

**Teachable moments: Potential for behaviour change among
people with Type 2 Diabetes and their relatives**

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October 2018

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**Thesis submitted in partial fulfilment for the degree of
Doctor of Philosophy**

“Not every ill comes to destroy you. This has made me healthier and happier and sometimes it even makes you stronger”

Paul Sorvino on his type 2 diabetes

Abstract

Background: There are naturally occurring health events, such as illness diagnosis, that motivate people to spontaneously adopt healthy behaviours. Such events are often referred to as teachable moments. They have the potential to increase the effectiveness of behaviour change interventions, when people are already motivated to change behaviour. However, it is unclear what makes illness diagnosis a teachable moment for some people but not for others. This project aims to identify the factors determining whether and for whom diagnosis of type 2 diabetes is a teachable moment, and to explore the components of a potential intervention to reduce the risk of type 2 diabetes among high-risk groups.

Method: A mixed-methods design, divided into two studies, was employed. The first study was a qualitative study and used semi-structured interviews (n=10 patients and n=13 relatives). It explored the changes occurring in people after diagnosis of type 2 diabetes in oneself or a family member in an effort to identify what factors make diagnosis a teachable moment. The study also explored people's suggestions for a potential diabetes prevention intervention. The second study was a quantitative study and used postal questionnaires (n=85 patients and n=55 relatives). It investigated the relationship between potential teachable moment factors and primary outcomes (physical activity, diet, interest in diabetes-related information and education course).

Results: This mixed-methods study suggests that the factors that may make diagnosis of type 2 diabetes a teachable moment for patients are outcome expectancy, perceived control, severity, self-concept or social role, gender and time since diagnosis; and for relatives: perceived risk, severity, self-concept or social role, and gender. Although there was lack of complete alignment in factors identified through different methods, this study advances understanding of when interventions may be more (or less) successful. The study makes recommendations for potential interventions to capitalise on the teachable moment criteria.

Conclusion: The current project highlights the complexity of teachable moment criteria and their relationship with behaviour change. Future research is required to further uncover these criteria and their utility for health promotion.

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S3: Summary tables on illness perceptions of type 2 diabetes

S4: Summary tables on risk perception of type 2 diabetes

S5: Summary tables on type 2 diabetes prevention interventions

List of Outputs

Journal articles

Dimova E, Mohan AM, Swanson V, Evans JM. (2017). Interventions to prevent type 2 diabetes in relatives: A systematic review. *Primary Care Diabetes*, **11**, 313-326

Dimova E, Ward A, Swanson V, Evans, J. (2017). Patients' illness perceptions of type 2 diabetes, *Current Diabetes Reviews*, doi: 10.2174/157339981466617122721484

Conferences

Dimova, E. (2017) *Teachable moments and Type 2 Diabetes*. Presented at PhD Forum's 3rd Annual Research Conference, Sheffield Hallam University

Dimova, E. (2017). *Teachable moments and type 2 diabetes*. Presented at the 3 Minute Thesis Competition (finalist), University of Stirling

Dimova, E. (2017). *Communal coping and type 2 diabetes*. Presented at the Faculty of Health Sciences and Sport Annual Conference, University of Stirling

Dimova, E. (2017). *Communal coping and type 2 diabetes*. Presented at the Faculty of Health Sciences and Sport Self-Care Enhancing Research Group, University of Stirling

Dimova, E. (2016). *Perceptions of type 2 diabetes: Literature review vs Interview findings*, Division of Psychology Annual Conference, University of Stirling

Dimova, E. (2016). *Perceptions of type 2 diabetes: Literature review vs Interview findings*, Faculty of Health Sciences Annual Conference, University of Stirling

Dimova, E. (2015). *Teachable moments and type 2 diabetes*. Presented at the School of Health Sciences Annual Conference, University of Stirling

Public Engagement

Dimova, E. (2016). *Teachable moments and type 2 diabetes*. Public talk at the Science Cabaret, University of Stirling

Dimova, E. (2016). *Teachable moments and type 2 diabetes*. Public talk to members of a Diabetes Support Group, West Lothian.

Teaching

Dimova, D. (2017) and (2018). Family Approaches to Long-term Conditions. Lecture presented at Alterations in Health and Implications for Nursing Care 2 (SHSU09A) module, University of Stirling

Abbreviations

BMI – Body Mass Index

NHS – National Health Service

WHO – World Health Organisation

NICE – The National Institute for Health and Care Excellence

IPQ-R – Illness Perceptions Questionnaire – Revised

RCT – Randomised Controlled Trial

GP – General Practitioner

SIMD – Scottish Index of Multiple Deprivation

SCQF – Scottish Credit and Qualifications Framework

Funding

This project was funded by the Economic and Social Research Council (ESRC) through the Health studentship pathway. Support for study costs was also provided by Clinical Research Network (CRN), Wessex.

Acknowledgements

Thank you to my supervisors, Josie Evans and Vivien Swanson, for the guidance and support; the Economic and Social Research Council (ESRC) who saw potential in the project and funded the PhD; all the organisations who helped with recruitment and the participants who made this project a reality; Iain Crombie and Linda Irvine, who gave me the research experience and confidence to embark on a PhD; my family whose belief in my abilities has been a motivating factor throughout my whole life; Neil for being encouraging and supportive and Gino and Miley for always cheering me up.

Part 1: Introduction and Literature Reviews

Chapter 1: General introduction

1.1 Introduction and rationale

The diagnosis of illness can be a profound moment in people's lives as it is a reminder of health and mortality. Despite the nature of the illness, it often affects both physical and psychological wellbeing and its effects are rarely limited to the person who has been diagnosed but extend to their family. Diagnosis of illness can challenge people's knowledge and perception of the particular illness, their identity and the support available to them. It can also trigger a period where people try to adjust to their new reality by making changes to their diet, physical activity and general lifestyle. For example, when someone is diagnosed with lung cancer they may decide to stop smoking. Their family members who smoke may also decide to stop smoking. Events that have the potential to motivate people to adopt such spontaneous behaviour change are often referred to as "teachable moments" (McBride et al., 2003). The concept of the "teachable moment" is underpinned by accepted conceptual models, which highlight the importance of certain cueing events or "cues to action" (e.g. illness diagnosis) that prompt motivation for behaviour change (Hochbaum, 1958; Meleis et al., 2000; Weinsten et al., 2008). However, not all people make changes following illness diagnosis suggesting the cues to action do not always become teachable moments when people are more likely to adopt new behaviours. This raises questions about what makes illness diagnosis a teachable moment and for whom it is a teachable moment. This concept is appealing because it suggests that interventions can be timed to take advantage of naturally occurring cueing events, such as illness diagnosis, as people are already considering or making behaviour changes. However, despite such practical implications of the teachable moment concept, there is limited research exploring how and why it occurs. In addition, even though there is a plethora of references to the diagnosis of an illness in a relative or friend as a precursor of behaviour change (whether or not explicitly defined as a teachable moment) (Meiler et al., 1997; Lemon et al., 2004; Rabin et al., 2007; McBride et al., 2008; Patterson et al., 2010) there have been limited attempts to understand the mechanisms, underpinning the success or otherwise of teachable moments in promoting behaviour change (McBride et al., 2003; Lawson & Flocke, 2009).

This PhD applies the concept of the teachable moment to a chronic illness that is an important area of health promotion and a key NHS problem - type 2 diabetes (NICE, 2008). The prevalence of type 2 diabetes is increasing at an alarming rate. The risk factors and

strategies to reduce the risk of type 2 diabetes are well-known. However, there is limited research showing effectiveness in changing people's behaviour to prevent type 2 diabetes. Timing formal interventions to coincide with the illness diagnosis and capitalise on people's increased receptivity or spontaneous behaviour change during the teachable moment, may mean that low-intensity and low-cost interventions could have greater impact.

The aims of this PhD were to identify the contextual factors on whether and for whom the diagnosis of type 2 diabetes is a teachable moment, and to explore the components of a potential intervention to reduce the risk of type 2 diabetes among high-risk groups. This thesis presents a mixed-methods investigation that included two studies. The first was a qualitative study comprised of semi-structured interviews. It explored the changes occurring in patients and relatives shortly after diagnosis of type 2 diabetes in an effort to identify the factors that may make diagnosis a teachable moment. This study also asked people to make suggestions on the components of a potential intervention to reduce the risk of type 2 diabetes among high-risk groups. The second study was a quantitative cross-sectional study including questionnaires. It investigated the relationship between potential teachable moment criteria and changes in individuals' behaviour.

1.2 Study background: Teachable moments

1.2.1 What is a teachable moment?

Teachable moments are naturally occurring health events in people's lives that may lead individuals to make health behaviour changes (McBride et al., 2003). During a teachable moment, people may be more open to consider health risks and engage in health behaviour change (McBride et al., 2003). It has been suggested that the effectiveness of interventions for behaviour change can be increased if they are targeted at the time of a health event, which is a teachable moment, such as illness diagnosis in oneself or in a family member (McBride et al., 2003; Cohen et al., 2011; Schnoll et al., 2013). However, there is limited research on what makes a health event, such as illness diagnosis, a teachable moment. Previous research has been conducted primarily in the field of cancer with two studies suggesting potential mechanisms for the teachable moment. McBride et al. (2003) have hypothesised that whether an event will suffice as a teachable moment for a patient depends on the extent to which it i) increases peoples' perceptions of personal risk ii) produces an emotional response and iii) produces a redefinition of social role or self-concept (although it may not necessarily have to fulfil all three conditions). More recently, it

was hypothesised that teachable moments share salient characteristics: i) the presence of a concern that is salient to the patient and relevant to an unhealthy behaviour ii) a link between the patient's concern and a health behaviour and iii) a response from the patient, indicating willingness to discuss and commit to behaviour change (Cohen et al., 2011).

These will be discussed in more detail in section 1.2.3

1.2.2 Theoretical basis

The concept of the teachable moment can be explained by drawing on the Health Belief Model (Hochbaum, 1958), Middle Range Theory of Transition (Meleis et al., 2000) and Precaution Adoption Process Model (Weinstein et al., 2008).

The Health Belief Model offers a model of variables that influence health behaviours (Hochbaum, 1958). It suggests that people weigh the benefits and costs of a particular action before they make a decision. First, people consider their perceived susceptibility to illness and the seriousness of this particular illness in terms of severity and potential impact on everyday life (Hochbaum, 1958). Once a person has considered the potential threat (e.g. illness), they weigh the benefits and costs associated with a health behaviour that may reduce the health risk. For example, if someone believes they are at an increased risk of developing type 2 diabetes (perceived susceptibility) and they also believe that type 2 diabetes is a serious condition that can lead to severe complications (perceived seriousness), then they might be more likely to engage in physical activity to reduce the likelihood of developing type 2 diabetes. Their behaviour would also be influenced by the perceived benefits (e.g. reduced blood pressure, social benefits) and the barriers to physical activity (e.g. expense, fatigue). The part of the Health Belief Model relevant to teachable moments is the suggestion that certain events, "cues to action", can trigger behaviour change (Hochbaum, 1958). They could be internal (e.g. headache) or external cues (e.g. illness diagnosis). If we go back to the above example, a person's motivation to engage in physical activity to reduce their chances of developing type 2 diabetes could be increased if a family member is diagnosed with type 2 diabetes (external cue). Cues to action have been closely linked to the concept of the teachable moment, because they might provide an opportunity to intervene when people are already considering behaviour change.

According to the Middle Range Theory of Transition (Meleis et al., 2000) changes in health and illness create a process of transition and people in transition may be more aware of risks that may affect health. For example, after illness diagnosis in oneself or in a family

member, people enter a transition process where they may experience changes in perceptions and behaviour. Meleis et al. (2000) explored the transition process through a series of studies, which resulted in the identification of several transition properties: awareness, engagement, change and difference, time span and critical points and events. Awareness is related to recognition and knowledge of the transition experience. Awareness influences the level of engagement which relates to behaviours such as seeking information, actively preparing or using role models (Meleis et al., 2000). Transitions are the result of change and they also result in change. People need to face the fact that they might feel different, be perceived as different and see the world in a different way (Meleis et al., 2000). Transitions have a certain time span and they could be short-term or long-term. Finally, some transitions are associated with identifiable marker events, such as illness diagnosis or start of treatment. Marker events are critical turning points which could lead to increased awareness of change and active engagement with the transitional process, thus they may serve as teachable moments (Meleis et al., 2000).

According to the Precaution Adoption Process Model (Weinstein, 1988) adoption of a new precaution or cessation of a risky behaviour requires deliberate steps unlikely to occur outside of conscious awareness. At some initial point in time, people are unaware of the health issue (Stage 1) but when they first learn something about it, they are no longer unaware although they may not be engaged by it either (Stage 2). A cueing event, such as illness diagnosis in oneself or a relative, could act as a teachable moment and create or increase awareness of a health issue (e.g. type 2 diabetes) and increase people's motivation to move through the stages of decision making and taking action. People who reach the decision-making stage (Stage 3) have become engaged by the issue and are considering their response. This decision-making process can result in one of three outcomes: suspension of judgment and remaining in Stage 3; decision to take no action and moving to Stage 4; decision to adopt precaution and moving to Stage 5. For those who decide to adopt the precaution, the next step is to initiate the behaviour (Stage 6). A seventh stage, if relevant, indicates that the behaviour has been maintained over time (Stage 7). Movement backward toward an earlier stage can also occur, without necessarily going back through all the intermediate stages.

1.2.3 Use of “teachable moments” in the literature

The Health Belief Model (Hochbaum, 1958), Middle Range Theory of Transition (Meleis et al., 2000) and Precaution Adoption Process Model (Weinstein et al., 2010) may help understand teachable moments by linking them with specific cueing events or cues to action. However, they do not explain how cues to action (cueing events) become teachable moments. In addition, the concept of the teachable moment lacks a conceptual or theoretical framework and varies in the way it has been used by different researchers and clinicians. Lawson and Flocke (2009) explored the ways the term “teachable moment” has been used in the literature and placed the results into three categories. The first category describes the concept of the teachable moment as **an unpredictable opportunity** and a useful time to facilitate change. However, the inability to predict teachable moments requires additional resources so health care professionals are trained to recognise these opportunities. The second category describes the teachable moment as **a specific event or context**, marked by an increased capacity for change therefore making it a good time to implement an intervention. Such events can also be unpredictable and include hospitalisation and illness diagnosis. However, Lawson and Flocke (2009) argue that teachable moments are not necessarily unpredictable and that they could be created through interactions. This is supported by Cohen et al. (2011) who claim that people do not experience health events in isolation, but make sense of experiences through social interactions. Discourse between physicians and patients could be used as a building block for teachable moments (Cohen et al., 2011). Cohen et al. (2011) suggest that everyday concerns, not only major health events, could become teachable moments as long as they have specific salient characteristics which can become apparent through interactions thus allowing health professionals to recognise a teachable moment. The first feature of teachable moments is the presence of a salient concern that has an obvious health behaviour component. The second feature is a link between the health concern and the health behaviour. Finally, teachable moments include a response from the patient that indicates commitment to change. Cohen et al. (2012) argue that these features could occur through interaction. For example, a physician could introduce a health behaviour that is relevant to the patient’s salient concern and then connect the two and highlight their causal relationship.

The third category of teachable moments, identified by Lawson and Flocke (2009) in the literature, focuses on **modelling the teachable moment** and proposing mechanisms under which teachable moments operate. Such studies conceptually developed and empirically tested teachable moments in the fields of smoking cessation and cancer (McBride et al.,

2003a; McBride & Ostroff, 2003b; McBride et al., 2008). McBride et al. (2003) conducted a systematic review using the terms “teachable moment” and “opportunities” and identified four categories of teachable moments in smoking cessation: clinical visits, abnormal test results, pregnancy, and hospitalisation/disease diagnosis. McBride et al. (2003) suggested a heuristic model for teachable moments and a set of criteria for a cueing event to become a teachable moment for smoking cessation. These criteria include: risk perceptions and outcome expectancies, affective response and change in social role or self-concept (McBride et al., 2003). First of all, in order for a cue to action to be a teachable moment, it needs to increase people’s perception of personal risk and outcome expectancies. According to McBride et al. (2003) events that provide people with direct experience of risk may override optimistic bias and increase motivation for smoking cessation. Similarly, events that increase individuals’ expectancies of the potential outcomes related to smoking or smoking cessation (e.g. lung cancer; better health) are more likely to be teachable moments. The second criterion is affective response. Events that elicit strong emotional responses, negative or positive, may be appraised as significant and meaningful, and as such, they may enhance the likelihood of a teachable moment (McBride et al., 2003). Finally, in order for a cue to action to suffice as a teachable moment, it needs to produce change in social role or self-concept. Events may be seen as more personally relevant if they affect one’s self-esteem and feelings of control and endanger positive expectations of the future (McBride et al., 2003). For example, events that elicit changes in perceived norms or self-concept that make smoking incompatible with role obligations or that diminish smoking-related self-esteem would be optimal teachable moments (McBride et al., 2003).

More recently, it was hypothesised that teachable moments share salient characteristics: i) the presence of a concern that is salient to the patient and relevant to an unhealthy behaviour ii) a link between the patient’s concern and a health behaviour and iii) a response from the patient, indicating willingness to discuss and commit to behaviour change (Cohen et al., 2011).

The majority of research on the potential of teachable moments after illness diagnosis has been conducted in the fields of cancer and smoking cessation. Gritz et al. (2005) summarised successful and unsuccessful interventions for smoking cessation for cancer patients and suggested that cancer diagnosis is a window of opportunity for health professionals to implement smoking cessation interventions. They also reported that awareness of the connection between diagnosis and smoking cessation is crucial for increasing motivation to quit

smoking (Gritz et al., 2005). Similarly, a small qualitative study by Stead et al. (2012) demonstrated that patients need to be aware of the risk factors for their condition (i.e. adenoma) and relate these to personal behaviours, in order for the diagnosis to be a teachable moment. These studies provide support for Cohen et al.'s (2011) salient characteristics of a teachable moment. Finally, the time since diagnosis appears to be crucial for the adoption of preventative health behaviours. Bluethmann et al. (2015) showed that greater time since cancer diagnosis predicted lower fruit and vegetable consumption and more cigarette smoking.

The role of illness diagnosis as a teachable moment for health promotion is further explored in chapter 2.

1.3 Study background: Type 2 diabetes

1.3.1 What is type 2 diabetes?

Type 2 diabetes is a chronic health condition that occurs when the body cannot use insulin effectively (Guariguata, 2013). In a healthy organism, the pancreas secretes the hormone insulin, which moves glucose (sugar) from the blood to other parts of the body (Diabetes UK, 2014). Insulin acts like a key that allows glucose to enter the cells where it is converted into energy. Blood glucose is balanced within a specific range as a result of carbohydrate uptake from food, production of insulin from the pancreas and utilisation of glucose by the cells (WHO, 2006). When a person has type 2 diabetes, the pancreas produces enough insulin but the body cannot use it effectively and as a result the glucose cannot enter the cells and be converted into energy (WHO, 2006). The diagnostic criteria, as defined by the World Health Organisation (WHO, 2006), for diabetes are displayed in Table 1.

Table 1 Diagnostic criteria for diabetes

Fasting plasma glucose	≥7.0mmol/l (126mg/dl)
2-h plasma glucose*	or
	≥11.1mmol/l (200mg/dl)

* Venous plasma glucose 2-h after ingestion of 75g oral glucose load

The symptoms of type 2 diabetes include excessive thirst, frequent urination, sudden and unexplained weight loss and extreme tiredness (Diabetes UK, 2014). However, these

symptoms can take a long time to manifest themselves and as a result many people with type 2 diabetes remain undiagnosed for years by which time the body is damaged by the increased levels of glucose in the blood (IDF atlas, 2013). Diabetes-related complications include cardiovascular disease, kidney disease, retinopathy (eye disease), amputation (most commonly lower limbs), depression, neuropathy (damage to the nerves), sexual dysfunction, complications during pregnancy, dementia and lower life expectancy (Massi-Benedetti, 2002; Diabetes UK, 2014). In 2012, it was estimated that 1.5 million deaths worldwide were attributable to diabetes (WHO, 2016).

In 2014, it was estimated that almost 3.7 million people in the UK have diabetes (Diabetes UK, 2017). Type 2 diabetes represents 90% of all diabetes cases (Diabetes UK, 2017). Prevalence is highest in Wales (6.7%), followed by England (6.0%), Northern Ireland (5.3%) and Scotland (5.2%). Diabetes UK also estimates that approximately 12 million people in the UK are at increased risk of type 2 diabetes (Diabetes UK, 2015). The estimated direct annual cost of prevention and managing type 2 diabetes in the UK is £8.8 billion, 80% of which is spent on complications (Hex et al., 2012). In addition, indirect costs (e.g. productivity) are estimated to be £13 billion (Hex et al., 2012). However, this burden may be underestimated because approximately 19% of people living with type 2 diabetes remain undiagnosed (Diabetes UK, 2014). Hex et al. (2012) estimate the cost of type 2 diabetes in the UK to rise to £35.6 billion by 2035/2036.

1.3.2 Who is at risk of type 2 diabetes?

The causes of type 2 diabetes are complex and include genetics (Pierce, 1995; Weijnen, 2002), lifestyle (Spruijt-Metz et al., 2014) and an interplay between genetics and lifestyle (Walker et al., 2008). As a result of this, there are three groups of people who may be at increased risk of developing type 2 diabetes: first-degree relatives of people with the condition (due to shared genetics), partners of people with type 2 diabetes (due to living together and having a similar lifestyle) and people who live with their relative with type 2 diabetes (due to a combination of genetics and shared lifestyle).

People with family history of diabetes are four times more likely to develop the condition (Annis et al., 2005). From a biological perspective, Frayling (2007) identified the genetic variants that increase the risk of type 2 diabetes, showing that the greater the number of variants carried by an individual, the greater their risk of developing type 2 diabetes. Weijnen et al. (2002) showed that the risk of developing diabetes may be influenced by the

specific family member who has the condition. For example, having a sibling with diabetes confers a relative risk of 1.8. The risk of developing the condition is between 2.0 and 3.4 if one's mother has it, between 1.4 and 3.5 if one's father has it and between 2.6 and 3.4 if both parents have diabetes.

While heritability is an important risk factor, behavioural factors (e.g. exercise, diet, obesity) may have a great impact on the development of type 2 diabetes (Spruijt-Metz et al., 2014). A recent review of evidence shows that physical activity and diet high in fiber, fruit and vegetables, have protective effects against the risk of type 2 diabetes. Sugar-sweetened beverages, sedentary behaviour, stress and sleep duration (<6 hours or >9 hours), on the other hand, increase the likelihood of developing type 2 diabetes. Family history is an independent predictor of type 2 diabetes with results from a multi-cultural study showing that most of the risk associated with family history is unexplained by major risk factors including body mass index (BMI) and physical inactivity (InterAct Consortium, 2013). However, first-degree relatives of people with type 2 diabetes have been shown to consume unhealthy diets, with higher intake of fat and lower intake of carbohydrates (Adamson et al., 2001). This highlights the fact that first degree relatives of people with type 2 diabetes are at particularly high risk of developing the condition due to genetic predisposition and "inherited lifestyle".

People who live together often share common living environments, eating habits, physical activity levels and social habits (Kolonel & Lee, 1981) and tend to have similar BMI (Hippisley-Cox et al., 2012). Khan et al. (2003) showed that spouses of patients with type 2 diabetes are at increased risk of developing the condition. In addition, a recent meta-analysis showed that spousal history of diabetes is associated with 18% risk increase for diabetes, independently of BMI (Leong et al., 2014). Leong et al. (2014) suggest that spousal diabetes is a robust signal for diabetes risk and a potential tool for earlier diabetes detection.

1.3.3 Why type 2 diabetes?

Despite the increasing prevalence of type 2 diabetes and the known risk factors for it, health promotion in people with a family history of type 2 diabetes is under-researched. This is surprising given there is sound empirical evidence showing that reduction in sedentary behaviour and increase in physical activity are beneficial for the prevention of type 2 diabetes (Hu et al., 1999, 2001, 2003; Kriska et al., 2003; Jeon et al., 2007; Yates, 2008, 2009). Previous studies have used the identification of relatives of people with type 2 diabetes as a recruitment strategy to identify high-risk groups for diabetes prevention (Brekke,

2005; Evans, 2005, Whitford, 2009) and physical activity promotion (Kinmonth, 2008), but never at the time of diagnosis in the relative. Diagnosis in a relative may be a “health scare”, which creates a teachable moment when people are more motivated to engage in and adhere to lifestyle advice (McBride et al., 2003). This suggests that the effectiveness of lifestyle interventions could be increased by timing them to take advantage of the effect of type 2 diabetes diagnosis on relatives’ motivation and intention to adhere to lifestyle advice. This accords with McBride et al. (2003) who state that “*timing formal interventions to take advantage of these naturally occurring events might increase the effectiveness of self-directed and low-intensity interventions that are also low in costs and amenable to widespread dissemination*” (p.156). Exploring the potential of type 2 diabetes diagnosis to be a teachable moment for patients and the relatives of patients with type 2 diabetes, may shed light into the mechanisms underpinning the teachable moment and its potential to increase the effectiveness of behaviour change interventions to prevent type 2 diabetes in high-risk groups. It will also show whether the teachable components identified by McBride et al., (2003) in the field of lung cancer are relevant to type 2 diabetes and whether they can be targeted in any potential interventions. This is of importance as cancer is often considered to be more threatening compared to type 2 diabetes (Walter, Emery, Braithwaite & Marteau, 2004)

1.4 Project structure and research questions

This PhD aims to refine the concept and improve the applicability of teachable moments in health promotion by exploring the contextual factors on whether and whom for the diagnosis of type 2 diabetes is a teachable moment. In addition, the PhD discusses the components and mode of delivery of a potential intervention to prevent type 2 diabetes among the relatives of patients with this condition. The PhD structure follows the aims of the project. It starts with a literature review that establishes the theoretical and research background on teachable moments and type 2 diabetes. The project has a mixed-methods design with two studies. The first, includes interviews with people with type 2 diabetes and the relatives/partners of people with the condition in order to discover the cognitive and behavioural changes that occur following diagnosis of type 2 diabetes and explore people’s preferences for a potential intervention to prevent type 2 diabetes. The second study includes a questionnaire that further assesses the potential factors, identified in the interviews, which may make diagnosis of type 2 diabetes a teachable moment. The project structure is displayed below:

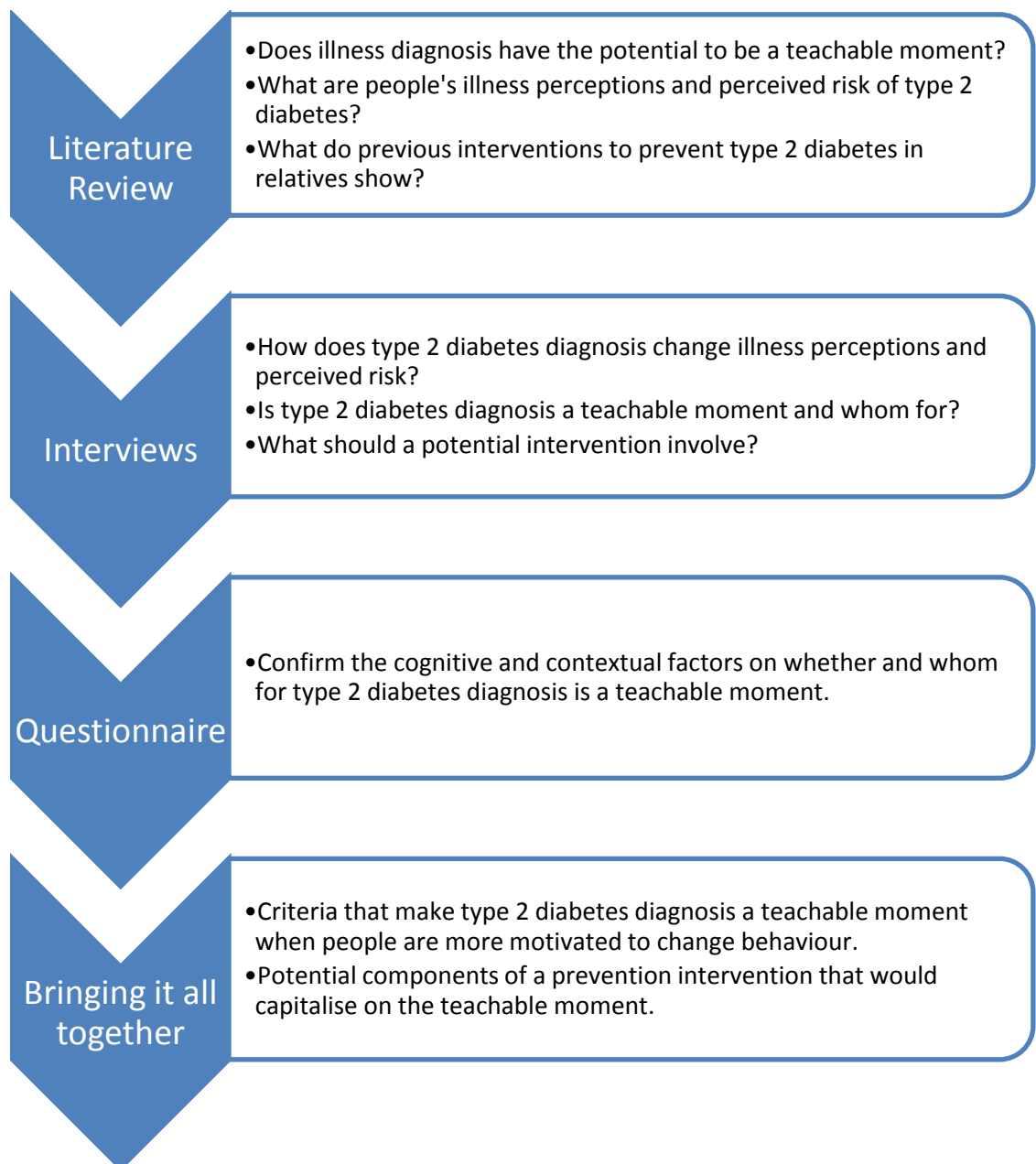


Figure 1 PhD structure

The overall PhD aims were divided into several specific research questions (RQs):

RQ1: Has illness diagnosis been utilised as a teachable moment and for whom is it a teachable moment? (Rationale: Important lessons could be learned about the utility of illness diagnosis as a teachable moment; Method: Scoping review; Chapter 2, section 2.1).

RQ2: Has the potential of teachable moments been explored in the field of type 2 diabetes? (Rationale: To establish whether the potential of type 2 diabetes diagnosis to be a teachable moment has been explored before; Method: Scoping review; Chapter 2, section 2.2).

RQ3: What does published research show about people's illness perceptions of type 2 diabetes? (Rationale: The impact of illness diagnosis on behaviour depends on people's perceptions of the particular illness; Method: Scoping review; Chapter 3. Section 3.1).

RQ4: Does previous research indicate that people with family history of diabetes have increased perceived risk of developing type 2 diabetes? (Rationale: Perceived risk is a predictor of behaviour change; Method: Scoping Review; Chapter 3, section 3.2).

RQ5: What does published research show about successful intervention strategies, used in Randomised Controlled Trials, for type 2 diabetes prevention in the relatives of people with the condition? (Rationale: In order to make suggestions for a future intervention, successful strategies should be identified; Method: Systematic Review; Chapter 4).

RQ6: How does type 2 diabetes diagnosis affect patients and their relatives, in terms of perceptions, behaviour and relationships?(Rationale: To explore the cognitive and behavioural changes that occur in patients and relatives following diagnosis of type 2 diabetes; Method: Interviews; Chapter 6).

RQ7: What criteria need to be fulfilled for the diagnosis of type 2 diabetes to be a teachable moment? (Rationale: To address the overarching PhD aim; Method: Interviews and questionnaires; Chapter 6 and Chapter 7).

RQ8: Are the newly identified criteria for a teachable moment associated with engagement in physical activity and healthy diet, and interest in receiving information about type 2 diabetes? (Rationale: To confirm the identified factors that may characterise a teachable moment when people change their behaviour; Method: Questionnaire; Chapter 7).

RQ9: What recruitment methods, intervention components and mode of delivery would be acceptable to potential participants? (Rationale: In order to make suggestions for a future intervention, its acceptability by the target population should be explored; Method: Interviews; Chapter 8).

1.5 Structure of thesis

This thesis contains nine chapters, divided into four parts: 1) Introduction and Literature Reviews, 2) Methodology and methods, 3) Study findings and 4) Discussion and conclusions.

The first part contains four chapters, the first of which is this general introduction. The aim of the first part is to establish the research background on teachable moments, illness diagnosis and type 2 diabetes. The chapters in this part follow a similar structure and always end with a conclusion that addresses the relevant research question.

Chapter 2 aims to explore whether illness diagnosis has been shown to be a teachable moment and whether the concept of the teachable moment has been applied to type 2 diabetes. These aims are addressed with two scoping reviews. The first scoping review (section 2.1) summarises research that has explored the potential of illness diagnosis to be a teachable moment. The second scoping review (section 2.2) looks at previous research that has applied the concept of the teachable moment to type 2 diabetes.

Chapter 3 explores people's perceptions of type 2 diabetes and perceived risk of type 2 diabetes in people with family history of the condition. These are important as the impact of diagnosis may depend on people's individual views of the particular illness. The chapter contains two scoping reviews. The first one (section 3.1) reviews previous research on illness perceptions of type 2 diabetes. The second scoping review (section 3.2) looks at previous research on perceived risk of type 2 diabetes among people with family history of the condition.

Chapter 4 is a systematic review of previous behaviour change interventions that aimed to prevent type 2 diabetes in the family members of people with the condition. It identifies successful recruitment and intervention strategies in order to aid suggestions for a future intervention.

Part two of the thesis contains one chapter: Chapter 5: Methodology and Methods. The chapter begins with a general introduction and a reminder of the research questions. It explains the study's philosophical underpinnings and overall design before describing the methods of each study within the overall mixed-methods investigation. The subsections follow the same structure describing the aim, sampling, recruitment, data collection, data analysis and ethical consideration for study one (interviews) and study two (questionnaires).

Part three of the thesis presents the study findings and contains three chapters.

Chapter 6 presents the findings from the qualitative study. It starts with the study background before describing study participants, emotional response to diagnosis, experiences of type 2 diabetes of patients and their relatives and the changes in role and relationships following diagnosis of type 2 diabetes.

Chapter 7 focuses on the results from the quantitative study and the association between the teachable moment criteria, suggested in Study One and primary outcomes (physical activity, diet, interest in diabetes-related information and diabetes-related course). The chapter presents the study background before describing the participants and the statistical results from the associations with each primary outcome.

Chapter 8 also presents findings from the qualitative study and describes participants' suggestions for a potential intervention to prevent type 2 diabetes among high-risk groups. It begins with the study background and describes participants' suggestions on recruitment methods, intervention timing, components and mode of delivery.

Part four of the thesis contains one chapter on discussion and conclusions. The chapter begins with a reminder of the need for the project and the project research questions. It then presents a consolidated discussion of findings from the qualitative and quantitative studies to answer the questions: *What constitutes a teachable moment?*; *What makes a cueing event a teachable moment?*; *What is the optimal time for a teachable moment?* and *What is the best way to intervene?*. The chapter then discusses the strengths and limitations of the current study, and its implications, before making suggestions for future work. The chapter ends with reflections on doing a PhD before providing a brief project conclusion.

Chapter 2: Previous research on Teachable moments

The literature review part of this project aims to establish the research background to the potential of illness diagnosis to be a teachable moment, people's perceptions of type 2 diabetes and previous efforts to reduce the risk of type 2 diabetes among individuals at high risk of developing the condition (i.e. relatives of people with type 2 diabetes). As Boote and Beile (2005) say *"a researcher cannot perform significant research without first understanding the literature in the field"* (p. 3). Guided by the purpose of the review, it was deemed appropriate to conduct scoping reviews to address research question 1: **Has illness diagnosis been utilised as a teachable moment and for whom is it a teachable moment?** (section 2.1) and research question 2: **Has the potential of teachable moments been explored in the field of type 2 diabetes?** (section 2.2.). A scoping review is a technique, used to "map" relevant literature in order to address broad topics where different study designs are applicable (Arksey & O'Malley, 2005). Scoping reviews are often undertaken to examine the extent and nature of research activity in a particular field, to summarise research findings and to identify research gaps in the literature (Arksey & O'Malley, 2005). Scoping reviews do not address issues of quality appraisal, so they have the potential to produce a large number of studies with different study designs and methodologies (Arksey & O'Malley, 2005).

A framework for scoping reviews, designed by Arksey and O'Malley (2005) and refined by Levac et al. (2010), was used in order to undertake the scoping reviews in a rigorous and transparent manner. The framework has six stages (described below), the last one of which is optional:

Stage 1: Identifying the research question: involves a combination of a broad research question with a clearly articulated scope of inquiry (i.e. defining the concept, target population and outcomes).

Stage 2: Identifying relevant studies: involves selecting search terms, databases and limits. The balance between feasibility, breadth of coverage and comprehensiveness need to be considered.

Stage 3: Study selection: involves developing inclusion and exclusion criteria and applying them to the identified studies.

Stage 4: Charting the data: involves making decisions about the key items of information to be extracted and charted.

Stage 5: Collating, summarising and reporting the results: involves presenting the data and applying meaning to the results by using numerical descriptions and thematic analysis.

Stage 6 (optional): involves seeking views and contributions of stakeholders to enhance the review. The purpose of this stage should be clearly established prior to its undertaking. *(The current reviews do not include this stage).*

2.1 Teachable moments and illness diagnosis

2.1.1 Introduction

The Health Belief Model (Hochbaum, 1958), Middle Range Theory of Transition (Meleis et al., 2000) and Precaution Adoption Model (1988) suggest that illness diagnosis may be a “cue to action”, a marker event or a cueing event that increases motivation to change behaviour. However, the diagnosis of an illness is not an individual experience. It usually affects the whole family and may be perceived as a call for action for relatives (Breitkopf et al., 2014). Rolland (1994) argues that after illness diagnosis, families try to understand and “deal with” the illness together. People may perceive the illness as an “uninvited guest” that becomes a third member in couple’s dyadic relationships, so it needs to be incorporated into their lives (Rolland, 1994). Studies, primarily in the field of cancer, show that diagnosis affects relatives’ self-identity, social role, and levels of depression and anxiety (Gray et al., 2000; Edwards & Clarke, 2004; Senden et al., 2015). The fact that illness diagnosis affects the whole family and triggers cognitive and behavioural changes in the relatives of a patient, suggests that diagnosis may be a teachable moment not only for patients but also for their relatives and partners. However, there has been no evaluation of the evidence to support the potential of illness diagnosis to be a teachable moment (either broadly or for specific illnesses) for patients or their relatives. In addition, teachable moments for healthy populations may be different from teachable moments for patients and may present different challenges (McBride et al., 2008).

The first aim of this literature review is to summarise previous literature exploring the potential of illness diagnosis as a teachable moment for patients and their relatives. A systematic search was carried out in order to identify all relevant studies that explicitly mention the notion of the teachable moment.

2.1.2 Search strategy and study selection

The research question for this review was: “Has illness diagnosis been utilised as a teachable moment and for whom is it a teachable moment?”. A librarian from University of Stirling assisted in the development of key terms, which may differ from one database to

another, and advised on what databases may be more likely to produce the type of studies the review was seeking. The selected databases were MEDLINE, PsychINFO, CINAHL, ASSIA and ProQuest. The reference lists of all included studies were searched by hand in order to identify relevant studies that may have been missed by the strategy. The search terms included “teachable moment*”, “diagnosis”, “diagnosis related groups”, “diagnosis+”. No limits were set as the aim was to identify all studies that report utilising illness diagnosis as a teachable moment. All databases were searched from inception until May 2015. The review included empirical quantitative and qualitative studies, and systematic reviews that explored the potential of illness diagnosis as a teachable moment. It also included studies that reported the effectiveness of interventions delivered at the time of illness diagnosis and that referred to this as a teachable moment. Only studies in English were included. Studies were excluded if they tested the effectiveness of an intervention in patients or their relatives but did not use the phrase “teachable moment”. Studies that explored the potential of teachable moments but not in relation to illness diagnosis were excluded. Study protocols were also excluded. The criteria were developed post-hoc after initial familiarisation with the literature, and applied in a two-step process. In the first step, they were applied to the titles and abstracts of the identified studies. If the relevance of a study was not clear from the abstract, the full text of the study was assessed.

RefWorks was used to manage the references identified by the search. Each database, the years it covered and the date it was searched were recorded. This was important if there is any likelihood that the searches will be updated in the future.

Twenty five studies were included in the review (Figure 2).

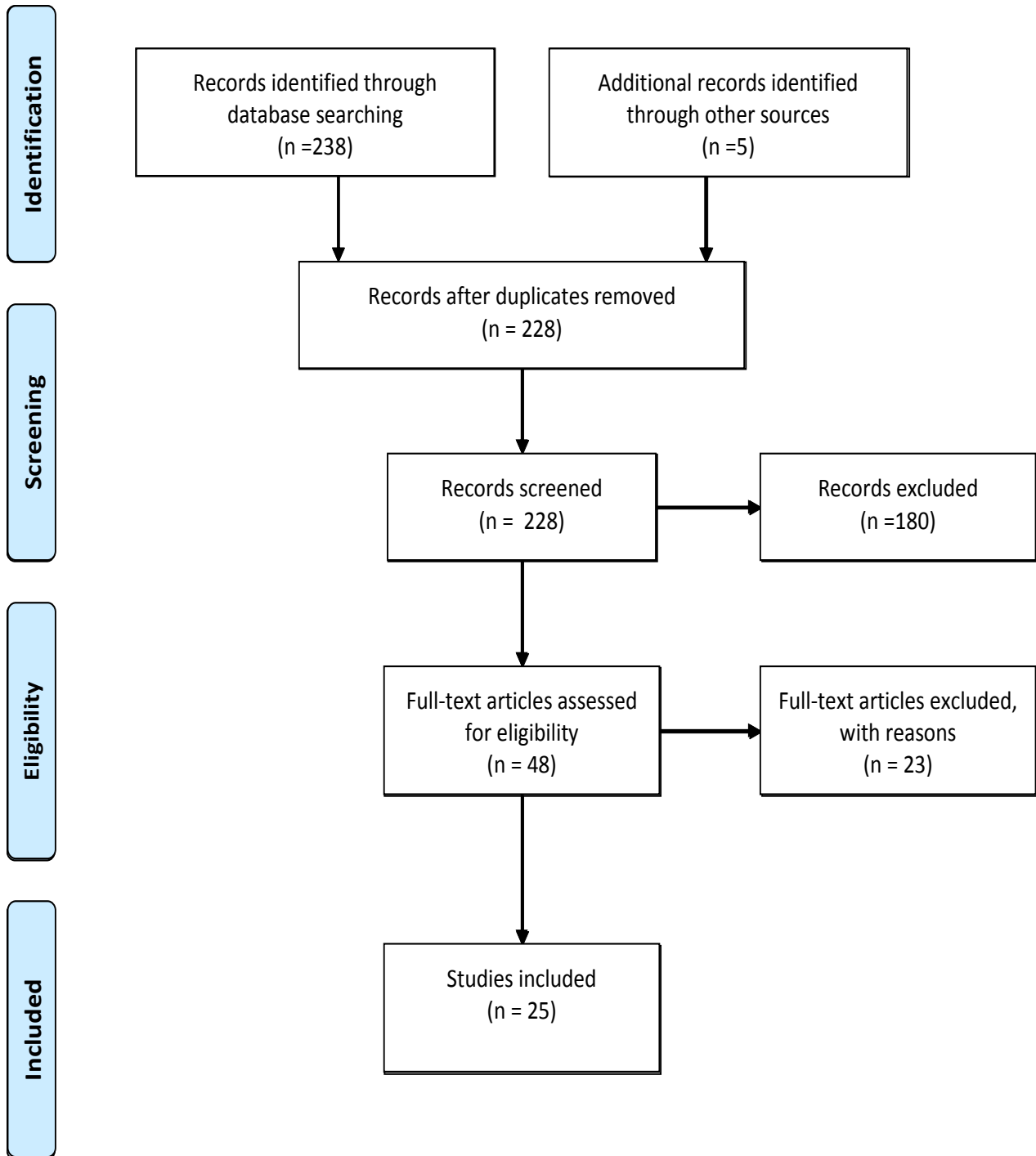


Figure 2 Identification and selection of studies

(Adapted from Moher et al., 2009).

Data extraction was conducted using two different forms – one for quantitative and one for qualitative studies. The quantitative form included: author and year; study aim(s) relevant to the current review; country; participants (number and characteristics); design; measure(s); results; study limitations. The qualitative studies form included: author and year; study aim(s) relevant to the current review; country; participants (number and characteristics); design/methodology; findings; study limitations (in supplementary material on CD).

2.1.3 Results and findings

Twenty five studies were included in the review. Twenty four were published in peer-reviewed journals and one was a PhD thesis. No systematic reviews that met the inclusion criteria were identified. The majority of studies were published between 2000 and 2015 with only one study published prior to this (1993). Studies were carried out in the USA (17), the UK (2), Australia (1), Canada (1), Denmark (1), India (1), Sweden (1) and Turkey (1). Nineteen studies employed a quantitative methodology and six used a qualitative methodology. Sample size varied from 29 to 23 420 in the quantitative studies and from 9 to 444 in the qualitative studies.

Five studies tested an intervention delivered at the time of illness diagnosis in an effort to assess the potential of a diagnosis as a teachable moment (Gritz et al, 1993; Geller et al., 2006; Sharp et al., 2008; Demark-Wahnefried et al., 2014; Azar et al., 2015). One study assessed the acceptability and impact of an intervention in patients facing the prospect of a diagnosis (i.e. suspected cancer) (Tang et al., 2014). The remaining studies explored subjective diagnosis experience, behaviour changes after diagnosis and correlations between behaviour changes and psychosocial factors and demographic characteristics (McBride et al., 2000; Lemon et al., 2004; Humpel et al., 2007; Alfano et al., 2009; Luftman, 2009; Thresia et al., 2009; Butler et al., 2010; Hayes et al., 2010; Patterson et al., 2010; Davey et al., 2012; Nicholson et al., 2012; Stead et al., 2012; Bidstrup et al., 2013; Hayran et al., 2013; Schnoll et al., 2013; Breitkopf et al., 2014; Sabiston et al., 2014; An., 2015; Coa et al., 2015).

Five studies used a comparison group (Gritz et al., 1993; Geller et al., 2006; Schnoll et al., 2013; Demark-Wahnefried et al., 2014; Azar et al., 2015). Two of these studies were randomised controlled trials (Gritz et al., 1993; Geller et al., 2006), one was a randomised feasibility trial (Demark-Wahnefried et al., 2014), one was a prospective observational study

(Schnoll et al., 2013) and one used observational data to explore the effectiveness of different interventions delivered in ambulatory care organizations (Azar et al., 2015).

In order to gain understanding of when and whom for the diagnosis of illness is a teachable moment, the findings from this review describe the characteristics of studies, which show that: illness diagnosis is a teachable moment that triggers behaviour change, illness diagnosis provides a window of opportunity (i.e. a teachable moment) to implement interventions and illness diagnosis is not a teachable moment.

Ten studies found that illness diagnosis is a teachable moment for behaviour change (Grtiz et al. 1993; Lemon et al. 2004; Luftman 2009; Butler et al. 2010; Davey et al. 2012; Nicholson et al. 2012; Hayran et al. 2013; Breitkopf et al. 2014; Tang et al. 2014; An, 2015).

Twelve studies showed that illness diagnosis itself may not be sufficient to prompt behaviour change but presents an opportunity for interventions (Geller et al. 2006; Humpel et al. 2007; Sharp et al. 2008; Alfano et al. 2009; Thresia et al. 2009; Hayes et al. 2010; Patterson et al. 2010; Stead et al. 2012; Bidstrup et al. 2013; Schnoll et al. 2013; Azar et al., 2015; Coa et al. 2015). A few of these studies found that the potential of illness diagnosis to be a teachable moment depends on the presence of certain factors, such as emotional response (Humpel et al., 2007), perception of risk and susceptibility (Humpel et al., 2007; Tang et al., 2014) and a clear link between behaviour and health outcomes (Hayes et al., 2010; Humpel et al., 2007; Stead et al., 2012; Thresia et al., 2009).

Three studies did not find support for the suggestion that illness diagnosis is a teachable moment for behaviour change (McBride et al. 2000; Demark-Wahnefried et al. 2014; Sabiston et al. 2014). McBride et al. (2000) and Demark-Wahnefried et al. (2014) suggest that illness diagnosis may be a stressful experience when people feel unable to make changes. Sabiston et al. (2014) conclude that the time after treatment provides a better opportunity for intervening compared to the time after diagnosis.

The characteristics of these studies are presented in the table below.

Table 2 Characteristics of studies on teachable moments and illness diagnosis

Potential of illness diagnosis to be a teachable moment	Population	Illness	Time since diagnosis
Diagnosis as a teachable moment that promotes behaviour change	4 in patients 2 in first-degree relatives or spouses 2 in patients and relatives 2 relationship between patient and relative not specified	2 head and neck cancer 2 breast cancer 2 lung cancer 1 colorectal cancer 1 lymphoma 1 different cancers (22.1% not specified, 20.4% breast, 14.3% lung, 13.4% colorectal, 11.6% non-colorectal GIS, 7.5% haematological, 7.1% other, 2.5% gynaecological, 2.1% head and neck. 1 diabetes	3 < 12 months 1 > 12 months 1 prospective diagnosis 5 not reported
Diagnosis as an opportunity to intervene	8 in patients 3 in patients and relatives 1 relationship between patient and relative not specified	1 head and neck cancer 1 prostate cancer 2 breast cancer 1 melanoma 1 adenoma 3 patients with different cancers (not specified in 2 studies; in the other study: 41.6% breast cancer, 19.8% other, 14.9% melanoma, 10.9% cervical, 6.9% colon/rectal, 5.9% ovarian). 1 other health conditions 2 diabetes	2 < 12 months 4 > 12 months 6 not reported
Diagnosis is not a teachable moment	2 in patients 1 in patients and relatives	2 breast cancer 1 breast and prostate cancer	2 < 12 months 1 > 12 months

Seven studies explored the direct relationship between demographic factors and teachable moments (McBride et al., 2000; Lemon et al., 2004; Humpel et al., 2007; Luftman, 2009; Butler et al., 2010; Nicholson et al., 2012; Bidstrup et al., 2013). One study showed that increased age is associated with decreased likelihood of improving physical activity and smoking cessation in breast cancer patients (Lemon et al., 2004). Humpel (2007), on the other hand, found that older people are more likely to make positive dietary changes. Higher education and full-time employment have also been linked to positive behaviour changes (Lemon et al., 2004; Humpel et al., 2007). Luftman (2009) found gender and age differences in smoking behaviour. Females, especially non-smokers over the age of 35 and family members of cancer patients, were more likely to speak up about smoking and to stop smoking.

Nicholson et al. (2012) showed differences in smoke exposure among children with lymphoma varied according to marital status and socio-economic status with a 47% reduction for married parents as compared to singles and a 51% reduction for high socio-economic status families compared to low status ones.

Two studies did not find a relationship between demographic factors and health behaviours. Butler et al. (2010) found that the degree of motivation to quit smoking was not related to age, gender, ethnicity, education, marital status, employment status, income, or cigarettes smoked per day among the relatives of lung cancer patients. Similarly, Bidstrup et al. (2013) did not find any associations between demographic factors and changes in BMI, tobacco and alcohol consumption among women with cancer.

