by engagement with work beyond the individually

focused reflective models of Schön (1983; 1987), the psychologically based work of Eraut (2000; 2004) and the sociocultural work of Lave and Wenger (1991).

The STS field, with its focus on science and technologies in social contexts, is uniquely placed to contribute important insights. The preoccupations of such research are not primarily on questions of education. However, what is so relevant for my study are the detailed understandings of health-care work, the implications for associated professional learning and the possibility of informing the design and development of educational interventions that are best likely to support health-care professionals.

One of the key approaches that STS scholars bring to the study of health-care practice is a way of paying attention to more than the human and social elements in any given instance. This sociomaterial sensibility accords equivalent attention to both human and non-human elements; and understands non-human elements as dynamic and active rather than as inert objects waiting to be manipulated (Law, 2004; Latour, 2005). This sociomaterial sensibility works to foreground the technologies and the effects they produce rather than, for example, the experiences of the professionals using technologies.

### **Technologies in health care**

Here is one oft-cited example of how an STS study traces social and material entanglements to open new understandings of technology. In their work focused on water pumps as a public-health technology, de Laet and Mol (2000) show the ways in which the water pump is not only constitutive of local Zimbabwean communities but is also constituted by those same communities. As they explain so carefully, the water pump is not a water pump unless it is installed into a well, maintained and operated by a community and until it actually works to pump water. The technology is not simply the device; rather the technology comprises the people who use it, the adaptations in response to local conditions as well as the concrete casings in which the pump is sited, and so on. The boundaries of the technology are fluid (de Laet and Mol, 2000), and this fluid technology works to

organise communities as they install, operate and maintain the pump over time, adapting their comings and goings to sustain the provision of clean water.

STS researchers have examined such issues as the way in which digital technologies unsettle existing arrangements and change the nature of health-care professional work. Technologies such as digital blood glucose monitors help delegate to patients many of the responsibilities formerly restricted to health-care professionals (Lupton, 2013a; 2013b), creating new roles and expectations for both patients and professionals. Webcams, used to support the provision of health care at a distance (telehealth), unleash unpredictable responses from health-care professionals and from patients, as both groups tinker and experiment with the technology in order to accommodate it into their everyday work and lives (Pols and Willems, 2010). What these studies have in common is that they show the wide-ranging effects of technologies: these devices are not simply 'used' in instrumental ways. Instead, STS researchers understand these technologies as active participants, exerting influence and creating effects.

Examining the implementation of technologies, and their effects, entails recognising the performative and dynamic nature of everyday work practices (Halford et al., 2015). In a rich exploration of the implications for and the production of gendered aging, Halford et al. (2015) show the entangled relations among particular technologies, particular work tasks and particular embodied experiences. Concluding that the 'gender-age-technology' relation might be sometimes troubled and sometimes untroubled, Halford et al. (2015, p. 505) argue for the importance of inquiring about 'the intersection of professional and organisational processes, dynamic work-life relationships across the life course and materialities in daily working practices'.

Technologies are not always the kinds of easy solutions they are sometimes assumed to be (Pope et al., 2013). On the contrary, technologies destabilise many hitherto established ways of doing things. In an examination of a new computer decision-support system as it was implemented in emergency health-care settings, Pope et al. (2013) show the ways in which technologies are not reducible



to delineated technological objects but are better understood as inextricably entwined with sets of practices. These sets of practices are the ongoing appraisal and adjustment (Pope et al., 2013) that enable the embedding of the technology.

Technologies actively initiate changes in the nature of health-care work (Petракaki et al., 2016). Arguing that technologies are not just facilitators of change but are materially constitutive of change, Petракaki et al. (2016) show the effects of introducing an electronic patient record. By examining the relations among the electronic patient record and professional identity, Petракaki et al. (2016) show that this technology redistributed professional health-care work, expanded nursing roles and curtailed professional autonomy.

Technologies also initiate changes for the ways in which patients engage in health care, and this creates corresponding changes for health-care professionals. In her study of cardiac telehealth, Oudshoorn (2007, 2011) has shown that the introduction of new technologies can lead to patients being expected to take increasing responsibility for their own health. For example, patients might be expected to monitor their own health and to decide when to seek help based on the information this monitoring produces, often whether they feel able and willing to engage with this change or not. When the introduction of new technologies brings with it associated changes in the details of working practices, health-care professionals adapt and respond but not always in expected ways. Sometimes, technologies are subverted as professionals revert to previous ways of working or work around the technologies by drawing on their own existing expertise (Oudshoorn, 2011).

### **Medicine and health care**

Technologies are not the only phenomena to be investigated this way. An edited collection of writings titled *Differences in Medicine: Unraveling Practices, Techniques and Bodies* (Berg and Mol, 1998) focused exclusively on the heterogeneous nature of medicine and on health care more broadly, investigating the practices and performances that come together to constitute disease in

particular ways. For example, a study of the pathology laboratory in a cervical screening programme (Singleton, 1998) examined work practice in the laboratory. In detailing the network of relations (doctors' letters, specimens, microscopes, pathologists, policies, and so on) and the way in which the laboratory both constructed and accommodated uncertainties, Singleton (1998) showed how the laboratory negotiated and made durable its position in the programme.

In a very different study, Timmermans et al. (1998) examined the development of a classification system for nursing work. Focusing on the negotiations aimed at balancing standardisation with professional discretion, the classification system was understood as a nonhuman actor with wide-ranging effects. These effects were sometimes unpredictable. For example, making some aspects of the nursing role more prominent and visible created increased opportunities for external surveillance and regulation (Timmermans et al., 1998). Moreover, in the process of bringing some aspects forward, others were simultaneously excluded from normal understandings of the nursing role because of the ways in which they remained unarticulated within the classification system (Timmermans et al., 1998).

Besides the sociomaterial sensibility already mentioned, Berg and Mol's (1998) edited collection has another important feature that has helped to inform my own research: the book makes a deliberate effort to weave together a strand of work that is different from sociological studies that have tended to focus on the experience of illness. Instead, the editors argue for attention to disease and show that examining the practice and performance of disease makes visible the 'so-called hard core of medicine, the business of medical judgments, decision making, intervention ... focusing on the very biomedical facts that for such a long time seemed beyond the grasp of philosophers and social scientists' (Berg and Mol, 1998, p. 3). A similar plea has been made more recently, arguing that in the field of sociology, ignoring the clinical concerns and therapeutic aims of medicine risks perpetuating insensitivity to what health care is all about

(Timmermans and Haas, 2008; Timmermans, 2013), thereby potentially missing important aspects of its nature.

### **Examining the enactment of disease**

The careful, critical examination of medicine and disease rather than illness proposed by Berg and Mol (1998) opens an intriguingly different space in which to engage with educational questions of health-care professional practice. The move is not intended to brush aside the important work of those who have critiqued and challenged the dominance of the medical model (for a comprehensive summary see Nettleton, 2013). Rather, it becomes possible to take disease seriously (Timmermans and Haas, 2008). Acknowledging that disease is very much a part of the work that health-care professionals do enables attention to the ways in which these clinical details matter for educational researchers examining health-care professional learning, practice and knowledge. Finding ways of bringing educational and sociological concerns into dialogue with understandings of health care and disease, without losing sight of the significance of many clinical details such as biomedical risks and prognoses, offers important routes to understanding the full range of influences on professional learning, practice and knowledge.

Different from many other researchers, Mol (2002, p. 27) insists that ethnographers 'need not stop short as soon as they come across machines or blood'. This approach to the study is of course a sociomaterial sensibility that can be seen elsewhere, but the difference, and the richness, is in Mol's (2002) persistent willingness to engage with even the most complicated, technical details of medical practice. Her work aims to speak across disciplines, most notably to sustain and further develop particular forms of dialogue between medicine and sociology (Mol, 2002).

Describing her research as praxiographic, Mol (2002) denotes the ethnographic roots of the approach. However, the term also marks a careful step away from the conventional ethnographic focus on human meaning and interpretation. Instead,

a praxiography attends to bodies and materialities. Most importantly, bodies and materialities are understood as recursively performed into being through particular sets of practices. It is these practices that are the central focus of her research.

In a lyrical and painterly account of events and practices in a hospital, Mol (2002) examines the different forms of atherosclerosis that are performed. Atherosclerosis is a hardening of the arteries, which can cause problems with blood flow to the limbs and also to internal organs such as the brain, heart and kidneys. Showing the range of ways in which atherosclerosis is 'done differently', Mol (2002) argues that atherosclerosis is not simply perceived, or understood differently by pathologist, surgeon and patient. Atherosclerosis is ontologically different when performed in the pathology laboratory, under the surgeon's knife and on the stairs that patients struggle to climb.

In a similarly fine-grained study, which also engages with clinical minutiae, Mol (2008) uses diabetes as a case study in order to examine care practices. This time, rather than exploring how diabetes itself materialises, the focus is on how caring for diabetes is 'done'. Troubling the persistent logic of patient choice, Mol (2008) argues that care emerges as a complicated set of practices, which is not better understood through casting patients as selective customers. What is so exceptional about this study, and so useful for my own area of inquiry, is that it pays careful attention to the plethora of blood-test results, medical complications and biomedical interventions implicated in diabetes care, without becoming narrowly focused on medical concerns.

### **Performative ontology**

An important feature of Mol's (2002; 2008) writing is her recognition and exploration of the provisional, indeterminate nature of reality. Mol is not unique in this; a range of other scholars (see, for example, Latour, 2005; Law and Singleton, 2005; Barad, 2007) have argued that reality is performed into being, and used such ideas to investigate the ways in which particular phenomena are

enacted. I discuss these issues in further detail in chapter three. At this point, however, I note that what I found so useful about Mol's (2002; 2008) approach is that she employed such concepts in studies of health-care practice.

Attending to the ways in which specific practices perform particular realities into being underlines the possibility that things might always be otherwise. Arguing that reality is situated, specific and relational, Mol (2002) highlights that her aim is not to portray an exclusive truth of medical practice. Much like atherosclerosis, the research writings themselves might also always be otherwise, because 'the practices forcing an object to speak are crucial to what can be said about it' (Mol, 2002, p. 158). This recognition and analysis of multiple enactments of reality keeps an open mind, always attuned to the particular possibilities and limitations contributed by researchers and research activities.

In summary, STS studies focus on science and technologies in social contexts, including health-care contexts. By sustaining attention to both human and non-human entities, these approaches contribute insights related to such issues as digital technologies reconfiguring health-care work, the effects of laboratory practices and the enactment of disease. In my own study, these STS approaches have helped me to sustain similar attention to the technologies and practices that help to configure and reconfigure the professional work of supporting self-management in paediatric diabetes.

### **Sociomaterial approaches in educational studies**

Increasingly, educational researchers draw on such sociomaterial ideas to unsettle and push beyond what Fenwick and Nerland (2014) have called disembodied, decontextualised and dematerialized ways of understanding learning, knowledge and practice. Building on sociocultural studies, such as Wenger (1998), which have recognised the social and collective nature of much that goes on in the name of professional learning, sociomaterial sensibilities attend to more than the human and social. Materials and materiality are understood to matter; that is, they are understood to make material differences

that matter. Technologies, tools, buildings, policies, and so on, are understood to be as much a part of professional learning as human beings, although different strands of research accord slightly different forms of attention and significance to materiality in the relational gatherings of people and things investigated. However, investigating 'things' does not imply investigating 'objects'; rather, the focus in such approaches is sociomaterial relations among things-in-connection. Moreover, 'things' are not examined as if they exist independently and self-evidently but are instead conceived of as performed in and through particular sociomaterial relations.

Of the many approaches currently in vogue in educational research, I focus here on two in particular because they have special relevance for my study. The first, actor network theory, is not only increasingly used in educational research, it also informs many studies that focus on health-care practice, such as Law and Singleton's (2005) examination of alcoholic liver disease, Singleton's (1998) study of cervical screening programmes and Zukas and Kilminster's (2014) investigation of professional medical responsibility. The second approach, epistemic objects (Knorr-Cetina, 2001; 2006; 2007), offers specific ways of examining the mobilisation and circulation of knowledge in everyday work, and has also been employed in health-care settings, to explore practices in clinical nursing procedures (Nerland and Jensen, 2014).

### **Actor network theory**

Actor network theory (ANT) is a collection of ideas that has become more prominent in educational research recently. As others have repeated often, ANT cannot be captured as a single theoretical approach (Law, 2004; Latour, 2005; Fenwick and Edwards, 2010). Instead, ANT is better appreciated as a loose but recognisable constellation of sensibilities and concepts. In particular, ANT offers ways of examining the ways in which associations of social and material entities come together and the ways in which these associations stabilise, dissolve and reassemble (Fenwick and Edwards, 2010). ANT pays equivalent attention to social and material entities, understanding that materials participate actively in

producing particular phenomena. In this way, for example, learning, knowledge and practice are conceived of as effects of sociomaterial assemblages (Fenwick et al., 2011).

Researchers drawing on ANT to examine sociomaterial assemblages turn their attentions to the relations *among* things rather than to the things themselves. This focus affords investigation of, for example, the ways in which pedagogical practices are produced and the ways in which particular associations create and circulate some knowledge while at the same time constraining other knowledge. Showing the ways in which knowledge can be understood as incoherent and problematic, rather than easily defined and transported, Fenwick and Edwards (2010, p. 35) suggest that ‘education could be about experimenting and intervening rather than simply the (re)presenting of facts’. This persistent attention to the possibilities for education, knowledge and learning to be otherwise is a key contribution of ANT.

Perhaps more explicitly than other sociomaterial approaches, ANT seeks to trouble neat and tidy accounts of the world, insisting that research and researchers attend to the inherent messiness of the phenomena under investigation (Law, 2004). This commitment entails recognising that research methods are less about reporting phenomena already ‘in the world’ and more about research methods participating in and resonating with the world to produce particular accounts (Law, 2004). There is an understanding that research methods produce effects in the world and often in the phenomena investigated.

### **Epistemic objects**

Another way of approaching the study of professional knowledge and practice is through the work of Knorr-Cetina (2001; 2006; 2007). Although her work focused on the study of scientific knowledge, particularly in laboratories, the concepts she developed have been brought to bear on questions of education.

One of Knorr-Cetina’s strands of work was the rise of the knowledge society, and the associated presence not just of circulating knowledge but also of knowledge

practices. That is, ways emerged of engaging with such knowledge (Knorr-Cetina, 2001). Drawing on these ideas to examine knowledge and knowledge practices in professional contexts, Nerland (2012) and Nerland and Jensen (2010; 2014) have shown the considerable local knowledge work that is part of professional engagement with, for example, research findings or medical treatment protocols.

Two key concepts in this approach are epistemic objects and epistemic practices. Epistemic objects are not simple or neatly bounded objects. Rather, epistemic objects are complex and fluid. Epistemic objects are so called because when professionals encounter them, epistemic work is invited. Epistemic objects generate questions, and 'call upon practitioners to explore, validate, document' (Nerland and Jensen, 2014, p. 27). This work of exploring and questioning, and so on, is the work of epistemic practice.

Focusing on epistemic objects and practices opens up means of analysing the ways in which abstracted knowledge, such as that codified for example in best-practice guidelines, is adapted and translated to accommodate local specificities. Tracing the circulation of knowledge demonstrates links between local work settings and wider knowledge cultures (Nerland and Jensen, 2014). For example, academic journals circulate research findings and clinical procedures constitute one mode of further developing and circulating those findings as practices (Nerland and Jensen, 2014).

Although epistemic objects do specify aspects of how to proceed in professional work, they are also 'always unfolding ... always in the process of being materially defined' (Knorr-Cetina, 2001, p. 181). This characteristic of being incomplete and open to changes helps to draw attention to the ways in which epistemic practices can be stabilising but also sometimes explorative (Nerland and Jensen, 2010). Epistemic objects and epistemic practices are intertwined as the object unfolds in and through the translational work it invites (Nerland and Jensen, 2014). The always-unfolding characteristic of epistemic objects is a point of ontology rather than epistemology. The argument is not that epistemic objects are differently



understood as they unfold, rather than the unfolding is the ongoing performance of the epistemic object itself.

In summary, these sociomaterial approaches to educational research draw attention to the ways in which learning and knowledge materialise in and through relations among human and non-human entities. Educational researchers argue convincingly that sociomaterial ideas have much to contribute to questions of professional education in health care (Bleakley et al., 2014; Fenwick, 2014), not least because of the scope to attend to the wide range of medical technologies, tools and devices that help to constitute diagnosis, treatment and care provision. However, it is important to take account of the very particular commitments these sociomaterial ideas demand. Conventional understandings of structure and agency are seriously troubled (Latour 2005; Fenwick and Edwards, 2010) by the emphasis on phenomena as effects of particular sociomaterial assemblages.

One useful way of gathering together the theoretical and methodological implications of sociomaterial ideas is to engage with the work of Barad (2003; 2007). Educational researchers are increasingly employing Barad's ideas in their own investigations of knowledge and learning (see, for example, Jackson and Mazzei, 2012; Hughes and Lury, 2013; Taylor, 2013; Fenwick, 2014) and I have found her ways of detailing the nature and implications of entanglements and indeterminacy to be particularly useful in my own research. I devote chapter three to exploring and discussing the aspects of her work that have most informed my own study.

### **Informal professional learning**

As I near the end of this chapter, I pause to draw together some of the arguments emerging from the literatures already discussed. In doing so, I am creating a space in which to incorporate one further key strand of educational literature, which focuses on informal learning in the workplace.

Learning, as I understand it in this study, is not purely a cognitive phenomenon of individual minds. On the contrary, learning can be conceptualised as a sociomaterial phenomenon, emerging from heterogeneous relations among people and things. In my study of professional learning in health care, there are two particular aspects of such heterogeneous relations that warrant further attention. The first is the effects of technologies, which are increasingly central to the work of health-care provision. Sociomaterial sensibilities direct attention to technologies as active participants in health care and in learning. In this way, technologies are investigated not as brute tools to be used but as actors that are constitutive of health care and of learning. The second important feature to consider is the enactment of disease, rather than the experience of illness. Such consideration helps to account for the ways in which disease and biomedical concerns contribute to understandings of how health-care professionals provide care, and the ways in which they learn, or come to know their work.

Learning can be investigated through examination of everyday work practice. Such examination offers ways of studying the materialisation of learning, or to put it another way, of studying learning as a practical accomplishment. Learning can be understood as a collective, embodied, situated accomplishment; an effect of complex sociomaterial relations. In this way, attention is drawn to the configurations and reconfigurations of work practices, in all their mundane detail. With such foci on everyday health-care practice, I make a deliberate move to study *informal* professional learning. I am not focused on more formal educational programmes, such as initial undergraduate degrees for medicine or nursing, nor am I focused on organised training events that might be delivered in health-care settings. Instead, workplaces are recognised as key sites of learning (Billett, 2002).

### **Learning in and through work**

The informal professional learning that I investigate is embedded in arrangements for work and in the actions and conversations of work (Fenwick, 2008). This focus emphasises the informal learning that unfolds in everyday work

practices, as professionals encounter challenges and problems and find ways of responding. Following Fenwick (2008), these workplace challenges and problems are investigated as learning struggles, thereby offering ways of examining the fine-grained intricacies of professional learning in particular problems of health care. This shift to learning struggles, rather than thinking of problems of policy implementation, or problems of health-care practice, is important. Informal learning is often not recognised as learning at all in workplaces and instead tends to be considered as simply part and parcel of everyday work (Boud and Middleton, 2003).

Studies of informal learning have also engaged construals of learning as an emergent phenomenon, or to put it another way, as an effect that is more than the logical sum of identifiable parts (Johnsson and Boud, 2010). Emphasising the spontaneous and unpredictable nature of learning, Johnsson and Boud (2010) suggest that the intentional design of learning is problematic. Arguing that notions of workplace learning curricula are inherently reductionist, Johnsson and Boud (2010) suggest that such notions are based on assumptions that all variables are identifiable and open to manipulation. Rather than designing learning curricula, what is key for Johnsson and Boud (2010) is the recognition of work practices as learning practices and the possibility of creating learning spaces among such practices.

These ways of understanding learning as emergent in and through everyday work practice are helpful in my study. Approaches to professional workplace learning often assume that intentional pedagogical interventions are focused on student or novice practitioners and can be delivered and supported by more experienced professionals. For example, learners might be gradually inculcated into a field of practice by more experienced others through the progressive sequencing of exposure to and engagement in more difficult tasks (Lave and Wenger, 1991). Learning might be enhanced through coaching or through modelling the work of senior colleagues (Billett, 2002). Such approaches, while helpful in some instances, are less immediately useful in circumstances where *all* professionals are facing seismic transformations in work practice.

The point to make here is that *everyone* is learning. As I have already outlined in chapter one, there are enormous shifts in the organisation of health care, increasingly rapid and widespread technological changes and extensive reconfigurations of professional roles and responsibilities. Helping professionals to learn the work of supporting self-management in such circumstances cannot rely on pedagogical interventions based on and facilitated through an existing body of expertise. What is required is a focus on informal professional learning through sustained investigation of the particular workplace learning struggles that health-care professionals encounter. Making such learning struggles visible is one way of enabling health-care educators to recognise the potential of informal workplace learning (Boud and Middleton, 2003). Further, recognising such potential increases the scope for the careful deployment and effective utilisation of pedagogical interventions (Boud and Middleton, 2003).

### **Chapter summary**

This chapter has drawn together key literature from educational studies and from science and technology studies (STS). In relating to this literature, I have differentiated my study from those that focus on learning as a kind of cognitive reasoning or as a psychological phenomenon of individual minds. I have also shown that I am not exploring learning as social participation, even though such approaches have contributed helpful recognition of the social arrangements for learning. Instead, my study is aligned with the work of certain educational researchers who focus on sociomaterial arrangements for learning. By sociomaterial arrangements I mean the heterogeneous networks of assemblages that comprise relations among human and non-human entities. In such work, learning is construed as an effect of sociomaterial arrangements; thus, opening the way to examine the materialisation of learning.

My study also speaks to and is informed by the research of certain scholars using practice-based approaches who examine the fine-grained details of everyday work practices. In these approaches, learning is understood as embedded, embodied, situated and collective. Learning can therefore be examined as a

practical accomplishment that is more than human and includes relations among, for example, buildings, technologies, bodily substances, policies, medicines and diseases. These researchers offer an empirical way of generating insights into the ways in which professionals come to know in their every day work.

In this particular study I am not focused on learning that emerges through formal programmes of education, nor am I focused on learning that emerges from organised training events. Rather, I am interested in informal professional learning as it emerges in and through work. In particular, I have argued that investigating work problems as learning struggles will enable attention to the considerable challenges facing health-care professionals who are currently trying to support self-management in times of enormous change.

Given the need to engage with complicated technical and biomedical details of health-care practice, I have drawn from the work of particular STS researchers who have examined the enactment of disease and the complex effects of technologies in health care. I have also related to such literature particularly in terms of its ability to help me move away from foci on human experiences and interpretations. Instead, I seek to focus on learning as enactment and on the particular relations among human and non-human entities that help learning to materialise. With this sensibility, I recognise the entangled relations among social and material entities. However, engaging with these entanglements, and with the notion of indeterminacy, is not easy.

In order to explore and be able to work with such ideas, I turn to the work of Karen Barad. Although she is not an educational researcher, Barad (2007) has contributed detailed consideration of knowledge as direct engagement in and of the world. What makes her arguments so illuminating is her painstaking development of an ontological-ethical-epistemological framework (Barad, 2007), which opens up ways of understanding the significance of sociomaterial entanglements. More than this, her steady insistence on accounting for the *nature* of sociomaterial entanglements, as well as their significance, seeks to offer

a particular way of examining phenomena as patterns of ‘mattering’, that is, as patterns of material effects. Chapter three, next, explicates the specific dimensions of Barad’s (2007) theoretical approach that have most informed my own study.

### 3 Theories are Not Just in the Mind

Knowing is a matter of differential responsiveness (as performatively articulated and accountable) to what matters.

(Barad, 2007, p. 379)

In this chapter I turn to focus on one of the key theoretical and methodological resources that influenced my study: the work of Karen Barad. I have opted to devote a full chapter to particular aspects of Barad's (2003; 2007) ideas, because they had such significance for my own learning and for the way in which I approached my research. Sociomaterial ideas are difficult: in the words of Orlikowski (2007, p. 1437), 'there is no social that is not also material, and no material that is not also social'. Grappling with such indeterminacy is not straightforward, especially in empirical research (Leonardi, 2013; Fenwick et al., 2016). Distinguishing among researcher/researched, for example, becomes extraordinarily challenging with/in methodologies that refute conventional categories and structures and engage in perpetual disassembly of hitherto assumed boundaries.

I focus on three main ideas in Barad's work that I have found particularly useful in my own study: the concept of diffraction; her way of thinking about/with phenomena; and her overall framework of agential realism. In doing this I am aware that I am making selections that matter, or to put it another way, that my selections have material effects. I acknowledge that this chapter is not a comprehensive account of Barad's entire approach but rather a way of showing how particular aspects of her thinking have informed my own research. Throughout the chapter I also include contributions from others who have used her ideas.

In the next section, I begin with the aspects of her work that I found most helpful: first, the particular concept of entanglement she employs and second,

the ‘tissue of ethicality’ (Barad, 2007, p. 396) that runs through her work. Because her background in physics is so important to her ideas, I also include a brief account of the quantum theories that most influence her thinking. In subsequent sections the chapter shows the significance of the shift produced by taking phenomena as the unit of analysis. Last, after recounting the ways in which these ideas claim to reconfigure understandings of causality, the chapter concludes with a consideration of the explicit ethical commitments in this approach.

### **Sociomaterial entanglements and ethics**

The sociomaterial commitments that Barad (2007) respects are not unique to her particular approach; indeed, many others share such attention to the ways in which materials and materiality matter (see, for example, Mol, 2002; Law, 2004; Latour, 2005; Fenwick and Edwards, 2011). The focus, as discussed in the previous chapter, is neither on social nor on material but instead on relational connections. It is the connectedness that matters: social and material are entangled, and the aim is to examine the nature of entanglements.

Entanglements are a particular preoccupation for Barad (2007), but they also feature in the work of researchers in fields such as organisation studies (see, for example, Orlikowski, 2007), and in education (see, for example, Sørensen, 2009). What I have found useful about Barad’s (2007) approach is her insistence on the importance of the specificity of entanglements. What matters is not simply that social and material are entangled or, for example, that medicines and technologies might be entangled with professional regulation in the emergence of professional knowledge. Insisting on a highly detailed examination of entanglements pushes further: engaging, for example, with particular medicines and with specific features or qualities of particular medicines in particular instances. This emphasis on specificity works well with my interest, already discussed in chapter two, in attending to the everyday details of professional practice, even where these details are biomedical and not the natural habitat of educational research.



The concept of entanglements, for Barad (2007), is also a way of underlining the need for investigative approaches to be attuned to the specific phenomenon at hand (Barad, 2007). For Barad (2007), this specific attunement is not simply about ensuring research methods align with research foci. It is much more than that, and emphasises that investigative approaches not only investigate, but also constitute.

I discuss the issue of entanglements and specificity further throughout this chapter but for now, I explain briefly by saying that I use Barad's (2007) approach to examine the ways in which technological change influences the emergence of professional knowledge (chapter five); care regimens as epistemic phenomena (chapter six); and the troubling notion of empowerment (chapter seven). These areas of importance are important because of their prevalence in the selected literature and in the observations and conversations of my fieldwork, but they also emerge in and through my selection of particular methodology, methods and modes of analysis (more of that in chapter four). This process is one of making known, rather than one of discovery, and Barad (2007) is careful to recognise her (my) part in the making.

Ethics and responsibility are fundamentally threaded into Barad's (2007) approach. For Barad (2007), knowing entails accountability. The work of selecting some foci for attention, while at the same time inevitably excluding other foci, is not simply a way of examining the world: it is a way of constituting the world (Barad, 2007). Researchers are irrevocably entangled with phenomena under investigation, and Barad (2007, p. 396) calls us to 'meet the universe halfway, to take responsibility for the role that we play in the world's differential becoming'. Perhaps more than other sociomaterial approaches, Barad (2007) incorporates an explicit ethical dimension: one that not only installs the researcher firmly in the research (the view from somewhere, rather than the view from nowhere or from everywhere) but one that also crafts a way of recognising the productive nature of knowledge making. The world and our knowledge of it emerge together (Fenwick et al., 2011).

## Two physicists

Barad is both physicist and philosopher. Her theoretical contribution to understanding science and the ethics of knowing is a richly detailed articulation of ‘the conditions for the possibility of objectivity, the nature of measurement, the nature of nature and meaning making, and the relationship between discursive practices and the material world’ (Barad, 2007, p. 24). Although the development of her theoretical framework, agential realism, is not based on her own empirical research, Barad puts her ideas to work by engaging with the empirical research of others. Many of her ideas are anchored in the work of two eminent physicists, Niels Bohr and Werner Heisenberg, and their opposing theories are significant for much of what follows in this chapter.

Quantum physics might be considered an odd choice to include in my thesis, but Barad’s detailed explication of issues of objectivity and measurement has far-reaching implications for understanding her theoretical and methodological approach. A brief interlude into the different theories contributed by Bohr and Heisenberg helps to clarify the nature of these implications. This overview also introduces the way in which Barad (2007) conceptualises ‘phenomena’.

The opposing theories developed by Bohr and Heisenberg address issues of objectivity and measurement. Heisenberg asserted that we cannot know both the position and momentum of a particle simultaneously because when we try to measure the particle’s characteristics, we inevitably disturb its momentum (Barad, 2007). This is a point of epistemology and outlines the limitations of what can and cannot be known. In contrast, Barad (2007) explains that Bohr argues the point is not epistemological but ontological. It is not that the position and momentum values cannot be known simultaneously but that particles do not have these values simultaneously; the values simply do not exist at the same time.

This is a fundamentally important point about the nature of reality, and Barad (2007) goes on to explain that Bohr challenges the idea that independent things have their own fixed and determinate properties. Instead, Bohr highlights the

effects of the process of measuring things on the becoming of those things. Barad (2007) uses the light-wave duality paradox as an illustration of this point. The central problem is that light cannot be both wave and particle but that in certain experimental conditions it seems to behave as one or the other – it has the properties either of wave or of particle. Barad (2007) explains that Bohr resolves this paradox by reframing wave and particle not as physical objects but as mutually exclusive phenomena. The ontological position derived from this work is not the same as proposing that there are different ways of seeing the world; instead, the position is that the world is differently materialised according to specified conditions.

Thinking with the concept of phenomena instead of objects, is a way of recognising the effects of the experimental conditions – or, following Bohr and Barad (2007), the measuring apparatus. In his investigation of the wave-particle paradox, Bohr showed that if the measuring apparatus identifies light as a wave, the resulting pattern is a wave pattern; yet if the measuring apparatus identifies light as a particle, the resulting pattern is a particle pattern (Barad, 2007). The measuring apparatus is not simply an observational instrument; rather it works as a material embodiment of concepts and ideas to help shape and produce particular phenomena. Theories are not just in the mind, they are physical arrangements that participate in material ways. Barad uses this account to argue that there is no traditional assumption of separateness between the observer and the observed, or to put it differently, that the world and our knowledge of it are irrevocably entangled.

### **Studying entanglements: a diffractive methodology**

Respecting entanglements, and finding ways of studying them without resorting to disentangling, is a persistent challenge (Barad, 2007; Leonardi, 2013). It is difficult to avoid either collapsing social and material into one and the same, or alternatively, treating social and material as if they each are determinate entities with fixed boundaries. Diffraction, or more particularly Barad's diffractive

methodology, is employed as a way of responding to this challenge (Barad, 2007). Diffraction provides a way of attending to differences as relational.

However, such challenges of finding ways to engage with data differently are not unique to Barad. Sociomaterial approaches often seek to disrupt taken-for-granted ways of understanding the world (see, for example, Latour, 2005), and to make visible the messy, non-linear processes that constitute research practice (see, for example, Law, 2004). This diffractive methodology is Barad's (2007) means of reaching across and beyond conventional approaches.

Diffraction is interference (Barad, 2007). As a physical phenomenon, diffraction is the overlapping and movement of waves: examples include water, light and sound waves (Barad, 2007). As an illustration, dropping two stones into a still pond creates diffraction patterns as the ripples in the water overlap with one another (Barad, 2007). As the ripples encounter one another (or the stones) as obstacles, the diffraction pattern that is produced emerges from the interference of the obstacle (Barad, 2007). Recognising that diffraction is interference (Barad, 2007) highlights that diffraction is as much about making a difference as it is about examining difference (Barad, 2007).

A diffraction pattern is produced as individual waves ripple outwards, always and only provisionally individual, always combining together as a spreading pattern of multiple waves. One of the ways in which diffraction can be a useful heuristic is by highlighting that the pattern produced entails some form of repetition and differentiation (Hughes and Lury, 2013), and this helps begin linking the concept to empirical research. So, for example, Barad (2007) talks about trying to read ideas diffractively: together and through one another in order to create and examine the diffractive patterns that are produced. For Barad (2007), this diffractive reading differs from other modes of careful reading that seek to read ideas against one another or against a fixed argument, for example. For other researchers, the value of this diffractive approach is its affordance of appreciation for data as lively, perhaps troublesome (Taylor, 2013) and also its effect of 'enacting flows of differences, where *differences get made* in the process of

reading data through one another' (Taguchi and Palmer, 2013, p. 676, italics in original). The diffractive focus on patterns of difference, rather than on recurring themes, was a heuristic I found invaluable in my own research and I discuss this further in chapter four.

In her development of this diffractive methodology, Barad (2007) draws from Haraway's (1997) earlier work. Both draw attention to the ways in which diffraction can challenge reliance on the concept of reflection. A key shared argument is that while reflection re-presents more or less the same elsewhere, as a mirror does, diffraction is a tool for attending to difference (Barad, 2007; Haraway, 1997). Diffraction is a means of shifting away from optical metaphors (Barad, 2007; Haraway, 1997) that presume an a priori 'seeing' subject and an a priori object-to-be-seen.

Importantly, diffraction is not merely about looking and seeing differently. By way of novel illustration, Barad (2007) describes the brittlestar, which is a sea creature hitherto thought to have no eyes. However, Barad (2007) recounts biological research by Aizenberg et al. (2001) which contradicts that assumption. Barad (2007) explains that, in fact, Aizenberg et al.'s (2001) research suggests that the brittlestar comprises multiple 'eyes':

Brittlestars don't *have* eyes; they *are* eyes. It is not merely the case that the brittlestar's visual system is embodied; its very being *is* a visualising apparatus ... For a brittlestar, being and knowing, materiality and intelligibility, substance and form, entail one another ... There is no optics of mediation.

(Barad, 2007, p. 375, italics in original)

What this quote highlights is that rather than steering researchers to *see* differently, a diffractive methodology emphasises sensing and participation. A diffractive methodology is productive 'worlding' (Taguchi and Palmer, 2013), or in

other words, a diffractive methodology is direct engagement and accountable intervention. The point is not that brittlestars are accountable, but that a diffractive methodology affords no capacity for standing apart from the world.

These entangled states present considerable difficulties when researchers engage the ideas in empirical work (Leonardi, 2013). For ‘if we are always in the middle – part of what we study, not above or beyond what we observe, if we are not on the way to some kind of synthesis or conclusion ... how are we to make a start or come to an end?’ (Hughes and Lury, 2013, p. 792). Respecting indeterminacy, and trying to study entanglements with indeterminate boundaries, Barad (2007) turns again to the work of the physicist Niels Bohr.

### **Thinking of/with ‘phenomena’ instead of ‘objects’**

Already described at the beginning of this chapter, Bohr investigated the light wave–particle paradox. He showed that if a measurement is made that identifies the electron as a particle, then the result of the experiment is a particle pattern. With a different apparatus, which instead identifies the electron as a wave, the result is a wave pattern. A key insight here is that neither result is truer than the other; rather, the resulting pattern is a phenomenon produced in part by the measuring apparatus.

This approach of thinking of/with ‘phenomena’ assumes that the measuring apparatus and the ‘object’ are inseparable in any finite way. Arguing that ontology and epistemology are not separate, Barad (2007) asserts that theoretical concepts are not simply ideations. Instead, the point is that theoretical concepts are materially present in the physical arrangements, or the measuring apparatuses, that help to produce the phenomenon being described (Barad, 2007): *ideas matter*.

Moreover, measuring apparatuses are not considered as simple observing devices (Barad, 2007). The measuring apparatus works as a boundary-drawing practice (Barad, 2007), contributing to the emergence of the phenomenon being

measured. This recognition of the work of boundary-drawing practices marks the shifting and impermanent nature of boundaries and takes account of entanglements.

Arguing that there are no pre-existing boundaries between subject and object does not imply that there are no boundaries but instead that boundaries are actively configured and reconfigured. Using the well-known example of a person in a dark room with a stick, Barad (2007) explains the ways in which provisional boundaries might be understood. In brief, the person might hold the stick and examine it as object, or the person might hold the stick and use it to examine the room. The stick might be subject or object, but it cannot be both at once.

Boundaries are provisional. Boundaries are produced in and through ongoing and dynamic processes. In the example above, the phenomenon of observation is a dynamic and specific set of relations among observer–observed. However, there are no a priori assumptions delineating either observer or observed. Agency is not attributed in advance. Instead, agential separability (Barad, 2007) emerges through the action of observing as observer–observed are temporarily delineated.

This enacting of boundaries is what Barad (2007) terms the agential cut. The agential cut resolves the indeterminacy of entanglements. At the same time, there is recognition of the provisional nature of this resolution. The agential cut is not a finite cutting apart but instead enacts a boundary that exists within the phenomenon. For Barad (2007), there is no ‘outside’ the phenomenon; rather, she coins the phrase ‘exteriority within’ to respect the perpetually entangled state of agential relations.

With this conceptualisation of phenomena, Barad (2007) proceeds to make another shift, away from the term ‘interaction’ and instead introduces the term ‘intra-action’. Using the former, for Barad (2007), is too close to accepting that absolutely delineated entities encounter one another. Instead, the term ‘intra-action’ restates the emphasis on entanglements, while still providing a way of examining the details. Intra-action between observer–observed, for example,

makes it possible to account for the work of observing without ignoring the entangled agential relations comprising the phenomenon of observation.

In an effort to summarise all of these ideas, the following definition of phenomena marks a pause in this chapter and gathers together many of the unfamiliar terms mentioned thus far:

Phenomena are differential patterns of mattering ('diffraction patterns') produced through complex agential intra-actions of multiple material-discursive practices or apparatuses of bodily production, where apparatuses are not mere observing instruments but boundary-drawing practices – specific material re-configurings of the world – which come to matter.

