Exploration of the Psychosocial Impact of Coeliac Disease on Adults and Their Family Members

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Abstract

Coeliac disease (CD) is an autoimmune condition triggered by the consumption of gluten; a protein found in grains. In addition to the biological impact, CD impacts the psychosocial wellbeing of people with the condition. The sole treatment available for CD is a life-long gluten-free diet. Food and eating form a key behaviour in daily family life. The management of CD takes place in the family home and external social environment. Family can influence the behaviour and health of individual members. Evidence of how CD impacts family members, and how families support the management of CD is sparse. This thesis explored the lived experiences of nine families with an adult with coeliac disease, examining the psychosocial impact through an integrated biopsychosocial theoretical framework. The research adopted a participatory approach consulting with adult, child, and young person groups, on the research design. Individual (n=18) and dyadic (n=3) participant-generated photo-elicited interviews were conducted via online synchronous video. Transcribed interview data were analysed using reflexive thematic analysis. Data generated three distinct themes of family life; adjusting to life with CD; family life at home with food; and navigating the external social world. An overarching theme, ‘the perpetual presence of coeliac disease’, threaded these themes together. The adult with CD had the initial burden of orchestrating family adjustment to CD. All family members changed food related behaviours at home, constructing a conducive environment to support the management of CD. In the wider social world, stigma and negative affect were experienced by children and adults with CD. This thesis contributes to participatory research methods literature, demonstrating feasibility of public consultation, and application of participatory-photograph methods online. The research contributes to the wider literature on the psychosocial impact on families living with CD, having implications for the inclusion of family members in the management of CD.
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2 Introduction

2.1 Research Rationale

One in a 100 people in the United Kingdom (UK) have coeliac disease (CD), an autoimmune, condition triggered through gluten ingestion (Lebwohl & Rubio-Tapia, 2021). The incidence of CD is increasing yet CD is often misdiagnosed and misunderstood (Ludvigsson & Murray, 2019). Currently, the only known treatment for CD is a life-long gluten-free diet, that for the majority of people successfully resolves symptoms (Anupam Rej & Sanders, 2021). Food provides daily structure through mealtimes, providing nutritional, social, and psychological benefits (Ogden, 2010). Many people live in family groups where food accompanying behaviours are often associated with gendered family roles (Working Families, 2019). Family members influence the health and wellbeing of each other, providing positive and negative benefits, performing an important role in the psychological adjustment and management of long-term conditions (Martire & Schulz, 2007). The interaction of psychological and social factors is described as psychosocial (Peter, Helfer, Golz, Halfens, & Hahn, 2022). Evidence has shown a psychosocial impact on people with CD, with an emphasis on women with CD (Hallert, Sandlund, & Broqvist, 2003; Sverker, Ostlund, Hallert, & Hensing, 2007). The prevalence of CD is higher in women compared to men despite research showing both equally as likely to have CD. The dietary based treatment for CD, combined with the embedded function of food in daily family life strongly suggests a psychosocial impact on all family members. This indicates the need to understand the impact of CD on families given the potential influence on family members health, wellbeing, and the
management of CD. Limited evidence reports a negative psychosocial impact on adult partners of a person with CD with uncertainty surrounding the underpinning causes and exclusion of other family members (Ferretti, Branchi, Dell’Osso, Conte, & Elli, 2017; Ludvigsson, Roy, Lebwohl, Green, & Emilsson, 2017; Roy et al., 2016; Sverker et al., 2007).

This research sought to explore the psychosocial impact of CD on adults and their family members, the whole family experience of living CD, using an integrated conceptual theoretical framework employing a biopsychosocial framework (Engel, 1977). and the family systems illness model (Rolland, 1987). Exploring the lived experience of people with long-term health conditions and their families, affords a rich insight into the perspectives and experiences. The findings from lived experiences also have the potential to identify barriers and facilitators to help support other people with the CD. The aim for this research was to understand the lived experience of families living with coeliac disease within the United Kingdom.

Little prior research has been conducted into whole families living with CD, with a scarcity including the experiences of children and young people living with an adult with CD. This research aimed to explore the psychosocial factors related to the experience of family members living with CD as social relationships affect psychological wellbeing and health behaviours. Research on CD has tended to focus on people with CD with a paucity on the experiences of men. The findings from this research will inform future research into supporting families living with CD, and potentially gender specific healthcare.

This research aimed to answer the following questions:
1. What are the lived experiences of family members living with an adult with coeliac disease?

2. What are the psychosocial impacts on family members living with coeliac disease?

3. How do the psychosocial impacts differ between men and women living with coeliac disease?

4. What are the implications for supporting people and their families to live with coeliac disease?

2.1.1 Research Background

In this section, the personal context grounding the thesis is discussed, my inspiration for the research and how my position altered during the process. The research employed a Reflexive Thematic Analysis (RTA), where reflexivity formed a vital component throughout the research process (Braun & Clarke, 2022). Researcher subjectivity is foregrounded as an essential component of RTA including the personal position in relation to the research topic (Braun & Clarke, 2021). Reflexivity included personal, functional, and disciplinary reflexivity, in how these values shaped the research and the knowledge produced.

This thesis is a product of an Open University (OU) studentship that I was awarded in 2018. The proposal originated from my interest in the psychology of living with long-term health conditions and the impact on families. My interest in families living with CD was inspired through research into inflammatory bowel disease, where participants disclosed the difficulty in explaining the condition (the physical, social, and psychological) to family members (Hughes, Fischer, Goodliffe, Irving, & Moss-Morris, 2017). At a similar time, an acquaintance
divulged being diagnosed with CD, and shared how this impacted their life and the lives of their family members. Exploring the literature identified scarce knowledge and resources for families living with CD. This series of events sparked my curiosity into exploring families experiences of living with CD, with an emphasis on the psychosocial impact, and whether any potential support was required. Several participants in this research inquired as to whether I was 'coeliac', so I feel it is important to state at the beginning of this thesis that I do not have CD nor do any of my family members.

My exploration into families experiences of living with CD changed from my initial proposal, where although I argued for family support, there was an absence of children and young people. This became apparent during my literature review, discussed in Chapter 3 with a rarity of the presence of children and young people, in families living with long-term conditions, prompting further investigation into the inclusion of these populations within research design. The inclusion of adult family members was additionally sparse with only five studies identified during the literature search. These are presented in Chapter 3 section 3.5. To address these absences, throughout the research a participatory approach was adopted. The research was conducted over two stages. Firstly, a consultation stage, working with children, young people, and adults as research advisors with expertise on living with a medical dietary condition. The consultation informed the study design and the participant documents for stage two. Secondly, the data generation stage, where the experiences of children, young people, and adults living with an adult with CD, were sought using participant-generated photographs. A broad approach was taken to allow the freedom to capture everyday life with CD without predefined criteria. All
recruitment took place online with interviews conducted via online synchronous video during the COVID-19 global pandemic. Participant-generated photo-elicitation interviews were conducted with nine families, 24 participants in total. This included eight participants aged eight to 16 years and ten adult participants with CD. All participants were a family group at the point of CD diagnosis and had lived with CD for a number of years. The interviews explored everyday life through participants photographs. The results showed all family members were impacted by CD and were actively involved in the family (self)-management of the condition. Results also showed the meaning of food in the home and the challenges faced by families eating outside the home environment. The adjustment to living with CD and family life had a psychosocial impact on family members. The results strengthen the need for family psychosocial support for life with CD. The research has implications for supporting the inclusion of all family members, including children and young people, in research exploring living with long-term conditions.

2.1.2 Thesis Overview
This thesis contains nine chapters including this introduction. In the following chapter, the Literature review (Chapter 3), provides a biopsychosocial overview of CD describing the effect on an individual. The concept of family is discussed in conjunction with the importance of the often-neglected role of family in the management of long-term conditions. An overview of the concept of gender is provided in relation to family gender roles and the influence on health and family behaviours. The chapter then considers food and eating from a biopsychosocial perspective arguing that biological, psychological, and social factors are
influential interrelated factors in shaping food and eating behaviours. Finally, the scarce known literature on CD and family members is examined.

The methodological approaches used to explore the psychosocial impact on families living with CD are presented in Chapter 4 together with the conceptual theoretical frameworks guiding the research.

Chapter 5 presents Stage One of the research methods, the consultation with child, young person and adult research advisors on the research design and participant documents.

Chapter 6 details Stage Two of the research method. The procedures are explained including ethical considerations and how data were analysed. The chapter concludes with a reflective section on the research process.

Chapter 7 presents the first of three analysis chapters detailing how CD is perpetually present for families living with condition. The chapter then describes through the main theme, “It’s a learning curve all the way”: from the unknown to family norm, participants introduction to CD and the process of adjustment as they learnt to live with the condition, constructed over three sub-themes.

Chapter 8, the second analysis chapter, describes how families live with CD within the home environment through an umbrella theme, family life at home with food, and three main themes and sub-themes. Chapter 9, the final analysis chapter detailing family life in the wider external social world through an overarching theme, navigating the external world with coeliac disease, and three main themes and one sub-theme. Together the three analysis chapters describe families journeys of learning to live with CD, the stressors experienced
and the individual and family coping and support mechanisms used. Some photographs taken by participants are shared within these chapters.

Finally, **Chapter 10** provides a summary of the research results, how these relate and contribute to the wider literature. The chapter concludes considering the implications for practice and directions for further research.
3 Literature Review

The aim of this research was to explore families lived experience of CD focusing on the psychosocial affect. To understand living with CD this research took a multidisciplinary approach drawing on the literature from health, psychology, and sociology. The medical background of CD opens the chapter to provide an understanding of the condition before moving on to discuss the psychosocial impact on adults with CD. The evidence presented on CD and the psychosocial impact of CD provides the foundations for the research. The next section discusses what is family, the importance of family in promoting the health and wellbeing of its members as well as the impact of a long-term condition on the family. The role of family is argued as vital in supporting the management of long-term conditions. The following section presents the gendered roles within families and how they shape health and behaviour. Next food and eating are considered, exploring the functional and psychosocial properties. Food and eating are then examined in relation to CD, as the treatment for CD is a gluten-free diet. Subsequently the literature on family members and CD are reviewed to assess the limited knowledge. Finally, the identified gaps in the literature are summarised.

3.1 Coeliac Disease

Coeliac disease (CD)\(^1\) is a long-term autoimmune condition triggered through consumption of dietary gluten in association with a genetic predisposition and

\(^1\) Coeliac disease is also known as; gluten enteropathy, acquired CD, sprue nontropical, congenital CD, celiac sprue, gluten-sensitive enteropathy, or gluten intolerance, and in the United States celiac disease.
environmental factors (Lebwohl & Rubio-Tapia, 2021; Ludvigsson et al., 2014; Ludvigsson & Murray, 2019). Gluten is a complex protein found in grains; wheat, rye, and barley (Biesiekierski, 2017). The clinical characteristics of CD are chronic inflammation and atrophy of the small intestine lining disrupting digestion and nutrient absorption (Lebwohl, Sanders, & Green, 2018). The biological symptoms of CD are multisystemic including gastrointestinal (diarrhoea, abdominal pain, nausea, bloating), extraintestinal (weight loss, anaemia, lethargy), neurological (cerebellar ataxia, headaches), dermatological (dermatitis herpetiformis) plus an increased chance of developing additional autoimmune conditions (type 1 diabetes, thyroid disease) (Caio et al., 2019; Jericho, Sansotta, & Guandalini, 2017; Lebwohl et al., 2018; Ludvigsson et al., 2014). Clinical diagnosis of CD in the UK requires serological and intestinal biopsy testing (Rej & Sanders, 2021).

Coeliac disease can present at any age though diagnosis can take several years making the age of onset unclear (Gray & Papanicolas, 2010; NHS, 2016; Rej & Sanders, 2021). A higher prevalence of CD is reported in families with first degree relatives diagnosed with CD, consistent with associated genetic factors however, while the genetic presence is necessary for disease development it does not determine development of CD with environmental factors a strongly suggested influence (Lebwohl et al., 2018; Ludvigsson & Murray, 2019; Lundin & Wijmenga, 2015). The reported prevalence of CD is almost twice as high in women compared to men, but screening research suggests an equal balance indicating gender health behavioural responses as a potential cause for the disparity (Ludvigsson & Murray, 2019; West, Fleming, Tata, Card, & Crooks, 2014). Globally the incidence of CD is increasing with
approximately one in a 100 people in the UK diagnosed with CD and many more likely to remain undiagnosed (Lebwohl & Rubio-Tapia, 2021; Taylor et al., 2021; West et al., 2014). The treatment for CD management is a lifelong strict gluten-free diet, as currently no identified cure is available, which for 80 per cent of people, successfully resolves most of the associated physical symptoms (Caio et al., 2019; Lebwohl et al., 2018; Rej & Sanders, 2021). In the UK gluten-free staple food products such as bread and flour were formerly available through prescription, however in 2020 availability of prescribed gluten-free food varies across the nations and between NHS clinical commissioning groups (Hanci & Jeanes, 2018).

Maintaining a gluten-free diet creates a high treatment burden for people with CD (Shah et al., 2014). Grains form a staple ingredient found in many common foods for example pasta, bread, sauces, and pastries. The addition of gluten in food products is widespread including less apparent food products such as ice-cream, salad dressings, seasonings, soy sauce, chocolate, stock, sausages, processed meat, seitan (meat substitute) and many everyday products including toothpaste and medication (Biesiekierski, 2017; Flamez, Clark, & Sheperis, 2014). Maintaining a gluten-free diet includes avoiding consuming food cross contaminated with gluten.

Cross contamination\(^2\) occurs when gluten protein is transferred, directly or indirectly, onto a food product. Even if removed, for example gluten containing bread from a plate, traces of gluten remain making it unsafe for a person with

\(^2\) In America the term 'cross-contact' refers to the direct or indirect transfer of gluten protein and 'cross contamination' describes food exposure to bacteria.
CD to consume. A tiny amount of gluten can make a person with CD unwell, less than a crumb, gluten protein is invisible to the human eye making it difficult to identify whether food has been cross contaminated. Food to food is a direct form of cross contamination while object to food, for example cooking utensil stirring gluten pasta used to stir gluten-free pasta, and skin to food for example handling gluten bread then touching gluten-free bread are indirect sources. Cross contamination can occur in commercial food processing for example oats are naturally gluten-free, but become unsafe for consumption when processed in the same environment with other cereals (Black & Orfila, 2011). Food preparation, commercial and domestic, are sources of potential gluten cross contamination for example using the same cooking oil to cook gluten and gluten-free food or the same toaster (Black & Orfila, 2011). The avoidance of gluten in everyday life presents challenges due to its widespread and often unexpected presence. Although maintaining a gluten-free diet often successfully alleviates physical symptoms this does not alleviate the psychological and social challenges experienced which are potentially the cause of distress (Bacigalupe & Plöcha, 2015; Elfström, Sundström, & Ludvigsson, 2014; Houbre, Costantini, Pouchot, Tarquinio, & Muller, 2018; Möller et al., 2021). The increasing prevalence, familial link and dietary based treatment make it imperative to understand the family experience of living with CD to enable the provision of appropriate support.

### 3.1.1 The Psychosocial Impact of Coeliac Disease

The World Health Organisation (WHO) define health as “a state of complete physical, mental and social well-being and not merely the absence of disease
and infirmity” (World Health Organization, 1948). Psychological factors include emotions, cognitions, and behaviour. These factors impact the response to an illness at all stages from the illness onset to adaptation and ongoing outcomes. This response is illustrated in adults with CD who describe a process of change through a narrative of the journey from pre-to-post diagnosis (Rose & Howard, 2014). Psychosocial symptoms are often described as ‘invisible symptoms’ the ones others are unable to see and sometimes difficult for people to express verbally. The studies discussed in this section 2.1, have employed a variety of self-report questionnaires measuring psychological constructs and not clinical assessments. A key limitation is that, although clinical levels, and below, of depression and anxiety are reported, it is unclear if participants were receiving any therapeutic or pharmacological support for these. The intertwining of psychological and social factors presents challenges in determining underlying causal factors. These psychological and social factors need to be considered together as they interact.

The interrelatedness of individual psychological factors with the surrounding social factors are defined as psychosocial factors. Rose & Howard, (2014) proposed a theoretical, living with CD psychosocial model. At the centre of the model is a ‘changed identity’ created by the four interacting surrounding categories discussed next. First, the ‘social invisibility’ category is grounded on the invisibility of a gluten-free diet socially, of the social anxiety. Secondly, ‘living with widespread ignorance’ based on the lack of public awareness of CD and the need to constantly educate others about CD. Thirdly, ‘grief and accepting the trade-off’ grounded on the loss of health through CD diagnosis and the consequence of the requirement of dietary restriction. The fourth category,
‘creating a coeliac community’, grounded on the dislike of feeling different from the normal community. Together these categories depict the psychosocial impact on people diagnosed with CD providing an insight but only from the perspective of the person with the condition thus excluding family members. The model is possibly outdated as data informing the model were collected in 2009 and since then societal changes have occurred with increased availability gluten-free foods and wider array of diets. However, the model does provide a good starting point to understand living with CD.

3.1.2 Emotional Impact of Coeliac Disease

A recurrent pattern of the negative emotional effect of living with CD has been reported in many studies (Rose & Howard, 2014; Taylor, Dickson-Swift, & Anderson, 2013; Zingone et al., 2015). Compared to healthy populations depression and anxiety are higher in adults with CD at both pre-and post-diagnosis (Sainsbury & Marques, 2018). For some adhering to a gluten-free diet has reduced depression suggesting gastrointestinal symptoms are related (Zingone et al., 2015). However the relationship is inconclusive with depression and anxiety reported in adults with asymptomatic CD suggesting the underlying physical symptoms are not the potential trigger (Sainsbury & Marques, 2018). Adherence to a gluten-free diet is not indicated as a factor but depression and anxiety may affect dietary adherence (Ford, Howard, & Oyebode, 2012). These studies present mixed results, with the relationship between CD, depression and anxiety ambiguous as other possible mediating factors are not explored. The assumption is that the causal factor is CD when other social factors could be the cause.
Social factors in CD are associated with emotional impacts. Social factors are related to family, cultural and occupational relationships, support, and identity, these are an important concern in health as they shape health behaviour and outcomes (Haslam et al., 2018). In people with CD a significant impact on social activities with family, friends and colleagues is reported illustrating the effect on social factors (Lee, Ng, Diamond, Ciaccio, & Green, 2012). To manage the stressors many people, adopt avoidance behaviours through the reduction of social activities outside the home environment (Rose & Howard, 2014).

Increased levels of stress are experienced in CD with the fear of gluten contamination in the home and external environments (Almagro et al., 2018). In addition to this, stress can be triggered through the perceived burden on others (Houbre et al., 2018). However, avoidance behaviours can be counterproductive with social isolation and loneliness reported indicating stress as a factor in the role of depression in CD (Stone, Storey, & Hughes, 2012). This potentially could impact the socialisation of families, having psychosocial implications for all family members.

Stigma, a devalued social identity, can challenge health by placing a perceived stressor on people (Major & O’Brien, 2005). Stress triggers biological and psychosocial responses (Morey, Boggero, Scott, & Segerstrom, 2015). In CD a stress response can be triggered through the perceived stigma of CD (Houbre et al., 2018). Stigma exists in the relationship between the attribute or characteristic and an audience in a specific context (Goffman, 1963). Stigma “conveys a social identity that is devalued in a particular social context” (Crocker, Major, & Steele, 1998, p.505). Controllability and
visibility/concealability influence the subjective experience of stigma. Controllable stigma is where people have chosen a devalued social identity such as smoking, whereas uncontrollable stigmas are when people have no choice such as illness. Visible stigmas are where a person’s physical characteristics, such as age, physical disability, and gender, are apparent to others influencing how others perceive and interact with a person. For example, in healthcare gender influences treatment received with women having poorer outcomes compared to men (Mauvais-Jarvis et al., 2020). Visible stigmas are difficult to conceal whereas some stigmas, for example illness can be concealed. Goffman (1963) describes those who do not possess stigma as ‘normals’, suggesting a continuum between stigma and normal. For adults with CD a stigma is suggested around perceptions of a gluten-free diet as ‘abnormal’ with research reporting social invisibility at events causing isolation (Rose & Howard, 2014). Stigmatisation surrounding a gluten-free diet was also reported in children and young people with CD (Bongiovanni, Clark, Garnett, Wojcicki, & Heyman, 2010; White, Bannerman, & Gillett, 2016).

These studies indicate that a gluten-free diet conveys an ‘abnormal’ diet, a deviation from the norm, a devalued social identity. Additionally, the symptoms of CD could be perceived as stigmatising due to the gastrointestinal nature (Dibley, Norton, & Whitehead, 2018). Perceived stigma could impact on family activities as well as the health of all family members therefore important to understand whether family members of people with CD perceive CD related stigma as unclear.
3.1.3 Quality of Life in Coeliac Disease

Quality of life often includes emotional and social components so is used as a psychosocial measure. The construct of quality of life is multidimensional including psychological, social, economic and biological dimensions (Fallowfield, 1990). The term quality of life is familiar in the UK, although its subjective and multidimensional nature make it difficult to define due to the breadth of possible definitions (Joyce, McGee, & O’Boyle, 1999). There exists no consensus as to what quality of life is, thus presenting challenges in assessing evidence. In clinical trials into health-related conditions, quality of life is a necessary measure, often included as a secondary outcome (Fayers & Machin, 2015). Within health research the measures used for quality of life differ making it difficult to generalise across studies. Additionally, terms to describe quality of life measures differ with multiple definitions within the literature (Karimi & Brazier, 2016). Awareness of these is essential to aid understanding of research exploring the psychological impact, treatment, and diagnosis in people with CD. Acknowledgement of these differences is crucial, as from a health perspective the emphasis could be functional factors thus excluding social factors for example the impact of a relationship breakdown on health. Whilst knowing the functional effect of CD is worthwhile, how people define and perceive their quality of life is vital. However, defined measurements of quality of life that impose researchers value judgements of patients potentially miss valuable details. Quality of life is an individual’s subjective perception of value in their own life in social, psychological and physical dimensions (Pinto, Fumincelli, Mazzo, Caldeira, & Martins, 2017).
Consequently, it is important to consider quality of life as associated with psychosocial factors.

Compared to healthy populations people with CD report a reduced quality of life (Sainsbury, Mullan, & Sharpe, 2015). However, the relationship between quality of life and a gluten-free diet is unclear, with some studies reporting poor adherence and low quality of life and others high adherence and low quality of life (Sainsbury & Marques, 2018; Zingone et al., 2015). Adopting a gluten-free diet is a major lifestyle change that entails dietary education and behaviour change. Many adults find dietary changes challenging. Adults diagnosed during childhood with CD report better quality of life in contrast to those with a CD diagnosis received in adulthood (Lee et al., 2012). Reasons for this are unclear, although during childhood parents would manage a gluten-free diet and provide support to manage CD whereas diagnosis in adulthood often entails sole responsibility for the condition management and educating family members. This has important implications for early diagnosis and treatment. Yet parents of children with CD report a lower quality of life compared to parents without children with CD (De Lorenzo et al., 2012). These studies strongly indicate that a gluten-free diet impacts quality of life highlighting the role of how family members can support a gluten-free diet but also how family members need support.

### 3.2 The Role of Family in Health

People with CD often live with families, so this section presents why it is important to understand the experience of family members. By default,
everyone holds a subjective idea of family, therefore it is important to discuss family to address commonly held assumptions. This thesis does not aim to provide a definitive definition of ‘family’, instead to provide an overview of the complexity of ‘family’, and of family in the context of long-term health conditions. Often the disciplines of health, psychology, and sociology approach family in the context of illness in terms of individuals rather than family groups. In this section firstly, the concept of family is explored followed by a discussion on the social and psychological functions of family. Next the importance of family members in long-term health conditions are presented before concluding with the inclusion of family in the self-management of health conditions.

3.2.1 What is a Family?
Family can be described as a social construct, a fluid complex multifaceted social phenomenon that adjusts across the life course of its members. The temporal changes, complexity in family structure and meaning are demonstrated through the many definitions of ‘family’ reflecting the societal period (Olson, Baiocchi-Wagner, Kratzer, & Symonds LeBlanc, 2012 p5; Turner & West, 2015,p10). How family is defined depends on the focus of interest including structural and cultural factors. Family structures have historically evolved in the UK from a traditional heteronormative model, defined structurally as a male and a female with dependent child(ren) who resided together as a social unit, to a myriad of diverse contemporary family forms that encompass same-sex couples and single parents (Turner & West, 2015). In 2021 families with no dependent children were the most common in the UK reflecting the decline in UK family size also the number of adult children living with parents
increased from 2018 and cohabiting couples (Clark, 2022; Yates & Warde, 2017). The traditional homogenous heteronormative representation of family is rejected as no longer representative of UK families. The Office for National Statistics (ONS) (2022) define family as ‘a married, civil partnered or cohabiting couple with or without children, or a lone parent with at least one child who live at the same address. Children may be dependent or non-dependent’. The ONS definition comprises unmarried couples, same sex couples, adoptive parents, and childless couples thus reflective of the diverse family structures in the UK. The terms ‘childless’ and ‘childfree’ imply a deficit model, with having children as the default norm. The broadness of family structures presents challenges for those researching families as no single definition applies. Society is a critical factor, having an influencing role on family with culturally specific societal family norms and formal official definitive norms restricted to birth, marriage, adoption and residence (Tillman & Nam, 2008). Interestingly research asking children to define family found that children are considered as a necessary part (Morrow, 2018, p273). Children’s definitions are perhaps due to the influence of cultural societal norms of families including children and a reflection of their self-identity of belonging to a family group. This highlights how perceptions of family differ according to life stage, as by contrast an adult couple will often identify themselves as a family (Braithwaite et al., 2010).

Structural family definitions can emphasise the familial biological commonality and recognise the social identity, but the dynamic fluid diverse psychological and social function of family, doing family, is absent. Within a family the members function both individually and as a group. Approaching family from the
perspective of practices captures the change to understand family by what they do (Morgan, 1996). Carol Smart cites the work of Janet Finch and David Morgan “most studies on family life focus almost exclusively on households or parent/child” (2007, p.33). Smart (2007), proposed the Theory of Personal Life in recognition of the shift from traditional family life to one that considers meaningful relationships, not family structures. The focus is on ‘what families do’, explored through multiple theoretical concepts; relationality, embeddedness, biography, memory, and imaginary (Smart, 2007). These concepts, although interlinked, are able to be drawn upon individually. The aim of this thesis is to explore the lived experience of family so the emphasis is on what families do, not family structure. Based on the many ways family can be formed and the emphasis on family practices meaning ultimately ‘family’ is defined by its individual members, without biological and legal restrictions, thus creating a unique social group (Ganong & Coleman, 2014; Smart, 2007). In this research the concept of family is a self-defined group of two or more individuals, one who is an adult, who consider themselves a family with the focus on what they do.

3.2.2 The Social and Psychological Role of Family

Families are universally found dynamic social groups adapting to daily change over the life course. A family is interactive creating their own daily routine behaviours and rituals performed by its members, such as celebratory religious events, for example Christmas. Social norms influence family behaviour, these are defined as:
Rules and standards that are understood by members of a group that guide and/or constrain social behaviour without the forces of law. These norms emerge out of interaction with others; they may or may not be stated explicitly, and any sanctions for deviating from them come from social networks, not the legal system. (Cialdini & Trost, 1998, p152)

Social factors such as culture, gender, household income and family environment influence family behaviours (The Health Foundation, 2018). Much of family life is private in the home environment characterised by the mundane events of life. Living in a shared environment, the stress, behaviour, health, and mood of daily life affect all family members (Umberson & Montez, 2010). The family home provides a shared safe space for family members, although for some families homes are unsafe when harms are encountered. Within families, members have a close relationship embedded with strong emotions including love and trust (Smart, 2007). A function, purpose and quality of social relationships concern social support. Studies have shown that married and cohabiting people live longer than single people, an indication of the benefits of social support (Kiecolt-Glaser & Wilson, 2017). There are different types of social support, these include; instrumental by aiding with a problem or providing resources; information giving advice and providing; emotional providing reassurance (Haslam et al., 2018). A distinction exists between perceived available support and actual received social support. Perceived social support is often prospective for example ‘there is someone at home who can help me’. Whereas actual social support is always retrospective based on past experience, for example ‘my partner cooked dinner when I worked late’. Social
support gender differences are argued to exist with women providing more emotional support to men and women (Albanese et al., 2018). Social support is a behavioural coping strategy that can provide a buffer from stressful life events (Deek et al., 2016). Family can take many forms, yet most are underpinned through intimate relationships and commitment. Relationships influence intimate partners wellbeing and health (physical and mental) both positively and negatively as well as that of any children within the family (Kiecolt-Glaser & Wilson, 2017; Lavner, Karney, & Bradbury, 2016). Distressed marital relationships are associated with depression forming a bidirectional relationship with poorer quality relationship linked to depression, and distress in relationship linked to depression (Kiecolt-Glaser & Wilson, 2017). Depression is associated with poorer health outcomes due to the physiological stress response increasing health risk (Sainsbury & Marques, 2018). Health behaviours are associated with depression, such as poor diet, exercise, and sleep, are all evidenced as having a detrimental impact on health outcomes (Davis, Campbell, Hildon, Hobbs, & Michie, 2015). Economic pressures can create problems within relationships causing chronic stress increasing partners response to specific events (Lavner et al., 2016). Family relationships can positively influence members wellbeing and health. Intimate partners are often confided in at times of stress with greater life satisfaction reported by those in relationships compared to those who are single (Umberson & Montez, 2010). Partners can influence health outcomes by encouraging positive health attitudes and behaviour (Arden-Close & McGrath, 2017). Family plays a significant role in the health and wellbeing of its members, with this interaction determining health outcomes.
3.2.3 Family and Long-Term Health Conditions

The diagnosis of a long-term condition requires adjustment to illness behaviours, lifestyle, any loss of function, and social changes, conceptualised as stressors (Årestedt, Benzein, & Persson, 2015). Long-term conditions can be seen as a stressor in three ways; coping with the diagnosis, coping with the crisis of a long-term condition and adjustment to the long-term condition (Rolland, 1987). Coping is a dynamic process balancing situational and personal factors that unfold over time and not a one-off response. A failure to adjust and cope to a long-term condition appropriately can have a major impact on quality of life for the person and their family members (Whitehead, Jacob, Towell, Abu-qamar, & Cole-Heath, 2018).

Crisis theory of physical illness examines how people cope when challenged with an illness diagnosis representing the disruption to a person’s personal and social identity (Moos & Schaefer, 1984). A physical illness is argued to create changes to identity, location, role, and social support, conceptualised as a crisis. Once confronted with the crisis of an illness there are three process that constitute the coping process; 1) cognitive appraisal of the illness for example, the seriousness of condition, how long will it last, past experience, social influences and health literacy affect the appraisal. 2) adaptive tasks, three are illness specific tasks; dealing with symptoms; relationships with healthcare staff; and dealing with treatment. Four are general tasks, preserving an emotional balance; self-image and maintaining a sense of mastery and control; sustaining relationships with family and friends; and preparing for an uncertain future. 3)
coping skills: appraisal, problem, and emotion focused coping, these are separate coping mechanisms not stages. Appraisal focused coping concerns understanding the illness and accepting or avoiding the reality of the situation. Problem focused coping involves seeking information and support to aid making the situation manageable. Emotion focused coping concerns managing emotions and maintaining equilibrium. Crisis theory assumes people are motivated to maintain a state of equilibrium and normality through an appraisal of the illness and application of adaptive tasks and coping skills that determine adjustment, adaptive or maladaptive to the long-term condition.

Coping is defined as ‘the process of managing stressors that have been appraised as taxing or exceeding a person’s resources. The efforts to manage … environmental and internal demands’ (Lazarus & Launier, 1978). Stress can be understood as a stimulus, such as a demand on the person from their environment, or a response a general psychological/physiological reaction, or as a transaction. A transaction is the combination of a stimulus and response, a process that involves an interaction between the persons appraisal (is this stressful) and the reaction to her/his environment (Lazarus & Folkman, 1984).

The aim of coping is to reduce a stressful environment, to maintain a positive self-image and to continue relationships with others (Lazarus & Folkman, 1984). The experience of stress is subjective. How a person appraises a situation determines the response. For example, if the situation is perceived as having no impact on wellbeing, then it is deemed irrelevant (not stressful), if the situation is perceived as an actual or potential threat (a stressor) a coping strategy can be employed to reduce the threat level (Lazarus & Folkman, 1984). Behavioural coping strategies, especially social support can provide a stress buffer (Lazarus
& Folkman, 1984). The social support of family members can help reduce and alleviate the perceived stress of others. However, the perception of how support is perceived and received may differ between individual family members.

Family incorporates the emotional, behavioural, and cognitive functions of its members within the immediate and the broader environment in which they live. The emotional and behavioural support provided by family members to each other can be positive (supportive, loving) or negative (abusive, stressful) having an important role in determining the adjustment to and coping with long-term health conditions (Martire & Helgeson, 2017; Olson et al., 2012). In the UK about 15 million people have one or more long-term conditions with the number increasing (Pearson-Stuttard, Ezzati, & Gregg, 2019). The National Health Service (NHS) define a long-term condition as “a condition that cannot at present be cured but can be controlled by medication and therapies” which would include CD (NHS, 2020). Coeliac disease requires self-management since most of the time individuals are managing their illness outside of a healthcare context (Eaton, Roberts, & Turner, 2015). The Health Foundation define self-management for people with long-term conditions as involving “caring for their body and managing their illness, adapting everyday activities and roles to their condition and dealing with emotions that arise from having the condition’” (2014). Effective self-management requires the integration of biological, psychological, and social factors (Silvia, 2011). The role of family is important for adaptation to changes in lifestyle to cope with health conditions (Årestedt et al., 2015). A qualitative systematic review exploring the role of a family member in supporting self-management of long-term conditions found families played a vital role in the promotion and support of self-management
(Whitehead et al., 2018). The review included conditions that required medication and informal caring, such as dementia, which are not required for CD. Research has reported the negative impact on the health and wellbeing of partners of people with long-term conditions and children and young people (Boström & Nilsagård, 2016; Culley et al., 2017; Lam, Lehman, Puterman, & DeLongis, 2009). The focus is often on health conditions with physical functional impairments or deteriorating health (Samuel-Hodge, Cene, Corsino, Thomas, & Svetkey, 2013). These studies illustrate the impact of long-term conditions on the wellbeing of partners, but often without indication of the impact on children.

In western societies four to twelve per cent of children and young people live with a parent with a long-term condition (Sieh, Meijer, Oort, Visser-Meily, & Van Der Leij, 2010). A child or young person’s understanding of illness will be based upon their developmental stage and real-life experience (Boote et al., 2016; Morrow, 2018). For the purposes of this study, a child was defined as aged three to eleven years and a young person (adolescent) as twelve to eighteen years. A limitation of many studies is the ‘lumping’ of children and young people together without consideration of developmental stage or age. In many studies, in the case of children, the parent will be interviewed on their behalf, thus the child’s experience is communicated via parents’ interpretation (Cederborg, Hultman, & Magnusson, 2012; Pitchforth et al., 2011). Where children and young people’s views have been collected through interviews their voice is overlooked in the results, with more emphasis placed on parents’ experiences and minimal quotes from children and young people.
included (Pitchforth et al., 2011). The experience of children and young people is important to a full understanding, as many can fear developing the illness, have low self-esteem, depression and somatic complaints (Sieh et al., 2010). These can impact children and young people more than the illness of a parent. Having a parent with a long-term condition can have a negative psychological impact on children with anxiety and depression reported in older children (Pakenham & Cox, 2014). Family meal times have been indicated to provide psychological benefits, thus suggesting these could provide a protective buffering effect for children (Prior & Limbert, 2013). This has implications for families living with CD, as to counteract the potential impact of poor psychological wellbeing the buffering effects of family cohesion during mealtimes could be disrupted due to the underlying treatment of CD (gluten-free diet). The understanding of family’s experiences of living with CD can provide an insight into the lives of children and young people. Therefore, including children and young people’s experiences, not parental interpretations, can provide an insight into living with CD to provide an understanding.

3.2.4 The Role of Family Support in Self-Management of Long-Term Conditions

Long-term conditions place a large burden on the NHS so improved self-management can help reduce demand on NHS resources (Lowry, 2016; Panagioti et al., 2014). Many long-term conditions can be effectively self-managed daily in the home environment where the role of the family is fundamental in supporting self-management (Eaton et al., 2015). People with CD spend most of their time outside of medical care often living with
others, family members. The management of long-term conditions requires behavioural changes (Whitehead et al., 2018). Behaviour is defined as “anything a person does in response to internal or external events. Actions maybe overt (motor or verbal) and directly measurable or, covert (activities not viewable but involving voluntary muscles) and indirectly measurable, behaviours are physical events that occur in the body and are controlled by the brain” (Davis et al., 2015). This is an agreed definition across the disciplines of psychology, sociology, anthropology, and economics. The effective self-management of CD often entails lifestyle change, as diet, including related food processes, involves all the family. For people with CD self-management is essential as treatment involves a life-long gluten-free diet (Ludvigsson et al., 2014). Adherence in healthcare can be defined as the extent to which a patient’s behaviour matches the agreed recommendations from their healthcare professional (Clyne et al., 2009). The underpinning assumption in CD is that adherence to a gluten-free diet will improve patient outcomes (Sainsbury & Marques, 2018). However, these outcomes are reflective of physical symptoms not psychosocial symptoms. The adaption to a gluten-free diet requires dietary modifications that can impinge upon many lifestyle factors (Almagro, Martínez, Ruiz, & González, 2017; Rose & Howard, 2014). In the literature on CD evidence of support provided by family members is sparse.

The traditional approach to healthcare has been from an individual perspective. Increasingly the role family members perform in the care and support of others as well as the health impact this can have on themselves has been acknowledged (Morey et al., 2015; Viana et al., 2013).
Families are influential in the management of long-term conditions (Deek et al., 2016; Martire & Schulz, 2007). The number of family interventions to support a long-term condition is minimal with none known for CD (Ludvigsson et al., 2015; Martire & Helgeson, 2017). A qualitative systematic review on the role of family in supporting the self-management of long-term conditions concluded that family can promote positive health outcomes (Whitehead et al., 2018). The review did not distinguish any participant demographics from the included studies, so it is unclear whether these included child and young person family members nor did it indicate participants’ gender. These are important to include as the views of children and young people are often excluded despite health and wellbeing impacted by long-term conditions in the family (Martire & Helgeson, 2017). Additionally due to differing health behaviours and outcomes the inclusion of gender can promote understanding of family disease management.

### 3.3 The Role of Gender in Health and Family

Within research the terms sex and gender are used interchangeably when describing participants creating confusion as to what demographic is being reported. An example often found in demographic questions, the category ‘gender’ with male and female (sex characteristics) as response options (Hart, 2019). Although sex and gender intersect, clarity in reporting sex and gender is required within research as behaviours and needs differ (Hart, Saperstein, Magliozi, & Westbrook, 2019). Sex refers to the biological attributes of female or male or intersex that not only influence the appearance of
genitals but also the incidence and symptoms of diseases, for example immune response (Mauvais-Jarvis et al., 2020). Gender is socially constructed with gender norms and stereotypes shaping behaviours, roles, and values. Gender refers to the psychological, behavioural, social and cultural norms associated with identifying as a woman or man, masculine or feminine (American Psychological Association, 2015). The term ‘gender’ encompasses a broad diverse range of feminine and masculine expressions therefore is not a binary or static construct. Gender influences a person’s behaviour and relationships throughout their life course (Joy et al., 2021). Within gender are multiple constructs. A brief description is provided here of a few gender definitions. Gender norms are a socially constructed definition that includes the roles and expectations for women and men in a culture (American Psychological Association, 2015). Gender identity is the self-identification of gender, how one perceives themselves an internal sense of gender, this is a fluid not fixed characteristic. Gender expression describes how the cultural norms of gender are embedded including meal choices and behaviour. Gender roles refer to the cultural behavioural norms assumed to women and men. Gender roles and identity shape behaviours which influence health (mental and physical) outcomes (Hart et al., 2019). The complexity and multidimensional nature of gender are acknowledged, however this review focused on gender role norms as these influence everyday behaviours and health at the individual, family, and societal level (Mauvais-Jarvis et al., 2020).
### 3.3.1 Behavioural Gender Differences

Health seeking behaviour involves biological, psychological, and social factors. Differences are observed between the health seeking behaviours of women and men. Women are more likely to report long-term health conditions and symptoms compared to men, although both experience similar diseases (Regitz-Zagrosek, 2012). Encouraging men to access healthcare is a current health concern with research and campaigns to identify and address the underlying reasons why men do not access healthcare (Wilkins, 2014). Men have a higher suicide rate with the risk greatest during middle age yet few seek help for mental health (Mackenzie, Visperas, Ogrodniczuk, Oliffe, & Nurmi, 2019). More women are diagnosed with CD than men yet screening research found men and women were both as likely to develop CD, suggesting health-seeking behaviour as an explanation (Ludvigsson & Murray, 2019). For men psychosocial barriers, the conformity to gendered roles, are preventing help seeking behaviour (Fish, Prichard, Ettridge, Grunfeld, & Wilson, 2015). Understanding how to support men overcome these barriers to healthcare is important. Research into CD has a strong bias to women due to the increased numbers diagnosed with little evidence on the experience of men.

In the UK traditional gender role norms have existed within the home environment. Men were the breadwinners while women were responsible for household chores and caring for the family. From 2012 to 2017 social attitudes towards these gendered roles has shifted significantly with 75 per cent of people aged 18 to 34 years disagreeing that a woman’s role is to look after the home and family, and a man’s to provide an income (Phillips, Curtice, Phillips, &
Perry, 2018). However, these attitudes are not reflective across British society with people aged over 65 years, and people without formal qualifications disagreeing arguably signifying generational differences and the educational influence on attitudes (Phillips et al., 2018). The change in reported attitudes does not necessarily reflect changes in behaviour. Women report carrying out more household chores than men and low take-up by men of shared parental leave (Working Families, 2019). But these findings relate to families with two adults and children, so are not reflective of childless or adult and child families, although they highlight how attitudes towards gendered roles have changed but not behaviour. An awareness of this disparity is essential in aiding the understanding of psychosocial factors of why women and men adopt different health related behaviours when living with CD.

Distinguishing gender is necessary to assist understanding of coping and living with long-term conditions, as behavioural responses are proposed to differ between genders (Albanese et al., 2018; Fish et al., 2015; Friedemann, Buckwalter, & Emerita, 2014). The adoption of gendered household roles is argued to be a coping mechanism for women experiencing social exclusion (Aydin, Graupmann, Fischer, Frey, & Fischer, 2011). A review of studies of spousal support in type-2 diabetes reported gender differences in support (Albanese et al., 2018). Dietary adherence for men with type-2 diabetes for many is facilitated through women spouses’ support in procuring and preparing meals denoting a traditional gendered role behaviour performed within the home. This dietary support is not reciprocal for women, with men reported to undermine dietary adherence (Albanese et al., 2018). Some women report family and friends as providers of social support, not male partners, though it
should be noted that women often respond negatively to health management support offered by husbands (Albanese et al., 2018). The persistence of gendered roles is a possible explanation for differences in support, as some men do not perceive caregiving as their responsibility (Friedemann et al., 2014). The studies only included heterosexual couples, so understanding gendered roles in social support and dietary adherence in family groups with children and non-heterosexual couples is unknown.

Spousal support can be beneficial for dietary adherence which is important when maintaining a gluten-free diet. The perspective of people with CD is known, but a paucity of their partners (Ford et al., 2012). An understanding of behaviour in relation to gender offers the potential to identify the barriers and facilitators to provide gender relevant support. Women are often responsible for dietary management, where it is observed that women will cater for the dietary preferences of other family members (Ogden, 2010). This behaviour is reported in women with CD, where maintaining a gluten-free home environment is challenging with gender differences in management strategies (Zingone et al., 2015). Women with CD often cook a gluten containing meal for the whole family and a gluten-free meal for themselves, in contrast to men with CD who cook a gluten-free meal for the whole family (Hallert et al., 2003). This food-related behaviour is also found when women want to lose weight and will provide a different meal for family members suggesting this is related to gender role behaviour and not CD (Ogden, 2010). This illustrates how self-management differs between genders with the underpinning reason unclear.
3.3.2 Social and Emotional Gender Differences

For women a coping mechanism when experiencing social exclusion is the adoption of traditional gendered roles conveying the interactive nature of social and psychological factors (Aydin et al., 2011). Over time women with CD report more social difficulties than men, often avoiding social events (Zingone et al., 2015). Some women with CD avoid going out for meals and coffee with friends and relatives (Sverker et al., 2009). Women often seek social support from friends, so avoidance can lead to an absence of emotion-based support from friends triggering negative emotions including loss of self-confidence. Women with CD report loneliness and worry, and social isolation (Roos, Hellström, Hallert, & Wilhelmsson, 2013). For women with CD concerns regarding social life are higher compared men with CD (Hallert et al., 2003). Social relationships are important for wellbeing in both adult women and men, with family relationships indicated to be more important for men (Cable, Bartley, Chandola, & Sacker, 2013). Although recognising that social relationships are important, how this is experienced by family members is uncertain.

Gender influences the ways in which people cope with disease, with men reporting lower quality of life when experiencing long-term conditions (Flurey et al., 2016). Intentional non-compliance to a gluten-free diet in social contexts is reported more by men with CD compared to women providing a possible explanation as to why men report less social isolation (Lee et al., 2012). This could also explain why men with CD report a higher quality of life than women (Norström, Lindholm, Sandström, Nordyke, & Ivarsson, 2011). In contrast gender variances in quality of life are not found in all research (Ford et
A limitation of the research is it captures a snapshot that is perhaps unreflective of quality of life over a period and how quality of life is defined and measured varies between studies so not always comparable. An often underpinning assumption is perception of quality of life for women and men is the same however how men and women manage health differs as evidenced through health-seeking behaviours and self-management (Caroli & Weber-Baghdiguian, 2016; Regitz-Zagrosek, 2012). In CD the focus has been on women’s experience with little known about the experience of men with CD or as partners.

The emotional response to CD is reported to vary between genders with women reporting increased levels of depression and anxiety compared to men (Almagro, et al., 2018; Ford et al., 2012). Greater restrictions in daily life and distress are reported by more women than men with CD, with women expressing loneliness and worry (Hallert et al., 2003; Roos et al., 2013). The evidence suggests the psychosocial burden of CD is greater for women compared to men, but the direction of the relationship is unclear and is perhaps a result of the interaction of social and psychological factors. However, the differences could be due to gendered expectations with men wanting to be ‘masculine’ and not disclose illness, as men are less inclined to seek help for psychological health (Mckenzie, Jenkin, & Collings, 2016), making it uncertain whether men with CD do experience decreased psychological health or employ different coping mechanisms to women. Studies reporting the experience of men is limited highlighting the need for understanding the impact on all family members and not solely the person with the illness. Many of the studies
exploring CD are unclear about reported participant sex and gender characteristics.

3.4 Food and Eating

In this section the literature on food and eating are discussed as they are a large feature of family life and the treatment for CD. An overview of the literature on food introduces the section. The consumption of food is a necessary behaviour to sustain life forming a fundamental part of everyday life. Food is taken for granted and often overlooked until something threatens the provision such as affordability, availability, or safety. In the UK, 2021, a broad variety of foods are stocked all year with a vast array of eateries offering global cuisines. Food in the UK has a large social presence including television programmes, social media, apps, and public health campaigns. The consumption of food provides a social structure for the day through mealtimes, breakfast, lunch, and dinner. Food and eating behaviours are complex phenomena influenced by multiple factors. The focus of much food and eating literature concerns food related pathologies and healthy eating, particularly obesity (Chamberlain, 2004). Gluten is the causal factor for CD symptoms necessitating a specific gluten-free diet (treatment) consequently shaping food and eating behaviours. The emphasis of food and consumption in this section is firstly on the meaning of food from biological, psychological, and social perspectives recognising these are interrelated. Secondly, behaviours associated with food and eating are presented in an effort to provide a deeper insight to show food is far greater than its physical values arguably possessing stronger psychosocial values.
3.4.1 *Food and Eating from a Biological Perspective*

For most people essential dietary nutrients to sustain life are acquired through the direct consumption of food. The behaviour of consuming food (eating) is a form of embodiment: what people consume is literally embodied triggering physical sensations, responses, and changes. Biological and physical processes are involved throughout the eating process, from hunger sensations to defecation. The body releases the hormone ghrelin to signal hunger stimulating appetite, and leptin to signal satiety. Together the hormones maintain a bodily energy homeostasis\(^3\) (Adamska-Patruno et al., 2018). The behaviour of eating is physical, the moving of hands to transport food to the mouth, then chewing and swallowing food. Foods consumed can prompt physical responses such as belching, vomiting, abdominal pain, and flatulence. From a biological perspective eating is continued until a sense of satiety, the release of leptin, is experienced. However, people can and do continue to consume food beyond satiety indicating that the behaviour of food consumption is not solely for a biological purpose. People also eat when not feeling hungry demonstrating that consumption is not solely driven through biological signals but also psychological and social factors.

Foods consumed can promote or harm health with a healthy diet helping to protect against many noncommunicable diseases (World Health Organization., 2019). The behaviour of eating differs for people and is shaped through individual beliefs and specific dietary medical requirements, these include life threatening allergic reactions and diabetes (Kokkoris & Stavrova, 2021). In the

\(^3\) The sensations of appetite and satiety are complex biological interactions these are beyond the scope of the thesis.
case of CD, diets must exclude gluten so a person with CD would define healthy eating as a gluten-free diet. For people without a medical dietary condition knowing what food should be consumed for healthy diet does not determine practice (Kokkoris & Stavrova, 2021). Again, this demonstrates how food and eating are more complex than a biological drive.

The senses, olfactory, visual, and gustatory, influence what foods are consumed, providing cues of safety. Food odour is an important characteristic stimulating appetite (for example, the aroma of fresh bread) and influencing satiety (chemicals released during chewing food) as well as protective detecting spoiled food (offensive odour) thus influencing how it is perceived (safe or unsafe) by the consumer (Splane, Rowland, & Mitra, 2020). The visual appearance of food also influences consumption providing cues of texture and taste with inappropriately coloured food rejected for example green (rancid) meat and blue (mouldy) bread (Hutchings, 2011). The physical appearance of food is associated with consumption, for example if a meal looks appealing people are more likely to consume it (Hutchings, 2011). Food taste, a chemical gustatory sensation, is an important determining factor of consumption. Highly sensitive taste receptors located in the mouth detect sweet, salty, umami, bitter and sour stimuli (foods) (Splane et al., 2020). Taste is a subjective experience and can be influenced by negative experiences of food consumption, although adverse experiences do not always determine future aversion (Splane et al., 2020). Taste receptors detect harmful food for example spoiled food, however, taste receptors are not always able to detect food ingredients as evidenced in accidental gluten consumption where unknown until physical symptoms present (Satherley, Lerigo, Higgs, & Howard, 2022). Taste is influenced through social
factors with food perceived as tasting better when eating with others (Nakata & Kawai, 2017). The olfactory, visual, and gustatory senses are separate but intertwined and influenced by psychological and social factors subjectively influencing food choices.

3.4.2 Food and Eating from a Psychological Perspective

The psychology of food and eating is complex, incorporating multiple factors from emotions to the influence of consumer marketing (Ogden, 2010). Food related behaviours are shaped by individual cognitions, attitudes, and beliefs (Arbit, Ruby, & Rozin, 2017; Splane et al., 2020). Food choices are shaped by a person’s beliefs as illustrated in the wealth of personal dietary practices from omnivore to raw food. Many diets are based on individual beliefs such as religious and can also be driven by health belief concerns such as weight loss to reduce risk of developing diabetes to improve health status (Sobal, Bisogni, & Jastran, 2014). A dietary health choice differs from a medical dietary health need when a person must avoid consumption of a specific food or food group for medical reasons due to adverse effects (Wearne, 2017). A dietary health choice is motivated by a person’s belief whereas a health need requires a change in food choice belief. These differ from food preferences, like and dislikes, which are driven by subjective taste. Food choice is complex with social meanings influencing together with psychological factors.

Food, eating, and emotion have strong associations. A contemporary term ‘hangry’ is used to describe a person appearing angry due to hunger sensations (MacCormack & Lindquist, 2019). Emotion can be a driver in food consumption prompting seeking particular food as a source of comfort when experiencing distress or illness using food as an emotional self-management tool (Spence,
In contrast appetite loss is experienced by some people when distressed whereas over consumption of food can trigger emotions of regret due to physical discomfort or cognitive dissonance in response to consuming an avoided food during a weight loss diet (Splane et al., 2020). Emotional meanings are also attached to food such as disgust associated with a western aversion to consuming insects and positive emotions to a family favourite meal, or home-made food (Henshaw, 2013). The relationship between food, eating, and emotion is a developing area of research with serotonin argued to be produced in the gut thus stimulating positive emotion. The appearance of food is argued to enhance mood demonstrating the dynamic bidirectional relationship between food and emotion (Splane et al., 2020). Positive and negative emotions are embedded in food choice, taste, and meaning, illustrating how food is more than nutrition with much more going on under the surface, with meanings embedded in food and eating.

### 3.4.3 Food and Eating from a Social Perspective

Cultural and social meanings are embedded within food shaping behaviours within and outside the home. For many contemporary families dining in restaurants and other eateries is an everyday social norm in contrast to 20 years ago when eating out was perceived as a treat for special occasions (Lupton, 1996). Family behaviour in public is constrained by social norms, these are “a set of values and behaviours that govern behaviour in groups and societies’, maintaining social cohesion” (Harrison, 2003). When dining out a dispute with waiters can spoil the ambiance and create a tense dining experience rather than relaxed. Within the home food behaviours occur in a shared communal space, kitchen, and dining areas. Traditionally in family
homes women were seen as responsible for food, feeding the family, with men as the ‘bread winners’ (income providers) (Murcott, 2019). Recent studies indicate in contemporary families’ women are still perceived as responsible for food with men indicated to have increased involvement such as cooking a barbecue, although both women and men are responsible for contributing to household income (Warde, Paddock, & Whilians, 2020b). The change of women’s home social role, going to work, is portrayed negatively as a loss of food skills, omitting any change in the social role of men have an increased role within the home kitchen (Murcott, 2019). Some food types are perceived as gendered with sweet and lighter foods as feminine and heavy foods and meat seen as masculine (Lupton, 1996). Some men perceive vegetarianism as a threat to their masculinity (Love & Sulikowski, 2018). Food also represents cultural norms with birthday cakes and roast dinners maintained throughout the years (Murcott, 2019). Social stigma is perceived through certain diets that deviate from the social norm for example veganism (Major & O’Brien, 2005).

A meal is a central concept to the sociology of food and eating (Yates & Warde, 2017). “Food brings people together and eating is deeply engrained into social life” (Rozin, 2005). The majority of meals in the UK are consumed with family members, although weekday meals are not always consumed together due to conflicting employment and education commitments (Yates & Warde, 2017). During weekdays most meals, breakfast, and dinner, are consumed at home with lunch eaten out either purchased or brought from home (Working Families, 2019). Consuming food is often a social experience shared with friends or family in home and external environments, sometimes marking special occasions such as weddings, religious events, birthdays, and personal
achievements (Dunbar, 2017). A meal provides the opportunity for social communication. Food provides a vehicle for social bonding and opportunity for social interaction, the dinner table where a family sit to share experiences of the day while eating the family meal (Middleton, Golley, Patterson, Le Moal, & Coveney, 2020). Eating together as a family is argued to have health benefits although mealtimes can be a source of conflict (Murcott, 2019). The sharing of food is seen as an intimacy, a method to establish closeness (Dunbar, 2017). When people sit and eat together more food is consumed having a direct social influence. Social learning occurs during eating with children and young people more likely to eat foods eaten by family and friends (Fruh, Fulkerson, Mulekar, Ann Kendrick, & Clanton, 2011). Adults will consume disliked food to avoid offending others illustrating the social role and performance of food in maintaining relationships (Cruwys, Bevelander, & Hermans, 2014).

3.4.4 Food Behaviours: Planning, Shopping, Cooking, and Consumption

Food and eating contain interconnected biological, psychological, and social properties. In the literature often food and eating are explored from an individual perspective, yet family and food are synonymous stressing the need to consider these together. In the following section food behaviours from food choice to eating are discussed considering the psychosocial factors.

In the UK gender role differences are reported in the context of food related practices. Traditionally in the UK, women were responsible for household management, including the family diet catering for the preferences of partners and children (Murcott, 2019). This gendered social role is still evident at the time of writing as women are reported as being primarily responsible for grocery
shopping (Dhuria et al., 2021). Research by Warde et al. (2020b) reported women performing more food behaviours, meal planning, shopping, preparation and clearing away than men. Notably a very gradual shift between 1995 and 2015 is observed with men performing more food related behaviours, yet this still not equitable.

