Chapter 1

Literature Review

The aims of the thesis are exploratory in nature and, as such, no specific question is defined for the literature review. Instead, the aim is to scope literature relevant to main themes outlined in the introduction and identify where links can be made in separate fields. This chapter summarises academic and policy literature relevant to the main thesis themes regarding a) multimorbidity b)social care, c) the interaction of health and social care services, and d) administrative data linkage. 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 four parts following the main themes listed above. Section 1.1 describes why multimorbidity is important in the context of health and social care services and then provides an overview of academic literature and policy documents regarding multimorbidity and its definitions, measurement, and impact on health inequalities.

Section 1.2 focuses on social care from a number of perspectives: varying definitions of the term, differing international models of care delivery, how eligibility for social care is determined in the UK, how resources are allocated in Scotland, and finally selected social theories of eligibility and resource allocation.

Section 1.3 outlines the policy framework regarding health and social care services and the historical policy context of service integration. 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.

The final, short, section provides an overview of literature on the emerging research paradigm of administrative data linkage. The section discusses what linkage involves, its benefits and drawbacks, and finally briefly outlines the data sources selected for this project with a justification for their inclusion.

Give the nature of this review the search strategy for literature employed varying methods. The first section on multimorbidity leant itself to traditional database-based

(Medline, Web of Science, Google Scholar) searches for key terms: "multimorbidity", and "comorbidity" in relation to the subsection headings: "definitions", "measurement", and "health inequalities". As an overview of the whole topic and subsections was desired, initial searches were limited to include only systematic reviews and, where necessary, pertinent references from citation lists were retrieved and included. "Grey" literature was also searched for via websites of prominent think-tanks (e.g. the King's Fund), and Research groups (e.g. the International Research Community of Multimorbidity).

Literature on social care was mostly found from "grey" sources such as the King's Fund and Nuffield Trust, with a "snowball" method from reference lists employed to identify further relevant reading. In addition, the Social Care Institute for Excellence' resources list was also investigated for pertinent literature. As much of the focus of this section related to policy aspects, relevant publications from UK and Scottish Governments were sought.

Health and social care interaction and integration have recently been topics of high policy interest have been extensively covered by think-tanks. As a result, much literature in this section is informed by reports from these sources and the references contained within them. Section 1.3.3 included specific database searches for studies specifically investigating interactions in health and social care. Very few empirical studies in this area exist, although one recent systematic review helped guide further literature searches.

Background information on administrative data linkage was informed by reports produced by the Administrative Data Research Network (ADRN) and references contained within.

Initial searches of literature were conducted in Spring 2016 with continual updates. A formal update of all aspects was completed in May 2019. The review provides a detailed summary after each section with a synthesis of all sections contained in the chapter conclusion.

1.1 Multimorbidity

This section reviews relevant literature regarding multimorbidity. Firstly, an overview of the main themes found in the literature is provided before more in depth reviews of three main themes arising from this: concepts and definitions of multimorbidity, measures of multimorbidity, and finally multimorbidity in the context of health inequalities.

1.1.1 Context

At first sight, the definition of multimorbidity as the presence of two or more health conditions in one individual appears clear and concise. In fact, there are many competing concepts and definitions of multimorbidity in research literature resulting in confusing messages regarding epidemiology, measurement, and treatment (OECD, 2011; Almirall and Fortin, 2013; EGPRN, 2013; Lefevre et al., 2014; AMS, 2018). One systematic review found the prevalence of multimorbidity in the general population to vary between 13.1% - 71.8% in studies where different definitions had been employed (Fortin et al., 2012). Another, concentrating on primary care populations, reported variation of prevalence between 12.9% and 95.1% (Violan et al., 2014).

Despite this, it is generally accepted that multimorbidity is the norm for individuals with at least one chronic condition (OECD, 2011) in both high-income and low-to-middle-income countries (Afshar et al., 2015). It disproportionately affects those of lowest socioeconomic position (OECD, 2011; AMS, 2018) who can develop multimorbidity up to 10 to 15 years earlier than their most affluent counterparts and are more likely to have a mix of physical and mental health conditions (Barnett et al., 2012). Females are also disproportionately affected although evidence suggest this association can vary across countries (AMS, 2018).

There is also a consensus that multimorbidity is associated with a number of negative outcomes including: higher mortality (Gijsen et al., 2001; OECD, 2011; Jani et al., 2019), reduced quality-of-life (Fortin et al., 2004, 2005; OECD, 2011), reduced functional status (Kadam and Croft, 2007; OECD, 2011), and increased psychological distress (Fortin et al., 2006). All of these are likely contributors to the association of multimorbidity with increased use of healthcare services (Gijsen et al., 2001; Salisbury et al., 2011; OECD, 2011).

This raises a particular challenge to those responsible for delivering healthcare which has been traditionally structured around treating single diseases. This is partly due to the fact that many clinical guidelines are based on the results of Randomised Clinical Trials (RCTs) investigating the efficacy of a single treatment on a single disease (Moffat and Mercer, 2015; WHO, 2016a; Watt, 2017; AMS, 2018; Oliver, 2018a). The fact that those with multimorbidity are routinely excluded from such trials means the

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effectiveness of treatments (and presence of adverse events) in "the real world" are often unquantified (Moffat and Mercer, 2015; WHO, 2016a; Watt, 2017; AMS, 2018; Oliver, 2018a). The increased use of services also has financial implications for societies grappling with constraints imposed by austerity measures (Allen, 2018).

One potential solution to improve the efficiency of healthcare delivery is to focus resources in community and primary care services rather than expensive secondary care (WHO, 2015). Here, care can be focussed in a more holistic sense by identifying goals and targets in partnership with the individual themselves (WHO, 2016b; Watt, 2017; Mair and Gallacher, 2017). Services provided by healthcare professionals with generalist rather than specialist skills (such as multi-disciplinary teams in primary care), are best placed to deliver this type of care and can foster preventative, cost-effective measures for those with, or at risk of developing, multimorbidity (OECD, 2011; Moffat and Mercer, 2015; WHO, 2016a, 2016b; Watt, 2017; AMS, 2018; Rijken et al., 2018).

This is particularly true where primary care services are provided on a universal basis which widens the scope of access to service (OECD, 2011; WHO, 2016a, 2016b). That said, universal coverage in itself does not guarantee equitable access to care. First coined by Julian Tudor-Hart (1971), the Inverse Care Law describing reduced availability of good medical care in areas of highest need has been shown to be alive and well in countries with universal primary care coverage (Watt, 2002, 2018; Mercer and Watt, 2007; McLean et al., 2015; WHO, 2016b).

Given these many challenges, a recent Academy of Medical Sciences report (2018) highlights a number of areas where research into multimorbidity should be directed including: identifying trends and patterns of multimorbidity (including clusters of conditions), the determinants of condition clusters, prevention strategies, risk-assessment strategies, and healthcare (re)organisation. The NICE guideline on multimorbidity assessment and management (2016) suggests research should focus on: organisation of (primary) care, community assessment, medicines management, and the prediction of life expectancy. Absent from both these guidelines, save passing references, are consideration of the effect of multimorbidity on social care services.

Inclusion of social care as a factor associated with multimorbidity is justified by an earlier NICE guideline entitled, "Older people with social care needs and multiple long-term conditions" (2015). As the title suggests, the guideline frames social care needs as an additional dimension to the assessment required for people with multimorbidity. There are no recommendations, or indeed acknowledgement, of the effect multimorbidity may have as a driver of need for social care. Social support, along with other patient-relevant outcome measures (PROMs) (such as functional disability), are often included as independent variables indicating a modifying effect on multimorbidity rather than outcomes where multimorbidity may be a contributing factor (Nicholson et al., 2019). Recognition of this fact has led to calls for the social context of individuals with multimorbidity to be more fully investigated (Zullig et al., 2016; Smith et al.,

2018).

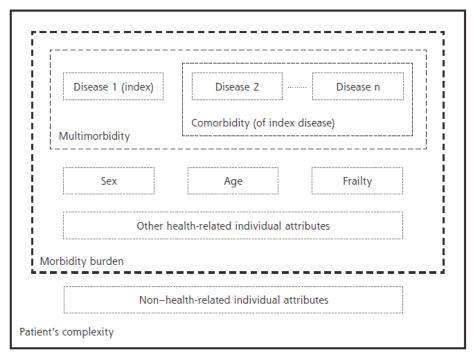
Whilst this gap in knowledge is the justification for the research carried out in the thesis, and further explored later in this chapter, the remainder of this section will expand on the themes outlined above with reference to multimorbidity. Those themes with particular relevance to the thesis are covered. Firstly, an overview of literature regarding the complexity of the concept and definition of multimorbidity is presented. This is followed by a review of the many methods that have been employed to measure multimorbidity. Finally, an overview of relevant literature regarding health inequalities in the context of multimorbidity is also presented with a specific focus on UK based literature.

