

**Towards integrated care: Using linked
data to explore health and social care
utilisation for adult residents of Barking and
Dagenham in 2016/17**

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Declaration

I, Jenny Shand confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Acknowledgements

I am indebted to the health and social care leaders across Barking and Dagenham, in particular Anne Bristow and John Brouder, whose leadership has enabled the inclusion of linked datasets in the research programme, and Simon Lam and Phil Canham who have worked collaboratively to create the dataset. The participation of all local and national leaders in the research interviews has been incredibly valuable.

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Abstract

Background

Better integration across all settings of care is a core ambition of the NHS to address the changing needs of an ageing population and achieve efficiency gains. This study created a novel individual level data resource to explore the use of health and social care services across five care settings, to evaluate the factors associated with this use, and the extent to which these factors vary by setting of care for residents of Barking and Dagenham in 2016/17.

Methodology

Mixed methods including: semi-structured interviews in Barking and Dagenham, Havering and Redbridge to understand system leaders' perspectives on working across organisation and sector boundaries; descriptive analysis of service utilisation across five settings of care (hospital, primary, community, mental health and social care) to compare population and cost volumes for 32 possible combinations of service use; a two-part regression model to calculate the combined effect of the probability of service use and the level of service use if there was one across a wide range of co-variables overall and by setting of care; matched analysis of the impact having an informal carer has on cost-weighted utilisation.

Results

Improving system finances was a key motivator for integration. The 2016/17 total costs for the cohort (114,393 residents) was £180.1 million. Two combinations of service use dominated cost and volume for the system, with a further eight combinations dominant for an individual setting. The relative impact of socio-

demographic, health and economic factors differed according to setting of care. Health and care costs were £2,662 higher for people registered in their primary care records to have a carer compared to those who did not.

Conclusions

Large, linked datasets, such as the one considered in this thesis, provide extensive opportunities to improve our understanding of service user patterns and the wider determinants of health.

Impact Statement

My research has created a novel dataset, spanning five settings of care and council information. This has demonstrated that it is both possible to link different datasets together at the individual level and shown examples of the kind of research that can be conducted within such datasets. The costing methodology for mental health and community services is particularly unique, owing to the use of patient level costing from the providers budget management system and the relationships with the organisation allowing us to access that internal cost data. In addition, linking at the individual level to some of the council datasets has enhanced understanding of social determinants of health and social care service use.

Locally, the health and council leaders are now working to use the dataset to widen their understanding of the service use of the local population and their needs. It has supported the development of a population health intelligence system, providing insights into which data fields are most relevant and priorities for future data linkage in neighbouring boroughs.

For researchers, the utility of the dataset is extensive and multiple research projects are in progress to expand the research undertaken in this PhD.

There has been significant interest from national policy makers regarding how the dataset was created and the linking process, with presentation and discussion at multiple forums to share the work with others.

My research has used robust research methods and generated new findings. The scope of the dataset allowed for extensive investigation of the determinants of health and social care service use. I used advanced econometric methods, such as two-part models, to assess the combined effect of both the probability of

service use and the level of service use if there was one. For other researchers, this provides information on the mean costs by setting of care for different patient sub-cohorts. In addition, the outputs highlight the characteristics that are associated with service use in each setting of care.

My research found that people who have a carer have higher costs across all settings of care compared to those with similar characteristics who do not have a carer. This challenges the assumption that all informal care is providing care substitution, or, at least, that additional service use induced by the carer may dominate any substitution effect. This has implications for how the economic contributions of carers is calculated, and for how to reduce inequalities in access of care for those without a carer.

My research has generated interest from different audiences. At the time of submission, one paper has been published in a peer-reviewed journal, a second paper has been accepted for publication following peer-review, and two further papers have been submitted. In addition, the research has been shared through oral presentations and posters in multiple national research conferences, in local system meetings, national policy forums and online blogs.

