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

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 [Burgess, 2012, Stewart et al., 2003, Glasby, 2017]. In addition to reducing variations in the provision of care across geographic areas, these policies hope to save public money by reducing unplanned admissions and delayed discharges from hospital whilst also improving the quality of services for individuals [Burgess, 2016, Scottish-Government, 2016b, OECD/EU, 2013].

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 [Petch, 2009, 2012b, Burgess, 2012, Robson, 2013, Weatherly et al., 2010, Stewart et al., 2003, Kaehne et al., 2017, Damery et al., 2016]. The continued drive to integrate services does, however, implicitly acknowledge that health and social care services are linked. How these services interact at the individual level and whether differing levels of provision in each service affects the other is not well understood [Glasby et al., 2011, **?**, OECD/EU, 2013].

Until recently many local authorities had attempted to protect front-line services, such as social care, from austerity cuts [Hastings et al., 2015]. However, given continued year-on-year reductions and a further 7.2% cut to local authority spending in 2016/2017 [Audit-Scotland, 2016a], the ability to protect social care from reductions in spend becomes less likely. Decreased local government budgets across the UK and Scotland since 2010 have affected those living in the poorest areas hardest [Hastings et al., 2015, Gannon et al., 2016]. If social care budgets decrease further, the question of whether the most deprived areas will feel these cuts most is of grave importance.

1.1 Aims and Objectives

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

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

Is multimorbidity status associated with levels of social care provided within *and* across local authorities? What is the best way to measure multimorbidity? Do clustering techniques offer a better understanding of this phenomenon?

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

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

Aims of the project are:-

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

The objectives of the project are:-

1. To assess how access to social care services varies for people with multimorbidity, especially by socioeconomic status.
2. To assess the impacts of social care service use on health service use and health outcomes for people with multimorbidity, where possible exploiting geographic differences in social care as "natural experiments".

3. To make recommendations for policy on the future of integration of health and social care services based on these results.
4. To assess tho what extant measures of multimorbidity and of health and social care service use can be operationalised using existing linked health and social care administrative data.
5. To make recommendations to policy makers on administrative data collections.

1.2   Scientific contribution

Explicit description of what thesis adds to knowledge

1.3   Conventions

Outline definitions

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

Chapter 2

Literature Review

2.1 Introduction

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

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

Section 2.3 outlines the policy framework regarding health and social care services, how these services are funded and delivered, and why they are linked. It then describes the legislation that made health and social care integration law in Scotland before reviewing empirical evidence of the nature of the interaction between health and social care services.

Section 2.4 describes why multimorbidity is important in the context of health and social care integration and then provides an overview of academic literature and policy documents regarding multimorbidity and its definitions, measurement, and epidemiology.

Add in paragraph or two outlining literature search strategy

2.2 Access to Social Care

Add intro paragraph

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

2.2.1 Definitions

There is no internationally (or nationally) accepted definition of social care. Indeed, the difference between what is social care and what is health care has no clear line of demarcation resulting in local variation in provision of services [McDonald, 2006]. The Organisation for Economic Co-operation and Development (OECD) and the European Union (EU) jointly published a report on Long Term Care (LTC) for older people discussing much of what may be described in the UK as social care. In the report, LTC is defined as,

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

[OECD/EU, 2013, pp38]

A recent NICE guideline [2015] addressing social care needs for older people with multiple chronic conditions used a definition provided in the UK Health and Social Care Act [2012]:-

> ""Adult social care"— (a) includes all forms of personal care and other
> practical assistance provided for individuals who, by reason of age, illness,
> disability, pregnancy, childbirth, dependence on alcohol or drugs, or any
> other similar circumstances, are in need of such care or other assistance, but
> (b) does not include anything provided by an establishment or agency for
> which Her Majesty's Chief Inspector of Education, Children's Services and
> Skills is the registration authority under section 5 of the Care Standards
> Act 2000." (The Health and Social Care Act 2012 c7, Part 3, Chapter 1,
> Section 65, Subsection 4)

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

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

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

[2007, pp. 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, pp.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, pp.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.

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 [OECD/EU, 2013, Anttonen, 2005, Colombo et al., 2011]. 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 [Anttonen, 2005, Deusdad et al., 2016, Pavolini and Ranci, 2008, Munday, 2003, Robertson et al., 2014, Colombo et al., 2011]. 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, Fernández-Alonso and Jaime-Castillo, 2016, Munday, 2003, Sapir, 2006].

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

Universal models of social care are characterised by; a) a single system being in place for delivery of services, b) nursing *and* personal care are provided for all individuals 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

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

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

[1] Spain and Greece have less well developed formal care services

local-government influence in both the raising of funds and delivery of services [Colombo et al., 2011, Fernández-Alonso and Jaime-Castillo, 2016, Munday, 2003, Sapir, 2006]. 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 [Robertson et al., 2014, Forder and Fernández, 2011, Eleftheriades and Wittenberg, 2013]. In Belgium, social care is viewed as a health risk and is financed through the health system with a cap on user-contribution. This results in a medical (rather than social) model of care delivery, mostly provided by nurses [Colombo et al., 2011].

In contrast to universal models described above where a single system is in place for social care delivery, mixed social care systems employ either; a) universal coverage via different sources/sectors or b) a mixture of universal and means-tested benefits [Colombo et al., 2011]. Whilst acknowledging the wide variation in systems, Colombo et al [2011] identify three subdivisions of mixed system models of social care as shown in table 2.1.

Parallel universal schemes provide social care via two or more sectors (e.g. nursing care via health provider and personal care from a non-healthcare source as seen in Scotland) [Colombo et al., 2011]. Major differences exist between countries in how this is delivered in practice with varying degrees of coverage. Income related universal benefits provide needs-based universal coverage of social care but benefits received vary according to

income [Colombo et al., 2011]. France provides a good example of this system where cash benefits are need *and* income based - benefits are paid at six levels of dependency, those with higher incomes are paid proportionally less and top-up care costs themselves [Colombo et al., 2011, Glendinning and Bell, 2008]. 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 [Fernández-Alonso and Jaime-Castillo, 2016, Munday, 2003, Sapir, 2006]. As this role is traditionally carried out by women, the Mediterranean model has attracted criticism from a feminist perspective [Munday, 2003].

The final model in Colombo et al's [2011] classification of social care in OECD countries is the means-tested safety net model (Table 2.1). In this model only those below a pre-determined threshold are entitled to state-provided social care. Despite the free provision of health care and some non-means-tested benefits, England is included in this category in the report. Presumably this is due to the fact that state support in a residential home in England is provided only after an individual has depleted both income *and* assets below a threshold [Colombo et al., 2011], a system not seen in other countries [1] [Glendinning and Bell, 2008].

Of the three models of social care described in this section, universal systems can be seen as having a number of advantages over the other two [Colombo et al., 2011, Glendinning and Bell, 2008]. Sharing the burden of social care provision among the entire population, either via general taxation or mandatory insurance schemes, results in a reliable, predictable source of finance enabling states to plan more effectively [Colombo et al., 2011, Glendinning and Bell, 2008, 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

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

variation in eligibility criteria within countries [Colombo et al., 2011, Glendinning and Bell, 2008, Charlesworth and Thorlby, 2012, Eleftheriades and Wittenberg, 2013, Forder and Fernández, 2011]. 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, pp.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 [Robertson et al., 2014, Charlesworth and Thorlby, 2012, Eleftheriades and Wittenberg, 2013, Forder and Fernández, 2011].

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 et al., 2016]. There is evidence those with more comprehensive coverage are reducing levels of care whilst those with less coverage are increasing provision [Colombo et al., 2011].

Given the marked variations in how social care is funded and delivered across countries, it may be expected that there are also marked variations in levels of access and utilisation. Colombo et al [2011] produced a chart (shown in figure 2.1) derived from OECD data that shows the proportion of over 65s receiving some form of social care across countries for which data is provided. The chart shows that having a universal or mixed system of social care provision (as described above) does not absolutely influence the number of people receiving care. For example, South Korea employs a universal (insurance-based) system and has one of the lowest proportions of older people receiving care, whereas

Figure 2.1: Older recipients of long-term care services as a share of the over 65 population, 2008
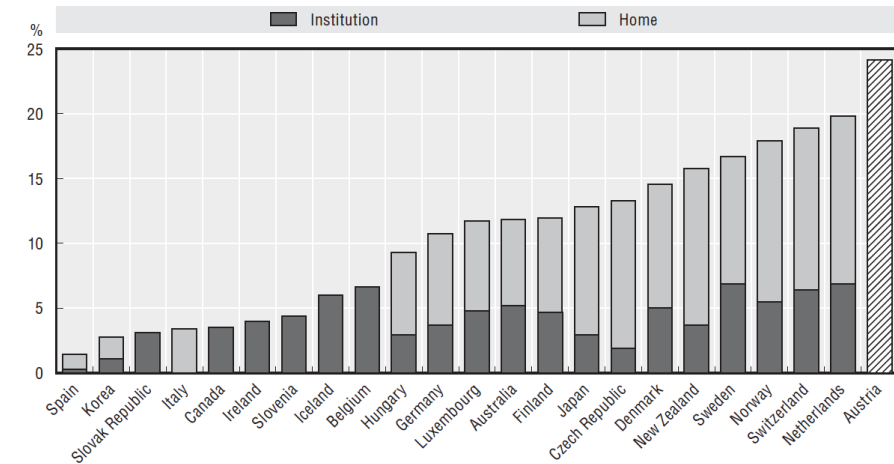
Note: LTC recipients aged over 65 years. Recipients refer both to home and institutional users. Data for Australia, Belgium, Canada, Denmark, Luxembourg and the Netherlands refer to 2007; data for Spain refer to 2009; data for Sweden and Japan refer to 2006. Data for Japan underestimate the number of 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*

Switzerland has one of the highest whilst employing a mixed system involving some universal and some means-tested benefits. This suggests that allocation of resources and eligibility criteria set within countries, as well as informal care, are likely to be more important in determining access to formal social care than any particular system of care delivery.