1.1.2 Concepts and definitions

Despite the increasing importance of multimorbidity on health care systems, there has been some debate internationally in finding an agreed definition of the term or concept (Almirall and Fortin, 2013; Lefevre *et al.*, 2014; AMS, 2018). This section outlines the differing terms and concepts used in academic literature.

One source of confusion that is commonly found in research relating to two or more health conditions is in the numerous ways in which it is labelled including: polymorbidity, polypathology, pluripathology, multipathology, and multicondition (Almirall and Fortin, 2013). The two most frequently used terms, multimorbidity and comorbidity, are often (incorrectly) used interchangeably despite a distinction being articulated over 20 years ago (van-den-Akker et al., 1996; Nicholson et al., 2019). Comorbidity was originally described by Fenstein (Feinstein, 1970, p. 467) who stated, "In a patient with a particular index disease, the term co-morbidity refers to any additional co-existing ailment." Van Den Akker et al.. (1996, p. 65) separated this term from multimorbidity which they described as , "...any co-occurrence of medical conditions within a person." In this sense, multimorbidity does not rely on the presence of a primary, or index, disease but refers to the overall state of multiple illnesses. The recent addition of a distinct MeSH heading for multimorbidity that can be used to search medical literature databases signals the importance of the difference in these terms (previously, only comorbidity was available as a MeSH heading) (Tugwell and Knottnerus, 2019).

An aide to further clarify this distinction is a broader conceptual framework provided by Valderas et al.. (2009) (figure 1.1) who characterise the construct of the multiple terms found in the literature into four main groups; (a) comorbidity – additional diseases in the context of an index disease, (b) multimorbidity – more than one disease within an individual (without reference to an index disease), (c) morbidity burden – total impact of physiological dysfunction linked to disease severity and (d) patient complexity – the effect of non-health characteristics (e.g. deprivation, culture, environment) on the whole.



Comorbidity: presence of additional diseases in relation to an index disease in one individual.

Multimorbidity: presence of multiple diseases in one individual.

Morbidity burden: overall impact of the different diseases in an individual taking into account their severity.

Patient's complexity: overall impact of the different diseases in an individual taking into account their severity and other health-related attributes.

Figure 1.1: Conceptual framework of co/multimorbidity. Valderas et al.. (2009)

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

Relying on the term for multimorbidity in figure 1.1 does not, however, completely solve the problem of definition. Intuitively, the term signifies more than one condition, but which conditions should be included? The findings of three systematic reviews have highlighted the myriad ways researchers have approached this problem (Groot et al., 2004; Diederichs et al., 2011; Huntley et al., 2012). Each review aimed to collate evidence of measurement tools in comorbidity or multimorbidity but from different perspectives: De Groot et al. (2004) searched for comorbidity indices to inform research into Multiple Sclerosis, Diederichs et al. (2011) specifically searched for multimorbidity measurement indices, whereas Huntley et al. (2012) searched for measures of multimorbidity used only in primary care research. The systematic reviews found 13, 39 and 17 exclusive ways of measuring multimorbidity or comorbidity respectively. Adding even

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further complexity, the number of medical conditions included in these measurements varied from 4 to 102 (Diederichs *et al.*, 2011).

More recently, a systematic review focused on which diseases, risk factors and symptoms are included in varying definitions of multimorbidity (Willadsen *et al.*, 2016). Whilst the majority of included studies in the review indicated multimorbidity as the presence of two or more conditions, Willadsen *et al.* (2016) found the total number of diseases, risk factors, and symptoms used varied from 4 to 147. Of the 167 included articles in the review, 115 different ways of defining multimorbidity were identified (Willadsen *et al.*, 2016). Another review found the number of conditions used in measures of multimorbidity varied from from 5 to 335 (Violan *et al.*, 2014).

Acknowledging the perverse impact this has on advancing knowledge through research, attempts have been made to find a unifying definition of multimorbidity that can be employed to facilitate synthesis of research findings. These included:

- 1. "being affected by two or more chronic health conditions in the same individual" (WHO, 2016)
- 2. "...any combination of chronic disease with at least one other disease (acute or chronic) biopsychosocial factor (associated or not) or somatic risk factor." (EGPRN, 2013)
- 3. "more than 1 long-term condition with any of the following:-
 - Difficulty managing treatments or day-to-day activities.
 - Care from multiple services and requiring care from a new service
 - Both long-term physical and mental health conditions
 - Frailty
 - Frequent use of unplanned or emergency care
 - Prescription of multiple, regular medicines"

(NICE, 2016)

In the NICE guideline (2016) there is an agreement with other commentators (Mercer et al., 2009) that basing the definition of multimorbidity on two or more health conditions only does not fully capture a clinically meaningful picture of the concept. The guideline highlights the fact that many people defined as multimorbid in this way may not be ill and have excellent quality of life requiring little or no health care input (NICE, 2016). Whilst definitions two and three above attempt to address this problem, it could be argued that they are, respectively, ambiguous and over-complex.

The most recent attempt to standardise a definition of multimorbidity has been provided with the AMS which in less ambiguous than that provided by the EGPRN and less complex than that posited by NICE.

"The co-existence of two or more chronic conditions, each one of which is either

- A physical non-communicable disease of long duration, such as cardiovascular disease or cancer
- A mental health condition of long duration, such as mood disorder or dementia
- An infectious disease of long duration, such as HIV or hepatitis C"

(AMS, 2018)

Although multimorbidity may seem to be an intuitive thing to understand, defining a useful concept of the term has proved to be much more difficult (OECD, 2011). The definition articulated by the AMS has the benefit of being relatively concise and clear and will be used to describe multimorbidity hereon in the thesis.

1.1.3 Measurement tools

Adding further complexity to conducting multimorbidity research is the many ways in which it can be measured. This section summarises literature explaining why this is so and presents recommendations from relevant systematic reviews.

Until recently, there were two main ways to measure multimorbidity: simple disease counts or using an index. Indices apply weights to either prescribed medications or medical conditions, sometimes along with other factors, in an attempt to capture the effect of disease severity on multimorbidity (which is crudely consistent with the term morbidity burden (figure 1.1)) (Groot et al., 2004; Diederichs et al., 2011; Huntley et al., 2012). Advanced computing power has added a third method of multimorbidity measurement through the identification of non-random clusters of medical conditions via statistical algorithms (Prados-Torres et al., 2014). These clusters can be used to help understand the aetiology of multimorbidity, assess the impact of clusters on health outcomes, and which determinants of multimorbidity are associated with clusters (Prados-Torres et al., 2014; AMS, 2018).

In primary care research, the most frequently used measurement is simple disease counts (Huntley et al., 2012). This may be because of the ease with which it can be administered compared to more complex indices e.g. the Charlson index (Charlson et al., 1987) the Chronic Disease Score (CDC) (Von Korff et al., 1992), or the Adjusted Clinical Group (ACG) system (Starfield et al., 1991) and their variations. It could be expected that indices may capture the complexity of multimorbidity more effectively, however Huntley et al. (2012) cite evidence that suggests simple counts of diseases or medications are almost as effective at predicting mortality or health care use in the primary care setting. Disease counts were also found by Huntley et al. (2012) to have good evidence to suggest they provide a robust measure of multimorbidity in relation to quality of life, as does the Charlson index (Charlson et al., 1987).

In many areas, access to data listing disease types for individuals can be problematic. Brilleman & Salisbury (2013) found a count of prescribed medicines was equivalent to a number of more complex indices when predicting primary care use and mortality in an English setting. This confirmed results found in a study of an American cohort (Perkins et al., 2004) where the authors also argued that indices developed in the secondary care setting, such as the Charlson index, should be used with caution in other settings despite adaptions. More recently, Wallace et al. (2016) found little difference between simple (count) and complex (index) measures and that medication-based measures were equivalent to diagnosis-based measures in predicting outcomes. The use of medicine counts as a proxy for multimorbidity offers a good alternative to disease-based counts or measures.

Recent research and academic discussion suggests identification of disease clusters may enable clearer answers to clinically relevant research questions than currently employed measures (Valderas et al., 2009; Holden et al., 2011; Marengoni et al., 2011; Sinnige et al., 2013; Islam et al., 2014; Prados-Torres et al., 2014; Le Reste et al., 2015). In systematic reviews of clustering methods, wide variations in approaches to clustering and characteristics of populations studied have been found(Prados-Torres et al., 2014; Ng et al., 2018). Statistical techniques employed in attempts to identify such clusters include: factor analysis, cluster analysis, the observed-to-expected ratio, multiple correspondence analysis (Prados-Torres et al., 2014; Clerencia-Sierra et al., 2015; Ng et al., 2018), principal component analysis, latent class analysis (Islam et al., 2014; Larsen et al., 2017), and machine learning techniques (Schiltz et al., 2017).

Prados-Torres et al. (2014) identified three groups of patterns common to all included studies in their review despite marked heterogeneity namely; cardiovascular and metabolic diseases, mental health conditions, and musculoskeletal disorders. No studies have yet demonstrated associations between clusters and health or health related outcomes, but identification of clusters remains a research priority in the immediate future (AMS, 2018).