(Barad, 2007, p. 140)

It is easy to underestimate the significance of the shift from thinking with the concept of 'objects' to thinking instead about 'phenomena'. However, some critiques of Barad's work tend to miss the important work that this shift performs, and so appreciating the significance helps engage with and respond to those critiques. The quote above does little to refute accusations of unhelpful density (see, for example, Leonardi, 2013), but it does weave together the key sensibilities and assertions. The important shift is towards a focus on phenomena as patterns of mattering, and not, borrowing from the words of Law and Singleton (2005), on the kinds of objects you can drop on your toe. Emphasising relationality, Barad (2007) argues that social and material cannot be separated in any finite way but are instead irrevocably entangled as material-discursive. The attention to phenomena both appreciates this inseparability and also implicates our creative participation (and responsibility) as researchers.

The empirical challenges of respecting sociomaterial commitments are many, and I discuss my own difficulties and responses in chapter four. At this point,



however, it is important to show that the shift from 'object' to 'phenomena' is a device that helps counter some of the challenges. To explain, I use an example given by Leonardi (2013, p. 66) in his account of the affordances and limitations of Barad's approach:

Actors in the world ... can relatively easily point to a hammer or a piece of software and say 'this is material' but they would likely have a hard time fathoming that a hammer was in any way social.

(Leonardi, 2013, p. 66)

This assertion makes sense, although there are some who would argue that the history, development, production and use of a tool such as the hammer indeed make it indisputably social as well as material (see, for example, Latour, 1988). Yet for Barad (2007), the point is not that the hammer is social. The point is that the hammer as object is not the unit of analysis. For Barad (2007), the unit of analysis is always phenomena. Much like de Laet and Mol's (2000) Zimbabwean water pump, already discussed in chapter two, the hammer is not a hammer until it is hammering, and so perhaps for Barad (2007) the phenomenon of 'hammering' might be a more appropriate unit of analysis than the object 'hammer'. The affordances of such a unit of analysis include the formulation of particular kinds of questions. For example, staying with the hammer, it becomes possible to ask not only about who hammers, or what a hammer does, but also about the ways in which hammering is produced.

As I move to consider Barad's (2007) overall framework of agential realism, the example of humans using objects/tools in a brute deterministic way is a useful foil for the profound shift that sociomaterial approaches offer. Describing agential realism as a way of reworking causality, Barad (2007) does not recognise agency as a purely human force. An everyday example is the often-repeated declaration that 'guns don't kill people, people kill people'. Whether the killing is a result of the gun, or of the person using the gun, is not necessarily the issue at

hand in an agential realist formulation. Instead, the foci are the particular intra-actions of specific material-discursive practices that work to constitute the phenomenon of killing.

### **Agential realism: reworking causality**

Calling her approach an ontological-ethical-epistemological framework, Barad (2007) draws together her ideas under the heading 'agential realism'. In the following sections I focus first on the implications for understanding agency and the ways in which these implications influence empirical research. Second, I turn to discuss more deeply the 'tissue of ethicality' (Barad, 2007, p. 396) that is such a persistent feature of this approach.

Agential realism accords attention to agential flows rather than conceptualising agency as a property to possess. Agency is neither attributed to humans nor attributed to objects. Agencies are distinct only in a relational sense (Barad, 2007). By this I mean that for Barad (2007), it is the flows of agential relations that become important: flows of agential relations produce, and emerge from, specific sociomaterial intra-actions, in the materialisation of particular phenomena.

Causality becomes a matter of accounting for specific patterns, rather than looking for intent. In the example phenomenon of gun crime, or even the phenomenon of a single shooting, accounting for specific patterns widens the possibilities for intervention beyond understanding individual human intent. In such accounts, attention might be drawn to the number of guns in the country, the availability of retail outlets selling guns, the environment, and so on. Determining cause becomes a provisional working through of the specific features of the phenomenon of interest, with a sustained focus on the dynamic connections among those features. In this way, it is possible to examine the particular intra-actions that contribute to the materialisation of phenomena.

The point is not that anything is possible but that this approach moves away from what Barad (2007) argues are flawed and restrictive binaries of free will versus determinism. With this sense of perpetually unfolding and materialising phenomena, the space for and the points of intervention grow. The possibilities are not endless, but they are more than one.

As a way of showing how agential realism generates particular insights, Barad (2007) relates a diffractive reading of the rich anthropological research work of Fernandes (1997). Taking the original study's detailed accounts of union politics in the everyday lives of the workers, Barad (2007) seeks to move beyond structural-discursive theorising to contribute material-discursive insights. Arguing that power relations can be usefully understood in light of the material constraints as well as the social forces at play, Barad (2007) generates a novel explication of the ways in which shop-floor dynamics materialise in the Indian jute mill that Fernandes (1997) investigated.

In one lively example, Barad (2007) teases out Fernandes' (1997) description of the sewing machines tightly packed together in the workspace of the factory. The close proximity of machines had the effect of supporting extensive contact between the workers, to the consternation of the managers (Fernandes, 1997). Barad (2007, p. 238) argues that this close proximity and its effect show the ways in which 'humans and machines together contest the individualisation of the nature of production'. The point is not that the sewing machines have intent but, rather, that 'the entangled, contingent and changing material conditions of the shop floor produce much more than saleable commodities, and the flow of capital is but one stream in a turbulent river of agencies' (Barad, 2007, p. 239). Identifying cause and effect becomes a troublesome task.

Agential capacity for gathering and organising as workers, in this factory, emerged in part through the physicality of the workplace, which in turn became significant through its entanglement with, for example, management practices aimed at separating and making individual workers visible. In a similar way, examining outdoor learning in schools, Quinn (2013) contends that social

inequalities are not in themselves agential without the participation of other elements.

The challenges raised by this reworking of causality are not insignificant. One problematic issue is that although this agential realist approach generates richly informative and particular accounts of selected phenomena, generating possible interventions or responses remains difficult. The disassembling of delineated, permanent boundaries between cause and effect emphasises complexity. Recognising the fluid, contingent nature of the intra-actions comprising phenomena might widen the scope for possible intervention, but this recognition is less helpful in narrowing the selection. I discuss this difficulty in my own research in chapter eight, but for now it links to a second issue: responsibility.

### **Barad's 'tissue of ethicality'**

Although humans are not accorded the agency to determine particular phenomena, neither are we exempt from responsibility. Our agential participation in phenomena, as part of the agential cuts that contribute to the emergence of phenomena, draws us firmly within the phenomena and the production. Trying to stand apart from entanglements makes no sense in this diffractive methodology.

The ethics of knowing is a theme that permeates Barad's (2007) work. Knowing is 'a matter of differential responsiveness (as performatively articulated and accountable to) what matters' (Barad, 2007, p. 379). Ethics, for her, is not simply conceived of in terms of correct procedures or consequences of actions, but rather about the cuts that are made and the attention that is paid. Knowing is intra-acting, in and of the world.

In her book *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning* (2007), Barad draws from the work of Levinas to explain her own particular construal of ethics. Taking as her starting point Levinas's emphasis on relational responsibility and the importance of

recognising and responding to the Other, Barad (2007) agrees that ‘the ethical subject is not the disembodied rational subject of traditional ethics but rather an embodied sensibility’ (Barad, 2007, p. 391). Levinas recognises ethics as responsibility to the (human) other and includes wider responsibilities: in the words of Christians (2011, p. 70), ‘in Levinasian terms, when I turn to the face of the Other, I see not only flesh and blood, but a third party arrives – the whole of humanity.’

Where Barad (2007) moves beyond Levinas is in her appreciation of such embodied sensibility as something not limited to *human* embodiment. Recalling the brittlestar, Barad (2007, p. 392) argues that ‘a humanist ethics won’t suffice when the “face” of the other that is looking back at me is all eyes, or has no eyes, or is otherwise unrecognisable in human terms’. The recognition of sociomaterial entanglements, of indeterminate boundaries and of multiple intra-acting phenomena demands a similarly sociomaterially attuned consideration of ethics.

In my own research, I have found such ideas both inspiring and also extraordinarily challenging. What was especially useful was the recognition of ethics as not simply relating to the responsible conduct of the study but rather to the wider way in which the study engages and configures the world. This recognition helped me to respect and also to examine the ways in which my attentions and selections might contribute to, create or dismiss particular configurings and reconfigurings. I recognised not only that my study ‘makes the world intelligible in specific ways’ (Barad, 2007, p. 394) but also that this production and amplification of some phenomena and not others is an unavoidably ethical practice.

However, what remains so challenging is the incomplete nature of such ideas. Without diminishing the persuasiveness of Barad’s (2007) onto-ethical-epistemological framework, it is unarguably difficult to grasp just how such ideas might best materialise in an empirical project. Perhaps part of the challenge is that broad guidance cannot usefully emerge from an approach that emphasises specificity. Certainly Rouse (2004) has highlighted the importance of recognising

that if Barad's (2007) conceptualisation of phenomena is the unit of analysis, then what is at stake is very much a kind of local intelligibility:

The intelligibility of practices ... depends upon an implicit mutual recognition of and by those to whom the practice matters, such that they (ought to) hold themselves responsible for their different interpretations, and accountable to one another.

(Rouse, 2004, p.12)

My own interpretation of the appreciation of local intelligibility is that what is entailed in employing this diffractive methodology is a careful and painstaking commitment to the entangled agencies of observing and measuring as they engage in and help to constitute a particular phenomenon. The particular details of each and every project are inherently constitutive of the methodology, rather than embellishments on a more fixed and generalised theory or framework.

### **Chapter summary**

In summary, Barad's (2007) ontological-ethical-epistemological framework offers a rich collection of ways in which to engage with and to know the world. Underpinned by an explicit focus on relational connections that is common to much sociomaterial research, Barad's (2007) unique contribution is her attention to the specificity of entanglements. Such attention is perhaps the aspect of her approach that I have found most useful and also most challenging. Drawing from her background as a physicist, Barad (2007) emphasises the effects of the process of measuring things on the becoming of those things. A key argument is that theoretical concepts are materially present in the physical arrangements, or the measuring apparatus, that investigate the phenomenon.

Barad's (2007) seminal shift to thinking of/with phenomena rather than about objects is an explicit recognition of the provisional nature of boundaries.

Moreover, this move recognises that boundaries are actively configured and reconfigured, and that the enacting of boundaries works as a provisional resolution of indeterminacy. This resolution is what Barad (2007) terms the agential cut. Barad's (2007) diffractive methodology is her response to the persistent difficulty of examining sociomaterial entanglements without collapsing back into separations of social and material. Proposing diffraction as a way of attending to differences as relational, and only provisionally determinate, Barad (2007) repeats her appreciation of knowledge making as productive; for her, diffraction is as much about making a difference as it is about examining difference.

With an overall framework she calls agential realism, Barad (2007) accords attention to agential flows. This accordance is in contrast to approaches that conceptualise agency as a property to possess. In this way, Barad (2007) argues, causality becomes a matter of accounting for specific patterns rather than a process of looking for intent. Deeply imbued with what she calls a tissue of ethicality (Barad, 2007), this approach draws from and extends the work of Levinas to appreciate ethics as embodied sensibility. However, Barad's (2007) particular construal of ethics does not consider such embodied sensibility as something limited to humans alone.

There are many challenges remaining for those seeking to respect such methodological and theoretical commitments in an empirical study. However, there are also possibilities for unique opportunities and insights. Chapter four, next, explicates my own efforts to engage Barad's (2007) diffractive methodology.

## 4 A Diffractive Methodology

A diffractive methodology is valuable in enabling us to notice, pinpoint and perhaps value more openly than we usually might, how that which is utterly provisional (knowledge) is smoothed, soothed and straight-jacketed into a 'finished' academic article.

(Taylor, 2013, p. 697)

In this opening quote, the reference to 'smoothing, soothing and straight-jacketing' sets the scene for the following pages. Research is characterised by both precision and precariousness, and so although much of this chapter details precise information, such as the number of participants (thirteen), the months of fieldwork (five), and the interviews conducted (thirteen), it is also a space in which to discuss the more precarious work, the serendipitous selections and the unexpected encounters. As Law (2004, p. 2) argues, and I agree, research accounts that are too tidy tend simply to 'distort into clarity' and risk underestimating the extent to which methodology and method help to produce that which they attempt to understand. Recognising these messier aspects of research is an important way of accounting for the decisions that are made and the attention that is paid. Such accountability is a key preoccupation of a diffractive methodology (Barad, 2007) and throughout the chapter I consider both the ethical challenges and also the ethical implications of the study, including my own participation as researcher.

In this first part of the chapter I outline the overall research design, questions and methodology before attending in more detail to the particular commitments of ethnographic approaches. In considering the demands of such approaches, I discuss the broad ethical issues that often arise and the implications for me as the researcher. I give special consideration to the particular effects of undertaking research in a children's hospital, which is a setting with great potential to evoke profound emotional responses. I then turn to account for the selection of the site



and the recruitment of the participants, as well as detailing specific ethical concerns that arose during the study.

In part two of this chapter I discuss the ways in which I generated and handled data that helped to answer the research questions. I realise that the term 'data' can sometimes work to obscure the researcher's role in producing what counts as 'data' in a particular study. However, I have opted to use the term because it is a concise way of indicating the field notes and transcripts that emerged from fieldwork and interviews. I recognise that my data are, in the words of Jackson and Mazzei (2012, p. ix), 'partial, incomplete, and always in a process of a re-telling and a re-membering'. Working with the diffractive analytical approach already discussed in chapter three, I show how Barad's ideas helped me to encounter the data in different ways, with results that proved both challenging and illuminating. The remainder of the chapter summarises the three broad areas of interest that constitute chapters five, six and seven respectively: technological change and the emergence of knowledge; care regimens as epistemic phenomena; and the troublesome notion of empowerment.

## **Part one**

### **Research questions and design**

The overall aim of the research was to examine informal professional learning in the work of supporting self-management in paediatric diabetes. In this context, I was specifically interested in drawing on a sociomaterial understanding of professional learning, rather than on purely social or psychological conceptualisations of learning. This sociomaterial understanding steered my attention towards the active participation of both social and also material influences, and perhaps most importantly, towards the connections among social and material influences. The research questions guiding the study were formulated as follows:

1. For health-care professionals, what practices and challenges emerge in the work of supporting self-management in paediatric diabetes?
2. What related processes and issues of professional learning unfold?
3. What in particular are the effects of insulin-pump technologies on professional learning?
4. What are the implications of the insights generated by questions (1), (2) and (3) for workplace pedagogies?

### **Ethnographic and praxiographic approaches**

Given the research questions listed above, and the associated focus on the fine-grained details of everyday clinical work, ethnographic approaches seemed a well-aligned option to guide the conduct of the study. Ethnography seeks direct engagement with the social world through participant observations, documentary analysis and examination of artefacts as well as interviews (Hammersley and Atkinson, 2007). Involvement in the day-to-day lives of the research participants is key, and there is a firm commitment to ‘study situations close up, intimately’ (Marcus, 2008, p. 4). Fieldwork remains a distinguishing characteristic of ethnographic approaches for some (Lewis and Russell, 2011) but there are also interesting arguments that refuse to privilege ‘field-based knowledge’ and propose instead that ‘sometimes fleeting engagement offers a more accurate reflection of lived experience than does any form of “deep hanging out”’ (Forsey, 2010, p. 569). This suggestion rests on the perceived value and importance of interviews as participant listening, and seeks to promote responsive flexibility to the changing places and spaces of social life rather than to instigate radically revised forms of ethnographic research (Forsey, 2010).

However, it is important to note that the anthropological roots of ethnography retain an inherent prioritisation of human perceptions and cultural influences. Ethnography, therefore, requires some reworking if it is to facilitate sustained attention to sociomaterial entanglements, and to Barad’s (2007) particular notion

of entangled agencies. I found Mol's (2002) conceptualisation of praxiography to be a useful way of making a distinction between a focus on professional practices and a focus on the professionals themselves. Already discussed in chapter two, Mol (2002) uses the term praxiography to denote a shift away from the conventional ethnographic focus on human meaning and interpretation. Instead, her praxiographic approach attends to practices, including bodies and materialities, and to the ways in which realities are recursively performed into being through particular sets of practices. I found that this sensibility of Mol's aligned well with Barad's (2007) attention to the material-discursive practices that produce phenomena through multiple intra-actions.

Praxiography shares much with ethnography, including methods of observation, interviewing, and attention to a wide range of documents and artefacts. Suggesting that it is possible to listen to stories 'in a realist mode', Mol (2002, p. 15) explains that her approach is to talk with people as if they were their own ethnographers, for example getting them to talk about the ways in which they live with disease and about the practices that perform disease.

However, praxiography is not simply a way of attending to objects such as microscopes, although Mol (2002) does advocate following objects and taking account of all kinds of events in the work of such research. Praxiography is more than this, and seeks to offer a way of attending to sociomaterial entanglements; in the words of Mol (2002, p. 157), praxiography examines phenomena by introducing an axis of practice that 'encompasses molecules and money, cells and worries, bodies, knives and smiles, and talks about all of these in a single breath'. A praxiography does not privilege people's perspectives and experiences, because a praxiographer is interested in the practices that perform phenomena into existence.

### **Being an ethnographic (praxiographic) researcher**

Identifying my position as a researcher was not simply a process of mapping coordinates according to theoretical frameworks and then taking up the

indicated stance. Instead, positioning myself as a researcher was an ongoing negotiation that depended on field encounters and research tasks as well as the previous professional and personal experiences that shaped my engagement with the research. A world characterised by entanglement raises the impossibility of the individual, separated human subject (Ellingson, 2011) and that includes me as a researcher. I understand my presence in the clinic, including the agential cuts I made as I worked to make sense of the data as materially constitutive of the insights and conclusions presented in this thesis. In the same way, I understand that the effects of my experiences as a health-care professional and as a parent of a child with diabetes participate in my knowledge of the world and in my research. Given the potency of those experiences in this particular research setting and study, I take time in this section to consider the implications in some detail.

Hospital settings can be difficult places to work and to observe (Hinshelwood and Skogstad, 2000), sometimes evoking powerful emotional responses. Witnessing the provision of health care often entails also witnessing the illness and distress of those who are being cared for (Skogstad, 2000), raising important questions about the impact on the researcher. In my own study, I found that my chosen research setting, which I will call City View Children's Hospital, sometimes had profound effects on me. Before discussing further the implications for my participation in the research setting, I illustrate these effects with the following two extracts from my field notes; the extracts describe parts of my journey to the clinic.

It's a long walk to get to the clinic, through grimy streets and high-rise flats, past the glowering hospital chimneys and the taxi drop-off points. Smokers huddle beneath a reproachful picture of a young chemotherapy patient. The double glass doors slide and jolt and the freezing air seeps inside. Parents in pyjamas with coats over the top, looking dazed, remind me of what happens in here. Children are ill, sometimes dying, as mums and dads murmur into mobile phones and look out beyond the car parks to the city squares.

(Field Notes, January 2013)

On this particular day I was especially struck by the distress of the people I passed in the more public areas of the hospital before arriving at the outpatient clinic. Perhaps as much as a consequence of witnessing such distress as of my understanding of the research methodology I had selected, I had no sense of myself as any kind of detached and neutral observer. Instead, I recognised that ethnographic (and praxiographic) researchers are inherently part of the social worlds they explore (Angrosino and Rosenberg, 2011), affected and affecting. There was also a second more immediate effect of the research setting, evident in the extract below, which describes the continuing journey from the hospital grounds to the outpatient clinic.

There's warmth and chatter inside, and the smell of hospital toast. The noises of the lift doors and trolley wheels mix with the sound of quickening footsteps and I take the stairs, not yet ready for contact and conversation. Higher and higher, surgical theatre blues and greens start to outnumber civvies, stethoscopes swing and battered case files make their way between wards and offices. Sunlight pours through the huge dusty windows that overlook the houses far below, and the grey-green floor stretches on through sprawling corridors, disappearing under rows of matching doors.

(Field Notes, January 2013)

I often chose to take the many flights of stairs instead of the lift, giving myself space to make the shift from outside to inside the hospital. The stairs afforded a more gradual transition from the clatter of the ground floor to the relative stillness of the outpatient clinics higher up, allowing me to focus and settle. Finding the state of mind to engage in the research setting, as the researcher and

with the research participants, can often take some time. Recounting her experiences of the first meetings and interviews with research participants, both as a novice researcher and later as a more experienced one, Beedell (2009, p. 102) describes feeling ‘mostly anticipation, but also dread, trepidation, intrigue, complacency and curiosity ... this is the final moment in which to prepare myself’. Such preparation can be challenging, because researchers experiencing powerful emotional responses can find it difficult to retain a capacity to think clearly (Doyle, 2013) and to sustain a lively engagement in the research setting (Alexandrov, 2009). I found that the time required to take the stairs, and the gradual immersion afforded by this extra time, helped me to establish something of what Alexandrov (2009, p. 45) calls ‘a reflexive distance towards [my] cognitive and emotional involvement with the field’. The point is not to affect a stance of feeling emotionally uninvolved but rather to tolerate and consider the discomfort and to actively explore the connections with the empirical research work at hand.

### **Research reflexivity**

I have written elsewhere (Doyle, 2013) about the multitude of different ways of conceptualising reflexivity and the differences between those who examine it as a broad social phenomenon (see Giddens, 1991) and those who examine it as a kind of individual sense-making (see Archer, 2003; 2007). In this chapter I focus more particularly on reflexivity as ‘reflectiveness among social researchers about the implications for the knowledge of the social world they generate of their methods, values, biases, decisions, and mere presence in the very situations they investigate’ (Bryman, 2008, p. 698). Employing reflexivity as a means of safeguarding a critical approach entails not simply recounting the various influences at play, but rather examining the particular ways in which those influences participate (Finlay, 2002; 2005; Doyle, 2013).

In my doctoral study, being at once a health-care professional and a parent of a child with diabetes brought both advantages and disadvantages for my role as a researcher. It helped that I arrived with a basic working understanding of concepts and terminology relating to insulin prescribing, carbohydrate counting

and blood glucose testing. Members of the clinic team were interested in my experiences as a parent of a child with diabetes and this helped me to engage with the research setting and with the participants. Having worked as a nurse previously, I felt a certain familiarity with general outpatient clinic procedures and this also helped the staff team to feel comfortable with me; more than once, team members commented, “You know what it’s like.”

On the other hand, the three roles had the potential to become muddled. For example, I was occasionally asked to give my opinion about an aspect of the way the clinic worked and the impact on children and families. I felt these questions merged my role as researcher and my personal experiences as a parent, and on these occasions I answered carefully, distinguishing between my research questions and my own personal views as a parent. These conversations were not especially problematic, but they required considerable thought and highlighted the ongoing negotiation of my role as researcher. In addition, the familiarity I felt in the clinic as a former health-care professional (albeit not in this clinic, nor in this field of health care) meant I occasionally accepted events and explanations too quickly, without the requisite curiosity. Supervision, conference presentations and research conversations with non-health colleagues all helped me to better question occasional superficial assumptions.

It was both useful and difficult that I had a wide range of emotional responses to my encounters in the clinic. My personal sensitivity to struggling parents and to recalcitrant teenagers was balanced by my professional empathy towards committed but frustrated nurses, kindly but exasperated dieticians and wise but weary doctors. Sometimes I heard things about the long-term effects of poorly controlled diabetes that I would prefer not to know. I managed this barrage of thoughts and feelings by writing field notes that included my personal reflections, carefully marked as such. I found that being able to review my notes about my personal responses to the research setting helped me to recognise noteworthy instances I might otherwise have overlooked: that which Hinshelwood and Skogstad (2000, p. 23) call the ‘under-life’ of the field notes discloses hitherto unappreciated gems when further considered. I show the

relevance of this reflexive consideration later in this chapter when I discuss my challenges in employing Barad's (2007) approach to diffractive analysis.

### **Research setting**

The research setting was the diabetes outpatient clinic of a busy urban paediatric hospital. In the UK, all children with type 1 diabetes access routine care and support through NHS outpatient clinics. It is common for children to be admitted to inpatient care at the point of initial diagnosis, and at times of crisis or concern, but I make a distinction between professional learning and knowledge for care in support of self-management (the focus of my study) and professional learning and knowledge for medical management of acute illness.

In Scotland there are six NHS hospitals with diabetes clinics within travelling distance of my home and the university. I chose City View Hospital because in comparison with the alternatives, it offered a team of thirteen health-care professionals, as opposed to perhaps only three or four in other regions. Moreover, the larger numbers of staff and the greater population of children with diabetes meant that clinics took place several times each week. These factors combined to open up a greater range of opportunities for me to engage with.

The function of the outpatient clinic in City View Hospital is to provide care for a local group of children with diabetes. Children attend this clinic, with their parents, usually every four months. Appointments can be more frequent if necessary, for example, if a child asks for extra help with an aspect of managing diabetes, or if the family needs additional support. In between the routine outpatient appointments, which were the main focus of my study, the staff team also provided support to, for example, primary and secondary school teachers, nurseries and occasionally sports clubs. Although routine outpatient care entails children and parents travelling to the clinic, sometimes the staff team visited families at home when there was a need for extra support or for a particular kind of support. However, because my focus of inquiry was professional learning in the



work of supporting self-management in the outpatient clinic, I did not observe professionals in other settings.

### **Ethical approval**

Ethical approval was sought and received from the University of Stirling School of Education Research Ethics Committee. Although the study took place in a hospital, research that is limited to the involvement of NHS staff recruited as participants by virtue of their professional role does not require NHS Research Ethics Committee Review (Department of Health, 2011). Prior to the start of the study, I consulted both the local NHS Research Ethics Service and the local Research and Development Management Office responsible for City View Hospital. I provided a one-page outline of the study and both offices gave permission for the study and confirmed that further NHS ethical review was not required.

The ethical conduct of research is of course not limited to securing initial approval, and the continuing process of ensuring the well being of all involved is discussed further in the following sections. Particular issues arose in relation to the recruitment and consent of research participants, the intermittent presence of staff who were not participating in the study, the presence of children and parents, and protecting anonymity. All of these issues are discussed at length in the subsequent sections of this chapter.

### **Negotiating access**

I first approached the lead clinician, the senior medical consultant, to introduce a brief description of my proposed study and to ask if it would be possible to meet to discuss whether I might spend time in the clinic. In spite of my worries about failing to secure permission to access an appropriate research site, this particular outpatient clinic team was supportive, enthusiastic and interested. A few weeks after meeting the consultant, I met the lead nurse together with one of the dieticians and explained the nature of the proposed research. After providing a

short email, which was circulated to the team on my behalf, I was invited to attend a team meeting to discuss my request in person.

The wider clinical team attended the team meeting and it became apparent that outpatient clinics were delivered across two different hospitals, with staff members allocated to one or other site. In discussion with the team, I opted to undertake the study in one hospital site only. This decision avoided repeated movement between hospitals and protected my research time in one clinical area, thereby avoiding a more diluted experience that might have resulted from trying to work across two sites. The opportunity for depth of engagement was more important than trying to make comparisons across multiple settings.

## **Recruitment**

Initial recruitment of participants presented unexpected challenges. Staff members were, as far as I could tell, uniformly relaxed about participating in the research. It is possible that many of the staff members were well used to having observers and to explaining their clinical work practices to others. City View Hospital is a large teaching hospital and in the five months I was there, a steady flow of visiting professionals spent time with various members of the team and joined a range of staff meetings. Nonetheless, my own purpose in the clinic was quite different, and entailed generating data with a view to publication, and I was keen to ensure that prospective participants understood what was being asked. My verbal description and the written information I provided explained that participation was voluntary and that participants could withdraw at any time, as well as clarifying that the focus of inquiry was on professional learning and clinical work practices rather than children or health-care outcomes.

They asked me for the participant information (Appendix 1) and consent forms (Appendix 2) I had brought and I placed a bundle on the table. As I began to outline how to return the forms, all team members took a form and began completing it. I cautioned that it made sense to think the information over before deciding, but the team advised me that this created unnecessary work for them

and built unhelpful delay into the project. In the end I accepted the signed forms and proceeded by seeking verbal confirmation as I came into contact with each participant in subsequent weeks. The nature of the environment necessitated repeated negotiation about which activities to observe and which staff members to speak with according to clinic priorities, and so it was usual for me to check each day that participants were willing to let me be involved.

Ongoing recruitment was required when two new nurses joined the team. On these occasions I had the opportunity to meet with both nurses to explain the study and to give them the consent forms and the recruitment information. Both nurses took a few days to consider the information before returning the signed forms and confirming verbally that they were willing to participate.

Overall, this willingness to engage in the research was very welcome and it led to a very positive experience for me as well as helping to generate rich and interesting data. However, it was important that I remembered to situate this enthusiastic participation within ethical safeguards. For example, the speed of initial consent, despite my attempts to slow things down, meant that it was imperative I checked and rechecked for verbal consent at the point of each observation, interview and conversation. In the event this was easy to do because each time I visited the clinic there were three or four different events I could choose, each one involving different participants. This required ongoing negotiation and participants tended to either actively invite me to observe or to specifically exclude particular events from the available choices. In this way I felt confident that no undue pressure was exerted.

### **The participants**

The research participants were the regular core professional members of the staff team: the four doctors, seven nurses and two dietitians. All members of the team based in City View Hospital agreed to participate. Because of the small number of participants, I do not provide a detailed description of each individual staff

member. In order to better safeguard each person's anonymity, I describe instead more general characteristics of each professional group.

The dieticians don't just talk about dietetics, and the nurses don't just talk about nursing, and the doctors don't just talk about medicine, compared to other clinics where you maybe see the dietician in one room and the doctor in another and the nurse in another, the roles are, yes we've got distinct boundaries, and professional boundaries, but they blur at the edges a bit.

(P13, Interview December 2012)

Members of the staff team explained to me that the way City View Hospital clinic works is distinctive when compared to other paediatric diabetes clinics they know. They emphasised that although each of the three different disciplines brought specific expertise, much of the work of supporting children and parents entailed working across each other's professional boundaries. Consequently, it was usual for children to see two or even three different members of staff together in a small group consultation, as opposed to seeing each professional one by one, which is often the arrangement in other clinics.

Overall leadership for this paediatric diabetes service is provided by the senior consultant, the senior nurse and the senior dietician. Each takes special responsibility for the organisation and delivery of work pertaining to their own professional discipline, including, for example, the recruitment and line management of their own staff teams. In addition, the three senior professionals collaborate to oversee clinic functioning, plan ahead for future developments and respond to local and national strategic directives on behalf of the paediatric diabetes service.

The seven nurses had varying levels of experience, ranging from twenty years to the two new nurses who joined the team during my time in the clinic. These two

new nurses had many years of experience in other clinical areas but both were new to diabetes. There were no newly qualified nurses working in the clinic. The lead nurse provided clinical and managerial direction for the nursing team and worked closely with the senior consultant. The nursing role in City View Hospital Clinic was described to me as being the main point of contact for children and their parents, and 'doing a bit of everything to coordinate the child's journey through the clinic: using guidelines to adjust insulin, a bit of psychology and a bit of the dietician's role too' (P3, Interview October 2012).

The four doctors comprised one senior consultant, one associate consultant and two trainee doctors. Both consultants had many years of experience and had completed their own training programmes. The trainee doctors were at different stages of their own training programmes, though both were more than five years post-medical school. One of the specialist trainees was nearing the end of a training programme in paediatric diabetes and endocrinology and was approximately a year or two away from taking up a consultant post. The other trainee was approximately half way through a training programme in general paediatric medicine and was fairly new to diabetes. The particular role of the medical staff in City View Hospital Clinic includes prescribing initial doses of insulin and in overseeing the broad guidelines for the clinic within which other health-care professional groups such as the nurses and dieticians will make adjustments to insulin doses.

The two dieticians both had many years of experience, bringing between them almost forty years of working in the diabetes clinic. The role of the dietician was described to me as translating theoretical knowledge about dietetics into sensible advice. The dieticians helped children and their parents to understand the carbohydrate contents of different foods and to understand how to ensure insulin doses are appropriately matched to carbohydrate intake. The dieticians contributed specialist expertise about healthy eating, recommended portion sizes and the different ways in which particular food groups affect the body.

## Issues of consent

Ethnographic research commonly raises ethical issues relating to the presence of the researcher in the field (Angrosino and Rosenberg, 2011). The presence of the researcher can potentially disrupt whatever is being observed, in this case the normal functioning of the clinic. Moreover, the experience of being observed can feel intrusive and uncomfortable for participants. The ongoing processes of agreeing with participants when, where and how to observe are important ways of mediating the potential for disruption and discomfort. Another common problem is that observations conducted in a public place, or in a place such as a hospital or children's playground, raise difficulties around how to manage seeking consent because these kinds of settings are likely to be populated by people not actively participating in the particular research study (Angrosino and Rosenberg, 2011). The Scottish Educational Research Association (2005) has produced guidance addressing this issue, recognising that observational studies focused on activities and events not specific to individuals need not necessarily seek written consent from all persons present. It was these guidelines that provided the framework for my responses to managing these issues in my own study.

While I was undertaking research in the clinic there were four separate occasions when a temporary member of staff joined the clinic team. These comprised a doctor providing cover for an absent staff member, a doctor observing paediatric diabetes care, a student dietician observing clinic consultations and a dietician joining a staff teaching session. On each occasion I was present as an observer myself and although it was not practicable to seek written consent at these times, I sought verbal consent after explaining my role. These temporary staff members did not take part in interviews, they were not included in any audio recordings and they did not provide quotes or comments for the research.

Children and their families were also present during observations, but no personal data was collected from them or about them. The decision to exclude children and their families in this way took some time and was difficult for two

key reasons. First, the selected methodology recognises professional learning and knowledge as phenomena emerging from a constellation of perpetually connected material-discursive practices, and this necessarily includes children and their families as well as a wide range of other things. Second, the children's experiences, and their families' experiences, are an important consideration in the care of paediatric diabetes. As a researcher, I was (and am still) interested in the ways in which children and their families shape health-care provision. However, I needed to make an agential cut (Barad, 2007) somehow, to delimit the focus of inquiry and to allow some aspects to fade into the background as a means of foregrounding others. My overall research aim of examining professional learning and practice steered me away from prioritising the experiences of children and their parents.

The ethical difficulty was how best to ensure neither the children nor their families felt pressured to allow me to be present during their consultations. Written consent from every parent and child seemed disproportionate; children and families attend the outpatient clinic for around two hours, once every three or four months, and a meeting with me in order to secure written consent for a study that collected no personal information from them or about them would have increased their time in the clinic for no good reason. This approach might also have risked implying that the research focused on some aspect of patient experience of diabetes care and this would have been misleading. Both of these points were made in my application to the University of Stirling School of Education Research Ethics Committee.

In order to address this issue of ensuring that children and parents would, if they wanted to, request that I did not observe their consultation, the clinic team agreed to seek verbal consent from children and parents prior to each consultation. Each time I was to observe a clinic consultation, one of the professionals involved explained my role and purpose to the child and the parents before introducing me. At the point of introduction I was able to thank each family for allowing me to observe, and this gave an additional few minutes for either the child or the parents to change their minds. I provided patient

information sheets but the clinic team preferred that these were not routinely distributed, choosing instead to offer further information only to those who specifically asked for it.

No child or family member refused to allow me to join them, and the consultations I withdrew from were those that participating clinicians felt in advance might be inappropriate for me to observe. The reasons for these decisions were either that there were already too many people taking part in the consultation, such that the child or parents might feel overwhelmed, or that the child or parents were encountering such a level of difficulty with some aspect of their diabetes care that the consultation was likely to be too emotive or challenging. In total this happened on three occasions.

Because the clinic is part of a large teaching hospital, it is unremarkable for patients to be asked to allow observers to attend their consultations. During my time in the clinic there were often doctors, nurses and dieticians from other specialty areas who joined the team for one day or half day in order to learn more about paediatric diabetes. There were students undertaking short placements and occasionally staff members drafted in to cover absences. This does not undermine the need to seek consent but it does highlight that patients are used to being asked. However, it also raises questions about the extent to which children and their parents felt able to refuse, given the expectation that having observers join clinic consultations is an ordinary part of care in this hospital. In addition, it is also possible that some children and parents might have remained unsure of the different purposes and remits of different observers, despite the explanations offered.

This issue was a difficult one to resolve and I did so in part by paying close attention to the families during the consultation so that I could pick up any signs of discomfort and withdraw if necessary. I felt that my previous professional training and experience in mental health nursing and psychotherapy (with adults and children) would go some way towards helping me recognise discomfort. In the end, I did not feel the need to withdraw during any of the consultations.



Moreover, often the parents would make good-natured jokes with me about the clinic or the staff team, and sometimes the toddlers and younger children would try to engage me to play. In this way they often seemed comfortable with my presence, but it is also possible that there was simply no alternative, given the lead from the clinic team.

At times participants were so keen to show me aspects of diabetes care that I was invited to observe staff members attending to children at home and in inpatient hospital wards. I appreciated these invitations but I was careful to decline, in part because I felt that these settings were beyond the focus of the study (outpatient clinic care). More importantly I also felt that these settings were beyond the scope of the ethical approval I had secured. Children unwell enough to stay overnight in hospital, and their families, are perhaps likely to feel more vulnerable and to be less able to refuse my presence. Similarly, the study design did not take account of the particular ethical issues potentially arising in relation to home visits.

### **Protecting anonymity**

Managing the data generated entailed keeping names and workplace contact details of all consenting participants separately from other data in a locked filing cabinet at the University of Stirling. Digital voice recordings from all interviews were downloaded to the secure, password-protected University of Stirling computer and the original data were deleted from the portable recording device I used.

However, the protection of anonymity can create additional challenges for ethnographers (Angrosino and Rosenberg, 2011), because the ways in which this form of research is reported tends to include highly detailed accounts of very specific events. In an eloquent description of the aims of ethnographic writing, Narayen (2012) notes the importance of crafting characters that bring ideas to life, while also respecting any commitments not to disclose participants'

identities. Changing some personal details without altering the substance of the account is one response to this challenge.

In my own research, each consenting participant was allocated their own non-identifiable code, which I used in field notes and in transcriptions:

- D<sub>1</sub>, D<sub>2</sub>: The dieticians
- M<sub>1</sub>, M<sub>2</sub>, M<sub>3</sub>, M<sub>4</sub>: The doctors
- N<sub>1</sub> – N<sub>7</sub>: The nurses

In this thesis, I have opted to further disguise the participants by not revealing their professional backgrounds in the selected data extracts. The very small number of participants means that differentiating between professional disciplines would make it relatively easy to identify individuals, especially the dieticians and doctors whose numbers are smallest. Although this information might have been interesting background for readers, participant anonymity is paramount. Moreover, the research focus on work practices rather than on the workers themselves helps to remove the need for rich descriptions of individuals. Such a praxiographic approach focuses on how practices are enacted, and consequently, as Mol (2002) notes, the particular humans involved tend to remain 'shadowy' and not clearly differentiated.

The presence of children and parents is even more lightly drawn, because of course they are not participants in this research. The richest descriptions recount, for example, blood glucose results, care regimens, technologies, expressions of concern or confusion and physical movements – such as sitting back or leaning forward – in the consultation room. Enacted practices are examined in detail, but the children and parents are purposefully faded out.

