

Are We There Yet: Self-Management of Long-Term Physical Conditions During Emerging Adulthood

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy (PhD) is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

Signed: Orla Mooney ID No.: 16212969 Date: 01st June 2025

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Dedication

This thesis is dedicated to all the young people in Ballymun, especially my friends who died too young. I wish society didn't make it so hard for you to achieve your dreams. You motivate me every day to try make society one that works hard to lift people out of poverty and provide equal opportunities for every person, not just some. This is for you.

“Overcoming poverty is not a gesture of charity. It is an act of justice. It is the protection of a fundamental right to dignity and a decent life”

Nelson Mandela.

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List of Abbreviations

Abbreviation	Associated Word
AUDIT	Alcohol Use Disorders Identification Test
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CWP	Communication with Physicians
DWLS	Diagonal of the Weight Matrix for Estimation
ERSI	The Economic and Social Research Institute
GDPR	General Data Protection Regulation
GFI	Goodness-of-Fit Index
GUI	Growing Up in Ireland
HSE	The Health Service Executive
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
IDEA	Inventory of the Dimensions of Emerging Adulthood
ISRI	Identity Stage Resolution Index
LTPC	Long-Term Physical Conditions
MG-CFA	Multi-Group Confirmatory Factor Analysis
MMAT	Mixed Methods Appraisal Tool
MSPSS	Multidimensional Scale of Perceived Social Support
NHS	The National Health Service
no-LTPC	No Long-Term Physical Condition
OECD	The Organisation for Economic Cooperation and Development
PMCSMS	Perceived Medical Condition Self-Management Scale

PPI	Public and Patient Involvement
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analysis
QUAL	Qualitative
RMSEA	Root Mean Square Error of Approximation
SEM	Structural Equation Modelling
SEN	Special Education Needs
SRMSR	Standardized Root Mean Square Residual
SSRQ	Short-Form Self-Regulation Questionnaire
TLI	Tucker–Lewis Index
WLSMV	Weighted Least Squares Means and Variances

Abstract

Thesis Title: Are We There Yet: Self-Management of Long-term Physical Conditions during Emerging Adulthood

PhD Candidate: Orla Mooney

Self-management is a dynamic process of self-regulation by a person to manage the day-to-day consequences of living with long-term physical conditions (LTPC). Emerging adulthood, the transition between adolescence and adulthood, is a time of optimism with many life transitions, that brings different challenges and responsibilities. Arnett's Theory of Emerging Adulthood identifies five distinctive features of this developmental stage: identity exploration, instability, self-focus, feeling in-between, and possibilities. Across three studies, this research aimed to examine do emerging adults with and without LTPC differ in the distinctive features of emerging adulthood, and how do these features influence self-management behaviours among those living with LTPC. The first study, a systematic review of 30 papers found that emerging adults living with LTPC experience the five features of emerging adulthood within the context of their self-management, but that emerging adulthood can pose distinctive challenges to successful self-management, highlighting a need for comparative, quantitative research between emerging adults living with and without LTPC. Consequently, the second study, a secondary analysis of the Growing Up in Ireland dataset (n=4788), examined and found differences in those living with LTPC and their peers on factors linked with the five features of emerging adulthood. The third study, a cross-sectional survey (n=642) specifically examined Arnett's features of emerging adulthood in emerging adults living with and without LTPC and the relationship between emerging adulthood and self-management for those living with LTPC. Whilst emerging adults with LTPC experience emerging adulthood similarly to their peers, those with higher levels of instability reported a lower ability to self-manage their condition. This thesis provides valuable evidence that for emerging adults living with LTPC, the developmental stage of emerging adulthood can act as a risk factor for the self-management of their LTPC. These findings can inform future research, healthcare practice and government policy.

Chapter 1: Introduction

1.1 Overview of this Chapter

This multi-study thesis aims to address the research question: do emerging adults with and without long-term physical conditions (LTPC) differ in the distinctive features of emerging adulthood, and how do these features influence self-management behaviours among those living with LTPC. This chapter begins by defining long-term physical conditions and introducing the concept of self-management, including its relevance to managing long-term physical conditions across developmental stages. Key theories underpinning self-management are also introduced, along with challenges in researching and implementing self-management. Following this, Arnett's Theory of Emerging Adulthood is introduced, detailing its five distinctive features: identity exploration, instability, self-focus, feeling in-between, and possibilities. Finally, an overview of the current thesis, outlining its aims, rationale, and structure is presented.

1.2 Long-term Physical Conditions

LTPC are those that last for more than six months and up to a lifetime; therefore, they are prolonged and rarely cured completely (World Health Organisation, 2014; Stanton et al., 2006). Due to their prolonged nature, LTPC often require continuous management to mitigate their impact on a person's ability to function normally. Management of these conditions frequently involves the use of medication and/or other therapeutic interventions to control symptoms and improve quality of life (NHS, n.d.a). Some of the most common LTPC include cardiovascular diseases such as hypertension, chronic pain conditions like arthritis, respiratory illnesses such as asthma, diabetes, and neurological disorders like epilepsy (Dowrick et al., 2005; World Health Organisation, 2023). Within the literature there is

different terminology used in relation to health conditions, for example, disability, chronic illness, or chronic condition. The Health Service Executive (HSE) of Ireland uses the term long-term health condition to cover both long-term conditions (which are not always chronic) and chronic health conditions (HSE, n.d.a). For this thesis, this term is adapted to long-term physical condition (LTPC) to distinguish it from long-term mental health conditions.

Advancements in medicines, medical technology, and non-medical treatments throughout the 20th and 21st centuries have significantly contributed to an overall increase in life expectancy for individuals living with and without LTPC (Grady & Gough, 2014; Partnership for Solutions, 2004). Despite persistent health inequalities across the European Union (Mazeikaite et al., 2021), there have been notable improvements in public health outcomes. For example, the child mortality rates have decreased, falling from 12 to four per 1,000 live births between 1990 and 2020, while the probability of death among five to fourteen-year-olds dropped from 1.25 to 0.45 per 1,000 during the same period. Similarly, for those aged 20 to 24, the probability of dying decreased from 4.4 to 1.8 per 1,000 (The World Bank, 2020). Furthermore, the proportion of the population aged 65 and over in OECD countries is projected to double to 28% by 2050 (OECD Library, 2020). This increase in life expectancy has resulted in more individuals who were born with or acquired LTPC earlier in life living longer (Dowrick et al., 2005; Grady & Gough, 2014), and a rise in the number of individuals who develop LTPC later in life (Partnership for Solutions, 2004). For example, in Ireland, the prevalence of long-term conditions has steadily increased across the first four waves of the Irish Longitudinal Study on Ageing (TILDA), a longitudinal study examining the ageing population over the age of 50 (Turner et al., 2018). Additionally, there has been an increase in the prevalence of multimorbidity, where individuals live with multiple long-term conditions simultaneously (Salive, 2013).

The global disease burden of disability has significantly increased from 21% in 1990 to 34% in 2019 (Institute for Health Metrics and Evaluation, 2020) with long-term conditions (both physical and mental) accounting for 80% of this burden and approximately two-thirds of all deaths within the European Union (European Commission, 2022a). Individuals living with LTPC often present with complex healthcare needs, such as the management of multiple symptoms and multimorbidity, which necessitates frequent interactions with healthcare professionals (Salive, 2013; Turner et al., 2018). Consequently, LTPC represent the primary reason for healthcare visits in many countries, placing additional strain on already over-stretched healthcare systems and contributing to substantial government healthcare expenditures (OECD Library, 2020). For example, in Ireland, chronic non-cancer pain affects between 13 and 36% of the population (Raftery et al., 2011), imposing a significant financial burden on the healthcare system with a mean cost of €5,665 per patient per year (Raftery et al., 2012). In addition, across 30 OECD countries, conditions such as diabetes, asthma, chronic obstructive pulmonary disease, heart failure, and hypertension account for 5.8% of hospital bed days and, in 2016 alone, these conditions cost an estimated 21.1 billion US dollars (OECD Library, 2020).

For individuals living with LTPC, it can profoundly affect their lives as they adjust to new challenges, such as cognitive or physical impairments, adverse health risk behaviours, and sleep-related issues like insomnia (Megari, 2013). These conditions can also be significant sources of stress, leading to an increased risk of psychological issues such as anxiety and depression (Compas et al., 2012). For young adults who experienced the onset of LTPC during childhood, the impact can extend into various life domains, resulting in poorer overall educational and vocational outcomes (Maslow et al., 2011). A systematic review found that poor health during adolescence is linked to adverse outcomes in adulthood, including future unemployment, dependence on welfare, and reduced overall earnings when

compared to healthy peers (Hale et al., 2015). This means that alongside physical and mental challenges, there is an increased risk of economic hardship of having LTPC. For example, in Ireland, the estimated annual cost of living with a disability, depending on the severity of the condition, ranges from €8,700 to €12,300 (Indecon International Research Economists, 2021) and in the UK, it is approximately £12,120 (Wright et al., 2024). The extra cost of having a disability can lead to poverty and social exclusion (Indecon International Research Economists, 2021). The need to navigate a combination of these challenges can negatively impact the quality of life and overall well-being of those living with LTPC (De Ridder et al., 2008; European Commission, 2022b). For example, a systematic review found a substantial reduction in health-related quality of life associated with 308 different long-term conditions (Van Wilder et al., 2019).

Overall, the diagnosis of LTPC often marks the beginning of an extended process of treatment and adjustment, as individuals and their families navigate the disruptions to everyday life that accompany such conditions (Compas et al., 2012). These adjustments to living with LTPC span multiple life domains such as employment and family life, and can occur at varying times, with significant heterogeneity in how individuals adapt (Stanton et al., 2006). This process of adjustment requires a person to actively participate in managing their condition to maintain independence and enhance their quality of life over extended periods (Gray & Gough, 2014). Achieving a better quality of life, while also addressing the economic and service costs to healthcare systems, requires a unique and multidisciplinary approach that involves patients, their families, and health professionals in managing both the physical and psychological symptoms of LTPC (Dowrick et al., 2005; OEDC Library, 2021). Self-management is one such multidisciplinary approach, offering a sustainable strategy for the ongoing management of LTPC. By empowering individuals to take control of their health, self-management not only can improve symptom management, self-efficacy, knowledge and

acceptance of condition, and relationships with healthcare professionals which can all lead to an improvement in their quality of life, but it can also alleviate the burden on healthcare systems (Dowrick et al., 2005; De Silva, 2011).

1.3 What is Self-Management

Despite extensive research over the past 50 years, there remains a lack of consensus on a universal definition of self-management (Ellis et al., 2017). This challenge arises from the varied operationalisations of self-management across numerous studies, the application of over 80 different behaviour-change theories, and the diverse range of outcome measures used in self-management research (Velde et al., 2019). Across the literature, self-management has been described as a dynamic process of self-regulation (Schulman-Green et al., 2012), where an individual manages the day-to-day effects of living with LTPC (Barlow et al., 2002). This process involves using core self-management skills tailored to the individual, including problem-solving, decision-making, resource utilisation, forming of a patient/healthcare provider partnership, and taking action (Lorig & Holman, 2003). Lorig and colleagues' work on self-management programmes and the identification of these core skills has arguably made the most significant contribution to operationalising the concept of self-management (Bauer et al., 2023).

Individuals who self-manage recognise it as an ongoing process of inner negotiation, balancing contrasting perspectives that can have both pros and cons. These contrasts might include “being well today” versus being “well in the future,” or addressing social needs versus medical needs (Audulv et al., 2009). This means there is a vast range of self-management strategies that individuals living with LTPC use in their lives, and they do not progress through either their condition or its management in a linear way. The need for self-

management can also change over time, such as, with a progressive condition or as newer medical treatments become available (Audulv et al., 2011; Audulv, 2013).

Audulv et al. (2011) found that over a three-year period, self-management is an ongoing process involving continuous and dynamic cycles. Initially, individuals seek effective strategies, experimenting with different methods to find what works best. This phase is marked by trial and error. Once strategies are identified, the next phase involves weighing the costs against the benefits, evaluating the effort required versus the inconvenience or potential side effects. This cost-benefit analysis helps individuals decide which strategies are sustainable. Following this, routines and action plans are created to incorporate these strategies into daily life, such as taking medication with breakfast or developing a plan for managing a pain flare-up. Finally, there is ongoing negotiation to fit self-management into daily life, continually adjusting practices as circumstances change (e.g., new symptoms). This fluid, non-linear process emphasises the evolving nature of self-management over time.

Several barriers and facilitators to self-management have been identified, for example, age of diagnosis, type of LTFC, personal beliefs (e.g., perceived control), relationships with healthcare professionals and social support (Schulman-Green et al., 2016). The age of diagnosis can influence self-management, for example, individuals diagnosed as children might have better self-management due to more years of experience with self-management activities (Chao et al., 2014). Alternatively, individuals diagnosed as children may have acquired self-management habits from their parents in comparison to those diagnosed in adolescence or emerging adulthood where they may have a more active role in their self-management (Chao et al., 2014). In terms of type of LTFC, individuals living with progressive and degenerative conditions such as multiple sclerosis and Parkinson's disease experience unpredictability and complex progression that can require more targeted self-management support that requires more regular adjustments than a standardised approach

(Kulnik et al., 2019). In general, individuals living with LTPC have reported how important knowledge is as the basis for their self-management. This knowledge includes understanding the condition itself, the medication and treatment plan, and how to apply this information to their daily lives (Ko et al., 2018; Schulman-Green et al., 2016). Having knowledge can increase confidence in the positive effects of self-management, such as improved well-being and symptom control. This is a key motivator for the continuation of self-management behaviours (Audulv et al., 2009; Audulv et al., 2011). Effective self-management can provide individuals with a sense of control over their lives, improving overall quality of life (Velde et al., 2019).

Self-management places the patient at the centre of managing their long-term condition and it usually involves collaboration with healthcare professionals (Dowrick et al., 2005; Ryan & Sawin, 2009). This collaboration can very much act as a barrier or facilitator (Franklin et al., 2018; Schulman-Green et al., 2016). One factor is that many healthcare professionals still favour the traditional model of care, which involves providing generic, biomedical self-management information. Furthermore, due to time pressures, there can be a lack of consideration for the additional psychosocial issues that individuals can face (Franklin et al., 2018). However, self-management is enhanced when the relationship with healthcare professionals becomes a collaboration and is perceived as trusting, tailored, empathetic, and positive, with continuity of care (Franklin et al., 2018; Noordman et al., 2024). When healthcare professionals are trained and actively engage in a collaborative approach, it can lead to positive self-management outcomes such as improved self-efficacy, autonomy, and motivation to change (Noordman et al., 2024; Rochfort et al., 2018; Vainauskienė & Vaitkienė, 2021).

Self-management is also widely influenced by social support (Grey et al., 2006; Grey et al., 2015; Kelly & Berg, 2021; Ryan & Sawin, 2009). Social support can help to form a

collective network and when it has a positive influence, there is a collective efficacy, wherein a shared capacity for self-management is developed through mutual effort, support, perseverance, and influence (Vassilev et al., 2014). Within the family context, sharing self-management responsibilities or providing support can reduce feelings of isolation and enhance well-being and confidence, especially when family members promote autonomy (Whitehead et al., 2018). However, it can also present obstacles, such as a person feeling a loss of control over their life, if support is too invasive (Vassilev et al., 2014). The self-management process evolves over time, affecting both the individual and their family in diverse ways (Kelly & Berg, 2021; Ryan & Sawin, 2009). Social support is an interactive process, with the person living with LTPC assuming varying levels of responsibility over time, contingent on their willingness, ability, and the complexity of their condition (Schulman-Green et al., 2012). For example, the need for social resources varies across developmental stages such as adolescence or emerging adulthood (Wiebe et al., 2016).

To consolidate the extensive research on self-management, Velde et al. (2019) used Walker and Avant's eight-step concept analysis to propose a universally accepted definition. They identified ten attributes of self-management, categorised into three groups. Group A encompasses person-oriented attributes, where the individual (1) actively participates, (2) takes responsibility for the process, and (3) positively copes with adversity. Group B includes person-environment-oriented attributes, requiring that (4) the individual be educated about their condition; (5) self-management should be individualised; (6) there should be openness to fostering a partnership with healthcare providers; and (7) openness to social support. Group C summarises these attributes, highlighting that self-management (8) is a lifelong task that can fluctuate; (9) necessitates personal skills like problem-solving, decision-making, resource utilisation, forming a patient/healthcare provider partnership, and taking action; and (10) involves managing medical aspects, role management, and emotional management.

Based on these attributes, they define self-management as “the intrinsically controlled ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of their long-term condition(s) in partnership with their social network and the healthcare provider(s)” (Velde et al., 2019, p. 10).

1.4 Self-Management and Developmental Stage

Development is a lifelong process involving continuous changes in biological, socioemotional, and cognitive domains, all of which interact and influence each other (Kuther, 2017). The development of self-management expertise occurs over time as individuals move through various developmental stages, and each can pose different challenges (e.g., childhood, adolescence, emerging adulthood) that can affect the extent to which self-management responsibility is individual or shared with others, such as family (Clay et al., 1995; McCarthy & Grey, 2018; Paterson & Thorne, 2000). This means that it is unlikely that a single approach to self-management would be effective across all developmental stages (McCarthy & Grey, 2018). For example, young children often rely heavily on their parents or caregivers (Lewis et al., 2010). These parental figures play a significant role in ensuring treatment plans are followed and appropriate lifestyle choices are made (Camfield et al., 2017). Then, during the transition from childhood to adolescence, adolescents grapple with rapid social, biological, and psychological changes while also striving for increased independence from their parents or caregivers (Lewis et al., 2010).

Taking diabetes management as an example, parents typically handle much of the diabetes care for children aged 8 to 11 years. As the child moves towards 15 years of age, the challenge becomes gradually transferring some responsibilities to the adolescent, while parents continue to monitor and support this transition (Schilling et al., 2006). At this stage, adolescents may begin to take responsibility for bolusing and insulin dosing during the

daytime, while parents might retain responsibility for night-time management. While early adolescents may still seek emotional support from their parents, as they progress through adolescence, peer relationships gain importance, and the need for peer support from friend groups rises (Oris et al., 2016). For example, in a study on type 1 diabetes, adolescents in comparison to children reported significantly more peer support from friends for self-management tasks (Pendley et al., 2002).

These social relationships can serve as either risk or protective factors for health outcomes. For example, higher levels of relationship conflict and fewer social connections are risk factors associated with negative health outcomes, such as poorer self-management, even premature mortality (Holt-Lunstad, 2018). In addition, while peers can offer valuable support, they may also lack the necessary knowledge about the condition, especially about long-term outcomes, leading to inconsistent or detrimental support (Pendley et al., 2002). As adolescents reach 15 to 17 years, their independence in managing their condition continues to grow, peer networks grow, yet parents often remain involved by attending medical appointments, providing reminders to manage glucose levels, and handling tasks like sourcing and paying for prescriptions, representing a more shared approach to self-management (Schilling et al., 2006).

The transfer of self-management between parent and child is a socially complex process and may become more so, with the transfer to adult services between the ages of 16 – 21 years. During this period, the person with an LTTC becomes legally responsible for their own healthcare decisions, marking a significant shift in their self-management journey (Campbell et al., 2016; Giarelli et al., 2008). This transition is further complicated by the expansion of their social and support networks beyond the family, as they move into new environments such as college or the workplace. At this stage, they are likely to increase contact with peers and may begin to develop long-term romantic relationships, all while

trying to establish a community of peers and forge strong emotional ties (Wiebe et al., 2016; Hopmeyer et al., 2022).

Emerging adulthood (18-29 years) is a newer developmental stage (see section 1.7) and for emerging adults living with LTPC, they may maintain a reasonable overall quality of life, but their self-management may suffer due to the many transitions they face (McCarthy & Grey, 2018). As they progress into young and middle adulthood, they may encounter challenges in balancing work and family life, such as raising children, which can lead to a reduction in quality of life. For older adults, the challenges often intensify with increased comorbidities and cognitive decline, necessitating greater external support (McCarthy & Grey, 2018). Research examining self-management across the lifespan indicates that emerging adulthood requires more focused attention. Understanding self-management during this developmental stage, especially in relation to social support, is important for improving outcomes and ensuring better management of LTPC (Kelly & Berg, 2021; McCarthy & Grey, 2018).

1.5 Key Self-Management Theories and Frameworks

There are many psychological theories, frameworks and models of behaviour change informing self-management research (Mitchie et al., 2014). This thesis is informed by Social Cognitive Theory (Bandura, 1977), Self-Regulation Theory (Kanfer & Gaelick, 1991), and the Self and Family Management Framework (Grey et al., 2006; Grey et al., 2015). These theories and the framework have broad applicability to various LTPC and are widely used within the self-management literature.

1.5.1 Social Cognitive Theory

Social cognitive theory in relation to health postulates that individuals can achieve better health and longevity through self-management, specifically by exercising control over their health habits (Bandura, 1998) and is a cornerstone for self-management (Allegrante et al., 2019). Lorig and Holman (2003) found through their extensive research on self-management that enhanced self-efficacy is a core mechanism driving changes in health status within self-management interventions. The importance of self-efficacy and belief in capabilities is consistently highlighted in the research literature as fundamental components or prerequisites for effective self-management (Cane et al., 2012; Ko et al., 2018; Velde et al., 2019). Additionally, self-efficacy is often defined as a critical outcome in self-management interventions that include specific techniques designed to enhance it (Velde et al., 2019). A review also identified Social Cognitive Theory as one of the most prevalent theories underpinning self-management measurement tools. It found that many measures are based on the definition of self-efficacy, with 10 out of 28 measures reviewed directly underpinned by the theory (Packer et al., 2018).

The concept of self-efficacy suggests that belief in one's capabilities is a predictor of motivation and behaviour. This belief can be enhanced through mastery, modelling, reinterpretation, and social persuasion, leading to improved behaviour, thinking, motivation, and emotional well-being (Bandura, 1977). An individual's belief in their personal efficacy can influence self-monitoring and the processing of performance and outcome expectations. The more capable someone believes they are, the higher the goals they set, the more committed they remain, the more they review their progress, and they attribute failure to poor effort or deficient strategies, prompting adjustments (Bandura, 1998).

Social Cognitive Theory provides a framework for understanding that behaviours, the environment, and personal factors are determinants of each other, known as triadic

reciprocity. It highlights an individual's capability to regulate their emotions, cognitions, and behaviours and apply these to specific goals or problems (Lansing & Berg, 2014). The theory involves using basic capabilities supported by self-efficacy (Bandura, 1986).

Symbolising capability is the ability to transform experiences into mental models or symbols for future behaviour. Forethought capability is the ability to regulate behaviour with future thinking, involving anticipation, planning, and goal-setting. Vicarious capability is the ability to learn through modelling. Self-regulatory capability is the ability to motivate and regulate behaviour. Self-reflective capability involves analysing experiences through reflection and evaluation (Bandura, 1986).

For example, a person with chronic lower back pain who experiences regular flare-ups pays close attention to sensations, triggers, and context, noting that pain worsens after heavy lifting but eases with stretching. Using symbolising capability, they mentally categorise these experiences into a model of pain patterns and coping strategies. This framework helps them understand that heavy lifting intensifies pain, while stretching offers relief. Through forethought, they plan to mitigate flare-ups by assessing potential risks and preparing for triggers, such as pacing themselves or seeking assistance with lifting. By engaging in a pain management support group, they learn new techniques (vicarious capability) like safer lifting methods. Self-regulation is evident in their proactive monitoring and adjustment to pain levels, taking breaks when needed, and seeking additional resources. Self-reflection deepens their understanding of pain's impact on relationships, mood, and energy, helping them identify where more support could improve their quality of life.

1.5.2 Self-Regulation Theory

Self-Regulation Theory involves the cognitive processes by which individuals regulate or control their behaviour, motivated by a specific goal or endpoint (Kanfer &

Gaelick, 1991). Self-regulation is particularly needed when new behaviours are not yet automated, as there is a risk of reverting to prior behaviour when maintaining the new behaviour is what is required, such as sustaining a new exercise regime (Rothman, 2000). Once behaviours are automated, they require less attention, are harder to change, and can be performed alongside other activities. However, if new behaviours are needed, if goals are blocked, or if habitual responses are ineffective, self-regulation processes are initiated (Kanfer & Gaelick, 1991). Three sources of control interact to determine behaviour: the immediate environment, the biological system, and cues (Kanfer & Gaelick, 1991). For example, a person living with chronic back pain might use ergonomic equipment (immediate environment) to engage in work, take medication and practice mindfulness (biological system) to help regulate pain, and use reminders (cues) to take breaks. Situations like needing to work overtime might require changes in any of these sources, demonstrating the dynamic and fluctuating nature of self-regulation over time (Kanfer & Gaelick, 1991).

Self-regulation skills are central to successful daily self-management, for example, coordinating emotions (e.g., managing embarrassment), cognitions (e.g., making health-related judgements) and behaviours (e.g., adherence to medication) (Lansing & Berg, 2014). Sustained motivators are important for maintaining self-regulation efforts (e.g., regular reduction in pain flare-ups), and ongoing cognitive self-regulatory processes can lead to ego depletion. Factors such as stress can impact the ability to sustain effort, but once behaviours become habitual, they require less cognitive effort (Kwasnicka et al., 2016). This highlights the importance of integrating self-management into daily routines so that they become habitual.

Self-regulation is essential not only for self-management but also for developing positive social relationships, life adjustments, self-efficacy, and coping skills, and it is associated with better productivity, such as academic or employment success (Blair &

Diamond, 2008). It involves both individual and interpersonal processes, with parents, peers, and healthcare professionals playing significant roles (Lansing & Berg, 2014). For example, children learn emotional and behavioural regulation through observing parents, family members, and other adults as role models (Moilanen & Manuel, 2017). Research indicates that the ability to self-regulate increases with age (Hagler et al., 2016). Rapid gains in behavioural self-regulation occur between ages three and seven (Montroy et al., 2016), adolescents report the lowest levels of self-regulation, and emerging adulthood shows growth in self-regulatory strengths such as emotional control (Hagler et al., 2016). This highlights how important emerging adulthood is as a key developmental stage for developing positive behaviours, and then self-regulation continues to increase into young and middle adulthood (Hagler et al., 2016).

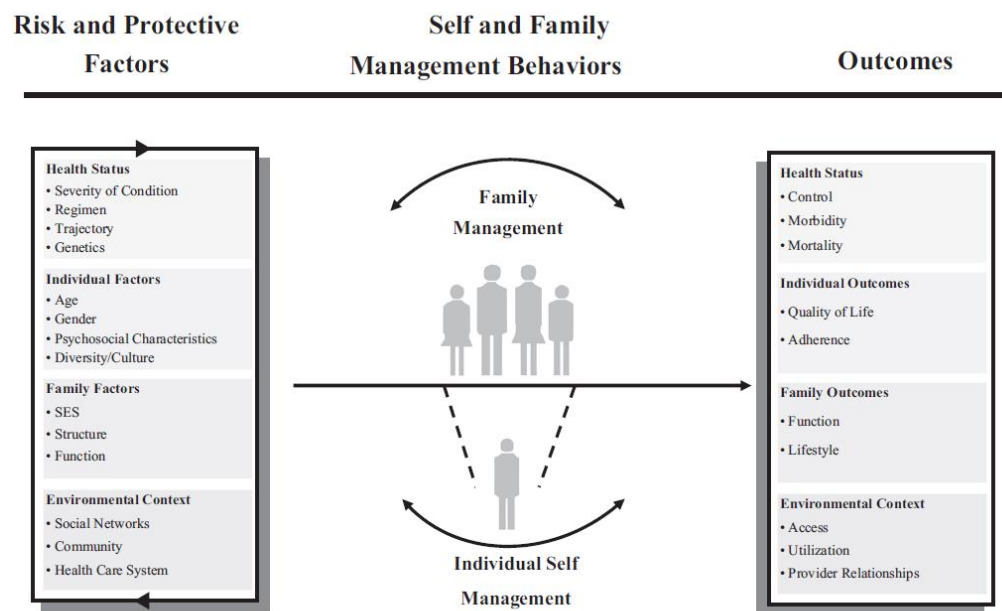
1.5.3 Self and Family Self-management Framework

The Self and Family Self-Management Framework (Grey et al., 2006; Grey et al., 2015) provides a comprehensive structure for understanding how self-management is shaped by individual, dyadic, and family dynamics across developmental stages. Developed to guide the work of two centres established by the Yale School of Nursing, this framework addresses the limited availability of models to develop and test self-management interventions (Grey et al., 2006). It highlights the dynamic and adaptable nature of self-management, emphasising that roles within self-management can change over time based on changing needs and circumstances. Central to the framework is the recognition that self-management is influenced by individual outcomes and modified by key risk and protective factors, such as the severity of a condition, self-efficacy, and social support. It conceptualises self-management as occurring across three interrelated dimensions: context, process, and outcomes (Grey et al., 2006; Grey et al., 2015). See Figure 1.1 for details.

The dimension of context encompasses risk and protective factors that can affect each other. These factors include condition-specific elements such as severity, regimen, trajectory, and genetics; individual-specific elements such as developmental stage and gender; psychosocial characteristics such as depression, self-efficacy, integration, and diversity; family-specific elements such as socio-economic status, structure, function, and diversity; and physical and social environment-specific elements such as social networks, community, and healthcare system. The dimension of process is based on health behaviour change and self-regulation theories. It requires knowledge and belief (e.g., self-efficacy, outcome expectancy), self-regulation skills and abilities (e.g., goal setting, self-monitoring), and social facilitation (e.g., support, collaboration). The dimension of outcomes is the engagement in self-management behaviour (individual and family), healthcare-related costs, health status (e.g., prevention, stabilisation), quality of life, and wellbeing, as well as the direct and indirect costs of health (Grey et al., 2006; Grey et al., 2015). The Self and Family Self-Management Framework (Grey et al., 2006; Grey et al., 2015) has broad applicability across many health conditions, reflects the complexity of self-management, and has been used internationally to guide research. Importantly, the original authors recognise the need to build and improve the framework as new data emerges and continue to do so (Grey et al., 2015; Schulman-Green et al., 2021).

Figure 1.1

Self and Family Management Framework. Reprinted from “A framework for the study of self-and family management of chronic conditions,” by M Grey et al., 2006, Nursing Outlook, Volume(54), 282. Copyright [2006] by Mosby, Inc.



1.6 Key Considerations in Researching and Implementing Self-Management

Despite the recognition of self-management as an important element of public health systems worldwide, its implementation and uptake remain inconsistent. Several factors contribute to this gap and span across researching self-management, to the development and implementation of interventions with healthcare professionals. There are different operationalisations of self-management and a multitude of behaviour-change theories and outcome measures to choose from (Velde et al., 2019). This lack of standardisation can create confusion and inconsistency in how self-management is understood, implemented, and measured, making it challenging to develop universally applicable strategies and interventions.

Self-management research and in particular research examining self-management interventions can sometimes suffer from inadequate or misapplied theory, improper implementation (e.g., delivery methods), short-term follow-up (e.g., some self-management skills like pacing can take a long time to develop post-intervention) and may be subject to publication bias (Allegrante et al., 2019; Dalgetty et al., 2019). Theories embody the collective understanding of the mechanisms that influence behaviour change, encompassing both mediators and moderators, as well as the a priori assumptions about human behaviour and its determinants (Davis et al., 2015). When the theory underlying an intervention is inadequate or incorrectly applied, it can lead to an inability to explain why an intervention was or was not effective. This, in turn, makes it difficult for other researchers to replicate or customise the intervention effectively (Booth & Carroll, 2015).

A recent review also highlighted significant variation in the components and outcome measures used in self-management interventions, which can complicate comparisons and hinder the generalisability of findings (Dineen-Griffin et al., 2019). For example, demographic variables such as gender, age, and ethnicity may be measured in ways that limit the ability to compare results across studies (Bauer et al., 2021). Moreover, certain constructs, for example, in The Self and Family Self-Management Framework, can be challenging to measure, particularly due to the heterogeneity of outcome measures. For example, in conditions like diabetes, researchers might debate whether to use a non-specific measurement alone or in conjunction with a condition-specific measure (Bauer et al., 2021; Silva et al., 2024). This inconsistency in measurement tools highlights the difficulty in achieving standardisation across studies, making it challenging to draw reliable and generalisable conclusions.

Additionally, research collaboration with healthcare professionals, across different support services, or even researchers in different fields, can be hampered by inconsistent

terminology (Martin et al., 2022). Michie (2024) highlighted how “we continue to use different terms for the same thing and the same term for different things” (e.g., self-management, self-care, and self-monitoring are often used interchangeably), and this complicates matters further. A shared language continues to be important to link disparate research and reaching consensus on definitions could be one approach to achieving this (Michie, 2024). For example, the work by Velde et al. (2019) on defining self-management represents a step toward standardisation. However, the challenge remains in ensuring these definitions are disseminated and adopted by other researchers in the field. With the current rate of publication, even systematic approaches to research can struggle to keep pace with new developments, making the adoption of consistent terminology an ongoing challenge (Michie, 2024).

1.6.1 Researcher by Experience

A promising solution to addressing some of the issues above related to research and in the design of interventions is the incorporation of public and patient involvement (PPI) and the inclusion of experts by experience in the research process. PPI involves conducting research in collaboration with members of the public, such as individuals living with various conditions, who are often regarded as experts by experience. Their experiential knowledge can significantly inform the overall design of research through co-development, ensuring that it more accurately reflects the realities and challenges faced by their communities (DCU, n.d.). Expert by experience researchers, such as the researcher of this thesis, are individuals who have first-hand experience with a particular topic. Similar to PPI, their involvement can deepen the understanding of the subject matter and enhance the relevance and impact of the research (Toikko, 2016). Understanding the perceptions and needs of those affected is important for shaping research and forming the foundation of effective interventions that

respond to real-world challenges (Udlis, 2011). By integrating expert by experience researchers and/or implementing PPI from the outset, research can be more patient-centred, with patient perspectives and needs directly influencing the research questions, design, theoretical frameworks, and interventions.

As a researcher with lived experience of complex regional pain syndrome, and several co-morbid conditions diagnosed during emerging adulthood my positionality offers a unique lens through which to approach this thesis. The lived experience of a self-management intervention and daily self-management routines is further enhanced by active engagement in two pain support groups and a postgraduate disability network, providing regular, direct contact with individuals living with long-term conditions across different developmental stages and the challenges they face. Furthermore, I completed three summer internships on The SEA-CHANGE study with a focus on self-management for head and neck cancer survivors. It was in seeing the challenges that others often face that led me to want to research self-management of LTPC. This contributes to a broader understanding rather than solely personal experience. Relying solely on personal experience has the potential to introduce bias. This lived experience has informed the research question, supported the navigation of literature and in identifying key theories, the overall design of the thesis and interpretation of the findings. The integration of lived experience as a researcher living with LTPC, aims to ensure the research is not only academically rigorous but also practically meaningful, grounded in the realities faced by emerging adults living with LTPC.

1.6.2 Role of Healthcare Professionals

Much research carried out about self-management and self-management is widely adopted by public health systems, such as the Health Service Executive in Ireland (HSE). However, its integration into primary care, such as, by general practitioners, remains

inconsistent (Noordman et al., 2024; Tharani et al., 2021). From the healthcare professionals' perspective, several challenges can hinder the adoption of self-management support. These include time constraints, increased workload, a lack of confidence, lack of experience and/or training, beliefs and attitudes towards self-management or the patient (e.g., perceptions of patient capability) and insufficient coordination or support from other healthcare professionals and resources (Lorig & Holman, 2003; Noordman et al., 2024; Tharani et al., 2021). Importantly, self-management is significantly enhanced when the relationship with healthcare professionals is collaborative, characterised by trust, tailored support, empathy, and continuity of care (Franklin et al., 2018; Noordman et al., 2024). When healthcare professionals are trained and actively engage in a collaborative approach, it can lead to positive self-management outcomes (Noordman et al., 2024; Rochfort et al., 2018; Vainauskienė & Vaitkienė, 2021). However, when this collaboration is lacking, it can act as a barrier to effective self-management (Franklin et al., 2018).

Furthermore, many healthcare professionals continue to favour the traditional biomedical model of care (Franklin et al., 2018), which often prioritises physical health issues and neglects the psychosocial aspects that are equally important for individuals living with LTFC (Franklin et al., 2018). For example, healthcare professionals may focus on medical goals, such as improving glycaemic control or weight loss (Schulman-Green et al., 2016; Udulis, 2011). In contrast, patients may have psychosocial goals, such as managing the pressure of multiple life roles, and the key challenge is integrating medical goals into their daily lives (Schulman-Green et al., 2016). The mismatch between patient and healthcare professional expectations and beliefs could be mitigated by better understanding of the factors that act as barriers to self-management (Schulman-Green et al., 2016). For example, this thesis aims to understand these factors for emerging adults living with LTFC.

1.6.3 Developmental Stage

Developmental stage is both a risk and protective factor in managing LTPC. It is an important factor in determining an individual's capacity and readiness to take on self-management responsibilities, as each stage presents distinct challenges and requirements (Wiebe et al., 2016). For example, as individuals transition from adolescence into emerging adulthood, the influence of parents typically diminishes, while peer influence becomes more prominent. This shift necessitates adjustments in the type and extent of support provided, highlighting the need for tailored approaches to self-management that are responsive to the evolving developmental needs of individuals (Grey et al., 2006; Grey et al., 2015; Kelly & Berg, 2021; Ryan & Sawin, 2009; Wiebe et al., 2016). The challenge of effectively supporting individuals with LPTC across different developmental stages remains a significant issue in healthcare (Clements et al., 2016; Davis et al., 2022; Sherifali et al., 2018; Wiebe et al., 2016) and this thesis aims to bridge the gap. Understanding the influence of the development stage of emerging adulthood on self-management of LTPC is important for developing responsive and effective tailored approaches.

1.6.4 COVID-19

COVID-19 had a global impact, causing major disruptions to daily life and posing not only a direct threat to physical health but also significant psychosocial challenges, such as increased anxiety and social isolation (Philip et al., 2020). Emerging adults with and without LTPC experienced disruptions such as remote learning, increased low mood, higher consumption of junk food, and changes in employment (Growing Up in Ireland, 2021b). Those with LTPC were and still are, often at a higher risk of severe illness, with instructions to shield from others (Fisher et al. 2021). However, the implementation of public health restrictions to mitigate the spread of the virus also had negative consequences for self-

management, including reduced physical activity, often essential for symptom management and difficulties in accessing medical care, such as doctor or outpatient appointments and even necessary medications (Palmer et al., 2020). As the data collection for this thesis was undertaken at a time when countries such as Ireland and the UK had recently emerged from their final lockdowns of the COVID-19 pandemic, this thesis will also consider the context and influence of the global pandemic influenced on self-management and the lives of emerging adults.

1.6.5 Benefits of Self-Management

Despite the many self-management research challenges identified, such as a universal definition, inadequate or misapplied theory, and collaboration from healthcare professionals, the body of research evidence strongly supports the view that self-management can yield significant benefits for patients and healthcare resources. This highlights that it is important to keep working to improve the research, and the implementation of self-management across healthcare systems, patients and healthcare professionals (Allegrante et al., 2019). Organisations, for example, the American Diabetes Association and wider national healthcare services, such as the HSE and the National Health Service (NHS), promote self-management as a key element of LTPC management (Holt et al., 2021; HSE, n.d.a; NHS, n.d.a). By working to resolve or reduce the challenges in researching and implementing self-management it can hopefully lead to increased adoption at all levels (i.e., healthcare systems, patients and healthcare professionals). Successful self-management can deliver better health, that is, quality of life, better healthcare such as reduced healthcare visits, and better value such as reduced healthcare costs (Ory et al., 2013).

1.7 Emerging Adulthood

Prior to Arnett's Theory of Emerging Adulthood and the identification of emerging adulthood (age 18-29) as a distinct developmental stage, Erikson described eight stages of development across the lifespan from infancy to old age (Erikson & Erikson, 1998). Erikson's theory focuses on how individuals grow over time and within a community and each stage of development is characterised by a conflict that must be navigated to progress. Erikson (1977) deemed these conflicts to be key developmental tasks, essential to shaping a person's identity and their relationships with others and if unresolved they could lead to psychological difficulties later in life. Stage five of the eight stage theory is adolescence (12 – 18 years): identity versus identity diffusion. This stage is about identity exploration and formation with the transition into adulthood. Adolescents consider different roles, values and beliefs but uncertainty can cause confusion (Erikson, 1968). While stage six (young adulthood 19-29 years): intimacy versus isolation is about developing intimate relationships and long-term commitments if identity has been well-developed in stage 5. If attempts at intimacy fail, isolation can happen (Erikson, 1968). Emerging adulthood (18-29 years), as a new and distinctive developmental stage, emerged due to social and economic changes across many countries, following four revolutionary changes that took place in the 1960s and 1970s, the Technology Revolution (e.g., shift from industrial to information processing), the Sexual Revolution (e.g., birth control pill), the Women's Movement (e.g., access to education and employment), and the Youth Movement (e.g., civil rights movement) (Arnett, 2015). Emerging adulthood encompasses the transition period from adolescence to adulthood and is characterised by its heterogeneity (Arnett, 2001). This stage is defined by a set of shared social and psychological experiences, where emerging adults navigate various life transitions (e.g., college, employment, moving homes) that do not follow a linear path into adulthood. The timing of these transitions can vary greatly, with some individuals entering adulthood

earlier or later than others, making emerging adulthood a particularly complex and dynamic stage of life (Arnett, 1994; 2000; 2001, Syed & Mitchell, 2013).

While the Theory of Emerging Adulthood was developed from an American context, Arnett (2000; 2001; 2015) emphasises that emerging adulthood is not a universal theory applicable to all individuals in the same way; there are both similarities and differences across cultures and groups. For example, cultural variations such as those between American and Chinese societies, or distinctions between college and non-college youth illustrate the diversity within this developmental stage. Furthermore, as developing countries become more economically advanced, the prevalence of emerging adulthood will increase. Despite these differences, there are sufficient similarities among individuals within this age group to classify them as emerging adults, suggesting that they reasonably belong to the same developmental stage (Arnett & Tanner, 2011). Consequently, Arnett encourages research across cultures, socioeconomic factors, and other subgroups to explore the heterogeneity and homogeneity within this stage (Tanner & Arnett, 2009).

In relation to Europe, Arnett (2006b) describes how the five features of emerging adulthood; identity exploration, instability, self-focus, feeling in-between and possibilities have been observed in ethnographic work by Carrie Douglass (2005) and colleagues. A consistent theme emerging from this work is the existence of a period marked by freedom and independence before the assumption of full adult responsibilities. In the context of Ireland and the UK, this stage is exemplified by the extension of education beyond the age of 18 (Chakravarty, 2024; GOV.UK, n.d.) and by declining marriage rates and an increase in the average age at first marriage (Central Statistics Office, 2020; Office for National Statistics, 2019). Furthermore, the Growing Up in Ireland study, the national longitudinal study of children and young people in Ireland is actively exploring this stage of the transition to adulthood. For example, whether participants consider themselves either adults or not adults

(McNamara et al., 2021). This thesis responds to Arnett's call for research across cultures, socioeconomic groups, and other subpopulations by examining emerging adulthood in greater detail in both Ireland and the UK and furthermore, in comparing the subgroups of emerging adults living with and without LTPC.

Emerging adulthood is a diverse stage marked by significant change and development, with most emerging adults in this stage remaining unmarried, childless and extending time in education, postponing the assumption of adult roles and responsibilities until their late 20s or early 30s (Arnett, 2000; Galanaki & Leontopoulou, 2017). For example, in Ireland, the national progression rate to higher education is 85% (Chakravarty, 2024). In relation to marriage, the average age at marriage in 2019 was 34.8 years for women and 36.8 years for men, compared to 24.3 and 26.5 years, respectively, in 1979 (Central Statistics Office, 2020). Furthermore, the act of marriage in Ireland, in general, declined from 22, 045 in 2014 to 19,673 in 2019 (Central Statistics Office, 2020). This delay in adopting traditional adult roles, such as marriage and parenthood, allows emerging adults to focus on personal development and to remain optimistic about their future, with numerous possibilities and life paths available to explore (Arnett, 2015). Research has shown that in Western countries, the main criteria for reaching adulthood have changed from the traditional adult markers (e.g., marriage) and are now closely tied to self-sufficiency and self-reliance: accepting responsibility for one's actions, identifying and adhering to a personal value and belief system, achieving financial independence, and establishing a more equal relationship with one's parents (Arnett, 1994; 1997; 2001; Galanaki & Leontopoulou, 2017).

Being in their 20s provides emerging adults with numerous choices and trajectories (Nelson, 2021). While many view this period as a time to be carefree and travel (Ravert, 2009), others see it as an opportunity to pursue education or prepare for future adult roles such as marriage and parenting (Nelson et al., 2015). The experience of emerging adulthood

is significantly influenced by socio-economic status, including educational attainment. Emerging adults from lower socio-economic backgrounds often perceive greater instability and face more responsibilities, creating pressure to transition into adulthood more quickly. They may need to assume adult roles and responsibilities earlier than their peers from higher socio-economic backgrounds (Landberg & Noack, 2019).

Further and higher education has become increasingly important for challenging low socio-economic status and establishing a career path. This shift reflects the transient nature of modern employment, where "jobs for life" are becoming less common. Further and higher education often leads to better-paying jobs, providing a pathway for individuals to improve their socio-economic standing and achieve greater career stability (Settersten et al., 2015). In Ireland, 63% of 25 to 34-year-olds have attained third-level education, and 60% of school-leavers from disadvantaged areas progressed to third-level education in 2023 (Central Statistics Office, 2022c; O'Brien et al., 2023). Moreover, higher education is associated not only with economic benefits but also with better health, more stable families, and increased civic engagement (Settersten et al., 2015). Nelson (2021) deems emerging adulthood distinctive; because of how young individuals do not feel yet adult, because of how they identify what makes an "adult" in the future and because of what they believe this third decade of life affords them in opportunities that no other time will.

Emerging adults are legally considered adults, embodying the notion of autonomy and independence. However, across various social, economic, and psychological markers, they often lack full independence or autonomy (Settersten et al., 2015). Recent research has highlighted that the brain, particularly the prefrontal cortex, continues to mature until around the age of 25 years. This area of the brain is crucial for rational thinking, complex judgement, decision-making, and reasoning. Its ongoing development can make it challenging for emerging adults to fully engage in these cognitive processes (Arain et al., 2013). Given that

the primary criteria for reaching adulthood revolve around self-sufficiency and self-reliance (Arnett, 1994; 1997; 2001; Galanaki & Leontopoulou, 2017), the maturation of the prefrontal cortex is integral to achieving these milestones (Arain et al., 2013). Consequently, emerging adults may not yet have reached their full cognitive capacity to manage the wide range of challenges that adulthood presents. This includes difficulties in assessing the consequences of their actions, managing risk-taking behaviour (Arain et al., 2013), and controlling their emotions (Nelson, 2021). This developmental stage can foster a sense of invulnerability to negative outcomes (Sussman & Arnett, 2014). Although emerging adults are capable of handling more complex cognitive tasks than adolescents, they still display less advanced cognitive abilities and less emotional regulation compared to older adults (Tanner & Arnett, 2009).

Emerging adulthood is also a stage that is often characterised by peak physical health (Murray et al., 2020), but it is also a time when risk-taking behaviour is notably high (Ravert, 2009). Emerging adults may seek out and engage in risky behaviours due to their legal status as adults, the reduced likelihood of parental monitoring, and a fear of missing out on certain opportunities before fully transitioning into the responsibilities of established adulthood, such as experimenting with substance use (Ravert, 2009). Additionally, their roles, such as being a student, are often less constrained compared to those of older adults, which can further encourage such behaviours (Arnett, 2000; Ravert, 2009).

In Ireland, although 85% of emerging adults are aware that condoms are effective in preventing sexually transmitted diseases, only one-third of those who are sexually active consistently use condoms (O'Mahony et al., 2021). This disconnect between awareness and action is reflected in the significant increase in sexually transmitted diseases among 15 to 24-year-olds, which rose by 38% in 2023 compared to the previous year (HSE-Health Protection Surveillance Centre, 2024). This suggests that while emerging adults may understand the

risks, they often do not fully internalise the potential consequences, feeling invulnerable or overly optimistic about the outcomes. Moreover, high-risk behaviours are implicated in the leading cause of death for 18 to 25-year-olds in the European Union, which is transport accidents (OECD Library, n.d.). Speeding contributes to 10–15% of all crashes and 30% of fatal crashes (European Road Safety Observatory, 2020). In Ireland, individuals aged 16 to 25 accounted for over a quarter of road fatalities in 2023, an increase from 16% in 2022 (Road Safety Authority, 2024). Among driver fatalities between 2014 and 2018 where speed was a factor, 71% were under 35 years of age, 53% of these drivers tested positive for alcohol, and 54% were not wearing seat belts (Road Safety Authority, 2022).

Emerging adults also exhibit higher rates of alcohol and drug use compared to any other age group (Camfield et al., 2017). In Ireland, 42% of emerging adults report drinking alcohol weekly, a stark contrast to only 4% of adolescents. Of those who drink weekly, 51% fall into the problem drinking range. Additionally, 40% of emerging adults have used drugs other than those prescribed for medical reasons, compared to 15% of adolescents who have tried cannabis (adolescents were not asked about other drugs), with 14% of these individuals categorised as having 'moderate to severe' drug use (Dooley et al., 2019). Gender differences can also play a significant role in risk-taking behaviours during emerging adulthood, with males being at a higher risk for substance abuse and engaging in risky activities such as crime (Norona et al., 2016). For example, in 2022, there were five female prisoners in the 18–24 age group in Ireland, compared to 1,118 male prisoners in the same age group (Irish Prison Service, 2022).

While the lifestyle factors associated with emerging adulthood may seem to encourage negative risk-taking, it is important to recognise that not all emerging adults engage in these behaviours or develop related problems (Sussman & Arnett, 2014). In fact, not all risk behaviours are inherently negative; some, such as exploring new relationships,

carry psychosocial risks but are also considered normative, adaptive, and consistent with the developmental tasks of this life stage (Ravert, 2009). Moreover, emerging adults who make mistakes and learn from them during this stage are practising self-regulation, which can lead to overall improvements in decision-making (Arain et al., 2013) and enhanced social competence (Moilanen & Manuel, 2017). Research by Nelson and Padilla-Walker (2013) indicates that emerging adults who thrive during this stage tend to have positive relationships with their parents, limit their involvement in potentially harmful behaviours, and navigate their identity development based on an internal set of values and beliefs. This suggests that flourishing during emerging adulthood is closely linked to strong familial support, careful risk management, and a solid foundation of personal values, which together contribute to healthier and more successful transitions into full adulthood.

Importantly, compared to other developmental stages such as adolescence or mid-to-older adulthood, the majority of emerging adults report feeling in a state of transition or "in-between" adolescence and full adulthood. They often describe themselves as being too old to be considered adolescents yet too young to be fully adult, reflecting an ongoing process of becoming an adult (Arnett, 2001; Nelson & Barry, 2005; O'Mahony et al., 2019; Reifman et al., 2007). Arnett (2001) found that when asked whether they had reached adulthood, 50% of emerging adults selected the option "in some respects yes, in some respects no," compared to 86% of young to midlife adults, underscoring this stage as one characterised by a sense of "feeling in-between". It is typically in their late 20s to early 30s that the majority of emerging adults start to report feeling that they have fully reached adulthood (Arnett, 2000; Arnett, 2001). In addition to this "feeling in-between", Arnett (2004, 2015) identified four other common and distinct features of emerging adulthood (see Table 1.1) that explain the psychosocial processes involved in this transition. These features are more prominent in emerging adults and serve to distinguish this stage from both adolescence and adulthood.

Each feature is referred to as an "age" to highlight its importance during this particular stage of the life span, and it is important to note that these five features are not mutually exclusive but are very much interrelated (Syed & Mitchell, 2013).

Table 1.1

The Five Features of Arnett's Emerging Adulthood (Arnett, 2004; 2015)

Features of Emerging Adulthood	Description
Age of Identity Exploration	Involves emerging adults exploring different types of relationships (e.g., romantic and sexual) and ideologies (e.g., political) looking to answer the question "who am I and what do I want?". Developing their sense of self as they become more independent from their parents and exit the second-level school systems
Age of Instability	Represents many explorations and transitions of this stage (e.g., starting college or new job, moving homes). The freedom and ability to make decisions means there are many opportunities for experimentation and risk-taking thus further increasing the instability of this stage
Age of Self-Focus	The freedom from restrictions and obligations means that this is very much an "age of self-focus" and by focusing on the self, emerging adults learn how to become self-sufficient
Age of Feeling In-Between	Emerging adults feel on the way to adulthood but not quite there, "in-between". They are gradually making their way to achieving the main adult goals of accepting responsibility for themselves, making independent decisions and becoming financially responsible for themselves
Age of Possibilities	It is an optimistic time as many different futures are possible with high hopes and great expectations. The potential for changing direction offers many choices for emerging adults to set and work towards achieving their goals

The age of identity exploration is a period where emerging adults actively seek to define their values, political stances, religious beliefs, ideal relationship partners, and future aspirations, using this time to clarify their sense of self (Arnett, 2015). This stage is characterised by a growing independence from parents and the freedom to make autonomous decisions, allowing them to experiment with various lifestyles, educational paths, jobs, and

relationships, thereby addressing any identity issues across these diverse facets (Arnett, 2006a). The age of instability arises from the numerous transitions, such as changes in education, employment, and relationships, making this a particularly unstable time for emerging adults (Arnett, 2015). It is often a period marked by both a desire for and a fear of independence, where experimentation and risk-taking are common due to the opportunities presented (Arnett, 2000; Ravert, 2009). The age of self-focus is afforded to emerging adults by the newfound freedom from the restrictions of adolescence and the obligations of adulthood, providing emerging adults with the autonomy to concentrate on themselves and enjoy the liberty to pursue their aspirations and interests (Arnett, 2004; Arnett, 2015; Nelson, 2021). The primary goal during this time is to develop the skills necessary to achieve self-sufficiency and self-reliance (Arnett, 1994; 1997; 2001; Galanaki & Leontopoulou, 2017). The age of possibilities reflects the high levels of optimism and hope that emerging adults typically have for their futures, with a broad range of life options perceived as available, such as potential relationships, job opportunities, social causes, and other avenues for personal growth (Arnett, 2015; Reifman et al., 2007). This stage offers emerging adults the opportunity to build a better life for themselves than their parents had, providing them with the potential to transform their lives in meaningful ways (Arnett, 2006a).

Emerging adults do not experience the features of this developmental stage in a linear or uniform manner, as there are numerous paths available to them as they acquire the knowledge and skills necessary for achieving a stable adulthood (Arnett & Mitra, 2020). Additionally, endorsements of the features of emerging adulthood tend to decrease as individuals age (Reifman et al., 2007; Skulborstad et al., 2016). Furthermore, female emerging adults often report fewer adult-like experiences compared to their male counterparts across all five features (Luyckx et al., 2009; Skulborstad et al., 2016). While

university students and graduates tend to endorse higher levels of identity exploration and instability in comparison to non-students (Kohútová & Kohút, 2024).

The way emerging adults navigate these paths is influenced by their personal, familial, and social resources at the onset of this developmental stage, as well as the support available to them throughout the journey (Wood et al., 2018). For example, positive parental relationships are associated with encouraging independent thinking (Kaniušonytė & Žukauskienė, 2018). Parental connectedness can mitigate the stress related to instability and provide a sense of reassurance as emerging adults develop autonomy and contributes to a more positive experience of the features of emerging adulthood (Nice & Joseph, 2023; Schnyders & Lane, 2018). Recent research also suggests that emerging adults who are employed, financially independent, and living away from their parents report a greater sense of adulthood and lower levels of instability (Blevins et al., 2021). Conversely, financial dependence is associated with higher levels of instability and the feeling of being in-between adolescence and adulthood, as well as lower levels of self-focus (Kohútová & Kohút, 2024). In Ireland, there is the possibility that the recent housing crisis (Central Statistics Office, 2021) may influence the experience of emerging adulthood, with moving out of home (a key marker of independence) becoming out of reach for many emerging adults (Central Statistics Office, 2022a). This is in line with the idea that country specific socio-economic factors can shape and influence the experience of emerging adulthood (Arnett, 2015).

Alongside the influence of parents and family, peer networks play a significant role in providing social support during emerging adulthood, a period typically marked by the expansion of friendship groups. For example, in one longitudinal study, 46% of participants aged 17/18 years reported having a friendship group of "three to five," which increased to 50% reporting more than ten friends by the age of 20 (O'Mahony et al., 2019). In terms of relationships, in another study, while 38.8% of emerging adult participants expressed

disappointment at not being in long-term relationships, this did not detract from most of the sample viewing this period as a time to pursue individual goals and interests (Beckmeyer & Jamison, 2023).

Emerging adulthood is characterised by numerous aspirations, but it is also marked by instability and uncertainty (Arnett, 2004; 2015). With greater opportunities and increased autonomy, emerging adults face choices that can lead to either positive outcomes, such as financial independence, or negative consequences, such as a criminal record, later in life (Lott, 2019). Overall, while this stage is full of exciting possibilities for the future, it is also a period of heightened risk for mental health concerns and engagement in risky behaviours (Cleveland & Goldstein, 2019).

There have been counter arguments to the concept of "emerging adulthood" as a new developmental stage. Côté (2014) suggested that the theory of emerging adulthood is unsubstantiated on several grounds and that it has created a myth that has influenced cultural change. He argues that the formulation was based on 300 interviews with Americans aged 18–29 years, and because the analytical strategy for extracting the five features of emerging adulthood was not reported, the theory was flawed. However, to encourage further research, Arnett and colleagues developed the Inventory of the Dimensions of Emerging Adulthood (IDEA) to test the empirical validity of the five features of emerging adulthood (Reifman et al., 2007).

Côté (2014) also argues that the theory does not apply universally to all young Americans, particularly those from lower socio-economic backgrounds who do not attend college, often referred to as the "forgotten half." He suggests that the idea of emerging adulthood misinforms parents and young people and causes policymakers to overlook the financial and emotional needs of current and future generations. Additionally, Hendry and Kloep (2007) argued that emerging adulthood sets the middle classes of Western societies as

the norm, with all other groups seen as deviations. However, Arnett has consistently maintained that emerging adulthood is not a universal concept but one that has emerged in industrialised economies due to social and economic changes (Arnett, 2001; 2011b). Arnett identifies sufficient similarities among individuals within this age group to classify them as emerging adults (Arnett & Tanner, 2011) and emphasises the need to be mindful of generalisations if mixed populations are not used in research (Mitchell & Syed, 2015).

Arnett (2000; 2001; 2015) calls for further research across cultures and subgroups (e.g., social class and education) to deepen the understanding and expansion of the theory. Suggesting that as countries become more economically developed, emerging adulthood will become more evident, as young adults are afforded more opportunities to explore the transitional stage between adolescence and adulthood (Arnett et al., 2011). It is no longer only the middle class who pursue further education, as seen in Ireland, where 60% of school-leavers from disadvantaged areas now progress to third-level education (O'Brien et al., 2023). Furthermore, a study with 800 Slovak participants comparing students and graduates with those who never attended university found that both groups experienced the five features of emerging adulthood, although students and graduates endorsed the "age of possibilities" more strongly (Kohútová & Kohút, 2024). A longitudinal study identified that emerging adults who do not attend college can be quite similar to their peers at certain times but differ at others, such as in income, employment, and parenthood (Mitchell & Syed, 2015). This finding highlights the need for caution in generalising findings from college-only populations and the importance of including non-college participants in research (Mitchell & Syed, 2015).

A mixed-method study examining the relationship between socio-economic status and the experience of emerging adulthood found that lower socio-economic emerging adults experienced emerging adulthood but with a perception of greater instability and a more other-focused perspective, as opposed to self-focused. They felt pressure to reach adulthood

quickly while also experiencing optimism. The qualitative interviews identified that certain features might mean something different to someone from a lower socio-economic background than to someone from a more affluent background (Landberg & Noack, 2019). Much research has now identified that emerging adults experience the five features of emerging adulthood, though the levels of endorsement can vary depending on factors such as age (Arnett & Mitra, 2020; Galanaki & Leontopoulou, 2017; Kohútová & Kohút, 2024; Reifman et al., 2007), college attendance (Arnett, 2016; Crocetti et al., 2015; Kohútová & Kohút, 2024; Nice & Joseph, 2023; Reifman et al., 2007), and culture (Crocetti et al., 2015; Seiter & Nelson, 2011; Sirsch et al., 2009). This suggests that it is also important to look at any other important distinguishing features that might influence the levels of endorsements of emerging adulthood. For example, health status, does having LTPC, influence the endorsement of the features of emerging adulthood.

Kloep and Hendry (2011) further argued against the idea of developmental stages in general, preferring instead to focus on the processes and mechanisms that drive change across any age, promoting continuous development. However, the lifespan has frequently been divided into a series of stages by many researchers, often based on certain age markers, such as prenatal, infancy, and early childhood (Syed, 2015). In this context, adulthood ranges from 18–65 years and includes stages such as middle adulthood. Given societal changes and increased longevity, it is unsurprising that new developmental stages have emerged (Syed, 2015). The entry into and exit from emerging adulthood are based on socio-cultural markers of the time, with underlying psychological features. For many, 18 marks the end of secondary schooling and legal adulthood, while the late 20s or even early 30s is often the time for assuming adult roles, such as marriage and parenthood (Syed, 2015). Arnett argues that there are many paths through any life stage, shaped by various factors (e.g., social class, gender, culture), emphasising the concept of "one stage, many paths" (Arnett, 2016).

Hendry and Kloep (2007) also contended that emerging adulthood does not advance the understanding of human development and that theories should not be postulated based on historical trends or fads. However, historical changes are not always mere fads; they often lead to long-term societal shifts (Syed, 2015). The four revolutionary changes that led Arnett to propose a new developmental stage were the Technology Revolution, the Sexual Revolution, the Women's Movement, and the Youth Movement of the 1960s and 1970s (Arnett, 2015). It is possible that further changes or new developmental stages might emerge within older adulthood as individuals continue to live longer, perhaps due to cognitive changes (Syed, 2015).

What is missing from the arguments above that are against the developmental stage of emerging adulthood, is any discussion of the biological process of brain maturation as a biological marker for emerging adulthood. Adolescence is not experienced in the same way by all adolescents across the world, and markers of adolescence and developmental tasks can vary across cultures (Syed, 2015). If biological markers, such as puberty, are used as evidence for adolescence as a stage, then the continued maturation of the brain until the age of 25 (Arain et al., 2013) could be argued as a biological marker for emerging adulthood. Therefore, emerging adulthood does advance the understanding of human development, as opposed to Kloep and Hendry's argument above. This ongoing development of the prefrontal cortex means that emerging adults may struggle with controlling emotions, delaying gratification, and thinking rationally beyond the moment (Arain et al., 2013). This supports the idea of a developmental stage characterised by high risk, exploration, optimism, and instability. It also explains why younger emerging adults (18–25 years) endorse the features of emerging adulthood more strongly and why there is a decline in endorsement as they age, with older emerging adults (26–29 years) beginning to report that they have achieved adulthood (Reifman et al., 2007).

While it has its critics, emerging adulthood is now widely accepted as a developmental stage (Schwartz, 2016). Although much of the research still comes from English-speaking countries, it is essential to consider research from countries where English is not the first language, even though publishing in English is common in some of these countries (Tello-Navarro et al., 2024). Emerging adulthood has become a global concept, with 57 different countries represented in the research (Swanson, 2016). Furthermore, research papers are published not only in the *Emerging Adulthood Journal* but also in journals such as the *Journal of Youth and Adolescence* and the *Journal of Adolescent Research* (Tello-Navarro et al., 2024). The *Infant and Child Development* journal recently expanded its scope to include studies from prenatal stages through to emerging adulthood (Syed, 2021). Arnett's theory also informs national research studies, such as the *Growing Up in Ireland* study, which includes emerging adults in its research waves (O'Mahony et al., 2021). In a review of the Theory of Emerging Adulthood 20 years on, it was highlighted that emerging adulthood is subjectively distinct not only because emerging adults do not consider themselves fully adult yet, but also because of their perceptions of what they need to achieve adulthood in the future (e.g., financial independence, reorganisation of parental relationships). It is also neurologically distinct, providing opportunities for activities that emerging adults believe no other life stage will offer, such as travelling and being carefree, or at least it is the stage that offers the most opportunities (Nelson, 2021).

1.8 The Present Thesis

The present thesis sets out to examine the self-management of LTPC within the distinctive development stage of emerging adulthood. While self-management in diabetes is well-researched, other LTPC have received comparatively less attention. This thesis therefore adopts a broader focus to address this and to inform future research across a wider range of

LTPC. It adopts a multi-study design comprising three separate studies (see Figure 1.2) to address the overarching research question: do emerging adults with and without LTPC differ in the distinctive features of emerging adulthood, and how do these features influence self-management behaviours among those living with LTPC.