2.2.3 Access to Social Care - Social Theory of Eligibility

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

[Eleftheriades and Wittenberg, 2013, pp.2

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

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

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

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

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

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

The term "candidacy" was first used by Dixon-Woods et al [2005; 2006] to form a concept

of how vulnerable individuals identified themselves as being eligible for a particular health service or intervention given for particular illnesses or health conditions. The theory was further explored and augmented by Mackenzie et al [2013; 2015] in relation to access and utilisation of all public services as a way to explore concerns about unequal distribution of uptake.

The theory argues that there are a number of social and cultural factors that contribute to an individual's interpretation of their eligibility for a given service and is based on a seven-stage model as shown in Table 2.2

Table 2.2: Seven stage model of candidacy

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

This is a much broader theory than that of street-level bureaucracy and focusses on the barriers and enablers individuals face/use when accessing services but in other respects it is trying to do the same thing - exploting how front-line interactions shape outcomes. *Do previous authors make this point? Seems obvious for them to have considered how their frameworks relate. Is it true to say that candidacy brings the service user's subjectivity into the picture (albeit constrained) as well as that of the bureaucrat? - NB* It could be argued that candidacy includes the concept of street-level bureaucracy in the third, fifth, and sixth stages of the model shown in table 2.2. "professional decision making" and "offers of and resistance to services" are areas where an interface between a service user and service professional takes place - much like the interactions described by Lipsky.

Investigating candidacy as a theory empirically again appears to be best served using

qualitative methods. The complex and dynamic nature of candidacy suggests identifying meaningful quantitative measures are unlikely. Both Dixon-Woods et al [2005; 2006] and Mackenzie et al [2013; 2015] employed critical interpretive synthesis in their studies.

Both of the social theories described in this subsection deal with the concept of eligibility and how, in the case of street-level bureaucracy, professionals exercise discretion on access to service and, in the case of candidacy, how service-users identify whether they are eligible and offer themselves for a service in the first place. Both theories describe complex interactions between individuals across an eligibility criteria barrier. The next section describes in detail this eligibility barrier in relation to social care in the UK, firstly from a Scottish perspective and then more broadly in the wider UK.

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

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

[Sharkey, 2006, pp.10]

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

In 2010 the Scottish Government published a report written in conjunction with the Convention of Scottish Local Authorities (COSLA) [Scottish-Government, 2010] and included the recommendation that the National Eligibility Framework developed by the Sutherland review into free personal and nursing care [2008] should be applied across all social care services. The framework has four criteria for assessing risk in relation to a person's care needs: critical, substantial, moderate and low [Scottish-Government, 2015a]. 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, pp.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, pp.20] which states that, "...further work will be undertaken by the Scottish Government and COSLA to assess whether there is merit in establishing national thresholds for access to formal support across all client groups."

Acknowledgement of problems with eligibility criteria and the promise of "further work" to be undertaken by the Scottish Government and COSLA is repeated in practitioner guidance on Self-Directed Support published in 2014 [Scottish-Government, 2014, pp.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, 2015a] 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 [Hastings et al., 2014, Le Grand, 1982, Tudor-Hart, 1971].

In England, the Care Act [2014a] 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, pp.2]. The minimum criteria for being eligible for care involves an individual having needs that impairs their ability to meet two or more of a designated list of outcomes (e.g. managing and maintaining nutrition or maintaining hygiene) [SCIE, 2015] and is set by the Secretary of State for Health [Abrahams et al., 2014].

In practice, the most likely outcome is that the minimum threshold that local authorities will have to provide care will be similar to the "critical" level of the National Eligibility Framework previously used in the FACS guidance [Burchardt et al., 2015, Abrahams et al., 2014] (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 [Burchardt et al., 2015, Abrahams et al., 2014]. Burchardt et al. [2015] state that only 2% of English LAs will have to widen their care threshold whereas 12% could now, legally, tighten care provision as a result of the Care Act. *This situation is not new and has been gradually worsening over the past decade and has profound impacts on the*

*quality of, and access to, social care [@RN374]***re-write Sharkey is 2006 makes no sense temporally - also spell out what "profound impacts" are**.

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

Burchardt et al. [2015] and Abrahams et al. [2014] recognise some positive changes to social care policy through the Social Care Act but are damning about past UK government social care policy in England and Wales. They cite chronic underfunding and cuts for over ten years resulting in fewer numbers of people receiving care at a time when demand is sharply increasing due to demographic change. The "intensification" of services on those with the most acute needs is cited by both sets of authors as counter-productive – ignoring those with moderate care needs completely derails one of the main purposes of the Care Act, preventative services. Indeed,

> "As well as lacking in moral sense, such an approach is economically unsound. Waiting for people to have high needs before providing care means that care will be more expensive, as well as pushing more older people into an already pressurised NHS"

[Abrahams et al., 2014, pp.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, 2016a]. There are wide variations in the number of hours of home care provided per population across local authorities [Audit-Scotland, 2012, Scottish-Government, 2016a]. 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, 2016a]. Audit Scotland [2012] also highlighted that intensifying services is likely to be a short-term solution with negative long-term impacts and suggests comparison of performance across Scotland would be beneficial in identifying good practice.

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

2.2.5 Access to Social Care - Social Theory of Resource allocation

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

[Le Grand, 1989, pp.3]

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

Criticism of Le Grand's conclusions cites subsequent research that shows empirical evidence indicating a reduction in inequalities and questions the assumption that the sole purpose of the welfare state is to achieve equality [Powell, 1995]. More recent research [Bramley et al., 2005, cited in; Hastings et al., 2014],[Hastings, 2007, Bramley and Evans, 2000] has shown that when comparing distribution of resources at neighbourhood level (rather than national level) there is higher spending in less affluent areas. However

some service were found to be "pro-rich" (education, pensions) and others "pro-poor" (parks, environmental services) [Bramley et al., 2005, cited in; Hastings et al., 2014]. Whether a service is more likely to be used by more or less affluent citizens is important in terms of resource allocation - particularly when services are being cut as shown by Gannon et al [2016] and discussed further in section 2.2.6.

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

Table 2.3: Six channels of middle class advantage

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

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

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"

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

In a similar fashion to Le Grand's work, the inverse care law has informed much research since first coined in the early 1970s but focusses specifically on healthcare. People living in more deprived areas have lower life expectancy and higher morbidity figures and therefore greater health needs [Baker et al., 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, pp.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 [McLean et al., 2015, Mercer and Watt, 2007]. 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)} [Scottish-Government, 2013, King et al., 2007]. 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, 2016c]. 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, 2016c]. A national figure for each service is set and each local authority receives a percentage of that figure based on estimates of the number of people that use that service (a capitation) and other secondary indicators such as area deprivation or rurality [Scottish-Government, 2016c, Smith, 2003]. 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, 2016c].

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

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

The expenditure for the first three items in this list as well as carers support & respite services and care home fees are calculated using population weighted indices for each local authority calculated from; the standardised mortality ratio, census data on self-report long term illness & people living alone, as well as pension credit data service for home based elderly) or council tax data (residential accommodation for the elderly). Services relevant to people with disabilities and the independent living fund are calculated depending on the number of people aged 16-64 in each local authority. Expenditure allocation for personal and nursing care for older people is derived from formulae calculated in the Scottish Government Health Directorate Distribution [Scottish-Government, 2016c].

The GAE formula has been in place for some time (initially outlined in 1992 [Scottish-Government, 2016c]). 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, 2016c]. Authorities have been managing this pressure by reducing spending in all areas of their budgets - with the exception of social work [Audit-Scotland, 2016c]. £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, 2016b]. However, given the 5% decrease

planned for 2016/17 Audit Scotland [2016c] 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, 2016b].

These budgetary pressures are difficult for local authorities to manage, but what is the outcome on service users? Using the "pro-rich/pro-poor" nomenclature initially used by [Bramley et al., 2005] (and discussed in section 2.2.5), 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, 2016c] 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 et al., 2015]. People living in deprived areas are more likely to engage in unhealthy lifestyle

behaviours, experience multimorbidity at a younger age, and live in overcrowded or unsuitable housing [Baker et al., 2015, Shaw et al., 2006].

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, 2017a]. 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, 2017a] 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, Mackenbach, 2012, McCartney et al., 2013, Nettleton, 2006].

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, Smith et al., 2016, Mackenbach, 2012]. 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 [Smith et al., 2016, Katikireddi et al., 2013, Asthana and Halliday, 2006, Nettleton, 2006]. 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 [Smith et al., 2016, Katikireddi et al., 2013, Asthana and Halliday, 2006, Scottish-Parliament, 2015]. 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 [Frank et al., 2015, Mackenbach, 2010, Peckham and Meerabeau, 2007].

(Might expand this a little more?)

2.2.8 Summary

There is no agreed standard definition of social care, a term often used synonymously is long-term care. The boundary between what is health care and what is social care is often blurry. The definition chosen for this thesis provided by Colombo et al [Colombo et al., 2011] encapsulates the wide number of services that make-up social care including nursing, personal, equipment, and technological. The definition also identifies that social care can be provided not only at home, but also in institutions or other community settings.

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

Eligibility for social care is determined via pre-specified criteria in all cases. How these criteria are set varies greatly across and within countries. In UK terms eligibility criteria are set by local authorities and have been greatly tightened in recent years as a response to budgetary constraint. Also observed is the process of "intensification" where greater

hours of social care are being delivered to smaller numbers of people with higher needs. This has potential to erode an important function of social care - preventing expensive unscheduled health care use.

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

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

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

There have been significant cuts to local authority budgets across the UK since 2008. Savings have been made whilst trying to protect front-line services but current and future cuts are likely to impact these services. Most local authority spending is on services used by those from lower socioeconomic positions thus cuts will disproportionately affect these people. Little is known about how access to social care differs across socioeconomic and geographic strata. In an age of austerity, the question of whether an inverse *social* care law exists remains unanswered.