## **Part two**

### **Methods of generating data**

#### **Observations**

The outpatient clinics took place twice each week, and lasted between three and four hours. Over a period of five months I joined almost every clinic, and I observed a total of fifty-six clinic consultations between different children and young people, their families and the health-care professionals supporting them. I also observed a range of other events that contributed to the work of the outpatient clinic. These other events comprised the first team meeting at the beginning of my contact with the clinic; two Journal Clubs, which comprised dedicated time set aside for staff learning and discussion or teaching; the 'pump live day', which was the day a small group of four children attended with their parents to be given their first insulin pump and instructions on how to use it; and a staff teaching session for clinic team members new to working with diabetes. In between these specific events I spent time in the communal areas of the clinic, observing and talking to team members as they worked.

I moved between different modes of observation depending on the events I observed. During the clinic consultations, I was entirely silent until the child and family left the room. This ensured the work of the clinic was uninterrupted, but it also allowed me to recede from proceedings enough to attend to the minute details and momentary glimpses that emerge most reliably through close and sustained attention (Reid, 1999). Inevitably, sometimes I was drawn into proceedings by a comment from one of the staff members or by one of the children or parents. These invitations to participate reminded me that any sense of externality I might indulge was quite partial and was recursively negotiated with others present. During observations of staff members engaged in general activities such as preparing case notes, reviewing files and responding to emails

and phone messages, I participated in more obvious ways by asking questions and listening to the explanations and commentaries that were offered.

I recorded handwritten field notes in a journal. During the clinic consultations I made these notes after the child and family had left the room and before another child and family arrived. This approach helped me to concentrate fully on the consultation and also lessened the potential for making children and families feel uncomfortable. During observation of other events I made notes at the time of observation. All handwritten notes were typed into word documents, usually the same day or the following day, for further analysis. Initially, other than the date, nature of event and participants present (using the anonymised codes already described), I did not organise the growing collection of field notes at all. I understand my field notes not as universal, indisputable fact, but as inevitably including, and produced through, what Mol (2002, p. 159) calls the researcher's 'fascinations, passions and theoretical baggage'. Each written piece records, in as much detail as I could manage at the time, my encounter with particular happenings, interwoven with my reflections, thoughts, feelings and sometimes imaginings, and including occasional memorable quotes from participants.

### **Interviews**

The interviews I conducted fell into two different types. The first set of six interviews took place earlier in the research project, and these encounters were focused on orienting me to the overall purpose and the working activities of the clinic. These early interviews also provided opportunities to better understand some of the biomedical details of diabetes and diabetes care and to clarify particular aspects of key practices I observed. Two doctors, two nurses and one dietician participated in these audio-recorded interviews, which took place in the clinical area in quiet rooms set apart from the general bustle of the clinic. I selected these participants to provide a range of experience from the longest serving to the relatively recently employed and also to introduce me to each of the nursing, medical and dietetic disciplines as they worked in this clinic. Each interview lasted between forty-five minutes and an hour and fifty-six minutes.

The second set of seven interviews arose slightly differently. I found that when I was observing and talking with staff members, they often described what they were doing in wonderful detail, without me having to ask. However, sometimes it was impossible to write notes at a pace sufficiently fast to do justice to the rich commentary provided. On these occasions I interrupted and requested permission to continue the conversation as an audio-recorded research interview. One example of this is an instance when the lead nurse talked me through the process for establishing, recording and monitoring the insulin doses required for children moving from using insulin injections to an insulin pump while we sat together at a desktop PC. Another example is when one of the doctors joined a conversation I was already having with two of the nurses and asked to discuss her experience of wearing a practice insulin pump over a weekend. At that point, the nurses and the doctor said that they were happy for me to remain present and to audio-record the discussion as a research interview. These interviews took place in the clinical area, once in a communal area because it was quiet and the nurse was using the PC to explain something, and on other occasions in quiet rooms set apart from the general bustle of the clinic. Each of these interviews lasted between twenty-five minutes and an hour and ten minutes.

In the thesis, I differentiate those interviews that arose naturally in the course of conversations during fieldwork by describing them as ‘work discussions’ rather than ‘interviews’. However, the differences between so-called naturally occurring data and interviews instigated by the researcher should not be exaggerated (Perakyla and Ruusuvuori, 2011). The researcher’s hand is, inevitably, in all of the research data generated.

Although all interviews took place in quiet spaces, mostly behind closed doors, there were frequent interruptions as staff members sought information and advice from one another. At these times I stopped the audio recording, so that there was no confusion about what and who was being recorded and also so that I did not inadvertently record confidential patient details.

For the interviews, I tried enlisting the help of a transcriber using a formal, signed agreement (Appendix 3) based on a template from the UK Data Archive for the Social Sciences and Humanities. However, having someone else transcribe the recording created unhelpful distance between the data and me, and I found that I had to correct many errors, particularly in relation to technical medical language. As a result, I did not pursue this approach and re-transcribed that particular interview myself as well as going on to transcribe all the others.

### **Texts, images and objects**

I gathered a small range of salient texts, images and objects, including documents and photographic images of the clinic space and of particular tools and technologies used to care for paediatric diabetes. The photographs were taken by me, using a Canon Powershot SX150 IS digital camera. There are no photographs of human participants, and the photographs were taken either before or after clinics when children and parents were not present. A full list and description of these texts, images and documents can be found below in table 1.

**Table 1 List of Texts, Images and Objects**

<b>Item</b>	<b>Description</b>
<b>Blood glucose diary (1)</b>	Small pocket diary, unique to this clinic, given to all children not using an insulin pump. The diary is used to record, in writing, blood glucose readings and insulin doses every day. Children are expected to complete the diary themselves once they are old enough. I collected a blank template that did not contain patient details. These diaries were important because they were part of clinic consultations; the way in which the health-care professionals try to understand children's recent blood-glucose control. The absence of the diaries was also important, as I show in later chapters of this thesis.
<b>Blood glucose diary (2)</b>	This revised version of the diary replaced the earlier version during my time in the clinic.
<b>Carelink sample</b>	These templates were publicly available replicas of the

<b>templates</b>	printouts produced by the software used to record blood-glucose levels and insulin doses, for those children using insulin pumps. I collected blank replicas that did not contain patient details from the manufacturer's website. These templates were essential parts of consultations with children using insulin pumps, and professionals spent considerable time and effort interpreting the various graphs and tables included in the templates.
<b>Patient health record</b>	This is a small folder of printed information given to all patients. It includes detailed guidance about how to manage insulin doses and most other aspects of managing diabetes. I was given this folder by one of the nurses when I first arrived in the clinic.
<b>Food for Life resource</b>	This is a small folder of printed information given to all patients. It includes detailed dietary information about how best to balance food groups for most effective diabetes control. I was given this folder by one of the dieticians when I first arrived in the clinic.
<b>Textbook about type 1 diabetes</b>	I was allowed to borrow a copy of this book, which was used very frequently as a reference aid and teaching resource by many staff members: Hanas, R. (2011) <i>Type 1 Diabetes in Children, Adolescents and Young Adults: How to Become an Expert in Your Own Diabetes</i> .
<b>Photographic images of the clinic</b>	These include the communal desk space area, the reception area, the large teaching room, and the collection of sharps boxes being labelled. These photographs helped to connect me to my early responses to the clinic, working less as a record of events and rather more as a record of the things that drew my attention early in the study.
<b>Photographic images of tools and technologies</b>	These include the HbA1c machine and blood samples, an insulin pump and the packaging box, an insulin injection pen with needles, a blood glucose monitor, the soft toys given to new insulin pump patients, and some of the staff teaching materials. Taking these photos helped to sensitise me to the

	participation of non-human entities, especially those that were frequently part of my observations and conversations in the clinic. The injection pens, blood glucose monitors, insulin pumps and HbA1c were integral to the health-care professionals' everyday work practices.
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### **Trustworthiness**

Before moving to discuss the data analysis in more detail, I pause to address issues of trustworthiness, and also the limitations of my study. Establishing that my research is trustworthy is not the same as establishing that my research is true. However, it does entail confirming that I have been truthful, and that I have generated and handled the data in trustworthy ways. Trustworthiness also relates to the rigorous conduct of the research: 'ethnography is more than casually observed opinion' (Angrosino & Rosenberg, 2011, p. 468). I have already discussed researcher reflexivity, and the personal and professional experiences that I brought to the study as well as the effects of the particular research site. In the following paragraphs I outline the ways in which I sought to strengthen my approach to analysis and interpretation.

I have made use of a range of opportunities to share and explore both the data and the interpretations in the work of analysing. Immersion in the field, at least as much as the participants and the constraints of doctoral study could facilitate, was an important feature. Moreover, the nature of my contact with the participants meant that I was engaged in perpetual dialogue about what they were doing, about what I thought I was seeing and about what each of us thought might be significant. Detailed logs of analytical development alongside particular selections of data help to create traceable accounts of emerging ideas, and I show examples of these later in this chapter. Supervision offered a space for particular scrutiny with my supervisors: sharing data and tentative analyses enabled consideration of my own interpretive biases. I gave a range of international



conference presentations at regular points throughout my research, which allowed me to consider critiques from senior academic colleagues who were undertaking research in related fields.

I had intended to share transcripts and early interpretations with participants as a way of conducting what is conventionally called 'member checking' in ethnographic research. However, the pressures of the clinic environment allowed no time for this during fieldwork. I agreed with participants that I would return at several points in the months after fieldwork to share and discuss data and interpretations. Despite their initial enthusiasm, my emails to the team went unanswered and I was unable to arrange a time to return. I understand that these health-care professionals were busy with clinical work and were also attending to a steady stream of observers and researchers, and so I did not pursue the issue further. For the team, creating space away from clinical work to discuss educational matters and research was incredibly difficult; I had already been given generous proportions of their time and energy throughout my fieldwork.

I was able to draw on my own professional medical education contacts and arranged to lead several seminar discussions for clinicians in a different institution. Although these clinicians were in no way connected to my research participants, they brought a wide range of health-care professional experience to the conversations about my study. As a result, I was able to explore my interpretations with a clinical professional audience, some of who were working in diabetes health care and many of who were grappling with new health-care technologies of one kind or another.

### **Limitations**

The limitations of my research relate to the general constraints that characterise much ethnographic research and also to some specific constraints that are particular to my own study. Recognition of such limitations helps to identify ways of responding, in order to moderate the potential for negative impact on the credibility and integrity of the research.

My study is limited by being small in scale and, as a result, the insights generated pertain only to one paediatric diabetes clinic and to one particular staff team. However, ethnographic research does sacrifice breadth for depth and the richness of the descriptions helps to make it easier for readers to discern the extent to which these insights might resonate more widely. Following Flyvbjerg (2011), my account of the research tries to facilitate openness rather than closure, by recounting detailed descriptions and careful interpretations. In this way, ‘the goal is to allow the study to be different things to different people’: to enable readers to wander different paths, to be attracted by particular insights and to respond in their own different ways (Flyvbjerg, 2011, p. 312).

The need for close collaboration with the research participants, in order to identify opportunities for observation and interview, meant that I was somewhat constrained by the pressures on the clinic as well as by the need to be actively invited to join particular clinic events. I note that such collaboration was also an essential ethical requirement, ensuring that I did not disrupt the work of the clinic and that children and parents had clear opportunities to refuse my presence. In short, I could not be everywhere nor see everything and I make no claims to have done so. However, following Ellingson (2011), I have tried to produce an account of my research that explains how I negotiated difficulties, and to be absolutely clear about what I did and did not do in this study.

### **‘Doing analysis’: percolation, diffraction and entanglement**

When St. Pierre (2011, p. 622) asks her doctoral students

to explain what they did when they thought they were ‘doing analysis’, they describe a multitude of activities – washing the car and weeding the garden (*the physicality of theorizing*), making charts and webs, talking with friends, writing, listening to music, reading transcripts, reading more theory, dozing on the couch, and so forth ... audit trails can’t capture that work.

(St. Pierre, 2011, p. 622, italics in original)

This is disarmingly honest and I concede that the account certainly describes at least some of my own doctoral ‘thinking-work’. Creating space to think was a central reason for undertaking doctoral research and I have learned the critical importance of this space and its capacity to generate insights and innovations through the percolation of ideas. However, I also needed a way of organising the writings and recordings, and the thoughts and feelings, that comprised my research data, and I needed a way of bringing this data into manageable and timely dialogue with the theories I selected to help me understand and make sense.

In this section of the chapter I discuss my approach to analysing the data I generated. I include the most helpful elements of Barad’s (2007) diffractive methodology, and also the struggles I encountered as I sought to organise and reduce the data without collapsing them into disconnected themes that I worried might betray the methodological commitment to appreciate sociomaterial entanglements. I show how Barad’s (2007) tissue of ethicality helped me to persist until I developed a more *useful* way of engaging with the data.

### **Diffractive reading**

A diffractive methodology provides a way of examining patterns of difference (Barad, 2007). Early in the study, one of the senior members of the clinic team commented, ‘Diabetes is a different illness with an insulin pump.’ Other professionals in the clinic echoed this assertion, and it also chimed with my own observations that the insulin pump was associated with, for example, particular work practices that were only evident in diabetes care that revolved around the insulin-pump technology. Already attuned to the participation of materials, I began to pay closer attention to the different ways in which professionals worked with the insulin-pump technologies compared with the ways in which they worked with insulin injections. Given the educational focus of the research, I was

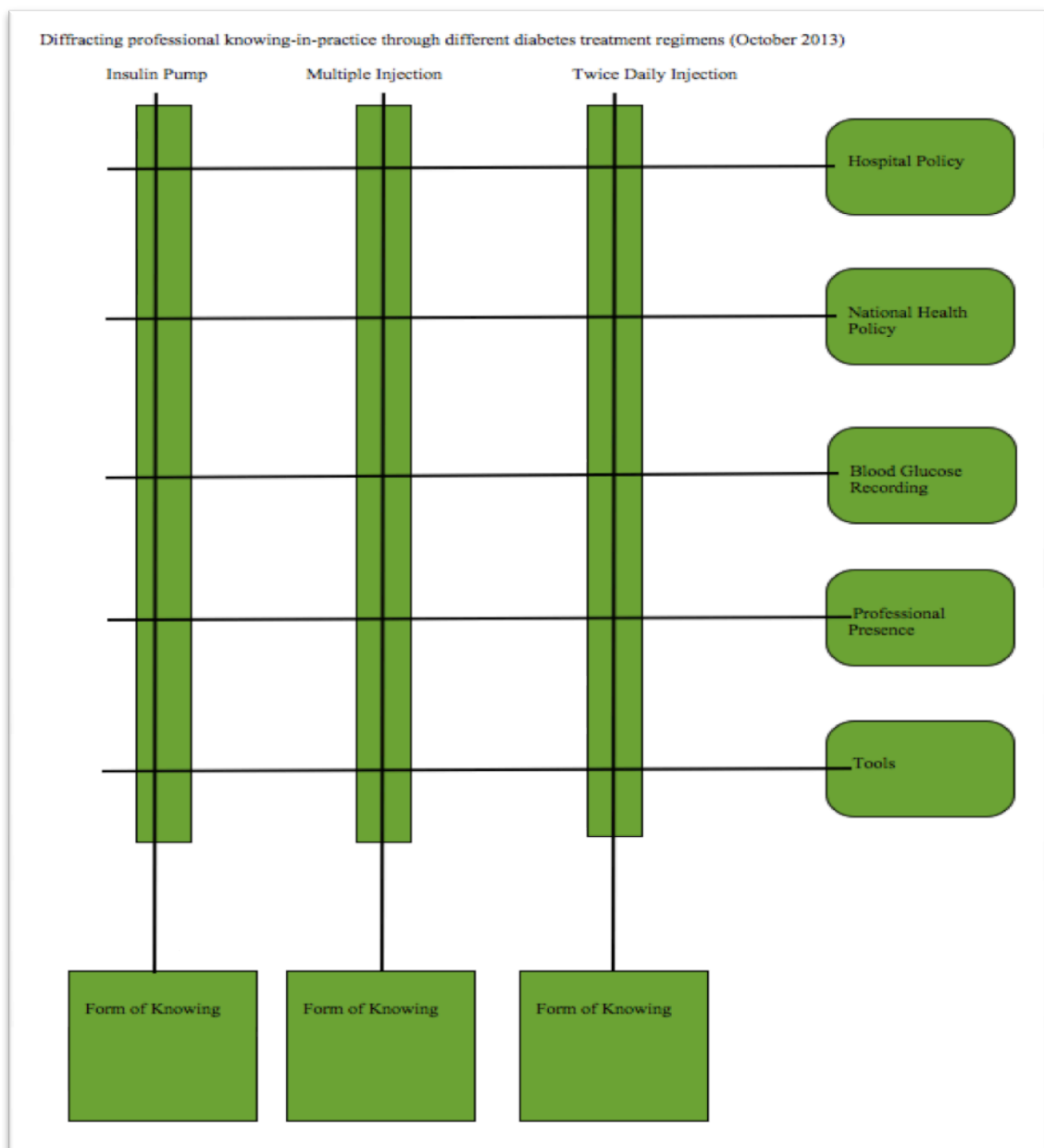
especially interested in the ways in which professionals came to know the different work practices associated with these particular technologies. Thus, *difference* became an organising concept, close to the substantive data and core to the mode of analysis.

In the first iterations of making sense of the data – that is, the gatherings of field notes, reflections, transcripts, photographs, and documents, I leaned heavily on Barad's (2007) invitation to read data diffractively. This invitation to read ideas through one another conjured images of criss-crossing, intersecting matrices, and I used these images to play with different ways of patterning the differences that emerged from early readings of my data. Although a diffractive approach to data analysis describes a way of reading the data through theories (Jackson and Mazzei, 2012) or perhaps reading the data through the researcher (Phillips and Larson, 2013), I was also interested in reading different strands of data through one another. In these early forays, I did not at first distinguish between the different forms of data such as the photographs, documents and field notes but was instead led by a focus on how work practices emerged in relation to different tools and technologies of diabetes care. It was not until later that I considered the alternative functions of, for example, the photographs I had taken, and the ways in which those photographs helped sensitise me to technologies (indicated in table 1) but were not analysed in the same way as the field notes and audio transcripts.

Through reading and rereading, I foregrounded tools and technologies by cutting together all mentionings and happenings that related to the insulin pump and, in turn, those that related to the two different types of insulin injections therapies. I used simple Microsoft Word documents, cutting and pasting from the original texts, until I had three long documents with details pertaining to each particular mode of administering insulin. I used the heuristic of diffractive reading as an explicit way of immersing myself in the data: reading each long strand of cuttings through one another; reading across and between each strand; exploring and experimenting with how best to articulate the differences across and between them, in relation to my research questions.

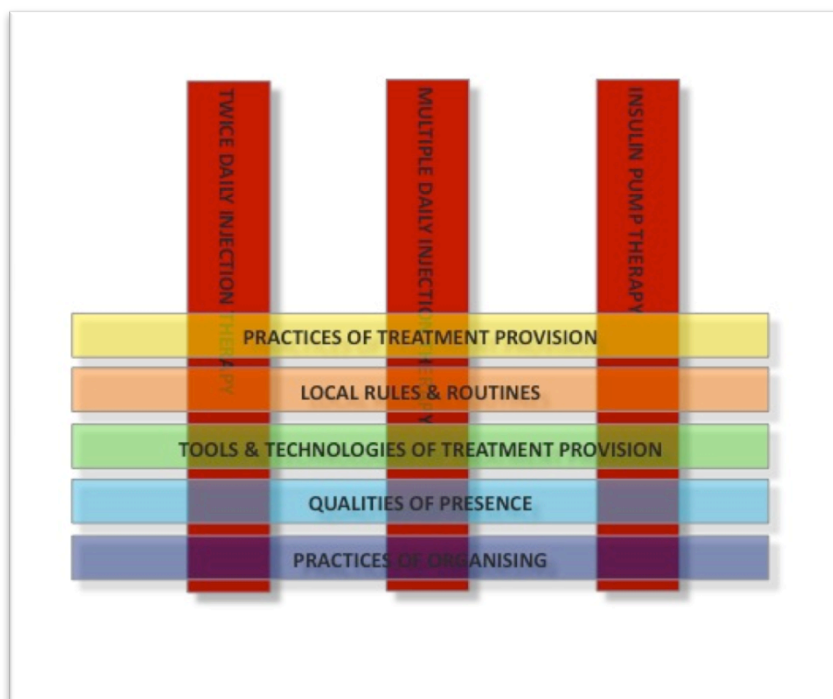
Figure 1, below, is an early visualization of my thinking and shows the major ideas surfacing. Figure 1 is included here as a rough working sketch of my understanding at the time, rather than a finished diagram. The three columns represent the data strands pertaining to each mode of administering insulin, and the horizontal themes name the ways in which it seemed that modes of insulin administration were differently influenced – for example, by particular policies – such that professional knowledge might emerge in different ways.

Figure 1 Diagram showing early data strands



Having made these first selections, which foregrounded the modes of administering insulin, I focused on each of the identified themes as provisional ways of examining the particular differences produced by each mode of administering insulin. With multiple rereadings of smaller gatherings of data I refined those first named themes into the ones illustrated in Figure 2 below: practices of treatment provision; local rules and routines; tools and technologies of treatment provision; qualities of presence; and practices of organising. Throughout this whole process the selections, cuts and themes emerged from the ongoing interplay of theoretical reading, literature work, my research questions and the original data generated. An example record of the analysis in process is available at Appendix 4. A slightly later example of interview transcripts diffracted, or read through, the different care regimens is available at Appendix 5.

**Figure 2** Diagram showing the development of data strands



### **Diffraction in empirical research**

However, just how to employ diffraction as a means of analysis in empirical research is far from clear (Leonardi, 2013), and I encountered a number of

problems. It was difficult to move from grappling with the whole data set to making appropriate reductions without breaking up the essential connections that constituted the intra-actions I sought to examine. Already discussed in chapter three, intra-actions are dynamic, productive connections that cannot be reduced to interactions between finite, separable, delineated entities. Dividing the data further – for example, into smaller data sets associated with tools and technologies of treatment provision – seemed impossible, because I understood those tools and technologies as sociomaterially entangled with the practices of treatment provision. It made no sense to tease apart the richly detailed accounts, which were laden with examples of the vibrant and tangled professional work of supporting self-management in paediatric diabetes. Fragmenting the data risked losing the tangles.

The prospect of losing the tangles was not only problematic methodologically, but also ethically. The themes named in the model at Figure 2 struck me as disconnected from my time in the clinic, and Barad's (2007) tissue of ethicality served as a challenge to strive for research insights that could, as far as possible, speak meaningfully to those participants who had given their time. This impasse was also related to my attempt to fit the data to the early models I developed. I began to wonder what I was missing, what I was not seeing. Reading through my field notes and transcripts again, I could see that there were many instances where health-care professionals talked about children becoming seriously ill or dying from the complications of diabetes, and yet I had not really attended to these instances in my consideration of emergent areas of interest. Alongside this, I could trace in some of my personal reflections my emotional response to the risks facing children and wondered whether I had indeed unintentionally avoided considering the effects of the professionals' concerns about risks. Perhaps also, my efforts to focus on practices rather than human experiences had led me to discount much of the rich data that pertained more immediately to human relations and relationships than it did to technologies.

Another rereading of the original transcripts and observations confirmed at least that the initial appreciation of differences produced by particular tools and

technologies still held as an important area of interest. Pushing this appreciation, I began to rewrite the field notes and transcripts by hand, using coloured pens. Perhaps the shift from the keyboard and digital software to handwriting entailed an effort to attain a kind of physical closeness to and engagement with the data; Ingold (2007, p. 3) has suggested that the physicality of writing, of putting pen to paper, retains an intimate link between ‘the manual gesture and the inscriptive trace’ that is somehow erased when using laptop and desktop computers.

### **Cutting out and colouring in**

Instead of cutting phrases and sentences out I coloured them in. In each set of field notes I used a black pen for the words and phrases that related to any tools and technologies: insulin pumps, injection pens, blood glucose monitors, and so on. Very quickly I realised the need to tease apart the practices associated with caring for diabetes from the tools and technologies that were part of those practices. I used a green pen for the words and phrases that pertained more to the work of, for example, recording blood glucose levels, rather than to the blood-glucose monitor itself. Given that de Laet and Mol (2000) might argue – and I would agree – that the blood-glucose monitor is not a monitor until it is engaged in the work of monitoring, this separation was inevitably provisional and not straightforward. However, because the full account is always present, the tensions remain visible and are not simply smoothed away.

I coloured all of my field notes and transcripts using Microsoft Word software. I added a third colour, blue, for the data that related in any way to human relationships. The extract below shows how this process of colouring in, rather than cutting out, produced a more organised data set. However, what is so important is that the selective focusing remains always provisional: the entanglements are preserved. More than this, the entanglements are also visible and therefore open to ongoing interrogation.

I talk with P9 afterwards. P9 says that the consultations with pump patients are different, because ‘more knowledge is required’. ‘The



conversations require a level of knowledge even to be on the pump, so the style of engagement is different. The pumps are inherently self-selecting: for some patients the pump would be suicide so they are not offered. Politicians don't understand. You can't just give patients a pump and let them self-care.'

(Field Notes, December 2012)

I have chosen this extract as an example because its multicoloured sentences illustrate the key areas of insight generated through my fieldwork and through my thesis work. At the core of this extract is the assertion that insulin pumps produce significant differences and that those differences can be understood through examining the relations and negotiations of responsibility between professionals and patients as well as through the particularities of care provision with this specific insulin-pump care regimen. Perhaps it would help to write that last sentence in colour: at the core of this extract is the assertion that insulin pumps produce significant differences, and that those differences can be understood through examining the relations and the negotiations of responsibility between professionals and patients as well as through the particularities of care provision with this specific insulin-pump care regimen.

Further analysis proceeded in layers. Working with the newly colour-coded and annotated transcripts and field notes, subsequent readings drew again on Barad's (2007) diffractive heuristic in order to read the data through selected theoretical approaches and with my research questions in mind. Accordingly, particularly resonant sections and data extracts were illuminated, and I gathered these together in tentative draft chapters for more detailed consideration. Three broad areas of interest emerged. First, I focused on the ways in which technologies make differences, and I did this with a particular sensitivity to the unfolding of learning in and through professional work practices. Second, I focused on the broader care regimens; that is the professional work practices of reviewing blood-

glucose results, adjusting insulin doses, and so on, and – following Knorr-Cetina (2001; 2006; 2007) – I did this with particular attention to the knowledge work entailed in such practices. Third, I focused on the relations among health-care professionals, children and parents as support for self-management is produced, drawing on Gherardi's (2001; 2010; 2012) concept of knowing-in-practice.

These three areas of insight form the basis of chapters five, six and seven. Chapter five examines the ways in which technological change influences professional learning: (1) by demanding new technical skills and capabilities; (2) by introducing new risks; and (3) by prefiguring particular courses of action and intervention. Chapter six analyses care regimens as always-unfolding epistemic phenomena, invoking professional knowledge work as an ongoing dimension of care provision. Chapter seven explores the tensions between the troublesome notion of empowerment and the situated practice of supporting self-management in paediatric diabetes.

### **Chapter summary**

This chapter has sought to provide a clear and yet not too smooth account of the methodology and methods that helped to constitute my study. Part one outlined the overall research design and the ethnographic and praxiographic approaches that informed the empirical work. In particular I discussed the (my) need for reflexive understanding of the impact of spending time in a children's hospital, and of recognising my own personal and professional responses to observing health care. These issues arose not only during fieldwork but also during subsequent analysis of the data generated.

Part one also focused on key matters of ethics, including those relating to the recruitment and consent of research participants, the intermittent presence of staff who were not participating in the study, the presence of children and parents and protection of the research participants' anonymity. Both the research site and also the research participants were described, although the participants were described not as individuals but rather in general terms of their different

professional groups. Each group, that is medicine, dietetics and nursing, was sketched in a way that indicated its particular roles in the work of the clinic.

In part two of this chapter, I focused on the generation and handling of data. I discussed the nuances of difference between the two forms of audio-recorded interviews and work discussions. I also discussed the range of slightly different approaches I took to participant observation, depending on the particular event I was observing and the extent to which the work of the clinic might have been disrupted.

I explored the work of analysing the data and examined my engagement with Barad's (2007) diffractive reading. I showed the ways in which this approach helped me to see particular patterns of difference that highlighted the insulin-pump technologies; thus drawing my attention to the care regimens more generally. In this way, *difference* became an organising concept for my approach to the data. I recounted my early selections of some key areas of interest, and showed the ways in which, ultimately, these seemed to close down the analysis too quickly. I explained the ways in which I found it extraordinarily difficult to employ a diffractive approach as a means of reducing the data, without fragmenting it altogether.

My solution was to colour sections of data *in* rather than cutting sections of data out. In this way, the multicoloured sentences helped to preserve the entanglements. As a result, the selective focus I adopted at any one time was always provisional, and always visible, and therefore always open to question. This approach, alongside careful rereadings of the data, yielded a set of three broad focal areas.

In summary, the three broad areas of interest that emerged in relation to informal professional learning were the effects of technological change, care regimens as epistemic phenomena and the troublesome notion of empowerment. Chapter five, next, is the first of three chapters, which are focused on each one of these areas. Chapter five explores in detail the wide-ranging effects of

technological change as health-care professionals learn to support self-management in paediatric diabetes.

## 5 Technological Change and the Emergence of Professional Knowledge

We're not, we don't have a lot of equipment, we're not resource heavy with regard to equipment and drugs and things like that, but it's mainly sitting down and talking to families.

(P1, Interview, October 2012)

Talking about the work of the health-care professionals in the clinic, this experienced professional proposes that 'equipment and drugs' are not a dominant part of supporting self-management. Uppermost in her thoughts are the interpersonal relations between workers, children and families. However, my conversations and observations in the clinic show something quite different from this opening quote. In fact, I would argue that the everyday work practices of the professionals in the clinic are saturated with equipment and drugs. In this chapter I do not seek to undermine the importance of relationships in health care, but I do show that knowledgeable care provision in support of self-management in paediatric diabetes is not *only* about relationships: knowledgeable care provision also entails grappling with technological change.

In particular, I focus on the changes created by the increasing use of insulin pumps. At the time of my research, clinics across Scotland were responding to a Scottish Government directive stipulating that insulin pumps should be available to at least one quarter of children with (type 1) diabetes (Scottish Government, 2012) within twelve months. This proportion was a significant increase for paediatric services. In the clinic I spent time in, the increase meant organising insulin pumps for four times as many children as previously catered for. One member of the clinic team spoke about the directive as follows:

The intention was good, because there was no question we were being choked in terms of access to an important resource, and all of us wanted more flexibility in terms of putting patients on pumps. But for a health minister to come up with a number and just arbitrarily impose it without consultation, without discussion about implications in terms of staffing, was dangerous, nothing short of dangerous. Reason being, and you know this as well as I do, that it's not about the hardware, it's about the support and training.

(P9, Interview, October 2012)

The political forces mentioned here are considered more fully in chapter eight, but for the moment the point I want to highlight is the reference to hardware. This professional asserts that the hardware is not the important issue, but I would argue something a little different. Following the work of science and technology studies scholars, who argue that particular technologies actively participate to produce important changes in existing arrangements, I show that these new diabetes technologies are not benign or inert. The insulin pump does have implications for professional support and training, as P9 states, but what is also important is that the affordances of the insulin pump matter; or in the words of Halford et al. (2015), that particular devices can be associated with 'distinctive outcomes'.

The policy directive had the effect of spotlighting what Starr and Strauss (1999) have called the invisible work of professionals as they come to know new technologies in work settings. This invisible work is the fine-tuning and modifications undertaken by professionals as they support the introduction of new technologies and respond to unanticipated problems. The accelerated increase in children using insulin pumps meant that more staff members were involved with the technologies, and on a more regular basis. Had I undertaken my research several years prior to the policy directive, I might only have seen a

handful of instances of professionals supporting children with insulin pumps. Instead, almost every outpatient clinic I observed included at least one consultation with a child and family using an insulin pump. Insulin-pump technologies and the effects of the technologies were particularly apparent when considered against the more established injection pens, which worked as a foil for the insulin pumps, throwing the differences into sharp relief.

The insulin pumps influence the emergence of professional knowledge in three particular ways. First, these technologies demand new technical skills and capabilities, though the challenges are not restricted to simply operating the insulin-pump device and extend to unsettling many wider work practices associated with care provision in this case. Second, these technologies prefigure different, yet still delimited, options for professional action and intervention, sometimes prompting resistance from the professionals involved. Third, these technologies introduce new risks and new professional responsibilities, augmenting the already high stakes in insulin administration (explained in chapter one).

### **Insulin pumps make differences that matter**

Several professionals in the clinic commented to me, 'Diabetes is a different illness with an insulin pump'. My interest is not so much in how diabetes materialises, as it might be if I were following Mol (2002) and her examinations of multiple ontologies of disease existing for patient, surgeon and pathologist. Rather, I am focused on how knowledgeable care provision materialises in this case, paying close attention to the differences that insulin pumps make.

Speaking about the nature of these differences, this professional described her experience as follows:

Oh, it does feel different, I think the focus is more on technology with the pumps. Now whether that's right or wrong, you get the impression that the families don't see it just as another way of delivering insulin, although

that is the message that they're all given, and you feel the focus is more, and I suppose it has to be, to be safe, on button pushing.

(P13, Interview, December 2012)

The shift in focus is acknowledged as the technical 'button pushing' moves centre stage, but there is also a tension introduced here. Families are given a message that is intended to shape their approach to the insulin pump simply as a mechanical device, just another way of giving insulin. However, the instrumentalist conceptualisation of the insulin pump as a mechanical device is at odds with the persistent accounts of differences. The implication in the quote above is that the families do not use that instrumentalist conceptualisation as a way of understanding. The 'message' given to families effectively erases recognition of the distinctive effects of the insulin pump, rendering it passive and interchangeable with other ways of giving insulin. In spite of this 'message', the accounts of difference point to alternative understandings.

One of the staff team is unequivocal about the challenges posed by the sophisticated digital technology:

If you think that managing an insulin regimen with injections is difficult, managing a pump with all of its parameters that can be fiddled with, is completely baffling, even to people who really understand injection therapy.

(P9, Interview, October 2012)

The parameters and the fiddling are illustrated in the following extract from field notes. The purpose of such a lengthy and detailed extract is not to approximate a user guide for readers. Instead, the intention is to show some of the considerable technical challenges. The extract also introduces some of the very specific



insulin-pump-related professional work of supporting patient self-management in paediatric diabetes. A little like a mobile phone, insulin pumps have a small screen and a series of menus and sub-menus. Particular functions can be selected using these menus. When professionals support children and families who are learning to use insulin pumps for the first time, much of the effort is focused on programming the device and helping the children and families to navigate the controls. It is difficult to overestimate the complexity of these tasks, and in this clinic the professionals (P1 and P2) spend several mornings with just three or four families at a time, focusing on using the pump settings. The field note below is from my observation of one morning group session with four families.

P1 talks through the screens – Utilities, then Alarms, not History or Alarm Type. P1 tells them to select a medium beep so they can hear it, but it's not too disturbing. They go to Auto Off and set for long overnight sleep, around 11 or 13 hours. They set the Low Reservoir Warning in time not in insulin units, so that the pump will warn when there is only enough insulin left to work for this amount of time – P1 says make it eight hours.

Back to Utilities, then Daily Totals (average) then Time and Date (in 24-hour clock), then Alarm Clock. Connect Devices function allows connection to a blood-glucose monitor, if using one that is compatible with the software, to upload readings onto the pump.

The Block function is not being used. The Self Test allows quality control tests to check for faults. Back to Utilities and the Capture Events option which P1 tells them to set to On. Language is set to English. P1 continues, using some handwritten sheets for reference but most of the instructions she gives are from memory. Each family is focused on their pump, working through the menus and making the settings as instructed.

P1 directs them all into the Main Menu, then to Basal, Basal Set Up. There is a Maximum Basal rate to set (these are different for each child at 2.5; 2.0; 1.0 and 1.0). The Patterns function is set to On and it allows different

profiles to be set for lifestyle changes such as weekends with less or more activities. The Temporary Basal Type is a percentage. Each family sets their own rates, working from an individual prescription sheet that P1 and P2 have provided. [...] P1 asks each family to programme their own rates as per the prescription. Afterwards, to check, P1 goes around the table and asks each child to go into the Basal Review screen and read out what it says.

(Field Notes, Pump Live Day, October 2012)

The digital technology in the pump changes the nature of insulin administration, affording new possibilities in the care of diabetes. In contrast to injection pens, which give a single, measured dose of insulin, insulin pumps allow much more precise adjustment of insulin doses. Because the insulin is administered continuously, in tiny amounts, doses can be set to infuse over several hours and at different rates. This means, for example, that babies, who need much less insulin than older children, can be given exactly the right amount much more easily than with injections. Toddlers with unpredictable eating patterns can receive just what they need when they need it. Teenagers sleeping late can set insulin rates to manage the biological early morning rise in blood-glucose levels that is typically difficult to address with injections.

As the health professionals themselves grapple with coming to know the insulin-pump technology, they encounter a range of challenges that have implications for the ways in which professional education might best be organised in this case. In the next interview extract, an experienced team member describes her uncertainties:

The pump side of things, I feel as though I'm fumbling in the dark a lot of the time, particularly when it comes to insulin to carbohydrate ratios and when, not so much that, but it's when you would use which bolus, when you would use a square wave, when you would use a dual wave, and so on,

because there's nothing in the literature. [...] I think some people are a bit scared about pumps, and don't ask me why, maybe it's just it's something new. I think maybe if you're a sort of gadgety person you might be more likely to sort of throw yourself into the deep end, rather than, because I mean the principles of diabetes management are the same, but I think some people shy away from it more than others because it's a piece of kit.

(P13, Interview, December 2012)

Although there is some insistence that nothing is changed, and the principles of diabetes management remain, there is also talk of 'fumbling in the dark' and feeling 'a bit scared'. In fact, there are very fine-grained and important differences in the everyday principles of diabetes management; the bolus, square wave and dual wave mentioned above are digital functions, and there is uncertainty about which one should be used in particular circumstances. Perhaps because at the time of this interview, the insulin pump was only just becoming a mainstream care regimen, P13's experience was that few written guidelines or articles were available. In this next extract too, questions are raised about key broad principles of diabetes management such as how to treat hypoglycaemia. Again, using a pump instead of injections introduces important differences that matter in significant ways. Previous arrangements no longer hold steady in the face of the changes initiated by new technologies.

But we're still learning, I would say we're still learning yet, you know. For instance, I know that a piece of work needs to be done on hypoglycaemia in pump therapy, because patients react very different with Lucozade if you like, if they have some Lucozade they seem to really rocket if they're on pump therapy. So I know we need to look at hypoglycaemia and think about how someone on pump therapy as opposed to injection therapy would manage hypoglycaemia, you know.

(P1, Interview, October 2012)

Managing hypoglycaemia, which means blood-glucose levels are too low, is another core dimension of professional support for patient self-management. Hypoglycaemia requires immediate ingestion of glucose in fast-acting form, typically dextrose tablets or Lucozade. However, the professional in this extract describes insulin pumps changing patient response to ingested glucose, so that blood-glucose levels are pushed much higher than necessary. In this way, knowing hypoglycaemia becomes changed; that which constitutes knowledgeable care provision destabilises and requires some reworking.

