



**Oilthigh
Glaschu**

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

David Alexander Gunn Henderson

MRes(Health Research), PGcert(Advanced Practice),
BSc(Nursing)

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

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Abstract

Blad de Blah blah blah. I may play about with centering and italicised styles here

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Acknowledgements

Again maybe play about with centering and layout.

How about a nice quotation at the end???

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
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
IADL	Instrumental activities of daily living
IJB	Integrated Joint Boards

List of Abbreviations

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
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 where increases in life expectancy have been driven by better health programmes and treatments has resulted in a growing proportion of the population being over the age of 60 (Beard *et al.*, 2016; AMS, 2018). Accompanying this growth is an increase in the prevalence of health conditions most likely to occur in middle-aged and older adults and also the presence of two or more chronic health conditions in one individual - the broadest definition of multimorbidity (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 contributing 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 policymakers and research.

Policymakers in developed countries have to identify ways of financing care where demand is increasing (due to older populations and increased multimorbidity), but supply is decreasing (due to the impacts of budgetary restraint following the financial crash of 2008)]. Simultaneously,

Need to add (OECD, 2011)

Providers - Shift to PC, specialist v generalist

Levels of multimorbidity in the Scottish population follow a stark socioeconomic profile with those of lower socioeconomic position having higher levels of multiple conditions and more complex care needs which develop 10-15 years earlier than their more affluent peers (Mercer *et al.*, 2009; Barnett *et al.*, 2012). This inequality in outcome is

compounded by the fact that primary care provision in areas of higher socioeconomic disadvantage, ergo areas of higher need, receive the same or less funding as other more affluent areas. This inequity in provision of service demonstrates existence of the inverse care law in primary care services (Tudor-Hart, 1971; Mercer *et al.*, 2012; McLean *et al.*, 2015) and has already been discussed in section 2.2.7.

Regardless of how it is defined, there is widespread recognition that multimorbidity is a growing problem worldwide with some evidence suggesting there are disproportionate effects for women and those of lower socioeconomic position (Barnett *et al.*, 2012; Violan *et al.*, 2014; AMS, 2018). Although the association between multimorbidity and increasing age is well documented (OECD, 2011; AMS, 2018), 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).

Health services, health research, and health guidelines are predominantly designed around single diseases (OECD, 2011; Moffat and Mercer, 2015; AMS, 2018). Clinical guidelines are often based on the results of Randomised Controlled Trials (RCTs) which often exclude those of older age, and those with multimorbidity. The absence of these groups in trials of treatments means (Bartlett *et al.*, 2005; Shenoy and Harugeri, 2015). evidence leaving those with multimorbidity being treated by multiple health practitioners with the risk of receiving multiple treatments from multiple specialities at risk of conflicting treatments

Individuals - treatment burden. Outcomes

One notable omission in literature *and* guidelines is effect on social care. Most position papers concentrate on *health* services. What about SC?? NICE guideline

edit this

Internationally, provision of social care has become one of the most important issues for policy makers in recent years (OECD/EU, 2013; Humphries *et al.*, 2016) \textit{Context, Trump, Korea, ISIS etc}. Some of the key principles of health and social care integration legislation in Scotland are aimed at improving care for those with multiple long-term health conditions - also known as multimorbidity (Scottish-Government, 2016c; Audit-Scotland, 2016b). In Scotland, approximately two-thirds of individuals receiving social care services are over the age of 65 (Scottish-Government, 2016e) 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

multipotentiality. However, no single data source exists that allows this comparison to be made. Nevertheless, guidelines exist for healthcare professionals to assist in assessing the social care needs of older people with multiple long term conditions (NICE, 2015). Multipotentiality is associated with a number of negative outcomes including increased health care usage (NICE, 2016). Whether multipotentiality increases use of social care services is unknown but this could have an important role in informing policy decisions regarding social care provision.

- MM
 - 1 OECD and high level documents
 - 2
 - 3 Health inequality
 - ..but no idea of effect on Social Care
- SC
 - SC delivered differently around the world
 - Funding issues
 - Revist Burchardt et al
- MM + SC
 - Important as increasing imp/explicit understanding of interaction
 - Policies reflect this, WHO etc.
 - Legislated in Scotland
 - Effect of SC on hospital admission
 - Evidence is sparce/poor
- Data Linkage
 - Offers potential to empirically investigate cross-sectoral questions
 - Measurement of social (or LTC) is important for a number of reseons - OECD(2013) page 18, Care co-ordination (integration) is not measured well pp 76, administrative databases potential to help these problems plus ideas for outcome measures pp 76 & 79, pp81 obstacles to data collection (overcome by data linkage in Soctland)
 - SG funding for PhD explicitly to do this 2020 vision + policy

1.2 Aims

- Identify best resource of sc data and assess suitability for research
- Create a linked dataset that can be used to answer questions relevant to the provision of health and social care services
- Describe the relationship between MM and SC

- Describe the relationship between SC use and unplanned hospital admission

1.3 Objectives

- Identify SC data sources by liaison with relevant stakeholders
- Identify best HC data sources suitable to achieve aims
- Assess to what extent measures of multimorbidity and health & social care service use can be operationalised using existing health and social care administrative data.
- Obtain governance approval for data linkage
- Clean and analyse linked data in accordance with aims and RQs
- Make recommendations to policy makers on administrative data collections.

1.4 Research questions

These broad issues inform the background of this thesis. Funding for the PhD was provided by the Scottish Government with the specific intention of exploring the possibilities of linking routinely held health and social care data to address these issues. Based on the aims and objectives described in chapter 1 and the literature reviewed in this chapter the following research questions have been formulated:-

In people over the age of 65 in Scotland:

1. (a) What are the socioeconomic, demographic, and geographic patterns in the use of social care?
 (b) Is there an association between multimorbidity status and the amount and type of social care use over time? Does this vary by the patterns described in 1(a)?
2. (a) Is there an association in the use of social care services, multimorbidity status and unscheduled health care use?
 (b) Do multimorbidity status and social care use predict mortality?

1.5 Scientific contribution

- First description of the relationship between SC and MM (in UK)
- First *national* level study looking at SC and unplanned hosp admission

1.6 Thesis structure

Below old stuff

Many countries, including the United Kingdom (UK), 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, 2016c).

The World Health Organisation (2015) cites relative inequalities in improvements of health and life expectancy, within and between countries, as justification for recommended structural change to healthcare (WHO, 2015). The paradigm shift in the method of service delivery is suggested in response to increasing long-term, chronic conditions forming the major burden of care worldwide. Integrating health and social care services and increasing primary care spend are cited as two potential ways of facilitating this shift in focus (WHO, 2015).

Policies introduced that facilitate integration of services have been implemented despite little evidence to suggest they will have the desired effect (Stewart *et al.*, 2003; Petch, 2009, 2012b; Weatherly *et al.*, 2010; Burgess, 2012; Robson, 2013; Damery *et al.*, 2016; Kaehne *et al.*, 2017). The continued drive to integrate services does, however, implicitly acknowledge that health and social care services are linked. How these services interact at the individual level and whether differing levels of provision in each service affects the other is not well understood (Glasby *et al.*, 2011; OECD/EU, 2013).

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 a further 7.2% cut to local authority spending in 2016/2017 (Audit-Scotland, 2016b), the ability to protect social care from reductions in spend becomes less likely. Decreased local government budgets across the UK and Scotland since 2010 have affected those living in the poorest areas hardest (Hastings *et al.*, 2015; Gannon *et al.*, 2016). If social care budgets decrease further, the question of whether the most deprived areas will feel these cuts most is of grave importance.

Ends

Chapter 2

Literature Review

This chapter identifies and summarises academic and policy literature relevant to the thesis. Literature regarding a) access to social care, b) health and social care interaction and c) multimorbidity is presented. As the main research is conducted with Scottish data, there is appropriate focus in the structures and policies regarding health and social care in this country. However, this is placed in the wider context of the UK and developed world.

The chapter is organised in three parts following the main themes listed above. Section 2.2 focuses on social care from a number of perspectives: varying definitions of the term, differing international models of care delivery, social theory of eligibility and resource allocation, and finally the impact on health inequalities.

Section 2.3 outlines the policy framework regarding health and social care services, how these services are funded and delivered, and why they are linked. 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.

Section 2.1 describes why multimorbidity is important in the context of health and social care integration and then provides an overview of academic literature and policy documents regarding multimorbidity and its definitions, measurement, and epidemiology.

Add in paragraph or two outlining literature search strategy

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 in the context of 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 (OECD, 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 (OECD, 2011) in both high-income and low-to-middle-income countries (Afshar *et al.*, 2015). It disproportionately affects those of lowest socioeconomic position (OECD, 2011; AMS, 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). 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 (Gijsen *et al.*, 2001; OECD, 2011; Jani *et al.*, 2019), reduced quality-of-life (Fortin *et al.*, 2004, 2005; OECD, 2011), reduced functional status (Kadam and Croft, 2007; OECD, 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 (Gijsen *et al.*, 2001; Salisbury *et al.*, 2011; OECD, 2011).

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, 2018). 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, 2018). 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). 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 (OECD, 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 (OECD, 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: indentifying 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 guidline on multimorbidity assessment and management (2016) suggests research should focus on: organisation of (primary) care, community assessment, medicines management, and the prediciton 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 reccomendations, 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 Feinstein (Feinstein, 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

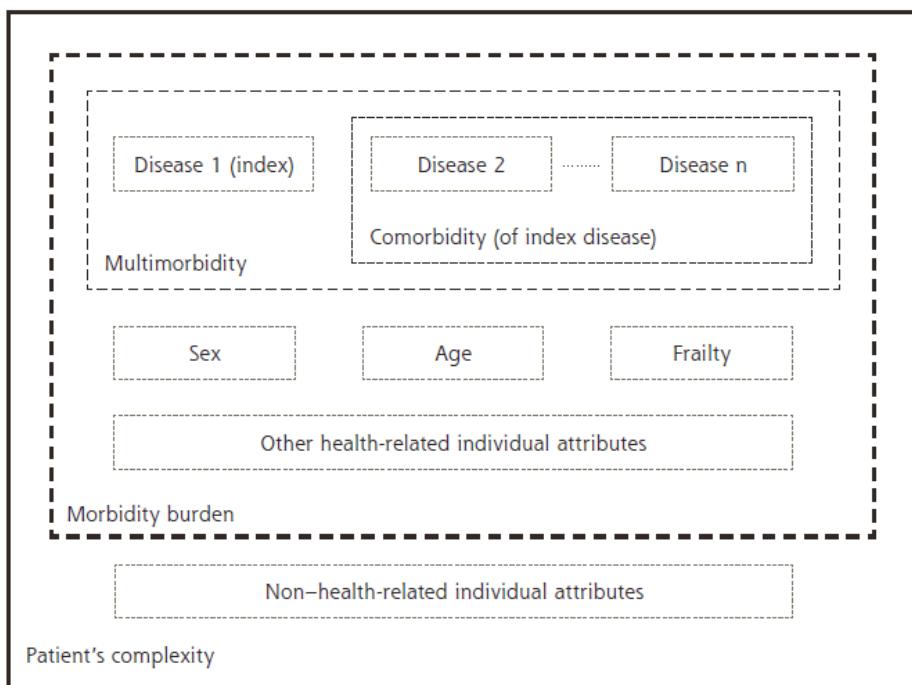


Figure 2.1: Conceptual framework of co/multimorbidity. Valderas et al. (2009)

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 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 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 (OECD, 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 adaptions. 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 policymakers 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.

“The term “health inequality” is usually employed to refer to the systematic differences in health which exists between different population groups (e.g. different social classes or ethnic groups)” (Smith *et al.*, 2016, p.1)

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, 2018). 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 engage in unhealthy lifestyle behaviours, experience multimorbidity at a younger age, and live in overcrowded or unsuitable housing (Shaw *et al.*, 2006; Baker *et al.*, 2015).

A recent analysis released by the Office for National Statistics suggests the gap in male life expectancy between 2015-2017 across local authorities in England was 8.5 years, in Northern Ireland 4 years, and in Wales 4.1 years (ONS, 2018). At 7.2 years the largest gap in male life expectancy in the UK was found in Scotland. Those born in

East Dunbartonshire were expected to live to 80.1 years, whereas those in Glasgow City were expected to live 73.3 years (ONS, 2018).

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 e.g. 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 for the need for it, in the population served”

Tudor-Hart, 1971

This argument, however, does not take into account 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 proportions of budgets has lead the King’s Fund to describe the situation in primary care in England and Wales as, “in crisis” (Baird *et al.*, 2016, p. 3).

In Scotland, the even distribution of GP workforce among the population means GP practices in the most deprived areas need to provide more consultations, for people with greater 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) 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 numbers 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 lack of a standard definition is mirrored in the myriad ways of measuring multimorbidity with various counts, indices, and clusters. Despite this, evidence suggests multimorbidity is increasing in prevalence and has a strong socioeconomic pattern. This pattern has implications for health inequalities, particularly through increased need and access to services. Very little research has been conducted into the effects of multimorbidity on social care services, despite acknowledgement that an interaction is likely to exist.

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 but raise 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 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). There is little research detailing the impact this has had on those no longer receiving formal care services although increases in delayed discharges from hospital in the UK are one outcome the cuts are thought to contribute to (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 means and needs-tested (Burchardt *et al.*, 2015; Humphries *et al.*, 2016), although there are 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 [ref] 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). 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).

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 eases some of the financial burden for users, access to care still regulated through the needs-test. Overall numbers of individuals in Scotland receiving social care continues to fall suggesting 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

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). The Organisation for Economic Co-operation and Development (OECD) and the European Union (EU) jointly published a report on Long Term Care (LTC) for older people discussing much of what may be described in the UK as social care. In the report, LTC 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, pp38)

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”— (a) 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, but (b) does not include anything provided by an establishment or agency for which Her Majesty’s Chief Inspector of Education, Children’s Services and Skills is the registration authority under section 5 of the Care Standards Act 2000.” (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 and 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.

A more clearly defined concept is that of *personal care* which has been provided for free in Scotland since 2002. The legislation introduced by the then Scottish Executive necessitated a clear definition and constitutes six dimensions (Cavaye, 2006, p. 256).

- personal hygiene: washing etc.
- 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.

Need a definition of reablement here also Try <http://www.careinfoscotland.scot/topics/care-at-home/>

Maybe an overall description of SCS social care - home care, telecare, equip etc. see data specification documents and (potentially) IJPDS paper

Personal care is, however, only one aspect of social care provision and clear definitions of other services provided to individuals are lacking. Nevertheless, the definitions of social (or long-term) care above all highlight services that are required to aid with an individual's functional or cognitive needs.

A final definition provided by Colombo et al(2011) will be used for the purposes of this thesis:-

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

This definition clearly captures the broad range of services that can be associated with social care that are only partially provided in other definitions. It acknowledges that social care can include a number of components including personal, nursing care and help with other domestic activities, and articulates the variety of settings where this can take place. 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.

Add a paragraph with synthesis and critical appraisal of definitions - perhaps before last definition to provide a justification for why it was chosen

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 into three main groups with subdivisions as shown in Table 2.1.

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

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

¹ Spain and Greece have less well developed formal care services

Table 2.1: Models of social care in OECD countries
adapted from Colombo et al (2011)

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 2.1.

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; 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 2.1). 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 ¹ (Glendinning and Bell, 2008).

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

¹A cap of approximately £72,000 total contribution was to be introduced in 2016 (Eleftheriades *et al.*, 2013)

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."

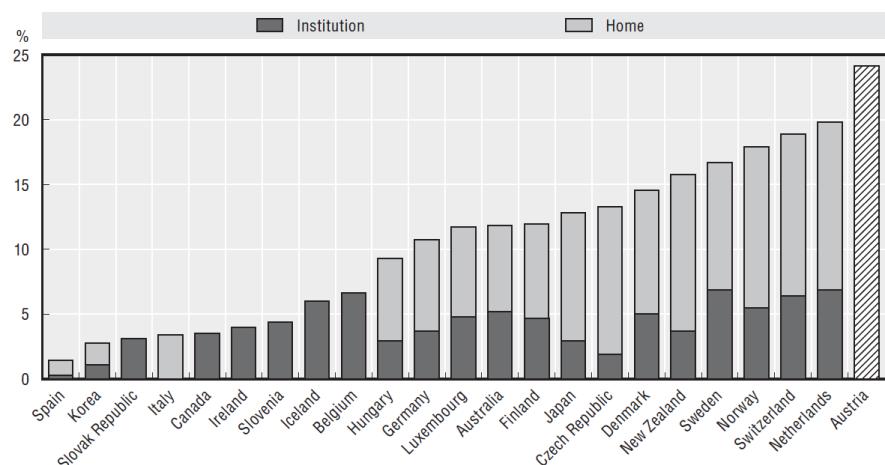
(Colombo *et al.*, 2011, p. 222)

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).

Need to mention typology does not cover quality or quantity of care.

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).



Note: LTC recipients aged over 65 years. Recipients refer both to home and institutional users. Data for Australia, Belgium, Canada, Denmark, Luxembourg and the Netherlands refer to 2007; data for Spain refer to 2009; data for Sweden and Japan refer to 2006. Data for Japan underestimate the number of recipients in institutions because many elderly people receive long-term care in hospitals. According to Campbell *et al.* (2009), Japan provides public benefits to 13.5% of its population age over 65 years. Austrian data represent recipients of cash allowances.

Source: OECD Health Data 2010.

StatLink <http://dx.doi.org/10.1787/888932401577>

Figure 2.2: Older recipients of long-term care services as a share of the over 65 population, 2008

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 allocation 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 Resource Allocation

2.2.4.1 Overview

Need to add rest of UK. See BMA, Burchardt, Humphries, Bottery etc. etc.

Local authorities in Scotland have a statutory obligation to provide social care to individuals they have assessed as eligible for care (Audit-Scotland, 2012). All local authority funding is provided by the Scottish Government via a block general revenue grant made up of a number of components textit{(Re-write - remember Tax and charges)} (King *et al.*, 2007; Scottish-Government, 2013). The majority of this 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, 2016a). 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, 2016a). 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 such as area deprivation or rurality (Smith, 2003; Scottish-Government, 2016a). 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, 2016a).

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 author-

ties 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, 2016a). 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, 2016a). Spending allocation for social care comes under the social work heading which is subdivided into 23 subcategories of services. Of these, nine are directly related to social care as defined for the purposes of this thesis (the others being based on e.g. children’s services);

- 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 in this list as well as carers support & respite services and care home fees are calculated using population weighted indices for each local authority calculated from; the standardised mortality ratio, census data on self-report long term illness & 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, 2016a).

2.2.4.2 Financial constraints

The GAE formula has been in place for some time (initially outlined in 1992 (Scottish-Government, 2016a)). 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) warn that social work (and specifically social care) budgets are now likely to be cut, which will likely result in a decrease in the quality of service (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 2.2.7), Gannon et al (2016) 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 (2016) 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 shown above, as there was an increase in spending between 2010/11 and 2014/15. 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.

Cuts to services reduce the potential for access to such services. If these cuts are disproportionately affecting more deprived communities it is likely unequal outcomes for these communities will be exacerbated. Given the close link of social care to health care, the question of whether social care influences health inequalities is important. The next section presents an overview of literature on health inequalities.

2.2.5 Access to Social Care - Eligibility in Scotland and the UK

2.2.5.1 Overview

"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, pp.10]

In Scotland, access to social care is needs-tested via assessment carried out by a social worker. The criteria for social care delivery, therefore, has a very important part to play in how services are accessed.

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 and 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 has a big influence on how individuals can access social care services.

Equity of access to services is directly influenced by an 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

again 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 numbers 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 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" (discussed 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 *add it to the above section also*. 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 *Link to Candidacy*. 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 (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).

2.2.5.2 Financial constraints

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 numbers of LAs are providing care for those with “moderate” needs and only providing care for those with “critical” needs (Abrahams *et al.*, 2014; Burchardt *et al.*, 2015). Burchardt *et al.* (2015) state that only 2% of English LAs will have to widen their care threshold whereas 12% could now, legally, tighten care provision as a result of the Care Act. *This situation is not new and has been gradually worsening over the past decade and has profound impacts on the quality of, and access to, social care* [@RN374] **re-write Sharkey is 2006 makes no sense temporally - also spell out what "profound impacts" are.**

A recent report by the House of Commons Communities and Local Government Committee (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 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 numbers of 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.*, 2014, p. 5).

A similar picture has been seen in Scotland. Absolute numbers of people receiving home care has steadily fallen over the last 10 years whilst the number of hours of care provided has increased (Scottish-Government, 2016e). There are wide variations in the number of hours of home care provided per population across local authorities (Audit-Scotland, 2012; Scottish-Government, 2016e). 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, 2016e). 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), Macleod 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.

2.2.6 Access to Social Care - Social Theory of 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]

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 (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).

something more on the substance here? One of Lipsky's key points is about how bureaucrats use their discretion, making moral judgements of 'deservingness', rather than need – or in addition to need. And result is that some groups tend to lose out - NB

Evans(2011) and Ellis (2010) 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.

is that why these restrictions were introduced? In order to damp down autonomy of street level b.s and achieve more standardised outcomes? NB

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.

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 2.2

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 2.2: 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 but in other respects it is trying to do the same thing - exploiting how front-line interactions shape outcomes. *Do previous authors make this point? Seems obvious for them to have considered how their frameworks relate. Is it true to say that candidacy brings the service user's subjectivity into the picture (albeit constrained) as well as that of the bureaucrat? - NB* 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 2.2. "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.

The next section describes in detail this eligibility barrier in relation to social care in the UK, firstly from a Scottish perspective and then more broadly in the wider UK.

2.2.7 Access to Social Care - Social Theory of 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, 1989, pp.3]

In his seminal book, “The strategy of equality”, Julian Le Grand (1982) investigated whether social and economic equality had been achieved since the introduction of post-war welfare spending. The book compares the distribution of public expenditure and outcomes across health, education, housing, and transport. It concludes, as highlighted in the quote above, that those with higher socioeconomic position benefited disproportionately from government social services spending across all sectors. Indeed , “...there persist substantial inequalities in public expenditure, in use, in opportunity, in access and in outcomes”(Le Grand, 1982, p. 4).

Criticism of Le Grand’s conclusions cites subsequent research that shows empirical evidence indicating a reduction in inequalities and questions the assumption that the sole purpose of the welfare state is to achieve equality (Powell, 1995). More recent research (Bramley *et al.*, 2005 cited in; Hastings *et al.*, 2014),(Bramley and Evans, 2000; Hastings, 2007) has shown that when comparing distribution of resources at neighbourhood level (rather than national level) there is higher spending in less affluent areas. However some service were found to be “pro-rich” (education, pensions) and others “pro-poor” (parks, environmental services) (Bramley *et al.*, 2005 cited in; Hastings *et al.*, 2014). Whether a service is more likely to be used by more or less affluent citizens is important in terms of resource allocation - particularly when services are being cut as shown by Gannon et al (2016) and discussed further in section [2.2.4](#).

Understanding why there are differences in resource allocation for different types of service has led to the investigation of “middle class capture” of services and how it is obtained (Gal, 1998; Matthews and Hastings, 2013; Hastings *et al.*, 2014). An adapted version of Gal’s (1998) six channel framework of middle class advantage described by Hastings et al (2014) is shown in table [2.3](#)

These six “channels” conceptualise the modes of how and why welfare spending in certain areas appears to benefit more affluent groups. In their study investigating street-cleansing services, Hastings et al (2014) observed the influence of middle class capture and some of the channels of advantage described in table [2.3](#) suggesting the

Channel	Description of channel ¹
Electoral	Large middle class more likely to vote thus political policies influencing welfare services more likely to be geared toward them.
Organisational	Unions and professional associations representing middle-class occupations have strong influence on welfare policy
Knowledge	Resources of education and access to information possessed by middle class mean they have better understanding of "how the system works" and therefore can better exploit it
Mass Media	Middle class has dominant role in media and can thus exert influence over how policy is covered. Also able to access and influence those that produce mass media more easily
Exit	Ability of middle class to leave public provision for private alternative influences public policy in order to avoid this happening.
Bureaucratic	Public services "run" by the middle classes therefore exert influence over how it is accessed and by whom.

¹ Adapted by Hastings et al [2014] from Gal [1998]

Table 2.3: Six channels of middle class advantage

theories of Le Grand (1982), described above, and Tudor-Hart, described below, should not be discounted.

ICL

There has been no research on whether the inverse care law is perceptible in social care - a service delivered, like primary care, in a community setting and also likely to have an impact on secondary health care use. (*But also perhaps influenced by access to primary care? I'm speculating here but if GPs can exercise any influence in getting people assessed (and hence allocated service), then places with better access to GPs then likely to have an advantage in access to social care - NB*) - look to NICE MM and SC Nor has any research specifically investigated variations in the distribution of social care services by socioeconomic position at the local level. Such research would add useful evidence to the debate regarding the strategy of equality and middle class capture.

The next section describes how social care is funded in Scotland and how cuts to services post-2008 may adversely impact less affluent members of the public.

2.2.8 Summary

There is no agreed standard definition of social care, a term often used synonymously is long-term care. The boundary between what is health care and what is social care is often blurry. The definition chosen for this thesis provided by Colombo et al (Colombo *et al.*, 2011) encapsulates the wide number of services that make-up social care including nursing, personal, equipment, and technological. The definition also identifies that so-

cial care can be provided not only at home, but also in institutions or other community settings.

Three broad models of social care are seen internationally; universal, mixed, and means-tested schemes. Within each of these models there are many different methods of delivery across countries and no easy comparison can be made identifying differences in outcomes across countries. It does appear that universal systems spread the risk of the costs of social care more equitably among the populations where it is employed. Importantly, every model of social care involves some user-contribution towards costs.

Eligibility for social care is determined via pre-specified criteria in all cases. How these criteria are set varies greatly across and within countries. In UK terms eligibility criteria are set by local authorities and have been greatly tightened in recent years as a response to budgetary constraint. Also observed is the process of “intensification” where greater hours of social care are being delivered to smaller numbers of people with higher needs. This has potential to erode an important function of social care - preventing expensive unscheduled health care use.

Eligibility for social care can also be affected by the individual in need, and those applying the pre-determined criteria. Social theories regarding this include “street-level bureaucracy” and “candidacy”. Both theories describe difficulties that may exist in individuals attempting to access public provided services, the latter in more detail and including aspects of the former. Both theories are best suited to being investigated with qualitative methods.

Allocation of resources for social care in Scotland are decided by local authorities. The monies they receive are dependent on a grant from the Scottish Government which is calculated via the GAE formula. The GAE formula allocates money for social care services based on a mixture of data from each local authority including; mortality and morbidity ratios, the amount of people living alone, and the ratio of people paying certain level of tax or receiving certain benefits. This formula has been in place for over 20 years and was agreed with COSLA.

Social theories regarding allocation of resources for public service suggest those with higher socioeconomic position are more likely to benefit from public spending than their less affluent peers. Empirical analysis of; “The strategy of equality”, “The inverse care law”, and “middle class capture” all suggest more affluent groups are better at accessing public services.

There have been significant cuts to local authority budgets across the UK since 2008. Savings have been made whilst trying to protect front-line services but current and future cuts are likely to impact these services. Most local authority spending is on services used by those from lower socioeconomic positions thus cuts will dispropor-

ately affect these people. Little is known about how access to social care differs across socioeconomic and geographic strata. In an age of austerity, the question of whether an inverse *social* care law exists remains unanswered.

2.3 Health and Social Care Interaction

2.3.1 Public Policy

Scotland "... is a paradoxical tapestry of rich resources, inventive humanity, gross inequalities, and persistent levels of disadvantage"

[Christie, 2011, pp.2]

Acknowledging demand for public services was likely to increase, the Scottish Government set up the Christie Commission on the future delivery of public services in 2010. In its final report (Christie, 2011), the commission made a number of pertinent observations including:-

Consider dropping bullets and describing in paragraphs

- Increasing demand for public services are due not only to demographic reasons but also because of a failure to tackle inequality
- Spending levels on public services is unlikely to return to 2010 levels until 2026
- Public services in 2010 were fragmented with no coordination and often different services duplicated work
- Public services had a "top-down" approach to delivery with institutional and professional needs given precedence over users

The recommendations of the commission included:-

- Better coordination and integration of public services
- Empowerment of communities in how services are structured
- Reduction in demand for services by focussing on prevention
- Improving performance and efficiency of services

These recommendations had profound effects on subsequent policy and legislation in Scotland, most notably in relation to health and social care services (Christie, 2011), although this was not the first policy aimed at improving coordination between these services. Previous policies aiming to increase cooperation between NHS health boards

and local authority provided social care included; the Joint Future Group (2000), the Community Care and Health (Scotland) Act (2002), Community Health Partnerships [2002], and the Integrated Resource Framework (Ferguson *et al.*, 2012).

2011 also saw the publication of the Scottish Government vision to achieve sustainable quality in the delivery of healthcare services by the year 2020 (Scottish-Government, 2011). Echoing some of the Christie Commission recommendations, the 2020 vision contained a number of objectives to change the way health and social care services are delivered including; a focus on prevention and self-management of health conditions, an expanded role for GPs and primary care, a focus on reducing hospital stays & providing treatments in a community setting, improving care for those with multimorbidity, and formally integrating health and social care services (Audit-Scotland, 2016b).

The inclusion of the last of these objectives - to formally legislate for the integration of health and social care - was in response to the fact that although previous policies had made some progress in improving co-ordination between health and social care services, this had not had a demonstrable impact on outcomes for users of these services (Audit-Scotland, 2011, 2015; Petch, 2012b). This was often as a result, among other things, of different cultures in health and social care organisations (Audit-Scotland, 2011). The difference in culture is perhaps understandable given the very different ways health and social care have been historically funded and delivered.

Health care in Scotland, like the rest of the UK, is provided via the NHS free at the point of need to all citizens (Ham *et al.*, 2013). This principal has remained in place despite many internal changes of structure (with some divergence from other parts of the UK)(Ham *et al.*, 2013). Front-line services are delivered by 14 geographically-based health boards (Ham *et al.*, 2013).

Provision of social care is the responsibility of the 32 Scottish local authorities who also either provide the services themselves, purchase provision through third-party private or voluntary organisations, or give individuals a budget to purchase provision themselves (Ham *et al.*, 2013). As discussed in section 2.2, this service is not universal and depends on a needs-test against set eligibility criteria. Means-testing is employed to determine user-contribution to non-personal and non-nursing care institutional care home costs.

Given such contrasting backgrounds, and most importantly separate silos of funding sources and budgets, integration of services had many barriers (Ham *et al.*, 2013). Building on the 2020 vision (Scottish-Government, 2011) objective of integrating health and social care, legislation to enact this structural change into law was announced in 2011. Section 2.3.2 describes these changes in more detail.

2.3.2 Health and Social Care Integration

"Our vision is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting. We will have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self-management. When hospital treatment is required, and cannot be provided in a community setting, day case treatment will be the norm. Whatever the setting, care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions. There will be a focus on ensuring that people get back into their home or community environment as soon as appropriate, with minimal risk of re-admission."

[Scottish Government, 2011, pp.2]

The Public Working(Joint Bodies) (Scotland) Act (HM-Government, 2014a) paved the way for the legal integration of health and social care services and all integrated authorities had management and structural plans in place by the Scottish Government's designated deadline of 1st April 2016. These reforms are seen as the "...most significant change to the way we care for and improve the health of our people, in their communities, since the creation of the NHS" (Scottish-Government, 2017a).

One of the most important changes this legislation made was that funding for the designated integrated services were to be provided from a single budget. In a report investigating future change to health and social care services in England, the Barker commission noted, "...moving to a single budget with a single commissioner is not a sufficient condition to tackle the myriad problems of integration that face health and social care. But we believe it is a necessary one" (Barker, 2014, p. 9).

Integration is expected to ensure; better outcomes, more efficient use of resources, reduction in hospital and residential long term care use, a shift in care closer to people's homes, and avoidance of the consequences of fragmented & uncoordinated care (Burgess, 2012, 2016; Audit-Scotland, 2015, 2016b; Scottish-Government, 2015c, 2016c). However, despite streamlining of budgets, there remain significant barriers in achieving these aims (Audit-Scotland, 2015, 2016b).

One of the key principles of the legislation is that health and social care is delivered under one of two models - the body corporate or lead agency model. The former sees the delegation of budgets from a health board and one or more local authorities to an Integrated Joint Board (IJB). This board is responsible for the delivery of care and develops a strategic plan for how services will be implemented (Scottish-Government, 2015c; Burgess, 2016; Kaehne *et al.*, 2017). The IJB consists of representatives from the health board, local authority/authorities, health professionals, social work profes-

sionals, voluntary sector workers, unpaid carers, and service users (Audit-Scotland, 2015; Burgess, 2016). The full extent of integrated services delegated to the IJB varies from area to area but as a minimum adult social care services, adult community health services, and some adult acute health services (particularly those that incur lots of emergency admissions) are delegated (Scottish-Government, 2015c; Audit-Scotland, 2015; Burgess, 2016; Kaehne *et al.*, 2017). The IJB decides how the delegated budgets will best achieve the aims of the strategic plan for the area and directs the NHS board and local authority/authorities to provide services according to this plan(Audit-Scotland, 2015; Kaehne *et al.*, 2017).

Under the lead agency model, a plan is made to divide the delivery of specific health and social care services to either the NHS board or a local authority (Scottish-Government, 2015c; Audit-Scotland, 2015; Burgess, 2016; Kaehne *et al.*, 2017). Funding for these services is transferred between the health board and local authority as agreed in a delivery plan (Audit-Scotland, 2015; Kaehne *et al.*, 2017). The lead agency plan between NHS Highland and Highland Council is the only one in place in Scotland - all other areas favouring the body corporate model (Scottish-Government, 2015c; Audit-Scotland, 2015; Burgess, 2016; Kaehne *et al.*, 2017). Under this plan, NHS Highland is responsible for the delivery of all adult health and social care services, whilst the council takes responsibility for children's community health and social care services (Burgess, 2016; Kaehne *et al.*, 2017).

Comparison of outcomes between the Highland partnership and all other IJBs will be of significant interest. One of the main aims of integration is to reduce unscheduled healthcare use, in particular unplanned admissions to hospital, which can be an indicator of a lack of social care support in an area (Scottish-Government, 2015c; Audit-Scotland, 2015, 2016b). There are other key performance indicators that have been set nationally as a way to audit the improvements (or lack thereof) made over time. These are focussed on outcomes on individuals and include self-report of health and wellbeing questions from surveys and statistics collected from routine data on service use (Scottish-Government, 2015a, 2016b; Kaehne *et al.*, 2017).

Early indicators suggest that integration authorities are still some way from making an impact on the delivery of services. In a report published immediately prior to IJBs taking control of services Audit Scotland (2015) suggested that disagreements over budgets, poor workforce planning, difficult to understand governance arrangements, and poor planning around involvement of the charity and private sectors meant that little improvement was likely to be seen in 2016/17.

2.3.3 Research on Health and Social Care Interaction

"There is tentative evidence that financial integration can be beneficial. However, robust evidence for improved health outcomes or cost savings is lacking"

[Weatherly et al, 2010 pp. 3]

Add in "Where is the NHS going wrong?" here ? also need to add in Witham et al (Witham et al., 2015)

The large scale structural change in health and social care services seen in Scotland and further afield is built on the expectation that more efficient social care provision can help reduce unplanned health care use. Although intuitive there is very little robust evidence to suggest this is the case (Stewart et al., 2003; Petch, 2009, 2012b; Burgess, 2012; Robson, 2013; Damery et al., 2016; Cameron, 2016; Kaehne et al., 2017). **clarify - refs predate Scottish integration - what were they measuring??**

Much research has been conducted on the *structural* elements of integration with little emphasis on *outcomes* for service users (Petch, 2012a). There has also been little attention paid to those who deliver front-line services, indeed, ".. a preoccupation with the process and mechanisms of joint working has diverted attention away from the central role played by the professions, who appear sceptical of the aims of these initiatives and distrustful of their professional colleagues" (Cameron, 2016, p. 12).

The lack of evidence around outcomes may be partially due to the difficulty in collecting data that can measure the interaction between health and social care services. A recent report for the OECD (2013) highlighted the paucity of good data regarding social care, even in countries known to have good data resources. The report also suggests that use of routine administrative data may be a useful tool in addressing this lack of evidence (OECD/EU, 2013). A small number of studies have been published in the last decade using linked-administrative data to look specifically at interactions between health and social care services.

Porter et al (2016), using Welsh data, reported that aggregate statistics of social care use and emergency admission to hospital showed no correlation. However, when analysing individual-level linked administrative data, those that received social care before an emergency admission episode were more likely to have fewer subsequent admissions with shorter lengths of stay than those that received social care only after an admission. The study period covered six years of data for adults over the age of 65 from one geographic area of Wales.

