# Type 2 diabetes mellitus and online learning:

# a patient-centred approach

By

Glenn Mason

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Approved by Professor Ian Wilson (chairperson of supervisory

committee)

# Certification of Originality

I, Glenn Mason

hereby declare that the work submitted to the Western Sydney

University Research Studies Committee for examination for the degree

of Doctor of Philosophy,

Titled:

*Type 2 diabetes mellitus and online learning:*

*a patient-centred approach*

is, to the best of my knowledge and belief, original except as

acknowledged in the text. This work has not been submitted for a higher

degree to any other institution.

Signed Glenn Mason ██████████

Date: 26/3/2018

PhD candidate

Western Sydney University

## Abstract

Type 2 diabetes mellitus is one of the most pressing global health problems. It is often considered to be a 'lifestyle condition' associated with distinct patterns of nutritional and physical activity. Treatment options can be biomedical or a combination of educational and biomedical approaches. Treatment strategies that focus on educational interventions in a health context tend to focus on psychological constructs (self-efficacy, for example) but are often under-theorised in terms of learning theory. Technology-based interventions are also similarly lacking in their employment of learning theory as they often tend to focus on the transactional nature of information flow between the user and adopted technology platform. This project, on the other hand, places learning theory at the core of the design of an online-based, patient-centred learning community for people with type 2 diabetes.

The project adopted a design-based research approach and the objective was to provide an environment conducive to the development of a community of practice and learning for participants with type 2 diabetes and to explore if the characteristics of transformative learning could be identified. Interviews, self-efficacy surveys and focus groups were conducted during various stages of the design. The analytical approach included activity theory and the community of inquiry framework.

The results demonstrate that a design-based research process can be effectively utilised for the development of an online patient-centred learning environment in the context of type 2 diabetes. It was shown that the adoption of the theory of transformative learning can help to frame the various types of learning that take place during the process associated with self-management of a chronic disease such as diabetes. Analysis of the engagement with the learning community

indicates that the characteristics of transformative learning were partially realised although a community of practice was not established. The study illustrates the role that a theory-rich patient-centred learning environment can play in the ongoing process of patient care in the context of type 2 diabetes. Interventions in other chronic disease contexts may also benefit from the results of this study.

# Acknowledgements

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# Table of abbreviations

| Term | Description |
|------|-------------|
| AT | Activity theory |
| BGL | Blood glucose level |
| CN | Charcot's neuropathy |
| CoP | Community of Practice |
| DBR | Design-based research |
| DM | Diabetes mellitus |
| HbA1c | Haemoglobin A1c |
| LMS | Learning management system |
| NSW | New South Wales |
| OHA | Oral hypoglycaemic agent |
| OLE | Online learning environment |
| PCoP | Potential community of practice |
| RCT | Randomised control trial |
| T1DM | Type 1 diabetes mellitus |
| T2DM | Type 2 diabetes mellitus |

| TAFE | Technical and Further Education College |
| --- | --- |

# Chapter 1. Introduction to the study

## Type 2 diabetes mellitus and chronic illness

Health and quality of life are often seen as two central dimensions of life. A person's individual level of health can have a profound effect on their psychological and emotional wellbeing as well having an effect on how they relate with others in their community. When one is healthy one's lived experience is not constrained by physiological limitations and punctuated by frequent visits to health professionals and yet this is the daily lived reality of people who suffer from chronic illnesses. Upon a diagnosis of a chronic illness, lives of individuals are often thrown into turmoil and they experience what the renowned adult educator Jack Mezirow has described as a 'disorienting dilemma' or, to paraphrase Martin Heidegger, we become more aware of our being in the world when our bodies break down (Carel, 2016). Type 2 diabetes mellitus (henceforth, T2DM) is one example of a chronic illness which can rupture the daily lived experience of those with the disease (Broom & Whittaker, 2004).

The prevalence of T2DM in Australia and in other developed and developing countries continues to rise. According to a recent report issued by the World Health Organisation (World Health Organisation, 2016), 102 million people were living with T2DM in 1980 and by 2014 this had risen to an estimated 422 million people. This global burden of the disease is leading to increased pressure on healthcare systems to deliver high quality of care in the treatment and management of this complex illness. However, due to the economic and process-related constraints that many healthcare systems experience, quality of care and provisions for ongoing management (including educational services) can sometimes result in sub-optimal patient

experiences and this is particularly apparent for patients with a chronic illness (Wagner et al., 2001).

T2DM is a metabolic disorder in which the body is no longer able to break down the build-up of sugar in the body due to a lack or ineffective use of insulin. The aetiology of the illness is complex although it is generally agreed to consist of a combination of lifestyle and genetic factors. Lifestyle factors can be conceptualised as both a causal factor in the development of the illness and as a component in the effective and ongoing management of the illness. This project is concerned with addressing the area of T2DM management and, more specifically, the role of learning in helping individuals with T2DM to manage and cope with their illness.

## Learning and T2DM

The problem of management in the context of T2DM is multi-faceted. It has a pharmacological component, behavioural or psychological dimension and it can even be conceived of as a 'contest for control' between the patient and the health provider – there is, therefore, even an ideological element to the way in which patient agency is conceived and integrated within a framework of care. Another crucial component is the role that learning can play in the ongoing management of the disease.

There is a crucial difference between what is meant by education and what is meant by learning. Learning, as argued by Merriam and Brocket (2007), refers to the process that is undertaken by learners and this manifests in individual cognitive states associated with individual learners. Education, on the other hand, refers to the intentionally designed learning environments which aim to create contexts for learners to achieve particular outcomes. Education, therefore, is

predicated on learning but learning does not always take place in intentionally designed, educational contexts.

There are two types of learning that take place in intentionally designed learning environments: formal learning and non-formal learning. Formal learning (Eraut, 2000; Marsick & Watkins, 2015; Mocker & Spear, 1982) takes place in institutionally-sponsored and intentionally designed environments. Non-formal learning refers to learning that takes place in a designed environment but does not require learners to learn against formal learning outcomes. Because formal and non-formal contexts have resulted from a process of learning design, the presence of a teacher (or facilitator) is also common (Schugurensky, 2000). This contrasts with informal learning which is not highly structured and Marsick et al (1999) describe informal learning as being 'predominantly experiential and non-institutional' (p. 88) and they cite examples such as self-directed learning, coaching and mentoring.

A typical learning environment for individuals with T2DM could be characterised as a non-formal learning environment because there is a set of learning outcomes (improving nutritional patterns of behaviour, for example) and the availability of an expert conducting educational sessions. The similarity between this kind of environment and the one being proposed in the present study is the intentional nature of the learning design. The key difference, however, is that traditional modes of T2DM education are facilitated by experts (usually diabetes educators) but in this study a learning design consisting of a fully patient-centred online learning environment is being proposed. The patients or participants are being conceived as both practitioners and experts.

## A patient-centred approach

There is currently no universally accepted definition of patient-centred care (Kitson, Marshall, Bassett, & Zeitz, 2013) although there are three themes that run through what is considered to be a patient-centred approach to healthcare. One of these themes is what Kitson et al. (2013, p. 8) call 'patient participation and involvement' and this includes dimensions such as patient autonomy and active participation in the construction of management plans. Once the patient is conceptualised as possessing these attributes it then becomes possible to conceive of a learning environment in which this autonomy and agency can be further supported and consolidated.

The conceptualisation of patient autonomy and agency represents the first step towards the development of a patient-centred learning environment. Such an environment requires patient-centred learning activities which have the potential to engage learners in reflecting on their illness practices and the impact of their illness on their daily lives. The patient-centred approach in this project is underpinned by four components:

1. Authentic learning

2. Transformative learning

3. Sociocultural theory

4. Community of practice model

   **Authentic learning.**   In essence, authentic learning activities are embedded in situated learning contexts in which real-life knowledge and experience are engaged during the learning process (Herrington & Oliver, 2000; Herrington, Reeves, & Oliver, 2013). In the context of a

health-based learning environment, therefore, authentic learning activities engage learners in tasks that relate to their everyday experiences and practice of having an illness.

**Transformative learning.**   The theorist who is most closely associated with transformative learning (henceforth, TL) is Jack Mezirow (Kitchenham, 2008). Although the theory has gone through at least four different iterations (Kitchenham, 2008), the central idea has remained the same.

For adults, learning takes place either within the context of present frames of reference or it can begin to push the boundaries of a learner's frames of reference and begin to question those frames and move towards an understanding of the world in which a new frame of reference or meaning perspective is integrated in one's life. All of the versions of TL share this basic understanding of learning process although in this study Mezirow's (2000) conceptualisation of TL will be adopted because it best fits the nature of the present dimensions of this study due to the combination of instrumental and emotional/psychological characteristics of coping with a chronic illness. This version is outlined below in Figure 1-1.
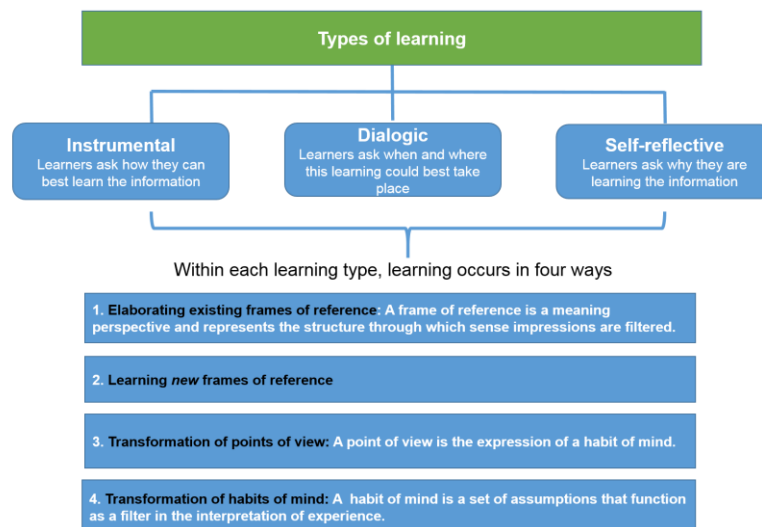


**Figure 1-1. Mezirow's version of TL (2000)**

To illustrate the process of transformative learning, Mezirow (2000, p. 22) has provided an outline of the phases of meaning that become clarified during the process of transformation:

1. A disorienting dilemma

2. Self-examination with feelings of fear, anger, guilt or shame

3. A critical assessment of assumptions

4. Recognition that one's discontent and the process of transformation are shared

5. Exploration of options for new roles, relationships and actions

6. Planning a course of action

7. Acquiring knowledge and skills for implementing one's plans

8. Provisional trying of new roles

9. Building competence and self-confidence in new roles and relationships

10. A reintegration into one's life on the basis of conditions dictated by one's new perspective

These events are not necessarily experienced in a linear fashion and there is broad acceptance by Mezirow and others (Mezirow, 2000) that the process of transformative learning is not necessarily a linear process and that the sequence of events described in the transformative process are not all experienced in a linear fashion.

In the design of authentic learning activities, an emphasis is placed upon engaging learners through contextually-based activities. In TL, the type of learning that may occur as a result of this participation is outlined (instrumental, dialogic and self-reflective) and TL is open to the possibility that any of these three learning types might promote learning that operates within frames of reference as well as learning that proposes a fundamental redefinition of the initial question or problem. TL is relevant to patient-based learning environments because the patient-

doctor relationship is rapidly evolving and frames of reference related to the patient/doctor

relationship (patient/doctor hierarchy, for example) are increasingly likely to be questioned,

especially in the area of chronic health in which patient self-management is encouraged.

**Sociocultural theory.**   Authentic learning activities constitute the building blocks of

the patient-based learning environment that is being proposed and TL provides the framework

for the types of learning that may occur in addition to the recognition that learners may operate

within present frames of reference, propose new ones or redefine the initial problem. The third

dimension in the patient-based learning environment that is being proposed, sociocultural theory

of learning, defines learning as a social process in which learning occurs as a result of social

interaction (Daniels, 2016).   Learning activities, in addition to being authentic and contextually

relevant, need to be designed in such a way that they promote interaction between participants in

the environment.

**Community of practice model.**   The term, community of practice (henceforth, CoP),

is generally attributed to Lave and Wenger (Hoadley, 2012) and in their early work (Hoadley,

2012), they outlined the fundamental features of learning as a situated and social process and,

more specifically, how learning occurs in a community through legitimate peripheral

participation. In later iterations, Lave and Wenger outlined a more prescriptive set of features

that define the nature of communities of practice (Wenger-Trayner & Wenger-Trayner, 2015)

such as domain (shared areas of interest), community and practice (community of practitioners).

A community of practice, in other words, can be defined as a community of practitioners who

share a common interest. This feature-based definition can also be used to describe an online

patient-based learning environment that is underpinned by sociocultural learning theory and in which shared areas of interest (T2DM) are mediated through authentic learning activities.

In the patient learning environment that is being proposed, the community of practice model will be adopted as the overarching unit of analysis. During the thesis, however, the term Potential Community of Practice (henceforth, PCoP) will be used to describe the unit of analysis because, although the intention in this project is to facilitate the design of a community of practice, the unit of analysis will be referred to as a PCoP until its status as a community of practice is evaluated.

## Research design and methodology

This was a qualitative research project and the primary mode of data collection was a range of semi-structured interviews conducted at various points during the research process. During the methods and methodologies chapter (chapter three) the alignment between the methods, methodologies and theoretical framework is outlined and the two central research questions are outlined:

1. How can an online patient-centred PCoP be established and;

2. Does an online patient-centred PCoP promote transformative learning? If so, in what way?

To address these questions, the following steps were undertaken.

1. The design and development of an online patient-centred PCoP.

2. The evaluation of the PCoP. This involved an analysis of the various iterations of the use of the environment. Design-based research (henceforth, DBR) was used to guide the

iterative process and activity theory (henceforth, AT) was used to frame the evaluative process.

In the preceding section, sociocultural theory was introduced and this theory is closely aligned with AT. Sociocultural theory asserts that learning and development results primarily from semiotic (i.e. speech) mediation that takes place in a social context (Daniels, 2004). AT is closely related to sociocultural theory and, as with sociocultural theory, also stems from the work of Vygotsky, although the unit of analysis is goal-directed activity. Both approaches, however, share the common assumption that cultural, social and historical forces shape learning and development.

The community of inquiry model (Garrison, Anderson, & Archer, 1999; Rourke, Anderson, Garrison, & Archer, 1999) was used to measure the levels of social interaction (social presence), knowledge sharing (cognitive presence) and facilitator involvement (teacher presence) in the PCoP.

**What is design-based research and why use it?**   Design-based research is a framework that has been used to help guide the process of the design, development and subsequent evaluation of proposed solutions to educational problems. It is seen as a methodological alternative to positivist or empirical approaches to educational research (Reeves, 2000) that lack situational depth and are limited in their scope to provide practice-based principles (Design-Based Research Collective, 2003).  DBR stresses the importance of an iterative approach to educational research in which phases of a solution are evaluated and modified and then applied to the problem under investigation. It is not easy, therefore, to indicate

when a project should end because this depends on a variety of factors during the stages of refinement of solutions to an identified problem.

In complex domains which have been under-theorised (such as this one) DBR is an appropriate methodology because it can help to begin the development of a set of practice and learning design principles in areas that have not received a great deal of attention in the literature. DBR, however, does not provide a set of evaluative tools since it is primarily a framework for the development of solutions to complex educational problems.

To fill this evaluative gap, AT was chosen to provide a tool to represent the various layers of complexity during each stage of the project.

**What is activity theory and what is its relevance?**   Online learning environments are complex socio-technical systems (Barab, Schatz, & Scheckler, 2004) and AT can be used to represent the social dimensions of learning environments (both internal in the learning environment and social relationships that exist outside the environment) in addition to the tools (online or otherwise) that individuals use to complete tasks or perform objectives. It is both a representational and a conceptual tool because it provides a language for schematising complexity and this language helps to conceptualise problematic areas (tensions in AT terminology) with a view to addressing them.

In this study, DBR was used to guide the development process in a domain that has been under-represented in the literature and AT provided the framework for the representation and conceptualisation of complexity and functioned as the theoretical lens through which learning was conceived.

**Theoretical perspective.**

The theoretical perspective that was adopted in this study is known as critical realism (Bhaskar, 1978; Walsh & Evans, 2014). The theory is a combination of an ontological positivism and epistemological relativism and is suited to the practice of research in the present context because it provided an epistemologically relativist foundation to the experiences of participants in the study as well as an ontologically positivist conception at the level of the pathophysiology of T2DM.

**The community of inquiry model and how it is used to measure social, teacher and cognitive presence in the PCoP.** Design-based research provides a framework for the design and development of practical solutions to educational problems leading to design principles relating to the context in question. In this project, AT functioned as a schema for the evaluation of the engagement in the PCoP. AT, however, does not provide the set of evaluative tools to measure the dimensions of engagement associated with online, collaborative learning environments. The community of inquiry model (Garrison et al., 1999) was adopted to address this gap. Therefore, the levels of social interaction and knowledge sharing that occurred during the engagement with the PCoP were measured using the dimensions of social, cognitive and teacher presence associated with the model.

## Chronic illness and technology

The presence of technology is ubiquitous and its effects on the practices associated with daily life are ongoing and profound. This project was an example of non-formal, online adult education in the context of T2DM and, as such, sits at the intersection between the educational affordances of online technology and the ongoing demands of self-management.

Technology is used extensively in the context of chronic disease management and this includes both web-based tools and 'wearable' technologies (Wildevuur & Simonse, 2015). Historically, web-based technologies have been used to deliver telehealth and telemedicine and there has traditionally been a biometric-oriented focus on the use of technology to transmit biomedical data. There is an indication, however, of a shift from the purely biometric application of technology to a model of technology use which is patient-centred (Wildevuur & Simonse, 2015). Patterns and examples in the use of technology in the context of chronic illness are explored in greater detail in the literature review. The review will indicate that the combination of online technology and its use in the context of T2DM self-management has the potential to be theorised and outlined as a nascent area of research.

This introduction concludes with an outline of the chapters that aim to carry out this goal.

## Clarification of terminology

**An online learning environment or community of practice?** During this thesis, the terms online learning environment (OLE) and potential community of practice (PCoP) will be used.

1. The OLE refers to the development and design of the initial learning activities that constitute the learning environment.

2. The PCoP refers to the *social* learning environment that was used by participants in the study.

**Are individuals in the study patients or participants?** The individuals who took part in this study can be characterised as patients because they were all individuals diagnosed with T2DM. The central challenge in this study was an analysis of a patient-centred approach to learning in the context of T2DM. At the same time, however, individuals can also be classified as study participants with a range of life experiences and histories in which T2DM plays a peripheral role. As a result, the term *participant* will be the preferred term that is used because it places an emphasis on the whole person and not just on the pathologised self.

## An outline of the thesis

**Chapter 2. Literature review.** In this chapter a review of the literature in technology and chronic care management, together with a survey of patient-centred learning environments, is provided.

**Chapter 3. Theoretical frameworks, methods and methodologies.** Key aspects of the methodologies (AT and DBR) that will be used have already been outlined and these will be further discussed in greater depth. The theoretical framework of critical realism that underpins the epistemological and ontological assumptions of this project will be outlined and the analytical method for the interpretation of interview data will be introduced and discussed.

**Chapter 4. Design of the PCoP.** A detailed outline of the steps that were undertaken to develop the initial learning design will be provided and this will introduce the reader to the use of AT in the representation of the complexity of the learning environment.

**Chapter 5. Learning designs and principles.** One of the characteristics of DBR projects is the importance placed on learning design principles that are derived from an analysis of the introduction of solutions at each iterative stage of a project. The principles associated with the initial learning designs are presented in this chapter.

**Chapter 6. Results.** This section represents the second major phase of the DBR project and represents an analysis of the use of the PCoP by several groups. Pre and post-use interviews were conducted and these interview data were analysed using thematic analysis. Design principles associated with each group's use will also be presented.

**Chapter 7. Discussion.**   Broader questions related to the methodologies used in the research are presented here together with reflections on the nature of the project and future research directions.

**Chapter 8. Conclusion.**   The thesis concludes with final reflections on the contribution that this research has made in the area of patient-centred learning and T2DM.

# Chapter 2. Literature review

There are two objectives to this chapter. The first is to review the nature of T2DM including the pathophysiology, epidemiology and treatment options that are available. This will lead to a discussion of the traditional pharmacological and non-pharmacological frameworks that are typically employed to address the treatment of T2DM. This will set the context for the second objective of the review. This will consist of:

1. A review of the traditional conception of technology in relation to the management of T2DM.

2. A review of the theoretical models and approaches associated with sociocultural models of learning, learning design, authentic learning and transformative learning theory.

These two reviews indicate that there is a gap in the literature in the development and subsequent analysis of online learning environments that are patient-centred, authentic and geared towards the development of patient agency and autonomy. A significant opportunity exists, therefore, to develop and evaluate such an approach and to use this approach to contribute to our understanding of the methodological and theoretical considerations of online patient-centred learning environments.

## Diabetes Mellitus: An Introduction

The metabolic disorder commonly known as Diabetes Mellitus (DM) is a condition characterised by high levels of glucose in the body or hyperglycaemia. Left unchecked, hyperglycaemia can lead to serious and life-threatening medical complications. Hyperglycaemia results from different

metabolic processes requiring different treatment regimes and requirements. These metabolic processes can be broken down into those that are characterised by deficiency in the level of insulin production and those that feature insulin resistance – the first process maps to the type of diabetes known as Type 1 Diabetes Mellitus (T1DM) and the second to T2DM.

For patients suffering from T1DM, treatment regimens will involve monitoring of diets, glucose levels in the blood and the regular administration of insulin with the aim of regulating and normalising glucose levels. The pathogenesis of those patients with T2DM , however, is more likely to reflect the multifactorial nature of the condition where the body's inability to use insulin effectively stems from a combination of the genetic predisposition to the development of T2DM (American Diabetes Association, 2008) and a range of lifestyle factors (e.g. lack of physical activity, sub-optimal dietary patterns) that contribute to the disruption of the metabolic processes that control glucose levels in the body (Powers, 2012). T2DM, therefore, is often referred to as a 'lifestyle disease' (Diabetes Australia Victoria, 2010). The third type of Diabetes Mellitus is known as gestational diabetes and, although it often clears post-partum, it can indicate an increased risk for the subsequent development of type 2 diabetes mellitus (Powers, 2012). To complicate matters further, however, effective treatment plans also depend on an understanding of the different pathophysiological stages of the disease. This is particularly the case in T2DM where primary prevention strategies might be used to target at-risk patients as opposed to the employment of tertiary prevention approaches for patients exhibiting full-blown T2DM and other co-morbidities.

**Type 2 diabetes mellitus.**  T2DM is the most common form of diabetes mellitus and it accounts for between 90-95% of diabetes cases (American Diabetes Association, 2008). The

aetiology of T2DM is characterised by a combination of genetic and environmental factors (Kahn, Vicent, & Doria, 1996) although the specific causes still remain unclear (American Diabetes Association, 2008).

    *Epidemiology.*   In a report investigating the projected rise of the prevalence of worldwide diabetes (Wild, Roglic, Green, Sicree, & King, 2004) it was estimated that the total number of people with diabetes will almost double between 2000 and 2030. In percentage terms, this represents a change from 2.8% in 2000 to 4.4% in 2030. This is also confirmed by worldwide epidemiological trends from the International Diabetes Federation suggesting large increases in prevalence rates across all parts of the world (International Diabetes Federation, 2007). Indeed, there is evidence to suggest that the greatest increase will take place in low and middle income countries with a particularly sharp increase in Asia  (Chan et al., 2009) where the increase is taking place among more affluent sections of the community. This contrasts against epidemiological trends in wealthier nations which suggest that lower socioeconomic groups are at higher risk of developing the disease (Shaw & Chisholm, 2003).

As would be expected, Australia is not immune from these global trends and statistics published by the Australian Institute of Health and Welfare (AIHW, 2008) and a 2005 AusDiab (Barr et al., 2006)  study confirm that the prevalence of T2DM is also increasing. In New South Wales (NSW), for example, this upwards trend is reflected in figures which point to a rise in the prevalence of diabetes mellitus from 6% in 2002 to 9% in 2016 (HealthStats NSW Centre for Epidemiology and Evidence, 2017). Increases in NSW in levels of obesity and lack of physical activity – the two main co-factors in the causal chain leading to T2DM – have also been observed (Australian Bureau of Statistics, 2010). T2DM is also over-represented in the

indigenous community in Australia with alarming disparities in prevalence between indigenous and non-indigenous across all age groups (HealthInfoNet, 2016).

Although the disease seems to be more prevalent amongst certain ethnic groups – indigenous populations in Australia (McDermott, Li, & Campbell, 2010; McNamara, Sanson-Fisher, D'Este, & Eades, 2011), for example – it is not clear whether it is particular genetic characteristics associated with particular ethnicities alone or a combination of genetics and environmental factors that predominate (Lu, Hu, & Gang, 2008). This multifactorial aetiological framework is complicated further because even though advances have been made in relation to the identification of genes responsible for the disruption of the metabolic system in T2DM (Smushkin & Vella, 2010), the exact mechanism of the gene-lifestyle interaction is unclear (Franks, Mesa, Harding, & Wareham, 2007; Lu et al., 2008).

*Pathophysiology.*   T1DM is a disorder of insulin production leading to elevated levels of blood glucose. The pathophysiology of T2DM, however, differs from T1DM and is essentially marked by insulin resistance and the failure of the β-cell to increase the level of insulin secretion to compensate for insulin resistance (American Diabetes Association, 2008; Kahn et al., 1996; Powers, 2012). In patients with T2DM, for example, glucose homeostasis is disrupted and the metabolic course of the disease is likely to begin with a diabetic patient exhibiting a near-normal level of glucose tolerance but as resistance to insulin increases, the pancreas is unable to sustain a level of insulin production to match the level of resistance and at this point, impaired glucose tolerance (IGT) develops. β-cell failure might then result in further declines in insulin secretion and increases in hepatic glucose production leading to the 'clinical hallmark' of diabetes i.e. hyperglycaemia in a fasting state (Kahn et al., 1996). This metabolic state can then lead to serious macrovascular and microvascular complications such as cardiovascular disease, stroke

and diabetic retinopathies, nephropathies and neuropathies (Fowler, 2008). Indeed, some have argued that stroke is two to six times more likely to occur in diabetic versus non-diabetic patients (Sander & Kearney, 2009) and is as strong a risk factor as a prior myocardial infarction for cardiovascular disease (Chamnan, Simmons, Sharp, Griffin, & Wareham, 2009).

Common risk factors for the development of T2DM include age, obesity and lack of physical activity (Kahn et al., 1996) although there is some debate about whether Body Mass Index (BMI) and not levels of physical activity might be a more appropriate predictor for T2DM (Fogelholm, 2010). Women who have had gestational diabetes are also at an increased risk of developing T2DM (Baptiste-Roberts et al., 2009).

T2DM, therefore, is a serious illness with significant physiological and pathological effects if it is not treated and can often result in shortened life spans (Leal, Gray, & Clarke, 2009).

*Treatment and prevention.* Chronic diseases are protracted in nature resulting in heavy psychological and physiological burdens for patients (Cudney, Sullivan, Winters, Paul, & Oriet, 2005; Whittemore & Dixon, 2008) as well as placing increasing pressures on healthcare systems attempting to manage often complex conditions. Their protracted nature is also complicated by the fact that there are often no known cures and that the conditions are unlikely to resolve themselves spontaneously (Dowrick, Dixon-Woods, Holman, & Weinman, 2005). It is no surprise, therefore, that the management of chronic illness has become an important discipline in its own right with its own set of issues and problems (Dowrick et al., 2005). In Australia, this is reflected in the existence and establishment of at least two centres (Flinders University's *Human Behaviour and Health Research Unit* and the University of New South Wales' *Centre for*

*Primary Healthcare and Equity*) focussing on issues of chronic disease management, self-

management strategies, policy issues, behavioural change and systems of coordinated care.

Although there are shared features between chronic illnesses as outlined above, each chronic

illness has its own set of therapeutic goals and targets. In the case of T2DM, the physiological

goal is for the patient to achieve an adequate level of glycaemic control in order to delay or

prevent the onset of complications associated with the condition (Avendonk & Rutten, 2009).

How this goal is achieved, however, depends on the therapeutic options that are available and the

way they are exercised. For example, should therapies be pharmacologically or non-

pharmacologically-based or a combination of both? To respond adequately to this question,

however, requires an understanding of the type of prevention strategy that is being applied – a

primary prevention strategy to *prevent* the growth of T2DM in the community differs

significantly from a tertiary level of prevention which is aimed at the management of

complications for patients already diagnosed with a condition. Additionally, the 'ideological'

position of the health professional could also be a factor with some favouring a disease-based

model and a central role for a polypharmacological approach to management (Spence, 2010).

*Pharmacological treatments.*   In a general practice context in Australia, a typical route

for the treatment of hyperglycaemia commences with a three-month programme of lifestyle

modification (improved dietary patterns and greater amounts of physical activity), the assessment

of blood glucose levels (BGL) using HbA1c (this refers to glycated haemoglobin and its

measurement reflects average glycaemia) after 3 months and, depending on BMI, the

introduction of oral hypoglycaemic agents (OHAs) – Metformin or Sulphonylurea – to help

reduce BGL if necessary. If the BGL target has not been achieved, traditional and new OHAs are trialled before the introduction of insulin.

*Non-pharmacological therapies.* From a clinical perspective, the most important issue for those with T2DM is the loss of weight, therefore, increasing levels of physical activity and adherence to particular dietary guidelines are seen as elements constituting the first mode of treatment for patients newly diagnosed with T2DM (South Australian Department of Health, 2002). Although the evidence base for the effectiveness of dietary and exercise-based treatment for patients *with* T2DM is not entirely conclusive, there is enough evidence to suggest that exercise alone helps to improve how the body reacts to insulin (Thomas, Elliott, & Naughton, 2006) and that exercise *and* following dietary advice can improve metabolic control (Nield, Summerbell Carolyn, Hooper, Whittaker, & Moore, 2008). The evidence for the *prevention* of T2DM seems to be slightly more conclusive and claims have been made that exercise regimes lead to reductions in HbA1c and greater insulin sensitivity (Zanuso, Jimenez, Pugliese, Corigliano, & Balducci, 2010) and that following dietary advice has a significant role in reducing the risk of developing T2DM (Nield et al., 2008).

*Patient adherence.* What the evidence-based research does not generally explore, however, is patient adherence to recommended treatment and, in the context of T2DM, there is evidence to suggest that patients are equally likely to erect barriers and resistance to insulin-based treatments (Brod, Kongsø, Lessard, & Christensen, 2009) and medication-based regimes (Mann, Ponieman, Leventhal, & Halm, 2009) as to non-pharmacological interventions (Lawton, Ahmad, Hanna, Douglas, & Hallowell, 2006). Additionally, there is also evidence that links poor patient understanding of T2DM with less effective management outcomes (Khunti et al., 2008).

The key, therefore, is that although *clinical reasoning* based on the most up-to-date research is used to develop treatment and illness management plans, patient reasoning, knowledge and health beliefs are perhaps more important in determining the eventual success or otherwise of proposed regimens (Khunti et al., 2008). This theme has also been reinforced by Mann et al (2009) where it has been shown that poor adherence to medication for low-income patients with T2DM is related to predictors such as concern about side effects, low levels of self-efficacy and a misunderstanding of the chronic nature of the disease amongst other variables.

*Intervention models.*   An understanding of the non-pharmacological approaches for patients with T2DM is central to the design of an intervention that is focussed on patient-based learning. Traditionally, non-pharmacological approaches have integrated a theoretical model (such as the transtheoretical, health belief model, theory of planned behaviour and social cognitive model) into an intervention; evaluation of the efficacy of the intervention is conducted to test the effectiveness of the construct under review. For example, the construct of self-efficacy, itself a by-product of social cognitive theory, is one of the most widely used constructs in the evaluation of interventions for people with T2DM (Lorig et al., 2012; Lorig, Ritter, Laurent, & Plant, 2006; Yu et al., 2012). These studies share a positivist framework to research design which tests for theory falsification, testability and controlling for variables (Lippke & Ziegelmann, 2008). There is, however, a fundamental difference in methodology adopted in these studies to the methodology and theoretical framework that forms the basis of the present study and this difference will be outlined in the following sections.

In addition to the fundamental differences at the level of methodology and theoretical framework adopted for the present study, the online platform through which the learning environment is

delivered is based on a conception of technology that is radically different from the traditional role of technology in the context of chronic disease management.

**Technology and chronic care management.**   The use of technology in the context of chronic care management often diminishes the level of patient agency in favour of a technological solution to self-management. This kind of 'technologism' represents the traditional approach to the integration of technology and patient health and the assumptions that underpin technology and its use in a health context are often overlooked. It is theorists of culture and society that are more likely to address these assumptions (Lehoux, 2008; Lupton, 2012). As Lupton (2012) says:

> "Will the 'nagging voices' of the health-promoting messages automatically issuing forth from a person's mobile device be eventually ignored by its user? Or will these messages incite even greater feelings of guilt and shame at one's lack of self-control and self-discipline? Alternatively, will m-health technologies produce a cyborg, post-human self in which the routine collection of data about bodily actions and functions is simply incorporated unproblematically into the user's sense of selfhood and embodiment? How will concepts of 'health' itself be shaped and understood in a context in which one's biometric indicators may be constantly measured, analysed and displayed publicly on Facebook or Twitter? Will the 'objective' measurements offered by mobile devices take precedence over the *'subjective' assessments offered by the senses of the fleshly body*?" [my italics] (p.242)

Lupton's point indicates a concern with the establishment of a hierarchy of validity in which the knowledge generated from studies that *measure* a range of objectively validated measurements

(HbA1C or self-efficacy, for example) is considered to possess more utility, importance and relevance than subjective accounts of illness and disease. This is a contentious issue and, in many ways, reflects what some people have called the 'paradigm wars' (Denzin, 2010) where methodological positions are taken that represent the spectrum of epistemological differences regarding the nature of knowledge, how it is generated, who generates it and why it is being generated.

This quote also suggests that if technology use, in the context of healthcare, is not critically appraised then its adoption can help to promote care that lacks a subjective dimension. In this project, on the other hand, technology (in our case, a web-based learning management system), is conceptualised as a tool that can promote learning and patients' agency vis-à-vis their self-management. This differs from the traditional approach regarding the role of technology in healthcare which does not view technology as embedded within a sociocultural network (Barnard, 1996).

*Technology in healthcare: a traditional approach.* A systems approach to chronic care management provides a language to model the information flows between human agents – patients and allied health professionals – and between machines – servers and clients. This approach is typically exemplified by a range of concerns and technologies such as electronic medical records, billing systems, clinical support decision systems, standards and coding systems and increasingly the use of handheld computers in healthcare settings (Rao, Hou, Golnik, Flaherty, & Vu, 2010). Chronic care management has now become a collaborative exercise between patients, allied health and medical professionals and this has resulted in the development of architectures to respond to this challenge. A typical architecture might include a home-based unit capable of recording and transmitting data (such as blood sugar levels) back to

a central storage server which can then be accessed by a primary care physician (Duplaga &

Winnem, 2006). This architecture says little about the level of education that might be needed to

engage with the technology but more about the information flows and feedback loops required

for the system to function effectively. Human agency, in other words, is minimalised and what

previously required a set of human interactions has been substituted by a flow of information

across machines (Papsdorf, 2015).

The approach adopted in this study, on the other hand, is concerned with the processes of

learning that underpin a patient's engagement with their own care and self-management. With a

health informatics or systems approach, technology facilitates and supports the flow of

information and tends to be neutral towards the level of engagement displayed by patients.  In

this study, technology facilitates a flow of ideas, knowledge and support and the effectiveness of

the technology is measured in terms of the way in which the objectives of transformative

learning are met. One is more a 'push' use of technology, the other an understanding of

technology as embedded within social practice. These two approaches reflect two different

paradigms of our understanding of the use of technology in chronic care management. The latter

paradigm is being adopted for the development of this project.

*Online web-based educational interventions.*   There have been numerous examples of

the use of technology and internet-based interventions in the context of diabetes and its related

risk factors (see Table 2-1). These studies differ over delivery methods and are mostly concerned

with exploring the role of technology-based interventions for improving metabolic parameters.

The studies have tended to analyse the results of *bespoke* systems that have been developed

using the backbone of the internet to deliver educational content or feedback mechanisms.

Although most of the studies displayed in Table 2-1 indicate a measure of success, three

systematic reviews from 2014 and 2016 (Cotter, Durant, Agne, & Cherrington, 2014; Hadjiconstantinou et al., 2016; Pal et al., 2014) suggest that the role of online technology and interventions across a range of constructs for people with T2DM is a contested area without clear outcomes. Technology-based intervention research is, therefore, still very much an embryonic field of research.

**Table 2-1. Selected examples of T2DM technology-based intervention studies from 2005 – 2015**

| Study | Delivery method/format/technology | Results |
|---|---|---|
| Noh et al. Web-based comprehensive information system for self-management of diabetes mellitus (2010) | Cell phone/Internet | Positive benefits for improving glycaemic control. |
| Yoo et al. A Ubiquitous Chronic Disease Care system using cellular phones and the internet (2009) | Cell phones/Internet | Improved multiple metabolic parameters. |
| Van der Weegen et al. It's Life: Mobile and Web-based Monitoring and Feedback Tool Embedded in Primary Care Increases Physical Activity: A Cluster Randomized Controlled Trial (van der Weegen et al., 2015) | Smartphone application | Improved levels of physical activity (in combination with counselling). |

| Liebreich et al. Diabetes NetPLAY: A physical activity website and linked email counselling randomized intervention for individuals with type 2 diabetes (2009) | Email/message board/online log | Improved levels of physical activity among participants. |
|---|---|---|
| Yoon KH, Kim HS. A short message service by cellular phone in type 2 diabetic patients for 12 months (2008) | SMS/Internet 'push' technology | Improved patients' blood glucose levels. |
| van Bastelaar et al. Web-based cognitive behavioural therapy (W-CBT) for diabetes patients with co-morbid depression: Design of a randomised controlled trial (2008) | Web-based/email | Not yet known. |
| Kim HS, Song MS. Technological intervention for obese patients with type 2 diabetes (2008) | Cell phone 'push' technology – patients sent optimal recommendations | Improved metabolic parameters. |
| Robertson et al. Control of type 2 diabetes mellitus using interactive internet-based support on a Northern Plains Indian reservation: A pilot study (2007) | Web | Improved HbA1c control. |

| | | |
|---|---|---|
| Quinn CC et al. WellDoc™ mobile diabetes management randomized controlled trial: Change in clinical and behavioral outcomes and patient and physician satisfaction (2008) | Internet/feedback supplied based on treatment/recommendations algorithm | Improved A1c levels. |
| Luzio S et al. Results of the pilot study of DIADEM: a comprehensive disease management programme for type 2 diabetes  (2005) | Web/Phone | Improved glycaemic control. |
| Lorig, K., P. L. Ritter, et al.  Online Diabetes Self-Management Program: A randomized study (2010) | Peer-led/Web | Improved self-efficacy. No improvement for participants on 'follow up' e-mail support lists. |

What is striking with these studies is the way in which most of them conform to one type of research design – most are designed as control-based studies where control groups are compared against those participating in the technology-based interventions. The main goal is to establish the effectiveness of technology usually in the form of internet-based interventions as a delivery mechanism for improving various outcomes associated with T2DM. What is not so clear, however, is how the interventions, at least in the examples above, were developed from the

perspective of theories of behavioural change or learning theories and this, I believe is an important omission and represents a significant gap in the literature. The studies, in other words, were under-theorised from the perspective of learning theory.

Another issue that arises from the reviewed literature is that most of the systems in question have been developed as systems to test a predictive variable of the research design without much consideration given to the educational design of the intervention[1]. This observation is reflected in the literature surveyed in PubMed, CINAHL or ProQuest (education database)[2] where there is little discussion of how the development of an intervention might benefit from the adoption of a rigorous educational design process. This is perhaps not surprising because the goal of a great deal of technology-based health initiatives is to explore the effectiveness of the delivery method in achieving clinical outcomes rather than a greater understanding of the educational design process itself. Indeed, this research trend is reflected in a  2010 'audit' of Internet and technology-based interventions in the treatment of diabetes (Kaufman, 2010) where most of the studies are concerned with the efficacy of the delivery method to improve outcomes .

The problem, therefore, is multidimensional and requires an approach that is more than the demonstration of the effectiveness of technology in relation to clinical outcomes. This project is a theory-driven approach and is interested in the development of a multi-dimensional, patient-centred approach to the development of technology-based educational interventions.

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[1] An exception to this is in Fonda et al (2010) where a user-centred approach to the development of a personal health application is adopted.

[2] A search was conducted without date restrictions using the search term "Type 2 diabetes" AND ("web-based" OR "web" OR "online") AND ("educational design" OR "learning design" OR "instructional design"). 47 results were returned from the ProQuest (education database) in which one study was relevant to the role of learning design in health-based interventions (Tamim & Grant, 2016) 6 studies were returned from CINAHL and none from PubMed.

## An authentic online patient-centred learning environment

The self-management of T2DM marks a clear shift away from a purely physician-directed approach to a philosophy of management that stresses the collaborative involvement between patients and allied health professionals in the co-construction of management plans. This shift, however, brings with it significant challenges with regards to the development of patient-centred learning designs. These challenges centre on the 'what' or the content of learning designs and the 'how' or pedagogical approach that is taken. Indeed, the variety of educational approaches applied to chronic care management reflects the multidimensional and complex nature of the problem. This variety has been highlighted in a meta-analysis of educational interventions in the context of T2DM (Fan & Sidani, 2009) where the following attributes of intervention elements were noted:

- Type of intervention (educational, behavioural, psychological, mixed)

- Teaching method (didactic, interactive, mixed)

- Strategies (Online/web, video, face-to-face, phone, mixed)

- Format (Group, one-on-one, mixed)

The authors were unable to identify any one attribute as having more predictive value in improving health outcomes compared to other elements but concluded that, across the range and types of educational interventions, effect sizes were greater for knowledge gain, improved blood sugar control and self-management behaviours. However, in a Cochrane review of the effectiveness of group-based learning versus individual patient education in the context of T2DM, no significant differences were found in terms of outcome measures (Duke, Colagiuri, & Colagiuri, 2009). This is an important finding for this study because it suggests that *format* (i.e.

group structure/size) might not be an important factor in establishing the parameters of the research design.

The results from this systematic review, however, need to be put in context because randomised controlled trials (RCTs) were the only designs under examination. In terms of research design, RCTs are significantly different from the research design proposed for this study and, although useful in highlighting the effectiveness of interventions measured by specific outcome measures, they lack the capacity to examine the meaning that patients ascribe to daily self-management practices, for example. This goal is much more likely to be carried out using an approach to evaluation that is qualitative in nature and that can analyse the cultural contexts (Greenhalgh, Chowdhury, & Wood, 2006) and subjective forces (Song & Lipman, 2008) which can play an important role in the practice of self-management. Ultimately, however, the RCTs in these studies are not learning environments. Rather, they are interventions designed to measure specific outcomes and this represents a marked difference from the objectives of this study.

**Authentic learning.** In the context of formal education, situation (the context) and cognition have often been separated and this has led to knowledge that is abstract and lacking in real-world utility. The theory of situated learning (Brown, Collins, & Duguid, 1989) addresses this by arguing that learning and context are inseparable and that any analysis of learning must include the situation or context in which learning takes place. The idea of authentic learning has emerged from this theory because it places an importance on learning activities that provide learners with an opportunity to engage in activities that reflect real-world contexts (Reeves, Herrington, & Oliver, 2002). Other design elements important to the authentic learning tradition include providing opportunities for collaborative learning and access to experts to provide modelling of

processes (Herrington & Oliver, 2000), promotion of social presence (Ryman, Burrell, Hardham, Richardson, & Ross, 2009) and opportunities for reflection (Reeves et al., 2002).

**The development of authentic learning environments.**   The term 'authentic learning' shares characteristics with a variety of theoretical positions on the nature of learning and its lineage can be traced back to the 'learning by doing' tradition developed by Dewey and later work on situated learning and anchored instruction (Herrington et al., 2013). The work of Herrington et al. (2013) has been instrumental in articulating the current model of authentic learning and its characteristics (these are design guidelines rather than prescriptive rules) of the model are outlined in Table 2-2 (adapted from Herrington et al.,2013).

**Table 2-2. Design guidelines for authentic learning adapted from Herrington et al. (2013)**

- An authentic context that reflects the way knowledge will be used in real life

- Authentic tasks

- Access to expert performances and the modelling of processes

- Multiple roles and perspectives

- Collaborative construction of knowledge

- Reflection

- Articulation

- Coaching and scaffolding

- Authentic assessment

Although authentic learning approaches have been used in a variety of formal learning contexts with a broadly stable set of theoretical assumptions (Herrington & Herrington, 2008), the amount

of literature related to the use of authentic learning strategies in the context of non-formal/informal learning lacks significant attempts [3] to develop theoretically principled accounts of how authentic learning can be used to support learning in a non-formal learning context. There is, however, one exception to this and Andersson and Andersson's article (2005) indicates how authentic learning can be used as one of the pedagogical foundations for the development of a community-based, inclusive learning environment. When the search is narrowed, however, the analysis, description and theoretical assumptions behind the development of authentic learning activities to develop non-formal patient-centred learning environments has not received attention in the literature [4].

**Learning design and communities of practice.** Online learning environments differ from traditional classroom settings because interaction between individuals is mediated by online tools and processes. In the development of these environments, significant and theoretically informed learning design decisions determine the type of tools that are used. Since the theoretical foundations of this study are predicated on the assumption that knowledge is the product of social interaction, the choice of tools in the learning management system (LMS) (e.g. forums) needs to be determined by the adopted theoretical approach (Huang, 2002). The community of practice model represents one conceptual framework for the development of an OLE and it will be adopted in this study. Although Lave and Wenger's model is characterised by

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[3] A search was conducted across the Education Research Complete (EBSCO), ERIC (ProQuest) and ProQuest education journal databases using the search term ("non-formal learning" OR "informal learning" with the Boolean operator "AND" and "authentic learning". The searches were conducted without date restrictions and across study abstracts. 1 study was returned from EBSCO, 4 from ERIC and 42 from the ProQuest education database. Of those returned, only one article (Andersson & Andersson, 2005) with a theoretical perspective aligned to the present project was of interest. The others were empirically-based studies conducted in formal learning contexts.

[4] Based on a combination of search terms including ("non formal learning" OR "informal learning) combined with the Boolean 'AND' operator for the search terms "patient" AND "health". The search was conducted across two medical/nursing databases (Pubmed and CINAHL) an education database – ProQuest. without date restrictions Although 24 studies were returned from Pubmed, 14 from CINAHL and 64 from ProQuest, none of them focussed on the development of patient-centred learning environments.

the defining feature of socialisation into practice through the process of legitimate peripheral participation (Cox, 2005) the model does not provide an account or a model of how an OLE can be run. Rather, as a theory of knowledge that falls within the tradition of situated learning theory (Hoadley, 2012), it provides a framework for understanding how knowledge is produced and replicated. The context in which this occurs can take place in an online or face-to-face environment. The affordances associated with online tools such as the capacity of representation in various formats (e.g. multimedia) and the distributed nature of online communication (Hoadley, 2012) means that the marriage between online platforms and the concept of communities of practice provides new and rich opportunities for distributed synchronous and asynchronous modes of interaction compared to traditional types of interaction. However, this does not address the question of the *design* of these communities and this is a crucial question because the present study is predicated on patients interacting through an initial set of learning designs.

The terms 'learning design' and 'instructional design' (the preferred term used in the United States) are often used interchangeably but learning design is the preferred term in this study because it anticipates the broader scope of the practice of design and indicates a learner-centred approach. In a formal educational environment, typical learning design elements include the design of learning activities and how these align with the objectives and the subsequent assessment of the concepts associated with the activities. The key difference between informal/non-formal and formal learning contexts, as Livingstone (2001) points out, is the presence or absence of institutionally-imposed curricular elements including, for example, assessment criteria.

With informal learning, the objectives, content and the means through which learning occurs is determined by the individuals engaged in the learning but with non-formal learning, a facilitator is likely to guide and facilitate the learning process (Livingstone, 2001). In non-formal learning environments, the alignment between learning activities and objectives is important because it frames the pedagogical intent behind the design of the learning environment. This enables learning activities and objectives to be aligned in such a way as to provide a learning environment which promotes participation and engagement.

Non-formal learning environments, therefore, can be designed and the community of practice model provides a framework for the practice of learning design in a non-formal context because it stresses the central role of a community of learners in sharing and constructing knowledge. Learning activities, within a non-formal community of practice, can be viewed as tools through which knowledge and skills sharing can take place.

There is a lack of research literature on the relationship between informal/non-formal learning design and communities of practice[5]. Although there is some work being carried out in the design of learning activities in the context of non-formal adult education (Yelich Biniecki & Conceição, 2016), there are no clear guidelines as to how to design effective and engaging learning environments in non-formal contexts using a community of practice model. To design these kinds of environments, the role of theory becomes crucial because it can inform the design beyond the parameters which current models offer. The sociocultural theory of learning is one

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[5] A search was conducted in ProQuest (education research complete and education database) and ERIC on the search terms "learning design" AND "community of practice" and ("non-formal learning" OR "informal learning"). Date restrictions were not specified. Most of the results were related to formal and work place educational environments. The ProQuest (education research complete) search returned 55 studies. One study about constructivist instructional strategies (Ruey, 2010) is relevant to the approach to learning design adopted in the present project. The search in ProQuest (education database) returned 106 studies none of which were considered relevant. The search in the ERIC database did not generate any results.

theory that can inform the construction of learning environments which intend to promote knowledge sharing and collaboration among its participants.

**Sociocultural models of learning and the construction of learning environments.**    Grabinger, Aplin, & Ponnappa-Brenner (2007) suggest that traditional approaches to learning design have roots in behaviourist models and are therefore unlikely to challenge learners to develop higher order and analytical skills. Sociocultural approaches, on the other hand, provide those working in educational contexts with the theoretical tools to construct learning environments that can promote exactly these kinds of learning outcomes through the construction of learning activities which stress the importance of knowledge sharing and peer-to-peer learning. This idea is not new and has roots that can be traced back to Vygotsky (Bonk & Kim, 1998; DeVane & Squire, 2012) but the ideas are powerful precisely because they provide a theoretical framework for understanding the nature of learning and subsequently the way in which learning activities and environments can be designed.

Adult learning theory is not a unified discipline. It is, as Merriam (2001) points out, a collection of approaches, models, theories and guiding principles that constitute the body of knowledge called adult learning. The theories of andragogy and self-directed learning are two important components of this body of knowledge (Merriam, 2001).

In terms of self-directed learning, the seminal work of Allen Tough (1971) represented the first systematic attempt to shape the discipline of self-directed learning (Merriam, 2001). In Tough's 1971 work, sixty-six adult learning projects were analysed and this yielded accounts of learning that were characterised by being systematic and conducted outside of the context of a formal

classroom or presence of an instructor. Some features of Tough's concept of self-directed

learning include learning that is intentional and deliberate, geared towards particular goals and

motivated to improve knowledge and skills. This type of learning became known as 'self-

directed learning' and has subsequently undergone various iterations of model-building and

refinement with regards to learning processes. Garrison's model (1997), for example, contains

three characteristics or dimensions: self-management, self-monitoring and motivation. Another

model, the staged model (Grow, 1991), advocates an approach to self-directed learning that

moves through stages of increasing levels of self-directed learning.

In a push to professionalize (and define) the discipline of adult learning, Malcom Knowles

resurrected the term andragogy (Davenport & Davenport, 1985; Knowles, Holton, & Swanson,

1998) to define the differences between the characteristics of learning for children and adults.

Andragogy defines the adult learner as someone who

- has the capacity for self-directed learning;

- uses their life experience as a learning resource;

- has learning needs that are aligned with changing social circumstances;

- has interests in knowledge that is problem-based and can be applied;

- is likely to be motivated by an internal desire to learn as opposed to external factors.

    (adapted from Merriam, 2001, p. 5)

These characteristics are broadly similar to the ones outlined by Illeris (2003, p. 22) who points

out that adult learners:

- draw on their own experiences during the learning process;

- align their learning with meaningful life goals or objectives;

- take responsibility for their own learning in which the level of responsibility is dictated by their own needs.

Adult learning (in a non-formal or informal context), therefore, is based on instrumental objectives, is grounded in lived experience (authentic learning) and is motivated by goals that fall outside the traditional goals of formal assessment found in a formal learning environment. In formal learning environments, adults encounter and engage in requirements that are determined by the institution and learning is driven, in large part, by the need to complete formal assessment tasks whether in the form of assessment *for/of* or assessment *as* learning (Laveault & Allal, 2016). In the absence of formal requirements and outcomes, therefore, the characteristics of adult learners become more prominent during the learning design process and these characteristics need to be engaged in the development of relevant and authentic learning activities.

***Transformative learning.*** Transformative learning theory is a theory of adult learning that draws on the ideas of sociocultural theory. The central concept that underpins sociocultural theory is "that human activities take place in cultural contexts, are mediated by language and other symbol systems, and can best be understood when investigated in their historical development." (John-Steiner & Mahn, 1996, p. 191). Learning and meaning making, therefore, take place in a social and cultural context and transformative learning theory argues that the way in which people view and make meaning of the world is determined by their frames of reference that have accreted in an individual through a variety of social interactions over time (Mezirow, 1997).

Mezirow (1997) points out that the goal of adult learning is the development of autonomous thinking but to concentrate solely on instrumental (the accrual of knowledge and skills) objectives does not, in and of itself, facilitate the development of this objective. The key insight of transformative learning, a theory championed and developed by Mezirow (Kitchenham, 2008), is that adult learning is a combination of instrumental knowledge and what transformative learning theorists refer to as communicative or dialogic reasoning. This dimension of learning refers to those aspects of the learning process that question the 'frames of reference' through which our beliefs, value and meaning systems are developed (Mezirow, 1997).

In Mezirow's 1985 version of his theory (Kitchenham, 2008; Mezirow, 1985), there are three types of learning – instrumental, dialogic and self-reflective. Instrumental learning is concerned with the mastery of the external world (e.g. procedural mastery of daily management tasks including dietary planning, taking medication etc.), dialogic learning refers to sharing experiences and perspectives (Lee & Brett, 2015) and self-reflective learning questions the assumptions, beliefs or values upon which information, knowledge of curriculum items are

based. Mezirow argues that three learning processes occur across these three types of learning. These are outlined in Table 2-3.

**Table 2-3. Definition of instrumental and self-reflective learning. Adapted from Kitchenham (2008)**

**Instrumental learning**: learning that involves practical mastery of the external world (e.g. procedural skills, planning diets etc.).

**Dialogic learning**: learning that involves sharing experiences and perspectives.

**Self-reflective (or communicative learning)**: learning which questions the assumptions of a given point of view or practice.