The first study is a systematic review designed to investigate whether the five features of emerging adulthood are evident in the self-management tasks and strategies employed by emerging adults with LTPC. This study will synthesise existing literature to provide a comprehensive understanding of how these features manifest in the context of managing LTPC during this developmental stage. The second study conducts a secondary data analysis of Wave Four of Cohort '98 of the Growing Up in Ireland national longitudinal study. This secondary data analysis compares, for the first time, emerging adults with LTPC to their peers without LTPC, focusing on factors linked to the five features of emerging adulthood. By doing so, this secondary analysis of GUI data aims to uncover potential differences in how these groups navigate the transition to adulthood. The third study is a cross-sectional survey specifically examining Arnett's five features of emerging adulthood in both emerging adults living with LTPC and their peers without LTPC. This study will specifically explore, for the first time, the relationship between these features of emerging adulthood and self-management of LTPC. This will provide an insight into how this important developmental stage impacts the self-management of LTPC in emerging adults. In addition, this study will allow for the examination of the psychometric properties of the Inventory of the Dimensions of Emerging Adulthood, the Perceived Medical Condition Self-Management Scale and Communications with Physicians Scale.

Given that emerging adulthood is a critical time for establishing long-term positive health behaviours understanding how the distinct features of this developmental stage interact with self-management is important. A deeper understanding of self-management during

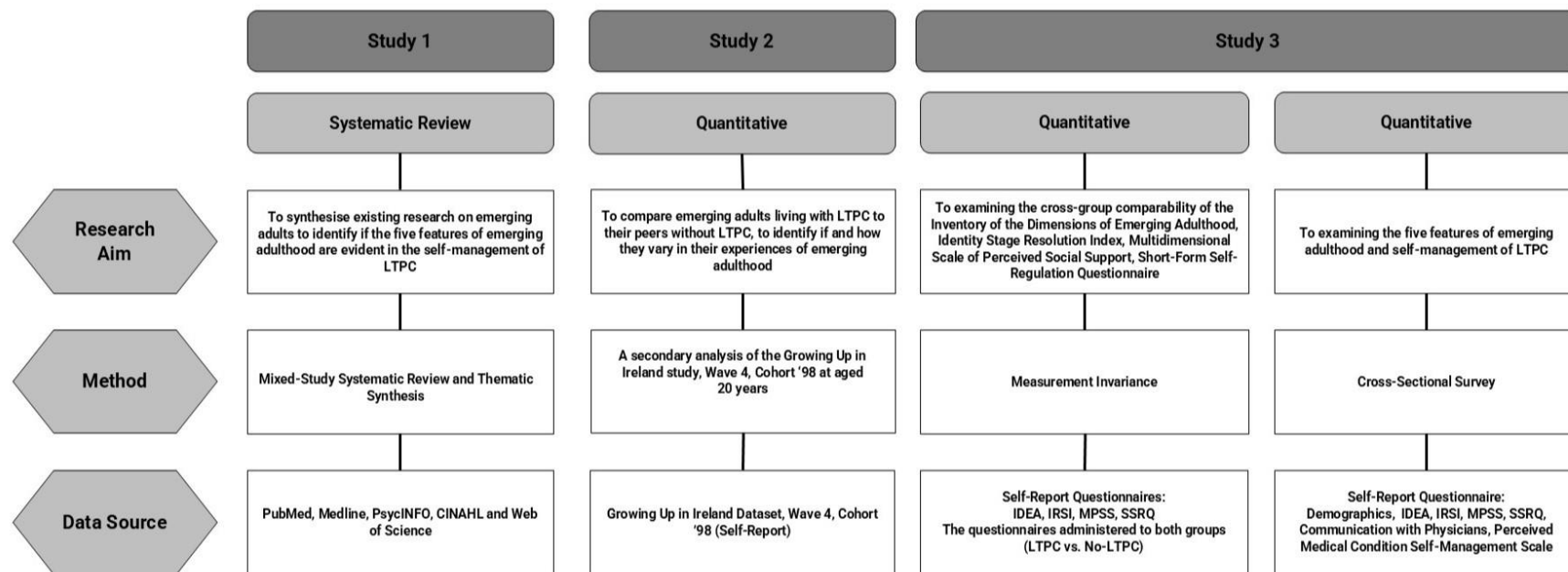
emerging adulthood can inform healthcare professionals about the specific challenges that emerging adults face, which may impact how they manage their LTPC. This understanding can also reduce the mismatches that often occur between patient and healthcare professional expectations and beliefs, fostering more collaborative and effective care relationships. Furthermore, this thesis aims to provide valuable insights for those developing self-management interventions for emerging adults. By targeting the most important issues faced by emerging adults during this developmental stage, future interventions can be more effectively tailored to meet the needs of this population.

1.9 Thesis Conspectus

This thesis comprises five chapters. Chapter One introduced self-management and emerging adulthood. Chapter Two details a systematic review on the self-management of LTPC during emerging adulthood. Chapter Three details the background, method, results and discussion of the secondary analysis of Wave Four of Cohort '98 from the Growing Up in Ireland (GUI) study. Chapter Four details the background, method, results and discussion of the survey on self-management and emerging adulthood. Chapter Five presents the overall conclusions and implications of the thesis.

Figure 1.2

Thesis Multi-Study Design



Chapter 2: Self-Management of Long-Term Physical Conditions during Emerging Adulthood: A Systematic Review

2.1 Overview of Chapter

This is a mixed-studies systematic review to synthesise existing research on emerging adults (aged 18 – 29 years old) to identify if the five features of emerging adulthood (i.e., the age of; identity exploration; instability; self-focus; feeling in-between; possibilities) are evident in the self-management of LTPC. In this chapter, the rationale, background, aim, methods and results for this systematic review will be presented and the findings and implications discussed. The research presented in this chapter has been adapted from the paper Self-Management of Long-Term Physical Conditions During Emerging Adulthood: A Systematic Review, published in the Journal of Emerging Adulthood, December 2023.

2.2 Rationale and Background

Emerging adulthood represents a significant transition stage where individuals aged 18 to 29 years navigate the complex shift from adolescence to adulthood. It is the age of identity exploration, instability, self-focus, feeling in-between and possibilities (Arnett 2004; 2015). Emerging adults report these features more than any other group, collectively distinguishing emerging adulthood from both adolescence and full adulthood (Syed & Mitchell, 2013). Emerging adults engage in identity exploration, seeking to define their values, beliefs, and future aspirations while experiencing a sense of instability due to the numerous transitions in education, employment, and relationships (Arnett, 2006a; 2015). This period of self-focus, driven by a newly found autonomy and freedom from traditional adult responsibilities, allows emerging adults to concentrate on personal growth and self-

sufficiency (Arnett, 2000; 2004; 2015; Ravert, 2009; Nelson, 2021). The optimism that accompanies the age of possibilities drives their aspirations for a better life, yet the uncertainties of this stage can also increase the risk of mental health concerns and engagement in risky behaviours (Arnett, 2015; Reifman et al., 2007).

Emerging adulthood can be further complicated for those living with a LTPC by additional social and psychological challenges that accompany the transition from adolescence, such as the transfer of self-management responsibilities from parents to the emerging adult who is living with LTPC. This coincides with the move to adult healthcare services, where emerging adults become legally responsible for their healthcare decisions (Campbell et al., 2016; Giarelli et al., 2008). As they expand their social networks and develop new relationships in settings such as college or the workplace, their self-management of LTPC can be affected by these multiple transitions (Wiebe et al., 2016; Hopmeyer et al., 2022). Emerging adults living with LTPC may struggle with maintaining consistent self-management practices due to the instability and social pressures of this developmental stage (Kelly & Berg, 2021; McCarthy & Grey, 2018). The challenges are compounded by socio-economic factors, with emerging adults from lower socio-economic backgrounds often facing greater instability and earlier transitions into adult roles (Landberg & Noack, 2019) which can impact their ability to manage LTPC effectively. Additionally, as the self-regulatory parts of the brain are still maturing, the susceptibility during this period to taking risks with self-management may lead emerging adults living with LTPC to take risks that affect health and development in the longer term (Arain et al., 2013).

Three recent review papers on emerging adults living with LTPC have highlighted the importance of considering self-management within emerging adulthood (Rasalingam et al., 2021; Shelley et al., 2020; Wentzell et al., 2020). However, none of these reviews focused exclusively on self-management. Two of the papers examined issues that emerging adults

living with LTPC conditions face during the development stage of emerging adulthood (Rasalingam et al., 2021; Wentzell et al., 2020), while the third examined how emerging adults living with and at risk of genetic conditions experience the five distinct features of emerging adulthood (Shelly et al., 2020).

Wentzell et al., (2020) conducted an integrated review, exploring how the challenges and transitions faced during emerging adulthood, such as moving out of home or attending college, might add to the understanding of diabetes distress; that is the emotional burden and worries of living with diabetes. The researchers found levels of diabetes distress to be highest in emerging adulthood compared to other age groups, due to the multiple transitions experienced across the social, emotional and physical components of life. In relation to self-management, change to personal and professional support networks were a challenge for emerging adults and this contributed to diabetes distress. Some emerging adults found it difficult to complete diabetes self-management tasks for reasons such as perceived stigma (e.g., peers not understanding life with diabetes) and reduced access to social support (e.g., living away from parents). Conversely, others found the change in support networks to be more positive (e.g., new connections). Similarly, positive emotional connection to new healthcare professionals was identified as important in the transition from paediatric to adult healthcare for overall self-management and particularly the management of diabetes distress. However, this review was solely limited to diabetes and primarily addressed only one aspect of self-management, changing support networks. Furthermore, while it did consider the age group of emerging adulthood, it did not examine these findings within the broader context of Arnett's five features of emerging adulthood.

Shelley et al. (2020) conducted a review of both qualitative and quantitative research focused on emerging adults living with genetic conditions and those at risk of developing such conditions. The study aimed to determine whether these emerging adults experienced

the five features of emerging adulthood and to explore the similarities and differences between the two groups. The researchers identified five key themes: independence; education, career, and employment; relationships and social life; family planning; and life perspective. Each of these themes aligned with two or more of the five features of emerging adulthood, with instability being the most prevalent. In terms of self-management, the study found notable differences in independence. Emerging adults living with genetic conditions tended to rely more heavily on family and medical professionals for both physical and financial support, which influenced their decisions regarding college and career choices, often preferring to remain close to medical care or family. Additionally, those with genetic conditions were more cautious about social environments and activities, such as smoking and alcohol consumption, and the severity of their condition was inversely related to their reported autonomy. While this review used the theory of emerging adulthood to explore if emerging adults living with, or at risk of genetic conditions experience the features of this developmental stage, the focus was on broader life experience rather than solely self-management. Nonetheless, it provided insight into some areas of self-management (e.g., independence), but left broader questions about self-management unanswered.

Finally, Rasalingam et al. (2021), in a qualitative metasynthesis, focused on the concept that emerging adulthood is an unstable, development stage that is in between the more stable periods of adolescence and adulthood. The study specifically explored how emerging adults with LTPC experience this transitional stage. The review identified several themes related to self-management, such as the importance of support networks (e.g., worry of loss of support from family members or financial dependence); working towards independence which depends on the severity of LTPC (e.g., adjusting career goals to specific health needs); issues with systemic resources (e.g., access to reliable personal care assistants); psychosocial challenges (e.g., limitations to socialising making it difficult to build friendships

or dealing with anxiety related to condition); and keeping a positive attitude (e.g., not engaging with negative thoughts). While this review provided insights into the experiences of young people regarding quality of life, self-management, and support networks during the transition to adulthood, it did not focus exclusively on self-management or solely on the 18-29 age group. Instead, it included a broader age range of participants, from 15 to 37 years. Consequently, the findings on self-management may not fully capture the unique experiences of emerging adults living with LTPC.

While these reviews have yielded some important information about the self-management experiences of emerging adults who are living with or at risk of conditions, to date there has been no systematic review that has been undertaken to specifically examine self-management within the period of emerging adulthood nor within the context of Arnett's theory of emerging adulthood. Given that emerging adulthood is a distinct developmental stage, separate from both adolescence and full adulthood, and is a critical period for the development of positive self-management skills and long-term health behaviours, the absence of a focused systematic review on this topic leaves a significant gap in our understanding of what it is that we know about how emerging adults with LTPC navigate their conditions during this pivotal stage.

Therefore, the aim of this review is to synthesise existing research on emerging adults (aged 18 – 29 years old) to identify if the five features of emerging adulthood (i.e., the age of; identity exploration; instability; self-focus; feeling in-between; possibilities) are evident in the self-management of LTPC. By undertaking this systematic review, a greater understanding will be gained of the impact of this diverse period of change and exploration on the self-management of LTPC. This will inform future research and help healthcare professionals understand the unique challenges that emerging adults with LTPC face as they

transition to adulthood and inform the development of support strategies that are tailored to their specific needs.

2.3 Method

This mixed studies systematic review includes quantitative, qualitative and mixed methods studies, following the framework outlined by Pluye and Hong (2014). The main rationale for including all types of research methodologies is to achieve a more comprehensive understanding of the complex phenomena involved in the self-management of LTPC during emerging adulthood (Heyvaert et al., 2013; Pluye & Hong, 2014). By integrating different types of studies, this review aims to capture a broader spectrum of insights, addressing the multifaceted nature of self-management behaviours and experiences in this unique developmental stage. The review was conducted and reported in accordance with the standards set by the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) Statement, ensuring a systematic and transparent approach to the synthesis of existing literature (Moher et al., 2009; Page et al., 2021; Sarkis-Onofre et al., 2021).

2.3.1 Search Strategy

A systematic search was conducted across five electronic databases (PubMed, Medline, PsycINFO, CINAHL and Web of Science) up to 15th February 2021, and then re-run ahead of publication up to 15th of February 2022. The search strategy combined controlled vocabulary and free-text search terms which were adapted to each database. One category was “Emerging Adult*” to capture papers relating to emerging adulthood and the second category related to self-management terms, using Boolean terms “OR” and “AND” to

combine the two together (see Table 2.1 for example). A further search of the reference lists of three review papers and all the final included papers supplemented the search.

Table 2.1

PubMed Search Strategy

Emerging Adulthood Terms	("Emerging adult*") AND
Self-Management Terms	((((((((((((((((((((("self care"[MeSH Terms]) OR ("self efficacy"[MeSH Terms])) OR ("self manag*")) OR ("self efficac*")) OR ("self monitor*")) OR ("self treat*")) OR ("self direct*")) OR ("self help*")) OR ("self care")) OR (Empower*)) OR (cope*)) OR (coping*)) OR ("self administration"[MeSH Terms])) OR ("self-admin*")) OR ("self concept"[MeSH Terms])) OR ("self concept*")) OR ("Consumer Participation")) OR ("patient compliance"[MeSH Terms])) OR ("patient compliance*")) OR ("patient participation"[MeSH Terms])) OR ("patient participation*")) OR ("Patient focus")) OR ("Management plan*")) OR ("Management prog*")) OR ("Behaviour change*")) OR ("behavior change*")) OR ("psycho-education")) OR (adherence))

2.3.2 Inclusion and Exclusion Criteria

Papers were included if they (1) were empirical, peer-reviewed papers published in English up to 15th February 2022; (2) had participants with a long-term physical condition and were aged 18–29 years of age (or where data for this group could be clearly disaggregated from other data reported); (3) discussed Arnett’s theory of emerging adulthood; (4) included research data relating to the self-management of a long-term physical condition; and (5) study design included qualitative, quantitative or mixed method data. In this review self-management is defined as, “the intrinsically controlled ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of their long-term condition(s) in partnership with their social network and the healthcare provider(s)” (Velde et al., 2019, p. 10).

2.3.3 Screening and Data Extraction

All titles and abstracts were imported into Covidence (www.covidence.org) and screened by one reviewer (OM). Titles and abstracts identified as potentially eligible were sourced and screened as full-text by one reviewer (OM). Queries were discussed and resolved through consensus with a second and third reviewer (PG, VL) and reasons for exclusion recorded (see Figure 2.1). Data extracted from the papers were author; country of study; study aim; method of data collection; type of long-term physical condition; sample size; age range and which of the five features of emerging adulthood was evident in the self-management findings of each paper (see Table 2.2). Extracted data were cross-checked by the second and third reviewers (PG, VL) and any discrepancies were resolved through consensus.

2.3.4 Quality Appraisal

All included papers were appraised using the Mixed Methods Appraisal Tool (MMAT), version 2018 (see Table 2.3) (Pluye et al., 2009; Hong et al., 2018). The MMAT is designed for use in systematic mixed studies reviews allowing for the appraisal of studies with diverse designs (Pluye & Hong, 2014). The tool contains 27 methodological criteria for appraising relevant studies using a nominal scale (Yes/No/Can't Tell) (<http://mixedmethodsappraisaltoolpublic.pbworks.com/>). Two criteria are screening questions for all studies, then five criteria each for qualitative, quantitative randomised control trials, quantitative non-randomised, quantitative descriptive, and mixed methods (Hong et al., 2018). As the final included papers had qualitative, quantitative descriptive and mixed method designs only, the quality appraisal applied the criteria for these types of studies only.

Figure 2.1

PRISMA 2020 Flow Diagram for Systematic Reviews Which Included Searches of Databases and Other Sources

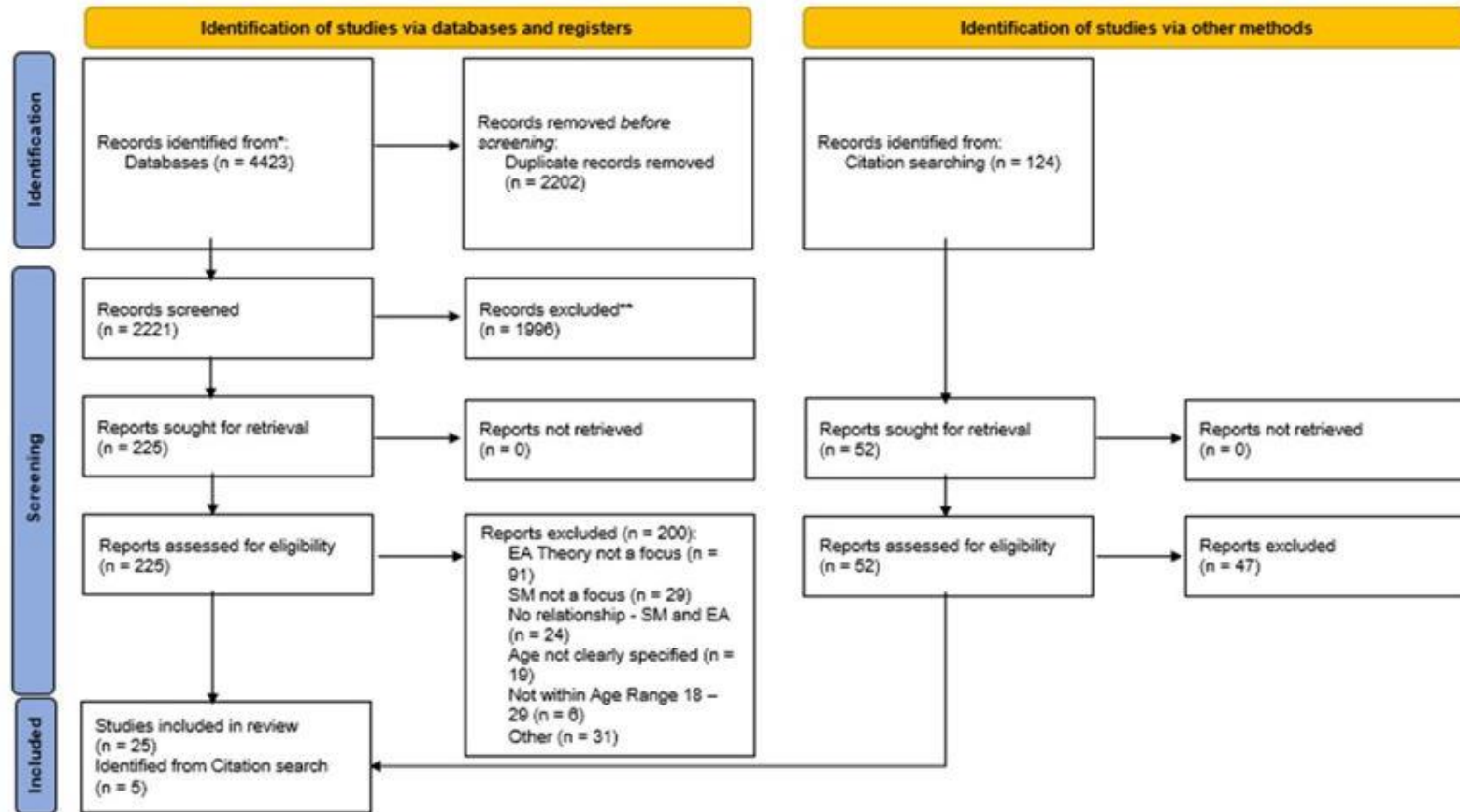


Table 2.2
Characteristics of Included Papers

Author	Country	Aim	Condition	Research Method**	Sample Size	Age Range	Features of EA evident in self-management
Bellin et al., 2013	USA	To explore psychological symptoms in emerging adults with spina bifida (SB) and their association with self-management and satisfaction with family functioning	Spina Bifida	Quant	48	19 - 26 years	Identity Exploration
Campbell et al., 2019	USA	This study examined changes in diabetes-specific family conflict, family responsibility for diabetes management tasks, and associations with glycaemic control up to one year post-high school	Type 1 Diabetes	Quant	79	Baseline 17 to 19 years	Identity Exploration, Instability, Self-focus
Ersig, 2019	USA	To explore the transition to adulthood for college students with type 1 diabetes (T1D) and their parents	Type 1 Diabetes	Mixed Method	25	18 – 24 years	Identity Exploration, Instability, Self-focus, Possibilities
Fredette et al., 2016	USA	To examine the quality of life among college students living with Type 1 diabetes (T1D). Inclusion criteria included age 18 to 24, current college student, and a diagnosis of T1D for at least 1 year	Type 1 Diabetes	Qual	24	18 – 24 years	Identity Exploration, Instability, Self-focus, Possibilities
Garvey et al., 2014 ^a	USA	To explore the experience of transition from paediatric to adult diabetes care reported by post transition emerging adults with type 1 diabetes (T1D), with a focus on preparation for the actual transfer in care	Type 1 Diabetes	Qual	26	M=26.2 years ±2.5 years	Identity Exploration, Instability, Feeling In-between

Author	Country	Aim	Condition	Research Method**	Sample Size	Age Range	Features of EA evident in self-management
Hanna and Hansen, 2020	USA	To provide insight into poorly understood diabetes self-management among emerging adults with type 1 diabetes (T1D) experiencing transitions	Type 1 Diabetes	Qual	25	19 – 26 years	Identity Exploration, Instability, Self-focus
Hanna et al., 2014a ^b	USA	To explore alcohol involvement trajectories and associated factors during the year post high school (HS) graduation among emerging adults with type 1 diabetes	Type 1 Diabetes	Quant	181	Baseline 17 to 19 years	Identity Exploration, Instability Possibilities
Hanna et al., 2014b ^b	USA	To examine the associations of DQOL with the demands and burdens of diabetes care among early emerging adults with type 1 diabetes during the year after high school graduation	Type 1 Diabetes	Quant	184	Baseline 17 to 19 years	Identity Exploration, Possibilities
Hanna et al., 2014c ^b	USA	Changes during the year post-high school were examined in perceptions of diabetes-specific conflict with parents, parent–youth shared responsibility, parental tangible aid, and parental autonomy support, and the moderating effects of living situation, gender, years with diabetes, and glycaemic control	Type 1 Diabetes	Quant	182	Baseline 17 to 19 years	Identity Exploration
Helgeson et al., 2014	USA	To examine whether adolescents' relationships with parents and friends predict health and risk behaviours during emerging adulthood	Type 1 Diabetes	Quant	132 with T1D/131 without	Average age 19 years	Identity Exploration, Instability

Author	Country	Aim	Condition	Research Method**	Sample Size	Age Range	Features of EA evident in self-management
Helgeson et al., 2018	USA	To examine the links of parent knowledge of children's behaviour to diabetes outcomes and to test a mediational model that focused on psychological distress and self-care behaviour	Type 1 Diabetes	Quant	107	M = 22.89 years	Identity Exploration
Higham et al., 2013	UK	To explore the hopes and fears of young adults with cystic fibrosis (CF)	Cystic Fibrosis	Qual	15	18 – 29 years	Identity Exploration, Instability, Possibilities
Huisman et al., 2012	USA	This study focused on understanding and exploring relationships between self-perceptions of emerging adulthood, autonomy, and quality of life	Early-onset Neuromuscular Conditions	Quant	24 with ENC/93 without	18 – 29 years	Identity Exploration, Self-focus
Johnson and Annesi, 2018	USA	To explore the reasons for weight gain and barriers to weight loss among emerging adults with obesity	Obesity	Qual	81	18 – 25 years	Instability Possibilities
Kamp et al., 2019 ^c	USA	To examine the relationship between two conceptualizations of social support (received and perceived availability of social support) and IBD-related self-management behaviours among emerging adults with IBD	Inflammatory bowel disease (IBD)	Quant	61	18 – 29 years	Feeling In-between

Author	Country	Aim	Condition	Research Method**	Sample Size	Age Range	Features of EA evident in self-management
Kamp et al., 2020 ^c	USA	To examine specific contextual factors (individual, condition-specific, and emerging adulthood factors) that influence received social support (total, informational, emotional, and tangible) among emerging adults (ages 18– 29 years) with IBD	Inflammatory bowel disease (IBD)	Quant	61	18 – 29 years	Identity Exploration
Labore et al., 2017	USA	To explore the meaning of transition to self-management in sickle cell disease	Sickle Cell Disease	Qual	12	21 – 25 years	Identity Exploration, Instability, Self-focus, Possibilities
MacDonell et al., 2015	USA	To explore the experience of living with asthma as an African American emerging adult, focusing in particular on controller medication adherence and reported barriers to medication adherence in the context of the transition into adulthood	Asthma	Qual	19	18 – 24 years	Instability, Self-focus
Majumder et al., 2017	USA	To examine changes in self-management behaviours after high school graduation in a cohort of emerging adults with type 1 diabetes	Type 1 Diabetes	Quant	64	Baseline 17 to 19 years	Identity Exploration, Self-focus
Markowitz et al., 2019	Canada	To inform the provision of tailored care and education by illuminating the individual lived experiences of emerging adults with type 1 diabetes	Type 1 Diabetes	Qual	33	18 – 24 years	Identity Exploration, Instability, Self-focus, Feeling In-between

Author	Country	Aim	Condition	Research Method**	Sample Size	Age Range	Features of EA evident in self-management
McCarty and Grey, 2018	USA	To analyse patterns of diabetes self-management behaviours and predictors of glycaemic control across the adult lifespan	Type 1 Diabetes	Quant	2478	18 – 24 years	Instability
Pyatak, 2011 ^d	USA	To understand how engagement in occupation influences young adults' ability to effectively manage diabetes and, how their diabetes self-management strategies shape their occupational participation	Type 1 Diabetes	Qual	8	18 - 25 years	Identity Exploration, Instability, Self-focus, Possibilities
Pyatak et al., 2013 ^d	USA	To explore motivations underlying nonadherent treatment decisions made by young adults with type 1 diabetes	Type 1 Diabetes	Qual	8	18 - 25 years	Identity Exploration, Instability, Self-focus, Feeling In-between, Possibilities
Ramchandani et al., 2019	USA	To explore developmental, situational, and organizational challenges experienced by a diverse group of emerging adults (18-29 years old) with type 1 diabetes (T1DM)	Type 1 Diabetes	Qual	21	18 – 29 years	Identity Exploration, Instability, Self-focus, Possibilities
Ritholz et al., 2014 ^a	USA	To explore perceptions that emerging adults with type 1 diabetes (T1D) have of their patient-provider relationships across the transition from paediatric to adult care	Type 1 Diabetes	Qual	26	M=26.2 years ±2.5 years	Identity Exploration, Instability, Self-focus, Feeling In-between

Author	Country	Aim	Condition	Research Method**	Sample Size	Age Range	Features of EA evident in self-management
Saylor et al., 2019 ^e	USA	To gain insight and understanding of emerging adult experiences after a diagnosed with type 1 diabetes mellitus (T1DM) and prior to or during college life experiences	Type 1 Diabetes	Qual	12	19 – 26 years	Identity Exploration, Instability, Self-focus, Possibilities
Saylor et al., 2022 ^e	USA	To (1) understand the impact of T1D on workplace relationships (2) explore the transition from an individual, interpersonal, community, and policy perspective	Type 1 Diabetes	Qual	12	18 – 29 years	Identity Exploration, Instability, Possibilities
Skedgell et al., 2021	USA	To characterise protective factors among a large, diverse sample of emerging adults with T1D, based on their perspectives about the resources and strategies they found most helpful to manage diabetes-related challenges	Type 1 Diabetes	Qual	62	M = 19.6 +/-1.3 years	Identity Exploration, Instability, Self-focus, Possibilities
Sparud-Lundin et al., 2010	Sweden	To explore the meaning of interactions with and support of self-management from parents and other significant others for young adults with type 1 diabetes	Type 1 Diabetes	Qual	13 (parents not in this review)	20 - 22 years	Identity Exploration, Self-focus, Possibilities

Author	Country	Aim	Condition	Research Method**	Sample Size	Age Range	Features of EA evident in self-management
Vallis et al., 2018	*See below	To compare clinical, psychological, education and social variables in emerging adults (aged 18–30 years) with Type 1 diabetes with their adult counterparts aged >30 years	Type 1 Diabetes	Quant	139	18 – 24 years	Possibilities

* Algeria, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, Netherlands, Poland, Russian Federation, Spain, Turkey, UK and USA

** Qual (Qualitative), Quant (Quantitative)

^a Articles reporting on the same study sample

^b Articles reporting on the same study sample

^c Articles reporting on the same study sample

^d Articles reporting on the same study sample

^e Articles reporting on the same study sample

Table 2.3
MMAT Quality Appraisal

Qualitative Papers	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	1. Is the qualitative approach appropriate to answer the research question?	2. Are the qualitative data collection methods adequate to address the research question?	3. Are the findings adequately derived from the data?	4. Is the interpretation of results sufficiently substantiated by data?	5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Fredette et al., 2016	Y	Y	Y	Y	Y	Y	Y
Garvey et al., 2014	Y	Y	Y	Y	Y	Y	Y
Hanna & Hansen, 2020	Y	Y	Y	Y	Y	Y	Y
Higham et al., 2013	Y	Y	Y	Y	Y	Y	Y
Johnson & Annesi, 2018	Y	Y	Y	Y	Y	Y	Y
Labore et al., 2017	Y	Y	Y	Y	Y	Y	Y
MacDonell et al., 2015	Y	Y	Y	Y	Y	Y	Y
Markowitz et al., 2019	Y	Y	Y	Y	Y	Y	Y
Pyatak et al., 2013	Y	Y	Y	Y	Y	Y	Y
Pyatak, 2011	Y	Y	Y	Y	Y	Y	Y
Ramchandani et al., 2019	Y	Y	Y	Y	Y	Y	Y
Ritholz et al., 2014	Y	Y	Y	Y	Y	Y	Y
Saylor et al., 2019	Y	Y	Y	Y	Y	Y	Y
Skedgell et al., 2021	Y	Y	Y	Y	Y	Y	Y

Quantitative Papers	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	1. Is the sampling strategy relevant to address the research question?	2. Is the sample representative of the target population?	3. Are the measurements appropriate?	4. Is the risk of nonresponse bias low?	5. Is the statistical analysis appropriate to answer the research question?
Bellin et al., 2013	Y	Y	Y	Y	Y	Y	Y
Campbell et al., 2019	Y	Y	Y	Y	Y	Y	Y
Hanna et al., 2014a	Y	Y	Y	Y	Y	Y	Y
Hanna et al., 2014b	Y	Y	Y	Y	Y	Y	Y
Hanna et al., 2014c	Y	Y	Y	Y	Y	Y	Y
Helgeson et al., 2014	Y	Y	Y	Y	Y	Y	Y
Helgeson et al., 2018	Y	Y	Y	Y	Y	Y	Y
Huisman et al., 2012	Y	Y	Y	Y	Y	C	Y
Kamp et al., 2019	Y	Y	Y	Y	Y	C	Y
Kamp et al., 2020	Y	Y	Y	Y	Y	C	Y
Majumder et al., 2017	Y	Y	Y	Y	Y	Y	Y
McCarty & Grey, 2018	Y	Y	Y	Y	Y	C	Y
Vallis et al., 2018	Y	Y	Y	Y	Y	C	Y

Mixed Method Papers	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	1. Is there an adequate rationale for using a mixed methods design to address the research question?	2. Are the different components of the study effectively integrated to answer the research question?	3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Ersig, 2019	Y	Y	Y	C	N	N	C

* Y (Yes), N (No), C (Can't Tell)

2.3.5 Data Synthesis

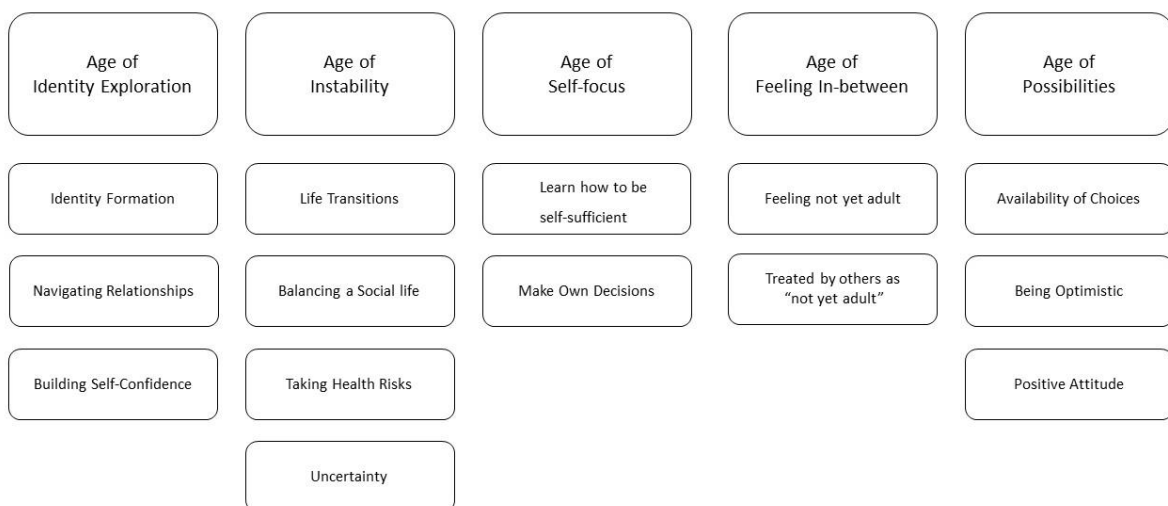
In synthesising the data from the included studies, a data-based convergent QUAL synthesis design (Hong et al., 2017; Pluye & Hong, 2014) was adopted in this systematic mixed studies review. This approach treats the data from all included studies, whether qualitative, quantitative, or mixed methods, as equally important for addressing the research question (Pluye & Hong, 2014). This involved data transformation and for the purposes of this systematic mixed studies review, quantitative data were transformed into qualitative data (Pluye & Hong, 2014). To wholly convert the quantitative data to qualitative, the researcher (OM) followed the recommendations of Gough et al., (2017) and included the broader perspective of the authors' conclusions to report the results for these studies as part of the results. This approach allowed for a full integration of the quantitative findings into the qualitative synthesis, ensuring that no critical information was lost during the transformation process.

Thematic synthesis (Thomas & Harden, 2008) was employed as the method of synthesis following the transformation of the data in this review. Thematic synthesis can range from a "deductive" model, where codes and themes are pre-identified, to an "inductive" model, where codes and themes emerge during the analysis process, and it can also incorporate elements of both approaches (Gough et al., 2017). This systematic review adopted a combined deductive and inductive model (Gough et al., 2017). The free codes and descriptive themes were developed inductively by analysing the self-management findings in conjunction with the definitions of each of the five features of emerging adulthood. The analytical themes were pre-defined as the five features of emerging adulthood, that is the age of; identity exploration; instability, self-focus; feeling in-between; and possibilities (Arnett 2004; 2015).

The thematic synthesis followed the three stages outlined in Thomas and Harden’s framework: first, the free line-by-line coding of the findings from primary studies (in this case, self-management findings); second, the organisation of these free codes into descriptive themes (with some overlap between stages one and two); and finally, the generation of analytical themes (Thomas & Harden, 2008; Gough et al., 2017). In this review, all relevant self-management data from the included papers was read and free-coded line-by-line. These codes were then organised into one or more of the 14 descriptive themes that were developed inductively (see Figure 2.2). In addressing the aim of this systematic review, the analytical themes were pre-defined as the five features of emerging adulthood and the descriptive themes were mapped onto these five features of emerging adulthood.

Figure 2.2

The Five Emerging Adulthood Analytical Themes and Mapped Descriptive Themes



2.4 Results

Database searches yielded 4423 results, with 2221 papers remaining after duplicates were removed. Following the initial screening of titles and abstracts, 1996 papers were removed, with 225 papers remaining for full-text screening and of these 25 papers were identified for inclusion. The reference lists of these 25 papers and three review papers were reviewed with a further 124 papers for full-text screening identified, of which five additional papers were included. Overall, a total of 30 papers were included in this review (see Figure 2.1).

2.4.1 Characteristics of Included Papers

Thirty papers describing 24 studies published between 2010 and 2022 were deemed eligible for inclusion and the characteristics are summarised in Table 2.2. Twenty-six papers were from the USA, one paper from Canada, Sweden, UK, and one paper included participants from 18 countries globally. The papers included qualitative ($n = 16$), quantitative ($n = 13$) and mixed-method ($n = 1$) designs. The LTPC examined were, type 1 diabetes ($n = 22$), inflammatory bowel disease ($n = 2$), asthma ($n = 1$), cystic fibrosis ($n = 1$), neuromuscular conditions ($n = 1$), obesity ($n = 1$), sickle cell disease ($n = 1$) and spina bifida ($n = 1$).

2.4.2 Thematic Synthesis

The analytical themes corresponding to the five features of emerging adulthood, the age of; identity exploration; instability, self-focus; feeling in-between; and possibilities (Arnett 2004; 2015) and their related descriptive themes are described below in detail. Identity exploration has three descriptive themes: identity formation, navigating relationships and building self-confidence. Instability has four descriptive themes: life transitions,

balancing a social life, taking health risks and uncertainty. Self-focus has two descriptive themes: learn how to be self-sufficient and make own decisions. Feeling in-between has two descriptive themes: feeling not yet adult and treated by others as not yet adult. Possibilities has three descriptive themes: availability of choices, being optimistic and positive attitude (See Figure 2.2 above).

2.4.2.1 Analytical Theme 1: The Age of Identity Exploration

The age of identity exploration is reflected in how emerging adults living with and self-managing LTPC are in the process of *identity formation*, exploring and *navigating relationships* and *building self-confidence* in their self-management ability. Exploring and forming their own identity is marked by questions such as “who am I, who and what do I identify with?”, as emerging adults seek to define themselves both personally and within the broader social context. The process of navigating relationships such as peer and romantic others helps to identify and solidify what qualities are important in themselves and others and helps them to gain a broad range of life experiences (e.g., new relationships at college and work). Similarly, navigating changing relationships with parents and healthcare professionals helps them to become more independent and take more responsibility for their own decisions and actions, for example, those related to healthcare and self-management. As they become more independent and take on these responsibilities, this builds self-confidence in their ability to self-manage their condition further solidifying their sense of self. Through these processes, the age of identity exploration is intricately linked with the development of self-management abilities, highlighting the interdependence of personal growth and health management during this formative stage. The age of identity exploration theme was evident in the self-management of LTPC across 25 papers (Bellin et al., 2013; Campbell et al., 2019; Ersig 2019; Fredette et al., 2016; Garvey et al., 2014; Hanna and Hansen, 2020; Hanna et al.,

2014a; Hanna et al., 2014b; Hanna et al., 2014c; Helgeson et al., 2014; Helgeson et al., 2018; Higham et al., 2013; Huismann et al., 2012; Kamp et al., 2020; Labore et al., 2017; Majumder et al., 2017; Markowitz et al., 2019; Pyatak, 2011; Pyatak et al., 2013; Ramchandani et al., 2019; Ritholz et al., 2014; Saylor et al., 2019; Saylor et al., 2022; Skedgell et al., 2021; Sparud-Lundin et al., 2010).

2.4.2.1.1 Descriptive Theme: Identity Formation

Across 16 papers identity formation was evident in participants' self-management strategies and tasks (Fredette et al., 2016; Garvey et al., 2014; Hanna and Hansen, 2020; Hanna et al., 2014a; Hanna et al., 2014b; Higham et al., 2013; Huismann et al., 2012; Labore et al., 2017; Markowitz et al., 2019; Pyatak, 2011; Ramchandani et al., 2019; Ritholz et al., 2014; Saylor et al., 2019; Saylor et al., 2022; Skedgell et al., 2021; Sparud-Lundin et al., 2010). The process of integrating LTPC into one's identity varied among emerging adults. For some, the acceptance of LTPC as part of their identity was a challenging, and at times resisted, process. Participants expressed how it was important to be normal, "I just want to stay as I am... like normal and...do normal things that...it makes me feel better psychologically. Like I'm normal. I'm doing normal things" (Higham et al., 2013: 377). With some participants feeling so strongly about this, they would fight against anything that might affect their "normality", "when it comes to treatment and if there's anything that basically makes me look different or is going to inconvenience me in any way from my normal life style, I'll fight against it" (Higham et al., 2013: 378). Others feared the stigma, leading them to conceal their condition and their self-management tasks "I was embarrassed for having diabetes and I wouldn't like to test or give insulin like in front of anyone" (Hanna & Hansen, 2020: 451).

However, not all struggled to accept their condition as part of their identity. For example, increasing self-care responsibility did not increase worry or decrease life satisfaction for participants who had lived with diabetes for at least nine years, indicating an acceptance of diabetes management as part of their identity and therefore a part of normal life (Hanna et al., 2014b). Moreover, some viewed their condition as a defining aspect of their identity, one that had even contributed positively to their personal growth, “I’ve thought a lot about how I wish that I didn’t have diabetes. But at the same time, I’ve also thought about how it has made me stronger as a person... if I did get the chance to change it, I don’t think I would” (Skedgell et al., 2021: 348).

2.4.2.1.2 Descriptive Theme: Navigating Relationships

As emerging adults leave behind adolescence and journey towards full adulthood, the process of navigating both old and new relationships helps to identify the qualities they value in themselves and others. This helps emerging adults to understand who they are or whom they want to be and determining the kind of people they want to include in their social networks. As these relationships evolve, whether with parents, peers, or healthcare professionals, emerging adults begin to take responsibility for themselves, further building their identity. Efforts to navigate new, current, and changing relationships were evident in self-management strategies and tasks across 22 papers (Bellin et al., 2013; Campbell et al., 2019; Ersig 2019; Fredette et al., 2016; Garvey et al., 2014; Hanna and Hansen, 2020; Hanna et al., 2014c; Helgeson et al., 2014; Helgeson et al., 2018; Higham et al., 2013; Kamp et al., 2020; Labore et al., 2017; Majumder et al., 2017; Markowitz et al., 2019; Pyatak, 2011; Pyatak et al., 2013; Ramchandani et al., 2019; Ritholz et al., 2014; Saylor et al., 2019; Saylor et al., 2022; Skedgell et al., 2021; Sparud-Lundin et al., 2010).

Navigating new personal relationships, particularly in environments such as college or the workplace, significantly impacts the self-management of LTPC for emerging adults. In navigating new relationships in the college environment, participants found themselves having to rely on individuals who may be relatively unfamiliar, such as roommates or colleagues, for essential support. For example, for emergency assistance “I live 2000 miles from home, so I'm in control and I count on my roommate to help out in an emergency. She's a nursing student so I trust her to know what to do...” (Ersig, 2019: 15). However, sometimes not knowing people well enough meant not knowing if they understood the seriousness of a condition “I keep Glucagon in my dorm room. I actually don't think my roommates know how to use it, but I've told them it treats low blood sugar” (Ersig, 2019: 15). In addition, some participants were not always comfortable to carry out essential self-management tasks in the new classroom environment at college, “it’s just that little beep from the monitor, and like I’m obviously, I’m drawing blood from my finger, so someone would be like, ‘what’s that guy doing?’ So . . . it’s just that little aspect of social anxiety, that sometimes keeps me from measuring it in class” (Ramchandani et al., 2019: 491).

This also lends itself to the workplace, where self-consciousness about managing LTPC is also evident. Participants often grapple with the visibility of their self-management tasks, which can lead to feelings of discomfort and fear of stigma among colleagues. For example, one participant highlighted how “the beeps are recognized around the office. It’s like oh that’s that guy who beeps” (Saylor et al., 2022: 153). This heightened awareness of being perceived as different can increase a fear of stigma from colleagues, “I get self-conscious, because I’m like I don’t want people looking at it [glucose level], like they’re going to judge me ... oh, you’re doing a bad job” (Saylor et al., 2022: 153). However, other participants also highlighted the importance of taking proactive steps to mitigate this stigma by educating their work colleagues. By providing accurate information about their condition

and self-management needs, they found that they could reduce misunderstandings and advocate for themselves more effectively, “don’t be afraid to stand up and be like well, as someone who is living with this disease, I can tell you that’s not true. Let me tell you this is actually how it is” (Saylor et al., 2022: 154).

Navigating changing and new “adult” relationships with healthcare professionals involves significant challenges for many emerging adults, particularly as they take on new self-management responsibilities that were previously shared or managed by their parents (e.g., no parents in appointments, being responsible for medication). This change was difficult for many participants in the transition from paediatric to adult care, “one of the hardest things . . . about adult care is rebuilding that relationship” (Ritholz et al., 2014: 43). Furthermore, emerging adults expressed a need for more developmentally appropriate care, “there was this age gap, like between age 18 and 22, when there were very specific lifestyle things that never got discussed either in pediatrics or adult” (Garvey et al., 2014: 194). This lack of insight from healthcare professionals into the lifestyle issues facing emerging adults, such as moving away to college and experiencing a social life was further highlighted, “[they say] don’t drink and don’t do drugs and don’t stay up late, and I’m like, did you go to college? Because, obviously not. Everyone’s going to do these things. You need to say yes, you shouldn’t drink – but if you do, then A, B, C, and D” (Pyatak et al., 2013: 713).

However, some participants reported a more positive experience, particularly when a collaborative approach was implemented by their new healthcare team. This team approach helped them to develop their new identity as an emerging adult and feel more empowered, “it definitely feels like a team because everyone is involved and you talk to them as though they’re, you’re on equal terms in the sense that you are all just trying to make you better” (Markowitz et al., 2019: 5). This sense of collaboration fostered a more supportive environment where emerging adults felt respected and involved in their care decisions.

Moreover, some emerging adults took proactive steps to find healthcare providers who understood the unique challenges of this developmental stage. One participant went to a number of endocrinologists until they found one specifically for young adults that understood emerging adulthood: “everyone actually knew . . . that I drink, and I don’t always eat what I should. There are just things that are realistic, that kids do, and so many doctors act like it doesn’t happen” (Pyatak, 2011: 466). This highlights the importance of healthcare professionals who are not only knowledgeable but also realistic and empathetic towards the lifestyle and challenges faced by emerging adults.

Becoming independent from parents or family is important for emerging adults, particularly in developing their own self-management strategies that fit with whom they are when becoming their own adults. In relation to navigating familial relationships and the self-management of their LTPC, experiences were mixed. Becoming independent in self-management during emerging adulthood was actively supported by parents for some participants, for example, “she [Mother] wasn’t always gonna be there to hold my hand and tell me do this and do that; I would have to do it on my own. She knows I can do it so she let go” (Labore et al., 2017: 73). Others continued to want to rely on parents even when they had moved out of home, “she’s been by my side since the start, she comes with me to the doctors and she knows what it’s all about...” (Sparud-Lundin et al., 2010: 133) and “when I feel sick or I don’t feel like waking up, my mom will check my blood sugar in the middle of the night like she did when I was little.” (Skedgell et al., 2021: 348).

Some participants, however, found their parents unable to let go, stifling their need to become independent. This over-involvement was evident with parents continuing to attend medical appointments and monitoring self-management tasks to ensure they are done correctly, “My mom tells me when dinner is going to be ready, so I can bolus. Sometimes I do, but usually I don’t. If I do it in the middle of the meal, she says, “What did Dr Hunter tell

you? You have to do it before, why are you doing it now?” (Pyatak et al., 2013: 714). In addition, it was found that for some participants, more diabetes-specific conflict and parental responsibility were associated with worse glycaemic control (Campbell et al., 2019). For a smaller number of participants, more fractured family relationships led to poorer self-management. In these cases, self-management tasks were sometimes used as a means to seek attention or express unmet emotional needs. For example, “I’ll tell my mom that I’m not checking my blood sugar and she says, “That’s not good.” But that’s all she says, she doesn’t say “Oh, why don’t you check it now?” ... It’s like I’ll just wait for somebody to tell me. I think it’s just something that I haven’t had, and I want to have just once” (Pyatak et al., 2013: 714).

For emerging adults who are navigating relationships with significant others while carrying out self-management of LTPC, they often find themselves in a process of exploring what qualities they value in others, as well as what their partners value in them. For some in relationships with significant others it was important that the partner show interest “rather than that he doesn’t bother about it, that would feel like he doesn’t care about me as a person” (Sparud-Lundin et al., 2010: 134). However, while the interest and support of a partner were valued, participants did not expect their significant others to take on the responsibility for their self-management, especially if the partner lacked the necessary understanding or experience “he doesn’t really understand this with insulin injections” (Sparud-Lundin et al., 2010: 134). Moreover, the dynamics of these relationships could also affect how participants perceived themselves and their roles within the relationship. For example, one participant felt bad for her partner due to being sick, maybe challenging her identity as a significant other, “I’ve been really poorly, it hasn’t made anything bad between my partner and our relationship, but I just feel awful sometimes because I’m just in bed all the time or I can’t do anything and he has to do everything” (Higham et al., 2013: 378).

2.4.2.1.3 Descriptive Theme: Building Self-Confidence

Self-confidence comes as emerging adults become more certain about who they are. Feeling not confident or confident in self-management tasks was evident across 13 papers (Fredette et al., 2016; Hanna and Hansen, 2020; Hanna et al., 2014a; Hanna et al., 2014b; Higham et al., 2013; Huismann et al., 2012; Markowitz et al., 2019; Pyatak, 2011; Pyatak et al., 2013; Saylor et al., 2019; Saylor et al., 2022; Skedgell et al., 2021; Sparud-Lundin et al., 2010). For some, a lack of support or unresolved identity struggles led to feelings of inadequacy and failure in managing their condition. For example, the participant mentioned previously who had no support from family and acted out to get attention, felt “I’m failing. I’m not even near the finish point. The starting line is right here, and I’m not getting far ... I want to get there so bad, it’s just I don’t know how to go about it ... There are days when I wake up and think, God, I feel like such a failure” (Pyatak et al., 2013: 715). Other participants expressed a lack of confidence due to fear of drawing attention to their condition in social settings “I still do umm, sort of with the tablets and taking medications and stuff. I have a little bit of a shuffle under a table. I’m not very open about things like that” (Higham et al., 2013: 378).

Conversely, participants who had developed a stronger sense of identity exhibited greater confidence in performing self-management tasks, even in public settings. For example, one participant stated, “I’ve gotten to a point where I’m comfortable sitting down at a table and just taking insulin” (Hanna & Hansen, 2020: 451). This confidence also empowered participants to advocate for themselves in social situations, for example when dealing with peer pressure to socialise, “it’s [diabetes] forced me to be even more assertive than I already was and especially when it comes to say being ill. ... If there is partying or

events if I say like, ‘No, listen I can't come. This makes my immune system more compromised than yours and I need to recover’” (Saylor et al., 2019: 78).

2.4.2.2 Analytical Theme 2: The Age of Instability

The age of instability is reflected in how emerging adults living with and self-managing LTPC are planning how to get from adolescence to adulthood and making that transition. This plan is subject to the instability of different *life transitions*, trying to *balance a social life, taking health risks and uncertainty*. During this period there can be numerous life transitions (e.g., starting college or a new job) which can mean revisions to the plan (e.g., changing college major or dropping out, changing jobs, moving homes). Importantly, many of these transitions are driven by identity explorations such as moving in with roommates or a significant other. This means that identity exploration and instability often go hand in hand. The transitional nature of this period can also mean emerging adults have more opportunities to socialise (e.g., college) and now have the freedom to decide if they want to socialise more frequently. Emerging adults with LTPC may have an extra challenge in trying to balance their social life with their self-management tasks. This period of instability is further complicated by the decisions emerging adults may make that involve health risks, such as missing medication or neglecting other aspects of their self-management regimen in favour of social activities. For some, the cumulative effect of these transitions and social pressures can lead to increased uncertainty, particularly in areas such as relationships, finances, and future plans. This theme of instability was reflected across 20 papers (Campbell et al., 2019; Ersig 2019; Fredette et al., 2016; Garvey et al., 2014; Hanna and Hansen, 2020; Hanna et al., 2014a; Helgeson et al., 2014; Higham et al., 2013; Johnson and Annesi, 2018; Labore et al., 2017; MacDonell et al., 2015; Markowitz et al., 2019; McCarty and Grey, 2018; Pyatak,

2011; Pyatak et al., 2013; Ramchandani et al., 2019; Ritholz et al., 2014; Saylor et al., 2019; Saylor et al., 2022; Skedgell et al., 2021).

2.4.2.2.1 Descriptive Theme: Life Transitions

Life transitions, such as moving out of home, going away to college, starting work and transitioning to adult healthcare make emerging adulthood a highly unstable stage. During this time, the self-management of LTPC must not only continue but may also require some emerging adults to take on this responsibility independently for the first time. The interaction between life transitions and self-management is evident across 14 papers (Ersig 2019; Fredette et al., 2016; Garvey et al., 2014; Hanna and Hansen, 2020; Johnson and Annesi, 2018; MacDonell et al., 2015; Markowitz et al., 2019; Pyatak, 2011; Pyatak et al., 2013; Ramchandani et al., 2019; Ritholz et al., 2014; Saylor et al., 2019; Saylor et al., 2022; Skedgell et al., 2021).

The transition to college represents a significant challenge for many emerging adults, particularly in managing their LTPC within the context of new routines and environments. This period often requires learning how to incorporate both existing and new self-management tasks into a new schedule. In participants living with obesity, 44% of participants reported that they experienced significant weight gain when they transitioned to college, due to busy schedules, increased access to poor food choices, overeating, and a reduction in extracurricular activities such as sports (Johnson & Annesi, 2018). For example, one participant explains “I was away from my parents and had free reign to do whatever I pleased. I ate out every day, drank alcohol socially, and did whatever I pleased. I have gained 35 pounds since the end of high school [2 years ago], and with the track I am on now, I will continue to gain weight” (Johnson & Annesi, 2018: 5). Similarly, those living with diabetes, faced challenges in maintaining a healthy diet and consistent lifestyle, leading to difficulties

in blood sugar management, “keeping my blood sugar in range is pretty stressful for me. I have become so busy that I completely forget to check my blood sugar for hours and my schedule changes every day so I have a hard time keeping my blood sugars in control” (Ersig, 2019: 14). The impact of blood sugar issues led to further issues such as impaired cognition, missing classes and assignments, even skipping tests (Fredette et al., 2016). This is highlighted by one participant in describing how all-encompassing living with diabetes is “living with diabetes in college is more than a full time job... it [T1DM] takes what parts of college are already anxiety inducing and already challenging and just adds a really thick extra layer to everything. There's really nothing that diabetes doesn't impact as far as like day to day, eating, studying, sleeping, exercising” (Saylor et al., 2019: 76).

Similarly, in transitioning into the workplace, while some experiences were positive, again emerging adults had to figure out how to fit their self-management tasks into their new schedule while also considering how it might impact colleagues. Worrying about the impact of carrying out their self-management tasks on others “brings on a whole new anxiety, because you realize you’re impacting everyone else around you” (Saylor et al., 2022: 155). In situations, where there was a lack of accommodations in the workplace, this also led to anxiety for some participants about asking for support, “it’s even scarier to ask for things ... or say I’m going to be late to work because my blood sugar is low and I can’t drive right now” (Saylor et al., 2022: 156). One participant felt the need to lie to their employer from fear of being judged for not managing their diabetes properly, “I lied, because I was embarrassed, because I was like I feel like I should be more prepared, ... so they’re like oh, I hope your migraine goes away, and I went home and I changed and stuff [insulin pump], and then I realized I need to be prepared” (Saylor et al., 2022: 155).

In healthcare, the transition from paediatric to adult care and changes in self-management targets significantly impacted overall self-management for emerging adults. The

shifting targets of self-management, such as maintaining optimal control of a condition, often left participants feeling as though they were in a continuous struggle, as highlighted by one participant “When I get to the finish point [of good control], it’s not really the finish point, because it’s not like I can stop once I pass it ... It would be another thing for me to just keep going after” (Pyatak et al., 2013: 713). While others felt the changes from paediatric to adult care created instability, “It was just so big, the transition... I had started there since I was 2 months old until 18. I mean they [pediatric providers] see you grow up... They’ve seen every A1C since you were 5 or 6 years old” (Ritholz et al., 2014: 43) and starting again “rebuilding that relationship” (Ritholz et al., 2014: 43). The independence gained from transitioning to adult healthcare coupled with moving away from home to college, meant that one participant was able to “get away” with a minimum amount of self-management, “during college, I went to the endocrinologist once a year, and I didn’t really do much with the information, and nobody really noticed” (Garvey et al., 2014: 194).

2.4.2.2.2 Descriptive Theme: Balancing a Social Life

The many transitions during emerging adulthood, such as college and work, often lead to an increase in the opportunities to socialise outside of college and work schedules. The freedom and independence gained during emerging adulthood means that those living with LTPC often face challenges in balancing their social lives with managing their condition. This balancing act often results in instability, as the competing demands of socialising and self-management create a lack of consistency in maintaining health routines. This was evident across four papers (Garvey et al., 2014; Hanna & Hansen, 2020; Saylor et al., 2019; Skedgell et al., 2021). The necessity of carrying out self-management tasks, such as taking medication or getting adequate rest, often clashes with the desire to participate in social activities, such as drinking alcohol or staying out late. For example, one participant said, “all

throughout college, the biggest thing I struggled with is balancing my health care and social life” (Garvey et al., 2014: 194). A key reason for prioritising socialising over self-management was wanting to fit in and be normal which links back to identity exploration, “as a student, I also want academics to be, you know, front and center as with my social life and friends and my boyfriend and not let diabetes rule... I'm still working on it.” (Skedgell et al., 2021: 350) or those managing conditions like diabetes, social activities such as drinking alcohol or staying up late pose additional risks. Even without consuming alcohol, simply staying up late can interfere with effective self-management, highlighting the difficulties of balancing social life with health needs, “Even without alcohol partying is dangerous. I can live without alcohol, but got to be like everybody else” (Saylor et al., 2019: 76).

2.4.2.2.3 Descriptive Theme: Taking Health Risks

There are several reasons why emerging adults may take risks with their health and it is not always done purposely. Consistency is important for the effective self-management of LTTC, such as taking daily medication or maintaining a regular sleep pattern. A lack of consistency is a health risk and creates instability in carrying out ongoing self-management tasks. Aside from the fact that the pre-frontal cortex can be still developing, affecting emerging adults’ ability to consider the consequences of their actions, other factors also contribute to this inconsistency. Emerging adults may experience burnout from the ongoing demands of managing their condition, leading to lapses in self-care. Additionally, poor planning can result in missed medications or inadequate rest, while the stigma associated with their condition may cause some to avoid necessary health routines in an effort to fit in or avoid drawing attention to themselves. Taking health risks was reflected in 11 papers (Hanna et al., 2014a; Helgeson et al., 2014; Higham et al., 2013; Labore et al., 2017; MacDonell et

al., 2015; Markowitz et al., 2019; McCarty and Grey, 2018; Pyatak, 2011; Pyatak et al., 2013; Ramchandani et al., 2019; Saylor et al., 2019).

Being tired or reaching burnout in carrying out self-management tasks such as checking blood sugars or taking medication was mentioned by a number of participants and led to rebelling and missing such tasks and risking their health. For example, one participant highlighted burnout in that “I was just so sick of testing my blood, ’cause I just didn’t want to do it anymore. So I didn’t do as many tests” (Pyatak et al., 2013: 713). Alternatively, some participants living with diabetes decided to rely on their bodies to tell them how their blood sugar was, even when they knew it was not reliable, “I’m not going to argue that it’s a good way of care, but your body does have signs for what your blood sugar is. It’s not an accurate method, but I know when [it’s] 69 and when it’s 300” (Pyatak, 2011: 465). Anxiety and denial also played a significant role in non-adherence, with some participants acknowledging their awareness of potential health consequences but struggling to accept them, “I know what will happen ... [But] for some reason, it doesn’t hit me. It’s like I know it, but I won’t accept that it’s going to happen” (Pyatak et al., 2013: 714).

Poor planning during social activities often resulted in missed medication doses or other lapses in self-management for some, for example, when socialising, “spend the night at a family member’s house and I didn’t bring my medicine, my inhaler” (MacDonell et al., 2015: 613). Additionally, with socialising, the desire to be normal sometimes meant “sacrificing your perfect A1C to like, have a good time with your friends because like, at the end of the day you just want to be like a normal college student too” (Ramchandani et al., 2019: 488). Moreover, social anxiety and fear of stigma further exacerbated these challenges, preventing some from carrying out necessary self-management tasks in public spaces, as one participant explained, “it’s just that little aspect of social anxiety, that sometimes keeps me from measuring it in class” (Ramchandani et al., 2019: 488). Finally, one paper found that

emerging adults have the lowest percentage of achieving recommended haemoglobin A1c levels, report the fewest blood glucose checks per day, and are more likely to miss insulin doses compared to other age groups (McCarthy & Grey, 2018: 1610).

2.4.2.2.4 Descriptive Theme: Uncertainty

Uncertainty of a situation or the future is unsettling and this lack of knowledge or certainty about an outcome can bring instability to a person's ability or confidence to self-management now or possibly in the future. Familial relationships, for example, can become a source of uncertainty, as highlighted by research showing that increased family conflict and excessive parental responsibility are linked to poorer glycaemic control (Campbell et al., 2019: 7). Financial uncertainty and self-management were highlighted in three papers (Ersig, 2019; Labore et al., 2017; MacDonell et al., 2015), with insurance being the main concern, "[I had difficulty getting my medications] when I was cut off of my insurance through SSI and social security disability. Other than that, I have my medications prescribed but then I can't get maybe one or two of them because they cost so much and my insurance doesn't cover it" (MacDonell et al., 2015: 616). Moreover, uncertainty about the broader future due to living with LTPC was a common theme across three papers (Ersig, 2019; Fredette et al., 2016; Higham et al., 2013), such as how their health might be in the future, "knowing that "...even though I take care of myself and am active, eventually the disease will overcome me" (Ersig, 2019: 15).

2.4.2.3 Analytical Theme 3: The Age of Self-Focus

The age of self-focus is reflected in how emerging adults who are living with and self-managing LTPC navigate the increased autonomy and independence that this developmental stage affords. As they gain greater freedom to *make their own decisions*, such as choosing

what to eat, when to socialise, they are learning *how to be self-sufficient*. This period of self-focus provides an important opportunity for developing and honing essential life skills, including those specifically related to self-management of their LTPC. This means that emerging adults, as independence is gained, have an opportunity to develop or try to improve life skills and for those living with LTPC, self-management skills. Being self-focused was evident in self-management strategies and tasks across 16 papers (Campbell et al., 2019; Ersig 2019; Fredette et al., 2016; Hanna and Hansen, 2020; Huismann et al., 2012; Labore et al., 2017; MacDonell et al., 2015; Majumder et al., 2017; Markowitz et al., 2019; Pyatak, 2011; Pyatak et al., 2013; Ramchandani et al., 2019; Ritholz et al., 2014; Saylor et al., 2019; Skedgell et al., 2021; Sparud-Lundin et al., 2010).