2.1.4 Summary of results and identification of research gaps and future research

The current review included 25 studies that explored the utility of illness diagnosis as a teachable moment for behaviour change. Although they have been carried out across different health conditions with participants with various demographic characteristics, the majority of observational studies demonstrate that illness diagnosis increases people's motivation to change. Experimental studies show that illness diagnosis provides a window of opportunity and a teachable moment for implementation of behaviour change interventions. Some of the studies also indicate that the time since diagnosis is crucial for achieving optimal results with interventions targeted as early as possible after illness diagnosis showing increased effectiveness. In addition, some of the studies in this review indicate that the

potential of teachable moments may depend on factors such as emotional response (Humpel et al., 2007), perception of risk and susceptibility (Humpel et al., 2007; Tang et al., 2014) and a clear link between behaviour and health outcomes (Hayes et al., 2010; Humpel et al., 2007; Stead et al., 2012; Thresia et al., 2009). This resonates with McBride et al.'s (2008) argument that in order for a cue to action (i.e. illness diagnosis) to suffice as a teachable moment, it needs to increase people's perception of personal risk and outcome expectancies and evoke a strong emotional reaction. This has implications for diabetes prevention as these factors could be part of a behaviour change intervention.

An important finding emerging from this review is the fact that illness diagnosis is a teachable moment not only for the patients but also for their significant others. The majority of studies which reported the relationship between the index patient and their relatives, involved first-degree relatives. One study also included spouses (Breitkopf et al., 2014) and one included friends of the patient (Humpel et al., 2007). This finding has implications for health promotion and illness prevention interventions among high risk groups (i.e. relatives of patients). Interventions, targeted at the time of illness diagnosis in a significant other, have the potential to achieve increased rates of behaviour change and delay or reduce the likelihood of people developing preventable health conditions, such as type 2 diabetes.

The studies included in this review show promising results about the potential of illness diagnosis as a teachable moment for behaviour change. However, the concept of the teachable moments is relatively new and it is unclear what mechanisms underpin its utility. The characteristics of people who may be more likely to change behaviour and/or benefit from behaviour change interventions delivered at the time of illness diagnosis are also unclear. Studies included in this review indicate that certain demographic characteristics, such as age, may influence participants' likelihood of adopting new health behaviours.

Several of the studies in this review show that illness diagnosis itself may not be sufficient to promote and sustain behaviour change. Studies suggest that the diagnosis provides an opportunity for interventions to be implemented among people who already have increased motivation to change behaviour. However, none of these studies have compared delivering an intervention at the time of illness diagnosis and a different time in order to provide support for the potential of diagnosis to increase intervention effectiveness. Future research needs to explore this in an effort to determine the optimal time for intervening and the level of intervention intensity needed to sustain long-term behaviour change.

Finally, patients may use their diagnosis as an opportunity to teach others about their experience and promote behaviour change. In one study, patients used their illness diagnosis as a platform to share their experience with non-family members (Luftman, 2009). Similarly, mothers used their diagnosis as an opportunity to lead by example and teach their children important lessons about the disease and how to cope in times of adversity (Davey et al., 2012). Such findings may have important implications for the design and delivery of behaviour change interventions among high-risk groups because they show that patients may be willing to discuss their condition and possible behaviour change with significant others.

The above findings need to be interpreted with caution because the studies suffer from several limitations. The majority of studies were carried out in the US and many studies report using homogenous samples. This can have an impact on the studies' external validity and reduce generalisability of the results. The way people perceive their illness can affect the potential of the illness to be a teachable moment. However, people's perceptions of illness may differ across cultures (Lawton et al., 2007; Hajos et al., 2011) suggesting teachable moments may depend on culture-specific experiences and perceptions. The use of self-report measures to assess health behaviours could also be considered a study limitation, as it can lead to response bias. Finally, an important disadvantage is the retrospective assessment of health behaviour change at the time of diagnosis. Although all the studies included in this review explore the potential of illness diagnosis as a teachable moment, the majority of studies do not provide information about the time since diagnosis. Only three studies recruited newly diagnosed patients or relatives of newly diagnosed patients (Lemon et al., 2004: within 8 weeks of diagnosis; Geller et al., 2006: within 1 month of diagnosis; Schnoll et al., 2013: within 6 months of diagnosis). Two of the studies report that some of the participants were newly diagnosed (Humpel et al., 2007: 2.7% within 3 months of diagnosis; McBride et al., 2000: within 0.4 years of diagnosis). The remaining studies assessed people's experience several years after illness diagnosis. The findings of these studies may be subject to recall bias.

2.1.5 Conclusion

This review shows that illness diagnosis provides a window for opportunity and a teachable moment for behaviour change among patients and their significant others. However, the concept of teachable moments is relatively new and raises questions around the mechanisms underpinning the concept, the characteristics of people more likely to benefit from

interventions delivered during the teachable moment and the nature of interventions that could achieve optimal results.

Table 3 Research question and findings on teachable moments and illness diagnosis

Research question	Findings and relevance to the overall project
<p>Has illness diagnosis been utilised as a teachable moment and for whom is it a teachable moment?</p>	<p>Illness diagnosis can increase people’s motivation to change and provide a window of opportunity for implementation of behaviour change interventions.</p> <p><i>Population:</i> Illness diagnosis can be a teachable moment not only for patients but also for their family members. This highlights the importance of exploring differences between patients and relatives in response to and experiences of type 2 diabetes.</p> <p><i>Type of illness:</i> Previous research has focused primarily on the potential of cancer diagnosis to be a teachable moment. Only three studies to date have been conducted in the field of diabetes.</p> <p><i>Demographics:</i> There is little evidence to suggest that teachable moments depend on certain demographic characteristics.</p> <p><i>Time since diagnosis:</i> The time since diagnosis may be crucial for achieving optimal results, with interventions targeted as early as possible after illness diagnosis, showing increased effectiveness. This provides support for the potential of teachable moments for behaviour change and the need to interventions to be implemented shortly after illness diagnosis.</p>

2.2 Teachable moments and type 2 diabetes

2.2.1 Introduction

This PhD applies the concept of teachable moments to type 2 diabetes. In order to do this, it is essential to know if the concept of the teachable moments has ever been applied specifically to the field of type 2 diabetes.

2.2.2 Search strategy and study selection

The research question for this review was: “Has the potential of the teachable moment been explored in the field of type 2 diabetes?”. The selected databases were MEDLINE, PsychINFO, CINAHL, ASSIA and ProQuest and a librarian assisted with the search terms for each database. The reference lists of all included studies were searched by hand in order to identify relevant studies that may have been missed by the strategy. A systematic search with the terms “teachable moment*”, “type 2 diabetes”, “non-insulin dependent diabetes mellitus”, MH “Diabetes Mellitus and Type 2” was conducted. All databases were searched from inception until June 2018. The review included empirical quantitative and qualitative studies, and systematic reviews that explore the potential of teachable moments in the field of type 2 diabetes. Only studies in English were included. Studies were excluded if they explored the concept of teachable moments in other health areas. Study protocols were also excluded. The criteria were developed post-hoc after initial familiarisation with the literature, and applied in a two-step process. In the first step, they were applied to the titles and abstracts of the identified studies. If the relevance of a study was not clear from the abstract, the full text of the study was assessed. One study, included in a previous scoping review (2.1), was not identified by this strategy although it appeared to meet the inclusion criteria (Thresia et al., 2009). The reason for this was because the study did not clarify if participants had type 2 diabetes or any other type of diabetes. The study author was contacted and they said that all of the participants had type 2 diabetes. As a result the study was included in the current scoping review. A study by An (2015) also did not specify whether participants had type 1 or type 2 diabetes. The author was contacted and he clarified that the study did not differentiate between different forms of diabetes. A decision was made to include the study based on the participant inclusion criterion for An’s (2015) study: “Diagnosed diabetes was identified by the answer of ‘yes’ to the interview question: ‘Have you ever been told by a doctor or health professional that you have diabetes or sugar diabetes?’”.

RefWorks was used to manage the references identified by the search. The selection process resulted in the identification of five studies (Figure 3).

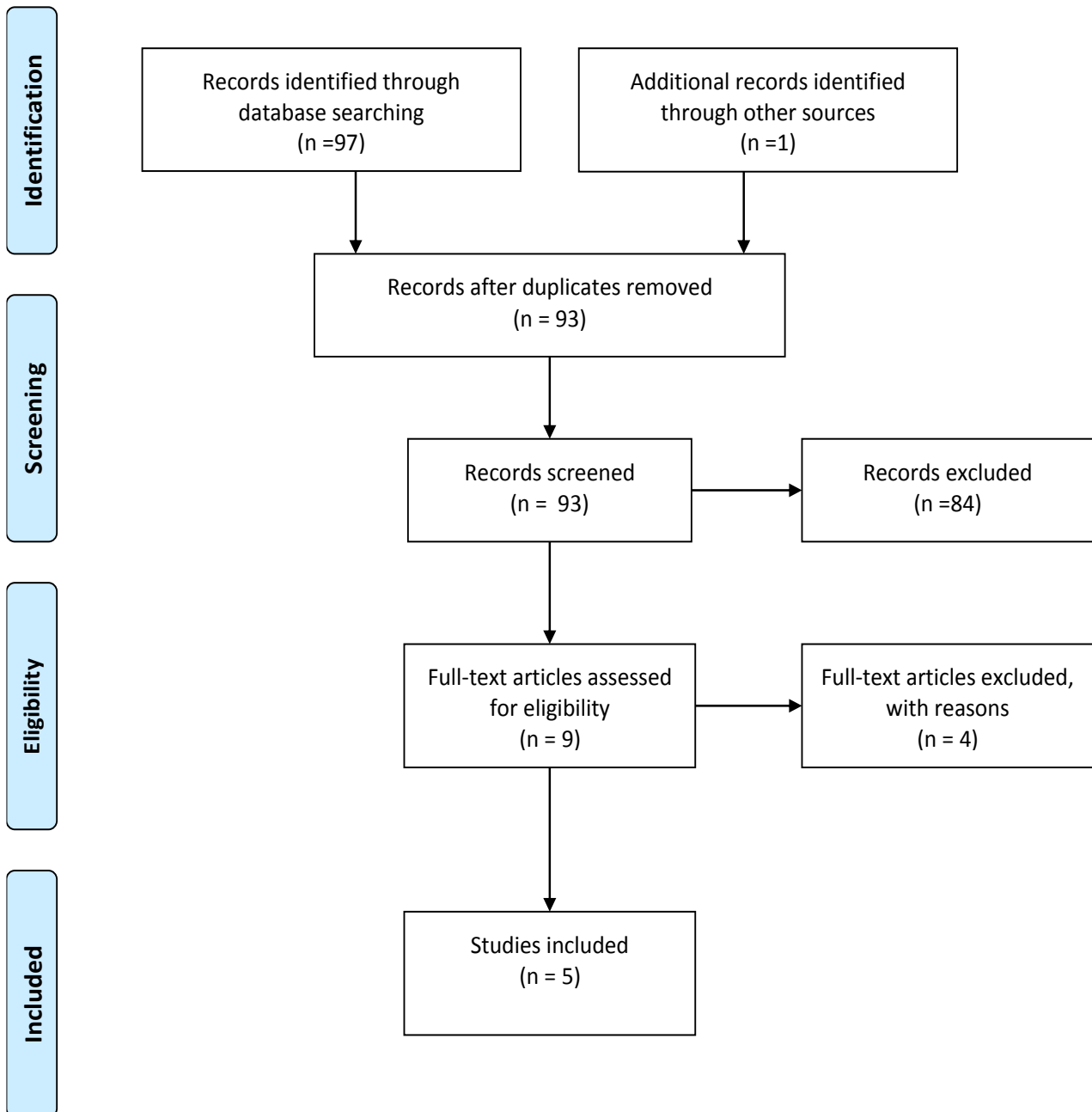


Figure 3 Identification and selection of studies

(Adapted from Moher et al., 2009).

The same data extraction forms, described in 2.1.2 were used (in supplementary material on CD).

2.2.3 Results and findings

The review included four quantitative studies (Tehrani et al., 2012; An, 2015; Azar, et al., 2015; Gallagher et al., 2015;) and one qualitative study (Thresia et al., 2009), published in peer-reviewed journals. They were conducted in Iran (Tehrani et al., 2012), India (Thresia et al., 2009) and the USA (An, 2015; Azar et al., 2015; Gallagher et al., 2015). Sample sizes were 29 (Tehrani et al., 2012), 409 (Gallagher et al., 2012), 444 (Thresia et al., 2009), 1 314 (Azar et al., 2015) and 5110 (of which 8%, approx. 408 people had diabetes; An, 2015).

Thresia et al. (2009) conducted interviews and case studies with men who have been recently diagnosed with type 2 diabetes and asked them about their smoking patterns, attempts to quit smoking and understanding of the relationship between smoking and type 2 diabetes. One hundred of the participants were current smokers and 265 were classified as “ever users”. “Ever users” included people who had either smoked or chewed tobacco in the week before diagnosis. The results showed that less than half of the participants who had used tobacco quit smoking after they were diagnosed with type 2 diabetes and 21% of the smokers and 25% of the chewers did this because they believed that smoking can aggravate their condition. In addition, 52% of people who continued to smoke after diagnosis did not believe smoking affects type 2 diabetes. Interestingly, 35% of the people who continued to smoke after diagnosis reported believing that smoking would aggravate their type 2 diabetes. The authors conclude that diagnosis of type 2 diabetes is a teachable moment for smoking cessation but patients need to be provided with specific information about the link between smoking and type 2 diabetes consequences.

Tehrani et al. (2012) explored the conversion rate of gestational diabetes into type 2 diabetes among 29 Iranian women. The study was a nested case control study on a sample, selected from a large population-based study (Tehran Lipid and Glucose Study, Hadaegh & Azizi, 2005). The results showed that the risk of developing type 2 diabetes after giving birth for women with gestational diabetes was 27.3% at 9-year follow up. The authors conclude that the timely recognition of gestational diabetes may be a teachable moment when women are motivated to make health behaviour changes and reduce their risk of developing type 2 diabetes.

An’s (2015) study was based on the premise that diagnosis of a chronic condition may present a teachable moment. It evaluated the role of diabetes diagnosis as a teachable moment in nutrition label use. It hypothesised that people diagnosed with prediabetes or diabetes pay more attention to daily diet compared to people who are not diagnosed with

prediabetes/diabetes. The sample included 5110 people who completed a home survey asking them how often they use the nutrition facts panel on food labels. The results showed that people with diagnosed diabetes were substantially more likely to report nutrition facts label use in daily grocery shopping compared to people without a diagnosis ($<.001$). However, the authors report study limitations such as the fact the results do not confirm a causal relationship and the study was cross-sectional so it is unclear whether use of nutrition facts labels precedes or follows the diabetes diagnosis. In addition, only 408 out of 5110 participants had diabetes and the study does not distinguish between different forms of diabetes. The authors conclude the diagnosis of diabetes may serve as a potential teachable moment that impacts positively on nutrition facts label use.

Azar et al. (2015) examined the effectiveness of clinic-based behavioural lifestyle (diet and/or physical activity) counselling/education intervention in promoting weight loss among people with newly diagnosed type 2 diabetes. People were diagnosed in the past 12 months and had no other serious clinical conditions where weight loss is not advised. There were four treatment options: formal behavioural lifestyle counselling only, medication only, counselling and medication and monitoring only (i.e. follow up visits). The results showed that people who were in the counselling and medication group lost the most weight in the first year, compared to the other groups ($p<0.001$). The study also found a “dose-response” relationship where effect size increased when patients attended four sessions versus 1-3 sessions, then plateaued after 4 sessions. The authors conclude that people who are newly diagnosed with type 2 diabetes may be particularly receptive to learning about diabetes self-management through lifestyle change. They suggest that clinicians should take advantage of the diagnosis as a teachable moment and refer people to formal counselling.

Gallagher et al. (2015) sought to find out if people’s interest in genetic testing for type 2 diabetes provided an opportunity for productive counselling. Participants who showed interest were randomised to receive risk counselling based on clinical risk factors for type 2 diabetes, risk counselling based on clinical and genetic factors for type 2 diabetes or no genetic counselling. The results showed that people were highly interested in genetic counselling and believed in the effectiveness of healthy eating and exercise for type 2 diabetes prevention. The study concluded that interest in genetic testing for type 2 diabetes among people at high risk of the condition provides a teachable moment for behaviour change counselling.

2.2.4 Summary of results and identification of research gaps

Five studies have explored the potential of teachable moments in the field of type 2 diabetes. Only three of them examined the possibility of diagnosis of type 2 diabetes to be a teachable moment and all three included patient-only samples. One study suggests that timely diagnosis of gestational diabetes may motivate women to change behaviour to delay or prevent the onset of type 2 diabetes (Tehrani et al., 2012). Another study proposes that interest in genetic testing for type 2 diabetes is an opportunity for behaviour change interventions. An (2015) and Azar (2015) show promising results about the potential of diagnosis of type 2 diabetes to be a teachable moment for behaviour change. However, there is not a comparison group in Azar et al.'s (2015) study so it is unclear whether people with newly diagnosed type 2 diabetes are more receptive to education about the condition, compared to people who are not newly diagnosed. The study by An (2015) was cross sectional so a causal relationship between diagnosis of type 2 diabetes and nutrition label use cannot be established. Evidence of the impact of type 2 diabetes diagnosis on behaviour change remains preliminary and highlights the need to understand whether diagnosis is a teachable moment for behaviour change. This is further complicated by the fact that people may not be aware of the link between type 2 diabetes and its potential consequences, which reduces the likelihood for the diagnosis to be a teachable moment (Thresia et al., 2009). Thresia et al. (2009) suggest that in order to capitalise on this potential teachable moment, patients need to be provided with specific information about the link between the health behaviour (e.g. smoking) and type 2 diabetes consequences. Thresia et al. (2009) also show that knowledge of behaviour and consequences may not be sufficient to prompt behaviour change as 35% of the participant continued smoking despite knowing it would exacerbate their type 2 diabetes. This suggests that other factors may play a role in the potential of type 2 diabetes diagnosis to be a teachable moment.

The review did not identify studies exploring the impact of type 2 diabetes diagnosis on the behaviour of relatives of patients. However, family members of people with type 2 diabetes may be at increased risk of developing the condition (see 1.3.2). When people find out they are at increased risk, they often engage in preventive health behaviours and open discussion about diabetes risk with their relatives (Qureshi & Kai, 2008; Vähäsarja, 2015).

2.2.5 Conclusion

Only three studies to date have explored the effect of type 2 diabetes diagnosis on people's health behaviour. This review highlights the urgent need for research that explores the impact of type 2 diabetes diagnosis on health behaviours of not only patients but also relatives of patients with type 2 diabetes.

Table 4 Research question and findings on teachable moments and type 2 diabetes

Research question	Findings and relevance to the overall project
Has the potential of teachable moments been explored in the field of type 2 diabetes?	There is a clear gap in exploring the potential of type 2 diabetes diagnosis to be a teachable moment for patients and especially for relatives of patients.

Chapter 3: Previous research on perceptions of Type 2 Diabetes

In order to address research question 3: **What does published research show about people’s illness perceptions of type 2 diabetes?** and research question 4: **Does previous research indicate that people with family history of diabetes have increased perceived risk of developing type 2 diabetes?**, two scoping reviews were conducted by following the framework, suggested by Arksey and O’Malley (2005) and Levac et al. (2010) (described in detail in Chapter 2).

3.1 Illness perceptions of type 2 diabetes

3.1.1 Introduction

Illness diagnosis can be a teachable moment for patients and their relatives (see 2.1). However, the impact of illness diagnosis and response to illness (e.g. self-management, use of health services) depend on people’s personal illness representations of their illness (Lawton et al., 2005). This idea stems from Leventhal’s Common Sense model, which proposes that people create their own subjective representations of illness (Leventhal et al., 1997). These illness representations influence the way people perceive and respond to illness. Leventhal et al. (1997) and Moss-Morris et al. (2002) describe seven components of illness representations: identity (symptoms), cause, timeline, consequences, control, illness coherence and emotional representation (Table 5).

Table 5 Illness representations.

Adapted from Leventhal et al. (1992), Moss-Morris et al. (2002) and Illness Perception Questionnaire (Weinman et al., 1996).

Illness representation component	Description	Example
Identity	The label, given to the condition and its symptoms.	“The fact that I feel tired all the time is a sign of type 2 diabetes”
Cause	The individual’s perception of the cause of the illness.	“Stress caused my disease”
Timeline	The perception of the illness as acute or chronic.	“My type 2 diabetes will last for a long time”

Consequences	Individual's beliefs about the consequences (e.g. physical, emotional, social) of the illness.	"Type 2 diabetes is a serious condition"
Control	Beliefs about whether the condition can be cured or controlled.	"There is little that can be done to improve my illness"
Illness coherence	People's subjective understanding of their disease.	"My type 2 diabetes doesn't make any sense to me"
Emotional representation	The emotions people experience in response to their illness.	"Type 2 diabetes makes me feel afraid"

The Illness Perception Questionnaire provides a quantitative measure of these illness representation components. Participants are asked to rate a number of symptoms they see as part of their illness (identity) and use a 5-point Likert scale (1-strongly disagree to 5-strongly agree) to provide responses to items such as "stress caused my disease" (cause), "my illness will last for a long time" (timeline), "my illness is a serious condition" (consequences), "there is little that can be done to improve my illness" (control), "my illness makes me feel afraid" (emotional representation) and "my illness doesn't make any sense to me" (illness coherence). Illness perceptions can act as barriers or facilitators to behaviour change (Leventhal et al., 1997; Harvey & Lawson, 2009). For example, a person with a family history of type 2 diabetes who believes that type 2 diabetes is a hereditary condition which cannot be prevented, may be less likely to engage in preventative behaviours, such as healthy eating and physical activity. On the other hand, a person who believes that type 2 diabetes is caused by unhealthy lifestyle and leads to severe health consequences, may be more motivated to change behaviour to delay or prevent the onset of type 2 diabetes.

The current review explores the perceptions of type 2 diabetes among patients with diabetes and relatives of such patients. This is important as whether a diagnosis is a teachable moment may depend on illness perceptions. Previous research shows that people with well-controlled type 2 diabetes experience coherence between diabetes management actions and corresponding results, which in turn enhances sense personal control and motivation to maintain the newly adopted behaviour (Tanenbaum et al., 2016). Perceptions about diabetes cause and consequences also have been shown to influence diabetes management strategies (Savoca et al., 2004). Perceptions of severity and perceived control of type 1 and

type 2 diabetes have been shown to be linked with eating, physical functioning and mental health (Hampson et al., 2000). This review will also provide information on the perceptions of type 2 diabetes among relatives of patients and how these differ between relatives and patients. This may support McBride et al.'s (2008) suggestion that teachable moments for healthy populations may be different from teachable moments for patients and may present different challenges (McBride et al., 2008).

3.1.2 Search strategy and study selection

The research question for this review was: "What does published research show about people's illness perceptions of type 2 diabetes?". The selected databases were MEDLINE, PsychINFO, CINAHL, ASSIA and ProQuest and a librarian assisted with the search terms for each database. The search terms included "illness perceptions", "illness representations", "attitude to health+", "attitude to illness+", "perceptions", "teachable moment*", "type 2 diabetes", "non-insulin dependent diabetes mellitus", MH "Diabetes Mellitus and Type 2". All databases were searched from inception until January 2017. The review included empirical quantitative and qualitative studies and systematic reviews, written in English. Studies that reported the perceptions of people with a family history of diabetes, patients with type 2 diabetes and/or their relatives or partners were included in the review. Studies were excluded if they reported the views of high-risk groups but not relatives/partners (e.g. other high-risk groups such as obese individuals or certain ethnic groups); if they presented opinions on a specific intervention programme; assessed the effectiveness of interventions that aim to alter perceptions of type 2 diabetes; tested the validity of the illness perception questionnaire; explored self-management behaviours among patients or reported patients' experience of living with type 2 diabetes. Study protocols were also excluded. The criteria were developed post-hoc after initial familiarisation with the literature, and applied in a two-step process. In the first step, they were applied to the titles and abstracts of the identified studies. If the relevance of a study was not clear from the abstract, the full text of the study was assessed.

RefWorks was used to manage the references identified by the search.

Thirty nine studies were included in the review (Figure 4).

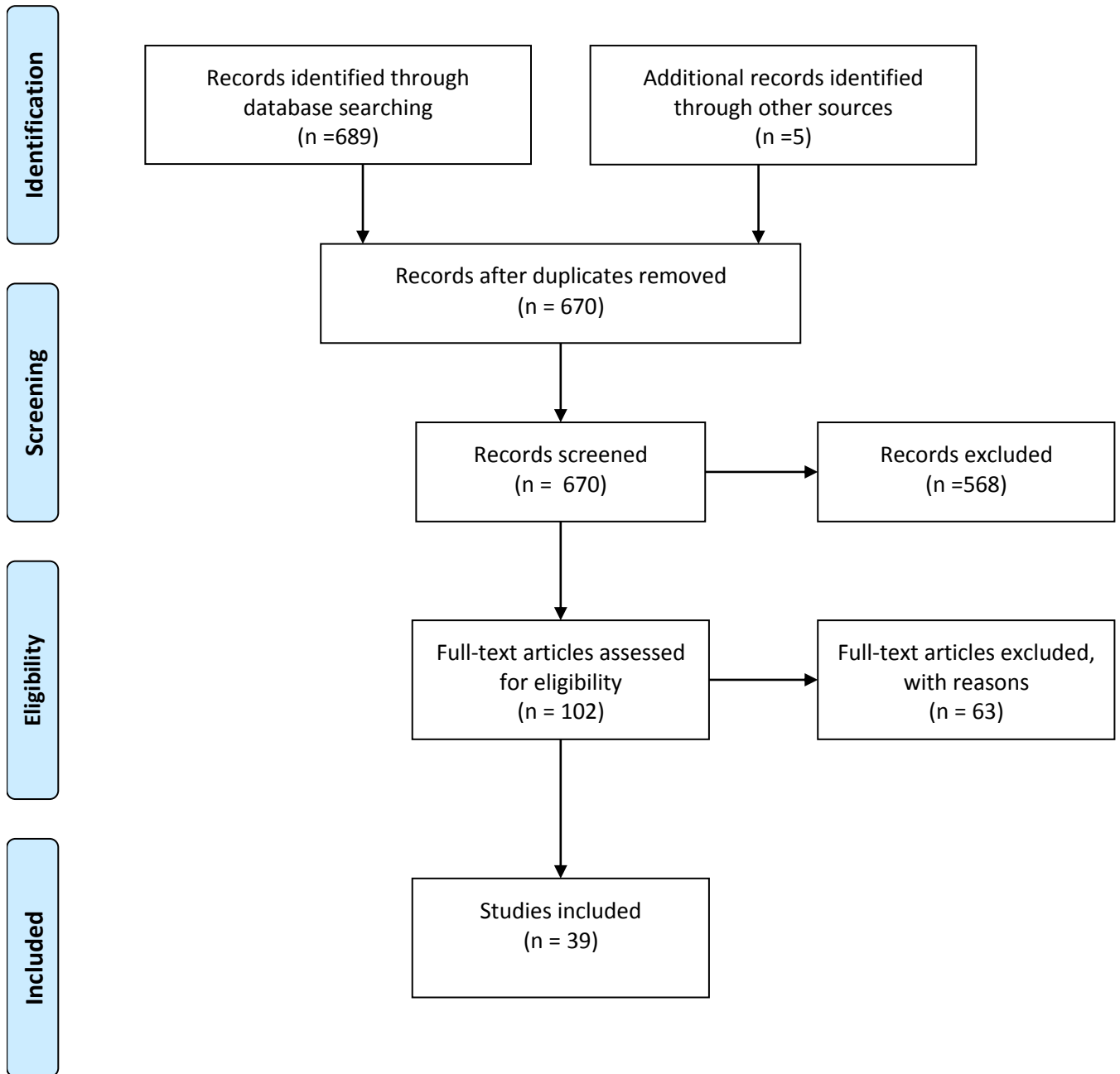


Figure 4 Identification and selection of studies

(Adapted from Moher et al., 2009).

Data extraction was conducted using two different forms – one for quantitative and one for qualitative studies. The quantitative studies form included: author and year; study aim(s) relevant to the current review; country; participants (number and characteristics); design; measure(s); results. The qualitative studies form included: author and year; study aim(s) relevant to the current review; country; participants (number and characteristics); design/methodology; findings (in supplementary material on CD).

3.1.3 Results and findings

Thirty nine studies were included in this review. Thirty of these studies documented patients' perceptions (28 published, 2 PhD theses), three reported on relatives'/partners' perceptions (all published) and six explored the views of both patients and their relatives/partners (all published).

Eight of the studies exploring only patients' perceptions were quantitative (Scollan-Koliopoulos et al., 2007; Wallymahmed, 2007; Calvin et al., 2011; Hajos et al., 2011; Scollan-Koliopoulos et al., 2011; van Esch et al., 2014; Ashur et al., 2015; van Puffelen et al., 2015;) and 22 were qualitative (Murphy & Kinmonth, 1995; Dietrich, 1996; Hernandez et al., 1999; Alcozer, 2000; Jayne & Rankin, 2001; Jezewski, 2002; Egede & Bonadonna, 2003; Peel et al., 2004; Ali, 2006; Macaden & Clarke, 2006; Naemiratch & Manderson, 2006; Lawton et al., 2007; Finucane & McMullen, 2008; Péres et al., 2008; Al-Qazaz et al., 2011; Everett, 2011; Hughes et al., 2012; Pistulka et al., 2012; Baggio et al., 2013; Nguyen, 2014; Yilmaz-Aslan et al., 2014; Habte et al., 2016). Seven of the quantitative studies used the Revised Illness Perception Questionnaire (IPQ-R) and one study assessed perceived seriousness, diabetes-related distress and worries about complications using independent items and a Likert scale (Hajos et al., 2011). The most commonly used method in the qualitative studies was interviews. Only three studies reported using a focus group (Egede & Bonadonna, 2003; Macaden & Clarke, 2006; Finucane & McMullen, 2008) and one reported the use of both interviews and focus groups (Jezewski, 2002). The study year ranged from 1995 to 2016 with the majority of studies conducted after 2005. The sample size varied from 66 to 1609 in the quantitative studies and from 7 to 46 in the qualitative studies. Participants included people with different socio-demographic characteristics. The duration of diabetes varied from 2.6 weeks to 45 years. Studies exploring only patients' perceptions were conducted mainly in the US (12) and the UK (5). Studies were also conducted in Brazil (2), Malaysia (2),

Mexico (2), The Netherlands (2), Canada (1), Germany (1), Thailand (1), Libya (1) and one study was carried out in several countries.

Only three studies exploring the perceptions of type 2 diabetes among relatives of people with type 2 diabetes were identified (Cullen & Buzek, 2009; Pijl et al., 2009; Gordon et al., 2013). All three of them were qualitative and used interviews as a primary method of data collection. Two of the studies were published in 2009 and one in 2013. The samples varied from six participants to 60. Participants included people with different socio-demographic characteristics. These studies were conducted in the UK, US and the Netherlands.

The search identified six studies that compared the illness perceptions of patients and their relatives (Chun & Chesla, 2004; Searle et al., 2007; White et al., 2007; White et al., 2009; Woolthuis et al., 2013; Dimitraki & Karademas, 2014). Four of the studies were quantitative and two were qualitative. All of the quantitative studies used the Revised Illness Perception Questionnaire (IPQ-R) to measure illness perceptions. One of the qualitative studies used interviews (Chun & Chesla, 2004) as a primary method of data collection while the other used focus groups (White et al., 2007). The year of publication ranged from 2004 to 2014. The samples in the quantitative studies varied from 164 to 227. The number of participants in the qualitative studies were 20 (Chun & Chesla, 2004) and 19 (White et al., 2007). Participants included people with different socio-demographic characteristics. These studies were conducted in Ireland (2), Greece (1), the Netherlands (1), the UK (1) and the US (1).

In order to allow for the simultaneous comparison between the views of type 2 diabetes patients and the views of the relatives of type 2 diabetes patients, the results of the identified studies are presented according to the illness representation components, described in Leventhal's (1997) Common Sense model. The process of data summarising included identifying information related to the illness representations components in each study. Information was included in the review if the authors referred explicitly to one of the components of the illness representations model. The number of studies reporting on each of the illness representation components is presented below, followed by a table summarising the key review findings.

Identity

Twelve studies investigated patients' perceptions (Murphy & Kinmonth, 1995; Dietrich, 1996; Alcozer, 2000; Jayne & Rankin, 2001; Jezewski, 2002; Naemiratch & Manderson, 2006; Wallymahmed, 2007; Nguyen, 2014; Yilmaz-Aslan et al., 2014; Ashur et al., 2015; van

Puffelen et al., 2015; Habte et al., 2016).

None of the studies identified in the review explored relatives'/partners' views of the symptoms of type 2 diabetes.

Consequences

Seventeen studies reported on patients' perceptions (Murphy & Kinmonth, 1995; Al-cozer, 2000; Jayne & Rankin, 2001; Jezewski, 2002; Ali, 2006; Macaden & Clarke, 2006; Scollan-Koliopoulos et al., 2007; Wallymahmed, 2007; Finucane & McMullen, 2008; White et al., 2009; Hajos et al., 2011; Hughes et al., 2012; Pistulka et al., 2012; Baggio et al., 2013; Woolthuis et al., 2013; Nguyen, 2014; van Esch et al., 2014; Yilmaz-Aslan et al., 2014; Ashur et al., 2015; van Puffelen et al., 2015; Habte et al., 2016).

Three studies explored perceptions of consequences of type 2 diabetes among the relatives of patients with type 2 diabetes, two of which compared these to the perceptions of patients (White et al., 2009; Gordon et al., 2013; Woolthuis et al., 2013).

Timeline

Nine studies explored patients' perceptions and showed mixed results (Jayne & Rankin, 2001; Wallymahmed, 2007; Calvin et al., 2011; Nguyen, 2014; van Esch et al., 2014; Yilmaz-Aslan et al., 2014; Ashur et al., 2015; van Puffelen et al., 2015; Habte et al., 2016).

None of the studies explored relatives' perceptions regarding the chronicity of type 2 diabetes.

Cause

Twenty two studies explored patients' perceptions of the cause of type 2 diabetes (Al-cozer, 2000; Jayne & Rankin, 2001; Jezewski, 2002; Egede & Bonadonna, 2003; Ali, 2006; Macaden & Clarke, 2006; Lawton et al., 2007; Wallymahmed, 2007; Finucane & McMullen, 2008; Al-Qazaz et al., 2011; Everett, 2011; Pistulka et al., 2012; Baggio et al., 2013; Nguyen, 2014; van Esch et al., 2014; Yilmaz-Aslan et al., 2014; Ashur et al., 2015; van Puffelen et al., 2015; Habte et al., 2016).

Four studies explored relatives' perceptions and knowledge of the causes of type 2 diabetes (White et al., 2007; Cullen & Buzek, 2009; Pijl et al., 2009; Gordon et al., 2013).

Three studies compared the views of patients and relatives (Chun & Chesla, 2004; White et al., 2009; Woolthuis et al., 2013).

Control

Fifteen studies explored patients' perceptions of control over type 2 diabetes (Murphy & Kinmonth, 1995; Jezewski, 2002; Egede & Bonadonna, 2003; Ali, 2006; Macaden & Clarke, 2006; Naemiratch & Manderson, 2006; Scollan-Koliopoulos et al., 2007; Wallymahmed, 2007; Scollan-Koliopoulos et al., 2011; Nguyen, 2014; van Esch et al., 2014; Yilmaz-Aslan et al., 2014; Ashur et al., 2015; van Puffelen et al., 2015; Habte et al., 2016;).

Only two studies examined relatives' beliefs about their ability to control the likelihood of developing type 2 diabetes (Cullen & Buzek, 2009; Pijl et al., 2009).

Three studies compared the views of patients and their relatives (Chun & Chesla, 2004; Searle et al., 2007; White et al., 2009).

Illness coherence

Twelve studies explored patients' understanding of type 2 diabetes (Hernandez et al., 1999; Alcozer, 2000; Jayne & Rankin, 2001; Egede & Bonadonna, 2003; Ali, 2006; Finucane & McMullen, 2008; Péres et al., 2008; Al-Qazaz et al., 2011; Scollan-Koliopoulos et al., 2011; van Esch et al., 2014; Yilmaz-Aslan et al., 2014; Ashur et al., 2015; van Puffelen et al., 2015).

None of the studies explored relatives' understanding of type 2 diabetes.

Four studies compared patients' and their relatives' knowledge of type 2 diabetes (Chun & Chesla, 2004; Searle et al., 2007; White et al., 2007; White et al., 2009).

Emotional representations

Sixteen studies explored patients' emotional representations of type 2 diabetes (Dietrich, 1996; Jayne & Rankin, 2001; Jezewski, 2002; Chun & Chesla, 2004; Peel et al., 2004; Ali, 2006; Finucane & McMullen, 2008; Péres et al., 2008; Everett, 2011; Hajos et al., 2011; Scollan-Koliopoulos et al., 2011; Hughes et al., 2012; Pistulka et al., 2012; Dimitraki & Kardemas, 2014; van Esch et al., 2014; Yilmaz-Aslan et al., 2014; Ashur et al., 2015; van Puffelen et al., 2015; Habte et al., 2016).

Two studies explored relatives' emotional representations of type 2 diabetes (White et al., 2009; Dimitraki & Kardemas, 2014).

The summary of review findings is presented in Table 6.

Table 6 Summary of review findings on illness perceptions of type 2 diabetes.

Illness representation	Patients	Relatives
Identity	Mixed results with some studies showing good and others poor understanding. Reported symptoms such as fatigue, weight loss, vision problems; belief that if there are no symptoms the disease does not exist.	-
Consequences	Patients reported physical (worse health status, body changes), psychosocial (voluntary and involuntary social isolation, loss of contacts, discrimination, loss of social functioning abilities, changes in social role, undermining social image, making people less “marriageable”), financial and social consequences of type 2 diabetes. Some studies showed poor knowledge of consequences and a belief that insulin can lead to complications. In many studies, cultural background influenced views (e.g. diabetes making people less marriageable).	Poor knowledge of long-term consequences, higher perception of severity compared to patients. Some studies found an association between relatives’ knowledge of consequences and that of patients.
Timeline	Majority of patients believed type 2 diabetes is permanent and life-long. Some patients however believed type 2 diabetes is acute and can be cured.	-
Cause	Awareness of causes such as heredity, unhealthy diet and lack of physical activity. Belief that strong emotions, such as fear and anger can cause diabetes. Difference	Mixed findings on heredity as a cause. Awareness of behavioural factors as causes. Some studies showed congruence while others

	in causal perceptions across ethnic groups. For example, Pakistani Indian patients reporting contextual factors (e.g. immigration, British medication) as causes and White patients reporting personal factors (e.g. unhealthy lifestyle).	dissimilarity in causal views between patients and relatives.
Control	Mixed findings: beliefs type 2 diabetes can be controlled through own behaviour, medication, traditional remedies, by God and by denying its existence. Control was associated with symptoms and complications avoidance. The role of cultural beliefs was noted in many studies.	Relatives, who believed that genetics caused diabetes, felt they could not prevent it by adopting a healthy lifestyle. Those who saw behaviour factors as causes of type 2 diabetes believed they could prevent it. Weight loss was not acknowledged as a prevention strategy. Relatives may perceive type 2 diabetes as more controllable compared to patients.
Illness coherence	Mixed findings. Type 2 diabetes described as silent, scary, unpredictable, loss of normalcy, a punishment and a death sentence. Understanding of type 2 diabetes was rooted in cultural beliefs (e.g. seeing type 2 diabetes as hot and cold dynamic).	Some indication partners may have better understanding of type 2 diabetes than patients.
Emotional representations	Primarily negative emotions, such as shame, guilt, anger. Emotional representations appeared to depend on the presence of family history of diabetes, the route to diagnosis, the experience of symptoms and the beliefs about the cause of type 2 diabetes	Spouses may be more anxious compared to patients.

3.1.4 Summary of results and identification of research gaps and future research

The classification of the 39 studies included in this review into seven categories enabled seven broad conclusions: 1) Patients with type 2 diabetes do not always experience any symptoms and as a result they perceive type 2 diabetes as an invisible illness. It remains unclear what relatives' perceptions of type 2 diabetes symptoms are. 2) Patients and their relatives are familiar with the potential consequences associated with type 2 diabetes. However, relatives may perceive these consequences to be more serious than patients do. 3) Most patients report that type 2 diabetes is a chronic condition although some believe it can be cured. The search did not identify any studies that explored relatives' perceptions of the chronicity of type 2 diabetes. 4) Patients and their significant others are aware of the causes of type 2 diabetes, although knowledge is poor in some ethnic groups. 5) Type 2 diabetes patients believe they can control their condition through changes in personal behaviour and medication. Some ethnic groups place greater significance on God and denial of the condition. Knowledge about prevention of type 2 diabetes is poor among the relatives of type 2 diabetes patients. 6) Type 2 diabetes is associated with a wide range of emotions, all of which are negative. There is some indication that relatives may be more anxious than patients when thinking about type 2 diabetes. 7) There are mixed findings regarding patients' and relatives' understanding of type 2 diabetes and these appear to be culture-bound.

These conclusions show that relatives may be motivated to consider behaviour change because they believe that type 2 diabetes is a serious condition. However, the paucity of research exploring relatives' perceptions of type 2 diabetes is apparent. Furthermore, studies also show that the diagnosis of type 2 diabetes is not an individual experience. It is a dyadic process which affects both the patient and their relative/partner (Scollan-Koliopoulos et al., 2007; White et al., 2009; Dimitraki & Kardemas, 2014). Illness representations may depend on the strength of personal perceptions as well as on the ways that each person evaluates partner's reactions and understanding of type 2 diabetes (Dimitraki & Kardemas, 2014). For example, patients' perceptions and actual control over type 2 diabetes affect their relatives' perceptions of control (Scollan-Koliopoulos et al., 2007; White et al., 2009). Route to diagnosis of type 2 diabetes can also affect relatives, with partners of patients with screening detected diabetes in comparison to partners of clinically diagnosed patients perceiving type 2 diabetes to have greater consequences for their own life (Woolthuis et al., 2013).

Further research is needed to explore patients' and their relatives' perceptions of type 2 diabetes. Such information would shed light into people's personal experience of illness and aid the design of appropriate behaviour change interventions that aim to prevent the development of type 2 diabetes. In one study participants suggested that a "critical event" would need to occur so they can consider behaviour change (Gordon et al., 2013). Participants defined a "critical event" as a physical event, such as diagnosis of type 2 diabetes occurring to them or a significant other, or being informed by a health professional of their likelihood to develop a certain illness. This suggests that diagnosis of type 2 diabetes may have the potential to be a teachable moment for behaviour change. However, when, how and for whom it is a teachable moment remain unclear.

These results need to be interpreted with caution because the studies in this review have a number of limitations. The studies were conducted in various geographical locations and illness representations may vary across countries (Hajos et al., 2011) and depend on ethnic background (Lawton et al., 2007). Similarly, the sample in many studies included immigrants who attributed the cause of their diabetes to acculturation and change of environment. Most of the studies used a one-to-one interview design with either patients or relatives. Interviews with patients and their relative/partner may be more appropriate in order to capture personal relationships and dyadic experience of type 2 diabetes. Inconsistency in measuring illness representations has also been observed with studies measuring from one to six of the illness representation components. Finally, several studies in this review used convenience sampling which reduces the generalisability of the results.

3.1.5 Conclusion

This review shows that there is paucity of research exploring relatives' perceptions of type 2 diabetes. Some studies indicate that compared to patients, healthy relatives may perceive type 2 diabetes as more serious with severe consequences. However, relatives may lack knowledge about prevention strategies. This highlights the need for behaviour change interventions among the relatives of type 2 diabetes patients. It also suggests that family members may be more receptive to such interventions because they already perceive type 2 diabetes to be a serious condition.

Table 7 Research question and findings on illness perceptions of type 2 diabetes

Research question	Findings and relevance to the overall project
<p>What does published research show about people's illness perceptions of type 2 diabetes?</p>	<p>This review shows mixed findings about the illness representations of type 2 diabetes among patients with the condition and people with family history of type 2 diabetes. Many previous studies have included marginalised or ethnic minority groups, whose perceptions of type 2 diabetes are influenced by their history and culture. In addition, the views of patients and relatives appear to be inter-connected. This highlights the importance of evidence-based interventions that are informed by the views of potential participants.</p>

3.2 Risk perception of type 2 diabetes

3.2.1 Introduction

Risk perception refers to the individual's judgment of the likelihood of experiencing an adverse event (Leventhal et al., 1999). It is different from actual risk, which is the objective likelihood of a certain adverse event occurring (Leventhal et al., 1999). Social cognitive theories, such as the Health Belief Model (Hochbaum, 1958) and the Common Sense Model (Leventhal, 1997) describe the importance of perceived risk as part of a person's health beliefs that influence the likelihood of performing health behaviours. Van der Pligt (1998) reviewed the literature on perceived risk as a predictor of precautionary behaviour and suggested that increased risk awareness provides a platform for behaviour change interventions. However, studies report a discrepancy between actual and perceived risk of type 2 diabetes (Harrison et al., 2003; Lavielle, 2014). For example, people at increased risk of developing diabetes, due to family history of the condition, may report low levels of perceived risk which could reduce the likelihood of engaging in preventative health behaviours (Harrison et al., 2003; Lavielle, 2014). Qureshi and Kai (2008) found that informing people about their risk of type 2 diabetes can lead to increased engagement in preventative health behaviours and open discussion about diabetes risk with family members. In addition, Vähäsarja (2015) showed that if people were surprised to find out about their increased risk

of type 2 diabetes, they were more interested in health promotion and more determined to change their behaviour.

The aim of this scoping review is to explore the risk perception of developing type 2 diabetes among the relatives and partners of people with type 2 diabetes. High perceived risk may lead to increased motivation to change behaviour in order to reduce the likelihood of developing type 2 diabetes. Low perceived risk on the other hand could be a barrier to engagement in type 2 diabetes prevention strategies. Diagnosis of type 2 diabetes could increase risk perception, which may prompt behaviour change.

3.2.2 Search strategy and study selection

The research question for this review was: “Does previous research indicate that people with family history or a partner with diabetes have increased perceived risk of developing type 2 diabetes?”. The selected databases were MEDLINE, PsychINFO, CINAHL, ASSIA and ProQuest and a librarian assisted with the search terms for each database. The search terms included "perceived risk", "risk perception*", "perception of * risk", "perceived likelihood", "perceived susceptibility", “teachable moment*”, “type 2 diabetes”, “non-insulin dependent diabetes mellitus”, MH “Diabetes Mellitus and Type 2”. The databases were searched from inception until June 2015.

The review included empirical quantitative and qualitative studies, and systematic reviews, that reported perceptions of risk of developing type 2 diabetes among people with a family history or a partner with diabetes. The review excluded studies that reported risk perceptions among the general population. Studies that aimed to alter perceptions of risk or test the validity of perceived risk scales were also excluded. The criteria were developed post-hoc after initial familiarisation with the literature, and applied in a two-step process. In the first step, they were applied to the titles and abstracts of the identified studies. If the relevance of a study was not clear from the abstract, the full text of the study was assessed.

RefWorks was used to manage the references identified by the search.

The criteria were applied in a two-step process which resulted in the identification of 14 studies (Figure 5).

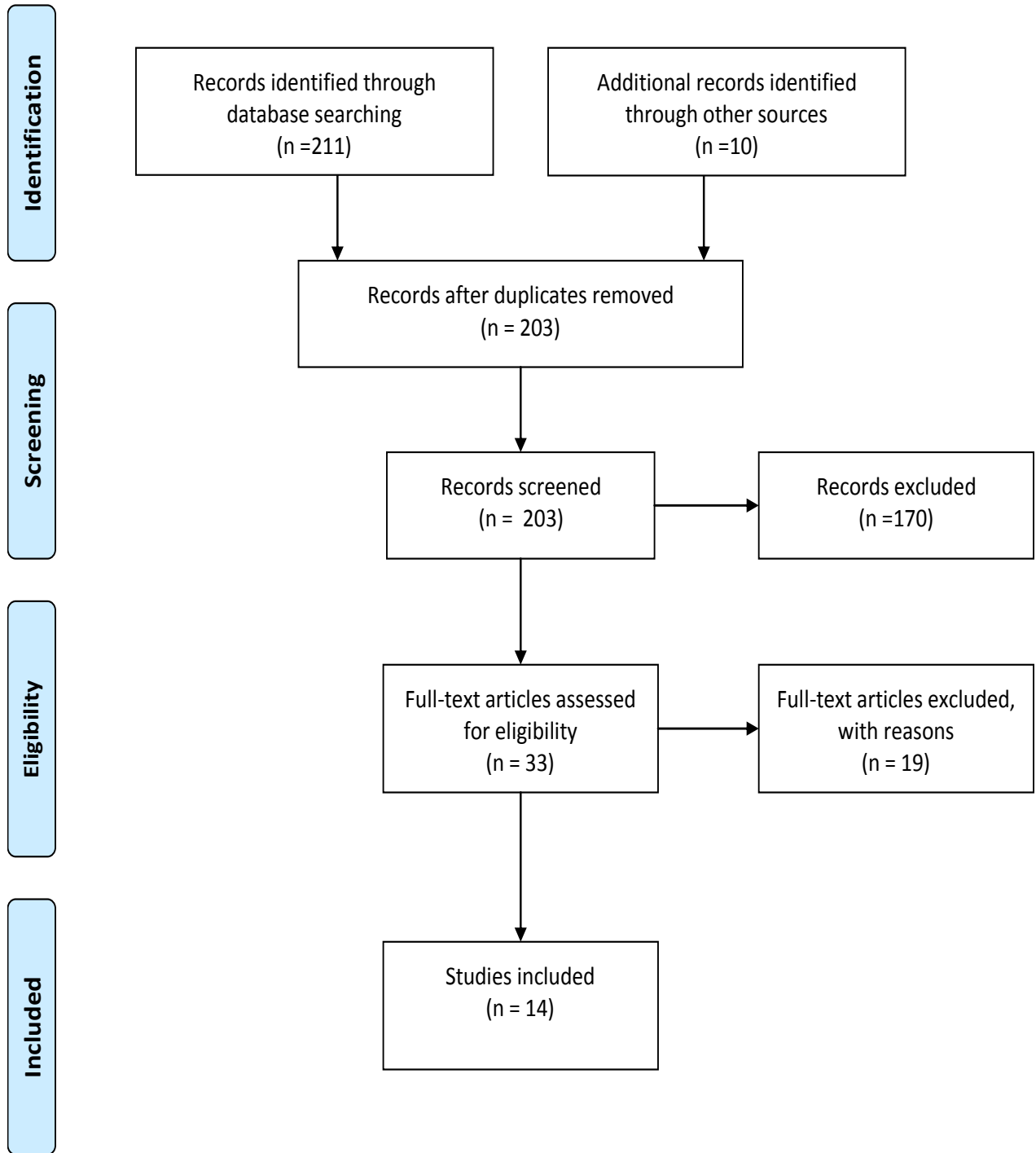


Figure 5 Identification and selection of studies

(Adapted from Moher et al., 2009).

Data extraction was conducted using two different forms – one for quantitative and one for qualitative studies. The quantitative form included: author and year; study aim(s) relevant to the current review; country; participants (number and characteristics); design; measure of perceived risk; perceived risk results. The qualitative studies form included: author and year; study aim(s) relevant to the current review; country; participants (number and characteristics); design/methodology; perceived risk findings (in supplementary material on CD).

