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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:

# 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

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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?

## CHAPTER 1. INTRODUCTION

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

## CHAPTER 2. LITERATURE REVIEW

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/>**

## CHAPTER 2. LITERATURE REVIEW

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

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

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

### 2.2.2 International models of social care

There are four ways in which social care can be provided to those in need; informally via family or community, formally via voluntary non-profit organisations, formally via the state, or formally via for-profit organisations (Munday, 2003). In Europe, increasing demand from users has led to many welfare systems being unable to adequately provide care (Pavolini and Ranci, 2008; Colombo *et al.*, 2011). Changes in demography, the labour market, democracy, and values have all contributed to the increasing pressure on formal care services (Anttonen, 2005; Colombo *et al.*, 2011; OECD/EU, 2013). There is wide consensus that lower birth rates and higher proportions of older people mean that a gap has emerged in the number of adult children able to provide informal care to their parents (Munday, 2003; Anttonen, 2005; Pavolini and Ranci, 2008; Colombo *et al.*, 2011;

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Robertson, Gregory and Jabbal, 2014; Deusdad, Pace and Anttonen, 2016). Traditionally, informal care was provided by women. As gender equality improves, more women are employed in non-domestic settings which also reduces the pool of informal social care available (Anttonen, 2005). Anttonen (2005) also cites changes in societal attitudes from “familism” to “individualism” as having an impact on informal care resources. These combined factors mean that informal care services are no longer as readily available and formal care mechanisms are increasingly required to provide social care. Pressures on these services has seen increased discussion and comparison of models of care across Europe over the last 20 years (Anttonen and Sipilä, 1996; Munday, 2003; Sapir, 2006; Fernández-Alonso and Jaime-Castillo, 2016).

In a report for the OECD, Colombo et al (2011) categorised the varying models of social care into three main groups with subdivisions as shown in Table 2.1.

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

## CHAPTER 2. LITERATURE REVIEW

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 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

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

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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).

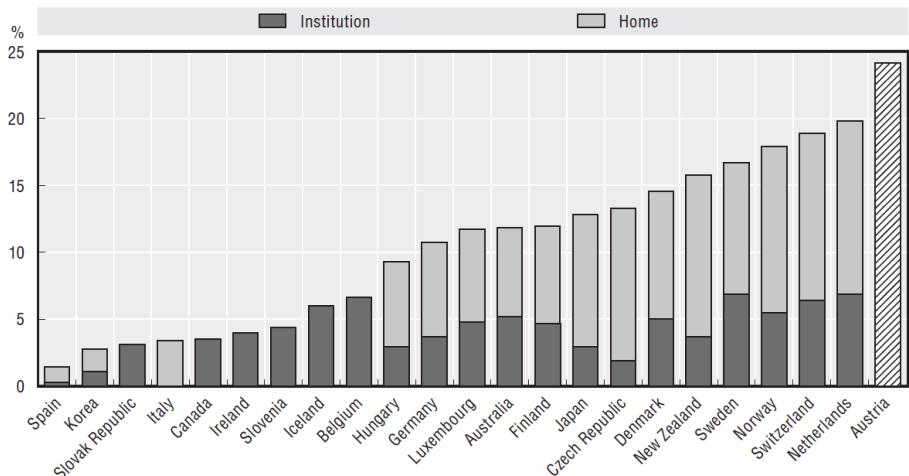
*Need to mention typologu does not cover quality or quantity of care.*

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. 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

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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>

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"

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/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

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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

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Table 2.2: Seven stage model of candidacy

<b>Stages of candidacy</b>	<b>Description of stage</b>
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

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

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

The Scottish National Eligibility Framework has striking similarities to that formerly used in England and described in Fair Access to Care Services (FACS) produced by the Social Care Institute for Excellence (SCIE) (2013). Exactly the same nomenclature is used to describe the eligibility categories of need. Newton and Browne (2008) critiqued a previous version the FACS guidance and found similar issues to those raised above regarding regional variations in service and concentration of services on those with the highest need. Their paper describes further issues with access to social care in the context of social theory described by Lipsky (1979) and “street-level bureaucracy” (discussed in section 2.2.3) where intentional and unintentional judgement of entitlement by social care workers have an impact on whether an individual receives care or not *add it to the above section also*. Newton and Browne (2008) also make the assertion that health and social care has never been accessed equitably by arguing that those with a greater ability to articulate needs and negotiate access are more likely to gain access to services *Link to Candidacy*. Although no citation is provided to back-up this argument, it has certainly been described elsewhere (Matthews and Hastings, 2013) and sits well in the broader discussion of inequitable access to services (Tudor-Hart, 1971; Le Grand, 1982; Hastings *et al.*, 2014).

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

In practice, the most likely outcome is that the minimum threshold that local authorities

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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;

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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

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(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

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

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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

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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

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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

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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]

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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

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

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

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

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

### 2.3.2 Health and Social Care Integration

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

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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

## CHAPTER 2. LITERATURE REVIEW

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;

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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

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paid to those who deliver front-line services, indeed, “.. a preoccupation with the process and mechanisms of joint working has diverted attention away from the central role played by the professions, who appear sceptical of the aims of these initiatives and distrustful of their professional colleagues” (Cameron, 2016, p. 12).

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

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

Using data from four areas in England, Bardsley et al (2012) found that older persons staying in residential care homes were less likely to use unplanned hospital services compared to those receiving social care at home. The study period was based over one year only and all those that died during the year were excluded from analysis which may have had some impact on results. Intensive social care delivered at home was associated with higher unplanned *and* planned secondary care use.

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

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

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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 paragrpah

### 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,

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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)

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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

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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.

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Despite the large number of multimorbidity indices available, Huntley et al (2012) cite evidence that suggests simple counts of diseases or medications are almost as effective as the more complex indices at predicting mortality or health care use in the primary care setting. However, when aiming to predict mortality in primary care, Huntley et al (2012) recommend the best measurement of multimorbidity to be provided by the Charlson index (Charlson *et al.*, 1987) and its variations. Measurement of multimorbidity in relation to primary care healthcare use can be predicted with equivalence by either; the Adjusted Clinical Group system (Starfield *et al.*, 1991), the Charlson index (Charlson *et al.*, 1987), or disease counts (Huntley *et al.*, 2012).

Disease counts were also found by Huntley et al (2012) to have good evidence to suggest they provide a robust measure of multimorbidity in relation to quality of life, as does the Charlson index (Charlson *et al.*, 1987). A count of medicines was found to be a good predictor of primary care use and mortality in a more recent paper (Brilleman and Salisbury, 2013). In their paper, Perkins et al (2004) argue that indices developed in the secondary care setting, such as the Charlson index, should be used with caution in other settings despite adaptions. More recently, Wallace et al (2016) found little difference between simple (count) and complex (index) measures when predicting hospital admission but noted that all measures of multimorbidity alone were poor predictors of the outcome.

