



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

<b>ADL</b>	Activities of daily living
<b>ADRC</b>	Administrative Data Research Centre
<b>CHI</b>	Community Health Index
<b>COSLA</b>	Convention of Scottish Local Authorities
<b>CoSS REC</b>	College of Social Sciences Research Ethics Committee
<b>CUP</b>	Continuous Urgent Care Pathway
<b>eDRIS</b>	electronic Data Research and Innovation Service
<b>ESRC</b>	Economic and Social Research Council
<b>EU</b>	European Union
<b>EGPRN</b>	European General Practice Research Network
<b>DPA</b>	Data Protection Act
<b>DSA</b>	Data Sharing Agreement
<b>FACS</b>	Fair Access to Care Services
<b>GAE</b>	Grant Aided Expenditures
<b>GDPR</b>	General Data Protection Regulation
<b>GP</b>	General Practitioner
<b>HSCA</b>	Health and Social Care Analysis
<b>IADL</b>	Instrumental activities of daily living
<b>IJB</b>	Integrated Joint Boards
<b>IQR</b>	Interquartile range
<b>ISD</b>	Information Services Division
<b>LA</b>	Local authority
<b>LTC</b>	Long term care

## Abbreviations

<b>NHS</b>	National Health Service
<b>NHSCR</b>	National Health Service Central Register
<b>NHS NSS</b>	National Health Service National Services Scotland
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NRS</b>	National Records for Scotland
<b>OECD</b>	Organisation for Economic Co-operation and Development
<b>ONS</b>	Office for National Statistics
<b>PBPP</b>	Public Benefit and Privacy Panel for Health and Social Care
<b>PC OOH</b>	Primary Care Out-of-hours
<b>PIS</b>	Prescribing Information System
<b>RAC</b>	Research Approvals Committee
<b>REC</b>	Research Ethics Committee
<b>SAS</b>	Scottish Ambulance Service
<b>SCIE</b>	Social Care Institute for Excellence
<b>SCS</b>	Social Care Survey
<b>SG</b>	Scottish Government
<b>SILC</b>	Scottish Informatics and Linkage Collaboration
<b>SIMD</b>	Scottish Index of Multiple Deprivation
<b>UBDC</b>	Urban Big Data Centre
<b>UCD</b>	Urgent Care Data Mart
<b>VPN</b>	Virtual Private Network

# 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 (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 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.**

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

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

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

This definition clearly captures the broad range of services that can be associated with social care that are only partially provided in other definitions. It acknowledges that social care can include a number of components including personal, nursing care and help with other domestic activities, and articulates the variety of settings where this can take place. Whilst it is common in Europe to describe "Long-term care" in relation to these services, this thesis will refer to "social care" as this is the most commonly used term in the UK. Furthermore, unless stated otherwise, reference to social care in this thesis will be with regard to care received by adults over the age of 65.

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

## 2.2.2 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 have 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.

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

Model	Countries where employed
<b>Universal coverage</b>	
a) tax based	Norway, Sweden, Denmark, Finland
b) public long-term insurance	Germany, Japan, South Korea, Netherlands, Luxembourg
c) health system	Belgium
<b>Mixed systems</b>	
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 <sup>1</sup>
<b>Means-tested safety net</b>	
	England, USA

<sup>1</sup> Spain and Greece have less well developed formal care services

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 <sup>1</sup> (Glendinning

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

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.

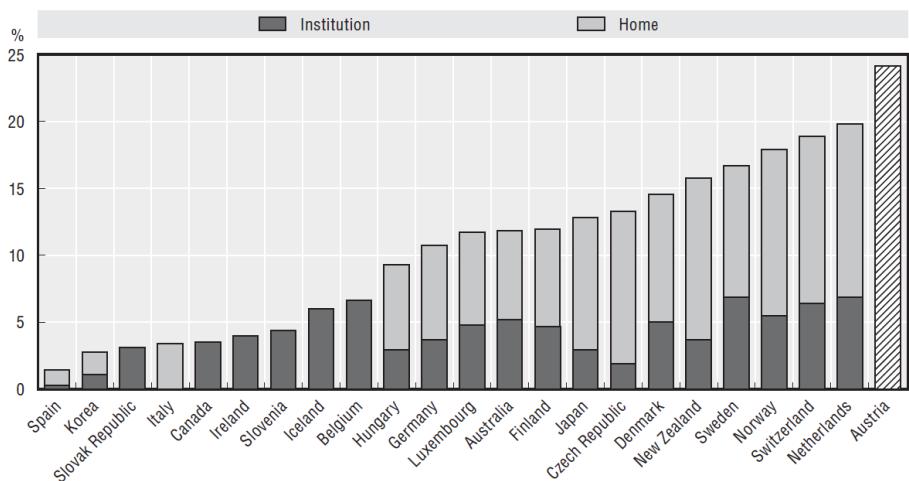
Disadvantages of universal systems are that they are generally more expensive to the state than other models of social care and can reduce the amount of informal care provided by relatives for elderly family (Colombo *et al.*, 2011; Eleftheriades and Wittenberg, 2013). The comprehensiveness of coverage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

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.

Figure 2.1: Older recipients of long-term care services as a share of the over 65 population, 2008



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>

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 methodological 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

Table 2.2: Seven stage model of candidacy

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

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."

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*[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 individ-

ual 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, 2016d). There are wide variations in the number of hours of home care provided per population across local authorities (Audit-Scotland, 2012; Scottish-Government, 2016d). 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, 2016d). 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”

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[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 services 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

Table 2.3: Six channels of middle class advantage

Channel	Description of channel <sup>1</sup>
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.

<sup>1</sup> Adapted by Hastings *et al* [2014] from Gal [1998]

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.

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

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*[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 is long-term care. The boundary between what is health care and what is social care is often blurry. The definition chosen for this thesis provided by Colombo et al (Colombo *et al.*, 2011) encapsulates the wide number of services that make-up social care including nursing, personal, equipment, and technological. The definition also identifies that 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"

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*[Christie, 2011, pp.2]*

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

*Consider dropping bullets and describing in paragraphs*

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

The recommendations of the commission included:-

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

These recommendations had profound effects on subsequent policy and legislation in Scotland, most notably in relation to health and social care services (Christie, 2011), although this was not the first policy aimed at improving coordination between these services. Previous policies aiming to increase cooperation between NHS health boards and local authority provided social care included; the Joint Future Group (2000), the Community Care and Health (Scotland) Act (2002), Community Health Partnerships [2002], and the Integrated Resource Framework (Ferguson *et al.*, 2012).

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

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

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

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

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

### 2.3.2 Health and Social Care Integration

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

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*[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"

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[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 com-

pared 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, 2016d) whilst approximately two-thirds of all those over the age of 65 have multimorbidity (Barnett *et al.*, 2012).

It would seem intuitive that a large proportion of those receiving social care have multimorbidity. However, no single data source exists that allows this comparison to be made. 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 Feinstein (Feinstein, 1970, p. 467) who stated, “In a patient with a particular index disease, the term co-morbidity refers to any additional co-existing ailment.” Van Den Akker et al. (1996, p. 65) 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 condi-

tions 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 social 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 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 5 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 10 summarises the thesis arguments and findings and places them in context.

# **Chapter 3**

## **Data Linkage, Information Governance, and Data Sources**

### **3.1 Introduction**

This chapter outlines the process of obtaining administrative data suitable to answer the thesis research questions. A brief description of data linkage research and the associated advantages and disadvantages of this approach are first 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. Finally, a description of the data sources used in the research is provided.

### **3.2 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.

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*[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 the data (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).

## 3.3 Information Governance

### 3.3.1 Introduction

Confidentiality of data subjects is an important consideration in any data linkage project. The benefits of administrative data linkage, outlined in section 3.2, 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.

### 3.3.2 Infrastructure

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

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*Elon Musk*

#### 3.3.2.1 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 Adminstrative Data Research Centres (ADRC), the Farr Institute, and the Urban Big Data Centre (UBDC) (SILC, 2017c).

#### 3.3.2.2 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 acces to the safe haven environment though 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 3.3.4.2.

### 3.3.2.3 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 sevices (ISD, 2010b). ISD held databases used in this thesis, the Prescribing Information System and Urgent Care Data Mart, are described more fully in sections [3.4.4](#) and [3.4.5](#).

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).

### 3.3.2.4 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 the NHS Central Register (NHSCR) which is held by NRS (NRS, 2018a) and described more fully in section ?? .

### 3.3.2.5 Health and Social Care Analysis

Health and Social Care Analysis (HSCA) is a division within the Socttish 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. HSCA 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 [3.4.2](#).

### 3.3.3 Approvals

As described in section 3.3.1, 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.

#### 3.3.3.1 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 online (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 C.

#### 3.3.3.2 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 E.

#### 3.3.3.3 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.

The approval letter for the main thesis project is shown in Appendix D, a fuller description data processing and the legal basis for this is presented in section [3.3.4](#).

### **3.3.4 Data processing**

#### **3.3.4.1 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 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).

### **3.3.4.2 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 3.3.2.2, 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 Lowthian & Ritchie (2017).

### **3.3.4.3 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. (include as appendix???)

## 3.4 Data Sources for Linkage

### 3.4.1 Introduction

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 Scottish population spine and death records, the Prescribing Information System, and the Unscheduled Care Data Mart. Each of these are described in more detail below.

### 3.4.2 Social Care Survey

The Social Care Survey (SCS) is collected annually by HSCA 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 HSCA 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, 2016d). HSCA produce a data specification document outlining the information that should be returned for the social care survey and this is sent to HSCA via a secure web-based system called ProcXed. This system supports data validation checks on transfer to improve data accuracy (Scottish-Government, 2016d).

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, 2016d). 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, 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, 2016d).

For the value of total weekly hours of home care, HSCA 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, 2016d). 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, 2016d). 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.

### **3.4.3 NHS Central Register 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 population spine 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 3.2). 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.

### **3.4.4 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).

### **3.4.5 Urgent Care Data**

The Urgent 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 the 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.

## 3.5 Timeline

Describe timeline of approvals process - major hurdles and barriers. **Maybe in methods??**

## 3.6 Conclusion

Brief summary of chapter here

# **Chapter 4**

## **Renfrewshire Council Exploratory Project**

### **4.1 Introduction**

As described in Section 3.4.2, the Social Care Survey (SCS) is collected annually by the Scottish Government and provides a snapshot of individuals receiving social care in all 32 Scottish local authorities during a census week - usually including the date the 31st of March (Scottish-Government, 2017f). The cross-sectional nature of this administrative data means it 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.

In order to gain a better understanding of the data the SCS captures an exploratory study was conducted to assess social care data for individuals from one local authority only. This project aimed to analyse complete data for all individuals over a ten-year period to assess the validity of the SCS as a representation of social care delivered in any given financial year. In particular, the exploratory analysis aimed to: quantify the number of home care users receiving home care during the census week as a proportion of the total number receiving home care in each year, identify what differences (if any) exist between individuals captured and not captured by the census, and assess whether values captured by the SCS (i.e. the total hours of home care provided) are representative of care received by an individual throughout the year. 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 proportion of all individuals that would be identified by two, three, or four survey repetitions per financial year.

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.

## 4.2 Background

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.

Renfrewshire Council area accounts for 3.2% of the total population of Scotland and has a similar proportion of individuals aged over 60 compared to the rest of the country (24.4% v 24.2%) (NRS, 2015). The mortality rate is very slightly higher than recorded for the rest of Scotland (10.9% v 10.3%) with the main causes of death being cancer, circulatory diseases, and respiratory diseases (NRS, 2015). Life expectancy at birth is lower than the Scottish average for both males and females (75.9 v 77.1 & 80.6 v 81.1) (NRS, 2015). Sixty-three percent of dwellings in Renfrewshire fall into the lowest council tax bands A-C (NRS, 2015) which is a higher than the percentage seen in the whole country (61%) (NRS, 2016). Of all datazones in the Renfrewshire Council area, 37.3% fall into the most deprived 30% of Scottish datazones - the ninth highest rate out of all 32 local authorities (Scottish-Government, 2017d). Datazones in the area show marked differences in SIMD scores with some of the most and least deprived datazones in the whole of Scotland and a spread of urban and rural neighbourhoods (Scottish-Government, 2017d).