The three processes of learning that occur across these types are:

- Learning that occurs within present frames of reference.

- Learning that incorporates new frames of reference to understand the world or to conduct an instrumental task differently.

- Learning that involves the redefinition of a problem because new frames of reference provide an insufficiently rich framework to resolve a problem. Mezirow calls this transformative learning through meaning transformation.

In terms of the application of transformative learning in the context of health, the way in which a patient interacts with their health professional is likely to be determined by their frame of reference vis-à-vis the social roles that are enacted during a medical visit. This might result in an interaction in which the patient is a passive partner (*uncritical patient),* a more active participant (*critical patient)* or, in the case of chronic disease, a fully engaged patient involved in the co-construction of his or her management plans (Brendel, 2009). In the language of transformative

learning, the shift from being an uncritical patient to a critical patient would involve a shift in a frame of reference and result in meaning transformation.

Patient-based learning, therefore, is a rich area for the application of transformative learning theory because the frames of reference (assumptions, prior knowledge and sets of beliefs and values) that patients bring to the doctor/patient relationship or how an instrumental task is applied have the potential to be interrogated and challenged in a peer-based, collaborative learning environment.

*Transformative learning and patient-based learning.* The establishment of a balance between everyday life and coping with diabetes is a daily challenge (Kneck, Klang, & Fagerberg, 2012). Learning, therefore, can play a vital role during what Glaser and Strauss (1968) have called the *illness trajectory.* This term was subsequently adopted by Corbin and Strauss (1985) to describe and categorise the various types of 'work' undertaken during the course of a chronic illness. The integration of instrumental knowledge in the daily life of an individual is likely to take place in conjunction with the requirement for 'biographical' work and a process of reassessment of one's life. These dimensions provide rich contexts for the application of adult learning and it is not surprising, therefore, that a range of educational approaches such as transformative, self-directed and problem-based learning have been applied in various chronic illness contexts (Baumgartner, 2011).

Transformative learning has been applied in a variety of chronic illness contexts such as HIV (Baumgartner, 2005), occupational therapy (Dubouloz, 2014), stroke (Kessler, Dubouloz, Urbanowski, & Egan, 2009) and rheumatoid arthritis (Dubouloz, Laporte, Hall, Ashe, & Smith,

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2004). A literature search in the context of transformative learning and diabetes [6] has revealed

studies in the literature with a focus on the application of transformative learning in a nursing

context (Smith-Miller & Thompson, 2013), transformative learning and its use in improving

health literacy and diabetes knowledge (Ntiri & Stewart, 2009) and the role of adult learning

theory (including transformative learning) in the context of chronic illness (Baumgartner, 2011).

Apart from these studies, however, there is not an extensive literature of the application of

transformative learning in the domain of diabetes either from the perspective of health

professional education or patient education[7]. This is somewhat surprising given the fact that

diabetes is one of the most commonly identified chronic conditions although, as we have seen,

the dominant paradigm in health and patient educational interventions tends to centre on the

investigation of models of health behaviour and their effectiveness in promoting behavioural

change (Webb, Joseph, Yardley, & Michie, 2010).The  traditional paradigm in health-based

educational interventions investigates the effectiveness of a particular model or theory of health

behaviour and *not* the creation of learning communities such as the 'online communities model'

referred to by Bleakley (2014)  where "…information is exchanged, and people support and

empower each other…through such activities patients may become experts in their own

conditions, more knowledgeable certainly than the family doctor." (p.93). The online

communities model views education and learning as a social process where the emphasis is on

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[6] Using EBSCO (education research complete), ProQuest (education database) and ERIC databases searches were conducted using the search term "transformative learning" and the Boolean AND with "diabetes". Date restrictions were not specified. The EBSCO (education research complete) search returned 58 results. The ERIC search returned 6 studies and the ProQuest (education database) returned 106 studies. Apart from three studies (Baumgartner, 2011; Ntiri & Stewart, 2009; Smith-Miller & Thompson, 2013) there was an absence of studies focussing on the role of transformative learning in the context of diabetes.

[7] . A search was conducted without date restrictions using the search terms "transformative learning" AND "diabetes" AND ("health professional education" OR "doctor education" OR "patient education") in the CINAHL, PubMed and EBSCO (education research complete databases. 9 results were returned from CINAHL, 0 results from PubMed and 9 from EBSCO.

the educational support, guidance and facilitation that can be provided during this process (Davenport & Davenport, 1985).

The management of T2DM is a complex process requiring both medical staff and patients' understanding of the appropriate treatment for the distinct phases of the condition. If complications arising from the disease are present, then this is likely to add to the uncertainty of clinical outcomes and more complex treatment plans. As the seriousness of the condition escalates, greater burdens are placed on the healthcare system and the health of the patient and greater questions are asked of the patient's ability to pursue an effective self-management regime. Therefore, not only is T2DM complex from the perspective of its aetiology and its pathophysiological progression but its complexity is also related to the management of the *chronic* nature of the disease. It is the combination of these different layers that is driving multidimensional approaches to management and this in turn requires a shift in our understanding of how to treat the condition (Bowman, Gregg, Williams, Engelgau, & Jack, 2003).

In a more patient-centred model of T2DM management that is being suggested in the current study, there is a greater emphasis on the emergence of patient autonomy as patients are required to become more involved in self-care as they liaise with relevant sectors of the healthcare community. One of the challenges is that if patients are required to become more involved in their own care they need to have a greater understanding of the *procedural* aspects of self-care (following an OHA regimen, an insulin-based treatment plan or testing their BGL, for example), the *preventive* aspects of self-care (i.e. lifestyle modification) as well as an overall understanding of T2DM as a metabolic disorder requiring often complex responses. Although T2DM educational programmes often contain these elements , it has been shown that knowledge alone

(or what Mezirow (1997) and Habermas would call instrumental learning) is not sufficient to increase levels of patient self-management (Heisler, Piette, Spencer, Kieffer, & Vijan, 2005).

**Transformative learning and online learning.** The context of online learning in the domain of higher education yields a far greater number of studies in the literature compared to its application in domains associated with chronic illness. A search was conducted[8] and search results for peer-reviewed articles were variable but the search mostly yielded articles about transformative learning and learning design considerations in various higher education contexts such as graduate courses in education (Boyer, Maher, & Kirkman, 2006; Reushle & Mitchell, 2009), undergraduate history units (Keegan, 2011) and a university course in intercultural understanding (Barraclough & McMahon, 2013). These examples could be considered case studies of the use of transformative learning with pedagogical intent.

Aside from case studies, the search also yielded articles that could best be described as theoretical position papers concerned with transformative learning perspective in education (Kalogeras, 2013) and one article focussing on learning design considerations and transformative learning outside of the formal educational context (Ryman et al., 2009). Proportionately, there are a great deal more articles that deal with the application and integration of a transformative learning framework in higher education context than in community or informal/non-formal settings. These settings lack some of the characteristics of institutionalised formal learning such as formal awards or explicit assessment outcomes and summative assessment tasks (Eraut, 2000).

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[8] The search terms of "transformative learning" with a boolean AND and "online" were used using EBSCO, ProQuest and ERIC databases from the year 2000 which was the period when the internet was reaching a degree of maturity in the community.

To sum up, the learning contexts that have employed transformative learning identified in the searches conducted to date have focussed on formal learning environments. There is, therefore, a significant opportunity to develop a theoretically principled learning environment based on transformative learning theory, authentic learning and sociocultural approaches to health-based adult learning in a non-formal context.

## Summary

It has been well documented that T2DM represents a significant health challenge for the community not only in Australia but worldwide. Significant effort has been employed to develop pharmacological and non-pharmacological strategies to deal with the phenomenon. Most of these approaches, however, have employed traditional methods. Pharmacological approaches target the disease at the level of physiology and most non-pharmacological approaches (support and educational interventions) have designed their interventions to test for efficacy against psychological or health promotion constructs or against biomarkers that function as proxies for the success of an intervention.

The approach adopted in the present study differs markedly from the traditional non-pharmacological approach because it represents the development of a principled and theoretically informed learning environment utilising a combination of a sociocultural model of learning, transformative learning and authentic learning theory.

Most theories have been developed over time and transformative learning theory is not an exception. There have been four major iterations of the theory (Kitchenham, 2008) and although they share similar characteristics, the version that will be adopted in the present study is found in Mezirow's (2000) version of his theory. Here, the three types of learning – instrumental, dialogic

and self-reflective – are identified as central components of the learning process through which meaning is negotiated via frames of reference and these components align with the dimensions of learning associated with the practice of self-management: instrumental learning aligns with learning procedural skills for T2DM self-management, dialogic learning represents the importance of learning through social interaction and self-reflection is a process through which frames of reference can be challenged, complemented or solidified. These three dimensions will be under investigation during the evaluation of the use of the learning environment.

The lack of exemplars in the literature that combine sociocultural theory, transformative learning and authentic learning design in a health-based, non-formal learning context points to a significant opportunity to explore and analyse the process of the development and use of a learning environment underpinned by a combination of these theories and approaches. The opportunities presented by approaches and models identified in this section will be addressed by this project in the following way.

The authentic learning environment will be developed from interviews and focus groups. The interpretation of the interview data will form the basis of authentic, patient-centred learning designs. The sociocultural model of learning identified in this section will provide the theoretical foundation for the design of a learning environment that participants will use to address the domain of self-management; this environment will be defined as an online community of practice. The learning objectives of the community will be shaped by the characteristics of transformative learning. The combination of these elements will underpin the authentic, patient-centred learning environment and learning will take place in an online-mediated environment in which participants will have the opportunity to share knowledge and self-management practices.

This represents a significant shift in the traditional application of technology in the domain of management of chronic illness.

Finally, the measures that have been applied to measure the success of an intervention have traditionally been psychological constructs or biomedical markers. This project will take a different approach and measure the nature of the learning that takes place through the lens of transformative learning theory.

The results of the evaluation of the use of the learning environment will be presented in chapter six and a discussion of the results will follow. In the next chapter, the methods, methodologies and theoretical perspectives will be described for the development of an online, patient-centred learning environment.

## Chapter 3. Theoretical frameworks, methods and methodologies

This chapter outlines the theoretical frameworks, methods and methodologies that were adopted for the development and trial of a patient-centred PCoP for individuals with T2DM.

The aim was to develop the initial set of learning designs (the learning environment) for people with T2DM. Unlike other web-based support and learning environments for people with T2DM, the intended outcomes were not measured against combinations of behavioural outcomes and biophysical measures (Glasgow et al., 2012; Lorig et al., 2010), or other measurement outcomes identified as important in the maintenance of self-care such as communication with health professionals or level of education (Wilkinson, Whitehead, & Ritchie, 2013) but against the theory of transformative learning associated with the work of Mezirow and others working in the field (Baumgartner, 2011; Mezirow, 1994; Mezirow, 2000). A sociocultural conception of learning was adopted in the development of the OLE with the intended objective of the development of a community of practice (Wenger, 1998) in which the shared repertoire of practice and knowledge becomes the foundation of an authentic, community-based resource for self-management for people with T2DM.

The study was conducted in two stages. These are described below.

The objective of the **first stage** was the development of a PCoP for people with T2DM. To pursue this aim individual interviews and focus groups were conducted. Individual interviews were held with people diagnosed with T2DM and the purpose of these interviews, using a semi-structured interview schedule (appendix 5), was to investigate the range of dimensions associated with how people coped with and managed their illness. Following on from the individual interviews, a semi-structured interview schedule (appendix 6) was developed based on the themes that emerged from the interpretation of the data from the individual interviews. The purpose of these focus group sessions was to investigate the role of education

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and technology in the management of T2DM. Thematic analysis was used to construct a set of interpretive claims or thematic elements based on the individual interviews and focus groups that were conducted. These elements, together with relevant criteria already established in the literature (Penn, Moffatt, & White, 2008; Whittemore & Dixon, 2008), were used to develop the PCoP. The learning designs that formed the basis of the PCoP were implemented in a popular open-source learning management system called Moodle©.

The aim of the **second stage** was to examine and investigate the nature of a nascent online patient-centred PCoP against the framework of transformative learning theory. To address this objective an iterative approach informed by DBR methodology (Anderson & Shattuck, 2012; Design-Based Research Collective, 2003; McKenney & Reeves, 2013) was adopted to evaluate the nature of the participation in the PCoP. Activity theory (Barab et al., 2004) was used to describe and conceptualise the emerging tensions and contradictions as four groups used the PCoP over the period of one year.

The PCoP was used by four groups and usage by each group represented one iterative phase of the cycle. Before and after each iteration, interviews were conducted with members of the participating group (either individually or group-based). A self-efficacy questionnaire (Beckerle & Lavin, 2013) was also administered at the beginning and end of each group's engagement. Changes to the learning designs were subsequently made after interview data had been analysed.

The following sections outline in detail the theoretical framework of the study, epistemological approach and the methods and methodologies associated with both stages of research. Ethics approval for the study was sought and obtained from the University of Western Sydney (University of Western Sydney H9440) and the Ethics Review Committee (RPAH zone) of the Sydney Local Health District (HREC/11/RPAH/160).

In the following sections, the elements that constitute the theoretical framework and methods and methodologies of this study will be outlined. These elements have been compiled into a table (see Table 3-1).

| Theoretical perspective | Epistemology and ontology | Methodologies | Data collection tools and methods |
|---|---|---|---|
| •Transformative learning<br>•Social constructionism | •Critical realism: ontologically realist and epistemologically constructivist | •Design-based research<br>•Activity theory | •Interviews (individual and focus groups)<br>•Questionnaires<br>•Personal email correspondence<br>•Online forums<br>•Thematic analysis and framework approach |

**Figure 3-1. The four components of the theoretical framework and methods and methodologies**

These elements will be addressed in the following order:

1. Theoretical perspectives

2. Epistemology and ontology

3. Methodologies

4. Methods

## Theoretical perspectives

**Transformative learning.** Patient autonomy has traditionally been seen as one of the foundations of medical ethics. There is not, however, a universally agreed definition of what it means. The traditional meaning of autonomy is derived from the philosophical tradition associated with Kant and Mill (Campbell, 2017) in which individuals are conceptualised as free to make their own decisions. The idealised individual makes these

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decisions based on their own values and free from external forces. As applied in the context

of healthcare, however, this definition is problematic because the environment of medical

care is inherently a social environment. This has given rise to models of patient autonomy

which are a great deal more nuanced and address the cultural, social and interpersonal

dimensions of a modern healthcare environment (Clayman, Gulbrandsen, & Morris, 2017;

Entwistle, Carter, Cribb, & McCaffery, 2010). The vast amount of information that is now

available to patients via the internet is an additional dimension that alters the traditional

balance between patients and health professionals (Tan & Goonawardene, 2017). Modern

patients, therefore, can find themselves in an environment in which patient autonomy can feel

like a burden and not an asset as they might feel overwhelmed with the amount and diversity

of available information especially if they have had negative health information seeking

experiences (Jiang & Street, 2017) . This environment, however, provides opportunities for

educators because of its complexity and the demands that it places on individuals, rather than

being a barrier, can be seen as the first step towards learning that is transformative in nature.

Transformative learning theory has developed a range of perspectives and interpretive

frameworks that have evolved over time. During a learner's life, however, the perspectives

that one is comfortable with can be challenged by what transformative learning theory calls

'disorienting dilemmas' (Mezirow, 1990b). These events constitute part of the learning

process in which individuals reassess the assumptions and interpretive frameworks that

determine their behaviour, values and belief systems. Transformative learning theory,

therefore, can be used as a framework to assist in the development of greater learner

autonomy as individuals navigate the psychosocial complexities of their illness and begin the

process of challenging the assumptions that they might have demonstrated with regards to

their illness. This is consistent with  the domain of adult learning as adult learners seek the

meaning of learning outcomes for their everyday practice as autonomous learners (Mezirow, 1997).

An illustration of the process of transformative learning might involve the mastery or competence of a procedure. Learning might initially take an instrumental form (learning how to perform more competently in any given domain) but it might end in personal beliefs and values being challenged and replaced with a new world view or, as Mezirow puts it, a frame of reference (Mezirow, 1997). In this case, previous assumptions are rejected in favour of a new set of personal values and beliefs. For Mezirow, the goal of transformative learning is to effect a change in a 'frame of reference'.

Transformative learning theory is one component of the theoretical framework that underpins this study, the other is the notion of social constructionism that falls within the family of sociocultural theory.

**Sociocultural theory and learning.** The underlying assumption of the model of learning associated with the idea of a CoP is the social nature of the learning process. This sociocultural understanding of learning has its roots in the work of Vygotsky (Hung & Chen, 2001) and it underpins the CoP tradition (Daniels, 2016; Hung & Chen, 2001). This contrasts with alternative theories of learning such as behaviourism or cognitivism which focus on the individual learner's repertoire of behaviours – in the case of behaviourism – and a model of learning concerned with the individual learner's underlying cognitive structures in the case of cognitivism (Murtonen, Gruber, & Lehtinen, 2017).

In this study, a sociocultural model of learning was adopted and this is reflected in the nature of the PCoP and the learning designs that were proposed.

**Epistemology and ontology.**   The adoption of ontological and epistemological positions constitutes an essential stage in the overall theoretical shape of qualitative research. Ontology is the study of the nature of reality and epistemology the study of ways of knowing about the world including the relationship of the researcher to those being researched (Creswell, 1998). In this study, healthcare is a domain in which biomedical science and its immediate beneficiaries – individual human beings – represent the main actors. It is a complex field because the knowledge claims made by biomedical science (the existence of an objective realm that is separate from the knowledge of the objective realm) are applied in the context of care at the level of individual patients. The ontological and epistemological status of an illness codified and interpreted by biomedical science is, therefore, very different from its status as an embodied experience.

The primary interest in this study lies at the level of how individuals experience chronic illness (T2DM) and the design, implementation and subsequent engagement in a learning environment that promotes knowledge sharing and collaborative practice. Since individuals are likely to experience illness in different ways this illustrates an epistemology that has constructionist roots in that there is the recognition that the realities of individuals are likely to differ and be determined by different life histories and trajectories. This contrasts with a positivist epistemology which argues that the goal of research is to measure and make knowledge claims about the one objective reality (Williams, Rycroft-Malone, & Burton, 2017).

For this study, critical realism was adopted as the underlying theoretical model to underpin the ontological and epistemological foundations of the research. The reason for this was that the theory provided a way of conducting the study that addressed the epistemology behind the subjective experiences of illnesses as well as the ontological status of T2DM. For example, during the individual interview stage of this research, the main interest was to explore and

investigate individual experiences of living and managing T2DM. The strategy for

conducting the focus group interviews was subsequently built upon the insights that emerged

from the interpretation and analysis gathered during the individual interviews. A critical

realist approach allowed the researcher to account for multiple ways of knowing and

experiencing the illness but at the same time to recognise the pathophysiological dimensions

of the illness.

      **A critical realist perspective.**  Critical realism is closely associated with the work

of the British philosopher Roy Bhaskar (Dyson, 2006). There are two key ideas in this

philosophical tradition that are important for the present study. The first is the idea of the

*epistemic fallacy* and the second relates to the notion of ontological levels. According to

Dyson, who builds on the work of Bhaskar, (Dyson, 2006), the epistemic fallacy is

committed when epistemology and ontology are conflated. Postmodern theorists in the

context of disability studies, for example, argue that the biological body can be reduced to

what is known about the body (Williams, 1999). This represents an epistemic fallacy because

the ontological realm exists outside of the realm of epistemology. Drawing a distinction

between the ontological and epistemological enables critical realism to position itself as

ontologically positivist and epistemologically constructionist. Why is this distinction

important in the context of health research and patient education? Walsh and Evans (2014)

provide a compelling argument for the relevance of critical realism in the context of the

research and practice of midwifery. Critical realism, as we shall see shortly, can also provide

a theoretical lens for our understanding of the relationship between people with diabetes and

the disease itself. As we have seen, one of the mechanisms for revealing the experiences of

people with diabetes is the interview but what does critical realism have to say about this data

collection method? The theoretical justification for the data collection method of the semi-

structured interview for people with T2DM can be made in the following way.  Bhaskar

(1978) argues that there are three ontological levels: the empirical, the actual and the real. The real is a generative layer or set of mechanisms that trigger and stimulate those events at the level of the actual. The events at the level of the actual are caused by these generative mechanisms and the empirical represents the layer of observable phenomena and the experiences of these phenomena. In terms of T2DM, the actual and the real inhabit the level of reality as it relates to the pathogenesis and diagnosis of the disease and the empirical to the observable and empirical phenomenon associated with the condition. One of these observable phenomena is Charcot's syndrome or Charcot's neuropathy (CN) which is, in turn, a complication of diabetic neuropathy. During the December 2012 focus group session one of the participants recounted an encounter between herself and a health professional. The diagnosis of CN was made on the basis of the participant's swollen foot, her own insensitivity to her foot and the misalignment between her bones with the joints in her foot. These were the observable and empirical signs generated by processes at the ontological level of the real. The following tables (Table 3-1 and Table 3-2) represent how CN might be characterised using Bhaskar's schema.

**Table 3-1. Ontological levels of CN using Bhaskar's three ontological layers**

> **Three ontological levels of CN**
>
> **The observable and empirical and individual experiences**
>
> - Individuals experience insensitivity in foot
>
> - Architectural misalignment between bones and joints
>
> - Swollen foot
>
> - Ulceration
>
> **The actual**
>
> - The emergence of the event (CN) caused by generative mechanisms

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**The real**

- Diabetes is one of the generative mechanisms of the development of neuropathy.

- The pathogenesis of those patients with T2DM reflects the multifactorial nature of the condition where the body's inability to use insulin effectively stems from a combination of the genetic predisposition to the development of T2DM (American Diabetes Association, 2008) and a range of lifestyle factors (e.g. lack of physical activity, sub-optimal dietary patterns) that contribute to the disruption of the metabolic processes that control glucose levels in the body (Powers, 2012). T2DM, therefore, is often referred to as a 'lifestyle disease' (Diabetes Australia Victoria, 2010).

**Table 3-2. The epistemological layer of CN**

**The epistemological layer of CN**

- Labelling of the complication (CN) by a health professional.

- To paraphrase Maxwell, critical realism is ontologically realist and epistemologically constructionist (Maxwell, 2012).

- Disease labels do not constitute the disease itself (Williams, 1999). As such, there is no one fixed epistemology of CN and, by extension, a fixed epistemology of other complications associated with T2DM does not exist either. Epistemologies of the real are historically and contextually contingent and describe but do not constitute the disease itself.

This kind of three-tiered model of ontology (Table 3-1) is commonly understood in the medical literature and forms the foundation of the biomedical reasoning process. Its importance for this study, however, lies in the fact that the level of the real is, to use Bhaskar's terminology, intransitive. This means that the identified mechanisms operate independent of mind and society – a complication can occur regardless of whether it is labelled with a formal diagnosis. How the symptoms and complications are managed by patients, however, will differ depending on a range of factors and therefore the relationship to the disease *by each individual* at the level of management is contingent on their attitudes, beliefs, values and knowledge. The interpretation of these differences is not a question of ontology but of epistemology.

Patients in this study share the common diagnosis of T2DM and therefore the generative mechanisms associated with the condition. A commonly shared disease is likely to result in a range of similar concerns but the way in which people cope and manage these concerns is also likely to be a function of individual contexts, characteristics and histories. The flexible nature of the semi-structured interview can capture this diversity and epistemological contingency but it can also reflect the idea that generative mechanisms can cause a range of common and shared symptoms.

     ***Critical realism and communities of practice.***   As with the first stage (interviews and focus groups), the second stage (participation and engagement in the PCoP) was underpinned by an ontological and epistemological perspective informed by critical realism (Nairn, 2012; Walsh & Evans, 2014). Although differing at an ontological level, the epistemological constructionism associated with critical realism aligns with a social constructionist perspective on learning because both share the assumption that knowledge and meaning are products of social interaction. Social constructionism can trace its roots from Vygotsky through to situated cognition and the community of practice perspective (Hung & Chen,

2001). The central idea behind the community of practice perspective exemplified in the work of Brown and Duguid (1991) and Lave and Wenger (Lave & Wenger, 1991; Wenger, 1998) states that the unit of analysis associated with learning does not reside at the level of the representation of mental schemas but rather that learning is best exemplified as a set of relational transactions between people as they interact in context and with each other (Hoadley, 2012). This idea sits closer to a metaphor of learning that is participatory rather than acquisitional (Sfard, 1998). It is a conception of learning that is embodied, situational and relational in which meaning is generated from the learning context.

For Lave and Wenger (1991) learning in a community of practice is defined as a process of legitimate peripheral participation in which a process of enculturation enables a learner to move from novice to expert through the sharing of knowledge and practices associated with the community. The objective of the current project was to design the initial conditions for the potential emergence of a community of practice. This in turn could provide the conditions for the emergence of expert patient facilitators to moderate and help sustain a set of shared online practices to encourage a self-sustaining community of practice.

## Methodologies

**Design-based research and activity theory.** Design-based research projects are characterised by a focus on local, authentic contexts from which learning design principles emerge after a series of iterative changes to an educational intervention are analysed and investigated (Anderson & Shattuck, 2012). The iterative cycles characteristic of DBR start at the point where practical problems are identified either in the literature or between researchers and practitioners (or both) and end with a set of guiding principles for learning design that have emerged from the use of the solutions in practice (Lautenbach, 2011;

Reeves, 2000; Reeves, Herrington, & Oliver, 2005). The DBR tradition has been criticised from various perspectives.

Dede (2004) argues that it is unclear at what point a study should be abandoned or be considered sufficiently promising for further exploration to take place. DBR has also been criticised for lacking a mature conceptual foundation and lacks the tools to "…do real design work in generating, selecting and validating design alternatives at the level at which they are consequential for learning." (diSessa & Cobb, 2004, p. 80) Additionally, due to the very specific contexts in which DBR studies are conducted, it has been argued (O'Donnell, 2004) that findings are too specific to the local context which makes it difficult to make generalisations based on an analysis of a study.

The DBR process in this study began with interviews and focus groups of people with T2DM. The aim was to elicit authentic empirical data relating to T2DM management and the identification of the scope, quality and nature of educational provision for people with T2DM including outlining the gaps in current levels of provision and future learning and educational needs. The interpretation of these data resulting in a thematic analysis of the empirical data represents the first phase of the DBR process in Figure 3-2. During the second phase, the first set of learning design principles that formed the first version of the PCoP were developed. Phases three and four relate to the iterative cycles of refinement of these principles based on real-world use of the learning environment.

The generation of a final set of learning design principles based on the evaluation of the iterative cycles concludes the DBR process in this study.

Design-based research phases · Implementation

| | |
|---|---|
| 1 | Analysis of practical problems by researchers and practitioners in collaboration |
| 2 | Development of solutions informed by existing design principles and technological innovations |
| 3 | Iterative cycles of testing and refinement of solutions in practice |
| 4 | Reflection to produce final 'design principles' and enhance solution implementation |

**Initial principles**
• Use of narrative
• Patient-centred approach to education
• Learning in a social context

**Data collection and thematic analysis**
• Interviews
• Focus groups

**Development of the potential community of practice (PCoP)**
• Design principles
• Learning designs are instances of principles
•Learning designs integrating aspects of data and themes from interviews and focus groups

Group 1 → Design principles
Group 2 → Design principles
Group 3 → Design principles
Group 4 → Design principles

Reflective practice and design principles

**Figure 3-2. Representation of design-based research based on the 'design-reflection-design' model (Amiel & Reeves, 2008)**

**The cyclic iterations.**   DBR projects are characterised by a process of 'design-reflection-design' (Amiel & Reeves, 2008) leading to a set of design principles derived from the implementation of a set of learning activities in a real-world context. Therefore, the point at which an intervention in a DBR project is completed is difficult to define because the set of iterations is likely to be affected by contextual factors as well as the aim and objectives of the study. In this study, four iterative cycles were deemed sufficient to derive a set of design principles that were contextually relevant and yet sufficiently abstract to be of interest to other education practitioners working in a similar field.

**Activity theory model.**   The roots of AT lie in the tradition of Russian psychology that argues that consciousness is not separate from behaviour but is part of a unified process through which activity in the world takes place. It is the concept of activity that sets AT apart from theories of human behaviour and other psychological models that tend to start from an investigation of the subject as the unit of analysis. AT posits that activity is the central unit of

analysis and that the fundamental characteristics of human behaviour are revealed through an analysis of activity (Kaptelinin & Nardi, 2006).

Human activity takes place in a sociocultural context and the relationship with the world is mediated through physical or conceptual tools. "Activity theory adopts the basic tenet of Vygotsky's theory that tools occupy a mediating role in human interaction with the world." (Verenikina, 2010, p. 19).

Physical or external tools are designed to manipulate or change the nature of the physical world (for example, machines) and serve as the means through which an intended activity is carried out. Internal or conceptual tools (e.g. theories, diagrams, models) are viewed as mediating layers through which activity takes place (Verenikina, 2010).

As is the case with theories that have had far-reaching consequences (Marxism, for example, has spawned a range of variants), AT has undergone at least three significant iterations since its inception. Engestrom (2015) is widely attributed with taking the original ideas of AT developed by Leontiev and Vygostky and creating a variant of AT with a set of interrelated categories through which activity can be understood. In addition to the subject/object/tool triad, Engestrom's model included rules and norms, community and division of labour. As pointed out by Engestrom, "[t]he concept of activity took the paradigm a huge step forward in that it turned the focus on complex interactions between the individual and his or her community." (pp. 134-135). An additional component of the work of Engestrom is that an analysis of the interrelated layers is likely to reveal factors that enable outcomes being met or as barriers to outcomes being realised. These factors can then be analysed with a view to changes being made in further iterations of a collective system or process (Bligh & Flood, 2017).

AT has been employed to serve various purposes in a range of contexts (Bligh & Flood, 2017). Using terminology adopted from Bligh and Flood (2017), AT has been used in this study to *apprehend complexity* and to *situate contexts*. The design of an OLE or PCoP assumes a set of complex relationships between learning designs and participants and these relationships can be examined once learners engage with the environment. This is at once a recognition of the complexity of the relationships that make up a learning environment (apprehension of complexity) as well as the specific characteristics of these factors (situated contexts).

AT was used as a theory to evaluate learner engagement in the PCoP and as a theory to help describe the characteristics of the learning environment. With this in mind, the initial learning designs for the first group and subsequent groups were described and represented using AT and this draws on work that has been carried out in the area of learning design and AT (Jonassen & Rohrer-Murphy, 1999; Uden, 2007).

The symbols used in the tables that make up the description of the learning designs were generated using the CompendiumLD package (see Table 3-3). This system has its roots in an Open University and Joint Information Systems Committee (JISC) project (The Open University, n.d.). The AT model follows the representation of AT associated with second generation activity theory associated with Engestrom (2015) but includes learning activities as one of the tools and mediating artefacts in a learner's engagement with a learning environment. This extends the work of those working in the field of AT and learning design since learning activities are often not explicitly identified in activity theory-centred work on learning design (DeVane & Squire, 2012; Jonassen & Rohrer-Murphy, 1999; Uden, 2007).

**Learning design and activity theory.** Learning Design is the practice of the development of learning designs as well as the discipline concerned with exploring the nature

of learning activities conceived of as patterns for learning. These patterns might reflect a range of pedagogical assumptions but at the basic, micro level a learning design is "…is a plan for potential activities with learners, which is to be distinguished from a particular implementation of this plan with a particular group of learners...The implementation of a learning design with a particular group of learners is called 'a running sequence'(Dalziel et al., 2016, p. 23). This conception of learning design (Dalziel et al., 2016) places an additional emphasis on the shareable nature of learning designs. Several learning designs may then be aggregated to form a larger set of activities covering a particular topic and these learning designs might then feed into the curriculum as a whole. This view of learning, however, is centred around learning as it is conceived in a formal environment and this is not fully representative of the learning context in this study. Therefore, although the discipline of learning design possesses the conceptual tools to describe the sequence and patterns of learning activities, the broader contextual parameters of the factors that have an impact on learning in an informal or non-formal context are lacking. This is not, in and of itself, a criticism of a learning design, rather an admission that a learning design approach is limited in the parameters that it can claim to represent. The power of AT as a schematic representative tool is that it can be inclusive of generic learning designs as well as reflecting the wider contextual factors that feature in a community of learners. Unlike Learning Design, it is not a tool for the construction of learning activities but can be conceived of as a tool for the representation of context within any given learning environment.

For example, AT tells us that learning activities represent one object through which educational activity is mediated. Others include tools and the rules and norms or educational discourses through which both designers and learners engage with the development and consumption of the required task. These and other parameters are outlined in Table 3-3.

**Table 3-3. The parameters of AT and their use in the learning design of the PCoP**

| Activity Theory parameter | Use in learning design |
|---|---|
| Learning activity | This is the learning activity or set of activities that constitute the learning tasks and requirements. |
| Subject | The learners using the learning environment. |
| Object and goals | Learners engage with tasks and peers in the learning environment. |
| Outcomes | The educational outcomes of learning activities. |
| Tools and mediating artefacts | Tools and resources can be physical (books, computers, internet) or conceptual. |
| Rules | These rules can be explicit or implicit. An explicit rule relates to task instruction and an implicit rule from the patient's perspective may be their lack of trust in the healthcare system which will have an impact on the relationship with their health professional. From a learning designer perspective, an implicit rule might be that learners have the capacity to interact with a computer using a keyboard. |
| Community | The patients are all members of the community and this includes networks such as family and friends. |

| | The level of collaboration in any given activity may depend on the characteristics of the group (subject), familiarity and capacity with the tools available, the help and support from others (community). |
|---|---|
| Division of labour | |

The theory, therefore, can be used as a tool *during* the construction of learning activities to remind practitioners of the importance of the modulating effects of context on participation and engagement with learning activities. As iterative changes are made to the learning environment AT becomes less of a tool for the design of a contextually-bound environment and more of an evaluative tool for guiding the development of learning activities and a tool for reflecting on their effectiveness. In the chapter on the use of the PCoP as a potential community of practice (chapter 6), AT will be further outlined and explored.

**The Community of Inquiry framework – a tool used to evaluate engagement with the PCoP.**   The Community of Inquiry (CoI) framework is associated with the work of Garrison, Anderson and Archer and their influential paper published in 1999 (Garrison et al., 1999). Philosophically, the framework represents an attempt at marrying two of the central components of Dewey's philosophy of education: inquiry and community (Karen, Garrison, & Jennifer, 2009). Concerned that these two dimensions could be lost in the technologism associated in the emerging area of online learning (Karen et al., 2009), a framework (CoI) to guide the development of pedagogically principled online learning environments was proposed. It is, as Maddrell et al. outline, "a theoretical framework for the optimal design of online learning environments to support critical thinking, critical inquiry, and discourse among students and teachers" (Maddrell, Morrison, & Watson, 2017, p. 245). The model proposes that the design of learning

environments, whose aim is the support of critical inquiry in a community of learners, needs

to be guided by design elements that can support this objective. In the CoI model, these

interdependent and multidimensional elements are called social presence, cognitive presence

and teacher presence. The framework is represented in Figure 3-4.
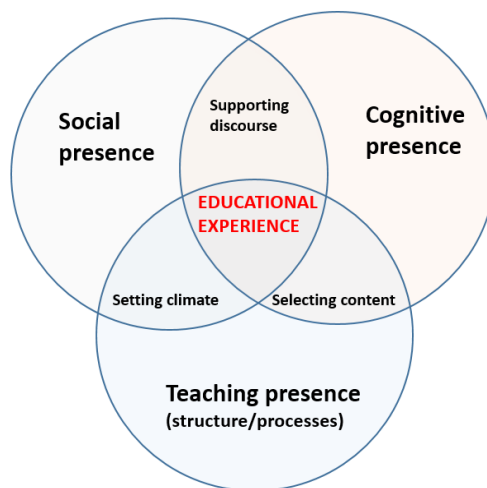


**Figure 3-4. The Community of Inquiry framework from Garrison et al (1999, p. 88)**

Social presence in an online community of learners is defined by indicators such as affective

expression, group cohesion and level of social interaction; Cognitive presence relates to  the

degree to which meaning is constructed and negotiated through sustained levels of reflection

and discourse in the community; Teaching presence includes factors such as the provision of

direct instruction, task and curriculum design and levels of facilitation (Akyol, Garrison, &

Ozden, 2009; Karen et al., 2009). The indicators that were used to evaluate the extent to

which these presences were in evidence in the PCoP were taken from Rourke et al (1999) for

social presence, Rodriguez (2014) for cognitive presence and Anderson et al (2001) for

teacher presence. The categories associated with each presence and their indicators are

outlined in Table 3-4, Table 3-5 and Table 3-6.

**Table 3-4. The dimension of social presence and its indicators from Rourke et al. (1999)**

### *Social presence*

| Category | Indicators |
|---|---|
| Affective | • Expression of emotions<br><br>• Use of humour<br><br>• Self-disclosure |
| Interactive | • Continuing a thread<br><br>• Quoting from others' messages<br><br>• Referring explicitly to others' messages<br><br>• Asking questions<br><br>• Complementing, expressing appreciation and expressing agreement |
| Cohesive | • Use of vocatives<br><br>• Addresses or refers to the group using inclusive pronouns<br><br>• Phatics (use of language to begin and sustain social interaction), salutations |

**Table 3-5. The dimension of cognitive presence and its indicators from Rodriguez (2014)**

### *Cognitive presence*

| Category | Indicators |
|---|---|
| Triggering | • Recognises, or identifies problems, concepts or issues<br><br>• Describes only the assigned reading |

| Exploration | • Adds to established points but does systematically defend/justify/develop |
| --- | --- |
| | • Presents relevant background information related to discussion topic |
| | • Asks questions seeking specialised information |
| | • Offers opinions |
| Integration | • Explores potential solutions, applications or conclusions |
| | • Draws conclusions or summarises discussion |
| | • Reference to previous message followed by substantiated agreement |
| | • Substantiated building on, adding to others' ideas |
| | • Synthesis: connecting ideas, integrating information from various sources |
| | • Providing rational justification |
| Resolution | • Applying, testing, defending or critiquing solutions or conclusions |
| | • Suggests applications or action to take |
| | • Commits to solutions or conclusions |
| Non-cognitive | • Clarifying discussion procedures |
| | • Encouraging |
| | • Not coded, off topic |

**Table 3-6. The dimension of teaching presence and its indicators from Anderson et al. (2001)**

*Teaching presence*

| Category | Indicators |
|---|---|
| Instructional/learning design and organisation | • Setting curriculum <br><br> • Designing methods <br><br> • Establishing time parameters <br><br> • Utilising medium effectively <br><br> • Establishing netiquette |
| Facilitating discourse | • Identifying areas of agreement/disagreement <br><br> • Seek to reach consensus/understanding <br><br> • Encouraging, acknowledging or reinforcing student contributions <br><br> • Setting climate for learning <br><br> • Drawing in participants, prompting discussion <br><br> • Assess the efficacy of the process |

| Direct instruction | <ul><li>Present content/questions</li><li>Focus the discussion on specific issues</li><li>Summarise the discussion</li><li>Confirm understanding through assessment and explanatory feedback</li><li>Diagnose misconceptions</li><li>Inject knowledge from diverse sources</li><li>Responding to technical concerns</li></ul> |
|---|---|

There is disagreement about how the dimensions of the CoI interact and contribute to student learning (Maddrell et al., 2017); context can also play a role in assigning different degrees of importance to the three interacting presences (Akyol et al., 2009). However, a recently conducted (2016) thematic synthesis of the use of the CoI framework (Kineshanko, 2016) has revealed that the framework continues to be used as a tool to guide the practice of learning design in online and blended learning contexts. This may be particularly important in non-formal contexts of learning, such as the present one, which may require that a greater emphasis is placed on the development of social presence in a learning community (Akyol et al., 2009).

## Phases of the iterative design-based research

### Phase one of the design-based research: analysis of practical problems by researchers and practitioners in collaboration

**Interview and focus groups.**   The objective of **phase one** was to develop a PCoP for people with T2DM. To implement this objective, individual interviews and focus groups were conducted for people with T2DM. The purpose of these interviews was to provide an authentic community perspective on experiences with living with T2DM. Allied with relevant themes from the literature, the themes emerging from these experiences were subsequently used to develop a set of authentic learning activities which informed the learning activities in the learning environment.

**The target population.**   A homogenous sample was sought using a purposive sampling approach (Palinkas et al., 2015). The target population was adults aged between 18 and 65 with one inclusion criterion, namely, a current diagnosis of T2DM. Since recruitment advertisements and flyers were placed in local libraries and newspapers, all of the patients (with the exception of one) were from the south west of Sydney. The patients, therefore, reflected a geographical homogeneity. This homogeneity, however, was a serendipitous effect rather than an intended outcome of the recruitment process.

*Recruitment of individual interviewees.*   An advertisement was placed in newspaper in South Western Sydney (Bankstown) seeking participants interested in taking part in one-on-one interviews to discuss their experiences of T2DM. Before the interviews, they were provided with participant information sheets (appendix 1).

Three Females and one male were interviewed. Interviews were held between the dates of December 2011 and December 2012. A semi-structured interview (appendix 5) was

conducted based on the McGill Illness Narrative Interview (Groleau, Young, & Kirmayer, 2006).

The purpose of the one-on-one interviews was twofold. Firstly, the narrative accounts of individuals with T2DM that were elicited during these interviews were subsequently used as learning design elements within the learning environment. Secondly, the analysis of the interviews was used to generate a set of concerns, issues and experiences that could then be validated, contested or complemented with the focus group participants. The focus groups became a forum for the interpretation of the results arising from the individual interview stage. This combination of individual and focus group data is an example of a 'triangulated' data set in which the interplay between interpretive findings at the individual and group level enhances the trustworthiness and interpretive richness of the findings (Lambert & Loiselle, 2008).

The individual interview represented the initial starting point for a patient-centred approach to the development of a PCoP. A sample size of four was therefore deemed sufficient to underpin this initial stage since the goal was not the attainment of thematic saturation. A description of the individual participants, their ages and method of recruitment is outlined in Table 3-7.

**Table 3-7. Method of recruitment of individual interviewees**

| Number of individuals | Gender | Age range and mean | Method of recruitment |
|---|---|---|---|
| 4 | Three females<br>One male | Age range: 45-70<br>Mean: 67 | Local newspaper advertisement (Bankstown) |

*Recruitment of focus group participants.* During September 2012, another advertisement was placed in a South Western Sydney newspaper (Campbelltown). A purposive sampling approach was taken (Palinkas et al., 2015) and participants were required to be between the ages of 18 and 65 and to have a current diagnosis of T2DM.

This advertisement (appendix 4) resulted in the recruitment of eleven participants with at least two of the participants being 'recruited' by one focus group participant. Focus groups were held in November 2012 and December 2012. A semi-structured schedule was used to conduct the sessions (appendix 6).

The function of the focus groups was to generate a range of ideas and perspectives on education and T2DM and the role of technology in the delivery of education for T2DM. The method of the focus group was chosen because it allowed participants to engage in collective meaning-making (Wilkinson, 1998). The themes that emerged from the interpretation of the interview data, together with relevant dimensions from the literature, contributed to the learning designs in the PCoP.

The focus group represents one of the data collection methods used to underpin the strategy of an iterative interpretive cycle that includes all phases of the study. The sample sizes at each phase therefore needed to be sufficiently powerful to generate data (and therefore themes) at each stage of the data collection process but they did not necessarily need to be powerful enough to generate thematic saturation because the data (and themes) at each phase formed a set of interpretive claims that were used to inform subsequent phases of the project. It is an example of a 'triangulated' data set (Lambert & Loiselle, 2008).

**Table 3-8. Description of recruitment of focus groups**

| Number of | Gender | Age range and mean | Method of |
|-----------|--------|--------------------|-----------|
|           |        |                    |           |

| participants | | | recruitment |
|---|---|---|---|
| 11 | **Focus group one** (November) <br><br> • Five males <br><br> • One female <br><br> Total=6 <br><br> **Focus group two** (December) <br><br> • Three males <br><br> • Two females <br><br> Total=5 | **Focus group one** (November) <br><br> • Age range: 58-65 <br><br> • Mean: 62 <br><br> **Focus group two** (December) <br><br> Age range: 50-65 <br><br> Mean: 57 | Local newspaper advertisement (Campbelltown) and 'snowball' recruitment |

**Interpretive frameworks for the analysis of data**

*The analysis of individual data.* The semi-structured interview recognises potential commonalities at the physiological/ontological and experiential levels and the fact that the questions were loosely structured around pre-defined themes indicates a recognition that experiences are likely to differ across different contexts. One person's management experiences are likely to be different from the next person's even though they share the same diagnosis and this claim is supported by the highly contextual nature of management strategies for T2DM documented in various studies (Chowdhury, Helman, & Greenhalgh, 2000; Clar, Barnard, Cummins, Royle, & Waugh, 2010; Concha et al., 2009). The varying types of management strategies in these studies are built around epistemological concerns relating to individual psychological constructs (self-efficacy, for example) underpinned by personal histories and contexts. In the context of chronic disease more broadly, individual management strategies are a combination of personal knowledge, skills and attitudes and the

practice of management (lifestyle changes, carrying out daily procedures etc.) (Audulv, Asplund, & Norbergh, 2012; Whittemore & Dixon, 2008). A tension emerges, however, when management is treated as if it was an ontological category featuring a set of universal mechanisms and procedures independent of context.

The aim of the individual interviews was to address this tension by providing a space for the expression of individual knowledge and experience related to management and experiences of living with T2DM. Capturing the partial, incomplete and contingent layer of knowledge associated with management strategies was the goal of the interpretation of the interview data.

Semi-structured interviews aim to collect data that is subjective and context-rich. As the set of questions are not rigidly structured, opportunities for the exploration of the subjective experiences of participants can be utilised. Since the participant's epistemological relationship to the world is viewed as a process of continual negotiation between the participant and the world around them, the semi-structured interview is a mechanism for capturing how different participants construct meaning in their own contexts (Barriball & While, 1994). This does not mean, however, that common experiences do not exist and the fact that a semi-structured interview begins with a set of reference points or questions underpins the idea that the semi-structured interview can be viewed as a method that aligns with a critical realist perspective on the ontological reality of illness and the way that illness is experienced and negotiated by individuals.

*The analysis of focus group data.* Themes that emerged from the interpretation of the individual interviews (for example, characteristics of self-management and the relationship with health professionals) in addition to more specific questions

concerning the provision of education and the role of technology for people with T2DM were combined to form the semi-structured interview schedule for focus groups (appendix 6). The use of the semi-structured approach for the focus groups complements the methodological reasons outlined in the previous section except the objective during the focus groups was to focus on the provision of educational services and the role of technology in education for people with T2DM. The semi-structured interview was used as a tool for focussing on specific questions related to these dimensions (Kelly, 2010).

*Data collection.* Individual interviews, focus groups and personal communication with participants represented the sources of data for the first phase of the study. Other forms of data were available during the second phase such as personal communication, interviews (individual and group), self-efficacy questionnaire results and engagement in the PCoP.

*Data analysis and validation.* Thematic analysis (Braun & Clarke, 2006) was used to analyse the data from the individual and focus group interviews. Thematic analysis, as Braun and Clarke (Braun & Clarke, 2006) point out, is a method used in qualitative research to identify, analyse and record patterns (or themes) in data. The claim is that precisely because it is not bounded by a set of parameters determined by a theoretical framework, thematic analysis can be used as a method to guide the extraction of patterns in data in research projects with varying theoretical perspectives. Thematic analysis is, therefore, a method and not a theoretical perspective. It is the adopted epistemological framework that drives the epistemological assumptions that are made relating to the data but the method itself remains agnostic to these assumptions – its job is to help guide the analysis of the data and as a tool to assist in the process of the interpretation of data.

The analysis of individual interview and focus group data was conducted using Braun and

Clarke's (Braun & Clarke, 2006) steps for thematic analysis (see Table 3-9) and the

affordances of nVivo © (software for facilitating the practice of qualitative research) enabled

the data and themes to be recorded and analysed systematically.

**Table 3-9. The stages of thematic analysis from Braun and Clarke (2006, p. 87)**

| Phase | Description of the process |
|---|---|
| 1. Familiarizing yourself with your data: | Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas. |
| 2. Generating initial codes: | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. Searching for themes: | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Reviewing themes: | Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis. |
| 5. Defining and naming themes: | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. |

The process that was used to analyse the individual interviews followed the steps outlined in

Table 3-9 but phase two was conducted in two stages. In the first stage, each individual

interview was analysed (phases one through to five) and this produced a set of themes that

were specific to each individual participant. The set of themes were then analysed for patterns

and common thematic elements (phases two through to five).

In terms of the focus group data, the process was less inductive than the analysis of individual data because the semi-structured interview schedule was directed to address specific questions with less of a focus on individual life histories. The analysis was carried out in a two-stage process (similar to the analysis of individual data). The first focus group was analysed, followed by the second and the themes related to each focus group were generated (phases two through to five). The themes were then subsequently analysed for common patterns and these (phases two through to five) and a final set of themes related to both focus groups was generated. A numerical value was provided to indicate the number of participants who contributed to a theme although it is not clear whether the establishment of prevalence in qualitative interpretation contributes to qualitative research findings (Braun & Clarke, 2006).

The process of analysis conducted for the individual interviews and focus groups reflect the recursive nature of the process of thematic analysis (Braun & Clarke, 2006).

Cresswell (1998) suggests that there are eight data validation strategies available to qualitative researchers that can enhance the credibility and trustworthiness of results from qualitative research. He suggests that at least two of them should be employed in a qualitative project (Creswell, 1998, pp. 201-203). In this study, three out of four of the most commonly utilised validation strategies were employed. A fourth commonly used strategy, member checking, was not applied as a validation strategy because it is not clear whether member checking enhances the outcome of research findings (Thomas, 2017). The data validation strategies that were used are listed in Table 3-10.

**Table 3-10. Three of Cresswell's evaluation data validation strategies. Adapted from Cresswell (1998, pp. 201-203)**

| Data validation strategy | Objective | How strategy was employed |
|---|---|---|
| Prolonged engagement and persistent observation in the field | Checking for misinformation, building trust with participants, observational rigour. | Observational diary entries were kept to enhance understanding of context, contact with participants was maintained prior to interviews. |
| Triangulation | Checking themes against extant literature (theory triangulation). | Engaged in reflexive process of interpretation of data throughout the interview stages. |
| Rich, thick descriptions | Refers to the reliability of transferability of findings. | Contextual data was provided about the participants to enhance the potential for transferability. |

**Phase two of the design-based research: development of solutions informed by existing design principles and technological innovations.**

The learning designs developed for phase two of the DBR process were implemented using various tools in Moodle©. This is an open-source platform providing a range of options for the construction of various types of learning activities (Moodle.org, 2013). The platform was designed to allow access via personal logins that were provided to the participants.

**Phase three of the design-based research: iterative cycles of testing and refinement of solutions in practice.** Phase three of the project represented the use-phase in which four groups over the course of 2014 and the early part of 2015 engaged

with the system. Interviews were conducted with participants (either individually or in groups) before and after their engagement in the PCoP. The participation by each group represented one iterative (Figure 3-5) cycle in the design process.
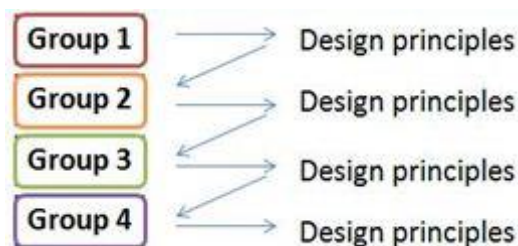


**Figure 3-5. Iterative cycles of the DBR process**

***Recruitment of participants for the PCoP***.   Participants were recruited using various recruitment strategies: a local South Western Sydney newspaper (Campbelltown), leaflets in two South Western Sydney area local library networks (Bankstown and Wollondilly), word of mouth and one example of 'snowball' (Lewis-Beck, Bryman, & Futing Liao, 2004) recruitment. Participants were required to be aged between 18 and 65 and newly diagnosed with T2DM (<= two years) – a key period for educational interventions that can mitigate the onset of further complications (Hastings & Chandler, 2015). Due to difficulties in recruitment, however, the newly diagnosed criterion was relaxed.

*Group one.*   Recruitment took place during February 2014 and use of the system began in March 2014. All the participants in this group were individually interviewed before participating.

*Group two.*   Two participants from the previous group were members of the second group and recruitment for new participants took place in May 2014. Use of the PCoP began in June 2014.

*Group three.*   Recruitment for the third group took place during September and October 2014 and use of the PCoP began in November 2014.

*Group four.*   Recruitment for the fourth group took place during January 2015 and use of the PCoP began in February 2015.

**Table 3-11. Method of recruitment of PCoP participants**

| Number of participants | Gender | Age range and mean | Method of recruitment |
|---|---|---|---|
| 12 | Seven female Five male | **Group 1:**<br><br>Age range: 39-55<br><br>Mean: 46<br><br>**Group 2:**<br><br>Age range: 45-65<br><br>Mean: 55<br><br>**Group 3:**<br><br>Age range: 51-56<br><br>Mean: 53<br><br>**Group 4:**<br><br>Age range: 44-55<br><br>Mean: 50 | Local newspaper advertisement (Campbelltown), local libraries (Wollondilly shire and Bankstown) and 'word of mouth' referrals |

***Methods of data collection and analysis for participation in the PCoP***

*Data collection.*   All participants were either interviewed separately or as part of a group both before and after their participation in the PCoP. A semi-structured schedule was used for the pre (appendix 7) and post-use interviews (appendix 8). Before the

interviews, participants were given participant information sheets to familiarise themselves with the nature of their participation. In addition, they were required to sign consent forms (appendix 2). The dimensions of interest in the pre-use interview included how technology was used in an everyday context, the role of technology in changing relationships (including those with health professionals) and establishing what kind of technology might be useful for improving diabetes self-management. The post-use interviews included the identification of the expectations of engaging with the PCoP, the nature of the learning environment including ease of use and relevance for self-management, the level of interaction amongst the participants and the role of technology in self-management and how the learning environment might be improved.

Other data sources included personal communication between the participants and the researcher, written content during participation in the PCoP and website usage in the form of usage statistics. Self-efficacy questionnaires were administered at the beginning and end of each group's participation.