An emerging method of measuring multimorbidity is to identify clusters of medical conditions that co-exist in individuals at rates higher than would be expected - or non-random prevalence. Recent research and academic discussion suggests identification of disease clusters may enable clearer answers to clinically relevant research questions than currently employed measures (Valderas *et al.*, 2009; Holden *et al.*, 2011; Marengoni *et al.*, 2011; Sinnige *et al.*, 2013; RN109; Prados-Torres *et al.*, 2014; Le Reste *et al.*, 2015). Statistical techniques employed in attempts to identify such clusters include: factor analysis, cluster analysis, the observed-to-expected ratio, multiple correspondence analysis (Prados-Torres *et al.*, 2014; Clerencia-Sierra *et al.*, 2015), principal component analysis, latent class analysis (Islam *et al.*, 2014; Larsen *et al.*, 2017), and machine learning techniques (Schiltz *et al.*, 2017).

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

Prados-Torres et al (2014) identified three groups of patterns common to all included studies in their review despite marked heterogeneity namely; cardiovascular and metabolic diseases, mental health conditions, and musculoskeletal disorders. Whilst identification of

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

### 2.4.4 Epidemiology

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

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

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

### 2.4.5 Summary

Multimorbidity is most commonly defined as the presence (or co-occurrence) of two or more long-term conditions in an individual. Debate continues as to the type and number of long-term conditions that should be included to provide a meaningful concept for individuals, clinicians and healthcare organisations. The lack of a standard definition is mirrored in the myriad ways of measuring multimorbidity with various counts, indices, and clusters. Despite this, evidence suggests multimorbidity is increasing in prevalence and has a strong socioeconomic pattern. As a result, policy needs to be tailored to account for the complex needs of the increasing numbers of people with multimorbidity.

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

## 2.5 Conclusion

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

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

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

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

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

In people over the age of 65 in Scotland:

1. (a) What are the socioeconomic, demographic, and geographic patterns in the use of social care?

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

### 2.5.1 Thesis structure

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

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

Chapter 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 & Information Governance

### 3.1 Introduction

intro paragraph - complete when finished

### 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]

need to add [@RN489]

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 that service 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

## CHAPTER 3. DATA & INFORMATION GOVERNANCE

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). This means specialist knowledge of the database and collection methods are required (Mazzali and Duca, 2015). Coding of health conditions are particularly susceptible to potential mis-classification or under-reporting of certain diseases (Walraven and Austin, 2012; Mazzali and Duca, 2015; Walesby, Harrison and Russ, 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 without the extra cost traditional observational studies might incur (Mazzali and Duca, 2015). 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).

**add in @RN491, Doidge & Harron** There are two main methods of linking data from disparate sources; deterministic matching and probabilistic matching (Fleming, Kirby and Penny, 2012; Harron, 2016). 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). 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). An important consideration when using probabilistic linkage is making an assessment of false-positive match rates (Fleming, Kirby and Penny, 2012; Harron, 2016). 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).

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).

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 Infrastructure

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

---

*Elon Musk*

#### 3.3.1 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 Urban Big Data Centre**

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

The linkage project described in this thesis was completed with the assistance of UBDC's controlled data service. This service helps researchers to access personal data that exists in administrative databases (UBDC, 2017a). In addition to a vigorous approval process, access to data is tightly controlled via safe haven IT architecture which monitors use of data and output of analyses to ensure individual anonymity is maintained (UBDC, 2017a). UBDC arranges access to the safe haven environment through liaison with eDRIS, provided by the Information Services Division (ISD) of NHS National Services Scotland (NSS) under the auspices of SILC.

### **3.3.3 electronic Data and Research Innovation Service**

ISD is a subdivision of NHS NSS (ISD, 2010). 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, 2010). This includes administering the large number of databases containing information on health service use in Scotland varying from maternity & births, to cancer services, and unscheduled health care (ISD, 2010).

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, 2010).

### **3.3.4 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 TTP.

### 3.3.5 Health and Social Care Analysis

Health and Social Care Analysis (HSCA) is a division within the Scottish Government that provides statistic, economic, and research evidence to inform policy making in this area (Scottish-Government, 2017b). It is one of many Analytical Service Divisions (ASD) that provide analytical support, advice, and briefing to the Government. 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

## 3.4 Data Sources

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).

Why collected? How collected? Data Quality checks?

### 3.4.1 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, 2017g). Results are collated and published annually by HSCA in the "Social Care Services, Scotland" report (Scottish-Government, 2017g). As well as providing an overview of social care services, 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).

## CHAPTER 3. DATA & INFORMATION GOVERNANCE

The SCS has been collected in its present form since 2013 as a combination of two previous data collections - the Home Care and the Direct Payments Surveys (Scottish-Government, 2016d).

Some questions have remained constant throughout this period but there have also been some changes in definitions and measures. The most notable change in definition was that of hours of “Home care services” which pre 2013 included 24-hour-7-day-a-week and live-in services but excludes these from 2013 onwards (Scottish-Government, 2016d). These services are included under the measure of “Housing support services” in the more recent SCS (Scottish-Government, 2017f). Plots of home care hours in the “Social Care Services, Scotland” report highlight the break in time series (Scottish-Government, 2017g).

Information was collected on an individual basis for each Home Care client receiving home help services, meals services and community alarm / telecare services, as well as for clients receiving Direct Payments

Scheduled and actual hours.

### **3.4.2 Population Spine and Death records**

via eDRIS or direct NRS?? - demography and geography also.

### **3.4.3 Prescribing Information System**

Describe PIS

### **3.4.4 Unscheduled Care Data**

Describe USC data mart

## **3.5 Information Governance**

Use ADRN legal issues book Also use SG principles for DL Data linkage course material also.

### **3.5.1 Research Approvals Committee**

UBDC RAC process

### **3.5.2 Public Benefit and Privacy Panel**

PBPP Process

### **3.5.3 Ethics**

College ethics and waivers

### **3.5.4 Data sharing agreement**

DSA description

### **3.5.5 Safe Haven environment**

describe safe haven

## **3.6 Timeline**

Describe timeline of approvals process - major hurdles and barriers.

# **Chapter 4**

## **Renfrewshire Council Exploratory Project**

### **4.1 Introduction**

As described in Chapter 3, 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, 2017g). 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 (and the data it does not) 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 proportion of home care users identified by the SCS in each year, identify what differences (if any) exist between home care packages 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, 2017), 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.

SCS umbrella and breakdown with Renfrew data

## 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 ratio 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

## CHAPTER 4. RENFREWSHIRE COUNCIL EXPLORATORY PROJECT

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	

Renfrew (60.8 per thousand in 2010 to 48.9 per thousand in 2017). The 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 distribution of individuals receiving home care across each financial year?
- Are there differences in the types of home care package that are/are not captured by the census? Do these differences vary by age or gender?
- For packages that are captured by the SCS, is the value of total hours of home care received reflective of the total hours of home care received in the previous and following six months?
- What proportion of the total amount individuals receiving home care would be captured if more than one census was conducted in each financial year?