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 dipped a little 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). The

Table 4.1: Definitions of home care types

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	
Community Mental Health	
Extra Care Housing	
Housing Support	
Overnight Services	

absolute numbers of over 65s receiving home care in Renfrewshire in the 2010 census week was 1812 versus 1603 in the 2017 census (Scottish-Government, 2017e, supp.charts).

More recent versions of the SCS collect information on home care (such as personal care or reablement), housing support and meals services provided during the census week. In addition, data on services such as community alarm, telecare, social worker, and self-directed support that are provided at any time during the financial year is also collected (Scottish-Government, 2017e). The purpose of the exploratory project was to compare service provision of those services collected in the census week. As the vast majority of this data is focussed on home care services, the analysis concentrates on this service only. Home care refers to services received in the home such as personal care or reablement (described in section 2.2.1 and summarised in table 4.1).

### 4.2.1 Research Questions

- To what extent does SCS data capture the number of individuals receiving home care across each financial year?
- Are there differences in the age and gender of the individuals that are/are not captured by the census?
- Is there a difference in the intensity and duration of care provided those that are/are not captured by the census?
- For individuals that *do* have packages of care during the census week, is the value of total hours of home care received reflective of the total hours of home care received in the financial year?
- What proportion of the total amount of individuals receiving home care would be captured if more than one census was conducted in each financial year?

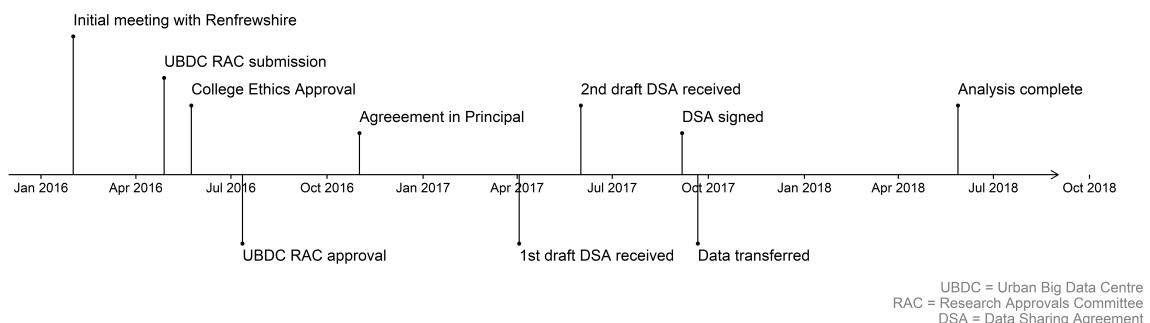
## 4.3 Methods

### 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 3.3.3.1 Approval from RAC was gained on 01/06/2016 (Appendix A). Ethical approval for the study was gained from the University of Glasgow College of Social Sciences Research Ethics Committee on 24/05/2016 (Appendix B).

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 4.1

Figure 4.1: 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.

For the purposes of analysis distinction is made between *episodes* and *packages* of home care. An episode of care refers to each instance a carer visits a home care client in their own home. A package of care is the collection of repeated episodes an individual routinely receives in a week.

Data provided for the purposes of this exploratory study included anonymised information on; how many days per week, how many hours per day, service provider (e.g. local authority or independent provider), type of care (e.g. mainstream or reablement), start date and end date for every episode of home care delivered to individuals in the Renfrewshire council area between April 2006 and April 2017. Demographic information detailing gender and year of birth was also provided.

As all episodes of home care were delivered over a period of time, data was provided for some episodes where the care was first delivered as early as 2004 or as late as Summer 2017 (e.g. a home care episode starting in December 2005 and running to December 2006 was included in the data transfer). Data detailing information on community alarm and telecare services provided by Renfrewshire council were not analysed as part of this project.

Analysis focussed on individuals over the age of 65. An unexpectedly large number of individuals ( $n = 112$ , 0.01%) had a year of birth recorded as 1900 (compared to  $n = 68$  born between the years 1901 and 1910). A similar phenomenon was reported in the SCS linkage process (described in chapter 5) with the deduction that 1900 was a code for missing data. In this analysis these records were omitted. To protect anonymity individual month and day of birth were not shared meaning age was calculable from year of birth only.

The SCS requests information on the total weekly hours of home care each individual received during the census week. To replicate this information, every episode of care in the exploratory dataset was summarised. For each episode of home care, the number of hours per day was multiplied with days per week to give a weekly total of home care hours for each episode. To identify *packages* of home care, episodes of home care with the same start and end date and of the same home care type, were added together. For example, an individual receiving home care of the type “Care at Home (Mainstream)” with an episode of care lasting 1 hour in the morning for 3 days a week, an episode of care lasting 45 minutes at lunchtime 7 days a week, an evening episode of 30 minutes 7 days a week, and night-time episode of 45 mins 7 days a week, would have a total weekly home care hours count of 17 hours per week for that home care type. Finally, the totals for all types of home care were summed to give an overall weekly total for each individual.

### **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 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. Maximum and minimum values and measures of central tendency of these weekly values were compared to the total number of individuals receiving home care, and total number of those not captured by the census, in each financial year.

As it was possible for individuals to receive more than one package of care in each financial year, individuals were grouped by those that had at least one package of care during the census week and those that had none. This enabled comparison of the proportions of each age group, gender, and type of home care received by whether an individual had been identified in the census or not.

To assess the difference in the type of care received by individuals in each of these groups, comparison was made of the total hours of home care and total duration of care they received. Linear regression models were fitted for the financial years 2010/11 to 2014/15 using total weekly hours of home care or package duration (in weeks) as dependent variables. A dummy variable indicating whether an individual had a least one package identified in a census was used as the independent predictor. To compare how differences in care varied across age, gender, and care type groups, further linear models using the same parameters were fitted to subsets of data containing these groups. This enabled comparison of intercept and coefficient values. 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 these analyses.

For individuals that received multiple packages of care, one of which was captured by a census, the net difference in total weekly hours of home care received across all packages was calculated in order to summarise the variation in care. For example, an individual initially receiving 6 hrs of care, experiencing a break in care to zero hours, and then receiving a new package of care of 7 hrs before a further drop to 2 hrs would have a net difference of  $(-6 + 7 - 5) = -4$  hours. The distribution of this value across all individuals was then assessed.

Additional variables indicating whether home care packages were “live” at three, four, six, eight, and nine months before the census of each financial year were appended to the dataset. This enabled counts of individuals who would be captured by six-monthly, four monthly, and three monthly census repetitions.

All data cleaning and analysis was conducted using the R language and environment for statistical computing version 3.4.0 (R-Core-Team, 2017) with additional software packages: **dplyr** v0.7.4 (Wickham and Francois, 2017), **tidyverse** v0.7.2. (Wickham and Henry, 2017), **forcats** v0.2.0 (Wickham, 2017), **purrr** v0.2.4 (Henry and Wickham, 2017), **lubridate** v1.6.0. (Grolemund and Wickham, 2017), **tibbletime** v0.0.2 (Dancho

and Vaughan, 2017), `magrittr` v1.5 (Bache and Wickham, 2014), `broom` v0.4.2 (Robinson, 2017), `ggplot2` v2.2.1 (Wickham and Chang, 2016), and `ggthemes` v3.5.0 (Arnold *et al.*, 2018) via the Integrated Development Environment RStudio v1.0.143 (RStudio-team, 2016). Data was held securely in the safe haven environment described in section 3.3.4.2

## 4.4 Results

### 4.4.1 Descriptive statistics

re-write this paragraph describing the time series in a better fashion - also re-check the numbers I don;t think these take account of reinclusion of mental health etc. packages

After data cleaning, information on 41,002 packages of home care received by 10,130 individuals during the period 2006 to 2016 were included in the analysis. The number of records retained at each stage of the cleaning process is shown in table 4.2. Of these packages, 28,775 described actual packages of care. The remainder described place holders for each individual where they were not receiving care, either because of a break in care or because care provision had ended altogether. These 12,227 records showed a value of zero for the total hours of homecare received and in the case of care provision having ended, showed an end date of 28th March 2016.

Table 4.2: Number of records at each stage of data cleaning

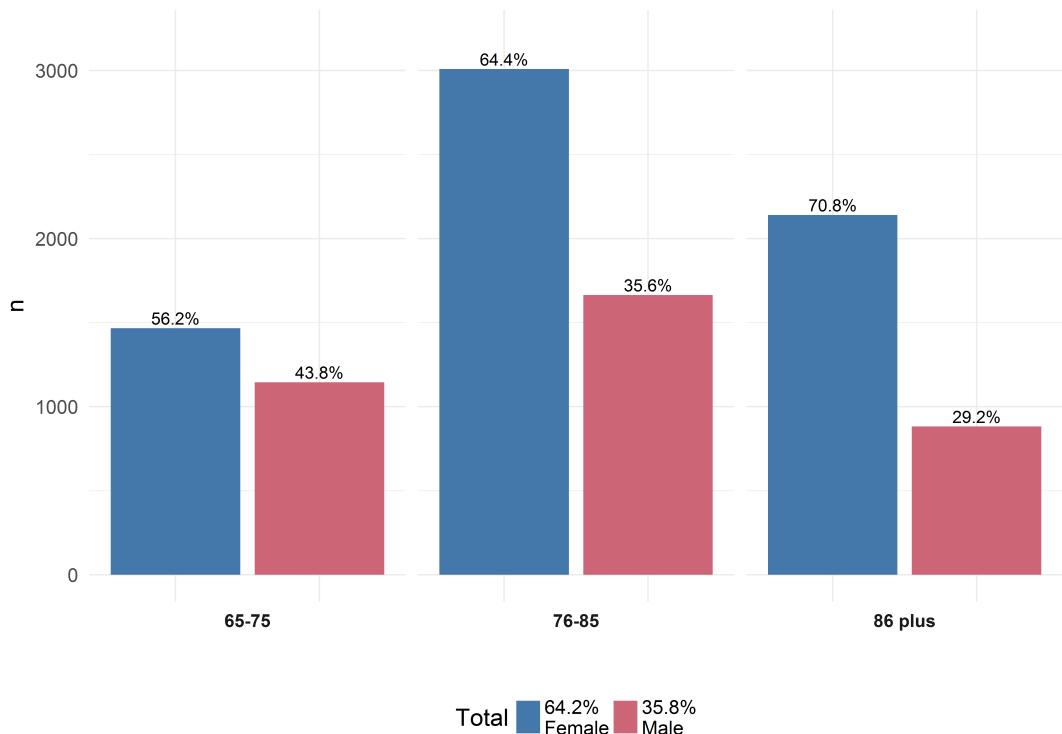
Data Cleaning stage	Number of records
Initial home care file	106,111
Including over 65s only	92,723
Summarised to packages of care	41,002 <sup>1</sup>
Packages of non-zero hours of care	28,775

<sup>1</sup> Total number of individuals = 10,310

Mean age of those included in the analysis was 80.8 years and median age was 81. Sixty-four percent of individuals ( $n = 6,515$ ) were female. Detailed breakdown of age and gender groups is shown in figure 4.2. The highest absolute numbers of individuals are found in the 76-85 age group. Statistical disclosure control meant that grouping an additional age group for over 95s was not possible.

Seventy-eight percent of home care packages ( $n=22,484$ ) were provided for “Care at Home (Mainstream)” with “Reablement” type packages making up the majority of the remainder (Figure 4.3). Only 60 packages of care for over 65s were classified as being provided

Figure 4.2: Count and proportion of individuals receiving home care by age and gender



for “Community Mental Health” or “Overnight Services” during the study period. “Reablement” packages were first coded as such in the financial year 2010/11 meaning “Care at Home (Mainstream)” made up an even larger proportion of care packages prior to this.

Almost two-thirds of home care packages in the study period provided care at intensities of less than 10 hours per week. Only 1,352 (4.7%) packages over the 10 year study period provided high intensity care of over 20 hours per week (figure 4.4). Eighty-five percent of packages lasted for less than one year (figure 4.5).

