



Oilthigh
Ghlaschu

Multimorbidity and Social Care: exploiting emerging administrative data sources in Scotland

David Alexander Gunn Henderson
MRes(Health Research), PGcert(Advanced Practice),
BSc(Nursing)

Submitted in partial fulfilment of the requirements of the degree of
Doctor of Philosophy (PhD)

School of Social and Political Sciences
College of Social Sciences
University of Glasgow

September 2019

Abstract

Background: Multimorbidity, the presence of two or more long-term health conditions, is increasing in prevalence worldwide. This is due to increasing life expectancy although 30% of those aged 45-65 are also affected. Multimorbidity is associated with a number of negative outcomes including increased mortality, lower quality-of-life, and lower functional status. Unsurprisingly, it is also associated with greater use of health services. Little is known, however, about whether people with multimorbidity also receive more social care. The aim of the research was to assess the relationship between multimorbidity and social care, and the association of multimorbidity and social care on unplanned admission to hospital.

Methods: A retrospective population-based observational study using linked administrative health and social care records was conducted. All individuals over the age of 65 with a valid Community Health Index (CHI) number in Scotland during the financial years 2011/12 to 2015/16 were included. A proxy measurement of multimorbidity derived from prescribing data was used. Logistic regression models reporting Average Partial Effects (APEs) were employed to investigate associations between outcome and explanatory variables. Use of social care was assessed using the Scottish Social Care Survey (SCS). In order to assess its validity, all social care data from one local authority was obtained and analysed to assess the proportion of home care users likely to be captured by the SCS.

Results: Over 1.1 million people were included in the cohort. 73% of participants were prescribed more than two repeat medicines. Multimorbidity was associated with receipt of social care. After adjustment for other variables, a 15% increased probability of receiving social care was observed for those in the highest multimorbidity group (receiving 9+ repeat medicines) compared to the lowest group (receiving 0-2 repeat medicines). Both multimorbidity and receipt of social care were associated with unplanned hospital admission after adjustment (9% increased probability of unplanned admission in the highest multimorbidity group, 7% increased probability for those that received social care). The SCS captured 60% of home care users representing up to 75% of all home care delivered in addition to all individuals receiving community alarm and telecare services.

Conclusion: This is one of the first studies to link health and social care data on a national scale. It showed an association between multimorbidity and use of social care. This finding is novel and indicates wider societal implications due to the increased prevalence of multimorbidity than has previously been described. Receipt of social care was also associated with increasing age, female sex, and lower socioeconomic position. Both multimorbidity and receipt of social care were associated with unplanned hospital admission. These findings have implications for policymakers interested in health and social care integration and the expected benefits of such reorganisation.

Contents

List of Tables

List of Figures

Academic outputs

Henderson, D., Bailey, N., McCowan, C., Mercer, S. (2018) Multimorbidity and access to social care: exploiting emerging administrative data sources in Scotland. *International Journal of Population Data Science*. 3(4) Conference Proceedings for IPDLC 2018.

Henderson, D., Bailey, N., McCowan, C., Mercer, S. (2018) Validation of the Scottish Social Care Survey using data from Renfrewshire Council. *International Journal of Population Data Science*. 3(2). Conference proceedings for the International Conference for Administrative Data Research 2018.

Henderson, D., Burton, J., Lynch, E., Clark, D., Rintoul, J., Bailey, N. (forthcoming). Data Resource Profile: the Scottish Social Care Survey (SCS) and the Scottish Care Home Census (SCHC). *International Journal of Population Data Science*.

Acknowledgements

I am indebted to my PhD supervisors, Professors Nick Bailey, Colin McCowan, and Stewart Mercer for their continued support and encouragement throughout the long, and occasionally tortuous, process of completing this thesis. It has really been a pleasure learning from, and working with, such esteemed colleagues.

I would also like to thank Dr Iain Atherton, for making me aware of this PhD opportunity in the first place and also for his support and encouragement throughout the process.

Administrative data research is reliant on many organisations and the individuals who work for them, sometimes without any contact with the research team at all. I am aware there will be many people whom I have never met, nor heard of, who had a part in enabling this project to happen - a thanks to all these individuals at: The Urban Big Data Centre, eDRIS, NHS National Services Scotland, ADRC-S, National Records of Scotland, the Scottish Government, and the University of Glasgow.

Of course, there are individuals who play a very important part and had a very *hands-on* relationship with the project. I would like pay particular tribute to Dr Mirjam Allik (previously of UBDC) and Amy Tilbrook (eDRIS/UBDC/ADRC-S and now Scottish Government).

Mirjam's guidance made the successful navigation of the complex approvals process required for research of this nature possible. Amy's work in co-ordinating the data linkage process, despite many setbacks, went a long way to ensuring this project did not fail. Furthermore, through the statistical disclosure control process of my (many!) research outputs, Amy proved to be the first sanity check on the analyses - thanks for catching my mistakes! People that understand the nuts and bolts of data linkage projects (and the realities of what can and cannot be achieved) are the unsung heroes of this branch of research - so once again a special thank you to you both.

This is one of the first projects to utilise the Social Care Survey in a research context. This would not have been possible without the help and support of Julie Rintoul and Ellen Lynch at the Health and Social Care analysis division at the Scottish Government. It was with dismay I learned of Julie's untimely death in June 2019. Her work with social care data over almost 20 years has laid the foundations for many exciting research opportunities now being realised.

I would also like to thank Dave Clark who undertook the indexing of the Social Care Survey to the NRS population spine - without this piece of work the thesis would look very different indeed!

One of the pleasures of the PhD process has been learning to code using open source software R via RStudio. Worldwide, academics and developers spend countless hours adding and improving the tens of thousands of packages of software available for use

with R. In the best cases detailed documentation or vignettes are also supplied making the learning process markedly easier. This work is then shared for all to use - free of charge. The list of individuals who contributed their own time to develop the many packages I have used for the analysis and reporting of this PhD likely runs to hundreds, if not thousands. For this I'd like to thank the R community, without whose tools I would never have managed to complete the complex data manipulation required for the project.

Formal processes have, however, also helped me on the road to academia. I was fortunate to earn an Early Career Clinical Fellowship offered by NHS Education for Scotland in 2012. This fellowship paid for my Masters education, granted me backfill time-off from my busy job as a nurse, and supported me to grow personally and professionally. To say the fellowship (and the MRes course at the University of Stirling it enabled me to complete) had life-changing effects would be an understatement. I'd therefore like to say thank-you to Ann Rae and all at ECCF for their support in setting me on a different road.

Completing this PhD from home in the Highlands would not have been possible without the generosity and hospitality of Mrs Lena Ramage for my trips to Glasgow - Tapadh leibh a'bhrònag.

Finally, I would like to thank my children, Seumas and Catherine (for tolerating a grumpy Dad, particularly over the final few months), and especially my wife, Shona. It has been a long time since I first said that I thought I might like to go to University. Life has been a roller-coaster since then and I would certainly have fallen off the tracks without you Shona. Tha gaol agam ort. *Gus an dèan am bàs ar sgaradh.*

Declaration

I declare, except where explicit reference is made to the contribution of others, that this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Printed Name: David Henderson

Signature:

List of Abbreviations

ACG	Adjusted Clinical Group
ADL	Activities of daily living
ADRC	Administrative Data Research Centre
AME	Average Marginal Effect
AMS	Academy of Medical Sciences
APE	Average Partial Effect
BNF	British National Formulary
CDC	Chronic Disease Score
CHI	Community Health Index
COSLA	Convention of Scottish Local Authorities
CoSS REC	College of Social Sciences Research Ethics Committee
CUP	Continuous Urgent Care Pathway
eDRIS	electronic Data Research and Innovation Service
ESRC	Economic and Social Research Council
EU	European Union
EGPRN	European General Practice Research Network
DPA	Data Protection Act
DSA	Data Sharing Agreement
FACS	Fair Access to Care Services
GAE	Grant Aided Expenditures
GDPR	General Data Protection Regulation
GP	General Practitioner
HSCA	Health and Social Care Analysis
IA	Integration Authority
IADL	Instrumental activities of daily living
ICD-10	International Classification of Diseases, 10th revision
IJB	Integrated Joint Boards

INN	International Nonproprietary Name
IQR	Interquartile range
ISD	Information Services Division
LA	Local authority
LTC	Long term care
MeSH	Medical Subject Heading
NHS	National Health Service
NHSCR	National Health Service Central Register
NHS NSS	National Health Service National Services Scotland
NICE	National Institute for Health and Care Excellence
NRS	National Records for Scotland
OECD	Organisation for Economic Co-operation and Development
ONS	Office for National Statistics
PBPP	Public Benefit and Privacy Panel for Health and Social Care
PC OOH	Primary Care Out-of-hours
PII	Personal Identifiable Information
PIS	Prescribing Information System
PROM	Patient relevant outcome measure
RAC	Research Approvals Committee
RCT	Randomised controlled trial
REC	Research Ethics Committee
SAS	Scottish Ambulance Service
SCIE	Social Care Institute for Excellence
SCS	Social Care Survey
SEP	Socioeconomic position
SG	Scottish Government
SILC	Scottish Informatics and Linkage Collaboration
SIMD	Scottish Index of Multiple Deprivation
UBDC	Urban Big Data Centre

List of Abbreviations

UCD	Urgent Care Data Mart
VPN	Virtual Private Network
WHO	World Health Organisation

Chapter 1

Introduction

1.1 Context

Worldwide demographic changes have seen increases in life expectancy and the proportion of the population over the age of 60 grow, partly due to better health programmes and treatments (Beard *et al.*, 2016; AMS, 2018). Accompanying this growth is an increase in the prevalence of multimorbidity - the presence of two or more chronic health conditions in one individual (Guthrie *et al.*, 2011; Mercer *et al.*, 2014; Beard *et al.*, 2016; NICE, 2016; AMS, 2018; The-Lancet, 2018). These changes are seen across the world in both high-income and low-to-middle-income countries where non-communicable diseases have replaced communicable diseases as the major burden of healthcare and contribute to two-thirds of all deaths (Imison, 2012; WHO, 2014; Beard *et al.*, 2016; AMS, 2018). The increasing prevalence of multimorbidity has profound impacts for clinicians, policy-makers and research.

There is some evidence suggesting that multimorbidity disproportionately affects women and those of lower socioeconomic position (Barnett *et al.*, 2012; Violan *et al.*, 2014; AMS, 2018). Those in the latter group are more likely to have a mix of physical and mental health conditions, which develop 10-15 years earlier than seen in their more affluent peers, and are thus more likely to have complex care needs (Mercer *et al.*, 2009; Barnett *et al.*, 2012). The association between multimorbidity and increasing age is well documented (Guthrie *et al.*, 2011; AMS, 2018). However, a large proportion of younger, working age adults also have multiple chronic conditions (Taylor *et al.*, 2010; Moffat and Mercer, 2015). In one landmark study, the absolute number of people with multimorbidity under the age of 65 was higher than for those over 65 (Barnett *et al.*, 2012). Given these demographic changes, and the implications of fiscal austerity on health outcomes (Karanikolos *et al.*, 2013), governments in high-income countries are having to identify ways of financing increasing demand for public services (Anderson, 2011).

