



**Oilthigh
Glaschu**

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

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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

ADL	Activities of daily living
ADRC	Administrative Data Research Centre
AME	Average Marginal Effect
APE	Average Partial Effect
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
IQR	Interquartile range
ISD	Information Services Division
LA	Local authority

Abbreviations

LTC	Long term care
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
RAC	Research Approvals Committee
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
UCD	Urgent Care Data Mart
VPN	Virtual Private Network

Quote

\begin{quotation} Alienation is the precise and correctly applied word for describing the major social problem in Britain today. People feel alienated by society. In some intellectual circles it is treated almost as a new phenomenon. It has, however, been with us for years. What I believe to be true is that today it is more widespread, more pervasive than ever before. Let me right at the outset define what I mean by alienation. It is the cry of men who feel themselves the victim of blind economic forces beyond their control. It is the frustration of ordinary people excluded from the processes of decision making. The feeling of despair and hopelessness that pervades people who feel with justification that they have no real say in shaping or determining their own destinies.

Many may not have rationalised it. May not even understand, may not be able to articulate it. But they feel it. It therefore conditions and colours their social attitudes.
\end{quotation}

James Reid. Rectorial Address delivered in the University of Glasgow. Friday, 28th April, 1972.

Chapter 1

Introduction

Revist Burchardt et al

Integration of health and social care became law in Scotland on 1st April 2016. Reflects patterns across the developing world to restructure health services to cope with demands of an ageing population.

Social Care of increasing policy (and political) importance. Link to healthcare (and demands on health services) becoming increasingly apparent (increase delayed discharge etc).

This, in part, due to long-term conditions now major burden of global disease (replacing infectious diseases). Large proportions of population have multimorbidity (OECD) which has a number of negative outcomes including mortality and health care use.

Association of multimorbidity and social care use is unknown.

PhD funding from Scottish Government to assess these topics. (2020 vision and other policy link)

Important part of the funding to link administrative data sources in order to identify the benefit of this process. *Measurement of social (or LTC) is improtant 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??*

(Need WHO policy outlines and other suitable high-level policy docs in this section)

Many countries, including the United Kingdom (UK), have recently seen policies implemented that aim to integrate the provision of health and social care services \href{RN234} (Stewart, Petch and Curtice, 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, Petch and Curtice, 2003; Petch, 2009, 2012b; Weatherly *et al.*, 2010; Burgess, 2012; Robson, 2013; Damery, Flanagan and Combes, 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, Dickinson and Miller, 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.

1.1 Aims and Objectives

Does an inverse *social* care law exist? i.e. Does the allocation of resources (via funding formulae) to Local Authorities negatively impact on those areas with higher need?

Furthermore, does access to social care vary across Local Authorities - is there a “postcode lottery” in terms of service provision i.e. does application of eligibility criteria depend on where you live?

Is multimorbidity status associated with levels of social care provided within *and* across

local authorities? What is the best way to measure multimorbidity? Do clustering techniques offer a better understanding of this phenomenon?

Important to understand how access to social care influences health care use and mortality - do those with multimorbidity and social care have different outcomes from those with multimorbidity and no social care?

The thesis has both substantive and methodological aims. Substantively, it aims to contribute to the debate surrounding health and social care integration by looking specifically at a group that are likely to be regular users of both health and social care services, i.e. those with multimorbidity. Methodologically, the thesis aims to contribute to efforts to improve the exploitation of administrative data as a means to analyse public service performance and effectiveness.

Aims of the project are:-

1. Describe and compare social inequalities in the use of social care services using linked health and social care data.
2. Explore the effects of social care use for those with multimorbidity on
 - (a) unscheduled health care use and
 - (b) mortality.

The objectives of the project are:-

1. To assess how access to social care services varies for people with multimorbidity, especially by socioeconomic status.
2. To assess the impacts of social care service use on health service use and health outcomes for people with multimorbidity, where possible exploiting geographic differences in social care as "natural experiments".
3. To make recommendations for policy on the future of integration of health and social care services based on these results.
4. To assess whether what extant measures of multimorbidity and of health and social care service use can be operationalised using existing linked health and social care administrative data.
5. To make recommendations to policy makers on administrative data collections.

1.2 Scientific contribution

Explicit description of what thesis adds to knowledge

1.3 Conventions

Outline definitions

- Social care refers to Adult social care (with link to subsection [2.2.1](#))
- Multimorbidity and morbidity burden as opposed to comorbidity (with link to subsection [2.4.2](#))

Chapter 2

Literature Review

2.1 Introduction

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, 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 2.4 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

2.2 Access to Social Care

Add intro paragraph

Consider restructuring section a)International models, b) resource allocation, c) eligibility. OR theory altogether and then Scotland only at end

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

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

2.2.2 International models of social care

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). 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, Gregory and Jabbal, 2014; Deusdad, Pace and Anttonen, 2016). Traditionally, informal care was provided by women. As gender equality improves, more women are employed in non-domestic settings which also reduces 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).

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.

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)

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

The tax-based universal models, also known as the Nordic model of care, have strong local-government influence in both the raising of funds and delivery of services (Munday, 2003; Sapir, 2006; Colombo *et al.*, 2011; Fernández-Alonso and Jaime-Castillo, 2016). Overall responsibility remains with national government which also contributes funds, often dependent on local population need and structure (Colombo *et al.*, 2011). Public long-term insurance schemes are mandatory in the countries that employ them, although

the age at which citizens begin to contribute varies (e.g. only over 40s contribute in Japan) (Colombo *et al.*, 2011; Forder and Fernández, 2011; Eleftheriades and Wittenberg, 2013). These models have found it increasingly difficult to fund provision and have either increased user-payments or decreased coverage in recent years (Forder and Fernández, 2011; Eleftheriades and Wittenberg, 2013; Robertson, Gregory and Jabbal, 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 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.

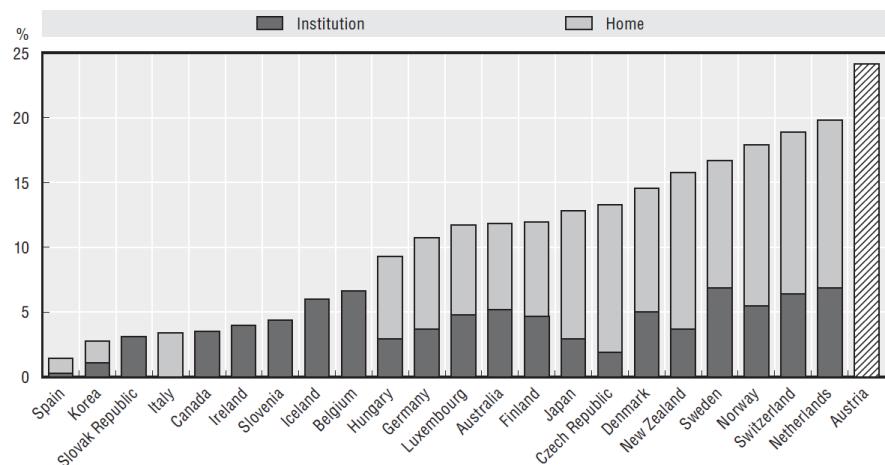
Disadvantages of universal systems are that they are generally more expensive to the state than other models of social care and can reduce the amount of informal care provided by relatives for elderly family (Colombo *et al.*, 2011; Eleftheriades and Wittenberg, 2013). The comprehensiveness of coverage 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, Gregory and Jabbal, 2014).

Need to mention typologu 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

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

beginning to blur (Deusdad, Pace and Anttonen, 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 2.1: 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 2.1) 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.

2.2.3 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, Hill and Buffat, 2016). Street level bureaucrats can be teachers, police officers, nurses, social workers, or any other worker providing a public service (Hupe, Hill and Buffat, 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 method-

ological problems (Hupe, Hill and Buffat, 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.

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

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

[Sharkey, 2006, 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 2.2.3) 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, Green and Mortimer, 2014).

In practice, the most likely outcome is that the minimum threshold that local authorities will have to provide care will be similar to the “critical” level of the National Eligibility Framework previously used in the FACS guidance (Abrahams, Green and Mortimer, 2014; Burchardt, Obolenskaya and Vizard, 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, Green and Mortimer, 2014; Burchardt, Obolenskaya and Vizard, 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, Green and Mortimer, 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.

2.2.5 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, Evans and Noble, 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, Evans and Noble, 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 2.2.6.

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

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

"The availability of good medical care tends to vary inversely with the need for it in the population served"

[The Inverse Care Law: Tudor-Hart, 1972]

In a similar fashion to Le Grand's work, the inverse care law has informed much research since first coined in the early 1970s but focusses specifically on healthcare. People living in more deprived areas have lower life expectancy and higher morbidity figures and therefore greater health needs (Baker, Mawby and Ware, 2015). However, the poorest neighbourhoods in England have been reported to have 62.5 General Practitioners (GP) per 100,000 population whereas the most affluent neighbourhoods have 76.2 per 100,000 (CfWI, 2014) which suggests health provision does not match need. 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). Poorer access to primary health care is associated with greater demand for unnecessary admission to hospital (Rosano *et al.*, 2013; Weston *et al.*, 2016) which is responsible for high proportions of healthcare expenditure.

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.

2.2.6 Access to Social Care - Resource Allocation in Scotland

Local authorities in Scotland have a statutory obligation to provide social care to individuals they have assessed as eligible for care (Audit-Scotland, 2012). 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 - rememeber Tax and charges)} (King, Pashley and Ball, 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 authorities are estimates of relative, rather than absolute, spending needs in that area. The “green book” reporting the annual settlement for local authorities in Scotland stresses that the values allocated for different services are not budgets or targets and that local authorities are free to spend resources (other than ring-fenced monies) as they see fit (Scottish-Government, 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).

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, Evans and Noble, 2005) (and discussed in section 2.2.5), 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.

2.2.7 Health inequalities

In the UK, poverty remains the largest predictor of relative ill health and has associations with increased morbidity, multimorbidity, and decreased life expectancy (Baker, Mawby and Ware, 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, Dorling and Smith, 2006; Baker, Mawby and Ware, 2015).

The influential Marmot review into health inequalities found that those in the most deprived areas of England die, on average, seven years earlier than their most affluent peers (Marmot *et al.*, 2010) with the gap in life expectancy increasing between 1995 and 2008 (National-Audit-Office, 2010). Subsequent research by the King’s Fund suggests

the gap in life expectancy reduced between the periods 1999-2003 and 2006-2010 (Buck and Maguire, 2017). The report warns that this improvement may be due to the spending and policy decisions of the New Labour Government of the early 2000s and that recent austerity measures in the UK may undermine the progress made (Buck and Maguire, 2017). Indeed, the most recent analysis released by the Office for National Statistics (2016) suggests the gap in male life expectancy in England is now 9.1 years. In Northern Ireland, the male life expectancy gap is the lowest of all four UK nations, however those in the poorest neighbourhoods die, on average, four years earlier than those in the most affluent areas (ONS, 2016). In Wales the gap is slightly larger at 4.2 years (ONS, 2016). There is a gap of seven years in life expectancy at birth in Scottish males - those born in East Dunbartonshire can expect to live to 80.5 years, whereas those in Glasgow City can expect to live 73.4 years (ONS, 2016).

The Scottish Government reports statistics on healthy life expectancy which is defined as the number of years people can expect to live in good health (Scottish-Government, 2017c). The most recent figures suggest men and women in the most deprived areas can expect to become ill 25.1 and 22.1 years earlier than their most affluent peers respectively (Scottish-Government, 2017c) meaning Scotland has the highest level of health inequality in western and central Europe (Mackenbach *et al.*, 2008; Popham and Boyle, 2010).

There are many theories as to why inequalities in health exist across socioeconomic position (Asthana and Halliday, 2006; Nettleton, 2006). 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, Collins and Mackenzie, 2013).

There have been many critiques of other theories proposed in the last 35 years which focus on differing numbers of proposals (Asthana and Halliday, 2006; Nettleton, 2006; Peckham and Meerabeau, 2007; Mackenbach, 2012; Smith, Bambra and Hill, 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, Bambra and Hill, 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, Bambra and Hill, 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).

(Might expand this a little more?)

2.2.8 Summary

There is no agreed standard definition of social care, a term often used synonymously with 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 social 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 disproportionately 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

Add intro paragraph

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 principle 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 professionals, 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 (???)

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, Petch and Curtice, 2003; Petch, 2009, 2012b; Burgess, 2012; Robson, 2013; Damery, Flanagan and Combes, 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 Multimorbidity

Add intro paragrphah

2.4.1 Why focus on Multimorbidity?

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 multimorbidity. 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). Multimorbidity is associated with a number of negative outcomes including increased

health care usage (NICE, 2016). Whether multimorbidity increases use of social care services is unknown but this could have an important role in informing policy decisions regarding social care provision.

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 2.2.5.

It is too early to say if health and social care integration result in better or worse outcomes for people with multimorbidity. However, in order to make that assessment, a fuller understanding of the term “multimorbidity” is required. The rest of this section outlines the academic literature regarding concepts of multimorbidity, how it is defined, how it is measured, and finally epidemiological research.

2.4.2 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). Van den Akker et al (1996) first made the distinction between the terms comorbidity and multimorbidity. Comorbidity was originally described by Fenstein (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) used the term multimorbidity to describe, “...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.

Further development of definitions is provided by Valderas *et al.* (Valderas *et al.*, 2009) who characterise the construct of the term comorbidity found in the literature in 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 patient outcomes and (d) patient complexity – the effect of non-health characteristics (e.g. deprivation, culture, environment) on morbidity burden.

Valderas *et al.* (2009) discuss these four constructs of comorbidity 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).

A further definition of multimorbidity is offered by the European General Practice Research Network (EGPRN) who report findings of a systematic review in the construction of their definition. Citing over 100 different definitions for multimorbidity in academic research, the EGPRN (Le Reste *et al.*, 2013, p. 1) aimed to clarify the concept of multimorbidity and define the term as:

"...any combination of chronic disease with at least one other disease (acute or chronic) biopsychosocial factor (associated or not) or somatic risk factor."

This definition goes some way to capture the complexity of the concept of multimorbidity as explained by Valderas *et al.* (2009) but has not ended debate on the matter.

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).

In a recently published guideline, the National Institute for Health and Care Excellence (NICE) (NICE, 2016) acknowledge the complexity of defining multimorbidity. NICE agree 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). For this reason the guideline is aimed at people with 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)

Although multimorbidity may seem to be an intuitive thing to understand, defining a useful concept of the term has proved to be much more difficult (Guthrie *et al.*, 2011). The most commonly accepted term in academic literature is; “the co-occurrence of two or more long-term conditions in an individual.” This definition will be used for the purposes of this thesis.

2.4.3 Measurement

The findings of three recent systematic reviews have highlighted the myriad ways researchers have approached the measurement of multimorbidity (Groot *et al.*, 2004; Diederichs, Berger and Bartels, 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. The number of medical conditions included in these measurements varied from 4 to 102 (2011). Most indices are developed from secondary care populations but many have been adapted for other populations including primary care (Diederichs, Berger and Bartels, 2011; Huntley *et al.*, 2012).

There are two main ways of measuring multimorbidity: simple disease counts or using an index which applies weights to either prescribed medications or medical conditions and other factors in an attempt to explain severity of illness (Groot *et al.*, 2004; Diederichs, Berger and Bartels, 2011; Huntley *et al.*, 2012). 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 such as the Charlson index (Charlson *et al.*, 1987) or Chronic Disease Score (Von Korff, Wagner and Saunders, 1992) and their variations.

Despite the large number of multimorbidity indices available, Huntley et al (2012) cite evidence that suggests simple counts of diseases or medications are almost as effective as the more complex indices at predicting mortality or health care use in the primary care setting. However, when aiming to predict mortality in primary care, Huntley et al (2012)

recommend the best measurement of multimorbidity to be provided by the Charlson index (Charlson *et al.*, 1987) and its variations. Measurement of multimorbidity in relation to primary care healthcare use can be predicted with equivalence by either; the Adjusted Clinical Group system (Starfield *et al.*, 1991), the Charlson index (Charlson *et al.*, 1987), or disease counts (Huntley *et al.*, 2012).

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). A count of medicines was found to be a good predictor of primary care use and mortality in a more recent paper (Brilleman and Salisbury, 2013). In their paper, Perkins *et al* (2004) argue 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 when predicting hospital admission but noted that all measures of multimorbidity alone were poor predictors of the outcome.

An emerging method of measuring multimorbidity is to identify clusters of medical conditions that co-exist in individuals at rates higher than would be expected - or non-random prevalence. 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; RN109; Prados-Torres *et al.*, 2014; Le Reste *et al.*, 2015). 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), principal component analysis, latent class analysis (Islam *et al.*, 2014; Larsen *et al.*, 2017), and machine learning techniques (Schiltz *et al.*, 2017).

In their systematic review of clustering methods, Prados-Torres *et al* (2014) found wide variations in approaches to clustering and characteristics of populations studied. As opposed to many of the studies included in the review, they recommend future attempts at clustering diseases use; population-sized datasets, statistical techniques that are suited to the dichotomous nature of diagnostic variables, and large numbers of conditions from which to form clusters (Prados-Torres *et al.*, 2014).

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. Whilst identification of groups may have some benefit in terms of identifying causal mechanisms between diseases, whether they are useful or meaningful in clinical terms is a matter of debate.

2.4.4 Epidemiology

Due to the wide variations in definitions and measures of multimorbidity. It is unsurprising that there is marked heterogeneity in reports of multimorbidity prevalence. Fortin et al (2012) illustrate this by reporting variations in the prevalence of multimorbidity from 3.5% to 98.5% across 21 studies included in their systematic review. The variation in findings is explained by the vastly different populations, settings, data collection techniques, and definitions of multimorbidity used by included studies.

A more recent systematic review concentrating on primary care populations and aiming to describe prevalence, causes and patterns of multimorbidity (Violan *et al.*, 2014) found reports of multimorbidity prevalence between 12.9% and 95.1%. Similar variations in definitions, measures and populations were found. The number of conditions used to estimate multimorbidity prevalence varied between 5 and 335 (Violan *et al.*, 2014).

In an attempt to standardise conditions to be considered using international disease classification labels, a more recent paper included 60 conditions (Calderón-Larrañaga *et al.*, 2016). Van den Akker et al [-RN91] highlighted the complications that can arise when attempting to measure prevalence of multimorbidity and suggest that certain decisions made in study design will depend on the specific question being interrogated by researchers (e.g. the number of diseases to include in the measure of multimorbidity or the age-range of the sample). The systematic reviews of Violan et al (2014) and Fortin et al (2012) may reflect the varying decisions made by research teams in study design. Despite the difficulties in synthesizing evidence on heterogeneous studies, Violan et al (2014) found strong relationships between multimorbidity and: age, female gender, low socioeconomic status, and mental health across studies in their review.

2.4.5 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. As a result, policy needs to be tailored to account for the complex needs of the increasing numbers of people with multimorbidity.

**Need to pull multimorbidity together with social care. MM high health care costs and also has an impact on socal care use - see feedback notes.
ALSO use NICE guideline on social care for people with MM**

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.

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?

2.5.1 Thesis structure

Chapter ?? is a methodological chapter with the aim of identifying clinically meaningful clusters of health conditions from a nationally representative dataset. Given the wide approaches to measuring multimorbidity, identifying clusters of individuals with similar multimorbidity profiles could act as a useful control variable in analysis of outcomes. The chapter investigates whether finite-mixture models can identify meaningful clusters from the dataset.

Chapter 3 discusses the institutions and infrastructure that enable data linkage to take place in Scotland. Each of the data sources used in the linkage is described in detail. This chapter also describes the complex information governance process involved with completing data linkage projects and how a “safe haven” environment is used for data analysis.

Chapter ?? describes the methods employed to answer the above research questions. A rationale of how the study cohort was chosen is provided along with a description, for each data source, of the methodological techniques used to link to the cohort, the techniques used to clean data, and how summary measures were produced. Statistical methods used to answer each research question are also described.

Social care data for the main linkage project was obtained using the Social Care Survey published by the Scottish Government (as described in chapter 3). This is cross-sectional data. In a short stand-alone results chapter, chapter 4 describes a pilot study based on 10 years of social care data from one Scottish local authority area - Renfrewshire council. The temporal variation in the amounts of home-care individuals received over this 10 year period is analysed to provide some validation of the measure of hours of home care used in the main linkage project.

Chapter ?? describes the results of analyses related to each research question.

Chapter 9 summarises the thesis arguments and findings and places them in context.

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 Data Linkage

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, Kirby and Penny, 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, Harrison and Russ, 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 (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, Harrison and Russ, 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, Harrison and Russ, 2017).

There are two main methods of linking data from disparate sources; deterministic matching and probabilistic matching (Fleming, Kirby and Penny, 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, Kirby and Penny, 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, Kirby and Penny, 2012; Harron, 2016; Doidge and Harron, 2018). An important consideration when using probabilistic linkage is making an assessment of false-positive match rates (Fleming, Kirby and Penny, 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, Kirby and Penny, 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).

3.2 Information Governance

Confidentiality of data subjects is an important consideration in any data linkage project. The benefits of administrative data linkage, outlined in section 3.1, 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.

3.2.1 Infrastructure

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

Elon Musk

3.2.1.1 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).

3.2.1.2 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 3.2.3.2.

3.2.1.3 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 [3.3.3](#) and [3.3.4](#).

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).

3.2.1.4 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 [3.4](#).

3.2.1.5 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 [3.3.1](#).

3.2.2 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.

3.2.2.1 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).

The approval for the main linkage project is shown in Appendix A.

3.2.2.2 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).

The CoSS REC approval letter for the main linkage project is shown in appendix B.

3.2.2.3 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 C. A full description of data processing including its legal basis is presented in section [3.2.3](#).

3.2.3 Data processing

3.2.3.1 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).

3.2.3.2 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 3.2.1.2, 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).

3.2.3.3 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 which is shown in Appendix D.

3.3 Data Sources for Linkage

Research conducted with administrative data requires a thorough description of databases used (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 (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.

3.3.1 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, 2017f). Results are collated and published annually by HSCAD in the "Social Care Services, Scotland" report (Scottish-Government, 2017f). 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 3.4.

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.

3.3.2 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 3.1). 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.

3.3.3 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).

3.3.4 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.

3.4 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 [3.3.2](#)) 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 similar match rates and compare receipt of care within these sub-groups.

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

3.5 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 3.3.

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 `tidyverse` v0.7.2 (Wickham and Henry, 2017), `dplyr` v0.7.4 (Wickham and Francois, 2017), `lubridate` v1.6.0 (Grolemund 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).

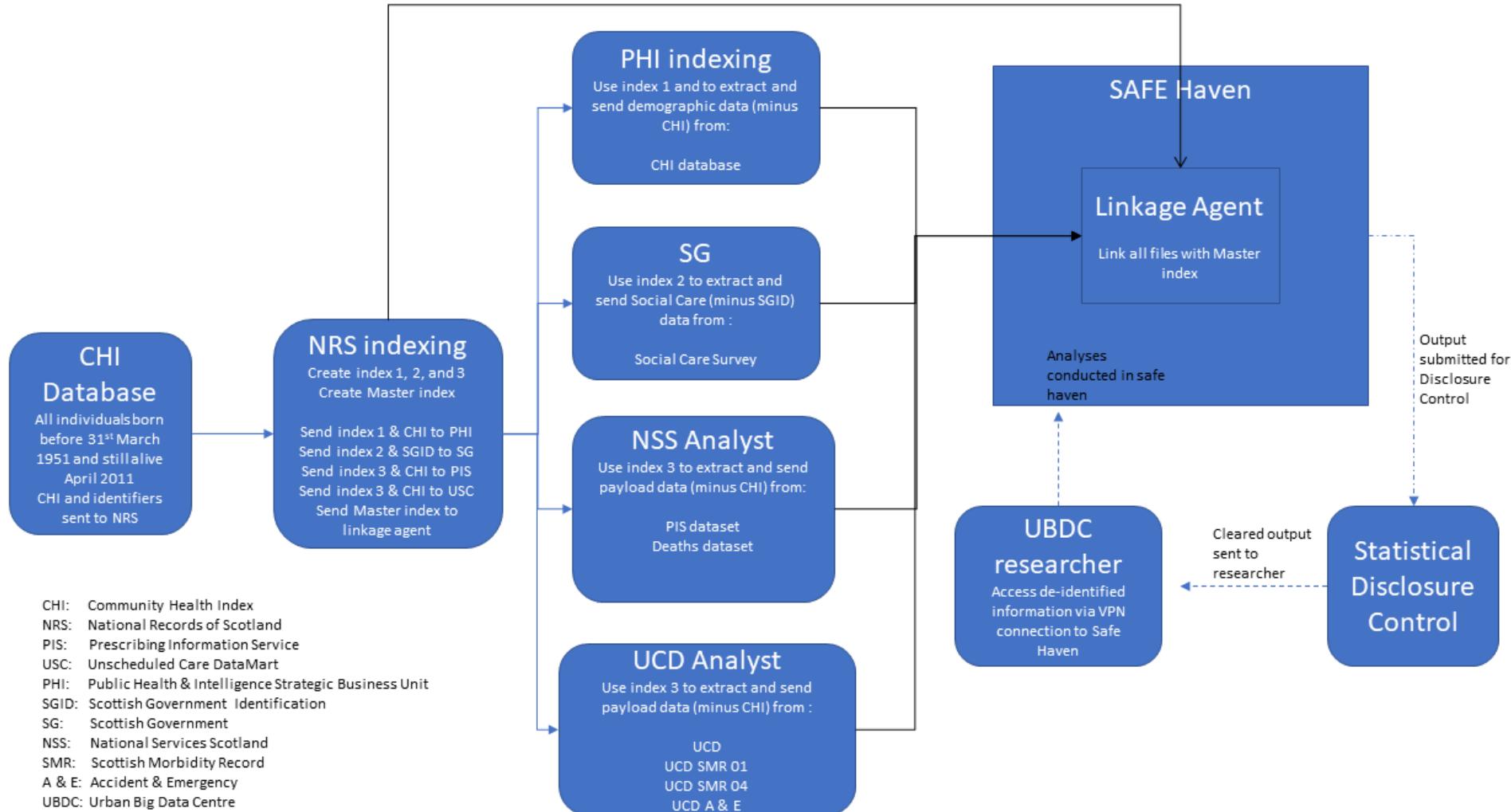


Figure 3.1: Data linkage diagram

3.5.1 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 (Grolemund 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.

3.5.2 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 were a number of variables indicating the weekly hours of home care (if any) each

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

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 3.5.5).

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 3.5.5).

3.5.3 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 E. 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

3.5.4 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 3.3.4.

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.

3.5.5 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 3.5.1) 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 3.5.2, 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 3.4 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 3.5.2, 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 3.4) within 4% of each other (e.g. 96-99.9%, 92-95.9% etc.)

3.6 Statistical methods

3.6.1 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, Hensher and Swait, 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 ~ 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 3.4), 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, Wang and Ai, 2004; Mood, 2010; Mustillo, Lizardo and McVeigh, 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, Arnold and Arel-Bundock, 2017).

3.6.2 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 3.6.1).

3.7 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

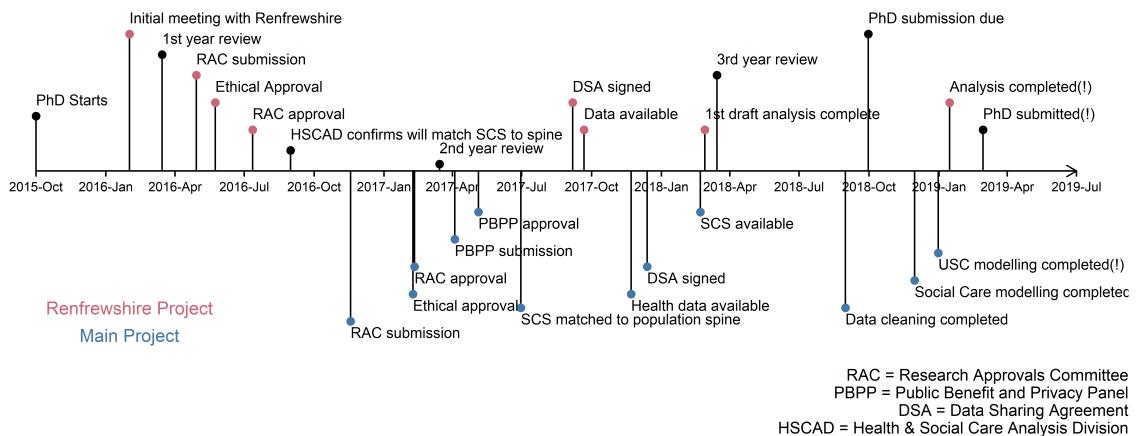


Figure 3.2: Timeline of Thesis project

Government confirmed it would make the Social Care Survey available for linkage. This process was not completed until the end of June 2017 (section 3.4).

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 3.3.1, 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. The most recent surveys collect data on all individuals who receive a community alarm service, a telecare service, self-directed-support payments, 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, 2017f). The cross-sectional nature of the data collected for these second group of 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 chapter estimates the numbers of individuals receiving home care “missed” by the SCS and compares their demographic make-up and type of care received to those who are “captured” by the SCS census. 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 a census quarter, rather than a census week.

All data relating to home care services from Renfrewshire council was 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 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.

Over the study period, between 57.3% and 62.8% of all individuals receiving home care in each financial year received home care during the census week. This percentage would increase by approximately 10% if a quarterly census were implemented. There were no major differences in age and sex between those missed and captured by the SCS. However, those missed were more likely to receive care over a shorter total time period with a higher intensity of care provision (measured by weekly hours of care received).