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Abbreviations

ACO	Accountable Care Organisation
A&E	accident and emergency
ASU	acute stroke unit
ATE	average treatment effect
BCF	Better Care Fund
B&D	Barking and Dagenham
BHR	Barking and Dagenham, Havering and Redbridge
BMI	body mass index
CCG	clinical commissioning group
CTV3	Clinical Terms Version 3
ESA	Employment Support Allowance
GDPR	General Data Protection Regulation
GLM	generalised linear model
GP	general practice
HASU	hyper-acute stroke unit
HiAP	Health in All Policies
HRG	Healthcare Resource Group
ICS	Integrated Care System
IMD	Index of Multiple Deprivation
JAD	Joint Assessment and Discharge
LBBD	London Borough of Barking and Dagenham
LHCRE	Local Health and Care Records Exemplar
LSOA	Lower Layer Super Output Area
NELFT	North East London NHS Foundation Trust
NHS	National Health Service

NICE	National Institute for Health and Care Excellence
OCD	Obsessive Compulsive Disorder
ONS	Office for National Statistics
PMB	provider marginal benefit
PMC	provider marginal cost
QALY	quality-adjusted life year
SMB	system marginal benefit
SMC	system marginal cost
SMI	Serious Mental Illness
STP	Strategic Transformation Plan
UPRN	Unique Property Reference Number

1 Introduction

Year-on-year social care funding reductions and a £22 billion funding gap for the National Health Service (NHS) in England require health and care services to reduce the prevalence and severity of health need. Better integration across all settings of care to deliver efficiency gains alongside patient benefit is a core ambition of the NHS. However, to date, hospital and primary care data have dominated analysis of service use and less is known about population-wide use of other care settings, notably community, mental health and social care. This thesis describes the development of a novel linked dataset and an analysis of service use by setting of care for a cross-sectional sample of adult residents (aged 19 and above) of Barking and Dagenham (B&D) between 1st April 2016 and 31st March 2017.

1.1 Background and context

The growing prevalence of chronic diseases and an ageing population (1), coupled with a funding gap of £22 billion (2), are challenging the sustainability of the NHS in England. In December 2015, NHS planning guidance in England announced 44 Strategic Transformation Plans (STPs) (3). These five-year plans cover an identified geographical “footprint” (average population size circa 1.2million), include all aspects of NHS funding, and are required to describe how to close the funding gap as well as focus on better integration with social care and other local authority services. Overspend in acute care inevitably dominates the agenda, which is reflective both of where the system’s highest costs are and of the need to make short-term and immediate progress (4). This, in turn, reduces attention on population health initiatives; typically there is a long lead time before the impact of population health initiatives are realised.

The funding challenges are not only present in the NHS. There is growing political and public concern about the funding and delivery of social care services for older and disabled people. Since 2010, the funding from central government to local government has been reduced. Between 2010/11 and 2015/16 this equated to a 37% reduction in funding (5). By 2020, combined local government current and capital spending as a share of the economy will reach its lowest point since 1948 (6). Councils are responsible for education, housing, social care for the elderly and disabled, local roads, waste collection and other services. Changes to the central funding grant will see over half of councils (168 councils) receiving no grant funding by 2020, with retainment of local business rates as the prime funding source. Top-ups and tariffs will be extended to protect authorities with lower levels of business rate income.

Adult social care accounts for a minimum 30–35% of local authority spending; reductions in overall council funding have translated into reductions in social care funding (7). The King's Fund estimated 26% fewer older people received local authority-funded social care support between 2009 and 2013/14 (8). Some of this is the consequence of changes to eligibility criteria rather than changes in need, which makes the impact on people hard to quantify.

Spending on health services increasingly dominates public spending, but it is not directly used to address the social causes of poor health, which collectively are the primary drivers of health outcomes. Marmot describes this as a “health paradox” (9) whereby those that are tasked with health are only responsible for health services, not for the key determinants of health that lie outside the health care system. It is suggested that only 10–15% of the health of an individual is attributable to access to high quality health services (10, 11). The opportunity for other sectors to improve health is therefore extensive (12). The NHS “Long Term Plan”(13) places a strong emphasis on health inequalities with regard to access

to health services and health outcomes; however, there is limited discussion about prevention and no reference to social determinants of health. Local authorities are best placed to tackle social determinants of health, with spending and services across education, housing and crime. However, the financial position of local authority budgets described above presents a challenge to making progress on social determinants of health and, in turn, health needs.

1.2 Integration and efficiency

In this context of scarce resources, policy and system leaders across health systems aim to make optimal use of resources to maximise outcomes for a population, taking into account changing wants, needs and new discoveries. The funding gap across health and social care equates to the need for approximately 4% efficiency gains per year. Integrated care has become a long-standing ambition of health policy nationally and internationally as a means to achieving efficiency gains alongside improved patient experience and outcomes.

