

Understanding the experiences of cardiovascular disease management in low income areas

MPhil thesis

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Contents

ABSTRACT.....	5
1. Chapter 1 INTRODUCTION: HEALTH INEQUALITIES.....	6
1.1. Health Inequalities Definition.....	7
1.2. The social roots of Health Inequalities	8
1.3. Lifestyle factors and Health Inequalities	9
1.4. Low Socioeconomic Status as a risk factor	10
1.5. Methodology in Health Inequalities research	11
1.6. Health Inequalities in the UK.....	12
1.6.1. Qualitative research in Health Inequalities in the UK.....	15
1.7. Health Inequalities in the North West Coast.....	17
1.7.1. Liverpoolian context.....	20
1.8. Putting a face to Health Inequalities through biographical disruption theory	21
2. Chapter 2 INTRODUCTION: FOOD INSECURITY	24
2.1. Food Insecurity Definition	25
2.2. Measurement of Food Insecurity.....	27
2.3. Food Insecurity in North America.....	29
2.3.1. USA.....	29
2.3.2. Canada.....	30
2.3.3. Food insecure household characteristics.....	30
2.3.4. Income and Food Insecurity.....	31
2.3.5. Assistance Programmes	31
2.3.6. Chronic health conditions	33
2.3.7. Older adults.....	34
2.3.8. Medication access.....	35
2.4. Food Insecurity in Europe.....	36

2.4.1.	Searches	38
2.4.2.	Food Insecurity in the UK.....	43
2.5.	Food Insecurity and Cardiovascular Diseases.....	47
2.6.	Aims of the study.....	49
3.	Chapter 3 METHODOLOGY	50
3.1.	Justification.....	51
3.2.	Methods of data collection.....	52
3.2.1.	Interviews.....	52
3.2.2.	Demographic information questionnaire	53
3.3.	Sample characteristics	53
3.4.	Recruitment	57
3.4.1.	Struggles and challenges of the recruitment.....	58
3.5.	Data collection	60
3.5.1.	Insights from the data collection	60
3.6.	Data analysis.....	61
3.6.1.	Thematic analysis	62
3.7.	Governance, Ethics and Confidentiality	63
3.8.	Dissemination	64
4.	Chapter 4 RESULTS.....	65
4.1.	Theme 1: Chronic illness as a disruptive experience.....	67
4.1.1.	Chronic illness narratives: disruption or deterioration?.....	67
4.1.2.	What is happening?	68
4.1.3.	Personal identity	70
4.2.	Theme 2: Struggling for money	72
4.2.1.	I just live	72
4.2.2.	Worry and stress.....	75

4.2.3.	Support from others	75
4.3.	Theme 3: Coping with poor lifestyle.....	76
4.3.1.	I am not healthy	76
4.3.2.	I am not eating healthily	77
4.3.3.	Eating on the edge	78
4.4.	Theme 4: Reflections on current care	80
4.4.1.	Deprived neighbourhoods	80
4.4.2.	Medication usage.....	80
4.4.3.	Inequalities on health	81
5.	Chapter 5 DISCUSSION.....	83
5.1.	Summary of the study findings.....	84
5.1.1.	Disruptive experience or another chapter in their life story?	84
5.1.2.	Economic realities	87
5.1.3.	Healthier living	90
5.1.4.	Placing the findings in context	92
5.2.	Strengths and limitations.....	95
5.3.	Next steps	96
5.4.	Conclusions.....	96
6.	REFERENCES.....	101
7.	APPENDICES	112
	Appendix 1 Flow chart	113
	Appendix 2 Topic guide.....	114
	Appendix 3 Participant Information Sheet	116
	Appendix 4 Participant consent form	119
	Appendix 5 Demographic information questionnaire	120
	Appendix 6 Recruitment advertisement.....	123

Appendix 7 Recruitment field notes	124
Appendix 8 Data collection field notes	131
Appendix 9 Health and Life Sciences Committee on Research Ethics Approval	133
Appendix 10 Summary of the findings.....	134
Appendix 11 Results field notes.....	136

ABSTRACT

Justification: Cardiovascular diseases (CVD) are one of the main causes of death and disability in the UK. This study's principal aim was to produce a thorough picture of everyday reality for people with CVD and other chronic health conditions who live in economically deprived neighbourhoods in Liverpool and are themselves experiencing economic difficulties.

Methodology: this was a qualitative, exploratory study based on in-depth semi-structured qualitative interviews conducted with 14 participants whose cardiovascular health was compromised between July and August 2017. The study sample included 14 people (3 women) ranged from 54 to 76 years of age. Thematic analysis was used for data analysis and the biographical disruption concept was used as theoretical reference to explore the results. Wider health inequalities literature supplemented the individual experiences of chronic illness.

Results: Four main themes emerged from the data: (1) "how illness has affected me and those close to me" (2) "struggling for money", (3) "coping with poor lifestyle", and (4) "reflections on current care". The varied nature of participants' narratives about their chronic illness indicated that the experience of biographical disruption depends on the wide social-economic and cultural factors (macro-context) of the individual.

Discussion: A better understanding of the barriers that interfere with low-income individuals' decision-making process is needed to be able to support people with chronic conditions living in more disadvantaged areas, to self-manage their health and wellbeing more effectively. This study suggests that biographical disruption theory combined with health inequalities evidence enhances the study of experiences of chronic illness management.

1. Chapter 1 INTRODUCTION: HEALTH INEQUALITIES

Chapter 1 content:

This first chapter gives a broad health inequalities definition. In this chapter, a thorough analysis of why low socioeconomic status presents a risk factor for health inequalities is presented at the national and local level. National health inequalities as well as more local inequalities in health are covered. Health inequalities in the UK are not only presented by geographic region, but also by age, gender, and ethnicity. Special focus is given to the North West Coast as this thesis explores the presence of health inequalities among individuals living a low income area in Liverpool (North West Coast).

1.1. Health Inequalities Definition

Health inequalities are defined by the World Health Organization (WHO) as differences in health status or in the distribution of health determinants between different population groups (World Health Organization 2017). In addition to this definition, health inequalities have also been considered “avoidable and unfair” (Whitehead 1992). Health inequalities could be attributed to biological variations, free choice, as well as external environment (Economic and Social Research Council 2017). These determinants may have a great impact on people's risk of getting ill, sickness prevention, or the effectiveness of treatments (Economic and Social Research Council 2017).

The determinants of health were described by Dahlgren and Whitehead in 1991. Their diagram (**Figure 1**) is the most representative illustration of health determinants (NHS Education for Scotland). It depicts the factors that may influence both individual and community wellbeing.

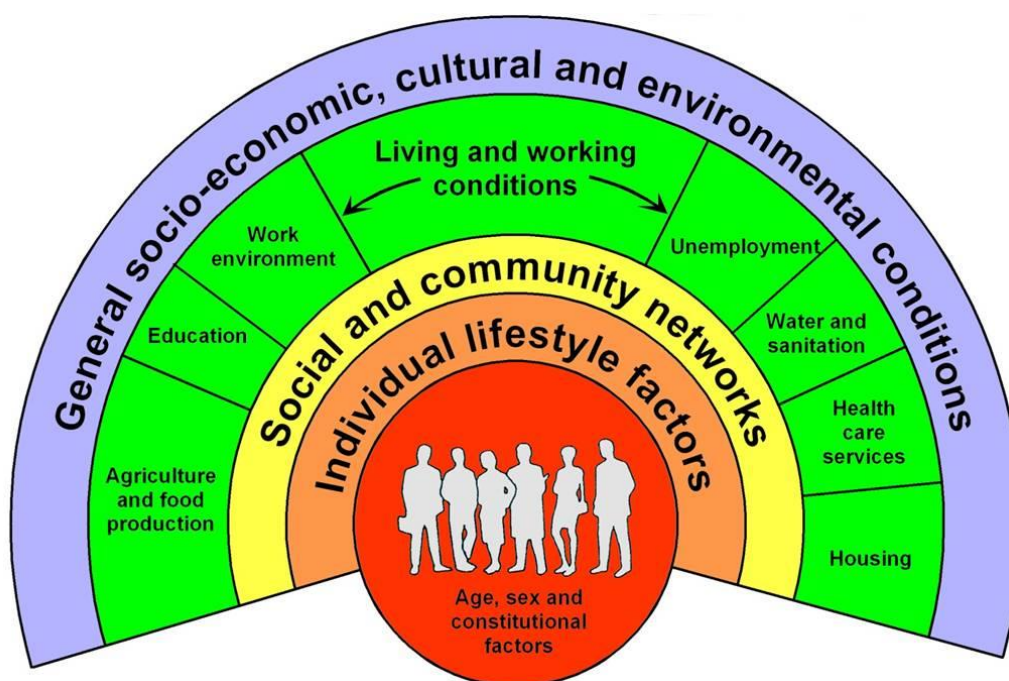


Figure 1. The Dahlgren-Whitehead model. Source: Dahlgren and Whitehead (1991) *Policies and Strategies to Promote Social Equity in Health*. Stockholm, Sweden: Institute for Futures Studies.

According to the authors (Dahlgren and Whitehead 2007), the determinants of health are distributed in layers of influence and they affect an individual's health status. First, the outermost layer contains macroeconomic, cultural and environmental conditions which are widespread among the overall society. The second layer covers the living and working conditions, food supply, and access to essential goods and services. Specifically, that is, water and sanitation, agriculture

and food, access to health (and social care) services, unemployment (and welfare), work conditions, housing (and living environment), education and transport. Social and community networks (third layer) also have an influence into the individual's ability to preserve his/her health. The innermost layer includes personal lifestyle factors such as drug taking, smoking habit, diet and exercise. These layers could be malleable by policy. However, in the centre of the figure, the individual's characteristics (age, sex and constitutional factors) are immovable.

1.2. The social roots of Health Inequalities

The difficulty of addressing the causes of health inequalities was compiled by *Smith, Bambra and Hill (2016)* in the book entitled "*Health Inequalities*". This sets out a broad account of the health inequalities situation within the UK context. Several chapters of this book explained a switch in the health inequalities policy: from individually focused health interventions or "downstream" approach (treatment, care, individual behaviour change) to the core social problems or "upstream" approach (political, economic, social intervention) (Smith, Hill et al. 2016). They stated that health inequalities might be mainly caused by social determinants of health.

The World Health Organisation defines the social determinants of health as "the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries" (World Health Organization 2018).

Link and Phelan acknowledged in 1995 the "fundamental causes" of health inequalities (Link and Phelan 1995): income, wealth, power, knowledge and status. These social causes could lead to worse health (Smith, Bambra et al. 2015). In this way, health inequalities will endure as long as social inequalities are overlooked. Therefore, tackling social causes should be a priority for policies and programmes seeking to diminish health inequalities (Smith, Hill et al. 2016).

Similarly, Professor Michael Marmot in "*Fair Society Healthy Lives, the Marmot Review*" stated that "social and economic differences in health status reflect, and are caused by, social and economic inequalities in society" (Marmot 2010). Also, he identified six domains that cause health

inequalities: early child development, education, employment and working conditions, minimum income for healthy living, healthy and sustainable places to live and work, and taking a social determinants approach to prevention.

The social determinants of health may help us to understand the health inequality gap. A study that gathered evidence from systematic reviews (Bambra, Gibson et al. 2009) aimed to elucidate pertinent interventions to tackle the determinants of health and detect the effects of interventions on health inequalities. As the majority of the interventions intend to reduce health inequalities by modifying individual lifestyle factors such as diet and physical activity, this “umbrella” review was focused on the social determinants of health, that is, the outer two layers of Dahlgren and Whitehead. The study suggested that interventions in the fields of housing and the work environment had a positive impact on health inequalities among disadvantaged population. However, there was limited evidence of the impact on health inequalities for the interventions involving other social determinants of health (e.g. transport, unemployment and welfare). They identified no reviews on interventions involving macroeconomic, cultural and environmental conditions (the outermost layer). The article concluded that the effects of interventions on reducing health inequalities remained unclear and it would be key to exploring how policies alter health in order to extrapolate the outcomes to finally tackle health inequalities.

1.3. Lifestyle factors and Health Inequalities

As mentioned above, new health policies aim to tackle inequality using “upstream” interventions rather than individual lifestyle interventions (Smith, Hill et al. 2016, Williams and Fullagar 2018). Despite this shift, the political agenda in healthcare is altered by hints of neoliberal ideology that stress individualised responsibility in people’s lifestyles. The influence of neoliberalism on health inequalities policies tend to ensure that the individual is the one to blame when the interventions aiming lifestyles do not work (Williams and Fullagar 2018). This emphasis on lifestyle is not only fruitless (e.g. ethnographic studies from (Williams and Gibson 2018)) but also manages to attenuate the underlying social factors that also impact on people’s health and behaviours (Marmot 2010).

There is no evidence that proves the effectiveness of lifestyle-based interventions on narrowing health inequalities (Acheson 1998, Jepson, Harris et al. 2010, Williams and Fullagar 2018).

Jepson's umbrella review did not find evidence of the effectiveness of "downstream" interventions (healthy eating, physical exercise, smoking, alcohol misuse, sexual risk taking and illicit drug use) in reducing health inequalities. It may be due to the fact that different groups respond differently to behavioural change interventions (Jepson, Harris et al. 2010). For instance, those more wealthy are more prone to change their eating habits, give up smoking and increase physical activity than those less wealthy. As a result, health gap the between rich and poor may broaden. *Dorling and Thomas (2009)* pointed out that health policy strategies to improve people's health have not been enough and suggested that "a government that proposes to narrow the inequalities gap by helping people to make 'healthier choices' in their daily lives is likely to be one which is out of touch with the realities of life for the most disadvantaged. Health inequalities in Britain did not occur, increase and persist because people 'chose' not to be healthy and because people 'chose' poverty" (p. 13).

As this thesis explores healthy eating habits and food insecurity within the context of a deprived neighborhood, more emphasis is given to lifestyle interventions targeting healthy eating. *McGill's* systematic review examined whether healthy eating interventions were equally effective for all sections of the population (McGill, Anwar et al. 2015). The review included 36 studies that were classified into two categories: "upstream" or "price" interventions (e.g. applying taxes on unhealthy foods and subsidies for healthier foods) and "downstream" or "person" interventions (e.g. health education and dietary counselling). The article concluded that the "upstream" interventions were more likely to reduce inequalities, while "downstream" interventions appeared most likely to enlarge inequalities.

1.4. Low Socioeconomic Status as a risk factor

In developed countries, health inequalities are more pronounced for those with low socioeconomic status (SES) (Mackenbach, Stirbu et al. 2008). A recent meta-analysis using data from 48 independent cohort studies in more than 1.7 million people, found that low SES was clearly associated with premature mortality (Stringhini, Carmeli et al. 2017). There was decrease in life expectancy by 2 years for men and women with low SES. In comparison, other strong independent predictors of premature mortality were high alcohol intake with 0.5 year's decrease

in life expectancy, obesity with 0.7, hypertension with 1.6, physical inactivity with 2.4, diabetes with 3.9 and current smoking with 4.8 years (Stringhini, Carmeli et al. 2017).

Although most European countries have had a considerable decline in mortality in lower socioeconomic groups and absolute inequalities (i.e. the difference in rates or means between socioeconomic groups) have been reduced over two decades (from 1990 to 2010), this result may not be due to the effect of policies aiming to reduce these health inequalities (Mackenbach, Kulhanova et al. 2016). The findings from *Mackenbach et al.* suggested that the reductions in absolute inequalities in mortality are attributed to improvements in illness prevention and treatment rather than the effect of policies for decreasing health inequalities.

Despite of the effect of low SES on health, the WHO has not established low SES as a risk factor (Stringhini, Carmeli et al. 2017). However, the WHO does aim to reduce premature mortality from non-communicable diseases by 25% by 2025 tackling other risk factors such as the use of alcohol, physical inactivity, tobacco use, high blood pressure, intake of salt, diabetes and obesity.

1.5. Methodology in Health Inequalities research

Smith, Bambra and Hill (2015) contend that quantitative approaches had not captured a good understanding of the causes of the health inequalities. On one hand, quantitative research investigates thoughtfully health inequalities using experimental approaches to describe and monitor differences in health status, and commonly focuses on individualised behaviours of health and disease. In the UK, the routine collection of data on mortality and employment rates had enabled the description of health inequalities.

On the other hand, qualitative approaches search for the broad structures and circumstances that shape the behaviours of individuals. While quantitative research purely describes, qualitative research has the potential to understand extensively the social and economic context. Thus, qualitative approaches have great potential for generating evidence about ways to reduce health inequalities (Smith, Bambra et al. 2015).

1.6. Health Inequalities in the UK

Since the 1840s, the UK has benefited from solid improvements in life expectancy (Wistow, Blackman et al. 2015). In 1948, the UK introduced its National Health Service (NHS) providing universal health service free at the point of care. Although the health service was intended to cover the whole population, inequalities in health in the UK were noticeable and started broadening since the late 1970s. In order to document this issue, the “*Black Report*” was released in 1980 (Townsend, Davidson et al. 1988). The authors of the “*Black Report*” associated the health inequalities with differences in incomes, working conditions, unemployment rates, standards and levels of education, housing conditions, transport facilities, smoking, diet and alcohol consumption. Indeed, the recessions of the 1980s and 1990s revealed that unemployment is inversely associated with morbidity and mortality, rising the likelihoods of poor health (Whitehead 2014). During Margaret Thatcher’s government (1979-1990), attempts to narrow the health gap were not only blocked but also there were significant escalations in socioeconomic and health inequalities during this period (Scott-Samuel, Bambra et al. 2014). The Thatcherism also delivered neoliberal policies in its agenda (Scott-Samuel, Bambra et al. 2014). Health inequalities were prioritised under the Labour government of 1997 to 2010 by increasing social investment, principally in deprived areas (Wistow, Blackman et al. 2015). However, following the 2008-2009 recession, the government applied welfare reform reducing total public spending. These funding constraints might have an effect on the growth of health inequalities by 2012 (Barr, Higginson et al. 2017). The austerity policy also reduced NHS funds, and increased opportunities for the private sector involvement. Both the restricted funds and the introduction of the private sector are suggested to be diminishing the NHS’s capability to tackle health inequalities (Whitehead 2014).

The UK aims to reduce socioeconomic inequalities in mortality nationally, standing out from its European counterparts in terms of collecting data, developing and implementing programmes to tackle inequalities (Bauld, Day et al. 2008, Mackenbach, Kulhanova et al. 2016). As result, over the past few decades, Scotland, England and Wales have accomplished a 20-35% decrease of absolute inequalities in mortality among both men and women (Mackenbach, Kulhanova et al. 2016). A decrease in absolute inequalities was achieved as a result of developing and implementing national programmes to reduce inequalities in health. However, policies and targets could differ between England, Northern Ireland, Scotland, and Wales, as a result of the devolution of healthcare policy to the devolved nations. For instance, Wales focused on improving cancer and

coronary heart disease mortality while Northern Ireland endeavoured to improve life expectancy of the poorest in society (Bauld, Day et al. 2008).

Research on geographical inequalities has focused on disparities in the numbers of premature deaths concluding that geography noticeably matters for health (Smith and Easterlow 2005). National evidence suggests an increase in geographical inequalities in health (Pearce, Mitchell et al. 2015). The data collected by the UK Office for National Statistics over the last decade shows that the North East and the North West are the regions with the lowest life expectancy at age 65 for both males and females from 2006-08 to 2010-12 (Office for National Statistics 2014). Therefore, this geographical perspective demonstrates that people with poorer health status may not be equally distributed across the UK but concentrated in the North East and the North West. From a historical perspective, Dorling and Thomas (2009) spotted geographical inequalities evaluating life expectancy from 1921 to 2006. They measured standardised mortality ratios (SMR), which are the ratio of the observed number of deaths in an area divided by the expected number predicted to occur over a particular time period. In the period 1921 to 1925, the SMR was 2, that is, a person aged under 65 was twice as likely to die if they lived in the poorest areas rather than in the wealthiest. This ratio increased by the end of the 1930s up to almost 3. Since the 1930s, this ratio has been up and down corresponding the rises in mortality inequalities with the Second World War (SMR increased during 1930s to 1953) and the Conservative government of Thatcher (SMR increased during 1979 to 1996). The authors suggested that housing policy (such as social housing, 'right to sell'¹ your house to the council and become a tenant and to facilitate people with poorer health and lower income to live in more wealthy areas) would greatly reduce geographical inequalities (Dorling and Thomas 2009). Similar recommendations regarding housing policies have been made elsewhere (Bambra, Gibson et al. 2009).

Moving beyond the statistical data routinely collected to illustrate the geographical health inequalities, qualitative work of the lived experience of inequality seeks to explore and explain geographical health inequalities through the meaning of place and social identity for those living within a particular context (Bolam, Murphy et al. 2006, Keene and Padilla 2018). Places hold symbolic meanings that may impact on the health of their residents, for example, negative representations of place adversely affect its residents' health indirectly through stress and coping

¹ (as opposed to the previous 'right to buy' policy introduced for social housing tenants during the Thatcher government)

mechanisms (Airey 2003). Lived experiences of the physical environment and subjective relations between the individual and the community using a person-in-context framework have the potential to explain geographical health inequalities (Popay, Thomas et al. 2003, Bolam, Murphy et al. 2006). Lay perceptions on geographical health inequalities in two socially contrasting areas have been explored through different qualitative methodologies: focus group discussions (Davidson, Mitchell et al. 2008), ethnographic (Garthwaite and Bamba 2017) and interviews (Popay, Bennett et al. 2003, Garthwaite and Bamba 2017).

As “place matters for health” (Smith and Easterlow 2005), it is worth introducing the North-South divide within the UK health inequality context. A report entitled “*Due North: Report of the Inquiry on Health Equity for the North*” addressed the disparities in health between the North of England (North West, North East, Yorkshire and Humberside) and the rest of England (Whitehead 2014). It pointed out that these differences had been acknowledged since 1965, establishing the “north-south divide” (Hacking, Muller et al. 2011). In all regions of England, health declines with increasing socioeconomic disadvantage. As a result, wide health inequalities were found between different socio-economic groups across England. Yet the North of England often faces the brunt of these inequalities. For instance, poor neighbourhoods in the North were likely to have worse health than areas with similar levels of deprivation in the rest of England (Whitehead 2014).

From a life-course approach, children’s health determines not only the prevalence of diseases during childhood and adolescence but also predicts health and illness in adulthood (Graham 2009). As a national example, the Millennium Cohort Study reported health inequalities in early stages of life (Petrou, Kupek et al. 2006). Among other outcomes, the study found that children from deprived areas were more likely to have an incomplete set of immunisations in their first year (Institute of Education University of London 2011). In addition, health inequalities have been acknowledged during adulthood in England and Wales but tend to narrow when ageing (Graham 2009).

The gap between male and female life expectancy at birth gradually narrowed between 1991 to 1993 and 2012 to 2014 in England and Wales (Office for National Statistics 2015). In 2012 to 2014, life expectancy for new-born baby boys was highest in Kensington and Chelsea (83.3 years) and lowest in Blackpool (74.7 years). For new-born baby girls, life expectancy was highest in Chiltern (86.7 years) and lowest in Middlesbrough (79.8 years). Thus, women have longer life expectancy than men. However, beyond biological differences, gender inequalities in health subsist in our

society in terms of social roles, status, stereotypes and expected behaviour (Ostrowska 2012). Despite the efforts to narrow the gender gap in UK, gender inequalities such as labour market opportunities, education and earnings still remain in the UK.

Health inequalities within and between ethnicities have been examined in the UK (Darlington-Pollock and Norman 2017). The 2011 Census indicated that England and Wales have become more ethnically diverse (Office for National Statistics 2011). However, the current migration trend is changing with a reduction of immigration (Office for National Statistics 2017), which may be attributable to the new migration policies and the UK's proposed withdrawal from the European Union. Boundaries such as discrimination or language might drive ethnic inequalities in health.

Yet, health inequalities still persist among British individuals (Public Health England 2017). However, government policies such as The English health inequalities strategy proved to decrease geographical inequalities in life expectancy (Barr, Higgerson et al. 2017). The English health inequalities strategy aimed to reduce by at least 10% the gap in life expectancy between the fifth of local authorities with the worst health and deprivation indicators (these targeted areas were located in the 88 most health-deprived areas in England and were named the Spearhead areas) and the population as a whole. It focused on supporting families; engaging communities in tackling deprivation; improving prevention, treatment, and care; and tackling the underlying social determinants of health.

1.6.1. Qualitative research in Health Inequalities in the UK

Qualitative literature in health inequalities is presented along this first chapter in order to complement the quantitative research in the topic. Nonetheless, this section focuses exclusively on qualitative research in the UK context for two main reasons. Firstly, qualitative methodology is used in this study. This brief review will help to place the findings of my study and enrich the discussion within the UK context. Secondly, as mention in the above section [1.5. Methodology in Health Inequalities](#), qualitative research not only allows to embrace the findings but also extends the understanding of the social and economic context in which the health inequalities are taking place (Smith, Hill et al. 2016). Therefore, a qualitative approach to the topic may develop further the why and how of health inequalities assisting in its decrease.

How health inequalities are perceived among all the actors (members of the public, policy-makers, researchers)? What can they do to reduce health inequalities? Qualitative research on

perceptions on health inequalities has showed diverse understandings of this concept (Bolam 2005). In order to address the different perspectives on health inequalities, this section presents evidence from members of the public, policy-makers and researchers on the topic.

Qualitative evidence from members of the public revealed that people living in more disadvantaged socioeconomically situation doubted the notion of health inequalities (Blaxter 1997, Popay, Bennett et al. 2003). These two studies compared the views on health inequality among people living in two socially contrasting areas. *Blaxter (1997)* used a review of ethnographic, interview, and survey data to explore lay ideas about health and the causes of illness. He found that people facing chronic illness or severe disability tended to define their own health as good and those socioeconomically more disadvantaged distrusted the idea of inequality. *Popay et al. (2003)* carried out a large mixed-method study. Using in-depth interviews, they found that people living in a relatively disadvantage area were reluctant to accept the existence of health inequalities, while the quantitative data showed that they pointed out that the area had effects on health. However, more recently, another qualitative study exploring lay perspectives on health inequalities in two socially contrasting areas (Garthwaite and Bambra 2017) identified that people living in the most deprived areas believed that the gap in life expectancy was mostly due to individual lifestyle factors such as smoking habits, alcohol or healthy diet; but also income, housing, and stress were acknowledged to explain the inequality. In addition, those living in the most deprived areas recognized judgement and stigma associated with the place of residence (Garthwaite and Bambra 2017). The perceived stigma may contribute to widening the health gap, so effective interventions should avoid stigmatization (Bolam 2005). To sum up, qualitative literature has found that members of the public may not share the same notion of health inequalities. This differences in perception may be due to the different methodologies used to address the lay perceptions on health inequalities in qualitative studies (Garthwaite and Bambra 2017). Finally, during the time gaps between these three studies: (Blaxter 1997, Popay, Bennett et al. 2003) vs (Garthwaite and Bambra 2017), it is possible that publicity about health inequalities in the media for example, may have influenced perceptions on health inequality by raising awareness among the public of health inequality gap.

A qualitative residential workshop facilitated a discussion among policy advisors on evidence production and health inequalities reduction (Petticrew, Whitehead et al. 2004). In order to take action, this group of policy advisors pointed out the need of holding good quality research; some decisions however were taken without empirical information. Health policy decisions should be

decided more carefully avoiding evidence misuse or erroneous interpretations of the research findings (Cummins and Macintyre 2002). Participants of the workshop (Petticrew, Whitehead et al. 2004) also identified a lack of information on the effectiveness and cost-effectiveness of policies tackling health inequalities.