1.1.4 Multimorbidity and health inequalities

A core interest of policy-makers is the effect of ageing populations and multimorbidity on health inequalities. This section provides a broad overview of important themes in health inequality literature, including the effect of health service access on inequalities.

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

There is no biological reason for poorer people to have worse health or to die earlier than the richest (Marmot, 2015). Yet over the last five decades. despite overall trends,

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the most disadvantaged in society have seen slower improvements in health and life expectancy than the most affluent resulting in a widening gap in health outcomes. (WHO, 2008; Scottish-Parliament, 2015; Scottish-Government, 2018). A well documented gradient running from the most affluent to the most deprived has been observed (Graham, 2007; Marmot et al., 2010). There are a number of social determinants of health that contribute to this situation including: access to healthcare, deprivation, quality of housing, and unemployment (Wilkinson and Marmot, 2003; Marmot, 2005; WHO, 2008).

Health inequalities have been observed between and within countries all over the world regardless of relative prosperity (WHO, 2008). The Black report (1980), published by the UK Government almost 40 years ago, brought the subject of health inequality to international attention (Asthana and Halliday, 2006). It both described and attempted to explain the phenomenon present in the UK. Successive governments commissioned subsequent reports that have described similar findings and new insights (Whitehead, 1987; Acheson and Barker, 1998; Marmot et al., 2010). However, there has been little progress in implementing recommendations from these reports and thus little progress in reducing disparities in health (Mackenbach, 2010; McCartney et al., 2012; Frank et al., 2015; Smith et al., 2016).

In the UK, poverty remains the largest predictor of relative ill health and has associations with increased morbidity, multimorbidity, and decreased life expectancy (Baker *et al.*, 2015). People living in deprived areas are more likely to engage in unhealthy lifestyle behaviours, experience multimorbidity at a younger age, and live in overcrowded or unsuitable housing (Shaw *et al.*, 2006; Baker *et al.*, 2015).

A recent analysis released by the Office for National Statistics suggests the gap in male life expectancy between 2015-2017 across local authorities in England was 8.5 years, in Northern Ireland 4 years, and in Wales 4.1 years (ONS, 2018). At 7.2 years the largest gap in male life expectancy in the UK was found in Scotland. Those born in East Dunbartonshire were expected to live to 80.1 years, whereas those in Glasgow City were expected to live 73.3 years (ONS, 2018).

There has been some argument that research on health inequalities has placed an overemphasis on deprivation at the expense of understanding the role of access to health services, particularly in the UK where there is universal health coverage (Hellowell and Ralston, 2016). This is important because e.g. poorer access to primary health care is associated with greater demand for unnecessary admission to hospital which, in turn, is responsible for higher proportions of healthcare expenditure (Rosano *et al.*, 2013; Weston *et al.*, 2016).

Research in countries where markets play a greater role in health care delivery, such as the USA, are more likely to produce literature focusing on service access (Hellowell and Ralston, 2016). This is likely due to the fact that those of lower socioeconomic position are less able to pay market-price for health care - thus reducing access. This

underpins the theory of the "inverse care law" which states that,

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

Tudor-Hart, 1971

This argument, however, does not take into account statistics and research showing that universal health care in itself does not guard against the inverse care law.

People living in more deprived areas have lower life expectancy, are more likely to have multimorbidities and therefore have greater health needs (Baker et al., 2015). However, the poorest neighbourhoods in England have been reported to have 62.5 GPs per 100,000 population whereas the most affluent neighbourhoods have 76.2 per 100,000 (CfWI, 2014). This suggests health provision does not match need - indicating the presence of the inverse care law(Watt, 2002, 2018; Marmot, 2018). Recent planned changes in policy to distribute primary care funding based on population age are likely to exacerbate this situation (Mercer et al., 2012). Indeed, increases in workload with deteriorating proportions of budgets has lead the King's Fund to describe the situation in primary care in England and Wales as, "in crisis" (Baird et al., 2016, p. 3).

In Scotland, the even distribution of GP workforce among the population means GP practices in the most deprived areas need to provide more consultations, for people with greater needs, at the same funding level as practices with fewer resource demands (Mercer and Watt, 2007; McLean *et al.*, 2015). The inverse care law is alive and well in the UK, despite universal coverage.

There are many theories as to why inequalities in health exist across socioeconomic position (Asthana and Halliday, 2006; Nettleton, 2006) with intensive research dating back to the Black report published by the UK government (Black, 1980). Some of these, such as statistical artefact and biological reasons, were rejected as being implausible by the Black report (Macintyre, 1997). To a large extent, epidemiological evidence and theoretical argument has agreed with that view (Asthana and Halliday, 2006; Nettleton, 2006; Mackenbach, 2012; McCartney et al., 2013).

Of the other theories proposed in the last 35 years, there have been many critiques and numbers of proposals (Asthana and Halliday, 2006; Nettleton, 2006; Peckham and Meerabeau, 2007; Mackenbach, 2012; Smith et al., 2016). Whilst arguments over which theory is most plausible to explain the cause of health inequality, most researchers agree on ways to remedy disparities in health outcome. These are the redistribution of income, wealth, and political power (Asthana and Halliday, 2006; Nettleton, 2006; Katikireddi et al., 2013; Smith et al., 2016). Although health services have an important role to play, it is the "upstream" policies of redistribution that will make the biggest impacts in improving health outcomes across society (Asthana and Halliday, 2006; Katikireddi et al., 2013; Scottish-Parliament, 2015; Smith et al., 2016). Whilst this has been known for some time, government policies in the UK to date have not addressed these issues

and have thus failed to make meaningful improvements in health inequalities (Peckham and Meerabeau, 2007; Mackenbach, 2010; Frank et al., 2015).

1.1.5 Summary

Multimorbidity is most commonly defined as the presence (or co-occurrence) of two or more long-term conditions in an individual. Debate continues as to the type and number of long-term conditions that should be included to provide a meaningful concept for individuals, clinicians and healthcare organisations. The most recent definition posited by the AMS aims to capture the broad concept of multimorbidity whilst remaining concise and clear.

There are myriad ways of measuring multimorbidity with various counts, indices, and clusters. The best way to measure multimorbidity for research depends on the setting and questions to be answered. Where good data is difficult to come by, simple counts of diseases or medicines have been shown to have proved comparable to predicting mortality and health care use as more complicated indices.

Evidence suggests multimorbidity is increasing in prevalence and has a strong socioe-conomic pattern. This pattern has implications for health inequalities, particularly through increased need and access to services. Empirical evidence of the inverse care law in UK primary care poses hard questions for policy makers in the context of financial austerity.

Very little research has been conducted into the effects of multimorbidity on social care services, despite acknowledgement that an interaction is likely to exist. Given the increasing prevalence of multimorbidity, understanding the relationship with social care services is of paramount importance in order for policies and services to be adequately allocated.

1.2 Social Care

Before exploring any interaction between multimorbidity and social care, it is necessary to first explore the concept of social care in isolation. This section reviews literature on definitions of social care, how social care is delivered in an international context, how resources for social care are allocated in the UK, how eligibility criteria are determined in the UK, and provides an overview of relevant social theory literature with regards to service allocation and access.

1.2.1 Context

As with multimorbidity, there are many ways of defining social care. What would be described as social care in the UK (Humphries *et al.*, 2016) is often called long-term care (LTC) in other countries (Deusdad *et al.*, 2016). The next section (1.2.2) investigates in detail the differing definitions of social care, but in general the term refers to services provided to those that struggle with activities of daily living to enable them to live as full a life as possible (BMA, 2014; Deusdad *et al.*, 2016; National-Audit-Office, 2018).

There are four ways in which social care can be provided to those in need; informally via family or community, formally via voluntary non-profit organisations, formally via the state, or formally via for-profit organisations (Munday, 2003). In Europe, increasing demand from users has led to many welfare systems being unable to adequately provide care (Pavolini and Ranci, 2008; Colombo et al., 2011). Changes in demography, the labour market, democracy, and values have all contributed to the increasing pressure on formal care services (Anttonen, 2005; Colombo et al., 2011; OECD/EU, 2013). A recent study found that increased demand for services was fuelled not only by the increase in the overall number of older people, but also the fact that they live longer periods of their life with care needs (Kingston et al., 2017). Some argue this should be considered a triumph of modern medicine but raise concerns for individuals and societies about how to provide and pay for these additional care needs (Dilnot, 2017).