2.4.2.3.1 Descriptive Theme: Learn how to be Self-Sufficient

Learning how to be self-sufficient within self-management was evident across 15 papers (Campbell et al., 2019; Ersig, 2019; Fredette et al., 2016; Hanna & Hansen, 2020; Huismann et al., 2012; Labore et al., 2017; MacDonell et al., 2015; Majumder et al., 2017; Markowitz et al., 2019; Pyatak, 2011; Pyatak et al., 2013; Ramchandani et al., 2019; Ritholz et al., 2014; Saylor et al., 2019; Skedgell et al., 2021). Some participants were just at the beginning of becoming self-sufficient and voiced how they needed to learn more about taking care of themselves, for example, “I want to learn more about [diabetes care], but in a way I’m kind of scared to learn more because I’m going to realize how much more I’m going to have to do to take care of myself” (Pyatak et al., 2013: 713). Others were further along in their self-management journey, learning to become more self-sufficient by learning from past mistakes, similar to trial and error, “a lot of it is learning from your mistakes and just learning as you go to have a better management plan for yourself” (Saylor et al., 2019: 78). For some, the development of self-sufficiency was facilitated by collaborative relationships with

healthcare professionals. These participants appreciated the shift from a directive approach in paediatric care to a more consultative relationship in adult care, where they felt more involved in decision-making, “a two-way conversation... You know when you’re little, at least I felt, changes were kind of forced on you, and now [adult care] it’s more of looking for a solution that’s going to work with who you are and what you do” (Ritholz et al., 2014: 43). For others it was the realisation that their parents were not around anymore to manage their care and that they needed to take responsibility for themselves, “It’s when you’re alone, whether it’s in college or the first time you’re being away from your parents, and you realize that you know, you’re kind of all you have to take care of yourself. That’s the first time when you’re like, ‘My parents aren’t around, I can’t do these things I used to do when I was younger” (Ramchandani et al., 2019: 490).

Many participants reported taking responsibility for themselves in the realisation of the seriousness of their condition, for example, “it’s not a game. [Diabetes] is real for me, it’s like life or death kind of a situation. So, I really just have to do right by it” (Skedgell et al., 2021: 348). With this understanding, planning ahead became an important task and could be as simple as setting phone reminders, checking blood sugar regularly and ensuring to carry the correct insulin doses (Skedgell et al., 2020: 350), or developing a routine, “I would say that’s probably the core routine of my normal weekday . . . bedtimes remain similar, eating times are similar, and then for the diabetic stuff just kind of follows in a natural pattern” (Hanna & Hansen, 2020: 450). Importantly, some participants expressed frustration in how they were being self-sufficient but still experiencing issues and uncertainty, “the fact that I can’t get everything right despite my hard work sometimes extraneous, uncontrollable conditions will impede me and I can’t do anything about it” (Ersig, 2019: 15). The importance of advocating for oneself was also important in order to be able to carry out some self-

management tasks, “that's where I think you have to advocate for yourself and say I need a lunch break” (Saylor et al., 2019: 78).

2.4.2.3.2 Descriptive Theme: Make Own Decisions

Making decisions is an important part of self-focus and self-management as emerging adulthood is a time of taking responsibility for oneself; this was evident across five papers (Huismann et al., 2012; MacDonell et al., 2015; Pyatak, 2011; Pyatak et al., 2013; Saylor et al., 2019). For participants living with early onset neuromuscular conditions, attitudinal autonomy which is associated with goal setting and decision making was positively correlated with quality of life (Huismann et al., 2012). A specific example of decision-making for participants living with diabetes was whether to opt for insulin pump treatment. This decision was complex and multifaceted, reflecting the personal and medical considerations that come into play. For one participant, it meant a difficult decision on whether to leave a clinic with healthcare professionals who were trusted but did not provide this treatment option (Pyatak, 2011: 466). For another, the pump would be a reminder of illness “I just don’t want a medical device attached to me all the time. To me [an insulin pump] is a mini IV, and it would be a constant reminder” (Pyatak, 2011: 466). Yet for another participant it was the best decision as the pump enabled self-control and efficiency “[I remember] feeling like I can’t eat, and all my food was counted to the last second... I was like, I can’t do this. There’s no way that would have lasted” (Pyatak, 2011: 466).

Non-adherence to medication was a common issue among many participants, driven by a variety of reasons, often rooted in the complex nature of emerging adulthood and the quest for autonomy. One prevalent reason for non-adherence was rebellion against the perceived burden of treatment regimens. A participant shared their frustration of having to take two different medications daily, “basically, when I had to take the [two different

medications], I was supposed to take it like every day, but I got to the point where I said “I’m not taking it,” because it was too much” (MacDonell et al., 2015: 614). Others justified their non-adherence by believing they could control their condition without medication, “but I think I could, I kinda could be off asthma, like I could have got over my asthma . . . so I really didn’t take my medicine like that” (MacDonell et al., 2015: 614). This reflects a common tendency among emerging adults to test the boundaries of their self-management, sometimes underestimating the necessity of continuous treatment. Making decisions is a way for emerging adults with LTPC to focus on what they consider important, even when these decisions may have negative consequences for their health. For example, one participant who took “vacation” from treatments, “at this point, I make it such a small part of my life, that I can’t do this minimal amount of care forever. It wouldn’t be healthy” (Pyatak, 2011: 464).

2.4.2.4 Analytical Theme 4: The Age of Feeling In-Between

The age of feeling in-between is reflected in how emerging adults living with and self-managing LTPC, during emerging adulthood, can often feel “in-between” adolescence and adulthood, and *feeling not yet adult*. Additionally, emerging adults may encounter situations where they are *treated by others, including healthcare professionals and family members, as “not yet adults”* in the carrying out of their self-management tasks. This unique position of being neither fully adolescent nor fully adult adds an extra layer of complexity to the self-management of LTPC. The age of feeling in-between was evident in self-management strategies and tasks across five papers (Garvey et al., 2014; Kamp et al., 2019; Markowitz, 2019; Pyatak et al., 2013; Ritholz et al., 2014).

2.4.2.4.1 Descriptive Theme: Feeling Not Yet Adult

Feeling not yet like an adult and its interaction with self-management was evident in four papers (Garvey et al., 2014; Kamp et al., 2019; Markowitz, 2019; Ritholz et al., 2014). Some participants felt intimidated by the change to adult healthcare and the expectation that they are now expected to be fully responsible for themselves, for example, “It’s [college] a vulnerable time [...] whoever your doctor is, just because you’re assigned as an adult doesn’t mean you’re necessarily ready to face adult situations” (Garvey et al., 2014: 194) and “independence is a scary thing as much as it is a positive thing” (Ritholz et al., 2014: 44). The feeling of being "in-between" adolescence and adulthood also had practical implications for self-management, particularly in medication adherence. Kamp et al., (2019) using the Inventory of Dimensions of Emerging Adulthood scale (Baggio, et al., 2014), found a correlation between feeling in-between and medication adherence. Participants who reported lower levels of feeling in-between were more likely to adhere to their medication regimen, whereas those with higher levels of feeling in-between were more prone to non-adherence.

2.4.2.4.2 Descriptive Theme: Treated by Others as “Not Yet an Adult”

Some participants found themselves not being treated like an adult in relation to their self-management, sometimes by healthcare professionals and other times by family; this was highlighted in two papers (Garvey et al., 2014; Pyatak et al., 2013). Participants reported some healthcare professionals lecturing them if they reported non-adherence and highlighted that the responses were often not relevant to emerging adults’ lifestyle, “[They say] don’t drink and don’t do drugs and don’t stay up late, and I’m like, did you go to college? Because, obviously not. Everyone’s going to do these things” (Pyatak et al., 2013; 713). In addition to professional care, familial involvement in healthcare also appeared to blur the lines of independence for some emerging adults; one participant highlighted how their mother was

still attending medical appointments and monitoring them at home even though they were in adult care (Garvey et al., 2014, p. 714).

2.4.2.5 Analytical Theme 5: The Age of Possibilities

Emerging adulthood while being a time of instability is also the time of greatest opportunity for emerging adults living with LTPC. It is full of possibilities, has an *availability of choices* about the future and filled with high hopes and expectations. In relation to self-management, there is the freedom to choose to do what suits them in relation to their lifestyle at a moment in time, even if it may negatively affect their health in the future. There is the ability to be *optimistic* about a future full of possibilities even living with LTPC which can encourage emerging adults to develop a *positive attitude* about their condition and the self-management of said condition. Such an outlook may foster resilience and a proactive approach to self-management. The age of possibilities was evident in self-management strategies and tasks across 16 papers (Ersig 2019; Fredette et al., 2016; Hanna et al., 2014a; Hanna et al., 2014b; Higham et al., 2013; Labore et al., 2017; Johnson and Annesi, 2018; MacDonell et al., 2015; Pyatak, 2011; Pyatak et al., 2013; Ramchandani et al., 2019; Saylor et al., 2019; Saylor et al., 2022; Skedgell et al., 2021; Sparud-Lundin et al., 2010; Vallis et al., 2018).

2.4.2.5.1 Descriptive Theme: Availability of Choices

Being a time of many possibilities can provide choices for emerging adults, before making the self-management decision that suits them. This was evident across five papers (Johnson & Annesi, 2018; MacDonell et al., 2015; Pyatak, 2011; Pyatak et al., 2013; Saylor et al., 2019). It may be as simple as the choice to take medication or not: “this medicine was getting on my nerves . . . I just went in a big old drawer and just looked at all the medicine

that I had to take for my asthma. It was ridiculous, so I wrote on the drawer, “Do not take medicine” and I did [not take it] for a week” (MacDonell et al., 2015: 614). For others, feeling overwhelmed by having so many choices available often led to poor self-management decisions, for example, in participants living with obesity, being away from home meant they could eat what they wanted when they wanted “I didn’t have my mom there telling what to eat and what not to eat. I didn’t know how to cook. So, I just ate fast food” (Johnson & Annesi, 2018: 6). Similarly, being on “all you can eat” meal plan at college, “it is easy to just go to the commons [dining hall] and eat all the unhealthy food” (Johnson & Annesi, 2018: 7).

2.4.2.5.2 Descriptive Theme: Being Optimistic

Being optimistic about living with LTPC and in carrying out self-management strategies and tasks was evident across seven papers (Ersig, 2019; Fredette et al., 2016; Pyatak, 2011; Pyatak et al., 2013; Skedgell et al., 2021; Sparud-Lundin et al., 2010; Vallis et al., 2018). Being hopeful can help emerging adults living with LTPC be confident about the possibility of managing their condition in the future and to maintain a positive outlook on their overall life trajectory. For example, “You can still live the life you would live without diabetes” (Skedgell et al., 2021: 348). Several participants identified optimism as helping them to change from negative to positive ways of thinking leading to them to be successful with their goals, such as improved glycaemic control (Fredette et al., 2016; 1603). However, this optimism sometimes bordered on denial, where participants displayed an unrealistic expectation that poor self-management behaviours would not lead to negative consequences. For example, a participant was in denial about the consequences of high blood sugar, “I know what will happen ... [But] for some reason, it doesn’t hit me. It’s like I know it, but I won’t accept that it’s going to happen” (Pyatak et al., 2013: 714) and another was “hoping that

should an emergency arise, emergency medical services will be able to assist me” (Ersig, 2019: 15).

2.4.2.5.3 Descriptive Theme: Positive Attitude

Having a positive attitude allowed participants to not catastrophise about their condition which allowed them to stay open to possibilities and be hopeful. This was evident across eight papers (Fredette et al., 2016; Higham et al., 2013; Labore et al., 2017; Markowitz et al., 2019; Pyatak, 2011; Ramchandani et al., 2019; Saylor et al., 2019; Skedgell et al., 2021). This positive attitude was often seen in self-talk by participants, to stay in the present moment, which is an important self-management tool, rather than worrying or catastrophising about the future, “It’s more ‘what’s life like in the present’ rather than what’s in the future” (Higham et al., 2013: 377) or “I have to deal with it [SCD] for the rest of my life. So you take it day-by day, just live every day” (Labore et al., 2017: 74). For some, a positive attitude was cultivated through education and engagement with their condition, which transformed their perspective. One participant described how learning about diabetes allowed them to view their condition in a more positive light, “I feel like I can make an impact now. I knew nothing about diabetes before and now I know about it. I donate to the cause and I do walks and I have been able to meet a lot of people too . . . it seems that’s been a positive . . . a network and feeling like I have a cause I care about” (Fredette et al., 2016: 1604).

2.5 Discussion

This review found that the five features of emerging adulthood are present in the self-management strategies and tasks of emerging adults living with LTPC. Furthermore, it found that emerging adulthood is a particularly unstable and diverse time, marked by numerous life transitions for those living with LTPC. These transitions require a balancing act which can

pose significant challenges to successful self-management, sometimes increasing the risks to both current and long-term health outcomes.

In this review, the emerging adulthood feature, the age of identity exploration, was strongly evident in self-management, as emerging adults with LTPC found out who they were, while navigating relationships and building their self-confidence. Exploring one's identity is a complex process that can be further challenged with LTPC. For some emerging adults, accepting their condition and integrating it into their identity had a positive impact on their self-management (Hanna et al., 2014b; Skedgell et al., 2020). However, the desire to "feel" normal (Higham et al., 2013) was a common theme, with some emerging adults feeling that it was important to fight against being different, going to great lengths to avoid appearing different from their peers (Higham et al., 2013). This struggle for normalcy sometimes meant making decisions that led to poorer self-management. Additionally, the stigma of living with LTPC caused some emerging adults to hide their self-management tasks from others, even at times, missing carrying them out altogether (Hanna & Hansen, 2020).

Emerging adulthood is a developmental stage during which emerging adults explore and expand their networks beyond the family (Hopmeyer et al., 2022; Wiebe et al., 2016). Previous research has highlighted that in addition to being important for the transition to adulthood, navigating shifting interpersonal influences and changes to support systems (e.g., familial support) is also important for the self-management of LTPC during emerging adulthood (Shelley et al., 2020; Rasalingam et al., 2021; Wenstzell et al., 2020). This review provides support for this in highlighting the changes in support systems (e.g., college peers) and how relationships, especially family, can act either as a facilitator or as a barrier to self-management. It also finds that for many emerging adults with LTPC, their ability to self-manage effectively is closely tied to building confidence and further developing their sense of self. Emerging adults reflected on positive facilitators that allowed them to take on more self-

management responsibilities with increased confidence as they became more independent, such as supportive parents (Labore et al., 2017), peers taking on more important support roles (Ersig, 2019) and new healthcare relationships with professionals that understand the lifestyle issues of emerging adulthood (Pyatak, 2011; Markowitz et al., 2019). Conversely, other emerging adults highlighted relationship barriers that affected their ability and confidence to self-manage such as too much parental control (Campbell et al., 2019; Pyatak et al., 2013), continued reliance on parents to carry out self-management tasks (Skedgell et al., 2021; Sparaud-Lundin et al., 2010) and some highlighted their need for more developmentally appropriate healthcare (Garvey et al., 2014; Pyatak et al., 2013). Future research on emerging adults living with LTPC should consider how navigating relationships may impact the ability of an emerging adult to take on responsibility for self-management tasks and the important role this plays in forming their identity as an adult.

The age of instability brings numerous life transitions, as emerging adults are transitioning to college or the workplace, moving out of home and expanding social and support networks (Wiebe et al., 2016). Previous research has found that during this period emerging adults have many competing priorities (Audulv et al., 2009) and those living with LTPC face significant challenges in balancing their social environments with the demands of their treatment regimens (Shelly et al., 2020). This review supports these findings, highlighting that the life transitions associated with college, work, and moving out can negatively impact the ability of emerging adults to consistently carry out self-management tasks, such as taking medication, maintaining healthy eating habits, and getting adequate rest and exercise (Ersig, 2019; Johnson & Annesis, 2018; Saylor et al., 2019; Saylor et al., 2022). Furthermore, the newfound independence and freedom to socialise can make this a time of experimentation and taking risks (Arnett 2004; 2015). This can further complicate the carrying out of self-management tasks, the desire to fit in socially, combined with

opportunities to engage in activities like drinking alcohol or staying up late, can impede the adherence to treatment regimens and pose additional health risks (Garvey et al., 2014; Hanna & Hansen, 2020; Saylor et al., 2019; Skedgell et al., 2021). The existing evidence does not elucidate how instability might vary between emerging adults; however, the findings suggest that it is important to consider how unstable this period may be and how it is a time of heightened experimentation and risk-taking. This understanding is essential for developing more developmentally appropriate support systems that cater to the unique self-management needs of emerging adults living with LTPC.

The age of self-focus allows emerging adults the freedom from restrictions and obligations typically associated with adolescence, to focus on themselves and learn how to become self-sufficient (Arnett 2004; Arnett 2015). Reflective of this period of self-focus is that the two most valued criteria regularly reported in previous research by emerging adults for becoming an adult are accepting responsibility for themselves and making independent decisions (Arnett 1997; 1998; Sharon 2016). Accepting responsibility and making decisions are also both important skills for successful self-management (Lorig & Holman, 2003). In line with this, this review highlighted the relevance of this feature of emerging adulthood in the self-management strategies and tasks for emerging adults with LTPC. For example, the findings provide evidence that emerging adults living with LTPC know that they need to take responsibility for their own healthcare and self-management as they become more independent from their parents (Ramchandani et al., 2019). Many begin a trial-and-error process (Saylor et al., 2019) that enables them to begin to implement plans and routines that fit in with their busy lives (Hanna & Hansen, 2020; Skedgell et al., 2021). However, others are still in the early stages of learning how to become self-sufficient in their self-management and may be uncertain of where or how to start (Pyatak et al., 2013), thus requiring more support. In addition, this review shows that for decision-making related to implementing self-

management strategies, emerging adults often need non-judgmental support that considers their lifestyle, such as considering the reasons behind the decision to be non-adherent to medication, for example, the experiences of side effects and signs of burnout (MacDonell et al., 2015). Understanding how self-sufficient an emerging adult is in their ability to self-manage and furthermore, considering what their lifestyle needs are (e.g., schedules, socialising) for their self-management decision-making process can help healthcare professionals to determine what level of self-management support is necessary.

The age of feeling in-between is about how emerging adults feel “on the way” to adulthood but not quite there, feeling “in-between” adolescence and full adulthood (Arnett, 2001; Nelson & Barry, 2005; Reifman et al., 2007). The findings of this review show that emerging adults living with LTPC feel “in-between” and can feel intimidated and not fully ready for the challenges of adult healthcare and taking on self-management responsibilities (Garvey et al., 2014; Ritholz et al., 2014). Notably, one study (Kamp et al., 2020) utilised a specific emerging adulthood measure, a shortened version of the Inventory of Dimensions of Emerging Adulthood scale (Baggio et al., 2014) and found a significant correlation between higher scores on "feeling in-between" and greater non-adherence to medication. In addition to feeling in-between, some emerging adults found themselves not being treated as adults by parents and/or some healthcare professionals which could also act as a barrier to taking on self-management responsibilities (Garvey et al., 2014; Pyatak et al., 2013). This aligns with research indicating that most parents perceive their children as no longer adolescents but not yet fully adults, further complicating the transition to self-management (Nelson et al., 2007). To better understand the impact of this transitional stage on self-management, future research should incorporate emerging adulthood scales to assess the extent to which emerging adults experience each of the five features of emerging adulthood and how this relates to taking on self-management responsibilities.

Emerging adulthood, despite its inherent instability, is a period marked by optimism, positivity, and numerous possibilities, offering emerging adults various choices regarding how they live their lives and the paths they take toward adulthood (Arnett 2004; Arnett 2015). This review found that emerging adults with LTPC can face a range of choices in relation to how they proceed with self-management strategies and tasks. Some emerging adults make their choice based on what fits their busy lifestyle which might lead to a risky decision, such as not taking medication (MacDonell et al., 2015). Others, when faced with a range of choices can feel overwhelmed, resulting again in a poor decision (Johnson & Annesi, 2018). However, this is also a time for optimism and positivity. This review also found that optimism for emerging adults living with LTPC can work in two ways in relation to self-management. Firstly, some emerging adults were optimistic about their future and believed that self-managing LTPC would not hold them back nor narrow their future possibilities (Skedgell et al., 2021). While secondly, other emerging adults tended to be in denial about the consequences of risky health choices in their self-management, being overly hopeful and optimistic about a positive outcome (Ersig, 2019; Pyatak et al., 2013). In line with previous research (Rasalingam et al., 2020), this review found that having a positive attitude, particularly one focused on staying in the present moment, can help emerging adults reduce anxiety about managing their LTPC in the long term and keep future possibilities open (Higham et al., 2013; Labore et al., 2017). Given these findings, it could be beneficial for healthcare professionals to capitalise on emerging adults' ability to see this period positively as a time of opportunity and work to create positive attitudes around self-management and the future. By framing self-management as a part of the broader array of life possibilities, healthcare providers can help emerging adults view this developmental stage as a time of opportunity rather than limitation.

2.6 Strengths and Limitations

The main strength of this systematic review is that it is the first to specifically examine self-management during emerging adulthood through the lens of Arnett's Theory of Emerging Adulthood. By doing so, it highlights how the features of emerging adulthood can act as a barrier or a facilitator to successful self-management and the balancing act required to successfully navigate having LTPC during this developmental stage. The findings help researchers and healthcare professionals to understand the complexities of emerging adulthood and how important this stage is for setting up positive self-management skills for the future. The findings also contribute valuable insights to both the wider emerging adulthood and self-management literatures about the needs and challenges of the emerging adulthood population living with LTPC.

There were also limitations to this review. Firstly, only English language papers were included which means some important results may have been missed through publication bias. Secondly, as recommended by Hong et al., (2018), in the quality appraisal, papers are not assigned grades for how low or strong they are methodological-wise. This may mean that some low-quality papers may have contributed little to the overall aim. Thirdly, we chose only to include papers on emerging adults aged 18 – 29 years, it is possible that parents, peers and healthcare professionals may have useful information to add. Finally, the quantitative papers had limited data which may have limited their contribution to the synthesis.

2.7 Conclusion and Implications for Thesis

In conclusion, this systematic review highlights the importance of researching emerging adults living with LTPC as a group that is distinct from adolescence or adulthood, as many of the challenges faced, fall "in-between" those experienced by either adolescents or full adults. It found that emerging adults living with LTPC experience the five features of

emerging adulthood within the context of their self-management. Emerging adults living with LTPC engage with self-management strategies but can face challenges due to the many life transitions and the balancing act between these transitions and managing a condition, that make this a highly unstable developmental stage. This systematic review demonstrates that there is a clear need for a greater understanding of how much an emerging adult living with LTPC is experiencing emerging adulthood, in that, to what extent each of the five features is present and of the challenges posed to self-management (e.g., social support). Furthermore, it is particularly noteworthy that of the 30 papers included in the review, none compared emerging adults living with LTPC to their peers who are not living with LTPC.

Understanding if there are similarities or differences between the two groups would add to the wider knowledge of the experience of emerging adulthood and the self-management of LTPC. Overall, exploring the five features of emerging adulthood and self-management could have important implications for emerging adults living with LTPC. It could inform and assist healthcare professionals in providing support and designing more targeted self-management supports or interventions in the future that better address the unique challenges faced by emerging adults with LTPC.

Chapter 3: Emerging adults living with Long-Term Physical Conditions in Ireland: A Secondary Analysis of The Growing Up in Ireland Wave Four of Cohort '98 Dataset

3.1 Overview of Chapter

This study is a cross-sectional secondary data analysis of the Growing Up in Ireland (GUI) dataset, specifically Wave Four of Cohort '98. GUI is the national population-based longitudinal cohort study of children and young people, funded by the Government of Ireland through the Department of Children, Equality, Disability, Integration and Youth. It was established to examine the factors that shape critical stages of development across the lifetime (ERSI, n.d.). Using the GUI dataset, this study seeks to compare emerging adults living with LTPC to their peers living without LTPC, to identify if and how they vary in their experiences of emerging adulthood using Arnett's Theory of Emerging Adulthood. In this chapter, the background, aim, methods, results and discussion of this study are outlined. As a note to this chapter, disability is used as a term alongside LTPC as the GUI study and published studies from the various datasets use this term. It is important to highlight that not all people living with LTPC would consider themselves to have a disability.

3.2 Rationale and Background

As identified in the systematic review (Chapter Two), and in the broader self-management and emerging adulthood literature few studies have explored the comparative experience of emerging adults living with LTPC to their peers without LTPC through the lens of Arnett's Theory of Emerging Adulthood, that is, specifically examining the five features: identity exploration, instability, self-focus, feeling in-between and possibilities. Emerging adults living with LTPC likely experience the normative features of emerging adulthood but face additional challenges during this time, such as transitioning to adult healthcare and

increased self-management responsibilities for their LTPC. Consequently, the degree to which they experience the features of emerging adulthood might vary due to living with LTPC. Understanding how they navigate this developmental stage in comparison to their peers can guide future research and healthcare policy. It can help healthcare professionals identify areas of concern for emerging adults with LTPC, improving the development of care strategies and support systems tailored to their unique needs.

3.2.1 Population-Based Studies

Population-based studies are typically longitudinal, featuring large datasets of high quality that are representative of significant populations of interest. They are often commissioned and stored by organisations, such as government-funded agencies (Pienta et al., 2011), are usually available for use as secondary data, and made available through open source, at little or no cost to other qualified researchers for comparative analysis (Donnellan et al., 2011; Pienta et al., 2011). These population-based studies have many benefits, such as, the estimation of prevalence rates (e.g., asthma, obesity); the assessment of risk factors over time or during a particular developmental stage (e.g., obesity and heart issues); high quality data; and better external validity, where the findings from a cohort can be generalised back to the population. Furthermore, these studies through secondary analysis often allow for the examination of variables that form part of the dataset but were not part of the original hypotheses (Szklo, 1998). By surveying the same individuals from a population over time, the data provides both point-in-time and over-time evidence for policy, building a rich databank of information. Overall, population studies and secondary analysis of said studies can strengthen national research infrastructure and enable better international comparisons (Growing Up in Ireland, n.d.).

3.2.2 The Growing Up in Ireland Population-Based Study

In Ireland, the main population-based longitudinal study prior to 2000 was the Irish Census of Population, which is carried out every four years (Central Statistics Office, n.d.a). In 2000, the National Children's Strategy published by the Department of Health and Children identified a need for further evidence-based population research related to the well-being of children and childhood (Murray et al., 2010). To achieve this goal, Growing Up in Ireland (GUI), the national longitudinal cohort study of children and young people, was established in 2006. GUI examines the factors that shape critical stages of development across the lifetime (ERSI, n.d.). It covers topics such as family structure, housing, education, work, health, and relationships, aiming to provide a statistical basis for improving future planning, decisions, and policies about services for children, young adults, and their families in Ireland (Central Statistics Office, n.d.b). GUI began in 2006, following two cohorts of children: Cohort '98, born in 1998, and Cohort '08, born in 2008 (Central Statistics Office, n.d.b). The GUI datasets are available for secondary analysis upon request by qualified researchers. GUI has offered researchers the opportunity to examine various aspects of child and adolescent development through the previous Waves of both Cohorts. This current Wave Four of Cohort '98 at aged 20 years, offers researchers the opportunity to cross-sectionally examine participants who are in emerging adulthood.

Bronfenbrenner's (1972) bio-ecological model serves as the underlying conceptual framework for the longitudinal GUI study as it proposes that a person's developmental outcomes are influenced by both the person's biological make-up and their environment. Notwithstanding this, it was recognised in finalising the procedures and questionnaires for Wave 4 that the participants who were now 20 years of age were entering a new and different phase of their lives (emerging adulthood) and that this needed to be reflected in new topics, scales and questions (O'Mahoney et al., 2021). To this end, McNamara et al (2021) refer to

Arnett's work when referring to the inclusion of some new items related to the transition to adulthood, for example, risk-taking, and whether participants consider themselves either adults or not adults, or rather in-between both. To the researcher's knowledge, to date the data from Wave 4 has not been analysed through the lens of Arnett's theory, specifically, the five features of emerging adulthood (O'Mahony et al., 2021). GUI also gathers data about disability. This is structured in a way that allows for emerging adults living with LTPC to be identified separately as a group and therefore, allows a comparison with their peers who do not have LTPC. This affords us the opportunity to carry out a secondary analysis of emerging adults living with LTPC and their peers without LTPC, during emerging adulthood in Ireland. By comparing these two groups, we aim to understand how LTPC affects the experience of emerging adulthood.

There is a small body of research using GUI data that has explored disability using various definitions, focusing on younger cohorts and with different objectives. One study that examined 13-year-olds with disabilities noted disparities based on gender and socio-economic status and found that these children were more likely to report disliking school and experiencing bullying (Gallagher et al., 2020). Another study investigated socio-economic factors affecting children with disabilities, with a subgroup who had migrant status. Migrant status was not found to affect socio-economic outcomes, but impairment status did. Impairment was significantly associated with gender, primary caregiver educational attainment and household income (Swift et al., 2021). Additionally, research on special education needs (SEN) and cumulative disadvantage in early school leaving and post-school pathways found that children identified at age 9 with SEN were at higher risk of early school leaving, particularly in socio-economically disadvantaged contexts (Carroll et al., 2022a). In a related study, the researchers found that, all else being equal, individuals with disabilities had higher progression rates to further education and training but lower participation in

degree courses at universities (third-level education) compared to their peers (Carroll et al., 2022b). Additionally, a study on the economic impact of chronic child disability confirmed significant financial challenges for families, resulting in reduced income and overall standard of living due to the extra costs associated with disability (Roddy, 2022). To the researcher's knowledge, prior to the current secondary analysis, there are no published studies specifically on emerging adults living with LTPC using GUI data.

3.2.3 Arnett's Theory of Emerging Adulthood

Arnett's Theory of Emerging Adulthood (Arnett, 2004; 2015) defines this developmental stage by five features: identity exploration, instability, self-focus, feeling in-between, and possibilities (see Chapter 1.7 for details).

To navigate emerging adulthood successfully, with or without a LTPC, involves various risk and protective factors across personal (e.g., identity formation), social (e.g., peer networks), and family domains as autonomy develops (Kaniušonytė & Žukauskienė, 2018; Nice & Joseph, 2023; Wood et al., 2018). Choices made during this time can set an emerging adult up for positive outcomes in the future (Nelson, 2021). Although emerging adulthood is known for peak health (Murray et al., 2020), challenges during emerging adulthood can influence the establishment of long-term positive health behaviours for the future, such as regular healthy eating and exercise (Daw et al., 2017; Nelson et al., 2008). For those emerging adults who are living with LTPC, they also need to build self-management strategies and routines as poor management can lead to long-term health complications (McGeachie et al., 2016).

3.3 Aim of this Secondary Analysis of GUI data

In industrialised countries like Ireland, emerging adults experience profound changes in education, employment, and personal relationships, which shape their future trajectories. During this time, personal, social, and family factors are influential in helping to navigate emerging adulthood successfully. Emerging adults with LTPC likely experience the normative features of emerging adulthood but may face additional challenges. The degree to which they experience emerging adulthood might vary due to living with LTPC, and for emerging adults living with LTPC, this is currently not known.

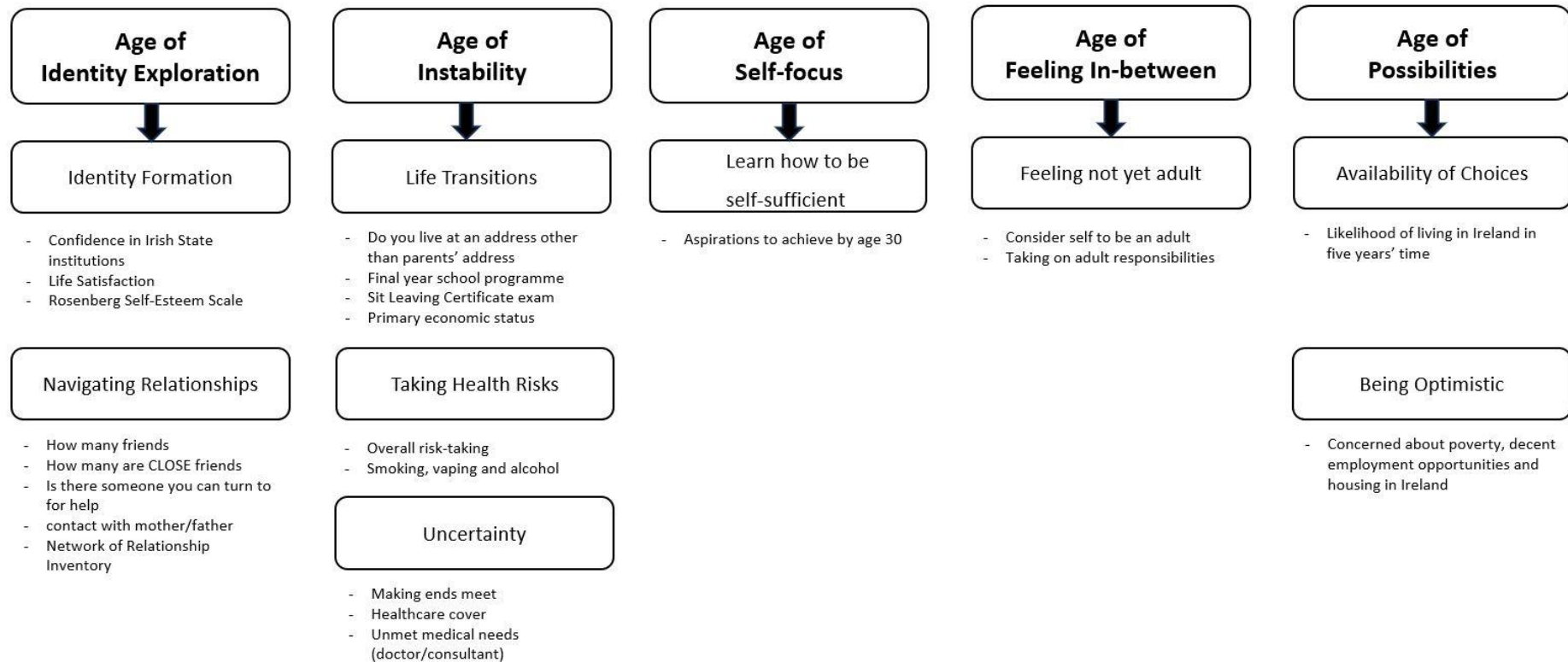
To address this, the aim of this study is to conduct a cross-sectional, secondary analysis of the Wave 4 dataset of the GUI study, Cohort '98, which consists of emerging adults aged 20 years. This secondary analysis seeks to compare emerging adults living with LTPC to their peers living without LTPC, to identify if and how they vary in their experiences of emerging adulthood.

3.3.1 Objectives and Hypotheses

In identifying if and how emerging adults with and without LTPC vary in their experiences of emerging adulthood using the five features of Arnett's Theory of Emerging Adulthood, a series of objectives and hypotheses were developed and tested. The five features of Arnett's Theory of Emerging Adulthood are examined by mapping (see section 3.4.5 for more details on mapping) relevant questions or scales from the GUI Wave Four's questionnaire onto each feature; the age of identity exploration, the age of instability, the age of self-focus, the age of feeling in-between and the age of possibilities (see Figure 3.1).

Figure 3.1

Relevant GUI questions mapped onto the five features of emerging adulthood



Objective 1: To determine whether there are differences or associations between two emerging adult groups (living with LTPC and without LTPC) on key variables in the GUI dataset related to identity exploration. These variables are grouped based on relevance to identity formation (measured by Confidence in State institutions, Life Satisfaction, and the Rosenberg Self-Esteem Scale) and navigating relationships (measured by friendships, parental relationships, and general family relationships).

Hypothesis 1.1: Confidence in state institutions relates to identity formation as emerging adulthood is a time for resolving any identity conflicts by forming values, beliefs and opinions about the world, for example, religion and politics. While there is limited evidence on how emerging adults with LTPC perceive Irish State institutions (church, education, police, social welfare, healthcare, politicians, courts and media), previous research highlights that as children and adolescents they may have experienced bullying in school (Gallagher et al., 2020), as emerging adults living with LTPC they face difficulties in transitioning to adult healthcare services (Wentzell et al., 2020), and overall, they have an increased risk of economic hardship for the future (Indecon International Research Economists, 2021). Therefore, it is hypothesised that there will be no significant association between group membership (LTPC vs. no-LTPC) and Confidence in State institutions, except for education, social welfare, and healthcare institutions. Emerging adults with LTPC are expected to report lower confidence in these three institutions.

Hypothesis 1.2: Identity exploration during emerging adulthood is about finding out who you are as a person (Arnett, 2004, 2015), and life satisfaction is about how you feel about your life at a point in time (Diener, 1984). Previous research has found a significant reduction in health-related quality of life associated with 308 different chronic conditions (Van Wilder et al., 2019). Therefore, it is hypothesised that emerging adults with LTPC will report lower levels of life satisfaction in comparison to their peers.

Hypothesis 1.3: While some emerging adults accept their condition as part of their identity (Hanna et al., 2014b), it can be more complex for others who struggle with acceptance (Higham et al., 2013). As there is mixed evidence, it is hypothesised that emerging adults living with LTPC will report similar levels of self-esteem to their peers.

Hypothesis 1.4: Emerging adulthood is a time for expanding peer networks and becoming more independent from family (Hopmeyer et al., 2022; Wiebe et al., 2016). Social relationships can act as a risk or protective factor for health (Holt-Lunstad, 2018). For those living with LTPC, some rely on new support networks (Ersig, 2019) and others may hide their condition from peers due to fear of stigma or embarrassment (Ramchandani et al., 2019; Saylor et al., 2022). However, there is insufficient evidence to suggest that emerging adults with LTPC experience friendships differently than their peers. Therefore, it is hypothesised that there will be no significant associations between group membership (LTPC vs. no-LTPC) and the number of friends, close friends, or having someone in life to turn to.

Hypothesis 1.5: During emerging adulthood, family can either facilitate or hinder both the self-management of LTPC (Shelley et al., 2020) and the overall transition through this developmental stage (Arnett, 2006a). Given the mixed evidence on the role of family, it is hypothesised that there will be no significant association between group membership (LTPC vs. no-LTPC) and contact with parents, nor differences between the two groups in terms of the quality of their relationships with their mother and father or overall family cohesion.

Objective 2: To determine whether there is a difference between two emerging adult groups (LPTC vs. no-LTPC) on key variables in the GUI dataset related to the age of instability, specifically focusing on life transitions, taking health risks, and uncertainty.

Hypothesis 2.1: Emerging adulthood is characterised by numerous life transitions, such as moving out of the parental home (Arnett, 2004; 2015). Previous research has

indicated lower rates of achieving certain developmental milestones among those with LTPC, including a 22% lower rate of leaving home (Pinquart, 2014). Therefore, it is hypothesised that there will be a significant association between group membership (LTPC vs. no-LTPC) and living arrangements, with emerging adults living with LTPC expected to report living at home more than their peers.

Hypothesis 2.2: Emerging adults with LTPC have been found to have lower educational attainment than their peers without LTPC (Maslow et al., 2011; Pinquart, 2014). In Ireland, this is supported as people with disabilities also face lower rates of accessing education and employment (Kelly & Maitre, 2021). Previous GUI research found in comparison to peers, those with disabilities had greater progression to further education and training, but lower participation in degree courses in universities (Carroll et al., 2022b). Furthermore, in Ireland, one-third of people with disabilities, compared to two-thirds of people without disabilities, report employment as their main economic status and is the fourth lowest rate in the EU (Kelly & Maitre, 2021). Therefore, it is hypothesised that there will be a significant association between group membership (LTPC vs. no-LTPC) and the type of final second-level education programme taken, sitting the final examination and their primary economic status at the time of the interview. More specifically, it is hypothesised that emerging adults living with LTPC are more likely to have taken the Leaving Certificate Applied or Leaving Certificate Vocational Programme compared to their peers, less likely to have sat the final examination, less likely to study at higher education and more likely to indicate they are unemployed or unable to work or study due to permanent disability or illness.

Hypothesis 2.3: Emerging adulthood is characterised by instability and experimentation (Arnett, 2004; 2015), with high levels of risk-taking being a leading cause of death among 18-25-year-olds in the EU (OECD Library, n.d.). Emerging adults have higher

rates of alcohol and drug use compared to any other age group (Camfield et al., 2017). In Ireland, 42% of emerging adults drink weekly, with 51% of these individuals falling into the problem drinking range (Dooley et al., 2019). Emerging adults, in general, can usually describe the risks associated with behaviours such as smoking, vaping, and drinking alcohol but may be overly optimistic about the potential long-term health consequences of risk-taking (O'Mahony et al., 2021). Research on risk-taking among emerging adults with LTPC typically focuses on health-related risks (e.g., medication adherence, socialising). As outlined in chapter 2, the systematic review found evidence that emerging adults living with LTPC take health-related risks, such as missing sugar checks and medications and in socialising with friends, such as drinking alcohol. Overall, however, there is insufficient evidence to determine if emerging adults living with LTPC engage in fewer risk-taking behaviours than their peers. Therefore, it is hypothesised that there will be no significant associations between the two groups (LTPC vs. no-LTPC) regarding overall willingness to take risks, engaging in risky health behaviours, including smoking, vaping, and the frequency of alcohol consumption (AUDIT).

Hypothesis 2.4: Previous research in Ireland highlights an increased risk of economic hardship associated with having disabilities (Indecon International Research Economists, 2021). Families and individuals with disabilities often experience financial uncertainty with reduced household income and an overall lower standard of living due to the additional costs of disability (Roddy, 2022). Therefore, it is hypothesised that there will be a significant association between group membership (LTPC vs. no-LTPC) and financial hardship, with emerging adults living with LTPC experiencing greater difficulty in making ends meet.

Hypothesis 2.5: Families and individuals with disabilities can experience reduced incomes (Roddy, 2022), contributing to financial uncertainty with an increased risk of poverty (Hale et al., 2015; Indecon International Research Economists, 2021). This can mean

reliance on medical cards, which often entail longer waiting times for healthcare, which can be common among this demographic (Whyte et al., 2020). Furthermore, emerging adulthood is the time when private health insurance cover will be ending, if covered by a parents' private health insurance plan (Parkins, 2024) and when a person begins to be assessed as an adult by the health service executive for eligibility for a medical card (HSE, n.d.b). Therefore, it is hypothesised that there will be a significant difference group membership (LTPC vs. no-LTPC) and medical coverage, and more unmet medical needs, that is, less likely to see a doctor or consultant when they needed to. Specifically, emerging adults living with LTPC are expected to be more likely to rely on a medical card than peers and report more unmet medical needs in comparison to peers.

Objective 3: To determine whether there is a difference between the two emerging adult groups (living with LTPC and living without) on a key variable relating to the age of self-focus, that is, learning to be self-sufficient.

Hypothesis 3.1: Emerging adulthood is a time deemed to have less restrictions and obligations than full adulthood, a time to focus on the self and learn to be self-sufficient, and work towards life goals (Arnett 2004; Arnett 2015). Emerging adults learn how to be self-sufficient by setting goals that they think are important to achieve and begin working towards them. GUI asks emerging adults about their aspirations and how important it is to have achieved certain goals, that reflect becoming self-sufficient, by age 30. The literature indicates that having LTPC can add more challenges, with lower success rates for both developmental and psychosocial milestones (Kelly & Maitre, 2021; Maurice-Stam et al., 2019; Pinguart, 2014; Wood et al., 2018), however it can be very much a time of optimism about the future which may mitigate worries about becoming self-sufficient and achieving goals (Arnett 2004; Arnett, 2015). Therefore, it is hypothesised that there will be no

significant differences between the two groups (LTPC vs. no-LTPC) on each item of what is important to have by the age of 30 (a home, good job, dream job, long-term romantic relationship, child, degree, a year abroad, car, be financially secure).

Objective 4: To determine whether there is a difference between the two emerging adult groups (living with LTPC and living without) on a key variable relating to the age of feeling in-between, that is, feeling not yet adult.

Hypothesis 4.1: Emerging adults, more than any other age group, endorse higher levels of feeling in-between (Arnett, 2001; Nelson & Barry, 2005; O'Mahony et al., 2019; Reifman et al., 2007). For emerging adults living with LTPC, feeling in-between was represented in two ways in the findings of the systematic review (see chapter 2): feeling not yet adult and being treated by others as not yet adult. However, the available research does not provide sufficient evidence to determine how emerging adults living with LTPC endorse feeling in-between or how they perceive to have grown-up in comparison to peers. The GUI study asks all emerging adults if they considered themselves to be an adult and how they perceive themselves to have grown up in comparison to peers. Therefore, it is hypothesised that there will be no significant association between group membership (LTPC vs. no-LTPC) and if they consider themselves to be an adult or how they perceive themselves to have grown up in comparison to their peers.

Objective 5: To determine is there a difference between the two emerging adult groups (living with LTPC and living without) on key variables relating to the age of possibilities, that is, availability of choices and being optimistic.

Hypothesis 5.1: Emerging adulthood is often regarded as a period of great possibilities and opportunities, with many choices for the future and much optimism about

the future (Arnett, 2004; Arnett, 2015). There is no research available to determine how emerging adults living with LTPC might differ on choices for, or optimism about the future. Therefore, it is hypothesised that there will be no significant association between group membership (LTPC vs. no-LTPC) and where emerging adults think they will be living in five years' time.

Hypothesis 5.2: For these same reasons, it is hypothesised that there will be no significant association between group membership (LTPC vs. no-LTPC) and concerns about current issues in Ireland; poverty, employment and housing.

Table 3.1
Objectives and Hypotheses

Objective 1: Age of Identity Exploration	To determine whether there are differences or associations between two emerging adult groups (living with LTPC and without LTPC) on key variables in the GUI dataset related to identity exploration.
<i>Identity Formation</i>	
Hypothesis 1.1	There will be no significant association between group membership (LTPC vs. no-LTPC) and Confidence in State institutions, except for education, social welfare, and healthcare institutions. Emerging adults with LTPC are expected to report lower confidence in these three institutions.
Hypothesis 1.2	Emerging adults with LTPC will report lower levels of life satisfaction in comparison to their peers without LTPC.
Hypothesis 1.3	Emerging adults living with LTPC will report similar levels of self-esteem to their peers without LTPC.
<i>Navigating Relationships</i>	
Hypothesis 1.4	There will be no significant associations between group membership (LTPC vs. no-LTPC) and the number of friends, close friends, or having someone in life to turn to.
Hypothesis 1.5	There will be no significant association between group membership (LTPC vs. no-LTPC) and contact with parents, nor differences between the two groups in terms of the quality of their relationships with their mother and father or overall family cohesion.
Objective 2: Age of Instability	To determine whether there is a difference between two emerging adult groups (LPTC vs. no-LTPC) on key variables in the GUI dataset related to the age of instability.
<i>Life Transitions</i>	
Hypothesis 2.1	There will be a significant association between group membership (LTPC vs. no-LTPC) and living arrangements with emerging adults living with LTPC expected to report living at home more than their peers without LTPC.
Hypothesis 2.2	There will be a significant association between group membership (LTPC vs. no-LTPC) and the type of final second-level education programme taken, sitting the final examination and primary economic status at the time of the interview. It is hypothesised that emerging adults living with LTPC more likely to have taken the Leaving Certificate Applied or Leaving Certificate Vocational Programme, less likely to have sat the final examination, less likely to study at higher education and

Table 3.1
Objectives and Hypotheses

	more likely to indicate they are unemployed or unable to work or study due to permanent disability or illness compared to their peers without LTPC.
<i>Taking Health Risks</i>	
Hypothesis 2.3	There will be no significant associations or differences between the two groups (LTPC vs. no-LTPC) regarding overall willingness to take risks and risky health behaviours, including smoking, vaping, and the frequency of alcohol consumption (AUDIT).
<i>Uncertainty</i>	
Hypothesis 2.4	There will be a significant association between group membership (LTPC vs. no-LTPC) and financial hardship, with emerging adults living with LTPC experiencing greater difficulty in making ends meet.
Hypothesis 2.5	There will be a significant difference between group membership (LTPC vs. no-LTPC) and medical coverage, and more unmet medical needs, that is, less likely to see a doctor or consultant when they needed to. Specifically, emerging adults living with LTPC are expected to be more likely to rely on a medical card than peers and report unmet medical needs in comparison to peers.
Objective 3: Age of Self-Focus	To determine whether there is a difference between the two emerging adult groups (living with LTPC and living without) on a key variable in the GUI dataset relating to the age of self-focus.
<i>Learn how to be Self-Sufficient</i>	
Hypothesis 3.1	There will be no significant differences between the two groups (LTPC vs. no-LTPC) on each item of what is important to have by the age of 30 (a home, good job, dream job, long-term romantic relationship, child, degree, a year abroad, car, be financially secure).
Objective 4: Age of Feeling In-Between	To determine whether there is a difference between the two emerging adult groups (living with LTPC and living without) on a key variable in the GUI dataset relating to the age of feeling in-between.
<i>Feeling not yet Adult</i>	
Hypothesis 4.1	There will be no significant association between group membership (LTPC vs. no-LTPC) and if they consider themselves to be an adult or how they perceive themselves to have grown up in comparison to their peers.

Table 3.1*Objectives and Hypotheses*

Objective 5: Age of Possibilities	To determine is there a difference between the two emerging adult groups (living with LTPC and living without) on key variables in the GUI dataset relating to the age of possibilities.
Hypothesis 5.1	There will be no significant association between group membership (LTPC vs. no-LTPC) and where emerging adults think they will be living in five years' time.
Hypothesis 5.2	There will be no significant association between group membership (LTPC vs. no-LTPC) and concerns about current issues in Ireland; poverty, employment and housing.

3.4 Method

3.4.1 Research Design

The secondary data for this study is drawn from Wave Four of Cohort '98 of the GUI study. Cohort '98 have been followed since age nine and Wave Four has collected data from these participants at age 20 years. Although the GUI study is longitudinal, the additional emerging adulthood data collected during Wave Four, such as questions about feeling adult and taking on adult responsibilities allows for a secondary cross-sectional analysis to examine emerging adults living with LTFC to their peers living without LTFC, to identify if and how they vary in their experiences of emerging adulthood.

The GUI study received ethical approval from the Health Research Board of Ireland's ethics committee in 2006 and 2007 (Murray et al., 2010). Further ethical approval for Wave Four of Cohort '98 was granted by an independent ethics committee convened by the Department of Children and Youth Affairs (McNamara et al., 2021). The data post-collection was anonymised and is stored with the Central Statistics Office. Access was requested through email and approved through the Central Statistics Office (see Appendix A1). The dataset for Wave Four was then received by email with download instructions and a password for the file. No further ethical approval was required to carry out a secondary analysis of the anonymised GUI data.

3.4.2 GUI Wave Four Sample

The GUI participants for Wave Four of Cohort '98 were born between the 1st of November 1997 and the 31st of October 1998. The initial sample for Wave One (8,568 cases) were from a random sample across 910 schools in Ireland. All previous participants were approached to take part in Wave 4, unless they had requested not to be contacted for future waves, not eligible (i.e., moved abroad or young person deceased) or moved with no

forwarding address, with 7,976 eligible. Wave Four consisted of a final sample of 5190 cases (61% of original participants) who were residents in Ireland since the age of 9 years and continued to be residents at age 20 years. This is a reduction since Wave One of 3,378 (Growing Up in Ireland, 2021a). Unlike other Waves, a breakdown of non-responders is not provided, but it is highlighted that it follows similar patterns of non-response that is typical for longitudinal research (McNamara et al., 2021), for example, attrition is typically higher among males, minority groups, one-parent and non-marital households, less-educated and low-income families (Watson and Wooden, 2009). Those from more advantaged backgrounds are over-represented in the Wave Four sample, with 29% in the highest income quintile group, while the percentage in the general population in this quintile is 19%. 13% of the sample are in the lowest quintile group, while the percentage in the general population in this quintile is 22% (McNamara et al., 2021).

3.4.3 GUI Data Collection of Wave Four

Data for Wave Four of cohort '98 was collected by GUI researchers in the cohort's homes, between August 2018 and June 2019. Each participant completed the main interview (questionnaire) face-to-face with a GUI researcher who visited their home, followed by a self-complete section which was done on a laptop provided by the researcher as the questions were deemed to be more sensitive, for example, smoking and alcohol (O'Mahony et al., 2021). Participants were not required to answer questions if they did not wish to.

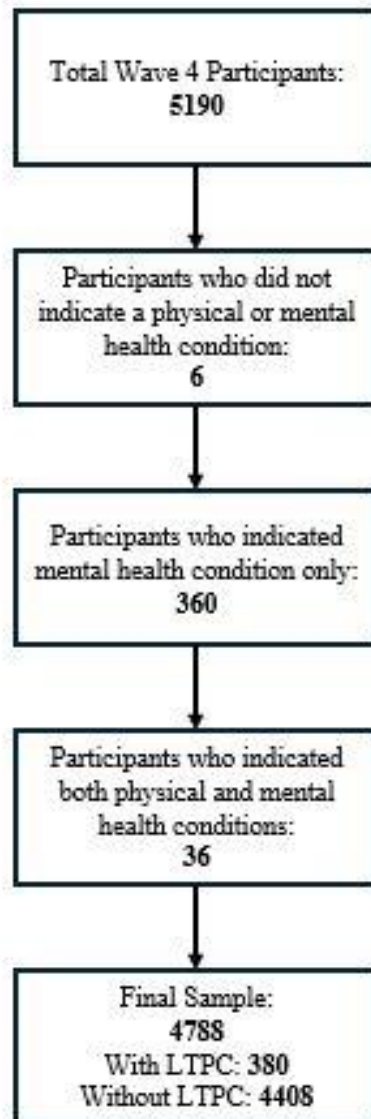
3.4.4 Secondary Data Analysis Sample

In identifying the sample for the secondary data analysis, the question on whether participants had any on-going chronic physical or mental problem, illness or disability was used. The subsequent options for conditions were the nervous, endocrine, digestive or

musculoskeletal systems, other illness and mental illness. Of the 5190 Wave Four participants, six participants did not respond to these questions and were subsequently removed from the sample. Among the remaining participants, 396 indicated they had a mental health condition, and of these, 36 also reported having a physical condition. As the focus of this study was those living with or without a LTPC, participants with mental health conditions (396), which included the 36 who also reported having a physical condition, were removed from the sample, resulting in a final sample size of 4788 for this secondary data analysis (see Figure 3.2). Within this sample, 380 (8.6%) indicated they had LTPC and 4,408 did not have LTPC. All participants were of similar age, overall and when split by group (LTPC vs. no-LTPC) as they were all born in 1998, approximately 1% were 19 years, 91% were 20 years and 8% were 21 years. Gender split was similar both overall and when split by group (LTPC vs. no-LTPC) at approximately 49% males and 51% females.

Figure 3.2

Secondary Data Analysis Sample



3.4.5 Survey Materials from GUI Wave Four included in Secondary Data Analysis

Relevant variables from the GUI survey (See Appendix B.1 – B.10) were grouped together that map on to each of the five features of adulthood (See figure 3.1); identity exploration (identity formation and navigating relationships); instability (life transitions, taking health risks, and uncertainty); self-focus (learning to be self-sufficient); feeling in-between (feeling not yet adult); and possibilities (availability of choices and being optimistic). For example, the age of identity exploration is about exploring “who am I?” which includes developing own opinions on topics such as state institutions like politics, media, healthcare and social welfare. This is why the questions about state institutions were mapped onto identity formation under the age of identity exploration. The age of instability is marked by transitions, such as moving out of home, therefore living at or away from home was mapped onto life transitions. The age of self-focus is about focusing on the self and setting goals for the self and so aspirations to achieve by aged 30 was mapped onto learning how to be self-sufficient. The age of feeling in-between is about not feeling fully adult, so the question “do you consider yourself to be an adult” was mapped onto feeling not yet adult. The age of possibilities is about being optimistic for the future and consequently concerns about poverty, employment and housing were mapped onto being optimistic.

3.4.5.1 Sociodemographics

The sociodemographic questions analysed in this secondary data analysis are age, gender, living arrangements, medical cover, education and primary economic status and family equivalised household income (quintiles). Data were analysed from the question that asked about any on-going chronic physical or mental health problem, illness or disability and the nature of this problem, illness or disability (see Appendix B.1). The data collected for question (QD3) was re-coded by the GUI interviewer to the ICD-10 classifications (QD2).

The data from the question on whether they were hampered in their daily activities by this problem, illness or disability (QD6) which was derived from the European Community Household Panel (ECHP/Living in Ireland survey 1994-2001) was also analysed.

3.4.5.2 Age of Identity Exploration

3.4.5.2.1 Identity Formation

Data relating to Identity Formation were analysed from the GUI survey questions (see Appendix B.2) on how much confidence participants had in various State institutions in Ireland; church, education, police, social welfare, healthcare, politicians, courts and media (QB3), how satisfied they were with their own life in general (QG3) and the Rosenberg Self-Esteem Scale (Rosenberg, 1965) which measures the degree to which participants felt positively or negatively about themselves (QG1), with a four-point scale ranging from 1 (strongly disagree) to 4 (strongly agree). GUI reduced the scale to six-items in Wave Three (17/18-year-olds) and kept the same six items for Wave Four. No reason was provided by GUI for the reduced scale, but it demonstrated good internal consistency, Cronbach's $\alpha=.73$, when it was used in Wave 3 of GUI with age 17/18 years (Murphy et al., 2019). Higher scores indicate higher self-esteem.

3.4.5.2.2 Navigating Relationships

Data relating to Age of Identity Exploration and Navigating Relationships were analysed from the GUI survey questions (see Appendix B.3) on (1) friendships; how many friends participants had (QA1), how many friends were close friends (QA2) and if they had someone in their life they could usually turn to for advice (QH7); and (2) the parent-child relationship; were they in regular contact with their mother/father figures (QH1, QH2, QH4, QH5) and the Network of Relationship Inventory with Father/ Mother which measures the

quality and characteristics of the parental relationships with their father and mother. This is taken from measures used by the German PAIRFAM study (Thonnissen et al., 2014). This inventory includes items that measure aspects of admiration, conflict, intimacy and unreliability within the parent-child relationship. Internal reliability, Cronbach's alpha for this scale at age 17/18 of Growing Up in Ireland was, for mothers' intimacy $\alpha = .82$, admiration $\alpha = .80$, conflict $\alpha = .84$, reliability = .56 and for fathers' intimacy $\alpha = .83$, admiration $\alpha = .85$, conflict $\alpha = .87$, reliability = .63 (Murphy et al., 2019). Finally, data relating to family cohesion and how well members of their family got on with each other (QH8) were analysed.

3.4.5.3 Age of Instability

3.4.5.3.1 Life Transitions

Data relating to Age of Instability and Life Transitions were analysed from the GUI survey questions (see Appendix B.4) on living arrangements that is if participants lived on a regular basis at an address other than their Parental Address (QHC1), the Leaving Certificate programme they took in their final year at school (QF3), if they sat the Leaving Certificate examinations (QF8) and what their primary economic status (e.g., working, further education, higher education) was at the time of the interview (QG2).

3.4.5.3.2 Taking Health Risks

Data relating to Age of Instability and Taking Health Risks were analysed from the GUI survey questions (see Appendix B.5) on how willing participants were to take risks, on a scale of 1 - unwilling to 10 - fully prepared (QA5). In relation to risky health behaviours, data were analysed from questions on how often participants smoke (QB3), how often they use an electronic cigarette (QB8) and the Alcohol Use Disorders Identification Test or AUDIT (QB9-QB25) which is a 10-item screening tool by the World Health Organisation to assess if

alcohol consumption is harmful based on a total score, 0 – 7 lower risk, 8 – 15 increasing risk, 16 – 19 higher risk, 20+ possible dependence (Babor et al., 2001). The AUDIT demonstrated good internal consistency, Cronbach's alpha $\alpha=.76$, when it was used in Wave 3 of GUI with age 17/18 years (Murphy et al., 2019).

3.4.5.3.3 *Uncertainty*

Data relating to Age of Instability and Uncertainty were analysed from the GUI survey questions (see Appendix B.6) on financial uncertainty during emerging adulthood, about making ends meet in general and health costs as emerging adults become responsible for their own financial and health decisions. Data will be analysed from questions on what degree of ease or difficulty participants had in making ends meet, financially (QK2), if they are covered by a medical card – and get medical services free of charge (QD14) or covered by private medical insurance (QD15), and if they needed to see a doctor or consultant on the last 12 months, but did not (QD10, QD12).

3.4.5.4 Age of Self-Focus

3.4.5.4.1 *Learn how to be Self-Sufficient*

Data relating to Age of Self-Focus and Learning How to be Self-Sufficient were analysed from the GUI survey questions (see Appendix B.7) on aspirations to achieve by age 30. These questions asked GUI participants to rate ten categories of aspirations (a home, good job, dream job, long-term romantic relationship, child, degree, a year abroad, car, be financially secure) that reflect becoming self-sufficient by age 30 with a rating of 1 not at all important to 10 very important (QJ1a – QJ1j).

3.4.5.5 Age of Feeling In-between

3.4.5.5.1 Feeling Not Yet Adult

Data relating to Age of Feeling In-between and Feeling Not Yet Adult were analysed from the GUI survey question (see Appendix B.8) on whether GUI participants considered themselves to be an adult (QA2). This question was taken from one of the subscales (the Adult Identity Resolution Scale [AIRS]), of the Identity Stage Resolution Index (ISRI). The ISRI (see Appendix E.8) is a two-factor six-item questionnaire designed to measure the accumulation of identity capital (Côté, 2016). Data (see Appendix B.8) were also analysed from the question that asked in terms of taking on adult responsibilities would you say you grew up faster, slower or at about the same rate as other people your age (QA3).

3.4.5.6 Age of Possibilities

3.4.5.6.1 Availability of Choices

Data relating to the Age of Possibilities and the Availability of Choices were analysed from the GUI survey question (see Appendix B.9) on choosing where to live in the future, more specifically the item asking how likely participants thought that they would still be living in Ireland in five years' time (QC4).

3.4.5.6.2 Being Optimistic

Emerging adulthood is a time of optimism for now and for the future. Data relating to the Age of Possibilities and Being Optimistic were analysed from the GUI survey questions (see Appendix B.10) where participants were asked to rate their level of concern about three particular social issues in Ireland; poverty, access to decent employment and access to housing (QB10f, QB10g, QB10h) that can affect current and future lives.

3.5 Data Analysis

Data analysis was carried out within R 4.3.0 (R Core Team, 2023). The GUI dataset provided subscale or total scores for scales (i.e., Rosenberg Self-Esteem Scale, Network of Relationships Inventory, AUDIT). Descriptive statistics were calculated where appropriate. To determine if there were any significant differences between the two groups (LTPC vs. no-LTPC) on the variables related to the five features of emerging adulthood, different statistical tests were used as appropriate (see Table 3.2). Welch Two Sample t-tests were conducted for mean group comparisons. Hedge's *g* was run to calculate effect size with thresholds for interpretation being small (0.15), medium (0.40), and large (0.75) (Brydges, 2019). Chi Square tests for independence were conducted to examine the relationship between categorical variables. Cramér's *V* was calculated to assess the strength of association, with interpretation thresholds depending on the degrees of freedom (Kim, 2017). Fisher's exact tests were conducted when the assumptions for the Chi-Square test were not met, particularly with small sample sizes (Kim, 2017). These statistical tests were conducted at a significance level of $p < 0.05$. A Bonferroni Correction for multiple comparisons was then applied to reduce the risk of Type I errors.

Table 3.2
Summary of Group Comparison Tests

Age of Identity Exploration (Objective 1)	
<i>Identity Formation</i>	
Confidence in State Institutions (H1)	Chi-squared test of independence
Life Satisfaction (H2)	Welch Two Sample t-test
Rosenberg Self-Esteem Scale (H3)	Welch Two Sample t-test
<i>Navigating Relationships</i>	
Number of Friends (H4)	Chi-squared test of independence
Number of Close Friends (H4)	Fisher's exact test
Someone to Turn To (H4)	Chi-squared test of independence
Contact with Mother (H5)	Fisher's exact test
Contact with Father (H5)	Chi-squared test of independence
Network of Relationship Inventory (H5)	Welch Two Sample t-test
Age of Instability (Objective 2)	
<i>Life Transitions</i>	
Living Arrangements (H1)	Chi-squared test of independence
Final School Programme (H2)	Fisher's exact test
Final Exam Sat (H2)	Chi-squared test of independence
Primary Economic Status (H2)	Fisher's exact test
<i>Taking Health Risks</i>	
Willingness to Take Risks (H3)	Welch Two Sample t-test
Smoking (H3)	Chi-squared test of independence
Vaping (H3)	Fisher's exact test
Alcohol (AUDIT) (H3)	Welch Two Sample t-test
<i>Uncertainty</i>	
Making Ends Meet (H4)	Chi-squared test of independence
Medical Card (H5)	Chi-squared test of independence
Private Health Insurance (H5)	Chi-squared test of independence
Unmet Medical Needs(H5)	Chi-squared test of independence
The Age of Self-Focus (Objective 3)	
<i>Learning to be Self-Sufficient</i>	
To have by Age 30 (H1)	Welch Two Sample t-test
The Age of Feel In-Between (Objective 4)	
<i>Feeling Not Yet Adult</i>	
Consider Self to be Adult (H1)	Chi-squared test of independence
Taking on Adult Responsibilities (H1)	Chi-squared test of independence
The Age of Possibilities (Objective 5)	
<i>Availability of Choices</i>	
Living in Ireland in 5 Years (H1)	Chi-squared test of independence
<i>Being Optimistic</i>	
Concerns of Issues in Ireland (H2)	Fisher's exact test

3.5.1 Post-hoc Regression Analyses

Where there were significant differences between emerging adults with and without LTPC, these were explored in greater detail within the LTPC group only, to see whether the impact of the LTPC, gender and parent education levels significantly predicted the outcome of the variable. Drawing on earlier GUI studies that focused specifically on disability and found that gender, level of impairment and parent education levels influenced greater disparity (Carroll et al., 2022a; Swift et al., 2021). Severity of condition and gender are also highlighted as key risk and protective factors within the Self and Family Management Framework (Grey et al., 2006). These variables were included as the independent variables in this post hoc regression analyses of the group of emerging adults living with LTPC.