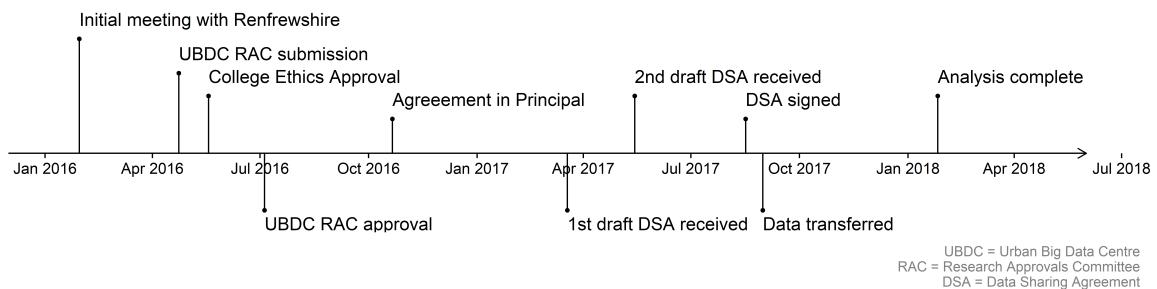
## 4.3 Methods

### 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 3.5.1 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 principal 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.

Data provided for the purposes of this exploratory study detailed 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

## CHAPTER 4. RENFREWSHIRE COUNCIL EXPLORATORY PROJECT

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 packages 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 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 nighttime 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 comparison of packages at different time points 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, measures of central tendency and range of these weekly values were compared to the total number of individuals receiving home care in each financial year and visualised. Comparison was also made of the number of individuals receiving home care in the census week to figures returned by Renfrewshire council to the SCS for the same census week.

## CHAPTER 4. RENFREWSHIRE COUNCIL EXPLORATORY PROJECT

For the financial years 2011/12 - 2015/16 (the study period of the main thesis project) data was subset to identify those packages of home care that were “live” during the week including the 31st of March and those that were not “live” i.e. (those that would not have been captured by SCS census). These subsets were then compared by visualising the distribution of package duration and intensity (i.e. the total hours of homecare provided) across age and gender groups. The non-parametric Mann\_Whitney U test was used to compare differences between groups with p-values <0.05 accepted as showing a statistically significant difference. 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, they were omitted from the comparative visualisations and analysis.

In order to assess whether the value of the total hours of homecare provided was representative of care in the six months preceding and following the census week, data was subset by individuals who only received a single package of care in the 12 months surrounding the census and those that received multiple packages of care. For those that received single packages of care, and therefore had an accurate measurement of their total hours of care, the distribution of the duration of these packages was assessed. For those that received mutiple packages of care, and therefore had differing values of hours of home care, the net difference in total hours of care received across all packages was calculated in order to summarise the variation from the reported hours of each individual. For example, an individual intially 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 indiviudals 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 packages **dplyr** v0.7.4 (Wickham and Francois, 2017), **tidyr** 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), **magrittr** v1.5 (Bache and Wickham, 2014), **broom** v0.4.2 (Robinson, 2017), and **ggplot2** v2.2.1 (Wickham and Chang, 2016) via the Integrated Development Environment RStudio v1.0.143 (RStudio-team, 2016). Data was held securely in the safe haven environment described in section 3.5.5

## 4.4 Results

### 4.4.1 Descriptive statistics

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 placeholders 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 ( $n = 6515$ ) 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 ( $n=22484$ ) 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 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 (47%) packages over the 10 year study period provided high intensity care of over 20 hours per week (figure 4.4). Eight-five percent of packages lasted for less than one year (figure 4.5).