Figure 4.3: Count and proportion of home care type

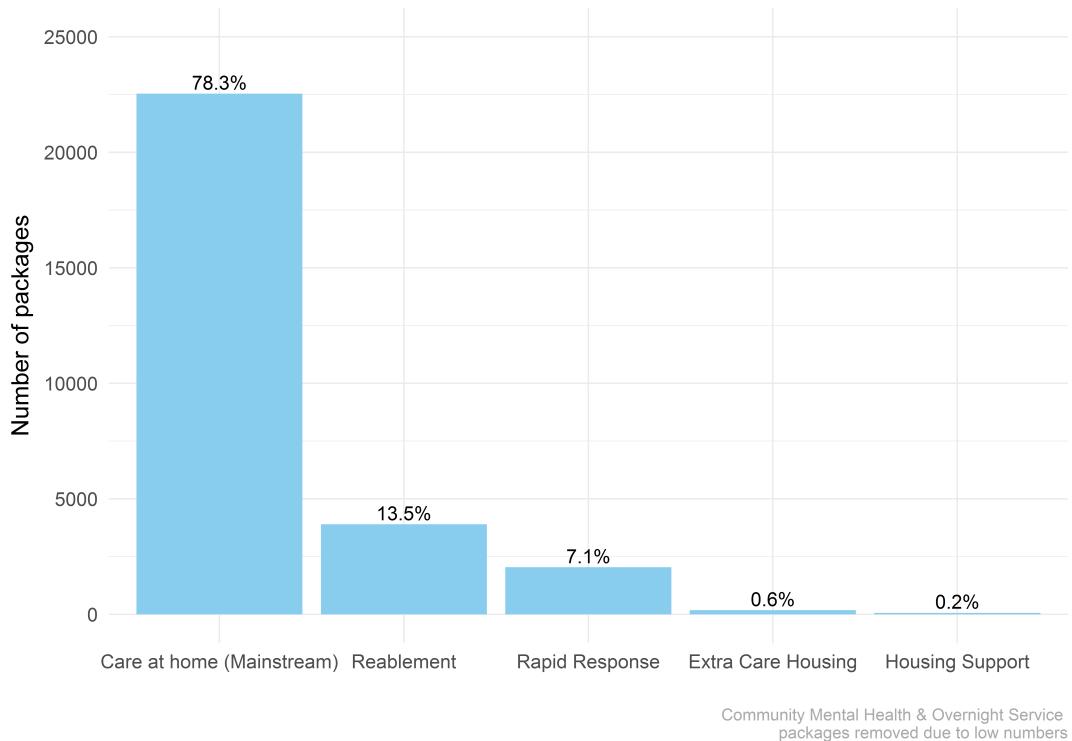


Figure 4.4: Count of packages of care by intensity

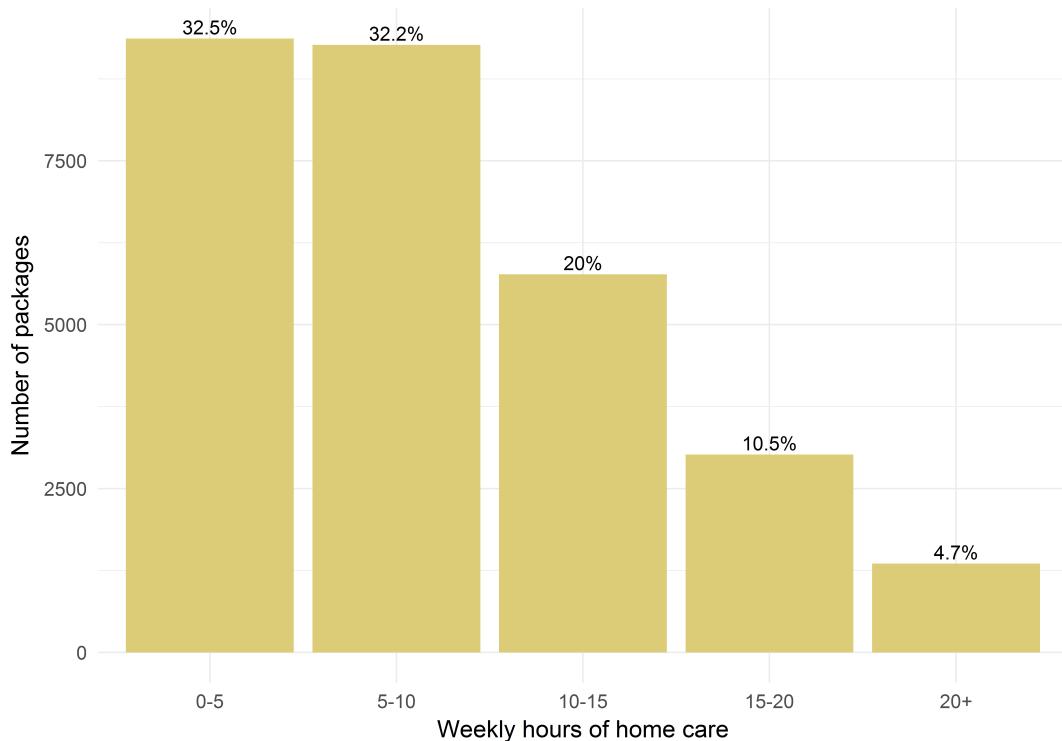
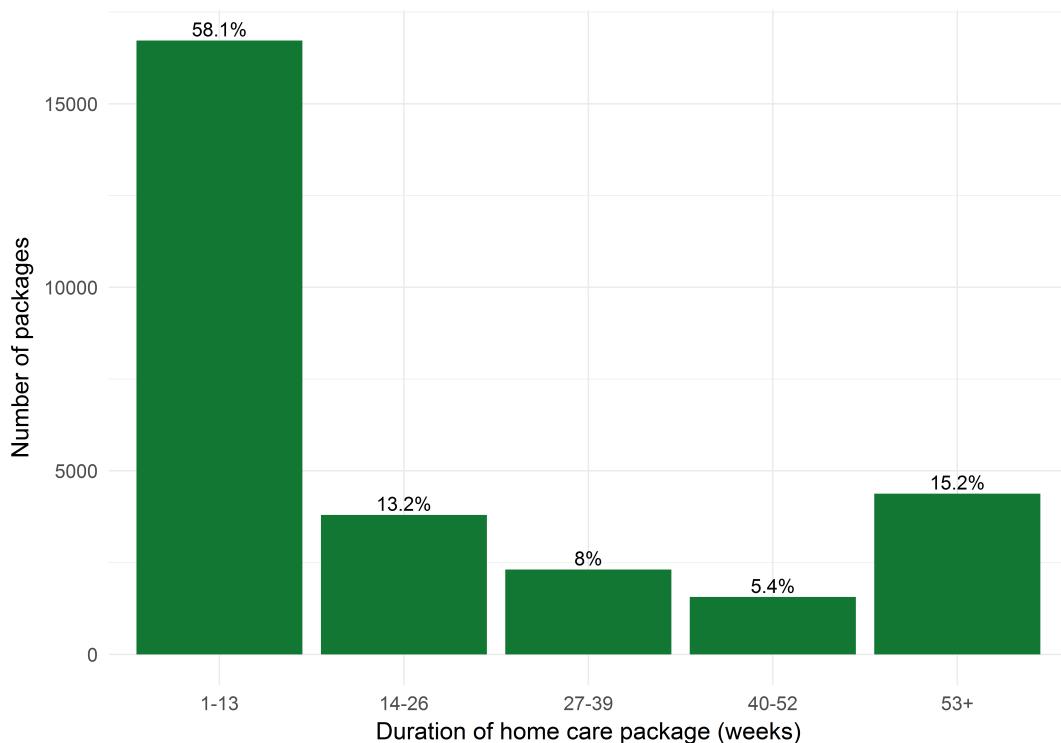


Figure 4.5: Count of packages of care by duration



#### 4.4.2 Distribution of individuals receiving home care

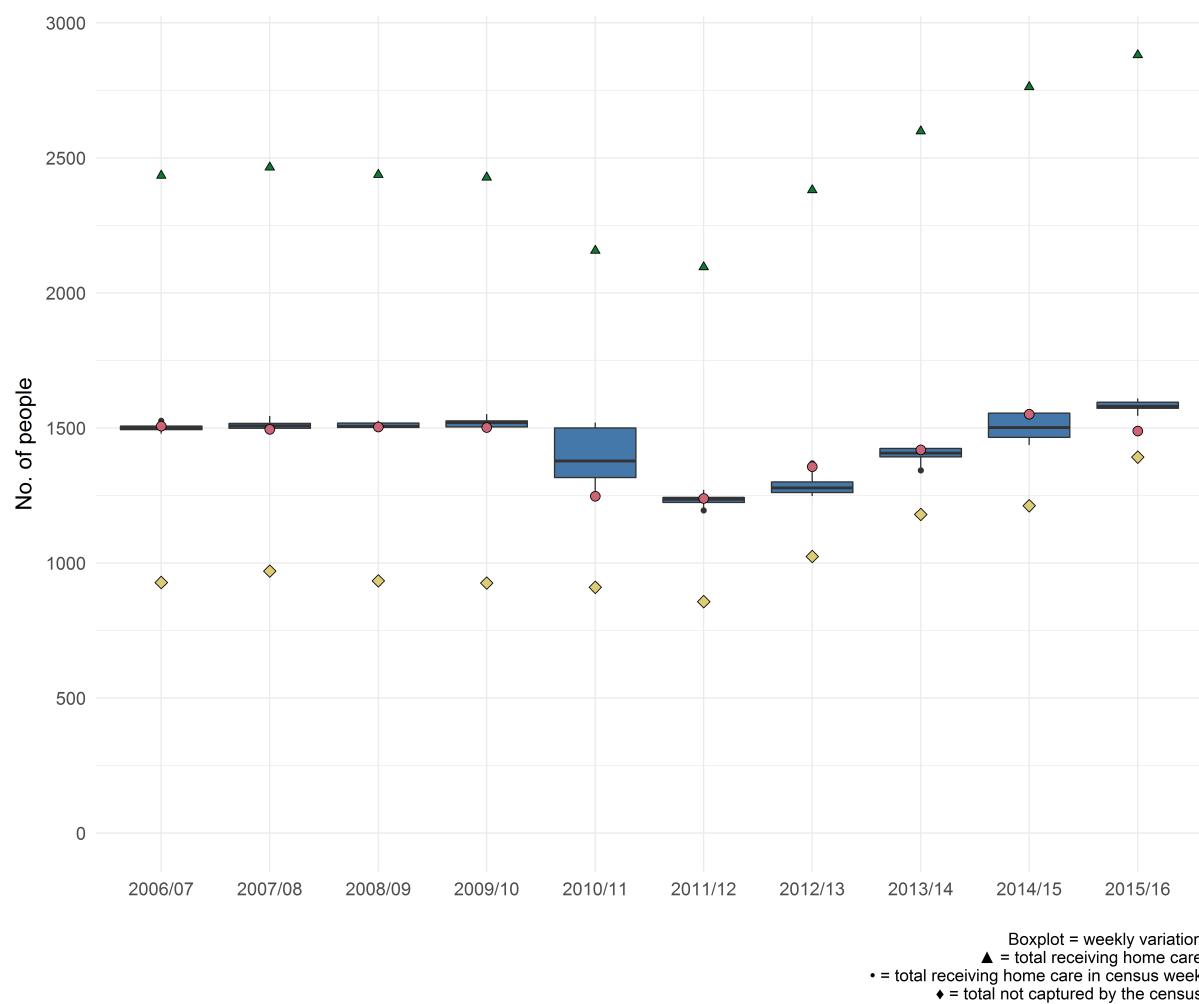
Table 4.3 and figure 4.6 show the variation in the number of people receiving home care during each financial year. There is little weekly variation within years with the exception of financial year 2010/11 which saw a large drop in the total number of individuals receiving care. The variation in years following this show gradual increases and overall numbers return to pre-2010/11 levels by 2014/15.