2.3 Health and Social Care Interaction

Add intro paragraph

2.3.1 Public Policy

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

[Christie, 2011, pp.2]

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

Consider dropping bullets and describing in paragraphs

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

The recommendations of the commission included:-

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

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

2011 also saw the publication of the Scottish Government vision to achieve sustainable quality in the delivery of healthcare services by the year 2020 [Scottish-Government,

2011]. Echoing some of the Christie Commission recommendations, the 2020 vision contained a number of objectives to change the way health and social care services are delivered including; a focus on prevention and self-management of health conditions, an expanded role for GPs and primary care, a focus on reducing hospital stays & providing treatments in a community setting, improving care for those with multimorbidity, and formally integrating health and social care services [Audit-Scotland, 2016a].

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

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

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

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

2.3.2   Health and Social Care Integration

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

[Scottish Government, 2011, pp.2]

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

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, pp.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 [Audit-Scotland, 2015, 2016a, Burgess, 2012, 2016, Scottish-Government, 2015b, 2016b]. However, despite streamlining of budgets, there remain significant barriers in achieving these aims [Audit-Scotland, 2015, 2016a].

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, 2015b, 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, 2015b, 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, 2015b, 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, 2015b, Audit-Scotland, 2015, Burgess, 2016, Kaehne et al., 2017]. Under this plan, NHS Highland is responsible for the delivery of all adult health and social care services, whilst the council takes responsibility for children's community health and social care services [Burgess, 2016, Kaehne et al., 2017].

Comparison of outcomes between the Highland partnership and all other IJBs will be of significant interest. One of the main aims of integration is to reduce unscheduled healthcare use, in particular unplanned admissions to hospital, which can be an indicator of a lack of social care support in an area [Scottish-Government, 2015b, Audit-Scotland, 2015, 2016a]. 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, 2015c, 2016d, Kaehne et al., 2017].

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

2.3.3   Research on Health and Social Care Interaction

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

[Weatherly et al, 2010 pp. 3]

Add in "Where is the NHS going wrong?" here

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 [Petch, 2009, Burgess, 2012, Robson, 2013, **?**, Stewart et al., 2003, Damery et al., 2016, Kaehne et al., 2017, Cameron, 2016, Petch, 2012b]. **clarify - refs predate Scottish integration - what were they measuring??**

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

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

using linked-administrative data to look specifically at interactions between health and social care services.

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

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

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

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

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

of the interaction between health and social care services.

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

2.3.4 Summary

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

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

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

2.4 Multimorbidity

Add intro 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, 2016b, Audit-Scotland, 2016a]. In Scotland, approximately two-thirds of individuals receiving social care services are over the age of 65 [Scottish-Government, 2016a] 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 [Barnett et al., 2012, Mercer et al., 2009]. This inequality in outcome is compounded by the fact that primary care provision in areas of higher socioeconomic disadvantage, ergo areas of higher need, receive the same or less funding as other more affluent areas. This inequity in provision of service demonstrates existence of the inverse care law in primary care services [Tudor-Hart, 1971, Mercer et al., 2012, McLean et al., 2015] and has already been discussed in section 2.2.5.

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

2.4.2   Definitions

Despite the increasing importance of multimorbidity on health care systems, there has been some debate internationally in finding an agreed definition of the term or concept [Almirall and Fortin, 2013, Lefevre et al., 2014]. Van den Akker et al [1996] first made

the distinction between the terms comorbidity and multimorbidity. Comorbidity was originally described by Fenstein [Feinstein, 1970, pp.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, pp.65] used the term multimorbidity to describe, "...any co-occurrence of medical conditions within a person." In this sense, multimorbidity does not rely on the presence of a primary, or index, disease but refers to the overall state of multiple illnesses.

Further development of definitions is provided by Valderas et al. [Valderas et al., 2009] who characterise the construct of the term comorbidity found in the literature in four main groups; (a) comorbidity – additional diseases in the context of an index disease, (b) multimorbidity – more than one disease within an individual (without reference to an index disease), (c) morbidity burden – total impact of physiological dysfunction linked to patient outcomes and (d) patient complexity – the effect of non-health characteristics (e.g. deprivation, culture, environment) on morbidity burden.

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

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

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

This definition goes some way to capture the complexity of the concept of multimorbidity

as explained by Valderas et al. [2009] but has not ended debate on the matter.

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

In a recently published guideline, the National Institute for Health and Care Excellence (NICE) [NICE, 2016] acknowledge the complexity of defining multimorbidity. NICE agree with other commentators [Mercer et al., 2009] that basing the definition of multimorbidity on two or more health conditions *only* does not fully capture a clinically meaningful picture of the concept. The guideline highlights the fact that many people defined as multimorbid in this way may not be ill and have excellent quality of life requiring little or no health care input [NICE, 2016]. For this reason the guideline is aimed at people with more than 1 long-term condition with any of the following:-

- Difficulty managing treatments or day-to-day activities.
- Care from multiple services and requiring care from a new service.
- Both long-term physical and mental health conditions.
- Frailty.
- Frequent use of unplanned or emergency care.
- Prescription of multiple, regular medicines.

[NICE, 2016]

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

2.4.3 Measurement

The findings of three recent systematic reviews have highlighted the myriad ways researchers have approached the measurement of multimorbidity [de Groot et al., 2004, Diederichs et al., 2011, Huntley et al., 2012]. Each review aimed to collate evidence of measurement tools in comorbidity or multimorbidity but from different perspectives: De Groot et al [2004] searched for comorbidity indices to inform research into Multiple Sclerosis, Diederichs et al [2011] specifically searched for multimorbidity measurement indices, whereas Huntley et al [2012] searched for measures of multimorbidity used only in primary care research. The systematic reviews found 13, 39 and 17 exclusive ways of measuring multimorbidity or comorbidity respectively. 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 et al., 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 [de Groot et al., 2004, Diederichs et al., 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 et al., 1992] and their variations.

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

Disease counts were also found by Huntley et al [2012] to have good evidence to suggest they provide a robust measure of multimorbidity in relation to quality of life,

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

An emerging method of measuring multimorbidity is to identify clusters of medical conditions that co-exist in individuals at rates higher than would be expected - or non-random prevalence. Recent research and academic discussion suggests identification of disease clusters may enable clearer answers to clinically relevant research questions than currently employed measures [Le Reste et al., 2015; RN109; Prados-Torres et al., 2014; Sinnige et al., 2013; Holden et al., 2011; Marengoni et al., 2011; Valderas et al., 2009]. 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 3 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 4 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 4). This is cross-sectional data. In a short stand-alone results chapter, chapter 6 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 7 describes the results of analyses related to each research question.

Chapter 8 summarises the thesis arguments and findings and places them in context.

Chapter 3

Measuring Multimorbidity

3.1 Introduction

As Chapter 2 showed, multimorbidity can be defined as the presence of two or more chronic health conditions within an individual [NICE, 2016]. It is associated with higher mortality [Gijsen et al., 2001], increased use of health care [Gijsen et al., 2001, Salisbury et al., 2011], psychological distress [Fortin et al., 2006], worse quality of life [Fortin et al., 2004, 2005], and worse functional status [Kadam and Croft, 2007]. It not only affects older people but has been observed in greater absolute numbers in those under the age of 65 and affects those with lower socioeconomic status disproportionately [Barnett et al., 2012]. As the proportion of older people in the population increases, multimorbidity is expected to affect increasing numbers of people in the future [Guthrie et al., 2011, Imison, 2012].

Many of the negative outcomes associated with mulitmorbidity are due to the structure of healthcare delivery which tends to concentrate treatment goals towards single diseases [Guthrie et al., 2011, Starfield et al. [2005]]. As a result healthcare for individuals with multimorbidity can, at best, preferentially treat one disease to the detriment of others or, at worst, cause harm and affect patient safety e.g. through medication interactions [May et al., 2009].

Epidemiological research into multimorbidity has tended to count numbers or report proportions of health conditions. There is, however, marked heterogeneity in the population considered and the number of diseases included in measurement. As a result,

prevalence rates of multimorbidity have been shown by systematic reviews to vary widely in the general population from 13.1% - 71% [Fortin et al., 2012] and 12.9% - 95.1% [Violan et al., 2014]. There has been little research into the prevalence of combinations of diseases and non-random, co-occurrence of diseases partly due to the high number of theoretical combinations meaning large samples and complex calculations are required [van den Akker et al., 2001, Cornell et al., 2009]. More recent research has applied a variety of statistical techniques to overcome this problem [Prados-Torres et al., 2014].

Identification of non-random co-occurrence of health conditions is important for a number of reasons; a) to gain a better understanding of the complicated nature of multimorbidity, b) to help assess the impact multimorbidity has on health outcomes, c) to help assess the sociodemographic differences in prevalence of multimorbidity which could have implications for health policy and the delivery of health services, and d) unexpected non-random associations could prompt further research into possible causal mechanisms for the association.

The objective of this chapter was to apply a novel two-way clustering framework to a large dataset based on the Scottish population, The framework aims to identify clusters of the most significant non-random co-occurrence of health conditions and multimorbidity patterns among individuals [Ng, 2015]. The specific aims were to a) Identify non-random associations of health conditions from the dataset, b)identify if meaningful, homogeneous sub-groups of individuals according to groups on non-random conditions can be formed, c) assess the sociodemographic make-up of identified clusters.

Add para describing purpose of this chapter to overall thesis

3.2 Background

Previous clustering attempts in the field of multimorbidity have employed a number of different statistical techniques including; factor analysis, cluster analysis, the observed to expected ratio, multiple correspondence analysis [Prados-Torres et al., 2014], principal component analysis, and latent class analysis [Islam et al., 2014]. Each of these techniques is a variant of latent variable modelling where clusters are deemed unobserved, or latent, variables that can be measured indirectly depending on the values of two or more observed variables [Collins and Lanza, 2013]. In their systematic review of

clustering techniques, Prados-Torres et al [2014] found marked heterogeneity in the numbers of diseases included in analyses, populations studied, and resulting clusters of conditions. The authors recommended that future attempts at clustering should be conducted using large numbers of diseases and in population-based datasets as opposed to sub-groups of populations.