Figure 4.2: Breakdown of age and gender

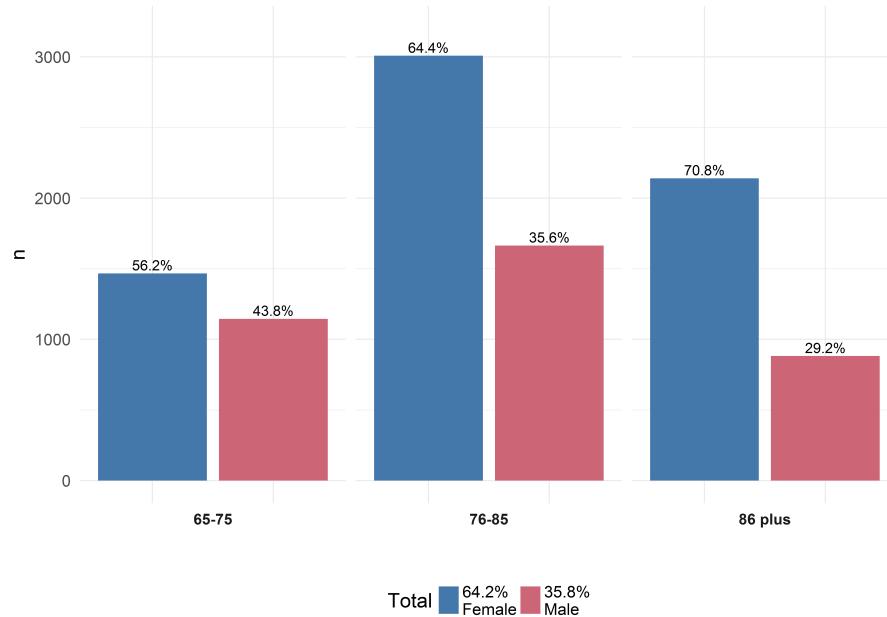


Figure 4.3: Count and proportion of home care type

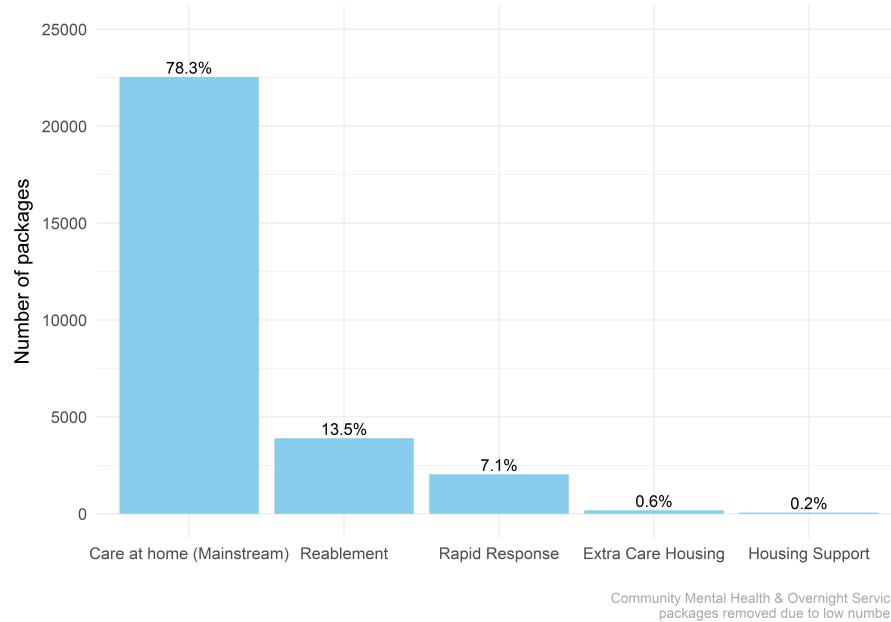


Figure 4.4: Count of packages of care by intensity

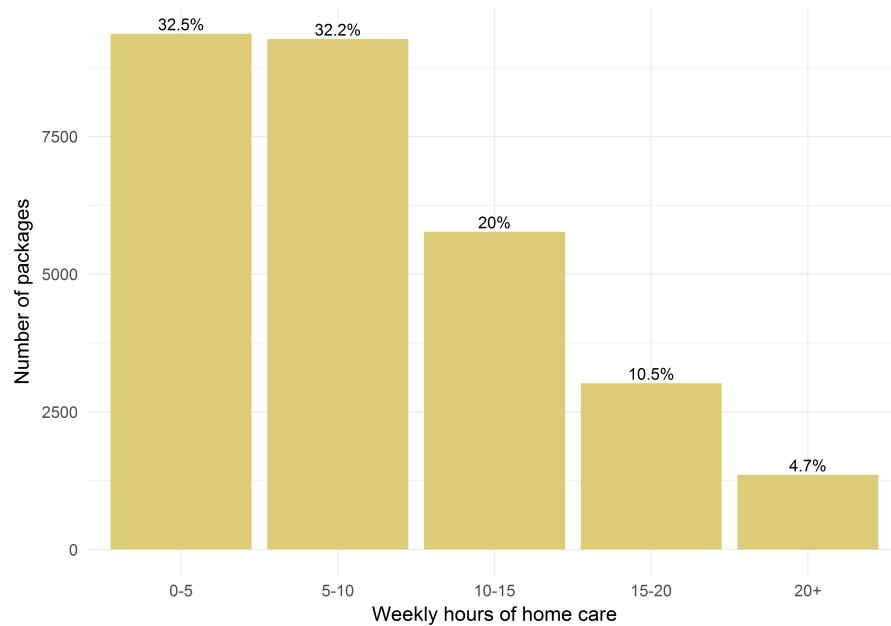
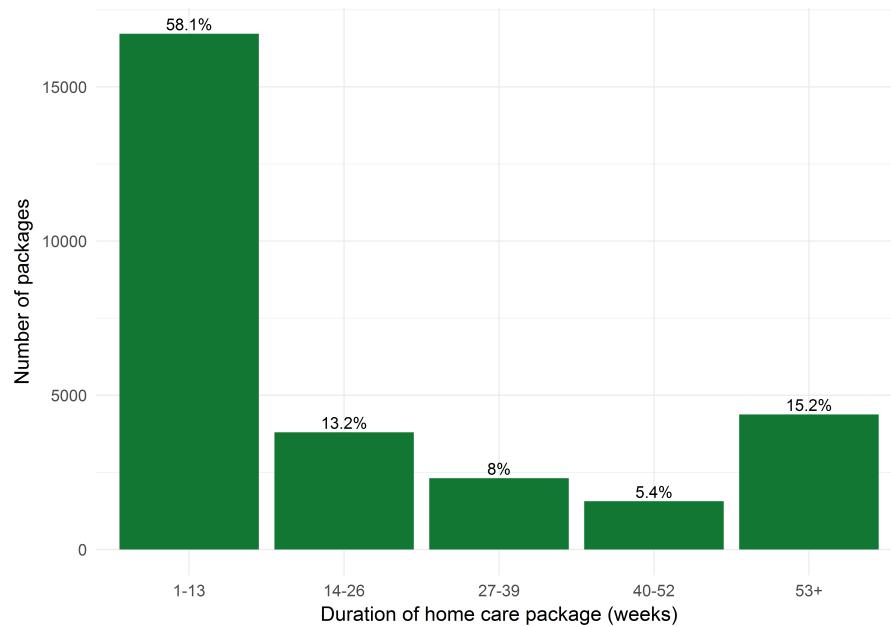


Figure 4.5: Count of packages of care by duration



#### 4.4.2 Distribution of individuals receiving home care

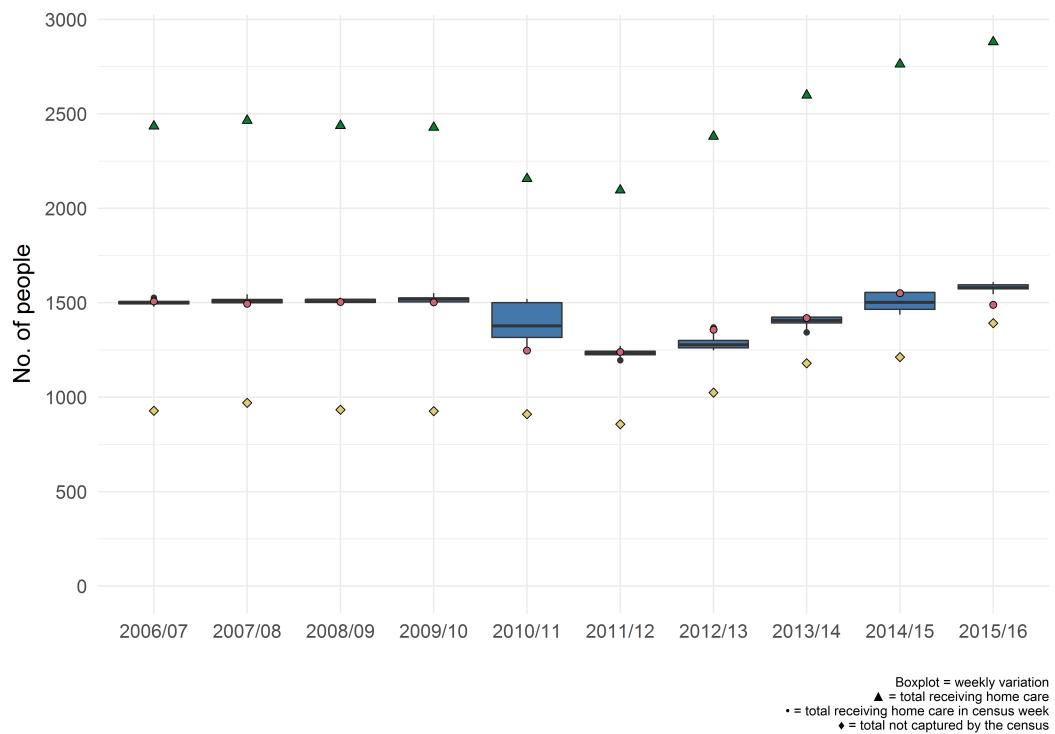
Table 4.3 and figure 4.6 show the variation in the number of people receiving home care during each financial year. There is little weekly variation within years with the exception of financial year 2010/11 which saw a large drop in the total number of individuals receiving care. The variation in years 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 Variation in care packages captured by census

This section needs re-analysed to take into account combined duration of care for those with multiple packages