Figure 4.6 and table 4.3 also indicate that number of individuals receiving home care and captured by the census is between 51.7% and 61.9% of the total number of individuals that will receive care in that year. The trend shows a decreasing proportion of individuals are captured by the census.

Table 4.3: Variation in the number of individuals receiving home care

Financial Year	min	max	mean	sd	median	range	IQR	Total individuals receiving home care	Total individuals not captured by census	Ratio of individuals captured by census (%)
2006/07	1479	1527	1502.51	11.75	1501	48	15	2435	928	61.89
2007/08	1488	1544	1508.65	12.61	1508	56	18	2465	970	60.65
2008/09	1486	1527	1508.63	9.96	1508	41	16	2438	934	61.69
2009/10	1488	1551	1516.43	15.62	1520	63	24	2428	926	61.86
2010/11	1256	1520	1399.39	90.85	1378	264	176	2157	910	57.81
2011/12	1195	1271	1234.19	15.21	1236	76	19	2096	857	59.11
2012/13	1248	1369	1288.44	36.55	1278	121	39	2381	1024	56.99
2013/14	1343	1436	1405.52	21.17	1408	93	31	2599	1180	54.60
2014/15	1437	1568	1505.50	44.68	1502	131	90	2763	1212	56.13
2015/16	1545	1609	1582.60	13.27	1580	64	21	2881	1392	51.68

Figure 4.6: Variation in the number of individuals receiving home care



#### 4.4.3 Comparison of individuals with/without any packages in the census

Table 4.4 shows the number of individuals with at least one package captured by the census compared to those that have zero packages during the census week in each financial year. There is very little variation in the proportions in each group over time. **This needs to be a table showing the number of individuals with only one package of care in the year and the number with multiple packages and should be in section 4.4.6**

As shown in figure 4.7, there is very little difference in age and gender groups between those that are not captured by the census in each year compared to those that are represented in the census.

Figure 4.8 shows that there are similar proportions of individuals receiving each type of homecare in each financial year regardless of whether or not they have any packages of care

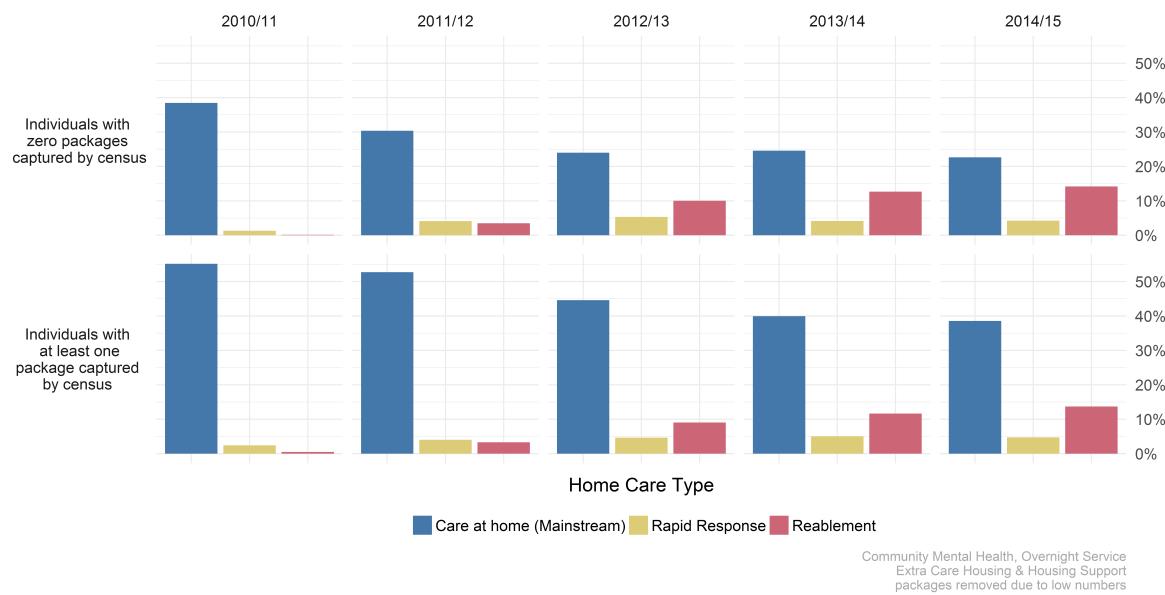
Table 4.4: Count of individuals with packages captured by census

Financial Year	Individuals with zero packages captured by census (n)	Individuals with at least one package captured by census (n)
2010/11	864 (40.3%)	1279 (59.7%)
2011/12	797 (38.2%)	1289 (61.8%)
2012/13	945 (39.8%)	1430 (60.2%)
2013/14	1080 (41.7%)	1513 (58.3%)
2014/15	1138 (41.4%)	1614 (58.6%)

Figure 4.7: Proportion of individuals receiving home care



Figure 4.8: Proportion of individuals receiving home care



captured by the census. The figure also shows the increasing proportion of “Reablement” packages over time from almost no packages in 2010/11 to approximately 14% of all packages delivered in 2014/15. “Care at home (Mainstream)” type packages saw a drop from approximately 82% to 60% of all packages over the same period.

#### 4.4.4 Comparison of package intensity for individuals with/without any packages in the census

Comparison of the total weekly hours of home care (intensity) that individuals with/without any packages in the census receive (figure 4.9) shows that there is very little difference in median values. However, as time progresses, the median value for total hours of home care is slightly larger for those with no packages of care captured in the census.

This trend is shown in table 4.5 which shows the intercept and coefficient of total hours of home care in linear regression models for each year (in bold) with presence of at least one, or zero packages in the census as a categorical predictor. Over time, the intercept value increases from 6.26 hours in 2010/11 to 8.41 hrs in 2014/15 indicating a general increase in intensity for individuals with at least one package in the census. There is a statistically significant difference in the amount of hours of care received between those that have at least one package in the census and those that have no packages in every financial year. The coefficient value is negative in 2010/11 but positive in all other years and increases over time. However, the difference in groups is modest (the 1.2 hrs increase in intensity

in 2014/15 is equivalent to approximately 10 minutes extra care per day).

Figure 4.9: Variation in intensity of home care

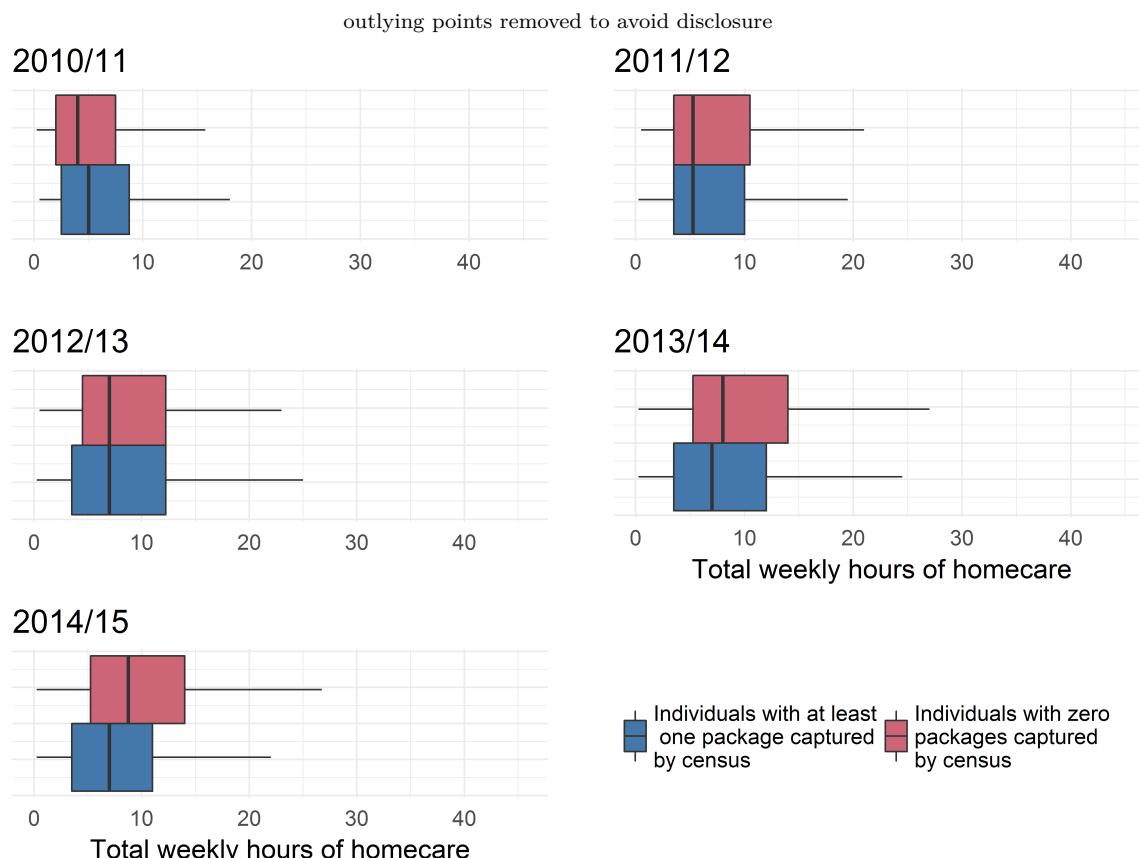


Table 4.5 also shows the results of the same linear regression model applied separately to individuals from groups of different gender, age, and home care type. The differences between these groups become more apparent over time with all groups (apart from the “Rapid Response” care type) showing statistically significant differences in 2014/15. Intercept values for total hours of home care vary slightly across different groups with “Rapid Response” and “Reablement” packages more likely to have higher values - particularly in later years. Differences between groups also vary with older age groups and “Reablement” care type packages showing larger coefficient values for those with zero packages captured by the census. The largest difference is seen for “Reablement” packages in 2014/15 with an expected 2.14 hrs increase for those with zero packages compared to those with at least one package in the census. This is equivalent to an 18.3 minute increase in care per day. The variation in total hours of care between home care types is plotted in figure 4.10.

Table 4.5: Regression models of package intensity

Financial Year	Gender	Age group	Type of home care		estimate	std.error	statistic	p value
2010/11				(Intercept)	6.255	0.115	54.630	
				No package in census	-0.415	0.193	-2.147	<0.05
	Female			(Intercept)	6.184	0.134	46.091	
	Female			No package in census	-0.435	0.234	-1.861	0.063
	Male			(Intercept)	6.450	0.220	29.338	
	Male			No package in census	-0.428	0.346	-1.237	0.217
		65-75		(Intercept)	7.200	0.243	29.573	
		65-75		No package in census	-1.534	0.417	-3.678	<0.05
		76-85		(Intercept)	5.803	0.164	35.386	
		76-85		No package in census	-0.084	0.276	-0.303	0.762
		86 plus		(Intercept)	6.065	0.204	29.764	
		86 plus		No package in census	0.119	0.340	0.349	0.727
			Care at home (Mainstream)	(Intercept)	6.266	0.118	53.245	
			Care at home (Mainstream)	No package in census	-0.430	0.198	-2.177	<0.05
			Rapid Response	(Intercept)	5.470	0.490	11.169	
			Rapid Response	No package in census	0.332	0.908	0.365	0.716
			Reablement	(Intercept)	9.958	1.602	6.216	
			Reablement	No package in census	-1.792	3.582	-0.500	0.625

Table 4.5 continued from previous page

Financial Year	Gender	Age group	Type of home care	estimate	std.error	statistic	p value	
2011/12			(Intercept)	6.754	0.118	57.119		
			No package in census	0.426	0.203	2.097	<0.05	
	Female		(Intercept)	6.701	0.146	46.012		
	Female		No package in census	0.485	0.251	1.929	0.054	
	Male		(Intercept)	6.871	0.201	34.101		
	Male		No package in census	0.297	0.344	0.866	0.387	
		65-75	(Intercept)	7.414	0.224	33.119		
		65-75	No package in census	-0.504	0.434	-1.161	0.246	
		76-85	(Intercept)	6.391	0.175	36.605		
		76-85	No package in census	0.718	0.291	2.468	<0.05	
		86 plus	(Intercept)	6.576	0.229	28.772		
		86 plus	No package in census	0.892	0.373	2.390	<0.05	
			Care at home (Mainstream)	(Intercept)	6.551	0.127	51.631	
			Care at home (Mainstream)	No package in census	0.295	0.223	1.323	0.186
			Rapid Response	(Intercept)	7.770	0.413	18.826	
			Rapid Response	No package in census	0.748	0.634	1.180	0.239
			Reablement	(Intercept)	8.573	0.480	17.868	
			Reablement	No package in census	0.250	0.737	0.339	0.735