4.2 Background

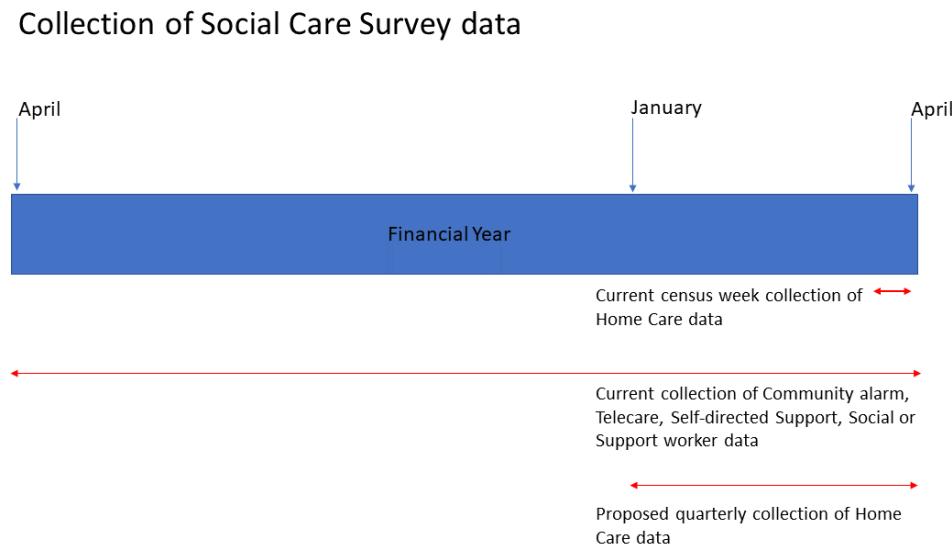


Figure 4.1: Time periods for which SCS data is collected

Figure 4.1 depicts the differing time periods over which variables are collected by more recent versions of the SCS and the proposed quarterly 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

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. Whilst it is difficult to quantify numbers of people who fall into the former category with unlinked administrative data, 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 quarterly collection of data (ISD, 2017a), the exploratory project also aimed to quantify the percentage of all individuals that would be identified by

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

collection of home care data in quarter 4 of each financial year (this quarter is the proposed time period for collection of the 2017/18 census).

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 Renfrewshire (Scottish-Government, 2017d) (see also figure 5.3 which indicates a very even spread of individuals over 65 in each SIMD decile).

In terms of social care, the 2017 SCS (Scottish-Government, 2017e, supp.charts) shows that the proportion of over 65s receiving home care provided or administered by Renfrewshire 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 to those seen in Renfrewshire (60.8 per thousand in 2010 to 48.9 per thousand in 2017). Absolute numbers of over 65s receiving home care in Renfrewshire in the 2010 census week was 1526 versus 1614 in the 2017 census (Scottish-Government, 2017e, supp.charts).

4.2.1 Research Questions

- To what extent does SCS data capture the number of individuals receiving home care across each financial year?
- How much would this increase by if a quarterly, rather than weekly, census was employed?
- Are there differences in individuals that are/are not captured by the census?
 - by age and gender,
 - by type of care received,
 - by the length of time they receive care for, or
 - 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 [3.2.2.1](#) Approval from RAC was gained on 01/06/2016 (Appendix F). Ethical approval for the study was gained from the University of Glasgow College of Social Sciences Research Ethics Committee on 24/05/2016 (Appendix G).

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

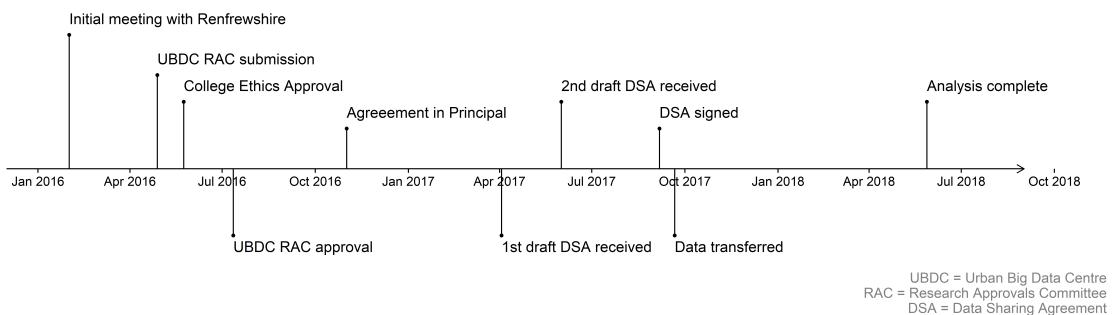


Figure 4.2: Timeline of Renfrewshire exploratory project

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.). 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, 2017e).

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.

Duration of care was calculated by the time elapsed from when an individual first received any home care to the census week in each financial year. Sub-analysis of individuals who did not receive care during the census week included a calculation of duration of care from the start of the financial year to the termination of home care receipt. Average total weekly hours of care was calculated by summing the weekly hours of care of each care type received by an individual and calculating the mean value received over the course of the financial year. Observations where an individual was not actively receiving care were dropped from the time series. As the home care packages of the types “Community Mental Health”, “Overnight Services”, “Housing Support”, and “Extra Care Housing” accounted for less than one percent of packages of care, 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. (Gromelund 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 [3.2.3.2](#)

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 4.2: Characteristics of observations in time series

There were 10,437 individuals included in the time series over the whole study period. Table 4.2 shows the number of observations and individuals in the time series initially increased from 2006/07 to 2009/10 before falling to 2011/12 and then increased again to 2013/14. There were 2435 individuals included in the time series in 2006/07 and 2799 included in 2013/14. 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).

	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16
Records	77554	79627	82765	83752	77734	69618	73287	82874	87071	91870
N	2435	2486	2577	2577	2323	2262	2537	2799	2962	3106
Mainstream	2383	2367	2329	2278	2047	1757	1762	1998	2164	2244
Meals Service	0	331	958	958	900	857	846	923	985	1017
Reablement	0	<30	<30	<30	<30	344	930	871	895	930
Rapid Response	131	267	134	148	<30	181	254	197	182	123
Extra Care Housing	0	<30	73	102	101	100	110	101	120	118
Housing Support	<30	<30	<30	<30	<30	<30	<30	<30	<30	<30
Overnight Services	31	43	49	54	38	69	89	96	59	54
Mental Health	<30	<30	<30	<30	<30	<30	<30	<30	<30	<30

Individuals can receive more than one service in any year
Small numbers suppressed to prevent individual disclosure

Table 4.3: Count of individuals receiving each type of home care service

The “Care at home (Mainstream)” home care service accounts for the vast majority of all home care delivered during the study period (table 4.3). There were only slightly less individuals receiving this service in 2015/16 compared to 2006/07 (2244 v 2382). However, the level was not stable throughout the whole study period with a notable decrease between 2009/10 and 2012/13 before recovering. Meals and Reablement are the next most utilised services. Reablement was very rarely utilised before 2011/12. Other services show very low numbers (in some cases too low to meet safe haven statistical disclosure control requirements).

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 4.4)

	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 4.4: Counts of individuals receiving home care

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

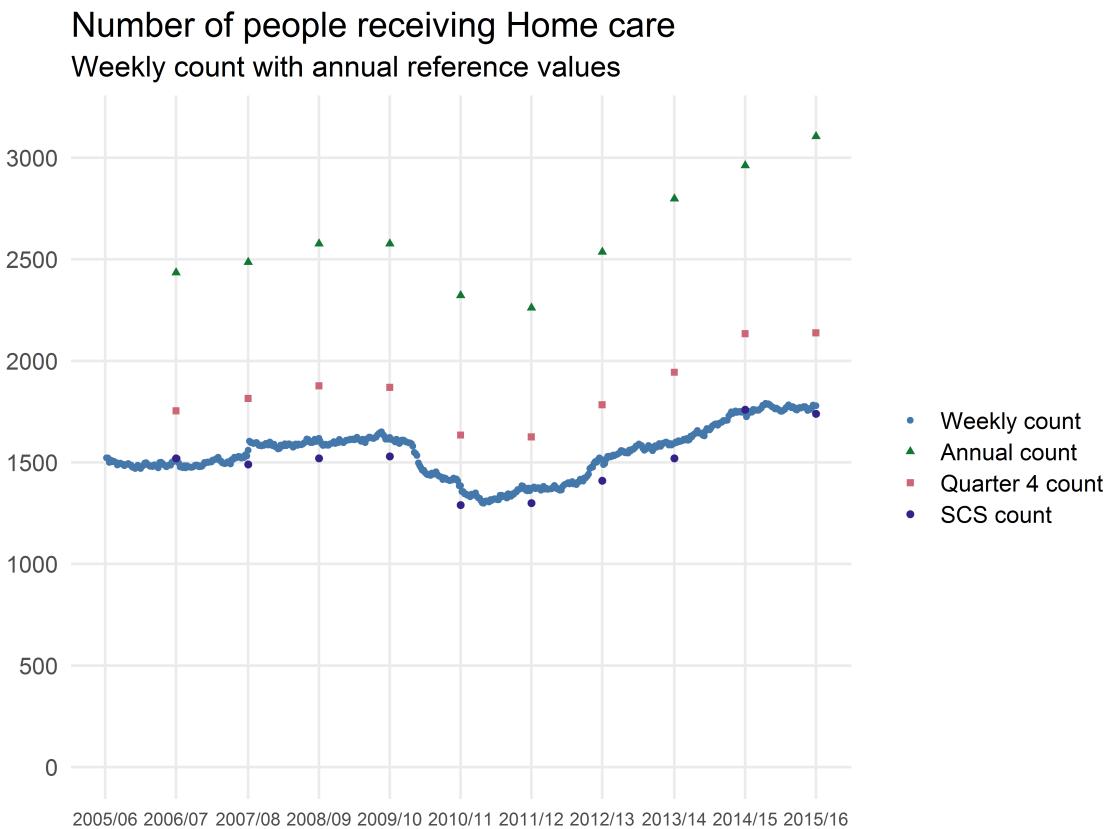


Figure 4.3: Counts of individuals receiving home care

individuals receiving care would be eligible for inclusion in the SCS. Again the percentage decreases over time from 72% in 2006/07 to 68.8% in 2015/16 (table 4.4).

Finally, figure 4.3 and table 4.4 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.

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

4.4.3.1 By age and gender

Overall, there is a similar pattern comparing the age and sex of individuals receiving home care that do and do not receive care during the census week. In financial year 2015/16 (figure 4.4) higher percentages of females are seen in all age groups regardless of whether individuals had received care during the census week. The percentage of females is higher in age groups over 80 for those receiving care during the census week.

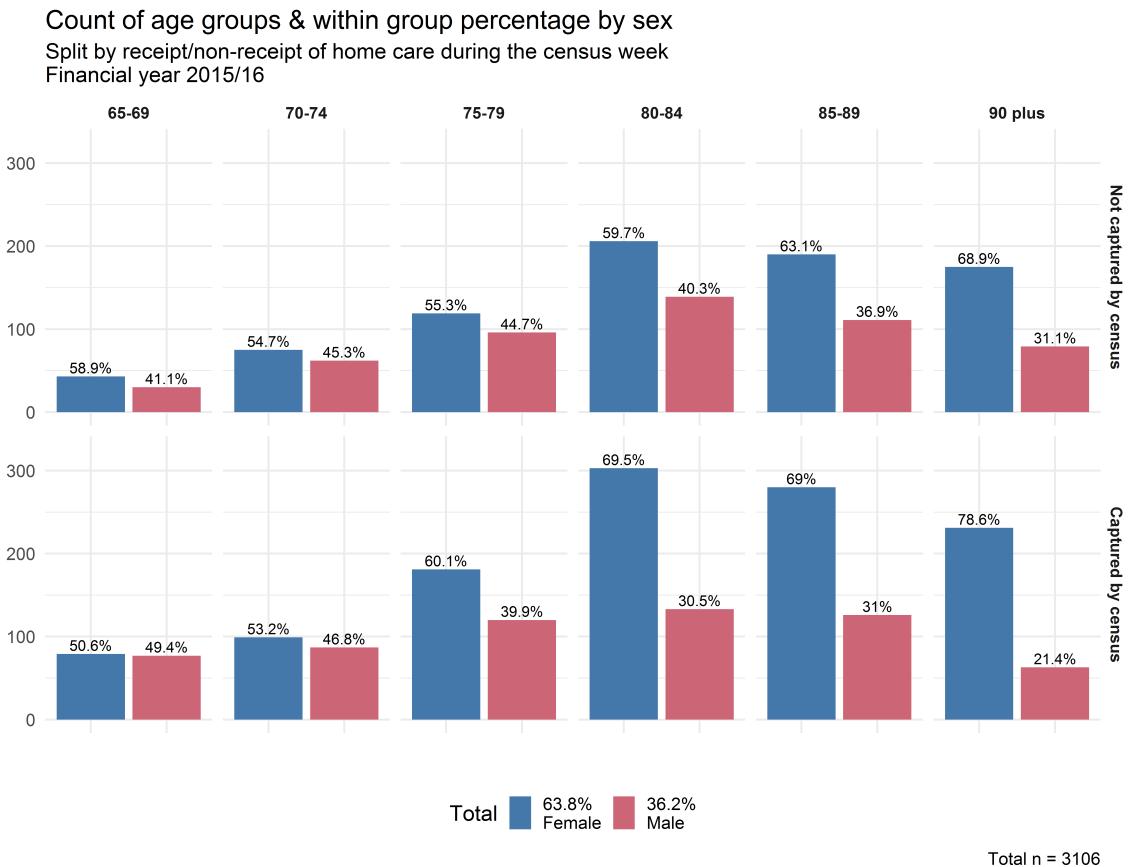


Figure 4.4: Age and sex groups receiving home care

However, given the low overall numbers (3106 total for 2015/16), a small change in any age group can change shift these differences. (*Think I need to show graphs from other years in an appendix. There is indeed random variation but I suppose I need to show it OR take the percentage figures out of plot! Pattern would look similar and wouldn't need to explain away the small differences?*).

4.4.3.2 By type of care

The introduction and increasing usage of reablement services over time shown in table 4.3 can be seen clearly in figure 4.5. Notably, from 2013/14 onwards, there are more absolute numbers of individuals who receive this service and are not captured by the SCS census than receive reablement and are included in census counts. There are fewer individuals receiving other type of service in the group not captured by the census, as would be expected given the counts shown in figure 4.3 and table 4.4. Despite this, overall proportions of care receipt are broadly similar.

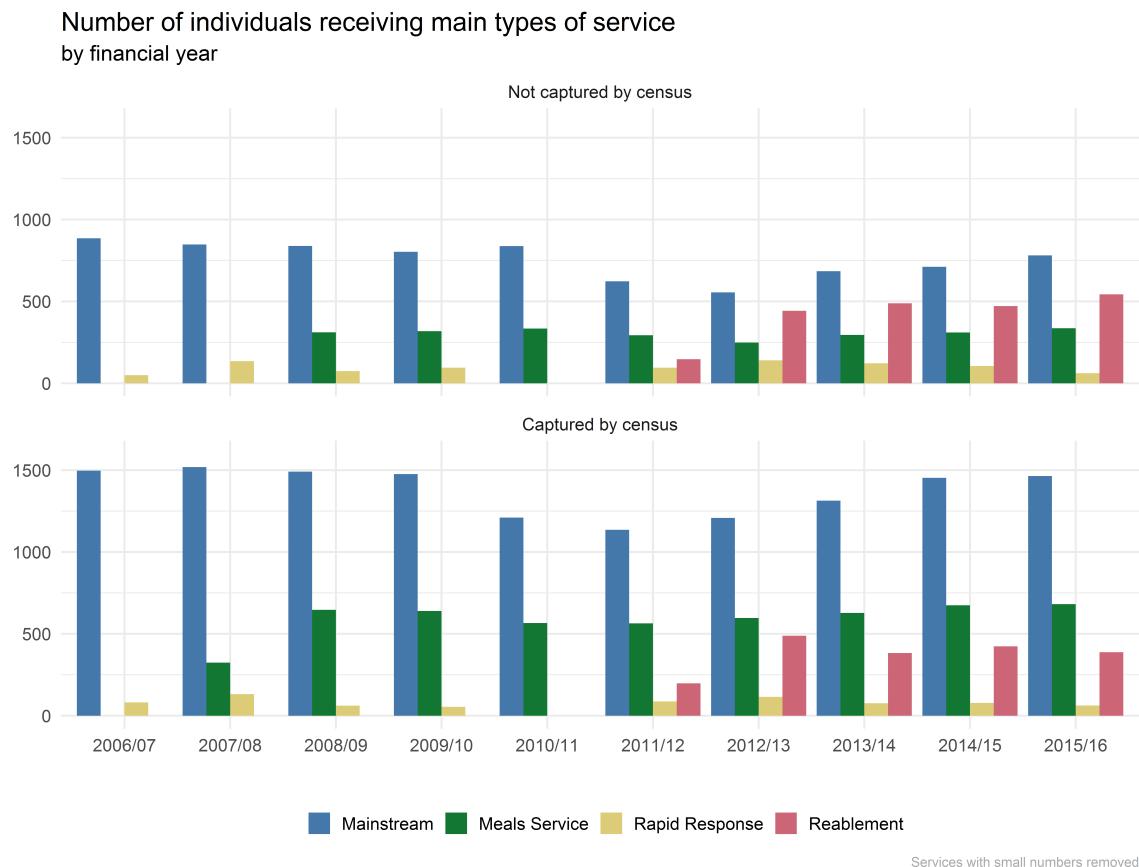


Figure 4.5: Types of home care

4.4.3.3 By duration of care

The median duration of home care for individuals whose care overlaps with the census week in each year is higher than for those whose care does not (figure 4.6). The largest difference in median values is approximately 6 months seen in 2010/11. When broken down by care type (figure 4.7) median values for Mainstream and Meals services are higher than seen in figure 4.6 whilst values for Rapid Response and Reablement services are notably lower. Distribution and median values are slightly larger for Mainstream and Meals services for those captured during the census week of each financial year.

Subsetting the data to consider only those missing from the census in each financial year (by definition receiving less than 52 weeks of care) and calculating duration of care from the beginning of the financial year to the termination of care reveals even distributions across care types (figure 4.8). Some variation is seen, particularly with Rapid Response services, which is likely to reflect smaller numbers of individuals receiving care. Median values range from approximately 23-24 weeks at lowest, to approximately 30-31 weeks at highest.

**Distribution of duration of care
from home care start date to census week
in each financial year**

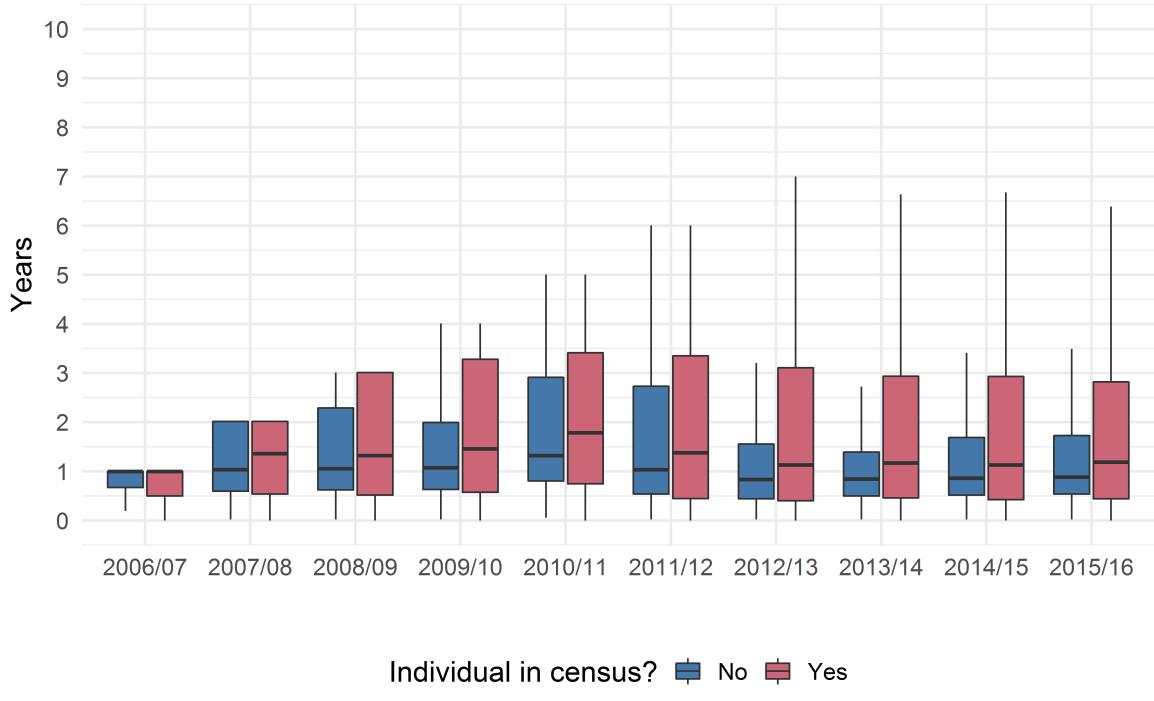


Figure 4.6: Duration of home care

**Distribution of duration of care, from home care start date
to census week in each financial year
by home care type and receipt/non-receipt of care in census week**

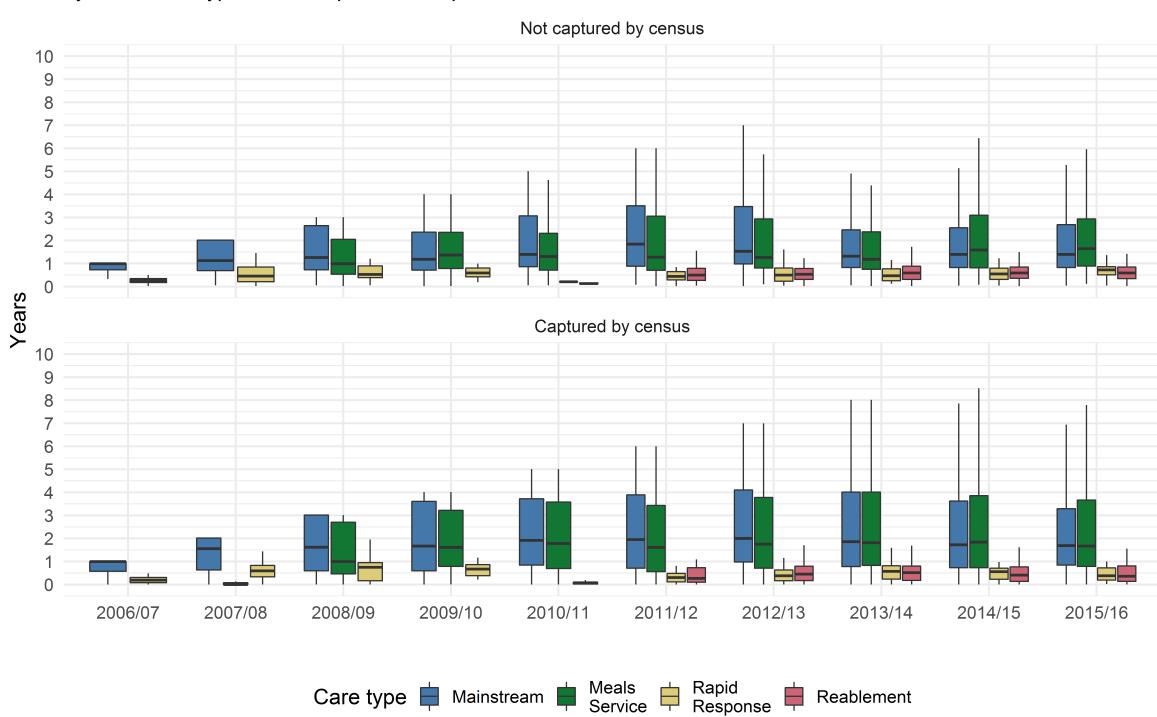


Figure 4.7: Duration of home care, by home care type

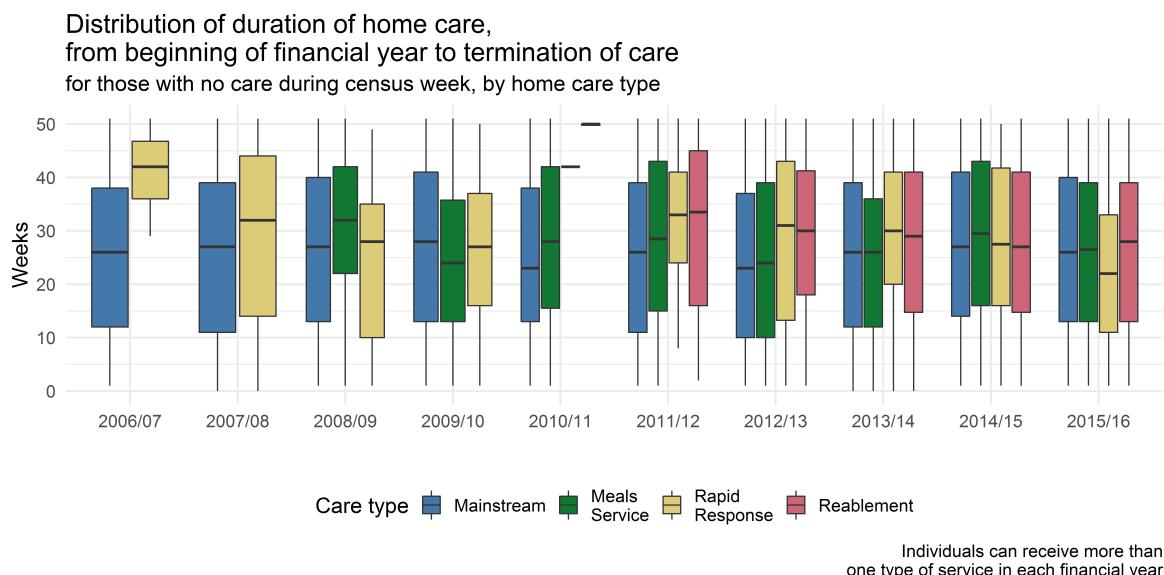


Figure 4.8: Duration of home care within financial years, by home care type

4.4.3.4 By average total weekly hours of care received

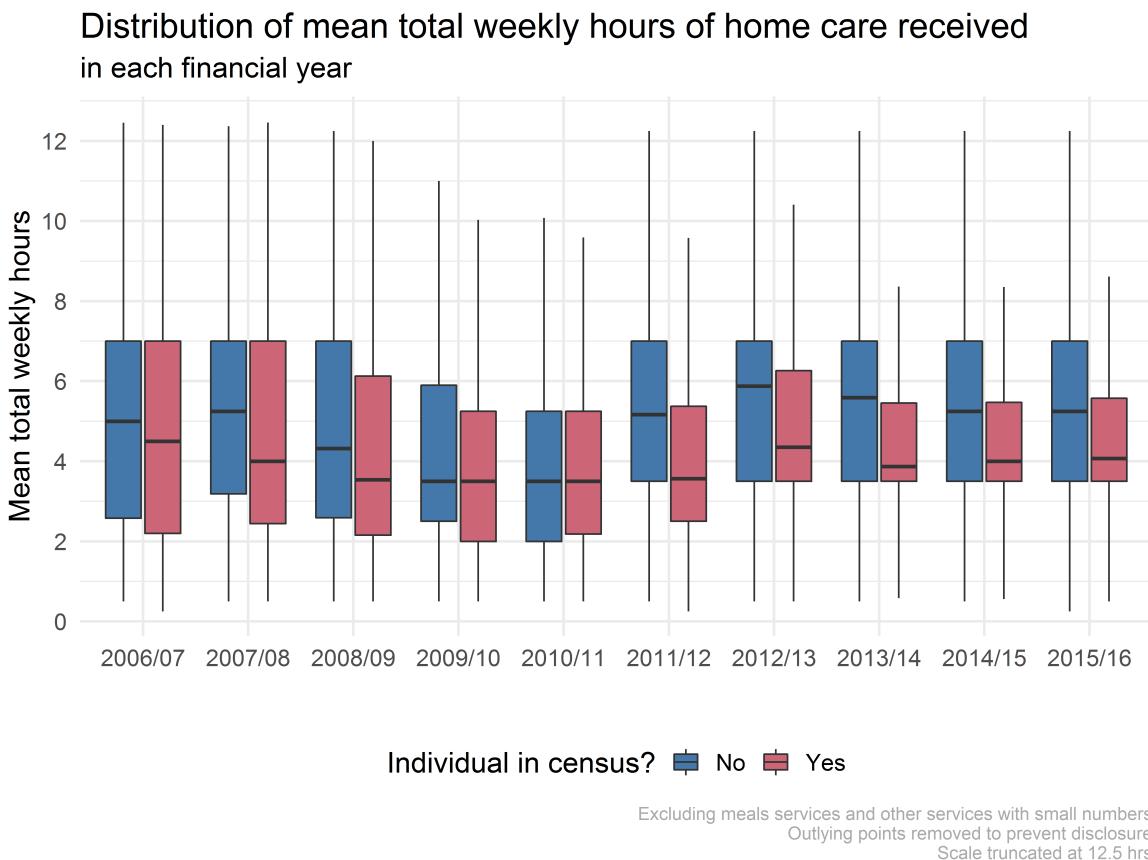


Figure 4.9: Total weekly hours of home care

Figure 4.9 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. A likely cause of this pattern is the increase in usage of Reablement services (figure 4.10). 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).