*Data analysis.* The thematic analysis approach described by Braun and Clarke (Braun & Clarke, 2006) was used to analyse all the individual and group-based interviews conducted prior to and after participation in the PCoP. As with the interview and focus group data associated with the development of the learning environment, the stages of thematic analysis outlined by Braun and Clarke (2006) were followed (see Table 3-9). The three stages of thematic analysis that were carried are outlined in Figure 3-6.
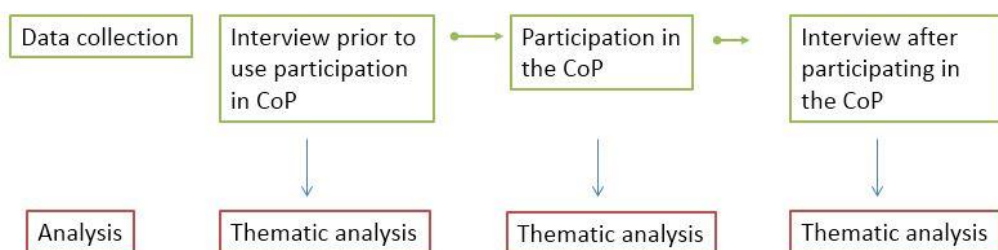
**Figure 3-6. Data collection and data analysis of phases two and three**

The self-efficacy questionnaires were analysed by descriptive statistics using Excel© (Microsoft) to establish mean self-efficacy scores within each group. However, the number of participants did not warrant the statistical power to establish effects that may be of potential interest (e.g. between levels of participation and self-efficacy).

Other data such as website usage statistics were obtained and recorded using Excel©.

**Phase four of the design-based research: refining and finalising the design principles.** The development of a set of design principles represents one of the central objectives of a DBR project (Anderson & Shattuck, 2012; Design-Based Research Collective, 2003). Design principles were developed and proposed for each iteration and these were fed into the design phase of subsequent iterations. A final set of design principles emerged from this iterative cycle.

## Summary

In this chapter, the theoretical perspectives, epistemology, ontology, and methods and methodologies that were used in this study were described. A combination of transformative learning and a sociocultural model of learning underpin the two research questions that drive the study. Transformative learning theory is a theory of adult learning and it states that the process of adult learning represents the acquisition of new frames of reference for the interpretation of experiences. A sociocultural model of learning proposes that learning is inherently a social activity. Taken together, these two theories underpin the central objectives of this study, namely, how might a patient-based online community of practice be established (sociocultural model of learning) and whether transformative learning can be promoted within this community.

Critical Realism is a combination of ontological realism and epistemological constructionism. A critical realist interpretation of the present study recognises the causative, objective physiological processes that occur in the body that result in the diagnosis of T2DM (ontological realism). The epistemological perspective of critical realism is perhaps more pertinent for this study because the semi-structured interview schedules, analysis of empirical interview data and the development of the learning environment were developed around the critical realist epistemological position. This states that historical patterns of behaviour and sets of values and beliefs differ from person to person and the knowledge one has of the world results from the interplay of these contextual factors.

The methodologies of DBR and AT build on this fundamental premise. DBR represents a research practice that addresses real-world educational problems and the evaluation of the solutions to these problems takes place in the context in which they are set. The nature of knowledge construction during iterations is, therefore, not something that can be fixed in advance since the knowledge generated in each iteration will result from the nature of social interaction resulting from the characteristics of the learners and other contextual factors. Since DBR is a mode of conducting research and not an evaluative tool, AT was adopted as a descriptive and evaluative tool to aid in the analysis of the contextual nature of the DBR process.

The critical realist premise was also in evidence in the methods of data collection and analysis because the semi-structured interview is a format that recognises shared events (diagnosis of T2DM) and the different experiences of those events (self-management of T2DM). The analysis of data resulting from the semi-structured interviews and other modes of data collection including email and short message service (SMS) correspondence and text-based data from forum interactions was conducted using thematic analysis.

In the following chapter, the development of the PCoP will be outlined.

# Chapter 4. Design of the PCoP

In this chapter, phase one of the DBR cycle is outlined (see Figure 4-1). This chapter is presented in two sections.

In the first section, the thematic elements associated with the interpretation of the individual interviews are presented. In the second section, results from the analysis of the focus group sessions are outlined. These sections relate to the first phase of the DBR cycle (phase one in Figure 4-1).
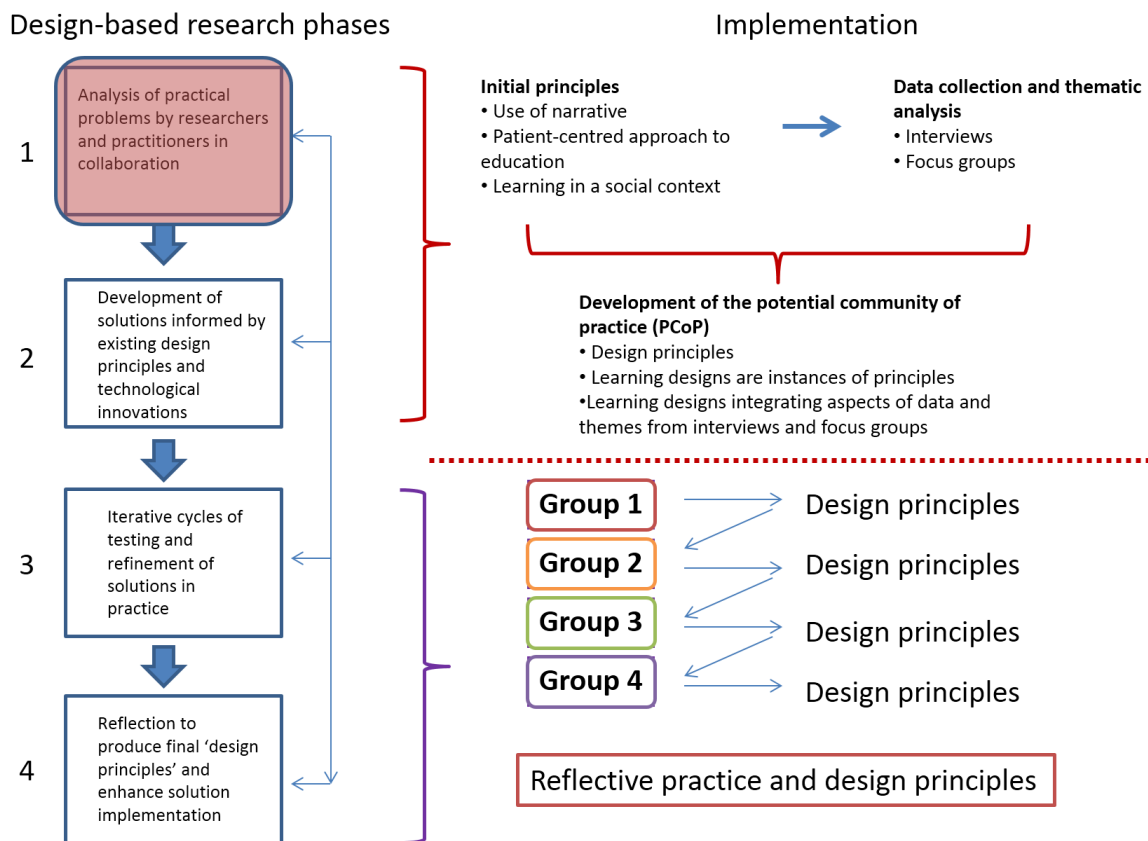
**Figure 4-1. Phases of the design-based cycle**

## Individual interviews and focus groups

**Individual interviews.**   To address the first phase in the design-based cycle, four individual interviews with people with T2DM were conducted. These interviews were followed by two focus groups which built on the themes that emerged from the interpretation of the individual data. The interviews and focus groups represented the two modes through which the first phase of the design-based cycle was addressed.

Individual interviews were conducted to provide narrative accounts from people living with diabetes. The intention was to use the narrative elements from individual interviews to:

1. Inform the design of the focus group interview schedule and;

2. To operate as elements within learning activities to trigger discussions about living with T2DM. This approach uses a precedent set in Greenhalgh et al's study (2010) in which narratives were used to inform the development of an educational program for people with T2DM.

These narrative accounts were subsequently supplemented with relevant aspects of the literature (e.g. Broom & Whittaker, 2004; Lawton, Peel, Parry, Araoz, & Douglas, 2005) to develop learning designs related to the lived experiences of individuals diagnosed with diabetes.

**Focus groups.**   The areas that were covered in the individual interviews were broader than the focus applied in the focus group sessions. The intention in the individual interviews was to mine a set of individual experiences of people with T2DM that would yield a rich understanding of the lived experience of T2DM; this would have been more difficult to achieve in the social context of a focus group. The intention behind conducting the focus groups, on the other hand, was to elicit responses to the role of education and technology in

the context of T2DM and less on the lived experience of illness and, therefore, the social context was viewed as more appropriate given the objectives.

The themes that subsequently emerged from the interpretation of the focus group data were combined with the themes from the individual interviews to build a picture of the lived experience of T2DM and how people with T2DM might address some of the educational challenges related to the illness. This represents **phase one** (see Figure 4-1) of the design-based cycle.

**Phase two** (see Figure 4-1) of the design-based cycle was then addressed by combining elements from the relevant literature and the themes from the individual interviews and focus groups to inform the development of a set of learning designs for the PCoP. These learning designs are presented in chapter five.

## Analysis of individual interviews

In the previous chapter, the research questions for this project were outlined. The first question asks what are the principles related to the establishment of an online community of practice for people with T2DM and the second question asks what are the characteristics of participation in this community that promote transformative learning and assist in the self-management of T2DM.

The first question is underpinned by the theory of the situated and social nature of the learning process (Brown et al., 1989) and this idea is embedded in the model of learning associated with the community of practice perspective (Hoadley, 2012; Lave & Wenger, 1991). This theory of learning, however, does not address how such a model of learning might be actualised or the shape of the characteristics of a learning environment underpinned by a sociocultural conception of learning. It does not address, in other words, the first phase

(phase one in Figure 4-1) of the DBR cycle. This stage of the DBR process is addressed through a combination of two elements.

The first is the belief of the centrality of patient-centred care and the related domain of patient-centred learning with a specific focus on peer support in the management of T2DM. The central idea is that peer support is central to assisting individuals to cope with their illness and a narrative approach is one method that can be used to develop learning environments when working in this paradigm (Greenhalgh, 2009). To develop these narratives, and to gain a rich understanding of what it means to live with T2DM, individual interviews and focus groups were conducted. These two ideas – one related to a conception of learning and the other to a philosophy of care and, by extension, a philosophy of patient learning – represent the cornerstone of an educational design philosophy represented by phase one in Figure 4-1.

Phase one of the design-based cycle represented an opportunity to enrich the conceptual framework of patient-centred learning with real-world narratives from people living with T2DM. To do this, individual interviews and focus groups were conducted. In the following sections of this chapter the analysis of these interviews is outlined and discussed. The ages of the individuals are presented and a brief description of each individual's social and personal characteristics, which were based on observational notes taken after the interview, are provided in Table 4-1.

**Table 4-1. Description of individual characteristics of individual interviewees**

| Interviewees | Individual contexts |
|---|---|
| | |

| AR (female, 58 years of age) | <ul><li>Very willing to offer a range of opinions and very articulate.</li><li>Lived with son (diagnosed with gigantism) in housing commission property.</li><li>Father was an alcoholic and experienced a fractured family upbringing.</li></ul> |
|---|---|
| SP (female, 67 years of age) | <ul><li>Lived with grandchild (22 years old) in housing commission property.</li><li>Grew up in the bush with very humble background – father was a trapper.</li><li>Lost focus a few times during the interview.</li><li>Very close with grandchildren.</li></ul> |
| MM (female, 69 years of age) | <ul><li>Obesity was a problem with an impact on self-image.</li><li>Bariatric surgery improved obesity and self-image/esteem improved.</li><li>Very active in the community.</li><li>Travels.</li><li>Able to manage her diabetes well.</li><li>'Worked hard' all her life. Financially stable/secure.</li><li>Family history of diabetes.</li><li>Overall sense of a woman who is confident and content.</li></ul> |

| RF (male, 74 years of age) | <ul><li>Qualified pilot.</li><li>Lived with wife (from Vietnam) who is his main carer.</li><li>Knowledge of history of illness and history of care distributed shared with wife.</li><li>Emotionally restrained.</li><li>Enjoys gardening.</li></ul> |
|---|---|

**Identification of themes in the individual interviews.** The themes in the following section are organised into three distinct categories. Braun and Clarke's (2006) distinction between latent and semantic themes was used to organise themes that could operate:

1. As highly contextual thematic elements which were as close to the data as possible so they could be used in the design of the semi-structured interview schedule for the focus groups and in the learning designs (semantic themes) and;

2. As standalone concepts of discourses more akin to themes found in the literature in the area of sociology of health. For example, the latent themes found in Broom & Whittaker (2004) and Webb (2009).

To satisfy the requirement of becoming a theme, each theme was required to have at least one quote from two different participants associated with it. This was true for both the latent and semantic themes. In each table, the participant whose quote is attributed to a theme is specified and the reference to a theme or sub-theme is indicated by a numerical value. For example, in the theme of *having diabetes*, all four participants referred to the theme at least

once (Table 4-3). Enumeration for each theme or sub-theme was capped at one. Therefore, if there was more than one reference to a theme or sub-theme this was not enumerated.

*Latent themes.* The feeling of being treated as a disease and not a person was a recurring theme in the individual interviews. One of the reasons behind this can be traced back to the medicalisation discourse which operates at an individual, organisational and systemic level (Lupton, 1997) and helps shape the meaning of medicine and how it is practised. The theme of *the body as contested territory – the discourse of medical science versus 'me'* is an example of a latent theme that emerged from the interpretation of the semantic themes and characterises participants' feelings of being pathologised and not being treated as individuals during their interactions with health professionals and the health system. Three out of the four participants expressed sentiments that accord with this theme and this is summed up in the following quote:

> "Doctors need to listen to their patients and listen with their heart as well as a stethoscope." (AR)

Another example of a latent theme was the theme of *'naughty behaviour' and the moral dimension of the management of diabetes*. The meaning underlying this theme relates to how patients can sometimes feel that their behaviour is being policed and that there is an element of transgression or of feeling 'naughty' if suggested routines or practices are not adhered to. The moral language used in the management of illness has been echoed in previous studies in the context of diabetes (Broom & Whittaker, 2004) and obesity (Throsby, 2007). In this study, this moral dimension is expressed by one of the two interview participants who felt that they had displayed transgressive behaviours and are to blame for the consequences:

"I eat chocolate biscuits and…I do naughty things and I know

…exactly what I'm doing and then I have a horrible headache and I

think, well, you did it yourself…" (MM)

Although the development of latent themes are of interest (see Table 4-2), the objective of the

analysis was to generate a set of semantic themes that could be used to inform the focus

group interview schedule and subsequent learning designs. As a result, semantic themes

(Braun & Clarke, 2006) or themes that are very close to the meanings expressed at the level

of the data, were considered to have a greater degree of applicability to the overall aims of the

research.

**Table 4-2. Identification of latent themes in individual interviews**

| **Latent themes** |
| --- |
| The body as contested territory – the discourse of medical science versus 'me' (3/4 – AR, MM and RF). |
| 'Naughty behaviour' and the moral dimension of the management of diabetes (2/4 – AR and MM). |

*Semantic themes.* The interpretation of individual data generated the following

semantic (Braun & Clarke, 2006) themes: *having diabetes*, *participant knowledge of diabetes*,

*health professionals and patient relationship*, *agency and control*, *support and education*,

*family and social history*. The themes and sub-themes are presented in Table 4-3.

**Table 4-3. Themes and sub-themes from the analysis of individual interviews**

| Themes | Sub-themes |
|---|---|
| **– Having diabetes** (4/4 – AR, MM, RF and SP) | • Illness work (3/4 – AR, RF and SP)<br><br>• Biographical work (3/4 – AR, RF and SP)<br><br>• Everyday work (2/4 – MM and RF) |
| **Participant knowledge of diabetes** (3/4 – AR, RF, SP) | • Explanatory models of T2DM (4/4 – AR, RF, MM and SP)<br><br>• The body as 'black box' (1/4 – RF)<br><br>• Fatalism (1/4 – RF) |
| **Health professionals and patient relationship** (3/4 AR, MM, SP) | • Paternalism (2/4 – AR and MM)<br><br>• Absence of patient-centred communication (3/4 AR, MM and SP) |
| **Agency and control** (4/4 – AR, MM, RF and SP) | • Contest for control: limitations on agency imposed by T2DM (4/4/ – AR, MM, RF and SP)<br><br>• Self-blame (2/4 – MM and SP) |
| **Support and education** (4/4 – AR, MM, SP and RF) | • Being overwhelmed (3/4/ – AR, MM and SP)<br><br>• Lack of tailored educational approach (1/4 – MM)<br><br>• Futility of education (1/4 – RF)<br><br>• Reflective practice (1/4 – MM) |

| | |
|---|---|
| | • Functional support (2/4 – RF and SP) |
| | • Structural support (4/4 – AR, MM, RF and SP) |
| **Family and social history** (4/4 – AR, MM, RF and SP) | • Family and social history (4/4 – AR, MM, SP and RF) |

**Having diabetes.**   Although the effects of having T2DM on the lives of participants differed, all the participants lived through a health-based event (diagnosis of T2DM) that subsequently became an integral part of their lives. Rather than shaping their identities, all participants were eager to point out that having T2DM did not define who they were as individuals or dictate the shape of their identities, but rather, having T2DM was another element in the fabric of their complex lives and identities. Having diabetes for SP, for example, was part of a process of adaptation and became part of her repertoire of tacit knowledge:

> "It can be a lot of little things sometimes that you don't even think of. You've just adapted".

For RF, the potentially disruptive nature of T2DM could be muted by tempering it with a stoic acceptance of the condition:

> "[You] just keep going.  As they say, you can't cry over spilt milk and
>
> you can't sit and be sorry for yourself all the time."

The idea of having T2DM but not being defined by T2DM was strongly asserted by AR:

> "It's just something I live with. You might as well ask me what does it mean to be
>
> 178 cm. and blond haired! It's just a part of who I am."

In a similar vein, MM said that "you've still got to live your life" in response to a friend's recent diagnosis of T2DM. Although all the participants indicated that T2DM was an additive process in the context of one's life history, this did not mean that the effects of the condition were not felt on many levels. Participants were still required to 'work' at their illness to maintain an equilibrium between having the illness and living one's life. The nature of the work undertaken by the participants aligns with Corbin and Strauss's analysis of work in the context of people who have T2DM. According to Corbin and Strauss (1985) individuals with chronic illness undertake three lines of work: 'Everyday life work', 'illness work' and 'biographical work'. These three categories encapsulate what is meant by 'having diabetes' because they encompass the routine dimensions of self-management (illness work), the emotional complexities of dealing with a chronic illness (biographical work) and the recognition that life does not stop with a diagnosis of chronic illness (everyday life work).

'Illness work' covers a range of self-management behaviours from management of medication regimens:

> "I ended up on insulin, but just the one dose at night." (MM)

> "So now I'm on a daily injection of stuff called Lantus." (RF)

through to the management of nutrition and diet:

> "…it's butter and cheese that's the big problem for me." (AR)

> "…you've got to be aware of what you're eating, that's one of the
>
> main things…" (MM)

"I still basically do the same things now as what I did previous, I

haven't changed that much, apart from my eating habits." (RF)

Bury (1982, p. 169) calls chronic illness "a major kind of disruptive experience" and this idea

also find echoes in Mezirow's concept of the 'disorienting dilemma' in which chronic illness

can often function as the first stage towards reframing one's assumptions about the world

(Baumgartner, 2011). With the individual interviewees, this disruption took two forms. One

of these was the use of the emotional language of disruption. For example, RF is

'devastated':

"I was sad and desperate because one doctor said they were going to

amputate my foot, and the next, the day of the operation, said they

might have to take my leg off.  I was bloody devastated." (RF)

The other form is the language and expression of loss. SP is unable to perform the types of

pleasurable quotidian activities that she had previously been accustomed to:

"The only outlet I had was the garden. Can't do that anymore." (SP)

"I get down sometimes because I can't exercise, I can't do a lot of things. A lot of

foods I can't have. Gave up smoking. And now I can't even have my occasional glass

of wine for Christmas or anything like that. Erm, so er I've just got the grandkids."

(SP)

For AR, due to complications associated with T2DM, loss took a physical form:

"Losing toes means you also lose a lot of your balance." (AR)

'Everyday life work' refers to those occupational, domestic and essential tasks that constitute

the daily routine of living. Some everyday tasks were disrupted by the onset of diabetes –

"The only outlet I had was the garden. Can't do that anymore." (SP) – but the prevailing

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attitude was not to foreground the illness to such an extent that it would subsume and take over the requirements of daily life. As RF and MM say:

> "You've still got to live your life." (MM)

> "I haven't changed that much, apart from my eating habits." (RF)

Although the diagnosis of T2DM was a significant event in all the participants' lives the shape of their self-management practices (illness work) and the impact that the diagnosis had on their lives (biographical work and everyday work) differed. This is not surprising given that one's individual context is likely to have an effect on one's self-management practices (Schulman-Green, Jaser, Park, & Whittemore, 2016).

In this section, an analysis of the lived experience of the patients with T2DM was provided. In the following section, an analysis of the epistemological nature of the participants' relationship with T2DM is outlined.

**Participant knowledge of diabetes.** In the individual interviews, a variety of dimensions of the lived experience and knowledge and meaning of T2DM were expressed and communicated. For example, the explanatory causal model linking heavy drinking with diabetes is questioned in the following way:

> "I've got some friends that drink far too much and they've got big pot
>
> bellies and they look like bloops on legs, but they haven't got diabetic
>
> symptoms or have been diagnosed with it." (RF)

This line of reasoning, characterised by an almost pre-ordained determinism, is echoed by RF in the first quote and a conception of the body as a black box in the second:

> "You either get it or you don't." (RF)

"Why does your pancreas stop working?  You wouldn't know." (RF)

For SP, a lack of knowledge, stress and genetic factors are identified as constituting the causes for the development of T2DM:

"I didn't know about the intolerance thing. I think mainly ignorance…probably if I knew then what I know now it would be a lot different." (SP)

"I think I was living under constant stress all the time. That could've been one of the things…but as I said, hereditary has got a bit to do with it." (SP)

A sophisticated understanding of disease models is expressed by SP and AR:

"When I was told I was insulin intolerant I didn't think you know I'd get the diabetes then…I didn't know about what the intolerance meant, in fact I didn't know until I asked the educator the other day and she drew me a diagram on what it was and I was rather surprised." (SP)

"You can walk a very narrow path which means that you don't have any symptoms but it's like being an alcoholic. You're an alcoholic for life. In fact, the similarities between alcoholism and diabetes are quite similar."(AR)

The last quote by AR reveals the phenomenon of what some have called the 'absent' diabetic body (Lawton, Peel, et al., 2005) which creates particular challenges for health professionals to communicate the seriousness of T2DM in the absence of symptoms.

The importance and broader relevance of the current theme is that patient knowledge is often treated as an inferior form of knowledge when contrasted against the bio-medical model. This is particularly true in the context of 'adherence' studies (Popay & Williams, 1996). In the medical literature, the objective for the patient is to attain a level of knowledge consonant with a bio-medical understanding of illness and its pathological processes. Often this

consonance is defined as 'adherence' and although the field of 'adherence' is contentious and politically charged (Trostle, 1988), work continues to be pursued in this area and is focussed on the relationship between patients' knowledge and beliefs and adherence to recommended treatment options (Al-Qazaz, Hassali, Shafie, Sulaiman, & Sundram, 2010). These might come in the form of medication regimens (Sweileh et al., 2014) or recommended behavioural or self-management adjustments (Heisler et al., 2005; Iqbal, Morgan, Maksoud, & Idris, 2008).

A different perspective on patient knowledge, however, receives its inspiration from the field of the sociology of health (Popay & Williams, 1996) and seeks to position lay knowledge of illness and disease as an important component in an individual's construction of the meaning of illness and disease. This lay knowledge can often go beyond the narrow boundaries prescribed by the bio-medical model and touch on physical, social and emotional dimensions of illness (Lawton, Peel, et al., 2005). As Stacey (2003) says:

> "Ordinary people…develop explanatory theories to account for their material, social and bodily circumstances. These they apply to themselves as individuals, but in developing them they draw on all sorts of knowledge and wisdom, some of it derived from their own experience, some of it handed on by word of mouth, other parts of it derived from highly trained practitioners. Thus, lay explanations go beyond common sense, in that explanations beyond the immediately obvious are included." (p.142)

Lay knowledge is often expressed in narrative form (Hurwitz, Greenhalgh, & Skultans, 2008) and it is important for health professionals to be able to derive meaning from patient narratives, such as the ones identified above, as they develop holistic profiles of patients (Greenhalgh & Hurwitz, 1999).

The analysis of the data related to the theme in this section indicates a depth of reflection about the onset of their own illnesses and the characteristics of the aetiology and pathophysiology of T2DM. A focus on patient knowledge of T2DM has implications in an educational context because the patterns of experience of chronic illness can be used to structure the development of educational programs (Greenhalgh et al., 2010). The challenge, however, is to design learning environments that can utilise both the patterns of chronic illness as experienced by patients and to engage learners in context-dependent patient narratives that aim to address individual concerns or learning requirements. The learning designs that were developed in this study have aimed to address this pedagogical challenge.

**Health professionals and patient relationship.** According to Vermeire et al. (2001), the relationship between patients and health care providers needs to change from a paternalistic model (Spence, 2012) to a model in which patients are considered to be partners in the decision making process. Patients' beliefs and knowledge about their illness, therefore, become key elements in the establishment of a management plan. The co-construction of a plan of care, however, requires a level of communication which places an emphasis on listening to patients' concerns. This level of communication was lacking for AR:

> "Now hearing is different from listening. A lot of doctors hear what I say but I'm dashed if they listen in that it goes in one ear and out the other. A little bit more compassion." (AR)

Communication, in other words, needs to constitute a practice which combines medical expertise, empathy and a willingness to engage with the affective features of a patient's concerns. For AR and MM, paternalism is an additional feature of the type of communication that was experienced:

"Well they can talk in such high-falutin terms that it goes straight over my head or they can talk to me as if I'm about 10 years old." (AR)

"Some of them sort of talk down to you which doesn't work." (MM)

Relationships built on the kind of paternalism and emotional detachment experienced by AR and MM are problematic if one of the objectives of the patient-health provider relationship is to develop a model of care in which patients are viewed as partners. Rather than being helpful, this kind of communication can become a barrier to the provision of care (Vermeire et al., 2007). The key question, therefore, is how the patient-health provider relationship might be improved. One of the ways in which this might be done is to understand how patients express agency and control over the management of their T2DM.

**Agency and control.** Agency operates on two levels. The performative aspect of agency refers to the capacity of individuals to make choices against and within constraints imposed by structural factors while the conceptual nature of agency sees it as one half of the agency-structure conceptual model which is a feature of modern sociological theory (Best, 2003; Shilling, 1992). In the social sciences, agency and structure are representative of the individual's (agency) relationship with the wider societal forces that can have an impact on how one operates as an individual within society (Sewell, 1992). In a health context, the change from the idea of the patient as a passive observer informed by Parsons' concept of the sick role to that of the autonomous patient in which responsibility for the construction of a management plan is shared was underpinned by recasting the patient as an autonomous individual with a key role to play in the management of their illness (Armstrong, 2014). However, although this increased level of patient responsibility was a fundamental assumption in the construction of self-management programs (e.g. Lorig, 2012) this perspective can sometimes over emphasise the goal of self-efficacy and mastery and under

emphasise the process of the construction of patient identity (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). The concept of patient-centred care addresses this problem by recognising the subjective and contextual factors that can constrain or enable autonomy and agency (Liberati et al., 2015) and which can affect the management goal of self-efficacy or the process of identity construction. In the context of the lived experience with chronic illness, patient agency can be conceptualised not only against the constraints on agency imposed by social structure but by the limitations placed on agency by the physiological consequences of chronic illness (Kelly & Field, 1996). Both constraints can have implications for the construction of identity as can be seen in the quotes from the participants below. The theme of 'contest for control' best captures the interplay between the biographical disruption caused by the physiological disruption of T2DM while 'self-blame' is a consequence of too much agency in the absence of self-control. 'Structural constraints', on the other hand, are constraints that were explicitly articulated by participants as representing contextual factors that could negatively impact the likelihood of compliance or adherence to management plans.

*A contest for control.*   For the participants, physiological disruption led to biographical disruption which, in turn, had consequences for the ongoing process of the construction of identity. For example, the constraints on agency imposed by T2DM and a subsequent feeling of lack of control over sugar levels are expressed by RF as follows:

> "I've coped fairly well actually. Although, I did and still do feel
>
> despondent if my sugar levels get too high, but there's not much you
>
> can do about it." (RF)

It is not clear whether the lack of control in the arena of T2DM influenced other areas of RF's life. SP expresses a similar lack of control that results from a very constrained scope for agency in the context of chronic illness:

> "Everything's just snowballing. When a car breaks down you can take it to a garage but when a body breaks down there's nowhere you can take it." (SP)

> *Self-blame.*   Agency is also recognised and affirmed as a negative factor in a behavioural trajectory that leads to self-blame:

> "Whereas I know my diabetes, especially when I was big… and you had the off days when you really did feel off… I knew it was my own doing because I'd eaten the wrong thing. " (MM)

In many ways, the manner in which these individuals have expressed their agency reveals a willingness to undertake the 'illness work' required for self-management but there is also the recognition of the constraints that T2DM imposes on the capacity to take action and this leads to what has been called a 'contest for control' (Stein quoted in Broom & Whittaker, 2004, p. 2376) against the backdrop of a struggle for self-discipline (Broom & Whittaker, 2004):

> "I can control the diabetes you know with what I eat and what I do and all that so I always…just like to be in control of everything I do you know." (SP)

> *Structural constraints.*   Structural constraints to exercising agency were also recognised by AR but not by the other participants. For example, financial constraints were recognised by AR as a significant barrier.

> "They're [nurses] not living with the constraints that I've got including social and budgetary constraints."

For the participants in this study, the sources of the contextual conditions which affected their capacity to exercise agency were physiological and structural in nature and these, in turn, had effects on the ways in which participants constructed their identities and managed their T2DM on a daily basis.

**Support and education.**   In a broad sense, the theme of support and education represented the informal or formal services that were provided to participants in the context of the management of T2DM.  There was less emphasis on the value and role of self-directed learning in T2DM management compared to the focus group participants and participants expressed a broadly negative view of the formal educational services offered by health authorities. Support was cast as being provided both intra-family and at the level of informal support networks.

*Education.*   Individuals were critical of the manner of the delivery of educational services. The overwhelming sentiment was the feeling of being bombarded with information:

> "Because you've got people you should do this and people on the side saying you shouldn't do that. It's coming at you from all directions…You get confused." (SP)

> "But when you get into it with all the foods you're not allowed to have, with all the things the dieticians tell you and it just gets too much." (AR)

It was also felt that information was not pitched at an appropriate level leading to confusion:

> "I couldn't get it through that I knew what she was talking about and it was…a very, very basic explanation…She never really told me what I should be eating and what I shouldn't be eating.  And by the time I'd finished up, I was perturbed." (MM)

The negative experiences with service provision at the institutional and personal level run counter to at least one study focussing on service provision (including education) for people with T2DM. In the Lawton et al. study (2005) there was a level of satisfaction with services that was absent in the individual interviewees of the present study. A further set of interviews with a larger sample size would need to be conducted to pursue perceptions of service provision in greater depth and to determine if the negative experiences of formal educational provision is widespread in an Australian context.

Complementing the negativity of the provision of education, RF questions the value of providing any educational support at all. For RF, education is futile once the natural history of the pathophysiology of T2DM has reached a certain stage:

> "Well, I don't think it made any difference because I know what
>
> causes diabetes. I knew before I was diagnosed what caused
>
> diabetes." (RF)

There is the recognition for RF, however, that education might play a role in helping to prevent the onset of T2DM and, by extension, further complications – "…it would probably help people in future." RF says.

*Social support.*   The role that social support plays in T2DM is complex. For some, clinical outcomes such as the measurement of HbA1c values, represent the standard against which the success or otherwise of social support is measured (Stopford, Winkley, & Ismail, 2013). Other measurement outcomes include behavioural, psychosocial and perceptions of support (Strom & Egede, 2012). Another approach is characterised by a focus on the development of a greater understanding on the meaning and experiences of coping with T2DM and one of the dimensions of living with diabetes is the role that social support plays in assisting individuals cope with the illness (Vermeire et al., 2007).

Two types of support were important for the participants: family support and support networks. These two modes are broadly aligned to the two types of social support identified by Holt-Lunstad and Uchino (2015), namely, functional and structural social support.

Functional support refers to the type of support that can be provided to individuals to improve the social, emotional and psychological wellbeing of the person with T2DM. Structural support, on the other hand, refers to the degree to which individuals are integrated within social networks such as families, T2DM support or church groups, for example (van Dam et al., 2005).  Functional and structural support was in evidence in the interview data in the following way.

RF identified the key role of his wife in his care and the gendered nature of the distribution of functional care was in evidence when RF says:

> "She'd know more about it than I do. I don't take much notice of
>
> things." (RF)

Combined structural and functional support is also in evidence. For SP, her family is the structural network through which care and support are received:

> "My family's very protective of me. If I don't answer the phone it would have rang
>
> again. And if I didn't answer it the 2nd time the call would go out." (SP)

For AR, the church represents the support structure and caring and support is distributed among members of the support group:

> "Being in a church we care about each other. It's sort of like a big extended
>
> family…So you join together in a clique and we try to bring foods that are not going
>
> to do as much damage." (AR)

The educational provision that was offered to participants was viewed as sub-optimal and the criticism concerned the lack of alignment between educational provision and individual knowledge of T2DM and a pedagogically-based criticism of educational provision lacking in structure and coherence. It is not clear whether the social support that participants experienced was able to fill this educational gap but it is clear that social support was very important for both 'illness' and 'biographical' work.

**Family and social history.**   Although T2DM is a complex disease which results from the interaction between genes and the environment, there is evidence to suggest a strong genetic basis for T2DM (Lyssenko & Laakso, 2013). It is, therefore, not surprising that T2DM was part of the family histories for AR (mother, father, aunts), MM (brother, grandmother) and SP (mother, brothers, sisters). Not all participants, however, shared a family history of T2DM. Asked if there was a family history of diabetes in RF's family RF replies in the negative but also offers a possible explanation behind the development of his T2DM:

> "No, nobody, nobody. At the time, I was being diagnosed with
>
> diabetes I weighed over 90 kilograms, whether that had anything to
>
> do with it or not, I don't know." (RF)

In conjunction with a social history, a family history can provide health practitioners and specialists with important information to assist in the development of a management plan and to understand the patient in his or her totality. For our participants, reflecting on family history provided them with the opportunity to provide factual information as well as to reflect on the meaning of their illness.  For SP, it was an opportunity to develop a causal understanding of her mother's T2DM ("her diabetes was from her obesity") and for AR a causal connection between obesity and T2DM was also offered:

> "She got it when she was in her late 40s and she got it through obesity. I believe that's what caused it." (AR)

The opportunity for AR to recount her family history also led her to extend the narrative to touch on aspects of her social history in which humour played a part:

> "Dad was alcoholic which didn't exactly help things. He and mum broke up and he got a girlfriend over in the Philippines and they went to a faith healer and my dad was cured of his diabetes. Funny thing is he was dead 2 years later." (AR)

Some themes were not as prevalent as the ones outlined above and these themes are described in the next section.

*Themes with one reference.*   In addition to the themes that achieved a degree of prevalence over the four individuals who were interviewed, some themes were unique to individuals and these are presented in Table 4-4.

**Table 4-4. Themes with one reference**

| Themes with one reference |
| --- |
| The future (RF) |

| The contested space of care (AR) |
| --- |
| Education and prevention (SP) |
| Faith and spiritual life (AR) |

These themes consolidate a picture of the complex personal landscape of living with T2DM. AR, in particular, was someone who addressed a whole range of issues with deep insight and her personality came across very strongly during the interview. This is in evidence in her unwillingness to cede to requests from health professionals – "The nurses say I should always wear slippers to protect my feet. I don't find it very practical." This is an example of *the contested space of care* because it highlights the ongoing relationship, which is sometimes a contested one, between patients and health professionals in the context of management and care. AR was also the only person to hold spiritual beliefs and her faith was an important tool for her continuing struggle with illness – "Faith gives us the strength to go on…It doesn't heal us."

Although education was not the primary focus of the interviews, a reference to the importance of education in the context of prevention did occur once. If an educational strategy is implemented, however, it needs to be tempered with a learning design that does not bombard individuals with information – "Education but not bombarded" as SP says. Finally, RF's emotional vocabulary was restrained throughout the interview and his reflections tended towards the pragmatic and the 'here and now'. His thoughts on the future, however, reveal a mix of resignation and contentment and a reflective landscape that was largely absent during the interview:

"I hope for another 20 years, but I don't think so. I've got, I'll be 75 this year, so I guess three score and ten have passed that and 20 years with diabetes, so I'm fairly lucky really. What can one expect?"

The themes with one reference complete this section on the analysis of the individual interviews.

**Conclusion.** There exists a broad alignment between the themes that emerged from the analysis of the individual interviews and the factors affecting chronic illness self-management. This alignment was indicated in a recent metasynthesis of factors affecting the management of chronic illness (Schulman-Green et al., 2016). In this analysis, factors such as life history and characteristics, health status, resources, working and living environment and relationship with the healthcare system were identified as being the most salient factors and the development of a patient profile with these categories in mind would have the potential to lead to more positive outcomes for patient management.

The objective of the individual interviews was to gain an in-depth understanding of how patients coped and made meaning of their illness. This aligns with phase one of the DBR cycle in Figure 4-1. In the process of interpreting the interview data, several themes emerged and they paint a picture of the complex practical, emotional, social and epistemological layers of living and coping with diabetes. The themes and narratives that emerged from this process were used to develop the semi-structured interview questions for the focus groups. Additionally, some of the narratives and themes from the individual interviews and focus groups were subsequently integrated into the initial set of learning designs.

## Analysis of focus group interviews

The focus groups were conducted using a semi-structured interview schedule (appendix 6). This schedule was informed by some of the themes (specifically, having diabetes and support and education outlined in Table 4-3) that emerged from the individual interviews in addition to the research questions that guided the focus group sessions. These questions were:

1. What were the experiences of the provision of T2DM-specific education?

2. How might technology be used to improve the educational experiences of people with T2DM?

The themes that were not chosen to inform the interview were considered peripheral to the main aims of the focus group discussions. This did not mean, however, that they were peripheral to the overall results because at least one of these themes – "*'naughty behaviour' and the moral dimension of the management of diabetes*" recurred in the December focus group. This indicates the existence of a recurring thematic pattern spanning the interviews and focus groups. It could be argued that the focus groups functioned as a proxy for the theoretical sampling for the themes that emerged from the interpretation of the individual interview data (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009).

The categories in the interview schedule encompassed the three broad themes of self-management, agency and education. The primary focus, however, was on attempting to elicit from the participants their thoughts on educational initiatives for people with T2DM and to then use these insights to develop the learning design for the PCoP.

Analysis of the focus groups was conducted using a combination of thematic analysis (Braun & Clarke, 2006) and a concurrent focus on the frequency of emerging themes, consideration of individual contexts and the emergence of broad themes (Rabiee, 2004) during the process of analysis.

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Interpretation of the focus group session data led to the emergence of five major themes: *having diabetes, education, relationship with health professionals* and *management and family and social history.* Themes and sub-themes are presented in the table (Table 4-5).

**Table 4-5. Themes and sub-themes from the analysis of focus group interviews**

| Themes | Sub-themes |
|---|---|
| Having diabetes | • Illness work<br><br>• Biographical work<br><br>• Everyday work<br><br>• Meaning and learning |
| Education | • Health system-centred education<br><br>• Patient perspectives on learning<br><br>    o Learning environment<br><br>    o Learning resources<br><br>    o Pedagogy and educational strategy<br><br>    o Conceptions of learning and role of the learner |
| Relationship with health professionals and management | • Patient-centred communication.<br><br>• Paternalism.<br><br>• System. |
| Family and social history | • Family history.<br><br>• Social history. |

To provide an indication of the level of group engagement with the themes from each of the focus groups (Rabiee, 2004), the information from Table 4-5 has been further detailed in

Table 4-6. This indicates the number of participants who interacted or participated in a dialogue associated with each sub-theme. For example, there was a total of 24 references to the theme of *lllness work* associated with the theme of *having diabetes.* In the November group, five out of six participants contributed to the sub-theme and in the December group, there were four out of five. In both focus groups, therefore, nine people contributed to the theme of *lllness work* 24 times. This indicates that the occurrence of this sub-theme was significantly greater than other sub-themes associated with the theme of *having diabetes.*

**Table 4-6.Themes and sub-themes from the analysis of focus group interviews broken down to indicate pattern of occurrence in groups**

| Themes | Sub-themes |
|---|---|
| Having diabetes | • Illness work (24 references)<br><br>   o November group = 5/6<br><br>   o December group = 4/5<br><br>• Biographical work (4 references)<br><br>   o November group = 2/6<br><br>   o December group = 1/5<br><br>• Everyday work (2 references)<br><br>   o November group = 1/6<br><br>   o December group = 1/5<br><br>• Meaning and learning (5 references)<br><br>   o November = 1/6<br><br>   o December = 2/5 |
| Education | • Health system-centred education (18 references)<br><br>   o November group = 4/6<br><br>   o December group = 2/5 |

| | |
|---|---|
| | • Patient perspectives on learning<br><br>    o Learning environment (9 references)<br><br>        ▪ November group = 4/6<br><br>        ▪ December group = 1/5<br><br>    o Learning resources (11 references from November group only)<br><br>        ▪ November group = 4/6<br><br>    o Pedagogy and educational strategy (35 references)<br><br>        ▪ November group = 5/6<br><br>        ▪ December group = 2/5<br><br>    o Conception of learning and role of the learner (25 references)<br><br>        ▪ November group = 4/6<br><br>        ▪ December group = 2/5 |
| Family and social history | • Family history (1 reference from November group only)<br><br>    o November = 1/6<br><br>• Social history (13 references)<br><br>    o November group = 2/6<br><br>    o December group = 3/5 |
| Relationship with health professionals and management | • Paternalism (2 references)<br><br>    o November group = 1/6<br><br>    o December group = 1/5<br><br>• Patient-centred communication (2 references)<br><br>    o November group = 1/6<br><br>    o December group = 1/5 |

| | |
|---|---|
| | • System (13 references) |
| | o November group = 4/6 |
| | o December group = 1/5 |

Table 4-6 indicates the degree of participation in each of the groups across the sub-themes and helps to provide a picture of the spread of contribution associated with each of the sub-themes across the two focus groups. This difference in the level of 'coverage' is an important dimension of the analysis of focus group data (Rabiee, 2004). It also played an important function in the establishment of the analytical route from the generation of thematic elements in the interpretive process through to their subsequent use in the development of the learning environment.

These themes and their associated sub-themes are semantic (Braun & Clarke, 2006) in nature and although latent themes did emerge from the interpretation and analysis of the data, the semantic themes presented below were considered to be more relevant for the subsequent development of the learning designs for the learning environment.

**Having diabetes.** The three dimensions of the 'work' associated with the lived experience of chronic illness outlined by Corbin and Strauss (1985) provide a framework for ascribing meaning to the focus group participants' experiences of living with T2DM. The definitions of the lines of work used to categorise the focus group data are the same as the ones provided in individual interviews section. Although the definitions are the same, differences were found in emphasis. For example, although the three lines of work are in evidence in both the individual interview and focus group data, there was a greater emphasis on 'illness work' and its various dimensions in the focus group data. This might be a function

of the social nature of the interview itself which helped to open avenues of discussion and interaction around living with T2DM.

Although the three lines of 'work' are useful for framing the various aspects of living with T2DM, the boundaries between them were not strictly demarcated. For example, there was an interplay between 'illness work' and 'everyday life work' in the context of nutrition. In both focus groups, food and eating were framed as functional requirements rather than social (and sensual) events. This led to what became a *calculus of nutrition* for some participants in which portion sizes were controlled and the amount of carbohydrates strictly regulated. As a participant from the December focus group says:

> "I ate about between 10 and 12 total grams of total carbohydrates per main meal and that, there might have been, what, 10 or less grams left for the day, and that might be split between one or two snacks and that was my food for the day and I'd go four, five, six hours in between eating and in a flash I just reversed diabetes." (F1 – December focus group)

Food became an arena for control through the regulation of portion sizes ("I ate off side plates. I don't eat off dinner plates." – F1 December focus group). This illustrates the drift from what should be considered everyday life work (eating) to nutrition and eating becoming examples of illness work. This represents a loss that is more difficult to identify but just as significant as the physiological manifestations of T2DM. This loss is expressed as follows:

> "I just don't view food anymore as yummy." (F1 – December focus group)

More traditional examples of illness work were in evidence and involved the taking of medication although discussion about participants' medication regimens was not thematically significant.

The dimension of 'biographical work' was impacted by the physiological limitations imposed by T2DM ("I won't be able to drive a car.  So that's my life greatly affected." – F1 – December focus group) and 'everyday work' was significantly affected by financial and geographical constraints for one participant (F1 December focus group).

The impact of T2DM on participants' daily routines was therefore significant and had significant practical consequences. The identity of participants was also affected as the trajectory of living through the 'disorienting dilemma' of T2DM and subsequent reflection on the meaning of the illness led to transformations of individual identity and how having the disease was a "life-changing process" for one participant in the December focus group. A changed identity was also evident from a participant in the same focus group:

> "I feel like a new person, I don't feel like the same person anymore, just I've changed that much." (F1 – December focus group)

The sub-theme of 'illness work' was populated with the most contributions in the theme of *having diabetes* and this was also the sub-theme with the highest proportion of contributors from each focus group (five out of six in the November group and four out of five in the December group). This is perhaps not surprising given the fact that descriptions of 'illness work' require less interpretive work and are likely to lead to less exposure of the self in a social setting compared to other dimensions such as 'biographical work' or 'meaning and learning'.

*Meaning and learning.*   For Mezirow, meaning and learning are inextricably linked. Meaning is the act of interpreting experience and meaning becomes learning when interpretations are used to guide one's actions and inform decision making (Mezirow, 1990b). Transformative learning begins when the assumptions that are used to inform our interpretation of experience are questioned. Querying the foundations of our interpretive

schemas represents, for Mezirow, the process of 'critical reflection' (Mezirow, 1990b).

There are clear illustrations of Mezirow's conception of learning in both the November and

December focus groups and they can be thematically grouped as illustrations of 'lifestyle

change'. One participant (F1 – December focus group) became a regular gym attendee and

for the same participant, the 'disorienting dilemma' of T2DM led to profound lifestyle

changes involving nutritional patterns of behaviour – an example of how the construction of

meaning can lead to learning:

> "I had a change of eating and I can't ever go back. If I go back, I know what the
>
> consequences will be. So that has to be a permanent change." (F1 – December focus
>
> group)

The interpretive schema associated with the concept of a 'diet' is questioned by the following

participant and a new interpretive frame is put in its place. This is an example of critical

reflection in which diet is conceived as constituting just one element of one's lifestyle:

> "The first thing you've got to remember is there's no such thing as a diet. You don't
>
> have a diet, you have a lifestyle change." (M4 – November focus group)

This is also an example of what Mezirow calls perspective change (Mezirow, 1997) and

represents an essential element in the trajectory of learning that is transformative in nature.

Meaning and learning will be further discussed in chapter six when learning in the PCoP is

analysed.

**Education.** This overarching theme encompasses two sub-themes: *health system-centred education* and *patient perspectives on learning.* The first of these themes relates to experiences about how the health system has delivered educational services and the nature of these services. The second was sub-divided into four sub-themes:

*Learning environment*. This theme encompasses participants' views on the context in which learning takes place such as online environments or within peer support groups.

*Learning resources*. This theme relates to participants' view on the medium of communication related to learning. This might be pamphlets, videos or online material.

*Pedagogy and educational strategy*. This theme covers participants' ideas on the type of pedagogical strategies that might be employed for people with T2DM.

*Conceptions of learning and the role of the learner.* This includes participant observations on how people learn, the environments in which they learn and the place of self-directed learning.

**Health system-centred education.** Fragmented educational experiences were particularly characteristic of the experiences of the November focus group and participants criticised the lack of integration between the various health services. As a result, participants from both focus groups articulated new models of care and education that were based on the idea of an integrated educational service or a "one stop shop" (November focus group) which could provide structural cohesion to the provision of education. Another dimension of system-provided education that was criticised was the mode of delivery of educational programs. This criticism was particularly prevalent in the November focus group in which dissatisfaction was expressed about the didactic pedagogy employed by health educators which can lead to disengagement: "We had the dieticians stand up and start talking about

mono– saturated and polyunsaturated fats, and I could see these

people going zzzz." (M4 – November focus group)

Participants from the November focus group indicated that they would appreciate a more

interactive educational approach – "it actually needs to be interactive…the education is

virtually passive" (M2 – November focus group). The conception of the patient as passive

consumer of information, however, was not universally shared. As one participant from the

November focus group indicates, it is incumbent on patients themselves to actively engage

with the education that is provided:

"What you do with it is up to you.  You need to find a way to make it

more active." (M2 – November focus group)

**Patient perspectives on learning.**  Although some participants' educational

experiences with the health system were fragmented and of uneven quality,

when the provision of care is integrated with the provision of education this

can help promote peer support in the context of an integrated model of care:

"From the people in the clinic and the clinic itself all being one thing,

we motivate each other." (M1 – November focus group)

A learning environment without the involvement of health professionals in which patients

themselves constitute both experts and learners can be characterised as a patient community

of practice in which learning results from an exchange of ideas, knowledge and experience

between members of the learning community. The concept of the CoP further extends the

idea of the social nature of learning by delineating the philosophical roots of this tradition as

well as providing a model through which social practices and learning can be analysed

(Wenger, 2010). Learning in a CoP is not just what Mezirow, following Habermas, calls

'instrumental reason'(Mezirow, 1997) or what Wenger calls 'techniques' (Wenger, 2010).

Identity and becoming are also key dimensions of the learning process (Wenger, 2010) and this is an important insight because there is a link between how identify and self is formed through the experience of illness (Aujoulat et al., 2008).

***Learning resources.*** A patient-centred CoP can be viewed as the reification of a sociocultural conception of learning. The success or otherwise of such a community depends on the members in the community interacting in such a way to promote opportunities for learning. These opportunities can be viewed as learning resources which are formed through interaction with others. The potential of the development of such a community resource for patients with T2DM was expressed in the following way:

> "And I learnt more today than I did at that bloody forum put on by diabetic council on Thursday night, I learnt more today listening to you folks than what I did attending that." (M4 – November focus group).

This idea of a patient-based learning community was reinforced in the same focus group by another participant:

> "Now, you tell me you talk about education and learning things, the best place we can learn is from ourselves." (M4 – November focus group)

The internet was identified by participants as providing a potential set of resources although participants were wary of the undifferentiated knowledge that the internet can sometimes provide:

"There is so much garbage out there…you have to filter it somehow

and a lot of it comes out of Wikipedia which anybody can alter." (M5

– November focus group)

Although there was a degree of scepticism about the capacity of the internet

to function as a substitute for medical expertise:

"I'm not one that hears [that after] I'm told a medical thing like at the

doctors and go home and rush off onto the Internet." (F1 – December

focus group)

The internet was viewed as resource through which a peer support network

might be established:

"Peer support out there on internet, groups, whatever, yeah, don't hide

us, put us, put us out there." (M1 – December focus group)

The concept of peer support is complex and involves many factors ranging from taxonomies

of the types of individuals involved (lay to professional) to the domains such as informational

or emotional through which support is being provided (Dennis, 2003). It is also an important

tool in the array of management options for T2DM (Lorig et al., 2012; Strom & Egede, 2012)

although it is not clear which models of peer support might be more beneficial (Dale,

Williams, & Bowyer, 2012). The learning that takes place in a shared learning environment

can sometimes be missed by those working in a health context since there is often a focus on

health outcomes (Dale et al., 2012; Dennis, 2003) rather than a focus on the dynamics of the

learning that takes place in such an environment. This is precisely the gap that can be filled

by the adoption of a theoretical framework informed by transformative learning and the

concept of a CoP. This framework can provide a theoretical lens through which to analyse the

learning that occurs in a community of learners.

***Pedagogy and educational strategy.*** Strategies to address the role that education might play for people with T2DM revolved around an educational campaign in which the elements of shock were put forward as triggers for behavioural change. This was particularly evident in the November focus group. The consequences of inaction could form the basis of an educational campaign:

> "Make them scared, make people take interest and be involved… if
>
> you want people to be involved in it, I'm sorry, you've got to scare
>
> them." (M2 -November focus group)

In addition, real-life experiences were identified as potential elements in an educational strategy although support for this idea was equivocal. As one participant says:

> "Not me, I switch off, I don't care about other people's stories, that's their stories, not
>
> mine." (M2 – November focus group)

Public awareness campaigns were identified as possible sites of educational intervention because T2DM is viewed as an 'invisible' disease. These could be preventive (quote one) and an integrated educational resource could also be provided (quote two):

> Quote one: "There should be mandatory testing…through a pharmacist when you're
>
> 55 or whatever, just a little, you know, blood sample, because who would see you've
>
> got diabetes?" (F1 – November focus group)

> Quote two: "They could get education awareness made through the caravan which is
>
> funded for breast screening…There could be specific nurses and perhaps a doctor
>
> there to help people through the whole thing about it and education." (F1 – November
>
> focus group).

***Conceptions of learning and the role of the learner.*** The idea of 'self-education' was identified as an important element in one's educational and illness trajectory. Those patients who pursue a course of self-education are much more likely to succeed:

> "I think it's the people that help themselves are the ones that are
>
> trying to educate themselves and read about it are the ones have a
>
> better outcome." (F1 – December focus group)

Indeed, self-education can prove to be the difference in one's capacity to avoid complications arising from T2DM:

> "The more people that will read and educate themselves, the better,
>
> because they at least might have some idea when something is going
>
> wrong, to avoid drastic situations like ending up with Charcot's like I
>
> almost did." (F1 – December focus group)

In an analysis of self-directed learning, Brookfield (1994) suggests that one of its constituents is the idea of 'authentic control'. This is defined as the learner's capacity to exercise control over the decisions related to their learning and to have freely available access to the range of materials and resources relevant to their learning. Although there is not enough evidence in either focus group to suggest that participants exercised 'authentic control' over their learning, the fact that they were exposed to management and educational experiences that were fragmented in nature suggests that this gap might have contributed to the lack of control over their own learning. 'Self-education' was one way that was used to address this gap and for one participant, the process of addressing this educational deficit created a sense of 'empowerment':

> "I find a lot of information now on the net that asks, that empowers
>
> me to ask questions." (M5 – November focus group)

Learning, therefore, from this participants' point of view, was not merely concerned with the accretion of knowledge and skills. There was the recognition that the consumption of internet-based information had the potential to facilitate the construction of an 'empowered' and more active role in the patient-health professional relationship.