Table 4.5 continued from previous page

Financial Year	Gender	Age group	Type of home care	estimate	std.error	statistic	p value	
2012/13			(Intercept)	8.375	0.118	70.736		
			No package in census	0.586	0.202	2.896	<0.05	
	Female		(Intercept)	8.460	0.144	58.950		
	Female		No package in census	0.363	0.249	1.458	0.145	
	Male		(Intercept)	8.190	0.209	39.100		
	Male		No package in census	1.031	0.348	2.964	<0.05	
		65-75	(Intercept)	8.034	0.231	34.830		
		65-75	No package in census	0.917	0.383	2.394	<0.05	
		76-85	(Intercept)	8.398	0.181	46.311		
		76-85	No package in census	0.544	0.306	1.779	<0.05	
		86 plus	(Intercept)	8.611	0.212	40.545		
		86 plus	No package in census	0.391	0.381	1.027	0.304	
			Care at home (Mainstream)	(Intercept)	8.054	0.140	57.715	
			Care at home (Mainstream)	No package in census	0.139	0.248	0.561	0.575
			Rapid Response	(Intercept)	10.172	0.388	26.193	
			Rapid Response	No package in census	-0.218	0.589	-0.370	0.712
			Reablement	(Intercept)	8.830	0.262	33.668	
			Reablement	No package in census	1.806	0.419	4.309	<0.05

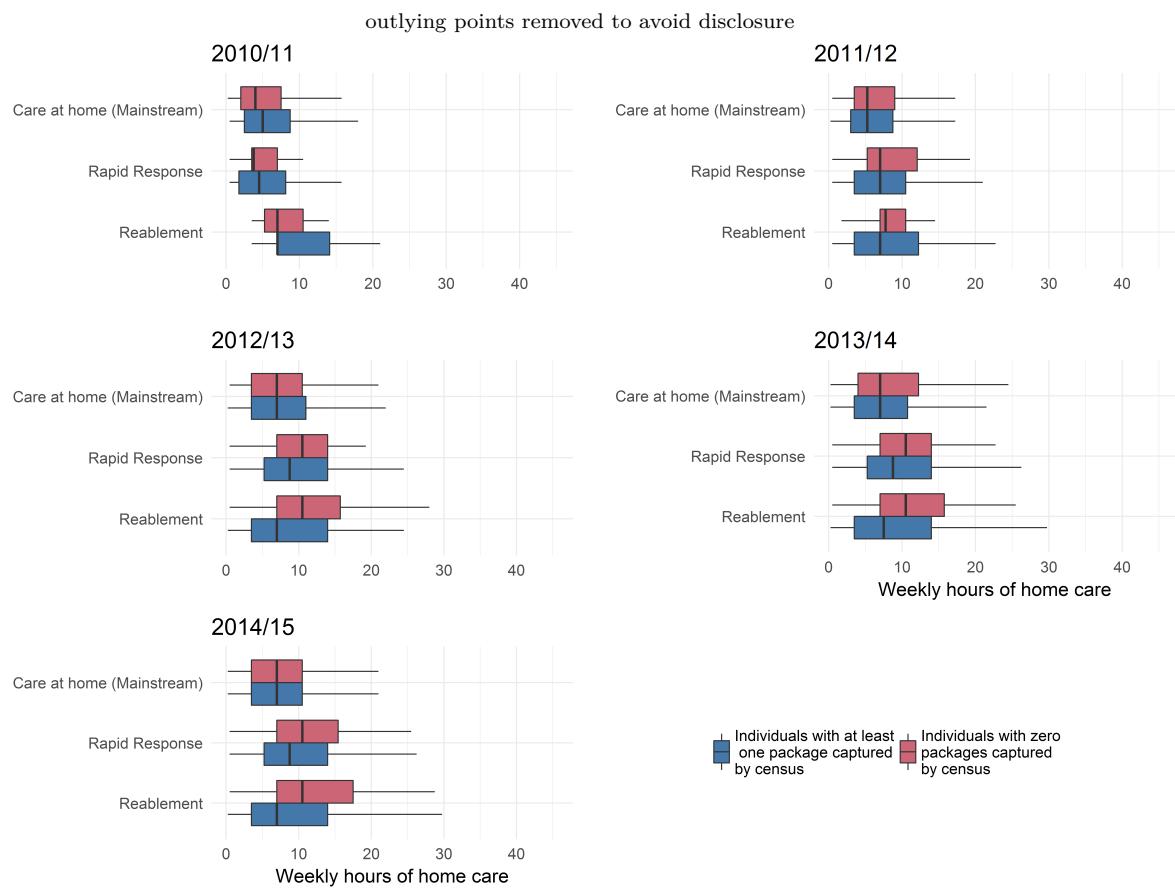
Table 4.5 continued from previous page

Financial Year	Gender	Age group	Type of home care	estimate	std.error	statistic	p value	
2013/14			(Intercept)	8.531	0.117	72.894		
			No package in census	0.995	0.198	5.038	<0.05	
	Female		(Intercept)	8.560	0.145	58.926		
	Female		No package in census	1.092	0.253	4.322	<0.05	
	Male		(Intercept)	8.464	0.196	43.167		
	Male		No package in census	0.844	0.313	2.699	<0.05	
		65-75	(Intercept)	8.624	0.222	38.794		
		65-75	No package in census	0.774	0.387	2.001	<0.05	
		76-85	(Intercept)	8.420	0.176	47.958		
		76-85	No package in census	0.953	0.295	3.233	<0.05	
		86 plus	(Intercept)	8.607	0.221	38.879		
		86 plus	No package in census	1.240	0.367	3.378	<0.05	
			Care at home (Mainstream)	(Intercept)	8.159	0.143	57.052	
			Care at home (Mainstream)	No package in census	0.766	0.247	3.101	<0.05
			Rapid Response	(Intercept)	9.621	0.356	27.037	
			Rapid Response	No package in census	0.944	0.603	1.565	0.118
			Reablement	(Intercept)	9.239	0.241	38.259	
			Reablement	No package in census	1.364	0.383	3.562	<0.05

Table 4.5 continued from previous page

Financial Year	Gender	Age group	Type of home care	estimate	std.error	statistic	p value	
2014/15			(Intercept)	8.411	0.114	73.466		
			No package in census	1.197	0.189	6.340	<0.05	
	Female		(Intercept)	8.369	0.141	59.267		
	Female		No package in census	1.298	0.234	5.539	<0.05	
	Male		(Intercept)	8.498	0.195	43.498		
	Male		No package in census	0.996	0.319	3.126	<0.05	
		65-75	(Intercept)	8.427	0.219	38.538		
		65-75	No package in census	0.878	0.383	2.294	<0.05	
		76-85	(Intercept)	8.374	0.169	49.619		
		76-85	No package in census	1.175	0.280	4.201	<0.05	
		86 plus	(Intercept)	8.458	0.222	38.051		
		86 plus	No package in census	1.456	0.347	4.194	<0.05	
			Care at home (Mainstream)	(Intercept)	8.004	0.138	57.848	
			Care at home (Mainstream)	No package in census	0.623	0.238	2.617	<0.05
			Rapid Response	(Intercept)	9.992	0.385	25.960	
			Rapid Response	No package in census	0.694	0.612	1.134	0.257
			Reablement	(Intercept)	8.898	0.230	38.757	
			Reablement	No package in census	2.135	0.352	6.072	<0.05

Figure 4.10: Variation in intensity of home care - by type



#### 4.4.5 Comparison of package duration for individuals with/without any packages in the census

Figure 4.11 shows a comparison of the total duration of care for individuals with or without any packages captured by the census for each financial year. A clear difference can be seen for those with no packages captured by the census who have much shorter total duration of care. Results of linear regression models fitting package duration against presence or not of at least one package in the census (table 4.6) confirms statistically significant differences between all groups (with the exception of “Reablement” packages in 2010/11). These differences are large e.g. the overall coefficient in 2014/15 is -54.32 weeks suggesting individuals with zero packages captured by the census have care duration, on average, over a year shorter than those with at least one package in the census.

Intercept values in table 4.6 gradually decrease over time which is likely due to censoring at the end of the time series. Within years there is a large difference in intercept values. Older age groups, as well as “Rapid Response” and “Reablement” type packages all show much lower values than the total seen in each year. Variation in duration of care by home care type is plotted in figure 4.12

Figure 4.11: Variation in duration of home care

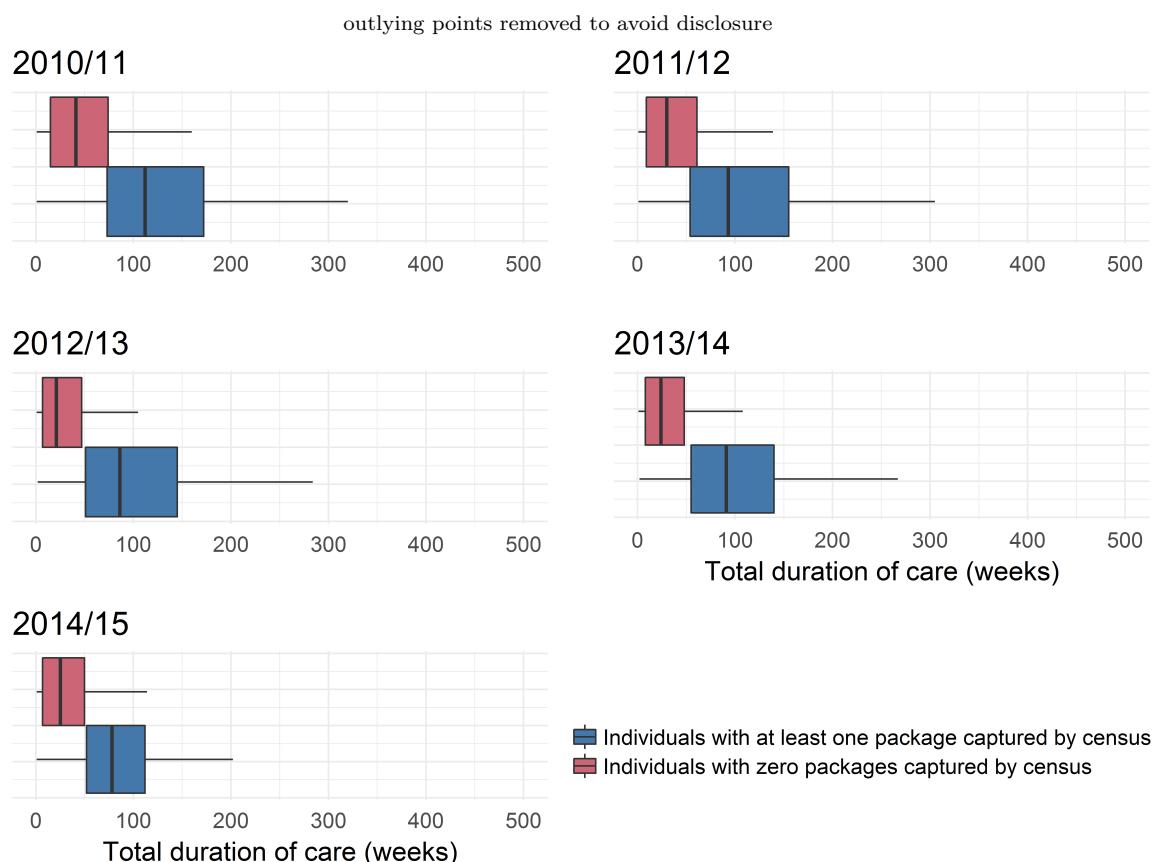


Table 4.6: Regression models of package duration

Financial Year	Gender	Age group	Type of home care	estimate	std.error	statistic	p value
2010/11			(Intercept)	131.19	1.55	84.80	
			No package in census	-76.55	2.62	-29.18	<0.05
	Female		(Intercept)	132.62	1.83	72.40	
	Female		No package in census	-75.29	3.20	-23.54	<0.05
	Male		(Intercept)	127.36	2.89	44.12	
	Male		No package in census	-78.09	4.59	-17.01	<0.05
		65-75	(Intercept)	146.55	3.31	44.22	
		65-75	No package in census	-98.60	5.68	-17.35	<0.05
		76-85	(Intercept)	130.26	2.29	56.81	
		76-85	No package in census	-73.53	3.89	-18.89	<0.05
		86 plus	(Intercept)	117.76	2.51	46.83	
		86 plus	No package in census	-60.34	4.21	-14.32	<0.05
		Care at home (Mainstream)	(Intercept)	131.56	1.58	83.35	
		Care at home (Mainstream)	No package in census	-76.67	2.67	-28.77	<0.05
		Rapid Response	(Intercept)	140.74	7.85	17.92	
		Rapid Response	No package in census	-90.23	14.54	-6.21	<0.05
		Reablement	(Intercept)	17.57	5.87	2.99	
		Reablement	No package in census	-11.24	13.98	-0.80	0.43401