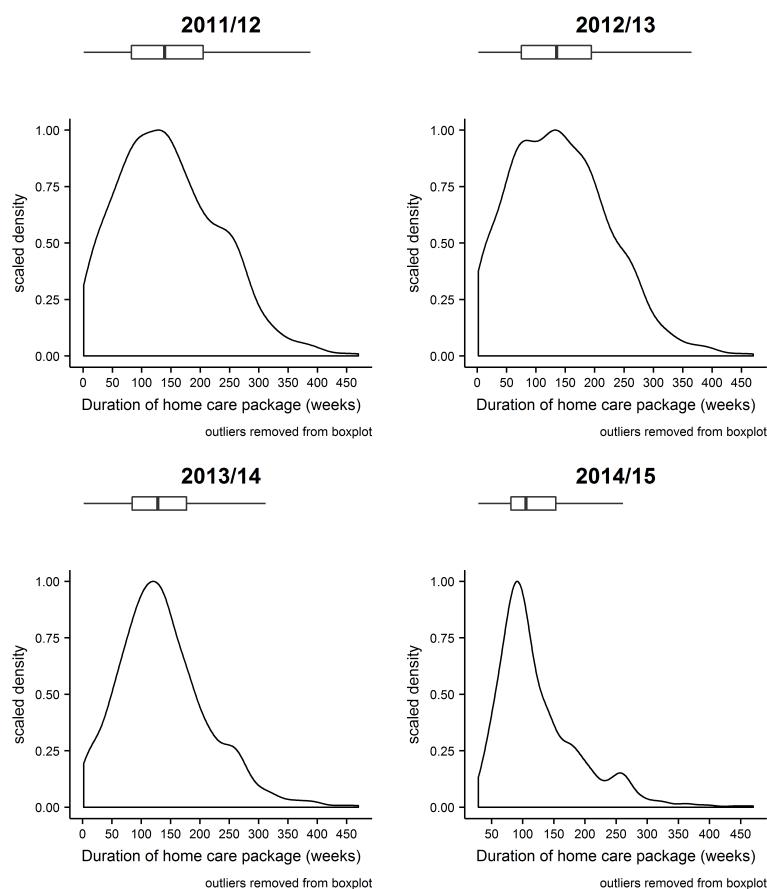
Between the years 2011/12 and 2014/15 a gradual decrease from 50.3% to 39.4% of individuals captured by the census received only one package of care in the 12-month period surrounding the census. The remaining individuals received more than one package of care in the same time period.

Those who did not see a change in their care pacakge were more likely to have a longer lasting package of care than seen across the whole dataset with a median value of between 105 and 139 weeks across years (table 4.4 and figure 4.7). At the census week in each financial year three-quarters of individudals had packages of care that lasted for at least 75 weeks. This compares to almost 85% of all packages lasting less than 52 weeks as previously shown in figure 4.5.

Table 4.4: Summary statistics of package duration (weeks) for individuals receiving a single package of home care in 12 months surrounding the census week

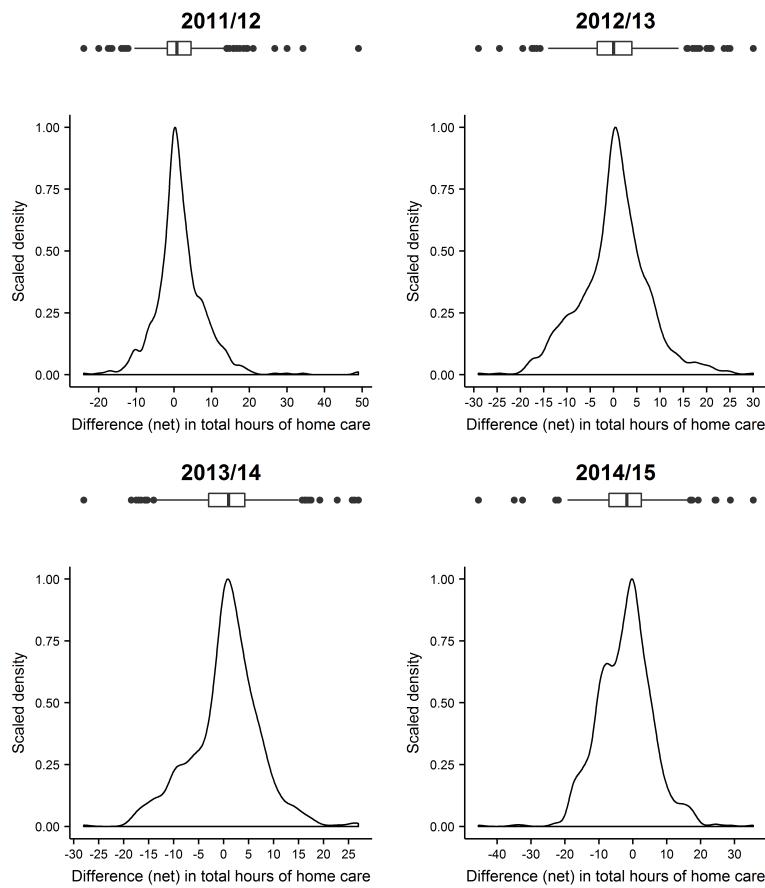
Financial Year	Individuals (n)	Individuals (%)	25th Percentile	Median	75th Percentile	IQR
2011/12	623	50.3	82.5	139	205	122.5
2012/13	675	49.7	75	135	194.5	119.5
2013/14	667	47.0	84.5	128	177	92.5
2014/15	612	39.4	81	105	153.25	72.25

Figure 4.7: Distribution of package duration for individuals receiving a single package of homecare in the 12 months surrounding the census week



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Figure 4.8: Distribution of net difference in total hours of home care in 12 months surrounding the census week for individuals with multiple packages of care



Over time, an increasing number of individuals received multiple packages of care in the 12 months surrounding the census date of each year. The variation in the net difference in total hours of homecare between these packages is shown in table 4.5 and figure 4.8. Whilst there are some outlying points in every year, median values are close to zero with the interquartile range varying from 6.3 to 9.5 hours. Over time, values of net difference were more likely to be negative. In 2011/12 the interquartile range was between -1.75 and 4.5 hours, whereas in 2014/15 it was between -7.0 and 2.5 hours.

Table 4.5: Summary statistics of net difference in total hours of homecare in 12 months surrounding the census week for individuals with multiple packages of care

Financial Year	Individuals (n)	Individuals (%)	25th Percentile	Median	75th Percentile	IQR	Min	Max	Range
2011/12	616	49.7	-1.75	0.75	4.5	6.3	-24	49	73
2012/13	682	50.3	-3.5	0	3.9375	7.4	-29	30	59
2013/14	752	53.0	-3.0	1	4.25	7.2	-28	27	55
2014/15	940	60.6	-7.0	-1.75	2.5	9.5	-45.5	35.5	81

#### 4.4.4 Comparison of individuals with no packages in census

Figure 4.9 shows that there are similar proportions of individuals receiving each type of homecare in each financial year regardless of whether they have any packages of 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.