Arbit et al. (2017) describe food choices as ‘laden with meanings that figure importantly in humanity’s symbolic, social, ecological, and economic worlds’ capturing the many influences on food choice decisions. Conscious food choices are shaped by social and personal identities becoming habitual with food choice arguably influencing identity. A gluten-free diet determines food choices thereby constructing personal and social identity. The development of a meaning of food in life questionnaire, based on qualitative interviews, identified five key factors; moral, sacred, social, health, aesthetics, demonstrating that food does not solely hold health and pathological meanings (Sobal et al., 2014).

**Cooking and meals**

Cooking food is reported as a socially important activity (Daniels, Glorieux, Minnen, & van Tienoven, 2012). Women interestingly finding cooking more pleasurable when living alone, in contrast to men who gain more pleasure when cooking for a partner and children (Daniels et al., 2012). These findings suggest that for women, catering for the preferences of others is burdensome removing the pleasure of cooking conflicting with qualitative findings reporting women as getting more pleasure from cooking for a family (Daniels et al., 2012). Women are reported to do more everyday cooking than men, whereas men are more likely to cook on social occasions (Yates & Warde, 2017). Men will often
barbecue, a social bonding meal comparable with a roast, frequently cooking with a beer, described as a ‘familiar masculine marker of sociality’ (Metcalfe, Dryden, Johnson, Owen, & Shipton, 2009). Consuming beer is used as a tool to express masculinity and social group identity (Fugitt & Ham, 2018). Beer consumption is linked with Western culture and is associated with social activity, constructing a masculine identity (Emslie, Hunt, & Lyons, 2013). Men are more likely than women to have meals prepared for them including buying meals when out (Yates & Warde, 2017) however the unpinning reason(s) why are unknown. The survey conducted by Yates and Warde (2017) provides an insight into where and who people eat with, but not what is consumed, also the findings are from individuals making it unclear whether all members of families experience eating together the same.

Fielding-Singh, (2017), conducted interviews exploring food practices with adolescents and their parents, of whom 14 were fathers. Findings reported a perceived difference in the diets of mothers and fathers, with mothers seen as healthy eating and fathers unhealthy by adolescents. Additionally, mothers were responsible for ‘food work’ (grocery shopping, cooking), with fathers seen as occasionally picking up groceries on their return home. Adolescents and mothers perceived fathers as lacking the skills for dietary planning. Mothers reported feeling responsible for providing family meals even in the few instances when fathers purchased groceries mothers were stressed as fathers were seen to purchase unhealthy food and not consider the taste preferences of family members. Two fathers responsible for family food work expressed the same concerns as many mothers, regarding dietary health and food work hinting towards how behaviours could reshape gender roles. A study exploring
parents responses to child food preferences found that mothers provided meals catering for individual tastes and preferences with some providing multiple meals to cater for different family tastes (Thompson, Cummins, Brown, & Kyle, 2016). In contrast, in other families all members ate the same meal at mealtimes, with this seen as a key social behaviour of parenting. Nine families with children participated with a key adult member (eight female) from each taking part in participant-generated photo elicitation interviews with only three partners participated in the interviews. For some families the roles of buying food and cooking were shared, although narratives indicated that mothers were responsible for deciding on meals and ensuring all provisions were available for men to cook. This finding is reflective of research reporting women being responsible for grocery shopping, and making decisions on what food to purchase with only ten per cent of the sample, men, and women, sharing responsibility (Charles & Kerr, 1988). These studies show how food choices and food acquisition are gendered roles.

The domain of feeding families is perceived as gendered belonging to women. A large longitudinal study conducted in Canada exploring many different topics around family and food recruited 105 families: of these 65 had an adult male in the family group with only 18 agreeing to be interviewed (Beagan et al., 2014). The experiences of men and food are sparse in the literature, making it unclear why men are less involved in family food. Possible explanations are that women perceive feeding families as their responsibility and are reluctant to share or give control to men. Alternatively, men perhaps do not want to assume any food work roles within families. However, a man living alone or with another man would perform food behaviours as well as some men living with women. A
different research strategy could facilitate men with a family sharing their food experiences to understand the missing piece in family food practices.

The Meal

Georg Simmel (1858-1918), a German sociologist argued that “although eating is common to everyone it is also supremely individual, people can see and hear the same thing, but what the individual eats no one else can eat under any circumstances”, placing the meal at the centre of social relationships (Murcott, 2019). Meals provide structure, regulating family life at social and behavioural levels with eating together as a family argued to promote relationships and good health (Yates & Warde, 2017). Middleton et al. (2022) designed the Family Meal Framework highlighting how the activities surrounding providing a family meal require multiple interacting complex components, including physical tasks and decision-making cognitions (Middleton, Golley, Patterson, & Coveney, 2022). Meal making is not a single discrete event but a series of ongoing continuous events. Family meals facilitate family cohesion providing an opportunity for communication that sometimes can be confrontational (De Almeida et al., 2016). The family meal is perceived to be a fundamental UK cultural practice (Middleton et al., 2022). The media portray a family meal as a positive social practice (Oleschuk, 2020). Murcott (2019), argues that the concept of a normative happy family meal is a misnomer, with many negative emotional and behavioural experiences being common. The commitments of daily life such as employment and social activities can present challenges to the commensality of family meals with meals not always consumed together (Warde, Paddock, & Whilians, 2020c). The reality of regular family meals is perhaps mythical as ‘family meals require coordination and consideration of
multiple individual needs, preferences, and schedules’ (Middleton et al., 2022). Family meals are a unique, catering for individual members taste preferences and dietary needs. A family meal does provide the opportunity to communicate and to build relationships (Middleton et al., 2022). But not everyone thinks of family meals as ‘desirable’ they can be places of conflict. Family meals are a key factor in promoting health and wellbeing of members with positive family functioning associated with family meals (Robson, McCullough, Rex, Munafò, & Taylor, 2020). The research indicates family meals are a social bonding opportunity with health benefits, but is this the result of the food consumed or social interaction or an interaction of both factors?

A distinction exists between ‘meal’ and ‘mealtime’ with family members sharing a ‘mealtime’ eating different meals (Thompson et al., 2016). A qualitative study conducted found parents and children ate dinner together, with the reason for not eating some meals together being conflicting schedules and other commitments (Skeer, Sonneville, Deshpande, Goodridge, & Folta, 2018). These were seen as barriers to meals, both children and parents valuing time eating together. Rules included table manners (etiquette), for example not using phones at the table. Rules around food and eating were declared but not discussed in any detail, those narrated were around encouraging the consumption or not of foods. Mealtimes provided an opportunity for social communication sharing practical information as well as more in-depth conversations plus disagreements between siblings. The study shows that the behaviour of eating requires social skills.

An online survey reported that people were more likely to eat dinner with family members with weekday breakfast eaten alone and lunch with friends or work
colleagues (Metcalfe et al., 2009; Yates & Warde, 2017). For many people, eating out, breakfast, lunch, and dinner pre-COVID-19, was perceived as an accepted social norm and as a familiar practice (Yates & Warde, 2017). A survey conducted in 2019 reported dinner as the meal most likely to be eaten or brought away from the home (Fuller, Bankiewicz, Davies, Mandalia, & Stocker, 2019). The survey was conducted in the UK with 13 per cent of respondents who reported adverse reactions. Men were more likely than women to buy meals out (Yates & Warde, 2017). Fuller et al. (2019), also reported that previous experience of a dining venue, word of mouth and recommendation from family and friends were the key influences when deciding on where to eat out. Feeling comfortable when eating out is an important consideration for many people (Yates & Warde, 2020). Reasons for eating out include taste and sociality. In contrast to 1995, in 2015 people planned less before eating out, often only deciding an hour or day before the meal with people often returning to previous restaurants and eating out with family more (Paddock, Warde, & Whillans, 2017). The findings indicate that eating out has become a normalised practice in the UK and is no longer just for special occasions. Special events are defined as birthdays, anniversaries, life events or treats. These events are typically planned in advance in contrast to impromptu meals. Family meals out are perceived to be labour and time saving. In public family behaviour is constrained by social norms.
3.4.5 Food and Coeliac Disease

Food plays a fundamental role in life spanning across psychosocial and biological dimensions. The treatment and cause of CD is food related therefore essential to include as this has significant social and psychological implications (Ogden, 2010). Although in the UK availability of gluten-free foods has increased it still remains problematic for people with CD (NHS England, 2018; Hanci & Jeanes, 2018). Grocery shopping can be time consuming as labels need to be checked for gluten ingredients and processing contamination risk. Dining choice outside the home can be limited although many eateries are beginning to offer gluten-free meals (Almagro, Almagro, Ruiz, González, & Martínez, 2018). When eating at social events the risk of unintentionally consuming gluten can be high as many are unaware of hidden gluten ingredients and cross contamination risks. However difficulties are experienced with many reporting fear, anger and shame at social occasions outside the home (Bacigalupe & Plocha, 2015). The dietary requirements of CD are often overlooked or perceived as abnormal, creating feelings of invisibility and stigma (Bacigalupe & Plocha, 2015; Rose & Howard, 2014). However, given the social and psychological factors embedded within food, research has been conducted solely from the perspective of people with CD, therefore how family members experience the social process and the effect on them is uncertain. Family meals are associated with positive social and psychological benefits (Fruh et al., 2011). The sharing of meals and eating together as a family can be challenging when catering for specific dietary needs, potentially creating a fractured social structure and interpersonal conflict.
Living with CD may affect the lives of family members who correspondingly can help or hinder in CD management. Coeliac disease shares a similarity with food allergies as both require meticulous avoidance of certain food products which can have practical, psychological and social consequences (Pitchforth et al., 2011). Adults with food allergies experience social isolation and difficulties with interpersonal relationships (Polloni et al., 2017). While dietary treatment appears practically as non-invasive it is associated with psychological and social factors that impact upon health and wellbeing. Family members can help mediate these effects through supportive mechanisms.

3.5 Family Members and Coeliac Disease

From a practical and psychosocial perspective family members are fundamental to support living with CD, and though research has been carried out on the impact of CD surprisingly few studies have attempted to investigate the impact on family members.

Literature searches were performed using the following databases: MEDLINE, CINAHL, AMED, PsycINFO, PsycARTICLES, and Academic Search Elite during October and November 2018, and April 2022. The searches were limited to English language, 2007 to 2019/2022, and academic journals. Keywords included:

- coeliac disease; celiac disease; long-term condition; chronic condition; chronic illness
- family members; family relationships; family experiences; family; relatives; caregivers; adults; children; young people; next of kin
• Psychosocial; social support; psychological
• Diet; food; burden dietary restriction

Terms were combined using the operators OR and AND. Truncation was used for the term’s family and child. Wildcards used for alternative spellings of coeliac disease. The searches retrieved 1885 papers. These were screened by title then abstract. Two studies were identified. Reference lists of articles concerning coeliac disease were also searched leading to the identification of a further three studies. Table 1 provides a summary of the five identified studies.

These studies are now presented beginning with a study conducted for a dissertation concerning dietary sacrifice in couples with CD, exploring shared diets in adult couples where one member had CD (Alley, 2015). Next, a larger research study applying mixed-methods explored the negative experiences of partners of people with CD, publishing two articles, one concerning the dilemmas experienced and the second exploring the data from a gender perspective (Sverker, Ostlund, Hallert, & Hensing, 2007; Sverker et al., 2009). Then, quantitative studies exploring partners burden of living with CD are discussed (Ferretti et al., 2017; Roy et al., 2016). Finally, a study reporting anxiety and depression in the spouses of people with CD is considered (Ludvigsson et al., 2017). Whilst all the studies employed different methods the commonality is the inclusion of adult partners of people with CD. Many of the studies employed quantitative methods providing a restricted experiential insight possibly missing key information. When little is known of experiential phenomena, open qualitative approaches are the most appropriate, providing insight into experiences to build further research ensuring relevant questions
are being asked. These five studies are presented grouped by research method.
### Table 1

**Characteristics of Included Studies**

<table>
<thead>
<tr>
<th>Author(s) &amp; Year</th>
<th>Country</th>
<th>Study Aim</th>
<th>Method</th>
<th>Participants</th>
<th>Main Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sverker et al. (2007)</td>
<td>Sweden</td>
<td>Explore ‘dilemmas’ experienced by close adults living with a person with CD</td>
<td>Critical incident technique through semi-structured interviews</td>
<td>N=23 (17 male)</td>
<td>Three main categories of CD dilemmas: Disease related worries; management of daily life; disturbances in social life.</td>
</tr>
<tr>
<td>Sverker et al.(2009)</td>
<td>Sweden</td>
<td>Explore consequences of experienced dilemmas in daily life for people with CD and their close relative</td>
<td>Mixed methods. Critical incident technique through semi-structured interviews and food behaviour questionnaire</td>
<td>People with CD N=43 Close relative N=23</td>
<td>The consequences of CD in daily life for all participants was associated to cognitive, social, emotional, and physical factors.</td>
</tr>
<tr>
<td>Roy et al. (2016)</td>
<td>United States of America</td>
<td>Degree of burden on adult partners of people with CD</td>
<td>Cross-sectional online survey's</td>
<td>Patients with CD N = 94 Partners N = 94</td>
<td>45% patients reported high quality of life and gluten-free diet adherence. 63% partners reported little or no burden Increased partner burden associated with poorer relationship satisfaction.</td>
</tr>
<tr>
<td>Ferretti et al. (2017)</td>
<td>Italy</td>
<td>Evaluate the impact of CD on caregivers’ life</td>
<td>Cross-sectional survey</td>
<td>Caregivers of people with CD N=55</td>
<td>CD impacted on caregivers’ quality of life. Caregivers of people with CD diagnosed longer than 10 years reported higher levels of concern.</td>
</tr>
<tr>
<td>Ludvigsson et al. (2017)</td>
<td>Sweden</td>
<td>Examine the impact of CD on caregivers</td>
<td>Statistical analysis using Swedish government agency data</td>
<td>Parents and spouses of people with CD, and control cases</td>
<td>Depression and anxiety higher in parents of children with CD compared to control at the point of diagnosis.</td>
</tr>
</tbody>
</table>
3.5.1 Dietary sacrifice in coeliac relationships

A masters dissertation explored the dietary sacrifice in coeliac relationships based on the premise that cohabiting partners and spouses consume similar foods with a paucity of research exploring the implications of “a non-dieting partner voluntarily joining the dietary changes of the other” a potential positive mechanism for relationships (Alley, 2015). This behaviour is termed an act of sacrifice, a positive coping process. The research was conducted in America with cohabiting adult couples, one with CD and one non-CD member. Two hundred and twelve dyads completed questionnaire measures, 88 per cent female, 71 per cent married and 92 per cent heterosexual. The study switches terminology relating to sex and gender, making it unclear as to whether gender behavioural norms or sex are variables of interest. The analyses reported a positive significant effect of shared diet and relationship satisfaction. A shared diet approach to support health and wellbeing reported a good relationship in contrast to those who shared a diet to avoid negative experiences. An avoidance approach is an ineffective form of support and not productive for a relationship. The research provides an insight into how dietary motives, approach or avoidance, can influence relationships. However, women (97 per cent) reported being responsible for grocery shopping and cooking, indicating women with CD cooked gluten-free meals for all family members. The data from males with CD was excluded as many reported frequent non-adherence to a gluten-free diet, compared to females, making it unclear whether males are non-adherent to a gluten-free diet due to absence of dietary support or for other reasons. Many of the participants (88 per cent) had children. Whether the families ate together was unreported and the experiences of children absent.
Overall, the research provides a useful insight into how dietary behaviours can influence relationships and health.

3.5.2 Dilemmas Experienced Living with Coeliac Disease

The research study by Sverker and colleagues (2007; 2009) in Sweden was conceivably the first to explore the experiences of close relatives living with people with CD. The Sverker et al.(2007) study aim was to explore the ‘dilemmas’ experienced by close adults living with a person with CD, focusing on the negative experiences and the strategies employed to manage these. Close relatives were defined as spouses, cohabitants and parents living at the same address. The main finding of the study was how CD impacted upon the lives of close relatives and how this potentially could be addressed through improvements in knowledge. However, the focus was on the negative experiences described as ‘dilemmas’ so not providing a rounded richer picture of the experience of everyday living with CD.

The Sverker et al. (2007) study on close relatives living with a person with CD reported a multitude of negative emotions. These were experienced within the home environment and outside during social interactions with others, including extended family members. In the home environment a fear of contaminating the person with CD with gluten was reported together with a burden of CD due to the increased domestic work. Close relatives reported experiencing guilt when consuming food containing gluten as many believed eating a gluten-free diet was supportive, but experienced mental conflict in not wanting to stop eating gluten food they enjoyed. A perception of the person with CD possessing power and control over the family diet and food related social interactions was reported.
thus being a potential source of conflict. In contrast to this participant’s reported feeling angry and disappointed if catering excluded gluten-free food when dining at extended family members’ homes. This also caused feelings of awkwardness in social interactions and reduced the pleasure in traveling abroad. To cope with living with CD, avoidant behaviours were adopted. Strategies included not attending social events, not dining out and consuming the same gluten-free diet, possibly to avoid the perceived stigma of CD and the reduce the risk of the cross contamination. For many social activities were impacted creating social isolation. Interactions with family and friends are an important source of support for quality of life and wellbeing (Haslam et al., 2018). The Sverker et al. (2007), study draws attention to the importance of considering family members of those with CD due to the emotional and social impact.

Although the study by Sverker et al. (2007), provides an insight into the negative psychosocial impact of CD, there are numerous limitations. The main weakness is the method employed. The authors employed a critical incident technique to investigate ‘dilemmas’ experienced by a patient which “cause disturbances in the performance of his/her everyday life”. Dilemmas are defined as ‘perplexing’ or ‘awkward situations’. Semi-structured interviews were conducted asking participants to describe their three most recent dilemmas in their ‘everyday life when they were hindered by or reminded of being a close relative to someone with CD’. The authors’ underpinning assumption was that all participants had experienced negative dilemmas. There are temporal difficulties with this as it is unclear when the reported dilemmas occurred, suggesting memory bias. In addition, the family ‘dilemma’ may have resolved or escalated. Factors such as relationship length and time living with CD may

influence the coping and adjustment to CD, yet these were unprovided. How long people had been living with a person with CD was undetermined. If these were all people newly diagnosed with CD, they could be expected to experience negative events as the family adjusts to living CD, alternatively this group could have been living with CD for a long period and poorly adjusted. These are important factors as people diagnosed during childhood with CD cope better with living with CD compared to adulthood diagnosis (Lee et al., 2012). Due to the scarcity of knowledge of the everyday lived experience of CD an inductive qualitative interview approach would have allowed a more in-depth understanding. This would allow understanding of the whole experience, positive and negative, providing an understanding of how these occur and change over time. A key limitation of the study is the exclusion of children. Children are often found within family structures, but although the authors have included two parents of adult children the experiences of children aged under 18 years were not included. It is unclear from the demographic data if any of the family groups included children. Given the reported impact on adults it is important to understand the impact on children as in other long-term conditions it is known to influence quality of life and wellbeing (Pakenham & Cox, 2014). However, this study provided a base for further research into families experiences of living with CD.

The Sverker et al. (2009) study reported on the dilemma consequences of women and men with CD and close relatives with a gender difference reported in food social contexts. The critical incident technique was employed to explore gender with the addition of a food behaviour questionnaire to both the person with CD and a close relative (Sverker et al., 2009). Interview data were
analysed deductively for the consequences of dilemmas. Close relatives had a 52 per cent attrition rate; as a mixed methods study this poses a threat to validity, with the reasons for attrition not reported. The data are unclear on the number of women and men with CD participating. The study, Sverker et al. (2009), provides an example of using sex and gender terms synonymously (Hart et al., 2019). The questionnaire data reported women (47 per cent) and men (52 per cent) in households where both members were responsible for cookery habits. The article reports on the dilemmas previously reported in the earlier paper (Sverker et al., 2007) adding some gender specific aspects. Women with CD and close relative men reported constant thoughts and actions preplanning daily life due to gluten. Close relative men reported restricted holiday choices and impossibility to have a ‘normal way’ holiday as a consequence of living with CD. Women and men with CD reported feeling shame in response to dilemmas experienced around CD and social eating situations. Overall women and men with CD reported similar consequences of dilemmas living with CD. Overall, the research reported in these two articles provides a base for further research into families experience of living with CD, an area overlooked.

### 3.5.3 The Burden of Coeliac Disease for Partners

In contrast to the qualitative research conducted by Sverker et al. (2007;2009), three studies have investigated the burden of CD on adult partners employing quantitative methods. The first two studies presented are from one research group. Firstly, research conducted in America explored the degree of burden to partners of people with CD using survey methods (Roy et al., 2016). Ninety-four couples participated aged 21 to 82 years, with 71 per cent of people with
CD female. Partners’ data reported a 29 per cent mild to moderate burden, eight per cent moderate-to-severe burden and the remainder no burden. The majority of partners reported that CD rarely or never impacted social life. A higher burden was associated with a weaker partner relationship. The authors note the burden of CD in partners is similar to partners of people with other organic long-term conditions suggesting CD requires understanding, acceptance, and support from partners. Interestingly partners who had been in a relationship for ten years and longer were more likely to report experiencing mild-to-moderate burden possibly due to ongoing support for person CD. The underpinning cause for poor relationship quality is unclear with many potential non-CD explanations. The research demonstrates the need for further investigation to understanding why CD is burdensome to partners.

The research group next explored emotional partner burden further in a larger sample size in Sweden (Ludvigsson et al., 2017). The study explored anxiety and depression, as signs of burden, in parents and spouses of people with CD through medical records. A clinical diagnosis of depression or anxiety were more common in caregivers to people with CD with increased risk before diagnosis and four to eight years following diagnosis. The increased depression and anxiety prior to CD diagnosis can probably be explained by the onset of CD symptoms without knowing the cause. The findings could also be coincidental. Parents with a child diagnosed with CD were more likely to receive a clinical diagnosis of depression or anxiety compared to partners. However, partners may experience poor mental health below clinical levels or not seek medical care.
Ferretti et al. (2017) applied a quantitative approach in Italy to explore the burden of CD on ‘caregivers’ in Italy. The study aimed to assess the burden of CD on caregivers’ lives through a questionnaire cross-sectional design. Results reported a reduction in the level of concern experienced by caregivers from time of diagnosis to time of study, and an impact on caregiver’s quality of life. However, caution is required when interpreting these results due to limitations in the methods. Firstly, there was a bias in the population sample as participants were recruited at a coeliac meeting so had an active interest in CD. The participants were predominantly first-degree relatives and female consequently, not representative of CD ‘caregivers’ as more women than men are diagnosed with CD, so the expectation would be to see more male participants (West et al., 2014). Secondly, there are numerous issues concerning the self-report questionnaires that comprised of multiple-choice questions and a visual analogue scale. These were unvalidated measures, not standardised, thus producing uncertainty about the subjective construct and reliability of the questions. This is particularly pertinent for a main question asking about impact on lifestyle. The question asked, ‘how much did the diagnosis of CD of the patient affect your lifestyle?’ followed by asking ‘if any degree in lifestyle change which aspect was the one most involved’, providing a choice of; economic aspect; social life; working life; family life. No scales (i.e., 0 = no concern, 10 = highest concern) were provided on the corresponding lines. The lack of clarity in measurement makes it unclear how to determine how much participants were impacted, thus raising questions about the validity of the reported results. Additionally, responses were limited to one choice so if family life was selected, which would be a reasonable assumption due to gluten-free treatment, the
study provided no information on how or any changes that have occurred or impacts in other life areas. Finally, caution is needed regarding the results as the assumption is caregivers were present prior to diagnosis and at diagnosis. The mean age at point of diagnosis was 18 years with a variance of plus or minus 16 years indicating that some caregivers’ family member was diagnosed in childhood. Therefore, some participants were notably parents: this has added factors as parenting a child with an illness differs greatly from being a partner of a person with illness. A retrospective bias can be assumed given that CD can take between four to thirteen years to be diagnosed, plus the duration since diagnosis (Gray & Papanicolas, 2010).

A difference in levels of concern was not reported between pre-diagnosis and diagnosis. Possible explanations for this are unfamiliarity with CD symptoms, memory, or not being present pre-diagnosis. A decrease in concern was observed from diagnosis to point of study suggesting an association with lessening of symptoms in response to treatment. A caveat is that concern was greater in those diagnosed for more than ten years; this is perhaps due to parental concerns of adult children’s self-management of CD. Sociodemographic factors of lower education levels and unemployment were associated with increased stress, but whether this was due to CD or other factors, such as the stress caused by unemployment, is unclear, although how stress was measured is unknown. Nevertheless, the evidence presented from Ferretti et al. (2017) reveals an impact on family members. However, much uncertainty still exists about the impact of CD on family members.
3.6 Conclusion

Overall, the literature provided evidence of the impact of living with CD on the adult with CD. The evidence presented showed a significant impact on the psychosocial wellbeing of people with CD, with a need for emotional and practical support (Norström et al., 2011; Rose & Howard, 2014; Zingone et al., 2015).

Previous research recognises the importance of the role of family in providing critical support in the management of long-term health conditions (Whitehead et al., 2018), yet key gaps in the literature revealed limited research on adult partners, living with an adult with CD, with uncertainty around what support they provide.

The studies discussed in this review show little is known about the lived experience of people living with CD and their families. The evidence shows how families influence the health and wellbeing of each other but how families live with CD is unknown (Martire & Helgeson, 2017). This gap in the literature needs addressing to facilitate the best possible outcomes for all family members, adults, young people, and children.

Gender roles are indicated to influence coping with CD as well as food behaviours within the family home (Hallert et al., 2003). However, the understanding of this is limited in the literature. Further research needs to be conducted to explore gender roles as this affects family self-management and has implications for clinical practice with tailored gendered support for CD.
The food literature review, across biological, psychological, and social perspectives highlighted the many embedded properties surrounding food and consumption. Food plays an essential functional role in everyday life with the support from family members vital in adjusting to diet related conditions, yet in CD how food in families is managed is unclear with the experiences of children and young people unknown (Bacigalupe & Plocha, 2015).

The limited research on adult partners, living with a person with CD, suggest a psychosocial impact on partners, but this is unclear (Ferretti, Branchi, Dell’Osso, Conte, & Elli, 2017; Sverker, Ostlund, Hallert, & Hensing, 2007).

In conclusion the literature found evidence of living with CD from the perspective of adults with CD, limited evidence on the psychosocial effects on adult partners and none including children and young people living with an adult with CD demonstrating the need for further research. To address the gaps identified in the literature review, an exploratory study was conducted to understand the lived experience of adults with CD and all their family members.
4 Methodology

This chapter presents an overview of the methodology adopted to explore the lived experience of families living with coeliac disease and the method applied to conduct the first stage of this research. Firstly, the considerations and debates in situating the research approach are discussed. This is followed by the epistemological position, and the underpinning theoretical frameworks that situated the research. The final part of the chapter presents the research design.

4.1 Research Paradigm

This research was initially approached adopting a pragmatic approach, applying the method best suited to answer the research questions, as often applied in health research. My background is in health psychology which facilitates acceptance of both qualitative and quantitative research methods, providing a toolbox of resources to draw upon (Cornish & Gillespie, 2009). The biopsychosocial framework grounding this thesis rejects the biomedical view of health, an approach perceiving health and illness objectively as a single reality (Engel, 1977). Seeking to explore family members experiences I recognised multiple realities would be formed using a qualitative approach but I was unsure of my underpinning research paradigm assumptions. Drawing upon literature from multiple disciplines around philosophical approaches and the underpinning assumptions created confusion for me. Merriam and Tisdell (2015) explained the confusion succinctly:
There is no consistency across writers of how the philosophical foundations of qualitative research is discussed – theoretical traditions and orientations (Patton, 2015), philosophical assumptions and interpretative frameworks (Creswell 2013) and epistemology and theoretical frameworks. (Crotty 2013)

For example, ontology is described as ‘the study of being’ by Crotty (1998, 10) and the “nature of reality” by Lincoln and Guba, (1985, 37). As the research progressed, the understanding of philosophical perspectives, and recognition of the implications of these on the research data collection and interpretations developed. The philosophical approach taken shifted from pragmatic to social constructionism in recognition of families shared and individually constructed social meaning.

_Social Constructionism_

The philosophical branch of ontology, the nature of being, can be considered on a spectrum, with realism and relativism at opposite extremes (Guba & Lincoln, 1994). Realism maintains that there is one objective reality (the world exists independent of humans) in contrast to the subjectivity of relativism which emphasises multiple realities (a world does not exist outside human thought) (Braun & Clarke, 2022). Social constructionism holds that knowledge and meaning are created and not discovered, shaped by the social context and culture within which it was created (Schwandt, 2003). Reality is therefore the subjective experience of daily life, with reality constructed through interaction and context and in relation, rejecting the realist view of only one single reality. Social constructivism supports the interaction of multiple perspectives of family
members, and the construction of meaning between them. Conversation is argued as an important means to maintain, modify, and reconstruct reality (Berger & Luckman, 1991).

The research is positioned within a subjectivist epistemology, but the research is at the centre of the objectivist-subjectivist continuum, as there are shared meanings that can be understood and known (Daly, 2007). Families and individuals can construct shared meanings related to living with CD. Adopting a psychosocial approach includes the social aspect within psychology focusing on meanings and family systems. As discussed in the literature review, family and health are connected emphasising the importance of including the immediate family household members to understand family experiences. Handel (1997) conceptualised families as: ‘complex active agents in constructing their own family life, and we conceptualize each family member, each child as well as each adult, as an agent whose actions contribute to shaping that family’s interdependent life together—and apart’. This concept illustrates how family members have agency constructing socially shared and individual meanings around living with coeliac disease, recognising that children and young people have social agency and rights (Mayall, 2015). During interactions meanings are constructed Daly (2007, p.34) explains:

This approach in qualitative family research is interested in understanding the broader patterns of meaning construction that exist within the project sample, a shift from individual meanings to the generic patterns of meaning that contribute to an understanding of the research phenomenon.
**Phenomenology**

Phenomenology is the philosophy concerned with the study of lived experience, the phenomena of consciousness (van Manen, 2007). Phenomenology is applied as methodology, theory and a method, but as Allen-Collinson, (2009) declares ‘the ‘phenomenological ‘method’ is much more than a specific research technique, but rather embraces a whole way of thinking and being’ (Davidsen, 2013; Van Manen, 2017). A critical aim of this research was understanding the lived human experience, therefore I drew inspiration from the field of phenomenology, and in particular the work of Merleau-Ponty, as this approach seeks to describe the way the world is perceived by the person experiencing it (Merleau-Ponty, 2012). The focus of phenomenology is the study of consciousness, the lived experience (Davidsen, 2013). The foundational phenomenology work of philosopher Edmund Husserl (1859-1938) proposed that human experience (knowledge) was through the body with the theory of intentionality, in that conscious acts are intentional (Merleau-Ponty, 2012).

Merleau-Ponty, an existentialist philosopher, built on Husserl’s work focusing on embodiment and perception in relation between the body and mind, objective, and experienced world (Merleau-Ponty, 2012). The existential phenomenology of Merleau-Ponty (2012) who proposed a phenomenon was interpreted through ones lived body, the body is experienced inside and out, with being-in-the world an often taken for granted experience as we are often not conscious of our bodies when engaging in daily activities (for example when reading a book) in contrast to when our attention is drawn to our bodies during illness. Perception and consciousness are core elements for Merleau-Ponty. How the mind and
body are one, lived through the embodied conscious experience of being in the world. The body is used to perceive the world and respond in time and space. Existentialist themes seek to understand the experience of living as ‘an embodied being in a particular physical and social world’ (Willig & Billin, 2011) through asking the question ‘what is the world like for this person?’, which allows for multiple perspectives of the world. Willig and Billin, (2011) explain that there are many different lifeworld’s (lived experiences) due to the array of human realities and existences. However, it is argued lifeworld’s share fundamental existential themes to understand lived experiences; spatiality (lived space), corporeality (lived body), temporality (lived time) and relationality (lived human experiences) (Willig & Billin, 2011).

For research exploring living with coeliac disease, a health condition, an inspired existentialist phenomenological approach is appropriate. A fundamental principle of existentialism is the interrelatedness and influencing nature of the body, world, and consciousness (Allen-Collinson, 2009). This principle supports the biopsychosocial model of health (Engel, 1977) that defines health as an interaction of biological (body), social (world) and psychological (consciousness). The approach seeks to understand what it is to be human, the incorporation of psychological and physiological elements.

This research adopted a social constructionism approach drawing on phenomenology to explore the lived experienced of families living with CD.
4.2 Theoretical Frameworks

This research draws together literature from multiple topics, CD, family, and food from health, psychological and social perspectives. The multidimensional aspects are unique to CD suggesting the application of theories are required to understand living with CD (Hoyt & Stanton, 2012). However, the biopsychosocial model of health (Engel, 1977) provides the framework for this research as it encompasses the key components of this research biological (CD), and psychosocial (family). There are not many theoretical models to explain families and chronic health conditions, with many health theories and models explaining individual responses to an illness. Building on the biopsychosocial model of health, the family systems illness model (Rolland, 1987), provides a conceptual framework to understand the psychosocial challenges of families living with a long-term condition. Based on the literature review findings exploratory research applying broad models that incorporate biological, psychological, and social factors is fitting, as these shape family behaviours. These two models provide the research framework.

4.2.1 Biopsychosocial Model of Health

The biopsychosocial model of health was developed to address the gaps in the biomedical model to provide an integrated and holistic approach to health (Engel, 1977). The foundations for the biomedical model of health, in Western medicine, stem from Descartes theory of mind-body dualism, often referred to as Cartesian dualism; the separation of the ‘mind’ from the ‘body’ (Engel, 1977). This approach assumed a reductionist approach to understanding health,
therefore excluding the influence of psychological and social factors on health. The biomedical model defined health as an absence of disease and illness symptoms and was a dominant model for health (Hatala, 2012). From this perspective health promotion such as a reduction of social and psychological risk factors would be ignored with a focus on the avoidance of pathogens. The biomedical model, although useful for developing successful treatments such as immunisation programmes, does not account for the largest, often preventable, influence on health, behaviour, which is influenced by psychological and social factors (The Health Foundation, 2018). Building on the biomedical model, the biopsychosocial model was proposed, integrating biological, psychological, and social factors in the approach to health (Engel, 1977). The incorporation of these factors facilitates a holistic approach to health and healthcare, as seen in the UK National Health Service delivery of a holistic patient-centred care approach (NHS, 2018b). The biopsychosocial model provides a “blueprint for research, a framework for teaching and a design for action in the real world of health care” Engel (1977). The interactive components of the biopsychosocial model provide a framework to understand the factors contributing to health. The ‘bio(logical)’ component contributes biological characteristics including bacteria, genes, and structural defects; the ‘psy(cho)logical’ component includes behaviour, beliefs, emotions, coping, stress; the ‘social’ component includes family relationships, socioeconomic, and environment. Figure 1 illustrates the biopsychosocial model.
A limitation of the biopsychosocial model is vagueness around how the three components interact, with little detail on the contents (Bolton & Gillet, 2019). However, since the biopsychosocial model’s conception in 1977 a wealth of evidence has evolved advancing understanding of the interplay between biological, psychological, and social factors (Woods, 2018). The biopsychosocial model has been widely applied to health education, health conditions, family therapy, and families and health (Woods, 2018). The use of
the model as an underpinning epistemological framework has also been proposed highlighting the many strengths of the model and evidence supporting its application (Hatala, 2012).

As discussed in the literature review (Chapter 3, section 3.1), CD encompasses all components of the biopsychosocial model with physical symptoms experienced by many, in addition to difficulties in social situations as well as family relationships (Sverker, Hensing, & Hallert, 2005). The literature review (Chapter 3, section 3.2) also reported how families affect health behaviours, biological systems, and psychological wellbeing (Kiecolt-Glaser & Wilson, 2017; Martire & Helgeson, 2017). The theoretical psychosocial model of living with CD was grounded in the psychosocial effects of living with CD, with negative experiences dominant within the model (Rose & Howard, 2014). Whilst not explicitly stated, the psychosocial model provides an example of the integration of the biopsychosocial components. The model is grounded in the biological component of CD, with the psychosocial effects as a consequence, an interaction, of living with CD. The biopsychosocial model provides the ideal broad framework to explore living with CD, knowing the disease impacts people with CD biologically, psychologically, and socially. Previous research has proposed qualitative methodologies are essential to understanding the biopsychosocial perspective of CD (Rose & Howard, 2014; Satherley et al., 2022). The need for a biopsychosocial approach is argued to provide a broader understanding to improve treatment and outcomes for patients and their family members (Culley et al., 2017; Nutting & Grafsky, 2018). The biopsychosocial model of health (Engel, 1977) is the underpinning theoretical framework for this research.
4.2.2 The Family Systems Illness Model

Family systems theory, a conceptual theoretical approach, offers an approach to study the interior of family life. The theory describes family as dynamic with interacting parts, based on the assumption of a connectedness between the parts, but to understand the family the system needs to be viewed as a whole, with interacting sub-systems (Kantor & Lehr, 1975). The family processes are viewed as an interacting dynamic social system to achieve family and personal goals through adaptive, information-processing, and open systems (Kantor & Lehr, 1975). A key principle of systems theory is positive and negative feedback enabling adjustments to be made (Kantor & Lehr, 1975). The theory was developed to understand everyday family interactions through everyday events, processes within the larger system of society and environment. Families, when faced with long-term illness, are required to adjust to the disruptions of the illness and family evolvement through its life cycle. To address the specific disruptions related to long-term conditions and families, building on this theory the family systems illness (FSI) model provides a biopsychosocial theoretical approach to understand families living with a long-term illness (Rolland, 1987, 2005). The model is based on a biopsychosocial systemic interaction between the family and health condition, viewing family relationships as a positive resource (Rolland & Williams, 2005). How families adjust to long-term conditions is determined by psychosocial factors throughout the FSI model. The FSI has three dimensions, (1) a psychosocial typology of illness, (2) illness time phases, and (3) key family systems components (Rolland, 2018). Figure 2 provides an illustration of the three dimensions.
How family members understand each other’s expectations at each stage is important. The psychosocial typology of illness dimension shows how illness can be classified based on similar illness characteristics. These are: illness onset, the trajectory, illness outcome, incapacitation (functional or cognitive impairment), the level of uncertainty and degree of predictability of illness.
progression. Each of these characteristics’ places differing psychosocial demands on family including disrupting family life physically and emotionally. For example, a social impact of taking employment leave to accompany family members to medical appointments and the emotional distress (fear, worry) of possible illness outcomes. The illness of a family member has a ripple effect on the whole family with an acute onset (for example myocardial infarction) requiring a rapid response in contrast to a gradual onset (for example Alzheimer’s) with a protracted adaptation. In contrast a relapsing disease, such as Crohn’s disease, has periods of stability with no symptoms and those with flare-ups. These can disrupt family functioning due to the uncertainty surrounding illness flare-ups.

The major illness time phases dimension concerns the longitudinal nature of long-term conditions through three illness time phases; the initial crisis phase including diagnosis and adjustment; the chronic phase; and the terminal phase. Figure 3 provides an illustration of the timeline and illness phase characteristics. This dimension provides a temporal pattern of an illness journey.

**Figure 3** *Family Systems Illness Model Timeline and Phases of Illness*

Figure 3 Timeline and phases of illness Rolland, J. S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family process*, 26(2), 203-221. Reprinted with permission from John Wiley and Sons
The third dimension, components of family functioning are grounded in the four basic domains of family functioning: (1) organisation/structural patterns, (2) communication processes, (3) belief systems, and (4) family life course. These components include cultural, gender and socioeconomic influences.

provides a diagram of the three illness dimensions.

Based on the FSI when stressors arise families adjust to regain a state of stability (homeostasis) which provides a framework that can understand the processes of adjustment when a family is challenged. The FSI conceptualises the family as the focal point of understanding the biopsychosocial processes (Rolland, 2018). Families who have a member with CD must adapt to the diagnosis and subsequent challenges experienced. Literature is scarce on how families adjust and live with CD.

The FSI model was applied to explore the experience of families when a member was hospitalised with a critical illness. The findings indicated the need to acknowledge and include the family in the critical illness experience, revealing the complexity and support provided by being family (Eggenberger & Nelms, 2007). The approach has also been applied to explore young people’s experiences of family meals, recommending a whole family approach to improve experience of family meals (Prior & Limbert, 2013). The FSI was applied to families living with a long-term health condition, using quantitative measures investigating the relationship between parents, with long-term condition, and their children, looking at factors including mental health, family functioning, and stress, with findings emphasising the importance of family
relationships (Sieh, Dikkers, Visser-Meily, & Meijer, 2012). These studies indicate the suitability of the FSI model, recognising the need to include all family members when a member has a long-term condition and potential psychosocial impact on family members to explore family experiences of living with CD.

The FSI focuses on interactions and connections between individual family members that influence each other but, they do not exist in isolation instead they are constructed in relation to an external society. The biopsychosocial model concerns the important interaction of biological, psychological, and social factors in health conditions. These factors contribute to the management of long-term conditions such as living with CD. The research problem can be applied to this framework and used to support the discussion.

4.3 Qualitative Research

Rationale for a Qualitative Design

Within research the two common method paradigms are quantitative and qualitative. Each of these approaches has a range of methods to draw upon based on the research question and underpinning assumptions. Quantitative approaches are underpinned by a positivist epistemological viewpoint (Braun & Clarke, 2022). This approach employs controlled prescriptive research methods, hypothesis testing to determine causal relationships between variables seeking an objective real world (Bishop, 2015). In contrast, qualitative approaches offer flexibility to explore, understand, and interpret the experience
of participants, collecting a complex and detailed account, thereby allowing for multiple versions of reality (Smith, 2003). Qualitative methods collect words (spoken and written) and images as data, drawing on a range of data collection techniques from face-to-face interviews to visual methods (Drew & Guillemin, 2014). The methods allow deep rich knowledge and meaning to be obtained. Quantitative methods use numerical data often with large sample sizes for statistical power limiting the data according to the measures selected which can result in missing informative data. By contrast, qualitative methods acknowledge and value subjectivity and enable the ‘voice’ of participants to be heard, often through small sample sizes.

The disciplines of sociology, psychology, and health share methodological approaches, historically all drawing predominantly upon quantitative methods. These were viewed as superior to qualitative methods, with many positivist values applied to qualitative methods (Braun & Clarke, 2021). It can be argued that a paradigm shift has occurred in these disciplines with a broadening of qualitative methodologies and methods applied in research (Savage & Burrows, 2007). Across all these disciplines an increase in qualitative research is observed indicating recognition of how these methods can provide contextual and comprehensive data. In health research this is evidenced through increased public involvement, and funding and regulatory body requirements (Brady & Graham, 2019). When exploring novel phenomena, a qualitative approach is warranted, rejecting the positivist values that devalue the experiential knowledge from families.

To understand the lived experience of health conditions and to explore family experiences qualitative methods have been utilised applying in-depth interviews
for data collection (Morris, Love, van Aar, Liles, & Roskell, 2018; Taylor, Dickson-Swift, & Anderson, 2013). Previous research concerning people living with CD, as identified in the literature review, predominantly focused on people with CD revealing a paucity regarding family members, therefore possibly asking the wrong questions missing valuable insights and a crucial source of knowledge. Seeking multiple perspectives of family members enables a voice to be given to often unheard views and the opportunity to uncover unique insights of living with CD (Hudson, 2016). Exploring the whole family experience, it was recognised that many multiple realties within and between families may exist, with no objective reality to be formed. Family research employing qualitative methods reported themes capturing the individual experience and the family experience illustrating how the approach can be applied to explore the experiences of individuals and whole families (McCarthy, 2003). Therefore, a qualitative approach was employed for this research to explore families’ experiences.

**Photo-Elicitation Interview Methods**

Interviews are a popular qualitative method widely applied in sociology, psychology, and health to explore lived experiences; however, a plethora of methods exist within the qualitative paradigm reflecting the growing diversity of methods such as visual (Kanagasabai, 2018; Lachal, 2012). Participatory visual research techniques provide active opportunities for participants’ engagement and ‘voice’ in research (Pauwels, 2015). One such approach is the use of visual stimuli to promote dialogue (Pauwels, 2015). Effective visual stimuli are photographs, prompting memory, recall and recognition, as pictures are generally remembered better than words (Harper, 2002). Photography and
photographs are a common feature in daily life playing an important social role. Globally, in 2017, an estimated 1.2 trillion digital photographs were taken (Statista, 2019). This illustrates how photography has become a social norm, a socially engaged practice facilitating autobiographical memories. The taking and sharing of photographs is a common daily phenomenon, with high accessibility, usability and editability aided through advances in technology. The advent of the smartphone has helped facilitate the widespread sharing of photographs including to wider audiences through social media platforms. Photo-elicitation ‘is based on the simple idea of inserting a photograph into a research interview’ to help ‘evolve deeper elements of human consciousness than do words’ (Harper, 2002). Photographs enable people to reflect on everyday life that normally they perhaps do not consider (Harper, 2002). John Collier (1957) is regarded as the founder of photo-elicitation as he used the technique to explore families’ experiences resulting in deeper richer cognitive and emotional information in contrast to standard verbal interviews. The social normative practice of taking and sharing of photography combined with high ownership of smartphones makes photo-elicitation a more familiar and accessible method.

The technique of photo-elicitation has been widely used in social community, and health research. There are two primary forms of photo-elicitation, one researcher-generated images, and second participant-generated where participants provide the images, either previous images or ones taken for the purpose of the research. Photographs provide an opportunity to reflect on everyday life that little thought is given to, allowing capture of life experiences (Banks 2001; Rose, 2007). Many everyday family behaviours are habitual (practiced norms, mundane) making them challenging to capture without
prompting reflection. This makes participant-generated photographs a useful method to explore events in a person’s daily life, the everyday unconsciously performed behaviours, the being-in-the-world (Merleau-Ponty, 2012). Participant-generated photographs used as part of the research interview facilitate how participants make conscious sense of their everyday life experiences (Collier, 1957). The inclusion of photographs helps to build rapport between a participant and researcher (Richard & Lahman, 2013) and encourages active engagement with the research. Participant-generated photographs provide control of the interview to the participants, in which they are the expert, as they can chose what photographs to share and discuss, as well as their interpretation of the image. The technique can address power dynamic relationships between the interviewer and participant although as Pauwels (2015) distinguishes, the image is produced for research not social purposes. Participant-generated images can support participants in expressing difficult to verbalise experiences as well as supporting children with developing verbal competencies, (Clark-Ibáñez, 2004; Lomax, 2012a). The contents of photographs allow the sharing and defining of concerns and or issues, and of what they mean to participants.

The literature review in Chapter 3 demonstrated how the views of children and young people are often excluded in family research, despite being active family group members. The experiences of children and young people living in a family with coeliac disease are critical to capture as long-term conditions impact all family members. Encouraging children and young people to share everyday family life could be challenging. However, this can be addressed through engaging them in a participatory visual method to choose their experiences to
share, encouraging their ‘voice’ (Lomax, 2012). Previous research has found that photo-elicitation empowers children, aiding conversations as an effective tool to explore family, food and health (Ford et al., 2017; Lachal et al., 2012; Mandleco, 2013). Participant-generated photographs provide information on how participants understand and interpret their world. This can challenge any assumptions the researcher may hold. Photo-elicitation has been found to be productive with children providing rich insights to their worlds including family routines (McCloy, White, Lee Bunting, & Forwell, 2016; Rose, 2016). Photo-elicitation guidance from Rose (2016) was applied in this research.

Based on the evidence from previous studies, participant-generated photograph-elicitation interviews were used in this research to support participants engagement with the research, giving participants agency, facilitating an active position in the research process, and to set the agenda to identify aspects of particular relevance to their experience of the research topic. In addition, they enabled conscious reflection on everyday experiences and encouraged sharing of the meaning behind the image. The inclusion of participant-generated photographs in this research was a tool to support participants’ engagement in the research, especially children and young people, rather than being based on visual theories (Rose, 2016).

### 4.4 Involvement Model of Research

Many organisations strongly advocate public and stakeholder involvement in research including the Economic and Social Research Council (ESRC), UK Research and Innovation (UKRI), and the National Institute for Health Research (NIHR). Public involvement now forms an essential criterion of many research
funding bodies. Members of the UKRI including The Open University, are committed to improve public involvement in research with the practice incorporated in disciplines including health, environmental, and education (UKRI, 2022; Hatton, 2020; Brandsen, 2018). Within the UK it is widely recognised in health and social based research that public involvement is fundamental (Staniszewska et al., 2018).

The involvement of the public is evidenced to improve the quality and impact of research (Brett et al., 2010). The expertise of people with lived experience of health conditions contributes novel insights, shaping research priorities and increasing the feasibility and acceptability of research methods to participants. The positive impact of public involvement on research design is observed through improved participant recruitment, including reaching seldom heard groups, and project retention (Crocker et al., 2018). Additionally, benefits are reported in public involvement members’ increased research knowledge, opportunity, and confidence (Brett et al., 2010).

Between disciplines and organisations several different terms are used to describe how public involvement is defined and termed although the underlying principles of valuing equal partnership in knowledge production are analogous (Brady & Graham, 2019). Additionally, due to some similarities blurring the boundaries, some confusion exists around participatory and involvement research.

This research employed both, working with public involvement on the design and procedure components of the study and applied a participatory method for data generation. While the emphasis of this section is on public involvement a
brief overview of participatory research is provided to introduce the approach and illustrate the distinction between the two practices. The public involvement in this research informed the participatory method applied which is presented in Chapter 5.

**Participatory research**

Participatory research is an umbrella term encompassing a variety of approaches including community-based, action research and user-centred design, often applied for the purpose of action or to produce change (Vaughn & Jacquez, 2020). Participatory approaches have been applied in healthcare, education, and community research (Creighton et al., 2017; Fitzgerald et al., 2021; Warner et al., 2016). The aim of participatory approaches is to co-construct knowledge and meaning in partnership with researchers and people affected or involved with the phenomenon of study (Wilkinson & Wilkinson, 2018). The research approach is based on the premise that those most impacted by the research take the lead meaning participants are in control of the research agenda, as the researcher hands the power to participants (Rose, 2018). This type of approach is often used to generate community change (for example public health) and working with children. In these approaches participants can be actively involved in all stages of the research process, including being sources of research data and analysing data.

**Involvement research**

Public involvement in research is collaborative where researchers work with lay members, who are often experts through experience. Involvement or sometimes described as co-production, is defined as ‘research being carried out ‘with’ and
‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE, 2012). The definition ‘public’ includes family members, carers, potential patients, patients, and members of the general public (NIHR, 2014).

Involvement is when the public and or patients are active partners throughout a research project or during any stage(s) of the research process from conception to dissemination (INVOLVE, 2012).

Within involvement research there are different ways the public can become involved in research such as public engagement and consultation. The UKRI (2022) defines involvement as:

Stakeholder or participant involvement in research and innovation is an effective way to ensure research impact and provides an opportunity for researchers to engage with and learn from others affected by and interested in the proposed project. Wider involvement in designing and conducting research can confirm that the project best addresses the needs of individuals and communities. It can also ensure that different forms of knowledge, experience and expertise are valued and used throughout the research process from the earliest stages.

Public involvement enables a research team with all the necessary knowledge and expertise to actively work in partnership to plan, conduct and disseminate a research project. Public involvement research has globally increased in recognition of the benefits it can provide in all areas of the research process from conception to dissemination (Biddle et al., 2021; Brett et al., 2014; Tembo et al., 2021). In public involvement research the involvement of everyone at each stage of the research is not essential dependent on the expertise required
at each stage (Brearley, 2018). A component of involvement is consultation where lay people are involved in the research design. Consultation can occur at the research development stage where views can be considered when making decisions (Shaw, 2011; Brady, 2017). The practice of consultation is often applied to inform participatory research (Slatterly, 2020). Figure 4 illustrates how, and at what points the public can be involved in the research planning. The model was based on children and young people but can also be applied to adults as the principles and process are the same.

**Figure 4 Model of Public Involvement in Research**

![Model of Public Involvement in Research](image)

People are actively involved in aspects of the planning and process of research.

- Consulted about the research
- Collaborators in the research
- Ownership of the research

**Note.** The figure depicts the increasing control of the research process. This figure is adapted from the Model of children and young people’s involvement in research (Shaw, 2011).

A key distinction between participatory and involvement research is the embedding of participants within all areas of the participatory research, in contrast to involvement where people are solely members of the research team, thereby not sources of research data. Involvement differs from research participation such as focus groups which are used as a tool to collect research
data, whereas public involvement is to inform research decisions (Doria et al., 2018). Also, often in participatory approaches participants directly benefit from the research such as community projects, whereas in involvement projects others benefit. The overlaps between the two practices in many areas of the research process illustrate the blurring between them and highlight why it is necessary to provide a definition of how they are applied in this research. In the context of this research, consultation was a process for involving members of the public, experts with lived experience of food related conditions, as research advisors.

4.4.1 Benefits of Consultation on Research Design

The incorporation of meaningful public involvement in doctoral research is viable and beneficial (Coupe & Mathieson, 2020; Dawson et al., 2020). Challenges to embedding involvement are temporal, with the doctoral research having a specified timeframe and the time required to recruit, support and train people in research. For institutions with established public involvement groups and co-ordinators this process is easier. Ability to recompense people for their time and expertise presents additional challenges as often not included within doctoral budget. To address these challenges seeking public expertise for specific stages of the research can reduce pressure on time restrictions and financial resources. For this study the design stage was identified as the most appropriate and beneficial point to work with ‘experts through experience’, informing the viability of the project as a whole and identifying any potential difficulties.

The inclusion of experts through experience in novel research is indispensable, especially when literature to draw upon is limited. To be able to explore
everyday life with CD it was imperative to understand what was important to different generational groups within a family. As an adult and someone with no experience of a medical dietary condition, it was valuable to have an insight into what this is like, to ensure the proposed research protocol was relevant and feasible. The best people to advise me on this were those with this knowledge and experience of life with a dietary condition, especially children and young people, as they are the experts on their own lives (Lomax, 2012a).

Due to the novelty of this research, exploring families’ experiences of living with CD, having the expertise of people during the research design and procedure was fundamental to delivering a participant centred design. A qualitative approach was appropriate to answer the main research question, the lived experience of families living with CD, with a proposed participatory component to empower participants, especially children and young people. To facilitate this, I proposed a participant-generated photo-elicitation interview method. Research conducted using photo-elicitation interviews often does not report the practicalities of taking the photographs or the format (digital or hard copies) viewed during the interview. In studies reporting the photographic device the rationale for using devices were based on practical reasons and others where young people were offered disposable cameras that were perceived as ‘uncool’.

In one study the child participants used digital cameras and had greater technological abilities than the adult researchers (Ford et al., 2017). To inform interview topic guides expertise on the lived experience of a dietary condition requiring specific food avoidance was essential, so relevant interview questions were asked. The perspectives of adults, young people and children with lived expertise could ensure the interview topic guides were relevant to different age
groups within family groups. This provided clarity on the research tools to improve the acceptability to participants as well as ensuring the feasibility of the proposed method. The proposed participatory method created ethical and practical questions including the taking and sharing of photographic images. In photo-elicitation research the medium through which images are viewed is often unreported. How images are viewed has implications for reflection thus recall. Printed images are tactile and can be laid out allowing participants to easily view them all compared to digital images where often images are viewed singularly. Those studies using digital images have reported uploading from a digital camera to a laptop during the interview with it being unclear as to who had control of the images (Genevieve 2017). To provide a deeper understanding of how best to facilitate participants’ engagement with images required expert advice.

Consultation included the development and critical reviewing of participant documents; recruitment adverts, participant information sheets, and consent forms, to ensure they were comprehensible and readable (Knapp et al., 2011). The average reading age in the UK is nine years therefore all participant documents had to be written in plain English to ensure valid informed consent to participate. Providing comments and advice on the protocol and specific methods influenced the relevance and acceptability of the study design to people, helping to reduce attrition (Crocker et al., 2018). Consultation involvement can include where and how to recruit participants and strengthen support for a research ethics application (INVOLVE, 2016). Consultation provides a better experience of research for participants.
In addition to the pragmatic reasons to enhance the research design, public involvement has moral reasons, as a democratic society the right of citizens to have a voice in publicly funded research. Secondly, the United Nations convention on the Rights of the Child includes protection and participation in society, allowing children and young people to engage directly in all stages of the research process rather than be represented by parents or guardians (Akhtar & Nyamutata, 2020).