Using data from four areas in England, Bardsley et al (2012) found that older persons

staying in residential care homes were less likely to use unplanned hospital services compared to those receiving social care at home. The study period was based over one year only and all those that died during the year were excluded from analysis which may have had some impact on results. Intensive social care delivered at home was associated with higher unplanned *and* planned secondary care use.

In Sweden, Condelius et al (2008) found that individuals using high amounts of community health & social care services were also likely to use large amounts of emergency hospital services. This suggests community services may not reduce unplanned health care use. The study period focussed on hospital admissions over one year in the over-65 age group and found a small number of individuals with high multimorbidity had higher use of all primary healthcare, social care, and secondary care services compared to others with lower multimorbidity levels.

In a large comprehensive study in Australia, Kendig et al (2012) linked a population survey to administrative health and social care databases. The purpose of this study was to identify clusters of service users and did not specifically measure the interaction between health and social care services. Using k-means cluster analysis, the study identified nine clusters of service utilisation - three of which accounted for the vast amount of total use.

Differences in the systems of health and social care, data types, outcomes, and analysis techniques make it impossible to draw robust conclusions from these studies. They each demonstrate, however, that linking administrative data sources is a feasible option for this type of research and that these techniques may be able to improve understanding of the interaction between health and social care services.

Need to synthesise this section and draw a conclusion. Also see Colin's comments in feedback word doc for section notes

2.3.4 Summary

Public policy in Scotland has been edging towards greater integration of health and social care services since the devolved Scottish Parliament was set-up in 1997. A lack of progress in shifting care from secondary to community settings through policy alone prompted legislation to formalise the integration of these services - a law which came into effect on the 1st April 2016.

Almost all areas of Scotland have opted to employ a body-corporate model of integration where health boards and local authorities devolve responsibility and budgets to an Integrated Joint Board that sets local priorities and directs how services will be delivered. Early indications suggest IJBs have not yet overcome governance, budgetary,

or workforce issues to make any improvements in nationally set outcome indicators.

Very little research has been conducted into the interaction of health and social care services at the user level. Most studies and reports focus on the structural implications of integrating care instead. Novel techniques involving the linkage of administrative data sources at the individual-level are a feasible way of filling the gap in knowledge about the interaction of these services and the impacts they have on service-users.

2.4 Administrative Data Linkage

- Best way to empirically investigate MM + SC is through data linkage. Spiers et al.
- Section will briefly describe linkage
- Also mention difficulties in obtaining data?

2.4.1 Context

Record linkage refers to a merging that brings together information from two or more sources of data with the object of consolidating facts concerning an individual or an event that are not available in any separate record.

[OECD, 2006]

Administrative data is data that is generated when individuals use a service of some description. Often in research terms, and exclusively in this thesis, administrative data refers to data generated by the use of *public* services (Pavis and Morris, 2015; Mazzali and Duca, 2015). This data can describe the provision of a specific service or how it was administered by the provider (Pavis and Morris, 2015; Mazzali and Duca, 2015). As the above definition outlines, record linkage involves joining data about individuals from two or more administrative databases together (Fleming *et al.*, 2012; Harron, 2016) and is being increasingly used in social science research (Atherton *et al.*, 2015; Bell *et al.*, 2016).

Using administrative data for research purposes has a number of advantages and disadvantages. The data is not collected for research purposes and as such may lack specific information relevant to a researcher's line of inquiry (Mazzali and Duca, 2015). This also reduces the ability of a study to adjust for all potential confounding variables, decreasing the ability to make causal inferences from analyses (Mazzali and Duca, 2015). There is the potential for ambiguity about the coding of variables in a database and

what each code represents (Mazzali and Duca, 2015; Atherton *et al.*, 2015; Walesby *et al.*, 2017) which means specialist knowledge of the database and collection methods are required (Mazzali and Duca, 2015). Administrative databases also have the potential to contain data of questionable quality and high levels of missing data (van-Walraven and Austin, 2012; Hashimoto *et al.*, 2014; Harron *et al.*, 2017). Data can be missing for the same reasons as seen in other forms of research but, in addition, individuals may also be missing due to failure to interact with a service or because insufficient information was available to accurately match records during the data-linkage process (Harron *et al.*, 2017).

Advantages of administrative databases are that they enable large, often population sized, sample sizes because they are generated from service use (Mazzali and Duca, 2015; Pavis and Morris, 2015; Walesby *et al.*, 2017). This characteristic also reduces the potential for sampling bias (Mazzali and Duca, 2015). Well maintained administrative data can offer information over long periods of time including very recent data (Pavis and Morris, 2015). This can make inferences from research findings more robust with excellent levels of external validity without the extra cost traditional observational studies might incur (Mazzali and Duca, 2015; Harron *et al.*, 2017). The potential to link administrative databases from a number of sources is a significant advantage and offers insights into how services interact (Mazzali and Duca, 2015; Atherton *et al.*, 2015; Walesby *et al.*, 2017).

There are two main methods of linking data from disparate sources; deterministic matching and probabilistic matching (Fleming *et al.*, 2012; Harron, 2016; Doidge and Harron, 2018). Where differing datasets possess common unique identifiers, deterministic matching simply links data using this identifier. Probability matching methodology can be employed in the absence of a common unique identifier (Fleming *et al.*, 2012; Harron, 2016; Doidge and Harron, 2018). Using this method, a probability of two records matching correctly is calculated based on how well the records match based on a set of common partial identifiers such as name, date-of-birth, and postcode (Fleming *et al.*, 2012; Harron, 2016; Doidge and Harron, 2018). An important consideration when using probabilistic linkage is making an assessment of false-positive match rates (Fleming *et al.*, 2012; Harron, 2016; Doidge and Harron, 2018). There are three main strategies to assist with this assessment; measuring error using “gold-standard” data (such as a validated external datasets), sensitivity analyses (comparing results across differing linkage parameters), and comparing linked and unlinked data according to characteristics (such as sociodemographic subgroups) (Harron, 2016).

Scotland is home to some of the best administrative databases in the world (Pavis and Morris, 2015). This is particularly due to the high-quality of health datasets that have been collected and maintained for over 40 years (Fleming *et al.*, 2012; Pavis and Morris, 2015). Whilst linkage of differing health datasets has become common over

this period, new cross-sectoral linkages are beginning to emerge such as health and educational data (Wood *et al.*, 2013), and health and social care data (Witham *et al.*, 2015). These cross-sectoral linkages are providing new insights that have the potential to have lasting impact on policy and provision of services (Pavis and Morris, 2015; Atherton *et al.*, 2015).

2.4.2 Data sources in Scotland

- LAs have SC, but SCS. Agreed to be linked August 2016
- ...but cross-sectional- Renfrew
- Lack of PC data makes MM research hard - PIS

2.5 Conclusion

Access to social care varies significantly internationally and is influenced in two main ways; allocation of resources to providers of social care, and how these providers distribute services within local areas. Eligibility criteria are the main means of how services are rationed. Demographic change has resulted in increasing demand on social care services at the same time as budgets in the UK and Scotland have been drastically cut.

In response, new models of service delivery have been sought by governments. In Scotland, the formal integration of health and social care services has been implemented with the dual aims of increasing efficiency and quality of service. Individuals with multimorbidity are high users of both health and social care and are likely to be able to benefit most if integration achieves its aims.

Intuitively, social care can prevent unplanned used of unscheduled health care services but there is little evidence that suggests this is the case. Lack of data, particularly on social care, has made it difficult to understand the interaction between these services. Routinely collected administrative data, along with new methods of linking records across sectors means that it is now possible to address this lack of evidence. One small study (Porter *et al.*, 2016) shows that linking individual-level health and social care data shows associations hidden in aggregate statistics.

Measuring multimorbidity is an inexact science with variation in the methods and number of conditions used. Simple counts of diseases or medicines have been shown to be as efficacious a predictor of health care use as more complicated indices. Methods using statistical techniques to cluster regularly co-occurring health conditions may

provide new insights into the social patterns of multimorbidity. *Data sources available make it difficult to measure multimorbidity as per recommended definitions*

Chapter 3

Methods

This chapter outlines the process of obtaining administrative data suitable to answer the thesis research questions and has seven sections. Firstly, a brief description of administrative data linkage research and its associated advantages and disadvantages are discussed. The following section provides a detailed description of the strict information governance protocols required including: the infrastructure used, the approvals process, and the legal framework enabling the research to take place. Thirdly, a thorough description of the data sources used in analysis is provided outlining their source, reasons for collection, and any known quality issues. In the fourth section, the process of probabilistically matching personal identifiers from the Social Care Survey to a research population spine is described. This process enabled the linkage of social and health care data sources. The fifth section describes how the study cohort was created including the data wrangling procedures necessary to join together data from disparate sources. The penultimate section outlines the statistical methods applied to the data in order to answer the thesis research questions. Finally, An illustrated timeline depicting the major stages of the overall project is displayed with a brief description.

3.1 Information Governance

Confidentiality of data subjects is an important consideration in any data linkage project. The benefits of administrative data linkage, outlined in section 2.4, are dependent on research being conducted in a legally and ethically competent fashion. Whilst full anonymisation would be an effective way to protect data subjects confidentiality, it is almost impossible to achieve this with individual-level data suitable for research purposes (Harron *et al.*, 2017).

As an alternative, a process involving robust approvals review, researcher training with associated responsibilities and sanctions, and safe haven settings are used to preserve

data subject confidentiality (Harron *et al.*, 2017). This section outlines how this process was applied for the purposes of the data linkage completed in this thesis. Firstly, the various organisations that provide the infrastructure that enabled the data linkage to take place are briefly described. An overview of the various approvals and ethical panels is then provided, followed by the legal framework which enabled data processing to take place with a brief description of how confidentiality is maintained during the linkage process.

3.1.1 Infrastructure

The key test for an acronym is to ask whether it helps or hurts communication.

Elon Musk

3.1.1.1 Scottish Informatics and Linkage Collaboration

The Scottish Informatics and Linkage Collaboration (SILC) is an umbrella term for a number of support services that are available to individuals wishing to conduct research using linked administrative data (SILC, 2017c). Services include computing resources (provided by the University of Edinburgh), research and project coordination advice (provided by the electronic Data Research and Innovation Service (eDRIS)), and an indexing service (provided by the National Records of Scotland (NRS)) (SILC, 2017c). SILC currently has three partner institutions; the Administrative Data Research Centres (ADRC), the Farr Institute, and the Urban Big Data Centre (UBDC) (SILC, 2017c).

3.1.1.2 Urban Big Data Centre

Funding for this PhD was provided by the Scottish Government and the Economic & Social Research Council (ESRC). The bid for funding was won by UBDC which is based within the University of Glasgow. UBDC as an organisation is also funded by the ESRC and brings together data scientists and social scientists with research interests relevant to urban living such as; housing, transport, migration, and health (UBDC, 2017b). UBDC has six partner universities; Edinburgh, Bristol, Cambridge, Reading, Sheffield, and Illinois-Chicago.

The linkage project described in this thesis was completed with the assistance of UBDC's controlled data service. This service helps researchers to access personal data that exists in administrative databases (UBDC, 2017a). In addition to a vigorous

approval process, access to data is tightly controlled via safe haven IT architecture which monitors use of data and output of analyses to ensure individual anonymity is maintained (UBDC, 2017a). UBDC arranges access to the safe haven environment through liaison with eDRIS, provided by the Information Services Division (ISD) of NHS National Services Scotland (NSS) under the auspices of SILC. A more detailed description of the safe haven is given in section [3.1.3.2](#).

3.1.1.3 electronic Data and Research Innovation Service

ISD is a subdivision of NHS NSS (ISD, 2010b). NSS is a national NHS board in its own right and works with the other NHS boards, particularly the 14 geographic health boards, to provide centralised services such as; procurement, legal support, IT, and public health intelligence (NSS, n.d.). As a division of NSS, ISD provides, among other things, support for the latter two of these services (ISD, 2010b). This includes administering the large number of databases containing information on health service use in Scotland varying from maternity & births, to cancer services (ISD, 2010b). ISD held databases used in this thesis, the Prescribing Information System and Unscheduled Care Data Mart, are described more fully in sections [3.2.3](#) and [3.2.4](#).

eDRIS is part of ISD and provides services under SILC (SILC, 2017b). It is detailed specifically with assisting research using health administrative datasets. Researchers using the eDRIS service have a named research assistant who provides advice on; data sources, study design, the information governance approvals system, access to the safe haven environment, and review of analysis outputs to ensure disclosive information cannot be inferred (ISD, 2010b).

3.1.1.4 National Records of Scotland

NRS collects and maintains information about the people of Scotland including births, deaths, and marriages (NRS, 2017). In addition to producing annual reports and population estimates, NRS provides the indexing service under SILC which enables anonymous linking of administrative databases as a Trusted Third Party. This is made possible using an indexing spine which is based on the NHS Central Register (NHSCR) and held by NRS (NRS, 2018a). This is described more fully in section [3.3](#).

3.1.1.5 Health and Social Care Analysis Division

The Health and Social Care Analysis Division (HSCAD) is a division within the Scottish Government that provides statistic, economic, and research evidence to inform

policy making in this area (Scottish-Government, 2017b). It is one of many Analytical Service Divisions (ASD) that provide analytical support, advice, and briefing to the Government. HSCAD creates reports and publications in a number of key areas including; social care, care homes, and mental health and is responsible for collecting and publishing the Social Care Survey (SCS) described in section 3.2.1.

3.1.2 Approvals

As described above, one of the ways in which data subject confidentiality is maintained in data linkage projects is through a rigorous and robust approvals process. Three separate approvals were required for the purposes of data linkage in this thesis.

3.1.2.1 Research Approvals Committee

Data linkage for the project was facilitated by UBDC's controlled data service. In order to utilise this service, the research proposal required approval from the UBDC Research Approvals Committee (RAC). A full list of RAC members is available on-line (UBDC, 2017a). This committee is independent of UBDC and approves use of funds and infrastructure in UBDC and includes a lay member of the public (UBDC, 2017a). An application to use the controlled data service is judged on its academic merit, public benefit, skill of research team, and alignment with UBDC aims before being approved (UBDC, 2017c).

3.1.2.2 Ethics

Ethical approval for data analysis was sought and gained from the University of Glasgow College of Social Sciences Research Ethics Committee (CoSS REC). A blanket ethical approval, obtained by eDRIS from the NHS East of Scotland REC, covers research that uses NHS Health data, does not involve direct contact with data subjects, has peer-review approval, stores data in the national safe haven, and is conducted by research teams based in the UK (ISD, 2010a). The main linkage project therefore only required further approval from CoSS REC to cover the non-health related data (i.e. the Social Care Survey).

3.1.2.3 Public Benefit and Privacy Panel for Health & Social Care

In addition to RAC and College ethical approval, the main thesis project also required clearance from the Public Benefit and Privacy Panel for Health & Social Care (PBPP).

This was because data from NHS sources were being used. The PBPP acts as a decision making body with delegated responsibility from NHS Scotland Chief Executive Officers and the Registrar General (Scottish-Government, n.d.). Using terms of reference and guiding principles, the panel adjudicates whether research projects using administrative data generated by the NHS in Scotland can be used for research purposes. The panel ensures that the basis for disclosing data has a clear public benefit and ensures the legal framework for accessing and processing data is sound.

Add short para on data management: archive and destruction

The approval letter for the main thesis project is shown in Appendix A. A full description of data processing including its legal basis is presented in section 3.1.3.

3.1.3 Data processing

3.1.3.1 Legal framework

The permissions and linkage of data for this project were completed in advance of the European Union (EU) General Data Protection Regulation (GDPR) coming into effect in May 2018. The information governance was informed by antecedent laws including the Data Protection Act (DPA) (1998). However, as the study period was known to overlap with the implementation of GDPR, all legal documentation was completed to ensure compliance with the incoming regulation.

Data sharing and processing can be completed without consent of data subjects as long as certain criteria, explicitly named in legislation, are met (Bell *et al.*, 2016). For the purposes of this thesis fair processing of data was completed, without consent, in accordance with three legislative paragraphs:

- Schedule 2:(6) of the DPA.
 1. The processing is necessary for the purposes of legitimate interests pursued by the data controller or by the third party or parties to whom the data are disclosed, except where the processing is unwarranted in any particular case by reason of prejudice to the rights and freedoms or legitimate interests of the data subject.
- Schedule 3:(8) of the DPA (emphasis added)
 1. The processing is necessary for medical purposes and is undertaken by
 - (a) a health professional, or

- (b) a person who in the circumstances owes a duty of confidentiality which is equivalent to that which would arise if that person were a health professional.
- 2. In this paragraph “medical purposes” includes the purposes of preventative medicine, medical diagnosis, *medical research*, the provision of care and treatment *and the management of healthcare services*
- Paragraph 9 of the Data Protection (Processing of Personal Data Order 2000(SI 2000 No.417)).

The project has clear and substantial public interest in the information it will provide to inform the delivery of public services. The data processing is necessary to enable this research to take place. The project does not support measures of analysis with respect to any individual. Finally, the project will not cause any substantial damage or distress to any individual.

Lawful processing of data for the purposes of the project is in accordance with a further two legal acts:-

- Social Work (Scotland) Act 1968.

8 Research

1. The Secretary of State may conduct or assist other persons in conducting research into any matter connected with his functions or the functions of local authorities in relation to social welfare, and with the activities of voluntary organisations connected with those functions.
2. Any local authority may conduct or assist other persons in conducting research into any matter connected with their functions in relation to social welfare.
3. The Secretary of State and any local authority may make financial assistance available in connection with any research which they may conduct or which they may assist other persons in conducting under the provisions of this section.

- National Health Service (Scotland) Act 1978

47 Education and research facilities. (2)Without prejudice to the general powers and duties conferred or imposed on the Secretary of State under the Scottish Board of Health Act 1919, the Secretary of State may conduct, or assist by grants or otherwise any person to conduct, research into any matters relating to the causation, prevention,

diagnosis or treatment of illness, or into such other matters relating to the health service as he thinks fit.”

Information governance for the project was also informed by the “Guiding Principles for Data Linkage” report produced by the Scottish Government (2012). These guidelines, themselves informed by legislation such as the DPA, highlight the importance of public interest, transparency, and privacy when conducting data linkage projects with publicly held data sets.

In order to preserve anonymity whilst linking administrative data from different agencies, a method known as “linkage using a separation of functions” is employed (Pavis and Morris, 2015; Harron, 2016). This process involves the use of a Trusted Third Party (TTP) to process non-anonymised information in order to link more than one dataset together. The TTP receives personal information (e.g. names, addresses and dates-of-birth) from the data controllers of the administrative datasets to be used and creates index “keys” to send back to the data controllers to attach to their data (Pavis and Morris, 2015; Harron, 2016). The TTP creates a lookup table of index “keys” relevant to each dataset and sends these to a linkage agent. The linkage agent receives data from the data controllers *without* personal information and links them together using the “keys” created by the TTP and makes this available to a researcher in a secure environment (Pavis and Morris, 2015; Harron, 2016). This process means the TTP receives lots of personal information but no other information, the researcher has access to information relevant to their study but no personal information, and the data controllers share information about individuals in their datasets without compromising anonymity and without seeing data from each others databases (SILC, 2017a).

3.1.3.2 Safe Haven environment

Another integral part of ensuring the confidentiality of data subjects within large, linked administrative data is by holding such data in a safe haven environment (Harron *et al.*, 2017). As described in section 3.1.1.2, access to data for this thesis was administered via UBDC’s controlled data service and further liaison with eDRIS to enable use of the NSS National safe haven. All data shared for the purposes of the thesis was transferred by data controllers to the safe haven by secure file transfer protocol.

The safe haven enables secure data storage and access via a Virtual Private Network (VPN) connection with strict access control. This environment does not enable external access of any kind i.e internet or saving & printing facilities (ISD, 2010c). In order to retrieve output of analyses, work was submitted for statistical disclosure control which was conducted by eDRIS employees. This process ensures that data taken out of the safe haven cannot be used, either on its own or by being combined with other data, to

breach the privacy of any individual (ISD, 2010c; Harron *et al.*, 2017). A full guide to statistical disclosure control is provided by Lothian & Ritchie (2017).

3.1.3.3 Data sharing agreement

For the purposes of the main linkage project, a three-way data sharing agreement (DSA) between the University of Glasgow, NHS National Services Scotland, and Scottish Ministers (Scottish Government) was signed. This detailed the purpose of data sharing, as well as the transfer, protection, and security of data. The roles and responsibilities of each organisation in relation to relevant data protection legislation are clearly detailed in the DSA.

3.2 Data Sources for Linkage

Research conducted with administrative data requires a thorough description of databases used (van-Walraven and Austin, 2012). This should include a description of the purpose of the data collection and the methods employed to collect data. This enables appraisal of any potential biases that may exist within the databases (van-Walraven and Austin, 2012; Mazzali and Duca, 2015). There are 4 main sources of data used in the main analyses of this thesis: the Social Care Survey, the National Records of Scotland population spine and death records, the Prescribing Information System, and the Unscheduled Care Data Mart. Each of these are described in more detail below.

3.2.1 Social Care Survey

The Social Care Survey (SCS) is collected annually by HSCAD for the Scottish Government to provide descriptive statistics of the amounts of social care delivered by each of Scotland's 32 local authorities (Scottish-Government, 2017e). Results are collated and published annually by HSCAD in the "Social Care Services, Scotland" report (Scottish-Government, 2017e). The SCS reports provide an overview of social care services for the public and policy makers. In addition, certain measures captured by the SCS are used in funding formulae to calculate allocation of resources to each local authority (e.g. number of people receiving home care) (Scottish-Government, 2016a).

All 32 Scottish local authorities collect information on social care as part of their management systems (Scottish-Government, 2016e). HSCAD produce a data specification document outlining the information that should be returned for the SCS and this is sent

to HSCAD via a secure web-based system called ProcXed. This system supports data validation checks on transfer to improve data accuracy (Scottish-Government, 2016e). The SCS contains unique ID numbers generated by local authorities but does not routinely collect CHI numbers. In order for the SCS to be linked to health data sources, HSCAD commissioned work to link it to the NRS population spine using probabilistic linkage techniques. This process is described more fully in section [3.3](#).

The SCS has been collected in its present form since 2013 as a combination of two previous data collections - the Home Care Census and the Self Directed Support (Direct Payments) Survey (Scottish-Government, 2016e). Individual-level data has been collected since 2010. Some questions have remained constant throughout this period but there have also been some changes in definitions and measures.

The most recent SCS (2017) collected information on all individuals that received community alarm, telecare, self directed support (SDS) or social work/ support worker services during the previous financial year. In addition, individuals that received home care services, meals, housing support, shopping, or laundry services during a specified census week are included in the survey.

Before 2013/14, information on telecare and community alarm services was only collected for individuals receiving these services during the census week. Furthermore, the value for total weekly hours of housing support services was included in the value of home care services. The separation of these services acknowledges that housing support is often regarded as 24-hour-a-day-7-day-a-week service (Scottish-Government, 2016e).

For the value of total weekly hours of home care, HSCAD request details on scheduled and actual hours of care delivered. Some local authorities are able to return both values, others only return one value. Where both are returned, actual hours of home care are used in official reporting (Scottish-Government, 2016e). Approximately 129,000 people received community alarms and/or telecare services, approximately 60,000 received home care services, and approximately 8,000 received SDS funding in 2016/17 (Scottish-Government, 2016e). The overlap of individuals who receive more than one of these services is unknown.

The cross-sectional nature of the survey, and in particular the census week variables, mean that the SCS only collects a sample of the entire population that receive social care in Scotland in any given financial year. It is unknown how large this sample is. It is also impossible to infer whether the values of total weekly hours of home care delivered to individuals is representative of the care they receive throughout the financial year. In order to gain a better understanding of these issues, an exploratory project, using a richer data set, was conducted as part of this thesis and is reported in chapter [4](#).

3.2.2 NRS population spine and Death records

The ‘Research population spine’ is a copy of the National Health Service Central Register (NHSCR) and is controlled by NRS (NRS, 2018a). The spine contains over 9 million records and is updated quarterly. There are very strict policies which govern access to the offline secure server where the spine is stored.

The NHSCR is used operationally for the purpose of transferring GP records (NRS, 2018a). Despite the name and the fact it is used for transferring patients records, the NHSCR does not hold medical records themselves. It contains records of anyone who was born in Scotland, who registers with a GP in Scotland, or who dies in Scotland. Variables included are: forename, middle name, surname, date of birth, gender, postcode, and country of birth.

This resource is extremely useful for administrative data linkage projects. Data sources that don’t contain a CHI number (such as the SCS) can be matched to the population spine using deterministic and probabilistic methods (see section 2.4). This then allows linkage to CHI-based data sources enabling cross-sectoral projects, such as the main analyses in this thesis, to be possible.

NRS also collates the register of deaths which includes details of every death in Scotland since 1855 (NRS, 2018b). Details on the date of death were requested for all individuals in the thesis study cohort.

3.2.3 Prescribing Information System

The Prescribing information system (PIS) contains all community prescribed medicines for every individual in Scotland from 2009 onwards. Data is collected to provide payment to community pharmacies for the medicines dispensed to the population. The data base can be linked to health sources via the Community Health Index (CHI) number. A full description of the PIS database and its applicability to research has been published by Alvarez-Madrazo et al (2016).

3.2.4 Unscheduled Care Data

The Unscheduled Care Data Mart (UCD) is a database collated by ISD for the purpose of understanding a patient journey through emergency and urgent care services (ISD, 2017b). It is a linkage of routine health data from a number of sources controlled by ISD: NHS24 telephone triage service, Scottish Ambulance Service (SAS), primary care out-of-hours services (PC OOH), Accident & Emergency (A & E), acute emergency

inpatient admissions (both general and mental health), and deaths. Data is available from 2011 with the exception of PC OOH data which is available from 2014. CHI numbers are available on all records.

Continuous Urgent Care Pathways (CUPs) are calculated that join together records from each of these sources that occur within 24 hrs of each other (or for services occurring within 48hrs of an acute emergency admission)(ISD, 2017b). Details of all variables listed in UCD are available in a background paper published by ISD (2017b). In addition to service use, UCD flags presence of any of 14 long-term health conditions in any of the above datasets and, additionally, any acute admission from 1981 onwards.

3.3 Making social care data available for linkage

The SCS does not routinely include CHI number as part of its annual data collection but does have fields for other personal identifiable information (PII) such as name, date-of-birth, gender, and postcode. In order to make the SCS available for linkage to health sources, HSCAD commissioned work to probabilistically match these identifiers to the NRS population spine (described in section [3.2.2](#)) and create read-through indexes for linkage purposes. This work has not been published but a short report was produced.

The report described the variable quality in PII provided to the SCS by local authorities. One local authority, Clackmannanshire, returned only month/year of birth and truncated postcode data to the SCS. This meant only 1% of its records could be matched to the population spine. For this reason it was recommended that records for Clackmannanshire not be included in any analyses.

Of the remaining 31 local authorities, 17 returned date-of-birth data where a disproportionate number of records had the *day* of birth recorded as “01”. Therefore these council areas had their records matched separately from the other 14 areas using a refined matching algorithm.

Using this approach an overall linkage rate of 91.2% for 31 local authorities (removing Clackmannanshire) was achieved to the population spine. Sensitivity analysis revealed fairly consistent match rates across age, sex, and SIMD deciles. However, there was much more variation in match rates at the local authority level which ranged from 76.7% to 97.9% as shown in table [3.1](#).

The variation in linkage rates indicates non-random missing data for SCS data derived from population spine indexes. This makes comparison of receipt of social care across local authority areas complex and a national comparison is not possible. One potential way of creating meaningful comparisons is to create sub-groups of local authorities by

Local Authority	Linkage rate of SCS records to NRS population spine (%)
Angus	98.5
Dumfries & Galloway	98.5
Falkirk	97.9
Inverclyde	97.2
Argyll & Bute	96.9
South Lanarkshire	96.9
East Ayrshire	96.8
North Ayrshire	96.6
Stirling	96.5
East Renfrewshire	95.7
Glasgow City	95.7
Shetland Islands	95.5
South Ayrshire	95.4
Eilean Siar	95.2
Fife	94.7
Perth & Kinross	94
East Dunbartonshire	93.9
Edinburgh, City of	93.8
Aberdeenshire	91.5
Orkney Islands	91.4
Moray	91
Dundee City	90.6
East Lothian	86.9
West Dunbartonshire	85.1
Scottish Borders	84.2
West Lothian	83.9
Aberdeen City	82
Renfrewshire	81.1
Midlothian	80.1
Highland	79.2
North Lanarkshire	76.7

Table 3.1: Local authority linkage rates to NRS population spine

similar match rates and compare receipt of care within these sub-groups.

3.4 Creating a linked health and social care dataset

The study cohort included all individuals in Scotland born before 31st March 1951 and alive during the study period 1st April 2011 to 31st March 2016. This identified all those over the age of 65 (and those turning 65 during the study period). Data for the cohort was extracted from the research population spine held by NRS with CHI numbers allowing linkage to the other datasets described in section 3.2.

As figure 3.1 shows, linkage keys from the extracted cohort were sent by an eDRIS coordinator to various health and social care data sources for extraction of information relating to any of these individuals in the target data source. Specific variables requested, the time period they were requested over, and cleaning and wrangling of these data sources is described in the following section.

The aim of cleaning and wrangling was to create one row of data for each individual for each financial year (1st April - 31st March) of the study period. This format is based on the principals of tidy data (Wickham, 2014). Financial years were chosen as the time period of interest because the social care survey reports home care usage in a census week which is usually at the end of March. As each raw data file provided was in differing formats, this required differing approaches and relied heavily on data manipulation software packages `tidyR` v0.7.2 (Wickham and Henry, 2017), `dplyr` v0.7.4 (Wickham and Francois, 2017), `lubridate` v1.6.0 (Gromelund and Wickham, 2017), `stringr` v1.2.0 (Wickham, 2015), `forcats` v0.2.0 (Wickham, 2017), `data.table` v1.10.4 (Dowle *et al.*, 2018), and `zoo` v1.8-0 (Zeileis *et al.*, 2018) in the R language and environment for statistical computing version 3.4.0 (R-Core-Team, 2017) via the Integrated Development Environment RStudio v1.0.143 (RStudio-team, 2016).

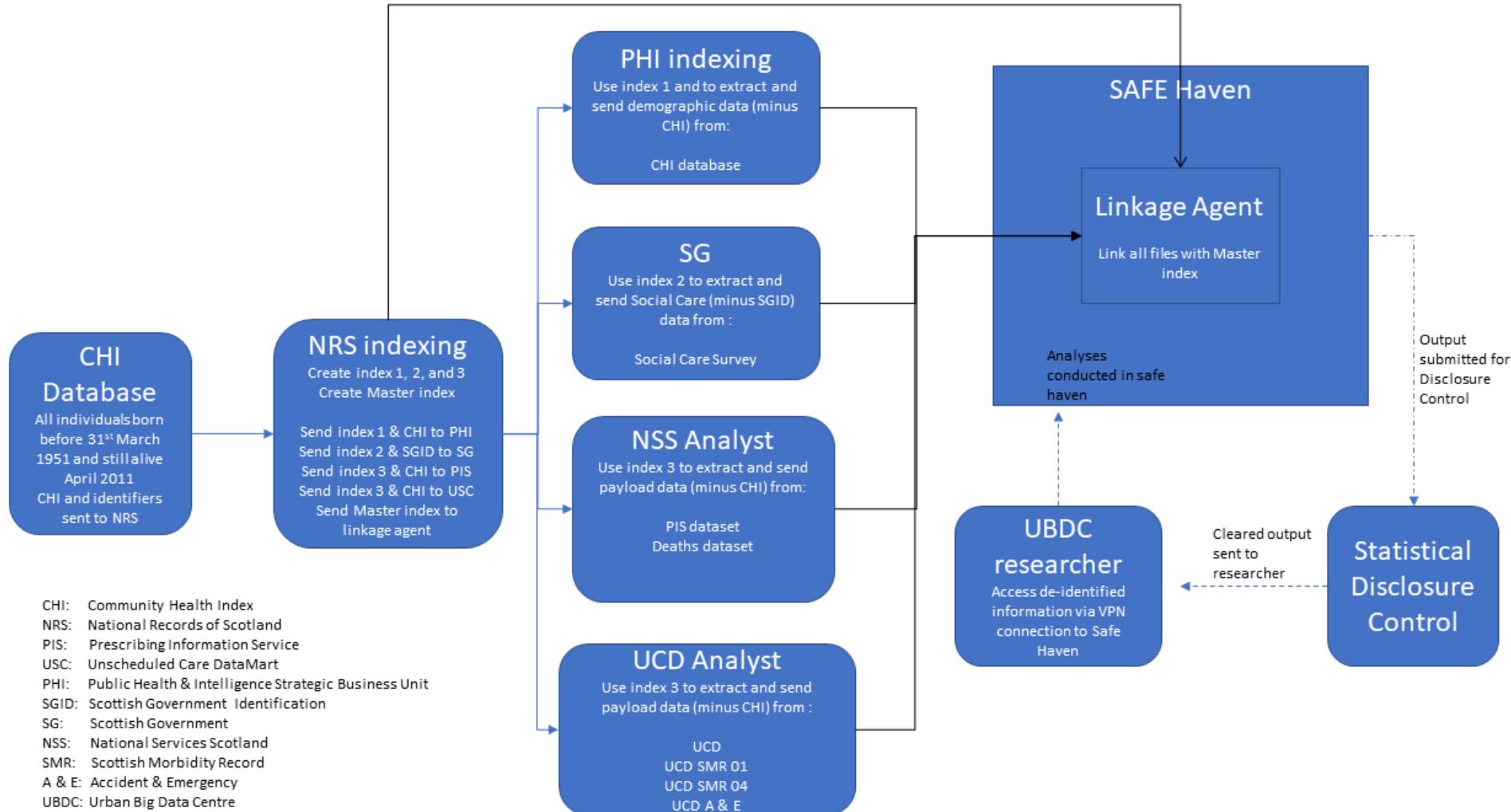


Figure 3.1: Data linkage diagram

3.4.1 Demographic, geographic, and deaths information

Demographic information for all eligible individuals identified from the population spine was extracted by the Public Health and Intelligence: Strategic Business Unit at NSS. This was joined with a flag variable indicating if an individual was resident in a care home (from prescribing data) in a single file which was made available in the national safe haven. SIMD decile was assigned as per the most recent version of the area-based measure (Scottish-Government, 2016d).

Only month and year of birth were provided to avoid disclosure of identifiable information. Age was calculated by flooring each individual's **day**-of-birth to the 1st day of the **month**-of-birth provided, and then calculating the difference between this pseudo date-of-birth and the 31st of March in each financial year.

The number of observations, individuals, and the differing variables in this raw demographic file are shown in table 3.2.

Number of rows	Number of individuals	Variables
1,348,310	1,134,445	Index, year/month of birth, year/month of death Sex, Address start date, Address end date, Care home flag, Previous Local Authority, Current Local Authority, Current Health Board, SIMD decile

Table 3.2: Demographic file data

As the table indicates, some individuals had more than one row of information indicating multiple addresses during the study period (and thus potential multiple values for local, authority, health board, care home flag, and SIMD decile). To overcome this, financial year time intervals were created using the `lubridate` R package (Gromelund and Wickham, 2017). Dummy variables were then created indicating the age, local authority of residence, health board of residence, and SIMD decile during each financial year (with null values where not applicable). The variables were then gathered to long format in order to reshape the data to include one row of data per individual per financial year. Where an individual had multiple addresses during one financial year, the most recent value for local authority, health board, and SIMD decile was used. This resulted in a data frame of 7,775,410 observations pertaining to 1,134,445 individuals.

3.4.2 Social Care Survey

Data from the Scottish Care Surveys 2010 - 2016 (including separate Home Care Census and Self-Directed Support surveys for earlier years) were extracted by a Scottish Government analyst and transferred to the national safe haven in a single file. There

Number of rows	Number of individuals	Included variables	Derived variables	Dropped variables
663,809	227,345	1. Index (ID) 2. Living alone 3. Community Alarm 4. Other telecare	1. Total weekly hours of home care 2. Home care hours group (e.g 1-5, 6-10 etc.) 3. Alarm or Telecare flag	1. Client Group 2. Eligibility Category 3. Housing Support 4. Multi Staffing 5. Scheduled Hours 6. Actual Hours

Table 3.3: Social Care Survey file data

were a number of variables indicating the weekly hours of home care (if any) each individual received, whether these were provided by the local authority or an independent organisation, and whether they indicated the scheduled hours of home care or the actual number of hours delivered. There is some discrepancy between local authorities on which value (scheduled, or actual) of home care is returned to the Scottish Government for the SCS. Some authorities return scheduled only, others actual hours only, and yet others return both values. The SCS reports statistics based on the actual hours of home care delivered where available and uses the scheduled value where it is not. This convention was also used for the purposes of this thesis.