### Relationships with health professionals.

The use of the term 'health professional' is used to connote allied health professionals as well as general practitioners and medical specialists. Focus group discussions related to relationships with health professionals, revealed a similar thematic concordance that was in evidence with individual interviewees. This concordance, however, did not mean that the level of criticism found in the individual interviews and focus groups was similar as the criticism of health professionals in the focus groups was a great deal more muted. Several dimensions of the relationship with health professionals emerged from the interpretation of the data such as an absence of patient-centred communication and a degree of paternalism. In addition, the competence of health professionals was questioned and the idea of the patient as someone who can play a role in the co-construction of treatment was suggested ("I think I could actually educate them with my experience" F1 – December focus group).

### Family and social history. Family and social histories did not feature as

prominently in the focus group discussions compared to the data in the individual interviews. There were at least four participants out of eleven who could trace a family history of T2DM and a causal model, linking patterns of nutritional behaviour in the home to the development of T2DM, was suggested by one participant (M5) from the November focus group.

## Summary

The literature covering the broad territory of the experience of living with a chronic illness is extensive and there is a degree of concordance between the themes that emerged from the individual interviews and the themes identified by several authors (Ambrosio et al., 2015; Broom & Whittaker, 2004; Bury, 1982; Whittemore & Dixon, 2008). This is not surprising given that themes associated with chronic illnesses share many of the characteristics (Ambrosio et al., 2015) that were identified in the interviews. The analysis of individual interviews, therefore, facilitated an understanding of the complexity of living with T2DM whereas the focus groups provided a community-centred conception of the potential shape of a collaborative learning environment.

The overall picture that emerged from the focus group sessions was that living with T2DM represented a complex process of negotiation between the demands of daily life and self-management of the illness. Although the themes that emerged from the interpretation of the data in both focus groups covered similar territory, there was a difference in emphasis. For both groups, the uneven nature of the quality of management and educational services created a space for participants to question the quality of the health and educational services being provided. To address this gap, the November focus group began to promote a patient-centred model of education and learning – a patient-centred PCoP for people with T2DM. The December focus group, although equally critical of the system-wide gaps in the provision of educational services, focussed less on a community conception of learning and more on a conception of learning as an individual activity.

There were some key differences, however, between the themes from the individual interviews and focus groups. In particular, the affordances of a collaborative learning environment (the theme of the *learning environment)* in which the social attributes of a group

can be leveraged to promote contextual and situated learning (the theme of *conception of learning and role of the learner)*, emerged as themes and these became central elements in the design of the initial learning environment.
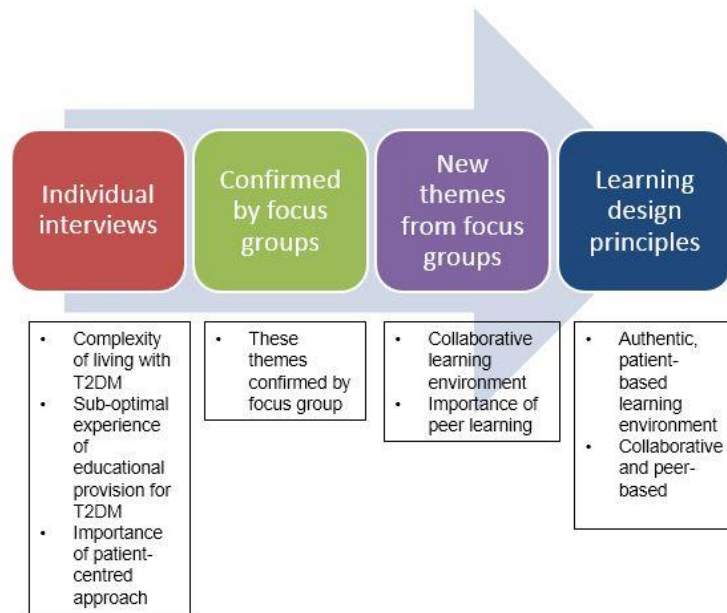


**Figure 4-2. Themes from individual interviews and focus groups combined to shape learning design principles**

Although collaborative learning environments have been extensively studied in the context of formal learning environments, there is a relative lack of literature in the context of these kinds of environments applied in a non-formal learning context. The results from the focus groups, in conjunction with the literature on situated learning and sociocultural theory, were instrumental in helping to shape the nature of the learning environment that was developed. Figure 4-2 describes the analytical route that was taken from the themes that emerged from the interpretation of individual and focus group interviews to the design principles of the first iteration of the learning environment. These principles will be presented and discussed in the following chapter.

# Chapter 5. Learning Designs and Design Principles

In chapter four, the analysis of individual interviews and focus groups was presented. This analysis represented the first phase in this design-based research study and maps to the first phase as illustrated in Figure 5-1.

In this chapter, the learning designs and design principles that map to the second phase (see Figure 5-1) of the cycle are presented. The design principles represent a set of educational guidelines for the development of the learning activities. These learning activities are the constituent parts of what is called the PCoP or learning environment and they are outlined in detail in the rest of this chapter.

**Design-based research phases**                    **Implementation**

| | |
|---|---|
| **1** — Analysis of practical problems by researchers and practitioners in collaboration | **Initial principles** <br>• Use of narrative <br>• Patient-centred approach to education <br>• Learning in a social context |
| | **Data collection and thematic analysis** <br>• Interviews <br>• Focus groups |
| **2** — Development of solutions informed by existing design principles and technological innovations | **Development of the potential community of practice (PCoP)** <br>• Design principles <br>• Learning designs are instances of principles <br>• Learning designs integrating aspects of data and themes from interviews and focus groups |
| **3** — Iterative cycles of testing and refinement of solutions in practice | **Group 1** → Design principles <br>**Group 2** → Design principles <br>**Group 3** → Design principles <br>**Group 4** → Design principles |
| **4** — Reflection to produce final 'design principles' and enhance solution implementation | **Reflective practice and design principles** |

**Figure 5-1. Phases of the design-based cycle**

## Design principles

The design principles in this chapter relate to what Herrington and Reeves (2011) call 'phase two' of the DBR cycle and what is also referred to as phase two in Figure 5-1. It is the phase in which relevant theories from the literature and empirical data are combined to guide the development and implementation of a practical solution to a problem that has emerged in an educational context.

In this research, the overarching problem that emerged from the interpretation of the interview data was the fragmented management and educational experiences for patients with T2DM. The uneven nature of the educational experiences was a product of the lack of integrated educational services. Combined with the complexity of having diabetes and the failure of an integrated, system-wide educational infrastructure, participants often felt underserved by the healthcare system.

Educational solutions to the fragmented management and educational experiences in both focus groups differed. However, they both shared a view of learning that placed the patient at the centre of the educational experience. In the November focus group, a peer support approach to support and education was discussed and a perspective on learning as a social, patient-based activity was offered as an alternative to the current model of educational provision ("The best place we can learn from is ourselves." M4 – November focus group). Participants in the December group placed less emphasis on the social nature of learning and more of the responsibility that an individual has towards his or her learning ("I think it's the people that help themselves are the ones that are trying to educate themselves." F1 – December focus group).

These patient-based perspectives on learning were utilised in the first iteration of the learning environment by drawing on some of the data from the interviews to create a set of textual,

patient-based material that could be used to facilitate the beginning of discussions. Apart from their use at the learning design level, these perspectives resonated with the model of patient learning that underpins this study.

These are both patient-centred perspectives on learning and they correspond with the patient-centric model that has been adopted in this study. Additionally, the social model of learning associated with the November focus group aligns with the theoretical model of learning that is adopted through the learning designs that were developed. What the data from the interviews does not provide, however, is a model of learning that identifies the educational aims and objectives of a patient-centric, social model of learning. This is not surprising given that the aim of the interview process was not to elicit these kinds of ideas but what this does highlight, however, is the role of theory – in our case, a social model of learning – to conceptualise empirical interview data.

At a lay level, the participants from the November focus group proposed that a peer network could provide a positive learning environment. At a theoretical level, thinkers deeply linked to a sociocultural model of learning such as Brown, Collins and Duguid (1989) and Lave and Wenger (1991) argue that this type of situated and contextually-bound learning that the November focus group participants proposed is the very definition of learning. What these models of learning do not provide, however, are mechanisms for challenging the status quo and without educational aims and objectives for challenging current arrangements (for example, between doctors and patients), these communities of practice can potentially become systems for the reproduction of currently held values and beliefs rather than the production of novel ways of thinking or of framing experience (Langendyk, Mason, & Wang, 2016). To address this gap in the sociocultural model of learning and to help guide the development of a set of educational aims and objectives of the learning environment, the family of ideas associated with transformative learning (Kitchenham, 2008) was added to the

model. These two theories form the basis of the theoretical framework that underpins the learning environment and its educational characteristics. All the empirical and theoretical sources used for the development of the first set of design principles are illustrated in Figure 5-2.
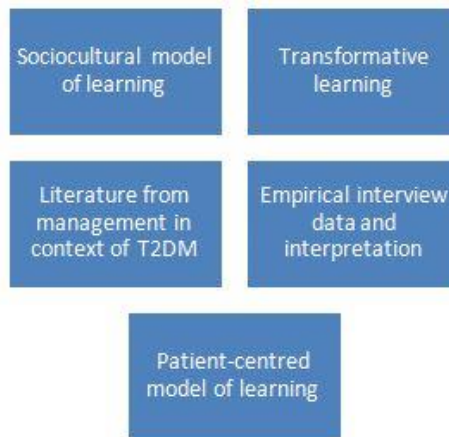


**Figure 5-2. Sources for design principles of the first iteration of the learning environment**

With this in mind, the following design principles for the first iteration of the learning environment were proposed:

The objectives of transformative learning in the context of T2DM can be facilitated through participating in a patient-based online learning environment or patient-based community of practice. To encourage the ongoing interaction that can sustain the growth and development of a potential community of practice, learning activities:

- Promoted participation and engagement through authentic and contextually relevant activities (diaries);

- Encouraged individual reflection and group-based discussions in the context of authentic problems (individual reflection and group discussion);

- Provided opportunities for participants to engage in activities that promote agency and control in the context of T2DM self-management (finding and sharing internet-based resources).

Additionally, an online learning management system was used as a tool to:

- Support the development of a patient-based community of practice for a geographically dispersed set of patients with T2DM and;

- Encourage the participation of patients in a patient-based community of practice who were unable to meet face-to-face.

The principles outlined above were developed as learning designs and subsequently implemented as activities within the Moodle© learning management system.

## Learning designs

In the following section, an ontological and epistemological perspective (a critical realist view) on the nature of the learning designs is presented together with an explanation of how AT was used as a schema for the representation of contextual information related to the learning designs. This is followed by an outline of how the pedagogical characteristics of the learning designs are represented through the 'learning design toolkit'.

The learning designs of the first iteration of the PCoP are described and outlined using three views:

1. a participant-centred view i.e. the activities as they are presented to the participant;

2. an AT view describing the context in which the activities are embedded, and;

3. a learning design toolkit view which outlines the pedagogical characteristics of each learning activity.

These descriptions follow a chronological pattern, that is, week one is described and then week two and so on.

An AT view was used to ensure a schematically uniform representation of each task and this view also enabled the systematic evaluation of the use of the learning environment and a learning design toolkit view was used to represent the pedagogical characteristics of each learning activity.

**A critical realist perspective.**   It is clear from the themes that emerged from the interview data (individual and focus groups) that the complexity of living with diabetes was distributed across a range of parameters. These range from patient relationships with health professionals to the 'work' (Corbin & Strauss, 1985) of daily management. There were aspects of these experiences that were highly contextual and applicable to individual participants (for example, mobility status or employment profiles) and there were some features of their experiences that were underpinned by the reality of managing a disease with common bio-medical parameters such as diabetes.

In critical realist terms, this is an example of a combination of an objective reality (pathology of diabetes) against epistemic and social realities that are unique to individual participants. The learning designs that have been developed reflect the ontological realist nature of diabetes and management strategies (for example, there is a focus on physical activity and nutrition) but at the same time recognising the contextual factors that individuals bring to the learning environment. For example, participants are required to reflect *individually* on the barriers and challenges that they face in engaging with physical activity tasks and they are then required to share their individual reflections with the group. This task reflects the concern for individual context as well as the role that physical activity can play in the management of diabetes.

**Activity theory representation.**   As indicated in the chapter on methodology (chapter three), an AT perspective was used to represent and capture the layers of complexity associated with the learning designs in the learning environment. Using an AT perspective, a learning design is not just a collection of end user instructions presented to the user together with its pedagogical characteristics. The representation of a learning design also needs to include the conceptual and physical tools that a user might use to engage with the task, the explicit rules (instructions) and implicit rules (management history) that affect how they engage with task, the social network or community that helps the user engage with the task, the way in which collaborative tasks in the learning environment are distributed and the outcomes associated with engaging in the task. These parameters are illustrated in Figure 5-3 and the icons associated with the model are also used in the description of the learning activities. The AT 'nodes' are broken down into a table (Table 5-2) with illustrations of their meaning in the context of a learning design.

**A pedagogical representation.**   Although an AT representation of learning designs represents a powerful lens through which to conceptualise contextual factors and mediating elements in a learning design, AT lacks the pedagogical language to describe the underlying pedagogical characteristics of proposed learning activities. In the design of learning environments, a wide array of theoretical positions can be adopted. Typically, the range spans from instructional design approaches inspired by behaviourist ideas to constructionist models of education and socially situated learning. The plethora of theories, however, makes it difficult to practice what Conole et al. (2004) have called 'theory-informed design' because each theory possesses a set of underlying philosophical values about the defining characteristics of learning; starting from any one of these positions often results in the exclusion of ideas from other traditions. In order to break this impasse, Conole et al. (2004) propose what they call a 'learning design toolkit' to aid practitioners in the

development of learning designs that are theoretically informed. This toolkit idea was adopted to describe the learning designs in the PCoP and builds on previous work on the transformation of patient-derived themes into learning design (Mason, 2012).

*An example: description of a learning design for a 'food diary' activity using the learning design toolkit.*   Dietary management plays a role in an integrated approach to lifestyle options available to people who have T2DM (Nield et al., 2008). One way of encouraging a greater degree of reflexivity in nutritional behaviour is the food diary (Zepeda & Deal, 2008). A learning design approach to the description of a food diary can describe the educational shape of an activity thereby mapping underlying educational theories to learning activities and creating a framework to describe the features of each activity. This provides a way to identify educational features of an activity which makes the modification of learning activities a principled rather than ad hoc practice.

**Table 5-1. A learning design for a food diary**

| *Activity* | *Individual-Social* | *Non-reflective-Reflective* | *Experiential-Informational* |
|---|---|---|---|
| *Food diary* |  |  |  |

We can see that the food diary activity can be described across the dimensions of Individual/Social, Non-reflective/Reflective and Experiential/Informational. The dot in each of these dimensions represents where the activity sits within each dimension. The food diary in its current form sits midway between an individual learning and social activity because although learners in the PCoP will not be sharing food diaries with other learners, participants will use the diary to discuss nutritional issues during visits with health professionals. This

gives the activity its social character. Keeping a food record is also a reflective activity because it requires learners to reflect upon their nutritional practices. It is also more experiential than informational because learners are required to record their own authentic experiences. Learners are, therefore, conceived as active participants in the learning process rather than passive recipients of information.
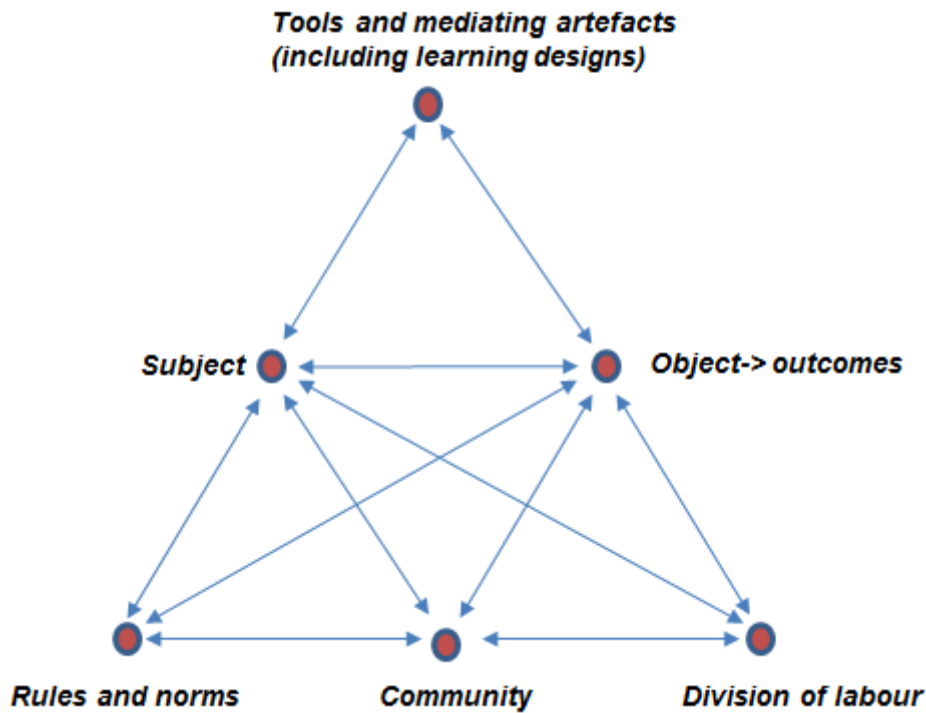


**Figure 5-3. Second generation AT model**

**Table 5-2. AT parameters and their meaning**

| Activity Theory parameter | Use in learning design |
|---|---|
| Learning activity/activities | This is the learning activity. This might be an individual reflective task or a collaborative one. The pedagogical characteristics of the task will be outlined here. The three pedagogical dimensions are: |

| | |
|---|---|
| | • Individual/social |
| | • Non-reflective/reflective |
| | • Experiential/informational |
| Subject | This is the participant using the learning environment. |
| Object | Engagement with a learning activity is the object through which social interaction is facilitated. |
| Outcomes | The outcomes relate to the educational objectives of each activity. |
| Tools and mediating artefacts | Tools and resources may be physical or conceptual. For example, users engage with the learning environment using Moodle© and they engage with resources embedded in learning activities. Conceptual tools might refer to personal epistemologies of T2DM that can influence engagement with management tasks. |
| Rules | These rules can be explicit or implicit. An explicit rule outlines the instructions for each task. <br><br> An implicit rule from the perspective of the subject can be seen as a guide to action that has been developed over time and is part of a patient's identity. For example, this might relate to a patient's management history or the relationship they have had with health professionals. |

| | | |
|---|---|---|
|  | Community | This is the social network of family and friends that constitutes the subject's social world. |
|  | Division of labour | At the level of a learning activity, this is the distribution of engagement with an activity within a group. |

Although the learning designs aimed to form the initial boundaries of a potential online patient-centred community of practice for individuals with T2DM, the content of the learning designs differed in a few ways. For example, one of the learning designs (week four - food diary and nutrition) is informed by a combination of insights that emerged from individual interviews (from the 'illness work' dimension in the theme of *having diabetes* and the theme of *patient knowledge of diabetes*, for example) in addition to the literature on nutrition and T2DM. Another learning design (week five – physical activity) is based around the literature associated with lifestyle changes and the management of T2DM.

Figure 5-4 represents the first or home page of the learning environment. Subsequent pages and sections are identified and represented in the following set of learning designs. They follow the temporal sequence indicated by the left hand menu in Figure 5-4. In all of the following designs, activities are described as either individual or group activities. *Individual* activities are reflective in nature in which participants are required to reflect on aspects of their management with the option of then reporting back to the group. *Group* activities are collaborative in nature in which group members share experiences and knowledge with other members of the learning community.

## Home page of the PCoP



**Figure 5-4. The home page of the PCoP**

The learning designs for each week are outlined in greater depth below.

### Week one

Prior to engaging in learning activities, participants were required to complete a self-efficacy questionnaire (Beckerle & Lavin, 2013) and this is followed by the first 'icebreaker' activity (introduce yourselves).

**Table 5-3. Week one task instructions**

| |
|---|
| Please take about 5 minutes to **introduce yourselves**. This might include your name, how long you've had your diabetes and what you'd like to get out of your participation in the group. |

**Table 5-4. Breakdown of week one task using AT and the learning design toolkit**

| | |
|---|---|
| Learning | Individual/social: |

| activity/activities | Non-reflective/reflective: <br><br> Experiential/informational: <br><br> This activity is partly individually-based and partly social in nature. The reflection required is minimal although the level of reflection is likely to differ depending on the confidence of the learner to reveal personal details. It is also more of an experientially-based activity because the success of the activity is reliant upon disclosure of a degree of personal information. |
|---|---|
| Subject | People with diabetes who are participating in the project. |
| Object | Using the PCoP learning environment and, in particular, the forum tool to greet other participants. |
| Outcomes | The development of 'social presence' (Rourke et al., 1999) and familiarity with the use of the forum tool. |
| Tools and mediating artefacts | • PCoP learning environment (the forum tool). <br> • iPad. <br> • Personal devices (laptops/desktops/phones). <br> • 'How to' resources in the PCoP learning environment. |
| Rules | **Explicit**: Following instructions for completing the activity. <br><br> **Implicit**: Familiarity with submitting personal information in an online space; Interactive medium of forum-based tools and exposure of the self in an online context. |

|  Community | Other participants in the learning environment and friends and family. Possible recognition from health professionals with involvement in the project. |
|---|---|
|  Division of labour | Mainly an individual activity although the implicit assumption is that participants will read other participants' posts. |

## Week two

Table 5-5. Week two task instructions

As part of this project several people have been interviewed. This is a selection of the issues that they have raised. Spend some time thinking about what they have said and reflect on your take on these experiences.

**Using the forum**

1. Click on the topic you're interested in (orange circle) **or** start a new topic by clicking on 'Add a new discussion topic'.

2. **Replying**

- Once you have clicked on a topic you'll need to reply to it.

- Click on the post you're interested in and in the next screen you'll see a link called 'reply'

- Click on 'reply' and start writing!

3. **Questions to ask yourself when replying**

- Are any of the management experiences relevant to you? Why?

- Can you add any of your own personal experiences to any of the experiences in the forum?

- How important do you think it is to share experiences?

**Table 5-6. Breakdown of week two task using AT and the learning design toolkit**

| Learning activity/activities | Individual/social:   Non-reflective/reflective:   Experiential/informational:   This activity differs substantially from the previous one because learners are expected to interact (read or respond) to other posts. Learners are required to reflect on their own experiences and share these experiences with others. |
|---|---|
| Subject | People with diabetes who are participating in the project and facilitator. |
| Object | Using the PCoP learning environment and, in particular, the forum tool to share management experiences of having diabetes. |
| Outcomes | <ul><li>Peer-to-peer interaction in a common domain of interest.</li><li>Practical and instrumental knowledge is shared within the community.</li></ul> |
| Tools and | <ul><li>PCoP learning environment (the forum tool).</li><li>iPad.</li></ul> |

| mediating artefacts | <ul><li>Personal devices (laptops/desktops/phones).</li><li>'How to' resources in the PCoP learning environment..</li></ul> |
|---|---|
| Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants share a domain of interest (diabetes). Participants share an interest to improve strategies to manage their diabetes. |
| Community | Other participants in the learning environment and friends and family. Possible recognition from health professionals with participant's involvement in the project. |
| Division of labour | Participants take on two roles based around two dimensions:<ul><li>To reflect and to provide *individual* accounts of misconception.</li><li>To engage with other members and their accounts of misconceptions and reflect on other contexts.</li></ul> |

**Week three**

Table 5-7. Week three task instructions

1. How many times have you thought that you have understood how something works only to be told that you really haven't!

In this activity, we'll be thinking about this question in relation to diabetes and these are just some questions to get you thinking before the next screen.

- What is your understanding of diabetes?

- Has your understanding changed since you've been attending sessions?

- How important is knowing about diabetes for daily management?

2. In as few words as possible how would you explain what diabetes is?

**Table 5-8. Breakdown of week three task using activity theory and the learning design toolkit**

|  Learning activity/activities | Individual/social: <br><br>Non-reflective/reflective: <br><br>Experiential/informational: <br><br>This activity is based on an individual's knowledge of the nature of T2DM and whether this has had an impact on their self-management. |
|---|---|
|  Subject | People with diabetes who are participating in the project. |
|  Object | Using the PCoP learning environment and, in particular, the forum tool to share management experiences of having diabetes. |
|  Outcomes | There is evidence to suggest that there is a link between improved glycaemic control and patient education (Bruce, Davis, Cull, & Davis, 2003; Iqbal et al., 2008). This activity builds on these insights as well as empirical interview data (*patient knowledge of diabetes* theme in analysis of individual interview) and is primarily interested in exploring the link between subjective knowledge of |

| | | diabetes and self-management practices. |
|---|---|---|
|  | Tools and mediating artefacts | • PCoP learning environment (the forum tool).<br><br>• iPad.<br><br>• Personal devices (laptops/desktops/phones).<br><br>• 'How to' resources on in the PCoP learning environment. |
|  | Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants are comfortable writing about their understanding of diabetes – they might feel that this is a 'test' of their knowledge but this is not the intention of the activity. |
|  | Community | This is a reflective and individual activity in which the participant is required to interact with the task requirements and not with other participants. |
|  | Division of labour | This is not an example of an activity that is predicated on the value of interaction leading to the construction of knowledge. Participants take on the role of a reflective practitioner but are not required to reflect on other individual contexts. |

**Table 5-9. Week three group task instructions**

---

**Activity of the week forum – misconceptions**

Take some time to note down any **misconceptions** that you have or have had about diabetes

and **share these with your peers** – you may find that you share similar issues!

---

**Table 5-10. Breakdown of week three group task using activity theory**

| | |
|---|---|
| Subject | People with diabetes who are participating in the project. |
| Object | Using and the PCoP learning environment, in particular, the forum tool to share misconceptions of the nature of diabetes. |
| Outcomes | This activity seeks to build on the individual reflection on the nature of diabetes and to share these reflections with the group. |
| Tools and mediating artefacts | • PCoP learning environment (the forum tool).<br><br>• iPad.<br><br>• Personal devices (laptops/desktops/phones).<br><br>• 'How to' resources in the PCoP learning environment.<br><br>• Posts from other participants. |
| Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants are comfortable sharing individual reflections on the nature of diabetes. Participants will use posts from other participants to reflect on their own contexts. |
| Community | This is a combination of a reflective and shared learning activity requiring participation from individuals in the group. |

|  Division of labour | Participants take on two roles based around two dimensions: <ul><li>To reflect and to provide individual accounts of their misconceptions.</li></ul> To engage with other accounts of misconceptions and reflect on other individual contexts. |
|---|---|

## Week four

**Table 5-11. Week four individual task instructions**

---

**Activity of the week – Food diary**

People involved in this project have talked about how useful a food diary has been. **Over the next week try and fill out as much of this food diary as possible** and **during your next visit with an allied health professional** use it to discuss your nutritional patterns.

The food diary was developed using the food diary available from http://www.diabetes.co.uk/food/food-diary.html.

**Before** you start recording anything in the diary take a look at this video (from healthtalkonline.org). Are there any experiences in this video that are similar to yours? If you want to discuss any dietary related matters click here – it will take you to the 'food diary' forum.

---

**Table 5-12. Breakdown of individual week four task using activity theory and the learning design toolkit**

|  Learning | Individual/social: |
|---|---|

| activity/activities | Non-reflective/reflective: 

Experiential/informational: 

This is an individual, experiential task that complements the next collaborative activity. |
|---|---|
|  Subject | People with diabetes who are participating in the project. |
|  Object | Engaged in the PCoP and, in particular, the Moodle© database tool to contribute to a food diary. |
|  Outcomes | The goal of the activity is to promote individual reflection on nutritional choices. It builds on individual interview data ('illness work' in the *having diabetes* theme from individual interviews) which outlines the importance of food diaries for some participants as a tool for regulating nutritional choices. This practice relates to the idea that self-assessment has a role to play in changing dietary behaviour (Zepeda & Deal, 2008). Additionally, from a transformative learning perspective, this is a task in which frames of reference are employed by participants to reflect on current nutritional choices. This reflection becomes critical if frames of references are challenged (Mezirow, 1990b).The educational intention behind the learning activity is informed by this perspective. |

| | |
|---|---|
|  Tools and mediating artefacts | • PCoP learning environment (the forum tool).<br><br>• iPad.<br><br>• Personal devices (laptops/desktops/phones).<br><br>• 'How to' resources in the PCoP learning environment. |
|  Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants are familiar with the form of diary activities. Participants use the opportunity of self-assessment to reflect on dietary choices. |
|  Community | This is a reflective and individual activity in which the participant is required to interact with the task requirements and not with other participants. |
|  Division of labour | This is not an example of an activity that is predicated on the value of interaction leading to the construction of knowledge. Participants take on the role of a reflective practitioner but are not required to reflect on other individual contexts. |

**Table 5-13. Week four group task instructions**

| |
|---|
| **Activity of the week forum – Food diary**<br><br>• Have you used a food diary before?<br><br>• Has it been useful? In what way? |

> - Will you continue using one?

**Table 5-14. Breakdown of week four group task using activity theory and the learning design toolkit**

| | |
|---|---|
| Learning activity/activities | Individual/social: <br><br>Non-reflective/reflective: <br><br>Experiential/informational: <br><br>This activity builds on the previous individual activity but learners are required to share their experiences of using a diary and discuss the utility of a diary as a tool for self-management. |
| Subject | People with diabetes who are participating in the project. |
| Object | Using the PCoP learning environment and, in particular, the forum tool to share food diaries and reflections. |
| Outcomes | This activity seeks to build on engagement with contributions made to a food diary and to share instrumental knowledge (practical food tips) and reflections on dietary choices. |
| Tools and mediating artefacts | - PCoP learning environment (the forum tool).<br><br>- iPad.<br><br>- Personal devices (laptops/desktops/phones).<br><br>- 'How to' resources in the PCoP learning environment. |

| | |
|---|---|
| | • Posts from other participants. |
| Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants are comfortable sharing individual reflections related to their food diaries. Participants will use posts from other participants to reflect on their own choices and relate to other participants' contexts and dietary choices. |
| Community | This is a combination of a reflective and shared learning activity requiring participation from individuals in the group. |
| Division of labour | Participants take on two roles based around two dimensions:<br><br>• To provide individual accounts of their misconceptions;<br><br>• To engage with other accounts of misconceptions and reflect on other individual contexts. |

**Week five**

Table 5-15. Week five individual task instructions

> **Activity of the week – Physical activity diary**
>
> **Before** you start recording anything in the diary take a look at this video (from healthtalkonline.org). Are there any experiences in this video that are similar to yours? If you want to discuss any dietary related matters click here – it will take you to the '**physical activity diary**' forum

**Table 5-16. Breakdown of week five individual task using activity theory and the learning design toolkits**

| | |
|---|---|
| Learning activity/activities | Individual/social: <br><br> Non-reflective/reflective: <br><br> Experiential/informational: <br><br> This is similar to the food diary activity and is based on participants providing individual reflections on physical activity using a diary format. |
| Subject | People with diabetes who are participating in the project. |
| Object | Using the PCoP learning environment and, in particular, the Moodle© database tool to contribute to a physical activity diary. |
| Outcomes | The goal of the activity is to promote individual reflection on physical activity. Physical activity has an important role to play in the management of T2DM (Thomas et al., 2006) and the learning goal of this activity is to promote the development of the capacity for critical reflection on their levels of physical activity. |
| Tools and mediating artefacts | • PCoP learning environment (the forum tool). <br><br> • iPad. <br><br> • Personal devices (laptops/desktops/phones). <br><br> • 'How to' resources in the PCoP learning environment. |

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| | |
|---|---|
| Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants are familiar with the form of diary activities. |
| Community | This is a reflective and individual activity in which the participant is required to interact with the task requirements and not with other participants. |
| Division of labour | This is not an example of an activity that is predicated on the value of interaction leading to the construction of knowledge. Participants take on the role of a reflective practitioner but are not required to reflect on other individual contexts. |

**Table 5-17. Week five group task**

| |
|---|
| • Have you used a physical activity diary before?<br><br>• Have you found it useful? If so, why and if not, why not.<br><br>• Will you continue using a physical activity diary? |

**Table 5-18. Breakdown of week five group task using activity theory and the learning design toolkit**

| | |
|---|---|
| Learning activity/activities | Individual/social:<br><br>Non-reflective/reflective:<br><br>Experiential/informational: |

| | | |
|---|---|---|
| | | This activity is similar to the discussion activity based around the food diary. It is a social, reflective and experientially-based task. |
| | Subject | People with diabetes who are participating in the project. |
| | Object | Using the PCoP learning environment and, in particular, the forum tool to share food diaries and reflections. |
| | Outcomes | This activity seeks to build on engagement with the production of a physical activity diary and for participants to share individual contextual barriers of the challenges and barriers of engaging in physical activity. |
| | Tools and mediating artefacts | <ul><li>PCoP learning environment (the forum tool).</li><li>iPad.</li><li>Personal devices (laptops/desktops/phones).</li><li>'How to' resources in the PCoP learning environment.</li><li>Posts from other participants.</li></ul> |
| | Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants are comfortable sharing individual reflections related to their food diaries. Participants will use posts from other participants to reflect on their own choices and relate to the contexts of other participants. |

| | |
|---|---|
| Community | This is a combination of a reflective and shared learning activity requiring participation from individuals in the group. |
| Division of labour | Participants take on two roles based around two dimensions: <ul><li>To provide descriptive accounts of their levels of physical activity to the group;</li><li>To interact with other participants' accounts.</li></ul> |

**Week six**

Participants were required to complete the same self-efficacy questionnaire that they completed during the first week.

*Optional and ongoing activities.* There were two activities that were considered optional. Participants were encouraged, during weekly communication, to contribute to a diary using the blog tool throughout the period of their participation. They were also encouraged, through weekly communication, to share resources (such as links on the internet) with other participants. These activities are outlined in greater detail below.

**Weekly blog activity**

Table 5-19. The weekly blog task

We're interested in your thoughts on:

1. How often do you use twitter? How often do you use the Moodle site? Which one do you prefer and why? How do you think this site could be improved?

2. Has participating in the project improved your confidence in being able to manage your diabetes? How?

3. Can you indicate how collaborating and sharing with others has given you more

confidence to manage your diabetes or cleared up questions you might have had. Do you feel

part of a learning community? In what way?

4. Have you learnt anything new? Can you give some examples.

**Table 5-20. Breakdown of the reflective blog task using activity theory and the learning design toolkit**

|  Learning activity/activities | Individual/social:  <br><br> Non-reflective/reflective:  <br><br> Experiential/informational:  <br><br> This is an activity based on an individual's reflection on their participation in the learning environment. |
|---|---|
|  Subject | People with diabetes who are participating in the project. |
|  Object | Using the PCoP learning environment and, in particular, the Moodle© 'lessons' tool to engage with the task. |
|  Outcomes | The goal of the activity is to promote individual reflection on the impact that using the tool has had on the self-management of diabetes, the use of the tool itself in terms of its usability against other modes of interaction and the sense of 'social presence' (Garrison et al., 1999) in the online environment. |

| | |
|---|---|
| Tools and mediating artefacts | • PCoP learning environment (the forum tool)<br><br>• iPad.<br><br>• Personal devices (laptops/desktops/phones)<br><br>• 'How to' resources the PCoP learning environment. |
| Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Participants are familiar with the form of diary-like activities. |
| Community | This is a reflective and individual activity in which the participant is required to interact with the task requirements and not with other participants. |
| Division of labour | This is not an example of an activity that is predicated on the value of interaction leading to the construction of knowledge. The task requires individual reflection rather than social interaction. |

## Sharing resources activity

**Table 5-21. Sharing resources activity**

| |
|---|
| Use this forum to share resources that you've found on the web or elsewhere. |

**Table 5-22. Breakdown of sharing resources activity using activity theory and the learning design toolkit**

| | |
|---|---|
| Learning | Individual/social: |

| activity/activities | Non-reflective/reflective: <br><br> Experiential/informational: <br><br> This activity requires learners to reflect on internet-based material that they have found useful and to share it with others. Additionally, this is the most informational of all the activities because it requires learners to read web-based material that others have posted. |
|---|---|
| Subject | People with diabetes who are participating in the project. |
| Object | Using the PCoP learning environment and, in particular, the Moodle© 'forum tool to engage with the task. |
| Outcomes | The goal of the activity is to promote the sharing of knowledge (specifically websites) among participants thus contributing to the 'cognitive' presence (Garrison et al., 1999) of the community. |
| Tools and mediating artefacts | • PCoP learning environment (the forum tool). <br><br> • iPad. <br><br> • Personal devices (laptops/desktops/phones). <br><br> • 'How to' resources in the PCoP learning environment. |
| Rules | **Explicit**: Following instructions for completing the activity. <br><br> **Implicit**: Participants are familiar with the form of diary-like |

| | | |
|---|---|---|
| | | activities. |
|  Community | | This is a reflective and individual activity in which the participant is required to interact with the task requirements and not with other participants. |
|  Division of labour | | Participants take on two roles based around two dimensions:<br><br>• To provide descriptive accounts of their levels of physical activity to the group;<br><br>To interact with other participants' accounts. |

The learning designs in tables Table 5-3 to Table 5-22 are consolidated and outlined in the table (Table 5-23).

**Table 5-23. Breakdown of learning designs using learning design toolkit representation**

| Individual or group-based activity | Week | Description | Pedagogical dimensions |
|---|---|---|---|
| Group | One | Introduce yourselves | Individual-social:<br><br><br><br>Non-reflective-reflective:<br><br><br><br>Experiential-informational: |

| | | | |
|---|---|---|---|
| | | |  |
| Group | Two | Discussion of management experiences | Individual-social:<br><br><br>Non-reflective-reflective:<br><br><br>Experiential-informational:<br> |
| Individual | Three | What do you think diabetes is? | Individual-social:<br><br><br>Non-reflective-reflective:<br><br><br>Experiential-informational:<br> |
| Group | Three | What does the group think diabetes is? | Individual-social:<br><br><br>Non-reflective-reflective:<br><br><br>Experiential- |

| | | | informational:  |
|---|---|---|---|
| Individual | Four | What have you been eating? (food diary) | Individual-social: <br><br>Non-reflective-reflective: <br><br>Experiential-informational:  |
| Group | Four | What have you been eating? | Individual-social: <br><br>Non-reflective-reflective: <br><br>Experiential-informational:  |
| Individual | Five | How active have you been (physical activity diary) | Individual-social: <br><br>Non-reflective-reflective:  |

| | | | |
|---|---|---|---|
| | | | Experiential-informational:<br> |
| Group | Five | Discuss your physical activity | Individual-social:<br><br><br>Non-reflective-reflective:<br><br><br>Experiential-informational:<br> |
| Individual | Ongoing | Weekly blog | Individual-social:<br><br><br>Non-reflective-reflective:<br><br><br>Experiential-informational:<br> |
| Group | Ongoing | Share resources | Individual-social:<br><br><br>Non-reflective-reflective: |

| | | | |
|---|---|---|---|
| | | | Experiential-<br><br>informational: |

## Summary

The first two phases in design-based research studies (Figure 5-1) are the identification and analysis of practical problems and the development of solutions to address the identified problem using existing design principles and relevant technologies. This chapter has addressed the problem of fractured management and educational experiences of people with T2DM by drawing on a sociocultural model of learning, the literature on T2DM management and empirical data from the individual interviews and focus group sessions. This has resulted in the development of a set of learning design principles that underpin the proposed online learning environment.

The ten learning designs that formed the initial structure of the learning environment were described using three views. The first view was a description of the learning activity that was presented to the user (i.e. the elements of the interface in the PCoP website) and the second was a deeper view of each learning design using AT and the learning design toolkit.

AT was chosen to describe the learning designs because it can be used to schematically represent the elements of complexity that constitute the learning experience. These elements were then systematically described using the parameters of the theory. The representation of the pedagogical characteristics of the learning designs were outlined using ideas adapted from the learning design toolkit. Taken together, these views provide a schematic framework for

the representation of learning designs that incorporate pedagogical and socio-technical dimensions.

The iterative phase of design-based research concerned with the refinement and testing of educational solutions (phase three of Figure 5-1) is addressed in the next chapter. AT plays a key role as an evaluative tool in this chapter as the use and engagement with the environment is evaluated. This also represents the point at which the online learning environment became a social learning environment in which participants engaged with the learning activities.

# Chapter 6. Results

## Introduction

In the previous chapter, the learning designs and principles associated with the first iteration of the PCoP were outlined. This represented the second phase of the design-based process as illustrated in Figure 6-1. The third phase of the DBR cycle as represented in Figure 6-1 refers to the iterative cycle of refinement and testing of the learning designs that were proposed in the previous chapter. This chapter describes the iterative cycle that was undertaken.

This chapter is broken down into four major sections and these correspond to the groups that engaged in the PCoP. Each section contains an analysis of group participation and analyses of the interviews conducted prior to participation. Lastly, learning design principles associated with each iteration are presented.

Four groups of participants took part in this study between February 2014 and February 2015. After newspaper advertisements were placed in local media outlets, participants were allocated group membership on a 'first come first served' basis. The membership of each group contained either three (group three) or four (groups one and four) participants. Membership of each group consisted of new members as well as participants from previous groups. The first, third and fourth groups participated in the PCoP but the formation of group two proved to be problematic due to the inability to form a group and, as a result, participation in the PCoP did not occur. Data from participation in the second group, therefore, was largely absent although the fact that the two participants in group two did not engage in the PCoP suggests that the failure to find new participants in the second group led to a lack of interest in the current members to participate and engage in the PCoP.

**Data collection.** Prior to engaging with the PCoP, participants in each group took part in semi-structured interviews and completed a self-efficacy questionnaire (Beckerle & Lavin, 2013) which was delivered using SurveyMonkey©. The construction of the interview conducted before engagement in the PCoP (see appendix 7) was informed by questions related to how technological tools (i.e. the parameter of the tool in activity theory) mediate social relationships including relationships with health professionals. The post-use interview (see appendix 8) was designed using further parameters in activity theory such as tools, rules and norms, the community and division of labour. These interviews were either conducted as individual interviews (group one) or as group interviews (groups three and four). All of the interviews were analysed using thematic analysis with a focus on the development of semantic themes (Braun & Clarke, 2006).
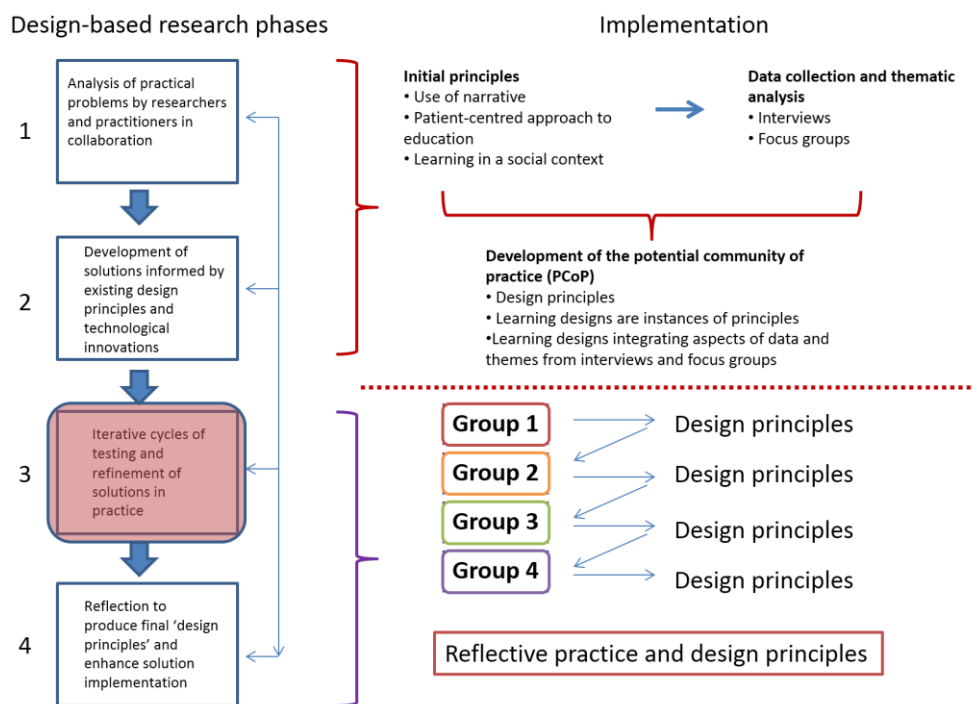


**Figure 6-1. Design-based research phases and implementation**

The interview process was carried out for the four groups in the following manner.

**Table 6-1. Description of the interview process for each group**

| Group | Pre-use interviews | Post-use interviews |
|---|---|---|
| Group one | All interviews were conducted individually. | One interview was conducted with YS and another interview with YS and DK. PW and KA were available to be interviewed. |
| Group two | No interviews took place. A pre-use survey was completed by CA. | No post-use interviews were conducted. |
| Group three | An interview was conducted with (MS, MW and MT) participants as a group. | Two individual interviews were conducted with MS and MW. MT was unavailable to be interviewed. |
| Group four | Three participants (MC, MC1 and NH) were interviewed as a group (PC was unavailable). | MC and MC1 were interviewed together. NH and PC were interviewed individually. |

All of the interview data were analysed using thematic analysis (Braun & Clarke, 2006). In addition to the interviews that were conducted, interactions and posts from engagement in the PCoP were compiled and usage data that were made available via the Moodle© logs were used to measure page views (participation by observing) against active participation (posts on discussion forums).

The contextual information provided for each participant was complemented by the diabetes self-efficacy scores from the self-efficacy questionnaire that participants undertook prior to their engagement in the PCoP.

The limitations of using the self-efficacy data for meaningful analysis will be explored in the discussion chapter.

## Group one

**Recruitment.** An advertisement was placed in a local paper in February 2014 and four participants were recruited.

Four interviews were conducted with two males (45 and 46 years old) and two females (39 and 55 years old). One interview was held at the participant's house in November 2013 and three were held at the Western Sydney University School of Medicine in March 2014. Length of interviews varied between eight and 22 minutes. All interviews were recorded, transcribed and analysed using thematic analysis. The ages of this group and the dates which they were diagnosed with T2DM are presented in Table 6-2.

**Individual contexts of participants.** The interpretation of the data from the pre-use interviews yielded three significant dimensions related to individual contexts. These were:

- the impact of the macro forces of technological capital on an individual's capacity to participate in an online learning environment;

- a varied array of clinical and social histories (see Table 6-3); and

- length of time individuals had been diagnosed with T2DM (see Table 6-2).

The data in Table 6-2 are important for two reasons. Firstly, there was a difference of six years between one participant's diagnosis and the participant who had been diagnosed with T2DM for the longest period of time. Although this group was not an established learning community at the start of their participation, this raises interesting questions about the relationship between levels of knowledge and expertise associated with date of diagnosis (Baumgartner, 2012; Weaver, Lemonde, & Goodman, 2014) and how this might shape the dynamic of interaction between members in the online community. This question will be explored in the discussion of the analysis of the interpretation of the post-use data.

**Table 6-2. Participants in group one and date diagnosed with T2DM**

| Participant | Date diagnosed with diabetes |
| --- | --- |
| Male 45 years of age (DK) | 2007 |
| Male 46 years of age (PW) | 2010 |
| Female 55 years of age (YS) | 2010 |
| Female 39  years of age (KA) | 2013 |

In addition to the information related to dates of diagnosis (Table 6-2), additional information from participants was elicited during the interviews. This included information on employment profiles and family history. This contextual information is presented in Table 6-3.

**Table 6-3. Individual contexts of participants in group one**

| Participants | Individual contexts |
| --- | --- |
| DK | <ul><li>Mother and father diagnosed with T2DM.</li><li>Eldest daughter diagnosed with insulin resistance.</li></ul> |

| | |
|---|---|
| | • 'Disorienting dilemma' of daughter's insulin resistance led to re-appraisal of self-management strategies.<br><br>• Government employee. |
| PW | • Employed as a shift worker. This affected PW's ability to construct regular self-management patterns. |
| YS | • One of the few members of her community with access to the internet.<br><br>• Lacks mobility and is mostly home-bound. |
| KA | • Raising a family.<br><br>• History of gestational diabetes. |

These contexts indicate that the first group was composed of individuals with a diverse range of social and clinical histories and capacities.

**Thematic analysis.** In the following section, a thematic analysis of the individual interviews that were conducted prior to engagement with the learning environment, is presented. The focus related to the thematic analysis in this set of interviews was narrower than the analysis that was conducted on the individual interviews and focus groups because a focus had to be adapted to determine how prior and current use of technology might have an impact on the shape of the engagement in the PCoP. As with the analysis of the individual interviews outlined in chapter four, an idiographic approach was not adopted because the aim was to use the semi-structured interview (appendix 7) to collect data that represented a collection of shared experiences.

*The internet: dimensions of use, critical appraisal and relationships with health professionals and others.* The three domains of internet use identified in thematic analysis were: information for self-management, formal learning and a tool for

everyday living. These domains related to the ways in which participants used the internet.

Participants also offered a critical perspective on the undifferentiated nature of knowledge on

the internet and offered some perspectives on their expectations of the benefits of technology.

The theme of relationships refers to the shape of relationships with health professionals as

well as family and friends and how these are mediated through the internet. These themes are

outlined in Table 6-4.

**Table 6-4. Themes from interviews conducted prior to engagement in the PCoP**

| Themes | Sub-themes |
|---|---|
| Use of the Internet (4/4 – DK, PW, YS and KA) | <ul><li>Information for self-management (3/4 – PW, YS and KA)</li><li>Formal learning (1/4 – YS)</li><li>A tool for everyday living (4/4 – DK, PW, YS and KA)</li></ul> |
| Expectations and a critical dimension (2/4 – PW and KA) | <ul><li>Expectations (2/4 – PW and KA)</li><li>Undifferentiated knowledge (2/4 – PW and KA)</li></ul> |
| Relationships (2/4 – PW and YS) | <ul><li>Health professionals (2/4 – PW and YS)</li><li>Family and friends (1/4 – PW)</li></ul> |

To indicate the distribution of themes across individuals within the group, themes and sub-

themes are associated with a number and the participants who contributed to them. Individual

attributions, however, are only counted once.

*Information for self-management.* The internet was treated as a repository of

information and performed the function of helping to fill in knowledge gaps that some

participants felt were not being addressed during face-to-face encounters with health professionals. However, there was also the recognition that access to internet-based information could lead to self-diagnosis which was not considered necessarily beneficial.

***Formal learning.*** One participant was familiar with tools (Moodle©) in the delivery of online courses.

***A tool for everyday living.*** All participants used the internet for a range of purposes from banking to health and non-health-based information. All the participants used social media tools such as Facebook© although they had minimal exposure and minimal interest in Twitter©. Facebook© was primarily used as an informal communication tool and it was not generally used by participants to connect and follow topics of interest although one participant was interested in using it to set up a web presence for her home-made jams.

In terms of using the internet as a tool for learning, there was a recognition by one participant that, although information about diabetes is freely and widely available on the internet, a more fruitful approach might be to harness the affordances of the social capacities of the internet to design an environment for a community of learners. However, the idea of the development of a patient-based community of practice, which was prevalent in the focus group discussions identified in chapter four, was not in evidence in the interview data.

***Undifferentiated knowledge and expectations of technology.*** Although the internet was an important everyday tool, two participants (KA and PW) recognised the undifferentiated nature of internet-based information. As PW says:

> "I'm also sceptical with the internet, you know, you don't just believe everything that's on there." (PW).

Not all knowledge available on the internet, therefore, was seen as trustworthy and health

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professionals were seen as gatekeepers of this undifferentiated knowledge.

There was a tension between the educational philosophy of the PCoP with its focus on collaboration and promoting the development of a community of learners and one participant's (KA) understanding of the role of technology in the context of learning and education. Participants were asked what kind of technology they would like to see being developed for people with diabetes. Although responses varied depending on each individual context, technology is viewed as having the potential to offer a simple solution to the complexities of management. One participant would like to see technology that complements the self-management process:

> "I'd love something to tell me to eat now or…Something that could tell I don't know
> if it's even possible but they say to you and this is the big thing if it's not right then
> just keep self-adjusting your insulin." (KA)

Another would like a system to help him manage his schedule that would help reduce some of the complexities of self-management. This was particularly important for this participant (PW) due to his irregular employment patterns.

***YS's use of the PCoP before group use.***   One of the participants (YS) engaged with the online learning environment twice – once as an individual user and the second time as part of the first group. The analysis in this section refers to the individual interview that was conducted with YS using a semi-structured interview schedule (appendix 9) based on her *individual* participation in the environment.