Table 4.6 continued from previous page

Financial Year	Gender	Age group	Type of home care		estimate	std.error	statistic	p value
2011/12			(Intercept)	111.31	1.44	77.39		
			No package in census	-67.55	2.49	-27.09	<0.05	
	Female		(Intercept)	113.67	1.73	65.70		
	Female		No package in census	-67.69	3.00	-22.55	<0.05	
	Male		(Intercept)	106.17	2.58	41.15		
	Male		No package in census	-67.21	4.46	-15.06	<0.05	
		65-75	(Intercept)	122.75	2.72	45.06		
		65-75	No package in census	-85.49	5.27	-16.23	<0.05	
		76-85	(Intercept)	109.74	2.25	48.73		
		76-85	No package in census	-67.86	3.79	-17.92	<0.05	
		86 plus	(Intercept)	101.08	2.49	40.60		
		86 plus	No package in census	-49.92	4.13	-12.09	<0.05	
			Care at home (Mainstream)	(Intercept)	117.92	1.58	74.84	
			Care at home (Mainstream)	No package in census	-68.29	2.78	-24.56	<0.05
			Rapid Response	(Intercept)	79.82	4.45	17.96	
			Rapid Response	No package in census	-55.49	7.03	-7.89	<0.05
			Reablement	(Intercept)	63.15	3.16	19.98	
			Reablement	No package in census	-51.53	5.06	-10.18	<0.05

Table 4.6 continued from previous page

Financial Year	Gender	Age group	Type of home care	estimate	std.error	statistic	p value	
2012/13			(Intercept)	104.68	1.20	87.51		
			No package in census	-69.14	2.06	-33.51	<0.05	
	Female		(Intercept)	105.59	1.45	72.89		
	Female		No package in census	-67.85	2.53	-26.84	<0.05	
	Male		(Intercept)	102.72	2.12	48.49		
	Male		No package in census	-71.45	3.57	-20.01	<0.05	
		65-75	(Intercept)	120.31	2.73	44.05		
		65-75	No package in census	-80.02	4.61	-17.34	<0.05	
		76-85	(Intercept)	102.25	1.77	57.92		
		76-85	No package in census	-67.40	3.01	-22.38	<0.05	
		86 plus	(Intercept)	95.62	1.87	51.00		
		86 plus	No package in census	-63.47	3.35	-18.94	<0.05	
			Care at home (Mainstream)	(Intercept)	117.05	1.52	77.20	
			Care at home (Mainstream)	No package in census	-71.43	2.71	-26.38	<0.05
			Rapid Response	(Intercept)	85.41	3.12	27.40	
			Rapid Response	No package in census	-60.22	4.88	-12.34	<0.05
			Reablement	(Intercept)	69.45	1.64	42.46	
			Reablement	No package in census	-55.95	2.68	-20.91	<0.05

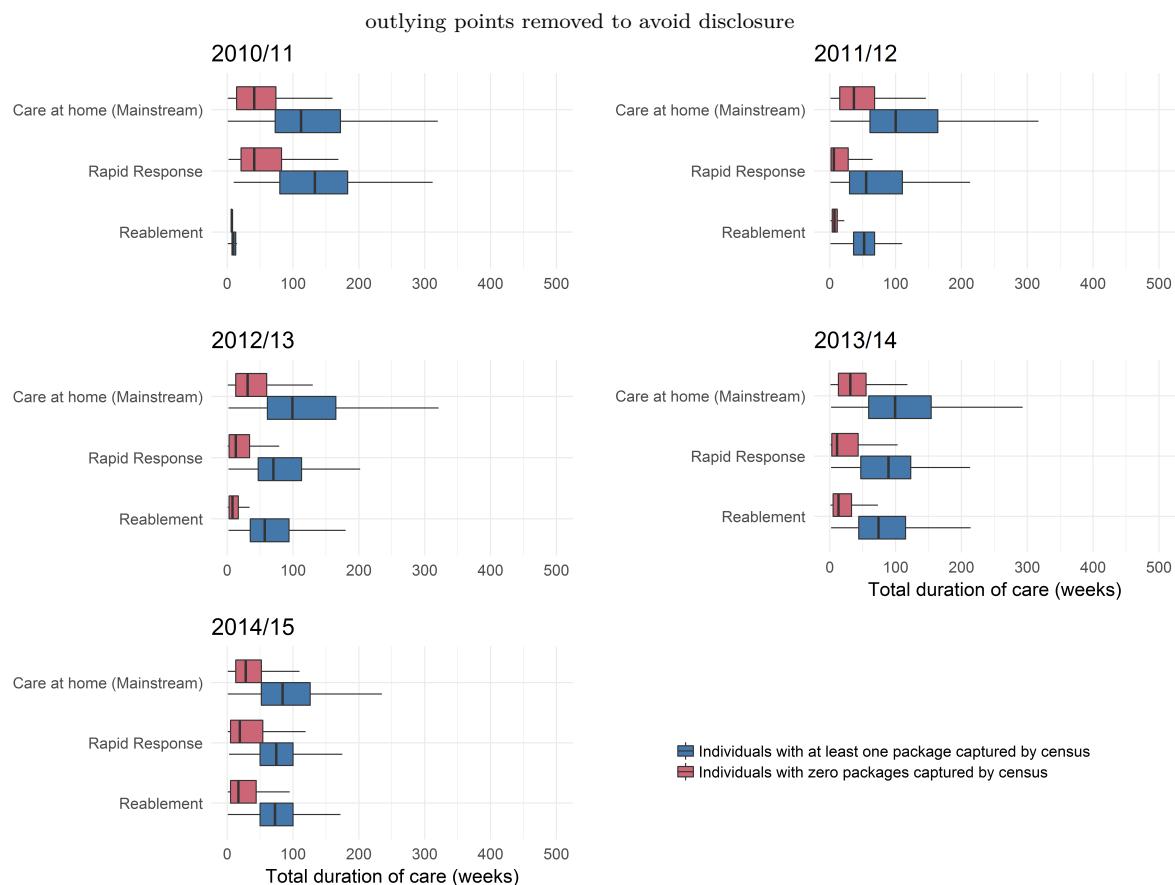
Table 4.6 continued from previous page

Financial Year	Gender	Age group	Type of home care	estimate	std.error	statistic	p value	
2013/14			(Intercept)	104.94	1.09	95.88		
			No package in census	-68.39	1.86	-36.75	<0.05	
	Female		(Intercept)	107.27	1.38	77.99		
	Female		No package in census	-68.11	2.41	-28.20	<0.05	
	Male		(Intercept)	99.80	1.77	56.28		
	Male		No package in census	-67.59	2.84	-23.78	<0.05	
		65-75	(Intercept)	121.50	2.42	50.14		
		65-75	No package in census	-86.25	4.23	-20.39	<0.05	
		76-85	(Intercept)	103.77	1.62	63.93		
		76-85	No package in census	-68.17	2.74	-24.87	<0.05	
		86 plus	(Intercept)	91.45	1.69	53.97		
		86 plus	No package in census	-52.46	2.84	-18.44	<0.05	
			Care at home (Mainstream)	(Intercept)	114.43	1.46	78.32	
			Care at home (Mainstream)	No package in census	-69.58	2.54	-27.40	<0.05
			Rapid Response	(Intercept)	93.32	3.05	30.59	
			Rapid Response	No package in census	-67.26	5.30	-12.69	<0.05
			Reablement	(Intercept)	82.70	1.49	55.68	
			Reablement	No package in census	-61.07	2.38	-25.69	<0.05

Table 4.6 continued from previous page

Financial Year	Gender	Age group	Type of home care		estimate	std.error	statistic	p value
2014/15			(Intercept)	90.76	0.99	91.86		
			No package in census	-54.32	1.63	-33.23	<0.05	
	Female		(Intercept)	91.79	1.20	76.25		
	Female		No package in census	-54.28	2.00	-27.11	<0.05	
	Male		(Intercept)	88.64	1.73	51.27		
	Male		No package in census	-54.28	2.83	-19.19	<0.05	
		65-75	(Intercept)	106.95	2.30	46.56		
		65-75	No package in census	-71.40	3.98	-17.95	<0.05	
		76-85	(Intercept)	84.83	1.34	63.13		
		76-85	No package in census	-48.84	2.24	-21.79	<0.05	
		86 plus	(Intercept)	85.24	1.68	50.62		
		86 plus	No package in census	-47.48	2.65	-17.91	<0.05	
			Care at home (Mainstream)	(Intercept)	98.60	1.40	70.59	
			Care at home (Mainstream)	No package in census	-56.46	2.41	-23.46	<0.05
			Rapid Response	(Intercept)	80.31	2.52	31.88	
			Rapid Response	No package in census	-45.33	4.02	-11.28	<0.05
			Reablement	(Intercept)	75.47	1.26	59.82	
			Reablement	No package in census	-48.43	1.95	-24.79	<0.05

Figure 4.12: Variation in duration of home care by care type



#### 4.4.6 Variation in care packages captured by census

Descriptive statistics of the net difference in total hours of home care for those individuals that have at least one package captured by the census *and* more than one package in a financial year are shown in table 4.7. The variation is plotted in figure 4.13. The median value of the net difference in total hours of home care for individuals with multiple packages of “Care at home (Mainstream)” is close to zero in all years with interquartile ranges (IQR) varying from 4.25 to 8.5hrs. These individuals account for approximately 60% of all those captured by the census with multiple packages of care.

The remaining individuals see larger negative values for the net difference in total hours of home care over the financial year with wider IQR values. Linear regression of the net difference in total hours of homecare with home care type as an explanatory variable (table 4.8) shows statistically significant results in all years except 2010/11.