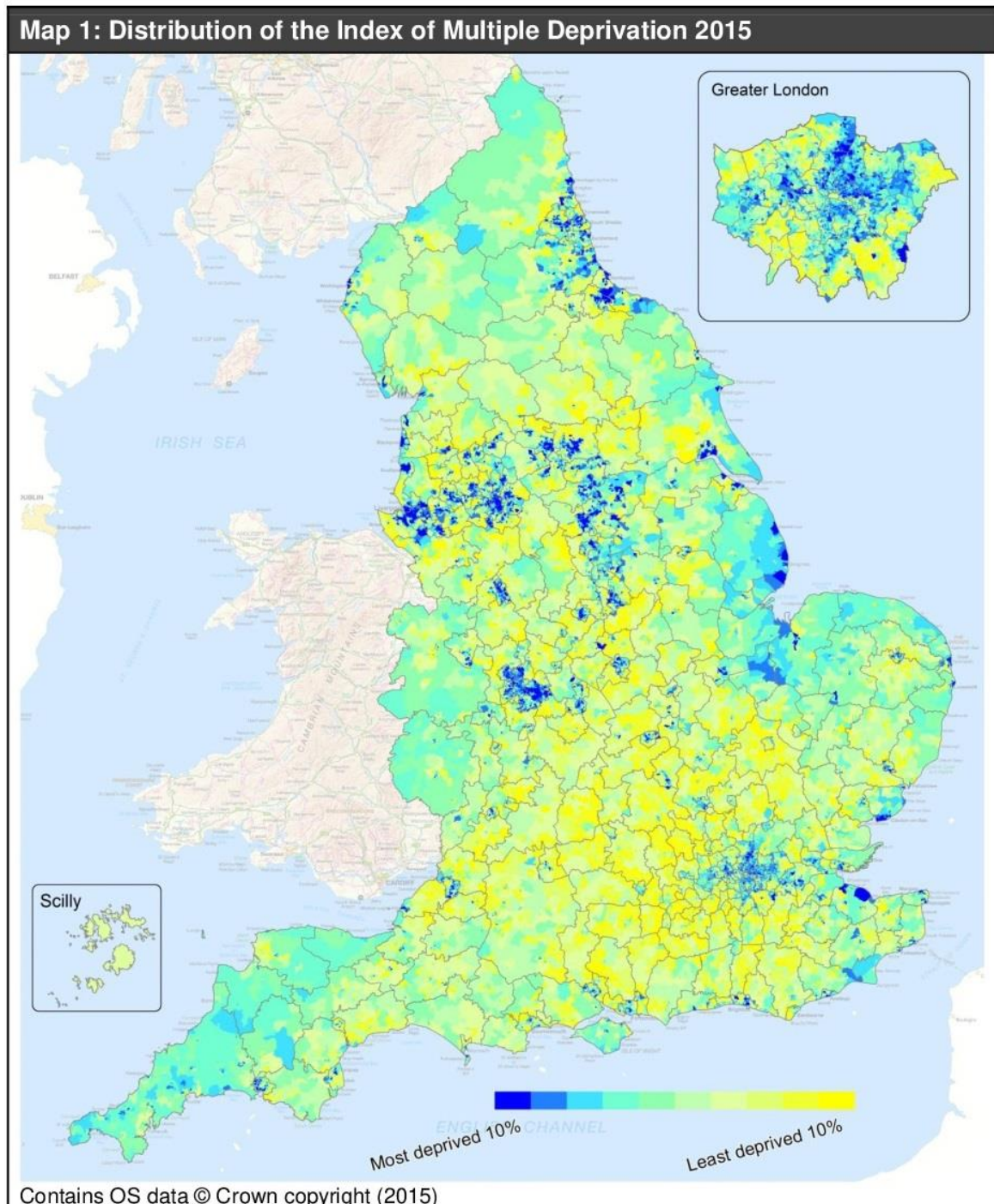
Both policy-makers and researchers play a role in narrowing the health gap; however, interests and expectations may differ between research and policy (Petticrew, Whitehead et al. 2004). Despite of the actions taken to narrow the health gap, evidence shows that health inequalities are still persistent across the UK (Garthwaite, Smith et al. 2016). How to effectively undertake research and what to research on were questions addressed in a discussion on resolutions to health inequalities with 52 UK researchers (Garthwaite, Smith et al. 2016). The participants assigned the persistence of health inequalities to unsuccessful policies, the complex nature of the topic and research funding constraints. In order to reduce the health gap, these UK researchers proposed several ideas such as the use of mixed methods, a more interdisciplinary approach, better understanding on the impact of the policy reform and the improvement of the evaluation of interventions, specially their efficacy and cost-effectiveness (also reported by policy-makers (Petticrew, Whitehead et al. 2004)).

Ultimately, it is considered to be of utmost importance that the perceptions of members of the public, researchers and policy-makers views are taken into account in order to create public health evidence that may help to understand and narrow health inequality across the UK (Petticrew, Whitehead et al. 2004).

1.7. Health Inequalities in the North West Coast

“Due North” (Whitehead 2014) documents the health divide between the North and the rest of England. In this thesis, special emphasis is given to the North, specifically the North West Coast, as the setting of this project is a deprived neighbourhood in the city of Liverpool. The North West Coast is among the most disadvantaged regions of the UK facing high rates of health inequalities (Wood 2006, Whitehead 2014) and deprivation (Department for Communities and Local Government 2015). The English Indices of Deprivation 2015 are based on 37 separate indicators, organised across seven distinct domains of deprivation (Income Deprivation; Employment Deprivation; Health Deprivation and Disability; Education, Skills and Training Deprivation; Crime;

Barriers to Housing and Services; and Living Environment Deprivation) which are combined, using appropriate weights, to calculate the Index of Multiple Deprivation 2015 (Department for Communities and Local Government 2015). *Map 1* illustrates the geographical spread of deprivation across England, which is clearly clustered in the North.



Map 1: Distribution Index of Multiple Deprivation 2015 across England. Published in: “The English Indices of Deprivation 2015” by Department for Communities and Local Government.

Based on the life expectancy key indicator, the statistics for England displayed that the health gap was still large (Office for National Statistics 2017). Life expectancy over the years had improved its numbers in the North West. In 2001-2003, life expectancy at birth in the North West for males was 74.8 years and for females was 79.5 years. The latest figures from 2014-2016 showed that average life expectancy for males was 78.2 years and for females was 81.7 years. However, the difference is still notable when comparing this region with the most recent national numbers (2014-2016): average life expectancy at birth in England was 79.5 years for males and 83.1 for females.

Regarding the mortality rates, the latest statistics from 2014-2016 showed a higher number of avoidable deaths in the North (Office for National Statistics 2018). Of the five local authorities with the highest avoidable mortality rates, three were located in the North West region. The Office for National Statistics defines the avoidable deaths as “as preventable (could avoided by public health interventions in the broadest sense), amenable (could be avoided through good quality healthcare) or both, where each death is counted only once; where a cause of death is both preventable and amenable, all deaths from that cause are counted in both categories when they are presented separately”. Particularly, Liverpool was among one of the 324 local authorities in England with the highest avoidable mortality rates for males in 2014-2016. The mortality rate was 404.5 deaths per 100,000 males in Liverpool, while East Dorset was the lowest-ranked local authority in England with a mortality rate of 170.2 deaths per 100,000 males. Although the Office for National Statistics did not indicate explicitly the numbers of the causes of avoidable deaths, it pointed out that in the Northern regions of England, the death rates for potentially avoidable causes (e.g. certain cancers, respiratory and heart disease) were significantly higher than in the South.

A study, using both qualitative and quantitative methods, explored the lay perceptions of health inequalities in two cities (Salford and Lancaster) in the North West of England (Popay, Bennett et al. 2003). The views of people living in both one area relatively disadvantaged and one area relatively advantaged are compared. In the survey, people living in disadvantaged areas acknowledged geographical health inequalities while the in-depth interviews revealed that people living in disadvantaged areas were reluctant to accept the concept of health inequalities.

Higher unemployment rates, lower wages, higher levels of chronic illness and disability, and poorer working and living environments are some of the socio-economic causes of health

inequalities that are affecting the North West region (NIHR CLAHRC North West Coast 2017). In order to tackle these problems, the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) focuses on the needs of vulnerable people living the North West Coast. The CLAHRC has developed the Health Inequalities Assessment Toolkit (HIAT) to help ensure that all activities or research projects have potential to contribute to reducing health inequalities (National Institute for Health Research 2017). It contains four sections that may be applied in any order. All sections have several questions to address health inequalities through applied health research as well as to check the inclusion of members of the public. Section 1 aims to clarify how health inequalities influence the problem of a specific research question. Section 2 plans to design the research project to have the maximum effect on reducing health inequalities. Section 3 helps to evaluate and monitor the effect of the research project on health inequalities and their causes. Finally, section 4 considers wider effects on health inequalities of the research project.

1.7.1. Liverpoolian context

The historical legacy of heavy industry in the North and its decline led to adverse consequences for economy and health outcomes (high rates of chronic disease and disability). It resulted in concentrations of poverty that have persisted in areas for generations (Whitehead 2014). From the 1980s to the early 2000s, Liverpool registered higher rates of unemployment and worse health outcomes in comparison with the rest of the UK (Brien and Kyprianou 2017). There was an upgrading on these socio-economic measures by 2000s due to public health and education initiatives of the City's Primary Care Trust resulting in improvements in the statistics for cardiovascular disease and obesity rates (Brien and Kyprianou 2017). Since 2010, the welfare reform measures have been jeopardising health and social services, worsening the health gap and affecting greatly those living in disadvantaged areas (Whitehead 2014). The local authority cuts in Liverpool also have affected around 55,000 households (Liverpool City Council 2017). The reform cumulative impact report released in 2017 revealed that Liverpool had the fifth highest financial loss in the country with approximately £157M loss per annum. The report highlights specific impacts of cutting benefits upon certain groups such as long term sick or disabled population, families with children, young people or working age social sector tenants. Finally, this report provided 14 case studies that detailed the consequences of the cumulative impact of the local

authority cuts on the groups mentioned above. For instance, risk of homelessness, under-occupation penalty, frozen credits, struggle to buy food and distress.

Similarly, the Liverpool Mental Health Consortium collected experiences of users, focus groups and an Open Forum discussion on austerity, welfare reform and cuts to services (Liverpool Mental Health Consortium 2017). The report shown that the associations were struggling to maintain basic services and the users confirmed that they had lost services as well as experienced a reduction in income due to welfare reform. They reported its impact on their mental wellbeing: *“feeling more anxious and sad. It has led to me feeling suicidal – I do not want to live with the stress any more”* (p. 13).

The project *“Getting by?”* portrayed the life of 30 working families in Liverpool facing economic adversity during 2014 - 2015 where one or both parents were in low paid employment (Kyprianou 2015). The families disclosed their struggles and challenges managing their budget through weekly spending diaries tracking their income and expenses and regular in-depth interviews. The study showed that the families were struggling for money and they had to cut back on spending by reducing their bills. Some of the families put on the heating on when was absolutely necessary or when having young or sick children. The financial problems impacted on their family life resulting in high levels of stress and worry, family tensions and partners working long hours. These financial pressures also impacted on their children. For instance, the parents were trying to ensure that the children at least had a healthy diet; however, four of the families had to use food banks over the period of the study. Some of the families were receiving benefits and the parents noticed the shame and stigma attached to it, especially the stereotype of the lone female parent having children living off the state.

1.8. Putting a face to Health Inequalities through biographical disruption theory

Michael Bury formulated the concept of biographical disruption in 1982 based from his study of chronic illness (Bury 1982). Biographical disruption has its focus on the illness itself recognizing the changes in life situation occasioned by the disruptive onset of the illness, such as adaptations of the lifestyle and social relationships rearrangements; and the development of a new identity

in relation to the chronic illness. *Bury* (1982) established three elements of biographical disruption. Firstly, this concept explains the way illness interrupts the future plans of an individual and the taken-for-granted features. Consequently, it takes place the rethinking of the person's biography and self-concept. Finally, there is an attempt to normalise the individual's disrupted life by using material and social resources.

Next, *Bury* defined three different responses of adaptation after a chronic illness event, implying biographical disruption (*Bury* 1991). "Coping" refers to the thinking process of how to tolerate the effects of the illness. The term "strategy" is the actions that people take to manage the chronic illness. The term "style" refers to the way that people communicate their chronic condition, which could vary from embracing to denying it.

The concept of biographical disruption has been reviewed and extended (*Williams* 2000). Chronic illness may be biographically anticipated or considered to be inevitable in old age rather than a disruption (*Pound, Gompertz et al.* 1998). Furthermore it may be experienced as biographical continuity or flow as a part of an ongoing life story (*Faircloth, Boylstein et al.* 2004). Illness could also act as confirmation or reinforcement of a pre-existing chronic illness experience (*Carricaburu and Pierret* 1995). Chronic illness could also be experienced as a "death sentence" meaning that life is already over (biographical abruption) (*Locock, Ziebland et al.* 2009). Another linked concept is biographical reinstatement, reflecting the normalisation of symptoms and the integration of the illness experience into normal life (*Sanderson, Calnan et al.* 2011). Finally, biographical work concept has been used to explain symptomless chronic condition, that is, when the illness does not provide bodily signs of sickness and disability (*Felde* 2011).

In this thesis, *Bury's* concept will be used for understanding individual experiences of chronic illness - cardiovascular disease precisely - as life disruption as well as the attitudes and actions that participants acquired following their disruption (micro-context). However, biographical disruption is not sufficient to explain the diversity of experiences of chronic illness as its focus on the illness may mask and reduce the impact of the wide social-economic and cultural factors (macro-context) on the chronic condition of the individual (*Williams* 2000, *Lawton* 2003). *Bury's* original article (1982) on biographical disruption intends to address issues of class in it. *Bury* examined young rheumatoid arthritis sufferers who experienced different levels of biographical disruption depending on their class or at least socio-economic circumstances. In this way, he intended to straddle micro and macro issues through the focus on biography, although it is mostly

focused on the micro context of the participants. As *Bury* (1991) recognises “the need to consider the wider context is important at a time of rapid change in the health field” (p. 543). Hence, it is important to frame the experiences of cardiovascular disease in their broad context by using a person-in-context approach rather than context as independent variable. In this study, I aim therefore to expand his original focus and include a more detailed look at the economic, lifestyle and environmental factors that impinge on the degree of biographical disruption. There is a need to supplement or go beyond the macro context, so for this purpose I will use wider health inequalities literature. To sum up, the individual experience of cardiovascular disease will be explored through biographical disruption taking into account the macro-contextual influence of health inequalities, that is, placing the person in his/her specific context. While biographical disruption will allow me to understand individual experiences, the health inequalities focus will allow me to appreciate how this individual experience is influenced by the context. Hence, the combination of both micro and macro may allow to see the bigger picture.

Moreover, special focus is given to food insecurity in this thesis because of researcher’s interests, and the lack of UK research to place this element in context of ill health and relative poverty. The illness-wellness continuum is affected by food insecurity where the socioeconomical context of the individual definitely plays a role in the equation. Consequently, food insecurity is emphasized in this thesis ([Chapter 2](#) presents an extensive background on food insecurity). Also, a specific objective of this study was to explore the food insecurity dimension among individuals with cardiovascular disease who lived in an economically disadvantaged neighbourhood in Liverpool.

2. Chapter 2 INTRODUCTION: FOOD INSECURITY

Chapter 2 content:

Initially, chapter 2 defines food insecurity and establishes the differences between food security, food insecurity (FI) and hunger. Although food insecurity has increased in developed countries, the big picture of FI in those countries is still unclear. This chapter presents a review of the literature focusing first on the US where the greatest number of studies are carried out regarding food insecurity. Then, the search for European countries was limited to studies published in Spain, Belgium, Italy, Greece, Finland, The Netherlands, Germany and the UK.

Evidence about the measurement of food insecurity across countries is also discussed in this chapter. Within the aims of the study, evidence on the relationship between FI and chronic diseases, particularly cardiovascular diseases, is discussed.

Finally, the chapter explains the aims of the study as well as the reasons why this project may provide some useful insights for national organisations.

2.1. Food Insecurity Definition

The Food and Agriculture Organization of the United Nations stated that food security exists “when all people at all times have physical, social and economic access to food, which is safe and consumed in sufficient quantity and quality to meet their dietary needs and food preferences, and is supported by an environment of adequate sanitation, health services and care, allowing for a healthy and active life” (Food and Agriculture Organization 2012).

Previously, in 1990, the Life Sciences Research Office (LSRO) of the Federation of American Societies for Experimental Biology and the American Institute of Nutrition prepared a report defining food insecurity (FI) as well as hunger (Anderson 1990). Food insecurity exists whenever there is “limited or uncertain availability of nutritionally adequate and safe foods or limited or uncertain ability to acquire acceptable foods in socially acceptable ways”. Hunger in its meaning of “the uneasy or painful sensation caused by a lack of food” is in this definition “a potential, although not necessary, consequence of food insecurity. Malnutrition is also a potential though not necessary consequence of food insecurity.... Hunger, as a recurrent and involuntary lack of access to food which may produce malnutrition over time, is discussed as food insecurity in this report”.

The Food Standards Agency adopted *Anderson’s* food insecurity definition in the Low Income Diet and Nutrition Survey conducted across the UK between 2003 and 2005 (Nelson, Erens et al. 2007). The Food Foundation lightened that “socially acceptable ways” includes “without resorting to emergency food supplies, scavenging, stealing, or other coping strategies” (Taylor and Loopstra 2016). In addition, the UK Government warned about trying to capture all facets of food insecurity in a single definition: “There is no single definition of food insecurity. The factors that impact on household food security are complex. There are multiple indicators such as quality, variety and desirability of diet as well as total intake, not all of which are measured consistently”.

Literature tends to define the determinants of FI as a “complex mix” of environmental, biological and social factors without going into much detail (Craven 2017). *Craven* aimed to elucidate this messiness through a flexible model (see *Figure 2*) that may allow to turn the theory of the determinants of FI into practice (this model will be explained in more detail in section [2.1. Measurement of Food Insecurity](#)). Food insecurity is not linear, it is dynamically interconnected

instead. Therefore, the complexity of FI should not be simplified and its theory and methods should reflect it.

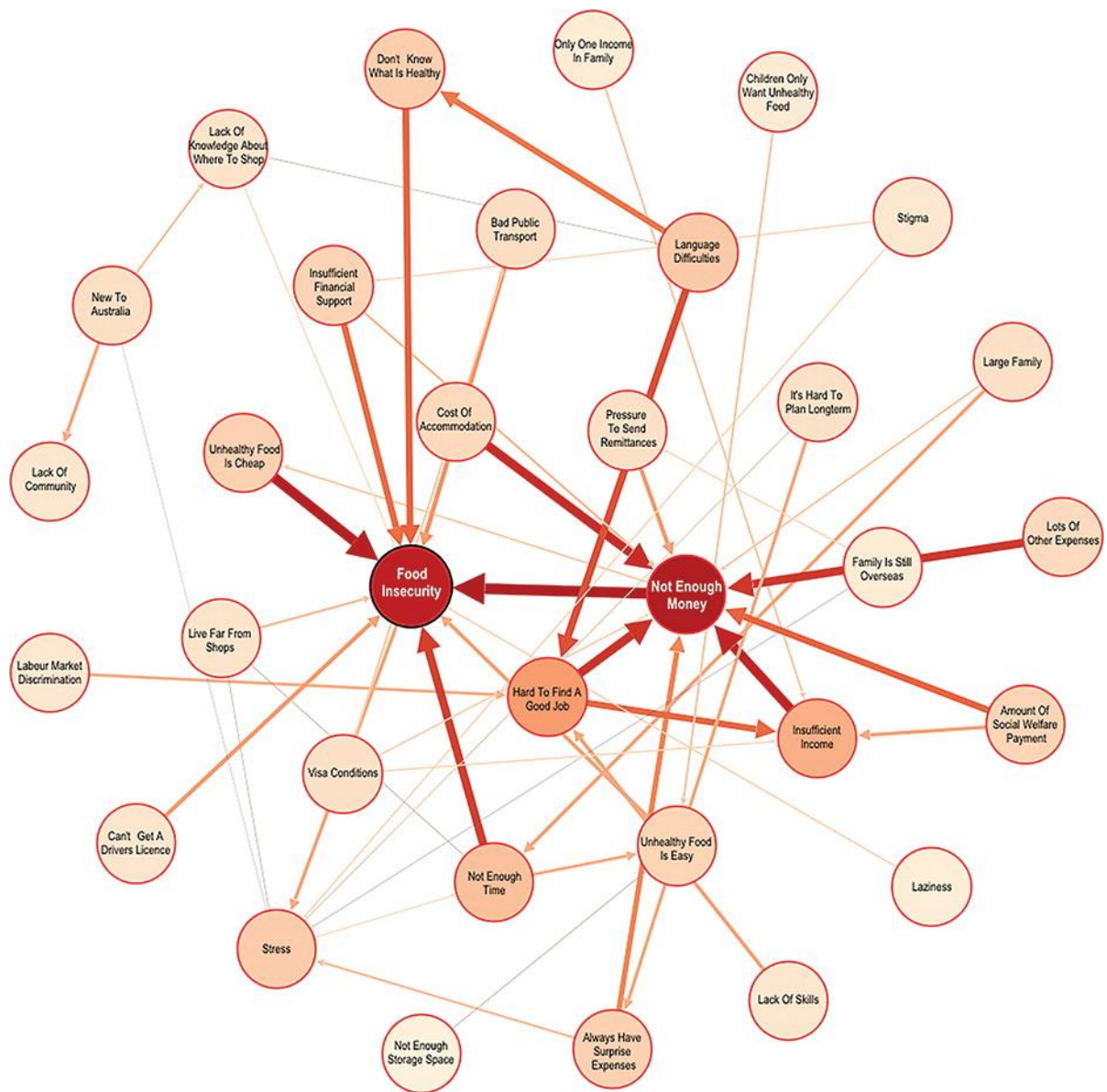


Figure 2. Aggregate model of Sydney fuzzy cognitive maps showing edge intensity. Published in 'System Effects: A Hybrid Methodology for Exploring the Determinants of Food In/Security' by LK Craven, 2017, *Annals of the American Association of Geographers*, 107, p. 1019.

The number of food insecure people has increased in the US from 2001 to 2009 (Gundersen, Kreider et al. 2011) and in the EU from 2004 to 2012 (Loopstra, Reeves et al. 2015, Loopstra, Reeves et al. 2016). Several multi-item tools to measure FI will be reviewed in section 2.2. [Measurement of Food Insecurity](#). Despite the validity of the current tools to measure FI, it is necessary to develop a reliable instrument to measure the four dimensions of FI (availability,

access, utilization and stability) at all levels (individual, household, community). These tools may underestimate the prevalence of people who are food insecure, but in any case there is evidence to support an overestimation (Ashby, Kleve et al. 2016).

Food insecurity across countries will be enlightened in both sections [2.3. Food Insecurity in North America](#) and [2.4. Food Insecurity in Europe](#). Its prevalence and the negative health consequences have been investigated mainly in North America, particularly in the US. There is scarce literature in EU. In spite of the limited data from the EU, the UK seems to be the country with more available literature on this issue. In addition, as the context of this thesis is the North West Coast of England, more emphasis will be given to the data from the UK.

A flow chart depicting concepts on FI after the literature review of [Chapter 2 INTRODUCTION: FOOD INSECURITY](#) is shown in [Appendix 1 Flow chart](#).

2.2. Measurement of Food Insecurity

The USDA Household Food Security Survey Module (FSSM) was introduced as the routine questionnaire used in the US and Canada (with adaptations) (US Department of Agriculture 2016). The measure is based on a set of 18 questions for households with children and a subset of 10 of these 18 questions for households without children. Based on the number of affirmative responses, the households are classified into 4 different groups: food security, marginal food security, low food security and very low food security. The last two categories are often combined into the category of “food insecure”.

The FSSM has not only been used in the US and Canada but also Australia and France; and has been considered as a valid tool for the UK population (Harvey 2016). In addition to this, *Gundersen* proposed to use this tool in Europe as a standardized measure to make cross-country comparisons (Gundersen 2016).

However, a recent systematic review (Ashby, Kleve et al. 2016) stated that despite of FSSM validity and reliability, it could not capture all the magnitude of FI as it only assesses food access due to financial constraints. This article remarked that the four dimensions (availability, access, utilization and stability) of FI should be considered in a tool that aims to assess food security. The

systematic review identified 8 valid and reliable tools, in addition to the FSSM, to measure FI in developed countries. These potential tools measured mainly the access to food as well.

Another tool to assess the prevalence and severity of FI was developed by the Food and Agriculture Organization (FAO) of the United Nations (UN). The Food Insecurity Experience Scale (FIES) measures the access to food at individual or household level (Ballard, Kepple et al. 2013). It measures severity of FI based on people's responses to questions about constraints on their ability to obtain adequate food. The FIES consists of eight short yes/no questions and its aim is to use the same scale easily across the countries.

Some efforts have been made to monitor FI in the UK. Gallup World Poll in 2014 measured British people experiences of FI using the FIES (McGuinness, Brown et al. 2016). Also, the UK's Low Income Diet and Nutrition Survey developed a food security scale (*Figure 3*) based on 15 questions, 10 for adults and 5 for children (Holmes 2007). Each question asked whether the condition or behaviour occurred at any time during the previous 12 months due to lack of money or other resources to obtain food. Some findings from both surveys are explained in section 2.4.5. [Food Insecurity in UK](#).

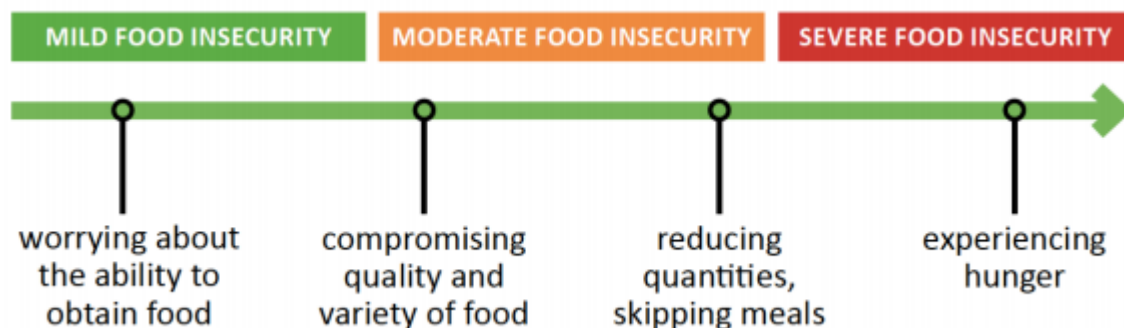


Figure 3. Classification of food insecurity used for the UK's Low Income Diet and Nutrition Survey, 2007. Published in 'Too Poor to Eat: Food insecurity in the UK' by A. Taylor and R. Loopstra, 2016. Retrieved December 30, 2017, from <http://foodfoundation.org.uk/wp-content/uploads/2016/07/FoodInsecurityBriefing-May-2016-FINAL.pdf>

According to the Food Foundation, quantitative data on household food insecurity is not currently collected through any routine national survey in the UK (The Food Foundation 2016), unlike the US where a food security supplement was added to the Current Population Survey. The Food Foundation suggests to add a short list of questions to existing survey instruments such as the Health Survey for England. The current numbers do not fit together (2014 Gallup World Poll

registered 17 times more people being food insecure than those who lived in households receiving food from Trussell Trust foodbanks) (The Food Foundation 2016), so there is a need to measure FI accurately (also see section 2.4.5. [Food Insecurity in UK](#)). Despite the validated tools to measure FI, the Food Foundation mentions qualitative data as a source of valuable information to capture all dimensions of FI. Finally, the Food Foundation highlights the negative health consequences in terms of duration, severity and costs as a consequence of FI.