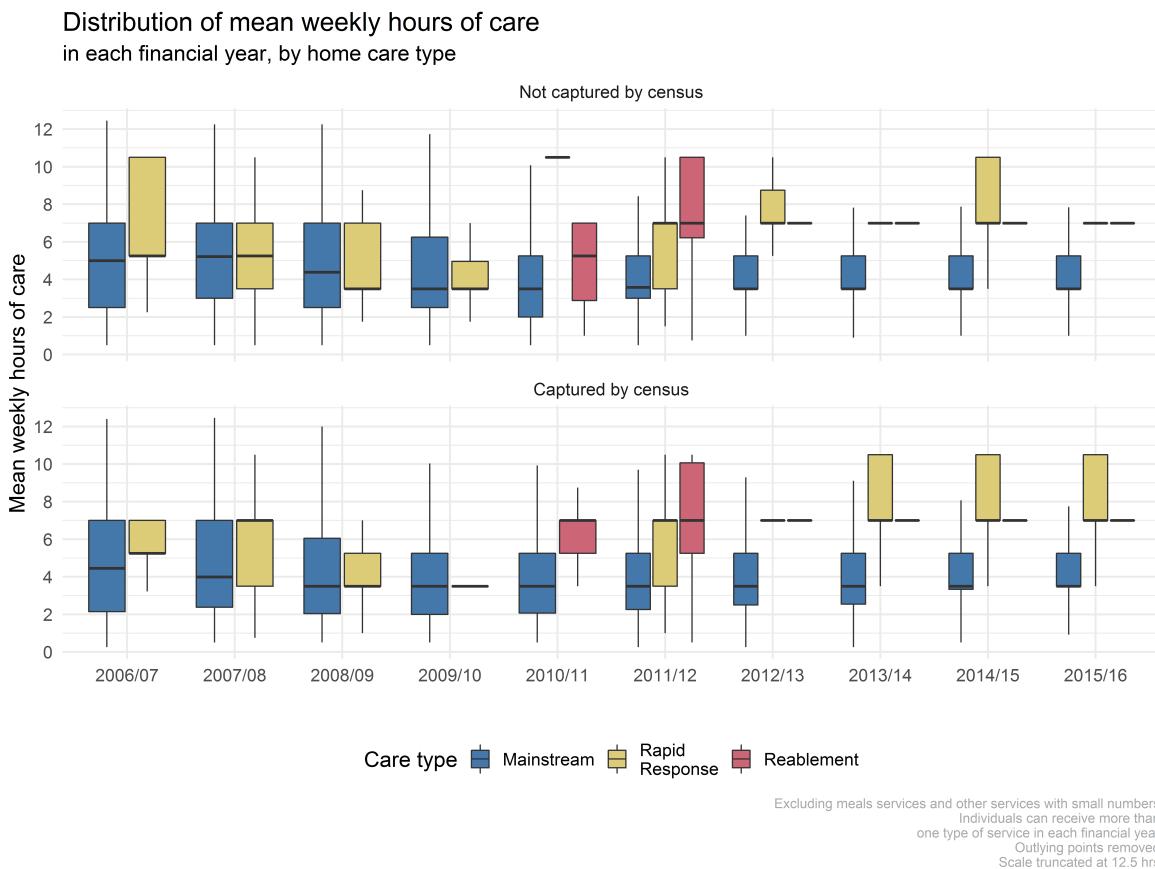


Figure 4.10: Total weekly hours of home care, by care type

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. Assessing the percentage of individuals captured in the census over time shows a small decrease from 2010/11 onwards which coincides with the introduction of Reablement home care services. These services tend to be shorter in duration of care and are delivered with a higher intensity (measured by average hours of care delivered per week). Collecting home care data over a census quarter, rather than a census week, would result in approximately 70% of home care users being captured in the SCS.

There are no stark differences in age and gender between individuals that are missed compared to those captured by the SCS census. The types of home care received across these groups is also similar. As expected, given the percentages of those captured in the census, the number of individuals receiving each type of service is higher in the captured group with the exception of Reablement type services. Following its introduction in 2010/11, the number of users of Reablement service missed by the census increased over time and absolute numbers are higher than those in the captured group in later years.

This is important given the very different aim of Reablement (and Rapid Response) services and has an impact when measuring the duration and intensity of services.

Those captured in the census tend to have been receiving care for a longer period than those that were missed. This pattern is more evident when broken down by type of care received. Overall, Mainstream and Meals services are delivered for between one and four years, whilst Reablement and Rapid Response services are typically delivered over periods lasting less than one year.

When measuring the duration of home care from the start of a financial year to the termination of care for users *not* captured in the census, there are even distributions across all care types. Given they generally last for less than a year, 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.

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 4.10 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 may be receiving them for between one and four years and also those receiving short forms of care that happen to overlap the census week.

Whilst quantifying the proportion of home care users is useful, interpretation of the coverage of the most recent years of the SCS 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 receive 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.

4.5.2 Limitations

This analysis is limited by the fact that data was obtained from only one local authority area. It is impossible to know if the number of individuals captured or not by the SCS in the Renfrewshire area is indicative of numbers across the country. 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 of the proportion of home care users identified by the SCS in any given financial year. Although generalisation to the whole of Scotland is not possible, 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%.

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 and therefore these differences 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. 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 - Descriptive statistics

This chapter outlines the characteristics of the cohort and distributions of pertinent variables in three sections. The first section contains tabulation and visualisation of counts and percentages of individuals in the cohort overall, 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 final section focusses on deprivation. A table with counts and percentages split by SIMD deprivation quintile is provided plus visualisations of the distribution of SIMD deciles by age & sex and local authority. Where distributions were found to be similar across all years of data a reference year, financial year 2013/14, is used for visualisation purposes. This is the middle year of the study period.

Descriptive statistics of social care and unscheduled care measures are not presented in this chapter but in chapters [6](#) and [7](#) respectively where the focus is on these variables specifically.

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 a least one repeat prescription in any given year, whilst the percentage of individuals using unscheduled care services

Variable	Value	2011/12	2012/13	2013/14	2014/15	2015/16
N in cohort		870896	895100	908295	920639	924325
N died		35870 (4.1)	41701 (4.7)	39348 (4.3)	42365 (4.6)	37992 (4.1)
Sex	Male	382585 (43.9)	395922 (44.2)	404480 (44.5)	412115 (44.8)	415953 (45.0)
	Female	488311 (56.1)	499178 (55.8)	503815 (55.5)	508524 (55.2)	508372 (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	256761 (29.5)	269042 (30.1)	274946 (30.3)	278705 (30.3)	282554 (30.6)
	70-74	206129 (23.7)	208829 (23.3)	211466 (23.3)	214387 (23.3)	215897 (23.4)
	75-79	170452 (19.6)	173474 (19.4)	175400 (19.3)	176745 (19.2)	175279 (19.0)
	80-84	124677 (14.3)	127606 (14.3)	128500 (14.1)	130151 (14.1)	130131 (14.1)
	85-89	73698 (8.5)	74937 (8.4)	75990 (8.4)	77619 (8.4)	77699 (8.4)
	90-94	30732 (3.5)	32711 (3.7)	33710 (3.7)	34150 (3.7)	33432 (3.6)
	95 plus	8447 (1.0)	8501 (0.9)	8283 (0.9)	8882 (1.0)	9333 (1.0)
N with >=1 repeat medicine		775627 (89.1)	795495 (88.9)	807924 (88.9)	818667 (88.9)	821813 (88.9)
Receiving social care		89769 (10.3)	99111 (11.1)	98361 (10.8)	125619 (13.6)	125367 (13.6)
Receiving home care		41642 (4.8)	42149 (4.7)	42746 (4.7)	42232 (4.6)	41172 (4.5)
Resident in care home		36513 (4.4)	33292 (4.0)	31397 (3.7)	29089 (3.3)	28136 (3.2)
>= 1 USC episode		259137 (29.8)	272574 (30.5)	270872 (29.8)	289504 (31.4)	285013 (30.8)
>=1 hospital admission		133153 (15.3)	141868 (15.8)	141745 (15.6)	147757 (16.0)	145741 (15.8)
>=1 A & E attendance		172747 (19.8)	181728 (20.3)	184100 (20.3)	190563 (20.7)	185736 (20.1)

All values n(%) unless otherwise stated

Column-wise percentages within grouped variables

Table 5.1: Characteristics of study population

(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.

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.

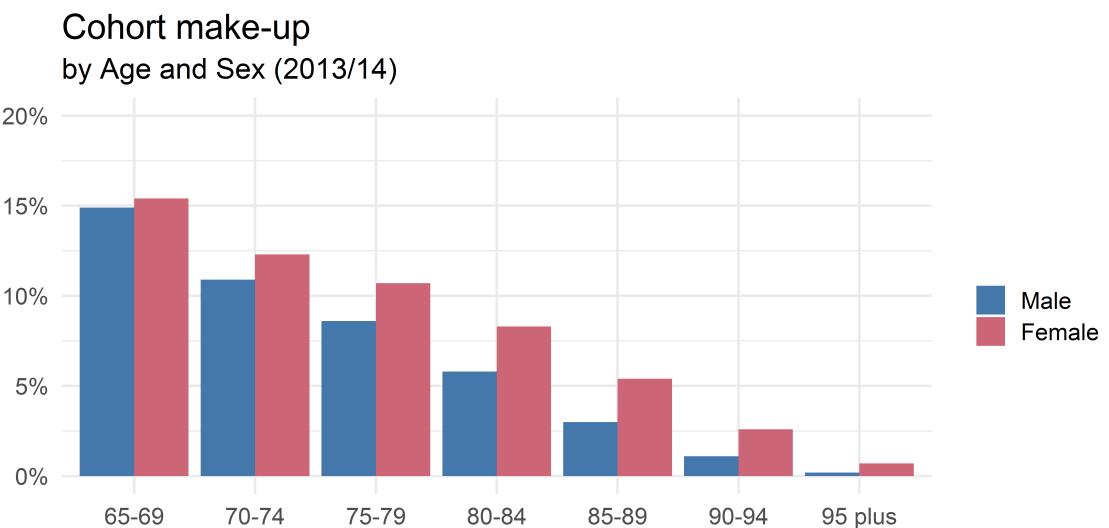


Figure 5.1: Age and sex distribution. N = ?

5.1.3 Mortality

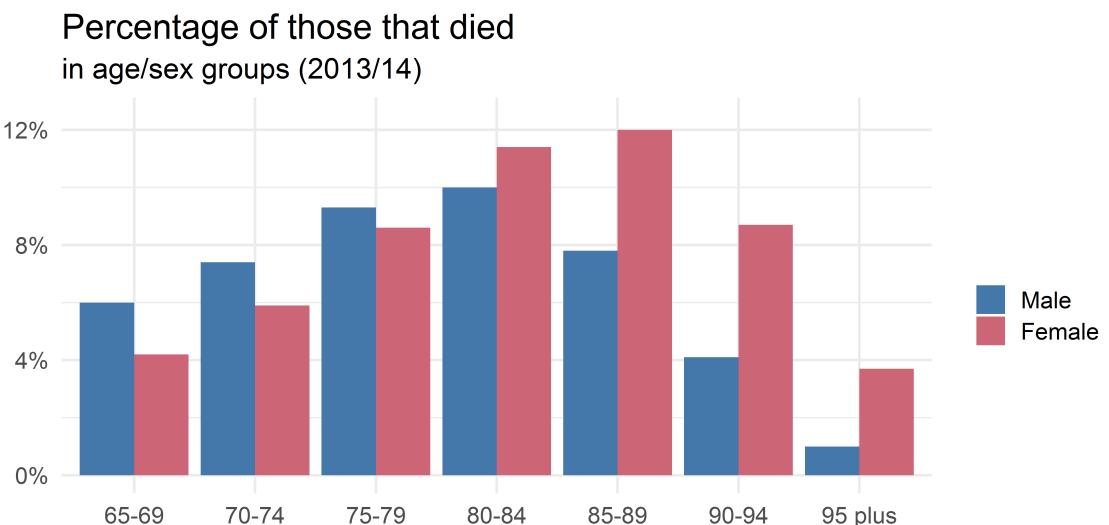


Figure 5.2: Mortality. N = 39,348

In 2015/16, ?% (? individuals) of the cohort died. Figure 5.2 shows how these deaths were distributed across age and sex groups (with similar patterns seen in other years). The highest percentage of deaths (almost ?%) occurred in the 80-84 age group with females accounting for slightly more than half of these. The difference in the percentage of deaths between males and females increases from this group in older age groups, whereas higher percentages of men died in age groups below 80-84.

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.

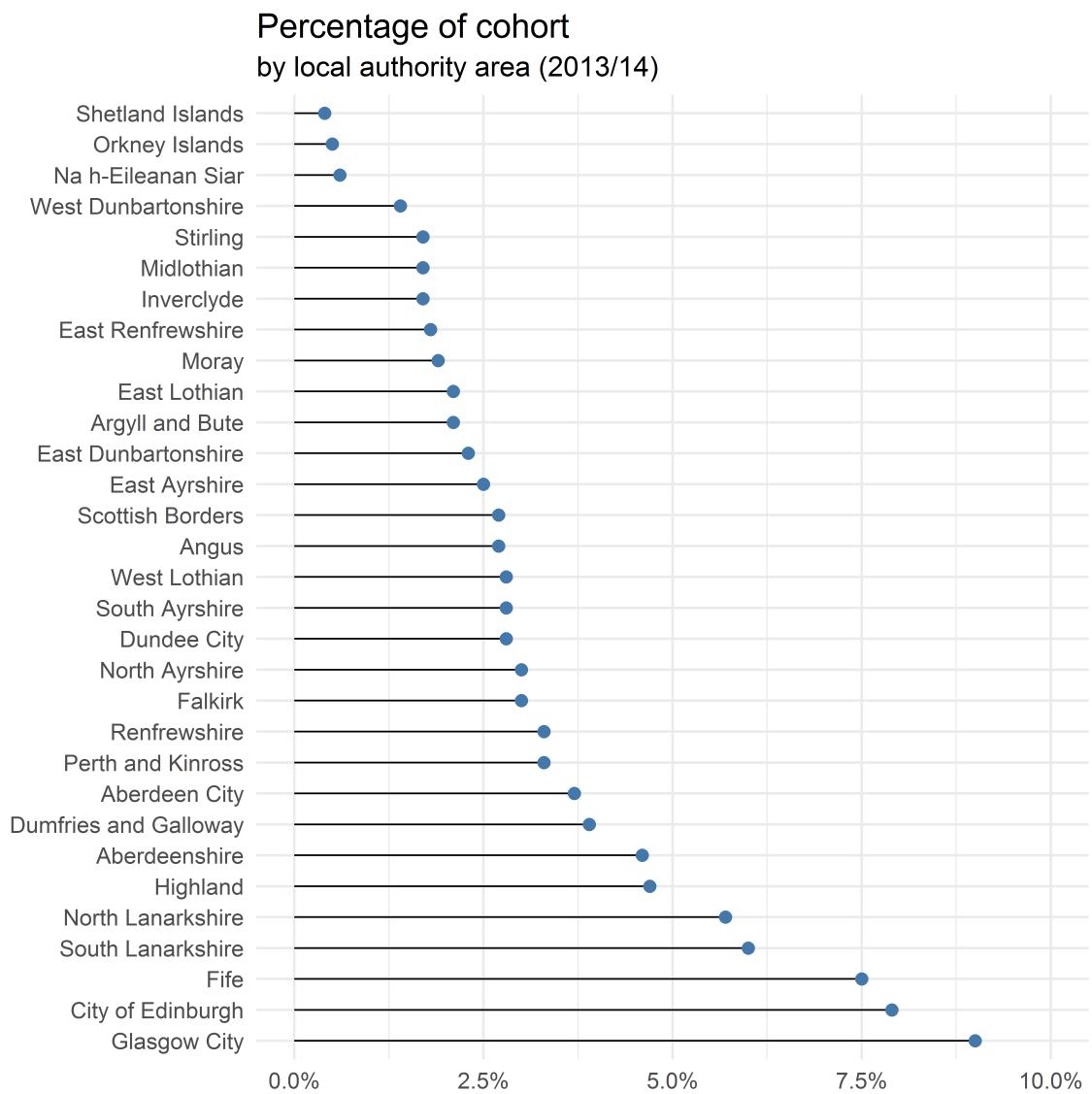


Figure 5.3: Distribution of cohort by local authority. N = 908,295

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.

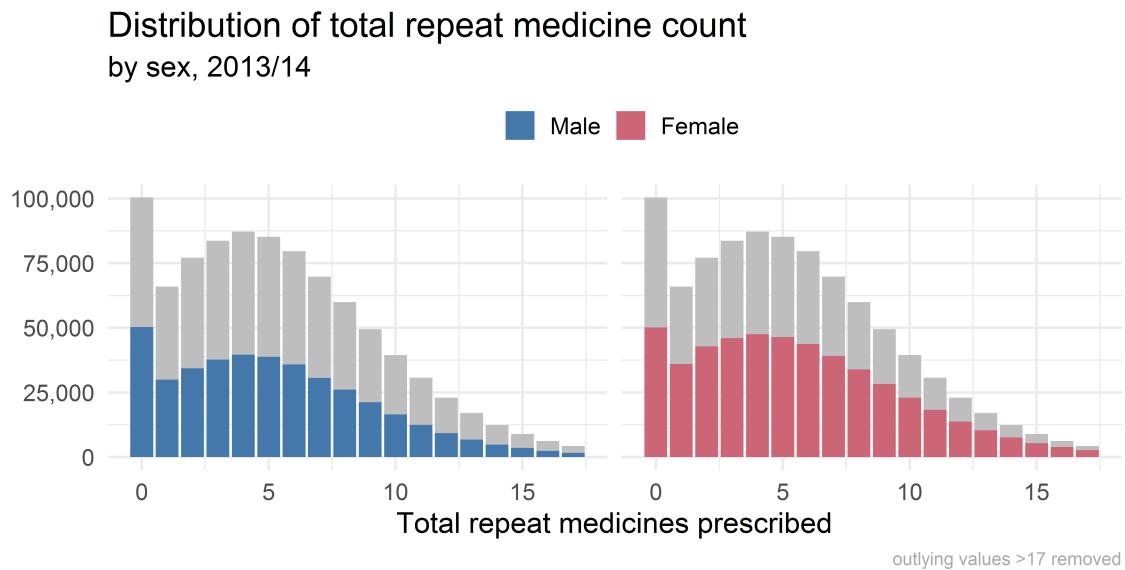


Figure 5.4: Number of individuals receiving specific counts of repeat medicines. N = 908,295

5.2.2 Percentage by sex, age group, and deprivation

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 !!) 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.

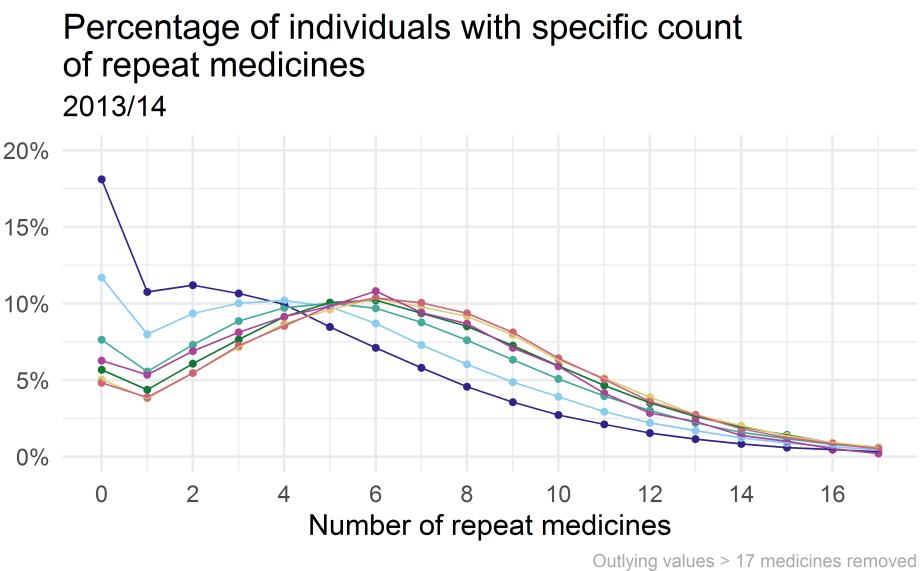


Figure 5.5: Repeat medicine proportion by age group

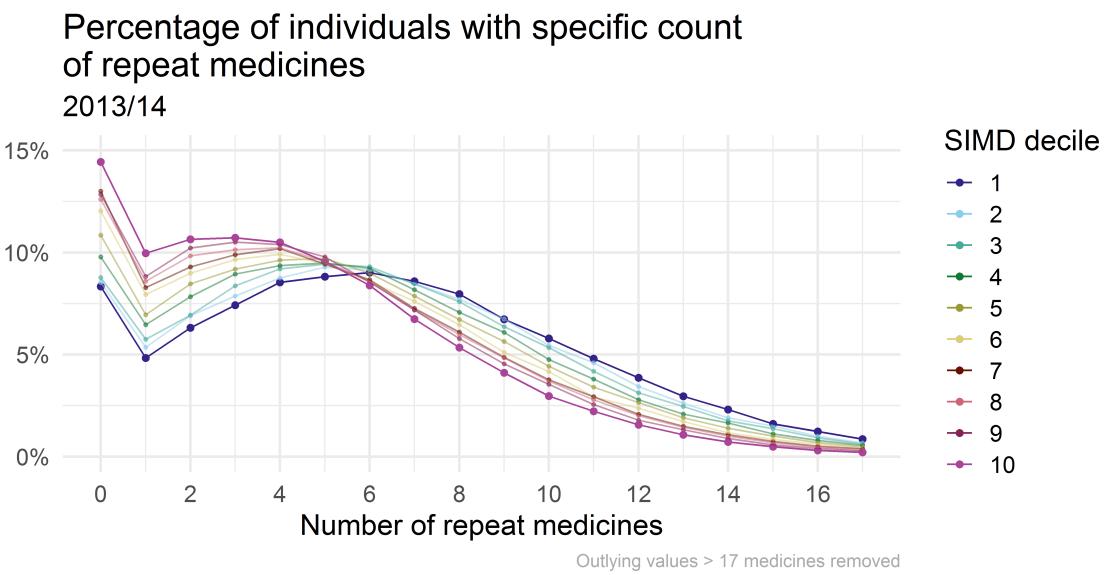


Figure 5.6: Repeat medicine proportion by SIMD decile

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 7.

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.

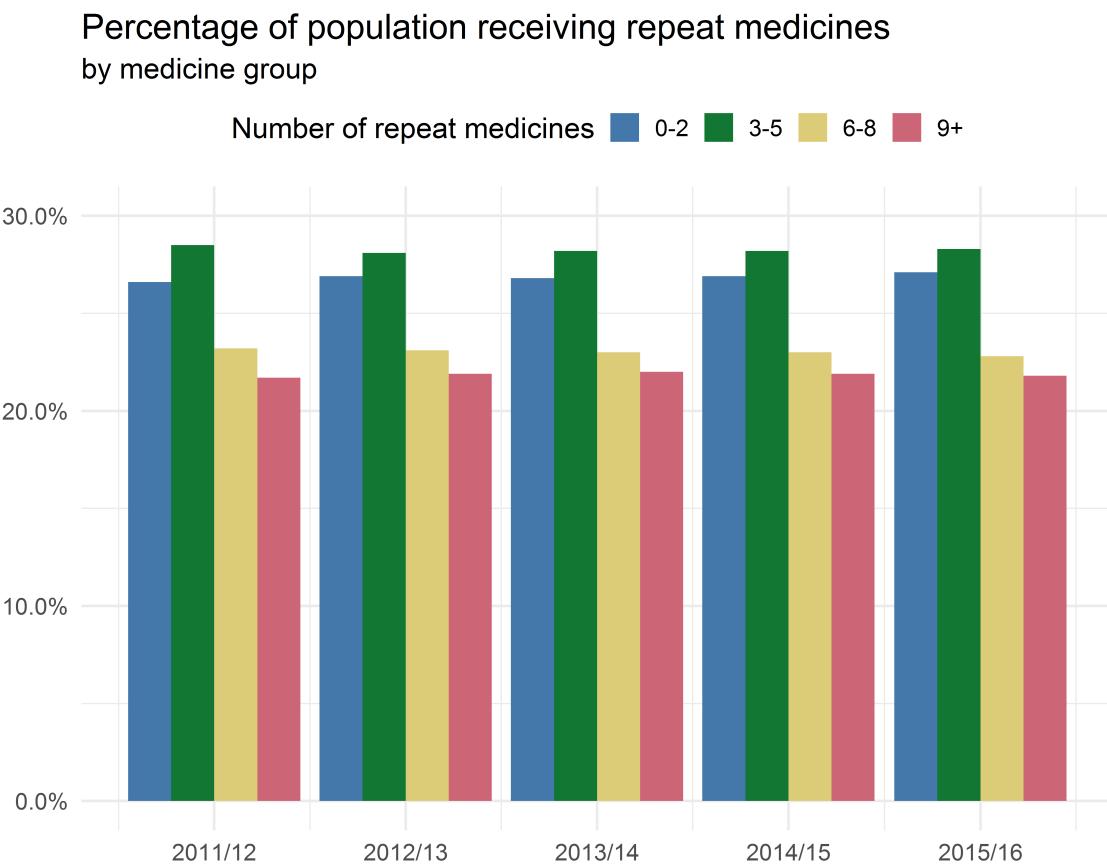


Figure 5.7: Distribution of repeat medicines by group (labelling needs changed)

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 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 plus	Total
Sex	Male	114587 (28.3)	116021 (28.7)	92542 (22.9)	81330 (20.1)	404480
	Female	128812 (25.6)	139958 (27.8)	116708 (23.2)	118337 (23.5)	503815
Mortality	Dead	11033 (28.0)	9163 (23.3)	8145 (20.7)	11007 (28.0)	39348
	Alive	232366 (26.7)	246816 (28.4)	201105 (23.1)	188660 (21.7)	868947
Age	Mean (SD)	71.9 (6.5)	74.4 (7.3)	76.2 (7.6)	76.9 (7.5)	
	65-69	109385 (39.8)	79387 (28.9)	47733 (17.4)	38441 (14.0)	274946
Age grop	70-74	60865 (28.8)	62884 (29.7)	46143 (21.8)	41574 (19.7)	211466
	75-79	35600 (20.3)	49618 (28.3)	45250 (25.8)	44932 (25.6)	175400
	80-84	20506 (16.0)	34127 (26.6)	35731 (27.8)	38136 (29.7)	128500
	85-89	10772 (14.2)	19150 (25.2)	22039 (29.0)	24029 (31.6)	75990
	90-94	4745 (14.1)	8582 (25.5)	9972 (29.6)	10411 (30.9)	33710
	95 plus	1526 (18.4)	2231 (26.9)	2382 (28.8)	2144 (25.9)	8283
SIMD decile	1	15032 (19.1)	19109 (24.3)	19726 (25.1)	24730 (31.5)	78597
	2	17560 (20.5)	21864 (25.5)	21378 (24.9)	24919 (29.1)	85721
	3	20158 (21.2)	25362 (26.7)	23823 (25.0)	25786 (27.1)	95129
	4	22929 (23.8)	26458 (27.5)	23302 (24.2)	23519 (24.4)	96208
	5	25318 (26.0)	27504 (28.3)	22736 (23.4)	21673 (22.3)	97231
	6	28038 (28.8)	28081 (28.8)	21909 (22.5)	19462 (20.0)	97490
	7	28107 (30.4)	27125 (29.3)	20247 (21.9)	17025 (18.4)	92504
	8	27318 (30.9)	26338 (29.8)	19155 (21.6)	15718 (17.8)	88529
	9	28098 (31.7)	27041 (30.5)	18956 (21.4)	14465 (16.3)	88560
	10	30841 (34.9)	27097 (30.7)	18018 (20.4)	12370 (14.0)	88326
Any form of social care	No Social Care	235947 (29.1)	236930 (29.3)	181564 (22.4)	155493 (19.2)	809934
	Social Care	7452 (7.6)	19049 (19.4)	27686 (28.1)	44174 (44.9)	98361
Any USC episode	No USC	203026 (31.9)	195075 (30.6)	139718 (21.9)	99604 (15.6)	637423
	USC	40373 (14.9)	60904 (22.5)	69532 (25.7)	100063 (36.9)	270872

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

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

5.3 Deprivation

5.3.1 Participants

Table 5.3 shows the characteristics of the cohort broken down by SIMD deprivation quintiles in financial year 2013/14. Quintile 1 indicated individuals living in the most deprived 20% of Scottish datazones and quintile 5 the most affluent. Of the 39,348 deaths in 2013/14, a higher percentage (22.8%) are found in quintiles 1 & 2. Only 15.3% of deaths were recorded for individuals living in the most affluent 20% of datazones.

Overall there were smaller absolute numbers of individuals living in quintile 1 datazones than in other quintiles. This pattern was present for both Males (17.5%) and Females (18.5%) and across all age groups. The average age of participants (between 74 and 75 years old) was similar across all deprivation quintiles.

There was a smaller average number of repeat medicines prescribed to those in quintile 5 (4.7, SD 3.7) compared to those in quintile 1 (6.5, SD 4.4). A positive linear trend is observable in the numbers and percentages receiving 0-2 repeat medicines from quintile 1 (32,592, 13.4%) to quintile 5 (58,939, 24.2%). The opposite (i.e. a negative linear trend) is observed for numbers and percentages of those receiving over 9 repeat medicines from quintile 1 (49,649, 24.9%) to quintile 5 (26,835, 13.4%).