3.2.3 Results and findings

Fourteen studies, published in peer-reviewed journals, were included in this review (Forsyth & Goetsch, 1997; Farmer, Levy & Turner, 1999; Harwell, Dettori, Flook, Priest, Williamson, Helgerson & Gohdes, 2001; Pierce, Harding, Ridout, Keen & Bradley, 2001; Kim, Choi, Kim, Oh & Shinn, 2002; Adriaanse et al., 2003; Nishigaki, Kobayashi, Hitomi, Yokomura, Yokoama, Seki & Kazuma, 2007; Qureshi & Kai, 2008; Cullen & Buzek, 2009; Gallivan, Brown, Greenberg & Clark, 2009; Pijl, Henneman, Claassen, Detmar, Nijpels & Timmermans, 2009; Dorman et al., 2012; Gordon, Walker & Carrick-Sen, 2013; Reyes-Velázquez & Sealey-Potts, 2015). The search did not identify any systematic reviews or grey literature. The majority of studies were published after the year 2000 with only two studies published prior to this (1997 and 1999). Studies were carried out in the USA (7), the UK (3), the Netherlands (2), Japan (1) and South Korea (1).

Eleven studies employed a quantitative methodology and three had a qualitative design (Cullen & Buzek, 2009; Pijl et al., 2009; Gordon et al., 2013). All of the quantitative studies were cross-sectional and sample size varied from 30 to 3 323 participants. All of these studies measured risk perception by asking participants if they perceived themselves to be at risk of developing type 2 diabetes or how likely they think they are to develop type 2 diabetes. Four studies explored risk perception in the general population and presented the demographic characteristics of the whole sample which included people without family history of diabetes (Harwell et al., 2001; Adriaanse et al., 2003; Gallivan et al., 2009; Reyes-Velázquez et al., 2015). These studies were included in the review because they report on the relationship between family history and perceived risk of developing type 2 diabetes. The qualitative studies used interviews as a primary data collection method and sample sizes were 6, 9 and 39.

The participants were under the age of 35 in four studies (Forsyth & Goetsch, 1997; Kim et

al., 2002; Nishigaki et al., 2007; Gordon et al., 2013) and over the age of 35 in five studies (Farmer et al., 1999; Pierce et al., 2001; Qureshi & Kai, 2008; Dorman et al., 2012; Pijl et al., 2009). The remaining studies did not report the age of the participants.

The majority of participants in two studies were male (Forsyth & Goetsch, 1997; Kim et al., 2002). Four studies did not report the gender of participants with family history of diabetes (Harwell et al., 2001; Adriaanse et al., 2003; Gallivan et al., 2009; Reyes-Valázquez et al., 2015). The majority of participants in the remaining studies were female.

Only six studies reported participants' BMI and in only one study mean BMI for the sample was over 25 (Cullen & Buzek, 2009).

In order to provide an organisational structure to the review and to explore differences in perceived risk, the risk perceptions of different family members are summarised separately.

Offspring of patients with diabetes

Five studies explored the risk perception of developing type 2 diabetes among the offspring of people with type 2 diabetes (Forsyth & Goetsch, 1997; Pierce et al., 2001; Kim et al., 2002; Nishigaki et al., 2007; Gordon et al., 2013).

Forsyth and Goetsch (1997) reported that people with at least one parent with type 2 diabetes perceived themselves to be significantly more at risk than people without a family history of diabetes ($p < 0.001$). This is supported by Nishigaki et al. (2007) who found that 74% of the offspring recognised they were at higher risk for diabetes because they have family history of it. This represented significantly higher risk perception in comparison to people who thought they are at increased risk due to lifestyle ($p < 0.001$).

Gordon et al. (2013) reported mixed results about risk perception in the offspring of type 2 diabetes patients. In their study, half of the participants believed their risk was the same as the general population and the other half believed it was higher. Participants who believed themselves to be at increased risk described different lifestyle and family risk factors as potential causes of type 2 diabetes (e.g. family history and weight status). On the other hand, participants who believed they had the same risk as the general population offset negative lifestyle factors with positive behaviours (e.g. lack of exercise but healthy eating). Finally, people who rated themselves at increased risk and believed that the onset of type 2 diabetes was inevitable, postponed the perceived time of onset to an age similar to that of their parents' diagnosis (Gordon et al., 2013). Gordon et al. (2013) also explored the relationship

between perceived risk and weight status but found no correlation between the two variables.

Finally, two studies showed that people whose parents have type 2 diabetes do not have increased risk perception. The majority of participants in Kim et al.'s (2002) study did not consider themselves at increased risk of developing type 2 diabetes with only 10.9% thinking they might develop it in the future. Similarly, Pierce et al. (2001) found that 66% of participants thought that it was not very likely or not at all likely that they would develop diabetes. However, when asked about their perceived risk if their parents did not have type 2 diabetes, 47% thought it would be less likely that they would develop type 2 diabetes while 50% thought it would be as likely and only 3% thought it would be more likely. Pierce et al. (2001) also found that increased perceived risk of developing type 2 diabetes was associated with parents having talked to their offspring about diabetes risk ($p=0.04$) and frequency of worrying about developing diabetes ($p<0.001$).

Siblings of patients with diabetes

Only one study explored the perceived risk of developing type 2 diabetes among the siblings of patients with diabetes (Farmer et al., 1999). The results showed that 37.9% of the siblings considered themselves at increased risk of developing type 2 diabetes. However, having a parent as well as a sibling with diabetes was strongly associated with perceptions of increased risk ($p<0.00001$) (Farmer et al., 1999). Other factors associated with perceived risk of developing type 2 diabetes among the siblings of patients with diabetes were gender (female, $p=0.003$) and age (35-54 years, $p=0.003$). On the other hand, BMI was not significantly related to perceived risk.

Offspring and/or siblings of patients with diabetes

Two studies explored perceived risk of developing type 2 diabetes among a sample of both siblings and offspring of patients with diabetes (Adriaanse et al., 2003; Pijl et al., 2009). Adriaanse et al. (2003) found that 40% of people with a parent or a sibling with diabetes perceived themselves at risk of type 2 diabetes, compared to 20% of participants without family history of the condition. Similar to previous studies (Farmer et al., 1999; Gordon et al., 2013) obesity was not associated with higher perceived risk and neither was higher age (over 65) (Adriaanse et al., 2003). In contrast, Pijl et al. (2009) showed that fewer than half of the participants with a parent or a sibling with diabetes, perceived themselves to be at a

slightly higher risk of type 2 diabetes, compared to other people of the same age. In addition, increased risk awareness was not associated with worry about getting type 2 diabetes (Pijl et al., 2009). Pijl et al. (2009) did not find a correlation between increased risk and diabetes worry, which contradicts previous findings by Pierce et al. (2001).

People with family history of diabetes

Six studies investigated perceived risk of developing type 2 diabetes among people with family history of diabetes without specifying the relationship between the index patient and the relative (Harwell et al., 2001; Qureshi & Kai, 2008; Cullen & Buzek, 2009; Gallivan et al., 2009; Dorman et al., 2012; Reyes-Velázquez & Sealey-Potts, 2015). Harwell et al. (2001) found that 42% of people with family history of diabetes considered themselves at risk of diabetes. This was particularly relevant for people under the age of 65 years who were obese and female. Similarly, 78% of the participants in another study reported correctly their increased risk of type 2 diabetes (Cullen & Buzek, 2009). Gallivan et al. (2009) also showed that family history of diabetes was a significant predictor of perceived risk ($p < 0.01$), which is also influenced by age (under 65 years) and obesity. Furthermore, 50% of the participants who perceived themselves to be at increased risk of type 2 diabetes had an immediate family member with diabetes, compared to 14% of the participants who did not perceive themselves to be at risk of type 2 diabetes (Gallivan et al., 2009). Dorman et al. (2012) also found that people with family history of diabetes perceived themselves to be at increased risk of developing type 2 diabetes in comparison to people without family history of the condition (perceived risk score: 2.58 and 3.22 respectively). Level of perceived risk increased further if the participants had relatives with both diabetes and coronary heart disease or stroke ($p < 0.0001$). This shows that the levels of perceived risk increased with the number of health conditions in the family. Reyes-Velázquez & Sealey-Potts (2015) found that participants who had a blood relative with diabetes in their nuclear family had a moderately high risk perception ($M = 6.58$, $p = 0.000$). Finally, Qureshi & Kai (2008) compared the risk perception among people with family history of diabetes who were either not informed of their risk of type 2 diabetes or who were informed by their health professional. The results showed that the informed group was more likely than the uninformed group to recognise their personal risk of type 2 diabetes (56% vs. 14%). However, 44% of the informed group still considered themselves not to be at risk (Qureshi & Kai, 2008).

3.2.4 Summary of results and identification of research gaps and future research

This review included 14 studies that explored the risk perception of developing type 2 diabetes among the relatives of people with the condition. The majority of studies included participants whose parents had diabetes. Several of the studies included participants with family history of diabetes without specifying the relationship between the index patient and their relative. Risk perception among the siblings of type 2 diabetes patients was rarely explored. Although the target groups varied, the majority of studies indicated that relatives of patients with type 2 diabetes perceived themselves to be at increased risk of developing the condition. Three studies found that participants did not report increased perceived risk of type 2 diabetes (Farmer et al., 1999; Pierce et al., 2001; Kim et al., 2002) and two studies showed mixed findings (Pijl et al., 2009; Gordon et al., 2013;). However, although these studies suggest that family history itself may not be the strongest predictor of perceived risk of type 2 diabetes, they indicate that other factors may strengthen this relationship. For example, when presented with a hypothetical question about the likelihood of developing type 2 diabetes if their parent did not have type 2 diabetes, participants' perception of risk decreased (Pierce et al., 2001). On the other hand, risk perception may be increased by open communication about the condition within the family (Pierce et al., 2001). Although people with family history of diabetes, appear to be aware of their risk of developing type 2 diabetes, they are not always informed about the risk. Qureshi and Kai (2008) demonstrated that relatives of diabetic patients who were informed by health professionals about their increased risk of developing type 2 diabetes reported making more health behaviour changes in order to prevent the onset of the condition. Having both a sibling and a parent with type 2 diabetes has also been shown to increase levels of perceived risk (Farmer et al., 1999). Risk perception of type 2 diabetes among relatives may also be influenced by factors such as gender, age and weight status. Some studies show that people younger than 65 may report increased risk perception compared to people over 65 (Farmer et al., 1999; Harwell et al., 2001; Gallivan et al., 2009). There is also some indication that women, compared to men, may be more likely to report increased risk (Farmer et al., 1999; Harwell et al., 2001). There is limited evidence to suggest a positive relationship between BMI and risk perception (Gallivan et al., 2009).

Overall, studies exploring risk perception among people with family history of diabetes show a diverse picture. However, due to the limited number of studies identified in this review, it is not possible to compare risk perception among different family members (e.g.

siblings vs. offspring). Furthermore, this review did not identify any studies that explored risk perception among the partners/spouses of type 2 diabetes patients. This is surprising given the relationship between unhealthy lifestyle and type 2 diabetes.

The findings in this review showed that perceived risk is a complex concept that may require the use of contextually sensitive measures. The relationship between family history and risk perception appears to be moderated by factors, such as age, gender and weight status. There could also be other factors, such as personality, similarity in lifestyle, geographical proximity and closeness of the relationship between patient and relative that could shed further light into risk perception and the experience of type 2 diabetes. One study in this review suggested that people do not engage in health protective behaviours if they are not aware of the link between the specific behaviour and type 2 diabetes (e.g. physical activity, Forsyth & Goetsch, 1997). This provides support for findings that the salience of the relationship between behaviour and health outcomes is a criterion for a teachable moment when people's motivation to change behaviour is increased (Cohen et al., 2011). This suggests that simple interventions, such as physician's advice may be as effective as intense behaviour change interventions if delivered at the right time and to the right target group. The time of type 2 diabetes diagnosis in a family member may be an excellent teachable moment and a platform for behaviour change as it may increase perceived risk of type 2 diabetes in the relatives of the patient.

The above findings need to be interpreted with caution because the studies included in this review share several limitations. All of the quantitative studies had a cross-sectional design and as such they provide only a description of the data and limit the ability to make causal attributions. Similarly, the qualitative studies in this review quantified risk perception by presenting the number or percentage of people who perceived themselves to be at high risk of developing type 2 diabetes. More in-depth information is needed to understand the impact of family history of diabetes on risk perception. Finally, most studies relied on one- or two- item, self-report measures to assess family history and risk perception of diabetes. Risk perception is a complex concept, which may be affected by various factors (e.g. age, gender, relationship with patient, lifestyle) and may change over time. Increased understanding of risk perception in family members of people with type 2 diabetes would shed further light into people's potential motivation to engage in risk reducing health behaviours.

3.2.5 Conclusion

The findings from this review demonstrate that although risk perception is a complex concept, influenced by an array of other factors, many people with family history of diabetes see themselves at increased risk of developing type 2 diabetes.

Table 8 Research questions and findings on risk perception of type 2 diabetes

Research question	Findings and relevance to the overall project
Does previous research indicate that people with family history or a partner with diabetes have increased perceived risk of developing type 2 diabetes?	Many relatives believe they are at increased risk of type 2 diabetes but this perception is affected by factors, such as age, gender, and weight status. More research is needed to explore why some people do not perceive themselves to be at risk of type 2 diabetes and whether or not diagnosis in a relative increases this perception. Research is needed to explore risk perception of type 2 diabetes among partners of people with the condition.

Chapter 4: Previous research on Type 2 diabetes prevention interventions

A systematic review was conducted to address research question 5: **What does published research show about successful intervention strategies, used in Randomised Controlled Trials, for type 2 diabetes prevention in the relatives of people with the condition?** A systematic review is a review of all empirical evidence that fits pre-specified eligibility criteria to answer a specific research question (Higgins & Green, 2011). A systematic review, rather than a scoping review, was deemed appropriate to answer this research question for two reasons. First, scoping reviews address broader questions where different study designs are applicable (Arskey & O'Malley, 2005) while the current research question is specific and requires the collation of studies with specific study designs (i.e. Randomised Controlled Trials). Second, scoping reviews do not assess study quality, which may not be relevant or possible when studies with different designs are included in the review. However, for this part of the review, it was important to assess study quality in order to identify effective strategies for type 2 diabetes prevention.

4.1.1 Introduction

A “health scare”, such as an illness diagnosis, may be a teachable moment for high-risk individuals when they are more motivated to engage in and adhere to lifestyle advice (Anderson et al., 2013). It has been suggested that behaviour change programs, which target high-risk individuals are more effective than those targeting the whole population, because if people learn that they are at high-risk, then they might be more willing to change behaviour (Anderson et al., 2013). The high-risk approach to prevention is also a cost-effective use of resources, directed at individuals who are at greatest need (e.g. first degree relatives of type 2 diabetes patients) (Rose, 2001). Finally, high-risk individuals are likely to gain more benefit from the intervention for the same likelihood of harm as lower-risk individuals (Rose, 2001). This has been demonstrated by Gill and Cooper (2008) who conducted a review of prospective studies and diabetes prevention trials, looking at the protective effects of physical activity against type 2 diabetes. The review showed that vigorous physical activity is most beneficial for high-risk groups (e.g. people with family history of diabetes). First-degree relatives and partners of people with type 2 diabetes represent a group at high risk of type 2 diabetes (Pierce, 1995; Weijnen et al., 2002). Therefore identifying and intervening in the relatives of people with type 2 diabetes is important and could form part of an effective diabetes prevention strategy. There is compelling evidence that lifestyle improvements, such as increase in physical activity and healthy diet, and weight loss, could decrease the

likelihood of developing type 2 diabetes in high-risk groups (Kirk et al., 2003; Klein et al., 2004; Di Loreto et al., 2005; Gillies et al., 2007). The Finnish Diabetes Prevention Study (Lindström et al., 2003) was one of the first to demonstrate that type 2 diabetes can be prevented through a lifestyle intervention. Similarly, the Diabetes Prevention Program Research Group (2002) found that compared to placebo, the lifestyle programme in the study decreased the incidence of diabetes by 58% over three years, which was considerably greater than the beneficial effect of metformin (medication used to treat type 2 diabetes; 31% risk reduction).

Although early prevention could be of great importance to the first-degree relatives and partners of people with type 2 diabetes, little is known about the effectiveness of lifestyle interventions in this presumably motivated target group. This systematic review synthesises previous published randomised controlled trials (RCTs) in order to identify successful recruitment and intervention strategies for type 2 diabetes prevention in relatives and partners of people with the condition.

4.1.2 Search strategy and study selection

The research question for this review was: “What does published research show about successful intervention strategies, used in Randomised Controlled Trials, for type 2 diabetes prevention in the relatives of people with the condition?”. The selected databases were MEDLINE, PsychINFO, CINAHL, ASSIA and ProQuest and a librarian assisted with the search terms for each database. The search terms included “random* control* trial*”, “RCT”, “type 2 diabetes”, “non-insulin dependent diabetes”, “NIDDM”, “family+”, “spouse*”, “partner*”, “sibling*”, “parent*” and “offspring*”. All databases were searched from inception until June 2018.

RCTs were included if they aimed to modify behaviours, known to delay or prevent type 2 diabetes (e.g. physical activity, healthy diet) and were delivered to the relatives and/or partners of people with type 2 diabetes. Studies were excluded if they were not in English, if they were not RCTs, if they were feasibility studies or protocols or if the participants did not have a relative/partner with type 2 diabetes (or if this was not reported). The criteria were applied in a two-step process. In the first step, they were applied to the titles and abstracts of the identified studies. If the relevance of a study was not clear from the abstract, the full text of the study was assessed. RefWorks was used to manage the references identified by the search.

The criteria were applied in a two-step process which resulted in the identification of seven studies (Figure 6). The additional search through the reference lists of included articles identified a narrative review that explored successful prevention strategies for the prevention of type 2 diabetes among people with family history of diabetes (Heideman et al., 2011). This led to the addition of a study, which was not identified by the initial search strategy (Brekke et al., 2003, 2004, 2005a, 2005b). The search strategy was designed to identify RCTs while Brekke et al.'s (2003, 2004, 2005a, 2005b) study was an intervention controlled trial where participants were randomised into treatment groups through the process of minimisation. Minimisation is based on the principle of randomisation although participants are allocated to treatment groups on the basis of specific characteristics such as gender or BMI (Altman & Bland 2005). Minimisation is appropriate for controlled trials with small samples because it minimises the imbalance between different factors (Altman & Bland, 2005).

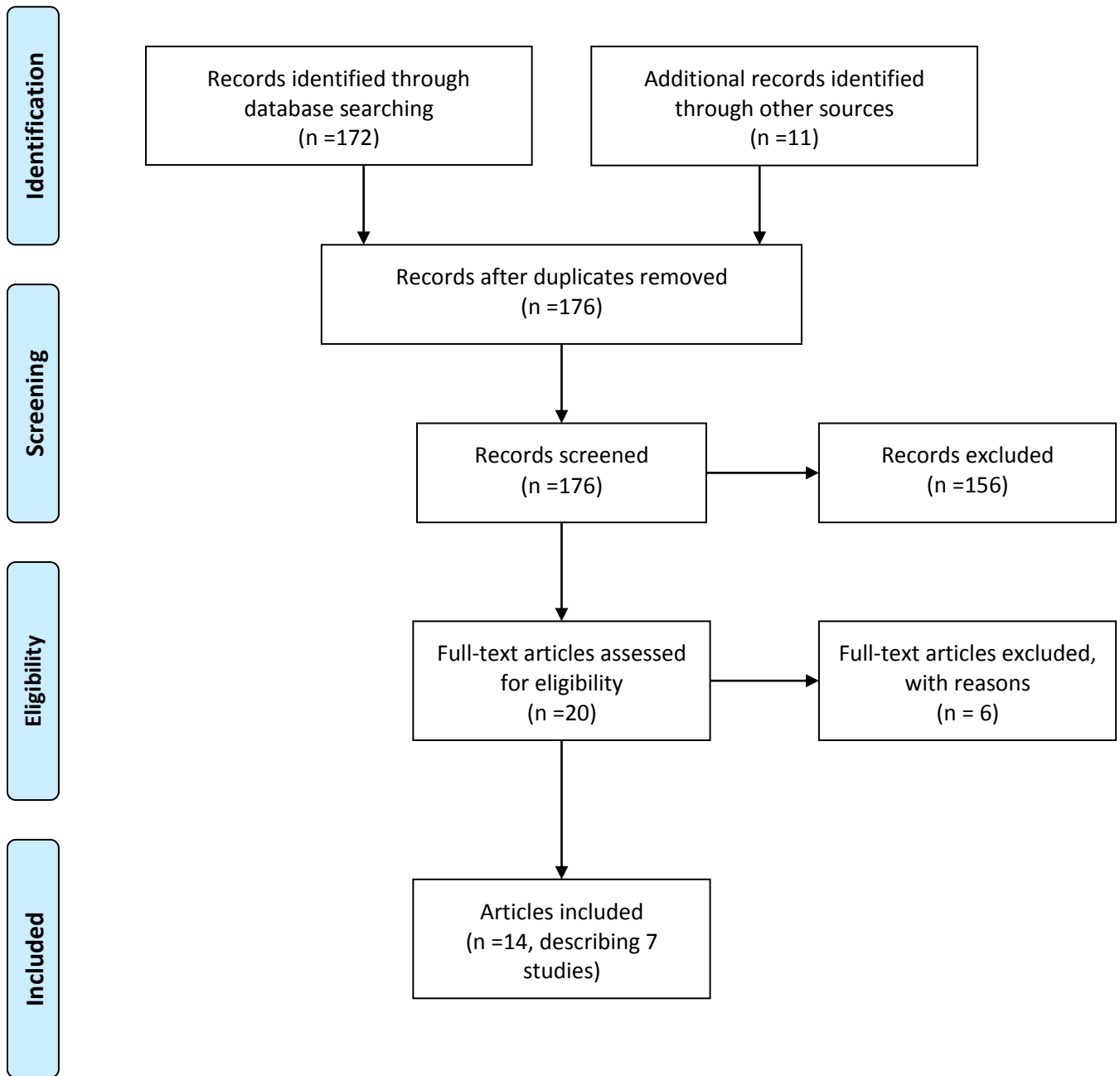


Figure 6 Identification and selection of studies

(Adapted from Moher et al., 2009).

The extracted articles were reviewed on the basis of author and year, study aims, participants, intervention design and components, measures, results and limitations (in supplementary material on CD). In order to gain understanding of commonly used intervention strategies and strategies used in studies that showed effectiveness, these were classified according to the Behavior Change Technique (BCT) Taxonomy (Abraham & Michie, 2012). The reported strategies in each intervention were extracted. Then the BCT taxonomy was used to find out if each strategy in the intervention is an established behaviour change technique, as defined by the BCT taxonomy.

4.1.3 Assessment of study quality

Study quality was assessed using the Cochrane Collaboration's tool for assessing risk of bias (Higgins et al., 2011). The tool provides a systematic and transparent method of assessing risk of bias across several domains (Higgins et al., 2011). Assessors are required to assign "high risk", "low risk" or "unclear risk" of bias, based on the sources of bias, which include random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data and selective reporting. The tool also provides an opportunity to assess bias, based on other sources that assessor considers to be relevant (Higgins et al., 2011).

4.1.4 Results and findings

Seven studies, published in 14 articles in peer-reviewed journals, were included. The majority of studies were published between 2000 and 2015 with only one study published prior to this (1998). Studies were conducted in the Netherlands (2), the USA (2), Japan (1), Sweden (1) and the UK (1). Interventions were delivered to parents and siblings of people with type 2 diabetes (DiAlert trial: Heideman et al., 2011, 2012, 2015; Tokunaga-Nakawatase et al., 2014), offspring only (Wing et al., 1998; ProActive trial: Williams et al., 2004; Kinmonth et al., 2008; Hardeman et al., 2009), first-degree relatives (relationships not specified) (Brekke et al., 2003, 2004, 2005a, 2005b; Pijl et al., 2009), or partners (Gorin et al., 2008).

Three of the studies were at high risk of bias in one (Wing et al., 1998), two (Heideman et al., 2011, 2012, 2015) or three domains (Tokunaga-Nakawatase et al., 2014), including lack of blinding, incomplete outcome data and selective reporting. While there were no obvious sources of bias in the other four studies, the presence of unclear risk in at least one domain for each of them indicates that many studies fail to provide sufficient information

for bias to be adequately assessed.

Table 9 Assessment of study quality

	Random sequence generation.	Allocation concealment.	Blinding of participants and personnel.	Blinding of outcome assessment.	Incomplete outcome data.	Selective reporting.	Other sources of bias.
Wing et al., 1998	L	U	L	L	U	L	H ¹
Brekke et al., 2003	L	U	U	U	L	L	L
Gorin et al., 2008	L	L	U	L	U	L	L
Proactive trial, 2004	L	L	U	L	L	L	L
Pijl et al., 2009	L	L	U	U	L	L	L
Tokunaga-Nakawatase et al., 2012	L	L	H	L	H	H	L
Heideman et al., 2011	L	L	H	L	L	L	H ²

^{1.} High risk of other bias because there was a significant difference in session attendance between groups.

^{2.} High risk of other bias because the study was underpowered; anthropometric measurements were not blinded to treatment allocation; intervention fidelity was not objectively measured.

In order to aid the development of guidelines for a future intervention the results of this review are organised according to recruitment methods, intervention components and mode of delivery, and study outcomes.

Recruitment methods

It is useful to learn from previous studies how participants were recruited. The information was used to inform potential recruitment strategies for the next stage of the PhD.

Three main recruitment strategies were identified: advertising in the community (Brekke et al., 2003, 2004, 2005a, 2005b; DiAlert study, 2011, 2012, 2015; Wing, 1998), recruiting through relatives with diabetes (Gorin et al., 2008; ProActive trial, 2004, 2008, 2009) or identifying people at high risk (defined by having a relative with diabetes) when they had a healthcare contact (Brekke et al., 2003, 2004, 2005a, 2005b; DiAlert study, 2011, 2012, 2015; Pijl et al., 2009; Tokunaga-Nakawatase et al., 2014).

Three of the studies did not provide sufficient information to assess participation response (Brekke et al., 2003, 2004, 2005a, 2005b; Heideman et al., 2011, 2012, 2015). In the ProActive trial, only 365 (24%) relatives were recruited from a pool of 1,521 trial participants with type 2 diabetes (Williams et al., 2004; Kinmonth et al., 2008; Hardeman et al., 2009). In the LookAHEAD trial, 357 (7%) partners were recruited from 5,145 trial participants with type 2 diabetes (Gorin et al., 2008). In the other two studies, 53% (Pijl et al., 2009) and 40% (Tokunaga-Nakawatase et al., 2014) of eligible relatives identified through their own health care contacts agreed to take part. However, Tokunaga-Nakawatase et al. (2014) did not state how many people needed to be screened in order to identify eligible people and in Pijl et al.'s (2009) study there was an initial population screening of over 11,000 people (Spijkerman et al., 2002).

Intervention components and mode of delivery

The studies generally incorporated lifestyle interventions focusing on diet and/or physical activity, and behavioural strategies (e.g. goal setting, self-monitoring) that were group and/or individually based, with one study exploring the communication of familial risk (Pijl et al., 2009). The behaviour change strategies were mapped against the BCT taxonomy (Abraham & Michie, 2008). The most often used strategies were “provide information on consequences”, “prompt specific goal setting” and “prompt self-monitoring of behaviour”.

Studies were too heterogeneous in terms of intervention components to allow for a meta-analysis to be conducted.

Two studies delivered an intervention, which included information about diet, exercise or both, in a group environment (Brekke et al., 2003, 2004, 2005a, 2005b; Wing et al., 1998). Wing et al.'s (1998) trial was the most intensive trial, consisting of three intervention and one control arms, utilising 12 behaviour change strategies and lasting two years. Participants attended frequent group meetings over a period of one year and received two refresher courses during the second year. The sessions included information on diet, exercise or both (depending on intervention group). The control group received a self-help

manual with information on healthy eating, exercise and behavioural strategies for weight control. The intervention in Brekke et al.'s trial (2003, 2004, 2005a, 2005b) utilised seven behaviour change techniques and compared the efficacy of two intervention groups against a control group. The intervention consisted of two educational sessions and unannounced phone calls for four months. One of the intervention arms focused on diet modification while the other combined diet and exercise advice. The control group received a letter informing participants to maintain their lifestyle. One year later, participants in the control group received the same intervention as the diet group.

Three studies delivered the intervention to individuals (Pijl et al., 2009; Tokunaga-Nakawatase et al., 2014; ProActive trial, 2004, 2008, 2009). The ProActive trial (Williams et al., 2004; Kinmonth et al., 2008; Hardeman et al., 2009) used 10 behaviour change strategies and compared the efficacy of a lifestyle intervention, delivered by a trained facilitator either over the phone or in person. The intervention lasted 12 months and focused on behavioural strategies such as goal setting, action planning, self-monitoring and building support from family and friends. Participants in the comparison group received an advice leaflet. Pijl et al. (2009) conducted an RCT where participants attended one meeting and were informed of their genetic risk of type 2 diabetes. The intervention used two behaviour change techniques. Participants in the control group received a five-year risk estimate which was based on general risk factors. The trial, conducted by Tokunaga-Nakawatase et al. (2014) tested a lifestyle intervention that provided participants with tailored, concrete lifestyle recommendations via email in addition to a pamphlet about general diabetes prevention. This trial used three behaviour change techniques. The control group received the same pamphlet and conventional routine care.

Two studies included a combination of individual and group mode of delivery (Gorin et al., 2008; Heideman et al., 2011, 2012, 2015). Gorin et al. (2008) delivered an intervention to people with type 2 diabetes but aimed to explore the indirect intervention effect of the participants' spouses. The intervention utilised five behaviour change techniques. Participants attended five group meetings and two individual sessions over the course of one year and received training in self-monitoring, problem solving, goal setting, relapse prevention and enhancing social support. Participants in the enhanced usual care program were offered three information group meetings per year that provided information on diabetes, nutrition and physical activity. The intervention in the DiAlert trial (Heideman et al., 2011, 2012, 2015) was based on the Health Action Process Approach, utilised eight behaviour change techniques and consisted of two interactive group sessions. The sessions involved

discussion about risk factors for type 2 diabetes, benefits and barriers of lifestyle changes, self-monitoring, physical activity, nutrition and setting personal action plans. In addition to these sessions, participants received four newsletters providing information about healthy eating and physical activity. Participants in the control group received a brochure with information about heredity and general risk factors for type 2 diabetes.

Study outcomes

Intervention effectiveness and outcomes varied across studies. Five of the seven studies reported significant changes in reported primary outcomes (e.g. weight loss, calorie intake, waist circumference). One study observed intervention effectiveness during the intervention but not at follow-up (Tokunaga-Nakawatase et al., 2014) and one did not report significant changes in primary outcomes (Kinmonth et al., 2008; Hardeman et al., 2009).

Two studies showed that a combination of diet and exercise leads to most significant sustained changes in participants' behaviour (Wing et al., 1998; Brekke et al., 2003, 2004, 2005a, 2005b). Wing et al. (1998) showed that weight loss decreased the risk of type 2 diabetes with 31% in comparison to no change in weight. Participants in the diet group reported significant decrease in daily calorie intake and weight, which was sustained for a year. The diet plus exercise intervention led to increased physical activity and significant weight loss, which was maintained for two years. However, the study also showed significant difference in session attendance between groups, which may have affected the results. Brekke et al. (2003, 2004, 2005a, 2005b) reported significant decrease in body weight, waist circumference and sagittal diameter in the diet plus exercise group, compared to the control group. At one year follow up, participants showed significant changes from baseline to follow-up in most dietary adherence measures in both intervention groups. Although the strength of these changes diminished, they were maintained two years after the intervention. In addition, decrease in body weight was sustained over two years within the diet plus exercise group.

Gorin et al. (2008) found significant correlations between the behavior of type 2 diabetes patients and their spouses. Over the one-year period of the study, the spouses of intervention participants lost significantly more weight and significantly reduced energy intake, in comparison to the spouses of control participants.

Pijl et al. (2009) reported significant increase in healthy eating and marginally significant changes in physical activity for participants in the intervention group. However, their behavioural intentions did not differ from the intentions of participants in the control group.

The DiAlert trial (Heideman et al., 2011, 2012, 2015) reported significant sustained decrease in waist circumference and improved systolic blood pressure in the intervention group. However, the intervention did not affect intention to change behavior, self-efficacy and outcome expectancies and did not lead to significant changes in diet, physical activity, smoking or alcohol intake. These results should be interpreted with caution as the DiAlert trial was at high risk of bias for not concealing treatment allocation and anthropometric measurements from participants and trainers, for not providing objective assessment of intervention fidelity and for being underpowered.

Tokunaga-Nakawatase (2014) reported intervention effectiveness during the intervention but not thereafter. Although changes in total energy intake were observed between the groups at 6 months, there were no significant differences in energy intake, physical activity or biomedical factors at 12 months after the intervention. This study was at high risk of bias for selective reporting, lack of explanation for missing data and not blinding participants to study group.

The intervention in the ProActive trial (Kinmonth et al., 2008; Hardeman et al., 2009) did not lead to significant changes in physical activity, weight, BMI, waist circumference, blood pressure or cholesterol.

4.1.5 Summary of results and identification of research gaps and future research

This systematic review shows that there has been limited research evaluating interventions that target modifiable risk factors for type 2 diabetes in the relatives and partners of people with the condition. This is particularly true for partners, which is surprising given that partners of people with type 2 diabetes are at increased risk of the condition due to shared lifestyle factors (Khan et al., 2003; Leong et al., 2014). One study in this review showed a significant correlation between the behaviour of patients and their spouses, which lead to behaviour changes in the untreated spouse (Gorin et al., 2008). This shows the need to further explore how the relationship between patients and their partners can be used as a mediator for behaviour change. In addition, theories such as Common Dyadic Coping (Bodenmann et al., 2011), Communal Coping (Lyons et al., 1998) and Family Systems Theory (Crossno, 2011) suggest that couples and families may appraise illness as a joint problem that requires joint action. Previous studies also show that people with type 2 diabetes often inform their relatives about familial risk of type 2 diabetes without formal

prompting from health professionals (Whitford et al., 2009; van Esch et al., 2012). This highlights the potential of utilising family communication as a tool for prevention of type 2 diabetes. Research in the area of cancer (Demark-Wahnefried et al., 2014) indicates that capitalising on the bond between family members may promote behaviour change by increasing self-efficacy and joint problem solving.

Capitalising on family communication may not always be feasible, so relatives can be informed about familial risk of type 2 diabetes by health professionals or during an intervention. One study in the current review showed that communication of genetic risk can lead to short-term changes in behaviour (Pijl et al., 2009). This suggests that such interventions require further investigation as they are simpler and cheaper than complex lifestyle interventions.

Four of the studies in this review demonstrated intervention effectiveness (Wing et al., 1998; Brekke et al., 2003, 2004, 2005a, 2005b, Gorin et al., 2008; Pijl et al., 2009). However, the intervention components and modes of delivery across these studies are too heterogeneous to allow for a number of successful components to be identified. The use of defined behaviour change techniques, as per the BCT taxonomy (Abraham & Michie, 2008) varied, ranging from two to twelve, but there was no clear link between the number of techniques and intervention effectiveness. Only two studies demonstrated sustained behaviour change at two years follow-up (Wing et al., 1998; Brekke et al., 2003, 2004, 2005a, 2005b). Although intervention intensity differs, both studies showed that participants who receive a combination of diet and exercise education report the most significant decrease in body weight. However, such interventions are intensive and costly. In addition, intensive interventions can sometimes have the opposite effect and lead to distress and negative quality of life in participants (Marrero et al., 2014).

The systematic review also raises questions about effective strategies for recruiting the relatives and partners of people with type 2 diabetes. Recruitment of relatives through health care contacts appears to be the most promising approach. However, the number of people who need to be screened in order to identify eligible participants may be high and complicated by logistic and financial reasons.

This review allows the identification of several limitations with the evidence base in the area of type 2 diabetes prevention among high-risk groups. A severe limitation is the paucity of high-quality research which aims to prevent type 2 diabetes among the relatives of type 2 diabetes patients. Furthermore, only one RCT has been conducted in the UK and the intervention was not more effective in promoting behaviour change than an advice leaflet.

Another limitation of the studies, included in this review, is the lack of long-term outcomes. Future research should focus on sustained behaviour change. None of the studies in this review provide information on the time since type 2 diabetes diagnosis in the target patient. In line with McBride et al. (2008) and the notion of the teachable moment, it could be suggested that the effectiveness of such interventions could be increased if they are delivered at the time of diagnosis. In addition, no RCTs have utilised the relationship between the type 2 diabetes patient and their significant others as a mediator for behaviour change.

4.1.6 Conclusion

It remains unclear how best to promote health behaviour change among the family members of type 2 diabetes patients. Intervention components and intervention intensity across studies in the systematic review varied, with those targeting diet and physical activity reporting the most significant changes in primary outcomes. However, such interventions may be costly and demanding on participants' time. In addition, the time of intervention delivery (i.e. at the time of illness diagnosis) as well as the personal relationships between family members have not been explored although they may be essential for increasing intervention effectiveness.

The review also shows that finding simple and effective methods to identify and recruit the relatives of people with type 2 diabetes remains a challenge.

Table 10 Research question and findings on type 2 diabetes prevention interventions

Research question	Findings and relevance to the overall project
What does published research show about successful intervention strategies, used in Randomised Controlled Trials, for type 2 diabetes prevention in the relatives of people with the condition?	<p>Interventions that focus on diet and exercise led to most significant changes in primary outcomes. Communication of familial risk is under-researched. Recruitment through health care contacts appears to be an effective approach.</p> <p>The review identified two main challenges that need to be addressed to optimise type 2 diabetes prevention in the relatives and partners of people with the condition: the development of effective and sustainable</p>

	interventions and simple and feasible methods of recruiting potential participants.
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Part 2: Methodology and Methods

Chapter 5: Methodology and methods

5.1 Introduction

The purpose of the project is to explore the concept of the teachable moment in an attempt to identify the factors that make a cueing event, such as illness diagnosis, a teachable moment. It also aims to suggest components and mode of delivery of a potential intervention to prevent type 2 diabetes among the relatives of patients with this condition. The research reviewed in chapter 2 showed that illness diagnosis increases people's motivation to engage in health behaviours. However, the potential of type 2 diabetes diagnosis to be a teachable moment has not received much attention. Chapter 3 found mixed evidence on illness representations and perceived risk of type 2 diabetes showing that the utility of perceptions in guiding behaviour needs to be explored further. The systematic review in chapter 4 demonstrated lack of research evaluating interventions to prevent type 2 diabetes in people with family history of the condition.

Chapter 5 describes the mixed methods study, conducted as part of the PhD research, and used to address the gaps in the application of teachable moments to type 2 diabetes and the need for simple, cost-effective interventions to prevent type 2 diabetes in people with a family history of the condition. The chapter begins with an outline of the research questions the mixed-methods study answers (5.2). It then describes the overall philosophical underpinnings and study design (5.3) before explaining the methodology and methods of each study within the mixed-methods study: interviews (5.4) and questionnaires (5.5).

5.2 Research questions

The overall aim of this PhD project is to refine the concept and improve applicability of teachable moments in health promotion by exploring the contextual factors on whether and for whom the diagnosis of type 2 diabetes is a teachable moment. This aim was divided into nine specific research questions. The scoping reviews and systematic review answered the first five questions. The mixed-methods study addresses the remaining four. The parentheses indicate which chapter each question is addressed in:

RQ6: How does type 2 diabetes diagnosis affect patients and their relatives, in terms of perceptions, behaviour and relationships? (Chapter 6: Study One: Changes following type 2 diabetes diagnosis and teachable moment criteria).

RQ7: What criteria need to be fulfilled for the diagnosis of type 2 diabetes to be a teachable moment? (Chapter 6: Study One: Changes following type 2 diabetes diagnosis and teachable moment criteria and Chapter 7: Relationship between the criteria for a teachable moment and changes in behaviour).

RQ8: Are the newly identified criteria for a teachable moment associated with engagement in physical activity and healthy diet, and interest in receiving information about type 2 diabetes? (Chapter 7: Study Two: Relationship between the criteria for a teachable moment and changes in behaviour).

RQ8: What recruitment methods, intervention components and mode of delivery would be acceptable to potential participants? (Chapter 8: Study One: Type 2 diabetes prevention interventions).

5.3 Philosophical underpinnings and study design

The researcher's philosophical position relates to ontology, epistemology and methodology. Ontology is concerned with the nature of existence (Bryman, 2012). In other words, is the phenomenon under investigation real? Epistemology relates to the theory of knowledge (Bryman, 2012) or how the phenomenon under investigation is learned. Methodology is concerned with the strategies we use to explain the phenomenon under investigation. (Bryman, 2012).

The three most common philosophical paradigms were considered for this research: positivism, interpretivism and pragmatism. From an ontological perspective, positivism holds that there is an objective reality (Snape & Spencer, 2003). From an epistemological perspective, knowledge can be developed through accumulation of verified facts (Snape & Spencer, 2003). Positivists believe that researchers should eliminate bias, remain emotionally detached from the objects of study and empirically justify stated hypotheses (Johnson & Onwuegbuzie, 2004). Positivism is associated with quantitative research which typically adopts a deductive approach where hypotheses are developed and tested.

Interpretivism sits on the opposite end of the spectrum in comparison to positivism. It holds that there is no single truth and realities are constructed by individuals and influenced by social interactions (ontology) (Howe, 2004). From an epistemological perspective, interpretivists believe that reality needs to be interpreted on the basis of how people make sense of the world around them (Snape & Spencer, 2003). Interpretivism is associated with

qualitative research, which is inductive because it describes ideas and concepts as they occur naturally (Snape & Spencer, 2003). Positivism and interpretivism are primarily concerned with observing the world rather than the practical consequences of ideas. Pragmatism states that the meaning of an idea or a concept is the practical consequences of the idea/concept (Peirce, 1878). It argues that reality is constantly changing and is interpreted in light of its usefulness (ontology). Pragmatism is about the interaction of knowledge and action and the transformation of a current situation in the interest of improvement (epistemology) (Dewey, 1938; Cronen, 2001). In an article, Peirce (1878) illustrates this point by saying that *“we come down to what is tangible and practical as the root of every real distinction, no matter how subtle it might be; and there is no distinction of meaning so fine as to consist in anything but a possible difference of practice”*(p. 293). The overarching aim of this project is to refine theory and improve its applicability, rather than merely observe events. This is closely aligned with the fundamental principle of pragmatism.

Pragmatism is associated with mixed-methods research, which involves a combination of qualitative and quantitative methods (Johnson & Onwuegbuzie, 2004; Creswell et al., 2011). Mixed-methods research has the potential to answer a broad range of research questions by combining the strengths of both quantitative and qualitative research (Brannen, 2005). Given the complex nature of teachable moments and the lack of research on what makes type 2 diabetes a teachable moment, a mixed-methods study was appropriate in order to provide a deeper and more comprehensive understanding of teachable moments than would be possible if only one method was used. After deciding to use mixed-methods, consideration was given on the order and priority of each phase. As the concept of the teachable moment is understudied, it was appropriate to first conduct the qualitative phase in order to uncover the factors that may shape people’s response to diagnosis. However, the factors identified through interviews with a small group of participants would not be generalisable. A quantitative study with a larger sample, considered to be more representative of the target population, was used to refine the findings from the qualitative study. Each study was given equal priority within the mixed-methods design as both studies aimed to answer the same research question: i.e. what criteria need to be fulfilled for the diagnosis of type 2 diabetes to be a teachable moment?.

Figure 7 represents the epistemology, ontology and methodology of pragmatism and how they have informed the PhD.

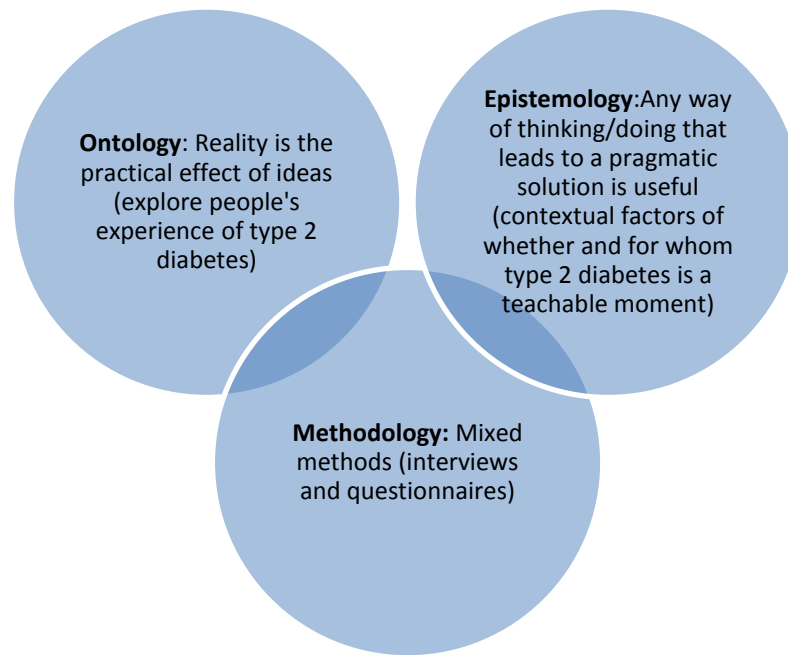


Figure 7 Ontology, epistemology and methodology

According to Ritchie and Lewis (2003) quantitative and qualitative research can be combined in different ways to form a mixed-methods study. When a study explores an underdeveloped or complex subject, qualitative methodology precedes quantitative in order to define concepts and structure questions. On the other hand, when findings need further explanation, qualitative research follows quantitative as words and narrative can add meaning to numbers (Brannen, 2005). Finally, both types of research can be used alongside each other when both the number and nature of the same phenomenon need to be explained (Ritchie & Lewis, 2003). Such convergence of findings provides stronger evidence for conclusion and adds insight that may be missed when a single method is used (Brannen, 2005). In addition, mixed methods approaches increase generalisability of findings and provide more complete knowledge to inform theory and practice (Brannen, 2005).

The potential ways of employing a mixed-methods approach is further elaborated by Bryman (2007). Bryman's (2007) descriptions of each mixed-methods approach are summarised below:

1. Triangulation: involves the convergence of different methods by emphasising the corroboration between quantitative and qualitative data.
2. Complementary: involves the clarification of the results from one method with the results from another.
3. Development: uses the results from one method to inform the other method.

4. Initiation: aims to recast the questions or results from one method with questions or results from the other method.

5. Expansion: seeks to extend the range of enquiry by using components of different methods.

The current study uses a development approach where the qualitative phase precedes the quantitative. The qualitative phase explores an understudied concept and the results are used to inform the quantitative phase (Figure 8).

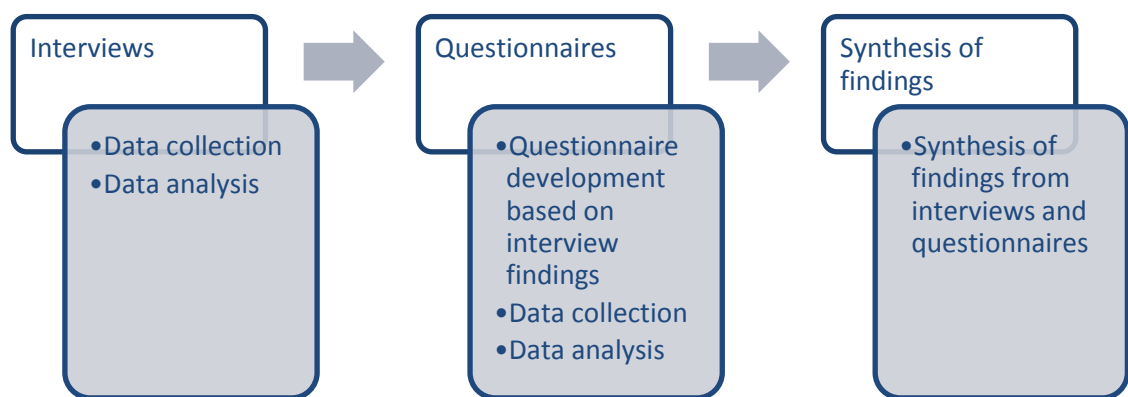


Figure 8 Schematic of the developmental mixed-methods design

The major challenge in using mixed-methods is the integration of quantitative and qualitative methods in order to provide an integrated analysis (Bryman, 2007). Bryman (2007) suggests that in order to overcome this challenge, the researcher needs to be guided by the study rationale and research questions, and the reason for using mixed-methods. The fact that data do not always “fit” together also needs to be acknowledged. Uprichard and Dawney (2016) propose the so called “diffraction” approach, which provides researchers with new ways to deal with data that do not integrate well. The conduct of the current mixed-methods project was guided by Bryman (2007) and Uprichard and Dawney (2016).

5.4 Study One: Interviews

5.4.1 Aim

The aim of Study One was to identify potential factors that may make diagnosis of type 2 diabetes a teachable moment by uncovering the cognitive and behavioural changes that occur in people with type 2 diabetes and their relatives at the time of type 2 diabetes diagnosis. This study also explored participants' views on potential components and mode of delivery of an intervention to reduce type 2 diabetes among high risk groups.

5.4.2 Sampling and recruitment strategies

There are two types of sampling in research: probability and non-probability sampling. Probability sampling relies on randomisation in order to ensure all members in a given population have an equal chance of being selected while non-probability sampling does not rely on randomisation (Bryman, 2012). Study One used non-probability convenience sampling to recruit participants. Convenience sampling is concerned with selecting members of the target population that meet certain practical criteria, such as easy accessibility, geographical proximity, availability at a given time, or willingness to participate (Bryman, 2012). Convenience sampling was used due to practicality, both in terms of time and cost.

Based on the causes of type 2 diabetes (section 1.3.2), the target group of participants for the current study were: people with type 2 diabetes, first-degree relatives of people with type 2 diabetes (whether they live with the patient or not) and spouses of people with type 2 diabetes (who live with the patient). In order to explore people's experience shortly after diagnosis, I wanted to recruit newly diagnosed people (relatives or newly diagnosed people), so the inclusion criteria were:

- Adults over the age of 18 who have been diagnosed with type 2 diabetes in the past 6 months.
- Adults over the age of 18 who have a first-degree relative or partner who has been diagnosed with type 2 diabetes in the past 6 months.

The exclusion criteria were:

- Adults under the age 18.
- Adults who have been diagnosed with type 2 diabetes more than 6 months ago.

- Adults whose first-degree relative/partner has been diagnosed with type 2 diabetes more than 6 months ago.
- People who do not speak English.

The lower age limit was set at 18 to ensure that only adults who can give informed consent were selected. Several people who were diagnosed more than 6 months ago contacted me but according to the above inclusion criteria, they were excluded. However, during an interview one participant shared his thoughts on the inclusion criteria saying that people diagnosed in the past one year may still view themselves as newly diagnosed. He said that type 2 diabetes is a chronic illness people have for the rest of their lives, so a diagnosis in the past one year is still considered to be recent. As a result, the inclusion criterion changed to “people who consider themselves (their relative) to be newly diagnosed”. People who were initially excluded were contacted, made aware of the change in inclusion criteria and asked if they were still willing to take part.