Although household income was also found to influence disparity for individuals with disabilities in these studies (Carroll et al., 2022a; Swift et al., 2021), this variable was not included in the post hoc analyses. This was because those from more advantaged backgrounds are over-represented in the completed sample (Growing Up in Ireland, 2021a) and this variable had 65 missing answers from 380 participants (17%) in the LTPC only group. Due to the nature of the dataset, where not all participants answered every question, missing data was excluded from the regression analyses. This approach ensured that each regression model was based on complete cases (see Table 3.4 for number of missing cases). These regression analyses were conducted in R 4.3.0 (R Core Team, 2023).

For these predictor variables, impairment of LTPC was captured by the variable 'impact of condition on daily life,' which is ordinal with three levels: "none," "to some extent," and "severely". Parent educational attainment was collapsed from the original six categories: None/Primary School, Lower Secondary, Hi Sec/ TechVoc/UppSec+Tech/Voc, Non-Degree, Primary Degree and Postgrad, into three categories: Leaving Certificate not completed ("lc not completed"), Leaving Certificate completed or further education ("lc or

fe”) and higher education (“higher ed”). Gender has two levels (“male, “female”). Variables were collapsed into analytically significant categories, to counter small sample sizes in some original categories and so that the results were easier to interpret while still capturing the key differences within a variable, for example, educational attainment and primary economic status.

For the outcome variables, final school year programme was collapsed from four categories: Regular (Established) Leaving Certificate, Leaving Certificate Applied (LCA), Leaving Certificate Vocational (LCVP), Something else, into two categories (“regular lc” and “other”), and remained significant when group comparison was rechecked. Primary economic status was collapsed from the original ten categories: Studying Further Education course (PLC), Studying higher Education course (University or Inst. Of Technology), In FULL-TIME paid employment or paid internship, In PART-TIME paid employment or paid internship, Unpaid internship, Apprenticeship, On a Solas (FAS) course, Failte Ireland, Teagasc etc. /Private training course/Youthreach, Unemployed, Engage in minding the home or family/ Unable to work or study due to permanent disability or illness, into four categories (“higher education”, “further education”, “not working” and “working”), rather than and remained significant when group comparison was rechecked. Medical cover has three levels ("not covered", "doctor only", "full card"). Unmet medical needs for doctor and consultant both have two levels ("at least once", "no"). Perception of feeling adult has four levels, GUI collapsed the first two into one, ("a little true/ not at all true", "somewhat true", "true for the most part", "entirely true"). Perception of taking on adult responsibilities has three levels ("slower", "at the same rate", "faster”). For the variables that that were collapsed, group comparisons were re-run to confirm the variable was still significantly different between the two groups (LTPC vs. no-LTPC).

For the outcome variables that were categorical with two levels, the final year school programme, sitting the final exam, unmet medical needs for doctor and consultant, logistic regression models were conducted. This approach is suitable for binary outcome variables where each category is mutually exclusive (Hosmer et al., 2013). For outcome variables with three or more unordered categories, primary economic status and medical cover, multinomial logistic regressions were conducted. This technique is appropriate for variables with multiple categories and provides odds ratios as estimators, accommodating both categorical and continuous predictor variables (Hosmer et al., 2013). For outcome variables that are ordinal with three or more categories, perception of being an adult and perception of taking on adult responsibilities, ordinal logistic regressions were conducted. This technique is appropriate for ordered categorical variables and provides estimates of the odds of being in a higher category relative to all lower categories (Hosmer et al., 2013). For the outcome variables that were scale-based, life satisfaction scores, scores from the AUDIT scale for alcohol consumption and owning a car by age 30, linear regression models were conducted (Hosmer et al., 2013).

3.6 Results

3.6.1 Characteristics of Sample (Emerging Adults Living with LTPC and without LTPC) included from Cohort '98 at 20-years-old in Secondary Data Analysis

The final sample consisted of 380 participants living with LTPC and 4408 participants without LTPC. For emerging adults living with LTPC, 47.1% of the sample were male compared to 49.2% without LTPC and 52.9% were female compared to 50.8% without LTPC. Regarding family income, 10.3% of those with LTPC were in the lowest quintile compared to 10% of those without LTPC, while 22.6% of those with LTPC were in the highest quintile versus 23.5% of their peers without LTPC. In terms of living arrangements, 68.4% of emerging adults with LTPC lived at home, compared to 63.3% of those without LTPC. Medical cover differed across groups with 24.7% of those with LTPC having full

medical cards, compared to 15.4% of those without LTPC, while 50.8% had private health insurance compared to 57.2% of those without LTPC. Educational attainment showed that 89.3% of those with LTPC completed the regular Leaving Certificate, compared to 95.2% of those without LTPC, and 5% did not sit their final exam versus 1.6% of those without LTPC. Regarding principal economic status, 5.3% of emerging adults with LTPC were in further education compared to 2.8% without LTPC, 58.3% were in higher education compared to 69.1% of their peers, 3.4% were unemployed compared to 1.5%, and 1.8% were unable to work compared to 0.5% without LTPC (see Table 3.3). For emerging adults living with LTPC only, their on-going chronic physical health problem, illness or disability, was re-coded by the interviewer to the ICD-10 classifications of LTPC (see Table 3.4). For those with LTPC, when asked if their condition hampered their daily life, 35.1% said no, 58.3% said to some extent and 6.6% said, yes, severely. Tests of significance between those with and without LTPC for relevant sociodemographic variables that relate to emerging adulthood and self-management are reported throughout section 3.6.2.

Table 3.3
Sociodemographic Characteristics of Sample

Variable	Overall	With LTTPC	Without LTTPC
N	4,788	380	4408
Age (19 – 21 years)			
19 years	48 (1%)	5 (1.3%)	43 (1%)
20 years	4357 (91%)	349 (91.8%)	4008 (90.9%)
21 years	383 (8%)	26 (6.9%)	357 (8.1%)
Gender			
Male	2346 (49%)	179 (47.1%)	2167 (49.2%)
Female	2442 (51%)	201 (52.9%)	2241 (50.8%)
Equivalised Household Annual Income			
Lowest	481 (10%)	39 (10.3%)	442 (10%)
2 nd	652 (13.6%)	53 (13.9%)	599 (13.6%)
3 rd	818 (17.1%)	60 (15.8%)	758 (17.2%)
4 th	921 (19.2%)	77 (20.3%)	844 (19%)
Highest	1121 (23.4%)	86 (22.6%)	1035 (23.5%)
*missing	795 (16.7%)	65 (17.1%)	730 (16.6%)
Living Arrangements			
I live at my parental address	3049 (63.7%)	260 (68.4%)	2789 (63.3%)
I have another non-parental address	1739 (36.3%)	120 (31.6%)	1619 (36.7%)
Medical Card			
Yes, full card	774 (16.2%)	94 (24.7%)	680 (15.4%)
Yes, doctor only	158 (3.3%)	13 (3.4%)	145 (3.3%)
Not covered	3807 (79.5%)	268 (70.6%)	3539 (80.3%)
*missing	49 (1%)	5 (1.3%)	44 (1%)
Medical Insurance Policy			
Yes	271330 (56.7%)	193 (50.8%)	2520 (57.2%)
No	1951 (40.7%)	177 (46.6%)	1774 (40.2%)
*missing	124 (2.6%)	10 (2.6%)	114 (2.6%)
Final Year School Programme			
Regular Leaving Certificate	4537 (94.7%)	339 (89.3%)	4198 (95.2%)
Leaving Certificate Applied	86 (1.8%)	8 (2.1)	78 (1.8%)
Leaving Certificate Vocational	101 (2.1%)	18 (4.7%)	83 (1.9%)
Something else	61 (1.3%)	15 (3.9%)	46 (1%)
*missing	3 (0.1%)	0	3 (1%)
Did you sit the Leaving Certificate			
Yes, I sat it once	4597 (95.2%)	349 (91.8%)	4213 (95.6%)
Yes, I sat it more than once	135 (2.8%)	12 (3.2%)	122 (2.8%)
No	98 (2%)	19 (5%)	73 (1.6%)
Primary Economic Status (time of interview)			
Studying FE course (PLC)	145 (3%)	20 (5.3%)	125 (2.8%)
Studying HE course (TU or Uni)	3263 (68.1%)	222 (58.3%)	3041 (69.1%)
Full-time paid employment or paid internship	758 (15.9%)	74 (19.4%)	684 (15.5%)
Part-time paid employment or paid internship	247 (5.2%)	23 (6.1%)	224 (5.1%)
Unpaid internship	38 (0.8%)	4 (1.1%)	34 (0.8%)
Apprenticeship	129 (2.7%)	4 (1.1%)	125 (2.8%)
SOLAS/ Failte Ireland/ Teagasc/ Private/	27 (0.6%)	5 (1.3%)	22 (0.5%)
Youthreach			
Unemployed	81 (1.7%)	13 (3.4%)	68 (1.5%)
In the home/ unable to work – disability	30 (0.6%)	7 (1.8%)	23 (0.5%)
Taking year out	50 (1%)	4 (1.1%)	46 (1%)
*missing	20 (0.4%)	4 (1.1%)	16 (0.4%)

Table 3.4
Type of Long-Term Physical Condition in the LTPC Group

Condition	N (%)
Disease of the Nervous System	37 (9.7%)
Disease of the Endocrine System	38 (10%)
Disease of the Digestive System	40 (10.5%)
Disease of the Musculoskeletal System	70 (18.4%)
Other Illness	98 (25.8%)
*missing	97 (25.6%)
Total Conditions**	283

** a participant can have more than one condition

3.6.2 Group Comparisons of Emerging Adults Living with LTPC and Those Without LTPC

To determine if there were any significant differences or associations between the two groups (LPTC vs. no-LTPC) on the relevant variables related to the five features of emerging adulthood, statistical tests as outlined in section 3.6 and Table 3.2 were conducted.

3.6.2.1 The Age of Identity Exploration

To address objective one, whether there is a difference between emerging adults with LPTC and without LTPC on key variables in the GUI dataset that relate to the age of identity exploration was examined. Three hypotheses relating to identity formation and two hypotheses relating to navigating relationships were tested (see Table 3.1).

3.6.2.1.1 Identity Formation

The Bonferroni correct significance threshold for identity formation was set at $p = 0.005$ ($0.05/10$) and the corrected p-value is reported for each test. To test the hypothesis that there will be no significant association between group membership (LTPC vs. no-LTPC) and confidence in Irish State institutions, except for lower confidence to be reported in the education, social welfare, and healthcare institutions by emerging adults living with LTPC, Chi-Squared tests of Independence or Fisher's Exact tests were conducted. No significant

associations were found for church $\chi^2(3) = 11.62, p = 0.088$, Cramer's $V = 0.05$, education $\chi^2(3) = 5.59, p = 1$, Cramer's $V = 0.03$, police $\chi^2(3) = 14.15, p = 0.027$, Cramer's $V = 0.05$, social welfare $\chi^2(3) = 0.53, p = 1$, Cramer's $V = 0.01$, healthcare $\chi^2(3) = 6.22, p = 1$, Cramer's $V = 0.04$, politicians $p = 0.029$, courts $\chi^2(3) = 5.81, p = 0.902$, Cramer's $V = 0.04$ or media $\chi^2(3) = 14.26, p = 1$, Cramer's $V = 0.05$. These results indicate that confidence in these institutions is similar across both groups (see Table 3.5 for percentages). The findings do not support the hypothesis that that emerging adults living with LTPC would report significantly lower confidence in the education, social welfare, and healthcare institutions.

Table 3.5
Confidence in Irish State Institutions by Group

		Without LTPC Percentage	With LTPC Percentage
Church	Low Confidence	82.4	81.4
	High Confidence	17.2	17.3
Education	Low Confidence	30.9	35.5
	High Confidence	69.1	64
Police	Low Confidence	25.2	33.4
	High Confidence	74.6	65.5
Social Welfare	Low Confidence	43.7	44.5
	High Confidence	51.9	49.7
Healthcare	Low Confidence	41.4	44.5
	High Confidence	58.2	54.7
Politicians	Low Confidence	81	81.3
	High Confidence	17.4	16.5
Courts	Low Confidence	34.1	36.3
	High Confidence	63.3	59.8
Media	Low Confidence	71.8	67.6
	High Confidence	27.9	31.1

To test the hypothesis that emerging adults living with LTPC would report lower levels of life satisfaction than their peers without LTPC, a Welch Two Sample t-test was conducted. The mean life satisfaction score in those living without LTPC was 7.17 ($SD = 1.68$), while the mean life satisfaction score in those living with LTPC was 6.65 ($SD = 1.89$). The results found a significant difference in group means on life satisfaction, $t(420.91) = 4.45$, $p < 0.001$, $g = 0.27$. This finding supports the hypothesis that emerging adults living with LTPC report lower levels of life satisfaction than their peers without a LTPC.

To test the hypothesis that emerging adults living with LTPC would report similar levels of self-esteem on the Rosenberg Self-Esteem Scale to their peers without LTPC, a Welch Two Sample t-test was conducted. The mean self-esteem score in those living without LTPC was 11.96 ($SD = 3.29$), while the mean self-esteem score in those living with LTPC was 11.33 ($SD = 3.59$). The results found no significant difference in group means on self-esteem, $t(420.51) = 3.24$, $p = 0.013$, $g = 0.25$. This finding supports the hypothesis that both groups report similar levels of self-esteem.

3.6.2.1.2 Navigating Relationships

The Bonferroni correct significance threshold for navigating relationships was set at $p = 0.004$ ($0.05/14$) and the corrected p-value is reported for each test. To test the hypothesis that there would be no significant associations between “how many friends”, “close friends”, or “someone in life to turn to” and group membership (LTPC vs. no-LTPC), Chi-Squared tests of Independence or Fisher’s Exact tests were conducted. No significant associations were found between group membership (LTPC vs. no-LTPC) and number of friends $\chi^2(3) = 13.56$, $p = 0.049$, Cramer’s $V = 0.05$, number of close friends $p = 0.455$ and having someone to turn to $\chi^2(1) = 1.28$, $p = 1$, Cramer’s $V = 0.01$. These findings support the hypothesis that

emerging adults living with LTPC experience friendships in a similar way to their peers without LTPC.

To test the hypothesis that both groups will report similar relationships with their parents and family, Chi-Squared tests of Independence or Fisher's Exact tests were conducted for contact with parents, while Welch Two Sample t-tests were conducted for the Network of Relationships Inventory subscales with father and mother (admiration, conflict, intimacy, and unreliability) as well as family cohesiveness. No significant association was found between group membership (LTPC vs. no-LTPC) and contact with mother $p = 0.56$ or father $\chi^2(2) = 7.25, p = 0.373$, Cramer's $V = 0.04$.

The mean for admiration of father for those living without LTPC was 8.01 ($SD = 1.81$), while in those living with LTPC was 7.63 ($SD = 2.03$). There was no significant difference in group means on admiration with father $t(361.44) = 3.23, p = 0.019, g = 0.21$. The mean for conflict with father for those living without LTPC was 4.81 ($SD = 1.62$), while in those living with LTPC was 5.05 ($SD = 1.68$). There was no significant difference in group means on conflict with father $t(368.46) = -2.47, p = 0.197, g = -0.15$. The mean for intimacy with father for those living without LTPC was 5.27 ($SD = 1.94$), while in those living with LTPC was 5.23 ($SD = 2.02$). There was no significant difference in group means on intimacy with father $t(369.36) = 0.27, p = 1.000, g = 0.02$. The mean for unreliability of father for those living without LTPC was 3.23 ($SD = 1.64$), while in those living with LTPC was 3.50 ($SD = 1.79$). There was no significant difference in group means on unreliability of father $t(364.9) = -2.70, p = 0.101, g = -0.17$.

The mean for admiration of mother for those living without LTPC was 8.42 ($SD = 1.58$), while in those living with LTPC was 8.19 ($SD = 1.69$). There was no significant difference in group means on admiration of mother $t(406.90) = 2.45, p = 0.207, g = 0.14$. The mean for conflict with mother for those living without LTPC was 5.14 ($SD = 1.49$), while in

those living with LTPC was 5.26 ($SD = 1.50$). The results found no significant difference in group means on conflict with mother $t(412.70) = -1.44, p = 1.000, g = -0.07$. The mean for intimacy with mother for those living without LTPC was 6.24 ($SD = 1.98$), while in those living with LTPC was 6.33 ($SD = 2.02$). There was no significant difference in group means on intimacy with mother $t(412.23) = -0.84, p = 1.000, g = -0.04$. The mean for unreliability of mother for those living without LTPC was 3.11 ($SD = 1.44$), while in those living with LTPC was 3.30 ($SD = 1.60$). The results found no significant difference in group means on unreliability of mother $t(401.5) = -2.16, p = 0.438, g = -0.10$.

For family cohesion, the mean for those living without LTPC was 7.84 ($SD = 1.77$), while in those living with LTPC was 7.47 ($SD = 1.94$). There was no significant difference in group means $t(422.05) = 3.50, p = 0.007, g = 0.16$. These findings support the hypothesis that emerging adults living with LTPC experience similar relationships with their parents and overall family cohesion as their peers without LTPC.

3.6.2.2 The Age of Instability

To address objective two, whether there is a difference between emerging adults with LPTC and without LTPC on key variables in the GUI dataset that relate to the age of instability was examined. Two hypotheses relating to life transitions, one hypothesis relating to taking health risks and two hypotheses relating to uncertainty were tested (see Table 3.1).

3.6.2.2.1 Life Transitions

The Bonferroni correct significance threshold for life transitions was set at $p = 0.0125$ ($0.05/4$) and the corrected p-value is reported for each test. To test the hypothesis that there will be a significant association between having LTPC and living at home, a Chi-Squared test of Independence was conducted. No significant association was found $\chi^2(1) = 4.63, p =$

0.206, Cramer's $V = 0.03$. This does not support the hypothesis that emerging adults living with LTPC are more likely than their peers to live at home.

To test the hypothesis that emerging adults living with LTPC are more likely to have taken the Leaving Certificate Applied or Leaving Certificate Vocational Programme, less likely to have sat the final examination, less likely to study at higher education and more likely to indicate they are unemployed or unable to work or study due to permanent disability or illness, Chi-Squared tests of Independence or Fisher's Exact tests were conducted.

A significant association was found between having LTPC and the final school year programme taken $p = 0.002$. 10.7% of emerging adults living with LTPC took final school year programmes other than the regular Leaving Certificate in comparison to 4.7% of their peers. A significant association was also found between having LTPC and sitting the final exam $\chi^2(2) = 214.06$, $p < 0.001$, Cramer's $V = 0.07$. 5% of emerging adults with LTPC did not sit the final exam in comparison to 1.6% of their peers. Additionally, a significant association was found between having LTPC and primary economic status $p = 0.002$. 58.3% of those with LTPC were studying at higher education level in comparison to 69.1% of their peers. Furthermore, 3.4% of those with LTPC indicated they were unemployed in comparison to 1.5% of their peers, and 1.8% with LTPC indicated they were unable to work due to disability compared to 0.5% of their peers. These findings support the hypothesis that emerging adults living with LTPC were more likely to have taken the Leaving Certificate Applied or Leaving Certificate Vocational Programme, less likely to have sat the final examination, less likely to study at higher education and more likely to indicate they were unemployed or unable to work or study due to permanent disability or illness.

3.6.2.2.2 Taking Health Risks

The Bonferroni correct significance threshold for taking health risks was set at $p = 0.05/4 = 0.0125$ and the corrected p-value is reported for each test. To test the hypothesis that there will be no significant difference or association between the two groups (LTPC vs. no-LTPC) regarding overall willingness to take risks and risky health behaviours (including smoking, vaping, and alcohol consumption), several statistical tests were conducted. A Welch Two Sample t-test was conducted for willingness to take risks and alcohol consumption (measured using the AUDIT Scale). A Chi-Squared test of Independence and a Fisher's Exact test were conducted for smoking and vaping, respectively.

For those living without LTPC the mean on willingness to take risks was 6.51 ($SD = 1.92$), while in those living with LTPC the mean was 6.60 ($SD = 2.12$). There was no significant difference in group means $t(433.04) = -0.31$, $p = 1.000$, $g = 0.04$. The mean AUDIT score (alcohol consumption) in those living without LTPC was 10.30 ($SD = 4.93$), while the mean AUDIT score in those living with LTPC was 9.45, ($SD = 4.97$). There was a significant difference in scores between the two groups on AUDIT scores $t(391.71) = 3.03$, $p = 0.01$, $g = 0.15$. No significant associations were found for group membership (LTPC vs. no-LTPC) and smoking $\chi^2(3) = 2.60$, $p = 1$, Cramer's $V = 0.03$ or vaping $p = 0.534$. These findings partially support the hypothesis, indicating no significant difference or association between the two groups (LTPC vs. no-LTPC) in overall willingness to take risks and risky health behaviours, except for a significant difference in alcohol consumption, with emerging adult living with LTPC reporting lower AUDIT scores (lower alcohol consumption).

3.6.2.2.3 Uncertainty

The Bonferroni correct significance threshold for uncertainty was set at $p = 0.05/5 = 0.01$ and the corrected p-value is reported for each test. To test the hypothesis that there will

be a significant association of having LTPC and financial hardship, specifically that emerging adults living with LTPC would experience greater difficulty in making ends meet, a Chi-Squared test of Independence was conducted. No significant association was found $\chi^2(5) = 5.99, p = 1$, Cramer's $V = 0.05$. This finding does not support the hypothesis that emerging adults living with LTPC experience greater difficulty in making ends meet compared to their peers.

To test the hypothesis that emerging adults living with LTPC are more likely to rely on a medical card and report unmet medical needs (for doctor and consultant visits) compared to their peers, Chi-Squared tests of Independence were conducted. A significant association was found between having LTPC and having a medical card $\chi^2(2) = 23.03, p < 0.001$, Cramer's $V = 0.07$. Specifically, 24.7% of emerging adults living with LTPC indicated they had a full medical card compared to 15.4% of their peers. No significant association was found between having LTPC and having private health insurance $\chi^2(1) = 5.69, p = 0.09$, Cramer's $V = 0.03$. A significant association was found between having LTPC and unmet medical needs for doctors' visits $\chi^2(1) = 31.34, p < 0.001$, Cramer's $V = 0.08$. 23.7% of emerging adults living with LTPC reported that there was at least one occasion in the last 12 months when they needed to see a doctor but could not, compared to 13.2% of their peers. A significant association was also found between having LTPC and unmet medical needs for consultants' visits $\chi^2(1) = 36.05, p < 0.001$, Cramer's $V = 0.09$. 9.2% of emerging adults living with LTPC reported that there was at least one occasion in the last 12 months when they needed to see a consultant but could not, in comparison to 3.1% of their peers. These findings support the hypothesis that emerging adults living with LTPC are more likely to rely on a medical card and report unmet medical needs compared to their peers.

3.6.2.3 The Age of Self-Focus

To address objective three, whether there is a difference between emerging adults with LTPC and without LTPC on key variables in the GUI dataset that relate to the age of self-focus was examined. One hypothesis relating to learning to be self-sufficient was tested (see Table 3.1).

3.6.2.3.1 *Learning to be Self-Sufficient*

The Bonferroni correct significance threshold for uncertainty was set at $p = 0.05/9 = 0.006$ and the corrected p-value is reported for each test. To test the hypothesis that there will be no significant differences between the two groups (LTPC vs. no-LTPC) regarding how important it is to achieve various life goals by the age of 30 (including having a home, a good job, a dream job, a long-term romantic relationship, a child, a degree, a year abroad, a car, and financial security), Welch Two Sample t-tests were conducted.

For the aspiration of having one's own home by age 30, the mean for emerging adults living without LTPC was 7.92 ($SD = 2.29$), while the mean for those living with LTPC was 7.82 ($SD = 2.54$). No significant difference was found between the two groups $t(430.09) = 0.70$, $p = 1$, $g = 0.04$. Regarding being in a good job by age 30, the mean for those living without LTPC was 9.03 ($SD = 1.32$), while the mean for those living with LTPC was 9.04, ($SD = 1.39$). No significant difference was found between the two groups on being in a good job by age 30 $t(437.31) = -0.21$, $p = 1$, $g = -0.01$. Regarding being in a dream job by age 30, the mean for those living without LTPC was 7.66 ($SD = 2.01$), while the mean for those living with LTPC was 7.53 ($SD = 2.31$). No significant difference was found between the two groups on being in a dream job by age 30 $t(427.50) = 1.11$, $p = 1$, $g = 0.06$. For being in a long-term relationship by age 30, the mean for those living without LTPC was 7.08 ($SD = 2.23$), while the mean for those living with LTPC was 6.89 ($SD = 2.43$). No significant

difference was found between the two groups on being in a long-term relationship by age 30 $t(433.5) = 1.48, p = 1, g = 0.09$. For having a child by age 30, the mean for those living without LTPC was 4.83 ($SD = 2.87$), while the mean for those living with LTPC was 4.43 ($SD = 2.96$). No significant difference was found between the two groups on having a child by age 30 $t(440.04) = 2.55, p = 0.10, g = 0.14$.

For having a degree by age 30, the mean for those living without LTPC was 8.42 ($SD = 2.55$), while the mean for those living with LTPC was 7.91 ($SD = 2.93$). No significant difference was found between the two groups on having a degree by age 30 $t(427.57) = 3.28, p = 0.010, g = 0.19$. For having travelled by age 30, the mean for those living without LTPC was 7.41 ($SD = 2.59$), while the mean in those living with LTPC was 7.07 ($SD = 2.87$). No significant difference was found between the two groups for having travelled by age 30 $t(431.19) = 2.19, p = 0.259, g = 0.13$. For owning a car by age 30", the mean for those living without LTPC was 8.21 ($SD = 2.33$), while the mean for those living with LTPC was 7.56 ($SD = 2.77$). A significant difference was found between the two groups on owning a car by age 30 $t(424.15) = 4.46, p < 0.001, g = 0.27$. Emerging adults living with LTPC indicated that owning a car by age 30 was less important to them compared to their peers. For being financially secure by age 30, the mean for those living without LTPC was 9.07 ($SD = 1.33$), while the mean for those living with LTPC was 8.95 ($SD = 1.64$). No significant difference was found between the two groups on being financially secure by age 30 $t(420.64) = 1.42, p = 1, g = 0.09$.

The findings partially support the hypothesis that there would be no significant differences between the two groups (LTPC vs. no-LTPC) on each aspiration and how important it is to have by the age of 30. While no significant differences were found for having a home, a good job, a dream job, a long-term romantic relationship, a child, a degree,

having travelled, or being financially secure, owning a car by age 30 was significantly less important to emerging adults living with LTPC compared to their peers.

3.6.2.4 The Age of Feeling In-Between

To address objective four, whether there is a difference between emerging adults with LTPC and without LTPC on key variables in the GUI dataset that relate to the age of feeling-in-between was examined. One hypothesis relating to feeling not yet adult was tested (see Table 3.1).

3.6.2.4.1 Feeling Not Yet Adult

The Bonferroni correct significance threshold for learning to be self-sufficient was set at $p = 0.05/2 = 0.025$ and the corrected p-value is reported for each test. To test the hypothesis that there will be no significant association between the group membership (LTPC vs. no-LTPC) and if they considered themselves to be an adult or how they perceive to have grown up in comparison to peers, Chi-Squared tests of Independence were conducted. A significant association was found between group membership (LTPC vs. no-LTPC) and the perception of being an adult $\chi^2(3) = 12.84, p = 0.010$, Cramer's $V = 0.05$. Specifically, 20.8% of emerging adults living with LTPC felt it was entirely true that they considered themselves to be an adult, compared to 24% of their peers. Additionally, 51.6% of those with LTPC felt it was true for the most part, compared to 52.9% of their peers, and 27.6% felt it was somewhat, a little, or not at all true compared to 23% of their peers. There was also a significant association between group membership (LTPC vs. no-LTPC) and the perception of having grown up in comparison to peers $\chi^2(2) = 27.67, p < 0.001$, Cramer's $V = 0.08$. Among those with LTPC, 46.3% felt they grew up faster than their peers (35.4%). Additionally, 45.9% felt they grew up at the same rate as their peers (59.6%) and 7.7% felt

they grew up slower compared to their peers (5%). These findings do not support the hypothesis that there would be no significant associations between group membership (LTPC vs. no-LTPC) and the perceptions of adulthood, or the rate of taking on adult responsibilities, with emerging adults living with LTPC having different perceptions to their peers.

3.6.2.5 The Age of Possibilities

To address objective five, whether there is a difference between emerging adults with LTPC and without LTPC on key variables in the GUI dataset that relate to the age of possibilities were examined. One hypothesis relating to the availability of choices and one hypothesis relating to being optimistic were tested (see Table 3.1).

3.6.2.5.1 Availability of choices

No Bonferroni correction was applied. To test the hypothesis that emerging adults with LTPC will report similar expectations to their peers regarding their likely living situation in five years' time, a Chi-Squared test of Independence was conducted. No significant association was found $\chi^2(3) = 4.57$, $p = 0.206$, Cramer's $V = 0.03$. This finding supports the hypothesis that emerging adults with LTPC report expectations similar to their peers about where they will likely live in the future.

3.6.2.5.2 Being Optimistic

The Bonferroni correct significance threshold for being optimistic was set at $p = 0.05/3 = 0.017$ and the corrected p-value reported for each test. To test the hypotheses that emerging adults with LTPC would report similar levels of concern to their peers regarding current issues in Ireland (poverty, access to employment and housing), Fisher's Exact tests were conducted. No significant associations were found for poverty, $p = 1$, access to

employment $p = 0.837$ or access to housing $p = 1$. These findings support the hypothesis that there are no significant differences between emerging adults with LTPC and their peers in terms of their concerns about these current issues in Ireland.

3.6.3 Summary of Group Comparisons of Emerging Adults Living with LTPC and Those Without LTPC

Emerging adults living with LTPC are similar to their peers without LTPC across many variables associated with the five features of emerging adulthood, with some notable differences. For the age of identity exploration, emerging adults with LTPC reported lower levels of life satisfaction compared to their peers. There were no differences in levels of confidence in Irish State institutions, self-esteem, or in navigating relationships (number of friends or close friends, having some-one to turn to, contact with mother or father, network of relationships or family cohesion).

For the age of instability and life transitions, both groups were similar in terms of their living arrangements. However emerging adults living with LTPC were more likely to have pursued alternative final school year programmes, less likely to have sat for the final examination, and less likely to be engaged in higher education than their peers without LTPC. Additionally, a greater proportion of those with LTPC were unemployed or unable to work or study due to disability or illness. In relation to taking health risks, no notable differences were found in willingness to take risks, smoking, or vaping between the groups. A significant difference was identified in alcohol consumption, with emerging adults living with LTPC reporting lower AUDIT scores (lower alcohol consumption) compared to their peers. For uncertainty, there were no significant associations between group membership (LTPC vs. no-LTPC) and making ends meet or having private healthcare. However, emerging adults with

LTPC were more likely to have medical cards and to report unmet medical needs, such as not being able to visit a doctor or consultant when needed.

For the age of self-focus and learning to be self-sufficient, no significant differences were found between the groups on aspirations to own a home, be in good job, a dream job, a long-term romantic relationship, have a child, have degree, have travelled, or being financially secure by age 30 years. However, a significant difference was found for aspiring to own a car by aged 30 years, which was lower in emerging adults living with LTPC. For the age of feeling in-between and feeling not yet adult, significant associations were found between group membership (LTPC vs. no-LTPC) and perceptions of being an adult and how they perceive themselves to have taken on adult responsibilities in comparison to peers. Emerging adults living with LTPC reported they felt less adult compared to their peers, however they also reported that they felt they had grown up faster than their peers. For the age of possibilities and the availability of choices, no significant association was found between group membership (LTPC vs. no-LTPC) and where they expect to live in five years' time. In relation to being optimistic, no significant associations were found between group membership (LTPC vs. no-LTPC) and concerns about current issues in Ireland: poverty, employment and housing.

3.6.4 Key Predictors of Outcomes for Emerging Adults with LTPC

Where significant differences were identified between emerging adults with and without LTPC on variables reflecting key emerging adulthood features, regression analyses were conducted to see if impact of LTPC, parental educational attainment and gender predicted these key emerging adulthood outcome variables, life satisfaction, final school year programme, sitting the final exam, primary economic status, alcohol consumption, having a

medical card, unmet medical needs, car ownership by age 30, perceived adulthood, and perceived rate of growing up, within the LTPC group only.

3.6.4.1 Age of Identity Exploration

3.6.4.1.1 Identity Formation

The group comparisons between emerging adults living with LTPC and their peers living without LTPC found that those living with LTPC report lower levels of life satisfaction. To examine the relationship between the impact level of LTPC (none, to some extent, and severe), parent educational attainment (Leaving Certificate not completed, Leaving Certificate or Further Education completed, and Higher Education completed) and gender (male, female) on life satisfaction scores for emerging adults living with LTPC, a linear regression model was conducted.

The overall model was not statistically significant $F(5, 337) = 1.412, p = 0.219$. Rating the impact of LTPC as “to some extent” (compared to none) significantly predicted life satisfaction scores $\beta = -0.704, t(337) = -2.155, p = 0.031$. However, when the rating for impact of LTPC was “severe” (compared to none), this did not significantly predict life satisfaction scores $\beta = -0.060, t(337) = -0.278, p = 0.781$. This suggests that emerging adults living with LTPC experiencing a moderate impact of LTPC reported lower life satisfaction scores. Parental educational level did not predict life satisfaction scores, when parents had not completed the Leaving Certificate (compared to higher education) $\beta = 0.105, t(337) = 0.297, p = 0.766$, nor when parents had completed the Leaving Certificate or further education (compared to higher education) $\beta = -0.064, t(337) = -0.286, p = 0.775$. Gender did not predict life satisfaction scores either $\beta = 0.231, t(337) = 1.125, p = 0.261$. These findings suggest that while the impact of LTPC does have a statistically negative effect on life satisfaction, parent

educational attainment and gender do not, and the majority of the variance is influenced by other factors not included in the model.

Table 3.6*Predictors of Life Satisfaction Scores in Emerging Adults with LTPC*

Variable	Categories	Life Satisfaction			
		β	SE	$t(5, 337)$	P-Value
Impact of LTPC (None)	To some extent	-0.704	0.327	-2.155	0.032
	Severe	-0.600	0.216	-0.278	0.781
Parent educational level (Higher Education)	Leaving Certificate not completed	0.105	0.354	0.297	0.766
	Leaving Certificate or Further Education	-0.063	0.222	-0.286	0.775
Gender (Male)	Female	-0.321	0.205	1.125	0.2613

* β = Coefficient SE = Standard Error t = t-statistic

3.6.4.2 Age of Instability

3.6.4.2.1 Life Transitions

The group comparisons between emerging adults living with LTPC and their peers living without LTPC found that emerging adults living with LTPC were more likely to have pursued alternative final school year programmes and less likely to have sat the final Leaving Certificate examination. Additionally, they were less likely to be engaged in higher education and a greater proportion of those with LTPC were unemployed or unable to work or study due to disability or illness. To examine the relationship between the impact level of LTPC, gender and parent educational attainment on the likelihood that emerging adults with LTPC would be in an alternative final year school programme compared to the regular Leaving Certificate, a logistic regression model was conducted.

The model was statistically significant $\chi^2(3) = 28.66, p < 0.001$. Rating the impact of LTPC as “to some extent” (compared to none), significantly predicted being in an alternative final year school programme $\beta = 1.233, p = 0.007, OR = 3.43, CI [1.38, 8.42]$. However, when the rating for impact of LTPC was “severe” (compared to none), this did not significantly predict being in an alternative final year school programme $\beta = 0.181, p = 0.574, OR = 1.20, CI [0.63, 2.23]$. Parent educational attainment significantly predicted the likelihood of being in an alternative final year school programme. There was a significantly higher likelihood of emerging adults with LTPC being in an alternative final year school programme when their parents had not completed the Leaving Certificate (compared to higher education) $\beta = 2.936, p < 0.001, OR = 18.84, CI [4.57, 128.42]$ and when their parents had completed the Leaving Certificate or further education (compared to higher education) $\beta = 2.067, p = 0.006, OR = 7.90, CI [2.28, 49.85]$. Gender was not a significant predictor of being in an alternative final year school programme $\beta = -0.163, p = 0.655, OR = 0.849, CI [0.41, 1.75]$.

These findings (see table 3.7) suggest that the impact of LTPC significantly predicts the likelihood of being in an alternative final year school programme when the impact is "to some extent". Parent educational attainment is also a significant predictor, with emerging adults whose parents did not complete the Leaving Certificate or who completed the Leaving Certificate or further education having a significantly increased likelihood of being in an alternative final year school programme compared to those whose parents completed higher education. While gender does not significantly predict the likelihood of being in an alternative final year school programme.

To examine the relationship between the impact level of LTPC, gender and parental educational attainment on the likelihood that emerging adults with LTPC would sit their final Leaving Certificate exam, a logistic regression model was conducted. The model was not statistically significant $\chi^2(5) = 8.39, p = 0.136$. However, rating the impact of LTPC 'to some extent' (compared to none) significantly predicted the likelihood of sitting the Leaving Certificate exam $\beta = 1.354, p = 0.028, OR = 3.87, CI [1.10, 13.65]$. Rating the impact as "severe" (compared to none) did not significantly predict the likelihood of sitting the Leaving Certificate exam $\beta = 0.137, p = 0.755, OR = 3.87, CI [1.10, 13.65]$. Parental educational attainment did not predict sitting the Leaving Certificate exam either when parents had not completed the Leaving Certificate (compared to higher education), $\beta = 0.994, p = 0.334, OR = 2.70, CI [0.31, 23.52]$ nor when parents had completed the Leaving Certificate or further education (compared to higher education) $\beta = 1.283, p = 0.097, OR = 3.61, CI [0.96, 23.46]$. Furthermore, gender was not a significant predictor $\beta = -0.180, p = 0.726, OR = 0.84, CI [0.30, 2.34]$.

These findings (see Table 3.8) suggest that rating the impact of LTPC "to some extent" significantly increases the likelihood of sitting for the Leaving Certificate exam in comparison to those who are not impacted by their LTPC. However, rating the impact as

severe (compared to none), parent educational attainment and gender did not significantly affect the likelihood of sitting the exam. This suggests that other factors not included in the model may better explain the likelihood of sitting the Leaving Certificate exam for emerging adults with LTPC.

Table 3.7

Predictors of Final School Year Programme Taken in Emerging Adults with LTPC (Logistic regression model with Regular LC as Reference Category)

Variable	Categories	Alternative Final Year School Programme		
		β	P-Value	OR [CI]
Impact of LTPC (None)	To some extent	1.233	0.007	3.43 [1.38, 8.42]
	Severe	0.181	0.574	1.20 [0.63, 2.23]
Parent educational level (Higher Education)	Leaving Certificate not completed	2.936	0.000	18.84 [4.57, 128.42]
	Leaving Certificate or Further Education completed	2.067	0.006	7.90 [2.28, 49.85]
Gender (Male)	Female	-0.163	0.655	0.849 [0.41, 1.75]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

Table 3.8

Predictors of Sitting the Leaving Certificate Exam in Emerging Adults with LTPC (Logistical Regression Model with Sitting Leaving Certificate Exam as Reference Category)

Variable	Categories	Did Not Sit Leaving Certificate Exam		
		β	P-Value	OR [CI]
Impact of LTPC (None)	To some extent	1.354	0.028	3.87 [1.10, 13.65]
	Severe	0.137	0.755	1.15 [0.46, 2.67]
Parent educational level (Higher Education)	Leaving Certificate not completed	0.994	0.334	2.70 [0.31, 23.52]
	Leaving Certificate or Further Education completed	1.283	0.097	3.61 [0.96, 23.46]
Gender (Male)	Female	-0.180	0.726	0.84 [0.30, 2.34]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

To examine the relationship between the impact level of LTPC, parent educational attainment and gender on the likelihood of emerging adults living with LTPC being in different primary economic statuses (“further education”, “not working” and “working”), compared to higher education, a multinomial logistic regression model was conducted. Rating the impact of LTPC as “to some extent” (compared to none) was a significant predictor of being in the “not working” category compared to higher education $\beta = 1.635$, $p < 0.001$, OR = 5.13, CI [1.95,13.48]. However, rating the impact as “severe” (compared to none) was not a significant predictor of being in the “not working” category $\beta = 0.607$, $p = 0.112$, OR = 1.84, CI [0.87, 3.89]. For the likelihood of being in further education compared to higher education, impact was not a significant predictor when the impact was “to some extent” $\beta = 0.754$, $p = 0.241$, OR = 2.13, CI [0.60, 7.50] nor when it was “severe” $\beta = -0.051$, $p = 0.907$, OR = 0.95, [0.40, 2.25]. Similarly, for the likelihood of working compared to higher education, the impact level was not a significant predictor when it was “to some extent” $\beta = 0.035$, $p = 0.945$, OR = 1.04, CI [0.38, 2.80] nor when it was “severe” $\beta = 0.498$, $p = 0.122$, OR = 0.61, CI [0.32, 1.14].

Parent educational attainment significantly predicted the likelihood of being in further education compared to higher education when parents had not completed the Leaving Certificate $\beta = 1.470$, $p = 0.030$, OR = 4.35, CI [1.15,16.46] and predicted the likelihood of being in work compared to higher education $\beta = 1.346$, $p = 0.003$, OR = 3.84, CI [1.57,9.40]. However, parent educational attainment did not significantly affect the likelihood of being in the "not working" category for those whose parents did not complete the Leaving Certificate $\beta = 0.805$, $p = 0.256$, OR = 2.24, CI [0.56, 8.99] or for those whose parents completed the Leaving Certificate or further education $\beta = -0.249$, $p = 0.620$, OR = 0.78, CI [0.29, 2.09].

Gender was also a predictor of being in the working category, with males less likely to be in this category compared to higher education, $\beta = -0.802$, $p = 0.002$, OR = 0.45, CI

[0.27,0.75]. However, gender did not significantly affect the likelihood of being in further education $\beta = -0.257$, $p = 0.581$, OR = 0.77, CI [0.31, 1.93] or the "not working" category $\beta = -0.560$, $p = 0.230$, OR = 0.57, CI [0.23, 1.42].

These findings suggest that the impact of LTPC has varying effects on current primary economic status, and it significantly increases the likelihood of being in the "not working" category compared to higher education when the impact is "to some extent". Parent educational attainment significantly increases the likelihood of being in "further education" and "working" compared to higher education. Gender is a significant predictor for the likelihood of being in the "working" category compared to higher education, with males less likely to be in the "working" category.

Table 3.9*Predictors of Primary Economic Status in Emerging Adults with LTPC (Multinomial Regression with Higher Education as Reference Category)*

Variable	Categories	Further Education			Working			Not Working		
		β	P-Value	OR [CI]	β	P-Value	OR [CI]	β	P-Value	OR [CI]
Impact of LTPC (No)	To some extent	0.754	0.241	2.13 [0.60, 7.50]	0.035	0.945	1.04 [0.38, 2.80]	1.635	0.001	5.13 [1.95, 13.48]
	Severe	-0.051	0.907	0.95 [0.40, 2.25]	0.498	0.122	0.61 [0.32, 1.14]	0.607	0.112	1.84 [0.87, 3.89]
Parent educational level (Higher Education)	Leaving Certificate not completed	1.470	0.030	4.35 [1.15, 16.46]	1.346	0.003	3.84 [1.57, 9.40]	0.805	0.256	2.24 [0.56, 8.99]
	Leaving Certificate or Further Education completed	0.070	0.885	1.07 [0.38, 3.04]	0.482	0.105	1.62 [0.90, 2.90]	-0.249	0.620	0.78 [0.29, 2.09]
Gender (Male)	Female	-0.257	0.581	0.77 [0.31, 1.93]	-0.802	0.002	0.45 [0.27, 0.75]	-0.560	0.230	0.57 [0.23, 1.42]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

3.6.4.2.2 Taking Health Risks

The group comparisons between emerging adults living with LTPC and their peers living without LTPC found a significant difference in alcohol consumption, with emerging adult living with LTPC reporting lower AUDIT scores (lower alcohol consumption scores). To examine the relationship between the impact level of LTPC, parent educational attainment and gender on AUDIT scores for emerging adults living with LTPC, a linear regression model was conducted.

The model was statistically significant $F(5, 308) = 3.300, p = 0.006$. Rating the impact of LTPC “to some extent” (compared to none) did not significantly predict AUDIT scores $\beta = -0.710, t(308) = -0.835, p = 0.405$, nor when the rating was “severe” (compared to none) $\beta = -0.543, t(308) = -0.900, p = 0.369$. For parent educational attainment, not completing the Leaving Certificate (compared to completing higher education) was a significant predictor of alcohol consumption $\beta = -2.472, t(308) = -2.534, p = 0.012$, with emerging adults with LTPC whose parents had not completed the Leaving Certificate scoring lower AUDIT scores than their peers whose parents had completed higher education. Completing the Leaving Certificate or further education (compared to completing higher education) was not a significant predictor $\beta = -0.642, t(308) = -1.067, p = 0.287$. Gender significantly predicted AUDIT scores $\beta = -1.637, t(308) = -2.909, p = 0.004$, with being a male predicting lower scores than being a female. These findings suggest that while the impact of LTPC does not significantly predict alcohol consumption, parent educational attainment and gender do. Having a parent who did not complete the Leaving Certificate and being male predicts lower AUDIT scores in emerging adults with LTPC.

Table 3.10*Predictors of Alcohol Consumption (AUDIT) in Emerging Adults with LTPC (Linear Regression)*

Variable	Categories	AUDIT			
		β	SE	<i>t</i> (5, 337)	<i>P</i> -Value
Impact of LTPC (None)	To some extent	-0.770	0.923	-0.835	0.405
	Severe	-0.543	0.603	-0.900	0.369
Parent educational level (Higher Education)	Leaving Certificate not completed	-2.471	0.979	-2.524	0.121
	Leaving Certificate or Further Education completed	-0.642	0.601	-1.067	0.287
Gender (Male)	Female	-1.637	0.563	-2.909	0.004

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

3.6.4.2.3 Uncertainty

The group comparisons between emerging adults living with LTPC and their peers living without LTPC found that emerging adults living with LTPC were more likely to rely on a medical card and report unmet medical needs (doctor and consultant) compared to their peers. To examine the relationship between the impact level of LTPC, parent educational attainment and gender on the type of medical cover ("not covered", "doctor only", "full card") in emerging adults with LTPC, a multinomial logistic regression model was conducted.

Rating the impact of LTPC as "to some extent" (compared to none) was a not significant predictor of having a doctor only card compared to no cover $\beta = 0.337$, $p = 0.682$, OR = 1.40, CI [0.28, 7.02] nor a predictor for having a full medical card $\beta = 0.678$, $p = 0.069$, OR = 1.97, CI [0.95, 4.09]. Rating the impact as "severe" (compared to none) was not a predictor of having a doctor only card $\beta = 0.555$, $p = 0.344$, OR = 1.74, CI [0.55, 5.51] but it was a significant predictor for having a medical card $\beta = 0.541$, $p = 0.036$, OR = 1.72, CI [1.03, 2.85].

Parent educational attainment, that is not completing the leaving certificate (compared to completing higher education) was a significant predictor of having a doctor only card $\beta = 2.297$, $p = 0.017$, OR = 9.95, CI [1.52, 65.17] and a significant predictor of having a full medical card $\beta = 2.228$, $p < 0.001$, OR = 9.28, CI [3.83, 22.45]. Completing the Leaving Certificate or further education (compared to completing higher education) was not a significant predictor for having a doctor only card $\beta = 0.851$, $p = 0.297$, OR = 2.34, CI [0.47, 11.59] but it was a significant predictor of having a full medical card $\beta = 0.793$, $p = 0.015$, OR = 2.21, CI [1.16, 4.20]. Gender was not a significant predictor of having a doctor only card $\beta = 0.066$, $p = 0.913$, OR = 1.07, CI [0.23, 2.52], or having a full medical card $\beta = 0.410$, $p = 0.132$, OR = 1.51, CI [0.88, 2.57].

The findings (see Table 3.11) suggest that for emerging adults living with LTPC, rating the impact level of LTPC as severe, and parental education levels significantly influence the likelihood of having a doctor only card or full medical card compared to having no cover. Specifically, individuals who rate the impact of their LTPC as severe have a higher likelihood of obtaining a "full card." Additionally, parental education levels, particularly when the parents of emerging adults with LTPC have not completed their Leaving Certificate, are significant predictors for both "doctor only" and "full card" cover. Gender does not significantly predict medical cover status in this model.

To examine the relationship between the impact level of LTPC, parent educational attainment and gender on unmet needs on needing a doctor in the last 12 months but being unable to access service (at least once, no), a logistic regression model was conducted. The model was statistically significant $\chi^2(5) = 12.277, p = 0.031$. Rating the impact of LTPC as "to some extent" (compared to none) was not a significant predictor of unmet needs for visiting a doctor in the last 12 months $\beta = -0.688, p = 0.060, OR = 0.50, CI [0.25, 1.05]$ nor was rating the impact as "severe" a significant predictor either $\beta = -0.233, p = 0.356, OR = 0.79, CI [0.48, 1.31]$. Parental educational attainment did not significantly predict unmet needs, with neither "Leaving Certificate not completed" compared to "Higher Education" $\beta = 0.172, p = 0.741, OR = 1.19, CI [0.45, 3.55]$ nor, "Leaving Certificate completed or further education" compared to "Higher Education" $\beta = -0.514, p = 0.089, OR = 0.60, CI [0.32, 1.07]$. Gender was also not a significant predictor $\beta = -0.489, p = 0.072, OR = 0.61, CI [0.36, 1.04]$.

These findings (see Table 3.12) suggest that the impact of LTPC, parent educational attainment and gender do not significantly predict unmet needs for doctor visits. Parent educational attainment and gender also show potential effects, but they do not reach

conventional levels of statistical significance. The overall model fit is statistically significant, indicating that the predictors collectively improve the fit over the null model.

Table 3.11*Predictors of Medical Cover in Emerging Adults with LTPC (Multinomial Regression with No Cover as Reference Category)*

Variable	Categories	GP Card Only			Full Medical Card		
		β	P-Value	OR [CI]	β	P-Value	OR [CI]
Impact of LTPC (None)	To some extent	0.337	0.682	1.40 [0.28, 7.02]	0.678	0.069	1.97 [0.95, 4.09]
	Severe	0.555	0.344	1.74 [0.55, 5.51]	0.541	0.036	1.72 [1.03, 2.85]
Parent educational level (Higher Education)	Leaving Certificate not completed	2.297	0.017	9.95 [1.52, 65.17]	2.228	0.001	9.28 [3.83, 22.45]
	Leaving Certificate or Further Education completed	0.851	0.297	2.34 [0.47, 11.59]	0.793	0.015	2.21 [1.16, 4.20]
Gender (Male)	Female	0.066	0.913	1.07 [0.23, 2.52]	0.410	0.132	1.51 [0.88, 2.57]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval**Table 3.12***Predictors of Unmet Medical Needs in Emerging Adults with LTPC (Logistical Regression with At least Once as Reference Category)*

Variable	Categories	Unmet Medical Needs GP		
		β	P-Value	OR [CI]
Impact of LTPC (None)	To some extent	-0.688	0.060	0.50
	Severe	-0.233	0.355	0.79 [0.48, 1.31]
Parent educational level (Higher Education)	Leaving Certificate not completed	0.172	0.741	1.19 [0.45, 3.55]
	Leaving Certificate or Further Education completed	-0.514	0.089	0.60 [0.32, 1.07]
Gender (Male)	Female	-0.489	0.072	0.61 [0.36, 1.04]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

To examine the relationship between the impact level of LTPC, parent educational attainment and gender on unmet needs on needing a consultant in the last 12 months but being unable to access service (at least once, no), a logistic regression model was conducted. The model was not statistically significant $\chi^2(5) = 7.92, p = 0.161$. Rating the impact of LTPC as “to some extent” (compared to none) was a significant predictor of unmet needs for visiting a consultant in the last 12 months $\beta = -1.068, p = 0.032, OR = 0.34, CI [0.13, 0.97]$. Rating the impact of LTPC as “severe” (compared to none) was not significant $\beta = -0.017, p = 0.961, OR = 0.98, CI [0.51, 2.00]$. Parental educational attainment did not significantly predict unmet needs when parents had not completed the Leaving Certificate compared to Higher Education $\beta = -0.327, p = 0.660, OR = 0.72, CI [0.18, 3.61]$. Similarly, when parents had completed the Leaving Certificate or further education compared to higher education was not a significant predictor $\beta = -0.711, p = 0.139, OR = 0.49, CI [0.18, 1.19]$. Gender was also not a significant predictor $\beta = -0.075, p = 0.848, OR = 0.93, CI [0.42, 1.99]$.

These findings suggest that rating the impact of LTPC as “to some extent” significantly predicts unmet needs for consultant visits; rating the impact as “to some extent” was associated with a lower likelihood of having unmet needs. Rating the impact as "severe", parent educational attainment and gender do not significantly predict unmet needs in relation to consultant visits.

Table 3.13

Predictors of Unmet Medical Needs (Consultant) in Emerging Adults with LTPC (Logistical Regression with At least Once as Reference Category)

Variable	Categories	Unmet Medical Needs Consultant		
		β	P-Value	OR [CI]
Impact of LTPC (None)	To some extent	-1.068	0.032	0.34 [0.13, 0.97]
	Severe	-0.017	0.961	0.98 [0.51, 2.00]
Parent educational level (HE)	Leaving Certificate not completed	-0.327	0.660	0.72 [0.18, 3.61]
	Leaving Certificate or Further Education completed	-0.711	0.139	0.49 [0.18, 1.19]
Gender (Male)	Female	-0.075	0.848	0.93 [0.42, 1.99]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

3.6.4.3 Age of Self-Focus

3.6.4.3.1 *Learn how to be Self-Sufficient*

The group comparisons between emerging adults living with LTPC and their peers living without LTPC found that emerging adults living with LTPC indicated that owning a car by age 30 was less important to them compared to their peers. To examine the relationship between the impact level of LTPC, parent educational attainment and gender on the importance of owning a car by age 30, a linear regression model was conducted.

The model was not statistically significant $F(5, 344) = 2.126, p = 0.062$. Rating the impact of LTPC as “to some extent” (compared to none) did not significantly predict the importance of car ownership by age 30 $\beta = -0.547, t(344) = -1.136, p = 0.257$ nor did rating the impact of LTPC as “severe” $\beta = -0.210, t(344) = -0.661, p = 0.509$. Parent educational attainment was not a significant predictor when parents had not completed the Leaving Certificate compared to higher education $\beta = 0.635, t(344) = 1.234, p = 0.218$. However, when parents had completed the Leaving Certificate or further education compared to higher education, it was a significant predictor of the importance of car ownership by age 30 $\beta = 0.981, t(344) = 3.018, p = 0.003$. This suggests that emerging adults whose parents completed the Leaving Certificate or further education are more likely to place importance on owning a car by age 30. Gender was not a significant predictor of car ownership $\beta = -0.129, t(344) = -0.429, p = 0.668$.

These findings suggest that parent educational attainment, specifically when parents have completed the Leaving Certificate or further education compared to completing higher education, significantly predicts the importance of owning a car by age in emerging adults with LTPC. However, the rating of impact of LTPC (“to some extent” or “severe”) and gender do not.

Table 3.14*Predictors of Aspiration to Own a Car by Age 30 in Emerging Adults with LTPC (Linear Regression)*

Variable	Categories	Own a Car by Age 30			
		β	SE	$t(5, 337)$	P-Value
Impact of LTPC (None)	To some extent	-0.547	0.481	-1.136	0.257
	Severe	-0.210	0.317	-0.661	0.509
Parent educational level (Higher Education)	Leaving Certificate not completed	0.635	0.515	2.234	0.218
	Leaving Certificate or Further Education completed	0.981	0.325	3.0198	0.003
Gender (Male)	Female	-0.129	0.300	-0.429	0.668

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

3.6.4.4 Age of Feeling In-Between

3.6.4.4.1 Feeling Not Yet Adult

The group comparisons between emerging adults living with LTPC and their peers living without LTPC found that emerging adults living with LTPC had different perceptions of adulthood and taking on adult responsibilities compared to their peers. To examine the relationship between the impact level of LTPC, parent educational attainment and gender on the perception of being an adult ("a little true /not at all true", "somewhat true", "true for the most part", "entirely true"), an ordinal logistic regression model was conducted.

The model was statistically significant $\chi^2(5) = 78.40, p < 0.001$. Rating the impact of LTPC as “to some extent” (compared to none) was a significant predictor of the perception of feeling adult $\beta = 0.780, p = 0.027, OR = 2.18, CI [1.09, 4.39]$. Rating the impact as “severe” (compared to none) was not a significant predictor $\beta = 0.349, p = 0.127, OR = 1.43, CI [0.91, 2.22]$. Parent educational attainment was also a significant predictor, with "Leaving Certificate not completed" compared to “higher education” a significant predictor $\beta = 0.781, p = 0.028, OR = 2.18, CI [1.09, 4.39]$. Parents completing the leaving certificate or further education(compared to higher education) was not a significant predictor $\beta = 0.071, p = 0.753, OR = 1.07, CI [0.69, 1.67]$. Gender was not a significant predictor $\beta = -0.398, p = 0.057, OR = 0.67, CI [0.44, 1.01]$. These findings (see Table 3.15) suggest that the impact of LTPC and parent educational attainment have a significant effect on the perception of being an adult, but gender does not.

To examine the relationship between the impact level of LTPC, parent educational attainment and gender on taking on adult responsibilities ("slower", "at the same rate", "faster" than their peers), an ordinal logistic regression model was conducted. The model was statistically significant $\chi^2(5) = 57.35, p < 0.001$. However, none of the predictor variables significantly predicted the perception of taking on adult responsibilities in emerging adults

living with LTPC (see Table 3.16). Neither rating the impact of LTPC as “to some extent” $\beta = 0.296$, $p = 0.390$, OR = 1.34, CI [0.69, 2.69] nor “severe” $\beta = -0.033$, $p = 0.886$, OR = 0.97, CI [0.62, 1.52] significantly predicted the perception of taking on adult responsibilities. Parent educational attainment did not significantly predict the perception of taking on adult responsibilities, with neither “Leaving Certificate not completed” $\beta = 0.453$, $p = 0.224$, OR = 1.57, CI [0.76, 3.30] nor “Leaving Certificate completed or further education” $\beta = 0.145$, $p = 0.527$, OR = 1.16, CI [0.74, 1.81] compared to “Higher Education” showing significant effects. Gender was also not a significant predictor of the perception of taking on adult responsibilities $\beta = 0.008$, $p = 0.970$, OR = 1.01, CI [0.66, 1.53].

Table 3.15

Predictors of 'Feeling Like an Adult' in Emerging Adults with LTPC (Ordinal Logistic Regression with "a little true not at all true" as Reference Category)

Variable	Categories	Perception of Feeling Adult		
		β	P-Value	OR [CI]
Impact of LTPC (None)	To some extent	0.780	0.027	2.18 [1.09, 4.39]
	Severe	0.349	0.127	1.43 [0.91, 2.22]
Parent educational level (Higher Education)	Leaving Certificate not completed	0.781	0.028	2.18 [1.09, 4.39]
	Leaving Certificate or Further Education completed	0.071	0.753	1.07 [0.69, 1.67]
Gender (Male)	Female	-0.398	0.057	0.67 [0.44, 1.01]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

Table 3.16

Predictors of Taking on Adult Responsibilities in Emerging Adults with LTPC (Ordinal Logistic Regression with Slower as Reference Category)

Variable	Categories	Taking on Adult Responsibilities		
		β	P-Value	OR [CI]
Impact of LTPC (None)	To some extent	0.296	0.390	1.34 [0.69, 2.69]
	Severe	0.033	0.886	0.97 [0.62, 1.52]
Parent educational level (Higher Education)	Leaving Certificate not completed	0.453	0.224	1.57 [0.76, 3.30]
	Leaving Certificate or Further Education completed	0.145	0.527	1.16 [0.74, 1.81]
Gender (Male)	Female	0.008	0.970	1.01 [0.66, 1.53]

* β = Coefficient OR = Odds Ratio CI = Confidence Interval

3.6.5 Summary of Key Predictors of Outcomes for Emerging Adults with LTPC

For emerging adults living with LTPC, the regression analyses provided further insight into the impact of LTPC, gender and parent educational attainment on key aspects of emerging adulthood; life satisfaction, final school year programme, sitting the final exam, primary economic status, alcohol consumption, having a medical card, unmet medical needs, car ownership by age 30, self-perception of adulthood, and perceived rate of growing up. Impact of LTPC, parent educational attainment, and gender were found to influence many of these outcomes, suggesting that these factors can influence how emerging adults living with LTPC navigate their transition into adulthood.

In terms of identity formation (age of identity exploration), rating the impact of the LTPC on their daily life as “to some extent” (compared to none) predicted lower life satisfaction scores in emerging adults with LTPC. Regarding life transitions (age of instability), rating the impact of LTPC as “to some extent” significantly predicted the likelihood of being in an alternative final school year programme. Furthermore, emerging adults whose parents did not complete the Leaving Certificate, and those whose parents completed the Leaving Certificate or further education, had a higher likelihood of being in an alternative final school programme compared to those whose parents completed higher education. Rating the impact of LTPC as “to some extent” (compared to none) also significantly increased the likelihood of sitting the final Leaving Certificate exam and significantly increased the likelihood of being in the "not working" category compared to higher education. Parent educational attainment was a significant predictor of primary economic status as emerging adults whose parents did not complete the Leaving Certificate had a higher likelihood of being in further education and working, compared to those whose parents completed higher education. Gender was also a significant predictor of current

economic status, with males being less likely to be in the "working" category compared to higher education.

With taking health risks (age of instability), the analysis found that emerging adults whose parents did not complete the Leaving Certificate had significantly lower AUDIT scores, indicating lower alcohol consumption. Furthermore, males had significantly lower AUDIT scores compared to females. In terms of uncertainty (age of instability), rating impact of LTPC as "severe" was associated with having a medical card. Parent educational attainment significantly affected the likelihood of having a "GP card only" or a "full medical card". Emerging adults whose parents did not complete the Leaving Certificate had higher odds of having a "GP card only" or a "full medical card" compared to those whose parents completed higher education. Additionally, rating the impact of LTPC as "to some extent" significantly predicted unmet needs for consultant visits with impact "to some extent" associated with a lower likelihood of having unmet needs.

In relation to self-sufficiency (age of self-focus), the analysis found that emerging adults whose parents had completed the Leaving Certificate or further education were more likely to place a higher importance on owning a car by age 30. Finally, in terms of feeling like an adult (age of feeling in-between), rating the impact of LTPC "to some extent" significantly predicted the perception of feeling like an adult. Parent educational attainment was also a significant predictor, with higher perceptions of feeling adult among those whose parents had lower educational attainment.

3.7 Discussion

This cross-sectional data secondary analysis of GUI data, the Irish national longitudinal study for children and young people, sought to investigate whether emerging adults living with LTPC differed to their peers without LTPC in their experience of emerging

adulthood, utilising Arnett's Theory of Emerging Adulthood. To carry out this secondary data analysis, the questionnaire from GUI Wave Four of Cohort '98 was reviewed, and relevant items were aligned with the five features of emerging adulthood. The analyses found that emerging adults living with LTPC report similar experiences to their peers without LTPC on many variables relevant to emerging adulthood but show notable differences on others. This prompted further analysis focusing solely on emerging adults living with LTPC and exploring how the daily impact of their condition, parent educational attainment and gender affects these key emerging adulthood variables. Overall, the findings from this study provide a nuanced view of how living with a LTPC can influence how emerging adulthood is experienced.

3.7.1 Age of Identity Exploration

The age of identity exploration is a critical phase for emerging adults. In forming their identity, emerging adults are looking to determine their own values and beliefs. This may involve forming political beliefs or making determinations about religion and spirituality.

The comparative analyses found that both emerging adults living with LTPC, and their peers reported similar levels of confidence in eight Irish State institutions: church, education, police, social welfare, healthcare, politicians, courts, and media. Both groups expressed high confidence in education, police, and courts, moderate confidence in social welfare and healthcare, and low confidence in church, politicians, and media. While it had been expected that both groups would report similar confidence in church, police, politicians, courts and media, it was expected that emerging adults living with LTPC would report lower confidence in education, social welfare and healthcare.

The observed low confidence in the church, politicians, and media among participants is reflective of broader societal trends in Ireland, particularly among young people. For

example, the 2022 Census reports that 26% of individuals aged 15 to 29 now identify as having no religion (Central Statistics Office, 2022b). Engagement with the political process is notably low: of the 35% of Cohort '98 eligible to vote in the 2016 general election, only 51% were registered, and of those, just 35% voted. This results in only 12% of Cohort '98 having voted in that election (Murray et al., 2021). In Ireland, only 46% of people report trusting news most of the time (Comisiún na Meán, 2024) and among 18 – 24-year-olds, only 28% reported a high interest in news (Murrell et al., 2023).