An important decision in any clustering research is which statistical technique to apply to a given dataset. Collins & Lanza [2013] argue that when the latent variable (cluster) and the observed variables used to identify the latent variable are categorical in nature, Latent Class Analysis (LCA), a version of a finite mixture model, is an appropriate statistical technique to employ. Other techniques such as factor or cluster analysis rely on latent and/or observed variables being continuous in nature [Collins and Lanza, 2013]. The aim of this chapter is to identify whether homogeneous sub-groups of individuals can be identified from a dataset of diseases represented by binary, categorical data. Such sub-groups would also be categorical in nature suggesting LCA is an appropriate technique to apply.

The limitation to LCA is that as the number of observed variables increases it becomes more difficult for the LCA model to be well identified [Collins and Lanza, 2013]. This is because the first step of LCA is to create a contingency table of all possible combinations of outcomes. For example, in a simple dataset with two binary Yes/No variables there are $2^2 = 4$ potential response outcomes; No/No, Yes/No, No/Yes, and Yes/Yes. In the example of the dataset used in the current chapter with 40 health conditions recorded as binary variables the number of cells in the contingency table will contain 2^{40} (over 1 trillion) cells. This makes good model identification highly unlikely. Ideally the ratio of n/W where n denotes the sample size and W denotes the number of potential response outcomes should be as high as possible [Collins and Lanza, 2013]. When this ratio is very small there are only two options to overcome the problem, "...increase the amount of known information or reduce the amount of unknown information." [Collins and Lanza, 2013, :93]

In response to the "high-dimensional" problem created when trying to identify latent variables from health datasets with large numbers of diseases, Ng [2015] proposed a two-way model to identify multimorbidity clusters. The first step of this method is to "clump" diseases in the dataset into statistically correlated groups of conditions thereby reducing the number of variables and therefore the size of contingency table of

potential responses. This first step is described in more detail in Ng et al [2012]. The second step of the method then aims to identify latent groups of individuals based on response patterns to these "clumped" groups with a finite mixture model similar to LCA [Ng, 2015]. This technique was applied to an Australian national health survey which contained self-reported responses of the presence of 24 physical and mental health conditions with full results detailed in Ng [2015]. The aim of this chapter is to identify whether this technique is valid in a much larger dataset of administrative health data.

3.3 Methods

3.3.1 Data

In Scotland, much multimorbidity research has been informed by the Scottish Programme for Improving Clinical Effectiveness in Primary Care (SPICE-PC) dataset [Agur et al., 2016, Barnett et al., 2012, Elder et al., 2007, McLean et al., 2015]. Diagnostic data from the year 2007 is available on 1,754,133 people in Scotland drawn from 314 general practices. The anonymised dataset has information on the presence of 32 physical and 8 mental health conditions (?? add box with list of diseases??) in addition to age, gender and deprivation index data. Diagnostic data is derived from codes entered into IT systems in General Practices and prescription data. A full description of the 40 included diseases and the methods used to classify them is available as supplementary information in Barnett et al [2012]. The analysis for this chapter was restricted to adults over the age of 18 resulting in n=1,426,196. (10% sample of this so far!!) Ethical approval for secondary analysis of the SPICE-PC dataset using LCA was granted by the Research Ethics Committee of the College of Social Sciences at the University of Glasgow on 29/04/2016.

3.3.2 Analysis

The two-way method proposed by Ng [2015] was applied to the above dataset of 40 health conditions. Firstly groups of conditions that co-occur are identified and then latent groups of individuals are identified using a mixture model approach. To identify the groups of conditions that co-occur the method aims to calculate the significant

pairwise multimorbidity between all conditions. The asymmetric Somer's D statistic was used to quantify the degree of random co-morbidity with all pairs of health conditions. Significance of the Somer's D statistic for each pair of conditions was calculated using the Benjamini-Hochberg procedure [Benjamini and Hochberg, 1995] to control the false discovery rate (FDR) with $\alpha = 0.001$. Diseases were then clustered into overlapping groups using a "clumping" procedure based on the technique described by Jardin & Robson [1968] and fully described as equation 11 in Ng et al [2012]. The strength of multimorbidity in each cluster was calculated using the average pairwise Somer's D statistics of disease within the group. From these overlapping groups, non-overlapping groups of diseases were created using an amended version of the algorithm specified in Ng [2015]:-

1. Name the cluster with the highest strength as the first group and then remove its member health conditions in all subsequent clusters with smaller strength. Each member in a cluster must have the condition with which the pairwise concordance statistic is maximum in the same cluster;

2. Repeat (1) for the next cluster and name it as a group if it is not 'singular' (singular cluster is defined as a cluster consisting of a single health condition);

3. If a group is formed in (2), remove its member health conditions in all subsequent clusters with smaller strength or singular clusters;

4. Repeat (2) and (3) until all clusters are visited;

5. Put the condition in a singular cluster into a predefined group where more than half of the member conditions are significantly comorbid with the condition;

6. Name those remaining singular clusters as a singular group.

A matrix was then created assigning a score to individual observations for each identified non-overlapping group. Scores were assigned as:-

- 1 for having no diseases within the group
- 2 for having one of the diseases in the group
- 3 for having 2 or more diseases within the group.

In the second part of the analysis a mixture-model of multivariate generalised Bernoulli distributions was applied to the matrix of these scores in order to identify latent groups of individuals according to response patterns to the score matrix. The most appropriate number of latent groups to fit the dataset was determined by the lowest Bayesian

Information Criterion (BIC) and substantive theoretical analysis. Models with 3 to 9 latent groups were compared to find best model fit. Each observation was then assigned to the latent group for which the posterior probability was highest. Descriptive analysis of sociodemographic difference in latent group was then employed to identify patterns in groupings.

All statistical analysis was completed using R version 3.3.3 [R-Core-Team, 2017]. Two-way clustering was conducted with amended code provided by Ng[2015]. Data manipulation and visualisation was conducted using tidyverse packages [Wickham, 2017] and the corrplot package.

3.4 Results

3.4.1 Pairwise correlation

With α controlled at 0.001, 143 of a possible 780 pairwise correlations proved to be significant. A matrix showing all statistically significant correlations is shown in Figure 3.1. The number of expected false positives for 143 pairs is less than 1.

3.4.2 Grouping diseases

Using the "clumping" procedure detailed in Ng [2015], Thirty-eight overlapping groups of conditions were found as shown in Table 3.1

Six diseases; Epilepsy, Learning Disability, Sinusitis, Crohns, Anorexia, Psoriasis/Eczema did not have strong enough pairwise correlations to be included in any of the 38 groups. Thirteen non-overlapping groups were derived from the results of the clumping method using the algorithm described above and named according to the characteristics of the member disease in the groups as shown in Table 3.2.

A further four diseases; Diverticular disease, Prostate, IBS, and Dyspepsia were excluded from the non-overlapping groups. These four conditions did not appear in any groups with the diseases with which they had strongest pairwise correlation, a condition that had to be met in the first stage of the algorithm described above.
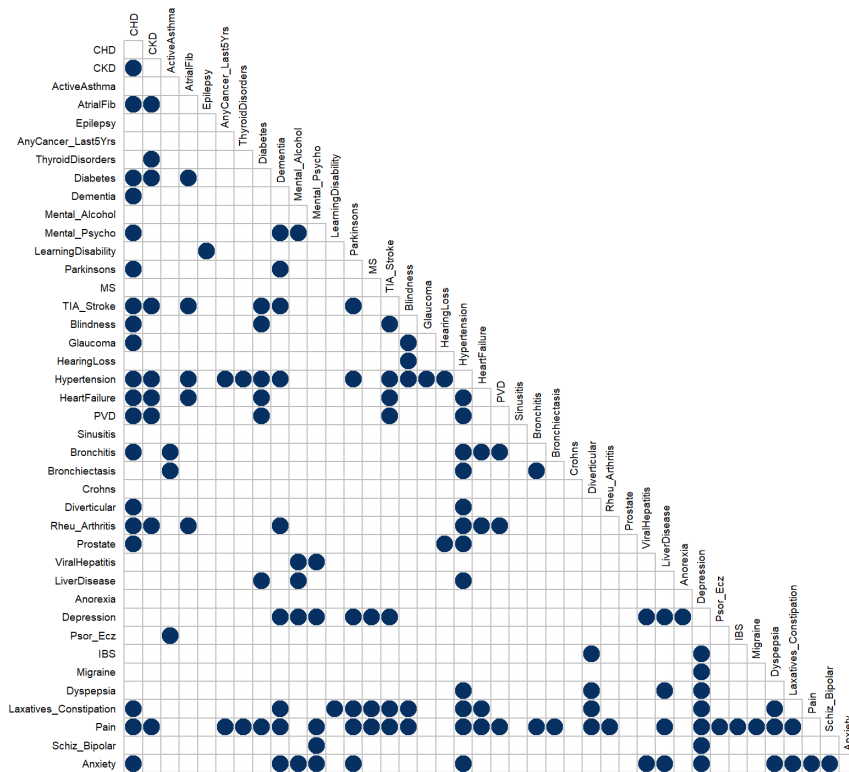
Figure 3.1: Significant Pairwise Correlations