YS had access to internet-based technology and she was in a position to provide information to individuals in her local community. In this way, her level of knowledge capital was associated with her access to the internet:

> "A lot of people in the area said we know you've got a computer and can you tell us
> what Cushing's disease is? Or can you tell us what bipolar is? Or something like that.
> And I said look I can't tell you but I can get the answers for you like the symptoms
> and things like that. I just go on the internet type it up and print it out…here you are
> 10c or 20c or whatever the paper is." (YS)

She was familiar with accessing the internet on a regular basis due to her participation in a
Technical and Further Education College (TAFE) course and when not familiar with
technologies her practice involved 'trial and error':

> "I never read the instructions that were in the box. Like most men they don't ask for
> directions. They just go and that's what I did for a change." (YS)

Her engagement with the learning environment triggered a level of reflection that led to a
significant change in lifestyle practices associated with nutrition and physical activity. Not
only did YS begin to 'start walking more' she began to reflect on the health benefits of
walking:

> "It's made me realise that if I walk its better benefits for me as well as helping me
> diabetes in a way too." (YS)

Reflection was also a key component in her desire to improve her nutritional practices:

> "I started watching what I was eating a bit more like because I had to write a diary.
> I'm thinking gee what did I actually have today and then I started writing it down and
> then I started putting it in there like sandwiches or a tin of soup or something like that
> whereas before I wouldn't have given it another thought." (YS)

The exploration of different lifestyle practices reflects the planning, acquisition of knowledge
and the trying out of new roles identified by Mezirow (1994) as key stages in the

transformative process. In this example, YS's new role is characterised by a level of reflective practice related to the self-management of her T2DM and the planning and acquisition of knowledge relates to her use of writing to explicitly articulate plans of action. What this exemplifies is that reflective practice does not necessarily have to begin through the engagement with others in a learning community. For YS, the learning environment functioned as a framing device for promoting individual reflection on her daily management practices. This might have contributed to her higher self-efficacy scores after her engagement with the learning activities as recorded in Figure 6-2.
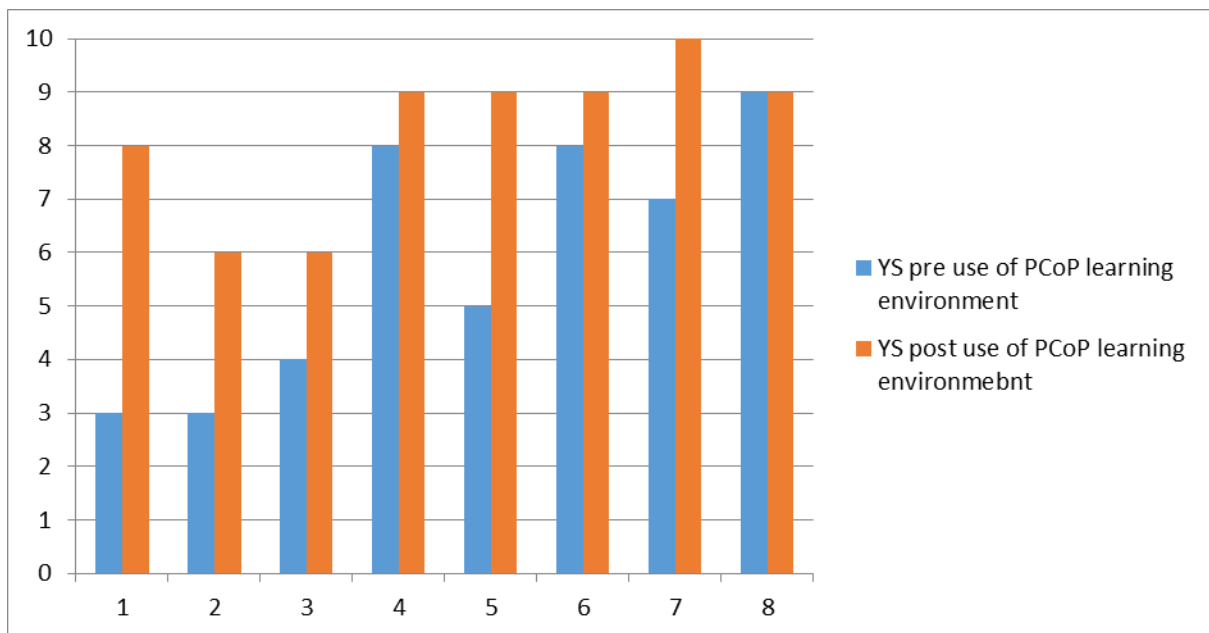


**Figure 6-2. Self-efficacy survey results for YS before and after engaging with the learning environment**

The self-efficacy survey that was conducted was based on the Stanford self-efficacy scale for self-management of diabetes (Beckerle & Lavin, 2013). In Figure 6-2, the x-axis represents the questions related to activities pertaining to the self-management of T2DM and the y-axis refers to the scale. One represents a low level of confidence and 10 a high level of confidence in being able to perform a particular task. All of the self-efficacy surveys that were

subsequently conducted were based on this instrument. The eight tasks or activities in the survey are:

1. How confident do you feel you can eat your meals 4 to 5 hours every day, including breakfast every day?

2. How confident do you feel that you can follow your diet when you have to prepare or share food with other people who do not have diabetes?

3. How confident do you feel that you can choose the appropriate foods to eat when you are hungry (for example, snacks)?

4. How confident do you feel that you can exercise 15 to 30 minutes, 4 to 5 times a week?

5. How confident do you feel that you can do something to prevent your blood sugar level from dropping when you exercise?

6. How confident do you feel you know what to do when your blood sugar level goes higher or lower than it should be?

7. How confident do you feel that you can judge when the changes in your illness mean you should visit the doctor?

8. How confident do you feel that you can control your diabetes so that it does not interfere with the things you want to do?

Apart from the last dimension on the self-efficacy scale (how confidently an individual can control his/her diabetes so that it does not interfere with their daily life), YS's self-efficacy scores were higher than they were when compared to the pre-PCoP usage. This raises the question of the relationship between YS's use of the system and factors contributing to increased levels of reflection regarding her self-management practices and higher post-use

self-efficacy scores. Questions related to the status of the self-efficacy scores are discussed further in the discussion chapter.

**Individual contexts.** Although some common themes emerged from the interpretation of the data from the interviews conducted with participants in group one, individual contexts and life histories obviously differed. It is important that these are recognised because they can function as significant barriers (or enablers) to engagement in learning opportunities. These barriers and enablers were recognised in the work of McClusky (Main, 1979; McClusky, 1970) in his calculus of power-load margin theory. Load is defined as either internal or external so this could range from the load associated with daily living (external) or the life expectancies that are set by the individual such as goals, ideals and values (internal). These interact with elements associated with power and these include external elements of power such as physical, social and knowledge capital and internal dimensions such as an individual's coping skills and resiliency. The margin between power and load results in an individual's margin. If one's load is significantly higher than one's power then one's capacity to engage is likely to be negatively affected whereas if one has a high index of power and low level of load, the likelihood of engaging and participating is likely to increase.

This theory has an important role to play in the present context because of its focus on the individual's circumstances in the determining an individual's capacity for involvement in a learning environment. This was particularly true in PW's case. Asked if his shift work had an impact on his ability to plan his management around his T2DM he replied that it was "pretty much impossible." A high load such as shift work would therefore also be likely to function as a significant barrier in one's involvement in a learning project. Clearly articulated external

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load barriers were also identified by participants in subsequent groups and they were interpreted as significant barriers to involvement.

Although family history did not constitute one of the initial questions, some participants did address this question. For one participant, the fact that his daughter was diagnosed as someone with pre-diabetes functioned as a trigger for a more serious exploration of the management options available to him.

> "But six months before, my elder daughter just like that insulin resistance. So at that time, I actually wake up so it's going wrong something. From that time, I changed myself." (DK)

This could also be interpreted as what Mezirow would call a 'disorienting dilemma' (Mezirow, 1990b) or what Illeris calls a 'breakdown of biographical continuity' (2003) that possibly led to the participant's involvement in the study. The reasons for involvement in the study by other participants are less clear cut and there is space for more interpretive scope. In the following quote, it is not clear that the event of visiting a health professional should be considered as an antecedent to his involvement in the study. Exactly what the missing ingredient might be that led this participant to participate is not clear.

> "Yeah, I realised it was diabetes, I thought something is a bit funny here and so yeah, I've went to the doctor and here I am." (PW)

For one participant (PW), his work schedule could function as a factor in determining how successfully he might be able to manage his condition

> **"PW**: I just finished at 5.30 this morning, and then I got woken up at 9.00. The next week I'm on afternoon shifts.

> **Interviewer:** It obviously does affect your ability to plan ---

**PW:** It does, yeah.

**Interviewer:** The shift thing?

**PW:** Yeah, it's pretty much impossible."

This is an example of how the presence of external load can negatively impact the capacity of an individual to practise self-management in the context of a chronic illness like T2DM.

*Self-efficacy.* In a health context, self-efficacy is a construct that is interpreted as being predictive of health behaviours – the higher the level of self-efficacy in a given domain the higher the likelihood of a person being able to complete tasks. It is for this reason that self-efficacy is an important theory that underpins approaches to self-management. An exploration of self-efficacy outcomes is sometimes combined with physiological outcomes (Lorig et al., 2010) and self-efficacy also figures in studies of the role of internet-based systems for other chronic diseases (Lorig et al., 2008; Lorig et al., 2006). Other non-physiological dimensions such as knowledge of T2DM and patient participation have also been investigated (Heinrich et al., 2012). Although studies exist that explore the relationship between self-efficacy and performance in formal online learning environments (Hodges, 2008; Lynch & Dembo, 2004; Smolka, Johnson, Glover, & Dodds, 2009) there is a research gap in studies concerned with the relationship between T2DM self-efficacy and subsequent participation in a patient-centred CoP[9]. There is potential, in other words, to examine the relationship between self-efficacy and subsequent participation in a learning community. Do higher levels of self-efficacy, for example, contribute to an individual's level of contribution

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[9] A search was conducted, without date restrictions, in PubMed, CINAHL and EBSCO (education research complete) databases using the search terms "self-efficacy" AND "patient learning" AND "diabetes". The PubMed and CINAHL searches did not yield any results. The EBSCO search returned two studies of interest that utilised aspects of social learning theory (Naik, Teal, Rodriguez, & Haidet, 2011) and experiential learning (Tang, Funnell, Brown, & Kurlander, 2010) in educational interventions that measured self-efficacy.

in a learning environment? And will the communicative characteristics of a learning community be enhanced if learners have high levels of self-efficacy?

Given the lack of number of participants in this project, however, the aim of using the self-efficacy questionnaire in this study, was not to examine links between self-efficacy and subsequent engagement in the PCoP, but to provide additional data to illustrate the possible influence of contextual factors on the 'illness work' of individuals.

Prior to their engagement with the PCoP, participants of this group completed a self-efficacy questionnaire (Beckerle & Lavin, 2013) (appendix 10). Three participants completed the questionnaire and the results are presented in Figure 6-3. In this image, the *y* axis represents the responses out of ten from each question. The *x* axis represents the questions.
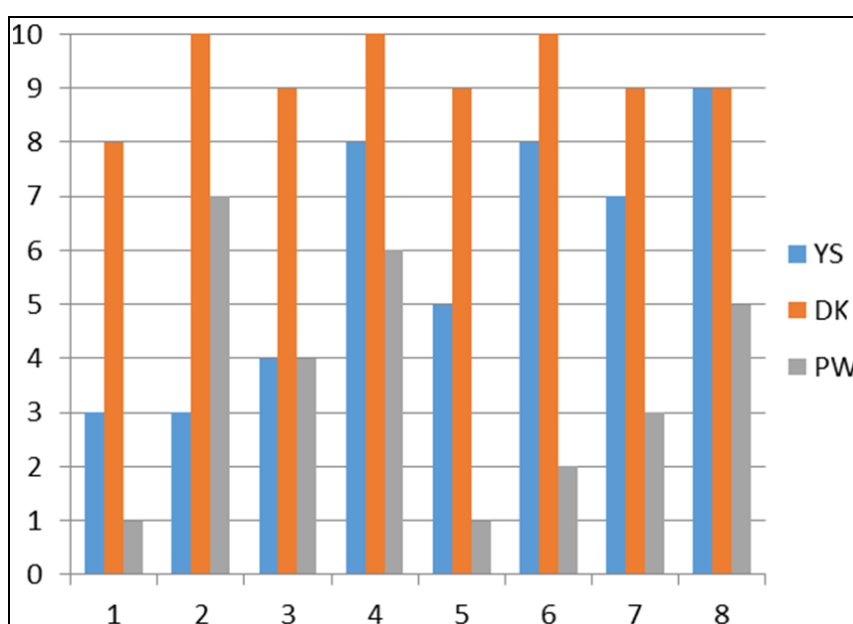


**Figure 6-3. Self-efficacy questionnaire results for group one prior to engagement with the PCoP**

Although the number of participants was not sufficient to draw significant statistical results, the questionnaire data from each group indicate the emergence of some interesting questions. For example, it is clear that PW did not feel he had the capacity to plan his meals effectively (question 1 of the questionnaire) and this is an example of a high load factor impacting

directly on PW's capacity to manage his T2DM. Given PW's subsequent lack of significant involvement in the PCoP, this is significant. PW was also significantly less involved in discussions in the OLE and this may be due to a combination of a high load factor together with generally lower levels of self-efficacy compared to YS and DK.

**Engagement with the PCoP and analysis of engagement.** The framework of the Community of Inquiry model (Garrison et al., 1999) was used to analyse the interaction associated with the forums in the PCoP because its underlying objective is the development of a community (often online) that can support learning (Akyol et al., 2009). Other models such as the Interaction Analysis Model (Lucas, Gunawardena, & Moreira, 2014) tend to focus on knowledge construction (i.e. cognitive presence) with less emphasis on the role of social presence in a community of adult learners.

The three dimensions (social, cognitive and teacher presences) associated with the model were measured. Social presence indicators were borrowed from Rourke et al (1999) and cognitive presence indicators were taken from Rodriguez (2014). The indicators associated with teacher or facilitator presence were from Anderson et al. (2001). The unit of analysis was the essential meaning embedded in each post. If one of the indicators associated with cognitive presence, for example, was linked to a post then this would receive a value of one. Where there was more than one possible meaning, these were coded separately to capture multiple meanings. Rather than listing the indicators, examples are provided that capture the meaning of the indicators that were identified.

Posts that were linked to the explicit development of social presence occurred in the first 'icebreaker' activity. YS, for example, offered some personal information about her week and ended with an implicit invitation for others to share their experiences:

"Tomorrow is garden day, planting new vegetables and herbs. My sugar has been up and down but I found by setting my phone for lunch has saved me getting headaches. When you want to do and show others that you can do things first thing is to look after ourselves. My down time is my grand-children and my animals. Hope all had a good week." (YS)

Cognitive presence was more prevalent than social presence although it was more likely to be characterised by posts that Rodriguez (2014) refers to as 'exploration' in which questions are asked, opinions offered and some background information is presented. An example of an 'exploratory' post in the 'management experiences' forum is YS providing her opinion on being blamed for an unorthodox physiological reaction to her management plan:

"I find it strange that my body doesn't respond the way some doctors think and then they blame me. Have they thought it maybe medication?"

In the same forum, YS poses a question:

"Many people assume that when you get rid of your weight you are free of diabetes. But are you?"

To which DK replies:

"I don't think so. One my friend's mother just 35 kg she is 65 year old and on 20 unit insulin twice a day. Weight is a one factor from lot of others like family history, lifestyle, stress management skills, food habits. As per my understanding stress has big role to make me diabetic. Let night work not proper rest but stress is big."

This last post is 'integrative' because there is a reference to a previous post and evidence is presented to address the previous rhetorical question. Integrative examples were quite rare (two examples in total) across all the forums.
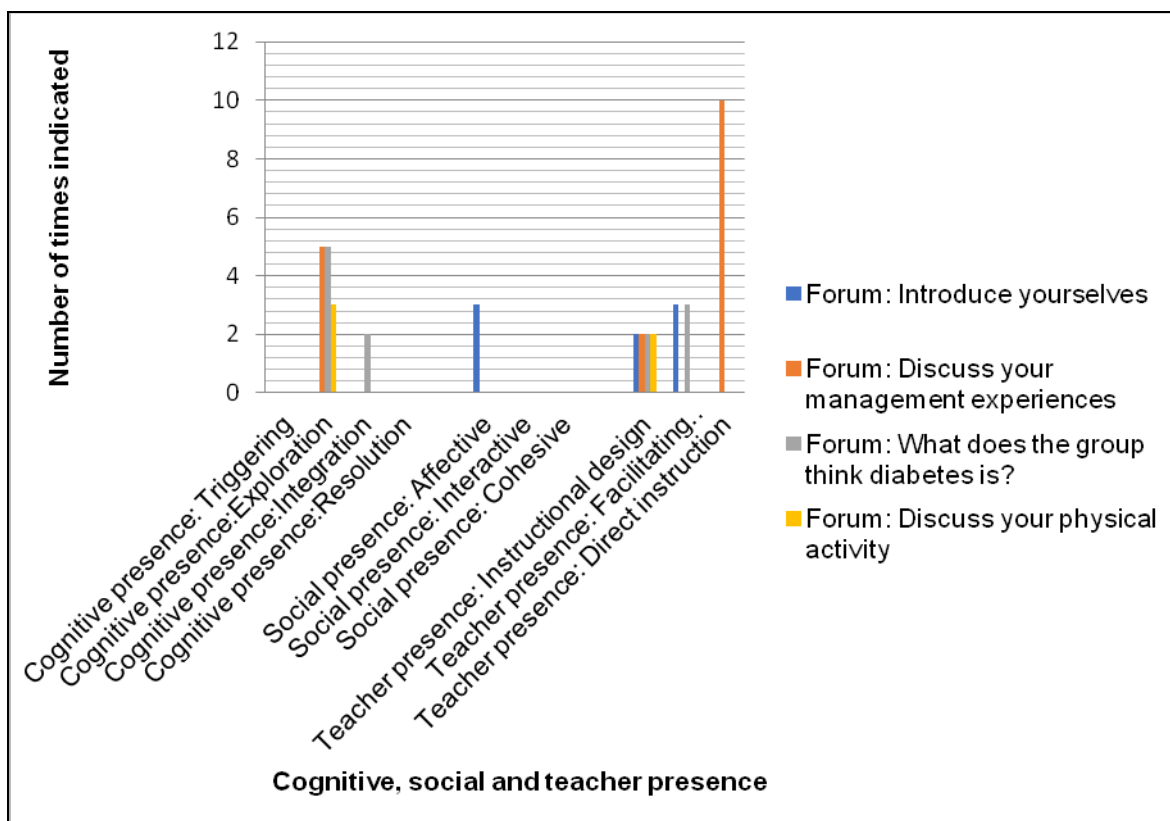
**Figure 6-4. Analysis of the first group's use of the discussion forums using the Community of Inquiry model**

Teacher or facilitator presence was in evidence in the forums in the form of 'instructional design' directives such as informing which activity will be the focus during any one week. The indicator of 'facilitation of discourse' was indicated in most forums. For example, in the 'What does the group think of diabetes' forum this question was posed by the facilitator:

"How have you responded to health professionals when you disagree with what they have said?"

It received this response which is a good example of how a patient might pursue the co-construction of a management plan:

"You suck it up and keep your cool. You ask them to try and see your point of view. Ask them the questions. Make a list of questions for them to answer." (YS)

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'Direct instruction' (i.e. the provision of content) was not in evidence in the forums because the objective was to encourage participants to share their experiences and ideas and this accords with the overall educational objectives of the PCoP.

An overall picture of the analysis of the forums using the CoI framework is provided in Figure 6-4. The analysis shows that there was not a great degree of social presence although there were indications of the beginning of the co-construction of knowledge as participants sought to refer and reply to posts. The level of interaction required for sustained and meaningful interaction, however, was not sustained and this could have contributed to a decline in forum participation during the last weeks of the session.

### Usage statistics and communication between participants and researcher.

Correspondence with the researcher was in the form of text messages and tweets. The most active participant (DK) was a user of Twitter© (he subscribed to and read Twitter© feeds) and it was used between the researcher and DK as platform for communication.

Correspondence between the facilitator and either KA and PW was sporadic. It is not clear why this is the case but for one of the participants (KA) it was communicated to the researcher that she had had problems accessing the internet using the iPad and then suffered severe electricity loss to her house (KA). The other relatively inactive participant (PW) attempted to communicate with the researcher but any meaningful communication was not forthcoming.

After six weeks, two participants (YS and DK) returned for a follow up interview. Attempts were made to set up available times to interview KA and PW but lack of communication between KA and PW and the principal researcher meant that interviews did not materialise.

***PCoP – usage statistics.*** There were at least two different modes of engagement in the PCoP – 'page view' engagement and 'content adding' participation. The difference between 'page views' and 'adding content' correlates to those users who might be reading and reflecting on posts without actively contributing against those users who are active contributors to the learning community. These parameters were measured using Moodle© logs. What this chart (see Figure 6-5) shows us is that, per individual, there were significantly more page views than posts and that participation indicated non-engagement (KA), minimal and peripheral engagement (PW) and more active engagement (YS and DK) with the PCoP.
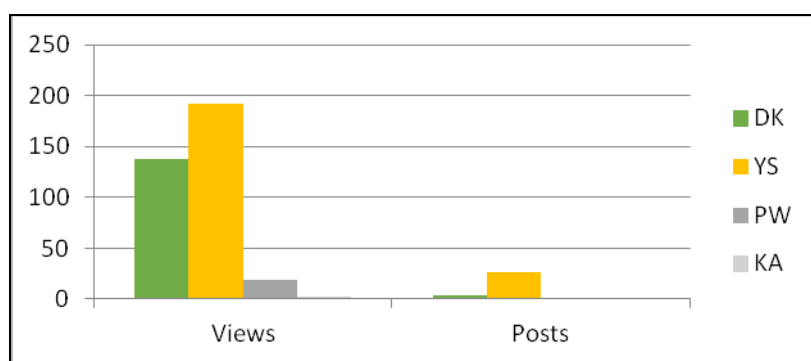


**Figure 6-5. Usage statistics and page views versus posts for the first group**

*Sim card – usage statistics.* Sim card usage shows a similar pattern to usage of the website. The usage pattern of the most active participant is spread over time whereas the least active participants have patterns clustered around particular dates.

**Post-use interviews and analysis.** Participation and engagement with the PCoP was generally low and this was not helped by two members of the group withdrawing during the middle of the program. Their withdrawal was not signalled to the principal researcher, but their complete lack of participation indicated a de facto withdrawal from the project.

At the end of the ten-week period in June 2014 a semi-structured interview was conducted with the two remaining members (appendix 11) – DK and YS. Activity theory functioned as a

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lens to explore engagement in the PCoP against the backdrop of its intended educational outcomes. In terms of the analysis of the first iteration of the use of the PCoP, the parameters of the tool, the division of labour and community were the focus of enquiry.

The tool (PCoP) was a focus because of its role in mediating the interaction between participants. The parameter of division of labour was used to analyse the interactive dynamic between participants and the community dimension was a focus of enquiry because it facilitated the analysis of the consolidation and application of learning by participants in the context of their relationship with health professionals. Questions concerning their participation in the PCoP in the context of their use of other collaborative tools such as Facebook© constituted the focus on rules and norms. The following questions, therefore, formed the basis of the interview questions.

1. How have the technological tools of the online learning environment (Moodle©, Twitter©) complemented, enhanced or acted as barriers to the intended outcomes of transformative learning? (Tool).

2. How have participants engaged with the collaborative learning activities? Has collaboration contributed to any dimensions associated with transformative learning? (division of labour).

3. Has participation in the learning environment affected their relationships with health professionals? If so, in what way? (community).

4. How does the PCoP differ from other tools such as Facebook© (rules and norms).

Thematic analysis (Braun & Clarke, 2006) was used to interpret the interview data conducted and this interpretation yielded several themes that fell under two broad categories – the

experience and use of social media and engagement and participation in the PCoP. These are

outlined in Table 6-5.

**Table 6-5. Themes and sub-themes of analysis of the first group's use of the PCoP**

| Themes | Sub-themes |
|---|---|
| Experience and use of social media (2/2 – DK and YS) | • Unconstrained environment (2/2 – DK and YS) |
| Participation in the PCoP (2/2 – DK and YS) | • Complicated tools (2/2 – DK and YS)<br><br>• Lack of informational content (2/2 – DK and YS)<br><br>• PCoP as a tool for face-to-face social networking (2/2 – DK and YS)<br><br>• Sharing experiences (1/2 – YS)<br><br>• Social presence (2/2 – DK and YS)<br><br>• Taking on new roles (2/2 – DK and YS) |

*Experience and use of social media.* Both participants who were interviewed (YS

and DK), were familiar with Facebook© and used the technology for informal

communication. They did not indicate a preference for using Facebook© to interact with

other people with T2DM due to their perception of Facebook© as an unconstrained

environment for undifferentiated knowledge relating to T2DM. Additionally, Facebook© was

not considered to represent a safe learning environment.

*Participation in the PCoP*

*Complicated tools.* The OLE was developed using Moodle's© learning

management system and this proved to be less of a challenge than the use of Twitter©

although both systems proved to be difficult to use on an iPad© and the lack of control with

certain configurable features of the iPad© such as the keyboard and predictive text.

Participants were, however, willing to experiment to achieve intended outcomes. All the

original members of the group also had access to home computers and home systems and

iPads© were used interchangeably by the two interviewees.

*Lack of informational content.* Both interviewees indicated that there was a

lack of informational content in the PCoP.

*PCoP as a tool for face-to-face social networking.* The PCoP was seen as a

tool that could complement face-to-face contact with others interested in sharing experiences

of self-management of T2DM.

*Sharing experiences.* The potential of the PCoP as a platform for sharing

experiences of T2DM was recognised although there was little interest in the videos of

narratives of self-management that were integrated into the interface.

*Lack of social presence.* A clear level of dissatisfaction emerged with the

lack of interaction during the group phase. This led to disembodied online experiences and

this lack of interaction diminished the collaborative nature of the learning experience. The

absence of photographs associated with the participants was also seen as a problem.

Photographs, as YS says, "give you an idea that you're talking to somebody."

Social presence is one of the elements of the CoI model (Rourke et al., 1999) and refers to the

ability of learners to project a social and affective presence in a learning community.

Analysis of the interview data revealed the lack of social presence as well as its potential role

in driving a greater degree of participation and interaction. This lack *and* importance is

summed up by one of the participants feeling like "a one-man band" and the interview data

suggests that there was a significant lack of 'social presence' (Kehrwald, 2007; Rourke et al.,

1999) in the online community. This suggested that without initial face-to-face contact participation and interaction was likely to suffer. In subsequent iterations (groups three and four) participants were, therefore, required to attend group interviews before participating. Meeting face-to-face prior to participating, although important, was one factor among many that could help to contribute to higher levels of interaction.

*Taking on new roles.* Although the lack of interaction was identified as a potential barrier to increased engagement and participation, both participants were willing to take on the role of facilitator in subsequent groups. In addition, there was enthusiasm for learning designs that required group members to upload resources and materials that were of relevance. Interestingly, one of the participants (YS) took her involvement in the study as an opportunity to expand the parameters of involvement from online to face-to-face modes:

"Yeah, we could all meet up one day a week, one day a month and go for coffee."

The willingness to take on a new role in the PCoP and to engage in new forms of face-to-face engagement is an indication that engagement with the environment generated at least one outcome associated with transformative learning. The willingness to take on a new role aligns with one of Mezirow's features of the process of transformative learning (Mezirow, 1994) but the fact that the participation rates were low across all the required tasks indicates that other intended outcomes such as collaborating on forms of instrumental knowledge associated with diabetes management were not met. The same could also be said for outcomes associated with communicative (or dialogic) reasoning – the critical reflection on one's own and others' assumptions would be hard to sustain in an environment with minimal rates of interaction. This proved to be the case with this group.

It was difficult to determine if the renegotiation of relationships with health professionals took place during the period of the study because neither of the participants had had

consultations with allied health, specialists or general practitioners. Participants did express a willingness, however, to take on new roles as active facilitators within the learning environment. Finally, the rules and norms associated with online collaborative learning (sharing knowledge and experiences, for example) were not familiar to one of the group members and his conception of learning was teacher-centric when referring to the explicit rules of communication that were put in place for the PCoP:

> "I can see even I get the mail too, every time, when you put something, I get email too, so I get both, both ways when I get time I will go through that, but it's good like, yeah, you are doing very well, actually…But it's all right, I will follow you." (DK)

YS, on the other hand, was familiar with Moodle© and its use in a formal learning environment:

> "I'm doing assessments at the moment so I need to (*use the internet* – my words) every day. We use Moodle© for TAFE." (YS)

Therefore, although a 'disorienting dilemma' (Kitchenham, 2008) in the form of T2DM was a precondition for participation in the PCoP, it was not sufficient to promote collaborative and sharing practices in the community. The explicit rules associated with the structure of the weekly tasks in the PCoP, however, were appreciated.

**Transformative learning in the PCoP.**   For Mezirow, transformative learning occurs across three learning types (instrumental, dialogic and self-reflective) and three learning processes (learning within frames of reference, learning new frames of reference and learning through a transformation of point of view or habit of mind) (Mezirow, 2000). These dimensions (together with examples) are outlined in Table 6-6.

**Table 6-6. Examples of transformative learning and T2DM self-management**

| Dimensions | Instrumental | Dialogic | Self-reflective |
|---|---|---|---|
| Learning within frames of reference. | Development of dietary plans. | Sharing experiences and ideas with others. | Reflection to encourage greater adherence to lifestyle or medication regimens. |
| Learning new frames of reference. | Introduction of new dietary elements (e.g. sweet potatoes vs. standard potatoes). | Becoming a self-directed learner in the use of the internet as a tool for information. | Beginning to question the hierarchical nature of relationship between patient and health professional. |
| Learning through transformation of points of view and habits of mind (meaning transformation). | Thinking about diet as one component in lifestyle change. | Participant in a patient-centred community of practice. | Patient as expert and relationship between health professionals seen in terms of cooperative development of self-management plans. |

The analysis from the community of inquiry model outlined in Figure 6-4 indicates that there was a small amount of dialogic learning (e.g. exposure of the self in the introductory activities and a small degree of interaction) but that this did not extend to any significant discussions of instrumental knowledge. Interestingly, however, a discussion between YS and DK did reveal a level of self-reflection questioning the authority of biomedical reasoning as it

related to their own individual contexts. A summary of the dimensions of transformative

learning for the first group is outlined in Table 6-7.

**Table 6-7. Dimensions of transformative learning from the first group**

| Dimensions | Instrumental | Dialogic | Self-reflective |
|---|---|---|---|
| Learning within frames of reference. | No significant evidence. | There was evidence of social interaction between DK and YS. | Degree of self-reflection. |
| Learning new frames of reference. | No significant evidence. | Using the PCoP as a means of communication and sharing experiences. | Beginning to question the authority of biomedical reasoning as too general and broad. |
| Learning through transformation of points of view or habits of mind (meaning transformation). | No significant evidence. | No significant evidence. | A redefinition of the problem would have been to place the patient at the centre of the health management process but this discussion did not occur. |

**Summary of results.** The analysis of the interview data revealed several tensions (represented by the crosses) between dimensions represented in the AT model below Figure 6-6.
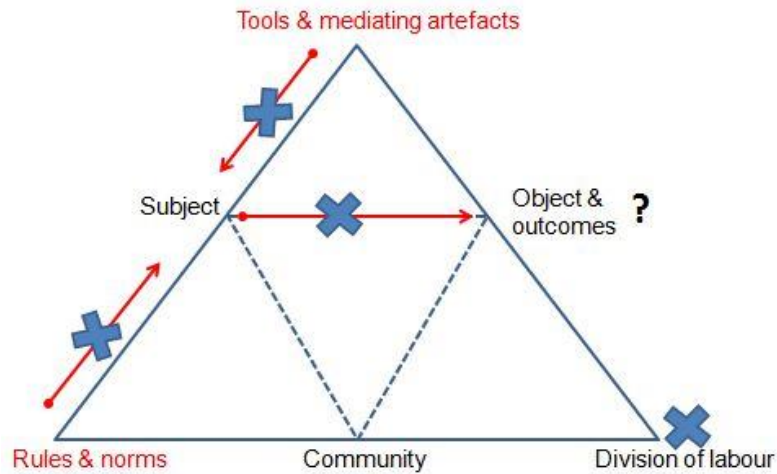


**Figure 6-6. AT representation of the use of the PCoP by the first group**

Disembodied online experiences dampened the enthusiasm to participate and significantly contributed to the way in which division of labour in the group was distributed. Based on the interpretation of the post-use interview data, the lack of interaction was a result of the complicated nature of the interface, the number of learning activities and some of the contextual barriers such as employment patterns. These relate to the *tools and mediating artefacts* and *subject* parameters respectively.

In terms of *rules and norms*, the absence of explicit expectations for participation (e.g. one post and one reply per week) may also have been a contributing factor but expectations for participation were communicated via weekly (sometimes more frequent) emails to participants.

The pedagogy that underpins the PCoP is based on a sociocultural conception of learning in which learning opportunities are embedded and facilitated through social interaction. An

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online patient-centred learning environment, based on authentic learning activities and social interaction, was developed using these ideas. For one participant, however, there was an indication of a misalignment between the underlying pedagogical characteristics of the PCoP and their expectations. This misalignment is suggested by DK ("it's alright, I will follow you").

Overall, there was a low level of participation in the learning environment. As a result, the intended outcomes of improved levels of instrumental knowledge such as improving nutritional practices or practising forms of communicative and dialogic discourse such as collaborative reflection were unevenly and only partially realised. The following list is a summary of the interpretation of the interview data of the first group (before and after the use of the PCoP), analysis of interaction using the CoI model and usage statistics.

1. Learning designs must combine simple interfaces with authentic learning activities.

Too many options for interaction were provided. Although participants did not find using Twitter© difficult at the level of navigating its interface, they did not use it in the way that it was initially intended. The idea of using Twitter©, for example, as a platform for establishing 'social presence' and as an immediate mode of communication in the network was not taken up. In the next iteration, Twitter© was not used as a communication medium and learning designs were simplified and based on the affordances of Moodle©-based tools.

Learning design in a formal, higher education context needs to be driven by the underlying design imperative of the development and design of engaging, authentic learning activities. Of the ten characteristics of authentic learning activities defined by Reeves et al (2002), the one that has most relevance in the present study is that of the 'real world relevance' (Reeves et al., 2002, p. 565) of learning activities. The present study represents an application of this design principle into a non-formal learning context.

2. Shared health experiences do not necessarily ensure collaboration

The fact that a shared diagnosis did not contribute to high levels of 'social presence' and instant rapport with other participants in the network suggests that sharing common health experiences may be a necessary but not sufficient condition for interactive engagement in a shared interest online learning community. The problem that confronts health-based learning environments is that they are, to a certain extent, a reflection of the concept of the sick role. The sick role, however, only allows for the performance of the sick role at the expense of other rules that one may legitimately perform (Varul, 2010). To concentrate on the establishment of a learning community based solely around the shared experiences and practices associated with being chronically ill may therefore be problematic.

3. Familiarity with informal interactive tools does not necessarily ensure participation in more formal learning contexts

The norms of informal interaction that participants were familiar with (for example, Facebook©) were not carried over into a more formal learning environment. This suggests that although participants were familiar with online modes of interaction associated with social media, the requirement to interact with others in a more formal learning environment is more concerned with the establishment of 'social presence' and community cohesion than individual capacities and competencies with online technologies. Communicative competence in informal settings, in other words, does not necessarily transfer to formal environments (Johnson, 2009).

4. Facilitation is crucial in cohorts without expert users

The promotion of cohesion and collaboration in online communities is fostered by facilitators (Gunawardena, 1995). Without facilitation in the PCoP phase, engagement with the learning

activities would have been hard to achieve due to the number of collaborative spaces that were available to the participants. For example, discussion forums were associated with learning activities but comments were sometimes scattered throughout a range of forums. To achieve participation in the form of focussed discussions tight facilitation is therefore required in a community of users and this is particularly the case with users who might be participating in unfamiliar interfaces.

5. Collaboration is not a necessary precondition for critical reflection

Collaboration is not a necessary precondition for critically reflecting on one's patterns of lifestyle behaviour. This was clearly the case with one of the participants whose individual use of the system framed a set of questions that led from individual reflection to changed behaviour. Learning environments, therefore, need to be flexible and adaptable to the way in which they are being used and evaluation needs to be sensitive to the value that individual participants are deriving from their engagement in the range of activities that are on offer.

**Learning design principles.** Based on the results of the analysis of the pre-use interview data, the use and analysis of the PCoP and post-use interview data, the following design principles were proposed (Table 6-8).

**Table 6-8. Learning design principles based on participation in the PCoP by the first group**

| **1. Tools for interaction must be simple and kept to a minimum.** |
| --- |
| The use of Twitter© was proposed to enable participants to engage with each other on a daily basis but this option was not taken up because participants found the interface to be difficult. Additionally, the Twitter© option increased the number of spaces for interaction but this had the unintended consequence of increasing the complexity of the PCoP as a tool for interaction. Additionally, although the iPad© was provided to participants in order to address |

the possible lack of internet access, all participants were familiar with and had personal access to the internet.

Navigational clarity and intuitive interfaces have been identified as important factors in student experiences of online learning in a higher education context (Jaggars & Xu, 2016). These factors are of even greater importance in the context of non-formal education because not all participants (as was the case in this study) will be familiar with interfaces that are used to deliver formal educational material such as Moodle©. This means that the attributes of tools for interaction (navigation and interface) must clearly signal the nature of the activity with minimal complexity. The combination of Twitter© and the Moodle-based interface as tools for interaction, however, resulted in a level of complexity that negatively affected the nature of the engagement in the PCoP.

In the next iteration, there was more emphasis on the simplification of the interface.

**2. To promote engagement and participation facilitation can be conducted by participants and facilitators** *but the responsibility of the moderator and facilitator needs to be increased to encourage and support ('orchestrate') the participation*

Weekly tasks were emailed to participants and this was an important communication channel and enabled participation to be structured around weekly tasks. It was an important component of teacher or facilitator presence. To encourage participant-led facilitation each subsequent group included members of prior groups.

This principle accords with findings that highlight the importance of the role of the moderator and facilitator in the development of health-based online learning environments learning environments (Smedley & Coulson, 2017).

**3. Promotion of social interaction prior to online participation is important.**

According to Tu (2000), "Social interaction between learners…is required for social learning to occur. No interaction – no learning." (p.30). For Tu, social interaction is the process that underpins the development of social presence (defined in chapter two) in a learning community. Social interaction, therefore, is central to the development of social presence.

There was evidence in the interview data to suggest that the social interaction prior to online participation would have been valued if it had occurred. In the next iterations, participants were interviewed as a group so as to encourage more group cohesion and social presence in the PCoP.

**4. Learning designs need to be simple and authentic.**

In a community of participants in which an online community-based learning environment might be a novel experience, learning designs need to be simple and the interface in which learning designs are embedded also need to be simple. Additionally, authentic tasks related to individual experiences of self-management are an important platform through which knowledge and ideas can be shared (Andersson & Andersson, 2005) leading to sustained and meaningful interaction.

Principles one and four map to the dimension of the tool in activity theory whereas principles two and three map to the parameter of rules and norms (see Figure 6-7 for AT representation of use of PCoP by the first group). AT was used to represent the focus of the design principles because it provides a framework for drawing attention to the contextual nature of each of the groups and how a focus on design principles relating to one activity theory parameter such as 'rules and norms' may not be as important for another group. In this light, AT was a powerful evaluative mechanism for highlighting the contextual characteristics of each iteration of the PCoP.

***An activity theory view.*** In Figure 6-6, a number of tensions between the various

activity theory parameters are diagrammatically represented. The function of the learning

design principles was to address these tensions and build in modifications to the next iteration

of the PCoP.

The activity theory model below (Figure 6-7) represents the intended outcome of the next

iteration in which participants (*subjects)* would interact with each other through the learning

activities (*tools and artefacts)* to contribute to levels of knowledge construction (*division of*

*labour)* that could lead to the outcomes being met. To do this, the interface was simplified

and the number of learning activities was decreased. Additional modifications included the

requirement to meet face-to-face before engaging online (*rules and norms)* and the continued

role of the moderator and facilitator in guiding facilitation and initial discussions

(*community).*
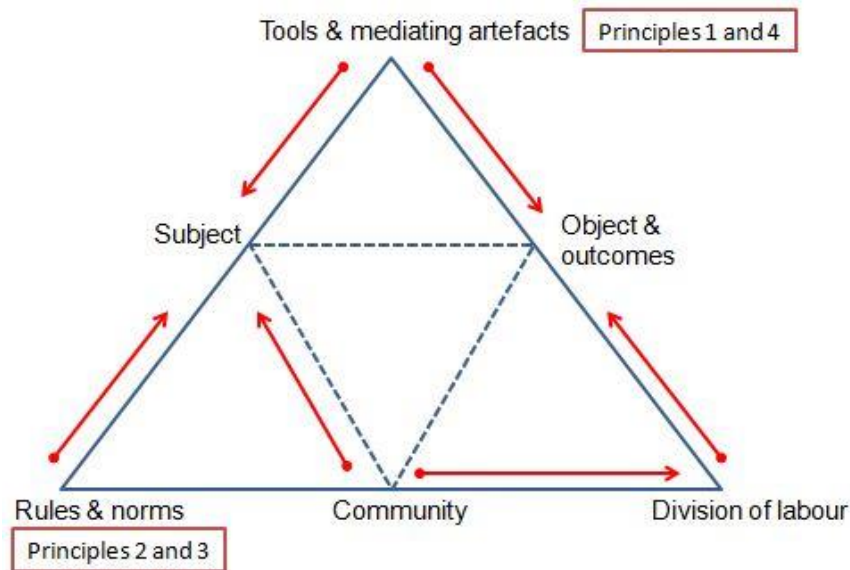


**Figure 6-7. An AT representation of the application of learning design principles leading to intended**

**outcomes**

These learning design principles were put in place for the subsequent iteration of the PCoP.

## Group two

The recruitment process was similar to the one conducted for group. An advertisement was placed in a local newspaper and interest to participate in the study was sought from members of the local community.

Two participants from the previous group agreed to become members of the second group and recruitment for new participants took place in May 2014. The objective of including YS and DK in the second group was to consolidate their willingness to take on roles as facilitators and to act as expert users in the PCoP. It was hoped that this would promote the characteristics of a PCoP in which participants more familiar with the PCoP would assist newer members of the community to participate and engage with the learning activities and to contribute to "…an environment in which learners become increasingly adept at learning from each other and at helping each other learn in problem-solving groups." (Mezirow, 1997) (p.11).

Although several people showed an interest in the study, the task of recruiting participants was more difficult than anticipated because initial communication between the researcher and potential participants did not extend to further communication about interview dates and times. In addition, with one participant, although a meeting was arranged to discuss the details of the project, this participant did not attend the meeting. One participant was eventually recruited (CA) via a colleague but due to her geographical location, a face-to-face interview was not possible. Three participants (CA, YS and DK) (Table 6-9) were not viewed as sufficient, however, and the recruitment process was continued although it failed to yield any further interest.  An online questionnaire (appendix 12) was sent out to CA to establish her level of technological competence and her use of technology within the context of the

management of her diabetes. Interpretation of the questionnaire responses revealed someone who was highly competent with technology across a range of platforms, questioned the 'disembodied' nature of online interaction and was sceptical of the value of self-directed learning in the context of diabetes given the gravity of the illness. CA did, however, value the role of the internet as a repository of material that helped clarify the nature of medical terms and conditions. For CA, using the internet in this way constituted a way to create a partnership with her health professionals.

**Table 6-9. Participants in group two and their dates of diagnosis with T2DM**

| Participant | Date diagnosed with diabetes |
|---|---|
| Male 45 yrs (DK) | 2007 |
| Female 55 yrs (YS) | 2010 |
| Female 65 yrs (CA) | 2000 |

The changes to the PCoP align with three AT parameters: subjects, rules and norms and tools.

*Participants.* As has already been indicated in the design principles which emerged from group one, participants from the first group were encouraged to participate in the second group.

The first modification aligns with the idea of legitimate peripheral participation (Lave & Wenger, 1991) in which initial participation and engagement in a community is legitimately peripheral but through a process of enculturation in the community, this participation loses its peripheral nature and participants that were once peripheral begin to take on more of a central role. 'Expert' community members play a key role in this process and it was hoped to re-define the roles of YS and DK as expert members of the community given that they had already participated quite substantially over the course of a few months. The question of the

re-definition of their role was put to them and they agreed to take it on. The 'provisional trying out of new roles' is also one of Mezirow's (1994) phases of transformative learning although the implication is that the negotiation of roles has resulted from a learning process rather than being instituted as part of a top-down learning design change.

***Rules and norms.***   Secondly, the problem of the disembodied nature of participation in group one was addressed by proposing that groups meet face-to-face before participating online. The instructions that related to the 'icebreaker' forum activity were changed and participants were encouraged to upload photographs of themselves.

***Tools and learning designs.***   Thirdly, changes at the level of the 'tool' involved the removal of some learning activities and removal of the use of Twitter© as a two-way communication tool. Twitter© was kept as a one-way tool, however, and the objective was to use it as a mechanism to send messages to participants embedded in the PCoP as a 'Twitter© stream' panel.

Based on the first design principle (simplicity of tools including learning designs) that emerged from the first group's use of the PCoP the following changes to the PCoP were made:

- The physical activity diary and forum from the first group's use of the PCoP were consolidated into one forum activity.

- The food diary and forum from the first group's use of the PCoP were consolidated into one forum activity.

It was hoped that these changes would promote the affective dimension of social presence in the PCoP and, as a result, promote greater engagement in the activities.

*New learning design.*   A new learning design (Table 6-10) included the use of a new Moodle© 'chat' tool. This required participants to provide their own one sentence definition of diabetes.  It was hoped that this activity would promote individual reflection and social interaction using a very simple 'texting' mode of communication that they were familiar with.

**Table 6-10. AT representation of individual reflection in one sentence on the nature of T2DM**

| | |
|---|---|
| Learning activity/activities | The outline of the learning activity requires participants to describe what diabetes is in one sentence. |
| Subject | • Participants in group two<br><br>• Previous participants |
| Object | Using the PCoP learning environment and, in particular, the chat tool to reflect on the nature of diabetes in one sentence. |
| Outcomes | To compose individual reflection on what T2DM means to the individual participant or how they would define it. |
| Tools and mediating artefacts | • PCoP learning environment (the chat tool).<br><br>• iPad.<br><br>• Personal devices (laptops/desktops/phones).<br><br>• 'How to' resources in the PCoP learning environment. |
| Rules | **Explicit**: Following instructions for completing the activity. |

| | | |
|---|---|---|
| | **Implicit**: Familiarity with expressing personal opinions and doing this in online context. | |
|  Community | Other participants in the learning environment and friends and family. Possible recognition from health professionals with involvement in the project. | |
|  Division of labour | Mainly an individual activity although the implicit assumption is that participants will read other participants' chat texts. | |
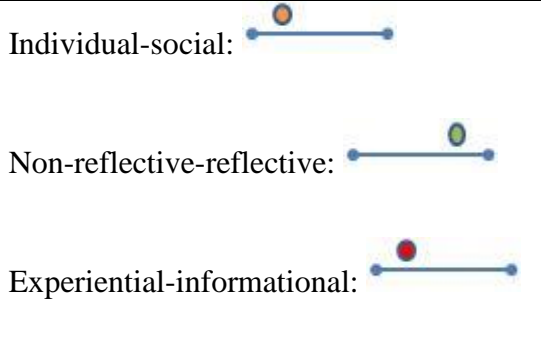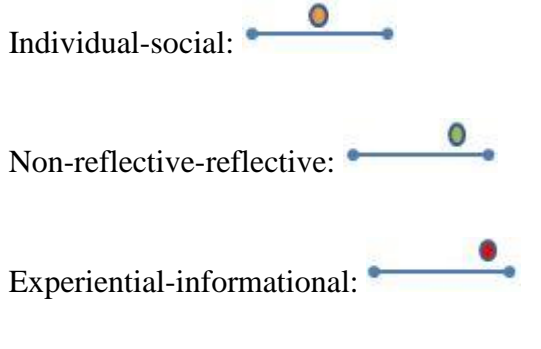
**Learning toolkit representation of second iteration of the PCoP.** The learning design toolkit (Conole et al., 2004) was introduced in chapter five and this provided the language to describe the characteristics of learning designs. Table 6-11 represents the shape of the second iteration of the PCoP. It is not significantly different from the first iteration although two individual (diary) learning activities were removed.

**Table 6-11. Learning design toolkit representation of the PCoP**

| Individual or group-based activity | Week | Description | Pedagogical dimensions |
|---|---|---|---|
| Group | One | Introduce yourselves | Individual-social:  <br><br> Non-reflective-reflective:  <br><br> Experiential-informational:  |

| Group | Two | Discussion of management experiences | Individual-social: <br><br>Non-reflective-reflective: <br><br>Experiential-informational:  |
|---|---|---|---|
| Individual | Three | In one sentence, what do you think diabetes is? | Individual-social: <br><br>Non-reflective-reflective: <br><br>Experiential-informational:  |
| Group | Three | What does the group think diabetes is? | Individual-social: <br><br>Non-reflective-reflective: <br><br>Experiential-informational:  |
| Group | Four | What have you been eating? | Individual-social: <br><br>Non-reflective-reflective: <br><br>Experiential-informational:  |
| Group | Five | Discuss your physical activity | Individual-social: <br><br>Non-reflective-reflective: <br><br>Experiential-informational:  |

| Individual | Ongoing | Weekly blog | Individual-social:  <br><br> Non-reflective-reflective:  <br><br> Experiential-informational:  |
|---|---|---|---|
| Group | Ongoing | Share resources | Individual-social:  <br><br> Non-reflective-reflective:  <br><br> Experiential-informational:  |

**Participation and engagement with the learning environment.** The second

group was proposed to commence in June 2014 even though it was recognised that three

people did not constitute an optimal number. As with the first group, emails were sent to

participants directing them to the relevant weekly activities.

CA used the system for a few weeks but reported that it placed a great strain on her computer

and introduced bugs into her system. CA and DK used the system after this but in a very

limited fashion. YS and DK were also given access to the system subsequently but did not

interact as 'expert' users with other participants from the third and fourth groups. CA's

frustration with the learning environment is summed up in the following quote which was

received as an email communication:

> "I think regrettably I need to bow out of the program, as I have not done anything of
>
> value so far. If I could speak with you in front of my computer and face to face I may
>
> get better results. It seems your directions to set up confused me and maybe I hit some
>
> wrong buttons, I don't know! I do know I am the sort of learner, on this sort of thing

to be physically shown what to do and spoken to about how it all functions, it absorbs better."

**Group two and self-efficacy.** There were no self-efficacy scores for this group.

**Design principles.** The principles that were drawn from the first group were put in place for this iteration. However, they were not able to be tested due to the way in which the group disbanded. Although YS and DK were given the option to continue their participation in the group and provided roles as facilitators they were not provided the opportunity to perform this role in practice and the lack of extra participants diminished the nature of the learning community. In sum, the quantity of participants was not sufficient to support the emergence of an effective CoP.

The design principles from the first iteration were carried over to the learning design stage associated with the third group.

## Group three

To recruit members of the third group, an advertisement was placed in the local newspaper during September and October 2014. Several people expressed an interest in the study and the recruitment process resulted in three participants agreeing to take part in the project. Two of the participants (YS and DK) from the first group were invited to join the group and were provided with access to the PCoP.

The third group participated in the study between November and December 2014. The design principles from the first group were applied to the learning designs with further attempts at simplifying the tools of collaboration together with the requirement that participants were to meet each other face-to-face before participating in the online environment. A pre-use group interview was conducted with three participants and two one-on-one interviews were held after the six-week period of use.

In the first and second groups, the dates of diagnosis were evenly distributed. However, as can be seen in Table 6-12, although there was not a significant difference between two participants (MW and MS), the amount of time associated with MT's diagnosis with T2DM was significantly greater than the other two participants. The analysis of the pre-use interviews, engagement in the PCoP and the post-use interviews will reveal the significance (or lack of) of this difference.

**Table 6-12. Ages of participants in group three and dates diagnosed with T2DM**

| Participant | Age at time of participation | Date diagnosed with diabetes |
| --- | --- | --- |
| | | |

| MT | 53 | 1994 |
|----|----|------|
| MW | 51 | 2013 |
| MS | 56 | 2011 |

The profile of the third group (outlined in Table 6-13) differed from the first group and second groups. Two out of three participants (MW and MS) in the third group used the internet as a tool in their professional and personal lives. This type of work-life integration with internet-based tools did not emerge during the interviews with individuals in the first group primarily because two participants were not employed (KA and YS), one participant was employed as a shift worker outside of an office setting (PW) and although one participant worked as a government employee it was not clear how he used the internet in his workplace. In the second group, the integration of the internet in the dimensions of work and personal life was not a factor because one of the participants (CA) was retired with the other two participants (DK and YS) being from the first group.

It could be argued that the characteristics of the third group had a two-fold effect on the nature of participation in the third group. Firstly, the practice of using the internet to improve levels of cultural capital (specifically formal learning through online courses) created a level of expectation of the PCoP at odds with its pedagogical intention and, secondly, the significant professional and personal barriers apparent during the group's participation affected the group's capacity to interact and engage with each other.

**Table 6-13. Individual contexts of participants in the third group**

| Participants | Individual contexts |
|--------------|---------------------|
|              |                     |

| MT | Diagnosed the longest amount of time out of everyone in the group. Significant family issues reduced capacity to participate. |
|---|---|
| MW | Worked at local school. Used internet for formal courses. |
| MS | Self-employed. High level use of internet (formal courses, marketing). Busy family schedule. |

**Interviews prior to engagement with the PCoP.**  An interview using a semi-structured schedule (appendix 7) was held with three participants before they began to use the system. This had two functions. There was clearly a lack of interaction in the first group and this led to a feeling of being in a "one-man band". To address this, a change in the learning design was implemented for the third group and this meant that, where possible, subjects were required to meet each other face-to-face before engaging with each other online. The function of the interview before the period of online engagement had two purposes: to conduct an in-depth interview of the full group as well as giving people the opportunity to meet each other face-to-face – to put, in other words, a face to name.  The learning design change was a response to the feeling of isolation in the first group which in turn was an attempt to improve the level of social presence in the third group by requiring initial face-to-face contact.

The objective was to address some of the weaknesses in online *asynchronous* communication identified by media richness theory and social context cues theory. The latter stresses the inherent lack of a synchronous feedback loop (Daft & Lengel, 1986; Whitty, 2008) that is a

characteristic of asynchronous online communication but an essential feature of face-to-face communication. The former refers to the level of social cues within an online environment that can modulate the feeling of the 'social' nature of participation (Gunawardena, 1995). There are, therefore, at least two theoretical lenses which can help to guide the design and evaluation of online learning communities. Media richness theory emphasises the tools that are used that can contribute to participation and social context theory highlights the type of social cues that can mitigate or improve asynchronous discussion. The scope of the present project does not allow for these theories to be applied as evaluative or design lenses but any future application might be of interest to studies that are interested in evaluating the nature of participation in learning communities that use asynchronous discussion tools.

**Thematic analysis.** The analysis of the group interview yielded three themes and multiple sub-themes and these are outlined in Table 6-14. The distribution of participants associated with each theme and sub-theme is indicated next to each theme to provide a clear indication of the occurrence and attribution of themes to participants.

**Table 6-14. Themes from the pre-use interview of the third group**

| Themes | Sub-themes |
|--------|-----------|
| Dimensions of being a patient (3/3 – MT, MW, MS) | • The patient as expert (1/3 – MT) <br><br> • The collaborative patient (1/3 – MT) <br><br> • Infantilising the patient (1/3 – MW) <br><br> • Emotional challenges (1/3 MT) <br><br> • Lack of certainty and conflicting information for self-management (3/3 – MT, MW and MS) |

| | |
|---|---|
| | • Disorienting dilemmas (2/3 – MT and MW)<br><br>• Personal sense of failure and responsibility (1/3 – MT)<br><br>• Contextual forces – employment patterns and effects on self-management (1/3 – MT) |
| Self-management (3/3 – MT, MW and MS) | • Lifestyle changes and adaptive strategies (2/3 – MT and MW)<br><br>• Medications (3/3 – MT, MW and MS) |
| Relationship with health professionals | • Negative experiences (2/3 – MT and MW)<br><br>• Positive experiences (1/3 – MS) |
| Explanatory frameworks (3/3 – MT, MW and MS) | • Explanatory frameworks |
| Internet and social media (3/3 – MT, MW and MS) | • Effect on interpersonal relationships (2/3 – MW and MS)<br><br>• Tool for supporting and sustaining relationships (3/3 – MT, MW and MS) |
| Internet and information seeking (3/3 – MT, MW and MS) | • Seeking health-based information (3/3 – MT, MW and MS)<br><br>• Seeking non health-based information (1/3 – MT) |

*Dimensions of being a patient.* Although the main objective of the interview at this stage of the process was to elicit responses to participants' relationship with technology in the context of T2DM, the theme of *dimensions of being a patient* emerged from the interpretation

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of the interview data. One participant in particular (MT) struggled with the emotional

challenges posed by T2DM and was clearly subject to the challenges of Corbin and Strauss's

'biographical work' (1985) associated with chronic illness as well as a personal sense of

responsibility for being someone diagnosed with diabetes. As MT says:

> "This [T2DM] is what you pay for, doing to your body what you've done, you've got
>
> to pay." (MT)

This sense of 'payback' resonates with what, following (Goffman, 1968), Broom and

Whittaker have called the *spoiled identity of diabetes* (Broom & Whittaker, 2004). This refers

to the moral deficit often associated with T2DM such as the 'lifestyle' nature of the disease

and people's lack of ability to control behaviours such as nutritional practice.