The National Institute of Health Research and INVOLVE (NHS, Health Research Authority) has published guidelines supporting public involvement (INVOLVE, 2012; NIHR, 2014). However, it is argued these have little theoretical or methodological underpinnings (Rose, 2014). Concerning this several systematic reviews have been conducted to assess the impact of public involvement (Brett et al., 2010; Crocker et al., 2018). A limitation of these is the individuality of involvement due to the uniqueness of individual research projects, project outcomes and evaluation of involvement impact, making it difficult for comparisons (Greenhalgh et al., 2019). Despite limitations, the inclusion of experts through experience improves the research quality through knowledge and experiential insight (Staniszewska et al., 2017; Young et al., 2020). This interdisciplinary research explored living with coeliac disease including potential implications for supporting people, so drew on the guidelines and practices from health, psychology, sociology, and research with families, and children.

Based on the beneficial evidence of public involvement, the inclusion of children and young people as research participants and the novelty of the research, I decided to work with adults, young people, and children as Research Advisors.
to design the research methods. Working with research advisors during the research design was viewed as beneficial for several reasons; improving the research experience of participants; recruitment and retention into the study; acceptability of the research methods; and ensuring readability of participant documents. The next chapter explains the involvement with people, who were experts through lived experience, in the research design.
5 Stage 1: Consultation with Research Advisors on the Research Design and Participant Documents

This chapter explains how the Research Advisors (RA) were consulted on the research design for this study to inform the second stage of the research. First the purpose of the RA are provided then how RA were recruited. Next the consultation meetings are explained. Followed by the meeting decisions regarding interview topic guides, feasibility of participant-generated photographs, participant recruitment strategies and feedback on the participant documents. The chapter ends with an evaluation of the consultation process and recommendations for future work with RA.

Children, young people, and adults, referred to as Research Advisors (RA), actively worked in consultation with me, as the researcher, to improve the research design and materials as well as providing the opportunity to shape research and learn new skills. The term parent in this chapter refers to the person(s) legally responsible for a child or young person.

Figure 5 provides an illustration of the processes required to establish teams of RA, and the tasks performed.
To inform working with adult public the INVOLVE guidelines and guidance from Imperial College London, in conjunction with literature were used (INVOLVE, 2012; NIHR, 2014, 2018). In health research guidance for the involvement of children and young people was less well established and recognised as an area requiring further development (INVOLVE, 2016; Sonpal et al., 2019). Working with children and young people is beneficial to all stakeholders as illustrated by Generation R, an established and active involvement group (Boote et al., 2016). To support working with children and young people I consulted guidance written by children and young people for researchers, applying the recommendations such as regular breaks and snacks (INVOLVE, 2019). Additionally, advice was sought from the Open University Children’s Research Centre on working with children, local school partnerships and ethical considerations. The guidance was all drawn upon to help ensure the information provided and involvement in
the research were engaging for children and young people. In addition to guidelines, I was able to draw on prior research experience of establishing and working with adult patients and the public in health research involvement (Goodliffe et al., 2019; Young et al., 2019).

The purpose of working with RA in the design and planning of this research was to improve the relevance, clarity and feasibility of the design as follows:

1) The involvement of RA was central to identify areas of importance to inform interview guides to ensure relevant topics were included for people living with coeliac disease.

2) The advice of RA on the feasibility and acceptability of employing a participatory method – participant-generated photographs – and the tools and processes required for the taking and sharing of photographs.

3) The input of RA in recruitment strategies to improve response and retention rates.

4) Review participant literature for readability, appearance, clarity, and comprehension.

To inform future involvement in research, RA were also asked to complete an evaluation of their involvement as knowledge of involving people aged eight to 17 years in research is limited. All RA were invited to be involved in the dissemination of the process of working together.

To provide an understanding of everyday life three teams of Research Advisors were established to reflect differences across the life course: adults; young people (aged 13-17 years); and children (aged 8-12 years). Separate teams for people aged under 18 years were created to reduce the influence of peer
pressure and accommodate differences in the developmental stage (Gibson, 2012). The team sizes were small with a maximum of five RA to ensure all advisors would be able to contribute at meetings. The aim was to recruit a mix of genders. It is not standard practice to seek ethical approval for public involvement as the fundamental principle of involvement is working with research teams, so equal partners. However, although RA aged under 18 years were not participating in the main research, in the interest of best practice and safeguarding as stipulated by the Open University Human Ethics Committee (OUHREC) ethical approval was sought (HREC/3206/Goodliffe). Additionally, I updated my safeguarding training and enhanced Disclosure and Barring Service check (DBS). Ethical approval was not sought for adult RA.

5.1.1 Research Advisor Recruitment Procedure

The overall research aim was to provide an understanding of family members’ experience of living with coeliac disease so people with or who had a family member with a dietary condition, were sought for public involvement. Dietary conditions included coeliac disease, food intolerance and food allergy. This was to reflect expertise in daily avoidance of specific foods. Diet related disorders such as anorexia nervosa were excluded as these are primarily psychological conditions whereas dietary conditions have a primary physiological cause. Additional RA criteria included being aged eight years and over, willing to provide advice, and living within a 20-mile radius of Milton Keynes the location for meetings.

Recruitment for RA took place during January and February 2020 with information tailored for adults, young people, and children. Research Advisor documents were critically reviewed by my relatives and friends, aged 12 to 56
years. All communication with people aged under 16 years was through their parents. An information leaflet was sent by post or email, depending on preference, to all enquirers still interested following initial contact. (For Research Advisor Information Leaflets see; Appendix A child; Appendix B young people; Appendix C adult). Parents had to enquire on behalf of their child or young person (see Appendix D). After one week, if no response was received from enquirers, a follow-up email was sent to ask if the enquirer or/and child or young person had any questions and whether they were still interested in the RA role.

The opportunity for adult RA were only advertised internally through the OU online notice board. This generated enough volunteers with eleven adults enquiring about the adult RA role via email or telephone. Following being provided with further information about the RA role, three did not respond, one lived outside of the catchment area, one had a prior commitment on the proposed meeting date, and another withdrew as nervous.

For children and young people, a school local to the Open University in Milton Keynes, with 2044 registered pupils, agreed to email all parents details regarding the RA opportunity. Due to a low response rate the opportunity was also advertised on social media (Facebook) and the internal Open University online notice board. Twelve parents approached on a child or young person’s behalf, three did not respond after being provided with details, two had prior commitments on the proposed meeting date, one withdrew, and one responded after the meeting. Interested people were offered an in-person informal meeting to discuss the role and meet me. This was to help reduce any anxiety and concerns before the research group meeting. One child and parent accepted
this offer and we all met for 30 minutes in a private room at the child’s school. Prior to the research meeting contact and location details were provided to parents and adult RA.

5.1.2 Research Advisory Members, Meetings and Objectives
I chaired all the advisory team meetings and had the support of a fellow researcher for the young people’s meeting. All the team meetings were two and a half hours, broken-up with two refreshment/comfort breaks. Drinks and suitable dietary snacks were provided as these were reported as an essential requirement by children and young people advising research (INVOLVE, 2016). Dietary requirements were taken before the meeting for catering.

The adult RA team were all women aged 27 to 52 years. Three had a dietary condition and two had family members with a dietary condition. The research advisory meeting with adult RA was held on the afternoon of Saturday 22\textsuperscript{nd} February 2020 in the OU library Milton Keynes where we had sole access.

The children and young people research advisory meetings were held on Saturday 7\textsuperscript{th} March 2020 at the Open University Milton Keynes campus. The child RA team meeting was held in the morning (9:30–12:00) and the young person RA team meeting in the afternoon (13:00–15:30). Support was planned for the child RA meeting but due to unforeseen circumstances, this was not possible on the day. One child RA, due to illness, was unable to attend the meeting. This worked out well with two child RA, a girl, and a boy both aged 11 years, attending the meeting. Both had the experience of living with a family member with a dietary condition and one also had personal experience. The young person RA team were aged 13 to 16 years, three girls and one boy. Two had dietary conditions. Two had no experience of dietary conditions but joined
the team to share the experience of being a young person and increase the team size making it more dynamic and less daunting for the other two members. The team meetings were held in the ‘Creative Lab’ as the laboratory is conducive for creating an informal relaxed setting with colourful soft comfortable furnishings (sofas, beanbags). Each team met in the atrium area of the building where assent/consent forms, contact detail forms and register were completed by RA, parents, and me (see Appendix E for consent form). Housekeeping was explained and parents were shown the Creative Lab, so they knew the location of their child or young person. The Creative Lab is only accessible to authorised persons, so for child protection purposes ideal. Parents who stayed waited in the atrium area of the building where the breaks were taken.

The meeting agenda was identical for all three team meetings. A PowerPoint presentation was used to provide a visual aid of the agenda and meeting objectives. Figure 6 shows a screen shot of the agenda. The team meetings started with a welcome, housekeeping and overview of the meeting agenda. Next, we all introduced ourselves and did an ice-breaker activity. Due to the instant talkative and friendly nature of all adult RA an ice-breaker activity was perceived unnecessary, and introductions (except the researcher) were not performed until the first break.
A brief overview of the research process in general and the proposed research project was given to provide context for the three meeting objectives; 1) designing an interview guide; 2) feasibility of participant-generated photographs; 3) participant recruitment.

The first objective was to design an interview guide. Figure 7 shows a screenshot of the prompts used to encourage reflections on daily life to inform the interview guide. To help reflect on what is important to us in everyday life in the children and young people meetings we each completed a ‘relationship circle’, where we included people, activities, and things that we valued. In the centre was the person, with two surrounding rings to write these in with the most important things in the closest ring and less important in the second ring. We then discussed these. Using this information together we did a mind map (child
group) and bullet points (young person group) of items they thought were important to ask people being interviewed. We then had a refreshment break where children and young people had a tour of the other laboratories. These research laboratories differ from those found in most schools as they include technologies to research gaming, eye tracking, observations, and a recording studio. In the adult advisory meeting, the discussion began with a prompt to consider daily life that naturally evolved into a rich open discussion regarding everyday life areas perceived as important to explore with participants.

**Figure 7** Screen Shot From Children and Young Person Advisory Group Meeting Interview Guide Suggestions

The second objective was exploring photographic devices and photographs to determine the feasibility of participant-generated photographs. Figure 8 shows a screen shot to support methods discussion. Research Advisors were shown a selection of cameras (disposable camera, iPad, digital camera, mobile phone)
to consider suitable photographic devices. How many photographs, if any limit (minimum or maximum), to take was carefully considered along with how many photographs participants should share during their interview. Who would be included in photographs was considered, and if relevant how consent to take photographs of others could be sought. How participants could share photographs with me was discussed. How this should be done was agreed as a team.

Figure 8  Screen Shot of Research Advisory Meeting Questions to Discuss

*Photographs*

- How?
- Who?
- How many photos?
- How many days?
- Hard or digital copies?
- How to share with researcher?
- Sharing photographs?

The third objective was participant recruitment. Suitable places and platforms to target potential participants were discussed. I had designed a draft participant recruitment advert that all RA commented on to improve.
At the end of the meeting, I explained to all RA how we had designed the procedure for a research study. They were reminded that they would be sent participant documentation based on their decisions for critical review. Each RA decided how they preferred to give feedback on participant literature (email, in person, telephone) as well as a choice of a £20.00 gift voucher (Love2Shop or Amazon). Each team agreed on the amount of time needed to give feedback. Travel expenses were reimbursed to all.

During the all the meetings I had taken notes plus additional notes made by child and young people RA. My notes were not shared with RA with the exception of the adult RA. The notes were shared with adult RA for comment to ensure I had captured all details regarding the interview guide as the team had not written shared notes. The meeting decisions informed the research design and participant documentation. All RA were emailed participant documentation for review, and all provided feedback either via email or telephone.

Following feedback, an evaluation form was sent to understand what went well and what could be improved for the development of the researcher skills, and future research as knowledge is especially limited on working with RA aged under 18 years. RA were asked how they would like to be included in any research outputs.

### 5.2 Research Advisory Team Meeting Outcomes

All RA contributed to the objectives working in collaboration, agreeing through consensus final decisions. The decisions from each advisory meeting were drawn together in the participant documentation. An exception to this was the suggestion from a member of the adult advisory team for an exhibition using
participant generated photographs to raise awareness of CD. The opinion of
other RA was sought on the idea.

5.2.1 Designing Interview Topic Guides
Understanding what matters to people in everyday life in the specific population
of interest, families living with CD, was essential to help ensure that interview
topic guides asked relevant questions reflecting values and different age
groups. The inclusion of interview topic guides for the research was to provide
prompts in relevant areas if required and a backup guide in the event of
participants not sharing photographs. Additionally, as the researcher, I had no
direct experience of coeliac disease or any dietary conditions, so RA provided
an invaluable insight into this experience. The adult advisory team meeting
spent longer discussing factors to consider in the interview guide compared to
the other two meetings, while the children and young people meetings focused
on generating questions to ask people of a similar age. The meetings generated
interview guide topic questions based on food, family activities, practical
challenges, education, social groups, and interaction.

For all teams, wellbeing (mental) and physical activity were important with
maintaining these forming a key part of daily life. Food and family were central
to all teams, however why they were important differed.

Food

The adult RA team reported food as a key concern at home and away from
home. Within the adult RA team differences in questions between those with a
dietary condition and those without were expressed. Adult RA without a dietary
condition conveyed strongly about providing protection from the dietary
contaminate, advocating for family members with dietary needs in social environments. They did not feel uncomfortable doing this. In contrast adult RA with a dietary condition voiced the opposite, not wanting to burden family members with dietary needs and feeling uncomfortable outside the home in relation to attention around dietary needs. These factors were not reported by the child and young person RA teams who viewed food as important and did not perceive any barriers to food inside or outside the home. Child and young person RA with dietary conditions described coping well with avoiding specific foods and reported no concerns. The children and young person teams described parents managing food in the home so not something they had to consider. The purchasing of food arose during meetings with many RA commenting on how even when purchasing food products regularly the checking of ingredients was still required due to changes in processing and ingredients. The meeting discussions around food indicated that interview questions around food would differ between adults with CD, and adults and children, as well as providing insights into potential avenues of enquiry with research participants.

*Everyday life*

In the reflection activity discussion, family members and doing family activities were valued by all members at the children and young people meetings. However, young person RA thought it would be strange to ask someone questions about their family with peer groups coming across as more important. The children and young people advisory teams both stated education played a central part in everyday life. This varied depending on the educational stage with education dominating all areas of life for those due to take exams. Both
teams also stated communication with friends as an important factor, with mobile phones central in facilitating this. These devices allowed interaction and provided entertainment. The children and young people RA meetings created questions asking about morning routine, favourite activities, likes, dislikes, pets, and friendships. Members of the children RA team highlighted how the routine of everyday life varied at the weekend. Examples of questions devised by the child RA’s, ‘what do you like about school?’; ‘what kind of friend do you like?’. Figure 9 below shows the mind map created by child RA’s during the meeting.

**Figure 9** Mind Map of Interview Questions Generated at Children’s Advisory Group Meeting
The young person team proposed questions along themes similar to the child RA around likes, dislikes, education, friendship, entertainment, and free time. Examples of questions generated at the young person meeting ‘what do you do to relax?’; who do you support – football?’; ‘what weird things have happened to you?’ Figure 10 below shows the questions generated at the young person advisory meeting scribed by the one of the members.

Figure 10 Young Person Advisory Group Meeting Interview Question Ideas

Specific areas raised by all adult RA were not being taken seriously with challenges reported in social life, employment, education, and medical care. Planning was a key feature to reduce any potential problems inside and outside the home, including holidays. Going out for a meal was not spontaneous with menus being checked before going and being given ‘the folder’ (special dietary
menu) when dining at restaurants. One adult RA summed it up well with the comment received in a restaurant from server, ‘three coeliac and one normal’. Others reported being asked ‘how allergic to gluten are you?’ illustrating the challenges presented around social interactions and food. Adult RA also advised of challenges around accessibility of bathroom facilitates outside of the home environment. In the adult team meeting, all members (excluding me) expressed the emotional impact of living with a dietary condition. Negative emotions dominated (scared, guilt, embarrassment) with the recognition of kindness in response to others accommodating actions. The challenges and concerns voiced in the adult team were not expressed by younger RA possibly demonstrating how parents protect children or how these behaviours are the accepted norm for younger people so not perceived as problematic.

Overall, the types of question at each advisory meeting differed, adults included emotion and challenges, young people around educational pressures, and children’s what people like and do. This illustrates developmental and life span stages which need to be taken into consideration when designing interview topic guides and during interviews. Having the expertise of RA for the interview guides enabled the inclusion of relevant prompt questions and also potential questions to help build up rapport with participants.

5.2.2 Feasibility of Participant-Generated Photographs
Research advisors at all team meetings agreed participant-generated photographs as an acceptable method. Next, in each team meeting we discussed practicalities firstly by contemplating photographic devices. Interestingly members of the child team had not seen a disposable camera before and spent more time considering photographic device options than the
other RA teams. Both the children and young people teams considered the quality of images, something the adult team did not perhaps being a generational reflection in the taking of images. Digital cameras, due to good image quality, were initially the preferred device for the young people team before deciding on mobile phones due to ease of use and portability. Mobile phones were unanimously agreed on in all meetings as the most suitable device for taking photographs due to the ease of use, portability, and high levels ownership. The young people team pointed out the benefit of being able to store photographs in different files on mobile devices, enabling separate storage of images for research purposes. It should be noted all RA owned mobile phones.

Next the inclusion of other people in photographs was discussed, whether others should be included and if yes gaining their permission. Some adult and young people RA were aware of General Data Protection Regulations (GDPR) and consent. The young people meeting had a detailed discussion on the forbidden usage of mobile phones within school with all agreeing this should be allowed for research purposes as school formed an important part of daily life. I explained seeking approval from parents, pupils, teachers, and governors to use mobile phones within school and including identifiable images would be a lengthy process and problematic. From a practical perspective seeking approval from potentially multiple schools and corresponding stakeholders was unviable within the PhD timeframe confines. At all meetings the inclusion of others (friends and family) in photographs was agreed as essential. The research advisory teams all agreed it was acceptable and feasible to seek people’s permission before taking their photograph. The young people team explained how they would ask someone for permission. Both the children and adult teams
raised points about making it clear to participants not to stage photographs. This point was raised by the adult team during a discussion on holding an exhibition of the non-identifiable images from the research, not wanting participants to stage photographs.

Next the length of time for participants to take photographs was considered by all teams. All RA thought the inclusion of weekends important as these differed from the regular routine of weekdays. The children and adult teams proposed seven days and the young people team six days. Discussion was then held on whether a limit needed be placed on the number of photographs from research participants. I explained the maximum duration of the research interview would be one hour to not overly burden or fatigue participants. Members of the adult team proposed sending a top daily three photographs, but other team members felt this would be unachievable so a compromise was agreed with the sharing of seven for the research with the participant able to take as many as they wanted to. The young people team reached the same decision while the child team decided a maximum of 42 photographs with seven to be shared.

How to view photographs was discussed in great depth by the child group who preferred digital copies, as you can zoom in on things in the photographs and it is better for the environment as not printed. This view contrasted with the other two groups whose preference was for paper copies of photographs as these are easier to share, more straightforward, formal, and presentable. The sharing of paper copies was also discussed as preferable as tactile with the ability to see them all and move around easily. It was decided to allow participants to decide how they would like to view the photographs.
The electronic sharing of images, due to a perceived risk of images being intercepted by unauthorised persons, had been a significant concern raised by The Open University HREC. The concern was explained to all teams and discussed. All teams agreed to the electronic sharing of photographs via email, WhatsApp, or using other online tools as these are popular and easy to use methods. Parents sending the photographs on behalf of participants aged under 18 years was agreed as acceptable and feasible by the children and young people teams. The printing of photographs by an external company was acceptable to adult and young person teams. Adult RA raised awareness of what the images could contain, for example toilets. The adult team suggested using the photographs for an exhibition to raise awareness about living with coeliac disease. The idea was shared with the other two teams who agreed. The incorporation of an exhibition into the dissemination of the research was intended but unable to take place due to COVID-19 restrictions.

5.2.3 Participant Recruitment Strategies
All meetings generated ideas for places to advertise for research participants. The children team discussed ideas including a specific study web site, use of music, and Google adverts. To encourage people the team suggested a token of appreciation for taking part in the research in the form of a gift voucher, although when I explained that unfortunately, no money was available, they still thought people would be interested in participating to help others. The young person team put forward restaurants and schools as suitable sites. The adult team advised of specific local gluten-free cafes, bakeries, and online support groups as well as the Coeliac UK charity. All meetings suggested social media, especially Facebook, as a good place to advertise for study participants.
A draft of a recruitment advert was shared with all teams. The children and young people teams discussed the visual appearance of the advert proposing the inclusion of bright colours, happy images, and text format. The adult team spent more time discussing interview topics and potential recruitment sites so gave feedback on the advert after the meeting. The advice from RA on advertising was invaluable as those living with coeliac disease were aware of venues that catered for gluten-free diets as well as closed groups unknown to me. Assistance was offered by adult RA in accessing these groups which I accepted.

5.2.4 Participant Documents
At advisory meetings the relevance and importance of research participant documents was explained to support RA in reviewing the documents. The cover letter sent with review documents included a reminder for RA of the purpose. During the participant documentation feedback period (March 2020) the UK entered the first national lockdown due to the COVID-19 pandemic, therefore all the in-person feedback was rescheduled and took place via telephone and email.

The decisions made at the meetings informed the research design and participant documentation. The draft recruitment advert was edited based on RA advice and decisions agreed in the meetings. The recruitment advert, participant information sheets, assent form, consent form and photograph permission form, tailored where relevant for children, young people, and adults, were circulated to all RAs for comments. Comments were given via email or telephone as lockdown restrictions prohibited in-person meeting. All RA
provided constructive feedback from language used to the formatting of images. Some examples of the feedback received from each team of RA are provided:

Adult RA participant documentation feedback

Feedback from adult RA included changing language used, such as ‘pseudonymised’ to ‘names changed’ and breaking up bulky paragraphs into smaller chunks to improve readability.

I have gone through your documents, and they appear clear and concise. The advert is good as it is not too wordy, and the colours are eye-catching.

‘Recruitment Advert:

I love the pictures of the families showing all the variations of family that you are interested in joining the project. I hope it will generate a lot of interest.

Adult photograph consent form:

Nice and clear. I like the use of bold to highlight the important passages.

Adult informed consent:

You use the word 'pseudonymised' here and in the interview topic guide. I think this might need to be reconsidered as it is not a word that everyone will be familiar with.

Information sheet for participants:

I found one paragraph confusing. "What is the purpose...?" In the second paragraph of that section, you write "You must be an adult" and then later "You need to be aged 8 or over". I think that you mean the
lead participant needs to be an adult and all those taking part need to be aged 8 or over, but I feel that this isn't clear.

Young person RA participant documentation feedback
Feedback from young person RA also pointed out the term 'pseudonymised' needed to be changed to ensure people would understand it.

Recruitment Advert:

The recruitment advertisement shows and explains very clearly the goals and requirements of the project, and the criteria a participant would need to have in order to take part in the project. It is laid out in a way that highlights the main points of the advert, and the images of the different family dynamics promotes inclusivity and invites a more diverse audience.

Information sheet for participants:

I think the first attachment the photos should be a bit smaller and the ones at the top should be in line with each other, the heading should also have a space from the open university logo to keep it neat.

Interview topic guide: Suggested additional questions;

Can you tell me about food in your daily life? Would be hard to do the research now, as no-one’s daily life is normal now’ ‘might want to say ‘before the outbreak.'
Child RA participant documentation feedback

Feedback from children RA group included constructive suggestions on appearance as well as content.

Information sheet for participants:

The information sheet is good, but the photo can be improved. We are trying to show a smile and this photo doesn't emphasise that. A miniscule detail here, but can you change the ticks to bullet points for we don't want to think this has already been done before.

Interview topic guide:

The interview guide is very chunky, so I was thinking splitting it down into different sections or at least remove some non-vital parts. I like how you have put the subheadings in a different colour to classify it better. I also like the manners in not just this piece, but the whole article, with words like Thank You.

As a consequence of the COVID-19 pandemic, the research design had to be altered to comply with UK government public health policy to ensure the health safety of all involved with the research. The design was modified to conduct any in-person components of the research online via online synchronous video. The research design is presented in Chapter 6. The modified design was reviewed and approved by three adult RA and one child RA and their parent. The participant literature was edited in response to RA feedback and submitted as part of the research ethics application to the Open University HREC for approval.
All RA were very supportive of the research project and great teams to work with.

5.3 Evaluation of Public Involvement and Recommendations

To inform future public involvement work and develop my practice, RA were asked to complete evaluation forms. All RA (n=11) completed evaluation forms, assisted by the promise of a gift voucher on return. The evaluation forms covered all elements of involvement and overall comments on the experience of being a RA. The original plan had been to post a paper evaluation form to RA so they could be returned anonymously to me at The Open University. This was not possible as the Open University campus was closed due to COVID-19. In the interest of safe practice, my home address was not disclosed instead RA were asked to email evaluation forms. They were sent as electronic word documents to allow RA to edit them, unfortunately on two evaluation feedback forms the participant document reviewing and involvement was missing as the final section had shifted onto an additional page. The next section provides the evaluation feedback from all RA on the overall experience.

5.3.1 Evaluation Feedback from Research Advisors

Research Advisor recruitment

Several RA (n=6) heard about the opportunity through family members or friends. Followed by the Open University internal online notice board (n=3), the
school notice board \((n=1)\) and Facebook \((n=1)\). The amount of information provided before the meeting was enough for all RA.

**Research meeting**

Research advisors reported the information provided at the meeting was the optimal amount. At the meeting, teams were provided with an overview of the research process and the research being discussed. Overall, the small team size was preferred though a person in the smallest group \((n=3)\) suggested a larger group to seek more opinions.

All groups were provided with refreshments. The variety of dietary requirements made this challenging. Catering provided for adult RAs included a selection of biscuits and fruit plus hot drinks from a vending machine. The child and young person RA catering comprised of popcorn, biscuits, and fruit. Refreshments were highly recommended for children and young people involved in research design, so their feedback was relevant \((\text{INVOLVE}, 2019)\). Adults were not asked for feedback on refreshments. Parents were informed about refreshments plus the supporting colleague was a registered nurse. The refreshments were reported as okay by children and young people with a recommendation of cereal bars for future public involvement.

All RA reported meeting objectives and associated activities interesting. Here are a selection of evaluation comments:

*It was creative, and we got to write and design to help other people* (Child RA)

*I liked the photography task and the beginning* (Young person RA)
It was an engaging experience overall and I enjoyed meeting people in a similar situation to my own (Adult RA)

Many RA found the involvement an opportunity to reflect, listen and learn:

I chose this answer because it really gave me time to think about how my life is effected by my brother (Child RA)

Because you got to say your honest opinions and it was inclusive (Young person RA)

It was interesting to hear other people’s experiences and I learned about others too (Adult RA)

Research Advisors reported being able to express own ideas, having these listened to and valued:

All the ideas I gave were carefully listened to and discussed (Child RA)

Samantha made sure to ask everyone for input (Young person RA)

Everyone was given the chance and opportunity to talk and discuss their thoughts and feelings. There were no judgements made, it was a safe space (Adult RA)

The majority of RA found giving feedback on participant documents interesting, none reported it as boring. Document feedback methods adapted due to the lockdown, from in-person to email and telephone:

The researcher was very helpful and patiently listened to everything I said (Child RA)
Very simple (Young person RA)

*Tried to look at it objectively and put myself in position of someone taking part in an interview, Samantha was very clear that all feedback was wanted and not to shy away from any suggestions* (Adult RA)

Except for one RA who was already very knowledgeable on research methods, all RA reported an improved understanding of research design, and all said they would be a research advisor again. Verbal accounts reported that none of the RA had been involved in research in an involvement capacity previously.

Research Advisors’ recommendations for future groups

For adult involvement meetings, introductions were suggested:

*Perhaps allow everyone to introduce themselves first and explain reasons for taking part (although everyone did this as meeting progressed)* (Adult RA)

This is valued feedback as I had assumed due to the conversation before the meeting starting that adult RA were comfortable with each other, so I omitted the ice breaker activity. In future adult RA meetings, encouraging people to introduce themselves will be done together with an ice breaker task.

Young people suggested having input at the meeting planning stage,

*Maybe you could plan it out before then show it to us then ask us how to improve* (Young person RA)
Including younger members in planning meeting agendas and activities would be beneficial. Having the input of members could help with deciding how much time to allow for topics.

5.3.2 Recommendations and Reflections for Future Public Involvement

The school response rate of 3.7 per cent was low based on a school role of 2044 pupils. According to the UK Food Standards Agency (FSA), one to two per cent of adults and six to eight per cent of children in the United Kingdom have a food allergy with one in 100 people having coeliac disease (Wearne, 2017).

Based on the FSA data in the local school an estimated 40 parents and 102 school pupils would have had a food allergy and 20 people (parents or children) having coeliac disease. An explanation for the low response rate is the assumption that parents read emails from school, so possibly the email was unread by parents. This method of recruitment has been found in studies to be ineffective (Engward, Goldspink, Iancu, Kersey, & Wood, 2022). On reflection emails solely to parents were not necessarily in the best interest of children as some parents volunteered their child without consulting them in the hope it would provide a better understanding of the parent’s dietary condition and improve coping of their own dietary condition. This illustrates the loss of autonomy for children and young people in recruiting via parents. Having child and young person involvement enables them to have autonomy, so the recruitment response was not reflective of the underlying public involvement ethos. Interestingly, the child and young person teams proposed recruitment adverts in schools suggesting posters targeting children and young people as a more effective recruitment method. A solution to allow some autonomy whilst maintaining child protection for future child and young person involvement in
research would be for adverts targeted directly to young people and children with the proviso that parents need to contact the researcher.

The young person RA team made a valid point about school playing a large part in the lives of school-age people and highlighted that mobile phone use for many in school was prohibited. They provided some effective solutions to the taking of photographs in a school setting however due to practical considerations and potential ethical concerns this was not a viable option. Practically it would require the permission of many gatekeepers from teachers through to school governors as well as pupils. It is likely the request would be declined as many schools operate a policy of restricted mobile phone use during the school day. This is further complicated as location, the number of schools, parents, and pupils involved was unknown until participant recruitment making it unfeasible. Additionally, the time remaining to complete the research was not enough to seek ethical approval and permission from all concerned to incorporate this into the research. Ethically the inclusion of being able to take photographs in school has many concerns. This point demonstrates the value of working as a team to identify what is important to the research population of interest and feasible from a research perspective.

As well as discussing where photographs were taken the OU HREC had been concerned about the inclusion of people in images, so this was an important item to be discussed. The inclusion of other people in photographs was discussed in-depth with everyone agreeing the inclusion of others was acceptable and normal. Taking photographs of family and friends was an accepted practice. No concerns were expressed about asking others for permission to include them in the photograph and explaining the research. It
was agreed that identifiable images would not be publicly shared. The taking of non-identifiable photographs was also agreed as suitable. Working with RA on this issue provided support on the ethics application for participants to be able to share images of others with the researcher for the purposes of data collection. This improved the quality of the research by providing participants complete freedom regarding what photographs to take to capture their daily life.

For me as a researcher exploring living with CD, the process of purchasing refreshments was insightful into what people with dietary conditions experience as checking the ingredient list was time consuming and, in some cases, impossible to read due to small print. Many products although not containing the avoided food were often produced in factories containing it thereby making it unsafe for consumption. This provided an insight into some challenges of grocery shopping for a dietary condition.

A consideration for future groups from an ethical perspective is siblings being in the same group as could either be supportive or not. In this instance, it did not occur, but I was concerned about one potential family who enquired about the opportunity as the parent stated the child with the food allergy was very anxious and not coping well viewing the RA role as a supportive solution. I explained to the parent the purpose of the opportunity clarifying the focus was on research design not dietary education or support.

For future groups providing budgets and time frames would be useful for RA as some ideas proposed were unfeasible. Although this could be viewed as restrictive, the aim of having public involvement is to improve the research, it provides a framework for all members. An exception to this would be having
public involvement at the conception of research where budgets and time frames are planned.

Although meeting decisions were written and agreed with notes taken the recording of meetings as an aide memoir would have been useful to ensure nothing had been missed. When working with young people spending more time building group rapport would be worthwhile. At the meeting it took a while for discussion with young people RA to flow. After the break where we had chatted about COVID-19 the flow improved with members appearing more comfortable.

Overall, RAs reported a positive experience of involvement in research design and materials. As a researcher I felt reassured that RAs reported inclusion within the meetings as well as willingness to be involved again in future research. Constructive feedback from RA has provided areas for future improvement when working with public involvement. These can be applied in future research.

5.4 Conclusion
Overall working with the RA improved the relevance, acceptability, and feasibility of the research design and materials. The involvement of RA resulted in the design of interview guides with topics that were relevant to adults with CD and their adult, young person, and child family members. The photograph-participatory method was deemed feasible for research participants, with guidance agreed on the inclusion of other people, methods to take and share images, and a maximum number of photographs for interview inclusion.
Research advisors provided invaluable advice identifying suitable places to advertise the research therefore helping to reach the target audience. Linking to the research design was the participant documents. Critical constructive feedback from RA supported the production of clear comprehensible research participant documents. The decisions made informed and enriched the research design, ethics application and research materials. The RA evaluation provided me with areas for skills development to apply in future work with public involvement and dissemination. Everyone, all RA, engaged in the process, making it a very enjoyable, rewarding, and motivating experience for all.
6 Stage 2: Methods and Data Generation with Families with CD

This chapter starts by foregrounding the exceptional circumstances that people were living through during the research data collection. The social context played a role in shaping the research design, recruitment, data generation and analysis. Secondly the research design is presented, grounded in the decisions made in consultation with the Research Advisors. Next the research recruitment and participants from nine families are detailed. Then the data generation through participant-generated photo-elicitation interviews are described. This is followed by the ethical considerations, an important aspect of concern within the research given the population included children and young people, photographic images, and a health condition. The data analysis, a reflective thematic analysis, is then presented before the chapter concludes with a reflexive section.

6.1 Pandemic Disruption to Daily Life

As mentioned in the previous chapter, the World Health Organisation declared a global pandemic in March 2020 (World Health Organization, 2020). This research was conducted during an unprecedented global pandemic that impacted people socially, psychologically, and biologically disrupting daily life. In the months preceding March 2020, the global spread of COVID-19 was widely reported as the virus approached the UK. People observed the devasting impact of COVID-19 through the widely reported high mortality rates and strict
lockdown measures imposed upon citizens in other nations. Although the pandemic had a global impact, since the research was conducted in the UK, only the national restrictions are explained here as these shaped the research and provide an illustration of the exceptional milieu people were living in.

On 23rd March 2020 in the UK the first national lockdown was announced. A ‘lockdown’ required people to remain at home and they were only allowed to leave to purchase groceries, exercise once a day (only with other household members) and to work from home where possible, avoiding all non-essential contact and travel. Only essential shops, such as grocery retailers, were allowed to trade, while to enter these people had to wear protective face masks and queue to enter stores as numbers inside were restricted, to shop alone, and socially distance (physically stay two metres away from other people). All educational establishments were closed with teaching delivered online with great variations between schools and formal examinations cancelled with teachers guiding final awards. Where possible people worked from home, others were furloughed (a UK government scheme that paid peoples’ salaries), so education and employment were performed at home. People were unable to mix with other households leaving many isolated. Families were unable to visit relatives in care homes or hospitals, weddings were cancelled and rescheduled. Some people deemed as clinically vulnerable were told to shield (not leave home). In response local communities and online food retailers provided support.

Restrictions began to be lifted in June 2020 with the phased re-opening of schools and non-essential shops. Also, people were permitted to meet outside in a maximum group size of six. Travel corridors to other countries opened,
however these were often closed at short notice in response to rising COVID-19 cases creating a panic to return to the UK before quarantine restrictions were imposed. July 2020 saw the re-opening of hospitality venues and hairdressers, and an increase of gatherings up to 30 people. August 2020 saw the lifting of lockdown restrictions on indoor entertainment venues such as theatres and soft play establishments. In September 2020 restrictions were tightened again in response to increasing COVID-19 cases. Legally people who tested positive for COVID-19 were required to self-isolate at home with any people they had been in contact with advised to test and self-isolate. From March to September 2020 daily updates on the number of infections and deaths from COVID-19 were reported. The period constantly changed for people, for example school classes, hospitality and entertainment venues closed at short notice due to outbreaks. Other core social practices were impacted such as funerals had restricted attendees with no social contact (hugging) or wakes, wedding ceremonies had limited guests, with no visitors or limited during births and deaths. There were reports of family members communicating with loved ones in hospital via synchronous online video usage.

Many of the restrictions were imposed to protect the NHS whose resources, human and physical, were stretched having an ongoing impact. The restrictions disrupted many fundamental social practices affecting people psychologically, socially, and biologically. Many people experienced social isolation during lockdowns, relationships were strained with families all living and working in the same space, distress at not being able to visit loved ones in hospital impacting on mental health of all. It was a period of great uncertainty and change, challenging peoples’ coping resources. However, the lockdown provided many
people with the opportunity to pause and reflect prompting changes in personal values and goals. Also, it became a natural experiment for people to work from home. Due to the extraordinary circumstances the research was conducted under an appreciation of the changing and uncertain social context is necessary.

6.1.1 Research Pandemic Re-Design: Adaptation of Methods from In-Person to Online
COVID-19 restrictions disrupted societal functioning triggering a nationwide and individual process of adaption with, where able, people remaining at home, so employment and education took place from home. Consequently, my research methods were adapted to provide health security for participants and myself as well as complying with pandemic-related UK legal restrictions. Fortunately, advances in internet mediated communication combined with these resources being available in many homes, provided the opportunity to continue safely with the research. Throughout this research process period (March to September 2020) the OU policy was no in-person research. The exceptional context under which this research took place is important to acknowledge as it shaped the research.

In response to the exceptional circumstances (March 2020) the OU HREC immediately prohibited all in-person contact with participants, advising where feasible to move to remote interactions with participants, providing guidance on when ethics amendments and research pausing were required. Following consultation with my Research Advisors on the COVID-19 situation (presented in Chapter 5), I accordingly adapted the proposed recruitment process and data
generation method to include online methods then submitted the ethics
application to the OU HREC. At this point no one knew the duration or impact of
the pandemic, so I prepared for the event of social (physical) distancing
restrictions not being lifted, seeking advice on the practical and ethical
challenges of an internet-based field work setting to inform method adaptation.

Guidance for Conducting Online Research. I explored the literature
and online social media seeking evidence-based guidance. The benefit of a
global pandemic was the sharing of resources and increased global
accessibility, no geographical barriers, with synchronous video seminars
broadcast via the internet. A global collaborative shared an electronic
document containing a wealth of resources for ‘doing fieldwork in a pandemic’
(Lupton, 2020). In April 2020 I attended online seminars delivered in Australia
by Professor Debra Lupton on ‘Conducting Qualitative Fieldwork during COVID’
and in America by Dr Janet Salmons ‘When the “field” is online: qualitative data
collection’. These seminars covered the practical and ethical issues of on-line
research, providing signposts to supporting literature and resources. Ethical
concerns were around addressing privacy issues in shared home spaces and
data protection, whilst practical issues concerned people having access to
online tools and familiarity with using them. To aid method adaptation the
qualitative e-research framework was consulted ensuring all potential method
areas were considered (Salmons, 2018). The framework covers key points
including type of data, selecting online technology, addressing ethical issues
and method.

The literature provided examples of online-based interviews, predominantly
using Skype (an online platform that enables synchronous video and audio
communication) (Deakin & Wakefield, 2014; Janghorban, Roudsari, & Taghipour, 2014) as well as other non-synchronous interview methods for example Messenger interviews (Jowett, Peel, & Shaw, 2011). Reflections on conducting interviews via Skype illustrated benefits seen through greater flexibility of interview time and venue. The concern around establishing rapport through synchronous video in the absence of pre-interview in-person interactions, social pleasantries (offering refreshments, handshakes) can be overcome through building a relationship through email communication (Deakin & Wakefield, 2014). However, it has been argued that technical problems, such as the loss of internet connection, can negatively affect rapport due to the loss of flow (Seitz, 2016). Research conducting interviews using Messenger (text based) reported a loss of rapport and emotion, while potentially the interview momentum was lost due to the excessive interview duration of three hours resulting in fatigue of both participant and interviewer (Jowett et al., 2011). The evidence recommended building a relationship through communication to facilitate rapport and to keep interview duration to an hour to maintain engagement (Lo-lacono, Symonds, & David, 2016). From an ethical perspective it has been argued that it is easier for participants to withdraw from online interviews, as they can simply press a button to leave without having to utter a word, providing them greater control (Deakin & Wakefield, 2014; Janghorban et al., 2014). Seitz (2016) suggests that there is a loss of body language and nonverbal cues through video interviews. Communication via online video can reduce visible body language however a person’s facial expressions are evident and often upper body movements such as hand gesticulations, are visible, also voice tone can signal many cues (Lo-lacono et al., 2016). The seminar and
literature guidance aided adaptation of the research method to accommodate the reality of the social circumstances.

**Online Accessibility.** Pre-pandemic in January 2020 in the UK 96 per cent of the population had access to the internet with 92 per cent of adults using the internet with adults aged 16 to 44 years going daily online (Office for National Statistics, 2021). There are many formats of internet mediated communication including text (emails, messaging), audio and video. Many internet mediated communication software and applications were available at the time of the pandemic including Skype, Facetime, MS Teams, Zoom, and these became key tools enabling people to communicate for work, education, and pleasure, for example on-line business meetings, school lessons, and quiz nights. The pandemic changed communication with many people adopting online methods and with an exponential growth in video communication for example between January and April 2020 the number of users of Microsoft Teams increased from three to 6.5 million and Zoom 659,000 to 13 million (Ofcom, 2020). The pandemic facilitated harnessing the potential of the internet to study human experience. The increased usage of internet-mediated tools enabled people to develop technological confidence becoming familiar with software. For many people during the UK lockdown the internet provided the only means for social communication.

The research method was successfully adapted, however at that time point in April 2020 there was no realisation of the duration or ongoing impact of COVID-19, in what became a constantly changing context.
6.2 Research Design
As detailed in the previous chapter, the decisions made together with the research advisors determined procedures within the method, including recruitment and participant documentation. The research design had to be modified in response to the constant evolving social context occurring during the data collection period. To illustrate these changes the original research design is presented here together with the necessary adaptations.

Data collection had two parts: firstly, an initial briefing interview, and secondly a participant-generated photo-elicitation interview. Figure 11 provides a flow diagram of the research stages. In the original design it was intended to hold all interviews in person, either in family homes or a private room at the university campus. These were revised in response UK public health guidelines to minimise the risk of spreading coronavirus. The amended design made all contact through telecommunication. Firstly, an initial briefing interview was held with each family group of participants to answer any queries, establish a relationship, and provide guidance regarding taking photographs and arrange photo-elicitation interviews. (For Participant Information Sheets see; Appendix F child; Appendix G young people; Appendix H adults and Consent Forms: Appendix I child and young person; Appendix J adult). I met each family via online synchronous video. Due to university campus closure, and the suspension of postal collections, participants were requested to complete demographic forms (see Appendix K child and young person; Appendix L adult; Appendix M adult with CD) and consent forms electronically or email a photograph of the completed paper copy. All participant documents were emailed or posted to participants.
Participants were asked to take photographs of anything they viewed that described their everyday experience of living with CD. The aim was to keep the guidance broad and neutral to minimise influencing participants’ choice of photographs. Seven days were provided to take photographs to include weekdays and weekends as decided through consultation. Participants were
free to use whatever digital photographic device was most suitable for them. Digital devices were considered as beneficial in allowing participants to easily take, delete, select, and share photographs. The original design proposed offering participants use of digital cameras if desired. However, in the event these could not be offered as the devices were stored in closed offices. It was hoped that family groups would share photographic devices where necessary. Based on consultations participants were advised they could take as many photographs as they wanted and asked to select seven to share with the researcher to discuss during the photo-elicitation interview.

The seven photographs were asked to be sent together the day before the interview to enable the researcher to print these prior to the interview. Participants, or their parent or guardian in the case of children and young people, were asked to send the photographs to the researcher via whatever electronic means suited them. How the photographs were securely sent was agreed with each family group to accommodate differing technological availability, knowledge, and skills.

A preference for printed images was expressed as this was agreed to be more engaging, enjoyable, tactile, and easier to share. The premise of hard copies was to enable participants to select images in the order they wanted to discuss them. The original plan to accommodate photograph viewing preferences was to provide a digital tablet to view photographs via a screen and printed hard copies of images. Participants’ photographs were printed to ensure I knew which image the participant was referring to during the interview.
Interviews were conducted via online synchronous video. Children and young people could choose to have a parent or guardian present during the photo-elicitation interview. Interviews were audio recorded using a portable digital recording device, but no video recordings were made.

Participant-generated photo-elicitation interviews were structured by participants’ chosen photographs, using open-ended questions, and guided by topic guides for opening questions and prompts. These differed for children, young people, and adults. (For interview topic guides see Appendix N child; Appendix O young person; Appendix P adult). On completion of the interview, consent and assent were sought for permission regarding the inclusion of photographic images in future dissemination and an exhibition Appendix Q. For online interviews, these were discussed with the participant and if applicable parent/guardian, with corresponding documents sent to the participant. The participant was asked to choose a photograph to discuss with the researcher, and to share why they took the photograph. The duration of interviews was expected to be 60 minutes for adults and 30 minutes for children and young people.

6.2.1 Recruitment
The businesses which had been identified as locations to physically advertise the study were closed in compliance with UK public health Coronavirus Act (2020) regulations. Consequently, the recruitment strategy had to be adapted to solely online adverts. Coeliac UK (a registered charity) agreed for the research to be advertised via their social media platforms. In the case of CD research, participant recruitment is often through CD support organisations, so by default reaching those people actively seeking information, guidance, and support.
Recruitment of participants took place from May to July 2020 through online adverts placed on the Open University virtual internal notice board, and social media platforms Twitter, and Facebook via two gluten-free bakeries. The use of multiple recruitment sites assisted in reaching people who are not members of CD support organisations. The advertisement offer from Coeliac UK was unrequired due to sufficient responses to the recruitment advert via other sources.

Fifteen people responded to the recruitment adverts. All respondents were screened using the inclusion criteria and sampling framework. Respondents that met the criteria were sent the relevant participant documentation packs for their family. After one week, to allow family groups time to read and discuss the information, I contacted the lead family member to enquire whether they had any questions and interest in participating. Four people did not respond after receiving the participant documentation for reasons unknown, one person did not meet the inclusion criteria and two people enquired after recruitment for the study had finished. A total of nine families were recruited (Open University \( n=6 \), Facebook \( n=3 \)). None of the participants withdrew from the research.

6.2.2 Participants

For exploratory qualitative research there is not a prescriptive formula, as there is with quantitative research, to determine the optimal sample size. In qualitative research the number of participants can range from one upwards depending upon the type of study and analysis applied (Fugard & Potts, 2015). A review of qualitative research sample sizes found a mean sample size of 25 participants in health sciences employing a phenomenological approach (Guetterman, 2015). Research exploring the lived family experience recruited seven to 12
families resulting in 22 to 42 participants, which included adults and children (De Almeida et al., 2016; Wennick & Hallström, 2006b). Drawing on these for guidance, this research aimed to recruit nine families each with an adult member diagnosed with CD. The focus of this research was on family experience; therefore, a definitive number of participants was not provided as the number of participants was dependent upon the size of families and the number of eligible and consenting members in each group.

The literature review, Chapter 3 section 3.2 demonstrated the way in which family is a dynamic, diverse, and fluid social grouping. To ensure a broad capture of family forms this research the recruitment advertisement contained images of different family structures to attract a diverse range of family groups. A key feature of interest in this study was family life, what family ‘do’, the everyday emotional, behavioural, and cognitive elements. The concept of family applied to this research was a self-defined group of two or more individuals who consider themselves a family with the focus on what they do ("Families and households in the UK - Office for National Statistics, 2016.; Ganong & Coleman, 2014; Morgan, 1996; Smart, 2007). To participate in the research families needed to comprise of two or more people, one of whom had to be an adult with CD, who ordinarily resided together and self-identified as a family.

Purposive sampling criteria were employed to ensure a homogenous sample of families with an adult member diagnosed with coeliac disease (Smith, Flowers, & Larkin, 2009). Clinical data were not collected so diagnosis of CD was self-reported and not verified through medical records. A minimum of four families with members aged eight to 17 years were sought to address the paucity in the literature of experiences in this age group. The family groups sampling
consisted of one and two parent families with child/ren aged from eight to 18 years of age and adult families without children or adult children. The diagnosis of CD is higher in women, so it was anticipated that there would be increased numbers of women compared to men (Ludvigsson & Murray, 2019; West et al., 2014).

The research also employed additional inclusion criteria of: living together as a “family” for over a year; aged over eight years (Gibson, 2012); the capacity to consent; understanding of English language; and access to synchronous online video communication technology unless safe to meet in-person (World Health Organization., 2020). The latter criterion removed geographical boundaries. Research advisors who had worked with me in the previous consultation stage were excluded from participating.

**Participant Demographics.** A total of 24 participants were recruited, consisting of three children, five young people, and sixteen adults, from nine families all living in the UK. The majority of participants (87%) identified as white British and 13 per cent as white Other. Ten adult participants had CD, four men and six women, with time since diagnosis of CD ranging from three to 36 years. Six adults with CD had other family members (immediate and wider) with CD. In one family both adults had CD and another family, one adult and one child. Participants were five girls aged ten to 16 years; three boys aged eight to 13 years; eight women aged 30 to 80 years; and eight men aged 29 to 70 years. Eight participants were in education, 13 in employment and three retired.

The relationship status of adult participants was as follows; one single; two co-habiting; eleven married; one divorced; and one widowed. Adult participants in
relationships were all in heterosexual partnerships and had lived together from six to 43 years. Each participating family were together as a family group when the adult with CD received the diagnosis including, where applicable, child members. Four families had two members; two had three members; and three had four members. In one family a child member was unable to participate as aged under eight years, and in another family one adult member did not participate for reasons unknown.

All family members were given a randomly selected pseudonym and each family was given a randomly selected food-based pseudonym surname. Figure 12 below shows each family and their members.

**Figure 12 The Family Groups**

![Family Groups](image)

**6.2.3 Demographic Descriptions of Each Family Group**

In this section a brief summary of each participating family group and details of how they were interviewed are provided.
Alice & James Rice

Alice, aged 66 years has CD, is employed and has been married to James aged 69 years who is retired for 43 years. Both identified as white British. Alice was diagnosed with CD 36 years ago. Alice has no other long-term conditions. They were interviewed separately using a computer via Whereby (online video conferencing tool).

Phillip & Ava Sugar

Phillip aged 70 years has CD, is retired, and has been married to Ava aged 65 years, who is employed, for 42 years. Both identified as white British. Phillip was diagnosed with CD three years ago. He has other long-term conditions. They were interviewed separately using a computer via Zoom.

Karl & Ellie Pickles

Karl aged 29 years, was diagnosed with CD six and a half years ago and has lived with Ellie for seven years. Ellie aged 30 years, was diagnosed with CD nine years ago and has other long-term conditions. They had begun their relationship when Ellie was diagnosed. Both are employed, identified as white British with no other family members with CD. They were interviewed separately; both used a computer via MS Teams.

Mark & Heather Berry

Mark aged 51 years, was diagnosed with CD 20 years ago. He is single, has other long-term conditions, and has always lived with Heather his widowed mother aged 80 years. Both identified as white British with no other family
members with CD. They were interviewed together using a tablet computer via Whereby.

_Isabella, Liam & Emma Sage_

Isabella aged 41 years, was diagnosed with CD three and a half years ago and is married to Liam aged 43 years. They have been married for 18 years and have one daughter Emma aged 10 years. Isabella has other long-term conditions. The couple are both employed and identify as white Other. Isabella was interviewed individually and sat in on the interviews with Liam and Emma. All were interviewed using a computer via Zoom.

_Joseph & Harry Bean_

Joseph aged 41 years was diagnosed with CD seven years ago and his son Harry aged eight years participated. Joseph was employed and had no other long-term conditions. Both identify as white British and were interviewed together using a tablet computer via Facetime.

_Sally, Mick, Daisy & Leon Plum_

Sally aged 42 was diagnosed with CD eight years ago. She has been married to Mick for 23 years. Mick is aged 44. Both employed. They have two children Daisy aged 16 and Leon aged 13, all identified as white British. Sally, Mick, and Daisy were interviewed alone, and Leon was interviewed with Sally present. All were interviewed using mobile phones via WhatsApp.

_Kirsty, Louise & Kerry Cherry_

Kirsty aged 42 was diagnosed ten years ago with CD and has other long-term conditions. She is employed and has been married for 23 years. She has two
daughters Louise aged 16 years and Kerry aged ten years. They identified as white British. No other family members have CD. Interviewed separately, although all were present in the room using a laptop computer via Zoom.

**Anne, Dave, Lucy & Jacob Parsley**

Anne aged 44 years was diagnosed five years ago with CD and has other long-term conditions. She has been married to Dave for 20 years and they have two children, Lucy aged 15 years and Jacob aged 13 years. Anne and Dave are both employed. They are a white British family. Anne and Dave were interviewed individually, and Lucy and Jacob together. All were interviewed using a computer via MS Teams.

### 6.2.4 Data Generation

All interviews were held via online synchronous video with both the participants and myself as interviewer, being in our respective homes. To accommodate participants’ commitments, flexibility around a choice of interview days and times was offered, including weekends and evenings. Families were able to choose the synchronous video platform (Zoom, Whereby, WhatsApp, FaceTime, MS Team) to meet, using whatever worked best for them. The first interviews took place between May and August 2020. All family members were present at the initial interview to discuss the research. I spoke directly with each member, although each family had a member who took the conversation lead. The novel situation we were all experiencing helped build rapport and eliminate the awkwardness of meeting for the first time via synchronous video. Technical glitches were experienced but accepted by all as part of the novel
circumstances. All the interviews with children and young people took place when educational establishments were closed due to COVID-19 or the summer holiday. With the exception of one adult participant interviewed in September 2020, all employed adult participants were working from home during the data generation period.

**Participant-Generated Photographs.** Participants or parents of those aged under 16 years sent photographs to me. They were sent via WhatsApp, MS Teams, and email. Participants shared photographs the day before their scheduled interview or the day of their interview or at the interview. Problems were experienced sending images to my OU email address, with emails being returned to participants. To overcome this, images were sent to the dedicated research mobile phone. Some participants sent photographs numbered with captions. The number of photographs shared varied from four to seven. A mixed response was received from adult participants regarding taking photographs for the research. For some it was pleasurable:

> Well I just love taking photographs and I just love the whole descriptive thing. I just rattled through them, and I didn’t really think about it very much I just snap snap snap

(Agent)

Whilst for others it was burdensome:

> But it was a bit of a, I had to keep reminding myself to think about it (taking photographs), [...] I think it’s just it’s become quite part of everyday that I forget that I’m doing something different
One adult participant used an image from Google to illustrate their life as they were unable to capture the experience due to COVID-19. Some adult participants shared retrospective photographs. One young person shared photographs using an iPad during the interview. Parents sent photographs on behalf of children and young people; in a couple of cases confusion occurred around the photographs as the parent had shared different photographs: ‘this picture, wait is this also at Jess’s house ... that is one of Jess’s toys’ (Child). All participants captured images and shared photographs.

**Participant Interviews.** A total of 21 interviews were conducted between May and September 2020. Participants used mobile phones, tablet computers and laptop computers for interviews. I used a laptop for all interviews. An Olympus WS-833 digital voice recorder captured the interviews. Flexibility regarding how they were interviewed was given to participants to accommodate apprehensive children and young people as well as the availability of quiet spaces within homes. One interview had to be rescheduled due to audio issues. In this instance the participant and I wrote messages to each other and held them up to the screen. In another interview there was a need to switch online platforms due to access difficulties. Three interviews were dyadic; Parsley family siblings Lucy and Jacob; Bean family Joseph (father) and Harry (son); Berry family Mark (son) and Heather (mother). One adult had their spouse sat off camera, and four children had a parent present off camera who contributed to the interview. All other interviews were individual. The mean duration of dyadic \((n=3)\) interviews was 59 minutes, individual adult \((n=13)\) interviews 58 minutes, and child and young person interviews \((n=5)\) 32 minutes.
At the start of each interview the process was explained to the participant(s) together with an emphasis of interest on their experience. Participant-generated photographs empowered participants as they decided before the interview what photographs to share and the order of discussion during the interview. The method is flexible and empowering with one adult participant changing photographs to share during the interview. To start the interview and to build rapport participants were asked to tell me something about themselves, for example any hobbies. All the adult participants with CD, except one, shared their CD diagnosis journey spontaneously. All participating adults were talkative and keen to share their experiences. The dyadic interviews provided support for participants with a comfortable relationship portrayed with demonstration of banter. Young people appeared comfortable while children benefitted from parental support even when this was not always welcomed. Participants were then asked about their photographs and invited to select an image to discuss. I printed hard copies of participant-photographs sent in advance of the interview and held them up to the screen to ensure the same image was being discussed. Some participants had planned the photograph sequence in advance, others selected images during the process and not all participants had access to photographs during the interview. I held up participants photographs to the camera, asking them to choose one to discuss. One participant shared their photographs though MS Teams; this worked well as the participant selected the photograph for discussion, empowering them and providing clarity around the photograph being discussed. During a WhatsApp interview the screen was paused while the participant selected photographs. One young person selected photographs on a tablet computer during the interview, showing the interviewer
via the camera on a mobile phone. The intention of the photo-elicitation interview had been to empower participants selecting photographs to discuss and an opportunity to reflect on photographs (Harper, 2002). The method of sharing photographs made this challenging.