There is wide consensus that lower birth rates and higher proportions of older people mean that a gap has emerged in the number of adult children able to provide informal care to their parents (Munday, 2003; Anttonen, 2005; Pavolini and Ranci, 2008; Colombo et al., 2011; Robertson et al., 2014; Deusdad et al., 2016). Traditionally, informal care was provided by women. As gender equality improves, more women are employed in non-domestic settings which has reduced the pool of informal social care available (Anttonen, 2005). Anttonen (2005) also cites changes in societal attitudes from "familism" to "individualism" as having an impact on informal care resources. These combined factors mean that informal care services are no longer as readily available and formal care mechanisms are increasingly required to provide social care. Pressures on these services has seen increased discussion and comparison of models of care

across Europe over the last 20 years (Anttonen and Sipilä, 1996; Munday, 2003; Sapir, 2006; Fernández-Alonso and Jaime-Castillo, 2016).

These issues are particularly salient given financial constraints in public funding following the financial crash of 2008. (Humphries et al., 2016; Deusdad et al., 2016; Bottery et al., 2018). In countries where a large proportion of services are provided from the public purse, austerity measures have resulted in cuts in the number of people receiving social care (Burchardt et al., 2015; Humphries et al., 2016; Deusdad et al., 2016). Indeed social care provision in England covers only the poorest of individuals with the highest care needs (Ham, 2019). There is little research detailing the impact this has had on those no longer receiving formal care services although increases in avoidable admissions to, and delayed discharges from, hospital in the UK are one outcome the cuts are thought to contribute to (Charlesworth and Thorlby, 2012; Humphries et al., 2016).

In the UK there is an important difference between social care and health care funding and access. Health care is universally provided free at the point of need by the NHS. Social care is commissioned by local, rather than central, government and is means (with the exception of free personal care in Scotland) and needs-tested (Burchardt et al., 2015, 2018; Humphries et al., 2016). There are, however, many areas where the services overlap (BMA, 2014). These arrangements are poorly understood by the public, many of whom only find out they are required to pay for social care at the moment they first need it (Humphries et al., 2016; Bottery et al., 2018).

Some argue that social care has been relegated in terms of policy importance because is not directly provided by national government (Burchardt et al., 2015). The most recent UK government social care green paper has been delayed on numerous occasions (Atkins, 2019) which may indicate political apprehension in addressing the difficult decisions that are required in order to find a funding solution for social care (Bottery et al., 2018; Ham, 2019). This may be due to the negative effect on electoral success encountered by political parties willing to discuss these difficulties at the 2010 and 2017 general elections (Bottery et al., 2018). Nevertheless, state intervention of some kind is the only way of addressing the gap between supply and demand as private insurers are unwilling to enter the social care market due to the unpredictability of risk (Dilnot, 2017; Bottery et al., 2018; Ham, 2019).

In 2002 the reccomendations of a Royal Commission on long term care for older people (Sutherland, 1999) were ignored by the UK government. Scotland was the only part of the UK to implement the policy of free personal care for those over the age of 65 - regardless of means (Bowes and Bell, 2007). The policy, which is still subject to a needs-test, has more recently been extended to all adults (Scottish-Government, 2019). Although the removal of a means-test for free personal eases some of the financial burden for users, access to care still regulated through the needs-test. Overall numbers of individuals in Scotland receiving social care continues to fall suggesting eligibility

criteria for receiving care are tightening. Moreover, free personal care does not remove the most expensive outlay in terms of social care - namely the high costs of residential care (Bowes and Bell, 2007).

This section reviews literature on these broad issues in more depth in five sections. The first section outlines definitions of social care and related terms. Next, the varying ways social care is delivered internationally are investigated. The third and fourth sections review literature on resource allocation and eligibility criteria respectively, where necessary distinguishing between policy differences in Scotland compared to the rest of the UK. The final section presents literature relating to social theory of resource allocation, eligibility for services, and the impact of social care on health inequalities.

1.2.2 Definitions

This section identifies the different ways social care has been defined in literature in the UK and internationally. Further definitions relevant to the thesis, particularly in relation to social care sub-services provided in Scotland are also discussed.

1.2.2.1 Social Care

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). 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"— ... 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, ..." (The Health and Social Care Act 2012 c7, Part 3, Chapter 1, Section 65, Subsection 4)

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

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

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

(2007, p. 4)

Huxley et al.. (2007) are critical of this service-based definition and argue that social care is intended to improve general well-being for those that are in need. As quality of life is an important factor of well-being, Huxley et al.. (2007) argue that wider issues regarding environment and the quality of public and private services also play an important role in social care. Indeed, Daly and Lewis (2000, p. 287) argue that social care is "...an activity and set of relations lying at the intersection of state, market, family (and voluntary sector) relations."

This view is reflected in an aspirational constitution for social care published by an independent, cross-party think-tank (Bartlett and Guglielmi, 2009). The authors argue that all citizens should have an equal ability to live and control a full and active life. Where this is not possible the state should have a duty to provide the necessary help, in whatever form that is required, to individuals who require it.

These definitions benefit from being somewhat succinct but fail to articulate the range of interdisciplinary services that are sometimes required for social care users. Two further definitions, provided in international reports, go some way to addressing this shortfall. The OECD and the EU jointly published a report on long term care for older people discussing much of what may be described in the UK as social care. In the report, long term care 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)

The second definition provided by Colombo et al. (2011) classifies social care as:-

- 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.

Both this and the previous OECD/EU definition clearly capture the broad range of services that can be associated with social care that are only partially provided in other definitions. They acknowledge that social care can include a number of components including personal, nursing care and help with other domestic activities and implicitly identify that social care can include components of *health* care. The latter definition also articulates the variety of settings where this can take place and the provides examples of the differing professional capacities of individuals that may provide care. These additional references result in a more complete (and still succinct) definition and will be used for the purposes of this thesis (although the use of the term "low-skilled" to describe carers is contentious).

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.

1.2.2.2 Scottish sub-service definitions

The Social Care Survey (SCS) is collected annually by the Scottish Government to provide statistics of the type and amounts of social care delivered by each of Scotland's 32 local authorities (Scottish-Government, 2017c). The SCS is used for empirical analysis in later chapters of this thesis and a description of its collection is provided in section ??. However, whilst many of the sub-services of social care delivered by local authorities are self-explanatory (e.g. shopping or laundry), some sub-services require a fuller explanation which are provided here.

The term "home care" can refer to a number of services delivered to individuals in their own home (Gatherum and MacAskill, 2017) which are described in table 1.1.

The SCS also identifies individuals who are specifically receiving "personal care". As previously discussed in section 1.2.1, personal care is provided for free in Scotland but not in the rest of the UK. Given this variation, accurately defining personal care is important. The legislation implementing free personal care introduced by the then Scottish Executive articulated a clear definition which constitutes six dimensions and is used to identify eligibility for receipt of free care (Cavaye, 2006, p. 256).

• personal hygiene: washing etc.

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Type of home care	Definition
Care at Home (Mainstream)	The aim of care at home is to help vulnerable people of all ages live independently and securely in their own homes by providing personal and housing support services. Care at home services are provided very much on each individual's own circumstances and needs.
Reablement	Provides support and encouragement to help keep up or increase the skills and confidence needed to be able to return home after a stay in hospital or after an illness. Most people referred for care at home will receive a reablement service in the first instance to help support and improve independence. Long term services can be provided following reablement if ongoing support is needed.
Rapid Response	Rapid intervention care at home aimed at preventing hospital admissions or facilitating hospital discharges while longer term care packages are put in place.
Community Mental Health	Care at home service designed to support service users of the Community Mental Health team to live independently in the community
Extra Care Housing	Care at home based on site for tenants of Local Authority extra care housing complexes
Housing Support	Care at home services to support service users to maintain tenancies and live independently in the community
Overnight Services	Care at home provided through the night for service users requiring 24 hour support (overnight defined as between 7pm - 7am)
Meals Service	Provision of either hot or cold meals to a service user

Table 1.1: Definitions of home care types

- 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.

Other services the SCS collects data on are receipt of "community alarm" and "other telecare services" (Scottish-Government, 2017c). Individuals are defined as receiving a community alarm if they are

"A person in receipt of a technology package which consists of a communication hub (either an individual home hub unit or part of a communal system e.g. the alarm system within sheltered housing), and a button/pull chord/pendant which transfers an alert/alarm/data to a monitoring centre or individual responder."

Whereas an individual is defined as receiving telecare is they are

"A person in receipt of a technology package which goes over the basic community alarm package..., and includes any other sensors or monitoring equipment e.g. (not an exhaustive list): linked pill dispensers, linked smoke detectors, linked key safes, bogus caller buttons and door entry systems, property exit sensors, [or] extreme temperature, flood, falls, [or] movement detectors."

(Scottish-Government, 2017c, p. 30)

The final service requiring specific definition is that of "self-directed support" (SDS). This service was introduced in Scotland in 2013 to provide eligible social care users with more choice in how they received their care via four options: a) by choosing and arranging their own support and managing the budget to do so as a direct payment,

b) by choosing the type of support they received and delegating the local authority or other organisation to arrange the care and manage the budget, c) by delegating the local authority to choose and arrange the support, or d) a mixture of each of the previous options (Audit-Scotland, 2017; Gatherum and MacAskill, 2017). Notably, the recent Audit Scotland report into SDS (2017) identified very small numbers of individuals have been offered or taken up any of these options.