Health care systems are investigating how to integrate the patient experience across care settings and pathways and how health care systems can transition from managing episodes of treatment to managing whole population health. This is particularly necessary for patients with chronic conditions, whose care transcends traditional institutional health care boundaries. At a system level the consequence of not getting it right can be overuse of hospital care, or duplication or omission of important components of care. For patients, it can be complicated to navigate between the different providers, and can result in poor care, unnecessary hospital admission and avoidable mortality (14).

Across the literature there are numerous definitions of integrated care and differing underlying concepts (15). In addition, there are different levels of

integration, ranging from care integration for particular individuals, for specific diseases or population groups, to care integration for an entire population (14, 16). Central to all this is the ambition to have user-centred approaches in the design and delivery of services to minimise duplication and maximise user experience and health outcomes.

The 1997 NHS white paper, “The New NHS: modern, dependable”, highlighted the importance of collaboration across health and social care, centred on the needs of the patient (17). The power of integration to address NHS efficiency challenges is centred on the wide variation in avoidable use of hospital care, although the formal evidence remains undeveloped (18). Whilst the Health and Social Care Act 2012 focused on extending competition and choice in the NHS alongside devolved decision making, implementation of the Act led to several amendments to explicitly promote integrated care. This included the creation of Health and Wellbeing Boards, creating conditions for collaboration at a local level for a defined geography and reinforcing the importance of local authority partnerships.

Our population is ageing, with the number of people living in the UK aged 85 or above expected to more than double by 2041 (19, 20). As a consequence, frail older populations with complex and multiple needs are likely to form a growing proportion of our society and be a group that will interact with the whole system from social care through to hospital services. As such, elderly populations and those with multiple long-term conditions have dominated the integration agenda, presenting a challenge for service delivery in a system that has historically been organised to deliver episodic and curative care (21, 22).

Economic efficiency refers to making optimum use of scarce resources.

Integration has the potential to improve both allocative efficiency and technical

efficiency. Allocative efficiency refers to how different resource inputs are combined to produce a mix of different outputs (i.e., *doing the right things*); for example, allocating resources to achieve the most health gain for the population served or interventions in community services to prevent future hospital admissions. Technical efficiency on the other hand is concerned with achieving maximum outputs with the least cost (i.e., *doing things right*) (23); for example, reducing unit costs by reducing lengths of stay or shifting care to more cost-effective settings out of hospital.

Whilst technical efficiency is important, the NHS policy to promote increased integration of care across settings predominantly aims to improve allocative efficiency, with the latest policy ambitions requiring all health and social care organisations to work together as an Integrated Care System (ICS) (13) with a combined budget to allocate resources in a way that can achieve the most health gain for a defined population.

Allocative efficiency is frequently considered in the context of health technology assessments, assessing the cost per quality-adjusted life year (QALY) of different treatment options, and agreeing thresholds for the introduction of an individual intervention. Those interventions with low incremental cost per QALY can maximise the health benefits secured from limited funds. However, allocative efficiency can also be considered in the context of integration and system-wide thinking. For example, this may involve examining whether the correct mix of health and social care services is funded, such that at a given aggregate level of expenditure, health outcomes are being maximised. This requires allocation of funds between settings of care, including prevention, primary care, hospital care and long-term care to secure the maximum level of health-related outcomes for a given population. It is possible at a system level that there are components (such as clinical teams or organisations) that are performing efficiently (achieving

technical efficiency) whilst on several metrics the system as a whole is allocatively inefficient, such as treatment taking place in the wrong setting (e.g., patients attending emergency departments instead of primary care) or inadequate skill mix of staff (e.g., patients seeing consultants when their needs could have been met with a nurse consultation). Consideration of a broader system-wide perspective may show that decision makers have misallocated resources between preventative and curative services, and that technically efficient teams are operating within an allocatively inefficient system

Furthermore, across health and social care there is a high level of *interdependent productivity*, and the actions of different parts of the system can have positive and negative impacts on the productivity of another part of the system, such as a hospital provider. For example, in areas where there is high performing community and social care services, length of stay and delayed discharges are likely to be lower for older people who are delayed in hospital due to delays mobilising home-based support. This would increase the hospital provider's productivity and technical efficiency.