### 6.3 Ethical Considerations

Ethical considerations are not solitary discrete events but an ongoing, active, dynamic practice throughout the research process from conception to dissemination and beyond. The rationale of ethical practice is to draw upon ethical principles to guide research conduct (British Psychological Society, 2014). Participatory research involving participant-generated photographs, participants aged under 16 years and family experiences of a health condition raised many ethical considerations. To inform ethical reasoning and conduct, many sources of guidance were consulted, including the British Psychological Society Code of Human Research Ethics (2014)\(^4\), Code of Ethics and Conduct (2018) and Ethics Guidelines for Internet-mediated Research (2017) and The Open University (2017) Code of Practice for Research. Specific ethical guidelines on the collection and dissemination of photographic images generated by participants were sparse and as stated by the British Sociological Association the uniqueness of each research context means a standard template is not viable, so visual research resources were drawn upon to inform good ethical practice, including Visual Ethics: Ethical Issues in Visual Research (Wiles et al., 2008); British Sociological Association: Ethics Guidelines and Collated Resources for Digital Research and the International Visual Sociology Association (Papademas, 2009). The visual methodology

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\(^4\) The British Psychological Society updated the Code of Human Research Ethics in 2021
literature was consulted as well in conjunction with attending relevant conferences and seminars plus consultation with expert Dr Wendy Martin (supervisor) (Howell et al., 2015; Lomax, 2012; Pauwels, 2010; Rose, 2016). Additionally, I drew on previous research experience, including researching sensitive topics, with clinical and non-clinical populations and Good Clinical Practice<sup>5</sup> training with Kings Health Partners (2016) and Leicester NHS (2018). The research method, using participatory photographs, and researching with participants aged under 16 years were novel for me, therefore I considered it important to seek guidance and advice to inform my practice to minimise any potential risk to participants and self.

On the 30<sup>th</sup> of April 2020 The Open University Human Research Ethics Committee (HREC) granted a favourable opinion to conduct this research (HREC/3585/Goodliffe). The ethics application included face-to-face and electronic communication with participants as at the point of application the COVID-19 pandemic was evolving. Due to the exceptional circumstances face-to-face interaction with participants was not permitted until official notification was received from the HREC, due to the health risk to participants and researcher. In compliance all communication with participants was conducted electronically. To preserve the participants’ anonymity, demographics and descriptions of the photographs referred to in relation to ethical considerations are not disclosed here.

Although I was entering people’s homes virtually, I still showed my university identification badge to people to authenticate my identity as a researcher.

<sup>5</sup> Good Clinical Practice training includes ethical practice, recruitment, informed consent, and document management.
Before commencing participant recruitment I returned to some of my research advisors for guidance on whether to conduct the study during COVID-19. At the time of the research the UK and globally were experiencing a constantly changing social environment. For many people it was a period of increased stress and anxiety. Participating in the research was entirely voluntary and people were free to withdraw at any point. In contrast to my concern, people were keen to participate, in some cases it perhaps gave families something to do.

6.3.1 Consent and Assent
A fundamental ethical practice is ensuring people are provided with sufficient information to make an informed choice to voluntary consent. All potential participants were fully informed with written and verbal details of the research. Tailored participant information was provided for adults, young people, and children. At the first interview I spoke to the family as a group and directly to each person to ensure all were fully aware about what participating in the research involved. This was important as not all families were able to appear simultaneously together on video camera, so by speaking individually I was able to assess whether people understood the research and were happy to participate. Written details were provided before the interview to allow families time to read and discuss the participant information. During the first interview any questions were answered. Questions asked were primarily around what to photograph. No data were collected at this interview, with participants requested to return Consent, Assent (where applicable) Forms and demographic questionnaires before the next interview. Assent was sought from participants aged eight to 16 years to involve them in the decision-making regarding
participation in the research. Parental consent was required for people aged under sixteen years as well as themselves giving assent. Consent and assent were an ongoing process throughout data collection for all participants.

I sought additional external advice in reference to a participant with Downs Syndrome as my knowledge and experience of seeking consent from people with learning difficulties was minimal. I wanted to ensure that the person understood what they were consenting to. As with all participants I spoke to them directly to confirm they were fully aware of what the research involved.

Consent also included consent to appearing in other family members’ photographs as part of the research. The need for consent from others was verbally discussed at the first interview and included in the adult Informed Consent Form (Appendix J). When reviewing the participant documentation for the purposes of this chapter, I was surprised to note that these points were not written in consent forms for participants aged eight to 16 years. The form had been reviewed by the research advisors, as well as an ethics review panel, and myself, all of whom were aware of the importance of consent around photographic images appearing to be an illustration of human error. Fortunately, in this case photographic consent had been verbally discussed at the first interview and agreed with participants. The shared photographs only contained images of family members with one participant even seeking consent from adult child to share a photographic image of them as a child. It poses the question of how ‘read’ and understood are research documentation by reviewers and participants stressing the value of verbally discussing research terms.
**Photo-elicitation Interviews.** Prior to the photo-elicitation interview, participants were reminded of their right to withdraw without reason from the research without giving a reason and advised they were under no obligation to participate. Participants were advised at interview how to withdraw their data and a final date three weeks later by which to request this by.

I monitored child behaviour for signs for ongoing assent and considered developing competencies in terms of language skills and attention span (Gibson, 2012). If a child or young person was not engaging with the interview or other behaviour indicated that they were uncomfortable being interviewed, I gently asked if they wanted to stop or have a break explaining that it was not a problem to do so. If any participant continued to be visibility non-consenting, I would close the interview. I questioned the assent of a child during an interview when the child appeared reluctant to participate. This was an awkward situation as the parent was keen for the child to participate. During the interview it emerged that the child appeared cross with the parent due to actions taken in relation to COVID-19 and was argumentative with the parent contradicting what they said. In this interview I kept the questions very brief, enabling the child to share their interests. The parent contributed to the interview, attempting to encourage the child, and interrupting when the child was talking. I asked the child if they wanted to stop, but the parent intervened encouraging the continuation of the interview, so I drew the interview to a close as quickly as possible. It was challenging balancing the autonomy of the child and respecting that the parent provided consent and knew their child better than I did.

The issue of consent and assent around photographs arose. For ethical reasons all communication with children and young people was conducted
through their parent(s) who therefore sent all photographs to me. During separate interviews with a child and young person, it became apparent that the parent had mixed up the two sets of photographs and shared some that the child had not selected. In another interview with a child, the parent had shared a photograph that the child had not agreed to share. When I showed the photograph, the child was embarrassed, expressing their horror to their parent. I explained that we did not have to discuss the photograph. However, the child agreed to do so. They described what the photograph was about. I asked one question then we moved on to spare the child’s discomfort. These cases raise issues around upholding autonomy for children and safeguarding. Children and young people are often proficient in technology use, so a potential solution to balancing these issues would be for them to send photographs to the researcher, copying in the parent(s), thus providing autonomy for the child whilst keeping parent(s) informed.

The photographs shared during the interviews are the legal property of participants. A separate photograph permission form was used for unidentifiable photographic images regarding the inclusion of photographic images in future dissemination of the research including an exhibition. Permission is preferable as this allows the use of the photographic images without having to disclose the owner and provides the owner with clarity and reassurance on the future use of images. Each photograph was numbered with specific permissions recorded. Children and young people were asked for permission to use their photographs and, if applicable, additional permission was obtained from their parent or guardian (Appendix P). Photographs were not shared outside the research without explicit consent.
6.3.2 Photographic Images
In addition to the researcher seeking consent, participants also were requested to seek consent before taking photographs of identifiable individuals as part of the research. Verbal consent was deemed suitable to reduce the ethical burden on participants, which was also reflective of the normality of the taking and sharing of photographs in daily life. Consultation with Research Advisors suggested the inclusion of other people would be normal and asking others for photographic verbal consent acceptable (Burningham et al., 2019; Whiting, 2015; Wiles, Coffey, Robison, & Heath, 2010). For many children and young people, the taking and sharing of self-images on social media networking sites are perceived as a normal everyday practice (Bond, 2014). Participants were advised not to take photographs of any illegal activities as the researcher could be legally obliged to share these with the relevant legal body. Photographs that contained identifiable images of people, pets or places were used for discussion during the interview and will remain confidential between the participant and myself to maintain anonymity and protect confidentiality. All identifiable photographs remain the property of the participant.

6.3.3 Confidentiality
Within the Participant Information Sheets, consent, and assent forms, as well as at the start of the interview, participants were informed of the instances when I would have to breach confidentiality. During the interviews no safeguarding, risk of harm or illegal activity concerns were indicated so there was no requirement to breach confidentiality (British Psychological Society, 2014).

To preserve participant confidentiality during interviews I took care not to introduce topics or details raised by another family member (Ummel & Achille,
On a couple of occasions adult participants said things such as, ‘my partner must have told you …’, to which I always responded, ‘no, why don’t you tell me’ to maintain participant confidentiality. A few adult participants were surprised at their partner not mentioning what they perceived as pertinent events. Although ‘no’ indicated events had not been shared I was confirming what had not been said. Some couples shared completely opposing accounts of the same experience, a holiday experience, in this case I was unable to challenge what had previously been disclosed to maintain participant confidentiality.

To minimise the risk of potential identification all participants were assigned pseudonyms and during transcription any identifying data pseudonymised or anonymised. Pseudonymisation differs from anonymisation as it still potentially allows indirect identification providing limited protection. During research dissemination there is a potential risk information could be recognised by other family members. Therefore, reasonable measures have been applied to minimise this using pseudonymisation to describe family groups, and all quotes are referred to as ‘adult’ or ‘child and young person’.

### 6.3.4 Assessment of Risk

**Participant Risk.** The risk of harm to participants was assessed as low for this study but for some participants talking about experiences could have triggered distress. The interview topic guide was informed by people living with food related conditions (adult, young person, and child family members) who disclosed unprompted positive and negative personal experiences related to coeliac disease and other dietary conditions without any apparent difficulties.
The opportunity to share experiences was viewed as positive and the taking and sharing of photographs a normal daily practice. Some adult participants expressed the view that the opportunity to share experiences was therapeutic (Perry, Grace Bigelow, & Grace, 2020). Research participants took part on a voluntary basis, with the sharing of routine daily life events not expected to be a greater risk of harm than compared to everyday life. It is acknowledged that research involving people aged under 16 years has more than minimal risk. In response to this and the potential risk to adult participants an attempt was made to identify potential risks and ways to minimise them.

Interactive synchronous online video interviews enable the interviewer to detect non-verbal cues of any distress although it is accepted that not all aspects of the participants’ body language can be seen. Other studies using online synchronous interviews to research sensitive topics, have reported that the method enables participants to talk about experiences they perhaps would have found difficult to discuss face-to-face, with some participants preferring online interviews compared to face-to-face interviews (Ayling & Mewse, 2009; Deakin & Wakefield, 2014). The acceptability of online synchronous video interviews was expressed by research advisors in consideration of the COVID-19 (March 2020) exceptional circumstances.

Potential participants were made fully aware before providing informed consent that the research was about living with CD and required the taking of photographs. During an interview, responses to questions are perhaps influenced by the presence of a family member due to a consideration of not wanting to upset other family members (Nutting & Grafsky, 2018). A family member could disclose something during the interview that others had not
previously been aware of, thus exposing tensions or conflict (Taylor & De Vocht, 2011). It was unclear from previous research with people with CD whether they had disclosed the invisible impact to family members. Therefore, to minimise any potential distress, individual interviews for this research were conducted in order to provide a safe place to freely express individual experiences without the concern of upsetting close others. In practice all interviews, due to COVID-19, occurred online with participants at home with other family members as the option to conduct interviews outside the home environment was removed. Access to privacy was accentuated within homes as in many cases all family members were at home. I was aware of potential limited privacy within the family home during interviews with other family members present in the room or in another area of the home. Many adult participants had access to a room where they closed the door for privacy. For one family, although members were interviewed ‘individually’, others were present off camera in the family lounge. Some family members asked to be interviewed together creating dyadic interviews that worked really well, with banter between family members and negotiations of how they perceived events. The presence of other family members within the home potentially impacted on the experiences shared during the data collection with participants perhaps not wanting to be overheard sharing sensitive information that could upset or distress or create conflict with other family members. In contrast participants in the dyadic interviews perhaps shared more as they contributed to each other’s experiences.

Individual interviews were offered to children and young people to allow the voice of children to be heard as adults are often more articulate (Wennick & Hallström, 2006a). However, to support children’s participation, a choice to
have a parent present during the interview was provided (Skjerning, Hourihane, Husby, & DunnGalvin, 2017). The intention was to provide children and young people a red card to hold up to stop the interview for any reason, but due to COVID-19 risk of transmission on surfaces, this was not provided. In one child interview where the parent was present off screen, when the child was sharing their feelings of sadness related to their exclusion from events, I noticed the child becoming sad due to their facial expression and use of language; I was also aware that the parent could become distressed in response. Rather than focusing on the event, using information which the child had disclosed about friends, I was able to move the discussion towards another event. Had I been in the room with the parent and child, and thus able to see physical reactions, I perhaps would have responded differently, exploring the topic further. I was uncomfortable exploring a distressing situation further when the child was already upset due to COVID-19 restrictions. The interviews took place during a period when meeting other people was prohibited.

Plans were in place in the event of an adult participant becoming distressed during the interview, with information signposting them to their GP or other support services. In the case of children or young people displaying distress, I would have sought permission to inform their parent that they had become distressed, but not the reason thus maintaining confidentiality. In the instance of any safeguarding concerns the Open University Safeguarding Policy would have been implemented. While conducting the research, some adult participants shared distressing events and the experience of negative emotions. Participants were asked if they wished to have a break or end the interview, but
none did and all continued with the interview, coping well. None of the interviews conducted raised concerns to trigger support for participants.

**Researcher Risk.** Plans were also in place for the safety of the researcher; however, these were unrequired as all interviewing took place from the safety of my home. Removing face-to-face contact with participants removed lone worker and travel risks for the researcher. Risks associated with lone working and travel had been considered with procedures planned to minimise them. All communication with participants was through a research specific mobile and university email account. I did not disclose any personal contact details to participants.

**6.3.5 Data Management**

The processing and security of the research data complied with the EU General Data Protection Regulation and the UK Data Protection Act (2018). All data subjects were in the United Kingdom where all data processing took place. All participant data were stored securely in password-protected files on a secure computer only accessible to the researcher. Participants were assigned a unique anonymised participation code with the corresponding key file stored separately from personal details in a password-protected file. All electronic data were stored in password protected files on an OU password protected computer with secure encrypted storage, only accessed by the researcher. Data were not stored on shared drives. The OU uses Microsoft Office 365 One Drive providing each user with 1TB of storage, which was enough to store the research data. One Drive encrypts data and backs up documents every 12 hours. The data is stored in a secure facility. The OU IT system is kept up to date with security patches and updates. In accordance with OU policy, I changed my computer
passwords every 90 days. Microsoft Office 365 is compliant for the following international standards: ISO27001 and EU Data Protection Directive's requirements; ISO27018, protecting privacy of personal information. The data were physically backed up on the hard drive of the OU computer; this has 148GB of available storage. I was responsible for the daily back-up of data. The OU IT Manager is responsible for the OU One Drive. All hard copies of data, research advisor data, were stored in a locked cabinet in a secure Open University office. All audio data were deleted after transcription. All photographic images without permissions were destroyed following the interview. Participants’ personal data will be deleted on completion of the research. The research data (interview transcripts) will be stored on the Open University open research data online data repository for a minimum of 10 years. Personal details of those participants requesting a final summary of findings will be destroyed once they have been sent.

6.4 Reflexive Thematic Analysis
Thematic analysis is an umbrella term for a family of methods widely applied within qualitative research. This method family shares the underpinning principle of searching for patterns of shared meaning within data, through a process of systematic coding to generate themes shaped through the theoretical approach and research values enabling the application to various epistemological and theoretical frameworks (Braun & Clarke, 2013, 2022). Moreover, thematic analysis offers flexibility suitable for inductive and deductive approaches providing many options to convey semantic, latent, manifest, or implicit meanings (Braun & Clarke, 2021). The three main approaches to thematic analysis are reflexive, codebook, and coding reliability (Braun &
Clarke, 2022). Reflexive thematic analysis enables an inductive analytic process whereas codebook and coding reliability approaches are conducted with some or all priori codes or themes (Braun & Clarke, 2021). As an exploratory study assuming an inductive approach this research applied a Reflexive Thematic Analysis (RTA). A key feature of RTA is the subjectivity of me, the researcher, taking an active role in generating data with participants. The 'reflexive' process facilitated the incorporation of my subjectivity within the analysis, recognising my influence in generating the data and analysis. The original RTA guidelines (method) have been reviewed and refined by Virginia Braun and Victoria Clarke (2021), providing increased clarity of the method and strong emphasis on researcher reflexivity (Braun & Clarke, 2013; Braun & Clarke, 2021; Hanna & Mwale, 2017). In recognition of researcher subjectivity in data analysis and the underpinning theoretical assumptions, the term ‘emerged’ is not relevant instead the terms ‘constructed’, ‘developed’ and ‘generated’ are used to describe the data analysis reflecting how themes are produced through a process of systematic analytic engagement with the data (Braun & Clarke, 2021). The themes constructed are presented in three analysis chapters, not findings or results chapters, as recommended by Braun and Clarke (2021) to avoid suggestions of discovery. The updated RTA method guided data generation.

In keeping with reflexivity, I kept a journal from the initial interview of family groups to the writing-up of analysis of results. Entries included how I felt, differences or similarities between participants, questions that arose, observations and the quality of interviews. I reflected on my notes during data generation and analysis.
The six-phase process to conduct a RTA were used to guide data analysis (Braun & Clarke, 2021, 2022). The process is iterative and not finalised until written-up. The six phases are 1) familiarisation with the dataset, 2) coding, 3) generating initial themes, 4) developing and reviewing themes, 5) refining, defining, and naming themes, 6) writing up. Each phase is now discussed before concluding with a description of the quality appraisal process.

6.4.1 Phases of Reflexive Thematic Analysis

1) Dataset familiarisation: transcription and emersion

I listened to all the interview audio files, transcribed them verbatim, then checked the transcripts against audio recordings for accuracy. The process of transcription began soon after the first interview. A predominantly inductive approach was taken where I noted anything that caught my interest as I transcribed reflecting on salient points and noticing points where experiences could have been further explored (Braun & Clarke, 2021). Given that the research was conducted to address a research question a purely inductive approach was not applied. The approach was prioritised to a participant-based meaning (Braun & Clarke, 2013). I became aware during transcription of how I was applying health psychology theories to data, for example coping and behavioural theories. I also noted commonalities with other long-term autoimmune conditions and assumptions that I made as a mother. Using reflexivity enabled recognition of my subjectivity and analytical perspective (Braun & Clarke, 2021). Transcribing interviews bolstered familiarisation through immersion in the data. On transcription completion the interviews were printed, read, and reread multiple times with notes made in the margins, sections of text highlighted, and observations recorded in a journal. As I read...
the dataset I kept asking ‘what is the world like for this person’. Once I became familiar with the data noticing patterns of meaning I transferred the files into NVivo 12, (QSR International, 2018) a data computer software tool, for data management and analysis. I initially divided the dataset into participant groups, people with CD, adult family members, and children and young people, then family groups before bringing the dataset back together. This process is discussed later in reflexivity.

2) Coding

I systematically coded the dataset thematically applying code labels, firstly at the individual level, secondly people with CD, thirdly adult family members and finally children and young people. Next I performed a second level analysis family groups followed by a third level analysis across families (Van Parys, Provoost, De Sutter, Pennings, & Buysse, 2017). The data analysis presented here is across families as the focus of my research is family experience. I did consider analysing family groups as case studies however during coding it became apparent of more similarities than differences between families. Coding can be at the semantic level, the explicit meaning of the data expressed by participants and latent coding an interpretative implicit meaning of data (Braun & Clarke, 2022). Meaning was coded at both the semantic and latent levels depending on the data being interpreted. As argued by Braun and Clarke (2013; 2019) the researcher plays an active subjective role in interpreting the data for meaning, identifying the codes and themes to answer the research question. Throughout data analysis I kept switching from hard copies of transcripts to NVivo. Both methods offered benefits and disadvantages. The physicality of the data made it easier to visualise, see patterns, develop codes, and see the
dataset as a whole. This was a messy process physically and cognitively. Coloured pens and Post-it’s were used to highlight meaningful text and record observations. Transcripts were cut-up creating piles of shared initial codes. Engaging physically with data facilitated an intimate immersion. The disadvantage of manual coding is the need to still organise data electronically to transfer quotes into research documents. Next the dataset was coded in NVivo developing and refining the manual coding. This again became a messy process with the generation of nodes (NVivo’s term for codes), sometimes an overwhelming number of nodes. I worked through the nodes identifying shared concepts and meanings to reduce the number of nodes and begin the development of clusters under candidate themes, illustrated in Figure 13 and Figure 14. When the number of nodes were reduced these were printed, cut-up and sorted into candidate themes shown in Figure 15.
Figure 13 Codes Being Generated

Figure 14 Code Bin: Discarding Codes

Figure 15 Post-It Theme Development with Illustrative Quotes
3) Generating initial themes

Theme development was an active recursive process, sometimes tracing back to the original data source to check the meaning fitted within the potential theme. Codes were clustered into candidate themes that addressed the research questions. When initially clustering codes to capture the data I realised, they all centred around the person with CD. I returned to the codes and developed more appropriate candidate themes that captured the family experience. Repeated iterations at this stage help develop the data through exploration of different interpretations (Byrne, 2021). An example of one of my discarded themes was ‘at home in the kitchen with CD’ with sub themes of ‘expensive medicine’ and ‘bread’. The shared meaning of ‘bread’ became incorporated later in the analysis into the theme ‘negotiating family: shopping, cooking and eating’. Other discarded potential themes included ‘unknowingly living with coeliac disease’ and ‘changing diet’ which captured the meaning of the phenomena of being diagnosed with coeliac disease solely from the perspective of people with CD and excluded meanings in the data from family members. I clustered the codes combining those with shared meanings to form themes and sub-themes constructing a narrative based on the dataset. Once a coherent picture of the data developed the analysis progressed into the next phase of theme development.

4) Developing and reviewing themes

Once I had produced candidate themes they needed developing and reviewing. This was an iterative process to and froing between data, codes, and candidate themes assessing the fit of candidate themes to the data. A clear central organising concept developed with CD as a thread running through all the
themes. Within this was the concept of time and space in relation to living with CD. The development and refinement of themes continued until a clear relationship became evident.

5) Refining, defining, and naming themes

In this phase I ensured each theme had a clearly defined essence and fitted with the other themes, like a puzzle piece to the overall narrative answering the research questions. ‘The presence of coeliac disease’ theme was interwoven through all the themes. The themes represented the journey families experienced from the adjustment to coeliac disease into the family and how this shaped life outside the family home.

6) Writing-up

When originally writing this section the final stage of reflexive thematic analysis was absent. I returned to this section after writing-up my analysis chapters. When writing-up the analysis continued iteratively. I returned at points to the original data, questioning decisions made and seeing data from different perspectives. The overarching theme remained, and the patterns constructed in the dataset as separate spaces for all families. The themes were further refined and named during this process. The data analysis, presented over three chapters, is grounded in a distinct experiential pattern of firstly learning to live with CD, followed by family life within the shared home and thirdly life outside the home. Figure 16 provides a thematic map of the final themes and sub-themes illustrating the three patterns.
Figure 16 Thematic Map Illustrating the Final Themes and Sub-Themes

The journey of shock, surprise, and relief: a diagnosis of coeliac disease

‘It’s a learning curve all the way’: from the unknown to the family norm

‘It’s like learning to drive’: adjusting to a gluten-free diet

Seeking support to cope with treatment

‘That magic word, cross contamination’: shared and separated kitchen spaces

‘Playing Russian Roulette’: family compromises eating away from home

The invisible becoming visible: revealing coeliac disease

Negotiating family: food, cooking and eating

Food for all: stocking the family kitchen

Penalised for gluten-free food: limited expensive medicine

Social inclusion and exclusion: the psychosocial affect

Escape from everyday life: family

Food tastes and choice: bread, pizza, pasta

A healthy diet: food and body image

The Perpetual Presence of Coeliac Disease

Legend

Umbrella theme
Main theme
Subtheme
Process of quality appraisal

This section is situated at the end of data analysis as it relates to the rationale for conducting the research, how the research was conducted and data analysis. How to assess the quality of qualitative research requires different quality standards from quantitative research. Qualitative research is conducted through different theoretical and philosophical assumptions that underlie procedures therefore several quality checklists are available (Stenfors, 2020). For assessing quality and rigour in inductive qualitative research Nowell and Albrecht (2018) proposed criteria. These criteria were applied to appraise the quality and rigour of this study. The literature review (chapter 3) describes the phenomenon of interest and presents the gap in literature arguing why this was important to address. The rationale for the theoretical and methodological choices underpinning the research are stated in chapter 4. Rigour in research can be argued as the 'appropriate execution of that method' and providing an audit trail of the decisions made (Nowell & Albrecht, 2018).

The phases of RTA provide an audit trail of evidence for the decisions made. Maintaining a detailed combined paper and electronic trail allowed me at all stages of the data analysis to systematically keep track of how the themes were generated, enabling the rechecking of codes and themes throughout the process. This included returning to the raw data, transcripts, during the process. As illustrated in the presented phases of RTA, this was not a linear process but an iterative process. The process also included regular discussions with my supervisory team to review and reflect on theme development. During these discussions alternative perspectives were offered helping to facilitate a deeper insight into the data. Articulating my thoughts and ideas with my supervisory
team helped organise and clarify coding and themes providing an external check on the research process. Demonstrating how the research data analysis has been conducted through a detailed description supports the credibility and quality (Nowell, Norris, White & Moules, 2017). A further demonstration of quality was the keeping of a reflexive journal throughout the research and reflected upon during data analysis (Braun & Clarke, 2021; Nowell et al., 2017).

6.4.2 Participant-Generated Photographic Images
Participant-generated photographic images were used as an interview elicitation tool to stimulate reflection on daily life and empower participants (Harper, 2002). The photographs played a central role in data generation with some incorporated within the analysis chapters to exemplify themes. The photographs were not subject to analysis, although some are presented in the analysis chapters to illustrate participants’ experiences. An overview is provided here to give readers a snapshot of the participant-generated images contents, a window into participants’ experiences.

I sorted participant-photographs based on the visual image, not the meaning given by the participant, creating piles of collated images. Food-related images accounted for the majority of participant-generated photographs. They consisted of ingredients lists on food packaging; food storage, for example the insides of kitchen cupboards and fridges; people preparing food in kitchens; plates of food; food products such as rice and pies; loaves of bread; cookery books; gluten-free alcoholic beverages, for example bottles of cider and wine. Food outside the home encompassed menus from both physical eateries and online food delivery; meals shared with family and friends and take away food.
such as pizza in boxes; prescriptions for gluten-free food. The non-food images depicted purses and money, activities such as bike riding and crafts either with other family members or alone, and family pets. The adults’ images centred more around food in contrast to children and young people who focused on activities and hobbies.

Participants were asked at the end of interviews if there was anything they would have liked to have taken a photograph of but had not been able to. For some participants COVID-19 impacted the taking of photographs with Heather, whose household was shielding, explaining: ‘well it was a job to think up enough things to send really if I could have gone out and gone to a cafe or something like that and taken photos’. To overcome this pre-COVID-19 photographs were shared, combined with photographs taken for the research to illustrate living with coeliac disease. Another adult participant shared an image that depicted people socialising, as this was something they were unable to capture due to COVID-19. In contrast to these an adult spoke of not capturing the consequence of gluten poisoning:

*Don’t know quite know how I would have taken a photograph of it sometimes when (child) and I … when both of us have had gluten in our diets we look a lot paler and red eyed and both our resilience goes down, Child gets very teary at some things something and nothing … I am not sure how you would take a picture of that unless we deliberately poisoned ourselves with gluten and then get very pale and red eyed and weepy and just everything becomes a lot harder and I wanted to take a picture of what that looks like but the opportunity didn’t come up and we*
didn’t particularly want to go and do it … get sick, it’s not like a visible illness in the sort where you have an arm dangling off or something

As described the invisibility of being poisoned with gluten, the psychological and social impact, would not be easy to capture through a photograph. Without knowing the cause for the physical appearance, recognition of CD is invisible.

For some participants living with CD had become an embedded normalised daily life practice with a non-CD family member explaining:

For us it's kind of just normal so we never think anything of it, yeah it was good I had to think about it a lot cause it's just things you would do every day without thinking about I kind of sat down and thought about things

Supporting how the use of photographs to capture and reflect on the mundaneness of everyday life required conscious cognitive processing. For all participants the taking of photographs facilitated a reflective opportunity that was further accentuated through the COVID-19 disruption to normal daily life. Participant-generated photographs enriched the data through the capture of daily life and thoughts triggered.

6.5 Reflexivity on Data Generation
‘The researcher is the instrument through which research results are produced’ (Lincoln & Guba, 1985).

Reflexivity forms a fundamental part of reflexive thematic analysis placing an emphasis on the subjective role of the researcher in the construction of the collection, selection, and interpretation of the research data (Braun & Clarke, 2022). The subjectivity of the researcher is viewed and recognised as central to
the process and not seen as problematic. Braun & Clarke, (2013) state how researchers bring their ‘own histories, values, assumptions, perspectives, politics and mannerisms into research’ shaping from how interest formed in the research topic to analysis. Reflexivity involves ways of questioning our attitudes, thoughts, and habitual reactions to strive to understand our roles in relation to others (Bolton & Gillet, 2019; Holloway & Biley, 2011). To be reflexive is to examine our involvement and become aware of the limits of our knowledge and how our behaviour may influence or affect others. This allows us to look more critically at circumstances and relationships and help review and revise ways of being and relating (Lazard & Mcavoy, 2017). Reflexivity is a process by which researchers are able to evaluate and develop explicit awareness of themselves (Shaw, 2010). This includes ‘where they are coming from’ or ‘positionality’, and the formulation of a statement about the values, beliefs, interests, and ambitions that might shape the research interest and thus its focus (Braun & Clarke, 2013). Many factors may be important to consider when thinking about positionality, such as ethnicity, age, previous life experiences, social identity, role, and personality. The extent of influence seen will vary greatly and correlate to the most relevant individual factors and the specifics of the research.

During the research process I made assumptions that I became aware of and potentially others I am not. From a gender perspective I was horrified at how women’s symptoms were dismissed by medical professionals. Whereas I am alert to gender health inequalities, listening to examples was disturbing also assuming the women had justified it through being provided with some (incorrect) treatment and unaware it was also related to gender. During these accounts I consciously reminded myself that my role was to interview people
and not inform them about gender health inequalities. During data analysis I recognised my gendered assumption had been that mothers (women) were responsible for feeding families, shopping, and cooking. I was primarily horrified at myself for holding such a gender biased perception, realising how I had transposed my actions as a mother onto the family groups. On reflection I could see how embedded gender roles are into society and while I identified them rapidly in others it was not so obvious in myself. I returned to the data to seek any other instances where I had made gendered assumptions, none were obvious. With some participating women I empathised with the ‘role’ of mother feeding a family. In others, sympathy wanting to support them in managing their condition which they had accepted. When approaching the data as I became conscious sometimes I was applying health-based theories and literature to understand the data making assumptions. Many of these I identified but not my definition of a healthy diet that avoided foods high in sugar and fat. One of my supervisory team provided a different perspective on the definition of healthy eating, for people with CD a healthy diet is one that excludes gluten. The process of data analysis was messy, making it difficult to sometimes distinguish when assumptions were being made. I found it useful discussing my analysis with others who took a different interpretation broadening my approach to the data.

Where I had endeavoured to recruit inclusively, my assumptions on family groups became challenged with an older mother and adult son living together. This family challenged many assumptions, as very mistakenly I had assumed they had a quiet life staying at home when in fact they lived the completely opposite life. This was my first dyadic interview. I had been apprehensive, but
my concerns were rapidly dispelled with an engaging interview containing humour and some banter between and with participants. On reflection I had been concerned, following consultation with the literature on conducting dyadic interviews, that participants would be reluctant to discuss family life. I conducted three dyadic interviews during data generation, the first discussed previously, second a father and young son and third a sister and brother. In these interviews the conversation flowed easily and contained friendly banter and, in the case of the sibling interview, differing perspectives on family life. These differed from the interviews where a parent had sat in with a child either as a silent observer or providing prompts but not engaging with the conversation.

Interviewing online removed all geographical boundaries but provoked a heightened consciousness of any background noise within my home which in the event, dogs making noise, helped establish rapport with participants. Interviewing online via video provoked a strangeness of waiting in virtual rooms for participants to join. The absence of normal social norms when participants arrived, such as enquiring about their journey to the interview and offering refreshments, were instead replaced with conversations around online video technology, for example saying, ‘can you see me okay?’

This highlighted to me how as a researcher I was shaping the data. With regard to my practice as an interviewer, during transcription I noticed some of my questions were too long, identifying this early on enabled me to change my questioning technique making it shorter and more concise. The combination of awareness of screen fatigue and participants often at home all together increased my endeavour to maintain the time boundary. Interestingly, when participants were reminded about the allocated interview time coming towards
an end, they were happy to continue. I was unsure whether this was due to an opportunity to discuss their CD experiences or have a conversation with a non-family member. Also related to COVID-19 was the high number of food-related photographs shared. I was unsure whether this reflected being stuck at home or a true portrayal of life with CD. Food plays a key part of family life that was undoubtably heightened during COVID-19 with meals providing a daily structure, increased opportunity for some to cook, and some challenges surrounding the purchase of specific foods (Chee, Koziel Ly, Anisman, & Matheson, 2020; Middleton et al., 2020). On reflection I realised that participants were capturing daily life with CD that was lived during the context of a pandemic. Several participants had plenty to discuss without the need for photographs, although the photographs really shaped the discussion allowing poignant topics to be discussed.

After conducting all the individual and dyadic interviews I deliberated on the most informative method to draw the data analysis together. I took several approaches looking at participants by different groups such as all the children together and family groups. During the data analysis I realised that my focus had been on the person with CD and not the family group. I returned to the data and restarted the analysis exploring what it was like for all members with a focus on family life.
7 Perpetual Interruption: The Presence of Coeliac Disease

7.1 Introduction
This chapter firstly presents an overarching theme threaded through all the themes, ‘the perpetual presence of CD’. The theme describes how at the family and individual level within the shared home environment and in the wider external social world CD is present, shaping behaviours. Next the main theme describing the lived experiences leading to a family member being diagnosed with CD, ‘it's a learning curve all the way: from the unknown to family norm’ is discussed. Within this theme are three interlinked subthemes describing the temporal journey families experienced going from the unknown entity of CD to the acceptance and normalisation of CD within the family. The first subtheme, ‘the journey of surprise, shock and relief: a diagnosis of coeliac disease’ explores the introduction of CD into families, followed by the second subtheme, ‘seeking support to cope with treatment’, conveying the practical, social, and emotional support and coping mechanisms deployed to implement treatment. The third subtheme, ‘it’s like learning to drive: adjusting to a gluten-free diet’, illustrates the change of family behaviours required to support the family management of CD. These themes provide the context for how families adjusted to protect the health of the adult with CD. The following two analysis chapters describe the lived experience of family members once they had adapted to live with CD. The themes have a temporal element reflecting the shifting dynamics of family as new behaviours become habitual. The analysis is
presented with the aim of providing an in-depth understanding of the lived experiences of families living with CD. At the chapter close a summary of participants photographs is provided.

Within this chapter commentary from the themes is illustrated using participants’ quotes together with photographs (where consent has been given to reproduce\(^6\)) taken by participants. To preserve anonymity participant quotes are referenced as ‘adult’ or the initials ‘CYP’ denoting child or young person. For those participants with coeliac disease there are the initials ‘CD’ and for family members there are the initials ‘FM’. Please refer to Chapter 6 section 6.2 for a reminder of participant demographics. The terms adults, young people and children in the text refer to the people who participated in the research.

### 7.2 The Perpetual Presence of Coeliac Disease

An overarching umbrella theme threaded through all the themes is ‘the perpetual presence of coeliac disease’. The uniqueness of the theme encapsulates how for a family CD is always present. This theme captures how all adults, young people and children expressed implicitly and explicitly the impact of CD on food and associated practices inside and outside the home environment. In particular, the biological, emotional, and social presence of CD is a feature of the phenomena within a family and for the individual members.

*When we, when (spouse) was diagnosed, that free life of going wherever you want and eat is definitely not any more with us*

(Adult, FM)

As the quote signals a boundary imposed on family life through capturing how

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\(^6\) Permission for reproduction of non-identifiable images for purposes connected to this research was sought.
the arrival and presence of CD shaped family life. All families experienced these phenomena in their everyday lives, for example an adult described cooking pasta at home in the family kitchen: ‘That [saucepan of gluten pasta] would be one side of the cooker, wife’s [saucepan gluten-free pasta] will be the other so we don’t splash or anything like that water’ (Adult, FM). The experience reflects the family food cooking practices in homes with gluten-free and gluten foods, just one of many examples of CD shaping family behaviours within the home. The presence of CD is evidenced during shopping with a child detailing in a frustrated tone: ‘Particularly every time we go into a shop if there’s anything gluten-free mum is instantly buying it’ (CYP, FM) denoting the emphasis given to gluten-free foods. Again, this is one of many examples of family experiences depicting life with CD. The influence of CD determining places to eat outside the home was portrayed: ‘Usually I look them up online [restaurants] and see what their menus are to see if they’ve got anything [gluten-free]’ (Adult, FM). One women’s experience bears similarity to other families where CD determines the eateries for family meals. The experiences exhibit the behaviours displayed in response to CD when performing everyday activities. For family members without CD, even when eating away from home without the adult family member with CD, the absence of CD is noted as illustrated:

*Interviewer:* When you have lunch at her (friend) house is it very different from lunch at your house?

*CYP:* Yeah, hers is so much more like simple if you get me

*Interviewer:* Go on then, why is it simple at her house?

*CYP:* Like you don’t have to use separate things and it’s all just one thing

(CYP, FM)
In a home with a gluten-free diet, attention when preparing meals is required to avoid cross contamination, increasing the demand of the task as the CYP described concerning the use of multiple utensils. The CYP had a nut allergy, so their experience suggests that avoiding nut consumption is easier, less cognitively and physically demanding than avoiding gluten, even when eating away from their home, accentuating the powerful presence of CD determining many families’ food associated behaviours. When deciding on what food to consume a complexity of dietary choices are experienced by adults with CD:

*If you think how many times a day you think about food, if you like food, how many times a day you think about food and then think about that then add an extra layer on, I want food but what can I eat, rather than I want food, I'll have that*

(Adult, CD)

The quote illustrates how the presence of CD determined food choice. Factors around food such as availability, taste and cost are modifiable, but a gluten-free diet is a non-modifiable factor. In contrast for people without CD the presence of CD did not determine what foods they can consume but does influence food preparation and storage in the home environment and eating experiences outside the home when with the adult with CD. There was no escape from CD for the adult with CD as described:

*Every single thing I have to think gluten, okay avoid it or not avoid it. Problems gone going to bed, but even I had dreams many many times I have, but I was eating a normal doughnut and I was going to my husband you know how delicious they are, he says oh my God they are gluten, I don't care, so even at night in your dreams*
The quote captures CD as a perpetual presence from which there is no escape in reality and dreams for adults with CD, reflecting the conscious and subconscious presence of CD. By comparison, family members without CD can escape from CD when eating away from the family home without the family member with CD. The characteristics of CD are biologically embodied within the person with CD, becoming additionally enhanced through the avoidance of ingesting gluten, a form of embodiment, therefore a perpetual presence within the family group (Chamberlain, 2004; Rej, Aziz, & Sanders, 2019). The experiences of adults with CD illustrate the perpetual presence of CD physically and cognitively.

The photograph (Figure 17) captured by an adult FM illustrates the perpetual presence of CD, with no escape for their spouse with CD, as surrounded by reminders from fields to kitchens. The photograph summarises the presence of CD in many settings connected to food and eating, from field to plate.
The ‘perpetual presence of CD’ umbrella theme describes the embeddedness of CD within families. The lived experiences feature the health need of the adult family member with CD at the centre influencing family food and connected behaviours inside and outside the shared home environment. The next section presents analysis generated on experiences on the arrival of CD and the treatment.
7.3 “It’s a Learning Curve all the Way”: From the Unknown to Family Norm

Until this all came along [CD] we never knew so I don’t know it’s one of those things in I don’t know it’s a learning curve all the way

(Agent, FM)

The quote above from one adult FM mirrors the experiences of many adult family members when first informed of CD. The diagnosis of CD and corresponding treatment, a gluten-free diet, was a life changing event for people with CD and their family. All adults with CD were diagnosed in adulthood and were in their respective family groups, including all children and young people, prior to and at the point of CD diagnosis between three to 36 years ago. Participants led data generation with adults spontaneously sharing their narratives about CD becoming part of their life. The children and young people did not recollect experiences around their parents’ diagnosis viably due to their age at the time. The first theme presented captures the clinical introduction of CD into families. ‘It’s a learning curve all the way: from the unknown to family norm’ captures families’ journeys as they transitioned from the arrival of CD through a period of adjustment embedding CD as a family norm. The theme provides the experiential foundations detailing how families responded to the diagnosis of CD and how learning to cope with treatment, a gluten-free diet, changed everyday practices and beliefs developing family CD management skills. For all families CD became incorporated into the family identity, a family

7 At the time of the research eight participants had been diagnosed with CD in the past 10 years, and two participants diagnosed 20 and 36 years ago.
norm (Rolland, 1987). The theme illustrates how family members had to accept CD to learn to live with it. The theme begins at the start of adults’ CD journeys.

7.3.1 The Journey of Shock, Surprise, and Relief: A Diagnosis of Coeliac Disease

The phenomenon of a diagnosis of CD was particularly poignant to adults with CD, as prior to discussing their photographs they were all, except one, keen to share their journey to diagnosis. An adult with CD, who had additional health conditions, shared their experience of living with CD, while their family member provided an overview of when the person was diagnosed with CD:

*would go for months eating normally and then have a violent upset cause you just take it as one of those things, and then he started getting really ill and that was it he had the biopsy done […] yes its nothing now it doesn’t bother us now*

(Agent, FM).

For the one family the need to share events and the process of adjustment, their illness narrative, was not crucial as over the years the family had experienced many health conditions and participated in other health-based research,

8, therefore previous opportunities to share their illness narrative (Frank, 2013). Many adults with CD utilised being interviewed as an opportunity to share their chosen self-stories and be listened to. For example, an adult with CD commented during the interview ‘I'm feeling like this is a therapy session’. The telling of illness narratives permits people to share the disruption and the reconstruction of self-identity (Frank, 2013). A changed identity in response to a

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8. During the initial interview discussion regarding prior participation in health research and health conditions were disclosed.
diagnosis of CD was the central concept of the Living with CD: a psychosocial model, described in Chapter 3 section 3.1 (Rose & Howard, 2014). ‘I had biopsy and so yeah they confirmed on coeliac disease and my journey started and my life change completely absolutely everything was changed’ (Adult, CD).

The self-disruption and CD treatment disruption produced a ripple affect influencing the behaviours, beliefs, and attitudes of family members as illustrated throughout this theme. The consequences were life changing for some families creating a personal and social disruption to the person with CD and the family group (Moos & Schaefer, 1984; Rolland, 1987).

For all adults the CD diagnosis was unexpected. For one family, the diagnosis came as a shock, and uncommonly, they both were diagnosed with CD (Moos & Schaefer, 1984). One adult was diagnosed first after experiencing a sudden onset of severe and debilitating physical symptoms as she explained:

> I didn't have any gradual symptoms that I noticed it literally happened within 24 hours, I was feeling a bit tired and then all of a sudden I just couldn't function as a human anymore and so I went to the doctors and [...] they put me on a suspected bowel cancer thing which I was really scared about, but then they did the blood test and it came up straight away that it was coeliac so that was when I got referred to the hospital

(Adult, CD)

The quote depicts the emotional rollercoaster of uncertainty surrounding an illness, transitioning from being healthy one day to experiencing a life-threatening condition the next, how suddenly life can change. While the other adult received a surprise after abdominal surgery, being informed they had CD:
They (doctors) had come back to me with some results and tests they had done when I had been in (hospital) to say you know you have coeliac as well so obviously I knew what it was, but I thought that was a bit of a kick in the teeth at the time I was quite down

(Adult, CD)

The quote illuminates how possessing knowledge and experience of CD, and certain illness beliefs, does not reduce the psychological impact of being diagnosed with the condition. The adverse psychosocial impact was possibly heightened due to knowing about CD treatment and associated dietary implications. The quotes exemplify the emotional impact on adults of an unexpected illness and diagnosis triggering distress, signifying that illness has more than a physical impact on a person.

These experiences contrast with those of other adults with CD who had experienced symptoms for a number of years prior to receiving a CD diagnosis, with physical symptoms often being misinterpreted or dismissed by themselves and others. Three adult women were prescribed increasing doses of iron medication to address the fatigue experienced; this was unsuccessful as the underlying cause for the fatigue was CD affecting absorption of nutrients. Iron deficiency is a common symptom in people with undiagnosed CD (Anupam. Rej & Sanders, 2021). The diagnosis of CD was prompted through self-identification (subsequently medically confirmed), through the diagnosis of other family members and in rare cases by General Practitioners (GP). This illustrates the low general public and health practitioner awareness of CD symptoms as well
as exemplifying the time taken for a relevant diagnosis (Norström et al., 2011; Schultz, Shin, & Coppel, 2017).

The dismissal of CD symptoms by the family GP remains a source of anger for both adults in two families. Whereas in other families the person with CD directly dealt with healthcare professionals, the adult through caring for his spouse, became drawn into the process as they described:

> Spouse was really ill she ended up in bed, she had chronic diarrhoea, I got prescriptions from the doctor and eventually having got a third one that was some sort of diarrhoea cure had taken it into the pharmacy. When I went to collect it, the pharmacist said I need to have a word with you, I'm not happy to prescribe this I can't keep prescribing the same sort of acute things I'm uneasy about it I want you to talk to your doctor about it. So, I spoke to the doctor … whose quite an arrogant man, really wasn't very happy being challenged in that way even by a pharmacist… eventually he came out to see her and decided that she was so unwell that he actually got a consultant brought out from the hospital to see her

(Aadult, FM)

Another adult also had their symptoms dismissed, leading to years of living unknowingly with CD. When they were finally diagnosed and felt well, it triggered anger towards their GP having spent years unnecessarily feeling unwell:

> I've certainly had it for at least 18 years because there is a skin rash dermatitis herpetiformis which I had … it was the most painful thing I could remember, it was all over my body … you wanted to tear your skin
off it was awful and I spent three, four months going to the doctors trying to get some sort of diagnosis. The GP never referred me to a specialist and I am still quite angry about that cause I think if they had, if it had been a skin specialist they would have diagnosed it in five seconds well you’ve got coeliac disease but they didn’t and so for the next, its 15 years later, 10 years later I was diagnosed and in that time I was knackered all the time lethargic and I was just thinking is this what getting older feels like, I was 30

(Aadult, CD)

The anger expressed years later indicates the psychosocial poignancy of diagnosis, and the impact of having symptoms dismissed and feeling ignored. The case of the adult spouse demonstrates the emotional impact on partners, whereas the other quote highlights the biological and psychological impact of a delayed diagnosis. The experience of a long-term illness diagnosis and the events often leading up to it, are significant life-changing events for people (Rolland, 1987). Many adult family members described their partners’ CD symptoms pre-diagnosis as normal for the adult with the condition. Some non-CD adults recalled being concerned and worried about partners:

She [his wife] would be tired permanently all the time and not knowing what was causing it, just giving her more and more iron that was all the doctor was doing, giving more and more iron just to see if that fixed it and it just didn’t …more frustrating than anything else because I couldn’t do anything

(Aadult, FM)
Witnessing the ill health of family members is distressing especially when causes are unknown or treatment ineffective against symptoms, leaving loved ones feeling powerless to help (Kiecolt-Glaser & Wilson, 2017). In contrast to the poignancy and emotion of adults, the children and young people recounted no recollection of parental illness prior to the CD diagnosis nor of the diagnosis itself. The children and young people were aged between six months and ten years old when their parent was diagnosed with CD. The illness-related behaviours of parents were perhaps the accepted family normality for children and young people therefore less memorable. Additionally, any potential disruption to family life could have been buffered by the ‘well’ parent.

The physical symptom severity of CD is indicated as a driver for diagnosis, due to the potential threat to life. The emotional impact on several adults with ‘milder’ symptoms of having concerns dismissed and unvalidated can be distressing with repeated visits to a healthcare professional and unsuccessful treatments worrying and tiring for people (Hawley, 2015). The relationship between a doctor and patient involves a degree of trust to provide the best care, so when symptoms are misdiagnosed or dismissed it creates a cognitive dissonance for the patient potentially impacting on future healthcare relationships (Hawley, 2015). An impact on psychological wellbeing of adults is evident as demonstrated through the adults’ narratives, with the negative emotions experienced.

Whatever the experience leading to receiving a diagnosis of CD, the definitive labelling of symptoms and subsequent treatment, a gluten-free diet, had a dramatic life changing impact on all family members. Firstly, all family members had to learn about CD and adjust food behaviours accordingly to support a
gluten-free diet. The diagnosis changed behaviours within and outside the home. The families had to implement changes to food-related behaviours in the shared home environment. Patterns developed, through the data, of coping and adjustment at home and obtaining gluten-free food. The shocking surprise diagnosis of CD and consequent implications, shattered career plans for an adult negatively impacting on their wellbeing:

I finished university and I was training to join the army I wanted to go to Sandhurst and be an officer back then and I had my appendix out just before my army medical … so if you have an operation you need to wait at least a year before you are allowed to reapply to join the army … I knew what it (coeliac disease) was but I thought that was a bit of a kick in the teeth at the time. I was quite down, I had quite a bad appendix thing so obviously I have a huge scar on my stomach, I can’t really move around a lot and my career has just gone up in flames, it was a tough time

(Adult, CD)

Due to their life stage, a young person beginning their career, the biographical disruption was particularly poignant illustrating how a CD diagnosis can impact on life plans.

The diagnosis of CD brought emotional relief for the adult family members who had been concerned about the health of their loved ones. In some family groups other immediate and extended family members (parents, adult siblings, children) were diagnosed with CD at a similar time, sometimes bringing immense relief as the undiagnosed CD disease had become life-threatening.
Prior to their own CD diagnosis and son’s subsequent diagnosis, the adult initially experienced the seriousness of CD through their parent:

*It took a very long time with my mother, she was in hospital for two months as she was so soo ill, just losing weight …but then somebody had the bright idea to test for coeliac and it came back as a positive result*

(Adult, CD)

Another adult had a similar experience with his son and father simultaneously seriously unwell with undiagnosed CD. They recounted the horror and relief:

*At the same time my father had lost half of his body weight, and I mean the only way I can describe how he looked was like the pictures you see of Auschwitz survivors and absolutely skeletal … coeliac disease, the diagnosis of it, was perhaps the biggest relief I could of had because in some ways it’s a serious condition, but there’s no medicine required, there’s no course of treatment, it’s just stop eating wheat and you are fine and we all got better*

(Adult, CD)

As the quotes illustrate undiagnosed CD can become a life-threatening condition striking at any age creating a period of great uncertainty and distress for family members (Ludvigsson & Murray, 2019). Yet once diagnosed with CD, the prognosis and treatment provide immense relief, with family members knowing that health can be successfully treated and managed. For these adults, who both had children with CD, the treatment for CD was perceived as less invasive; a lifetime gluten-free diet was perceived as preferrable to a lifetime of
medication.

For one family the diagnosis of CD occurred during a health crisis when one partner was receiving treatment for a life-threatening disease. The diagnosis of CD had a less notable impact:

*It was a great relief (diagnosis of CD) when you think of all the other things it could have been, nasty things it could have been…It was diagnosed in the middle, he might of said that, when I was going through treatment for cancer … it wasn’t headline news completely ignored oh you have coeliac great fine he got no just forgotten about, he didn’t get a lot of attention shame*

(Adult, FM)

When sharing their narrative around events leading to their diagnosis, the person gave a brief concise account that did not mention spouse’s illness. In association with other adults’ experiences, the threat to life takes priority over other considerations, indicating a hierarchy of illness based on the perceived level of threat to life. This family experience provides an example of disease prestige. The concept of disease prestige is described as diseases and specialities associated with technologically sophisticated, immediate and invasive procedures in vital organs located in the upper parts of the body are given high prestige scores, especially where the typical patient is young or middle-aged … low prestige scores are given to diseases and specialities associated with chronic conditions located in the lower parts of the body or having no specific bodily location, with less visible treatment procedures, and with elderly patients’, (Album & Westin, 2008). Cardiovascular disease and
breast cancer are understood by people and recognised as illnesses warranting support and care, so are seen as high prestige in contrast to low prestige diseases, those harder to understand or where the perceived cause is by individuals’ lifestyle for example smoking and lung cancer (Stone, 2018). Additionally, support for diseases with embarrassing stigmatising symptoms, such as bowel functions, is lower despite bowel cancer being a common cancer in the UK (Bupa, 2022). Awareness of CD is perhaps reduced due to low disease prestige and stigmatising symptoms in combination with perceived low threat to life.

For many adults CD was a novel medical condition until either themselves or an extended family member were diagnosed with the condition. One adult provided an example where their sister newly diagnosed with CD called them: ‘I remember the phone call quite clearly actually, so I remember thinking I have no idea what that [CD] is so I was trying to comfort her [sister] while also Googling what the hell is coeliac disease’ (Adult, CD). This extract demonstrates how many people are unaware of CD until it is brought to their attention. One adult recalled a low awareness of specific dietary needs, through observation of free-from foods in the supermarket:

I had never really heard of coeliac disease, not the way I know it now […] there’s probably not a lot out there for the average person to know about. I’d seen a lot of the free-from foods and things and I just didn’t really understand what it was for to be honest with you, a bit ignorant of me really, but until you are touched by it or know someone with it then you don’t really pay much attention

(Agent, CD)
Although free-from food sections are apparent in grocery stores, which are social public spaces, minimal attention is given as they are irrelevant to many people, with no consideration given to the underpinning reasons as to why free-from foods are for sale. For many families an intimate knowledge of CD was learnt through lived experience when the condition had relevance and implications to them. They also touched on a paucity of knowledge about CD within the general public, highlighting the low public profile of CD, with the question ‘what is CD’ reflected throughout the ongoing lived social experience.