As a result, many countries have recently seen policies implemented that aim to integrate the provision of health and social care services (Stewart *et al.*, 2003; Burgess, 2012; Glasby, 2017). In addition to reducing variations in the provision of care across geographic areas, these policies hope to save public money by reducing unplanned admissions and delayed discharges from hospital, whilst also improving the quality of services for individuals (OECD/EU, 2013; Burgess, 2016; Scottish-Government, 2016b). There is, however, little evidence showing the efficacy of these policies on desired outcomes (Stewart *et al.*, 2003; Petch, 2009; Weatherly *et al.*, 2010; A Petch, 2012; Burgess, 2012; Robson, 2013; Damery *et al.*, 2016; Kaehne *et al.*, 2017). Nevertheless, the continued drive to integrate services implicitly acknowledges that health and social care are services with a link.

Similarly, whilst much previous (and suggested) research on multimorbidity is aimed at understanding its effect on health care services (AMS, 2018), a gap in knowledge describing its relationship with social care exists. In Scotland, approximately two-thirds of individuals receiving social care are over the age of 65 (Scottish-Government, 2016d) whilst approximately two-thirds of all those over the age of 65 have multimorbidity (Barnett *et al.*, 2012). It would seem intuitive that a large proportion of those receiving social care have multimorbidity. However, no single data source exists that allows this comparison to be made. This reflects the paucity of good social care data seen internationally (OECD/EU, 2013).

All this comes against a backdrop of reductions in the number of people receiving formal social care services since 2010 in both England and Scotland as a result of financial austerity measures (Macleod and Mair, 2015; Burchardt *et al.*, 2015; Scottish-Government, 2017e). Until recently many local authorities had attempted to protect front-line services, such as social care, from austerity cuts (Hastings *et al.*, 2015). However, given continued year-on-year reductions and further cuts to local authority spending (e.g. in Scotland a further 7.2% in 2016/2017 (Audit-Scotland, 2016b)), the ability to protect social care from reductions in spend becomes less likely. These decreases in local government budgets across the UK have affected those living in the poorest areas hardest (Hastings *et al.*, 2015; Gannon *et al.*, 2017) which poses questions of equitable access to services (Oliver, 2018b).

These questions are valid given the presence of the inverse care law in UK primary care settings where, “The availability of good medical care tends to vary inversely with the need for it in the population served. This inverse care law operates more completely where medical care is most exposed to market forces, and less so where exposure is reduced.” (Tudor-Hart, 1971). This is demonstrated by higher ratios of General Practitioners to population in England’s most affluent neighbourhoods (CfWI, 2014; Stafford *et al.*, 2018) and inequitable resource allocation in Scotland (Mercer and Watt, 2007; McLean *et al.*, 2015). Given the unequal distribution of cuts to services

discussed above, presence of an inverse social care law is possible.

There are, therefore, numerous areas where deeper understanding of the relationships between health and social care would be beneficial. This PhD research was commissioned by the Scottish Government, via the Economic & Social Research Council (ESRC), with the explicit aim of doing this via administrative data linkage using Scottish resources. Research of this type is ideally suited for investigating cross-sectoral relationships and is being increasingly used in the social sciences (Atherton *et al.*, 2015). Linking data from NHS and local authority social care sources has proved problematic in the past (Witham *et al.*, 2015), although new sources of data may provide the potential to overcome these barriers.

1.2 Aims

The thesis has three aims as follows:

1. Identify the best source of social care data in Scotland that can be linked to health data at an individual level (ideally in a national context) and assess its suitability for research
2. Create a linked dataset that can be used to answer questions relevant to multimorbidity and the provision of health and social care services
3. Demonstrate the ability of this dataset to answer pertinent cross-sectoral questions by undertaking analysis to explore the associations between multimorbidity, social care, and unplanned hospital admission.

Given past difficulties in linking health and social care data (Witham *et al.*, 2015), the first aim of the research involved liaison with relevant stakeholders in local and national government as well as appraisal of any relevant on-line materials and is discussed fully in section ??.

After identification of data that *could* be linked, the next aim was to realise this linkage. This process first required appraisal of the ability to accurately measure multimorbidity and social care with the identified sources. Furthermore, as described in Section ??, probabilistic matching of the SCS to CHI records was required to enable linkage. This work was commissioned by the Scottish Government and carried out by an analyst at the National Records of Scotland.

In order to be granted information governance approval to link these sources of data together, and also to achieve aim number 3, relevant research questions had to be formulated. Based on the literature reviewed in chapter 2, the following questions were derived:

1.3 Research questions

In people over the age of 65 in Scotland:

1. (a) What are the socioeconomic, demographic, and multimorbidity patterns in the use of social care?
 (b) Is there an association between receipt of social care and multimorbidity status. Does this vary by the patterns described in 1(a)?
2. Is there an association between unplanned hospital admission, multimorbidity, and the receipt of social care?

1.4 Thesis structure

There are eight chapters, including this introduction, in the thesis.

Chapter 2 reviews literature relating to the main themes of the thesis: multimorbidity, social care, health and social care, and administrative data linkage. As much of the work of the project is exploratory in nature, a systematic review of literature was not appropriate. Instead, each section of the chapter provides a contextual review of literature relevant to its topic from academic and policy sources.

Chapter ?? details methods employed for the main project analysis. Firstly, a description of the information governance procedures that were required in order to access the sensitive data used in analyses is provided. This is followed by a detailed description of the administrative data sources used. The third section briefly describes the indexing of the social care survey to the National Records of Scotland (NRS) population spine which enabled linked of social care data to CHI databases. Following this, a section detailing the extensive data cleaning and manipulation process applied to the numerous raw data files to enable analysis is provided. The fifth section discusses the statistical methods applied in order to answer the stated research questions. The final section provides a timeline of the PhD project and briefly discusses important temporal milestones.

Chapter ?? is a stand-alone chapter. The literature review and liaison with relevant stakeholders identified that the Social Care Survey (SCS) would be the best source of data to link to health records at a national level. However, some variables of the survey only collect information of individuals during a census week. This chapter attempts to quantify what proportion of the total number of people receiving home care in any given financial year are captured by the SCS. This was done by completing a data-sharing agreement with one local authority area and obtaining all social care records from a ten-year period. Comparison is made between individuals who received care in the census week with those who did not.

Chapter ?? provides detailed descriptive statistics of the large, linked health and social care cohort in five sections: the characteristics of the cohort by age, sex, and geography, the distribution of repeat prescribed medicines, the distribution of deprivation, the distribution of receipt of social care, and the distribution of unplanned admission to hospital.

Chapter ?? provides results of statistical models relevant to the two research questions. As described in Chapter ??, linkage rates of the SCS to the CHI register varied at the local authority level. This made comparison across council areas more difficult. In order to overcome this, two groups of data including local authorities with similar match rates were created in models relevant to research question 1. Both research questions are answered via logistic regression models reporting Average Partial Effects (APEs).

Chapter ?? discusses the key findings of the research in context, compares findings with previous research, addresses the numerous strengths and weaknesses of the project, and makes recommendations for future research.

Finally, Chapter ?? provides a brief conclusion to the thesis as a whole.

Chapter 2

Literature Review

The aims of the thesis are exploratory in nature and as such, no specific question is defined for the literature review. Instead, the aim is to scope literature relevant to the main themes outlined in the introduction and identify where links can be made across separate fields. This chapter summarises academic and policy literature relevant to the main thesis themes regarding a) multimorbidity, b) social care, c) the interaction of health and social care services, and d) administrative data linkage. As the main research is conducted with Scottish data, there was a focus on the structures and policies regarding health and social care in this country. However, this is placed in the wider context of the UK and high-income countries.

The chapter is organised in four parts following the main themes listed above. Section 2.1 describes why multimorbidity is important in the context of health and social care services and then provides an overview of academic literature and policy documents regarding multimorbidity and its definitions, measurement, and impact on health inequalities.

Section 2.2 focuses on social care from a number of perspectives: varying definitions of the term, differing international models of care delivery, how eligibility for social care is determined in the UK, how resources are allocated in Scotland, and finally selected social theories of eligibility and resource allocation.

Section ?? outlines the policy framework regarding health and social care services and the historical policy context of service integration. It then describes the legislation that made health and social care integration law in Scotland before reviewing empirical evidence of the nature of the interaction between health and social care services.

The final, short section provides an overview of literature on the emerging research paradigm of administrative data linkage. The section discusses what linkage involves, its benefits and drawbacks, and outlines the data sources selected for this project with

a justification for their inclusion.

Given the nature of this review, the search strategy for literature employed varying methods. The first section on multimorbidity leant itself to traditional bibliographic database searches (Medline, Web of Science, Google Scholar) for key terms: “multimorbidity” and “comorbidity” in relation to the subsection headings: “definitions”, “measurement”, and “health inequalities”. As an overview of the whole topic and subsections was desired, initial searches were limited to include only systematic reviews and, where necessary, pertinent references from citation lists were retrieved and included. “Grey” literature was also searched for using websites of prominent think-tanks (e.g. the King’s Fund), and research groups (e.g. the International Research Community of Multimorbidity).

Literature on social care was mostly found from “grey” sources such as the King’s Fund and Nuffield Trust, with a “snowball” method from reference lists employed to identify further relevant reading. In addition, the Social Care Institute for Excellence’s resources list was also investigated for pertinent literature. As much of the focus of this section related to policy aspects, relevant publications from UK and Scottish Governments were sought.

Health and social care interaction and integration have recently been topics of high policy interest and have been extensively covered by think-tanks. As a result, much literature in this section is informed by reports from these sources and the references contained within them. Section ?? included database searches for studies specifically investigating interactions in health and social care. Very few empirical studies in this area exist, although one recent systematic review helped guide further literature searches. One included reference (Porter, no date), is an unpublished report requested directly from the authors.

Background information on administrative data linkage was informed by reports produced by the Administrative Data Research Network (ADRN) and references contained within.

Initial searches of literature were conducted in Spring 2016 with continual updates. A formal update of all aspects was completed in May 2019. The review provides a detailed summary after each section with a synthesis of all sections contained in the chapter conclusion.

2.1 Multimorbidity

This section reviews relevant literature regarding multimorbidity. Firstly, an overview of the main themes found in the literature is provided before more in-depth reviews of three main themes arising from this: concepts and definitions of multimorbidity, measures of multimorbidity, and finally multimorbidity with regard to health inequalities.

2.1.1 Context

At first sight, the definition of multimorbidity as the presence of two or more health conditions in one individual appears clear and concise. In fact, there are many competing concepts and definitions of multimorbidity in research literature resulting in confusing messages regarding epidemiology, measurement, and treatment (Guthrie *et al.*, 2011; Almirall and Fortin, 2013; EGPRN, 2013; Lefevre *et al.*, 2014; AMS, 2018). One systematic review found the prevalence of multimorbidity in the general population to vary between 13.1% - 71.8% in studies where different definitions had been employed (Fortin *et al.*, 2012). Another, concentrating on primary care populations, reported variation of prevalence between 12.9% and 95.1% (Violan *et al.*, 2014).

Despite this, it is generally accepted that multimorbidity is the norm for individuals with at least one chronic condition (Guthrie *et al.*, 2011) in both high-income and low-to-middle-income countries (Afshar *et al.*, 2015) and is increasing in prevalence (AMS, 2018; Lyons *et al.*, 2018). It disproportionately affects those of lowest socioeconomic position (Guthrie *et al.*, 2011; AMS, 2018; Stafford *et al.*, 2018) who can develop multimorbidity up to 10 to 15 years earlier than their most affluent counterparts and are more likely to have a mix of physical and mental health conditions (Barnett *et al.*, 2012; Stafford *et al.*, 2018). Females are also disproportionately affected although evidence suggests this association can vary across countries (AMS, 2018).