The important point emerging here is that the tools and technologies matter, that is, they produce material effects. Knowing the insulin pump is not the same as knowing injections. The stabilised arrangements for knowledgeable care provision have shifted and reconfigured as new technologies participate. Technologies have a tendency to transform problems rather than to solve them (Oudshoorn, 2011), and as a result, previous understandings and ways of doing things are disturbed. Putting technologies to work requires a kind of tinkering to make them fit (Pols and Willems, 2010). Yet the tinkering is more than simply training professionals to operate the insulin-pump device; the tinkering entails coming to know the insulin pump as an aspect of knowledgeable care provision.

### **Coming to know the insulin pump**

Investigating professional learning as an ongoing, dynamic process of ‘coming to know’ helps open up questions about how such ‘coming to know’ is accomplished. In my study, attention is directed not to formal programmes of education but instead to the active work of ‘coming to know’ in everyday clinical settings.

There’s nothing to beat the experience, I don’t think it’s something you can learn by reading a book, I don’t think it’s something you can go to a

conference and learn about, I think it's something that you actually have to just do.

(P3, Interview, October 2012)

You cannot sit down and read a book, you know you go cross-eyed at it, there's too much, [...] the way we've learnt in the past [is] by pressing the buttons, because you remember what you've seen previously.

(P2, Interview, October 2012)

These professionals articulate their sense of emergent knowing as direct physical engagement: 'something you do' by actually 'pressing the buttons'. This physical engagement speaks to Prentice's (2007; 2013) notions of embodied medical knowing and her recognition of the importance of bodily practice in situated clinical settings. Prentice gives a richly detailed account of bodily practice as a central way of coming to know in the field of medicine, and a particular aspect of her work is the fostering of new techniques and practices resulting from the introduction of new technologies. Although her focus is on the medical education and training of new surgeons, her ideas resonate powerfully in the case of professionals coming to know insulin pumps and supporting patient self-management. For the professionals in this clinic, one of the ways of coming to know insulin pumps is to spend a few days wearing one, remaining attached to the device and using the programme of functions to deliver simulated doses of insulin throughout the day:

P11 arrives and has been wearing a practice pump over the weekend. P11 says it has been a fantastic learning experience, and she has now a good understanding of what it feels like to wear a pump and what needs to be done throughout the day. She feels more confident now in the clinic and not so daunted by patients who come in wearing a pump. P11 has some

questions too, and P12 shares her experiences of wearing the practice pump. P12 felt worried about using a hot-water bottle at night next to the insulin reservoir in the pump unit, and was unsure what to do when she set a wave to deliver insulin but then wanted a shower. P11 agreed and talked about setting a dual wave to deliver insulin, then forgetting to eat because she was on the phone. P12 talked about how quickly she forgets the skills when not using them all the time.

(Field Notes, Clinic, December 2012)

This extract gives examples of the ways in which operating the insulin pump often clashes with ordinary daily life; such as whether and how to remove the device in order to shower and whether the heat in a hot-water bottle will damage or interfere with the device. Supporting patient self-management entails finding ways of helping patients anticipate and deal with these clashes. Not knowing what to expect or how to manage was daunting for this doctor, but she found a way of knowing by doing. Although the pump device does not contain insulin when used in this way, the professionals do insert a fine plastic tube via a needle into the abdomen and remain connected to the device. Consequently, the questions raised above assume real importance because both showers and hot water bottles have the potential to damage the pump, and they are the kinds of concerns raised by children and their parents.

However, the following extract shows the limitations of this approach. Although wearing the insulin pump generates valuable insights into the ways that technology meets body and makes particular demands, in the end the body without diabetes acts differently when compared to the body with diabetes:

P11: You have to change it every 72 hours or so, now I don't really like needles and I think it's very tempting to leave it on. Do you think another day would be ok? I mean I know we ideally say to patients—

P1: We would always advocate that you do not do that, okay? D'you see if you go to the adult centres, you quite often find adults leaving it on for five and six days you know, but if patients came back to us and said we're leaving it in four days sometimes, we would always say, no, it should really be changed after three.

P11: Okay, right. But I mean there is no reaction there, the site's healthy.

P1: Yeah.

P11: And I think, rather than injecting another needle, I thought, oh, I'll probably postpone it by another day [laughs].

P1: You do, you do, you do get away with that, quite often the patients though, their blood-glucose levels start to drift up come the third day, you notice that, the cannula is needing changed at that point, and actually some people, it happens after the second day, so you might have to change every two days because of that.

P11: Mhmm.

P1: So as soon as these blood glucose levels start to drift up you absolutely need to change the cannula.

P11: Right, right, that makes perfect sense, just even for the pain or the local reaction it's not worth it, it's probably more than that.

(Work Discussion, December 2012)

Here, one team member (P11) is sharing her experiences and asking questions of two colleagues (P1 is the only one who speaks in this extract) in the team. P11 knows that children in the clinic are always told to remove their cannula after three days, and to reinsert a new one in a slightly different place. This instruction is partly to ensure that the skin remains healthy and does not become irritated or

infected by the cannula. P<sub>11</sub> realised that because her skin did not seem at all inflamed after three days, she would be tempted to avoid the inconvenience of resiting the cannula and simply delay the procedure for an extra day. Her question is about knowing the appropriate advice to give to children and families who might present in the clinic with the same query. P<sub>1</sub> highlights that for someone with diabetes, the skin around the cannula is not the only consideration. The cannula works to deliver insulin and it is this insulin delivery that must also be considered. After three days, it is common for a cannula to become less efficient and consequently, blood-glucose control suffers. For the body with diabetes, the cannula must be changed.

This bodily difference between P<sub>11</sub> and a child with diabetes highlights the fundamental importance of the specificities of what Barad (2007) would call intra-actions that participate in the emergence of knowledge. The health-care professional has come to know the insulin-pump technology as it participates with her own body, and so she ‘comes to know’ without the material effects of a body that cannot produce insulin and without the material effects of a cannula delivering insulin. These specific differences work to constitute the emergence of specific knowledge. The point here is less about the fidelity of simulation and its capacity to recreate a particular reality: the pedagogic potential of simulation is not necessarily undermined by the impossibility of mirroring each and every detail in a particular reality (Hopwood et al., 2016). Instead, the important point is that the emergent knowledge relies on the specific details, inherently and inescapably constituted by those details. The discussion continues as P<sub>11</sub> recounts further challenges encountered.

P<sub>11</sub>: I actually checked my blood glucose after eating, started the bolus, em, and eh, but then I had a phone call five minutes into that, and I was on the phone for 20 minutes.

P<sub>1</sub>: Uhuh.

P<sub>11</sub>: Should’ve suspended it, shouldn’t I?



P1: [Pause.] Well, it depends.

P4: You'd have had the bolus.

P1: You'd have had the bolus, you can suspend the bolus in the middle of it being delivered, d'you know what I mean? But actually, the bolus is given relatively quickly, you know. If you've had the bolus, you've had the bolus.

P11: You need to eat.

P1: You need to eat.

P11: [Laughs.] And that happened twice, you know, I was like, oh my god!

P4: You have to just say, I'll phone you back.

P11: Yeah, uhuh, uhuh.

P1: Right, we had a girl not so long ago, who was em, took her bolus before lunch at school.

P11: Uhuh.

P1: The janny [school janitor] was retiring, so she took her bolus, went and sang a couple of songs at this special assembly they were doing for the janny leaving, and she promptly fainted, you know, because she'd had her bolus beforehand.

P11: So that would happen to me. [Laughs.] Okay, 'Have To Eat', in capital letters! [Laughs, writing notes.]

(Work Discussion, December 2012)

P11 describes pressing the buttons on the pump to give a simulated dose of insulin, but then she becomes caught up in conversation and forgets to eat. The questions that follow are about what to do when there is more insulin in the body

than is required. Once insulin is administered, it is essential to eat because the insulin works to lower blood-glucose levels. If no food is ingested, blood-glucose levels will drop too low and loss of consciousness will follow, as in the example given by P1. This risk is also present when injections are used, but here P11 raises an issue unique to the pump. P11 knows that the pump has a digital function that 'suspends' the delivery of insulin, at the press of a few buttons. What she does not know is whether and how it might have helped her in the situation described. P1 and P4 are able to explain that in this instance the 'suspend' function would not stop the delivery of insulin. The bolus dose is given quickly, and it is not possible to then stop the insulin reaching the body. The pump technology introduces new possibilities but these possibilities have limitations: using the 'suspend' function, as an alternative to eating, would be unsafe in the examples given here.

### **The insulin pump actively participates**

Coming to know the insulin pump is an ongoing achievement that entails taking account of everyday life circumstances and events as well as the affordances and limitations of the technology. The insulin pump actively participates in this ongoing achievement: the insulin pump is not benign or inert. Sometimes, the insulin pump takes the initiative and issues instructions, prompting a need for professionals to respond. Moreover, these commands to act are not always expected, confirming again the emergent nature of this 'coming to know'.

P2: And you know although we've had training on the pumps and things, there's bound to be little bits and pieces that are maybe more extended things, you know things that maybe the patient can use further down the line, that they don't need to know right at the very start. But, you know, there's always going to be things that you find out, whether it's practical, or whether it's from the actual technical side of the pump.

Researcher: You're really learning on the go?

P2: Oh absolutely, absolutely. And it can only be a good thing, because it means you can pass it on to the next group. One of the things actually, that, em, the thing I was alluding to earlier on was a Capture Event option that's in the pump, and that was a thing we didn't really use because we didn't have the Carelink package. But this means people can, say if they do a blood-glucose level outwith a mealtime, they can actually capture that event, em, they can record that blood glucose within the pump. Somebody had called up to say it had taken them straight into the wizard part of the pump where they would need to deliver a bolus. They weren't sure if they should have done that, and they didn't know how to get out of it, and there was a panic going on at three o'clock in the morning. That was a big learning curve for me, straight away that morning as soon as they phoned up, because I wasn't aware that it did that. I thought that it just captured it, I wasn't aware that if your blood-glucose level was high it took you to the bolus part of the pump and it prompted you to deliver a bolus. You could get out of it if you didn't want to do the bolus, but, very quickly on the spot I learned about that you know, because as the parent was talking, you're quickly going through—

Researcher: You're flicking through the book?

P2: Yes, absolutely, so you know, it's in there now, and that information has been passed to the subsequent group we had after that.

(P2, Interview, October 2012)

P2 describes very clearly the iterative, unfolding work of accomplishing knowledgeable care provision with insulin pumps. For P2, her initial training in how to operate the insulin pump device is extended by encountering and responding to events as children and families self-manage their diabetes. In the encounter described above, there is confusion because what was originally understood as a straightforward mechanism for recording a blood-glucose level

unexpectedly morphed into a command to act. The Capture Event function did not merely capture the event. Instead, this function prompted another function. The pump suggested delivering an insulin dose in response to the blood-glucose level.

In this instance, the digital technology in the insulin pump plays a significant part, creating particular conditions by responding to the 'captured' blood-glucose information. Issuing a command to act, the insulin pump necessitates decision making about options for action. P2 states that 'you could get out of it *if you wanted to*', indicating that although it is technically possible to overrule the insulin pump at that point, a decision must be made about whether or not overruling the insulin pump is desirable. In reaching this decision, all those involved hesitate because they are party to information the pump does not have. The contextual information that is missing from the software in the insulin-pump technology must somehow be supplied and taken into account: it is three o'clock in the morning, and other considerations about the child's state of health indicate that an additional insulin dose is not required. However, there is a further complication because everyone is unsure *how* to overrule the pump. P2 describes 'quickly going through' while she is talking to the parent, and in the interview she made gestures that suggested she was simultaneously turning the pages of a book. A swift return to the instruction manual provides the answer, which is then shared with this family and later with other families.

One way of understanding this account of knowledgeable care provision is through Barad's (2007) conceptualisation of knowing as differential responsiveness and accountability, as part of a network of practices. As diabetes technologies become increasingly mainstream care options, the professional work of supporting self-management in paediatric diabetes now entails knowing whether and how to comply with or overrule the insulin pump. Characterising knowledge as accountable participation in a specific network of practices helps to make visible the new dimensions of professional practice that have emerged, and continue to emerge.

## **Working *around* the insulin pump's flow of instructions**

The insulin-pump device is encoded with software that produces patterns of instructions. These instructions respond to blood-glucose information and also to programmed rates and doses of insulin, all of which are programmed into the device by the children and parents with the support of health-care professionals. Depending on which device settings are selected and active, the patterns of instructions can work to issue warnings, stop insulin administration, ask for more information, specify particular actions and limit the range of possible actions. For example, an alarm will sound when the insulin reserves are low, reminding the user to insert a new insulin cartridge, and the basal (background) insulin rates can be limited so that increases are only permitted within a controlled range.

When children first begin using insulin pumps, they and their parents attend small group sessions so that they can receive a device and set it up. Operating the pump is a carefully choreographed selection of some pre-programmed functions but not others, in harmony with individualised rates and doses of insulin. In the following extract, the professional oversees the input of child-specific information and works both with the technology and around it:

P<sub>1</sub> directs families back to the Bolus Wizard to Edit Settings. First they switch the Wizard on, then Carbohydrate Units (in grams) then Blood Glucose Units (mmols) then Carbohydrate Ratios. For carbohydrate ratios, families use the prescription and P<sub>1</sub> tells them to look in the first column (they all vary, 7, 6, 18 and 18). P<sub>1</sub> directs them back to the Edit screen, then Wizard (On), Carb Ratio Blood Glucose Units, Sensitivity: use individual prescription rates for this. For one patient, the pump asks if the dosage is correct and states, 'Outwith normal range'. P<sub>1</sub> guides the family to respond OK to set this anyway.

(Field Notes, Pump Live Day, October 2012)

Workarounds have been described as informal strategies that are devised to get things done in spite of the constraining impacts of technologies (Fenwick and Edwards, 2010). For example, construction workers have been shown to adapt health and safety recommendations in order to proceed more quickly with the job at hand (Gherardi, 2006). In her study of cardiac telecare, Oudshoorn (2011) has also shown some of the ways in which professionals subvert and resist the prescribed courses of action stipulated by health-care technologies. Her focus is largely on the ways that technologies reshape professional identities and realign boundaries of work, whereas here I show insulin pumps modifying the conditions of possibility for professional learning and knowledge.

The extract above highlights the important negotiations between professional expertise, the insulin-pump technology and the person connected to the device. Here, families input information about each individual child's own particular insulin to carbohydrate ratios. The professionals provide this information, which allows the bolus wizard in the insulin pump to take over the precise calculation of how much insulin to deliver, based on how much carbohydrate the child intends to eat. The bolus wizard warns that the programmed amounts are more than would normally be expected, but the warning is overruled. Professional expertise dictates the safety limit is inaccurate and should not be heeded in this instance. Knowledgeable care provision becomes not only about knowing the technology, but also entails knowing when and how to work around the technology.

Although the pump can assume some responsibilities, in effect, the professional *selectively* delegates these responsibilities to the device. This selective delegation becomes an important aspect of professional knowledge in this case. Another example follows in this extract from observation of a clinic consultation:

Mum had already increased the basal rate between 1400 and 1800, and P9 agrees that was appropriate and advises increasing it slightly more. Mum makes this change in the pump settings while P9 continues talking. There is a discussion about swimming and gym, and whether there is a way to

work around the pump technology so that it [the pump] can be removed for swimming and gym but then replaced to bolus for snack or to correct if required. The pump cannot anticipate exercise and so P9 advises giving only half the correction dose advised by the pump.

(Field Notes, December 2012)

This parent is supported to adjust the rates of insulin administration. Next, the health-care professional supports the parent to work around the instructions given by the insulin pump. In this instance, the pattern of instructions encoded in the device is not able to take account of the necessary environmental and social information. The period of exercise requires that the next dose of insulin be smaller than usual, but the pump recommends an insulin dose that is still too high. The health-care professional formulates a response that incorporates the specific contextual information and overrules the pump's sequence of instructions. In this instance, the responsibility for calculating the insulin dose is not delegated to the insulin pump. Instead, the insulin pump's inability to take account of specific contextual information makes it unreliable in this instance, and the health-care professional is required to recognise and respond to this unreliability. These are Fenwick and Edwards' (2010) workarounds: informal strategies, devised to ensure that self-management support proceeds in spite of the constraining effects of the insulin-pump device.

### **Working *with* the insulin pump's flow of instructions**

The bolus wizard is the particular algorithmic sequence of instructions that is used to calculate insulin doses. Previously, when using an injection regimen, children and families would use their individual prescribed insulin ratios and do their own calculations to work out how much insulin to take. So, for example, a sandwich and an apple might add up to sixty units of carbohydrate. A child using a ratio of one unit of insulin for every six units of carbohydrate can calculate

relatively easily that the required injected dose of insulin is ten units. When the bolus wizard is used, the calculation is adjusted to take account of the basal rate of insulin already being infused in the background, and this is a more complicated piece of work. In the following exchange, P<sub>11</sub> is the health-care professional who has spent a few days attached to an insulin pump as a means of coming to know it. Her account highlights some of the effects of trusting the bolus wizard to get it right:

P<sub>11</sub>: Mhmm, and especially I think when the pump is trying to calculate, the pump's already considering the active insulin, so the numbers to work through when you try to put it into the bolus wizard there'll be lots of numbers to look at and it becomes very difficult to cross check every number. I was trying to calculate, so what was my carb ratio, what was it calculating to? And I was just cross checking everything, but then I actually gave up on that. [Laughs.]

P<sub>1</sub>: Aye. I know.

P<sub>4</sub>: You lose track of it.

P<sub>11</sub>: I need to say, okay that's it, if it says three units, I'll go with it, uhuh.

P<sub>1</sub>: Absolutely.

P<sub>11</sub>: Yeah. But isn't it amazing, because before that, obviously you would be counting and really checking how much your insulin—

P<sub>4</sub>: and making a decision about your insulin.

(Work Discussion, December 2012)

The team member (P<sub>11</sub>) with the practice pump has tried to cross check the calculations made by the insulin pump so that she can be sure the administered dose is correct. In the end, the calculation is so complicated that the only choice



is to defer to the bolus wizard. P11 is struck by the different nature of the individual's participation in the administration of insulin and by how strange it feels to defer in this way. P4 concurs, recognising that the person taking the insulin no longer leads the decision making about dosage. In this instance, the responsibility to decide the insulin dose is delegated to the pump. Although there is some discomfort in the delegation, the implication here is that the complexity of the calculation limits the possibility of things being otherwise: manual calculation is simply not feasible.

The digital technology in insulin pumps prescribes modes of operating that initiate disturbances in the arrangements for professional knowing. The technology is sophisticated, meaning that sometimes professionals' options are limited, and there is little choice but to work with the flow of instructions. However, the technology is not always party to comprehensive contextual information, meaning that at other times, professional expertise must work to proceed outside the flow of instructions. This shifting participation and selective delegation is not insignificant; the stakes are high in insulin administration, not only because the risk of errors is considerable but also because those errors can have potentially serious consequences for children.

For the professionals, knowing the appropriate response is a key dimension of recognising and mitigating risks. Knowledgeable care provision, understood as Barad's (2007) concept of accountable participation in a network of practices, requires attention to the particular risks that insulin pumps bring forth. Moreover, recognising that knowledge is differential responsiveness (Barad, 2007) helps to make visible the professional work of engaging responsibly with those risks.

### **Insulin pumps bring forth particular risks**

The combination of a potent medicine and a complicated method of administration means that professionals often grapple with concerns about safety:

I talk with P9 afterwards. P9 says that the consultations with pump patients are different, because 'more knowledge is required. The conversations require a level of knowledge even in order to be on the pump, so the style of engagement is different. The pumps are inherently self-selecting: for some patients the pump would be suicide so they are not offered. Politicians don't understand. You can't just give patients a pump and let them self-care.'

(Field Notes, Clinic, December 2012)

Safety concerns weave through the wider professional work of supporting different care regimens and also through negotiations of responsibility in self-management, and I address the concerns in those contexts in chapters six and seven respectively. Here, I focus on the safety concerns that relate more specifically to the pump technology. Together, the technology and associated concerns work to introduce a requirement for particular professional approaches and considerations. In this quote, P9 makes several important points: that insulin pumps are not automatically available to all; that professionals undertake gate-keeping roles in terms of offering or not offering the technology; and that the technology itself participates in the gate-keeping by inviting selection of some children but not others.

P9's comments about requiring 'more knowledge' and a different 'style of engagement' highlight two important issues. First, there is clear recognition that insulin pumps change the arrangements for knowledgeable care provision. Second, I would argue that what is at stake here is not an increase in the quantity of knowledge, as if knowledge was a delineated, quantifiable object. Instead, what is at stake is a dynamic reconfiguring, as in Barad's (2007) conceptualisation of knowing as differential responsiveness and accountability. In this case, professional knowledge is indeed a direct engagement: an answerable participation in specific arrangements that include technologies and risks.

P9's use of the word 'suicide' casts an important and powerful shadow, raising two issues. First, the word indicates the potential for devastating consequences should self-care proceed unchecked. The second issue is the way in which the word 'suicide' seems to move choice and responsibility for death onto the patient who is using the insulin pump. This movement seems at odds with the general thrust of the quote, which otherwise pertains to the need for professional intervention so that patients are *not* necessarily permitted to make their own choices.

In the extract above, and in the one below, P9 reinforces earlier points about the hardware not being interchangeable with injections in any kind of straightforward way.

The flexibility we've got now has got pluses and minuses, because if you don't do it right, you can really make a mess of it. That's why pumps are dangerous, because there's no safety margin, you've got six hours, and if you're not watching it, it's going to bite you. And you try telling [the Scottish Government health minister] that.

(Work Discussion, January 2013)

The point P9 makes here is that the precision delivery of insulin entails particular risks. The pump delivers only rapid-acting insulin, unlike injection pens, which administer slow and rapid-acting insulins (either separately or in a mixed format). The significance of this difference is that if a dose of insulin is missed, or if the pump malfunctions or becomes dislodged, a child would very quickly have no insulin in his or her body. P9 notes that serious and potentially fatal illness would quickly follow, within approximately six hours, because children with diabetes need insulin in their bodies in order to survive. P2 highlights the same thing below.

P2: You know, we really want them to realise how important that is, you know, because when they go onto pump therapy they've not got any background [slow acting] insulin, you know, if the pump comes loose or if the cannula comes out or anything like that, then they don't have that there. So, you know, we need to make sure they recognise the importance of it, it's tenfold now, how important that is, compared to before.

(P2, Interview, October 2012)

Insulin pumps bring forth different safety concerns when compared to injections. These safety concerns are not minor issues. The two extracts above allow the risks to remain slightly opaque, with phrases such as, "It's going to bite you" and, "It's tenfold now, how important that is". However, the following comment is much more sobering.

P8: He's dangerous on a pump because his risk of ketoacidosis is enormous, and he's not testing so he's the sort of person who could, you know, easily go off one weekend to a mate's place and, you know, be found dead in bed.

(Work Discussion, January 2013)

The risk of death or serious illness is magnified. This health-care professional is acutely aware that children and young people can die easily and quickly if their diabetes is inadequately managed. Professional knowledge in this case must take account of the narrower margins of error contributed by insulin-pump technology. This effect of the technology is a key dimension of the conditions of possibility for professional knowledge; differential responsiveness and accountability emerges with and through specific attention to these risks.

The narrower margins of error become more luminous in light of the complicated technology and the need for professionals to spend time coming to know insulin pumps. The effects on hitherto established ways of doing things, and even on the core principles of diabetes care, introduce significant tensions and uncertainties. Moreover, although the algorithmic safety settings provide some ways of reducing the risk of insulin dose errors, the limitations of those algorithms raise two further challenges. First, the patterns of instructions encoded in the insulin pumps cannot always account for every important detail in all particular circumstances. Second, and related to the first, professionals initiate a range of ways of working around these limitations, drawing on their own professional expertise to respond outside the flow of instructions. New considerations emerge: offering or not offering insulin pumps to children and parents entails discerning the extent to which these new and augmented risks can be managed and mitigated.

### **Chapter summary**

Despite some claims that insulin pumps ‘interface smoothly with humans and compatible devices’ (Welsh et al., 2010, p. 37), in fact, the interfacing is not at all smooth. These technologies are active participants, reconfiguring previous ways of understanding and arrangements for practice. This chapter has shown that insulin pumps contribute to professional learning and knowledge in this case in three key ways: first, by demanding new technical skills and capabilities; second, by prefiguring particular possibilities for action; and third, by introducing new risks.

Although there is repeated assertion that the principles of diabetes care remain unchanged, in fact, the fine-grained differences matter in significant ways. Professionals need time to come to know insulin pumps, and direct physical engagement – or bodily practice in the situated clinical setting (Prentice, 2013) – is a valued means of knowing for many of the practitioners in this clinic. The specificities are constitutive; the limitations of simulation are highlighted as the body without diabetes shapes emergent knowing in unexpected ways. Without

easily accessible sets of widely established understandings, professional knowing in this case is a kind of ongoing, negotiated achievement.

Part of this negotiation entails working with and around encoded patterns of instructions built into the insulin-pump devices. Professional knowledge is permeated with prefigured options and associated resistances, so that in some ways the insulin pumps work to code professional knowledge as well as to code diabetes care practices. Discerning when and how to delegate responsibilities to the device, for example, through the calculation of insulin doses, is a new dimension of knowledgeable care provision.

The new risks introduced by the insulin pumps' precision delivery of insulin create particular shadows that intensify the potential consequences of knowing or not knowing. Many of the professional sayings and doings presented here are interwoven with the ever-present possibility of errors causing serious illness or death. One particular response to these concerns entails offering or withholding insulin pumps and identifying those children and parents considered at risk of making potentially dangerous mistakes. This response draws attention to a wider range of issues that extend beyond the device technology, incorporating questions about (1) alternative care regimens; (2) selection and monitoring of children and parents; and (3) decision making about moving between care regimens. Chapter six, next, examines these issues.

## 6 Care Regimens as Always-Unfolding Epistemic Phenomena

It's quite difficult to teach people self-management in the first place, it's even harder if you have to say, 'Well, now you're on a different way of giving insulin we have to teach you some different rules.' So, mixed insulin demands a different set of disciplines from, if you like, the anarchy or potential anarchy of basal bolus. And that gives us another problem, because you may have been dealing with someone whose life is totally chaotic and you're then trying to impose rigidity, because if you give them a mixed insulin at breakfast they've got to have a snack in the middle of the morning, they've got to have their lunch at the right time, and if you're not sure of that, then that's another risk.

(P9, Interview, October 2012)

This opening quote captures several of the challenges that face the professionals who work to support self-management. Different ways of administering insulin entail particular sets of 'rules' and associated activities; for example, the previous chapter examined the wide-ranging differences introduced by insulin pumps. In the quote above, P9 highlights that there are also a range of different approaches to organising injections therapies. These 'sets of disciplines', or care regimens, are significant for the children and their families, for example, in terms of planning food intake at particular times and in particular quantities. Implicit in the quote above, there are also corresponding implications for health-care professionals. For P9, knowledgeable care provision unfolds with careful attention to the modes of insulin administration, the required activities that support particular modes of insulin administration, and the presence, absence and management of risk factors such as chaotic lifestyle.

The key argument in this chapter is that care regimens constitute and are constituted by professional knowledge. Professional knowledge emerges in and

through care regimens. The specificities of care regimens *matter*. The specificities of care regimens are entangled in professional knowledge; following, among others, Barad (2007) and Orlikowski (2007), the relations between care regimens and professional knowledge can be characterised as mutual constitution.

One way of exploring this unfolding professional learning in more detail is to draw on the concept of epistemic objects and practices, which was developed by Knorr-Cetina (2001; 2006; 2007). Epistemic objects are not neatly bounded objects. Rather, epistemic objects are complex and fluid, and they are so-called because when they are encountered, epistemic (knowledge) work is invited. Epistemic objects generate questions, and this work of questioning and exploring is the work of epistemic practice.

Epistemic objects are ‘always unfolding’ (Knorr-Cetina 2001, p. 181). This characteristic of being always incomplete is important: epistemic objects and epistemic practices are intertwined as the object unfolds in and through the translational work it invites (Nerland and Jensen, 2014). Or, to put this last point another way, the epistemic object comes into being and is performed through the ongoing epistemic work. One example is the way in which a medical protocol, as an epistemic object, invites epistemic practices when professionals encounter it. The protocol itself evolves even as it is performed, because the local knowledge work adapts and translates it to take account of local specificities.

However, rather than examining epistemic objects and practices as separate but closely intertwined entities, as Knorr-Cetina (2001) might, I am drawing on Barad’s (2007) conceptualisation of phenomena. In this way, I am able to focus on epistemic phenomena, thereby foregrounding the ontological indeterminacy of entanglements between epistemic objects and epistemic practices. Knorr-Cetina (2001) does not suggest that epistemic objects are simple, delineated entities, but neither does she attune to indeterminacy. What I have found so useful in my own research is that thinking of/with the concept of phenomena makes it possible to recognise and examine phenomena that are only *provisionally recognisable* as phenomena. So, for example, although a medical protocol ‘holds’ as an epistemic



object, a care regimen in paediatric diabetes, with all of its tangled and temporary connections, supports and offshoots, is much more difficult to approach in this way. Thinking of/with the concept of phenomena makes it possible and useful to articulate care regimens as epistemic phenomena.

In this case of paediatric diabetes, a care regimen can be understood as a particular approach to blood-glucose control. Thus, a care regimen comprises particular tools and technologies, such as an insulin pump or injections as well as the associated supplies such as rapid and/or long-acting insulin, needles, plastic tubing to connect the pump, and so on. A care regimen includes particular approaches to recording blood-glucose levels, perhaps handwriting in a paper diary or alternatively using the digital recording functions on an insulin-pump device. Already indicated at the beginning of this chapter, a care regimen also entails a particular set of activities aimed at making the regimen work in everyday life, for example, through particular eating habits or arrangements for exercise.

In the pages that follow, I show the ways in which care regimens are both encountered and also made and remade. The encounters between children, parents and health-care professionals are described, and show increasingly complex exchanges. In some instances, the usual arrangements for gathering and making sense of information are disrupted, making visible the extent of knowledge work ordinarily mobilised. The challenges and significance of working closely with children and parents is explored, introducing some of the difficulties of understanding responsibility in supporting self-management in paediatric diabetes, which are examined more fully in chapter seven. In the final pages of this chapter, I focus on the insulin-pump care regimen and show some of the care regimen-specific instances of exploration and closure – and the juggling between different forms and flows of information.

## **Introducing care regimens**

When I started most people were on two doses of insulin a day, morning and teatime, and when I started, most people weren't testing their blood glucose four times a day. [...] And then basal bolus came along and we were saying, not only do you have to do your blood sugar at lunchtime, you have to have an insulin injection ... and then pumps came along and by this time next year we'll be talking about [25 per cent of] patients at our clinic on pumps.

(P3, Interview, October 2012)

This health-care professional is talking about the range of ways in which diabetes can be managed. Thanks to ongoing advances in medical care, different types of insulin are available, such as rapid- and slow-acting forms, and of course, as already discussed in chapter five, insulin pumps have evolved as prominent new technologies in this field. As a result, professionals must adapt the support they provide for patients. Not only are there different nuances associated with each care regimen, but also these regimens co-exist in the range of possibilities for care. More recent developments have not eclipsed earlier approaches; instead, a variety of care regimens jostle for space. For the professionals, this variety of care regimens entails corresponding knowledge work in order that knowledgeable care provision is appropriately tailored to the local and specific needs of children and their parents. The next section describes the key features of the main care regimens discussed in the following pages. Information about care regimens is based on the textbook used in the clinic, by Dr Ragnar Hanas (2011).

### **Mixed insulins injection therapy**

This care regimen has been used for many years. Mixed insulins comprise medium and longer-acting insulins, and ensure that a background level of insulin is maintained throughout the day. Fewer injections are needed, making it a

simpler regimen to follow for some children and families. However, the steady concentration of insulin maintained throughout the day makes it necessary to sustain very regular eating patterns. Children using this regimen must eat at the same times each day, with regular mid-morning and mid-afternoon snack times too. Fixed carbohydrate amounts must be adhered to, and so there is little flexibility to eat more or less if children are so inclined. The other key disadvantage with this regimen is that the reduced opportunity for precise insulin dosing results can make it more difficult to control blood-glucose levels throughout the day.

### **Basal bolus injection therapy**

This care regimen comprises rapid-acting and longer-acting insulins, given in separate injections. Rapid-acting insulins are given just before eating, at each mealtime, and the longer-acting insulins are given morning and evening, approximately twelve hours apart. Rapid-acting insulin doses are calculated using insulin to carbohydrate ratios, individualised for each child and variable according to time of day and activity levels. This variability makes the regimen more complicated than mixed insulins but also more flexible because children do not have to stick to fixed amounts of carbohydrate. The improved precision can make it easier to control blood-glucose levels throughout the day.

### **Insulin-pump therapy**

Also known as Continuous Subcutaneous Insulin Infusion (CSII), insulin-pump therapy enables very precise administration of insulin. This precision means CSII can make it easier to control blood-glucose levels throughout the day. Because the insulin is delivered continuously, there is no need to use longer-acting insulins. Rapid-acting insulins are used in tiny quantities, and the rates of infusion can be adjusted by the hour if necessary.

Having introduced the basic features of the key care regimens in the clinic, I turn now to discuss the professional knowledge work that emerges in the everyday practices of supporting self-management.

### **Professional knowledge work**

Children attend the outpatient clinic with their parents approximately once every four months. Appointments can be more frequent if there are issues to address, perhaps at one- or two-monthly intervals for a short period. During clinic appointments, the professionals gather and analyse the information they need in order to be able to ascertain the nature of support each child and parent requires. On arrival in the clinic, children undergo the HbA<sub>1c</sub> blood test. In this clinic, the blood is analysed on site, meaning the HbA<sub>1c</sub> results become available while the children are being seen.

The professional work of gathering information, selecting, prioritising and making sense is considerable. This work is not about simply connecting information with practice; rather it is a collaborative enterprise, relying on a range of actors including the children and parents, the professionals, and the different care regimens. There is also codified biomedical knowledge about, for example, the implications of poor blood-glucose control, medical risks and available treatments.

HbA<sub>1c</sub> blood tests are done in the clinic. Blood is taken and it is analysed using a machine on the premises. There is a printout of the result, one for the clinic and one for the lab. Results are left out on the desk for professionals to collect as they see the children. P12 comments that she can't imagine doing the clinic without this result, because it's the most reliable indicator of how well blood-glucose levels are being controlled.

(Field Notes, October 2012)

P<sub>12</sub>'s comment about the HbA<sub>1c</sub> test draws attention to questions of how different information is privileged or held to be valid or invalid and to the ways in which professionals might select and attend to particular information. The HbA<sub>1c</sub> test result, given that it is considered to be 'most reliable', is particularly influential. This test measures glycated haemoglobin, which in lay terms means roughly how 'sugary' the red blood cells are. The HbA<sub>1c</sub> result gives an overall indication of average blood-glucose levels in the previous three months. The result applies to three-monthly periods because red blood cells die and renew every eight to twelve weeks.

P<sub>12</sub>'s comment also alludes to an important dimension of professional work, namely, trying to discern how well or otherwise children and their parents are managing to control blood-glucose levels. Establishing the nature of children's progress entails gathering and attending to a variety of information and generally involves reviewing a combination of electronic patient notes on the hospital PC, the paper case files and the handwritten diaries (or the software printouts for insulin pumps) completed by children/parents and brought to the clinic. Conversations with the children and parents also yield information about current insulin doses and day-to-day management of diabetes care. The following field note describes a clinic appointment between a child and two health-care professionals, and shows some of these conversations.

The next patient is discussed using case notes, and some minor concerns are noted, then the computer log is checked. HbA<sub>1c</sub> results are improving a little. Patients bring a diary of results and also sometimes sheets of paper for the ones that wouldn't fit in the diary. P<sub>11</sub> looks over these and asks what correction doses he uses – 1:1, which surprises P<sub>11</sub> and P<sub>1</sub>. P<sub>11</sub> asks if he encounters hypos with this dose, but the answer is no. There are no significant problems emerging from the recorded results. Further discussion shows fixed carbohydrate amounts are used to calculate insulin doses for each meal, meaning the same amount is eaten each day. P<sub>1</sub> agrees this seems to be working but explains to the patient that it is possible to be more flexible if he is more or less hungry at certain times.

Reviewing the case notes and computer files gives the professionals a chance to recall the previous appointment outcomes and to compare the HbA<sub>1c</sub> results. The same professionals do not always see the same children at each visit so this review is key to sustaining some continuity in terms of monitoring progress and exploring whether advice given at previous appointments has been followed. In this instance, the review elicits some minor concerns but also some news regarding the improved HbA<sub>1c</sub> result.

Establishing how well children and families are doing is not simply about checking compliance with a fixed regimen; instead, there is a continual need for carefully informed adjustment. The diary of blood glucose results plays a key role. The clinic professionals recommend that the diary of blood-glucose results is completed daily, and there is space for each blood-glucose test result to be recorded. Results could be entered up to ten times each day. In the encounter described above, the results are largely on target and no changes are needed, meaning that the balance between food intake and insulin doses is working to keep blood-glucose levels near normal. If the diary shows many results that are too low, professionals might recommend smaller insulin doses and conversely, if the diary shows results that are too high, increased insulin doses are likely to be advised.

This constant fine-tuning is an important feature of the professionals' work. The care regimen is not stabilised. Instead, the care regimen is open and contingent; continually formed and performed in ongoing ways. In the consultation above, the health-care professionals are surprised by the child's correction dose, which they worry about possibly being too high. A correction dose is an extra dose of rapid-acting insulin, given when blood-glucose levels are found to be too high. It might be used at a mealtime or between meals if no food is being eaten. The amount of a correction dose is calculated using a ratio based on how much

insulin individual children require. Children and parents calculate their individualised correction dose using this table, reproduced below in figure 3, which is on the back page of each blood glucose diary.