The similarities and differences in how families responded to the diagnosis of CD demonstrate both the uniqueness and commonalities of family groups. The diagnosis of CD for one person created a family ripple effect, due to the genetic link triggering CD screening for offspring in family groups and some extended family members. A person’s sister’s diagnosis of CD triggered their diagnosis and the subsequent testing of other women and girl extended family members. One family, in consultation with the doctor, decided not to test the children for CD, however the option was left open:

Me and my husband did have a chat with the doctor at some appointment … they basically said are they (children) showing any symptoms and I was like no, so I think one of them is stunted growth, I mean they’re both giants and all this sort of thing, I just said no, they’re both fine. They said in our opinion, just wait, when they show symptoms then have it the back of your mind … so it’s a conversation I have had with them (children) and they both know they can (be tested) if they want

(Adult, CD)
In contrast, another family had the children tested for CD (both were negative) but no other extended related family members, whereas another participants diagnosis cascaded to their mother, sister, and children:

*The thing is my mum always had put hers down to irritable bowel syndrome and never really questioned it again and just ignored it, and it was only through me being diagnosed that she was like, I wonder if I am, and it just snowballed with her and my sister ... both the children have been tested, child is negative whereas child comes back with an immune deficiency, so sometimes he goes a bit bloated sometimes so I do question whether he's borderline*

(Adult, CD)

Some parents (of adults) and adult siblings, though displaying CD symptom indicators, declined CD testing. One adult’s father due to other health conditions, while their brother declined testing for reasons unknown. Another participant’s brother, although suggestive of CD symptoms, declined testing as did other participants parents:

*I told my parents about my coeliac and I asked them to test, but they said no unfortunately we don’t want to start this even; it’s too complicated a life if you have this diagnosed*

(Adult, CD)

One family with children living at home had three generations (grandparent, parent, child) with CD. This impacted on the family management of CD as the primary focus of concern was the welfare of the child not the parent with CD:
We (parents) were very worried about our son, so we took him to the doctors and thankfully they diagnosed him (with CD) incredibly quickly which was great

(Adult, CD)

The primary shift of concern was also apparent in another family who also experienced three generations with CD. For this family the grandparent was diagnosed first, providing social modelling on living with CD for the parent, who in turn provided support and modelling for their child. During data generation this adult, whose son is now an adult, shared past events, indicating how protecting and reducing the psychosocial impact of CD on her son had been a primary concern:

The time he was growing up and going to other children’s birthday parties, I would make a cake at home and give him a slice to take with him so that when the cake was cut, and the other children had cake, he could have cake… This (CD) is not the sort of thing that changes somebody from having a normal childhood to an abnormal childhood … you just have to be a wee bit extra careful till they know to be a wee bit extra careful themselves

(Adult, CD)

For adults with children with CD, the primary focus of concern was protecting the physical and psychosocial wellbeing of the child removing the focus from themselves. The multigenerational effects across families prompted concern as well as providing vital support.
7.3.2 **Seeking Support to Cope with Treatment**

In the UK the clinical standard diagnostic CD test required people to continue to consume gluten while waiting for a confirmatory endoscopy (Rej & Sanders, 2021). Knowing the cause of their symptoms motivated most adults with CD to immediately implement dietary changes: ‘I just stopped dead you know there was no way I was going to eat gluten if it was bad for me’ (Adult, CD). An exception to this was the delayed acceptance of a CD diagnosis: ‘I mean I was in denial [diagnosis CD]’ (Adult, CD), signifying that a form of psychological disease acceptance was required to implement necessary treatment (Moos & Schaefer, 1984).

One adult, who had experienced a sudden debilitating onset of symptoms, after their blood test results had shown CD and while they were waiting for an endoscopy, recounted their reaction:

> I had access to the internet and did my own research and realised it was a diet lifelong thing and I just went immediately to the shop and went strict gluten-free overnight and when I say strict […] I wouldn't touch anything, I won't touch anything that had things on it that ‘may contain’ I wouldn't touch anything that that wasn't registered with Coeliac UK the charity. If I brought any little thing, I literally wouldn’t put anything to my mouth that didn’t have a coeliac accreditation thing, they were okay for people with coeliac so it was tough but I felt better within a couple of days and so I carried on

(A Adult, CD)
Dietary changes require complex behavioural changes driven by biological, psychological, and social factors. Implementing dietary changes rapidly indicates a strong driving motivating factor for people with CD. The symptoms had been impacting on the ability of adults with CD to engage with family life (fatigued) and employment (absence), an illustration of the biopsychosocial impact on adults with CD. Dietary changes are challenging to implement and maintain as suggested through the numerous diet support organisations. A strong motivating factor to consume a gluten-free diet for most adults with CD, was the alleviation from physical symptoms. The benefits of treatment were a continuing motivating factor for adults with CD as described: ‘I felt better within a couple of days and so I carried on’ (Adult, CD). In contrast, for asymptomatic CD difficulties in maintaining a gluten-free diet are reported, arguably due to an absence of association between experienced physical symptoms and food (gluten) ingestion indicating biofeedback playing an important motivating role (See, Kaukinen, Makharia, Gibson, & Murray, 2015). Unlike other autoimmune conditions, the burden of treatment falls on the person with CD, who needs to obtain and consume gluten-free food to prevent triggering CD symptoms (Ludvigsson & Murray, 2019; Whitaker, West, Holmes, & Logan, 2009).

A process of change began for all families from the point of CD diagnosis as they learnt how to manage living with CD. Traditionally, communication by healthcare professionals has been solely with adult patients, excluding family members (Lacobucci, 2017). The inclusion of family members is not currently integrated into NHS adult patient standard practice as the care model is patient-centred, exceptions apply in cases where relatives are informal careers (NHS, 2018b). Gluten-free dietary advice for CD treatment was provided by an NHS
dietician to most adults with CD, with no psychological, social, or family
treatment-management support provided (NHS, 2016). Consequently,
educating family members about CD and disease management was the
responsibility of the adult with CD, as recalled:

*Wife was pretty much a source of knowledge a source of how to tackle
[CD], but even some advice from dieticians she met at hospital was
quite, I will say basic from what she told me … She did a lot of self-study
about this disease and actually she helped me to understand the disease
and to learn about the disease because I didn’t have any knowledge*

(Adult, FM)

The treatment for CD medicalises food: ‘I go to the pharmacy to get bread’
(Adult, CD). Some staple gluten-free products are available on prescription,
although availability is dependent on local NHS clinical commissioning group
policy (Linton et al., 2018). Prescribed gluten-free foods often include flour,
bread, and pasta. Following the diagnosis of CD, the family grocery shopping
required modifying as to include gluten-free products, an unfamiliar and new
criterion for all adults. A cautionary approach was taken by adults with CD,
wanting reassurance of food safety. As an earlier quote exemplified ‘I literally
wouldn't put anything to my mouth that didn't have a coeliac accreditation’. A
pattern of concern developed, with several adults expressing about learning
which food products were safe (gluten-free) to consume. This was a time-
consuming stressful process, as described:
When you are diagnosed, for me it was such a shock I didn’t know where to go, my first shopping at Tesco’s when I was first diagnosed it took me more than four hours… I didn’t know what to buy

(Agent, CD)

They were not alone in their experience of searching for and finding food safe to consume. When first diagnosed safety assurance was sought when purchasing food to ensure it met gluten-free standards.

The need for reassurance of food safety is a common factor, despite advances in food labelling is apparent. As discussed in Chapter 3, gluten is invisible so visual or olfactory signs used to detect inedible food are redundant, necessitating a reliance on correct food product labelling when purchasing groceries. The emotional impact of food safety is indicated with an underpinning fear of embodying gluten and consequently harming oneself. To minimise the fear adults with CD sought assurance from reputable trustworthy sources, predominantly Coeliac UK. Advice from dieticians often included signposting to Coeliac UK, the only UK CD charity that provides resources and support for living with CD (a membership fee is payable to access all Coeliac UK resources). All adults mentioned Coeliac UK, who previously produced a regularly updated booklet guide on gluten-free eating that was remembered by those who had lived with CD for over 20 years. Adults diagnosed over ten years ago relied on paper booklets advising on gluten-free foods, whereas others diagnosed nine years ago, and one diagnosed three and a half years ago, were able to search instantly online for advice on the Coeliac UK website. Despite improvements in the labelling of food packaging, initial reassurance from Coeliac UK, as a reputable source, was still sought. For people with CD, food
poses a threat to health so continual checking of food labelling allows identification of any changes to product ingredients. The preventative behavioural change in food purchasing reduced the chances of a decline in health and impact on ability to function in daily life.

One adult, a long-term supporter of Coeliac UK recalled:

Coeliac Society (original name of Coeliac UK) we joined that as soon as he was diagnosed more or less and been in touch with it ever since, you know members get a magazine

(Agent, FM)
Figure 18  *CUK Food & Drink Directory*

Figure 18 shows the image of the Coeliac UK directory shared to explain living with CD. After many years of living with CD, the adult had gained plenty of experience so no longer felt the need for additional support from the Food and Drink directory produced by Coeliac UK. The directory had been used as a grocery and meal practical support tool for several years, to provide a gluten-free diet for their family member:

*Interviewer: So, do you use the food and drink directory?*
Adult: Well as I say not so much now because I know it all, it sounds awful I don’t mean I know it all, but I know all what I need to I know

(Agent, FM)

The support provided by Coeliac UK facilitated the development of necessary knowledge and skills to support the family in managing CD. Similar to other adults, confidence was gained, leading to the successful management of CD within the home. The Coeliac UK directory has now evolved due to technological advances into an online app that some adults continue to use, providing assurance of food safety:

I joined coeliac organisation (Coeliac UK) so I have lots of information from them and I have an app on my phone so I can scan product in shop and it is telling me whether it’s gluten-free or not

(Agent, CD)

The assurance of food safety was also provided through Coeliac UK Crossed Grain Trademark, certifying products suitable for a gluten-free diet, hence providing confidence in products:

I wouldn’t touch anything that didn’t have that wasn’t registered with Coeliac UK the charity, I literally wouldn’t put anything to my mouth that didn’t have a coeliac accreditation thing

(Agent, CD)

For many adults, Coeliac UK has played an essential ongoing role in supporting practically and emotionally living with CD, demonstrating both the initial and
ongoing need for social support. However, not all adults with CD were happy about being signposted to Coeliac UK:

_I joined (Coeliac UK), I went to see a nutritionist after I was diagnosed which was useful just to discuss what I am going to eat now and make sure my diet was okay, and she was very good at promoting the Coeliac UK saying you must join you must, so I did and I tend to like to join organisations, but I just found it all too intense. I mean people were meeting up in place, and meeting up in the local garden centre for a chat about being coeliac, and I thought no why do you want to do that, so I haven’t renewed my subscription to the Coeliac UK, it sounds like a secret brotherhood so no I haven’t related to it_  

(Agent, CD)

Support needs differ for adults as the quote demonstrates; they were seeking social opportunities but preferred not to dwell on CD. Whereas others had joined Coeliac UK for practical dietary support and reassurance, the experience shared indicates wanting social support but not through the sharing of illness narratives. The joining of Coeliac UK is portrayed as compulsory by dieticians a possible indication of the paucity of available support through the NHS and other reputable sources for people living with CD.

Social media sites were accessed for advice and discussions by adults with CD, as well as other online resources demonstrating the necessity for ongoing practical and social support:

_I am also on Facebook and I am on their coeliac disease page and also_
the ones for like coeliac bargains or something like that, people post offers on there, but the ones like the coeliac one, is obviously quite good and as lot of people go on there newly diagnosed and people are always giving you tips and stuff yeah so that is really helpful

(Adult, FM)

There was a distinct difference between families who had other family members with CD and those without. Having extended family members with CD provided valuable support in learning to cope with CD, helping all family members with the adjustment to living with CD and normalising the disease. For example, as one explained:

She (sister with CD) was supportive, and it helped ‘cause she was four, six months ahead of me … in a way it's quite nice cause my kids have got their cousins to just talk about it (CD) and they’re quite close to them so they've got bit support with it as well

(Adult, CD).

The mutual extended family support helped reduce the social isolation often experienced in long-term conditions (Rodham, Rance, & Blake, 2010). Social support from other people experiencing the same illness can reduce feelings of social isolation, knowing you are not the only person, additionally helping cope in the transition from diagnosis to effective family-management (Lee, Wolf, Contento, Verdeli, & Green, 2016).

In contrast, the support and acceptance of CD from extended family members for two women with CD created distress. Both had parents who struggled to understand the necessary treatment:
They [parents] just don’t accept it and when I go home to my mum, even though they try really hard to be supportive, my mum says things like you could have a bit of that I am sure it wouldn’t hurt you

(Adult, CD)

Even visiting family is really very difficult because no one understood me if I say sorry I really cannot eat what you have cooked

(Adult, CD)

For both women having to continually explain to parents their inability to consume foods containing gluten, became stressful with parents’ refusal to accept the diagnosis, creating social conflict, which was the opposite of social support. The social conflict also underpins the psychosocial properties of food and eating in families, a key social interaction.

Family members are critical for providing emotional and practical support when learning to cope with a long-term condition (Whitehead et al., 2018). A woman’s experience provides an example, describing how her husband was a key source providing practical support to cope with the change in family diets and behaviours:

He’s (husband) the cook mostly in the family, better than me, so he’s been in a way, he’s been doing a lot more of the adjusting than I have in a sense that he’s the one who has adjusted the household eating habits much more and he’s yeah obviously we’ve just kind of re arranged the household

(Adult, CD)
A pattern of social support was demonstrated in all families, influenced by the availability and accessibility of support, as well as the unique needs for each family group. The treatment for CD, a gluten-free diet, required behavioural changes to family food practices inside the home environment, and the external social environment when in the company of the adult with CD. Without the social support provided by family members coping with CD would be challenging. Families who had experienced managing a food allergy in children were able to draw on the skills developed to accommodate a gluten-free diet:

*Adult:* Child’s had a nut allergy since she was a baby, so we have always been aware of making sure things are kept aside washing hands in between, I do a lot of washing hands in between cooking and preparing foods […] or whatever but it’s just habit now you don’t even think about it

*Interviewer:* Do you think having to manage child’s nut allergy as a baby was helpful in terms of managing coeliac disease

*Adult:* Definitely yeah, it definitely helped as you are more aware of where you are touching, yeah it’s like touching raw meat, you want to wash your hands quite quickly afterwards so it’s like the same thing as that really, it’s like if we eat nuts, […]if we’ve both (parents) handled them we will always wash our hands

(Agent, CD)

The family’s behavioural food allergy practices have been effective as the child is now a young person.

Adults drew on a variety of coping resources official and social to support them and their families in response to diagnosis of CD. For one, social support aided acceptance of CD diagnosis and treatment:
Partner sort of gradually convinced me that actually it’s [CD] serious and you are not able to […] process nutrients effectively et cetera and you really did to like go down to nothing [no gluten]

(A Adult, CD)

The context was fairly unique as they had experienced their partner being diagnosed with CD and so was aware of the necessary dietary changes required to manage CD:

For some time already I had been, I was well aware of what coeliac was and the gluten-free diet looked like for some time before […] I didn’t necessarily take it [CD] as seriously as I should of because I thought that a little knowledge is dangerous right, I thought that I knew what it was [CD] and I thought it was a food intolerance thing and so I would still eat for probably the first year I would still eat bits and pieces

(A Adult, CD)

The experience demonstrates how prior experience and knowledge of an illness does not automatically mean acceptance of an illness label or implementation of medically advised treatment. The participants illness beliefs possibly deterred acceptance of the condition, the knowledge of the dietary change required combined, as presented earlier, with the biographical disruption caused. The experience demonstrates the role family members can play in supporting acceptance and treatment of an illness. The experience demonstrates the psychological and social impact of CD, illustrating how CD is more than simply a biological medical condition. These experiences provided insight into the start
of living with CD in family life, although full recognition was not realised by adults until they were living with CD themselves.

### 7.3.3 ‘It's Like Learning to Drive’: Adjusting to a Gluten-Free Diet

For families, the medical diagnostic label of CD came together with the necessary treatment, a gluten-free diet, the only known current and available treatment option (Anupam. Rej & Sanders, 2021). To implement a gluten-free dietary change effectively and safely, dietary knowledge and safe food handling practices are required. Once families had been introduced to CD the next stage in their journey was about learning and implementing the treatment. The adjustment to including a gluten-free diet and avoiding gluten cross contamination impacted on all family members, especially their behaviours in the family kitchen, an area designed for food storage and handling. This sub-theme describes the initial impact of CD treatment and how families coped implementing changes to family food and connected behaviours. Families learnt to adapt through the development of new habits, integrating a gluten-free diet and embedding CD into the family identity.

Adjusting to live with CD was a shared learning experience for all family members, as described:

> My husband he was a bit like me he didn't have a clue what it [gluten-free] was and we've kind of, just gone from scratch through figuring out what it is and how to get through it and to sort of live it, really

(Agent, CD)
Implementing a gluten-free diet involved all family household members, requiring new behaviours to protect the health of the family member with CD. Across the dataset adults described learning about CD and changing their behaviours to manage CD. Knowing about CD differed from putting into practice behavioural changes within the family home. Illness beliefs shaped how families coped with CD management. These beliefs changed with increasing knowledge and experience of CD treatment. Patterns within the dataset reflected behaviour, belief, and attitude changes. The change of behaviours around food required conscious attention, with accidental gluten cross contamination occurring during the adjustment process.

Eliminating consumption of gluten from the diets of adults with CD was not as straightforward as portrayed by medical clinicians and dietitians, as described:

Till this happened [CD] I just didn’t realise how much wheat was in stuff,
just chips where they coat with flour just to stop them sticking together,
the processed cheese that you get in bags it’s just got little bits of flour in,
you wouldn’t want, why would you put flour on cheese

(Agent, FM)

The inclusion of gluten in some food products was a surprise for most adults. The need to read food labelling revealed unexpected ingredients for adults increasing dietary awareness. Many assumptions are made about foods eaten with often minimal consideration or checking of what is being consumed (Black & Orfìla, 2011). For families without any pre-CD food allergies, CD triggered a need to check food labelling for gluten to ensure the safety of food consumed. This was a new behaviour that families had to implement to support the family-
management of a gluten-free diet, protecting the health of the family member with CD.

For the adult with CD, gluten cross contamination posed the greatest threat, so families adapted food storage and handling behaviours within the home. Realisation of gluten ingestion occurred when physical symptoms were experienced, when it was too late to avoid. Cross contamination in CD is when gluten-free food comes into contact with gluten; these include food-to-food, equipment-to-food, or person-to-food. The risk of cross contamination was present in both the home and external environment. Experiencing cross contamination was referred to by a number of adults with CD as being ‘poisoned’: ‘After I got off the plane where I had been poisoned (served a gluten containing meal by mistake)’ (Adult, CD). Two families converted from gluten-containing homes to a completely gluten-free home reducing the risk of cross contamination within the home. Families with children and young people who consumed gluten shared more experiences of family adjustment to a gluten-free diet. While two-adult families shared experiences that demonstrated their support for a gluten-free diet, illustrating how over time the family had learnt to live with CD. However, as participant indicated: ‘It [CD] really isn’t a deal in my life anymore it really isn’t’ (Adult, FM), implying there were times when CD presented challenges. The invisibility of gluten presented difficulties when educating family members, especially as any consequences did not impact them directly creating some friction in relationships and ill health:

**Sorry, I make mistakes, but she took this burden to where she was actually hit quite heavily, so there was maybe a little bit tension sometimes and arguments that we were not paying the same attention**
as wife [with CD], obviously because we [family members] were not affected as much as she was, but over time we understood, as I said the transition was initially quite difficult because paying attention to everything, and we were sometime thinking she was sometimes exaggerating but seeing her next day feeling not so well

(A Adult, FM)

Experiences such as those described in the above extract provide examples of how learning and implementing new behaviours for the health of a family member was difficult both practically and emotionally. For adult members changes in food related practices within the home environment required greater conscious effort when compared to children and young people who had parents to remind them: I get a little bit paranoid they'll [children] contaminate […] I just tend to shout at them when they get a little bit too near [to gluten-free pudding] with the custard spoon (Adult, FM). The analogy of learning to drive a car, where at first you have to pay complete attention to your actions and then they become unconscious, automatic behaviours, was used to describe the implementation of new food related behaviours by two men without CD:

I suppose you just have got to make some conscious changes to begin with but then once you have made those conscious changes. It’s like driving a car, you can go on auto pilot after that and it is easy, but you’ve got to accept the change first to know what to do

(AAdult, FM)

It’s like driving a car, initially when you are starting you are constantly thinking what you are doing, what kind of sign you seeing, and it’s over
time when you starting to drive more and more you're basically becoming more relaxed because your brain actually gets use to and understanding what the rules are similar to our conversion and transition. Initially it was like driving car after passing the exam a lot of stress, a lot of attention to details and thinking about what I am doing now. We are still three and a half years after diagnosed, but it’s much easier to not constantly thinking where I need to put this one, where is this one going, we learn basically how to drive. More so our brain doesn’t need to constantly focus on this. It’s basically becoming a habit and we can relax more or think about something else when we are doing things because it’s becoming like a robot. Yeah, we know that this is gluten-free, this is going to this place, we don’t have to think where this product from, is going, basically becoming a habit

(Adult, FM)

Both men discussed having to pay attention to behaviour and how the development of new behaviours takes time. One talks about accepting the need to change and the other how changing behaviour is hard, but it becomes less cognitively demanding with practice. This captures a process of change for families, highlighting the underpinning psychosocial driving factors. Food forms a significant part of daily family life with habitual behaviours being challenging to change (Middleton et al., 2020).

The motivation to change behaviour and adopt habits was driven extrinsically by the need to protect the health of a family member. The following quote from adult partner when asked whether it had taken a while to change his cooking behaviours, illustrates his motivation for behavioural change: ‘not really no
cause obviously the seriousness of it, if she does get contaminated, she just loses all energy and wants to go to bed it was pretty quick’ (Adult, FM). The motivation is an important factor in changing behaviour. The experiences of adults without CD illustrated the development of habitual behaviours, these are embodied behaviours responding appropriately to the environmental demands (Moya, 2014). For adults with CD, the benefits of a gluten-free diet were a strong motivating factor with life-changing benefits:

*The relief was instant as soon as I knew and I went on the diet, it just changed my life, if only I had known. They [doctor] said it could take a few days it could be a few months, but it was instant really*

(Adult, CD)

*When I stopped, cut gluten out my diet, it was like a renaissance, you go this is what normal people feel like*

(Adult, CD)

These benefits of treatment were observed by all adults: ‘it had an impact in that he felt better’ (Adult, FM).

The relief from physical symptoms impacted on the other adults who were pleased to see loved ones feeling well. During data analysis a pattern developed where children and young people spoke about habitual behaviours performed at home implicitly related to CD and the prevention of cross contamination: ‘The butter you can’t double dip if I accidently spread, and I don’t have enough I have to get a new knife out’ (CYP, FM). To avoid making the parent with CD unwell, care is taken to avoid cross contaminating shared food
products. Here, CYP described the normal family behaviour in their home for handling butter to prevent contamination from crumbs containing gluten. A familiar protective behaviour practiced across the dataset.

The children and young people recognised the underpinning reason for many family CD behaviours, as explained:

Because if we’ve touched bread or something we’ll have to wash our hands before we can before we touch anything else that mum that she can eat

(CYP, FM)

To illustrate their experience of preventing cross contamination at home, one CYP shared a photograph of themselves standing holding a grey towel in one hand and a piece of white kitchen roll in the other hand, to illustrate a protective behaviour practiced at home to protect their mother from gluten:

I usually have to have a kitchen roll or towel because like, if I use the towel then there will still be gluten on the towel, and if my mum uses it again then she’ll have the gluten on her hands or something like that

(CYP,FM)

Children and young people had high awareness of cross contamination prevention, recognising potential sources of gluten contamination and what actions they needed to perform to minimise any harm. All were cognisant of protecting the parent with CD from gluten.

Families had all adjusted to living with CD over time, embedding CD in their shared group identity, becoming the norm for their family: ‘I think it’s [coeliac
disease] just a thing it becomes part of your life’ (Adult, CD). Although CD became a family norm, it was recognised that this was different for other families. For example, a CYP explained:

It’s just weird ‘cause with mum we just don’t really talk about her illness [CD] really so it’s not something, it’s like a big deal to other people when they know but for us it’s kind of just normal, so we never think anything of it

(CYP,FM).

The quote from CYP also demonstrates how, following a period of adjustment, CD and associated treatment practices become absorbed into families lives. For children and young people, CD is more of a family norm, with recognition, as CYP states, that for other people CD is problematic. The children and young people possessed a good awareness and acceptance of different dietary requirements and preferences.

For adults, a temporal change of beliefs occurred following familiarity with CD and treatment, creating an assumption that other people knew about CD, in conjunction with a perceived increased public awareness of CD:

I must say three years ago it was much, much, worse. Right now, during last three years, everything has changed, especially last year, there is more and more gluten-free products, people are more aware

(Agent, CD)

Once adults had learnt about CD there was an expectation that all eateries should be aware of CD and associated food practices:
‘I think in a way it’s a lot easier being coeliac now than it would of been 20 years ago, now it’s quite prevalent and you go to lots of restaurants and they fully expect and are often able to cater for what we want

(Adult, CD).

Following diagnosis and implementing treatment adults’ beliefs towards being aware of CD and understanding CD changed: ‘I just thought people were faffing about being fussy’ (Adult, FM). Several adults believed an experience of dietary conditions was required to understand them, as explained:

_I always found it [CD] a bit of an irritation […] Holly is coming she’s b***** coeliac what does that mean again […] so memories of dealing with coeliacs, so I was very intolerant of coeliacs back then I must admit_

(Adult, CD)

The adult expressed a clear distinction between awareness and understanding of CD; from being aware of CD and experiencing it as a frustration, to then gaining a personal experience and developing an understanding leading to a complete alteration of his perspective towards CD. Adults with prior experience of CD before own diagnosis, recognised on reflection, an attitude changes towards CD. Over a period of time, families learn to adjust and manage a gluten-free diet within the home, with the outside world presenting challenges as alluded to: ‘yes, its [CD] nothing now, it doesn’t bother us now, it’s only when you go out or something like that’ (Adult, FM).

Compared to other long-term conditions, CD is particularly challenging due to the dietary nature and the shared food environment. The diagnosis of CD
impacted all family members. From a biological perspective, for some family members, it exposed a predisposition to CD triggering the option for testing. The diagnosis for all adults with CD provided a treatment to address the biological symptoms experience offering a source of physical relief. The diagnosis for all adults provided emotional relief. Implementing the treatment, a gluten-free diet initiated emotional and social challenges within the home. All family members had to cooperate to protect the health of the adult with CD, demonstrating the unique social nature of family groups.

7.4 Summary of Participant-Generated Photographs

In this analysis chapter an absence of supporting participant-generated photographs is apparent for two reasons. Firstly, the chapter focus is on the family journey from diagnosis of CD and the process of adjustment in coping with the treatment, which is a gluten-free diet. The shared experiences were not reflective of current everyday family life but a reflective opportunity for when a significant life change occurred. A couple of adults shared historic photographs to depict notable moments. These included sharing the image of the CD diagnosis report, an item that held significant emotional value for the person. Another photograph showed a child’s birthday party with candles about to be blown out on a birthday cake. The parent had gone to tremendous effort to bake a gluten-free birthday cake, as the child had CD, signifying the desire to practice normal western cultural food behaviours when living with CD. Additionally, it showed a parent with CD aiming to construct a ‘normal’ childhood for a child with CD, so diverting the focus away from the adult with CD. This again triggered many emotions for the adult sharing the photograph. These
photographs are not shared in this thesis to maintain the anonymity and confidentiality of the participants and others within the photographs. The second reason for the absence is that very few photographs corresponded with the theme of this chapter concerning learning to live with CD. Adults did not require the use of photographs to narrate the life event of a diagnosis of CD and subsequent effect exemplifying how prompts were not required to recall these significant memories.

7.5 Conclusion
The analysis presented in this chapter outlines the arrival of CD into the lives of families. The data generated describes the process of change, the learning curve families experienced in response to a diagnosis of CD. The diagnosis of CD and consequent treatment impacted on all family members. The biological diagnosis triggered optional CD testing for immediate and extended family members. The treatment for CD prompted utilising family coping and support strategies, drawing on practical and psychosocial resources. All family groups experienced a period of adjustment, adopting new behaviours. The adult with CD took initial responsibility for educating other family members. Once all family members had developed the necessary preventative treatment behaviours the management of CD became a shared family responsibility and incorporated into the family identity. The chapter provides the background to the disruption of CD for families and the psychosocial impact of the response to an illness crisis, how families coped and changed behaviours. The following two analysis chapters describe everyday life with CD at home and the wider social world.
8 Family Life at Home with Food

8.1 Introduction
When analysing the dataset, a clear distinction developed between family life within and outside the home. This analysis chapter reports on themes constructed through families experiences of living with CD within their home. The themes are set within the boundaries of the home, a shared private family space containing communal areas. Three themes and subthemes are presented 1) food for all: stocking the family kitchen CD; 2) ‘that magic word cross contamination’: shared and separated kitchen spaces; 3) negotiating family: shopping, cooking, and eating. The themes encapsulate family daily life in the family home environment, with families constructing their own living environment balancing the needs of members. For family groups, the presence of CD shaped shared spaces, behaviours, and food processes within the home. Intertwined throughout is the commonality of food, highlighting the influence of food in family functioning. All family members were very supportive in protecting the member with CD from gluten. Family life around food within the home prompted opportunities for communication and unspoken displays of care and love.

As in the previous analysis chapter commentary from the themes are exemplified using participants quotes together with participant-generated photographs. To preserve anonymity participant quotes are referenced as 'adult' or the initials ‘CYP’ denoting child or young person. For those participants with coeliac disease there are the initials ‘CD’ and for family members there are the initials ‘FM’. Please refer to Chapter 6 section 6.2 for a reminder of
participant demographics. Those who participated in this research are referred to in the text as families, adults, young people, and children.

8.2 Food for All: Stocking the Family Kitchen
The family home is generally considered a place of safety where family members provide care for each other. This theme describes how the families created and maintained a safe space monitoring food brought into their homes. All adults began vigilance for gluten prior to food entering the home environment, starting when purchasing groceries. Adults checked the ingredients list, and food processing environmental warnings on food packaging when making purchasing decisions in grocery stores in-person and online. The behaviour of checking food labelling for gluten was practiced by all adult family members, something that has become easier over time with practice. Checking for food safety is a habitual habit formed as part of coping and adjustment to a gluten-free diet, becoming an embedded adult habit. The need to check food labelling is essential if the family member with CD is going to consume the product, also knowing what products in the home contain gluten.

Many adults in families shared the responsibility for grocery shopping: ‘yes we usually go [shopping] on a Thursday morning both of us go’ (Adult, FM). The task of grocery shopping formed part of the shared routine household behaviours:

\[ \text{It's a household where we share all the household duties apart from I don't hoover at all I hate hoovering that's the only thing I don't do, we don't do each other's ironing either} \]

(Agent, CD)
Some adults described family behaviours performed when grocery shopping to minimise any conceivable chance of gluten cross contamination:

*When we go shopping, are doing shopping, we now have bags where we put in pretty much gluten-free product in one bag and the products which are not gluten-free in other bags just to not cross contaminate. We basically developed this one to ease and help to maintain that cross contamination to minimal*

(Adult, FM)

In one family, household food tasks were shared differently with the woman responsible for the grocery shopping and her husband the cooking, so the tasks were performed individually but connected. Whereas in another family, the woman undertook the regular grocery shopping with her husband, grocery shopping when hosting social occasions. The experiences of adults revealed similarities and differences between families in grocery shopping behaviours but in all families these tasks were shared in some way demonstrating how families negotiate everyday behaviours that are tailored for their social group. Most grocery shopping narratives were not reflective of the UK social norm, where women are reported as mainly responsible for family grocery shopping (Working Families, 2019).

When grocery shopping a woman described how her husband spent time checking ingredients:

*He's way more adventurous than me, he stands there looking at labels for ages, it's so boring and I'm like hurry up, but I think because he wants to get a bit more adventurous. He takes the time to, let's try this sauce*
and this one, and this is okay for you whereas I’d be like let’s just stick to what we have, I can’t be bothered’

(Agent, CD)

She described the emotional and practical social support from her husband encouraging the consumption of novel foods together with reassurance of food safety. The positive social support provided by an adult family member, aided coping with CD treatment. The habitual behaviour of checking ingredients occasionally produced mistaken purchases when focusing on ‘gluten-free’, as experienced by one adult who shared a photograph of a mistaken purchase Figure 19:

I think I only made the mistake because I was looking for gluten-free vegetable stock and saw the gluten-free on that I thought it must be vegetable stock because that was in my head, and ended up with gravy granules […] when I’m shopping I do tend to have to look and I do still occasionally bring things home that I shouldn’t bring home […] you have to be a bit careful when you’re shopping and sometimes, because you’re so busy looking for the gluten-free thing, you actually get the wrong thing, you get anything with gluten-free rather than the right thing’

(Agent, FM)
The experience showed how easily mistaken grocery purchases could be made when attention is focused on ‘gluten-free’ more than the product. When behaviours become automatic or habitual, other factors can be missed, as attention is directed in this instance to the gluten-free status. The need for increased vigilance when grocery shopping is a shared family CD management strategy. The checking of ingredients on food labelling was practised by a CYP with CD, as recalled: ‘we had to read the ingredients [gravy packet] to make sure [gluten-free] because we were having gravy, chips, and peas and pork it was important’ (CYP, FM). Having a medical dietary condition necessitates the checking of food labels before consumption as CYP who has a nut allergy, described: ‘then you’ve got to check every packet to see if it’s got nuts in like we do all the ingredients’ (CYP, FM).
The behaviours of children and young people with medical dietary conditions differed from other children and young people who did not mention themselves checking food packaging for gluten but would check when prompted by a parent:

_CYP_: I don’t really offer her (mother with CD) stuff I don’t like sharing my food but I sometimes I will check the back and stuff when she asks if she can eat it or not I’ll check it for gluten stuff

_Interviewer_: I must admit I would never think of wine gums as having wheat in

_CYP_: It’s they say that in the factory it “may contain”, so she doesn’t even get the chance cause then she will be sick

(CYP, FM)

When living as a family with a medical dietary condition the responsibility for food safety remains with the adults, parent(s). However, when a child or young person has a medical dietary need, they themselves need to be aware of what they are consuming to prevent illness, assuming responsibility for managing their health condition through behaviours taught by parents. All adults took responsibility for food brought into the communal family home. The differences in food responsibilities show how adults take responsibility for the health of the family group, whereas children and young people are responsible at the individual level in helping maintain their own health condition.

When grocery shopping the essential checking of food labelling sometimes gave unexpected, (see Figure 20) surprising results:
It wouldn’t occur to me it’s a tea bag right, why is a tea bag going to have gluten in it, but it does […]. There are so many things that you just don’t think are going to have gluten in them and they do, or they may contain traces of or made in a factory that contains, all that and stuff. Sometimes you think, like crisps, well it’s going to be potatoes and salt but gluten, or tea bags where herbal teas and things again it just wouldn’t occur to me that, but you have to be very vigilant and check everything. So, we do a lot of checking of ingredients in shops.

(Agent, CD)

**Figure 20** *The Surprise of Gluten in Tea Bags*

The quote exemplifies how the inadvertent consumption of gluten can occur, demonstrating the critical importance for people with CD to check all food labelling.
Checking food labelling is a continuous social support behaviour for adults:

*There was something I brought the other day that I didn’t dream would have wheat in it, taramosalata has got wheat in it [...] we haven’t had it for years and I thought for a change I would get that and then it had a warning on the top of the lid contains gluten*

(Adult, FM)

The experience demonstrates the importance of food labelling and the benefit of clear labelling to warn consumers of potential harm. In the UK legal requirements stipulate the mandatory requirement for food businesses to inform consumers if cereals containing gluten are contained in the food or drink provided. For families living with CD the ingredient list on consumable products signalled how to handle the product in the home environment and who could safely consume it, consequently supporting family management of CD.

Checking food labelling is necessary when the person with CD is an intended consumer also to prevent cross contamination. For families with a gluten-free home all products are checked to ensure consumption safety.

Grocery shopping online became necessary for some families shielding during COVID-19, and for others the social behaviours imposed limiting the physical handling of products in supermarkets, thereby reducing the risk of viral transmission, caused distress:

*I hate going food shopping [...] now with the COVID it’s one of the most stressful experiences for me because you have to look at the back of every packaging to see what’s in it before you buy it. And when you can only walk up one aisle and you’ve got other people trying to dodge you, and you are standing there looking at a pack and you are picking things*
up, you can’t eat that, so you are putting things back. You feel other people watching you, looking at you, like you’ve touched that now so you need to buy that because its COVID, and you can’t be touching things and putting things back, but obviously I need to do that because why would I buy something I can’t actually eat […]. I ended up coming back with food which wasn’t gluten-free because I thought it was, but I just felt that I couldn’t look at the ingredients enough […]. So, I am just doing as much food shopping as I can online because its much less stressful

(Agent, CD)

The experience highlighted the necessity, when grocery shopping, to check food packaging for gluten to ensure purchased products were safe for consumption. During the COVID-19 pandemic, social behaviour restricted the handling of food products to prevent viral transmission. Conversely a behaviour targeted at protecting public health triggered an increased stress response in people with medical dietary needs. The experience demonstrated the impact of perceived social pressure in conforming to social behaviours, even when posing a potential risk to own health.
Online shopping (see Figure 21) provided positive benefits for families sourcing gluten-free food, addressing staple food shortages, and providing an opportunity to try new gluten-free foods:

*Shortages but we actually found quite a lot of food online and we bought some extra supplies [...] we are doing bread so we bought big bags of*
flour [...] which is a few kilogrammes of flour [...] industrial scale we couldn't get them from the supermarkets they were basically out of stock

During COVID-19, grocery stores experienced food shortages as a consequence of consumers bulk purchasing (panic buying) affecting the availability of gluten-free food. This impacted on people with CD as a limited range of gluten-free products were available and often restricted to larger retailers. Some localised gluten-free retailers diversified offering goods online supplying a wider geographical market:

There is a lot of specialist gluten-free delivery places out there already [...]. A lot of places that normally just are a little bakery or somewhere in Devon have started selling stuff online because they had to close down the premises, so there was a lot of specialist food available online, if you are willing to pay for it […]. I just ended up buying loads of boxes of like gluten-free bread, doughnuts, and cakes. Things just keep arriving, or pies and quiches and things so, I just well, exciting for a while […] whereas previously I would of told myself I couldn’t really justify the expense of ordering. I ordered at one point 40 gluten-free dumplings […] I would never have justified that normally; you could freeze them and they have lasted me for ages and they are really nice

Online gluten-free shopping provided a positive opportunity for many people with CD enabling safe shopping for many families. The experience of grocery shopping impacted all families during COVID-19 presenting additional
psychosocial challenges as well as pleasurable opportunities for some to experience new gluten-free foods.

8.2.1 Penalised for Gluten-Free Food: Limited Expensive Medicine
All adults commented angrily on the high cost of gluten-free food, expensive medicine, and the limited number of retailers stocking gluten-free food products. The image in Figure 22 was a common photograph taken by adults with and without CD to depict the high cost of gluten-free food.

Figure 22 Expensive Medicine

One adult's quote reflected the thoughts and emotions of the majority of the adults:
I think with its a stamp of gluten-free it’s like there right [food producers and retailers] to charge three times the amount for everything, it does annoy me and especially when they [retailers] do like a special week out in one year as coeliac week and I think like, what, it’s not really a treat is it when you’ve got this [CD] a whole lifetime to have one week of bargains it’s like rubbish

(Associated, CD)

As illustrated in the above extract, ‘it’s like their right to charge three times the amount…’ reflecting the frustration and anger at the prices normally charged, especially for products considered basic staple foods such as bread, pasta, and cereal. Profiteering is perceived from supplying gluten-free food, a necessary medical diet, for people with CD. Across the data, staple gluten-free foods in comparison to the gluten equivalent were perceived as more expensive. Having a ‘special week’ was perceived as insulting suggesting retailers’ lack of understanding of CD, which is a lifelong condition and not a ‘treat’. To address the high cost of gluten-free food adults pro-actively sought gluten-free food and bulk purchased goods when on offer at retailers:

I will now just buy things when they are cheap so when there’s pasta on offer we’ll buy it and we’ll pile it up and we’ll stockpile it […]. Actually, to illustrate my point I had paid for everything and then walked out the shop and walked back and saw them [reduced gluten-free crumpets] and was like I am not leaving without them, so I went and brought them as well … Its really just the essentials that are more expensive, we do eat plenty of pasta, but we also probably eat more rice and potatoes than we would
These experiences are found in many adult’s experiences, the purchasing of gluten-free products when on offer or reduced in price, often using social media platforms to share and discover when retailers have special offers. Figure 23 shows the photograph shared by a women with CD to explain the high expense of gluten-free food and planning a specific shopping trip to purchase gluten-free food whilst on offer.
Requiring gluten-free food for medical reasons is not an optional dietary choice; it is necessary.

Several adults experienced restricted choice in where to shop in-person for gluten-free food. Larger supermarkets were reported to often stock a range of gluten-free products, with smaller grocery stores reported as stocking minimal or no products. Families with children and young people bought both gluten and gluten-free versions of certain food products, for example pasta, as the cost to feed all the family on gluten-free pasta was deemed too expensive. This differed...
in adult families where both adults would often consume gluten-free foods: ‘so I might just as well, you know, I’m gluten-free as well nearly’ (Adult, FM).

Children and young people had a different experience from adults not commenting on cost but instead conveying the irritation of having duplicate products to prevent cross contamination, both gluten-free and with gluten:

_We were cooking some pasta and we had to make two different things like we had to make one for our pasta for our like spaghetti and then we also made a carbonara and then we had to make one for our mum [...] so we had to make two separate batches of food which would also mean we’d have to buy more that is kind of a nuisance_ (CYP, FM)

All adults reported no direct financial impact on family living standards but resentment at the high expense and limited availability of gluten-free foods. The availability of gluten-free food on prescription to adults with CD varied depending on where they lived. One adult commented on having to provide her date of birth to access prescribed gluten-free food as well as having to collect food from the pharmacy:

_Who else has to give their date of birth before they can get a loaf of bread. I could just go into Sainsburys and buy gluten-free bread because it is available, it is just available now but I don’t go, I go to the pharmacy to get bread_ (Adult, CD)

Pharmacies dispense prescribed medication therefore the collection of gluten-free food from a pharmacy emphasises the medical aspect of CD which is absent in a supermarket where food is not perceived as a medicinal product. In
supermarkets gluten-free food is seen as a dietary choice and displayed with other food products not in the medicines section. Adults able to access prescribed gluten-free food did due to the high cost when purchased from retailers. One adult’s experience reflected the pattern generated in the data of experiences of accessing gluten-free food on prescription across the UK:

*Gluten-free prescriptions are just a pile of crap basically, so I lived in Wales [...] where all prescriptions are free for everybody [...] I basically had a list, a six-page list of things that I could get on prescription, they included pizza bases, biscuits, bread, rolls, anything that I wanted I could have. I would just tick the box and go and collect it, no questions asked, it would just be there. In England it is so different it’s so hard you might as well not bother. Though in Buckinghamshire, they don’t do anything on prescription that is classed as gluten-free unless it is flour [...] so I do get flour on prescription just because flour is really expensive*

(Agent, CD)

For people with CD health inequalities are evident across the UK, in terms of access to prescribed gluten-free food (Linton et al., 2018; NHS, 2018a). The high cost of gluten-free food could impact other areas of family life as well as the ability to purchase gluten-free food.

### 8.3 ‘That Magic Word, Cross Contamination’: Shared and Separated Kitchen Spaces
This theme describes how families managed food within the home. Two patterns were generated in the data, an absence of gluten and a shared but separated space. Within some family kitchens where gluten food products were stored physical boundaries existed to keep gluten-free food uncontaminated: ‘the kitchen is divided gluten-free stuff, normal stuff’ (Adult, CD). This behaviour is performed in homes where family members cater for gluten and gluten-free diets.

Two families, one where both adults had CD and the second an adult and child both with CD, had created and maintained gluten-free environments avoiding purchasing any products containing gluten foods: ‘we just said we wouldn’t have any gluten in the house, so we didn’t’ (Adult, CD). For this family the motivating factor for a gluten-free home was enabling all family members to eat the same food at mealtimes. In contrast, the second family of two adults with CD have constructed a gluten-free home together to provide a safe environment: ‘we have a gluten-free household the house is completely gluten-free we don’t have anything in here that isn’t gluten-free and so it’s kind of our safe place’ (Adult, CD). In this family the pets consumed a gluten-free diet to minimise all possible contact with gluten (see Figure 24).
The home space is an important source of security. Violation of this space with gluten creates distress as illustrated by an adult with CD who had to negotiate sharing their safe space when their mother visited, who does not understand CD, in order to control any gluten products, making a comprise to accommodate both parties:

*My mum has it [gluten snacks] in a cool bag that seals so that’s so I mean that’s okay and if she does need to eat anything like that then I ask her to go and do it upstairs in the bedroom that we have, so at least it’s kind of contained*

(Adult, CD)
Controlling gluten in the home space was evident when some families hosted social events within homes. Hosting social events empowered families to provide a safe gluten-free space to socialise for the adult with CD. An adult without CD described hosting a family birthday with extended family members at home:

*Strudel, that was the other weekend a birthday, and obviously (spouse) can’t eat that, (sister) [both have CD] can’t eat that so we just we put it inside just not to annoy them […] but no we just put it [gluten food] inside so, ‘cause (spouse) and (sister) were outside*

(A adult, FM)

A photograph was shared of this family social event exhibiting the table laden with gluten containing food inside, while outside in the garden spouse sat with family members and gluten-free food. Living areas within homes are shared family spaces, so safe spaces require negotiation and the cooperation of all members to maintain.

Controlling the shared space within homes was how many families managed gluten and gluten-free products, with shared and separate spaces, and with the intention to protect the adult with CD from gluten. Families performed protective behaviours within kitchens and dining areas so gluten and gluten-free food could be stored, prepared, and consumed by all family members. Family kitchens had dedicated gluten-free spaces for the storage of gluten-free food with a specific gluten-free cupboard being a common feature. Figure 25 shows the storage area in a home. An adult with CD shared their corner of gluten-free
products on the right, on the top shelf: ‘That’s my little corner the rest of it is all normal stuff and that is my little corner of gluten-free rubbish’ (Adult, CD).

**Figure 25 My Little Corner of ‘Stuff’**

A kitchen cupboard was primarily a safe storage space within a gluten containing environment. However, in homes with children and young people the cupboard also served an additional function. Figure 26 shows a gluten-free cupboard which only the adult with CD eats from, apart from the flour which is consumed by all family members, and discreetly raided by young people and children in need of chocolate.
The adult was not alone, as some mothers with CD hid ‘sweet treats’ in their gluten-free cupboards, with some children and young people disclosing how they raid the cupboard for the ‘goodies’ as disclosed by a CYP:

She [mum] hides like chocolate and stuff in there I know it’s in there. That’s where I first look when I’m looking for a snack, ’cause there normally is because she can have like plain chocolate and stuff, so she gets loads of that I’ve taken some of that before

(CYP,FM)
Although physically separated, the gluten-free cupboard contents, are shared and consumed by younger family members in ‘emergencies’. The gluten-free cupboards and contents were perceived by all family members as belonging to the person with CD: ‘what I think of as her biscuits because they are gluten-free’ (Adult, FM). Many family homes also had separate spaces within freezers and fridges to keep gluten and gluten-free foods apart to protect the adult with CD from gluten cross contamination. In contrast to the gluten-free cupboard, a family member also described the gluten cupboard and the shared food storage areas within the kitchen:

*The gluten cupboard, which has the kids’ stuff in has cereals and biscuits, all the other stuff that we have is in a pantry which has got all our rice’s, so I am just trying to think what there is on the shelf it’s like all the soups obviously gluten-free the baked beans […] just trying to think what gluten product is in there, so nothing with gluten in on the main area so the majority of stuff we buy is neutral. It’s just those extreme products like the white breads and the cereals we keep separately everything else can be mixed*

(Adult, FM)

The shared space within the family kitchen also includes cooking appliances and equipment. Food is separated to minimise risk of mixing-up gluten-free food with gluten food when the gluten equivalent is cooked. How families shared the space to prevent gluten cross contamination varied according to the individual family functioning and resources, finding solutions together. As CYP described the family behaviour in her home: ‘we’re not allowed to use any of the same
facilities that she (mother with CD) uses like the toaster, (CYP, FM). In this family home, as in others, within the shared kitchen space are two toasters, gluten and gluten-free, meaning not all areas and equipment within the space are shared. Family members needed to know what appliances and equipment are shared and not shared to support CD management:

*We’ve got two separate totally separate toasters [adult CD] got her own we’ve got ours and they are on different sides [of the kitchen] so the kids don’t accidentally drop their toast into the gluten-free toaster*  

(Agent, FM)

Good communication is required to ensure all family members are clear about kitchen behaviours. Figure 27 shows how one family reduced the risk of gluten cross contamination using reminders, labelling separate sponges for cleaning (yellow sponge has a gluten-free sticker) to reduce human error:

*I do sometimes worry about knives and forks ’cause I think everybody’s knife and fork tray sometimes gets crumbs in it, so do worry so I do sort of sometimes you know, clean that out and stuff*  

(Agent, CD)

Support and care in behaviour were taken to protect the health of the adult member with CD. All the family members were knowledgeable about food ingredients and practised preventative kitchen behaviours. The underpinning motivation was driven by psychosocial factors, to protect and care for family members. Having shared family household rules reduces the burden on the adult with CD providing a safe home environment.
The food handling protective behaviours within the home were automatic for children and young people, as these were their family norm, although parents provided reminders as CYP described:

*Another big thing adding like leaving breadcrumbs around cause if you’ve left breadcrumbs somewhere it can contaminate her food and then she can get ill so my dad’s kind of strict about that like wiping up after you’ve done something*

(CYP, FM)
The prevention of gluten cross contamination is a key family CD management behaviour practised by all members where any food handling within the home is carefully managed. An example of a family strategy to prevent cross contamination is marking names on butter lids is seen in Figure 28

**Figure 28** *Separate Pots for Mum to Prevent Cross Contamination*

‘No double dipping’ is a common (un)shared food behaviour in many families with children and young people. Behaviours around butter and dips were recounted ‘we have to have a separate butter or I have make sure I don’t leave any crumbs in it’ (Adult, FM) and sometimes accidents occurred:

> Sometimes I think we are used to it now, that if there’s two butters out we’ll just stick to one of them but, sometimes maybe with the butter or the hummus we sometimes accidently do it [double dip] the only thing
about that is she [mother with CD] has to get a new pot of hummus or butter

(CYP, FM)

Children and young people were very aware of potential sources of cross contamination from many gluten sources for them it is the family norm. For example, a CYP explains:

Well, when we make pancakes and stuff we have gluten-free flour, also I don’t think we own any normal non-gluten free flour because it gets in the air so everything has to be gluten-free

(CYP, FM)

Children and young people followed food handling behaviour rules even when disliking them, recognising these are necessary to protect the parent with CD. A CYP explains what she has to do after eating garlic bread:

CYP: Well I had to vacuum or put them [crumbs] in the bin or at the end of my eating I have to sweep them all up and stuff

Interviewer: So, do you mind clearing them up?

CYP: umm sometimes I don’t really like doing it all the time

(CYP, FM)

These are non-negotiable boundaries that are especially practised in all families with children and young people, with no double dipping in butter or dips, and the removal of gluten crumbs a shared feature. The exception to this is the family
who are gluten-free, where the risk of gluten cross contamination in the home is low due to gluten absence in the home.

For adults, adjusting to daily food related behaviour within the home environment was demanding, requiring conscious attention, in contrast to children and young people. The support of family members within the shared home environment was seen as critical in preventing cross contamination and avoiding gluten consumption. Over time the number of cross contamination incidents decreased as families learnt the best way for them to manage gluten within the home creating and maintaining a safe environment:

> It was a little bit slower for the children obviously ‘cause they didn’t get it but then they are fine now you know they just stick to their own stuff and you know and [adult, CD] hardly ever gets contaminated at home

(Agent, FM)

8.4 Negotiating Family: Food, Cooking and Eating

This theme, ‘negotiating family; food, cooking, and eating’ describes the interconnected psychological, and social factors surrounding family cooking behaviours, dietary choices, and consumption. Families negotiated the task of cooking based on the family situation, with many families sharing the responsibility for cooking meals. For adults with CD this required trusting other family members not to contaminate food with gluten during the preparation and cooking process. Dietary choices were shaped through needs and taste preferences. Family meals varied with some families eating the same food together, whilst other families had a variation of food in the meal, gluten and
gluten-free, and others ate different meals together and others different meals apart. The psychosocial meaning of certain meals drew all families together such as a roast dinner or celebration. Family life at home, cooking and eating illustrates how families constructed their own unique yet similar behaviours surrounding cooking, diet, and tastes.

Within the dataset both uniqueness and similarities between families’ cooking behaviours developed. The responsibility for cooking family meals varied in families based on external commitments, trust, and cooking ability. All family members contributed to cooking in some form, daily or occasionally, except for one family where the woman assumed the role of daily cooking for the family due to her husbands’ cookery skills absence. At times responsibility for cooking became a burdensome chore as her family members were reluctant to go to out to eat:

_Sometimes it is difficult because I have to cook and I have a busy life, I have to everyday cook, and in the beginning, it was really difficult and now it's much easier because my family absolutely loves eating homemade food and they at some point even, I said before lockdown just go to restaurant and have something please just leave me … I was really just go to the restaurant, no we're not we don't like restaurant food anymore, so they really really enjoy they feel benefit but for me it's another burden because I have to make it, I have to make time I have to change my lifestyle completely to adapt all of that_

(Access, CD)

The worry of being ‘poisoned’ was of high concern to this adult, being highly sensitive to gluten combined with unpleasant experiences of cross
contamination. For this family the alternative to cooking for family members was to dine away from home, not cook a meal in the family kitchen. The burden of cooking fell on the adult as in her family she had always cooked, removing the pleasure. This experience supports research reports of women who do not enjoy cooking for others, and is an example of the stereotypical gendered role of cooking within family groups (Fuller et al., 2019).

In adult only families, and in some families with children and young people where both parents worked, the role of cooking for the family was shared between women and men. This behaviour is not reflective of contemporary western modern household roles where women are reported as responsible for family cooking especially in heterosexual families with children (Families, 2017; Working Families, 2019). In one older adult family, when asked if the other adult cooked:

No, he would still be there at lunch time I think if I waited for him to cook, he does cook, he cooks Saturday lunch, he always does a sea food stir fry Saturday lunch and he makes teas and coffees and bits and pieces, he does do cooking

(Adult, FM)

For this family it was easier and quicker for the adult without CD to assume responsibility for cooking, as other adult had a learning disability, although they did make some household culinary contributions. Lifestyle and life stage were also moderating factors for this family. After many years catering for multiple immediate and extended family members, one adult took an easier approach to
the family meal preferring meals out. The cultural generational gender norm would be, as an older woman and a parent, to assume family catering responsibility (Murcott, 2019).

Another family had negotiated different cooking behaviours. The father was the primary chef, with the family young person self-catering to reduce the burden on her father catering for the different family diets:

*I just prefer it ‘cause what you want, like when my dad has to cook for us. He has to cook for (sister) as well and cause (sister) 10, so she doesn’t eat a lot of stuff yet, and I’m vegetarian and mums coeliac, so it’s kind of harder to cook something that we all want, so usually my dad ends up making like two or three meals, so I just cook for myself*  

(CYP, FM)

Girls in other families would cater for others, although not always willingly:

*I would just cook for myself no cause what mum will normally do is her and dad will eat something and then she’ll go they will go out and have gluten-free fish and chips and that and she will go (sister) will you make quick pasta for you and your brother*  

(CYP, FM)

Cooking for themselves provided young people with a sense of independence and autonomy reflective of the life stage helping to build confidence. In contrast to older adult, at the opposite end of her life stage, who would rather not cook. For adults with CD, eating meals cooked and prepared by other family members requires trusting others to take care when preparing and cooking food to ensure meals are safe to consume. The behaviour of cooking does not appear related
to CD as many adults cooked prior to diagnosis, some changes in cooking behaviours are indicated through life stage changes, with one woman historically doing the family cooking but as family members have aged the task has become shared. This highlights how many adults, with and without CD, have adapted to new cooking behaviours to prevent gluten cross contamination, illustrating family social support. Children and young people have learnt how to prepare and cook gluten-free and gluten meals.

Inspiration for meals to cook reflected a gender pattern distinction within the data. Women with and without CD, kept cookery books (see Figure 29) used for meal recipes:

I do have a couple of gluten-free cook books but to be perfectly honest most recipes are perfectly adaptable unless you were going to make a suet pudding which I wouldn’t but if you were you would just adapt it and most of the things that I eat well actually to be honest most recipes you just look on the web these days don’t you but l do like my books because they are you know so very reminiscent of other times in my life

(Adult, CD)
Consideration of meal choice and adapting recipes to cater for a gluten-free diet relates to the caring stereotypical gender role often associated with women and food. One woman described a favourite recipe from a cookery book:

*I do a puy lentil with porcini mushrooms, actually the full recipe has got meatballs in it but, I am now at the stage I don’t bother with the meat balls, I just make the puy lentils they are soo good and either have them with a roast chicken leg or something or instead of making the meatballs, which are a bit of a faff time and care about it, now because there’s that element where we can’t have certain things we don’t feel deprived at all in terms of what we eat. No and yeah when I was looking up recipes trying different things when you are eating food of that quality you have nothing to miss*

(Adult, FM)

The quote touches on how cookery books have aided in providing pleasurable meals, ameliorating the absence of gluten from the family diet. Pleasure from
cooking is similar for other women as described when discussing the photograph of the meals she had cooked:

*Interviewer: Is this your normal standard of presentation?*

*Adult: Yes, yes, it is to be fair and then sometimes I make homemade guacamole with avocados I eat a lot of those or sour cream*

*Interviewer: Do you enjoy cooking?*

*Adult: Yes I do yeah, I mostly do from scratch however we do have fish in breadcrumbs I buy from frozen a lot of the time it’s easier or chicken in breadcrumbs*  

(Agent, CD)

As alluded to, whilst enjoying cooking, there were occasions where quick meals are cooked, a shared behaviour for adults within the dataset.