Figure 4.9: Proportion of individuals receiving home care

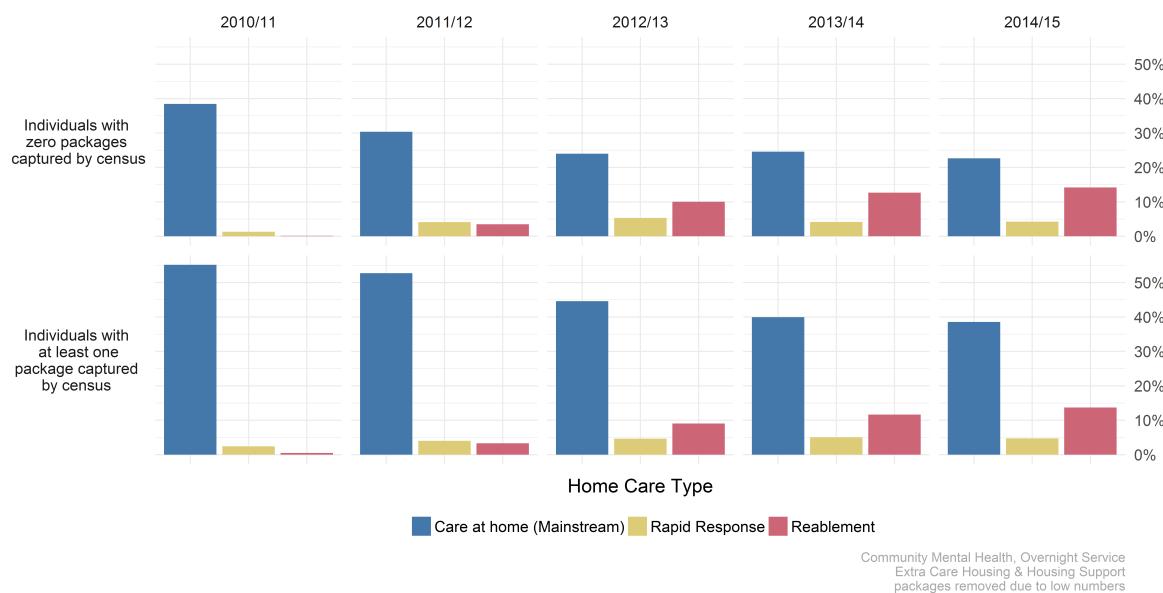


Figure 4.10: Variation in intensity of home care

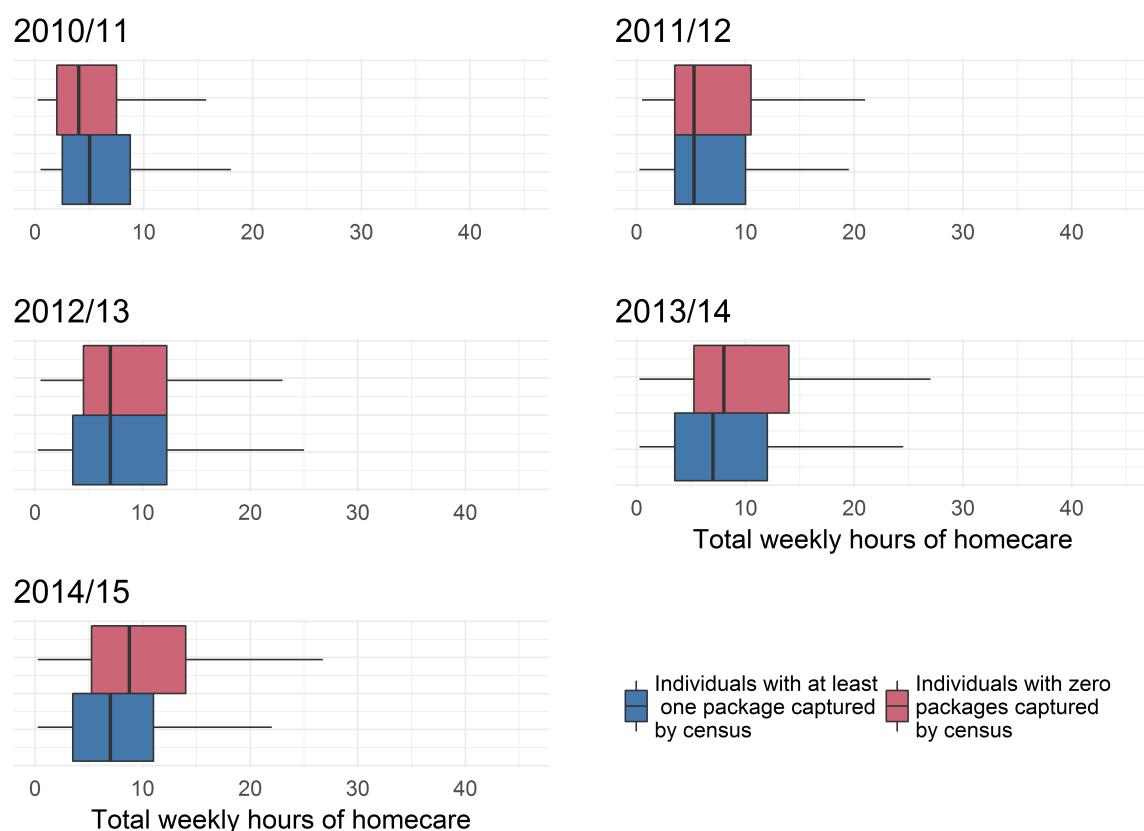
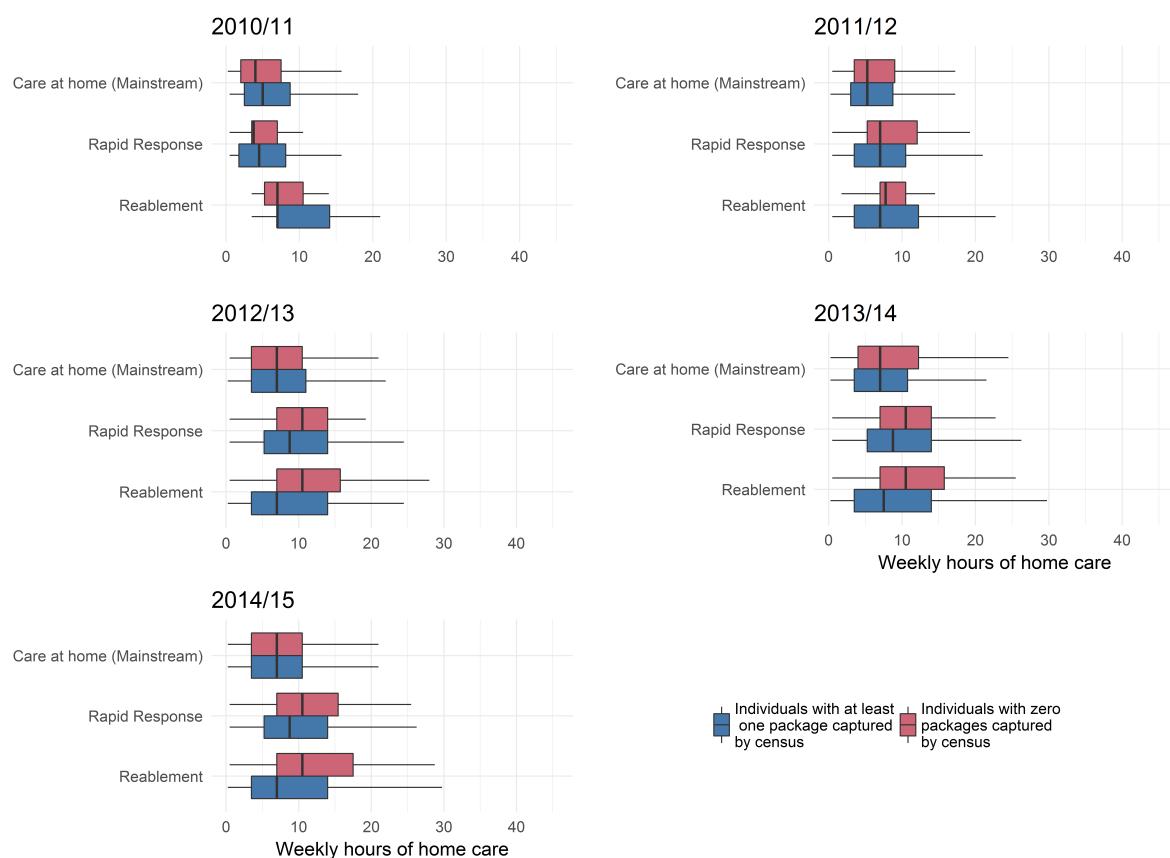