Variable	Value	Quintile 1 (most deprived)	Quintile 2	Quintile 3	Quintile 4	Quintile 5 (most affluent)	Total
Mortality	Died	8959 (22.8)	8962 (22.8)	8349 (21.2)	7046 (17.9)	6032 (15.3)	39348
Sex	Male	70907 (17.5)	83011 (20.5)	87587 (21.7)	82626 (20.4)	80349 (19.9)	404480
	Female	93411 (18.5)	108326 (21.5)	107134 (21.3)	98407 (19.5)	96537 (19.2)	503815
Age	Mean (SD)	74.7 (7.3)	74.9 (7.4)	74.6 (7.4)	74.5 (7.5)	74.6 (7.5)	
Age group	65-69	47882 (17.4)	55306 (20.1)	59210 (21.5)	57137 (20.8)	55411 (20.2)	274946
	70-74	38889 (18.4)	44234 (20.9)	45917 (21.7)	42256 (20.0)	40170 (19.0)	211466
	75-79	32993 (18.8)	38296 (21.8)	37087 (21.1)	33792 (19.3)	33232 (18.9)	175400
	80-84	24116 (18.8)	28154 (21.9)	27036 (21.0)	24593 (19.1)	24601 (19.1)	128500
	85-89	13441 (17.7)	16486 (21.7)	16187 (21.3)	14771 (19.4)	15105 (19.9)	75990
	90-94	5662 (16.8)	7211 (21.4)	7453 (22.1)	6728 (20.0)	6656 (19.7)	33710
	95 plus	1335 (16.1)	1650 (19.9)	1831 (22.1)	1756 (21.2)	1711 (20.7)	8283
Total repeat medicines	Mean (SD)	6.5 (4.4)	6 (4.2)	5.4 (4.1)	5 (3.9)	4.7 (3.7)	
Medicines group	0-2	32592 (13.4)	43087 (17.7)	53356 (21.9)	55425 (22.8)	58939 (24.2)	243399
	3-5	40973 (16.0)	51820 (20.2)	55585 (21.7)	53463 (20.9)	54138 (21.1)	255979
	6-8	41104 (19.6)	47125 (22.5)	44645 (21.3)	39402 (18.8)	36974 (17.7)	209250
	over 9	49649 (24.9)	49305 (24.7)	41135 (20.6)	32743 (16.4)	26835 (13.4)	199667
Receiving social care		23633 (24.0)	25467 (25.9)	20380 (20.7)	15749 (16.0)	13132 (13.4)	98361
Receiving home care		10206 (23.9)	11145 (26.1)	8843 (20.7)	6920 (16.2)	5632 (13.2)	42746
>=1 episode USC		58410 (21.6)	61517 (22.7)	55668 (20.6)	49048 (18.1)	46229 (17.1)	270872
>=1 hospital admission		32936 (23.2)	33390 (23.6)	29349 (20.7)	24360 (17.2)	21710 (15.3)	141745
>=1 A & E episode		42587 (23.1)	43166 (23.4)	36376 (19.8)	31184 (16.9)	30787 (16.7)	184100

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

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

The largest percentages of individuals receiving social care and unscheduled care services were found in SIMD quintile 2 with decreasing proportions to quintile 5. Levels of social care and unscheduled care use were higher in quintile 1 compared to quintile 3 although still less than seen in quintile 2.

5.3.2 Deprivation by age and sex

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.

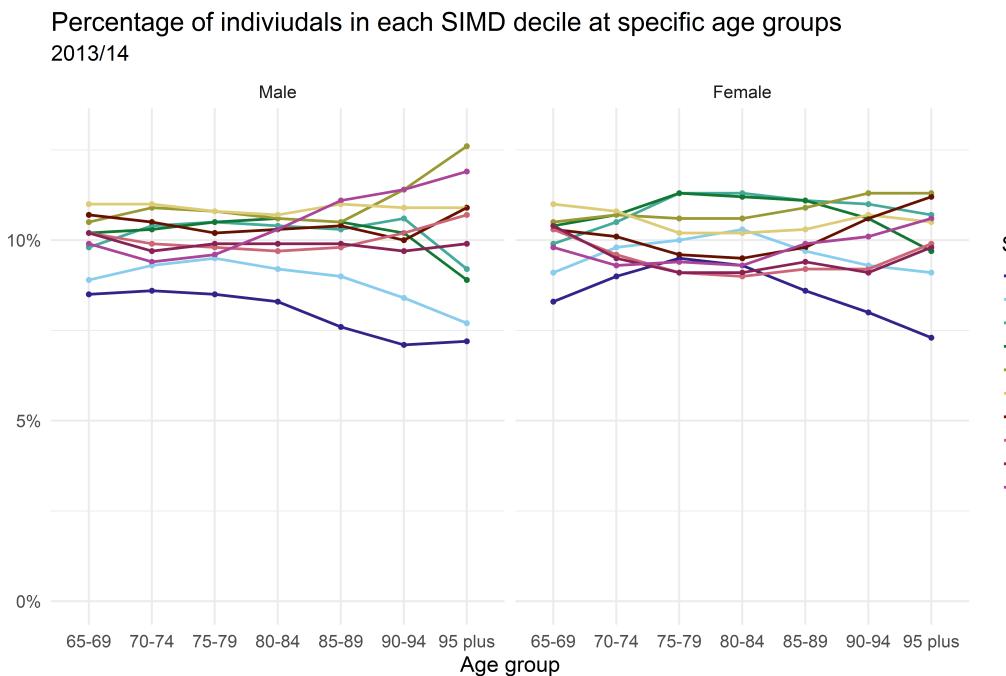


Figure 5.8: Breakdown of population by age group, sex, and SIMD decile (Decile 1 - most deprived)

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)

Chapter 6

Results 2: Social Care and Multimorbidity

This chapter reports results of an analysis conducted to answer research question 1 (link to section). As described in section 3.6.1, 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.

The chapter is split into three sections. The first reports descriptive statistics of receipt of social care for the whole cohort using financial year 2013/14 as a reference year. Plots showing the relationship between the receipt of social care and age, sex, deprivation status, and multimorbidity status are provided.

The remaining sections report results of logistic regression models applied to each year of data for two subsets of the main cohort. The models in the second section were run on a subset of individuals from the nine local authorities where a match rate of over 96% was achieved when linking the SCS to the population spine. The models in the third section were applied to the subset of individuals from the nine local authorities with a match rate of 92-95.9%. These subsets were used to enable comparison of local authorities with similar match rates (thus, similar levels of missing data - section {stats-rq1})

6.1 Overall Descriptive statistics

Figure 6.1 shows that as age increases, higher percentages of individuals receive social care in financial year 2013/14. This pattern is consistent across all years of data. There is an uneven split by sex. Females have higher percentages of individuals receiving any form of social care than males at all ages. At age 85, ~20% of males and ~32% of females received any form of social care. The difference between the percentage of

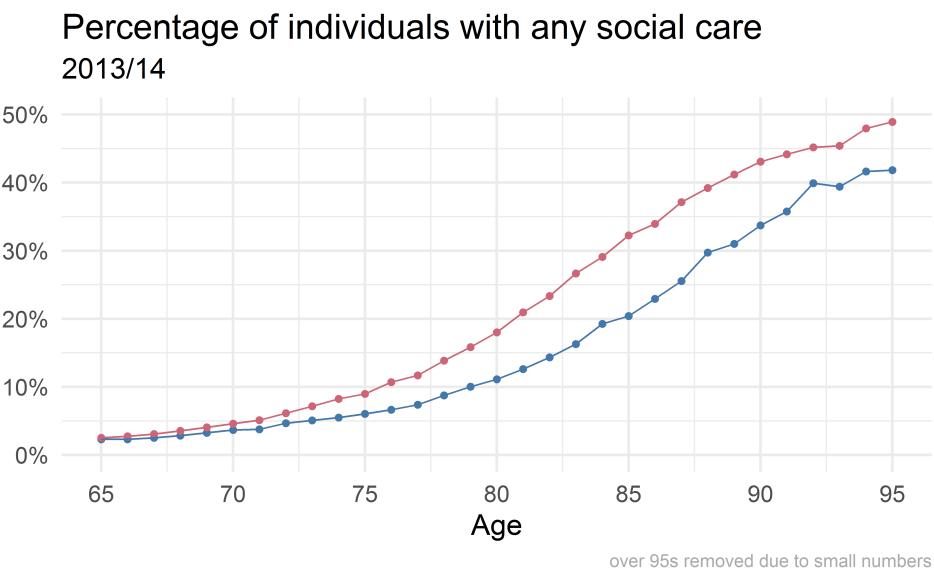


Figure 6.1: Percentage of individuals receiving social care by sex at specific ages. 2013/14

males and females receiving care increases as age increases. There is a mild reduction of this trend over the age of 90.

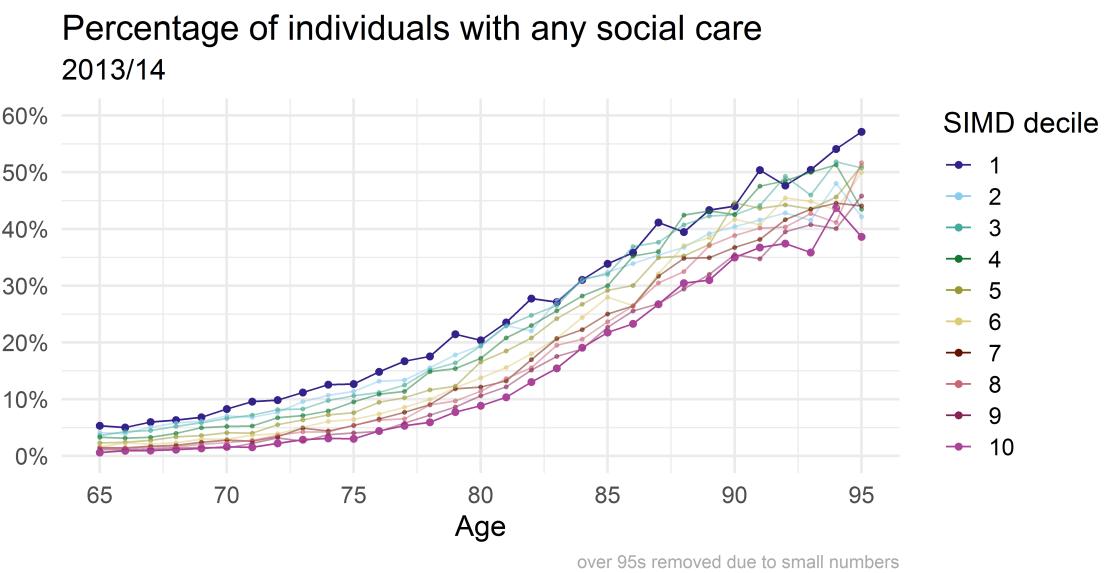


Figure 6.2: Percentage of individuals receiving social care by deprivation at specific ages. 2013/14

Figure 6.2 also shows the increase in the percentage of individuals receiving any form of social care as age increases. The split by SIMD decile shows that those resident in SIMD decile 1 datazones (most deprived) have higher percentages receiving social care at all ages (with the exceptions of ages 88 and 92). There is a clear gradient from decile 1 to decile 10 (most affluent) which has the lowest percentages at all ages (except at over the age of 90 where small numbers introduce wider variation).

A third figure charting the increase in the percentage of individuals receiving any form

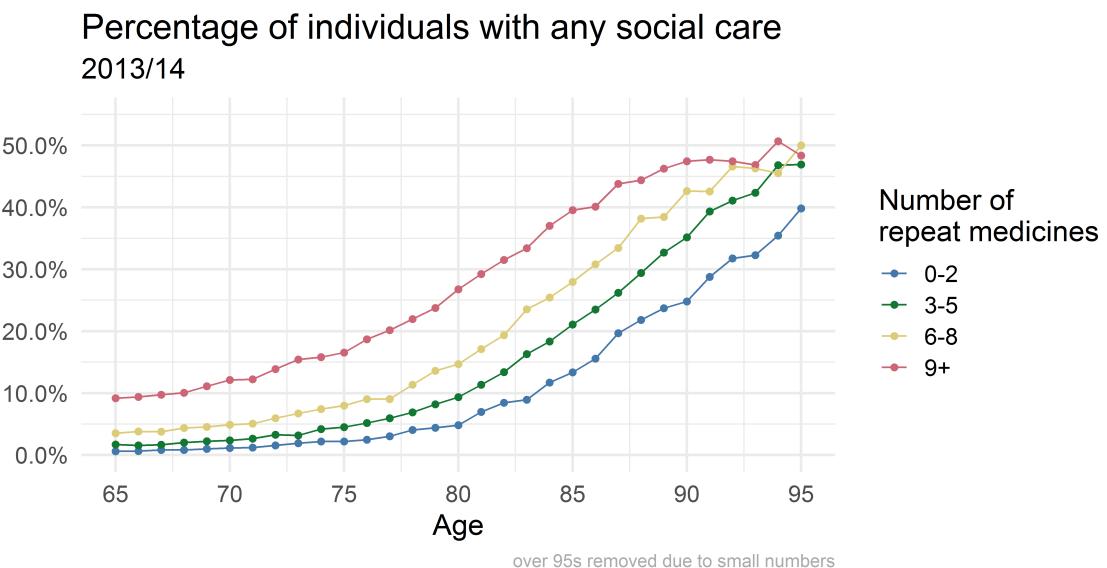


Figure 6.3: Percentage of individuals receiving social care by multimorbidity (repeat medicine) group at specific ages. 2013/14

of social care as age increases in 2013/14 is shown in figure 6.3. The split in this figure shows that individuals receiving nine or more medicines have much higher percentages receiving social care at all ages. For example, ~5% of individuals with 0-2 repeat medicines at age 80 receive some form of social care, whereas ~26% of individuals receiving 9 or more repeat medicines at age 80 are found in the SCS.

6.2 Models for councils with link rate greater than 96%

This section reports results of logistic regression models detailed in section 3.6.1 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.

In total, five models are reported - one for each financial year of data. As cohort data was subset, descriptive statistics of this subset are first reported. This is followed by results of goodness of fit tests applied to each model of data. Model effects are reported as Average Partial Effects (APEs). As with previous results, financial year 2013/14 is used as a reference year where patterns are consistent across all years of data.

Restate model

6.2.1 Descriptive statistics

Table 6.1 shows a breakdown of the cohort in financial year 2013/14. There were a total of 221,763 individuals from the nine included local authority areas in this financial year. A higher percentage of females (15.6%) compared to males (8.5%) received social care. Only 3.1% of those aged 65-69 received social care whereas 71.2% of those over the age of 95 did so. SIMD was modelled as a continuous variable. The median value of 4 (IQR 4) was lower (more deprived) for those that received social care than for those that did not (Median 5, IQR 4). A small proportion (3.3%) of those in the lowest multimorbidity group (0-2 repeat medicines) received social care whereas over a quarter (26.4%) of those in the highest multimorbidity group received care.

Variable	Value	No Social Care	Social Care	Total	p-value
Sex	Male	91792 (91.5)	8538 (8.5)	100330	<0.001
	Female	102532 (84.4)	18901 (15.6)	121433	
Age group	65-69	69238 (96.9)	2205 (3.1)	71443	<0.001
	70-74	51808 (94.1)	3222 (5.9)	55030	
	75-79	38603 (88.8)	4854 (11.2)	43457	
	80-84	22838 (77.0)	6822 (23.0)	29660	
	85-89	9114 (59.5)	6216 (40.5)	15330	
	90-94	2399 (42.0)	3318 (58.0)	5717	
	95 plus	324 (28.8)	802 (71.2)	1126	
	SIMD (continuous variable)	Median (IQR)	5 (4)	4 (4)	<0.001
Repeat medicines group	0-2	56488 (96.7)	1918 (3.3)	58406	<0.001
	03-May	58323 (91.9)	5161 (8.1)	63484	
	06-Aug	44023 (85.3)	7614 (14.7)	51637	
	9 plus	35490 (73.6)	12746 (26.4)	48236	

Total N used in model = 221,763

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 6.1: Characteristics of those receiving/not receiving social care for council with linkage rate 96% - 99.9%. 2013/14

As there was a change in the method of data collection from 2014/15 onwards (described in section 3.3.1), percentages of individuals receiving social care in each local authority is reported across all years of data in table 6.2. With the exception of financial year 2011/12, Falkirk council has the highest proportion of individuals receiving care in all years. Whilst percentages of individuals receiving care are stable across years in some local authorities, there are noticeable increases in values for others from 2014/15 onwards (particularly in North Ayrshire, Dumfries & Galloway and Argyll & Bute).

Local Authority	2011/12	2012/13	2013/14	2014/15	2015/16
Falkirk	14.8	16	15.8	16.8	16.5
Angus	15.8	14.7	14.1	14.6	12.8
East Ayrshire	13.7	13.9	14.1	14.8	14.8
Inverclyde	12.7	13	13	14.1	17.5
South Lanarkshire	12.2	11.9	12.9	13.7	13.2
Stirling	11.7	11.8	12.6	13.1	13.3
North Ayrshire	11.3	11.6	11.9	13.8	13.4
Dumfries and Galloway	9	8.7	8.1	10.6	11.3
Argyll and Bute	8.7	9.1	9.6	12.1	10.8

Table 6.2: Percentage of over 65s receiving social care, by local authority

6.2.2 Goodness of fit

Financial Year	McFadden's pseudo R^2	Deviance	Log Likelihood	Deviance (null model)	Log likelihood (null model)
2011/12	0.252	116463.376	-58231.688	155736.471	-77868.236
2012/13	0.255	119558.387	-59779.194	160465.022	-80232.511
2013/14	0.256	123591.938	-61795.969	166009.028	-83004.514
2014/15	0.264	133386.433	-66693.217	181158.55	-90579.275
2015/16	0.268	133304.348	-66652.174	182135.575	-91067.788

Table 6.3: Goodness of fit for model applied to each year of data

Table 6.3 shows the results of diagnostic tests for the models applied to each financial year of data. McFadden's pseudo R^2 statistic ranges from 0.252 for the model applied to 2011/12 to 0.268 for the model applied to 2015/16. This suggests the the model has an excellent fit to all years of data and gets better in more recent years.

6.2.3 Average Partial Effects

Figure 6.4 plots the Average Partial Effects (APEs) of each model whilst table 6.4 shows the values for the reference year 2013/14 only. Age has the largest positive effect of receiving social care with the probability approximately 60% higher for those over 95 compared to those aged 65-69 in all models (specifically 62.5% in 2013/14). Age bands 90-94, 85-89, and 80-84 also show very strong effects (~50%, ~30%, and ~17% higher probability of receiving social care across all models).

Multimorbidity has a lesser, but still strong, effect on receipt of social care. Those receiving 9 or more repeat medicines are ~17% more likely to receive social care compared to those receiving 0-2 repeat medicines (16.3% in 2013/14). 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.

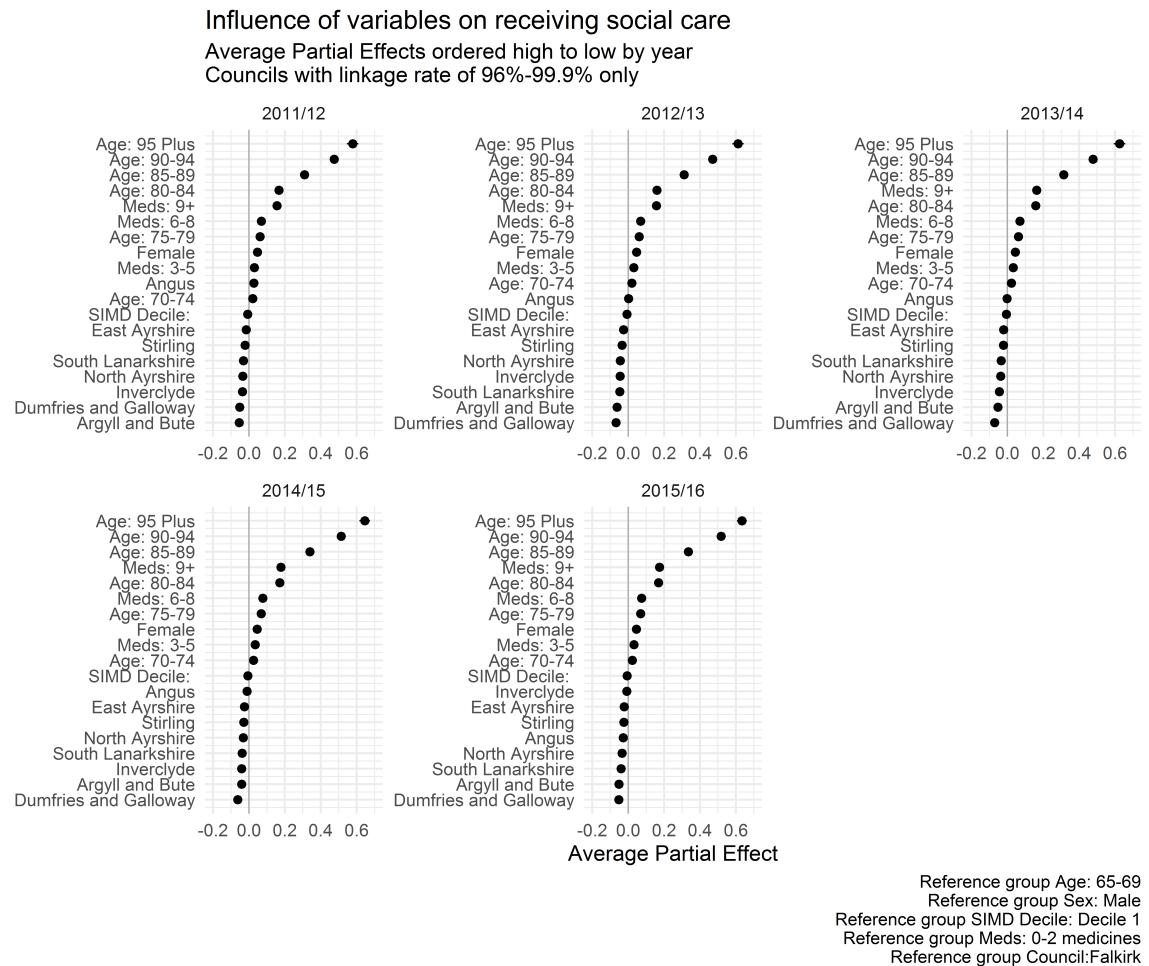


Figure 6.4: Average partial effect plot. Local authorities with linkage rate 96% - 99.9%

Despite large differences seen in percentages between males and females receiving social care (figure 6.1 and table 6.1), after controlling for other variables the APE of being female compared to male is relatively small (a 4.4% increase in probability in 2013/14).

Figure 6.5 shows the conditional effect of SIMD on receipt of social care for individuals living in local authorities with a 96% - 99.9% match rate of SCS records to the population spine. Because SIMD was modelled as a continuous variable the APE of -0.006 shown in table 6.4 indicates an instantaneous effect and represents the coefficient of the slope in figure ref6.5 at the average value of SIMD (5.22, SD 2.60). As the low value indicates, after adjustment for other variables in the model, the conditional effect of SIMD is slight and varies by 1.8% across deciles (0.029 (95%CI 0.025-0.032) in decile 1 to 0.011(95% CI 0.010-0.013) in decile 10).

After adjusting for all other variables in the model there remains variation in the likelihood of receiving social care across local authorities. In some cases this variation is small (e.g. in 2013/14 there is a 0.2% decrease in the probability of receiving social care in Angus compared to Falkirk) but can also have larger values (e.g. a 7% decrease in probability of receiving social care in Dumfries & Galloway compared to Falkirk). The variations in APEs reflect, to some extent, the differences in percentages of individuals

Variable	Average Partial Effect	Lower 95% confidence interval	Upper 95% confidence interval
Age: 95 Plus	0.625	0.592	0.657
Age: 90-94	0.477	0.463	0.49
Age: 85-89	0.314	0.306	0.321
Meds: 9 plus	0.163	0.159	0.167
Age: 80-84	0.158	0.154	0.163
Meds: 6-8	0.07	0.067	0.073
Age: 75-79	0.061	0.058	0.064
Female	0.044	0.042	0.047
Meds: 3-5	0.032	0.029	0.035
Age: 70-74	0.022	0.019	0.024
Angus	-0.002	-0.008	0.005
SIMD Decile:	-0.006	-0.007	-0.006
East Ayrshire	-0.021	-0.027	-0.015
Stirling	-0.022	-0.029	-0.015
South Lanarkshire	-0.035	-0.04	-0.031
North Ayrshire	-0.038	-0.043	-0.033
Inverclyde	-0.045	-0.051	-0.039
Argyll and Bute	-0.053	-0.059	-0.047
Dumfries and Galloway	-0.071	-0.076	-0.066

Reference group for age: 65-69

Reference group for meds: 0-2 repeat medicines

Reference group for sex: Male

Reference group for local authority: Falkirk

Table 6.4: Average partial effects. 2013/14

receiving care reported in table 6.2. This indicates the other variables in the model (namely:age, sex, multimorbidity, and deprivation) and their interactions do not explain the variation at local authority level.

Although figure 6.4 is coded to include error bars plotting the 95% confidence intervals, the intervals are so small they are obscured by the effect point. As an example, in table 6.4, the largest difference between the lower and upper threshold is 0.065 (for age 95 plus). This likely reflects the large number of observations in each model which has the effect of reducing the standard error estimates.

Figure 6.6 charts APEs for each value of each variable (excluding local authority) across all models. There are very small increases in the APE from 2014/15 for age groups over the age of 80 and the 9 and over medicine group. All other variables have consistent APE values across models fitted to each year of data.

Figure 6.7 shows APEs for each councils across all models. Although there appears to be more fluctuation than seen in figure 6.6 the scale of the y-axis is much reduced in this figure. The largest change is seen in Angus council whose APE shows a steady decline with an approximate 0.05 difference between 2011/12 and 2015/16 values.

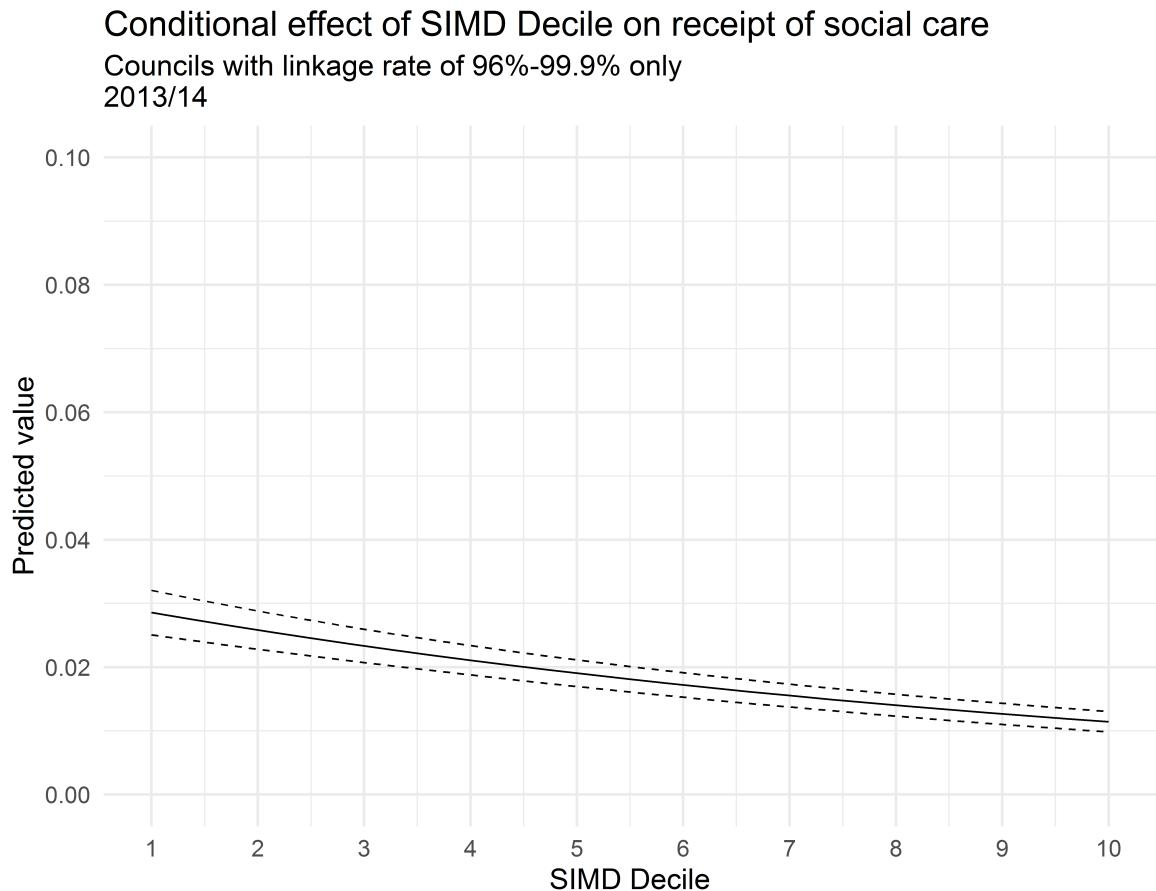


Figure 6.5: Conditional effect of SIMD on receipt of social care

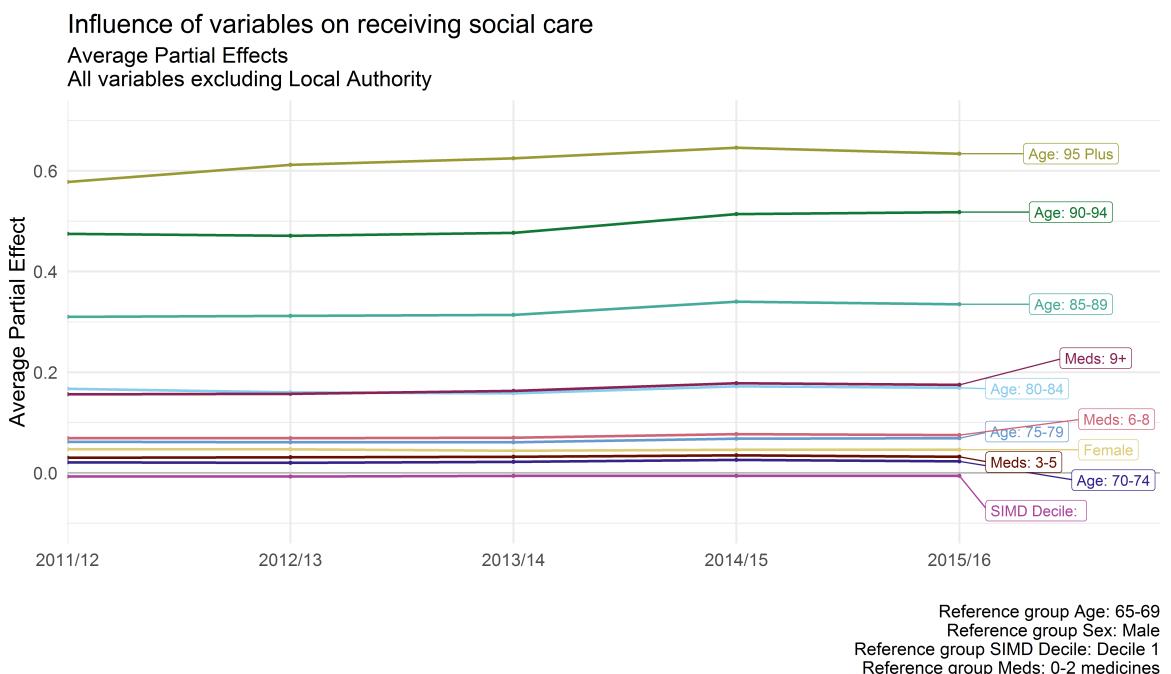


Figure 6.6: Average partial effect across models (a)

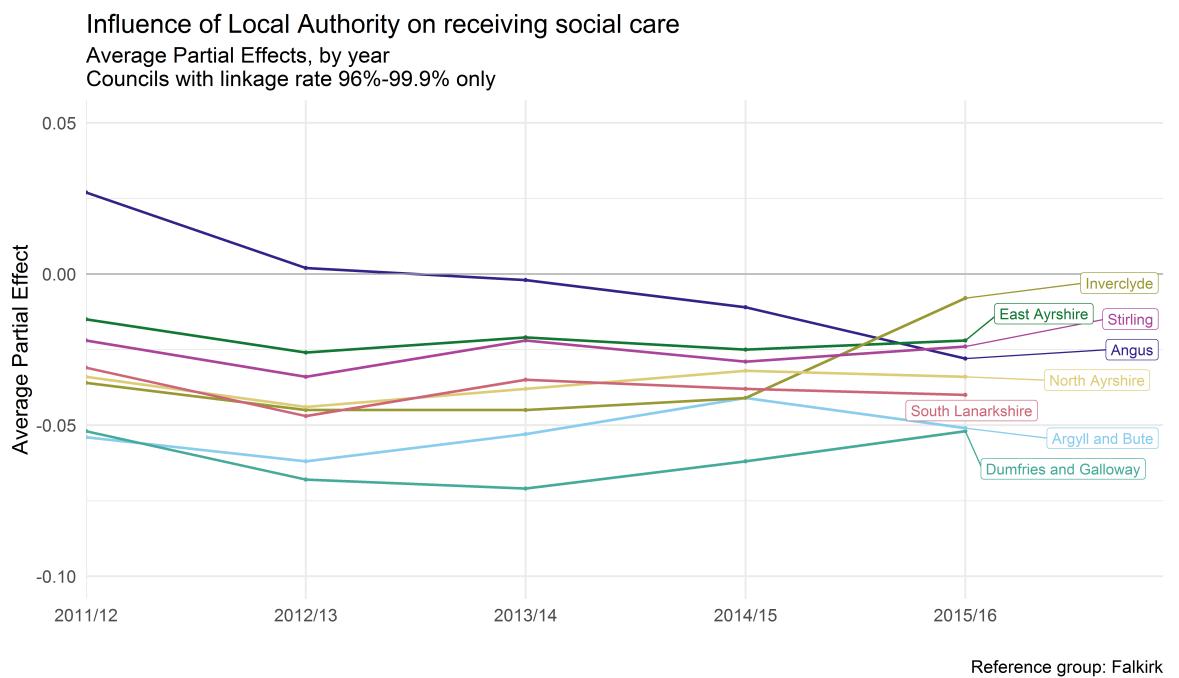


Figure 6.7: Average partial effect across models (b)

6.3 Model for councils with link rate between 92% and 95.9%

This section is a repetition of the previous section 3.6.1 with one main difference. The results are of logistic regression models run with a subset of data including individuals from the nine local authorities where a match rate of between 92% and 95.9% was achieved when linking the SCS to the population spine.