1.2.3 International models of social care

In a report for the OECD, Colombo *et al.* (2011) categorised the varying models of social care employed internationally into three main groups with subdivisions as shown in Table 1.2.

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

¹ Spain and Greece have less well developed formal care services

Table 1.2: Models of social care in OECD countries adapted from Colombo et al. (2011)

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

The tax-based universal models, also known as the Nordic model of care, have strong local-government influence in both the raising of funds and delivery of services (Munday, 2003; Sapir, 2006; Colombo et al., 2011; Fernández-Alonso and Jaime-Castillo, 2016). Overall responsibility remains with national government which also contributes funds, often dependent on local population need and structure (Colombo et al., 2011). Public long-term insurance schemes are mandatory in the countries that employ them, although the age at which citizens begin to contribute varies (e.g. only over 40s contribute in Japan) (Colombo et al., 2011; Forder and Fernández, 2011; Eleftheriades and Wittenberg, 2013). These models have found it increasingly difficult to fund provision and have either increased user-payments or decreased coverage in recent years (Forder and Fernández, 2011; Eleftheriades and Wittenberg, 2013; Robertson et al., 2014). In Belgium, social care is viewed as a health risk and is financed through the health system with a cap on user-contribution. This results in a medical (rather than social) model of care delivery, mostly provided by nurses (Colombo et al., 2011).

In contrast to universal models described above where a single system is in place for social care delivery, mixed social care systems employ either; a) universal coverage via different sources/sectors or b) a mixture of universal and means-tested benefits (Colombo *et al.*, 2011). Whilst acknowledging the wide variation in systems, Colombo *et al.* (2011) identify three subdivisions of mixed system models of social care as shown in table 1.2.

Parallel universal schemes provide social care via two or more sectors (e.g. nursing care via health provider and personal care from a non-healthcare source as seen in Scotland) (Colombo et al., 2011). Major differences exist between countries in how this is delivered in practice with varying degrees of coverage. Income related universal benefits provide needs-based universal coverage of social care but benefits received vary according to income (Colombo et al., 2011). France provides a good example of this system where cash benefits are need and income based - benefits are paid at six levels of dependency, those with higher incomes are paid proportionally less and top-up care costs themselves (Glendinning and Bell, 2008; Colombo et al., 2011). The final subdivision of mixed social care models has some universal entitlements provided alongside means-tested services e.g. free provision of nursing care with means-testing for personal care.

Colombo et al. (2011) include Spain and Greece in this final subdivision of mixed social care models but note these countries have formal care systems that are much less developed than elsewhere in the OECD. Sometimes referred to as the Mediterranean model, informal care from family and other sources constitutes the main form of social care in these countries (Munday, 2003; Sapir, 2006; Verbeek-Oudijk et al., 2014; Fernández-Alonso and Jaime-Castillo, 2016). As this role is traditionally carried out by women, the Mediterranean model has attracted criticism from a feminist perspective (Munday, 2003).

The final model in Colombo $et\ al.$'s (2011) classification of social care in OECD countries is the means-tested safety net model (Table 1.2). 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 (Glendinning and Bell, 2008). A cap of £72,000 total contribution was to be introduced in 2016 following the recommendations of the Dilnot Commission (Dilnot, 2011; Eleftheriades and Wittenberg, 2013), however this plan was subsequently dropped by the UK government in 2017 (BBC-News, 2017; McKenna, 2017).

Of the three models of social care described in this section, universal systems can be seen as having a number of advantages over the other two (Glendinning and Bell, 2008; Colombo *et al.*, 2011). Sharing the burden of social care provision among the entire

population, either via general taxation or mandatory insurance schemes, results in a reliable, predictable source of finance enabling states to plan more effectively (Glendinning and Bell, 2008; Colombo et al., 2011; Forder and Fernández, 2011). Mixed systems of social care can still result in considerable costs for those that require care, whereas the costs to individuals in the means-tested system can be "catastrophic" (Colombo et al., 2011, pp240). The means-tested system can also be perceived as unfair for those that need to sell assets (such as a house) to pay for care, particularly when there is variation in eligibility criteria within countries (Glendinning and Bell, 2008; Colombo et al., 2011; Forder and Fernández, 2011; Charlesworth and Thorlby, 2012; Eleftheriades and Wittenberg, 2013). A particular advantage of a universal social care system is that it,

"...generally reduces utilisation of more expensive health care services and professionals (e.g. hospital care, doctors) for long-term care needs, for example by making "social hospitalisation" of frail people with [social care] needs more difficult."

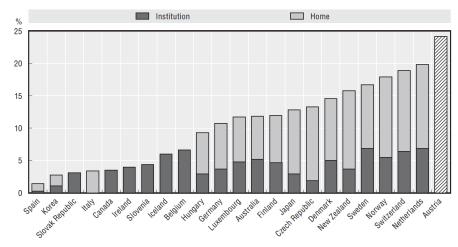
(Colombo et al., 2011, p. 222)

Given the pressures on state budgets and the desire to adequately fund care services, this seems a particularly useful benefit of the universal coverage model of social care.

Disadvantages of universal systems are that they are generally more expensive to the state than other models of social care and can reduce the amount of informal care provided by relatives for elderly family (Colombo *et al.*, 2011; Eleftheriades and Wittenberg, 2013). The comprehensiveness of coverage can be over-burdensome for the state with a number of countries recently having to cut service or increase user-contributions to compensate for increasing demand (Forder and Fernández, 2011; Charlesworth and Thorlby, 2012; Eleftheriades and Wittenberg, 2013; Robertson *et al.*, 2014).

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; Verbeek-Oudijk *et al.*, 2014).

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 1.2) derived from OECD data that shows the proportion of over 65s receiving some form of social care across countries for which data is provided. The chart shows that having a universal or mixed system of social care provision (as described above) does not absolutely influence the number of people receiving care. For example, South Korea employs a universal (insurance-based) system and has one of the lowest proportions of older people receiving care, whereas Switzerland has one of the highest whilst employing a mixed system



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

Source: OECD Health Data 2010.

StatLink *** http://dx.doi.org/10.1787/888932401577

Figure 1.2: Older recipients of long-term care services as a share of the over 65 population, 2008

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.

1.2.4 Eligibility for social care in 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, p.10

A significant difference between Scotland and the rest of the UK is that no means-test is included for receipt of personal or nursing care whether this is provided at home or in a residential setting (Bowes and Bell, 2007; Burchardt et~al., 2018). In England this has resulted in only those with the lowest wealth and greatest need receiving any form of public-funded care (Bottery et~al., 2018). An individual will only receive full state funding for their care if their wealth assets are below a lower threshold of £14,250. Partial funding is provide where assets are between this figure and an upper threshold of £23,250. Any individual with assets over £23,250 must pay for all aspects of their care (Humphries et~al., 2016; Bottery et~al., 2018; The-King's-Fund, 2018; Care and Social, 2019).

Adding confusion to this system is the definition of "asset" in the means-test which varies depending on the type of care required. If a permanent move to a care home is required then home-owners' houses are included as an asset. If home care is required then the house is not included as and asset (Bottery et al., 2018; The-King's-Fund, 2018). Estimates suggest over half of all care home fees in England are paid by individuals (or their families) with approximately £1bn in fees paid annually from private sources (Humphries et al., 2016).

Across the UK there are variations in means testing thresholds and services to which they are applicable as described in a King's Fund report (2018). The lower and upper threshold values in the means test in England are the same in Northern Ireland but only apply to personal and nursing care - accommodation costs being free from the means-test. Wales has a more generous upper threshold of £40,001 applicable to all forms of care with no lower threshold. The lower and upper thresholds of £16,500 and £26,500 in Scotland are only applicable to accommodation costs (which can be the most expensive outlay) (Bell and Bowes, 2006; The-King's-Fund, 2018). All over the UK, means-tests have not changed in line with inflation meaning less people are eligible as time progresses e.g. in England, financial thresholds are 12% lower in real-terms in 2018/19 compared with 2010/11 (Thornby $et\ al.$, 2018; Phillips and Sampson, 2018).

Regardless of threshold level, some individuals in all four UK nations (estimated as 1-in-10 in England) will be unlucky enough to have to pay very high care costs (over £100,000 towards social care over their lifetime in some cases) which cannot be insured against (Dilnot, 2011; The-King's-Fund, 2018). These costs have been described as "catastrophic" (The-King's-Fund, 2018) and are widely seen as unfair (Dilnot, 2017).

Given these issues with means-tests, the criteria governing eligibility via needs-testing for receiving social care are important - and contentious. Needs-testing in all UK countries is carried out via assessment by a social worker. In Scotland, personal care is provided free for those that are deemed eligible but there is considerable variation across local authorities in how eligibility is determined.