There is also a consensus that multimorbidity is associated with a number of negative outcomes including: higher mortality (Gijssen *et al.*, 2001; Guthrie *et al.*, 2011; Jani *et al.*, 2019), reduced quality-of-life (Fortin *et al.*, 2004, 2005; Guthrie *et al.*, 2011), reduced functional status (Kadam and Croft, 2007; Guthrie *et al.*, 2011), and increased psychological distress (Fortin *et al.*, 2006). All of these are likely contributors to the association of multimorbidity with increased use of healthcare services (Gijssen *et al.*, 2001; Salisbury *et al.*, 2011; Guthrie *et al.*, 2011; Lyons *et al.*, 2018).

This raises a particular challenge to those responsible for delivering healthcare which has been traditionally structured around treating single diseases. This is partly due to the fact that many clinical guidelines are based on the results of Randomised Clinical Trials (RCTs) investigating the efficacy of a single treatment on a single disease (Moffat and Mercer, 2015; WHO, 2016a; Watt, 2017; AMS, 2018; Oliver, 2018a). The fact that those with multimorbidity are routinely excluded from such trials means the

effectiveness of treatments (and presence of adverse events) in “the real world” are often unquantified (Moffat and Mercer, 2015; WHO, 2016a; Watt, 2017; AMS, 2018; Oliver, 2018a). The increased use of services also has financial implications for societies grappling with constraints imposed by austerity measures (Allen, 2018).

One potential solution to improve the efficiency of healthcare delivery is to focus resources in community and primary care services rather than expensive secondary care (WHO, 2015; Stafford *et al.*, 2018). Here, care can be focussed in a more holistic sense by identifying goals and targets in partnership with the individual themselves (WHO, 2016b; Watt, 2017; Mair and Gallacher, 2017). Services provided by healthcare professionals with generalist rather than specialist skills (such as multi-disciplinary teams in primary care), are best placed to deliver this type of care and can foster preventative, cost-effective measures for those with, or at risk of developing, multimorbidity (Guthrie *et al.*, 2011; Moffat and Mercer, 2015; WHO, 2016a, 2016b; Watt, 2017; AMS, 2018; Rijken *et al.*, 2018).

This is particularly true where primary care services are provided on a universal basis which widens the scope of access to service (Guthrie *et al.*, 2011; WHO, 2016a, 2016b). That said, universal coverage in itself does not guarantee equitable access to care. First coined by Julian Tudor-Hart (1971), the Inverse Care Law describing reduced availability of good medical care in areas of highest need has been shown to be alive and well in countries with universal primary care coverage (Watt, 2002, 2018; Mercer and Watt, 2007; McLean *et al.*, 2015; WHO, 2016b).

Given these many challenges, a recent Academy of Medical Sciences report (2018) highlights a number of areas where research into multimorbidity should be directed including: identifying trends and patterns of multimorbidity (including clusters of conditions), the determinants of condition clusters, prevention strategies, risk-assessment strategies, and healthcare (re)organisation. The NICE guideline on multimorbidity assessment and management (2016) suggests research should focus on: organisation of (primary) care, community assessment, medicines management, and the prediction of life expectancy. Absent from both these guidelines, save passing references, are consideration of the effect of multimorbidity on *social* care services.

Inclusion of social care as a factor associated with multimorbidity is justified by an earlier NICE guideline entitled, “Older people with social care needs and multiple long-term conditions” (2015). As the title suggests, the guideline frames social care needs as an additional dimension to the assessment required for people with multimorbidity. There are no recommendations, or indeed acknowledgement, of the effect multimorbidity may have as a driver of need for social care. Social support, along with other patient-relevant outcome measures (PROMs) (such as functional disability), are often included as independent variables indicating a modifying effect on multimorbidity

rather than outcomes where multimorbidity may be a contributing factor (Nicholson *et al.*, 2019). Recognition of this fact has led to calls for the social context of individuals with multimorbidity to be more fully investigated (Zullig *et al.*, 2016; Smith *et al.*, 2018).

Whilst this gap in knowledge is the justification for the research carried out in the thesis, and further explored later in this chapter, the remainder of this section will expand on the themes outlined above with reference to multimorbidity. Those themes with particular relevance to the thesis are covered. Firstly, an overview of literature regarding the complexity of the concept and definition of multimorbidity is presented. This is followed by a review of the many methods that have been employed to measure multimorbidity. Finally, an overview of relevant literature regarding health inequalities in the context of multimorbidity is also presented with a specific focus on UK based literature.

2.1.2 Concepts and definitions

Despite the increasing importance of multimorbidity on health care systems, there has been some debate internationally in finding an agreed definition of the term or concept (Almirall and Fortin, 2013; Lefevre *et al.*, 2014; AMS, 2018). This section outlines the differing terms and concepts used in academic literature.

One source of confusion that is commonly found in research relating to two or more health conditions is in the numerous ways in which it is labelled including: polymorbidity, polypathology, pluripathology, multipathology, and multicondition (Almirall and Fortin, 2013). The two most frequently used terms, multimorbidity and comorbidity, are often (incorrectly) used interchangeably despite a distinction being articulated over 20 years ago (van-den-Akker *et al.*, 1996; Nicholson *et al.*, 2019). Comorbidity was originally described by Fenstein (1970, p. 467) who stated, “In a patient with a particular index disease, the term co-morbidity refers to any additional co-existing ailment.” Van Den Akker *et al.* (1996, p. 65) separated this term from multimorbidity which they described as “...any co-occurrence of medical conditions within a person.” In this sense, multimorbidity does not rely on the presence of a primary, or index, disease but refers to the overall state of multiple illnesses. The recent addition of a distinct MeSH heading for multimorbidity that can be used to search medical literature databases signals the importance of the difference in these terms (previously, only comorbidity was available as a MeSH heading) (Tugwell and Knottnerus, 2019).

An aide to further clarify this distinction is a broader conceptual framework provided by Valderas *et al.* (2009) (Figure 2.1) who characterise the construct of the multiple terms found in the literature into four main groups: (a) comorbidity – additional diseases in the context of an index disease, (b) multimorbidity – more than one disease within an individual (without reference to an index disease), (c) morbidity burden – total impact

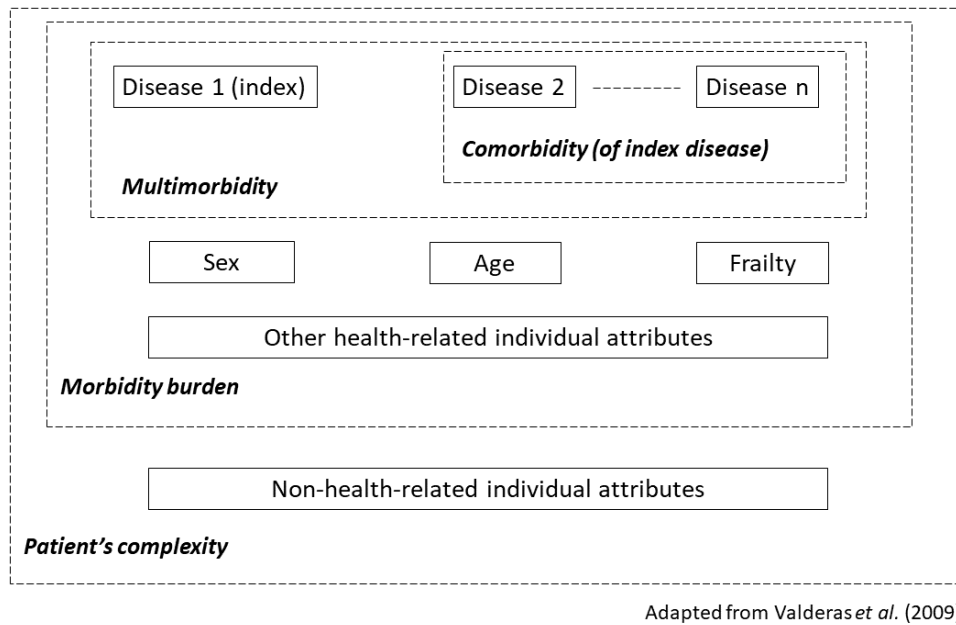


Figure 2.1: Conceptual framework of co/multimorbidity

of physiological dysfunction linked to disease severity and (d) patient complexity – the effect of non-health characteristics (e.g. deprivation, culture, environment) on the whole.

Valderas *et al.* (2009) discuss these four constructs further in relation to three main research areas: clinical care, epidemiology & public health, and health service planning. It is suggested that comorbidity may be a more valid definition for use in specialist clinical care, whereas multimorbidity and morbidity burden would be more appropriate in primary care research. In epidemiological and public health research, the definitions of either comorbidity or multimorbidity would be of use depending on the origin of the diseases being studied and the particular research questions being investigated. Morbidity burden and patient complexity are the most appropriate definitions for research exploring healthcare use and costs (Valderas *et al.*, 2009).

Relying on the term for multimorbidity in Figure 2.1 does not, however, completely solve the problem of definition. Intuitively, the term signifies more than one condition, but which conditions should be included? The findings of three systematic reviews have highlighted the myriad ways researchers have approached this problem (Groot *et al.*, 2004; Diederichs *et al.*, 2011; Huntley *et al.*, 2012). Each review aimed to collate evidence of measurement tools in comorbidity or multimorbidity but from different perspectives: De Groot *et al.* (2004) searched for comorbidity indices to inform research into Multiple Sclerosis, Diederichs *et al.* (2011) specifically searched for multimorbidity measurement indices, whereas Huntley *et al.* (2012) searched for measures of multimorbidity used only in primary care research. The systematic reviews found 13, 39 and 17 exclusive ways of measuring multimorbidity or comorbidity respectively. Adding even further complexity, the number of medical conditions included in these measurements

varied from 4 to 102 (Diederichs *et al.*, 2011).

More recently, a systematic review focused on which diseases, risk factors and symptoms are included in varying definitions of multimorbidity (Willadsen *et al.*, 2016). Whilst the majority of included studies in the review indicated multimorbidity as the presence of two or more conditions, Willadsen *et al.* (2016) found the total number of diseases, risk factors, and symptoms used varied from 4 to 147. Of the 167 included articles in the review, 115 different ways of defining multimorbidity were identified (Willadsen *et al.*, 2016). Another review found the number of conditions used in measures of multimorbidity varied from 5 to 335 (Violan *et al.*, 2014).

Acknowledging the perverse impact this has on advancing knowledge through research, attempts have been made to find a unifying definition of multimorbidity that can be employed to facilitate synthesis of research findings. These included:

1. “being affected by two or more chronic health conditions in the same individual” (WHO, 2016)
2. “...any combination of chronic disease with at least one other disease (acute or chronic) biopsychosocial factor (associated or not) or somatic risk factor.” (EGPRN, 2013)
3. “more than 1 long-term condition with any of the following:
 - Difficulty managing treatments or day-to-day activities.
 - Care from multiple services and requiring care from a new service
 - Both long-term physical and mental health conditions
 - Frailty
 - Frequent use of unplanned or emergency care
 - Prescription of multiple, regular medicines”
 (NICE, 2016)

In the NICE guideline (2016) there is an agreement with other commentators (Mercer *et al.*, 2009) that basing the definition of multimorbidity on two or more health conditions *only* does not fully capture a clinically meaningful picture of the concept. The guideline highlights the fact that many people defined as multimorbid in this way may not be ill and have excellent quality of life requiring little or no health care input (NICE, 2016). Whilst definitions two and three above attempt to address this problem, it could be argued that they are, respectively, ambiguous and over-complex.