The participants were recruited through community outreach. Studies reviewed during the literature review demonstrated that recruitment of people with type 2 diabetes through posters and flyers is commonly used (see 4.1.4). In order to target a diverse group of potential participants, I placed posters and flyers in different community venues and advertised the study online. For the posters and flyers, geographical location was a practical consideration so recruitment was targeted in Forth Valley, Scotland. I expected recruitment to be challenging so I made a detailed list of potential places, including their address and contact details. I sent an email or posted a letter, explaining the project and asking for permission to place the study poster and flyers on the notice board at the particular location. One week after this, I visited the locations to either provide the marketing materials (if permission was given in response to the email or letter) or to ask for permission in person (if no response was received). The posters (Appendix 1) and flyers (Appendix 2) were placed in 109 locations across Forth Valley, including community centres, libraries, charity shops, bowling clubs, golf clubs, local post office branches, local pharmacies and the University of Stirling. Only two places refused to display the poster.

The online recruitment strategy included adverts on social media and different employers’ internal email. Diabetes UK was contacted and they agreed to advertise the study on their website, newsletter and social media pages. Large employers, such as Tesco, ASDA, First Buses and Scot Rail, were also contacted via email. Unfortunately, these employers either did not respond or were not able to assist. Falkirk council, Stirling council and job

centres in Falkirk and Stirling were contacted via email asking them to circulate a recruitment message to their staff via email or place a poster on their notice board. Stirling council and Falkirk job centre offered assistance. The study was also advertised on the University of Stirling internal portal. A study advert was circulated via email to staff at the Faculty of Health Sciences and Sport and the Faculty of Natural Sciences. The study was also advertised through friends and family who were asked to suggest it to people they knew and to share a study advert on Facebook. A detailed list of all locations can be seen in Appendix 3.

People who showed interest in the study by getting in touch with me were asked to indicate their preferred means of communication, so I could explain the study in detail and screen them for eligibility. If they were eligible to take part, I asked the potential participant to nominate one non-diabetic family member (e.g. a first-degree relative or a co-habiting partner) who might be willing to take part in the study (or nominate the relative with diabetes if it was the family member who got in touch). The participant was then asked to provide their family member with the study flyer and my contact details and ask them to contact me if they were willing to take part in the study. All potential participants were then sent a participation information leaflet. Two versions of the leaflet were developed – one for type 2 diabetes patients and another for the family members of type 2 diabetes patients (Appendix 4 and Appendix 5). A week after the participant information leaflet was sent, I contacted the potential participants to ask if they would like to take part in the study and to arrange an interview. At this stage participants could indicate if they would like to attend the interview alone or with their family member/partner. The option of a telephone interview was also offered.

Sample size is an important consideration in research. It is usually argued that in qualitative research the sample size is determined by data saturation, which is reached when no new themes emerge (Mason, 2010). However, some researchers suggest that in small projects, such as a PhD, the sample size usually lies under 50 (Ritchie & Lewis, 2003) with the minimum sample size being 15 participants (Mason, 2010) and the ideal sample size being 25 (Charmaz, 2006). In order to allow for data saturation and follow recommendations, I aimed to recruit 10 to 15 newly diagnosed patients with type 2 diabetes and 10 to 15 relatives of newly diagnosed patients with type 2 diabetes. These did not need to be matched in order to allow for inclusion of people who did not have eligible relatives or whose relatives were not willing to participate.

5.4.3 Data collection

This study aimed to explore people's individual experience of type 2 diabetes, such as response to diagnosis and how the illness affected them and their family. For this reason, interviews were deemed to be the most appropriate data collection method. According to Gill et al. (2008) the purpose of a research interview is to "*explore the views, experiences, beliefs and/or motivations of individuals on specific matters*" (p.292). There are three types of interviews: structured, semi-structured and in-depth interviews (unstructured). These types are often placed on a continuum with the structured interview being more similar to a questionnaire and the unstructured interview more similar to a natural conversation (Walliman, 2006; Gill et al., 2008). Semi-structured interviews consist of several key questions which define the main topics that need to be explored thus allowing the interviewer to explore other ideas that emerge during the interview (Gill et al., 2008). According to Gill et al. (2008) semi-structured interviews are particularly useful in healthcare because they provide guidance on what to talk about. An interview could be conducted either face-to-face or over the phone. Telephone interviews are more practical when resources are limited (Walliman, 2006). Face-to-face interviews allow the interviewer to observe visual cues, such as body language, thus allowing them to notice when a question has not been understood correctly (Walliman, 2006). Face-to-face or phone (where face-to-face was not possible), semi-structured interviews were deemed appropriate for the current study in order to ensure focus on research questions but allow flexibility to explore topics that emerge during the interview and that I deemed appropriate to explore further. Steps were taken to minimise difficulties associated with face-to-face interviews. To avoid technical difficulties I always made sure the recorder was working a day before the interview. I also had spare batteries during the interview. Recordings were transferred onto a password protected computer as soon as possible after the interview. To address contextual difficulties, the interviews were conducted in a location convenient for the participants. In most cases, this included a visit to the participant's home. Other venues included meeting rooms in a library or local hotel and participant's workplace. The rooms were always private to ensure confidentiality. Participants were given £10 as reimbursement for their participation.

According to Walliman and Appleton (2009) "*The most important point when you set up an interview is to know exactly what you want to achieve by it, how you are going to record the information, and what you intend to do with it*" (p. 175). This means that an interview schedule needs to be carefully designed in order to allow the researcher to collect data needed to answer the research question. The interview schedule for this study was guided

by the research questions and previous research on factors that affect behaviour (e.g. illness representations, McBride et al.'s, 2008 criteria for a teachable moment). Before the interview started I made sure participants were familiar with the participant information leaflet. Any questions were answered before written informed consent was obtained (Appendix 6). Participants completed a short questionnaire on demographic characteristics (one for patients and one for relatives: appendices 7 and 8). According to recommendations (Walliman, 2006; Walliman & Appleton, 2009; Baumbusch, 2010; Arthur et al., 2014) the interview started with factual questions to ease participants in and establish rapport. Sensitive issues, such as changes in the way people perceive themselves, were discussed once rapport had been established. The last questions provided closure and aimed to leave participants feeling empowered and listened to. In addition, questions were open-ended and non-leading to gather objective data and avoid influencing individual answers. The content of the interview schedule was developed based on the literature review findings. It explored people's illness perceptions of type 2 diabetes, family members' perception of their risk of developing type 2 diabetes, changes in perception and behaviour following diagnosis in oneself or in a family member, and suggestions for future interventions to prevent type 2 diabetes among the relatives of type 2 diabetes patients. The interview schedule and how it was used during the interviews is displayed in table 11.

Table 11 Interview schedule and example interview questions

Interview Schedule	Example interview questions
<p>Written questions: demographics, time since diagnosis, route to diagnosis, relationship with the patient; family history of type 2 diabetes; number of relatives with type 2 diabetes</p> <p>Illness representations: identity, consequences, timeline, cause, severity, control, emotional representation, illness coherence.</p> <p>- How have these changed since diagnosis?</p> <p>Knowledge of strategies to prevent type 2 diabetes onset/complications</p> <p>Perceived risk of developing type 2 diabetes</p> <p>- How did it change after diagnosis?</p> <p>Impact of diagnosis on health behaviours for the patient and the relative; barriers to behaviour change?</p> <p>Impact of diagnosis on self-concept and/or social role?</p> <p>Communication of the diagnosis to family members</p> <p>Information about potential interventions:</p>	<p>I: Do you want to first tell when you got diagnosed and how it happened?</p> <p>I: (to wife): Were you there when he got the diagnosis?</p> <p>I: How long after the diagnosis did you tell [wife]?</p> <p>I: How did you both feel about it?</p> <p>I: What do you think causes it?</p> <p>I: And has your knowledge about causes changed since diagnosis?</p> <p>I: And what do you think the symptoms are?</p> <p>I: It seems like now when you are thinking in retrospect, you are identifying symptoms that at the time you didn't know were symptoms?</p> <p>I: And what do you think the consequences of type 2 diabetes could be?</p> <p>I: And do you think it's easy to manage?</p> <p>I: Thinking about managing but also thinking about prevention, do you think it's preventable and how easy is it to prevent it?</p>

<ul style="list-style-type: none"> - Best way to recruit relatives of type 2 diabetes patients - Preferred intervention components (e.g. group sessions, individual meetings; frequency of sessions; diet; exercise) - Preferred mode of intervention delivery (e.g. in person, phone, email, newsletters) 	<p>I: Saying that, do you think there is stigma associated with type 2 diabetes?</p> <p>I: So have you changed your perception then of that stigma?</p> <p>I: Do you think type 2 diabetes is a serious condition?</p> <p>I: Is that to say that it will last forever but you can limit the impact, or can you go back and reverse it?</p> <p>I: Do you feel like you understand type 2 diabetes as a condition?</p> <p>I: Thinking about all the things you have said have any of your perceptions of type 2 diabetes changed as a result of the diagnosis?</p> <p>I: And now thinking about behaviour, what's changed in terms of behaviour for both of you?</p> <p>I: Have you experienced any challenges, you mentioned cakes and about your daughter, it sounds like you've got a dilemma there, are there any other challenges in terms of trying to manage your type 2 diabetes?</p> <p>I: You are kind of answering my next question about if you feel like your social responsibility has changed? Like now you feel you have to police in a way...</p> <p>I: You said you haven't told any of your colleagues, do you want to tell me why not?</p> <p>I: Have you told your friends?</p> <p>I: And has the diagnosis changed the way you see yourself?</p>
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	<p>I: What do you think about your chances of developing type 2 diabetes?</p> <p>I: I am moving on to the last bit of the interview, the relatives and partners of type 2 diabetes patients are sometimes at a very high risk of developing it themselves, so I want to pick your brains about a possible way to prevent it or delay it in people who are at high risk.</p> <p>I: What do you think is the best way to identify relatives and get them involved in any study or in an intervention?</p> <p>I: So you think an actual education session either in a group or individually, but it has to be face to face? Do you think that would be most effective?</p> <p>I: Or it could be a combination of both?</p> <p>I: And how do you think we should find these people? For this project I used posters but they are not particularly effective. How do you think we could actually find the relatives?</p> <p>I: So when do you think then is the best time to go and speak with the relatives, how soon after diagnosis?</p> <p>I: Okay. Have you got any other thoughts on prevention among high risk groups?</p> <p>I: Right, okay, that's all the questions. Thank you.</p>
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Data collection took five months (between November 2015 and March 2016).

5.4.4 Data analysis

The interviews were audio recorded and transcribed verbatim. A substantive approach to data analysis was taken by focusing on capturing and interpreting what people said (Spencer et al., 2014). It followed the Framework approach, suggested by Spencer et al. (2014), which is a form of thematic analysis that moves from data driven descriptives to abstract themes. This approach is better adapted to research that has specific questions and a priori issues that need to be explored, as it helps to facilitate case analysis and develop theory. Framework approach is based on the assumption that the researcher stays close to the original data in order to “capture, portray and explain the social worlds of the people under study” (Spencer et al., 2014, p.279). Although a priori issues guide the thematic framework, it is important to stay open-minded and not force data to fit the a priori issues (Srivastava & Thomson, 2009). Framework analysis provides systematic and clear stages to the analytic process, thus allowing people to see the stages, by which the results were obtained (Lacey & Luff, 2009).

Overall, the process is divided into “data management” stage and “abstraction and interpretation” stage, where the first is concerned with familiarisation, sorting and labelling data while the latter focuses on teasing out concepts and creating analytic themes. This approach consists of several steps, which move from organising through describing to interpreting data. Not all stages of the approach are mandatory because they depend on the research questions and study aims. Framework approach is flexible thus allowing the research questions and data to guide the process. For example, in some cases, data management and abstraction and interpretation could be conducted concurrently, so data are organised while conceptual categories that describe the data are created (Spencer et al., 2014).

The table below describes the different steps in data analysis, recommended by the Framework approach and how they were followed during data analysis.

Table 12 Data analysis approach

Step	Description	Current study
Familiarisation	Immersion into the data to gain an overview and identify subjects of interest.	I did not use a transcription service, so the process of familiarisation was aided by the fact I transcribed all the data. In addition, I read through all

		transcripts multiple times until I felt I am familiar with the data.
Constructing an initial framework	Refining and sorting the topics of interest into themes and subthemes that comprise the initial framework.	The initial framework followed the interview schedule, as I already had specific questions in mind. I developed descriptive themes and subthemes, based on 3 transcripts that gave diverse views. At this stage, I also recorded issues that were not covered by the interview schedule and initial framework.
Indexing and sorting	Applying labels to chunks of data so that similarly labelled data can be further analysed.	I applied the thematic framework to all transcripts, including where each topic is being discussed. This was done manually by reading transcripts and writing in the margins.
Reviewing data extracts	Reading through the initial framework and refining it.	I read through the initial framework and examined sections of the data that were not included in the framework in order to refine it.
Data summary and display	Writing a summary of each sub-theme and participant in a set of matrices.	The matrices I created had a slightly different structure to the one, suggested by Spencer et al. (2014) as I found it more helpful to include direct quotes and limit summaries, thus enabling me to stay close to the original text. I also found it easier to explore data vertically rather than horizontally.
Developing categories	Reviewing all themes, mapping the diversity of views and experiences, identifying underlying dimensions and proposing key themes.	During this part of the analysis, I went back to the framework with all the quotes and potential themes and started detecting elements they had in common. For example, I looked at the social role theme and the quotes within and started to notice that some people talked about changes in relationship balance and role reversal. I noted these elements onto the framework. After this, I worked systematically through the framework to decide whether each

		extract provided a new category or it was part of an existing category.
Mapping link-ages	Exploring the links between different themes.	During this stage I started to link themes and participants. I looked for connections between perceptions and behaviours across participants and perceptions and behaviours for the same participant. This enabled me to identify the characteristics of people, who were more proactive in changing their behaviour, suggesting the experience of a teachable moment.
Explanation	Providing explanations by searching for key factors that account for patterns within the data.	At this stage, I started to look for the factors that lead to different experiences and behaviours. This stage followed immediately after the mapping linkage and at times happened simultaneously, as some explanations were explicitly given by participants. Finally, negative cases were examined. The final themes and subthemes are presented in Appendix 9.

I did not use data software and analysed data by hand using “post-its” and then entered the data into Excel. In order to progress through the different stages of data analysis, I rearranged the post-its and Excel cells. The final products were copied and pasted into word and tables with themes and subthemes were created to aid understanding of the data findings. The information gained from the analysis was used to:

- 1) Explore changes in people’s perceptions, knowledge and behaviour after diagnosis of type 2 diabetes.
- 2) Explore changes in people’s perceptions and knowledge after diagnosis of type 2 diabetes in their relative.
- 3) Explore potential factors that increase the potential of the diagnosis of type 2 diabetes to be a teachable moment for behaviour change in patients and first-degree relatives/partners of type 2 diabetes patients.

5.4.5 Ethical considerations

Risk and burdens: Ethical approval was obtained from the University of Stirling, School of Health Sciences ethics committee (now General University Ethics Panel) (October, 2015, Appendix 10). An amendment to conduct phone interviews was approved in November, 2015 (Appendix 11). The potential for risks and burdens for participants in this study was considered to be very low. According to the Social Research Association (2003) undue intrusion, such as overburdening participants and asking questions that would not benefit the research, should be avoided. These considerations were taken into account when designing the interview schedule. However, the questions asked participants to talk about their illness experience, so there was a possibility that participants could become distressed when talking about health-related issues. To address this, the only people present during the interview were the participant and I, unless the participant requested their family member to be interviewed at the same time. Participants were informed that they did not need to answer questions that may cause distress. I attended a training course on conducting semi-structured interviews before undertaking the study. I am also trained in Motivational Interviewing-based skills so I conducted the interviews using skills such as open questions and reflective listening, in order to minimise the possibility of distress. None of the participants showed signs of distress. However, if they did, I would have moved on to the next question or asked the participant if they wanted to terminate the interview.

The Ethics committee expressed a concern about participants being coerced into taking part in the study. The issue that people should make a decision to participate without any pressure is a recurrent theme within ethical codes. To address this, an opt-in principle of participation was employed whereby if someone recommended a family member, they were asked to give my contact details to the nominated family member and ask them to contact me directly. In addition, two versions of the participation information leaflet were developed – one for the patient and one for the relative. Informed consent was sought from all participants.

One of the aims of the interview was to explore the risk perception of developing type 2 diabetes among the first-degree relatives and partners of type 2 diabetes patients. Questions about perceived risk were approached carefully as participants may not have been aware of the risk factors for type 2 diabetes. After the interview, participants were informed that they could be at increased risk of developing the condition and were advised to seek more information on the Diabetes UK website or to speak with their GP.

The probability of any major risks for me while conducting the interviews was considered to be very low. I would have discontinued the interview if I felt my safety was threatened by any change in the participants' behaviour. A lone worker policy was put in place where I informed my primary supervisor of the time and location of the interview and texted her when the interview was completed. If the supervisor had not received a text message within 2 hours of the start of the interview, she would have contacted me and if contact was not established, she would have alerted the police.

Consent: Informed consent was obtained prior to the start of the interview after the participant had had the opportunity to read the participant information leaflet and ask questions about the study. The following steps were taken into account in order to obtain informed consent from all participants:

- 1) The study was fully described to participants in plain language.
- 2) Participants were informed that their participation was voluntary and that they could withdraw at any point without giving a reason.
- 3) It was explained that the interview and questionnaire data will be kept confidential.
- 4) I ensured that participants understood what was required from them before signed consent was obtained.

Confidentiality and anonymity: Personal data obtained during the interviews were anonymised by assigning participants unique identifying numbers. Each number contained two letters: I and either P or R, and two numbers. The I was followed by a number and indicated the interview number; P indicated that this quote belonged to a person with type 2 diabetes; and R indicated that the quote belonged to a relative of a person with type 2 diabetes; P and R were followed by a number, which indicated participant number out of the whole sample of either patients or relatives. For example, I1P1 would be interpreted as interview one, patient one; I3R5 would be interpreted as interview three, relative five.

Before the interviews, I collected demographic data including personal information about participants' names and addresses. This was done so I could use the postcode to calculate Scottish Index of Multiple Deprivation scores (SIMD), to contact participants if they wished to pilot the questionnaire in Study Two and to send participants a copy of the study findings. I explained this to all participants and made it clear that they were under no obligation to provide personal data, and that not providing such data would not affect their participation in the study.

Participants' anonymity was ensured and participants' names or personal details are not reported in the thesis, neither will they be reported in any future publications. Consent forms and demographic data are stored in a locked cabinet at the premises of University of Stirling. The audio-recordings, transcripts and field notes are stored on a password-protected university computer or in a locked cabinet at University of Stirling. I am the only person who has access to confidential data.

Potential benefits to participants: There were no direct benefits for research participants in this study, as the study was designed to explore specific issues and refine the applicability of theoretical concepts. However, there may be a future benefit for people at high risk of developing type 2 diabetes. A potential future intervention could lead to increased physical activity, improved dietary habits, improvement in metabolic measures and delay or prevention of the onset of type 2 diabetes in the relatives of type 2 diabetes patients.

5.5 Study 2: Questionnaires

5.5.1 Aim

The aim of Study Two was to explore the relationship between the newly identified teachable moment criteria and changes in participants' physical activity and diet, and their interest in receiving information about type 2 diabetes and/or attending a training course.

5.5.2 Sampling and recruitment strategies

The quantitative phase of this study used non-probability convenience sampling to recruit participants. Recruitment relied on the availability of GP practices that agreed to assist with recruitment and on the availability of patients, who met the inclusion criteria in each practice. Participant recruitment occurred in Scotland and England. In Scotland, it was facilitated by the Scottish Primary Care Network (SPCRN). SPCRN identified practices in Scotland who were willing to take part in the study. Once practices agreed to assist, SPCRN staff identified eligible patients from each practice. The aim of the study was to find out what factors are associated with changes in behaviour following a recent type 2 diabetes diagnosis in oneself or a family member. For this reason, a "recent diagnosis" was defined as diagnosis in the past one year. The inclusion criteria were:

- Diagnosis of type 2 diabetes within the previous year
- Over 18 years of age

- Being able to read and write
- No mental health diagnosis in the past 5 years

GPs within the practice were asked to review the list of eligible patients to ensure that the questionnaire was not sent to any individual who had died, or was not able to give informed consent. I sent SPCRN the number of required study packs per practice and they posted them to each patient. SPCRN then provided an invoice for postage costs and for their time. These were paid from the study budget.

The process was similar in England but the majority of work was carried out by GP practices and a research coordinator in Wessex. The research co-ordinator approached practices and gave me a list of interested practices and their key contacts. I then communicated with each individual practice to arrange recruitment of eligible participants. Practices who agreed to take part searched their databases and GPs screened patients for eligibility. Once a practice had a list of eligible patients, I sent them the relevant number of study packs, which they then posted to the patients. In one site (Solent, England) a research nurse who regularly met newly diagnosed patients with type 2 diabetes introduced the study to eligible participants and handed them study packs. Practices were reimbursed for their time by Clinical Research Network (CRN), Wessex, which provided additional funding. Practices provided invoices for postage costs, which were paid from the study budget.

Monthly recruitment figures were uploaded on the CPMS website.

Sample size is important for quantitative studies, with bigger samples being more representative of the general population (Bryman, 2012). As one of the aims of this study was to explore the feasibility of the recruitment method for patients and relatives of patients, a sample size calculation was not performed. The sample size was determined by availability of resources, time and population. Initially, recruitment was planned to take place in Scotland but sites in England were added at a later stage. In Scotland, the SPCRN predicted at least 10 practices would agree to assist. On average, there are around 24 newly diagnosed patients per practice per year (information provided in personal communication with the SPCRN), which meant that around 240 patients would be approached. In England, 24 practices agreed to take part in the study. The number of newly diagnosed cases of type 2 diabetes per year per practice in England was similar to the one in Scotland (information provided in personal communication with the Research Coordinator in Wessex).

Initially, it was estimated that sample size would be a minimum of 48 patients (20% response rate), based on participation from Scottish GP practices. If all of these patients

handed a questionnaire to at least one family member, the number of family members would have also been 48. If all 24 practices in England took part and response rate was also 20%, another 116 patients and 116 relatives would have taken part in the study. The response rate was calculated on the basis of response rates from similar studies (Harris et al., 2007; Munro et al., 2014) and the potential to adopt strategies, recommended to optimise response rates (Edwards et al., 2002; Brannen & Moss, 2012). This is discussed in more detail in section 9.8.2.

5.5.3 Data collection

This study explored the relationship between behaviour change and factors believed to underpin whether diagnosis of type 2 diabetes was a teachable moment. Questionnaires were deemed appropriate for this aim. Questionnaires are used when an answer is needed to a clearly defined set of questions in order to allow researchers to refine descriptive assertions (Babbie, 2007; Walliman, 2009). Questionnaires can be administered by a researcher in the form of structured interviews or can be self-completed by participants (Bryman, 2012). Self-completed questionnaires eliminate researcher bias and make it easier for participants to be honest about sensitive subjects (Brace, 2008; Walliman, 2009). In addition, they are cheap and easy to administer and can be designed to assist the analysis stage (Walliman, 2009). However, a pre-determined question structure, complex or repetitive questions, desire to provide socially acceptable answers and memory failure, could lead to missing data or the collection of inaccurate data (Brace, 2008). Fortunately, guidance exist on how to design questionnaires to minimise such drawbacks (Peat et al., 2002; Brannen, 2012). Peat et al. (2002) suggest a questionnaire design checklist that outlines the different steps a researcher can take (Table 13).

Table 13 Questionnaire design checklist

Questionnaire design checklist*
Decide on outcome, explanatory and demographic data to be collected
Search the literature for existing questionnaires
Compile new and existing questions in a logical order

Put the most important questions to the top
Group questions into topics
Decide whether to use scale or categories for replies
Reach a consensus with co-workers (<i>supervisors</i>) and experts
Simplify wording and shorten as far as possible
Decide on coding schedule
Conduct a pilot study
Refine questions and formatting
Test repeatability and establish validity

*Peat et al. (2002)

The questionnaire in the current study contained a predefined set of questions, which were developed on the basis of the literature review and the interview findings in Study One (Chapter 6). They asked participants about their response to diagnosis and changes in perceptions of type 2 diabetes, self-concept, social role and behaviour. The majority of questions were closed format with a limited range of answers, using a Likert scale. For some of the questions, participants had to give examples by using the provided boxes. Two questionnaires were developed: one for patients and one for relatives of patients with type 2 diabetes. The questionnaire aimed to assess the factors that are associated with changes in behaviour, following diagnosis of type 2 diabetes in oneself or in a family member. The outcome variables were change in physical activity, change in diet, interest in receiving information about type 2 diabetes and interest in attending a course on type 2 diabetes. Changes in diet and physical activity were chosen as these are the main lifestyle changes believed to improve diabetes outcomes in patients and reduce the risk of type 2 diabetes in relatives. Interest in information and a course on type 2 diabetes were chosen as potential indicators of people's increased receptiveness of lifestyle advice. This is in line with a previous study that regarded intervention buy-in as a response consistent with the occurrence of a teachable moment (McBride et al., 2008).

The questionnaires were developed following recommendations by Peat et al. (2002). There are no validated questionnaires that retrospectively assess change in cognition and behaviour. However, Global Rating of Change Scales (Kamper et al., 2009) are used for assessing patient improvement/deterioration in clinical settings. The current questionnaire

was developed following examples from Global Rating of Change Scales. Questionnaire items (arranged according to topics) and the source of the scale are described below.

Table 14 Questionnaire items

Patient questionnaire	Relative questionnaire
Monitors and blunterners ¹	
<p>When I was diagnosed with type 2 diabetes, I tried to find as much information as possible about type 2 diabetes.</p> <p>When I was diagnosed with type 2 diabetes, I asked the doctor/nurse questions about type 2 diabetes.</p> <p>When I was diagnosed with type 2 diabetes, I did not want to know anything about type 2 diabetes.</p> <p>When I was diagnosed with type 2 diabetes, I refused to believe I had it.</p>	<p>Not assessed as relatives have not been diagnosed with type 2 diabetes</p>
Severity ²	
<p>Compared to before you were diagnosed with type 2 diabetes, how would you describe your current thoughts about how serious type 2 diabetes is?</p> <p>Compared to before you were diagnosed with type 2 diabetes, how would you describe your current thoughts about potential consequences of type 2 diabetes?</p>	<p>Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your current thoughts about how serious type 2 diabetes is?</p> <p>Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your current thoughts about potential consequences of type 2 diabetes?</p>
Self-concept ³	

Compared to before you were diagnosed with type 2 diabetes, how would you describe yourself now?	Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe yourself now?
Social role ⁴	
Compared to before you were diagnosed with type 2 diabetes, how would you describe your responsibilities around the house or for the family? Compared to before you were diagnosed with type 2 diabetes, how would you describe your responsibilities at work?	Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your responsibilities around the house or for the family? Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your responsibilities at work?
Communal coping ⁵	
Since you were diagnosed with type 2 diabetes, who would you consider to be your main source of support? With this person/these people in mind, to what extent do you agree with the statements: <i>I see type 2 diabetes as something that is our issue that we face together</i> <i>I have a real feeling that we are going to work through this together, whatever the outcome</i>	Thinking about your relative/partner with type 2 diabetes, to what extent do you agree with the statement: <i>I see type 2 diabetes as something that is our issue that we face together</i> <i>I have a real feeling that we are going to work through this together, whatever the outcome</i>
Outcome expectancy ⁶	
Compared to before you were diagnosed with type 2 diabetes, to what extent do you think exercise is important for controlling your type 2 diabetes?	Not assessed as it is covered under perceived risk.

<p>Compared to before you were diagnosed with type 2 diabetes, to what extent do you think diet is important for controlling your type 2 diabetes?</p> <p>Compared to before you were diagnosed with type 2 diabetes, to what extent do you think medication is important for controlling your type 2 diabetes?</p>	
<p>Perceived control (over type 2 diabetes)⁷</p>	
<p>There is a lot, which I can do to control the symptoms of type 2 diabetes.</p> <p>What I do can determine whether my type 2 diabetes gets better or worse.</p> <p>The course of my type 2 diabetes depends on me.</p> <p>Nothing I do will affect my type 2 diabetes.</p> <p>I have the power to influence my type 2 diabetes.</p> <p>My actions will have no effect on the outcome of my type 2 diabetes.</p>	<p>Not assessed as relatives have not been diagnosed with type 2 diabetes</p>
<p>Perceived risk⁸</p>	
<p>Not assessed</p>	<p>Compared to before your relative/partner was diagnosed with type 2 diabetes, how likely do you think you are to develop type 2 diabetes...</p> <p><i>...at some point in the future?</i></p> <p><i>... in the next year?</i></p> <p><i>... if you exercise regularly?</i></p> <p><i>... if you have a healthy diet?</i></p>

Physical activity and diet ⁹	
<p>Compared to before you were diagnosed with type 2 diabetes, how would you describe the amount of exercise you do now?</p> <p>Compared to before you were diagnosed with type 2 diabetes, how would you describe your diet now?</p> <p>Participants were asked to provide details. (See appendix 12)</p>	<p>Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe the amount of exercise you do now?</p> <p>Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your diet now?</p> <p>Participants were asked to provide details. (See appendix 13)</p>
Information/course on type 2 diabetes ¹⁰	
<p>If available, would you be interested in attending an educational course about type 2 diabetes?</p> <p>If possible, would you be interested in receiving information about type 2 diabetes?</p>	<p>If available, would you be interested in attending an educational course about type 2 diabetes?</p> <p>If possible, would you be interested in receiving information about type 2 diabetes?</p>
Demographic information ¹¹	
<p>Age, education, employment status, relationship status, duration of type 2 diabetes, self-rated health status and who they live with</p>	<p>Age, education, employment status, relationship status, duration of type 2 diabetes in a relative, self-rated health status and who they live with</p>

¹Adapted from Miller's Behavioural Style Scale (Miller, 1987). Monitors are people who actively seek information in response to threat (e.g. diagnosis of type 2 diabetes in oneself). Blunters experience less urgency to do anything in response to threat.

²Adapted from the IPQ-R (Moss-Morris, 2002) and Global Rating of Change Scales (Kamper et al., 2009).

³Based on the Head Injury Semantic-Differential Scale (Vickery et al., 2005). The scale contains 20 pairs of words and participants fill in the scale twice, so change can be calculated. The scale was adapted to resemble a Global Rating of Change Scale. The number of items was reduced after piloting to include only items, relevant to type 2 diabetes.

⁴Not based on an established scale. Developed on the basis of the interview findings.

⁵Adapted from Afifi et al.'s (2011) measure of communal coping. Communal coping refers to appraising a problem as a joint problem and taking joint action to address it. It could be a facilitator for behaviour change.

⁶Adapted from the Multidimensional Diabetes Questionnaire (Talbot et al, 1997).

⁷Adopted from the IPQ-R (Moss-Morris et al., 2002).

⁸Based on Ronnis (1992) about conditional and unconditional health threats.

⁹Developed by following an example of a scale, used in a study assessing participants' recycling behaviour before and after a lifestyle programme (Staats & Harland, 1995) and the Food Frequency Questionnaire (NHANES, 2008).

¹⁰ Not based on an established scale

¹¹Self-rated health status has been shown to provide an objective measure of health and a subjective measure of appraisal about oneself in terms of personal health (Sillen et al., 2005). Participants were asked to rate their health on a 4-point Liker scale (0-poor, 1- fair, 2-good or 3-excellent).

Questionnaires can be delivered personally, by post or by email. Postal questionnaires have the advantage of being cheaper than personally administered questionnaire, although more expensive and time consuming, than email questionnaires (Brill, 2011). Another advantage and the main reason for choosing postal questionnaires for this study is that they can reach a wide range of people, including people who do not have access to or use the internet. There are disadvantages associated with postal questionnaires. The data entry process can be laborious and time consuming (Brill, 2011). It is impossible to control the order of item presentation and participants can read the whole questionnaire before answering any questions (Brill, 2011).

This study employed a quantitative design where questionnaires were posted to potential participants (see 5.5.3). In postal questionnaires, the initial delivery of the questionnaire is typically in the form of a survey pack (Brill, 2011). Each questionnaire pack contained an invitation letter on GP headed paper and signed by the patient's GP (appendix 14); three participant information sheets (one for patient, two for relatives, appendices 15 and 16) three consent forms (appendix 17); a questionnaire for the patient and two questionnaires for a partner and/or any family members who were above the age of 18 years (Appendices

12 and 13); one freepost envelope so participants could return the completed questionnaires. After 80 questionnaire packs were sent, no one returned all three questionnaires. Participants returned either one completed questionnaire, reporting they did not have any relatives to complete the other questionnaire, or they returned two completed questionnaires. In order to reduce study costs, only two questionnaire packs (one for the patient, one for a relative/partner) were sent to the remainder of participants.

Data collection in Scotland took 10.5 months. Practices in Scotland were approached on the 13th of February 2016 and recruitment ended in the end of December 2017. Data collection in England took 5 months. Practices in England were approached after HRA approval was granted on the 11th of August 2017. Recruitment ended in December 2017. Fourteen practices in England and 7 in Scotland assisted with recruitment.

5.5.4 Data analysis

The analysis intended to address two objectives. The first one was assessing the association between contextual and personality factors (e.g. perceived risk; perceived severity; self-concept) and participants' behaviour. The second objective was assessing the association between contextual and personality factors and interest in receiving diabetes-related information and/or attending an educational course. Regression was considered to be appropriate for data analysis as regression is used when we want to predict outcome variables from one or more predictor variables (Brannen & Moss, 2012).

After all participant data were entered into SPSS, the data analysis stage started with coding each variable. I coded variables appropriately, based on the way they have been assessed in other studies (Table 15).

Table 15 Variables

Variable	Scoring
Monitors/Blunters	A summary score was calculated by subtracting blunting from monitoring sum scores. A median split procedure was then employed and the sample was divided into monitors and blunters (Miller & Mangan, 1983).

Severity	The ratings were summed with a higher score indicating bigger increase in perception of severity (Moss-Morris, 2002).
Self-concept	The ratings were summed with a higher score indicating a bigger change in self-concept (Vickery et al., 2005).
Social role	Binary variable: increase vs no change or decrease in social role.
Communal coping	The ratings were summed with a higher score indicating a higher degree of communal coping (Afifi et al., 2011).
Outcome expectancy	Binary variable: belief behaviour is important for a specific outcome vs lack of belief) (Talbot et al, 1997).
Perceived control	The ratings were summed with a higher score indicating bigger increase in perception of control (Moss-Morris et al., 2002)
Perceived risk	The ratings were summed with a higher score indicating bigger increase in perception of risk (Ronnis, 1992).
Physical activity/diet	One item for each variable – a higher score indicating a bigger change.
Interest in information/course on type 2 diabetes	Binary variable: interest vs no interest

Frequencies and reliability tests were performed to ensure variables are coded correctly. During data exploration, it became clear that the frequencies in outcome variables were often too small on certain points of the Likert scale, so diet and exercise were dichotomised. The other two outcome variables (interest in receiving information about type 2

diabetes and interest in attending a course) were already binary variables. As a result a binary logistic regression was considered appropriate. Binary logistic regression is used when an outcome variable is binary categorical and independent variables are continuous or categorical. This means we can suggest which of two categories a person is likely to belong to given certain other information (Brannen & Moss, 2012). The first step in building the regression model, was the exploration of the univariate association between each independent variable (i.e. suggested factors for a teachable moment) and each outcome. The study included seven independent variables for patients (monitors/blunters, self-concept, social role, severity, control, communal coping, outcome expectancy) and five for relatives (self-concept, social role, severity, communal coping, perceived risk). There were four outcome variables considered to suggest the occurrence of a teachable moment (change in diet, change in physical activity, interest in receiving information about type 2 diabetes and interest in attending a course on type 2 diabetes). All independent variables identified as significant ($p < 0.05$) during the model building step were entered into a binary logistic regression in order to explore their association with each outcome variable. If the model was significant, age, gender and time since diagnosis were entered to form the final regression model.

5.5.5 Ethical considerations

Risk and burdens: The study was granted ethical approval by the University of Stirling NHS, Invasive or Clinical Research (NICR) committee (December, 2016, appendix 18) and by the NHS proportionate review sub-committee of South Central Hampshire (January, 2017, appendix 19). R&D approval was granted by NHS Forth Valley (research site, appendix 20) and NHS Tayside (participant identification centre, appendix 21) (January, 2017). HRA approval for sites in England was granted in August 2017 (appendix 22).

The potential for risks and burdens for participants was considered to be very low. There was a low possibility that a participant might become distressed when answering questions about their thoughts and behaviour since diagnosis of type 2 diabetes. To address this the questionnaire was piloted among participants who took part in Study One. Six patients and two relatives of patients with type 2 diabetes provided feedback.

Consent: Informed consent was sought by including a consent form, attached to each questionnaire. The form contained boxes that asked participants to initial but they were not asked to sign the form as this would have removed their confidentiality.

Confidentiality and anonymity: Staff from SPCRN sent the study packs to eligible patients in Scotland. Staff from GP practices sent study packs to patients in England. I had no access to patient data, such as names and addresses. The questionnaires were indexed by a unique identifying number so that returned questionnaires from patients and relatives/partners could be linked. Each number contained two letters and two numbers. The first letter indicated the GP practice and the second was either P (patient) or R (relative). The first number indicated the number of the survey pack and the second number indicated the number of the participant. For example, A1P1, A1R1 and A1R2 would be the first patient and their two relatives from GP practice A. I am the only person who had access to the anonymised questionnaires, which are stored in a locked cabinet at the University of Stirling.

Potential benefits to research participants: There were no direct benefits for research participants in this study, as it was designed to explore specific issues and refine the applicability of theoretical concepts. However, there may be a future benefit for people at high risk of developing type 2 diabetes. A potential future intervention could lead to increased physical activity, improved dietary habits, improvement in metabolic measures and delay or prevention of the onset of type 2 diabetes in the relatives of type 2 diabetes patients.

Part 3: Study findings

Chapter 6: Study One: Changes following Type 2 diabetes diagnosis and teachable moment criteria

6.1 Introduction

Chapter 6 presents the findings from the first study that included qualitative interviews to explore changes in people's perceptions and behaviours following diagnosis of type 2 diabetes in oneself or in a family member. The chapter begins by summarising previous research that highlighted the need for the current study (6.2) before presenting the study findings (6.3). The findings include a summary of the sample (6.3.1), people's emotional response to type 2 diabetes diagnosis (6.3.2), experiences of type 2 diabetes of patients (6.3.3) and of relatives (6.3.4) and changes in roles and relationships following diagnosis (6.3.5). Finally, the chapter presents the potential criteria for a teachable moment and discusses them in relation to previous research (6.4). It concludes that not all of McBride et al.'s (2003) criteria are relevant to type 2 diabetes and that there may be other factors that increase the likelihood of type 2 diabetes diagnosis being a teachable moment (6.5).

6.2 Background

6.2.1 Summary of previous research

The literature review identified several gaps in the existing literature on teachable moments and type 2 diabetes. Chapter 2 (section 2.1) showed that illness diagnosis provides a window for opportunity and a teachable moment for behaviour change among patients and their relatives. However, it also demonstrated that the concept of the teachable moment is under-theorised with the majority of studies failing to identify the mechanisms that underpin it. The limited number of studies that explored potential mechanisms suggest that in order for diagnosis to be a teachable moment it needs to trigger changes in emotional representation (McBride et al., 2003; Humpel et al., 2007), perception of risk, susceptibility and severity (McBride et al., 2003; Humpel et al., 2007), self-concept and social role (McBride et al., 2003) and create a clear link between a salient concern and a health behaviour (i.e. outcome expectancy) (Humpel et al., 2007; Thresia et al., 2009; Hayes et al., 2010; Cohen et al., 2011; Stead et al., 2012). In addition, the limited research raises questions about whether or not diagnosis of illness in a partner or a relative is a teachable moment for behaviour change. Chapter 2 (section 2.2) also showed that only three studies to date have suggested that the diagnosis of type 2 diabetes may be a teachable moment (Thresia et al., 2009; An, 2015; Azar et al.,

2015). However, all three of these studies used patient samples and only one suggested a potential teachable moment mechanism (i.e. a link between type 2 diabetes and smoking behaviour, Thresia et al., 2009).

In addition to the above teachable moment factors, there are known determinants of behaviour such as illness representations (Glasgow et al., 1997; Leventhal et al., 1997; Harvey & Lawson, 2009) and risk perception (van der Pligt, 1998; Qureshi & Kai, 2008) that may further explain the mechanisms underlying teachable moments. Chapter 3 (section 3.1) showed mixed findings on illness representations of type 2 diabetes. It also demonstrated that the views of relatives are rarely explored although they affect and are affected by the views of the patients (Scollan-Koliopoulos et al., 2007; Dimitraki & Kardemas, 2014). Chapter 3 (section 3.2) also showed that relatives of people with type 2 diabetes do not always believe they are at increased risk of getting the condition. More research is needed to find out if diagnosis of type 2 diabetes in a relative increases risk perceptions.

The literature review supports the need for research exploring what makes diagnosis of type 2 diabetes a teachable moment i.e. when patients and relatives become more motivated to change their behaviour and more receptive to lifestyle advice.

6.2.2 The current study

The aim of this PhD is to identify the contextual factors behind whether and whom for the diagnosis of type 2 diabetes is a teachable moment, when people are more likely to engage in and adhere to lifestyle advice. In order to do this, semi-structured interviews were conducted to explore changes in people's perceptions and experiences following diagnosis of type 2 diabetes. This chapter addresses research questions 6: **How does type 2 diabetes diagnosis affect patients and their relatives, in terms of perceptions, behaviour and relationships?** and 7: **What criteria need to be fulfilled for the diagnosis of type 2 diabetes to be a teachable moment?**

During data analysis, two groups of participants emerged: patients who appeared to have been very proactive in the management of their type 2 diabetes (indicated by changes in their behaviour) and patients who needed time to adjust to the diagnosis. As a result, the findings are presented according to these two groups of people. Patients were placed in the first group if they talked about active management of their condition by changing their behaviour and adopting specific problem-solving strategies for self-management. Patients were placed in the second group if they were more likely to talk about avoidance or reliance

on others for self-management. The comparison of perception and behaviour changes between these two groups enabled the identification of factors, which might make the diagnosis of type 2 diabetes a teachable moment for patients.

Similarly, two groups of relatives emerged: people who adopted protective health behaviours in an effort to decrease their own risk of developing type 2 diabetes and people who changed their behaviour in order to support their relative with type 2 diabetes. The two groups were not exclusive of each other. Many of the people who changed behaviour for their own health also provided support for their relative with type 2 diabetes. The analysis focused on the predominant focus people placed on the reasons for changing their behaviour. There were no people who did not fall within one of the two groups. The comparison of perception and behaviour changes between these two groups enabled the identification of factors which may make the diagnosis of type 2 diabetes a teachable moment for the family members of patients with type 2 diabetes.

6.3 Findings

6.3.1 Participants

Forty two people showed interest in the study by contacting me over phone or email (22 patients, 20 relatives). These were screened by asking them when they/their relative were diagnosed with type 2 diabetes and if they considered themselves/their relative to be newly diagnosed. Seventeen people were not included in the study because they did not consider themselves (or their relative) to be newly diagnosed (the range of time since diagnosis in excluded people was 4-25 years). Twenty five people were eligible to take part (11 patients, 14 relatives). Two people did not respond after initial contact was made. Twenty three participants took part in the interviews. Ten were people with type 2 diabetes and 13 were relatives of people with type 2 diabetes. Relationships included two families (father, mother, two daughters; father, mother, daughter); a mother-daughter dyad; and three couples. The remainder were either a patient or a relative whose family members were unable to take part. Seventeen semi-structured interviews were conducted with the 23 participants. Interviews took place in participants' homes (N=6), private rooms at University of Stirling (N=6), a local hotel (N=1), a local library (N=1) and a private office at a participant's workplace (N=1), and over the phone where I was in a private room (N=2). Thirteen of the interviews were individual and four included the patient and their relative(s) (Table 16).

Table 16 Participants and form of interview

Participant number	Type of participant and relationship with patient (if a relative)	Form of interview
I1R1	Relative, mother	Relative only, interviewed alone
I2R2	Relative, daughter	Interviewed together with sister, mother and father (I2R3, I2R4, I2P1)
I2R3	Relative, daughter	Interviewed together with sister, mother and father (I2R2, I2R4, I2P1)
I2R4	Relative, wife	Interviewed together with daughters and husband (I2R2, I2R3, I2P1)
I3R5	Relative, wife	Interviewed together with husband (I3P2)
I5R6	Relative, daughter	Relative only, interviewed alone
I6R7	Relative, wife	Interviewed together with husband (I6P4)
I8R8	Relative, husband	Interviewed separately from wife (I4P3)
I9R9	Relative, daughter	Relative only, interviewed alone
I11R10	Relative, daughter	Interviewed separately from mother (I10P6)
I12R11	Relative, son	Relative only, interviewed alone
I13R12	Relative, husband	Interviewed together wife (I13P7)
I16R13	Relative, daughter	Interviewed separately from parents (I6P4, I6R7)

I2P1	patient	Interviewed together with daughters and wife (I2R2, I2R3, I2R4)
I3P2	patient	Interviewed together with wife (I3R5)
I4P3	patient	Interviewed separately from husband (I8R8)
I6P4	patient	Interviewed together with wife (I6R7)
I7P5	patient	Patient only, interviewed alone
I10P6	patient	Interviewed separately from daughter (I11R10)
I13P7	patient	Interviewed together with daughter (I13R12)
I14P8	patient	Patient only, interviewed alone
I15P9	patient	Patient only, interviewed alone
I17P10	patient	Patient only, interviewed alone

The characteristics of participants are presented in table 17 below. Where only a relative of someone with type 2 diabetes took part, they were asked when and how their family member got diagnosed.

Table 17 Participant characteristics

	Patients	Relatives
Ne	10	13
Duration of type 2 diabetes	Range: 3 weeks – 18 months Mean: 7.9 months Median: 6.5 months	Duration of diabetes in their relative with the condition: Range: 6 weeks – 11 months Mean: 6.8 months Median: 8 months

Route to diagnosis	5 presenting GP with symptoms; 3 periodic screening; 1 visit GP for other reasons; 1 after gestational diabetes	Route to diagnosis for their relative with type 2 diabetes: 2 presenting GP with symptoms, 1 usual check up
Relationships with patient	-	6 daughters, 3 wives, 2 husbands, 1 son, 1 mother. 6 share genetics but live apart from patient 2 share genetics and live together 5 do not share genetics and live together
Gender	5 male, 5 female	10 female, 3 male
Age	Range: 37-71 years Mean: 53.6 years Median: 51 years	Range: 18-68 years Mean: 41.17 years Median: 45.5 years
SIMD (Scottish Index of Multiple Deprivation)¹	Range: 2-10 Mean: 5.7 Median: 6	Range: 2-10 Mean: 6.92 Median: 6
Education	9 had education after high school (2 PhD, 1 MSc, 2 BAs/BSc, 1 one year at university, 1 Diploma, 1 Police promotion exam, 1 HNC, 2 current students)	9 had education after high school (3 PhD, 1 MSc, 2 BAs/BSc, 2 college, 1 SHND, 3 current students)
Employment	4 full-time, 3 retired, 2 unemployed, 1 part-time	4 full-time, 4 part-time, 2 unemployed, 1 self-employed, 1 retired, 1 other
Relationship status	8 in a relationship, 2 single	12 in a relationship, 1 single
Family history of diabetes	5 yes, 5 no Number of relatives with diabetes: 1-4	8 yes, 5 no Number of relatives with diabetes: 1-4
How they heard about the study	5 word of mouth (relative who took part or someone who saw advert) 2 University of Stirling portal 1 Diabetes UK newsletter 1 Falkirk Sensory centre	7 word of mouth (through patient who took part or someone who saw advert) 2 University of Stirling email 2 University of Stirling portal 2 Stirling council intranet

	1 West Lothian Diabetes support group social media page	
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¹Scottish Index of Multiple Deprivation (SIMD): SIMD is used to identify areas of multiple deprivation in Scotland. It ranks small areas from most deprived (ranked 1) to least deprived (ranked 10) (<http://www.gov.scot/Topics/Statistics/SIMD>).

6.3.2 Emotional response to diagnosis

Diagnosis of type 2 diabetes in oneself or a family member often provoked an emotional response. Participants talked about experiencing various emotions, such as shock, anger, sadness, disappointment and fear. Emotional experience did not seem to differ between patients and family members. Many people talked about experiencing similar emotions but there was a notable difference in the way different people responded to their emotions. In some patients the surprise and shock upon diagnosis receipt evoked feelings of numbness and fear:

“In the first month of thinking I had this and then being diagnosed around that time I did struggle to sleep on three or four occasions thinking about dying and having these kind of strange intrusive thoughts, which is odd. I’ve never had that before in my life.”

I3P2, male

The shock and surprise in other patients acted as main motivators for behaviour:

“A bit sort of shocked really, but surprised, you know, that was all really...and then to just find out more about it. That was it...just to see what I could do and what I couldn’t do” I2P1, male

The quotes above illustrate that patients often used emotive words, such as “dying”, “shocked” and “frightened”, to communicate the negative experience of being diagnosed with type 2 diabetes.

Not all patients were surprised to find out they had type 2 diabetes and some even expected the diagnosis because they either displayed symptoms or because they were aware of their family history of diabetes. In many cases patients and relatives felt relief because the diagnosis provided an explanation for previous poor health and allowed them to “*know their enemy*” and make changes to control their condition:

"I suppose initially I actually felt quite relieved 'cause I thought well I've not been well and I thought there is something I can do about this" I13P7, female

Others felt relieved because they did not perceive type 2 diabetes to be a very serious condition:

"I wasn't entirely surprised. I was relieved that it wasn't anything, and when I say more serious, I mean that it's controllable and stuff like that." I6R13, husband

One participant described the fact that his father has type 2 diabetes as "annoying":

"... I wasn't so surprised and then obviously I kind of thought it's annoying 'cause I need to make sure I am kind of more careful I guess." I12R11, son

The current sample included only one parent of a person with type 2 diabetes. This mother felt helpless before her son was diagnosed because she noticed deterioration in her son's health. The quote also suggests feelings of frustration when the son did not take actions to improve his health:

"I felt helpless really before he was diagnosed because I knew he was heading for a fall. I knew he was becoming ill. Well, to say that I knew is maybe an over...more of a claim than...I did know that he was going to be ill if he didn't act on it, if he didn't watch his diet and if he didn't reduce weight, just feel ...I suppose you can tell your children things but they will not listen to you." I1R1, mother

The same woman also felt worry about her son's ability to maintain the required changes in order to control his type 2 diabetes:

"I am worried that he will fall back" I1R1, mother

Participants also reported going through "an emotional rollercoaster" before and after the diagnosis of type 2 diabetes. Some reported feeling "frustrated" and "worried" in the period between being tested and getting the test results. Others were "mad" at the way the GP practice communicated their test results and the long period of time they had to wait to get an appointment to discuss the diagnosis with their doctor. Others found it "annoying" and "frustrating" that they were not able to link the symptoms with type 2 diabetes, which might have led to an earlier diagnosis.