Many variables requested from the SCS had large amounts of missing data. There were also coding issues with extra values present that had no corresponding description in the provided metadata. Variables with these issues were dropped and not included in analyses. Table 3.3 lists the variables included and excluded after data cleaning.

A small fraction of observations (198 pertaining to 129 individuals) had an impossible value of weekly hours of home care greater than 168 hrs (more than 24hr-7-day-a-week care). These records were dropped from the dataset after the entire social care file had been joined to other sources of data (described in section 3.4.5).

Assessment for duplicated rows indicated 4,357 individuals had more than one row of data for some years of data. Inspection of these additional rows indicated a change in value for some variables (e.g. a flag indicating use of community alarm services positive in one row and negative in another, or different values for client group in multiple rows). These additional rows amounted to 1.1% of observations in the SCS. The exact cause of these duplications is unknown. One possible explanation is that duplication was created when records from different sources were joined together in advance of being sent for linkage. A further potential cause is the duplication of records created by the process of recycling identification numbers in some local authorities. Given the small percentage of records this affected, individuals with duplicated information were also dropped from the dataset after being joined to other files (as described in section 3.4.5).

3.4.3 Prescribing Information Service

Community prescribing information for all individuals in the cohort were extracted from the Prescribing Information System (PIS) by analysts from ISD. For each quarter of the study period (Quarter 1 2010/11 to Quarter 4 2015/16) a list of medicines prescribed to each individual was extracted and transferred in one file to the national safe haven. This file contained 134,377,877 observations of four variables: The financial year and quarter, the BNF subsection code, The approved name of the medicine, and a count of how many times the medicine was prescribed in the quarter. Coding errors were found in 138,973 observations (wrong number of digits in the BNF subsection or characters found in the count variable) and these were dropped from analysis.

The count of medicines was based on the BNF classes included in a count of polypharmacy by Guthrie et al (2015). The additional material provided on-line with this paper included a table of included drugs. This table was amended to remove BNF subsections 3.9.1, 3.9.2, and 13.9. The latter section includes different forms of shampoos whilst the former 2 sections include preparations for coughs. These were not deemed necessary to be included in overall counts. Two BNF subsections not included in the Guthrie et al table were deemed important to include as testing revealed large numbers of prescriptions included medicines from these sections would have been omitted otherwise. These sections were 2.2.4 (Potassium sparing diuretics with other diuretics) and 2.2.8. (Diuretics with potassium). In total, 198 medicines listed in the BNF were not included and rows with these medicines were removed from the PIS file. A full list of these medicines is shown in Appendix B. Table 3.4 shows the cleaning process.

Reasons	Records dropped	Records remaining
Initial data file	N/A	134,377,877
Coding errors	138,973	134,238,904
Did not appear in Guthrie et al (2012) table	1,427,643	132,811,261
BNF sections 3.9.1, 3.9.2, & 13.9	645,900	132,165,361

Table 3.4: Data cleaning of PIS file

A summary measure for each individual was created counting the total number of repeat medicines prescribed in each financial year. To be eligible in the count, a medicine had to be prescribed in at least 2 quarters of each financial year. This meant one-off prescriptions, such as antibiotics for a transient infection, were not included in the overall count. A separate count was conducted for individuals who died in the first quarter of each financial year (and thus unable to have medicines prescribed in two quarters). The total number of unique medicines prescribed in the first quarter was used for these individuals. Each participant could thus have a maximum of 6 observations, one for each financial year. A second count was created totalling the number of chapters of the BNF that each individual had medicines prescribed from as

a crude measure of body systems being treated. Table 3.5 shows the total observations and variables in the cleaned PIS file.

Number or rows	Number of individuals	Variables
5,501,820	1,066,395	1. Index (id) 2. Financial Year 3. Total medicines (n) 4. Total chapters (n)

Table 3.5: Description of cleaned PIS file

3.4.4 Unscheduled care measures

Unscheduled care information for all individuals included in the cohort was extracted from unscheduled care data mart (UCD) by an analyst from ISD. The raw file contained 3,772,402 observations from 845,893 individuals. Each observation related to a single continuous urgent care pathway (CUP) as described in section 3.2.4.

In a similar fashion to the wrangling conducted with demographics data, dummy variables were created indicating if each observation occurred within specified financial years during the study period. This enabled data to be reshaped to a long format with individuals having one or multiple rows of data for each financial year. To create one observation per individual per year, data with information on each CUP was nested within a data frame as a list column (described by Wickham & Grolemund (2017, ch.20)). With data in this format, summary measures were derived by applying functions to the list column utilising the `purrr` R package (Henry and Wickham, 2017). Derived information included counts of total USC episodes, acute admissions to hospital, A & E attendances, and total number of long-term conditions identified from admissions and A & E data. The format of the cleaned UCD data frame is described in table 3.6

Number of rows	Number of individuals	Variables
1,951,755	845,516	1. Index (id) 2. Year 3. USC episodes (n) 4. Acute admissions (n) 5. A & E attendances (n) 6. Long-term conditions (n)

Table 3.6: Description of cleaned USC file

Data were available beyond the study period ending 31st March 2016. Records outside this end date were dropped when this file was joined with the other sources of data which is described in the next section.

3.4.5 Joining sources together

Following cleaning and formatting of each individual file, further wrangling was completed which joined each file together in a parent data frame to be used for analysis. This involved loading individual files in one-by-one and joining them together using the “full join” function from the R package `dplyr` (Wickham and Francois, 2017) using the unique index number as the joining parameter. This process ensured all records were retained, even if an index number was only present in one file.

With all study data now in one data frame, further cleaning and tidying was required. This was an iterative process. As initial descriptive and statistical analysis was completed, identification of errors and data quality issues required repetition of the joining process to address these issues. This process is now described with a summary provided in table 3.7.

	Number of rows	Total number of rows remaining after join/drop
Cleaned demography file	7,775,410	7,775,410
Cleaned prescribing information file	5,501,820	8,057,604
Cleaned social care file	611,711	8,068,275
Cleaned unscheduled care file	1,951,755	8,090,967
After age and death tidying process		8,101,317
Duplicates	568	8,100,749
Missing data for Local Authority	44,380	8,056,369
Age <65 OR Clackmannanshire OR data for 2017/18	1,832,446	6,223,923
Home care hours >168 per week	198	6,223,725
Died before 65 years of age	8809	6,214,916
Implausible SIMD value	23	6,214,893
Data from years 2010/11 OR 2016/17	1,695,587	4,519,306

Table 3.7: Joining files together and cleaning process

Once all files had been joined together the parent data frame contained 8,094,256 observations. As there were discrepancies over time periods for which data was provided in different files, the calculation of age from the demographic file was not always present for all years of data (e.g. where demographic data was returned for the years 2015-2018 and PIS data was available from 2011-2018). To overcome this, age was recalculated from the pseudo date-of-birth (described in section 3.4.1) for all financial years. Where an individual died during a financial year, the age variable was left empty which required additional rows to be added in some cases.

As described in section 3.4.2, Approximately 4000 individuals had duplicated social care information for some years of data. These rows, and other duplicates created by the cleaning process involving age and date-of-death variables, were then dropped.

For the same reasons that age values were not shown in every year of data, values for sex, local authority of residence, health board, and SIMD decile were missing from 50,284 of observations (**1.11% of the final cleaned data frame**). These observations were filled by carrying the last observation forward. Whilst this would not have

affected values for sex, potential error could have been introduced to the other variables. Given the small percentage of affected observations this was deemed acceptable. Despite this, there were still 7,435 records with missing values for local authority. Cross referencing these individual rows with the raw demographics data file revealed the values for local authority in these observations were true missing data (not created by data manipulation). Given the small proportion of records these represented they were dropped from the data frame.

A further 1,832,443 observations were then removed from the data frame. These observations were for years of data where individuals were either: (a) under 65 years of age (the cohort comprised individuals over 65 or *turning* 65 during the study period), (b) resident in the Clackmannanshire local authority area (linkage rates of the social care survey to the indexing spine were too low to be reliable in this council. (See section 3.3 for details), or (c) contained unscheduled care data for financial year 2017/18 which was well beyond the study period.

Exploratory data analysis revealed three data quality issues that required further observations to be dropped from the data frame. Firstly, as described in section 3.4.2, 168 observations contained implausible values for weekly hours of home care (>168 hrs). These had not been removed as whilst cleaning the social care file so were dropped here. Secondly, calculating average age for each individual revealed 8,808 observations with a null value. Further inspection of these observations identified each individual had only one observation and had died before their 65th birthday. The inclusion criteria for the cohort stated individuals should be “born before 31st March 1951 and alive during the study period 1st April 2011 to 31st March 2016”. This meant, for example, an individual born on Christmas day 1949 and dying at age 64 on Christmas day 2013 was extracted as part of the cohort data. These observations were also dropped from the parent data frame. Finally, 23 rows of data were found to have implausible values for SIMD decile. These observations were from individuals living in either the Shetland Islands or Na h-Eileanan Siar which only have data zones in 5 deciles making values outwith these deciles impossible.

Whilst the study period had been defined as 1st April 2011 to 31st March 2016 some data files contained observations outwith this period. These 1,695,602 observations were maintained for exploratory analysis but were dropped for final analysis. Thus, the final parent data frame used for all reported analyses contained 4,519,255 observations.

Derived grouping variables were created for age group (5 year bands), repeat medicines group (4 groups of similar size: 0-2, 3-5, 6-8, and over 9 repeat medicines), and linkage group (grouping councils that had linkage rates (described in section 3.3) within 4% of each other (e.g. 96-99.9%, 92-95.9% etc.)

3.5 Statistical methods

3.5.1 Research question 1

To address the question of how multimorbidity plus sociodemographic and geographic factors influence the utilisation of social care, logistic regression models were fitted separately to each financial year of data. The dependent variable in these models was receipt of any form of social care, measured by presence or not in the social care survey. Observations where an individual had died during the financial year (therefore had no chance of appearing in the SCS at the end of March) and where an individual did not receive social care but was resident in a care home (therefore not eligible for home-based social care) were excluded from the model.

Independent variables and interaction terms were added incrementally to assess impact on model fit which was measured by McFadden's pseudo R^2 (McFadden, 1974) calculated by the formula

$$R^2_{McFadden} = 1 - \frac{\ln(LM_1)}{\ln(LM_0)}$$

Where:

$\ln(LM_1)$ = log likelihood of the fitted model and:

$\ln(LM_0)$ = log likelihood of the null model (with intercept only as a predictor).

McFadden's R^2 values are not analogous with R^2 values calculated from linear models. Instead, values of 0.2 - 0.4 represent an excellent model fit (McFadden, 1977,p35; Louviere *et al.*, 2000,p55).

The final models included: sex, age group, repeat medicines group, SIMD decile of residence, and local authority of residence as independent variables. Interaction terms were fitted between: sex & age group, age group & repeat medicines group, SIMD decile & repeat medicines group, and SIMD decile & local authority of residence. Exploratory models had revealed a linear effect of SIMD decile on receipt of social care thus, given the complexity of interaction terms and subsequent computational requirement, SIMD was fitted as a continuous term in the final models. The R code for the model was as follows:

```
#Create a function for the model
sc_model <- function(my_df){
  glm(scs_flag ~                 #the formula for the model
       sex*age_grp +
       simd*meds_grp +
```

```

    age_grp*meds_grp +
    council*simd,
  family = binomial(), #logistic regression
  data = my_df)         #identify which data to use
}

sc_model_* <- #Each model given a number. Here denoted with *
thesis %>% #Name of main dataframe
#Drop variables not in the model
select(index, year, scs_flag, sex, age_grp, simd, meds_grp,
       council) %>%
group_by(year) %>%
#Nest data for each year into a list column
nest(.key = "year_data") %>%
#Create model column using above function
mutate(mod_var = map(year_data, sc_model),
       #Tidy coefficients using broom::tidy into a column
       tidy_var = map(mod_var, tidy),
       #compute AMEs and add as a column
       marginals = map2(mod_var, year_data,
                        ~margins_summary(.x, data = .y)))

```

As different local authorities had differing linkage rates from the social care survey to the NRS population spine (section 3.3), comparison between them is problematic as there are differing levels of what is essentially missing data. To account for this, separate models were fitted including only councils with similar linkage rates and therefore similar levels of missing data. For the purposes of this thesis, only councils with a high linkage rate of either 92-95.9% or 96-99.9% were included in models. This meant, overall, two models were fitted separately to five individual years of data resulting in 10 final models.

With the exception of SIMD decile, all independent variables were categorical in nature with a number interaction terms fitted as described above. Odds-ratios are reported for individual independent variables but interaction terms cannot be reported in this manner and doing so often results in misinterpretation (Ai and Norton, 2003; Norton *et al.*, 2004; Mood, 2010; Mustillo *et al.*, 2018). Therefore, in order to provide a measure of the magnitude of the effect of each variable (taking into account interaction effects), estimates are reported as average partial effects (APEs) described by Mood (2010, p75) with the formula

$$\frac{1}{n} \sum_{i=1}^n \beta_{x_1} f(\beta_{x_i})$$

Where:

β_{x_1} = the log odds-ratio for variable x_1 ,

β_{x_i} = the value of the logit for the i -th observation, and

$f(\beta_{x_i})$ = the probability distribution function of the logistic distribution with regard to β_{x_i}

The effect estimate describes the average marginal effect (AME) at a specific value of x_1 . Williams (2012,p325) provides an intuitive example of how APEs are calculated and interpreted which has been adapted to reflect the fitted model and uses the “sex” variable as an example here

- Go to the first case. Treat that observation as if they were male regardless of actual sex. Leave other values of independent variables at their observed value. Compute the probability of receiving social care with the fitted model (including interaction terms).
- Repeat, but change the value of sex to female.
- The difference in the two probabilities is the partial (marginal) effect for that case.
- Repeat for every observation in the data.
- Compute the average of all the partial effects. This gives the APE for being female.

As Williams (2012) observes, this has the effect of comparing hypothetical populations - one female, one male - with the same observed values for other explanatory variables in the model. The only differences between these hypothetical populations is their sex with the estimate describing the differences in the probability of them receiving social care.

Where categorical variables have more than one value (e.g. age group), the APE describes the average difference in the probability between the observed value and the reference value for that variable (in the case of age group the reference value is 65-69 years of age). Deprivation status was modelled as a continuous variable therefore the APE is an instantaneous effect reflecting the slope of the predicted probability curve at the mean value of SIMD. Therefore the value cannot be interpreted directly as a coefficient and a one-step change does not directly increase the value of the probability with the APE. To aid interpretation, plots depicting the conditional effect of SIMD on the receipt of social care were generated.

Reporting APEs has the advantage that effects can be compared across groups, across samples, and across models (Mood, 2010). APEs were calculated with standard errors

and 95% confidence intervals using the R package `margins` v.0.3.23 (Leeper *et al.*, 2017).

3.5.2 Research question 2

A similar strategy as applied to research question one was applied to research question two. The aim in this analysis was to assess the impact of sociodemographic factors, as well as multimorbidity and receipt of social care, on use of unscheduled care services. Again, logistic regression models were fitted to each financial year of data. Three separate models were run using: any unscheduled care use, any admission to hospital, or any attendance at A & E in the six months *after* the end of the financial year as dependent variables. The first of these models measured use of both services included in the other two models in addition to other unscheduled care services namely: NHS24, GP out-of-hours (OOH), and Scottish Ambulance Service (SAS) use. The second and third models were included separately given the considerable policy interest in these specific areas.

The time frame was chosen as receipt of social care is measured by having a record returned in the SCS which includes a census week at or around the end of each financial year. Measuring unscheduled care use in the 6 months following this period offered the most accurate assessment of the effect of social care receipt on the dependent variables.

Observations for individuals who died in the financial year were excluded (as having no chance of receiving USC six months later). However, unlike the social care models in research question 1, those living in care homes were included with this status included as an independent variable. Exploratory models revealed little variation in partial effects across local authority or health board areas and these factors were not included in the final models reported. As social care was an independent, rather than dependent, variable, models were not broken down by linkage rate to SCS.

The final models included: sex, age group, repeat medicines group, SIMD decile, receipt (Yes/No) of USC in the year prior to the outcome period, receipt (Yes/No) of social care, residence (Yes/No) in a care home, and death (Yes/No) in the six months after the end of the financial year as independent variables. Interaction terms were fitted between: sex & age group, SIMD decile & repeat medicines group, and age group & repeat medicines group.

```
#Create a function for the model
usc_model <- function(my_df){
  glm(usc_six ~               #the formula for the model
       sex*age_grp +
       simd*meds_grp +
```

```

    age_grp*meds_grp +
    usc_flag + scs_flag +
    care_home + dod_six,
  family = binomial(), #logistic regression
  data = my_df)         #identify which data to use
}

sc_model_* <- #Each model given a number. Here denoted with *
thesis %>% #Name of main dataframe
#Drop variables not in the model
select(index, year, scs_flag, sex, age_grp, simd, meds_grp,
       council) %>%
group_by(year) %>%
#Nest data for each year into a list column
nest(.key = "year_data") %>%
#Create model column using above function
mutate(mod_var = map(year_data, sc_model),
       #Tidy coefficients using broom::tidy into a column
       tidy_var = map(mod_var, tidy),
       #compute AMEs and add as a column
       marginals = map2(mod_var, year_data,
                        ~margins_summary(.x, data = .y)))

```

As in previous models, model fit was assessed using McFadden's pseudo R^2 and estimated effects were reported as APEs (section 3.5.1).

3.6 Timeline

Figure 3.2 depicts major milestones during the thesis project, including a separate analysis conducted with data from Renfrewshire council. The journey through the approvals and analysis process for that project is reported in chapter 4, therefore this description focusses on the main analysis project. Renfrewshire information is depicted to provide context to the time frame of the whole project, in particular the availability of that data arriving only shortly before the availability of data for the main project.

Part of the first year of the project was spent scoping potential sources of administrative social care data and appraising their usefulness for research purposes. It was not until near the beginning of the second year, August 2016, that HSCAD at the Scottish

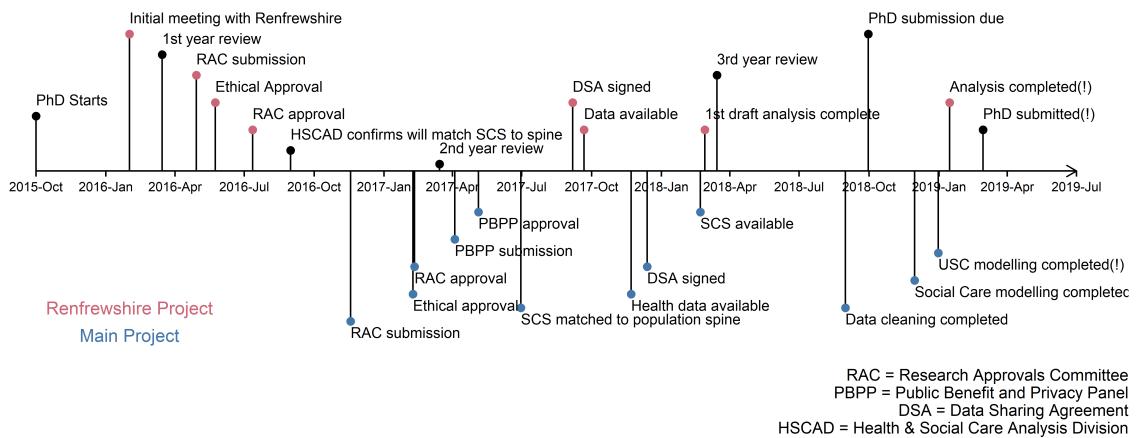


Figure 3.2: Timeline of Thesis project

Government confirmed it would make the Social Care Survey available for linkage. This process was not completed until the end of June 2017 (section 3.3).

Approvals process through the UBDC RAC was governed by its bi-annual submission process - with approval for the main project being requested in Autumn 2016. Approval from this committee was necessary before applying to the PBPP which gave its approval for the main project in May 2017, subject to completion of a DSA between relevant parties. This was finally signed (Appendix D) in November 2017. Some health data from ISD was made available for analysis slightly prior to this date, and shortly after data from the Renfrewshire project had been made available. Social care data was finally transferred, enabling full cleaning and analysis for the main project to commence, in February 2018.

Chapter 4

Renfrewshire Council Exploratory Project

4.1 Introduction

As described in Section 3.2.1, the Social Care Survey (SCS) is collected annually by the Scottish Government and provides information on the types and amounts of social care delivered to individuals in all 32 Scottish local authorities. This information is collected in two ways depending on which service an individual may receive. Since 2014/15 the survey has collect data on all individuals who receive a community alarm service, a telecare service, self-directed-support, or assistance via a social or support worker at any time during the financial year. Home care data is collected only for individuals receiving these services during a census week - usually including the date 31st March (Scottish-Government, 2017e). Prior to 2014/15, all data was collected for the census week only. The cross-sectional nature of the data collected for home care services means that the SCS does not identify every individual who receives social care in any given financial year. This has implications for the interpretation of research projects using the SCS and the statistical inferences that can be applied to the data when linked with other sources of information.

This aim of this chapter is therefore to estimate the completeness of the SCS and give an indication of the demographic make-up and type of care received to those who are “captured” by the SCS census compared to those who are not. This is done by a descriptive analysis of complete data from one local authority area which also identifies how many more individuals receiving home care would be identified by collecting data from one census quarter, rather than a one census week.

All data relating to home care services from Renfrewshire council were de-identified and transferred securely to a safe haven environment to enable analysis. Information

of differing types of home care services were summarised and a weekly time series indicating the amount of service provision in each week for each individual was created for the period April 2006-March 2016. This enabled quantification of the amount of people receiving care in each week, quarter, and financial year, and the total amount of care provided over each financial year.

4.2 Background

Collection of Social Care Survey data

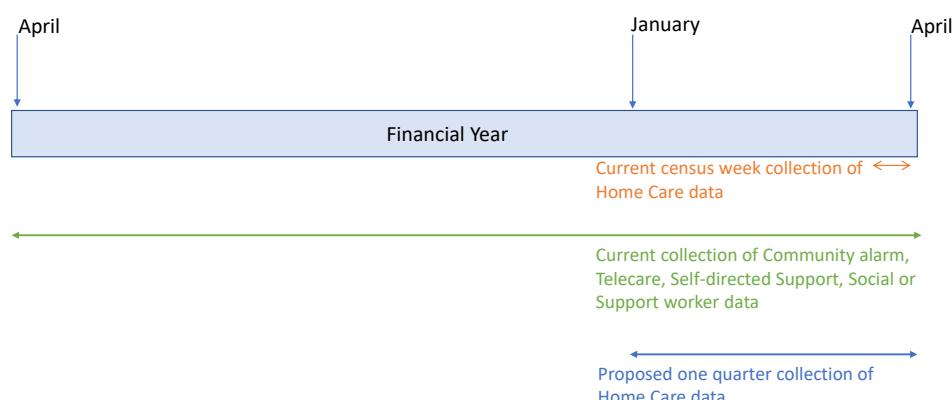


Figure 4.1: Time periods for which SCS data is collected

Figure 4.1 depicts the differing time periods over which variables are collected by more recent versions of the SCS and the proposed one quarter collection of data for financial year 2017/18. The convention in this chapter is to refer to the data collected during the census week collectively as “Home care”. This term can, however, refer to a number of services which are described in table 4.1

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 4.1: Definitions of home care types

Two reasons that individuals may receive home care services but not be captured by the SCS include death before the census week and receipt of short-term home care services over a period not including the census. Whilst it is difficult to quantify numbers of people who fall into the former category with administrative data not linked to death records, this chapter provides some insight into levels of the latter. Given intentions to amalgamate the SCS with administrative resources collected by ISD and move to a one quarter collection of data (ISD, 2017a), the exploratory project also aimed to quantify the percentage of all individuals that would be identified by collection of home care data in quarter 4 of each financial year (this quarter was the proposed time period for collection of the 2017/18 censs. Official statistics are expected to be published in April 2019).

As social care data in Scotland has rarely been used for research purposes, this exploratory project also offered the opportunity to assess the format, content, and suitability of the data from a research perspective. Ideally, data would be analysed from a number of local authorities for comparison. However, as described below, acquiring sensitive data of this nature is a lengthy and complicated process, relying heavily on the goodwill of the participating local authority. Despite early intentions to approach multiple local authorities, practical considerations limited the project to data collected from Renfrewshire Council.

The decision to approach Renfrewshire Council as a potential source of data was due to convenience given previous cooperation between the council and UBDC on other projects. Another local authority was also approached but preliminary discussions suggested that whilst the purpose of proposed research was supported, the council was unlikely to be able to provide sufficient resource to facilitate data sharing. Preliminary meetings with data analysts from Renfrewshire council confirmed that data could be provided to facilitate the proposed research and the formal process of obtaining data using UBDC's controlled data service was instigated in April 2016.

Despite there only being a single source of data, Renfrewshire Council offers an excellent location in which to explore the receipt of social care given it is fairly representative of Scotland as a whole. It is the 10th largest local authority with 3.2% of the total population of the country. It has a similar proportion of individuals aged over 60 compared to the rest of the country (24.4% v 24.2%) (NRS, 2015) and the mortality rate is only slightly higher than recorded for the rest of Scotland (10.9% v 10.3%). Some of the most and least deprived datazones in the whole of Scotland as well as a spread of urban and rural neighbourhoods are present in the Renfrewshire council area (Scottish-Government, 2017c).

In terms of social care, the 2017 SCS (Scottish-Government, 2017d, supp.charts) shows that the proportion of over 65s receiving home care provided or administered by Ren-

frewshire Council reduced between 2011 and 2015 but has nearly returned to 2010 levels (52.4 per thousand in 2010, 49.4 per thousand in 2017). Historically, this is lower than levels seen across Scotland as a whole, although national levels are now very similar (60.8 per thousand in 2010 to 48.9 per thousand in 2017). The absolute number of over 65s receiving home care in Renfrewshire in the 2010 census week was 1526 versus 1614 in the 2017 census (Scottish-Government, 2017d, supp.charts).

4.2.1 Research Questions

1. What proportion of individuals receiving home care across each financial year are captured
 - (a) during the SCS census week?
 - (b) during a notional collection of data from quarter 4 of each year?
2. What proportion of all home care provided in each financial year is received by
 - (a) those captured during the SCS census week?
 - (b) those receiving care during a notional collection of data from quarter 4 of each year?
3. Are there differences in individuals that are/are not captured by the SCS census?
 - (a) by age and gender,
 - (b) by type of care received,
 - (c) by the length of time they receive care for, or
 - (d) by the weekly hours of home care they receive?

4.3 Methods

4.3.1 Project approvals and timeline

The exploratory project utilised the controlled data service provided by UBDC and therefore required approval from UBDC's Research Approvals Committee (RAC). This process is more fully explained in section [3.1.2.1](#). Approval from RAC was gained on 01/06/2016. Ethical approval for the study was gained from the University of Glasgow College of Social Sciences Research Ethics Committee on 24/05/2016 (Appendix C).

Following academic and ethical approval the process of obtaining a data sharing agreement (DSA) between the University of Glasgow and Renfrewshire council was instigated. This involved the production of an agreement in principle and privacy impact assessment as a basis for the DSA. Production of the DSA involved the input of legal

teams from both institutions as well as liaison with data analysts at Renfrewshire council and UBDC. The initial draft was produced by the local authority with amendments from both sides before final completion and signing 06/09/2017. Final transfer of data took place on 21/09/2017. An illustration of this timeline is shown in figure 4.2

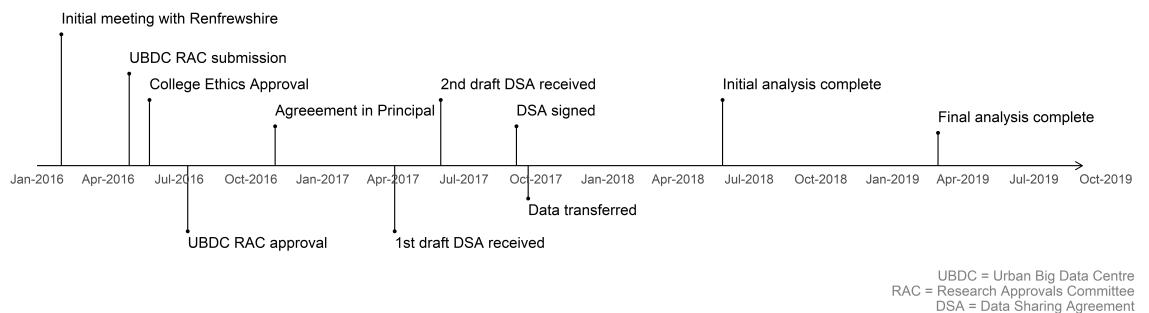


Figure 4.2: Timeline of Renfrewshire exploratory project

4.3.2 Data

As with all services provided by Renfrewshire council, home care data is collected to ensure efficient management of the service and as evidence of service provision (Renfrewshire-Council, 2015). Recording of individual episodes of care also helps with budgetary management of the service.

Data was provided in the format of one observation per individual per *episode* of care. Each observation contained variables on: how many days per week and how many hours per day of home care an individual received for each type of care (e.g. mainstream or reablement etc. as described in table 4.1). In addition, variables indicating the start and end dates of each episode as well as the service provider (e.g. local authority or independent provider) were present. Data was provided for all home care episodes in the Renfrewshire council area between April 2006 and April 2017. Demographic information detailing gender and year of birth was provided in a separate file. The provision of year of birth only meant age had to be calculated from the 1st of January in the provided year.

4.3.3 Analysis

To enable analysis of the proportion of individuals captured by the census in each year, a time-series was created for the study period 27th March 2006 to 28th March 2016 at weekly intervals. The value of total hours of home care each individual was receiving for each type of service at each of the 523 weekly time points was identified. From this time series, weekly counts of the total number of individuals receiving home care were calculated. Additional tables counting the number of individuals receiving home care

in quarter 4 of each financial year were also created. In order to validate the method used to count individuals, comparison was made between counts for each census week and the value indicated to be receiving home care in the SCS (Scottish-Government, 2017d).

As it was possible for individuals to receive home care of more than one type or experience gaps in provision of care in each financial year, individuals were grouped by those that had received any type of care during the census week and those that had none. This enabled comparison of the proportions of each age group, gender, as well as the type, amount, and duration of home care received between groups that were identified in the census or not.

Pseudo ID	Number of care episodes in year	Weekly hours of home care	Number of meals received	Duration of care (weeks)	Value of total care per episode (hours + meals x duration)	Value of total care per year (sum of total episode value)
1	1	4	2	52	312	312
2	2	4	0	12	48	168
2	2	3	0	40	120	168
3	3	0	7	12	84	276
3	3	3	7	12	120	276
3	3	5	7	6	72	276
4	1	3	0	52	156	156
5	2	4	7	35	420	450
5	2	8	7	2	30	450

Table 4.2: Pseudo table exemplar of calculation of total care received

To report the proportion of all home care provided to individuals captured (or not) by the census, an aggregate value of total care provided was required. To facilitate this, a variable was created indicating the number of changes in care an individual received during each year (e.g. moving from 4hrs to 3hrs of care per week table 4.2). The total care per episode was calculated by multiplying the sum of weekly hours and number of meals received per week by the number of weeks each episode of care lasted within each financial year. From these values, it was then possible to calculate a total value for each individual in each financial year. Adding values for all individuals in each financial year gave a value for total home care delivered and percentages of this value received by those captured during the SCS census week or quarter 4 of each year could then be calculated.

To the author's knowledge, no previous research or published statistics has created a measure indicating the comparative value of one meal with hours of home care provided. The above method effectively assigns a value of 1hr of home care to each meal per week delivered. The outcome required for this analysis is to identify what proportion of care is delivered to those captured by census periods and it is therefore not necessary to identify a true comparative figure for meals to hours of home care.

Duration of care was calculated by the time elapsed from the beginning of each financial year to either the week where care was terminated or, for those with receiving care for over one year, to the end of the financial year. Average total weekly hours of care was calculated by summing the weekly hours of care of each care type received by an

individual calculating the mean value received over the course of the financial year. As the home care packages of the types “Community Mental Health”, “Overnight Services”, “Housing Support”, and “Extra Care Housing” accounted for small percentages of care delivered, individuals receiving these types of care were omitted from comparative plots.

All data cleaning and analysis was conducted using the R language and environment for statistical computing version 3.5.1 (R-Core-Team, 2017) with additional software packages: `dplyr` v0.7.8 (Wickham and Francois, 2017), `tidyverse` v0.8.2. (Wickham and Henry, 2017), `forcats` v0.3.0 (Wickham, 2017), `purrr` v0.3.0 (Henry and Wickham, 2017), `lubridate` v1.7.4. (Golemund and Wickham, 2017), `tibbletime` v0.1.1 (Dancho and Vaughan, 2017), `ggplot2` v3.1.0 (Wickham and Chang, 2016), and via the Integrated Development Environment RStudio v1.1.453 (RStudio-team, 2016). Data was held securely in the safe haven environment described in section 3.1.3.2

4.4 Results

4.4.1 Overall time series

	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16
Observations	77554	79627	82765	83752	77734	69618	73287	82874	87071	91870
N =	2435	2486	2577	2577	2323	2262	2537	2799	2962	3106
N Female (%)	1709 (70.2)	1725 (69.4)	1736 (67.4)	1736 (67.4)	1591 (68.5)	1523 (67.3)	1657 (65.3)	1831 (65.4)	1945 (65.7)	1982 (63.8)
N Male (%)	726 (29.8)	761 (30.6)	841 (32.6)	841 (32.6)	732 (31.5)	739 (32.7)	880 (34.7)	968 (34.6)	1017 (34.3)	1124 (36.2)
Mean age	81.7	81.8	81.9	82.2	82.5	82.5	82.6	82.7	82.7	82.5
SD age	7.7	7.8	7.9	7.9	8	8.1	8.1	8	8	7.9

Table 4.3: Characteristics of observations in time series

There were 10,437 individuals included in the time series over the whole study period. Table 4.3 shows the number of observations and individuals in the time series increased overall from 2006/07 to 2015/16 with a notable dip in 2010/11. There were 2435 individuals included in the time series in 2006/07 and 3106 included in 2015/16. The percentage of females decreased from 70.2% in 2006/07 to 63.8% in 2015/16. Mean age remained stable varying between 81.7 years - 82.5 years (SD 7.7-8.1).

Individuals could receive more than one type of care service within any financial year. Calculating the percentage of all individuals receiving each type of service within each year reveals that the most utilised type of care was “Care at home (Mainstream)” services (table 4.4). This accounted for the vast majority of all home care delivered during the study period, however the percentage of individuals receiving this service decreased over time (98% in 2006/07 to 72% in 2015/16). Meals and Reablement are the next most utilised services. Reablement was very rarely utilised before 2011/12 but then quickly became more heavily used with approximately one-third of individuals

	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16
Records (n)	77554	79627	82765	83752	77734	69618	73287	82874	87071	91870
N (n)	2435	2486	2577	2577	2323	2262	2537	2799	2962	3106
Mainstream	98	95	90	88	88	78	69	71	73	72
Meals Service	0	13	37	37	39	38	33	33	33	33
Reablement	0	0	0	0	1	15	37	31	30	30
Rapid Response	5	11	5	6	0	8	10	7	6	4
Extra Care Housing	0	1	3	4	4	4	4	4	4	4
Housing Support	1	1	1	1	<1	<1	<1	<1	<1	<1
Overnight Services	1	2	2	2	2	3	4	3	2	2
Mental Health	<1	<1	<1	<1	<1	<1	<1	<1	<1	<1

Individuals can receive more than one service in any year
All values rounded to nearest percent unless otherwise denoted

Table 4.4: Count of individuals receiving each type of home care service

receiving this service between 2012/13 and 2015/16. Other services are much less utilised with very low percentages of individuals receiving them.

4.4.2 Counts of individuals receiving home care

Approximately 60% of all individuals receiving home care in each financial year also received care during the census week. This indicates they would have observations returned to the SCS (figure 4.3). The percentage receiving care during the census week decreases over time from over 62% in 2006/07 to 57.3% in 2015/16 (table 4.5)

Figure 4.3 also shows that were the census period extended to include all those receiving home care during the last quarter of each financial year, approximately 70% of all individuals receiving care across the whole year would be returned in the SCS. Again the percentage decreases over time from 72% in 2006/07 to 68.8% in 2015/16 (table 4.5).