The most recent attempt to standardise a definition of multimorbidity has been provided with the AMS which is less ambiguous than that provided by the EGPRN and less complex than that posited by NICE:

“The co-existence of two or more chronic conditions, each one of which is either

- A physical non-communicable disease of long duration, such as cardiovascular disease or cancer
- A mental health condition of long duration, such as mood disorder or dementia
- An infectious disease of long duration, such as HIV or hepatitis C”

(AMS, 2018)

Although multimorbidity may seem to be an intuitive thing to understand, defining a useful concept of the term has proved to be much more difficult (Guthrie *et al.*, 2011). The definition articulated by the AMS has the benefit of being relatively concise and clear and will be used to describe multimorbidity hereon in the thesis.

2.1.3 Measurement tools

Adding further complexity to conducting multimorbidity research is the many ways in which it can be measured. This section summarises literature explaining why this is so and presents recommendations from relevant systematic reviews.

Until recently, there were two main ways to measure multimorbidity: simple disease counts or using an index. Indices apply weights to either prescribed medications or medical conditions, sometimes along with other factors, in an attempt to capture the effect of disease severity on multimorbidity (which is crudely consistent with the term morbidity burden (Figure 2.1)) (Groot *et al.*, 2004; Diederichs *et al.*, 2011; Huntley *et al.*, 2012). Advanced computing power has added a third method of multimorbidity measurement through the identification of non-random clusters of medical conditions via statistical algorithms (Prados-Torres *et al.*, 2014). These clusters can be used to help understand the aetiology of multimorbidity, assess the impact of clusters on health outcomes, and which determinants of multimorbidity are associated with clusters (Prados-Torres *et al.*, 2014; AMS, 2018).

In primary care research, the most frequently used measurement is simple disease counts (Huntley *et al.*, 2012). This may be because of the ease with which it can be administered compared to more complex indices e.g. the Charlson index (Charlson *et al.*, 1987), the Chronic Disease Score (CDC) (Von Korff *et al.*, 1992), or the Adjusted Clinical Group (ACG) system (Starfield *et al.*, 1991) and their variations. It could be expected that indices may capture the complexity of multimorbidity more effectively, however Huntley *et al.* (2012) cite evidence that suggests simple counts of diseases or medications are almost as effective at predicting mortality or health care use in the primary care setting. Disease counts were also found by Huntley *et al.* (2012) to have good evidence to suggest they provide a robust measure of multimorbidity in relation to quality of life, as does the Charlson index (Charlson *et al.*, 1987).

In many areas, access to data listing disease types for individuals can be problematic.

Brilleman & Salisbury (2013) found a count of prescribed medicines was equivalent to a number of more complex indices when predicting primary care use and mortality in an English setting. This confirmed results found in a study of an American cohort (Perkins *et al.*, 2004) where the authors also argued that indices developed in the secondary care setting, such as the Charlson index, should be used with caution in other settings despite adaptations. More recently, Wallace *et al.* (2016) found little difference between simple (count) and complex (index) measures and that medication-based measures were equivalent to diagnosis-based measures in predicting outcomes. The use of medicine counts as a proxy for multimorbidity offers a good alternative to disease-based counts or measures.

Recent research and academic discussion suggests identification of disease clusters may enable clearer answers to clinically relevant research questions than currently employed measures (Valderas *et al.*, 2009; Holden *et al.*, 2011; Marengoni *et al.*, 2011; Sinnige *et al.*, 2013; Islam *et al.*, 2014; Prados-Torres *et al.*, 2014; Le Reste *et al.*, 2015). In systematic reviews of clustering methods, wide variations in approaches to clustering and characteristics of populations studied have been found (Prados-Torres *et al.*, 2014; Ng *et al.*, 2018). Statistical techniques employed in attempts to identify such clusters include: factor analysis, cluster analysis, the observed-to-expected ratio, multiple correspondence analysis (Prados-Torres *et al.*, 2014; Clerencia-Sierra *et al.*, 2015; Ng *et al.*, 2018), principal component analysis, latent class analysis (Islam *et al.*, 2014; Larsen *et al.*, 2017), and machine learning techniques (Schiltz *et al.*, 2017).

Prados-Torres *et al.* (2014) identified three groups of patterns common to all included studies in their review despite marked heterogeneity namely: cardiovascular and metabolic diseases, mental health conditions, and musculoskeletal disorders. No studies have yet demonstrated associations between clusters and health or health related outcomes, but identification of clusters remains a research priority in the immediate future (AMS, 2018).

2.1.4 Multimorbidity and health inequalities

A core interest of policy-makers is the effect of ageing populations and multimorbidity on health inequalities. This section provides a broad overview of important themes in health inequality literature, including the effect of health service access on inequalities.

“Health inequalities are the systematic, avoidable and unfair differences in health outcomes that can be observed between populations, between social groups within the same population or as a gradient across a population ranked by social position.”
(McCartney *et al.*, 2019, p.28)

There is no biological reason for poorer people to have worse health or to die earlier than the richest (Marmot, 2015). Yet over the last five decades, despite overall trends,

the most disadvantaged in society have seen slower improvements in health and life expectancy than the most affluent - resulting in a widening gap in health outcomes. (WHO, 2008; Scottish-Parliament, 2015; Scottish-Government, 2018b; McCartney *et al.*, 2019). A well documented gradient running from the most affluent to the most deprived has been observed (Graham, 2007; Marmot *et al.*, 2010). There are a number of social determinants of health that contribute to this situation including: access to healthcare, deprivation, quality of housing, and unemployment (Wilkinson and Marmot, 2003; Marmot, 2005; WHO, 2008).

Health inequalities have been observed between and within countries all over the world regardless of relative prosperity (WHO, 2008). The Black Report (1980), published by the UK Government almost 40 years ago, brought the subject of health inequality to international attention (Asthana and Halliday, 2006). It both described and attempted to explain the phenomenon present in the UK. Successive governments commissioned subsequent reports that have described similar findings and new insights (Whitehead, 1987; Acheson and Barker, 1998; Marmot *et al.*, 2010). However, there has been little progress in implementing recommendations from these reports and thus little progress in reducing disparities in health (Mackenbach, 2010; McCartney *et al.*, 2012; Frank *et al.*, 2015; Smith *et al.*, 2016).

In the UK, poverty remains the largest predictor of relative ill health and has associations with increased morbidity, multimorbidity, and decreased life expectancy (Baker *et al.*, 2015). People living in deprived areas are more likely to experience multimorbidity at a younger age, live in overcrowded or unsuitable housing, and (potentially as a result of socioeconomic conditions) engage in unhealthy lifestyle behaviours (Shaw *et al.*, 2006; Baker *et al.*, 2015).

Figures released by the Office for National Statistics suggests the gap in male life expectancy at birth between 2015-2017 across local authorities was highest in England at 9.1 years; from 74.2 years in Blackpool to 83.3 years in Hart. In Northern Ireland the gap is 4 years and in Wales 4.1 years. Those born in East Dunbartonshire were expected to live to 80.1 years, whereas those in neighbouring Glasgow City were expected to live 73.3 years giving a gap of 7.2 years in Scotland (ONS, 2018). The overall UK gap in life expectancy at birth at local authority level is, therefore, exactly ten years (between Glasgow City and Hart) (ONS, 2018, supplementary data).

There has been some argument that research on health inequalities has placed an over-emphasis on deprivation at the expense of understanding the role of access to health services, particularly in the UK where there is universal health coverage (Hellowell and Ralston, 2016). This is important because poorer access to primary health care is associated with greater demand for unnecessary admission to hospital which, in turn, is responsible for higher proportions of healthcare expenditure (Rosano *et al.*, 2013;

Weston *et al.*, 2016).

Research in countries where markets play a greater role in health care delivery, such as the USA, are more likely to produce literature focussing on service access (Hellowell and Ralston, 2016). This is likely due to the fact that those of lower socioeconomic position are less able to pay market-price for health care - thus reducing access. This underpins the theory of the “inverse care law” which states that,

“The availability of good medical care tends to vary inversely with the need for it, in the population served. This inverse care law operates more completely where medical care is most exposed to market forces, and less so where exposure is reduced.”

Tudor-Hart, 1971

There are, however, statistics and research showing that universal health care in itself does not guard against the inverse care law.

People living in more deprived areas have lower life expectancy, are more likely to have multimorbidities and therefore have greater health needs (Baker *et al.*, 2015). However, the poorest neighbourhoods in England have been reported to have 62.5 GPs per 100,000 population whereas the most affluent neighbourhoods have 76.2 per 100,000 (CfWI, 2014). This suggests health provision does not match need - indicating the presence of the inverse care law (Watt, 2002, 2018; Marmot, 2018). Recent planned changes in policy to distribute primary care funding based on population age are likely to exacerbate this situation (Mercer *et al.*, 2012). Indeed, increases in workload with deteriorating budgets has led the King’s Fund to describe the situation in primary care in England and Wales as “in crisis” (Baird *et al.*, 2016, p. 3).

Equalising the number of GPs across geographic areas does not, on its own, solve the issue of equitable access to service. In Scotland, there is an even distribution of GP workforce among the population. However, in the most deprived areas GPs need to provide more consultations, for patients with more complex needs, at the same funding level as practices with fewer resource demands (Mercer and Watt, 2007; McLean *et al.*, 2015). The inverse care law is alive and well in the UK, despite universal coverage.

There are many theories as to why inequalities in health exist across socioeconomic position (Asthana and Halliday, 2006; Nettleton, 2006; McCartney *et al.*, 2019) with intensive research dating back to the Black Report published by the UK government (Black, 1980). Some of these, such as statistical artefact and biological reasons, were rejected as being implausible by the Black Report (Macintyre, 1997). To a large extent, epidemiological evidence and theoretical argument has agreed with that view (Asthana and Halliday, 2006; Nettleton, 2006; Mackenbach, 2012; McCartney *et al.*, 2013).

Of the other theories proposed in the last 35 years, there have been many critiques and

a number of proposals (Asthana and Halliday, 2006; Nettleton, 2006; Peckham and Meerabeau, 2007; Mackenbach, 2012; Smith *et al.*, 2016). Whilst arguments over which theory is most plausible to explain the cause of health inequality, most researchers agree on ways to remedy disparities in health outcome. These are the redistribution of income, wealth, and political power (Asthana and Halliday, 2006; Nettleton, 2006; Katikireddi *et al.*, 2013; Smith *et al.*, 2016). Although health services have an important role to play, it is the “upstream” policies of redistribution that will make the biggest impacts in improving health outcomes across society (Asthana and Halliday, 2006; Katikireddi *et al.*, 2013; Scottish-Parliament, 2015; Smith *et al.*, 2016). Whilst this has been known for some time, government policies in the UK to date have not addressed these issues and have thus failed to make meaningful improvements in health inequalities (Peckham and Meerabeau, 2007; Mackenbach, 2010; Frank *et al.*, 2015).

2.1.5 Summary

Multimorbidity is most commonly defined as the presence (or co-occurrence) of two or more long-term conditions in an individual. Debate continues as to the type and number of long-term conditions that should be included to provide a meaningful concept for individuals, clinicians and healthcare organisations. The most recent definition posited by the AMS aims to capture the broad concept of multimorbidity whilst remaining concise and clear.