It is argued that the complex concept of FI should not be oversimplified (Craven 2017). As mentioned in section 2.1. [Food Insecurity Definition](#), an aggregate model for understanding the determinants of FI has been recently developed by *Craven* in order to assess this oversimplification (Craven 2017). His “hybrid methodology” is a mapping exercise that was built, first, by ninety-one Afghan migrants living in Sydney’s western suburbs who reported food insecurity. Secondly, it was aggregated into a fuzzy cognitive map showing nodes and the intensity between its connexions that represent the identified barriers to food security. From this fuzzy cognitive map, it is apparent that money and other factors that result in low income (e.g. high cost of accommodation and difficulties to find a job) matter. Also, wide socioeconomic factors were affecting FI as well as (un)healthy choices. *Craven* finally argues that the method cannot be detached from practice: a mapping exercise as well as a theoretical analysis are likely to help researchers and policymakers to describe the wide range of determinants of FI and design intervention strategies.

2.3. Food Insecurity in North America

2.3.1. USA

Historical trends for FI in the US over the last 15 years could be explained in three periods (Coleman-Jensen, Rabbitt et al. 2016). From 2001 to 2007, the FI rate remained fairly stable around 11% (pre-recession levels). Next, the prevalence of FI went up to 14% in 2008, staying around this percentage till 2014. This rise in the prevalence may be due to the economic recession starting in this time period. Unexpectedly, the FI prevalence decreased to 12.3% in 2016, a statistically significant fall. This latest prevalence is still above the 2007 pre-recessionary level of 11 percent.

The majority of studies on FI in developed countries have taken place in the US. The US Department of Agriculture (USDA) collects information on food access and adequacy, food spending, and sources of food assistance for the US population annually. In order to assess US food security, the validated 18-item US Household Food Security Scale is used in the supplement to the Current Population Survey (CPS) (Coleman-Jensen, Rabbitt et al. 2016). Also, this 18 item questionnaire was adapted in 2004 to measure household food insecurity in Canada (Health Canada 2004). Although both countries use the same tool, the respective terminology and classification schemes differ, so the results between US and Canada are not directly comparable (Tarasuk, Mitchell et al. 2014).

2.3.2. Canada

In Canada, data on FI is collected through the Canadian Community Health Survey (CCHS), a cross sectional survey administered by Statistics Canada that collects health related information from about 60,000 people per year. The most recently published data (Tarasuk, Mitchell et al. 2014) from 9 participating jurisdictions (Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island, the Northwest Territories, and Nunavut) showed that when they are considered together, 12.0% of households (1.3 million households) experienced some level of food insecurity during the previous 12 months in 2014. More than 1 in 6 children under 18 years old lived in households that experienced food insecurity (approximately 1 million children). The North of Canada registered the highest levels of food insecurity, registering 46.8% in Nunavut and 24.1% in the Northwest Territories. While the prevalence of food insecurity in the North of Canada hit a peak in 2014, food insecurity appeared to remain at the levels experienced in prior years in most parts of Canada with no statistically significant changes in prevalence. The same report revealed that 62.2% of food insecure households were reliant on wages or salaries from employment.

2.3.3. Food insecure household characteristics

In the US, some demographic and economic characteristics were associated with food insecurity. These include: households headed by Black or Hispanic people; women/men living alone; a never married person; a divorced or separated person; households with children under age 6; and low educational attainment (Gundersen, Kreider et al. 2011, Coleman-Jensen, Rabbitt et al. 2017). In addition, households with children were more likely to be food insecure than households without children (Gundersen, Kreider et al. 2011, Coleman-Jensen, Rabbitt et al. 2017). However, those

children were usually shielded from FI; the children eat first and adults tended to reduce quality and quantity of food intake. In about half of food insecure households with children in 2015, only adults were food insecure (Coleman-Jensen, Rabbitt et al. 2016).

In 2014, Canadian households having an income below the Low Income Measure (29.2%), being Aboriginal (25.7%), being black (29.4%), and renting rather than owning one's home (24.5%) were more likely to be food insecure.

2.3.4. Income and Food Insecurity

In the annual Economic Research Report of Household Food Security in the United States, the USDA estimated that the typical household spent \$50.00 per person each week on food in 2016 (Coleman-Jensen, Rabbitt et al. 2017). As food spending was an indirect indicator of food consumption, a reduction in household food spending could lead to various aspects of food insecurity such as disrupted eating patterns and reduced food intake. Therefore, food-secure households typically spent more on food than food-insecure households, particularly, the median food-secure household spent approximately 27% more for food than the median food-insecure household in 2015 (Coleman-Jensen, Rabbitt et al. 2016). Nevertheless, food spending did not rise proportionately as income increases, so low-income households spent greater proportion of their income on food than do high-income households (Coleman-Jensen, Rabbitt et al. 2016).

There was an inverse relationship between income and FI, that is, the probability of being food insecure declines with higher income (Gundersen, Kreider et al. 2011), however, poverty was not always synonymous with FI. Surprisingly, a large number of poor households were food secure and a large number of non-poor households were food insecure (Gundersen, Kreider et al. 2011). According to these authors, one possible explanation for being food insecure in non-poor households could be due to the inadequacy of current income used for measure this purpose. For instance, the average household income over a two-year period predicted the household insecurity better than the current income.

2.3.5. Assistance Programmes

There are several Federal Food and Nutrition Assistance Programs for different population groups funded by US Department of Health and Human Services and the US Department of Agriculture (Kamp, Wellman et al. 2010, US Department of Agriculture 2016). There are food distribution programs such as The Commodity Supplemental Food Program (CSFP), The Emergency Food

Assistance Program (TEFAP) or Food Distribution Program on Indian Reservations (FDPIR); child nutrition programs such as Child and Adult Care Food Program (CACFP), National School Lunch Program (NSLP), Fresh Fruit and Vegetable Program (FFVP), School Breakfast Program (SBP), Summer Food Service Program (SFSP) or Special Milk Program (SMP); Supplemental Nutrition Assistance Program (SNAP); nutrition program for Women, Infants, and Children (better known as the WIC Program); and nutrition assistance programs for older adults such as The Older Americans Act (OAA), Commodity Supplemental Food Program or Senior Farmers' Market Nutrition Program.

In this section, only the three largest Federal Food and Nutrition Assistance Programs in the US are further described below: the Supplemental Nutrition Assistance Program (SNAP), The National School Lunch Program (NSLP) and The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). Both SNAP and NSLP are apparently effective on easing food insecurity (Gundersen, Kreider et al. 2011).

The SNAP is the largest food assistance program in the US reaching 28 million people each month via an Electronic Benefit Transfer card used to purchase food at most grocery stores. The level of benefits received is determined by income and family size. SNAP helps those eligible for nutrition assistance to make healthy eating and active lifestyle choices. The main goal of SNAP is to alleviate food insecurity which resulted in a 12% decrease in the prevalence of very low food security after few months of program admission (Nord and Golla 2009). Food insecurity is more prevalent in households enrolled in SNAP than in other low-income households (Nord and Golla 2009, Gundersen, Kreider et al. 2011).

The NSLP is a federally assisted meal program operating in over 101,000 public and non-profit private schools and residential child care institutions that choose to take part in this lunch program. The schools receive cash subsidies and donated commodities from the USDA for each meal they serve. In return, they must serve lunches that meet Federal requirements, and they must offer free or reduced price lunches to eligible children. Although the NSLP was designed to meet nutritional objectives, evidence has suggested that it may also ease food insecurity (Gundersen, Kreider et al. 2011).

The WIC Program serves to safeguard the health of low-income women, infants and children up to age 5 who are at nutritional risk by providing nutritious foods to supplement diets, information

on healthy eating, and referrals to health care. The federal WIC food package was revised in 2009 to include more fruits, vegetables, whole grains, and lower-fat milk. Children participating in the WIC program reported a better nutrient intake compared with their peers who lived also in low-income households (Tester, Leung et al. 2016).

The effects of FI on health outcomes have been described but the direction of the association remains unclear: is FI triggering poor health outcomes? Or do poor health outcomes result in FI? (Gundersen, Kreider et al. 2011). The health effects of food insecurity have been further explored among children rather than adults (Seligman, Laraia et al. 2010). Despite the wide variety of scales used to identify FI and psychological health outcomes in children and adolescents, FI is associated with children's behavioral, academic and emotional problems such as aggressive behaviour, compromised academic performance or depression (Shankar, Chung et al. 2017).

2.3.6. Chronic health conditions

In US adults, there was a positive association between FI and chronic disease, such as diabetes and obesity, showed by cross-sectional studies (Seligman, Laraia et al. 2010, Laraia 2013). In order to avoid the physical sensation of hunger and maintain caloric intake, adults might tend to eat low-cost, energy-dense and nutritionally poor food. These unhealthy eating behaviours could have considerable implications with regard to incidence, prognosis and management of chronic diseases (Seligman and Schillinger 2010, Laraia 2013). These recurring strategy was proposed by Seligman and Schillinger (2010) as the Cycle of Food Insecurity and Chronic Disease.

Laraia's review (2013) on FI and chronic disease revealed that FI was highly associated with diabetes among North American adults. In addition, diabetes management in food insecure adults was related with poor health outcomes, unhealthy diet and high rates of health care use. The author proposed a model that describes the influence of household FI on chronic diseases and health outcomes in which the chronic stress experienced by food insecure households led to a preference for highly palatable foods. This stress response may have triggered visceral adiposity and insulin resistance, and increasing the risk of chronic diseases. More extensive literature on chronic disease risk factors and cardiovascular diseases can be found in section [2.5. Food Insecurity and Cardiovascular Diseases](#).

Particularly, there has been an extensive research on weight gain or obesity and FI. According to a recent meta-analysis, there is general consensus of a positive association between food

insecurity and high body weight in adult women in high-income countries, but the association is less clear or absent in men, children and in low and middle income countries (Nettle, Andrews et al. 2016). Other reviews however suggests that FI is not associated with childhood obesity (Gundersen, Lohman et al. 2008, Gundersen, Garasky et al. 2009).

Commonly, chronic diseases are self-reported in the surveys resulting in an underestimation of the number of diseases (Seligman, Laraia et al. 2010). Chronic disease information is frequently collected through nationally representative data samples, as self-reported health information is easier and less expensive to collect. This underestimation in chronic disease diagnoses has been studied in relation to food insecurity (Seligman, Laraia et al. 2010). The findings from multiple waves (1995-2010) of the longitudinal health interview survey in the USA indicated that almost 30% of participants had inconsistencies in self-reporting their chronic diseases across interview waves (Cigolle, Nagel et al. 2016). In addition, they found that respondents with inconsistencies were older, women, Hispanic ethnicity, unmarried, less educated and lower income than those with no inconsistencies.

The effects of FI surpass physical health issues and may alter mental health, likewise mental health problems could be not only the consequence of FI but also the cause of FI. In a recent and nationally representative sample in the US, FI was positively related to depression (Leung, Epel et al. 2015). Other study carried out in 12 states revealed that the prevalence of frequent mental distress and insufficient sleep was significantly greater among food insecure adults (Liu, Njai et al. 2014).

2.3.7. Older adults

A large number of studies on FI have been conducted among older people. Older adults are less likely to be food insecure than younger populations (Lee, Fischer et al. 2010). Nevertheless, an accurate monitoring and health policies of senior populations becomes essential since this group is increasing in number (Vilar-Compte, Gaitán-Rossi et al. 2017). The same way that poverty rates for those aged 65 and over may be underestimated, e.g. the official measure VS. the Supplemental Poverty Measure (Fox 2017); older adults may be more likely to be food insecure due to physical limitations, health conditions, social isolation and lack of transportation. As the joint statement by the American Dietetic Association, the American Society for Nutrition, and the Society for Nutrition Education asserted: “all older adults should have access to food and nutrition programs that ensure the availability of safe, adequate food to promote optimal nutritional status.

Appropriate food and nutrition programs include adequately funded food assistance and meal programs, nutrition education, screening, assessment, counselling, therapy, monitoring, evaluation, and outcomes documentation to ensure more healthful aging". The US Department of Agriculture has some federal food and nutrition assistance programs for older adults such as Supplemental Nutrition Assistance Program, Commodity Supplemental Food Program, Child and Adult Care Food Program, and Seniors' Farmers Market Nutrition Program (Kamp, Wellman et al. 2010).

Food insecurity among senior Americans is scrutinised by the Current Population Survey (Ziliak and Gundersen 2017) using the FSSM. The last report in 2015 revealed that 14.7% of older adults, or 9.8 million were classified as marginally food insecure (one or more affirmative FSSM questions). Although the new data shown a significant fall on the proportion of seniors facing the threat of hunger between 2014 and 2015, the rate still remained higher than at the start of the Great Recession in 2007. Once again, those who are racial or ethnic minorities living in US (e.g. African American and Hispanics older adults) were more likely to be threatened by hunger. The same for those living in states in the South and Southwest, those with lower incomes, and those who were younger (ages 60-69).

Food insecurity measurement among elders may not be precise as FSSM was mainly designed for families with children and it doesn't consider other barriers that older people face such as limited mobility or transportation (Wolfe, Frongillo et al. 2003). In order to address these uncovered aspects, Wolfe et al proposed an elderly-augmented FSSM. Together with other literature (Kamp, Wellman et al. 2010, Lee, Fischer et al. 2010), they noticed that the majority of old people experienced one or more chronic health problem as well as eating a balance diet became crucial for their wellbeing and their chronic condition, so getting the "right foods for health" was reflected in the new questionnaire. Additionally, these new questions could be extended to people with chronic disease but further research is needed to test its validity (Wolfe, Frongillo et al. 2003).

2.3.8. Medication access

US literature about cost-related medication nonadherence (CRN) in older adult population demonstrated that those food insecure were more likely to report higher levels of CRN (Sattler and Lee 2013, Afulani, Herman et al. 2015). Similarly, FI is not only associated with CRN among persons with chronic diseases (Berkowitz, Seligman et al. 2014) but also existent among general

nonelderly adults population (Herman, Afulani et al. 2015). Also, FI was associated with CRN among individuals with diabetes (Knight, Probst et al. 2016, Patel, Piette et al. 2016).

2.4. Food Insecurity in Europe

The new context of recession has an enormous impact on the life of European citizens (Loopstra, Reeves et al. 2015). The prevalence of FI has risen in the EU as a whole between 2009 and 2012 but there are some differences across countries. Great increases in FI were found in Hungary, UK, Greece or Italy. However, countries such as Austria, Poland, Germany or Portugal reduced FI over this period and others such as Spain, Belgium or Sweden remained stable (Loopstra, Reeves et al. 2016). Food insecurity (% of adults affected) in European countries in 2014 can be found below (*Figure 4*). Some Balkan countries and some of the countries affected greatly by the 2009 recession seemed to have the highest percentages of food insecure adults, while the Northern countries ranked low.

Rising unemployment and falling wages are strong statistical determinants of increasing FI, but at high levels of social protection, these associations could be prevented (Loopstra, Reeves et al. 2016). When social protection spending is high, the effects of rising unemployment and falling wages on FI become mitigated.

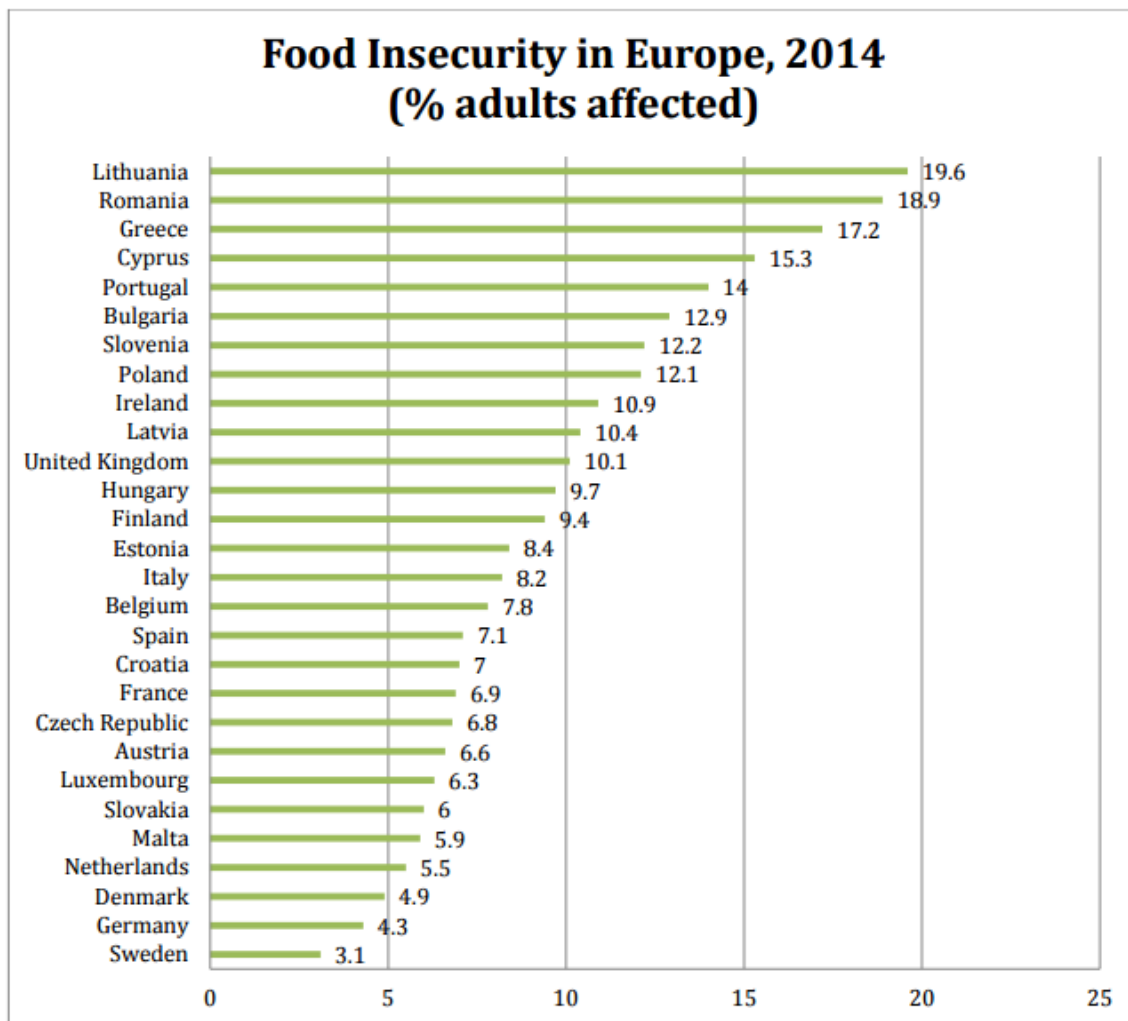


Figure 4. Food insecurity in European countries in 2014. Published in ‘Too Poor to Eat: Food insecurity in the UK’ by A. Taylor and R. Loopstra, 2016. Retrieved December 30, 2017, from <http://foodfoundation.org.uk/wp-content/uploads/2016/07/FoodInsecurityBriefing-May-2016-FINAL.pdf>

Relative inequalities (i.e. the ratio of rates for a certain outcome across socioeconomic groups) found across Europe suggested worse health in groups of lower SES (Mackenbach, Stirbu et al. 2008). The magnitude of these inequalities between groups of higher and lower SES was large in the eastern and Baltic regions and small in some southern European countries. A following study from *Mackenbach et al.* showed that apart from Lithuania, all European countries registered strong mortality declines in lower socioeconomic groups, among both men and women over the period 1990-2010 (Mackenbach, Kulhanova et al. 2016). For instance, Spain (Barcelona), Scotland, England and Wales, and Italy (Turin) achieved a 20-35% decline of absolute inequalities in mortality among both men and women. However, only England, Sweden, Norway and Finland developed and partially implemented national strategies to reduce health inequalities.

2.4.1. Searches

This search was limited to studies published in Spain, Belgium, Italy, Greece, Finland, The Netherlands, Germany and UK searching in the scientific on-line database PubMed using the following search terms: “food insecurity” AND country, e.g. “food insecurity” AND Spain. To be included, studies were required to be conducted in humans, related to food insecurity, using scientific method or a review article (applying CASP tool), accessible and reporting an outcome of interest. Studies were identified and subsequently included or excluded through title and abstract screening in both English and Spanish. Further papers were identified and added to this review.

2.4.1.1. Food Insecurity in Germany, Belgium and Italy

There is scarce literature in EU about FI. From the European countries listed above, there were no studies of interest from Germany, Italy and Belgium.

Figures 5, 6 and 7 depict country flow charts of the systematic literature review for this study selection (Germany, Italy, and Belgium respectively).

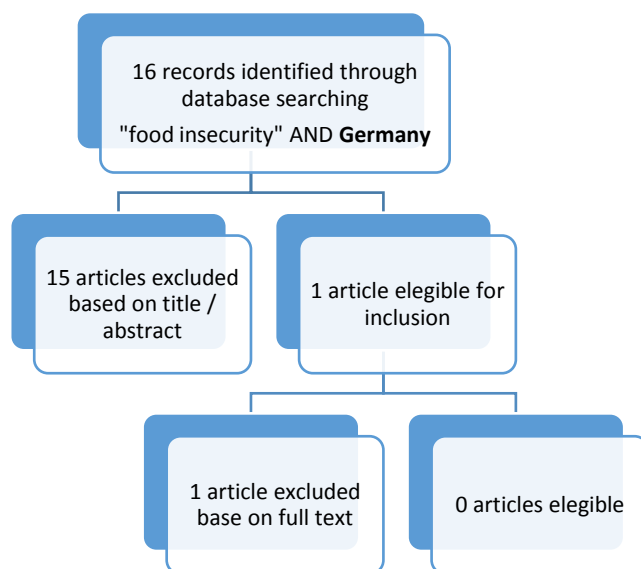


Figure 5. Search of food insecurity in Germany.

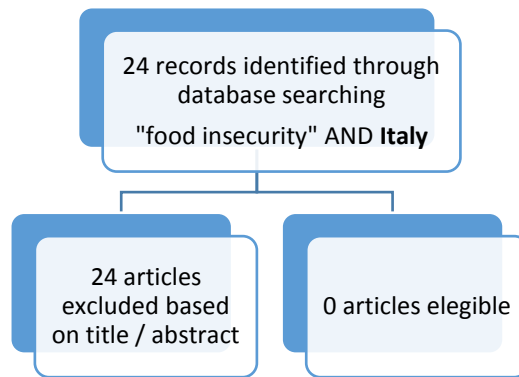


Figure 6. Search of food insecurity in Italy.

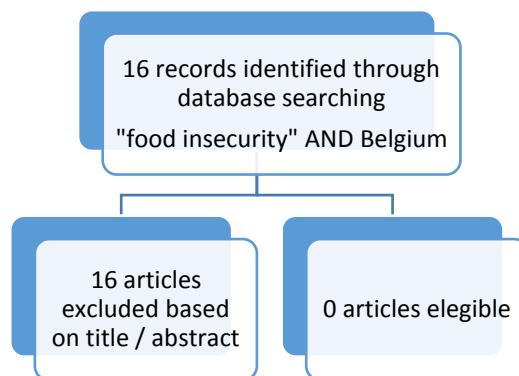


Figure 7. Search of food insecurity in Belgium.

2.4.1.2. Food Insecurity in Spain

It is important to consider the impact of the economic crisis on food consumption in Spain. The high unemployment rate and the real estate crisis might have modified the eating habits of the Spaniards by replacing the Mediterranean for less quality diets (Antentas and Vivas 2014). Spanish citizens had reduced their food spending in order to save money by changing the store where they do the groceries, reducing the total amount of food purchased and swapping costly comestibles for low-priced ones. This deteriorated diet was associated with increasing rates of obesity (Antentas and Vivas 2014).

There are no official data on the prevalence of FI in Spain (see below *Figure 8*). However, the Spanish Society of Public Health and Health Administration (La Sociedad Española de Salud Pública

y Administración Sanitaria) contests that 4% of the Spanish population lack resources to afford a basic daily diet (Antentas and Vivas 2014). Also, the Food Bank Spanish Foundation registered an increase in the numbers of bank users and the food given from 834,400 users and 69,500 ton of food in 2007 to 1,5 million users and 152,932 tons of food in 2015 (Federación Española de Bancos de Alimentos 2015).

A minimum budget for a Healthy Food Basket in Spain (SHFB) taking into account the type of family and Spanish preferences and feasibility has been estimated (Carrillo Alvarez, Cusso-Parcerisas et al. 2016). In this study, kitchen equipment was provided. The monthly cost of this basket ranges from 131,63 € to 573,80 € depending on the type of family. Two practical applications were identified: first, it can serve to inform policies designed to guarantee food access about the minimum needed to sustain healthy eating for different types of family. Secondly, it can be used as an educative tool to promote healthy eating.

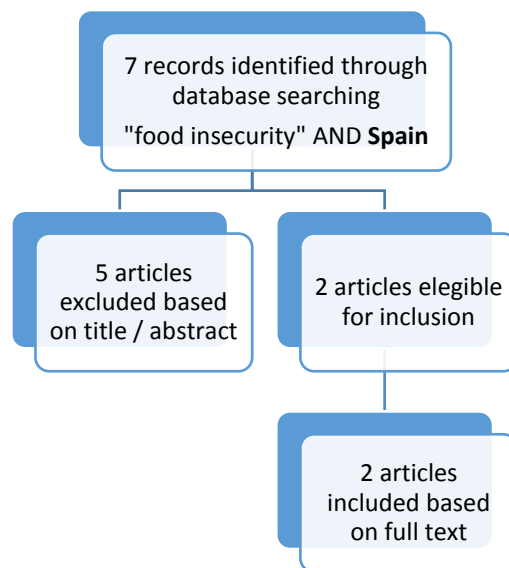


Figure 8. Search of food insecurity in Spain.

2.4.1.3. Food Insecurity in Greece

The socioeconomic status of Greek population has been impacted by the financial crisis starting in 2009. As a result of the Greek Depression, some humanitarian action has taken place to help those most in need. The DIATROFI (Program on Food Aid and Promotion of Healthy Nutrition) program was carried out in 2012 on 16,000 families and aimed to alleviate FI, particularly in

children (Petralias, Papadimitriou et al. 2016). The DIATROFI program was the first school feeding program in Greece presenting that 60% of the families polled suffered food insecurity while 23% lived a state of FI and hunger. In this study, the FI levels were measured using the FSSM. The findings indicated remarkable feasibility of this nationwide school-based program on food aid and promotion of healthy nutrition in Greece, suggesting that the participation in this program may reduce FI among children. In order to ease the current situation sparked by the economic crisis, the DIATROFI program recently started a food aid program which also promotes healthy eating habits. In addition, the study showed that FI was higher for children in middle and high schools compared with children in kindergarten and elementary schools.