For MT, his *spoiled identity* has arisen because of his lack of control. This resonates with the

theme of *self-blame* that emerged from the interpretation of the individual interviews. Other

participants did not share MT's sense of personal failure and personal challenges brought on

by T2DM although two participants (MT and MW) did share what have been called

'disorienting dilemmas' associated with their diagnoses of T2DM. What participants all

shared, however, was the challenge of managing conflicting information about the

management of T2DM and the resulting lack of certainty associated with the self-

management of T2DM.

***Self-management.*** All three participants were on some form of medication for lowering blood glucose levels and MT and MW engaged in adaptive lifestyle changes including changing exercise and nutritional patterns.

***Relationship with health professionals.*** There was not an overwhelmingly positive or negative attitude towards health professionals although two participants (MT and MS) recounted narratives of time-deprived visits to general practitioners and medical centres.

***Explanatory frameworks.*** All the participants provided their own individual explanatory frameworks for aspects of their illness. MW viewed stress and anxiety as a trigger for sub-optimal nutritional patterns as well as affecting her blood sugar levels. For MS, stress and anxiety were precipitating factors in her development of T2DM after the birth of her twins. For MT, increased blood sugar levels were directly related to a sedentary lifestyle.

***Internet use: social media and information seeking.*** Social media tools such as Facebook© were extensively used by all participants. The use of Facebook© exemplified their adoption of social media technologies and it was particularly used as a tool for maintaining ties with family and friends and supporting and sustaining friendships. MS did note, however, that online forms of communication can lead to 'disembodied' forms of interaction and this was not viewed as a positive cultural trend. This extensive use aligns with current research on the use of Facebook© as one of the primary tools for social engagement in the social media space (Wilson, Gosling, & Graham, 2012).

Nettleton et al (2005) contend that there are three prevailing attitudes towards seeking health information using the internet. The 'celebratory and empowering' attitude views the internet uncritically as a tool for patient empowerment, the 'concerned and dangerous' is a perspective largely held by the medical profession and views the internet with suspicion as a

potentially dangerous tool. Finally, the 'contingent and embedded' sits between these two opposing views and sees the internet as a tool for promoting patient agency embedded within a formal health context or as a tool in the co-construction of management and care between patients and health professionals. For the participants, their use of the internet illustrates aspects of the 'celebratory and empowering' and 'contingent and embedded perspectives' since they were all comfortable in using the internet to fill gaps in knowledge or to seek out information of interest relating to T2DM as well as consolidating health-based information provided by health professional. At the same time, however, MT and MW were cautious about the tendency to 'self-diagnose' using internet-based sources and this is a theme that resonated with the theme of *undifferentiated knowledge* from the pre-use interviews from the first group.

*Self-efficacy.* The self-efficacy scores for the third group prior to engagement with the PCoP are presented below in Figure 6-8. MT did not complete the questionnaire. The scores indicate that Mich S was comfortable with the self-management of lifestyle factors but scored significantly lower on the maintenance of a daily nutritional pattern (question 1 in appendix 10). The scores for MW indicate that she was comfortable with self-management at the level of lifestyle choices but was less confident about determining courses of action based on changes to her blood sugar levels or other changes with her T2DM.



## Group 3

| Self-efficacy score | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 |
|---|---|---|---|---|---|---|---|---|
| Mich S | 3 | 7 | 6 | 9 | 9 | 8 | 10 | 9 |
| Mich W | 9 | 7 | 7 | 10 | 5 | 1 | 1 | 9 |
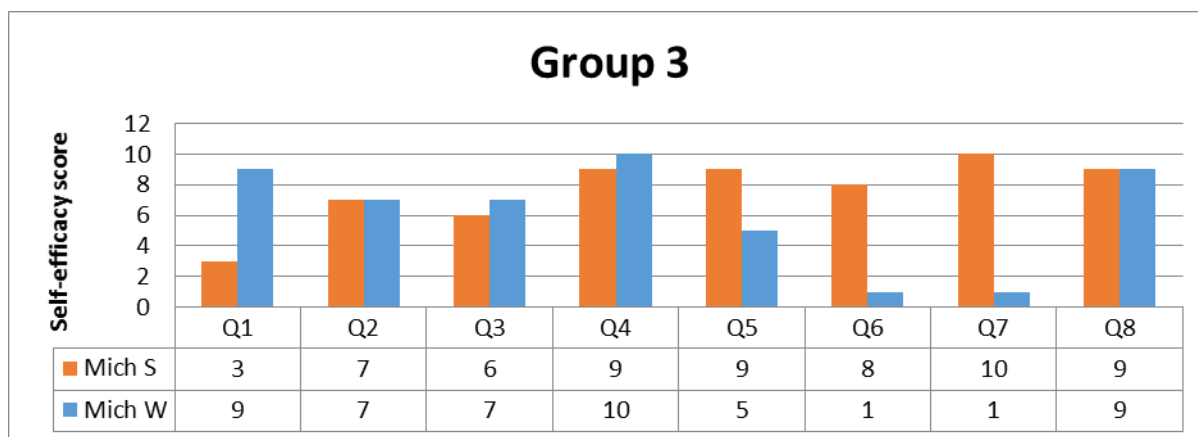
**Figure 6-8. Self-efficacy scores for the third group prior to use of the PcoP**

*Summary.* Overall, the third group consisted of individuals who used the internet extensively in all aspects of their lives. The integration between work and life for MS and MW was an example of this. In terms of seeking health-based information, the internet was also used extensively but a critical attitude to the practice of self-diagnosis was maintained. Although the internet was used to pursue online learning opportunities (MW and MS), the type of sustained and ongoing interaction that is required for knowledge construction in a forum-based context was not a desirable form of learning for MS. For her, a community of practice based around a set of resources with feedback from content experts which could be accessed at any time, represented her ideal pedagogical model.

**The third iteration of the PCoP.** The third iteration of the PCoP consisted of one less learning activity compared to the second iteration, two consolidated learning designs and the introduction of a new tool. As with the second iteration of the PCoP, learning designs are represented using two views: an AT view and a learning design toolkit view.

*Consolidated learning designs.* Based on the learning design principles (one and four) that emerged from the interpretation of the use and analysis of the first group's use of the PCoP, two new learning designs were developed and one new tool was used to deliver one of the learning activities. Although these learning designs were based on the previous iterations, the design of a weekly menu task (Table 6-15) was a more authentic learning activity compared to its first iteration and the physical activity task (Table 6-16) was more structured than the first version of the task.

Overall, the third iteration of the PCoP had one less learning activity – the *diabetes in one sentence* activity was dropped – and two consolidated activities (physical activity and

nutrition) with the aim of simplifying the PCoP by reducing the number of tasks and the creation of a less complex navigational interface for the *management experiences* activity.

Activity theory representations of the two new learning designs are described in Table 6-15 and Table 6-16.

**Table 6-15. AT representation of 'design a perfect weekly menu' activity**

| | |
|---|---|
| Learning activity/activities | • To design a perfect weekly menu based on trigger questions to facilitate responses. |
| Subject | • Participants in group three (collective subject).<br><br>• Previous participants (collective subject). |
| Object | • Using the PCoP learning environment to post up perfect weekly menus. |
| Outcomes | • To reflect on nutritional patterns, share nutritional patterns and reflect on experiences of others in the community. |
| Tools and resources | • PCoP learning environment (the chat tool).<br><br>• iPad.<br><br>• Personal devices (laptops/desktops/phones).<br><br>• 'How to' resources in PCoP learning environment. |
| Rules | **Explicit**: Following instructions for completion of the activity.<br><br>**Implicit**: Familiarity with expressing personal opinions and doing this in online context. |

| | Community | Other participants in the learning environment and friends and family. Possible recognition from health professionals with involvement in the project. |
|---|---|---|
| | Division of labour | This is a combination of an individual and group activity. |

**Table 6-16. AT view of the 'barriers and challenges to physical activity' learning activity**

| | Learning activity/activities | Reading resources on barriers and challenges to physical activity and reflecting and responding to them. |
|---|---|---|
| | Subject | <ul><li>Participants in group three (collective subject).</li><li>Previous participants (collective subject).</li></ul> |
| | Object | Using the PCoP learning environment to post personal experiences of barriers and challenges to physical activity. |
| | Outcomes | To reflect on patterns of physical activity, to share individual experiences and reflect on other experiences in the community. |
| | Tools and resources | <ul><li>PCoP learning environment (the chat tool).</li><li>iPad.</li><li>Personal devices (laptops/desktops/phones).</li><li>'How to' resources on diabetesed.com.au.</li></ul> |
| | Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Familiarity with expressing personal opinions and |

| | | |
|---|---|---|
| | | doing this in online context. |
|  Community | | Other participants in the learning environment and friends and family. Possible recognition from health professionals with involvement in the project. |
|  Division of labour | | This is a combination of an individual and group activity. |

*The introduction of a new tool.*   The new tool that was introduced in the PCoP was Padlet© ([www.padlet.com](www.padlet.com)). It is an electronic post-board and it was used to deliver the *management experiences* activity. This tool was introduced in response to the first learning design principle that emerged from the first group's use of the PCoP. It was hoped that this would be a simpler tool for people to use since it would instantly display individual posts on a post-board screen rather than posts being displayed in a typical, asynchronous forum nested format.

*Learning toolkit representation of third iteration of the PCoP.*   A learning design toolkit representation of the third iteration of the PCoP is described in Table 6-17.

**Table 6-17. Learning toolkit representation of the third iteration of the PCoP**

| Individual or group-based tasks | Week | Description | Pedagogical dimensions |
|---|---|---|---|
| Group | One | Introduce yourselves | Individual-social: <br><br>Non-reflective-reflective:  |

| | | | |
|---|---|---|---|
| | | | Experiential-informational: |
| Group | Two | Discussion of management experiences | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |
| Group | Three | Design your perfect weekly menu | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |
| Group | Four | Physical activity: barriers and challenges | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |
| Individual | Ongoing | Weekly blog | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |
| Group | Ongoing | Share resources | Individual-social: <br><br> Non-reflective-reflective: |

| | | | Experiential-informational:  |
|---|---|---|---|
| | | | |

## Use and analysis of the PCoP

*User instructions.* After the interview was conducted with the group, a navigational tour of the PCoP was provided to all participants. At this stage, they were also provided with internet-enabled iPads which they could use to access the PCoP. A brief description of what could be expected during the next six weeks was then outlined. Participants were informed that they could contact the principal researcher with questions at any point. As with group one, communication from the principal researcher consisted of weekly reminders of tasks and learning activities that were the focus of each week.

*Community of Inquiry model.* As with the first group, the CoI framework (Garrison et al., 1999) was employed as a model to analyse the forum-based interactions in the group. As can be seen in the following figure (Figure 6-9) , the only interaction occurred in the *introduce yourselves* forum. Participants did not engage in any other of the activities.
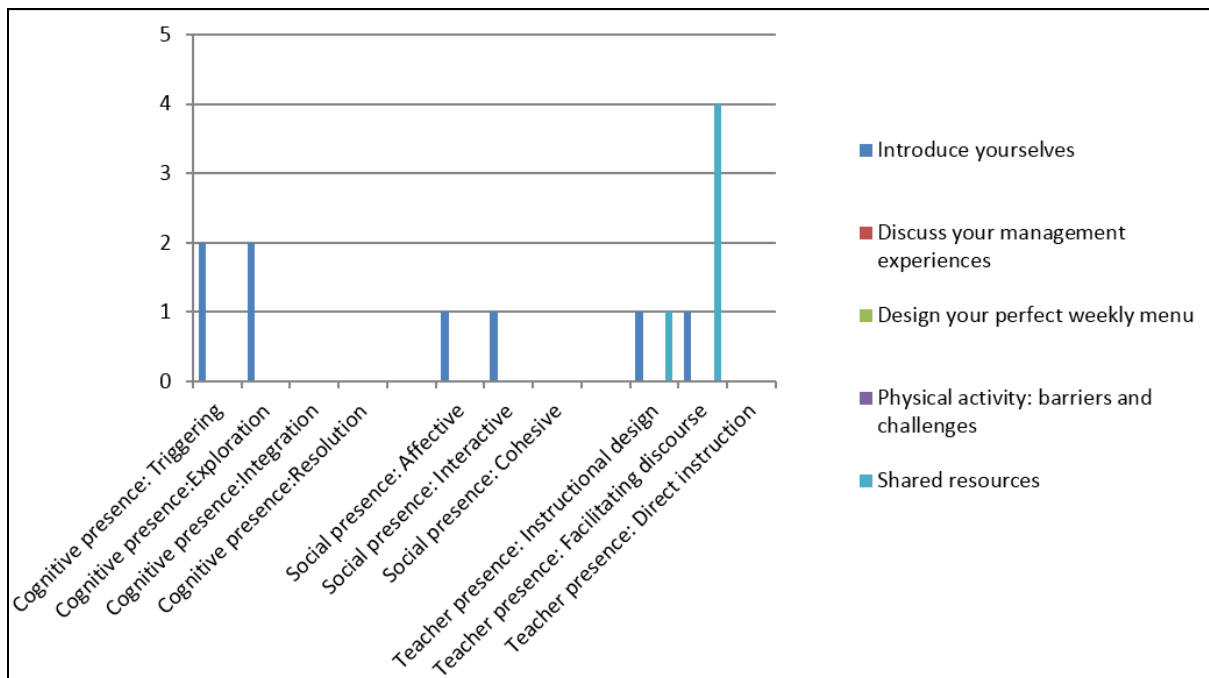


**Figure 6-9. Community of Inquiry representation of participation in the PCoP by the third group**

**Usage statistics and communication**

*PCoP – usage statistics.* 'Page views' and 'adding content' in the PCoP were generated from the Moodle© logs. As with the first group, the chart (Figure 6-10) indicates various levels of engagement with the CoP. MW and MS viewed pages and contributed to the PCoP. The other participants – YS (a participant from the first group) and MW – viewed pages but did not make any active contributions to discussions.
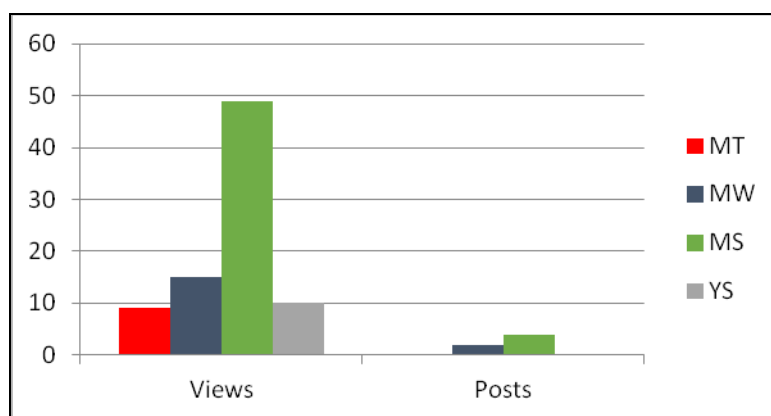


**Figure 6-10. Graph displaying 'page views' and 'posts' in the PCoP by the third group**

*Sim card – usage statistics.* Sim card usage was not analysed because the participants had access to their own personal devices and internet plans.

**Post-interviews and analysis.** After the period of engagement with the PCoP had expired, two participants (MW and MS) were interviewed using a semi-structured interview schedule (appendix 8) to elicit their experiences on the use of the PCoP. MT was unable to be interviewed.

Although MS and MW were interviewed separately, common thematic patterns emerged during both interviews. These common themes are outlined in Table 6-18. There were two themes and one sub-theme that emerged from the interpretation of the interview with MS that were not in evidence in the interview with MW. These were related to MS's reflections on

how the PCoP might be improved through the employment of a different a tool and

suggestions for a different type of learning activity. The sub-theme associated with MS and

not MW relates to a reflection on the lack of interaction related to the level of knowledge

construction and interaction.

**Table 6-18.Themes common to participants (MS and MW) from the third group**

| Themes | Sub-themes |
|---|---|
| Role of the moderator and facilitator (2/2 – MW and MS) | • No sub-theme |
| Expectations and the value of the PCoP (2/2 – MW and MS) | • No sub-theme |
| Reflection on barriers to engagement (2/2 – MW and MS) | • Internal (1/2 – MS)<br>• External (2/2 – MW and MS) |
| The environment of the PCoP (2/2 – MW and MS) | • Interface (2/2 – MW and MS)<br>• Learning activities (2/2 – MW and MS) |

*Role of the moderator and facilitator.* During the time in which participants were

engaging with the PCoP, the moderator (principal researcher) sent out weekly emails with

links to learning activities as well as emails to encourage participation and interacted in the

forums to build social presence. Despite these efforts, there was a low level of participation in

the learning tasks. Both participants, however, did appreciate the focus that was provided by

the frequent communications from the principal researcher.

*Expectations and value of the PCoP.* The expectations of MW and MS

corresponded with one of the main intended outcomes of participation in the PCoP, namely,

the practice of sharing experiences and learning from others. However, due to the low level of interaction, this outcome was difficult to achieve.

***Reflection on barriers to engagement.*** Two types of factors were identified by MS and MW as contributors to low levels of engagement. The 'internal' factor relates to the level of knowledge construction. From the perspective of sociocultural theory, knowledge is transformed and constructed through individual and collective interaction (Delahunty, Verenikina, & Jones, 2014) and it is clear that the absence of posts discouraged participants to engage due to the lack of material with which to engage. As MS says, "I couldn't see anybody else's post". The external factor relates to what we have referred to as a 'load' factor. As discussed during the analysis of the first phase, load factors can play an important role in shaping one's self-management plans in the context of T2DM. For MS and MW, external load factors such as extremely busy working schedules and the management of domestic issues (MS's first floor of her house flooded during this period) were identified as being barriers to engagement.

***The environment of the PCoP.*** Learning activities and the interface constitute this theme. MS and MW reacted positively to the 'menu design' activity and MW was positive about the learning activities. At the level of the PCoP as a tool, however, there was a significant difference between MW and MS. MS found the PCoP to be difficult to use ("it was too hard to use") and a lack of familiarity with the interface ("I have never seen that kind of application before") led to challenges that were difficult to overcome. MW, on the other hand, was not challenged by the interface. As she says:

> "I didn't find it confusing at all. I didn't go on to twitter© at all but the website was fine."

Due to the lack of familiarity with the interface and the fact that it was an additional system that had to be accessed, MS suggested that Facebook© might have been a more effective choice of technology. MW did not provide alternative technologies since she did not share the same level of frustration with the interface as MS. In terms of additional learning activities, MW provided a suggestion in which an expert would be invited to provide expertise at a particular time and on a particular day. MW suggested that this would have allowed her to plan to participate at a certain time.

*Dimensions of transformative learning in the third group.* The representation of the interaction in the third group using the CoI model (Figure 6-9) indicates that there was even less interaction in the third group compared to the first. As a result, the evidence for dialogic learning was minimal. However, the experience in participating and using the PCoP did generate a high level of reflection on the nature of the learning experience in an online PCoP. These reflections were elicited during the post-use interviews and indicated that a synchronous model of learning might be more beneficial for people with busy personal and professional lives. This represents a shift in learning design that would entail pre-specified periods of interaction.

Although the degree of reflection from participants that was evinced from the interviews was significant, this level of reflection was not in evidence during the asynchronous discussions, The absence of the dialogic dimension crucial to the process of transformative learning (Lee & Brett, 2015)  contributed to the absence of self-reflection and the sharing of instrumental knowledge.

Table 6-19 describes the dimensions of transformative learning that were in evidence during the third iteration.

**Table 6-19. Dimensions of transformative learning from the third group**

| Dimensions of transformative learning | Instrumental | Dialogic | Self-reflective |
|---|---|---|---|
| Learning within frames of reference. | No significant evidence. | No significant evidence in online interaction. | No significant evidence |
| Learning new frames of reference. | No significant evidence. | In post-use interview the nature of the asynchronous model of learning used in the PCoP was questioned. | No significant evidence |
| Learning through transformation of points of view or habits of mind (meaning transformation). | No significant evidence. | In the post-use interview there was a redefinition of learning as a synchronous event-based model. | No significant evidence |

**Summary of results.**   The third group consisted of three individuals: MT, MS and MW. All three participants were interviewed prior to their participation in the PCoP and MW and MS were interviewed after their participation. MT was unable to be interviewed due to a personal tragedy. Additionally, MS and MW completed a T2DM self-efficacy questionnaire before engaging with the system.

All group members were highly experienced users of Facebook© and two participants (MW and MS) had used the internet previously to engage in formal courses. The emotional challenges associated with T2DM were most acutely experienced by MT although the lack of certainty associated with having T2DM was felt by all members of the group. Adaptive strategies in the form of lifestyle modifications and changes were put in place by MT and MW and all group participants were on some form of medication to address their T2DM.

Their engagement with the PCoP was characterised by a significant number of page views but there was clearly a lack of interaction among participants and this had an obvious impact on the level of knowledge that was shared in the community. This is indicated in the low levels of social and cognitive presence in the forum discussions (see Figure 6-9).

The post-use interviews indicated that MT and MS were under a great deal of professional and domestic stress during their period of participation and this was seen by both as a major barrier to engagement. These can be viewed as external 'load' factors. Internal factors, such as the interface characteristics or the learning activities in the PCoP, were viewed differently by MW and MS. MS found the interface to be a challenge and suggested that a more orthodox interface (such as Facebook©) would have been more likely to increase her level of participation. MW did not find any difficulty in using the interface and both MW and MS were positive about the authentic learning activities.

The learning model adopted in the PCoP was based around the practice and reflection on self-management tasks (diets/menus and physical activity) and general discussions of self-management. MW and MS were drawn to these activities and not the more general activity based around self-management discussions. MW suggested that a learning activity based around an event in which an expert might be available during a specified time frame would have been of interest to her. This type of 'event-based' learning would have suited her busy domestic and professional schedule more than the asynchronous model. This represented an example of 'learning through meaning transformation' as the benefits of asynchronous learning were questioned and a new synchronous model was proposed as an alternative model.

**An activity theory view.** The major tensions in this representation of the third group's use of the PCoP represented by the model below (Figure 6-11) are at the level of the learning activities (*tools and mediating artefacts)* and the participants themselves (*subjects).* Taken together, this meant that the outcomes of the learning activities were difficult to achieve. A simplified interface for the delivery of the forum-based activities was introduced (*tools and mediating artefacts)* but this created a degree of confusion because some participants were unable to use the interface. The Moodle©-based discussion forum was then re-introduced but this was viewed by one participant as being difficult to use.

All the participants were extremely busy with personal or professional (or a combination of both) life during the period of participation and this proved to be a major barrier to sustained and ongoing participation.
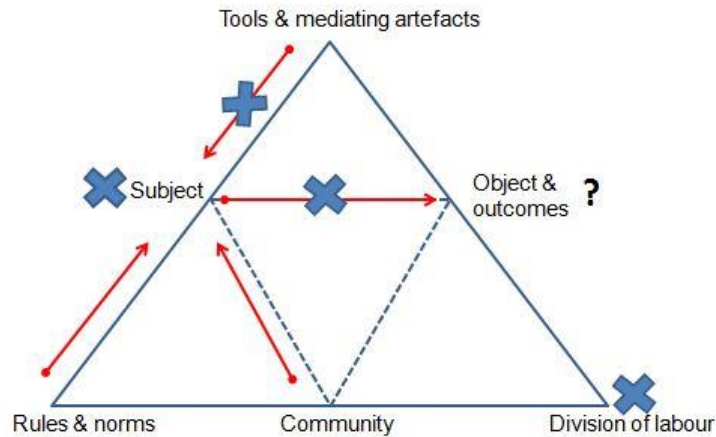
**Figure 6-11. An AT representation of the use of the PCoP by the third group**

The learning design principles outlined below were developed to address these issues and they were embedded in the next iteration.

## Learning design principles

The following learning design principles in Table 6-20 were proposed after the first group used the PCoP.

**Table 6-20. Learning design principles from the use of the CoP by the first group**

| |
|---|
| 1. Tools for interaction must be simple and kept to a minimum. |
| 2. To promote engagement and participation facilitation can be conducted by participants and facilitators. |
| 3. Promotion of social interaction prior to online participation is important. |
| 4. Learning designs need to be simple and authentic. |

In the light of the pre-use and post-use interviews, it is clear that principles one and four were still very important to the participants and these principles were therefore recycled into the

learning design principles that emerged from the third group's use of the PCoP. The utility of

the second and third principles, on the other hand, was less easy to identify.

It was clear that YS's and DK's (two participants from the first group) participation was

minimal and members of the third group did not facilitate any emerging discussions. In the

absence of individual learner facilitated discussions leading to the growth of cognitive and

social presence in community, however, the moderator's and facilitator's role was crucial in

providing a focus for group activity.

The promotion of social interaction through conducting face-to-face interviews with each

group prior to the use of the PCoP was seen as important by the first group but as less

important by the third group and it was difficult to identify the reasons for this difference. As

a result, this principle was retained because, although it was not universally seen as an

important component of the development of social presence, it was felt that it would

minimise disembodied online experiences and allow participants to associate a face with a

name.

Therefore, based on the third iteration of the design-based research cycle the following

learning design principles were proposed.

**Table 6-21. Learning design principles from the use of the PCoP by the third group**

**1. Tools for interaction must be simple and kept to a minimum.**

During the development stage of the third iteration of the PCoP, a new electronic post board

tool (Padlet©) was embedded within the Moodle© environment and its function was to

deliver the management experiences activity. It became apparent, however, that the personal

technology infrastructure available to MS and MW was not able to support the technology

and this resulted in an unacceptable level of frustration. As a result, this learning activity was

abandoned. Therefore, although the affordances of particular tools might seem to offer potential advantages, they can also distract attention away from engagement and participation in a social learning environment.

**2. The role of the moderator and facilitator is crucial in providing focus and the ongoing development of social and cognitive presence.**

The first and third groups benefited from having a constant 'teacher presence' (Garrison et al., 1999) in the form of frequent email communication and frequent forum posts by the principal researcher. Without this crucial involvement, the groups would not have functioned.

**3. Promotion of social interaction prior to online participation is important.**

Although there was not a level of universal agreement that face-to-face interaction was crucial prior to online interaction, this is still an important learning design principle because there was enough evidence in the post-use interviews to suggest that some individuals prefer being able to put a name to a face. For this reason, this principle was put in place for the fourth iteration and a face-to-face group interview was required.

**4. Learning designs need to be simple and authentic.**

The development of more authentic learning activities which would allow participants to practice the tasks required of them and then to reflect on them in discussion forums was one of the most important changes made in the third iteration for the third group. MW and MS viewed the diet and physical activity learning activities positively and these were therefore retained for the fourth iteration.

***An activity theory view.*** The learning design principles that emerged from the interpretation of the use of the PCoP and the interpretation of the post-use interviews are represented below (Figure 6-12) using activity theory.
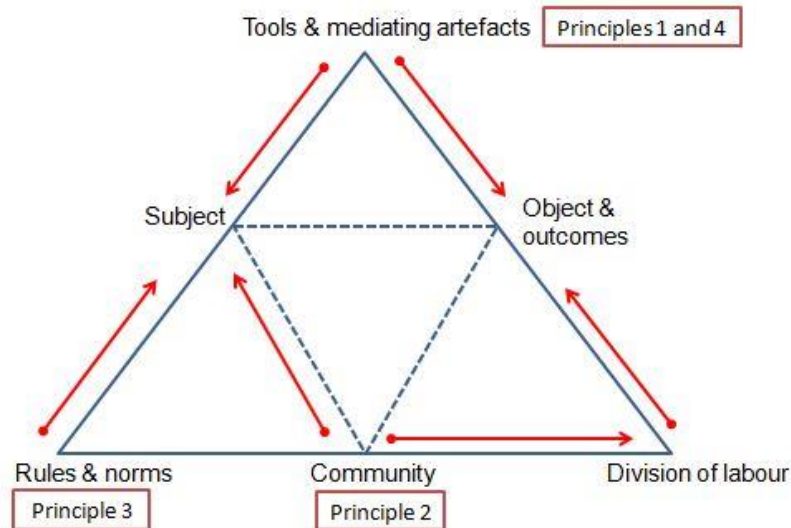


**Figure 6-12. AT model of learning design principles from the use of the PCoP by the third group**

This view indicates that learning activities that are simple and authentic (principle four) coupled with a simple interface for interaction (principle one) are likely to have an effect on the way the participants interact with the system (*subject*) and the outcomes of this interaction. Similarly, the third principle states that having face-to-face introductions prior to online participation (*rules and norms*) will create an environment in which participants (*subjects*) will be more likely to interact with each other. Similarly, the moderator's and facilitator's role (*community*) is crucial in promoting engagement and participation and this can have the intended effect of creating an environment in which knowledge construction (*division of labour*) in the PCoP contributes to the intended outcomes.

It was hoped that embedding these principles into the fourth iteration of the PCoP would lead to greater levels of interaction (hence the lack of tensions in the model) and hence to greater levels of social and cognitive presence.

**Summary of results.**   The third group consisted of three participants. After an initial face-to-face meeting prior to online participation, the group engaged in the PCoP over an eight-week period. The level of interaction was relatively low and the lack of interaction and knowledge sharing were related to two factors: the constraints on time imposed by personal and professional factors and the lack of familiarity with the interface.

The consequence of this was that some of the intended objectives of transformative learning were met during the post-use interview and not during the online interactions. This indicates that participation in the PCoP functioned as a tool to frame a discussion about the benefits of models of learning (asynchronous or synchronous) and this represented an example of 'learning through meaning transformation' as participants began to redefine and address the issue of barriers to online engagement and participation.

## Group four

The use of the PCoP by the fourth group represents the fourth and last iteration of this design-based project.

In the last section, an analysis of the participation and engagement by the third group with the learning environment was provided. Four learning design principles were proposed, and the shape of the PCoP in this iteration reflects those principles. These changes are outlined in Table 6-22 and in the AT model in Table 6-23.

**Table 6-22. Changes to the PCoP adopted for the fourth group**

| Changes to the PCoP | Reason for change | Based on learning design principles |
|---|---|---|
| Private diaries replace blogs. | The blog tool was too complicated. This was replaced by a forum-based tool with privacy settings. | Design principle one from third iteration. |
| Twitter panel. | This was added to increase 'teacher presence' and complemented the weekly communications between the moderator/facilitator and participants. | Design principle two from third iteration. |

**Table 6-23. AT representation of changes made to the PCoP for the fourth group**

| | |
|---|---|
| Learning activity/activities | **Pedagogical dimensions**<br><br>**Individual private diary**<br><br>Individual-social:<br><br>Non-reflective-reflective:<br><br>Experiential-informational: |
| Subject | • Participants from group four.<br><br>• Previous participants. |
| Object | Using PCoP learning environment to post reflections on the use and value of the PCoP |
| Outcomes | To reflect on the value of the PCoP and the educational value of participation in the PCoP. |
| Tools and resources | • PCoP learning environment (the forum tool).<br><br>• iPad.<br><br>• Personal devices.<br><br>• (laptops/desktops/phones). |
| Rules | **Explicit**: Following instructions for completing the activity.<br><br>**Implicit**: Familiarity with individual reflection in context of T2DM. |

| | This is an individual activity. |
|---|---|
| Community | |
| Division of labour | There is no division of labour in this activity since it is based on individual, private reflections. |

The diet activity (design your perfect menu) and exercise activity (barriers and challenges to physical activity) were retained as these were positively received and they constituted the core of the authentic learning activities. The resource sharing activity was also retained using the tools that were used to deliver it from the first iteration. The general discussion of management issues, however, did not constitute one of the activities because it was felt that there were too many learning activities in the previous iteration and that these diluted the opportunities for sustained engagement. A learning toolkit representation of the fourth iteration of the PCoP is outlined below (Table 6-24).

**Table 6-24. Learning toolkit representation of the fourth iteration of the PCoP**

| Individual or group-based activity | Week | Description | Pedagogical dimensions |
|---|---|---|---|
| Group | One | Introduce yourselves | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |

| Group | Three | Design your perfect weekly menu | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |
|-------|-------|--------------------------------|------------------------------------------------------------------------------------------|
| Group | Five | Physical activity: barriers and challenges | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |
| Individual | Ongoing | Private diary | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |
| Group | Ongoing | Share resources | Individual-social: <br><br> Non-reflective-reflective: <br><br> Experiential-informational: |

Chapter 6. Results

***Recruitment.*** Advertisements were placed in a local newspaper during January 2015 and four participants were recruited. Three participants attended a group pre-use interview in late January 2015 in which a semi-structured interview was conducted using a semi-structured interview schedule (appendix 7).

The ages of the group including date of diagnosis is outlined in Table 6-25 and individual contexts of participants are described in Table 6-26.

**Table 6-25. Ages of participants in group four and date diagnosed with T2DM**

| Participant | Age at time of participation | Date diagnosed with diabetes |
|---|---|---|
| NH | 44 | 2013 |
| PC | 50 | 2014 |
| MC1 | 53 | 2013 |
| MC2 | 53 | 2007 |

Information on the individual contexts of participants is outlined below.

**Table 6-26. Individual contexts of participants in group four**

| Participants | Individual contexts |
|---|---|
| NH | Former school teacher. Taking break from teaching. |
| PC | Self-employed. |

| MC1 | School teacher.<br><br>Extremely busy professional life. |
|-----|-----|
| MC2 | Stay at home mother. |

*Self-efficacy.*   Three participants completed the self-efficacy questionnaire prior to their engagement with the PCoP (see Figure 6-13).  The scores indicate that both MC2 and MC1 were generally confident of their capacity for self-management and this was reflected in their high levels of control with regards to lifestyle choices and capacity for self-management. NH's scores, however, reflected an individual who was less certain of his capacity for self-judgement and lack of confidence in his capacity to control his blood sugar levels.



| Group 4 — Self-efficacy score | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 |
|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| NH | 2 | 7 | 7 | 5 | 2 | 2 | 10 | 10 |
| MC1 | 10 | 10 | 6 | 10 | 8 | 10 | 8 | 10 |
| MC2 | 10 | 10 | 10 | 10 | 10 | 10 | 9 | 8 |
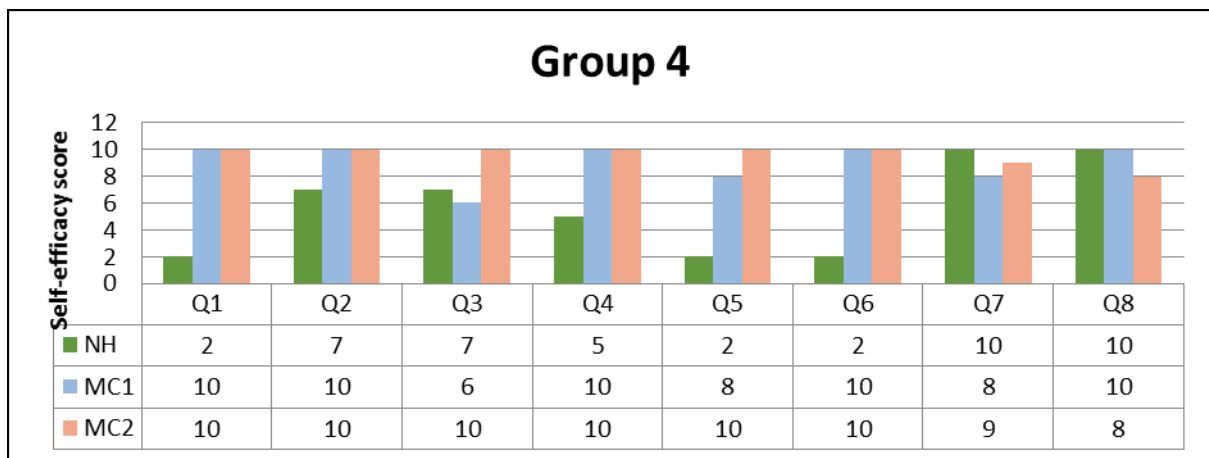
**Figure 6-13. Self-efficacy scores for three participants from the fourth group**

**Pre-use Interviews.**   Three major themes emerged from the interpretation of the data: *dimensions of being a patient*, *information seeking behaviour* and *reflections on and use of technology.* These themes together with their related sub-themes are outlined in Table 6-27. As with previous interpretations of interview data, the number of times a theme or sub-

theme was referred to is quantified to indicate the shape of thematic spread through the

interview data.

**Table 6-27. Themes from the pre-use interviews conducted for the fourth group**

| Themes | Sub-themes |
|---|---|
| Dimensions of being a patient (3/3 – MC1, MC2 and NH) | • Uncertainty (1/3 MC1) <br><br> • Support (1/3 MC1) <br><br> • The Importance of being in control (1/3 – MC1) <br><br> • Living with T2DM (2/3 – MC2 and MC1) <br><br> • Positive effects of T2DM (2/3 – MC1 and NH) |
| Information seeking behaviour (3/3 – MC1, MC2 and NH) | • Non-health seeking behaviour (1/3 – MC1) <br><br> • Health-seeking behaviour (2/3 – MC2 and NH) <br><br> • The Internet and undifferentiated knowledge (1/3 – MC1) |
| Reflections on and use of technology (3/3 – MC1, MC2 and NH) | • Participation in online courses (1/3 – MC1) <br><br> • Facilitation of support network (1/3 – MC1) <br><br> • The quantified self (1/3 – MC2) <br><br> • Tools for decision making (2/3 – MC1 and NH) <br><br> • Devices used (3/3 – MC1, MC2 and NH) <br><br> • Social media use <br><br>     o No use (1/3 – MC1) <br><br>     o Use of various platforms (2/3 – MC2 and NH) |

The themes in the table are described in greater depth below.

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***Dimensions of being a patient.*** The emotional complexity of having T2DM was not a theme that featured prominently in the interview although for MC1 and MC2 the challenges of the 'daily work' of T2DM were significantly felt when outside of the home environment. As MC1 says "…you eat stuff that you really shouldn't because you don't have the choice that's available to you."

The diagnosis of T2DM had significant positive effects for MC1 and NH. For NH, the event led to marked changes in dietary choices which led to an overall improvement in his health ("my health has improved out of sight"). For MC1, the diagnosis was defined as a "wake up call" leading to the setting of life goals that took a different shape or were absent prior to the diagnosis.

***Information seeking behaviour.*** The internet was used for the acquisition of health and non-health related information although there was a greater emphasis on the use of the internet in a health context. There was a balanced view of the value of the health-related knowledge sourced via the internet as the internet was used to complement existing knowledge as well as to provide extra information that is sometimes missing from consultations with health professionals. As MC2 says, the internet can provide "the finer details of what the health professional sometimes doesn't tell you". NH, on the other hand, relied more on the function of the health professional as the expert to provide any relevant information on health-related issues.

The nature of internet-based knowledge was questioned by MC1 on two levels. Its trustworthiness was queried ("just because it's online doesn't mean to say it's right") as well as the tendency for knowledge to take a general shape rather than taking a personalised form.

***Reflections on and use of technology.*** All three participants were heavy users of the internet and had access to and familiarity with various devices. The nature of the internet as a

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tool with various affordances ranged from the facilitation of social networks, as an instrument for 'quantifying the self' (Shin & Biocca, 2017) and as an aid in the decision making process. Non-internet based technologies (such as Calorie King©) were also used.

MC2 used a commercially available instrument (fitbit©) for recording daily exercise patterns in two ways. It was used as a device to increase her individual level of exercise as well as being used as a tool to promote greater levels of activity in her social network. As MC2 says:

> "We can all challenge each other...we're finding that some days you don't feel like exercising and you'd sort of have a look and go, they've done so many steps now, I better ramp it up and get going."

Two out of three participants (MC2 and NH) were users of Facebook©, one out of three was a user of Twitter© (NH) and one participant (MC1) did not use social media although she was the only one who had participated in a formal online learning course.

### Use and analysis of the PCoP

*User instructions.* After the pre-use interview was conducted, three of the participants were introduced to the PCoP and provided with a basic tour. The fourth participant (PC) was not present at the pre-use interview. This did not deter him from participating and his ability to use the features of the environment without any direct instruction was one of the features of his engagement in the project.

*Community of Inquiry model.* Four activities were analysed using the parameters from the CoI model (see Figure 6-14). This general shape of the data shows us that there was quite a high level of 'triggering' activity in the shape of initial posts in the 'Introduce

yourselves' and 'Design your perfect weekly menu' activities and this kind of activity was less evident in the 'shared resources' activity.

*Introduce yourselves.*   The objective of this 'icebreaker' activity was the development of social presence before the more 'cognitive' and reflective activities were introduced. All the participants engaged in the activity. Affective language was used (for example, "Gday folks", "Hi everyone") and an interactive thread developed around the theme of 'fitbits' and the interest of one participant (MC1) in joining a fitbit© group facilitated by MC2. Through this level of interaction, a degree of group cohesiveness began to develop.

*Design your perfect weekly menu.* All three dimensions of the CoI model (cognitive, social and teacher presence) were in evidence in the weekly menu activity and in this activity there were also signs of exploration. For example, there was an exchange between PC and MC1 on the topic of variation in the weekly menu and this represented an exploration of the practice of varying weekly menus. Although PC and MC1 did not practice a great deal of variation in their weekly menus, only PC attempted to integrate their discussion by reflecting on how planning menus can be exhausting. As PC says:

"After another week of carefully planning what to consume I deserve a break."

Social presence was also developed during participants' engagement with the activity and this was especially apparent during MC's and the facilitator's interaction. Teacher presence was also quite prominent and questions such as "Are there any variations to your weekly menu? How do you negotiate with others in your immediate family circle or is this not an issue?" were used to prompt further discussion.

*Physical activity: barriers and challenges.* The level of engagement with this activity was lower than the previous two activities across all the dimensions of the model. Although there were instances of 'triggering', these did not form the basis of any kind of sustained interaction. The exception to this was MC2's post which lead to PC's interest in purchasing a fitbit©.

Two barriers to physical activity were indicated by PC and MC2. For PC, his barrier was time and for MC2, several falls resulted in an erratic pattern of physical activity. Her use of the fitbit© prompted her to reflect on the amount of time she spent on walking ("It's amazing how little you walk").
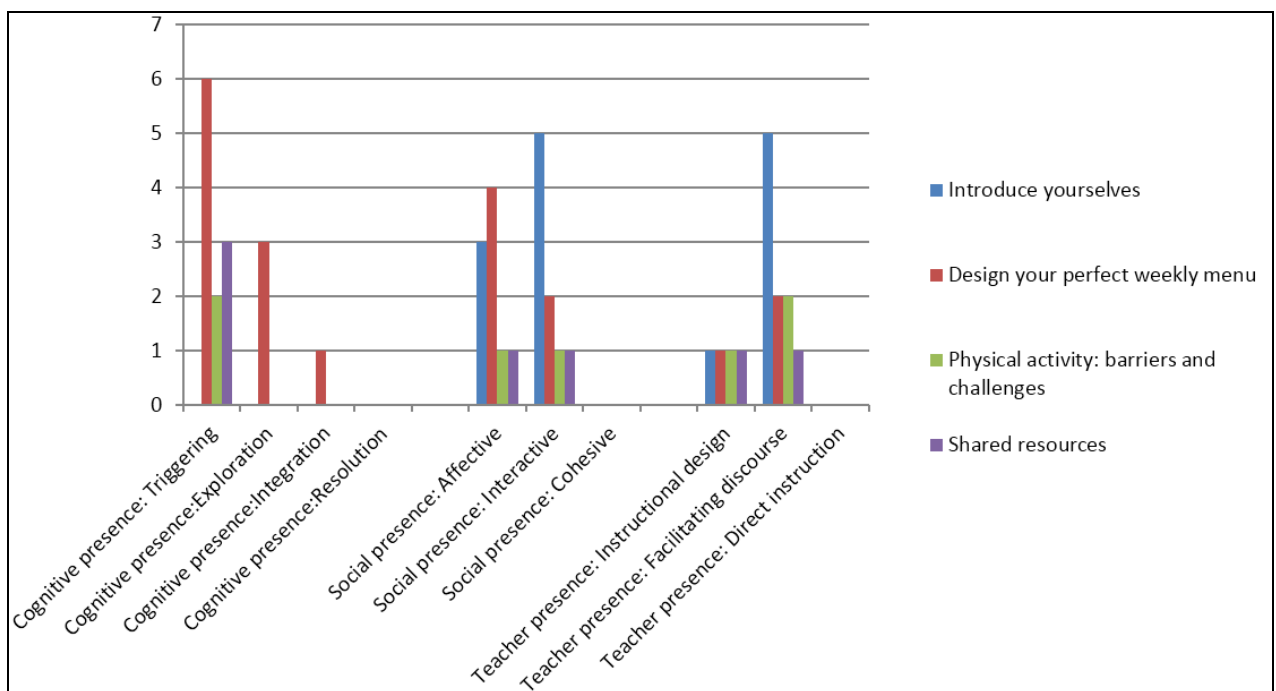


**Figure 6-14. Community of Inquiry representation of interaction in the fourth group**

*Private diaries.*   A private diary space was set up to allow participants to reflect on

two questions:

- If their participation in the project provided them with confidence to manage their

  T2DM or provided them with any fresh insights.

- If their participation in the project contributed to their learning about T2DM.

Three participants (MC1, MC2 and NH) used the space and provided nine diary entries in

total (MC1 made three, MC2 made four and NH made two). Entries by NH and MC2 were

mostly descriptive in nature in which weekly events were described. MC2 suggested that it

was too early to determine the effect of participation on her T2DM although NH indicated

that his participation had a positive effect on his confidence and capacity to manage his

T2DM:

> "Participating in this research has given me a bit more confidence by knowing that
>
> other people are in the same situation as I am. This is encouraging. By having to
>
> research and read about diabetes and diet I feel I am better informed. Sharing it with
>
> others and having discussion may also offer insight into the condition."

The entries of MC1, on the other hand, were characterised by their descriptive nature as well

as reflecting the theme of the 'contest for control' that was encountered in the chapter on the

design of the PCoP (chapter four) called *Contest for control: limitations on agency imposed*

*by T2DM*. For MC1, the "contest for control" reflected a tension between the demands and

requirements of her professional and personal life against patterns of behaviour (such as gym

routines) that were considered important for the maintenance of her health.

The goal-oriented nature of some of MC1's entries reflects her significant efforts in the realm

of 'illness work' ("I have kept up my 3 personal training sessions per week. More and

different meetings but I am determined not to let it take away from my exercise program"),
'everyday work' ("I have had a very busy start to the school year. Children with special needs
are always very demanding") and 'biographical work' ("Don't think I will ever forget the
devastation of that day. However, I have worked hard and have progressed well"). These
thematic characteristics reflect what Corbin and Strauss called the 'three lines of work' in
chronic illness (1985) and the dimension of 'illness work', in particular, is indicative of the
kind of reflective practice that is used in the process of problem-solving and decision making
(Satariyan & Reynolds, 2016).

**PCoP – Usage statistics.**    The data on page views and posts was extracted from the
Moodle© logs. These data show two peaks for page views for MC2 and PC and although
MC1 contributed the most in terms of numbers of posts, her page views were significantly
less than for MC2 and PC. However, although there was a significant difference in the
proportion of page views versus posts, the data also show that all the participants posted
content. This means that none of the participants could be characterised as 'lurkers' or
passive participants (Lev-On & Adler, 2013) in which participation is defined as the practice
of viewing content and not posting content. Numerical and log-generated data (see Figure
6-15), however, do not confer meaning on the nature of the participation in the PCoP. The
analysis of the post-use interviews presented below was conducted to gain greater insight into
the patterns of participation.
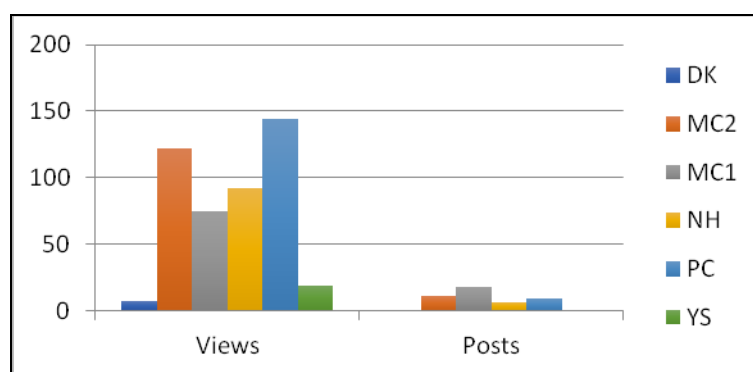
**Figure 6-15. 'Page view' and 'posts' generated by participants in the fourth group**

*Post-use interview and analysis.* Three interviews were conducted after the period of participation. One interview was conducted with MC1 and MC2 and two separate interviews were conducted with NH and PC. The interview schedule (appendix 8) was the same for all the interviews. Although three interviews were conducted, the unit of analysis for the interpretation of the data consisted of three interviews grouped together. The themes that emerged were therefore grouped into one table (Table 6-28). As with the presentation of previous interpretations of interview data, each theme or sub-theme indicates the participants who contributed to it.

**Table 6-28. Themes from the post-use interviews conducted for the fourth group**

| Themes | Sub-themes |
|---|---|
| Dimensions of being a patient (1/4 – MC1) | • Conceptualising disease (1/4 – MC1)<br><br>• Patient as expert (1/4 – MC1)<br><br>• Living with T2DM (1/4 – MC1) |
| Expectations of the PCoP (2/4 – MC1 and MC2) | • Expectations (2/4 – MC1 and MC2) |
| Reflections on the use of the PCoP (4/4 – MC1, MC2, NH and PC) | • Provision of support (1/4 – MC2)<br><br>• A safe learning environment (1/4 – PC)<br><br>• Face-to-face introduction (4/4 – MC1, MC2, NH and PC)<br><br>• Contextual barriers to participation (3/4 – MC1, MC2, NH) |

| | |
|---|---|
| | • The value of the learning activities (3/4 – MC1, NH and PC)<br><br>• Interaction and participation (4/4 – MC1, MC2, NH and PC)<br><br>• The interface (4/4 – MC1, MC2, NH and PC) |
| Improvements to the PCoP (3/4 – MC1, NH and PC) | • Improvements to the PCoP |

*Dimensions of being a patient.* The theme of *dimensions of being a patient* was not distributed widely across the contributions in the post-use interview. MC1 was the only participant to raise issues related to this theme. In the sub-theme *Living with T2DM* MC1 referred to the 'treadmill' of the 'illness work' associated with having diabetes. As MC1 puts it:

> "Sometimes you do feel like you're on that treadmill all the time because it's meal preparation and it's carbs and it's exercise and it's blood testing and it's carbs, and you never stop."

Descriptions such as these constitute the content of this sub-theme. The other sub-themes associated with the theme (*conceptualising disease* and the *patient as expert*) were not as significantly represented.

*Expectations of the PCoP.* The two expectations offered by MC1 and MC2 related to the acquisition of knowledge. The first expectation represented the hope that participation in the project would lead to learning more about the disease. The second expectation was related to learning from other people's experiences of coping with and managing their illness.

# Chapter 6. Results

*Reflections on the use of the PCoP.* The learning design principle (principle three) associated with the third iteration, namely, the importance of the development of social presence prior to online engagement, took the form of face-to-face introductions and interviews priors to online participation. This principle was not universally endorsed. One participant (MC1) was in favour of meeting face-to-face while MC2, on the other hand, expressed a degree of ambivalence towards this requirement. MC2 interacted with PC freely although as MC2 says, "she didn't really know him". PC and NH, on the other hand, did not view a face-to-face as a necessary pre-requisite for subsequent online participation. NH cited Facebook© as an example of an online system of communication that was not contingent on prior face-to-face contact.

Reflecting on their use of the PCoP in terms of their allocation of time to participation, three participants (MC1, MC2 and NH) were unable to devote the amount of time they would have liked. The demands of their personal and professional lives often constrained the amount of time they could devote to the project. However, once participants were able to find the requisite time, the value of learning with others through the various learning activities was appreciated. MC1 was the most active participant in terms of posts and she was also the participant who most clearly expressed the value of the learning through other people's experiences. NH, on the other hand, was more passive in his level of engagement (measured by number of posts) and he preferred to use the PCoP as a repository of knowledge although he did experience difficulties with the interface. PC was more of an active participant than NH and like NH, he found the PCoP to be a useful portal for links to various aspects of T2DM. Apart from MC1, none of the participants articulated views on the authentic learning activities.

The level of interaction (measured by posts) was at a lower level than participation in the PCoP (measured by the number of views and posts). For some (PC), interaction was largely a product of accident rather than design:

> "I know that there's some people who won't reply, there's others who will."

For NH, on the other hand, levels of interaction were a function of the amount of time available to participants and MC1 expressed a view that interaction is likely to be greater at the start of a project such as this and then taper off towards the end.

MC1 provided insights into the nature of asynchronous forum-based learning that resonate with the theme of disembodied online learning or the theme of the 'one-man band' that emerged from the first iteration. Since a reply to a post is the only measure of recognition that an individual has read a post, when replies are not received this creates a sense that you are "typing into cyberspace" (MC1). Facebook©, according to MC1, has created the mechanism of the 'like' button to mitigate or lessen the possibility of having disembodied online experiences.

In terms of the interface, all the participants experienced degrees of difficulty in their use of the PCoP although they were ultimately successful in both viewing and writing posts. Difficulties ranged from the use of a "clunky" (NH) interface to the system "freezing" (MC2).

*Improvements to the PCoP.*   Suggestions for improvement fell under two categories. One related to improvements at the tool level. PC suggested that the PCoP should become an 'app' while MC1 and NH suggested that a 'chat room' or Twitter© type tool might be useful mechanisms for the introduction of a synchronous dimension to interaction. MC1 suggested that this type of real-time tool might function as a tool for supporting others in contrast to the reflective, asynchronous nature of the PCoP. Real-time events could also be

scheduled to occur at certain times and, according to MC1, this would benefit those with busy

personal and professional lives. This suggestion is similar to the theme of 'event-based'

learning that emerged from the interpretation of the post-use interviews in the third iteration.

*Dimensions of transformative learning from the fourth group.* Since there was a

significantly higher level of social interaction in the PCoP for the fourth group (see Figure

6-14), this meant that there was also a higher potential for dialogic learning. Self-reflective

learning occurred in the private diary posts but was not in evidence in any of the online

interaction. During the post-use interviews, however, NH reflected on the value of the PCoP

as a tool in his self-management. This is an example of a shift in a frame of reference as self-

management begins to be viewed as a collaborative enterprise rather than being a wholly

individual practice. In a similar vein, the discussion related to the fitbit© generated a

conception of physical activity as a social practice rather than an individual activity. The

dimensions of transformative learning related to the fourth group are outlined in Table 6-29.