As in the previous section, descriptive statistics of the subset are first reported, followed by goodness-of-fit statistics for each model, and finally model effects reported as APES. Again, financial year 2013/14 is used as a reference year for tables and plots where patterns are consistent across all years of data.

6.3.1 Descriptive statistics

Variable	Value	No Social Care	Social Care	Total	p-value
Sex	Male	123403 (92.7)	9767 (7.3)	133170	<0.001
	Female	149820 (87.2)	22090 (12.8)	171910	
Age group	65-69	90061 (97.4)	2439 (2.6)	92500	<0.001
	70-74	67124 (95.2)	3371 (4.8)	70495	
	75-79	54207 (91.1)	5292 (8.9)	59499	
	80-84	35853 (82.5)	7604 (17.5)	43457	
	85-89	17993 (70.1)	7684 (29.9)	25677	
	90-94	6603 (60.0)	4400 (40.0)	11003	
	95 plus	1382 (56.4)	1067 (43.6)	2449	
	SIMD (continuous variable)	Median (IQR)	6 (6)	5 (6)	<0.001
Repeat medicines group	0-2	79000 (97.1)	2339 (2.9)	81339	<0.001
	03-May	79976 (92.7)	6266 (7.3)	86242	
	06-Aug	61183 (87.2)	8980 (12.8)	70163	
	9 plus	53064 (78.8)	14272 (21.2)	67336	

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 6.5: Characteristics of those receiving/not receiving social care for council with linkage rate 92% - 95.9%. 2013/14

Table 6.5 shows a breakdown of the cohort in financial year 2013/14. There were a total of 305.080 individuals from the nine included local authority areas in this financial year. A higher percentage of females (12.8%) compared to males (7.3%) received social care. Only 2.6% of those aged 65-69 received social care whereas 43.6% of those over the age of 95 did so. SIMD was modelled as a continuous variable. The median vale of 5 (IQR 6) was lower (more deprived) for those that received social care than for those that did not (Median 6, IQR 6). A small proportion (2.9%) of those in the lowest multimorbidity group (0-2 repeat medicines) received social care whereas over a fifth (21.2%) of those in the highest multimorbidity group received care.

Local Authority	2011/12	2012/13	2013/14	2014/15	2015/16
Shetland Islands	18.3	18.4	17.3	15.5	16.6
Glasgow City	14.3	14.7	11.9	11.4	11.8
Na h-Eileanan Siar	11.6	10.8	11.7	12.3	16.9
East Renfrewshire	10.2	9.4	11.3	13.8	18.6
City of Edinburgh	9.7	9.8	10.4	12.6	11.2
East Dunbartonshire	9.8	10.1	9.9	11.8	12.4
Fife	9.3	9.6	9.4	10.9	11.3
Perth and Kinross	8.5	9.4	8.7	13.9	11.3
South Ayrshire	8.5	8.8	8.8	10.5	12.1

Table 6.6: Percentage of over 65s receiving social care, by local authority

As there was a change in the method of data collection from 2014/15 onwards (described in section 3.3.1), percentages of individuals receiving social care in each local authority is reported across all years of data in table 6.6. With the exception of financial year 2015/16, Shetland Islands council has the highest percentage of individuals over 65 receiving care in all years. It also shows a reduction in values after 2014/15 as does Glasgow City council. Other councils have more stable levels for the first three years of data and notable increases from 2014/15 onwards.

6.3.2 Goodness of fit

Financial Year	McFadden's pseudo R^2	Deviance	Log Likelihood	Deviance (null model)	Log Likelihood (null model)
2011/12	0.195	161593.493	-80796.747	200854.348	-100427.174
2012/13	0.199	166393.132	-83196.566	207622.681	-103811.3405
2013/14	0.199	163548.526	-81774.263	204215.311	-102107.6555
2014/15	0.216	177081.266	-88540.633	225815.462	-112907.731
2015/16	0.219	178813.735	-89406.867	228954.547	-114477.2735

Table 6.7: Goodness of fit of model applied to each year of data

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 0.195 for the model applied to 2011/12 to 0.219 for the model applied to 2015/16. The models applied to the most recent two years of data have a good fit, whereas the previous three models are only marginally below the threshold of 0.2 generally regarded as representing an excellent fit.

6.3.3 Average Partial Effects

Figure 6.8 plots the Average Partial Effects (APEs) of each model whilst table 6.8 shows the values for the reference year 2013/14 only. Age has the largest positive effect of

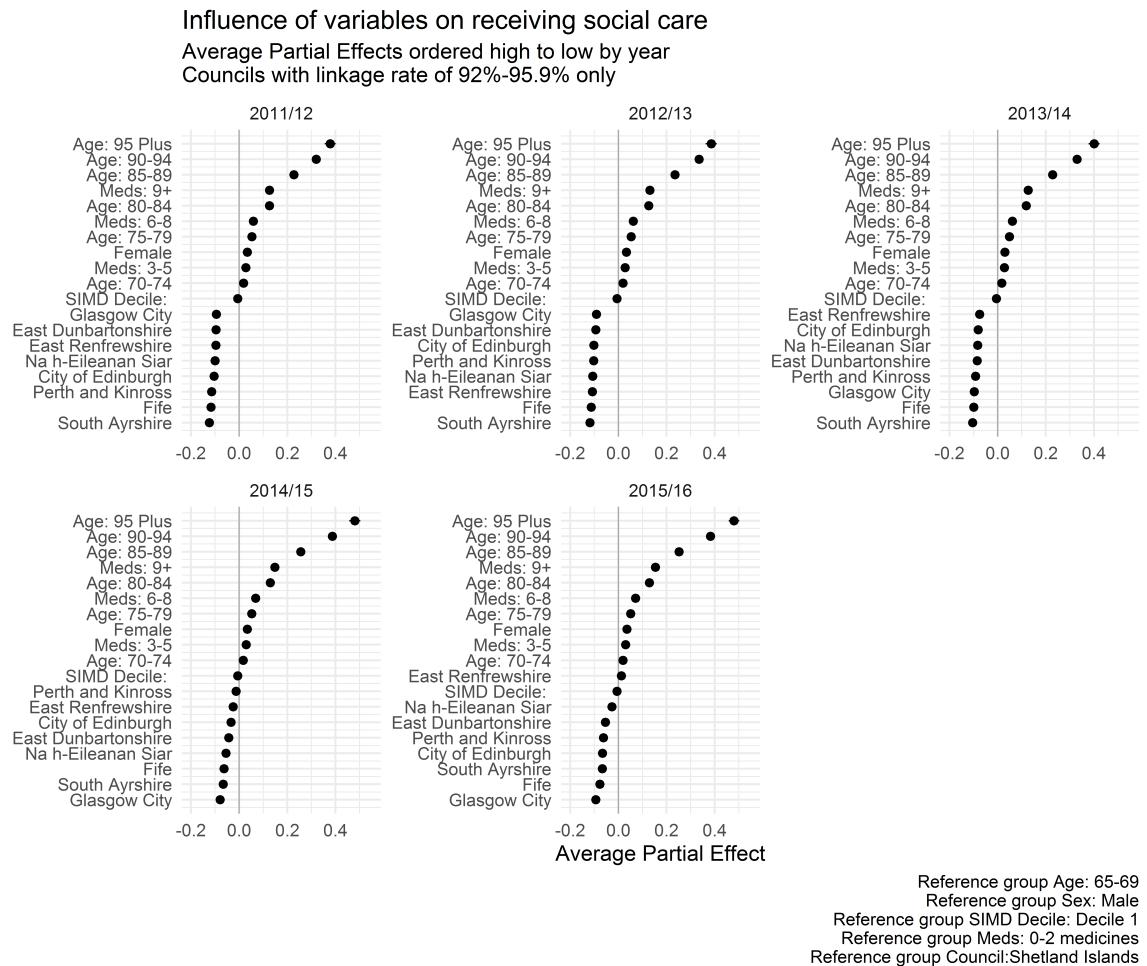


Figure 6.8: Average partial effect plot. Local authorities with linkage rate 92% - 95.9%

receiving social care with the probability approximately 40% higher for those over 95 compared to those aged 65-69 in all models (specifically 40.1% in 2013/14). Age bands 90-94, 85-89, and 80-84 also show very strong effects (~33%, ~20%, and ~12% higher probability of receiving social care across all models).

Multimorbidity has a lesser, but still strong, effect on receipt of social care. Those receiving 9 or more repeat medicines are ~12% more likely to receive social care compared to those receiving 0-2 repeat medicines (12.7% in 2013/14). 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 ~6% and ~3% increased probability of receiving social care compared to those receiving 0-2 medicines.

Despite large differences seen in percentages between males and females receiving social care (figure 6.1 and table 6.5), after controlling for other variables the APE of being female compared to male is relatively small (a 3% increase in probability in 2013/14).

Figure 6.9 shows the conditional effect of SIMD on receipt of social care. SIMD was modelled as a continuous variable, therefore the APE of -0.005 shown in table 6.8 indicates the coefficient of the slope in figure ref6.9 at the average value of SIMD (5.76,

Variable	Average Partial Effect	Lower 95% confidence interval	Upper 95% confidence interval
Age: 95 Plus	0.401	0.378	0.424
Age: 90-94	0.33	0.32	0.34
Age: 85-89	0.228	0.223	0.234
Meds: 9 plus	0.127	0.123	0.13
Age: 80-84	0.119	0.115	0.122
Meds: 6-8	0.061	0.058	0.063
Age: 75-79	0.049	0.046	0.051
Female	0.03	0.028	0.032
Meds: 3-5	0.028	0.025	0.03
Age: 70-74	0.017	0.015	0.019
SIMD Decile:	-0.005	-0.006	-0.005
East Renfrewshire	-0.075	-0.092	-0.058
City of Edinburgh	-0.081	-0.096	-0.065
Na h-Eileanan Siar	-0.083	-0.1	-0.066
East Dunbartonshire	-0.085	-0.102	-0.069
Perth and Kinross	-0.092	-0.108	-0.076
Glasgow City	-0.097	-0.112	-0.081
Fife	-0.099	-0.115	-0.084
South Ayrshire	-0.104	-0.12	-0.088

Reference group for age: 65-69

Reference group for meds: 0-2 repeat medicines

Reference group for sex: Male

Reference group for local authority: Shetland Islands

Table 6.8: Average partial effects. 2013/14

SD 3.10). As the low value indicates, after adjustment for other variables in the model, the conditional effect of SIMD is slight and varies by 1.1% across deciles (0.025 (95%CI 0.023-0.028) in decile 1 to 0.014(95% CI 0.012-0.015) in decile 10).

In models from earlier years (2011/12 - 2013/14) there is a large difference between the APE of all councils compared to Shetland Islands. However, between the other councils there is much less variation in APEs (e.g in 2013/14 there is a 2.9% difference in the probability of receiving social care between the extremes of East Renfrewshire and South Ayrshire). In later models (2014/15 & 2015/16) the variation in APEs has a more linear trend and ranges by ~10% difference in the probability of receiving social care.

As in previous models, confidence intervals are very tight and difficult to visualise. Again, this is likely due to the large number of observations included in the models and the resultant reduction of standard errors.

Figure 6.10 charts APEs for each value of each variable (excluding local authority) across all models. There are increases in the APE from 2014/15 for age groups over the age of 80 and the 9 and over medicine group. This is more marked for older age groups.

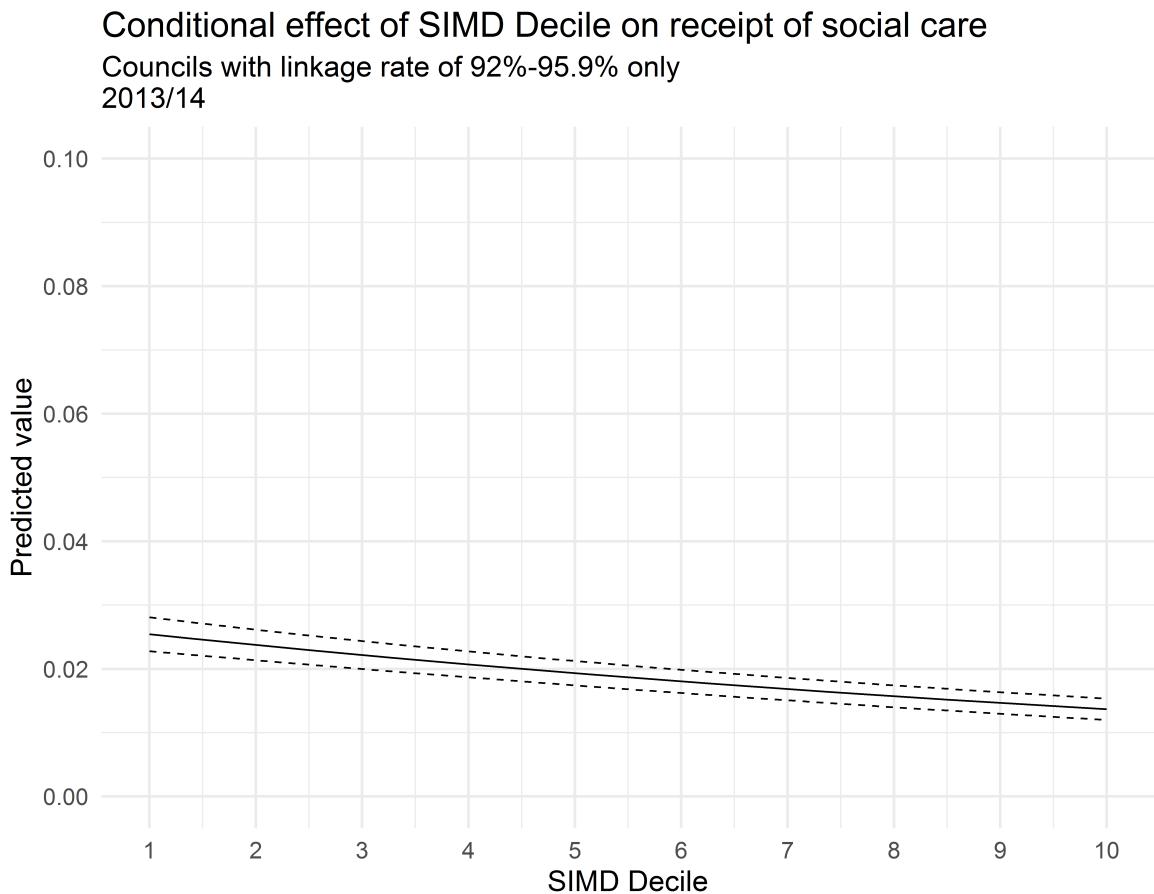


Figure 6.9: Conditional effect of SIMD on receipt of social care

For example there is a ~8% increase in probability of receiving social care for over 95s from 2014/15 onwards. All other variables have consistent APE values across models fitted to each year of data.

Figure 6.11 shows APEs for each council across all models. The most notable trend is the decrease in APEs across all councils in 2014/15 compared to Shetland Islands. This size of this decrease is larger in some councils (e.g. Perth & Kinross ~ 0.07) compared to others (e.g. Glasgow City ~ 0.02). Again the difference in scale compared to figure 6.10 should be noted. The relative size of the differences in APE is small in comparison to, for example, the difference between the APE of being 95 plus in 2013/14 and 2014/15 seen in the previous figure.

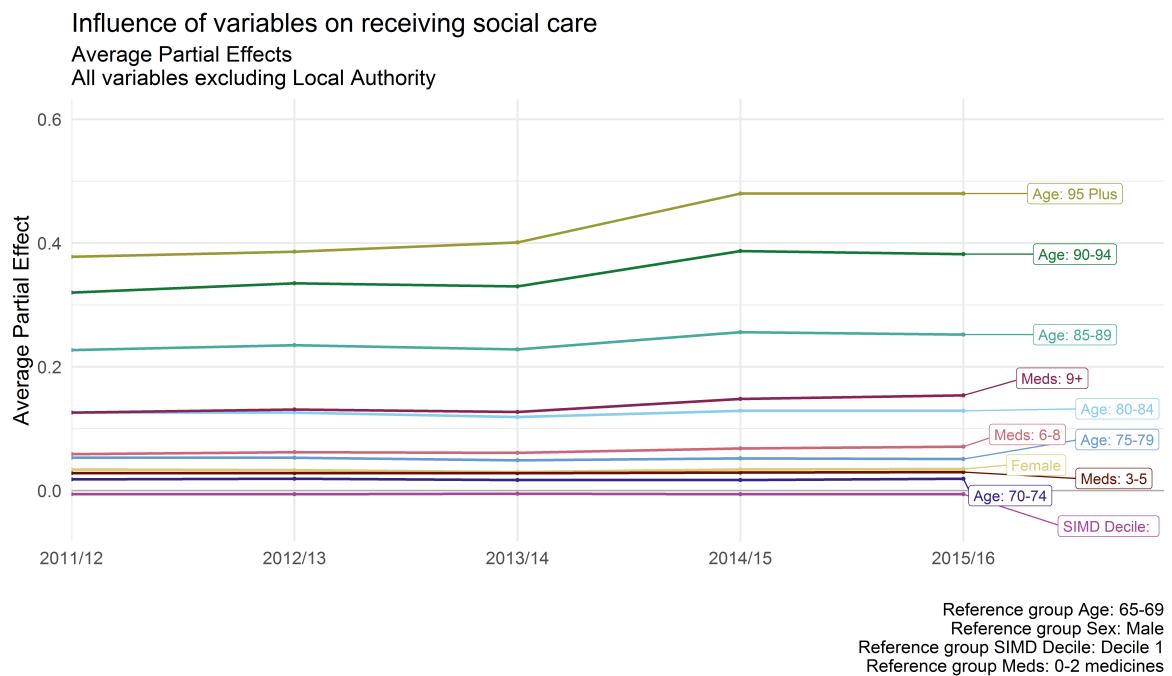


Figure 6.10: Average partial effect across models (a)

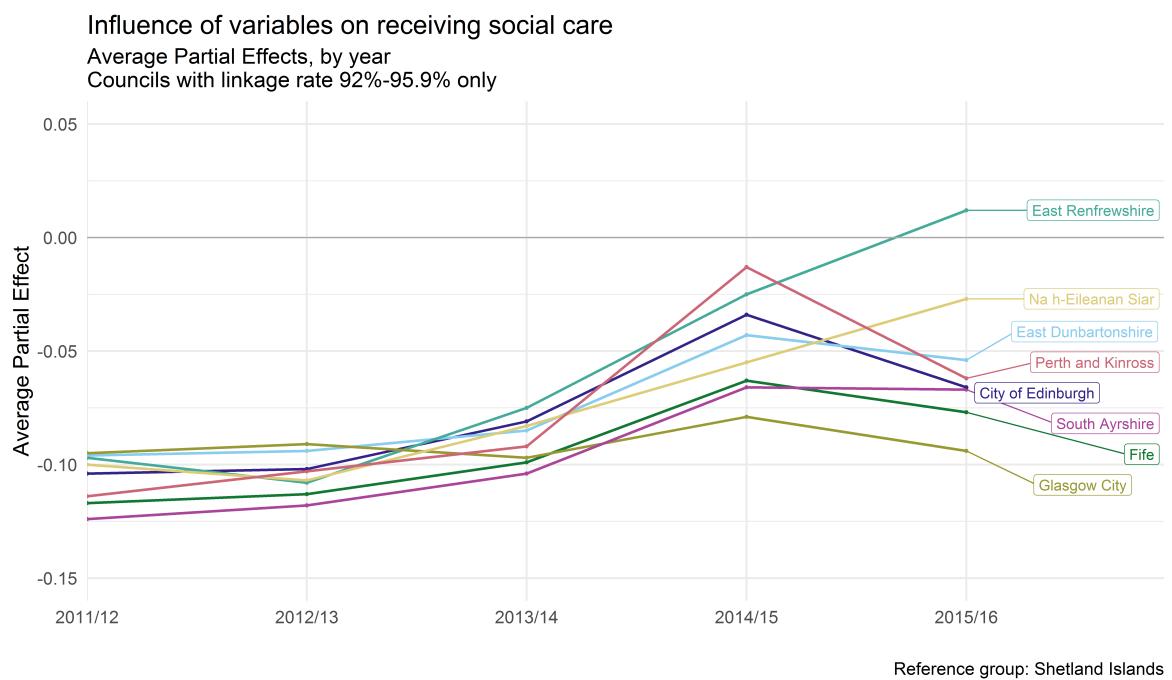


Figure 6.11: Average partial effect across models (b)

Chapter 7

Results 3: Social care, multimorbidity, and unscheduled health care use

This chapter reports results of an analysis conducted to answer research question 2 (link to section). As described in section 3.6.2, receipt of unscheduled care was measured in three ways: presence of any unscheduled care episode in the unscheduled care data mart (including acute hospital admission, A & E, NHS24, GP OOH, or SAS), and specifically by any admission to hospital or attendance at A & E as outcomes in their own right.

The chapter is split into three sections. The first reports descriptive statistics of receipt of unscheduled care for the whole cohort using financial year 2013/14 as a reference year. Plots showing the relationship between the receipt of unscheduled care and age, sex, deprivation status, and multimorbidity status are provided.

The remaining sections report results of logistic regression models applied to each year of data for each of the three outcome measures. Contingency tables of each outcome measure by sociodemographic characteristics, model diagnostics in the form of goodness-of-fit tables, and plots depicting Average Partial Effects (APEs) for included independent variables are provided in each of these sections.

7.1 Overall Descriptive statistics

Figure 7.1 shows that as age increases, there are higher percentages of individuals receiving any form of USC in 2013/14. This pattern is consistent across all years of data. Unlike the corresponding plot for social care (figure 6.1), there are no major differences in the percentages of males and females using USC. Approximately one in

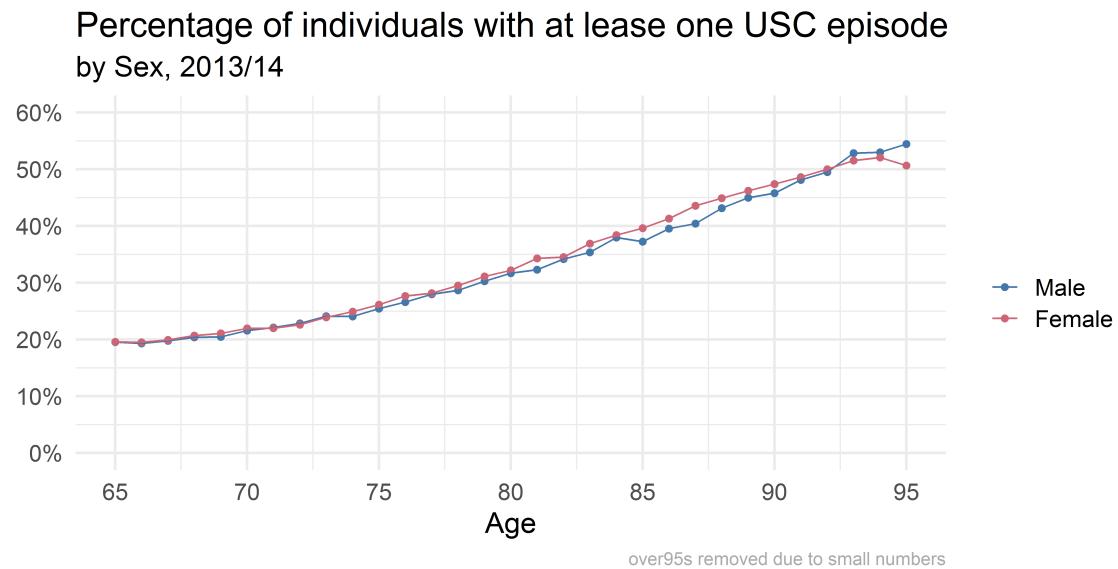


Figure 7.1: Percentage of individuals using USC by sex at specific ages. 2013/14

five of those aged 65 used USC in 2013/14, compared to approximately one in three of those aged 80, and over half of those aged 93 and above.

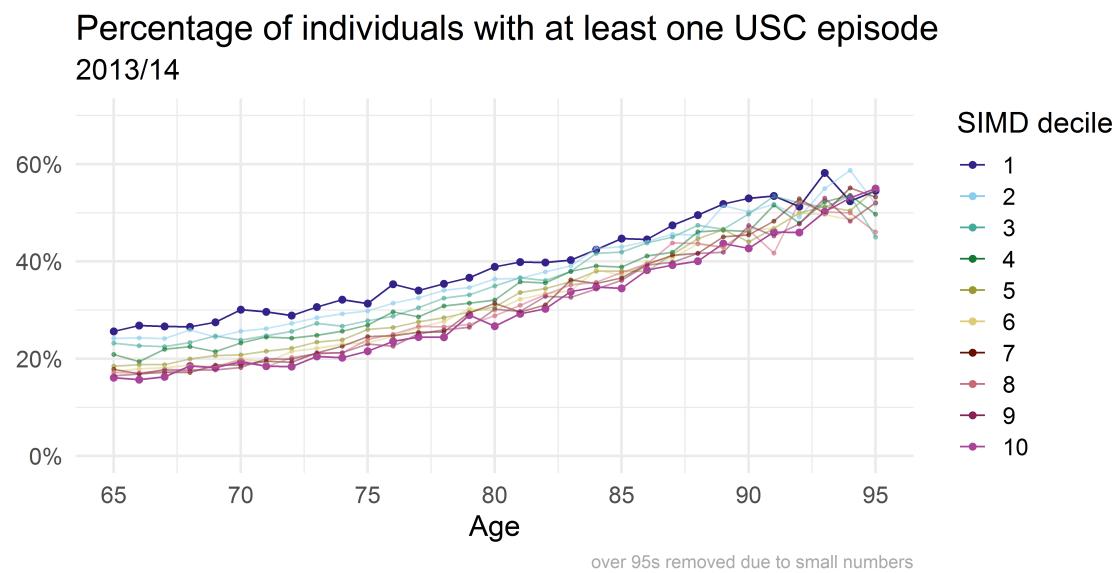


Figure 7.2: Percentage of individuals using USC by deprivation at specific ages. 2013/14

Figure 7.2 also shows an increase in the percentage of individuals using USC as age increases. As in the previous figure an average of approximately 20% at age 65 and close to 50% of those aged 93 and over used USC. However, this figure demonstrates a gradient in the percentages of individuals using USC at all ages moving from SIMD decile 1 (most deprived) to decile 10 (most affluent). At age 65 approximately 23% of those in decile 1 used USC compared to approximately 18% in decile 10. At age 80 the figures are almost 40% and 28% respectively.