Table 4.7: Variation in net difference of total hours of homecare by care type

Financial Year	Type of home care	number of packages	number of unique individuals	mean	sd	median	IQR	25th percentile	75th percentile
2010/11	Care at home (Mainstream)	1456	561	0.23	5.01	-0.13	4.25	-2.00	2.25
2010/11	Rapid Response	54	21	-1.04	3.97	-0.13	4.63	-3.31	1.31
2010/11	Reablement <sup>1</sup>	*	*	-4.20	5.75	0.00	10.50	-10.50	0.00
2011/12	Care at home (Mainstream)	1241	437	0.73	5.52	0.25	5.25	-1.75	3.50
2011/12	Rapid Response	133	47	-1.42	7.25	-1.75	8.75	-7.00	1.75
2011/12	Reablement	119	38	-5.52	5.28	-5.25	7.00	-10.00	-3.00
2012/13	Care at home (Mainstream)	1528	486	0.42	7.49	0.00	6.50	-3.00	3.50
2012/13	Rapid Response	242	72	-2.55	7.33	-2.50	10.75	-8.75	2.00
2012/13	Reablement	537	167	-4.61	7.39	-5.25	10.00	-10.00	0.00
2013/14	Care at home (Mainstream)	1648	498	-0.37	7.50	0.00	8.00	-4.50	3.50
2013/14	Rapid Response	277	87	-3.52	7.70	-3.75	12.25	-8.75	3.50
2013/14	Reablement	672	209	-2.52	8.80	-3.50	13.00	-9.50	3.50
2014/15	Care at home (Mainstream)	1373	468	0.28	7.03	1.00	8.50	-3.50	5.00
2014/15	Rapid Response	241	73	-1.94	10.29	-3.50	14.00	-10.50	3.50
2014/15	Reablement	643	216	-2.75	7.94	-2.25	10.50	-8.75	1.75

<sup>1</sup> Numbers too low to be disclosed

Figure 4.13: Variation in net difference of total hours of care by care type

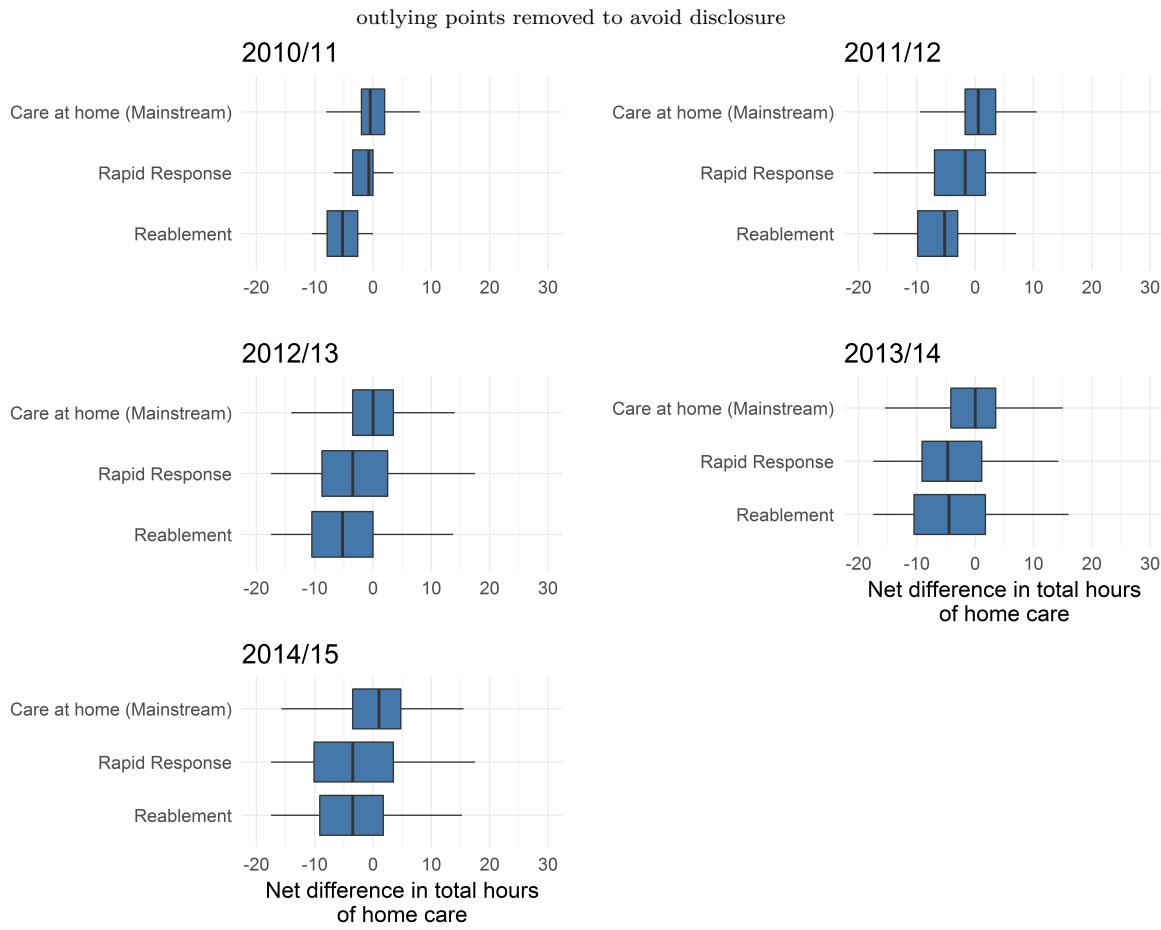


Table 4.8: Regression models of net difference in total hours of care by home care type

Financial Year		estimate	std.error	statistic	p value
2010/11	(Intercept)	0.0562	0.1973	0.2846	
	Rapid Response	-1.3300	1.0386	-1.2805	0.2009
	Reablement	-5.3062	3.3102	-1.6030	0.1095
2011/12	(Intercept)	0.7082	0.2739	2.5858	
	Rapid Response	-2.5433	0.8790	-2.8936	<0.05
	Reablement	-6.2806	0.9684	-6.4857	<0.05
2012/13	(Intercept)	0.1091	0.3313	0.3292	
	Rapid Response	-2.9493	0.9222	-3.1981	<0.05
	Reablement	-5.2183	0.6551	-7.9661	<0.05
2013/14	(Intercept)	-0.4347	0.3440	-1.2637	
	Rapid Response	-3.5078	0.8921	-3.9321	<0.05
	Reablement	-3.2064	0.6328	-5.0675	<0.05
2014/15	(Intercept)	0.0459	0.3481	0.1320	
	Rapid Response	-2.3576	0.9476	-2.4879	<0.05
	Reablement	-3.5078	0.6194	-5.6627	<0.05

## 4.4.7 Multi-census

Table 4.9: Proportion of individuals captured by census and hypothetical multi-census in each financial year

Financial Year	Total receiving home care (n)	Captured by census (%)	Captured by six-monthly census (increase) (%)	Captured by four-monthly census (increase) (%)	Captured by three-monthly census (increase)(%)
2006/07	2435	62.1	75.5 (13.4)	80.9 (18.8)	84.2 (22.1)
2007/08	2465	60.7	74.5 (13.8)	80.1 (19.4)	83.2 (22.4)
2008/09	2438	61.7	75.0 (13.3)	81.3 (19.6)	84.5 (22.8)
2009/10	2428	61.9	75.5 (13.7)	81.1 (19.2)	83.9 (22.0)
2010/11	2157	57.8	72.8 (15.0)	82.9 (25.1)	85.8 (28.0)
2011/12	2096	59.1	73.4 (14.3)	78.9 (19.8)	82.6 (23.5)
2012/13	2381	57.0	68.2 (11.3)	73.9 (16.9)	77.8 (20.8)
2013/14	2599	54.6	68.1 (13.5)	73.7 (19.1)	78.8 (24.2)
2014/15	2763	56.2	69.7 (13.5)	86.6 (30.4)	87.8 (31.6)
<b>Mean</b>	<b>2418</b>	<b>59.0</b>	<b>72.5 (13.5)</b>	<b>79.9 (20.9)</b>	<b>83.2 (24.2)</b>

Table 4.9 shows the percentage of the total number of individuals receiving home care in each financial year that would be captured if six-monthly, four monthly, or three-monthly census had been conducted and the increases these would signify. A bi-annual census would have captured an average of 72.5% of individuals that received home care during the study period - an average increase of 13.5% from the census. Tri-annual census collection would have captured an average 79.9% of individuals (average increase of 20.9%) whilst a quarterly census collection would have captured an average 83.2% of individuals (average increase of 24.2%).

The largest increases are seen in the years where the number of individuals captured by a single census are relatively low compared to other years, in particular 2010/11, 2013/14, and 2015/16.

## 4.5 Discussion

### 4.5.1 Findings

This exploratory project has investigated the variation in packages of care from one Scottish local authority area and aimed to: a) quantify the proportion of individuals in receipt of home care during Social Care Survey census week, b) describe the differences in individuals that receive some care during the census week and those that don't, c) validate the value of total weekly hours of care compared to the rest of the financial year for those that *do* receive some care during the census, and d) assess the difference in the proportion of individuals that would be captured by hypothetical extra census dates.

Between 51.7% and 61.9% of all individuals receiving home care in the years 2006/07 to 2015/16 had “live” packages of care during the SCS census week. The trend is decreasing with the minimum value being recorded in the most recent year of data. This trend likely

reflects the increase seen in the proportion of “Reablement” type packages of care which are designed to be implemented for short periods of time following hospital discharge. The shorter duration of these packages means they are less likely to coincide with the census date. There are no significant differences in the overall proportion or demographic structure of the group that are not captured by the census compared to the group that are in each financial year.

Individuals that have no packages of home care captured by the census in each year have a considerably shorter total duration of care. This is seen across all care types and age and gender groups. The most likely explanation for this is that no matter what care type, some individuals go on to require longer term care and thus receive more contiguous packages which eventually coinciding with a census date. Those that have zero packages captured by a census truly are short-term users of care. It is impossible, with this data, to account for what proportion of this is due to care no longer being required, to mortality, or to other causes.

Those without any packages captured by a census are also more likely to have slightly more total hours of home care per week. This is a moderate increase and affects individuals receiving “Reablement” type care to a greater extent. The difference for individuals receiving “Care at home (Mainstream)” type packages (the large majority) is equivalent to, on average, 10 minutes per day extra care.

For approximately 50% of individuals that *do* have at least one package of care captured by a census - the value of total weekly hours of home care that they receive in the census week is absolutely representative. This is because they only receive one package of care during the financial year and are likely recipients of long-term care. **Make sure the results show this clearly**

The remaining individuals receive multiple packages of care during the financial year or stop receiving care altogether. There are differences in the variation in the net-difference of total hours of home care for these individuals depending on the type of care they receive. Individuals with “Care at home (Mainstream)” type packages (again a majority) show mild variation with median values close to zero. Half of these packages in 2014/15 (the year with the widest IQR) see a net difference value between -30 minutes to +40 minutes of care per day.

Those receiving “Reablement” or “Rapid Response” type packages (**quantify**) are more likely to have negative net difference values. It is possible these are short-term packages of care that started soon before the census and end soon after resulting in negative values. The IQR in 2014/15 indicates half of these packages see variations of care between -75 or -90 to +15 or +30 minutes of care per day respectively.

Adding an additional 1, 2, or 3 census weeks in each financial year to the data analysed in

this project increases the proportion of individuals that would be surveyed by an average of 13.5%, 20.9%, or 24.2% to 72.5%, 79.9%, or 83.2% respectively.

## 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 generalised to a national level. However, given the difficulties in obtaining data of this kind, the analysis gives some indication to stakeholders of the validity of the SCS.

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 discrepancy in later years. Eligibility to be included in the home care census has changed over the years (e.g. “Housing Support” 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.

### Did not account for SEP

## 4.5.3 Implications

The analysis in this chapter suggests the SCS provides a good cross-sectional sample of individuals receiving home care in any given financial year. The proportion of this sample appears to be decreasing in more recent years but still accounts for at least half of all individuals receiving care.

Increasing the frequency of data collection to four times a year could potentially increase the sample size to approximately 83%. Whether the extra administrative resources associated with this would be too great for both local authority and Scottish Government analytical teams is a matter which would require further consideration. This would certainly result in more short-term packages of care being captured by data collection enhancing the representativeness of the SCS.

The value of total hours of home care returned to the SCS is an accurate cross-sectional value but is not completely indicative of care received throughout a financial year. A

majority of individuals have no, or only a modest, variation in the total weekly hours of home care they receive during a financial year. However, a proportion of individuals (**25%??**) have large changes in total hours of homecare and these cannot be indented in SCS data. The main analysis in this thesis, and any other research using the SCS as a data source, cannot infer home care receipt over a year from this value as it risks producing biased results. Collection of start and end dates of all home care packages received in a financial year in the SCS would rectify this problem.

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 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 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.

Each individual in the dataset has data with multiple values of Scottish Index of Multiple Deprivation (SIMD) for different time periods. Future analysis should include this variable with the correct SIMD score added to the time series at the appropriate time period. Accounting for socioeconomic position in all analyses would provide a richer picture of service allocation. Time constraints prevented such analysis in this chapter.