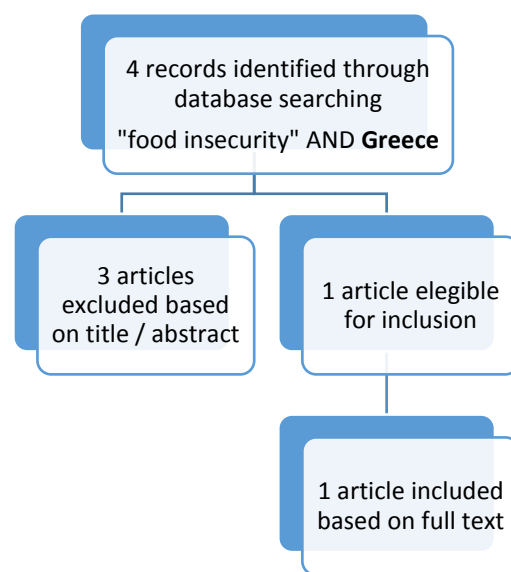


Figure 9. Search of food insecurity in Greece.

2.4.1.4. Food Insecurity in Finland

Food insecurity has been nearly unexplored in the Nordic countries (see *Figure 10*). As these prosperous societies have presumably little differences in wages and strong social welfare programs, it is generally assumed that FI is inexistent (Borch and Kjærnes 2016).

An online representative survey from four of five Nordic countries (Iceland is missing) aimed to assess the prevalence and risk of FI in Denmark, Finland, Norway and Sweden in April 2012 (Borch and Kjærnes 2016). In order to address FI, the Question HH1 from the FSSM battery, which includes statements indicating an inadequate amount of food intake due to a lack of money or

resources in the last 12 months, was introduced in a Nordic web survey on eating habits. 37.2% Finnish participants reported risk of experiencing food insecurity, while Norwegians, Danes, and Swedes were 28.2, 29.1, and 27.8%, respectively. In Finland, 4% were at high risk of experiencing food insecurity in terms of reporting that they sometimes or often do not have enough food to eat.

Another Finnish study carried out in 1994, indicated that 2.7% was food insecure (Sarlio-Lahteenkorva and Lahelma 2001). Food insecurity was assessed by five questions (four of them correspond largely with questions in the FSSM) in which individuals with four out of five affirmative responses were classified as hungry. The study also found that the association between FI and BMI is curvilinear, that is, both thinness and obesity were associated with FI in adults. Findings that differ from more recent studies suggesting a positive association between FI and high body weight in adult women in high-income countries (see section 2.3.7. Obesity).

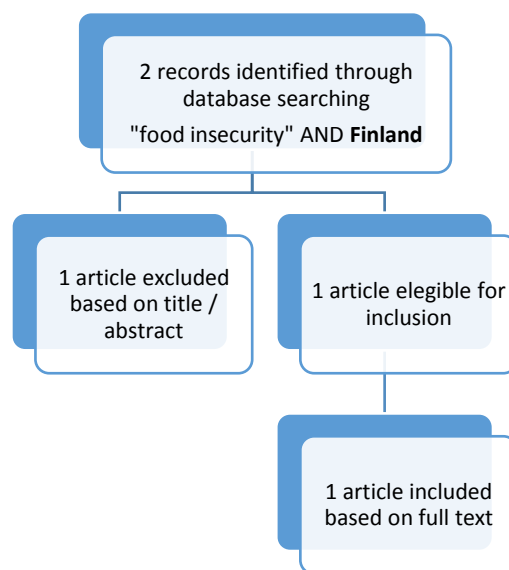


Figure 10. Search of food insecurity in Finland.

2.4.1.5. Food Insecurity in The Netherlands

The Netherlands is ranked fourth in the recently published Economist Intelligence Unit's 2016 Global Food Security Index (The Economist Intelligence Unit 2016). Despite of this, there were 664,000 households (9.4% of the total Dutch population) living below the low-income threshold (Neter, Dijkstra et al. 2014).

In 2013, the food banks provided weekly over 35,000 food parcels supporting approximately 85,000 individuals in the Netherlands. A Dutch study determined the prevalence of low (72.9%) and very low (40.4%) food security among food bank recipients (Neter, Dijkstra et al. 2014). A translated version of the six-item FSSM was used for measuring the food security status of the participants according to the USDA guidelines: score 0 or 1 is food secure; score 2–4 is low food security; and score 5–6 is very low food security. The Dutch food bank users in this study had healthier lifestyle than general Dutch population presenting high proportion of smokers and obesity.

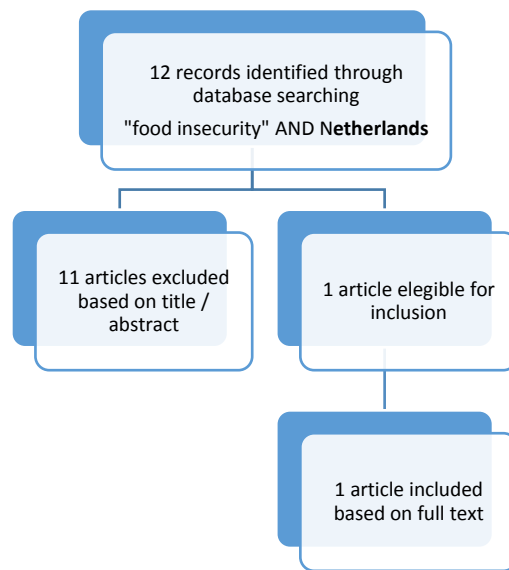


Figure 11. Search of food insecurity in The Netherlands.

2.4.2. Food Insecurity in the UK

In this thesis, special emphasis is given to the FI literature in the UK, as the setting of this project is a deprived neighbourhood in the city of Liverpool. Then, this review/section can help to set a context and place the findings.

The Institute for Fiscal Studies predicts that despite the increase in employment and the falling in inflation, absolute poverty across the population in the UK as a whole will be unchanged (Browne and Hood 2016). While absolute pension poverty is projected to decrease, absolute child poverty is likely to grow. Therefore, household income inequality is expected to increase between 2015-16 and 2020-21.

In 2014, the UK Faculty of Public Health described the increasing malnutrition and hunger as a “public health emergency”. The number of malnutrition related admissions to hospital in England had doubled numbers between 2008-09 and 2012-13 (from 3000 to 5500 cases) (Health and Social Care Information Centre 2013). The Poverty and Social Exclusion research project funded by the Economic and Social Research Council, reported that about 4 million children and adults in the UK are not properly fed and more than one in four adults skip meals, so other family members can eat (Gordon, Mack et al. 2013). Besides, the Institute for Fiscal Studies stated that due to the economic recession, the UK households have reduced the spending on food and calorie intake, choosing more calorie dense food with poorer nutritional quality, as well as switching from fresh fruit and vegetables to processed food (Griffith, O’Connell et al. 2013).

The UK has not been regularly monitoring household experiences of FI. Firstly, it was measured in 2003-2005 by Low Income Diet and Nutrition Survey, only including low-income households. Later on, in 2014, the Gallup World Poll was carried out in a small but nationally representative sample. In addition to these surveys, some estimations have been made through the numbers from Food Banks, although the reliability of this data is questioned. Importantly, this information only depicts a particular moment but FI may vary over time, as income or household requirements change. Examples include; school holidays; temporary unemployment; and larger budgets for medicines, or heating (depending on the time of the year).

The UK’s Low Income Diet and Nutrition Survey addressed household experiences of FI between 2003 and 2005 (Holmes 2007). This national survey was conducted by the Food Standards Agency and published in 2007. The aim was to provide evidence to develop new food policies as well as narrow health inequalities. It provides strong and nationally representative evidence on eating habits, lifestyle and dietary intake of low income individuals. In this sample, 71% were classified as living in food secure households while the remaining 29% were classified as food insecure (mild, moderate or severe food insecurity) households at some time during the year, meaning their access to enough food was limited by factors such as lack of money or other resources (e.g. storage facilities, transport). Almost 40% of the low income population in this survey reported that in the past year, they had worried their food would run out before they had money to buy more, 36% indicated that they could not afford to eat balanced meals, 22% reported reducing or skipping meals, and 5% reported not eating for a whole day, because they did not have enough money to buy food. Some associations between food security and nutrient intake revealed that the mean nutrient intake as a percentage of the Estimated Average Requirement (EAR) or the

Reference Nutrient Intake (RNI) was higher for women and girls in food secure households compared to women and girls in mildly or moderately/severely food insecure households. Nevertheless, this association was weaker for men and boys.

Also, household experiences of FI in the UK was measured using the FIES developed by the FAO. In 2014, 1,000 interviews were conducted by telephone or mobile phone through the 2014 Gallup World Poll. Although the survey was nationally representative, the FAO referred to this data as “preliminary” because of the small sample. The findings indicated that 10% of individuals aged 15 or over were food insecure, meaning to struggle to get enough food to eat. This percentage is equivalent to 8.4 million people living in households where, at least one person, experienced FI. Among these people, 4.5% experienced a severe level of FI, typically having gone a whole day without eating at times during the year, because they could not afford enough food. There is no comparable data in the UK to determine fluctuations over recent years (McGuinness, Brown et al. 2016, Taylor and Loopstra 2016).

The Trussell Trust is a network of foodbanks in the UK that provides emergency food and support to people in crisis (The Trussell Trust 2017). Between 2008-2009 and 2016-2017, it reported that the number of people given 3 days emergency food bank supplies had risen from 25,899 to 1,182,954. Of this number, 436,938 of these parcels went to children. Low income (26.45%), benefit delays (26.01%) and benefit changes (16.65%) were the primary causes for referral to the Trussell Trust (*Figure 12*).

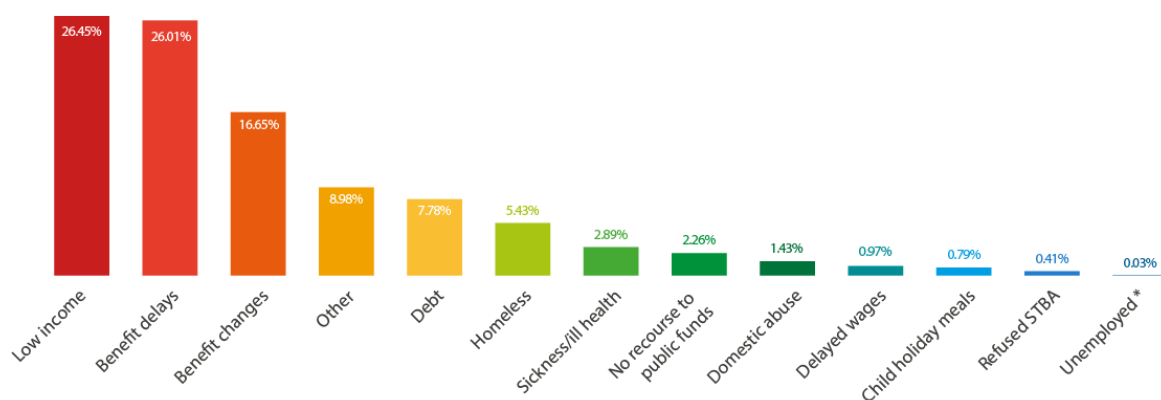


Figure 12. Reasons for referral to Trussell Trust Food Banks in 2016. Published in *the Trussell Trust*, Retrieved December 30, 2017, from <https://www.trusselltrust.org/news-and-blog/latest-stats/>

There is a substantial rise in the food bank usage over the last few years in UK, nevertheless, the data collected is confusing and inaccurate (Ashby, Kleve et al. 2016). It is noticeable the difference

between the reported numbers from both the Trussel Trust and Gallup World Poll. Gallup World Poll showed that 17 times more people lived in food insecure households than those who lived in households receiving food from Trussell Trust food banks (The Food Foundation 2016). Therefore, food bank data may underestimate FI. It would be necessary to measure FI accurately, not rely on food bank numbers and monitor household experiences of food insecurity regularly (Loopstra and Tarasuk 2015).

An ethnographic-design study carried in the UK indicated that many foodbank users confessed having mental health problems like depression or anxiety (Garthwaite, Collins et al. 2015). The foodbank was presented as a place with a relaxed atmosphere to alleviate feelings of shame and to talk with someone, enhancing the sense of community. Some foodbank users were aware of how to eat healthily (especially, those with food intolerances or other illnesses related with food) but they could not afford nutritious food. The study observed that foodbanks failed when giving certain food for special needs (irritable bowel syndrome, coeliac disease...). Although these foodbank users remarked that the food parcel was a “lifeline”, the adequacy and the effectiveness for people with health problems was questioned. Also, volunteers and referring agencies highlighted the need of cookery courses and advice on meal planning for foodbank users.

As far as this review is concerned, little research in FI has focused on children in the UK. A recent mixed-methods approach study in South London showed that the parents limited their own food intake in order to provide more food to their children (Harvey 2016). This finding is consistent with those from the USA research. Almost all parents in this study reported that they were unable to afford balanced healthy meals for their family. In addition to this, the study found a relatively high consumption of low-cost takeaway meals. Food security status was assessed using the FSSM and children’s perceptions and experiences of FI were assessed by one-to-one semi-structured interviews that, in some cases, were not consistent with the data provided from their parents.

Some research in the UK has highlighted the negative impact of the school breaks on children’s weight and food provision (Harvey-Golding, Donkin et al. 2015, Domone, Mann et al. 2016, Graham, Crilley et al. 2016). These results are consistent with US previous findings (Gundersen, Kreider et al. 2011).

2.5. Food Insecurity and Cardiovascular Diseases

Cardiovascular Diseases (CVD) are the number 1 cause of death globally but it could be avoided by addressing its risk factors (World Health Organization 2017). The WHO calculated that 17.7 million people died from CVDs in 2015, that is, 31% of all global deaths. CVD involves coronary heart disease (heart attack, angina and heart failure), stroke, transient ischaemic attack (TIA or “mini-stroke”), peripheral arterial disease and aortic disease. Risk factors for developing cardiovascular disease include: family history of CVD, over 50 years of age, male gender, smoking, unhealthy diet, harmful use of alcohol, high blood pressure, high blood cholesterol levels, South Asian and African or Caribbean background, diabetes, obesity and physical inactivity (National Health Service 2016). Many attempts have been made to understand the connections between risk factors but these links make difficult to weigh up their discrete influence (Stringhini, Carmeli et al. 2017).

Food insecurity is related to chronic diseases and particularly to CVDs (Weiser, Palar et al. 2015) (see *Figure 13* below). *Seligman et al* found significant association between FI and cardiovascular risk factors in US adults (hypertension and diabetes but not hyperlipidemia) (Seligman, Laraia et al. 2010). Also in the US, participants of the Survey of the Health of Wisconsin who were food insecure were significantly less likely to have good cardiovascular health compared to participants who were food secure (Saiz, Aul et al. 2016). Analysis of the National Health and Nutrition Examination Survey 2003-2008 revealed that adults aged 30 to 59 years with very low food security showed evidence of increased predicted 10-year cardiovascular disease risk (Ford 2013). The same study reported no significant associations between food security status and cholesterol (these results are consistent with (Seligman, Laraia et al. 2010)).

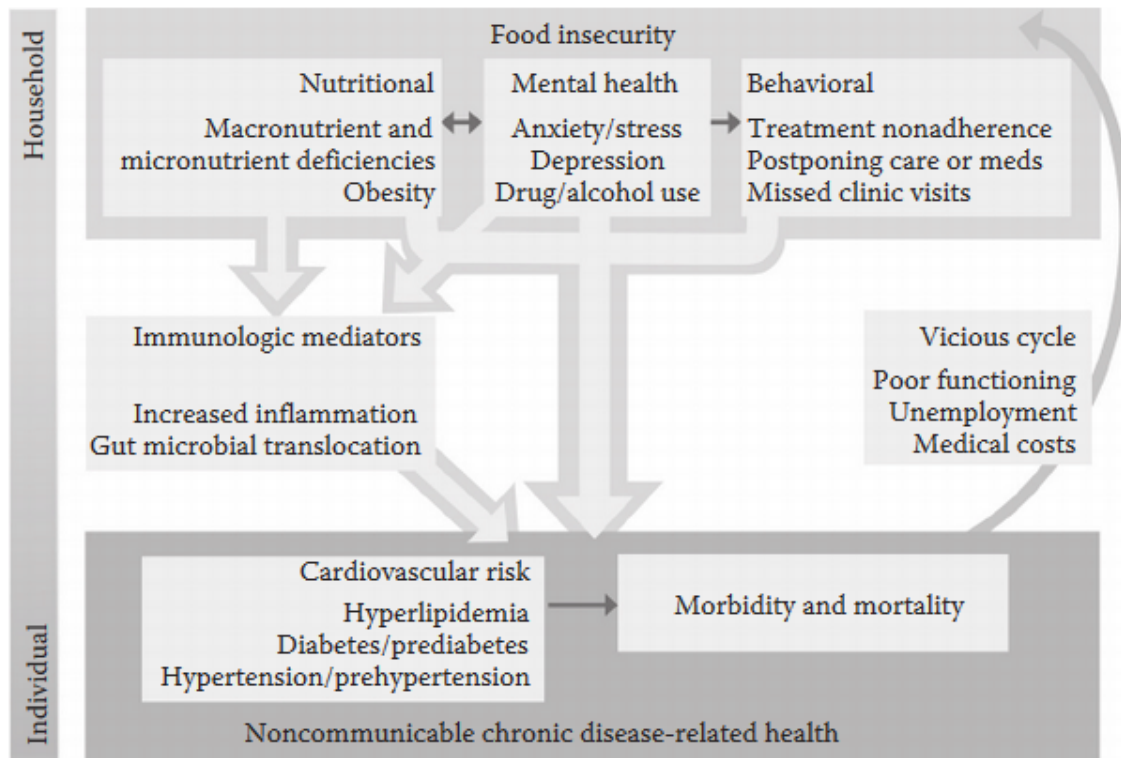


Figure 13. Three pathways link food insecurity and cardiovascular disease: nutritional, mental health and behavioural. Published in "Food Insecurity and Health" (p. 29), by S. Weiser, 2015.

In the UK, the National Diet and Nutrition Survey 2007 (NDNS) programme collected information on the dietary habits and nutritional status of a national sample of the most materially deprived households from the UK (Nelson, Erens et al. 2007). Regarding blood pressure, 42% of men and 35% of women had hypertension. This was higher in men and women aged 65 and over (62% and 63%, respectively) compared with those aged 19-34 (18% and 7%, respectively). Also, 45% of men and 60% of women with hypertension were on drug treatment.

Overall, Coronary Heart Disease (CHD) mortality declined from 2000 to 2007 in England but this fall was more noticeable in those socially advantaged compared to deprived groups, suggesting persisted inequalities in cardiovascular health (Bajekal, Scholes et al. 2012). In this study, the reduction of CHD in both affluent and deprived groups was attributable to improved medical therapies rather than a CVD risk factors reduction (also noted in Scotland (Hotchkiss, Davies et al. 2014)). Although inequalities broadened, it may not be explained by the treatment uptake as therapies were equally distributed across social groups by NHS. CVD risk factors slightly improved over this period, perhaps due to UK policies for salt reduction, tobacco control and healthier eating.

2.6. Aims of the study

Although health inequalities are monitored and investigated in the UK (see [Chapter 1 Health Inequalities](#)), little is known about food insecurity and its relation with chronic health diseases in British low-income individuals (see section [2.4.2. Food Insecurity in the UK](#)). The vast majority of the literature on food insecurity is based on the US population. Despite of the fact that the US is a developed country too, the findings may be significantly different in the UK. Even the findings may differ across the UK owing to geographical health dissimilarities.

Health inequalities and food insecurity were chosen as key themes for this project because both are linked to poor health outcomes and poverty (as shown in [Chapter 1](#) and [Chapter 2](#)). Therefore, this study's principal aim was to produce a thorough understanding of everyday reality of people with CVD or other chronic illnesses who lived in deprived economically neighbourhoods in Liverpool (Fazakarley) experiencing economic difficulties. We sought their experiences of CVD management and aimed to understand the influence of factors that may be involved in their CVD management such as food insecurity and medication adherence; so, using a qualitative approach would allow us to illustrate the complexity and variability of people's experiences. We intended to identify whether there is a negative impact on their health and wellbeing due to their limited resources to get healthy food and medication. In addition, we wanted to investigate their daily choices; whether they prioritized to afford a healthy diet, drugs prescription or other life necessities. Thus, we elicited the experiences of low income people whose cardiovascular health is compromised in order to build the evidence base and identify priority areas for future research.

These results will facilitate data from individuals facing food insecurity and chronic health conditions. Although the findings from this study will be context-specific, they may help to understand the situation in other populations nearby Liverpool. This project could also result in valuable findings to be used by Liverpool Clinical Commissioning Group, Local Authorities and their public health teams, and the National Institute of Health Research Collaboration for Leadership in Applied Health Research and Care North West and other partners along the UK. The National Institute of Health Research Collaboration for Leadership in Applied Health Research and Care will benefit from the findings to develop a grant application.

3. Chapter 3 METHODOLOGY

Chapter 3 content:

Chapter 3 explains the methodology used for this study. It outlines the reasons for choosing a qualitative approach as well as Thematic Analysis as a tool chosen for data analysis. In addition, it covers recruitment methods such as in-depth semi-structured interviews and demographic information questionnaire. It also describes the main characteristics of the sample. In this chapter, the recruitment and data collection are not only explained but also discussed giving some perceptions for a better interpretation of the study as a whole. Finally, ethics approval details and dissemination purposes.

3.1. Justification

The rationale behind choosing a qualitative research approach for this project were a combination of epistemological and practical commitments (Braun and Clarke 2013). First of all, the research question itself determined the methodology, that is, the exploration and understanding of lived experiences by people living in low income areas. Secondly, while complex problems such as food insecurity or management of chronic illness can be quantified, it is also necessary to describe the complexity and variability of how people experience them by using a qualitative approach. Thirdly, understanding the context and environment could inform health care service reviews. There is still uncertainty within the UK context to be confident about the relevant aspects and variables affecting individuals living in deprived areas. These study findings should inform research questions and funding opportunities within the National Institute of Health Research Collaboration for Leadership in Applied Health Research and Care and other research funding organisations in the UK.

Qualitative research serves to inform about everyday reality, personal socioeconomic circumstances, emotional experiences, and behaviours and identities developed to cope with inequalities in health that quantitative research has not been able to represent precisely. Therefore, the social phenomena as well as the understanding of the causes of health inequalities could be richly reflected by a qualitative approach. Measurement should not be set aside, but rather that to combine both types of research will facilitate a broader comprehension (Elliott, Popay et al. 2015).

The rationale of this present research project was to generate new knowledge on the topic (the literature on CVD management in low income individuals in the UK is scarce), the approach (a qualitative method to explore experiences in CVD management in low SES people is not commonly used), and the context (the North West Coast region with its high health inequalities within a UK context (Whitehead 2014)).

3.2. Methods of data collection

3.2.1. Interviews

Interviews are the most common method of data collection in qualitative research (Braun and Clarke 2013). Face-to-face contact between researchers and participants have typically been considered as the ideal way to collect data; the ‘gold standard’ (Novick 2008). Also, interviews are perfectly suited to seek explore experiences (Braun and Clarke 2013).

In this study, in-depth semi-structured qualitative interviews were conducted with participants whose cardiovascular health was compromised. The interviews were topic guided and conversational in nature. Informed by the literature and according the aims of the study, a topic guide was prepared in advance (see [Appendix 2 Topic guide](#)). The outline was shared with supervisors, and finally revised and refined. Unlike a structured interview, which produces standardised responses, the semi-structured interview allowed the interviewee to talk about unanticipated areas which were important to them as well as to address potentially the anticipated research question areas. The new interesting ideas that arose during the interviewing, were added into the interview schedule and explored over the course of the subsequent interviews (see the questions underlined in the [Appendix 2 Topic guide](#)).

The interviews explored the experiences and perspectives of members of the public from Fazakerley (Liverpool) managing their CVD when money was tight. The topic guide was split into four major sections. The first section included questions related to their daily life, their chronic illness and its management. In this first section, we intended to build rapport with the participant. The second section of questions explored their medication adherence. During the course of the interviews, the researchers — Sara Estecha Querol (SEQ) and Pam Clarke (PC) — found that the majority of the participants were exempted from prescription costs (n=13). The researchers asked the participants to imagine a scenario in which they had to pay for their prescriptions in order to enrich and broaden the data collected. The third section addressed dietary choices, food insecurity and food bank utilisation. Finally, some questions about trade-off decision making among basic needs, including food, medications, and other necessities were included.

Each interview was audio recorded, previous consent (see [Appendix 3 Participant information sheet](#) and [Appendix 4 Participant consent form](#)) was given by the participant. The face-to-face interviews were conducted in English. Audio files were transcribed verbatim and as soon as

possible after the interview. The lead researcher (SEQ) transcribed 6 of the audio files, which were checked by PC afterwards. However, the rest of audio files were transcribed by a professional transcription agency. The agency signed a declaration of confidentiality and, as instructed, adhered to the study protocol for data handling and storage.

One advantage of in-person interviews was capturing of body language in addition to verbal and other non-verbal cues. Thus, it was possible to note and record when the participant appeared to experience discomfort with some of the questions. Immediately after each interview, the researchers (SEQ and PC) took field notes detailing initial reflections, adding any contextual elements which may be missed in an audio recording and any primary insights for analysis.

3.2.2. Demographic information questionnaire

A short questionnaire was provided to the participants to collect demographic information (see [Appendix 5 Demographic information questionnaire](#)). Age, employment status, income, benefits, food bank use, number of persons living in the same household and ethnicity were asked. This questionnaire was completed prior to the interview to get to know the participant and frame the subsequent development of the conversation.

3.3. Sample characteristics

The participants were individuals living in a low income area with a self-reported CVD. CVD and risk factors for developing CVD are previously defined in section [2.5. Food Insecurity and Cardiovascular Disease](#). The participants were recruited from the deprived neighbourhood of Fazakarley in Liverpool and thus likely to face economic problems.

The sample size of this study was determined by the research question, the quality of the data obtained (the amount of useful information obtained from the participants) and the available resources, using a purposive approach to sampling where feasible. In this study, 14 qualitative interviews were conducted (SEQ conducted 9 and PC did 5). This number was sufficient to attain saturation, the point at which no new themes are evident from continuing interviews. Saturation refers to the point when additional data fails to generate new information (Morse 1995).

Table 1 shows the characteristics of the study individuals. The study sample included 14 people (3 women) ranged from 54 to 76 years of age (mean=62.5 years). Eleven participants have had a stroke, as well as other chronic health conditions such as obesity, depression, epilepsy and diabetes. Self-identified ethnicity of all participants was white except one “mixed ethnic group”. None of the participants were working and all were receiving welfare benefits. Two of the participants reported the usage of food bank. We also used the Index of Multiple Deprivation 2015 (IMD) in order to place the living conditions of the participants and understand how these conditions shape their narratives.