There are myriad ways of measuring multimorbidity with various counts of different diseases, indices, and clusters. The best way to measure multimorbidity for research depends on the setting and questions to be answered. Where good data is difficult to come by, simple counts of diseases or medicines have been shown to have proved comparable to predicting mortality and health care use as more complicated indices.

Evidence suggests multimorbidity is increasing in prevalence and has a strong socio-economic pattern. This pattern has implications for health inequalities, particularly through increased need and access to services. Empirical evidence of the inverse care law in UK primary care poses hard questions for policy makers in the context of financial austerity.

Very little research has been conducted into the effects of multimorbidity on social care services, despite acknowledgement that an interaction is likely to exist. Given the increasing prevalence of multimorbidity, understanding the relationship with social care services is of paramount importance in order for policies and services to be adequately allocated.

2.2 Social Care

Before exploring any interaction between multimorbidity and social care, it is necessary to first explore the concept of social care in isolation. This section reviews literature on: definitions of social care, how social care is delivered in an international context, how resources for social care are allocated in the UK, how eligibility criteria are determined in the UK, and provides an overview of relevant social theory literature with regards to service allocation and access.

2.2.1 Context

As with multimorbidity, there are many ways of defining social care. What would be described as social care in the UK (Humphries *et al.*, 2016) is often called long-term care (LTC) in other countries (Deusdad *et al.*, 2016). The next section (2.2.2) investigates in detail the differing definitions of social care, but in general the term refers to services provided to those that struggle with activities of daily living to enable them to live as full a life as possible (BMA, 2014; Deusdad *et al.*, 2016; National-Audit-Office, 2018).

There are four ways in which social care can be provided to those in need: informally via family or community, formally via voluntary non-profit organisations, formally via the state, or formally via for-profit organisations (Munday, 2003). In Europe, increasing demand from users has led to many welfare systems being unable to adequately provide care (Pavolini and Ranci, 2008; Colombo *et al.*, 2011). Changes in demography, the labour market, democracy, and values have all contributed to the increasing pressure on formal care services (Anttonen, 2005; Colombo *et al.*, 2011; OECD/EU, 2013). A recent study found that increased demand for services was fuelled not only by the increase in the overall number of older people, but also the fact that they live longer periods of their life with care needs (Kingston *et al.*, 2017). Some argue this should be considered a triumph of modern medicine even though it raises concerns for individuals and societies about how to provide and pay for these additional care needs (Dilnot, 2017).

There is wide consensus that lower birth rates and higher proportions of older people mean that a gap has emerged in the number of adult children able to provide informal care to their parents (Munday, 2003; Anttonen, 2005; Pavolini and Ranci, 2008; Colombo *et al.*, 2011; Robertson *et al.*, 2014; Deusdad *et al.*, 2016). Traditionally, informal care was provided overwhelmingly by women. As gender equality improves, more women are employed in non-domestic settings which has reduced the pool of informal social care available (Anttonen, 2005). Anttonen (2005) also cites changes in societal attitudes from “familism” to “individualism” as having an impact on informal care resources. These combined factors mean that informal care services are no longer as readily available and formal care mechanisms are increasingly required to provide social care. Pressures on these services has seen increased discussion and comparison

of models of care across Europe over the last 20 years (Anttonen and Sipilä, 1996; Munday, 2003; Sapir, 2006; Fernández-Alonso and Jaime-Castillo, 2016).

These issues are particularly salient given financial constraints in public funding following the financial crash of 2008. (Humphries *et al.*, 2016; Deusdad *et al.*, 2016; Bottery *et al.*, 2018). In countries where a large proportion of services are provided from the public purse, austerity measures have resulted in cuts in the number of people receiving social care (Burchardt *et al.*, 2015; Humphries *et al.*, 2016; Deusdad *et al.*, 2016). Indeed, social care provision in England covers only the poorest of individuals with the highest care needs (Ham, 2019). There is little research detailing the impact this has had on those no longer receiving formal care services although increases in avoidable admissions to, and delayed discharges from, hospital in the UK are one outcome the cuts are thought to contribute to (Charlesworth and Thorlby, 2012; Humphries *et al.*, 2016).

In the UK there is an important difference between social care and health care funding and access. Health care is universally provided free at the point of need by the NHS. Social care is commissioned by local, rather than central, government and is both means-tested (with the exception of free personal care in Scotland) and needs-tested (Burchardt *et al.*, 2015, 2018; Humphries *et al.*, 2016). There are, however, many areas where the services overlap (BMA, 2014). These arrangements are poorly understood by the public, many of whom only find out they are required to pay for social care at the moment they first need it (Humphries *et al.*, 2016; Bottery *et al.*, 2018).

Some argue that social care has been relegated in terms of policy importance because is not directly provided by national government (Burchardt *et al.*, 2015). The most recent UK government social care green paper has been delayed on numerous occasions (Atkins, 2019) which may indicate political apprehension in addressing the difficult decisions that are required in order to find a funding solution for social care (Bottery *et al.*, 2018; Ham, 2019). This may be due to the negative effect on electoral success encountered by political parties willing to discuss these difficulties at the 2010 and 2017 general elections (Bottery *et al.*, 2018). Nevertheless, state intervention of some kind is the only way of addressing the gap between supply and demand as private insurers are unwilling to enter the social care market due to the unpredictability of risk (Dilnot, 2017; Bottery *et al.*, 2018; Ham, 2019).

In 2002, the recommendations of a Royal Commission on long-term care for older people (Sutherland, 1999) were ignored by the UK government. Scotland was the only part of the UK to implement the policy of free personal care for those over the age of 65 - regardless of means (Bowes and Bell, 2007). The policy, which is still subject to a needs-test, has more recently been extended to all adults (Scottish-Government, 2019). Although the removal of a means-test for free personal care eases some of the finan-

cial burden for users, access to care is still regulated through the needs-test. Overall numbers of individuals in Scotland receiving social care are continuing to fall which suggests eligibility criteria for receiving care are tightening. Moreover, free personal care does not remove the most expensive outlay in terms of social care - namely the high costs of residential care (Bowes and Bell, 2007).

This section reviews literature on these broad issues in more depth in five sections. The first section outlines definitions of social care and related terms. Next, the varying ways social care is delivered internationally are investigated. The third and fourth sections review literature on resource allocation and eligibility criteria respectively, where necessary distinguishing between policy differences in Scotland compared to the rest of the UK. The final section presents literature relating to social theory of resource allocation, eligibility for services, and the impact of social care on health inequalities.

2.2.2 Definitions

This section identifies the different ways social care has been defined in literature in the UK and internationally. Further definitions relevant to the thesis, particularly in relation to social care services provided in Scotland, are also discussed.

2.2.2.1 Social care

There is no internationally (or nationally) accepted definition of social care. Indeed, the difference between what is social care and what is health care has no clear line of demarcation resulting in local variation in provision of services (McDonald, 2006). A recent NICE guideline (2015) addressing social care needs for older people with multiple chronic conditions used a definition provided in the UK Health and Social Care Act (2012):

“ “Adult social care”— ... includes all forms of personal care and other practical assistance provided for individuals who, by reason of age, illness, disability, pregnancy, childbirth, dependence on alcohol or drugs, or any other similar circumstances, are in need of such care or other assistance, ...” The Health and Social Care Act 2012 c7, Part 3, Chapter 1, Section 65, Subsection 4

The NICE guideline (2015) advises that social care planning for people with multimorbidity should include holistic assessment of biopsychosocial factors including sexual, spiritual, cultural, and communication needs. It should also consider access to leisure and social activities whilst incorporating issues regarding mobility and transport. Specifically, the guideline cites: self-care, taking medicines, learning, volunteering, maintaining a home, financial management, employment, socialising with friends, and hobbies as activities that all patients should be able to take part in should they

wish to. Social care assessment should assess the ability of the individual to achieve this.

A more succinct definition of social care is used in a report to the Minister for Care Services at the UK Department of Health:

“The group of services that provide personal care and support to people in social situations – such as family; the community; a communal setting; to help them achieve independence and to promote their positive contribution as citizens.”

Platt, 2007,p.4

Huxley *et al.* (2007) are critical of this service-based definition and argue that social care is intended to improve general well-being for those that are in need. As quality of life is an important factor of well-being, Huxley *et al.* (2007) argue that wider issues regarding environment and the quality of public and private services also play an important role in social care. Indeed, Daly and Lewis (2000, p. 287) argue that social care is “...an activity and set of relations lying at the intersection of state, market, family (and voluntary sector) relations”.

This view is reflected in an aspirational constitution for social care published by an independent, cross-party think-tank (Bartlett and Guglielmi, 2009). The authors argue that all citizens should have an equal ability to live and control a full and active life. Where this is not possible, the state should have a duty to provide the necessary help, in whatever form that is required, to individuals who require it.

These definitions benefit from being somewhat succinct but fail to articulate the range of interdisciplinary services that are sometimes required for social care users. Two further definitions, provided in international reports, go some way to addressing this shortfall. The OECD and the EU jointly published a report on long-term care for older people discussing much of what may be described in the UK as social care. In the report, long-term care is defined as:

“... a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL). This “personal care” component is frequently provided in combination with help with basic medical services such as “nursing care” (wound dressing, pain management, medication, health monitoring), as well as prevention, rehabilitation or palliative care. Long-term care services can also be combined with lower level care related to “domestic help” or help with instrumental activities of daily living (IADL).” OECD/EU, 2013,p.38

The second definition provided by Colombo *et al.* (2011) classifies social care as:

- a) a group of services such as: skilled nursing care, social work, personal care, medical equipment & technologies, and therapies. Delivered by,
- b) a range of professionals such as: nurses, low-skilled carers, or allied health professionals. In,
- c) various locations such as: at home, in an institution, or via community care.

Both this and the previous OECD/EU definition clearly capture the broad range of services that can be associated with social care that are only partially provided in other definitions. They acknowledge that social care can include a number of components including personal, nursing care, and help with other domestic activities. They also implicitly identify that social care can include components of *health* care. The latter definition also articulates the variety of settings where this can take place and provides examples of the differing professional capacities of individuals that may provide care. These additional references result in a more complete (and still succinct) definition and will be used for the purposes of this thesis although the use of the term “low-skilled” to describe carers is contentious.

Whilst it is common in Europe to describe “long-term care” in relation to these services, this thesis will refer to “social care” as this is the most commonly used term in the UK. Furthermore, unless stated otherwise, reference to social care in this thesis will be with regard to care received by adults over the age of 65.

2.2.2.2 Scottish service definitions

The Social Care Survey (SCS) is collected annually by the Scottish Government to provide statistics of the type and amounts of social care delivered by each of Scotland’s 32 local authorities (Scottish-Government, 2017e). The SCS is used for empirical analysis in later chapters of this thesis and a description of its collection is provided in Section ???. However, whilst many of the services of social care delivered by local authorities are self-explanatory (e.g. shopping or laundry), some require fuller explanations which are provided here.

The term “home care” can refer to a number of services delivered to individuals in their own home (Gatherum and MacAskill, 2017) which are described in Table 2.1.

The SCS also identifies individuals who are specifically receiving “personal care”. As previously discussed in Section 2.2.1, personal care is provided for free in Scotland but not in the rest of the UK. Given this variation, an accurate definition of personal care is important. The legislation implementing free personal care, introduced by the then Scottish Executive, articulated a clear definition which constitutes six dimensions, and which is used to identify eligibility for receipt of free care (Cavaye, 2006, p. 256).