Table 3.1: Overlapping groups of diseases derived from "clumping" procedure

Group	Diseases Included	Strength
1	CHD, CKD, AtrialFib, Hypertension, HeartFailure, Rheu-Arthritis, PVD	0.2833
2	CHD, CKD, AtrialFib, Diabetes, TIA-Stroke, Hypertension, HeartFailure	0.2806
3	CHD, CKD, Hypertension, HeartFailure, Rheu-Arthritis, Pain	0.2653
4	CHD, Hypertension, Prostate	0.2622
5	CHD, CKD, Diabetes, TIA-Stroke, Hypertension, HeartFailure, Pain	0.259
6	CHD, TIA-Stroke, Hypertension, HeartFailure, Laxat-Constip, Pain	0.2525
7	Mental-Alcohol, LiverDisease, Depression, Anxiety	0.2512
8	CHD, Hypertension, HeartFailure, Bronchitis, Pain	0.2487
9	CHD, CKD, Diabetes, TIA-Stroke, Hypertension, PVD, Pain	0.2348
10	CHD, CKD, Hypertension, PVD, Rheu-Arthritis, Pain	0.2331
11	Mental-Alcohol, Mental-Psycho, ViralHepatitis, Depression, Anxiety	0.2324
12	Mental-Psycho, Depression, Schiz-Bipolar, Anxiety	0.2304
13	CHD, Hypertension, Diverticular, Laxat-Constip, Pain	0.2294
14	Depression, Migraine, Pain	0.2278
15	CKD, ThyroidDisorders, Hypertension, Pain	0.2262
16	CHD, Blindness, Glaucoma, Hypertension	0.2236
17	Depression, Dyspepsia, Laxat-Constip, Pain, Anxiety	0.218
18	MS, Depression, Laxat-Constip, Pain	0.2178
19	CHD, Diabetes, TIA-Stroke, Blindness, Hypertension, Pain	0.2171
20	ActiveAsthma, Bronchitis, Bronchiectasis	0.2166
21	CHD, TIS-Stroke, Blindness, Hypertension, Laxat-Constip, Pain	0.2138
22	CHD, Hypertension, PVD, Bronchitis, Pain	0.2114
23	CHD, Dementia, Parkinsons, TIA-Stroke, Hypertension, Laxat-Constip, Pain	0.2068
24	Dementia, Parkinsons, Depression, Laxat-Constip, Pain, Anxiety	0.2068
25	CHD, Dementia, Hypertension, Rheu-Arthritis, Pain	0.204
26	Diabetes, Hypertension, LiverDisease, Pain	0.1964
27	Dementia, Mental-Psycho, Depression, Pain, Anxiety	0.1939
28	Hypertension, Diverticular, Dyspepsia, Laxat-Constip, Pain	0.1938
29	CHD, Dementia, Parkinsons, Hypertension, Laxat-Constip, Pain, Anxiety	0.1922
30	Hypertension, Bronchitis, Bronchiectasis, Pain	0.1917
31	Blindness, HearingLoss, Hypertension	0.179
32	Dementia, Parkinsons, TIA-Stroke, Depression, Laxat-Constip, Pain	0.173
33	HearingLoss, Hypertension, Prostate	0.1729
34	AnyCancer-Last5Yrs, Hypertension, Pain	0.1707
35	Hypertension, LiverDisease, Dyspepsia, Pain, Anxiety	0.1593
36	Depression, IBS, Pain	0.1563
37	CHD, Dementia, Mental-Psycho, Pain, Anxiety	0.1385
38	Diverticular, IBS, Pain	0.1226

Table 3.2: Non-overlapping groups of diseases derived from Ng algorithm

Disease group name	Diseases included
Cardiovascular	CHD, CKD, AtrialFib, Hypertension, HeartFailure, Rheu-Arthritis, PVD
Diabetes/Stroke	Diabetes, Stroke
Pain/MS	Laxatives/Constipation, Pain, MS
Mental Health/Liver	Mental/Alcohol, Liver Diseases, Depression, Anxiety
Psychosis	Mental-Psycho, Viral Hepatitis
Sciz/Bipolar	Sciz-Bipolar
Migraine	Migraine
Thyroid	Thyroid disorders
Blindness	Blindness, Glaucoma
Respiratory	ActiveAsthma, Bronchitis, Bronchiectasis
Neurodegenerative	Dementia, Parkinson's
Hearing Loss	Hearing Loss
Cancer	Any Cancer in Last 5 years

3.4.3 Grouping individuals

Individuals were assigned a score depending on the number of diseases they had in each of the non-overlapping groups according to the criteria described above. The finite mixture model of multivariate generalised Bernoulli distributions was then applied to this dataset in order to identify latent groups of individuals depending on their scores for each of the 13 groups, based on presence of 30 diseases. BIC scores suggested the model for nine latent groups had best fit to the data. The nine-group model was compared with the model with second-lowest value of BIC, that for eight latent groups. However, despite offering a more parsimonious solution, the eight-group model did not provide a more substantive theoretical fit to the data. Thus, the nine-group model was deemed best fit and analysed further.

Item-response probabilities for the nine-group model are shown in Figure 3.2.

Each latent group was labelled according to these item response probabilities as follows;

- Latent Group 1. **Well**. High probabilities of having no diseases in any of the groups.
- Latent Group 2. **Cardiovascular only**. Item response in this Latent group have more than 50% chance of having at least 1 condition from the Cardiovascular group. High probabilities of having no diseases in any of the other groups.
- Latent Group 3. **Cancer**. Individuals in this group have almost 100% probability

Figure 3.2: Item response probabilities for nine latent group model

of having had cancer in last 5 years. Weak probabilities across some other groups.

- Latent Group 4. **Mental Health/Pain** High probability of having at least one diseases from Pain/MS group and at least one disease from Mental Health/Liver group.

- Latent Group 5. **Mental and Physical Multimorbidity** High probabilities of having at least 1 cardiovascular, diabetes/stroke, Pain/MS, and Mental health/Liver disease. This group also has the highest probability across latent groups for having 1 respiratory disease.

- Latent Group 6 **Physical Multimorbidity** High probability of a least one cardiovascular disease and one of Diabetes/Stroke.

- Latent Group 7. **Physical multimorbidity (Strong Cardio)**. Similar to Latent group 6 but individuals in this group are more likely to have 2 or more cardiovascular diseases.

- Latent Group 8. **Dementia with Mental/Physical MM** Individuals in this latent group have almost 100% probability of having dementia or Parkinson's. Also highly likely to have at least one Cardiovascular disease and mildly raised probability of having mental health or psychosis diseases.

- Latent Group 9. **Mental Health only**. High probability of having a least 1 of the Mental Health/Liver group diseases. Also mildly raised probabilities in the Psychosis and Sciz_Bipolar groups.

Proportionate size of each of the assigned latent variable groups is shown in Figure 3.3.

The "Well" latent group was by far the largest group with almost 70% of individuals within it. The other groups formed much smaller proportions of the data.

3.4.4 Sociodemographic breakdown of latent groups

Each of the Histograms of Age for each of the latent groups shown in Figure 3.4 show variation in distribution. The "Well" and "Mental Health only" groups have a much younger age distribution compared to the other groups. The "Dementia" group has a much older distribution.

Figure 3.5 shows higher proportions of males in the "Physical MM" latent group. The "Well" and "Physical MM high Cardio" groups have even splits by gender. All other groups have higher proportions of females.
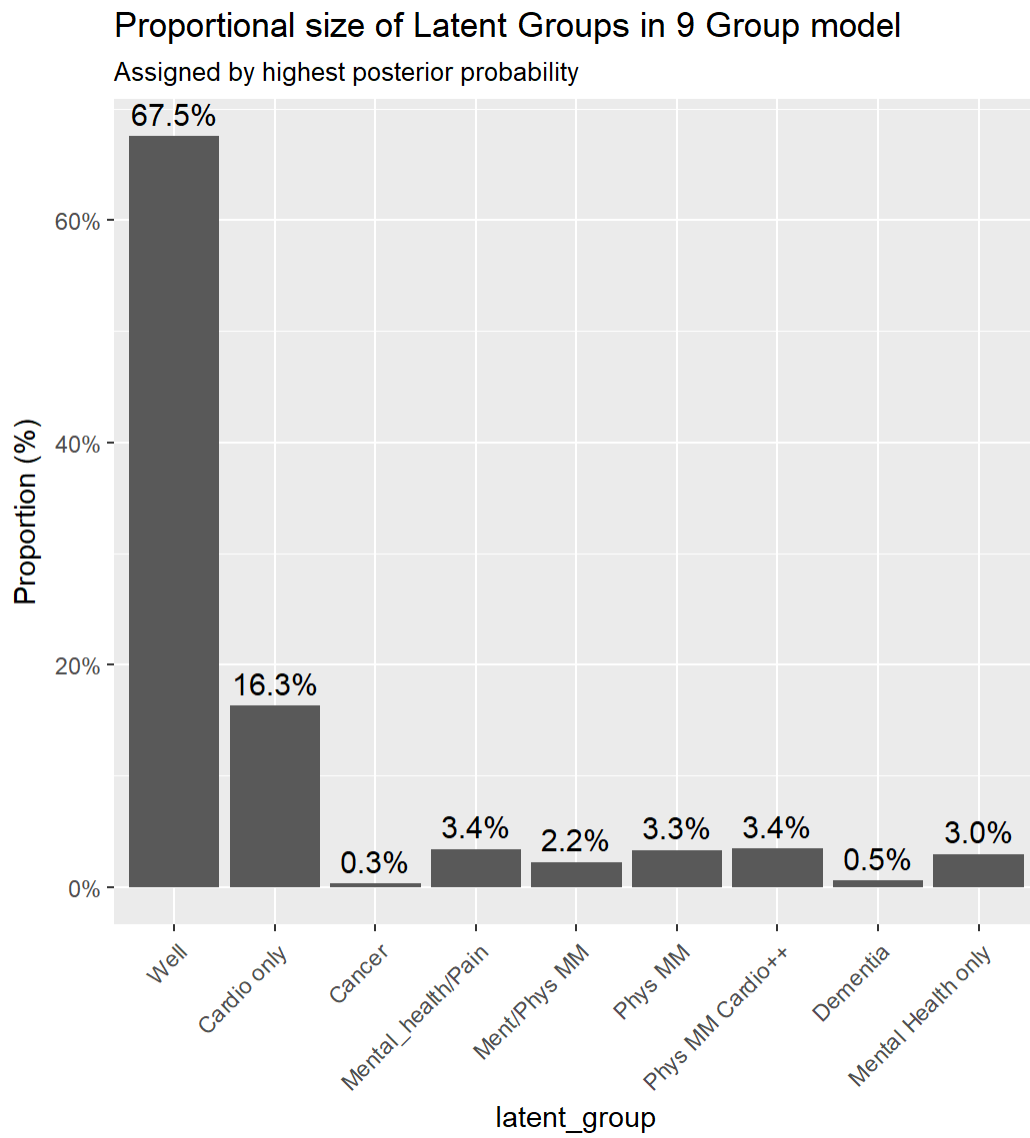
Figure 3.3: Latent Group Proportions