Men who cooked shared experiences of cooking meals:

*Now I can cook I am certainly a better cook than I was a few years ago, I would actually say I am better at making things now with whatever we have in the fridge*  

(Agent, CD)

In some families cooking meals required cooking gluten and gluten-free products:

*I’ll do (wife’s) pasta gluten-free and then obviously ours as normal, it’s strange her pasta you get the spaghetti if you don’t keep moving it in the thing it will all just congeal into one big lump no you’ve got to stir like mad*
[...] yeah, so it takes a bit more cooking effort in as normally you just like whack it in

(Adult, FM)

The quotes show the cognitive (creating a meal from available ingredients), physical (the act of cooking), and socioemotional (increased effort to cook gluten-free food for family) processes cooking a meal requires.

Some families hosted social events at home including food when men would often be responsible for sourcing the food and cooking, taking great care to ensure all diets were catered for and no cross contamination occurred:

There was 14 of us and so there was a vegan, 3 vegetarians, 3 coeliacs, 1 nut allergy, and 2 milk allergies so he [husband] did it all for us, he knows he’s really good so he went to the shop and just he got everything

(Adult, CD)

Wider social cooking generated a pattern of barbeques for most men, possibly a reflection of the time of year the research was conducted Spring Summer, also the lifting of lockdown restrictions where physical in-person socialising could happen outside.

There were interesting gender differences, with men cooking family meals and more likely than women to cook meals for home social events (Working Families, 2019). Men cooking meals for social occasions are reflective of cultural gender norms, especially barbeques, which is seen as a very masculine behaviour (Love & Sulikowski, 2018). The shared responsibility for cooking everyday meals in many families indicates a shift in behavioural traditional
gender roles within the home, reflective of UK public attitudes but not necessarily behaviour.

A baking pattern developed for most women and girls with mixed experiences. For example: ‘I use to bake a bit and I had to make gluten-free things and that was a bit annoying because of the texture it’s hard to bake with it’ (Adult, FM) whereas another woman had a different experience: ‘I make my cakes the same I do the same recipe I don’t add anything different the flour (gluten-free) is just as good really’ (Adult, CD). Even one woman, who did not cook meals at home, did some baking: ‘oh yes I made some little gluten-free pancakes and I made those and I put some chocolate on’ (Adult, CD).

Figure 30 ‘I Love Baking’
Data indicated baking as an activity enjoyed by most women and girls: ‘I do cook from scratch when I do cook and I know what I am doing I am a keen baker’ (Adult, CD) and a CYP enjoyed making her hot cross buns Figure 30. A woman described consuming the cakes she baked, a shared pleasurable experience demonstrated through the number of cakes consumed:

*I do a bit of gluten-free baking [...] I made, and we’ve eaten three full Christmas cakes since lockdown. I mean full sized Christmas cakes because its soo full of fruit the gluten-free flour doesn’t have the same effect. You wouldn’t know it was gluten-free. So that is the one I make, but we both love it, so we are just like having it with every cup of tea but its stopped. I will make them before yeah that and flapjacks or something*

(Adult, FM)

All goods baked at home were gluten-free enabling all family members to devour them. Correspondingly some men discussed baking in terms of the consumption of baked goods not baking (see Figure 31), many of them commenting on how delicious gluten-free cakes are:

*I meant to take a photo before it was empty but wife makes an absolutely delicious gluten-free ginger cake so it was just to show that you there are some good sides to it, so actually some good baking and that is a particularly good thing and that's why the box is empty [...] wife enjoys baking and it [CD] hasn’t stopped her from baking and it hasn’t stopped me from enjoying the stuff she makes*

(Adult, FM)
Baking is a symbolic behaviour signifying care and love. For those consuming the baked goods it is a pleasurable experience. Baking is a form of stress reduction a behaviour that significantly increased during the pandemic (Chee et al., 2020). Baking provides a perceived sense of control and increased wellbeing and connection with other people (Farmer, Touchton-Leonard, & Alyson, 2018).

All the families incorporated gluten-free food and eating behaviours within their home, managing to cater for the dietary needs of all family members. But the
inclusion of a gluten-free diet varied for families reflecting the uniqueness of family groups.

Apart from the two families who all had a gluten-free environment at home, in other families there was no expectation for other family members to eat a gluten-free diet at home. For example, ‘I definitely haven't made the whole family go gluten-free there would be mutiny from my husband probably as much as yeah the other two (children)’ (Adult, CD). The quote highlights the unacceptability of a gluten-free diet for all the family, indicating family members’ willingness to change food related behaviours to accommodate a gluten-free diet, but not food preferences.

All families were similar, having to consider gluten-free food choices, although three families had additional dietary considerations influencing meals, medical reasons, and dietary preferences based on personal beliefs. Consequently, family meals were adapted according to each diet with CYP identifying as the only member in his family with a ‘normal diet’: ‘but I am like the only one that eats normal food’ (CYP, FM). Based on the data, for many people, the concept of a ‘normal’ diet was structured on the assumption that any diet excluding specific food ingredient(s) or groups is ‘abnormal’ using a ‘normal’ diet as a benchmark to compare any variations of diet.

In a family the adults (parents) both ate a gluten-free diet, sharing meals, whilst the children had separate diets to cater for dietary beliefs (vegetarian) and tastes (fussy eater) as adult describes: ‘we've just kind of re-arranged the household I mean it's not a gluten-free household… it will typically be a gluten-free meal for both of us [ adults]’ (Adult, CD). The experience of diet was split
between parents and children. One family diet was shaped by both parents, one requiring a gluten-free diet and the other a dietary belief (vegetarian). In this family dietary comprises are made around the health of the child as well as supporting the dietary differences. Here the wife describes supporting her husband’s dietary beliefs and daughters’ dietary needs:

*Last year my husband decided to be vegetarian I joined as well but it is really tricky to keep gluten-free and being vegetarian as well so I’m not 100% vegetarian but sometimes I have to compromise and buy stuff which is with meat […] when I make meat for my daughter*

(Agent, CD)

Capturing further dietary beliefs and practices the husband justified why, based on health grounds, a gluten-free diet was nutritionally unsuitable for his daughter and himself:

*For the healthy people gluten-free diet is not as well […] from what I understand this is not super healthy and as I said we moved to the gluten-free pretty much diet however we also trying me and daughter we are trying to as well keep the gluten as well in our blood*

(Agent, FM)

The experiences of this family illustrate the complexity and compromises around negotiating family diets and balancing dietary needs. A different approach was taken with the whole family group consuming a gluten-free diet at home when a child with CD is in the family group. When considering the needs of multiple family members compromises often need to be made. In contrast a
predominantly gluten-free diet at home was a commonality in adult only families.

The three experiential descriptions show how the phenomenon of diet is constructed within families shaped by CD all with the underpinning goal to feed all family members. The families demonstrated how despite having the commonality of CD how this was managed was based upon the family attitudes and beliefs, individual family behaviours.

8.4.1 Food Tastes and Choice: Bread, Pizza, Pasta
This theme describes the influence on food tastes with three foods: bread, pizza and pasta constructing a strong pattern across the dataset. All family members mentioned one or all of these three foods in regard to taste. The subjective sensory pleasure associated with some foods makes it challenging for some adults not to consume food which they like ‘wife gets really upset if she can’t have the bread when Sainsburys are pumping out the fresh bread smell and she’s like oh god’ (Adult, FM). The sensory pleasure is more than the act of putting food in the mouth; smell can stimulate desire for certain foods, as husband described the effect on wife. For families, excluding the gluten-free homes, the continuation of eating gluten within the home is often driven by taste, although there is an element of guilt surrounding the consumption of gluten in the home in the presence of the person with CD. Non-CD adults perceive the emotional difficulty for the person with CD, as husband described: ‘I still eat (gluten) and wife’s quite good and doesn’t kick up a fuss if I am sat there eating a white breaded sandwich that’s about that thick’ (Adult, FM). The family relationship shows how wife has not expected or asked her family to go gluten-free knowing how much they enjoy eating gluten containing foods. The
husband appreciates his wife not commenting on his consumption of gluten foods, although a hint of uncomfortableness and social awkwardness is indicated by ‘wife’s quite good’. The mutual understanding of family members’ feelings fosters a supportive relationship.

In contrast, one woman no longer makes a favourite family pie:

*Adult: But I haven’t made one [steak pie] for years since he’s diagnosed, I’ve not I mean I think that would be torture for him to watch us eat steak pie so I don’t make it*

*Interviewer: You don’t make it at all?*

*Adult: I haven’t made it since he was diagnosed [photograph, Figure 32] (Adult, FM)*

In families’ certain meals hold psychosocial values, as the adult described with pies; they are something she made for all the family when their children were younger, so they possess sentimental meaning for her and other family members. The adult talks of missing pies (see Figure 32), so her photograph of a pie counter in an award-winning pie shop holds a certain irony, with regard to something she no longer makes for her family as to not upset her husband. Pie held strong family meanings. The absence of pie within the family home provides an example of a dietary sacrifice (Alley, 2015). Certain foods, meals, hold psychosocial meanings for people.

*Figure 32 Missing Pies*
A distinct data pattern developed in all families in the consumption of bread, pizza, and pasta as common daily food. Bread particularly arose as a significant food for adults. Globally bread is a basic staple food with many associated psychosocial values (Dunbar, 2017). Apart from gluten-free homes, at home ‘normal’ (gluten containing) bread was provided by parents, so bread did not concern children and young people. But bread in the context of crumbs potentially causing cross contamination concerned children and young people, such as double dipping, putting crumbs from the bread onto the butter. A CYP reported the delicious taste and social pleasure of sharing garlic (gluten) bread with her father which overrode the associated, not so fun task, to remove all the crumbs:

*It’s usually shared between me and my dad, that’s my dad next to me [referring to her photograph] and we were having a really nice garlic bread […] I had to vacuum or put them [crumbs] in the bin at the end of my eating I have to sweep them all up and stuff*

(CYP, FM)

Bread for all adults held meaning, the whole phenomenon involved in the consumption of bread, the smell, taste, and satisfaction. Bread within family
homes varied. For many adults without CD bread was perceived as the one food they were unable to give up, or substitute, primarily based on the taste of gluten-free bread. The data pattern constructed a meaning of sympathetic bread consumption in two-adult families.

**Figure 33 Tasty Gluten-Free Bread**

Some adults without CD made compromises around the type of bread within the home no longer purchasing fresh loaves:

*I don’t have loads of bread lying about the kitchen or anything anymore there’s no point as there it’s only me it would go stale, we put it in the freezer and I take out, I mean it has cut down the amount of bread I eat remarkably because there isn’t a nice fresh loaf sitting there in the corner anymore which there always was because husband was huge great bread eater huge and he had to give it up just overnight so it does not lie about it’s in the freezer*
Prior to CD fresh bread was a staple kitchen feature for this family. The wife demonstrates empathy towards husband through the physical removal of bread from view, and concealment in the freezer. The bread consumed in the homes of two adult families changed, packaged sliced bread replaced fresh bread as seen as a less desirable alternative, indicating a sensitivity towards the adult with CD. One family purchased gluten-free bread from a local bakery with both members consuming it:

*They [bakery] bake some lovely bread, their bread is absolutely gorgeous, well I do now, I use to get my own bread but I kept it in the freezer and remembered to get it out each day which I didn’t, if I left it out I didn’t eat it, I don’t eat enough it would go mouldy […] it seems silly and this bread [gluten-free] is so nice so I might just well eat it*

The taste of bread influences consumption, with mixed opinions on the palatability of gluten-free bread illustrating the subjective nature of taste. Some adults with CD enjoyed the taste while others expressed a dislike for gluten-free bread:

*For a while gluten-free bread was so expensive and so horrible that we just wouldn’t buy it and I didn’t eat it […] I certainly loathe to eat bread [gluten-free] still that hasn’t been toasted*
In families with children and young people, a parent acknowledged gluten-free bread is the only gluten-free food her family members do not consume:

*But gluten-free bread nobody else will eat unless they absolutely have to and I can't tell anymore cause I can't remember what bread tastes like and I'm fine with it but that's the one thing that I can't make anyone else eat gluten-free bread*

(A Adult, CD)

Although the adult’s memory of the taste of gluten containing bread has faded, a hint remains in mention of other family members not willing to consume it. Another adult exemplifies the importance of taste describing the emotional impact of bread:

*Of everything I miss the most its bread, I have tried many different sorts brands types with different things that go on top of it and stuff like that, there were a few I like and they're okay but, it's never quite the same*

(A Adult, CD)

For them the taste of bread containing gluten is a loss, part of having CD, although missing bread the adult resists temptation and does not consume the bread containing gluten stored within her home. The importance of gluten-free bread taste led some families to making bread, an ongoing process seeking to improve taste and textures:

*Any bread is actually made by us, we have a bread maker and basically, we are making bread by our own. We are trying to find some good*
ingredients as well and adding some extra, and we found that bread is 100 times better than the gluten-free one

(Agent, FM)

The adults all demonstrated the subjectivity of taste, but all shared the commonality of bread consumption regardless of whether they consumed gluten or gluten-free, indicating the significant role of bread in family diets. The experiences also demonstrated the temporal alteration of taste and the search for some to find the tastiest gluten-free bread. The psychosocial properties of bread were illustrated in the adults’ meanings, the emotional values associated with taste sensations and sensitivity towards the loss of eating and sharing a fresh loaf of gluten containing bread. In some families forgoing themselves to minimise loss to adult with CD. Families negotiated the tastes and dietary needs of all members purchasing gluten-free and gluten bread catering for all members.
Bread in the form of pizza was a favourite food of all the boys and some of their parents:

*Interviewer: Are you a big pizza fan?*

*CYP: [nodding] ... My favourite topping is pepperoni or the ham and tomato, mushroom I like yum*  

(CYP, FM)

The CYP shared a photograph
Figure 34 of home delivered pizza. The consumption of pizza, as a shared family experience, occurred inside and outside the home environment. Pizza provoked a pleasurable experience especially when delivered from outside to the home, signifying a special treat: ‘Dominos is a rare treat we don’t have it that often’ (CYP, FM). A father shared a family favourite recipe for ‘turbo pizza’ he had invented and enjoyed cooking for his children delivering pleasure and social bonding for all: ‘Something for the kids I cook what’s called turbo pizza […] leave it 3 minutes and it comes out and it’s like a thin and crispy pizza and they love it so for lunch’ (Adult, FM). Taste preferences influence parents’ food provision for children and young people as the example from father shows. Pizza for some family members, holds psychosocial meanings, the emotional pleasure of consumption and provision in the social context of family relationships.

Another common family food similarity was pasta with many households consuming a mix of gluten-free and gluten pasta within the home: ‘if I make a pasta and I say it's gluten-free pasta, she'll [daughter] say I’m not eating it’ (Adult, CD). The CYP is not alone in her dislike of gluten-free pasta:

The only thing I cook separately is I am not that keen on gluten-free pasta I don’t know people keep telling me its ok but nah I like ordinary
pasta so but, that’s no hardship to do two wee pans instead of a bigger pan the sauce doesn’t matter

(Agent, FM)

In families accommodating gluten-free and gluten diets cooking involved two products to cater for dietary needs and taste preferences. This was a commonly observed catering behaviour for families. Extra attention to behaviour was expressed when simultaneously cooking gluten and gluten-free pasta due to the risk of cross contamination. The subjectivity of taste is reflected again with all the family eating gluten-free pasta as described:

Sometimes they (children) have a gluten-free pasta and they can’t taste the difference, it is just as nice, the only reason why I don’t do it all the time is because of the cost’

(Agent, CD)

The quote illustrates how economic factors can influence family diets more than psychological (taste preferences).

Whereas pasta featured regularly on family everyday meal menus the thought of pasta did not provoke the same passion as pizza and bread. For the one family (two adults), both eat gluten-free, pasta is regularly served for dinner: ‘Wednesday is spag bol, Thursday is shepherd’s pie or lasagne’ (Agent, FM) suggesting a routine everydayness around pasta whereas pizza was perceived as a special treat. Taste potentially influenced the positive emotional reactions as the combination of pizza ingredients are considered rewarding, argued to possess addictive properties, with pizza perceived as the ultimate comfort food (Schulte, 2018). Most non-CD family members will eat gluten-free pasta but not gluten-free bread, again indicating the importance of taste and satisfaction from
consuming food. Bread, pizza, and pasta were popular food choices for all families, however adults with CD only had the gluten-free choice whereas other family members (except one) were able to enjoy both gluten-free and gluten foods. The meanings associated with food, and economic considerations, are combined with the necessity of a gluten-free diet when catering for families, influencing the purchasing, preparation, cooking, and consumption of food. These meanings illustrate the multifactorial dynamic processes for feeding families indicating an additional consideration for families with CD.

Family members spoke of enjoying consumption of gluten-free cakes and other sweet foods (pancakes & puddings), with some adults indicating a preference for gluten-free or not being able to taste a difference compared to a gluten equivalent: ‘certain things as a lot of the gluten-free stuff actually taste better so I think puddings are definitely better’ (Adult, FM).

The importance of shared eating (the same food) for one participating family meant all food within the home being gluten-free and sitting together to eat. Eating together as a family formed part of family practice and values for many families:

> They just, but they all [family members] pile in, and its actually it’s a way to get everyone together ‘cause unless its food time daughter goes oooh I’m bored can I go and speak to my friends, and so the food it at least it keeps everyone there and you can talk then

(Adult, FM)

The adult FM describes the use of food as a tool to bring family members together at mealtimes providing a space for family social communication and
strengthening social bonds. Family members would not necessarily be eating the same food, but it would involve sitting together, the bringing together of the family group. For example:

Other situations it's more likely that she [mum] just has to cook her food after ours so she doesn't eat separately but her food is never always like done at the same time as ours yeah… when it's normally like a family dinner we all do stay and wait

(CYP, FM)

Whilst young people were not so concerned about eating with family members, they recognised it formed part of their family behaviour. Even when young people normally ate separately from other family members a Sunday roast dinner drew them together to share a family meal. For example, a CYP described when asked if her family sit and eat together: ‘my dad cooks for us all sometimes we will have Sunday roast together […] we don’t really usually do the whole family dinner thing’ (CYP, FM). Certain meals hold psychosocial values for families drawing them together such as a family roast or birthday cake. The social interaction of sharing food strengthens social bonds through food as a communication tool (Dunbar, 2017). Food symbolises love and caring in family groups providing comfort, security, and an opportunity for interpersonal relations.

8.4.2 A Healthy Diet: Food and Body Image
A pattern developed in the dataset grounded in the experiences of many adult men around health linked to food and body image, in other words a healthy
lifestyle. As presented earlier in the main theme, many men disclosed consuming baked goods. This pattern follows on from there with the ‘health’ meaning of food rather than pleasure, the enjoyment from consuming homemade cake, with many men expressing consumption of a ‘healthy’ diet. Some men also stressed the importance of being physically active with some concern around physical body appearance. One man was the only exception perceiving health in connection to food as a benefit to wife’s health:

*The only benefit really is wife is not feeling tired and … she knows what she can and can’t eat now … you realise … that you do have to think, not plan a meal is the wrong word, but just … how … I don’t know the best way to say it as in … it’s made you more aware of what you can cook and who you can cook it for really*  

(Adult, FM)

The extract illustrates a previous inattentiveness to food ingredients and dietary conditions with a recognition that food can be harmful to health. Similarly, another man discussed food and health as a family healthy lifestyle including healthy eating and being active:

*Initially before we knew about this disease, about cross contaminations gluten products, we didn’t use any diets. Okay we are quite active, we try to eat healthy and be active, so we never use any diet. So obviously going to the gluten-free is something which was okay, we now need to stick to some kind of rules and things, requirements*  

(Adult, FM)
The family healthy lifestyle had been disrupted altering how the family could maintain a healthy diet with restrictions. Maintaining health, in addition to food, included physical activity. A healthy diet for most men was connected to physical body concerns aspiring not to gain weight: ‘Wife probably eats more biscuits than I do just because I worry about my weight a bit, I try not to have biscuits in the house’ (Adult, FM). The removal of tempting ‘fattening’ goods from the home for men was echoed by a woman talking about baking during lockdown: ‘not as much as I would have liked (baking) as I got banned from it … he says he’s put on 5 pounds because I was making cakes, they were very nice’ (Adult, FM). The woman baked gluten-free cakes and the man would eat gluten-free biscuits demonstrating the challenges people experience when trying not to consume specific foods opting for the removal of temptation in the absence of will-power. For men some food was seen as harmful, unhealthy with a visibly detrimental impact on physical bodily health. Removing ‘fattening’ food for men is interesting as ‘gluten’ food was primarily absent in family homes of men with CD, not the homes of women with CD. Gender differences are indicated between the self-efficacy of adult men and women in not controlling eating behaviours. The underlying motivating factors are unclear. None of the women or girls mentioned body weight or concerns around weight gain or body image.
Physical activity held importance for many men in the prevention of weight gain. One man in addition to his ‘healthy’ diet is physically active with cycling and sailing:

I keep an eye on my weight as I can fluctuate my weight quite easily, and so with the, I use the Apple watch and I’ve been keeping a strong eye on the exercise I’ve been doing […]. I have been doing at least an hour a day exercise, and I manged to do an hour every day for 30 days, so that was a mix of like 10 mile runs, 30 mile bike rides and things like that, and so I think my the month stats I’ve burnt active exercise calories around about 24000 calories which I was thinking that’s good that’s good and I
jumped on the scale and I hadn’t lost a pound so I was like how much
more must I have been eating [lockdown] oh my god

(A Adult, FM)

The motivation to exercise was strongly driven by a desire not to gain weight as
described. The importance of physical fitness is highlighted with a man
describing lifted weights in his home gym: ‘I lift a few kilos of weights I have a
power cage’ (Adult, CD) whereas another man found alternative physical
exercise options when unable to play golf or cricket due to lockdown
restrictions, doing online workouts at home instead:

I done him this morning [Jo Wicks fitness routine] I do it again at 3 o'clock
a bit later on yeah I do a lot of same ones where in the morning I do
power squats work a bit harder then do it again

(A Adult, CD)

A father and son had an interesting exchange during the interview on the
father’s running times, with the son kindly pointing out that his father had taken
longer to run. The exchanges illustrate the interpersonal relationship with the
son noticing the norm for his father.

Physical activity, as a health promotion behaviour, formed part of daily life for
men prior to and during the UK lockdown. The importance of being healthy and
the benefits, not overweight and physically fit were important as described: ‘I’ve
kept it off [weight] too, which is really nice, so going hill walking I am now
carrying a stone less up the mountain which is great fun’ (Adult, CD). For most
adult men some form of physical activity for fitness and health was important.
For most of the men the health behaviours were individually self-motivated with
weight prevention and body image key factors. In contrast women and girls did not discuss physical activity for health purposes. One woman mentioned horse riding, but this was for pleasure, emotional benefits, not exercise purposes: ‘I love it [horse riding], [...] it always makes you feel better’ (Adult, CD). All the girls mentioned some form of physical activity, all for pleasure not physical fitness. Two boys also engaged in physical activity for fun. Physically activity for women, young people and children were for psychological and social benefits, a positive emotional experience enjoyment rather than a physical body outcome. Whereas the motivating factor for physically active men was health and fitness. All the men with CD were physical active possibly an indication of wanting to have some control over their physical body. Body image developed as key motivating factor a concern typically reported in women with more reports of men and body image concerns.

Health for adult women concerned maintaining health through a gluten-free diet either for self or spouse reflecting a gendered norm of women caring for family. For all families health was perceived as family concern and an individual concern for adults with CD. Differences between the health beliefs of men and women indicate differing psychosocial values. For most men in everyday life, dietary concerns were preventing weight gain and engagement in physical activity, primarily underpinned by an avoidance of a visible health condition, obesity. This has implications for supporting men with CD and their families with the expectation of removal of gluten foods in home potentially creating friction within families. Awareness of men’s health concerns around weight and body image. The gendered differences have implications for supporting people living with CD.
For most people without CD, a freedom of food choice exists with no fixed predetermined criteria. Food choice is influenced by other factors such as taste and cost facilitating spontaneous decisions, whereas for people with CD the focus begins on what food can be consumed and determining food choice. However, a linking food choice commonality is health. For a person with CD the priority is health maintenance, avoiding gluten, whereas for many people without CD health and diet are modifiable, as unhealthy food can be consumed in the knowledge action can be taken to counteract any effects, whereas with CD this is not a modifiable factor, there is no post gluten consumption remedy. For families living with CD food and health hold different beliefs and values for individuals.

8.5 Summary of Participant-Generated Photographs

Participant-generated photographs representing the themes constructed in this analysis chapter strongly featured food and kitchens. All family members contributed photographs to the topic of life at home with CD. Many family members shared photographs containing bread and baked goods. The cost of gluten-free food was symbolised by photographs containing cash and purses, reduced labels on gluten-free foods and screenshots of social media posts of gluten-free offers in supermarkets. The separation of food in the kitchen was characterised by photographs containing images of gluten-free foods in cupboards and fridges. Images of family cooking at home were captured, the preparation of meals with chopping boards (and people) separated, the meal ingredients, gluten-free toasters on kitchen worktops, segregated food on baking trays and separated saucepans on hobs. Participants shared
photographs of family meals served on plates and families sat together at tables. Photographs capturing family social occasions were shared, some of these were retrospective photographs shared to illustrate events pre-lockdown. Displays of cookery books, screen shots of TV food programmes and gluten-free recipes were shared. Participants included family pets in photographs sharing anecdotes about the pet’s characteristics. CYP\textsuperscript{9} photograph of the family cat lying in the middle of CYP bed was edited with the words ‘my bed now’ to describe how the family pet cat assumed ownership of CYP bed: ‘yes I edited this one [photograph] because I wanted to, it says Mog [cat] she’s on my bed and she does this every night […] also when she needs a cuddle’ (CYP, FM). Pets were considered family members requiring love and attention. Some participating children and young people shared photographs depicting their everyday hobbies such on a bike jumping ramps and playing Minecraft a popular computer game.

\section*{8.6 Conclusion}
This chapter has explored the ways in which families live with CD at home. The necessity for a gluten-free diet shaped all food related behaviours in the family home. In the family kitchen all family members knew and implemented CD management behaviours. The family kitchens were shared spaces made safe for the member with CD through family food related behaviours. Families have developed coping and supportive behaviours. Families functioned together to construct a safe shared environment for the member with CD. From awareness of foods ingredients brought into the home, to how these are handled and

\textsuperscript{9} Permission not provided to use photograph.
stored within the home. These behaviours require communication between family members, knowledge, and trust. The practice of food behaviours is vital in protecting the adult with CD from gluten. Families catered for different taste preferences with sensitivity towards particular food recognised. Differences between men and women formed around health and baking. All family members contributed to making the home a shared safe space to live, providing safety and security within the home. Inside the home an active family management of CD was delivered.
9 Navigating the External Social World with Coeliac Disease

9.1 Introduction
The data generated a clear pattern concerning family life with CD in the wider social world. This chapter presents the data analysis of the experiences and challenges faced by families navigating the external social world together with CD. These differed from those observed within the safe boundaries of the family home environment. When at home the family members provided food security and ensured a low risk of gluten poisoning, built on trust and through established family routine food related practices as presented in the previous analysis chapter. For adults with CD the food security provided at home disappeared in the wider social world, exposing increased risks when eating. The presence of CD impacted behaviours and perceptions, shaping many food and eating experiences in the social world for families when accompanied by the adult with CD. During the COVID-19 lockdown periods, different social challenges were present, with all everyday family routines, including grocery shopping, employment and education disrupted in some manner. In contrast, some social challenges were removed during lockdown periods as people were unable to dine away from home in eatery venues or other people’s homes, removing the risk of cross contamination and the need to reveal CD. The abrupt change to social behaviours provided by COVID-19 provided an opportunity for people to reflect on social life pre-pandemic. The stark contrast possibly accentuated often accepted behaviours.
The overarching theme for this chapter is ‘navigating the external social world with coeliac disease’. Underpinning this are three main themes; 1) social inclusion and exclusion: the psychosocial affect; 2) the invisible becoming visible: revealing coeliac disease; 3) ‘playing Russian roulette’: family compromises eating away from home, with the subtheme; escape from everyday life: family holidays. As with all the themes the perpetual presence of CD and food are key influences. Before each theme a description is provided.

At the chapter close, I share a reflexivity section related to all the introduced data themes (Braun & Clarke, 2022).

As in the previous analysis chapters, commentary from the themes is exemplified using participants’ quotes together with participant-generated photographs. To preserve anonymity participant quotes are referenced as ‘adult’ or the initials ‘CYP’ denoting child or young person. For those participants with coeliac disease there are the initials ‘CD’ and for family members there are the initials ‘FM’. Please refer to Chapter 6 section 6.2 for a reminder of participant demographics. Those who participated in this research are referred to in the text as families, adults, young people, and children.

### 9.2 Social Inclusion and Exclusion: The Psychosocial Affect

A pattern developed in the dataset of experiential inclusion and exclusion from social occasions for many adults with CD. The theme describes the psychosocial impact on family members and the family group. Social interaction beyond the immediate family and activities outside the home were important for all family members ranging from family events to playing golf: ‘Come Thursday afternoons and they [adult and friend] go and play golf […] he’s played golf for
oh many years now’ (Adult, FM). This had heightened prominence following the absence of physical in-person social interaction with non-household members during the ongoing COVID-19 pandemic throughout the data generation period. All family members were acutely conscious of the absence of extended family and friends. Although the societal situation was not caused by CD, the importance of social interaction to all family members was evident and relevant to their lived experience.

For all children and young people, the physical social starvation of friends became apparent: ‘The school is closed which was not fun […] usually I would see all of my friends like every day’ (CYP, FM). All children and young people missed attending school and the regular social interaction with friends, although social communication through technology helped to cushion the physical in-person absence:

* CYP: *Mostly on my phone […] so I play games while chatting to my friends […]* yeah (sigh) it is quite strange [not attending school]*

* Interviewer: Are you able to chat to your friends on your phone that you would normally see at school?*

* CYP: Yeah FaceTime*

(CYP, FM)

Some children and young people played online interactive games with friends. For one who has CD, playing virtually with friends brought additional benefits as he was able to virtually make a cherry cake, eat it and share with friends:
I like Minecraft, and you can get loads of foods that I am not allowed in it
...you can only get one cake in Minecraft, basically like cherry cake, 3
buckets of milk, two sugar, one egg, and three wheat... actually you can
[share] ‘cause if you have one cake you place it on the floor then you
take a bite, but it doesn’t all go at once like other things, take a bite then
like a little piece comes off and then your other friend can take a bite

(CYP, FM)

Using a virtual world to socially interact and communicate when unable to
physically provided an extension of self through a virtual life game for many
children and young people. In this case, the virtual self-extension provided an
opportunity to perform behaviours unsafe in the physical (real) world, such as
‘eating’ cake containing gluten. The quote also illustrates the social behaviour of
sharing food to strengthen relationships with friends. For children and young
people using online tools for social communication and interaction was a normal
pre-pandemic behaviour.

One CYP had experienced exclusion from a school food event, where she had
cooked a meal at school to share, but her mother, because of CD was unable to
attend. The CYP described the experience:

I never get to go on school meals with my mum, like the Christmas
dinners because events or Valentine’s Day or Mother’s Day, then my
mum can’t come and have the food with me, which is kinda sad because
my friends always go, and I can’t. I have to stay in class eating the food
on my own.

(CYP, FM)
This experience illustrates multiple social exclusions. The CYP was socially excluded from sharing a social experience with her mother and peer group, two important relationships. The parent with CD was also socially excluded, unable to attend the social event with their child, an opportunity to show support and share an experience. The example illustrates the important psychosocial meanings of food and the negative effect when CD creates a barrier to socialisation.

A data pattern of social exclusion developed showing employed adults with CD excluded from shared eating occasions in the workplace:

Someone’s birthday at work and they’ve brought in a cake, and it’s not gluten-free, and they’ve not brought in anything else that is gluten-free and you haven’t brought anything because you didn’t know. Then you are kind of forced into a social situation where everyone is sat round eating a nice cake and you have to sit there looking at everybody, and although no one did it on purpose, you feel very much alone, and you can suffer from anxiety and depression just because it’s sometimes an excluding illness

(Agent, CD)

The quote describes the negative psychosocial impact of social exclusion from a shared occasion in the workplace. The symbolic meaning of the food (a birthday cake) and the associated behaviour (joining together as a group), facilitates a celebration promoting positive emotions and social bonding. Yet for the person with CD the opposite is experienced, negative emotions, social isolation, and awkwardness. The exclusion is further exemplified through not
knowing about the event in advance so unable to buffer exclusion by coming prepared with gluten-free cake. A type of double layered exclusion, not knowing about the event and not being able to participate in the cake consumption. The sense of isolation experienced when surrounded by people captures the positive and negative psychosocial impact and the powerful meaning of food. The CD experiences of individual family members outside the home are brought into the family home having an indirect impact on all the family.

Figure 36 *Safe Place*
In contrast an adult described the opposite experience, a positive psychosocial affect at the surprise and delight of being included:

*They [son and family] came round for a dinner. He did a barbecue for his mother’s birthday, and he made this gluten-free cake lemon drizzle cake and it was great, it really was nice and for my son to be making a gluten-free cake was just stunning*

(CD, 70, M, Sugar)

The inclusion in celebratory food social occasions with extended family members provoked a powerful positive emotional reaction. When illness needs are considered, it provides validation for the person through inclusion. For birthday celebrations some families shared gluten-free and gluten birthday cakes. For example, one adult explained: ‘If there’s birthdays my sister will quite often make a little extra birthday cake for me which is gluten-free, so yeah very lucky really’ (Adult, CD). The partaking in the social occasion with gluten-free food is implied as more important to people with CD than eating identical food; in the case of birthdays any cake suffices. Across the dataset a pattern of similarities was generated through birthday and Christmas events, where families celebrated together with extended family members. A gluten-free Christmas dinner was eaten by many families:

*Like Christmas lunch and that he [older son] uses gluten-free gravy and sausages the pigs in blankets things yes and he will make a trifle as well that is gluten-free*

(Agent, FM)
One husband describes how a gluten-free Christmas dinner enabled his wife to be included and not excluded with separated dishes signifying the symbolic importance of everyone sharing a meal together:

*Christmas dinner she’ll [mother] do to the gravy and stuff like that without gluten she’ll try and do the Yorkshire pudds without gluten, so it’s instead of wife having her little thing there and we got a big bowl there, like if she does the stuffing and stuff like that she’ll do it all gluten-free so which is good*

(Adult, FM)

The adult had mixed emotions about everyone, immediate and extended family members, eating a gluten-free Christmas dinner feeling awkward and guilty while also appreciating someone considering her dietary needs:

*My mother-in-law’s, very good she yeah, so she did like a whole Christmas dinner for us ‘cause everybody had to go gluten-free, I did feel quite guilty I said please don't make them yeah, so she's yeah, she's good*

(Adult, CD)

Celebrations often include food, with meals holding many psychosocial benefits for families promoting positive emotions, enjoying time together to strengthen social connections and boosting wellbeing (Fruh et al., 2011). Yet for some adults with CD, it can trigger conflicting psychosocial cognitions and emotions creating an inner turmoil and avoidance of social occasions:
It's sad last year we had a wedding my family, so I didn't go, it wouldn't be possible. Everyone would ask me, why you don't eat, why you don't drink, why don't you do all that, so I thought explaining it a million times no, so I'm missing so you know I'm missing celebrations I am missing socialising

(Agent, CD)

The consequences of the embarrassment and perceived social stigma resulted in avoidance of social events for the family group indicating the wider social impact on families. If attending social events where uncertainty surrounded availability of gluten-free food, some adults would encourage the adult with CD to eat prior to attending to ensure they had eaten something, as explains:

If we are going out to a do like a wedding or an official function I will always say to wife [with CD], just eat something now and get it down you because you know that more than likely you are only going to be disappointed on what's going to be there, so just load up now and if you can eat it will be a bonus and its very rare to be fair that anything crops up that is like oh wow, I've been fantastically catered for

(Agent, FM)

The adult touched on being disappointed, but this was in relation to the availability of food and not to feeling socially excluded. Differences in family social expectations developed, some avoided social events and others attended encouraging buffering behaviours. These illustrate the different coping and support mechanisms employed by families. For adults without CD this alludes to the drive for social inclusion possibly not realising the psychosocial implications
for the person with CD or assuming encouraging them to socialise is providing positive support:

> Once I’ve eaten that’s gone [uncomfortableness] … yeah I’m thinking even if they [friends] have picky bits out, and if they are unsure I just don’t have any, which is fine, but yeah so once the kind of food bit is out of the way […] I’m also I’m very careful I don’t want to hurt people’s feelings, so yeah I go no its fine I’m not hungry I don’t want any and all that kind of stuff

(Agent, CD)

Social interaction with extended family members and friends who had limited understanding of CD became difficult for some families. Several families overcame this barrier through hosting food-based social occasions. Taking control of the social situation to ensure inclusion was demonstrated by some adults with CD, as one explained:

> We [work] have a big Christmas dinner every year which I organise … so I was able to choose where we went […] mostly coincidental, I just like I am just good at organising stuff […] but yes it was, it did have the advantage that I could pick somewhere that was okay for me, but also because I was aware of dietary restrictions in general, so I’d pick. It was easy mostly as to where we went […], so I was able to find somewhere [restaurant] that would cater for everyone where there was something, possibly some people wouldn’t of thought about those things and just booked somewhere and hoped everyone could you know cope

(Agent, CD)
Being able to select the eatery venue ensured inclusion. The quote also elucidates how catering for multiple dietary needs disperses the dietary focus from CD and highlights how people without awareness of dietary conditions may not consider dietary requirements when choosing venues. This was demonstrated by one:

> When we get invited somewhere say like a family gathering or whatever and they pick a restaurant, and it’s a restaurant that we haven’t been to, and then we have to kind of call them [restaurant] and make sure they are okay with gluten-free and kind of stuff like that, so new places can be a little bit stressful

(Agent, CD)

Having advance notice of intended restaurants for social occasions with extended family and friends provided adults with CD a degree of control. Prior to attending social events they could assess whether the restaurant could cater for a gluten-free diet. This added a negative psychosocial element for several adults with CD and as the example states, the process is stressful. Assessing menus in advance reduced the embarrassment and awkwardness experienced when meeting friends socially, knowing gluten-free dietary needs are catered for, as explained:

> Meet up with friends for a meal and I don’t want, I would never say well look remember me gluten-free, I just don’t want to make that kind of fuss, so I would phone ahead and say I will need gluten-free and most places are either very, very, switched on and have a separate menu and
just say that’s not a problem or come a discuss it with you, that’s less marvellous to be honest

(Agent, CD)

The purpose of checking is not solely the provision of gluten-free options, but also about the perceived risk of cross contamination. The previous quote illustrates the aspiration to be perceived as ‘normal’ and not allow CD to determine whether they can join friends for a social meal. This hints at an underlying stigma surrounding CD, wanting to conceal the condition, and be socially included as normal not different (Crocker, Jenkinson, & Peters, 2018; Goffman, 1963). Adults with CD illustrated many behaviours to facilitate inclusion at social events. For other family members social events presented no challenges, although an expectation was for the adult with CD to attend social events. Most of the adults without CD indicated no awareness of the psychosocial discomfort experienced by adults with CD.

Food became a barrier when socialising as well as a facilitator. Families employed different coping mechanisms. One coping strategy applied was avoidance through abstaining from social events which avoided the psychosocial discomfort of attending, but also created discomfort through the distress of not attending. Other coping strategies included abstaining from food at the social occasion and eating beforehand to avoid revealing CD to hosts. Taking control is another coping strategy through choosing venues to meet socially or contacting venues in advance when someone else has chosen the venue, to ensure they provide gluten-free dining options, or hosting social food events in their own home. These coping strategies reduce potential negative
psychosocial factors, not having to ‘make a fuss’ breaching social norms or be a burden reducing distress. When support is provided by hosts in providing gluten-free meals for some adults with CD this creates a psychosocial discomfort, a perception of ‘making everyone eat gluten-free’ to the opposite where it is perceived positively and accepted. Social inclusion and exclusion affected all family members with the emotional impact increased in adults with CD.

The social and emotional value of sharing food with friends and family is poignant. Social interaction through food provides support for people’s wellbeing. Food is a barrier to socialisation and a facilitator. Families employed different coping mechanisms. For most children and young people although eating was a feature in daily life it was not of such relevance in their extended family social interactions.

9.3 The Invisible Becoming Visible: Revealing Coeliac Disease

This theme captures how CD is an invisible health condition until it is revealed consequently becoming visible. To an unknown observer when a person with CD is exhibiting symptoms the cause remains unknown. Effective management of CD prevents symptoms for most people with CD so typically people do not display any symptoms rendering the disease invisible (Lebwohl & Rubio-Tapia, 2021). Potential exposure to food, beverages, and eating prompts revealing CD. Once revealed CD brings attention to the person with CD and those accompanying them creating a socially and affective phenomena. The ‘invisible becoming visible: revealing CD’ theme contributes to the overall analysis
through the description of how in the public sphere CD remains hidden until revealed, creating an impact on adults with CD and their accompanying family members.

The physical bodily effect of CD can present visibly through appearance and symptoms as explained:

*The symptoms are a little bit anti-social they can be very embarrassing and if you are really not well you just need the comfort of your own house really*  

(A Adult, CD)

The experience captures the social expectations and stigma surrounding bowel functions perceiving them as ‘anti-social’. The digestive symptoms, diarrhoea, flatulence, bloating, nausea, abdominal pain, present in other illness, so easy for misperception of the underlying cause (Ludvigsson & Murray, 2019). The previous quote also illustrated the emotional impact on the person with CD and the security provided in the home environment away from the perceived negative social judgement. Home provides privacy, support and security that are important for people’s psychological wellbeing. In the UK social rules require physical control over bodily functions creating a stigma around bowel functions such as faecal matter and flatulence (Chelvanayagam, 2014). Social stigma surrounding bowel functions remains in the UK with recent UK public campaigns targeted to address these, such as bowel cancer aimed to encourage people to discuss bowel functions to improve health outcomes (Bupa, 2022). However, in CD the visible symptoms are not solely bowel functions:
When it goes wrong [poisoned with gluten] and you get sick it’s not like a visible illness in the sort where you have an arm dangling off or something […] I still go to work, sometimes when I am like that [poisoned] and people think, […] I worked for someone who thought I was like some kind of drug addict ‘cause I’d come in. It was one of my colleagues who said you really shouldn’t be here you look dreadful, and I explained what had happened […] where I had been poisoned

(Agent, CD)

As described above, the symptoms make CD visible to the external world however, due to the lack of awareness of CD these are often misperceived and associated with other causal factors. A phenomenon observed in people with diabetes having a hypoglycaemia attack is where, rather than assisting, people perceiving the person to be drunk and ignoring them, when they urgently require medical attention.

Someone came up to me at work, and I used to work with her quite closely […]it was probably a good 9 to 12 months later, and she came up to me and she went, oh my God Anne, you look so much more like yourself she goes she didn’t quite pinpoint it, but she’s probably being kind, but I think she just said you did use to look quite tired and washed out and now you look back to yourself

(Agent, CD)

The visibility of CD symptoms can also prompt the same response from people making incorrect assumptions based on a person’s appearance and behaviour. To correct misperceptions, which can reflect negative social beliefs, people with
CD have to reveal and explain their health condition, consequently making it visible.

Having to disclose CD forms part of the routine when eating outside of home: ‘When going out for dinner and obviously we have to ask for a gluten-free menu’ (Ellie, CD, FM, 30, W, Pickles). Most people with CD dislike the attention asking for a gluten-free menu finding it an uncomfortable and stigmatising experience:

> I just don't like all the fuss around it, every time I go into a restaurant I have to talk about being coeliac and needing things to be gluten-free, I really don’t want to talk about it

(Agent, CD)

When dining at restaurants children and young people also experienced feeling awkward and embarrassed when a parent asked about CD options and procedures: ‘A bit awkward yeah … and then she [mother] has to get like a gluten sometimes she gets a gluten-free menu so just to tell her what she can eat and what she can't eat’ (CYP, FM). Figure 37 shows the experience of a CYP when eating out with a parent with CD. Asking for a special gluten-free menu makes CD become visible to people outside the family. People with CD also experienced similar emotions, as for example captured:

> I hate having to I don't want to be centre of attention and I don't want to make a fuss of anything I am not a fussy eater I will eat any food even out of politeness and so it annoys me that I have to be fussy … I am quite confident that I don’t want to be ill myself so I will say. We do like going to places where it makes it easier if they have got the symbols at the side, like no gluten, it makes life so much more easier, as in some places you
go to they hand over a big massive folder for you to sift through and
that’s a pain in the arse and that’s really drawing attention to yourself,

having a big file and having to search through what you can can’t have

(Adult, CD)

Whereas one adult disliked being made a fuss of having to reveal CD, another
adult in contrast disliked being seen as a fussy eater. Both disliked the
perception of being an awkward customer. The experiences are similar to most
adults with CD, the discomfort surrounding revealing CD publicly and the
necessity for gluten-free meals.

**Figure 37 A ’Different’ Menu**

A different menu physically distinguishes the diner as different, a social sign of a
diet that varies from ‘normal’. Making CD visible socially exposes the family as
different from the ‘norm’ with most people with CD, young people and children preferring menus with symbols indicating which dishes are gluten-free:

_They [restaurants] could do something, they could put like gluten-free next to all the meals if its say some restaurants do it they have gf ve for gluten-free or vegan_

(CYP, FM)

The experience for non-CD adult family members differs with protective supportive behaviour which is received with mixed responses. Some people with CD welcome others reducing their discomfort, for example one stated: ‘Because he [husband] knows I hate doing it, so sometimes he will ask for me or if something arrives and I am worried about whether it really is gluten-free he might kind of call someone over just to check for me’ (Adult, CD). Another trusted person asking removes any direct psychological discomfort and social awkwardness, providing reassurance that food is safe to consume and emotional and practical support.

However, for some adults with CD the experience of family social support is not always welcomed, due to the perceived fuss and attention. For example: ‘Oh yeah, I’m terrible wife says sometimes she will say just let it go’ (Adult, FM). Adult family members want to care and protect their family and often report feeling frustrated at the lack of understanding of CD by eatery employees when eating out. They do not report any awkwardness or stigma when making the invisible CD visible. Adult family members provide different types of support based on their family relationship. The adults with CD, young people and children experienced stigma associated with CD. A negative perception is
associated with requiring a diet that differs from the social norm. Additionally, culturally in the UK people do not like to be perceived as making a fuss. The data patterns show that adults without CD do not perceive CD as stigmatising or attention seeking, perhaps a form of deferred responsibility where they are acting on behalf of another person, rather than them having the condition. Alternatively, the concern for a loved one’s health dominates other beliefs as a necessary protective behaviour. Making CD visible was a distressing social experience for some adults with CD, young people, and children. The social stigma, not wanting to be identified as different from the norm creates embarrassment, anxiety, and distress (Crocker et al., 2018). Children and young people often want to fit in with the social norm and do not want to be perceived as different, although young people express individuality, they want their family to be perceived as normal.

For some families revealing CD to friends was awkward, not wanting to offend hospitality:

*It has a huge impact on when we going visiting friends, obviously we tried to tell them because sometimes someone is preparing food and wife is not eating it, is like she feels sometimes embarrassed and feeling a little bit, why she’s not eating food that someone spent some time to prepare. We tried to first of all tell them, first listen it’s not because she doesn’t like you or your food, but this is because of the disease, but normally she’s taking her food with her. It’s definitely different than it used to be*

(Adult, FM)
For some adults with CD having family or friends with different dietary needs or preferences provided a buffer in helping to reduce dietary related stigma, as they were not the only person eating a diet that differed from the norm:

*My best friend is vegan, so that can sometimes be complicated too feed both of us together, but she’s fairly very good about dietary stuff ‘cause she also has her own restrictions*  

(Adult, CD)

Explaining to eateries presented challenges, especially for one family, both adult members having CD created disbelief from many eateries when requesting a gluten-free menu:

*It is also bad, as when we do go out to eat in restaurants, because we are both coeliac and we both ask for gluten-free, people tend to think that we are a kind of hyper sporty crazy like diet couple that want to eat gluten-free because we’ve heard that some famous tennis player is eating gluten-free and that means we need to eat gluten-free because we want to be this instatagram perfect couple. And so they think that we are lying because whenever have they come across a couple that has got coeliac disease, so we do get a lot of both of you, both of you, and you have both got it, and you are like this kinda stuff, and we are like just yeah, yes, yesss, so we do have that a lot as well. We get funny looks and things and people think that one of us is just kinda doing it for the other person, whereas actually we are in the same boat, that is a weird thing*  

(Adult, CD)
However, as explained this also has benefits:

Absolutely in that you know that there is somebody else there who agrees with your perspective before you start, so you are not the only one on the table that is going to say, oh can we look at this

This illustrated how they worked together as a team when CD difficulties arose when eating out:

She’s quite happy to speak up for herself, as am I. I think that I’m probably the one that will pull the trigger on let’s just go first, but you know she is more likely to tell them off until they give us a discount

(Agent, CD)

Not being the only person reduced the stigma providing social and psychological support for each other. Although, similar to social experiences with differing dietary requirements, reducing social isolation support was unique with the underlying commonality of CD providing support. Eating out together as a family could be a stressful experience due to the presence of CD. Revealing CD to eateries could prompt a cautionary approach from eateries when preparing gluten-free meals. When dining out at eateries many families experienced waiting an unacceptable length of time for their meals to be served. Families reported feeling frustrated as well as hungry. For example, one described after waiting over an hour for meals to be served:

We said just bring anything out and he [restaurant owner] said, he wanted to make sure I didn’t make any mistakes with all your allergens,
which I got, but I did feel a bit frustrated as I had pre-booked and I wasn’t a walk in off the street and that we are a good customer

(Agent, CD)

Frustration and anger at the use of CD as an excuse was also expressed by adults at eateries who hide behind legalistic jargon afraid to confirm what is gluten-free. An adult recounted an experience where a café wanted her to sign a disclaimer before serving her with any food:

There was a café where they told me that I couldn’t have the rice because it wasn’t gluten-free, and I was rice is gluten-free, and they said I had to sign a waiver if I ate it to say that I’d agreed to eat it, eaten it against their advice and I just left. I was like this is incredibly stressful at this point I just wanted to go somewhere else

(Agent, CD)

The fear of some eateries had been experienced by many adults with the Pret a Manger case perceived as an influencing factor (Natasha’s Law, 2021). In contrast to the fearful eateries some were perceived as not taking CD seriously, the risk of cross contamination, due to the trend of optional gluten-free diets:

I don’t think that fashion has really helped when gluten-free became a fad diet and it was everywhere and everyone was going gluten-free, I really don’t think it helped people with coeliac disease, it gave us all a really bad name as if we were just putting it on because we wanted to be the new thing

(Agent, CD)
These experiences illustrated the exceptionally stressful challenges families can face when eating out, revealing CD due to public fears possibly due to lack of understanding. An adult with CD described how despite increased availability of gluten-free products most people do not understand what CD is:

*No one understood, I must say three years ago it was much, much, worse, during last three years everything has changed, especially last year there is more and more gluten-free products people are more aware, but still people think it's a diet, so you fancy right now gluten-free diet.*

(AAdult, CD)

The quote suggests people perceive a gluten-free diet as an option, a dietary choice, not as a medical necessity for people with CD. Many family members perceive eateries as not understanding why people with CD need gluten-free food. The array of different types of diets creates confusion surrounding the seriousness of CD as the treatment requires dietary avoidance, a commonality with food allergies and intolerances, in contrast to other autoimmune diseases that are often pharmacologically treated (Shah et al., 2014). The experience of adult with CD with a work colleague illustrates misunderstanding of CD:

*I had a colleague who was dairy-free and we use to talk quite a lot about the restrictions of having dietary stuff and how difficult it was and then she would bring in things with gluten and offer them to me and I was like we’ve had all these conversations about how I have got coeliac disease and my colleague, who sits next to me, I don’t think really understood what coeliac disease was ‘cause even quite recently said something about you know it’s not a medical condition and I was like it is a medical*
condition its literally it’s a disease I had an endoscopy... anyway a bit frustrating ... but because it’s the effect of it is a dietary restriction and people don’t think of those as being medical

(Agent, CD)

The quote exemplified many people’s experiences where a person has heard of CD but lacks comprehension regarding the medical validity of CD, not an optional dietary choice. Even when attention is drawn to a health condition through personal experience or public campaigns such as the Coeliac UK’s annual CD awareness week, many members of the public will be oblivious as they are unaffected (Coeliac UK, 2022a). The low awareness of CD is potentially evidenced through the estimated high number of undiagnosed cases additionally increased due to COVID-19 restrictions (Rej, Aziz, & Sanders, 2020; Valitutti, Troncone, Pisano, & Ciacci, 2021). The focus of public health campaigns are often on health protection for example breast cancer and diabetes (Anastasi & Lusher, 2019; Public Health England, 2018). The low general public awareness of CD potentially contributes to the surrounding stigma.

The audience influences which autobiographical stories are shared. This is apparent as most adults with CD were keen to share their illness narrative with me, a person conducting research on CD from a trusted organisation and interested audience (Frank, 2013). However, when in public such as in a restaurant, the desire is to conceal their illness not wanting to reveal it, suggesting stigma around CD, and wanting to be seen as a member of the healthy society. The audience is therefore indicated as important when sharing illness narratives.
9.4 ‘Playing Russian Roulette’ : Family Compromises Eating Away from Home

This theme captures how eating outside the safety of the home environment is comparable to playing Russian roulette; taking an action that has the potential risk of serious harm. For an adult with CD, this means having to take a risk when eating outside the home, in the hope food is gluten-free. The theme contributes to the overall research providing an insight into the risks taken by adults with CD when with family members in the wider social world. Showing, when the adult with CD is poisoned how it impacted, not solely on them, but upon other family members.

Spending time together away from the family home forms part of family life. Eating out together often forms part of the experience, sometimes for special occasions or when away on holiday. A key determinant when eating away from home was consideration of the health needs (gluten-free) of the adult with CD. An adult with CD explained eating food outside the home: ‘You can’t tell you know by taste, there’s a Russian roulette element to eating out’ (Adult, CD), the risk of being poisoned with gluten. One adult described how being poisoned with gluten feels: ‘For me I would be ill for about a week, it’s literally I can’t absorb any nutrition for a week, so you are just walking round like a zombie and its horrible you know horrible’ (Adult, CD). Feeling like a ‘zombie’ provides an illustration of how functioning as a person ceased as a consequence of consuming gluten thereby limiting the ability to actively participate in daily family life. When eating as a family group outside the family home the availability of gluten-free food and risk of cross contamination are considered. Families
employed different strategies and practices reflecting the family coping mechanism.