Finally, figure 4.3 and table 4.5 show the difference between counts of individuals receiving care in each census week produced by this analysis and the value shown in the SCS. There is some variation with slight over and under counts in different years. The largest difference is an over count of 103 individuals in 2012/13 and the smallest an undercount of 5 individuals in 2006/07.

	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16
Census week count	1515	1560	1619	1623	1385	1373	1513	1594	1746	1779
Value returned to SCS	1520	1490	1520	1530	1290	1300	1410	1520	1760	1740
Difference	-5	70	99	93	95	73	103	74	-14	39
Annual count	2435	2486	2577	2577	2323	2262	2537	2799	2962	3106
% of annual count in census	62.2	62.8	62.8	63	59.6	60.7	59.6	56.9	58.9	57.3
Quarter 4 count	1754	1815	1877	1870	1635	1626	1784	1944	2134	2138
% of annual count in Q4	72	73	72.8	72.6	70.4	71.9	70.3	69.5	72	68.8

Table 4.5: Counts of individuals receiving home care

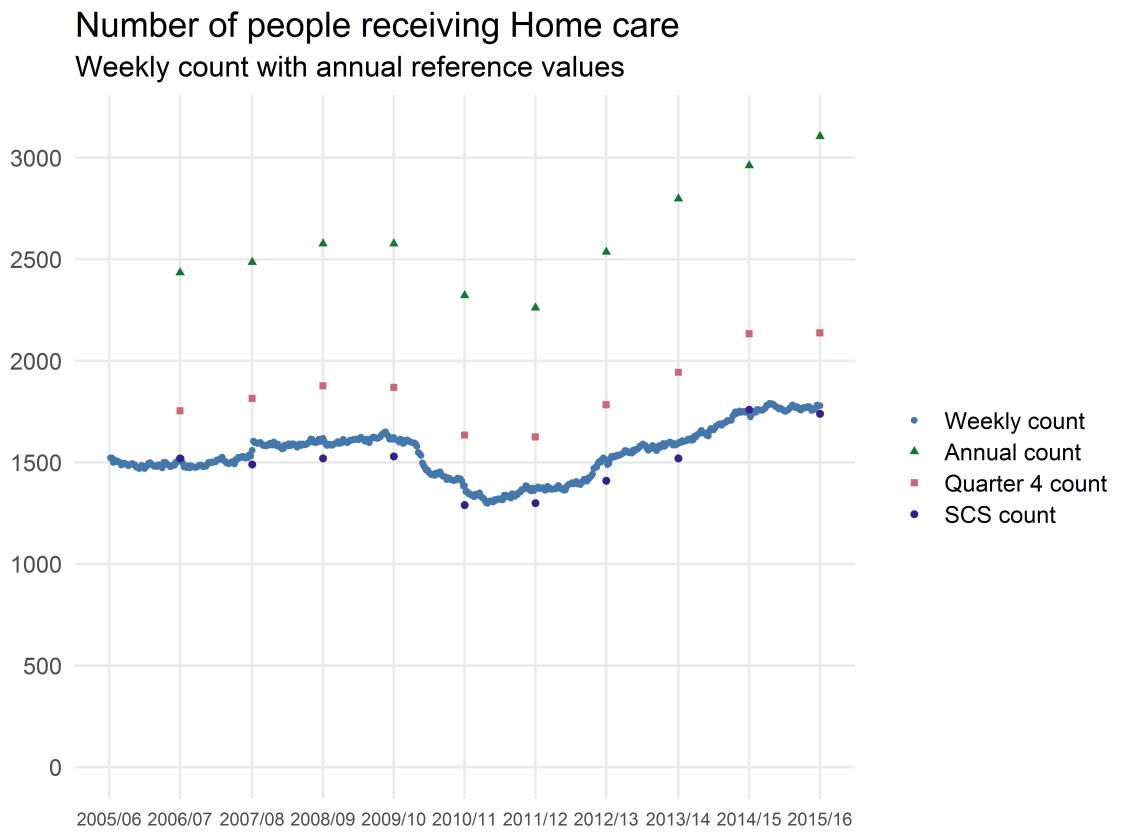


Figure 4.3: Counts of individuals receiving home care

4.4.3 Total care provided

Whilst the percentage of individuals captured by the census varied from 57% to 62%, the share of all home care provided these individuals received (calculated by the sum of total hours of home care per week and number of meals per week multiplied by the number of weeks of care) varied from 71% to 78% (figure 4.4). This value peaked in 2009/10 and has gradually reduced since then.

If the home care data had been collected from quarter 4 in each year, this value would have risen to between 84% and 88% (figure 4.5).

Share of total home care hours provided
Split by individuals receiving care in SCS census week

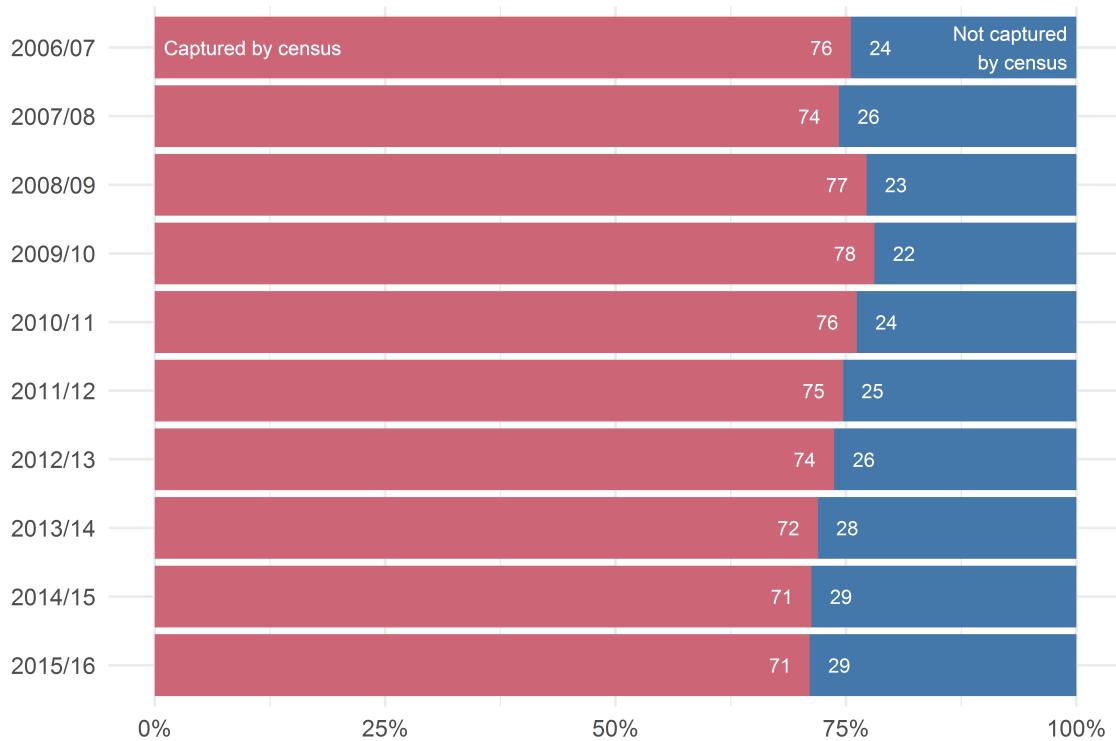


Figure 4.4: Share of all home care received by individuals

Share of total home care hours provided
Split by individuals receiving care in notional quarter 4 census period

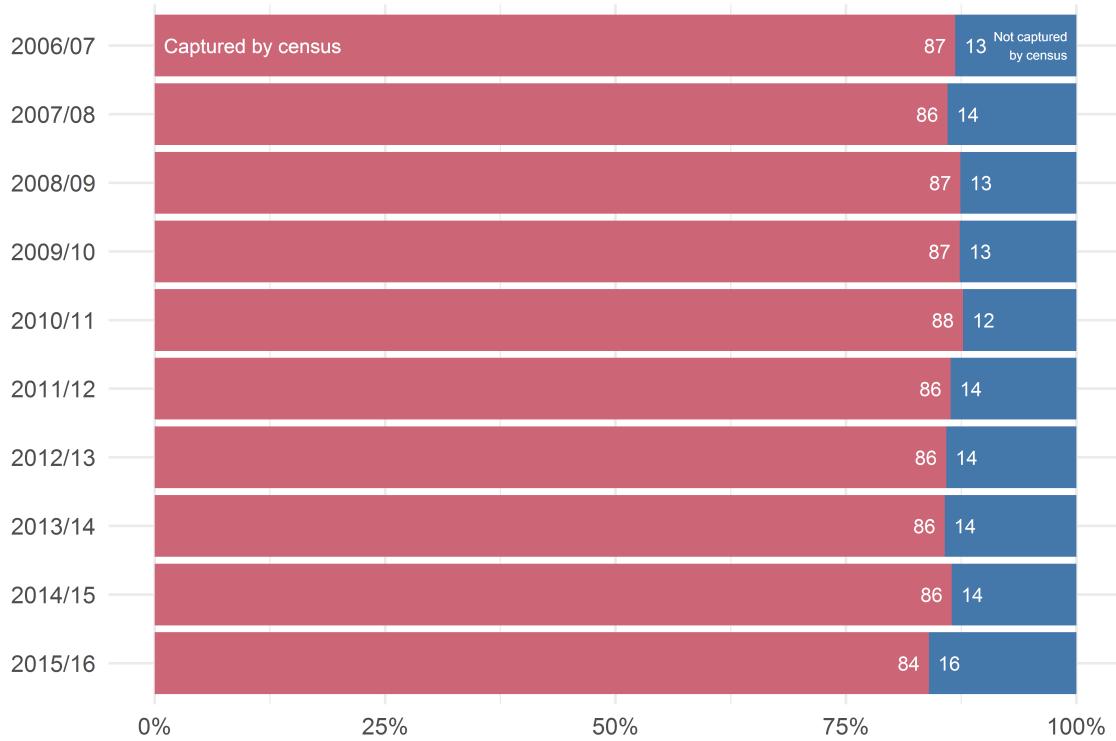


Figure 4.5: Share of all home care received by individuals - notional one quarter census

4.4.4 Comparison of individuals by receipt of care during the census week

4.4.4.1 By age and gender

Percentage of individuals receiving home care by age group and sex
Financial year 2015/16

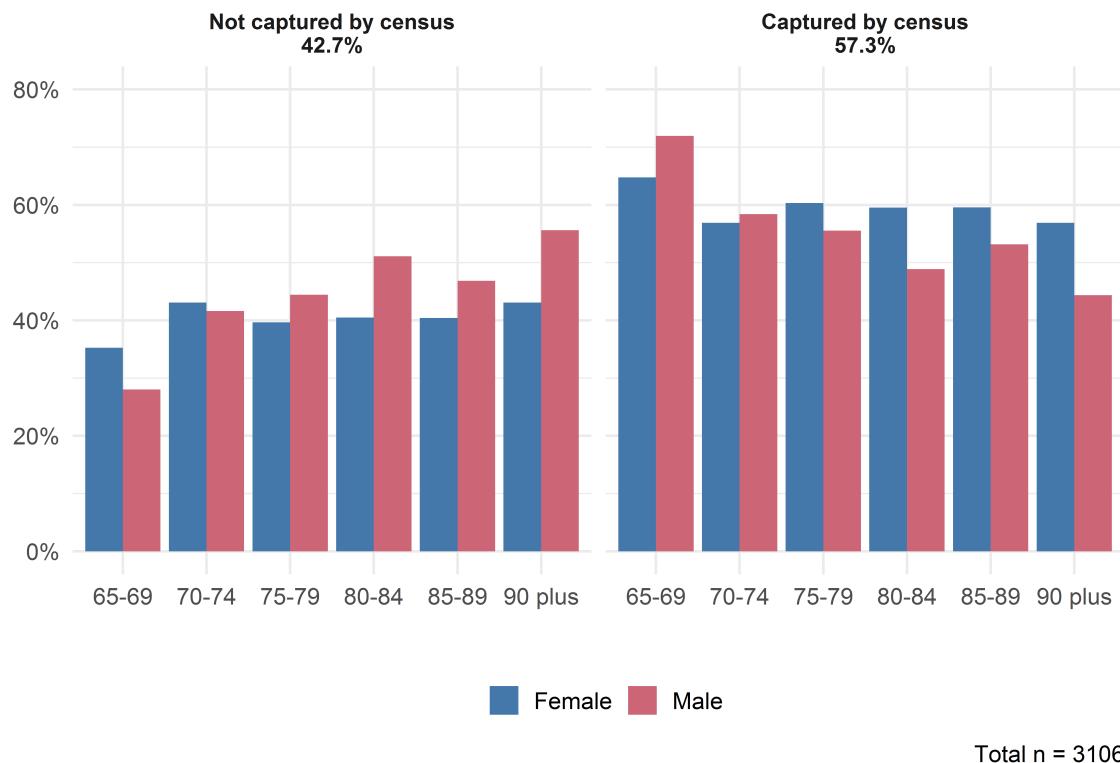


Figure 4.6: Age and sex groups receiving home care

There are some variations in the percentage of individuals receiving home care when grouped by receipt of care during the census week (figure 4.6). The percentage of males and females aged 65-69 not captured by the census is below the overall figure of 42.7% in 2015/16 whilst there is a higher proportion of males in age groups over 80 (similar patterns are seen across all years). It follows that the opposite is true for the group captured by the census where higher percentages of 65-69 year old males and females and lower percentages of males in older age groups than the 57.3% overall figure are seen. Apart from these differences, the distribution of receipt of care follows the overall pattern.

4.4.4.2 By type of care

The introduction and increasing usage of reablement services over time shown in table 4.4 can be seen clearly in figure 4.7. Higher than average percentages of those receiving Reablement and Rapid Response services are *not* captured by the census. Conversely,

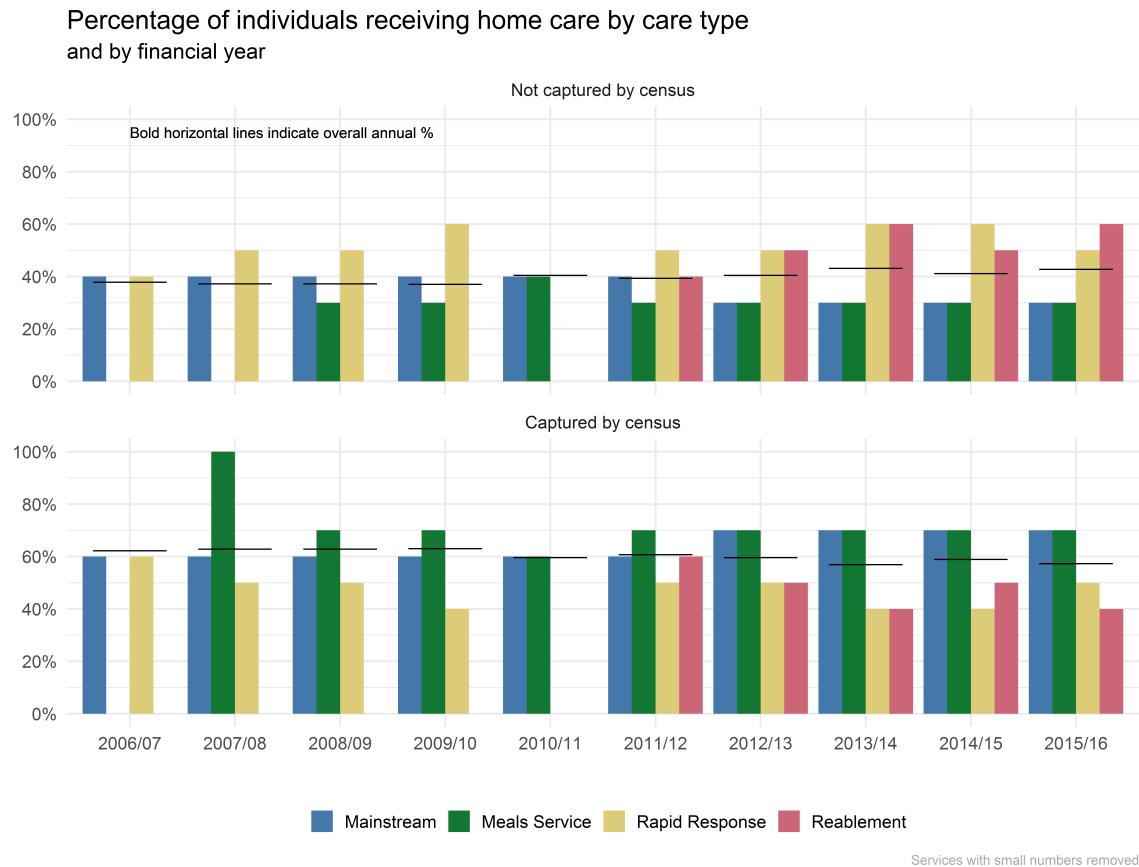


Figure 4.7: Types of home care

below average percentages of those receiving Mainstream and Meals services receive care during periods not including the census week. The lower panel of figure 4.7 shows the opposite picture.

4.4.4.3 By duration of care

The median duration of home care for within each financial year for individuals whose care overlaps with the census week is considerably higher than for those whose care does not (figure 4.8). The distribution of duration of care is tight around 52 weeks for those captured by the census. Those not captured have a wider, even distribution of care duration. These patterns remain when broken down by care type (figure 4.9).

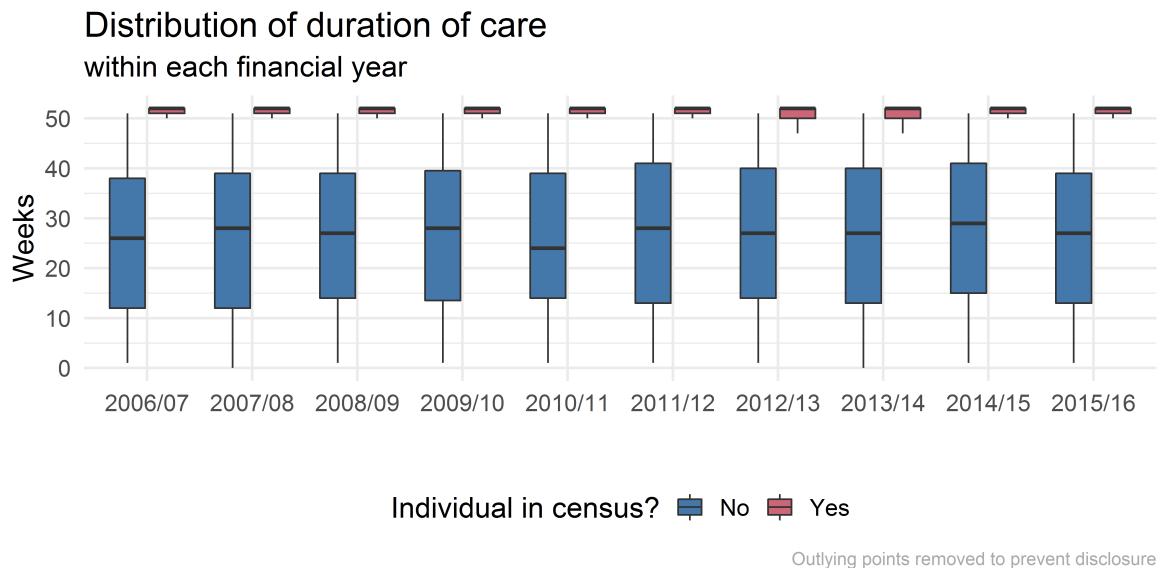


Figure 4.8: Duration of home care

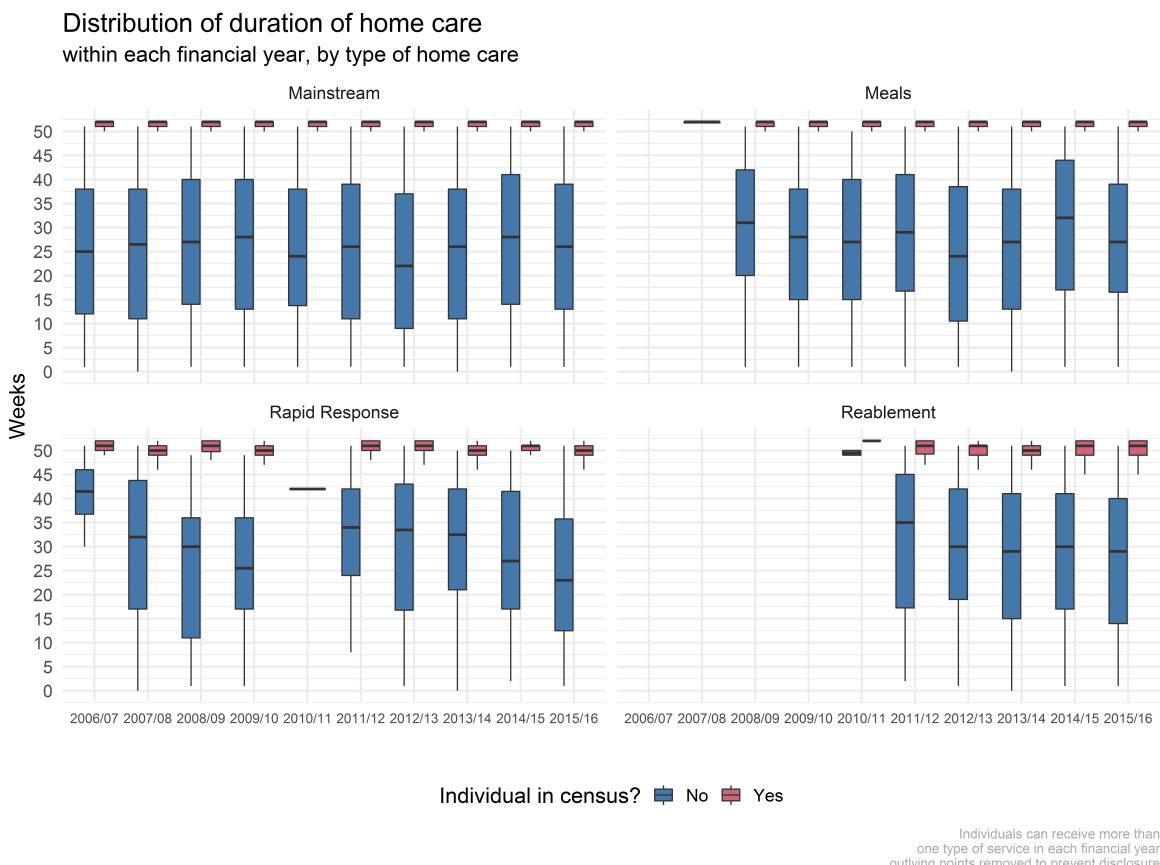


Figure 4.9: Duration of home care, by home care type

4.4.4.4 By average total weekly hours of care received

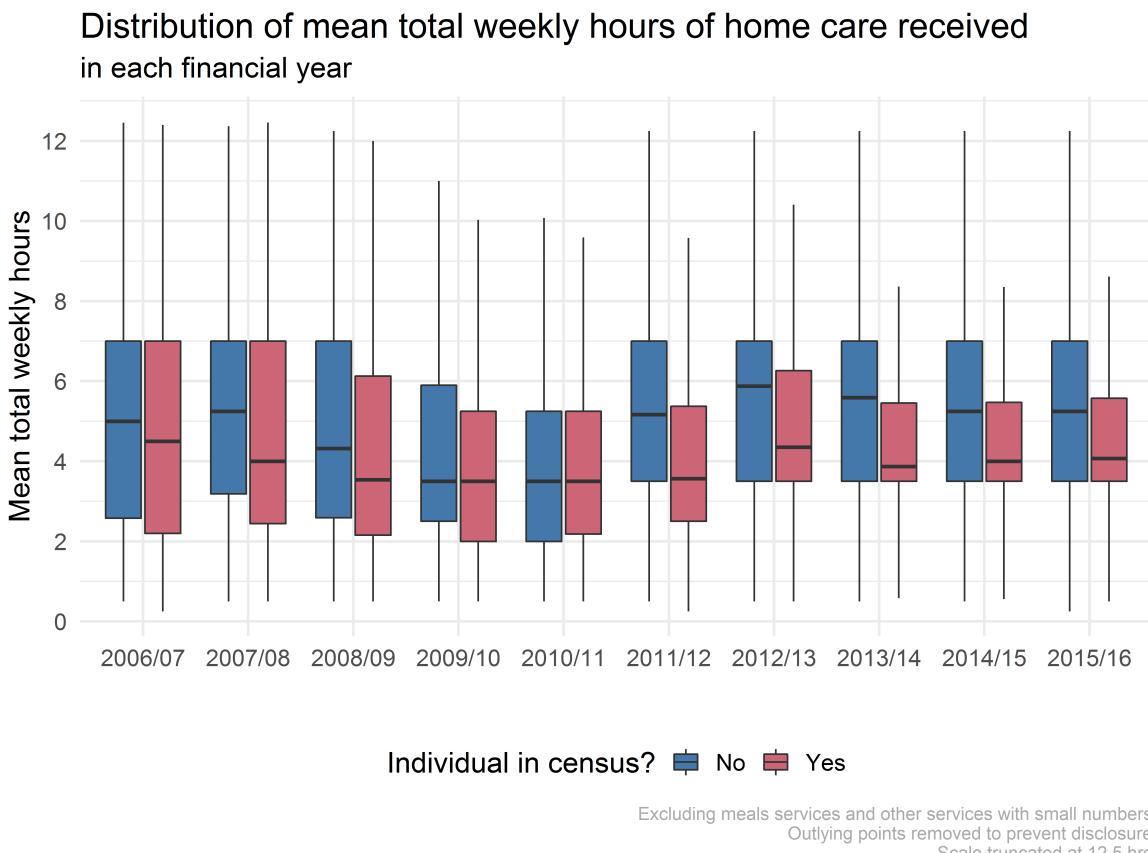


Figure 4.10: Total weekly hours of home care

Figure 4.10 plots the distribution of mean total weekly hours of home care received by individuals in each financial year. With the exception of 2009/10 and 2010/11, the median value of mean total weekly hours of home care received is lower for the group who received care that overlapped the census week. The difference between median values in each group is higher from 2011/12 onwards. This coincides with the increase in usage of Reablement services (figure 4.11). From 2012/13 onwards the distribution of weekly hours of care for Reablement services is so tight that no box or whiskers are visible in the plot which instead shows a line at 7 hours in both groups. Comparison of the distribution of mean weekly hours shows similar values within care types across both groups (captured or missed by the census).

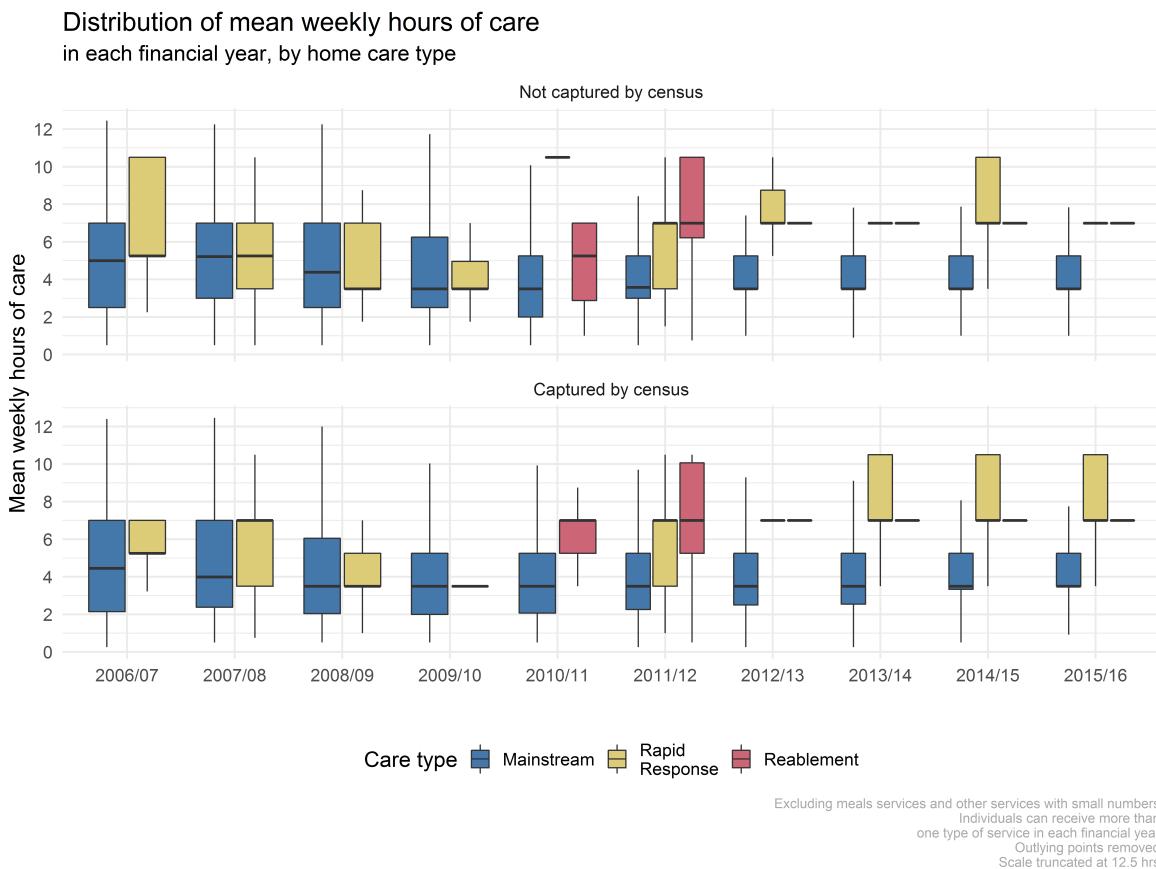


Figure 4.11: Total weekly hours of home care, by care type

4.5 Discussion

4.5.1 Findings

In the Renfrewshire council area, approximately 60% of individuals who receive home care are likely to be captured in the SCS. Since 2010/11 (the year when individual-level data was first collected by the SCS) these individuals receive between 70% & 75% of all home care delivered during the entire financial year. If a census quarter, rather than a census week, had been used as the data collection period, then over 70% of individuals, receiving approximately 85% of all home care delivered, would have been captured. There are no major differences in the age and gender of those captured in the census although there is some variation at higher and lower age ranges. Individuals receiving Mainstream and Meals services are more likely to be captured in the census than those receiving Reablement or Rapid Response services. The nature of these latter services contributes to the fact that those missed by the census are much more likely to receive care over a shorter number of weeks albeit with higher intensity care provision (measured by average weekly hours of care received).

Identification of the percentage of individuals receiving care during the SCS census week and, more importantly, the share of all social care provision they receive indicates

the only best-estimate of SCS coverage to date. Knowledge that individuals receiving home care who are captured in the census receive up to three-quarters of all provision suggests this section of the SCS already has good coverage. This is likely to improve with proposed new data collection periods which could capture individuals receiving in excess of four-fifths of all care delivered. The data made available by Renfrewshire council did not indicate where services had stopped due to mortality. Therefore, the figures suggested for the proportion of home care users captured by the SCS are likely to be an underestimate where analyses model social care data from the SCS and omit individuals who died (such as those found in chapter 6).

Whilst quantifying the percentage of home care users and the share of care they receive is useful, interpretation of the coverage of the most recent years of the SCS (from 2014/15 onwards) must also consider the fact that individuals receiving telecare or community alarm services at any time in the financial year are included. It is possible that individuals who receive one of these services may also have home care during the financial year but not at a time that coincides with the census date. This could result in an overestimate of the proportion of individuals missed by the census in this analysis. Given those with home care outwith the census week are more likely to receive short bursts of care, the magnitude of this potential error is likely to be small, though difficult to quantify.

For those *not* captured in the census, there are even distributions of duration of care across all types. Given their temporary nature, this would be expected for Reablement and Rapid Response services. The fact that the distribution is even for those receiving Mainstream or Meals services (which generally last more than a year) indicates a random aspect as to when the service comes to an end supporting the hypothesis that death may be a cause of cessation of care.

Those that *are* captured in the census tend to have been receiving care for a longer period. Interestingly, those captured by the census and receiving Reablement or Rapid Response services also had longer overall durations of care compared to those not in the census. Both Reablement and Rapid Response services are intended as short, stop-gap interventions but it is possible some individuals go on to require longer-term care and end up being re-classified as receiving Mainstream services. This may explain the slightly wider distribution of duration for individuals captured by the census receiving these services compared to Mainstream or Meals services.

Reablement and Rapid Response services are delivered with greater intensity as measured by average total weekly hours of care received. The lack of variation in this value for Reablement services seen in figure 4.11 indicates almost all individuals receiving this service do so for seven hours a week (most likely as one-hour-per-day). There are no major differences between the distributions of mean weekly hours within care types.

Considering all similarities and differences between groups of individuals captured and not captured in the census a picture emerges indicating that those missed by the census have either ceased to receive care altogether (most likely due to death), or were in receipt of short, intense forms of home care such as Reablement or Rapid Response services. The census is likely to catch individuals in receipt of Mainstream or Meals services who have been receiving them for longer terms and also those receiving short forms of care that happen to overlap the census week.

4.5.2 Limitations

This analysis is limited by the fact that data was obtained from only one local authority area. Whether the number of individuals captured or not by the SCS in the Renfrewshire area is indicative of numbers across the country is unknown. Given each of the 32 local authorities in Scotland have bespoke methods of delivering and recording social care the findings from this analysis can not be immediately generalised to a national level. The findings do, however, give the only indication yet attempted of how representative the SCS is.

Furthermore, the method of summarising data into packages of care is subjective and may differ from the method used by Renfrewshire council to complete the SCS. Absolute numbers of individuals receiving home care in each financial year in this analysis are similar to those returned by Renfrewshire council to the SCS overall with some mild discrepancies. Eligibility to be included in the home care census has changed over the years (e.g. “Housing Support” and “Overnight Services” being included as home care and then collected as a separate type of service in later years) and the collection of individual-level data did not begin until 2010/11. Whether this has changed how data is collated at the local level for return to SCS is unknown but may explain differences in counts.

4.5.3 Implications

The findings from this analysis provide the only estimation to date of the proportion of home care users identified by the SCS in any given financial year. Caution is required when generalising these findings to the whole of Scotland. However, the findings suggest a plausible figure to aid interpretation of administrative data linkage research conducted with the SCS (such as described in other chapters of this thesis). Inclusion of all home care users receiving services over quarter 4 in the 2017/18 census should increase the percentage of users captured by approximately 10% to roughly 70% and coverage of all care delivered from pproximately 70%-75% to approximately 80%-85%.

The analysis of the data from Renfrewshire council has shown there are different patterns in the duration and intensity of home care packages according to the type of care being provided (e.g. between “Care at home (Mainstream)” and “Rapid Response” type packages). The SCS does not collect data on the categorisation of care type - apart from a single flag identifying Reablement services in more recent collections. Therefore the differences in services cannot be accounted for in research using the SCS. Adding a standardised classification of home care type to the SCS would allow a richer interpretation of home care users for both official statistical reporting and research purposes.

4.5.4 Future work

Future work using this data should consider the difference in individuals receiving care at different time intervals (e.g. first six months of the financial year). If the census week were to capture a higher proportion of individuals in a more narrow time-frame then alternative types of statistical analyses, such as time-to-event (survival) analysis, may be possible using SCS data.

The data from Renfrewshire council also offers the opportunity to longitudinally analyse home care use by age, gender, and type of home care groups. Quantifying any differences in the change over time in the amount of home care used would be of interest to both researchers and local authority providers.

4.6 Conclusion

Analysis of individual level social care data from Renfrewshire council area suggests that the number of people recorded as receiving home care by the Social Care Survey captures approximately 60% of the total number of people that will receive home care during a financial year. These individuals receive 70%-75% of all social care provision in any year. Those not captured during a census week are likely to be individuals who died or received short-term care only. Collection of additional data in the SCS, such as start and stop dates for all packages of care and type of home care delivered, would improve the inferences that can be made from the SCS currently.

Chapter 5

Results 1 - Descriptive statistics

This chapter outlines the characteristics of the cohort by providing descriptive statistics of pertinent variables in five sections. The first section concentrates on characteristics by age & sex, by mortality, and by geography. The next section focusses on the proxy measurement of multimorbidity, repeat medicine counts, and its distribution by sociodemographic variables. The third section focusses on deprivation, the fourth on receipt of any form of social care, and the final section characterises unplanned admissions to hospital. Where distributions were found to be similar across all years of data a reference year, financial year 2015/16 - the most recent of the study period, is used for visualisation/tabulation purposes.

5.1 Age, sex, mortality, and geography

5.1.1 Participants

There were 1,100,675 individuals included within the study across all years with increasing numbers in each financial year as shown in Table 5.1. Percentages in each gender group and of those that died were relatively stable across the study period. Age was also relatively stable across all years with almost one-third of the cohort in each year being aged between 65 and 69 years old whilst over half were under the age of 75.