Figure 3.4: Histograms of Age, by Latent Group
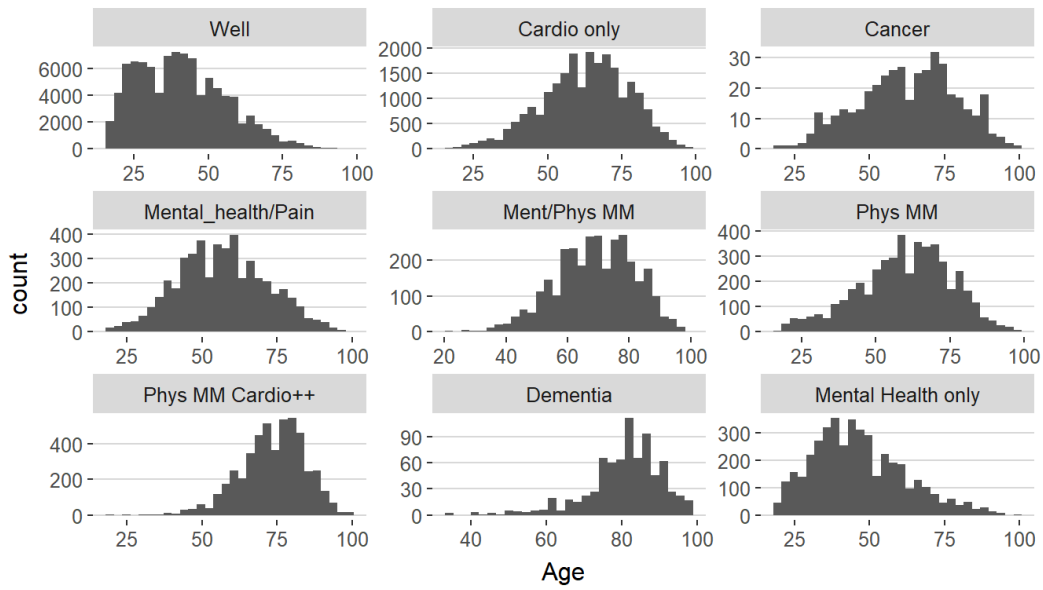
Figure 3.6 shows distribution of deprivation across latent groups by Carstairs Decile. There are clear gradients in the "Mental Health & Pain", "Ment/Phys MM", and "Mental Health only" groups with much higher numbers of people in Decile 10 (most deprived) areas.
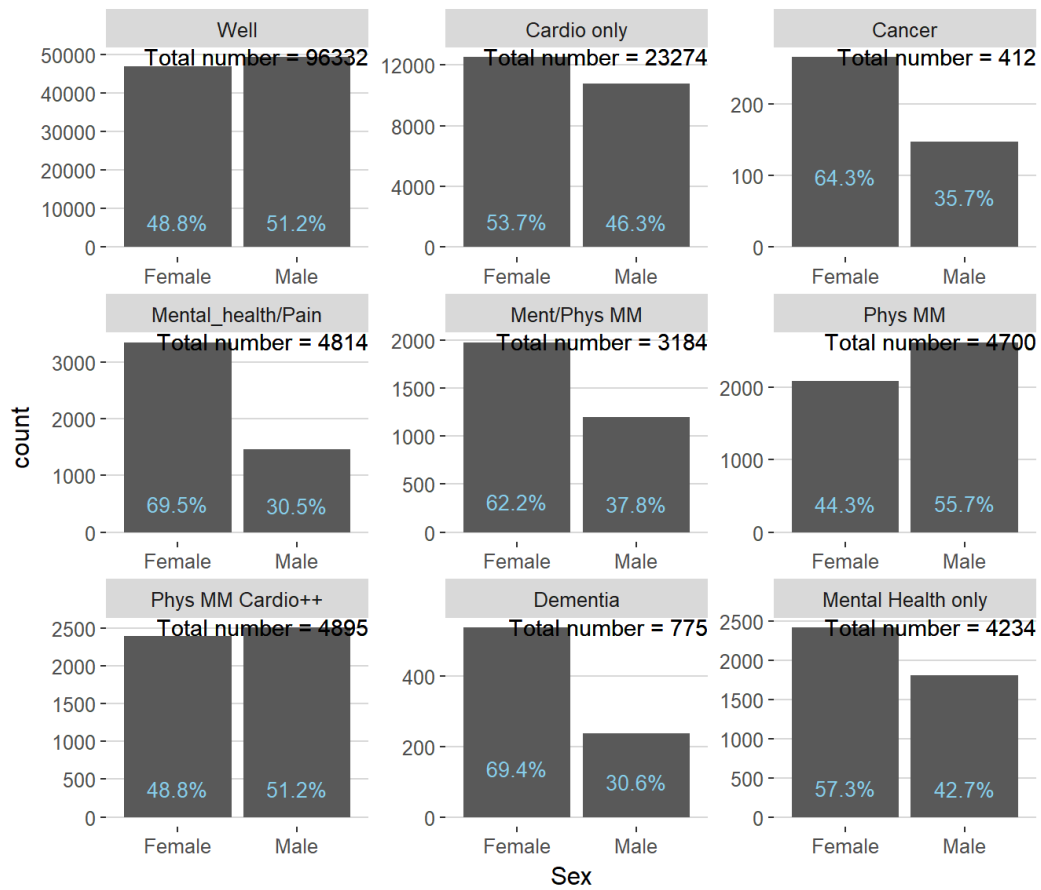
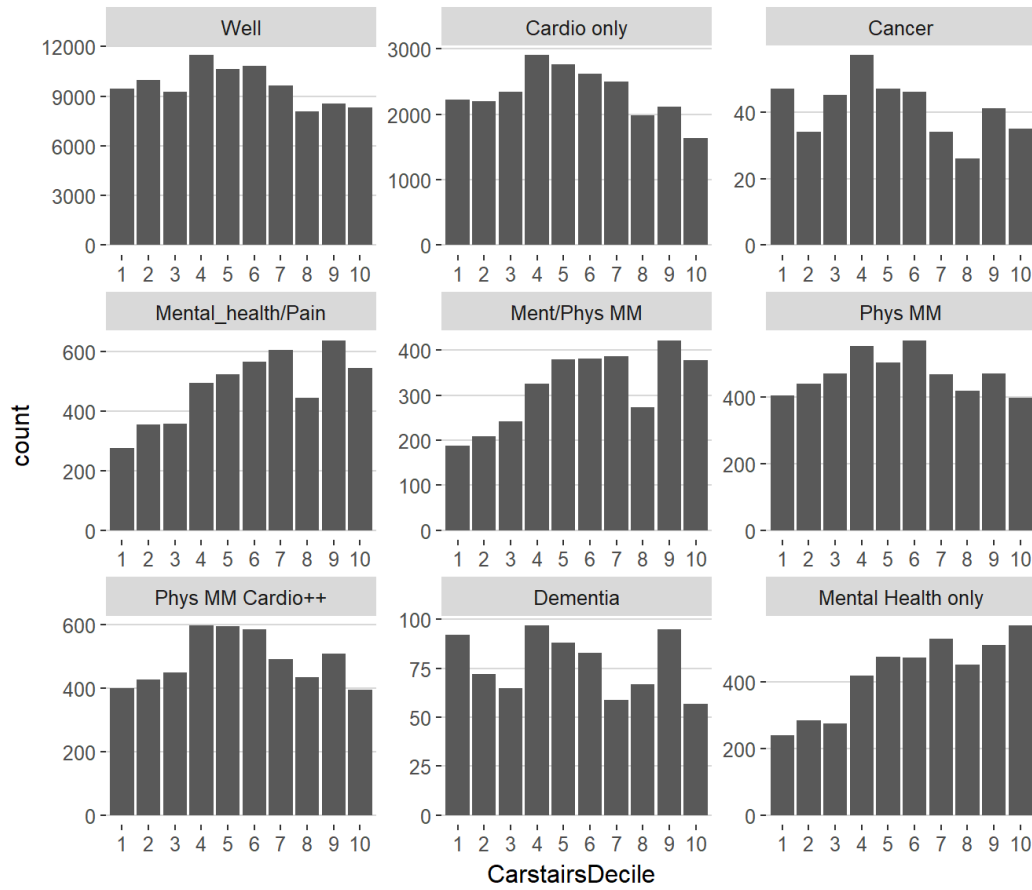Figure 3.5: Count of Sec, by Latent Group - with Proportions

Figure 3.6: Count of Carstairs Decile, by Latent Group

3.5   Discussion

When proposing the two-way clustering method, Ng [2015] applied the technique to Australian survey data of 24 self-reported diseases from n=8841 respondents. These were "clumped" into nine non-overlapping groups of diseases with four latent groups of individuals being identified by the mixture model. Given the different classification of diseases, the nature of how data were collected, and the different populations, it is unsurprising that results from the present study are markedly different. What is of interest is whether the technique provided a meaningful representation of the data which can be used to improve the understanding of multimorbidity within this population.