**Table 6-29. Dimensions of transformative learning from the fourth group**

| Dimensions of transformative learning | Instrumental | Dialogic | Self-reflective |
|---|---|---|---|
| Learning within frames of reference. | Discussion about new tools for promotion of physical activity (fitbit©) . | Significant evidence in social presence activity (introduce yourself) and discussion about fitbit©. | Evidence in private diaries of descriptive reflection of daily activities. |
| Learning new frames of | Tools can aid self- | Using the CoP as a | Reflection by NH on |

| reference. | management of T2DM. | means of communication, sharing experiences and increasing confidence. | the value of a CoP in increasing his confidence. |
|---|---|---|---|
| Learning through transformation of points of view or habits of mind (meaning transformation). | Physical activity conceived as a social and not individual activity. | Suggestion of the adoption of a synchronous model (note: this suggestion resulted from the post-use interview and not as part of online discussions). | NH begins to see a PCoP as a valuable tool in framing self-management practice. |

*An activity theory view*.   There were less tensions in this activity theory view (Figure 6-16) compared to the first and third iterations although the tension associated with the *subject* or participant was still significant. This tension related to the time constraints on participants imposed by their personal and professional lives – hence the tension associated with the subject. The learning activities (*tools and mediating artefacts)* were used passively (links to T2DM resources) or actively (authentic learning activities) and the group managed to interact and share experiences and knowledge (*division of labour)* leading to the acquisition of instrumental knowledge (*object and outcomes)*. The role of the moderator or facilitator (*community)* in guiding initial discussions was again crucial in the development of participation in the PCoP. Additionally, for some participants the requirement to meet face-

to-face (*rules and norms)* promoted social presence which led to a more embodied online learning experience.
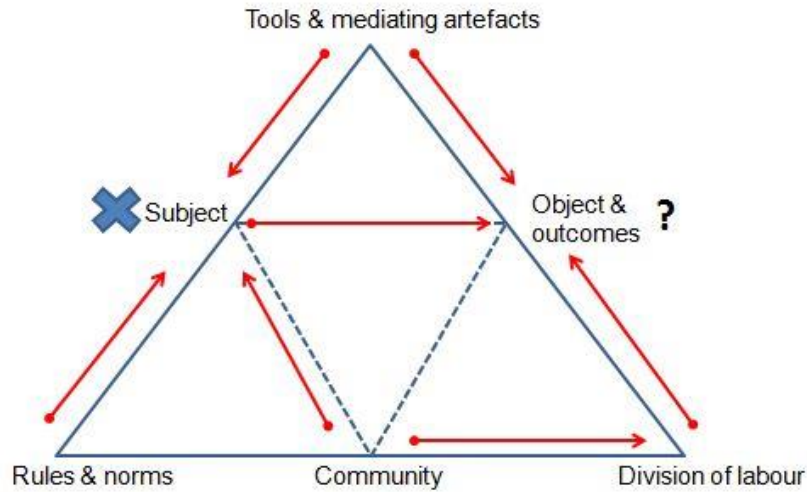


**Figure 6-16. AT representation of the tensions in the use of the PCoP by the fourth group**

The following learning design principles were developed to address the issues that arose during the fourth group's use of the PCoP.

**Learning design principles.**   The learning design principles from the third iteration (Table 6-30) were used to develop the fourth iteration of the PCoP.

**Table 6-30. Learning design principles from the use of the PCoP by the third group**

1. Tools for interaction must be simple and kept to a minimum.

2. The role of the moderator or facilitator is crucial in providing focus and the ongoing development of social and cognitive presence.

3. Promotion of social interaction prior to online participation is important.

4.  Learning designs need to be simple and authentic.

The tool (forum tool) that was used in the fourth iteration was not different from the tool used in the first, second or third iterations. The one major change was that the forum tool was re-purposed to function as a space for private diaries. The key idea was to use one tool to create an interface with familiar properties and navigational consistency. This was a lesson learned from the third iteration because during that iteration a new tool (Padlet©) was introduced to potentially simplify interaction. This was not a successful change because some users had difficulties in using it and the tool used to implement the learning activities was then changed back to the forum tool. The first design principle, therefore, still applies.

The role of the facilitator was still crucial during all stages of participation and it was particularly important for those participants (NH) who experienced some difficulties navigating the PCoP. For those participants (MC1) who were more actively engaged, the role of the facilitator was less crucial in facilitating interaction.

There was a degree of ambivalence about the requirement for face-to-face introductions prior to online engagement. However, due to its importance for some participants (MC1 in particular) the principle still applies for this project. In a community of learners with larger numbers, prior face-to-face meetings might not be possible and, following the comments of PC, the construction of social presence (and subsequent knowledge construction) could develop using purely online modes of communication.

The interaction in the fourth iteration was more evenly spread than in the first and third iterations and discussions occurred across a range of activities including one authentic learning activity (the 'diets' activity). The value of the 'diets' activity was clearly articulated by MC1 but other participants did not provide a view on either of the authentic learning activities. All the participants, however, did value the knowledge and information they were able to gain from links to T2DM resources that were provided. The spread of interest in the

various activities indicated a group comprising individuals willing to share experiences around particular dimensions of 'illness work' as well as those who were more comfortable in taking a more passive role.

The learning design principles associated with the fourth iteration of the PCoP are presented below (Table 6-31). Although the principles are similar to the principles associated with the third iteration, there is one major addition. It was clear from the analysis of the post-use interviews from the third and fourth groups that an event-based learning activity would be useful for those with busy personal and professional lives. The often negative effects (particularly in terms of restricted time frames) of contextual barriers to participation could be mitigated by synchronous, event-based learning. In the next iteration of the PCoP, the affordances of synchronous and asynchronous tools would help to promote an environment in which participants could reflect on their experiences as well as to share information and experiences in real-time.

**Table 6-31.Learning design principles from the use of the PCoP by the fourth group**

1. **Tools must be kept simple and kept to a minimum** *in order to ensure navigational familiarity and consistency.*

The development of a consistent interface was considered to be more important than the introduction of tools that *prima facie* were easier to use. This was particularly true with the third group because the introduction of tools that, on the surface, seemed easier to use complicated the tasks that participants were required to engage in.

Interface design, however, is clearly not the only factor that determines the successful use of technologies for learning (Hong, Tai, Hwang, Kuo, & Chen, 2017) and this project demonstrates that other factors such as alignment between participant expectations and

pedagogical intent and face-to-face communication prior to online interaction were also factors in determining a participant's engagement in the learning community.

2. **Event-based and synchronous learning can help to promote participation** *especially for those with very constrained schedules.*

The design of an asynchronous forum in which the goal is continued and sustained participation was difficult to achieve and the forums in the first, third and fourth iterations represent examples of this difficulty. The combination of asynchronous forums and the external 'load' of busy personal and professionals contributed to disembodied online experiences and feelings of being in a 'one-man band'. The analysis of the post-use interviews in the third and fourth iterations provided evidence of these types of experiences. This does not mean, however, that asynchronous discussion forums do not have a place in the context of health-based learning (Smedley & Coulson, 2017) and other formal educational settings (Verenikina, Jones, & Delahunty, 2017).

Event-based, synchronous learning has the capacity to counteract this by enabling participants to structure their time in such a way so as to be available at certain times. This approach to learning design, therefore, might mitigate the 'load' factors that can contribute to sub-optimal opportunities for engaging in activities that lie outside the daily activities that characterise busy personal and professional lives.

3. **Learning designs need to be simple and** *authentic learning activities need to provide a focus around 'illness' work.*

Learning designs based on authentic activities in a non-formal context can provide a focus for participants to share their experiences (Andersson & Andersson, 2005). The designs must be simple to encourage participation and engagement and this is especially true for participants

with a range of experiences with online learning. Additionally, learning designs need to provide a focus on 'illness' work because these activities are more likely to engage potential learners.

4. **The role of the facilitator and moderator is crucial in providing focus and the ongoing development of social and cognitive presence**.

The role of the facilitator was important in the first, third and fourth iterations and, in a nascent CoP, the facilitator has an important role in the facilitation of discussions (Smedley & Coulson, 2017)

5. **Promotion of social interaction through face-to-face contact prior to online participation is important** *but not essential.*

Disembodied experiences are often characteristic of online social exchanges (Tian, 2017) but online interaction can also exhibit what Goffman, referred to in Tian, calls 'cognitive recognition' (Tian, 2017). The interpretation of the interview data did not conclusively demonstrate participants preferred an embodied interactive experience (i.e. face-to-face) prior to the participating online or whether 'cognitive recognition' through online interaction was sufficient. There was, however, enough evidence from the post-use interviews to suggest that face-to-face contact played an important role in creating an initial level of social presence that was later leveraged in group interaction leading to sharing of knowledge (e.g. the fitbit© discussion). The value of face-to-face interaction prior to online communication is clearly an area of research that requires more attention (Okdie, Guadagno, Bernieri, Geers, & McLarney-Vesotski, 2011).

***An activity theory view.*** This is an activity theory view (Figure 6-17) of the learning design principles outlined in the table.
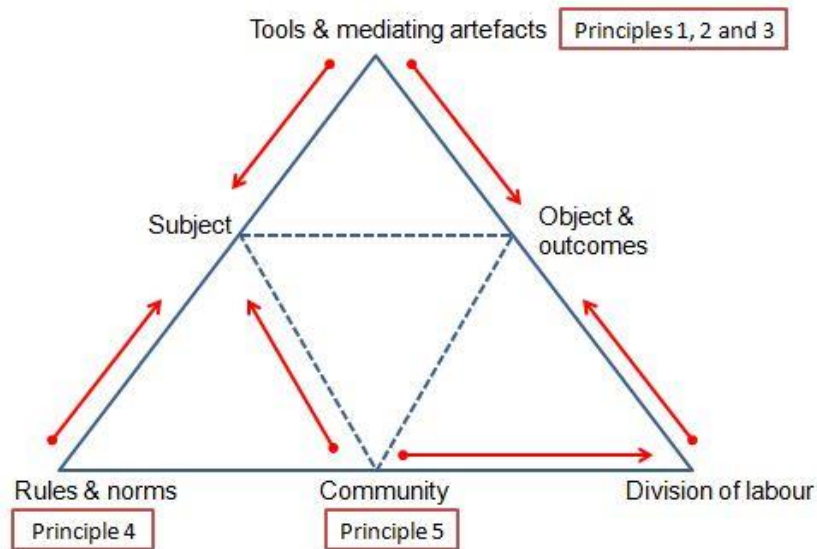


**Figure 6-17. AT model of learning design principles from the use of the PCoP by the fourth group**

The relationships between the different activity theory parameters suggested by the table are similar to the relationships associated with the learning design principles for the third phase. Since learning activities represent *tools and artefacts*, this model indicates that learning activities (principles two and three) and the interface or platform through which activities were delivered (principle one) can have an effect on the nature of participation (*subjects*). As with the third phase, the moderator's and facilitator's role (*community*) had an effect on the level of participation as did the requirement that participants meet face-to-face before online participation (*rules and norms*). Taken together, the elements that constitute this model can potentially contribute to the level of knowledge sharing (*division of labour*) required for the intended outcomes of a future iteration of this project.

***Summary of results.*** This was a group of four participants. A face-to-face meeting and interview was held prior to participating in the PCoP and the period of participation occurred over an eight-week period.

The level and quality of interaction in this group was significantly higher compared to groups one and three. Experiences and instrumental knowledge (diets, lifestyle practices) were shared through the learning activities and knowledge and information was acquired through the provided links to T2DM. The interaction was also underpinned by a high level of social interaction which created a cohesion that was lacking in previous groups.

Three types of learning in the PCoP associated with transformative learning were in evidence – instrumental learning (fitibit© discussion), dialogic learning (PCoP as a means of communication and sharing of ideas) and self-reflection (private diaries). These three types of learning emerged from participation in the PCoP and at least one of them (instrumental learning) emerged as an example of 'learning through meaning transformation' as a discussion was generated which indicated the value of using tools (fitbit©) to socialise the experience of physical activity. Additionally, one participant (NH) valued his participation in the PCoP because it highlighted the value of sharing ideas and experiences with others. This is a further example of 'learning through meaning transformation' because the participant could view an online PCoP as a tool in the practice of his self-management. Self-management, for this participant, is no longer conceived as an individual activity but as social activity.

As with the third group, the post-use interviews revealed an interest in the adoption of a synchronous model of learning. In subsequent iterations of the learning environment an event-based, synchronous learning activity could be added to the design of the system to

address the time constraints and mitigate the external load factors experienced by adult

learners.

## Summary

This chapter reports on the third and fourth design-based research phases represented in

Figure 6-18 below, namely, the iterative cycles of testing and refinement of solutions in

practice (phase three) and reflection to produce final 'design principles' and enhance solution

implementation (phase four).
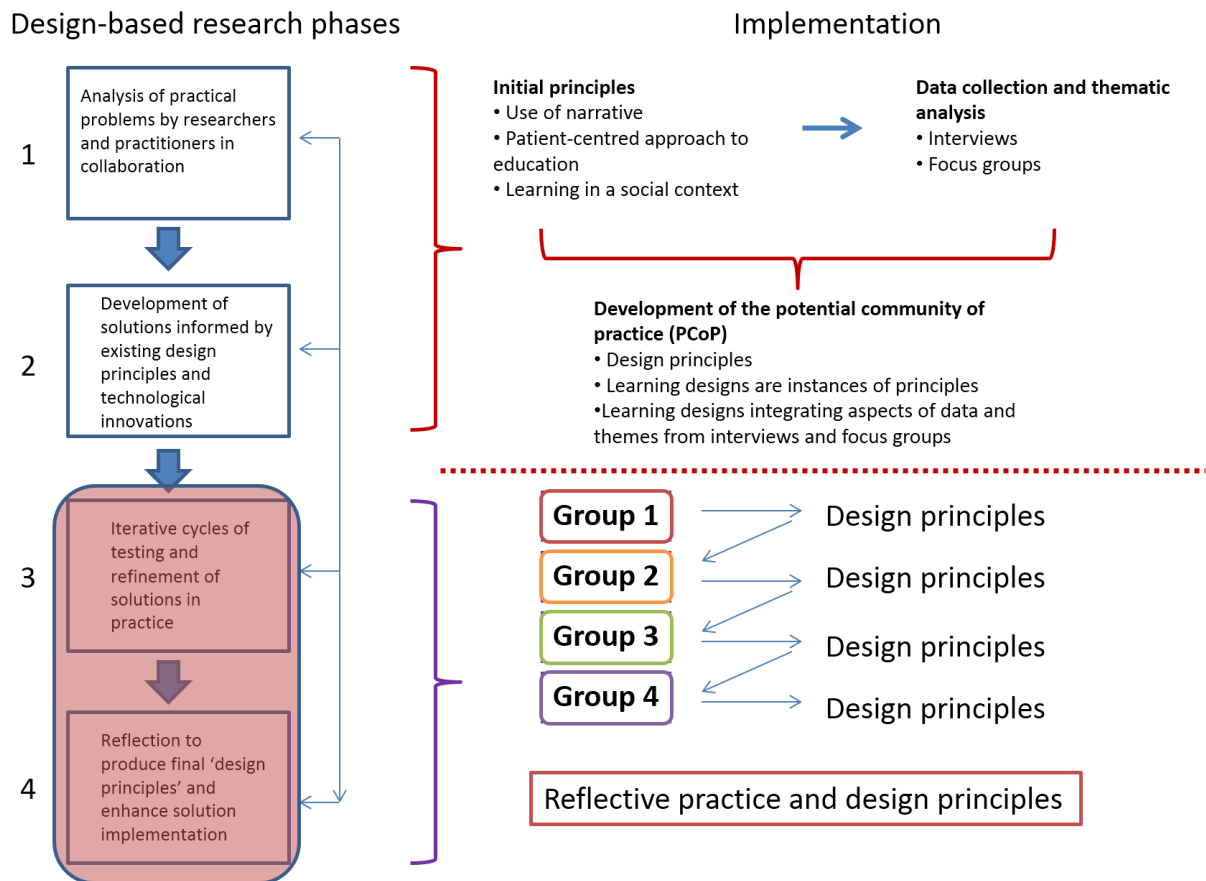


**Figure 6-18. An outline of the design-based research phases**

Four groups constituted the third phase in which the PCoP was iteratively tested in practice.

For each iteration, design principles were outlined and these principles were based on an

analysis of the pre-use interviews, engagement with the PCoP, usage data and post-use

interviews. Since there is no theoretical end-point of any DBR study, a decision was made to end the study at the fourth iteration because a recurring set of learning design principles had become to be established. Additionally, a new principle (principle two) had emerged after the fourth iteration and this would have entailed the introduction of a new learning design together with a new tool as well as the possible use of health professionals in a synchronous learning activity. This would have signalled a shift in emphasis from a patient-centred community to one based on a mix of patient and health professional voices and perspectives. This would have required a different set of theoretical assumptions about the nature of the learning environment as a patient-centred environment for sharing knowledge and experiences.

For the first iteration of four participants, the initial set of learning design principles were outlined in chapter five. The underlying assumptions of these principles were based on the following ideas about the nature of adult learning:

1.  Learning is situated and contextual (Brown et al., 1989) and results from social interaction (Lave & Wenger, 1991; Wenger, 1998).

2.  Online social interaction can be implemented using asynchronous discussion forums (Verenikina et al., 2017).

3.  Authentic learning activities are the foundation of learning environments that aim to engage participants in learning that has real-world utility (Herrington et al., 2013).

"Knowledge" as Brown, Collins and Duguid argue is "fundamentally 'situated,' being in part a product of the activity, context and culture in which it is developed." (Brown et al., 1989, p. 1). The knowledge and experiences that were elicited from the individual interviews, focus groups and interviews/information gathered from participants in four of the groups, were examples of the situated nature of learning that takes place during the course of having a

chronic illness. The social nature of the learning process is a well-established tradition in learning theory (Daniels, 2016) and social interaction is viewed as a process that produces learning as well as functioning as a pedagogical principle that informs the design of learning activities (Verenikina et al., 2017). In this project, asynchronous discussion forums were adopted as the tool in the development of interactive learning activities.

The characteristics of the learning activities were informed by the knowledge and experiences that resulted from the interpretation of the data from the initial interviews/focus groups as well as the subsequent interviews with participants who engaged in the learning environment. The theoretical sources and the empirical interview data were the sources for the development of the first iteration of the learning environment.

In the first group, the relative absence of active participation resulted in a disembodied online experience for participants and this contributed to a lack of sustained and active engagement. The absence of sustained and ongoing interaction meant that the intended outcomes of transformative learning were only partially met. In addition to their thoughts on interaction, participants also reported on the complex nature of the interface although the learning activities and material were well received.

The reasons for the nature of interaction as it took place in the first group were two-fold. Employment patterns (example of an external load factor) severely constrained the capacity for engagement for one participant and the analysis of post-use interview data revealed that the number of activities together with the complex interface of some of the tools functioned as barriers for participation. The learning design principles, therefore, reflected these concerns and an emphasis on the development of a simpler interface with fewer activities was the focus for the next iteration. The requirement for participants to meet face-to-face to foster a greater sense of social cohesion in the PCoP was also put in place.

Since the second group did not end up taking place, the principles and the PCoP that were developed for the second group were put in place for the third iteration.

The third iteration comprised three participants in addition to those who wished to participate from the first group. Personal and professional issues constrained the capacity for all individuals to participate in a sustained manner and the complexity of the interface, for one participant, was a barrier. Although there was a level of passive participation (measured by the number of page views) to suggest interest in the PCoP, the relative lack of active participation resulted in partial realisation of the intended transformational learning outcomes. The learning design principles were similar to those in the first group with an emphasis on simple, authentic learning designs and the requirement to meet face-to-face before online participation.

The last iteration was, in many ways, the most successful. The analysis of the group's activity was based on the same sources of data used for the first and third iterations. Although all participants were subject to personal and professional pressures, the level of passive and active participation in this group was significantly higher compared to groups one and three. There was evidence of sharing of knowledge at the level of instrumental knowledge and a well-developed level of social cohesion in the group. In addition, the learning activities and learning materials were appreciated for the value that they provided. The professional composition of the group may have contributed to its success because two of the participants were teachers or ex-teachers and one of these participants drew explicit parallels between her school-based blogs and the nature of the discussion forums in the PCoP. An understanding of the *theory* of knowledge construction, therefore, contributed to the *practice* of knowledge construction.

Several transformative learning dimensions were realised during the online interaction and the post-use interviews. Three examples of 'learning through meaning transformation' were generated through the use and participation in the PCoP and the post-use interview yielded another example of this learning process as participants questioned the asynchronous nature of the learning model that was adopted. Across the instrumental and self-reflective types of learning, a move from viewing self-management as an individual activity to a social and collaborative activity was in evidence. This represents a significant transformative learning outcome.

Although the learning design principles associated with the last iteration were similar to the principles for the first and third iterations, there was one significant difference. There was the suggestion in the third group that a synchronous learning model might be more successful than the asynchronous approach that was adopted. This theme was reiterated in the fourth group with the suggestion of a synchronous event-based learning activity in which health professionals would be available at a specified time and date. The implementation of this idea would have represented the adoption of a significantly different approach and this would lie outside the scope of the parameters of the present study.

# Chapter 7. Discussion

In chapter six, the iterative cycle of refining the learning environment (phase three of the DBR process) was described and final design principles (phase four of the DBR process) based on this iterative cycle were proposed.

This chapter has several objectives. The first will be to outline some of the limitations of the design of the study. The second will be to provide a broader interpretive scope to the results and to provide some critical reflections on the objectives of the study. The third will consider some future avenues of research and ways that the findings in the present study may be extended and consolidated.

## A patient-based community of practice

T2DM is a complex illness requiring a combination of a variety of health services to address its various dimensions. These include the services of educators, allied health providers, GPs and specialists. In the large and unwieldy bureaucracy of health service provision, however, the concerns of the patient or the 'patient voice' can sometimes be overlooked. These concerns can take various forms and, in the classic work of Corbin and Strauss (1985), they are identified as 'three lines of work', that is, 'illness', 'daily' and 'biographical' work. In this study, another 'line of work' – online learning in the context of T2DM – was explored and examined.

The aims of the study were to examine

- how an online Community of Practice for people with T2DM could be established and;
- if participation in this community might foster transformative learning.

To address these aims, a DBR approach was adopted and the phases associated with this chosen methodology were followed. In chapters four and five, an analysis of the real-world challenges faced by people with T2DM was carried out (phase one) leading to a set of initial learning design principles (phase two). These principles were used to develop a potential community of practice and engagement with this community by three groups (phase three), via an interpretation of a range of data sources, and this led to a final set of learning design principles (phase four).

## The patient voice

T2DM is a complex illness because it raises significant challenges for those working to understand the nature of the pathophysiology of T2DM and for healthcare practitioners working in T2DM management.  Due to the 'lifestyle' nature of the illness, the traditional hierarchy between the physician and patient is also being challenged as patients are required to become increasingly more responsible for the management of their illness. This shift towards self-management is likely to continue, particularly in the context of chronic illnesses such as T2DM and this will, in turn, continue to affect the learning needs and requirements of patients as they come to terms with the complex management requirements of T2DM. Learning, therefore, will continue to play a crucial role in the management landscape of T2DM.  Exactly what shape an approach to learning might take is the subject of this project and the following propositions underpin the approach that was taken in this study.

> 1. In the context of T2DM, patients are at the centre of the learning experience.

> 2. Patients are a community of learners but peer-to-peer learning is under-utilised as an approach to learning.

3. The affordances of online technologies can be leveraged to support patient peer-to-peer learning in the creation of an online learning environment that is patient-centred – an online patient-centred community of learners.

The articulation of the patient voice in the context of a patient-centred learning environment was, therefore, the principle reason for conducting this study. The research questions that form the foundation of this project are an extension of these three positions because they ask how such a community might be set up and whether the type of learning reflected in an online patient-based community of practice can be, or is, transformative in nature.

## The learning context: lifelong learning and health

The PCoP that constituted the unit of analysis in the second part (phases three and four) of the study is a tool for learning that was designed to address the self-management and learning challenges faced by the participants. As such, it should be viewed as one tool among many used by each one of the participants during their paths of lifelong learning. During this trajectory, adult learning can take three forms: formal learning, non-formal learning and informal learning (Boeren, 2011). Formal learning is associated with intentional learning (and design) in an institution which leads to some sort of qualification and this can span from primary school through to tertiary education (Eraut, 2000; Marsick & Watkins, 2015; Mocker & Spear, 1982). Non-formal education is intentional learning that takes place outside of the formal environment. Examples include adult literacy courses or the development of skills in a community setting. Although informal learning can take place within a formal or non-formal environment (Marsick et al., 1999) the definition of Schugurensky's (2000) is instructive because it highlights the fact that informal learning takes place outside of the *curricula* provided by formal and non-formal learning environments.

The learning that took place during this study is clearly not an example of learning that took place in a formal learning environment. According to Schugurensky (2000), the key difference between non-formal and informal learning is the involvement of a facilitator or educator in the learning process. Informal learning, he argues, is defined by the absence of a facilitator whereas a facilitator or educator is likely to be involved in the direction of events in a non-formal learning environment. Others contend, however, that informal learning can benefit from a degree of facilitation (Marsick & Watkins, 2001). A working definition of either of these two forms of learning is likely to incorporate elements from either form but the organised nature of this study indicates that the study falls under the category of non-formal learning as opposed to informal learning. This study, therefore, represents an example of non-formal learning but with aspects of informal learning such as self-directed learning in a social environment combined with a degree of facilitation.

One of the challenges of this project has, therefore, been the alignment of the methodological framework that was used in the design and iterative cycles of the project with the goals of a non-formal learning environment – in our case, an online PCoP for people with T2DM. The implementation of a design-based research approach in a non-formal learning environment suggests that non-formal online learning environments in the domain of chronic illness could benefit from the framework used in this research. There might also be opportunities to apply this framework to other non-formal learning areas.

## Limitations and delimitations of the study

According to Leedy (2013), research studies are subject to two types of limitations. The first are limitations that are objective in nature and refer to those factors that are outside of the researcher's control such as the number of participants that result from the recruitment process. The other type of limitation is known as a delimitation and relates to factors that

define the boundaries of the study that have been set and these include the research questions, theoretical perspectives, methodological approaches and the features of the population that are considered to be of interest.

**The exploratory nature of the research.**    In terms of delimitations associated with the population under investigation, although the description of socio-demographic attributes, age and gender or educational levels (Diep, Cocquyt, Zhu, & Vanwing, 2016) were important for the interpretation of the individual and group interviews, the focus of the study was not on the analysis of the predictive nature of any one of these variables on participation in the learning environment. The objective was explorative in nature in which a range of factors such as the interface, social context of participants and the nature of online participation, informed by the framework of AT, were the essential elements under review. As such, the participants in the study were not stratified according to characteristics such as gender, socioeconomic, ethnic or educational backgrounds even though these represent common factors for analysis of patients, for example in sociological studies on illness experiences (Pierret, 2003). The age of participants, however, was included although a recent examination of typologies of internet users in Australia (Borg & Smith, 2018) suggests that for a particular type of user (instrumental user), there is not a marked difference between the numbers of these types of users between the ages of 18 and 65 although for people over 65 the numbers did decrease significantly.

Further possible variables for stratification include personal lifestyle characteristics, health status and duration of T2DM, resources, environmental characteristics and the health care system (Schulman-Green et al., 2016).

In a further study, an exploration of any one of these factors or characteristics might illustrate the various dimensions of illness experiences.

Chapter 7. Discussion

**Design-based research and the question of thematic saturation.** DBR is a response to traditional experimental methods for the prediction and explanation of learning in classroom settings. Unlike traditional empirical approaches (Cotton, Lockyer, & Brickell, 2009), DBR is a method in which theory development occurs in-situ and insights gained during the process of theory development are iteratively fed back into educational interventions. The first phase of a DBR project will typically address a practical problem in an educational context and subsequently develop an initial solution which is characterised by research and insights elicited from a community of practitioners working in the field.

Due to the iterative nature of the DBR process, the choice of DBR to frame the process that resulted in the formulation of learning design principles, meant that interpretive findings from the iterative cycles were contextually bound. In the first phase of this project, individual interviews and focus groups were conducted to aid in the development of the learning designs. The objective of this phase was to broadly explore individual experiences (affective, cognitive/education and practical) and to use these experiences to build a semi-structured interview schedule for the focus groups. The thematic analysis conducted on the individual interviews did not, therefore, require a level of saturation that other studies require because the objective was not saturation (Mason, 2010) but rather a set of *initial* insights which could be used during the focus group stage. The range of initial insights could have been increased with an increased sample size (Crouch & McKenzie, 2006) but four individuals was considered sufficient in order to generate the initial set of thematic elements.

There were two principle objectives associated with conducting the focus groups. The first was to elicit insights into issues associated with educational support for people with T2DM and the second was the application of these insights, together with themes generated from the

individual interviews, to develop learning designs that could be used to form the first iteration of the PCoP. The process of achieving data saturation, therefore, should be seen as a chain of data events beginning with the individual interviews and ending with the fourth iteration of the DBR process. The focus group stage was one data element within the broader context of the project and did not represent a fully discrete stage of data collection and interpretation. The emphasis, therefore, was less on 'enumeration' to establish validity and more on establishing conceptual and interpretive clarity during the meaning making process (Crouch & McKenzie, 2006).

**The question of sample size and validity of findings.** Sample size, as it relates to focus groups, is often invoked to establish the validity of findings that result from the interpretation of focus group data. However, this does mean that the relationship between focus group sample size and the subsequent establishment of validity is an exact science. Although the concept of data saturation (Onwuegbuzie et al., 2009) is often applied to establish the point at which the iterative process of data collection and interpretation ends, this does not mean that saturation is the only method that can be used to determine the required number of focus groups to meet the aims of the research. Establishment of validity through the focus group process can also depend on the complexity of the research question (Carlsen & Glenton, 2011) as well as the research design (Fusch & Ness, 2015). Individual interviews and focus groups can also be combined to collect data and this method can be used in the process of the establishment of data saturation (Fusch & Ness, 2015).

## Methodologies and theoretical perspectives

**Design-based research – is there an optimal time to stop refining and evaluating?** DBR is an approach that combines the development of theory in the

context of pursuing practical objectives in an educational context. Theory development takes the form of learning design principles that have emerged from the interpretation of the data associated with the iterative design cycles coupled with an analysis and synthesis of relevant literature. One of the issues with DBR, however, is that since theory development is linked to the iterative design cycle, it is difficult to determine the point at which a DBR project should come to an end (Anderson & Shattuck, 2012). The fact that it is difficult to pre-determine the end-point of a DBR project is also a function of the nature of DBR. Since DBR is essentially a philosophical approach to the introduction of learning designs in real-life contexts, it is the method of analysis (in our case, thematic analysis) coupled with the subsequent interpretation of data that will determine the point at which it makes sense to end the intervention and analysis of the project data. There are also practical considerations that will constrain the ongoing nature of a DBR project such as the ongoing capacity for recruitment of participants in addition to budget-related issues (Anderson & Shattuck, 2012). The latter reflects a potential limitation of any research project.

In the context of the present study, decisions needed to be made regarding the point at which DBR phases one and two (see Figure 7-1) could constitute discrete phases. In this study, phases one and two represented the combination of issues arising from the literature and analyses of the individual and group focus data. Although more individual interviews and focus groups could have been conducted, it was felt there were significant alignments between themes emerging from the literature with regards to the self-management of T2DM and the fractured experiences of post-diagnosis care to suggest that the development of learning designs for the PCoP could be justified.

# Chapter 7. Discussion

During phase three, four iterations of the PCoP were analysed. The fourth iteration was the last one in which participants engaged. A decision was made to end the study at this point because a significant theme had emerged from the analysis of the data that would have required a change in the philosophical approach that was initially adopted and this would have led to subsequent practical issues to contend with such as the recruitment of external T2DM experts to conduct 'event-based' synchronous sessions.  The characteristics of the PCoP would have changed from being purely patient-based to a combination of patient and expert input and the mix of modes of communication would have been both synchronous and asynchronous. The latter would have been trivial to implement but the combination of patient and expert voices would have significantly altered the pedagogical and technological shape of future iterations of the PCoP. Hence, an 'event-based' approach was not adopted and the fourth iteration became the last iteration. Any future iterations of this study, however, will be free to incorporate these ideas in a subsequent iteration of the learning environment.

Design-based research phases        Implementation
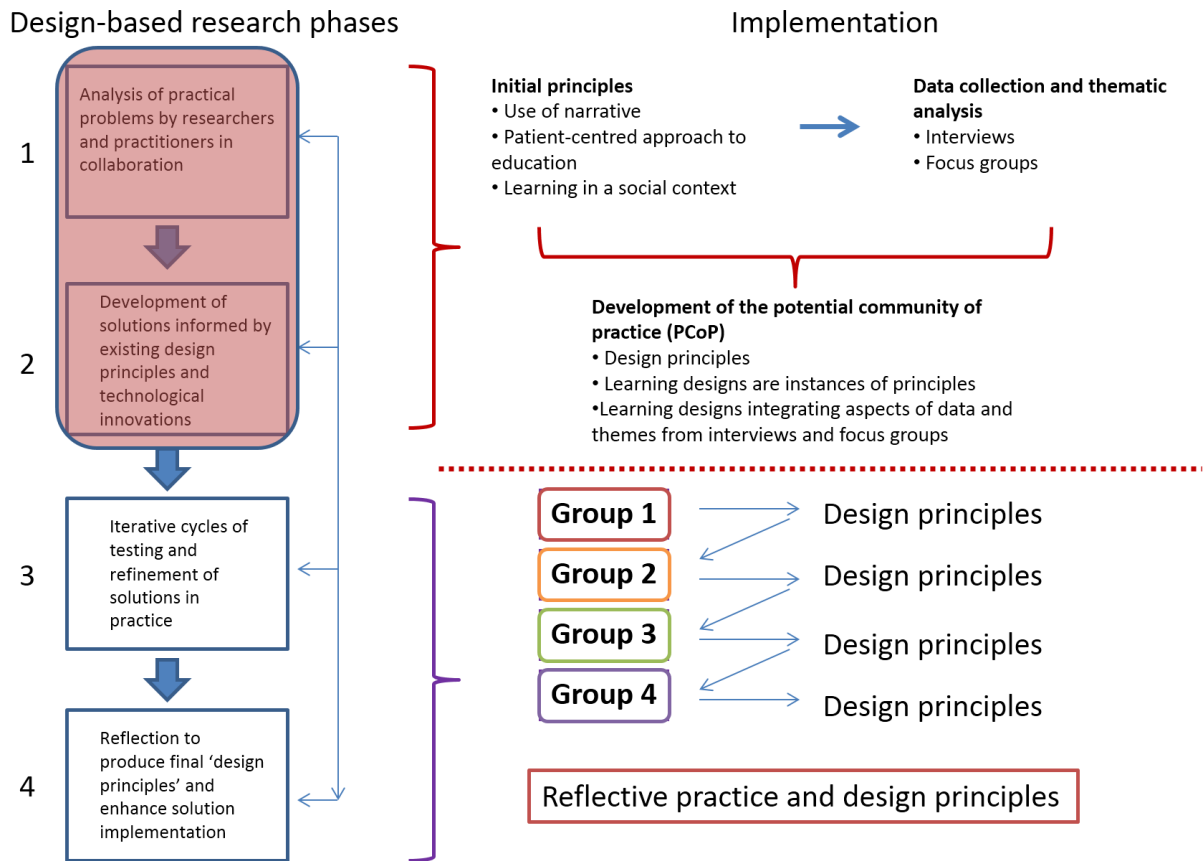


**Figure 7-1. Description of the design-based research cycles of the study**

## Transformative learning and patient-centred learning

There are two central characteristics of transformative learning that have persisted through its various iterations (Kitchenham, 2008). The first is the idea of the experience of a 'disorienting dilemma' (Mezirow, 2000) and the second is the idea of critical reflection in which learners use new 'frames of reference' and 'meaning perspectives' through which perspective transformations and re-interpretations of the world take place. Transformative learning, therefore, would seem like an ideal theoretical framework for the development of a patient-centred learning environment because it places the patient's experience at the centre of the learning process. The healthcare system, on the other hand, because it deals with a large number of patients mediated through highly complex administrative systems, often lacks the capacity and resources to address individual concerns and issues and therefore

misses opportunities to engage in learning that is anything other than purely instrumental, prescriptive and didactic (Philipi, 2010). As can be seen from the various interviews conducted in this study, this type of teaching or educational approach is unlikely to engage learners in discussions about their own needs and contexts and therefore will be valued less than learning that is engaging and based on an individual's experiences. Transformative learning, on the other hand, provides a theoretical framework with which to develop a patient-centred approach to learning and provides an opportunity for

> "…patients [to] realize that the power for many health outcomes resides in themselves and not in their relationship with their provider" (Philipi, 2010, p. 46).

Transformative learning theory, however, is not without its critics (Newman, 2012). Newman suggests that transformative learning should be viewed as nothing other than 'good learning' and that the distinction between instrumental and higher-order learning in which new frames of references are engaged to interpret the world with different lenses, is not as distinct as Mezirow contends. This criticism, in fact, is borne out during the fourth iteration of the PCoP where instrumental learning about fitbits© became a valuable point of discussion for participants and led to one participant taking up the opportunity to use the device in his daily self-management. The higher order modes of learning (critical reflection), therefore, should not be viewed as a superior form of learning. Both types of learning (see Figure 7-2) can contribute to ongoing discourse and this should be viewed as a positive outcome. Transformative learning outcomes that are instrumental in nature, therefore, can contribute to shifts in frames of reference. An example of this occurred with the fourth group's participation in which physical activity was discussed as constituting both social and individual elements and this contributed to frame of reference about physical activity that included both individual and social dimensions.
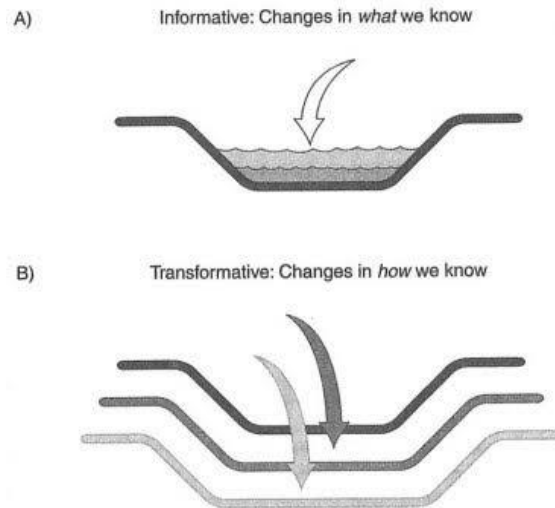
**Figure 7-2. A diagram representing the differences between levels of transformative learning (Kegan, 2000)**

Other critics point to a lack of critical reflection concerning some of the key assumptions of transformative learning such as whether transformation should be viewed as an inherently positive outcome (Taylor & Cranton, 2013) and Mezirow's lack of attention to power relations (Taylor & Snyder, 2012). One criticism that is particularly relevant to the current study concerns what Mezirow calls the 'ideal conditions of discourse' that are central to the process of transformative learning. Mezirow says:

> "Effective discourse depends on how well the educator can create a situation in which those participating have full information; are free from coercion; have equal opportunity to assume the various roles of discourse (to advance beliefs, challenge, defend, explain, assess evidence, and judge arguments); become critically reflective of assumptions; are empathic and open to other perspectives; are willing to listen and to search for common ground or a synthesis of different points of view; and can make a tentative best judgment to guide action. These ideal conditions of discourse are also ideal conditions of adult learning and of education" (Mezirow, 1997, p. 10)

Some of these conditions have been criticised. Why, Newman (2012) asks, should we be empathic to perspectives that are underpinned by bigotry or prejudice and why is consensus necessarily an objective to be pursued if the ideas underpinning the consensus are inimical to social equity? These are valid criticisms but the present study suggests that an ideal condition of discourse should also include the mode of communication through which discourse is mediated. In our case, this means including the several layers of technology that were used in the study such as the LMS, the tools in the LMS, Twitter© and iPad© hardware and, as has been documented in this study, there were significantly different individual capacities related to the use of these technologies.

**The optimal conditions for learning in an online setting.** The field of conversation ethics in online settings (Luppicini, 2009) provides one framework for how the ideal conditions for online discourse might be satisfied. Luppicini suggests that "…successful online learning communities are viewed as learning conversation systems where meaning emerges from conversation flowing freely between participants" (Luppicini, 2009, p. 102). In this model, several principles (e.g. truthfulness, clarity and relevance) which constitute this framework are proposed but they are related to the characteristics of dialogue rather than consisting of external factors that might have an impact on how conversation flows between participants in an online setting. What can this framework add to the question of optimal conditions for learning in an online setting?In this study, we have seen that external 'load' factors, pedagogical intentions built into the learning activities and capacity to navigate the interface were important dimensions in the engagement with the learning environment. For example, in terms of the usability of an interface, a tool that one person finds easy to interact with might pose problems for someone else and this variability was evident in participants' use of the learning environment. It would be difficult, therefore, to establish a universally acceptable interface because factors such as economic, cultural and technological levels of

capital interact in such a way as to produce users with highly variable levels of access and engagement with technological tools (Selwyn, 2002). If self-efficacy and capacity with self-management are further factors, then this adds further complexity to the development of a patient-centred online environment. This suggests that a conversational framework primarily focussed on the attributes of dialogue between participants may not provide a sufficiently powerful lens for the development of a framework that seeks to define ideal conditions of online discourse.  It would seem, therefore, that it is necessary to broaden the definition of the elements that constitute the optimal conditions for learning in an online setting due to the array of factors that constitute engagement with digital tools. This study contributes to this question because several design principles were proposed that emerged from the iterative process of evaluation of the learning environment. These principles could be viewed as the first step towards the development of a set of conditions for online learning in the context of learning and T2DM.

## Activity theory and the representation of complexity

Healthcare systems are vast organisations in which complex interactions of knowledge and practice are enacted daily. In these systems, individuals and units of organisation work towards goals and sometimes these goals are complementary and sometimes they are contested. In the language of AT, contested 'objects of activity' are called contradictions or tensions and these contradictions have been analysed in various healthcare contexts (Engeström, 2001; Greig, Entwistle, & Beech, 2012). AT has also been used as an evaluative tool in the context of education such as the professional development of teachers (Yamagata-Lynch & Haudenschild, 2009), evaluation of technology (Rybacki, 2009; Scanlon & Issroff, 2005), social media (Rambe, 2012) and community-based adult learning (Mukute & Lotz-Sisitka, 2012). Also, there are examples of the use of AT in combination with complexity theory in an attempt to grasp the complexity of modern organisations affected by the

escalation of information and communications technologies such as the internet (Hasan, Kazluaskas, & Crawford, 2010). In patient learning, AT has been used as a tool to articulate the complex implicit and explicit relationships in the development of patient-centred learning designs (Schaffer, Reyes, Kim, & Collins, 2010). In this study, AT was used in two ways.

Firstly, it was used to develop a framework for the representation of a patient-centred learning environment. This framework enabled the representation of learning designs at the level of tools and mediating artefacts in addition to the relationships between learners, their health professionals and other members in the community. The constituent parts of a patient-based environment, therefore, include both the learning designs through which communication and discourse takes place in addition to the array of relationships that form a person's place in the community. This use of AT in the representation of complexity is outlined in Figure 7-3.
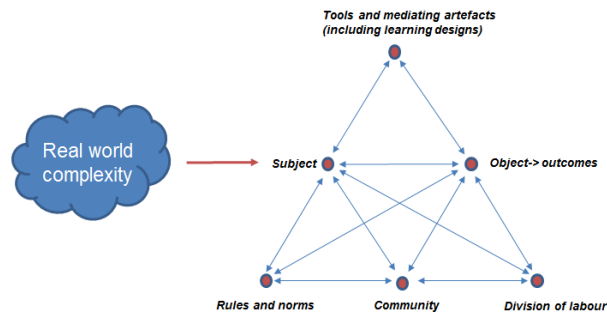


**Figure 7-3. AT and the representation of complexity**

Secondly, AT was used to provide an interpretive and conceptual framework (Nardi, 1996) for the analysis of each of the iterative stages during the DBR process. This enabled the tensions between the various parameters to be identified and for comparisons between the tensions in the various iterations to be made. For example, in the first and third groups, the division of labour between learners was minimal whereas in the fourth group the interaction between participants was substantially greater. Factors such as a greater familiarity with the

implicit rules of the PCoP (the value and role of knowledge sharing in the learning process) played a part in this increase.

Additionally, AT was used as a general framing theory throughout the analysis of all the interviews to ensure that the complexity of the relationship between learning, external factors (such as employment or personal matters) and relationships with health professionals was an ongoing factor in the analysis. For example, relationships with health professionals can sometimes act as a motivator for increasing levels of self-management (as was the case with the holistic care received by some participants in the focus groups) but they can also cause a degree of confusion especially during the early stages of the diagnosis of T2DM (as was the case with several participants). These experiences are likely to produce learners with varying levels of competence across a range of practice and knowledge domains.

AT, therefore, can be used as a tool to represent the complexity of a patient-based learning environment as well as an evaluative framework for the ongoing analysis of the use of a PCoP. It is a framework that shares similarities with a social theory of learning because, in the same way that cognition and context are co-determined in social learning theory, the parameters in AT (individual and social) are also co-determined. Furthermore, it is a model which recognises the products of social engagement (semiotic tools such as language and artefacts such as an LMS) as well as the social interactions that help produce the conditions for the emergence of such tools (Wenger, 2010).

In short, a complete model of an online patient-centred learning community benefits from marrying an understanding of the complexities of online patient-centred learning as a complex socio-technical system with a theory of learning that can describe and explain the type of learning that takes place in such an environment.

In this project, the community of practice model together with the theory of transformative learning was combined to form the learning theory component that underpinned the patient-centred PCoP.

## Communities of practice and transformative learning

**Was the learning community a community of practice?** We have seen how some participants felt like being involved in a 'one-man band' when engaging in the PCoP but the question that needs to be asked is whether this was a function of participation in an online T2DM-based learning community in general or whether there were specific characteristics of the learning environment and participants in this study that helped to create an environment lacking in significant levels of interaction.

The intention of phase three (iterative cycle of evaluation of the learning environment) of the study was to facilitate the formation of a community of practice. The community of practice model is part of the family of ideas associated with social and situated learning theory and provides both an explanatory framework for learning and an approach to the development of a learning environment (Hoadley, 2012). It is an explanatory model because it argues that knowledge results from the complex interplay between context and the individual. Knowledge (and subsequently meaning) should be seen as a property that emerges from this interplay (Hoadley, 2012; Hung, Looi, & Koh, 2004). This model, which is most often associated with the work of Lave and Wenger, also provides a descriptive and anthropological account of how this type of learning takes place in various organisational and cultural contexts (Lave & Wenger, 1991; Wenger, 1998).

According to Henri and Pudelko (2003), however, not all learning communities can be defined as communities of practice. As Henri and Pudelko put it, "All learning communities are not communities of practice; they undertake and participate in various activities which

promote various types of learning." (p.476). If this is the case, what are the defining characteristics of communities of practice? And what are the attributes of learning communities that are not defined as communities of practice? Was the learning community in this study a community of practice?

The reason why the learning community in this study was defined as a potential community of practice (PCoP) was that one of the aims of the research was to investigate how a community of practice could be established. To define the learning community as a community of practice prior to the final evaluation and analysis associated with the research process would have been to assume the presence of elements within the community that constitute its identify as a CoP.

According to Wenger-Trayner (2015), a community of practice is characterised by being a shared domain of interest in which knowledge, ideas and practice are shared and distributed in a community of practitioners. Wenger-Trayner call these three attributes domain, community and practice (Wenger-Trayner & Wenger-Trayner, 2015). Henri and Pudelko's definition (2003) of a community of practice shares similar characteristics with one major difference. They introduce the concept of 'learning and identity' as a defining parameter. This is outlined for three types of learning communities in Table 7-1. It is clear, however, that if we adopt Henri and Pudelko's model (2003), the learning community that was established shared similarities with what Henri and Pudelko have called a "learners' community" and a "community of interest" and not a community of practice. For example, groups one, three and four did not demonstrate 'explicit practices of identity construction' nor did they systematically engage in the construction of artefacts through collaborative communicative practices.

**Table 7-1. The characteristics of 'learning identity' in learning communities as identified by Henri and Pudelko (2003)**

| Learning and identity in a community of interest | • Value of participation in the community is personal rather than serving a collective goal.<br><br>• Knowledge sharing is not directed to the creation of collective artefacts.<br><br>• Lack of shared intentionality of community as a group. |
|---|---|
| Learning and identity in a learners' community | • The explicit goal of the community is to learn.<br><br>• Collective participation is the means through which learning takes place. |
| Learning and identity in a community of practice | • The existence of shared and common needs.<br><br>• Construction of artefacts though knowledge sharing.<br><br>• Explicit practices of identity construction. |

Although the type of learning community that emerged during the research process was not a community of practice, this does not mean that the goal of the establishment of a community of practice is not worth pursuing. The trend towards patient-centred health and the emphasis on self-management is likely to continue given the prevalence of lifestyle conditions such as T2DM. As a result, innovative methods of learning that aim to consolidate experiences of health and the role of learning in the modern healthcare system will continue to be relevant.

The community of practice model has the potential to facilitate the type of learning required in this context due to its stress on the role of enculturation in a community (legitimate peripheral participation), the construction of a sense of group identity (to counter feelings of patient alienation) and ongoing and sustained interaction that can result in learning that meets

the needs of the individuals in the community as well as continuing to sustain the goals of the learning community.

The abbreviation of PCoP, therefore, will continue to be used to define the unit of analysis associated with group participation in the learning environment.

**Was transformative learning achieved?**   As discussed in Chapters two and three, transformative learning represents a process in which instrumental learning and self-reflection combine to create the foundations through which "critical reflection on assumptions" (Mezirow, 1997) can begin to be made. As Mezirow says:

> "We transform our frames of reference through critical reflection on the assumptions upon which our interpretations, beliefs, and habits of mind or points of view are based. We can become critically reflective of the assumptions we or others make when we learn to solve problems instrumentally or when we are involved in communicative learning." (Mezirow, 1997, p. 7)

This synthesis between instrumental and communicative learning is important to note because it indicates that transformative learning can occur within the domain of instrumental knowledge in addition to more abstract domains in which assumptions, beliefs or values are questioned. In terms of participation in the PCoP, where there were greater levels of social interaction, dialogic learning (sharing experiences) was in evidence. The content of the online dialogues focussed mainly on instrumental knowledge (improving dietary planning and increasing levels of physical activity). Self-reflective learning (questioning assumptions) was not in evidence during any of the online interaction but it was present during the post-use interviews (the suggestion of synchronous learning models, for example) in addition to the focus group discussions in which the model of a patient-based community of practice was suggested (November focus group).

There is a case to be made therefore, that the PCoP functioned as a tool through which participants could reflect on their learning preferences and self-management practices. If transformative learning is viewed as a process that occurs across types of learning (instrumental, dialogic and self-reflective) then there was evidence in the post-use interviews that engagement in the PCoP provided a framework through which transformative learning was promoted. In AT terms, the interviews and participation in the PCoP could be conceived as tools for the promotion of reflection.

## Implications for the practice of learning design in the context of chronic illness and learning

The diagnosis of T2DM can have far-reaching psychological and pathophysiological consequences (Boyle, Saunders, & Drury, 2016). It is, in other words, a life-changing event and, for the participants in this study (individual interviewees and focus group and PCoP participants), the diagnosis triggered a range of responses from reflecting on the nature of the disease through to a change in lifestyle practices. These different responses reflect what it means to accommodate, integrate and reflect on change in one's life and, most importantly, incorporate all the various dimensions of what we mean by learning such as problem-solving, the practice of instrumental reasoning and critical reflection (Mezirow, 1990a). These aspects of learning are in evidence in formal, informal and non-formal learning contexts and are the learning practices that adults bring to bear to varying degrees during the course of their lifelong learning of which health-related learning is but one part.

Based on the typology suggested by Schugurensky (2000), this study is an example of non-formal learning. That is, it is learning that sits between formal learning (characterised by propaedeutic processes, formal assessments, classroom-based and a rigid institutional hierarchy) and informal learning which can still occur within institutions but is typically not

highly structured and which is often self-directed (Marsick & Watkins, 2001). Non-formal learning, on the other hand, is structured learning but takes place outside of formal educational institutions and is not contingent upon formal processes such as accreditation, assessment and the following of institutionally-sanctioned curricula. In the case of this study, the 'curriculum' was the set of learning activities developed using a combination of the interpretation of data from individual interviews and focus groups and the interpretation of patient experiences of T2DM from the literature (Broom & Whittaker, 2004; Bury, 1982; Lawton, Parry, et al., 2005; Peel, Parry, Douglas, & Lawton, 2004).

The appreciation of where this study sits in the formal/non-formal and informal learning spectrum is important because in a non-formal environment, learning design decisions need to be based on the needs of the learners and not on a set of activities divorced from authentic contexts. As Herrington says, "In everyday life, people solve problems and learn new and better ways to do things with the context, resources and means available to them...Authentic learning is based on such an approach." (Herrington, 2015, p. 61). The approach of authentic learning, therefore, recognises that there is a significant overlap between formal/non-formal and informal learning in people's daily lives. As Cameron and Harrison (2012) say:

> "We argue for a reframe from the focus on the differences between forms of learning to a focus on the connections, relationships and interrelatedness between these learning forms. We assert this will provide a much richer and fuller picture of the variables and contextual influences at play when individuals and groups engage in learning across a diverse range of learning spaces and across time. This reframe recognises the fluid and dynamic nature of the complex interplay that is learning." (p. 305)

The establishment of the interrelatedness of different forms of learning, therefore, is the first step towards the development of a multi-faceted evaluative lens which can capture the complexity of the interplay between the various individual contexts in a learning community. This kind of pluralistic framework can help improve our understanding of the nature of complex and diverse learning communities and help to highlight the reasons why some communities might be more successful than others. The fourth group, for example, displayed higher levels of participation and engagement than other groups and one of the reasons for this level of engagement could have been how individual contexts (two participants were teachers in group four) helped to contribute to an alignment between the pedagogical intentions of the learning design and the application of these intentions by participants in the learning community.

## The theoretical, methodological and practical contributions of the study

Edelson (2002) describes the two key goals of DBR. The first aligns with the DBR approach adopted in this study, namely, the development of an iteratively refined solution to a practical problem in an educational context. The second goal relates to the opportunity that a DBR approach provides for theory development based on the analysis of the processes that were undertaken to refine the final learning designs and their embodiment in a working system. Edelson (2002) describes three types of theories that design-based approaches can develop - domain theories, design frameworks and design methodology. I will use this framework to describe the theoretical and methodological contributions that this study has made.