The third figure charting the increase in the percentage of individuals using USC as age increases in 2013/14 is presented in figure 7.3. This figure shows a noticeably different

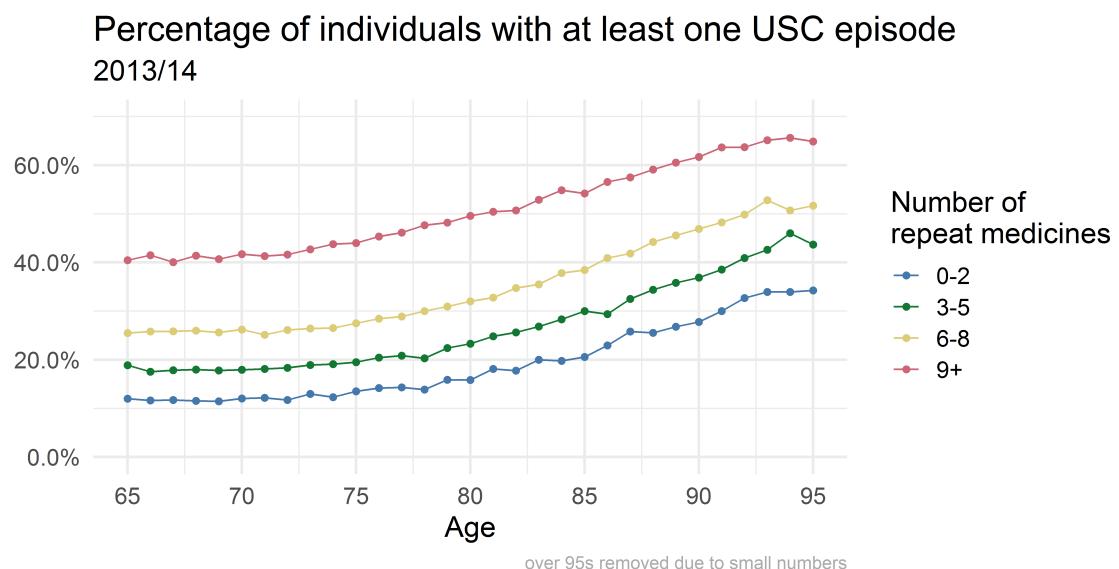


Figure 7.3: Percentage of individuals using USC by repeat medicines group at specific ages. 2013/14

pattern to those seen in figures 7.1 and 7.2. Individuals prescribed nine or more repeat medicines have a much higher than average percentage use of USC at all ages (40% at age 65 and over 60% above the age on 90). Those receiving 6-8 repeat medicines also have slightly higher than average use of USC whilst those in the other two groups have below average use at all ages.

7.2 Any form of unscheduled care

This section reports results of logistic regression models detailed in section 3.6.2. The outcome variable in these models is receipt of any form of unscheduled care (A & E attendance, acute admission to hospital, NHS24, GP OOH, or SAS) in the six months after the end of each financial year.

As seen in the previous chapter, a model is reported for each year of data from 2011/12 to 2015/16. The section is split into three subsections: a contingency table of descriptive statistics for the outcome variable is provided, followed by a table reporting goodness-of-fit measures for each model, before a final subsection with tables and plots detailing the APEs of each variable on the outcome. Where trends of results across years are similar, financial year 2013/14 is used as a reference in tables and plots.

Restate model

7.2.1 Descriptive statistics

Table 7.1 shows a breakdown of the cohort in financial year 2013/14. There were a total of 868,947 individuals included in the model for this financial year. A higher percentage of females (20.4%) compared to males (18.5%) accessed some form of USC. As many as 85.2% of individuals who died in the six months after the end of year 2013/14 also used USC in that period. Use of USC increased with age, 13.2% of those aged 65-69 compared to 44% of those age above 95. The median value for SIMD of 5 (IQR 5) for those that used USC was lower than for those that did not (median 6, IQR 5). Those in the lowest multimorbidity group, 0-2 repeat medicines, had a lower percentage (9.9%) of individuals using USC compared to those in the highest group (34.5%). Individuals using social care, USC in the year prior to the outcome period, or living in a care home all had higher percentages of USC use compared to those not using these services (42.5% v 16.7%, 36.4% v 13.3%, and 46.3% v 18.6% respectively).

Variable	Value	No USC	USC	Total	p
Sex					
	Male	314876 (81.5)	71657 (18.5)	386533	<0.001
	Female	384090 (79.6)	98324 (20.4)	482414	
Mortality					
	Alive	696150 (81.9)	153813 (18.1)	849963	<0.001
	Died	2816 (14.8)	16168 (85.2)	18984	
Age group					
	65-69	235255 (86.8)	35667 (13.2)	270922	<0.001
	70-74	173603 (84.2)	32628 (15.8)	206231	
	75-79	134403 (79.8)	33972 (20.2)	168375	
	80-84	89077 (74.2)	30998 (25.8)	120075	
	85-89	45708 (67.0)	22505 (33.0)	68213	
	90-94	17322 (60.3)	11386 (39.7)	28708	
	95 plus	3598 (56.0)	2825 (44.0)	6423	
SIMD	Median (IQR)	6 (5)	5 (5)		<0.001
Repeat Medicine Group					
	0-2	209453 (90.1)	22913 (9.9)	232366	<0.001
	3-5	208839 (84.6)	37977 (15.4)	246816	
	6-8	157037 (78.1)	44068 (21.9)	201105	
	9+	123637 (65.5)	65023 (34.5)	188660	
Any form of social care					
	No Social Care	643430 (83.3)	128911 (16.7)	772341	<0.001
	Social Care	55536 (57.5)	41070 (42.5)	96606	
Any USC episode in previous year					
	No USC	548628 (86.7)	84022 (13.3)	632650	<0.001
	USC	150338 (63.6)	85959 (36.4)	236297	
Resident in care home					
	No Care Home	673354 (81.4)	154242 (18.6)	827596	<0.001
	Care Home	16826 (53.7)	14533 (46.3)	31359	

Total N used in model = 868,947

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 7.1: Characteristics of those with/without any USC use in the six months following end of 2013/14

7.2.2 Goodness of fit

Table 7.2 shows the results of diagnostic tests for the each model. An improvement is seen in values of McFadden's R^2 over time although values are lower than seen with social care models (range 0.128 - 0.140).

Financial Year	McFadden's pseudo R^2	Deviance	Log Likelihood	Deviance (null model)	Log Likelihood (null model)
2011/12	0.128	693271.367	-346635.683	794787.923	-397393.962
2012/13	0.128	704196.663	-352098.332	807111.451	-403555.725
2013/14	0.138	733843.874	-366921.937	851217.72	-425608.86
2014/15	0.14	735740.669	-367870.334	855953.525	-427976.762
2015/16	0.139	742481.81	-371240.905	861898.907	-430949.453

Table 7.2: Goodness of fit for model applied to each year of data

7.2.3 Average Partial Effects

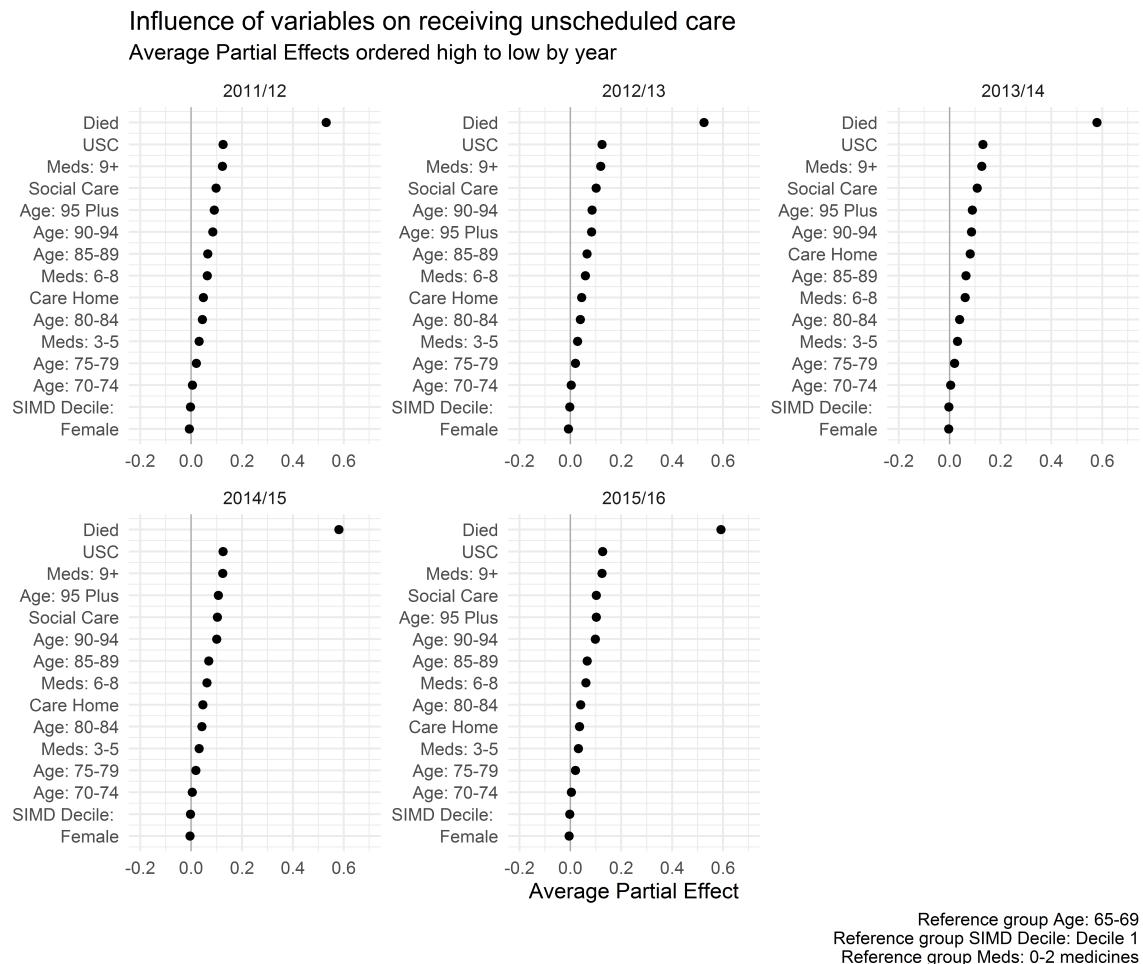


Figure 7.4: Average Partial Effect plot

Figure 7.4 plots the APEs of each model and table 7.3 shows the values of these effects for financial year 2013/14. Dying during the outcome period of interest has the largest positive effect on use of USC. The APE for dying in 2013/14 indicates an increase in the probability of using USC of almost 60% compared to those still alive. Of the remaining variables in the model, previous use of USC, higher multimorbidity, receipt of social care, and increasing age are associated with higher use of USC.

The difference in probability of using USC for those that had used USC in the year prior to the outcome period was 13.1% in 2013/14, whilst the difference for those who

Variable	Average Partial Effect	Lower 95% Confidence Interval	Upper 95% Confidence Interval
Died	0.579	0.57	0.589
USC	0.131	0.129	0.134
Meds: 9+	0.126	0.123	0.128
Social Care	0.108	0.105	0.112
Age: 95 Plus	0.089	0.075	0.103
Age: 90-94	0.086	0.08	0.092
Care Home	0.081	0.077	0.086
Age: 85-89	0.064	0.06	0.068
Meds: 6-8	0.061	0.059	0.064
Age: 80-84	0.039	0.036	0.041
Meds: 3-5	0.031	0.028	0.033
Age: 75-79	0.019	0.016	0.021
Age: 70-74	0.004	0.002	0.006
SIMD Decile:	-0.003	-0.003	-0.002
Female	-0.004	-0.006	-0.002

Reference group for age: 65-69

Reference group for meds: 0-2 repeat medicines

Table 7.3: Average Partial Effects 2013/14

appeared in the 2013/14 SCS was 10.8%. Those with highest levels of multimorbidity (9 or more repeat medicines) had a 12.6% increase in probability of using USC compared to those in the lowest multimorbidity group (0-2 medicines). The APE increased through multimorbidity groups - a 3.1 % increase in probability of USC use for those with 3-5 repeat medicines and a 6.1% increase for those with 6-8 repeat medicines compared to the lowest group were found in 2013/14. A similar trend was seen through age groups where the APE increased from 0.4% (age group 70-74) to 8.9% (age group 95 plus) compared to the reference age group (65-69). Living in a care home also had a positive effect on USC use although this was of a lower magnitude than seen with previous USC use or social care receipt (8.1%). After adjustment for other variables in the model, females were found to have less probability of using USC than males although the magnitude of the effect size was negligible (0.4% decrease in probability in 2013/14).

SIMD was the only independent variable modelled as a continuous variable. Table 7.3 shows an APE of -0.003 (-0.3%) for 2013/14. As this is an instantaneous effect the conditional effect of SIMD in 2013/14 is plotted in figure 7.5 to aid interpretation.

The plot shows that after adjusting for other variables in the model, the conditional effect of SIMD varies by only 1.6% across deciles(0.103 (95% CI 0.101-0.107) in decile 1 to 0.087 (95% CI 0.084-0.089) in decile 10). The APE of -0.003 found in table ref indicates the coefficient of the slope of this plot at the average value of SIMD (5.6 SD 2.8).

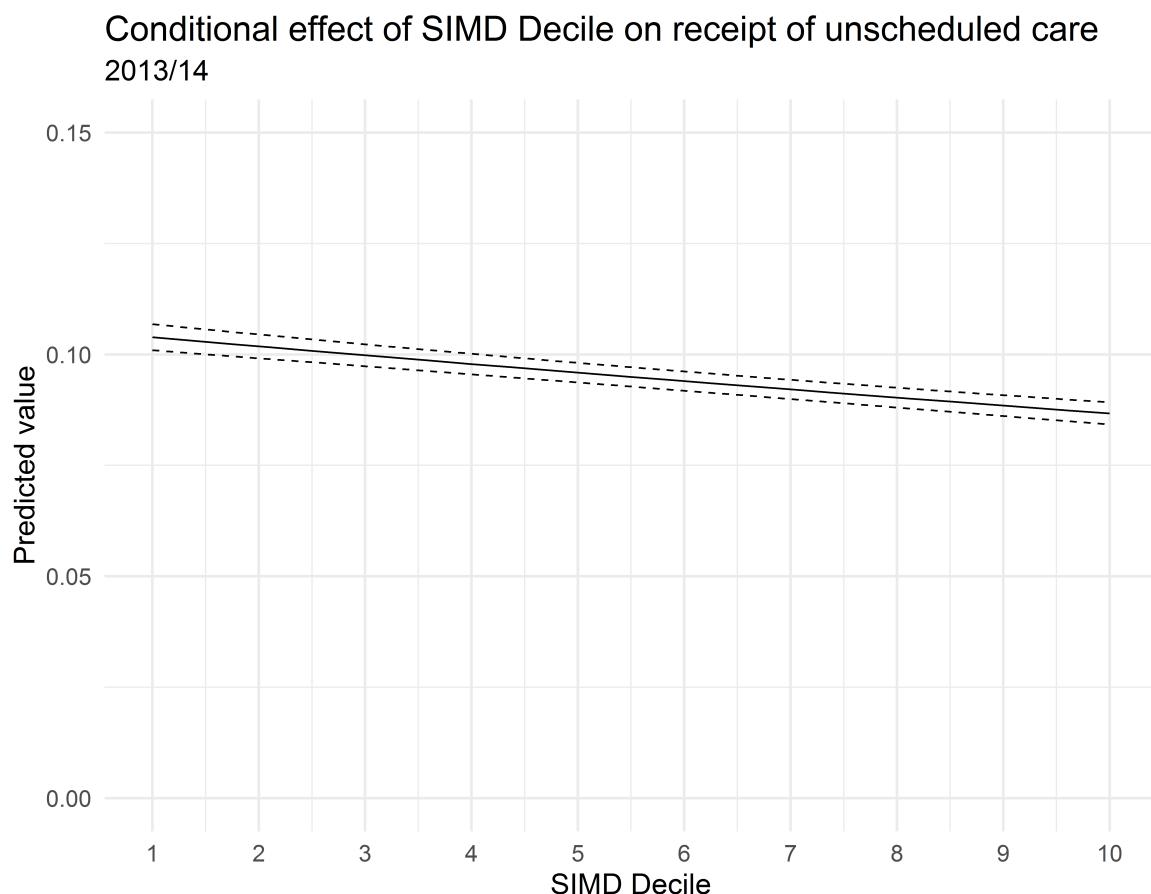


Figure 7.5: Conditional effect of SIMD on receipt of USC

Figures 7.6 and 7.7 show an alternative view of APEs over time. These are split into two charts to make visualisation easier. In figure 7.6 effect sizes for previous USC use, social care receipt and multimorbidity groups remain stable across time in different models. The APE for death during the outcome period increases slightly from 2013/14 onwards.

Figure 7.7 again shows stable APEs for sex, SIMD and lower age groups and slight increases for age groups 85-89 and above. A fluctuation in the APE for care home to 0.08 is recorded in 2013/14 compared to the year before and after where values are approximately 0.05.

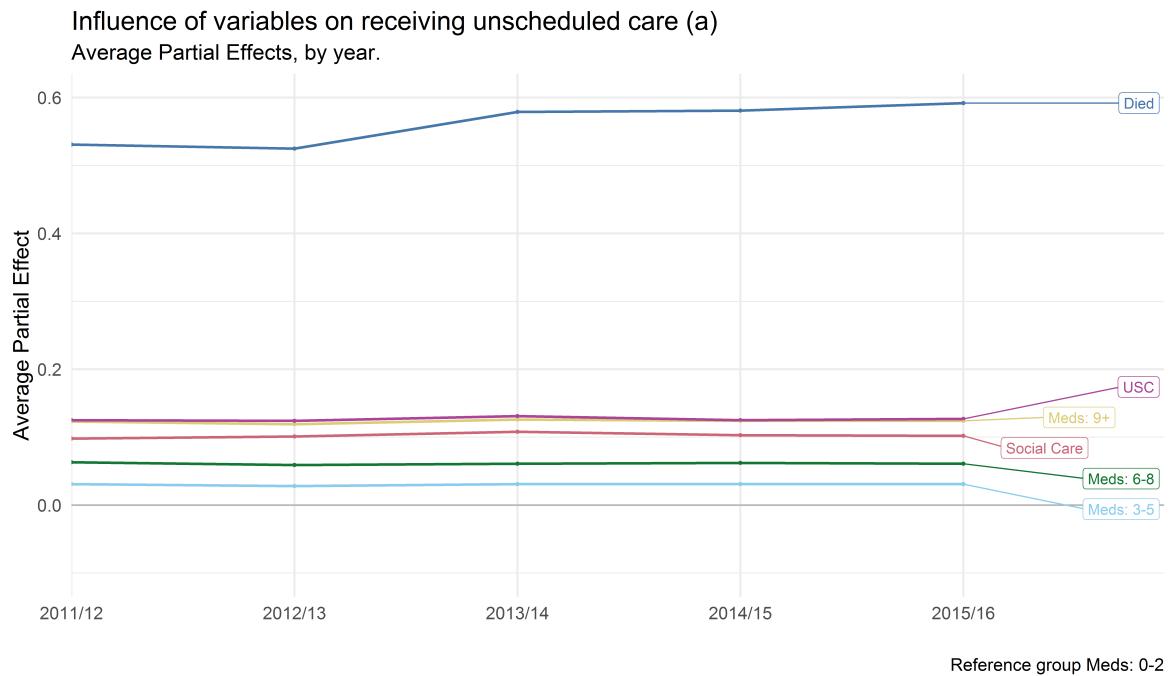


Figure 7.6: APE of variables on receipt of any USC over time (a)

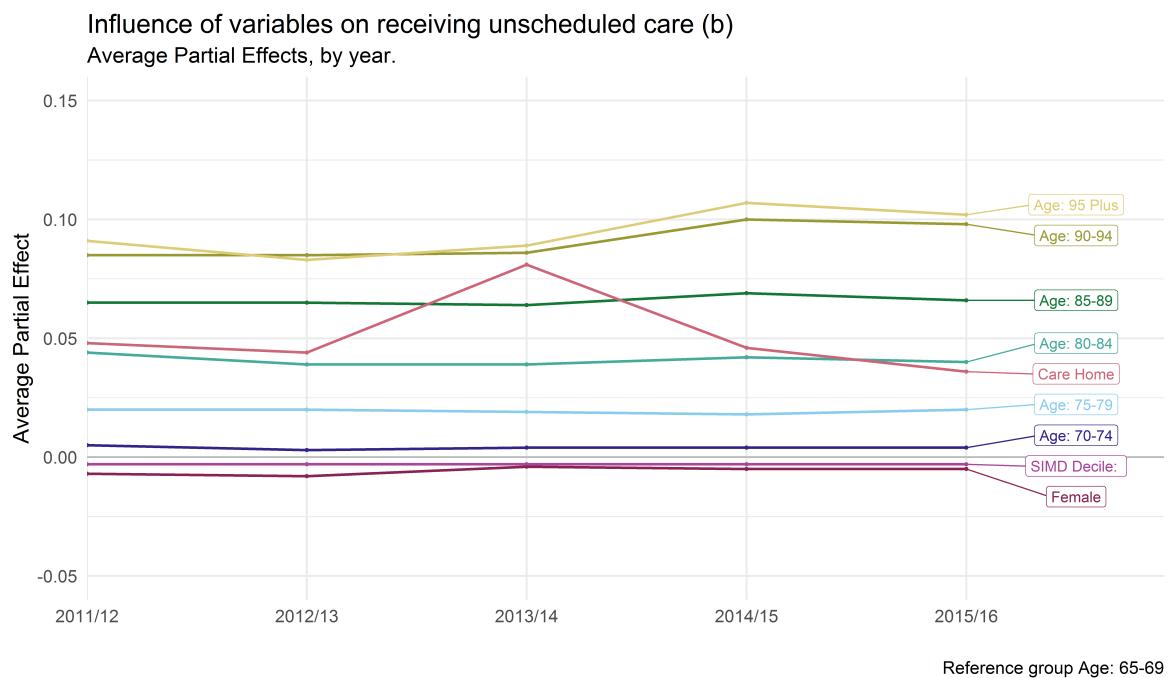


Figure 7.7: APE of variables on receipt of any USC over time (b)

7.3 Acute admission to hospital

This section reports results of logistic regression models detailed in section 3.6.2. The outcome variable in these models is acute admission to hospital in the six months after the end of each financial year.

The section follows the same format as presented in the previous section with the outcome variable being the only difference in analyses.

7.3.1 Descriptive statistics

Variable	Value	No Unscheduled Acute Admission	At least one unscheduled acute admission	Total	p
Sex	Male	351063 (90.8)	35470 (9.2)	386533	0.173
	Female	438554 (90.9)	43860 (9.1)	482414	
Mortality	Alive	781081 (91.9)	68882 (8.1)	849963	<0.001
	Died	8536 (45.0)	10448 (55.0)	18984	
Age group	65-69	256976 (94.9)	13946 (5.1)	270922	<0.001
	70-74	191795 (93.0)	14436 (7.0)	206231	
	75-79	151900 (90.2)	16475 (9.8)	168375	
	80-84	104231 (86.8)	15844 (13.2)	120075	
	85-89	56587 (83.0)	11626 (17.0)	68213	
	90-94	22971 (80.0)	5737 (20.0)	28708	
	95 plus	5157 (80.3)	1266 (19.7)	6423	
	SIMD	Median (IQR)	6 (5)	5 (4)	<0.001
	Repeat Medicine Group	0-2	223999 (96.4)	8367 (3.6)	
	3-5	230936 (93.6)	15880 (6.4)	246816	
	6-8	180667 (89.8)	20438 (10.2)	201105	
	9+	154015 (81.6)	34645 (18.4)	188660	
	Any form of social care	No Social Care	716249 (92.7)	56092 (7.3)	<0.001
		Social Care	73368 (75.9)	23238 (24.1)	96606
	Any USC episode in previous year	No USC	597421 (94.4)	35229 (5.6)	<0.001
		USC	192196 (81.3)	44101 (18.7)	
Resident in care home	Not Care Home	754195 (91.1)	73401 (8.9)	827596	<0.001
	Care Home	25993 (82.9)	5366 (17.1)	31359	

Total N used in model = 868,947

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 7.4: Characteristics of those with/without any acute unscheduled hospital admission in the six months following end of 2013/14

Table 7.4 shows a cross table of the cohort in 2013/14 with regard to the outcome variable. As seen in the previous section, there were a total of 868,947 individuals included in the model for this financial year. There was little difference between the percentage of males (9.2%) and females (9.1%) that were admitted to hospital during the outcome period and the difference between these groups was not statistically significant. A majority (55%) of those that died during the outcome period were admitted to hospital. An increase in the percentage of individuals being admitted to hospital is seen through age groups from 5.1% of those aged 65-69 to 20% of those aged 90-94 with a slight reduction in those aged over 95 (19.7%). Increases are also seen through multimorbidity groups from 3.6% for those prescribed 0-2 repeat medicines to 18.4% for

those prescribed nine or more repeat medicines. Higher percentages of the population using social care (24.1%), unscheduled care in the year prior to the outcome period (18.7%), and those resident in care home (17.1%) had an admission in the outcome period compared to those not using these services (7.3%, 5.6%, and 8.9% respectively). The median value of SIMD (5, IQR 4) was lower than that for those with no admission (6, IQR 5).

7.3.2 Goodness of fit

Financial Year	McFadden's pseudo R^2	Deviance	Log Likelihood	Deviance (null model)	Log Likelihood (null model)
2011/12	0.147	430546.273	-215273.136	504861.738	-252430.869
2012/13	0.144	438334.205	-219167.103	512022.779	-256011.39
2013/14	0.144	450790.356	-225395.178	526463.251	-263231.625
2014/15	0.143	454587.839	-227293.92	530154.674	-265077.337
2015/16	0.142	459709.093	-229854.546	535881.304	-267940.652

Table 7.5: Goodness of fit fro model applied to each year of data

Table 7.5 shows the results of diagnostic tests for each model. The value of McFadden's R^2 decreases slightly over time from 0.147 to 0.142. Although values are lower than seen for social care models fitted in the previous chapter, they are slightly higher than found for models using any USC use reported in the previous section.

7.3.3 Average Partial Effects

Figure 7.8 plots the APEs of each variable in each model and table 7.6 shows the values of APEs for financial year 2013/14. As reported in models where any USC use is the outcome variable in the previous section, dying during the outcome period has the largest APE. This magnitude of this effect is, however, lower than seen in the previous section (34.6% increase in probability of admission compared to almost 60% increase in any USC use). High multimorbidity (nine or more repeat prescriptions) has the next highest positive APE, In 2013/14 this group had a 7.7% increase in probability in being admitted to hospital compared to those from the lowest group (0-2 repeat medicines). Those with 6-8 and 3-5 repeat medicines had increases in probability of admission of 3.5% and 1.6% respectively. Use of any form of unscheduled care in the year prior to the outcome period or receipt of social care during the SCS census week was associated with increases in the probability of admission to hospital in 2013/14 of 6.7% compared to those with no prior USC use and 6.0% for those with no social care receipt respectively. The was an incremental increase in APE through age groups from those aged 70-74 (0.7%) to those aged 90-94 (6.0%) compared to those age 65-69.