Figure 3 Patient diary showing correction dose calculation

**Correction Dose & Insulin Sensitivity**

**How to calculate a correction dose of insulin using Insulin Sensitivity (IS)**

1. Work out insulin Total Daily Dose (TDD):  
→ *add all bolus & basal insulin doses for one day*
2. Work out Blood Glucose (BG) fall for each insulin Unit taken (Insulin Sensitivity):  
→ *divide 100 by TDD*
3. Work out required fall in Blood Glucose (\* e.g. to upper limit of target range):  
→ *subtract 8 mmol/l\* from current Blood Glucose*
4. Work out correction dose of insulin (add to regular dose or give separately):  
→ *divide fall in Blood Glucose required by insulin Sensitivity*

**How to calculate a correction dose of insulin using Table Below**

1. Use **Ketone Dose** if BG 14 mmol/l & Ketones mod/large or over 1.0 mmol/l.
2. Use **Correction Dose (CD)** if Blood Glucose over 8 mmol/l but **no** ketones.
3. Add all insulin doses taken in a single day to give "Total Daily Dose" (TDD).
4. Find TDD in column on left & current BG in row at top of Table below.
5. **Correction Dose** is shown by point where TDD row and BG column meet.
6. A CD of 1 or more Units may be added to a meal-time rapid-acting insulin dose, or may be given as a separate injection at non-meal times if needed.
7. \*0.5 Unit CD dose may be added to a meal-time dose, but **not** given separately.
8. If no half-unit pen available round correction dose **down** to nearest whole unit.
9. Do NOT give a CD within 4 hours of another dose of rapid-acting insulin.
10. Consider only correcting as if BG 20 mmol/l, even if BG actually higher, or halving suggested dose & reviewing effect later (see table below).
11. ALWAYS discuss CD with Diabetes Team before using, or if any problems.

TDD	IS	Current Blood Glucose ( <i>if over 20 mmol/l consider treating as for 20 mmol/l</i> )											
		8-9	10-11	12-13	14-15	16-17	18-19	20-21	22-23	24-25	26-27	28-29	30+
10-11	10	-	-	-	*0.5	1	1	1	1	1.5	1.5	2	2
12-13	8	-	-	*0.5	*0.5	1	1	1	1.5	1.5	2	2	2
14-15	7	-	-	*0.5	1	1	1	1	1.5	1.5	2	2	2.5
16-19	6	-	-	*0.5	1	1	1.5	1.5	2	2.5	2.5	3	3.5
20-24	5	-	*0.5	1	1	1.5	2	2	2.5	3	3.5	4	4
25-29	4	-	*0.5	1	1.5	2	2.5	3	3.5	4	4.5	5	5
30-39	3	*0.5	*0.5	1	1.5	2	3	3.5	4	4.5	5	6	6
40-49	2.5	*0.5	1	1.5	2	3	4	4	5	6	7	8	8
50-59	2	*0.5	1	2	3	4	5	6	7	8	9	10	11
60-69	1.7	*0.5	1	2	4	5	6	7	8	9	10	12	13
70-79	1.4	1	2	3	4	5	7	8	9	11	12	14	15
80-89	1.3	1	2	3	5	6	8	9	11	12	14	16	17
90-99	1.1	1	2	4	5	7	9	10	12	14	16	18	19
100+	1	1	2	4	6	8	10	12	14	16	18	20	22

See Page I 20-23 in the Patient Held Record for more information on Correction Doses 31

Calculating the correction dose can be complicated and time-consuming for many children and/or parents, and it is important to get it right. If too much

insulin is taken, hypoglycaemic episodes can occur and this is what the health-care professional asks, but it seems that the higher-than-expected dose is working without causing any problems. In this instance, after probing for further information in response to the unexpected insulin dose, the health-care professional's concerns are modified by the child's account. As others have commented (see, for example, Moser and Law, 2006; Mort and Smith, 2009), the information that contributes to the emergence of professional knowledge is always an imperfect mash-up, both complete and incomplete and stabilising only fleetingly.

Knowledgeable care provision entails synthesising daily blood-glucose recordings, the HbA<sub>1c</sub> blood test result and insulin amounts. These measurements and numbers are then considered in light of further information about food intake, exercise levels and possible problems with hypoglycaemia. Knowledgeable care provision is a collaborative enterprise, relying on detailed descriptions from children and their parents, as in the following extract.

P<sub>1</sub> asks questions to get the patient to talk through the daily routine – what do you do when you get up, how many carbohydrate units do you have for breakfast, how much insulin would you take for that? She works through the whole day. P<sub>11</sub> comments afterwards that she learns a lot from the way P<sub>1</sub> asks the questions, mentioning specifically the way P<sub>1</sub> finds out what is happening but also checks the family's understanding of what they do. [...] The blood-glucose diary is used to review the daily results recorded in there, and the HbA<sub>1c</sub> guides professional understanding of overall blood-glucose control. The professionals comment that the patient's diet sounds good and advice is given about not varying carbohydrate amounts at mealtimes because of the mixed insulin regimen.

(Field Notes, November 2012)



P1 is systematic, working through the whole day, asking questions to generate all the information she needs. The family's answers are complemented by the information in the diary and by the HbA1c result. The dietary advice here contradicts that given in the previous extract: the different care regimens necessitate very different restrictions in terms of how and when children might eat. The care regimen and professional knowledge materialise together, entangled, in this ongoing performance.

Thus far, I have shown two relatively unproblematic encounters between children and the professionals who provide diabetes care and support self-management. These encounters have introduced many of the actors that constitute and participate in the arrangements for care. However, many of the clinic appointments were much more complicated and serve to highlight the range and extent of knowledge work that is mobilised by care regimens.

### **Disruptions**

The sociomaterial arrangements for knowledgeable care provision include the recorded blood-glucose levels, the HbA1c test result, the insulin doses, the children's (and their parents') accounts of daily lifestyle and also codified biomedical knowledge. In the following extract from field notes, the usual arrangements are disrupted.

The next patient arrives, with no monitor and no diary. There is no HbA1c result either because the machine is not working. The health-care professionals ask the patient about his insulin injections and further discussion suggests [blood-glucose] control was poor at the last clinic. The health-care professionals ask the patient to go and bring mum in. There is a long chat about the lack of information making it impossible to make adjustments to insulin doses.

(Field Notes, December 2012)

Without an HbA<sub>1c</sub> test result, the professionals have lost what one health-care professional in a previous extract called the ‘most reliable indicator’. In this consultation, there is no anchor of reliability that normally helps to ground professionals’ understanding of children’s progress. Moreover, there is no possibility of reviewing recent blood-glucose results in the diary. There is also uncertainty about insulin injections, in terms of how much insulin is being taken each day. The consultation continues in the following extract.

The staff members convey their concerns about DKA (diabetic ketoacidosis) and say, “What happens if you die this afternoon and we’re all in court saying, yes, he told us he was thirsty and drinking a lot, and then you die and we did nothing.” A plan is made for mum to phone each day for the next week with blood-glucose readings so that at least the patient is kept safe. They agree and the staff members reiterate the importance of sharing written information in the diary so help and advice can be given.

(Field Notes, December 2012)

The worried professionals create and discuss a scenario in which the young person becomes fatally ill and dies. The professionals are unable to make recommendations about insulin doses, or to assess what intervention to make, and their concern about ‘doing nothing’ is woven into the imagined scenario as part of legal proceedings against negligent practitioners. Partial resolution comes as the parent is enrolled to share the missing information with the clinic, on a daily basis, and the diary is highlighted as a significant means of accessing professional support.

The absence of detailed information from the child and parent shifts the focus from adjusting insulin doses and lifestyle. Codified biomedical knowledge about potential risks of diabetic ketoacidosis actively participates in the accomplishment of care provision, producing a new focus on immediate safety. A

similar situation unfolds in the next consultation, but the difficulty is not so much about the absence of information as establishing the veracity of the information.

The patient we are about to see is not doing well according to the PC notes from recent appointments. The patient arrives and mum joins very soon after. The HbA<sub>1c</sub> result is 117 and so P<sub>10</sub> is very worried because this is extremely high. The blood-glucose meter has been left at home but the diary has been filled in – P<sub>10</sub> is not convinced by the results in light of the HbA<sub>1c</sub> level and she is concerned about immediate medical implications. P<sub>10</sub> suggests hospital admission might be needed. P<sub>10</sub> leaves the room briefly to ask P<sub>1</sub> to join the consultation. [...] P<sub>1</sub> joins the consultation to test blood ketones levels and they are okay at 0.3, so admission is not so urgent. Another outpatient appointment is arranged for tomorrow, with careful blood-glucose testing and supervised insulin injections tonight and tomorrow morning.

(Field Notes, November 2012)

The professionals know already from the case notes that diabetes care is problematic. The HbA<sub>1c</sub> test result is extraordinarily high, well above the clinic's target level of 59, and this result arouses significant professional concern. Codified biomedical knowledge participates here: clinical guidelines (Scottish Intercollegiate Guidelines Network, 2010) advise that rising HbA<sub>1c</sub> levels are associated with serious, long-term complications such as kidney disease, eye disease, heart attack and stroke. Moreover, because the HbA<sub>1c</sub> result is held to be highly reliable, it is the blood-glucose diary that raises doubts when these two sets of information seem misaligned.

Further codified biomedical knowledge about the risk of diabetic ketoacidosis participates to cause concern about the possible need for immediate hospital admission. Knowledgeable care provision entails responding to this collection of

concerns and initiating another medical test, which measures the level of ketones in the blood. In this way the health-care professional reaches an understanding that allows the urgency to subside because the blood ketones level is within near-normal limits. Attending to issues of safety entails balancing conflicting sources of information, and as Mort et al. (2005) have shown, sometimes believing, sometimes questioning and sometimes discounting particular information.

However, the professionals in this clinic are contending not only with the psychosocial needs and preferences of children and their parents but also with the biomedical knowledge of serious health problems. Rather than privilege either concern, I am exploring how these different interests participate in the emergence of knowledgeable care. There are tensions between providing care and encouraging patients to make choices about what kinds of care they want and do not want (Mol, 2008), especially when the consequences of not providing care are likely to be serious. In paediatric settings where children's developing autonomy must be considered alongside parental concerns (Silverman, 1987; Hawthorne et al., 2011), these tensions are particularly complicated.

### **Knowing with children and parents**

In the context of supporting self-management in paediatric diabetes, professional knowing is a collaborative enterprise. This collaborative work is complicated for two broad reasons. First, and as already shown in previous sections of this chapter, the professionals rely on children and parents to give accurate, detailed accounts of their diabetes care. Second, the professionals must also discern the capabilities of the children and parents, because these capabilities have important implications. The particular nature of professional support is influenced, for example, by the extent to which children are able to undertake aspects of their own diabetes care and the ability of parents to interpret blood-glucose results.

The focus of this section is on showing the knowledge work of discerning the capabilities of children and their parents. Specifically, this knowledge work

includes discerning the accuracy and veracity of particular information, selecting among contradictory information and balancing conflicting priorities.

In the following extract, there are again concerns about immediate medical risks, but this situation is different because there is no absence of information and there are no doubts as to the veracity of information. Instead, this parent is unsure how to manage diabetes and she has not been able to make sense of and respond to the blood-glucose results.

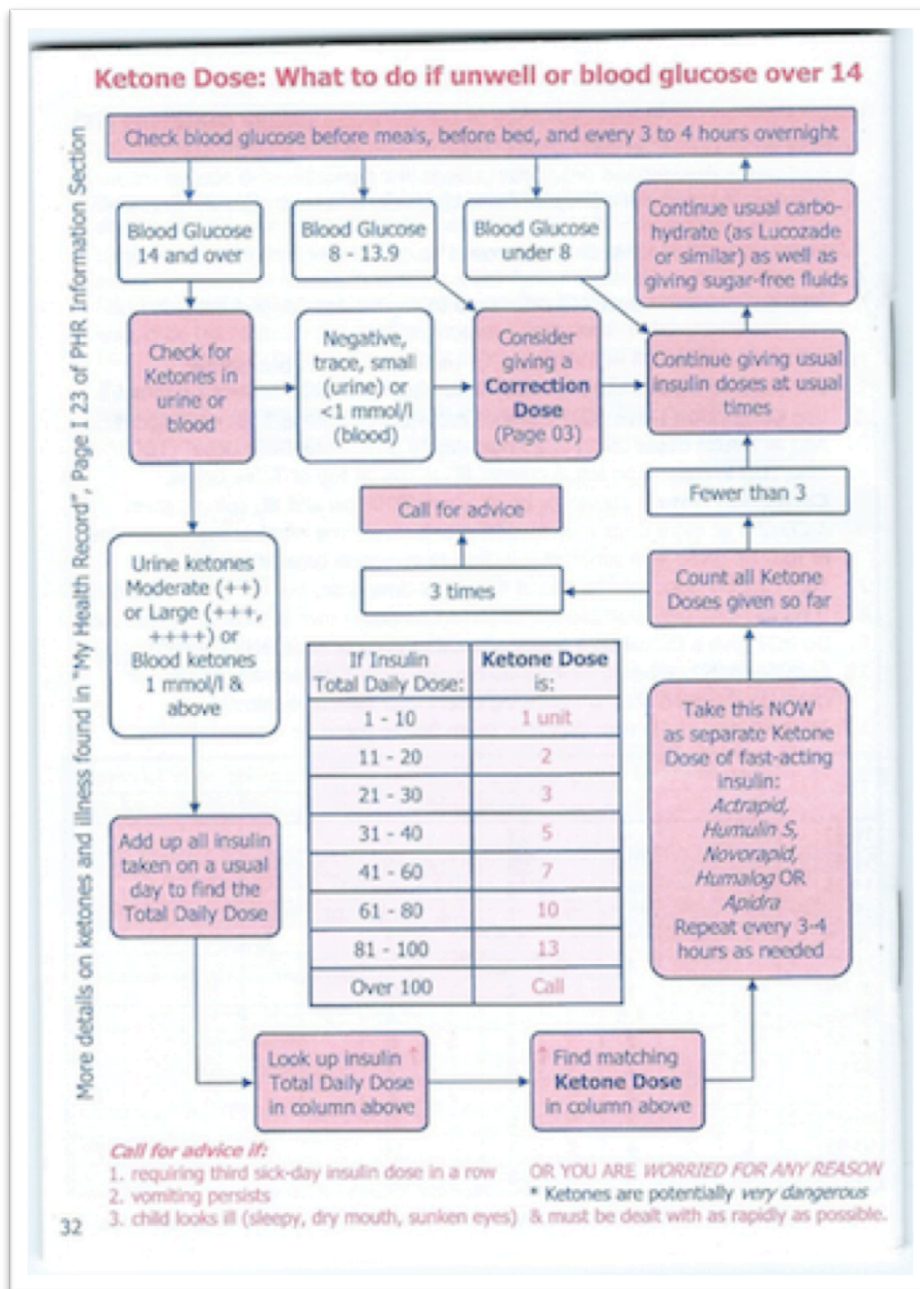
The diary is filled with very high blood-glucose readings. P13 is trying to help a parent who is not sure what to do. It seems that the clinic answer phone has a message saying that a member of the clinic staff will call back in two or three days, and this can put parents off sometimes. P13 explained it is fine to leave a message explaining it's important and help is needed 'sooner rather than later'. Doses are discussed, carbohydrate amounts, injection sites and school as well. Ketones are checked and are recorded as moderate/large, so a ketones dose of insulin is given in the clinic after checking the dose with one of the doctors. There is a long chat about blood-glucose levels, the honeymoon period, ketones doses, sick day doses, correction doses, how ketones are made and the fact that the body gets fuel from intake of carbohydrate. A lot of information and instructions are given. The diary and the charts with ketones doses are explained, insulin amounts are increased and the new doses recorded in a new diary for mum. They are advised to check ketones levels again in the afternoon and to phone the clinic if the result is positive, and again at teatime.

(Field Notes, December 2012)

The high blood-glucose readings lead to immediate action. This time, ketones levels are measured using a urine testing stick instead of a digital blood ketones monitor. The resulting measurement is given not as a numerical value but as a

general quantity; a result of 'moderate/large' requires prompt insulin, which is given during the consultation. In the rest of the consultation, the professional work of supporting self-management includes helping the parent to be able to contact the clinic more easily, and also ensuring that contact between the parent and the clinic is maintained during this period of concern about raised ketones levels. The parent's uncertainty about how to respond to high blood-glucose results, and the lack of knowledge about the consequent risk of raised ketones levels, leads to a lengthy discussion about how to manage diabetes. In this consultation, the health-care professional talks through several complicated processes of calculating insulin doses. These are challenging tasks for children and parents to understand. A ketones dose of insulin, for example, is different from the correction dose described earlier in this chapter and is calculated using another table at the back of the diary, reproduced below in figure 4.

Figure 4 Patient diary showing ketone dose calculation



For professionals, supporting children and parents to manage their diabetes care entails not only ensuring that information such as this is communicated but also requires a judgement of sorts. Not all children can work with these flow charts and tables of figures – and neither can all parents. One study estimated that caring for children’s diabetes necessitates mastery of some six hundred discrete tasks (Coffen and Dahlquist, 2009). Establishing the extent of child and parental

capacity to undertake these tasks, and the extent and nature of professional input required, remain key aspects of professional work.

The table at figure 5 represents particular codified knowledge, but the codified knowledge on its own is not enough. The biomedical knowledge of blood-glucose levels that cause significant harm, and the calculations of insulin doses required to respond to rising levels of ketones in the body, are essential resources for knowledgeable care provision but they must be augmented. The professionals must engage in knowledge work. An example of this knowledge work is evident in the following extract. The health-care professional describes spending time gathering details about a child's normal food intake and insulin doses in order to recommend adjustments to insulin ratios. However, in this instance, the information he gathers is full of inconsistencies.

P8: A girl I saw in clinic last Wednesday. It took me 50 minutes for her to tell me what she was eating the day before she came into hospital ... 50 minutes. Why? Because she was trying to think about what she should tell me rather than actually what she'd eaten. So I asked her what she'd had for lunch for example. Tuna sandwich. Okay. Anything else? No. What did you drink? No added sugar drink or water. You have any fruit? Yes, I had two tangerines, or something. Where'd you get that from? I get it from Tesco's every day. You have tuna fish every day? Every day. So. P13 goes to see her to talk to her the next day. And her sister, the girl's sister, happened to be there. So out comes the tuna fish sandwich story, [and her sister said] 'No you don't, you go to the chip van every day. You have, you always have chips and curry sauce and then you might have a fritter or two'. So, she had ten [blood-glucose] results in the last seven days before clinic above 30. Her mother – she's on 130 units of insulin – her mother swore blind to me that she was giving all the injections. She was said to have been taking 40 - *four zero* - units of Novorapid at dinnertime, the mother gave that apparently. And I gave her six the day she came in instead of 40. She was hypo. So if I'd given her 40, I would have killed her.



Relying on the accounts from children and parents entails attending to the given details but crucially, also considering and understanding those details in light of and alongside other knowledges. The health-care professional in this extract describes juggling between knowledges, recognising inconsistencies and remaining open to different possibilities. This work is less about simply choosing and privileging one form of knowledge and more about what Barad (2007) might call reading different knowledges through one another. As the care regimen unfolds, the health-care professional works to specify the particular details of care provision in this instance. These are Knorr-Cetina's (2001) moments of exploration. In their research examining the accomplishment of safe anaesthetics practice, Mort et al. (2005) have suggested the importance of not prematurely privileging particular knowledge or information and instead sustaining 'agnosticism' when balancing priorities and trying to make sense.

The health-care professional's engagement with heterogeneous flows of information and knowledge, including codified biomedical knowledge, enables him (P8) to adapt to the specificities of the situation at hand. The translational epistemic work entails moments of exploration and closure as the particularities of knowledgeable care provision materialise. Discerning the proposed forty units of insulin as an unusually large dose at this particular juncture, the health-care professional opts to administer much less. P8's final comment is sobering, and underlines the significance of this professional knowledge work. Concerns about safety and risks of harm are important dimensions of professional knowledge work, and I focus more explicitly on them later in this chapter and in chapter seven. For now, I turn to examine one particular care regimen in more detail and to explore the particular difference it makes.

## **Insulin-pump care regimen and the difference it makes**

The first patient is a boy with an insulin pump. At first I wonder why no diary or blood-glucose monitor has been brought to the appointment, but then I realise all the results are on a graph on the computer at the desk, from the insulin pump. The system is called Carelink, and there is a personal version for patients and a pro version for professionals. The patient uploads the information before the clinic appointment and shares the password with the staff so they can access it. On this occasion, the readings, boluses and glucose levels are shown, but many results are missing. P8 spends time showing the 'capture' function on the pump and explains how to use it. (I note my field notes for this consultation are sparse, and reflect on my struggle to make sense of the different presentation of the insulin pump and data.)

(Field Notes, October 2012)

The arrangements for the insulin-pump care regimen differ in significant ways from the arrangements for other regimens. By the time I observed the consultation in this extract above, I was newly accustomed to handwritten diaries and blood-glucose monitors. However, my confusion is evident. The conversation proceeds and it takes a minute or so before my attention is drawn from the empty space between the child, parent and professional (where I expect the usual leaning forward and craning to see the diary) and towards the PC screen on the desk. I record the most basic of notes, not really understanding the words yet, and try to mark the difficulty by adding the sentence in brackets later when I type up.

I talk with P4 after the clinic and ask her about the insulin-pump data. She tells me that often the data from the pump are uploaded by patients without the 'event capture' function being used, and that this is significant

because the information received by the professionals informs the advice they give about insulin dose adjustments. She explains that, for example, if the patient has several hypoglycaemic events that are not recorded on the pump but only recorded on the glucose monitor and treated by the patient, the professionals will not have the required information to know that the insulin dose needs to be reduced. Many patients forget about this function because it is not automatic.

(Field Notes, October 2012)

Children using insulin pumps do not usually complete handwritten diaries. Insulin pumps store information about each insulin dose given and about rates of insulin infused over every hour. This information can be uploaded to a shared electronic space, but the insulin-pump user must initiate the upload. The professionals in the clinic can only access the information once the insulin-pump user shares the password. Blood-glucose results will be included in the stored information, but only when the child or parent has manually entered these into the insulin-pump device. There is potentially much more information provided than with other regimens, but P4 notes it is frequently incomplete.

The professional knowledge work required in support of this care regimen is markedly different from other regimens. Gathering information is different work. For example, the blood-glucose information itself is presented in a different format. The two images below show the differences in presentation and layout of information and also the increased volume of information provided by the pump. The first image below, at figure 5, shows a blank diary page with space for one week of blood-glucose results. This diary is the one given to children using injections regimens, and either the children or their parents fill in the spaces by hand.

Figure 5 Patient diary showing blank page for blood glucose recording

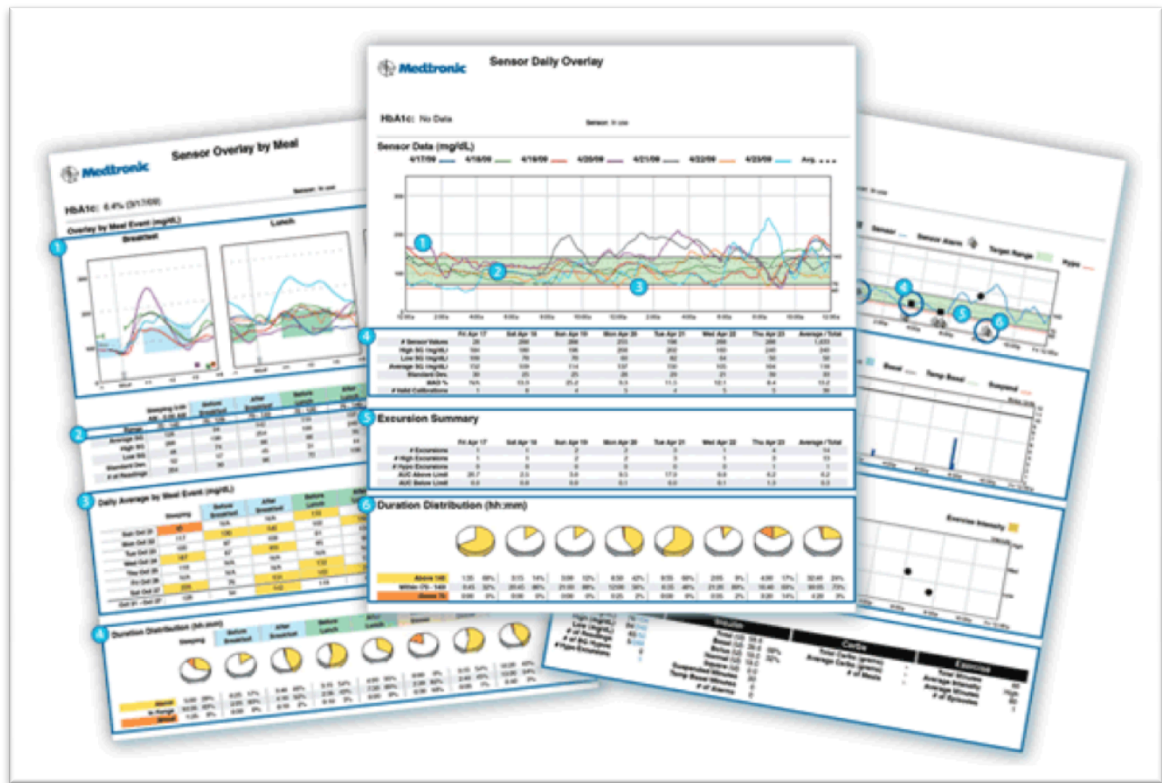
### Daily Blood Glucose Results

Insulin Type	ICR (U/10g)	Mon	Tue	Wed	Thu	Fri	Sat	Sun
B								
B								
L								
T								
T								
S								
Early morning result								
B R E	Over 8							
	4 - 8							
	Under 4							
90 mins after meal								
L U N	Over 8	DID	YOU	WRITE	DOWN	CORREC	TION	DOSES?
	4 - 8							
	Under 4							
90 mins after meal								
T E A	Over 8							
	4 - 8							
	Under 4							
90 mins after meal								
S U P	Over 8							
	4 - 8							
	Under 4	ARE	YOU	WRIT	-ING	RESULTS	EVERY	DAY?
90 mins after meal								
Overnight result								

3 low or high results at same time of day means change is needed NOW. See Pages G01 & G02 in "My Health Record"

Use Ketone Dose if glucose over 14 & ketones mod, large, or 1 mmol/l & over 07

Figure 6 Screenshot showing software reports produced by insulin-pump technologies



(© 2016 Medtronic Minimed, Inc., image from [www.professional.medtronicdiabetes.com](http://www.professional.medtronicdiabetes.com))

This image above, at figure 6, shows an example of the charts and graphs produced by the insulin-pump software package Carelink, which was the one used in this clinic. These charts and graphs are screenshots from the manufacturer’s website. I was unable to collect samples from the clinic because patient details are included on each page. However, these screenshots help to give a sense of how Carelink differs from the handwritten diaries. One senior clinician has called the printouts from insulin pumps in general ‘an overwhelming mess of data’ (Greene, 2014, p. 250), and certainly the health-care professional talking in the extract below acknowledges the initial difficulties navigating the Carelink resources.

But even just learning how to sit and look at and read the Carelink package, you know that was quite a thing, because there’s a lot of information on it, and you know really stopping and getting your head

round about that was quite tricky to start off with, but I think you had no time to actually dwell on it because you had to just get on with it because there was [sic] so many coming in.

(P2 Interview, October 2012)

Making sense of the uploaded information is a relatively painstaking process, particularly if there are several requests for advice from different families. On the morning of the observation recounted below, twelve families uploaded information and asked for help. Each of these twelve sets of data comprises multiple pages of information, much like the images in the Carelink screenshot on the previous page. The experienced health-care professional works between the PC screens, the calculator and a pen and paper.

P2 is working through Carelink data from insulin-pump users, reading information from the PC screen and using a calculator as she scrolls up and down to different sections of the data, writing notes with a pen onto an A4 piece of paper. [...] P4 asks P2 if she is okay. P2 replies that she is, there are twelve emails about the pumps, but she has most of the day to answer. She explains that sometimes whoever is working on these emails has to complete all queries by midday. P2 uses two A4 sheets of paper with handwritten notes from the data uploaded to Carelink. P2 is making sense of the information on screen so that she can advise about appropriate dosage rates for patients' insulin pumps. Because the different information is on different pages of the uploaded document, not everything can be seen at once. The handwritten notes provide a way of gathering key information in one place. From the outside, this process seems solitary, silent and characterised by intense concentration.

(Field Notes, November 2012)

The knowledge work here entails producing a new form of the selected information: the handwritten page. P2 cannot simply make use of the uploaded information in its digital form. Instead, she becomes involved in working with the information to change it, or as Lupton (2013b, p. 265) observes, ‘re-embedding’ the information in the context in which it will be used. The work of translating enables the digital information to adapt to the local specificities of care provision, such that different sections of the available data can be taken apart and reconfigured together in ways that better contribute to local care provision.

In contrast, the health-care professionals in the extract below are reading information on the PC, from one child’s insulin pump, in the consulting room immediately before the child attends for a clinic appointment. The biomedical details are too complex to explain here, and in any case the important points relate to the ways in which they grapple with such complexity. As they talk aloud, their conversation gives a sense of their struggles to work through the series of screens. The conversation is a perpetual movement, a kind of back and forth between each party, attending to the details on each screen, articulating the selected important features, questioning particular points and settling on an understanding. Knorr-Cetina (2001) has highlighted this oscillation between moments of closure and exploration as an important characteristic of epistemic phenomena.

P9: Em, oh [sighs], I have no idea what you’re supposed to do there with that graph there, I mean, what are you supposed to do with that?!

P4: Oh, that’s just rubbish, no that bit’s better cause that bit breaks it down, doesn’t it, to, em, breakfast lunch and dinner? But even at that—

P9: I still think it’s a dog’s breakfast [mumbling].

P4: Probably the only thing it’s good for is the average carbs [carbohydrates] and the average insulin.

P9: Right. Okay, so, em, average total daily dose 33.3, 25 and a half versus 7 point, right, so, his numbers are, eh, pretty all over the place. [Pause.] He's not on enough insulin.

P4: Is he only on 7 units basal [slow acting background insulin]?

P9: That's what it says. [Pause.] so his sugars at breakfast are, generally okay, and then it goes to ... [Something I can't hear.]

P9: Yeah, he's not on enough insulin, in the wee small hours, is he, so that's, consistently it's at two o'clock in the morning, now, but he's getting corrections at two o'clock in the morning.

P4: Every night.

P9: Now, why would you do that rather than do an increased basal rate? Why would you do that? Why would anybody do that?

(Work Discussion, January 2013)

This perpetual oscillation emphasises the always unfolding, always in the process of being materially defined, nature of epistemic phenomena. The care regimen here is not fixed; the health-care professionals figure out and stabilise the care regimen by attending to, selecting and evaluating the information. The information might flow, but it is also fluid (Moser and Law, 2006) in that it changes and is changed in the professional work of knowing. It is of note that with this care regimen, more of the knowledge work progresses before the child and parent are even in the consulting room. The Carelink charts and graphs speak in the absence of the child and parent; although P9's questions (at the end of this extract) sound rhetorical, just at the point he asks these questions there is no one to answer, no one to explain the reasons behind particular actions.

Epistemic phenomena are made and remade in the knowledge work. In this case of paediatric diabetes, I conceptualise care regimens as epistemic phenomena.



Rather than separating epistemic work from epistemic object, this conceptualisation appreciates the constitutively entangled nature of care regimens and professional knowledge work. In this way, although the professional work of knowing becomes provisionally discernible as care regimens are encountered, the relations between knowledge and regimen are construed as intra-actions (Barad, 2007) rather than interactions. The effect of this construal is to recognise the constitutive significance of the local and specific arrangements for care provision in the emergence of professional knowledge.

### **Knowledgeable care provision**

In the following extracts, a health-care professional talks about a child using an insulin pump. All of the extracts in this section are from the same account, but I have included them as a series of quotes in order to examine the issues in turn. As a whole, the account shows some of the instances of exploration and closure, the selection and evaluation of different information, the participation of the child and the various blood-glucose results, Carelink data printouts and HbA<sub>1c</sub> test, and the emergence of knowledgeable care.

P8: So this boy came up early January, and I saw him and he came with no meter, no diary. He hadn't downloaded his pump data since August last year. And his HbA<sub>1c</sub> was 9.7 per cent, the equivalent, and having said to him in May last year that not managing your pump properly was dangerous and that we would seriously consider stopping someone on a pump if they weren't managing their diabetes properly, he was suitably contrite at that time and burst into tears in May and said, you know, he was very sorry, he'd let everyone down and he was mortified and he'd do it.

(Work Discussion, January 2013)

HbA<sub>1c</sub> test results used to be expressed as a percentage but are now given as a value measured in mmol/mol. In this clinic, the target range would likely have been around 6.5–7.5 per cent, so 9.7 per cent is considerably higher than desired. In the account above, the combination of no detailed information about blood-glucose levels and a worryingly high HbA<sub>1c</sub> result raise concerns for this health-care professional. Here, knowledgeable care in support of self-management entails attending to issues of risk and safety, and establishing limits on what is and is not permissible with this care regimen.

Anyway we got to January and he wasn't playing the game and I said, "Look, I think you should come off your pump," and he said, "I don't want to," and I said, "Well, I tell you what, you download your data, I'll have a look at that and then we'll make a decision, but at this point I think you should come off your pump." And, so it took about five days before any data was downloaded onto the website and when I saw it [sic], for the five days since I'd seen him at clinic he was bolusing six, eight times a day, but the two or three weeks before that he had numerous examples where he had a bolus at two o'clock in the morning and the next one wouldn't be until 11 p.m.

(Work Discussion, January 2013)

Professional knowledge work entails bringing codified biomedical knowledge (such as health risks and optimal patterns of insulin administration) into dialogue with the every day operationalisation of the insulin-pump care regimen (such as the actual bolusing activity recorded on the Carelink data) and the engagement with the child and family (such as the downloading of requested data and the child's preferences about whether to continue with the insulin pump). As shown earlier in this chapter, the professionals seek a detailed understanding of the ways in which children (and their parents) manage diabetes.

I said, “You know, you're in lunch, why can't you set an alarm?” and he says, “Well I do,” and I said, “Tell me what happens at lunchtime,” and he said, “Well, I put my alarm on my watch, and it goes off. I've got an alarm on my phone and it goes off before lunch. And then usually when I'm standing in my queue at the cafeteria, the alarm on my pump goes off.” And I said, “Well, why don't you bolus then?” And he said, “I don't know.” And I said, “You've got three alarms and they go off every day!” It means he's dangerous on a pump because his risk of ketoacidosis is enormous and he's not testing [his blood glucose], so he's the sort of person who could, you know, easily go off one weekend to a mate's place and, you know, be found dead in bed.

(Work Discussion, January 2013)

The insulin-pump care regimen that is materialising here includes missed doses of insulin, very little recorded data and infrequent blood-glucose testing. In these circumstances, this care regimen is not only ineffective at managing diabetes but also actively presents serious risks to the child's health. Knowledgeable care provision entails taking account of all of these presenting features.

However, this extract also highlights the challenges this child faces each day. The challenges are complex, and not resolved here by the health-care professional asking, “Why don't you do it?”, because the child (according to the health-care professional's account) is not able to say. Mol (2008) has written extensively about the problem of patient choice and the mistaken idea that self-care in diabetes simply entails making a decision to do it. On the contrary, Mol's (2008) detailed study of adults with diabetes shows that everyday monitoring of blood-glucose levels and administering insulin is messy and complicated, that technologies are often surprising rather than predictable, and that the fine-grained demands of life regularly create insurmountable difficulties.

P8 describes balancing the biomedical risks of serious illness with trying to support the child's preference to continue with the insulin-pump regimen. In the end, the risks are considered to be too great. The insulin-pump regimen is removed as a possible option, the two remaining injection regimens are offered, and the child is invited to choose.

P8: The next thing was, I asked, "You know, you've got a choice, you can go onto a split mixed injection in the morning which won't be as great for your blood sugars, but it means you don't have to do an injection at school or you can go onto basal bolus and we'll review things in three months' time. And depending not so much on your HbA<sub>1c</sub>, but depending on your attitude and your approach and how you're getting on with your parents and how you engage with us, we'll then make another decision." And he said, "I'll go on the mixed."

P<sub>12</sub>: Really?

P8: Yeah. And I thought, okay, that means that I felt very comfortable with my decision then because I thought, you've just said, you know, you don't want to really have the responsibility of looking after this at school.

(Work Discussion, January 2013)

Here, the HbA<sub>1c</sub> test result is clearly set aside as a lesser priority. Instead, the child's willingness and capacity to engage with the multiple facets of the care regimen are described as most important. In this account, the biomedical implications of each care regimen are weighed against the demands of operationalising the care regimen every day. The effect of the care regimen on overall blood-glucose control is no longer the key consideration as immediate safety becomes the driving concern. The unsafe insulin pump has been withdrawn as an option. As part of establishing which care regimen will take its place, the health-care professional highlights that blood-glucose control is likely

to be negatively affected by choosing the simpler care regimen, but nonetheless defers to the child's choice.

There are tensions between promoting patient choice and providing responsible care (Mol, 2008), and perhaps it is this tension that underpins the second health-care professional's surprised response. The child opts for the care regimen that is easier in terms of daily commitments, yet all are aware that this choice could have long-term health implications. However, in the concluding remarks, P8 again balances these incomplete and conflicting flows of information and knowledge. P8 works with and around the biomedical concerns, the child's wishes and capacities, and the particular self-care demands of each care regimen.

### **Chapter summary**

This chapter has focused on examining care regimens as epistemic phenomena; that is, on understanding care regimens as phenomena that mobilise the knowledgeable work of care provision in support of self-management. The care regimens (insulin pump, basal bolus and mixed insulins) not only initiate knowledge work, but the particular arrangements for these care regimens actively contribute to the particular professional knowledge that emerges. I draw on the work of Barad (2007) to make a shift from thinking 'object' to thinking 'phenomena'; thus emphasising care regimens as only provisionally determinate in ongoing performances. In this way, care regimens are constituted by and constitutive of professional knowledge.

The professional knowledge work shown in these pages is not simply a matter of connecting information with practice. Instead, multiple streams of knowledge tangle with incomplete and imperfect flows of information. Professionals balance conflicting and competing interests, selecting and prioritising, questioning and discounting.

Foregrounding the insulin-pump care regimen highlights the very particular effects of specific arrangements for care. Professional knowledge emerges in and

through these arrangements, such that abstracted biomedical knowledge is only one resource among many. The biomedical implications of each care regimen are weighed against the demands of operationalising the care regimen every day. Discerning the extent to which children and parents can cope with these demands is an important dimension of this work, especially when there are significant potential risks of harm. Balancing the promotion of child (and/or parental) autonomy with the provision of safe care is one of the recurring themes in the latter half of this chapter. Chapter seven, next, addresses this particular challenge in more detail.

## 7 The Troublesome Notion of Empowerment

I suppose the word that's most often used in terms of self-management is about empowerment, and I despise that word. Absolutely hate it, because it is trite and it is too small a word for what has to be done. There's a sense in it that it's just about, teach them and then they can do it. Teach them and then it's no longer our problem. And I don't think it's like that at all.

(P9, Interview, October 2012)

The notion of empowerment featured often in the conversations I had with the professionals in this clinic, perhaps in part because it has emerged as a prominent self-care strategy for long-term health conditions (Wallerstein, 2006). Empowerment is also now embedded as a key dimension of service provision in diabetes care (Scottish Government, 2014), making it a useful focus of analysis in this study. Already shown in chapter one, empowerment is also a key feature in educational resources developed for health-care professionals.