"And they wanted Wednesday morning and you couldn't make one Wednesday morning so that meant there was two weeks between the tests and then a week for the results, it just felt like...see in the month beforehand it was quite frustrating feeling"

like “I am completely certain that this person has got type 2 diabetes” and they are having no treatment, which means he is walking around with all this sticky blood and could have a stroke or whatever at any time. So...I thought I would feel better when you got the diagnosis ‘cause you’re gonna get treatment and I did to a degree but on the day that you actually got the diagnosis I felt quite disappointed and upset because you’d hoped that you were wrong, you know...” I3R5, wife

“I was surprised I was upset because I thought I knew anyway and that was a good thing, now it means you could get treatment so I didn’t really feel like that because what I felt was upset, even though I knew intellectually it was a good thing” I3R5, wife

One woman reported feeling “awful” because of the lack of understanding and support from nurses:

“The first time the nurses made me feel awful when I thought it was my fault when I did everything that I could to have my sugars at the levels they wanted them at. (...)some of the comments, they were just like “oh eat less”, “go out and do some exercise” and in the end of the day I was 9 months pregnant, you can’t go out and exercise.” I4P3, female

In summary, many people felt similar emotions in response to diagnosis but the responses to these emotions varied across participants. People also talked about feeling different emotions in the different stages of type 2 diabetes: from showing symptoms, to waiting for test results to getting the diagnosis and managing the condition, to looking forward to the future.

6.3.3 Experiences of people with type 2 diabetes

People who adopted problem-solving strategies: “... it has to do with facing up to diabetes”

Some people with type 2 diabetes were quick to accept the fact that they had type 2 diabetes and quickly adopted problem-solving strategies, such as seeking information, planning and restraint. They described their immediate response to the diagnosis as a “know your enemy” moment and accepted their new reality:

“...it was like that’s it and now I need to remember that there are different rules for me than there are for everyone else” I15P9, male

This participant saw the diagnosis as an opportunity to get better:

"...the diabetes might be the start of a...like an unpleasant road to getting better but in the best case scenario" I15P9, male

These patients believed type 2 diabetes to be something *"you've gotta get on and deal with it"* (I2P1, male) and it is their personal responsibility to look after their health:

"I take it personally that I have an issue with my health that needs to be addressed or there will be consequences and I just get on with it" I17P10, male

They were active in obtaining information about their condition by borrowing and buying books and searching the internet. They also wanted more information that was personally relevant to them and were not completely satisfied with the information provided by health professionals:

"They [health professionals at an education course] didn't give you so much ideas for recipes and I felt it was slanted very much at what you might call a traditional type 2 diabetic who actually needed to lose weight or keep their weight sort of under control or at kind of standard level, so I suppose because of that I maybe looked a bit further to try and find more ideas" I13P7, female

Patients appeared to have always been aware of the potential complications that can result from type 2 diabetes. However, the diagnosis made these complications personally relevant and increased people's perception of diabetes severity:

"But it's only when it's in your face and it's you that it has any real meaning." I10P6, female

"I already knew about certain complications but it brings it more home to you when you've actually been diagnosed as that and you have to be wary of certain situations" I14P8, female

The increased relevance of complications prompted some people to consider the worst possible outcome of the current situation and perceive type 2 diabetes as a potentially fatal condition. This increased motivation to change behaviour:

"I guess I was a little bit frightened but it was more the idea that if I didn't sort it out then I wouldn't get, I have a little boy who is 2 and a half now, and I wouldn't get to see him go to school unless I did something." I15P9, male

The patients who adopted problem-solving strategies were also more likely to experience change in their self-concept. They made a comparison between their behaviour before and after the diagnosis and evaluated who they are on the basis of that:

"I am extremely tired all the time whereas I was a woman before who wouldn't think twice of, just constantly being on the go, would never sit down. But now I am so tired, when I finish a day's work I am exhausted which is not like me at all. I've become somebody else" I14P8, female

In some cases the desire to maintain one's identity appeared to motivate people to adopt new health behaviours:

"But remarkably now I've got my diet relatively under control but I've been a bit naughty recently, but relatively under control, I am back to firing and doing all sorts of again, I run up and down staircases, I'm emailing people, it's like, you know, she is back!" I10P6, female

In other cases, type 2 diabetes was seen as an opportunity to redefine one's identity. Below is a quote from a patient who reported frequent overeating, which he believed has contributed to the development of type 2 diabetes:

"...To what extent is eating, especially now that I know the consequences, to what extent is that self-harm, you know...(...)it's deliberately destructive (...) there's a lot of questions like: How do I see myself and what is it about? And I think the diet...working out my identity with food, working out my relationship there, is part of a big thing for me in terms of how I see myself and the diabetes has definitely changed and I might be opening myself up to some unpleasant things about destructive behaviours and how I can duck relationships..." I15P9, male

The redefinition of identity also triggered a desire to "fit in" and find one's place in the wider community of people with type 2 diabetes. However, this was not always easy:

"So I think there's something there like sort of type 2 men that are like "acht I don't care" and then there seems to be an older community of type 2 women that have this stereotype around them that they sit around and talk about, you know, how terrible it

is that they can't eat biscuits or something like that, this is from newsletters I get and things I read online and communities and like, none of these fit with my identity..."

I15P9, male

Patients also constructed their identity by differentiating themselves from other people with type 2 diabetes. Some patients talked about the “*good diabetic*” versus the “*bad diabetic*” where the “*bad diabetic*” is a person who is overweight and who displays poor self-management:

“So I take it as quite a serious thing although it is quite clear that a lot of people don’t” I17P10, male

“But you see that with maybe some people with diabetes, when you look at it, it’s a stereotyping again, obviously quite fat and maybe they don’t look after themselves right either but they get the type 2 diabetes and I think maybe they’re expecting some miracle medication to cure it and then something will happen to their feet. (...) It’s the same sort of...like I am not blaming people and that for having it but it’s a sort of laziness because you are eating so much and you are watching the telly and all these other things come into place. Well... maybe you don’t wash as much and you don’t check as much and things like that as well.” I2P1, male

These patients were motivated to face their new reality and adopt new behaviours that would help in their self-management in controlling type 2 diabetes. They talked about changes such as increasing exercises, reducing carbohydrate and sugar intake, decreasing portion size and caring for their feet. Although changes and approaches to diabetes management varied across participants, these patients had specific rules that guided their behaviour. These were person-specific and were guided by people’s knowledge and perceptions of their illness:

“But if I am looking at a packet of something, I kind of have a look and if it’s less than, like I have this number in my head, it’s like 10 grams of carbohydrate per 100 gram and if it’s under that then I might have a look at it, if it’s over that I won’t, you know...” I15P9, male

Another patient talked about “*imaginary*” techniques to diabetes management:

"I am having to go dog walking with my fantasy dog. To stop that falling asleep on the sofa 'cause I think that's diabetic as well. I don't know if it is but in my head it is."

I10P6, female

"I have this imaginary thing in my head where I see the glucose spiking up and going down, and spiking up and going down, and that's bad. I have this thing in my head about there are foods I can eat and things I can do that would keep this more like a soft curving wave." I10P6, female

The people who adopted problem-solving techniques shared a desire to overcome the challenges they faced as a result of having type 2 diabetes. One patient said that the secret to managing diabetes successfully is changing one's mind set and not feeling sorry for oneself:

"But I think it has to do with facing up to diabetes. It's more than anything to do with it" I10P6, female

"...Pain doesn't mean that you've got to sit down, have a cup of tea, have a cake and feel sorry for yourself..." I10P6, female

People who needed time to adjust: "There is a period of denial in the beginning, isn't it?"

There were only two patients in this sample who did not appear to adopt a problem-solving approach in their self-management immediately after diagnosis. One person talked about going through a period of avoidance and denial of the diagnosis:

"And I presume it's fairly common if not, close to 100% common that there is any kind of bereavement process, there is a period of denial in the beginning, isn't it? None of this can be happening to me, not really being able to process what's going on..." I3P2, male

The avoidance period may be explained by fact that the impact of type 2 diabetes on this patient appeared to be so great that he felt unable to make changes or accept the diagnosis:

"In the first month of thinking I had this and then being diagnosed around that time I did struggle to sleep on three or four occasions thinking about dying and having these kind of strange intrusive thoughts, which is odd. I've never had that before in my life."

I3P2

This patient appeared to be experiencing change in identity but he struggled to accept it:

"I think I've been on a bit of an emotional rollercoaster as well in terms of...being numb, avoiding it for a bit and trying to let it sink in and trying to work out how to manage the fact that...I was used to feeling fine and now I prick myself...getting into some kind of a routine..." I3P2, male

This perceived change in self-concept appeared to decrease the patient's motivation to tell people about his diabetes:

"I have a very high profile, high power job, leading people and...that stigma, I know, it will be in their mind...so I need to carefully think about that and manage that in the appropriate time" I3P2, male

This in turn triggered difficulties in the management of his condition as he talked about the difficulty in finding a private place to do his blood test, so no one will see him:

"Can I do that in the car in the car park or to drive down the road, can I do it in the gents toilet, do I do it on my desk, all that kind of stuff" I3P2, male

One of the patients did not experience the negative consequences of type 2 diabetes, which appeared to decrease his desire to adopt problem-solving techniques and actively manage his condition:

"...to be honest, at the moment, I haven't really noticed what it's done to me" I6P4, male

"I am pretty laid back about most things. I know that diabetes...I am not taking it lightly, I do regard diabetes as a serious illness...erm...but I havnnae seen it flattening [killing] any of my relatives. They've...the ones that have had it for several years, they are just continuing with their normal life." I6P4, male

These patients were less likely to actively seek information about their condition:

W: "I mean we bought books and we read some of them" I3R5, wife

P: "I haven't finished any of them" I3P2, male

Interviewer: "Do you feel you understand it?"

P: "I understand as much as I feel I need to" I6P4, male

Interviewer: "How much is that?"

P: "I am no...if I do something that's gonna make it worse, I'd hope somebody either

the doctor or a nurse or [wife] would point out that I was doing it...other than that, do I need to understand it? As long as the doctor does. I don't have any great desire to research it." I6P4, male

These patients also appeared to rely on their relatives for the management of type 2 diabetes. In both cases their wives were active in obtaining information about the condition by searching the internet and buying books about type 2 diabetes. In addition, the partners took responsibility for changing the patients' diet in order to manage their condition:

"She is telling me what to eat and I eat it" I6P4 male

Patients in this sample were interviewed shortly after the diagnosis of type 2 diabetes. Although the two participants mentioned above reported going through a period of avoidance and being reliant on partners for management of diabetes, it cannot be suggested that these patients did not adopt a problem solving approach at a later stage.

The table below summarises the characteristics of people who were active in diabetes self-management and those of people who needed time to adjust. These characteristics may be what made type 2 diabetes diagnosis a teachable moment for this sub-sample.

Table 18 Characteristics of patients with problem-solving strategies versus those who needed time to adjust

Characteristics of patients who adopted problem-solving strategies	Characteristics of people who needed time to adjust
Desire to seek information	Limited desire to seek information
Linking specific behaviours with specific diabetes-related outcomes (i.e. outcome expectancy)	Reliance on relatives for self-management A period of avoidance and denial
Talking about controlling type 2 diabetes	Struggle to accept changes in self-concept

Increased perception of severity and complications	
Embrace/Combat changes in self-concept	

6.3.4 Experiences of family members of people with type 2 diabetes

Relatives who adopted an active approach: “To me the incentive is that you are fit and healthy”

The people in this group adopted an active approach in response to the diagnosis of type 2 diabetes in their relative. They believed they were at increased risk of developing type 2 diabetes and adopted strategies to prevent the condition or to delay its onset and minimise its potential impact. The majority of participants in this sub-group were offspring of patients with type 2 diabetes. After their parent’s diagnosis, they started seeking information about the condition in order to increase their understanding of it:

“If it is genetic, maybe we should know more about it, so we can keep an eye for ourselves” I2R4, daughter

Having a parent, recently diagnosed with type 2 diabetes in addition to the better understanding of the condition appeared to increase people’s perception of personal risk of type 2 diabetes and sense of responsibility to prevent it:

“I knew he’s [father] had quite a bad lifestyle but I never realised how much it has actually affected him, which then made me panic about myself” I5R6, daughter

“...bloody hell, everything seems to be mounting up that I’ve got a good chance of getting this..., so I need to make sure that I do as much as I can not to bring it on myself” I12R11, son

Additionally, they described the diagnosis in their parent as a trigger for changing their behaviour:

“So I don’t know if it was really my dad getting that but I have become quite aware recently of just watching sugar and I try...for instance my, I tried to drink less fruit juice before, but now I even try and eat less cakes and stuff like that.” I12R11, son

“...before then [diagnosis] I was thinking: I’m fine, I don’t need to worry about my life; but as soon as that happened [father got diagnosed] it was like: wait, what about

if I am gonna get diagnosed, how's that gonna affect me in the future?; It's made me think sort of well ahead of what I should be. It's made me think: right, I need to do this, I need to do all this to stop myself from getting into that position. So it's kind of gave me a wake-up call as to stop myself from ever reaching that position" I5R6, daughter

One participant, a mother whose son was recently diagnosed with type 2 diabetes, talked about increasing her physical activity and reducing the amount of fruit she eats and described type 2 diabetes as a motivator for sustained behaviour change:

"So I think most days we are doing exercise. So I suppose it is in the background, helping us to think "keep healthy"." I1R1, mother

Similarly, the son of a person with diabetes, believed that being healthy is a good incentive for changing behaviour:

"To me the incentive is that you are fit and healthy but I guess for some people that's not enough." I12R11, son

The diagnosis in a family member challenged people's perceptions of causes and who is more likely to develop type 2 diabetes:

"My dad is by no means, he is fit sort of, he is 55 but he is pretty fit for his age, like, I would have never thought, he is not overweight or anything, but he got it so I am sort of like, it's not just the stereotypical people that get it, you do need to be careful of what you eat and I try and I try and I am probably a little bit more careful of what I eat because of that." I12R11, son

This was reinforced by increased perception of the severity of type 2 diabetes. Similarly to the patients in this sample, relatives considered the potential impact of type 2 diabetes after it became personally relevant to them:

"I didn't realise the severity of it. I always thought it was just, if you get your life back on track, it wouldn't affect you anymore but obviously it can stay with you for the rest of your life. So...it's a bit more severe than I thought it ever could be." I5R6, daughter

"I guess that's sort of changed because you realise it is quite serious and when it happens to someone close to you, it is scarier, you know what I mean, and you kind of want to know a lot about it and understand it so..." I2R2, daughter

In addition, the changes in risk perception and diabetes severity created a feeling of necessity for behaviour change. People talked about having a healthier lifestyle as something they have to do rather than something they choose to do. This is evident in the words they used, such as “made” and “need”:

“I used to love, I could never drink water, but now I am kind of been made to drink water thinking “if I have this fizzy drink, I could end up like my dad”. I have certain meals, I treat myself once a week, but certain meals I watch what sugar is in it with...when it comes to treats, it would always be fruit instead of a bag of crisps or something. So everything ‘s kind of changed.” I5R6, daughter

“I kind of thought it’s annoying ‘cause I need to make sure I am kind of more careful I guess” I12R11, son

Some of the relatives acknowledged the fact that they may not be able to prevent type 2 diabetes. However, they chose to adopt protective behaviours as a way to minimise the potential impact diabetes can have on their life, if it is not prevented:

“There is a risk that no matter how healthy we are, we can get it later on in life maybe at the same age dad got it so that, maybe you couldn’t prevent it, but can certainly try and have a healthy lifestyle so when it does happen you have already got better controls already in place to deal with it if it does happen but if people are just unhealthy generally, I suppose you could prevent it by being healthier and not getting it in the first place.” I2R2, daughter

Relatives who focused on providing support: “I wasn’t too concerned about me getting it”

The second type of people in the sample of relatives were people who talked about behaviour change in relation to the target patient. These people made a clear distinction between their behaviour and that of their relative and considered themselves to be at low risk of developing type 2 diabetes. In addition, the people who changed their behaviour primarily to support the patient, rather than to reduce their own risk of type 2 diabetes, were mostly partners of patients with type 2 diabetes.

The centrality of the patient was evident in people’s accounts when talking about behaviour change:

"I wasn't too concerned about me getting it but I thought I need to do it [exercise] to support her [wife with type 2 diabetes] I8R8, husband

W: "Yeah, so I wouldn't eat chocolate in front of him now"

P: "Which is completely ridiculous because obviously I see other people eating chocolate but it's the way you feel and I can understand that" I3P2, male

W: "So for pudding I don't eat chocolate, so I don't need these kind of things when [husband] is around." I3R5, wife

Some relatives admitted that the initial changes they made in their behaviour in order to support the patient were not sustained for a long period of time:

"We don't buy as much stuff anymore. And [patient] has always had quite a sweet tooth so... yeah, we think about that more but I can't do without chocolate (...) I was quite good at the start, I didn't...I stopped buying anything at all and I probably lost about half a stone but after a while just kind of start getting things again because I really missed it (...) but it's sort of difficult in the beginning you a bit feel bad if I am buying something that [patient] maybe can't have...but after a while I just have it anyway." I2R3, wife

One way to explain the lack of sustained behaviour change is that the people in this group were more likely to perceive themselves at low risk of developing type 2 diabetes:

"I don't have any family history of it. I am not overweight, in fact I'm probably working my way up to at least the end of the normal continuum but always been underweight until the last 5 years. No genetic predisposition. No history of overweight. Very low [risk] I would have thought." I3R5, wife

Others did not perceive themselves to be at increased risk merely on the basis of having a parent with type 2 diabetes:

"...I don't think necessarily in relation to my dad, it's just how I feel about myself and how...but it makes me think 'cause I don't actually look at my dad and think "type 2 diabetes, oh that means I am necessarily gonna get it". I don't necessarily think of it as a correlation between that and a sort of a familial thing." I9R9, daughter

One participant, the husband of a woman with type 2 diabetes, did not change his behaviour to reduce his own risk of type 2 diabetes because he did not perceive the condition to be serious:

"I would imagine because I am getting older that there are risk of catching anything, so it's, it doesn't scare me, type 2 doesn't scare me. I get a lot more scared about catching some other or having some other problem, so it really doesn't bother me".

I13R12, husband

Relatives who did not change their behaviour compared their behaviour to that of the patient, and made a clear distinction, suggesting that their behaviour would decrease the likelihood of developing type 2 diabetes:

*"There is a small history in the family. I take a much more proactive approach to my health. And if I thought that I was at risk, I would probably take some action to try and reduce that risk."*I6R7, wife

"Well, I watch what you eat, you know...there are so many things that I wouldn't do from, you know, you put half an inch of what I think...and I can't eat, I couldn't eat a sandwich that you made without you taking the butter off it because you put on...you put more butter on a sandwich than I put cheese on it, you know...you have cream, custard and ice cream all together on your pudding and I would never do...I would want to vomit before I do that, so I think we are just brought up with very different attitudes to eating." I3R5, wife

In addition to making a distinction between their lifestyle and their relative's lifestyle, one participant believed that people should enjoy their life and not worry about getting ill:

"I live life as I live life and I am a smoker and I know that's really bad for me but I don't stress about things like that, don't worry about it. And also I do, I mean, I could be wrong but.....my dad drunk a lot and he still drinks a lot and I told him he drank far too much and whether that caused the diabetes or not...well, whisky has got a lot of sugar and things in it. I do believe that's got a lot to do with, maybe not the diabetes maybe it is, I don't know, but to do with his health problems now. And I am not a drinker so...there will be some things he does, I don't and vice versa but I am not gonna stop doing...no, I think you should enjoy that as well." I16R13, daughter

The table below summarises the characteristics of people who changed behaviour to reduce their risk of type 2 diabetes and those of people who changed behaviour to support

the patient. It is suggested that for the first group diagnosis of type 2 diabetes in their relative was a teachable moment. The characteristics outlined below may be what made type 2 diabetes diagnosis a teachable moment for this sub-sample.

Table 19 Characteristics of relatives who changed behaviour to reduce their risk versus to support the patient

Characteristics of relatives who change behaviour to reduce own risk	Characteristics of relatives who change behaviour to support the patient
Linking specific behaviours with reduced likelihood of developing type 2 diabetes (i.e. outcome expectancy) Increased perceived risk of developing type 2 diabetes Increased perception of diabetes severity	Low perceived risk Clear distinction between own lifestyle and that of relative with type 2 diabetes

6.3.5 Changes in roles and relationships

The importance of the whole family in managing type 2 diabetes was evident in participants' accounts. In almost all cases, family support appeared to be essential for reinforcing positive behaviour change:

"If your family encourages you to get takeaways still, you are not gonna feel as bad whereas if your whole family is eating a salad, I know that that's an extreme, and then you order a pizza they are going to be "what are you doing?" and it's gonna be...you are gonna be less likely to do it, I think" I2R11, son

Families in this sample appraised the diabetes diagnosis as "our" problem indicating it requires joint actions from the whole family. This is evident in the use of "we" in the quotes below:

*"I was happy it was at least something **we** can control." I2R2, daughter*

*"...you know when you fly longhaul, on KLM you can go and help yourself to snacks but it's things like sugary snacks and things like that so...**we** had to plan the journey a*

*lot more differently. I mean we've been a few times and we've all been together, the six of us all travel together and you take lots of chocolate bars and things like that and you have a duvet day on the plane and watch movies but this time **we** had to take...**we** had to think about what we were doing because of...the last times we flew we were delayed quite a lot, so **we** had to make sure that if we were gonna be delayed **we** had to think ahead, so that was quite a thing that could have caused, the consequences could have been quite bad for that." I2R3, wife*

The centrality of type 2 diabetes in the decisions family members made in relation to diet was apparent. Many families talked about joint changes in diet:

"If I was cooking dinner that night, I would have to watch how much sugar was in it, how many calories he [father with type 2 diabetes] could have, and we couldn't eat most of the foods, we've always eaten" I5R6, daughter

"I suppose that's changed for me as well. We had a wee Halloween party on Saturday and I was gonna make cupcakes, and I thought: oh full of sugar, so I made a fruit sculpture, it was like a shark so I did that because it meant that dad can have it and he didn't really need to worry about it 'cause we didn't have high sugar fruits and I thought it's better for everyone as well..." I2R2, daughter

There was only one patient in this study who talked about changing her own dietary habits but cooking separately for her family. Although she said that she would not want her family to change their diet, she expressed a desire for support from her relatives:

"I don't impose my diet on my family, they can have whatever they want but for them to understand why I am eating something different to what they choose to." I14P8, female

Later in the interview, she said her family has become more protective of her, which indicates a supportive family environment despite the fact that relatives did not change their dietary habits.

This joint approach to managing type 2 diabetes was facilitated by open communication within the family about the condition:

"I havvnae hidden it, I've told them. (...) I am quite open about it." I6P4, male

"Oh yeah, he was sort of very much in the picture because I said, I think I texted him the day I had been and I said "oh God my blood sugars are really high and might be diabetic" I13P7, female

However, open communication about diabetes did not extend beyond the family circle:

"...It's a private matter and it's another thing you wouldn't tell people at work, you don't need to because they don't need to know." I3P2, male

"If I went out for a meal with friends who don't really know I am diabetic then I will just eat normally and adjust and take more insulin to cope with that" I14P8, female

Although families adopted a joint approach to managing type 2 diabetes, their individual appraisal of the situation differed. This was particularly evident in partners. In the conversation below, the patient indicated implicit need for independence and a belief that he is in control of his condition. His partner, however, engaged in active management of the patient's condition. Although the husband believed that he could control his own condition in situations where control may be challenged, the wife's individual perception of diabetes management influenced the way she helped her husband manage type 2 diabetes:

W: Socialising I think is a challenge 'cause you go to someone else's house and they decide what you eat. Everyone else is drinking wine or beer and snacking on crisps and eating chocolate brownies

P: What's wrong with that? I can manage I3P2, male

W: It's just me then. Well I watch you and I suppose as well...

P: What, if I am eating some crisps or whatever it's been put out, you'd rather I wasn't?

W: eeh... so for me one of the changes is knowing what's supportive and what's not, so the challenge existing is trying to police and say "you can't do this and you can't do that, you know, do you really need to eat that or should you be eating that, you know" because it's not gonna help, you know, 'cause you can just eat it when I'm not there, if you wanted to, but I find it hard to resist the urge to interfere. I3R5, wife

A similar pattern of perceptions was observed in a couple where the wife was diagnosed with type 2 diabetes. Although the partners appraised the situation differently, the wife expressed a desire to encourage her partner to adopt health behaviours:

"He tries to be healthy. I make him be healthy but it's rubbish...he would just eat anything..." I4P3, female

These differences in individual perceptions led to the adoption of traditional gender roles where the woman is the primary care giver. This was present independently of whether the male or the female had type 2 diabetes. In partner relationships, the balance of the relationship often changed:

"I think probably the balance in our relationship has changed. I would probably see me having more of a caring role than I had before" I6R7, wife

In parent-offspring relationships, role reversal was observed where daughters adopted a caring roles:

"He's [father with type 2 diabetes] doing okay, he struggles from time to time, I think he eats sweet packets so that gives me a reason to shout at him for it" I5R6, daughter

"I would say usually, growing up your dad looks after you, but I'm suddenly thinking I need to look more after my dad as well." I2R2, daughter

Although men supported their relatives' ability to manage type 2 diabetes and encouraged them to engage in exercise and have a healthy diet, they were more likely to avoid leadership and adopt the role of an observer who is happy to *"go along with it"*:

"I mean I understand that, you know, what [wife]'s got, you know, I am quite happy to go along with it and if I need to pig out or something, I'm probably gonna do it."

I13R12, husband

"So I do try and get him to go out, like I always invite him for runs and stuff like that (...) He is very aware that it's his diagnosis and it's up to him to manage it himself"

I12R11, son

Dealing with illness together affected relationships by bringing people closer together:

"...we are growing together as a couple more and more every day I think" I15P9, male

"...kind of closer with my mum 'cause I am worried about her" I11R10, daughter

In one family, the diagnosis led to the formation of a shared identity within the family:

W: It's weird now, 'cause [daughter 1] can't really eat dairy and her partner has a condition called PKU, I don't know if you've heard of that, but he can't eat protein so we kind of got this little unit going on here... I2R3, wife

D2: Cause I am vegetarian I2R2, daughter

W: And [daughter 2]'s partner can't eat either meat or dairy, so we kind of got this

unique...he eats a lot of sugar...it's a kind of a... I think it's strange little outfit... I2R3, wife

In summary, families often viewed type 2 diabetes as a joint problem that requires joint actions. This was facilitated by open communication about the condition. In some cases, diagnosis of type 2 diabetes led to changes in relationship balance where female partners adopted caring roles and role reversal where female offspring adopted caring roles. Type 2 diabetes also brought people closer.

Table 20 Changes in roles and relationships following diagnosis of type 2 diabetes

Reported changes in roles and relationships
Appraising type 2 diabetes as a family problem and taking joint actions to manage it
Open communication about type 2 diabetes
Changes in family roles (changes in relationship balance and role reversal)
Importance of gender (i.e. women more likely to adopt caregiving roles)
Type 2 diabetes as bringing people together

6.4 Discussion

The interview findings showed that the diagnosis of type 2 diabetes affects patients and their family members. Two groups of patients were observed in the current sample: people who adopted problem solving strategies and people who needed time to adjust to their new reality. Similarly, family members either adopted an active approach to reduce their risk of type 2 diabetes or changed their behaviour to support the patient. In addition, people talked about managing type 2 diabetes as a family. Many families talked about it openly and made changes to diet together, although the level of involvement from family members was not always equal. A gender difference was observed where women adopted a caring role and had the urge to impose a specific diet on their relatives. The reported changes in perceptions, behaviour and relationships allowed for the identification of factors that may contribute to the existence of a teachable moment. It is suggested that the cognitive changes, experienced by people, who talked about actively changing their behaviour, could be the facilitators that make diagnosis of type 2 diabetes a teachable moment. Each of this is discussed below in relation to previous research.

Affective response: McBride et al. (2003) suggest that events that elicit strong emotional responses are appraised as significant and as such increase the likelihood of a teachable moment. The current study did not find support for this. People reported experiencing a range of emotions, primarily negative, but these did not appear to be linked with their behaviour. People who reported adopting active self-management techniques and people who needed time to adjust reported experiencing similar emotions but their response to the emotions differed. For example shock and surprise in the first group triggered motivation for behaviour change while in the second group they led to a period of denial and avoidance of the diagnosis. As a result, it is suggested that affective response may not be associated with whether diagnosis of type 2 diabetes is a teachable moment.

Monitors and Blunters: Some patients adopted problem-solving approaches, such as information seeking, planning how to manage their type 2 diabetes and employing specific self-management strategies. These patients could be described as monitors - active seekers of information. According to Miller (1987) monitors are very responsive to threat, they amplify the impact of the threat and require as much information as possible in order to deal with it. This is supported by the current findings that demonstrate that problem solvers perceived type 2 diabetes to be a serious condition, so they proactively searched for information and strategies for self-management. This suggests that people who are monitors are more likely to respond positively to information and interventions about type 2 diabetes and the diagnosis would be a teachable moment for them. On the other hand, there were patients who experienced a period of denial and needed time to adjust to their diagnosis. They can be described as blunters- experiencing less urgency to deal with the threat (Miller, 1987). They also tended to talk about reliance on family members to take active management of their condition during the avoidance period. This may suggest that the diagnosis was not a teachable moment for them.

Outcome expectancy: Increased outcome expectancy was also found to be a facilitator for behaviour change for both patients and relatives. Participants in the current study reported various strategies to either minimise the consequences of type 2 diabetes or the risk of getting it, including drinking water instead of juice and reducing carbohydrate intake. This supports McBride et al's (2003) criteria and previous research showing that beliefs that specific behaviours would lead to specific illness-related outcomes are associated with changes in self-management (Rabin & Pinto, 2006; French et al., 2012).

Perceived risk: Perceived risk has been shown to influence the likelihood of adopting health-related behaviours (Health Belief Model, Hochbaum, 1958; Common-sense model,

Leventhal, 1997; McBride et al., 2003). As previously shown (section 3.2), the first degree relatives of people with type 2 diabetes believe they are at higher risk of getting type 2 diabetes, compared to the general population. However, this study shows that type 2 diabetes diagnosis increases risk mostly in the offspring of patients with this condition. Partners of patients were less likely to experience increase in their perception of personal risk. One explanation for this is because partners compared their behaviour with that of the patient and often made a clear distinction by identifying differences in health-related behaviour.

Perceived control: Perceived control is a known predictor of behaviour (Ajzen, 1985). Patients in the current sample often talked about having their diet or glucose levels under control. Some people also mentioned diabetes-related stigma and the belief that people who lack control are more likely to develop type 2 diabetes. The concept of control can be linked to the perception that people are responsible for their own health (Minkler, 1999; Yoder, 2002). According to Yoder (2002) people are told how to improve their health by eating properly and exercising which can then lead to blame, if people do not control their health. This suggests that people are praised for being health-conscious but they are also blamed for being ill (Yoder, 2002). This is linked to self-concept and the view of some patients in the sample. They perceived themselves to be “good diabetics” therefore people who do not manage their diabetes well are “bad diabetics” and they are more likely to be blamed for the causes and consequences of their condition. This view has been shown to be shared by “healthy” people who often assign responsibility and blame to people with type 2 diabetes, which in turn reduces empathy and increases anger towards patients with type 2 diabetes (Anderson-Lister & Treharne, 2014). This is also related to open communication and is important for self-management as patients may not tell friends and colleagues about their condition, which would make self-management and control over type 2 diabetes harder and not as effective.

Severity: The findings provide support for Leventhal’s common-sense model (1997), the Health Belief Model (Hochbaum, 1958) and McBride et al.’s (2003) criteria by demonstrating that perceptions of diabetes severity guide behaviour. More specifically, patients whose perception of diabetes severity increased after diagnosis talked about specific strategies for the management of type 2 diabetes, such as strictly controlling their carbohydrate intake and going for walks with “an imaginary dog”. Similarly, relatives who believed type 2 diabetes to be more serious than they previously thought, were more motivated to adopt protective

health behaviours to reduce their risk of getting type 2 diabetes. This suggests that diagnosis of type 2 diabetes was a teachable moment for patients whose perception of diabetes severity increased following diagnosis.

Self-concept: Patients who adopted problem solving strategies in response to type 2 diabetes considered how the diagnosis has changed the way they see themselves (i.e. their self-concept). This supports McBride et al. (2003) who say that changes in self-concept may be indicative of a teachable moment. The diagnosis brought changes in people's lives and challenged their ability to perform tasks that they had previously performed. Previous studies have explored the disruption in identity following a chronic condition and showed that after an illness diagnosis people experience identity transformation and describe themselves in a different way (Asbring, 2001; Ellis-Hill & Horn, 2000). For example, Kneck et al. (2011) found that newly diagnosed patients with type 2 diabetes focused on understanding and coming to terms with their condition. They evaluated their previous behaviours in order to decide which behaviours could be continued and which had to be changed. Participants in Kneck et al.'s (2011) study also tried to understand the changes in their body and self in response to the new reality. Patients in the current study who experienced changes in identity, were either motivated to adopt strategies that would allow them to keep their previous identity or they welcomed the identity changes as an opportunity for the situation to improve. Similarly, people with well-controlled type 1 diabetes talk about accepting their condition and experiencing a personal challenge and a journey where they live with type 1 diabetes (Smith et al., 2018). Patients who appeared to experience a period of denial also reported changes in identity but they struggled to accept them. Although relatives did not explicitly talk about changes in self-concept, they talked about adopting caring responsibilities, which may suggest a shift in self-concept.

Social role: McBride et al. (2003) suggest that changes in social roles and obligations contribute to the potential of illness diagnosis to be a teachable moment. The patients in the current sample did not report changes in their roles. Only one female patient talked about a change in her family role by cooking two separate meals – one for herself and one for her family members, thus adopting an additional responsibility after diagnosis. However, relatives, especially women, talked about changes in their roles within the family. Some women talked about monitoring the patient's diet and engaging in "policing", which often resulted in a shift in relationship balance (women adopting a caring role) and role reversal (children telling parents what to do). Similar changes in family roles following diagnosis of diabetes

have been observed before (Samuel-Hodge et al., 2012). Samuel-Hodge et al. (2012) found that women are more likely to adopt multi-caregiving roles.

Communal coping: The current study shows that when presented with a health threat (i.e. diagnosis of type 2 diabetes) families use cooperative strategies to deal with their new reality. The appraisal of a problem as a joint problem and the adoption of collective problem solving techniques has been referred to as communal coping (Lyons et al., 1998). It can occur in pairs (e.g. partners) and in groups (e.g. families) and has been linked to better health outcomes (Rohrbaugh et al., 2012; Rentscher et al., 2015). According to Lyons et al. (1998) communal coping has three main characteristics: communal coping orientation, communication about the stressor and cooperative action. Communal coping orientation refers to the appraisal of a problem as a joint problem and a belief that it requires joint action. This is implicitly illustrated in the current study by the use of the pronoun “we”. Families often referred to type 2 diabetes as something they have to deal with together and mentioned making changes as a family. In addition, people engaged in open communication about type 2 diabetes with their family members. The degree of open communication appeared to decrease or disappear when considering people outside the family circle, such as friends and colleagues. Finally, families engaged in cooperative action, demonstrated by the fact that many relatives of people with type 2 diabetes started cooking differently to accommodate the patients’ new diet regimen. The role of the family cook in successful diabetes management has also been highlighted in the field of type 1 diabetes (Smith et al., 2018). Coping together with illness may be crucial for the existence of a teachable moment as collective efforts to address an illness have been linked with better self-management behaviours in people with type 2 diabetes (Johnson et al., 2013b; Khan et al., 2013). For example, Johnson et al. (2013b) found that when patients and partners handled stress through joint discussion, they were both more confident in the patient’s ability to self-manage their type 2 diabetes. This was ultimately associated with eating more healthily and participating more frequently in exercise.

Demographic characteristics: The findings suggest that gender may affect the likelihood of changing one’s behaviour. The scoping review (section 2.1) also showed that gender, among other factors (e.g. age, education, employment status) may be related to the likelihood of adopting healthy behaviours following diagnosis. The current study found that women often tried to control the patient’s environment by cooking differently. Similarly, female patients talked about managing their own condition and sometimes adopting multi-caring roles. Women’s tendency to adopt care-giving roles and men’s to be dependent on

their spouses have been demonstrated before (Samuel-Hodge et al., 2000; Hara et al., 2014; Li et al., 2014).

This study shows that diagnosis of type 2 diabetes has the potential to be a teachable moment for patients and their relatives. It identifies the factors that may increase the likelihood of type 2 diabetes diagnosis being a teachable moment. The table below outlines these factors.

Table 21 Criteria for a teachable moment

Patients	Relatives
Being a monitor (i.e. actively seeking information)	-
Increased perception of severity	Increased perception of severity
Changes in self-concept	Changes in social (family) role
-	Increased perception of personal risk of getting type 2 diabetes
Outcome expectancy (link between a behaviour and an outcome)	Outcome expectancy
Communal coping (collective efforts to address the illness)	Communal coping
Perceived control over type 2 diabetes	-
Gender	Gender

6.5 Conclusion

The current study shows that two of the criteria identified by McBride et al. (2003) (i.e. increased perception of risk and outcome expectancies, and change in social role or self-concept) are relevant to both patients and family members of patients with type 2 diabetes. However, it did not provide support for the role of emotional response in creating a teachable moment. In addition, the study found that other factors may contribute to the potential of type 2 diabetes diagnosis to be a teachable moment: being a monitor, perception of severity, feeling in control of one's type 2 diabetes, communal coping and gender.

Table 22 Research questions and findings on changes after diagnosis and teachable moment criteria

Research question	Findings and relevance to the overall project
<p>How does type 2 diabetes diagnosis affect patients and their relatives, in terms of perceptions, behaviour and relationships?</p>	<p>Emotional response: People experienced primarily negative emotions but responses to these emotions varied and did not appear to be linked with whether type 2 diabetes was a teachable moment.</p> <p>Perceptions: Type 2 diabetes diagnosis appeared to increase perceptions of diabetes severity (in patients and relatives), personal risk of developing type 2 diabetes (in relatives) or diabetic complications (in patients), and triggered changes in self-concept (in patients) and social role (relatives).</p> <p>Behaviour: Type 2 diabetes triggered desire to seek information and adopt strategies for self-management in one group of patients. Other patients experienced a period of denial and avoidance. Relatives often changed their health behaviours (diet and physical activity) either to support the patient or to minimise their own risk of developing type 2 diabetes.</p> <p>Relationships: Families appraised type 2 diabetes as a family illness that requires joint actions. Some gender differences were observed in the provision of support. Type 2 diabetes appeared to strengthen relationships by bringing people closer together.</p>
<p>What criteria need to be fulfilled for the diagnosis of type 2 diabetes to be a teachable moment?</p>	<p>Being a monitor/ Active seeking of information (patients)</p> <p>Outcome expectancy that a specific behaviour would lead to a specific outcome (patients and relatives)</p> <p>Increased perceived risk of type 2 diabetes (relatives)</p>

	<p>Perceived control over one's type 2 diabetes (patients)</p> <p>Increased perception of diabetes severity (patients and relatives)</p> <p>Change in self-concept (patients) and/or social role (relatives)</p> <p>Communal coping (patients and relatives)</p> <p>Importance of gender</p>
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Chapter 7 Study 2: Relationship between the criteria for a teachable moment and changes in behaviour

7.1 Introduction

Chapter 7 presents the findings from the second study that included a cross-sectional survey that explored the association between the possible factors that make diagnosis of type 2 diabetes a teachable moment (identified in Study One) and four primary outcomes (i.e. changes in physical activity and diet, and interest in receiving information and attending a course on type 2 diabetes). The chapter begins by summarising the findings from the qualitative study (7.2), which formed the basis of this study (Chapter 6). It then builds on Chapter 5 by providing details about the specific study methods (7.3). The results include a summary of the sample (7.3.1) and description of the associations between teachable moment factors and primary outcomes: changes in physical activity (7.3.2), changes in diet (7.3.3), interest in receiving information on type 2 diabetes (7.3.4) and interest in attending a course on type 2 diabetes (7.3.5). Finally the chapter discusses the results in relation to the findings from Study One and to previous research and concludes that the criteria for a teachable moment vary between population groups (patients vs relatives) and may be different for different behaviours.

7.2 Background

7.2.1 Summary of previous research

Chapter 6 revealed that type 2 diabetes diagnosis triggers a series of changes in perceptions and behaviour in patients and relatives. Following diagnosis, some patients report increased perception of diabetes severity and outcome expectancy that a specific behaviour would lead to a diabetes-related outcome, a need to maintain or redefine their identity, a desire to actively seek information about type 2 diabetes and engagement in cooperative coping with their family members. The patients who reported the above changes appeared more likely to adopt problem-solving strategies and were thus deemed to have experienced a teachable moment. Similarly, some relatives also appeared to have experienced a teachable moment. These people changed their behaviour to minimise their own risk of type 2 diabetes. After diagnosis, their perception of diabetes severity and perceived risk increased, their roles in the house often changed, they believed that adopting specific actions would

minimise their risk of type 2 diabetes and they engaged in joint coping with the patient. In addition gender appeared to affect people's experiences.

Chapter 6 resulted in the identification of factors that could be associated with the diagnosis of type 2 diabetes being a teachable moment. This provided the basis for Study Two, which explores these factors on a larger scale in an attempt to further support their validity.

7.2.2 The current study

The aim of this PhD was to identify the contextual factors that affect whether and for whom the diagnosis of type 2 diabetes is a teachable moment, when people are more likely to engage in and adhere to lifestyle advice. In order to do this, the factors identified in Study One were used to develop a questionnaire and explore their relationship with changes in behaviour and interest to receive information about type 2 diabetes and/or attend a training course. This chapter addresses research question 8: **Are the newly identified criteria for a teachable moment associated with engagement in physical activity and healthy diet, and interest in receiving information about type 2 diabetes?** The study makes the assumption that change in behaviour (i.e. increase in physical activity and/or healthy eating) indicates that the diagnosis of type 2 diabetes was a teachable moment. Interest in receiving information about type 2 diabetes and/or attending an educational course were included as primary outcomes as they may indicate increased likelihood to take part in a potential behaviour change intervention.

7.3 Results

Data were analysed by conducting a series of binary logistic regressions. The first step was a model building step where the univariate relationship between each independent variable and each outcome was explored (section 5.5.4). There were eight independent variables: monitors (binary, monitors vs blunters), self-concept (continuous, a total score of sum of all items, with higher scores indicating a bigger change in self-concept), social role (binary, increase vs no change or decrease), severity (continuous, a total score of sum of all items, with higher scores indicating bigger increase in perception of severity), control (continuous, a total score of sum of all items, with higher scores indicating more perceived control), communal coping (continuous, a total score of sum of all items, with a higher score indicating a higher degree of communal coping), outcome expectancy (binary, belief of importance of diet/exercise for controlling type 2 diabetes vs lack of belief of importance) and perceived risk (continuous, a total score of sum of all items, with higher

scores indicating bigger increase in perception of risk). There were four outcome variables: changes in diet (binary, change vs no change), changes in physical activity (binary, change vs no change), interest in receiving information about type 2 diabetes (binary, yes vs no) and interest in attending a course on type 2 diabetes (binary, yes vs no). All independent variables identified as significant ($p < 0.05$) during the model building step were entered into a binary logistic regression in order to explore their association with each outcome variable. If the model was significant, age, gender and time since diagnosis were entered to form the final regression model.

7.3.1 Participants

The number of sent questionnaires was 634. Of these, 168 were returned (26.5% response rate) but 27 were excluded (21 because diagnosis was received over 12 months ago, 1 identical questionnaire, 1 not a relative of someone with type 2 diabetes, 3 time since diagnosis not reported, 1 not reported whether they have a relative with type 2 diabetes). The final sample included 86 people with type 2 diabetes and 55 relatives of people with type 2 diabetes. The mean (M) age for patients was 64.2 years (N=78, Min=34, Max=89, SD= 12.4). The mean age for relatives was 60.6 years (N=54, Min=22, Max=85, SD=14.2). The mean time since diagnosis reported by patients was 5.7 months (N=86, Min=1 week, Max=12 months, SD=3.9). The mean time since diagnosis reported by relatives was 5.7 months (N=55, Min=1 week, Max=12 months, SD=3.9). The remaining demographic characteristics are presented in Table 22.

Table 23 Participant characteristics

Characteristics	Patients	Relatives
Gender	N=85 50 male (59%) 35 female (41%)	N=55 21 male (38%) 34 female (62%)
Education after school	N=85 49 yes (58%) 36 no (42%)	N=54 37 yes (69%) 17 no (31%)
Highest education	N=49 17 < SCQF level 6 * 7 - SCQF levels 7-8 14 - SCQF levels 9-10 5 - SCQF levels 11-12	N=37 16 < SCQF level 6 3 - SCQF levels 7-8 10 - SCQF levels 9-10 8 not reported

	6 – not reported	
Employment	N=86 22 full-time (25%) 7 part-time (8%) 4 unemployed (5%) 47 retired (55%) 6 other (7%)	N=55 20 full-time (36%) 3 part time (5%) 30 retired (55%) 2 other (4%)
Student status	N=73 1 full-time (1%) 72 not a student (99%)	N=41 1 full-time (2%) 2 part-time (5%) 38 not a student (93%)
Relationship status	N=84 16 single (19%) 68 in a relationship (81%)	N=54 3 single (6%) 51 in a relationship (94%)
Health status	N=57 2 poor (3%) 6 fair (11%) 33 good (58%) 16 excellent (28%)	N=49 1 poor (2%) 7 fair (14%) 28 good (57%) 13 excellent (27%)
Living with	N=80 13 alone (16%) 47 with a partner (59%) 3 with a flat mate (4%) 13 with family (16%) 3 with offspring (4%) 1 with a sibling (1%)	N=54 1 alone (2%) 38 partner (70%) 1 flat mate (2%) 13 family (24%) 1 sibling (2%)
Source of support	N=85 60 partner (71%) 2 parent (2%) 2 sibling (2%) 5 offspring (6%) 3 wider family (4%) 6 friends (7%) 4 other (5%) 2 no one (2%) 1 myself (1%)	n/a
Who has type 2 diabetes	n/a	N=53 47 partner (89%) 5 parent (9%) 1 offspring (2%)

*SCQF – Scottish Credit and Qualification Framework identifies the level that has been studied in a particular subject. Level 1-6 – no higher education; Level 7 – Certificate of Higher Education; Level 8 – Diploma of Higher Education; Level 9 – Bachelor’s or Graduate

Diploma/Certificate; Level 10 – Honours Degree; Level 11 – Masters or Postgraduate Diploma/Certificate; Level 12 – Doctoral Degree

The descriptives for all predictor variables for each sample are presented in Table 23.

Table 24 Descriptives for predictor variables

Variables	Patients	Relatives
<p>Monitors/blunters (binary) <i>Assumption:</i> Being a monitor would be associated with change in outcomes, indicating a teachable moment.</p>	<p>N=86 Monitors N= 42 (48.8%) Blunters N= 44 (51.2%)</p>	n/a
<p>Outcome expectancy for physical activity (binary) <i>Assumption:</i> A belief that physical activity is important for change in outcomes, would be associated with change in outcomes, indicating a teachable moment.</p>	<p>N=85 Physical activity important for controlling type 2 diabetes N=65 (76.5%) Physical activity not important for controlling type 2 diabetes N=20 (23.5%)</p>	n/a
<p>Outcome expectancy for diet (binary) <i>Assumption:</i> A belief that diet is important for change in outcomes, would be associated with change in outcomes, indicating a teachable moment.</p>	<p>N= 85 Diet important for controlling type 2 diabetes N=70 (82.45%) Diet not important for controlling type 2 diabetes N= 15 (17.7%)</p>	n/a

<p>Perceived risk (continuous)</p> <p><i>Assumption:</i> A higher score showing higher perception of risk would be associated with change in outcomes, indicating a teachable moment.</p>	<p>n/a</p>	<p>N=48</p> <p>M=8.29</p> <p>Min.=4</p> <p>Max.=15</p>
<p>Perceived control (continuous)</p> <p><i>Assumption:</i> A higher score showing higher perception of control would be associated with change in outcomes, indicating a teachable moment.</p>	<p>N=83</p> <p>M=27.18</p> <p>Min. = 16</p> <p>Max. =30</p>	<p>n/a</p>
<p>Severity (continuous)</p> <p><i>Assumption:</i> A higher score showing higher perception of severity would be associated with change in outcomes, indicating a teachable moment.</p>	<p>N=85</p> <p>M=7.93</p> <p>Min. = 2</p> <p>Max. = 10</p>	<p>N=55</p> <p>M=7.60</p> <p>Min.=4</p> <p>Max.=10</p>
<p>Self-concept (continuous)</p> <p><i>Assumption:</i> A higher score showing bigger change in self-concept would be associated with change in outcomes, indicating a teachable moment.</p>	<p>N=81</p> <p>M=49.11</p> <p>Min. = 32</p> <p>Max. =76</p>	<p>N=55</p> <p>M=33.27</p> <p>Min.=26</p> <p>Max.=45</p>
<p>Social role (binary)</p>	<p>N=86</p>	<p>N=52</p>

<p><i>Assumption:</i> Change in social role would be associated with change in outcomes, indicating a teachable moment.</p>	<p>Increase in social role: N= 13 (15.1%)</p> <p>No change/decrease in social role: N=73 (84.9%)</p>	<p>Increase in social role: N= 11 (21.2%)</p> <p>No change/decrease in social role: N=41 (78.8%)</p>
<p>Communal coping (continuous)</p> <p><i>Assumption:</i> A higher score showing higher degree of communal coping would be associated with change in outcomes, indicating a teachable moment.</p>	<p>N=78 M=8.27 Min. = 2 Max. = 10</p>	<p>N=55 M=8.75 Min.=2 Max.=10</p>

The unadjusted correlations between all independent variables and outcomes are included in Appendix 23.

7.3.2 Associations with physical activity

Patients

Forty four patients reported increase in physical activity and 41 reported no change or decrease. Thirty six out of the 44 patients who increased their physical activity reported what changes they had made: 17 changed one aspect of their physical activity (e.g. walking, cycling, jogging, housework), 13 changed two aspects, five changed three aspects, one changed four.

The variables that showed significant associations with changes in physical activity (the dependent variable) during the model building step included outcome expectancy for exercise, severity, control and self-concept. These were entered into a binary logistic regression and indicated that there was a statistically significant association between outcome expectancy for exercise, severity, control and self-concept, and whether there were changes in physical activity (the dependent variable) ($\chi^2(4)=24.28, p<0.001$). Overall, the model explained 35.7% (Nagelkerke R²) of the variance in physical activity and correctly classified

71.8% of cases. The only statistically significant contribution to the model was made by outcome expectancy (the belief that exercise is important for controlling type 2 diabetes) ($p=0.006$). The overall model remained significant even when age, gender and time since diagnosis were added ($\chi^2(12) = 22.30, p=0.002$). The final model explained 36.0% (Nagelkerke R^2) of the variance in physical activity and correctly classified 73.6% of cases. Outcome expectancy remained significantly associated with changes in physical activity ($p=0.013$). The remainder of variables did not make a significant contribution to the final model: control ($p=0.18$), severity ($p=0.62$), self-concept ($p=0.59$), age ($p=0.64$), gender ($p=0.17$), time since diagnosis ($p=0.32$). This suggests that people who believe exercise is important for controlling type 2 diabetes are more than twice as likely to increase their physical activity, compared to people who did not believe exercise was important.