The first step of the two-way clustering technique resulted in 13 non-overlapping groups being formed. As a result of this process, ten of the diseases recorded in the dataset were excluded from the final groups. Six diseases; Epilepsy, Learning Disability, Sinusitis, Crohns, Anorexia, and Psoriasis/Eczema did not have strong enough pairwise Somer's D correlation statistics with any other disease to be included in the non-overlapping "clumping" procedure. A further four diseases; Diverticular, Prostate, IBS, and Dyspepsia did not appear in any non-overlapping group with the disease with which they had the strongest Somer's D correlation. Identifying which diseases do not co-occur at non-random levels is a particularly interesting finding and adds to the debate about which diseases should be included in any multimorbidity measure.[be explicit – do you think this suggests we shouldn't count these 10 in any MM measure and, if so, why? -NB] Of the 40 diseases present in the SPICE-PC dataset, in this analysis, only 30 diseases co-occurred with enough statistical power to be added to non-overlapping disease groups and considered in the mixture model.

Past research has highlighted associations between; mental health and thyroid problems, mental health and pain, and diseases associated with the metabolic syndrome [Prados-Torres et al., 2014]. As shown in figure 1, there is no pairwise correlation between any mental health diseases and thyroid disorders in the present study. Pain is associated with a large number of conditions, including mental health diseases. Diseases associated with metabolic syndrome such as, hypertension, coronary heart disease, diabetes, stroke, and heart failure all show correlations with each other to varying degrees. Prados-Torres et al [2014] also identified associations between Chronic Obstructive Pulmonary Disease (COPD) and Gastroesophageal reflux disease (GORD) with mental health diseases. No associations with between any respiratory disease and mental health diseases is apparent

in figure 1. The SPICE-PC dataset does not record GORD, however Dyspepsia may be considered a similar diagnosis and has pairwise correlations with both Depression and Anxiety.

The non-overlapping disease groups were named according to the characteristics of the diseases present in each, however many diseases appeared in groups that may not come from similar aetiology. The groups reflect diseases that commonly co-occur and therefore do not always fit into clinically recognisable groups. Individuals are scored as to the number of diseases they have from each group. This results in a loss of some information but the advantage of this method is that it reduces the number of variables in the dataset making the likelihood of identifying a good mixture model much more likely.

Applying a mixture model of multivariate generalised Bernoulli distributions to these 13 non-overlapping disease groups identified nine latent groups as described above. These groups are clinically recognisable with some showing presence of diseases from only one disease group and others illustrating a more multimorbid population. Clear distinctions between mental and physical disease are made enabling individuals to have diseases from both groups. In their systematic review of clustering studies of multimorbidity, Prados-Torres et al [2014] found that included studies reported between three and twenty diseases clusters. From these they found three most common groups of diseases; cardiovascular, mental health, and musculoskeletal. Latent groups in the current study also contain cardiovascular and mental health elements, although they do not reflect any groups that could be identified as musculoskeletal.

Clear sociodemographic patterns were identified in the latent groups. Those classified as belonging to a latent group with mental health involvement such as; mental health/pain, mental and physical multimorbidity, or mental health only, were more likely to be female and from lower deprivation deciles. Two similar latent groups; physical multimorbidity and physical multimorbidity high cardiovascular, had clear age differences with the former more likely to have younger male individuals assigned to it. These findings are similar to simple analyses of the same dataset which identified those in the most deprived areas being more likely to develop physical and mental health multimorbidity 10-15 years earlier than their more affluent peers [Barnett et al., 2012].

3.5.1 Limitations

The two-step method proposed by Ng [2015] enables reduction of dimensions in datasets with large numbers of disease variables making model good identification of mixture models more likely. This, however, results in a loss of detail making interpretation of results more difficult. Report of the item-response probabilities shown in figure 4 identifies that individuals have a probability of having none, one, or two of the diseases in any group. It is impossible to identify exactly which diseases. Hypertension with 13.4% of individuals is the highest reported disease in the SPICE-PC . To what degree this accounts for individuals having one disease in the cardiovascular group across latent classes is unknown.

This is particularly a problem as the non-overlapping groups formed by the two-way clustering method do not always follow recognised clinical groupings. For example, Rheumatoid arthritis is found in the cardiovascular group despite being a connective tissue disorder. It is the only disease in the group that does not directly affect the cardiovascular system. The reason it is found in this group may be due to the association of increased NSAID use with cardiovascular outcomes (ref) resulting in frequent co-occurrence. As some latent groups are classified as "Cardiovascular only", there is a possibility that small numbers of people with only Rheumatoid Arthritis are misclassified. [This is could be down to nomenclature and I maybe need to revisit group names. It does not get rid of the problem that for the group with high probs for the cardio/rheum disease we can't distinguish which disease the individual has]

When clustering individuals, fitting a finite mixture model of multivariate generalised Bernoulli distributions makes the assumption that the indicator variables used to identify latent groups are independent. In a dataset containing medical conditions such as e.g. Hypertension and Coronary Heart Disease, or Atrial Fibrillation and Stroke, this assumption is clearly violated. However, ignoring the independence assumption for multivariate categorical variables often results in better fit than when more complicated techniques are applied to account for non-independence of indicator variables [Ng, 2015, Hand and Yu, 2001, Topchy et al., 2005].

Results presented here account for 10% of the SPICE-PC dataset due to the heavy computational requirements of fitting the finite mixture model. Confirmation of results on the whole dataset is required.

3.5.2   Future research

Sociodemographic comparison in the current study was limited to visualisation of histograms. More detailed reports of measures of central tendency and comparison of latent groups with sociodemographic variables such as Carstairs decile with logistic regression is warranted. SPICE-PC data also contains variables on lifestyle factors such as smoking status and alcohol intake. These variables should be included in further comparisons.

A further calculation offered in the two-way clustering technique [Ng, 2015] is the calculation of a multimorbidity score to each latent group and to each individual in the dataset based on their disease profile and posterior probabilities. Such as score would be continuous in nature and would offer the benefit of comparison with sociodemographic variables such Carstairs score or Age. Such comparisons would be amenable to well-recognised regression techniques.

Part 1 of the two-step method involves reducing the dimensions of the dataset to be amenable to mixture modelling. Using the outcome of this first step, the non-overlapping groups, Ng's technique for clustering individuals should be compared to Latent Class Analysis which is also a suitable technique for the nature of the data [Collins and Lanza, 2013]. In supplementary material, NG [2015] compared his two-step method with Latent Profile Analysis and found it inferior to the two-step method. Latent Profile Analysis is a mixture model for continuous indicator variables [Collins and Lanza, 2013] and would not be suitable for the SPICE-PC dataset.

3.6   Conclusion

A novel two-step method for clustering health conditions and individuals was applied to large, population representative, dataset of administrative primary care data. The method found 10 of the 40 conditions in the dataset did not co-occur with other diseases strongly enough to included in further analysis. Thirty conditions were "clumped" into 13 groups of commonly co-occurring conditions and individuals in the dataset were assigned a score depending on the number of disease within each group they had. From this information nine latent groups of individuals were identified with a finite mixture model. These groups reflected varying degrees of physical, mental and physical/mental

multimorbidity and showed sociodemographic patterning.

Chapter 4

Data

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

[OECD, 2006]

Administrative data is data that is generated when individuals use 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 administerd [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 [Harron, 2016, Fleming et al., 2012] and is being increasingly used in social science research [Atherton et al., 2015, Bell et al., 2016].

There are two main methods of linking data from disparate sources; deterministic matching and probabilistic matching [Harron, 2016, Fleming et al., 2012]. Where differing datasets possess common unique identifiers, determinsitic matching simply links data using this identifier. Probability matching methodology can be employed in the abscence of a common unique identifier [Harron, 2016, Fleming et al., 2012]. Using this method, a probability of two records matching correctly in calculated based on how well the records match based on a set of common partial identifiers such as name, date-of-birth, or postcode [Harron, 2016, Fleming et al., 2012].

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 [Pavis and Morris, 2015, Fleming et al., 2012]. 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].

4.1 Infrastructure

4.1.1 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 the Urban Big Data Centre (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, 2017]. UBDC has six partner universities; Edinburgh, Bristol, Cambridge, Reading, Sheffield, and Illinois-Chicago. It is also one of three UK research institutions that offer help for researchers using linked administrative data - the others being; The Administrative Data Research Network (ADRN) and the Farr Institute.

The linkage project describe in this thesis was completed with the assistance of UBDC's controlled data service which in turn liaises closely with the electronic Data and Research Innovation Service (eDRIS), provided by the Information Services Division (ISD) of NHS National Services Scotland (NSS). *More on controlled data plus ref to 4.3.1

4.1.2 electronic Data and Research Innovation Service (eDRIS)

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, services and support for IT and public health intelligence [ISD, 2010]. eDRIS is part of ISD and 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 (described in section 4.3.2), access to the safe haven environment (described in section 4.3.5), and review of analysis outputs to ensure disclosive information cannot be inferred [ISD, 2010].

4.1.3 Analytic Services Division

Describe Ellen and co.

4.1.4 National Records of Scotland

Describe NRS

4.2 Data Sources

4.2.1 Social Care

Descibe Social Care Survey

4.2.2 Population Spine and Death records

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

4.2.3   Prescribing Information System

Describe PIS

4.2.4   Unscheduled Care Data

Describe USC data mart

4.3   Information Governance

Use ADRN legal issues book Also use SG priniciples for DL

4.3.1   Research Approvals Commitee

UBDC RAC process

4.3.2   Public Benefit and Privacy Panel

PBPP Process

4.3.3   Ethics

College ethics and waivers

4.3.4   Data sharing agreement

DSA description

4.3.5   Safe Haven environment

describe safe haven

4.4 Timeline

Describe timeline of approvals process - major hurdles and barriers.

Chapter 5

Methods

5.1 Cohort

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

5.2 Linkage process

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 6 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 statisitics were used to answer research questions.