P9's description of empowerment as small and trite might well fill readers with some dismay. However, the quote is helpful because it draws attention to the differences in the ways that the notion of empowerment has been understood and employed. For example, community empowerment has been employed as a basis for health reform, and many such approaches are critically aware of the challenges: Wallerstein and Bernstein (1988; 1994) recognise the importance of power relations and argue that when one group names the health problem for another, the conditions for empowering practices are undermined. However, in spite of such contributions, it is not unusual in health-care policy, for example, for empowerment to be conceived of as something that can be 'done' to others as a way of producing officially recommended improvements in health (Spencer, 2014). P9's explanation of his dislike of the notion highlights that what he

considers empowerment to be does not in fact relate at all closely to the work he has to do. This perceived dissonance raises questions about the nature of the work of supporting self-management, and the implications of employing such a notion of empowerment as a way of engaging in that work.

In this chapter I draw on the work of Gherardi (2006; 2010; 2012) to examine the ways in which professionals support self-management, paying particular attention to the notion of empowerment as it features in conversations and observations. Following Gherardi (2010; 2012), the knowledge for this work of supporting self-management is not construed as an object but rather as a situated activity: as knowing-in-practice. Examining the situated activity of knowing-in-practice entails examining material-discursive practices, where practices are 'modes, relatively stable in time and socially organised, of ordering heterogeneous items into a coherent set' (Gherardi, 2006, p. 34). Practices are not just patterns of activities, but rather they are ongoing and recognisable ways of accomplishing things (Gherardi, 2012). This particular approach enables attention to the ways in which the work of supporting self-management is accomplished.

Practices are material-discursive in that the focus is not on conceptual structures and cognitive processes but on sociomaterial arrangements. Although Gherardi's approach is a sociomaterial one, and thus aligns well with my study, her approach employs materiality differently from Barad. Focusing, for example, on the ways in which materiality, such as technologies, might activate professional knowledge in particular ways, Gherardi (2010) does argue that technologies are active participants yet does not emphasise the indeterminacy of material-discursive entanglements in quite the way that Barad (2007) does. What I have found particularly helpful in my own research is Gherardi's (2006) attention to the ordering processes that enable a practice to be produced and reproduced over time.

Following Barad's (2007) conceptualisation of material-discursive practices as irreducible to material *and* discursive helps sustain attention to the mutually constitutive relations that contribute to the emergence of the phenomenon



under investigation. That is, investigating professional learning as it unfolds in the work of supporting self-management, including the ways in which the notion of empowerment features, is enriched by recognition of entangled relations. These entangled relations include those among, for example, technologies, care regimens, flows of information, negotiations of responsibility, safety, risk and authority.

### **Reading practice in multiple ways**

Gherardi's (2010; 2012) approach to reading practice in multiple ways affords scope to examine three different dimensions. One way is to focus on the everyday recursive practices of supporting self-management, particularly empowerment. A second way is to focus on the practical organisation and engagement of knowledge 'in situ'. A third suggestion is to focus on the dynamic creation and recreation of the conditions for practice, including, for example, the unanticipated effects of practice. For Gherardi (2010), these three readings allow exploration of what the practice accomplishes, of how knowing-in-practice is enacted and the wider effects of the practice as it contributes to the reproduction of particular conditions for practice.

In my study, I borrow from Gherardi (2010) to explore the practical accomplishment of supporting self-management in this clinic and to explore the extent to which the rhetoric of empowerment corresponds to the work of supporting self-management.

The remainder of the chapter is structured as follows. After defining the particular notion of empowerment that influences policy and literature in diabetes health care, I introduce the arrangements and practices that help to accomplish support for self-management. I include the particular challenges that the professionals discussed as they talked about empowering children and parents. Data extracts from observations and conversations show the professionals grappling with complicated issues of safety and risk as they work to connect the notion of empowerment that pervades policy literature and

professional educational resources to the everyday work of supporting self-management. A particularly difficult consultation event concludes the chapter, drawing together a number of questions about the misleading nature of the rhetoric of empowerment and the extent to which it is a useful conceptualisation of the work of supporting self-management.

### **Defining empowerment in diabetes: a troublesome notion**

The notion of empowerment that has evolved and been shaped for health-care policy differs from that envisaged by sociological writers such as Freire (1970). Freire's (1970) highly political emphasis on critical consciousness-raising has been narrowed and tailored to fit as the focus on political emancipation shrinks. The purpose of health empowerment is often tightly linked to predefined desirable health outcomes (Spencer, 2014). For example, public health approaches might aim to 'empower' people to exercise more or to eat more healthily. Importantly, the designation of some health outcomes as 'desirable' is not always explicitly negotiable: 'a major goal of patient empowerment is to improve adherence to agreed self-care regimens' (Meetoo and Gopaul, 2005, p. 31). Thus, in health care, patients might be 'empowered' towards ends that are selected for them.

This way of connecting empowerment strategies to predefined goals contrasts with Freire's (1970) ambitions for creative liberation. In his seminal work *Pedagogy of the Oppressed*, Freire (1970, p. 65) wrote that 'attempting to liberate the oppressed without their reflective participation in the act of liberation is to treat them as objects which must be saved from a burning building'. Importantly, in the fields of education and community development, empowerment is not something that can be given to people or done to people. Participatory processes are a fundamental part of empowerment. Although Wallerstein (2006), in a report for the World Health Organisation, does recognise that the aims of empowerment strategies will and should vary according to particular participants, issues and contexts, and actively encourages participatory public and community health interventions, a slightly different approach has evolved in some areas of health care. In literature specifically focused on diabetes, the

following definition is one that is widely used – and it is one that is markedly different from Friere’s (1970):

Empowerment is fundamentally an outcome of diabetes education. Patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others to improve the quality of their lives.

(Anderson and Funnell, 2003, p. 454)

As a self-care strategy for diabetes, the knowledge, skills, attitudes and self-awareness listed here pertain inevitably to the tasks of insulin administration, blood-glucose testing and carbohydrate counting. Consequently, the concept of empowerment is unavoidably bounded by biomedical preoccupations (Scambler et al., 2014), creating tensions between ideas of self-determination and choice and the serious medical consequences of not engaging in self-management of diabetes. Such a narrowly focused definition might perhaps help to delimit the health-care work of ‘empowering patients’. However, the following addition to the definition, from some of the same authors above, introduces complications:

The philosophy of empowerment would acknowledge and respect a person’s wish to transfer power back to the health-care professional. The choice remains with the patient, even when the choice is to decline power. Patients who choose to remain the passive recipients of care are responsible for that choice and its consequences.

(Funnell et al., 1991, p. 40)

In this formulation, empowerment entails gifting power from the professional to the patient in order that predefined consequences can be avoided. The participation of the patient is limited to choosing whether or not to accept this

gift of power and the predefined aims. Moreover, power is construed as an unproblematic object, bounded and available to be handed back and forth.

Empowerment in diabetes health care is a troublesome notion. With its wide-ranging histories of political emancipation and educational transformation, thinking of/with the concept of empowerment in some areas of health care might contribute the kind of public participation that drives successful community health projects. However, the biomedical preoccupations and the high stakes in diabetes serve to complicate efforts at identifying collaborative aims. Moreover, there are additional challenges of supporting self-management in paediatric diabetes, where empowerment might be a strategy for engaging either children or parents, or perhaps both in different ways and in different instances.

The purpose of highlighting these ways of thinking of/with the concept of empowerment is to frame the data extracts in the following pages. If I am to pay particular attention to empowerment as it features in the professional work of supporting self-management, I need to specify what I am looking for. My focus, then, is on moments of conflict, issues of risk and safety, collaboration and participation, engagement with children and parents, shared decision making, and on the everyday accomplishment of supporting children and their parents to manage their diabetes. I am also attuned to instances of dissonance, where the stated aims of empowerment seem at odds with the everyday work of empowering.

### **Empowerment in the paediatric diabetes clinic**

I turn now to the ways in which the notion of empowerment featured in City View Hospital. I begin with some of the explanations and discussions offered by a key informant, P9, who talked in some detail about empowerment and the particular implications for the work of this clinic. Although self-management and empowerment approaches are prioritised in a number of other long-term conditions such as chronic heart disease and asthma, there are particular differences in diabetes, as the following quote explains:

Giving people the complete freedom to manage their own health is an unusual thing in medicine and it's extremely unusual for people to dose adjust. I mean, I can't think of any other medicines where people do it quite so freely, em, no, I can't think of anything, so it's an unusual situation.

(P9, Work Discussion, January 2013)

Taking ownership of lifestyle changes such as healthy diet and appropriate exercise, even when coupled with self-administering medicines, still usually entails following a professionally prescribed dose of whichever drug is indicated. This quote above highlights the difference for those with diabetes, who are expected to make independent adjustments to their insulin doses on a routine basis. This difference emerges in part through the influence exerted by the insulin itself: the very particular characteristics of insulin as a risky medicine, and one that must be administered in highly variable amounts, intra-acts with the particular care regimens discussed in the previous chapter and with the professional practices of supporting self-management explored in this chapter.

The freedom that is referred to is described as something unusual in medicine; perhaps something that does not sit entirely comfortably with all health-care professionals, especially those who have worked predominantly in acute care settings where patients are typically very ill and reliant on medical expertise (Scambler et al., 2014). In addition, such freedom is perhaps not always easy or desirable for all patients, some of who prefer clear direction from health-care professionals (Zoffman and Kirkevold, 2012).

Wallerstein (2006) suggests that empowering does not comprise any standardised set of interventions; rather, there is a need for local adaptation to particular contexts. In this clinic, there is also a sense of the need to adjust interventions to take account of the individual differences between patients.

If you come to me and you're unsure about something and I say, "I don't know, do you think maybe we should do a bit of this, or maybe, I've read about this, what do you think?" Some people respond positively to that, some people say this is great, this is inclusion, this is empowerment. Some people go, "I don't know, you're the doctor! You're useless! He's hopeless that doctor, he can't make up his mind!"

(P9, Interview, October 2012)

Each encounter brings particular considerations about the different desires, abilities and capacities of those who are being supported to self-manage. The drive to shift professional roles from dominant to supportive or facilitative (Wallerstein, 2006) is not at all straightforward, illustrated in this doctor's description of trying to share decision making with those who still might expect a more directive style of consultation.

There are added challenges in paediatric settings. Supporting self-management for children with long-term health conditions relies, to varying degrees, on the involvement of parents or carers (Modi et al., 2012). The extent and nature of parental involvement changes with the age and developmental stage of the child (Spencer et al., 2010) and requires a kind of ongoing negotiation between parent, child and professional (Tates and Meeuwesen, 2001). The notion of empowering children and/or parents raises a number of tensions.

You know it's a tough game having diabetes. It's a real bummer and it's not developmentally appropriate to ask children to do what we ask them to do. To ask a 15-year-old to be responsible for their own health, to be thinking about the future, in other than the vaguest of terms of, don't smoke, don't get pissed every night and don't take drugs, em, it's ridiculous, it's unreasonable. But what choice have we got?

(P9, Work Discussion, January 2013)

The point that P9 makes about professionals having no choice is an important one; this work raises difficult issues. The nature of diabetes is such that taking insulin, measuring blood-glucose levels and paying attention to carbohydrate intake is essential for survival, and professionals work to support these essential activities. Consequently, although there is recognition that what is expected of children is often unrealistic and unfair, there is a sense too that the children themselves have little choice. For young children of course, parents are closely involved.

To begin with it's usually, if it's a young child, it's the parents, and the child has minimal responsibility. Maybe their only responsibility is to own up if they've eaten the wrong thing, so that the wrong action doesn't happen afterwards. And they might do some blood tests and things, maybe do one at school and write it on a bit of paper or something and bring it home, or show it to the teacher. That might be as much as they do. The parents do most of it, and we're in the background.

(P9, Interview, October 2012)

In this account, parents are clearly accorded a central role in diabetes care provision, and the child is tasked with some smaller, discrete activities, for example, during the school day. This highlights a key challenge in supporting self-management in paediatrics: the patient will always be the child with diabetes, but the person managing the diabetes might sometimes be the parent. The professional work of supporting self-management entails attending to both children and parents – and raises difficult questions about the nature and purpose of empowering practices.

The other point about the child is [that] paediatrics is necessarily very different from adult medicine. We've got a changing individual at the centre of all this. So, an extremely common problem, in fact, it's so common it's the norm, child gets diabetes at two or three years old, and

then suddenly at 14 years we discover they know nothing about diabetes, and we're surprised. Well, why should we be? They've had it done to them all these years. It's formulaic.

(P9, Interview, October 2012)

When parents manage their young child's diabetes, supported by the health-care professionals, the child might be (more or less) compliant with insulin administration and blood-glucose testing, but perhaps not always listening or engaging with the details of diabetes care. The transition to being an older child, and the corresponding expectations that he or she will come to manage his or her own diabetes care, is very often problematic according to this health-care professional. These challenges of sharing and overseeing diabetes care, including discerning when and how to support the parent to develop the child's capacities for self-management, were evident in many of the clinic consultations I observed, and are considered throughout in this chapter.

In essence, professionals supporting self-management in paediatric diabetes aim to facilitate children, with varying levels of support from their parents, to be able to monitor blood-glucose levels; regularly administer variable doses of insulin several times each day; to adjust insulin doses based on patterns of blood-glucose results; to match insulin intake to carbohydrate intake; and to account for periods of exercise, inactivity and illness by adjusting insulin and carbohydrate intake accordingly. An empowerment approach, as set out in health-care literature and policy, seeks to promote patient choice, autonomy and collaboration in setting goals and outcomes for diabetes care (Anderson and Funnell, 2003).

### **Empowerment in clinic consultations**

This section moves into the fine-grained details of the clinic consultations. The consultation described in the next field note pertains to an older child who



attended on his own. In this clinic, it was normal for children older than twelve years to be seen by the professionals before their parent or parents were invited to join the discussion. Here, this child has brought a diary full of blood-glucose results to review with the health care professional.

The diary shows very chaotic results with highs of 27 and lows of three. P13 says, “It’s your diabetes, your consultation, you have to decide what to do, I’m not going to tell you.” P13 gets few answers to her questions about why insulin doses have not been changed in response to blood-glucose readings. There also seems to be uncertainty about how to use correction factors or the tables [these tables for patients show the correction factor for different total daily dose]. The HbA1c is not available because the machine is broken. P13 sits back and ask the patient why he comes to the clinic. P13 continues and the implication seems to be that if no attention is paid to the advice from the clinic then what is the point in attending.

(Field Notes, December 2012)

This was a difficult consultation to observe, and even now the field notes make for uncomfortable reading. There is a striking dissonance between the exchange in the consultation and the definitions of empowerment in the opening sections of this chapter. In health-care literature, and in many of the available resources for health-care professionals, empowerment aims to involve patients, to draw on their expertise, to enable their active participation in care provision and to support a transformation of power relations. In this consultation, such aims are not really evident in the exchange described.

On a first reading it might be easy to castigate the health-care professional for not providing the requisite support and understanding, and for not adopting the recommended facilitative approach. Caution is required because this exchange is a brief snapshot of what is likely to be a broader relationship, perhaps spanning many years and informed by many other exchanges. However, it is possible to

discern some of the material-discursive practices that help to accomplish this instance of self-management support. The review of blood-glucose results is key and shows that the results are not within the ranges recommended by the clinic. Moreover, biomedical knowledge participates to highlight the risks to which this child is currently exposed because of his blood-glucose results. The child's lack of ability or willingness (it is not clear which, or if it is something else altogether) to adjust insulin doses also participates, as does the health care professional's move to 'sit back' from the consultation. The absence of the HbA<sub>1c</sub> result is also a significant influence as there is no 'reliable' indicator, in biomedical terms, of the current bodily impact of the blood-glucose results. The consultation proceeds.

P<sub>13</sub> gives him the diary and says why don't you make your own plan. Some notes are jotted down. P<sub>13</sub> adds a few more. P<sub>13</sub> says, "If you don't want to change we can't make you." P<sub>11</sub> joins us. P<sub>13</sub> carries on, "What should I do? Should I shout at you and say this is terrible? Should I pat you on the back and say, what a shame you've got diabetes?"

(Field Notes, December 2012)

In the extract above, the diary participates, and perhaps, once it is handed over by the health-care professional, works to locate responsibility for the plan with the child. Amplifying this shift, the professional withdraws further by saying, "If you don't want to change, we can't make you." In one sense the invitation to the child to 'make your own plan' certainly makes the child central to the planning, but the somewhat confrontational questions effectively undermine any obvious sense of partnership. Together these two extracts illustrate the troublesome notion of empowerment that seemed to permeate many consultations. At this point, the child's parent joins the consultation.

The patient's mum joins us and there is talk about the patient's responsibility to carry out the plan. P<sub>13</sub> says, "You need action to get satisfaction." The patient is asked to tell his mum what has been

discussed, and what should be written in the GP letter. Some additional family stressors are discussed. P<sub>13</sub> advises regular chats between the patient and mum so they can both keep an eye on the blood-glucose readings.

(Field Notes, December 2012)

With the parent in the room, there is continued effort to have the child participate in particular ways. The child is to be responsible, to inform the parent and to word the letter to the family doctor. Wider family issues participate here too, including additional demands on the parent and the relationship between the parent and the child with diabetes. Right at the end of this consultation, there is a barely noticeable shift that involves the parent in the diabetes care. After such a lengthy focus on the child's role in caring for his own condition, this small intervention from P<sub>13</sub> extends the duty to manage blood-glucose levels to both parent and child. Following this last minute invitation to the parent, the family leaves, and the professionals talk about the consultation.

The family leaves. There is ongoing discussion between P<sub>13</sub>, P<sub>7</sub> and P<sub>11</sub> about the lack of parental involvement – “why isn't she helping, monitoring – she doesn't care.”

(Field Notes, December 2012)

This abrupt shift in emphasis belies the earlier overwhelming focus on the child. Inviting the child to lead the planning of care, to set his own priorities and to articulate his own judgement about the importance of self-managing diabetes worked to exclude the parent. This exclusion persisted not only while the parent was physically out of the room, but also was maintained even when the parent joined the consultation. The child is given a clear role as an independent decision maker, and he is expected to self-manage according to his own priorities and

preferences. Yet there are also implicit requirements to care for blood-glucose levels. Moreover, there are powerful expectations of this parent, which are not expressed to her. Indeed, not only are these expectations kept from her, that which is communicated to her actually contradicts what the professionals later say they think is required. Consequently, the opportunity to attend to and explore the importance, challenges and possibilities of parental support is lost entirely.

These extracts show multiple sociomaterial influences on the accomplishment of self-management support. In the consultation described, professional efforts at empowering such as sharing decision making and being led by the child's preferences intra-act with biomedical knowledge of risks, absence of biomedical knowledge of immediate bodily state, practices of blood-glucose reviewing and the written diary of instructions, predefined health-care aims, parent-child relations and the capacities of the child as well as the parent. For the professionals, there are significant challenges in negotiating and engaging such a dynamic arrangement. Much like the consultation discussed above, a similar event unfolds in the following extract, with a different family on the same day.

There is a long discussion about the need to make changes, the patient must want to improve things, how concerned everyone is, how things really have to change, so he will feel better and be healthier. They agree. When they leave, anger is expressed towards the parent. They ask how she can behave this way, she has never been able to help him manage his diabetes, there have been concerns on and off for many years since diagnosis when he was very small. There is exasperation and frustration about why people don't manage their diabetes when it is so important.

(Field Notes, December 2012)

What is perhaps more evident in this extract than in the previous one is the nature of the difficulties the professionals talk about for themselves. The issue in

the account above is much less about lack of understanding of the experience of living with diabetes, for example, and much more about being preoccupied with fear of serious health-care consequences for children. Such expressions of anger towards the parent, reserved for professional ears only (and for me, as a researcher), collide with expressions of frustration towards the children themselves and participate too in the ongoing accomplishment of self-management support.

Following Gherardi (2010), one question to ask of the analysis here might be, how does empowerment emerge from the recursiveness of the activity? This form of questioning allows comparison of 'the rhetoric of the practice's use with the situated uses that emerge from its being practised' (Gherardi, 2010, p. 505). One important answer to this question is that, in fact, empowerment does not emerge: empowerment is not an accurate description of that which emerges from the situated practice broadly described as empowering. Instead, that which emerges might be more accurately described as coercive persuasion.

Introducing the term 'coercive persuasion' might be provocative but one advantage is that it draws attention to the pressure exerted by the professionals as they support self-management. The term also draws attention to the paucity of choices for children and parents as they navigate life with type 1 diabetes: the consequences of not self-managing are stark, because children cannot survive without appropriate and regular administration of insulin. Such dependence on insulin exerts force for children, for parents *and* for health-care professionals and on the arrangements for supporting self-management.

In the clinic consultations presented, the notion of empowerment seems to accomplish something unintended: the work of supporting self-management loses its focus. The professionals shift their engagements back and forth between child and parent, and these shifts in emphasis are not always declared or even tangible for the child and parent concerned. Expressions of anger and fear are reserved for colleagues. Predefined biomedical aims collide with attempts at shared decision making. I consider the educational implications of this muddle in

terms of educational interventions and resources, taking account of some particular working practices but not others in chapter eight. For now, I move to examine further problems with using the notion of empowerment in the work of supporting self-management.

### **Empowering within safe limits**

According to the policies and guidelines already indicated, empowerment aims to transform power relations and to enable patients to exercise greater control over the management of their own health care (Wallerstein, 2006). However, the nature of health, the details of health care and the role of evaluative judgments about what constitutes adequate management remain somewhat ephemeral in this definition. Through extracts from conversations and observations, I am showing that the every day accomplishment of these aims is extraordinarily challenging. Insulin is a potentially dangerous medicine: mistakes are both easy and costly. In the case of diabetes, devolving health care to children and their families entails risks, and it is these risks that are considered in this section. The health-care professional in the next quote speaks about trying to 'let go' of concerns about safety.

A lot of the medicalisation of routine diabetes management is our security blanket as professionals. It's about us saying we understand this and you don't have to. And where this became apparent to me was when we first had patients with [insulin] pumps who really got it and were doing a great job. And you would be sitting in clinic with all of these boxes on the computer screen that you have to fill in, and I just suddenly thought, "Sod it, why am I doing this? I don't need to know. I need to be cool with them doing it." It's like your child leaving home and you stop asking them if they've got clean socks on. You just have to let it go.

(P9, Interview, October 2012)

This account explores the question of how much monitoring is really needed and how much the professionals need to be involved in overseeing the management of diabetes care. Here, the emphasis is on facilitating children and families to manage as independently as possible. Empowering entails the professionals 'being cool with it': devolving responsibility, in part, by not asking too many questions and not completing too many forms.

However, the inescapable issue is that the risks of harm from insulin errors are persistent. The following quote is from the same health-care professional later in the same interview, and it helps to illustrate the dilemma that the professionals must navigate. P9 is explaining that adjusting insulin doses can sometimes lead to serious problems if children and parents make the wrong decisions.

They sometimes mistakenly believe that it's safer to increase the long-acting insulin than the short-acting insulin, because I suppose their thought process, which is logical, is that a rapid acting insulin is a bit more dangerous because it's a bit nipper [faster]. "It might cause hypos so therefore we're not going to touch that, but we'll put the long one up because that's really gentle and long acting, and nothing much is going to change." And that's fine until they get a big imbalance, and they end up on tonnes of basal, and not a lot of short, and the problem then is that if everything stays the same every day, it all goes along very nicely. Then wee Johnny does some exercise or misses his lunch and has a catastrophic hypo.

(P9, Interview, October 2012)

It is possible for children and parents to make a series of adjustments to insulin doses without any support from the health-care professionals. Unless children or parents actively choose to telephone and ask for advice, an imbalance between long-acting (basal) and rapid-acting (bolus) insulin rates like the one described here will only be recognised at a routine clinic appointment. These appointments

only happen once every three or four months, and many insulin-dose adjustments could be made in between appointments. Consequently, the professionals rely on children and parents to either make the correct decisions or to telephone for guidance. The risks are significant: a catastrophic hypo as described here might mean the child becoming suddenly unconscious – possibly with seizures – and subsequent hospital admission as a result.

In paediatric diabetes, increased patient participation and devolved decision making is not only about rebalanced interpersonal power relations. For the professionals, a sizeable dimension of the work entails knowing the balance between letting children and parents proceed without too much intervention and yet, simultaneously, accounting for the limits of children's and parents' capacities to self-manage. Supporting self-management is material-discursive work: the materiality of medicines, specifically insulin, exerts force and makes demands; bodily responses to blood glucose and the availability or absence of biomedical knowledge all participate too.

### **Empowering: knowing in practice**

This section draws on Gherardi's (2010, p. 505) approach to examining the 'knowledgeable collective action that forges relations and connections among all the resources available and constraints present'. Again, knowledge is construed not as an object but as active engagement. Codified information about empowerment strategies, for example, cannot simply be applied; rather, knowledgeable practice entails engaging these strategies 'in situ' and adapting and adjusting as required. The following extracts are examined to show the ways in which efforts at empowering entangle with the biomedical concerns that are so prominent in paediatric diabetes. In particular, I focus on the problems arising when either children or parents (or both) are reluctant or decline to engage with particular professional recommendations. In these circumstances, professionals must discern the nature and extent of specific risks and proceed in ways that prioritise the safety of the child. In the following extract, this team member recounts several major challenges in the care of a young girl.



P8: So this girl, while I think she's kind of the problem, I think certainly the mum is as well. [...] [Patient's name] has admitted to me that she omits her insulin, but her mum is supposed to have full responsibility. Em, but she's been in ketoacidosis a few times. Her HbA<sub>1c</sub> is at the moment 100.

(P8, Work Discussion, January 2013)

In this account, the medical history is invoked to explain the severity of the concerns: the HbA<sub>1c</sub> is much higher than the recommended clinic target of 59, and there have been multiple incidences of diabetic ketoacidosis (a potentially fatal medical emergency resulting from lack of insulin). Both of these considerations confirm the ongoing risk of significant harm. This extract also reintroduces the troublesome blurring of focus between the child and parent as both are implicated in the success or failure of the plan for diabetes care. P8 continues, explaining some of the background to recent events.

She's 14, roughly, so she's been, you know, while we've been having these conversations she's been 13, 12 or 13. [...] I said, "You need to get your HbA<sub>1c</sub> under 80 otherwise we will involve social services." And it [the HbA<sub>1c</sub>] was, it actually went up.

(P8, Work Discussion, January 2013)

Having first specified the age range of the child, the doctor introduces limits to autonomy in self-management, and takes account of biomedical concerns in order to modify the aims of supporting self-management. Here again, what emerges is more accurately described as coercive persuasion rather than empowerment. First, diabetes care must proceed in such a way that the HbA<sub>1c</sub> measure is reduced below a defined threshold. Second, the consequences of not managing in this way are named: the professionals in the clinic will seek the involvement of social work services in order to protect the interests of the child.

Despite this approach, blood-glucose control worsened, and the next extract describes an encounter with the child herself.

[She said] “I was young and I'm, I think I'm more responsible now and I understand the problem.” So I said, “Fine, we'll put you on basal-bolus, here are some starting doses, keep in touch with me every week, here's my mobile number, you can text me whenever you like, you know you can get your mum to do it if you feel more comfortable, that's fine.” And I haven't heard from her.

(P8, Work Discussion, January 2013)

The focus moves from the parent's inattention to the child's capacity to self-manage. Here, there is interplay between different flows of information and knowledge as the health-care professional tries to introduce a different care regimen in collaboration with the child, all the while instigating a carefully tailored means of monitoring progress. There are efforts at enabling the child to participate in the decisions about her insulin regimen and to shape the plan for her diabetes care, yet these efforts are constrained by the very specific and non-negotiable aim of reducing HbA<sub>1c</sub>. The child is given the job of communicating with the health-care professional, so that blood-glucose results and insulin doses can be reviewed and adjusted with the guidance of the clinic. However, this approach has not been successful, and the following extract shows that relations with the family remain difficult.

We have threatened her over the last six months with social services and mum's threatened me, she said, “You can't do this, I'll get my lawyers onto you.” And I said, “Fine, you know, you go and do that, do what you need to do. Her HbA<sub>1c</sub> is appalling and nothing works so, I'm only looking out for the interests of your daughter.”

(P8, Work Discussion, January 2013)

It is not easy to reconcile the rhetoric of empowerment with the situation that unfolds in these extracts. In circumstances like the one described, articulating the work of supporting self-management as ‘empowerment’ actively obscures the nature of that work. Moreover, this is not a question of academic fields: conceptualisations of empowerment from education and community development literature make no more sense here than conceptualisations of empowerment from diabetes health-care literature. The rhetoric of empowerment simply does not correspond with the material-discursive practices of supporting self-management relayed in this chapter. Thinking otherwise, with different concepts, becomes possible in part by recognising the extent and nature of this dissonance. Such thinking, and experimenting with different possibilities, forms the basis of chapter eight.

### **Empowering, risk and protection**

The dialogue reported in the following sections follows two professionals deciding on a response to the non-attendance of the same child and parent already discussed in the preceding pages. The difficulties they encounter show the challenges of knowing the most appropriate and proportionate response. The work of supporting self-management is highly specific, and constituted of and through multiple contingent factors in a given instance. This extract begins as the health-care professionals realise the family has not arrived for the clinic appointment.

P8: I don't think we can hit the panic button until we know what has happened, you know, there could have been a death in the family, I don't know, they're innocent until proven guilty.

P11: To be honest, even if there was a death in the family, they could have at least phoned.

P8: No that's true, but that is actually not what we're about here, we want to make sure her blood-sugar control is better, and her engagement with us is secondary. If she has an HbA1c of 60, and she hasn't contacted us, I don't care.

(Work Discussion, January 2013)

The decision to be reached relates to whether this child and parent can continue to manage their diabetes care without greater intervention from the professionals in the clinic. In the first sentences P8 establishes that he prefers to approach this decision carefully; that there can be no assumptions without solid grounds. The HbA1c result is specified as concrete information that will help guide the professional response. Moreover, adequate blood-glucose control is the only priority here. If the HbA1c result is acceptable, the question of the family keeping the clinic informed becomes irrelevant. As the conversation continues, the second team member reintroduces the issue of contact between the child, parent and professionals as reasonable grounds for concern.

P11: But what does all that suggest to you? That she's not been in touch and she's not come to clinic and her HbA1c is higher than 100?

P8: [...] but I don't have proof, and just being skeptical doesn't make it, you can't hit the panic button, because once you've let the genie out of the bottle, once you've gone down the social work route—

P11: I know.

P8: You can't reel this back in.

(Work discussion, January 2013)

Knowing the most appropriate and proportionate response entails curating information about the child's state of health, the child's ability to undertake a range of key tasks, the parent's capacity to oversee and undertake a range of key tasks and the calculated medical risks inherent in diabetes care. Finally, for P8, knowing the most appropriate and proportionate response also depends on the provision of concrete proof that confirms the present quality of the child's overall blood-glucose control. Also implied in this dialogue, but not explicitly stated, is the professionals' worry about events spiralling out of control. Discerning the extent of force required plays out here as a careful weighing of actual and possible circumstances, and there are repeated efforts to reach consensus. The dialogue continues as the professionals move towards formulating a response to the missed appointment. The work of sorting through possible actions is difficult, and there is some hesitation about how best to proceed.

P11: What are you going to do then if she doesn't come? I'm assuming she's not coming this morning.

P8: I will text the mother and say, we were expecting you in clinic today.

P11: Would you phone her or text her.

P8: Em—

P11: I think you might be better to try and phone her.

P8: Yeah, maybe, I was just thinking, you know, if I text her, I can just say, 'Look we were expecting to see you in clinic today, clearly this is a priority, and we are looking to make sure things are better, and if not, as we have discussed, we have to involve other agencies.' She would know what that means. I don't think, if I sent you that text, she won't ignore me.

(Work Discussion, January 2013)

For now, the work of supporting self-management is focused firmly on engaging the parent rather than the child. Two proposed actions serve to incorporate an additional delay before formally notifying social work services. First, the intention to send a text message entails awaiting a response from the parent. Second, the emphasis remains on ‘making sure things are better’, and so there will be a need to gather further key information (such as the HbA<sub>1c</sub> result). In the extract below, P8 makes explicit the intention to wait a little longer.

P8: I don't think we lose anything by waiting 24 hours to see what happens, but, she's on a, what do you say? A shoogly nail.

P11: I can't believe they didn't come.

P8: Well, I think what we'll do is we'll, I'll ask P9 or [another colleague] to see them next week, because even if I see them on Wednesday, I'm away, and then it's hard to follow up. I think it would be easier. I mean, I could sit in with P9 and hand them over, because someone's going to have to follow this up next week and the week after and the week after that, so I think P9 would probably, I mean P9 might be appropriate—

P11: Yeah, to try and go down that route—

P8: Because I think this mother will try to sue us.

(Work Discussion, January 2013)

A ‘shoogly nail’ refers to an unstable fixing that is liable to come unstuck. The expression is a Scots colloquial one, more usually ‘a shoogly peg’. Used in this extract, the suggestion is that the situation is precarious, and the formal notification of social work services might yet be needed. The involvement of a colleague attends to the complication of P8's planned annual leave, and perhaps also helps alleviate some of the pressure of working with a complex set of circumstances. A hitherto unarticulated aspect of this pressure appears just at the end of the conversation: ‘this mother might sue us’. There is a sense of enormity

about the decisions, an understanding that the consequences might be dramatic, both for the family and for the clinic.

The repeated movement towards a forceful response with this family, and then the work of de-escalating that response, suggests a desire to get the decision just right. The importance of ongoing contact and steady oversight of blood-glucose control are evident in the statement about following up week after week. For the professionals, collaboration both with the family and with colleagues serves to reassure and to mitigate the need for coercion.

P8: Within the hospital with liaison, we have very good links, and we have control, but what happens is liaison then pass it on to a local team and once that happens then you're not sure. Well, usually they're too soft, because they don't appreciate the life-threatening nature of the condition, but sometimes they go in heavy, you know, and that, it's a fine line sometimes.

(Work Discussion, January 2013)

The fine line that P8 talks about is the carefully nuanced accomplishment of protecting the health and interests of the child, engaging the child, engaging the parent and sustaining a working relationship between child, parent and professionals. Local social work teams are described as having limited understanding of the biomedical concerns that are so prominent in paediatric diabetes care, and this adds to the unpredictable consequences of introducing external agencies. The professionals in this diabetes clinic are grappling with concerns that those external agencies might make decisions and take actions that the clinic team would not themselves recommend. These concerns are important participants in the entanglements that constitute knowledgeable professional work here. In the last extract of this chapter, one health-care professional gives a vivid thumbnail sketch of some of the other conditions that influence the work of supporting self-management.

I can only imagine what it must be like to be 12, 13, 14. It's hard enough being in puberty, let alone with a life-threatening condition that everyone's, you know, telling you that you need to do better all the time. My heart really goes out to these kids. [...] And there's a mum, her child with diabetes, you know, metaphorically I just want to hug a lot of the parents here. And the young people, because I just think, you know, you, I know that coming to clinic is like an interrogation. But we have 15 to 20 minutes three times a year to try and find out what's going on.

(P8, Work Discussion, January 2013)

This sensitive understanding of the daunting collection of tasks devolved to children and their parents is another important consideration in examining the accomplishment of self-management support. There is recognition that children and parents might have mixed feelings about engaging in multiple complicated self-care tasks (Coffen and Dahlquist, 2009) and that the relentless nature of these self-care tasks might impact on well-being (Sullivan-Bolyai et al., 2003; Mol, 2008). This recognition influences the work of supporting self-management, perhaps sometimes slowing moves to exert pressure on children or parents, perhaps sometimes softening the nature of pressure exerted.

What is also embedded in this narrative, alongside the empathy for children and parents, is a sense of anxiety and urgency about the need to establish professional understanding. The clinic consultations are conveyed as extremely time-limited, and the word 'interrogated' is a powerful expression of the relations between professionals and families.

This last section has shown that the work of supporting self-management is highly specific, and is constituted of and through multiple contingent factors in a given instance. The work of sorting through possible actions is difficult, and professionals move back and forth, escalating and de-escalating the amount of pressure on the child and on the parents. The overall aim seems to be the



accomplishment of a delicate balance: protecting the health and interests of the child, engaging the child, engaging the parent and sustaining a working relationship between child, parent and professionals.

### **Chapter summary**

This chapter has argued that the notion of empowerment, even when acknowledged to be heterogeneous, is not an accurate articulation of the professional work of supporting self-management. Drawing on Gherardi's (2006; 2010; 2012) approach, and on data extracts from my time in City View Hospital, I have shown that the everyday material-discursive practice of supporting self-management in paediatric diabetes is not predominantly focused on promoting the autonomous participation of children, nor on negotiating shared aims with children. Instead, it is much more concerned with the highly complicated ongoing discernment of safe parameters within which children and parents might reasonably be allowed to contribute to diabetes management.

The term 'coercive persuasion' seems a more accurate description of the work of supporting self-management. Although potentially provocative, the term does at least attend to the paucity of choices for children and parents as they navigate life with type 1 diabetes. The term also recognises the pressure exerted by professionals, and the pressure on professionals, as they seek to ensure children have appropriate and regular administration of insulin.

Examining knowing-in-practice (Gherardi, 2006; 2010) shows that the work of supporting self-management emerges in and through a range of highly specific intra-actions (Barad, 2007). This work is not simply about rebalancing interpersonal power relations. In a given instance, this work of supporting self-management is constituted in and through specific material-discursive practices that comprise, for example, biomedical concerns, the specific self-care capacities of children and parents, the specific available care regimens, the specific risks of harm from insulin errors, the specific possibilities for collaboration and the specific pressures exerted.

While much of the rhetoric in health-care literature, policy documents, educational resources and guidelines for health-care professionals aspires to promote the autonomous participation of those with long-term conditions, this aspiration is especially challenging for professionals working with and between children and their parents. The muddled conceptualisation of the work as ‘empowerment’ serves to contribute a highly problematic blurred focus. Consequently, it is not always clear whether the work of supporting self-management is focused on the child with diabetes or the parent who supports the child to self-manage. Indeed, the data extracts presented in this chapter illustrate the fluid movement of focus between child and parent, even from moment to moment within the same consultation.

The troublesome notion of empowerment obscures the particular nature of the work of supporting self-management. What is so important is that because the nature of the work is obscured, the educational interventions and resources intended to support knowledgeable practice often fail to address or even to acknowledge the kinds of challenges illustrated in this chapter. The implications of this assertion are discussed in chapter eight, next, towards considering what forms of educational initiatives might best facilitate the accomplishment of professional support for self-management in paediatric diabetes.

## 8 Implications for Professional Education

For education, questions of study hover around finding the points for potential intervention and transformation. For example, rather than asking how teachers might better motivate or deliver instruction to learners, these [sociomaterial] orientations might ask: where are the weak links in the networks that entrench particular behavioural patterns; where are the ambivalences that open spaces for new possibilities; or where are the perturbations that can be amplified in the complex adaptive systems of a classroom, community or human mind?