Figure 4.11: 2013/14. Variation in intensity of package (hrs) - by type



#### 4.4.5 Multi-census

Table 4.6: 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 4.6 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%).

Unsurprisingly, 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

- 60% sample
- Same type of people
- Same type of packages
- Different types of packages not accurately captured by categorisation?

This exploratory project has investigated the variation in packages of care from one Scottish local authority area. It has found that figures returned by Renfrewshire council to the SCS represent between 58.4% and 63.7% of the total number of individuals that the council provided home care for in the financial years 2006/07 to 2015/16.

Counts of individuals produced by this analysis appear to be similar to those returned by Renfrewshire Council to the SCS for the years 2006/07 to 2010/11. Thereafter, counts are slightly less. This could be due to changes in the way data was returned to SCS from

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the year 2011 onwards. There have also been changes in the criteria of which individuals should be included in counts of home care since 2011 that could not be replicated in this analysis.

*Packages not captured by the census tend to be of much shorter duration and have a higher intensity (measured by total hours per week) than those packages that are seen in the census weeks.* (Maybe drop this - need to focus more on difference in individuals rather than packages) More recent years have seen a greater proportion of packages being delivered for Reablement type services at the expense of Care at home (Mainstream) type packages of care. However, reablement services only account for a maximum of 8% of packages captured by the census and 21.5% not captured by the census with much lower proportions in earlier years.

Coupled with the finding that roughly half of individuals with “live” care packages during the census week have only a single package of care in the six months pre and post census, usually with a long duration, a picture emerges of two types of “Care at Home (Mainstream)” packages. The first type are long-term packages, sometimes lasting multiple years. The second type have much shorter duration and mirror many of the characteristics of “Reablement” type packages (*but I haven’t accounted for multiple packages received by one individual*). Whether these packages are misclassified, or if the recent addition of “Reablement” packages as a care type has not yet filtered through to data categorisation is unknown.

Returns to the SCS by local authorities do not distinguish between types of home care but provide a value of total weekly hours of home care only. This analysis shows that variables detailing the weekly hours of homecare received by an individual may disguise differing underlying types of care being delivered.

*Needs para on implications for research - taking into account re-analysis of multi-packages - if duration of care is more similar then can happily say that SCS is a good 60% representative sample of individuals receiving home care and can be dealt with in the same way as any other type of cross-sectional data (with better power than most surveys). If not, then need to quantify the error and suggest that analysis with SCS must take account of this error. Also need to bear in mind that ~50% of those captured by SCS will have variation in the amount of care they receive in the year surrounding the census but there is no way of identifying these individuals with current SCS variables*

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.

Furthermore, the method of summarising data into packages of care is subjective and may differ from the method used by Renfrewshire council. There is some comfort in the similarity of results for some years shown in figure 4.6, however there are notable differences, particularly in later years, suggesting structural differences in methods. The year 2010 was the first in which individual level data was collected by the Scottish Government which may have led to different methods of collating data. Furthermore, changes have been made at varying intervals for what constitutes home care with differing types of care, e.g. Housing Support being included as home care and then collected as a separate type of service in later years.

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.