- personal hygiene: washing etc.

Type of home care	Definition
Care at Home (Mainstream)	The aim of care at home is to help vulnerable people of all ages live independently and securely in their own homes by providing personal and housing support services. Care at home services are provided very much on each individual's own circumstances and needs.
Reablement	Provides support and encouragement to help keep up or increase the skills and confidence needed to be able to return home after a stay in hospital or after an illness. Most people referred for care at home will receive a reablement service in the first instance to help support and improve independence. Long-term services can be provided following reablement if ongoing support is needed.
Rapid Response	Rapid intervention care at home aimed at preventing hospital admissions or facilitating hospital discharges while longer term care packages are put in place.
Community Mental Health	Care at home service designed to support service users of the Community Mental Health team to live independently in the community
Extra Care Housing	Care at home based on site for tenants of Local Authority extra care housing complexes
Housing Support	Care at home services to support service users to maintain tenancies and live independently in the community
Overnight Services	Care at home provided through the night for service users requiring 24 hour support (overnight defined as between 7pm - 7am)
Meals Service	Provision of either hot or cold meals to a service user

Table 2.1: Definitions of home care types

- personal assistance: help with dressings, prostheses etc.
- continence management: toileting, catheter management etc.
- food and diet: help with eating, food preparation etc.
- problems of immobility:
- simple treatments: help with medicines, creams, oxygen therapy etc.

Other services the SCS collects data on are receipt of “community alarm” and “other telecare services” (Scottish-Government, 2017e). Individuals are defined as receiving a community alarm if they are:

“A person in receipt of a technology package which consists of a communication hub (either an individual home hub unit or part of a communal system e.g. the alarm system within sheltered housing), and a button/pull chord/pendant which transfers an alert/alarm/data to a monitoring centre or individual responder.”

Whereas an individual is defined as receiving telecare if they are:

“A person in receipt of a technology package which goes over the basic community alarm package..., and includes any other sensors or monitoring equipment e.g. (not an exhaustive list): linked pill dispensers, linked smoke detectors, linked key safes, bogus caller buttons and door entry systems, property exit sensors, [or] extreme temperature, flood, falls, [or] movement detectors.”

Scottish-Government, 2017c, p.30

The final service requiring specific definition is that of “self-directed support” (SDS). This service was introduced in Scotland in 2013 to provide eligible social care users with more choice in how they received their care via four options: a) by choosing and arranging their own support and managing the budget to do so as a direct payment, b) by choosing the type of support they received and delegating the local authority or other organisation to arrange the care and manage the budget, c) by delegating the local authority to choose and arrange the support, or d) a mixture of each of the

previous options (Audit-Scotland, 2017; Gatherum and MacAskill, 2017). Notably, the recent Audit Scotland report into SDS (2017) identified that very small numbers of individuals have been offered or taken up any of these options.

2.2.3 International models of social care

In a report for the OECD, Colombo *et al.* (2011) categorised the varying models of social care employed internationally into three main groups with subdivisions as shown in Table 2.2.

Model	Countries where employed
Universal coverage	
a) tax based	Norway, Sweden, Denmark, Finland
b) public long-term insurance	Germany, Japan, South Korea, Netherlands, Luxembourg
c) health system	Belgium
Mixed systems	
a) parallel universal schemes	Scotland, Italy, Czech Republic, Poland
b) income-related universal benefit or subsidy	Ireland, Australia, Austria, France
c) mix of universal and means-tested (or no) benefit	Switzerland, New Zealand, some Canadian Provinces, Spain, and Greece ¹
Means-tested safety net	England, USA

Adapted from Colombo *et al.* (2011)

¹ Spain and Greece have less well developed formal care services

Table 2.2: Models of social care in OECD countries

Universal models of social care are characterised by: a) a single system being in place for delivery of services, b) nursing *and* personal care are provided for all individuals meeting defined eligibility criteria, and c) some form of charge is levied on service-users (Colombo *et al.*, 2011). Three subdivisions of universal coverage social care models are identified in this classification.

The tax-based universal models, also known as the Nordic model of care, have strong local-government influence in both the raising of funds and delivery of services (Munday, 2003; Sapir, 2006; Colombo *et al.*, 2011; Fernández-Alonso and Jaime-Castillo, 2016). Overall responsibility remains with national government which also contributes funds, often dependent on local population need and structure (Colombo *et al.*, 2011). Public long-term insurance schemes are mandatory in the countries that employ them, although the age at which citizens begin to contribute varies (e.g. only over 40s contribute in Japan) (Colombo *et al.*, 2011; Forder and Fernández, 2011; Eleftheriades and Wittenberg, 2013). These models have found it increasingly difficult to fund provision and have either increased user-payments or decreased coverage in recent years (Forder and Fernández, 2011; Eleftheriades and Wittenberg, 2013; Robertson *et al.*, 2014). In Belgium, social care is viewed as a health risk and is financed through the health system with a cap on user-contribution. This results in a medical (rather than social) model of care delivery, mostly provided by nurses (Colombo *et al.*, 2011).

In contrast to universal models described above where a single system is in place for social care delivery, mixed social care systems employ either: a) universal coverage via different sources/sectors or b) a mixture of universal and means-tested benefits

(Colombo *et al.*, 2011). Whilst acknowledging the wide variation in systems, Colombo *et al.* (2011) identify three subdivisions of mixed system models of social care as shown in Table 2.2.

Parallel universal schemes provide social care via two or more sectors (e.g. nursing care via health provider and personal care from a non-healthcare source, as seen in Scotland) (Colombo *et al.*, 2011). Major differences exist between countries in how this is delivered in practice with varying degrees of coverage. Income related universal benefits provide needs-based universal coverage of social care, but benefits received vary according to income (Colombo *et al.*, 2011). France provides a good example of this system where cash benefits are need *and* income based - benefits are paid at six levels of dependency, those with higher incomes are paid proportionally less and top-up care costs themselves (Glendinning and Bell, 2008; Colombo *et al.*, 2011). The final subdivision of mixed social care models has some universal entitlements provided alongside means-tested services e.g. free provision of nursing care with means-testing for personal care.

Colombo *et al.* (2011) include Spain and Greece in this final subdivision of mixed social care models but note these countries have formal care systems that are much less developed than elsewhere in the OECD. Sometimes referred to as the Mediterranean model, informal care from family and other sources constitutes the main form of social care in these countries (Munday, 2003; Sapir, 2006; Verbeek-Oudijk *et al.*, 2014; Fernández-Alonso and Jaime-Castillo, 2016). As this role is traditionally carried out by women, the Mediterranean model has attracted criticism from a feminist perspective (Munday, 2003).

The final model in Colombo *et al.*'s (2011) classification of social care in OECD countries is the means-tested safety net model (Table 2.2). In this model only those below a pre-determined threshold are entitled to state-provided social care. Despite the free provision of health care and some non-means-tested benefits, England is included in this category in the report. Presumably this is due to the fact that state support in a residential home in England is provided only after an individual has depleted both income *and* assets below a threshold (Colombo *et al.*, 2011), a system not seen in other countries (Glendinning and Bell, 2008). A cap of £72,000 total contribution was to be introduced in 2016 following the recommendations of the Dilnot Commission (Dilnot, 2011; Eleftheriades and Wittenberg, 2013), however this plan was subsequently dropped by the UK government in 2017 (BBC-News, 2017; McKenna, 2017).

Of the three models of social care described in this section, universal systems can be seen as having a number of advantages over the other two (Glendinning and Bell, 2008; Colombo *et al.*, 2011). Sharing the burden of social care provision among the entire population, either via general taxation or mandatory insurance schemes, results in a

reliable, predictable source of finance enabling states to plan more effectively (Glendinning and Bell, 2008; Colombo *et al.*, 2011; Forder and Fernández, 2011). Mixed systems of social care can still result in considerable costs for those that require care, whereas the costs to individuals in the means-tested system can be “catastrophic” (Colombo *et al.*, 2011, pp240). The means-tested system can also be perceived as unfair for those that need to sell assets (such as a house) to pay for care, particularly when there is variation in eligibility criteria within countries (Glendinning and Bell, 2008; Colombo *et al.*, 2011; Forder and Fernández, 2011; Charlesworth and Thorlby, 2012; Eleftheriades and Wittenberg, 2013). A particular advantage of a universal social care system is that it:

“...generally reduces utilisation of more expensive health care services and professionals (e.g. hospital care, doctors) for long-term care needs, for example by making “social hospitalisation” of frail people with [social care] needs more difficult.”
(Colombo *et al.*, 2011, p.222)

Given the pressures on state budgets and the desire to adequately fund care services, this seems a particularly useful benefit of the universal coverage model of social care.

Disadvantages of universal systems are that they are generally more expensive to the state than other models of social care and can reduce the amount of informal care provided by relatives for elderly family (Colombo *et al.*, 2011; Eleftheriades and Wittenberg, 2013). The comprehensiveness of coverage can be over-burdensome for the state with a number of countries recently having to cut service or increase user-contributions to compensate for increasing demand (Forder and Fernández, 2011; Charlesworth and Thorlby, 2012; Eleftheriades and Wittenberg, 2013; Robertson *et al.*, 2014).

A recent examination of the effects of the 2008 financial crisis on the way social care is delivered across Europe suggests that the distinctions between social care models is beginning to blur (Deusdad *et al.*, 2016). There is evidence those with more comprehensive coverage are reducing levels of care whilst those with less coverage are increasing provision (Colombo *et al.*, 2011; Verbeek-Oudijk *et al.*, 2014).

Given the marked variations in how social care is funded and delivered across countries, it may be expected that there are also marked variations in levels of access and utilisation. Colombo *et al.* (2011) produced a chart (shown in Figure 2.2) derived from OECD data that shows the proportion of over 65s receiving some form of social care across countries for which data is provided. The chart shows that having a universal or mixed system of social care provision (as described above) does not absolutely influence the number of people receiving care. For example, South Korea employs a universal (insurance-based) system and has one of the lowest proportions of older people receiving care, whereas Switzerland has one of the highest whilst employing a mixed system involving some universal and some means-tested benefits. This suggests that alloca-

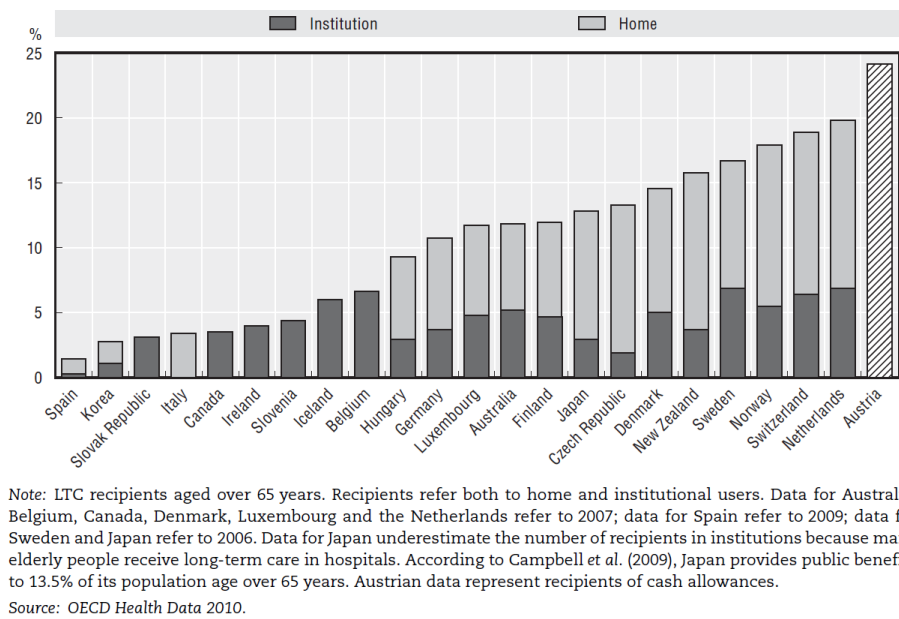


Figure 2.2: Percentage of over-65s in selected OECD countries receiving long-term care, 2008

tion of resources and eligibility criteria set within countries, as well as informal care, are likely to be more important in determining access to formal social care than any particular system of care delivery.