(Fenwick et al., 2011, p. 170)

I turn now to consider the insights generated across previous chapters specifically in terms of implications for professional education. In this chapter I am not focused on how best to support self-management in paediatric diabetes. Instead, I am focused on the ways in which educational interventions might best help health-care professionals learn the work of supporting self-management in paediatric diabetes.

This quote is one that has helped me to read across the insights generated through my research. Teasing out just what chapters five, six and seven can tell us about the educational needs of health-care professionals has entailed asking the kinds of questions posed above. As Fenwick et al. (2011) counsel, sociomaterial research orientations draw attention to such happenings as network links, ambivalences and perturbations. By focusing on the sociomaterial arrangements for learning, there is scope to examine the enabling and constraining forces that contribute to the materialisation of particular effects. In examining such forces, there is increased scope for interference that generates learning, and the different ways of interfering become more visible. Following what might by now be termed a *tradition* of sociomaterial researchers

investigating professional education (see, for example, Sørensen, 2009; Fenwick et al., 2011; Mulcahy, 2012; Hopwood, 2014; Nerland and Jensen, 2014; Zukas and Kilminster, 2014), I am drawn to think in terms of sensibility to dissonance, durable relations, pliable connections and tensions. These dynamics can help to indicate ways of perhaps disturbing or modifying particular influences in order that alternative learning assemblages might develop and endure.

In this chapter I argue that a key role for professional education in this complex problem of health care is to help develop a methodology of workplace learning. Educationalists and educational research can make a worthwhile contribution because health-care professionals in frontline services are not, by and large, focused on education and learning. These health-care professionals, unsurprisingly, are engaged in the provision of health care. In City View Hospital, for example, the focus is on doing the work of supporting self-management, and although there is thoughtful awareness of the need to adapt and respond to the enormous challenges faced, detailed consideration of potential workplace pedagogies is not a foremost consideration.

A methodology of workplace learning, developed in collaboration with health-care professionals in frontline services, could help to identify the potential points of intervention. In the following pages I explore what a methodology of workplace learning for professionals might be in this case, and show how it might help to address the issues raised in preceding chapters. I show that such an approach could promote recognition of learning strategies already in place, making it possible to strengthen and protect the resources required for their endurance. Such an approach could also help to augment existing learning strategies, by complementing these ongoing activities with additional pedagogical interventions. In particular, I argue that a prerequisite for such an approach is that it takes critical account of the nature of the work and the specific practices that are to be the focus of learning. Otherwise, as I discuss in the final sections of this chapter, pedagogical interventions are less likely to help professionals respond to the workplace problems they encounter and more likely to create problems by obscuring the nature of the work.

## **The role for education in complex problems of health care**

In this section I clarify the ways in which I am thinking about education in these questions of how best to help health-care professionals learn to support self-management in paediatric diabetes. I develop the warrant for a methodology of workplace learning by bringing together the workplace problems explicated in chapters five, six and seven, and by emphasising the learning struggles (Fenwick, 2008) embroiled in those problems. I show that examining the fine-grained details of what health-care professionals actually do in their everyday work of supporting self-management helps to make clear the very nature of that work. Importantly, recognising the nature of the work raises significant questions about both learning and also about practice in this case.

### **Professional learning**

In thinking about the educational interventions that might best enhance health-care professionals' learning; therefore, my focus is on what some (see, for example, Eraut, 2004) call informal learning that happens in workplaces. As a reminder, the definition of professional learning that I employ is Fenwick's (2008, p. 19): 'expanding possibilities of flexible and creative action in contexts of work'. In this study, I conceptualise professional learning as a phenomenon that unfolds in everyday work practices; an emergent phenomenon that is an effect of what Barad (2007) terms 'intra-acting' human and non-human forces. However, thinking with such conceptualisations can create challenges for efforts to structure pedagogical interventions (Johnsson and Boud, 2010): if learning is construed as situated, embedded, embodied and contingent on specific sociomaterial arrangements for work practice; then, what is entailed in pedagogy? For Fenwick and Landri (2012), such sociomaterial construals of learning call for corresponding recognition that pedagogy might be similarly uncertain and contingent. A question I have found eminently useful in my engagement with these ideas is Mulcahy's (2012, p.127): 'what needs to be assembled in order for learning to manifest?' This question, along with the

concepts described, helps to direct attention not only to what is assembled, but also to the potential for making particular learning assemblages more likely or more durable.

When I talk about educational implications, therefore, I am talking about the workplace pedagogies that might be designed and employed to complement and augment such learning. Such pedagogies might include, for example, intentional and indirect guidance that can be accessed as part of everyday work, and the ways in which workplaces afford opportunities to participate in work activities (Billett, 2002). Technologies themselves have also been recognised as inherently pedagogical (Mathisen and Nerland, 2012) because of the ways in which they organise and curate access to knowledge and because of the ways in which they often specify a particular order of tasks to be undertaken. Given the range of understandings that accrue to this term ‘pedagogy’, it is worth pausing at this point to explain the way in which I use it, before going on to the specific implications of my study for enhancing workplace pedagogies.

### **Pedagogy**

Pedagogy, following Zukas (2006), can be considered more than a narrow focus on instructional techniques. Instead, pedagogy can be considered ‘a critical understanding of the social, policy and institutional context, as well as a critical approach to the content and process of the educational/training transaction’ (Zukas and Malcolm, 2002, p. 215). Such definitions highlight the need to examine the purpose of workplace pedagogies as well as their nature and content. Moreover, the effects that workplace pedagogies have on the wider world are also essential considerations (Fenwick and Landri, 2012).

In the context of supporting self-management in paediatric diabetes, workplace pedagogies involve health-care professionals who are no longer in initial pre-registration programmes of education. In City View Hospital, the nurses, doctors and dieticians brought varying levels of clinical experience, and none was newly qualified. Such absence of formal programmes of education, which might offer

more or less structure for learning strategies, and might organise learning opportunities into curricula, opens up a space. The gathering of learning strategies that helps these health-care professionals learn to support self-management in paediatric diabetes evolves gradually, over time. Workplace pedagogies grow organically, jostling for space among various competing work pressures and commitments, and settling, perhaps provisionally, into forms that fit.

### **Scrutinising the arrangements for learning**

Scrutinising the arrangements for learning in work helps to make visible the particular gatherings of influences that exert force on professional learning as it unfolds. For example, one key insight is that commercial companies exert influence: the proliferation of technological change in paediatric diabetes, and the increased provision of insulin pumps to children, is supported by insulin-pump manufacturers' engagement in health-care professional learning. One important question might be: to what extent is it assumed that highly complex and expensive technological care regimens are the optimal approach to caring for paediatric diabetes, and to what extent do educational interventions offer scope to explore and interrogate any such assumptions? Similarly, even although there is not a formal educational programme focused on supporting self-management in paediatric diabetes, there is a national approach to the development and provision of educational resources intended for use in the workplace; one example is the online resource developed by NHS Education for Scotland, mentioned in chapter one and discussed more fully later in this chapter. The nature, purpose and effects of such arrangements for learning warrant scrutiny.

Through such scrutiny, a key aim of this chapter is to show what can be understood from examining the workplace problems and evolving pedagogies, in order to make recommendations for a more coherent approach to enhancing learning. Otherwise, as Fenwick (2008) notes, professionals are forever required to reinvent the wheel, through cycles of trial and error. In calling for a more coherent approach, I advocate an approach to enhancing learning that is more

carefully aligned to the learning struggles encountered and that better shares knowledge about workplace pedagogies among health-care professionals.

### **Learning struggles**

The workplace problems that professionals encounter can be considered as problems of learning (Fenwick, 2008). Such a move is important, because it helps to highlight a number of significant issues that are often otherwise ignored. For example, workplace problems might not be recognised as problems of learning at all but instead construed as problems of policy implementation. In this way, professionals might continue to grapple with challenges, but the informal learning that unfolds in everyday work is rendered invisible (Boud and Middleton, 2003). The point here is not that all workplace problems are problems of learning. Rather, the point is that exploring problems with a sensibility to issues of learning sometimes opens new lines of inquiry and new scope for intervention.

Recognising workplace problems as problems of learning helps to draw attention to the learning struggles (Fenwick, 2008) that are in play as professionals meet those challenges and respond. Examining the learning struggles, in turn, helps to increase the scope for pedagogic intervention (Boud and Middleton, 2003). More than just an increase in scope however, examining the workplace problems as learning struggles can help to ensure that pedagogical interventions are attuned to the nature of the work. This point is important: although knowledge about workplace problems can quickly become knowledge about workplace pedagogies (Fenwick, 2008), what I am showing in this thesis is that if the available knowledge about workplace problems lacks fine-grained detail and is indeed a particularly and unwittingly partial knowledge, then the corresponding educational interventions are highly likely to miss the mark.

### **Workplace problems**

Looking across chapters five, six and seven, I draw attention to a number of key workplace problems. To summarise, in chapter five these are related to the ways



in which digital technologies contribute to the reorganisation of health-care work, including by introducing new risks and by changing professional roles and responsibilities. In chapter six, I show the ways in which care regimens, including new care regimens, initiate what Knorr-Cetina (2001) calls epistemic work for the health-care professionals involved. In chapter seven, I explore the ways in which calls to empower people with long-term conditions inadvertently obscure many crucial dimensions of the work of supporting self-management in this case.

My focus, of course, is on the learning struggles embroiled in those issues. For example, Fenwick (2008, p. 18) notes that new technologies are ‘fundamentally changing what and how people learn in work’; in my research, digital insulin-pump technologies are doing just that, as health-care professionals figure out how best to support children, and their parents, to self-manage with these new devices. As I have shown, the impact of technological change is not simply restricted to learning how to operate these new devices. On the contrary, the implications are much wider.

New technologies demand new technical skills and capabilities, not only in terms of how to operate specific devices but also in terms of accommodating and adapting to specific devices. For example, the insulin pump as a care regimen is more than just the device itself but extends to the associated software programme that records and shares information about blood-glucose levels and insulin administration as well as to the particular alterations in self-management support required. Such alterations include, for example, the changed approach to treating low blood-glucose levels, which is prompted by the different way in which insulin pumps and canulas infuse insulin into bodies when compared with injections and needles. The very principles of health care in this case are changed by the participation of new technologies, as the health-care professionals in City View Hospital grapple with new software programmes, new risks and new bodily responses to infused rather than injected insulin.

These impacts of technological change are interwoven with the impacts of privileging self-management as a response to rising numbers of people with long-

term conditions. Emphasising personal responsibility for health, and recognising patients as experts in their own health care, entails more or less devolution of roles and responsibilities formerly restricted to health-care professionals. At the same time, as I have shown in this thesis, the complicated care regimens and complex technologies combine to create new risks. For questions of professional learning and workplace pedagogies, the point to register is that health-care professionals are increasingly called upon to undertake new tasks. In particular, professionals are engaged in gate-keeping access to new technologies in order that only those most able to manage safely will be offered insulin pumps. Professionals are also collaborating with children and parents in ways that balance children's developing autonomy, parental responsibilities, biomedical concerns and now also the affordances and constraints of digital diabetes technologies. Professionals select care regimens from among a growing range of options, and negotiate such selections with children and, where appropriate, their parents.

#### **(Re)defining the nature of the work**

Taking these insights together, I am showing that supporting self-management in paediatric diabetes is very much concerned with discernment. In particular, the study shows the centrality in practice of highly complicated, perpetual discernment of safe parameters within which children, and their parents, might reasonably be allowed to contribute to diabetes management. In examining the detailed, situated work of supporting self-management, I show that even although the health-care professionals in City View Hospital do make efforts to share decisions about diabetes care with children and with parents, and do also try to take account of the preferences of children in planning diabetes care, a multitude of other very important influences are also in play. The work of supporting self-management is not simply about rebalancing interpersonal power relations. Nor is it about necessarily promoting the autonomy of children with diabetes, in spite of the emphases in health-care policy literature and guidance. For example, I show that health-care professionals are also engaged in

considerations of biomedical knowledge of risks, and the presence or absence of biomedical knowledge of immediate bodily state. Health-care professionals are engaged in practices of blood-glucose reviewing and examining the handwritten diaries and software printouts as well as trying to take account of pre-defined health care aims, parent-child relations, the capacities of the child and the capacities of the parent.

I have shown that for health-care professionals, there are enormous challenges in negotiating and engaging such a dynamic arrangement of considerations. What is so important is that in current approaches to providing educational interventions for the professionals supporting self-management, often the challenges in this work remain unaddressed. Consequently, although the health-care professionals themselves evolve some strategies for learning, much of the policies, literature and guidance are poorly aligned to the specific problems encountered.

Without recognition of and response to the key challenges recounted, the clinic team is left to manage two significant effects. First, as Fenwick (2008) has observed, health-care professionals are compelled to struggle and to reinvent strategies for learning over and over again, perhaps repeating the mistakes of others and unnecessarily duplicating effort. Second, health-care professionals are encouraged to focus on those particular aspects of the work that *are* addressed through available pedagogical interventions, while other aspects of the work that are not addressed become invisible. I discuss these two effects, and the scope for developing workplace pedagogies, in more detail in the following pages.

### **Scope for workplace pedagogies**

Overall, this section moves to indicate what a methodology of workplace learning might entail and to show how such an approach might be useful. I begin by focusing on the learning strategies that have already evolved in relation to insulin-pump technologies and suggest ways in which these might be augmented. One particular phenomenon of interest in these existing learning

strategies is the participation of commercial companies, and I discuss the wider effects of such participation, including the role for critical pedagogical responses.

### **Recognising the work of coming to know insulin-pump technologies**

In City View Hospital, insulin pumps invited exploration and initiated considerable epistemic work on the part of the health-care professionals involved. One of the key learning strategies employed, as I showed in chapter five, was for individual professionals to spend time directly connected to an insulin pump, and to 'wear' the device for a few days. It is worth noting that such approaches have been critiqued (see Fox, 2010) for their disproportionate emphasis on the difficulties of impairment. These critiques argue that approaches such as spending a day in a wheelchair, or as if blind, simply 'deny the wide-ranging and fluid nature of disability' (Fox, 2010, p. 44). As a consequence, the strength and capacity for adaptation becomes minimised.

However, the efforts in City View Hospital were less focused on simulating the experience of living with diabetes and more aimed at coming to know the insulin-pump technology. This kind of embodied knowing through situated bodily practice has been explored by Prentice (2013) as a central way of coming to know in the field of medicine, and it was certainly valued by the professionals in City View Hospital. This approach offered them a way of experimenting, of becoming sensitised to the insulin-pump care regimen, perhaps in ways similar to Prentice's (2013) eloquent description of a surgeon:

Searing a line on the liver requires coordination of hands, eyes and instruments, as well as the ability to fluidly translate between two and three dimensions. Dissection of a tumour that lies deep in the liver requires the skilled use of the knife and simple bodily techniques that steady the surgeon's hands.

(Prentice, 2013, p. 12)

The pedagogical value of what Prentice (2013) calls haptics, or sensations of touch, and the physicality of such embodied knowing, resonates powerfully with the example of professionals' engagement with insulin pumps. In chapter five, I explained that P11 inserted a canula into her own abdomen, tried to accommodate the insulin pump's demands into her daily activities of eating, sleeping, socialising and showering and participated in its algorithmic instructions – all as a means of coming to know it. P11 explored the ways in which her own body met insulin-pump technology. Also important in this learning through direct engagement are the related activities immediately afterwards: for P11, having worn the insulin pump over a weekend, the opportunity to narrate experiences, to ask questions, to share concerns and to explore dilemmas yielded considerable further learning. It was these further explorations, with colleagues, that augmented her bodily coming-to-know.

Making the most of such informal strategies for learning requires that they are recognised and legitimised as pedagogies that support work. For Billett (2002), workplace affordances such as the potential for observing others, listening to others and contributing ideas are key aspects of learning in work. Supporting such learning by organising the arrangements for work accordingly, and creating spaces for what Johnsson and Boud (2010) call group-talk to explore problems or resolve issues, is much more likely to be possible if the pedagogical value of such activities is explicitly recognized, sufficiently resourced, and even rewarded. Otherwise, such activities might simply be overlooked and viewed as 'work' rather than 'learning in work' (Boud and Middleton, 2003). As a consequence, the specific arrangements that make this kind of learning possible might not endure.

### **The participation of commercial companies**

It is of note that the policy directive, Chief Executive Letter (CEL) 4, (Scottish Government, 2012) that mandated the rapid mainstreaming of insulin pumps made no provision for professional learning. The policy directive acknowledged that health boards across Scotland would need additional resources to cover the costs of purchasing insulin pumps, and also that children and parents would

need additional support to come to know insulin-pump care regimens, but there was no recognition that the health-care professionals themselves had learning needs that required substantial attention and resources.

One of the significant aspects of this absence of a coherent approach to supporting professional learning in this case is that the commercial companies who manufacture and sell insulin-pump technologies have intervened. In some ways this arrangement seemed to work well in City View Hospital. The commercial companies were able to make a small number of insulin pumps available for the health-care professionals to use over weekends; thus enabling the bodily practice discussed above. Representatives of these commercial companies were also able to visit the clinic when needed; for example, as I described in chapter five when a different type of waterproof insulin pump was required for a particular child. Because different pumps often have different functions and capabilities, as well as different software programmes for recording and monitoring blood-glucose levels and insulin administration, it was helpful for the staff team to have this kind of pedagogical support from the commercial companies involved. It is perhaps also likely that commercial companies might be better placed than more traditional educational institutions to develop and deliver options for workplace learning quickly and flexibly, partly because they are able to anticipate and accommodate technological progress as it pertains to their own products.

However, reliance on commercial companies raises many questions about potential conflicts of interest. As I have shown throughout this thesis, and many others have argued before me (see, for example, Pols and Willems, 2010; Oudshoorn, 2011; Fenwick et al., 2014; Halford et al., 2015; Fenwick and Edwards, 2016), digital technologies are reconfiguring professional roles, practices and responsibilities. Digital technologies not only reorganise the arrangements for health-care work, including the work of supporting self-management, but the algorithmic instructions encoded in these technologies alter the nature and scope of professional decision making. In chapter five I have shown, for example, the ways in which professionals engage in selective delegation of responsibility to

insulin-pump technologies by choosing to work with or around the flows of instructions issued.

For my focus on workplace learning, the tensions and questions relate to what Mathisen and Nerland (2012) have called the inherent pedagogies of technologies, so called because technologies organise knowledge, specify particular tasks to be undertaken and stipulate an order in which things must be done (Mathisen and Nerland, 2012). Such recognition calls attention to what is being taught and learned as technologies participate in the organisation of professional practice, and asks whose interests are prioritised in the specification and sequencing of tasks and in the associated pedagogies. The role for educational intervention in this case might, for example, follow Fenwick and Edwards' (2016) suggestion of promoting critical thinking about the effects of technologies, including their marketing and production, and the particular values inscribed in such technologies. However, the extent to which the opportunities provided by commercial companies might actually afford this kind of critical thinking is highly questionable.

It is not so much the participation of commercial companies in professional learning that is problematic; collaboration among technology developers and health-care professionals, as well as children and parents, might generate highly novel insights for all. Rather, it is the absence of a coherent approach to addressing the wider issues that is so concerning. The point is that the inherent pedagogies in diabetes technologies are, for now, largely in the control of commercial manufacturing companies.

### **Learning the specificities of supporting self-management**

As I mentioned earlier, if education as workplace learning is to be effective, it must begin with clear recognition of the nature of the work and the specific practices that are the intended focus of learning. Conversely, approaches to workplace learning that misunderstand or misconstrue the nature of the work are highly problematic. There are two reasons for this. First, and perhaps most

obvious, if the nature of the work is misconstrued, then the pedagogical interventions are likely to be misaligned. I have already shown in chapter seven, and I discuss further in this section, the troublesome notion of empowerment in this case and the way in which it obscures the highly complicated work of discerning safe parameters within which children and parents might reasonably be allowed to contribute to self-management. As a consequence, many of the learning struggles related to this complicated work remain unaddressed.

To explain further, I return to the example of the national online learning module that was developed for use in the workplace. Divided into four sections, this module (NHS Education for Scotland, n.d.) focuses on Building Partnerships, Sharing Decision-Making, Enthusing and Empowering, and Facilitating Enablement. Each section lists the knowledge and skills required, so, for example, the section 'Enthuse and Empower' states that health-care professionals should know 'how to use behaviour change theories and strategies, understand how to use health facilitation and coaching techniques, and have knowledge of how to tap into the person's existing skills, coping strategies and strengths'. This generic approach to supporting self-management, while not wholly unhelpful, does not address the specific learning struggles that the health-care professionals in City View Hospital encountered.

In comparison, the detailed accounts I provide in chapters five, six and seven of this thesis show that health-care professionals are engaged in quite different struggles from those suggested by the national module's focus. The work of care provision unfolds in moments of exploration and closure as health-care professionals handle multiple and contradictory flows of information. The specific details of paediatric diabetes care regimens constitute and are constituted by the emergent knowledge that stabilises, fleetingly and provisionally, in the everyday practices of supporting self-management.

The workplace problems of supporting self-management also mutate. As I show in chapter six, what begins as a problem of gathering information then morphs into a problem of selecting, prioritising, questioning and discounting particular



information; then into a problem of evaluating risks posed by particular care regimens; then into the negotiation of new responsibilities levered by technological change; and so on. Such rapid mutation suggests that a series of disconnected approaches to workplace pedagogy might be less resonant than interventions that are fluid enough to enable and encourage spontaneous experimentation in learning. By this, I mean that instead of focusing on one discrete problem at a time, pedagogical interventions might be designed to provoke what Barad (2007, p. 379) calls 'differential responsiveness to what matters': in other words, much less about codified and generalised principles and much more about the unfolding of accountable engagement with the world. One example might be designating time for detailed team or small-group case discussions that highlight what Knorr-Cetina (2001) calls the oscillation between moments of exploration and closure. In this way, health-care professionals might examine their own work in supporting self-management, attending to the ways in which the clinic clarifies and confirms recent blood-glucose levels, insulin doses and the extent to which children and their parents might safely manage particular care regimens; the ways in which potential risks are identified and evaluated; the ways in which alternative care regimens are selected; and the ways in which priorities for action are set.

### **The need to attune to the nature of the work**

In this final section of chapter eight, I consider the implications for professional learning and for professional practice of misconstruing the nature of the work of supporting self-management in this case. I argue that if some aspects of professional work become disproportionately emphasised, and other aspects recede from view, sustaining focus is extraordinarily challenging. As a result, identifying how best to enhance professional learning becomes doubly difficult, because even recognising and naming the specific workplace problems is challenging.

## **Empowerment or coercive persuasion**

As I explained in chapter one and in chapter seven, empowerment is a central aspiration in the educational resources, health-care literature and policy documents that discuss the provision of support for self-management (see, for example, Long Term Conditions Alliance Scotland, 2008; Department of Health, 2012; NHS Education for Scotland, 2012). Key emphases include exhortations for health-care professionals to share decision making, to rebalance interpersonal power relations, to promote patients' autonomy and choice and to privilege patients' personal responsibilities for their own health care (Wallerstein, 2006). To be clear, I do not seek to undermine these aspirations, although I acknowledge and have already discussed some of the many tensions and controversies. For example, there are debates about the wider social effects of asking people to engage in more frequent and more complicated monitoring of bodily functioning (see, for example, Oudshoorn, 2011; Lupton, 2013a, 2013b), and about whose interests are prioritised in such requests (Law and Mol, 2004; Mol, 2008).

However, rather than dismiss these aspirations wholesale, I argue that, at present, these emphases are accorded disproportionate attention in educational interventions and that focusing so heavily on such abstract dimensions of human relations misses the significant work that health-care professionals undertake in and through the specific arrangements of health-care practice. As I have shown in chapters five, six and seven, predefined biomedical aims collide with attempts at shared decision making, and the professionals grapple over and over again with what it means to promote patients' autonomy when the patient is a child or young person and when a choice to reject self-management might lead to serious illness or death.

To repeat, health-care professionals engage in significant work of discerning safe parameters within which children, and their parents, might reasonably be allowed to contribute safely to diabetes management. This work is, as I have shown, highly complicated. That many of the details of this work tend to recede

from view is of concern for two reasons. First, and perhaps most obvious, if the work is not visible, then it is very difficult to design pedagogies to enhance learning in relation to that work. Second, and perhaps less immediately obvious, if the specific nature of the work is neither visible nor named, the opportunities for professionals to evolve their own learning strategies diminish sharply. More than this, I argue that the work itself becomes more difficult because its nature is obscured.

Conceptualising the work as empowerment contributes an unhelpfully blurred focus because it is difficult to focus on a task that purports to be one thing yet has all the qualities of another. In suggesting that the work is more akin to a kind of coercive persuasion, I am drawing attention to the forces that exert pressure, and to the constraints within which support for self-management materialises. There is a limited range of choices for children, for parents and for professionals: the consequences of not self-managing are stark, because children cannot survive without appropriate and regular administration of insulin. Such dependence on insulin exerts force and often seems to contribute a sense of anxiety and urgency as the risks of harm from errors, inattention or inability are continually appraised and reappraised.

Supporting self-management is a carefully nuanced accomplishment of protecting the health and interests of the child, engaging the child, engaging the parents and sustaining a working relationship between child, parents and professionals. Incorporating technological change and new care regimens are integral aspects of the work: establishing just which children and which parents can safely manage particular responsibilities in any given instance is material-discursive work that entails attending to multiple complex forces. Educational interventions that persist in rendering this work invisible are not helping.

### **Towards a methodology for workplace learning**

For a methodology of workplace learning in this case, specificities matter. Repeated calls for health-care professionals to shift away from paternalistic

models of care (Zoffman and Kirkevold, 2012; Sadler et al., 2014) and instead to adopt professional roles that are more facilitative and less dominant (Wallerstein, 2006) seem doomed to fail unless the conditions, constraints and affordances of everyday clinical work practice are recognised and addressed.

An argument for a methodology of workplace learning is not a call to codify all of the informal learning that unfolds in everyday work. The informal learning I have been tracing in this research is irrevocably entangled in the arrangements for work: embedded, situated, embodied and contingent. Some would argue that construing learning as emergent makes it difficult to structure pedagogical interventions at all (see, for example, Johnsson and Boud, 2010). However, rather than somehow trying to restrict the more spontaneous, less predictable features of emergent learning, I am instead seeking to propose a more coherent approach that might enable the kind of ‘holding in tension’ of structured and informal pedagogy that Aberton (2012) suggests.

Therefore, I have not attempted to recommend a detailed curriculum. Such detail is not only beyond the scope of my thesis but also beyond the scope of my own expertise. What I propose here is a methodology that brings *together* health-care professionals and educationalists, towards assembling an approach to sharing experiences and expertise, and enhancing learning in and for work. This collaboration respects the need for attention to the details of specific health-care work problems and specific health-care work practices. Such collective sharing of experiences and expertise might help to mitigate the perpetual reinvention of wheels that Fenwick (2008) has cautioned against and the potential for repeated duplication of effort as many clinic teams grapple with problems that resonate across countries. Such a collective, collaborative and coordinated approach might actively promote recognition of and attention to the learning needs of health-care professionals, which is especially important in relation to policy directives like CEL 4 (Scottish Government, 2012), which mandated increased provision of insulin-pump care regimens.

The particular pedagogies employed might not need to be especially novel in and of themselves. Examples might include collaborating across organisations to prepare ready-to-hand information about particular changes wrought by insulin-pump technologies, including producing job aids in the form of brief written materials. Structures for staff team discussions, attentive to the constraints of health-care contexts, would be useful. Materials to support these could be simple: guides containing dilemmas, suggestions for facilitators or a series of questions and answers that anticipate and explore some of the particular challenges encountered. Most critical, as I have emphasised throughout this chapter, is explicit recognition of the important work of learning. Even making explicit the profound challenges and uncertainties at stake in these practices of supporting self-management is helpful. Workplace pedagogy can enable staff to develop language for the particular challenges they encounter, make space to discuss these challenges, and encourage open sharing of the everyday strategies they negotiate together.

I have shown in this chapter the clear potential for drawing on detailed knowledge of workplace problems and existing learning strategies in order to inform the development of workplace pedagogies best able to support health-care professionals in this case. So, for example, although it might well be relevant to help health-care professionals to better understand the experiences of those living with a long-term condition, as Lawton et al. (2015) and Pickard and Rogers (2012) have recommended, there are other areas that require urgent attention.

### **Chapter summary**

In this chapter I have examined the role for education in the question of how best to help health-care professionals learn to support self-management in paediatric diabetes. I have argued that a key role for education is to help develop a methodology of workplace learning, by which I mean a more coherent, coordinated, collaborative and collective approach to workplace pedagogy than is currently in place.

In exploring what a methodology of workplace learning might entail, I have shown that recognising the nature of the work that health-care professionals undertake in their efforts to support self-management is a fundamentally important aspect of designing and developing the kinds of workplace pedagogies that might enhance learning. The detailed accounts of health-care practice in previous chapters have already shown the very particular challenges encountered and also the moment-by-moment struggles of learning that unfold in a range of instances. This chapter has looked across the insights in chapters five, six and seven to focus on the conclusion that supporting self-management in this case is very much concerned with the highly complicated perpetual discernment of safe parameters within which children, and their parents, might reasonably be allowed to contribute to diabetes management.

I have shown the ways in which a methodology of workplace learning could promote recognition of professional learning strategies already in place, making it possible to strengthen and protect the resources required for their endurance. Such an approach could also help to augment existing learning strategies, by complementing these ongoing activities with additional pedagogical interventions. In particular, I have argued that a prerequisite for a methodology of workplace learning is that it takes critical account of the nature of the work that is to be the focus of learning. Otherwise, pedagogical interventions are far less likely to help professionals respond to the workplace problems they encounter, and much more likely to create problems by obscuring the nature of the work. Chapter nine, next, draws this thesis to a close.

## 9 Conclusions

When local conclusions are, for a moment, reached, those conclusions will be transferable only with effort, difficulty, care and caution from where they were created.

(Law, 1994, p.194)

In this final chapter, I draw together the various strands of exploration and argument across the thesis. I return to the research problem and the research questions posed in the opening pages, and I set out the answers that this study offers. I consider the wider implications of the study, and in doing so I am mindful of Law's (1994) advice, above, to temper conclusions with careful recognition of the specific arrangements for knowledge making. I state the contribution to scholarly knowledge and make key recommendations for policy and practice. I suggest a number of possible directions for further research, and finally, I reflect on my own development as a researcher.

### **Restating the research problem**

In the introductory chapter, I explained that health-care services continue to prioritise self-management as a response to rising numbers of people with long-term conditions (Department of Health, 2014; Scottish Government, 2016). In a corresponding move, health-care professionals are increasingly expected to focus on providing *support* for people who are self-managing. However, little is known about how best to help health-care professionals *learn* to provide support for self-management (Health Foundation, 2011), and it is here that my study makes a contribution. My study sought to extend current knowledge by exploring what health-care professionals actually do in their work of supporting self-management and by examining how they learn to respond to the challenges encountered. The overall aim was to inform educational interventions that might enhance such learning.

By bringing together key literature from educational studies, science and technology studies, and organisation studies, I have understood work problems as learning struggles, and recognised learning as a sociomaterial phenomenon that can be investigated as a practical accomplishment. I have focused on examining informal professional learning as it unfolds in everyday health-care practice. I have argued that paediatric diabetes is an important locus for this research, because the complexity of policy directives, reconfigured arrangements for care and technological change generate considerable learning challenges for health-care professionals. Moreover, as I have shown, diabetes is a difficult condition to manage, and the consequences of not managing well are potentially devastating. These difficulties are especially complicated for health-care professionals learning to support self-management in paediatric settings because of the need to attend not only to the child with diabetes, but also to the parents.

### **Answering the research questions**

The specific questions I set out to address are:

1. For health-care professionals, what practices and challenges emerge in the work of supporting self-management in paediatric diabetes?
2. What related processes and issues of professional learning unfold?
3. What in particular are the effects of insulin-pump technologies on professional learning?
4. What are the implications of the insights generated by questions (1), (2) and (3) for workplace pedagogies?

Before taking each question in turn, I summarise the key methodological and theoretical approaches that have most informed my research.

From the field of educational research, I have been most informed by sociomaterial approaches, which unsettle what Fenwick and Nerland (2014) have called disembodied, decontextualised and dematerialised ways of understanding



knowledge and learning. These approaches construe learning as enactment (Sørensen, 2009; Fenwick and Edwards, 2010; Mulcahy, 2012), and examine the ways in which learning materialises. Accordingly, the study of professional work practices is recognised as a highly useful way of understanding ‘seamless know how’ (Hager, 2013). One approach to examining practice that I have used in my own study is to trace the epistemic work (Knorr-Cetina, 2001) of professionals. Following Nerland and Jensen (2014), such epistemic work can be traced in the moments of exploration and closure as professionals handle multiple and contradictory flows of information and engage in local translation of knowledge.

From the field of organisation studies I have drawn heavily on the work of Gherardi (2006; 2010; 2012), whose attention to the ‘organising’ arrangements of everyday work practice helped me attune to the ways in which support for self-management is accomplished. With a focus on the ordering processes that enable a practice to be produced and reproduced over time, Gherardi (2006) shows the ways in which a practice becomes recognisable as the established way of doing things. In my own study, I have employed the concept of knowing-in-practice in order to illuminate not just the ordered nature of practices, but also the moment-by-moment enactment of learning, as practitioners come to accomplish work practice in unfamiliar and changeable contexts.

Methodologically, I have drawn on ethnographic approaches, which included spending time observing and talking with health-care professionals as they supported children, and their parents, to manage diabetes. However, I was also informed by Mol’s (2002) praxiographic sensibilities, which enabled me to push beyond ethnographic preoccupations with human experience and interpretation. The concept of praxiography offered an empirical approach that ‘encompasses molecules and money, cells and worries, bodies, knives and smiles, and talks about all of these in a single breath’ (Mol, 2002, p. 157). The careful, critical study of medicine and disease as it is enacted, rather than the human experience of illness, offered scope to engage with what Berg and Mol (1998, p. 3) have termed ‘the so-called hard core of medicine’. Such science and technology scholars showed me a way of attending to the complicated, technical and technological

details of health-care practice, which I have argued are so important in the educational questions of professional learning investigated here.

I found that my grasp of sociomaterial commitments became much firmer through my engagement with Barad's (2007) ontological-ethical-epistemological framework. What I found so useful about her work was the ways in which it helped me to engage with the implications of recognising indeterminacy among social and material entities. Barad's (2007) particular use of the concept of entanglements underlined, for me, the need for investigative approaches to be attuned to the specific phenomenon at hand.

I found that Barad's (2007) explicit attention to the ethics of knowing, and her argument that knowing entails accountability, was an exceptionally useful theoretical and methodological resource. It is not so much that hers is unique as a sociomaterial approach accounting for ethics, but that her persistent incorporation of what it means to know, of 'meeting the universe halfway' (Barad, 2007) and of our responsibility in the productive 'worlding' (Taguchi and Palmer, 2013) that knowledge making entails, helped me to consider such issues repeatedly in my own research.

In summary, this particular combination of literatures and approaches has helped me to trace myriad intricacies of professional learning in this case. In the following section, I take each research question in turn in order to show the answers that this thesis offers.

### **RQ 1: Practices and challenges in the work**

I have shown that some of the most difficult aspects of supporting self-management in paediatric diabetes are the tensions among efforts to balance policy aspirations for empowerment with biomedical knowledge about risks to immediate and long-term health. Rather than privilege either concern, I have shown the ways in which these different interests create challenges in this work of supporting self-management. There are tensions between providing care and encouraging patients to make choices about what kinds of care they want and do

not want (Mol, 2008). In paediatric settings where children's developing autonomy must be considered alongside parental concerns (Silverman, 1987; Hawthorne et al., 2011), these tensions are particularly complicated. Predefined biomedical aims collide with attempts at shared decision making, and the professionals grapple over and over again with what it means to promote patients' autonomy when the patient is a child or young person and when a choice to reject self-management might lead to serious illness or death.

I have shown that health-care professionals in paediatric diabetes also face additional problems of discerning the extent to which children, and their parents, are able to handle particular care regimens. Establishing how well children and their parents are managing does not simply entail monitoring and encouraging compliance with a fixed regimen. Instead, there is a continual need for carefully informed adjustment. The professional work of gathering information, selecting, prioritising and making sense is considerable. This work is not simply about connecting information with practice; rather it is a collaborative enterprise, relying on a range of actors. Supporting self-management is material-discursive work: the materiality of medicines, specifically insulin, exerts force and makes demands; bodily responses to blood glucose and the availability or absence of biomedical knowledge all participate too.

Many of the clinic appointments are complicated rather than straightforward, and the absence of information sometimes creates problems for professionals as they figure out how to respond. The professionals rely on detailed accounts of blood-glucose control and insulin administration provided by children and parents. However, I have shown that a crucial dimension of supporting self-management is the work of considering and understanding those accounts in light of and alongside other knowledges. Professionals juggle between different knowledges, recognise inconsistencies and remain open to different possibilities. This work is less about simply choosing and privileging one form of knowledge over others and more about what Barad (2007) might call reading different knowledges through one another.

I have argued that the notion of empowerment circulating in much of the health-care literature, policy documents, educational resources and guidelines for health-care professionals is troublesome in paediatric diabetes. Aspirations to promote the autonomous participation of those with long-term conditions is especially challenging for professionals working with and between children and their parents. In paediatric diabetes, increased patient participation and devolved decision making is not only about rebalanced interpersonal power relations. For the professionals, a sizeable dimension of the work entails knowing the balance between letting children and parents proceed without too much intervention and, yet, simultaneously accounting for the limits of children's and parents' capacities to self-manage. The muddled conceptualisation of the work as 'empowerment' serves to contribute a highly problematic blurred focus. Consequently, it is not always clear whether the work of supporting self-management is focused on the child with diabetes or the parent who supports the child to self-manage.

Of special note here are the challenges posed by technological change, which has certain implications for professional roles and responsibilities and introduces new risks for health-care provision. I discuss these implications further, specifically in relation to insulin-pump technologies, in answer to the third research question, below. However, at this point I reiterate that as diabetes technologies become increasingly mainstream care options, the professional work of supporting self-management entails adapting and modifying care in response to unanticipated problems. That which constitutes knowledgeable care provision destabilises and requires some reworking.

## **RQ 2: Processes and issues of professional learning**

In answer to RQ 2, I have drawn from the work of key educational researchers (Fenwick, 2008; 2010; Mulcahy, 2012; Fenwick et al., 2014; Nerland and Jensen, 2014) to examine the learning struggles that are in play as health-care professionals encounter and respond to particular workplace problems. In doing so, I have shown the ways in which professional learning unfolds in moments of

health-care provision. Seeking a detailed understanding of the ways in which children and their parents manage diabetes care regimens, professionals engage in knowledge work, or what Knorr-Cetina (2001) has called oscillation between moments of exploration and closure. Professional knowledge work entails bringing codified biomedical knowledge (such as health risks and optimal patterns of insulin administration) into dialogue with the every day operationalisation of the insulin-pump care regimen (such as actual insulin administration activity recorded on the Carelink data) and the engagement with the child and family (such as the downloading of requested data and the child's preferences about whether to continue with a particular care regimen). When the usual arrangements for gathering and making sense of information are disrupted, the extent of knowledge work ordinarily mobilised becomes clearly visible.