In terms of healthcare, the vast majority of individuals had at least one repeat prescription in any given year, whilst the percentage of individuals using unscheduled care services (including unplanned admissions and A & E attendances) were relatively stable over time. In contrast, the pattern in *absolute* numbers with a prescription or using health services shows a gradual increase over time shadowing the increase in overall numbers in the cohort in each year.

Variable	Value	2011/12	2012/13	2013/14	2014/15	2015/16
N in cohort		870923	895113	908300	920647	924323
N died		35874 (4.1)	41702 (4.7)	39346 (4.3)	42365 (4.6)	37992 (4.1)
Sex	Male	382598 (43.9)	395927 (44.2)	404478 (44.5)	412128 (44.8)	415968 (45.0)
	Female	488325 (56.1)	499186 (55.8)	503822 (55.5)	508519 (55.2)	508355 (55.0)
Age (years)	Mean (SD)	74.8 (7.4)	74.7 (7.4)	74.7 (7.4)	74.7 (7.4)	74.7 (7.4)
Age group (years)	65-69	256764 (29.5)	269044 (30.1)	274946 (30.3)	278708 (30.3)	282563 (30.6)
	70-74	206133 (23.7)	208831 (23.3)	211466 (23.3)	214391 (23.3)	215895 (23.4)
	75-79	170455 (19.6)	173475 (19.4)	175402 (19.3)	176749 (19.2)	175279 (19.0)
	80-84	124680 (14.3)	127608 (14.3)	128500 (14.1)	130149 (14.1)	130135 (14.1)
	85-89	73705 (8.5)	74938 (8.4)	75992 (8.4)	77620 (8.4)	77694 (8.4)
	90-94	30737 (3.5)	32712 (3.7)	33711 (3.7)	34149 (3.7)	33428 (3.6)
	95 plus	8449 (1.0)	8505 (1.0)	8283 (0.9)	8881 (1.0)	9329 (1.0)
N with >=1 repeat medicine		775647 (89.1)	795502 (88.9)	807927 (88.9)	818717 (88.9)	821862 (88.9)
Receiving social care		88036 (10.1)	95827 (10.7)	95128 (10.1)	106242 (11.1)	107441 (11.6)
Receiving home care		41642 (4.8)	42149 (4.7)	42746 (4.7)	42232 (4.6)	41172 (4.5)
Resident in care home		36514 (4.4)	33293 (4.0)	31397 (3.7)	29107 (3.3)	28156 (3.2)
>= 1 USC episode		259147 (29.8)	272580 (30.5)	270874 (29.8)	289539 (31.4)	285059 (30.8)
>=1 hospital admission		133158 (15.3)	141873 (15.8)	141746 (15.6)	147779 (16.1)	145770 (15.8)
>=1 A & E attendance		172754 (19.8)	181732 (20.3)	184101 (20.3)	190588 (20.7)	185767 (20.1)

All values n(%) unless otherwise stated

Column-wise percentages within grouped variables

Table 5.1: Characteristics of study population

Social care services show slightly less stability in terms of numbers and percentages of individuals receiving care. A jump of approximately 10,000 people receiving any form of social care is found between financial years 2013/14 and 2014/15. This pattern is not observed for those receiving home care services where absolute numbers are relatively stable across the study period. Conversely, the number flagged as living in a care home shows a gradual decrease over time.

5.1.2 Age and sex

Using financial year 2015/16 as a reference, figure 5.1 shows the breakdown by age and sex (similar patterns are seen across all years of data). There are more females than males in every age group with the difference between sexes widening as age increases. Over half of the cohort are under the age of 74 and over a quarter are between the ages of 75 and 84.

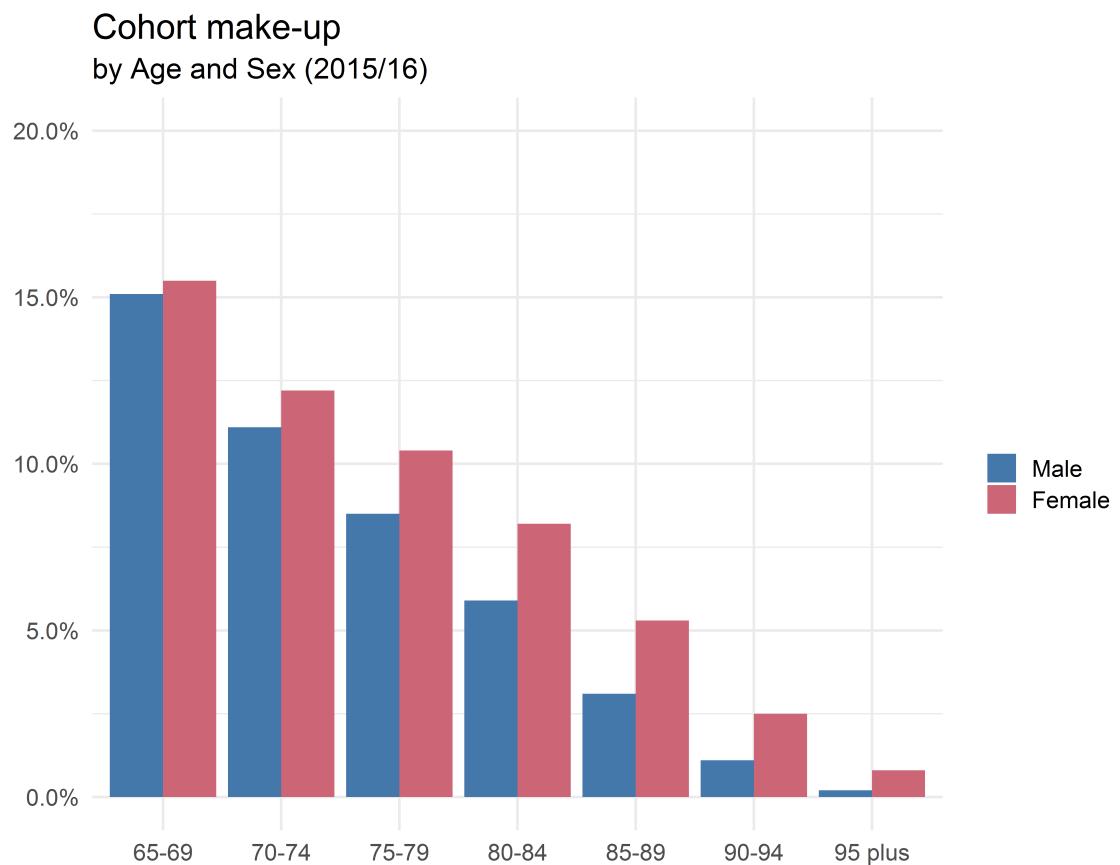


Figure 5.1: Age and sex distribution. N = 924,323

5.1.3 Mortality

In 2015/16, 4.1% of the cohort died (37,992 individuals). Figure 5.2 shows how these deaths were distributed across age and sex groups (with similar patterns seen in other years). The highest percentages of deaths (approximately 20%) occurred in the 80-84 and 85-89 age groups with females accounting for over half of these. The difference in the percentage of deaths between males and females increases from the 80-84 age groups to older age groups, whereas higher percentages of men died in age groups below 80-84.

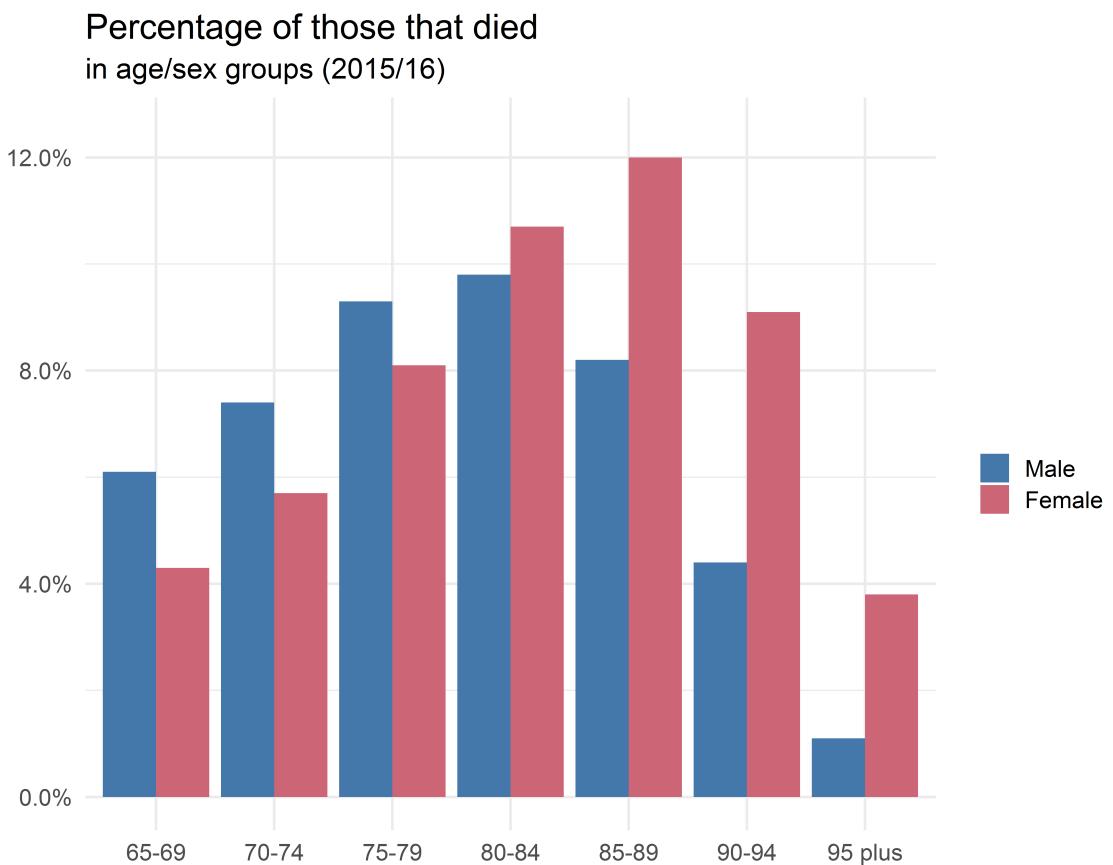


Figure 5.2: Mortality. N = 37,992

5.1.4 Local authorities

Figure 5.3 shows the percentage of individuals in the cohort that lived in each local authority area in financial year 2015/16. The largest percentages of individuals are found in Glasgow and Edinburgh city areas, whilst the smallest number are found in the three island local authorities. This is as expected based on the general population distribution.

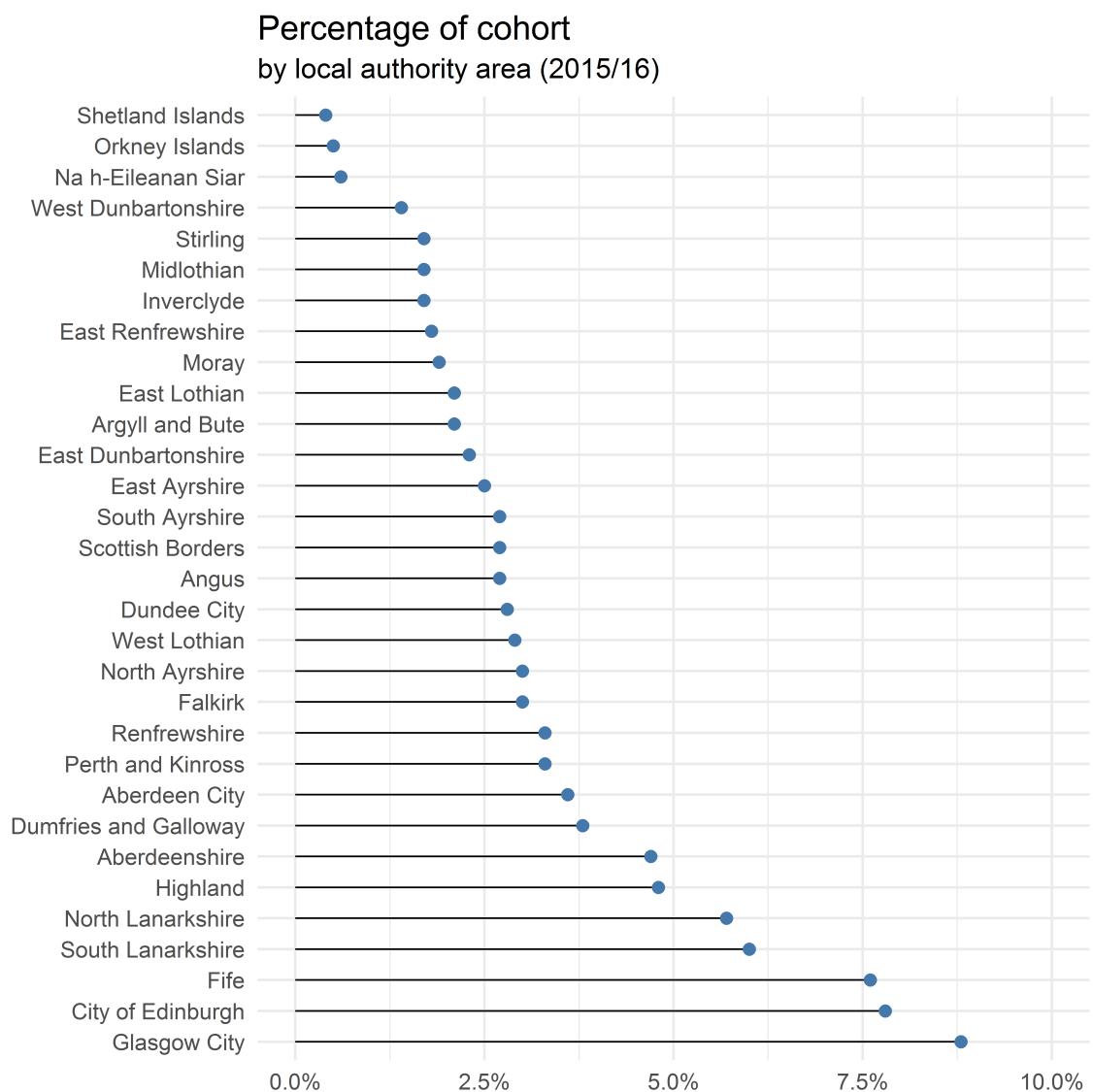


Figure 5.3: Distribution of cohort by local authority. N = 924,323

5.2 Repeat medicines

5.2.1 Distribution by sex

The distribution of number of repeat medicines prescribed in 2015/16 reveals the most common value to be zero (figure 5.4). Otherwise, a positively-skewed normal distribution is seen with higher numbers of females receiving every number of repeat medicines. This pattern is repeated across all study years.

Distribution of total repeat medicine count by sex, 2015/16

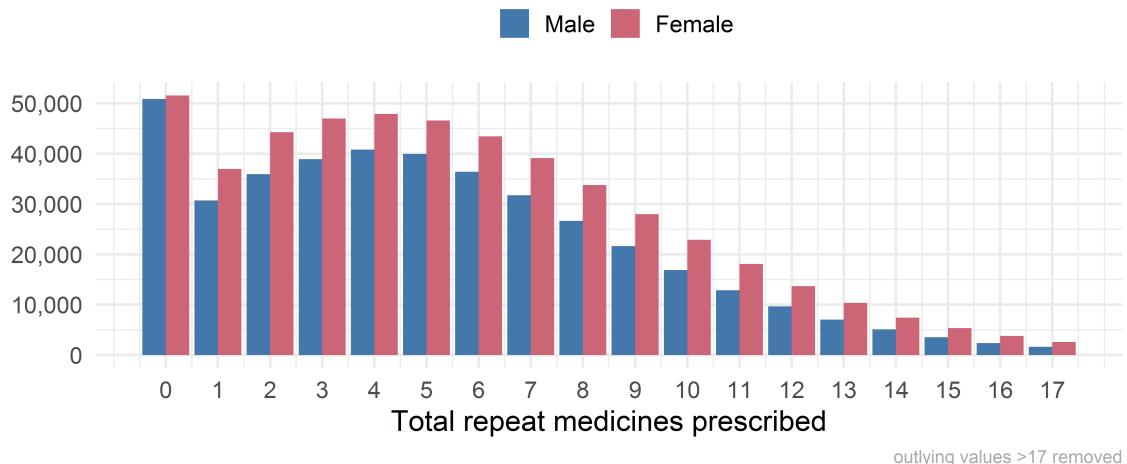


Figure 5.4: Number of individuals receiving specific counts of repeat medicines. N = 908,295

5.2.2 Percentage by sex, age group, and deprivation

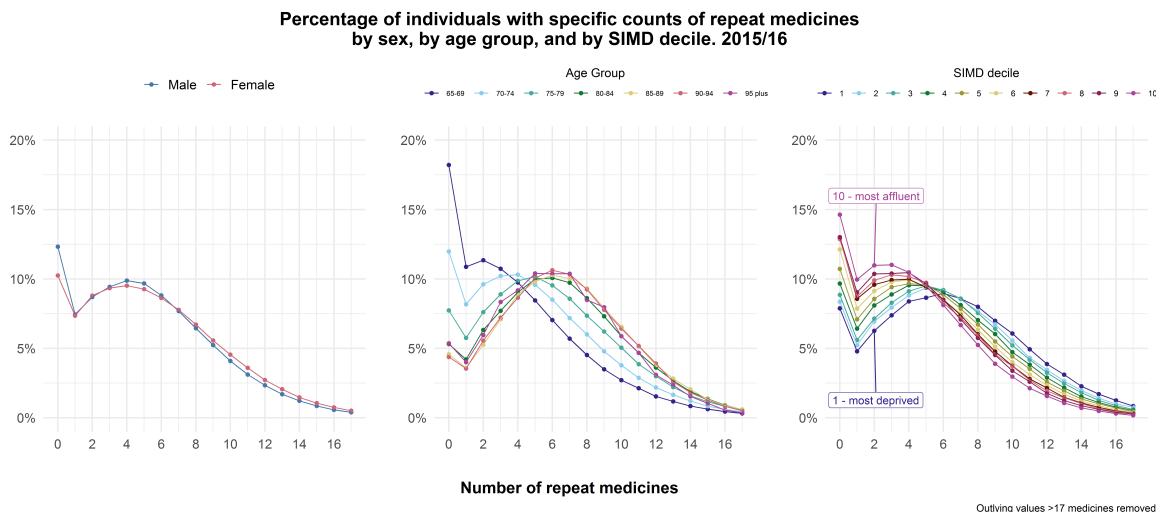


Figure 5.5: Percentage of individuals receiving repeat medicines

Despite overall numbers for specific counts of medicines being higher for females, the *percentage* of males and females receiving repeat medicines is similar as shown in the left-hand panel of figure 5.5. There are, however, differences in the pattern of percentages by age groups and SIMD deciles. The shape of the distribution shifts further to the right for both older age groups and more deprived SIMD deciles. Combining these factors (figure 5.6) reveals that the differences in deprivation deciles is more pronounced at younger ages and is much less obvious in older age groups where overall numbers are smaller.

Percentage of individuals with specific counts of repeat medicines
by age group and SIMD decile. 2015/16

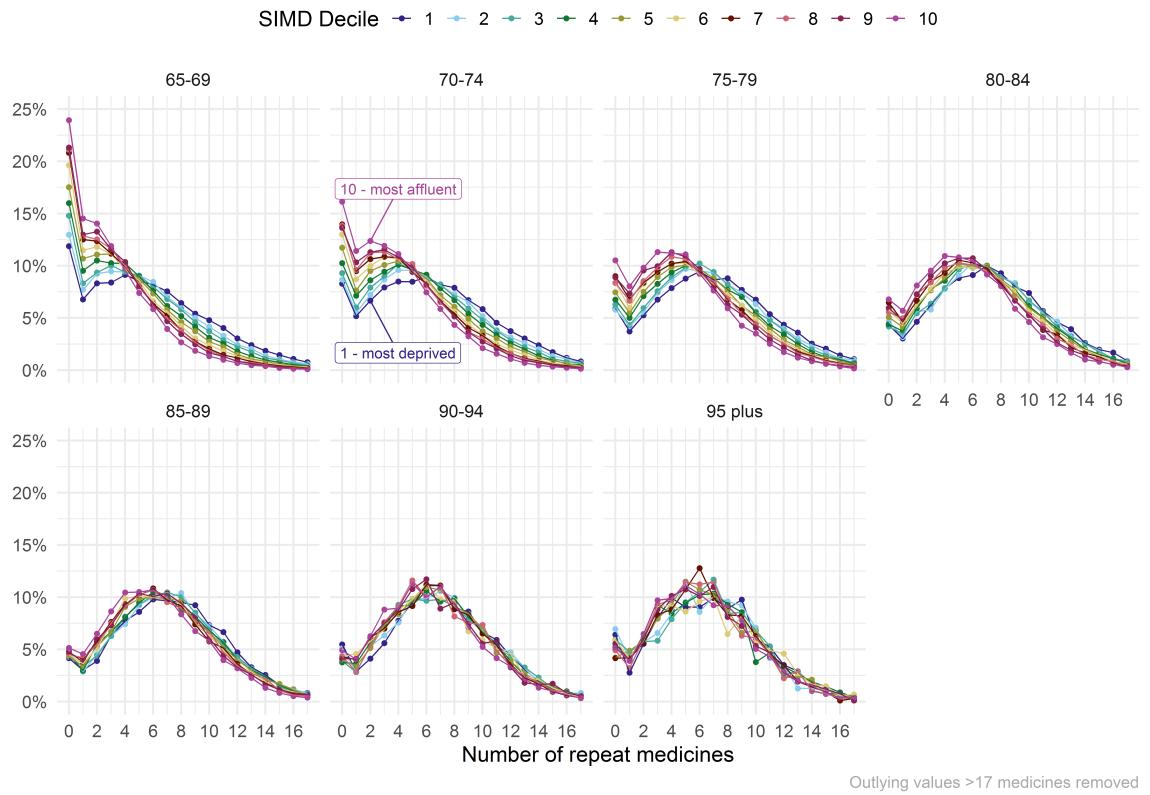


Figure 5.6: Repeat medicines by age group and SIMD decile

5.2.3 Multimorbidity (repeat medicine) groups

Figure 5.7 shows the distribution of the percentage of individuals receiving numbers of repeat medicines within defined groups. Each group contains either slightly more or less than 25% of the total cohort with 0-2 and 3-5 groups being slightly larger. The same pattern is seen across all years of data. These groups are used as a proxy measurement of multimorbidity in models reported in chapters 6 and ??.

A higher percentage of females are found in the highest multimorbidity group (9+ repeat medicines), whereas a higher percentage of men is found in the two lowest groups(0-2 & 3-5 repeat medicines, table 5.2). The average age of individuals in each multimorbidity group rises with severity from 72 years in the lowest group to 77 years in the highest. Percentages of individuals in the lowest multimorbidity group run from high to low through age groups whilst the opposite is found in the highest multimorbidity group.

A stark pattern is seen in deprivation status. Less than one-in-five individuals living in decile 1 received 0-2 repeat medicines whereas almost one-third of those in decile 10 are in this lowest multimorbidity group. The percentage of individuals in the 0-2 group increases in a linear fashion through the deprivation deciles from most deprived to most affluent. Conversely, almost a third (30.8%) of those in the most deprived SIMD decile

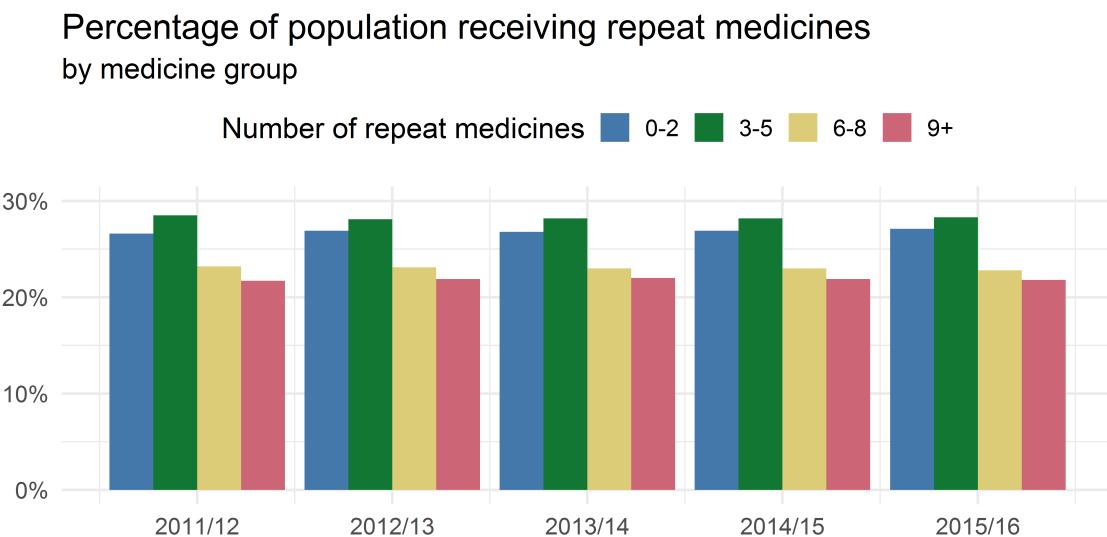


Figure 5.7: Distribution of repeat medicines by group (labelling needs changed)

were in the highest multimorbidity group. Only 13.6% of those in the most affluent decile were found in this group. Again, a (negative) linear trend in percentages going through SIMD deciles is observed.

There is a noticeable relationship between service use and multimorbidity groups. Only 7.6% of those receiving social care and 14.9% of those having at least one unscheduled care episode received between 0-2 repeat medicines. This compared to 44.9% of those receiving social care and 36.9% of those using unscheduled care services who were in the 9 and over repeat medicine group.

Variable	Value	Repeat Meds: 0-2	Repeat Meds: 3-5	Repeat Meds: 6-8	Repeat Meds: 9+	Total
Sex	Male	117562 (28.3)	119689 (28.8)	94790 (22.8)	83927 (20.2)	415968
	Female	132807 (26.1)	141500 (27.8)	116330 (22.9)	117718 (23.2)	508355
Mortality	Dead	8326 (21.9)	9182 (24.2)	8657 (22.8)	11827 (31.1)	37992
	Alive	242043 (27.3)	252007 (28.4)	202463 (22.8)	189818 (21.4)	886331
Age	Mean (SD)	72 (6.3)	74.4 (7.2)	76.3 (7.6)	77 (7.5)	
Age group	65-69	113437 (40.1)	81178 (28.7)	48460 (17.2)	39488 (14.0)	282563
	70-74	63704 (29.5)	64409 (29.8)	46413 (21.5)	41369 (19.2)	215895
	75-79	36591 (20.9)	50161 (28.6)	44150 (25.2)	44377 (25.3)	175279
	80-84	20398 (15.7)	34397 (26.4)	36557 (28.1)	38783 (29.8)	130135
	85-89	10337 (13.3)	19841 (25.5)	22793 (29.3)	24723 (31.8)	77694
	90-94	4479 (13.4)	8612 (25.8)	10033 (30.0)	10304 (30.8)	33428
	95 plus	1423 (15.3)	2591 (27.8)	2714 (29.1)	2601 (27.9)	9329
SIMD Decile	1 - most deprived	14317 (18.6)	18460 (24.0)	19313 (25.1)	24980 (32.4)	77070
	2	17247 (20.2)	21936 (25.7)	21373 (25.0)	24786 (29.0)	85342
	3	20252 (21.3)	25209 (26.6)	23726 (25.0)	25734 (27.1)	94921
	4	23053 (23.9)	26627 (27.7)	23088 (24.0)	23532 (24.4)	96300
	5	25748 (26.1)	27977 (28.4)	22904 (23.3)	21834 (22.2)	98463
	6	28867 (28.9)	28914 (29.0)	22146 (22.2)	19940 (20.0)	99867
	7	29569 (30.9)	27851 (29.1)	20850 (21.8)	17415 (18.2)	95685
	8	28977 (31.3)	27783 (30.0)	19723 (21.3)	15981 (17.3)	92464
	9	30020 (32.3)	28256 (30.4)	19781 (21.3)	15005 (16.1)	93062
	10 - most affluent	32319 (35.5)	28176 (30.9)	18216 (20.0)	12438 (13.6)	91149
Any form of Social Care	No Social Care	241929 (29.6)	240595 (29.5)	181094 (22.2)	153264 (18.8)	816882
	Social Care	8440 (7.9)	20594 (19.2)	30026 (27.9)	48381 (45.0)	107441
Any USC episode	No USC	209153 (32.7)	196097 (30.7)	137476 (21.5)	96538 (15.1)	639264
	USC	41216 (14.5)	65092 (22.8)	73644 (25.8)	105107 (36.9)	285059

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

USC = Unscheduled care

Table 5.2: Cohort 2013/14 by Multimorbidity (repeat medicine) groups

5.3 Deprivation

5.3.1 Participants

Breaking the cohort down by deprivation quintile reveals that there were fewer males and females in quintile one compared to other quintiles in 2015/16 (table 5.3). There was, however, a higher percentage of deaths in this quintile than would be seen if deaths were distributed equally across the population - where a value of 20% would be expected. This pattern is also present for quintiles two and three. Only 15.7% of individuals resident in quintile 5 datazones died in 2015/16.

There is little difference in average age across deprivation quintiles. Nevertheless, taking into account the lower overall numbers in quintile one, there are noticeably lower percentages of individuals in the 90-94 and 95 and over age groups compared to other quintiles.

Individuals resident in quintile five datazones were more likely to receive less repeat medicines with lower mean values compared to other quintiles. A positive linear pattern is observable in the numbers and percentages receiving 0-2 repeat medicines from quintile 1 (31,564, 12.6%) to quintile 5 (62,339, 24.9%). The opposite (i.e. a negative linear trend) is observed for numbers and percentages of those receiving over 9 repeat medicines from quintile 1 (49,766, 24.7%) to quintile 5 (27,443, 13.6%).

Variable	Value	Quintile 1 (most deprived)	Quintile 2	Quintile 3	Quintile 4	Quintile 5 (most affluent)	Total	
Sex	Male	71081 (17.1)	83977 (20.2)	89996 (21.6)	86628 (20.8)	84286 (20.3)	415968	
	Female	91331 (18.0)	107244 (21.1)	108334 (21.3)	101521 (20.0)	99925 (19.7)	508355	
Mortality	Died	8398 (22.1)	8688 (22.9)	8099 (21.3)	6848 (18.0)	5959 (15.7)	37992	
	Alive	154014 (17.4)	182533 (20.6)	190231 (21.5)	181301 (20.5)	178252 (20.1)	886331	
Age	Mean (SD)	74.7 (7.3)	74.9 (7.4)	74.7 (7.4)	74.6 (7.4)	74.7 (7.5)		
	65-69	48977 (17.3)	56371 (19.9)	60557 (21.4)	59224 (21.0)	57434 (20.3)	282563	
Age group	70-74	37526 (17.4)	44042 (20.4)	46823 (21.7)	44840 (20.8)	42664 (19.8)	215895	
	75-79	31883 (18.2)	37192 (21.2)	37658 (21.5)	34598 (19.7)	33948 (19.4)	175279	
	80-84	23666 (18.2)	28274 (21.7)	27279 (21.0)	25350 (19.5)	25566 (19.6)	130135	
	85-89	13338 (17.2)	16545 (21.3)	16579 (21.3)	15570 (20.0)	15662 (20.2)	77694	
	90-94	5533 (16.6)	6968 (20.8)	7352 (22.0)	6639 (19.9)	6936 (20.7)	33428	
	95 plus	1489 (16.0)	1829 (19.6)	2082 (22.3)	1928 (20.7)	2001 (21.4)	9329	
	Total repeat medicines	6.6 (4.4)	6 (4.2)	5.4 (4.1)	5 (3.9)	4.6 (3.7)		
	Medicines group	Mean (SD)						
Receiving social care	0-2	31564 (12.6)	43305 (17.3)	54615 (21.8)	58546 (23.4)	62339 (24.9)	250369	
	03-May	40396 (15.5)	51836 (19.8)	56891 (21.8)	55634 (21.3)	56432 (21.6)	261189	
	06-Aug	40686 (19.3)	46814 (22.2)	45050 (21.3)	40573 (19.2)	37997 (18.0)	211120	
	9+	49766 (24.7)	49266 (24.4)	41774 (20.7)	33396 (16.6)	27443 (13.6)	201645	
Receiving home care	24848 (23.1)	27209 (25.3)	22531 (21.0)	18033 (16.8)	14820 (13.8)	107441		
	10063 (24.4)	10482 (25.5)	8504 (20.7)	6694 (16.3)	5429 (13.2)	41172		
	>=1 episode USC	59898 (21.0)	63211 (22.2)	59044 (20.7)	52933 (18.6)	49973 (17.5)	285059	
	>= 1 unplanned hospital admission	33362 (22.9)	33625 (23.1)	30222 (20.7)	25601 (17.6)	22960 (15.8)	145770	
>= 1 A & E attendance	41212 (22.2)	42645 (23.0)	37409 (20.1)	32794 (17.7)	31707 (17.1)	185767		

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

USC = Unscheduled care

Table 5.3: Characteristics of study population by deprivation quintile 2013/14. N = 908,295

In terms of service use, the largest percentage of individuals receiving social care was found in quintile two with decreasing percentages to quintile five. The second highest percentage of social care users were found in quintile one.

5.3.2 Deprivation by age and sex

Percentage of individuals in each SIMD decile at specific age groups
2015/16

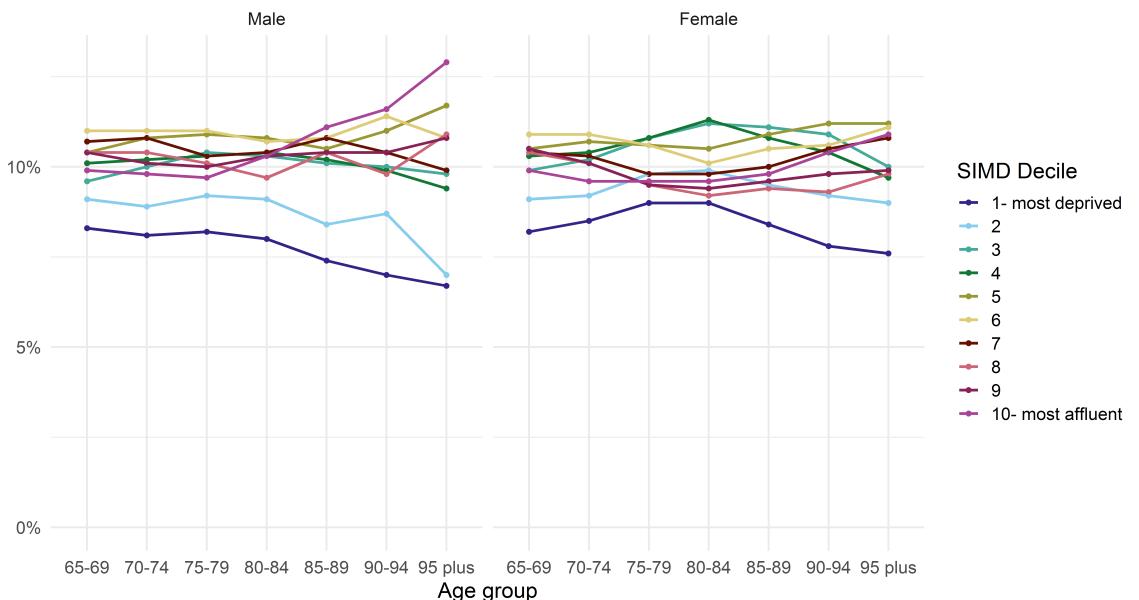


Figure 5.8: Breakdown of population by age group, sex, and SIMD decile

Figure 5.8 shows that the percentage of the cohort living in SIMD decile 1 areas is below 10% for both sexes and decreases with age. Males in decile 2 also show lower

percentages and a reduction in overall make-up of the cohort at older ages.

5.3.3 Deprivation by local authority

The percentage of individuals from the cohort living in each of the SIMD deciles by local authority area of residence in the financial year 2013/14 is shown in figure 5.9. The figure reveals large variation in percentages in each decile according to each local authority. For example approximately one-third of individuals in the City of Edinburgh live in a decile 10 datazone (the most affluent) whilst a similar number live in a decile 1 datazone in the Glasgow City area. Fife and Renfrewshire councils (and to a lesser extent South Ayrshire and South Lanarkshire) show the most even distribution of population across deprivation deciles albeit with slight discrepancies. Island local authority areas do not contain datazones from all 10 deciles and tend to have populations concentrated in the middle of the spectrum (a pattern also present in the Highland council area with smaller percentages seen at the extremes).