Although confidence in the police and courts was high among emerging adults, it is important to note that emerging adults from minority or lower-income families, particularly those in socially deprived areas, may report lower confidence due to negative personal experiences. If those from more socially deprived areas are under-represented in the dataset, it could skew the reported confidence levels in police and courts.

Contrary to previous research that found those with disabilities are more likely to report disliking school (Gallagher et al., 2020), both groups demonstrated high confidence in the education system. This discrepancy might be due to the exclusion of mental health conditions in this secondary analysis and/or or attrition from the GUI study by those with more challenging educational experiences. There was also no significant difference in confidence in the social welfare system, but this may have arisen due to less exposure to this system due to their age or if those from lower socio-economic backgrounds are under-represented in the dataset. In terms of moderate confidence in healthcare, Ireland is experiencing a two-tiered healthcare system with high costs of private care and long waits in the public system (Darker et al., 2023; OECD, 2023; Whyte et al., 2020). These issues, coupled with observations of the two-tier system across various types of media, may have influenced emerging adults' moderate confidence. Overall, no significant differences were observed between emerging adults living with LTPC and their peers without LTPC in their

confidence across the eight Irish State institutions. However, the ratings of low, moderate or high confidence provides insight into how emerging adults in Ireland may be developing their own values and beliefs, such as those towards these institutions.

Developing a “sense of self” during the age of identity exploration is a key part of transitioning to adulthood and this may be influenced by living with LTPC. Self-esteem is an attitude towards oneself and encompasses both positive and negative beliefs (Rosenberg et al., 1995). In line with expectations, emerging adults living with LTPC reported similar self-esteem scores as their peers. This supports the findings of the systematic review, which found that while some emerging adults living with LTPC struggle to integrate their condition into their identity, others successfully incorporate it without diminishing their self-regard. This finding suggests that self-esteem does not differ significantly between emerging adults with and without LTPC, indicating that it may not require specific attention from healthcare professionals unless there is evidence of low self-esteem.

Life satisfaction represents a cognitive judgemental process that encompasses involving internal and external evaluations of one’s life circumstances, with subjective values assigned by the individual (Diener et al., 1995). As expected, emerging adults living with LTPC reported lower life satisfaction levels compared to their peers without LTPC. Further analysis into the experiences of the group of emerging adults living with LTPC only, found that those who reported moderate daily impact of LTPC reported significantly lower life satisfaction scores than those who reported no daily impact. This aligns with previous research that found chronic conditions present physical, mental, and emotional challenges that can reduce autonomy and life satisfaction (Compas et al., 2012; Megari, 2013; Shelley et al., 2020). Additionally, this finding supports research that found a reduction in health-related quality of life across 308 different chronic conditions (Van Wilder et al., 2019). These

findings highlight the importance of considering what the daily impact of LTPC is for an emerging adult, such as are they experiencing difficulties managing college or work.

Navigating and exploring relationships is also an important aspect of identity exploration during emerging adulthood. As emerging adults move away from secondary school and become more independent from their parents, their peer networks expand (Hopmeyer et al., 2022; Wiebe et al., 2016). Although previous research within the GUI framework indicates that children and adolescents with disabilities are more susceptible to bullying (Gallagher et al., 2020), potentially complicating peer interactions, findings from the systematic review (Chapter Two) found mixed experiences among emerging adults living with LTPC when navigating and exploring relationships. Some emerging adults reported fears of stigma associated with having LTPC, however they did not necessarily report a negative impact on peer relationships. Other emerging adults living with LTPC viewed their expanding social networks as a positive influence on their lives. Consistent with expectations, no significant differences were observed between emerging adults living with LTPC and their peers regarding the number of friends, number of close friends, or availability of support. Similarly, as expected, both groups reported positive relationships with their parents and families. Relationships can act as either a risk or a protective factor for navigating emerging adulthood, with or without LTPC. For emerging adults living with LTPC, understanding their peer and family relationships can provide an insight for healthcare professionals into what social supports they have around them to support managing their condition/s and where they may need extra support.

3.7.2 Age of Instability

The age of instability is characterised by many transitions, including moving in and out of the parental home, starting and finishing college and/or employment and experiencing

newfound freedoms (Arnett 2004; 2015). This period is marked by heightened experimentation and risk-taking (Arnett, 2000; Ravert, 2009).

Contrary to expectations, there was no significant difference in the number of emerging adults living with and without LTPC living at home. Previous research had indicated lower rates of success with developmental milestones, such as leaving home (Pinquart, 2014), for emerging adults living with LTPC and how needing to be at home for support could influence decisions such as what college to attend (Shelley et al., 2020). The similar numbers of emerging adults without LTPC reported to be living at home might be explained by the recent housing crisis in Ireland which has broadly impacted emerging adults' ability to move out (Central Statistics Office, 2021). For example, the average weekly rent saw a 37% increase from 2016 to 2022 (Central Statistics Office, 2022a) putting moving out beyond reach for emerging adults, who would typically have a low income. This delayed marker of independence is further evidenced by a 13% increase to 41% in emerging and young adults living at home between the 2016 and 2022 Censuses (Central Statistics Office, 2022a). Financial constraints were the primary reason for 62% of young adults remaining in their parental homes, as of 2021 (Central Statistics Office, 2021). This finding suggests that there is a broader delay across both emerging adults living with LTPC and their peers in achieving both financial and parental independence, which are key markers of adulthood for emerging adults (Arnett, 1994; 1997; 2001; Kendig et al., 2014; Galanaki & Leontopoulou, 2017).

The Leaving Certificate year signifies the end of second-level schooling and the first major educational transition in the Irish context. The Leaving Certificate year is one where many emerging adults turn 18 years old (become legally adult) and begin to plan out a future path for themselves (e.g., what to study at college). For emerging adults living with LTPC, they can face even more challenges. Previous research has reported poorer educational

outcomes and risk of future unemployment for those living with LTPC (Hale et al., 2015; Maslow et al., 2011; Maurice-Stam et al., 2019; Pinquart, 2014). The GUI research that has been conducted with children and adolescents found an elevated risk for those with disabilities, of leaving school prematurely or, if they remain, a tendency to opt for further education over higher education at university (Carroll et al., 2022a; 2022b). Furthermore, Ireland in general, has been identified as having one of the widest gaps in the EU, for education qualifications for individuals with disabilities, in 2018 only 39.9% aged 30 – 34 years had higher education qualifications (Eurostats, 2018). In 2021, Ireland had the largest employment gap in the European Union at 38.6% for individuals with disabilities (European Commission, 2022c). In line with the findings cited above, and as expected, emerging adults living with LTPC differed in their final year school programme choices, whether they sat their final exam, and their primary economic status. In comparing emerging adults living with LTPC to their peers without LTPC, the analysis found that those with LTPC were more frequently enrolled in alternative final year school programmes such as the Leaving Certificate Applied or Vocational rather than the traditional Leaving Certificate. Emerging adults living with LTPC were also more likely than their peers not to sit their final exam. In relation to primary economic status, emerging adults living with LTPC were less likely to be in higher education, and more likely report being unemployed in comparison to the peers without LTPC.

Further analysis into the experiences of emerging adults living with LTPC only, found that those experiencing moderate daily impacts of their condition were more likely to participate in these alternative school programmes in comparison to those who did not experience a daily impact. This pattern was also influenced by the educational background of their parents. When their parent/s had not completed the Leaving Certificate or when they had completed the Leaving Certificate and/or further education, emerging adults living with

LTPC were less likely to pursue higher education and more inclined towards further education or employment. Interestingly, the likelihood of sitting the final Leaving Certificate exam increased among those experiencing moderate daily impacts of LTPC. Future research could explore what personal (e.g., resilience) or external (e.g., social support) factors might influence this educational engagement when experiencing some level of impact daily of their LTPC.

In analysing further primary economic status in emerging adults living with LTPC, those with a moderate daily impact were more likely to not be working compared to those who had no daily impact of their LTPC. If parents had not completed the Leaving Certificate exam, emerging adults living with LTPC were less likely to be in higher education and more likely to be in further education or working, but parent education level did not influence being unemployed. In relation to gender, male emerging adults with LTPC were more likely to be in higher education compared to females, indicating a gender disparity in educational attainment within this group. This is particularly worthy of attention given that that female graduates represented more than half of all higher education graduates in Ireland in 2017 (Central Statistics Office, 2019b). However, important to note is although females outperform males in educational attainment, this reverses in employment, with females aged 25 – 34 years less likely to be employed (OECD, 2024). Recognising the unique challenges, is important, to ensure that adequate educational supports and resources are made available.

The findings related to parents' educational attainment are somewhat consistent with broader trends in Ireland, where young people whose parents have higher education are more likely to pursue higher education themselves. Specifically, seven in ten young people with parents who had higher education continue to higher education, while only three in ten whose parents had lower secondary education reach this level as adults (Central Statistics Office, 2019a). However, this trend is even more pronounced for emerging adults living with LTPC

who this thesis has identified are more likely to take an alternative Leaving Certificate programme and less likely to attend higher education than their peers without LTPC. Highlighting the importance of understanding their unique educational and socio-economic challenges and understanding how living with a LTPC can influence their experience of the features of emerging adulthood. It is important that Ireland work towards closing the education and employment gaps that exist (Eurostat, 2018; Kelly & Maitre, 2021). This can help emerging adults living with LTPC reach their full potential and minimise disparities in education and employment outcomes. This targeted support can enhance life prospects and improve overall life satisfaction, while reducing disability costs to the State.

It is widely known that emerging adults have the highest incidence of risk-taking behaviours, such as the highest rates of alcohol and drug use (Camfield et al., 2017; Dooley et al., 2019). The systematic review found that some emerging adults living with LTPC engage in health risks to integrate socially and balance their busy schedules and social lives with the management of their condition, while others remained aware of potential consequences associated with such risks and were more careful with their social activities. As expected, the analysis found no significant differences in overall willingness to take risks between the groups. Both groups also reported similar smoking and vaping habits, with over 40% participants smoking or vaping occasionally or on a regular basis. This finding might be attributed to the ongoing development of their prefrontal cortex (Arain et al., 2013), where there may be a lack of understanding or undue optimism about the long-term health consequences of their actions (Pyatak et al., 2013; Ersig, 2019).

Considering the previous similarities in risk-taking behaviours, it was surprising to find a difference in alcohol consumption between the two groups. Emerging adults living with LTPC reported lower alcohol consumption. For certain types of LTPC, alcohol may pose more immediate risks, such as inducing seizures (Camfield et al., 2017). Furthermore,

previous research suggests that some emerging adults living with LTPC are cautious of social environments and activities (Saylor et al., 2019; Shelley et al., 2020).

In further examining alcohol consumption among the LTPC only group, it was found that the impact of the condition did not significantly influence consumption levels. This finding suggests that simply having a condition may encourage individuals to exercise more caution when drinking alcohol. Parent educational attainment was found to influence alcohol consumption although not in the way that might be expected. Research shows that low education in parents typically leads to less frequent but heavier drinking in young people (Wells & Östberg, 2018). Similarly, research using GUI data, found that lower parental social class and education levels predicted a higher probability of being an unhealthy smoker and drinker (Nolan & Smyth, 2020). However, in emerging adults living with LTPC, those whose parents had not completed the Leaving Certificate had lower alcohol consumption than those whose parents had completed higher education. Another surprising finding in this group was that males reported lower alcohol consumption than females, despite the fact that males typically engage in more risk-taking behaviours (Irish Prison Service, 2022; Norona et al., 2016). These findings are important as they suggest that emerging adults living with LTPC may already be cautious about excessive alcohol consumption, particularly males. However, this caution does not apply universally within the group, highlighting the need for awareness about the role of alcohol and socialising during emerging adulthood. Understanding these dynamics can help in developing effective strategies to promote safer drinking behaviours tailored to the unique challenges faced by those with LTPC.

Uncertainty contributes to instability during emerging adulthood. The systematic review highlighted that emerging adults living with LTPC often feel uncertain about their financial situation, with particular concerns regarding the costs associated with managing their condition. In Ireland, this is compounded by the high risk of economic hardship faced

by individuals with disabilities (Indecon International Research Economists, 2021) and the two-tier healthcare system (Whyte et al., 2020). In comparing emerging adults living with LTPC to their peers, it was unexpected to find that both groups reported similar abilities to make ends meet financially. While initially unexpected, this finding makes more sense considering that lower-income participants are underrepresented compared to those with higher incomes. In both groups, approximately one-quarter experienced at least some difficulty in making ends meet. However, the groups differed in terms of medical cover and unmet medical needs for both doctor and consultant visits in the last 12 months, all of which can contribute to healthcare uncertainty.

In the wider population of Ireland, children whose parents have only lower secondary education face a 16.2% risk of poverty in adulthood compared with 6.2% when parents have third level education (Central Statistics Office, 2019a). For those with LTPC, socio-economic disadvantage is associated with primary caregivers being less likely to have a third level qualification among other factors (Roddy, 2022). Financial hardship also persists into adulthood; those who reported a poor financial situation as a child face an 18.2% risk of poverty as an adult (Central Statistics Office, 2019a). Not surprisingly, emerging adults living with LTPC were more likely than their peers to have a medical card which entitles them to free healthcare.

In examining this further, a moderate daily impact of LTPC was not linked to an increased likelihood of having either a "doctor only" card or a full medical card. However, a severe daily impact of LTPC significantly predicted having a full medical card. When parents had not completed the Leaving Certificate, this increased the likelihood by approximately nine times of having either card compared to not having a card. When parents had completed the Leaving Certificate and/or further education, emerging adults living with LTPC were over two times as likely to have a medical card compared to not having a card. These findings

align with research on younger GUI cohorts, which found that impairment status and low socio-economic factors, including parents' low educational attainment, contribute to poor socio-economic outcomes for children with disabilities and LTPC (Swift et al., 2021).

Families of emerging adults with LTPC and emerging adults themselves, are more likely to experience reduced income due to the cost of disability (Roddy, 2022), making them eligible for either a doctor-only card or a full medical card. Although possessing either card reduces healthcare costs, Ireland's two-tiered healthcare system can lead to longer waiting times for healthcare (Whyte et al., 2020), potentially contributing to lower life satisfaction and overall quality of life for those with LTPC.

When comparing emerging adults living with LTPC on unmet medical needs related to needing but being unable to visit a doctor or consultant in the past 12 months, there were notable differences. Contrary to expectations, those who reported their daily impact of LTPC as moderate reported fewer unmet needs for seeing a consultant in the last 12 months. One possible explanation is that for emerging adults with impactful LTPC, consultants may schedule biannual or annual review appointments, potentially reducing the need for emergency visits. In addition, it can be easier to get an emergency appointment with a consultant if you are already a patient of the clinic. Neither parent educational attainment nor gender influenced unmet medical needs. These findings highlight the importance of regular medical appointments, as they can help reduce the necessity for emergency visits. Ensuring consistent and proactive healthcare management may be key in addressing the medical needs of emerging adults living with LTPC. This may be especially important as emerging adulthood is a time when emerging adults living with LTPC are transitioning to adult healthcare and some do find this transition difficult as identified in the systematic review. Regular and structured follow-up appointments may help mitigate transition challenges.

3.7.3 Age of Self-Focus

Emerging adulthood offers emerging adults the freedom from the restrictions of childhood and adolescence, providing a new autonomy to pursue their self-interests (Arnett, 2004; Arnett, 2015; Nelson, 2021). In the systematic review, this autonomy was represented by learning how to be self-sufficient and making own decisions. Self-sufficiency was examined through questions about what aspirations participants considered important to achieve by age 30. These aspirations become goals to work towards and individuals learn to become self-sufficient on the journey, for example, working towards becoming financially secure.

The groups were compared on nine aspirations that they ranked as important or not important by age 30: owning a home, having a good job, achieving a dream job, being in a long-term romantic relationship, having a child, obtaining a degree, spending a year abroad, owning a car, and being financially secure. In line with expectations, both groups reported similar aspirations across all categories, with the exception of owning a car by age 30. The most important ones being having a good job and being financially secure and the lowest was having a child. This aligns with the shift in the main markers of adulthood from traditional ones, such as getting married and having children, to newer ones like accepting responsibility, making independent decisions, and becoming financially responsible (Arnett, 2004; 2015).

In relation to car ownership by age 30, emerging adults living with LTPC ranked it as less important (7.56 out of 10) compared to their peers (8.21 out of 10). For those with LTPC, certain conditions, such as epilepsy, can affect their ability to drive. For those with specific physical disabilities, adapting a car can be expensive. While grants and tax relief are available (Citizens Information, n.d.a.), they are not always approved. Furthermore, while insurers cannot refuse cover or charge higher premiums because of a disability, they can charge

higher premiums for car modifications (Chill, 2022). Additionally, individuals receiving disability allowance in Ireland have access to a free travel pass, reducing the need for a car for travelling around Ireland, such as for hospital appointments. As of July 2024, this benefit has been extended to people not receiving the allowance but certified as unable to drive, such as those with seizures (Government of Ireland, 2024).

Previous research has identified that goal setting is positively correlated with quality of life (Huisman et al., 2012). Overall, it is an encouraging finding that at age 20, emerging adults living with LTPC have most of the same hopes and goals as their peers. It is reflective of what they believe is important to work towards in achieving adulthood and becoming self-sufficient.

3.7.4 Age of Feeling In-Between

One of the key research findings related to emerging adulthood is that emerging adults often report feeling "in-between" adolescence and adulthood, a sentiment expressed more frequently than by any other age group (Arnett, 2001; Nelson & Barry, 2005; O'Mahony et al., 2019; Reifman et al., 2007). For emerging adults living with LTPC, the systematic review found that, in terms of taking on and being responsible for the self-management of their conditions, they sometimes felt "not yet adult." They also reported being treated as not fully adult by parents and healthcare professionals. This underpins the idea that, being designated as an adult does not necessarily equate to being prepared to handle adult responsibilities. Moreover, this feeling can be exacerbated when individuals are treated as "not yet adults," such as being lectured by healthcare professionals about what not to do or having parents insist on attending hospital appointments.

It was expected that those with LTPC would be similar on both considering themselves to be an adult and on taking on adult responsibilities in comparison to peers

without LTPC. However, it was found that emerging adults living with LTPC were less likely to report feeling fully adult compared to their peers, however, when reflecting on taking on adult responsibilities, those with LTPC were more likely to perceive themselves as having matured faster than their peers. While further research is needed to explore this in more detail, it is possible that they may not feel as adult if they are still dependent on the support of family for their care, both financially and physically.

Further analysis of the perception of feeling adult found that while in general emerging adults living with LTPC reported feeling less adult to peers, those who experienced a moderate daily impact of their LTPC were more likely to feel adult compared to those who reported no impact. One possible explanation for this increased sense of adulthood is that they are engaging in more self-management activities than peers who do not experience daily issues. They may need to be more mindful of certain restrictions they must place on themselves, such as medication adherence and socialising. The responsibility for self-management generally begins before emerging adulthood, such as starting to take responsibility for some insulin doses during adolescence or setting reminders to take medication (Lewis et al., 2010; Mooney et al., 2021; Schilling et al., 2006). Additionally, having parents with lower educational attainment (i.e., not completing the Leaving Certificate) was also associated with an increased feeling of adulthood. This finding aligns with previous research indicating that lower socio-economic status is linked to increased pressure to reach adulthood quickly (Landberg & Noack, 2019).

In examining how emerging adults living with LTPC perceived themselves to have grown up in comparison to peers, neither daily impact of condition, parent educational attainment nor gender influenced why they felt they grew up faster than their peers. This aspect requires further investigation to understand what factors contribute to this perception. These contrasting perceptions highlight the complex and multifaceted nature of the transition

to adulthood for emerging adults with LTPC, suggesting that while they may not feel entirely adult, they also recognise the accelerated maturity that often accompanies managing a long-term condition. Previous research found that a lower level of feeling in-between has been linked to better medication adherence (Kamp et al., 2019), suggesting that assessing the feeling of being "in-between" may be important for targeting self-management support effectively.

3.7.5 Age of Possibilities

The age of possibilities is characterised by emerging adulthood as a time of great opportunity and numerous choices. During this period, emerging adults are afforded the freedom to explore what future they want, including delaying commitments to long-term plans by taking on further education or deciding to go travelling (Nelson, 2021; Ravert, 2009). This secondary analysis of GUI data looked at the availability of choices in relation to where participants felt they would be living in five years' time. As expected, both emerging adults living with LTPC and their peers had similar responses, indicating comparable expectations about their future living arrangements. Regarding being optimistic, it was expected that both groups would report similar levels of concern about poverty, access to employment, and housing in Ireland. While both groups shared similar levels of concern, it was surprising that both groups had high concerns for all three issues.

In terms of poverty, neither group reported significant difficulties overall, in making ends meet. However, that emerging adults living without LTPC reported living at home in the same numbers as those with LTPC, could be indicative of low-income issues and the housing crisis. In considering employment, in 2018/19 Ireland had low unemployment overall, with 5.5% in December 2018 and 4.8% in December 2019, although for 15 – 24 years it was 12.5% and 12.6% respectively. This suggests that it may be more difficult for emerging

adults to secure employment. Additionally, for the question about living in Ireland in five years' time, over 50% of both groups reported wanting to live abroad for employment and financial reasons. At the age of 20, during a phase typically marked by optimism, this finding suggests that growing inequalities in Ireland may be dampening emerging adults' hopes and optimism for the future.

The widely publicised social issues faced in Ireland over the past decade, such as housing, homelessness, and employment challenges, likely contribute to the high concern for about poverty, access to employment, and housing in Ireland if not for themselves, then for others around them. These types of crises can undermine emerging adult's feeling of having many possibilities for the future. More research is needed to understand the reasons behind such high concerns for emerging adults and to investigate whether the increased risk of poverty that already exists for those living with LTPC also plays a role in their specific concerns (Indecon International Research Economists, 2021).

3.8 Strengths and Limitations

To the researcher's knowledge, this analysis is the first comparative study of emerging adults living with LTPC and their peers without LTPC, using the lens of Arnett's Theory of Emerging Adulthood, not only using the GUI data but also within the broader LTPC literature. This analysis provides valuable insights into how emerging adults living with LTPC vary from their peers without LTPC in their experiences of emerging adulthood.

There were limitations to this study. Firstly, it must be acknowledged that 39.4 % of participants dropped out across the Waves of Cohort '98. The original sample for this cohort comprised 8,568 9-year-olds at Wave 1, which reduced to 5,190 (60.6%) 20-year-olds by Wave 4, representing a drop out number of 3,378 across the waves (Growing Up in Ireland, 2021a). Attrition is generally higher among minority groups, single-parent families, and low-

income families (Watson & Wooden, 2009). Children with primary caregivers with lower educational attainment and/or from lower income households were more likely to drop out of the GUI study than their peers in other groups (Swift et al., 2021). Within the Wave 4 dataset used in the secondary data analysis, only 13% of participants were in the lowest income quintile, compared to 29% in the highest income quintile. Additionally, a further indication of income levels was that in the GUI dataset, 82.2% of parents of emerging adults living with LTPC and 91.1% of those without LTPC reported owning their homes outright or having a mortgage. This is higher than the general population where the 2022 Census reported that 66% of homes in Ireland were owner-occupied (Central Statistics Office, 2022a). It is important to consider the representation of those from lower socio-economic backgrounds when considering these results and generalising to the wider populations of emerging adults living with and without LTPC.

Secondly, in considering emerging adults living with LTPC in the GUI dataset, it is important to note that it is only possible to focus on LTPC at a general level (e.g. physical disability). Consequently, it is not possible to distinguish between different conditions or to examine differences that might arise as a result of the progressive nature of a condition or age of diagnosis. Furthermore, in relation to emerging adults living with LTPC, while one of the questionnaires was carried out with an interviewer, a second questionnaire containing more sensitive questions (e.g., alcohol, drugs and sexual activity) was done by the participants on a laptop. Due to this self-reported questionnaire, it is possible that those with more severe LTPC might not have been able to take part.

Thirdly, this study examined impact of LTPC, parental educational attainment and gender to predict the features of emerging adulthood in emerging adults with LTPC. Participants were not required to answer all questions. This presented a challenge and, in some cases, resulted in the inability to use certain variables in this analysis (e.g., equivalised

income). Future research should consider other variables, including income, that might potentially impact outcomes. Fourthly, while this Wave of the GUI study was informed by Arnett's Theory of Emerging Adulthood for certain questions relating to the transition to adulthood, the primary conceptual framework for the longitudinal study is Bronfenbrenner's (1972) bio-ecological model. As a result, this Wave of the study was not designed to measure emerging adulthood directly and therefore limited the scope of data related to the five features of emerging adulthood. Fifthly, the participants were mostly 20 years of age, this may not have captured the full breath of emerging adulthood. Finally, this analysis only conducted a cross-sectional analysis of one Wave due to the age of participants and the next data collection at age 25 years had not been completed by the time of the analysis. Not carrying out a longitudinal analysis can miss patterns that occur over time during emerging adulthood. Future research using a longitudinal design could aim to build on this study, for example, when Wave Five becomes available for this group, Cohort '98, at aged 25 years.

3.9 Conclusion and Implications for Thesis

In conclusion, this cross-sectional secondary data analysis of Wave Four of the Cohort '98 dataset from the GUI longitudinal study provides valuable insights into the experiences of emerging adults living with LTPC compared to their peers without LTPC, during emerging adulthood. To the best of the researcher's knowledge, it is the first comparative analysis of emerging adults living with and without LTPC, using the lens of Arnett's Theory of Emerging Adulthood. The findings highlights while emerging adults living with LTPC share many similar experiences with their peers, they also face specific differences. The influence of the daily impact of their LTPC, parental educational attainment and gender were particularly evident in areas such as educational outcomes and employment status. This analysis strengthens the argument that emerging adulthood is a critical

developmental stage that requires further research especially for emerging adults living with LTPC.

Chapter 4: The Experience of Emerging Adulthood and its Relationship to the Self-Management of a Long-Term Physical Condition

4.1 Overview of Chapter

This study is a cross-sectional survey of emerging adults (18 – 25 years) and will (1) compare emerging adults living with and without LTPC on factors related to self-management and emerging adulthood; (2) examine whether the experience of the five features of emerging adulthood, as measured by a standardised scale specifically developed to measure to what extent some-one perceives and identifies with the five features of emerging adulthood, vary based on having a LTPC and the factors above related to self-management and emerging adulthood that showed significant differences between emerging adults with and without LTPC; and (3) examine the relationship between the five features of emerging adulthood and self-management for emerging adults living with LTPC. In this chapter, the rationale, background, aim, objectives and hypotheses will be presented for this study. This chapter will also detail the method, analytical approach, results and discussion.

4.2 Rationale and Background for Cross-Sectional Survey

The systematic review (Chapter 2) found that the five features of emerging adulthood are present in the self-management strategies and tasks of emerging adults living with LTPC. The challenges of identity exploration were evident in identity formation, relationships, and self-confidence. Some emerging adults with LTPC accepted their condition as part of their identity, aiding self-management, while others resisted, leading to poor decisions. Relationships were also challenging as they relied on new peer networks while gaining independence, though some parents struggled to transfer self-management responsibilities. Fractured family relationships further impacted self-management and self-confidence. Life

transitions, such as college, employment, and transferring to adult healthcare, heightened instability. Emerging adults struggled to incorporate self-management into new schedules, feared carrying out tasks in public, and had to build new healthcare relationships. This balancing act led to health risks like missing medication or appointments. Uncertainty about finances, insurance, and the future added to their stress.

Increased autonomy meant learning self-sufficiency, but some were overwhelmed, particularly when physically distanced from parents. Realising the seriousness of their condition, some took risks with their health, leading to potential long-term consequences. Feeling "in-between" was common, as many felt unprepared for adult healthcare expectations, while others were not treated as adults by healthcare professionals or parents, limiting their ability to take responsibility. The optimism of emerging adulthood sometimes led to unrealistic expectations, with some believing poor self-management would not have negative consequences.

The systematic review highlighted the need to study emerging adults as distinct from adolescents and full adults, given their unique self-management challenges. It found they experience the five features of emerging adulthood within the context of self-management, reinforcing that this stage is highly unstable. However, the systematic review also highlighted the need for a deeper understanding of the extent to which emerging adults with LTPC experience the features of emerging adulthood and the specific challenges these features pose to self-management, such as social support. It also highlighted a lack of quantitative research comparing those with and without LTPC, notably, none of the 30 papers included in the review compared emerging adults with LTPC to their peers without LTPC. Finally, there were a lack of studies examining the five features of emerging adulthood: identity exploration, instability, self-focus, feeling in-between and possibilities using a dedicated measure to examine the challenges posed by emerging adulthood to self-management.

The secondary analysis of Wave Four of Cohort '98 of the GUI study (Chapter 3) addressed this gap to some extent. Growing Up in Ireland is a national longitudinal cohort study of children and young people in Ireland examining factors that shape critical periods of development across the lifetime. The secondary data analysis of GUI data, Wave Four of Cohort '98 at aged 20 years, explored whether there were differences between emerging adults living with and without LTPC on variables related to Arnett's features of emerging adulthood. It is important to note that GUI does not include specific questions on the features of emerging adulthood, but rather relevant questions collected by GUI were mapped onto the different features of emerging adulthood (see Figure 3.1).

The findings showed that while emerging adults with LTPC shared many experiences with their peers without LTPC, they differed in key areas. Those with LTPC reported lower life satisfaction, particularly when their condition had a moderate daily impact. They were more likely to leave school early, choose alternative final school year programmes over the Leaving Certificate, and were less likely to attend higher education. A moderate daily impact of LTPC was linked to not sitting the final exam, not working, and opting for alternative school programmes. Lower parental education further influenced educational and employment outcomes.

Emerging adults with LTPC reported lower hazardous alcohol consumption than their peers without LTPC. Within the LTPC group only, males reported lower alcohol consumption scores than females. In terms of healthcare, emerging adults living with LTPC were more likely to have a full medical card and reported fewer unmet needs than their peers without LTPC. Those with severe LTPC impact were most likely to have a full medical card, while lower parental education increased the likelihood of having either a GP card or full medical card. A moderate LTPC impact reduced unmet needs for medical consultant visits and was associated with feeling more like an adult, as was lower parental education.

To the best of the researcher's knowledge, it is the first comparative analysis of emerging adults living with LTPC and their peers on variables related to emerging adulthood. Whilst the findings identified that emerging adults living with LTPC experience many similarities with the peers during emerging adulthood, there are also noteworthy differences. What the secondary analysis did not address was whether the features of emerging adulthood are associated with self-management behaviour in those living with LTPC as the GUI does not include any measure of self-management, nor did it include a dedicated and standardised measure of the five key features of emerging adulthood. The GUI sample were also aged 20 years rather than the wider age range of 18 – 25 years and were living in Ireland only. These issues are addressed in this cross-sectional study.

The systematic review and the secondary analysis of GUI data collectively provide valuable insights into the experience of emerging adulthood for both emerging adults living with and without LTPC. These findings highlight the importance of studying emerging adulthood as a distinct developmental stage, particularly for those living with LTPC who can face significant challenges in areas such as education, employment and healthcare. However, further research is needed to quantitatively measure the extent to which emerging adults with LTPC differ from their peers across the features of emerging adulthood using a standardised measure and to examine how these differences impact self-management. This will provide a more comprehensive understanding of emerging adulthood and the self-management of a LTPC, guiding future research, and identifying specific areas where healthcare professionals can develop care strategies and tailor support to the needs of emerging adults living with LTPC; thereby improving self-management outcomes and overall quality of life for emerging adults living with LTPC.

4.3 Aim of this Cross-Sectional Survey

The aims of this study are to: (1) compare emerging adults living with and without LTPC on factors related to self-management and emerging adulthood. These factors are mapped onto the five key features outlined in Arnett's Theory of Emerging Adulthood (see Figure 4.1); (2) examine whether the experience of the five features of emerging adulthood, as measured by the standardised scale specifically developed to measure to what extent someone perceives and identifies with the five features of emerging adulthood, vary based on having a LTPC and the factors above related to self-management and emerging adulthood that showed significant differences between emerging adults with and without LTPC; and (3) examine the relationship between the five features of emerging adulthood and self-management for emerging adults living with LTPC. In this study, emerging adults are identified as those aged between 18-25 years. Previous research has indicated that individuals in this age group are more likely to endorse emerging adulthood as a time of identity exploration, possibilities, and feeling in-between, compared to those aged 26-29 years (Crocetti et al., 2015). This age range is also characterised by the highest levels of risk-taking (Arnett, 2000; Camfield et al., 2017; Ravert, 2009), which poses a greater potential risk to self-management.

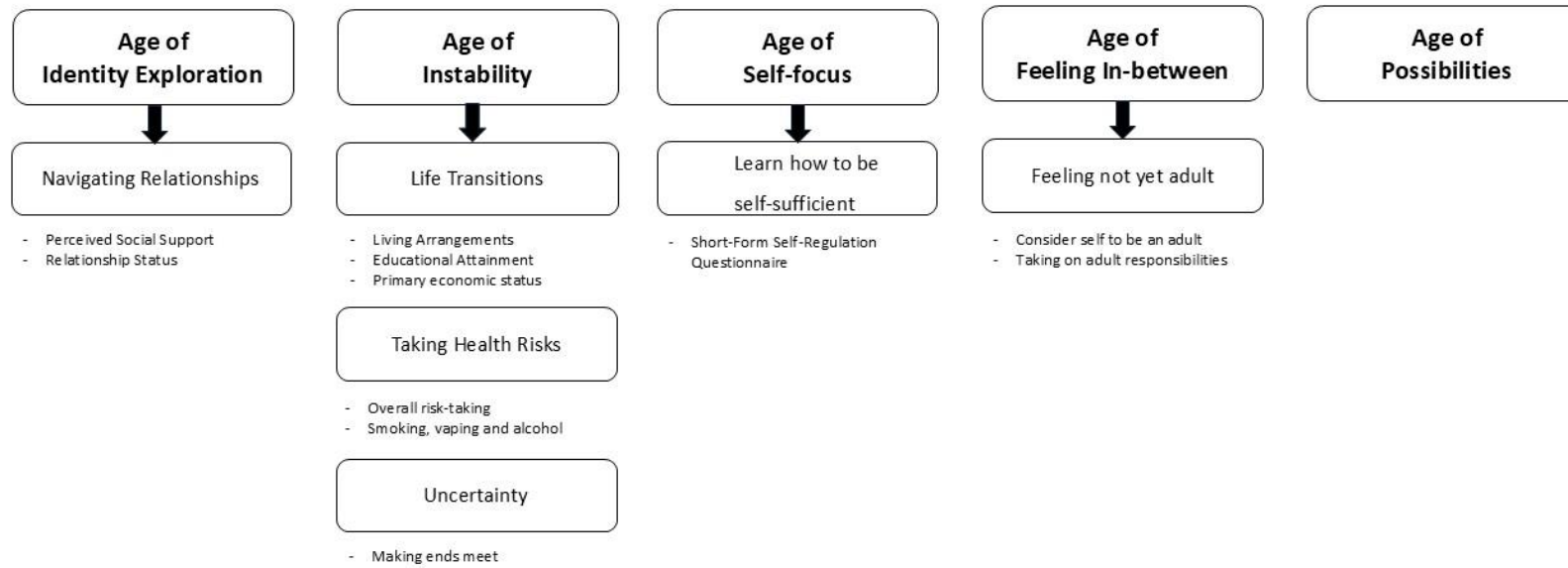
4.3.1 Objectives and Hypotheses

The factors related to self-management and emerging adulthood and mapped onto the five features of emerging adulthood (see Figure 4.1) were drawn from a review of the literature (Chapter One), the systematic review (Chapter Two), and the secondary analysis of GUI data (Chapter Three). These include perceived social support, relationship status, living arrangements, educational attainment, primary economic status, risk-taking, risky health

behaviours, perceived financial management, self-regulation, considering self to be adult and taking on adult responsibilities. See Table 4.1 for objectives and hypotheses.

Figure 4.1

Factors related to self-management and emerging adulthood mapped onto the five features of emerging adulthood



Objective 1: To examine whether there are differences or associations between two groups of emerging adults (LTPC vs. no-LTPC) on key variables related to self-management and the age of identity exploration. This involves examining navigating relationships, including perceived social support and relationship status.

Hypothesis 1.1: Social support is important for the successful navigation through emerging adulthood (Woods et al., 2018) and acts a facilitator for successful self-management (Schulman-Green et al., 2016). The systematic review identified social support as both a facilitator and barrier to self-management, while the secondary analysis of GUI data found that emerging adults living with LTPC experience friendships and familial relationships similarly to their peers without LTPC. Therefore, it is hypothesised that both groups (LTPC vs. no-LTPC) will report similar levels of perceived of social support.

Hypothesis 1.2: Emerging adulthood is a period marked by identity exploration, which includes the exploration of both short-term and long-term relationships (Wiebe et al., 2019). This exploration is considered a normative and adaptive developmental task for emerging adults (Ravert, 2009). However, living with LTPC can impact psychosocial milestones, including the development of intimate relationships (Maurice-Stam et al., 2019). Therefore, it is hypothesised that group membership (LTPC vs. no-LTPC) will be significantly associated with relationship status and emerging adults living with LTPC will be more likely to report being single in comparison to their peers.

Objective 2: To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on key variables related to self-management and the age of instability. This involves examining life transitions, including living arrangements, educational attainment, and primary economic status, taking

health risks, including overall risk-taking and risky health behaviours, and uncertainty, including making ends meet financially.

Hypothesis 2.1: Available research suggests that emerging adults living with LTPC may have lower success rates in achieving developmental milestones, such as living independently from home (Pinquart, 2014; Shelley et al., 2020). However, the secondary analysis of GUI data found no significant differences in living arrangements between emerging adults with LTPC and their peers without LTPC at aged 20 years. Furthermore, during the pandemic, many emerging adults, especially students moved back to their family homes due to campus closures and financial difficulties (Preetz et al., 2022). Therefore, it is hypothesised that there will be no significant association between group membership (LTPC vs. no-LTPC) and living arrangements, with both reporting similar living arrangements.

Hypothesis 2.2: Existing research indicates that emerging adults with LTPC may have lower educational achievements (Kelly & Maitre, 2021; Maslow et al., 2011; Pinquart, 2014). The secondary analysis of GUI data also found some notable differences in educational outcomes. Emerging adults living with LTPC were less likely to participate in the regular Leaving Certificate programme and sit their final exam in comparison to their peers. Therefore, it is hypothesised that there will be a significant association between group membership (LTPC vs. no-LTPC) and educational attainment, with emerging adults living with LTPC reporting lower levels of educational attainment in comparison to their peers.

Hypothesis 2.3: Research suggests that in addition to poorer educational achievements, emerging adults with LTPC may also experience lower vocational achievements (Kelly & Maitre, 2021; Maslow et al., 2011). The secondary analysis of GUI data found that emerging adults with LTPC were more likely to report unemployment compared to their peers. Therefore, it is hypothesised that there will be a significant association between group membership (LTPC vs. no-LTPC) and primary economic status,

with emerging adults living with LTPC more likely to report unemployment in comparison to their peers.

Hypothesis 2.4: Emerging adulthood is generally a time of increased risk-taking (Arnett, 2000; Ravert, 2009), partly due to the ongoing development of the prefrontal cortex, which is responsible for determining the consequences of actions (Arain et al., 2013). However, the secondary analysis of GUI data found that emerging adults living with LTPC reported similar levels of overall willingness to take risks as their peers. Therefore, it is hypothesised that there will be no significant difference in the willingness to take risks between the two groups (LTPC vs. no-LTPC), with both groups reporting similar levels of risk-taking behaviour.

Hypothesis 2.5: Emerging adults living with LTPC may engage in risk-taking behaviours as they attempt to balance their social lives and schedules with the demands of self-management (e.g., staying out late). The systematic review found evidence that this balancing act can sometimes lead to poor health decisions, such as missing medications. The secondary analysis of GUI data found no significant differences between emerging adults living with LTPC and their peers in relation to smoking and vaping, but it did find that emerging adults with LTPC reported lower alcohol consumption than their peers. In line with these findings, it is hypothesised that there will be no significant association between group membership (LTPC vs. no-LTPC) and smoking, vaping, or non-prescription drug use, but there will be a significant association with the frequency of alcohol consumption, with emerging adults living with LTPC reporting lower frequency of alcohol consumption than their peers without LTPC.

Hypothesis 2.6: Achieving financial independence is one of the main criteria identified by emerging adults for reaching adulthood (Arnett, 2001). The systematic review highlighted that emerging adults living with LTPC can face financial uncertainty, often

relying on family for ongoing financial support or worrying about issues such as medical insurance while striving for financial independence. Additionally, wider research indicates an increased risk of economic hardship for those living with LTPC (Indecon International Research Economists, 2021). Contrary to this, the secondary analysis of GUI data found that both emerging adults living with LTPC and those without LTPC reported being reasonably able to make ends meet financially. However, it is possible that those experiencing more significant financial difficulties were not equally represented in that analysis. Therefore, it is hypothesised that group membership (LTPC vs. no-LTPC) will be significantly associated with financial stability, with emerging adults living with LTPC reporting more difficulty in making ends meet in comparison to their peers.

Objective 3: To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on key variables related to self-management and the age of self-focus. This involves examining learning how to be self-sufficient, specifically, self-regulation.

Hypothesis 3.1: Self-regulation is recognised in the literature as critical for general positive life adjustments (Blair & Diamond, 2008). It underpins the trial-and-error processes that emerging adults use in navigating both self-management (Lansing & Berg, 2014) and emerging adulthood (Hagler et al., 2016). As it is important for both self-management and navigating emerging adulthood, it is hypothesised that there will be no significant difference in self-regulation between the two groups (LTPC vs. no-LTPC), with both groups reporting similar levels of self-regulation.

Objective 4: To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on key variables related to self-management and the age of feeling in-between. This involves examining the perception

of feeling adult, specifically, if emerging adults consider themselves to be fully adult and how they perceive themselves to have taken on adult responsibilities in comparison to peers.

Hypothesis 4.1: Emerging adults report feeling in-between more than any other group (Reifman et al., 2007). The systematic review found that emerging adults living with LTPC experienced this "in-between" feeling in two ways: feeling as though they were not yet an adult and being treated by others as not yet adult. The secondary analysis of GUI data found that emerging adults living with LTPC were less likely to perceive themselves as fully adult in comparison to their peers, however, they were more likely to feel they took on adult responsibilities faster than their peers. Therefore, it is hypothesised that group membership (LTPC vs. no-LTPC) will be significantly associated with the perception of feeling adult and taking on adult responsibilities, with emerging adults living with LTPC feeling less adult but taking on adult responsibilities faster than their peers.

Objective 5: To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on age and gender.

Hypothesis 5.1: Age is a variable of importance due to its relevance to the endorsement of the features of emerging adulthood. Younger emerging adults tend to express these features more strongly (Reifman et al., 2007); therefore, it is essential to consider the age of participants in both groups, given the age range of 18–25 years. It is hypothesised that there will be no significant difference between the two groups (LTPC vs. no-LTPC) in terms of age.

Hypothesis 5.2: As gender can influence participation in certain activities, such as education and risk-taking (Norona et al., 2016), it is important to assess whether there is a difference between the two groups (LTPC vs. no-LTPC) in gender distribution. It is

hypothesised that there will be no significant difference between the two groups (LTPC vs. no-LTPC) in terms of gender.

Objective 6: To examine whether the experience of the five features of emerging adulthood vary (as measured by the IDEA scale), based on having LTPC and/or the factors above related to self-management and emerging adulthood that showed significant differences between the two groups (LTPC vs. no-LTPC).

The systematic review highlighted the need for a deeper understanding of the extent to which emerging adults with LTPC experience the features of emerging adulthood in comparison to peers. It highlighted two key gaps: firstly, a lack of quantitative and comparative research and secondly, that only one study (Kamp et al., 2020) utilised a designated measure of emerging adulthood. This objective seeks to examine whether group membership (LTPC vs. non-LTPC) and the significant variables identified in Objectives 1-5 are associated with the five features of emerging adulthood, utilising the Inventory of the Dimensions of Emerging Adulthood (IDEA). No *a priori* hypotheses are being tested in this objective.

Objective 7: To examine whether self-management in emerging adults living with LTPC varies based on the extent to which some-one perceives and identifies with the five features of emerging adulthood (as measured by a standardised scale specifically designed to measure these five features), impact of the condition, and the factors identified in Objectives 1-5 that are associated with the features of emerging adulthood and self-management.

The systematic review found that there is evidence of the five features of emerging adulthood in how emerging adults self-manage their LTPC. These emerging adults engage with self-management strategies but can face challenges due to the instability that marks this

developmental stage, as well as the need to balance multiple life transitions typical of emerging adulthood.

Hypothesis 7.1: Although identity exploration was evident in self-management in the systematic review, the findings were mixed. Some emerging adults found it easier to accept and integrate their condition into their identity, while others struggled, seeking to feel “normal.” Navigating relationships during this time facilitated self-management, as in the case of parental support, or acted as a barrier, such as needing more developmentally appropriate healthcare support. The secondary analysis of GUI data found that emerging adults living with LTPC reported lower life satisfaction scores compared to their peers, though they navigated peer and familial relationships similarly. Given the overall evidence of identity exploration among emerging adults living with LTPC, it is hypothesised that there will be a significant association between identity exploration and self-management and higher endorsements of identity exploration will be associated with poorer self-management.

Hypothesis 7.2: Instability was evident in the self-management strategies and tasks of emerging adults in the systematic review. Emerging adults living with LTPC faced numerous life transitions and competing priorities (e.g., socialising, navigating timetables) that impacted their ability to manage their condition. The secondary analysis of GUI data found significant differences between emerging adults living with LTPC and their peers without LTPC, particularly in areas related to education and uncertainty. Therefore, it is hypothesised there will be a significant association between instability and self-management, and higher endorsements of instability will be associated with poorer self-management.

Hypothesis 7.3: Emerging adulthood is a time of learning how to be self-sufficient and accepting responsibility (Arnett 1997; 1998; Sharon 2016). The systematic review found that while many emerging adults living with LTPC acknowledged the need to take responsibility for their healthcare and self-management, some struggled with this challenge.

The secondary analysis of GUI data found that emerging adults with and without LTPC reported similar aspirations and goals to be achieved by age 30. As self-focus during this stage involves trial-and-error processes and goal setting, it is hypothesised that there will be a significant association between self-focus and self-management, and higher endorsements of self-focus will be associated with better self-management.

Hypothesis 7.4: Although there was less evidence in the systematic review for the age of feeling in-between, the evidence that existed showed that some emerging adults living with LTPC felt intimidated and not fully ready for the challenges of adult healthcare and self-management responsibilities. Additionally, others found themselves not being treated as adults by parents and/or healthcare professionals. The secondary analysis of GUI data found that emerging adults with LTPC reported feeling less adult than their peers but that they had taken on adult responsibilities faster. Therefore, it is hypothesised that there will be a significant association between feeling-in-between and self-management, and higher endorsements of feeling in-between will be associated with poorer self-management among emerging adults living with LTPC.

Hypothesis 7.5: Although emerging adulthood is often unstable, it remains a time of optimism, positivity, and possibilities (Arnett, 2004; 2015). The systematic review found that the availability of choices and being optimistic could act as either barriers or facilitators to self-management for some emerging adults living with LTPC, with some being overly optimistic about the consequences of negative health behaviours. However, maintaining a positive attitude can help others stay in the moment and worry less about the future. Additionally, the secondary analysis of GUI data found that emerging adults in both groups (LTPC vs. non-LTPC) were generally lacking in optimism about their future, particularly regarding housing, employment, and poverty. Given the varied impact of optimism and possibilities on self-management, it is hypothesised that there will be no significant

association between the endorsement of possibilities and self-management among emerging adults living with LTPC.

Table 4.1
Objectives and Hypotheses

Objective 1: Age of Identity Exploration	To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on key variables related to self-management and the age of identity exploration.
Navigating Relationships	
Hypothesis 1.1	Both groups (LTPC vs. no-LTPC) will report similar levels of perceived of social support.
Hypothesis 1.2	Group membership (LTPC vs. no-LTPC) will be significantly associated with relationship status and emerging adults living with LTPC will be more likely to be report being single in comparison to their peers.
Objective 2: Age of Instability	To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on key variables related to self-management and the age of instability.
Life Transitions	
Hypothesis 2.1	There will be no significant association between group membership (LTPC vs. no-LTPC) and living arrangements, with both reporting similar living arrangements.
Hypothesis 2.2	There will be a significant association between group membership (LTPC vs. no-LTPC) and educational attainment, with emerging adults living with LTPC reporting lower levels of educational attainment in comparison to their peers.
Hypothesis 2.3	There will be a significant association between group membership (LTPC vs. no-LTPC) and primary economic status, with emerging adults living with LTPC more likely to report unemployment in comparison to their peers.

Table 4.1
Objectives and Hypotheses

Taking Health Risks Hypothesis 2.4	There will be no significant difference in the willingness to take risks between the two groups (LTPC vs. no-LTPC), with both groups reporting similar levels of risk-taking behaviour.
Hypothesis 2.5	There will be no significant association between group membership (LTPC vs. no-LTPC) and smoking, vaping, or non-prescription drug use, but there will be a significant association with frequency of alcohol consumption, with emerging adults living with LTPC reporting lower frequency of alcohol consumption than their peers.
Uncertainty	
Hypothesis 2.6	Group membership (LTPC vs. no-LTPC) will be significantly associated with financial stability, with emerging adults living with LTPC reporting more difficulty in making ends meet in comparison to their peers.
Objective 3: Age of Self-Focus	To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on key variables relating to self-management and the age of self-focus.
Learn how to be Self-Sufficient	
Hypothesis 3.1	There will be no significant difference in self-regulation between the two groups (LTPC vs. no-LTPC), with both groups reporting similar levels of self-regulation.
Objective 4: Age of Feeling In-Between	To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on key variables relating to self-management and the age of feeling in-between.
Feeling not yet Adult	
Hypothesis 4.1	Group membership (LTPC vs. no-LTPC) will be significantly associated with the perception of feeling adult and taking on adult responsibilities, with emerging adults living with LTPC feeling less adult but taking on adult responsibilities faster than their peers.
Objective 5 Age & Gender	To examine whether there are differences or associations between two groups of emerging adults (living with LTPC and without LTPC) on age and gender.
Hypothesis 5.1	There will be no significant difference between the two groups (LTPC vs. no-LTPC) in terms of age.

Table 4.1
Objectives and Hypotheses

Hypothesis 5.2	There will be no significant difference between the two groups (LTPC vs. no-LTPC) in terms of gender.
Objective 6	To examine whether the experience of the five features of emerging adulthood vary, as measured by the standardised scale specifically developed to measure to what extent some-one perceives and identifies with the five features of emerging adulthood, based on having a LTPC and the factors above related to self-management and emerging adulthood that showed significant differences between the two groups (LTPC vs. no-LTPC)
Objective 7	To examine whether self-management in emerging adults living with LTPC varies based on the extent to which some-one perceives and identifies with the five features of emerging adulthood (as measured by a standardised scale specifically designed to measure these five features), the impact of the condition and the factors identified in Objectives 1-5 that are associated with the features of emerging adulthood and self-management.
Hypothesis 7.1	There will be a significant association between identity exploration and self-management and higher endorsements of identity exploration will be associated with poor self-management.
Hypothesis 7.2	There will be a significant association between instability and self-management, and higher endorsements of instability will be associated with poorer self-management.
Hypothesis 7.3	There will be a significant association between self-focus and self-management, and higher endorsements of self-focus will be associated with better self-management.
Hypothesis 7.4	There will be a significant association between feeling-in-between and self-management, and higher endorsements of feeling in-between will be associated with poorer self-management.
Hypothesis 7.5	There will be no significant association between possibilities and self-management.

4.4 Method

4.4.1 Cross-Sectional Survey Design

This study was a cross-sectional survey of emerging adults (aged 18-25 years) living with LTPC and without LTPC. Ethical approval for this study was obtained from Dublin City University Research Ethics Committee (DCUREC/2021/207, see Appendix C.1).

4.4.2 Study Sample

4.4.2.1 Inclusion and Exclusion Criteria

Emerging adults aged between 18 years and 25 years were eligible to take part in this study phase. As highlighted above, the age range of 18-25 years are more likely to endorse the features of emerging adulthood compared to those aged 26-29 years (Crocetti et al., 2015). This age range is also characterised by higher levels of risk-taking (Arnett, 2000; Camfield et al., 2017; Ravert, 2009), which poses a greater potential risk to self-management. Emerging adults outside of this age range were excluded from taking part.

For those with LTPC, this was defined as one that has lasted more than 6 months and required ongoing management (e.g., medication, medical visits, therapies) (NHS, 2021). The categories of LTPC from the NHS are different to those used in the GUI secondary analysis. The GUI data collection was carried out face-to-face and conditions disclosed were coded as per the International Classification of Diseases 11th Revision by the interviewer. The categories as per the NHS include

- Diabetes
- Cardiovascular (e.g., Hypertension, Angina)
- Chronic Respiratory (e.g., Asthma, Chronic Obstructive Pulmonary Disease)
- Chronic Neurological (e.g., Multiple Sclerosis, Epilepsy)
- Chronic Pain (e.g., Arthritis)

- Other Long-Term Physical Conditions (e.g., Chronic Fatigue Syndrome, Irritable Bowel Syndrome).

The participants were asked to confirm that the diagnosis was medically confirmed by a doctor.

4.4.4 Recruitment

For the recruitment of emerging adults with and without LTPC, recruitment was conducted through Facebook and Instagram advertisements and sharing across other social media platforms (i.e., LinkedIn and Twitter). Various advocacy organisations were also contacted to specifically target emerging adults with LTPC.

4.4.4.1 Facebook Advertising

A Facebook page for the study, called “Are We There Yet” with the researcher’s photograph, contact details and a brief introduction to the study (see Appendix D.1), was set up to facilitate recruitment. Across several weeks, the researcher shared posts from health-related charity pages (e.g., Epilepsy Ireland, Chronic Pain Ireland), so potential participants could see that the page was actively managed. Having a dedicated Facebook page enabled the set up and management of advertisements through Meta’s Ad Centre. A recruitment campaign was created and set up to run throughout January – May 2022 using the recruitment flyer and a written post (see Appendix D.2). The campaign objective was for Facebook to target people who would be most likely to click the survey link. The advertising audience was set to 18-25-year-olds and locations such as Ireland, the United Kingdom (UK), England, Wales, Scotland, and Northern Ireland (see Appendix D.3). On clicking the link, participants were brought to the Plain Language Statement (See Appendix E.1) at the start of the survey on the Qualtrics platform. The advertisement post was pinned to the top of the Facebook

project page so that it was easy for advocacy organisations or individuals to share on their pages or in private Facebook groups. Facebook automatically shares the advertisement on Instagram.

4.4.4.2 Additional Social Media Platforms

The researcher's personal account was used on Twitter due to the difficulty in building up a follower base on a new Twitter account. The researcher created a Twitter banner (i.e., a header that is seen when people click onto profile) from the recruitment flyer and pinned a post with the same details as Facebook at the top of the Twitter feed (see Appendix D.4). The researcher tweeted the post regularly and invited Twitter followers to take part in the survey if they were eligible and/or share the link. Dublin City University and the School of Psychology shared the study on several occasions, and it was reshared by some of their followers. Advocacy organisations were given the Facebook and Twitter links, if they agreed to share the survey with their social media followers. The same process of inviting followers to share the recruitment advertisement was used for LinkedIn.

4.4.4.3 Advocacy Organisations

Participants living with LTPC were also recruited through various advocacy organisations (e.g., Chronic Pain Ireland, Diabetes Ireland). Using Google and the categories from the NHS definition for LTPC, the researcher identified and emailed relevant advocacy organisations across Ireland and the United Kingdom. The email introduced the researcher and supervisors, provided a brief overview of the study and a link to the recruitment post on Facebook and Twitter. The recruitment flyer (see Appendix D.5), plain language statement (see Appendix E.1) and ethical approval (see Appendix C.1) were also attached to the email. Organisations were then asked if they would be happy to share the recruitment flyer and/or

survey link with their members and/or social media followers through their website, groups, newsletters or social media channels (see Appendix D.6 for sample email and list of organisations). Thirty-nine advocacy organisations were contacted and 23 confirmed that they would share the survey through at least one of their channels (see Appendix D.6 for sample email and list of organisations). Some of the organisations did not respond to the emails (and follow-ups) and others advised they had policies to only share research funded by themselves.

4.4.5 Procedure

An online survey was created using the DCU Qualtrics platform: dcupscpsychology.eu.qualtrics.com. The survey was set up as anonymous, that is, it collected no identifying data including IP addresses. On accessing the survey, participants landed on the plain language statement (see Appendix E.1) which outlined the study background, eligibility criteria, participant involvement details, what data was to be collected, confidentiality, right to withdraw, benefits, risks, data storage and the study team's contact details. At the end of the plain language statement, participants completed an informed consent form (see Appendix E.2). Participants were required to confirm yes to all seven consent questions to proceed. If a participant clicked no to any of the consent questions, the survey ended as they did not provide full consent and a message thanking them for their time was presented (see Appendix E.3). Additionally, the first demographic question of the survey was "What is your age in years (You must be between 18-25 years to take part)" with a drop-down menu for participants to choose from 18 years, 19 years, 20 years, 21 years, 22 years, 23 years, 24 years, 25 years and 'I am not between 18-25 years'. Those who chose 'I am not between 18-25 years', the survey ended as they did not meet the inclusion criteria, and the "thank you for your time" message was presented to them. The survey took approximately 10 to 15 minutes

to complete. At the end of the survey participants were presented with the message thanking them for their time.

4.4.6 Survey Materials

The survey was designed by the researcher, guided by the findings from the systematic review (Chapter Two), the GUI secondary data analysis findings (Chapter Three) and the wider literature relating to Arnett's Theory of Emerging Adulthood. The decisions regarding the survey self-management measures chosen were further underpinned by the self-management theories (see Chapter 1, section 1.5) and the researcher's experience with self-management (see Chapter 1, section 1.6.1). See Figure 4.2 for administration of measures.

4.4.6.1 Sociodemographic and LTPC Characteristics

The sociodemographic characteristics (see Appendix E.4 – E.12) collected were age, gender, nationality and country and years of residency, ethnicity, living arrangements, relationship status, number of children, if full-time education including third level was completed, highest completed level of education, primary economic status, split of living costs between self and parents, how easy or difficult it is to make financial ends meet, risky health behaviours (smoking, vaping, alcohol, drugs), COVID-19 impact (income, mental and physical health, and social life) and if they had LTPC diagnosed by a medical professional that required ongoing management. For those participants who answered yes to the LTPC and ongoing management questions, some additional information was collected including type of diagnosis using the NHS categories (cardiovascular, diabetes, respiratory, neurological, pain, other), if more than one LTPC, the diagnosis with the most impact on their life (they would be asked to consider this diagnosis when answering questions), age at diagnosis, difficulty in carrying out daily activities (using five variables: learning, remembering or concentrating;

dressings, bathing or getting around inside home; going outside the home alone to shop or visit places; working at a job, business or attending college; and participating in other activities, measured by the impact being, never, sometimes, often or always), healthcare cover (free healthcare, GP visit card, health insurance on someone else's policy, own health insurance policy, do not have free healthcare or health insurance, other) and meeting the financial cost of healthcare needs (with great difficulty to very easily). The sociodemographic questions were informed by questions used in the Census from the Central Statistics Office of Ireland (CSO.ie) and in the survey used in the Growing Up in Ireland (GUI) longitudinal research for Cohort '98 at age 20 years (growingup.gov.ie).

4.4.6.1.1 COVID (administered to all participants)

The cross-sectional survey was conducted between January and December 2022, when Ireland and the UK had recently emerged from lockdown due to the COVID-19 pandemic. As COVID-19 pandemic had the potential to influence the experience of emerging adulthood, the survey asked participants about its impact on their income, mental and physical health, and social lives. The question asked participants if COVID had impacted them 0 – 10 scale (0 being very much negatively and 10 being very much positively).

4.4.6.2 Self-Management Measures (administered to LTTPC only)

4.4.6.2.1 Communication with Physicians (CWP)

This three-item questionnaire (see Appendix E.5) was developed to measure the self-management behaviour of communication with doctors for the Chronic Disease Self-Management Programme at Stanford University (Lorig et al., 1996). It is a six-point scale that uses 0 “never” to 5 “very often”. It asks participants to rate how often they prepare a list of questions, ask questions about what they want to know or don't understand about

treatment and discuss personal problems that may be related to the illness. Cronbach's alpha (α), ranged between .77 and .92 for the self-efficacy measures for the Chronic Disease Self-Management Programme, that includes the Communication with Physician Scale (Lorig et al., (1996). The score is the addition of the three items, with a higher score indicating better communication.

4.4.6.2.2 Perceived Medical Condition Self-Management Scale (PMCSMS)

The PMCSMS (see Appendix E.6) is a widely used, one-factor, eight-item questionnaire that was modified from the general Perceived Health Competence Scale (PHCS) which measures a person's self-reported ability to manage a chronic condition and determines the extent to which they feel in control (Smith et al., 1995). It can be used with the wording of "chronic condition" or can be modified to a specific condition (Wallston et al., 2011; Wallston et al., 2007). It is measured on a five-point scale, 1 "strongly disagree" to 5 "strongly agree." and questions 1, 2, 6 and 7 are reverse-scored. It asks participants how much they agree with a statement to assess perceived self-management such as "I handle myself well with respect to my condition" and "It is difficult for me to find effective solutions for problems with managing my condition (reverse scored). Cronbach's alpha (α), ranged between .78 (Wallston et al., 2011) and .834 (Wallston et al., 2007). Higher scores indicate better perceived self-management of a condition.

4.4.6.3 Emerging Adulthood Measures (administered to all participants)

4.4.6.3.1 Inventory of the Dimensions of Emerging Adulthood (IDEA)

The IDEA (see Appendix E.7) is a five-factor, 31-item questionnaire designed to measure the individual differences in how emerging adults perceive and identify with the five features of emerging adulthood: identity exploration (seven items), instability (seven items),

self-focus (three items), feeling in-between (three items), and possibilities (five items) (Reifman et al., 2007). There is a separate sub-scale called "other-focus" that is not part of the primary theory of emerging adulthood and was developed for comparison with other age groups. Therefore, the responses related to the "other-focus" sub-scale will be excluded from the statistical analysis leaving 28 items. Participants are instructed to consider a five-year period consisting of the previous 2.5 years, the present, and the next 2.5 years. They are asked to indicate their level of agreement or disagreement with each statement using a four-point Likert scale: 1 "strongly disagree" to 4 "strongly agree". Each sub-scale represents the extent to which individuals identify with a specific aspect of emerging adulthood. Reifman et al., (2007) ran exploratory and confirmatory analyses which identified a five-factor model (excluding other sub-scale) and combining the results of two studies, found only five item loadings smaller than .45, however, it is important to note that some of the subscales did exhibit large correlations ($r > .7$) with each other. The researchers also found internal consistency reliability coefficients for the subscales were generally strong, with Cronbach's alpha (α) between .70-.85. Furthermore, the test-retest reliability correlations (over a one-month interval) ranged from .64-.76, except for the "feeling in-between" subscale (.37). Higher total scores on the subscales indicate a higher level of identification with that feature and a higher overall score on the IDEA scale indicate a higher level of identification with emerging adulthood.

4.4.6.3.2 The Identity Stage Resolution Index (ISRI)

The ISRI (see Appendix E.8) is a two-factor six-item questionnaire designed to measure the accumulation of identity capital (Côté, 2016). That is, as young people transition into adulthood, they can accumulate different types of identity capital. This process is connected to Erikson's idea that successfully resolving the stage of identity formation marks

the completion of the transition to adulthood (Erikson, 1968). Identity capital is about resources such as, sociological (e.g., parent's social class, wealth) and psychological (e.g., ego strength, internal locus of control). The questionnaire measures progress towards adulthood and establishment within a community. It is measured on five-point scales, ranging from 0 'not at all true' to 4 'entirely true'. Two factors have been consistently found in numerous studies, with three items measuring the feeling of being an adult (the Adult Identity Resolution Scale [AIRS]), and three items measuring the feeling of societal integration (the Societal Identity Resolution Scale [SIRS]). The Cronbach's alpha (α) ranges from 0.64 to 0.77 for each three-item scale (Côté, 2006; Côté, 2016). Higher scores indicate that a person identifies more with being an adult and having achieved societal integration. This scale was included as GUI used one question (Participants were asked "You consider yourself to be an adult") from the subscale, the Adult Identity Resolution Scale. That same question is used in the analysis below.

4.4.6.3.3 Taking on Adult Responsibilities

Taking on adult responsibilities was measured with one question (see Appendix E.9), taken from Wave Four, Cohort '98, which asked, "In terms of taking on adult responsibilities, would you say you grew up faster, slower or at about the same rate as other people your age?", with the options "faster", "at about the same rate" and "slower".