Most adults when deciding on where to go out for a meal, would check potential eatery venues for gluten-free options to ensure catering for all family members:

*I think we would always check yeah [...] it is always worth checking because you want somewhere where it’s no problem, rather than yes of course we’ll make a fuss and make you feel uncomfortable about it*

(Adult, FM)

The behaviour of checking eateries in advance helped reduce the risk of exclusion from the eatery and stressful experiences. Several adults have learnt from unpleasant dining experiences the warning signs of an eatery unable to cater for a gluten-free diet:

*For people that don’t list allergens on the menu we try and avoid it because then it usually means, that is one of those ones, where we need to fight and we can’t, we don’t really want that, we don’t really want to have to fight just to eat out, we would just really like to have a relaxing time*

(Adult, CD)

A similarity for some families was the routine of having a takeaway often on a Friday night. Choosing a take-away food venue presented similar challenges to physically going out for dinner, again with warning signs of increased risk:

*Every Friday night we get a takeout, so you click on the gluten-free option and it’s like six and 25 vegetarian options [...] online takeaway type menus they don’t have the allergens listed very often in the way in*
some places […]. I tend to just call up the place and say, this needs to be gluten-free and can you do that, are you sure, and it’s the question, the endless questions about cross contamination do you fry things in the same fryer […] I tend to avoid lots of places, like you don’t just get a kebab on the way home from the pub in the way perhaps I use to do, so yeah you are more choosey about I guess where you are eating

(Agent, CD)

The quote exemplified the necessary cautionary practising when ordering takeaway meals to confirm they are gluten-free. The range of choice is reduced for people with CD and the simplicity of using an online take-away delivery service is removed due to the necessity to ensure food ordered is gluten-free. For other families, previous experience of a takeaway provided reassurance of food safety, increasing the likelihood of return custom in this knowledge:

When we get takeaways, we will go back to the same places again and again we know that it is fine, rather than go somewhere new and then just have that stress of is this going to be gluten-free, did they understand what we meant

(Agent, CD)
Across the dataset a pattern developed with adults, who had learnt through adverse experiences, of the types of eatery venues presenting a high risk of being poisoned through cross contamination. However, as an adult without CD explained finding a suitable eatery venue also includes a menu offering gluten-free options that appeal to people’s food tastes:

**Adult:** Usually I look them up online and see what their menus are see if they’ve got anything he’d like

**Interviewer:** Okay so it’s about what food Mark likes to eat as well as gluten-free?

**Adult:** Yes, some have got a gluten-free menu separately, but sometimes they have just got perhaps one dish or two dishes on their menu that he
can eat. We can usually, we often go to similar the same pubs, country pubs or something like that.

(Aadult, FM)

Finding suitable restaurants can be a time-consuming process that some children and young people find annoying when unable to eat at restaurants they prefer due to gluten-free restrictions. Adults made the decision on where to eat with children occasionally involved.

Not all families checked for gluten-free options in advance when eating out. A family took chances:

No, we normally show up and say I’m coeliac, and they look at you, and no I want a gluten-free menu oh, so then they bring this little thing or whatever, is normally a card or then have the booklet some do so, but you go to some places now, I find Indians quite good cause its but sometimes you just don’t know how they’re preparing out the back. I know that sounds may sound unkind, but we went to an Italian in Bakewell where wife’s sister lives and walked in there, the guy there was yeah I’m coeliac you can have whatever you want on the menu cause it’s all gluten-free pasta, so he obviously got it straight away, Italian you know there is wheat in everything

(Aadult, FM)

The quote above illustrates an assertiveness stating the need for a gluten-free meal and expecting the eatery to provide this having a sense of control over the situation. However, the underlying element of risk is present having to trust eateries food handling behaviours. For most adults the fear of being
contaminated is minimised when eating at venues where an employee has CD, providing assurance of food safety for all adults enabling: ‘Everyone to have a nice meal without having to worry about anything’ (Adult, CD). A pattern developed in the dataset of adults highly rating and returning to eateries revealing personal experience of CD or demonstrating gluten-free knowledge and behaviours. So, although the adult indicated an element of spontaneity when eating out, similar to other adults, they often dined out or had take-aways from known familiar safe providers.

The behaviour of checking food safety at eateries became habitual as described when ordering food at a restaurant, which is completely gluten-free, as strange due to normally having to check before ordering that food is gluten-free:

*It is all gluten-free, so they don’t stock anything that has gluten and, so it’s great. As you go there, when you look at the menu, in my head I keep sort of thinking I have to ask the waiter or waitress does that contain gluten, and you just you have to stop yourself. I don’t have to ask cause nothing contains gluten you know isn’t that great*

(Agent, CD)

Eatery venues perceived as safe provided the opportunity for families to dine together without any additional food safety stressors. The accreditation by Coeliac UK provided food safety for several families, with Pizza Express highly rated as feeling safe eating there. To reduce the risks, when invited to dine at the homes of some family and friends, some adults with CD, offered to host social occasions. Eating in the homes of other adults with CD felt more
comfortable regarding food safety as they understood the necessary food practises.

Being poisoned with gluten impacted all other family members, as one member becoming unwell had an effect on all the others. Across the data, adults without CD expressed the symptoms of the family member with CD and how it impacted on the person’s functioning, but not how it impacted on family life. Children and young people did describe the impact of the parent with CD becoming ill, however this was perceived as not affecting them but instead the other parent. Two CYP explained how they each perceived the impact on family members when their mother accidentally consumed gluten:

CYP 1: *For her yeah, for us no, she'll be really sick and then she'll have to take like, I wouldn’t’ say like a day to recover, but she'll still not be feeling great in the morning. It's more that she’ll have to wait quite a couple hours before she'll feel better again, it's more dad that probably has to deal with it*

CYP 2: *What happens is, if she’s sick and stuff like that and she’s ill, she stays up most of the night and I am pretty sure that affects dad*

CYP 1: *That doesn't affect me, but I feel bad for her so*

CYP 2: *And then I'm pretty sure either in the morning, I think that means because he gets, he doesn't get as much sleep he gets moody*

CYP 1: *I think he sleeps through it*

CYP 2: *Yes, that’s if he could get to sleep. I think if mums constantly getting up and stuff like that and drinking water then he can’t get to sleep*
The sibling perspectives show the emotional impact on all family members when the adult with CD is poisoned. The father caring for his wife, the son recognising his father’s mood change and the reasons why, and the daughter expressing sympathy for mother being unwell. An unwell family member has an impact on other family members (Martire & Helgeson, 2017).

Not having to consider food availability and gluten risk outside the home provides freedom from CD on eatery options. Children and young people shared the experience of eating outside the home with the parent without CD where no barriers are present. For example, one CYP talked about going sailing with his father and enjoying a burger afterwards and another CYP went skiing and enjoyed sharing cake with her father. For the parent and child these are shared social experiences.

*CYP*: Yeah, we would go to the (sailing) club house and get some food, but that is shut now ‘cause coronavirus

*Interviewer*: So that must be interesting going to the club house for food just you and dad, what is that like?

*CYP*: It’s better for us

Family members without CD can escape from CD outside the shared home. Emotions of sadness and guilt are experienced by some children and young people when a parent with CD is present at the eatery venue but does not participate in eating.
A CYP explained the consequences of her mother being ill on multiple occasions after eating in restaurants (suspected cross contamination) resulting in an avoidance of eating food outside the home:

CYP: *We sometimes go to restaurants, but it’s usually just me and my dad and my mum stays at home, or we eat at the restaurant my mum eats at home, it usually works like that yeah*

Interviewer: *Is that okay?*

CYP: *mmmm I would prefer her to eat with us, it’s a little bit sad because she isn’t enjoying like really good food as we like good food, we like to eat*

(CYP, FM)

The example illustrates the psychosocial impact on the CYP, the absence of her mother in shared family social experiences. The meaning of shared eating experiences together as a family help to promote social bonding, an emotional boosting event (Dunbar, 2017). Similarly, one mother took her two children to eat at eateries where she knowingly was unable to eat anything because of the cross contamination risk and no availability of gluten-free food, as they wanted to go:

*She’ll [mum] say we can go there, then when we go there it will be like a pizza place or something, where the only reason she actually let us go is because we wanted to go not ‘cause there’s stuff for her. I feel bad, but then sometimes it slips from my memory, but then she’ll like makes passing comments saying something like, that smells good and then I do feel bad just a little bit awkward*
For children and young people, the poisoning risk to the parent with CD creates a negative dining experience, but the affect does not prevent consumption of the food or deter asking to be taken to eatery venues. While often a shared commensality experience, when dining outside the home, the meal choices are determined by subjective preferences based on the eatery menu enabling people to consume different meals. This differs from eating at home where often an adult has decided what meals to cook. The pleasure derived from food consumption overrides the psychosocial awkwardness of the situation. The behaviour of women feeding children and not themselves is indicative of a cultural gender norm that women should care and nourish their children and be willing to go without herself to please and feed her children (Murcott, 2019).

Children and young people expressed a range of negative emotions from annoyance to sadness in response to the impact of CD on family life involving eating outside the family home. Families make many compromises when selecting eatery venues. Some family members would rather eat out to avoid the chore of cooking, accompanied by the family member with CD, whereas an adult with CD who had lost trust in eateries would stay at home and send her family members out to eat. All families shared the similarity of facing risks when eating away from the safe home environment, but the risk management and coping strategies differed. Some families checked eatery venues in advance, others once they had arrived and one adult with CD avoided eating out. Families all experienced stressful and reassuring encounters with eatery venues. To mitigate the possibility of no available safe food to consume most adults with CD carried emergency food with them.
9.4.1 Escape from Everyday Life: Family Holidays

This sub-theme is unique as it details the importance of spending social time together as a family, away from home and daily routines. The theme contributes to the research by showing the value of holidays to adults and how they are viewed as less important to children and young people. All adults discussed holidays in the UK and further afield. Children and young people commented on searching for safe eateries for meals. The presence of CD shaped many aspects of family holidays. The dataset generated similarities and differences between family holidays with planning a key feature. During the data generation period two families experienced a holiday and another had a holiday postponed: ‘Yes in fact we should be in Ireland now shouldn’t we’ (Adult, FM). All other holiday experiences were retrospective, signifying the importance of holidays perhaps accentuated by the COVID-19 ban on travel abroad.
One family were adventurous having travelled globally, from Ireland to Asia, without any hesitancy. Holidays were a favourite activity with age the only barrier. All holidays were extensively planned and organised, with foreign embassies contacted for advice and advising travel operators in advance of dietary requirements. The family travelled without concern. They shared a photograph of some of the travel language cards they used Figure 39.

An adult shared the experience of their ‘emperors meal’ in China, a special memorable gluten-free meal:

*Adult: And the emperor food it was a fish with custard*

*Interviewer: With custard*
Adult: Well, I tried it and said what’s that, tasted it, said right mum it is custard on top of the fish, oh my god

Interviewer: Did it taste okay?

Adult: Yeah it was nice

(AAdult, CD)

The adult with CD enjoyed visiting places where movies had been filmed with little consideration to food, but as their experience shows, a willingness to try gluten-free dishes from around the world. Research and advance planning formed part of the holiday experience for most families:

We (daughter and mother) both looked up restaurants that we could eat at, luckily Iceland is really good for coeliac and vegetarian food, so there were a lot of places that catered for both […] We made a list separately and then we, I kind of showed them to her and we looked through the menus together and made sure there was something everybody would eat

(CYP, FM)

For a special occasion one husband organised a surprise holiday for his wife. His experience highlights the amount of planning and research to arrange a gluten-free holiday:

I took her to New York for her birthday and I started planning […] I did it months before we went ‘cause it was a surprise […] I gave her four days and I only went to gluten-free restaurants all across New York city in Manhattan. I just made sure that I made enquires, everyone was literally
gluten-free only and she loved that ‘cause obviously she could just relax and have what she wanted off the menus. It was really nice for her to enjoy it, we still did the things you do in New York, but I think it was really nice that she didn’t feel that tenseness of oh my god can I eat this or can’t eat that or what if its cross contaminated, it was just a case of look just go order what you want and don’t worry about it

(Agent, FM)

The recognition in the quote is of relieving the burden of eating out when planning the holiday and recognising the stress experienced when eating outside of the home.

For some families CD has changed holiday locations from anywhere globally to urban areas in countries aware of CD, to ensure gluten-free availability, and avoiding travel to some countries amid language barrier concerns. These are the compromises the family made to go on holiday. For example, an adult explained: The planning of the holiday is a challenge now, it takes a lot of time to you know searching, the making sure that where we are going, that there will be food for wife’ (Adult, FM). Family holidays with CD required an additional layer of planning as food availability needed to be considered. Adult family members and some young people contributed to holiday planning, taking an active role in sourcing gluten-free eateries, illustrating the role of family in supporting CD management. The type of holiday accommodation families stayed at included all-inclusive hotels and self-catering. For one adult without CD the behaviour of other hotel guests, the lack of consideration in food handling or CD awareness, during all-inclusive dining provoked an emotional
response regarding language communication barriers and concern for adult with CD:

We've been on holidays where it's an all-inclusive and you pay a lot more money and they're a lot more attentive to that sort of thing [cross contamination]. We've been on other holidays that are all-inclusive where it is a free for all in the buffet, someone's over there and got their bread and they are stood there and they buttering their bread with a knife instead of putting it a bit on their plate, it can't be a bit of a mine field, and I'm at the back just getting annoyed at people that are foreign and just don't understand what you're saying or don't really give a shit to be honest with you, so like where the kids in the breakfast, toasting the bread and it's just contaminating everything and it just can't be nice for her, but she just gets on with it. Really it depends on where you go, I suppose, and what sort of holiday you are having, but all-inclusive sometimes can be a pain in the bottom

(Agent, FM)

When in a shared communal food environment an absence of control over food handling behaviours is present, unlike a served eatery, where handling food is restricted and can be questioned. As the experience shows the emotional response to the inability to control food safety, ultimately underpinned the motivation to protect adult from becoming ill.

Staying in self-catering accommodation provided control over CD management ensuring a gluten-free diet could be maintained when away from the home environment. To stay safe a family self-catered on holiday to avoid any potential
contamination, opting for self-catering holiday accommodation being very cautious:

*Going on holidays it's a nightmare because logistically literally logistically we have to plan our holiday, so I can buy product that I can cook for myself. I have to take everything with me because I cannot trust kitchenette in the place when we go I cannot travel freely as I used to*  

(Adult, CD)

The additional stressors experienced by the adult with CD illustrate the importance of a family holiday, how these challenges were addressed enabled spending valuable social time with family members. For some adults holiday locations are restricted by CD, nevertheless taking a holiday is a voluntary behaviour for adults, perhaps less so for children and young people, indicating the importance for families to go on holiday, a typically enjoyable behaviour.

When holidaying the need remains for a gluten-free diet, this can be challenging when eateries are unfamiliar and when language barriers are faced. Language, in terms of food labelling, did not appear to present difficulty as one explained when exploring gluten-free products in foreign supermarkets:

*I think it’s fun anyway going round supermarkets abroad and seeing what the differences are, but and so handily, gluten is the same in most languages. I looked a while ago and actually yeah, the word gluten is gluten mostly, so it’s quite easy to spot, I mean looking at ingredient lists so yeah it’s a habit*  

(Adult, CD)
An adult shared a photograph of banana chip packaging purchased during her holiday in Iceland. Although on holiday, the everyday CD management behaviours are still performed, such as checking food labelling, showing the perpetual presence of CD.

Experiences of dining out abroad varied with an element of risk taking involved when not on an all-inclusive or self-catering holiday, having to find places to eat:

_We went to Greece a couple of years ago and that was great, and the food was lovely, but you weren’t really sure what you were eating sometimes, although you weren’t really sure what the ingredients were that you were eating. So, what I find is I'll either just suck it up sometimes and accept that there’s a risk, or I will eat more basic food if I am on holiday […]. I don’t speak Greek, I might avoid things and just eat like a very basic meal like souvlaki and rice or something and do that deliberately and maybe miss a bit of the cuisine, but I think again you miss a lot more if you are ill the next day._

(Agent, CD)

As indicated in the quote, dietary risks were made when presented with language barriers with the compromise of enjoying the location rather than local cuisine.

Sometimes unexpected dining treasures are found on holiday when gluten-free dining options had not been explored in advance as explained:

_We went to Dubai, that was quite nice the hotel there, they were very, very, very good. Where you had the a la carte meal it was not gluten-free, but there was hardly any gluten in anything. It was just a really good_
menu ‘cause she likes …not Chinese food but Asian food […], they have a nice Asian restaurant there, was quite nice … it suited wife [with CD] as well as us. It was a lovely hotel and you had to book in the restaurant, you couldn’t just turn up, and you know gluten-free oh yes yes that’s fine yep, that hasn’t got it in, that hasn’t got it in, that hasn’t got it and whatever you want we will make without it

(Agent, FM)

For families finding places that cater for all members relieves any stressors allowing the family to enjoy commensality. The social function of meals strengthens social connections promoting psychosocial benefits for families. Going on a family holiday provided the opportunity for families to strengthen social bonds. Finding eatery venues that provided gluten-free meals was sometimes challenging when abroad:

*Well, it did get to be a bit waring. It was a bit sort of, I mean it takes some of the enjoyment away from it if he’s really struggling to find something to eat on a menu, and we’d got out night after night and there was this very limited choice it does take a bit of the pleasure out of it*

(Agent, FM)

Children and young people also expressed the difficulties:

*Most nights we eat out and then that’s also kind of a bit harder as well because we normally what we’ll do is, it will be much easier because once my mums gone to a restaurant she’ll know like she’ll kinda know what’s gluten-free and what she can order, especially if she gets the same thing at the restaurant, whereas if she gets something new or if*
she goes to a new restaurant she has to keep on asking for a new menu gluten-free menu and asking what she can eat

(CYP, FM)

When challenges were experienced in finding eatery venues who catered for a gluten-free diet it created a negative psychosocial experience as illuminated: 'take a bit of the pleasure out of it'.

Self-catering removed challenges of sourcing gluten-free eateries and provided an opportunity to decrease chances of becoming unwell through gluten, enabling preparation of packed meals to take on excursions:

*We [family] have some trips. I remember we went to Croatia, and we took some sailing excursion, and they were serving like fish and foods during this sailing experience, but we were enjoying that food, but wife was basically stick with her sandwiches*

(Agent, FM)

For the adult with CD, making her own packed lunch, facilitated participation in holiday activities with her family however, they were disappointed for her missing out on the culinary experience and as a family the shared experience. The psychosocial impact of CD in some cases becomes increased on holidays.

Another adult with CD provided a contrast of holiday eating out experiences in the UK and abroad:

*‘If we are holidaying in England, we normally go down to Salcombe and we know where to eat there, and a lot of the restaurants, to be fair aren’t very good at being gluten-free friendly. So it is a bit of pain just hope one*
day things will change [...]. It's a place that we will always visit the children love it Going aboard we have been to numerous places, to be fair the European people out in Europe, are much more advanced than us in this country being aware of gluten-free. So everything is labelled up and you only have to say sin-gluten or whatever, and they are just like on it bringing out everything for you, whereas this country we've been to hotels and I've had nothing it's been terrible like a bit of fruit or something for breakfast it's really poor.

(Adult, CD)

The food and eating form part of the holiday experience, with CD sometimes limiting where families were safe to eat. Family members being unwell impacts on all the whole family so the protective actions taken by adults to avoid this benefited the whole family group. Extensive planning and research pre-holiday mitigated these affects. For all adults going on holiday had importance, for some, holidays created stressful events around food and reduced the pleasure. Children and young people were not as concerned about holidays as adults, although the psychosocial impact, awkwardness and social stigma were present yet while annoying the impact appeared to be the same as going out dine when at home. For children and young people, the dining experience away from home with a parent with CD presented the problem not geographical location. All families experienced similar challenges regarding holidays, how these were experienced differed with positive and negative meanings, reflecting the uniqueness of family. One adult captured the meaning of holidays for adults with CD, the determination to travel reflected that the experience of family
holidays outweighs the dietary challenges: ‘I wouldn’t ever let it [CD] stop us going abroad ever not at all no’ (Adult, CD).

9.5 Summary of Participant-Generated Photographs
Participant-generated photographs representing the themes constructed in this analysis chapter included photographs taken for the purposes of the research and historic photographs. One child shared a photograph of the Christmas dinner invitation they were unable to share with parent, a reminder of a less happy event. Interviews that took place as lockdown restrictions were easing included menus displayed in restaurant and take-away windows. When hospitality restrictions lifted photographs included menus taken inside restaurants. Photographs of family members eating fish and chips outside and a bottle of gluten-free soya sauce to depict good take-away meals. Photographs from previous family holidays were shared, these included menus and family members seated together eating. Similar to the previous analysis chapter food and eating featured strongly. A powerful photograph of a bed depicted a safe place for when living with CD in the outside world became too much. Some adults included photographs of gluten-free alcohol exemplifying how some socialisation habits and identities had changed. Adults shared more photographs than children and young people about life outside the home.

9.6 Conclusion
This chapter presents data analysis specific to the social world outside of family homes. A distinct difference is present between inside and outside the home environment. For family members the outside social world changed when with the person with CD. For children and young people, the COVID-19 pandemic
during data collection emphasised the meaning of social relationships (friendships). The theme, social inclusion and exclusion: the psychosocial affect, illustrates how the virtual world provides the space for social interaction. The COVID-19 pandemic provided an opportunity for participants to reflect on social life pre-pandemic. Playing Russian roulette captures the element of risk involved when eating as a family away from home. Although, the direct effect of gluten consumption is on the member with CD it has an indirect effect on other family members. The theme invisible becoming visible captures the stigma and embarrassment associated to disclosing CD when eating out. Adult partners do not express experiencing this. The experience of a family where they both have CD differs. How families cope when eating away from home varies from planning to spontaneous. All families travelled applying the same strategy as eating out.

The themes in this chapter demonstrate how the psychosocial impact of living with CD is greater outside the boundaries of the home setting. The external social world presents challenges as living with CD differs from social norms. The challenges for people with CD, young people and children have a negative emotional impact in contrast to other adult members who provide support and appear less upset, possibly because it is not them with CD. Although other adults provide support at times there is an expectation for the person with CD to ‘get on with it’ regardless of the potential challenges. Overall, the analysis indicates the need to support families living with CD to reduce the negative affect of the social world and raise public awareness to help reduce the stigma experienced when eating away from home.
9.7 Analysis Reflexivity

In this section I share my reflections from during the data analysis and when writing-up the data analysis chapters (Braun & Clarke, 2022).

It became striking during data analysis how much food shaped family lives within homes. Considerable time was spent discussing food in families, likes and dislikes, as well as family favourites. The importance of bread was a surprising find, not just the taste, but the psychosocial meaning to families. The data challenged my unconscious assumptions around food and health. One participant spoke about consuming cakes and other food which I, as the researcher, perceived as unhealthy. When reframed for the participant in question, perception altered with the gluten-free food deemed healthy as safe for them to consume. Sweet food, obesity and poor health have been interlinked by government policy along with many health campaigns promoting weight loss to improve health outcomes.

In the developing data it became noticeable how men discussed body image and weight, although aware that body image for some men is a mental health concern. It was surprising only men spoke about body image and weight and no women or girls providing a refreshing change from the literature. Another welcome gender disparity developed hearing girls’ engagement in physical activity through choice for enjoyment, very different from the norm in the UK where girls’ participation in physical activity alarmingly declines with age.

The experiences of one CYP struck me as very poignant when describing the benefits of a virtual life, how it provided opportunities to otherwise in reality harmful experiences. Virtual reality has potential application in the treatment of
mental health illness however, I had never considered the application for the ‘virtual’ consumption of harmful foods.

Since beginning this research I have developed a heightened awareness of CD. I have been surprised at the number of people I have met along my journey who have CD or know of someone with the condition. When dining out I consciously look to see what the gluten-free options are. In some restaurants on arrival, you are asked whether you have any dietary requirements or if you would like a gluten-free menu. When travelling I now look at menus to see what dietary requirements are catered for or not. Coincidently my last two holidays abroad have included people with coeliac disease, one a young man aged 28 years and the other a woman in her fifties. This provided a whole new insight, an opportunity to temporarily live with CD. One holiday involved sharing a villa where my knowledge of cross contamination was put into practice. I was very conscious of not wanting to make the person unwell on their holiday. It provided an insight for the whole group, as when grocery shopping all the products were checked and gluten-free alternatives sought. The young man was very appreciative, but as a member of our holiday group I wanted to ensure he felt welcome and not excluded, I recalled experiences of my participants and would have felt awful if that had happened. He provided an interesting perspective as he saw no difference between having CD and being vegetarian when eating out, in terms of any stigma, as they both require different menus. From my perspective there was a massive difference, as I would not be unwell if I ate meat! My second holiday involved travelling around so dining out provided an interesting experience with vast variance in the understanding of gluten-free and availability. Fortunately, it was an English-speaking country. At times my
friend found it hard being unable to eat previously enjoyed foods, especially bread and having a very limited menu selection. Occasionally I noticed her husband becoming frustrated at her pointing out what she was unable to eat and emphasising what she could eat. She also appeared to experience some discomfort when choosing restaurants not liking her dietary needs determining where we ate. From my perspective this was no problem as for me sharing a mealtime was more important than what we ate, good food was just an additional bonus. These experiences worked both ways, having some knowledge and insight into CD enabled me to provide practical and emotional support while I gained insider experience into living and travelling with CD, albeit a brief snapshot. Without conducting this research my response to my friends may have differed, showing how the research process has shaped me as a person and not just my subjectivity shaping the research.
10 Discussion

10.1 Introduction
This chapter draws together the findings from this research and discusses how they contribute to the existing body of research and knowledge on living with CD. The chapter outlines the ways the study contributes theoretically and methodologically with recommendations shared for future family, food, and CD research. The strengths and limitations of the research are discussed before concluding the chapter.

This is the first qualitative study to explore the psychosocial impact of CD on family groups, furthering the wider literature on living with CD. This research contributes to an interdisciplinary field, comprising of health, psychology, and sociology, providing much needed experiential data from adults, young people and children living with an adult with CD in the UK. This research also contributes to the growing literature and practice of public involvement in research and participatory research methods, especially working with children and young people.

The analysis chapters presented the themes constructed using reflexive thematic analysis, creating an overarching theme and seven key themes with associated sub-themes. The themes reflected the experiences of participants’ journeys from the introduction of CD into the family, to living with CD in everyday family life. In this discussion chapter the themes are discussed focusing on how they address the research questions and contribute to the knowledge from previous research. This exploratory qualitative photo-elicitation interview study provides a rich account of the lived experiences of nine families with an adult with CD. Families were willing to permit access into what is
sometimes hard to access, the interior of family life but only through the lens of CD (Gabb, 2008).

This discussion chapter argues that families have adjusted, developing their own CD family-management strategy. This research provides supporting evidence of the significant impact of CD on all family members, arguing that all family members need to be included in the diagnosis/support of CD due to the familial impact, therefore the consideration of CD from a biopsychosocial model.

**Summary of Analysis**

The first analysis chapter introduced the umbrella theme woven through all the reported themes, ‘the perpetual presence of CD’. The chapter provided the background context on how families were disrupted by CD and the process of adjustment to manage CD. The diagnosis of CD impacted all family members showing how a biological disease affects the psychosocial functioning of families and individuals. The focus of previous research has been on the impact on the person with CD.

The second analysis chapter is set within the boundaries of family life at home, detailing how families lived with CD in their home. The themes describe the family CD management behaviours, including how the family constructed safe (gluten-free) spaces within the shared kitchen. The theme of ‘negotiating family: food, cooking and eating’ evidences the biopsychosocial meaning of food for families and individual members. Previous research has explored challenges and burdens of partners living with CD, not how families manage living with CD within the home.
The third analysis chapter situated outside the family home, ‘navigating the external social world’, encompassed the psychosocial and biological challenges presented. Social stigma and risk surrounding eating outside the home were concerns. These were overcome, with adults with CD accepting psychosocial discomfort to strengthen social bonds. In previous research the whole family experience of living with CD in the wider social world was limited, and with the voices of children and young children silent.

10.2 Disruption of Coeliac Disease Diagnosis on the Individual and Family Members

The diagnosis of CD created substantial disruption to family life for the adult diagnosed and their adult partner as a consequence of the necessary treatment. Pre-diagnosis CD symptoms were the normality for the adult experiencing them and their family. The functional impact of symptoms was primarily on the individual with CD, with adult partners psychologically concerned for the health of their partner. Previous research has reported that a diagnosis of CD affected adult partners but not how or the preceding events (Ferretti et al., 2017). While a CD diagnosis formed a significant life event for the adults, this was not echoed in the lives of children or young people.

The excessive delay taken from symptom onset to CD diagnosis mirrored the known international evidence, with the exception of an unusual rapid diagnosis following an acute severe symptom onset (Batlle, 2021; Lebwohl & Rubio-Tapia, 2021; Norström et al., 2011). Literature suggests symptoms are misattributed to irritable bowel syndrome (IBS) as an explanation for the many delays in CD diagnosis, but findings in this research indicate gender bias a
potential reason indicated through a commonality of women, of childbearing age, prescribed iron to treat fatigue (Lebwohl & Rubio-Tapia, 2021). Gender in undiagnosed-CD raises two concerns. Firstly, the delayed time to diagnosis is characteristic of the evidence regarding women under-diagnosed with autoimmune conditions, with symptoms typically misattributed to reproductive or psychological reasons (Fairweather & Rose, 2004). Secondly, more women are diagnosed with CD than men, though screening evidence shows an equal sex balance, indicating gender health behaviours as an explanation, with men avoiding seeking health treatment (Fish et al., 2015; Ludvigsson & Murray, 2019). This analysis in this study elicited the impact of a delayed diagnosis, causing a negative emotional effect on adults. The distress and loss of trust in healthcare practitioners can negatively influence future interactions impacting health (Hawley, 2015). The continued delay experienced in diagnosis of CD is concerning, raising health and wellbeing implications for individuals, families, and society that need addressing.

Health conditions with a genetic disposition cannot be considered purely from a biomedical perspective owing to the familial (psychosocial) implications, therefore requiring a holistic biopsychosocial approach. The findings in this research illustrated the disruption of a CD diagnosis due to the familial genetic component (Lebwohl & Rubio-Tapia, 2021; Lundin & Wijmenga, 2015; NHS, 2016). A ripple effect to immediate family members (children) and extended family members (parents and siblings) was found, posing the option of testing for CD. Adults started the ripple effect and were caught in the ripple effect. Findings indicated being tested for CD presented no concerns for children and young people, possibly because all were negative. A psychosocial impact was
seen in adults in the relief of children being negative for CD, but frustration with extended family members, suspected of having CD, declining testing. The refusal to be tested was observed particularly in men signifying avoidant health seeking behaviour potentially due to knowing the dietary treatment. These findings support how CD is not an individual biological medicalised event, but instead a biopsychosocial health event due to the integrated biological implications for other family members (social), eliciting a psychological (emotional) response.

How the diagnosis of CD was appraised depended on the cognitive appraisal of CD, and the adaptive tasks including emotional balance, sustaining relationships with family, and preparing for an uncertain future (Moos & Schaefer, 1984; John. S Rolland, 1987). The underpinning goal is for the individual to maintain a state of equilibrium, but also the family. The study findings show the interconnectedness of family members, how the health of one family member impacts on other family members. The impact on children and young people is suggested as buffered by parents maintaining a family state of equilibrium.

The stressor of a CD diagnosis triggered an illness crisis disrupting the personal and social identity for the adults diagnosed (Moos & Schaefer, 1984; Rose & Howard, 2014). The burden of educating family members about CD and preventative treatment fell on the adult with CD. For many families CD was a novel health condition, therefore a learning process and behavioural change for all family members (Rolland, 1987). The burden of adjustment created emotional friction in relationships, reflecting the difficulties in changing behaviour to protect the health of the adult with CD. The burden of educating
family members added to the treatment burden for adults with CD (Shah et al., 2014). Educating family members to support management of CD required a whole family approach providing practical and emotional support to cope with the illness adjustment.

The individual family member illness beliefs needed to be reconstructed and merged together with the interpretations of family members to construct the family meaning of CD creating a shared family norm. The restoration of the family sense of equilibrium involved the engagement of coping strategies. Support for individuals with CD and family members is sparse, although it is recognised that support is required to implement and maintain a gluten-free diet (Ludvigsson et al., 2015). Crisis theory provides a framework to understand how an individual responds to an illness diagnosis, recognising the disruption to personal identity, but perceives other family members as sources of support and not how the diagnosis impacts the social identity of the family. Family support for CD treatment management is required to help reduce the burden of disease on people with CD and the psychosocial impact on all family members.

**10.3 Family Adjustment to Coeliac Disease**
Coeliac disease impacted on all family members, requiring them to adjust, changing their behaviours and physical environment. Previous research has examined the impact on individuals with CD, or in the case of children, the impact on parents but not how all family members had to adjust to living with CD (Bacigalupe & Plocha, 2015; Ford et al., 2012; Houbre et al., 2018; Melicharova, Slavik, & Cervinkova, 2016; Sainsbury, Halmos, Knowles, Mullan, & Tye-Din, 2018; Vis & Scheepers, 2017).
Awareness and understanding of CD was low prior to diagnosis for most people. Consequently, people had limited gluten related dietary knowledge. A diagnosis of CD brought gluten into people’s conscious awareness, together with the need to understand food labelling and food handling behaviours. For adults this required a sudden shift in food behaviours and dietary knowledge as these were required for the preventive treatment of the family member with CD. As attention had been drawn to CD people became more consciously aware of CD in the surrounding environment. For children and young people this became the family norm with an increased awareness and acceptance of dietary needs and preferences. Coeliac UK run national campaigns to raise awareness of CD (Coeliac UK, 2022a). How effective these are is unclear as attention to health-related campaigns arguably tends to be those of personal relevance, life threatening conditions and health protection or high-profile media campaigns. The increase in gluten-free diets as a lifestyle choice has possibly added to the confusion around CD with misleading beliefs thinking it is optional and non-harmful. Understanding illness is often challenging for people without any underpinning experience. For those with CD and their families through experience they have learnt about CD and treatment with it becoming very normal for them, changing their beliefs. This research shows how through experience individuals and families developed and changed illness, CD, and beliefs.

The results of this study indicate the need for support when initially diagnosed with CD and ongoing support. The type and source of support influenced adjustment to living with CD. Extended family support and supportive organisations were vital especially as the burden of educating all family
members about CD and treatment was the responsibility of the adult with CD. Practical and emotional support assisted in the adjustment to life with CD. The availability of reputable sources is limited to NHS dietician’s and Coeliac UK with informal sources of support also accessed such as social media, for example Facebook (Coeliac UK, 2022b; NHS, 2016). When experiencing a perceived stressful event, social support provides a coping strategy (Martire & Helgeson, 2017). Coeliac disease is a lifelong condition with arguably differing demands impacting lifestyle along the life course (Price & Howard, 2017; John. S Rolland, 1987). When initially diagnosed the inclusion of family members in the education of CD and management techniques could help reduce the burden of disease on the person buffering the distress. The provision of increased practical and emotional support could lead to better biopsychosocial outcomes for all family members and not increase the psychosocial demands on the person with CD (Haslam et al., 2018; Houbre et al., 2018; Whitehead et al., 2018).

Little research has described how family members have adjusted and the strategies employed to manage CD. The treatment for CD, a gluten-free diet, is invasive into family food spaces. Prior literature states the risks to the health of people with CD through cross contamination and the concern of adult partners to minimise the risk, but not how families behave to protect the health of member with CD (Hall & Day, 2020; Sverker et al., 2007; Sverker et al., 2009). This study shows how families negotiated space inside the family kitchen catering for mixed gluten and gluten-free diets to maintain a safe protective environment. Some families created completely gluten-free homes to reduce any risk of harm. The adjustment to CD illustrated the process of how families
redefined their home and created a new meaning of safety within the home, to protect the health of the family member with CD. The change to shared family spaces required the support and motivation of all family members. These findings illustrate the role of all family members in the family(self)-management of CD. This demonstrates how CD impacts all family members and how families work together in caring for its members.

The findings show how adults developed a high vigilance of food brought into the home as a response to the diagnosis of CD in supporting the treatment. Results showed an increased awareness of food ingredients, within the family home, for all family members as a consequence of the gluten-free diet necessity, showing an interaction of biological needs (CD), family social needs, motivation, and cognition (psychological). This shows the level of family involvement in the daily treatment for CD.

The research findings found how a significant behaviour change was required by families to avoid cross contamination. Adjusting to managing a gluten-free diet also involved food handling practices within the home to avoid cross-contamination. Trust was required by the adult with CD, when eating meals cooked by family members, that they were gluten-free. Trust within family relationships is a form of emotional support (Whitehead et al., 2018). The findings in this study indicate some relationship friction while adjusting to managing a gluten-free diet. Forgiveness was also required when mistakes were made, gluten-free food cross contaminated with gluten, during the adjustment process. Once new family behaviours were established stressors within the home kitchen were reduced, illustrating the critical role family members play in supporting each other. The behavioural changes made by
families living with CD are unknown in the literature. These findings contribute to understanding how all family members implemented behavioural changes surrounding food to protect health. Also, the role of trust and forgiveness in family relationships demonstrating the psychosocial interaction within family relationships.

When performing new behaviours conscious attention is paid, then over time behaviours become habitual unconscious behaviours (Merleau-Ponty, 2012). The adjustment to CD and the gluten-free diet preventive treatment, in this research, occurred over a period time establishing new behaviours and changing habitual behaviours. The study found children and young people practicing CD food management as habitual behaviours and able to explain the underpinning reason for these. Family adult members modelled, monitored, and directed the food related behaviour of children and young people. The development of habitual behaviour relates to the philosophy of Merleau-Ponty. When a person consciously moves, the lived body in the world, carrying out actions until the body adapts to the intended meaning and the actions become habitual, thus a form of embodied consciousness (Merleau-Ponty, 2012). These findings contribute to understanding how adults support and buffer children and young people in behavioural change as well as how they are an important part of family management of CD. Previous research has not reported on how children and young people are involved in the adult management of CD which is surprising given that food is a form of social exchange within relationships.

Behaviour, and behaviour change are core aspects of the self-management of long-term conditions including CD. Self-management is a person’s ability to manage symptoms, treatment, physical and psychosocial consequences, and
associated lifestyle changes (Martire & Helgeson, 2017). The research results show how families developed shared CD management within the home. The inclusion of all family members promoted a whole family approach to supporting CD management, with all members directly involved. A systematic review reported the inclusion of all family members enables them to overcome any challenges together in supporting self-management of a long-term condition (Whitehead et al., 2018). The findings in this research reflect and support the inclusion of all family members when a member has CD, in adjusting to family home life. The treatment for CD is arguably more invasive to family life as food and meals structure daily life and form an opportunity for families to socially connect (Dunbar, 2017). The lived experience of family members living with CD clearly demonstrated how all family members are part of the family(self)-management of CD playing an influential role.

Adjustment to CD continues over a period of time with each stage having a unique set of psychosocial demands for the family (Rolland, 1987). The crisis phase includes the symptoms prior to diagnosis, so individuals who experienced a sudden onset of symptoms, start the crisis phase at the point of initial adjustment. This period includes a number of illness tasks as described by Moos and Schaefer (1984) in the crisis of an illness theory. During this period families learn to create meaning around the new CD identity through learning to master the management of CD. Rolland (1987) argues that during this period ‘families undergo a crisis reorganisation and develop a system flexibility towards future goals’. The chronic illness phase is characterised by periods of constancy in CD management and relapses when CD symptoms present, “ a psychosocial construct of the day-to-day living with a long-term
condition” (Rolland, 1987). This period is when the family have adjusted to living with CD.

10.4 How Families live with Coeliac Disease
This section discusses how families live with CD in their daily life. The management of CD became an embedded family behaviour involving all members. Family life with CD at home was focused on food and food related behaviours whereas in the wider social world the focus shifted to eating and the avoidance of gluten. At home families had constructed safe gluten environments, this safety was absent outside the home.

Family Life at Home
Psychosocial factors are suggested as a stronger predictor of wellbeing in people with CD (Möller et al., 2021). The findings in this research support this idea with active family management of CD providing positive psychosocial support to the adult with CD. Previous research excluded family members, so this research addressed the gap of how people with CD are supported by family members.

The ability to adhere to a gluten-free diet is strongly influenced by psychosocial factors. Previous research indicates many people with CD experience difficulty adhering to a gluten-free diet, reflective of the difficulties experienced by people making dietary changes (Sainsbury et al., 2018; Zingone et al., 2015). The findings in this study support a family approach to CD, enabling the adherence to a gluten-free diet, the only deviance from a gluten-free diet occurred accidently or initially after diagnosis during the adjustment process. Even in
homes containing gluten and gluten-free foods adherence to a gluten-free diet was indicated. This finding is interesting as changing dietary behaviour is hard.

In food allergies, an underpinning motivating factor to avoid ingestion of the allergen is, the threat to life, whereas in CD the ingestion of gluten triggers painful unpleasant symptoms, so arguably a less severe consequence. Questionnaire based research that explored partners perceived burden of CD, revealed that 37 per cent of participants reported a high burden of CD associated with poorer relationship quality (Roy et al., 2016). Based on this association it could be argued that a strong relationship supports adherence to a gluten-free diet. Relationship quality was not explored in this research but could be a probable factor in the adherence to a gluten-free diet signalling the importance of family members in supporting the adherence to a gluten-free diet. The psychosocial impact of partners sharing a gluten-free diet is associated with positive and negative outcomes dependent on the underpinning motivation to partake in a gluten-free diet (Alley, 2015). This finding provides evidence for taking a biopsychosocial approach to health conditions, as the integration of all components are required to understand the factors supporting adoption and maintenance of a gluten-free diet.

Food choice is influenced by multiple factors including taste, beliefs, personal and social factors (Furst, Connors, Bisogni, Sobal, & Falk, 1996). Family food choices involve accommodating members preferences and negotiating compromises. The research results showed a difference between families with children and young people adopting a mixed gluten and gluten-free diet, in contrast to adult only families where both adults predominantly consumed a gluten-free diet. This reflects the FSI dimension of family and individual life
cycles, the consistent factor of CD remains, and the family behaviours evolve. For example, when family members leave the family home and only two members remain it is perceived as easier for them both in the home environment to consume a gluten-free diet. In contrast families with children made food choices at home based on members food preferences. These findings indicate the need for family CD support to be tailored in consideration of the family's life stage.

Family food behaviours were driven by biological factors, taste, and psychosocial factors. In family homes dinner was often eaten with other family members, creating an opportunity for social bonding, but in homes with children and young people families did not always eat together due to weekday commitments (Middleton et al., 2020). The behaviour of sitting together to share a meal provided social value, however family members did not have to be eating the same food. Spending social time as a family provided an opportunity to strengthen social bonds with mealtimes providing a space for families to engage in this behaviour. Although not indicated in this research, for some family’s mealtimes can provide a negative psychosocial impact, for example through conflict. The psychosocial properties embedded in food were reported in the research findings. Food within the home was shaped by dietary preferences and needs. When consuming food at meal times different food could be consumed indicating the psychosocial importance of sitting together, an opportunity to communicate and socially bond (Dunbar, 2017). This finding is interesting as some particular meals held psychosocial meanings that drew families together in contrast to the mealtime bringing the family together. Sharing a meal that holds values and meanings with family members perhaps
increases the health and wellbeing more than sharing a mealtime together. For families social bonding through food held psychosocial value supporting the concept that food means more than nutrition.

The psychosocial value of food is often overlooked with an emphasis on the individual diet or maladaptive dietary habits. Social bonding can promote increased health and wellbeing for all family members (Dunbar, 2017; Middleton et al., 2020). This supports the argument for a biopsychosocial approach to be adopted when diagnosing and supporting people and families with CD, as food holds social, psychological, and biological values that need to be considered as a whole, not as individual constructs due to the interrelated factors.

**Family Life in the Social World**

The biopsychosocial factors were particularly poignant for families when eating outside the safety of the family home. Eating socially outside the home provoked stressors and negative emotions such as stigma due to CD the biological factor. The negative psychosocial impact in the research was reported in children, young people, and adults with and without CD. For non-CD adults concern around the safety of food (gluten-free) was stressful and the loss of pleasure when dining out due to the gluten-free challenges. When eating in public places the perceived social stigma remained invisible, the need for a gluten-free diet due to CD, revealed a deviation from a 'normal' diet (Goffman, 1963). Stigma places a stressor on people creating a biological and psychological response. The importance of family relationships overrode perceived social stigma with families continuing to share meals in eatery venues. Research around dietary stigma often focuses on weight, eating
disorders and food (Earnshaw & Karpyn, 2020), although research is growing around stigma and dietary choices such as vegan diets (Markowski & Roxburgh, 2018). The impact of stigma can be buffered through social support (Umberson & Montez, 2010). A shift is gradually beginning to occur in response to the many different dietary needs and preferences in society, however for perceived stigmas to fade social attitudes towards diet needs to change. Food and associated meanings are deeply embedded within culture making attitudes challenging to change. Stigma surrounding CD could be reduced through increased public dietary awareness, especially in educating eatery employees and placing dietary symbols on all eatery menus removing the necessity for separate menus. However, eateries have a legal duty to advise customers of ingredients to prevent adverse events, emphasised by the tragic death of a young person with a food allergy prompting “Natasha’s law” (2021) and the call for food allergen labelling on all individually freshly made products. In reaction to this many eatery venues are proactive in seeking customer dietary needs to avoid harming customers and legal action against them. Providing family management support that includes self-care strategies to support coping with stigma for adults, children, and young people, could help address this psychosocial impact on families.

With the exception of dermatitis herpetiformis (inflammation of the skin linked to CD), CD remains invisible within the gastrointestinal tract of the body (Anupam Rej et al., 2019). Within the home environment CD is visible through gluten-free food products and food behaviours practiced but is restricted to family members. In the external environment CD remains invisible until presented with a dietary encounter where it becomes visible. The illness is invisible until it
becomes an issue raised typically in social situations involving food or drink. In these situations, CD becomes visible. Frank Arthur, (2013) describes people living with long-term conditions as members of the ‘remission society’, people who are well but not cured. These people live in a state of limbo between wellness and sickness. The concept of the “remission society” challenges the definition of health as “state of complete, physical, mental and social wellbeing not merely the absence of disease or infirmity” (WHO, 1948) as the disease, CD, is never absent it is always present in the body but remains dormant until gluten is consumed. The term ‘remission society’ describes how for people with CD and their families, CD remains invisible until the situation prompts visibility. The invisible becoming visible is a commonly shared experience for people with CD and family members. A remission society suggests that people with long-term conditions are neither well or ill however many people with CD (and their family members) define themselves as well because they are symptom free, it is society and medicine that define people by illness.

Holidays provide an opportunity for a change in everyday life as well as an opportunity to enjoy family time (Hall & Holdsworth, 2014; Sthapit & Björk, 2017). The experiences in this research show how holidays hold importance for adults, an opportunity to spend time with family members. Children and young people enjoyed family holidays, but these held less value compared to the adults. Coeliac disease presented challenges when travelling with all families deploying their management strategies to enable a family holiday. This involved increased planning of trips with members prepared to do this to facilitate a holiday. Although not part of daily life, holidays were a regular event for families. The challenges of eating away from home remained with the families on
holiday, with compromises made on where to go and eatery choices. This shows the negotiations that take place between family members to reach agreements on shared social experiences.

The availability of gluten-free food in large grocery stores within the UK has increased overtime arguably fuelled by the demand for people seeking a lifestyle choice gluten-free diet (Kim et al., 2016). Gluten-free food availability in smaller local shops is scarce (Hanci & Jeanes, 2018). In addition to restricted availability gluten-free food was reported as expensive. Families experienced increased grocery bills with the necessary purchasing of gluten and gluten-free products such as bread. This was for two reasons, firstly affordability to feed a family with children and young people gluten-free is expensive. Secondly, the taste of gluten-free food is disliked by family members. Consuming a gluten-free diet is not optional for people with CD, it is a lifetime treatment (Lebwohl & Rubio-Tapia, 2021). In some NHS clinical commissioning groups gluten-free food is available on prescription although in England this is restricted to certain bread and mixes whereas in Scotland a greater selection is available free of charge through prescription (NHS, 2018a). The differing access within the UK to free staple gluten-free food on prescription demonstrates a health inequality for people with CD. The high cost of gluten-free food could be a barrier for families needing gluten-free food creating an adverse impact on the health of the person with CD and family life.

Food handling practices to support the management of CD within the home were important with all family members actively engaged, forming part of the families’ normal habitual behaviours. The family management of CD supports prior research arguing for the inclusion of family members in the self-
management of long-term conditions (Årestedt et al., 2015; Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Whitehead et al., 2018). This research illustrates how families constructed their own CD management support systems.

A key reason within the home for unshared spaces and cooking equipment is the prevention of cross contamination. Cross contamination can easily occur through a shared product such as crumbs from gluten bread in the butter being spread on gluten-free bread. Constant vigilance to prevent cross contamination is necessary requiring safe food behaviour practices. The prevention of cross contamination within the home can be controlled but not in the external social environment. Cross contamination presents a risk for people with CD when consuming food outside the home (Falcomer et al., 2020; Schultz et al., 2017). People reply on Coeliac UK accreditation for food safety when eating out as well as past positive experiences at eateries. Adults with CD are prepared to take a risk and consume food at eateries indicating the desire for shared social experiences with psychosocial benefits. However, for people with CD the risk when eating away from home, often taints the experience due to the stress experienced. In conjunction to this poor customer service was experienced by several families at eateries with catering for gluten-free meal the reason. For families these negative experiences remove the pleasure from dining out, thus impacting all the family.

Reading the ingredients list on food packing forms standard practice for families living with CD. The functional behaviour of people who ‘scrutinize information on food labels’ is associated with a clinical approach to food and are less ‘driven’ by aesthetic value of food (Kokkoris & Stavrova, 2021). This suggests
that for people with CD food has become a clinical function with arguably a loss of pleasure with implications for family members. However, a functional approach to food choice is necessary to protect the health of family member. The need to check food packaging labels is an ongoing behaviour as manufacturers can alter the ingredients. Coeliac UK provide practical support to people with CD that was accessed by participants demonstrating the need for reassurance when purchasing food as well as simplifying the process.

Each family in this research was formed before a CD diagnosis, so have experienced this journey as a group. Together they have adjusted and adapted to living with CD, experiencing some challenges during the process. Each family has successfully developed CD management behaviours. The relationships within the families have withstood the disruption and change of identity due to CD, arguably suggesting these are strong and supportive. The underpinnings of family relationships were not explored, so it is unclear whether the experience of CD has strengthened the relationship through bringing the family together in CD treatment management. This is an area for future research.

10.5 Gender, Food and Health
This section explains the analysis in relation to the concept of gender. The psychosocial impact of CD differed between men and women. The role of gender and food is discussed first followed by health.

In the UK gender role norms exist within family homes. Public attitudes towards these norms have evolved but not changed the gender role behaviour within homes (Phillips et al., 2018; Working Families, 2019). The findings in this research do not support gender role behaviour related to food and associated practices. The inclusion of family members in the management of CD, food
purchases, storage, preparation, and cooking, mean a shared responsibility within the home. Family relationships are important in shaping health outcomes (Haslam et al., 2018). All family members knowing and practicing behaviours to maintain a shared gluten safe environment, embedded them into CD management. This finding is also observed in gluten-free homes with non-gendered food related roles. Having shared family responsibility reduces the treatment burden for the person with CD (Hall, Shaoul, & Day, 2020). A positive psychosocial outcome is observed within the home through the reduction of CD food related stressors and supportive family relationships. These findings illustrate why it is important to consider family and health from a biopsychosocial approach as these components interact determining individual and family outcomes. Additionally, when supporting families with CD it should not be assumed family members practice gender food roles.

Psychosocial gender role variances were found in the meaning of specific food and meals. Men would consume gluten foods at home, but experience guilt as a consequence. Whereas the avoidance of specific foods was a support strategy employed by women to minimise distress to others. The findings show how food and consumption are ladened with psychosocial meanings for both women and men (Arbit et al., 2017). Some women avoided cooking food due to associated pre-CD memories of a shared favourite meal with family members (Warde, Paddock, & Whilians, 2020a). These differences suggest women are sensitive to emotional food associations possibly due to the ‘caring nature’ whereas for men food focus is on satisfying hunger. Women are more likely to cook different foods to accommodate varying tastes in contrast to men cooking only one meal. These findings support prior literature (Daniels et al., 2012). The meaning of
food behaviours is influenced through culture and social factors (Beagan et al., 2014). A behaviour observed in women dieters, was caring for the health of the family and feeding family members while abstaining themselves (Ogden, 2010). Women with CD were not concerned about diet but about feeding family. These findings highlight a distinction between the behaviour of performing grocery shopping and cooking, and the underpinning meanings, with women considering the tastes, needs and preferences of other family members and men only considering dietary needs. This suggests food behaviours have greater psychosocial values to women compared to men. However, this is a very binary perspective buttressed by social norms and stereotypes of women feeding families before themselves. Future research is required to explore this in greater depth.

Gender differences were observed in health beliefs and concerns. Perceptions of health differed for men and women. Coeliac disease creates a loss of bodily control that can be mastered through treatment, consuming a gluten-free diet. Exercise and diet provided a sense of bodily control for men, enabling influence over their body shape and physical fitness, perceived by men as healthy. Body image, concerning weight and physical fitness, is associated with perceived control. Having bodily control provides a sense of mastery and agency. Personal control includes the beliefs that one’s own behaviour can control the illness, and treatment control belief that prescribed treatment can control illness. In contrast health for women reflected maintaining a sense of health through a gluten-free diet not about overall food consumed or physical activity. These findings raise concerns for the coping strategies used by men with CD as
although being physically fit is perceived as healthy, caution is required around perceptions of body image.

The practice of baking serves a social function to socially connect, a gendered behaviour. Baking is shown to boost psychosocial wellbeing through providing a sense of accomplishment with food representing a shared experience and nurturing family members (Farmer et al., 2018). However, baking can be a coping mechanism providing a sense of control and mastery (Farmer et al., 2018). The COVID-19 lockdown provided an opportunity for people to bake, as reflected in the research findings with an increased production of baked goods during this period, as well as a coping strategy (Chee et al., 2020). In this research baking was a very gendered practice, with women and girls baking something they gained pleasure from doing. Men in this research cooked meals but did not bake. This finding is reflective on the gender norm of women baking. The practice of baking is a coping strategy for women whereas for men physical activity and diet was a coping strategy. These findings suggest a difference between the coping strategies of men and women with implications for supporting families.

Previous literature found men less supportive of women for health-related dietary conditions (Albanese, 2018). The findings in this research show no disparity in support with active dietary support given by both women and men. The findings in this research are not reflective of UK gender norms around cooking and food, except for baking which is also a coping strategy. However, it could be argued that the increased involvement with food and food related processes within the home, due to CD, have constructed gender neutral roles related to food related behaviours in the home due to the shared management.
These findings contribute to the understanding of families living with CD, providing an insight into the behaviours performed in family life including gendered coping strategies.

10.6 Contributions and Recommendations

10.6.1 Theoretical Contributions

The Biopsychosocial Model of Health

The biopsychosocial model was applied as a theoretical framework to explore living with CD (Engel, 1977). The integrated model was used to understand how CD is more than a biological health condition at the individual and family level. The biological component of CD shaped the psychosocial elements of living with CD, whilst the psychosocial elements can be argued to have shaped CD, the biological component, through the prevention of gluten contamination. Previous literature has argued that the biopsychosocial model factors are integrated (Woods, 2018). The research provides evidence for the application of the biopsychosocial model in the exploration and understanding of health conditions at the individual and family levels.

The adjustment to CD required, at the individual level, social factors including family and food, and psychological factors including coping. These factors overlapped with food at the centre demonstrating the biopsychosocial factors identified in this research and how food is often the instigating factor for behavioural and psychosocial responses. The biopsychosocial model is also
applicable to understand the whole family experience of living with CD. The integrated factors illustrate the supportive strategies families employ in the adjustment to and the daily management of CD as well as the challenges families face with CD.

Understanding the psychosocial impact of living with CD through a biopsychosocial framework raises the consideration of whether each component is given equal weight. Although CD was the central underpinning factor as demonstrated through the umbrella theme ‘the perpetual presence of coeliac disease’ the treatment, a gluten-free diet, arguably played a greater psychosocial role in the disease management. The key factor in managing CD was food, which forms part of daily life. This concerned the biological need to consume food integrated with the social and psychological factors associated to food and eating. For families living with CD the treatment management impacted upon food and related behaviours inside and outside the home. The diagnosis and adjustment phase of CD concerned all biopsychosocial components, once managed the condition and treatment concerned the social and psychological components of the model.

Coeliac disease was an unmodifiable factor due to the current incurability and absence of pharmacological treatment. The dietary treatment was a factor that families could manage. Therefore, food is at the centre of biopsychosocial model. The Family life at home with food themes; food for all: stocking the family kitchen; ‘that magic word, cross contamination’: shared and separated kitchen spaces; negotiating family: food, cooking and eating and sub themes are underpinned by the biological component of CD but all concern psychosocial factors around the treatment management for CD. Navigating the
external social world with CD themes; social inclusion and exclusion: the psychosocial affect; the invisible becoming visible: revealing CD; ‘playing Russian Roulette’: family comprises eating away from home, also are dominated with the psychosocial factors of CD.

It could be argued that taking a psychosocial approach to exploring families living with CD produces a bias towards these components but when living with long-term conditions it is often the psychosocial daily living with the disease that has the greatest impact in the daily management of the condition most of which occurs away from a medical setting. But the caveat to this is without the biological health condition the management would not be required. Therefore, in the family management of CD the biological component of CD although the driving factor is a smaller component with the combined psychosocial components being larger factors in living with CD in the home and wider social environments. Figure 40 provides a diagram of the biopsychosocial model with the main themes mapped onto the model and the size of the model components reflecting the importance. The application of CD to this model supports previous research into the need to include family members in the management of long-term conditions due to the psychosocial impact.