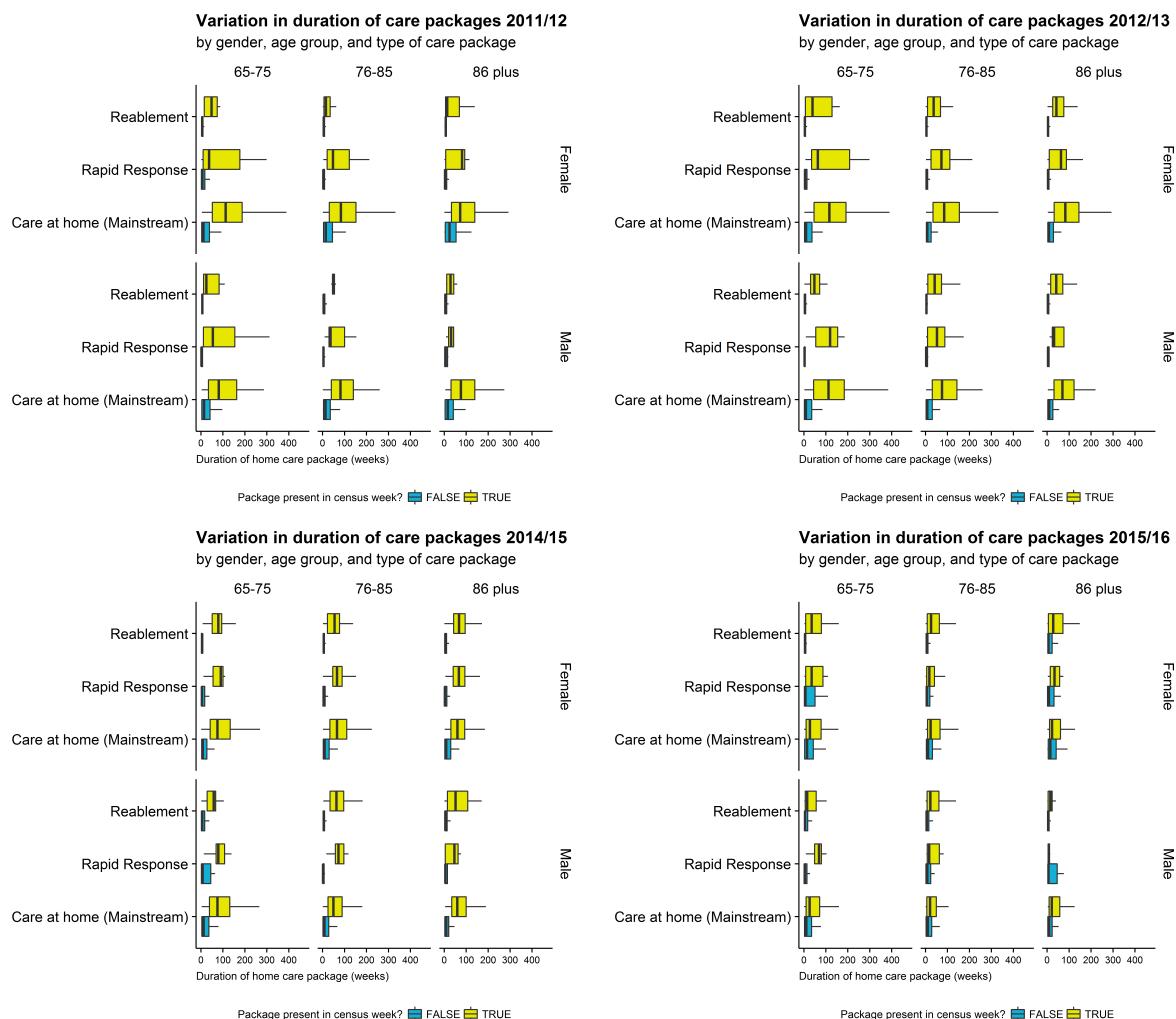
### **longitudinal analysis**

## **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 64% of the total number of people that will receive home care during a financial year. This has implications for the types of analysis that can be conducted with SCS in data linkage projects. Those individuals receiving care in the census week have packages of care that are broadly similar in duration and intensity. Some reablement packages of care may be misclassified.

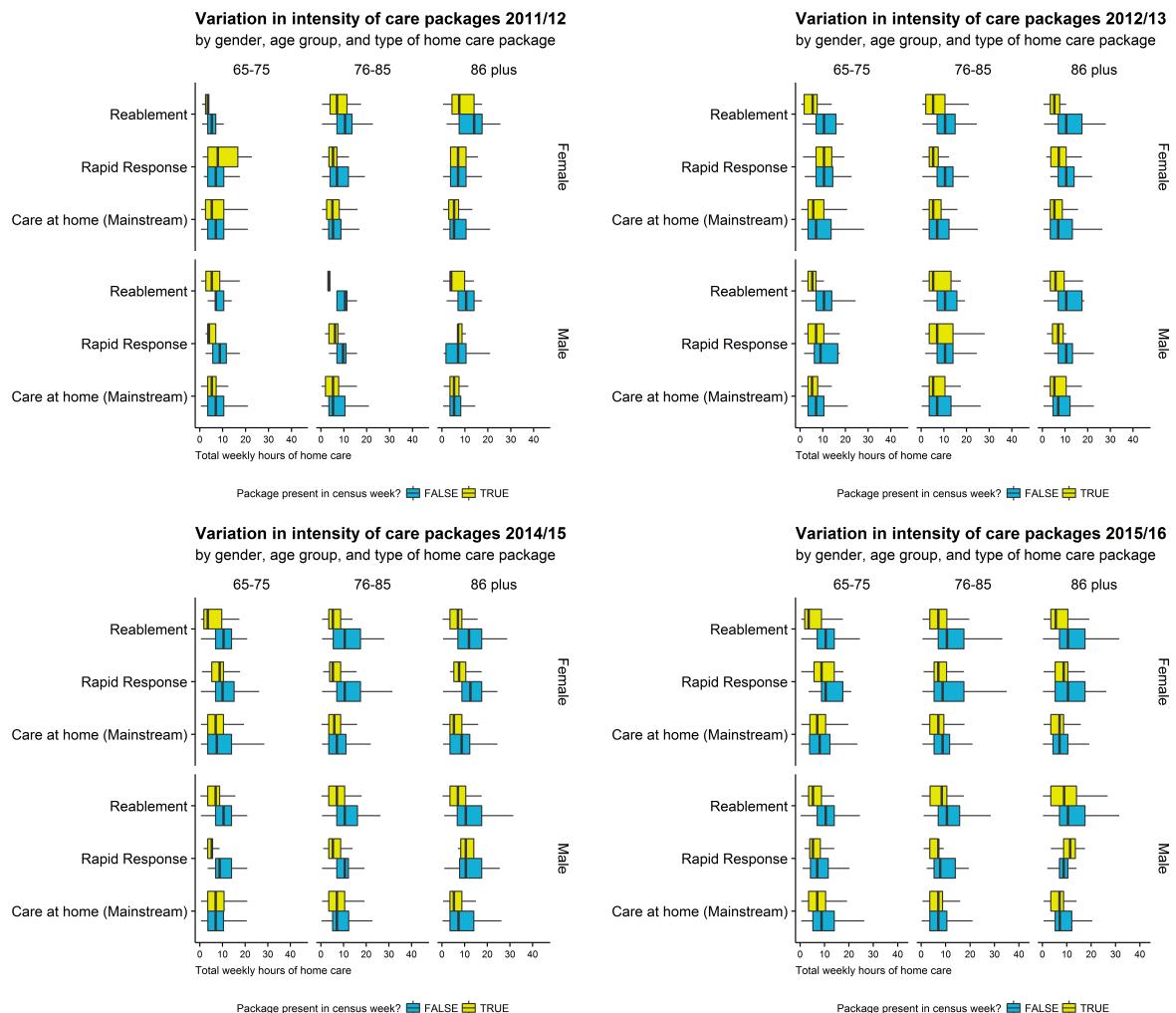
## **4.7 Supplementary charts**

Figure 4.12: Variation in duration - by care type - all years



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Figure 4.13: Variation in intensity - by care type - all years



# **Chapter 5**

## **Methods**

### **5.1 Cohort**

Describe the cohort - why it was chosen. How it was constructed

### **5.2 Linkage process**

#### **5.2.1 Social care linkage**

Describe probabilistic match to population spine with rates for each local authority

#### **5.2.2 Linkage to health sources**

Detail of linkage process with diagramme. In-depth detail here.

### **5.3 Summary measures**

#### **5.3.1 Social Care Survey**

Which variables were used and how summarised and cleaned (i.e. telecare as categorical etc.)

with reference to chapter 4 and measure of hours of social care

#### **5.3.2 Prescribing Information Service**

How PIS data was summarised and measures chosen

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

Which Local Authority? Which SIMD data?

### **5.3.4 Unscheduled care measures**

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

## **5.4 Statistical methods**

Which summary and model statistics were used to answer research questions.

# **Chapter 6**

## **Results 1**

### **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 Characteristics of cohort**

Long table

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

# **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**



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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. PBPP approval

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