4.4.6.4 Risk-Taking Measure

Risk-taking was measured with one question, taken from the GUI study (see Appendix E.10), which asked, "Are you generally a person who is fully prepared to take risks or do you try to avoid taking risks?", 0 means "unwilling to take risks" and 10 means "fully prepared to take risks".

4.4.6.5 Social Support Measure

4.4.6.5.1 *The Multidimensional Scale of Perceived Social Support (MSPSS)*

The MSPSS (see Appendix E.11) is a three-factor, 12-item questionnaire to measure the subjective assessment of social support adequacy from three specific sources: family, friends and significant other (Zimet et al., 1988). Participants are asked to indicate how they feel about 12 statements on a seven-point scale, ranging from 1 ‘very strongly disagree’ to 7 ‘very strongly agree’, with four statements relating to each source. Cronbach's alpha (α), for the Significant Other, Family, and Friends subscales, were .91, .87, and .85, respectively and the reliability of the total scale was .88 (Zimet et al., 1988). Higher scores indicate better perceived social support.

4.4.6.6 Self-Regulation Measure

4.4.6.6.1 *The Short-Form Self-Regulation Questionnaire (SSRQ)*

The SSRQ (see Appendix E.12) is a two-factor model, Impulse Control with 11 items and Goal Setting with 10 items to measure self-regulation capacity across the seven processes of self-regulation (Neal & Carey, 2005). It was developed from the 31-item shortened-form questionnaire (Carey et al., 2004) which was developed from the 63-item, Self-Regulation Questionnaire (SRQ) (Brown et al., 1999). Participants are asked to answer questions by circling the response that best describes them on a five-point scale, ranging from 1 ‘strongly disagree’ to 5 ‘strongly agree’. Cronbach's alpha (α) was calculated for both factors with overall alphas of 0.84 and 0.86 respectively (Neal & Carey, 2005). Higher scores indicate better self-regulation.

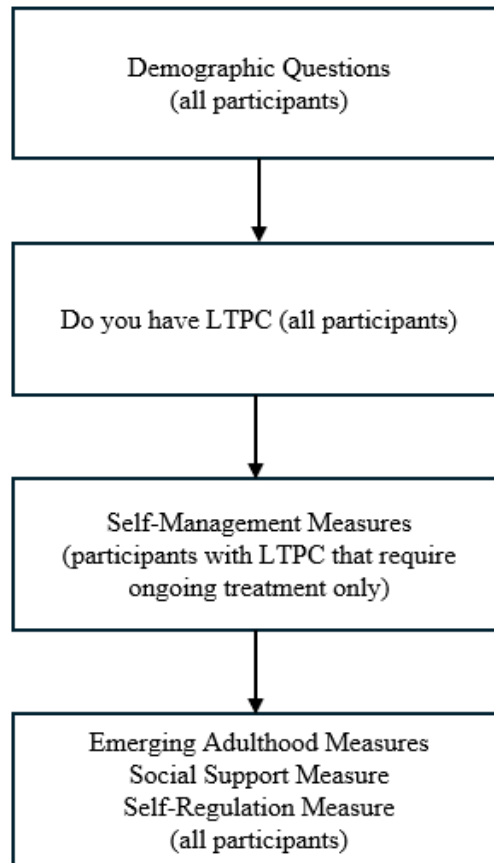


Figure 4.2. Administration of measures to participants

4.4.7 Pilot of Survey

After being reviewed by the researcher and project supervisors, the survey was piloted with three emerging adults known to the researcher, two aged 18 years and one aged 20 years. Feedback was provided on the overall survey to ensure that the instructions and questions were easily understood and the length of time to complete it. The feedback was that the survey instructions and questions were clear and easy to understand. Although the length of time to do the survey was mentioned by the pilot participants, they did not consider it to be overly tiring, and the section breaks and percentage bar at the bottom of the screen, helped them to progress without wanting to withdraw.

4.4.8 Ethical Considerations

As this study included emerging adults living with LTPC, it was identified that vulnerability was possible (e.g., fatigue), but the level of risk was deemed low. The survey was set up in such a way that participants could pause it and return later or withdraw fully at any time. In the plain language statement participants were advised of their right to withdraw at any time and that the risk of taking part in this questionnaire was deemed low but if they experienced any adverse effects, the names of two organisations that support young people were also provided (see Appendix E.1). Participants were also advised that no identifying information (names, emails, IP addresses) were being collected and that all answers were completely anonymised, remaining strictly confidential in line with General Data Protection Regulations. Approval was received from Dublin City University's Data Protection Unit to confirm that the study was GDPR compliant (see Appendix C.2). The online survey data was collected through Qualtrics, which is a secure password-protected software programme, and the anonymised file is stored on the researcher's password-protected laptop. The informed consent questions (see Appendix E.2) ensured that active consent was obtained.

4.5 Data Analysis

Data analysis was carried out within R 4.3.0 (R Core Team, 2023). Descriptive statistics were calculated where appropriate. Measurement invariance was conducted to ensure that valid comparisons between the two groups (LTPC vs. No-LTPC) could proceed. Group comparisons were then conducted (objectives one to five), followed by structural equation modelling to examine objectives six and seven.

4.5.1 Data Analysis for Measurement Invariance

To make valid comparisons between two groups, those living with LTPC and those living without LTPC, it is important to establish measurement invariance on scales administered to both groups. Psychological constructs such as beliefs and attitudes cannot be measured directly in psychology; therefore, we use observable indicators as substitutions for these latent constructs (Milfont & Fischer, 2010). In comparing a latent construct across groups (e.g., cross-culture, gender, academic levels) using an instrument such as a questionnaire, it is essential that each observed indicator has a consistent relationship with the latent variable in all groups, that is, do items mean the same to members of different groups and have what is called measurement invariance (Cheung, 2008; Cheung & Rensvold, 2002). Measurement invariance is the equivalence of a measured construct across two or more groups (Chen, 2008). By establishing measurement invariance, valid comparisons, interpretations, and conclusions can be made about the psychological construct across the groups and are meaningful (Cheng & Rensvold, 2002; Milfont & Fischer, 2010). For the current study, to make valid comparisons between the two groups, those living with LTPC and those living without LTPC on the four scales administered to both groups, multi-group confirmatory factor analysis (MG-CFA) was conducted to test for measurement invariance. Of the six scales used within the survey, four are used across both groups (IDEA, IRSI, MPSS, SSRQ) and therefore, it is deemed important to test for measurement invariance on these scales. For example, are the items for each of the five subscales of the IDEA scale, identity exploration, instability, self-focus, feeling in-between and possibilities, appropriate and understood in the same way across both groups (that is, those with and without LTPC).

Confirmatory factor analysis (CFA) is widely used to test for measurement invariance (Fischer & Karl, 2019; Milfont & Fischer, 2010). CFA specifically tests the underlying theoretical structure of a measurement scale (Fischer & Karl, 2019). MG-CFA is an extension

of CFA and tests whether the estimated parameters of two nested models remain consistent across groups and provides insights into the extent to which the underlying factor structure and relationships between variables hold true across the groups (Cheung & Rensvold, 2002). MG-CFA is the most common method for testing for measurement invariance across groups beginning with a baseline model (Boer et al., 2018; Van De Vijver & Fischer, 2009). Configural invariance (unconstrained or baseline model) assesses if the groups associate the same group of items with the same constructs (same conceptual frame of reference) and must be established for subsequent tests to be meaningful (Vandenberg & Lance, 2000; Cheung & Rensvold, 2002). It is important that the same item is associated in each group with the same latent factor, however, the factor loadings can differ (Chen, 2008). Metric invariance (loadings constrained) assesses whether the strength of the relationship between each item and underlying construct is the same across groups (similar factor loadings), at least partial is needed here for subsequent tests to be meaningful (Vandenberg & Lance, 2000; Cheung & Rensvold, 2002). Scalar invariance (loadings and intercepts constrained) assesses if the intercepts of observed variables remain consistent across groups and if reached it allows for valid comparisons (compare means) of the latent construct between groups (Vandenberg & Lance, 2000; Cheung & Rensvold, 2002). If measurement invariance is not achieved, a common approach is to perform exploratory analyses. These analyses aim to identify the source of the oddity. Once identified, the next step is to assess whether excluding specific items, factors, or samples could lead to improved indicators of measurement invariance (Fischer & Karl, 2019).

If the covariance structure inferred by the model is like the covariance structure of the sample data, then the model is considered suitable and this is indicated by using a goodness-of-fit index (GFI), the most used being the χ^2 statistic and a non-significant value means acceptance of the null hypothesis (Cheung & Rensvold, 2002). However, for larger sample

sizes, it is not a practical test and other goodness-of fit-indicators (GFI) are recommended as alternatives, for example, incremental fit and lack-of-fit indices (Bentler, 1990; Fischer & Fontaine, 2010). Incremental fit indices assume there are a number of models that are subsets of each other, or nested, the most common being the Comparative Fit Index (CFI) which compares the fit of a model to a previous or the Tucker–Lewis Index (TLI) (Bentler, 1990; Hu & Bentler, 1999). The larger the value of the CFI or TLI, the better the fit, 0.90 is seen as acceptable, while 0.95 and above is a good fit and changes in increments between models of equal or less than 0.1 are good but between 0.1 and 0.2 there may be differences between groups (Vandenberg & Lance, 2000). Lack-of-fit indices include, for example, the root mean square error of approximation (RMSEA) which considers degrees of freedom and penalises less parsimonious models (Browne & Cudeck, 1992). Cut-off recommendations in the literature are mixed, it is suggested that the RMSEA cut-off be 0.6, however, 0.8 might be appropriate as an upper limit (Vandenberg & Lance, 2000). If the value of the more restrictive model is within the 90% confidence interval, the restricted model can be accepted (Little et al., 2007). For the standardized root mean square residual (SRMSR), smaller values indicate less deviation (Hu & Bentler, 1999). It is common to use multiple GFIs in evaluating and reporting overall model fit (Cheung & Rensvold, 2002).

Lavaan 0.6-15 (Rosseel, 2012) in R.4.3.0 (R Core Team, 2023) was used to carry out MG-CFA analysis to test for measurement invariance across the four measures, between two groups of emerging adults (18 – 25 years), one group living with long-term physical conditions and a second group living without long-term physical conditions. Weighted Least Squares Means and Variances (WLSMV) suited for ordinal data, was used and Lavaan 0.6-15 used the Diagonal of the Weight matrix for estimation (DWLS) and the full weight matrix to correct standard errors and compute the test statistic (Lavaan, 2023). As the full information maximum likelihood method is not compatible with WLSMV, pairwise deletion was chosen

to deal with missing data (Enders, 2001). It was assessed with a series of increasingly constrained model comparisons (configural to metric to scalar) and based on changes in GFI and Yuan-Bentler scale-corrected chi-square difference tests (Cheung & Rensvold, 2002). As chi-squared is sensitive to sample size, other GFIs (e.g., CFI) can be preferable for assessing the model fit (Milfont & Fischer, 2010). GFI statistics were compared between models with additional between-group constraints (a) comparative fit index (CFI; $<.95$ for good fit; $<.90-.94$ for adequate fit), (b) the standardized root-mean-square residual (SRMR; $<.08$ for acceptable fit), (c) the root-mean-square error of approximation (RMSEA; $<.08$ for acceptable fit) (Hu & Bentler, 1999). Change in model fit was evaluated by the same GFI used, CFI (Δ CFI) less than .01, change in RMSEA (Δ RMSEA) less than .015, and change in SRMR (Δ SRMR) less than .03 supports measurement invariance (Chen, 2007).

4.5.2 Data Analysis for Group Comparisons of Emerging Adults Living with LTPC and Without LTPC

Group comparisons were conducted for objectives one to five to examine if there were any significant differences or associations between the two emerging adult groups those living with LTPC and those living without LTPC, on key variables related to self-management and emerging adulthood: perceived social support, relationship status, living arrangements, educational attainment, primary economic status, risk-taking, risky health behaviours, perceived financial management, self-regulation, considering self to be adult and taking on adult responsibilities.

A series of Welch Two Sample t-tests, Chi-Square test for independence and Fisher's exact tests were conducted to determine differences and associations between the two groups (see Table 4.2). Hedge's g and Cramér V were run to calculate effect size to quantify the magnitude of the differences observed. No effect size was calculated for the Fisher's tests as

this may not be reliable when there are tables with small, expected counts. It is recommended that the thresholds to interpret small, medium, and large effects for Hedge's g are 0.15, 0.40, and 0.75 respectively (Brydges, 2019). Cramer's V thresholds to interpret depend on the degrees of freedom (Kim, 2017). All statistical tests were conducted at a significance level of $p < 0.05$, Bonferroni Correction for multiple comparisons was then applied to reduce the risk of Type I errors.

Table 4.2
Group Comparison Tests

Variable	Test Type
Age of Identity Exploration	
Navigating Relationships	
Perceived Social Support	Welch Two Sample T-Test
Relationship Status	Fisher's Exact Test
Age of Instability	
Life Transitions	
Living Arrangements	Fisher's Exact Test
Education attainment	Fisher's Exact Test
Primary Economic Status	Fisher's Exact Test
Taking Health Risks	
Willingness to Take Risks	Welch Two Sample T-Test
Smoking	Chi-Squared Test of Independence
Vaping	Fisher's Exact Test
Alcohol	Fisher's Exact Test
Non-Prescription Drugs	Fisher's Exact Test
Uncertainty	
Making Ends Meet	Chi-Squared Test of Independence
The Age of Self-Focus	
Learning to be Self-Sufficient	
Self-Regulation	Welch Two Sample T-Test
The Age of Feel In-Between	
Feeling Not Yet Adult	
Consider Self to be Adult	Fisher's Exact Test
Taking on Adult Responsibilities	Chi-Squared Test of Independence
Gender	Fisher's Exact Test
Age	Welch Two Sample T-Test

4.5.3 Data Analysis for Structural Equation Modelling (SEM)

Objectives six and seven were examined using structural equation modelling (SEM) in R 4.3.0 (R Core Team, 2023). For objective six, group membership and the significant variables from objective one to five were included in a model as independent variables and the five subscales representing the five features of emerging adulthood (IDEA) as the dependent variables. For objective seven, five latent variables comprising the five features of emerging adulthood from the IDEA scale, the impact of LTPC (see Table 4.5) and the significant variables from objectives one to five were included in a model as independent variables and two latent variables, communications with physician's scale (Lorig et al., 1996) and the one-factor Perceived Medical Condition Self-Management Scale (Smith et al., 1995) as the dependent variables. The impact of LTPC was included as it is highlighted in the Self and Family Management Framework (Grey et al., 2006; Grey et al., 2015) as a key protective or risk factor for self-management and data on this was collected in the survey.

In assessing goodness-of-fit for CFI or TLI, 0.90 is seen as acceptable, while 0.95 and above is a good fit (Vandenberg & Lance, 2000). It is suggested that the RMSEA cut-off be 0.6, however, 0.8 might be appropriate as an upper limit (Vandenberg & Lance, 2000). For the SRMSR, smaller values indicate less deviation, such as, at or below 0.08 (Hu & Bentler, 1999). Weighted Least Squares Means and Variances (WLSMV), specifically utilising the Diagonal of the Weight matrix for estimation (DWLS), were used in Lavaan 0.6-15. These methods were chosen for their efficacy in handling categorical or ordinal data. By utilising appropriate weight matrices, WLSMV ensures accurate parameter estimation and hypothesis testing, correcting standard errors and computing test statistics accordingly (Lavaan, 2023).

4.6 Results

4.6.1 Survey Sample Description

In total, 642 participants completed the survey and were included in the analyses. This consists of two groups, 201 participants living with LTPC and 441 living without LTPC. Participants' sociodemographic characteristics are displayed for the overall sample and separately for each group in Table 4.3.

The age range for all emerging adults was 18 – 25 years, the mean age for the overall sample was 22.01 years, for those living with LTPC it was 22.31 years and for those living without LTPC, it was 21.87 years. 203 (31.6%) participants indicated that their nationality was Irish, 277 (43.2%) were part of the UK (English, Scottish, Welsh, Northern Irish), 97 (15.1%) were from other European countries, American or Australian and 65 (10.1%) were from other nationalities (e.g., Indian). Most participants were White Irish and any other White background (80.5%) with the rest of the sample being racial/ethnic minority individuals (19.5%). Over half of all participants were living at home with parents/guardians (51.70%), single (53.30%) and were currently students (65%).

In relation to the impact of COVID-19 on participants, of those living with LTPC, 38.8% reported a negative impact on their income in comparison to 30.8% of those without LTPC. 79.1% of those living with LTPC reported a negative impact on their mental health in comparison to 70.5% of those without LTPC. 64.2% of those living with LTPC reported a negative impact on their physical health in comparison to 44.9% of those without LTPC. Finally, 70.2% of those living with LTPC reported a negative impact on their social lives in comparison to 68% of those without LTPC. For the means and standard deviations for the four scales administered to all participants; Inventory of the Dimensions of Emerging Adulthood (IDEA), Identity Stage Resolution Scale (ISRS), Multidimensional Scale of

Perceived Social Support (MSPSS) and Short-Form Self-Regulation Questionnaire, please see Table 4.4.

Table 4.3
Participant Sociodemographic Characteristics

Variable	Overall	With LTTPC	Without LTTPC
N	642	201	441
Age Range (M ± SD)	18 – 25 years (22.01 ± 1.93)	18 – 25 years (22.31 ± 2.02)	18 – 25 years (21.87 ± 1.87)
Gender			
Male	147 (22.9%)	33 (16.4%)	114 (25.9%)
Female	470 (73.2%)	154 (76.6%)	316 (71.7%)
Non-binary	16 (2.5%)	10 (5%)	6 (1.4%)
Prefer to self-describe	6 (0.9%)	4 (2%)	2 (0.5%)
Prefer not to say	3 (0.5%)	0	3 (0.7%)
Nationality			
Irish	203 (31.6%)	85 (42.3%)	118 (26.8%)
UK	277 (43.2%)	91 (45.3%)	186 (42.2%)
European/US/Australia	97 (15.1%)	14 (7%)	83 (18.8%)
Other	65 (10.1%)	11 (5.4%)	54 (12.2%)
Ethnicity			
Irish Traveller	2 (0.30%)	1 (0.5%)	1 (0.2%)
White Irish	203 (31.6%)	86 (42.8%)	117 (26.5%)
Any other White background	312 (48.6%)	84 (41.8%)	228 (51.7%)
African	7 (1.1%)	1 (0.5%)	6 (1.4%)
Any other Black background	7 (1.1%)	1 (0.5%)	6 (1.4%)
Chinese	13 (2.0%)	2 (1%)	11 (2.5%)
Any other Asian background	39 (6.1%)	5 (2.5%)	34 (7.7%)
Other (including mixed background)	52 (8.1%)	18 (9%)	34 (7.7%)
Prefer not to say	7 (1.1%)	3 (1.5%)	4 (0.9%)
Living Arrangements			
I live with my parents/guardian	332 (51.7%)	125 (62.2%)	207 (46.9%)
I live alone in a house/flat	46 (7.2%)	9 (4.5%)	37 (8.4%)
I live with my partner only	62 (9.7%)	22 (10.9%)	40 (9.1%)
I live with other relatives only	19 (3%)	6 (3%)	13 (2.9%)
I live with other adults (some not related to me)	129 (20.1%)	27 (13.4%)	102 (23.1%)
I live in "digs" or lodgings	4 (0.6%)	1 (0.5%)	3 (0.7%)
I live in campus accommodation/Barracks	38 (5.9%)	8 (4%)	30 (6.8%)
Other	12 (1.9%)	3 (1.5%)	9 (2%)
Relationship Status			
Single	342 (53.3%)	121 (60.2%)	221 (50.11%)
In a long-term relationship	248 (38.6%)	62 (39.8%)	186 (42.2)
Co-habiting	27 (4.2%)	11 (5.5%)	16 (3.6%)
Married or civil partnership	11 (1.7%)	2 (1%)	9 (2%)
Separated or divorced	2 (0.3%)	2 (1%)	0
Widowed	1 (0.2%)	1 (0.5%)	0
Other	9 (1.4%)	1 (0.5%)	8 (1.8%)
Prefer not to say	2 (0.3%)	1 (0.5%)	1 (0.2%)
Primary Economic Status			
Student/pupil	417 (65%)	93 (46.3%)	324 (73.5%)
Working for payment/profit (employee/self-emp)	150 (23.4%)	71 (35.3%)	79 (17.9%)
Looking for first regular job	15 (2.3%)	6 (3%)	9 (2%)

Table 4.3
Participant Sociodemographic Characteristics

Unemployed (available for work)	20 (3.1%)	5 (2.5%)	15 (3.4%)
Looking after family/home	6 (0.9%)	0	6 (1.4%)
Unable to work - permanent sickness/disability	23 (3.6%)	21 (10.4%)	2 (0.5%)
Other	11 (1.7%)	5 (2.5%)	6 (1.4%)
Finished Education			
Yes	300 (46.7%)	115 (57.2%)	185 (42%)
No	342 (53.3%)	86 (42.8%)	256 (58%)
Education Level			
No formal education or training	1 (0.2%)	1 (0.5%)	0
Primary School or equivalent	2 (0.3%)	0	2 (0.5%)
Secondary Sch - Junior Cert, GCSE (equiv)	22 (3.4%)	9 (4.5%)	13 (2.9%)
Secondary Sch - Leaving Cert, A-Level (equiv)	267 (41.6%)	72 (35.8%)	195 (44.2%)
Technical or Vocational (equivalent)	11 (1.7%)	4 (2%)	7 (1.6%)
Advance Cert or Completed Apprenticeship	17 (2.6%)	10 (5%)	7 (1.6%)
Higher Certificate (or equivalent)	40 (6.2%)	13 (6.5%)	27 (6.1%)
Ordinary Bachelors Degree, Nat Diploma (equiv)	65 (10.1%)	15 (7.5%)	50 (11.3%)
Honours Bachelors Degree, Prof qualification (equiv)	135 (21%)	51 (25.4%)	84 (19%)
Postgraduate Diploma /Degree (equivalent)	61 (9.5%)	16 (8%)	45 (10.2%)
Doctorate (PhD) or higher (equivalent)	3 (0.5%)	2 (1%)	1 (0.2%)
Other	17 (2.63%)	8 (4%)	9 (2%)
Prefer not to say	1 (0.2%)	0	1 (0.2%)
COVID-19 Income			
Negative Impact	214 (33.3%)	78 (38.8%)	136 (30.8%)
Neutral Impact	230 (35.8%)	74 (36.8%)	156 (35.4%)
Positive Impact	198 (30.9%)	49 (24.4%)	149 (33.8%)
COVID-19 Mental			
Negative Impact	470 (73.2%)	159 (79.1%)	311 (70.5%)
Neutral Impact	41 (6.4%)	14 (7%)	27 (6.1%)
Positive Impact	131 (20.4%)	28 (13.9%)	103 (23.4%)
COVID-19 Physical			
Negative Impact	327 (50.9%)	129 (64.2%)	198 (44.9%)
Neutral Impact	108 (16.8%)	30 (14.9%)	78 (17.7%)
Positive Impact	207 (32.3%)	28 (20.9%)	165 (37.4%)
COVID-19 Social			
Negative Impact	451 (70.2%)	151 (75.1%)	300 (68%)
Neutral Impact	73 (11.4%)	20 (9.9%)	53 (12%)
Positive Impact	118 (18.4%)	30 (15%)	88 (20%)

Table 4.4
Means and Standard Deviations of Scales for both groups (LTPC and No LTPC)

Variable	Overall Mean (SD)	With LTPC	Without LTPC
Prepared to take risks	5.29 (2.29) [0 – 10]	5.00 (2.38) [0 – 10]	5.41 (2.24) [0 – 10]
Taking on responsibility	1.68 (0.79) [1 – 3]	1.57 (0.81) [1 – 3]	1.73 (0.77) [1 – 3]
IDEA total	89.61 (10.01) [53 – 110]	89.63 (10.36) [57 – 109]	89.60 (9.87) [53 – 110]
Identity Exploration	22.70 (3.51) [12 – 28]	22.61 (3.62) [13 – 28]	22.74 (3.47) [12 – 28]
Instability	22.20 (3.64) [8 – 28]	23.11 (3.41) [12 – 28]	21.79 (3.67) [8 – 28]
Self-Focus	18.98 (3.12) [9 – 24]	18.48 (3.35) [9 – 24]	19.20 (2.99) [9 – 24]
Feeling In-between	10.06 (1.86) [3 – 12]	10.03 (2.15) [3 – 12]	10.08 (1.72) [4 – 12]
Possibilities	15.68 (3.12) [5 – 20]	15.41 (3.43) [5 – 20]	15.80 (2.97) [5 – 20]
ISRI total	19.50 (4.68) [6 – 30]	19.28 (4.71) [6 – 29]	19.60 (4.67) [6 – 30]
Adult Identity	8.07 (2.56) [3 – 15]	7.84 (2.62) [3 – 14]	8.18 (2.53) [3 – 15]
Societal Identity	11.43 (2.89) [3 – 15]	11.45 (2.95) [3 – 15]	11.42 (2.87) [3 – 15]
MSPSS total	62.26 (14.03) [12 – 84]	60.39 (14.58) [16 – 84]	63.10 (13.71) [12 – 84]
Family	20.30 (5.75) [4 – 28]	19.78 (5.95) [4 – 28]	20.53 (5.65) [4 – 28]
Friends	20.74 (5.92) [4 – 28]	19.79 (6.46) [4 – 28]	21.17 (5.61) [4 – 28]
Significant Other	21.22 (6.44) [4 – 28]	20.81 (6.73) [4 – 28]	21.40 (6.31) [4 – 28]
SSRQ total	69.60 (2.83) [45 – 93]	69.99 (5.75) [45 – 93]	69.43 (5.55) [51 – 86]
Impulse Control	34.37 (4.30) [24 – 48]	34.75 (4.87) [24 – 48]	34.20 (4.02) [26 – 47]
Goal Setting	35.23 (3.98) [18 – 48]	35.24 (3.81) [21 – 45]	35.23 (4.06) [18 – 48]

Of those living with LTPC (see Table 4.5), many were living with more than one condition (47.8%), and the most reported conditions were other (47.3%) and chronic pain (41.3%). Having free healthcare was common with 124 (61.7%) reporting that they had access and only 19 participants (9.5%) indicating they had no type of cover at all. In relation to the impact of LTPC (see Table 4.6), 34.33% of participants reported never having difficulty with learning, remembering or concentrating, 38.31% sometimes had difficulty, 18.91% often had difficulty and 8.46% always had difficulty. 54.73% of participants reported never having difficulty with dressing, bathing or getting around inside home, 26.87% sometimes had difficulty, 14.43% often had difficulty and 3.98% always had difficulty. 41.29% of participants reported never having difficulty with going outside the home alone to shop or visit places, 32.84% sometimes had difficulty, 15.42% often had difficulty and 10.45% always had difficulty. 22.89% of participants reported never having difficulty with working at a job, business or attending college, 43.28% sometimes had difficulty, 19.90% often had difficulty and 13.93% always had difficulty. 14.43% of participants reported never having difficulty with participating in other activities (e.g., leisure or using transport),

49.75% sometimes had difficulty, 22.39% often had difficulty and 13.43% always had difficulty. See Table 4.6 for a breakdown of difficulty by condition. The means and standard deviations for the two scales; Communication with Physicians and Perceived Medical Condition Self-Management Scale administered to those with LTTPC only, are reported in Table 4.7.

Table 4.5
Type of Long-term physical Condition

Type of Condition	Frequency and Percentage
Cardiovascular	12 (6%)
Diabetes	22 (10.9%)
Respiratory	52 (25.9%)
Neurological	48 (23.9%)
Chronic Pain	83 (41.3%)
Other	95 (47.3%)
More than one condition	96 (47.8%)

Note: *Participants may have more than one condition, those who did were asked to think about the one that has the most impact on their daily lives when answering any health-related questions

Table 4.6*Type of Condition by Impact on Daily Life: Frequency and Percentage*

Type of Condition	Learning, remembering or concentrating	Dressing, bathing or getting around inside home	Going outside the home alone to shop or visit places	Working at a job, business or attending college	Participating in other activities
Overall					
Never	69 (34.33%)	110 (54.73%)	83 (41.29%)	46 (22.89%)	29 (14.43%)
Sometimes	77 (38.31%)	54 (26.87%)	66 (32.84%)	87 (43.28%)	100 (49.75%)
Often	38 (18.91%)	29 (14.43%)	31 (15.43%)	40 (19.90%)	45 (22.39%)
Always	17 (8.46%)	8 (3.98%)	21 (10.45%)	28 (13.93%)	27 (13.43%)
Cardiovascular					
Never	5 (41.7%)	6 (50%)	6 (49.9%)	5 (41.7%)	4 (33.3%)
Sometimes	3 (25%)	3 (25%)	2 (16.7%)	1 (8.3%)	2 (16.7%)
Often	4 (33.3%)	3 (25%)	2 (16.7%)	5 (41.7%)	4 (33.3%)
Always	0	0	2 (16.7%)	1 (8.3%)	2 (16.7%)
Diabetes					
Never	3 (13%)	17 (73.9%)	10 (43.5%)	4 (17.4%)	3 (13%)
Sometimes	14 (60.9%)	4 (17.4%)	10 (43.5%)	11 (47.8%)	15 (65.3%)
Often	4 (17.4%)	2 (8.7%)	2 (8.7%)	5 (21.8%)	3 (13%)
Always	2 (8.7%)	0	1 (4.3%)	3 (13%)	2 (8.7%)
Respiratory					
Never	29 (55.8%)	36 (69.2%)	30 (57.6%)	19 (36.6%)	6 (11.5%)
Sometimes	16 (30.8%)	9 (17.3%)	12 (23.1%)	22 (42.3%)	32 (61.5%)
Often	5 (9.6%)	4 (7.7%)	3 (5.8%)	5 (9.6%)	7 (13.5%)
Always	2 (3.8%)	3 (5.8%)	7 (13.5%)	6 (11.5%)	7 (13.5%)
Neurological					
Never	7 (14.3%)	17 (34.7%)	10 (20.5%)	6 (12.2%)	2 (4.1%)
Sometimes	19 (38.8%)	18 (36.7%)	17 (34.7%)	21 (42.9%)	20 (40.8%)
Often	17 (34.7%)	12 (24.5%)	11 (22.4%)	11 (22.4%)	19 (38.8%)
Always	6 (12.2%)	2 (4.1%)	11 (22.4%)	11 (22.4%)	8 (16.3%)
Chronic Pain					
Never	17 (20.2%)	23 (27.4%)	16 (19%)	7 (8.3%)	4 (4.8%)
Sometimes	30 (35.7%)	34 (40.5%)	33 (39.3%)	27 (32.2%)	30 (35.7%)
Often	25 (29.8%)	21 (25%)	21 (25%)	29 (34.5%)	31 (36.9%)
Always	12 (14.3%)	6 (7.1%)	14 (16.7%)	21 (25%)	19 (22.6%)
Other LTPC					
Never	29 (30.5%)	48 (50.5%)	39 (41.1%)	16 (16.8%)	17 (17.9%)
Sometimes	42 (44.2%)	23 (24.2%)	24 (25.3%)	42 (44.2%)	40 (42.1%)
Often	15 (15.8%)	19 (20%)	17 (17.9%)	18 (18.9%)	22 (23.2%)
Always	9 (9.5%)	5 (5.3%)	15 (15.8%)	19 (20%)	16 (16.8%)

Note: Participants may have more than one condition

Table 4.7*Means and Standard Deviations of Self-Management Scales (LTPC only)*

Variable	Overall Mean (SD)
Communication with Physicians	8.26 (3.50) [3 – 18]
Perceived Medical Condition Self-Management Scale	24.4 (7.31) [8 – 40]

4.6.2 Results: Measurement Invariance

To make valid comparisons between the two groups, those living with LTPC and those living without LTPC on the four scales administered to both groups (IDEA, IRSI, MPSS, SSRQ), multi-group confirmatory factor analysis (MG-CFA) was conducted to test for measurement invariance.

4.6.2.1 Inventory of the Dimensions of Emerging Adulthood

Model 1 (configural model) is the most lenient model and has no constraints. The resulting chi-square GFI was statistically significant, $\chi^2 (680) = 1768.188$, $p < 0.001$, CFI = 0.920, TLI = 0.911, RMSEA = 0.071, 90% CI [0.067, 0.075], SRMR = 0.087 (see Table 4.8), which is mixed but indicates acceptable fit. In constraining the loadings to be equal, the difference in χ^2 between Model 1 and 2 (metric model) is statistically significant: $\Delta \chi^2 (df = 23) = 35.626$, $p = 0.045$. The change in CFI (-0.007), TLI (-0.004), RMSEA (0.002), SRMR (0.002) are negligible which indicate good fit compared to Model 1, that the factor loadings are similar, and the added constraint is reasonable. With further constraining the intercepts to be equal, the difference in χ^2 between Model 2 and Model 3 (scalar model) is statistically significant, $\Delta \chi^2 (df = 23) = 53.940$, $p = 0.000$. The change in CFI (0.000), TLI (0.002), RMSEA (-0.001) or SRMR (0.001) are negligible. This means the intercepts of observed variables remain consistent across groups and we can accept the more restricted Model 3 compared to both Model 1 and 2.

4.6.2.2 Identity Stage Resolution Scale

Model 1 (configural model) is the most lenient model and has no constraints, The resulting chi-square GFI was statistically significant, $\chi^2 (16) = 31.274$, $p < 0.05$, CFI = 0.990, TLI = 0.981, RMSEA = 0.055, 90% CI [0.025, 0.084], SRMR = 0.044 (see Table 4.8), which indicates good fit. In constraining the loadings to be equal, the difference in χ^2 between Model 1 and 2 (metric model) is non-significant $\Delta \chi^2 (df = 4) = 4.089$, $p = 0.394$. The changes to CFI (0.000), TLI (0.004), RMSEA (-0.006) and SRMR (0.003) are negligible and indicate good fit compared to Model 1. With further constraining the intercepts to be equal, the difference in χ^2 between Model 2 and 3 (scalar model) is significant $\Delta \chi^2 (df = 4) = 18.529$, $p = 0.001$. The changes to CFI (-0.004), TLI (-0.002), RMSEA (0.002) and SRMR (0.005) are negligible. This means the intercepts of observed variables remain consistent across groups and we can accept the more restricted Model 3 compared to both Model 1 and 2.

4.6.2.3 Multidimensional Scale of Perceived Social Support

Model 1 (configural model) is the most lenient model and has no constraints. The resulting chi-square GFI was statistically significant, $\chi^2 (102) = 20.30$, $p = 1$, CFI = 1.000, TLI = 1.018, RMSEA = 0.000, 90% CI [0.000, 0.000] SRMR = 0.023 (see Table 4.8) and indicates good fit. In constraining the loadings to be equal, the difference in χ^2 between Model 1 and 2 (metric model) is significant $\Delta \chi^2 (df=9) = 5.158$, $p = .820$. The changes to CFI (0.000), TLI (0.000), RMSEA (0.000) and SRMR (0.001) are negligible, which indicates good fit compared to Model 1. With further constraining the intercepts to be equal, the difference in χ^2 between Model 2 and 3 (scalar model) is non-significant $\Delta \chi^2 (df = 9) = 5.352$, $p = 0.803$. The changes to CFI (0.000), TLI (0.000), RMSEA (0.000) and SRMR (0.001) are negligible. This means the intercepts of observed variables remain consistent

across groups and we can accept the more restricted Model 3 compared to both Model 1 and 2.

4.6.2.4 Short-Form Self-Regulation Questionnaire

Model 1 (configural model) is the most lenient model and has no constraints. The resulting chi-square GFI was statistically significant, $\chi^2 (376) = 556.614$, $p < 0.001$, CFI = 0.983, TLI = 0.981, RMSEA = 0.039, 90% CI [0.032, 0.046] and SRMR = 0.064 (see Table 4.8) and indicates good fit. In constraining the loadings to be equal, the difference in χ^2 between Model 1 and 2 (metric model) is significant $\Delta \chi^2 (df=19) = 41.163$, $p = 0.0023$. The changes to CFI (-0.014), TLI (-0.014), RMSEA (0.013) and SRMR (0.008) indicate that the metric model is an adequate fit compared to Model 1. With further constraining the intercepts to be equal, the difference in χ^2 between Model 2 and 3 (scalar model) is significant $\Delta \chi^2 (df = 19) = 39.879$, $p = 0.003394$. The changes to CFI (0.000), TLI (-0.001), RMSEA (-0.001) and SRMR (-0.001) are negligible. This means the intercepts of observed variables remain consistent across groups and we can accept the more restricted Model 3 compared to both Model 1 and 2.

Table 4.8*Goodness-of-Fit Indicators for each measurement scale per model*

Model	χ^2	<i>p</i>	<i>df</i>	CFI	Diff	TLI	Diff	RMSEA	90% CI	Diff	SRMR	Diff
Inventory of the Dimensions of Emerging Adulthood												
Configural	1768.188	.000	680	0.920	-	0.911	-	0.071	[0.067, 0.075]	-	0.087	-
Metric	1884.968	.000	703	0.913	-.007	0.907	-.004	0.073	[0.069, 0.077]	.002	0.089	.002
Scalar	1920.126	.000	726	0.913	.000	0.909	.002	0.072	[0.068, 0.076]	-.001	0.090	.001
Identity Stage Resolution Scale												
Configural	31.274	.012	16	0.990	-	0.981	-	0.055	[0.025, 0.084]	-	0.044	-
Metric	34.814	.021	20	0.990	.000	0.985	.004	0.049	[0.019, 0.075]	-.006	0.047	.003
Scalar	43.945	.008	24	0.986	-.004	0.983	-.002	0.051	[0.026, 0.075]	.002	0.066	.005
Multidimensional Scale of Perceived Social Support												
Configural	20.303	1.000	102	1.000	-	1.018	-	0.000	[0.000, 0.000]	-	0.023	-
Metric	23.682	1.000	111	1.000	.000	1.018	.000	0.000	[0.000, 0.000]	.000	0.024	.001
Scalar	24.798	1.000	120	1.000	.000	1.018	.000	0.000	[0.000, 0.000]	.000	0.025	.001
Short-Form Self-Regulation Questionnaire												
Configural	556.614	.000	376	0.983	-	0.981	-	0.039	[0.032, 0.046]	-	0.064	-
Metric	722.379	.000	395	0.969	-.014	0.967	-.014	0.052	[0.046, 0.058]	.013	0.072	.008
Scalar	749.813	.000	414	0.969	.000	0.968	-.001	0.051	[0.045, 0.057]	-.001	0.073	-.001

Abbreviations: χ^2 Chi-squared; *p*, p-value; *df*, degrees of freedom; CFI, comparative fit index; Diff, difference between models; TLI, Tucker- Lewis index; RMSEA, root mean square error of approximation; SRMR, standardized root mean square residual.

4.6.2.5 Conclusion of Measurement Invariance

The results provided quantitative evidence supporting the progression to comparing group means in the subsequent analyses of this chapter. Measurement invariance was tested using MG-CFA to determine whether participants from the two groups, those living with LTPC and those living without LTPC, interpreted the four scales (IDEA, IRSI, MPSS, SSRQ) in a similar manner. The MG-CFA involved comparing several nested models across both groups, beginning with configural invariance, followed by metric invariance, and finally reaching scalar invariance.

The key finding from this analysis is that measurement invariance was successfully established at the more constrained scalar level for all four scales. This achievement signifies that each scale reliably captures the underlying psychological constructs of the dimensions of emerging adulthood, identity stage resolution, perceived social support, and self-regulation, in a consistent manner across both participant groups. In practical terms, this implies that emerging adults living with LTPC and those living without LTPC interpret and respond to the four scales in a comparable fashion. This outcome is of importance for the subsequent phases of the statistical analysis. With measurement invariance confirmed, the comparison of group means could be confidently carried out enabling a deeper insight into unique experiences and challenges faced by each group during emerging adulthood. Moreover, the relationship between emerging adulthood and self-management for those living with LTPC could be examined.

4.6.3 Results: Group Comparisons of Emerging Adults Living with and Without LTPC

To examine if there were any significant differences or associations between the two groups (LTPC vs. no-LTPC) on variables related to the five features of emerging adulthood and self-management, several statistical tests were conducted (see Table 4.2). The variables

of interest: perceived social support, relationship status, living arrangements, educational attainment, primary economic status, risk-taking, risky health behaviours, making financial ends meet, self-regulation, considering self to be adult and taking on adult responsibilities, were mapped onto the five features of emerging adulthood (see Figure 4.1). Gender and age are also examined. These are grouped together as they are socio-economic variables, but they do not map onto any one specific feature of emerging adulthood.

4.6.3.1 The Age of Identity Exploration

To address objective one, whether there is a difference or associations between emerging adults with LTPC and without LTPC on key variables that relate to self-management and the age of identity exploration was examined. Two hypotheses relating to navigating relationships (including perceived social support and relationship status) were tested (see Table 4.1).

4.6.3.1.1 Navigating Relationships

The Bonferroni correct significance threshold for navigating relationships was set at $p = 0.013$ ($0.05/4$) and the corrected p -value is reported for each test. To test the hypothesis that both groups (LTPC vs. no-LTPC) will report similar levels of perceived of social support Welch Two Sample t -tests were conducted for the MSPSS subscales (significant other, family and friends). The mean for support from significant others for those living without LTPC was 21.40 ($SD = 6.31$), while in those living with LTPC was 20.81 ($SD = 6.73$). There was no significant difference in group means for significant others $t(350) = -1.035$, $p = 1$, $g = -0.09$. The mean for support from family for those living without LTPC was 20.53 ($SD = 5.65$), while in those living with LTPC was 19.78 ($SD = 5.95$). There was no significant difference in group means for support from family $t(353.68) = -1.473$, $p = 0.566$, $g = -0.13$.

The mean for support from friends for those living without LTPC was 21.17 ($SD = 5.61$), while in those living with LTPC was 19.79 ($SD = 6.46$). There was no significant difference in group means for support from friends $t(328.34) = -2.569$, $p = 0.426$, $g = -0.23$. These findings support the hypothesis that both groups report similar levels of social support from significant others, family and friends.

In examining relationship status, the variable was collapsed from eight categories (“single”, “in a long-term relationship”, “co-habiting”, “married or civil partnership”, “separated or divorced”, “widowed”, “other” and “prefer not to say”) into two categories: not in a relationship (“no relationship”) and in a relationship (“relationship”). Two categories were excluded as participants choose “other” or “prefer not to say”, resulting in the exclusion of 11 participants (see Table 4.3). To test the hypothesis that there will be a significant association between having LTPC and relationship status, a Chi-Squared test of Independence was conducted. No significant association was found between group membership (LTPC vs. no-LTPC) and relationship status $\chi^2(1) = 6.397$, $p = 0.046$, Cramer's $V = 0.10$. This finding does not support the hypothesis that emerging adults living with LTPC would be more likely to report being single compared to their peers.

4.6.3.2 The Age of Instability

To address objective two, whether there is a difference or associations between emerging adults with LPTC and without LTPC on key variables that relate to self-management and the age of instability was examined. Three hypotheses relating to life transitions (including living arrangements, educational attainment, and primary economic status), two hypotheses relating to taking health risks (including overall risk-taking and risky health behaviours) and one hypothesis relating to uncertainty (including making ends meet financially) were tested (see Table 4.1).

4.6.3.2.1 Life Transitions

The Bonferroni correct significance threshold for life transitions was set at $p = 0.017$ ($0.05/3$) and the corrected p-value is reported for each test. In examining living arrangements, the variable was collapsed from eight categories into two categories (see Table 4.3): living with family (“live with family”) and living away from home (“live alone or others”). To test the hypothesis that there will be no significant association between group membership (LTPC vs. no-LTPC) and living arrangements, a Chi-Squared test of Independence was conducted. A significant association was found between group membership (LTPC vs. no-LTPC) and living arrangements $\chi^2(1) = 12.411$, $p = 0.001$, Cramer's $V = 0.14$. This finding does not support the hypothesis that emerging adults living with LTPC would report similar living arrangements compared to their peers. 65.2% of those living with LTPC reported living with family compared to 49.8% of their peers.

In examining educational attainment, the variable was collapsed from eleven categories into three categories: Leaving Certificate or equivalent not completed (“lc not completed”), Leaving Certificate or equivalent and further education achieved (“lc or fe”) and higher education (“higher ed”). Two categories were excluded as participants choose “other” or “prefer not to say”, resulting in the exclusion of 18 participants (see Table 4.3). To test the hypothesis that there will be a significant association between group membership (LTPC vs. no-LTPC) and educational attainment, a Chi-Squared test of Independence was conducted. No significant association was found between group membership (LTPC vs. no-LTPC) and educational attainment $\chi^2(2) = 3.374$, $p = 0.553$, Cramer's $V = 0.74$. This finding does not support the hypothesis that emerging adults living with LTPC would report lower levels of educational attainment in comparison to their peers.

In examining primary economic status, the variable was collapsed from seven categories into four categories: student (“student”), working (“working”), unemployed,

looking for work or unable to work (“not working”) and looking after the family home (“family home”). One category was excluded as participants chose “other”, resulting in the exclusion of 11 participants (see Table 4.3 for individual categories). To test the hypothesis that there will be a significant association between group membership (LTPC vs. no-LTPC) and primary economic status, a Fisher’s Exact test was conducted. A significant association was found between group membership (LTPC vs. no-LTPC) and primary economic status, $p = 0.001$. This finding supports the hypothesis that emerging adults living with LTPC are more likely to report unemployment in comparison to their peers. 15.9% of those living with LTPC reported that they were not working. Of those, 3% reported they were looking for their first job, 2.5% were unemployed and 10.4% were unable to work due to illness or disability. For those without LTPC, 5.9% were not working. Of those, 2% reported they were looking for their first job, 3.4% were unemployed and 0.5% were unable to work due to illness or disability.

4.6.3.2.2 Taking Health Risks

The Bonferroni correct significance threshold for taking health risks was set at $p = 0.01$ ($0.05/5$) and the corrected p-value is reported for each test. To test the hypothesis that there will be no significant difference in the willingness to take risks between the two groups (LTPC vs. no-LTPC) a Welch Two Sample t-test was conducted. The mean for willingness to take risks for those living without LTPC was 5.00 ($SD = 2.38$), while in those living with LTPC was 5.41 ($SD = 2.24$). There was no significant difference in group means for significant others $t(349.58) = -2.053$, $p = 0.0204$, $g = -0.19$. This finding supports the hypothesis that both groups (LTPC vs. no-LTPC), would report similar levels of risk-taking behaviour.

To test the hypothesis that there is no significant association between group membership (LTPC vs. no-LTPC) and smoking cigarettes, vaping, or non-prescription drug use, but a significant association with frequency of alcohol consumption, Chi-Squared tests of Independence or Fisher's Exact tests were conducted. A Chi-Squared test of Independence was conducted for smoking cigarettes, options available were "I don't smoke", "used to smoke but don't now", "tried smoking once or twice", "smoke occasionally" and "smoke daily". No significant association were found between group membership (LTPC vs. no-LTPC) and smoking cigarettes $\chi^2(4) = 3.821, p = 1$, Cramer's $V = 0.08$. A Fisher's Exact test was conducted for vaping, options available were "I don't vape", "used to vape but don't now", "tried vaping once or twice", "vape occasionally" and "vape daily". No significant association were found between group membership (LTPC vs. no-LTPC) and vaping, $p = 1$. A Fisher's Exact test was conducted for frequency of taking non-prescription drugs, options available were "I don't take drugs", "monthly or less", "2 – 4 times per month", "2 – 3 times per week" and "4+ times per week". No significant association were found between group membership (LTPC vs. no-LTPC) and vaping, $p = 0.337$.

A Chi-Squared test of Independence was conducted for frequency of alcohol consumption, options available were "I don't drink alcohol", "monthly or less", "2 – 4 times per month", "2 – 3 times per week" and "4+ times per week". The variable was collapsed from these five categories into three categories: not drinking or less than monthly ("none to little alcohol"), regularly drinking alcohol 2 – 4 times per month ("reg alcohol") and risky frequency of alcohol consumption at 2 – 3 and 4+ times per week ("risky alcohol"). A significant association was found between group membership (LTPC vs. no-LTPC) and frequency of alcohol consumption $\chi^2(2) = 23.8, p < 0.001$, Cramer's $V = 0.19$. 67.9% of those living with LTPC indicated that they did not drink or drank monthly or less in comparison with 48.2% of their peers without LTPC. These findings support the hypothesis that there

would be no significant association between group membership (LTPC vs. no-LTPC) and smoking, vaping, or non-prescription drug use, but there would be a significant association with frequency of alcohol consumption.

4.6.3.2.3 Uncertainty

To test the hypothesis that group membership (LTPC vs. no-LTPC) will be significantly associated with making financial ends meet a Chi-Squared test of Independence was conducted. Options available were on a six-point Likert scale “with great difficulty” to “very easily”. The variable was collapsed from these five categories into two categories: some to great difficulty (“difficulty”), and fairly to very easily (“easily”). A significant association was found between group membership (LTPC vs. no-LTPC) and making financial ends meet $\chi^2(1) = 6.207, p = 0.013$, Cramer's $V = 0.10$. 52.4% of those living with LTPC reported they had at least some difficulty with making ends meet in comparison to 40.7% of their peers without LTPC. This finding supports the hypothesis that emerging adults living with LTPC would report more difficulty in making ends meet in comparison to their peers.

4.6.3.3 The Age of Self-Focus

To address objective three, whether there is a difference or associations between emerging adults with LPTC and without LTPC on key variables that relate to self-management and the age of self-focus was examined. One hypothesis relating to self-sufficient, specifically, self-regulation, was tested (see Table 4.1).

4.6.3.3.1 Learn how to be Self-Sufficient

The Bonferroni correct significance threshold for learning how to be self-sufficient was set at $p = 0.025$ ($0.05/2$) and the corrected p-value is reported for each test. To test the hypothesis that there will be no significant difference in self-regulation between the two groups (LTPC vs. no-LTPC), Welch Two Sample t-tests were conducted on the two subscales of the SSRQ: impulse control and goal setting. The mean self-regulation score for the impulse control subscale for those living without LTPC was 34.20 ($SD = 4.02$), while in those living with LTPC was 34.75 ($SD = 4.87$). There was no significant difference in group means for impulse control $t(310.69) = 1.375$, $p = 0.340$, $g = 0.13$. The mean self-regulation score for the goal setting subscale for those living without LTPC was 35.20 ($SD = 4.06$), while in those living with LTPC was 35.24 ($SD = 3.81$). There was no significant difference in group means for goal setting $t(387.87) = 0.027$, $p = 1$, $g = 0.00$. These findings support the hypothesis that both groups (LTPC vs. no-LTPC) would report similar levels of self-regulation.

4.6.3.4 The Age of Feeling In-Between

To address objective four, whether there is a difference or associations between emerging adults with LPTC and without LTPC on key variables that relate to self-management and the age of feeling-in-between was examined. One hypothesis relating to the perception of feeling adult, specifically, if emerging adults consider themselves to be fully adult and how they perceive themselves to have taken on adult responsibilities in comparison to peers, was tested (see Table 4.1).

4.6.3.4.1 *Feeling not yet Adult*

The Bonferroni correct significance threshold for feeling not yet adult was set at $p = 0.025$ ($0.05/2$) and the corrected p-value is reported for each test. To test the hypothesis that group membership (LTPC vs. no-LTPC) will be significantly associated with the perception of feeling adult and taking on adult responsibilities a Fisher's Exact test and a Chi-Squared test of Independence were conducted. A Fisher's Exact test was conducted to examine if group membership (LTPC vs. no-LTPC) was significantly associated with the perception of feeling adult, options available were on a five-point Likert scale "entirely true" to "not at all true". No significant association was found $p = 0.214$. A Chi-Squared test of Independence was conducted to examine if group membership (LTPC vs. no-LTPC) was significantly associated with taking on adult responsibilities, options available were "faster", "at about the same rate" and "slower". A significant association was found $\chi^2(2) = 21.697$, $p < 0.001$, Cramer's $V = 0.19$. 59.7% of those living with LTPC reported feeling that they grew up faster, compared to 46% their peers without LTPC. These findings partially support the hypothesis, it does not support that emerging adults living with LTPC would report feeling less adult than their peers, but it does support that they felt they took on adult responsibilities faster than their peers without LTPC.

4.6.3.5 Age and Gender

To address objective five, whether there is a difference or associations between emerging adults with LTPC and without LTPC on age and gender was examined. Two hypotheses relating to age and gender were tested. The Bonferroni correct significance threshold for age and gender was set at $p = 0.025$ ($0.05/2$) and the corrected p-value is reported for each test. To test the hypothesis that there will be no difference in age between group membership (LTPC vs. no-LTPC), a Welch Two Sample t-test was conducted. The

mean age in years for those living without LTPC was 21.87 ($SD = 1.87$), while in those living with LTPC was 22.31 ($SD = 2.00$). There was a significant difference in group means for age $t(365.05) = 2.549, p = 0.023, g = 0.22$.

In examining gender, options available were “male”, “female”, “non-binary”, “prefer to self-describe” and “prefer not to say”. The categories “non-binary”, “prefer to self-describe” and “prefer not to say” were collapsed into one category “other”. To test the hypothesis that there will be no significant association between group membership (LTPC vs. no-LTPC) and gender, a Chi-Squared test of Independence was conducted. A significant association was found between group membership (LTPC vs. no-LTPC) and gender $\chi^2(2) = 12.916, p = 0.003$, Cramer’s $V = 0.14$. Of emerging adults living with LTPC, 17.5% were male, 75.7% were female and 6.8% were other, compared to those without LTPC where 26.2% were male, 71.3% were female and 7% were other.

4.6.4 Summary of Group Comparisons: Emerging Adults Living with and Without LTPC

Some significant differences and associations were found between emerging adults living with LTPC and their peers without LTPC. For the age of identity exploration and navigating relationships, both groups reported comparable levels of perceived social support from significant others, family and friends. Additionally, no significant association was found between group membership (LTPC vs. no-LTPC) and relationship status.

For the age of instability, regarding life transitions, significant associations were found between group membership (LTPC vs. no-LTPC) and both living arrangements and primary economic status. Specifically, a higher percentage of emerging adults with LTPC were living with family compared to their peers without LTPC. Additionally, emerging adults with LTPC were more likely to be unemployed or unable to work due to illness or disability. However, there were no significant differences in educational attainment between the two

groups. In terms of taking health risks, no significant differences were found between the two groups (LTPC vs. no-LTPC) in overall risk-taking behaviour, smoking, vaping, or non-prescription drug use. However, a significant difference was found between the groups in the frequency of alcohol consumption, with those living with LTPC, drinking less often. Furthermore, in relation to uncertainty, a greater proportion of those with LTPC reported difficulty in making financial ends meet.

For the age of self-focus and learning to be self-sufficient, no significant differences were found between the two groups (LTPC vs. no-LTPC) in self-regulation with both groups reporting similar scores on the impulse control and goal-setting subscales of the SSRQ. For the age of feeling in-between, while no significant association was found between the two groups (LTPC vs. no-LTPC) and the perception of feeling fully adult, a notable difference was observed in the perception of taking on adult responsibilities. Emerging adults living with LTPC felt they assumed adult responsibilities faster than their peers.

Regarding age and gender, a significant difference was found in the age of the two groups (LTPC vs. no-LTPC), with those living with LTPC being slightly older on average. Furthermore, a significant difference was found between the two groups in terms of gender distribution with more females represented. The next step will examine if the experience of the five features of emerging adulthood varies, as measured by the standardised IDEA scale (Reifman et al., 2007) specifically developed to measure to what extent someone perceives and identifies with the five features of emerging adulthood, based on having a LTPC and the variables related to self-management and emerging adulthood above that showed significant differences between the two groups (LTPC vs. no-LTPC); living arrangements, primary economic status, frequency alcohol consumption, making ends meet, taking on adult responsibilities, age and gender.

4.6.5 Variations in the Experience of Emerging Adulthood: SEM Results

A structural equation modelling approach was taken in R.4.3.0 (R Core Team, 2023) to determine if the experience of the five features of emerging adulthood vary, as measured by the standardised IDEA scale (Reifman et al., 2007) specifically developed to measure to what extent someone perceives and identifies with the five features of emerging adulthood, based on having LTPC and the variables related to self-management and emerging adulthood in objectives one to five above that showed significant differences between the two groups (LTPC vs. no-LTPC): living arrangements, primary economic status, frequency alcohol consumption, making ends meet, taking on adult responsibilities, age and gender. These variables and group membership (LTPC vs. no-LTPC) were added to the model as predictor variables. The five latent variables representing the five features of emerging adulthood, derived from the IDEA scale (Reifman et al., 2007), were treated as outcome variables (See Figure 4.3).

The resulting Chi-Square goodness-of-fit index was statistically significant $\chi^2(524) = 1644.52$, $p < 0.001$, CFI = 0.910, TLI = 0.935, RMSEA = 0.059, 90% CI [0.056, 0.062], SRMR = 0.080. As the chi-square test is sensitive to sample size additional fit indices were considered. The CFI and TLI values of 0.910 and 0.935 respectively, suggest that the model fits the data reasonably well, with values closer to 1 indicating better fit. Furthermore, the RMSEA of 0.059 with a 90% confidence interval [0.056, 0.062] and SRMR of 0.080 are within the commonly accepted thresholds for adequate fit, indicating that the model provides a reasonable estimate of the observed data. The category reported first for all the following findings is the reference category.

None of the variables were found to be significantly associated with the age of identity exploration (see Figure 4.3). Living arrangements, primary economic status, making ends meet, gender, group membership (LTPC vs. no-LTPC) were found to be significantly

associated with the age of instability. For living arrangements, emerging adults who are living with family report significantly higher levels of instability compared to those who are living alone or with others ($\beta = -.080, p = 0.036$). For primary economic status, emerging adults who are students report significantly lower levels of instability compared to those who are working, not working or looking after the family home ($\beta = 0.053, p = 0.046$). For making ends meet, emerging adults who have more difficulty in making ends meet financially report significantly higher levels of instability compared to those who find it easier to make ends meet ($\beta = -0.165, p < 0.001$). For gender, males report significantly lower levels of instability compared to females and others ($\beta = 0.126, p = 0.002$). For group membership, emerging adults living without LTPC report significantly lower levels of instability compared to those who have LTPC ($\beta = 0.107, p = 0.010$).

Living arrangements and primary economic status were found to be significantly associated with the age of self-focus. For living arrangements, emerging adults who are living with family report significantly lower levels of self-focus compared to those who are living alone or with others ($\beta = 0.157, p = 0.004$). For primary economic status, emerging adults who are students report significantly higher levels of self-focus compared to those who are working, not working or looking after the family home ($\beta = -0.131, p = 0.003$).

Primary economic status, taking on adult responsibilities, age and gender were found to be significantly associated with the age of feeling in-between. For primary economic status, emerging adults who are students report significantly higher levels of feeling in-between compared to those who are working, not working or looking after the family home ($\beta = -0.064, p = 0.037$). For taking on adult responsibilities, emerging adults who felt they took on adult responsibilities slower than their peers report significantly higher levels of feeling in-between than those who felt they took on adult responsibilities at the same or faster rate ($\beta = -0.093, p = 0.001$). For age, as emerging adults got older, they reported lower levels

of feeling in-between ($\beta = -0.029, p = 0.019$). For gender, males report significantly lower levels of feeling in-between compared to females and others ($\beta = 0.172, p = 0.001$).

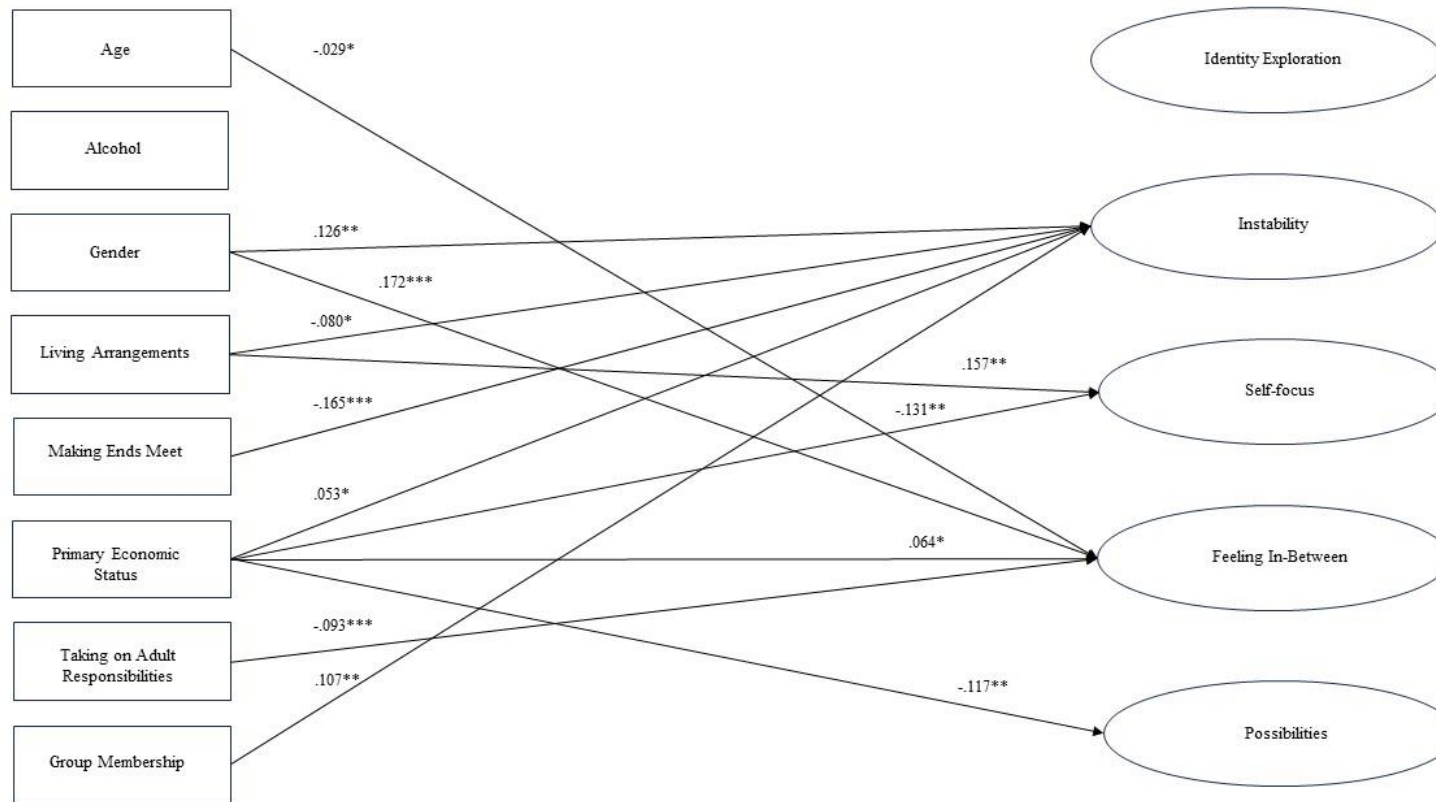
Primary economic status was found to be significantly associated with the age of possibilities. Emerging adults who are students report significantly higher levels of possibilities compared to those who are working, not working or looking after the family home ($\beta = -0.117, p = 0.002$).

4.6.6 Summary of Variations in the Experience of Emerging Adulthood: SEM

The model to determine if the experience of the five features of emerging adulthood vary, based on having a LTPC and the variables identified in the group comparisons, provided a reasonable fit to the data. Living arrangements, primary economic status, making ends meet financially, gender, and group membership (LTPC vs. no-LTPC) were associated with the age of instability, with emerging adults living with family, students, those experiencing financial difficulty, females and others and emerging adults living with LTPC reporting higher instability. Living arrangements and primary economic status were also related to the age of self-focus, with those living with family reporting lower levels of self-focus and students reporting higher levels self-focus. The age of feeling in-between was significantly associated with primary economic status, taking on adult responsibilities, age, and gender. Students, emerging adults who felt they took on adult responsibilities slower than their peers, younger emerging adults, females and others report higher levels of feeling in-between. Lastly, primary economic status was significantly related to the age of possibilities, with students reporting higher levels of perceived possibilities.

Figure 4.3

Variations of the experience of the five features of emerging adulthood



Note: Lines indicate significant effects. *** $p \leq .001$. ** $p \leq .01$. * $p \leq .05$.