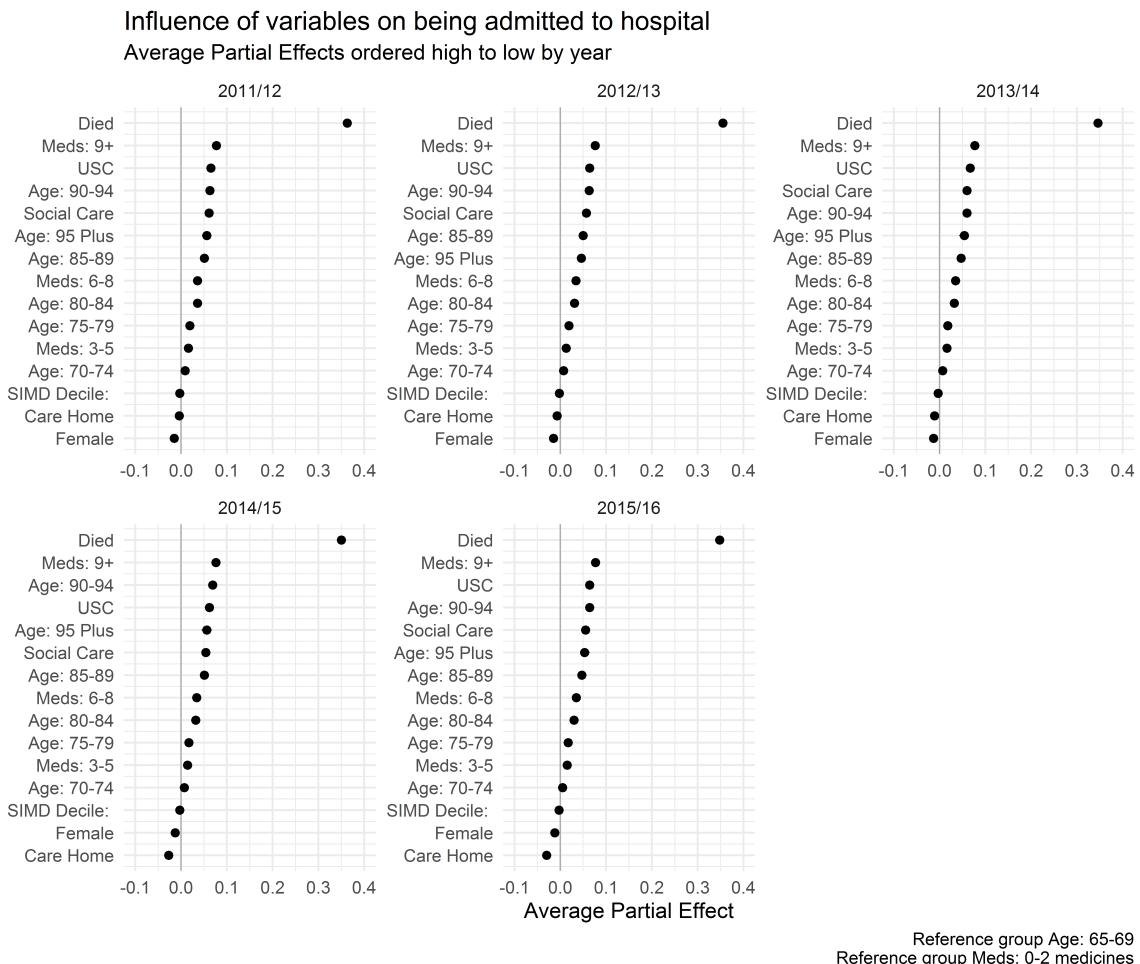


Figure 7.8: Average Partial Effect plot

Those aged 95 or above had a lower APE (5.4%) than their immediately younger age group.

There is a negative effect on admission to hospital for females compared to males with a difference in probability of 1.3%. This effect size is larger than seen in models where any form of USC was the outcome variable (section 7.2.3). Living in a care home also had a negative effect on admission to hospital after controlling for other variables in the model. The APE in 2013/14 was -0.011 indicating a 1.1% decrease in the probability of admission to hospital for those living in a care home. This value increases over time and the most recent model shows a 3% decrease in probability of admission.

Figure 7.9 shows the conditional effect of SIMD on admission to hospital during the six months following financial year 2013/14. As SIMD was modelled as a continuous variable the APE of -0.003 represents the coefficient of the slope in figure ref at the average value of SIMD (5.6, SD 2.8). After adjusting for other variables the conditional effect of SIMD varies by only 1% across deciles (0.034 (95% CI 0.032-0.036) in decile 1 to 0.024(95% CI 0.023-0.025) in decile 10).

Figures 7.10 and 7.11 are alternative plots of APE showing how effects vary across

Variable	Average Partial Effect	Lower 95% Confidence Interval	Upper 95% Confidence Interval
Died	0.346	0.337	0.355
Meds: 9+	0.077	0.075	0.079
USC	0.067	0.065	0.068
Age: 90-94	0.06	0.055	0.065
Social Care	0.06	0.058	0.062
Age: 95 Plus	0.054	0.043	0.064
Age: 85-89	0.047	0.044	0.05
Meds: 6-8	0.035	0.033	0.037
Age: 80-84	0.032	0.03	0.034
Age: 75-79	0.018	0.016	0.02
Meds: 3-5	0.016	0.015	0.018
Age: 70-74	0.007	0.005	0.009
SIMD Decile:	-0.003	-0.003	-0.002
Care Home	-0.011	-0.013	-0.009
Female	-0.013	-0.014	-0.012

Reference group for age: 65-69

Reference group for meds: 0-2 repeat medicines

Table 7.6: Average Partial Effects 2013/14

models through time. Two chart are provided to enable easier visualisation. Figure 7.10 shows effect sized of previous USC use, social care receipt, and multimorbidity groups are relatively stable across models. APEs for the flag indicating if an individual died during the outcome period reduce very slightly (by approximately 0.01 or 1% probability) from 2011/12 to 2013/14 and remain stable thereafter.

Figure 7.11 shows the APE for Care home decreasing across models of more recent periods from a negligible APE in 2011/12 to -0.03 (or 3% reduction in probability) in 2015/16. There are small fluctuations in APE for the oldest two age groups. Otherwise, younger age groups, SIMD, and sex show stable APEs across models.

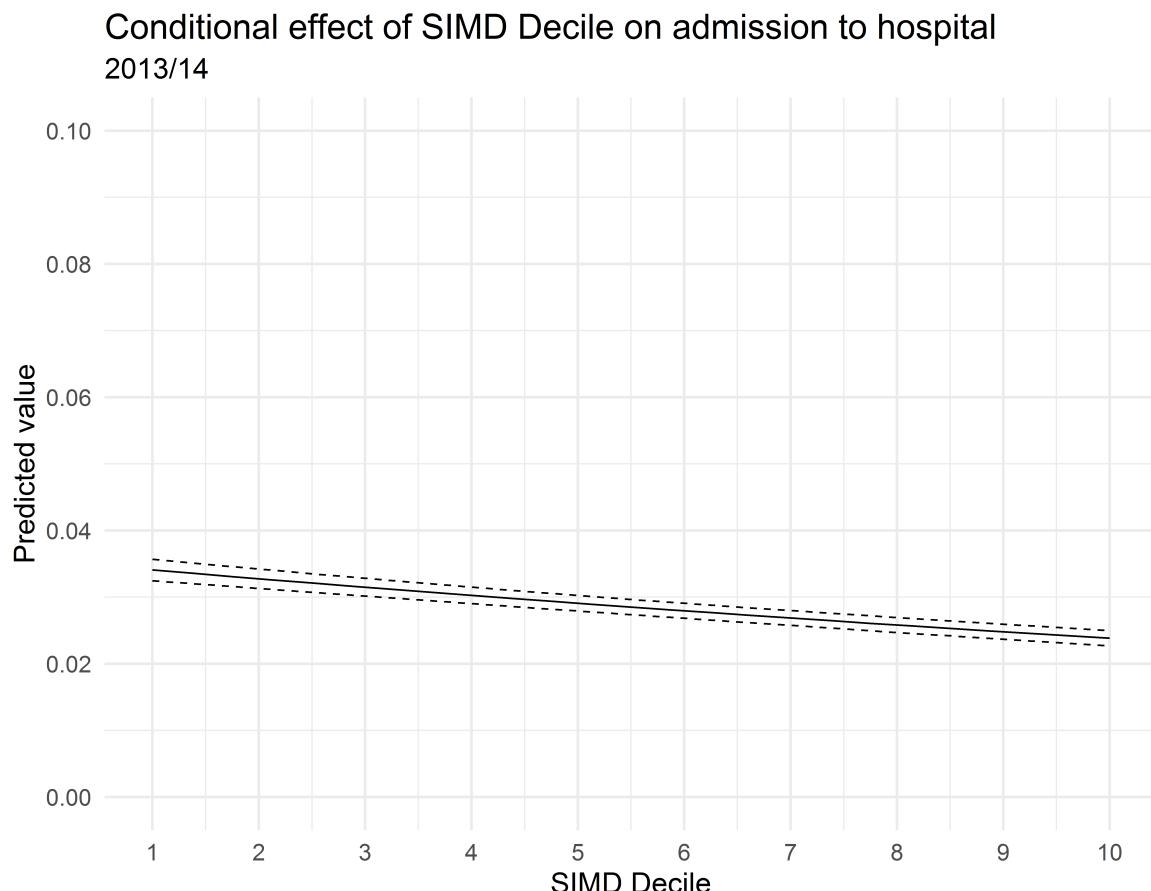


Figure 7.9: Conditional effect of SIMD on any unscheduled hospital admission

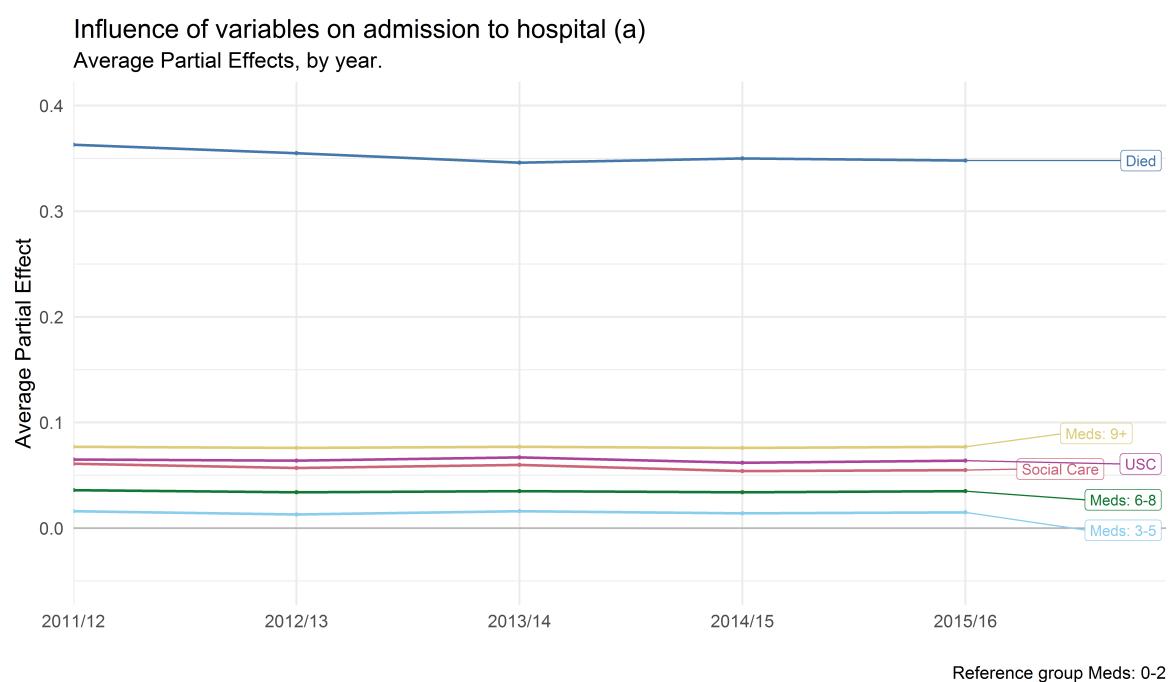


Figure 7.10: APE of variables on any hospital admission over time (a)

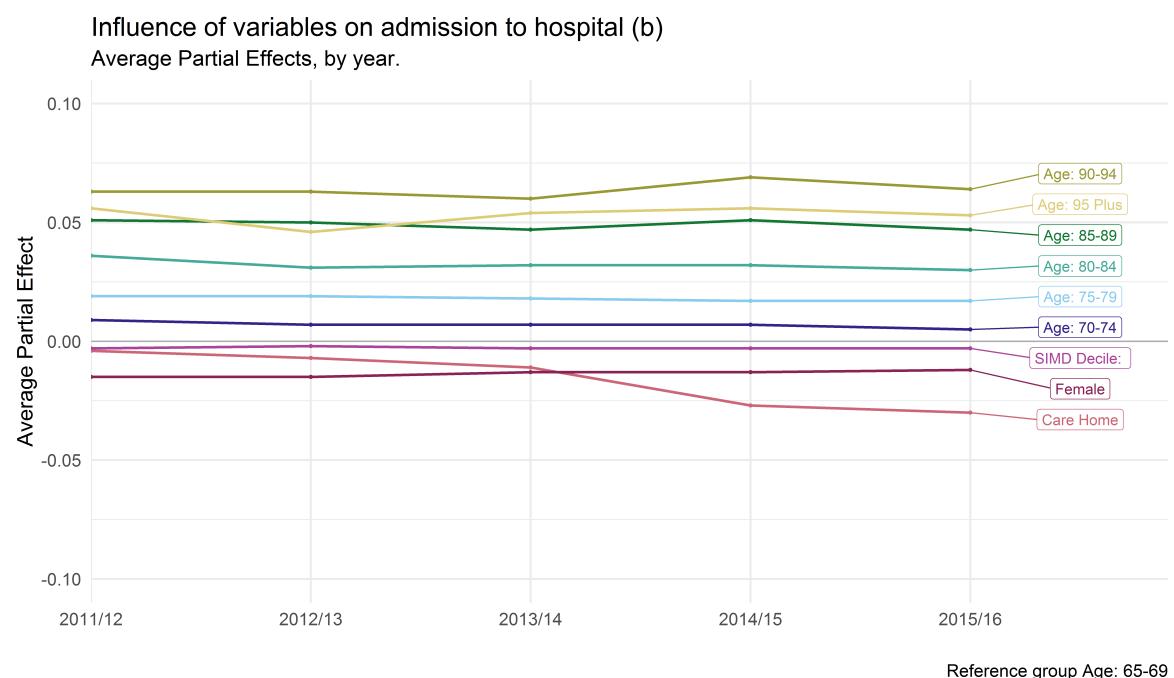


Figure 7.11: APE of variables on any hospital admission over time (b)

7.4 Attendance at A & E

This section reports the results of logistic regression models outlined in section 3.6.2. The section follows the same format as the previous two sections. The only difference in the analysis is that the outcome variable indicated any attendance at an Accident & Emergency department in the six months following the end of each financial year.

7.4.1 Descriptive statistics

Variable	Value	No A & E attendance	At least one A & E attendance	Total	p
Sex	Male	341078 (88.2)	45455 (11.8)	386533	<0.001
	Female	423448 (87.8)	58966 (12.2)	482414	
Mortality	Alive	754397 (88.8)	95566 (11.2)	849963	<0.001
	Died	10129 (53.4)	8855 (46.6)	18984	
Age group	65-69	248280 (91.6)	22642 (8.4)	270922	<0.001
	70-74	185485 (89.9)	20746 (10.1)	206231	
	75-79	147061 (87.3)	21314 (12.7)	168375	
	80-84	101027 (84.1)	19048 (15.9)	120075	
	85-89	55116 (80.8)	13097 (19.2)	68213	
	90-94	22518 (78.4)	6190 (21.6)	28708	
	95 plus	5039 (78.5)	1384 (21.5)	6423	
	Median (IQR)	6 (5)	5 (4)		<0.001
	Repeat Medicine Group	0-2	217959 (93.8)	14407 (6.2)	232366
		3-5	223580 (90.6)	23236 (9.4)	<0.001
		6-8	174382 (86.7)	26723 (13.3)	201105
		9+	148605 (78.8)	40055 (21.2)	188660
Any form of social care	No Social Care	692451 (89.7)	79890 (10.3)	772341	<0.001
	Social Care	72075 (74.6)	24531 (25.4)	96606	
Any USC episode in previous year	No USC	580821 (91.8)	51829 (8.2)	632650	<0.001
	USC	183705 (77.7)	52592 (22.3)	236297	
Resident in care home	Not Care Home	730451 (88.3)	97145 (11.7)	827596	<0.001
	Care Home	24838 (79.2)	6521 (20.8)	31359	

Total N used in model = 868,947

All values n(%) unless otherwise stated

Row-wise percentages within grouped variables

Table 7.7: Characteristics of those with/without any A & E attendance in the six months following end of 2013/14

Table 7.7 is a cross table showing attendance at A & E broken down by sociodemographic factors. A total of 868,947 individuals were included in the model for this financial year. A slightly higher percentage of females (12.2%) attended A & E compared to males (11.8%). Of individuals who died during the outcome period, 46.6% attended A & E over the same time frame. The percentage of those attending A & E increase with age from 8.4% of those aged 65-69 to 21.6% of those aged 90-94 (and 21.5% aged 95 and over). The median value of SIMD was lower (5, IQR 4) for those that attended A & E than for those that did not (median 6, IQR 5). In multimorbidity groups, the percentage of those attending A & E increased as the number of regular prescribed medicines increased incrementally from 6.2% for those receiving 0-2 medicines to 21.2% of those prescribed nine or more repeat medicines. Twenty-five percent of those receiving social

care compared to 10.3% of those that did not attended A & E during the outcome period following the end of 2013/14. Similarly, 22.3% of those that had used any form of USC in the year prior to the outcome period attended an Emergency Department compared 8.2% of those that did not. Finally, 20.8% of those living in a care home compared with 11.7% of those that did not had at least one attendance at A & E during the outcome period following 2013/14.

7.4.2 Goodness of fit

Financial Year	McFadden's pseudo R^2	Deviance	Log Likelihood	Deviance (null model)	Log Likelihood (null model)
2011/12	0.087	547700.3	-273850.2	600039.1	-300019.6
2012/13	0.087	560286.3	-280143.1	613680	-306840
2013/14	0.087	577390.7	-288695.3	632696.9	-316348.5
2014/15	0.084	574248.8	-287124.4	626795.9	-313397.9
2015/16	0.081	585741.7	-292870.8	637674.1	-318837

Table 7.8: Goodness of fit for models applied to each year of data

Table 7.8 shows low McFadden's R^2 values for all models ranging from 0.081 in the most recent year to 0.087 in 2011/12.

7.4.3 Average Partial Effects

Figure 7.12 shows the APEs for each variable in each model across years whilst table 7.9 shows the exact values for 2013/14 model. As seen in previous models relating to USC, dying during the outcome period had the largest partial effect on attendance at A & E. The increase in probability for attendance for those that died was 24.3% compared to those that were alive at the end of the outcome period. Prior use of USC in the 12 months before the outcome period showed a 8.5% increase in probability compared to those that had not used USC. There was an increase in probability of attending an emergency department for all multimorbidity groups compared to the reference group, 0-2 repeat medicines. These saw an increase in probability of 1.9%, 3.9%, and 8% for the 3-5, 6-8, and 9 plus repeat medicine groups respectively in 2013/14. An incremental increase in APEs for age groups is also seen ranging from 0.5% for the 70-74 group to 4.9% for 90-94 group compared to the 65-69 reference group. Social care had a positive effect on A & E attendance, those present in the 2013/14 SCS had an increased probability of 5.3% compared to those not in the SCS.

There is a negative effect for females compared to males in all models. However, in these models the effect is negligible (0.7% decrease in probability of attending A & E after 2013/14). Living in a care home also had a negative effect on admission to A & E

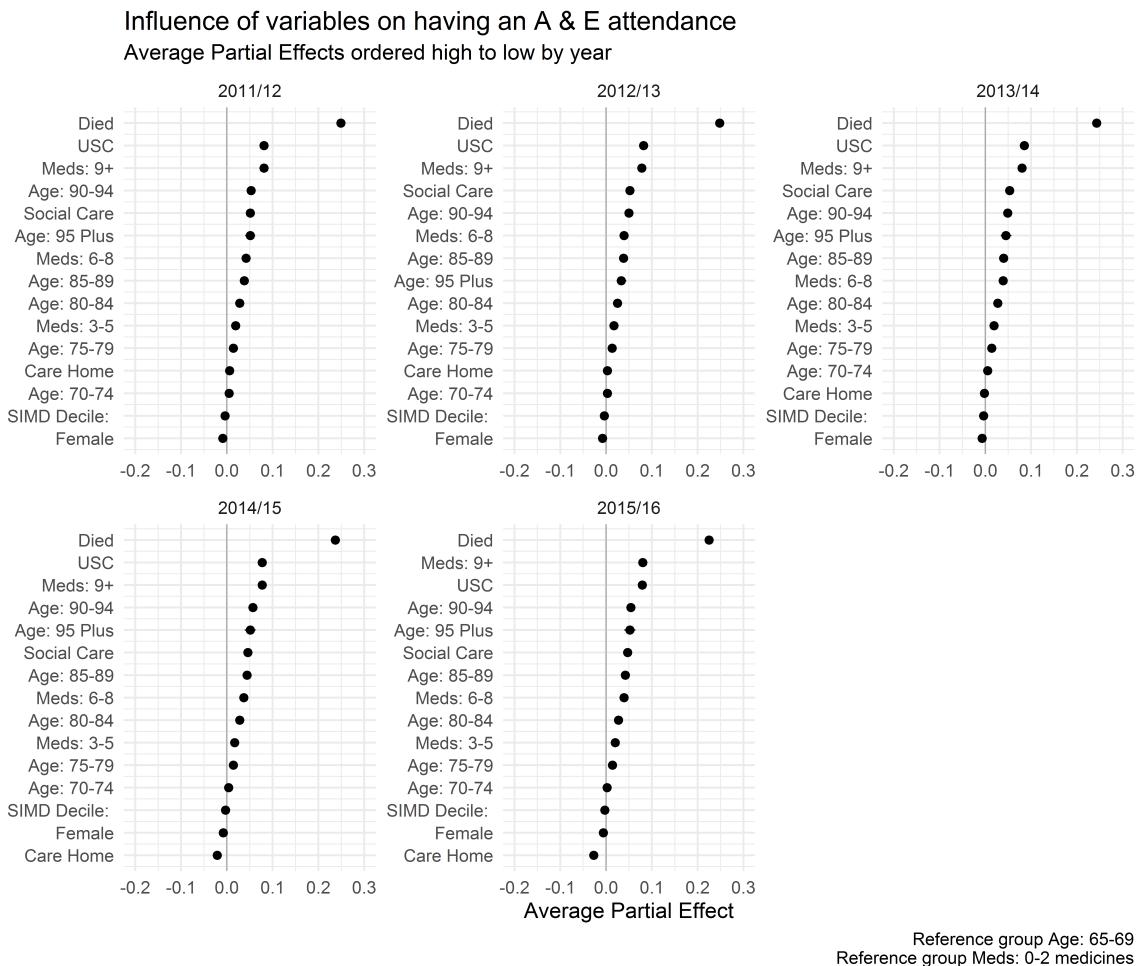


Figure 7.12: Average Partial Effect plot

after adjustment. In the 2013/14 model this effect is negligible (-0.002 or a decrease in probability of 0.2%) but the effect is larger in later models (-0.027 or a 2.7% decrease in probability).

Figure 7.13 shows the conditional effect of SIMD of attendance at an emergency department in the six months following the end of financial year 2013/14. The APE of -0.004 reflects the coefficient of the slope in figure ref at the mean value of SIMD (5.6, SD 2.8). The conditional effect of SIMD varies by 1.8% across deciles (0.069 (95% CI 0.067-0.071) in decile 1 to 0.051 (95% CI 0.049-0.053) in decile 10).

Figures 7.14 and 7.15 show APEs for variables charted across models through time. Figure 7.14 shows stable APEs across models for prior use of USC, social care, and multimorbidity groups. There is a very small reduction in the magnitude of APE for death during the outcome period in later models.

Figure 7.15 shows reduction an increase in the negative value of APE for those living in a care home compared to those that do not in later models. Older age groups show slight fluctuation in APE values over time whilst other age groups, SIMD decile and sex APEs appear steady across models.

Variable	Average Partial Effect	Lower 95% Confidence Interval	Upper 95% Confidence Interval
Died	0.243	0.234	0.251
USC	0.085	0.083	0.086
Meds: 9+	0.08	0.078	0.082
Social Care	0.053	0.05	0.055
Age: 90-94	0.049	0.043	0.054
Age: 95 Plus	0.045	0.034	0.057
Age: 85-89	0.04	0.036	0.043
Meds: 6-8	0.039	0.037	0.041
Age: 80-84	0.027	0.025	0.029
Meds: 3-5	0.019	0.017	0.021
Age: 75-79	0.014	0.012	0.016
Age: 70-74	0.005	0.002	0.007
Care Home	-0.002	-0.005	0.001
SIMD Decile:	-0.004	-0.004	-0.003
Female	-0.007	-0.008	-0.006

Reference group for age: 65-69

Reference group for meds: 0-2 repeat medicines

Table 7.9: Average Partial Effects 2013/14

Conditional effect of SIMD Decile on A & E attendance 2013/14

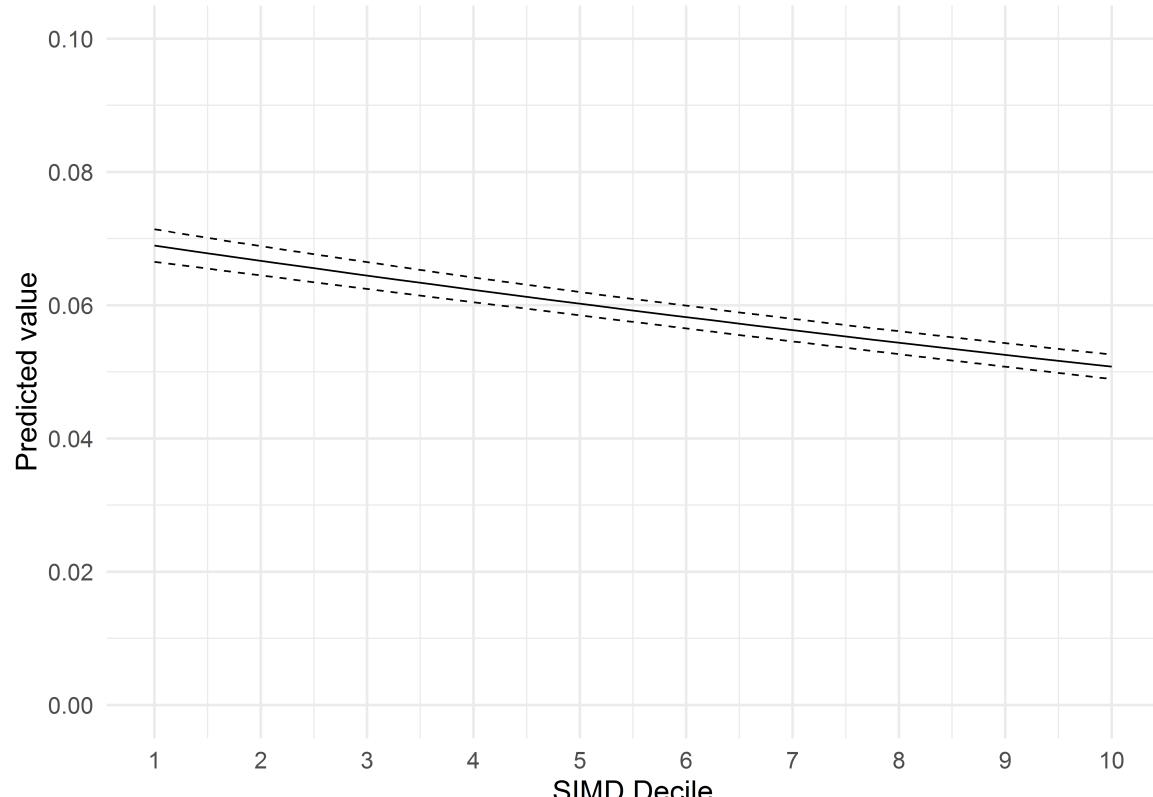


Figure 7.13: Conditional effect of SIMD on any A & E attendance

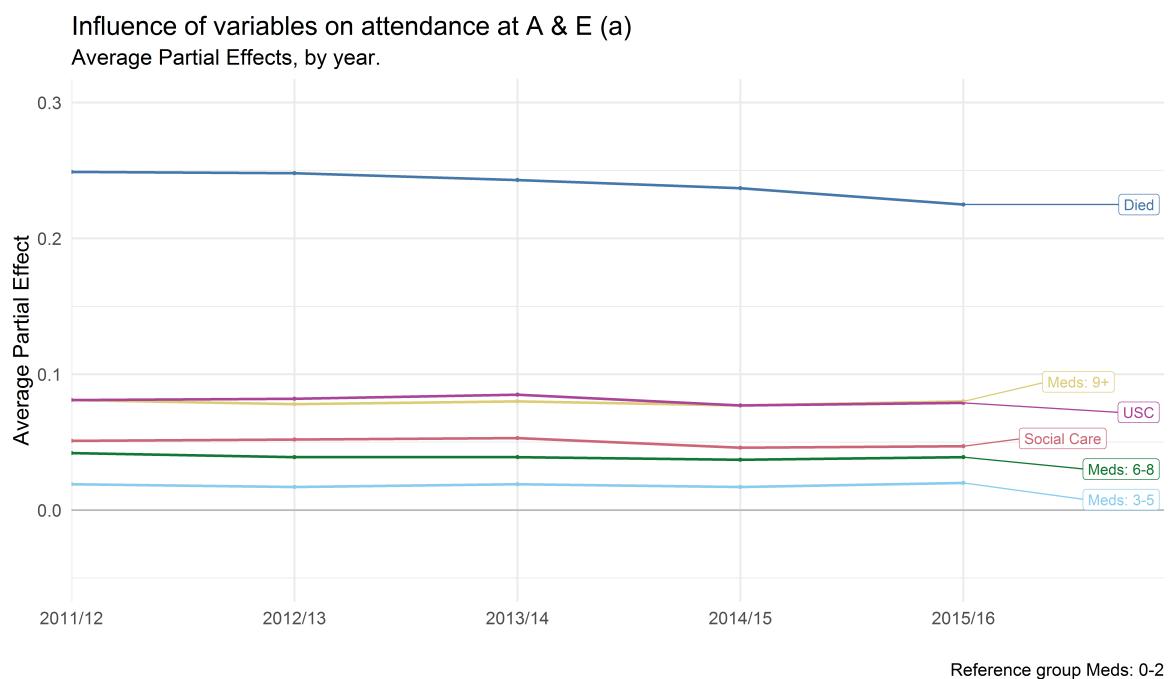


Figure 7.14: APE of variables on any A & E attendance over time (a)

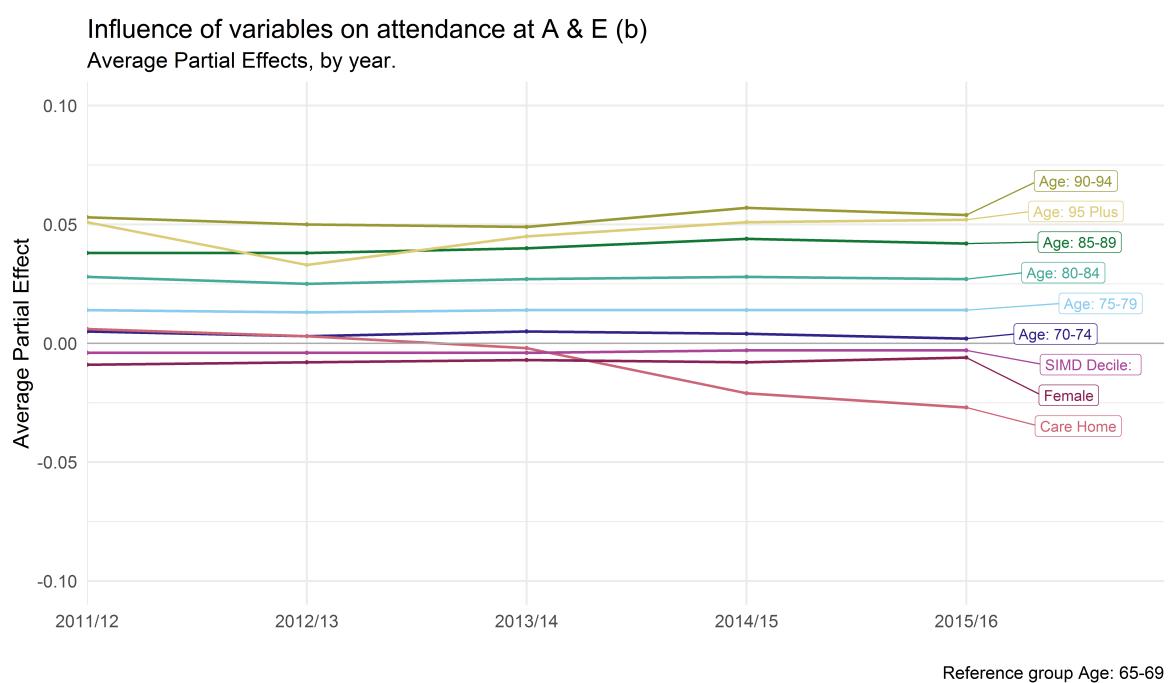


Figure 7.15: APE of variables on any A & E attendance over time (b)

Chapter 8

Discussion

8.1 Main outcomes

- The aim of this thesis was 1, 2, 3.