In 2010 the Scottish Government published a report written in conjunction with the Convention of Scottish Local Authorities (COSLA) (Scottish-Government, 2010) and included the recommendation that the National Eligibility Framework developed by the Sutherland review into free personal and nursing care (2008) should be applied across all social care services. The framework has four criteria for assessing risk in relation to a person's care needs: critical, substantial, moderate and low (Scottish-Government, 2015b). The critical and substantial levels of risk indicate social care needs should be addressed immediately or imminently, whereas a moderate level of risk may indicate either some or no services being required. There is no explicit description of "severity", or which care needs fall into each category. 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 the authorities have a big influence on how individuals

can access social care services.

Equity of access to services is directly influenced by the eligibility framework. Indeed, the strategy for self-directed support (Scottish-Government, 2010, p. 20) acknowledges this and states that such a framework "...can result in resources being narrowly focused on individuals with acute needs." However, the report goes on to state that growing demand and finite resources requires some form of eligibility assessment but this should not have a disproportionate effect on any one group of people requiring care.

The eligibility framework allows each local authority to set thresholds for access to care in line with local priorities and resources. This has the effect that access to services varies across differing council areas. The potential for regional variation is again acknowledged by the strategy for self-directed support (Scottish-Government, 2010, p. 20) which states that, "...further work will be undertaken by the Scottish Government and COSLA to assess whether there is merit in establishing national thresholds for access to formal support across all client groups."

Acknowledgement of problems with eligibility criteria and the promise of "further work" to be undertaken by the Scottish Government and COSLA is repeated in practitioner guidance on Self-Directed Support published in 2014 (Scottish-Government, 2014, p. 19) and that , "...it remains the case that local authorities should operate eligibility criteria to determine whether or not an individual assessed as having social care needs can access formal support and if so, which of their needs are to be met by that support."

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

The Scottish National Eligibility Framework has striking similarities to that formerly used in England and described in Fair Access to Care Services (FACS) produced by the Social Care Institute for Excellence (SCIE) (2013). Exactly the same nomenclature is used to describe the eligibility categories of need. Newton and Browne (2008) critiqued a previous version the FACS guidance and found similar issues to those raised above regarding regional variations in service and concentration of services on those with the highest need. Their paper describes further issues with access to social care in the context of social theory described by Lipsky (1979) and "street-level bureaucracy" (discussed in section 1.2.6) where intentional and unintentional judgement of entitlement by social care workers have an impact on whether an individual receives care or not. 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 (articulated by

the theory of "candidacy" also discussed in section 1.2.6). Although no citation is provided to back-up this argument, it has certainly been described elsewhere (Matthews and Hastings, 2013) and sits well in the broader discussion of inequitable access to services (Tudor-Hart, 1971; Le Grand, 1982; Hastings *et al.*, 2014).

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

In practice, the most likely outcome is that the minimum threshold that local authorities will have to provide care will be similar to the "critical" level of the National Eligibility Framework previously used in the FACS guidance (Abrahams et al., 2014; Burchardt et al., 2015) (and similar to that used in Scotland). This will legalise a shift that has already been occurring in England where fewer numbers of LAs are providing care for those with "moderate" needs and only providing care for those with "critical" needs (Charlesworth and Thorlby, 2012; Abrahams et al., 2014; Burchardt et al., 2015). Burchardt et al., (2015) state that only 2% of English LAs will have to widen their care threshold whereas 12% could now, legally, tighten care provision as a result of the Care Act.

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

More recent research suggests that those with moderate care needs are much more likely to have unmet need as informal care is unable to fill the gap left by formal care service (Burchardt *et al.*, 2018; Brimblecombe *et al.*, 2018)

A similar picture has been seen in Scotland where most councils now only provide care assessed as having Critical or Substantial risk (Audit-Scotland, 2016c). Absolute numbers of people receiving home care has steadily fallen over the last 10 years from under 70 per thousand aged over 65 in 2006 to under 50 per thousand in 2015 (Audit-Scotland, 2016c). At the same time, the number of hours of care provided has increased reflecting the "intensification" of services discussed above (Scottish-Government, 2017c). There are wide variations in the number of hours of home care provided per population across local authorities (Audit-Scotland, 2012; Scottish-Government, 2017c). 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, 2017c). 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), McLeod 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 - a view also shared by Audit Scotland (Audit-Scotland, 2012).

1.2.5 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). Whilst the previous section discussed how eligibility is determined, this section outlines how funding is allocated to those that are assessed as eligible for care. The strategies local

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authorities have employed to provide services during budgetary constraint are also discussed.

Local authority funding is provided by the Scottish Government via a block general revenue grant made up of a number of components in addition to revenue raised via local taxes and charges (King et al., 2007; Scottish-Government, 2013). The majority of the centrally provided grant is calculated via a formula known as the Grant Aided Expenditures (GAE) which accounts for over 80% of the general revenue grant (Scottish-Government, 2016a). The formula for GAE is calculated using what is called a "client group approach" and is based on 89 services provided by local authorities (Scottish-Government, 2016a). A national figure for each service is set and each local authority receives a percentage of that figure based on estimates of the number of people that use that service (a capitation) and other secondary indicators such as area deprivation or rurality (Smith, 2003; Scottish-Government, 2016a). For example, funding for primary school teachers is based on the number of children in primary education (primary indicator) and adjusted to take into account the percentage of pupils in small schools (secondary indicator) (Scottish-Government, 2016a).

The use of formulae to allocate public expenditure has potential to improve efficiency in spending and equity of distribution (Smith, 2003). Equity of distribution is achieved via the explicit nature of a formula framework with transparent methodology that can be debated and amended (Smith, 2003). The formula for the "green book" settlement was agreed with the Convention of Scottish Local Authorities (COSLA) (Scottish-Government, 2013). However, as King et al. (2007) note, GAE grants to local authorities are estimates of relative, rather than absolute, spending needs in that area. The "green book" reporting the annual settlement for local authorities in Scotland stresses that the values allocated for different services are not budgets or targets and that local authorities are free to spend resources (other than ring-fenced monies) as they see fit (Scottish-Government, 2016a). In effect, "...the capitation payments seek to offer comparable public sector organisations the opportunity to deliver some average level of service, assuming average responses to social and economic circumstances, and an average level of efficiency" (Smith, 2003, p. 309).

The "green book" outlines seven main areas of local authority expenditure from which the 89 services mentioned above are derived; Education, Social Work, Roads & Transport, Leisure & Recreation, Cleansing & Environment, Elections & Taxation, and Other Services (Scottish-Government, 2016a). Spending allocation for social care comes under the social work heading which is subdivided into 23 subcategories of services. Of these, nine are directly related to social care as defined for the purposes of this thesis (the others being based on e.g. children's services);

- service for home based elderly
- residential accommodation for the elderly
- casework and related administration: elderly

- services for people with disabilities
- casework and related administration: people with disabilities
- independent living fund
- carers support and respite services
- care home fees
- personal and nursing care for older people

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

The GAE formula has been in place for some time (initially outlined in 1992 (Scottish-Government, 2016a)). The more recent issue facing local authorities in terms of finance has been cuts following the 2008 financial crash. In the financial year 2016/17 the overall grant to Scottish local authorities was cut in real-terms by 5% which added to a cumulative real-term cut of 11% since 2010/11 (Audit-Scotland, 2016a). Authorities have been managing this pressure by reducing spending in all areas of their budgets with the exception of social work (Audit-Scotland, 2016a). £3.1 billion was spent on social work by Scottish local authorities in 2014/15 - an increase of 3% since 2010/11 and a third of all council spending (Audit-Scotland, 2016c). However, given the 5% decrease planned for 2016/17 Audit Scotland (2016a) warned that social work (and specifically social care) budgets are now likely to be cut, resulting in a decrease in the quality of service (Audit-Scotland, 2016c).

Although overall budgets have slightly increased, efficiency savings have been made by contracting the provision of social care to the private and voluntary sectors (Audit-Scotland, 2016c). In 2008, over 70% of home care clients in Scotland received care provided only by a local authority. In 2017, this figure was less than 50% - with private and voluntary sector organisations increasingly providing home care purchased by the local authority (Scottish-Government, 2017b). However, as discussed in section 1.2.4, savings have also been made by tightening eligibility criteria with the result that absolute numbers of individuals receiving care has fallen over the same period (Audit-Scotland, 2016c).

These budgetary pressures are difficult for local authorities to manage, but what is the outcome on service users? Using the "pro-rich/pro-poor" nomenclature initially used by (Bramley *et al.*, 2005) (and discussed in section 1.2.6.2), Gannon *et al.* (2017)

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 (2017) assigns older persons social work services as "pro-poor" along with local authority public transport but does not distinguish between the two in analysis. It is therefore difficult to dis-aggregate the specific effect of cuts on social care from the report particularly, as shown above, as there was an increase in spending between 2010/11 and 2014/15. Nevertheless, cuts expected to social care budgets from 2016/17 (Audit-Scotland, 2016a) are also likely to have a disproportionate effect on those with lower socioeconomic position.