Pseudonym	Age	Marital status	Employment status	Monthly household income	IMD*	Self-reported chronic illness(es)	Self-reported CVD risk factors
Terry	56	Divorced	Unfit to work	More than £800	NA	Stroke, obesity	Family history of CVD, smoking, poor diet, high blood cholesterol levels, obesity, physical inactivity
Diana	76	Divorced	Retired	More than £800	5,347 out of 32,844 LSOAs 20% most deprived neighb	Stroke, epilepsy, arthritis, diabetes, obesity, liver problems	Heavy smoker in the past, poor diet, high blood pressure, high blood cholesterol levels, diabetes, obesity
Stuart	55	Single	Unfit to work	Less than £400	5,347 out of 32,844 LSOAs 20% most deprived neighb	Arthritis, depression, anxiety, obesity	Family history of CVD, poor diet, high blood pressure, obesity, physical inactivity
Derek	68	Married or domestic partnership	Retired	More than £800	8,572 out of 32,844 LSOAs 30% most deprived neighb	Angina, stroke, arteriosclerosis, cervical spondylosis.	Family history of CVD, heavy smoker in the past, high blood pressure, high blood cholesterol levels.
Robert	55	Single	Unfit to work	More than £800	5,694 out of 32,844 LSOAs 20% most deprived neighb	Stroke, peripheral arterial disease, diabetes, obesity, vision problems	Heavy smoker, poor diet, high blood pressure, high blood cholesterol levels, diabetes, obesity.
James	55	Single	Unemployed with benefits	Between £400 - £800	14,459 out of 32,844 LSOAs 50% most deprived neighb	Stroke, depression	Family history of CVD, poor diet.
Clare	58	Single	Unfit to work	Less than £400	12,779 out of 32,844 LSOAs 40% most deprived neighb	Brain haemorrhage	High blood cholesterol levels.
Louis	75	Married or domestic partnership	Retired	Does not know	22,042 out of 32,844 LSOAs 40% least deprived neighb	Stroke, diabetes	Smoker in the past, high blood pressure, diabetes
Jacob	53	Divorced	Unfit to work	Less than £400	7,707 out of 32,844 LSOAs 30% most deprived neighb	Stroke, diabetes, obesity, epilepsy	Heavy smoker in the past, poor diet, high blood pressure, high blood cholesterol levels,

							diabetes, obesity, physical inactivity.
William	57	Married or domestic partnership	Unfit to work	More than £800	224 out of 32,844 LSOAs 10% most deprived neighb	Stroke, obesity	Family history of CVD, heavy smoker, poor diet, high blood pressure, high blood cholesterol levels, obesity, physical inactivity.
Liam	76	Married or domestic partnership	Retired	Between £400 - £800	6,568 out of 32,844 LSOAs 20% most deprived neighb	TIA, diabetes, obesity, arthritis, spondylosis	Poor diet, high blood pressure, high blood cholesterol levels, diabetes, obesity, physical inactivity.
Andrew	54	Married or domestic partnership	Unemployed with benefits	More than £800	22,517 out of 32,844 LSOAs 40% least deprived neighb	Stroke, epilepsy	None
Abigail	74	Married or domestic partnership	Retired	More than £800	1,964 out of 32,844 LSOAs 10% most deprived neighb	Stroke, thrombosis	High blood pressure
Jack	63	Single	Unemployed	Between £400 - £800	1,769 out of 32,844 LSOAs 10% most deprived neighb	Stroke, cancer	Smoker, poor diet, high blood pressure.

Table 1: Characteristics of the sample

*IMD= Index of Multiple Deprivation (2015) Layer Super Output Area (LSOA) is a geographic area. There are 32,844 LSOAs in England; where 1 is the most deprived LSOA.

3.4. Recruitment

The study involved purposive sampling of participants in which decisions concerning the inclusion of the participants were taken by the research team, based on capacity and willingness to participate in the research or their contribution with rich data to the aim of the project (Jupp 2006).

Snowballing was used as a sampling strategy. Researchers' and participants' networking helped to recruit other interested and eligible individuals. Snowballing is one of the few techniques that facilitates access to hard-to-reach groups (Barbour 2008). Normally, research is carried out among usual suspects (educated, white, middle-class) (Braun and Clarke 2013); however, our sample was scantily represented in research. These groups are typically viewed as hidden, hard to reach or difficult to engage with research collaboration (Braun and Clarke 2013). Therefore, a snowballing strategy and recruiting through organisations helped us to get better access to this population.

The researchers (SEQ and PC) went to Fazakerley food bank at St Paul's Church, Fazakerley Community Federation and the Merseyside Life After Stroke Group at the Old Roan Baptist Church to start with the recruitment. These three organizations are based in Fazakerley which is amongst the 20% most deprived neighbourhoods in the country according the Index of Multiple Deprivation (IMD) (Department for Communities and Local Government 2015).

The main route was to establish contact with these public organizations by asking key people to forward information about the study (participant information sheet and a flyer) to any eligible participants (see *Table 2* below). We used the word of mouth as well as recruitment advertisement (see [Appendix 6 Recruitment advertisement](#)) in public spaces. We first approached the Food Bank in Fazakerley because the research team supposed that food bank users would be likely to be facing food insecurity and economic problems. Then, we continued snowballing, so one organization led to the next. For instance, Slimming World, the free stop smoking service and the Stroke Association were organisations that potentially would have users with chronic illnesses. More details about the process of the recruitment and the associations can be found respectively in [Appendix 7 Recruitment field notes](#) and *Table 2: Recruitment strategy* in section [3.4.1. Struggles and challenges of the recruitment](#).

3.4.1. Struggles and challenges of the recruitment

The recruitment was not as easy and quick as expected. We understand that it could have been due to the nature of the group: low income individuals tend not to get involved in research (Braun and Clarke 2013) as well as the sensitive nature of the topic.

We also identified that people were more likely to take part in the study if they were a member of a well-established group (e.g. Stroke Association) rather than unaffiliated individuals that we met in other places such as the food bank, the Fazakerley Community Federation, local shops or Fazakerley Library (see the Outcomes in *Table 2*). First, the managers from the Stroke Association welcomed and introduced the researchers (SEQ and PC) to the members of the association. Also, the researchers went to the place where the members gathered weekly to meet with each other, to do the interviews. Therefore, an atmosphere of trust and convenience was guaranteed. In contrast, individual people would not call us to set up an interview, or would decide against the interview after an initial conversation because they might be not sure of the study or the researchers. Barriers to recruit “hard to reach” population such as enough initiative to call a researcher to volunteer for a study; large amount of time required to locate, select, and retain participants; and difficulty in establishing rapport have been also reported elsewhere (Abrams 2010).

Organisation	Key contacts	Approach	Outcome
Food Bank Fazakerley	Manager and volunteers	Introduced the study, and asked the workers to forward information about the study to the foodbank users.	Any foodbank user contacted us.
Fazakerley Health Forum	Health and wellbeing coordinator	Presented the study into the meeting, and asked to circulate the information to members of the public and/or potential key contacts.	Any member of the public or potential key contacts got in touch with us.
Fazakerley Community Federation	Manager, deputy manager, advice worker	Introduced the study, and asked the workers to forward information about the study to any eligible participants. They suggested the researchers to attend to an event at the Emmanuel Church. It was drop-in day on welfare advice for the local community. Also, three members of the public were approached and given information about the study.	Any participant referral. The three members of the public didn't express interest on taking part of the study.

Emmanuel Church	Church community worker	Drop-in day on welfare advice for the local community. Researchers held a stall with Fazakerley Federation benefits advisor, Citizens Advice (welfare and legal advice) and Liverpool Healthy Homes.	Two individuals were interested on the study and finally took part of the study. They were interviewed in their houses.
Stroke Association (North West)	Deputy Head of Operations	First, the study was discussed with the key contact. Next, the researchers attended to a group meeting in Fazakerley.	Several members of the Stroke Association expressed their interest verbally and arranged the interview at the first meeting. In later weekly meetings, consent was given and the interview was carried in the Stroke Association meeting location. 12 members took part of the study.
Local shops	Workers	Left fliers and information.	Anybody contacted us.
Free stop smoking service	Manager	Explained the study over the phone and asked to circulate information to any eligible participants.	Any possible participant contacted us.
LiveWire Liverpool	Health trainer	Explained the study over the phone and asked to circulate information to any eligible participants.	Any possible participant contacted us.
Fazakerley Community Library	Librarian	Explained the study, left fliers and asked to circulate information to any eligible participants.	Any possible participant contacted us.
Slimming World	Manager of the Fazakerley group	Explained the study, left fliers and asked to circulate information to any eligible participants.	Any possible participant contacted us.

Table 2: Recruitment strategy

Even though the members of the Stroke Association welcomed the study and 12 individuals from that group took part of the study, we believe that some declined to participate as we were seeking participants who were “struggling to afford food and/or prescribed medication”. Hence, the stigma and shame of “having a tight budget” may have worked against our study recruitment.

3.5. Data collection

Potential participants expressed interest verbally after the researchers (SEQ and PC) explained them the main features of their involvement in the study. Next, a suitable time, place and date for the interview was arranged. Before the interview, the participant was required to understand all the terms expressed in the participant information sheet and to sign the consent form. Field notes about the data collection can be found in [Appendix 8 Data collection field notes](#).

Participants were studied in their natural environment, so the interviews took place wherever the participant felt more confident and relaxed. The objective was to create a friendly atmosphere while conversational in nature. Twelve from fourteen interviews took place in the Stroke Association (Old Roan Baptist Church, Aintree Lane, Liverpool) and the remaining two in the participant's home.

3.5.1. Insights from the data collection

We acknowledged that taking part of the study might be a positive experience for the participants. There were several reasons why people took part of the study. Firstly, the collaborative purpose as William expressed: *“when I was at the hospital over the stroke ward there is a lot of erm... nurses, and doctors who were learning, used to come and ask me wanting to ask me questions and things. [...] They used to ask me questions and take bloods, I don't mind because they need to learn. They need to learn somewhere don't they, so I was always helpful”*. Another identified reason for taking part of the study was to give the participant a voice through the research. The interview provided the participants the opportunity to be heard and be valuable. Participants felt their experience vital to the research. The majority welcomed the chance to “tell their story”. Moreover, few were impatient to talk and express their concerns and complains to the researcher. Two participants brought notes to the interview in order not to miss any point. Despite of their tiny monthly household income, the voucher received at the end of the interview seemed not a decisive factor for taking part of the study.

There were various facts that made the interviewer and the participant broadly different from each other such as the country of origin, age and role in the society. However, the rapport was built quickly due to the previous “hanging out” and the small talk the researchers engaged in at Stroke Association meetings. The fact that the researcher (SEQ) was young and from Spain (the country that they used to go on holidays) made it easy to approach to them because they want

to know why she was there or where exactly she was from. Therefore, it was easy to make some small talk. It appeared that participants liked to spend time with someone different and young that goes there to find out more about them. Also, empowering participants was essential, that is, to treat them as experts regarding their own experience managing their chronic illness. By approaching the data collection in this way, the interviewer-participant hierarchy was minimised and as a result, it seemed that participants felt comfortable disclosing sensitive information during the interview.

Another issue faced during data collection was the nutrition advice information asked of the researcher (SEQ). Some of the participants were aware of the healthcare background of the researcher (SEQ) and wondered if they could get some advice on health. We noticed participant self-reflection in terms of self-awareness of lack of food literacy (e.g. “*I don’t know what is healthy to eat*”) as well as sense of purpose related to their search for health advice. Sharing their experiences may benefit the participants taking part in a qualitative study (Hutchinson, Wilson et al. 1994).

3.6. Data analysis

The data analysis was carried out throughout data collection, especially initial reflections after each interview, recorded as field notes. The researcher (SEQ) became familiar with the data reading the notes, demographic information and transcripts (Fathalla 2004).

For this study, the theoretical framework proposed by *Bury* (1982, 1991) on the subject of biographical disruption was used in conjunction with supplementary health inequalities literature to inform the final analysis to explore the experience of CVD as a biographical disruption (see [1.8. Putting a face to Health Inequalities through biographical disruption theory](#)). In addition to biographical disruption, thematic analysis was used as a tool of data analysis (Rousseau, Steele et al. 2014, Meirelles and Diez-Garcia 2018). *Braun and Clarke* stated a clear definition and guidelines for thematic analysis (Braun and Clarke 2006, Braun and Clarke 2013), which are used for this study analysis. The qualitative data analysis software NVivo was used to support the data analysis.

3.6.1. Thematic analysis

Thematic analysis was agreed by the research team to be the ideal tool for analysis due to its flexibility. Thematic analysis is a tool that can be used across different methods or approaches. Thematic analysis seeks to understand and reflect people’s everyday reality identifying themes across data (Braun and Clarke 2013). In this study, thematic analysis was used to identify patterns across data following the step-by-step guide from Braun and Clarke (2006).

First, the researcher (SEQ) became familiar with the data by reading the field notes and transcribed interviews. In addition, some first ideas were noted down. Secondly, initial codes were produced from the 14 interviews using NVivo software. After re-reading all codes, some were re-named and others transferred to another code due to its similarity. In total, 169 codes were identified. Next, these codes were organised into seven initial themes. By grouping codes, themes and patterns were identified and organised into categories to analyse (Braun and Clarke 2013). At this phase, a visual thematic “map” was built to sort the codes into themes (see picture below).



Themes were reviewed and its codes. Some codes were moved from one theme to another. Also, three of the initial themes were placed inside the themes, so they became subthemes. More subthemes were developed in other to create a more organised structure, especially for large and complex themes.

An inductive or “bottom up” approach was used to identify patterns within the data, that is, coding the data without trying to fit it into previous themes acknowledged by other studies, or the researcher’s interests (Braun and Clarke 2006). The researcher (SEQ) did her best to avoid having preconceived beliefs about the studied population by “bracketing” or setting aside prejudgments, experiences or hypotheses; although some knowledge about food insecurity and health inequalities was developed through the background reading. The patterns were thus not driven by the researcher’s theoretical interest in the topic, so the developed codes were not meant to fit into a pre-existing coding frame.

3.7. Governance, Ethics and Confidentiality

This research complied fully with the ethical practice guidelines laid out by the University of Liverpool (see [Appendix 9 Health and Life Sciences Committee on Research Ethics Approval](#)). The ethics approval was obtained on 26/05/2017 without any amendments two weeks after the research application (reference number 1815) by Health and Life Sciences Committee on Research Ethics (Psychology, Health and Society). NHS Research Ethics Committees review was not required as participants were not recruited through the NHS.

We did not expect there to be any physical risks associated in this research study. However, while conversing, the participant could feel discomfort with some of the questions. The researchers (SEQ and PC) tried to manage participant distress effectively by acknowledging people's distress (“are you ok? would you like to stop for a while?”). Any interview was stopped due to discomfort or distress. The researchers were expected to gather data in-depth about a sensitive issue, so they might have felt uncomfortable during the interview or emotionally affected afterwards.

This research fully complied with the Data Protection Act of 1998, in regards to the handling, processing, storing and destroying of the study data. All data, including consent forms, audio-recording devices, demographic information questionnaire, anonymised interview transcripts, field notes and participant contact details, were kept in locked filing cabinets and electronically

in a secure file store. Audio files were deleted from the recording devices and encrypted as soon as possible before electronic storage.

Information collected about subjects was not associated with the person to whom it refers. All data included in analysis and write-up were pseudo-anonymised, with removal of identifiable features, such as personal names. Any details necessary for interpretation (e.g. basic demographical information such as age or gender) were asked in a short questionnaire, and participants were advised of this. This process was managed by the researchers (SEQ and PC) during the course of transcription and transcript checking. The audio files were transcribed as soon as possible following the interviews. Each transcription was assigned a code. Only the researchers (SEQ and PC) had access to the secure electronic file which linked personal data to each code.

3.8. Dissemination

On completion of this research study, the results have been written up as part of the Lead Researcher's (SEQ) postgraduate research thesis and submitted for examination. The findings of the study will be submitted for publication in a peer reviewed journal and presented at conferences. In addition, this data may be used for further research.

A summary of the study's findings was sent to participants (see [Appendix 10 Summary of the findings](#)).

4. Chapter 4 RESULTS

Chapter 4 content:

For this study, biographical disruption theory coined by *Bury* (1982, 1991) was used in conjunction with supplementary health inequalities literature to inform the final analysis. In addition to biographical disruption, thematic analysis was used as a tool of data analysis. Data from 14 interviews were coded and grouped into four themes: (1) chronic illness as a disruptive experience (2) struggling for money, (3) coping with poor lifestyle, and (4) reflections on current care. These themes, along with their subthemes, are shown in the following table. There are several subthemes within each themes. Illustrative participant quotes are included within each thematic element to clarify the audit trail from data collection through analysis and interpretation.

Fourteen interviews, demographic information questionnaires and field notes were analysed to identify patterns across the participants' experiences on chronic illness management. Four main themes emerged from the data: (1) chronic illness as a disruptive experience (2) struggling for money, (3) coping with poor lifestyle, and (4) reflections on current care. These themes, along with their subthemes, are shown in *Table 3*. Themes and subthemes are described and illustrated with quotes from the interviews (*in italics*) with the participant's nickname. In addition, demographic information (see *Table 1: Characteristics of the sample* page 55) and field notes (see some examples in [Appendix 11 Interviews field notes](#)) are included along the thesis in order to facilitate the understanding of the findings.

Theme 1: chronic illness as a disruptive experience	Chronic illness narratives: disruption or deterioration?
	What is happening?
	Personal identity
Theme 2: struggling for money	I just live
	Worry and stress
	Support from others
Theme 3: coping with poor lifestyle	I am not healthy
	I am not eating healthily
	Eating on the edge
Theme 4: reflections on current care	Deprived neighbourhood
	Medication usage
	Inequalities on health

Table 3: Themes and subthemes of the study

4.1. Theme 1: Chronic illness as a disruptive experience

4.1.1. Chronic illness narratives: disruption or deterioration?

Using *Bury's* (1982) definition of biographical disruption, the findings of this study suggest that the experiences of chronic illness were biographically disruptive. However, the nature and extent of disruption varied among participants. Some stroke survivors reported that their life changed completely or as Derek revealed *"before the stroke, I had a future"*. Derek was studying for his degree and working part time at the age of 40 when he had his stroke. His plans of moving abroad with his family were interrupted by the disruptive experience of the stroke and they had to rearrange new plans for their future. For Diana, *"everything sort of fell apart"* when she turned 70 and had a stroke. Despite the stroke, some participants considered themselves lucky for having family or just for being alive.

I was very lucky with the stroke because I wasn't disable in as much as I couldn't walk. The only disability that's remaining with the stroke is memory. Part of my life just don't exist anymore and I am quite bad with trying to remember words. But that's really it. The stroke wise. (Diana)

Diana, who was divorced living by her own in a little detached bungalow with one dog and three cats, owed £15,000 on her mortgage. She also had epilepsy, arthritis, diabetes, obesity, liver problems and a knee operation coming. The stroke may have been a turning point for her but it was one difficulty among many.

As mentioned above, Diana's stroke was accompanied by other conditions. Diana described her co-morbidity as a *"slow deterioration"*, which gives the idea of continuity rather than a disruption (Faircloth, Boylstein et al. 2004). The majority of the participants reported they had suffered a stroke (n=11) in addition to other health chronic problems, including obesity (n=7), depression (n=2), diabetes (n=5), and cancer (n=1). The stroke survivors had to deal with both co-morbidities and the effects of the stroke. They reported sight problems, seizures, swallowing problems, memory loss, communication problems, paralysis and chronic fatigue after having experienced a stroke.

[The stroke] affects my left side, my left leg is a bit heavy but I can use everything else. My voice. My face is a bit dead this side, it is a bit hard to say if it is the stroke or the cancer because I have had cancer as well. (Jack)

Jack had his first stroke when he was 28 years old. He was paralysed from the neck downwards for a while. At that time, he also had tuberculosis. When he turned 61, he was in debt and had another stroke. Then, two of his brothers died. In addition, he suffered from cancer. It is possible that for Jack the stroke was not experienced as a profound crisis since he had lived through other crises such as financial hardship, illness and the death of two brothers (Pound, Gompertz et al. 1998). Stuart provides another example. He was working on temporary jobs at the same time that he was caring for his mother for 28 years. The last 4 years that he cared for his mother were very demanding as he had to be for his mother 24/7. His mother passed away in his arms. These life experiences were described as causing him to suffer with anxiety and depression. He was receiving the carer's allowance but it stopped 10 weeks after the person he was caring for passed away. By the time of the interview, he had not received any benefits for the past 14 weeks. As Stuart expressed in the following sentence, the onset of arthritis was added as a new element to his pre-existing problems.

Once you have got arthritis, it is never going to go away like, it is not a good thing to hear like but that is another worry on you... (Stuart)

4.1.2. What is happening?

Participants with arthritis recognised their chronic illness as painful. As an example, Liam was in great pain when he twisted his leg doing the groceries, and he decided to go to the doctor to check what was happening to his body. The experience of physical pain drew the attention of the participants to their bodies, which may finally lead to search for help (Bury 1982). It was noticeable the awareness of bodily stages for the participants as they could recall all the body parts that were damaged or in pain.

You get to a certain level of pain, and it is normal [...]. It is not good but that you know, when sometimes it hurts me when I am lying in bed, not even moving it hurts. My neck is not so bad. Now and again if I move funny the worst, the way it affects me mainly is driving. (Liam, 76)

Participants frequently described their limitations in activities as a result of their physical impediment. As Liam pointed out *"the most annoying thing is that I can't do what I used to do"*. He engaged in sports, photography and music concerts but he was limited because of the spondylosis in his neck and the arthritis. Terry was 47 years when he had his first stroke. His

balance was completely affected and consequently he had to stop working in the building sector. For these participants, the chronic illness entailed a disruption of the taken-for-granted features such as do sports or work (Bury 1982). The break of these assumptions involved new behavioural adjustments in their everyday life. Some participants also highlighted the inherent social component of the disruptive experience which had been reduced leading to a feeling of isolation.

Before I had my stroke I used to, when we used to go to parties I was always dancing, I didn't have to have a drink just the music, I like dancing and that. But now I can't get up and dance. So when you go to parties, I have to sit there and it makes me sad when I can't get up and dance. (William)

In this study, the “what is happening?” went beyond bodily states. Participants not only drew attention to their body but also to their minds. Some participants in this sample self-reported mental health problems such as depression or anxiety. Commonly, participants “*can't cope*” (James and Jack) with the new situation caused by their chronic illness, which may lead to the development of anxiety and/or depression. Mental problems were considered “*more difficult to address*” (James) and had a bigger impact on participants' health and lives. Participants were conscious of their mental state and its consequences such as family issues. James explained in this quote below how his mental state caused by the stroke affected his personal life.

Well, without beating about the bush, I am depressed, and I am aware that the way I am maybe affects other people. I mean, I said to you, I was living in [somewhere] when I had the stroke and now living in Liverpool, I mean, when I had the stroke I was living with my partner and she asked me to leave, and I am sure that it is because I couldn't cope with having had a stroke and I was and am depressed. (James)

Participants found it hard to deal with their mental state and work out different solutions, making them unable to sort out things and seek help on their own. Indeed some participants pointed out the necessity of being directed and guided through the day. Abigail related that she didn't want to do anything apart from sitting on a chair all day after her stroke, which occurred when she was 72. Her doctor suggested that she went to see a psychologist. She was very keen on trying it. Abigail gradually improved her depressive mental state and started again doing things by herself. James explained how difficult and demanding it was to work out resolutions when being depressed.

I said before about it's difficult to explain, I'll try to explain, I've written down here, 'when I put a key in the door, I quite often turn it the wrong way'. Now a couple years ago, if I turned to the wrong way, I would just think the door or the lock was broken. So I would stand there, just stand there and it might take minutes to make me think to turn it the other way. Now, I just put it in the door and if I turn it the wrong way I would, in a second, turn it the right way. [...] A year or two ago I stood there for 5 or 10 minutes. It is like, when you've had a stroke or when I had my stroke, I... whereas before I would come up with an idea in a second or a minute, it may now take a day or a week. (James)

For some participants in this sample, the disruptive experience of a chronic disease caused not only physical trouble but also mental health problems. The latter were usually less evident than physical ones. Participants felt left out, as nobody understood their ineffable mental state. Abigail and James were aware of their incomprehension.

I meet people and they say you look wonderful and when I say 'do you want to know about my brain?'. (Abigail)

I can walk up and down stairs and they think that's fine. (James)

4.1.3. Personal identity

A personal identity related to their health chronic condition was acquired by the participants of this study, suggesting that their sense of self had changed. The chronic illness prompted a new identity, which was revealed in the interviews by identifying themselves with their chronic illness. For instance, “*my name is William and I had a stroke*”. When asking William to tell something about himself and what was a normal day for him, he replied with the following words (note the times that he repeated “*I had my stroke*”). William’s narrative also reveals the process of re-thinking his life by emphasising the “before” and “after-now” (Bury 1982).

Well before I had my stroke I was erm... I was always on the go. But then when I had my stroke cause all my right side is weak, I need to get around with my stick now. When I had my stroke I was, my blood pressure was 220 /101 so when the ambulance come they said we have to take you to erm... when they think you might have a heart attack... (William)

Terry and Jack also had to re-examine the course of their life story when, by the age of 47 and 28 years old respectively, a stroke broke into their lives. Before their stroke, both participants

assumed that strokes only occurred among elders. As they were relatively young, the event was probably unanticipated for them (Pound, Gompertz et al. 1998). As Terry said “*I was too young to have a stroke*”. Then, they had to re-evaluate the meaning of chronic illness related to the process of ageing.

I thought it was only geriatrics that had strokes, even though I had one at 28, I thought well, it's an older person... I thought it was an older person's disease. (Jack)

There is a final response to the disruptive experience when individuals normalize and face the event using the resources available (Bury 1982). However, there is a wide range of the responses and the adaptations to the chronic illness. After a stroke, Robert and James “*couldn't be bothered*” to do sports, for instance. It “*didn't make sense*” for them anymore. On the other hand, participants, like Andrew and Louis, stated to keep themselves busy with volunteering or fixing things at the house. Even though they had parts of their body paralysed, they showed a strong determination and motivation to keep improving. Their achievements such as being able to articulate words and finally talk, getting over their depression and being able to walk made them feel proud of themselves. Andrew was completely paralysed and had no speech after his stroke at the age of 50. He received rehabilitation and speech therapy that helped him to be able to walk and speak again. These improvements were seen as big accomplishments and they were also compared with others' achievements. By the time of the interview, Andrew was not completely autonomous (some degree of paralysis) and he had some trouble finding some words (expressive aphasia), but he was positive about it and he felt that he had “*still got more to go*”.

In order to adapt to chronic illness, different responses are taken (Bury 1991). In this study, participants normalized the effects of the chronic illness by trying to recover the pre-illness self, to the extent possible (Bury 2001). The example of Andrew described above shows that he was taking action in order to regain voluntary movement and recover his speech. Diana narrated her strategic management of the falls caused by her epilepsy.

Sometimes, if I fall in the garden, I have to sit there quite a while before I can find a way to get myself up but there's no problem the dog brings the ball and expects me to play. Two weeks ago, I had to, I was sitting in the garden for almost an hour before I figured out if I crawl to the nearest bush I may be able to track myself up. (Diana)

As mentioned in section 1.8. [Putting a face to Health Inequalities through biographical disruption theory](#), individuals' chronic illness should be placed within its broad socioeconomic and cultural context. The following themes resulting from the Thematic Analysis will expand the experience of chronic illness by enhancing economic, lifestyle and environmental factors. As mentioned in section 1.8. [Putting a face to Health Inequalities through biographical disruption theory](#), biographical disruption theory is not sufficient to explain the macro-contextual influence of economic, lifestyle and environmental factors on the experiences of illness as a disruption.

4.2. Theme 2: Struggling for money

Experiences of managing tight budgets were common among participants except for three individuals who reported that they didn't have problems caused by low income. The detriment in their health (for ones) or the disruptive experience of chronic illness (for others) was frequently related to job loss, family problems or inability to work. These had considerable negative impacts on participants' budgets. A successful mobilisation of resources was key to strategically manage their chronic illness within financial hardship (Bury 1982).