Chapter 6

Renfrewshire Council Pilot Project

6.1 Background

Pilot project to get first look at social care data to determine structure and definitions. Main linkage project to use cross-sectional social care data - *is this reflective of social care provision throughout the year?* Also able to attach datazone and demogrpahic variables - is there variation in amounts of care across these variables? (potentially drop this second part)

6.1.1 Aims

- Describe the temporal variation in levels of care within financial years
- Describe variation in social care provision in Renfrewshire Council area by Age, Gender, and socioeconomic position. (potentially drop)
- Assess the quality of social care data for research purposes (potentially drop)

6.1.2 Research Questions

1. How does social care use vary within and across financial years 2006/07 - 2015/16?
2. Is there variation in the amount of social care delivered in the Renfrewshire Council area by Age, Gender, and Socioeconomic position? (?drop)

6.2 Methods

Describe manipulation of variables to produce summary stats.

Describe which methods used to summarise variation in care

Link to RAC approval process described in chapter 4 section 4.3.1. Also link to use of safe haven described in section **??**. Re-mention ethics. Note that PBPP not required fir this pilot

6.3 Results

There were n number of individuals in receiving homecare 2006 - 2016

n individuals received more than 50 hrs of homecare per week during the 10 years representing n packages of care. These are likely to be supported accomodation packages etc etc. (cut/paste from analysis re SCS return). These individuals were therefore dropped from analysis and all subsent results are based on n number of individuasls with packages less than 50 hrs per week.

Figure 6.1 shows the number of people receiving types of home care and number of people receiving care from different providers.

Table 6.1 Shows descriptive statistics of care packages in the dataset

Table 6.2 shows the breakdown of individuals receiving home care by financial year with annual difference and percetage calculated

Time series created 6,138,451 observations of home care at weekly intervals.

There were n number of continous care packages.

Table 6.1: Care package descriptive statistics

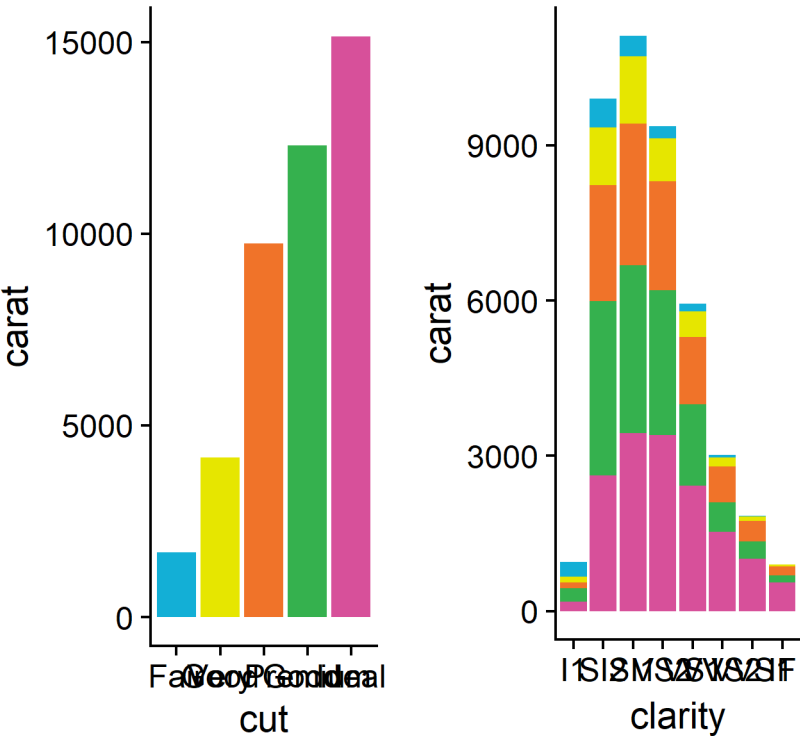|	Min	Max	Mean	Standard Deviation	Range	1st Quartile	3rd Quartile	NA
Package hours								
Package Duration								
Total Hours per week per individual								

Figure 6.1: Number of people receiving home care by type and provider

Table 6.2: Home care by Financial year

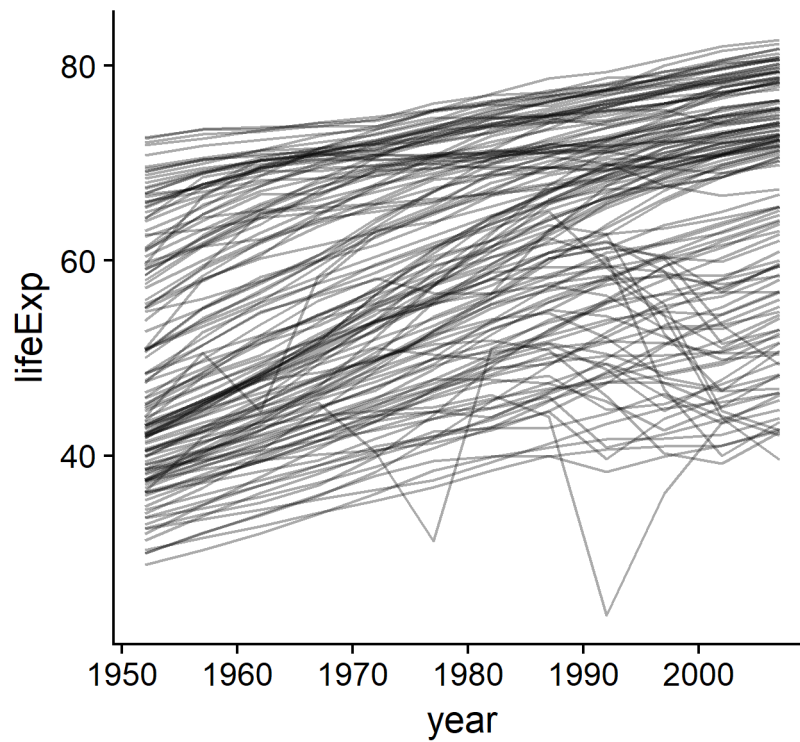| Financial Year	Number receiving home care	Difference from previous year	Percent change %
2006/07	3138	NA	NA
2007/08	3052	-86	-2.74
2008/09	3033	-19	-0.62
2009/10	2905	-128	-4.22
2010/11	2412	-493	-16.97
2011/12	2265	-147	-6.1
2012/13	1952	-313	-13.82
2013/14	2289	337	17.26
2014/15	2327	38	1.67
2015/16	2299	-28	-1.20

Figure 6.2: Temporal trend of care packages

n number of people experienced a break in care during the study period.

Figure 6.2 plots the hours of home care for each individual over the 10 year period.

Table 6.3 shows the absolute number of individuals who had no change, an increase, or a decrease in home care hours for each financial year with average increase/decrease wih sd calculated.

Facet Plot Of Histogram with designated bins 40 for 20 hrs spread as in Figure 6.3.

Table 6.3: Change in home care hours by year

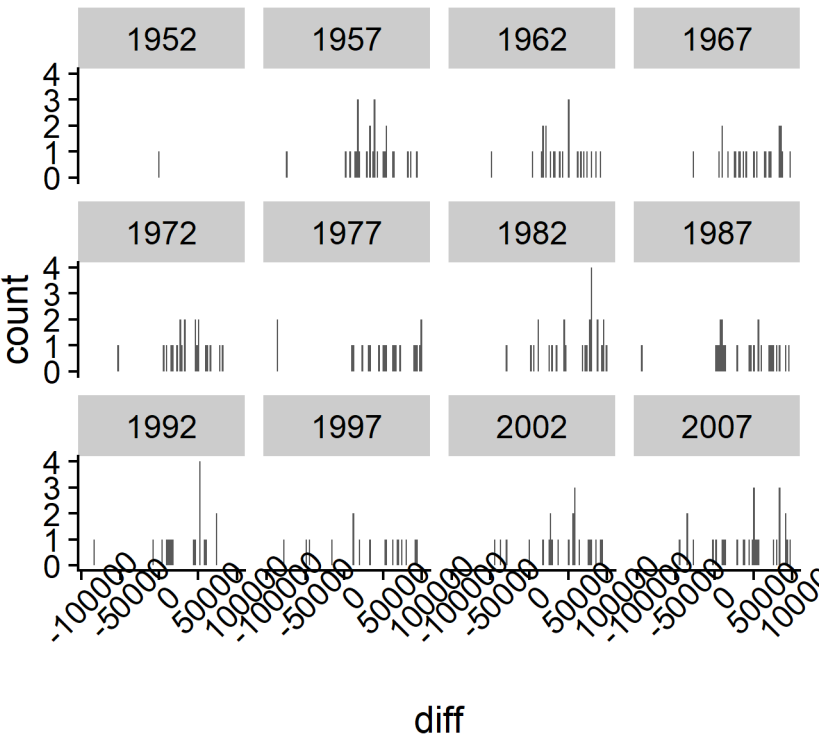|	Total N	No change in hours N(%)	Increase in hours N(%)	Average increase in hours mean(sd)	Decrease in hours N(%)	Average decrease in hours mean(sd)
2006/07						
2007/08						
2008/09						
2009/10						
2010/11						
2011/12						
2012/13						
2013/14						
2014/15						
2015/16						

Figure 6.3: Histogram of difference in care package hours, by year

6.4 Discussion

Implications - particular focus on variation in care throughout the year and whether care provided in a census week is a robust measure for research purposes (based on Renfrew results)

Limitations - One council only. Different collection and reporting methods across LAs etc etc.

6.5 Conclusion

Chapter 7

Results

7.1   Introduction

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

7.2   Data Linkage

Percent matches etc.

7.3   Characteristics of cohort

Long table

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

7.4 Social care and multimorbidity

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

7.5 Geographic variation in social care

Accounting for MM

7.6 Social care, multimorbidity, and unscheduled health care use

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

7.7 Social Care, multimorbidity, and mortality

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

7.8 Discussion

7.9 Conclusion

Chapter 8

Conclusion

Reccomendations :-

- Standardised score reflecting need/frailty/vulnerability required to accurately assess access to care (OECD pp181)

- disaggregate SCS a little - distinguishing reablement and intermediate care from LTC important!

- Measure outcomes relevent 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

Appendix A

Title A

Testing, testing. One-two, one-two.

Appendix B

Title B

Let's see what this looks like

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