Care regimens are not stabilised; instead, care regimens are open and contingent, formed and performed in ongoing ways. I have shown the ways in which care regimens are made and re-made in the encounters between children, parents and professionals in the clinic. Professional learning unfolds in and through the making of care regimens, and care regimens materialise in and through the emergence of professional knowledge. These are the relations of mutual constitution.

By focusing on what Gherardi (2006; 2010) calls knowing-in-practice, I have shown that the situated practice of supporting self-management in this case does not readily correspond to the notion of empowerment that tends to dominate many health-care policies and guidelines. Instead, the situated practice of supporting self-management is more akin to coercive persuasion. This dissonance is important. Although knowledge about workplace problems can quickly become knowledge about workplace pedagogies (Fenwick, 2008), I have argued that if the available knowledge about workplace problems lacks fine-grained detail and is, indeed, a particularly and unwittingly partial knowledge, then strategies to enhance learning will stumble. I suggest that workplace pedagogies need to be informed by careful appreciation of the specific practice that is to be the focus of learning.

I have also argued that there are unanticipated consequences of emphasising the interpersonal aspects of empowerment, such as rebalancing power relations, at the expense of the kinds of work practices and problems I have shown in this thesis. What I mean is that the work of supporting self-management becomes more difficult because its nature is obscured. Focusing on a task that purports to be one thing yet has all the qualities of another is not easy.

### **RQ 3: Effects of insulin-pump technologies**

Building on the work of others (see, for example, Pols and Willems, 2010; Oudshoorn, 2011; Fenwick et al., 2014; Halford et al., 2015) who have argued that technologies are neither inert nor passive, I have shown that insulin-pump technologies actively participate in the arrangements for health-care provision and in the arrangements for professional learning in health care. I have shown insulin-pump technologies prompting the need for new technical skills and abilities as well as creating new roles and responsibilities for health-care professionals and introducing certain new risks.

Specifically, insulin-pump technologies require health-care professionals to make highly selective delegations of responsibility for decision making to the algorithmic instructions encoded in the devices. Sometimes, the technology prescribes particular modes of operating and professionals work with the flow of instructions. However, at other times, the insulin pump's inability to take account of specific contextual information makes it unreliable. In such instances, professionals are required to recognise and respond to this unreliability, and they then choose to work outside the flow of instructions. For the professionals, knowing the appropriate response is a key dimension of recognising and mitigating risks.

The smaller margins of error in these technologies amplify the existing high stakes in insulin administration, generating new risks for health care. As a result, insulin pumps are not automatically available to all, and corresponding new responsibilities emerge for health-care professionals. In these new arrangements

for supporting self-management, health-care professionals become engaged in gate-keeping access to technologies. Such gate-keeping entails careful and ongoing evaluation of the abilities of children and parents to handle particular care regimens. Moreover, insulin-pump technologies participate in the gate-keeping by inviting selection of some children and parents but not others.

I have shown health-care professionals engaged in key learning strategies by finding ways of enabling direct physical engagement with insulin-pump technologies. In this way, health-care professionals come to know these technologies with and through their own bodies. I have raised serious questions about the involvement of commercial insulin-pump manufacturing companies in professional learning. Although these companies help by making insulin-pump devices available for bodily practice, there is a need to consider the extent to which highly complex and expensive technological care regimens are assumed to be the optimal approach to caring for paediatric diabetes. Whether commercial companies offer scope to explore and interrogate any such assumptions is not clear; indeed, I suggest there are unanswered questions about the extent to which such educational interventions are able to facilitate critical consideration of the wider effects of technological change.

In the next section I discuss the fourth research question, which focused on implications of the insights generated by these first three questions.

### **Implications of the research**

The sociomaterial writings that have informed my research have also helped me to know my own study as one that is not, following Mol (2002), portraying an exclusive or universal truth of health-care practice. Attending to the ways in which specific practices perform particular realities into being underlines the possibility that things might always be otherwise. Such recognition of multiple enactments of reality keeps an open mind; one that is always attuned to the particular possibilities and limitations contributed by researchers and research activities. Accordingly, in this discussion of implications, I am mindful that this

research is very much, following Barad (2007), a process of making known rather than a process of discovery.

Perhaps the most significant implication of this research is to argue for explicit recognition of the important work of learning. To repeat, learning unfolds in the everyday health-care practice of supporting self-management in paediatric diabetes, and this learning can be enhanced through workplace pedagogies. However, as I have argued throughout this thesis, if education as workplace pedagogy is to be effective, it must be informed by careful appreciation of the nature of the work and the specific practices that are the intended focus of learning.

There are profound challenges and uncertainties at stake in the practices of supporting self-management, which I have shown in this thesis. Making these challenges and uncertainties explicit is one of the most important ways in which workplace pedagogies might enhance professional learning in this case of paediatric diabetes. The pedagogies themselves might not need to be especially novel, but the pedagogical value of such activities must be explicitly recognised, resourced and even rewarded. Otherwise, the specific arrangements that make this kind of learning possible might not endure.

Recognising the learning that unfolds in the work of supporting self-management in paediatric diabetes entails attending to the impact of technological change. Learning strategies evolve and professionals find ways of responding to difficulties. In the end, professionals employ their own bodies as a way of coming to know new insulin-pump technologies, in collaboration with commercial manufacturing companies. There are advantages to such approaches, which I have already acknowledged. However, I have shown that technological change in this case of paediatric diabetes initiates wide-ranging and elaborate knowledge work in and through many aspects of everyday work practice, including in relation to the reconfiguring of health-care professional roles and responsibilities. That commercial companies have assumed a leading role in professional learning



must at least raise questions about what else needs to be in place. My answer is that one place to start is by developing a methodology for workplace learning.

In the next section I set out the contribution my study makes to scholarly knowledge, and I make certain recommendations for specific areas of policy and practice relating to health-care professional education for the support of self-management. I also note the limitations of my study and propose a number of potential directions for further research.

### **Contribution and recommendations**

The original contribution that my study makes is to rethink the role for health-care professional education as critical workplace pedagogy in complex problems of health care. Specifically, by bringing concepts and approaches from educational research into dialogue with questions of health-care practice in paediatric diabetes, I have refocused attention on the *learning struggles* of health-care professionals supporting self-management. The value of such refocused attention is that it opens up new understandings of professional learning in this context. As a result, more detailed knowledge about workplace problems and learning struggles might help to better align workplace pedagogies to the very specific nature of the work – and thus better enhance professional learning.

Through careful attention to the material-discursive practices of everyday work, I have shown that supporting self-management in paediatric diabetes is very much concerned with discernment. In particular, the study shows the centrality in practice of highly complicated, perpetual discernment of safe parameters within which children, and their parents, might reasonably be allowed to contribute to diabetes management. I have shown the very particular significance of insulin-pump technologies, which reconfigure professional roles, professional responsibilities and professional learning in paediatric diabetes.

In terms of recommendations for practice, I have argued in this chapter and in chapter eight that a key role for professional education is to help develop a methodology for workplace learning focused on supporting self-management in

paediatric diabetes. I have suggested several key features that such a methodology might adopt. Such an approach could promote recognition of learning strategies already in place, making it possible to strengthen and to protect the resources required for their endurance. Existing learning strategies could be augmented by complementing these ongoing activities with additional pedagogical interventions. In particular, I recommend that a prerequisite for such an approach is that it takes critical account of the nature of the work and of the specific practices that are to be the focus of learning. Otherwise, pedagogical interventions are less likely to help professionals respond to the workplace problems they encounter and much more likely to create problems by obscuring the nature of the work.

### **Limitations**

In this section I note the key limitations of my study. My study is limited by being small in scale and somewhat constrained by the need to acquiesce to the priorities of the clinic setting. Pertaining to the specificities of one clinic and one staff team, the insights generated are inevitably difficult to transfer elsewhere, as Law (1994) notes in the quote that opens this chapter. Moreover, the nature of the clinic environment afforded access only to events approved by the clinic team.

However, there are also mitigations that help to reduce the potential for these limitations to undermine my research. Ethnographic (and praxiographic) approaches tend to sacrifice breadth for depth, and the depth and richness of detail in my study helps to make it easier for others to discern the extent to which particular insights might resonate more widely. In turn, my analyses are offered with due recognition of what Mol (2002, p. 159) calls the researcher's 'fascinations, passions and theoretical baggage'. I make no claims to present a single truth, though I have recounted observations and conversations with care and with honesty.

## **Suggested directions for further research**

I turn now to suggest a number of possible directions for further research. Some of these suggestions arise from the insights generated through my own study, and some arise as a result of recognising the areas my study did not address. I discuss four particular gatherings of questions, which I argue warrant further attention: professional identity; the ways in which children and their parents contribute to the materialisation of professional learning; teachers learning to support self-management in schools; and the continued development of diabetes technologies.

Although I have shown and discussed in detail the difficulties that health-care professionals encounter in their work of supporting self-management in paediatric diabetes, I have not explored these difficulties specifically in relation to professional identity. However, the enactment of professional identity can indeed be usefully understood as a learning struggle (Fenwick, 2008). With this conceptualisation, there is scope for research focused on the difficulties of enacting particular professional identities, the learning strategies that evolve in response and the possibilities for pedagogical interventions. Moreover, as others have argued (Hager and Reich, 2014; Nerland and Jensen, 2014; Fenwick, 2016), the kinds of reconfigurations of professional roles and responsibilities such as those that I have explored in this study are contributing to the production of new professional identities. The specific learning work entailed in the enactment of new professional identities certainly warrants further research, and such research might help to deepen understanding of the particular education and learning implications of policy directives that seek to emphasise self-management and self-management support.

These questions of professional identity resonate across a range of areas where supporting self-management is important, not just in diabetes, for example, but also for professionals supporting people to self-manage asthma, epilepsy or chronic heart disease. Tracing the particular professional identities enacted, and the learning work entailed, would align well with a sociomaterial approach. In

this way, the heterogeneous networks of technologies, medicines, policies, and so on, pertaining to particular long-term conditions could be accounted for. As I have argued in this thesis, these kinds of considerations are important influences for the specific professional learning that materialises.

The nuances of supporting self-management in paediatric settings, specifically in relation to professional identity, are of interest because of the particular differences in the nature of the work. Health-care professionals are often engaged in balancing the developing autonomy of children with the responsibilities of parents and I have shown some of the ways in which such efforts at balancing disparate issues are at play in this case of paediatric diabetes. Exploring these issues with specific attention to the work and learning entailed in supporting children with different long-term conditions is another route to developing the insights generated in my study. Perhaps these kinds of concerns are likely to be of most interest in settings where the work of supporting self-management is technologically dense and/or entails grappling with biomedical risks.

The role of children and parents is an aspect of professional learning that I excluded early in the design of my study, and it comprises my second suggested gathering of possible questions for further research. Rather than not including the contributions of children, parents, siblings, grandparents and wider family members involved, these could instead be examined as integral parts of the networks of assemblages, or intra-actions (Barad, 2007), that enact professional learning. The inclusion of patients is already established in formal programmes of teaching in medical education, although there is a variety of ways in which patients might be invited to be involved (Towle et al., 2010; Bere et al., 2016). Moreover, as I argued in the opening chapter, there is growing interest and indeed expectation that educational programmes for all health-care professions draw on the expertise of those receiving health care.

Building from my own study, I have shown the moment-by-moment learning that emerges as health-care professionals handle multiple and contradictory flows of information. Understanding the ways in which children and their

parents contribute to such emergent learning, rather than only inviting children and parents to help teach in formal educational programmes, is an interesting and useful avenue for further research. As I have shown in this thesis, the proliferation of new diabetes technologies, and associated new care regimens, tends to create circumstances in which *everyone* is learning, and that includes children and parents. Sociomaterial sensibilities are especially helpful in these circumstances because they afford recognition and examination of the entangled relations that enable particular learning to materialise.

Staying with paediatric diabetes, but moving away from health-care professionals, brings me to my third area of interest for further research. Teachers in schools are increasingly expected to not only ensure that children's medical and health-care needs are met during the school day, sometimes they might also be engaged in actually undertaking or supervising health-care interventions (Childhood and Adolescent Diabetes Scotland, 2014; Department of Health, 2015). Children with diabetes attend school with insulin-pump technologies, blood-glucose testing monitors and insulin injections. Children cope with adjusting insulin according to periods of exercise and activity; they manage meal times, cooking lessons and unexpected snacks; and sometimes they require help from teachers to do so.

There are key questions to be asked about the ways in which teachers learn to provide these kinds of supports in schools, the challenges encountered, the learning struggles entailed and the learning strategies that evolve, including not least the kinds of workplace pedagogies best likely to help teachers. Given the expectations that paediatric health-care teams actively support teachers and schools (Children and Adolescent Diabetes Scotland, 2014), there is also scope to explore the issues of professional identity outlined earlier. For example, in what ways is teacher professional identity affected by engaging in health-care provision for children with diabetes? In what ways do health-care professional identities and teacher professional identities collide, become entrenched or reconfigure in the collaborative (or combative) efforts to ensure children with diabetes can participate in the life of the school?

The fourth and final area for further research I want to discuss is the ongoing development of diabetes technologies and the continued worth of examining educational issues. While drawing together the explorations and arguments in my thesis, I came across the news item below. I include it here as a way of showing the kinds of questions that could, and perhaps should, be asked of such continued technological development in this field.

Novo Nordisk, the pharmaceutical giant that specialises in diabetes, is working with IBM to create a 'virtual doctor'. The virtual doctor is a supercomputer known as Watson Health. It uses a broad range of health data to generate precise treatment advice for people with diabetes, such as insulin dose calculations. Initially, the researchers plan to input data from continuous glucose monitors for the computer to use, but the potential scope is much wider: food intake, insulin injection information and exercise data could also inform the advice given out by Watson Health.

(Diabetes UK, 2015)

This news item encapsulates a number of related question threads, which I have begun to explore in my own study but which would benefit from continued and extended exploration. When I read this news item as Barad (2007) might, that is, *through* my thesis rather than against it, the threads of questions begin to emerge. Perhaps, in light of my own research, what strikes me most about this news item is the absence of learning struggles: there seems to be an implicit suggestion that diabetes management is a clean and tidy business of multiple calculations. I am curious about the intention to 'input data', as if both the inputting and the data are entirely unproblematic and will lead in straightforward, *algorithmic* ways to the production of targeted instructions for insulin administration. I might speculate that there are strong underpinning assumptions of willing, compliant people with diabetes, who are predominantly concerned with meeting predefined biomedical targets for blood-glucose control.

I wonder about the relations among 'virtual' and 'real' health-care professionals, and about whether two giant commercial companies are willing or able to account for a variety of non-commercial interests of society as a whole. I wonder about the notion of the 'creation' of doctors, rather than the education, teaching or development of doctors. Finally, I wonder about which forms of knowledge and work might be privileged, amplified, erased or made invisible in such creative endeavours.

In summary, what is clear is that future research into the role for education in complex problems of health care is especially relevant in the current landscape of shrinking resources, massive reorganisation, enormous demographic change and, as above, technological revolution. There is considerable and continuing scope in such volatile landscapes for sustained attention to the implications for professions and for professionals, and for the nature and purpose of professional education. I have selected a small range of key areas for possible further study: health-care professional identity; the ways in which children and their parents contribute to the materialisation of professional learning; teachers learning to support self-management in schools; and the continued development of diabetes technologies. In particular, I have suggested ways in which a focus on the materialisation of informal professional learning constitutes a useful direction for such research.

### **Final remarks**

In this final section I consider my own development as a researcher, including the particular challenges of *being* a researcher in this study. There are some things I would do differently in future studies, and I give some thought to future career interests. I have realised what it means to learn, to think, and to write in layers or in spirals. This is not, mostly, the same as going round in circles. Rather, the point is that often I have found myself learning something I thought I learned quite some time ago, only to realise that *this* time, I am learning it differently. I could say that I have learned to tolerate not knowing, and feeling out of my

depth, and to recognise such discomfort as a precursor to finding my feet and generating something new. However, these are things I expect to learn again.

### **My own development as a researcher**

Of all that I have learned in the undertaking of this research, perhaps the issue that stands out in these closing reflections is the weight of responsibility of the researcher. I began this study with considerable professional experience of working in challenging and complex situations, with children and with parents, and with other health-care professionals. I was already acutely aware of my accountability and responsibility in most given instances, and had often encountered, and had to find ways of responding to, tensions in relation to maintaining a position of integrity in the face of difficulty. However, what I did not have was any experience of sustaining such efforts as a *researcher*.

The particular work of researching was new to me, and the specific responsibilities and accountabilities were new. In spending time with the doctors, dieticians and nurses in City View Hospital, I learned that I wielded considerable power as a researcher, and that therefore I also carried a duty to exercise that power very carefully. To repeat, the point here is not that I was unfamiliar with ethical frameworks. The point is that I was unfamiliar with the fine-grained details of doing ethical research, or to put it another way, with what it meant to spend five months observing, audio-recording and talking with people who became progressively more comfortable with my presence.

I learned, over and over again, that a signature on a consent form works to open up rather than to resolve ethical issues. I understood that the enthusiastic participation of the research participants brought with it a need for me to continually appraise and reappraise the implications of their participation. I realised that their openness necessitated careful responses from me. For example, I experimented with ways of continually reminding participants of my presence and purpose, yet at the same time trying not to inadvertently create discomfort or disrupt the work of the clinic. I made movements and changed position when I



thought I had been forgotten in clinic consulting rooms. I repeated the nature of my research often, and I sought verbal consent at every opportunity. I came to understand that, perhaps, the participants were so used to thinking about health research and the well-being of children and parents that they were not always mindful that my focus was different. I realised that as a researcher, my role was to ensure that they understood the nature of *their own* involvement in my study.

### **Things I might do differently**

Unexpectedly, the research participants' keen interest came to an abrupt end once my fieldwork was over. I had agreed, during my time in the clinic, that I would return at several points to share and check early insights and evolving interpretations and to hear responses from the clinic team. Dates, times and venues were to be organised using email. However, although I emailed several times, I did not receive any reply. Perhaps my own assumption that these conversations would be an integral part of my study meant that I had not adequately prepared the clinic team for ongoing engagement beyond the fieldwork. Such preparation is something I could do differently in future projects, although busy schedules of health professionals may never be able to accommodate all of the engagement that researchers might desire.

Nonetheless, I am somewhat disappointed to have missed these ongoing conversations with the research participants. My study may have been strengthened by the opportunity to take account of the clinic team's views, and the continued dialogue would have enhanced my development as a researcher. However, I fully understand that research with practitioners in busy organisations must be very flexible, and I plan to make contact once more, just in case the prospect of hearing about the finished project generates more interest.

Interviews also stand out as something that I will likely approach differently in future. With the benefit of hindsight I can see that my ability to initiate informative conversations improved considerably during my time in the clinic. I became better at steering interviews while at the same time allowing interviewees

to lead me into conversations that I could not anticipate. I noticed that when interviewees tried to ‘teach’ me about their work, they explicated details I could never have asked about directly. I recognise, too, that the research participants were very skilled at this ‘teaching’.

### **Looking forwards**

As I bring this thesis to a close, I hope for opportunities to further develop initiatives that bring together particular educational research with specific health-care practice. I have thoroughly refreshed my excitement about the kinds of learning in work that have the potential to transform the ways in which health-care professionals engage with, care for and support children and parents. I have also discovered a love for theory, which has enabled me to engage with ideas I might otherwise have missed. Grappling with Barad’s (2007) ontological-epistemological-ethical framework was an unexpected pleasure, both challenging and satisfying. Her approach helped me begin to articulate and to explore the relations among health-care work, professional learning, professional education, policy directives and biomedicine. I was, and continue to be, excited by the potential for interdisciplinary thinking and interdisciplinary research across these areas.

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# Appendix 1



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## Participant Information Sheet

### **Study Title: *Materiality and Moments of Professional Learning in Health Care for Paediatric Diabetes***

You are being asked to take part in a study so that I can examine how professional learning comes to life in the everyday work practices of NHS professionals. The findings from this study will help towards understanding how professional education can best meet the needs of NHS professionals. Please read this information sheet before you decide whether you would like to take part.

#### **Why have I been asked?**

All of the people working in the core team of the clinic are being asked if they would be willing to take part in this study. I would like to spend 3 half days per week, from September 2012 – January 2013, observing work practices and outpatient appointments, talking to professionals and perhaps observing some meetings in the paediatric diabetes clinic. I would also like to interview some of the professionals working in the clinic.

#### **Do I have to take part?**

Taking part in this study is entirely voluntary. You do not have to take part. If you do decide to take part, you will be asked to sign a consent form (enclosed with this information sheet). You are free to withdraw at any time and for any reason, and you do not have to explain why you changed your mind. If you do decide to take part, the researcher will negotiate with you about how best to make sure observing and talking to you does not disrupt your work, and you can ask the researcher to withdraw at any time.

#### **What will I have to do?**

You are being asked to allow the researcher to observe some of your working practices, outpatient appointments and to talk with you about aspects of your



work. The researcher will observe for a maximum of 90 minutes at a time but this might not all be with you, because the focus of the study is the clinic as a whole. The researcher will negotiate with you about how best to make sure observing and talking to you does not disrupt your work, and you can ask the researcher to withdraw at any time.

**Will my taking part in this study remain confidential?**

Yes. Only the researcher and two academic supervisors will have access to information collected in this study. Your name and work contact details will be kept completely separate from all other material you share, so that you cannot be identified. Direct quotes used in written reports and publications will not include names or any identifying details.

**What will happen to the results of this study?**

The information collected will be used to learn more about how professional learning comes to life in the everyday work practices of NHS professionals. Reports will be written for the University of Stirling, and shorter articles will be written for publication in academic journals. Summary reports of findings will be shared with participants. In the long term, the findings will help ensure education and training programmes for NHS professionals develop in ways that take account of how professional learning comes to life in everyday work practices.

**Who is organising and funding this research?**

The research is a PhD study, undertaken in the School of Education in the University of Stirling. The Economic and Social Research Council is funding this research. A Research Ethics Committee has approved the research.

**If you would like more information about the study**

You can contact the researcher:

Sarah Doyle 01786 467956 or [sarah.doyle@stir.ac.uk](mailto:sarah.doyle@stir.ac.uk)

You can contact the academic supervisors:

Professor Tara Fenwick 01786 467611 or [tara.fenwick@stir.ac.uk](mailto:tara.fenwick@stir.ac.uk)

Dr Liz Forbat 01786 466103 or [Elizabeth.forbat@stir.ac.uk](mailto:Elizabeth.forbat@stir.ac.uk)

**If you would like to speak to someone who knows about the study who is an independent advisor:**

Professor John Field is Director of Research in the School of Education. He is not part of the study and can be contacted for independent advice or if you have any complaints about this study.

Professor John Field 01786 466145 or [john.field@stir.ac.uk](mailto:john.field@stir.ac.uk)

## Appendix 2



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### Participant Consent Form

**Study Title: Materiality and Moments of Professional Learning in Health Care for Paediatric Diabetes**

Researcher: Sarah Doyle

Academic supervisors: Professor Tara Fenwick and Dr Elizabeth Forbat

### Please read each statement and tick the box if you agree

1. I confirm I have read and understand the information sheet dated April 2012 Version 1 for the above study.
2. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw at any time and for any reason. If I withdraw from the study my data will not be used.
4. I understand that information shared with the researcher during this study will be confidential and identifying information including my name, work contact details and signed consent forms will be kept separate from interview data.
5. I understand that my views and experiences may be quoted in reports or publications, but names and details will be changed so that I cannot be identified.

6. I understand that interviews will be audio recorded and typed up afterwards. Digital voice recordings will be destroyed at the end of the study.

7. I agree to take part in the above study.

Name \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

Participant

Name \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

Researcher taking consent

## Appendix 3

### Transcriber Confidentiality Agreement

This University of Stirling, ESRC funded research study focuses on professional learning in health care for paediatric diabetes. The researcher is Sarah Doyle, PhD candidate.

As a transcriber of this research, I understand that I will be hearing recordings of confidential interviews.

I understand that the content of the interviews is confidential and must not be shared with anyone other than the Researcher. I will not disclose, retain or copy information. I confirm that I will adhere to the agreement in full.

I, \_\_\_\_\_ agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. WAV files, CDs, transcripts) with anyone other than the Researcher.
2. Keep all research information in any form or format (e.g. WAV files, CDs, transcripts) secure while it is in my possession.
3. Return all research information in any form or format (e.g. WAV files, CDs, transcripts) to the Researcher when I have completed the transcription tasks.
4. After consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g. CDs, information stored on my computer hard drive).

Transcriber:

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(Print name) (Signature) (Date)

Researcher:

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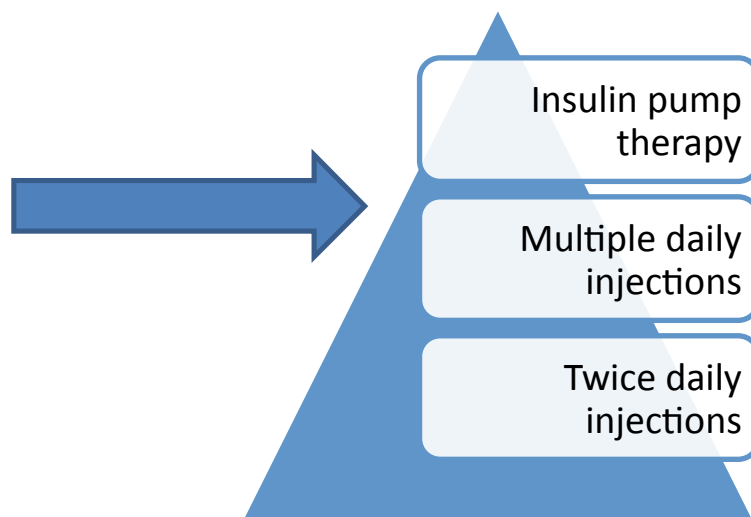
(Print name) (Signature) (Date)

## Appendix 4

### Data analysis: Overview of the process so far (April 2014)

Using the diffraction model, following Barad (2007)

Taking all of the gathered field notes, transcriptions from interviews and extended conversations and diffracting everything through the prism of the treatment regimens



Example log, Monday Clinic, field notes 191112

Insulin pump therapy	Multiple daily injections	Twice daily injections
<p>Using the PC to work through Carelink data from pump users, reading information from the PC screen and using a calculator, scrolling up and down between screens and then writing notes on an A4 pieces of paper</p> <p>12 emails with queries, P2 has all day to respond but sometimes there is only a morning in which to get replies to patients and families</p> <p>P4 talks about returning to the core service from the encapsulated pump service and <b>forgetting how to use the Magistral computer system</b></p>	<p>There are messages on the answerphone, from patients and families asking about blood-glucose readings and insulin doses, asking for help and advice</p> <p><b>Messages are written down so responses can be organised</b></p>	

<p><b>because she has been using Carelink for the last six months</b></p> <p>P2 uses two sheets of paper with handwritten notes from the data uploaded to Carelink</p> <p>The <b>different information is on different screens and so it cannot all be seen at once – the handwritten notes provide a way of gathering the information into one place</b></p> <p>From the outside this process seems solitary, silent and characterised by intense concentration</p>		<p>Paper case notes and the PC are used to review notes about a young person who is struggling to manage</p> <p>P11 and P1 are worried the <b>family do not understand how to manage diabetes</b>, although the older sibling has diabetes and might help</p> <p>P1 asks questions – what do you do when you get up, how many CHO units do you have for breakfast, how much insulin do you take</p> <p>Blood glucose diary used to review results</p> <p>Teaching about managing ketones, sick days</p> <p>There is a sense of confidence that things are being managed</p> <p>Advised <b>not to vary CHO amounts at mealtimes because of</b></p>
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		<p><b>this insulin regimen</b></p> <p>P11 appreciates working with P1 because she learns about how to gather information and how to engage with the family</p>
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This gives me three collections of data, organised according to insulin pump therapy, multiple daily injections and twice-daily injections. From this data set, I can discern three particular patterns of difference – different because they are phenomena that emerge differently according to the treatment regimen (emergent themes): tools and technologies, blood-glucose recording, and emotional texture. I began trying to pay attention to five or six different themes but once I grouped the data there were three major areas that were able to hold the other smaller issues.

Grouping all data:

<b>Blood Glucose Recording</b>		
Insulin pump therapy	Multiple daily injections	Twice daily injections
Software package Input blood glucose readings to the pump Excel spreadsheet Add data to the spreadsheet Upload data from home Staff view data on the PC in clinic Blood glucose monitor target range 5-6 HbA1c	Handwriting results Using paper diaries Using sheets of notepaper The school can use sheets of notepaper to record readings Carry diary to clinic Staff read the diary in clinic Target range 4-8	Often results are not written down

<b>Emotional Texture</b>		
Insulin pump therapy	Multiple daily injections	Twice daily injections
On the spot learning	Knowing	Patient distress
Collaboration	Teaching	Staff disheartened
Not knowing	Telling	Frustration
Suggesting	Authority	Staff lead
Shared space	Provocation	Limited expectations
Relaxed	Irritation	Disappointment
Learning from the patients	Routine	
Collegial		
Excited		
Daunted		

<b>Tools and technologies of insulin administration</b>		
Insulin pump therapy	Multiple daily injections	Twice daily injections
Carelink software, CD, USB	Novorapid insulin	Fewer injections
Password and username	Lantus insulin	Insulin pens
Canula 13+mm	Levemir insulin	Fixed CHO units
Canula sites	7,15 units	Fixed insulin
Pump functions	4mm needles	doses
“Capture event”	Long acting insulin	Mixed insulins
Buttons to press	Insulin pens	Skin lift
Novorapid insulin only	CHO units vary	Injection sites
0.3,0.6 (increments)	Insulin ratios	Written
No long acting insulin (+ risk)	Correction factors	instructions
Insulin reservoir	Written instructions	4mm needles
Infusion set (tubing)	Insulin cartridges	
CHO units vary	Skin lift	
Basal rates	Injection sites	
Bolus rates		
Pump wizard		
iphones		
Pump screen		
Programming instructions		

Input insulin doses into the pump		
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Working with this cut of the data, there are three phenomena that stand out: knowing the device, knowing (something about information, writing, programming...), and knowing and not knowing. I arrived at these through a process of close reading of the data and moving between literature and Barad's work. For example focusing on tools and (digital) technologies and my research question of professional knowledge/knowing, I've learned a bit about networks and educators, virtual spaces and devices – the operation of and engagement with devices is of interest here.

Focusing first on the phenomenon of knowing the device, I am using Barad's (2007) notion of entanglements that are simultaneously productive, constraining and exclusionary. I show the material conditions of the device working to constrain knowing such that some functions are necessarily delegated and some contexts are necessarily excluded. This analysis isn't complete but preliminary thoughts are below.

What is produced?

Invites touch – physical contact to get to know it, in a way not evident with the injection pens. Professionals wearing the pump but not simulating the injection regimen, letting patients feel the tubing, parents wearing the pump, pressing the buttons not reading the manual.

What are the constraints?

Demands trust – calculates, administers, warns, records, advises – the conditions (constraints, no?) for knowing the device. Cross-checking, iPhones, bypassing the wizard.

What are the exclusions?

Senior staff only, suicide for some patients, needs analytical thinking, not inherently empowering after all.

## Appendix 5

### Example of selected diffracted interview transcripts/June 2014

#### P1/a Interview

Insulin pump therapy	Basal bolus	BD Mix
<p>accelerated pump programme has made me sit up again</p> <p>worn the pump several times myself (with the companies that provide them)</p> <p>patients must be at an advanced level before they use pumps</p> <p>basal rates can be manipulated hourly</p> <p>bolus calculated and delivered same as injection or else delivered more slowly eg dual and square wave</p> <p>companies do advanced training for staff</p> <p>need to write a pathway for starting pump therapy</p> <p>have to look again at the technologies of the pumps</p> <p>Band 7s do pump therapy because they are senior and experienced</p> <p>encapsulated pump service challenges for wider NHS services such as AandE (how will they learn about pumps)</p> <p>new guidelines will have to go</p>	<p>sophisticated use of basal bolus required before starting a pump</p> <p>diabetes care has changed hugely – pumps and basal bolus are the way to treat</p> <p>have to understand the relationship between CHO and insulin, and correction doses</p> <p>[the changes in treatment] have increased our workload</p> <p>it's worrying if patients have tools they don't</p>	<p>patients on bd mix for years are now being asked to do basal bolus – a completely different thought process</p> <p>bd mix patients stick to fixed CHO amounts</p> <p>this can be a safer regimen for people who tend to forget lunchtime injections</p>

<p>through the policy committee – this is part of making sure patients are safe</p> <p>need to keep on top of the latest advances in technologies</p> <p>diabetes care has changed hugely – pumps and basal bolus are the way to treat</p> <p>we’re still learning about pumps – know the principles but still learning</p> <p>hypoglycaemia on pumps is different, might need different response (Lucozade seems too much)</p> <p>need to do more work on how best to use dual and square wave</p> <p>the frenzy of accelerated pump therapy is very difficult and challenging</p> <p>P1/b added dialogue: Learning from parents – it works both ways - insulin cartridges and taking them out of the fridge before adding to the reservoir [I think] lessens air bubbles; also tea tree cream lessens redness at</p>	<p>understand or aren’t applying properly</p> <p>are they safe? should they stay on this regimen?</p> <p>5 years ago we were still learning about basal bolus</p>	
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infusion sites		
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P1/c Interview

Insulin pump therapy	Basal bolus	BD Mix
<p>spreadsheets are still used for patients pump prescriptions</p> <p>getting to know over time what information needs to be included</p> <p>working out how much insulin should be prescribed and how, when patients move from basal bolus to pump</p> <p>family provides 3 day sample routine details</p> <p>total daily dose minus 10%</p> <p>50:50 or one third:two thirds</p> <p>be very careful about ketones with pump patients – less background insulin</p> <p>target blood glucose range is 5 or 6 on pumps (narrower)</p> <p>have to be able to convert back to basal bolus</p> <p>this conversion information is on the spreadsheet</p> <p>nurses prepare the prescription and discuss it with medical team who then agree/amend and sign it</p> <p>the form is complicated for families to understand at first</p> <p>staff take them through it slowly</p> <p>families set up Carelink at home, create username and password and share these with the clinic</p>	<p>working from information about basal bolus regimen</p> <p>injections work best at 50:50 split, one third/two thirds not effective</p> <p>can't give injections regularly at snack times</p>	

<p>the Medtronic Carelink charts do not show all of the information the team uses, so they have created their own spreadsheet</p> <p>wearing a pump with a catsuit is difficult!</p> <p>Carelink professional and Carelink patient – team find the separate systems unhelpful, have complained to no avail</p> <p>patients sometimes use pumps in ways that are unsafe and mean they need to be reverted back to basal bolus</p>		
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P9 Interview

Insulin pump therapy	Basal bolus	BD Mix
<p>Figuring out what caused a hypo and whether basal or bolus are to blame</p> <p>Previously 8% of clinic on pumps</p>	<p>split evening insulin regimen – this is not mentioned elsewhere, and means adding a novorapid dose at teatime</p> <p>Previously 67% of clinic</p>	<p>twice daily injections are a mark of failure</p> <p>failed on basal bolus therapy</p> <p>failed big time</p> <p>sometimes, it's exactly the right thing to do</p> <p>totally inflexible regimen</p> <p>keeping that person safe</p> <p>split evening insulin regimen – this is not mentioned elsewhere, and means adding a novorapid dose at teatime</p> <p>Previously 25% of clinic on split evening with 4 or 5 of those on twice daily</p>

<p>The pump is a mechanical device, same language as basal bolus</p> <p>We the staff are all fine with pumps mainstreaming means too many for a separate clinic politics of expanding was wrong, intention good though dangerous decision without additional resources and planning</p> <p>it's not [just] about the hardware, it's about the support and training can't give someone a box and say now go and read the book</p> <p>managing a pump is baffling, even for someone who really understands injections staff working with</p>	<p>on basal bolus</p> <p>Default position to change everyone on to basal bolus</p> <p>All new patients start on it</p> <p>Basal bolus is the same language as a pump</p>	<p>It's tricky to revert to this after basal bolus because the tools and rules are different</p> <p>can't use correction doses with this regimen because insulin can stack up then a bad hypo happens everyone gets demoralized</p> <p>numeracy is important for correction doses</p>
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pumps don't do anything else, they are immersed in it		
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P2 Interview

Insulin pump therapy	Basal bolus	BD Mix
<p>didn't use one function because didn't have the software to go with it</p> <p>used an excel spreadsheet before</p> <p>hard to get to know the Carelink charts</p> <p>no time to dwell on it, have to get on with it</p> <p>parents find things and functions and show the team, who then show other parents</p> <p>learning 'on the job' then go and look up the book</p> <p>the pump wizard responded to information about blood glucose and parents didn't know what to do, staff were also unsure – a big learning curve</p> <p>as the parent was talking on the phone, P2 is flicking through the book</p> <p>the pump recognises...takes to bolus advisor...says bg above target...do you want to bolus...</p> <p>panic</p> <p>now we know to press escape button</p> <p>you cannot sit down and read a book</p> <p>we don't do the books we want people to press the buttons</p> <p>for new starts – clear pump settings, get new batteries, go through each menu and sub menu together</p> <p>settings are important safety features</p> <p>enter basal rates and bolus advice</p> <p>put canulas in (Lenny the Lion)</p> <p>check settings against prescriptions</p>		

do the button pressing part of it explain and set parameters (safety limits) the wizard can calculate everything a big difference not being on long acting insulin dealing with small amounts/increments of insulin – decimal points no background insulin means ketones awareness is ten times more important than before – safety issue		
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### P3 Interview

Insulin pump therapy	Basal bolus	BD Mix
then insulin pumps, implications for school staff and the clinic providing teaching for school staff huge increase in numbers of patients on pumps they have to self-manage because we can't do it for all of them	then along came basal bolus, blood testing and injection at school increase in numbers of patients on basal bolus they have to self-manage because we can't do it for all of them	when I started most people were on insulin twice per day

### P13 Interview

Insulin pump therapy	Basal bolus	BD Mix
	difficult if 'maths isn't very clever' – counting carbs and working out insulin doses expert glucose meter calculates and 'tells them what to have' (insulin dose) phone app helps count carbs	

<p>feels as though I'm fumbling in the dark</p> <p>when to use which bolus – dual and square wave</p> <p>working with pump therapy – not much literature or research base</p> <p>trial and error</p> <p>understanding effects of fat and protein on CHO absorption and implications for insulin dose/rate</p> <p>not had much experience</p> <p>learning from families</p>	<p>technology helps</p> <p>managing lunchtime injections, hypos</p> <p>working around ideals to ensure safety</p> <p>carb counting was less popular in 70s and 80s – felt to be too difficult for people- changes in practices over time</p>	
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