Big point - Health and social care often discussed in terms of lack of social care's effect on delayed discharges etc. BUT, health is a major driver of social care use in the first place. Affirms need for joined up H & SC services (maybe not a big point!)

8.2 Findings

Go through all results and discuss

- 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*.
- Descriptives
- SC models - Big section. Combine discussion of both models >96
 - APEs show effects *after* adjusting for other variables (and interactions)
 - Big differences in overall numbers *and* percentages between models (>96 & 92-95.9). >96 has smaller numbers for very old and much higher percentage (approx 70%) receiving care compared to national average (approx 45%).
 - Second group of models include both largest cities...

- Age by far the biggest effect
- Female effect fairly small after adjustment for age and MM (compared to descriptives) - Does this warrant splitting by sex before modelling?
- Magnitude of effects important. (Note SIMD * 10 = similar effect of going from 65-69 to 75-79 i.e. being deprived ages you by 10 years)
- Variation in APE for LAs could be a few things e.g. budget cuts, data, random
- Bump in APE values for older age groups and high meds related to increase in comm alarm observations from 2014/15 onwards. *note very small effect changes**
- Fluctuating APEs for councils to do with baseline level of reference council also fluctuating. Again - *very small changes in APE*
- USC models - Big section
 - Overall smaller magnitude of effects *except* for the deaders.
 - Effects magnitude lower for admission and A & E compared to any USC
 - Care home positive effect for any USC but *negative* effect for admission and A & E
 - Overall poorer fitting models.
 - Fluctuation in APEs at older ages across models likely reflects smaller numbers *but* compare to SC models...
- Overall findings
 - Tight CIs likely reflect large sample size (wider CI for age > 95 small numbers)
 - Difference in R^2 for USC likely due to fact SC models are subsets of data rather than whole cohort.

8.3 Limitations

- This was limited by a, b, c (Need to talk about measures chosen, especially the meds MM measure and how I counted meds, here. Also need to discuss lack of PC data as a major limitation with respect to MM)
- Social care data - Levels home care steady for me but decreasing in SCS - why is linkage rate steady?
- No measure for living alone
- Census week for home care. Compare difference in any care and home care from tab 1 descriptives. Approx 60% (2013/14) of other care (mainly alarms) also use home care. Rough estimate of error.

8.4 Comparisons to previous research

- Compare to past research

8.5 Implications

8.5.1 LA Variation

- Implications are d, e, f - discuss in light of pro-rich/pro-poor framework
- Street-level bureaucracy? I doubt it. More likely differing knowledge/skills - failure to learn from other areas
- Inverse Care Law - no evidence with this research - !But not adjusted - future research
- As above - allocation according to resource not need in Renfrew

8.5.2 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

8.5.3 Linked Administrative Data Research

Discuss process of obtaining and analysing linked data Potentially useful for sg and others

Difficulties encountered

- Timeframe!!
- Safe Haven (software upgrade etc.)
- Benefits

8.6 Future research

- Future research should:-

- Link to census
- Measure *longitudinal* changes in social care and impact on usc
- Break down SCS and USC variables - any difference in home care patterns?
What about Admissions and A & E only?
- Look at e.g. those with over 9 meds and *didn't* get social care/usc. What's the craic with them?)

Chapter 9

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 RAC approval



An ESRC Data
Investment

RAC Project Decision Form

Version 3.0 (23 May 2016)

Title of Project	Using Linked Data to Understand Multi Morbidity and the Use of Social Care Data	
Lead applicant	Prof. Nick Bailey	
Date of RAC Panel meeting	10 February 2017	
RAC Panel decision	Support proposal	
	Support proposal subject to revisions and conditions in Part E	X
	Proposal acceptable standard but not supportable due to resourcing constraints - option to re-submit in next <i>Call for Expressions of Interest</i>	
	Do not support	

Part B: Grading summary

Criterion	Yes/No
Privacy and ethics	Yes
Feasibility	Yes

Please provide the average review panel score for each section listed below.

Criterion	Grade (out of 4)
Scientific merit	3
Potential for public benefit impact	3.33
Alignment to UBDC objectives	2.67

Total (out of 12):

9

Part C: RAC Panel Priority Grade

Priority	Yes
4 - Very high priority	
3 - High priority	
2 - Medium priority	X
1 - Low priority	
0 - Do not support	

Part D: Applicant feedback

Comments will be sent to the applicant(s) as feedback

Impact:

1. The proposed work is very valuable from the perspective of developing research capacity in this important area. Given the ageing of the population, and the very likely increase in the prevalence of co-morbidities, the research is very important in helping to better understand the implications of multiple morbidities for demand on social care services.
2. There will likely be considerable impact and benefit for informing public policy related to health inequalities and multiple morbidities. More information should be provided on how results will be disseminated to policy makers (workshops, website, blogs?) and details of possible academic journal articles and which journals will be targeted.
3. Inverse care laws and the development of more community based services is very topical and an area for reform. The data analysis may assist with the reform of health and social care – if the team have a plan for active engagement and dissemination of information.

Methods:

4. The authors mention that they will undertake longitudinal analysis 'if time permits' and hence there's a chance that the longitudinal aspects of the linked data may be ignored. Longitudinal analysis should be one of the key objectives given the rich linked dataset that the proposers are requesting.
5. The project may benefit from public policy experience and broader knowledge experience of potential/practice of linking of health and social care data.

UBDC Objectives:

6. The proposal has the potential for the findings to inform the work of other researchers or policy makers. The data will not add to UBDC Collection, nor be available directly to others – but this is normal for Controlled Data Service use.
7. The project will match health data with social care data, however it is not clear how wholly innovative this is from a big data perspective or for maximising the benefits from these links.
8. Fits with urban dimension and use of big data.

Part E: Required revisions and conditions of acceptance

Consider more complex models that take into account the longitudinal nature of the linked dataset. Provide more details on the proposed models and how they will address the research questions.

Provide clear dissemination strategies to inform policy and to the research community, and which journals will be targeted.

Appendix B. Main linkage. Ethical approval

**College of Social
Sciences**

Wednesday, 08 February 2017

Dear Mr David Henderson

College of Social Sciences Research Ethics Committee

**Project Title: Using linked data to understand the relationships between
Multimorbidity and the use of Health and Social Care**

Application No: 400160103

The College Research Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Any outstanding permissions needed from third parties in order to recruit research participants or to access facilities or venues for research purposes must be obtained in writing and submitted to the CoSS Research Ethics Administrator before research commences. Permissions you must provide are shown in the *College Ethics Review Feedback* document that has been sent to you.

- Project end date: 01/10/2018

The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:

(http://www.gla.ac.uk/media/media_227599_en.pdf) (Exemption approved).

- The research should be carried out only on the sites, and/or with the groups and using the methods defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment as an amendment to the original application. The *Request for Amendments to an Approved Application* form should be used:

<http://www.gla.ac.uk/colleges/socialsciences/students/ethics/forms/staffandpostgraduatesearchstudents/>

Yours sincerely,



Dr Muir Houston
College Ethics Officer

**Muir Houston, Senior Lecturer
College of Social Sciences Ethics Officer**
Social Justice, Place and Lifelong Education Research
University of Glasgow
School of Education, St Andrew's Building, 11 Eldon Street
Glasgow G3 6NH
0044+141-330-4699
Muir.Houston@glasgow.ac.uk

Appendix C. 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.

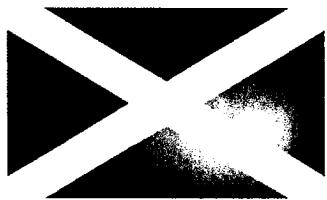
Please note that summary information about your application and its approval, including the title and nature of your proposal, will be published on the panel website (www.informationgovernance.scot.nhs.uk).

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 D. Data Sharing agreement



**The Scottish
Government**

OCSSA

Data Sharing Agreement

For the necessary sharing of Personal Data amongst

Scottish Ministers (Scottish Government)

And

University of Glasgow

And

NHS National Services Scotland

Contents	
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2 DATA	3
3 PURPOSES OF THE DATA SHARE	4
4 DATA TRANSFER	4
5 DATA PROTECTION	5
6 DATA SECURITY & MANAGEMENT OF A SECURITY INCIDENT	5
7 FREEDOM OF INFORMATION & EIR REQUESTS	5
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This Data Sharing Agreement (the “Agreement”) is amongst:

(A) Scottish Ministers (“Scottish Government”):

Organisation/Business Area	Scottish Government (Health & Social Care Analysis Division)
ICO Registration Number	Z4857137
Information Asset Owner (IAO)	Angela Campbell
Operational Contact Name and Job Title:	Julie Rintoul, Statistician, Health & Social Care Analysis Division Ellen Lynch, Senior Assistant Statistician, Health & Social Care Analysis Division

(B) “University of Glasgow”:

Organisation	The University Court of the University of Glasgow
ICO Registration Number	Z6723578
Information Asset Owner (IAO)	Nick Bailey – Professor Urban Studies
Operational Contact Name and Job Title:	David Henderson - PhD Student Nick Bailey – Professor Urban Studies

(C) The Common Services Agency (“NSS”)

Organisation	The Common Services Agency for the Scottish Health Service, commonly known as NHS National Services Scotland, constituted pursuant to the National Health Service (Scotland) Act 1978 and having its headquarters at Gyle Square, 1 South Gyle Crescent, Edinburgh, EH12 9EB
ICO Registration Number	Z5801192
Information Asset Owner (IAO)	Janet Murray
Operational Contact Name and Job Title	Amy Tilbrook – Research Co-ordinator

1 COMMENCEMENT AND DURATION

- 1.1 This Agreement commences when it is signed by all Parties and shall continue (unless terminated early) until 30/06/2025 with annual review provided for pursuant to Clause 8.
- 1.2 The “Authorised Person” for each Party is as listed in Part 1A of the schedule attached to and forming part of this Agreement (“Schedule”).

2 DATA

- 2.1 For the purposes of this Agreement “Data” means the Personal Data (as defined in the Data Protection Act 1998 (“DPA”)) described in Section 4 of the approved application to the Public Benefit and Privacy Panel submitted on behalf of the University of Glasgow (“Approved PBPP Form”) contained in Part 2 of the Schedule. Data also includes any linked datasets produced from the Data. The Approved PBPP

Form describes the University of Glasgow's project proposal in respect of which the Data will be used ("Project").

- 2.2 "NSS Data" is such of the Data listed on the Approved PBPP Form as deriving from NSS Scotland or the Directors of Public Health/CMO or The Registrar General of Births, Deaths and Marriages for Scotland (otherwise known as "National Records of Scotland") of HM General Register House, 2 Princes Street, Edinburgh EH1 3YY ("NRS"). "SG Data" is such of the Data listed on the Approved PBPP Form as deriving from Scottish Government.
- 2.3 Scottish Government is contributing the SG Data, NSS is contributing the NSS Data. NSS will link or procure the linkage of all the Data for University of Glasgow.
- 2.4 University of Glasgow will have a separate data processing agreement in place with NSS for linkage and storage of the Data in the NSS National Safe Haven.

3 PURPOSES OF THE DATA SHARE

3.1 Purposes

University of Glasgow agrees to only process the Data for the purposes of the Project as described in the Approved PBPP Form, (the "Purposes"). The Data will be used for no other purpose, and in no other way, than for the Purposes.

3.2 Further disclosure

University of Glasgow agrees not to disclose the Data to any third parties unless a Scottish Government Authorised Person and/or NSS Authorised Person as applicable has authorised the disclosure in writing (including e-mail).

3.3 Limitations on Data use

University of Glasgow agrees to:

- only carry out analysis as specified in the Approved PBPP Form; and
- not link any of the Data within any data other than the Data unless a Scottish Government Authorised Person and NSS Authorised Person have authorised the linkage in writing (including e-mail).

- 3.4 University of Glasgow shall only be permitted to process and analyse the Data in the Scotland-wide secure arrangement for the controlled storage, collation, management, dissemination and analysis of identifiable pseudonymised or anonymous data relating to individuals hosted at the University of Edinburgh and managed by NSS ("NSS National Safe Haven").

- 3.5 University of Glasgow agrees to comply with the Caldicott Principles in relation to access, storage and use of the Data.

4 DATA TRANSFER

- 4.1 Scottish Government agrees to transfer the SG Data to NSS National Safe Haven in accordance with the data transfer process described in Part B of the Schedule.

- 4.2 NSS agrees to make the NSS Data available to the University of Glasgow in the NSS National Safe Haven in accordance with the data transfer process described in Part B of the Schedule.

5 DATA PROTECTION

- 5.1 The Parties shall comply with any notification requirements under the DPA and duly observe all their obligations under the DPA which arise in connection with this Agreement. Further DPA matters are set out in Part 1C of the Schedule.
- 5.2 The Data Controller (as such term is defined in the DPA) position is as set out in Part 1C of the Schedule.

6 DATA SECURITY & MANAGEMENT OF A SECURITY INCIDENT

All Parties will take appropriate technical and organisational measures against the unauthorised or unlawful processing of Data and against the accidental loss or destruction of, or damage to, Data (a "Data Security Breach") including, but not limited to, the security measures in relation to data transfer set out in Part B of the Schedule and other measures in relation to security generally set out in Part D of the Schedule.

In the event of Data Security Breach:

- the Party suffering the Data Security Breach shall inform the other Parties immediately on becoming aware of such Data Security Breach and, in the case of University of Glasgow, in accordance with the mechanisms set out in Section 5.7.03 of the Approved PBPP Form;
- if a Data Security Breach is caused by a material breach of this Agreement by University of Glasgow, the Scottish Government or NSS may terminate this Agreement with immediate effect by giving notice to University of Glasgow in writing; and
- if a Data Security Breach is due to a material breach of this Agreement by University of Glasgow, Scottish Government or NSS as applicable may require any Data to be securely destroyed in accordance with HMG Information Assurance Standards. Confirmation in writing will be provided to all Parties that such Data has been deleted.

7 FREEDOM OF INFORMATION & EIR REQUESTS

The Parties shall co-operate in handling and disposing of any requests made to any of the Parties, under the Freedom of Information (Scotland) Act 2002 ('FOISA') and the Environment Information Regulations ('EIRs').

The Parties acknowledge that nothing in this Agreement is confidential. The Scottish Government agrees to publish this Agreement on its website.

Information requests received by any Party which relate to this Agreement shall be passed to the Authorised Persons for the Parties for consultation as soon as practicable after receipt and in any event within three working days of receiving the request.

8 AUDIT AND REVIEW

- 8.1 This Agreement shall be reviewed annually (first review 01/09/2018). At each review, use of the Data for the Purposes will be assessed by the Parties.

8.2 University of Glasgow agrees to:

- a) allow Scottish Government from time to time to conduct an on-site audit of University of Glasgow's confidentiality and security procedures and practices, provided reasonable notice is given to University of Glasgow and subject to reasonable and appropriate confidentiality undertakings, or
- b) provide a report of such an audit to Scottish Government and NSS, if requested.

8.3 Scottish Government agrees to liaise with NSS as soon as practicable following an on site audit pursuant to Clause 8.3(a) above in relation to the findings of such audit.

9 CHANGES TO THE AGREEMENT

Except expressly provided in this Agreement, no variation of this Agreement shall be effective unless it is in writing and signed by authorised signatories of all Parties.

10 RETENTION AND DELETION OF DATA

Unless the Agreement is terminated early in accordance with section 6, University of Glasgow agrees to retain the Data only for as long as such Data are required for the Purposes (the "Retention Period").

At the end of the Retention Period, NSS, as the data processor agrees to destroy or procure the destruction of the Data securely in accordance with HMG Information Assurance Standards and provide confirmation in writing to Scottish Government and University of Glasgow that the Data have been deleted.

11 TERMINATION OF AGREEMENT

Scottish Government or NSS may terminate this Agreement in the event of a material breach of this Agreement by University of Glasgow as described in Clause 6 above.

12 LIABILITY

12.1 Subject to Clause 13.4, no Party shall be liable to any other Party for any indirect or consequential loss or damage nor be liable to any other Party for loss of profit or loss or contracts, loss of business opportunity, revenue, goodwill or anticipated savings.

12.2 Subject to Clause 13.4, each Party's total aggregate liability under this Agreement shall be limited to £500,000 per incident or series of related incidents.

12.3 No Party excludes or limits liability to any other Party for fraud or fraudulent misrepresentation or for death or personal injury caused by negligence.

13 GENERAL

13.1 Any waiver of a right or remedy under this Agreement shall not be deemed a waiver of any subsequent breach or default. A failure or delay by a Party to exercise any right or remedy provided under this Agreement or by law shall not constitute a waiver of that or any other right or remedy, nor shall it prevent or restrict any further exercise of that or any other right or remedy.

13.2 In the event that any of these terms, conditions or provisions shall be determined by any competent authority to be invalid, unlawful or unenforceable to any extent, such term, condition or provision shall to that extent be severed from the remaining

terms, conditions and provisions which shall continue to be valid to the fullest extent permitted by law.

- 13.3 This Agreement shall be governed by and construed in accordance with Scots law.
- 13.4 In so far as this Agreement relates to a contract between Scottish Government and NSS, it is a NHS Contract pursuant to Section 17A of the National Health Service (Scotland) Act 1978.

14 SIGNATORIES

By signing this Agreement the Parties confirm that they accept its terms.

Scottish Ministers

Signature *Angela Campbell* Date 12/12/17

Health & Social Care Analysis Division
For and on behalf of Scottish Ministers

Scottish Ministers

Witness *David Dunc* Date 12/12/17

~~Directorate for Chief Medical Officer~~
For and on behalf of Scottish Ministers

The University Court of the University of Glasgow

Signature *David Duncan* Date 21/11/17

David Duncan, Secretary of Court
Claire Munro, Senior Contracts Manager

For and on behalf of the University Court of the University of Glasgow

Witness Signature: *AMANDA LEE MCCLURE*

Witness Name: *AMANDA LEE MCCLURE*

Witness Address: *COURT OFFICE, UNIVERSITY OF GLASGOW*

Date: 21/11/17

The Common Services Agency for the Scottish Health Service

Signature *Philip Couser* Date 13/11/17

Philip Couser, Director Public Health and Information Services

For and on behalf of The Common Services Agency

Witness Signature: *Jeanette Colvin*

Witness Name: *Jeanette Colvin*

Witness Address: *CURE SQUARE, EDINBURGH*

Date: 21/11/17

This is the Schedule referred to in the foregoing Data Sharing Agreement amongst Scottish Government, University of Glasgow and The Common Services Agency

KEY DETAILS

PART A AUTHORISED PERSONS

Any further information, including documents referred to, or any questions or comments relating to this Agreement should be directed to the following Authorised Persons, who may change from time to time in accordance with instructions from an Authorised Person in writing (including e-mail):

Name and contact details	
Scottish Ministers (Scottish Government) Authorised Persons	Ellen Lynch, Health & Social Care Analysis Division, Scottish Government, (Ellen.Lynch@gov.scot or SWStat@gov.scot) Julie Rintoul, Health & Social Care Analysis Division, Scottish Government, (Julie.Rintoul@gov.scot or SWStat@gov.scot)
University of Glasgow Authorised Persons	Mirjam Allik, UBDC, University of Glasgow, (Mirjam.allik@glasgow.ac.uk)
NSS Authorised Persons	Steve Pavis, eDRIS (s.pavis@nhs.net)

PART B DATA TRANSFER PROCESS

The data transfer is initially a one off transfer and will commence when the Agreement is signed by all Parties.

Scottish Government will transfer the SG Data (Social Care Survey extract) to the NSS National Safe Haven using the National Records of Scotland's Thru Managed File Transfer (or by an alternative method approved by the Scottish Government).

NSS will transfer the NSS Data to or otherwise make the NSS Data available in the NSS National Safe Haven [via a secure method approved by eHealth Division, Scottish Government.]

PART C DATA PROTECTION

1. Data controller responsibilities

The Parties acknowledge that for the purposes of the DPA:

Scottish Government is commissioning the Project and University of Glasgow is undertaking it. Scottish Government is contributing Data as Data Controller. NSS is contributing Data as either Data Controller directly or on behalf of the relevant Data Controller but other than contributing Data, is otherwise only undertaking service activities for University of Glasgow in

relation to the Project. NSS will be a Data Processor (as such term is defined in the DPA) for such service activities.

The Parties acknowledge that for the purposes of the DPA, upon receipt of or access to the Data by University of Glasgow, Scottish Government, University of Glasgow and NSS are joint Data Controllers of the Data.

2. Fair processing

See **Section 4.2, of the Approved PBPP Form.**

3. Lawful processing

The Parties are satisfied that the legal basis for sharing the Data and processing it for the purposes of the Project are:

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 Educational 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."

4. Conditions for processing

The parties are satisfied that Condition 6 of Schedule 2 to the DPA is met and for "sensitive personal data" Schedule 3, Condition 8 and Condition 10 (Regulation 9 of The Data Protection (Processing of Sensitive Personal Data) Order 2000) to the DPA is met.

Part IV Exemptions: 33 Research, history and statistics.

5. Subject Access and Subject disputes/disputes with Information Commissioner

Research and statistics exemption

The Parties are not obliged to respond to subject access requests in relation to the Data because the criteria for the research and statistics exemption in section 33 of the DPA are met:

1. the Data shall be processed for statistical and research purposes only;
2. the Data shall be processed in compliance with the 'relevant conditions' (as defined in section 33 DPA); and
3. no published research or statistics shall allow the identification of any data subject.

In the event of a dispute or claim brought by a Data Subject or the Information Commissioner concerning the processing of "Data" against any of the Parties, the Parties will inform each other about any such disputes or claims, and will cooperate with a view to settling them amicably in a timely fashion. Each Party shall abide by any decision of the Scottish Courts which is final and against which no further appeal is possible.

PART D SECURITY MEASURES

Security – the Data will be accessed, stored, used, transferred, retained, disposed and reviewed as outlined in the Approved PBPP Form.

The Data will be accessed by those listed under Section 1 of the Approved PBPP Form, via the NSS National Safe Haven.

Access Restrictions – Only those named under Section 1 of the Approved PBPP Form, should have access to the Data unless a Scottish Government Authorised Person and NSS Authorised Person has granted permission in writing (including e-mail).

Access to the Data should be limited to a need to know basis. Those named under Section 1 of the Approved PBPP Form, and other University of Glasgow staff or students who are working on the Project must have completed safe researcher training as specified in the Approved PBPP Form.

University of Glasgow agrees to ensure access to the Data is limited to those employees and students who need access to the Data for the Purposes. University of Glasgow agrees to provide a copy of the list of employees and students with access to the Data to Scottish Government and NSS following a request by the relevant Party in writing (including email).

University of Glasgow agrees to ensure that all employees and students with access to the Data have undertaken training in the laws relating to handling personal data and are aware of both University of Glasgow's duties and their personal duties and obligations under such laws and this Agreement.

PART 2 APPROVED PBPP FORM



Appendix_5_Ethics.d
ocx



Appendix_4_PIA.doc
x



Appendix_3_UBDC_
RAC_approval.docx



Appendix_2_Linkage
_Process.docx



Appendix_1_SC_vari
ables.docx



20170511 PBPP
Approval Letter 1617

20170616

1617-0304_PBPP

Amendment 14.6.17. Submission_v2.pdf



1617-0304 Henderson Amended Social Care Survey variable list.msg

Appendix E. 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

continued from previous page

Medicine Name	BNF subsection
UREA HYDROGEN PEROXIDE	12.01.03
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

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Medicine Name	BNF subsection
ALUMINIUM CHLORIDE HEXAHYDRATE	13.12.00
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

continued from previous page

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

continued from previous page

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 POTASSIUM HYDROXYQUINOLINE	13.11.02
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 F. Renfrewshire pilot. UBDC RAC approval



An ESRC Data
Investment

RAC Project Decision Form

Version 3.0(23 May 2016)

Title of Project	Renfrewshire Council social care data analysis	
Lead applicant	Prof Nick Bailey	
Date of RAC Panel meeting	1 st June 2016 (by telephone)	
RAC Panel decision	Support proposal	
	Support proposal subject to revisions and conditions in Part E	Yes
	Proposal acceptable standard but not supportable due to resourcing constraints - option to re-submit in next <i>Call for Expressions of Interest</i>	
	Do not support	

Part B: Grading summary

Criterion	Yes/No
Privacy and ethics	Yes ¹
Feasibility	Yes ²

Please provide the average review panel score for each section listed below.

Criterion	Grade (out of 4)
Scientific merit	3
Potential for public benefit impact	3 ³
Alignment to UBDC objectives	3 ⁴

Total (out of 12):

9

Part C: RAC Panel Priority Grade

Priority	Yes
4 - Very high priority	
3 - High priority	
2 - Medium priority	Yes
1 - Low priority	
0 - Do not support	

¹ Subject to approval of College of Social Sciences Research Ethics Committee, University of Glasgow.

² Subject to comments & conditions in Section D & E

³ More accurately 3.33.

⁴ More accurately 2.66

Part D: Applicant feedback

Comments will be sent to the applicant(s) as feedback

Given the general lack of robust evidence as to the benefits of social care, this work is urgently needed. Part of the strength of this project is that it will scope out a potentially important data resource. In addition, the work will enable the development of capacity through the development of understanding of available administrative data sources, as well as in the research training afforded to a doctoral student.

The application perhaps could have expanded more on the NHS CHI data it potentially could be linked with and that there are firmer plans in place to do this in order to maximise the potential of this work. It might be helpful to understand the project plan for this wider piece of work which is not explored in this application (beyond 4.7).

Note that there is no team member (Part C) from the Scottish Government or Renfrewshire Council which may add to the public benefit aspect of this piece of work. (See Part E below).

Data sharing agreement in place with the Scottish government and Renfrewshire council is assumed.

It would be useful if the proposer indicated why so few projects have been completed in this area, despite the willingness of public bodies to share. If there are obstacles, will these impact on the project? Is there a reason Renfrewshire has been chosen? Have other stakeholders expressed views on the need to progress this type of work?

I'm not clear whether the project will of itself produce data or whether this could be made available to other researchers, presumably in aggregate, anonymised form. Key to this will presumably be the terms on which the council will make the 'controlled data' in question available. Will it be limited to the researcher in question?

It could be made explicit who the PhD student is who will undertake the project. I assume it is Mr Henderson, who is the only person who will have access to the controlled data. I have minor reservations over the extent to which the PhD student has the necessary quantitative skills, the only reference is to a 'work placement'. However, my guess is that his PhD may require further training in this area and he will have the support of his eminently qualified colleagues.

Part E: Required revisions and conditions of acceptance

Para section 4.1 of the proposal states that it will inform future research using data from a number of local authorities in the greater Glasgow area. There is no assurance provided that this work is supported by a number of councils. Some assurance should be sought at this early stage that this engagement is underway to underpin the potential of this piece of work.

Dissemination at section 5.2 is mainly via academic researchers, conferences and academic papers. A clearer understanding of how opportunities will be established to engage and work with the public sector, including integrated joint boards, should be given at this early stage.

Overall there needs to be more distinction between the larger PhD project and the proposed data exploration and it is not always clear what will be done at this stage. For example, why is there a need to request surname and forename if there is no data linkage. At section 3 it is indicated that the controlled data service is needed; however, in Part B.2.6 it transpires that it is not required in this pilot phase. Pilot phase is not explained elsewhere in the application, so the true level of resources or full support required from UBDC probably need explored further. There is a question whether what is proposed is an 'exploratory' study rather than a 'pilot' study – it is useful to clarify the nature of study.

Finally, the proposed data exploration does not seem to test any hypothesis or have a set of research questions and it should be revised to include these. The project could outline more clearly what questions can be answered with these data.

Appendix G. 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.

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