4.6.7 Relationship between Emerging Adulthood and Self-Management: SEM Results

A structural equation modelling approach was taken in R.4.3.0 (R Core Team, 2023) to examine whether self-management in emerging adults living with LTPC varies based on the extent to which some-one perceives and identifies with the five features of emerging adulthood (as measured by a standardised scale specifically designed to measure these five features), impact of the condition which ranges from “never” to “always” (see Table 4.6), and the factors identified in Objectives 1-5 that are associated with the features of emerging adulthood and self-management: living arrangements, primary economic status, making ends meet, taking on adult responsibilities, age and gender. Although frequency of alcohol consumption was found to be significantly lower in emerging adults living with LTPC, it had no significant effects with any of the five features of emerging adulthood, and as such it was not included in this model. The five latent variables representing the five features of emerging adulthood, derived from the IDEA scale (Reifman et al., 2007), and the variables stated above, were treated as predictor variables. The two latent variables, communications with physicians (Lorig et al., 1996) and the one-factor PMCSMS (Smith et al., 1995) were treated as outcome variables (See Figure 4.4).

The resulting Chi-Square goodness-of-fit index was statistically significant χ^2 (1089) = 1571.79, $p < 0.001$, CFI = 0.912, TLI = 0.940, RMSEA = 0.0493, 90% CI [0.043, 0.054], SRMR = 0.087. As the chi-square test is sensitive to sample size additional fit indices were considered. The CFI value of 0.912 and the TLI value of 0.940 are above 0.90 and acceptable. While the SRMR of 0.087 is outside of the value to indicate good fit (<0.08), the RMSEA of 0.049 with a 90% confidence interval [0.043, 0.054] is within the commonly accepted thresholds for adequate fit. Taken together the fit indices suggest that the model fits the data reasonably well and that it provides a reasonable estimate of the observed data.

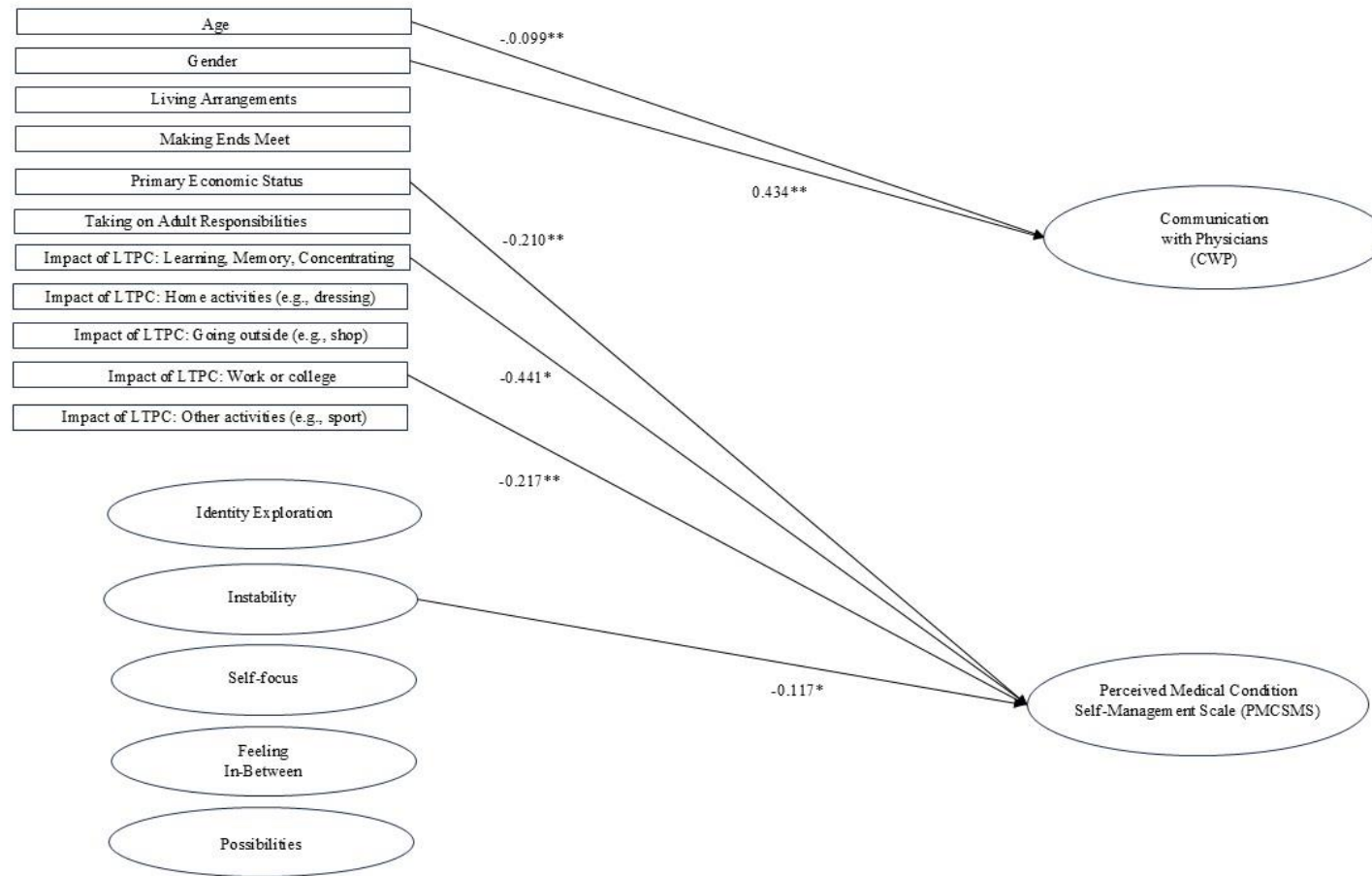
Contrary to expectations, the features of emerging adulthood: identity exploration and self-focus, as measured by the IDEA scale (Reifman et al., 2007) were not associated with poorer self-management, as measured by the PMCSMS (Smith et al., 1995) and CWP (Lorig et al., 1996). In line with expectations, the feature of possibilities, as measured by the IDEA scale (Reifman et al., 2007) was not found to be significantly associated with self-management as measured by the PMCSMS (Smith et al., 1995) and CWP (Lorig et al., 1996). As expected, instability, as measured by the IDEA scale (Reifman et al., 2007), while not significantly associated with communication with doctors, as measured by the CWP (Lorig et al., 1996), it was found to be significantly associated with perceived self-management, as measured by the PMCSMS (Smith et al., 1995). Specifically, emerging adults living with LTPC who experienced higher levels of instability reported lower levels of self-management ($\beta = -0.441, p = 0.045$). Additionally, primary economic status was found to be significantly associated with perceived self-management, as measured by the PMCSMS (Smith et al., 1995). Emerging adults living with LTPC who reported being students, reported higher levels of perceived self-management compared to their peers with LTPC who were employed, not employed or looking after the family home ($\beta = -0.210, p = 0.002$). For emerging adults living with LTPC where learning, memory, and concentration difficulties increased, perceived self-management was lower ($\beta = -0.117, p = 0.024$). Similarly, the more LTPC adversely affected work or college, perceived self-management was lower ($\beta = -0.217, p = 0.002$). Regarding communication with healthcare providers, age was positively associated with improved interactions; older emerging adults reported more effective communication ($\beta = 0.099, p = 0.005$). Gender differences were also significant, with females and individuals of other genders experiencing better communication compared to males ($\beta = 0.434, p = 0.006$).

4.6.8 Summary of Relationship between Emerging Adulthood and Self-Management

Emerging adults living with LTPC with higher levels of instability report lower levels of perceived self-management. Students living with LTPC reported higher levels of self-management than those working, not working or looking after the family home. Emerging adults with issues relating to learning, memory and concentrating, and those who experienced more difficulties with work or college experienced lower levels of perceived self-management. As emerging adults got older, they reported better communication with doctors. Males reported poorer communication in comparison to females and others.

Figure 4.4

The Relationship between Emerging Adulthood and Self-Management



Note: Lines indicate significant effects. $***p \leq .001$. $**p \leq .01$. $*p \leq .05$.

4.7 Discussion

The current cross-sectional study explored differences in factors related to emerging adulthood and self-management in emerging adults living with LTPC to their peers without LTPC (aged 18–25 years). For the first time, this study has advanced our understanding by specifically using the Inventory of Dimensions of Emerging Adulthood (IDEA) scale which was designed to measure the individual differences in how emerging adults perceive and identify with the five features of emerging adulthood: identity exploration, instability, self-focus, feeling in-between, and possibilities. Additionally, this study examined the relationship between these five features of emerging adulthood and the self-management of LTPC.

4.7.1 Group Comparisons Between Emerging Adults Living with and Without LTPC

The comparative analyses between emerging adults living with LTPC and their peers without LTPC found no significant differences or associations between the two groups (LTPC vs. no LTPC) in several key areas, including navigating relationships, as measured by the Multidimensional Scale of Perceived Social Support (MSPSS) and relationship status; life transitions, specifically educational attainment; taking health risks, including the overall willingness to take risks and engaging in risky health behaviours like smoking, vaping, or taking non-prescription drugs; learning how to be self-sufficient, as measured by the Short-Form Self-Regulation Questionnaire (SSRQ); and feeling not yet adult. However, significant differences or associations for variables relating to living arrangements, primary economic status, making ends meet, taking health risks, specifically alcohol consumption, the perception of adult responsibilities, age and gender.

The comparative analyses found that emerging adults living with LTPC were more likely to report living with family than their peers without LTPC (65.2% vs. 49.8%). Achieving certain developmental milestones, such as moving out of the family home, is

important for helping to achieve the main markers of adulthood; accepting responsibility, making independent decisions, and achieving financial independence (Arnett 2004; 2015). When considering difference in living arrangements, first the role of age and primary economic status differences found between the two groups need to be considered (LTPC vs. no-LTPC).

In the present study, all participants were between 18 and 25 years old, but emerging adults living with LTPC were slightly older at 22.31 years compared to their peers without LTPC 21.87 years. Those with LTPC were also more likely to report being finished with education (57.2% compared to 42% of peers). In both Ireland and the UK, where 83.49% of participants reported residing, it is common for emerging adults who have been attending college to move back home to their parental home (boomerang children) after graduation before they decide what is next for them (Lewis et al., 2016). Therefore, the slightly older age and the higher rate who indicated being finished with education in the emerging adult living with LTPC group, might contribute in some way to their higher rates of living with family. Furthermore, the Irish housing crisis cannot be ignored as a contributing factor. In looking at the participants in Ireland only at aged 24 to 25 years, 74.2% of emerging adults living with LTPC continue living with family, compared to 65.5% of their peers without LTPC. While in the UK at aged 24 to 25 years, 46.4% of those with LTPC remain living with family, compared to 23.3% of their peers.

Overall, the finding, that those with LTPC are reporting living at home in greater numbers than their peers, very much aligns with wider research that has found those with LTPC face greater challenges in reaching developmental milestones such as independent living (Pinquart, 2014; Shelley et al., 2020). Research by Shelley et al. (2020) has shown that emerging adults with genetic conditions often depend on family for both practical support (e.g., help with medical routines) and financial stability (e.g., access to parents' health

insurance), which can influence decisions regarding education or employment, particularly the need to remain at or near to home. That emerging adults living with LTPC might continue to live with family for financial reasons is not surprising considering the annual costs associated with disability are estimated to be between €8,700 and €12,300 in Ireland (Indecon International Research Economists, 2021) and approximately £12,120 in the UK (Wright et al., 2024).

The comparative findings on primary economic status found that emerging adults living with LTPC reported significant differences in their primary economic status to their peers without LTPC. One factor that may partially explain these differences is the slightly higher average age of those with LTPC (22.31 years). If already graduated, this might account for a smaller proportion of emerging adults living with LTPC being students (46.3% compared to 73.5%) and a larger proportion being employed (35.3% compared to 17.9%). This is supported by the finding that emerging adults living with LTPC reported similar educational attainment to their peers without LTPC. Perhaps more importantly, is that 15.9% of emerging adults with LTPC reported they were not working, in contrast to 5.9% of their peers without LTPC. Among those who were not working, 10.4% of emerging adults with LTPC were unable to work due to illness or disability, compared to just 0.5% of their peers without LTPC. This finding is consistent with previous research that found emerging adults living with LTPC may experience lower vocational achievements in comparison to their peers (Kelly & Maitre, 2021; Maslow et al., 2011). In addition, in Ireland, only one-third of people with disabilities, including those with LTPC, report being employed, compared to two-thirds of people without disabilities (Kelly & Maitre, 2021). In the UK, just over half of people with disabilities report being employed, compared to three-quarters of people without disabilities (Powell, 2024). The UK is in line with the European Union as a whole, half of people with disabilities are employed compared to three-quarters of people without

disabilities (European Commission, n.d.). That more emerging adults living with LTPC are unable to work due to illness or disability likely contributes to the higher likelihood of living with family rather than living alone or with others.

The comparative findings found no significant difference between emerging adults living with LTPC and their peers without LTPC in terms of overall willingness to take risks. No significant differences or associations were found for smoking cigarettes, vaping, or non-prescription drug use. However, a significant difference was identified with the frequency of alcohol consumption. Consistent with expectations, the current study found that emerging adults living with LTPC reported drinking alcohol less frequently than their peers without LTPC. Specifically, 68.2% of participants with LTPC indicated little to no alcohol consumption, compared to 47.6% of those without LTPC. This suggests that emerging adults with LTPC may be more conscientious about their alcohol intake. Lower alcohol consumption aligns with the findings from the secondary data analysis using GUI data (Chapter Three), in addition to findings from the systematic review (Chapter Two), that highlighted that some emerging adults with LTPC tend to avoid certain social environments and activities due to health concerns.

Consistent with expectations, the current study found that emerging adults living with LTPC reported more difficulty in making ends meet compared to their peers without LTPC. Financial uncertainty is common during emerging adulthood, as many emerging adults are managing their own money for the first time, with financial independence now considered one of the primary markers of reaching adulthood (Arnett, 2001). This finding that emerging adults living with LTPC reported more difficulty in making ends is particularly important as already mentioned above, a greater percentage of emerging adults with LTPC are unable to work due to illness or disability and overall, those living with LTPC are at an overall greater risk of experiencing economic hardship (Indecon International Research Economists, 2021).

The comparative analyses found no significant difference between the two groups (LTPC vs. no LTPC) in terms of their perception of feeling adult however, in line with expectations, emerging adults living with LTPC reported feeling that they grew up faster than their peers without LTPC. This suggests that while the subjective feeling of adulthood may not differ significantly, the responsibilities associated with adulthood may be more prominent for emerging adults living with LTPC. This could reflect additional responsibilities related to managing their health conditions that they may have taken on during adolescence and into emerging adulthood contributing to a stronger sense of taking on adult roles. Mooney et al., (2021) found that children and adolescents living with epilepsy were self-monitoring activities and restricting or avoiding activities when deemed necessary to manage their condition. Having self-management responsibilities may foster a stronger sense of maturity and adult-like roles.

Finally, in relation to the differences in age found between the two groups (LTPC vs. no-LTPC), those living with LTPC were slightly older than their peers without LTPC, with an average age of 22.31 years to 21.87 years. For gender, emerging adults living with LTPC had more females and emerging adults in the “other” category, than their peers without LTPC. This gender split (more females) does not have any direct considerations for the findings other than future research aiming to include a more balance split.

4.7.2 Variations in the Experience of Emerging Adulthood

These variables (age, gender, living arrangements, primary economic status, making ends meet, alcohol consumption and the perception of adult responsibilities) and group membership (LTPC vs. no-LTPC) were then examined to determine if they were associated with variations on the experience of emerging adulthood, that is the five features (identity exploration, instability, self-focus, feeling in-between, and possibilities), as measured by the

IDEA scale (Reifman et al., 2007). While no variables were significantly associated with the age of identity exploration several variables were linked to the other features of emerging adulthood, as measured by the IDEA scale (Reifman et al., 2007). Group membership, living arrangements, primary economic status, making ends meet, and gender were associated with the age of instability, while living arrangements and primary economic status were also significantly linked to the age of self-focus. Primary economic status, taking on adult responsibilities, age, and gender were significantly associated with the age feeling of being in-between. Additionally, primary economic status was significantly associated with the age of possibilities.

Group membership (LTPC vs. no-LTPC) was significantly associated with variation in the age of instability, as measured by the IDEA scale (Reifman et al., 2007). Emerging adults living with LTPC reported higher levels of instability than their peers without LTPC. This increased sense of instability among those with LTPC is likely due to the additional challenges they face in managing their condition, combined with the uncertainty about the future and concerns about their health. This is supported by the associations of living arrangements, primary economic status and making ends meet with the age of instability, as measured by the IDEA scale (Reifman et al., 2007), these variables are linked to life transitions and uncertainty (see Figure 4.1).

Emerging adults living with family reported higher levels of instability, as measured by the IDEA scale (Reifman et al., 2007), in comparison to their peers who were living alone or with others. Questions from the IDEA in relation to instability explore whether this life stage is characterised by confusion, restriction, stress, instability, high pressure, unpredictability, and worry. That those living at home endorse these feelings more frequently than those living alone or with others, suggests that, while they may be legally adults, there may be some barriers to achieving full independence and autonomy (Settersten et al., 2015).

Emerging adulthood is not only a confusing time for emerging adults themselves but also for their parents (Nelson et al., 2007). Parents may find it challenging to accept their child's autonomy, particularly when the emerging adult continues to live at home (Kloep & Hendry, 2010). Restrictions or rules imposed by parents might inhibit an emerging adult's full experience of college or work life, where socialising and experimentation are integral as peer networks expand (Ravert, 2009). Moving out of the family home generally leads to a shift in the power dynamic between parents and emerging adults, with boundaries being more clearly defined (Nice & Joseph, 2023). However, those who remain at home due to financial constraints (Nelson et al., 2007) or because the housing and rental markets do not afford them the opportunity to live independently, such as in the context of the Irish housing crisis (Social Justice, 2024), face additional challenges.

When considering the higher levels of emerging adults living with LTPC reporting feelings of instability, it is important to consider that they are also more likely to live with family. Therefore, it is likely, that for some, living with family is contributing in some way to the higher feelings of instability. The systematic review (Chapter Two) found that emerging adults living with LTPC often rely on family for both physical and financial support which influences decisions regarding education or employment, particularly the need to remain living at home. However, for some participants, parents were overly involved, such as through the monitoring of self-management tasks, which stifled independence and increased feelings of restriction, stress, and worry, even leading to poor adherence to self-management tasks, such as missing insulin doses. While social support is an essential part of both self-management and navigating emerging adulthood, over-involvement of parents may impact self-management of LTPC. Healthcare professionals if aware of this can support the emerging adult living with LTPC in advocating for independence in their self-management care with their parents.

In this study, primary economic status was also found to be significantly associated with the age of instability, as measured by the IDEA scale (Reifman et al., 2007). Interestingly, students reported lower levels of instability compared to their peers who were employed, unemployed, or looking after the family home. This contrasts with previous research, which found higher endorsements of instability in student populations compared to non-students (Crocetti et al., 2015; Kohútová & Kohút, 2024; Nice & Joseph, 2023). Social and economic changes can influence the endorsement of the five features of emerging adult (Arnett, 2004, 2015, 2016) and it is important to consider the impact of the COVID-19 pandemic, which began in 2020, on the experience of emerging adulthood. This survey was conducted between January and December 2022 at a time when many countries, such as Ireland and the UK had just finished their last major lockdown. For example, in Ireland, recurring lockdowns and restrictions on social activities were in place from March 2020 until January 2022, limiting interactions outside of households (Citizens Information, n.d.b.). In the survey participants were asked about the impact of COVID-19 on their income, mental and physical health, and social lives and all reported experiencing negative effects. However, students were less affected financially compared to those who were employed or unemployed and reported more significant negative social impacts compared to those who were employed.

This is not unexpected, given that college campuses were closed in many countries during much of the pandemic, with classes delivered online or in a hybrid model as restrictions were imposed. The typical student social experience was also curtailed as social activities were restricted (Growing Up in Ireland, 2021b). In Ireland, more than one-fifth of 22-year-olds moved back in with their parents at the start of the pandemic (Growing Up in Ireland, 2021b), a trend similar to the UK (House of Commons Library, 2021). This curtailment of social experiences may have reduced feelings of instability for students.

It is unsurprising that a significant association was found between making ends meet financially and the age of instability, as measured by the IDEA scale (Reifman et al., 2007). Emerging adults who reported more difficulty reported higher levels of instability, which includes feelings of confusion and stress. This aligns with broader research, which shows that emerging adults from lower socio-economic backgrounds perceive greater instability and face more responsibilities than their peers from higher socio-economic backgrounds (Landberg & Noack, 2019). As noted in the group comparisons, emerging adults living with LTPC reported more difficulty with making ends meet financially. As highlighted, there can be a huge financial cost to having a disability (International Research Economists, 2021; Wright et al., 2024). This aligns with the systematic review, where emerging adults living with LTPC expressed concerns about living into the future with their condition and how financial reliance on family can exacerbate these concerns, particularly regarding the affordability of health insurance as they age out of parental coverage.

The finding that gender was significantly associated with the age of instability, as measured by the IDEA scale (Reifman et al., 2007), highlights interesting patterns among emerging adults. Male participants, in general, reported lower levels of instability compared to both female and emerging adults in the “other” category. This is broadly in line with earlier research that found female emerging adults often report fewer adult-like experiences compared to males across all five features (Luyckx et al., 2009; Skulborstad et al., 2016). Previous research has also suggested that, when boys are growing up, they are often perceived by their parents as being strong enough to protect themselves, leading to greater autonomy and freedom (Mmari et al., 2018). This early autonomy granted to boys may explain why male emerging adults report lower feelings of instability, as they might experience fewer restrictions and less stress or pressure.

In this study, significant associations were found between living arrangements, primary economic status, and the age of self-focus, as measured by the IDEA scale (Reifman et al., 2007). First, considering living arrangements, emerging adults living with family reported lower levels of self-focus compared to their peers who were living independently or with others. Given the earlier discussions on living arrangements and instability, it is not surprising that emerging adults living at home, regardless of LTPC status, report lower self-focus. As emerging adults gain independence, they typically concentrate more on their own obligations and become less influenced by authority figures such as parents (Lancot & Poulin, 2018). However, for those still living at home, parental rules and overinvolvement may limit the freedom to make independent decisions, hindering personal development and self-focus. During emerging adulthood, emerging adults are less tied to obligations involving others, such as family, and are afforded the freedom to focus on their own identities and pursue their goals for the future, an age of self-focus (Arnett, 2004; 2015).

For emerging adults with LTPC, who are more likely than their peers without LTPC to be living at home, while it can present challenges, such as, limiting opportunities for independence and autonomy, there may also be potential benefits. The systematic review found that emerging adults with conditions such as obesity who lived independently struggled with poor eating habits and weight gain, while those with diabetes often neglected to monitor their blood sugar levels. This suggests that, for emerging adults with LTPC, living at home could mitigate some negative self-management behaviours. Familial support, such as reminders for blood sugar checks or adherence to healthier eating, can promote better health behaviours. While living at home may not be ideal for fostering full independence and autonomy (Blevins et al., 2021; Nice & Joseph, 2023), supportive parental relationships can play an important role in the development of long-term positive health behaviours for both emerging adults with and without LTPC (Daw et al., 2017; Nelson et al., 2008).

In relation to primary economic status and the age of self-focus, as measured by the IDEA scale (Reifman et al., 2007), students endorsed self-focus more than their peers who were working, not working or looking after the family home. This finding aligns with previous research, which also showed that students report higher self-focus (Nice & Joseph, 2023; Zorotovich, 2014). This is likely because college affords emerging adults the time to concentrate on personal growth, broaden their interests, and acquire new skills for the future (Nice & Joseph, 2023). For those in the study who were employed, financial responsibilities and other obligations might explain why they tend to be less self-focused (Nice & Joseph, 2023; Zorotovich, 2014).

It is, unsurprising that taking on adult responsibilities was found to be significantly associated with the age of feeling in-between in the further analysis exploring the variation in the experience of the five features of emerging adulthood as measured by the IDEA scale (Reifman et al., 2007). Emerging adults who felt that they took on adult responsibilities faster than their peers reported lower levels of feeling in-between. In the group comparisons, while both groups (LTPC vs. no LTPC) reported similar perceptions of not fully feeling adult, emerging adults with LTPC reported taking on adult responsibilities faster than their peers without LTPC. This is possibly due to the demands of managing their health. For example, having to self-monitor and restrict activities, when necessary, as a child or adolescent (Mooney et al., 2021) may be why there is this feeling of taking on adult responsibilities earlier than peers. This feeling of taking on adult responsibilities earlier than peers, being associated with lower levels of feeling in-between, suggests that those with LTPC may transition into adulthood more quickly in certain aspects but not overall.

Primary economic status was found to be significantly associated with the age of feeling in-between, as measured by the IDEA scale (Reifman et al., 2007). Students reported higher levels of feeling in-between compared to those who were working, not working, or

managing a household. This finding aligns with the wider emerging adulthood literature (Reifman et al., 2007; Zorotovich, 2014), which suggests that students often experience increased feelings of being "in-between" adolescence and adulthood in comparison to other groups. While students may be gaining independence and working towards their goals, they may still rely on family financially and not face more immediate adult responsibilities. This finding contrasts with the earlier result that students reported lower levels of instability. This suggests that the experience of instability among students may require further investigation, and the consideration of the role the COVID-19 pandemic may have played in influencing the experience of emerging adulthood.

In line with the broader emerging adulthood research (Arnett, 2000; Arnett, 2001; Reifman et al., 2007; Syed & Mitchell, 2013), age was found to be significantly associated with the age of feeling in-between, as measured by the IDEA scale (Reifman et al., 2007). As emerging adults got older their feelings of in-between decreased. This trend highlights the importance for healthcare professionals to be particularly mindful of younger emerging adults with LTPC who are younger and transferring to adult healthcare for the first time. They are likely to feel less adult and may experience an increased sense of uncertainty during this period of change. Therefore, they may require additional support, both in terms of navigating the adult healthcare system and taking on more self-management responsibilities.

Gender was also found to be significantly associated with the age of feeling in-between as measured by the IDEA scale (Reifman et al., 2007). Male emerging adults reported lower levels of feeling in-between compared to female and emerging adults in the "other" category. This finding aligns with earlier research, which indicates that female emerging adults often report fewer adult-like experiences than their male counterparts across all five features of emerging adulthood (Luyckx et al., 2009; Skulborstad et al., 2016). This gender difference may be linked to the earlier finding that males experience less instability

than females or those in the "other" gender category. The greater autonomy and freedoms that males tend to experience at a younger age (Mmari et al., 2018) could contribute to both their lower levels of instability and their reduced sense of feeling in-between.

While emerging adulthood is characterised by instability and feeling in-between, it is also characterised by a sense of possibilities and optimism, with many choices available to emerging adults (Arnett, 2004; 2015). A significant association was found between primary economic status and the age of possibilities, as measured by the IDEA scale (Reifman et al., 2007). Specifically, students reported significantly higher levels of possibilities compared to those who are working, not working or looking after the family home, consistent with previous research (Crocetti et al., 2015; Nice & Joseph, 2023; Reifman et al., 2007). College life often introduces emerging adults to new ideas, opportunities and diverse peer interactions, expanding their sense of optimism and future possibilities (Nice & Joseph, 2023; Reifman et al., 2007). In contrast, working emerging adults may perceive fewer possibilities, as they have often already committed to a career path, limiting exploration of different opportunities (Crocetti et al., 2015).

4.7.3 Relationship between Emerging Adulthood and Self-Management

In exploring then, the relationship between the five features of emerging adulthood, as measured by the IDEA scale (Reifman et al., 2007), the variables: living arrangements, primary economic status, making ends meet, adult responsibilities, age and gender and self-management, as measured by the Perceived Medical Condition Self-Management Scale (Smith et al., 1995) and Communication with Physicians Scale (Lorig et al., 1996). Alcohol was not found to be associated with any feature of emerging adulthood and was excluded. There were some notable findings. This analysis was for emerging adults living with LTPC only and as self-management was a key outcome, the impact of LTPC was also included.

Living arrangements, making ends meet and taking on adult responsibilities were not found to be significantly associated with self-management, as measured by the PMCSMS (Smith et al., 1995) and CWP (Lorig et al., 1996). Although living arrangements for emerging adults living with LTPC was associated with instability and self-focus previously, this finding might be facilitated by the positive relationships reported by participants with their families. That while living at home may not be ideal for fostering full independence and autonomy (Blevins et al., 2021; Nice & Joseph, 2023), which may impact instability and self-focus, in relation to self-management specifically, it may be having a positive effect. The reported positive familial relationships may be helping emerging adults living with LTPC in the development of long-term positive health behaviours (Daw et al., 2017; Nelson et al., 2008).

Making ends meet financially was not associated with self-management, as measured by the PMCSMS (Smith et al., 1995) and CWP (Lorig et al., 1996). This suggests that while financial strain may increase perceived instability, it does not necessarily impact how emerging adults with LTPC manage their condition or interact with healthcare providers. One possible explanation may be that 65.2% of emerging adults living with LTPC reported having free healthcare or a GP visit card and 19.5% reported having their own or being on someone else's health insurance policy. This suggests that although emerging adults living with LTPC are experiencing more difficulty in making ends meet financially than their peers without LTPC, it is not currently impacting on their ability to self-manage. Similarly, taking on adult responsibilities was not associated with self-management, as measured by the PMCSMS (Smith et al., 1995) and CWP (Lorig et al., 1996). Emerging adults living with LTPC reported taking on adult responsibilities faster than their peers without LTPC, suggesting that this is likely due to the demands of managing their health at a younger age. For example, they

may have taken on some self-management responsibilities in adolescence. Therefore, taking on adult responsibilities is not currently impacting on their ability to self-manage.

Primary economic status was found to be significantly associated with self-management, as measured by the PMCSMS (Smith et al., 1995) and CWP (Lorig et al., 1996). Students living with LTPC reported higher levels of perceived self-management compared to those who were working, not working or looking after the family home. The balance between maintaining a social life and managing financial uncertainty is known to be a key factor in contributing to the experience of instability during emerging adulthood (Arnett, 2004; 2015) and was also found to impact self-management in the systematic review (Chapter Two). It was unexpected that students living with LTPC reported higher levels of perceived self-management. As the data for this survey was collected in the year following the final lockdown related to the COVID-19 pandemic (in most countries) it is possible that unique conditions linked to the pandemic, influenced higher levels of perceived self-management. Factors such as moving back home, increased financial support, and reduced social pressures may have contributed to lower reported levels of instability among students, both with and without LTPC. For those with LTPC, these conditions may have also fostered higher levels of perceived self-management, as measured by the PMCSMS (Smith et al., 1995). However, further research is needed to confirm this and to explore if there are any long-term effects of these factors on emerging adulthood and self-management experiences.

In relation to the impact of LTPC on daily life, learning, memory, concentration, and attending work or college were significantly associated with perceived self-management, as measured by the PMCSMS (Smith et al., 1995). For emerging adults with cognitive challenges that posed more difficulties, perceived self-management was lower. These challenges may be more prevalent in some conditions than others, such as neurological disorders or chronic pain. For example, people with epilepsy often experience cognitive

impairment, with the affected cognitive areas depending on the location of the epileptic activity (Novak et al., 2022). While those living with chronic pain are often prescribed medications where the side effects can cause memory problems (NHS, n.d.b). Individuals on multiple medications, may face further cognitive difficulties (Terman et al., 2020). Cognitive impairment has been found to result in poor medication management and self-monitoring (Kim & Fritschi, 2021) which supports the finding of this study.

Emerging adults with LTPC who reported difficulties with attending work or college also reported lower perceived self-management, as measured by the PMCSMS (Smith et al., 1995). This finding aligns with insights from the systematic review (Chapter Two) which highlighted certain challenges to self-management during emerging adulthood, related to college and the workplace. It found that many emerging adults living with LTPC in college struggle to balance academic schedules with self-management tasks, often relying on new and sometimes unreliable peer relationships for support during episodes such as seizures or hypoglycaemia. Similarly, in the workplace, issues like fear of stigma, discomfort in carrying out self-management tasks, and reluctance to ask for necessary accommodations, such as flexible work schedules or safe environments for medical tasks, were common.

Healthcare professionals can play an important role in supporting emerging adults with LTPC who face cognitive impairments by encouraging the use of digital technologies like phone alarms for medication reminders or apps to track symptoms ahead of medical appointments. Where possible, healthcare professionals should encourage emerging adults living with LTPC to track both benefits and side effects when taking medications. This can then be reviewed so that the right combination or dose of medications can be achieved that give optimal benefits and minimal side effects. Additionally, healthcare providers can help emerging adults advocate for themselves in college or the workplace, guiding them on how to request accommodations like flexible work hours or private spaces for self-management

tasks, which could improve both self-management and reduce feelings of instability related to self-managing during emerging adulthood.

The relationship between age, gender, and communication with physicians, as measured by the CWP (Lorig et al., 1996), highlights another key area for tailored healthcare supports. Older emerging adults living with LTPC reported better communication with physicians, suggesting that experience and familiarity with the healthcare system may play a role in improving how comfortable they feel with healthcare professionals. These older emerging adults have had more time to adjust to the new healthcare relationships that come with transferring to adult healthcare, which typically happens between age 16 – 18 years. This finding aligns with the finding of the systematic review in how having to start with new healthcare professionals was often daunting and stressful. As emerging adults in general, which includes those living with LTPC, transition through emerging adulthood they report less feelings of “in-between” (Reifman et al., 2007; Skulborstad et al., 2016) which may also contribute to the finding that they report better communication with doctors.

In terms of gender, females and those in the “other” category reported better communication compared to males. This highlights the need for healthcare professionals to offer more tailored gender specific support. For male emerging adults, who often report lower levels of instability and feeling in-between, it may be that they feel uncomfortable asking questions or sharing information. Research has found that men in general, visit family doctors less often (Thomson et al., 2016), report shorter consultation times than female counterparts and ask less questions (Wenger, 2011). It may be important for healthcare providers to take a more proactive approach in engaging males in collaborative communication. In contrast, when communicating with females and those in the “other” category, healthcare professionals should be mindful that these individuals often experience higher levels of instability and feeling in-between, especially when they are younger (Luyckx et al., 2009; Skulborstad et al.,

2016). It is important to strike a balance between encouraging female and other emerging adults living with LTPC to take on adult responsibilities in managing their healthcare while recognising they may not yet feel fully adult. Tailoring communication in this way can foster a more supportive healthcare experience, better outcomes and build collaborative relationships.

Instability was the only feature of emerging adulthood found to be significantly associated with self-management, as measured by the PMCSMS (Smith et al., 1995). Emerging adults with LTPC who reported higher levels of instability reported lower levels of perceived self-management. This highlights the importance of addressing instability in the context of self-management. This study has highlighted how factors such as living arrangements, finances, and primary economic status can increase feelings of instability, creating barriers to effective self-management. Providing healthcare professionals with insights as to how instability manifests during emerging adulthood and the factors that contribute to it, can help to improve support and care for this group as well as fostering collaborative healthcare partnerships, which will empower emerging adults living with LTPC to be proactive in managing their health.

4.8 Strengths and Limitations

The main strength of this cross-sectional study is that it addresses a significant gap in the comparative quantitative research on emerging adults living with LTPC. Moreover, to the researcher's knowledge, this is the first study to directly compare emerging adults with LTPC to their peers without LTPC using a dedicated measure of emerging adulthood, providing valuable insights into how this developmental stage can influence self-management abilities and behaviours. By incorporating the findings of this study, healthcare professionals can tailor their support to address the developmental challenges faced by emerging adults with

LTPC during emerging adulthood. This could foster more collaborative healthcare partnerships, empower emerging adults to take proactive steps in managing their health and promote better long-term health outcomes for this population.

There were limitations to this cross-sectional study. Firstly, despite multiple recruitment routes, it is unclear whether emerging adults from lower-income backgrounds, who may experience greater social and economic disadvantages, were adequately represented and any generalisations made from this data back to the broader population must be cautiously interpreted. This limits the ability to explore how economic disparities may influence the experiences of emerging adults with LTPC in both managing their health and transitioning to adulthood. Secondly, participants were only included in the LTPC group if they reported that their diagnosis had been confirmed by a medical professional. As a result, emerging adults self-managing symptoms without a formal diagnosis were not captured in this study and may have resulted in the exclusion of important self-management insights from those who are managing undiagnosed conditions. Thirdly, the age range was limited to 18–25-year-olds. This decision was made because older emerging adults, aged 26–29, are less likely to strongly endorse the features of emerging adulthood compared to the younger age group. However, this limitation may have resulted in the exclusion of important self-management insights from those in the later stages of emerging adulthood, potentially overlooking how self-management behaviours evolve towards the end of this developmental stage. Fourth, the number of participants included in this study from other countries outside of Ireland and the UK were too small to make meaningful inferences about either cultural or socio-economic differences. Finally, this study was cross-sectional rather than longitudinal, which limits the ability to capture patterns and changes that occur over time. This means that like the exclusion of 26 – 29-year-olds, important insights may have been missed related to

how emerging adults evolve as they navigate both emerging adulthood and the self-management of LTPC throughout this developmental stage.

4.9 Conclusion and Implication for Thesis

In conclusion, this cross-sectional study of emerging adults (18 – 25-year-olds) living with and without LTPC offers valuable insights into the experience of emerging adulthood and its relationship to the self-management of LTPC. This study builds on the findings from both the systematic review (Chapter Two) and the secondary analysis of GUI data (Chapter Three). The systematic review identified that the five features of emerging adulthood are present in the self-management of LTPC, with the transition to adulthood presenting unique challenges to effective self-management. The secondary analysis of GUI data highlighted that while emerging adults with LTPC share many similar experiences with their peers, across variables related to the five features of emerging adulthood, key differences emerged in areas such as instability, including education and employment. This current cross-sectional study quantitatively assessed these differences using the IDEA to measure the individual differences in how emerging adults perceive and identify with the five features of emerging adulthood: identity exploration, instability, self-focus, feeling in-between, and possibilities and examined their impact on self-management for the first time. The findings highlight that emerging adults living with and without LTPC, often do not yet feel fully adult. For those living with LTPC, balancing personal, college, and work life with managing their condition presents significant challenges. The findings highlight that emerging adults with LTPC are more likely to experience instability in their lives and this feature of emerging adulthood requires more attention and tailored support from healthcare professionals to improve self-management outcomes.

Chapter 5: Conclusions and Implications

5.1 Overview of this Chapter

This chapter discusses the original contribution and key implications arising from the findings of Chapter Two (systematic review), Chapter Three (secondary analysis of GUI Wave 4, Cohort '98), and Chapter Four (cross-sectional survey) regarding emerging adulthood and the self-management of LTPC. This is followed by the strengths, limitations of the thesis, future research and overall conclusion.

5.2 Original Contribution of Thesis

The development of self-management skills and expertise occurs across the lifetime, with each developmental stage (e.g., emerging adulthood), presenting its own unique challenges. This multi-study thesis set out to examine whether emerging adults with and without LTPC differ in the distinctive features of emerging adulthood; the age of identity exploration, instability, self-focus, feeling in-between, possibilities, and to explore how these features might be associated with the self-management behaviours among those living with LTPC.

By employing the lens of Arnett's Theory of Emerging Adulthood for reviewing both the self-management and emerging adulthood literatures, and for the systematic review (Chapter Two), this thesis identified key risk and protective factors, such as self-regulation, living arrangements and social support, that are essential for navigating the self-management of LTPC and the broader developmental challenges of emerging adulthood. This dual focus shaped the design of each study, allowing for a more comprehensive understanding of the self-management of LTPC during this developmental stage of emerging adulthood.

This thesis makes a significant contribution to the self-management literature, in particular to our understanding of self-management during emerging adulthood. The previous literature had predominantly focused on emerging adults living with LTPC only and did not take into consideration the distinctive features of emerging adulthood as identified by Arnett's theory. Consequently, this thesis set out to directly compare emerging adults with LTPC to their peers without LTPC. This responds to Arnett's (2000; 2001; 2015) call for subgroup-specific research to explore how contextual factors might alter the degree to which emerging adults endorse the five features of emerging adulthood. This is essential not only for expanding the theory but also for refining our understanding of emerging adulthood as a developmental stage for diverse populations such as emerging adults living with LTPC.

A key overall finding from this thesis is that while emerging adults living with LTPC experience the five features of emerging adulthood, their experiences can differ significantly from those of their peers without LTPC on certain key risk and protective factors, essential for navigating both self-management and emerging adulthood. For example, for emerging adults living with LTPC, socio-economic (e.g., primary economic status) and health-related challenges (e.g., severity of condition) are associated with increased feelings of instability, compared to their peers without LTPC. Furthermore, these increased feelings of instability are associated with poorer perceived self-management of LTPC. This provides valuable evidence that for emerging adults living with LTPC, the developmental stage of emerging adulthood can act as a risk factor for the self-management of their LTPC. This represents an important contribution to the field of self-management in emerging adults living with LTPC, as effectively supporting individuals across various developmental stages remains a significant challenge in healthcare (Clements et al., 2016; Davis et al., 2022; Sherifali et al., 2018; Wiebe et al., 2016). This thesis demonstrates why it is important to develop not only targeted self-management supports but wider socio-economic supports tailored to the specific

challenges presented by emerging adulthood as a developmental stage to emerging adults living with LTFC.

In considering this thesis's contribution to the emerging adulthood literature, it is also important to consider how emerging adulthood as a developmental stage arose following significant social and economic changes across several countries (Arnett, 2015). These structural changes, which contributed to extended education, delayed marriage, and changes in labour market dynamics, informed a new developmental stage of emerging adulthood that were characterised by five features; identity exploration, instability, self-focus, feeling in-between and possibilities (Arnett, 2004; 2015). This is a developmental stage during which emerging adults navigate some key developmental milestones, such as moving out of the family home and becoming responsible for themselves (Arnett 2004; 2015; Crocetti et al., 2015; Nice & Joseph, 2023). The findings from this thesis demonstrate how global health crises, such as the COVID-19 pandemic and local socio-economic issues, such as, Ireland's ongoing housing crisis, can further shape and sometimes disrupt the experience of emerging adulthood, including delaying key developmental milestones (e.g., moving out of the family home). Such challenges can diminish the feelings of possibilities and optimism that typically characterise this developmental stage. This research extends our understanding of how new global or local conditions, can shape, or change the experience of emerging adulthood. Furthermore, these findings highlight the importance of understanding the impact of economic or pandemic-related events on emerging adults, providing critical insights for healthcare professionals and policymakers to develop buffers and support systems to mitigate future disruptions.

The systematic review in Chapter Two identified and synthesised existing research on emerging adults aged 18–29 years examining how the distinctive features of emerging adulthood intersect with the self-management of LTFC. It provided an insight into how the

five features of emerging adulthood can create challenges for emerging adults living with LTPC, as they balance self-management of their LTPC with navigating this developmental stage (e.g., navigating relationships and life transitions). This systematic review is unique in that, to the researcher's knowledge it is the first, to specifically explore self-management in emerging adults living with LTPC using the lens of Arnett's Theory of Emerging Adulthood. Overall, it found that emerging adults living with LTPC experience the five features of emerging adulthood within the context of their self-management strategies and tasks but face many challenges, due to the unstable nature of this developmental stage. It also highlighted a gap in comparative, quantitative research between emerging adults with LTPC and their peers without LTPC, highlighting the importance of such research to better understand their respective experiences and challenges. Furthermore, it recommended that assessing the extent to which emerging adults with LTPC experience the five features of emerging adulthood could help elucidate specific challenges for LTPC self-management during this developmental stage. Subsequently, Arnett's five features of emerging adulthood informed both the selection of items for the secondary analysis of the Growing Up in Ireland (GUI) data in Chapter Three and the design of the cross-sectional survey presented in Chapter Four.

The second study, a cross-sectional, secondary analysis of data from Wave Four of the GUI study, Cohort '98 (Chapter Two), addressed the gap in comparative quantitative research by comparing emerging adults living with LTPC to their peers without LTPC and identifying if they varied in their experiences of emerging adulthood, through the lens of Arnett's Theory of Emerging Adulthood. Significant differences were observed between the two groups in life satisfaction, part of identity formation in the age of identity exploration. Related to the age of instability, differences were noted on the final school year programme choice, the completion of final exams and primary economic status (life transitions). On taking health risks, differences were identified specifically with alcohol consumption. Related

to uncertainty were differences in medical card ownership, unmet medical needs (doctor and consultant visits). For the age of self-focus and learning to be self-sufficient, the only difference was found in the aspirations for car ownership by age 30. The age of feeling in-between had significant differences on both perceptions of adulthood, and the assumption of adult responsibilities relative to peers.

In this second study, there was also the opportunity to undertake further analyses focusing on emerging adults living with LTPC only, to explore three key risk and protective factors that might inform these observed differences, daily impact of condition, parent educational attainment and gender, as identified by the Self and Family Management Framework (Grey et al., 2006) and earlier GUI studies (Carroll et al., 2022a; Swift et al., 2021). When the condition was reported as affecting daily life “to some extent,” it was linked to lower life satisfaction, participation in an alternative final-year school programme, and an increased likelihood of being in the “not working” category of primary economic status. Interestingly, this level of impact “to some extent” also corresponded with an increased likelihood of sitting the Leaving Certificate exam and a decreased likelihood of having unmet needs related to consultant visits within the past year. When the condition was reported as “severe,” the likelihood of holding a medical card for healthcare cover increased. These findings highlight the need for healthcare and educational professionals to prioritise additional supports to emerging adults living with LTPC, particularly when they report experiencing at least some daily impact of their condition. Future research could explore how the daily impact of LTPC specifically influences educational engagement and self-management. It could also further investigate the finding that the level of impact “to some extent” was associated with an increased likelihood of sitting the Leaving Certificate exam. This raises important questions about the factors that enable these students to commit to their exams despite their health challenges. Potential factors such as resilience, social or

institutional supports may play a role in why these students are able to do so. Further exploration of these enabling factors could offer valuable insights into how similar supports might be adapted or expanded for students facing more severe challenges. Understanding the role that the severity of the condition plays in education could inform the development of more effective and equitable support practices for all students with LTPC.

Parent educational attainment was a significant predictor of several outcomes, in line with earlier GUI studies (Carroll et al., 2022a; Swift et al., 2021). Compared to having parents who completed higher education, having parents who had not completed the Leaving Certificate was associated with an increased likelihood of the emerging adult being in further education or employment, rather than higher education. A lower level of parental education (parents who had not completed the Leaving Certificate) was also associated with lower reported levels of alcohol consumption and an increased likelihood of holding either a “GP card only” or a “full medical card.” When parents had completed the Leaving Certificate or further education there was an increased likelihood of their child being in an alternative final-year school programme and increased feelings of adulthood. Additionally, when parents had completed either the Leaving Certificate or further education, emerging adults placed a higher importance on car ownership by age 30. As parental educational attainment was found to be associated with the educational outcomes of emerging adults, including the likelihood of continuing in education and accessing higher-level education, it highlights the importance of more targeted educational interventions from a young age. Children, adolescents and emerging adults living with LTPC are already at an increased risk of poorer education and vocational outcomes (Maslow et al., 2011) and this thesis found an additional layer of risk within this group: that those whose parents have lower levels of education, face even greater risks. Implementing additional educational supports (e.g., grinds) from primary school onwards, that support all emerging adults living with LTPC, with particular emphasis on

those from families with lower educational attainment may act as a buffer against the potential disadvantages of living with LTPC. These types of support can lead to more access to further and higher education, which can lead to better-paying jobs, provide a pathway for improved socio-economic standing and greater career stability (Settersten et al., 2015).

Gender, as another potential risk or protective factor (Carroll et al., 2022a; Grey et al., 2006; Swift et al., 2021), also showed significant associations. Male emerging adults living with LTPC were more likely to be enrolled in higher education than employed and reported lower alcohol consumption scores compared to their female peers living with LTPC. In relation to higher education, this finding is not aligned with recent statistics, where over half of higher education graduates have been female (Central Statistics Office, 2019b). This raises questions about whether female emerging adults living with LTPC may face certain barriers in accessing and navigating higher education. Identifying these challenges and implementing targeted supports could help achieve greater equity in educational attainment within this group. In relation to lower alcohol consumption scores among males living with LTPC compared to females this warrants further investigation. One possible explanation is that females identified as feeling more “in-between” adolescence and adulthood in the cross-sectional survey (Chapter Four). This aligns with broader research that reports fewer adult-like experiences for females compared to their male counterparts across all five features of emerging adulthood (Luyckx et al., 2009; Skulborstad et al., 2016). Feeling in-between might influence their engagement with risky behaviours such as alcohol consumption. Additionally, while emerging adulthood is often characterised by increased negative risk-taking behaviours, such as alcohol consumption, not all emerging adults engage in these behaviours or develop related issues (Sussman & Arnett, 2014). For males living with LTPC, the lower alcohol consumption scores may reflect a more cautious approach to health-related risks, potentially influenced by the type of their condition. Understanding the factors contributing to

these gender differences, can help in tailoring support strategies for both male and female emerging adults living with LTPC.

The secondary analysis of the Wave Four dataset from Cohort '98 of the GUI longitudinal study offers a valuable perspective on how emerging adulthood can vary for emerging adults living with LTPC compared to their peers without LTPC. Caution is required in generalising these findings to the wider population, given that emerging adults from lower-income backgrounds might not be equally represented. However, this analysis provides important insights into the key similarities and differences between the two groups, framed by Arnett's Theory of Emerging Adulthood. Moreover, it examines some of the risk and protective factors that may predict and contribute to these differences for emerging adults with LTPC, with a specific focus on the daily impact of LTPC, parental educational attainment, and gender highlighting some key areas for further research.

To further address the findings of the systematic review, build on the insights from the secondary analysis of GUI data, and to answer the overarching thesis question: do emerging adults with and without LTPC differ in the distinctive features of emerging adulthood, and how do these features influence self-management behaviours among those living with LTPC, the cross-sectional survey presented in Chapter Four was conducted with three primary aims; (1) to compare emerging adults living with and without LTPC on variables related to self-management and emerging adulthood; (2) to examine whether the experience of the five features of emerging adulthood, as measured by the Inventory of the Dimensions of Emerging Adulthood (IDEA), varies based on having a LTPC and the variables (mentioned in aim 1) that showed significant differences between emerging adults with and without LTPC; and (3) to investigate the relationship between the five features of emerging adulthood, as measured by the IDEA scale (Reifman et al., 2007), and self-management, as measured by the Perceived Medical Condition Self-Management Scale

(Smith et al., 1995) and the Communication with Physicians Scale (Lorig et al., 1996) among emerging adults living with LTPC only.

In the group comparisons on variables related to self-management and emerging adulthood, some significant differences were found. For the age of instability, significant differences were found in living arrangements (life transitions), a higher percentage of emerging adults with LTPC were living with family compared to their peers without LTPC. Additionally, emerging adults with LTPC were more likely to be unemployed or unable to work due to illness or disability (primary economic status). Those living with LTPC reported less alcohol consumption (taking health risk). Furthermore, in relation to uncertainty, a greater proportion of those with LTPC reported difficulty in making financial ends meet. For the age of feeling in-between, a notable difference was observed in that emerging adults living with LTPC felt they assumed adult responsibilities faster than their peers (feeling not yet adult). A significant difference was found in the age of the two groups (LTPC vs. no-LTPC), with those living with LTPC being slightly older on average and in terms of gender distribution, more females were represented in the LTPC group.

The variables where significant differences were noted; living arrangements, primary economic status, making ends meet, taking on adult responsibilities in comparison to peers, age, and gender, were combined with group membership (LTPC vs. No LTPC) in a structural equation model to determine their influence on the experience of the five features of emerging adulthood, as measured by the IDEA scale (Reifman et al., 2007). Living arrangements were found to be associated with the age of instability and self-focus, while primary economic status was linked to the age of instability, self-focus, feeling in-between, and possibilities. Alcohol consumption was not associated with any of the five features and was excluded from further analysis. Making ends meet was associated with the age of instability, and taking on adult responsibilities in comparison to peers was related to the age

of feeling in-between. Age was found to be associated with the age of feeling in-between, and gender was linked to the age of instability and feeling in-between. Finally, the presence of LTPC was associated with the age of instability.

The variables: living arrangements, primary economic status, making ends meet, taking on adult responsibilities, age, and gender, alongside five variables representing the impact of living with an LTPC and the five features of emerging adulthood were incorporated into a second structural equation model. This model examined the relationship between emerging adulthood, as measured by the IDEA scale (Reifman et al., 2007) and self-management, as measured by the PMCSMS (Smith et al., 1995) and CWP (Lorig et al., 1996), specifically for emerging adults living with LTPC only. The findings identified that emerging adults who reported higher levels of instability, being a student, experiencing issues related to learning, memory, and concentration, and facing difficulties with work or college reported lower levels of perceived self-management, as measured by the PMCSMS (Smith et al., 1995). Additionally, younger age and male gender were significantly associated with poorer communication with doctors, as measured by the CWP (Lorig et al., 1996).

To the researcher's knowledge, this is the first study to directly compare emerging adults with LTPC to their peers without LTPC using a dedicated measure of emerging adulthood. It offers valuable insights into the differing experiences of emerging adulthood and how this developmental stage, specifically, the feature of instability, may influence the self-management of LTPC. While generalisation to the wider population must be made cautiously, as it is possible that those experiencing greater social and economic disadvantages may not be adequately represented, this study still provides significant insights into the varying experience of emerging adulthood and its relationship to self-management of LTPC during this developmental stage.

5.3 Key Implications of Thesis

Emerging Adulthood has been widely accepted in recent years as a new and distinctive developmental stage and this thesis responded to the need for sub-group comparative research in this field. By comparing emerging adults living with LTPC to their peers without LTPC this research examined if they differed in their experience of emerging adulthood. Of importance was the utilisation of a dedicated measure of the features of emerging adulthood, the IDEA scale, which allowed for deeper understanding of how the five features of emerging adulthood; identity exploration, instability, self-focus, feeling in-between, and possibilities, were endorsed by both groups (LTPC vs. no-LTPC). Using comparative research through the lens of Arnett's Theory of Emerging Adulthood this thesis has identified that instability, one of the five features of emerging adulthood, is a particular risk factor to successful self-management for emerging adults living with LTPC.

Furthermore, this thesis highlights which individual and socio-economic factors (e.g., living arrangements and primary economic status) can contribute to increased feelings of instability, as measured by the IDEA scale (Reifman et al., 2007) and negatively affect self-management, as measured by the PMCSMS (Smith et al., 1995) and the CWP (Lorig et al., 1996). Additionally, the research has highlighted how global factors such as COVID-19 and local factors, such as a country's economic climate can influence the experience for emerging adults living with and without LTPC. These factors can influence not only the developmental milestones that typically accompany emerging adulthood but can also increase the challenges faced by emerging adults living with LTPC.

5.3.1 Implications for Clinical Practice

This thesis highlights the importance of understanding the role of developmental stages when supporting self-management among emerging adults living with LTPC. By

utilising a dual focus of self-management and the lens of Arnett's Theory of Emerging Adulthood, this thesis identified key risk and protective factors that are essential for navigating both self-management of LTPC and the challenges of emerging adulthood. The risk and protective factors derived from the Self and Family Management Framework (Grey et al., 2006; Grey et al., 2015) were consistently evident across the three studies in this thesis and are important for understanding how emerging adults living with LTPC self-manage during emerging adulthood. These factors are severity of condition, psychosocial factors (e.g., learning to be self-sufficient, feeling not yet adult, and maintaining optimism), age, gender, socio-economic status (e.g., finances and primary economic status), family structure and function, social networks, and community and healthcare systems (e.g., navigating relationships with parents and healthcare professionals).

The original authors of the Self and Family Management Framework advocate for the continued development of the framework as new data emerge (Grey et al., 2015; Schulman-Green et al., 2021). The findings from this thesis provide specific insights into the key risk and protective factors for emerging adults living with LTPC, which could inform adaptations of the framework to this developmental stage. Arnett's five features of emerging adulthood, particularly instability, could be incorporated into an adapted version of the framework tailored to emerging adulthood. In the case of this thesis, it has been identified clearly as a risk to self-management. An adapted emerging adulthood version of the Self and Family Management Framework could be a valuable tool for researchers, healthcare professionals and policymakers to develop tailored supports and guide future healthcare and socio-economic decisions.

This thesis found that risk factors found in the cross-sectional survey that influenced feelings of instability were living arrangements, primary economic status and financial difficulties. Factors specifically associated with self-management include age and gender

which affect communication with doctors, as measured by the CWP (Lorig et al., 1996), challenges with learning, remembering, concentrating, working, or studying, primary economic status and instability, as measured by the IDEA scale (Reifman et al., 2007), which negatively affect self-management behaviours, as measured by the PMCSMS (Smith et al., 1995). Male emerging adults living with LTPC reported poorer communication with doctors than their female counterparts. In line with wider emerging adulthood research (Luyckx et al., 2009; Skulborstad et al., 2016), males also reported feeling more adult than their female peers, which may suggest a reluctance to admit uncertainty or a lack of understanding about aspects of their self-management. Younger emerging adults living with LTPC also reported poor communication, possibly for similar reasons. These findings emphasise the need for developmentally appropriate healthcare, that could be supported by allocating additional time during consultations (where possible) to build a comfortable environment for younger and/or male patients to express concerns. Building collaborative relationships, a key component of self-management (Lorig and Holman, 2003; Velde et al., 2019), could be facilitated through techniques such as motivational interviewing, where professionals are trained in its application (Rochford et al., 2018).

Where healthcare professionals can also play a key support role is for those emerging adults living with LTPC who experience daily challenges with learning, remembering, or concentrating and/or working at a job, business, or attending college, factors that were found to negatively affect self-management, as measured by the PMCSMS (Smith et al., 1995). Practical interventions, such as recommending the use of phone apps or reminders for medication, appointments, or symptom tracking, can support these emerging adults. Utilising technology-based interventions can reduce the cost and dependence on healthcare professionals for additional services, for example, it was found that children and young people living with type I diabetes monitored their blood glucose more frequently when

exposed to techniques such as text messaging, mobile phone applications and interactive online tools (Knox et al., 2019). Moreover, providing developmentally appropriate healthcare, as highlighted in the systematic review (Chapter Two), is important. Accounting for the significant life transitions (e.g., starting college or work) and the balancing act (e.g., maintaining a social life) that emerging adults living with LTPC must manage alongside their self-management responsibilities. Collaboration with occupational therapists and college disability services can further enhance support through a multidisciplinary approach.

While emerging adults with LTPC face unique challenges, this thesis also found similarities between them and their peers without LTPC in factors such as strong family relationships, social support, positive self-esteem, effective self-regulation, and having goals and aspirations. These factors can act as protective supports, facilitating the transition through emerging adulthood and the development of self-management skills. Leveraging these protective factors in healthcare settings could mitigate risk factors and better support emerging adults with LTPC. Simply feeling heard by healthcare professionals can foster a sense of value and motivate self-management (Rochford et al., 2018).

This thesis provides valuable insights for healthcare professionals into the self-management challenges faced by emerging adults living with LTPC are facing during this developmental stage. Recognising the risk and protective factors specific to this group can help to develop more developmentally appropriate supports, bridging the gap between clinical goals of the practitioners and the psychosocial needs of emerging adults. However, barriers to integrating self-management support into care remain, as highlighted by healthcare professionals (e.g., frontline nurses and general practitioners) in Chapter One. These barriers include time constraints, increased workloads, a lack of training, beliefs about patient capability, and insufficient coordination or resources (Lorig & Holman, 2003; Noordman et al., 2024; Tharani et al., 2021). In Ireland, these challenges are compounded by a two-tiered

healthcare system, characterised by long waiting lists and time pressures on appointments (Whyte et al., 2020). An immediate action arising from this research is to look at ways to disseminate the findings of this thesis to healthcare professionals in formats that are concise, accessible, and require minimal cognitive load, for example, quick-reference guides, infographics or video summaries.

Despite these systemic challenges, Ireland's Department of Health and Health Service Executive (HSE) are prioritising patient-centred care, including self-management initiatives through the Sláintecare Integration Fund (Department of Health, 2022). Some of the new pilot programmes that were funded across 2019 – 2021 were The Headache clinic SIF project which focused on a move to nurse led clinics, a dedicated psychology service, self-care programmes and support groups which achieved a 23% reduction in waiting lists and an improvement in adherence to appointments (Department of Health, 2022). The "Living Well" programme which has been expanded to mainstream and available both online and in person has demonstrated significant improvements in quality of life, self-efficacy, and healthcare utilisation among participants (Department of Health, 2022). However, specific targeted supports for emerging adults (18 – 25 years) is lacking. The findings from this thesis could be used to inform and adapt self-management programmes such as "Living Well" to meet the specific developmental needs of this group, during a developmental stage that is key for establishing long-term positive health behaviours for the future (Daw et al., 2017; Nelson et al., 2008).

5.3.2 Policy Implications

Other risk factors contributing to feelings of instability and therefore posing risks to self-management include living arrangements, primary economic status, and financial difficulty. Addressing these broader socio-economic factors could help reduce feelings of

instability during emerging adulthood and foster improvements in self-management behaviours. However, these challenges often fall outside the remit of healthcare professionals, requiring broader societal and governmental support. For example, increasing access to affordable and suitable housing, and providing better financial support for individuals with LTPC (e.g., disability payments that recognise the extra cost of disability) would require substantial investment and policy changes at a national level.

Research across disability consistently highlights that individuals with LTPC are at greater risk of not achieving certain developmental milestones, such as moving out of the family home (Kelly & Maitre, 2021; Pinquart, 2014; Shelley et al., 2020), poorer educational and vocational outcomes (Maslow et al., 2011), and increased vulnerability to poverty (Indecon International Research Economists, 2021) compared to their healthy peers. The findings of this thesis strongly align with this broader research. Chapter Four found that emerging adults living with LTPC are more likely to live at home than their peers without LTPC. Chapter Three identified significant differences in educational attainment (e.g., completing final exams) between the two groups (LTPC vs. no-LTPC). Furthermore, both Chapters Three and Four highlighted disparities in primary economic status (e.g., less access to higher education and higher rates of unemployment), highlighting the socio-economic challenges faced by emerging adults living with LTPC. Importantly, demonstrated in this thesis, these socio-economic factors increase feelings of instability which negatively impact self-management.

The higher rates of unemployment and inability to work due to illness or disability among emerging adults living with LTPC highlight their financial vulnerabilities. It is unsurprising, therefore, that this group reported greater difficulties in making ends meet in the cross-sectional analysis (Chapter Four). The systematic review further emphasised that emerging adults with LTPC often express concerns about affording medications and

healthcare insurance. Improving access to equitable education and employment opportunities may be among the most effective strategies for enabling emerging adults living with LTPC to achieve developmental milestones and reduce their overall risk of poverty. Sufficient income not only contributes to a decent standard of living but also provides employment security, which can protect against other social insecurities (European Parliament, 2020), thereby reducing feelings of instability.

Considering the economic contexts of Ireland and the UK, where the majority of participants in Chapters Three and Four reside (100% in Ireland in Chapter Three; 31.62% in Ireland and 51.87% in the UK in Chapter Four), specific considerations are necessary for education and employment policies. In Ireland, individuals with disabilities face one of the largest gaps in educational attainment across the EU; in 2018, only 39.9% of individuals aged 30–34 years with disabilities had higher education qualifications, despite Ireland having one of the highest GDP per capita rates in Europe (Eurostat, 2018; European Commission, 2022c). Similarly in the UK, the sixth largest economy globally, only 24.9% of individuals aged 21 to 64 years with disabilities had a degree or equivalent, compared to 42.7% of non-disabled individuals. Furthermore, individuals with disabilities in the UK are almost three times as likely to have no qualifications (Sparkes et al., 2022).

Both countries also have significant disparities in employment opportunities for individuals with disabilities, raising concerns about continued or future unemployment, increased reliance on welfare, and reduced lifetime earnings (Hale et al., 2015; Indecon International Research Economists, 2021). In Ireland, only one-third of individuals with disabilities are employed, compared to two-thirds of individuals without disabilities (Kelly & Maitre, 2021). Similarly, in the UK, just over half of individuals with disabilities report being employed, in contrast to three-quarters of those without disabilities (Powell, 2024). The UK figures align with EU statistics, where 50% of individuals with disabilities are employed

compared to 75% of those without disabilities (European Parliament, 2020). While the European Union wants to foster equality and increase participation in education and employment for individuals with disabilities (European Parliament, 2020). Ireland's figures fall short of EU averages, demonstrating that even more significant work is needed to bridge this gap.

The findings of this thesis highlight the challenges emerging adults with LTPC face in achieving developmental milestones, such as moving out of home or accessing higher education. These socio-economic barriers contribute to increased feelings of instability, which can act as a barrier to the development of self-management skills essential for developing long-term positive health behaviours. It is important to support emerging adults living with LTPC in navigating both self-management and their transition to adulthood in a more equitable way. This would improve their socio-economic outcomes, health, and overall quality of life. Governments must prioritise investment, policy improvements, and efforts to foster equality in these areas.