Figure 5.9: Distribution of cohort by local authority and SIMD decile (Decile 1 - most deprived)

5.4 Social Care

Figure 5.10 illustrates that age is a significant contributing factor to the receipt of any form of social care with the percentage of the population receiving care increasing rapidly from age 65 to 95 regardless of sex, deprivation status or repeat medicine group. Despite this, there are noticeable differences within each of these groups with females, those in more deprived SIMD deciles, and those with higher multimorbidity status (measured by medicine group) showing higher percentages of individuals receiving social care at all ages. Looking across groups reveals a higher percentage of individuals prescribed nine or more repeat medicines receive care than any other group at all but the oldest ages.

The difference between the percentage of females and males receiving social care at all

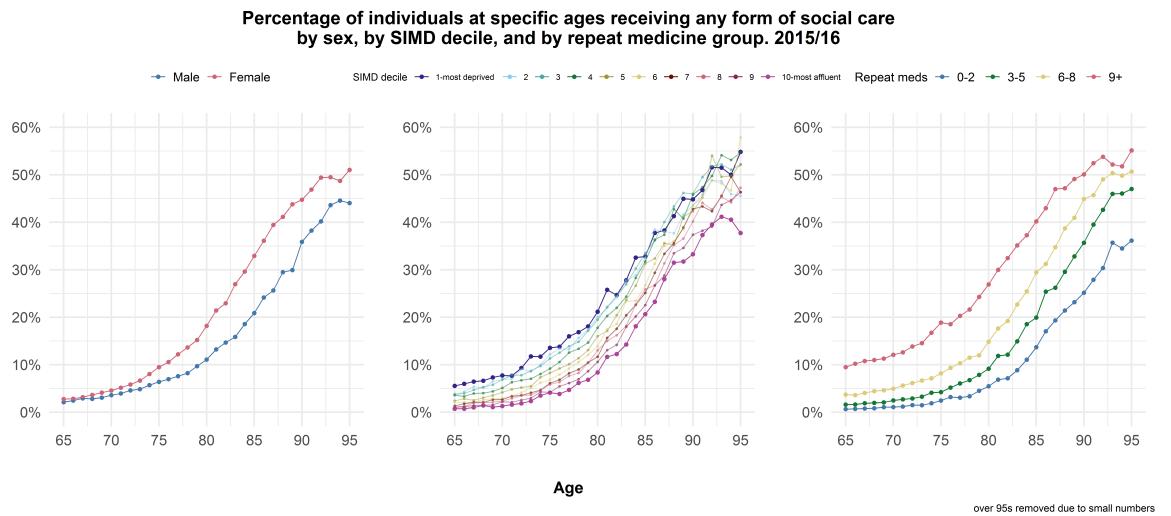


Figure 5.10: Receipt of social care (a)

ages is evident in both SIMD deciles one and ten (figure 5.11) suggesting deprivation status does not account for the difference in sex. This is also true for medicine groups with increasing percentages seen for both deciles from low to high medicine groups.

Percentage of individuals at specific ages receiving any form of social care by SIMD & sex, and SIMD & repeat medicine group. 2015/16



Figure 5.11: Receipt of social care (b)

5.5 Unplanned hospital admission

Age is also an important driver in the percentage of individuals having at least one unplanned hospital admission (figure 5.12), although this is to a lesser extent than seen for social care. In contrast to social care receipt there is relatively little difference between sexes on unplanned admission. Similarly to social care, however, there are marked variations within deprivation and multimorbidity groups. Again, those in more deprived areas and with higher repeat medicine counts being more likely to have an unplanned admission at all ages.

The percentage of individuals in deciles one and ten with a hospital admission is broadly similar when split by sex (figure 5.13), although there is a marginally higher rate of men with an admission seen in ages 80 and under in decile 10. Multimorbidity has an effect across SIMD deciles with higher percentages of unplanned admission in both deciles one and ten as the number of repeat medicines increases. The gap between deciles one and ten also increases through low to high medicine groups.

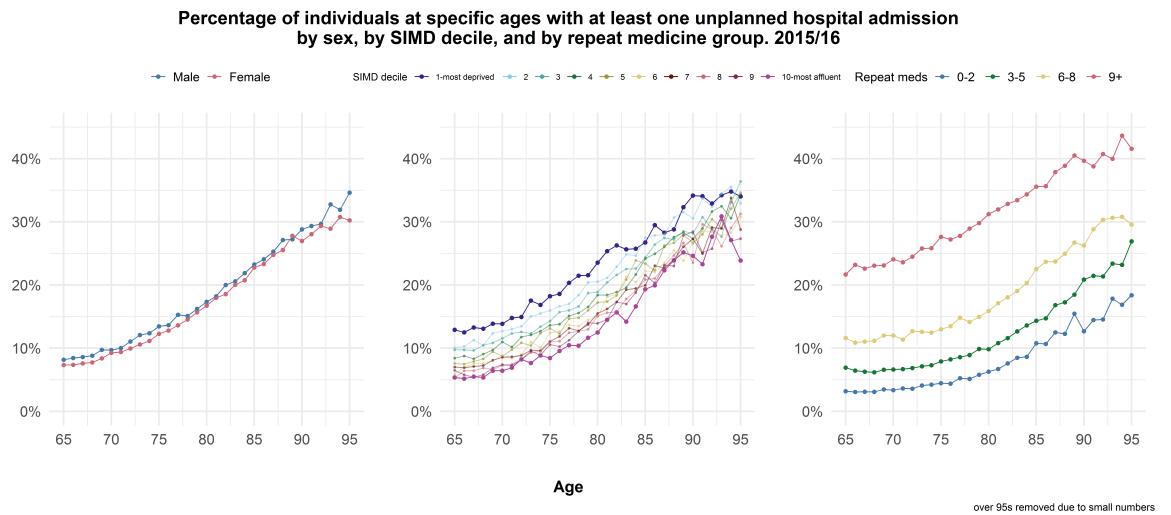


Figure 5.12: Unplanned hospital admission (a)

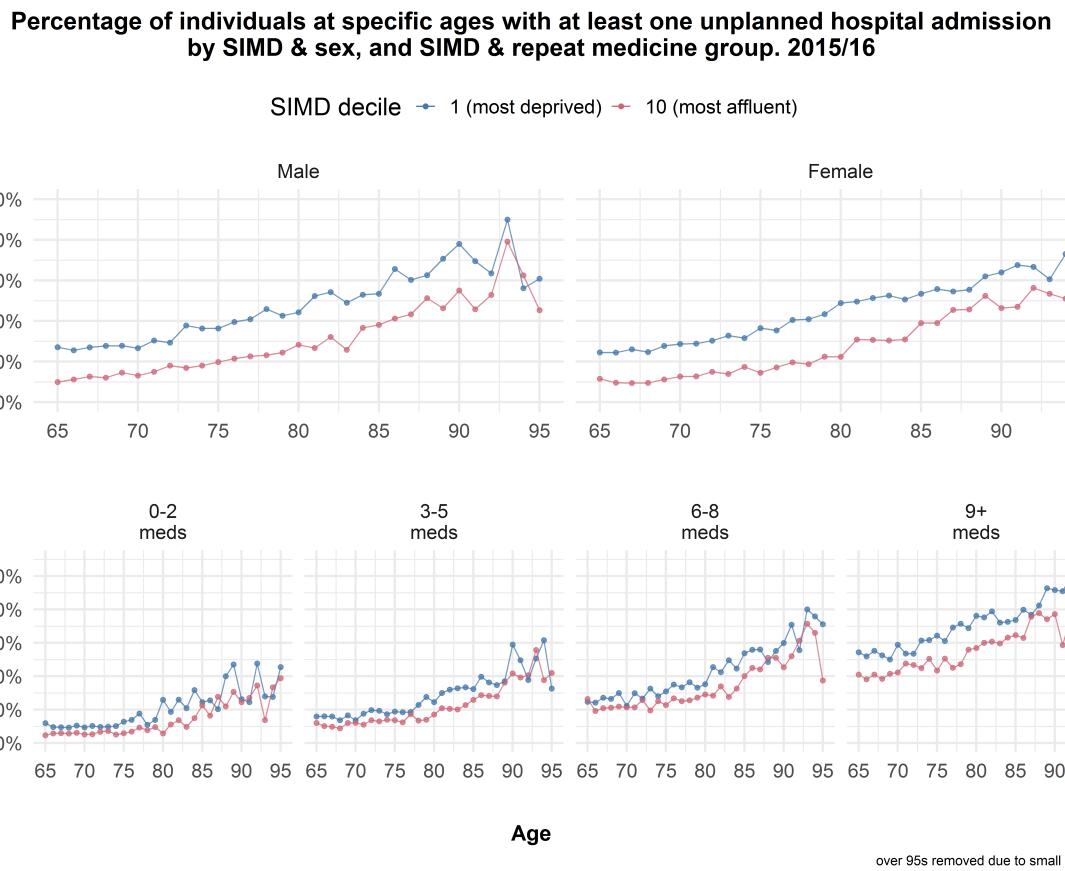


Figure 5.13: Unplanned hospital admission (b)

Chapter 6

Results 2: Models

This chapter reports results of an analysis conducted to answer research questions 1 and 2 namely:

In people over the age of 65 in Scotland:

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

As described in section 3.5.1, receipt of social care was measured by an individual having a record present in the SCS of any year. This could be in relation to any form of social care provided, or commissioned, by a local authority. As linkage rates from the SCS to the population spine varied at the local authority level, direct comparison of levels of care across all councils is impossible. For this reason two subsets, together representing ~58% of the overall cohort, are compared in relation to research question 1 in the first two sections of this chapter. The third and final section aims to answer research question 2.

6.1 Social care - subset 1

6.1.1 Models for councils with link rate greater than 96%

In this section results of logistic regression models applied to the subset of individuals in local authorities where a match rate greater than 96% was achieved when linking the SCS to the population spine. Nine local authorities are included in the logistic regression models: Falkirk, Angus, East Ayrshire, Inverclyde, South Lanarkshire, Stirling, North Ayrshire, Dumfries & Galloway, and Argyll & Bute.

In total, five models are reported - one for each financial year of data. As in the previous chapter, where results are broadly consistent across years, 2015/16 is used as a reference year to convey results.

The R code for the model fitted to this first subset of data was as follows:

```
glm(scs_flag ~ sex*age_grp + simd*meds_grp + age_grp*meds_grp + council*simd,
family = binomial(), data = thesis)
```

*#Flag for social care as dependent variable
#Interaction : Sex and Age group
#Interaction : SIMD and repeat medicines
#Interaction : Age group and repeat medicines
#Interaction : Council and SIMD
#logistic regression
#identify which data to use*

R automatically fits all included variables individually before adding interaction terms.

6.1.2 Descriptive statistics

There were 234,392 individuals included in the model for 2015/16 (table 6.1) which accounts for 25.4% of the overall cohort in that year. There are similar numbers included in models for other years. Proportions of females/males, age groups, SIMD decile, and repeat medicine groups are broadly similar to the overall cohort as reported in chapter 5. Also in concordance with results in chapter 5, table 6.1 shows higher percentages of females received social care as well as patterns indicating increasing social care use through age groups (young to old), SIMD deciles (affluent to deprived), and repeat medicine groups (low to high). Statistically significant results are found for all variables with Chi-squared tests for differences within groups.

There is notable variation in the percentage of individuals receiving social care depending on the local authority of residence ranging from 14.9% in Falkirk to 9.1% in

Variable	Value	No Social Care	Social Care	Total	p-value
Sex	Male	97151 (91.7)	8834 (8.3)	105985	<0.001
	Female	109096 (85.0)	19311 (15.0)	128407	
Age group	65-69	71604 (97.1)	2129 (2.9)	73733	<0.001
	70-74	53870 (94.6)	3052 (5.4)	56922	
	75-79	40083 (89.2)	4867 (10.8)	44950	
	80-84	24936 (78.2)	6970 (21.8)	31906	
	85-89	11302 (63.2)	6593 (36.8)	17895	
	90-94	3579 (50.4)	3523 (49.6)	7102	
	95 plus	873 (46.3)	1011 (53.7)	1884	
SIMD decile	1 - most deprived	15102 (83.1)	3066 (16.9)	18168	<0.001
	2	20121 (85.0)	3543 (15.0)	23664	
	3	23024 (85.3)	3974 (14.7)	26998	
	4	24301 (87.0)	3621 (13.0)	27922	
	5	24673 (88.5)	3196 (11.5)	27869	
	6	27751 (89.6)	3234 (10.4)	30985	
	7	20881 (89.4)	2470 (10.6)	23351	
	8	20264 (90.2)	2195 (9.8)	22459	
	9	19711 (91.4)	1853 (8.6)	21564	
	10 - most affluent	10419 (91.3)	993 (8.7)	11412	
Repeat medicines group	0-2	59467 (96.9)	1898 (3.1)	61365	<0.001
	3-5	61424 (92.2)	5189 (7.8)	66613	
	6-8	46699 (85.6)	7852 (14.4)	54551	
	9+	38657 (74.5)	13206 (25.5)	51863	
Local Authority	Falkirk	22839 (85.5)	3858 (14.5)	26697	<0.001
	Angus	20814 (88.2)	2793 (11.8)	23607	
	East Ayrshire	19294 (86.1)	3122 (13.9)	22416	
	Inverclyde	12793 (84.9)	2280 (15.1)	15073	
	South Lanarkshire	46724 (88.1)	6304 (11.9)	53028	
	Stirling	13202 (87.7)	1859 (12.3)	15061	
	North Ayrshire	23407 (88.3)	3094 (11.7)	26501	
	Dumfries and Galloway	30568 (90.9)	3073 (9.1)	33641	
	Argyll and Bute	16606 (90.4)	1762 (9.6)	18368	

Total N used in model = 234,392

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 6.1: Subset 1. Characteristics of those receiving/not receiving social care. 2015/16

Dumfries & Galloway. These values, unlike other variables in the models, can fluctuate over time as shown in table 6.1. There is no discernable pattern across council areas, some show gradual decreases over time, others gradual increases, whilst others fluctuate in both directions. Generally, all councils saw an increase in the percentage of those receiving care from 2014/15 onwards reflecting the change in data collection to include individuals receiving community alarm or telecare services at any time in the financial year. However, this increase was not sustained in all areas: Falkirk, Angus, and South Lanarkshire showing reductions in 2015/16 compared to the previous year.

	Data collected during census week only			Expanded data collection for telecare and alarm services	
	2011/12	2012/13	2013/14	2014/15	2015/16
Falkirk	14.1	15	14.8	15.2	14.5
Angus	15.1	13.8	13.5	13.7	11.8
East Ayrshire	12.9	13.3	13.2	13.8	13.9
Inverclyde	12.1	12.5	12.4	13.1	15.1
South Lanarkshire	11.7	11.4	12.4	13	11.9
Stirling	10.9	11.1	11.8	12.2	12.3
North Ayrshire	10.8	11	11.1	11.4	11.7
Dumfries and Galloway	8.4	8	7.5	8.1	9.1
Argyll and Bute	8.2	8.7	9.2	9.6	9.6

Table 6.2: Subset 1. Percentage of over 65s receiving any form of social care

6.1.3 Model results

Odds ratios for age groups and repeat medicine groups in the fitted model (for 2015/16) increase from young-to-old and low-to-high respectively (figure 6.1). Females are shown to be more likely to receive social care than males, whilst the effect of SIMD modelled as a continuous variable is marginally negative which indicates an increase in SIMD decile from deprived to affluent is associated with reduced chance of receiving social care. All local authorities show reduced odds of receiving social care compared to the reference group (Falkirk), but not all differences are statistically significant.

Given the difficulties in interpretation of interaction terms in logistic regression models (discussed in section 3.5), these are not shown in figure 6.1. Tabulation of full model results for 2015/16 are available in table 8.2 in Appendix D.

In order to aid interpretation of the magnitude of influence each variable has on the receipt of social care, Average Partial Effects (APEs) were calculated. These are discussed fully in section 3.5. In short, APEs indicate the marginal effect of each value of a variable on the outcome taking into account all other variables and interactions.

APEs for each variable in each model (year) are plotted in figure 6.2 with values for 2015/16 shown in table 6.3. Age has the largest positive effect of receiving social care with the probability approximately 45% higher for those over 95 compared to those aged 65-69 in all models (specifically 46.6% in 2015/16). Age bands 90-94, 85-89, and 80-84 also show very strong effects (~40%, ~28%, and ~15% higher probability of receiving social care across all models).

Multimorbidity also has a strong positive effect on receipt of social care, although the

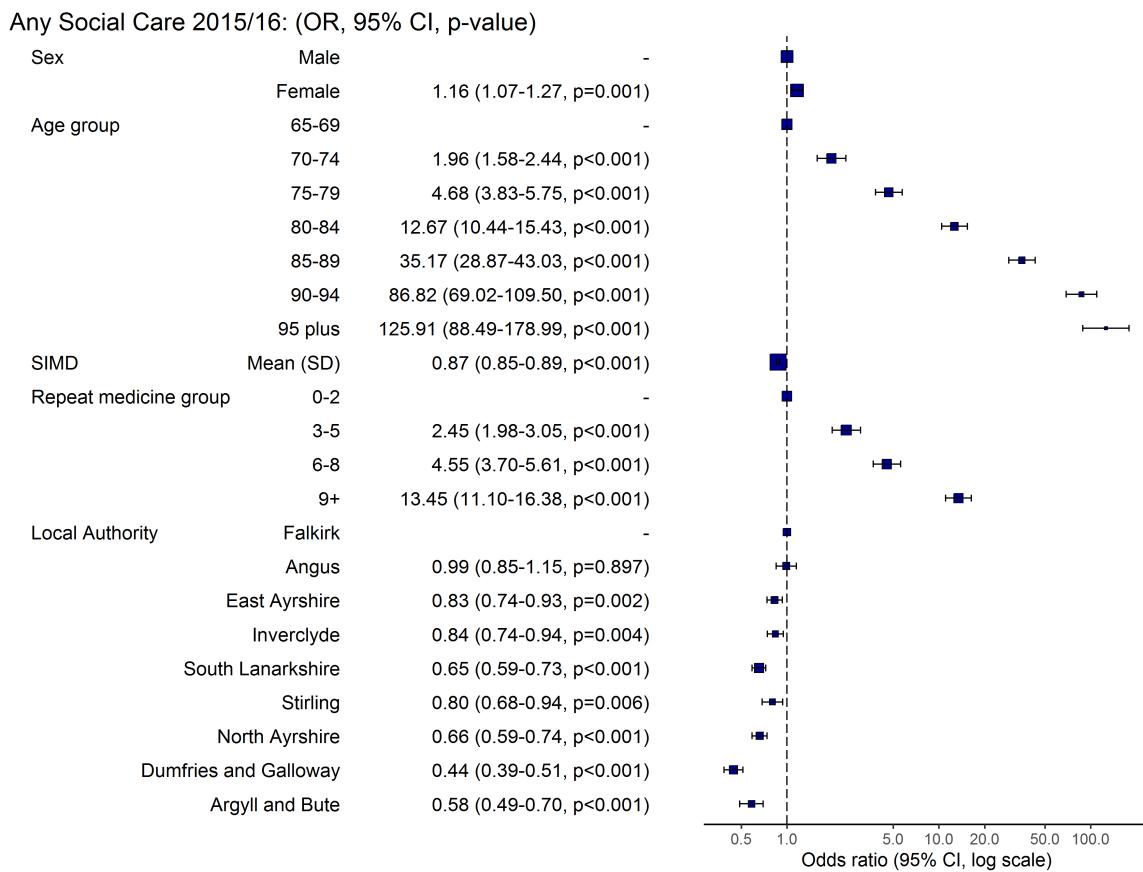


Figure 6.1: Subset 1 - odds ratios

magnitude of this effect is lower than that of higher age groups. Those receiving 9 or more repeat medicines have ~15% higher probability of receiving social care compared to those receiving 0-2 repeat medicines in all years (15.3% in 2015/16). This effect is a similar magnitude as the APE of being 80-84 compared to 65-69 years of age. Medicine groups 6-8 and 3-5 have respectively ~7% and ~3% increased probability of receiving social care compared to those receiving 0-2 medicines.

After controlling for other variables in the model females have an increased probability of receiving care of ~4% compared to males for all models (exactly 4% in 2015/16). SIMD decile was modelled as a continuous variable. The APE of -0.006 in 2015/16 (table 6.3) indicates the coefficient of the slope at the average value of SIMD (5.2, SD 2.6). The small value of this slope suggests SIMD decile had little effect on the receipt of social care. This can be seen in the conditional effect of SIMD shown in figure 8.1 in Appendix D.

With the exception of higher age groups where numbers are small, local authorities display more variation in APEs across models than other variables. This is more easily visualised in figure 6.3 which shows that the difference in APEs across councils is fairly stable and shows some narrowing in 2015/16.

Comparing the APEs shown in figure 6.3 to the difference in overall percentage of

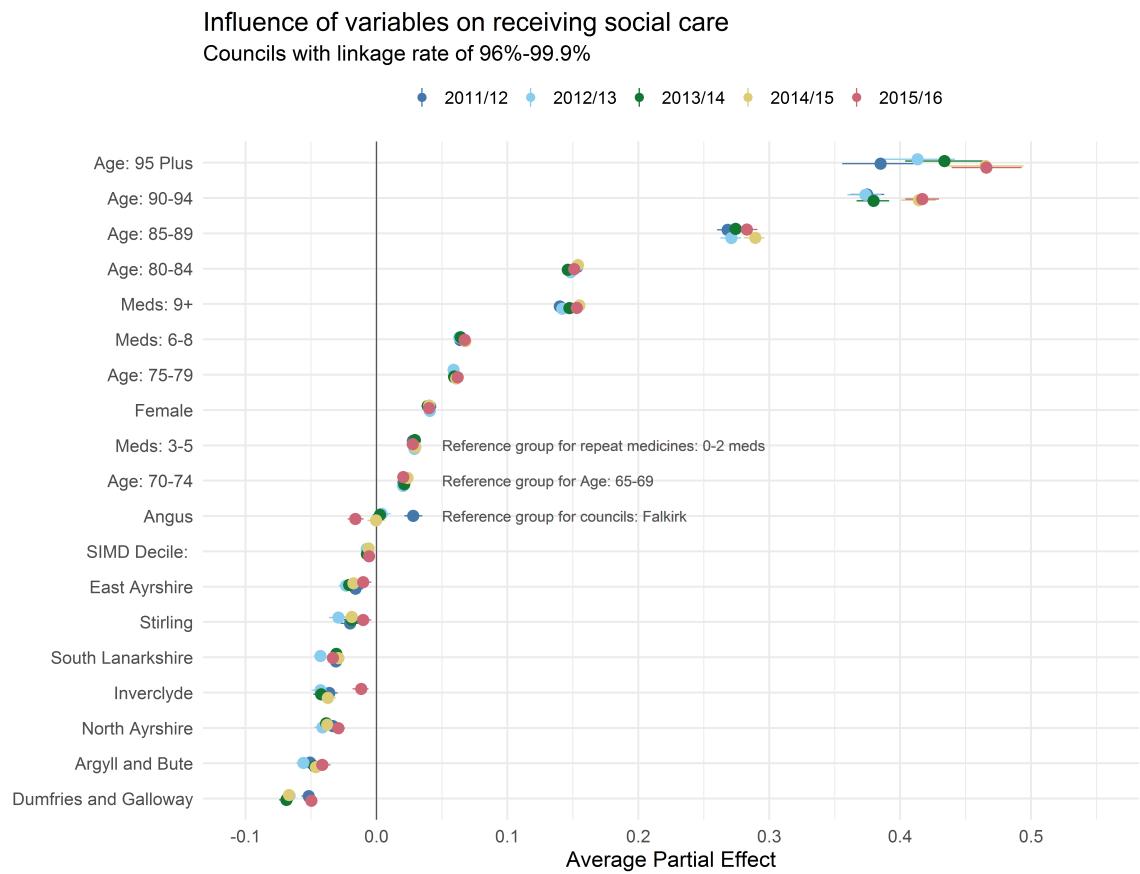


Figure 6.2: Subset 1. Average Partial Effects

individuals receiving social care (figure 6.4, adapted from table 6.2) shows that after controlling for age, sex, deprivation status, and multimorbidity status, APEs for some councils are less than would be expected.

For example, Inverclyde and South Lanarkshire councils have a higher percentage of individuals receiving social care compared to Stirling council (with the exception of 2015/16 where Stirling has a marginally higher percentage than South Lanarkshire, table 6.2 and figure 6.4). However, APEs (figure 6.3) suggest the probability of receiving social care in Inverclyde and South Lanarkshire is lower than Stirling in all models. Similarly, despite having higher overall percentages of individuals receiving social care, APEs for East Ayrshire are almost identical to those of Stirling. Conversely, the difference between the APE for Angus council and the reference value in Falkirk council is negligible in 2012/13 to 2014/15 despite there being a higher percentage of individuals in Falkirk receiving care.

Table 6.4 shows the results of diagnostic tests for the models applied to each financial year of data. McFadden's pseudo R^2 statistic ranges from 0.218 for the model applied to 2011/12 to 0.236 for the model applied to 2015/16. As discussed in section 3.5.1, this suggests the the model has an excellent fit to all years of data with improvement in more recent years.

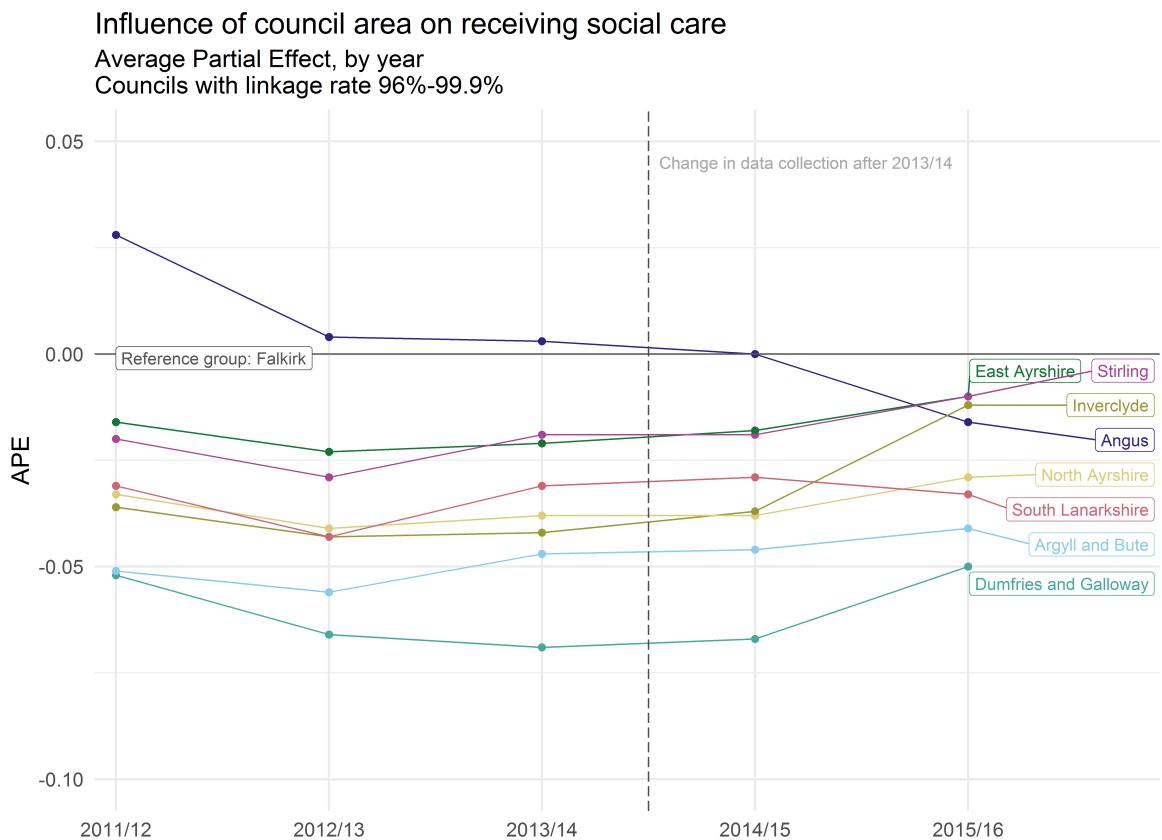


Figure 6.3: Subset 1. Local authority APE across models

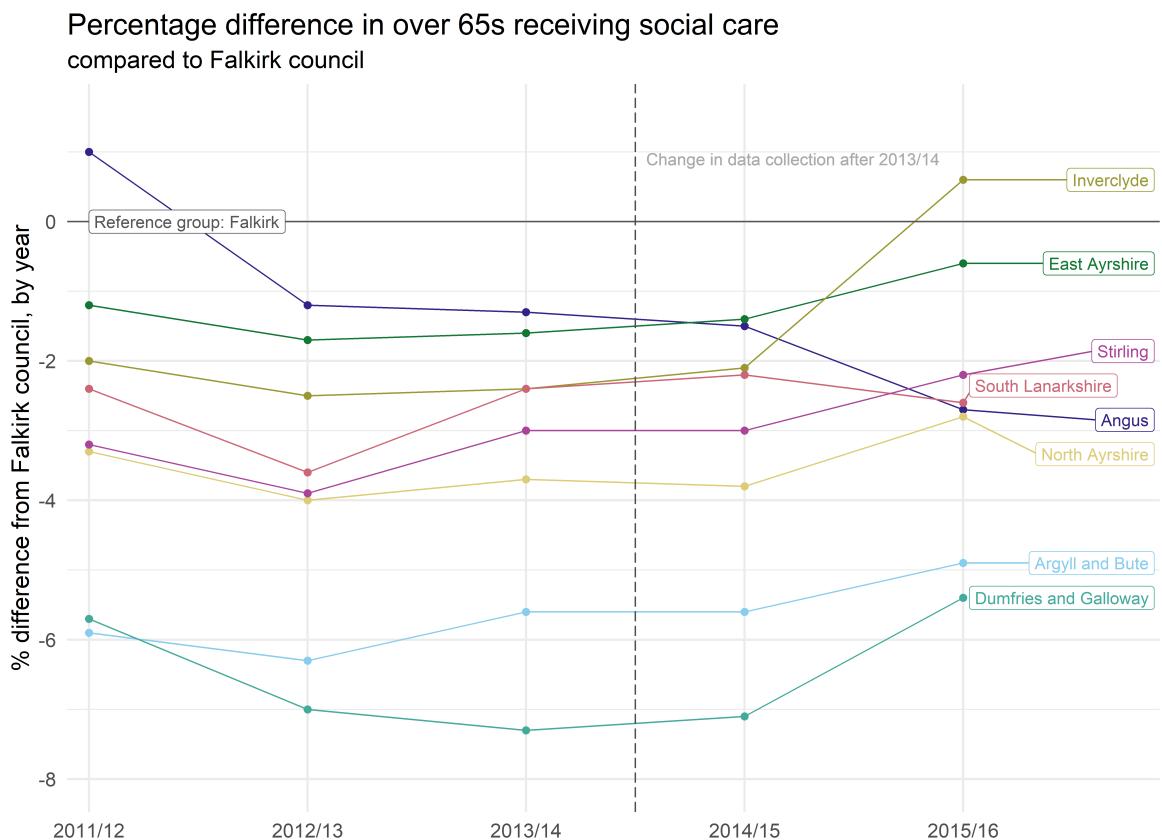


Figure 6.4: Subset 1. % difference in over 65s receiving social care

Variable	Average Partial Effect	Standard Error	p-value	Lower 95% CI	Upper 95% CI
Age: 95 Plus	0.466	0.014	<0.001	0.439	0.493
Age: 90-94	0.417	0.007	<0.001	0.404	0.43
Age: 85-89	0.283	0.004	<0.001	0.276	0.291
Meds: 9+	0.153	0.002	<0.001	0.149	0.157
Age: 80-84	0.151	0.002	<0.001	0.147	0.155
Meds: 6-8	0.067	0.002	<0.001	0.063	0.07
Age: 75-79	0.062	0.002	<0.001	0.059	0.065
Female	0.04	0.001	<0.001	0.038	0.043
Meds: 3-5	0.028	0.002	<0.001	0.025	0.031
Age: 70-74	0.02	0.001	<0.001	0.017	0.022
SIMD Decile:	-0.006	0	<0.001	-0.006	-0.005
East Ayrshire	-0.01	0.003	0.001	-0.015	-0.004
Stirling	-0.01	0.003	0.003	-0.017	-0.004
Inverclyde	-0.012	0.003	<0.001	-0.018	-0.006
Angus	-0.016	0.003	<0.001	-0.022	-0.01
North Ayrshire	-0.029	0.003	<0.001	-0.034	-0.024
South Lanarkshire	-0.033	0.002	<0.001	-0.038	-0.029
Argyll and Bute	-0.041	0.003	<0.001	-0.047	-0.035
Dumfries and Galloway	-0.05	0.002	<0.001	-0.055	-0.045

Reference group for age: 65-69

Reference group for meds: 0-2 repeat medicines

Reference group for local authority: Falkirk

Table 6.3: Subset 1. Average partial effects. 2015/16

Financial Year	McFadden's pseudo R ²	Fitted model			Null model			AIC	BIC
		Deviance	Log Likelihood	Degrees of freedom	Deviance	Log Likelihood	Degrees of freedom		
2011/12	0.218	122092.147	-61046.073	218335	156192.796	-78096.398	218389	122202.147	122768.319
2012/13	0.222	124626.619	-62313.309	223999	160148.076	-80074.038	224053	124736.619	125304.199
2013/14	0.222	128595.553	-64297.777	228726	165344.874	-82672.437	228780	128705.553	129274.282
2014/15	0.233	131849.309	-65924.654	231616	171893.338	-85946.669	231670	131959.309	132528.728
2015/16	0.236	131443.94	-65721.97	234337	172080.12	-86040.06	234391	131553.94	132124.002

Table 6.4: Subset 1. Goodness-of-fit

6.2 Social Care - subset 2

6.2.1 Models for councils with link rate between 92% and 95.9%

In this section results of logistic regression models applied to the subset of individuals in local authorities where a match rate between 92% and 95.9% was achieved when linking the SCS to the population spine. Nine local authorities are included in the models: Shetland Islands, Glasgow City, Na h-Eilenanan Siar, East Renfrewshire, City of Edinburgh, East Dunbartonshire, Fife, Perth & Kinross, and South Ayrshire.

In a similar fashion as the previous section, five models are reported - one for each financial year of data and where results are broadly consistent across years, 2015/16 is used as a reference year to convey results. Results here are restricted to show differences

with the models fitted in the previous section.

The R code for the model fitted to the second subset was identical to that reported in the previous section, the underlying subset of data being the only change.

6.2.2 Descriptive statistics

Variable	Value	No Social Care	Social Care	Total	p-value
Sex	Male	127450 (92.8)	9839 (7.2)	137289	<0.001
	Female	151392 (87.1)	22323 (12.9)	173715	
Age group	65-69	92859 (97.3)	2605 (2.7)	95464	<0.001
	70-74	68999 (95.3)	3428 (4.7)	72427	
75-79	54048 (91.5)	5038 (8.5)	59086		
	80-84	36738 (83.0)	7540 (17.0)	44278	
85-89	18252 (70.4)	7687 (29.6)	25939		
	90-94	6408 (58.7)	4505 (41.3)	10913	
95 plus	1538 (53.1)	1359 (46.9)	2897		
	1	31012 (86.8)	4727 (13.2)	35739	<0.001
SIMD decile	2	25243 (87.6)	3573 (12.4)	28816	
	3	21948 (86.5)	3416 (13.5)	25364	
4	23057 (87.7)	3223 (12.3)	26280		
	5	25118 (88.7)	3208 (11.3)	28326	
6	21785 (89.4)	2572 (10.6)	24357		
	7	23311 (90.9)	2338 (9.1)	25649	
8	26783 (91.3)	2548 (8.7)	29331		
	9	34987 (92.1)	3015 (7.9)	38002	
9+	45598 (92.8)	3542 (7.2)	49140		
	0-2	82052 (97.3)	2259 (2.7)	84311	<0.001
Repeat medicines group	3-5	81945 (93.1)	6084 (6.9)	88029	
	6-8	61694 (87.2)	9094 (12.8)	70788	
Local Authority	9+	53151 (78.3)	14725 (21.7)	67876	
	Shetland Islands	3393 (86.1)	548 (13.9)	3941	<0.001
Glasgow City	Glasgow City	67579 (88.4)	8853 (11.6)	76432	
	Na h-Eileanan Siar	4716 (85.4)	809 (14.6)	5525	
East Renfrewshire	East Renfrewshire	14084 (87.5)	2005 (12.5)	16089	
	City of Edinburgh	62236 (91.0)	6177 (9.0)	68413	
City of Edinburgh	East Dunbartonshire	18664 (92.0)	1626 (8.0)	20290	
	Fife	59594 (89.0)	7358 (11.0)	66952	
Fife	Perth and Kinross	26295 (90.1)	2893 (9.9)	29188	
	South Ayrshire	22281 (92.2)	1893 (7.8)	24174	

Total N used in model = 311,004

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 6.5: Subset 1. Characteristics of those receiving/not receiving social care. 2015/16

In this second subset, the nine included councils represented approximately 33% of the overall cohort (e.g. 311,004 individuals in 2015/16, table 6.5). There were smaller percentages of individuals receiving social care in all sociodemographic and multimorbidity groups compared to subset 1 (table 6.1). For example, 7.2% of males and 12.9% of females received social care in subset 2 compared to 8.3% of males and 15% of females in subset 1. Less than 10% of individuals over 65 received social care in four of the nine councils in subset 2 including the second largest council in Scotland - City of

Edinburgh. Only two councils in subset 1, Dumfries & Galloway and Argyll & Bute, provided less than 10% of over 65s with social care.