Table 25 Description of independent variables and odds ratios

Independent variables	Increased physical activity (n=44)	No change or decrease in physical activity (n=39)	Unadjusted univariate model (95% CI)	Adjusted model without age, gender and time since diagnosis (95% CI)	Adjusted model with age, gender and time since diagnosis (95% CI)
Outcome expectancy (1)					
1-exercise not important for controlling type 2 diabetes (n=19)	2 (11%)	17 (89%)	B=2.79 Exp.(B)=16.23 (CI: 3.43-76.71)	B= 2.63, Exp.(B)= 13.82 (CI: 2.10-90.87)	B= 2.48, Exp.(B)= 11.92 (CI: 1.67-85.02)
2-exercise important for controlling type 2 diabetes (n=64)	42 (66%)	22 (34%)			
Control (continuous variable, M=mean)	M=28.02	M=26.50	B=1.14 Exp.(B)=1.15 (CI: 1.00-1.33)	B=.14, Exp. (B)= 1.15 (CI: 0.94-1.41)	B= 0.14, Exp. (B) = 1.15 (CI: 0.94-1.42)

Whole sample: M = 27.18					
Severity (continuous variable, M=mean) Whole sample: M = 7.93	M=8.43	M=7.46	B=0.31 Exp.(B)=1.37 (CI: 1.05-1.77)	B=0.61, Exp. (B) = 1.06 (CI: 0.72 – 1.57)	B = 0.11, Exp. (B) =1.12 (CI: 0.72 – 1.72)
Self-concept (continuous variable, M=mean) Whole sample: M= 49.11	M=50.62	M=47.35	B= 0.08 Exp.(B)=1.09 (CI: 1.00-1.17)	B= 0.07, Exp. (B) = 1.07 (CI: 0.98 – 1.16)	B =0.07, Exp. (B) = 1.07 (CI: 0.97 – 1.18)
Age (continuous variable, M=mean) Whole sample: M=64.22	M=66.26	M=63.16	-	-	B= 0.01, Exp. (B) = 1.01 (CI: 0.96-1.06)
Gender (1) 1-male (n=48) 2-female (n=35)	27 (56%) 17 (49%)	21 (44%) 18(51%)	-	-	B= -0.88, Exp. (B) = 0.42 (CI: 0.12-1.45)
Time since diagnosis (continuous)	M=5.75	M=5.96	-	-	B= -0.08, Exp. (B) =0.93 (CI: 0.79 – 1.08)

variable, M=mean)					
Whole sample: M=5.79					

Relatives

Fourteen relatives of people with type 2 diabetes reported an increase in their physical activity and 40 reported no change or a decrease. Out of the 14 who reported an increase, 12 reported specific changes: five changed one aspect of their exercise (e.g. walking, cycling, jogging, housework), five changed two aspects and two change three aspects.

The only variable that showed a significant association with change in physical activity (the dependent variable) during the model building step was social role in the house. The results indicated that people who reported increase in social role in the house were also more likely to report increase in their physical activity (the dependent variable) ($\chi^2(1)=13.55$, $p<0.001$). Social role explained 33% (Nagelkerke R^2) of the variance in physical activity and correctly classified 82.7% of cases. The results from the final model (adjusted for demographic factors) indicated that there was a significant association between social role, age, gender, time since diagnosis and changes in physical activity ($\chi^2(4)=18.16$, $p=0.001$). Overall, the model explained 43.3% (Nagelkerke R^2) of the variance in physical activity and correctly classified 84.3% of cases. Social role in the house made a significant contribution to the model ($p=0.02$). This suggests that people whose social role in the house increased (i.e. they did more around the house such as housework and grocery shopping) were also more likely to report increase in physical activity. The other variables did not make a significant contribution to the final model: Age ($p=0.26$), Gender ($p=0.13$), Time since diagnosis ($p=0.45$).

Table 26 Description of independent variables and odds ratios

Independent variables	Increased physical activity (n=14)	No change or decreased physical activity (n=40)	Unadjusted univariate model (95% CI)	Adjusted model without age, gender and time since diagnosis (95% CI)	Adjusted model with age, gender and time since diagnosis (95% CI)
Social role (1) 1 – no change or decrease (n=41) 2 – increase (n=11)	6 (14.63%) 8 (72.73%)	35 (85.37%) 3 (27.27%) increased social role	B= 2.74, Exp.(B)=15.56 (CI: 3.19 - 75.86)	B= 2.74, Exp.(B)=15.56 (CI: 3.19 - 75.86)	B= 3.19, Exp.(B)= 24.38 (CI: 3.31- 179.46)
Age (continuous variable, M=mean) Whole sample: M=60.63	M=61.07	M=59.84	-	-	B= -0.03, Exp.(B)= 0.97 (CI: 0.92-1.02)
Gender (1) 1-Male (n=20) 2-Female (n=34)	3 (15%) men 11 (35.35%) women	17 (85%) men 23 (67.65%) women	-	-	B= 1.47, Exp.(B) = 4.32 (CI: 0.66-28.39)
Time since diagnosis (continuous variable, M=mean) Whole sample = 5.66	M=7.45	M=5.03	-	-	B= 0.08, Exp.(B) = 1.08 (CI: 0.89-1.31)

7.3.3 Associations with diet

Patients

Seventy one patients reported an increase in healthy eating while 14 reported either no change or increase in unhealthy eating. Out of the 71 patients who reported increase in healthy eating, 66 gave details: nine changed one aspect of their diet (e.g. less sweets, less carbs, more vegetables), 18 changed two aspects, 15 changed three aspects, five changed four, six changed five and 13 changed six aspects of their diet.

The variables that showed significant associations with changes in diet (the dependent variable) during the model building step included outcome expectancy for diet (the belief that diet is important for controlling type 2 diabetes) and control over one's type 2 diabetes. These were entered into a binary regression. The results from the regression in the patient sample indicated that there was a statistically significant association between outcome expectancy for diet, control and changes in diet (the dependent variable) ($\chi^2(2)=12.65, p=0.002$). Overall, the model explained 24.4% (Nagelkerke R²) of the variance in diet and correctly classified 85.5% of cases. Outcome expectancy and control made significant contributions to the model ($p=0.03$ and $p=0.005$, respectively). The model remained significant even when age, gender and time since diagnosis were added ($\chi^2(5)=18.49, p=0.002$). Overall, the final model explained 36.3% (Nagelkerke R²) of the variance in diet and correctly classified 86.7% of cases. The effects of outcome expectancy for diet and control remained significant ($p=0.02$ and $p=0.005$ respectively) suggesting that people who thought diet is important for managing type 2 diabetes and also felt in control of their management were more likely to increase healthy eating. The remainder of variables did not make a significant contribution to the final model: Age ($p=0.96$), Gender ($p=0.26$), Time since diagnosis ($p=0.15$).

Table 27 Description of independent variables and odds ratios

Independent variables	Increase in healthy diet (n=71)	No change or decrease in healthy diet (n=14)	Unadjusted univariate model (95% CI)	Adjusted model without age, gender and time since diagnosis (95% CI)	Adjusted model with age, gender and time since diagnosis (95% CI)
Outcome expectancy (1)	9 (60%) diet not important	6 (40%) diet not important for	B= 1.64, Exp. (B) = 5.17 (CI:	B= 1.61, Exp. (B) = 4.99 (CI: 1.17-21.21)	B= 2.07, Exp. (B) = 7.92

1-diet not important for controlling type 2 diabetes (n=15)	for controlling type 2 diabetes	controlling type 2 diabetes	1.45-18.37)		(CI: 1.39-45.27)
2-diet important for controlling type 2 diabetes (n=70)	62 (88.57%) diet important for controlling type 2 diabetes	8 (11.43%) diet important for controlling type 2 diabetes			
Control (continuous variable, M=mean) Whole sample: M = 27.18	M=27.69	M=24.46	B= 0.22, Exp. (B) = 1.25 (CI: 1.07-1.46)	B=0.24, Exp. (B) = 1.27 (CI: 1.07-1.50)	B= 0.28, Exp. (B) =1.33 (CI: 1.09-1.62)
Age (continuous variable, M=mean) Whole sample: M=64.22	M=64.50	M=64.08	-	-	B= - 0.002, Exp. (B) = - .99 (CI: 0.94-1.06)
Gender (1) 1 – male (n=49) 2- female (n=35)	39 (79.59%) men 31 (88.57%) women	10 (20.41%) men 4 (11.43%) women	-	-	B= 0.95, Exp. (B) = 2.58 (CI: 0.50-13.26)
Time since diagnosis (continuous variable, M=mean)	M=5.60	M=6.98	-	-	B=-0.15, Exp. (B) =0 .87 (CI: 0.71-1.05)

Whole sample: M=5.79					
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Relatives

Twenty seven relatives of people with type 2 diabetes indicated increase in healthy eating and 27 indicated no change or increase in unhealthy eating. Of the 27 who reported increase, 25 gave specific details: five changed one aspect of their diet (e.g. less sweets, less carbs, more vegetables), four changed two aspects, seven changed three and seven changed four aspects, one changed five and one changed six aspects.

The only variable that showed a significant association with change in diet (the dependent variable) during the model building step was perceived risk of type 2 diabetes. The results from the binary logistic regression showed that people who believed they are at increased risk of type 2 diabetes were less likely to change their diet ($\chi^2(1)=6.40$, $p=0.01$). The model explained 17% (Nagelkerke R^2) of the variance in diet and correctly classified 61.7% of cases. Perceived risk remained significant when age, gender and time since diagnosis were added to the model ($p=0.013$). However, the overall model was not significant ($\chi^2(4)=8.85$, $p=0.07$). The model explained 23.3% (Nagelkerke R^2) of the variance in diet and correctly classified 76.1% of cases. The other variables did not make a significant contribution to the final model: age ($p=0.98$), gender ($p=0.12$), time since diagnosis ($p=0.32$).

Table 28 Description of independent variables and odds ratio

Independent variables	Increase in healthy diet (27)	No change or decrease in healthy diet (27)	Unadjusted univariate model (95% CI)	Adjusted model without age, gender and time since diagnosis (95% CI)	Adjusted model with age, gender and time since diagnosis (95% CI)
Perceived risk (continuous variable, M=mean) Whole sample: M=8.30	M=7.30	M=9.42	B= -0.27, Exp.(B)=0.76 (CI: 0.61-0.96)	B= -0.27, Exp.(B)=0.76 (CI: 0.61-0.96)	B= -0.33, Exp.(B) = 0.72 (CI: 0.55-0.93)

Age (continuous variable, M=mean) Whole sam- ple: M=60.63	M=61.96	M=58.44	-	-	B=0.00, Exp.(B)= 1.00 (CI: 0.95-1.05)
Gender (1) 1-Male (n=20) 2-Female (n=34)	7 (35%) men 20 (58.82%) women	13 (65%) men 14 (41.18%) women	-	-	B= 1.18, Exp.(B) =3.26 (CI: 0.73-14.59)
Time since di- agnosis (continuous variable, M=mean) Whole sample = 5.66	M=5.92	M=9.42	-	-	B= -0.09, Exp.(B) = 0.91 (CI: 0.77-1.09)

7.3.4 Associations with interest in receiving information about type 2 diabetes

Patients

Sixty seven patients indicated they would like to receive information about type 2 diabetes while 16 indicated they would not.

The only variable that showed a significant association with interest in receiving information (the dependent variable) about type 2 diabetes was control. The results from the binary logistic regression indicated that people who felt more in control were more likely to want to receive information ($\chi^2(1)=4.32, p=0.04$). The model explained 8.2% (Nagelkerke R²) of the variance in interest in receiving information and correctly classified 77.8% of cases. The model remained significant even when age, gender and time since diagnosis were entered ($\chi^2(4)=11.18, p=0.025$). The model explained 22.3% (Nagelkerke R²) of the variance in interest in receiving information and correctly classified 79.5% of cases. Control and time since diagnosis made significant contributions to the model ($p=0.02$ and $p=0.02$ respectively). This suggests that people who felt more in control of their type 2 diabetes were more likely to want to receive information about type 2 diabetes. The longer the time

since diagnosis, the less likely people were to want receive information about type 2 diabetes. The other variables did not make a significant contribution to the final model: age ($p=0.76$), gender ($p=0.66$)

Table 29 Description of independent variables and odds ratios

Independent variables	Interested in receiving information (n=67)	Not interested in receiving information (n=16)	Unadjusted univariate model (95% CI)	Adjusted model without age, gender and time since diagnosis (95% CI)	Adjusted model with age, gender and time since diagnosis (95% CI)
Control (continuous variable, M=mean) Whole sample: M = 27.18	M=27.65	M=25.50	B= 0.15, Exp.(B)= 1.17 (CI: 1.01- 1.34)	B= 0.15, Exp.(B)= 1.17 (CI: 1.01- 1.34)	B= 0.19, Exp. (B)= 1.21 (CI: 1.02-1.42)
Age (continuous variable, M=mean) Whole sample: M=64.22	M=64.03	M=63.80	-	-	B= 0.01, Exp.(B)= 1.01 (CI: 0.96-1.06)
Gender (1) 1-Male (n=49) 2-Female (n=33)	39 (79.59%) men 27 (81.82%) women	10 (20.41%) men 6 (18.18%) women	-	-	B= -0.30, Exp.(B)=1.35 (CI: 0.36-5.07)
Time since diagnosis (continuous variable,	M=5.15	M=7.90	-	-	B= -0.21, Exp.(B) = 0.81 (CI: 0.69-0.97)

M=mean)					
Whole sample: M=5.79					

Relatives

Thirty relatives indicated they would like to receive information about type 2 diabetes and 20 indicated they would not.

There were no significant associations between the suggested teachable moment factors and interest in receiving information about type 2 diabetes (the dependent variable).

7.3.5 Associations with interest in attending a course on type 2 diabetes

Patients

Thirty nine patients indicated they would like to attend a course on type 2 diabetes while 40 indicated they would not like to.

The only variable that showed a significant association with interest in attending a course on type 2 diabetes (the dependent variable) was control. The results from the binary logistic regression indicated that people who felt more in control were more likely to want to attend a course ($\chi^2(1)=4.35, p=0.04$). Control explained 71% (Nagelkerke R²) of the variance in interest in attending a course and correctly classified 60.8% of cases. However, there was not a significant association between control and interest in attending a course on type 2 diabetes (the dependent variable) when age, gender and time since diagnosis were entered into the model ($\chi^2(4)=6.22, p=0.183$). The model explained 11.2% (Nagelkerke R²) of the variance in interest in attending a course and correctly classified 64.8% of cases. None of the variables made a significant contribution to the final model: control ($p=0.10$), age ($p=0.76$), gender ($p=0.39$), time since diagnosis ($p=0.09$).

Table 30 Description of independent variables and odds ratios

Independent variables	Inter-ested in attending a course (n=39)	Not inter-ested in attending a course (n=40)	Unadjusted univariate model (95% CI)	Adjusted model with-out age, gender and time since diagnosis (95% CI)	Adjusted model with age, gender and time since diagnosis (95% CI)
Control Whole sam-ple: M = 27.18	M=28.02	M=26.40	B= 0.14, Exp.(B)=1.15 (CI: 1.00-1.33)	B= 0.14, Exp.(B)=1.15 (CI: 1.00-1.33)	B= 0.13, Exp.(B)=1.13 (CI: 0.98-1.31)
Age (continuous variable, M=mean) Whole sam-ple: M=64.22	M=62.66	M=64.49	-	-	B=-0.01, Exp.(B)=0.99 (CI: 0.95-1.04)
Gender (1) 1-Male (n=47) 2-Female (n=31)	25 (53.19) men 14 (45.16%) women	22 (46.81%) men 17 (54.84%) women 1 missing	-	-	B= 0.45, Exp.(B)=1.56 (CI: 0.56-4.39)
Time since diagnosis (continuous variable, M=mean) Whole sam-ple: M=5.79	M=4.99	M=6.59	-	-	B= -0.12, Exp.(B).= 0.89 (CI: 0.78-1.02)

Relatives

Sixteen relatives indicated they would like to attend a course on type 2 diabetes while 34 indicated they would not like to.

There were no significant associations between the suggested teachable moment factors and interest in attending a course on type 2 diabetes (the dependent variable).

7.4 Discussion

This study explored the associations between the suggested factors for a teachable moment, identified in Study One, and changes in behaviour (i.e. diet and physical activity); making the assumption that positive changes in these outcomes indicated that type 2 diabetes diagnosis was a teachable moment. During a teachable moment people may become more receptive of information so interest in type 2 diabetes-related information/course was also considered to be indicative of a teachable moment. The discussion is structured around each of the proposed factors that may create a teachable moment.

Monitors and blunterners: According to Miller (1987) whether someone is a monitor or a blunter can be used to predict the adoption of behaviour strategies in response to stressors. Monitors are people who amplify the seriousness of a threat and actively seek information in order to address the threat. Blunterners may experience a period of denial. Whether a patient was a monitor or a blunter was not associated with changes in any of the primary outcomes. This contradicts the interview findings in Study One, which suggested that patients who actively sought information about type 2 diabetes also adopted self-management strategies. The lack of statistical significance for this association could be due to the question used to measure monitoring/blunting styles in the questionnaire. Participants may have interpreted the first part of the question (i.e. "when I was diagnosed with type 2 diabetes...") to indicate the time immediately after receiving the diagnosis, at which point patients are often given leaflets about type 2 diabetes. It is also possible that being a monitor may not be sufficient to trigger behaviour change and other factors may hinder people's likelihood to seek information and adopt specific behaviours. Previous research indicates that being a monitor is not associated with the use of a diabetes risk score test (Nijhof et al., 2008).

Outcome expectancy: According to McBride et al. (2003) events that increase people's expectancies of possible outcomes (good or bad) related to a particular behaviour and the value given to these outcomes are most likely to be teachable moments. The current study

confirms this. Outcome expectancy for exercise was significantly associated with changes in physical activity in patients. Similarly, outcome expectancy for diet was significantly associated with changes in diet in patients. These results support the findings from Study One where patients talked about adopting specific behaviours (e.g. reduce carbohydrate intake) because they believed this would help control their type 2 diabetes. This is also consistent with previous studies, which show that people need to be aware of the risk factors for the illness, relate these to personal behaviours and believe that adopting a specific behaviour would prevent or reduce the risk of illness (McBride et al., 2003; Rabin & Pinto, 2006; Humpel et al., 2007; Thresia et al, 2009; French et al., 2012; Stead et al., 2012). Similarly to the current study, French et al. (2012) found that patients who believed physical activity to be important for diabetes control were more likely to increase physical activity.

Perceived risk: Perceived risk of developing a condition may be a predictor of precautionary behaviour and a platform for behaviour change interventions (Van der Pligt et al., 1998). Perceived risk of developing type 2 diabetes was a significant predictor of changes in diet. The association was negative showing that people who felt at increased risk of type 2 diabetes were less likely to adopt a healthy diet. This contradicts the interview findings and previous research showing that people who were informed of their risk of type 2 diabetes are more likely to adopt protective health behaviours (Qureshi & Kai, 2008). In addition, perceived risk was not associated with changes in physical activity or interest in receiving information or attending a course on type 2 diabetes. This partly concurs with previous studies that have reported that perceived risk of type 2 diabetes is not associated with intention to be physically active or eat healthy (Blue, 2007; Hivert et al., 2009). There are several potential explanation for the lack of significance. First of all, people who felt at increased risk may have also felt that this risk cannot be reduced. Research shows that knowledge of causes and feelings of control over prevention of type 2 diabetes are important for behaviour change (Macaden & Clarke, 2006; Pijl et al., 2009). Pijl et al. (2009) found that people who believed genetics caused diabetes, felt they could not prevent it by adopting a healthy lifestyle while those who saw behavioural factors as causes of type 2 diabetes believed they could prevent it. Another explanation for the results from Study Two could be that people with a combination of risk factors (i.e. genetics and lifestyle) may have felt that behaviour change would not lead to positive outcomes. McBride et al. (2008) found that increased personal risk factors may diminish motivation to change behaviour as people may feel more fatalistic. Finally, knowledge of type 2 diabetes causes was not assessed so

the possibility of relatives in the sample being unaware of their risk of type 2 diabetes cannot be excluded. Pierce et al. (2001) found that offspring of people with type 2 diabetes often underestimate their risk and know little of preventive strategies.

Perceived control: Perceived control is a known predictor of behaviour (Ajzen, 1985). People who feel in control are more likely to engage in behaviour change. Perceived control over one's type 2 diabetes was positively associated with increase in healthy diet and interest in receiving information and attending a course on type 2 diabetes in the patient sample. This means that people who felt more in control were more likely to increase healthy eating and express interest in information about type 2 diabetes. This supports previous research showing that feelings of personal control are associated with adherence to diet regimen (Broadbent et al., 2011). However, Broadbent et al. (2011) also found a positive relationship between control and exercise. This relationship was only significant in the current study when control was an independent predictor of exercise. In the overall regression model, which included other factors that may predict a teachable moment, control did not make a significant contribution to the model. In addition, when demographics were entered into the model, control was no longer associated with interest in attending a course on type 2 diabetes. There are two potential explanations for these results. First, the confidence intervals suggest that in a bigger sample control might have remained a significant predictor in the final model. Second, the factors that are suggested to contribute to the potential of type 2 diabetes diagnosis to be a teachable moment are covariates in the model so their confounding could have affected the contribution of control to the model.

Severity: McBride et al. (2003) suggest that increased perception of severity is a criterion for a teachable moment. People who perceive a health threat to be serious may be more motivated to change their behaviour. Increased perception of diabetes severity was not significantly associated with any of the primary outcomes. Although it showed a significant association with exercise in patients in the model building step, severity was no longer significant when other factors were entered into the model. This could be due to the small size or to the confounding between the different teachable moment criteria entered into the model. A potential explanation for the lack of association between severity and the other outcomes could be poor understanding of diabetes severity. The scoping review (section 3.1) found that some people have limited knowledge of type 2 diabetes-related outcomes and that perception of severity may depend on the presence of complications (Jayne & Rankin, 2001; Habte et al., 2016), need for insulin and number of hospital visits (Macaden & Clarke, 2006). Although the questionnaire did not ask about complications, it asked about

general health and the majority of patients and relatives in Study Two reported good or excellent health status (86% patients, 84% relatives).

Self-concept and social role: McBride et al.'s (2003) heuristic suggests that events that prompt changes in perceived norms that make a specific behaviour incompatible with role obligations related to that behaviour will be optimal teachable moments. The more committed a person is to the role, the greater sense of obligation to comply with it and avoid stigma of non-compliance (McBride et al., 2003). Similarly, events that make specific behaviours incompatible with one's self-concept may diminish self-esteem, and become more likely to be teachable moments. For example, diagnosis of lung cancer may increase perceptions that smoking is unacceptable and desire to avoid the stigma of continued smoking, and this would increase motivation to quit (McBride et al, 2003). However, in the current study change in self-concept was positively associated with change in exercise in patients but only when other predictors were not included in the model. This further highlights the potential confounding between the different teachable moment criteria. The interview findings from Study One can shed light into the lack of significance of the relationship between self-concept and the other primary outcomes for patients. In the interview sample, there were patients who experienced changes in self-concept, reporting that after diagnosis they felt "like somebody else". This motivated them to engage in healthy behaviours in order to maintain their pre-diagnosis self-concept. Similarly, others did not want to be perceived as "bad diabetics" so they adopted health behaviours, thus supporting McBride et al.'s (2003) criterion. In other cases, however, the opposite was seen where people associated type 2 diabetes with stigma. One patient did not tell anyone he had the condition because he felt this would compromise his ability to be a leader at work. This appeared to hinder self-management as it presented difficulties in performing blood test at work where no one knew he had type 2 diabetes. Similarly, another patient did not disclose her diagnosis to her friends, which led to having to adjust insulin levels in response to poor diet control in social situations. The role of internalized stigma of type 2 diabetes has been highlighted before in a study where participants experienced role conflict and fear that if they disclose their condition they would be excluded from society (Kato et al., 2016). These feelings sometimes resulted in poor self-management in social situations (Kato et al., 2016). This suggests that change in self-concept may not be sufficient to motivate behaviour change in people with type 2 diabetes.

Change in social role in the house was significantly related with change in physical activity in relatives but not in patients. The relationship between social role and exercise could be explained by the interview findings that relatives who adopted a new role by caring for the patient, did more exercise in terms of housework. However, the lack of significance in the patient sample contradicts McBride et al.'s (2003) heuristic that patients may adopt a role that is consistent with expected roles following diagnosis. It remains unclear whether relatives did more housework because they felt they need to alleviate the burden from patients or because patients experienced diabetes-related ill health, which hindered their ability to perform household activities.

Communal coping: Communal coping refers to a family's appraisal of a problem as a joint problem and the adoption of collective strategies to address it (Lyons et al., 1998). Existing literature shows a positive relationship between communal coping and better health outcomes (Beverly & Wray, 2010; Johnson et al., 2013b; Khan et al., 2013). Communal coping was not significantly associated with any of primary outcomes in this study. This is surprising given the interview findings in Study One and existing literature on the positive relationship between communal coping and better self-management (Johnson et al., 2013b; Khan et al., 2013). One explanation for this could be the lack of standardised measure of communal coping. Another way to explain this result is through interdependence theory, which suggests that partners are interdependent and the interaction between the partners affects both members of the dyad: if either feels that the patient should do it alone, then spousal involvement will be irrelevant and if their efforts result in greater conflict spousal involvement will not be effective (Lewis et al., 2006). In addition, a previous couples-focused diabetes intervention has been ineffective in promoting collaborative problem solving and open communication about type 2 diabetes (Trief et al., 2011). This highlights the importance of exploring the individual views of patients and their family members and how they may affect behaviour change. The potential role of communal coping in the occurrence of teachable moments was not confirmed in the current study and requires further investigation.

Demographic characteristics: When exploring the impact of illness on people's lives, one must consider that health events occur in the wider context suggesting certain demographic factors can affect people's experience. The literature review (section 2.1) showed that age, gender, education and employment may be positively associated with changes in behaviour, such as healthy eating and smoking cessation. The results on the relationship between demographic characteristics and primary outcomes were mixed. The only significant

association was between time since diagnosis and interest in receiving information about type 2 diabetes in the patient sample. This relationship was negative, suggesting that the longer the time of diagnosis the less likely patients are to want to receive information about type 2 diabetes. This is not surprising as people may require information shortly after diagnosis and the longer the time since diagnosis, the more information they have accumulated about their condition. Time since diagnosis also had a negative association with physical activity in patients, with mean time since diagnosis lower in people who reported changes in physical activity. Although this was not statistically significant, the wide confidence intervals suggest that this could be due to the small sample size. This would support previous research showing that people are more likely to change behaviour in the first 6 months of diagnosis (Humpel et al., 2007) and provide support for the suggestion that type 2 diabetes diagnosis is a teachable moment.

The relationships between gender and primary outcomes were not significant. However, the lack of significance could be due to the small size, as demonstrated by the wide confidence intervals. The results showed that male relatives were more likely to increase physical activity and healthy diet while the opposite was true for patients – female patients were more likely to engage in physical activity and healthy diet. These associations could be explained by the interview findings in Study One, which showed that women often reported changing behaviour after being diagnosed with type 2 diabetes. Similarly, female relatives appeared to manage male patients' diet and encourage them to increase exercise. This finds further support in the literature, which shows that women often adopt caregiving roles and men tend to be dependent on their spouses (Samuel-Hodge et al., 2000; Hara et al., 2014; Li et al., 2014). It also confirms McBride et al.'s (2008) findings that being female was associated with intervention buy-in while men did not respond to diagnosis of polyp cancer in a manner suggestive of a teachable moment.

Age was not associated with any of the primary outcomes. This is not surprising given the mixed research on the topic with some studies showing that older people are less likely to exercise (Lemon et al., 2004) but more likely to adopt a healthy diet (Humpel et al., 2007) and others not reporting a relationship between age and behaviour change (Butler et al., 2010; Bidstrup et al., 2013).

7.5 Conclusion

The current study shows that the suggested criteria for a teachable moment are different for different groups (patient vs relatives) and for different behaviours (physical activity, diet, interest in information, interest in a course). It also suggests potential collinearity between the factors that may make diagnosis of type 2 diabetes a teachable moment. Table 30 summarises the criteria and their influence on primary outcomes.

Table 31 Research question and findings on the association between teachable moment criteria and primary outcomes.

Research question	Findings
<p>Are the newly identified criteria for a teachable moment associated with engagement in physical activity and healthy diet, and interest in receiving information about type 2 diabetes?</p>	<p>Monitors: being a monitor was not associated with changes in any of the primary outcomes.</p> <p>Outcome expectancy: positive relationships with change in physical activity and diet in patients.</p> <p>Perceived risk: negative relationship with healthy diet in relatives.</p> <p>Perceived control: positive relationships with all outcomes. However, in the final model the only significant relationships remained between control and healthy diet and control and interest in receiving information about type 2 diabetes in patients.</p> <p>Severity: positive association with exercise in patients but not when other teachable moment factors were entered into the model.</p> <p>Self-concept: positive association with exercise in patients but not when other teachable moment factors were entered into the model.</p> <p>Social role: positive relationship with changes in physical activity in relatives.</p> <p>Communal coping: not associated with primary outcomes.</p> <p>Demographic factors: Age not associated with primary outcomes; gender associated</p>

	<p>with primary outcomes despite lack of statistical significance (<i>note: wide confidence intervals</i>); time since diagnosis negatively associated with desire to receive information about type 2 diabetes and physical activity (<i>note: lack of statistical significance but wide confidence intervals</i>) in patients.</p>
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Chapter 8: Study 1: Type 2 diabetes prevention interventions

8.1 Introduction

Chapter 8 presents the findings from the first study that included qualitative interviews and elicited people's suggestions about potential ways to recruit family members for a behaviour change intervention, the optimal time for intervention delivery, and intervention components and mode of delivery. The chapter begins by summarising the results from the systematic review, which formed the basis of the current investigation (8.2). It then describes the study sample (8.3.1) and presents the findings from Study One by focusing on participants' suggestions about recruitment methods (8.3.2), intervention timing (8.3.3), intervention components (8.3.4) and mode of delivery (8.3.5). After that, the chapter discusses the findings in relation to previously employed interventions in an effort to provide suggestions for a potential intervention to prevent type 2 diabetes among the relatives/partners of people with the condition (8.4). The chapter concludes that the suggestions made by participants in the current study are underutilised in prevention research (8.5).

8.2 Background

8.2.1 Summary of previous research

The systematic review in Chapter 4 showed that there has been limited research evaluating interventions that target the modifiable risk factors for type 2 diabetes in relatives/partners of people with the condition. Only four out of the seven studies, included in the review, demonstrated intervention effectiveness (Wing et al., 1998; Brekke et al., 2003, 2004, 2005a, 2005b; Gorin et al., 2008; Pijl et al., 2009) and only two sustained the change at two-year follow up (Wing et al., 1998; Brekke et al., 2003, 2004, 2005a, 2005b). The review raised questions about simple, effective and sustainable interventions to promote health behaviour change among people at high risk of type 2 diabetes. It also highlighted the need for feasible methods of recruiting potential participants.

8.2.2 The current study

The second aim of this PhD is to inform a potential intervention targeting the modifiable risk factors for type 2 diabetes in the relatives and partners of people with the condition.

This section addresses research question 9: **What recruitment methods, intervention components and mode of delivery would be acceptable to potential participants?**

8.3 Findings

8.3.1 Sample

The participants are the same participants as described in 6.3.1.

8.3.2 Recruitment methods

Participants were asked about the best ways to recruit family members of patients with type 2 diabetes to a potential intervention. Participants agreed that the best way would be identify patients and either recommend the study to them or give them information about type 2 diabetes. Suggestions for identifying patients included through screening GP registers and the Diabetes UK member database; and by approaching people and placing posters and leaflets in GP practices, diabetic clinics and diabetes support groups.

8.3.3 Intervention timing

Participants believed that an intervention should be delivered shortly after diagnosis of type 2 diabetes in oneself or in a family member because during this time, people are more open to engage with it:

“There’s really no information about it [type 2 diabetes] until you are actually hit with it or somebody in your family gets it, that’s the only way you can start thinking: “hold on a minute”” I7P5, female

However, immediately after diagnosis may not be the appropriate time as people are still in shock:

Yeah, it’s getting the optimum time, isn’t it, to get in there. And probably....that’s where it hits them hardest isn’t it? They’ve got the diagnosis, give them a wee while just to sort of like, let that sink in with all the fears or concerns and everything, and maybe the education is the best just then.” I9R9, daughter

“I mean you do need a bit of time to get your head around what you've been diagnosed with, which is diabetes, lifelong, can't change it, can't revert it in most cases, so yes, you need time to absorb that information but any preventative stuff needs to come straight after I think, not a year later when you are maybe too far off for that”

I14P8, female

A few participants suggested specific time frames as the optimum time for intervention delivery, which varied from 2 to 6 months after diagnosis. Some participants believed that interventions should target not only adult family members but provide education for children in order to prevent their risk of developing type 2 diabetes later in life:

“Well, I suppose without a doubt when they are children. It’s got to be” I9R9, daughter

8.3.4 Intervention components

The majority of participants believed that people at high risk of type 2 diabetes should receive more information about the condition. According to one participant people’s lack of knowledge and awareness of type 2 diabetes have contributed to the increasing levels of the condition:

“As with a lot of these things, it seems that perhaps ignorance is the wrong word but unawareness leads to this sort of epidemic that we seem to be faced with at the moment, at least that’s the way it has been described at the moment.” I17P10, male

In addition, this participant believed that health education, rather than assigning blame, is needed to help people make healthier choices to prevent type 2 diabetes:

“I think unfortunately the publicity...given that information is concentrated very heavily on the cost of the condition and the fat and inactive diabetics who done that and are costing the country lots of money in terms of medication and hospital treatment etc. etc. I think it would be better if the concentration was more on better information, health education generally (...) And I think doing that, not inevitably, but suggesting that people’s lives later may be better if they take more care of themselves and not just diabetes but across the board, I think that would be a sensible approach.” I17P10, male

Individuals’ views on preferred types of information differed, with some saying they would like general information:

“I would want to know everything that folk know about diabetes: what causes it, why...what actually it is, what it does to your body, what causes it, what can be done to prevent it, also if you've got it, what can you do to stop it from getting worse or improve it, I don't even know if you can, you know, what the worst outcome can be,

what the best outcome can be, I would want to know absolutely everything about it.”

I16R13, daughter

“...there should be more information about it: what it means to be borderline, what it means to get type 2, what type 1 means, what families can do, what patients can do. It's like there is no information to get really, you have to actively go in and ask...”

I7P5, female

“...it's not very well advertised what the symptoms are. You obviously got...if it's something to do with stroke, you get the face thing...everything else seems to have a way of telling you what the symptoms are but it's type 2 diabetes more confusing...if you googled it, it would probably tell you you're dying like...but it's not.” I5R6, daughter

Others said they would be interested in the biological causes and mechanisms that underlie type 2 diabetes:

“But also something quite medical, sort of going into the details of diabetes, how it works inside you, you know what I mean, just that kind of thing, just so you can understand what it actually is rather than just being a name.” I2R4, daughter

Patients believed that people should be told that *“sugar is the enemy”* and they should be provided with information about *“the places that it can be found”*. In addition, interventions could provide more information about low-sugar alternatives to help people get into a habit of using these products:

“...you almost want to normalise low sugar (...) to try to wean the population off sugar as well” I12P7, female

Several of the participants debated the possibility of giving information about *“the worst case scenarios”* and providing graphic images on the consequences of type 2 diabetes. One patient considered the effectiveness of such intervention retrospectively:

“I have certainly now seen more horrific images of amputees etc. And the thought in my mind is have I seen those before would I have been...would that have had a bigger impact on me in terms of losing weight? So classic, isn't it? (...) Would I have responded better to more health messages? I honestly have no idea” I3P2, male

This idea could be further supported by the findings that some patients talked about changes in their awareness of certain aspects of their environment, such as obese people and people with amputations:

"I think once you are diagnosed you see more obese people, you notice it more and you just think diabetes. I don't know why, you just do" I2P1, male

"It's like...oh...you don't notice people's wheelchairs because sometimes people are just not allowed to go to their car but I am not super sensitive to the amount of amputees you see. Everywhere, not just in the hospital, and there is an awful lot of them" I10P6, female

It was also suggested that interventions should challenge the perception that if you do not have type 2 diabetes, you do not need to worry about it:

"Yeah, 'cause I do think one of the things about the risk, the stigma and also that notion of "the other", the other person and bla bla bla and it's not me therefore I can do whatever I want. And it's almost to shake people out of complacency, isn't it?" I12P7, female

"Do you actually make people not go and buy stuff or do you tax sugar or whatever you want to do but it's just the awareness of what this can do to you is just not there" I13R12, female

"But I do think people need to be made aware that diabetes can really happen to anybody, diabetes type 2 can really happen to anybody" I13P7, female

Others believed that a potential intervention should aim to change people's thinking rather than provide more information about the condition:

"I think it's got much more to do with your view on health and I think you can give people all the advice you like, you can do all sorts of preventative courses and approaches but it really comes down to changing people's view of their health, if you can change that." I6R7, wife

"So I don't know how to educate people. They've got to want it" I10P6, female

A few participants expressed a desire to receive tailored information about diet and general lifestyle:

"So you can show tricks and tips to help them eat more healthily" I1R1, mother

“That’s what I’m saying about lifestyle because everyone’s lifestyles are different so people could say: this is what I do and other people might have not thought about it (...)” I2R2, wife

This is further supported by a quote from a patient who attended an education course but felt that the course provided general knowledge, which was not tailored to participants’ needs:

“To be fair, I mean, the diabetic nurse at my original practice was very good and I got to go up to [hospital name] on a course about, you know, they showed you a plate and what each portion of the plate should be but they didn’t give you so much ideas for recipes and I felt it was still slanted very much at what you might call a traditional type 2 diabetic who actually needed to lose weight or keep their weight sort of under control or at kind of standard level so I suppose because of that I maybe looked a bit further to try and find more ideas.” I13P7, female

In addition, participants who proactively searched information about the condition said that the information they found is “confusing”:

“I tried doing my research but everything, I think, contradicts each other. Everything kind of bounces back off each other. One will say one thing, the next article will say something else. Doctors will tell you something else so you don’t know what is actually true or not.” I5R6, daughter

W: “The leaflets we got were confusing.

Interviewer: Were they? In what way?

W: They weren’t specifically targeted at diabetes. It was almost a bit like throwing everything at you so that...there were a bit like “how to look after your health”, “how to look after your kidneys”, “how to manage diabetes” ...I just didn’t find the information particularly helpful. I found what I could find myself online more helpful.”

I6R7, wife

8.3.5 Mode of intervention delivery

Opinions on the appropriate means for intervention delivery varied. Some people suggested that patients themselves can “tell everybody the message” because they are the people who have “seen the light”. Others suggested that teachers “with the right enthusiasm” can get the message across in a school environment. Participants also believed that

schools, health clinics and workplaces could provide more information about type 2 diabetes. One participant suggested that people respond better to health messages when they come from a celebrity or a role model:

"...celebrities that sort of thing, I think that has a real impact nowadays.(...) I bet you Jonah Lomu did more for, you know, people getting checked for kidney problems in rugby than any sort of health campaign anyone ever ran, so..." I15P9, male

Others believed that the responsibility for diabetes prevention should be placed upon sugar companies:

"...I think companies have a responsibility to reduce the sugar in their food 'cause most food has it and it's hard to avoid it..." I4P3, female

Finally, people believed that the media could be an effective medium for delivering information:

"One thing that I think is really really important is the media should be encouraged to focus on the fact that it's not just overweight people who get diabetes." I13P7, female

Participants discussed the potential ways an intervention could be delivered. Opinions varied and included: an open day clinic, leaflets, hearing about people's experience, adverts and educational courses.

Relatives of type 2 diabetes patients expressed the need to talk to a health professional about type 2 diabetes:

"It's easy to give someone a website and...it's easy for us to go and research it but actually sitting down and talking about it with someone, you'd probably understand it a lot better and you could ask a question, rather than just typing it into Google and sort of coming up with millions of results that don't really want to trust rather than you'd like to speak with someone who knows what they're talking about and you feel like you can trust them as well." I2R4, daughter

However, relatives thought that although a one-to-one appointment with a health professional would be their preferred option, it is not feasible. So they suggested an open day clinic which can be done at regular periods of time when people can visit the clinic, receive more information about type 2 diabetes and ask questions:

"...if there was kind of a clinic where nurses could maybe give you the information, that would be good. You know like in a health centre, you could have an open day for families of people who have been diagnosed..." I2R2, wife

Participants mentioned the fact that a lot of families do not live close together and that people have different needs, therefore would respond differently to a potential intervention. A localised leaflet was suggested as a practical way to inform people about services available in their area. Participants stressed the importance for a leaflet to come from a recognised body such as the NHS or a University.

"I guess it's reassurance as well and seeing something like an official leaflet and giving you somewhere you could go or somewhere you could phone if you want to know more about it and giving you like...yeah, just something like that, something official that you can trust." R4I2, daughter

"It might be worthwhile having a leaflet, an information leaflet that the person who is affected could give to the family and say: this is something that's happening to me and you might want to think about it for yourself. Particularly, I think for my daughter it would be quite useful, if she was triggered that way. But just something like the leaflet. I think logistically it would be quite difficult to do anything more in families that don't live in the same town." I1R1, mother

Some people believed the leaflets may not be an effective intervention:

"I think people ignore leaflets, I think that's not really a way to go. For some people, it's hearing about people's actual experience that makes it real" I14P8, female

Participants suggested a buddy system or a support group for patients and their family members, where someone with type 2 diabetes can talk about their experience of the condition:

Could have a little buddy system if some people are willing to share their experiences, you know. Somebody who's got diabetes, they could maybe, not every week, but they could maybe say "I don't mind chatting to a group of people" I2R2, wife

Others believed that a group environment is more suitable in order to break stereotypes about type 2 diabetes:

“That’s why I’m thinking for a group it would be helpful in that sense, plus also if you go to a group it might help break down the stereotype that it’s just old fat people who are lazy pigs who get this ‘cause it would be full of people like you and me.” I3R5, wife

Participants talked about people’s tendency to watch a lot of television and spend a lot of time on the internet. Some suggested an advert that could be placed on social media (eg. Facebook, YouTube) which provides more information about type 2 diabetes. This was a preferred option than obtaining information on websites:

“...would be handy if there was a thing put on by some doctors onto Youtube with them explaining the risks, explaining consequences and what the symptoms are, so that people, instead of going onto the NHS website and just, ‘cause that’s rather drastic when you go on it. It’s not the most pleasant thing to do. So it’s easier just to...most people would rather you tube it.” I5R6, daughter

Others suggested a TV advert, which can be very brief so they do not require people to pay attention:

“There is a lot of...people watch a lot of telly and adverts and...just brain wash them. They don’t need to know they are learning anything. Make it...when people are selling cigarettes, everything is...they have that flash branding, don’t they? Like that...quick sort of thing, people would take in and they don’t even realise” I4P3, female

There were relatives who believed that an educational course would be the most effective way to provide people with the information they need in order to enable them to make the desired behaviour changes:

“I think it’s hard to take in the sophisticated level of understanding that would be most beneficial to have from independent study, and I was thinking, a week-long full-time course would better where it’s interactive and you can ask questions and you can specific questions like: “in my house, we tend to have this....which is better A or B?” which might not say specifically in the book.” I3R5, wife

Patients who have attended type 2 diabetes course said that such courses should be available for family members of patients with the condition:

“I think when I went on sort of the DESMOND type course that families and carers should have the same course, just for awareness, just to see exactly what somebody with diabetes have got to manage” I14P8, female

8.4 Discussion

The findings from this study highlight the need for information provision to relatives of people with type 2 diabetes. People believed that there is low availability of accurate and reliable information about type 2 diabetes. Information from internet sources was described as contradictory and confusing. Relatives of patients expressed a desire to visit the patient's GP but they believed that this is not appropriate. The need for intervention to prevent type 2 diabetes in the first-degree relatives of patients with type 2 diabetes has been highlighted by previous literature (Harrison et al., 2003; Iraj et al., 2010; Heideman et al., 2011). Partners of patients have also been the focus of research which suggests that spousal diabetes is a robust signal for diabetes risk and a potential tool for early diabetes detection (Leong et al., 2014). The participants in the current study believed that the general public has low awareness and poor knowledge of this condition. Despite the availability of information on reliable websites, such as Diabetes UK and NHS choices, people believed that information about type 2 diabetes is not as readily available as information about other health conditions. This highlights that need for raising the public awareness of type 2 diabetes. This need has been acknowledged in the Scottish Government's a healthier future framework (2018) which sets an action plan for the development of resources available at easily accessible venues, such as libraries, workplaces, homeless services, community hubs and leisure centres. The plan will aim to raise public awareness of type 2 diabetes in an effort to reach people at high risk of the condition.

With the exception of several participants, who believed that the prevention of type 2 diabetes should be addressed using a whole population approach, participants said that delivering an intervention to the relatives of newly diagnosed patients with type 2 diabetes is essential for encouraging behaviour change. Participants believed that the best recruitment strategy for reaching the relatives of patients with type 2 diabetes was recruitment through patients with type 2 diabetes. Identifying relatives through the target patient has been shown to be an effective recruitment strategy (Brekke et al., 2003, 2004, 2005a, 2005b; Pro-Active trial, 2004, 2008, 2009; Gorin et al., 2008). However, the number of patients to be screened may be high thus requiring financial resources. Recruitment through posters can also be an effective recruitment strategy as demonstrated by Wing et al. (1998) and the current study.

Many participants believed that a potential intervention should be delivered soon after diagnosis of type 2 diabetes in a relative. There have not been any RCTs testing the effectiveness of an intervention delivered shortly after diagnosis of type 2 diabetes in a relative or partner. This is surprising and shows the need to capitalise on this time, which may be a teachable moment when people are more receptive to lifestyle advice and more motivated to change behaviour.

When asked about potential intervention components the majority of participants expressed the need for more information, especially tailored information about lifestyle and type 2 diabetes. However, people's views on the best way to deliver an intervention varied with some expressing a preference for meetings in person (e.g. with a health professional, educational course) while others preferred to receive a leaflet. The provision of information about diet and exercise and the ability to discuss self-management in either a group environment or over the phone have been shown to lead to sustained changes in participants' behaviour (Wing et al., 1998; Brekke et al., 2003, 2004, 2005a, 2005b). However, intensive trials can lead to attrition (Wing et al., 1998). A brief educational session in combination with tailored advice and/or phone calls, delivered shortly after diagnosis of type 2 diabetes in a relative/partner, may be an acceptable and effective intervention for sustained behaviour change and reduction of type 2 diabetes risk among high-risk groups such as the relatives and partners of people with the condition.

Finally, participants were asked to suggest potential modes of intervention delivery. Suggestions varied from more passive approaches, such as targeted leaflets and adverts to more engaging forms such as educational courses and open day clinics. All participants believed that type 2 diabetes information should be provided by a recognised source, such as the NHS, Diabetes UK or a University. In addition, relatives in this sample expressed desire to attend educational courses, which are currently offered to newly diagnosed patients. Celebrity endorsements and "buddy" systems were also mentioned as a potentially effective way to communicate information about type 2 diabetes and influence people's behaviour. The feasibility and effectiveness of such strategies have not been previously explored.

8.5 Conclusion

The findings from the interviews highlight the need for the provision of accurate and reliable information among the relatives of people with type 2 diabetes. Not all participants were willing to attend an educational course but many agreed that people would benefit

from a localised, targeted leaflet that comes from a recognised source and provides information about type 2 diabetes, healthy eating, local diet and exercise groups and classes, and local diabetes support groups and educational courses.

Table 32 Research question and findings on participants' suggestions for an intervention

Research question	Findings and relevance to the overall project
<p>What recruitment methods, intervention components and mode of delivery would be acceptable to potential participants?</p>	<p>Recruitment methods: The majority of participants said that potential interventions should identify people with type 2 diabetes and ask them to recommend relatives or pass information on to their relatives.</p> <p>Intervention timing: Interventions should be delivered shortly after diagnosis of type 2 diabetes in a relative or partner.</p> <p>Intervention components: Interventions should provide potential participants with information about type 2 diabetes and tailored, practical tips for changing lifestyle. Interventions should also provide an opportunity to ask questions or discuss issues with health professionals and other people who have experience in type 2 diabetes.</p> <p>Mode of intervention delivery: Leaflets, educational courses, support groups, open day clinics and online adverts were suggested by participants in the interviews.</p>

Part 4: Discussion and conclusions

Chapter 9: Discussion, implications and conclusions

9.1 Introduction

Diagnosis of illness in oneself or in a relative/partner is a cueing event, which may represent a teachable moment when people are more receptive to lifestyle advice and more motivated to improve health behaviour. However, not all individuals experience a teachable moment and make behaviour changes. This raises questions about the factors that influence whether and for whom a cueing event, such as illness diagnosis, becomes a teachable moment. This project explored the factors that may shape the way people respond to diagnosis of type 2 diabetes in oneself or in a family member. The study identified a group of people who have experienced a common health event (i.e. diagnosis of type 2 diabetes in oneself or in a family member) and retrospectively identified the characteristics of those who reported changing their behaviour. The project had a mixed-methods design with two studies. Study One was guided by an existing heuristic model for teachable moments (McBride et al., 2003) and included semi-structured interviews. It identified seven possible criteria for a teachable moment in patients and six in relatives of patients. These criteria were further assessed in a subsequent, quantitative study. Study Two showed mixed results and highlighted potential collinearity between the different criteria for a teachable moment. Outcome expectancy and perceived control in patients and perceived risk and social role in relatives appeared to have the strongest relationships with behaviour change. The results also showed that gender plays an important role in the way people appraise and respond to diagnosis of type 2 diabetes. Overall, this mixed-methods study provides support for the potential of type 2 diabetes diagnosis to be a teachable moment but highlights questions that remain unanswered. This chapter discusses the project findings in relation to previous research and implications for stakeholders. The chapter begins with a brief summary of the need for the current project (9.2) before outlining the answers to the research questions (9.3). It then brings together the findings from the two studies within the mixed-methods design by discussing what constitutes a teachable moment (9.4), what makes a cueing event a teachable moment (9.5), when the optimal time for a teachable moment might be (9.6) and the best way to intervene (9.7). The chapter then describes the strengths and limitations of the studies (9.8) and the project implications (9.9). It ends with suggestions for future work (9.10) and reflections on the research process (9.11).

9.2 The need for this project

Three key reasons drove the study.

First, illness diagnosis appears to create a teachable moment when people are more motivated to change their behaviour. However, this is under researched and it is unclear what criteria make an illness diagnosis a teachable moment, whether the criteria differ across health conditions and whether they are different for patients and their healthy relatives (Chapter 2, section 2.1).

Second, only three studies have looked at the potential of type 2 diabetes diagnosis to be a teachable moment (Thresia et al., 2009; An, 2015; Azar et al., 2015). They suggest the diagnosis is a teachable moment for patients but it remains unclear whether the diagnosis is a teachable moment for relatives. Furthermore, no study has explored in detail what makes the diagnosis of type 2 diabetes a teachable moment (Chapter 2, section 2.2).

Third, the systematic review (Chapter 4) highlighted the need for effective and sustainable interventions that target the modifiable risk factors of type 2 diabetes among the relatives of people with the condition. Targeting interventions to capitalise on the teachable moment may provide a platform for low-cost, effective interventions.

9.3 Research questions

This project had two overarching aims. The first was to identify the criteria that make diagnosis of type 2 diabetes a teachable moment. This was done by exploring the cognitive and behavioural changes that occur shortly after diagnosis and their relationship with changes in behaviour. The second aim was to suggest potential components of an intervention that targets the modifiable risk factors of type 2 diabetes in the relatives of people with the condition. In order to address these aims the project focused on nine research questions and employed a mixed-methods design which combined a qualitative study, using semi-structured interviews, and a quantitative study, using a cross-sectional survey.