2.2.4 Eligibility for social care in the UK

“It is through the eligibility criteria that resources are rationed, that is “need” is equated with “resources available”. This mechanism severely limited the idea that provision could be determined either by need or by the right to services.”

Sharkey, 2006, p.10

A significant difference between Scotland and the rest of the UK is that in the former no means-test is included for receipt of personal or nursing care whether this is provided at home or in a residential setting (Bowes and Bell, 2007; Burchardt *et al.*, 2018). In England, by contrast there is a strict means-test and this has resulted in only those with the lowest wealth and greatest need receiving any form of public-funded care (Bottery *et al.*, 2018). An individual will only receive full state funding for their care if their wealth assets are below a lower threshold of £14,250. Partial funding is provided where assets are between this figure and an upper threshold of £23,250. Any individual with assets over £23,250 must pay for all aspects of their care (Humphries *et al.*, 2016; Bottery *et al.*, 2018; The-King’s-Fund, 2018; Department-of-Health-and-Social-Care, 2019).

Adding confusion to this system is the definition of “asset” in the means-test which

varies depending on the type of care received. If a permanent move to a care home is required, home-owners' houses are included as an asset. If non-residential home care is required, the house is not included as an asset (Bottery *et al.*, 2018; The-King's-Fund, 2018). Estimates suggest over half of all care home fees in England are paid for by individuals (or their families) with approximately £1bn in fees paid annually from private sources (Humphries *et al.*, 2016).

Across the UK there are variations in means-testing thresholds and services to which they are applicable as described in a King's Fund report (2018). The lower and upper threshold values in the means-test in England are the same in Northern Ireland but only apply to personal and nursing care - accommodation costs being free from the means-test. Wales has a more generous upper threshold of £40,001 applicable to all forms of care with no lower threshold. The lower and upper thresholds of £16,500 and £26,500 in Scotland are only applicable to accommodation costs (which can be the most expensive outlay) (Bell and Bowes, 2006; The-King's-Fund, 2018). All over the UK, means-tests have not changed in line with inflation meaning fewer people are eligible as time progresses. For example, in England, financial thresholds are 12% lower in real-terms in 2018/19 compared with 2010/11 (Thornby *et al.*, 2018; Phillips and Sampson, 2018).

Regardless of threshold level, some individuals in all four UK nations (estimated as 1-in-10 in England) will be unlucky enough to have to pay very high care costs (over £100,000 towards social care over their lifetime in some cases) which cannot be insured against (Dilnot, 2011; The-King's-Fund, 2018). These costs have been described as "catastrophic" (The-King's-Fund, 2018) and are widely seen as unfair (Dilnot, 2017).

Given these issues with means-tests, the criteria governing eligibility via needs-testing for receiving social care are important - and contentious. Needs-testing in all UK countries is carried out via assessment by a social worker. In Scotland, personal care is provided free for those that are deemed eligible but there is considerable variation across local authorities in how eligibility is determined - which is discussed in more detail below.

In 2010 the Scottish Government published a report written in conjunction with the Convention of Scottish Local Authorities (COSLA) (Scottish-Government, 2010) and included the recommendation that the National Eligibility Framework developed by the Sutherland review into free personal and nursing care (2008) should be applied across all social care services. The framework has four criteria for assessing risk in relation to a person's care needs: critical, substantial, moderate and low (Scottish-Government, 2015b). The critical and substantial levels of risk indicate social care needs should be addressed immediately or imminently, whereas a moderate level of risk may indicate either some or no services being required. There is no explicit description

of “severity”, or which care needs fall into each category. In practice each local authority sets the criteria and decides at which level of risk they will provide social care (Scottish-Government, 2014) and thus the authorities have a big influence on how individuals can access social care services.

Equity of access to services is directly influenced by the eligibility framework. Indeed, the strategy for self-directed support (Scottish-Government, 2010, p. 20) acknowledges this and states that such a framework “...can result in resources being narrowly focused on individuals with acute needs.” However, the report goes on to state that growing demand and finite resources requires some form of eligibility assessment, but this should not have a disproportionate effect on any one group of people requiring care.

The eligibility framework allows each local authority to set thresholds for access to care in line with local priorities and resources. This has the effect that access to services varies across differing council areas. The potential for regional variation is acknowledged by the strategy for self-directed support (Scottish-Government, 2010, p. 20) which states that, “...further work will be undertaken by the Scottish Government and COSLA to assess whether there is merit in establishing national thresholds for access to formal support across all client groups.”

Acknowledgement of problems with eligibility criteria and the promise of “further work” to be undertaken by the Scottish Government and COSLA is repeated in practitioner guidance on Self-Directed Support published in 2014 (Scottish-Government, 2014, p. 19) and that, “...it remains the case that local authorities should operate eligibility criteria to determine whether or not an individual assessed as having social care needs can access formal support and if so, which of their needs are to be met by that support.”

Data is not available on levels of care provided by LAs for each of the National Eligibility Framework criteria or for the threshold that each LA provides care at. The Scottish Government collects an annual report of eligibility and waiting times for the first quarter of the year. A recent report (Scottish-Government, 2015b) provides information on the time individuals had to wait to receive assessment and the time individuals had to wait to receive care in the period January-March for the preceding five years. However, no absolute number of people in each category is provided.

The Scottish National Eligibility Framework has striking similarities to that formerly used in England and described in Fair Access to Care Services (FACS) produced by the Social Care Institute for Excellence (SCIE) (2013). Exactly the same nomenclature is used to describe the eligibility categories of need. Newton and Browne (2008) critiqued a previous version of the FACS guidance and found similar issues to those raised above regarding regional variations in service and concentration of services on those with the highest need. Their paper describes further issues with access to social care in the context of social theory described by Lipsky (1979) and “street-level bureaucracy” (dis-

cussed in Section 2.2.6), where intentional and unintentional judgement of entitlement by social care workers have an impact on whether an individual receives care or not. Newton and Browne (2008) also make the assertion that health and social care has never been accessed equitably by arguing that those with a greater ability to articulate needs and negotiate access are more likely to gain access to services (articulated by the theory of “candidacy” also discussed in Section 2.2.6). Although no citation is provided to back-up this argument, it has certainly been described elsewhere (Matthews and Hastings, 2013) and sits well in the broader discussion of inequitable access to services (Tudor-Hart, 1971; Le Grand, 1982; Hastings *et al.*, 2014).

In England, the Care Act (HM-Government, 2014b) aimed to reduce regional variations in eligibility in access to social care by imposing national minimum thresholds that local authorities would have a statutory obligation to provide. The Care Act also aimed to ensure local authorities provided care, “...as early as possible to help maintain well-being and independence, and potentially delay a situation where longer-term care and support might be required.” (SCIE, 2015, p. 2). The minimum criteria for being eligible for care involves an individual having needs that impairs their ability to meet two or more of a designated list of outcomes (e.g. managing and maintaining nutrition or maintaining hygiene) (SCIE, 2015) and is set by the Secretary of State for Health (Abrahams *et al.*, 2014).

In practice, the most likely outcome is that the minimum threshold that local authorities will have to provide care will be similar to the “critical” level of the National Eligibility Framework previously used in the FACS guidance (Abrahams *et al.*, 2014; Burchardt *et al.*, 2015); and similar to that used in Scotland. This will legalise a shift that has already been occurring in England where fewer local authorities are providing care for those with “moderate” needs and more are only providing care for those with “critical” needs (Charlesworth and Thorlby, 2012; Abrahams *et al.*, 2014; Burchardt *et al.*, 2015). Burchardt *et al.* (2015) state that only 2% of English local authorities will have to widen their care threshold whereas 12% could now, legally, offer services to fewer people as a result of the Care Act.

A recent report by the House of Commons Communities and Local Government Committee (House-of-Commons, 2017) confirmed reductions in the absolute number of people receiving care, the concentration of services in those with highest needs only, reduction in quality of care provided, and the resulting pressures this caused to the health service through increased emergency admissions and delayed discharges. The report highlights the perilous state of social care provision in England and urges immediate attention from the government to address funding shortfalls.

Burchardt *et al.* (2015) and Abrahams *et al.* (2014) recognise some positive changes to social care policy through the Health and Social Care Act but are damning about

past UK government social care policy in England and Wales. They cite chronic underfunding and cuts for over ten years resulting in fewer people receiving care at a time when demand is sharply increasing due to demographic change. The “intensification” of services on those with the most acute needs is cited by both sets of authors as counter-productive – ignoring those with moderate care needs completely derails one of the main purposes of the Care Act, preventative services. Indeed,

“As well as lacking in moral sense, such an approach is economically unsound. Waiting for people to have high needs before providing care means that care will be more expensive, as well as pushing more older people into an already pressurised NHS” (Abrahams *et al.*, p.5).

More recent research suggests that those with moderate care needs are much more likely to have unmet need as informal care is unable to fill the gap left by formal care service (Burchardt *et al.*, 2018; Brimblecombe *et al.*, 2018)

A similar picture has been seen in Scotland where most councils now only provide care assessed as having Critical or Substantial risk (Audit-Scotland, 2016c). Absolute numbers of people receiving home care has steadily fallen over the last 10 years from under 70 per thousand aged over 65 in 2006, to under 50 per thousand in 2015 (Audit-Scotland, 2016c). At the same time, the number of hours of care provided has increased reflecting the “intensification” of services discussed above (Scottish-Government, 2017e). There are wide variations in the number of hours of home care provided per population across local authorities (Audit-Scotland, 2012; Scottish-Government, 2017e). This may reflect different demographic make-up of each local authority although reductions in ratios per population can be seen in almost all local authorities (Scottish-Government, 2017e). Audit Scotland (2012) also highlighted that intensifying services is likely to be a short-term solution with negative long-term impacts and suggests comparison of performance across Scotland would be beneficial in identifying good practice.

In a report profiling the care at home sector in Scotland, MacLeod and Mair (2015) describe large decreases in absolute numbers of people receiving care at home over the ten years to 2013. There have also been significant reductions in the number of people receiving non-personal care (so called “mopping and shopping”). The increase in the number of hours of home care delivered by all services reflects a focus on smaller numbers of individuals with higher care needs. This means those with moderate or low personal care needs and those requiring “mopping and shopping” services are now less likely to receive publicly funded care. Echoing the views of Burchardt *et al.* (2015) and Abrahams *et al.* (2014), McLeod and Mair (2015) highlight the potential false economy of this situation – home care services are likely to reduce the need for costly emergency admissions to hospital and delay the requirement for more intensive home care packages - a view also shared by Audit Scotland (Audit-Scotland, 2012).