4.2.1. I just live

A tough financial situation was faced by the majority of the participants. Diana, 76 years old, who was living in a little detached bungalow, explained "*I don't live nicely, I just live*". Derek, 68 years old, said that "*I wouldn't call it comfortable*" living with a state pension. He was not able to have any savings and felt that all he had was "*borderline*". Some reported to "*be used to*" these circumstances. All were receiving welfare benefits that helped them to "*keep the head above water*" (Derek). However, for instance, Robert was struggling to sort out all the bills from his £73/week benefits. Jacob was left with no money for about 9 weeks after he had the stroke. Robert and Jacob had unpleasant experiences when being assessed or claiming for welfare benefits. Robert was asked by the staff why he had not killed himself and Jacob felt judged and stigmatised. It was often a complicated and exhausting procedure that involved lot of paperwork, court involvement or medical evidences compounded by their ill health.

Just the worst 12 months of my life. They asked me, in the assessment if I had ever contemplated suicide, and I said yes and they asked me what I was doing here still alive. That is how bad they were. They asked me why I was still alive, if I had tried to commit

suicide. That was a medical professional, supposed to be a medical professional. [...] Actually said to me, how come you are still alive. Why haven't you killed yourself properly. And that was one of the reasons that I said to the judge, in the tribunal and he was just totally disgusted. (Robert)

And having to go and claim benefits, it is not a very nice procedure. Because they don't treat you very well. [...] When you go and claim benefits now, some of the staff think that they are doing you a favour by giving you benefits even though I've worked for over 20 years and I am only taking out what I've paid in, you know, with tax and national insurance. So it is not like they are giving me anything but they just sometimes make you feel like a second class citizen. Not very nice. (Jacob)

None of the participants were working. Welfare benefits were therefore crucial due to lack of work related income. Terry was working in the building sector and “*earning good money and living comfortable*” before the stroke and he “*went from that to benefits*” struggling with his new financial situation, particularly at first until he learnt how to adjust. James was a freelancer owning a sport shop. He was not able to work after his stroke which affected his sense of self-worth: “*I wasn't able to work and that affected the sense of self-worth, doesn't it? You just don't feel good about yourself*”. Some participants felt depressed and hopeless because of their inability to work.

As a consequence of their financial hardship, participants had to control their expenses and prioritise. The participants had to carefully and consciously select their choices but the priorities varied among participants. James, who was the only one in this sample that had to pay for prescriptions, said that medicines and food are top of his list. By contrast, others' priorities were bills related, so food was not the top priority. Jacob's priorities were his mortgage and secured loan. Jack ensured his bills were paid first and the rest went for food plus £10 a day on cigarettes. Stuart's priorities were also his bills and “*have a roof over his head*”. Diana's biggest problem was losing her house because of her repayment mortgage and pointed out that the utilities: gas, “*lecky*”, phone and television were expensive. Heating was essential for Diana and Derek due to the diabetes and the anticoagulants, respectively.

It is about juggling you know. Again, refer back to the heating the house, you know when you are cold you don't think about eating, you don't think about you just want to heat the house, you want to be warm so... That's your priority that is what you do. And you face

your food the next day you know, I don't sit there and think well, if I don't put the heating on I can buy some food tomorrow, I think I want to be warm so I am going to be warm.
(Derek)

The tough financial situation made it difficult to have savings or even spare money, as Diana said “*a pound will help*”. The majority of the participants were living the day-to-day, economising on their expenses when possible and developing money saving strategies. Diana, whose only entertainment was the television, had phoned the company on several occasions to try to get the price reduced. Stuart had to sell some of his belongings to friends or second hand shops in order to “*try and make ends meet*”. James’s desperate strategy for saving money is exemplified in the following email that he sent to the researcher (SEQ) some days after the interview.

 Reply  Reply All  Forward
 Fri 04/08/2017 13:35
James
Stroke interview
To S.Estecha-Querol@liverpool.ac.uk

Hi Sara,

I hope you are well. I didn't say this the other day as it is slightly indelicate/embarrassing. After my stroke when I got home I only used one piece of toilet paper at a time. It was a pointless attempt to try and save money.

James

Sent from my iPad

It got to the stage where I had basically enough money to pay my bills but not enough money to live on. (Robert)

4.2.2. Worry and stress

The idea of worrying constantly about money became a way of life or a “*second nature*” (Derek) for most of the participants. Their worry about running out of money to pay the bills or food had a harmful effect on their chronic health condition. The stress produced by the threatening financial situation had a role in its deterioration as well. Derek and James admitted that money could mentally make a difference. On the other hand, Abigail stated that although she had a good private pension and did not have to worry as much about money, she “*did check on it and did not overdo things*”.

It is a constant stress of most of the people in there will tell you when you walk in the door, every day you are looking for the white envelope or the brown envelope to call you in so it is a constant, it is constantly on your mind. [...] You are waiting for it on the mat, let's go, go to go through it all again now you know we know it is coming and it is not nice to live with. [...] You later learn that things like stress, it is the worst thing in the world stress, that is one of the things you have got to learn to control and you can only control that with this [money]. (Derek)

These feelings were not only shared among the participants but also among those around them. Relatives worried about participants' health and checked on them often “*to make sure I am still...*” (Robert). Their families and neighbours were concerned about their delicate health condition which indirectly might have an undesirable effect on them as well. In order to relieve participants' worries, their families did the finances for them. For instance, William's and Andrew's wives took the control of the finances, as did Jacob's eldest daughter.

It is just a little bit of pressure. My daughter helps me, my eldest daughter. She'll go through my post. Like sometimes I won't open letters because I panic too much in case it's a bill. So my daughter will open them up and I give her permission to deal with them on my behalf and if there's any money there then I'll pay them. (Jacob)

4.2.3. Support from others

Support came from family, neighbours, friends, churches, associations or foodbanks; and it could be both material things such as food, money or furniture and less tangible things such as emotional support, speaking on the phone on their behalf, doing the decorating or gardening. Some participants, such as Diana, appreciated the help. However, getting support, especially

material things or money, made the participants feel embarrassed. Stuart felt ashamed for “*being needy*” affecting his sense of self-pride. Although he did not ask, church, friends and neighbours were willing to help him by giving meals. This could have potentiated stigma preventing Stuart to ask for more help.

But sort of like I hide away from them [church, friends, neighbours] in the end because I don't want to feel as though like I am some sort of like I don't know, for want of a better word like some sort of basket case like, let's all help Stuart type thing. (Stuart)

4.3. Theme 3: Coping with poor lifestyle

An unhealthy lifestyle and barriers to achieving a healthy life were identified by the participants. Financial hardship might shaped food choices. The adversity of the situation as well as the uncertainty about “*the healthy lifestyle*” also played a vital role in their choices. Food poverty or food insecurity - as defined by *Anderson* (1990) (see page 25) - was a reality for some participants in this study.

4.3.1. I am not healthy

An awareness of “unhealthy habits” and how those could harm their health, were reported by several participants. Smoking, unhealthy eating and insufficient physical activity were stated as the main barriers to a healthy lifestyle. After his third stroke, Terry was restricted to a wheelchair, which limited him from doing exercise so he put on lot of weight. He felt that he was not healthy and he noticed breathing problems caused by his smoking habit and the excess of weight.

Participants were aware of ways to improve their health. Also, whilst some expressed intentions or actions to change these unhealthy behaviours, others like Terry, reported that he “*couldn't see*” ways to make improvements. The fact that he was a wheelchair user living in a residential care home probably restricted his lifestyle choices and opportunities. Robert “*couldn't see himself*” being ready for a change.

To eat healthy and be a non-smoker is the ideal thing but... [...] I can't see me, at 54 years old I can't see me changes that much now. [...] I think I am set in my ways now. As long as I can stay healthy and clot less. (Robert)

However, numerous stroke survivors self-reported a healthy lifestyle before the event. They expressed anger, disappointment and surprise as they couldn't understand why it happened to them. Pound et al. (1998) also found feelings of anger and unfairness among young stroke survivors. The event was unanticipated for these young stroke survivors being able to understand why it happened to them. James's narrative also reveals the "why me?" question.

I never thought I was at risk of having a stroke. I mean, it is not like they can tell me to lose weight, stop smoking, stop drinking. I don't drink, I don't smoke... [...] I won the wrong lottery. They can't tell me why I had the stroke. (James)

4.3.2. I am not eating healthily

Participants were aware that their diet had undesirable effects on their chronic health condition. Despite their willingness to change their diet and make better healthy choices, some could not afford the recommended diet. Derek was told by the doctor that he needed to go on a diet for reducing his levels of cholesterol but Derek said that he couldn't afford the diet. By contrast, James believed that money wouldn't make any difference to his food choices.

I think my diet, being very honest about it, is the result of mental problems, or maybe that is an overly dramatic way to put it, mental issues. So, maybe the money wouldn't make whether I had a pound or million pounds, I don't think it would make any difference to me. (James)

Participants were also conscious of being overweight and its consequences and that losing weight could improve diabetes, blood pressure and walking. Losing weight was a common concern among those who self-identified themselves as obese, recognising that healthier eating could make a difference. Participants did try to eat healthily essentially by controlling unhealthy food intake, that is, "putting the brake" (Diana) or "cutting down" (Clare). Nevertheless, the convenience of ready prepared meals (Terry's quote) and the surplus availability of take away food (Robert's quote) made difficult to choose nutritious food wisely.

Normal day to day, a lot of the time I was eating ready prepared meals. [...] It was easier for when, if I come home from work or something like that you know, nuke it instead of spending hours cooking a meal. (Terry)

It was like food on the go, you stop at a café, at a service station and get some chocolate, some coke, a burger, and then of a night time we do our work, we would go out and have a burger or a kebab or sometimes a meal, but it was a lot of junk food all the time. (Robert)

The diet was not always a matter of choice for all participants. They had to rely on others' cooking skills or decisions when living in a family or in a residential care home. Terry, who lived in a residential care home, pointed out that the food provided was *"not healthy because of the way that it is cooked"*, the vegetables were *"soggy and horrible"* and the fruit was *"not fresh"*. Epilepsy, paralysis or a visual impairment were common causes that prevented participants cooking for themselves. Jacob said that his diet was poor because he was not allowed to cook since he might have a seizure while cooking. Instead, he had microwave meals, take away or his daughter and his ex-partner brought him food. Diana and Andrew declared that their diet was better when getting a carer but it seemed to be frustrating for Andrew since he couldn't feed himself due to his paralysis.

Lack of "food literacy" was noticeable among the participants. Food literacy involves knowledge, skills and food choices (Truman, Lane et al. 2017). While few admitted not to be sure of *"which is the right food to eat"* (Terry and Jacob), others believed that they ate healthily (Andrew, Abigail and Jack). However, the diet described by the latter group may not be the healthiest or most suitable diet for their chronic health condition.

I do like chips but I am finding it hard to swallow chips. Boiled potatoes, corned beef, boiled potatoes, tin meat, like mince beef and that. I can make my own scouse so I am alright with that. (Jack)

4.3.3. Eating on the edge

Lack of funds might influence food choices. Buying the cheapest food or reduced deals were frequent money-saving strategies for those who were struggling financially. However, Derek did noticed that *"the quality of the food in a cheap shop wasn't as good as in a quality shop"*. While Terry opined that one meal was the same price as two, Diana said that it was relatively cheap to feed herself. Experiences on food stability over time was defined as cyclical by Derek, again, depending on the funds available.

But I mean the food thing, I mean as I say I think we are, we are just on the borderline between struggling and being comfortable with it and it depends on the time of year.
(Derek)

When the money was not enough to buy food, support from family or friends was required. Although the participants felt grateful and showed appreciation, they also felt embarrassed for having to ask for food. Family and friends were not the only network providing food for those in need. Food banks played an important role when there was not enough money to buy food. Stuart and Jacob described their experiences of food banks. Both agreed on the nice atmosphere and the great treatment but *“people should never be in the position to use one”* (Stuart). Jacob lost his job when he had his stroke and was left with no money for about 9 weeks. Meanwhile he was waiting for the benefits to get payed, the council gave him a voucher for the food bank. Although he pointed out that people working there were very welcoming and helpful, he said that it was *“very degrading”* going to a food bank *“after working for so long”*. He felt embarrassed and went just once to the food bank, not even to the closest. However, Robert never went to a food bank because he was *“too proud to go”*. The inappropriateness of the parcel was pointed out.

I am not a fussy eater, I am not but half the time some of the stuff has only got a day or two, left on it and it is already like, on its way out and they give you a lot of stuff to make the packets up being like sauces and things, and if you are not one for cooking or, know how to cook you are never going to use the sauces. (Stuart)

Experiences of hunger were expressed by the same participants. Stuart had to control his limited budget very carefully. Although he wished sometimes to get some take-out, he didn't do it because it was out of his budget. He realised that buying the desired and required food was a taken-for-granted aspect, which was not longer stable for him: *“it is things you took for granted years ago, it is just, you just can't take for granted anymore”*. Stuart reported not getting many hot meals as well as having to miss some meals which resulted in acquiring strategies to feel full. Jacob felt hungry when the benefits stopped for 9 weeks. He admitted to be worried about running out of food. Once the benefits were sorted, he still panicked when *“the cupboards were empty”* four days before getting paid.

A lot of the time I do eat a lot of cereal to keep myself going rather than having meals. I will have cereal and a cup of tea and that, that's what... [...] You can get cereal really cheap

and that so... [...] I like the one from Aldi you can get that is pretty cheap obviously, it is the cheapest or what I will eat anything whatever I get given. But if I was going to buy I would just get the erm... it is like the rice flakes with like bits of fruit in for 79p, Aldi's own. [...] Or try and get a cheap loaf and just try and get beans and toast and things. (Stuart)

4.4. Theme 4: Reflections on current care

Participants expressed their dissatisfaction with some aspects of the health care system. During the interviews, participants took the opportunity to assert themselves, claimed some missing rights and explained the way that they felt inside the society. These participants' reflections about the wide socioeconomic context shaped and influenced their experiences of managing a chronic illness, therefore the experiences of illness can't be understood without the macro context.

4.4.1. Deprived neighbourhoods

The majority of participants lived within the most deprived areas in Liverpool. These are poor quality areas where the shops are scarce, there are few green areas and only a few community centres. Derek was living in a council state where he said *"there is nowhere to walk"*. He needed the car to go out because he could not stand the crowds in the buses and he required the toilet constantly due to the medication that he was on. The car was necessary for some of them in order to get around. Terry identified the *"unreliable"* transport as the cause of *"don't doing a lot [of activities]"*. William relied on taxis to go out and do the shopping.

Normal day I can go shopping in a taxi, I can carry a bag in a taxi, but when I get to the taxi with my trolley the taxi driver puts it in the taxi [...] There is one shop the garage opposite but, it is expensive. [...] I like to get out, I don't like being stuck in all the time. (William)

4.4.2. Medication usage

All participants except James were exempted from prescription costs. Free NHS prescriptions were offered to these individuals as they were over 60 years old, on benefits and/or suffering certain medical condition such as cancer, diabetes or epilepsy. To enrich the data, participants

were asked to imagine a hypothetical situation in which they had to pay for their prescriptions. They became horrified because they would have to “*cut down on food or something else*” (Diana). Participants agreed that without free prescriptions, they wouldn’t be able to afford the recommended medications, especially those who were poly-medicated (at least 8 participants in this sample). Stuart highlighted the distress that this situation would produce to him.

I have sat down and try and thought it out and it would probably be worse it would probably affect me worse I would probably be more down, and more stressed with the worry. I would probably be more stressed, probably more worried trying to cope. (Stuart)

4.4.3. Inequalities on health

While some participants received welfare advice and rehabilitation support such as care from clinical psychology, physiotherapy, occupational therapy speech therapy or orthoptists, others did not get any of these services. None of the participants had any dietary advice, although some expressed their wish to speak to a diet specialist. The use of care services seemed to be associated with the individuals’ capability to seek help for them. Mental health problems probably might worsen James’s ability to take actions to manage strategically his chronic illness, making him unable to seek for care services and support. By contrast, William claimed to be happy with the existing services as the NHS had been “*spot on*” with him. However, whilst the NHS was theoretically there to help, usually participants perceived that there was not encouragement from the providers: users had to request or seek support to receive it.

Maybe the NHS, if we use the NHS, or the government, needs to be more proactive. Because when I had my stroke, I can’t be proactive. Maybe now I can be a little bit reactive, but then this is what I was saying, three and a half years ago I couldn’t even react. (James)

Likewise, experiences of poor NHS information about accessing care was noticeable among these participants. Derek complained that “*everything that I know I have had to find out. There has been no help*”. Terry was disorientated when asking for his cholesterol outcomes. Jack felt extremely confused when at the age of 28, he got tuberculosis.

They said you had tuberculosis, I didn’t know what that was, I didn’t know it was TB, but at school, I had the injection at school, for the TB so you don’t get it again. The TB but I got it. But apparently the injection you get at school only lasts 3 years, no one ever tells

you, no one ever tells you that. Cause I kept saying it can't be TB because I have had the inoculation against it. (Jack)

Another frequent complaint was waiting to get an appointment for either the GP, surgical procedure or other healthcare appointments.

I've got to see the doctor to, to get to see the doctor you need a note from God but if I can get to the doctor, maybe. But I believe the waiting list for these operations is quite long. (Diana)

Several participants also characterised the government and the NHS as institutions that weren't helping them get through their illness process. Derek believed that there weren't enough social policies: *"I just think they keep going on about being a caring party and party for the people and they are not"*. James seemed disappointed and sceptical about health policies: *"it's maybe too late now in a lot of ways"*. He pointed out that prevention can save money and *"is so much better than cure"*. However, there is not enough money for prevention: *"all comes back to money"*.

One of the things I've thought since my stroke is how wonderful foresight is and how rubbish hindsight is. You maybe need to stop all these problems before they occur. It's not easy. (James)

The North – South divide emerged from Stuart's interview. He seemed to feel he was being treated as a second-class citizen or dismissed when making comparisons with people from the South. Some inequalities were listed:

It is just the people who are running the country at the minute they just don't care. That is the whole problem with the country. [...] The way I am feeling it is just like a class thing all the while like. That is the whole problem with anything to do with this country from my opinion and my visions from where I come from in the north it is just a class divide, and everything is a class divide. Down to sports, down to looking at people, people don't live in the real world from the south and that, everything is taken for granted up there because they have got everything jobs, everything all up there, all the money seems to go up there but it is not easy up north and that. (Stuart)

5. Chapter 5 DISCUSSION

Chapter 5 content:

This chapter includes a summary of the study findings where the data is interpreted according to biographical disruption theory and supported by further studies on health inequalities. It includes also the strengths and limitations of the project, and next steps for future research. Finally, a conclusion section summarises the discussion chapter.

5.1. Summary of the study findings

This study provides a novel and in depth understanding of the everyday reality of people with CVD or other chronic illnesses living in economically deprived neighbourhoods in Liverpool and experiencing economic hardships. Fourteen individuals described their experiences of chronic disease management and its negative impact on their health and wellbeing.

Based upon semi-structured interviews, Thematic Analysis yielded four themes. These themes and their interpretation are discussed below, and explored in the context of other relevant published research. Biographical disruption and health inequalities literature will allow to frame the experiences of chronic disease management for individuals living in a low income area.

5.1.1. Disruptive experience or another chapter in their life story?

In this study, Bury's concept of biographical disruption (1982) was used to theoretically underpin my analysis and interpretation of the rich description of participants' experiences of chronic illness and its management. This study not only focused on the experience of stroke but also collected data about other chronic problems such as depression, cancer or arthritis; self-reported cardiovascular risk factors such as obesity and diabetes; and effects of their CVD, such as seizures or paralysis. This approach allowed us to explain the diversity of experiences of chronic illness among participants. It also places the participants within the contexts of their daily lives since the event, but also, at times prior to the biographical disruption. Furthermore, these experiences were discussed within their contexts of managing these consequences of relative poverty and social disadvantage.

Participants reported different attributes of the chronic illness to their biography, that is, the nature and extent of disruption varied among participants. Bury's concept of biographical disruption (1982) fits, for instance, into Derek's narrative (page 67). He recognized how his life and plans for the future changed dramatically after his stroke, therefore, the chronic illness may be considered as a disruptive experience in Derek's biography. However, the concept of "*slow deterioration*" coined by Diana (page 67), indicates that individual's life was not disrupted by the onset of the chronic illness but rather the chronic illness was part of individual's life story (Faircloth, Boylstein et al. 2004). These diverse narratives reveal different experiences of chronic illness. Similarly, Reeve's study (2010) on experiences of terminal cancer identified two distinct narrative forms: biographical facture (disruption) and biographical flow (continuity).

The concurrence of more than one chronic illness was common among the participants and their narratives shifted from one illness to another (Faircloth, Boylstein et al. 2004). When asking Jack (page 67) how the stroke affected him, he outlined the additional problems of other chronic illness (cancer) since he was unsure if his facial paralysis was due to the stroke or the cancer. In this case, the stroke fused into a continuous chronic illness biography (various strokes, tuberculosis and cancer) and it might not be a disruption but another health problem in the current flow of his life narrative.

Various major crises were continuously happening along participants' life story. Some of the individuals in this sample were already familiar with pain, financial hardship, and death; so the onset of (another) chronic illness was not experienced as unusual crisis (Pound, Gompertz et al. 1998). For Stuart (page 68), his arthritis was nothing unexpected: *"it is not a good thing to hear like but that is another worry on you"*. He seemed to add this health problem on his "life-list" since he accepted that his arthritis would not disappear and that there were other worries in his life.

A frequent point in the participants' narrative was the fact that they were not able to *"do what I used to do"*. Due to the chronic illness and its effects, participants could not, for instance, play sports or work anymore (page 69). Also they brought into their narrative the "before" and "after" the onset of the chronic illness, revealing that their lives had to be reformulated and there was a disruption of the taken-for-granted aspects (Bury 1982). Participants' life stories after the chronic illness implied a disruption of such assumed everyday practices.

Pain was acknowledged by participants, leading to the consciousness of bodily stages (Bury 1982). The "what is happening?" moment for Liam was pain in his leg (page 68). This drew his attention to his body and he went for a medical check. He recognised that the pain *"is not good"* but he could stand a certain level of pain. In Bury's words (1991), he was coping or learning how to tolerate the effects of illness. Liam also said that the pain was *"normal"* when he moved, drove or lay on his bed, so he was incorporating the impact of the illness into his everyday life. In this study, participants not only spotlighted physical discomfort but also psychological pain and its impact on participants' health and lives (see James' example page 69). A fragile mental state had an impact on relationships and social interactions leading to isolation (see William's example page 69) or incomprehension (see Abigail's and James's quotes page 70). This was similarly found among Danish stroke survivors who reported a limiting of their activities and participation outside home showing avoidance behaviour (Pallesen 2014).

Despite the chronic disease and its physical consequences, it seems that mental health problems were more difficult to tackle and assess. In contrast to their response to physical symptoms and disabilities, none of the individuals of this sample with anxiety or depression sought for professional help, despite their consciousness of their painful mental state. Anxiety or depression seemed to make the participants mentally dependent on someone who could tell them what to do when they faced problems, since it was difficult and demanding to sort out relatively trivial issues on their own. This struggle possibly explains why the participants did not seek for help when suffering from psychological pain. As *Bury (1982)* explained, when suffering from a physical illness, the patient's access to medical knowledge allows them to separate the disease and selfhood. This separation of now-visible disease from self is key to facing the effects of the chronic illness and legitimating an individual's actions (*Bury 1982*). Knowledge about disease process, medications and treatment is necessary for success in managing chronic illness (*Schulman-Green, Jaser et al. 2016*). However, for some participants in this study, the difficulty to self-manage the chronic illness was not physical related but psychological. For this reason, I propose to broaden the concepts: now-visible disease and selfhood; and add the term "non-visible disease". The term "now-visible disease" was coined by *Bury (1982)* and refers to physical features of the chronic illness. The term "non-visible disease" suggested here indicates the psychological features of the chronic illness. Hence, individuals experiencing a disruptive event may re-examine the relationship between the now-visible disease, the non-visible disease and selfhood when facing the effects of the chronic illness. Yet, literature on biographical disruption has not paid attention to the mental state of individuals experiencing a chronic illness (*Williams 2000, Reeve, Lloyd-Williams et al. 2010*).

The sense of self had changed as a result of the disruptive experience. However, stroke survivors were determined to recover their pre-stroke sense of self, a consequence also referred to in earlier studies (*Bury 2001, Hubbard, Kidd et al. 2010*). For instance, Andrew (page 71) attempted to restore his mobility and his speech in order to recover his pre-stroke lifestyle and identity. Moreover, a self-imposed personal identity seemed to be developed by the eleven stroke survivors in this sample as their life revolved around their stroke and its after-effects. In a meta-ethnographic synthesis it was found that while there were chronic patients who perceived their "true and genuine" identity threatened by the illness, thus denying and hiding their health condition, others chose to accept it (*Röing and Sanner 2015*). Membership of the Stroke Association might contribute to the personal identity development. The participants were located

in a stroke-focused atmosphere that inclined their mental state towards the incident of their stroke and its consequences. For the aforementioned reasons, the setting where the interview took place might have reinforced their stroke self-identity.

Bury (1982) described the re-thinking of the person's biography as one of the elements of biographical disruption: why now? why me?. Terry and Jack (page 71) had to re-evaluate their lives after a stroke when being relatively young. After the disruptive event, the process of re-thinking started: they could not understand why this event had happened to them since they believed that only elders have strokes. Pound *et al.* (1998) studied the relationship between the onset of stroke and the age of working class individuals living in East End of London. They found that stroke survivors assumed that the event during old age was "inevitable" while having a stroke during young age was worse leading to feelings of anger.

In the process of experiencing a biographical disruption triggered by a chronic illness, there is a final response to the disruption, which aims to face the situation (Bury 1982). For some participants in this sample, it was noticeable in the struggle in overcoming their new illness experience. For instance, Robert and James "*couldn't be bothered*" to pursue activities that they used to enjoy (page 71). On the other hand, Andrew and Louis managed differently the impact of the illness by carrying out actions such as volunteering or fixing things at the house (page 71).

5.1.2. Economic realities

The financial hardship experienced by the participants in this study should be placed within the current time of austerity. Since welfare reforms have been applied in the UK, public spending has been considerably reduced (Barr, Higgerson *et al.* 2017). It introduced a wide range of reforms to the benefits system, tax credits system and NHS funds (Whitehead 2014). It has also worsened the health gap affecting specially those living in disadvantaged areas (Whitehead 2014). As mentioned in section 1.7.1. [Liverpool context](#) (page 20), the local authority budget in Liverpool was greatly reduced (Liverpool City Council 2017). In the context of this study, such budget cuts could have aggravated the economic issues among the participants.

In this study, experiences of financial hardship resulted in deprived and accustomed ways of living: "*I don't live nicely, I just live*" (Diana, page 72). All their most expensive belongings such as their house, car or television were perceived as limited "*everything is borderline*" (Derek, page 72) and economically supported by the welfare benefits "*if the benefits stop we are in trouble*".

Participants did not consider, for instance, their car as a luxury but as a necessity in order to make their life less dull and provide both physical and mental mobility. The television was the only source of entertainment for Diana as she could not afford hobbies (page 74). As a result of the constrained budget, participants consciously controlled their expenses, developed money saving strategies and established a priority scale where paying the bills was the top priority for the majority of participants (Jacob, Derek, Stuart, Jack and Diana, page 73). The project “*Getting by?*” illustrated similar findings (Kyprianou 2015). The Liverpoolian families participating in the study showed their financial hardship and the struggle of cutting back their daily expenses. In our study, once the bills were sorted, there was insufficient money to live decently at a time of austerity, which seemed to lead to feelings of deprivation: “*enough money to pay my bills but not enough money to live on*” (Robert, page 74).