RQ1: Has illness diagnosis been utilised as a teachable moment and for whom is it a teachable moment (Chapter 2, section 2.1)?

Illness diagnosis increases the likelihood of patients and their family members to engage in protective health behaviours. However, in some cases the diagnosis itself is not sufficient to trigger behaviour change and additional guidance and support may be needed. This has implications for health promotion with interventions, delivered as early as possible after illness diagnosis showing increased effectiveness.

RQ2: Has the potential of teachable moments been explored in the field of type 2 diabetes (Chapter 2, section 2.2)?

The concept of teachable moments in type 2 diabetes is under-researched. Only three studies to date have suggested that diagnosis of type 2 diabetes may trigger changes in patients' behaviour (Thresia et al., 2009; An, 2015; Azar et al., 2015). The potential of type 2 diabetes diagnosis to be a teachable moment for the relatives of patients with the condition has never been explored.

RQ3: What does published research show about people's illness perceptions of type 2 diabetes (Chapter 3, section 3.1)?

Previous research has explored primarily the perceptions of ethnic and minority groups, whose views are embedded in historical and cultural beliefs, which often differ from the views of people from the general population of the given country. The perceptions of people with family history of type 2 diabetes have rarely been explored. Some research indicates that relatives may have increased perception of severity, which suggests that they may be more receptive to behaviour change interventions and more motivated to adopt protective health behaviours.

RQ4: Does previous research indicate that people with family history of diabetes have increased perceived risk of developing type 2 diabetes (Chapter 3, section 3.2)?

The scoping review showed that relatives of people with type 2 diabetes often believe they are at increased risk of developing type 2 diabetes. However, the relationship between family history of diabetes and perceived risk may be affected by factors, such as age, gender and weight status.

RQ5: What does published research show about successful intervention strategies, used in Randomised Controlled Trials, for type 2 diabetes prevention in the relatives of people with the condition (Chapter 4)?

Interventions in relatives of people with type 2 diabetes show increased effectiveness when they combine diet and exercise components. Communication of familial risk of type 2 diabetes has been under-utilised as an intervention strategy, although it has the potential to increase engagement in protective health behaviours (Pijl et al., 2009). The most effective way to recruit participants to diabetes interventions may be through health care contacts. A need remains for effective and sustainable interventions in people at high risk of type 2 diabetes by virtue of having a relative or a partner with the condition.

RQ6: How does type 2 diabetes diagnosis affect patients and their relatives, in terms of perceptions, behaviour and relationships (Chapter 6)?

Participants experienced various, primarily negative, emotions in response to the diagnosis of type 2 diabetes. These included shock, fear, numbness, frustration, worry and relief. Based on reported changes in perceptions and behaviour, two groups of patients were observed in the current study: people who adopt problem-solving strategies and people who need time to adjust to their new reality. People who adopted problem solving techniques were characterised by increased awareness of severity of type 2 diabetes, desire to seek information about the condition, an active approach in response to changes in self-concept, feelings of control over their condition and the use of specific strategies for diabetes self-management. On the other hand, people who needed time to adjust were more likely to go through a period of avoidance and denial of their condition, and were more likely to rely on their relatives for the management of type 2 diabetes. Family members of people with type 2 diabetes also fell within two groups: relatives who adopted a proactive approach and relatives who changed behaviour to support the patient. Relatives who adopted a proactive approach changed their behaviour in an effort to minimise their own risk of developing type 2 diabetes. The diagnosis challenged their perception of diabetes causes and increased perceptions of diabetes severity and personal risk of type 2 diabetes. The supportive relatives changed their behaviour to support the person with type 2 diabetes and they did not believe they were at increased risk of the condition.

The most commonly mentioned behaviour change practices involved diet regulation with fewer participants mentioning changes in physical activity. This suggests that people may have narrow conceptions of behaviours, recommended to manage or prevent type 2 diabetes. Despite individual differences in behaviour change, families engaged in communal coping (Lyons et al., 1998). They perceived type 2 diabetes as a family problem, and talked openly about it and the ways its effects can be minimised. Although some gender differences were observed in response to type 2 diabetes, with women being more overprotective than men, all relatives appeared to provide encouragement and support for the patient.

RQ7: What criteria need to be fulfilled for the diagnosis of type 2 diabetes to be a teachable moment (Chapter 6 and Chapter 7)?

The interviews showed that the potential teachable moment criteria in relation to diagnosis for type 2 diabetes in patients could be: being a monitor, increased perception of severity, changes in self-concept or social role, outcome expectancy, communal coping and feelings of control of type 2 diabetes. The criteria for relatives could be: increased perception of severity, change in self-concept or social role, increased perceived risk of developing

type 2 diabetes and communal coping. The role of demographic factors, such as age, gender and time since diagnosis appeared to affect the above criteria. However, the questionnaire showed mixed results on the associations between these factors and primary outcomes. An integrated discussion of the factors is presented in section 9.5.

RQ8: Are the newly identified criteria for a teachable moment associated with engagement in physical activity and healthy diet, and interest in receiving information about type 2 diabetes? (Chapter 7)?

The quantitative study found several statistically significant relationships between teachable moment criteria and behaviour change. In patients: outcome expectancy was positively associated with changes in physical activity and diet; control had a positive relationship with all primary outcomes; severity and self-concept were positively associated with changes in physical activity. In relatives: perceived risk was negatively associated with change in diet; social role had a positive relationship with change in physical activity. The role of time since diagnosis and gender may affect the above relationships.

RQ9: What recruitment methods, intervention components and mode of delivery would be acceptable to potential participants (Chapter 8)?

Virtually all participants in the current study believed that lifestyle interventions should be delivered shortly after the diagnosis of type 2 diabetes in oneself or in a family member. Different participants wanted different information about the condition but the majority preferred tailored advice and the opportunity to ask questions and discuss their experience with health professionals and other people who have experience in type 2 diabetes. There was no consensus among participants about the most suitable mode of intervention delivery with some people preferring educational courses and support groups while others suggesting leaflets and online adverts. When asked about the best way to identify and reach people who are at increased risk of type 2 diabetes by virtue of having a relative with the condition, most participants agreed studies should identify patients and ask them to recommend a relative.

9.4 What constitutes a teachable moment?

Although the idea that a specific cueing event can be a teachable moment is intuitively accepted, it is unclear what constitutes a teachable moment. Previous studies exploring the potential of illness diagnosis to be a teachable moment (chapter 2) assumed that a teachable moment has occurred if participants engaged in specific behaviour change

(e.g. increase in physical activity, increase in healthy diet, smoking cessation, decrease in alcohol consumption). Similarly, in the current study diagnosis of type 2 diabetes was regarded as a teachable moment if people reported increase in healthy diet and/or exercise. In addition, interest in receiving information or attending a course on type 2 diabetes were believed to be indicative of increased receptiveness to behaviour change interventions. This is in line with a previous study that regarded intervention buy-in as a response consistent with the occurrence of a teachable moment (McBride et al., 2008). Such assumptions stem from the use of the term teachable moment to describe "*naturally occurring life transitions or health events thought to motivate individuals to spontaneously adopt risk-reducing health behaviours*" (McBride et al., 2003, p.156). The current study however showed that certain factors, thought to increase the potential of illness diagnosis to be a teachable moment, predict change in some behaviours but not in others. For example, perceived risk of developing type 2 diabetes was associated with changes in diet but not in physical activity. In addition, people's perceptions and knowledge of behaviours needed to be changed may further influence the potential of illness diagnosis to be a teachable moment. For example, people who believe that reduction in sugar consumption is the only way to control type 2 diabetes may not make other dietary changes or increase physical activity. Further work is required to identify the specific responses and behaviours that are indicative of a teachable moment. It remains unclear whether change in one type of behaviour (e.g. diet) following diagnosis is less of an indicator of a teachable moment compared to change in two or more types of behaviour (e.g. diet and physical activity).

9.5 What makes a cueing event a teachable moment?

Chapter 2 showed that illness diagnosis can sometimes trigger spontaneous behaviour change. In other cases it presents an opportunity where people are more motivated to change behaviour but they need guidance. Knowing what factors trigger spontaneous behaviour change is important as these factors can be addressed when offering guidance.

The findings on what makes a cueing event a teachable moment in the current mixed-methods study do not clearly converge. First, not all factors identified in the interviews had statistically significant relationships with the primary outcomes in the survey. Second, the study provides mixed findings on whether the factors for a teachable moment are similar for patients and their relatives. Finally, the study does not completely support the existing teachable moment heuristic (McBride et al., 2003). This suggests that the factors that make illness diagnosis a teachable moment may differ across health conditions, as McBride et al. (2003) looked at cancer while the current study looks at type 2 diabetes.

This shows that the concept of the teachable moment is not clearly demarcated. It can be explained differently by different research methods and different lenses. The factors that may make diagnosis of type 2 diabetes a teachable moment for patients and their relatives are summarised below:

9.5.1 Patients:

Outcome expectancy: In patients, the mixed-methods study provides strong support for the role of outcome expectancy in the occurrence of a teachable moment. People who believe that a specific behaviour would lead to a desired outcome were more likely to engage in behaviour change. This highlights the importance of outcome expectancy in behaviour change interventions.

Perceived control: This mixed-methods study provides support for the role of perceived control in changing behaviour. Patients in Study One often talked about the importance of having their diet or glucose levels under control. Study Two showed that perceived control over one's type 2 diabetes was positively associated with healthy diet and interest in receiving information about type 2 diabetes. The role of control in increasing physical activity appeared to diminish when other teachable moment factors were taken into consideration. These findings have implications for health promotion interventions. First, interventions need to capitalise on increasing people's perception of control. Second, interventions need to address barriers to perceived control over behaviour. This may be particularly relevant to people with mobility problems who may struggle to engage in physical activity. To address these, interventions should include established behaviour change techniques (Abraham & Michie, 2012) to help participants evaluate the barriers and facilitators to specific behaviours before setting realistic goals and increase confidence to change behaviour.

Severity: The overall study suggests that severity may be a criterion for a teachable moment in patients. However, in Study Two the effect of severity was decreased when other factors were entered into the model. This has implications for health promotion by showing that in order to increase the influence of severity on behaviour change, knowledge of diabetes severity needs to be addressed first, especially for people who associate severity with the presence of symptoms and complications. Furthermore, the relevance of diabetes severity to the individual may also need to be addressed. Previous research suggests that people consider type 2 diabetes to be a serious condition in general but not serious enough to affect them (Murphy & Kinmonth, 1995; Habte et al., 2016).

Self-concept and social role: This study showed that the relationship between self-concept and behaviour change in patients may be complicated by the existence of perceived stigma of type 2 diabetes. This has implications for practice as it is important to change patients' perceptions of stigma so they may be more likely to talk about their condition and engage in self-management in social situations. Similarly, self-management interventions need to be sensitive so not to imply blame. This means not praising people for being health-conscious and implying blame for poor self-management (Yoder, 2002). The study did not find support for McBride et al.'s (2003) heuristic that people may experience changes in social role after illness diagnosis.

Demographic characteristics: The current study shows that time since diagnosis and gender may be important factors that affect patients' behaviour. Shortly after diagnosis of type 2 diabetes people may be more likely to increase physical activity and require information on type 2 diabetes. This suggests that diagnosis of type 2 diabetes may be a teachable moment for patients when they are more receptive to advice and more motivated to change behaviour.

Gender appeared to be important for behaviour change. The mixed-methods study shows that female patients were more likely to engage in healthy diet and physical activity. Previous research also shows that male patients tend to be more dependent on their spouses (Samuel-Hodge et al., 2000; Hara et al., 2014; Li et al., 2014). This is important for health promotion as it suggests that interventions need to take into consideration the challenges, experienced by women with type 2 diabetes where they balance multiple roles of looking after their family while engaging in diabetes self-management.

9.5.2 Relatives:

Perceived risk: The project provides mixed findings to support the potential of perceived risk as a teachable moment criterion and its relevance for type 2 diabetes prevention interventions. While the interviews suggested that perceived risk may influence likelihood of behaviour change, the survey showed that increased perceived risk of type 2 diabetes has a negative relationship with changes in diet and does not affect likelihood of increasing physical activity. Previous research has shown that people do not always want to know about their diabetes risk due to fear of disease treatment and uncertainty (Nijhof et al., 2008). Health promotion interventions could address these concerns during a discussion on diabetes risk, which can be then used as a platform for further discussion that addresses other

teachable moment criteria, such as outcome expectancy and what behaviours can reduce the risk of type 2 diabetes.

Severity: The mixed methods study does not provide support for the role of severity in the occurrence of teachable moments. Although Study One suggested that relatives whose perception of diabetes severity has increased following diagnosis of type 2 diabetes, Study Two did not find significant associations between severity and primary outcomes. Compared to participants in Study One, those in Study Two were considered to be more representative of the population of people with a relative, recently diagnosed with type 2 diabetes. Previous research suggests that relatives often have poor understanding of diabetes severity (section 3.1). This has implications for health promotion suggesting that knowledge of diabetes severity may need to be addressed as part of a behaviour change intervention.

Self-concept and social role: Relatives of people with type 2 diabetes may not experience changes in self-concept but they may alter their social roles. This is primarily true for women who may become caregivers. This has implications for interventions as women who adopt a care-giving role experience more chronic health disorders (Bédard et al., 2005; del Rio-Lozano et al., 2013; Hara et al., 2014). Also, when female relatives engage in over protection, they may undermine the patient's confidence to control their own condition (Martire et al., 2002). Previous research has shown that different ways of coping with type 2 diabetes in partners are related to perceptions of illness and relationship satisfaction (Johnson et al., 2013a; 2013b). Interventions targeted at prevention of type 2 diabetes among relatives may need to focus on the potential changes in social role and capitalise on family communication to encourage alignment between the needs of the patient and the needs of the relative.

Demographic characteristics: The current study shows that gender may be important for behaviour change in relatives. Female relatives were more likely to adopt caregiving roles where they became protective of the patient and controlled their diet. Women's increased tendency to adopt caregiving roles has been highlighted before (Samuel-Hodge et al., 2000; Hara et al., 2014; Li et al., 2014) and has implications for behaviour change interventions. It suggests that interventions may need to be gender-sensitive and take into consideration traditional gender roles.

9.6 When is the optimal time for a teachable moment?

The mixed-methods study highlights the need for identifying the optimal time to intervene and provide behaviour change advice. However, it remains unclear when this optimal

time occurs. One of the scoping reviews (section 2.1) showed mixed results with some studies suggesting that people are more likely to change behaviour in the first 6 months following diagnosis (Humpel et al., 2007), others showing no effect of time since diagnosis on behaviour change (Bidstrup et al., 2013) and other studies suggesting that end of treatment may be a teachable moment (Sabiston et al., 2014). Interview findings in the current study suggested that the optimal time for intervention delivery is between the second and sixth month following diagnosis of type 2 diabetes, which was confirmed by the survey, which showed a negative association between time since diagnosis, behaviour change and interest in receiving information on type 2 diabetes. This has implications for interventions showing that interventions may not be well received if targeted too soon after diagnosis when the impact of illness may be too great. However, interventions targeted at a much later stage may not be as effective as people may either have already initiated behaviour change or no longer be receptive. McBride et al. (2003) suggest the existence of sub-events which provide windows for opportunity to encourage behaviour change. Capitalising on such events may increase intervention effectiveness over a longer period of time and thus lead to sustained changes in behaviour. For example, a patient who presents at their GP with elevated glucose levels may be more motivated to improve health behaviours. During discussion with the GP, a salient concern could be linked with a behaviour (outcome expectancy) or any other teachable moment factor in order to enhance motivation to change behaviour. However, relatives of patients are less likely to attend follow up appointments with the patient, so other opportunities for teachable moments for them need to be explored. More research on the experiences of relatives is needed to identify what cues to action (e.g. illness diagnosis; patient starting new treatment) may become teachable moments.

9.7 What is the best way to intervene?

This study has provided snapshots of the factors that make diagnosis of type 2 diabetes a teachable moment. Capitalising on these factors and adopting a tailored prevention approach may mean low-intensity interventions that are low in cost and amenable to dissemination could achieve better outcomes (McBride et al., 2008). The question remains how to address the proposed factors for a teachable moment and how interventions can be delivered.

McBride et al. (2003) suggest that conventional intervention modalities such as print materials, telephone or provider counselling can be adapted to take advantage of the

teachable moment by emphasising the teachable moment factors. This is supported by the current project as participants in the interviews (chapter 8) believed that a tailored leaflet from a recognised source of information could be an effective intervention strategy. Such information can be communicated to patients by their healthcare provider and then to relatives by the patients. The receipt of a leaflet may provide a platform for people to engage in open communication about type 2 diabetes with their relatives with the condition. Van Esch et al. (2012) found that patients often have the intention to talk about diabetes risk and primary prevention with their family members but they worry about knowing what to tell and whom to speak with. A leaflet can facilitate such discussions. The potential for learning from significant others (e.g. friends and family) is high. Research has already indicated that adult offspring of patients with diabetes generally seem receptive to being informed via the family system about reducing their diabetes risk (Pierce et al., 2000; Whitford et al., 2009). Additionally, the majority of patients recognise the necessity of disseminating risk and preventive messages in their family (Gnanalingham et al., 1997; Whitford et al., 2009; Nishigaki et al., 2009; van Esch et al., 2012). Whitford et al. (2009) show that people who have spoken with their relatives with diabetes about diabetes risk were more likely to see themselves at risk of type 2 diabetes, worry about diabetes and see diabetes as serious.

Another avenue for intervention delivery could be through healthcare professionals. Many of the relatives in the interview part of this project expressed desire to either attend appointments with the patient or have the opportunity to ask healthcare professionals questions about type 2 diabetes. This is supported by Nishigaki et al. (2008) who showed that the offspring of patients with type 2 diabetes want information directly from a medical professional. Research shows that people with type 2 diabetes and people at high risk of type 2 diabetes are more likely to engage in health behaviours if they have spoken with a health educator (Bazata et al., 2008). However, recent studies highlight the challenges in implementing interventions in primary care (Foster et al., 2016; Pressau et al., 2018) suggesting that GPs may be too busy to attend training and deliver interventions during patient appointments. However, nurse-led brief interventions may be easier to implement and have been shown to be effective for smoking cessation (Rice et al., 2017) and alcohol (Joseph et al., 2014). Diabetic nurses are in an excellent position to provide a brief intervention, based on the teachable moment factors, and then supplement this with a leaflet to encourage family communication. This would also allow people to ask questions specific to their lifestyle, which was indicated as important for participants in the current study (Chapter 8). Such tailored discussions would also enable nurses to address knowledge

and misconceptions about diabetes and required behaviour changes. For example, participants who believe that “sugar is the enemy” (Chapter 6) may benefit from a discussion highlighting the importance of a healthy diet, not only reduction in sugar intake, in combination with increase in physical activity. Similarly, knowledge of specific behaviours that may increase risk of developing type 2 diabetes could be addressed. Factors that may facilitate or hinder behaviour change (e.g. access to resources, mobility issues) could also be discussed. The importance of specific conditions that enable behaviour change is highlighted in the COM-B model (Michie et al., 2011). Although previous literature and this research suggest that teachable moments may trigger spontaneous behaviour change, the role of capability, opportunity and motivation should also be considered. According to the COM-B model, for any behaviour to occur people need to have the psychological and physical capability and motivation to change (Michie et al., 2011). In addition, opportunities that are outside people’s control may make a behaviour possible (or not) (Michie et al., 2011). In the context of diabetes, these could include increasing perception of control over type 2 diabetes, overriding habitual behaviour such as watching TV instead of going for a walk, considering physical capability to exercise and addressing financial opportunity to change lifestyle. Such an intervention could be developed by drawing on Flocke et al.’s (2012) teachable moment communication process (TMCP) model. The TMCP model enables health professionals to capitalise on teachable moments in practice by providing them with specific communication techniques. The model is similar to brief interventions in other fields as it involves identifying the patient’s salient concern, linking it to the behaviour, providing brief intervention, assessing readiness to change and responding in alignment (Flocke et al., 2012). This approach was evaluated by physicians as effective in engaging with patients and maintaining a positive relationship with them (Flocke et al., 2012). Patients can be encouraged to bring a relative to their appointment with the diabetic nurse where a brief intervention can be delivered.

A one off intervention session may spark initial motivation to change behaviour but fail to lead to sustained change (Tokunaga-Nakawatase et al., 2014). The intervention can be extended to incorporate specific sub-events. Opportunities for teachable moments may present during a follow-up appointment where a patient expresses a specific concern. Addressing the teachable moment criteria at diagnosis and then at sub-events may be crucial to sustaining interventions. Another way to sustain motivation to change behaviour past an initial intervention during a nurse appointment could be through the use of mobile phones. Recent statistics show that 94% of the people in the UK own a mobile phone (Ofcom, 2018).

In addition, mobile health interventions for the management of chronic disease show promising results (Fjeldsoe et al., 2009; Pal et al., 2013; Lee et al., 2018). Systematic reviews show that mobile phone interventions can lead to positive behaviour change outcomes (Fjeldsoe et al., 2009; Lee et al., 2018) and they are more effective than computer-based interventions (Pal et al., 2013). Mobile interventions have also been found to be effective for the promotion of physical activity, diet and weight loss as risk factors for cardiovascular disease (Stephens & Allen, 2013). Although the cost-effectiveness and long-term effects of such interventions have been under-researched, they may provide a feasible way of reaching a large number of at-risk individuals.

Interventions need to be tailored to address potential teachable moment criteria for patients and for their relatives. Although more research is needed to further identify how and for whom diagnosis of type 2 diabetes is a teachable moment, this study makes a significant contribution in understanding why people experience a teachable moment in response to diagnosis of type 2 diabetes and how this information can be used to tailor interventions. The findings from the two phases of this mixed-methods study are consolidated in table 32 alongside recommendations for interventions.

Table 33 Teachable moment criteria and recommendations for interventions

Teachable moment criteria	Is it a teachable moment criterion for patients?	Is it a teachable moment criterion for relatives?	Recommendations for interventions
Outcome expectancy	Yes	n/a	In patients, an explicit connection needs to be made between a salient concern and a behaviour.
Perceived risk	n/a	Knowledge about risk and behaviour	Interventions need to target knowledge about risk of developing

		need to be established first	type 2 diabetes. This could be followed by addressing outcome expectancy (i.e. what behaviours to engage in to reduce risk).
Perceived control	Mixed findings	n/a	Behaviour change interventions need to address knowledge on how to control type 2 diabetes, explore barriers to behaviour change and capitalise on increasing feelings of control.
Severity	Knowledge of severity needs to be established first	Knowledge of severity needs to be established first	Interventions need to target knowledge about severity of type 2 diabetes and its relevance to the patient.
Self-concept	Needs to be addressed with care as can result in poor self management due to type 2 diabetes-associated stigma	Not explicitly but may occur as a result of changes in social roles.	In patients, self-concept may be related to stigma so the patient's beliefs need to be explored if an intervention is to capitalise on self-concept. In relatives, self-concept may not be key for behaviour change although it may occur as a result of changes in social role.

Social role	Mixed findings	Yes, especially for women	Interventions need to be gender sensitive and target changes in social role to reduce the potential burden on women.
Demographic factors	Gender and time since diagnosis	Gender	Interventions need to be delivered at different time events (i.e. shortly after diagnosis and at meaningful sub-events). They may need to be gender sensitive.

9.8 Strengths and limitations of the study:

9.8.1 Study One

Study One included qualitative semi-structured interviews. Although the trustworthiness of qualitative research is usually questioned because validity and reliability cannot be assessed in the same way they are in quantitative research (Shenton, 2004), the strength of this study is that it took steps to minimise such issues. The current study followed Lincoln and Guba's (1985) criteria for trustworthiness. These include **credibility, transferability, dependability and confirmability**. **Credibility** refers to the "truth" of the findings and corresponds to internal validity in quantitative research (Lincoln & Guba, 1985; Shenton, 2004). One way to achieve credibility is to use established research methods (Shenton, 2004). The current study used semi-structured interviews and Framework Analysis which were deemed appropriate for the aims of the project. Another way to ensure credibility is to adopt tactics that allow participants to be honest (Shenton, 2004). I told participants that there were no right or wrong answers, their opinions were important and the interview data were kept confidential. I also explained that participation was voluntary and that they could withdraw at any point without giving a reason. Finally, I established rapport by using motivational interviewing-based techniques, such as being non-judgmental and empathic. Shenton (2004) suggests that frequent debriefing sessions, peer scrutiny and researcher's

reflective comments could also contribute to the credibility of research. These factors were taken into consideration as I made evaluative comments for each interview and discussed these comments alongside emerging findings with my supervisors and with type 2 diabetes patients who form the peer research forum at University of Stirling. **Transferability** is similar to external validity and shows that the findings could be applied to other contexts (Lincoln & Guba, 1985; Shenton, 2004). Lincoln and Guba (1985) believe that transferability can be established by a detailed description of field experiences. In order to achieve transferability I described the study population, data collection methods and the interview duration. **Dependability** is similar to reliability and shows that the findings are consistent and can be repeated (Lincoln & Guba, 1985; Shenton, 2004). In order to ensure dependability the study process needs to be described in detail (Lincoln & Guba, 1985; Shenton, 2004). I have provided detailed descriptions of the study design and implementation and I am aware of the strengths and weaknesses of the approaches that were taken. **Confirmability** can be described in terms of objectivity and refers to the extent to which the findings are free from respondent and researcher bias (Lincoln & Guba, 1985; Shenton, 2004). In order to achieve confirmability I tried to remain objective while collecting and analysing data and I had a clear audit trail, describing the steps taken from the design of the project to its evaluation. In addition, the research process and findings were examined by my supervisors.

One limitation of Study One is that sampling bias may have been introduced in the study (Bryman, 2012). The study used convenience sampling, which does not allow for strategic recruitment where there is a good variety and sample members differ in terms of key characteristics (Bryman, 2012). In addition, recruitment was carried out primarily in Forth Valley and people from these areas may have different experiences of healthcare of type 2 diabetes, compared to people who live in other parts of Scotland. Previous research has indicated that route to diagnosis and experience of healthcare can affect psychological outcomes (Lawton et al., 2005; Thoolen et al., 2006). Similarly, the study did not take into account psychosocial characteristics and ethnic, racial and socioeconomic background. Previous literature suggests that demographic and psychosocial factors, and ethnicity can affect behaviour change so these need to be controlled for and explored on a larger scale. (Park et al., 2007; McBride et al., 2000; Lemon et al., 2004; Humpel et al., 2007; Luftman et al., 2009; Moshagen et al., 2010; Nicholson et al., 2012).

Another important consideration for Study One is the fact that not all interviews included a patient and a relative from the same family. In some cases, members of the same

family were interviewed separately. Interviewing family members together can allow the researcher to gain a more complete picture of people's experiences and observe family dynamics (Bjørnholt & Farstad, 2014). However, in joint interviews people may not share certain views, especially if they think they could lead to conflict (Bjørnholt & Farstad, 2014). In this project, participants were given the option to either be interviewed alone or with a family member/partner.

9.8.2 Study Two

Study Two involved postal questionnaires. The use of questionnaires is fundamentally concerned with reliability and validity of the given scale (Bryman, 2012). The current study did not use a standardised questionnaire to assess cognitive and behavioural changes following diagnosis of type 2 diabetes. The validity and reliability of the scales used to measure the suggested concepts can be questioned. Wherever possible, items were adapted from existing scales. Several steps were taken to increase questionnaire validity. First, face validity was addressed by making clear decisions about the purpose and nature of the questionnaire, by reaching consensus between my supervisors and me about the structure and format of the questionnaire and by piloting the questionnaire with people from the target population. Content validity was addressed during data analysis by assessing internal consistency of each sub-category of the questionnaire and creating variables where items clustered together. Criterion and construct validity could not be assessed in the current study as there are no standardised measures to assess factors for teachable moments. Similarly, reliability could not be assessed as participants completed the questionnaire once. Bias related to question order may have been introduced in the study (Bryman, 2012). Although care was taken when designing the questionnaires, they were long so question-order bias cannot be excluded.

The sample size in Study Two was small. Although an effort was made to recruit a diverse sample of participants, considered to be representative of the whole population, the response rate was quite low (13%) compared to similar studies, which have reported 50% response rates (Harris et al., 2007; Munro et al., 2014). However, I was unable to adopt many of the strategies suggested to increase response rates to postal questionnaires, such as offering monetary incentives (due to budget constraints), using short questionnaires (due to the exploratory nature of the study), using recorded delivery (due to budget constraints), including stamped envelopes (due to budget constraints), contacting participants before sending the questionnaire (due to confidentiality and third parties recruiting participants),

contacting non-responders and providing them with a second copy of the questionnaire (due to confidentiality and third parties recruiting participants) (Edwards et al., 2002; Bran-
nen & Moss, 2012). In addition, time was a limitation as the duration of the PhD did not
allow for a longer period for waiting for responses from GP practices and patients. As a re-
sult response bias cannot be excluded suggesting that the characteristics of responders may
be different from those of non-responders.

9.8.3 The overall mixed-methods study

The current study employed a mixed-methods approach in order to identify the factors
that make a cueing event (i.e. diagnosis of type 2 diabetes) a teachable moment. The
strength of the project lies in the fact that the findings from each study within the mixed-
methods project were collated to provide a coherent picture of the concept of the teach-
able moment and reach “analytic density” (Uprichard & Dawney, 2016). The qualitative study
explored the experiences of type 2 diabetes in a sample of patients recently diagnosed with
type 2 diabetes and their relatives. The quantitative study further developed the identified
changes in perceptions and behaviours in a larger sample, believed to be more representa-
tive of the target population. However, the findings from both studies could not be clearly
integrated. In the qualitative study, it was not possible to explore whether the suggested
teachable moment criteria are interlinked. The quantitative study showed that the predic-
tive value of one criterion may be diminished when another criterion is taken into
consideration, suggesting potential collinearity between the factors. In addition, the partici-
pants in the qualitative study were a group of highly motivated people from the same
geographical area who may have similar experiences with healthcare. The quantitative
study was believed to include a sample that is more representative of the target population
and as such participants came from different geographical areas in Scotland and England
and have potentially had very different experiences of healthcare. However, the fact that
the findings did not clearly converge could be considered a study strength because it al-
lowed for deeper understanding of the complexities of the teachable moment. According
to Uprichard and Dawney (2016), mixed-methods research can provide empirical snapshots
of the studied phenomenon where findings do not always align. This allows researchers to
expose different layers and discover where interventions may be more (or less) successful.

9.9 Implications:

9.9.1 Theoretical implications

Despite references in the literature to illness diagnosis being a teachable moment, there is limited research on what makes it a teachable moment. McBride et al. (2003) have suggested a heuristic model that suggests that specific factors need to take place for diagnosis of cancer to become a teachable moment. The current study extends McBride et al.'s (2003) model by applying it to the field of type 2 diabetes. This has theoretical implications as it shows that the teachable moment heuristic is applicable beyond the cancer field and illness diagnosis in general can present a window of opportunity for behaviour change interventions. In addition, the study highlights the importance of the role of the whole family in responding to a health threat such as illness diagnosis. This adds new insight to understanding of teachable moments and shows that interventions should include family members rather than only patients or only relatives.

9.9.2 Implications for policy

Interventions are implemented more easily when they align with government priorities. In today's society, there is a drive to empower people to take charge of their health but this can also lead to blame. Recent government strategies have addressed this by proposing removal of unhealthy food at checkouts, excluding them from store deals, introducing new restrictions for advertising of unhealthy foods and consistent calorie labelling in restaurants (Department of Health and Social Care, 2018). Such a shift, if effective, may make it easier for people to select a balanced diet and in turn lessen type 2 diabetes-related stigma and the chances of people with type 2 diabetes being singled out for unwanted attention when they refuse desserts for example. In addition, type 2 diabetes prevention messages should be designed to avoid encouraging already existing stigma. For example, in 2016 Food Standards Scotland launched a campaign that suggested that unhealthy diet leads to diabetes (Daily Mail, 2016). After a public backlash primarily from people with type 1 diabetes the advert was amended to specify that unhealthy diet can lead to type 2 diabetes. However, such messages ignore the complex interplay of causes of type 2 diabetes suggesting a clear link between unhealthy diet and the condition and therefore reinforcing existing stigma. The role of stigma in the management of type 2 diabetes has been acknowledged in the 2018 Government Framework for prevention, early detection and early intervention of type 2 diabetes (Scottish Government, 2018). This framework sets out an action for a public

awareness campaign focused on positive messages around type 2 diabetes in an effort to address misconceptions and reduce stigma.

There is also a need for policy initiatives to not only promote self-care but also to provide people with the resources to engage in it. As demonstrated in this study through the concept of communal coping, people do not change their behaviour in isolation. Behaviour change happens within a social context and depends on the behaviour and the meaning people attach to this behaviour. Thus it requires a range of skills, including knowledge of type 2 diabetes, confidence and ability to engage in a specific behaviour, access to relevant resources and support from significant others and from health professionals (Redman, 2011; Dwarswaard & van de Bovenkamp, 2015; Diabetes UK, 2017). Current education courses for people with type 2 diabetes (e.g. Diabetes Education and Self-Management for Ongoing and Diagnosed, DESMOND, Deakin et al, 2006; the X-PERT Diabetes Programme, Davies et al., 2008) need to become more widely available and allow family members to attend. Despite the fact that access to such programmes is a priority area in the 2014 Diabetes Improvement Plan (Scottish Government, 2014), they are still not available in all primary care practices in the UK and require a referral, which may include a long waiting list. In addition, healthcare professionals in the practices do not receive training to provide follow-up support. Avery et al. (2016), NICE (2012) and Diabetes UK (2017) highlight the need for education and training for health professionals to enable them to provide support to people with type 2 diabetes. A training course for healthcare professionals is currently being tested in an RCT in Scotland (NHS Greater Glasgow and Clyde, 2018). Although its focus is on helping healthcare professionals encourage weight management in type 2 diabetes, if successful it could be adapted to cover other aspects of diabetes management and prevention. Therefore, it remains a need for an intervention that is available to all patients and their significant others, that provides training for health professionals, that can be delivered in primary care and that allows for the involvement of the patients' relatives.

Finally, the influence of wider social circumstances and socio-cultural context on people's decisions about healthy lifestyle choices cannot be ignored. At a broader level, the fact that poverty plays a key role in the development and management of type 2 diabetes is important (Chaufan & Weitz, 2009; Scottish Government, 2014). Poverty has been suggested to have a causal effect on type 2 diabetes thus affecting one's ability to prevent the condition independently of other factors (Chaufan & Weitz, 2009). This provides support for type 2 diabetes and general lifestyle resources to be available in venues, accessible to people

from vulnerable groups. NICE (2012) and the Diabetes Improvement Plan (Scottish Government, 2014) highlight the importance for accessible services and support for vulnerable groups.

9.9.3 Implications for health professionals

The integration of type 2 diabetes interventions in medical practice as part of diabetic nurse appointments may provide a promising avenue for type 2 diabetes management and prevention. Previous research has identified factors that need to be addressed to ensure adequate implementation of diabetes interventions in primary care (Mathews et al., 2014; Wozniak et al., 2015; Foster et al, 2016). Such factors include human resources, training, building trust and considering the impact of external factors. If an intervention is to be integrated in medical practice, then health professionals need to be able to support patients' autonomy. Although medical care is patient-centred the distinction between respecting patients' freedom to choice and patient involvement is not clear and affected by the fact that some patients choose to remain passive (Dwarswaard & van de Bovenkamp, 2015). Addressing the teachable moment factors may alter motivation not to remain passive but healthcare professionals need to acknowledge that changes can happen at sub-events and not necessarily immediately after diagnosis.

9.10 Future work:

This project provides mixed support for McBride et al.'s (2003) teachable moment heuristic. The qualitative study showed that emotional representation does not appear to affect people's behaviour as suggested by McBride et al. (2003). It also showed that there may be more than the three criteria that make illness diagnosis a teachable moment. However, McBride et al.'s (2003) model was developed in cancer. It could be suggested that the factors that influence the potential of illness diagnosis to be a teachable moment differ across conditions. The current study adds to existing knowledge, by showing that teachable moment criteria may be similar for patients and their relatives. This provides support for interventions to target dyads or family units. The teachable moment criteria in the current project were not associated with changes in all outcomes, thus indicating a potential influence of other factors. More research is needed to explore if and how the criteria for a

teachable moment differ across illnesses and populations (patients vs relatives) and what criteria are associated with what change in behaviour. Furthermore, the current study was cross-sectional so a claim cannot be made that the suggested teachable moment criteria predict behaviour. Future longitudinal studies can explore changes in people's perceptions and behaviour over time in order to more accurately predict behaviour change triggers and teachable moment criteria.

Although this study provides evidence for the potential of type 2 diabetes to be a teachable moment, further research in the field of type 2 diabetes is warranted. There is a need for tailored interventions that explore the effectiveness of teachable moment factors. Interventions should target all of the factors in order to explore their individual and joint influence on people's behaviour. In addition, participants' characteristics and perceptions need to be taken into account for potential interventions to be acceptable and feasible. This has been highlighted in NICE guidelines on preventing type 2 diabetes (2012). It is also important to identify the optimal time for intervention delivery. The time immediately after diagnosis may be too stressful so specific sub-events in the course of the illness may be more appropriate. However, research is needed to identify meaningful sub-events for type 2 diabetes. Studies with better designs are also needed. A comparison between people who have experienced a health threat and changed their behaviour and people who have experienced the same health threat but have not changed their behaviour may provide further insight into the mechanisms underlying teachable moments. Finally, it is important to design interventions that address ways to promote sustained behaviour change. This may involve the availability of regular support and opportunities for people to ask questions. One of the top 10 priorities for type 2 diabetes, as outlined by Diabetes UK (2017) is to understand how support can be best used to help people with and at risk of type 2 diabetes. According to NICE guidelines (2012) in order to provide ongoing support, interventions should encourage the involvement of family members and professionals, such as nurses, GPs, pharmacists.

9.11 Reflections

Reflecting on the research process was important for learning and developing myself as a researcher. Below I have discussed the key lessons that emerged for me while undertaking this PhD.

I wanted to use the PhD experience to develop my skills and enhance my CV so I took advantage of several opportunities: In the first year of my PhD, I attended as many training courses as possible; in the second year I was the Graduate Officer for the Faculty of Health Sciences and Sport, an editor for the University of Stirling postgraduate journal (SPARK), a member of the Faculty of Health Sciences and Sport Athena SWAN committee, and the lead organiser of monthly research skills seminars; throughout the duration of the PhD I was teaching, marking and supervising, and mentoring undergraduate students; in the last year of the project I took leave of absence and worked as a research fellow for six months. Taking on different responsibilities helped me understand how much workload I can take without comprising on the quality of my work.

Recruitment of participants for the quantitative part of the study took longer than expected, with additional time added to maximise response rates. During this time, it was tempting to take time off, but I remembered advice from previous PhD students about writing every day, so I utilised the time to write and edit chapters and draft papers for publication. Thinking back I am glad I found self-motivation and organised my time well, so I was able to submit the thesis on time. This has helped me be more organised and has already been useful in other aspects of my research career.

Reflecting back on the last three years, I can confidently say that I enjoyed doing a PhD. I did not necessarily expect to enjoy the process after hearing stories from previous PhD students. However, having worked in research before embarking on the PhD, was extremely useful in helping me to make decisions, prepare study materials and rely less on my supervisors. It also helped me to be more confident in my work, take ownership of my PhD at an early stage and steer the project.

9.12 **Conclusion:**

In conclusion, this thesis is consistent with previous suggestions that diagnosis of illness in oneself or in a family member is a teachable moment for behaviour change. The mixed-methods nature of the study advanced understanding by showing the complexity of factors that make diagnosis a teachable moment. The lack of complete alignment in factors identified through different methods is useful in understanding when interventions may be more (or less) successful. This study suggests the factors that may make diagnosis of type 2 diabetes a teachable moment for patients are outcome expectancy, perceive control, severity, self-concept or social role, gender and time since diagnosis; and for relatives: perceived risk,

severity, self-concept or social role, and gender. The project recommends future interventions should capitalise on the teachable moment factors. Interventions can be delivered by healthcare professionals and patients can be encouraged to communicate diabetes-related information with their relatives. The current mixed-methods study has theoretical implications by advancing understanding of the teachable moment concept; policy implications by highlighting the role of stigma in type 2 diabetes, the importance of social context, and the need for promotion and support for self-care; and healthcare implications by suggesting the possibility for diabetic nurses to deliver diabetes-related brief interventions. In the wider research context, the project suggests that future research is needed to explore if and how the criteria for a teachable moment differ across illness and populations, and the best way to capitalise on teachable moment criteria to ensure sustained intervention effectiveness.

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Appendices

Appendix 1 Recruitment Poster for Study One

Have **you** or
anyone in **your family**
recently been diagnosed with
type 2 diabetes?

If the answer is yes, we would like to hear about your experience for a
research project.

Please pick up a flyer, phone Elena on 07***** or email
elena.dimova@stir.ac.uk to obtain more information about our research
and how you can help.

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Type 2 diabetes, your family and you

“Type 2 diabetes, your family and you” is a study that explores the impact of type 2 diabetes diagnosis on people and their family members. We are looking for people who have either been diagnosed or have a family member or partner who has been diagnosed with type 2 diabetes in the past 6 months. Taking part in the study involves an interview where you can tell us more about your experience. The interview will be conducted in a time and place convenient for you and will last between 30 and 45 minutes. You will also receive £10 as reimbursement for your time.

For more information phone or text Elena on
07***** or email elena.dimova@stir.ac.uk

Appendix 3 Recruitment Venues for Study One

Falkirk council	
Community centres, N=17	<ul style="list-style-type: none"> ○ Bainsford community centre ○ Bonnybridge community education centre ○ Brightons community hall ○ Broompark community hall (Denny) ○ Camelon Community Project ○ Dawson centre ○ Denny community education centre ○ Ettrick Dochart community hall (Hallglen) ○ Grange community education centre ○ Greenpark ○ Maddiston community education centre ○ Mariner centre (Camelon) ○ Polmont sports centre ○ Reddingmuirhead community hall ○ Tamfourhill ○ WASP project (Denny) ○ Westquarter community project
Bowling clubs, N=13	<ul style="list-style-type: none"> ○ Bainsford ○ Bonnybride (post) ○ Burnhead ○ Camelon ○ Denny (post) ○ Falkirk ○ Falkirk Indoor bowling club ○ Grahamston ○ Larbert ○ Laurieston (post) ○ Polmont ○ Slamannan ○ Stenhousmuir
Golf clubs, N=6	<ul style="list-style-type: none"> ○ Bonnybridge golf club ○ Falkirk golf club ○ Falkirk Tryst

	<ul style="list-style-type: none"> ○ Glenbervie ○ Grangemouth golf club ○ Polmont golf club
Libraries, N= 5	<ul style="list-style-type: none"> ○ Bonnybridge library ○ Denny ○ Falkirk library ○ Larbert ○ Meadowbank library
Charity shop staff rooms, N=5	<ul style="list-style-type: none"> ○ British heart foundation (furniture) ○ British heart foundation ○ Salvation Army ○ Debra ○ Age Scotland
Other, N=11	<ul style="list-style-type: none"> ○ Slamannan pharmacy ○ Carronshore pharmacy ○ Maddiston pharmacy ○ Dobbie Hall, Stenhousemuir ○ Age Concern, Stenhousemuir ○ Life Fit Wellness, Falkirk ○ Forth Valley Sensory centre, Camelon ○ Falkirk Job centre – for staff only ○ Alexander Dennis, Camelon – took posters, not sure if they will display them ○ Falkirk stadium ○ Laurieston post office
Stirling council	
Community centres, N=13	<ul style="list-style-type: none"> ○ Allan centre (Bridge of Allan) ○ Alpha centre ○ Balfour ○ Bannockburn ○ Cambuskenneth ○ Cowie ○ Cornton centre ○ Hillpark centre ○ Hillview community centre ○ Mayfield centre ○ Parklands ○ Raploch campus – not allowed ○ Raploch Salvation Army community centre

Libraries, N=8	<ul style="list-style-type: none"> ○ Bannockburn ○ Bridge of Allan ○ Cambusbarron ○ Cowie ○ Dunblane ○ Fallin ○ Mayfield, St. Ninians ○ Plean
Bowling clubs, N=5	<ul style="list-style-type: none"> ○ Cowie ○ Denny ○ Dunblane ○ Polmaise (Fallin) ○ Stirling indoor bowling centre
Golf clubs, N=2	<ul style="list-style-type: none"> ○ Bridge of Allan ○ Brucefields
Charity shop staff rooms, N=7	<ul style="list-style-type: none"> ○ Marie Curie ○ PDSA ○ British heart foundation ○ Chest heart and stroke ○ Cancer UK ○ British red cross ○ CHAS
Clackmannanshire council	
Community centres, N= 3	<ul style="list-style-type: none"> ○ Bowmar ○ Hawkhill ○ Parklands, Alva
Libraries, N=2	<ul style="list-style-type: none"> ○ Alloa spiers ○ Sauchie
Bingo, N=1	<ul style="list-style-type: none"> ○ Premier
Golf clubs, N= 3	<ul style="list-style-type: none"> ○ Aloa ○ Tulliallan ○ Callander
Charity shops, N= 7	<ul style="list-style-type: none"> ○ Chest heart and stroke ○ Sense ○ Salvation army ○ Strathcarron hospice ○ Debra ○ Marie Curie ○ British heart foundation

<p>Emails</p>	<ul style="list-style-type: none"> ○ Scot rail ○ First group ○ Falkirk council ○ Stirling council ○ Clackmannanshire council ○ Citizen advice bureau Falkirk ○ Citizen advice bureau Stirling ○ Asda ○ Tesco – replied, will help through their occupational health team; waiting to hear back from them ○ Health sciences - advertised ○ Psychology – advertised ○ University of Stirling portal ○ Diabetes UK –newsletter, social media, website
<p>Total</p>	<p>109 locations, 12 emails</p>

Appendix 4 Participant Information Sheet for Patients, Study One



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Participant information leaflet

Type 2 diabetes, your family and you

Invitation to take part in a research study

Thank you for your interest in our research study and for getting in touch. This leaflet will give you some more information to help you to decide whether to take part in the study. You are being asked to take part in a research study, which is looking at the impact of type 2 diabetes diagnosis on patients and their family members or partners. Before you decide if you want to take part, we would like you to understand why the research is being done and what it would involve for you. Thank you for taking the time to read this leaflet.

Purpose of the research study

This is a study about type 2 diabetes and its impact on patients and their family members and partners. By family members, we mean parents, brothers or sisters, or offspring, whether or not they live with you.

Why have I been chosen to take part

We would like you to take part because you have been diagnosed with type 2 diabetes in the last 6 months.

After you have read this leaflet and have had a few days to think about it and discuss it with your relatives, a researcher will call you back to see if you and your relatives or partner wish to take part. If you wish to take part, you will be asked to take part in an interview. You can decide if you want to attend the interview alone or with your family member or partner. If your family member or partner does not wish to take part, you are still welcome to take part yourself.

Your participation in this research would benefit other people in the future if they are at increased risk of developing type 2 diabetes.

Time commitment and what we would like you to do

If you are eligible, we will ask you to take part in an interview which will be arranged at a time to suit you. The interview will include questions about your thoughts of type 2 diabetes and how it has affected you and your family. The interview will be held at a venue that suits you. The interview will last between 30 and 45 minutes.

Cost, reimbursement and compensation

You will receive £10 as reimbursement for your participation.

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Scottish Charity No. SC011159

Decisions about taking part and termination of participation

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. Participation is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without explanation and without penalty.

Risks

There are no known risks for you in this study.

Design of the study and ethical approval

The study was designed by a group of researchers from the University of Stirling. Funding has been provided by the Economic and Social Sciences Research Council. The Ethics Research Committee of the School of Health Sciences, University of Stirling, has approved the study.

Confidentiality

Any information obtained in the interviews will be kept confidential and securely stored. Only members of the research team will be able to listen to the interview recordings. Your name will not be disclosed, nor will details of your answers be given to anyone. No one will be able to link the data you provided to your identity and name. The audio recording of the interview and the interview transcript will be kept until the final report is completed, after which time they will be destroyed.

Participation in the study will be confidential unless the Chief investigator deems there to be a risk to the participant, for example if the patient was not reporting life threatening side effects or symptoms.

Study findings

If you decide to take part in the study and would like to receive information about the results of the study, please let us know, and we will forward a summary of the findings to you at the end of the study. The findings of this study may be published in a scientific journal but you will not be identified in any way.

Further information

If you have any questions or would like further information about the study, please contact Elena Dimova at the School of Health Sciences, University of Stirling (elena.dimova@stir.ac.uk).

If you wish to speak to an independent advisor about the study or if you have any complaints, please contact Prof. Jayne Donaldson at the School of Health Sciences, University of Stirling (jayne.donaldson@stir.ac.uk).

If you would like further information about type 2 diabetes, you can visit the Diabetes UK website (www.diabetes.org.uk), contact your GP or visit a local Diabetes support group. To find out where your local support group is, please email volunteering@diabetes.org.uk. You can also join the Diabetes support forum at diabetesupport.co.uk.



Participant information leaflet

Type 2 diabetes, your family and you

Invitation to take part in a research study

Thank you for your interest in our research study and for getting in touch. This leaflet will give you some more information to help you to decide whether to take part in the study. You are being asked to take part in a research study, which is looking at the impact of type 2 diabetes diagnosis on patients and their family members or partners. Before you decide if you want to take part, we would like you to understand why the research is being done and what it would involve for you. Thank you for taking the time to read this leaflet.

Purpose of the research study

This is a study about type 2 diabetes and its impact on patients and their family members and partners. By family members, we mean parents, brothers or sisters, or offspring, whether or not they live with you. We therefore want to look at how the diagnosis affects a patient's family members or partners and their thoughts and behaviours.

Why have I been chosen to take part

We would like you to take part because you have a family member or partner who has been diagnosed with type 2 diabetes in the last 6 months.

After you have read this leaflet and have had a few days to think about it and discuss it with your family member or partner who has type 2 diabetes, a researcher will call you back to see if you and your relatives or partner wish to take part. If you wish to take part, you will be asked to take part in an interview. You can decide if you want to attend the interview alone or with your family member or partner. If your family member or partner does not wish to take part, you are still welcome to take part yourself.

Your participation in this research would benefit other people in the future if they are at increased risk of developing type 2 diabetes.

Time commitment and what we would like you to do

If you are eligible, we will ask you to take part in an interview which will be arranged at a time to suit you. The interview will include questions about your thoughts of type 2 diabetes and how having a family member or partner with type 2 diabetes has affected you. The interview will be held at a venue that suits you. The interview will last between 30 and 45 minutes.

Cost, reimbursement and compensation

You will receive £10 as reimbursement for your participation.

Decisions about taking part and termination of participation

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. Participation is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without explanation and without penalty.

Risks

There are no known risks for you in this study.

Design of the study and ethical approval

The study was designed by a group of researchers from the University of Stirling. Funding has been provided by the Economic and Social Sciences Research Council. The Ethics Research Committee of the School of Health Sciences, University of Stirling, has approved the study.

Confidentiality

Any information obtained in the interviews will be kept confidential and securely stored. Only members of the research team will be able to listen to the interview recordings. Your name will not be disclosed, nor will details of your answers be given to anyone. No one will be able to link the data you provided to your identity and name. The audio recording of the interview and the interview transcript will be kept until the final report is completed, after which time they will be destroyed.

Participation in the study will be confidential unless the Chief investigator deems there to be a risk to the participant, for example if the patient was not reporting life threatening side effects or symptoms.