5.3.2.1 Ireland's Housing Crisis

Country specific socio-economic factors can shape and influence the experience of emerging adulthood, as highlighted by Arnett (2015). Recent research suggests that emerging adults who are employed, financially independent, and living away from their parents report a greater sense of adulthood and lower levels of instability (Blevins et al., 2021). Conversely, financial dependence is associated with higher levels of instability (Kohútová & Kohút, 2024). This thesis highlights how, in Ireland, the ongoing housing crisis may be influencing the experience of emerging adulthood for both those living with and without LTPC. Economic pressures in Ireland are likely increasing the feelings of instability while diminishing the feelings of possibility and optimism that typically characterise this

developmental stage. Widespread concerns about poverty, employment, and housing, as identified in Chapter Three, illustrate this trend. Representatives from the youth advisory panel to the Ombudsman for Children's Office in Ireland echoed these sentiments recently, describing how the current economic climate in Ireland is eroding their “hope” (Ombudsman for Children's Office, 2024).

For emerging adults living with LTPC, the housing crisis may further exacerbate existing barriers, making independent living even less attainable. The systematic review (Chapter Two) offers insights into the influence of living arrangements on emerging adults living with LTPC, particularly the ways in which living with family can heighten feelings of instability and affect self-management behaviours. It highlighted that, for some emerging adults living with LTPC, parental overinvolvement could stifle their independence, with parents continuing to monitor self-management tasks and even accompanying them to adult medical appointments. While fractured parent-child relationships often resulted in emerging adults intentionally neglecting self-management tasks. Overinvolvement and poor parental relationships, which can be magnified when living with family, can negatively impact self-management, impeding adherence of current tasks and in assuming responsibility for the development of new tasks and routines.

Family structure, such as living arrangements, is a key component of the Self and Family Management Framework (Grey et al., 2006) acting as either a risk or protective factor for self-management. Moving away from home to independent living, offers the opportunity to foster self-regulation and self-efficacy (Lansing & Berg, 2014; Schulman-Green et al., 2012; Velde et al., 2019). By exercising control over their own health decisions and habits, emerging adults living with LTPC build confidence in their self-management abilities, fostering a sense of mastery and a stronger commitment to maintaining their health (Bandura, 1997; 1998). These self-efficacy and self-regulation skills do not only underpin self-

management but are also integral for the broader transition to adulthood (Blair & Diamond, 2008). Arnett (2004; 2015) identifies the main markers of adulthood as accepting responsibility, making independent decisions, and achieving financial independence. Self-efficacy and self-regulation skills underpin the processes for working towards and achieving these markers of adulthood. However, for emerging adults with LTPC, living with family, while sometimes necessary, can delay progress toward these markers. Navigating emerging adulthood alongside the demands of self-management adds complexity, potentially contributing to those increased feelings of instability which in turn, can negatively affect the ability to self-manage their LTPC. The broader economic context in Ireland, not only impacts the immediate living arrangements of emerging adults living with LTPC but also undermines the developmental opportunities typically afforded during emerging adulthood, such as autonomy and self-sufficiency.

Autonomy should always be a central consideration for emerging adults living with LTPC, both in healthcare systems and especially in government policy and funding. Aligning and addressing the developmental goals of emerging adulthood and the challenges faced by this group can support them in navigating both emerging adulthood and the self-management of their LTPC. However, healthcare professionals can only do so much, as the primary responsibility lies with the Irish government. For those who cannot move out of the family home, whether it is for financial reasons and/or adequate resources for independent living are unavailable within their communities (Independent Living Movement Ireland, n.d.), it is important to allocate resources towards making their experience of living with family as autonomous as possible. For example, widening access to the free travel scheme (Department of Social Protection, 2024), more supported access to employment (AHEAD, n.d.), or increased access to personal assistants. These types of supports can reduce the need to rely solely on family members for everyday tasks and health management. This can lead to

reduced feelings of instability, fostering greater autonomy for self-management, and improving overall quality of life and long-term outcomes.

5.3.2.2 COVID-19 Pandemic

Global factors can also shape and influence the experience of emerging adulthood (Arnett, 2015). In the emerging adulthood literature students have typically reported higher endorsements of feeling in-between and instability, in comparison to other groups (Crocetti et al., 2015; Kohútová & Kohút, 2024; Nice & Joseph, 2023; Reifman et al., 2007; Zorotovich, 2014). The COVID-19 pandemic seems to have changed some of the experience of emerging adulthood. In contrast to the typical endorsements by students mentioned above, the cross-sectional survey (Chapter Four) students reported lower levels of instability compared to their peers who were employed, unemployed, or looking after the family home. Furthermore, emerging adults living with LTPC who reported being students, reported higher levels of perceived self-management compared to their peers with LTPC who were employed, not employed or looking after the family home.

As discussed in Chapter Four, these findings may be due to the mostly temporary socio-economic and structural conditions resulting from the COVID-19 pandemic. Data collection of the cross-sectional survey occurred between January and December 2022, just as the final lockdown restrictions were being lifted in most European countries, including Ireland and the UK. While all participants reported experiencing negative effects of COVID-19 on their income, mental and physical health, and social lives, students reported being less financially affected but more socially affected.

The balance between maintaining a social life and managing financial uncertainty is known to be a key factor in contributing to the experience of instability during emerging adulthood (Arnett, 2004; 2015). Considering that some of the unique pandemic factors

included, students moving back home (Growing Up in Ireland, 2021b; House of Commons Library, 2021; Preetz et al., 2022), increased financial support (e.g., pandemic unemployment payments), and reduced social pressures due to restrictions and lockdowns, these may have contributed to these findings of lower overall instability in students. These same factors may have also fostered the higher levels of perceived self-management found for emerging adults living with LTPC, as measured by the PMCSMS (Smith et al., 1995). For example, structural changes brought about by lockdowns, such as predictable routines and fewer competing demands on time, could have created an environment that made managing their conditions more feasible. Longitudinal research would be needed to confirm if there are any long-term changes related to the COVID-19 pandemic on the experience emerging adulthood or self-management of LTPC or to confirm if they were temporary.

5.3.3.3 Government and Policy Implications

Many of the risk factors identified in this thesis that contribute to increased instability and negatively impact self-management among emerging adults living with LTPC, such as housing insecurity, financial challenges, and education and employment disparities, lie beyond the direct control of healthcare professionals or the emerging adults themselves. While healthcare professionals cannot provide housing or reduce living costs, awareness of how these socio-economic issues can increase feelings of instability and negatively self-management is important. Empathetic, developmentally appropriate care can motivate emerging adults living with LTPC to seek solutions and improve self-management within the constraints they face.

A multidisciplinary approach involving doctors, nurses, occupational therapists, and school-based professionals such as counsellors or occupational therapists, could have the ability to provide extra support to help young people (from primary school through third-

level education) with disability engage in a more equitable education environment. However, implementing such multidisciplinary approaches requires substantial government investment and supportive policies. Therefore, it is important the findings of this thesis are disseminated in formats accessible to policymakers and governmental departments. For example, disseminating to relevant disability support organisations so they can develop targeted campaigns or policy recommendations aimed at addressing the socio-economic disparities faced by emerging adults with LTPC.

To address the systemic barriers faced by emerging adults with LTPC, the findings of this thesis could inform the development of policies aimed at reducing socio-economic challenges, minimising instability, and supporting self-management. Key policy initiatives might include subsidised housing programmes for emerging and young adults living with LTPC, increasing funding and supports for inclusive education and targeted employment initiatives. This type of investment would not only improve quality of life but yield long-term societal benefits such as increased workforce participation, economic contributions and reduced healthcare costs for the state.

5.4 Strengths, Limitations and Future Research

This thesis adopted a multi-study design that utilised a dual focus of self-management theories with Arnett's Theory of Emerging Adulthood to address the overarching research question: do emerging adults with and without LTPC differ in the distinctive features of emerging adulthood, and how do these features influence self-management behaviours among those living with LTPC. By utilising this dual focus approach across all three studies, the findings were framed as both developmentally and contextually relevant. This thesis responded to the lack of comparative research examining emerging adults living with LTPC and their peers without LTPC by conducting two quantitative, comparative studies, thus

addressing this important gap in the literature. Furthermore, it aligned with Arnett's (2015) call for subgroup-specific research by comparing these two groups (LTPC vs. no-LTPC) and their emerging adulthood experiences. Contributing valuable insights into how the developmental stage of emerging adulthood intersects with the self-management of LTPC. Furthermore, it highlights how global and local issues such as COVID-19 and Ireland's housing crisis can further shape both the experience of emerging adulthood and the self-management of LTPC.

While this thesis makes a significant contribution to the literature, it is not without limitations. As highlighted in Chapter Three and Four, caution must be exercised in generalising the findings to all emerging adults living with LTPC. Participants in both studies may not fully represent emerging adults from lower socio-economic backgrounds or those with more severe conditions. In addition, geographically, the number of participants from countries outside of Ireland and the UK in the cross-sectional survey (Chapter Four) were not large enough to analyse cultural or economic differences and future research could look to compare experiences of emerging adults living with LTPC across different cultures.

Both the quantitative, comparative studies were cross-sectional, and the results represent a point in time. Longitudinal research would provide a stronger basis for understanding how emerging adulthood influences self-management over time. For example, the forthcoming data from the Growing Up in Ireland study at age 25 could provide an opportunity to analyse changes across two emerging adulthood time points. This approach could also capture any long-term effects of global and local challenges, such as the COVID-19 pandemic and Ireland's housing crisis. Longitudinal research using a measure such as the Inventory of the Dimensions of Adulthood (IDEA) scale could explore how critical life transitions, such as moving from adolescence into emerging adulthood and then into full adulthood, influence both the five features of emerging adulthood and the self-management

of LTPC. This would offer valuable insights into key turning points or critical junctures, for example, do feelings of instability affect self-management similarly in adolescence or adulthood, or does their impact change over time? Such findings would inform the development of more tailored, developmentally appropriate healthcare interventions.

Future research could also explore condition-specific challenges within the framework of emerging adulthood and how the experience of different LTPC can influence the experience of self-management can influence self-management during this developmental period. Firstly, examining self-management among emerging adults with conditions that have a severe impact on daily life, such as fibromyalgia or endometriosis. Secondly, comparing the self-management experiences of individuals with childhood-onset LTPC to those who acquired or developed their conditions during adolescence or emerging adulthood. Similarly, future studies could compare the experiences of emerging adults living with progressive LTPC to those with non-progressive conditions. Finally, research could also explore how different types of LTPC interact with the five features of emerging adulthood, potentially identifying condition-specific patterns not captured in this thesis. Such findings could also enhance support systems and the development of interventions.

While this thesis incorporates qualitative findings from the systematic review, it did not have a specific qualitative study component. Incorporating interviews or focus groups with emerging adults living with LTPC, could provide rich, in-depth insights into their lived experiences. For example, this thesis demonstrates that emerging adults living with LTPC have difference experiences to their peers without LTPC. Qualitative research would help to understand why these experiences are different, such as identifying the specific factors that increase feelings of instability and negatively impact self-management. Similarly, qualitative research with healthcare professionals could offer valuable context regarding the barriers and opportunities they face in supporting self-management during emerging adulthood.

Examining beliefs and attitudes towards self-management in emerging adults, such as perceptions of patient capability, could bridge the gap between the medical goals of practitioners and the psychosocial goals of emerging adults. This could facilitate the adoption of self-management across all stakeholders.

5.5 Overall Conclusion

This thesis demonstrates how the experience of emerging adulthood can influence the self-management of LTPC, making a significant contribution to understanding the challenges faced by emerging adults living with LTPC during this key developmental stage. By integrating Arnett's Theory of Emerging Adulthood with self-management theories and frameworks, it has identified that the feature of instability is a key risk factor that negatively affects self-management. It found that individual and socio-economic factors such as age, gender, living arrangements, primary economic status and finances can contribute to increased feelings of instability. Furthermore, global and local issues, such as the COVID-19 pandemic and Ireland's housing crisis can further shape and disrupt the experience of emerging adulthood and how emerging adults living with LTPC self-manage. The findings of this thesis emphasise a need for developmentally appropriate healthcare that is mindful of the unique challenges faced by emerging adults living with LTPC during this developmental stage, particularly the role of instability in creating barriers to effective self-management. Furthermore, the findings highlight an urgent need for government investment and policy changes and policy changes to improve access to education, employment, and suitable housing. Such measures would support emerging adults living with LTPC by improving their long-term health, socio-economic outcomes, and overall quality of life.

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Appendices

A: Approval for use of Growing Up in Ireland Wave Four Dataset

12/2/24, 7:42 PM

Dublin City University Mail - Database Request



Orla Mooney <orla.mooney7@mail.dcu.ie>

Database Request

ISSDA <issda@ucd.ie>

21 February 2022 at 16:55

To: Orla Mooney <orla.mooney7@mail.dcu.ie>

Dear Orla,

Thank you for your email and application. You should have received the file via FileSender by now. You will need PKWARE (Windows only) or Keka (Mac) to unzip the file - WinZip will not work. You can download the free PKWARE reader at <https://www.pkware.com/zip-reader> or Keka at <http://www.kekaosx.com/en/>, or 7-zip for Linux at <http://www.7-zip.org/>.

It is case sensitive - please make sure you don't include any spaces before or after the password. Please let me know if you require any assistance. We also have a help section on our webpage with FAQs that may be of assistance to you: <http://www.ucd.ie/issda/help/>.

Kind regards,
Ruby
ISSDA Administrator

Irish Social Science Data Archive (ISSDA),
Leabharlann James Joyce UCD,
UCD, Belfield, Baile Átha Cliath 4,
Éire, D04 R7R0.



Leabharlann UCD
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Tá an ríomhphost seo agus aon chomhad a sheoltar leis faoi rún agus is lena úsáid ag an seolai agus sin amháin é. Is féidir tuilleadh a léamh anseo.

This e-mail and any files transmitted with it are confidential and are intended solely for use by the addressee. [Read more here.](#)

B.1: Questions Related to On-Going Chronic Physical or Mental Health Problem

D2. Do you have any on-going chronic physical or mental health problem, illness or disability?

Yes.....

☐1

No☐2

D3. What is the nature of this problem, illness or disability? Please describe as fully as possible.

[Int: Please record diagnosis, not symptoms of the problem. **If multiple, record most severe problem first**]

D6. Are you hampered in your daily activities by this problem, illness or disability?

Yes, severely☐1

Yes, to some extent☐2

No☐3

B.2: Questions Related to Identity Formation, Age of Identity Exploration

B3. [CARD B3] Please look at this card and tell me, for each item listed, how much confidence do you have in them, is it a great deal, quite a lot, not very much or none at all?

	A great deal	Quite a lot	Not very much	None at all
a. The church.....	☐ 1	☐ 2	☐ 3	☐ 4
b. The education system.....	☐ 1	☐ 2	☐ 3	☐ 4
c. The Gardai/police.....	☐ 1	☐ 2	☐ 3	☐ 4
d. The social welfare system.....	☐ 1	☐ 2	☐ 3	☐ 4
e. The health care system.....	☐ 1	☐ 2	☐ 3	☐ 4
f. Politicians.....	☐ 1	☐ 2	☐ 3	☐ 4
g. The courts system.....	☐ 1	☐ 2	☐ 3	☐ 4
h. The media/press.....	☐ 1	☐ 2	☐ 3	☐ 4

G3.If you were to describe how satisfied you are with your own life in general, how would you rate it on a scale of 0 to 10, 0 meaning you are extremely unsatisfied with your life in general, and 10 meaning that you are extremely satisfied with your life.

0 Extremely unsatisfied	1	2	3	4	5	6	7	8	9	10. Extremely satisfied
☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10

G1. Below is a list of statements dealing with your general feelings about yourself. Please indicate how much you agree with each statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
a. On the whole, I am satisfied with myself.	☐ 1	☐ 2	☐ 3	☐ 4
b. At times, I think I am no good at all.	☐ 1	☐ 2	☐ 3	☐ 4
c. I am able to do things as well as most other people.	☐ 1	☐ 2	☐ 3	☐ 4
d. I certainly feel useless at times.	☐ 1	☐ 2	☐ 3	☐ 4
e. All in all, I am inclined to feel that I am a failure.	☐ 1	☐ 2	☐ 3	☐ 4
f. I take a positive attitude towards myself.	☐ 1	☐ 2	☐ 3	☐ 4

B.3: Questions Related to Navigating Relationships, Age of Identity Exploration

A1. How many friends do you have? [TICK ONE BOX ONLY]

- None.....☐0 Between 6 and 10☐3
 One or two☐1 More than 10.....☐4
 Between 3 and 5☐2

A2. How many of your friends would you describe as CLOSE friends?

- None.....☐1 Some☐2 All☐3

H7. Is there someone in your life you can usually turn to for help and advice?

- Yes☐1 No☐2

H1. Are you in regular contact with your mother (or mother figure)?

- Yes☐1 No.....☐2 Mother deceased☐3 Prefer not to say☐4

H2. If yes, please answer the following questions about how often the following things happen with your mother (or mother figure):

	Never	Seldom	Sometimes	Often	Always
a. You tell her what you're thinking.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. You share your secrets and private feelings with her.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. She shows recognition for the things you do.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d. She shows you that she likes you.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e. You are annoyed or angry with each other.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f. You disagree and quarrel.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g. She disappoints you.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
h. You cannot rely on her.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

H3. Which of the following best describes your relationship with her?

- Biological or adoptive mother who lives here☐1 Foster mother☐4
 Biological or adoptive mother who lives elsewhere☐2 Grandmother☐5
 Stepmother☐3 Someone else.....☐3

H4. Are you in regular contact with your father (or father figure)?

- Yes☐1 No.....☐2 Father deceased☐3 Prefer not to say☐4

H5. If yes, please answer the following questions about how often the following things happen with your father (or father figure):

	Never	Seldom	Sometimes	Often	Always
a. You tell him what you're thinking.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. You share your secrets and private feelings with him.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. He shows recognition for the things you do.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d. He shows you that he likes you.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e. You are annoyed or angry with each other.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f. You disagree and quarrel.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g. He disappoints you.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
h. You cannot rely on him.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

H6. Which of the following best describes your relationship with him?

- Biological or adoptive father who lives here☐1 Foster father☐4
 Biological or adoptive father who lives elsewhere☐2 Grandfather☐5
 Stepfather☐3 Someone else.....☐3

H8. All families have their ups-and-downs. Thinking of a scale from 1 to 10, on average how well would you say that the members of your family get on? '1' means you don't get on at all and '10' means you get on very well.

1	2	3	4	5	6	7	8	9	10.
We don't get on at all									We get on very well
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10

B.4: Questions Related to Life Transitions, Age of Instability

HC1. Do you live on a regular basis at an address other than your Parental Address – this could be your Main Residential Address or a temporary or part-time address such as a student or work address.

Yes, I have another, non parental address ☐ ₁ →Go to HC2
No, I do not have another, non-parental address..... ☐ ₂ →Go to A1

F3. What programme did you take in your final year in school?

Regular (Established) Leaving Certificate ☐ ₁
Leaving Certificate Applied (LCA)..... ☐ ₂
Leaving Certificate Vocational (LCVP)..... ☐ ₃
Something else (please specify)..... ☐ ₄

F8. Did you sit the Leaving Certificate examinations?

Yes, I sat it once. ☐ ₁ Yes, I sat it more than once (i.e. repeated) ☐ ₂ No, didn't sit it ☐ ₃

G2. So, your current status is: _____

B.5: Questions Related to Taking Health Risks, Age of Instability

A5. [CARD A5] How do you see yourself: are you generally a person who is fully prepared to take risks or do you try to avoid taking risks? Please tick on the scale below, where the value 0 means "unwilling to take risks" and 10 means "fully prepared to take risks".

Unwilling to take risks Fully prepared to take risks

☐ 0 ... ☐ 1 ... ☐ 2 ... ☐ 3 ... ☐ 4 ... ☐ 5 ... ☐ 6 ... ☐ 7 ... ☐ 8 ... ☐ 9 ... ☐ 10

B3. Which of the following best describes you?

Only ever tried smoking Used to smoke but
once or twice not now Smoke occasionally Smoke daily

☐ 1 ☐ 2 ☐ 3 ☐ 4

B8. How often, if at all, do you currently use an electronic cigarette?

Daily Less than daily, but Less than weekly, but Less than monthly Not at all
☐ 1 at least once a week at least once a month ☐ 4 ☐ 5

B11. How often do you have a drink containing alcohol?

Never Monthly or less 2 - 4 times per month 2 - 3 times per week 4+ times per week
☐ 0 GO TO B26 ☐ 1 ☐ 2 ☐ 3 ☐ 4

B12. How many units of alcohol do you have on a typical day when you are drinking? (Please use the separate DRINKOGRAM sheet to help you.)

1 or 2 3 or 4 5 or 6 7, 8 or 9 10 or more
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
B13. How often have you had 6 or more units if female, or 8 or more if male, on a single occasion in the last year?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
B14. How often during the last year have you found that you were not able to stop drinking once you had started?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
B15. How often during the last year have you failed to do what was normally expected from you because of your drinking?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
B16. How often during the last year have you needed an alcoholic drink in the morning to get yourself going after a heavy drinking session?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
B17. How often during the last year have you had a feeling of guilt or remorse after drinking?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
B18. How often during the last year have you been unable to remember what happened the night before because you had been drinking?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

	No	Yes, but not in the last year	Yes, during the last year
B19. Have you or somebody else been injured as a result of your drinking?	☐ 1	☐ 2	☐ 3
B20. Has a relative or friend, doctor or other health worker been concerned about your drinking or suggested that you cut down?	☐ 1	☐ 2	☐ 3

B.6: Questions Related to Uncertainty, Age of Instability

K2.[CARD K2] You [and your spouse/partner] may have different sources of income. Concerning your [and your spouse/partner's] total monthly or weekly income, with which degree of ease or difficulty are you able to make ends meet?

With great difficulty

☐1

With difficulty

☐2

With some difficulty

☐3

Fairly easily

☐4

Easily

☐5

Very easily

☐6

D14. Are you covered by a medical card – and so get medical services free of charge?

Yes, full card☐1

Yes, doctor only card☐2

Not covered.....☐3

D15. Are you covered by private medical insurance (not just travel insurance)?

Yes☐1

No.....☐2

D10. Was there any time during the past 12 months when you really needed to consult a GP but did not?

Yes, there was at least one occasion☐1

No, there was no such occasion☐2

D12. Was there any time during the past 12 months when you really needed to consult a medical specialist but did not?

Yes, there was at least one occasion☐1

No, there was no such occasion☐2

B.7: Questions Related to Learn how to be Self-Sufficient, Age of Self-Focus

J1. [CARD J1] Here are some aspirations that people might hope to have achieved by the time they are 30. On a scale of 0 to 10 how important would it be for you to have achieved each of these by the age of 30.

0= Not at all.....10= Very important

	Not at all important										Very impo rtant
a. Have your own home	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
b. Have a good job	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
c. Be in your 'dream job'	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
d. Be in a long-term romantic relationship	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
e. Have a child	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
f. Have a degree	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
g. Spent a year (or more) abroad/travelling	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
h. Own a car	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
i. Be financially secure	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
j. Other (please specify) _____	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10

B.8: Questions Related to Feeling not yet Adult, Age of Feeling In-Between

A2. [CARD A2] On this card there is a statement about how people feel toward their life circumstances. Please use the scale provided to indicate how you feel in terms of the statement.

	Entirely true	True for the most part	Somewhat true	A little true	Not at all true
You consider yourself to be an adult.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

A3. In terms of taking on adult responsibilities would you say you grew up faster, slower or at about the same rate as other people your age

Faster.....	☐ 1	At about the same rate	☐ 2	Slower ...	☐ 3

B.9: Questions Related to Availability of Choice, Age of Possibilities

C4. [CARD C4] How likely do you think it is that you will still be living in Ireland in five years' time?

Very likely/almost certain to be living in Ireland	Probably living in Ireland	Possibly living in Ireland but also possibly living abroad	Very likely/almost certain to be living abroad
☐ 1	☐ 2	☐ 3	☐ 4

B.10: Questions Related to Being Optimistic, Age of Possibilities

B10. [CARD B10] Please rate how concerned you are about the following issues. Please give a score of 0 to 10 for each, where '0' means you are 'Not at all concerned' about the issue and 10 means you are 'Very Concerned'.

		Not at all concerned										Very Concerned
a.	Terrorism	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
b.	Climate change	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
c.	Racism	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
d.	Gender inequality	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
e.	Animal rights	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
f.	Poverty in Ireland	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
g.	Access to decent employment opportunities in Ireland	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
h.	Access to housing in Ireland	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
i.	Global gap between rich and poor countries	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10

C.1: Dublin City University Ethics Approval Letter

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University



Orla Mooney
School of Psychology

Prof. Pamela Gallagher
School of Psychology

Prof. Veronica Lambert
School of Nursing, Psychotherapy and Community Health

30th September 2021

REC Reference: DCUREC/2021/207

Proposal Title: "Are we there yet?" - The Journey through Emerging Adulthood and its Relationship with Self-Management of a Long-Term Condition

Applicant(s): Orla Mooney, Prof. Pamela Gallagher, Prof. Veronica Lambert

Dear Colleagues,

Thank you for your application to DCU Research Ethics Committee (REC). Further to expedited review, DCU REC are pleased to issue approval for this research proposal.

DCU REC's consideration of all ethics applications are dependent upon the information supplied by the researcher. This information is expected to be truthful and accurate. Researchers are responsible for ensuring that their research is carried out in accordance with the information provided in their ethics application.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

A handwritten signature in dark ink, appearing to read 'Dr. Melrona Kirrane'.

Dr. Melrona Kirrane
Chairperson
DCU Research Ethics Committee



Taighde & Nuálaíocht Tacalocht
Ollscoil Chathair Bhaile Átha Cliath,
Baile Átha Cliath, Éire

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C.2: Approval From Dublin City University's Data Protection Unit

8/19/24, 5:02 PM

Dublin City University Mail - Are We There Yet?



Orla Mooney <orla.mooney7@mail.dcu.ie>

Are We There Yet?

Geraldine Healy <geraldine.healy@dcu.ie>

6 September 2021 at 13:02

To: Orla Mooney <orla.mooney7@mail.dcu.ie>, veronica.lambert@dcu.ie

Dear Orla,
please find enclosed an updated version of the Screening Questionnaire that you submitted to the DPU last week.
I hope that you will be pleased to learn that you have DPU approval to proceed onto the next stage of your research.

With kind regards
Geraldine

—

Geraldine Healy

Comhordaitheoir Cosanta Sonraí | An tAonad um Chosaint Sonraí | Oifig an Phríomhoifigigh Oibríochtaí | Ollscoil
Chathair Baile Átha Cliath

Data Protection Co-ordinator | Data Protection Unit | Office of the Chief Operations Officer | Dublin City University

geraldine.healy@dcu.ie | + 353 1 700 7628

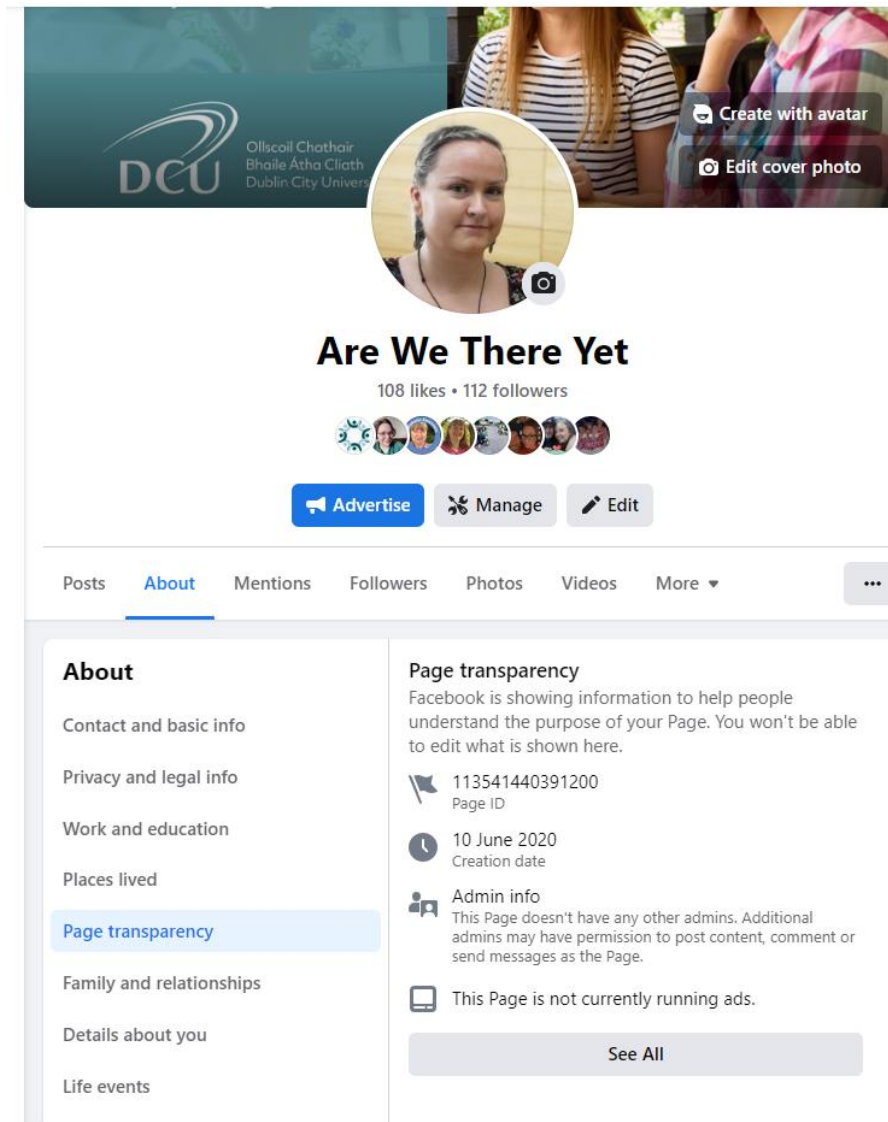
Seomra A143 | Foirgneamh Choláiste Albert | Campas Ghlas Naíon DCU | BAC 9 | D09 V209
Room A143 | Albert College Extension | DCU Glasnevin Campus | Dublin 9 | D09 V209



Links to University Webpages

[Office of the Chief Operations Officer](#) | [Data Protection](#)

D.1: Facebook Page for the Study, Called “Are We There Yet”



The screenshot shows a Facebook page for a study titled "Are We There Yet". The page header features a cover photo with the DCU logo and the text "Ollscoil Chathair Bhaile Átha Cliath Dublin City University". The profile picture is a circular photo of a woman. The page name "Are We There Yet" is prominently displayed, followed by "108 likes • 112 followers". Below this is a row of seven small profile pictures of other users. Action buttons for "Advertise", "Manage", and "Edit" are visible. The "About" tab is selected, showing a list of categories on the left and detailed page information on the right.

Are We There Yet
108 likes • 112 followers

[Advertise](#) [Manage](#) [Edit](#)

[Posts](#) [About](#) [Mentions](#) [Followers](#) [Photos](#) [Videos](#) [More](#)

About

- Contact and basic info
- Privacy and legal info
- Work and education
- Places lived
- Page transparency**
- Family and relationships
- Details about you
- Life events

Page transparency
Facebook is showing information to help people understand the purpose of your Page. You won't be able to edit what is shown here.

- 113541440391200
Page ID
- 10 June 2020
Creation date
- Admin info**
This Page doesn't have any other admins. Additional admins may have permission to post content, comment or send messages as the Page.
- This Page is not currently running ads.

[See All](#)

D.2: Recruitment Flyer and a Social Media Post

The image shows a Facebook post interface. On the left is a large flyer titled "Are We There Yet? We are looking for people who are:". The flyer lists criteria for participants: 18 to 25 years old, living with or without long-term physical conditions, and having 15 minutes to spare for an anonymous online survey in English. It includes the DCU logo and a QR code. On the right is the Facebook post content, which repeats the survey information and includes a link to the survey. Below the post are two replies from the author, "Are We There Yet", clarifying the types of conditions and the purpose of the survey.

Are We There Yet?
We are looking for people who are:

- 18 to 25 years old who are living WITH and WITHOUT long-term physical conditions
- Who have 15 minutes to spare to fill in an anonymous online survey in English

We want to understand the experience of being 18 – 25 years old and then what it is like to have a long-term physical condition in comparison to your peers

DCU
Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

Are We There Yet
4 January 2022

Hi Everyone 🙋 I need your help! If you are 18 - 25 (or you know anyone this age) and who would have 15 minutes to spare, can you please fill in and/or share my project link
<https://dcupsychology.fra1.qualtrics.com/.../SV...>
You do not need to live in Ireland but the survey is in English 🇬🇧 Thanks! Share, Share Share

17 likes, 12 comments, 23 shares

Like Comment Share

Most relevant

Author
Are We There Yet
We need people living with conditions (e.g. epilepsy, diabetes, asthma, MS, chronic pain, fibromyalgia, arthritis, heart conditions, CF, neurological conditions, IBD, and any other physical condition)
2 y Like Reply

Author
Are We There Yet
We also need people without conditions so that we can look at comparisons of how people experience the time of 18-25 years
2 y Like Reply

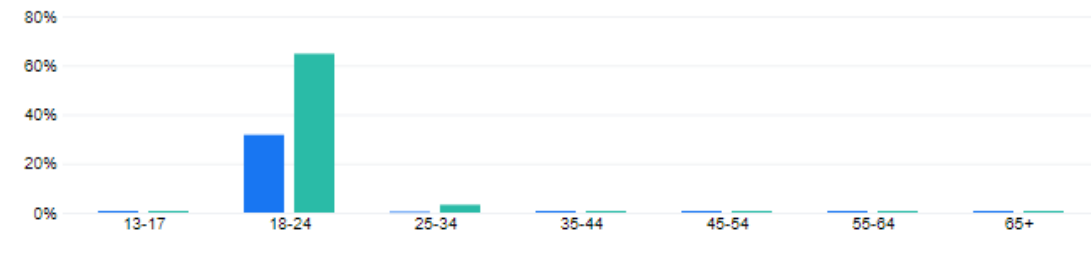
D.3: Facebook Advertising Sample Audience

Audience

This ad reached 228 people in your audience.

People Placements Locations

32.1% Women 67.9% Men



Audience details

Location – Living in

United Kingdom: England; Wales; Scotland; Northern Ireland and Ireland

Age

18-25

Edit Audience

D.4: Twitter Banner

Orla (PhD Candidate)
13.4K posts

Edit profile

Orla (PhD Candidate)
@OrlaNiMhaoinigh

PhD in Health Psychology (DCU), Adult Educator, living with Chronic Pain (CRPS).
From Ballymun to Castlereagh.

Born January 3, 1978 Joined March 2016

936 Following 959 Followers

Orla (PhD Candidate) @OrlaNiMhaoinigh · Jan 25, 2022

Twitter I need your help! If you are 18 - 25 (or know anyone this age), have 15 minutes to spare, can you please fill in &/or share my project link bit.ly/DCUPsychology
You do not need to live in Ireland but the survey is in English 🙏 Thanks
[#AcademicTwitter](#) [#AcademicChatter](#)

3 2

D.5: Recruitment Flyer for Organisations

Are We There Yet?
We are looking for people
who are:

- 18 to 25 years old
- Who have 15 minutes to spare to
fill in an anonymous online survey



Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University



D.6: Sample of Email and List of Organisations

12/3/24, 11:57 AM

Dublin City University Mail - Research request



Orla Mooney <orla.mooney7@mail.dcu.ie>

Research request

3 messages

Orla Mooney <orla.mooney7@mail.dcu.ie>
To: info@thriveabetes.ie

14 January 2022 at 08:00

Hello,

I am currently doing my PhD with Dublin City University under the supervision of Prof. Pamela Gallagher and Prof. Veronica Lambert. My research (survey) involves surveying 18 - 25-year-olds (Ireland & UK) who are living with long-term physical conditions (including diabetic conditions) and how they manage their conditions while experiencing the life changes that can happen during this period (e.g. college, first jobs, moving away from home, socialising, adult healthcare). I am also including 18 - 25 without physical conditions so I can compare them as a peer group. When reviewing the available research on managing long-term physical conditions I found that this age group has often been overlooked as a specific group and I feel it is an important period for life transitions and responsibilities, for people living with conditions.

I want to ask if Thriveabetes would be happy to share my recruitment flyer and/or survey link at any time in the coming month or two, depending on your schedule (e.g. sharing a link on social media, website, groups, newsletter etc.). I have attached a copy of the ethics approval from DCU, the information sheet and the flyer. I can also send a download of the survey if needed. The link for the survey is

https://dcuppsychology.fra1.qualtrics.com/jfe/form/SV_0CBdA3Okt1qsWCq

Or it can be re-shared/retweeted from

<https://www.facebook.com/AreWeThereYetResearch/>

<https://twitter.com/OrlaNiMhaoinigh/status/1478382127603490823>

If the research topic doesn't fit the requirements for sharing by the organisation, that is perfectly fine and thank you for considering it.

All support for this research is appreciated & warmest regards,
Orla

—

Orla Mooney

PhD Candidate | School of Psychology, Scoil na Síceolaíochta

Faculty of Science and Health | Dublin City University | Glasnevin Campus | Dublin 9 | Ireland

orla.mooney7@mail.dcu.ie |

Organisations

Irish Heart Foundation

Croí Heart & Stroke (Ireland)

Chest Heart & Stroke Scotland

Cystic Fibrosis Ireland

Diabetes Ireland

Thriveabetes (Ireland)

Diabetes UK

Diabetes NI

Chronic Pain Ireland

Fibromyalgia Ireland CLG (Ireland)

Fibromyalgia Action UK

FFU Scotland CIC

Arthritis Ireland

Arthritis Action (UK)

National Rheumatoid Arthritis Society

CRPS UK

BackCare Charity (UK)

Burning Nights CRPS Support (UK)

The Migraine Trust (UK)

National Axial Spondyloarthritis Society (UK)

Young Epilepsy (UK)

Epilepsy Ireland

Endometriosis Association Ireland

E.1: Study Plain Language Statement

Information Sheet

Study Title: “Are we there yet?” - The Experience of Emerging Adulthood and its Relationship to the Self-Management of a Long-Term Condition

What is this study about?

We are doing this study to find out about the period of emerging adulthood (18-25 years) and living with and managing a diagnosed, long-term medical condition during this time. Emerging adulthood is a period that can have many life transitions for a person, such as, being legally an adult, starting employment, continuing in education, moving away from home and moving to adult healthcare.

*A long-term condition is a condition that has been diagnosed by a medical professional, has lasted 6 months or more and requires some ongoing treatment (e.g. medication, GP visits, therapies).

We would like to survey people aged **18 – 25 years** who are living **with and without a long-term medical condition** so that we can understand “what it means to become an adult” and if there are similarities and/or differences to the experience of emerging adulthood.

Before you decide to take part please read the information below carefully and do not feel under pressure to make a quick decision to take part. You should clearly understand the benefits and risks of this study. You do not have to take part if you chose not to. This is called “informed consent”.

Who is conducting this study?

My name is Orla Mooney and I am a student at Dublin City University. I am currently doing my PhD research under the supervision of Prof. Veronica Lambert and Prof. Pamela Gallagher in the School of Psychology, DCU.

Email: orla.mooney7@mail.dcu.ie

If I decide to take part myself, what will I be asked to do?

You will fill in an online survey that asks questions about what you think being an adult is, what the experience of emerging adulthood is like, some demographical information and if you have a long-term condition, some additional health-related questions. The information

provided by you will be anonymous as no identifying information about participants is being requested.

How long will it take?

It will take between 15 and 25 minutes.

What are my rights if I join the study?

Participation in the study is entirely voluntary and if you agree to participate you have the following rights:

1. As this is an online study, the information collected is anonymised.
2. As participation is completely voluntary, you are free to withdraw from the study at any time for any reason without explanation. However, as the data gathered is anonymous once you submit your response to the survey it will not be possible to change your mind about participation because your data will not be identifiable from other participants.
3. Under the Freedom of Information Act, there is no identifying/personal data kept about you on file.

Data Confidentiality

Questions to gather general information about participants, such as age, gender, county, living arrangements etc. will be asked during the survey but no information that could identify a participant will be collected. Therefore, all information collected during the study will be anonymous, remain strictly confidential and in compliance with GDPR (no personal data collected). Only the research team will have access to the data and both the data and the results are anonymised. The data is being processed for legitimate purposes – see Article 6 and 9 of the General Data Protection Regulations 2016, if you are uncertain you can contact the researcher Orla Mooney or DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie Ph.: 7005118 / 7008257).

What are the benefits?

Although there are no direct benefits from taking part, this study will contribute to understanding what it is like to manage a long-term condition during emerging adulthood (18 – 25 years), inform future healthcare and healthcare professionals on how to tailor supports and add to the overall knowledge of emerging adulthood.

Are there any risks or downsides to taking part?

Risks are not expected from involvement in this study however, in case any of the questions have adversely affected you in any way, please feel free to contact the researcher Ms. Orla Mooney or to consult the following websites:

- Jigsaw <https://www.jigsaw.ie/>
- SpunOut <https://spunout.ie/about>

You can withdraw completely at any time during the survey until you have submitted it.

Is there anything else I need to know?

If you wish to find out the outcomes of the study, you can contact the research team following the completion of the study. If you would like to chat with me with any questions you may have about this research my contact details are:

Email: orla.mooney7@mail.dcu.ie

If participants have concerns about this study and wish to contact an independent person,
please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie

E.2: Informed Consent Online Questions

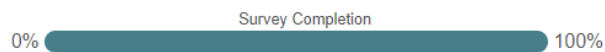
Please answer the following to indicate consent (you must consent to all options to proceed)

I confirm that I am over 18 years of age	Yes / No
I have read the information sheet (or had it read to me)	Yes / No
I understand the information provided	Yes / No
I have been provided with the contact details of the researcher if I have any questions to ask (see contact details above in information sheet)	Yes / No
I am aware that anonymised data will be collected and analysed	Yes / No
I understand that participation is <u>voluntary</u> and I am free to withdraw up to the point of clicking submit	Yes / No
I wish to take part in the <u>study</u> and I consent	Yes / No

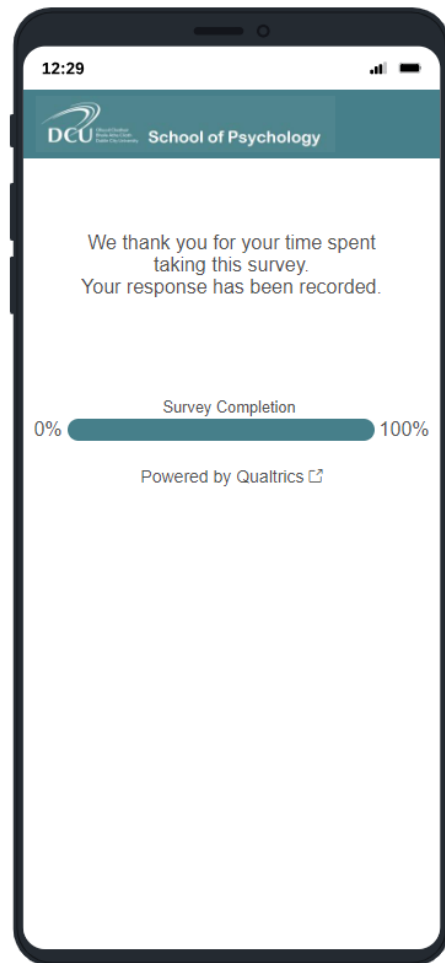
E.3: End of Survey: Thank you for your Time Message



We thank you for your time spent taking this survey.
Your response has been recorded.



Powered by Qualtrics [↗](#)



E.4: Sociodemographic and Health Questions

Demographics

...

Description

In this section you will be asked some questions that help us to better understand the characteristics of our participants

Q1

★ x→

▼  Skip to

End of Survey if I am not between 18-25 years Is Selected

What is your age in years? (You must be between 18 - 25 years to take part)

18 years ▼

Q2

★ x→

What is your gender?

- ☐ Male
- ☐ Female
- ☐ Non-binary
- ☐ Prefer to self-describe
-
- ☐ Prefer not to say

Q3

★ x→

What country do you currently live in?

- ☐ Republic of Ireland
- ☐ Northern Ireland
- ☐ England
- ☐ Scotland
- ☐ Wales
- ☐ Other
-

Q4



How many years have you lived in this country?

Q5



What is your nationality?

- ☐ Irish
- ☐ Northern Irish
- ☐ English
- ☐ Scottish
- ☐ Welsh
- ☐ Other

Q6

★ x→

How would you describe your ethnicity and cultural background?

- ☐ Irish Traveller
 - ☐ White Irish
 - ☐ Any other White background
 - ☐ African
 - ☐ Any other Black background
 - ☐ Chinese
 - ☐ Any other Asian background
 - ☐ Other (including mixed background)
 - ☐ Prefer not to say
-

Q7

★ x→

What are your main living arrangements?

- ☐ I live with my with parents/guardian
- ☐ I live alone in a house/flat
- ☐ I live in a house/flat with my partner only
- ☐ I live in a house/flat with other relatives only
- ☐ I live in a house/flat sharing arrangement with other adults - (at least some not related to me)
- ☐ I live in "digs" or lodgings (in a room in someone else's house possibly with some meals provided)
- ☐ I live in campus accommodation/Barracks
- ☐ Other

Q8

★ x→

What is your relationship status?

- ☐ Single
- ☐ In a long-term relationship
- ☐ Co-habiting
- ☐ Married or civil partnership
- ☐ Separated or divorced
- ☐ Widowed
- ☐ Other
- ☐ Prefer not to say

] Q9

★ x→

Do you have any children?

- ☐ Yes
- ☐ No

Q10



Have you completed your full-time education (including higher/third-level)?

- ☐ Yes
- ☐ No

Q11



What is your highest completed level of education?

- ☐ No formal education or training
- ☐ Primary School or equivalent
- ☐ Secondary School - Junior Certificate, GCSE (or equivalent)
- ☐ Secondary School - Leaving Certificate, A-Level (or equivalent)
- ☐ Technical or Vocational (or equivalent)
- ☐ Advance Certificate or Completed Apprenticeship
- ☐ Higher Certificate (or equivalent)
- ☐ Ordinary Bachelors Degree or National Diploma (or equivalent)
- ☐ Honours Bachelors Degree or Professional qualification, or both (or equivalent)
- ☐ Postgraduate Diploma /Degree (or equivalent)
- ☐ Doctorate (PhD) or higher (or equivalent)
- ☐ Other
- ☐ Prefer not to say

Q12



How would you describe your primary status?

- ☐ Student/pupil
- ☐ Working for payment/profit (employee/self-employed)
- ☐ Looking for first regular job
- ☐ Unemployed (available for work)
- ☐ Looking after family/home
- ☐ Unable to work due to permanent sickness/disability
- ☐ Other

Instruction

For each of the following living costs can you please indicate if you (and/or partner) pay for them personally and whether your parents/guardian pay for them - in full or part (you can click for both you and your parent if you both pay towards a cost)?

Q13

★

Rent/campus accommodation fees/mortgage

- ☐ Not applicable to me
 - ☐ I (and/or partner) pay for this cost in full
 - ☐ My parents/guardian pay for this cost in full
 - ☐ I (and/or partner) share costs with parents/guardian towards this cost
-

Q14

★

Utility bills

- ☐ Not applicable to me
- ☐ I (and/or partner) pay for this cost in full
- ☐ My parents/guardian pay for this cost in full
- ☐ I (and/or partner) share costs with parents/guardian towards this cost

Q15



Food

- ☐ Not applicable to me
 - ☐ I (and/or partner) pay for this cost in full
 - ☐ My parents/guardian pay for this cost in full
 - ☐ I (and/or partner) share costs with parents/guardian towards this cost
-

Q16



Transportation

- ☐ Not applicable to me
 - ☐ I (and/or partner) pay for this cost in full
 - ☐ My parents/guardian pay for this cost in full
 - ☐ I (and/or partner) share costs with parents/guardian towards this cost
-

Q17



Communication (phone, internet etc)

- ☐ Not applicable to me
- ☐ I (and/or partner) pay for this cost in full
- ☐ My parents/guardian pay for this cost in full
- ☐ I (and/or partner) share costs with parents/guardian towards this cost

Q18



Health costs (e.g. medical insurance, doctors etc)

- ☐ Not applicable to me
 - ☐ I (and/or partner) pay for this cost in full
 - ☐ My parents/guardian pay for this cost in full
 - ☐ I (and/or partner) share costs with parents/guardian towards this cost
-

Q19



Childcare

- ☐ Not applicable to me
 - ☐ I (and/or partner) pay for this cost in full
 - ☐ My parents/guardian pay for this cost in full
 - ☐ I (and/or partner) share costs with parents/guardian towards this cost
-

Q20



Debt payment (excluding mortgage)

- ☐ Not applicable to me
- ☐ I (and/or partner) pay for this cost in full
- ☐ My parents/guardian pay for this cost in full
- ☐ I (and/or partner) share costs with parents/guardian towards this cost

Q21



Social and leisure activities

- ☐ Not applicable to me
 - ☐ I (and/or partner) pay for this cost in full
 - ☐ My parents/guardian pay for this cost in full
 - ☐ I (and/or partner) share costs with parents/guardian towards this cost
-

Q22



Other regular living costs (e.g. clothing, toiletries, tobacco, pets)

- ☐ Not applicable to me
 - ☐ I (and/or partner) pay for this cost in full
 - ☐ My parents/guardian pay for this cost in full
 - ☐ I (and/or partner) share costs with parents/guardian towards this cost
-

Q23



Concerning your total income, with which degree of ease or difficulty are you able to make ends meet?

With great difficulty	With difficulty	With some difficulty	Fairly easily	Easily	Very easily
☐	☐	☐	☐	☐	☐

Q24

★ x→

How often do you smoke cigarettes?

- ☐ I don't smoke
 - ☐ Tried smoking once or twice
 - ☐ Used to smoke but don't now
 - ☐ Smoke occasionally
 - ☐ Smoke daily
-

Q25

★ x→

How often do you vape?

- ☐ I don't vape
 - ☐ Tried vaping once or twice
 - ☐ Used to vape but don't now
 - ☐ Vape occasionally
 - ☐ Vape daily
-

Q26

★ x→

How often do you drink alcohol?

- ☐ I don't drink alcohol
 - ☐ Monthly or less
 - ☐ 2 - 4 times per month
 - ☐ 2 - 3 times per week
 - ☐ 4+ times per week
-

Q27

★ x→

How often do you take drugs that have not been prescribed to you by a doctor (excluding nicotine and alcohol)?

- ☐ I don't take drugs
- ☐ Monthly or less
- ☐ 2 - 4 times per month
- ☐ 2 - 3 times per week
- ☐ 4+ times per week

Q28



How would you describe your physical health in general?

Excellent Very Good Good Fair Poor

☐ ☐ ☐ ☐ ☐

Q29



How would you describe your mental health in general?

Excellent Very Good Good Fair Poor

☐ ☐ ☐ ☐ ☐

Q30



Please confirm your opinion on these statements (0 being very much negatively impacted and 10 being very much positively impacted). Covid has impacted my...



Reminder



A long-term physical condition is a condition that has been diagnosed by a medical professional, has lasted 6 months or more and requires some ongoing treatment (e.g. medication, GP visits, therapies).

Examples of long-term physical conditions include: diabetes, cardiovascular (e.g. hypertension), chronic respiratory (e.g. asthma), chronic neurological (e.g. multiple sclerosis, epilepsy), chronic pain (e.g. arthritis, fibromyalgia), other long-term conditions (e.g. chronic fatigue syndrome, irritable bowel syndrome) etc.

Q31



▼  Skip to

End of Block if No Is Selected

Do you have a long-term physical condition/s that has been diagnosed by a medical professional?

☐ Yes

☐ No

Q32



▼  Skip to

End of Block if No Is Selected

Does your long-term physical condition/s require ongoing management and support (e.g. medication, injections, procedures, physio, diet, therapy etc.)?

☐ Yes

☐ No

Q33

★ x→

Please indicate whether you have a cardiovascular long-term physical condition (if yes, please specify your diagnosis)?

☐ Yes

☐ No

Q34

★ x→

Please indicate whether you have diabetes as a long-term physical condition (if yes, please specify your diagnosis)?

☐ Yes

☐ No

Q35

★ x→

Please indicate whether you have a chronic respiratory long-term physical condition (if yes, please specify your diagnosis)?

☐ Yes

☐ No

Q36

★ x→

Please indicate whether you have a chronic neurological long-term physical condition (if yes, please specify your diagnosis)?

☐ Yes

☐ No

Q37

★ x→

Please indicate whether you have a chronic pain related long-term physical condition (if yes, please specify your diagnosis)?

☐ Yes

☐ No

Q38

★ x→

Please indicate whether you have a long-term physical condition not specified above (if yes, please specify your diagnosis)?

☐ Yes

☐ No

Q39



If you have more than one long-term physical condition, please indicate which long-term physical condition has the most impact on your life (if only one please write not applicable or n/a)?

+ Add page break

Q40



At what age were you diagnosed with the long-term physical condition that has the most impact on your life?

Q41



Was this diagnosis at least 12 months ago or longer?

☐ Yes

☐ No

Q42



As a result of this long-term physical condition, do you have any difficulty in doing any of the following?

	Never	Sometimes	Often	Always
Learning, remembering or concentrating	☐	☐	☐	☐
Dressing, bathing or getting around inside home	☐	☐	☐	☐
Going outside the home alone to shop or visit places (e.g. GP)	☐	☐	☐	☐
Working at a job, business or attending college	☐	☐	☐	☐
Participating in other activities, for example, leisure or using transport	☐	☐	☐	☐

Q43

★ x→

For managing your healthcare and treatment do you mainly have?

- ☐ Free healthcare (e.g. medical card -Ireland, NHS - UK)
- ☐ A GP visit card
- ☐ Health insurance on someone else's policy (e.g. parents)
- ☐ Own private health insurance policy
- ☐ Do not have free healthcare nor health insurance
- ☐ Other

Q44

💡 ★ x→

Concerning your healthcare needs (e.g. medical appointments, therapies and complementary therapies)?, with which degree of difficulty or ease are you able to afford them?

With great difficulty	With difficulty	With some difficulty	Fairly easily	Easily	Very easily
☐	☐	☐	☐	☐	☐

E.5: Communication With Physicians Questionnaire

Instruction

When you visit your doctor, how often do you do the following:

Q45

Prepare a list of questions for your doctor

Never Almost never Sometimes Fairly often Very often Always

☐ ☐ ☐ ☐ ☐ ☐

Q46

Ask questions about the things you want to know and things you don't understand about your treatment

Never Almost never Sometimes Fairly often Very often Always

☐ ☐ ☐ ☐ ☐ ☐

Q47

Discuss any personal problems that may be related to your illness

Never Almost never Sometimes Fairly often Very often Always

☐ ☐ ☐ ☐ ☐ ☐

E.6: Perceived Medical Condition Self-Management Scale

Instruction

Thinking about your long-term physical condition (the one that affects you the most), please choose the answer that most represents you

Q48

It is difficult for me to find effective solutions for problems with managing my condition?

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
☐	☐	☐	☐	☐

Q49

I find my efforts to change things I don't like about my condition are ineffective?

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
☐	☐	☐	☐	☐

Q50



I handle myself well with respect to my condition?

Strongly disagree Somewhat disagree Neither agree nor disagree Somewhat agree Strongly agree

☐ ☐ ☐ ☐ ☐

Q51



I succeed in the projects I undertake to manage my condition?

Strongly disagree Somewhat disagree Neither agree nor disagree Somewhat agree Strongly agree

☐ ☐ ☐ ☐ ☐

Q52



I am able to manage things related to my condition as well as most other people?

Strongly disagree Somewhat disagree Neither agree nor disagree Somewhat agree Strongly agree

☐ ☐ ☐ ☐ ☐

Q53

Typically, my plans for managing my condition don't work out well?

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
☐	☐	☐	☐	☐

Q54

No matter how hard I try, managing my condition doesn't turn out the way I would like?

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
☐	☐	☐	☐	☐

Q55

I'm generally able to accomplish my goals with respect to my condition?

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
☐	☐	☐	☐	☐

E.7: Inventory of the Dimensions of Emerging Adulthood

Becoming an Adult



Instruction

...

First, please think about this time in your life. By "time in your life," we are referring to the present time, plus the last few years that have gone by, and the next few years to come, as you see them. In short, you should think about a roughly five-year period, with the present time right in the middle.

For each phrase shown below, please click in one of the columns to indicate the degree to which you agree or disagree that the phrase describes this time in your life. For example, if you "Somewhat Agree" that this is a "time of exploration," then on the same line as the phrase, you would click in the column headed by "Somewhat Agree".

Q56



Is this period of your life a...

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
time of many possibilities?	☐	☐	☐	☐
time of exploration?	☐	☐	☐	☐
time of confusion?	☐	☐	☐	☐
time of experimentation?	☐	☐	☐	☐
time of personal freedom?	☐	☐	☐	☐
time of feeling restricted?	☐	☐	☐	☐
time of responsibility for yourself?	☐	☐	☐	☐
time of feeling stressed out?	☐	☐	☐	☐
time of instability?	☐	☐	☐	☐
time of optimism?	☐	☐	☐	☐

time of high pressure?	☐	☐	☐	☐
time of finding out who you are?	☐	☐	☐	☐
time of settling down?	☐	☐	☐	☐
time of responsibility for others?	☐	☐	☐	☐
time of independence?	☐	☐	☐	☐
time of open choices?	☐	☐	☐	☐
time of unpredictability?	☐	☐	☐	☐
time of commitments to others?	☐	☐	☐	☐
time of self-sufficiency?	☐	☐	☐	☐
time of many worries?	☐	☐	☐	☐
time of trying out new things?	☐	☐	☐	☐
time of focusing on yourself?	☐	☐	☐	☐
time of separating from parents?	☐	☐	☐	☐
time of defining yourself?	☐	☐	☐	☐
time of planning for the future?	☐	☐	☐	☐
time of seeking a sense of meaning?	☐	☐	☐	☐
time of deciding your own beliefs and values?	☐	☐	☐	☐
time of learning to think for yourself?	☐	☐	☐	☐
time of feeling an adult in some ways but not others?	☐	☐	☐	☐
time of gradually becoming an adult?	☐	☐	☐	☐
time of being not sure if you have reached full adulthood?	☐	☐	☐	☐

E.8: The Identity Stage Resolution Index

Q57

Please use the scale provided to indicate how you feel in terms of these statements.

Q58



You consider yourself to be an adult

Entirely True

☐

True for the most part

☐

Somewhat true

☐

A little true

☐

Not at all true

☐

Q59



You feel you have matured fully

Entirely True

☐

True for the most part

☐

Somewhat true

☐

A little true

☐

Not at all true

☐

Q60



You feel you are respected by others as an adult

Entirely True

☐

True for the most part

☐

Somewhat true

☐

A little true

☐

Not at all true

☐

Q61



You feel you have found your niche in life

Entirely True

☐

True for the most part

☐

Somewhat true

☐

A little true

☐

Not at all true

☐

Q62



You feel you have settled on a lifestyle that you are satisfied with for the rest of your life

Entirely True

☐

True for the most part

☐

Somewhat true

☐

A little true

☐

Not at all true

☐

Q63



You feel you have found a community in which to live for the rest of your life

Entirely True

☐

True for the most part

☐

Somewhat true

☐

A little true

☐

Not at all true

☐

E.9: Taking on Adult Responsibilities Question

Q64

✱

In terms of taking on adult responsibilities, would you say you grew up faster, slower or at about the same rate as other people your age?

Faster

☐

At about the same rate

☐

Slower

☐

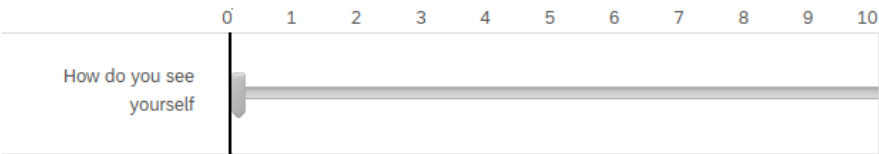
E.10: Risk-Taking Question

Q65

★ ...

Are you generally a person who is fully prepared to take risks or do you try to avoid taking risks?

0 means “unwilling to take risks” and 10 means “fully prepared to take risks”



E.11: The Multidimensional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support

Instruction

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Q66



There is a special person who is around when I am in need.

Very strongly
disagree

☐

Strongly
disagree

☐

Mildly disagree

☐

Neutral

☐

Mildly agree

☐

Strongly agree

☐

Very strongly
agree

☐

Q67



There is a special person with whom I can share joys and sorrows.

Very strongly
disagree

☐

Strongly
disagree

☐

Mildly disagree

☐

Neutral

☐

Mildly agree

☐

Strongly agree

☐

Very strongly
agree

☐

Q68



My family really tries to help me.

Very strongly
disagree

☐

Strongly
disagree

☐

Mildly disagree

☐

Neutral

☐

Mildly agree

☐

Strongly agree

☐

Very strongly
agree

☐

Q69



I get the emotional help & support I need from my family.

Very strongly
disagree

☐

Strongly
disagree

☐

Mildly disagree

☐

Neutral

☐

Mildly agree

☐

Strongly agree

☐

Very strongly
agree

☐

Q70



I have a special person who is a real source of comfort to me.

Very strongly
disagree

☐

Strongly
disagree

☐

Mildly disagree

☐

Neutral

☐

Mildly agree

☐

Strongly agree

☐

Very strongly
agree

☐

Q71



My friends really try to help me.

Very strongly
disagree
☐

Strongly
disagree
☐

Mildly disagree
☐

Neutral
☐

Mildly agree
☐

Strongly agree
☐

Very strongly
agree
☐

Q72



I can count on my friends when things go wrong.

Very strongly
disagree
☐

Strongly
disagree
☐

Mildly disagree
☐

Neutral
☐

Mildly agree
☐

Strongly agree
☐

Very strongly
agree
☐

Q73



I can talk about my problems with my family.

Very strongly
disagree
☐

Strongly
disagree
☐

Mildly disagree
☐

Neutral
☐

Mildly agree
☐

Strongly agree
☐

Very strongly
agree
☐

Q74



I have friends with whom I can share my joys and sorrows.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
☐	☐	☐	☐	☐	☐	☐

[+ Add page break](#)

Q75



There is a special person in my life who cares about my feelings.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
☐	☐	☐	☐	☐	☐	☐

Q76



My family is willing to help me make decisions.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
☐	☐	☐	☐	☐	☐	☐

Q77



I can talk about my problems with my friends.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
☐	☐	☐	☐	☐	☐	☐

E.12: Short-Form Self-Regulation Questionnaire

Short Form Self-Regulation Questionnaire

Instruction

Please answer the following questions by clicking the response that best describes how you are. Remember, there are no right or wrong answers.

Q78



I usually keep track of my progress towards my goals.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q79



I have trouble making up my mind about things.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q80



I get easily distracted from my plans.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q81



I don't notice the effects of my actions until it is too late.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q82



I am able to accomplish goals I set for myself.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q83



I put off making decisions.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q84



It's hard for me to notice when I've "had enough" (alcohol, food, sweets).

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q85



If I wanted to change, I am confident that I could do it.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q86



When it comes to deciding about a change, I feel overwhelmed by the choices.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q87



I have trouble following through with things once I've made up my mind to do something.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q88



I don't seem to learn from my mistakes.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q89



I can stick to a plan that's working well.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q90



I usually only have to make a mistake one time in order to learn from it.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q91



I have personal standards, and try to live up to them.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q92



As soon as I see a problem or challenge, I start looking for all possible solutions.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q93



I have a hard time setting goals for myself.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q94



I have a lot of willpower.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q95



When I'm trying to change something, I pay a lot of attention to how I'm doing.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q96



I have trouble making plans to help me reach my goals.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q97



I am able to resist temptation.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q98



I set goals for myself and keep track of my progress.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q99



Most of the time I don't pay attention to what I'm doing.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q100



I tend to keep doing the same thing, even when it doesn't work.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q101



I can usually find several different possibilities when I want to change something.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q102



Once I have a goal, I can usually plan how to reach it.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q103



If I make a resolution to change something, I pay a lot of attention to how I'm doing.

Strongly disagree

☐

Disagree

☐

Uncertain or Unsure

☐

Agree

☐

Strongly Agree

☐

Q104



Often I don't notice what I'm doing until someone calls it to my attention.

Strongly disagree
☐

Disagree
☐

Uncertain or Unsure
☐

Agree
☐

Strongly Agree
☐

Q105



I usually think before I act.

Strongly disagree
☐

Disagree
☐

Uncertain or Unsure
☐

Agree
☐

Strongly Agree
☐

Q106



I learn from my mistakes.

Strongly disagree
☐

Disagree
☐

Uncertain or Unsure
☐

Agree
☐

Strongly Agree
☐

Q107



I know how I want to be.

Strongly disagree
☐

Disagree
☐

Uncertain or Unsure
☐

Agree
☐

Strongly Agree
☐

Q108



I give up quickly.

Strongly disagree
☐

Disagree
☐

Uncertain or Unsure
☐

Agree
☐

Strongly Agree
☐

Research Dissemination

Publications

Mooney, O., Lambert, V., & Gallagher, P. (2023). Self-Management of Long-Term Physical Conditions During Emerging Adulthood: A Systematic Review.

Emerging Adulthood, 11(6), 1446–1468.

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