This financial hardship was often expressed as feelings of unfairness among the participants. Jacob worked until his stroke disrupted his ability to do so (page 73). After his stroke, Jacob was “*only taking out what I’ve paid in*”, when he felt judged by the staff working in the administration. Terry said that he was living comfortably working in the building sector before his stroke (page 73). His quote “*went from that to benefits*” may express discontent with his new financial situation driving to feelings of unfairness. Feelings of unhappiness and unfairness of having worked hard during life and after a disruptive chronic illness having to experience financial adversity were reported by Bury (1982). Terry pointed out the adjustment of his economic situation by highlighting the “before” and “after” his stroke. He seemed to experience a disruption of the taken-for-granted aspects regarding his wage, so eventually he might have to rearrange his budget (Bury 1982). Hence, the chronic illness changed the economic situation for some of the participants reducing opportunities for household income and forcing participants onto welfare benefits and relative poverty, which might have deteriorated the ill health.

An acceptable entitlement to welfare benefits may be a lifeline for participants and their families at a time of austerity. In this study, all participants were receiving welfare benefits. Experiences of claiming benefits and some barriers to a correct entitlement were reported by the participants. Some felt stigma in claiming financial help regardless of their chronic condition. The procedure was frequently disproportionate and frustrating, which may lead to suicidal feelings and embarrassment (Whittle, Palar et al. 2017). The local administering institutions possibly potentiated this stigma “*the staff think that they are doing you a favour*” (Jacob, page 73). Consequently, participants might have felt branded as “shirkers” and “scroungers” (Garthwaite

2011). Stigma towards welfare recipients is not only encouraged by the administration (Whittle, Palar et al. 2017) but also by print media (Reeves and de Vries 2016). The findings from this study further extend the previous literature by questioning the bureaucratic system.

The benefits claiming procedure was often misunderstood and hard to access for patients with chronic health problems, due the scarce information and complex claim forms (Chapple, Ziebland et al. 2004). Stroke survivors, for instance, might face mobility, communication and cognition challenges, which made the procedure more arduous. This procedure may be especially hard for those with debilitating mental health problems triggering under-claiming (Frost-Gaskin, O'Kelly et al. 2003). Indeed, mental health problems are the principal cause for being entitled to sickness-related benefits in the UK and the trends are increasing (Viola and Moncrieff 2016). Yet, British benefit recipients had worse health than the general population (Garthwaite, Bambra et al. 2014). Particularly, the Liverpool Mental Health Consortium shown that the cuts and austerity impacted greatly the mental wellbeing of Liverpoolian residents (Liverpool Mental Health Consortium 2017).

Financial worries may be linked with the incessant stress faced by the participants. This worry and stress had a noticeable negative effect on their health condition. Stress was money related and was defined as *"the worst thing in the world"* by Derek (page 75). Participants often lived with the pressure of bills to be paid. The task of dealing and paying the bills on their behalf, was eventually delegated to their families, so they *"panic"* less (Jacob, page 75). Relatives worried about their health and checked on them often *"to make sure I am still..."* (Robert, page 75).

Those with a reassuring network of family and friends (e.g. Andrew and Louis) seemed to have less economic problems than those without it (e.g. Robert and Jack). The presence or absence of a supportive social network was found to affect the course of chronic illness (Bury 1982), for instance, a supportive social network might be protective against the effects of disruption. Changes in social relationships may occur after a disruptive event (Bury 1982). Individuals may use their network and undertake actions in order to manage successfully the chronic illness (Bury 1991). For instance, participants in this study accepted money from family or furniture from neighbours. While some participants appreciated the help, others felt embarrassed *"for being needy"* (Stuart, page 75). Bury (1982) noticed that the stigma may affect individual's ability to mobilise resources to advantage. In this study, three elements might be the origin of participant's feelings of shame and stigma. First, getting but not being able to give to, or help, others. Secondly,

feeling the centre of people's charity "*sort of basket case like, let's all help Stuart type thing*" (Stuart, page 75). Finally, receiving help without even asking for it (Stuart, page 75).

5.1.3. Healthier living

Personal lifestyle factors such as smoking habit, diet or physical activity have been the target of health interventions, also called "downstream" interventions (Smith, Hill et al. 2016). Current evidence points out the necessity to switch to "upstream" interventions since the focus on lifestyle factors is ineffective and enlarges the health gap (Jepson, Harris et al. 2010, Marmot 2010, Williams and Gibson 2018) since people living in deprived areas do not benefit from behavioural change interventions (Jepson, Harris et al. 2010, McGill, Anwar et al. 2015). However, neoliberal policies are still on the health agenda focusing on lifestyle factors and underlining self-responsibility on lifestyle choices (Williams and Fullagar 2018). Neoliberalism seeks to blame those with chronic illness making them responsible for their impairments, which finally feeds stigmatisation (Scambler 2018). In addition, governments aiming to target the social determinants of health end up again undertaking lifestyle interventions (Hunter, Popay et al. 2010), as for instance, this recent study carried out in the North West aiming to tailor lifestyle interventions to low socio-economic populations (Coupe, Cotterill et al. 2018). According *Hunter, Popay et al.* (2010) a real change in health policies requires an appropriate government action and a radical shift in health policy implementation by tailoring interventions to the local context and empowering communities. Hence, whilst there still exists a promotion of behaviour change by encouraging adherence to a "healthy lifestyle" (Williams and Fullagar 2018) people living in the most disadvantaged areas "do not 'choose' not to be healthy" (Dorling and Thomas 2009). Interestingly, health behaviours were nevertheless the most important factor presented by participants to explain ill health when exploring lay perspectives on health inequalities (Blaxter 1997, Garthwaite and Bambra 2017). Similarly, UK narratives on experience of chronic illness management were framed within an individual responsibility discourse emphasising lifestyle choices (Vassilev, Rogers et al. 2017).

It is therefore interesting to note in the light of the evidence about upstream causes of health problems and inequalities outlined above, that smoking, unhealthy eating and insufficient physical activity were suggested as the main barriers for a healthy lifestyle by the participants. Indeed, these factors are, among others, key determinants of premature mortality (Stringhini, Carmeli et al. 2017). In addition, factors affecting food choice were also acknowledged: lack of

food literacy, convenience and excessive availability of junk food, not being able to cook, settled unhealthy habits and a lack of funds. Similar findings were also observed in the National Diet and Nutrition Survey conducted between 2003 and 2007 in low income populations in the UK (Nelson, Erens et al. 2007).

Among these factors affecting food decision-making, financial restrictions had a great impact on the participants, leading not only to unhealthy food selection, but also food poverty. The conscious selection of the cheapest food and reduced meals was determined by the funds available. While some participants pointed that they could not afford a healthier diet, others believed that money wouldn't make any difference to their food choices (page 77). *Vassilev et al.* (2017) also found that financial difficulties were unrelated to food choices whereas personal preferences and acceptability were more linked with food choices. Among UK respondents from *Vassilev's* study living in deprived settings accentuated their individual responsibility for unhealthy choices, which was felt as a failure with resulting self-blame and shame (Vassilev, Rogers et al. 2017). When it was complicated to afford to buy food, participants in this sample relied on family, friends or food banks. Feelings of shame and stigma were frequently reported by the participants in these scenarios. "*Too proud*" or "*I feel embarrassed*" were commonly used phrases (page 79). These experiences of shame might have prevented some participants to seek help resulting in skipping meals and not having enough quality nutritious food, which could have worsen participants' physical and mental health. Bury (1991) pointed out that stigma affects individuals' ability to mobilise resources. Participants also seemed to have sense of unfairness produced by the fact of having worked so hard and now being struggling to get food (page 79) (Bury 1982). Experiences of hunger and worry about running out of food were also reported by participants. These experiences were similarly reported among foodbank users in the UK (Garthwaite, Collins et al. 2015) and food insecure families living in South London (Harvey 2016).

Participants were aware of the negative impact of an inappropriate diet on their cardiovascular health. The recommended diet was often described as being unaffordable, and consuming an unbalanced diet could have a detrimental health impact. Further qualitative work has suggested that food insecure adults have difficulty affording healthy food which worsens their chronic diseases (Wolfe, Frongillo et al. 2003, Garthwaite, Collins et al. 2015). These findings have been also reported in quantitative based studies (Seligman and Schillinger 2010, Laraia 2013). Interestingly, the direction of this causality has been questioned by *Gundersen et al* (Gundersen, Kreider et al. 2011). The effect of food insecurity on health outcomes is clear but there is scarce

knowledge of whether a poor health condition would affect food insecurity. The authors proposed that the causality might occur in both directions.

In this study, the four dimensions of food insecurity were detected: availability, access, utilisation and stability (Ashby, Kleve et al. 2016). Availability implies “a reliable and consistent source of enough quality food for an active and healthy life. Food needs to be available in socially acceptable ways”. For some participants, food was not always available. Quotes such as “*the cupboards are empty*” or “*a lot of the time I do eat a lot of cereal to keep myself going rather than having meals*” meant that Stuart was experiencing hunger (page 79), so he was not receiving enough food to meet his nutritional needs. In addition, accepting food from family, friends or food banks are compensatory mechanisms for achieving food availability. Access refers to “the economic and/or physical resources required in order to put food on the table”. Participants reported that they couldn’t afford their preferred food choices or follow recommendations about healthy eating. Physical resources such as a taxi to go shopping (William, page 80) were necessary to access food. Utilisation refers to “the intake of sufficient and safe food which meets individual physiological, sensory and cultural requirements. It also refers to physical, social and human resources to transform food into meals”. Regarding food utilisation in this study, Terry noticed that the food at his residential care home was not fresh, he described it as tasteless and unhealthy (page 78). Additionally, Stuart found the parcel given by the food bank as inappropriate (page 79). Finally, stability recognises that “food insecurity can be transitory, cyclical or chronic”. Food instability may vary over time. This was acknowledged by Derek when pointing out “*it depends on the time of year*” (page 78).

5.1.4. Placing the findings in context

The majority of participants lived within the most deprived neighbourhoods in Liverpool which may have had a direct impact on their health. We identified some key linking factors: public infrastructure, job opportunities, means of transport, access to the NHS, pollution, food access, type of food available, safety and green areas. The impact that the neighbourhood has particularly on obesity outcomes and some driven-factors were acknowledge in Graham’s book chapter 9 (Graham 2009). Neighbourhoods influence health behaviours and outcomes (e.g. easy access to cheap junk food might cause a poor daily nutrient intake) as well as a long-term health impact (e.g. weight gain arising from an unbalanced diet over many years). Meanwhile, the availability of nutritious food stores and sport amenities might encourage healthier neighbourhoods. It is

therefore important to assess how social and physical environments can support good health and narrow health inequalities (Pearce, Mitchell et al. 2015). “Upstream” interventions like housing policies may encourage healthy and suitable places to live. These interventions may greatly reduce geographical inequalities improving at the last people’s health status (Bambra, Gibson et al. 2009, Dorling and Thomas 2009). For instance, facilitating people with poorer health and lower income to live in more wealthy areas (Arthurson 2010).

Place matters for health since life expectancy rates are greater in the poorer areas than wealthier areas (Dorling and Thomas 2009, Office for National Statistics 2017). However, it is also important to explore how people living in relatively deprived areas perceive their environment. Perceptions of place may impact on residents’ wellbeing (Airey 2003, Popay, Thomas et al. 2003, Bolam, Murphy et al. 2006). In this study, the majority of participants lived within the most deprived areas in Liverpool according the Index of Multiple Deprivation. Participants seemed to have the need to go out from their neighbourhoods (page 80), which suggests that the participants might hold negative representations of the place where they lived.

Although participants expressed some discontent about the health care system, free prescriptions were especially valued as participants would not be able to afford the recommended medication otherwise (page 80). Free NHS prescriptions were guaranteed for all participants in this sample except one, so participants did not report cost-related medication underuse. However, participants disapproved the waiting list, the insufficient information provided by the NHS and the prevention policies (pages 81 and 82). For instance, James noticed that despite of the fact that prevention can save money long-term, there is not enough investment in it (page 82). Indeed, prevention and control of non-communicable diseases is now out of the policy priorities agenda (Maher and Sridhar 2012). Even though prevention is more cost-effective than treatment, it has been suggested that behavioural change interventions targeting poor individuals may be less cost-effective (McGill, Anwar et al. 2015). Notwithstanding, it is important to consider the potential impact on widening health inequalities.

Participants felt unheard and misunderstood. They expected concern about their illness situation from service providers so that their needs would be met. However, the “logic of managed choice” in the UK accounts the patients for their own health and resource utilisation (Pilgrim, Tomasini et al. 2010). In this study, some participants were not able to look for care services self-sufficiently. Some factors could prevent or encourage people to seek help and access to health care. For

instance, trust in the NHS encourages patients to access health care as well as improving patient satisfaction and adherence to treatment through facilitating agreed management plans and congruence. This, will indirectly influence health outcomes (Calnan and Rowe 2005). On the other hand, perceived stigma may act as a barrier to accessing healthcare, which worsens chronic illness management and quality of life (Earnshaw and Quinn 2012). In this study, participants' inability to seek care services and support (e.g. *"when I had my stroke, I can't be proactive"*, James, page 81) suggests that their experience could be improved if the NHS was not only more accessible to them, but staff also to take the initiative and seek out those in need among low income areas in order to diminish health inequalities. Secondly, associations and community services could more actively promote individuals with a chronic health condition to engage with the range of available health services indicated as useful by a needs assessment. Despite some apparent inaction, participants described how they were willing to improve their health, especially their diet, findings also reported by the Low Income Diet and Nutrition Survey (Nelson, Erens et al. 2007). This willingness to improve their health and diet, narrates the individual responsibility discourse in managing chronic illness, where behaviour is considered to be the key to achieving a desirable health condition (Vassilev, Rogers et al. 2017).

As members of today's British society, the concept of second-class citizen flourished among the participants: *"the way I am feeling it is just like a class thing all the while like"*(Stuart, page 82). Two possible complementary hypotheses are proposed. One explanation would be the North – South divide (Green 1988, Hacking, Muller et al. 2011). As Stuart mention (*"it is not easy up north"*), some inequalities are observed between regions such as life expectancy, mortality rates, employment, welfare receipt, educational attainment, and health outcomes (Bambra, Barr et al. 2014, Whitehead 2014, National Institute for Health Research 2017). The second is related to the neoliberal ideological discourse which states straightforwardly that *"you get what you deserve"*. It suggests that lifestyle choices are to blame and makes the affected population responsible for its own impoverishment. Life becomes punitive and harsh for the *"less deserving"* ones (Whittle, Palar et al. 2017). People with few economic resources tend to believe that they are the only determinant driving them into the deserved situation, so it becomes impossible to change or improve their circumstances (Reading 2014). Moreover, neoliberal policymaking strategies such as service privatization, cuts in the public services, welfare retraction, gender and ethnicity discrimination led to widespread inequalities (Whittle, Palar et al. 2017).

5.2. Strengths and limitations

To the best of our knowledge, experiences of food insecurity especially among those at risk of CVD and other chronic illness still unexplored issues among deprived communities in the UK. Therefore, the main strength of this study is to add qualitative data on this topic within the North West Coast context. Biographical disruption was used as theoretical approach to study the experiences of chronic illness. In order to enrich these experiences, this study includes economic, lifestyle and environmental factors which impact on the degree of biographical disruption. Hence, biographical disruption theory and health inequalities evidence were combined to explain the diversity of experiences of chronic illness and how the wide social-economic and cultural factors (macro-context) impacted upon the chronic condition of the participants. This approach enriched the findings by not only analysing the meaning of the chronic illness management but also by giving an interpretation framed within the macro and the micro context of the individual. In addition, considering the scarce biographical disruption literature on cognitive elements of experiences and consequences, this study adds the concept of “non-visible disease” to indicate the psychological features of the chronic illness and also suggests that more in-depth research is needed to understand the “mental pain” of people experiencing biographical disruptions.

This study has some limitations. First, the funding and original question was food and medicines poverty among those at risk of CVD, so the data and the topic guide reflect this primary focus. The findings from this study demonstrate experiences of food insecurity in individuals living in low-income areas, however, access to medicines turned out to be less of a problem among this sample as, except one participant, all had access to free prescriptions. This study collected experiences of stroke and other chronic problems such as depression, cancer or arthritis; self-reported cardiovascular risk factors such as obesity and diabetes; and effects of their CVD, such as seizures or paralysis. Although this approach allowed us to explain the diversity of experiences of chronic illness among participants, the data were not collected initially for biographical disruption analysis, so more in depth narratives on the disruptive experiences of other chronic illness, self-reported cardiovascular risk factors and effects of their CVD could be missing. Second, twelve out of fourteen participants were recruited from the Stroke Association. Therefore, the findings may not be applicable to other deprived groups not represented in our sample, including people with other CVD, more severe disabilities and others who do not join health care associations. Although in this sample there is no other CVD apart from stroke, all participants self-reported at least one risk factor of CVD (e.g. obesity, high blood pressure, diabetes...). Third, in this sample there were

only three women which may be a result of the smaller number of women attending the Stroke Association compared with men. Gendered experiences of CVD management within individuals living in a deprived area was not explored because of the small sample of women in this sample and this was not among the objectives of the project. Further research on CVD management using biographical disruption theory should explore gender differences. Fourth, this in-depth preparation work was not possible in the event as the local areas were less developed as co-research sites than had been anticipated when the work was planned, as part of the NIHR CLAHRC it was set within. Finally, as lead researcher's (SEQ) mother tongue is not English, it may have limited her nuanced understanding of the interviews and interpretation.

5.3. Next steps

The findings from this study illustrate the complex every-day reality of people living in deprived areas coping with a chronic illness from a broad outlook through biographical disruption theory. Building on these findings, future research should develop more in depth understanding of food insecurity, mental health issues, food choices and local environment in deprived areas in the UK.

To complement the qualitative data, it would be useful to collect quantitative data using validated questionnaires that measure food insecurity (e.g. the FSSM), psychological distress (e.g. Depression, Anxiety and Stress Scale), height and weight, SES (e.g. Index of Multiple Deprivation, education, annual income) and dietary intake (e.g. 24-hour diet recall, food frequency questionnaire).

More in-depth collaboration and preparation work with the community would boost recruitment numbers and breadth. Researchers would need to work with local community champions, recruiting through a range of settings, including the NHS. This co-producing strategy will probably take more effort and time, but might prove worthwhile.

5.4. Conclusions

This study described and interpreted the everyday reality of 14 low-income individuals managing a chronic health disease. For analysis purposes and a better exposition of the findings, the data

were grouped into four themes. However, all themes are linked and it is not possible to understand one theme in isolation from the others. Participants' behaviours and reflections are framed by their socioeconomic context: individuals living in a low-income area of a developed country. Their story, therefore, needs to be related to this particular socioeconomic context and interpreted within this context. In addition, the theoretical framework proposed by *Bury (1982)* was used to understand individual experiences of chronic illness as a biographical disruption. As mentioned in section 1.8. [Putting a face to Health Inequalities through biographical disruption theory](#), *Bury's* concept has its limitations (a critical review of this framework can be found in (*Williams 2000*)), especially when explaining the impact of the wide social-economic and cultural factors (macro-context) on the chronic condition of the individual. *Williams (2000)* suggested that not all chronic illness are biographical, as that depends on context, biography as well as the point in the life course; instead, he suggested focussing on biographical disruption as a cause of chronic illness. The varied nature of participants' narratives about their chronic illness indicates that the experience of biographical disruption is context specific (*Pound, Gompertz et al. 1998, Williams 2000, Faircloth, Boylstein et al. 2004, Hubbard, Kidd et al. 2010, Felde 2011*): dependent upon previous experiences of illness, financial hardship, support from community networks or family, mental health issues and geographical disadvantages. Therefore, the variety of contexts creates heterogeneity of experiences (*Williams 2000*).

According to *Bury (1982)*, chronic illness is experienced as a disruption of the taken-for-granted features and future plans. This biographical disruption confines pain or signs exclusively to bodily stages. Although the experience of chronic illness for the participants in this sample implied body pain and consciousness of bodily stages, this study shows that the signs cannot be only restricted to embodied aspects. Participants experienced psychological pain and its impact on their health and lives. For some of them, the difficulties in self-management of their chronic illness was more psychological than physical. Here I have proposed to introduce the term "non-visible disease" to indicate the psychological features of the chronic illness. Other literature has also indicated the benefit of going beyond bodily signs (*Felde 2011*) and of introducing emotional capital or cognitive elements to better understand chronic health narratives (*Williams 2000, Reeve, Lloyd-Williams et al. 2010*).

When experiencing biographical disruption, there is a final response which aims to face and normalize the every-day situation (*Bury 1982*). At this stage, the individual mobilises both social and material resources. In this study, family not only played an essential role to help participants

with the management of their chronic health condition(s) but also brought them emotional support. It was key to overcoming their life-changing situation. Those who had a strong network felt lucky and reinforced; and had mitigated the mental distress compared with those who were facing their illness in solitude.

In this study, participants' responses and pathways to overcome the chronic illness differed, as do their coping strategies. This might depend on the severity of sickness and disability, other personal or psychosocioeconomic circumstances, point in the life course, or their environment and access to resources. Whether the chronic illness was a single event or one among a series of adverse events or circumstances might also influence how the biographical disruption was experienced or managed (Williams 2000, Reeve, Lloyd-Williams et al. 2010). Coping with adversity may empower the individual to manage the chronic illness as another negative challenge to overcome (Faircloth, Boylstein et al. 2004). Alternatively, the chronic illness may be one too many to cope with, so the biographical disruptive event is experienced as an overpowering one. Moreover, the experience of chronic illness may be felt and faced differently in the individual's biography depending on the type of chronic illness (e.g. cancer may be more disruptive and arthritis more anticipated). On the other hand, the same type of chronic illness can present different biographical forms (e.g. biographical flow and biographical fracture were found among terminal cancer patients (Reeve, Lloyd-Williams et al. 2010)). Co-morbidity suggests that the concept of chronic illness as biographical disruption should be reviewed. Co-morbidity should take into account examining all illnesses that shape individual's experience of ill health. When studying experiences of chronic illness, we may find that different illnesses have different levels of importance. *Faircloth et al. (2004)* noted that for some stroke survivors, the stroke became secondary since other co-morbidities such as diabetes had greater impact on their health. However, it is not possible to unpack these elements within this study, but future work could explore in more in-depth research and extend these concepts.

This study suggests that the nature and extent of disruption varies among individuals (e.g. anticipated, flow or disruption). Future work could develop "narrative analysis tools" to identify different narrative chronic illness patterns (Edwards and Gabbay 2007, Reeve, Lloyd-Williams et al. 2010) in order to support health care professionals in assisting management, mental pain, and strategies to cope and restore the disruptive experience of chronic illness. This would be especially relevant for care and support those who experience mental pain, as this study shows

that they seem not to seek for professional health and it could be consider more difficult to self-manage psychologically the chronic illness.

Individuals were confronted with serious economic issues. They had to prioritise (e.g. food, medicines or bills) and their decisions were not necessarily the most appropriate for their health condition. They were fully aware of worsening their health. Some manifested their willingness to change their unhealthy lifestyle and take some action in the near future, e.g. speak with a nutritionist. These participants were in the stage of contemplation as displayed in the Transtheoretical Model (Prochaska and Diclemente 1986), where the advantages and disadvantages of changing were being explored. On the other hand, others were situated in the stage of precontemplation due to lack of food literacy, lack of motivation, being unready for help or simply do not intend to take action. However, despite of their eagerness, they remained in the stage of contemplation (“chronic contemplation”) being their socioeconomic situation the main barrier to achieve a healthier lifestyle. We suggest that changing eating behaviors in low-income communities may not depend on their will or motivation, but on the circumstances, environment or merely the access to food.

This study shows that there were participants experiencing hunger, skipping meals and not having enough quality nutritious food. These experiences of food insecurity might have being the cause of participants’ mental distress and worry, as also stated by *Laraia* (2013). Her proposed model (page 33) elucidates that the household food insecurity is experienced as a chronic stressor that leads eventually to an augmented risk of chronic disease. In this study, mental health problems were reported among participants. As some participants pointed out, it is difficult to address them. Some of the reasons could be shame, stigma, not enough support from community and NHS providers, poor socioeconomic situation, or health state. Mental health problems might shape their ability to seek for help, so people living in disadvantaged areas managing a chronic illness might be in a cycle where the change depends more on the actions taken by the NHS or policymakers than their own. Despite the NHS’s current funding constraints which reduced its capability to tackle health inequalities, the NHS should actively engage in helping chronic ill individuals living in deprived areas in a time of austerity. In addition, health policies stressing responsibility on lifestyle choices should be replaced with “upstream” interventions empowering communities and avoiding potential stigmatization, so the health gap may narrow across the UK. Finally, this study suggests that more support is required: help and advice with finances,

emotional support from associations, regular checks provided by NHS, more information and access to support healthy choices.

Biographical disruption theory linked with Health Inequalities evidence may be a powerful combination to explore how experiences of chronic illness are underpinned by all layers of influence (determinants of health in Dahlgren-Whitehead rainbow 1991) and how they impact on individual's health status. This study suggests that factors such as economic, lifestyle and environmental (macro-context) influenced how individuals experienced and managed chronic illness. *Williams* (2000) suggested in the following paragraph that future work on biographical disruption should look at wider health inequalities literature expanding on psychosocial features of chronic illness "The relevance of biographical disruption, in short, both conceptually and empirically, may extend far beyond the traditional remit and concern with the personal consequences or significance of chronic illness, providing as it does a crucial aetiological link, via the emotionally expressive body, to on-going research within the life-events and inequalities literature concerning the psychosocial causes of disease. Biographical disruption, in this sense, does indeed have a 'healthy future' ahead of it" (p. 55).