1.2.6 Social Theory

1.2.6.1 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, free from organisational oversight (Lipsky, 2010). As a result, street-level bureaucrats control, "...the nature, amount, and quality of benefits and sanctions provided by their agencies." (Lipsky, 2010, p. 13). Using the term, "street-level" suggests that the theory is concerned with power, where it resides, and who wields it (Hupe et al., 2016). Street level bureaucrats can be teachers, police officers, nurses, social workers, or any other worker providing a public service (Hupe

et al., 2016) and their "...decisions..., the routines they establish, and the devices they invent to cope with uncertainties and work pressures effectively become the public policies they carry out" (Lipsky, 2010, p. xiii).

Evans(2010) and Ellis (2011) 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.

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 1.3

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

Table 1.3: Seven stage model of candidacy

This is a much broader theory than that of street-level bureaucracy and focusses on the barriers and enablers individuals face/use when accessing services but in other respects it is trying to do the same thing - exploring how front-line interactions shape outcomes. 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 1.3. "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.

1.2.6.2 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 postwar welfare spending. The book compares the distribution of public expenditure and outcomes across health, education, housing, and transport. It concludes, as highlighted in the quote above, that those with higher socioeconomic position benefited disproportionately from government social services spending across all sectors. Indeed, "...there persist substantial inequalities in public expenditure, in use, in opportunity, in access and in outcomes" (Le Grand, 1982, p. 4).

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

"pro-poor" (parks, environmental services) (Bramley et al., 2005 cited in; Hastings et al., 2014). Whether a service is more likely to be used by more or less affluent citizens is important in terms of resource allocation - particularly when services are being cut as shown by Gannon et al. (2017) and discussed further in section 1.2.5.

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 1.4

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

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

Table 1.4: Six channels of middle class advantage

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 1.4 suggesting the theories of Le Grand (1982), described above, should not be discounted.

There has been no research on whether the inverse care law (discussed in section 1.1.4) 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. It has, however, been suggested that the inverse care law does exist for social care (Oliver, 2018b). The reasoning for this is based on the premise that local authorities with larger proportions of less affluent residents are unable to generate the same income as richer local authorities, resulting in worse service access. This has not been empirically proved for social care specifically, but Hastings et al. (2017) found that cuts to local authority spending since 2010 do have a disproportionate effect on the most disadvantaged local authorities.

1.2.7 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 meanstested 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.

CHAPTER 1. LITERATURE REVIEW

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.

1.3 Health and Social Care

As has been shown, multimorbidity and social care are two areas of increasing policy importance. This section describes literature concerning the interaction between health and social care services. For some time it has been internationally recognised that the boundaries between these services are blurred and that increasing demand means the sustainability of current funding models is in jeopardy. There is also the view that effective social care services have the potential to prevent use of expensive health services. In Scotland, health and social care services were legally integrated in 2016 with the hope of achieving this aim. The section firstly provides some context to the policy background that led to the integration of health and social care. Secondly, a detailed description of the structural changes that the legislation implemented is described. Finally, Literature investigating the effectiveness of health and social care integration and the interaction of theses services is reviewed.

1.3.1 Context

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:-

- a) Increasing demand for public services are due not only to demographic reasons but also because of a failure to tackle inequality
- b) Spending on public services is unlikely to return to 2010 levels until 2026
- c) Public services in 2010 were fragmented with no coordination and often different services duplicated work
- d) 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 focusing on prevention, and improving the 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 (Audit-Scotland, 2018b). Previous policies aiming to increase cooperation between NHS health boards and local authority provided social care included; the Joint Future Group (2000), the Community Care and Health (Scotland) Act (2002), Community Health Partnerships [2002], and the Integrated Resource Framework (Ferguson et al., 2012).

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

The inclusion of the last of these objectives - to formally legislate for the integration of health and social care - was in response to the fact that 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 service users (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.

As previously discussed, 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). In contrast, 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 1.2, 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 1.3.2 describes these changes in more detail.

1.3.2 Health and Social Care Integration

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

[Scottish Government, 2011, pp.2]

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

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

Integration was 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 the avoidance of the consequences of fragmented & uncoordinated care (Burgess, 2012, 2016; Audit-Scotland, 2015, 2016b, 2018b; Scottish-Government, 2015c, 2016c). However, despite streamlining of budgets, there remain significant barriers in achieving these aims (Audit-Scotland, 2015, 2016b).

One of the key principles of the legislation was 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) later renamed to an Integration Authority (IA) (Audit-Scotland, 2018b). This authority is responsible for the delivery of care and develops a strategic plan for how services will be implemented (Scottish-Government, 2015c; Burgess, 2016; Kaehne et al., 2017; Audit-Scotland, 2018b). The IA 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, 2018b; Burgess, 2016). The full extent of integrated services delegated to the IA varies from area to area but as a minimum adult social care services, adult community health services, and some adult acute health services (particularly those that incur lots of emergency admissions) are delegated (Scottish-Government, 2015c; Audit-Scotland, 2015, 2018b; Burgess, 2016; Kaehne et al., 2017). The IA 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, 2018b; Kaehne et al., 2017).

Under the lead agency model, a plan is made to divide the delivery of specific health and social care services to either the NHS board or a local authority (Scottish-Government, 2015c; Audit-Scotland, 2015, 2018b; 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, 2018b; Kaehne et al., 2017). The lead agency plan between NHS Highland and Highland Council is the only one in place in Scotland - all other areas favouring the body corporate model (Scottish-Government, 2015c; Audit-Scotland, 2015, 2018b; 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 IAs will be of significant interest.

One of the main aims of integration is to reduce unscheduled healthcare use, in particular unplanned admissions to hospital, which can be an indicator of a lack of social care support in an area (Scottish-Government, 2015c; Audit-Scotland, 2015, 2016b, 2018b). 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 well-being questions from surveys and statistics collected from routine data on service use (Scottish-Government, 2015a, 2016b; Kaehne et al., 2017).

In a report published immediately prior to IAs 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. More recently Audit Scotland has reported that, although some improvements had been made, the core aims of integrated financial and strategic planning have not occurred in IAs and that the main barrier to achieving these aims remained the lack of collaboration at the institutional level (2018a). This view is shared by Pearson & Watson (2018) who interviewed 70 professionals involved in Scottish IAs, and also concluded that the potential gains of integration are not yet being realised.

1.3.3 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]

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 that integration strategies have this desired outcome (Stewart et al., 2003; Petch, 2009, 2012b; Burgess, 2012; Robson, 2013; Damery et al., 2016; Cameron, 2016; Kaehne et al., 2017). Much research has been conducted on the structural elements of health and social care integration with little emphasis on outcomes for service users (Petch, 2012a). There has also been little attention paid to those who deliver front-line services, indeed, ".. a preoccupation with the process and mechanisms of joint working has diverted attention away from the central role played by the professions, who appear sceptical of the aims of these initiatives and distrustful of their professional colleagues" (Cameron, 2016, p. 12).

The lack of evidence around outcomes may be partially due to the difficulty in collecting data that can measure the interaction between health and social care services. A 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. Spiers et al. (2018) recently produced a systematic review of this evidence focussing on the effect of any form of social care use on healthcare utilisation.

Of the twelve studies included in the systematic review, only seven were graded to be of "good" quality and high heterogeneity made comparison of studies problematic (Spiers et al., 2018). Where studies did report similar outcome and exposure measures, higher spending on social care or provision of nursing and residential care showed associations with reduced hospital admissions, delayed discharges, length of hospital stay, and secondary health care spending.

Two other studies not included in Spiers $et\ al.$'s(2018) review have been published in the last 10 years. 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.

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.

Spiers et al.'s(2018) systematic review is a welcome addition to the debate on the interaction between health and social care services. However, they rightly point out the difficulty in synthesising evidence from highly heterogeneous studies. 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. Although Spiers et al. remark, "...the overall direction of evidence was consistent", the limitations of the data, including paucity of home care data, means these results should be interpreted with caution - particularly as one study not included in the review shows evidence pointing in a different direction (Condelius et al., 2008). All these studies 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.

1.3.4 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 IAs 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.

Early studies show potential benefits for secondary health care outcomes derived from greater social care provision although the quality of this evidence is poor. There is also a lack of evidence relating to the effect of home care services on health care outcomes with the majority of studies focusing on the relationships between social care expenditure or residential services on outcomes.

1.4 Administrative Data Linkage

Administrative data linkage offers an excellent opportunity to investigate the aims set out for this thesis. As has been shown, this technique has been increasingly used in recent years to investigate interactions between health and social care services. Absent from much of this research, however, is investigation of the relationship between multimorbidity and social care services.

Increased availability of administrative data records mean the potential for researching policy-relevant questions is rapidly growing (Connelly et al., 2016). There are, however, many considerations to take into account compared to orthodox research data collection - particularly as the data is collected for reasons other than research (Connelly et al., 2016). This section briefly discusses the benefits and drawbacks of administrative data research before providing an overview of data resources relevant to the specific aims of this thesis.