Study findings

If you decide to take part in the study and would like to receive information about the results of the study, please let us know, and we will forward a summary of the findings to you at the end of the study. The findings of this study may be published in a scientific journal but you will not be identified in any way.

Further information

If you have any questions or would like further information about the study, please contact Elena Dimova at the School of Health Sciences, University of Stirling (elena.dimova@stir.ac.uk).

If you wish to speak to an independent advisor about the study or if you have any complaints, please contact Prof. Jayne Donaldson at the School of Health Sciences, University of Stirling (jayne.donaldson@stir.ac.uk).

If you would like further information about type 2 diabetes, you can visit the Diabetes UK website (www.diabetes.org.uk), contact your GP or visit a local Diabetes support group. To find out where your local support group is, please email volunteering@diabetes.org.uk. You can also join the Diabetes support forum at diabetesupport.co.uk.

Appendix 6 Consent Form for Study One



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Consent form

A study on type 2 diabetes diagnosis and its impact on patients and their family members

This study is designed to explore the ways in which type 2 diabetes affects people and their relatives. It looks at people's perceptions of type 2 diabetes and their experience of the diagnosis and its impact on thoughts and behaviours. Type 2 diabetes patients and at least one of their family members are invited to take part.

- 1 I confirm that I have read and understand the Participant Information Leaflet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time.
- 3 I understand that the interview will be recorded. I agree to the audio recording of the interview.
- 4 I agree to the use of anonymous extracts from my interview in conference papers and academic publications.
- 6 I agree to take part in the above study.

_____	_____	_____
Participant's name	Signature	Date
_____	_____	_____
Researcher's name	Signature	Date

University of Stirling FK9 4LA Scotland UK
Scottish Charity No. SC011159

Version 1 21.09.15

Appendix 7 Questionnaire for Patients, Study One



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School of Health Sciences

Participant Number:	Date:
----------------------------	--------------

Please answer the following questions about yourself.

Name

Date of birth

Mobile telephone number

Home telephone number

Address

House number

Street name

Postcode

Did you have any education after you left school?

Yes 1

No 2

If you did, what was the highest level?

Are you employed? (please tick one box only)

Yes, full-time

1

Yes, part-time 2

No, unemployed 3

Other, please specify. 4

If you are employed, what is your occupation?

Are you a student? (please tick one box only)

Yes, full-time 1

Yes, part-time 2

No 3

What is your relationship status? (please tick one box only)

Single 1

In a relationship 2

How long have you had type 2 diabetes for?

Do you have a family history of diabetes? Yes 1 No 2

If you answered yes to the above question, how many of your relatives have diabetes?

How did you hear about this study?

Appendix 8 Questionnaire for Relatives, Study One



UNIVERSITY OF
STIRLING

School of Health Sciences

Participant Number:	Date:
----------------------------	--------------

Please answer the following questions about yourself.

Name

Date of birth

Mobile telephone number

Home telephone number

Address

House number

Street name

Postcode

Did you have any education after you left school?

Yes 1

No 2

If you did, what was the highest level?

Are you employed? (please tick one box only)

Yes, full-time

1

Yes, part-time 2

No, unemployed 3

Other, please specify. 4

If you are employed, what is your occupation?

Are you a student? (please tick one box only)

Yes, full-time 1

Yes, part-time 2

No 3

What is your relationship status? (please tick one box only)

Single 1

In a relationship 2

Do you have a family history of diabetes? Yes 1 No 2

If you answered yes to the above question, how many of your relatives have diabetes?

How did you hear about this study?

Appendix 9 Data Analysis, Study One

Theme	Category/sub-theme	Code/detected element	Quote
People who adopt problem solving strategies	Monitors: seeking information	Seeking personally relevant information	<i>"They [health professionals at an education course] didn't give you so much ideas for recipes and I felt it was slanted very much at what you might call a traditional type 2 diabetic who actually needed to lose weight or keep their weight sort of under control or at kind of standard level, so I suppose because of that I maybe looked a bit further to try and find more ideas"</i> P7, female
	A wake-up call	Different rules	<i>"...it was like that's it and now I need to remember that there are different rules for me than there are for everyone else"</i> P9, male
		An opportunity to get better	<i>"...the diabetes might be the start of a...like an unpleasant road to getting better but in the best case scenario"</i> P9, male
		Personal responsibility for health; "get on with it"	<i>"I take it personally that I have an issue with my health that needs to be addressed or there will be consequence and I just get on with it"</i> P10, male
		"deal with it"	<i>"...you've gotta get on and deal with it"</i> P1, male
	Increased perception of severity	Potential complications becoming relevant	<i>"But it's only when it's in your face and it's you that it has any real meaning. And it's easy to slip a bit and have a few cakes and sandwiches and think: oh I got away with that, but it's cumulative, it will come back and it will come back to haunt you if you don't take, you know, real responsibility for your lifestyle"</i> P6, female

		Potential complications becoming relevant	<i>"I already knew about certain complications but it brings it more home to you when you've actually been diagnosed as that and you have to weary of certain situations"</i> P8, female
		Fatalistic about future; Potential complications becoming relevant	<i>"I guess I was a little bit frightened but it was more the idea that if I didn't sort it out then I wouldn't get, I have a little boy who is 2 and a half now, and I wouldn't get to see him go to school unless I did something."</i> P9, male
	Changes in self-concept	Becoming somebody else	<i>"I am extremely tired all the time whereas I was a women before who wouldn't think twice of, just constantly being on the go, would never sit down. But now I am so tired, when I finish a day's work I am exhausted which is not like me at all. I've become somebody else"</i> P8, female
		Changing behaviour to feel like oneself again	<i>"But remarkably now I've got my diet relatively under control but I've been a bit naughty recently, but relatively under control, I am back to firing and doing all sorts of again, I run up and down staircases, I'm emailing people, it's like, you know, she is back!"</i> P6, female
		Defining one's identity	<i>"...but at the same time there are big questions for me like: what was the overeating in the first place, you know, what happened first depression or the overeating and you know to what extent and you know not to be too dramatic, but to what extent is eating, especially now that i know the consequences, to what extent is that self-harm,</i>

			<p><i>you know...when...my last really bad episode of depression i was cutting myself and things and i've done that before, you know, and i wonder if the eating was part of that, it's deliberately destructive, you know, in a really negative way....there's a lot of questions like how do i see myself and what is it about? And i think the diet...working out my identity with food, working out my relationship there, is part of a big thing for me in terms of how i see myself and the diabetes has definitely changed and i might be opening myself up to some unpleasant things about destructive behaviours and how i can duck relationships..." P9, male</i></p>
		<p>Desire to "fit in" with new identity</p>	<p><i>"So I think there's something like sort of type 2 men that are like: acht I don't care" and then there seems to be an older community of type 2 women that have this stereotype around them that they sit around and talk about, you know, how terrible it is that they can't eat biscuits or something like that, this is from a newsletter I get and things I read online and communities and like, none of these fit with my identity..." P9, male</i></p>
		<p>Bad vs good diabetic</p>	<p><i>"So I take it as quite a serious thing although it is quite clear that a lot of people don't" P10, male</i></p>
		<p>Bad vs good diabetic</p>	<p><i>"But you see that with maybe some people with diabetes, when you look at it, it's a stereotyping again, obviously quite fat and maybe</i></p>

			<p><i>they don't look after themselves right either but they get the type 2 diabetes and I think maybe they're expecting some miracle medication to cure it and then something will happen to their feet. 'Cause being diabetic you can sort of feel how numb your feet are sometimes, you wouldnae actually know if they are cut, unless you looked at them so maybe people aren't taking the time to have a look and things as well and by that time they may not be able to cure it. Maybe by the time they find, it's too late. It's the same sort of...like I am not blaming people and that for having it but it's a sort of laziness because you are eating so much and you are watching the telly and all these other things come into place. Well... maybe you don't wash as much and you don't check as much and things like that as well."</i> P1, male</p>
	Strategies for self-management	Carbohydrate control	<p><i>"But if I am looking at a packet of something, I kind of have a look and if it's less than, like I have this number in my head, it's like 10 grams of carbohydrate per 100 gram and if it's under that then I might have a look at it, if it's over that I won't, you know..."</i> P9, male</p>
		Imaginary curve	<p><i>"I have this imaginary thing in my head where I see the glucose spiking up and going down, and spiking up and going down, and that's bad. I have this thing in my head about there are foods I can eat and things I can do that would keep this more like a</i></p>

			<i>soft curving wave.” P6, female</i>
		Imaginary dog walking	<i>“I am having to go dog walking with my fantasy dog. To stop that falling asleep on the sofa 'cause I think that's diabetic as well. I don't know if it is but in my head it is.” P6, female</i>
	Changing mind-set	Facing up to diabetes	<i>“...Pain doesn't mean that you've got to sit down, have a cup of tea, have a cake ad feel sorry for yourself...” P6, female</i>
		Facing up to diabetes	<i>“But I think it has to do with facing up to diabetes. It's more than anything to do with it” P6, female</i>
People who need time to adjust	A period of adjustment	Emotional rollercoaster	<i>“I think I've been on a bit of an emotional rollercoaster as well in terms of...being numb, avoiding it for a bit and trying to let it sink in and trying to work out how to manage the fact that...I was used to feeling fine and now I prick myself...getting into some kind of a routine...” P2, male</i>
		Bereavement process; denial	<i>“And I presume it's fairly common if not, close to 100% common that there is any kind of bereavement process, there is a period of denial in the beginning, isn't it? None of this can be happening to me, not really being able to process what's going on...” P2, male</i>
	Not experiencing consequences	no consequences	<i>“...to be honest, at the moment, I haven't really noticed what it's done to me” P4, male</i>
		Diabetes as not fatal	<i>“I am pretty laid back about most things. I know that diabetes...I am not taking</i>

			<i>it lightly, I do regard diabetes as a serious illness...erm...but I havnnae seen it flattening any of my relatives. They've...the ones that have had it for several years, they are just continuing with their normal life."</i> P4, male
	Reliance on relatives for self-management	passive management of diabetes	<i>"He doesn't get to choose what he eats because I cook the dinner and I do the shopping"</i> R5 referring to P2
		Passive management of diabetes	<i>"She is telling me what to eat and I eat it"</i> P4 male

Appendix 10 University ethical approval for Study One

PT/SN



7 October 2015

Ms Elena Dimova
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Professor Pat Hoddinott
Chair
School Research Ethics Committee

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Dear Elena

**Teachable Moments: Potential for Behaviour Change Among People at High Risk of Developing Type 2 Diabetes
SREC 15/16 – Paper No.37 – Version 1**

Thank you for attending the SREC Committee meeting on 7 October 2015, and discussing your application with members.

I am pleased to advise that your study has been approved, and we would like to wish you and your team all the best.

In order to recap, I have noted below points discussed and agreed:

1. Whilst your intention is to recruit from community settings, you agreed to return to the Committee should you require to recruit from clinical settings such as GP practices, hospitals, dental clinics, diabetes and retinal screening clinics.
2. Regarding recruitment of 'significant others', you advised that your contact details will be provided to participants who may have a 'significant other' willing to take part in the study. The onus shall be on them to make contact with you, thus avoiding any coercion issues. You shall ensure that you receive written informed consent from both parties.
3. With reference to 'Potential Risks and Safeguards', the Committee are satisfied that you shall ask only objective questions. You advised that, should participants become upset or distressed, your intention is to either move to the next question or terminate the interview as deemed necessary. Contact details for local support groups will be included in your information sheet.
4. Regarding confidentiality, you agreed to include within the Patient Information Leaflet the sentence: "Participation in the above study will be confidential, unless

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the Chief Investigator deems there to be a risk to the participant, for example if the patient was not reporting life threatening side effect or symptoms*.

May I remind you of the need to inform SREC prior to making any amendments to this protocol, of any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website.

<http://www.stir.ac.uk/health-sciences/research/ethics/>

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

Ref: SREC 15/16 – Paper No.37 – Version 1
Please quote this number on all correspondence

Yours sincerely



DR PATRICIA THOMSON
(Acting Chair)
School of Health Sciences Research Ethics Committee

Cc *Dr Josie Evans*
Dr Vivien Swanson

Appendix 11 University Ethics amendment approval for Study One



PT/SN

25 November 2015

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Dear Elena

**Teachable Moments: Potential for Behaviour Change Among People at High Risk of Developing Type 2 Diabetes
SREC 15/16 – Paper No.37 – Version 1**

Thank you for your letter of 20 November 2015 requesting amendment to your study.

I note from your correspondence that you are requesting an amendment on the following grounds:

- to conduct telephone interviews with participants who live in England.
- in order to address the issue of obtaining written consent prior to interview, you shall obtain oral consent immediately prior to the start of the interview, whereafter you will explain the study to the participant before reading out the consent form. You will then ask the participant to indicate whether they agree with the consent statements.

I would advise that I am happy to authorise this amendment by Chair's Action, and wish you well with your study.

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the Chief Investigator deems there to be a risk to the participant, for example if the patient was not reporting life threatening side effect or symptoms*.

May I remind you of the need to inform SREC prior to making any amendments to this protocol, of any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website.

<http://www.stir.ac.uk/health-sciences/research/ethics/>

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

Ref: SREC 15/16 – Paper No.37 – Version 1
Please quote this number on all correspondence

Yours sincerely



DR PATRICIA THOMSON
(Acting Chair)
School of Health Sciences Research Ethics Committee

Cc *Dr Josie Evans*
Dr Vivien Swanson

Appendix 12 Questionnaire for Patients, Study Two

Version 2 28/11/2016



UNIVERSITY OF
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Faculty of Health Sciences
and Sport

Participant Number: *Research use only*

Date:

Type 2 diabetes, your family and you

You should have recently received a letter from your GP inviting you to take part in a research study which is looking at the impact of type 2 diabetes on patients and their family members and partners. We would like you to take part because you have been recently diagnosed with type 2 diabetes. We would also like you to hand a questionnaire to your partner if you have one, and any of your family members, who would be willing to complete the questionnaire.

If you wish to take part, please fill in the questionnaire below. If your partner and/or relatives want to take part, please give them a questionnaire from the ones enclosed in this letter.

Your insight and information are very valuable for us in order to explore what people think, feel and experience after they have been diagnosed with type 2 diabetes. There are no right or wrong answers so please be as honest as possible. Your participation in this research may benefit other people in the future.

Any information provided in the questionnaires will be kept confidential and securely stored. Only members of the research team will be able to see it. The details of your answers will not be given to anyone else. No one will be able to link the data you provided to your identity and name. The questionnaires will be kept until the final report is completed, after which time they will be destroyed.

The questionnaire is divided into eight short sections and will take around 10-15 minutes to complete. The majority of questions ask you to circle the answer you find most suitable. If you do not want to answer certain questions, please feel free to leave them blank.

SECTION 1: Immediate response to diagnosis

Thinking about the time when you were diagnosed with type 2 diabetes, to what extent do you agree with the following statements:

	Strongly disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Strongly agree
When I was diagnosed with type 2 diabetes, I tried to find as much information as possible about type 2 diabetes.	1	2	3	4	5
When I was diagnosed with type 2 diabetes, I asked the doctor/nurse questions about type 2 diabetes.	1	2	3	4	5
When I was diagnosed with type 2 diabetes, I did not want to know anything about type 2 diabetes.	1	2	3	4	5
When I was diagnosed with type 2 diabetes, I refused to believe I had it.	1	2	3	4	5

SECTION 3: Feelings about yourself

Sometimes the way people feel about themselves may change as a result of being diagnosed with type 2 diabetes. Please circle the answer that you find most suitable.

Compared to before you were diagnosed with type 2 diabetes, how would you describe yourself now?

1	2	3	4	5
Less happy than before		Unchanged		Happier than before

1	2	3	4	5
Less in control than before		Unchanged		More in control than before

1	2	3	4	5
More worried than before		Unchanged		Less worried than before

1	2	3	4	5
Less attractive than before		Unchanged		More attractive than before

1	2	3	4	5
Less hopeful than before		Unchanged		More hopeful than before

1	2	3	4	5
More emotional than before		Unchanged		Less emotional than before

1	2	3	4	5
More irritable than before		Unchanged		Less irritable than before

1	2	3	4	5
More dependent than before		Unchanged		More independent than before

1	2	3	4	5
Less talkative than before		Unchanged		More talkative than before

1	2	3	4	5
More forgetful than before		Unchanged		Less forgetful than before

1	2	3	4	5
Less caring than before		Unchanged		More caring than before

1	2	3	4	5
Less confident than before		Unchanged		More confident than before

1	2	3	4	5
More bored than before		Unchanged		Less bored than before

1	2	3	4	5
Less valued than before		Unchanged		More valued than before

1	2	3	4	5
More difficult than before		Unchanged		More cooperative than before

1	2	3	4	5
Less friendly than before		Unchanged		More friendly than before

SECTION 4: Lifestyle

Please circle the answer that you find most suitable.

Compared to before you were diagnosed with type 2 diabetes, how would you describe your responsibilities around the house or for the family?

1	2	3	4	5
I do less than before		Unchanged		I do more than before

Compared to before you were diagnosed with type 2 diabetes, how would you describe your responsibilities at work?

1	2	3	4	5
I do less than before		Unchanged		I do more than before

If your diet has changed, which of the following do you consume and how often? For example, Fruit: 2 pieces a day before diagnosis; 3 pieces a day and I don't eat bananas anymore after diagnosis

	Before diagnosis	After diagnosis
Fruit		
Vegetables		
Carbohydrates (for example, pasta, bread, potatoes)		
Sweets		
Fruit juice		
Crisps		
Other		

SECTION 5: Coping with type 2 diabetes

Since you were diagnosed with type 2 diabetes, who would you consider to be your main source of support? By support we mean practical and emotional help. Please choose **only one** answer.

Spouse/Partner	
Mother/Father	
Sister/brother	
Daughter/Son	
Wider family	
Friends	
Other, please specify	

If you can, please hand a questionnaire to the person/people you chose as your main source of support.

SECTION 7: About you

How old are you?

What is your gender?

Male

Female

Other

Did you have any education after you left school?

Yes ₁

No ₂

If you did, what was the highest level?

Are you currently employed? (please tick one box only)

Yes, full-time

₁

Yes, part-time

₂

No, unemployed

₃

Retired

₄

Other, please specify.

₅

If you are employed, what is your occupation?

Are you a student? (please tick one box only)

Yes, full-time

₁

Yes, part-time

₂

No

₃

What is your relationship status? (please tick one box only)

Single

₁

In a relationship

₂

How long has it been since you were diagnosed with type 2 diabetes?

Who do you live with?

How would you rate your overall health status?

0

| 1

| 2

| 3

SECTION 8: Information about type 2 diabetes

We want to know if you would be interested in receiving information about type 2 diabetes or attending an educational course. Please note that indicating yes does not give us permission to send you information. The purpose of the question is to give us an idea of people's interest in receiving information and attending educational courses.

If available, would you be interested in attending an educational course about type 2 diabetes?	yes	no
If possible, would you be interested in receiving information about type 2	yes	no

Thank you for taking the time to complete the questionnaire

Please return your completed questionnaire in the free post envelope that is enclosed in this letter.

Further information

If you have any questions or would like further information about the study, please contact Elena Dimova at the Faculty of Health Sciences and Sport, University of Stirling (elena.dimova@stir.ac.uk).

If you wish to speak to an independent advisor about the study or if you have any complaints, please contact Prof. Jayne Donaldson at the Faculty of Health Sciences and Sport, University of Stirling (jayne.donaldson@stir.ac.uk).

If you would like further information about type 2 diabetes, you can visit the Diabetes UK website (www.diabetes.org.uk), contact your GP or visit a local Diabetes support group. To find out where your local support group is, please email volunteering@diabetes.org.uk. You can also join the Diabetes support forum at diabetesupport.co.uk.

Appendix 13 Questionnaire for Relatives, Study Two

Version 2 28/11/2016



UNIVERSITY OF
STIRLING

Faculty of Health Sciences
and Sport

Participant Number: *Research use only*

Date:

Type 2 diabetes, your family and you

You are reading this because your partner or relative has asked you to take part in a research study, which is looking at the impact of type 2 diabetes on patients and their family members and partners. We would like you to take part because you have a partner or relative who has been recently diagnosed with type 2 diabetes.

If you wish to take part, please fill in the questionnaire below. Your insight and information are very valuable for us to find out what people think, feel and experience after their partner/relative has been diagnosed with type 2 diabetes. There are no right or wrong answers so please be as honest as possible. Your participation in this research may benefit other people in the future.

Any information you provide in the questionnaires will be kept confidential and securely stored. Only members of the research team will be able to see it. We do not need you to add your name to your questionnaire and your results are anonymous. The questionnaires will be kept until the final report is completed, after which time they will be destroyed.

The questionnaire is divided into eight short sections and will take around 10-15 minutes to complete. The majority of questions ask you to circle the answer you find most suitable. If you do not want to answer certain questions, please feel free to leave them blank.

SECTION 1: Type 2 diabetes in your family

Can you please tell us who has type 2 diabetes in your family? (for example: partner, mother, child)

How long has it been since they were diagnosed with type 2 diabetes?

SECTION 2: Thoughts about type 2 diabetes before and after diagnosis

Please circle the answer that you find most suitable.

Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your current thoughts about how serious type 2 diabetes is?

1	2	3	4	5
Less serious than I thought before		Unchanged		More serious than I thought before

Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your current thoughts about potential consequences of type 2 diabetes?

1	2	3	4	5
Less serious than I thought before		Unchanged		More serious than I thought before

SECTION 3: Feelings about yourself

Please circle the answer that you find most suitable.

Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe yourself now?

1	2	3	4	5
Less happy than before		Unchanged		Happier than before

1	2	3	4	5
Less in control than before		Unchanged		More in control than before

1	2	3	4	5
More worried than before		Unchanged		Less worried than before

1	2	3	4	5
Less hopeful than before		Unchanged		More hopeful than before

1	2	3	4	5
More emotional than before		Unchanged		Less emotional than before

1	2	3	4	5
More irritable than before		Unchanged		Less irritable than before

1	2	3	4	5
Less talkative than before		Unchanged		More talkative than before

1	2	3	4	5
More forgetful than before		Unchanged		Less forgetful than before

1	2	3	4	5
Less caring than before		Unchanged		More caring than before

1	2	3	4	5
Less valuable than before		Unchanged		More valuable than before

1	2	3	4	5
More difficult than before		Unchanged		More cooperative than before

SECTION 4: Your risk of type 2 diabetes

Please circle the answer that you find most suitable.

Compared to before your relative/partner was diagnosed with type 2 diabetes, how likely do you think you are to develop type 2 diabetes...

	Much less likely than before	Slightly less likely than before	As likely as before	Slightly more likely than before	Much more likely than before
...at some point in the future?	1	2	3	4	5
... in the next year?	1	2	3	4	5
... if you exercise regularly?	1	2	3	4	5
... if you have a healthy diet?	1	2	3	4	5

SECTION 5: Lifestyle

Please circle the answer that you find most suitable.

Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your responsibilities around the house or for the family?

1	2	3	4	5
I do less than before		Unchanged		I do more than before

Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your responsibilities at work?

1	2	3	4	5
I do less than before		Unchanged		I do more than before

Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe the amount of exercise you do now?

1	2	3	4	5
I exercise less than before		Unchanged		I exercise more than before

If the amount of exercise you do has changed, which of the following actions do you take and how often do you engage in them? Please fill in the boxes giving as much details as you can. For example, Walking: 30 mins most days of the week before diagnosis; 45 minutes every day of the week after diagnosis

	Before diagnosis	After diagnosis
Walking		
Exercising (in the gym or at home)		
Jogging		
Gardening		
Housework		
Other		

Compared to before your relative/partner was diagnosed with type 2 diabetes, how would you describe your diet now?

1	2	3	4	5
Less healthy than before		Unchanged		Healthier than before

If your diet has changed, which of the following do you consume and how often? For example, Fruit: 2 pieces a day before diagnosis; 3 pieces a day and I don't eat bananas anymore after diagnosis

	Before diagnosis	After diagnosis
Fruit		
Vegetables		
Carbohydrates (for example, pasta, bread, potatoes)		
Sweets		
Fruit juice		
Crisps		

SECTION 6: Coping with type 2 diabetes

Please circle the answer you find most suitable.

Thinking about your relative/partner with type 2 diabetes, to what extent do you agree with the statement:

	Strongly disagree	Slightly disagree	Neither agree not disagree	Slightly agree	Strongly agree
I see type 2 diabetes as something that is our issue that we face together	1	2	3	4	5
I have a real feeling that we are going to work through this together, whatever the outcome	1	2	3	4	5

SECTION 7: About you

How old are you? _____

What is your gender? Male Female Other

Did you have any education after you left school? Yes ₁ No ₂

If you did, what was the highest level? _____

Are you currently employed? (please tick one box only)

Yes, full-time ₁

Yes, part-time ₂

No, unemployed ₃

Retired ₄

Other, please specify. ₅

If you are employed, what is your occupation? _____

Are you a student? (please tick one box only)

Yes, full-time ₁

Yes, part-time ₂

No ₃

What is your relationship status? (please tick one box only)

Single ₁

In a relationship ₂

Who do you live with? _____

How would you rate your overall health status? 0 | 1 | 2 | 3

SECTION 8: Information about type 2 diabetes

We want to know if you would be interested in receiving information about type 2 diabetes or attending an educational course. Please note that indicating yes does not give us permission to send you information. The purpose of the question is to give us an idea of people's interest in receiving information and attending educational courses.

If available, would you be interested in attending an educational course about type 2 diabetes? yes no

If possible, would you be interested in receiving information about type 2 diabetes? yes no

Thank you for taking the time to complete the questionnaire

Please return your completed questionnaire in the free post envelope that is enclosed in this letter.

Further information

If you have any questions or would like further information about the study, please contact Elena Dimova at the Faculty of Health Sciences and Sport, University of Stirling (elena.dimova@stir.ac.uk). Tel: 01786-466340

If you wish to speak to an independent advisor about the study or if you have any complaints, please contact Prof. Jayne Donaldson at the Faculty of Health Sciences and Sport, University of Stirling (jayne.donaldson@stir.ac.uk). Tel: 01786-466345

If you would like further information about type 2 diabetes, you can visit the Diabetes UK website (www.diabetes.org.uk), contact your GP or visit a local Diabetes support group. To find out where your local support group is, please email volunteering@diabetes.org.uk. You can also join the Diabetes support forum at diabetesupport.co.uk.

Appendix 14 GP Letter

Version 2 28/11/2016

Insert date here

GP headed paper

Insert name of patient here

Insert address here

Dear patient *insert name here*,

Teachable moments: Potential for behaviour change among people at high risk of developing Type 2 Diabetes

I am enclosing some information from a group of researchers at the University of Stirling who are carrying out a research study on the effect of a diagnosis of type 2 diabetes on people and their family members or partners. They are looking for people recently diagnosed with type 2 diabetes who can help them.

If you are interested in taking part in their study, a Participation Information Leaflet is enclosed, together with a questionnaire which they would like you to complete, and a free post envelope for return. The researchers are also asking if you can pass on questionnaires to family members or partners.

There is no obligation for you to take part in the research. Whether or not you take part will not affect your diabetes care in any way. If you wish any further information about the study, you may contact the researchers directly on 01786-466340.

Yours sincerely,
GP name

Appendix 15 Participation Information Sheet for Patients, Study Two

Version 2 28/11/2016



UNIVERSITY OF
STIRLING

Faculty of Health Sciences
and Sport

Participant information leaflet

Type 2 diabetes, your family and you

Invitation to take part in a research study

This leaflet will give you some more information to help you to decide whether to take part in a research study. We have asked your GP to send letters to everyone in the GP practice who has recently been diagnosed with type 2 diabetes. Before you decide if you want to take part, we would like you to understand why the research is being done and what it would involve for you. Thank you for taking the time to read this leaflet.

Purpose of the research study

This is a study about type 2 diabetes and how it affects patients and their family members and partners. By family members, we mean parents, brothers or sisters, or offspring, whether or not they live with you. We want to look at the effect of diabetes on patients and their family members or partners.

Why have I been chosen to take part?

You have been chosen to take part because you have been recently diagnosed with type 2 diabetes. We would also like you to hand a questionnaire to any of your family members or partner, who would be willing to complete a short questionnaire. Yours and your family's participation in this research may benefit other people in the future.

Time commitment and what we would like you to do

All you have to do is complete the questionnaire, which is enclosed with this leaflet. We will also provide a free post envelope so you can return the questionnaire back to us. The questionnaire will take around 10-15 minutes to complete. If you can, we are also asking you to hand the additional enclosed questionnaires to any of your family members or partner. Please return your questionnaire to us whether or not they want to take part.

Advantages and disadvantages of taking part in the study

Although there is no direct advantage to you or your family of completing these questionnaires, the results of the research may benefit other people in the future by finding new ways of trying to prevent diabetes. The main disadvantage is the time that you will give up by completing the questionnaire.

University of Stirling FK9 4LA Scotland UK
Scottish Charity No. SC0011159

Version 2 28/11/2016

Design of the study and ethical approval

The study was designed by a group of researchers from the University of Stirling. Funding has been provided by the Economic and Social Sciences Research Council. The NHS Research Ethics Committee has approved the study.

Confidentiality

Any information that you provide in the questionnaires will be kept confidential and securely stored. Only members of the research team will be able to see it. We do not need you to add your name to your questionnaire. The questionnaires will be kept until the final report is completed, after which time they will be destroyed.

Study findings

If you decide to take part in the study and would like to receive information about the results of the study, please let us know, and we will forward a summary of the findings to you at the end of the study. The findings of this study may be published in a scientific journal but you will not be identified in any way.

Further information

If you have any questions or would like further information about the study, please contact Elena Dimova at the Faculty of Health Sciences and Sport, University of Stirling (elena.dimova@stir.ac.uk). Tel: 01786-466340

If you wish to speak to an independent advisor about the study or if you have any complaints, please contact Prof. Jayne Donaldson at the Faculty of Health Sciences and Sport, University of Stirling (jayne.donaldson@stir.ac.uk). Tel: 01786-466345

If you would like further information about type 2 diabetes, you can visit the Diabetes UK website (www.diabetes.org.uk), contact your GP or visit a local Diabetes support group. To find out where your local support group is, please email volunteering@diabetes.org.uk. You can also join the Diabetes support forum at diabetesupport.co.uk.

Appendix 16 Participant Information Sheet for Relatives, Study Two

Version 2 28/11/2016



UNIVERSITY OF
STIRLING

Faculty of Health Sciences
and Sport

Participant information leaflet

Type 2 diabetes, your family and you

Invitation to take part in a research study

This leaflet will give you some more information to help you to decide whether to take part in a research study. We have asked your relative/partner who has recently been diagnosed with type 2 diabetes to hand this leaflet to people he/she thinks might consider taking part in the study. Before you decide if you want to take part, we would like you to understand why the research is being done and what it would involve for you. Thank you for taking the time to read this leaflet.

Purpose of the research study

This is a study about type 2 diabetes and how it affects patients and their family members and partners. By family members, we mean parents, brothers or sisters, or offspring, whether or not they live with you. We want to look at the effect of diabetes on patients and their family members or partners.

Why have I been chosen to take part?

We would like you to take part because you have a family member or partner who has been recently diagnosed with type 2 diabetes who has passed this leaflet on to you. Your participation in this research may benefit other people in the future.

Time commitment and what we would like you to do

All you have to do is complete the questionnaire, which is enclosed with this leaflet. We will also provide a free post envelope so you can return the questionnaire back to us. The questionnaire will take around 10-15 minutes to complete.

Advantages and disadvantages of taking part in the study

Although there is no direct advantage to you of completing these questionnaires, the results of the research may benefit other people in the future by finding new ways of trying to prevent diabetes. The main disadvantage is the time that you will give up by completing the questionnaire

Design of the study and ethical approval

The study was designed by a group of researchers from the University of Stirling. Funding has been provided by the Economic and Social Sciences Research Council. The NHS Research Ethics Committee has approved the study.

University of Stirling FK9 4LA Scotland UK
Scottish Charity No. SC011159

Version 2 28/11/2016

Confidentiality

Any information that you provide in the questionnaires will be kept confidential and securely stored. Only members of the research team will be able to see it. We do not need you to add your name to your questionnaire and your results are anonymous. The questionnaires will be kept until the final report is completed, after which time they will be destroyed.

Study findings

If you decide to take part in the study and would like to receive information about the results of the study, please let us know, and we will forward a summary of the findings to you at the end of the study. The findings of this study may be published in a scientific journal but you will not be identified in any way.

Further information

If you have any questions or would like further information about the study, please contact Elena Dimova at the Faculty of Health Sciences and Sport, University of Stirling (elena.dimova@stir.ac.uk). Tel: 01786-466340

If you wish to speak to an independent advisor about the study or if you have any complaints, please contact Prof. Jayne Donaldson at the Faculty of Health Sciences and Sport, University of Stirling (jayne.donaldson@stir.ac.uk). Tel: 01786-466345

If you would like further information about type 2 diabetes, you can visit the Diabetes UK website (www.diabetes.org.uk), contact your GP or visit a local Diabetes support group. To find out where your local support group is, please email volunteering@diabetes.org.uk. You can also join the Diabetes support forum at diabetesupport.co.uk.

Appendix 17 Consent Form for Study Two

Version 2 28/11/2016



UNIVERSITY OF
STIRLING

Faculty of Health Sciences
and Sport

Consent form

A study on type 2 diabetes diagnosis and its impact on patients and their family members

This study is designed to explore the ways in which type 2 diabetes affects people and their relatives. It looks at people's perceptions of type 2 diabetes and their experience of the diagnosis and its impact on thoughts and behaviours.

1 I confirm that I have read and understand the Participant Information Leaflet for the above study. I have had the opportunity to consider the information and I understand that I can contact the researchers if I have any more questions.

2 I understand that my participation is voluntary and that I am not obliged to complete or to return the questionnaire.

Researcher's name

Signature

Date

Appendix 18 University ethical approval for Study Two

PH/SF

14 December 2016

Ms Elena Dimova
Research Postgraduate
Faculty of Health Sciences & Sport
Room E009
Pathfoot Building
University of Stirling
Stirling FK9 4LA

UNIVERSITY of 
STIRLING

NHS, Invasive or Clinical Research (NICR)
Committee

Room G10
Pathfoot Building
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1786 467390
Email: nicr@stir.ac.uk

Dear Elena

Teachable Moment: Potential for behaviour change among people at high risk of developing Type 2 Diabetes
NICR 16/17 – Paper No.3

Thank you for your recent re-submission, which was discussed at the Committee meeting on.

I am pleased to advise that your study has been approved, and we would like to wish you and your team all the best.

However it was noted that you had not addressed point 5 from our previous letter:

5. A68.1, A 71.1. You will require R+D approval from NHS Tayside and NHS Forth Valley to conduct research with primary care patients. Please discuss your study with the lead NHS R+D Manager before you progress this application. In A71.1, you describe this as single centre, when it is a multi-centre study. For R+D approval, your lead R+D manager may suggest you contact the NRS co-ordinating centre in Aberdeen which oversees multi-centre studies
(see <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>).

Please also amend your application at A71-1 (pg20) to multi-centre.

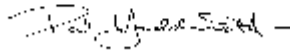
Once these amendments have been made, please email your form to nicr@stir.ac.uk for our records.

May I remind you of the need to inform NICR prior to making any amendments to this protocol, of any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the NICR webpage at:

<http://www.stir.ac.uk/research/integritygovernanceethics/researchethics/formsandguidance/>

NICR 16/17 – Paper No.3 (V2)
Please quote this number on all correspondence

Yours sincerely



Professor Pat Hoddinott
(Depute Chair)

Appendix 19 NHS Ethical Approval for Study Two



Health Research Authority

South Central - Hampshire A Research Ethics Committee

Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 3421328

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

24 January 2017

Miss Elena Dimova
PhD student
University of Stirling
Faculty of Health Sciences and Sport
FK9 4LA

Dear Miss Dimova

Study title:	Teachable moments: Potential for behaviour change among people at high risk of developing Type 2 Diabetes
REC reference:	17/SC/0043
Protocol number:	N/A
IRAS project ID:	217153

The Proportionate Review Sub-committee of the South Central - Hampshire A Research Ethics Committee reviewed the above application on 18 January 2017.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with

before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [cover letter for REC (1)]	1	06 January 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity]	1	09 January 2017
GP/consultant information sheets or letters [GP letter]	2	28 November 2016
Letter from funder [Letter from ESRC (funder)]		13 May 2016
Letter from sponsor [Sponsorship]	1	09 January 2017
Letters of invitation to participant [Letter patient]	2	28 November 2016
Non-validated questionnaire [Questionnaire patient]	2	28 November 2016
Other [Type 2 diabetes and you Questionnaire Relative]	2	28 November 2016
Other [Participant information leaflet Relative]	2	28 November 2016
Other [Study Summary]	2	28 November 2016
Participant consent form [Appendix 7 Consent]	2	28 November 2016
Participant information sheet (PIS) [PIS patient]	2	28 November 2016
REC Application Form [REC_Form_10012017]		10 January 2017
Research protocol or project proposal [Research proposal]	2	28 November 2016
Summary CV for Chief Investigator (CI) [CV CI]		28 November 2016
Summary CV for student [CV student, same as CV CI]		28 November 2016
Summary CV for supervisor (student research) [CV supervisor]		19 December 2016
Validated questionnaire	2	

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

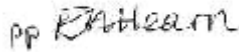
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

17/SC/0043	Please quote this number on all correspondence
------------	--

Yours sincerely



Dr Ronja Bahadori
Chair

Email: nrescommittee.southcentral-hampshirea@nhs.net

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers"

Copy to: Ms Joy Taylor
Ms Rosemary Wilson, NHS Forth Valley

Appendix 20 R&D Approval for Study Two, Forth Valley

NHS Forth Valley

Carseview House
Castle Business Park
Stirling
FK9 4SW

NHS
Forth Valley

Date: 30 Jan 2017
Your Ref:
Our Ref:
Direct Line: 01324214690
Email: FV-UHB.RandD-depart@nhs.net
R&D ref: FV994

Miss Elena Dimova
University of Stirling
Faculty of Health Sciences and Sport
Stirling
FK9 4LA

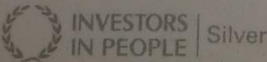
Dear Miss Dimova

Study title: Teachable moments: Potential for behaviour change among people at high risk of developing Type 2 Diabetes
NRES number: 17/SC/0043

Following the favourable opinion from the South Central - Hampshire A Research Ethics Committee on 24 January 2017, I am pleased to confirm that I formally gave Management Approval to the study above on 30 January 2017.



This approval is granted subject to your compliance with the following:

1. Any amendments to the protocol or research team must have Ethics Committee and R&D approval (as well as approval from any other relevant regulatory organisation) before they can be implemented. Please ensure that the R&D Office and (where appropriate) NRS are informed of any amendments as soon as you become aware of them.
2. You and any local Principal Investigator are responsible for ensuring that all members of the research team have the appropriate experience and training, including GCP training if required.
3. All those involved in the project will be required to work within accepted guidelines of health and safety and data protection principles, any other relevant statutory legislation, the Research Governance Framework for Health and Community Care and IHC-GCP guidelines. A copy of the Framework can be accessed via the Chief Scientist Office website at:
<http://www.cso.scot.nhs.uk/Publications/ResGov/Framework/RGFEdTwo.pdf>
and ICH-GCP guidelines may be found at <http://www.ich.org/LOB/media/MEDIA482.pdf>
4. As custodian of the information collected during this project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT security policies, until the destruction of this data.
5. You or the local Principal Investigator will be required to provide the following reports and information during the course of your study:
 - A progress report **annually**

 **INVESTORS IN PEOPLE** Silver

Chairman: Alex Linkston CBE
Chief Executive: Jane Grant

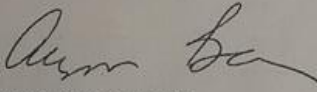
*Forth Valley NHS Board is the common name for Forth Valley Health Board
Registered Office: Carseview House, Castle Business Park, Stirling, FK9 4SW*

www.nhsforthvalley.com  Facebook.com/nhsforthvalley  @nhsforthvalley

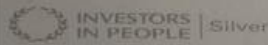
- Recruitment numbers on a **monthly** basis (if your study should be added to the NIHR research Portfolio you will receive a separate letter from the R&D Office detailing the steps to be taken)
- Report on SAEs and SUSARs if your study is a Clinical Trial of an Investigational Medicinal Product
- Any information required for the purpose of internal or external audit and monitoring
- Copies of any external monitoring reports
- Notification of the end of recruitment and the end of the study
- A copy of the final report, when available.
- Copies of or full citations for any publications or abstracts

The appropriate forms will be provided to you by the Research and Development office when they are needed. Other information may be required from time to time.

Yours sincerely

Pp 
MISS TRACEY GILLIES
Medical Director

CC: josie.evans@stir.ac.uk
vivien.swanson@stir.ac.uk




Chairman: Alex Linkston CBE
Chief Executive: Jane Grant

*Forth Valley NHS Board is the common name for Forth Valley Health Board.
Registered Office: Carseview House, Castle Business Park, Stirling, FK9 4SW*

www.nhsforthvalley.com  Facebook.com/nhsforthvalley 
[@nhsforthvalley](https://twitter.com/nhsforthvalley)

Appendix 21 R&D Approval for Study Two, Tayside



27 January 2017

Miss Elena Dimova
University of Stirling
Faculty of Health Sciences and Sport
Stirling
FK9 4LA

Dear Miss Dimova,

PIC APPROVAL LETTER - NHS TAYSIDE

<p>Title: Teachable moments: Potential for behaviour change among people at high risk of developing Type 2 Diabetes</p> <p>Chief Investigator: Miss Elena Dimova</p> <p>Local Collaborator: N/A</p> <p>Tayside Ref: 2017D0001 NHS Ref: NRS17/217153</p> <p>REC Ref: 17/SC/0043</p> <p>Sponsor: University of Stirling</p> <p>Funder: ESRC award via Scottish Graduate School of Social Science</p>

Many thanks for your request for NHS Tayside to act as a Participant Identification Centre (PIC) for the above study. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for NHS Tayside to act as a PIC in this case.

Approval is granted on the following conditions:-

- NHS Tayside is a Participant Identification Centre (PIC) only and is not a Research Site for this study.
- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulation, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).
- As custodian of the information collected during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.
- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R&D Office.

Please note you are required to adhere to the conditions, if not, NHS Tayside PIC approval may be withdrawn for the study.

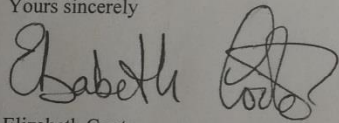
Approved Documents

Document	Version	Date
IRAS R&D form Protocol	V2	28/11/16
GP letter	V2	28/11/16
Patient GP letter	V2	28/11/16
Questionnaire patient	V2	28/11/16
Questionnaire relative	V2	28/11/16
Patient information leaflet relative	V2	28/11/16
Consent	V2	28/11/16
PIS patient	V2	28/11/16
Sponsor letter		09/01/17
Insurance		09/01/17
Funder letter		13/05/15
CV – Elena Dimova		
CV – Vivien Swanson		15/01/17
CV – Josie Evans		

May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R&D Office should you require further assistance.

Yours sincerely



Elizabeth Coote
Head of Non-Commercial Research Services

TAyside medical Science Centre (TASC)
Ninewells Hospital & Medical School
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c.c. Laura Stephen
TASC Feasibility Team

Appendix 22 HRA Approval for Study Two



Health Research Authority

Miss Elena Dimova
PhD student
University of Stirling
Faculty of Health Sciences and Sport
FK9 4LA

Email: hra.approval@nhs.net

11 August 2017

Dear Miss Elena Dimova

Letter of HRA Approval

Study title:	Teachable moments: Potential for behaviour change among people at high risk of developing Type 2 Diabetes
IRAS project ID:	217153
Protocol number:	N/A
REC reference:	17/SC/0043
Sponsor	University of Stirling

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA Approval, including:

- Working with organisations hosting the research
- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

IRAS project ID	217153
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If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 217153. Please quote this on all correspondence.

Yours sincerely

Insert Assessor/Senior Assessor Name

Job Title

Email: hra.approval@nhs.net

Copy to: *Ms Joy Taylor, University of Stirling, Sponsor contact*
Ms Rosemary Wilson, NHS Forth Valley, Lead NHS R&D contact

Appendix 23 Unadjusted correlations for independent variables and outcomes

Patients (first table) and Relatives (second table)

Correlations

		SRoleHouse	SRoleWork	Seveity	Communal.Coping	Self.Concept.Total	High.Low.Monitors	Control	OEEExerciseBinary	OEDietBinary	Course	Information	Exercise.Binary	Diet.Binary
SRoleHouse	Pearson Correlation	1	.186	-.086	.079	.325**	-.071	.082	.105	-.012	.067	-.062	.219*	.084
	Sig. (2-tailed)		.088	.434	.494	.003	.516	.460	.339	.915	.555	.576	.047	.444
	N	86	85	85	78	81	86	83	85	85	79	83	84	85
SRoleWork	Pearson Correlation	.186	1	.066	.087	.220*	.000	.115	.160	.157	-.179	-.148	.214	.141
	Sig. (2-tailed)	.088		.553	.451	.049	.997	.302	.145	.153	.117	.184	.054	.202
	N	85	85	84	77	80	85	82	84	84	78	82	82	84
Seveity	Pearson Correlation	-.086	.066	1	.145	-.146	.024	.206	.464**	.236*	.041	.027	.267*	.052
	Sig. (2-tailed)	.434	.553		.206	.194	.824	.062	.000	.030	.718	.810	.015	.635
	N	85	84	85	78	81	85	83	85	85	79	82	83	85
Communal.Coping	Pearson Correlation	.079	.087	.145	1	.238*	-.035	.394**	.129	-.028	.091	.014	.141	.139
	Sig. (2-tailed)	.494	.451	.206		.040	.763	.000	.260	.809	.446	.902	.225	.224
	N	78	77	78	78	75	78	77	78	78	73	75	76	78
Self.Concept.Total	Pearson Correlation	.325**	.220*	-.146	.238*	1	-.065	.120	.121	-.003	-.099	-.058	.240*	.072
	Sig. (2-tailed)	.003	.049	.194	.040		.563	.291	.282	.979	.391	.609	.033	.525
	N	81	80	81	75	81	81	80	81	81	77	79	79	81
High.Low.Monitors	Pearson Correlation	-.071	.000	.024	-.035	-.065	1	-.286**	-.020	-.171	-.115	-.091	-.129	-.143
	Sig. (2-tailed)	.516	.997	.824	.763	.563		.009	.859	.118	.313	.415	.244	.193
	N	86	85	85	78	81	86	83	85	85	79	83	83	85
Control	Pearson Correlation	.082	.115	.206	.394**	.120	-.286**	1	-.013	.033	.230*	.244*	.226*	.337**
	Sig. (2-tailed)	.460	.302	.062	.000	.291	.009		.908	.769	.041	.028	.042	.002
	N	83	82	83	77	80	83	83	83	83	79	81	81	83
OEEExerciseBinary	Pearson Correlation	.105	.160	.464**	.129	.121	-.020	-.013	1	.471**	.082	.021	.464**	.202
	Sig. (2-tailed)	.339	.145	.000	.260	.282	.859	.908		.000	.474	.849	.000	.063
	N	85	84	85	78	81	85	83	85	85	79	82	83	85
OEDietBinary	Pearson Correlation	-.012	.157	.236*	-.028	-.003	-.171	.033	.471**	1	-.138	.022	.156	.294**
	Sig. (2-tailed)	.915	.153	.030	.809	.979	.118	.769	.000		.224	.845	.159	.006
	N	85	84	85	78	81	85	83	85	85	79	82	83	85
Course	Pearson Correlation	.067	-.179	.041	.091	-.099	-.115	.230*	.082	-.138	1	.498**	.116	.029
	Sig. (2-tailed)	.555	.117	.718	.446	.391	.313	.041	.474	.224		.000	.314	.803
	N	79	78	79	73	77	79	79	79	79	79	79	77	79
Information	Pearson Correlation	-.062	-.148	.027	.014	-.058	-.091	.244*	.021	.022	.498**	1	-.020	.039
	Sig. (2-tailed)	.576	.184	.810	.902	.609	.415	.028	.849	.845	.000		.861	.728
	N	83	82	82	75	79	83	81	82	82	79	83	80	82
Exercise.Binary	Pearson Correlation	.219*	.214	.267*	.141	.240*	-.129	.226*	.464**	.156	.116	-.020	1	.221*
	Sig. (2-tailed)	.047	.054	.015	.225	.033	.244	.042	.000	.159	.314	.861		.045
	N	83	82	83	76	79	83	81	83	83	77	80	83	83
Diet.Binary	Pearson Correlation	.084	.141	.052	.139	.072	-.143	.337**	.202	.294**	.029	.039	.221*	1
	Sig. (2-tailed)	.444	.202	.635	.224	.525	.193	.002	.063	.006	.803	.728	.045	
	N	85	84	85	78	81	85	83	85	85	79	82	83	85

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Correlations

		Severity.Total	Selc.Concept.Total	Communal.Coping.Total	Perceived.Risk.Total	SocialRoleBinary	InfoEduCourse	InfoReceive	Exercise.Binary	Diet.Binary
Severity.Total	Pearson Correlation	1	-.006	.135	-.206	.190	.109	.094	.141	.240
	Sig. (2-tailed)		.967	.336	.161	.177	.452	.515	.310	.081
	N	55	55	53	48	52	50	50	54	54
Selc.Concept.Total	Pearson Correlation	-.006	1	.043	.000	.084	.108	-.060	-.137	.035
	Sig. (2-tailed)	.967		.761	1.000	.552	.455	.680	.323	.800
	N	55	55	53	48	52	50	50	54	54
Communal.Coping.Total	Pearson Correlation	.135	.043	1	.209	.011	.145	.119	.021	-.018
	Sig. (2-tailed)	.336	.761		.158	.941	.322	.414	.881	.896
	N	53	53	53	47	50	49	49	52	52
Perceived.Risk.Total	Pearson Correlation	-.206	.000	.209	1	-.200	-.055	-.012	-.093	-.361*
	Sig. (2-tailed)	.161	1.000	.158		.187	.724	.940	.533	.013
	N	48	48	47	48	45	44	44	47	47
SocialRoleBinary	Pearson Correlation	.190	.084	.011	-.200	1	.235	.207	.535**	.256
	Sig. (2-tailed)	.177	.552	.941	.187		.108	.162	.000	.067
	N	52	52	50	45	52	48	47	52	52
InfoEduCourse	Pearson Correlation	.109	.108	.145	-.055	.235	1	.578**	-.016	.000
	Sig. (2-tailed)	.452	.455	.322	.724	.108		.000	.912	1.000
	N	50	50	49	44	48	50	49	50	50
InfoReceive	Pearson Correlation	.094	-.060	.119	-.012	.207	.578**	1	.106	-.100
	Sig. (2-tailed)	.515	.680	.414	.940	.162	.000		.467	.494
	N	50	50	49	44	47	49	50	49	49
Exercise.Binary	Pearson Correlation	.141	-.137	.021	-.093	.535**	-.016	.106	1	.423**
	Sig. (2-tailed)	.310	.323	.881	.533	.000	.912	.467		.001
	N	54	54	52	47	52	50	49	54	54
Diet.Binary	Pearson Correlation	.240	.035	-.018	-.361*	.256	.000	-.100	.423**	1
	Sig. (2-tailed)	.081	.800	.896	.013	.067	1.000	.494	.001	
	N	54	54	52	47	52	50	49	54	54

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).