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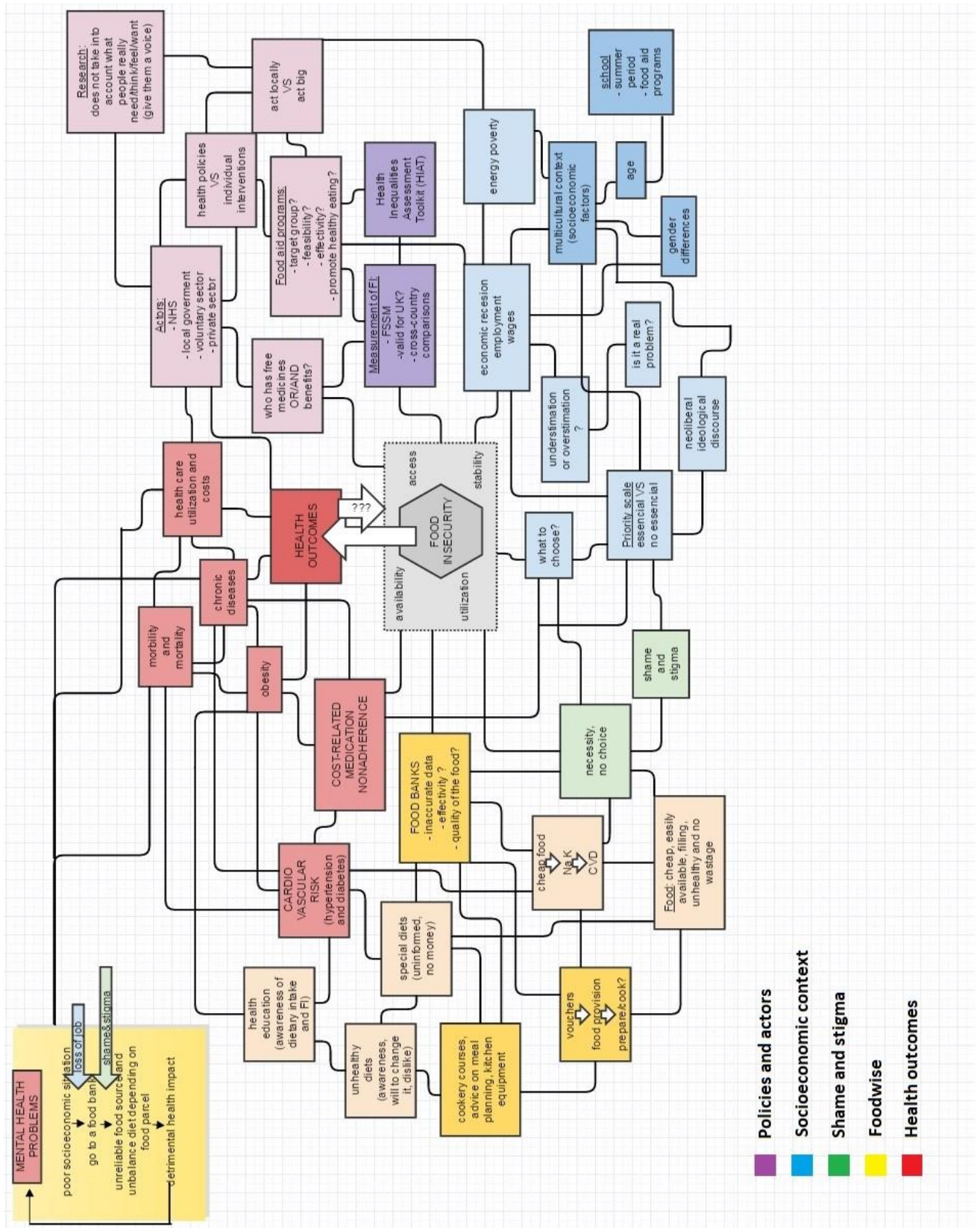
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7. APPENDICES

Appendix 1 Flow chart



Appendix 2 Topic guide

TOPIC GUIDE

I am interested in how having a cardiovascular health condition affects you, your family and your daily life.

Tell me about yourself. Who you live with? How is your life going? Can you talk me through a typical day? Leisure activities, working hours, take care of children/other people.

I am interested in hearing about your chronic health condition. Can you tell me more about it? How this affects to you? To your family? How do you manage it? What changes do you need to make? If you are going through a period when money is tight, does it affect to your health condition? In what extent? What is the most negative thing about having this health condition? The most positive thing (if any)? Do you use any healthcare facilitations (GP visits, hospitalizations...)? Are you happy with the NHS services?

Tell me about medicines. Do you take medicines? Have you been advised about medicines? Are there any you have been prescribed? Do you pay for them? If not, imagine a scenario in which you have to pay for the prescriptions, could you afford them?

I would like to know about your diet. What do you normally eat during the day? Do you think that you eat healthy? Why? What kind of food would you prefer to eat? Can you afford a balanced diet? What changes have you been recommend to make to your diet? Do you think that your diet is different in some way? In what sense?

Tell me about your experience in food banks. Do you go to food bank or have you been going in the past? Can you tell me what it is like for you? Were you ever hungry because you couldn't afford enough food? Have you been worried about running out of food? What do you do? How you feel then? How does it affect to your children or the rest of the members of the family?

Can you tell me how do you manage your budget? What goes first when money is tight? How do you decide what to prioritize? What about food or medicines, is it important for you when you make decisions? How to make decisions affects to you?

I think that's basically everything I had to ask you. Have you got anything else you would like to say or any kind of final thoughts or any thing you would like to follow up that I haven't asked you?

Questions underlined were added into the interview schedule and explored over the course of the subsequent interviews

Appendix 3 Participant Information Sheet



Participant Information Sheet

Understanding the experiences of cardiovascular disease management in low income areas

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and anyone else you wish.

Thank you for reading this.

Who is doing the study and who has approved it?

The study is being carried out by a research team from the University of Liverpool. The research and interviews will be conducted by Pam Clarke, Research Assistant; and Sara Estecha Querol, an MPhil student at the University of Liverpool. This study has been approved by the University of Liverpool's Research Ethics Committee.

What is the purpose of the study?

Cardiovascular disease is one of the main causes of death and disability in the UK. We are interested on investigating cardiovascular disease management when it is difficult to afford food and prescribed medication. We want to know about your experiences on the choices that you make when money is tight, and to understand your priorities.

Why have I been chosen to take part?

If you have a cardiovascular disease, we would really appreciate your participation in our study. Cardiovascular disease involves heart attack, angina, stroke, peripheral arterial disease and aortic diseases.

In addition, if you consider yourself at risk of cardiovascular disease, we would also really appreciate your participation in our study. Risk factors for developing cardiovascular disease include: being older than 60, having a family history of cardiovascular disease, smoking, poor diet, high blood pressure, high blood cholesterol levels, diabetes, obesity and physical inactivity.

Do I have to take part?

It is completely up to you whether or not you agree to take part. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part but then change your mind, you are free to do so at any time without giving a reason.

What will happen if I take part?

You will be asked to take part in an interview. You can choose to be interviewed on your own, or with a friend or family member present.

The interviews will involve you speaking face to face to the researchers, either Pam Clarke or Sara Estecha Querol, about your experience and your views of food, medicines and your choices.

We expect the interviews to last approximately 45-60 minutes, although they will last for as long as you would like to talk about your experience. With your permission, the interview will be audio recorded. You can stop the interview at any time, and you do not have to answer a particular question if you don't want to.

Where will the interview take place?

The interview will be carried out in the place, date and time convenient to you.

The researcher will travel to the social centre or your home if you prefer. Also, you are invited to attend to the University of Liverpool for the interview.

Will there be benefits to taking part?

You will receive a supermarket voucher as well as a summary of the study's findings, if you wish so.

You will be helping to develop our understanding of how it is like living with a chronic condition. Your experiences and perspectives are invaluable and we hope this work will facilitate knowledge to improve cardiovascular management, medication adherence and healthier dietary choices.

Are there any risks in taking part?

We do not expect there to be any physical risks associated in this research study. However, while conversing, if you feel uncomfortable with some questions, you can stop the interview at any time, without giving a reason. The confidentiality of the information you may provide and your anonymity is assured.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Pam Clarke (01517955324 or P.Clarke@liverpool.ac.uk) or Sara Estecha Querol (01517955418 or S.Estecha-Querol@liverpool.ac.uk) at the University of Liverpool and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Governance Officer at University of Liverpool on 0151 794 8290 (ethics@liv.ac.uk). When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

All the information that you give us will be kept strictly confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998.

This means that only the researchers will see what you have said. The audio-recording of your interview will be identified by a code number only. These audio-recordings will be transcribed, removing any identifying details such as people's names from the transcripts. We will ensure any

quotes that we may use in the write-up of the study remain anonymous. However, some general data (age, gender, working status...) asked in the “demographic information questionnaire” may appear in the research but in any case will be associated with the person to whom it refers, so your anonymity is guaranteed. This information is required for the better interpretation of the findings.

At the end of the study the research data, including consent forms, anonymised interview transcripts, field notes and your contact details, will be kept (in locked filing cabinets and/ or password protected university computers) for up to ten years.

What will happen to the results of the study?

After the study has finished, the results will be written up as part of Sara Estecha Querol’s postgraduate research thesis and submitted for examination. The results will also be submitted for publication in an academic journal and presented at conferences. Again, you will not be identifiable from the results.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can withdraw without giving a reason. You can also ask for your data (audio record, transcripts, quotes) to be removed from the study and destroyed.

How can I find out more?

Just get in touch with Pam Clarke or Sara Estecha Querol, who will be happy to answer any questions you might have:

Telephone no.: +44 (0) 1517955324 / +44 (0) 1517955418

Email address: P.Clarke@liverpool.ac.uk / S.Estecha-Querol@liverpool.ac.uk

Postal address: Institute of Psychology, Health and Society, University of Liverpool, Waterhouse Building, Liverpool, L69 3BX

Thank you for taking the time to reading this

This information sheet is for you to keep

Appendix 4 Participant consent form

PARTICIPANT CONSENT FORM

Understanding the experiences of cardiovascular disease management in low income areas

Researchers: Pam Clarke and Sara Estecha Querol

- | | Please
initial box |
|---|--------------------------|
| • I confirm that I have read and have understood the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| • I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline. | <input type="checkbox"/> |
| • I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. | <input type="checkbox"/> |
| • I understand and agree that my participation will be audio recorded. | <input type="checkbox"/> |
| • I am aware of and consent to use these recordings for the following purposes: Sara Estecha Querol's postgraduate research thesis, reports, publications in academic journals and presented at conferences. | <input type="checkbox"/> |
| • I agree for the data collected from me to be used in relevant future research. | <input type="checkbox"/> |
| • I understand that all the information provided will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the reports that result from the research. | <input type="checkbox"/> |
| • Please indicate whether you would like to receive a copy of the findings. | <input type="checkbox"/> |
| • I agree to take part in the above study. | <input type="checkbox"/> |

Participant Name	Date	Signature
Researcher	Date	Signature

Principal Investigators:

Mark Gabbay and Lillian Sattler
Department of Health Services Research
University of Liverpool
+44 (0)151 794 5610
M.B.Gabbay@liverpool.ac.uk

Researchers:

Pam Clarke and Sara Estecha Querol
Institute of Psychology, Health and Society
University of Liverpool
+44 (0) 1517955324
P.Clarke@liverpool.ac.uk
S.Estecha-Querol@liverpool.ac.uk

Appendix 5 Demographic information questionnaire



Demographic information questionnaire

Understanding the experiences of cardiovascular disease management in low income areas

For a better interpretation of the information that you can provide us in the interviews, we ask you kindly to fill out some general demographic information. Confidentiality and anonymity will be maintained and it will not be possible to identify you in any publications or reports that may result from this research.

Your name will not be linked with this demographic information.

If you feel uncomfortable filling out this questionnaire or you don't want to provide this data, feel free not to do it.

Name of the participant: _____

Year of birth: _____ Gender: _____

Number of adults in the household (including you): _____

Number of children in the household: _____

Location:

Liverpool

Blackpool

Knowsley

Employment status:

Unemployed with benefits

Unemployed

Working

Retired

Unfit to work

Ethnicity (how do you define yourself?):

- White
- Mixed/multiple ethnic groups
- Asian/Asian British
- Arab
- Black/African/Caribbean/Black British
- Other ethnic group: _____

Marital status:

- Single
- Married or domestic partnership
- Widowed
- Divorced
- Separated

What is your highest educational qualification (if any)?:

What is your highest professional qualification (if any)?:

Do you receive any welfare benefits?:

- Yes Please, specify: _____
- No

Do you use a food bank?:

- Yes Frequency: _____
- No

Annual household income:

- Less than £400 per month
- Between £400 - £800 per month
- More than £800

Could you indicate if you have had a cardiovascular disease?

- Heart attack
- Angina
- Stroke
- Peripheral arterial disease
- Aortic diseases
- Other: _____
- None from above

Do you consider yourself at risk of cardiovascular disease? Please, indicate which risk factor(s) you consider to have.

- Being older than 60
- Having a family history of cardiovascular disease
- Smoking
- Poor diet
- High blood pressure
- High blood cholesterol levels
- Diabetes
- Obesity
- Physical inactivity
- Other: _____

EXPERIENCES IN CARDIOVASCULAR DISEASE MANAGEMENT RESEARCH STUDY



Are you coping with long-term health problems?



Have you been advised to change your diet or take medicines?

Are you finding it hard to afford to do this?

If so, we would like to learn about your experiences.

We want to learn from you about what is most important and how you juggle with your illness when money is tight. Your experiences are essential for a better understanding of long-term illness management, so you can help us to improve and design future health policies.



If you decide to take part, we (Pam Clarke or Sara Estecha Querol) would like to talk to you face to face for about 45 minutes or for as long as you would like. We can meet you wherever is best for you (your home, community centre, local café...).

To say thank you for your time we want to give you a £10 TESCO VOUCHER

Any questions or if you would like to take part in the study, please just get in touch with **Pam Clarke** or **Sara Estecha Querol**. You can contact us by email P.Clarke@liverpool.ac.uk / S.Estecha-Querol@liverpool.ac.uk, by phone **01517955324 / 01517955418** or let us know the best way to get in touch.

P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418	P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418	P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418	P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418	P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418	P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418	P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418	P.Clarke@liverpool.ac.uk S.Estecha-Querol@liverpool.ac.uk Tel: 01517955324 / 01517955418
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Appendix 7 Recruitment field notes

02/06/2017

Formosa Drive 12:00

- Centre with people with learning disabilities

Shocking to see in there 20 users and only 4-5 workers. They were eating at the moment that we arrived. We thought that it was the Food Bank.

Very nice people, a woman introduced us to the people in the Food Bank. It was just in front of the Learning D centre.

- Food Bank. Settled in St Pauls Church

Very nice and friendly people and atmosphere. They offered us a cup of tea. We sat and chat with them. There were the ~~manager~~, one man, one woman and a old lady who seems to know everybody in the area.

We explained them the project and asked them to hang some adv and info.

A user came with a voucher and took some hygiene products as well.

The place was pleasant but empty at 12:00.

It is opened every Friday from 12:00 to 13:30

The manager said that depends on the period of the year, they get more or less people ("when is summer people don't come here, the alcoholic people go to the park to lie on the grass").

The old lady took us to the:

● Fazakerley Community Federation

She introduced us to the ~~manager~~ manager of the Federation and the deputy. We were welcome and they seemed interested on the study. I explained what was it about and they were happy to hang out some ads. they suggest us to speak with the Stroke Association. We were introduced to a Health & Wellbeing ~~coordinator~~ coordinator who works in the Community Federation too.

07/06/2017

● Fazakerley Community Federation 14:00

We stayed like an hour talking with a old lady in the FCF, about not only our study but also politics, weddings and so on.

We met ~~_____~~ and ~~_____~~ again. They were happy to let us put some more fliers.

We were introduce to ~~_____~~ who works in FCF as a social worker dealing with benefits, vouchers for the Food Bank and this kind of services for poor people.

He will talk to potencial participants and give them ^{the} participant info sheet.

I asked ~~_____~~ and ~~_____~~ about the best shop to buy food. they suggest Tesco.

We put up some ads in local shops.

We came back to FCF and talked with a woman who runs the "Slimming World" talks (every Wednesday at 5:00).

She was happy to target people for us.

Local everybody knows everybody.
~~thoughts~~ people is very nice and
friendly and happy to talk with us
and find out more info about our
study. there are lots of links
but first time when you talk with
people, they don't seem to come up
with the links that we are looking for
easily. It is not quick to obtain that
kind of things, you have to coax and
be talking to them for long time till
you get it. It is not they don't want
to tell it to you, they just need time
to think through.

22/06/2017

After 20 days without any call or email, I realised that we have to change the strategy a bit. Be more proactive. Engage people, "pushing them". Hanging around with a list and taking names and phones (then we'll call them later). Leave a list into the food Bank and FCF, so they can write down names and phones for us. Also, changing the recruitment adv. Shift its style making it more accessible and friendly. We added a pic of the researchers as it makes it more "human", so participant feels like having a conversation. With the pic people may become familiarised with our faces as we are hanging around.

23/06/2017

- Fazakerley Community Library. Morning
We left some flyers and posters. We found out about ~~Travis~~ who is a Health Trainer giving advise on Mondays in the Library. We planned to call her and see if she will be happy to help targeting people for us.
- We put some posters and gave some flyers to shops, petrol stations...
- Fazakerley Community Federation
We met with ~~Steve~~ again. We changed the old posters for the new ones.

I asked to some more members and they said no.

I guess I've reached a point ~~that~~ that all people interested on taking part of the study had spoken to me already or had express their interest to a volunteer/someone who can link them ~~with~~ to me. When someone is interested normally comes after me or when I ask they say straight away yes. So I didn't want to push more.

~~I~~ I can see who may be interested, who is hidden him/herself from me and who won't be suitable for the study (not economical issues or not being able to speak).

Anyway, I really like the experience and I have always felt very ~~welcome~~ welcomed.

When I was leaving and saying goodbye to everyone, the manager - member of the group (participant) spoke out loud

Appendix 8 Data collection field notes

27/06/2017

● Stroke Association 9:30

We arrived early. We felt very welcome, we were offered a cup of tea and we started talking with people about our research.

At 10:00, ~~the~~ ~~man~~ arrived and she explained to us that they gather every Tuesday to socialise like a small family in which everybody takes care of the other. She also told us how the finding works out.

Surprisingly (for me), it is more a social thing rather than a source of health advice. They have a physiotherapist but no one advises them in terms of diet, medication or lifestyles. The members

of the Association were ~~s~~ sitted around few tables making small groups but interacting among all of them. I could see some "leaders" in the group, like the funniest persons or social butterflies.

~~They~~ spoke out laugh and introducing us. We started going around the

small groups and explaining to them our research. They all seemed very happy and interested on taking part. Others were more reserved ^{→ save them time to think} but overall they expressed ~~interest~~ interest.

People was lovely, friendly and approachable. I highlighted the idea of a talk, because an interview could sound a bit formal and could ~~not~~ stop them from taking part of the study.

The fact that I am going and from Spain (the country that everybody likes and has been on holidays) makes ~~it~~ easy to approach to them, because they want to why I am here, where I am from, some small talk is easy to make and it is nicer ~~from~~ from them rather than start with something more formal as the research could look like.

- Les aigo en gracia -

A lovely old man before I started explaining in more detail what is the study about, already agreed to take part.

Appendix 9 Health and Life Sciences Committee on Research Ethics Approval



Health and Life Sciences Committee on Research Ethics (Psychology, Health and Society)

26 May 2017

Dear Prof Gabbay,

I am pleased to inform you that your application for research ethics approval has been approved. Details and conditions of the approval can be found below:

Reference:	1815
Project Title:	Understanding the experiences of cardiovascular disease management in low income areas
Principal Investigator/Supervisor:	Prof Mark Gabbay
Co-Investigator(s):	Miss Sara Estecha Querol, Prof Jason Halford
Lead Student Investigator:	-
Department:	Health Services Research
Reviewers:	Prof Graham Wagstaff, Dr Alexis Makin
Approval Date:	26/05/2017
Approval Expiry Date:	Five years from the approval date listed above

The application was **APPROVED** subject to the following conditions:

Conditions

- All serious adverse events must be reported via the Research Integrity and Ethics Team (ethics@liverpool.ac.uk) within 24 hours of their occurrence.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the research, please create and submit an amendment form using the research ethics system.
- If the named Principal Investigator or Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form using the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Health and Life Sciences Committee on Research Ethics (Psychology, Health and Society)

iphsrec@liverpool.ac.uk

0151 795 5420

Appendix 10 Summary of the findings



Dear participant,

First of all, I would like to thank you for taking part of the study named “*Experiences of cardiovascular disease management*” carried out by Pam Clarke, Sara Estecha Querol and Prof. Dr. Mark Gabbay at the University of Liverpool. Thanks to the contribution I have been able to better understand cardiovascular disease management, their food choices and priorities. We would like to also thank the Stroke Association for all the help and support.

I would like to give you a brief summary of the results of the study.

Experiences of cardiovascular disease management

Thesis project by Sara Estecha Querol

Objective: This study’s principal aim was to produce a thorough understanding of everyday reality for people with cardiovascular disease and other chronic health conditions who lived in economically deprived neighbourhoods in Liverpool.

Methodology: Interviews were conducted with 14 participants whose cardiovascular health was compromised.

Results: Participants’ chronic health condition had an impact on their physical and mental health as well as on people around them. Mental health problems shape their ability to seek help. The adversity of the financial situation played a key role in “forced” lifestyle choices. Bills may be paid but there is no spare money to live comfortably. Food poverty was a reality for some participants in this study.

Discussion: Lack of healthy lifestyle literacy, deprived environments, low welfare benefits, physical and mental health problems as well as budgeting skills have a direct impact in cardiovascular disease management in low income individuals and those around them. A better understanding of the barriers that interfere with low income individuals’ decision making process is needed to be able to support people with chronic conditions living in areas of deprivation, to self-manage their health and wellbeing more effectively. Finally, more support is required: help and advice with finances, emotional support from associations, regular checks provided by NHS, more information to support choices to health and wellbeing.

You have helped us to develop an understanding of what it is like living with a chronic condition. Your experiences and perspectives were invaluable for this study. We hope this project will facilitate knowledge to improve cardiovascular management, medication adherence and healthier dietary choices.

This study has two major policy implications. The first is intended to focus locally. The negative impact of the welfare reform on Liverpoolians has been well documented by several organizations and investigations. Understanding the impact of chronic illness in low income individuals in Liverpool and their every-day experiences of poverty, the local institutions could evaluate the services required by those in need. Nevertheless, austerity and adversity outcomes could, at least, raise awareness among the population and eventually pressure the institutions. The second is aimed at the NHS, which should be more proactive in helping chronic ill individuals living in deprived areas in order to tackle health inequalities. The findings of this study will hopefully have important implications for program design, policy decisions and practice recommendations. They must be carefully considered by policymakers and pave the way for further research.



I am very happy to inform you that I just finished writing up my thesis and I am ready to defend it.

Sara 😊

Thanks again for your participation!

Researchers:

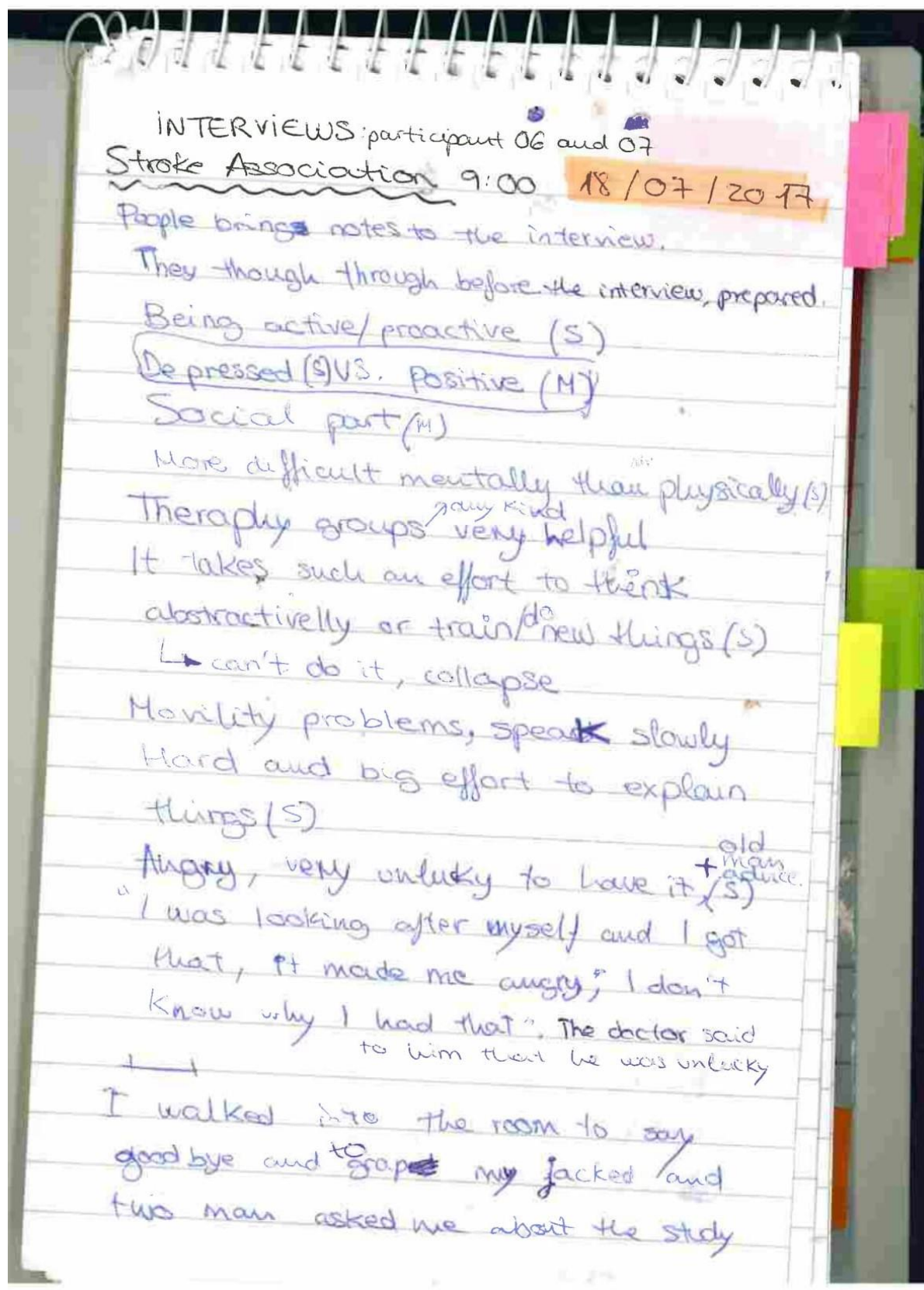
Sara Estecha Querol, Pam Clarke and Prof. Dr. Mark Gabbay

Department of Health Services Research

Institute of Psychology, Health and Society. University of Liverpool

S.Estecha-Querol@liverpool.ac.uk

Appendix 11 Results field notes



and if I was giving advice on health. One of them started asking questions about food "what it is good or what is not". They believed that ~~fucked~~ potatoes were good.

They didn't have much idea about what it is healthy. → lack of food literacy

they looked like they want to look after themselves, asking for advice but they ~~seem~~ ^{seem} that they don't know where to get that advice from.

They are aware of their condition, they are willing to take care of themselves but seems difficult to find someone or some organisation ~~that~~ that can help them.

They are ~~active~~ aware but not very proactive looking for it.

Barriers some where that don't allow them to figure it out.

▲ { not be bothered
not accessible
not aware of the resources } my believe

(if they had resources, they would use them)

It would be better if ^{NHS} they give it to you rather than if you have to go and find it. In this situation, after a CVD event they are in shock, depressed, left without any help, and it is hard for them to figure out things and get help.

Their brains are paralysed and they can not ~~think~~ think creatively and forward (barriers).

Tiene que estar a mano, accesible para que ellos lo vean.

I think → I believe, that they ^{became} more aware after they CVD event.

Interviews: participant 09 and 10
Stroke Association

01/08/2017

Depressed (09)

Lose their job (09)

Priorities: mortgage, bills... food goes out the end. (09)

Would take the advice (09)

Don't know what is healthy diet (09)

First that they want to talk is about

Personal identity. (10)
their stroke: how was it, what changed since then

Family support: wife, brothers and sisters... (10)

→ his sister started volunteering

Positivism and acceptance, carry on (10)

Planning to go to the dietitian (09 and 10)

Happy with NHS (10): he has to go,

NHS is always ready for him.

~~Not~~ Not taking care of the finances, someone does it for them (9 and 10) because he (09) panics.

They (09 and 10) are ~~keen on~~ ^{Keen on} taking part of the study because they believe that they are ~~helping~~ helping students to learn. Others take part of the research because they want you to give them a voice that can be heard (10)

This is a summary of independent research funded by the National Institute for Health Research (NIHR) CLAHRC NWC Programme. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.