### **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 between 52% and 62% of the total number of people that will receive home care during a

financial year. Those not captured during a census week are individuals receiving short-term care only. The value of total weekly hours of home care recorded during the census week, whilst an accurate cross-sectional figure, is not an accurate representation of care receipt over the whole financial year for a small proportion of individuals. Collection of additional data, 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**

## **Methods**

### **5.1 Making social care data available for linkage**

Describe method of matching SCS to Population Spine

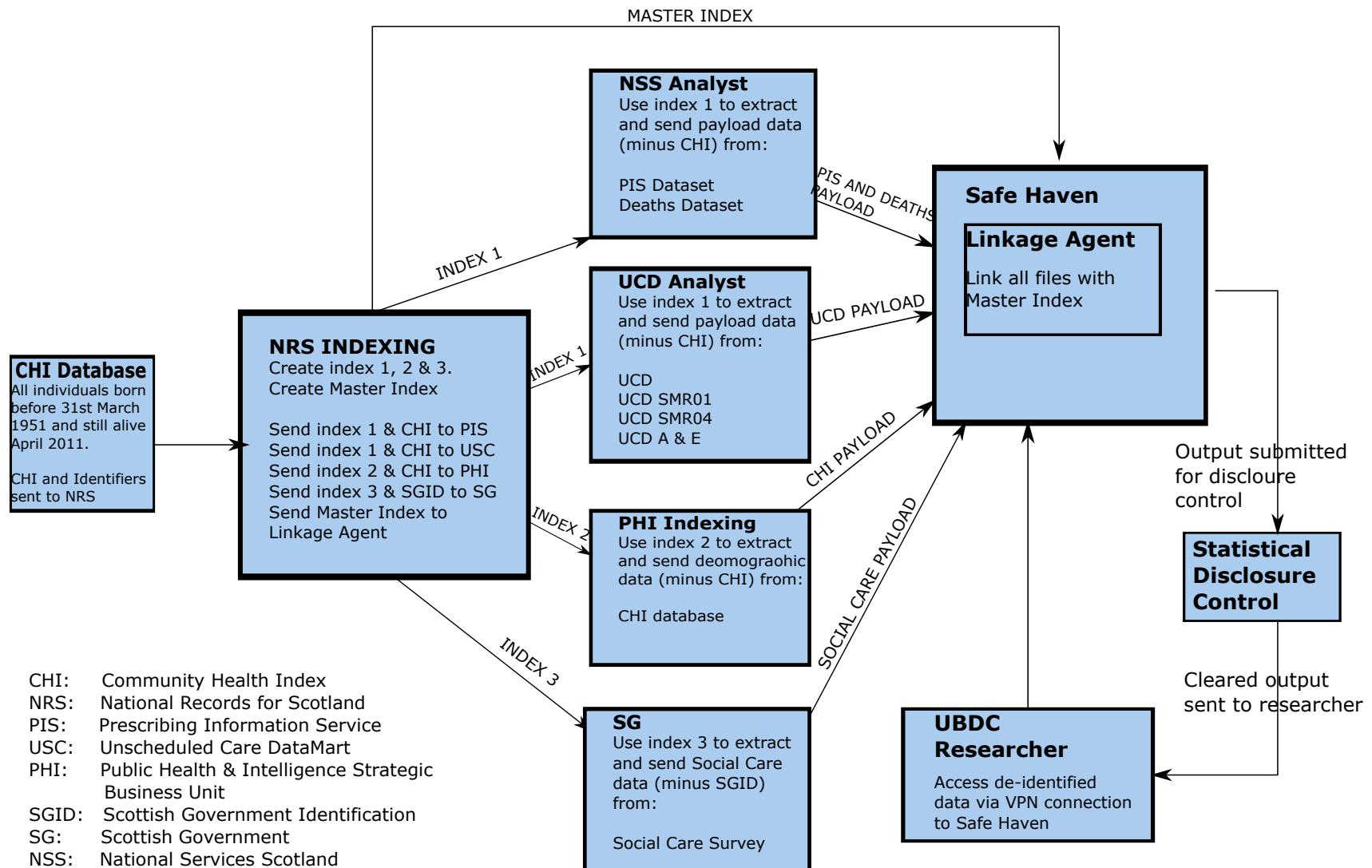
### **5.2 Creating a linked health and social care dataset**

#### **5.2.1 Setting and cohort**

Scotland has a population of approximately 5.4 million people. Health care is delivered via 14 territorial health boards whilst social care falls within the remit of 32 local authorities. Since 2016, health and social care services have been integrated and 31 Integrated Joint Boards (IJBs) have been created.

The 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 other datasets.

Figure 5.1: Data linkage diagram



CHI: Community Health Index  
 NRS: National Records for Scotland  
 PIS: Prescribing Information Service  
 USC: Unscheduled Care DataMart  
 PHI: Public Health & Intelligence Strategic Business Unit  
 SGID: Scottish Government Identification  
 SG: Scottish Government  
 NSS: National Services Scotland  
 SMR: Scottish Morbidity Record  
 A & E: Accident and Emergency  
 UBDC: Urban Big Data Centre

As figure 5.1 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.

### **Figure needs tidied up and should show datasets in same order as following subsections**

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 principles 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).

## **5.2.2 Demographic, geographic, and deaths information**

Table 5.1: Demographic file data

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

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 ((2016)). The number of observations, individuals, and the differing variables in this raw demographic file are shown in table 5.1.

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). Financial year time intervals were created for each financial year using the `lubridate` software 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 dataframe of 7,775,410 observations pertaining to 1,134,445 individuals.

### 5.2.3 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 individual received, whether they were provided by the local authority or an independent organisation, and whether these hours 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. Table 5.2 lists the variables included and excluded after data cleaning.

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. Once joined to other datasets (as described in section 5.2.7), all observations for the years of data where there were duplicates were dropped from the dataset.

**Don't forget the 198 rows (129 individuals) with total\_hours > 168!!**

Table 5.2: Social Care Survey file data

Number of rows	Number of individuals	Included variables	Derived variables	Dropped variables
		1. Index (ID) 2. Living alone 3. Community Alarm 4. Other telecare	1. Total weekly hours of homecare 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

### 5.2.4 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 online 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 F. Table 5.3 shows the cleaning process.

Table 5.3: Data cleaning of PIS file

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

A summary measure for each individual was created counting the total number of 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. An individual 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 requiring medication. Table 5.4 shows the total observations and variables in the cleaned PIS file.

Table 5.4: Description of cleaned PIS file

Number of rows	Number of individuals	Variables
5,473,640	1,066,103	1. Index (id) 2. Financial Year 3. Total medicines (n) 4. Total chapters (n)

### 5.2.5 Unscheduled care measures

Which years of data (remember OOH from 2014 onwards only)

How was usc data wrangled? Which summary measures were chosen?

### 5.2.6 Comorbidity scores

How created? short...

### 5.2.7 Joining sources together

Dropping rows etc. Report final n observations and individuals.

Table of variables.

## 5.3 Statistical methods

### 5.3.1 Descriptive statistics

### 5.3.2 Research question 1

### 5.3.3 Research question 2

# Chapter 6

## Results - Descriptive statistics

### 6.1 Introduction

Link to chapter 1 and chapter 2 re aims and research questions. Chapter 5 for methods

### 6.2 Data Linkage

Percent matches etc.

### 6.3 Descriptive data

label{results1-descr}

#### 6.3.1 Participants

Long table

- n
- Age - mean, median, range IQR.
- Sex
- Local Authority
- SIMD

#### 6.3.2 Age and sex

# **Chapter 7**

## **Results 2**

### **7.1 Social care and multimorbidity**

- Any SC by number of meds
- Hrs homecare by number of meds
- Telecare by number of meds
- etc.

### **7.2 Geographic variation in social care**

Accounting for MM

# **Chapter 8**

## **Results 3**

### **8.1 Social care, multimorbidity, and unscheduled health care use**

- National picture
- broken down by LA
- broken down by HB

# **Chapter 9**

## **Discussion**

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

I have found 1, 2, 3.

This was limited by a, b, c

Implications are d, e, f

Future research should g, h, i

# **Chapter 10**

## **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. Renfrewshire pilot. UBDC RAC approval**



---

An ESRC Data  
Investment

## RAC Project Decision Form

Version 3.0(23 May 2016)

<b>Title of Project</b>	Renfrewshire Council social care data analysis	
<b>Lead applicant</b>	Prof Nick Bailey	
<b>Date of RAC Panel meeting</b>	1 <sup>st</sup> June 2016 (by telephone)	
<b>RAC Panel decision</b>	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 <sup>1</sup>
Feasibility	Yes <sup>2</sup>

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 <sup>3</sup>
Alignment to UBDC objectives	3 <sup>4</sup>

**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	

<sup>1</sup> Subject to approval of College of Social Sciences Research Ethics Committee, University of Glasgow.

<sup>2</sup> Subject to comments & conditions in Section D & E

<sup>3</sup> More accurately 3.33.

<sup>4</sup> 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 B. 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

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**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.**

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**Recommendations (where changes are required)**

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

All resubmitted application documents should then be uploaded.

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

# **Appendix C. Main linkage RAC approval**



---

An ESRC Data  
Investment

## RAC Project Decision Form

Version 3.0 (23 May 2016)

<b>Title of Project</b>	Using Linked Data to Understand Multi Morbidity and the Use of Social Care Data	
<b>Lead applicant</b>	Prof. Nick Bailey	
<b>Date of RAC Panel meeting</b>	10 February 2017	
<b>RAC Panel decision</b>	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 D. Main linkage PBPP approval**

## Public Benefit and Privacy Panel for Health and Social Care

[nss.PBPP@nhs.net](mailto:nss.PBPP@nhs.net)

[www.informationgovernance.scot.nhs.uk](http://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: 11<sup>th</sup> 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 27<sup>th</sup> 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](http://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](mailto:nss.PBPP@nhs.net)

## **Appendix E. 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](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/>

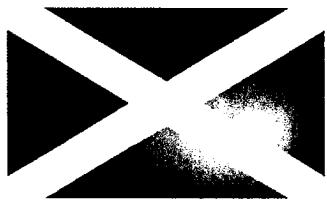
Yours sincerely,



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  
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# **Appendix E. 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**

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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):

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

### **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 G. 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 COMPOUND TOPICAL PREPARATIONS WITH LIDOCAINE	06.04.01 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

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Medicine Name	BNF subsection
FLUOROURACIL	13.08.01
UREA HYDROGEN PEROXIDE	12.01.03
METHYLPREDNISOLONE	10.01.02
GLUCOSE	09.02.02
CHLORHEXIDINE GLUCONATE	13.11.02
LIDOCAINE	15.02.01
AMYL METACRESOL 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
ORCIPRENALENE 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

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Medicine Name	BNF subsection
POVIDONE IODINE	13.10.05
GLUTEN FREE/WHEAT FREE MIXES	09.04.01
FOODS FOR SPECIAL DIETS	09.11.04
ALUMINIUM CHLORIDE HEXAHYDRATE	13.12.00
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

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Medicine Name	BNF subsection
LOW PROTEIN MIXES	09.04.01
BENZALKONIUM CHLORIDE	12.03.03
BENZOIN	03.08.00
CEFPODOXIME	05.01.02
ALCOHOL	13.11.01
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	12.03.04
CHLORHEXIDINE GLUCONATE	
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

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Medicine Name	BNF subsection
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
LOW PROTEIN PASTA	09.04.01
LIDOCAINE WITH EPINEPHRINE	15.02.01
AMYLMETACRESOL AND DICHLOROBENZYL ALCOHOL WITH ASCORBIC ACID	12.03.03
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
PROXYMETACAINA 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

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Medicine Name	BNF subsection
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
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 FLUORESCIN SODIUM	11.07.00
FLEXIBLE COLLODION	13.10.05
BECAPLERMIN	13.11.07
MIVACURIUM CHLORIDE	15.01.05
NORETHISTERONE ENANTHATE	07.03.02

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Medicine Name	BNF subsection
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

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