In this research findings the biological reflects the medical diagnosis of CD, the genetic link triggering testing of other family members and food from a biological perspective the need to eat. From a social perspective the findings generated showed an impact at the individual and family level on employment, education, home and wider social life. The psychological stigma experienced, distress and stress during the disease adjustment process. Overall, the application of the biopsychosocial enables a holistic approach to health with the integration of
social and psychological factors, recognising the interplay of these factors on the health outcomes for patients and their family members. The application of the model has implications for clinical practice and supporting families living with CD.
Figure 40 Diagram of Themes Mapped on to the Biopsychosocial Model

'It's a learning curve all the way': from the unknown to the family norm

**Family Life at Home with Food**
- Food for all: stocking the family kitchen
- ‘That magic word, cross contamination’: shared and separated kitchen spaces
- Negotiating family: food, cooking and eating

**Navigating the External Social World with Coeliac Disease**
- Social inclusion and exclusion: the psychosocial affect
- The invisible becoming visible: revealing coeliac disease
- ‘Playing Russian Roulette’: family compromises eating away from home
The Family Systems Illness Model

The family systems illness (FSI) model proposes people operate at an individual and group level (Rolland, 1987). This research contributes through support for the concept of how family functions in response to the diagnosis of a long-term condition, CD, and how the psychosocial demands alter through adjustment to the illness and developments in family life. The multidimensional FSI model considered all family members. The initial diagnosis of CD maps onto the FSI model dimension of the psychosocial typology of illness. However, CD has a varying symptom presentation from acute to gradual. An acute onset of CD symptoms prompted a rapid medical intervention and diagnosis, whereas gradual presentation entailed many consultations with GP’s and for some these continued for years. The FSI model argues that an acute-onset prompts a rapid deployment of emotional and practical crisis management skills, in contrast to a gradual-onset disease such as arthritis which allows for a longer family adjustment time. Coeliac disease mapped onto the timeline phase, as despite the events leading to the diagnosis of CD, this event promoted the rapid adjustment process to the condition. All families experienced the initial adjustment period, learning to manage CD and reaching a state of stability.

The illness course of CD, a non-fatal condition, falls between the FSI trajectories of constant and relapsing, with gluten ingestion the trigger for a relapse. This requires constant vigilance around food and eating to avoid gluten to prevent a relapse. The family management of CD minimised the instances of relapses within the home, and where possible outside the home. The disease course of CD is non-progressive, although associated with increased likelihood of developing additional autoimmune conditions (Lauret & Rodrigo, 2013).
During a relapse a person can become incapacitated due to gastrointestinal symptoms and at any time in public due to the perceived social stigma (White et al., 2016). The family provide psychosocial support to help adjust and regain a state of family stability in response to stressors.

The families participating in this research were at varying stages across the life course. The FSI reflected the developmental journeys families had experienced with CD and the psychosocial adjustments families made in response to changes, such as children leaving home. The model reflected the interactions within families and those with the wider social world and how families managed these. In families with children, interactions between members were constructed in how CD was managed. Within the public social context, the family experienced challenges that together they managed. The findings from this research offer support for understanding the family experience of living with a long-term condition, accounting for family development as well as disruptions experienced by families in daily life. The psychosocial challenges and facilitators are also reflected in the FSI thus supporting its application in understanding families living with CD at different life stages with potential to use in supporting families.

**Integrating the Biopsychosocial and Family Systems Illness Models**

This research provides an example of how the biopsychosocial and FSI models can be integrated to understand family management practices in the context of a long-term illness.

Firstly, many individuals had lived with symptoms for years having some impact intermittently on family members, but when the symptoms were labelled as CD
triggering the necessity for a gluten-free diet, at this point CD became a family disease. The diagnosis and subsequent treatment maps onto the biopsychosocial model (the social impact on family, psychological due to the emotional impact and behaviour changes in response to a biological condition) this combines with the FSI. The CD diagnosis maps on to the crisis phase having a psychosocial impact on family functioning as the family adjusts.

Applying an integrated model of the biopsychosocial and FSI models at the point of diagnosis can help understand the impact on both the individual and family. This has implications for the diagnosis of CD recognising that the whole family are impacted and through the provision of support can help facilitate a family adjustment to the condition and necessary treatment.

When a diagnosis of CD is received in following the initial crisis families adjust learning to manage the condition. The treatment for CD effects all family members not solely the person with the condition. For all family members this had a psychosocial impact with a temporal element as families learn to adjust. The family management of CD adjusts in response to family functions. These are intertwined with psychosocial factors. The findings in this research show how families function in CD management, altering in response to psychosocial demands, for example the family function to socialise and negotiate food tasks at home. The models are not static reflecting how family functioning changes in responses to the illness and vice versa. An illustration when family structures alter, children moving out, how the family adjusts changing dietary behaviours, so all eat gluten-free food. In contrast to this when on a holiday together as a family CD determines where families will eat. The biological needs of CD place differing psychosocial demands on family. The FSI model outlines illness
psychosocial typology, the phases of illness and family functioning in the context of CD with the biopsychosocial model providing an insight into the psychosocial factors related to functioning.

Integrating the biopsychosocial and FSI models provided a framework to understand the psychosocial impact of CD on adults and their family members. The models provide an integration of family, health and the psychosocial factors embedded in these constructs. The thesis advances thinking around the integration of the BPS and FSI models and the application in family practices in the context of long-term health conditions.

10.6.2 Methods Contributions
The use of public involvement in PhD research is scarce especially for children and young people (Coupe & Mathieson, 2020). The work with children and young people contributes to what has become recognised as an essential component to any research. Working with members of the public at any stage of the research process enriches the quality. The contributions of adults, young people and children enriched the quality of this research. A PhD by default presents the challenges of time and needing to be the work of the candidate, limiting the opportunities for external involvement in shaping the research. However, as this research demonstrates, working with research advisors can improve the feasibility and acceptability of research designs. In this research the expert advice of children and young people was particularly valuable ensuring methods and documentation were relevant and understandable. Working with research advisors assisted with ethical concerns, highlighted potential problems, for example the sharing of photographs, and warned of possible images, for example toilets. Working with research advisors took time to recruit
and organise, but with clear targets and planning can be achieved and is well
worth the effort. This research provides a valuable contribution to working with
research advisors, especially children and young people, on research design.

In response to the COVID-19 pandemic this research had to be adapted as
detailed in Chapter 6, section 6.1. Previous literature provided details of online-
synchronous video interviews and participant-generated photo-elicitation
interviews, but not in combination, and including children and young people. At
the time of data collection, a boom in video communication platforms occurred
in response to a demand for tools to maintain contact with others for personal,
education, and employment purposes (Office for National Statistics, 2021). The
taking of photographs is an everyday commonality facilitated by mobile
technologies. To conduct this research the inclusion of participant-generated
photographs was important to empower children and young people, to give
them control of the interview and encourage conversation. The greatest
challenge to this method was the diverse range of online video platforms
comfortably used by participants, and the number of electronic means to
securely share photograph images. The context that the research took place
under shaped the method, contributing to the successful employment of online
participatory research methods.

In relation to the applied methods, conducting research during the COVID-19
pandemic has also contributed to the global knowledge base. The context and
methods have demonstrated how research can be conducted during
exceptional circumstances. Additionally, this has potentially opened doors to
enable people who find it hard to access participating in research (people are
not hard to reach, researchers are not accessible), reach the seldom heard
voices, the people confined to homes or remotely situated, those caring for others, vulnerable people isolating, and a wealth of members of society who were perhaps unrepresented. The circumstances hopefully will bring beneficial contributions to future research.

The contribution of the inclusion of children and young people in this family research have demonstrated how all family members can participate in research to understand the lived experience of health conditions. The views of children and young people are often those of their parents especially around living with health conditions. With many long-term conditions patients spend a small amount of time in medical care (Eaton et al., 2015). The effective self-management of conditions at home is vital to improve quality of life for people and reduce the burden on the NHS. This research has found how children and young people are effectively involved in the family management of a parent’s CD. Demonstrating the need for them to be included in family research. This research has found children and young people are capable of practicing many food related protective behaviours, and are knowledgeable about dietary conditions, and more accepting of different dietary needs. This research also shows how children and young people are willing to actively participate in research. The inclusion of children and young people in this research has contributed to understanding the lived experience of CD.

10.6.3 Contributions to Future Family, Coeliac Disease and Food Research

This exploratory research provides the foundations for future research into families, CD, and food.
This research is arguably the first to explore the lives of families living with an adult with CD through photo-elicited interviews. The research has shown how families as a group and individual members are impacted by the diagnosis of CD. The ability of families to cope and adjust to support the preventative treatment for a family member is illustrated. How families changed the home environment and adopted new food related behaviours to support the management of CD within the home. Families played a vital role in providing support. This research has given an insight into family life with CD signalling the approach could be used to explore other long-term health conditions.

Understanding how families cope with living with CD can help support those who perhaps find adjusting to a diagnosis of CD challenging or experience difficulties adjusting to the management of CD across the life course.

Exploring the absence in the literature surrounding how families live with CD has provided an insight into how families manage. Previous research that included partners predominantly focused on the barriers to living with CD. This research demonstrates the supportive role families play in living with CD, highlighting the facilitating behaviours and psychosocial support families provide. The families in this research shared how they managed CD constructing a safe home environment and coped with challenges in the wider social world together. The results from this research can be used to guide future research into families living with CD. As this research demonstrates adults with CD often live in family groups and the management of CD effects the whole family, having a biopsychosocial impact. Understanding further the experiences of families can help inform CD family-management support using a biopsychosocial framework.
Food and food related behaviour were a strong feature of this research analysis. Food played a significant biopsychosocial role in family life and at the individual level. A surprise finding was how most people diagnosed with CD were able to stop eating gluten almost immediately and maintain a gluten-free diet. Family members were strongly indicated in supporting a gluten-free diet suggesting they are vital in this process. Implementing dietary changes rapidly indicates a strong driving motivating factor for people with CD. Most people struggle to make and maintain any dietary changes, as this requires behavioural changes as well as overcoming the psychosocial properties of food (Ogden, 2010). Future research could explore further the motivating factors and the role of family in supporting a gluten-free diet. An understanding of the underpinning mechanisms could potentially support other health populations with dietary needs who experience challenges changing diet and maintaining these.

10.6.4 Recommendations to Improve People’s Health

Recommendations for Public Awareness

The lack of awareness around CD is demonstrated through the findings of this research. Increasing public awareness has two related components. Firstly, to educate caterers and those serving food what gluten-free means for people with CD. Secondly, through increased awareness of CD symptoms to enable more people to recognise symptoms and seek treatment to address the number of people believed to be undiagnosed. Undiagnosed CD is associated with an increased risk of developing other long-term conditions and increased mortality
(Karhus et al., 2020). Raising awareness of CD can potentially improve the health and life quality of many people.

Public awareness of different dietary needs and preferences has increased as evidenced by the increased range of products available in grocery stores, improved labelling, and menu choices. However, what these diets are and why remain unknown to many people. In CD the assumption is it is a dietary choice, not need, therefore the seriousness of the condition is unknown and thus overlooked (Schultz et al., 2017). As CD symptoms typically are not life threatening in contrast to other dietary avoidance needs that trigger allergic responses, CD falls within the middle, not acutely life threatening and not a dietary preference. This has implications for supporting people as they are effectively public educators having the burden of explaining to others, this burden falls on all family members. Coeliac UK are the only organisation providing support in the UK, as evidenced in these findings. Coeliac UK are a resource for NHS dieticians to refer patients to as well as running campaigns to increase public awareness of CD. The research findings demonstrate the value of support from Coeliac UK to families and contribute to the need for continued support for the work of Coeliac UK.

Recommendations for Healthcare

The length of time taken for diagnosis indicates the low CD awareness amongst medical professionals. The literature is well evidenced with the significant length of time taken for people to be diagnosed with CD (Rej & Sanders, 2021). The findings from this research contribute towards the evidence providing an explanation for delayed/missed diagnosis. Living with undiagnosed CD, in
addition to the debilitating symptoms, impacts upon quality of life, for example extreme fatigue (Violato & Gray, 2019). This research additionally suggests gender assumptions in medical care with fatigue in women due to iron deficiency and dismissal of symptoms as psychosomatic (Winchester, 2021). Although Coeliac UK deliver awareness campaigns, the research findings indicate that symptoms are often dismissed, especially those of women. This research analysis indicated the time taken for a CD diagnosis as not having decreased. Recommendations for healthcare practice advocate routine screening for CD when people present with fatigue or abdominal symptoms (Lebwohl & Rubio-Tapia, 2021). Increasing public awareness would also promote healthcare practitioner awareness.

**Recommendations for Family-Management Support**

As illustrated in the research findings CD impacts all family members highlighting the necessity for support to be provided to all families to support family adjustment to managing CD. This would reduce the burden on the person with CD. Treatment for CD is food based involving dietary and food handling behaviours. Within family homes and lives food plays a significant role involving all family members not one person. For many families the sourcing and preparation of food are shared behaviours, for example adults taking turns to cook. Within the home all members use the kitchen, avoiding cross contamination, for example no double dipping in the butter. The successful management of CD requires the support of all family members therefore family-management. Advice and guidance should be provided to all family members as it impacts them. Providing support would help people cope, practically and emotionally with the necessary behavioural changes. Family-management
support could address the needs of all members, minimising the psychosocial impact as well as aiding preventative CD treatment.

10.6.5 Strengths and Limitations of the Research
A strength of this research is the increased ratio (3:2) of women to men (six women; four men) as the reported prevalence of CD is twice as high in women compared to men, though screening data suggests an equal balance (Ludvigsson & Murray, 2019). Research on CD research is often conducted on women, so the inclusion of men’s experiences contributes to the paucity in literature. Recruiting a higher number of men participants could be explained by the research method, using participatory photography as an engagement tool that is suitable for a range of ages. The participating men and boys were aged from eight to 80 years:

*I just love taking photographs and I just love the whole descriptive thing. I just rattled through them [photographs] and I didn’t really think about it very much I just snap snap*

(Agent, CD)

Also, using photography made the research appealing and accessible to a broad audience. It is recognised that between genders and within genders differences are present, but as a starting point using gender to begin to understand how it influences behaviour in health is important. Understanding gender responses can help identify relevant support to family members helping adjustment to CD and continued family management. Understanding the experiences of both men and women with CD contributes to the literature.
All participating families were economically able to afford the purchase of gluten-free foods but this is not reflective of UK society as a whole. In the UK the use of food banks has become a normalised practice with many people and families reliant on them, with numbers increasing (Bramley, Treanor, Sosenko, & Littlewood, 2021; Gorb, 2022). Foodbanks can adapt people’s parcels to meet dietary needs. In relation to this, gluten-free food is not available on prescription across all the NHS clinical commissioning groups (Hanci & Jeanes, 2018; Linton et al., 2018; NHS, 2018a). Based on these research findings families on a limited budget could find purchasing gluten-free food challenging due to the high cost. Furthermore, many families purchased gluten and gluten-free products, this would not be an option for food bank parcels where family compromises would need to be made, for example have foods naturally gluten-free. An absence of families experiencing financial hardship is particularly poignant within this research as at the societal level in the UK with increased living costs (Francis-Devine et al., 2022).

Recruitment for the study occurred during the COVID-19 pandemic lockdown so all recruitment was conducted online via gluten-free retailers and social media platforms (Chapter 6, section 6.2.1). The societal context perhaps influenced recruitment as families were stuck at home so participating in this research provided something to do. Families being at home together made it easier to speak to all family members together, a benefit of the wider social context.

The self-selected population sample were predominantly white British and white European potentially creating a limited dietary cultural perspective. Cultural diets were not a consideration of this research or ethnic background. The concern was to recruit family groups with an adult member who had CD, and
some families including children and young people. At the point of study design families were of greater importance than ethnicity to address.

A strength of this study is the inclusion of the experiences of all family members especially children and young people who are often excluded. The methods applied to conduct this research supported the inclusion of children and young people as research advisors and as participants. The involvement of children and young people as research advisors is being recognised as an essential part of research especially when the topic incudes them (Brady & Graham, 2019; Rouncefield-Swales et al., 2021). Including all family members contributed a multiple perspective account of living with CD which was previously absent.

Utilising synchronous online video to conduct interviews was a strength of the study. This method removed all geographical barriers presented by face-to-face interviews. Adapting to this method enabled the research to be conducted at a time when in-person meeting was prohibited. Online methods were accessible to a wide age range, eight to eighty years, challenging the stereotype that older people are technologically illiterate. As well as online interviews, participants photographs had to be shared electronically. This has potential transferability for future research with adults, children and young people removing geographical barriers, empowering people with mobility or health conditions to participate.

The application of participant generated photographs was a strength of the research with all participants engaging. The use of photographs provided participants freedom to choose what image to share and shape the interview (Bates, Mccann, Kaye, & Taylor, 2017; Harper, 2002). Some participants were
creative in this using previous photographs or images to illustrate what they wanted to say. The use of photographs provided a reflective opportunity for all participants. This was perhaps accentuated by the COVID-19 pandemic as participants were acutely aware of changes in daily life practices.

A caveat to online interviews was the loss of autonomy experienced by some children and young people. Due to ethical concerns around safeguarding the photographs taken by children and young people had to be shared by their parents with the researcher. In some cases, this resulted in a loss of autonomy for the child or young person, with parents selecting images. A possible solution to overcome this would be for children and young people to electronically share photographs directly with the researcher and copying the parent in. Disposable cameras for these groups are another consideration to provide full autonomy but many children and young people dislike these, also if misplaced could result in a data breach.

During interviews with some children and young people their parents contributed. In some cases, this was supportive, whereas in others it created conflict. Conducting interviews in-person on an individual basis could address this but children and young people feel more comfortable at home as well as secure having a parent present. So online synchronous video interviews with children and young people had both limitations and strengths.

10.7 Conclusion
This research set out to explore the lived experience of CD on adults and their family members. Utilising the biopsychosocial model, this research found that in families all members were impacted by CD, and all contributed to the family management of CD. The consultation with research advisors on the study
design supported the viability of the research. The use of photographs and interviews provided access into the worlds of families generating rich data providing a description of how families had been disrupted by CD and learnt to live with CD. The data constructed family life within the home and the wider social world. Living with CD had a psychosocial impact on all family members. The often-silent voices of children and young people were heard throughout the research process. Taking a biopsychosocial approach highlighted how the biomedical perspective of CD requires experiential knowledges to understand how CD impacts the lives of families experiencing CD. The findings suggest the provision of support for all family members. In conclusion, this research provided a novel insight into the private world of families, showing how they adjusted to live with CD, and how together as a family they manage CD.
References


UBC Press.


Daly, K. (2007). *Qualitative methods for family studies and human development.*
Sage.


Fielding-Singh, P. (2017). Dining with dad: Fathers’ influences on family food 386


https://doi.org/10.1177/1074840714532715


Hanci, O., & Jeanes, Y. M. (2018). Are gluten-free food staples accessible to all
https://doi.org/10.1136/flgastro-2018-101088


https://doi.org/10.1177/0022146519825749


https://doi.org/10.4236/ojmp.2012.14009

https://doi.org/10.1111/jep.12374


Ludvigsson, J. F., Card, T., Ciclitira, P. J., Swift, G. L., Nasr, I., Sanders, D. S.,...


Markowski, K. L., & Roxburgh, S. (2018). “If I became a vegan, my family and
friends would hate me:" Anticipating vegan stigma as a barrier to plant-based diets. https://doi.org/10.1016/j.appet.2018.12.040


Article 1


Article 2


Article 3


Article 4


Article 5


Article 6


Article 7


Article 8


Article 9


Opportunity to become a Research Advisor

Are you aged 8 -12?

Do you or a family member have a food related condition where you can’t eat certain types of food?

Do you live within 20 miles of Milton Keynes?

Would you like to influence research exploring what it is like living with coeliac disease?

If yes to these questions, look inside to find out more……
Hello,

I am seeking 4 children aged 8-12 years to help me with my research. I am doing some research to understand what everyday life is like for children and adults who live with someone who has coeliac disease.

**What is coeliac disease?**

Coeliac (pronounced see-lee-ak) disease is when a person can’t eat wheat, barley or rye because they contain gluten. The gluten makes the person ill. Gluten is found in foods like bread, pasta, cakes, sauces, ice-cream and sausages.

**Why is this research important?**

We know that people with coeliac disease sometimes find things to do with food difficult and this can make them upset. We don’t know what their family members think. So, this research aims to find out what it is like for family members living with coeliac disease to see if there is anything we can do to help.

**Why do I need your advice?**

Your advice is needed on deciding how to ask children in families with coeliac disease what this is like. The best people to advise me are children like you. You know what things children do and don’t like, and what is important to you. You are the experts.

Phase One Version 1 13.12.19
What would you have to do as a Research Advisor?

You will be invited to a meeting with 3 other children aged 8 to 12 and me. I will tell you a bit about research and some of my ideas.

Your job with the other advisors will be to advise on a good way for children to take part in the research.

You will need to listen to others and be happy to share your ideas.

Together we will do 3 activities.

1. Design an interview guide
2. Explore ways to include photographs in the research
3. Design an advert

The meeting will be relaxed with plenty of breaks.

After the meeting using what you have told me I will write an information sheet about the research, interview questions and an advert for the research.

I will send these to you to check that they are okay. You can let me know what you think in person, by email or phone.

To help working with future Research Advisors we will ask you what you thought and if you would make any changes.

Where will the meeting be held?

At the Open University in Milton Keynes. They will be on a Saturday and last for 2 and a half hours.
Will I get refreshments?
Drinks and snacks will be provided, catering for any dietary requirements.

What is in it for me?
To learn about research, have a say in how research is done, help to make research relevant and as a thank you for your time a £20 gift voucher. Travel expenses will also be reimbursed.

Will my details be kept private?
Yes, we will need your details and parent(s)/guardian so we can contact you about the project. These will be destroyed at the end of the project. All electronic data will be stored in a password protected computer. Paper copies will be kept in a locked filing cabinet in my office. We will also ask for your age, gender and family food condition. These details will be anonymous as your name will not be kept with them.

In the future we will present and publish on working with Research Advisors. We would like to acknowledge your part, so we will ask you and your parent(s)/guardian at the end of the project if you would like to be included.

What next?
If you are interested or want to find out more please ask your Mum or Dad or guardian to get in touch with me.

Thank you for taking the time to read this leaflet.

Samantha Goodliffe

samantha.goodliffe@open.ac.uk

01908 655265
Opportunity to become a Research Advisor

Are you aged 13 -17?

Do you or a family member have a food related condition where you can’t eat certain types of food?

Do you live within 20 miles of Milton Keynes?

Would you like to influence research exploring what it is like living with coeliac disease?

If yes to these questions look inside to find out more……
Hello,

I am seeking 4 young people aged 13-18 years to help me with my research. I am doing some research to understand what everyday life is like for children, young people and adults who live with someone who has coeliac disease.

**What is coeliac disease?**

People with coeliac disease are unable to eat foods containing gluten as this causes damage to their intestines. Gluten is a protein found in grains including wheat, barley and rye. in foods you would expect like bread some where you might not expect ice-cream, chocolate and frozen chips.

**Why is this research important?**

We know that people with coeliac disease can experience challenges avoiding gluten and often have poor mental health. We don’t know what their family members think. So, this research aims to find out what it is like for family members living with coeliac disease to see if there is anything we can do to help.

**Why do I need your advice?**

Your advice is needed on deciding how to ask young people in families with coeliac disease what this is like. The best people to advise me are young people like you. You know what things young people do and don’t like, and what is important to you. You are the young person expert.

**What would you have to do as a Research Advisor?**

You will be asked to come to a meeting with 3 other young people aged 13 to 18 and me. I will tell you a bit about research and some of my ideas.

Your job with the other advisors will be to advise take part in

Your job with the other advisors will be to advise take part in.

You will need to listen to others and share your ideas. Together we will activities:

1. Design an interview guide
2. Explore ways to include in the research photographs
3. Design an advert

The meeting will be relaxed with breaks.
After the meeting, using what you have told me, I will write an information sheet about the research, interview questions and an advert for the research. I will send these to you to see what you think of them. I will then call, email or meet you so you can tell me what you think about them.

To help working with future Research Advisors we will ask you what you thought and if you would make any changes.

**Where will the meeting be held?**
At the Open University in Milton Keynes. They will be on a Saturday and last for 2 and a half hours.

**Will I get refreshments?**
Drinks and snacks will be provided catering for any dietary requirements.

**What is in it for me?**
To learn about research, have a say in how research is done, help to make research relevant and as a thank you for your time a £20 gift voucher. Travel expenses will also be reimbursed.

**Will my details be kept private?**
Yes, we will need your details and parent(s)/guardian so we can contact you about the project. All electronic data will be stored in a password protected computer. Paper copies will be kept in a locked filing cabinet in my office. These will be destroyed at the end of the project. We will also ask for your age, gender and family food condition. These details will be anonymous as your name will not be kept with them.

In the future we will present and publish on working with Research Advisors. We would like to acknowledge your contribution, so we will ask you and your parent(s)/guardian at the end of the project if you would like to be included.

**What next?**
If you are interested or want to find out more please ask your Mum or Dad or guardian to get in touch with me. If you are 16 or over you can contact me directly yourself.

Thank you for taking the time to read this leaflet.

**Samantha Goodliffe**

samantha.goodliffe@open.ac.uk 01908 655265
Appendix C

Research Advisor Involvement Guide
Hello,

I would like to seek advice from adults, with or who live with someone who has a dietary condition, to influence a research project. For the purposes of this research dietary conditions are coeliac disease, food allergy or food intolerance.

**What is the research?**

I am conducting research to understand what everyday life is like for family members in a household where an adult has coeliac disease. We know that living with coeliac disease can be challenging for some people with the condition. But we don’t know how this affects their family members. This research aims to understand the experience of living with coeliac disease to help see if families need any support.

**Why do you need my advice?**

As people living daily with a dietary condition you understand what it is like, you are the experts. As researchers we have ideas, but we are not experts in living with a dietary condition. We may miss the issues that are important to you. Working together your expertise can help develop the research to explore what it is like for family members living with coeliac disease. This will result in better quality research that is relevant to the people of interest.

**What would I have to do as Research Advisor?**

You will be asked to attend a meeting with 3 -5 other adults to work in partnership to provide advice to ensure the proposed research is appropriate and relevant to people living with coeliac disease.

You will need to be happy to share your ideas and listen to others. Together we will design three key research components:

1. An interview guide
2. Exploring using photographs
3. Ways to recruit participants

After the meeting I will write an information sheet, interview questions and an advert based on what we have decided.
This documentation will be sent to you to comment on. To aid future work with Research Advisors we will ask you to complete an evaluation.

**Where will the meeting be held?**

At the Open University in Milton Keynes on a Saturday for 2 and half hours. Depending on peoples availability it will either the morning or afternoon.

**Will I be paid?**

This is a voluntary position however as a token of appreciation you will receive a £20 gift voucher and travel expenses will be reimbursed.

**Do I need any specialist skills?**

You do not require any previous research experience or specialist skills just a willingness to share your ideas and an experience of living with a dietary condition. You should live within 20 miles of Milton Keynes.

**Will my details be kept private?**

Yes, your details will only be accessed by the research team so we can contact you solely about the project. All data will be stored securely at the Open University. All electronic data will be stored in a password protected computer. Paper copies will be stored in a locked filing cabinet in my office. These will be destroyed at the end of the project. We will also ask for your age, gender and family food condition. These details will be anonymous as no personal details will be stored with them.

In the future we will present and publish on working with Research Advisors. We would like to acknowledge your contribution so we will ask you at the end of the project if you would like to be included, this is optional.

**Still interested?**

If you are interested or would like to find out more, please get in contact with me via the details below.

Thank you for your interest in this project and taking the time to read this leaflet.

**Samantha Goodliffe**
Appendix D

Dear Parent or Guardian,

You are receiving this letter because either your child or you have expressed an interest in the opportunity for them to be a Research Advisor.

I am conducting research for my doctorate into family members experiences of living with coeliac disease. This is to provide an understanding of the daily reality of living with the disease and to help identify any support needed. Children are members of family groups, so it is important their views are included in family research. The best people to advise me on how to include children in my research are children – they are the experts. So, I am seeking eight children to work with me as Research Advisors. They will be split into two separate groups of; 8-12 years and 13-18 years. Coeliac disease is diet related, so I need children who have or live with a family member who has coeliac disease or a food related condition e.g. allergy.

The Research Advisor (your child) would be required to attend one group meeting and afterwards provide feedback on documentation. Dependant on people’s availability, the advisory group meeting will take place either on a Saturday morning or afternoon. The meeting will be held at the Open University Milton Keynes campus and will be two and a half hours. In each group there will be a maximum of four children. During the meeting the Research Advisors will be presented with some research ideas and asked to share their opinions on them. Following the meeting I will send some written documents to your child for comment on. This will be to see if the content is engaging and makes sense to someone of your child’s age. The advisory group will be asked their preferred way to give comments; by email, telephone or in person. This will be after school hours or at the weekend. The reading and commenting on the documentation will take around 40 minutes.

Your child, as well as having the opportunity to shape a piece of research, will receive a £20 gift voucher as a token of appreciation for their valuable contribution. This will be sent to them after commenting on the documents.
Travel expenses for attending the meeting will also be reimbursed. Your child will be sent a summary of the meeting decisions and how they have been used in the research.

For your child to be a Research Advisor your permission is required. The Open University Human Research Ethics Committee have approved the advisory groups. Please contact me E: samantha.goodliffe@open.ac.uk T: 01908 655265 for further information, thank you.

Kind regards,

Samantha Goodliffe
Doctorate research student
School of Health, Wellbeing and Social Care
Appendix E
Child and Young Person Research Advisor

Assent and consent form

Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/xxxx

Researcher: Samantha Goodliffe  📧 samantha.goodliffe@open.ac.uk  ☎ 01908 655265

This form is to be completed by the child/young person with their parent/guardian

Please initial in box if you agree

➢ Being a Research Advisor has been explained to me
➢ I have read the information sheet about being a Research Advisor
➢ I have asked all the questions that I wanted to
➢ The questions have been answered in a way I understand
➢ I understand it is okay to stop being a Research Advisor at any time
➢ I am happy to be a Research Advisor

If any answers are ‘no’ you can ask more questions. But if you don’t want to be a Research Advisor, don’t sign your name. It is okay not to be a Research Advisor.
Advisor.

If you do want to be a Research Advisor, please write your name below, sign and today’s date

Your name (please print):
____________________________________________

Signature: ___________________________________________ Date: ____________________________

Your parent or guardian must write their name here too if they are happy for you to be a Research Advisor:

Print name: __________________________________________

Signature: ___________________________________________ Date: ____________________________

The researcher who explained being a Research Advisor to you needs to sign too:

Print name: Samantha Goodliffe  Signature: _______________________ Date: __________________

Thank you 😊
Appendix F
Information Sheet for Participants
aged 8 to 12 years

Exploration of the psychosocial impact of
living with coeliac disease; the lived
experience of family members

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3585/Goodliffe

We are conducting a study to understand what it is like for families living with coeliac disease.

We are inviting you and your family to take part in a research study.

You will need to:

• Take photos of daily life living with coeliac disease

• Talk about your photos during an interview with a researcher

Before you decide if you would like to join in it is important that you know why the research is being done and what you would have to do.

Please read this leaflet carefully with your parents. If something is unclear or if you would like more information, ask your parents to contact us.

What is the research about?

We know that people with coeliac disease find it challenging at times. We also know that family members are important in providing help and support. This research is to find out what it is like for all family members living with coeliac disease.

What will I have to do to take part?
If you agree to take part in this research, you and your family will meet the researcher, Samantha, either via an online video call or at your home or the Open University Milton Keynes. You will be asked to sign an assent form to say you agree to take part in the research. Your Mum, Dad or guardian will also have to give consent. You will be asked to complete a short questionnaire about you. This will take about 30 minutes depending on how many of your family members want to take part.

There are 2 activities for you to do.

1) For 7 days take photos that describe your everyday life living with coeliac disease. You can use your own device with a camera, or when able to, we can lend you a digital camera.

2) An interview with Samantha to talk about 7 photos of your choice. You can have your photos printed or to look at them on a screen. The interview will be arranged at a time suitable for you and will be either an online video call or face-to-face. It can be held at your home or a private room at the Open University Milton Keynes. You can ask your Mum, Dad or guardian to sit with you. The interview will last one hour and be audio recorded. This is so Samantha does not forget anything you tell her. After the interview you will not have to do anything else as part of this research.

What are the possible advantages of taking part?

We hope that people will find taking part in the research a good way to have their story heard. It is hoped that what we find out in the research can help improve services and support for people in the future. Some people feel good being listened to and talking about their own experiences.

What are the possible disadvantages of taking part?

We do not expect there to be any disadvantages to you in taking part but talking about daily life may trigger feelings. During the interview you do not have to talk about anything you do not want to. If you want to stop tell Samantha who won’t mind.

Will my taking part be kept confidential?

Yes, anything you tell us will only be accessed by the researchers involved in the research. It will all be stored securely at the Open University. Personal information, for example your name, will be kept separately from your interview data. When the interview recording is typed up any identifying details such as names and places will be changed. The recording will then be deleted.
We plan to publish the research findings in an academic journal and present the study at talks and conferences. Direct quotes, things you said, from interviews might be used. These quotes will not contain information that would enable you to be identified.

After the interview you will be asked if you would like to consent to the use of non-identifiable individual photos in presentations and publications.

The only limits to this confidentiality are if you were to tell us something that would be a reason for us to be worried about a wrongdoing or potential harm to yourself, or to someone else. In these circumstances it will be important for us to share this information appropriately.

**What will happen if I don’t want to carry on with the research?**

You may withdraw from this research at any time without giving reason. If you decide to withdraw your information and data will be destroyed. After your interview you will have 3 weeks to withdraw this data. As when your interview is typed-up any identifying details will be changed so we won’t be able to identify your interview. Ask your parents or guardian to tell Samantha by email or telephone if you want to withdraw from the research.

**What if there is a problem?**

If at any time during the research, you would like to comment or report a problem about any aspect of this research then please ask your parent or guardian to contact Samantha Goodliffe

[Email]

samantha.goodliffe@open.ac.uk or

[Phone]

01908 655265 / 07340 470448

or they can contact the researcher’s supervisor Dr Martin Robb

[Email]

martin.robb@open.ac.uk or [Phone] 01908 654221

**Thank you very much for taking the time to read this information sheet and for considering taking part in this study.**
Appendix G
Information Sheet for Participants aged 13 to 17 years

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3585/Goodliffe

You will be given a copy of this information sheet

Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

We would like to invite you to take part in a research study to understand family members experiences of living with coeliac disease. You need to take part in the study with an adult with coeliac disease who you live with. Before you decide if you would like to take part it is important for you to know why the research is being carried out and what it would involve for you. Please take time to read the following information carefully and discuss with others. Ask the researcher, Samantha, if there is anything that is not clear or if you would like more information.

What is the purpose of this research?

We know that people with coeliac disease find it challenging at times. We also know that family members are important in providing practical and emotional support. We are conducting this study to understand what it is like for family members living with coeliac disease.

What will I have to do to take part?

If you agree to take part in this study, you and your family will meet Samantha either online via video calling or when safe to meet in person at your home or the Open University Milton Keynes. You and your parent or guardian will be asked to sign a consent form and to complete a short personal details questionnaire. This will take around 30 minutes depending on how many family members agree to take part. There are 2 activities for your participation in this research. First over 7 days we would like you to take photos that describe your everyday life living with coeliac disease. You can use your own device with a
camera. When able to, we can lend you a digital camera. You will need to ask permission to take photos of other people, these can be unidentifiable (e.g. photo taken from behind). Secondly you will be invited to an interview with Samantha where you will need to choose 7 photos to share. Before the interview your parent/guardian will need to send the photos electronically to Samantha. The interview will be arranged at a time convenient for you and will be held via online video calling or face-to-face. You are welcome to ask your Mum, Dad or guardian to sit with you. When able to it can be held at your home or a private room at the Open University Milton Keynes. The interview will last an hour and be audio recorded. Once the interview has been completed you will not be required to do anything else as part of this research.

What are the possible advantages of taking part?

We hope that people will find taking part in the research a good way to ensure their perspective is heard. It is hoped that what we find out in this research can be used to help improve services and support for families living with coeliac disease in the future. Some people feel good being listened to and talking about their own experiences.

What are the possible disadvantages of taking part?

We do not expect there to be any disadvantages to you in taking part but talking about living with coeliac disease may induce feelings. During the interview you do not have to talk about anything you do not want to. You are free to stop the interview without giving a reason at any point. Samantha will be happy for you to do this.

Will my taking part be kept confidential?

Yes, all personal information as well as the questionnaire and interview data will only be accessed by the researchers involved in the research. All the information you provide will be stored securely at the Open University either in locked cabinets or password protected electronic files. Your data will be stored with a code to ensure anonymity. Personal information (for example your name)
will be kept separately from your interview data. The interview recording will be typed-up with any identifying details, names and places changed to fake ones. The recording will then be deleted.

Following the research, we plan to publish the findings in academic and medical journals and present the research at talks and conferences. Direct quotes from interviews might be used however these quotes will not contain information that would enable you to be identified.

After the interview you will be asked if you would like to consent to the use of non-identifiable individual photos in publications and presentations.

The only limits to this confidentiality are if you were to tell us something that would be a reason for us to be worried about a wrongdoing or potential harm to yourself, or to someone else. In these circumstances it will important for us to share this information appropriately.

**What will happen if I don't want to carry on with the research?**

You may withdraw from this research at any time without giving reason. If you decide to withdraw during the research your information and any data will be destroyed. The only exception to this is the interview data. It will not be possible to withdraw this data more than 3 weeks after the interview as identifying details will have been changed. Ask your parent or guardian to tell Samantha by email or telephone if you want to withdraw from the research.

**What if there is a problem?**

If at any time during the research, you would like to comment or report a problem about any aspect then please ask your parent or guardian to contact Samantha Goodliffe

✉️ samantha.goodliffe@open.ac.uk or ☎️ 01908 655265 /07340 470448

or contact the researcher’s supervisor Dr Martin Robb

✉️ martin.robb@open.ac.uk or ☎️ 01908 654221
Thank you very much for taking the time to read this information sheet and for considering taking part in this research.
Appendix H
Information Sheet for Adult Participants

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3585/Goodliffe

You will be given a copy of this information sheet to keep

Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

We would like to invite you to take part in a postgraduate research study, funded by the Open University, to understand family members experiences of living with coeliac disease. Taking part in this study requires one adult with coeliac disease and a minimum of 1 other family member aged over 8 years, who normally live together. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss with others. Ask us if there is anything that is unclear or if you would like more information.

What is the purpose of this study?

We know that people with coeliac disease find it challenging at times. We also know that family members are important in providing practical and emotional support. We are conducting this study to understand what it is like for all family members living with coeliac disease.

What will I have to do to take part?

If you agree to take part in this study, you and your family will meet the researcher Samantha either an online video call or when safe to do so in person at your home or the Open University Milton Keynes. You will be asked to sign a consent form and to complete a short demographic questionnaire. This will take around 30 minutes depending on how many family members consent to take part. If you have family members aged under 16 years who want to take part in the study, you will need to provide consent for them. The questionnaire will take no longer than 5 minutes to complete.
Next for the following 7 days we would like you to take photographs that describe your everyday life living with coeliac disease. You can use your own device with a camera, such as a smart phone. When safe to do so we can lend you a digital camera. You will need to gain verbal consent to take photographs of other people, these can be unidentifiable (e.g. image taken from behind, or of their foot). You can take as many photographs as you like. You will need to choose 7 photographs to share with Samantha. For in person interviews these will be printed. How to share the photographs will be agreed at the first meeting.

During the interview you will be invited to talk about your photographs to Samantha. The interview will be arranged at a time convenient for you and will be held online or face-to-face. It can be held at your home, a private room at the Open University Milton Keynes or other mutually agreed location. The interview will take an hour and be audio recorded. Once the interview has been completed you will not be required to do anything else as part of this research.

**What are the possible advantages of taking part?**

We hope that people will find participating in the study a good way to ensure their perspective is heard. It is anticipated that the information from this study will help improve services and support for people in the future. Often people can find the experience of taking part positive and find the opportunity to talk about their own experiences beneficial.

**What are the possible disadvantages of taking part?**

We do not expect there to be any disadvantages to you in taking part but talking about living with coeliac disease may induce feelings. If you feel uncomfortable due to any topics raised let Samantha know. You are not required to discuss anything you do not want to. You are free to stop the interview without giving a reason at any point.

**Will my taking part be kept confidential?**

Yes, all personal information as well as questionnaire and interview data will only be accessed by the researchers involved in the study. All the information you provide will be stored securely at The Open University either in locked cabinets or password protected electronic files. A code will be attached to your
data so it remains anonymous. Personal information (for example your name) will be kept separately from your interview data. The interview will be audio recorded. The recording will be transcribed with any identifying details such as names and places anonymised. The recording will then be deleted.

Following the study, we plan to publish the findings in academic and medical journals and present the study at talks and conferences. Direct quotes from interviews might be used, these will not contain information that would enable you to be identified.

After the interview you will be asked if you would like to consent to the use of non-identifiable individual photographs in publications and presentations.

The only limits to this confidentiality from the researcher would be if you were to tell us something that would be a reason for us to be worried about potential harm to yourself, or to someone else or a wrongdoing. In these circumstances it would be important for us to share this information appropriately.

**What will happen if I don't want to carry on with the study?**

You may withdraw from this study at any time without giving reason. If you decide to withdraw during the study your information and any data will be destroyed. The only exception to this is the interview transcript. It will not be possible to withdraw this data more than three weeks after your interview as all identifiable details will have been changed. You can tell Samantha by email or telephone if you want to withdraw.

**What if there is a problem?**

If at any time during the study you would like to comment or report a problem about any aspect of this study then please contact Samantha Goodliffe

✉️ samantha.goodliffe@open.ac.uk or ☎️ 01908 655265 / 07340 470448

or contact the researcher’s supervisor Dr Martin Robb

✉️ martin.robb@open.ac.uk or ☎️ 01908 654221
Thank you very much for taking the time to read this information sheet and for considering taking part in this research.
Appendix I

Consent Form

Participants aged 8 to 16 years

Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3585/Goodliffe

Researcher: Samantha Goodliffe

✉ samantha.goodliffe@open.ac.uk 📞 01908 655265

Please complete this form with your parent/guardian after you have read the information sheet and asked any questions. You will be given a copy of this form to keep.

Please initial in box if you agree

- I have read and understood the information sheet dated 30/04/2020
- I have asked all the questions that I wanted to
- The questions have been answered in a way I understand
- I understand that taking part is voluntary and it is okay to change my mind and to stop taking part in the research at any time without giving a reason
- I understand that I need to take photographs to share with the researcher as part of this research
- I understand that taking part in the research involves a voice recorded interview
• I agree to the use of direct quotes in publications and presentations that are made anonymous

• I give permission for my interview transcripts to be stored with restricted access in the Open University specialist data centre for 10 years so it can be accessed by other researchers

• I agree to take part in the research

If any answers are ‘no’ you can ask more questions. It is okay not to participate. If you do want to participate in the research, please write your name, today’s date and sign below

Your name (please print):

_____________________________________________

Signature: _____________________________Date: __________

Your parent or guardian must write their name here too if they are happy for you to participate:

Print name:

________________________________________________

Signature: _____________________________Date: __________

The researcher who explained about participating in the research to you needs to sign too:

Print name: Samantha Goodliffe

Signature: _____________________________ Date: __________

Thank you 😊
Appendix J

Adult Informed Consent Form

Project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

This project has been reviewed by, and received a favourable opinion from The Open University Human Research Ethics Committee, reference HREC/3585/Goodlife

Researcher: Samantha Goodlife samantha.goodlife@open.ac.uk 01908 655265

Please complete this form after you have read the information sheet. You will receive a copy.

Please initial the appropriate box if you agree

I have read and understood the information sheet dated 30/04/2020

I have been given the opportunity to ask questions about the research and my questions have been answered to my satisfaction.

I understand that my taking part is voluntary and that I can withdraw from the study at any time without having to give a reason.

I understand that three weeks after the interview I will be unable to withdraw my data as any identifying data will be anonymised and amalgamated with other data.

I understand that taking part in the study involves taking photographs, sharing photographs with the researcher and an audio-recorded interview.

When taking photographs of other people I understand I need to ask for their permission and explain the photograph is for a research study and will be shared with a research team.

I agree to the printing of my photographs.

I understand my personal information, such as phone number and address, will not be shared beyond the research team.

I agree to the use of direct quotes in publications (including a thesis), presentations and other research outputs provided anonymity is preserved.

I give permission for the interview data (pseudonymised transcripts) that I provide to be deposited under restricted access in the Open University specialist data centre for a minimum of 10 years.

I consent to other family members taking my photograph as part of the study.

If you would like to receive a summary of the final research findings, please provide the address (small or post) to send them: ________________________________

Print name: __________________________________________

Signature: __________________________________________ Date: ________________

Researcher name: Samantha Goodlife Signature: ________________ Date: ________________

Adult consent form V1 30.04.20
Appendix K
Participant code: ______

Demographic Questionnaire

Participants aged 8 – 18 years

Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3585/Goodliffe

Please circle your answer or write your answer in the space provided, thank you

Your age (years) ___________ How many people live in your family home? ______

How many brothers and sisters do you have? ______

How do you describe your gender?  Girl  Boy  Man  Woman
Prefer not to say

A gender not listed here  I don’t know  Don’t understand the question

How do you describe your ethnicity?

<table>
<thead>
<tr>
<th>White</th>
<th>Black or Black British</th>
</tr>
</thead>
<tbody>
<tr>
<td>British</td>
<td>Caribbean</td>
</tr>
<tr>
<td>Irish</td>
<td>African</td>
</tr>
<tr>
<td>Any other white background</td>
<td>Any other Black background</td>
</tr>
<tr>
<td>Mixed</td>
<td>Asian or Asian British</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>Indian</td>
</tr>
<tr>
<td>White and Black African</td>
<td>Pakistani</td>
</tr>
<tr>
<td>White and Asian</td>
<td>Bangladeshi</td>
</tr>
<tr>
<td>Any other mixed background</td>
<td>Any other Asian background</td>
</tr>
<tr>
<td>Other Ethnic groups</td>
<td>Prefer not to say</td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
</tbody>
</table>
Any other ethnic group

Do you have coeliac disease? Yes No

Do you have any other long-term health condition? Yes No

Thank you 😊 for completing the questionnaire
Appendix L

Participant code: ______

Demographic Questionnaire

Adult Participants

Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3585/Goodliffe

Please circle your answer or write your answer in the space provided, thank you

Your age (years) ________ How many people live in your family home? ________

How do you describe your gender? Man Woman Prefer not to say

A gender not listed here I don’t know Don’t understand the question

How do you describe your ethnicity?

White Black or Black British

  British Caribbean
  Irish African
  Any other white background Any other Black background

Mixed Asian or Asian British

  White and Black Caribbean Indian
  White and Black African Pakistani
  White and Asian Bangladeshi
  Any other mixed background Any other Asian background

Other Ethnic groups

  Chinese Prefer not to say
  Any other ethnic group

What is your relationship status?

Single Co-habiting Widowed Divorced/separated Married
If in a relationship, please state the number of years you have lived together ______

Do you have any long-term health conditions?  Yes  No

What is your occupation? ______________________________________________________

Thank you for completing the questionnaire 😊
Appendix M

Participant code: ______

Demographic Questionnaire

Adult CD Participants

Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3585/Goodliffe

Please circle your answer or write your answer in the space provided, thank you

Your age (years) ______ How many people live in your family home? ______

How do you describe your gender? Man Woman Prefer not to say

A gender not listed here I don’t know Don’t understand the question

How do you describe your ethnicity?

White

<table>
<thead>
<tr>
<th>British</th>
<th>Caribbean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irish</td>
<td>African</td>
</tr>
<tr>
<td>Any other white background</td>
<td>Any other Black background</td>
</tr>
</tbody>
</table>

Mixed

| White and Black Caribbean | Indian |
| White and Black African  | Pakistani |
| White and Asian          | Bangladeshi |
| Any other mixed background | Any other Asian background |

Other Ethnic groups

<table>
<thead>
<tr>
<th>Chinese</th>
<th>Prefer not to say</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any other ethnic group</td>
<td></td>
</tr>
</tbody>
</table>
What is your relationship status?

Single  Co-habiting  Widowed  Divorced/separated  Married

If in a relationship, please state the number of years you have lived together

____

*Please turn over*

How long have you been diagnosed with coeliac disease? ________ years

Does anyone else in your family have coeliac disease?  Yes  No

Do you have any other long-term health condition(s)?  Yes  No

What is your occupation?

______________________________________________

Thank you for completing the questionnaire 😊
Appendix N
Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

Children (8-12 years) interview topic guide

Introduction

Thank you for agreeing to take part in this interview.

- Before we start there are a few things I would like to mention. I am a PhD student studying at the Open University and this research is part of my thesis.
- The interview will last no longer than one hour.
- With your permission, I would like to audio record our interview today. This is for analysis and transcription purposes only. Is this okay with you?
- I will keep your information anonymous and confidential at all times. Your real name and the names of any others or places won’t be used when the interview is transcribed.
- As the interview is being transcribed and any real names replaced with pretend names you will only have three weeks from today to withdraw your interview data.
- You will select the photographs you want to talk about.
- As a reminder if I ask a question you do not want to answer please say or show this red card and we can move onto the next question. You have the right to stop the interview at any point and withdraw from the research, please tell me and we will stop.
- If you would like, you can have a parent or guardian to sit with you.
- Do you have any questions before we start?

Photo-elicitation guide (interview questions)

Questions will be based around photographs so participants will be asked to lay their photographs out and select one they would like to share with researcher first.

What was it like taking the photographs?
How did you decide on which photographs to share with me?

Thank you for sharing your photographs with me, would you like to choose one to tell me about?

Can you tell me about this photograph? Prompts; why did they choose to take that photo; what was going on around them at the time; how were they feeling at the time; how does looking at the photo now make them feel

Additional questions if needed;

- How much of your time does school and study take up?
- What do you like doing with your family?
- Can you tell me about food in your daily life before the outbreak and now?
- What do you do in your spare time?
- Can you tell me about what you like to do with your friends?
- What do you think about wellbeing?

Is there anything you have not taken a photograph of that you wanted to but didn’t?

Closing and ending

That is the end of my questions. Is there anything else you would like to add that you feel we have not covered?

Thank you very much for sharing your photographs and thoughts and experiences with me today. What you have told me will really help us to understand people’s experiences of living with coeliac disease.

- Are there any comments you would like to add?

We will now end the interview. With your permission I would like to talk about sharing the photographs with me, is that okay with you?

- Share via limited copyright for the purposes of education and dissemination including an exhibition.
- Will not include any identifiable photographs.
- Not be shared with anyone else or allowed to be used.
- The photographs will be securely stored.
• Complete the photographic permission form
• Are there any final comments you would like to make?
• Is there anything you would like to ask me?

Thank you
Appendix O
Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

Young person (12-17 years) interview topic guide

Introduction

Thank you for agreeing to take part in this interview.

- Before we start there are a few things I would like to mention. I am a PhD student studying at the Open University and this research is part of my thesis.
- The interview will last no longer than one hour.
- With your permission, I would like to audio record our interview today. This is for analysis and transcription purposes only. Is this okay with you?
- I will keep your information anonymous and confidential at all times. Your real name and the names of any others or places won’t be used when the interview is transcribed.
- As the interview is being transcribed and fake names used you will only have three weeks from today to withdraw your interview data.
- You will select the photographs you want to talk about.
- As a reminder if I ask a question you do not want to answer please say or show this red card and we can move onto the next question. You have the right to stop the interview at any point and withdraw from the research, please tell me and we will stop.
- If you would like to you can have a parent or guardian to sit with you.
- Do you have any questions before we start?

Photo-elicitation guide (interview questions)

Questions will be based around photographs so participants will be asked to lay their photographs out and select one they would like to share with the researcher first.

What was it like taking the photographs?

How did you decide on which photographs to share with me?
Thank you for sharing your photographs with me, would you like to choose one to tell me about?

Can you tell me about this photograph? Prompts; why did they choose to take that photo; what was going on around them at the time; how were they feeling at the time; how does looking at the photo now make them feel

Additional questions if needed;

- How much of your time does school and study take up?
- How often do you get to see your friends?
- What do you do in your spare time?
- Can you tell me about food before the outbreak in your normal daily life and now?
- How do you look after your wellbeing?

Is there anything you have not taken a photograph of that you wanted to but didn’t?

Closing and ending

That is the end of my questions. Is there anything else you would like to add that you feel we have not covered?

Thank you very much for sharing your photographs and thoughts and experiences with me today. What you have told me will really help us to understand people’s experiences of living with coeliac disease.

- Are there any comments you would like to add?

We will now end the interview. With your permission I would like to talk about sharing the photographs with me, is that okay with you?

- Share via limited copyright for the purposes of education and dissemination including an exhibition.
- Will not use any identifiable photographs.
- Not be shared with anyone else or allowed to be used.
- The photographs will be securely stored at the Open University
- Complete the photographic permission form
- Are there any final comments you would like to make?
• Is there anything you would like to ask me?

Thank you
Appendix P
Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

Adult interview topic guide

Introduction

Thank you for agreeing to take part in this interview.

- Before we start there are a few things I would like to mention. I am a PhD student studying at the Open University and this research is part of my thesis.
- The interview will last no longer than one hour.
- With your permission, I would like to audio record our interview today. This is for analysis and transcription purposes only. Is this okay with you?
- I will keep your information anonymous and confidential at all times. Your real name and the names of any others or places won’t be used when the interview is transcribed.
- As the interview is being transcribed and any identifying names of people and places changed you will only have three weeks from today to withdraw your interview data.
- You will select the photographs you want to talk about.
- As a reminder if I ask a question you do not want to answer just say so and we can move onto the next question. You have the right to stop the interview at any point and withdraw from the research, just tell me and we will stop.
- Children will be reminded they can have a parent or guardian to sit with them
- Do you have any questions before we start?

Photo-elicitation guide (interview questions)

Questions will be based around photographs so participants will be asked to lay their photographs out and select one they would like to share with researcher first.

What was it like taking the photographs?
How did you decide on which photographs to share with me?

Thank you for sharing your photographs with me, would you like to choose one to tell me about?

Can you tell me about this photograph? Prompts; why did they choose to take that photo; what was going on around them at the time; how were they feeling at the time; how does looking at the photo now make them feel.

Additional questions if needed;

- Are you/family member taken seriously?
- Do you have to plan outings/holidays/social events?
- What is the impact of food on your daily life before the pandemic and now?
- Are there any practical challenges you face?

Is there anything you have not taken a photograph of that you wanted to but didn’t?

Closing and ending

That is the end of my questions. Is there anything else you would like to add that you feel we have not covered?

Thank you very much for sharing your photographs and thoughts and experiences with me today. What you have told me will really help us to understand people’s experiences of living with coeliac disease.

- Are there any comments you would like to add?

We will now end the interview. With your permission I would like to talk about sharing the photographs with me, is that okay with you?

- Share via limited copyright for the purposes of education and dissemination including an exhibition.
- Not be shared with anyone else or allowed to be used for any other purpose.
- The photographs will be securely stored at the OU
- Complete the photographic permission form
- Are there any final comments you would like to make?
• Is there anything you would like to ask me?

Thank you
Photograph Consent Form (8-17 years)

Research project: Exploration of the psychosocial impact of living with coeliac disease; the lived experience of family members

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3055/Goodlife

Researcher: Samantha Goodlife samantha.goodlife@open.ac.uk 01908 655265

This form is to be completed by young people aged 16 years and under with their parent or guardian.

This form refers to photographs you took as part of the family members lived experience of coeliac disease. All the photographs will be securely stored by the research team. We would also like to use some of the photographs in presentations, publications and an exhibition arising from the project with your permission. Please indicate in one of the boxes below whether you are happy for us to do this. We have numbered the photographs to assist you. We won’t use any photographs outside the research team without your permission.

Please sign either 1 or 2 below

1. We give my consent for these photographs to be reproduced for educational purposes, in presentations, publications and an exhibition connected to the research. We understand that real names will not be used with the photographs. Please list the numbers of the photographs you give us permission to use, and where they can be used.

Please place a cross in the relevant box

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<th>Publications</th>
<th>Exhibition</th>
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If you allow your photographs to be used please write you name below, sign and today’s date.

Your name (please print) ____________________________

Signed: ____________________________ Date: ____________________________

Your parent/guardian must write their name here too if they are happy for you to share your photographs,

Name (please print) ____________________________

Signed: ____________________________ Date: ____________________________