A domain theory, as the term suggests, refers to the development of theory based on a process that is undertaken to address a problem in a particular domain. According to Edelson (2002), there are two types of domain theories: context theories and outcome theories. Context theories are characterised by analyses of contexts that are specific to the design challenge - in

the case of this study, the context theory is the need for patient-centred approaches to learning in the context of T2DM. Outcome theories, on the other hand, refer to a set of outcomes that result from an intervention. An outcome theory results from an evaluation of whether the desired outcomes were met. There were two desired outcomes in this study - the first was to establish whether an online community of practice could be established in the context of T2DM and the second was to evaluate whether the dimensions of transformative learning could be met in the community. The results from this study indicate that a community of practice was not established and that certain dimensions of the phases of transformative learning were in evidence. In subsequent iterations of this study, the desired outcomes could be evaluated against a revised practical artefact (i.e. a working PCoP) based on the learning design principles that resulted from the design-based process in this study. Edelson (2002) calls these principles 'design frameworks' and the development of the design framework in this study illustrates the contribution that this study has made to the design of online patient-centred learning environments in the context of T2DM.

A design framework, therefore, is a set of design guidelines that have been developed in a particular context. The framework is a practical artefact that can be used to drive the design of artefacts operating in similar contexts - in the case of this study, this might be in other areas of chronic illness. A design methodology, however, does not provide guidelines for the end product but is concerned with guidelines related to the process for the development of the practical solution. The following elements characterise the contribution that this study has made to the methodology of the development of an online patient-centred learning environment:

1. *The development of authentic learning activities*. This was achieved by conducting interviews and focus groups to elicit responses from participants about the experience of living with T2DM.

2. *The adoption of sociocultural theory to frame the conception of learning*. This is driven by the 'design conjecture' (Sandoval, 2004) that individuals in a community of participants are likely to benefit from other opinions, skills and knowledge in a community of learners with the same illness.

3. *The use of a design-based research approach to refine the solution to the development of an online PCoP*.

4. *The use of transformative learning theory to frame the desired outcomes*.

Taken together, these elements are significant because they provide future researchers working in the field with a methodological framework to pursue similar research in other areas of chronic illness or even in other areas of non-formal adult education. The adoption of this methodological approach can lead to the production of an enduring practical artefact (final design principles) and help to frame future theoretical work in sociocultural approaches to learning and chronic illness.

DBR is carried out in naturalistic contexts and this contrasts with psychological studies that are often undertaken in conditions that are highly regulated (Barab & Squire, 2004). The challenge of DBR is to characterise the complexity of naturalistic settings but at the same time to make theoretical advances in the field of learning that transcend the context of the study setting (Barab & Squire, 2004). Based on this understanding of the nature of theory development in the DBR tradition, what are the nature of the theoretical claims that can be made from this study?

1. *Effective communicative discourse in online settings is contingent on the interplay between the complex configurations of individual learner contexts*. This indicates that more research needs to be carried out in the field of transformative learning to characterise the features of optimal conditions for learning in online contexts.

2. *Online communities of practice can be designed as practical artefacts but their sustainability is contingent on frequent interaction among participants*. Further research is needed, therefore, that outlines the features of solutions that can maximise interactions. This might range from leveraging the affordances of software in a designed artefact through to a fuller understanding of the role of facilitators in a learning community.

3. *Sociocultural theory can be used as the theoretical framework to construct patient-centred online learning*. This is a significant theoretical contribution because it provides researchers with a guideline for the application of a theory-based approach to the development of online learning communities.

These theoretical contributions were derived from the local context of the present study. They are, however, broad enough to function as theories that can guide future work in health-based learning or even in other contexts in which learning is conceived of as a social activity.

## Implications for further research

**Longitudinal evaluation of the PCoP – another evaluative dimension**  A shared domain of interest is one of the attributes of a CoP (Wenger-Trayner & Wenger-Trayner, 2015). For each of the groups participating in the PCoP, this was the diagnosis of T2DM. During their engagement in the PCoP, participants engaged with each other in shared

tasks and the intention behind the learning design of these tasks was to promote interaction and discussion about a variety of self-management topics. Another feature of the identity of CoPs is that participants are practitioners within a community (Wenger-Trayner & Wenger-Trayner, 2015). In this study, each group could be defined as a community of practitioners because, as patients, they are experts in the practice of self-management and the 'three lines of work' (Corbin & Strauss, 1985) associated with chronic illness.

An outline of the definition of what constitutes a CoP helps to define the attributes of a CoP but does not, in and of itself, help to determine the success or otherwise of a CoP. We have seen that if transformative learning is viewed as a process rather than a particular set of end points (as in a formal learning context with learning outcomes and formal assessment thresholds), then the PCoP was successful in creating opportunities for participants to reflect on various aspects of their learning, attitudes and beliefs. An evaluative framework that incorporates a longitudinal dimension in which participants are able to reflect on the value of the CoP on their self-management practices would add to our understanding of the utility of a CoP as a tool in the ongoing process of self-management. This kind of longitudinal framework has been proposed by Wenger et al (Wenger, Trayner, & de Laat, 2011) and represents a framework based on the forms of value that can emerge from community interaction in a CoP.

**Table 7-2. Longitudinal evaluation of CoPs from Wenger, Trayner and de Laat (Wenger et al., 2011).**

**Cycle 1.** *Immediate value:* the activities and interactions between members have value in and of themselves

**Cycle 2.** *Potential value:* the activities and interactions of cycle 1 may not be realized immediately, but rather be saved up as knowledge capital whose value is in its potential to be

realized later.

**Cycle 3.** *Applied value:* knowledge capital may or may not be put into use. Leveraging capital requires adapting and applying it to a specific situation.

**Cycle 4.** *Realized value:* even applied new practices or tools are not enough. A change in practice does not necessarily lead to improved performance, so it is important to find out what effects the application of knowledge capital is having on the achievement of what matters to stakeholders.

**Cycle 5.** *Reframing value:* this happens when learning causes a reconsideration of how success is defined. It includes reframing strategies, goals and values.

Due to the nature of the evaluation strategy that was adopted in this study it would have been difficult to establish cycles three and four of the framework since this would have involved interviewing participants after they had had an opportunity to apply any knowledge or insights gained from community interaction in their lives. The interviews that took place after each of the group stages could only reasonably be used to establish the presence of value associated with the first two cycles. For example, there was value placed in the information contained in the online articles embedded in the PCoP and the discussion related to the fitbit© in the fourth group could have resulted in the transformation of potential value to applied value. The fifth cycle is very similar to Mezirow's ideas on 'reframing perspectives' and there was some evidence of this taking place particularly in YS's interview after her use of the learning environment and in one of the focus group discussions.

The adoption of a longitudinal framework (such as the one described in Table 7-2) to evaluate the value of the PCoP across the different longitudinal dimensions (applied, realized

and reframing) would allow these dimensions to be evaluated but this lies outside the scope of the present study.

**Was legitimate peripheral participation demonstrated in the PCoP?** One of the learning processes that forms part of the community practice model is the concept of legitimate peripheral participation (Lave & Wenger, 1991). The central idea is that communities are composed of experts and novices and that the movement from a novice to expert takes place through a process of enculturation. This movement from legitimate peripheral participation through to full participation in a community is not so much characterised by the acquisition of knowledge but by identity change as participants become full participants in a sociocultural practice related to a particular domain.

Due to the relatively small numbers in each of the groups, the process of legitimate peripheral participation was not able to be observed. This is unfortunate because the movement from a participant who is newly diagnosed with T2DM interacting with someone with experience in self-management would have added the parameter of identity change to the evaluation framework. The design for such a study would have required more participants per group and the duration of participation would have had to increase to promote ongoing and sustained interaction. The research question could then be directed towards an exploration of the relationship between transformative learning and identity change. How might, for example, a community of learners support participants through perspective changes and any subsequent changes in identity? This question would be of interest to those working in the broad area of non-formal adult education.

**What is the role of self-efficacy in the development of communities of practice?** The construct of self-efficacy for T2DM has been used to discuss the effectiveness of online interventions in the context of T2DM (Lorig et al., 2012; Lorig et al.,

2008). However, the number of participants was not sufficient to provide a statistically significant analysis of the effect of the PCoP on self-efficacy in T2DM. Rather, the self-efficacy results from the questionnaire were used as an additional (i.e. in combination with interview data from the focus groups) dimension to aid in the construction of individual contexts and as a tool to facilitate individual reflection on the capacity of participants to conduct tasks related to T2DM.

In a study with enough participants to conduct analyses that are statistically significant, the self-efficacy results could help to define the level of expertise in terms of 'illness work' of each participant and this could be used as a guide to compose the groups. For example, a group could be composed of participants with high (expert patients) and low (novice patients) self-efficacy scores. This would mean that the attributes of a novice or expert patient would be based on an individual's capacity to conduct self-management practices and not on the length that they have been diagnosed with T2DM. Several questions could then follow from this design such as: Does self-efficacy in novice patients improve in a community comprised of a mix of novice and expert patients? Do patients with lower self-efficacy contribute less and interact less in a community of learners? And at what point does the interaction increase? What is the relationship between self-efficacy and the success or effectiveness of a community of learners? Obviously, these questions could not be addressed in the present study, but they could constitute an interesting direction for future research with a more expansive scope.

**Developing pedagogical patterns: learning design and chronic illness** One of the underlying themes of the theory of learning design is the idea of pedagogical patterns and the question of whether these patterns can be applied across different content domains. In science teaching, a classic pattern would be 'predict-observe-explain' (Kearney, Treagust,

Yeo, & Zadnik, 2001). The learning designs in this study could best be described as a cycle of 'practice-reflection-interaction' in which authentic learning activities are used as the tool through which this process takes place. Critical realism tells us that at the level of ontology, chronic illnesses are combinations of different physiological processes and for a practitioner in health sciences it may or may not be important to establish whether physiological patterns exist between different chronic illnesses. For an educator working at the epistemological level (in critical realist terms) and chronic disease, it is also an open question whether the application of a pedagogical pattern may be applicable to one or more chronic illnesses.

Since the focus of the study was on people with T2DM this necessarily excluded an exploration of other chronic illnesses such as chronic respiratory diseases, cancers, mental illnesses and cardiovascular diseases (Sav et al., 2015). In a future comparative study, the experiences of different illnesses could be examined and two separate online learning environments developed. A comparative analysis using a DBR approach could then be used to examine the differing requirements and experiences of the two sets of users. Such an analysis could then feed into a set of learning design principles for two sets of groups suffering from two different chronic illnesses.

The implementation and subsequent analysis of a pedagogical pattern such as the one used in this study across two or more chronic illnesses could, therefore, represent an avenue for further exploration.

**How important is the concept of the 'sick role'?** The interpretation of the individual and group-based interviews has shown that Parson's concept of the 'sick role' (Parsons, 1975) is no longer a useful concept for the exploration of people's experiences as patients with T2DM. This is not surprising because the concept has since been challenged as being inadequate to deal with the increasingly less hierarchical relationship between doctors

and patients that has been partially brought on by the increasingly important role of self-management in the context of chronic illness (Crossley, 1998; Varul, 2010). Additionally, the integration between the 'three lines of work' that was evident in the participants' lives provides further evidence that having an illness is only one dimension of an individual's life. Being sick, therefore, represents a set of transactions between oneself and health professionals that the concept of the 'sick role' no longer covers. With this in mind, Frank (2016) has proposed what he calls the 'narrative subject' (or the 'sociological self' to use Greenhalgh's (2009) terminology) to replace the 'sick role' in which the individual is defined by 'discursive possibilities' (Frank, 2016) and no longer required to play the 'sick role'.

The concept of the 'sick role', therefore, has become increasingly marginalised because it no longer adequately reflects the complexity of living with a chronic illness in which the requirements of self-management are becoming increasingly more challenging. The concept of the 'expert patient' in which patients take on a greater share of self-management has now tended to supplant the concept of the 'sick role' and has become an important part of healthcare systems in the Western world (Greenhalgh, 2009). The conceptualisation of the patient in this study could be said to fall under the banner of the model of the 'expert patient'.

The model is not without its critics. Some have argued that the model of the 'expert patient' fails to address the system-wide inequities that can have an impact on access to resources that can facilitate self-management (especially internet-based resources) (Fox, Ward, & O'Rourke, 2005) and that the model does not take into account the holistic (family and social histories and political context) nature of the individual (Greenhalgh, 2009). Even though the idea of the 'expert patient' is not without issues, the conception of the patient as an 'expert patient' was adopted in the development of this study i.e. a patient-based, non-formal online learning environment for people with T2DM.

Learning results from participation in social learning environments (Brown et al., 1989).
With this in mind, this study demonstrates that a patient-based online learning environment
has the potential to contribute to the care and management of people with T2DM because it
enabled individuals to share their experiences and practices with others. Even though there
was not a great deal of interaction and the objectives of transformative learning were only
partially realised, there was evidence to suggest that a patient-based system directed towards
meeting the learning needs of people with T2DM could be implemented.

In future research, a focus on 'illness experience' would continue to yield interesting results
about the complex relationship between patients and the set of networks that form the
'narrative subject' or 'sociological self'. Placing the 'narrative self' at the heart of an online
learning environment will help to establish a patient-centred approach and ongoing
commitment to the learning needs of people with T2DM.

## Summary

This chapter represents a reflection on the design and results of the study as well as providing
signposts on future areas of research. At the level of methodology, a DBR approach was a
useful framework for the iterative development and evaluation of the ongoing use of a PCoP.
The use of AT as a tool in the representation of complexity complemented the analysis of the
interview data because it highlighted the nature of the complex relationships between patients
and the social networks that constitute what it means to be a patient and the tools (online or
otherwise) that patients use in their self-management practices. The community of inquiry
model in the analysis of the 'presences' in the PCoP in combination with AT and DBR
constituted an evaluative framework that could be used in future studies of learning
communities in which highly complex relationships and mediating artefacts can be identified.

Chapter 7. Discussion

The community of practice model provided a useful approach to investigate the potential of patient self-education in a learning community but the idea of identity change associated with the longitudinal evaluation of a CoP was outside of the scope of the present study. Mezirow's theory of transformative learning was a useful framework to explore the characteristics of learning within the PCoP and AT helped to create an evaluative framework that was multi-dimensional. For example, we have seen how the tools in the PCoP functioned as significant barriers for some but for others it did not pose an obstacle. The fact that there was this variation among participants suggests that technology-mediated learning should be considered as one parameter in the design of the set of optimal conditions of learning. AT can provide the framework to represent the conditions of learning as a set of interrelated factors.

Finally, this study contributes to the ongoing debate about the role of the patient in the self-management of T2DM. Individual participants who engaged in this project were not conceptualised as participants playing a 'sick role'. Rather, there was the recognition that they were complex individuals leading lives that required a degree of re-calibration in the light of a diagnosis of T2DM. As such, the learning environment that was developed provided individuals with a space to share experiences, practices and ideas with others in the learning community. Shared learning environments, such as the one developed in this project, have a significant role to play in the self-management of people with T2DM because they provide an environment through which individuals are able to engage in shared discussions about the lived experience and practices of the self-management of T2DM.

# Chapter 8. Conclusion

Type 2 diabetes mellitus is a significant public health issue and it represents a significant challenge not only for patients with the illness but for health professionals (allied health, GPs and specialists) working to improve the health of the community. T2DM is often called a 'lifestyle disease' and although this might downplay the role of genetic factors that play a role in the aetiology of the illness, there is a universal consensus that the management of the disease requires patients to pay careful attention to diet and other lifestyle factors such as physical activity. Treatment options that are non-pharmacological in nature have, therefore, tended to concentrate on areas of patient behaviour that are modifiable such as the promotion of optimal nutritional and physical activity behaviours and on attenuating psychological barriers to behaviour change through an exploration of the role of constructs such as self-efficacy and the health beliefs model.

The psychological approach (e.g. self-efficacy or health beliefs model) shares a common interest in the fundamental objectives of this study because its interest lies in an exploration of human behaviour and this obviously intersects very broadly with learning and education. However, although the psychological approach has been examined it is not the only perspective to self-management and this study is an example of an alternative approach that utilises educational theory and practice in the development of a patient-centred approach to the development of an online learning environment.

A patient-centred approach refers to the understanding of the central role of the patient in the management of his or her condition. This is part of the 'self-management' turn that many in the health professions have adopted. Although self-management has been extensively researched in the domain of T2DM, most notably by Kate Lorig and her associates (Lorig et al., 2010; Lorig et al., 2012), the approach taken has typically been under-theorised at the

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level of the educational processes and learning designs that form the foundation of these 'interventions'. This is one major gap that this study explores through the development of a principled, theoretically informed and patient-centred learning environment.

Since traditional 'self-management' approaches often lack educational frameworks this means that the broader objectives associated with learning are relegated to the periphery and these broader dimensions of learning (e.g. technological barriers, subjective and external factors mitigating engagement and participation) are precisely the kinds of areas that this study has explored.

A review of the literature indicated a lack of exemplars to guide the development of this kind of approach and, therefore, the ideas of authentic learning, situated learning (specifically the community of practice model) and transformative learning were reviewed to provide the theoretical foundations for the project. The theories of authentic and situated learning were reviewed to provide a theoretical foundation for a situated learning approach to the design of the learning environment and the transformative learning tradition was reviewed to provide a theoretical framework for the objectives associated with the learning environment.

The traditional role of technology in the context of chronic disease management has been to function as a tool to streamline the procedures often associated with self-management (such as blood glucose readings). Since this is first and foremost a project about adult learning, the limitations of this paradigm are obviously apparent and these limitations were explored and a possible alternative model of the study of the use of technology in patient education was suggested. The challenge, of course, is that online technology introduces a range of potential barriers to participation and engagement in learning because all communication and discourse is mediated through online tools. However, it is precisely these kinds of questions that were

of interest because they can contribute to practice guidelines for the development of online learning environments in the context of T2DM.

## Methods and methodology

The two research questions driving this study are (they are taken from the methods and methodology chapter):

1. How can an online Community of Practice for people with type 2 diabetes be established?

2. Does participation in an online Community of Practice for people with type 2 diabetes promote transformative learning? If so, in what way?

The first question broadly relates to the first phase of the study and the second question is associated with the second stage of the study in which study participants engaged in the system.

**Phase one.** The objective of the first phase of the study was to elicit information, knowledge and narratives from patients with T2DM. The first stage of this process entailed interviewing four individuals from the community using a semi-structured interview schedule based on the McGill Mini Narrative Interview schedule. The objective was to generate a broad understanding of the challenges faced by individuals with T2DM. Following on from this a thematic analysis was conducted and a set of themes emerging from the interviews were developed from the interpretation of the data.

Focus groups were then conducted and the objective was to focus more specifically on the educational experiences of the participants. A semi-structured interview was also used and themes emerging from the interpretation of the data were developed from the interview data.

The themes from the individual interviews and focus groups were then combined with sources from the literature and the adopted theoretical frameworks to develop the initial learning designs for the online learning environment. This formed the initial parameters of the patient-centred potential community of practice.

This phase is represented by the first two design-based research phases.

**Phase two.** The third and fourth design-based research phases (see Figure 8-1) represent the iterative cycles of refinement and evaluation of the learning environment.

To evaluate the use of the learning environment, each group was interviewed before and after their participation. Thematic analysis was used to interpret the data from the interviews into themes *associated with each group*. A set of themes that spanned across all four groups was not created because it was considered important to capture the contextual factors relevant to each of the groups. However, and as will become apparent during the summary of the results, thematic patterns did emerge across the groups.
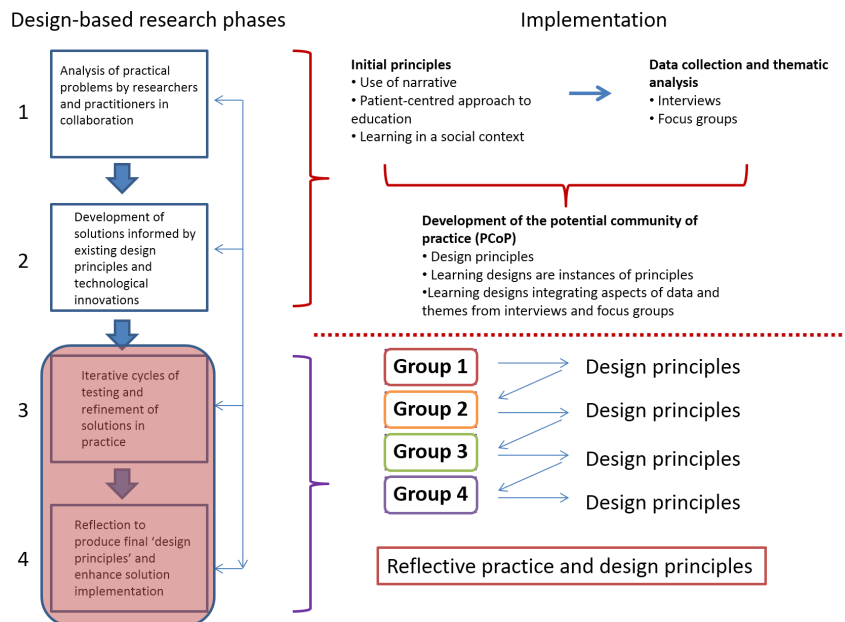


**Figure 8-1.Description of the design-based nature of the research study**

**Theoretical and methodological alignment.**   The theoretical perspectives, methodologies and methods are outlined in Figure 8-2. These elements align to create a cohesive and coherent methodological approach. For example:

- The theory of transformative learning complements the critical realist position on ontology and epistemology because it recognises the ontological reality of T2DM (or the level of the real, in critical realist language) but at the same time the different ways in which the illness can be negotiated by individual patients and this represents an epistemologically constructivist perspective.

- In turn, the methodologies of design-based research and activity theory complement the critical realist position because knowledge and the negotiation of meaning emerge from social discourse and practice. Epistemology, in other words, is contextually bound.

- Lastly, the data collection and interpretive methods are aligned with the theoretical perspectives and critical realism because semi-structured interviews by their very nature can account for different *individual* accounts of illness and at the same time recognise the ontological reality of the illness shared by patients. The interpretive method of thematic analysis can, in turn, capture these differences.

| Theoretical perspective | Epistemology and ontology | Methodologies | Data collection tools and methods |
|---|---|---|---|
| •Transformative learning<br>•Social constructionism | •Critical realism: ontologically realist and epistemologically constructivist | •Design-based research<br>•Activity theory | •Interviews (individual and focus groups)<br>•Questionnaires<br>•Personal email correspondence<br>•Online forums<br>•Thematic analysis and framework approach |

**Figure 8-2. Theoretical frameworks, epistemology and ontology and methods and methodologies of the study**

**Methodologies and evaluation.**   The iterative methodology of DBR is also aligned with critical realism because it can capture the contingent nature of knowledge construction as it occurs across different social groups. Similarly, the representational power of AT is such that it can capture the dimension of activity at an individual (individual subject) and group level (collective subject).

All the elements outlined in Figure 8-2 were used either instrumentally (data collection and interpretive method), philosophically (critical realism) or in an evaluative capacity (DBR and AT) during the development of the PCoP and the subsequent analysis of its use.

## Development of the learning community

The themes that emerged from the interpretation of the individual interviews and focus groups were used to aid in the development of the learning environment.

**Individual interviews.**   A total of six themes emerged from the interpretation of the data. Perhaps the two most important themes (based on the frequency which they occurred across the four interviews) were *having diabetes* and *agency and control*. There was a striking concordance between Corbin and Strauss's (1985) concept of 'three lines of work' and the sub-themes that form the theme of *having diabetes*. The impact of the illness on individuals was also very apparent and having the illness resulted in an ongoing 'contest for control' between the physiological and psychological impact of the illness and the need to satisfy the requirements of daily life. For the four individual interviewees, T2DM placed an exacting toll on their daily lives.

**Focus groups.**   *Having diabetes* was also a major theme that emerged from the interpretation of the focus group data. Because the interview schedule targeted educational experiences the themes that emerged from this set of data were less focussed on individual

experiences ('biographical work') and the phenomenology of daily life and more on the structural issues and uneven nature of the provision of education for T2DM. These fragmented educational experiences resulted in negative views on the quality of educational services although the idea of a patient-centred community of learners emerged from the 'November' focus group. This idea has obvious similarities with part of the conceptual framework that was used to develop the learning environment and represents a significant alignment between the conceptual intent of the learning environment and views from a community of patients. A patient-based community of practice, in other words, is not merely a conceptual component or a theoretical worldview, it can also be seen as an expression of the patient voice in the community requiring an alternative mode of educational delivery.

Taken together, the themes from the individual interviews and focus groups were used to inform the design of the learning environment and the development of the initial learning designs and principles.

## Learning designs and principles

Design-based projects are iterative and after each iteration design principles are developed that can be used to inform any subsequent iterations. This DBR project is no different. The first set of principles (this aligns with phase two of the DBR process outlined in Figure 8-1) were informed by the following sources:

- Sociocultural model of learning (including authentic learning).

- Transformative learning.

- Literature from the management of T2DM.

- Empirical interview data and interpretation.

**Representation of learning designs and principles.** Activity theory is a powerful representational tool for capturing the complexity of activities. It does not, however, provide a parameter to represent the shape or nature of learning designs. As a result, the learning design principles that were described and outlined were represented using a combination of activity theory and the learning design toolkit.

The idea of the learning design toolkit assumes that the design of theoretically principled learning activities should not be predicated on a practitioner's adherence to a particular educational philosophy (social constructivism, behaviourism etc.) but rather based on where an activity sits with regards to the three key dimensions or characteristics of learning activities – *individual-social*, *non-reflective-reflective*, and *experiential-informational*. This allows a learning designer to plan and design their activities using these pedagogical markers.

The adoption of the toolkit, however, indicates the existence of a paradox because this project was heavily influenced by a sociocultural view of learning and this seems to militate against the theory-agnostic approach that underpins the toolkit idea. The toolkit, however, was adopted first and foremost as a tool to represent the nature of learning activities within the broader representational framework of activity theory. The utility of this representational tool becomes more apparent in the evaluation of various iterations of the project because it allows for an easily digestible, visual representation of learning activities and how they might differ across iterations.

A total of 10 learning activities were developed for the first iteration of the learning environment and these were represented using a combination of AT and the toolkit.

## Engagement with the PCoP

This represents the third phase of the design-based process outlined in Figure 8-1. Four groups were assembled to participate in the PCoP between February 2014 and February 2015.

Three groups engaged with the PCoP and the second group was abandoned due to insufficient numbers. In the following section, the use of the PCoP by each group will be briefly outlined and the learning design principles associated with each group highlighted.

## Evaluation and data collection

*Interviews.*   The methods of semi-structured interviews and thematic analysis of interview data were used for all the groups. Individual or group-based interviews were conducted prior to and after the use of the PCoP. A semi-structured interview schedule based on the following themes was used to conduct the interviews:

- Technology in everyday life (social media, use of technology).

- Technology and relationships (including ones with health professionals).

- Technology and health (internet and health seeking behaviour).

A thematic analysis was subsequently carried out on the interview data.

After each group's engagement in the PCoP, interviews were conducted using around the following themes:

- Expectations (what were their expectations?).

- The interface and the learning activities (did the interface pose any barriers?).

- Division of labour within the learning environment (the level of participation in the community).

- The outcomes (was your participation and engagement useful? If so, in what way?).

Participants were also required to complete self-efficacy questionnaires prior to and after their participation.

***Moodle© discussions and logs.*** In addition to interview data, the discussions in Moodle© were available for analysis and they allowed the evaluation of the three presences (cognitive, affective and social) associated with the community of inquiry model. The logs were used to analyse the level of active and passive participation.

***Group one.*** Four participants took part in this group. All of them were highly experienced users of online technologies and social media platforms and used the internet as a tool for everyday living. There was also an understanding that the internet is often composed of undifferentiated knowledge. Interpretation of interviews conducted before engagement in the PCoP revealed three themes and sub-themes:

- *Use of the internet (a tool for everyday living)*

- *Expectations and a critical dimension (undifferentiated knowledge)*

- *Relationships (with health professionals and friends)*

In terms of participation in the PCoP, there was a low level of interaction (posts) between participants although there was a significant level of passive participation or views. Contextual barriers (employment patterns), a complicated interface and a misalignment between the underlying pedagogical intent of the PCoP and participants' expectations are reflected in the two major themes and seven sub-themes associated with the analysis of interviews conducted after the first group's engagement.

Transformative learning outcomes were partially realised across two dimensions: dialogic and self-reflective learning. Neither of these types of learning yielded evidence of 'learning through meaning transformation' although participants did begin to reflect on the nature of biomedical reasoning and begin the conceptual move towards the development of a patient-centred model of healthcare.

The learning design principles based on this group's use of the PCoP were:

      1. Learning designs must combine simple interfaces and authentic activities.

      2. Sharing the same diagnosis of T2DM does not ensure collaboration.

      3. Competency and familiarity with informal collaborative tools (e.g. Facebook©) does not ensure high levels of participation.

      4. Facilitation is important in an online non-formal learning context.

      5. Collaboration with others is not a necessary precondition for reflection.

The last design principle is based on the one of the participant's individual use of the system. Her engagement led to a significant re-appraisal of some of her lifestyle behaviours. This can be seen as an example of a shift in perspective or a 'frame of reference'.

      *Group two.*   Recruitment for the second group was undertaken but the formation of the group was aborted due to lack of availability and health issues on the part of participants. Members from the previous group were also invited to participate but due to the aborted formation of the group, this did not result in any level of engagement in group activity.

To simplify the interface and address the first principle from the first group, two learning designs were combined. The two authentic, 'lifestyle' activities about nutritional patterns and physical activity were simplified and transformed into single activities.

These modifications were put in place for the third iteration of the DBR process.

***Group three.*** The third group consisted of three people. Two of the participants used online technologies in their daily professional lives and the third was a proficient and frequent user of communication tools (e.g. Facebook©).

The analysis of the group interview before the group participated in the PCoP, revealed six themes, three of which are outlined below:

- The dimensions of being a patient

    o The most common sub-theme experienced by three participants was that of *lack of certainty and conflicting information for self-management*. Two out of three participants also experienced a *disorienting dilemma* due to the diagnosis with T2DM.

- Self-management

    o All participants described experiences with T2DM medications and the two out of three participants described their *adaptive strategies.*

- Use of internet and health seeking behaviours

    o All three participants used the internet extensively to search for health-related information and as a daily communicative tool.

As with engagement with the PCoP associated with the first group, there was a lack of significant interaction between group members. This meant that knowledge construction between participants was minimal and this was reflected in the relative absence of any of the three 'presences' occurring during this group's use. However, there were significantly more views than posts and this indicated that members were still interested in participating. The only significant transformative learning outcome emerged from the post-use interview and

not through online discussions in which participants questioned the model of asynchronous learning that was adopted. This is an example of 'learning through meaning transformation' since the meaning (and value) of asynchronous learning was being questioned.

The following points represent a distillation of the four themes and six sub-themes that emerged from the interpretation of the interview data.

- External factors

  o Two participants were under a great deal of professional and personal stress during the period of participation. McClusky's 'Theory of Margin' (Main, 1979) describes this as an example of heavy 'load' in which external factors outweigh an individual's capacity to deal with them thus resulting in a lack of participation.

- Authentic activities were more salient than general activities

  o General activities such as 'What is diabetes' were not viewed as being as useful as authentic, task-based activities.

- Asynchronous vs event-based learning

  o An asynchronous model was used to deliver all the activities. One participant suggested the introduction of scheduled events (perhaps facilitated by healthcare experts). This would allow for learning to be scheduled rather than ongoing.

Significant external 'load' figured prominently in all three participants' lives during their participation. This resulted in low levels of interaction and similar *disembodied online experiences* that were experienced in the first group.

The learning design principles to emerge from the third group were similar to the principles in the first group with two additions:

- The central role of the moderator and facilitator in facilitating the 'presences' in a PCoP.

- The importance of face-to-face contact prior to online engagement (in contrast with the first group, the third group met as a group before using the PCoP).

The learning design principles to emerge from the first and third groups were used to develop the learning environment for the fourth group.

*Group four.* There were four participants in this group. As with the other groups, they were mostly highly experienced and frequent users of online technologies. One participant had experience in online learning.

The following changes were made to the learning environment:

- Private diaries replaced blogs because the blog tool was too complicated.

- A Twitter© panel was introduced to increase teacher 'presence' and to aid in communication via the interface.

- The general discussion ('what is diabetes') activity was abandoned but the two authentic learning activities were kept.

In the interview conducted prior to the group's use of the learning environment, the general theme of *dimensions of being a patient* emerged and this included sub-themes (three in total) such as living with T2DM and the 'disorienting dilemma' of having T2DM. Other themes indicate that the internet was used as a tool for seeking information and as a decision- making tool. There was a total of three major themes and 14 sub-themes.

# Chapter 8. Conclusion

The analysis conducted to explore group interaction using the community of inquiry model highlighted significantly higher levels of interaction across all three 'presences' compared to interaction in previous groups. Knowledge construction (cognitive presence) took place (particularly around the discussion of fitbits©) and responses to posts indicated an interest in building cognitive and social presence in the environment.

In addition, there was also a greater degree of individual reflection (using the private diary tool) compared to other groups.

There was a similar pattern of views versus posts in this group compared to groups one and three and, as such, there were far more views than posts.

Although the levels of interaction, participation and engagement were significantly higher with this group, the issue of external 'load' was still a significant factor for two participants. The difference between this group and the third one, however, was that 'load' did not function as a significant barrier to participation. An analysis using activity theory points to a possible explanation for this.

- The interface was simplified and one activity was abandoned. The objective of social interaction was therefore the foreground activity and not the acquisition of skills to interact and master the interface. In AT terms, a simplified tool was introduced to ensure that mastery of the tool itself would become a secondary issue.

- Two of the participants were teachers and this helped to contribute to the community's understanding of the pedagogical intent of the learning environment. The pedagogical frame of reference of a collective subject (two teachers) were, therefore, aligned with the pedagogical intent of the PCoP.

- The role of the moderator and facilitator was again crucial in creating teacher 'presence' and the face-to-face interview prior to online engagement was important in the creation of social 'presence'. The continued role of the moderator and facilitator (principal researcher) continued to demonstrate the importance of the community (using AT terminology) in helping to meeting the objectives of the PCoP.

These factors contributed to a higher level of participation and engagement and this was reflected in a wider spread of the three 'presences' during the group's interaction. In terms of transformative learning outcomes, evidence of instrumental and self-reflective learning emerged from online discussions and private diary entries and dialogic learning took place during the online discussions. The outcomes associated with instrumental and self-reflective learning indicated that participation in the PCoP helped to frame a conceptual shift for some learners where self-management is conceptualised as a social and collaborative project and not as a purely individual activity.

## The contributions of the study

As outlined in the discussion chapter, this study has made contributions in the following domains:

1. The final learning designs represent an enduring practical artefact. These designs resulted from reflecting on the various iterative cycles of the study and can be used by researchers with interests in the application of design solutions in the context of chronic illness. They may also be of interest to researchers working in in non-formal learning outside of a health context.

2. The study was a theory-driven approach to the development of an online patient-centred learning environment. Using a combination of sociocultural theory and design-based research, the study demonstrated that this combination can be used as

the foundation for a design solution for online health-based learning. This represents the methodological contribution that the study has made.

3. The study has also made theoretical contributions to the landscape of educational research and these insights can be used by researchers to frame questions in further work. These are briefly outlined below:

   a. Effective communicative discourse in an online setting is contingent on complex parameters such as individual learner histories and contexts.

   b. The theory of transformative learning can be used to frame learning 'objectives' but the theory lacks a mature understanding of what constitutes the optimal conditions for learning (especially communicative learning) in an online setting. This represents a potentially productive avenue for future research.

These contributions that the study has made are now followed by a synopsis of the project in the next section.

## Conclusion

There were two main objectives of this study:

1. The development of an online learning environment for people with T2DM using the theoretical framework of situated learning and the community of practice model.

   o Iterative changes to the learning environment were made and learning design principles were developed during each stage.

2. The use of various analytical tools and frameworks (activity theory and community of inquiry model) to investigate whether the objectives of transformational learning were met.

Chapter 8. Conclusion

The process of the development of the PCoP was successfully implemented using an iterative approach underpinned by the design-based research model. The DBR approach ensured that iterative changes were principled and theoretically justified. This indicates that design-based research can be used as the framework through which non-formal, online learning environments for people with T2DM can be developed and evaluated. One of the next challenge for this approach would be to explore other health domains with a view to the development of more universal learning design patterns for learning environments for people with chronic illness.

There is a range of dimensions or 'learning states' associated with transformative learning and they range from the acquisition of instrumental knowledge and individual reflection through to 'frames of reference' being challenged and replaced with new worldviews and perspectives. It is clear from the analysis of the use of the PCoP and interviews that a range of elements that constitute outcomes associated with transformative learning were evident. Several participants, for example, discussed their 'disorienting dilemmas' with the diagnosis of T2DM and all participants reflected on the impact that T2DM had on their lives. There were also several examples of engagement with the three different types of learning (instrumental, dialogic and self-reflective) associated with transformative learning including instances in which 'learning through meaning transformation' took place. Some of these transformative learning outcomes emerged from online discussions and some from face-to-face interviews. This suggests that participation in the community functioned as a process through which conceptions of learning and the nature of self-management could be framed.

The general lack of participation and engagement in the PCoP raises questions about the significant difficulties in developing an online learning environment. These range from complex interfaces, external 'load' factors and a lack of commitment to a pedagogical model that requires high levels of user interaction. This suggests that Mezirow's concept of the

optimal conditions for learning needs to be updated for the 21st century and to include a discussion of the implications for learning using online tools.

The results from this study are significant because the participants' expectations of a seamless and integrated framework for the provision of educational services for people with T2DM were only being partially met. If this is a sentiment shared by broader sections of the community with T2DM then this indicates that alternative models of learning are required. The question, therefore, is what kind of model is needed to provide a patient-centred framework for learning? The development of an online platform combined with a theoretically informed learning environment was the route taken by this study. This represents a step towards the construction of an online, patient-centred framework for learning.

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# Appendices

## Appendix 1

**Health**
**South Western Sydney**
**Local Health District**
**NSW GOVERNMENT**

**RESEARCH STUDY INTO** *The design and development of an online educational intervention investigating the role of health beliefs in patients with type 2 diabetes*

**INFORMATION FOR PARTICIPANTS**

Date: 20th April 2011

**Introduction**

You are invited to take part in the design and development of online educational resources for people with type 2 diabetes. Type 2 diabetes is now one of the most prominent public health issues in Australia. The purpose of this study is to investigate the role of health beliefs in how patients manage this condition. To do this, a set of online educational resources will be developed based on the stories of people with chronic type 2 diabetes (phase 1 of the study). In phase 2, patients who are newly diagnosed with type 2 diabetes will be asked to use the educational resources at the same time as they are receiving their face-to-face educational sessions. The hope is that the online educational resources will help patients to manage their condition and improve their health outcomes.

The study is being conducted by Professor Ian Wilson (Foundation Professor of Medical Education, School of Medicine, Campbelltown campus), Professor Annemarie Hennessy (Foundation Professor of Medicine, School of Medicine, Campbelltown campus), Professor Anthony Maeder (Professor of Health Informatics, Campbelltown campus) and Glenn Mason (PhD candidate).

**Procedures**

You are invited to participate in phase 1 of the study.

If you agree to participate, you will be interviewed by Glenn Mason. The interview will cover a range of questions about your experience of having type 2 diabetes. The information you and other participants provide will be used to develop educational resources for people who have been newly diagnosed with type 2 diabetes. The interview will be audio recorded and will take about 1½ and 2 hours. It will be held at the Medical School at the University of Western Sydney on Mondays or Tuesdays or in your own home. You will be able to take a break during the interview if you wish and refreshments will be provided.

1 of 3

MASTER Information for participants – phase 1, Version 4, 20/4/2011
Campbelltown Hospital Version 1, 30th August 2011

# Appendix 2

University of
Western Sydney

## Participant Information Sheet (General)

An information sheet, which is tailored in format and language appropriate for the category of participant - adult, child, young adult, should be developed.

**Note:** If not all of the text in the row is visible please 'click your cursor' anywhere on the page to expand the row. To view guidance on what is required in each section 'hover your cursor' over the bold text. Further instructions are on the last page of this form.

**Project Title:** The design and development of an online educational intervention investigating the role of health beliefs in patients with type 2 diabetes

### Who is carrying out the study?

The study is being conducted by Professor Ian Wilson (Associate Dean, Teaching and Learning, Graduate School of Medicine, University of Wollongong), Professor Annemarie Hennessy (Foundation Professor of Medicine, School of Medicine, Campbelltown campus), Professor Anthony Maeder (Professor of Health Informatics, Campbelltown campus) and Glenn Mason (PhD candidate)

You are invited to participate in a study conducted by Professor Ian Wilson, Associate Dean, Teaching and Learning, Graduate School of Medicine, University of Wollongong.

### What is the study about?

The purpose of this study is to investigate the role of health beliefs in patients with type 2 diabetes and how they manage this condition. To do this, a set of online educational resources will be developed based on the stories of people with chronic type 2 diabetes (phase 1 of the study). In phase 2, patients who are newly diagnosed with type 2 diabetes will be asked to use the educational resources at the same time as they are receiving their face-to-face educational sessions. The hope is that the online educational resources will help patients to manage their condition and improve their health outcomes

### What does the study involve?

If you agree to participate, you will take part in a group session to discuss your ideas about developing educational material for people with type 2 diabetes. The results from the session will be used to create learning designs or a learning framework for people who have been newly diagnosed with type 2 diabetes.

### How much time will the study take?

The session will be video recorded and will take between 1.5 to 2 hours.

### Will the study benefit me?

While we intend that this research study furthers medical knowledge and may improve the treatment of diabetes in the future, it may not be of direct benefit to you.

### Will the study involve any discomfort for me?

No

Page 1 of 2

# Appendix 3

University of
Western Sydney

## Participant Information Sheet (General)

An information sheet, which is tailored in format and language appropriate for the category of participant -
adult, child, young adult, should be developed.

**Note:** If not all of the text in the row is visible please 'click your cursor' anywhere on the page to expand the row. To view
guidance on what is required in each section 'hover your cursor' over the bold text. Further instructions are on the last page
of this form.

**Project Title:** The design and development of an online educational intervention investigating the role of
social media in the education and management of type 2 diabetes

### Who is carrying out the study?

The study is being conducted by Professor Ian Wilson (Foundation Professor of Medical Education,
School of Medicine, Campbelltown campus), Professor Annemarie Hennessy (Foundation Professor of
Medicine, School of Medicine, Campbelltown campus), Professor Anthony Maeder (Professor of Health
Informatics, Campbelltown campus) and Glenn Mason (PhD candidate)

You are invited to participate in a study conducted by Professor Ian Wilson, University of Western Sydney
Medical School.

### What is the study about?

The study is interested in how patients who have already been diagnosed type 2 diabetes for a significant
time will be able to provide a range of support to newly diagnosed patients. To do this, the study will
investigate the role of social media (Twitter) as the central component of an online learning environment.
Another online module will also form part of the learning environment and this will include a set of
resources and discussion areas which participants will have access to. The study will investigate and
explore the nature of the interaction between the participants and seek to understand the effectiveness of
this kind of online educational design in the context of type 2 diabetes.

### What does the study involve?

If you agree to participate you will be asked to interact with participants in an online learning
environment using 2 online tools (iPad and a learning management system). Twitter will form the basis of
your everyday interaction with newly diagnosed patients and you will also be expected to engage with
online discussions as they emerge on the learning management system. You will be asked to fill out a
questionnaire at the beginning and end of the study and to participate in a short interview at the end of the
study.

### How much time will the study take?

A reasonable expectation is about 2 hours a week over a 6/8 week period.

### Will the study benefit me?

While we intend that this research study furthers medical knowledge and may improve the treatment of

## Appendix 4

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**Diabetes education project**

Be a part of a diabetes education study

- Are you between 18 and 65 years of age?

- Have you been diagnosed with type 2 diabetes?

- Are you interested in participating in group sessions to help design educational material for people with type 2 diabetes?

If you answered YES to these questions you may be eligible to participate in the group session phase of a research project looking into the role of online education for the management of type 2 diabetes.

The purpose of the study is to investigate how experiences of having type 2 diabetes can be used to build online educational resources and help others who have been newly diagnosed with type 2 diabetes.

The study is being conducted through the University of Western Sydney and Campbelltown hospital.

You will be paid $30 per hour to compensate you for your time and travel expenses.

Please call Glenn Mason at 0438 625 430 for more information.

This study has been approved by the Ethics Review Committee (RPAH zone) of the Sydney Local Health Network. Any person with concerns or complaints about the conduct of the study should contact the Executive Officer on 02 9515 6766 and quote protocol number X11-0115.

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This study has been approved by the UWS Human Research Ethics Committee. Any person with concerns or complaints about the conduct of the study should contact the committee on 02 4736 0229 or email humanethics@uws.edu.au or fax 02 4736 0013 and quote protocol number H9440.

# Appendix 5

The individual interview schedule based on McGill Illness Narrative Interview (Groleau et al., 2006) that was used for the four one-on-one interviews.

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**Section 1. INITIAL ILLNESS NARRATIVE**

*Q. Can you tell me when you experienced your diabetes for the first time?*

Prompts:

- Can you tell me what happened when you had *diabetes*?

- If you went to see a doctor, tell us about your visit to the doctor/hospitalization and about what happened afterwards.

- Did you have any tests or treatments for your diabetes?

---

**Section 2. PROTOTYPE NARRATIVE**

*Q. In the past, have you ever had a health problem that you consider similar to your diabetes?*

Prompts:

- In what way is that past health problem similar to or different from your current health problem of *diabetes*?

- Has a person in your family ever experienced a health problem similar to yours?

- Has a person in your social environment (friends or work) experienced a health problem similar to yours?

- Have you ever seen, read or heard on television, radio, in a magazine, a book or on

---

the Internet of a person who has had diabetes?

---

**Section 3. EXPLANATORY MODEL NARRATIVE**

*Q. According to you, what caused your diabetes? [List primary cause(s).]*

Prompts:

- Are there any other causes that you think played a role? [List secondary causes.]

- Why do you think your *diabetes* started when it did?

- What happened inside your body that could explain your *diabetes*?

- Do you think there is there something happening in your family, at work or in your social life that could explain your diabetes? How does that explain your *diabetes*?

- What does *diabetes* mean to you?

- What usually happens to people who have *diabetes?*

- What is the best treatment for people who have d*iabetes?*

- How do other people react to someone who has *diabetes?*

- Who do you know who has had *diabetes*?

- Is your diabetes somehow linked or related to specific events that occurred in your life?

---

**Section 4. SERVICES AND RESPONSE TO TREATMENT**

*Q. During your visit to the doctor for your diabetes, what did your doctor tell you that your*

*problem was?*

Prompts:

- Did your doctor give you any treatment, medicine or recommendations to follow?

  [List all]

- How are you dealing with each of these recommendations?

- Are you able to follow that treatment (or recommendation or medicine)?

- What made that treatment work well?

- What made that treatment difficult to follow or work poorly?

- What treatments did you expect to receive for your *diabetes* that you did not receive?

- What other therapy, treatment, help or care have you sought out?

- What other therapy, treatment, help or care would you like to receive?

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**Section 5. IMPACT ON LIFE**

*Q. How has your diabetes changed the way you live?*

Prompts:

- How has your *diabetes* changed the way you feel or think about yourself?

- How has your *diabetes* changed the way you look at life in general?

- How has your *diabetes* changed the way that others look at you?

- What has helped you through this period in your life?

- How have your family or friends helped you through this difficult period of your life?

- How has your spiritual life, faith or religious practice helped you go through this difficult period of your life?

- Is there anything else you would like to add?

# Appendix 6

The interview schedule used for the two focus group sessions conducted during November and December 2012. The schedule is based on the themes that emerged during the one-on-one interviews.

**Introduction**

- Introduction to project and its aims

- Introduce myself

- Introduction to the focus group sessions –what we want to get out of them

- Housekeeping – toilets etc.

- When participant says something make sure they use their name first time

**General**

**Q**: Tell me about the education that you've received for your T2DM? (General question to get people talking)

- Has it helped? In what way?

**Overwhelmed with information**

**Q**: How true is it to say that when you found out you had T2DM you were overwhelmed with information?

- How did you cope with this?

- Would have liked more education during that initial diagnosis stage? Why? How do you think that could have helped?

- What advice would you give to someone who has just been diagnosed? What kind of education do you think would help them? Why?

- What role do you think the internet can play in education for diabetes?

*"What do you think the best treatment for diabetes is? Education but not bombarded…I got weighed down with all the information."*

**Agency and control**

**Q**: Has the education you have received enabled you to feel more in control of your diabetes? In what way? Do you know feel more in control of your diabetes compared to when you were first diagnosed?

"When a car breaks down you can take it to a garage but when a body breaks down there's nowhere you can take it. That's what I think."

"Diabetes is what you make it I think. It's what you make it and it's how you treat it yourself in a lot of cases as to how bad it gets I suppose."

"The fact that I am I would say quite intelligent, quite capable of making my own choices and if my choices aren't exactly what you would choose for me well it's my life and I want to live it."

**Misconceptions**

**Q**: When you were first diagnosed did you have any misconceptions about T2DM that were

subsequently resolved? How did that happen? If they were explicitly identified would this have improved your management? How so?

Can you provide any similar examples to this one?

*"About when I was told when I was told I was insulin intolerant I didn't think you know I'd get the diabetes then. Yeah. Er cos I didn't know about what the intolerance meant in fact I didn't know until I asked the educator the other day and she drew me a diagram on what it was and I was rather surprised."*

## Management and education

**Q**: Who has provided the most effective/appropriate education? Can you give examples? How important has education been to help you with management?

- Dieticians?

- GPs?

- Nurse educators?

- The internet?

*"They're not actually living with the condition. They're not living with the constraints that I've got including social and budgetary constraints."*

*"I'm having problems trying to work out a diet that goes with everything. What's good for diabetes isn't good for the liver and vice versa."*

## The limits of education

**Q**: Are there limits to education? What can education do? How far can it go?

*"...the products designed for diabetics only come in the top price ranges. It's the same with the sugar substitute the diabetics are supposed to have. Used on a daily basis that works out pretty expensive."*

**The patient voice**

**Q**: In an ideal world tell me what you think the best education for T2DM would look like? Can you give some examples?

- Who would be involved?
- What's the role of the patient? The doctor? Allied health?

## Appendix 7

Interview schedule used for interviewing patients before involvement in the PCoP.

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**Technology and use/value**

Q: Can you provide some examples of how you use technology in your everyday life?

Q: Is technology important to you? In what way?

Q: Have you used Twitter© before? What do you think of social media?

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**Technology and relationships**

Q: Has technology changed the way you interact with people? In what way?

Q: Has technology changed the way you interact with health professionals? In what way?

---

**Technology and health**

Q: What kind of technology do you think you might be useful for your diabetes?

Q: Have you used technology to find out anything about your diabetes? How have you used this information?

---

# Appendix 8

Interview schedule used for interviewing patients after involvement in the PCoP.

---

**Expectations**

Q: What were your expectations before you started participating in the project?

---

**Tool: Interface and educational activities**

Q: Was the website easy to use?

Q: Which activities did you find most engaging? Why?

---

**Community/interaction**

Q: Why do you think there wasn't a lot of interaction?

- Do you think that meeting up with other members of the group was important? In what way?

Q: Did you feel that you received adequate support in the use of the website? Would you have liked to have received more?

---

**Use and value**

Q: Do you think a system like this can be useful for people with diabetes?

Q: How could it be improved?

# Appendix 9

Semi-structured interview schedule for YS after engagement with the system.

---

**Tool**

1. How easy was the system to use? What did you find difficult? Why? Did you get help to use it?

2. Can the instructions be improved?

3. Was the mobility of the iPad© important to you? If so, in what way?

4. When did you tend to use it?

5. Did you use Twitter©? If not, why not. If yes, why? Do you think it's a useful tool?

6. Have you used any other features of the iPad© (e.g. Browsing) apart from the Moodle© program? Examples.

---

**Rules**

1. Was it easy to follow what you were required to do?

2. Did the food and physical activity diaries make sense to you? Why?

3. Did you go through the other activities (e.g. Misconceptions)? Was this useful to you? Yes or no. In what ways?

4. Would you like to see anything else added?

---

**Management of diabetes**

1. Did using the system help you managing your diabetes? In what way? If not, why not.

**Health professionals/community**

1. Have you seen a health professional while using the system? If yes, has it changed your

relationship in any way with health professional in question?

# **Appendix 10**

Stanford self-efficacy questionnaire for people with T2DM (Beckerle & Lavin, 2013).

1. How confident do you feel that you can eat your meals every 4 to 5 hours every day, including breakfast every day?

2. How confident do you feel that you can follow your diet when you have to prepare or share food with other people who do not have diabetes?

3. How confident do you feel that you can choose the appropriate foods to eat when you are hungry (for example, snacks)?

4. How confident do you feel that you can exercise 15 to 30 minutes, 4 to 5 times a week?

5. How confident do you feel that you can do something to prevent your blood sugar level from dropping when you exercise?

6. How confident do you feel that you know what to do when your blood sugar level goes higher or lower than it should be?

7. How confident do you feel that you can judge when the changes in your illness mean you should visit the doctor?

8. How confident do you feel that you can control your diabetes so that it does not interfere with the things you want to do?

# Appendix 11

Post semi-structured interview schedule for the first group.

---

**Rules and norms**

- How different is this website compared to sites like Facebook©?

- Have you participated in online learning before?

- Did you feel obliged to complete the tasks that were set?

**Tool**

- How easy was the site to navigate?

- How easy was the iPad© to use? Did you use the iPad© to use the site or did you use a desktop?

- Twitter© wasn't used that much. Why do you think this is the case?

**Community**

- Have you spoken about your involvement in this project with your doctor or other health professionals?

**Division of labour**

- Were you expecting more interaction/participation? Why do you think there wasn't a great deal of interaction? How do you think this could be improved?

- Would meeting people face before participating online make a difference? Why do you think this might be the case?

---

# Appendix 12

Pre-use survey of the PCoP for CA.

- When were you born?

- Have you participated in online learning before? If yes, did you benefit from this experience? In what way? Were there any negative aspects to your online engagement?

- Can you provide some examples of how you use technology in your everyday life?

- Is technology important to you? In what way?

- Have you used Twitter© before? What do you think of social media?

- Has technology changed the way you interact with people? In what way?

- Has technology changed the way you interact with health professionals? In what way?

- What kind of technology do you think might be useful to you for your diabetes?

- Have you used technology to find out anything about your diabetes? How have you used this information?

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