	Data collected during census week only			Expanded data collection for telecare and alarm services	
	2011/12	2012/13	2013/14	2014/15	2015/16
Shetland Islands	17.8	16.8	15.9	14.8	13.9
Glasgow City	14.2	14.7	11.9	11.3	11.6
Na h-Eileanan Siar	11.6	10.7	11.6	11.2	14.6
East Renfrewshire	10.2	8.7	11.2	10.4	12.5
City of Edinburgh	9.5	9.1	9.7	10.5	9
East Dunbartonshire	9.6	9.9	9.7	10.3	8
Fife	9	9.3	9.1	10.5	11
Perth and Kinross	8.1	8.4	7.6	9.3	9.9
South Ayrshire	8.1	8.4	8.5	7.8	7.8

Table 6.6: Subset 2. Percentage of over 65s receiving any form of social care

Table 6.6 reveals that Shetland Islands council provided a much higher percentage of over 65 with social care than other councils in most years although this rate reduced over time. Other council areas show fluctuating percentages of their populations receiving social care. The change in data collection from 2014/15 onwards resulted in some councils showing a higher rate receiving care, whilst there was a drop in the percetnage receiving care in other areas.

6.2.3 Model results

Odds ratios for individual values show similar patterns, but lower values, to those found in subset 1. A full table of model results for subset 2 (2015/16) can be found in figure 8.2 and table 8.3 in Appendix D.

Broadly similar values for APEs are found for sociodemographic and multimorbidity group variables in subset 2 as were found in subset 1 (figure 6.5). The only slight exceptions were for the oldest two age groups and the highest multimorbidity group where APEs were slightly less and 85-89 age group where the APE was slightly higher compared to subset 1.

More variation is seen across years for council areas than was evident with subset 1 and noticeably larger confidence intervals can be seen in figure 6.5. Once again, comparison of overall percentages of individuals receiving social care (table 6.6 and figure 6.7) with APE values over time (figure 6.5) suggests some council areas have lower APEs than

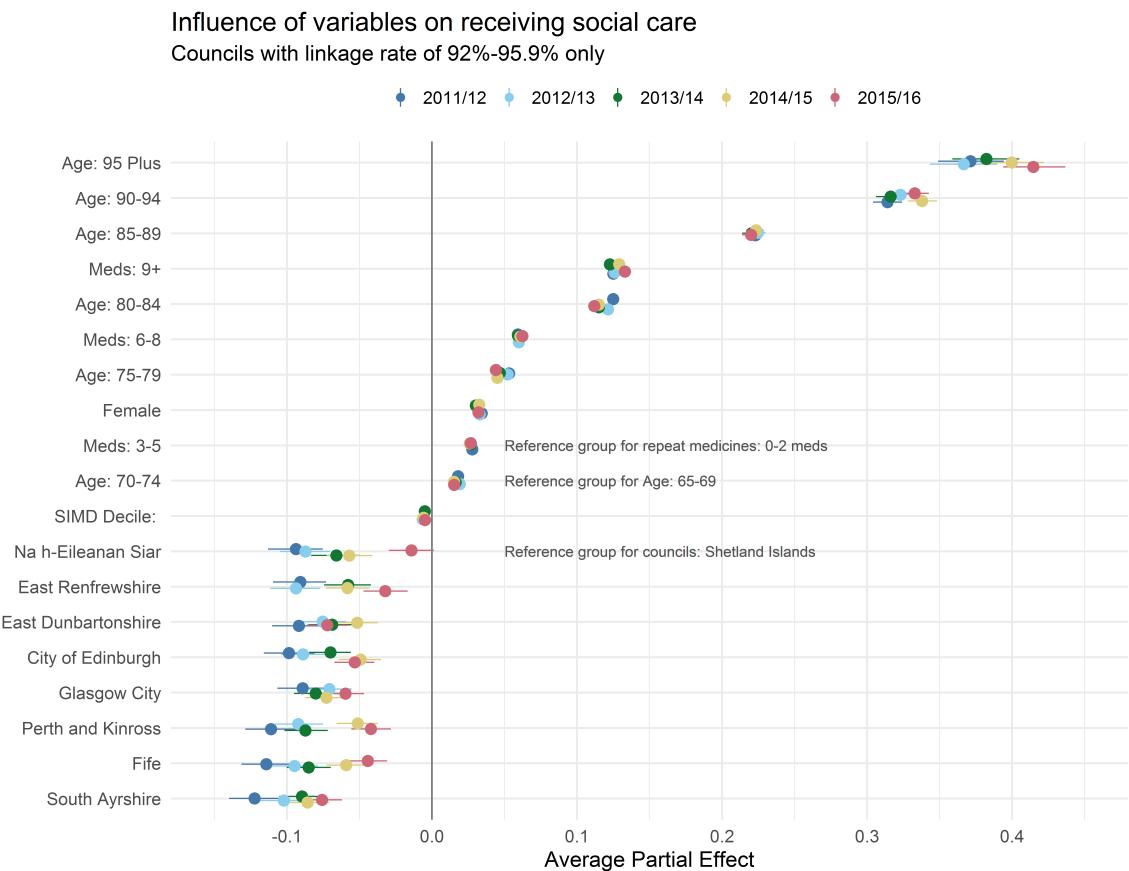


Figure 6.5: Subset 2. Average partial effect plot

may be expected.

The table and figures reveal that from 2011/12 to 2014/15 Glasgow City council has a higher percentage of individuals receiving social care than Na h-Eileanan Siar, East Renfrewshire, Fife, Perth & Kinross, and City of Edinburgh councils. However, the APEs in figure 6.6 show that after adjusting for all other variables in the model, there is a decreased probability of receiving social care in the Glasgow City area compared to these other councils. This pattern is repeated in 2015/16 with the exception that higher percentages of individuals receive care in Na h-Eileanan Siar and East Renfrewshire in this year. Table 6.7 shows the results of diagnostic tests for the models applied to each financial year of data. McFadden's pseudo R^2 statistic ranges from 0.196 for the model applied to 2011/12 to 0.209 for the model applied to 2015/16. The models applied to the most recent two years of data have an excellent fit, whereas the previous three models are only marginally below the threshold of 0.2 generally regarded as representing an excellent fit.

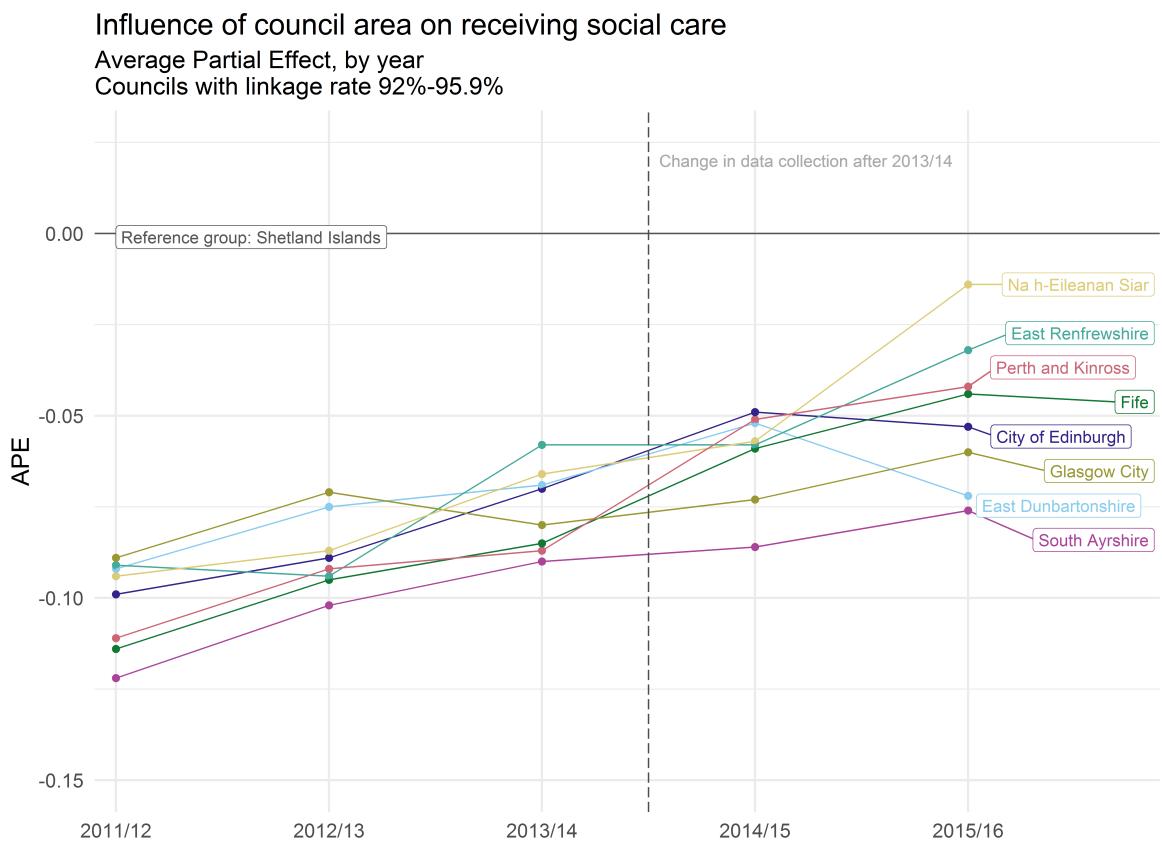


Figure 6.6: Subset 2. Local authority APE across models

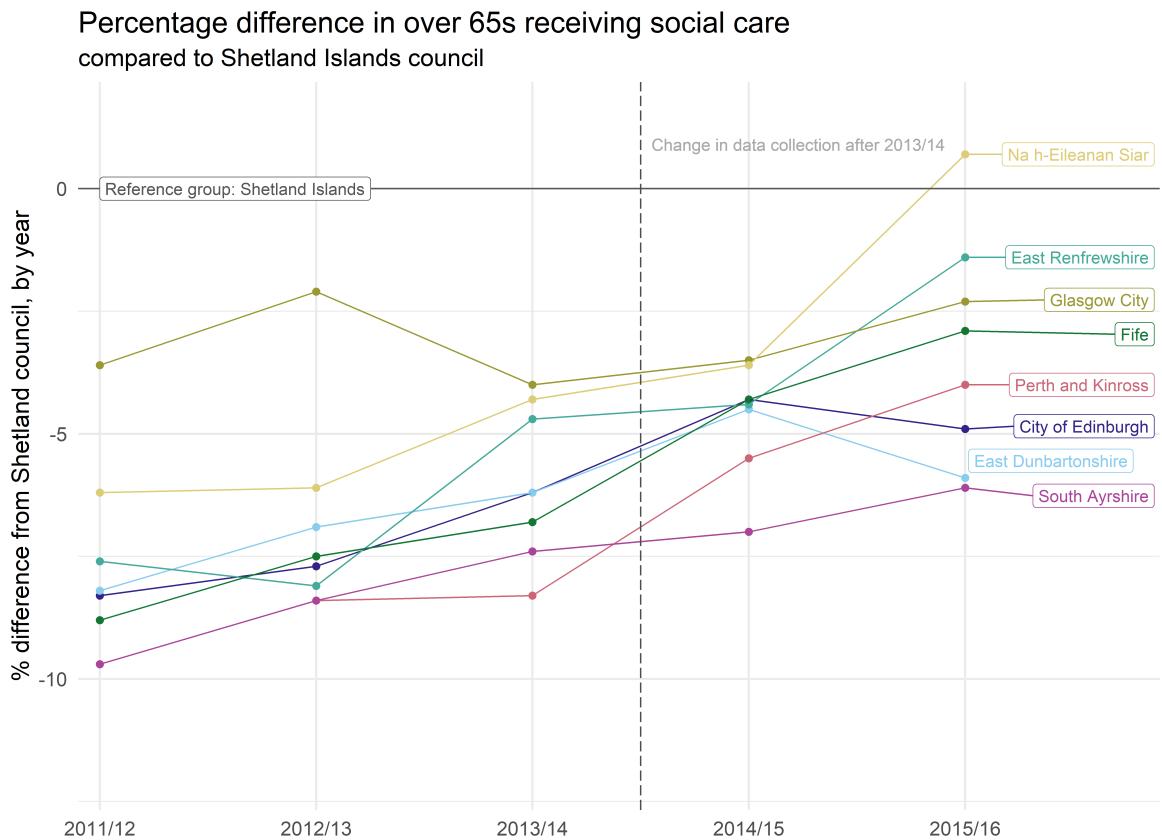


Figure 6.7: Subset 1. % difference in over 65s receiving social care

Financial Year	McFadden's pseudo R^2	Fitted model			Null model			AIC	BIC
		Deviance	Log Likelihood	Degrees of freedom	Deviance	Log Likelihood	Degrees of freedom		
2011/12	0.196	159534.227	-79767.114	293867	198430.468	-99215.234	293921	159644.227	160226.736
2012/13	0.198	162331.401	-81165.7	299514	202476.6	-101238.3	299568	162441.401	163024.956
2013/14	0.199	159148.11	-79574.055	305011	198718.545	-99359.2725	305065	159258.11	159842.666
2014/15	0.204	164081.461	-82040.731	308392	206217.188	-103108.594	308446	164191.461	164776.623
2015/16	0.209	163509.29	-81754.645	310949	206829.494	-103414.747	311003	163619.29	164204.906

Table 6.7: Subset 2. Goodness-of-fit

6.3 Unplanned hospital admission

In this section the dependent variable for modelling is any unplanned hospital admission in the six months following the end of each financial year. This time period was chosen to allow inclusion of social care (measured by presence in the SCS collected at the end of each financial year) as an independent variable in the model.

As in previous sections in this chapter, logistic regression models are applied to each financial year of data, five models in total, and 2015/16 is used as a reference year where results are consistent across models. Exploratory models revealed Local Authority and Health Board area of residence had little impact on outcomes so they were omitted from the final models. This meant data was not subset as in previous sections and models were fitted to the whole cohort in each year.

The R code for the model fitted to the data was as follows.

```
glm(adm_six ~ #Flag for unplanned hospital admission
     sex*age_grp + #Interaction : Sex and Age group
     simd*meds_grp + #Interaction : SIMD and repeat medicines
     age_grp*meds_grp + #Interaction : Age group and repeat medicines
     scs_flag*age_grp + #Interaction : Social care receipt and Age group
     usc_flag + #Any USC use in previous financial year
     care_home, #Flag indicating residence in a care home
     family = binomial(), #logistic regression
     data = thesis_usc) #identify which data to use
```

6.3.1 Descriptive statistics

In 2015/16, 886,331 individuals were included in the model representing 95.9% of the cohort in that year (table 6.8) with only those that died during the financial year being omitted from models. As such the sociodemographic make up is representative of the overall cohort. Chi-squared testing reveals no statistically significant difference between the numbers of females and males with an unplanned admission. There are however, statistically significant differences in all other groups with older, more deprived, and

Variable	Value	No unplanned admission	At least one unplanned admission	Total	p-value
Sex	Male	362216 (90.9)	36145 (9.1)	398361	0.221
	Female	444060 (91.0)	43910 (9.0)	487970	
Age group	65-69	264091 (94.8)	14522 (5.2)	278613	<0.001
	70-74	196494 (93.2)	14418 (6.8)	210912	
	75-79	152457 (90.4)	16208 (9.6)	168665	
	80-84	106369 (86.9)	15983 (13.1)	122352	
	85-89	58183 (83.1)	11831 (16.9)	70014	
	90-94	22701 (80.2)	5610 (19.8)	28311	
	95 plus	5981 (80.1)	1483 (19.9)	7464	
SIMD decile	1 - most deprived	63364 (86.9)	9527 (13.1)	72891	<0.001
	2	71876 (88.6)	9247 (11.4)	81123	
	3	80768 (89.4)	9602 (10.6)	90370	
	4	83216 (90.3)	8947 (9.7)	92163	
	5	85840 (91.0)	8456 (9.0)	94296	
	6	87908 (91.6)	8027 (8.4)	95935	
	7	84892 (92.2)	7215 (7.8)	92107	
	8	82592 (92.6)	6602 (7.4)	89194	
	9	83433 (92.8)	6519 (7.2)	89952	
	10 - most affluent	82387 (93.3)	5913 (6.7)	88300	
Repeat medicines group	0-2	233426 (96.4)	8617 (3.6)	242043	<0.001
	3-5	236155 (93.7)	15852 (6.3)	252007	
	6-8	181810 (89.8)	20653 (10.2)	202463	
	9+	154885 (81.6)	34933 (18.4)	189818	
Any form of social care	No Social Care	729724 (92.8)	56233 (7.2)	785957	<0.001
	Social Care	76552 (76.3)	23822 (23.7)	100374	
Any USC episode in previous year	No USC	601891 (94.5)	34814 (5.5)	636705	<0.001
	USC	204385 (81.9)	45241 (18.1)	249626	
Residence	Not Care Home	777019 (91.2)	75348 (8.8)	852367	<0.001
	Care Home	23535 (83.7)	4592 (16.3)	28127	

Total N used in model = 886,331

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 6.8: Characteristics of those with/without any unplanned hospital admission in the six months following end of 2015/16

individuals with higher multimorbidity being more likely to have an admission. Those in receipt of social care, with an episode of USC in the previous year, and those resident in a care home were also more likely to have an unplanned hospital admission.

6.3.2 Model results

Figure 8.3 and table 8.4 in Appendix D show odds ratios for individual variables in model fitted to data for 2015/16.

The APEs for models with unplanned admission to hospital as dependent variable are much lower in magnitude for all variables (figure 6.8 and table 6.9) compared with models fitted in sections 6.1.3 and 6.2.3 where social care was the dependent variable.

High multimorbidity, measured by prescription of 9 or more repeat medicines, has the largest magnitude of APE in the unplanned hospital admission model in all years (an 8.3% increased probability of having an unplanned admission compared to those with 0-2 repeat medicines in 2015/16, table 6.9). Other multimorbidity groups also show increases in probability of admission compared to the reference value with a linear

Influence of variables on admission to hospital

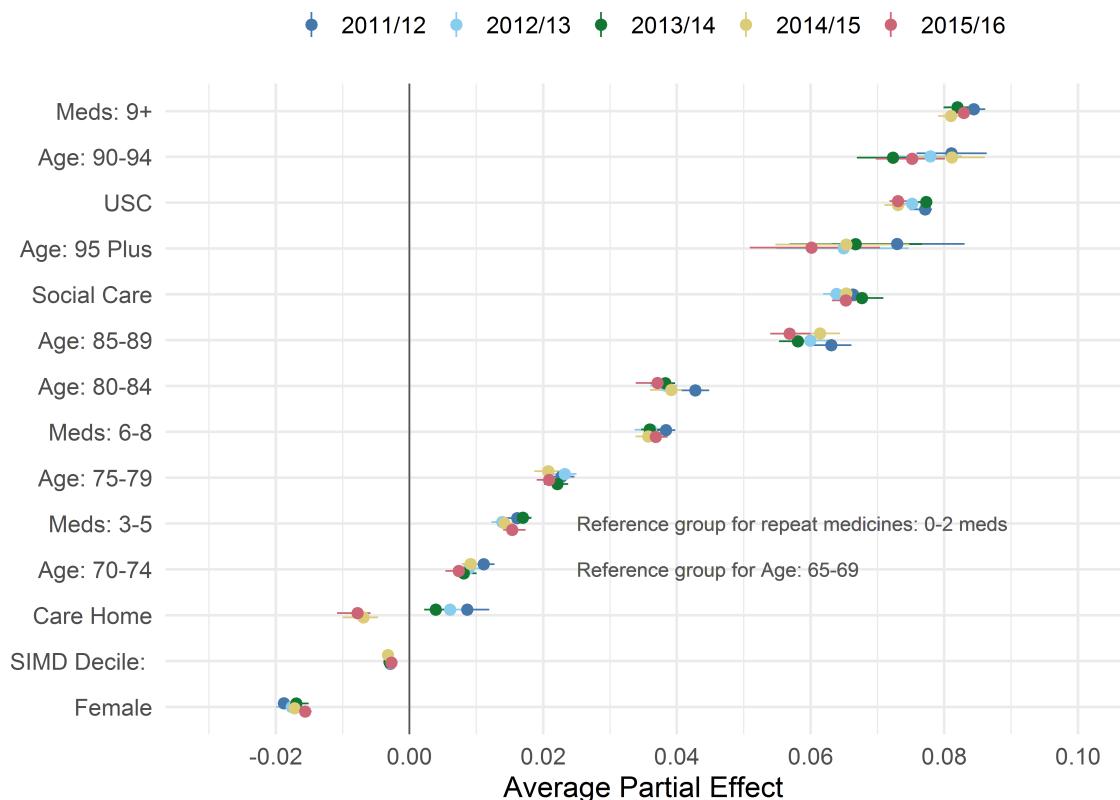


Figure 6.8: Unplanned hospital admissions. Average Partial Effects

increase from low-to-high multimorbidity.

In terms of other service use, having any USC episode in the previous financial year is associated with a ~7.5% increase in probability compared to those with no previous USC use. Similarly, receipt of social care measured in the SCS is associated with a ~6.5% increase in the probability of having an unplanned hospital admission compared to those with no social care. There is a split in the direction of the effect of living in a care home after 2013/14. After this year being in a care home is associated with a decrease in the probability of unplanned admission of almost 1% whilst in previous years the probability had increased by almost 1%.

Higher age groups are also associated with higher APEs compared to other variables in the models though there are wider confidence intervals than seen with social care models. Furthermore, the magnitude of the effect of increasing age is much lower than the effect on receipt of social care. For example, in 2015/16 being 90-94 is associated with a 7.5% increase probability of having an unplanned hospital admission compared to being 65-69. The corresponding value for receiving social care in that age group is a 41.7% increased probability (subset 1, section 6.1.3). Otherwise, linear increases in APEs are seen through age groups.

Despite no statistically significant difference in the number of males and females with

Variable	Average Partial Effect	Standard Error	p-value	Lower 95% CI	Upper 95% CI
Meds: 9+	0.083	0.001	<0.001	0.081	0.085
Age: 90-94	0.075	0.003	<0.001	0.07	0.08
USC	0.073	0.001	<0.001	0.072	0.075
Social Care	0.065	0.001	<0.001	0.063	0.067
Age: 95 Plus	0.06	0.005	<0.001	0.051	0.07
Age: 85-89	0.057	0.001	<0.001	0.054	0.06
Age: 80-84	0.037	0.001	<0.001	0.034	0.039
Meds: 6-8	0.037	0.001	<0.001	0.035	0.039
Age: 75-79	0.021	0.001	<0.001	0.019	0.023
Meds: 3-5	0.015	0.001	<0.001	0.014	0.017
Age: 70-74	0.007	0.001	<0.001	0.005	0.009
SIMD Decile:	-0.003	0	<0.001	-0.003	-0.003
Care Home	-0.008	0.001	<0.001	-0.011	-0.006
Female	-0.016	0.001	<0.001	-0.017	-0.015

Reference group for age: 65-69

Reference group for meds: 0-2 repeat medicines

Table 6.9: Unplanned hospital admission. Average Partial Effects. 2015/16

an unplanned admission in descriptive table 6.8, modelling reveals that females are almost 2% less likely to have an admission after adjusting for other variables (1.6% in 2015/16).

SIMD decile, again fitted as a continuous variable, has a very small effect on hospital admission after accounting for other variables. The coefficient of the slope at the average value of SIMD (5.6, SD 2.8) is -0.003 (table 6.9) indicating a very flat line which can be viewed in figure 8.4 in Appendix D

Financial Year	McFadden's pseudo R ²	Fitted model			Null model			AIC	BIC
		Deviance	Log Likelihood	Degrees of freedom	Deviance	Log Likelihood	Degrees of freedom		
2011/12	0.113	447862.4	-223931.2	821187.0	504865.0	-252432.5	821234.0	447958.4	448516.1
2012/13	0.112	454527.8	-227263.9	841129.0	512028.3	-256014.2	841176.0	454623.8	455182.7
2013/14	0.114	466492.6	-233246.3	858910.0	526463.8	-263231.9	858957.0	466588.6	467148.4
2014/15	0.111	471115.4	-235557.7	870332.0	530199.5	-265099.8	870379.0	471211.4	471771.8
2015/16	0.113	475554.4	-237777.2	880446.0	535977.2	-267988.6	880493.0	475650.4	476211.4

Table 6.10: Unplanned hospital admission. Goodness-of-fit

Table 6.10 shows the results of diagnostic tests for each model. The value of McFadden's R² is fairly stable over time varying from 0.111 to 0.114. These values are well below those seen for social care models and represent a poorer fit to the data in comparison.

Chapter 7

Discussion

7.1 Key Findings

7.1.1 Multimorbidity and social care

- Multimorbidity influences receipt of social care.
- ..though age is the biggest factor - likely due to frailty??
- APEs show effects *after* adjusting for other variables (and interactions) important to discuss what they mean and how i can compare across models.
- Lower rates of receipt in subset 2, but APEs similar across subsets. Edin and Glas in subset 2
- Female effect 4% diff in probability - more likely to live alone?
- Magnitude of effects important. 9+ meds == 80-84 ages. i.e. high multimorbidity same effect as aging 15-20 years
- Fluctuating APEs for councils to do with baseline level of reference council also fluctuating. Again - *very small changes in APE*

7.1.2 Renfrewshire

- Brief overview of discussion from chapter
- Also discuss implicit finding that finite number of places for social care in Renfrew. Allocation according to *resource* not *need*.

7.1.3 Unplanned hospital admission

- Overall smaller magnitude of effects
- High MM largest magnitude effect. Linear effect through groups

- Age not as big a driver as SC
- SC + USC drive admission. Likely means people with high needs use large amounts of *all* services.
- Link to "intensification" of SC in lit review. Numbers now so small, can't assess if protective effect for those with less need.

7.1.4 Descriptives

- Medicines decent measure of MM. Clear effects on SC and admissions
- SIMD effect of MM reduces with age

7.1.5 Social Care data

- Discuss quality and collection of SCS (place this nationally/internationally). Is there good sc data anywhere???
- What is good/bad - What have I learned?
- Consider quantifying home care *plus* alarm/telecare users

7.1.6 Linked Administrative Data Research

- Discuss process of obtaining and analysing linked data. Potentially useful for sg and others
- Timeframe!! Probabaly not a good idea to try this for a PhD given timelines
- Safe Haven. SDC and software upgrades
- Supervisors need to get used to appraising work *in* safe haven. 600 + outputs SDC. Also means format of how to appraise needs agreed. html??
- Good things???
- Point to move to re-use data rather than obtain-and-destroy approach

7.2 Comparisons to previous research

- ICL - nothing in SC so far?? Namecheck PC stuff
- Bardsley and SR of H & SC studies
- Kent economic paper
- MM stuff

7.3 Strengths and Limitations

7.3.1 Strengths

- Large, population sized linkage
- Marginal effects

7.3.2 Limitations

- Not really assessed Access to social care (mention time constraint?)
- Census week for home care. Compare 2013/14 and later years in table 5.1
- Linkage of SCS not consistent - difficult to make broad comparisons. Attempted to offset by subsetting. Home care stable though falling in SCS - why?
- No measure for living alone
- MM measure not validated - limited due to lack of access to PC data, Also means cannot address important MM questions as laid by AMS e.g. "Which clusters result in the greatest healthcare utilisation and greatest cost?"

7.4 Implications

7.4.1 LA Variation

- MM effect on SC raises important message for policymakers.
- Strong argument for universal PC is that it improves access and therefore chance to prevent ill health etc [@RN599, 7]. (although ICL still present)
- Social care is not universal therefore has poorer access therefore any hope of preventative care is unlikely
- *If* care was broadend - would need an accurate measure of *need* How should this be defined? How should care be allocted due to it?

7.5 Recommended future actions and research

7.5.1 Future research

- Measure *Longitudinal* changes in social care and impact on admission/usc
- Break down SC data - home care/telecare influence on outcomes
- Utilise USC data better - include A & E, NHS24 etc etc
- Check post-doc list

- Mortality
- Further investigate medicines as measure of MM - try chapter counts [@RN228] or continuous rather than categorical

7.5.2 A good title

- Broaden timeframe of SCS collection
- Support LAs to provide either CHI or easily provide all ID data for linkage
- Better access to Primary Care data for MM research

Chapter 8

Conclusion

Reccomendations :-

- Standardised score reflecting need/frailty/vulnerability required to accurately assess access to care (OECD pp181)
- disaggregate SCS a little - distinguishing reablement and intermediate care from LTC important!
- Measure outcomes relevant to social care (falls etc OECD 2013 pp59) OR link to outcome data e.g. preventable admission data, hip fracture data??
- Consider other forms of admin data to help with this e.g. Attendance Allowance??
 - Problem being coverage

Appendices

Appendix A. Main linkage PBPP approval

Public Benefit and Privacy Panel for Health and Social Care

nss.PBPP@nhs.net

www.informationgovernance.scot.nhs.uk



Mr David Henderson
University of Glasgow
School of Social and Political Sciences
Urban Big Data Centre
7 Lilybank Gardens
Glasgow
G12 8RZ

Date: 11th May 2017

Your Ref:

Our Ref: 1617-0304

Dear Mr Henderson

Re: Application 1617-0304/Henderson: Using linked data to understand the relationships between Multimorbidity and the use of Health and Social Care

Version: v1

Thank you for your application for consideration by the Public Benefit and Privacy Panel for Health and Social Care. Your application has undergone proportionate governance review and has been approved, subject to the following conditions:

- Please provide evidence that the Data Sharing Agreements, as detailed in the application, have been finalised prior to any transfer of data.

This approval is given to process data as specified in the approved application form, and is limited to this. Approval is valid for the period specified in your application until 27th April 2022. You are required to notify the Panel Manager of any proposed change to any aspect of your proposal, including purpose or method of processing, data or data variables being processed, study cohorts, individuals accessing and processing data, timescales, technology/infrastructure, or any other relevant change.

I would take this opportunity to remind you of the declaration you have made in your application form committing you to undertakings in respect of information governance, confidentiality and data protection. In particular you should be aware that once personal data (irrespective of de-identification or other controls applied) has been extracted from NHSS Board(s) and transferred to you, that you will then become the Data Controller as defined by the Data Protection Act (1998). Requests for access to NHS Scotland data as part of this approved application should be supported by evidencing a copy of your approval letter and application form to the relevant local board contacts/data providers.

Please note that summary information about your application and its approval, including the title and nature of your proposal, will be published on the panel website (www.informationgovernance.scot.nhs.uk).