1.4.1 Context

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

[OECD, 2006]

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

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

al., 2017) which means specialist knowledge of the database and collection methods are required (Mazzali and Duca, 2015). Administrative databases also have the potential to contain data of questionable quality and high levels of missing data (van-Walraven and Austin, 2012; Hashimoto et al., 2014; Harron et al., 2017). Data can be missing for the same reasons as seen in other forms of research but, in addition, individuals may also be missing due to failure to interact with a service or because insufficient information was available to accurately match records during the data-linkage process (Harron et al., 2017). Administrative databases are also likely to be less-structured and complex than e.g. collected observational surveys, and therefore will require extensive data cleaning and management in advance of substantive analysis (Connelly et al., 2016).

Advantages of administrative databases are that they enable large, often population sized, samples because they are generated from service use (Mazzali and Duca, 2015; Pavis and Morris, 2015; Walesby $et\ al.$, 2017). This characteristic also reduces the potential for sampling bias (Mazzali and Duca, 2015), indeed where whole-populations are included in cohorts this problem disappears altogether (sometimes referred to as n= all studies (Connelly $et\ al.$, 2016)). Such cohorts enable research of sub-samples or rare-events where the statistical power of traditional surveys would not be robust enough to form firm conclusions (Connelly $et\ al.$, 2016). Well maintained administrative data can offer information over long periods of time including very recent data (Pavis and Morris, 2015). This can make inferences from research findings more robust with excellent levels of external validity without the high cost traditional observational studies might incur (Mazzali and Duca, 2015; Harron $et\ al.$, 2017).

Perhaps the greatest advantage of administrative data research is the potential to link databases from a number of sources which can offer insights into how services interact (Mazzali and Duca, 2015; Atherton et al., 2015; Connelly et al., 2016; Walesby et al., 2017). However, linkage of data from disparate sources raises legal and ethical questions of privacy and consent. To overcome these concerns in the UK, infrastructure have been put in place to enable researchers to access sensitive data whilst maintaining individual privacy and legal compliance with data processing. A full description of this infrastructure in Scotland is provided by Pavis & Morris (2015) and the steps taken for this thesis are comprehensively covered in chapter ??. In general, approvals and review processes enabling access to linked administrative data aim to incorporate the "Five Safes" framework (Desai et al., 2016) summarised in table 1.5.

Safe Projects	Is the use of data appropriate?
Safe People	Can the researchers be trusted to use it in an appropriate manner?
Safe Data	Is there a disclosure risk in the data itself?
Safe settings	Does the access facility limit unauthorised use?
Safe outputs	Are the statistical results non-disclosive?

Table 1.5: Admin data - the Five Safes from Desai et al. (2016)

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

Scotland is home to some of the best administrative databases in the world (Pavis and Morris, 2015). This is particularly due to the high-quality of health datasets that have been collected and maintained for over 40 years (Fleming et al., 2012; Pavis and Morris, 2015). Whilst linkage of differing health datasets has become common over this period, new cross-sectoral linkages are beginning to emerge such as health and educational data (Wood et al., 2013), and health and social care data (Witham et al., 2015). These cross-sectoral linkages are providing new insights that have the potential to have lasting impact on policy and provision of services (Pavis and Morris, 2015; Atherton et al., 2015).

1.4.2 Data sources in Scotland

The first aim of this PhD project was to identify what sources of administrative social care data were available in Scotland and assess their suitability for research purposes. Ideally, given the other aims of identifying the relationship of multimorbidity with social care use, data that could be linked at a population level was desired. Whilst social care data is collected by all 32 local authorities, obtaining information from each of these authorities (including associated Data Sharing Agreements (DSA)), and then linking to health data was, from a logistical point of view, impossible to achieve during the lifetime of a PhD (and perhaps impossible to achieve at all). This meant linking data from a smaller number of councils seemed like the most likely route to achieve the project aims. However, this raised the question of whether comparisons would be possible across different IT systems, and still contained the logistic burden of multiple DSAs.

One alternative source of social care data, the Social Care Survey (SCS) (Scottish-

Government, 2017c), offered the only possibility of overcoming these problems. The SCS is collected annually by the Scottish Government and had, since 2010, required this information at an individual-level. Returns from all local authorities are statutory requirement and are received in a standardised format thus providing a national picture of social care use. However, the SCS does not contain an identifier that could be used to link to healthcare records.

Following meetings with Scottish Government (Health and Social Care Analysis Division(HSCAD)) analysts and other interested stakeholders, HSCAD commissioned probabilistic matching of SCS records to the National Records of Scotland (NRS) population spine in August 2016. This indexing exercise (more fully described in section ??) would match SCS records to Community Health Index (CHI) numbers thus facilitating linkage to NHS health resources and was completed in July 2017. The commissioning allowed the approvals process to begin and specific research questions to be formulated.

One potential issue with the coverage of the SCS remained. Many variables within the survey requested data on service use during a pre-specified census week. This means that the SCS does not capture all individuals who receive social care in any given financial year. No indication of the proportion of social care captured by the SCS existed. In order to quantify this, a separate project was conducted for this thesis to obtain *all* social care data from one local authority area. A fuller description of the justification for, and the results of, this process are presented in chapter ??.

With the process of obtaining suitable social care data underway, attention turned to health data sources required to allow analysis of the project aims. As described in section 1.1, definition and measurements of multimorbidity are numerous. A seminal study on multimorbidity conducted from routine records in Scotland (Barnett *et al.*, 2012) contained a measurement of multimorbidity as a count of conditions from a list of 40. This appeared to offer the best method of measurement for the aims of the thesis. However, in order to recreated this measure, data from primary care sources would need to be accessed and then linked to social care and other health data sources - the Barnett *et al.* (2012) study did not involve data linkage.

Primary care has historically been difficult to access in Scotland for linkage projects. New software for the extraction of primary care data was not available when data requests were being made for this thesis and, to date, permitted access to primary care data does not include multimorbidity status (ISD, 2019a). This meant alternative sources of morbidity data had to be considered. These included Scottish Morbidity Record (SMR) sources, however these only capture morbidity data on individuals who interact with secondary health care services. As the thesis aimed to assess the multimorbidity status of social care users in the community, reliance on secondary health care sources would not be satisfactory. The only alternative was to rely on a proxy measurement of multimorbidity.

As described in section 1.1.3, counts of prescribed medicines have been used in previous

research as a multimorbidity proxy and perform favourably compared to other measures in predicting mortality and health care use. Linking the Scottish Prescribing Information System (PIS) (Alvarez-Madrazo et al., 2016) to social care and other health data resources (via the CHI number) would allow a proxy measurement of multimorbidity to be created for all individuals in the study cohort.

The final aim of the PhD project was to assess the relationships between multimorbidity, social care, and unscheduled healthcare use. Browsing NHS Scotland Information Services Division (ISD) National Data Catalogue (ISD, 2019b) revealed the existence of the Urgent Care Data Mart (UCD) (ISD, 2017) which contained multiple variables relevant to unscheduled care including A & E attendance, unplanned hospital admission, and GP out-of-hours services - all linkable to other sources via the CHI number.

A full description of these data sources, the variables contained within that were requested, and the process of linkage and analysis are provided in chapter ??.

1.5 Conclusion

This literature review has covered four broad and differing, but linked, topics. Population ageing is resulting in increasing prevalence of multimorbidity which in turn results in higher demand for health and social care services. As a concept, multimorbidity is more complex than may be at first presumed and has suffered from ambiguity in terms of definition. There are many ways of measuring multimorbidity for research purposes but in some cases simple counts of diseases or medicines can provide comparable results to more complex methods. The link between multimorbidity and social care has not been empirically researched. Given the intuitive relationship between them, it is easy to justify research of this nature.

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 in the UK. As demands on social care services have increased, budgets in the UK and Scotland have been drastically cut. Research on all local authority spending suggests the costs of these cuts have fallen disproportionately on those of lower socioeconomic position. Whether this is also true of social care in particular is unknown. Given evidence of the inverse care law in health care receipt, identifying the effect of reduced social care provision on individuals and health service use is of high policy interest.

Despite lack of formal evidence, 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 health care (and potentially 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 home care, has made it difficult to understand the interaction between these services although recent reviews suggest being resident in a care home and higher social care expenditure can attenuate secondary care use.

Routinely collected administrative data, along with new methods of linking records across sectors offer the best opportunity to address this lack of evidence. Advances have been made, in terms of infrastructure and methodology, that enable investigation of difficult questions (such as those raised by this review) whilst maintaining data privacy and compliance with legislation. There remain, however, difficulties with this approach.

Data sources available make it difficult to measure multimorbidity as per recommended definitions and proxy measurements are often all that are available to researchers. Routinely collected social care data has never been used for research in a Scottish context.

Whilst it is exciting the opportunity to do so has now arisen, careful consideration of the quality and coverage of this data is important before inferences are made from analyses derived from it.

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