2.2.5 Resource allocation in Scotland

Local authorities in Scotland have a statutory obligation to provide social care to individuals they have assessed as eligible for care (Audit-Scotland, 2012). Whilst the previous section discussed how eligibility is determined, this section outlines how funding is allocated to those that are assessed as eligible for care. The strategies local authorities have employed to provide services during budgetary constraint are also discussed.

Local authority funding is provided by the Scottish Government via a block general revenue grant made up of a number of components in addition to revenue raised via local taxes and charges (King *et al.*, 2007; Scottish-Government, 2013). The majority of the centrally-provided grant is calculated via a formula known as the Grant Aided Expenditures (GAE) which accounts for over 80% of the general revenue grant (Scottish-Government, 2018a). The formula for GAE is calculated using what is called a “client group approach” and is based on 89 services provided by local authorities (Scottish-Government, 2018a). A national figure for each service is set and each local authority receives a percentage of that figure based on estimates of the number of people that use that service (a capitation) and other secondary indicators affecting needs and/or costs of provision such as area deprivation or rurality (Smith, 2003; Scottish-Government, 2018a). For example, funding for primary school teachers is based on the number of children in primary education (primary indicator) and adjusted to take into account the percentage of pupils in small schools (secondary indicator) (Scottish-Government, 2018a).

The use of formulae to allocate public expenditure has potential to improve efficiency in spending and equity of distribution (Smith, 2003). Equity of distribution is achieved via the explicit nature of a formula framework with transparent methodology that can be debated and amended (Smith, 2003). The formula for the “green book” settlement was agreed with the Convention of Scottish Local Authorities (COSLA) (Scottish-Government, 2013). However, as King *et al.* (2007) note, GAE grants to local authorities are estimates of relative, rather than absolute, spending needs in that area. The “green book” reporting the annual settlement for local authorities in Scotland stresses that the values allocated for different services are not budgets or targets and that local authorities are free to spend resources (other than ring-fenced monies) as they see fit (Scottish-Government, 2018a). In effect, “...the capitation payments seek to offer comparable public sector organisations the opportunity to deliver some average level of service, assuming average responses to social and economic circumstances, and an average level of efficiency” (Smith, 2003, p. 309).

The “green book” outlines seven main areas of local authority expenditure from which the 89 services mentioned above are derived; Education, Social Work, Roads & Transport, Leisure & Recreation, Cleansing & Environment, Elections & Taxation, and

Other Services (Scottish-Government, 2018a). Spending allocation for social care comes under the social work heading which is subdivided into 23 subcategories of services. Of these, nine (listed below) are directly related to social care as defined for the purposes of this thesis; the others being based on children's services or similar:

- service for home based elderly
- residential accommodation for the elderly
- casework and related administration: elderly
- services for people with disabilities
- casework and related administration: people with disabilities
- independent living fund
- carers support and respite services
- care home fees
- personal and nursing care for older people

The expenditure for the first three items on this list, as well as carers support and respite services and care home fees, is calculated using population weighted indices for each local authority derived from: the standardised mortality ratio, census data on self-report long-term illness and people living alone, as well as pension credit data (service for home based elderly) or council tax data (residential accommodation for the elderly). Services relevant to people with disabilities and the independent living fund are calculated depending on the number of people aged 16-64 in each local authority. Expenditure allocation for personal and nursing care for older people is derived from formulae calculated in the Scottish Government Health Directorate Distribution (Scottish-Government, 2018a).

The GAE formula has been in place for some time (initially outlined in 1992 (Scottish-Government, 2018a)). The more recent issue facing local authorities in terms of finance has been cuts following the 2008 financial crash. In the financial year 2016/17 the overall grant to Scottish local authorities was cut in real-terms by 5% which added to a cumulative real-term cut of 11% since 2010/11 (Audit-Scotland, 2016a). Authorities have been managing this pressure by reducing spending in all areas of their budgets - with the exception of social work (Audit-Scotland, 2016a). £3.1 billion was spent on social work by Scottish local authorities in 2014/15 - an increase of 3% since 2010/11 and a third of all council spending (Audit-Scotland, 2016c). However, given the 5% decrease planned for 2016/17, Audit Scotland (2016a) warned that social work (and specifically social care) budgets are now likely to be cut - resulting in a decrease in the quality of service (Audit-Scotland, 2016c).

Although overall budgets have slightly increased, efficiency savings have been made by contracting the provision of social care to the private and voluntary sectors (Audit-Scotland, 2016c). In 2008, over 70% of home care clients in Scotland received care

provided only by a local authority, in 2017 this figure was less than 50%. Private and voluntary sector organisations are now increasingly providing home care *purchased* by the local authority (Scottish-Government, 2017d). However, as discussed in Section 2.2.4, savings have also been made by tightening eligibility criteria with the result that absolute numbers of individuals receiving care has fallen over the same period (Audit-Scotland, 2016c).

These budgetary pressures are difficult for local authorities to manage, but what is the outcome on service users? Using the “pro-rich/pro-poor” nomenclature initially used by (Bramley *et al.*, 2005) (and discussed in Section 2.2.6.2), Gannon *et al.* (2017) investigated the social impact of spending cuts in Scotland. The report found that the vast majority of local authority spending is on services that are “pro-poor” i.e. services that are disproportionately used by people with lower socioeconomic position. As a result, despite attempts to protect these services, the cuts to local authority spending have a disproportionate effect on this societal group. Councils with higher numbers of the most deprived citizens are having to make the biggest percentage cuts in services defined as “very pro-poor” (e.g. social work for children and families or citizen’s advice). These findings echoed an earlier report from the project looking at cuts across the UK as a whole (Hastings *et al.*, 2015).

Gannon *et al.*’s report (2017) assigns older persons social work services as “pro-poor” along with local authority public transport but does not distinguish between the two in analysis. It is therefore difficult to dis-aggregate the specific effect of cuts on social care from the report particularly as there was an increase in spending between 2010/11 and 2014/15 (discussed above). Nevertheless, cuts expected to social care budgets from 2016/17 (Audit-Scotland, 2016a) are also likely to have a disproportionate effect on those with lower socioeconomic position.

2.2.6 Social theory

2.2.6.1 Eligibility

“...the *criteria* under which a given individual is eligible for publicly funded support for long-term care, and for how much support the individual is eligible, and the *processes* involved in selecting from the general population those who receive this support and determining for how much support each person is eligible”

[Eleftheriades and Wittenberg, 2013, pp.2

As discussed in section 2.1.4, the “inverse care law” describes how resources and funding does not flow fairly to those most in need in a primary care setting. This section provides additional social theory investigating why public resources may not be fairly distributed in the context of eligibility and allocation for/of social care discussed above.

Two social theories on how eligibility for public services are determined will be discussed in this subsection: street-level bureaucracy and candidacy.

The term street-level bureaucracy is generally credited to Michael Lipsky and his book of the same name (1979), along with its more recent revision (Lipsky, 2010). The theory investigates the extent to which front-line public service workers exercise discretion in which individuals of the general public are eligible to access any given service - doing so from a position of authority, free from organisational oversight and unconstrained by organisational policies (Lipsky, 2010). As a result, street-level bureaucrats control “...the nature, amount, and quality of benefits and sanctions provided by their agencies.” (Lipsky, 2010, p. 13). Using the term, “street-level” suggests that the theory is concerned with power, where it resides, and who wields it (Hupe *et al.*, 2016). Street-level bureaucrats can be teachers, police officers, nurses, social workers, or any other worker providing a public service (Hupe *et al.*, 2016) and their “...decisions..., the routines they establish, and the devices they invent to cope with uncertainties and work pressures effectively *become* the public policies they carry out” (Lipsky, 2010, p. xiii).

Evans (2010) and Ellis (2011) both provide a critique of street-level bureaucracy that suggests the theory needs to be augmented to take into account new structures of public services, particularly in social work, that place greater autonomy with managers than front-line workers. They argue that these new structures mean workers who deal face-to-face with public service users have less discretion about eligibility criteria and are more likely to have to justify eligibility decisions to senior members of staff who now wield more power in terms of service access.

Empirically exploring the effects of street-level bureaucracy poses a number of methodological problems (Hupe *et al.*, 2016). The use of large sample surveys of public sector workers investigating their views and how they make decisions is one way (e.g. Tummers and Bekkers (2014)). However Lipsky (2010) and Hupe *et al.* (2016) agree that qualitative interview techniques with public sector workers in their own workplace is the best way to fully understand how street-level bureaucracy impacts on front-line services.

In contrast to street-level bureaucracy, “candidacy” theory focuses on the ways in which service recipients influence resource distribution. The term “candidacy” was first used by Dixon-Woods *et al.* (2005, 2006) to form a concept of how vulnerable individuals identified themselves as being eligible for a particular health service or intervention given for particular illnesses or health conditions. The theory was further explored and augmented by Mackenzie *et al.* (2013, 2015) in relation to access and utilisation of all public services as a way to explore concerns about unequal distribution of uptake.

The theory argues that there are a number of social and cultural factors that contribute to an individual’s interpretation of their eligibility for a given service and is based on

a seven-stage model as shown in Table 2.3

Stages of candidacy	Description of stage
Self-identification of candidacy	Process by which individuals come to view themselves as legitimate candidates for particular services
The availability and accessibility of services	Knowing how to make contact with appropriate services in relation to identified candidacy
Permeability of services	Includes the level of explicit and implicit gate-keeping within a service and the complexity of its referral systems; in addition it refers the “cultural alignment” between users and services
Appearing at services and asserting candidacy	The work that an individual must do to assert their candidacy in an interaction with a service professional
Professional decision making	Candidacy as expressed by service user is validated or otherwise by service professional. This influences future offers of service
Offers of and resistance to services	Service may be appropriately or inappropriately offered by a professional and this may, or may not, be acted on by service user
Operating conditions and local production of candidacy	Incorporates factors that influence decision about future service provision (e.g. resources) and the relationship that develops between service users and professionals over a number of encounters

Table 2.3: Seven stage model of candidacy

This is a much broader theory than that of street-level bureaucracy and focusses on the barriers and enablers individuals face/use when accessing services. In other respects it is trying to do the same thing - exploring how front-line interactions shape outcomes. It could be argued that candidacy includes the concept of street-level bureaucracy in the third, fifth, and sixth stages of the model shown in Table 2.3. “Permeability of services”, “professional decision making”, and “offers of and resistance to services” are areas where an interface between a service user and service professional takes place - much like the interactions described by Lipsky.

Investigating candidacy as a theory empirically again appears to be best served using qualitative methods. The complex and dynamic nature of candidacy suggests identifying meaningful quantitative measures are unlikely. Both Dixon-Woods *et al.* (2005, 2006) and Mackenzie *et al.* (2013, 2015) employed critical interpretive synthesis in their studies.

Both of the social theories described in this subsection deal with the concept of eligibility and how, in the case of street-level bureaucracy, professionals exercise discretion on access to service and, in the case of candidacy, how service-users identify whether they are eligible and offer themselves for a service in the first place. Both theories describe complex interactions between individuals across an eligibility criteria barrier.

2.2.6.2 Resource allocation

“Almost all public expenditure on the social services in Britain benefits the better off to a greater extent than the poor”

[Le Grand, 1982, pp.3]

In his seminal book, “The strategy of equality”, Julian Le Grand (1982) investigated