I hope that your proposal progresses well,

Yours Sincerely

Ashley Gray
Panel Manager
NHS Scotland Public Benefit and Privacy Panel for Health and Social Care
Email: nss.PBPP@nhs.net

Appendix B

Table 1: Medicines not included in total counts

Medicine Name	BNF subsection
GLUCAGON	06.01.04
OILS FOR THE EAR	12.01.03
CHLORHEXIDINE GLUCONATE	12.03.04
ENTERAL NUTRITION	09.04.02
DOCUSATE SODIUM	12.01.03
EMOLLIENTS	13.01.01
SUNSCREEN	13.08.01
POVIDONE IODINE	13.11.04
OXYGEN CYLINDERS	03.06.00
MULTIVITAMINS	09.06.07
LIDOCAINE HYDROCHLORIDE WITH CHLORHEXIDINE GLUCONATE	15.02.01
WATER FOR INJECTIONS	09.02.02
HEPARINOID	13.14.00
DICLOFENAC	13.08.01
PROFLAVINE HEMISULFATE	13.10.05
RALOXIFENE HYDROCHLORIDE	06.04.01
COMPOUND TOPICAL PREPARATIONS WITH LIDOCAINE	15.02.01
FOODS FOR SPECIAL DIETS	09.04.01
COMPOUND PREPARATIONS WITH SALICYLIC ACID	13.07.00
KETOROLAC TROMETAMOL	11.08.02
BENZOCAINE	12.03.03
FOODS FOR SPECIAL DIETS	09.04.02
MAGNESIUM SULFATE	13.10.05
HYDROGEN PEROXIDE	13.11.06
FLUOROURACIL	13.08.01
UREA HYDROGEN PEROXIDE	12.01.03

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Medicine Name	BNF subsection
METHYLPREDNISOLONE	10.01.02
GLUCOSE	09.02.02
CHLORHEXIDINE GLUCONATE	13.11.02
LIDOCAINE	15.02.01
AMYLMETACRESOL AND DICHLOROBENZYL ALCOHOL	12.03.03
CETYLPYRIDINIUM CHLORIDE	12.03.03
SALICYLIC ACID	13.07.00
HEXETIDINE	12.03.04
GLUTEN FREE BISCUITS	09.04.01
GLUTEN FREE MIXES	09.04.01
GLUTEN FREE BREAD	09.04.01
GLUCOSE	06.01.04
CETRIMIDE AND CHLORHEXIDINE GLUCONATE	13.10.05
ORCIPRENALINE SULFATE	03.01.01
BOWEL CLEANSING SOLUTIONS	01.06.05
IMIQUIMOD	13.07.00
ENTERAL NUTRITION	09.04.01
OXYGEN CYLINDERS WITH SET	03.06.00
COMPOUND HERBAL PREPARATIONS	09.12.00
ZINC OXIDE	13.13.01
ALUMINIUM DIHYDROXYALLANTOINATE	13.12.00
CETYLPYRIDINIUM CHLORIDE WITH CHLOROCRESOL AND	12.03.04
LIDOCAINE HYDROCHLORIDE	
GLUTEN FREE/LOW PROTEIN BISCUITS	09.04.01
LOW PROTEIN BISCUITS	09.04.01
GLUTEN FREE PASTA	09.04.01
GLUTEN FREE/WHEAT FREE BISCUITS	09.04.01
GLUTEN FREE/WHEAT FREE BREAD	09.04.01
HYOSCINE HYDROBROMIDE	15.01.03
MIDAZOLAM	15.01.04
POTASSIUM PERMANGANATE	13.11.06
POVIDONE IODINE	13.10.05
GLUTEN FREE/WHEAT FREE MIXES	09.04.01
FOODS FOR SPECIAL DIETS	09.11.04
ALUMINIUM CHLORIDE HEXAHYDRATE	13.12.00

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Medicine Name	BNF subsection
GLUTEN FREE/WHEAT FREE PASTA	09.04.01
SODIUM CHLORIDE	09.02.02
HELICOBACTER PYLORI TEST	01.03.00
GLUCOSAMINE SULFATE	09.12.00
LIDOCAINE HYDROCHLORIDE	15.02.01
TRIAMCINOLONE ACETONIDE	10.01.02
GLUTEN FREE GRAINS/FLOURS	09.04.01
HYDROGEN PEROXIDE	13.10.05
APRACLONIDINE	11.08.02
PODOPHYLLUM	13.07.00
AMINO ACID SUPPLEMENTS	09.04.01
LIDOCAINE HYDROCHLORIDE	12.03.03
IODINE	13.11.04
CAMOUFLAGERS	13.08.02
COVERING AGENTS	13.08.02
CETOMACROGOL	13.01.01
GLUTARALDEHYDE	13.07.00
MENTHOL WITH EUCALYPTUS	03.08.00
CALCIUM FOLINATE	08.01.00
SILVER NITRATE	13.07.00
DEQUALINIUM CHLORIDE	12.03.03
GLUTEN FREE/WHEAT FREE GRAINS/FLOURS	09.04.01
CATHETER PATENCY SOLUTIONS	07.04.04
NEPAFENAC	11.08.02
HEXYLRESORCINOL	12.03.03
CETRIMIDE	13.10.05
PREDNISOLONE	10.01.02
CETRIMIDE AND CHLORHEXIDINE	13.11.02
GLUCONATE	
SODIUM PICOSULFATE AND	01.06.05
MAGNESIUM CITRATE	
SODIUM BICARBONATE	09.02.02
LOW PROTEIN MIXES	09.04.01
BENZALKONIUM CHLORIDE	12.03.03
BENZOIN	03.08.00
CEFPODOXIME	05.01.02
ALCOHOL	13.11.01

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Medicine Name	BNF subsection
CHLORHEXIDINE IN ISOPROPYL ALCOHOL	13.11.02
TETRACAIN	11.07.00
SYRUP	09.11.01
COMBINED FOOD PREPARATION	09.11.04
CHLORHEXIDINE IN METHYLATED SPIRIT	13.11.02
HYDROCORTISONE ACETATE	10.01.02
GLUCOSE	09.04.01
DIBROMOPROPAMIDINE ISETIONATE	13.10.05
ISOPROPYL ALCOHOL	13.11.01
INOSINE ACEDOBEN DIMEPRANOL	05.03.02
EPINEPHRINE	02.07.03
CHLORHEXIDINE GLUCONATE	13.10.05
THYMOL	12.03.04
DICLOFENAC	11.08.02
FLUORESCEIN SODIUM	11.08.02
LOW PROTEIN BREAD	09.04.01
TETRACAIN	15.02.01
ALFENTANIL	15.01.04
FOODS FOR SPECIAL DIETS	09.09.00
FOODS	09.04.02
CHLOROBUTANOL AND CHLORHEXIDINE GLUCONATE	12.03.04
FORMALDEHYDE	13.07.00
GLYCOPYRRONIUM BROMIDE	15.01.03
CHLORHEXIDINE DIGLUCONATE AND TETRACAIN HYDROCHLORIDE	12.03.03
OXYBUPROCAINE HYDROCHLORIDE	11.07.00
SOLVENT ETHER	13.11.01
PHLEUM PRATENSE	03.04.02
BENZOCAINE	13.02.03
TALC PURIFIED	13.02.03
PHOSPHATES (RECTAL)	01.06.05
DIAZOXIDE	06.01.04
BUPIVACAINE HYDROCHLORIDE	15.02.01
LIDOCAINE HYDROCHLORIDE WITH CHLORHEXIDINE GLUCONATE	12.03.03
TENECTEPLASE	02.10.02

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Medicine Name	BNF subsection
LOW PROTEIN PASTA	09.04.01
LIDOCAINE WITH EPINEPHRINE	15.02.01
AMYLMETACRESOL AND DICHLOROBENZYL	12.03.03
ALCOHOL WITH ASCORBIC ACID	
GENTIAN	09.07.00
PHENOL	13.11.05
ETYNODIOL DIACETATE	07.03.02
GLUTEN FREE/LOW PROTEIN PASTA	09.04.01
SODIUM BENZOATE	12.03.04
MISCELLANEOUS HERBALS	09.12.00
WITCH HAZEL	13.11.06
LOW PROTEIN CEREALS	09.04.01
GLUTEN FREE COOKING AIDS	09.04.01
SODIUM HYPOCHLORITE	13.11.04
CHLORHEXIDINE IN ISOPROPYL ALCOHOL	13.11.01
LACTASE	09.11.02
KETOROLAC TROMETAMOL	15.01.04
KETAMINE	15.01.01
MAGNESIUM CITRATE	01.06.05
CHLOROXYLENOL	13.11.05
LIDOCAINE WITH AMINOACRIDINE	12.03.03
ATROPINE SULFATE	15.01.03
PROXYMETACAIN HYDROCHLORIDE	11.07.00
ENTERAL NUTRITION	09.09.00
FLUOROURACIL WITH SALICYLIC ACID	13.08.01
LIDOCAINE AND TETRACAINE	15.02.01
PARAFFIN HARD	13.01.01
FENTANYL	15.01.04
FOODS FOR SPECIAL DIETS	09.11.01
MESNA	08.01.00
MOXIFLOXACIN	11.08.02
DECOGESTANT DROPS	03.08.00
BROMFENAC	11.08.02
HYDROGEN PEROXIDE	12.03.04
SODIUM CHLORIDE	07.04.04
LOW PROTEIN FOODS	09.04.01
LOW PROTEIN GRAINS/FLOURS	09.04.01
PHENOL WITH CHLORHEXIDINE GLUCONATE	13.10.05

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Medicine Name	BNF subsection
INGENOL MEBUTATE	13.08.01
GLUTEN FREE CEREALS	09.04.01
INTRAVENOUS NUTRITION SUPPLEMENTS	09.03.00
VITAMINS C AND D3 WITH FOLIC ACID	09.06.07
DINOPROSTONE	07.01.01
CRANBERRY	09.12.00
ALUMINIUM CHLORIDE	13.12.00
POTASSIUM CHLORIDE	09.02.02
BRIMONIDINE TARTRATE	13.06.03
BENZOYL PEROXIDE WITH	13.11.02
POTASSIUM HYDROXYQUINOLINE	
ULIPRISTAL	06.04.01
ALKYL SULFATE	13.11.03
PRILOCAINE HYDROCHLORIDE	15.02.01
RACECADOTRIL	01.04.03
DAPOXETINE	07.04.06
CARBOMER	11.08.03
POVIDONE IODINE	11.08.02
ERGOMETRINE MALEATE	07.01.01
LOW PROTEIN COOKING AIDS	09.04.01
PIRFENIDONE	03.11.01
LIDOCAINE HYDROCHLORIDE WITH FLUORESCEIN SODIUM	11.07.00
FLEXIBLE COLLODION	13.10.05
BECAPLERMIN	13.11.07
MIVACURIUM CHLORIDE	15.01.05
NORETHISTERONE ENANTHATE	07.03.02
SOAP	13.11.03
LANOLIN	13.01.01
FOODS	09.04.01
CIPROFLOXACIN WITH DEXAMETHASONE	12.01.02
INSULIN DEGLUDEC AND LIRAGLUTIDE	06.01.02
LIDOCAINE HYDROCHLORIDE WITH CETYLPYRIDIUM CHLORIDE	15.02.01
MULTIVITAMINS	09.10.00

Appendix C. Renfrewshire pilot. Ethical approval

Administrative & Academic Review Feedback

Ethics Committee for Non-Clinical Research Involving Human Subjects

Staff Research Ethics Application

Postgraduate Student Research Ethics Application

Application Details

Application Number: 400150182

Applicant's Name: David Henderson

Project Title: Renfrewshire Council Social Care Analysis

Application Status: Lead Review Complete - No Changes Required

Date of Administrative/Academic Review: 24/05/2016

NB: Only if the applicant has been given approval can they proceed with their data collection with effect from the date of approval.

Recommendations (where changes are required)

Where changes are required all applicants must respond in the relevant boxes to the recommendations of the Committee (on the following page) and upload this as the Resubmission Document through the system to explain the changes you have made to the application.

All resubmitted application documents should then be uploaded.

If your application is rejected a new application must be submitted via the online system. Where recommendations are provided, they should be responded to and this document uploaded as part of the new application. A new reference number will be generated.

Appendix D. Supplementary tables and plots

Table 8.2: Social care models. Subset 1. Model results 2015/16

Term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
(Intercept)	-4.251	0.103	-41.165	<0.001	0.014	0.012	0.017
Female	0.152	0.045	3.355	0.001	1.164	1.065	1.272
Age: 70-74	0.674	0.111	6.07	<0.001	1.962	1.578	2.439
Age: 75-79	1.544	0.104	14.86	<0.001	4.684	3.821	5.742
Age: 80-84	2.539	0.099	25.528	<0.001	12.666	10.422	15.391
Age: 85-89	3.56	0.102	35.006	<0.001	35.174	28.817	42.934
Age: 90-94	4.464	0.118	37.937	<0.001	86.818	68.937	109.337
Age: 95 Plus	4.836	0.18	26.931	<0.001	125.909	88.556	179.019
SIMD Decile:	-0.135	0.012	-11.03	<0.001	0.874	0.853	0.895
Meds: 3-5	0.898	0.11	8.173	<0.001	2.455	1.979	3.044
Meds: 6-8	1.515	0.106	14.265	<0.001	4.549	3.695	5.602
Meds: 9+	2.599	0.099	26.205	<0.001	13.452	11.075	16.338
councilAngus	-0.01	0.078	-0.13	0.897	0.99	0.849	1.154
councilEasy Ayrshire	-0.187	0.06	-3.122	0.002	0.83	0.738	0.933
councilInverclyde	-0.176	0.061	-2.895	0.004	0.838	0.744	0.945
councilSouth Lanarkshire	-0.425	0.053	-8.046	<0.001	0.654	0.589	0.725
councilStirling	-0.221	0.08	-2.75	0.006	0.802	0.685	0.939
councilNorth Ayrshire	-0.415	0.058	-7.202	<0.001	0.661	0.59	0.739
councilDumfries and Galloway	-0.811	0.072	-11.201	<0.001	0.444	0.386	0.512
councilArgyll and Bute	-0.538	0.09	-5.953	<0.001	0.584	0.489	0.697
Female:age_grp70-74	0.243	0.06	4.058	<0.001	1.275	1.134	1.433

Table 8.2 continued from previous page

Term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
Female:age_grp75-79	0.386	0.056	6.912	<0.001	1.472	1.319	1.642
Female:age_grp80-84	0.467	0.054	8.622	<0.001	1.595	1.435	1.774
Female:age_grp85-89	0.453	0.057	7.975	<0.001	1.572	1.407	1.757
Female:age_grp90-94	0.164	0.07	2.356	0.018	1.179	1.028	1.351
Female:age_grp95 Plus	-0.027	0.122	-0.224	0.823	0.973	0.766	1.236
SIMD Decile: :meds_grp3-5	0.045	0.012	3.86	<0.001	1.046	1.022	1.069
SIMD Decile: :meds_grp6-8	0.058	0.011	5.25	<0.001	1.06	1.037	1.083
SIMD Decile: :meds_grp9+	0.065	0.011	6.092	<0.001	1.067	1.045	1.09
Age: 70-74:meds_grp3-5	-0.277	0.126	-2.205	0.027	0.758	0.592	0.97
Age: 75-79:meds_grp3-5	-0.509	0.117	-4.34	<0.001	0.601	0.477	0.756
Age: 80-84:meds_grp3-5	-0.643	0.112	-5.74	<0.001	0.526	0.422	0.655
Age: 85-89:meds_grp3-5	-0.743	0.114	-6.521	<0.001	0.476	0.38	0.595
Age: 90-94:meds_grp3-5	-0.77	0.13	-5.928	<0.001	0.463	0.359	0.597
Age: 95 Plus:meds_grp3-5	-0.82	0.187	-4.373	<0.001	0.44	0.305	0.636
Age: 70-74:meds_grp6-8	-0.222	0.121	-1.831	0.067	0.801	0.631	1.016
Age: 75-79:meds_grp6-8	-0.596	0.113	-5.258	<0.001	0.551	0.441	0.688
Age: 80-84:meds_grp6-8	-0.856	0.108	-7.891	<0.001	0.425	0.344	0.526
Age: 85-89:meds_grp6-8	-1.065	0.111	-9.633	<0.001	0.345	0.278	0.428
Age: 90-94:meds_grp6-8	-1.189	0.126	-9.413	<0.001	0.305	0.238	0.39
Age: 95 Plus:meds_grp6-8	-1.278	0.183	-6.99	<0.001	0.279	0.195	0.399
Age: 70-74:meds_grp9+	-0.479	0.114	-4.216	<0.001	0.619	0.496	0.774
Age: 75-79:meds_grp9+	-0.886	0.106	-8.344	<0.001	0.412	0.335	0.508

Table 8.2 continued from previous page

Term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
Age: 80-84:meds_grp9+	-1.245	0.102	-12.234	<0.001	0.288	0.236	0.352
Age: 85-89:meds_grp9+	-1.764	0.104	-16.887	<0.001	0.171	0.14	0.21
Age: 90-94:meds_grp9+	-2.15	0.121	-17.721	<0.001	0.116	0.092	0.148
Age: 95 Plus:meds_grp9+	-2.259	0.179	-12.625	<0.001	0.104	0.074	0.148
simd:councilAngus	-0.034	0.013	-2.629	0.009	0.966	0.942	0.991
simd:councilEast Ayrshire	0.017	0.012	1.429	0.153	1.017	0.994	1.041
simd:councilInverclyde	0.01	0.012	0.814	0.415	1.01	0.987	1.033
simd:councilSouth Lanarkshire	0.011	0.01	1.065	0.287	1.011	0.991	1.03
simd:councilStirling	0.023	0.013	1.812	0.07	1.023	0.998	1.049
simd:councilNorth Ayrshire	0.019	0.011	1.686	0.092	1.019	0.997	1.042
simd:councilDumfries and Galloway	0.044	0.013	3.408	0.001	1.045	1.019	1.072
simd:councilArgyll and Bute	0.013	0.016	0.818	0.414	1.013	0.982	1.045

Conditional effect of SIMD Decile on receipt of social care
Councils with linkage rate of 96%-99.9% only
2015/16

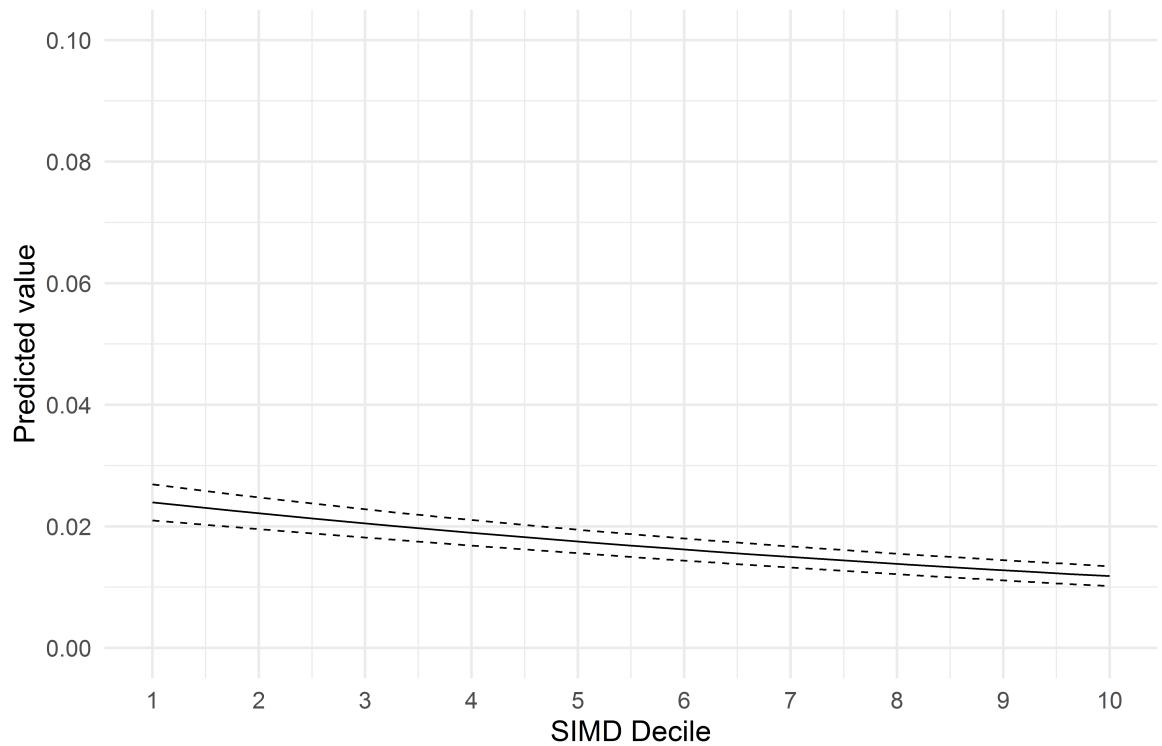


Figure 8.1: Subset 1. Conditional effect of simd on receipt of social care

Figure 8.2: Subset 2. Odds ratios. 2015/16

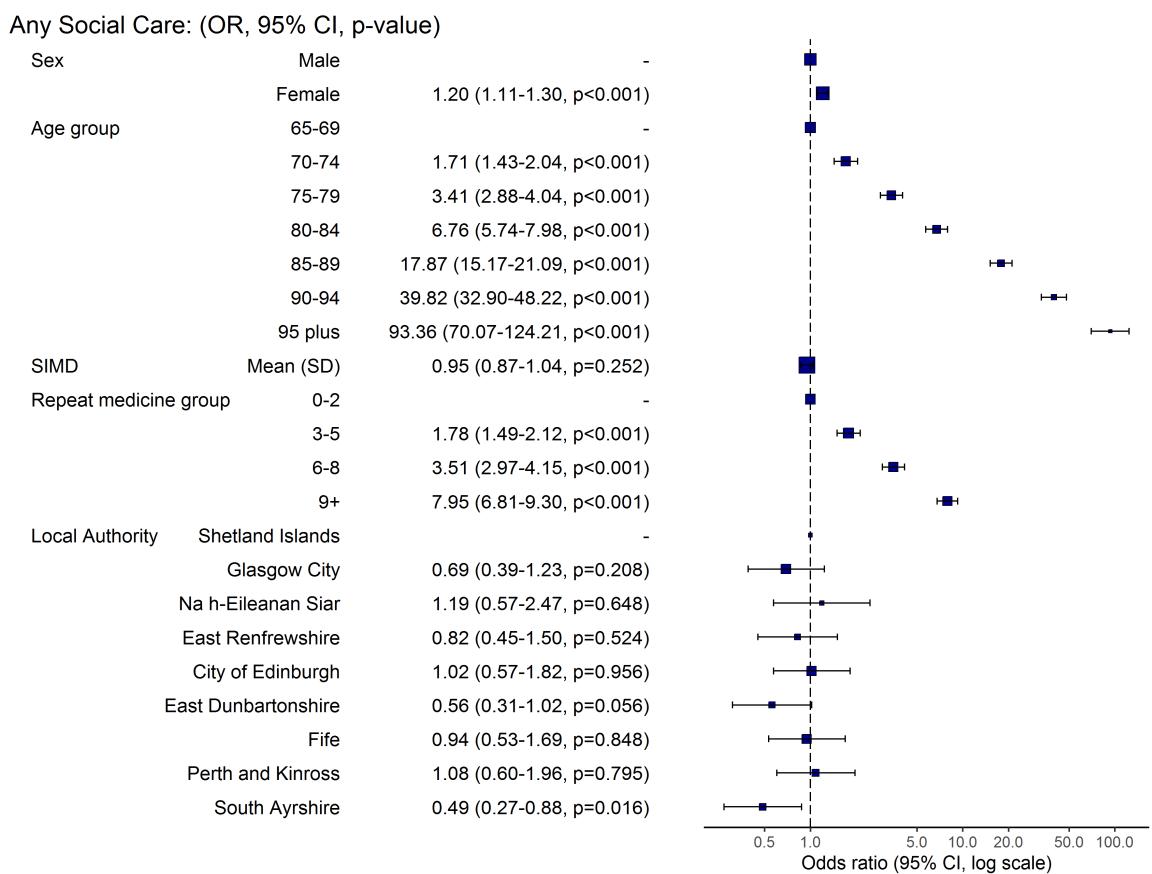


Table 8.3: Social care models. Subset 2. Model results 2015/16

term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
(Intercept)	-4.072	0.303	-13.448	<0.001	0.017	0.009	0.031
Female	0.185	0.041	4.539	<0.001	1.203	1.111	1.303
Age: 70-74	0.535	0.091	5.908	<0.001	1.708	1.43	2.04
Age: 75-79	1.226	0.086	14.24	<0.001	3.407	2.878	4.033
Age: 80-84	1.911	0.084	22.747	<0.001	6.76	5.734	7.971
Age: 85-89	2.883	0.084	34.285	<0.001	17.872	15.156	21.074
Age: 90-94	3.684	0.097	37.808	<0.001	39.824	32.9	48.206
Age: 95 Plus	4.536	0.146	31.075	<0.001	93.359	70.129	124.286
SIMD Decile:	-0.052	0.046	-1.145	0.252	0.949	0.868	1.038
Meds: 3-5	0.576	0.089	6.452	<0.001	1.78	1.494	2.12
Meds: 6-8	1.254	0.085	14.719	<0.001	3.506	2.967	4.143
Meds: 9+	2.073	0.079	26.096	<0.001	7.948	6.802	9.286
councilGlasgow City	-0.37	0.294	-1.259	0.208	0.69	0.388	1.229
councilNa h-Eileanan Siar	0.171	0.373	0.457	0.648	1.186	0.571	2.465
councilEast Renfrewshire	-0.195	0.306	-0.637	0.524	0.823	0.451	1.5
councilCity of Edinburgh	0.016	0.295	0.055	0.956	1.016	0.57	1.813
councilEast Dunbartonshire	-0.583	0.305	-1.911	0.056	0.558	0.307	1.015
councilFife	-0.057	0.295	-0.192	0.848	0.945	0.53	1.684
councilPerth and Kinross	0.078	0.302	0.26	0.795	1.082	0.599	1.953
councilSouth Ayrshire	-0.723	0.299	-2.417	0.016	0.485	0.27	0.872
Female:age_grp70-74	0.035	0.055	0.639	0.523	1.035	0.93	1.152

Table 8.3 continued from previous page

term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
Female:age_grp75-79	0.243	0.052	4.709	<0.001	1.275	1.152	1.411
Female:age_grp80-84	0.372	0.049	7.528	<0.001	1.451	1.317	1.598
Female:age_grp85-89	0.434	0.051	8.455	<0.001	1.543	1.395	1.706
Female:age_grp90-94	0.15	0.06	2.496	0.013	1.162	1.033	1.308
Female:age_grp95 Plus	-0.054	0.101	-0.536	0.592	0.948	0.778	1.154
SIMD Decile: :meds_grp3-5	0.043	0.009	4.906	<0.001	1.044	1.026	1.062
SIMD Decile: :meds_grp6-8	0.062	0.008	7.355	<0.001	1.063	1.046	1.081
SIMD Decile: :meds_grp9+	0.079	0.008	9.739	<0.001	1.082	1.065	1.099
Age: 70-74:meds_grp3-5	-0.11	0.106	-1.04	0.298	0.896	0.728	1.102
Age: 75-79:meds_grp3-5	-0.291	0.1	-2.926	0.003	0.747	0.615	0.908
Age: 80-84:meds_grp3-5	-0.161	0.096	-1.677	0.094	0.851	0.706	1.028
Age: 85-89:meds_grp3-5	-0.359	0.096	-3.759	<0.001	0.698	0.579	0.842
Age: 90-94:meds_grp3-5	-0.239	0.109	-2.198	0.028	0.788	0.637	0.974
Age: 95 Plus:meds_grp3-5	-0.691	0.154	-4.495	<0.001	0.501	0.371	0.677
Age: 70-74:meds_grp6-8	-0.167	0.101	-1.655	0.098	0.846	0.694	1.031
Age: 75-79:meds_grp6-8	-0.5	0.095	-5.251	<0.001	0.607	0.504	0.731
Age: 80-84:meds_grp6-8	-0.469	0.092	-5.1	<0.001	0.626	0.523	0.749
Age: 85-89:meds_grp6-8	-0.761	0.092	-8.297	<0.001	0.467	0.39	0.559
Age: 90-94:meds_grp6-8	-0.815	0.105	-7.773	<0.001	0.443	0.36	0.544
Age: 95 Plus:meds_grp6-8	-1.226	0.15	-8.16	<0.001	0.293	0.219	0.394
Age: 70-74:meds_grp9+	-0.197	0.094	-2.095	0.036	0.821	0.683	0.987
Age: 75-79:meds_grp9+	-0.63	0.089	-7.106	<0.001	0.532	0.447	0.634

Table 8.3 continued from previous page

term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
Age: 80-84:meds_grp9+	-0.78	0.086	-9.021	<0.001	0.458	0.387	0.543
Age: 85-89:meds_grp9+	-1.232	0.087	-14.208	<0.001	0.292	0.246	0.346
Age: 90-94:meds_grp9+	-1.527	0.101	-15.195	<0.001	0.217	0.178	0.264
Age: 95 Plus:meds_grp9+	-2.169	0.147	-14.791	<0.001	0.114	0.086	0.152
simd:councilGlasgow City	-0.056	0.045	-1.233	0.218	0.946	0.865	1.034
simd:councilNa h-Eileanan Siar	-0.058	0.064	-0.903	0.366	0.944	0.833	1.07
simd:councilEast Renfrewshire	-0.024	0.046	-0.513	0.608	0.977	0.892	1.069
simd:councilCity of Edinburgh	-0.114	0.045	-2.511	0.012	0.893	0.817	0.975
simd:councilEast Dunbartonshire	-0.046	0.046	-0.988	0.323	0.955	0.872	1.046
simd:councilFife	-0.077	0.045	-1.708	0.088	0.925	0.847	1.011
simd:councilPerth and Kinross	-0.098	0.046	-2.126	0.034	0.907	0.828	0.992
simd:councilSouth Ayrshire	-0.032	0.046	-0.687	0.492	0.969	0.885	1.06

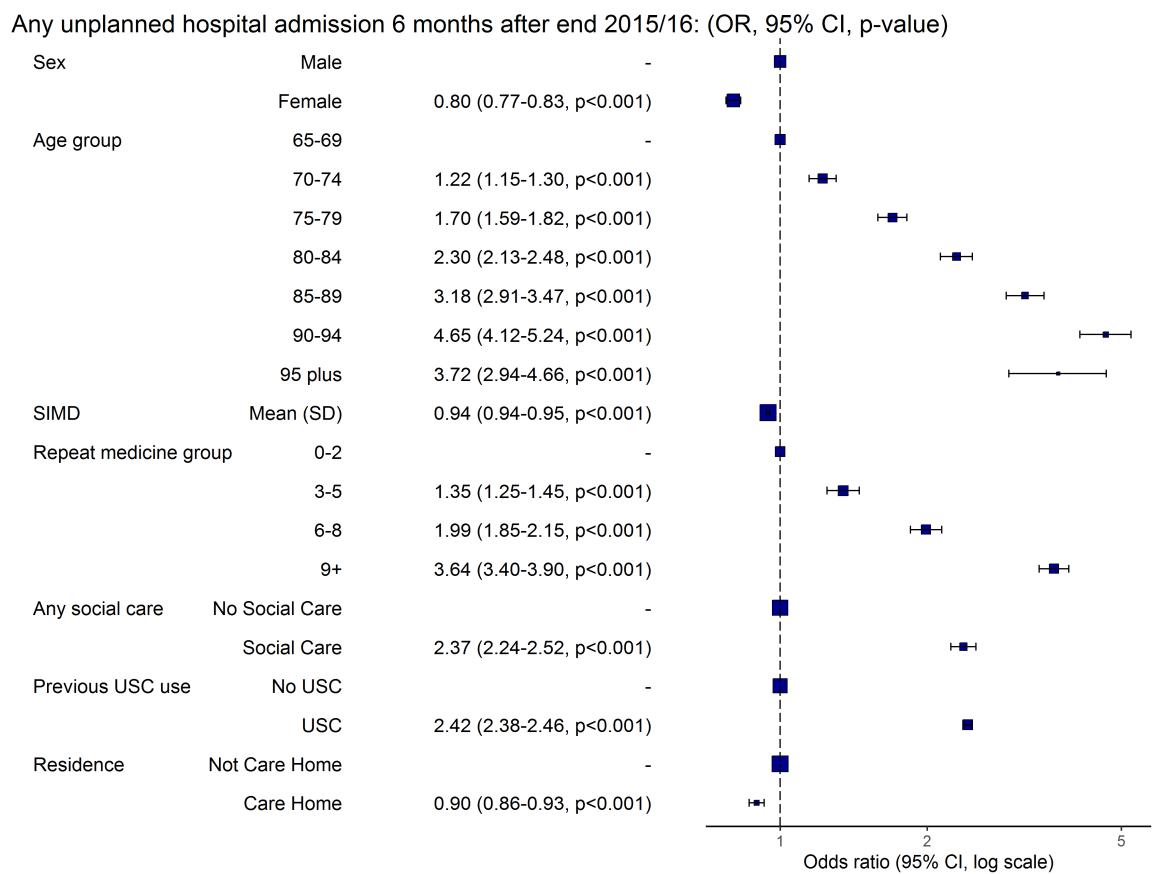


Figure 8.3: Unplanned hospital admission. Odds ratios 2015/16

Table 8.4: Unplanned hospital admission. Model results 2015/16

term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
(Intercept)	-3.404	0.031	-109.039	<0.001	0.033	0.031	0.035
Female	-0.22	0.018	-12.522	<0.001	0.802	0.775	0.83
Age: 70-74	0.2	0.033	6.132	<0.001	1.222	1.146	1.303
Age: 75-79	0.531	0.035	15.215	<0.001	1.7	1.588	1.82
Age: 80-84	0.832	0.039	21.489	<0.001	2.299	2.131	2.48
Age: 85-89	1.156	0.046	25.394	<0.001	3.179	2.907	3.476
Age: 90-94	1.537	0.062	24.894	<0.001	4.649	4.119	5.247
Age: 95 Plus	1.312	0.117	11.191	<0.001	3.715	2.952	4.676
SIMD Decile:	-0.057	0.004	-14.156	<0.001	0.945	0.937	0.952
Meds: 3-5	0.298	0.039	7.685	<0.001	1.347	1.248	1.453
Meds: 6-8	0.689	0.038	18.2	<0.001	1.992	1.849	2.145
Meds: 9+	1.292	0.035	36.427	<0.001	3.641	3.397	3.903
Social Care	0.865	0.03	28.526	<0.001	2.375	2.238	2.52
USC	0.885	0.008	107.661	<0.001	2.423	2.384	2.462
Care Home	-0.111	0.018	-6.06	<0.001	0.895	0.864	0.928
Female:age_grp70-74	0.05	0.025	2.001	0.045	1.051	1.001	1.104
Female:age_grp75-79	0.03	0.025	1.221	0.222	1.031	0.982	1.082
Female:age_grp80-84	0.01	0.025	0.387	0.699	1.01	0.961	1.061
Female:age_grp85-89	0.015	0.028	0.525	0.599	1.015	0.961	1.072
Female:age_grp90-94	-0.074	0.037	-1.984	0.047	0.929	0.863	0.999
Female:age_grp95 Plus	-0.041	0.072	-0.566	0.571	0.96	0.833	1.106

Table 8.4 continued from previous page

term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
SIMD Decile: :meds_grp3-5	0.016	0.005	3.224	0.001	1.016	1.006	1.026
SIMD Decile: :meds_grp6-8	0.022	0.005	4.646	<0.001	1.023	1.013	1.033
SIMD Decile: :meds_grp9+	0.02	0.005	4.261	<0.001	1.02	1.011	1.029
Age: 70-74:meds_grp3-5	-0.051	0.04	-1.257	0.209	0.951	0.879	1.029
Age: 75-79:meds_grp3-5	-0.107	0.042	-2.555	0.011	0.898	0.827	0.975
Age: 80-84:meds_grp3-5	-0.164	0.046	-3.589	<0.001	0.849	0.776	0.928
Age: 85-89:meds_grp3-5	-0.151	0.052	-2.911	0.004	0.86	0.777	0.952
Age: 90-94:meds_grp3-5	-0.268	0.068	-3.955	<0.001	0.765	0.67	0.874
Age: 95 Plus:meds_grp3-5	-0.231	0.119	-1.953	0.051	0.793	0.629	1.001
Age: 70-74:meds_grp6-8	-0.137	0.04	-3.411	0.001	0.872	0.806	0.943
Age: 75-79:meds_grp6-8	-0.229	0.041	-5.549	<0.001	0.795	0.733	0.862
Age: 80-84:meds_grp6-8	-0.274	0.044	-6.171	<0.001	0.76	0.697	0.83
Age: 85-89:meds_grp6-8	-0.383	0.051	-7.583	<0.001	0.682	0.617	0.753
Age: 90-94:meds_grp6-8	-0.626	0.066	-9.488	<0.001	0.535	0.47	0.609
Age: 95 Plus:meds_grp6-8	-0.535	0.115	-4.636	<0.001	0.586	0.467	0.734
Age: 70-74:meds_grp9+	-0.123	0.038	-3.281	0.001	0.884	0.821	0.952
Age: 75-79:meds_grp9+	-0.331	0.039	-8.461	<0.001	0.718	0.665	0.776
Age: 80-84:meds_grp9+	-0.463	0.042	-10.915	<0.001	0.629	0.579	0.684
Age: 85-89:meds_grp9+	-0.688	0.049	-14.103	<0.001	0.503	0.457	0.553
Age: 90-94:meds_grp9+	-0.962	0.064	-14.984	<0.001	0.382	0.337	0.434
Age: 95 Plus:meds_grp9+	-0.929	0.113	-8.196	<0.001	0.395	0.316	0.493
Age: 70-74:scs_flagsocial Care	-0.077	0.04	-1.927	0.054	0.926	0.855	1.001

Table 8.4 continued from previous page

term	estimate	std.error	statistic	p.value	odds_ratio	conf_int_low	conf_int_high
Age: 75-79:scs_flagsocial Care	-0.125	0.037	-3.369	0.001	0.882	0.82	0.949
Age: 80-84:scs_flagsocial Care	-0.265	0.036	-7.372	<0.001	0.767	0.715	0.823
Age: 85-89:scs_flagsocial Care	-0.361	0.037	-9.713	<0.001	0.697	0.648	0.75
Age: 90-94:scs_flagsocial Care	-0.36	0.044	-8.229	<0.001	0.698	0.64	0.76
Age: 95 plus:scs_flagSocial Care	-0.15	0.07	-2.154	0.031	0.861	0.751	0.987

Conditional effect of SIMD Decile on admission to hospital
2015/16

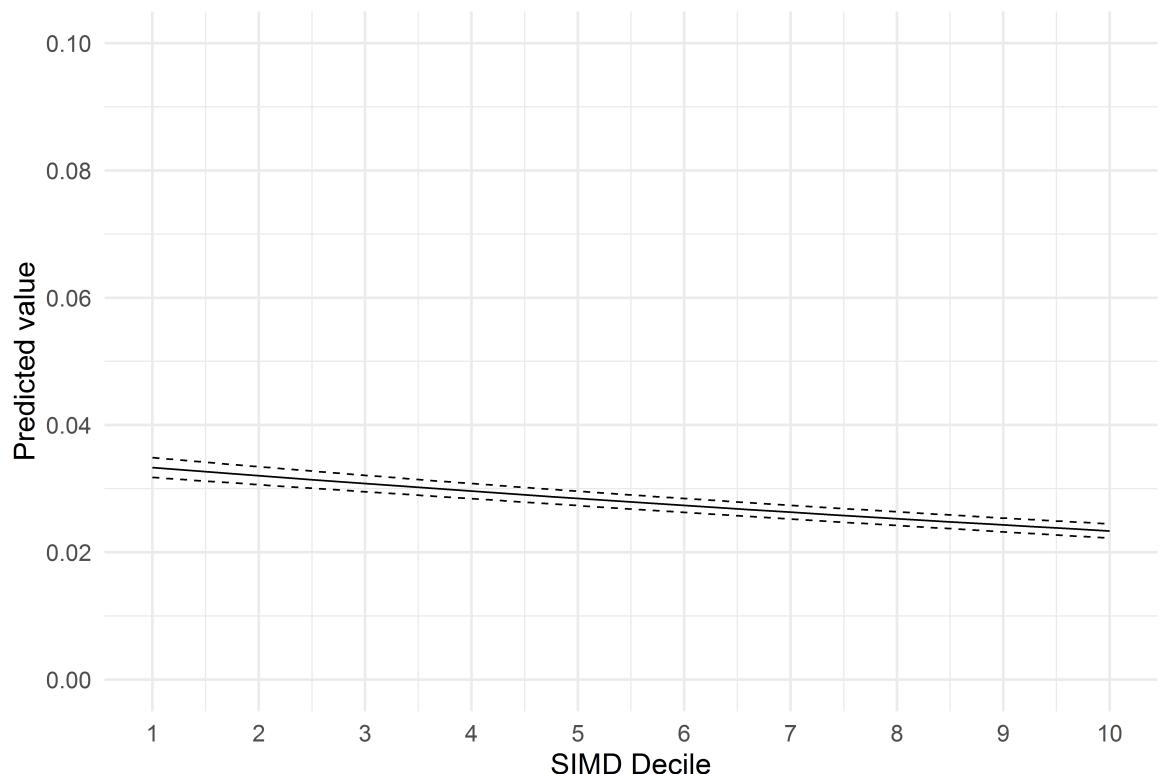


Figure 8.4: Conditional effect of SIMD on any unplanned hospital admission

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