1.3 Economic concepts for integration and cross-setting collaboration

There are several further economic concepts that provide important context for integration and cross-setting collaboration:

- Externalities - The actions of individual organisations can have an unintended impact on other organisations and/or the system as a whole
- Substitutes and complements - Different services can be complements or substitutes to other services
- Welfare economics - The health of a population is influenced by more than access to and quality of health and social care services

Each of these is described further in the following subsections.

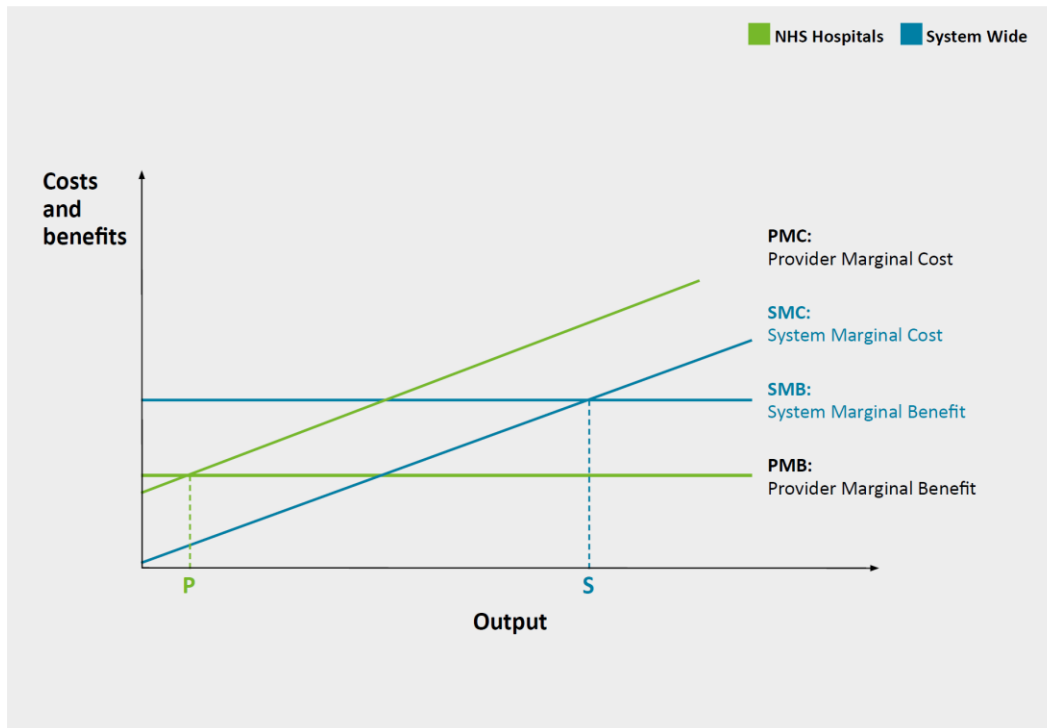
1.3.1 Externalities

The outputs of component parts of the health system should not be considered in isolation because they can have an impact on the wider health and care system in which they operate. For example, effective prevention services could reduce demand for health services, the actions of a hospital team at discharge could have implications for community and social care service packages, and poor accessibility of primary care services may lead to overreliance on accident and emergency (A&E) departments. The call for better integration across services aims to address some of these interdependencies. From an economic perspective, these can be thought of as externalities, the unintended consequences of the decision made by one organisation or setting of care on another and/or the whole system. Such decisions may result in benefits (positive externalities) or impose costs and/or harm (negative externalities) to other settings outside the setting where the decision was originally made(24, 25).

The example of the reconfiguration of stroke services across London can be used to illustrate this. In 2006, one of the recommendations of “Healthcare for London” (26), was to reform the provision of stroke services across London, in part to implement research from 1995 that demonstrated the benefits of rapid access to thrombolysis for certain patients who had had a stroke (27). This required moving from a local hospital model to all patients being treated in a hyper-acute stroke unit (HASU) for the first 48 to 72 hours of care after a stroke. Those not ready to be discharged home are transferred to an acute stroke unit (ASU). Across London, this required a reconfiguration of services from 34 hospitals treating patients who had had a stroke to 8 HASUs supported by 24 ASUs.

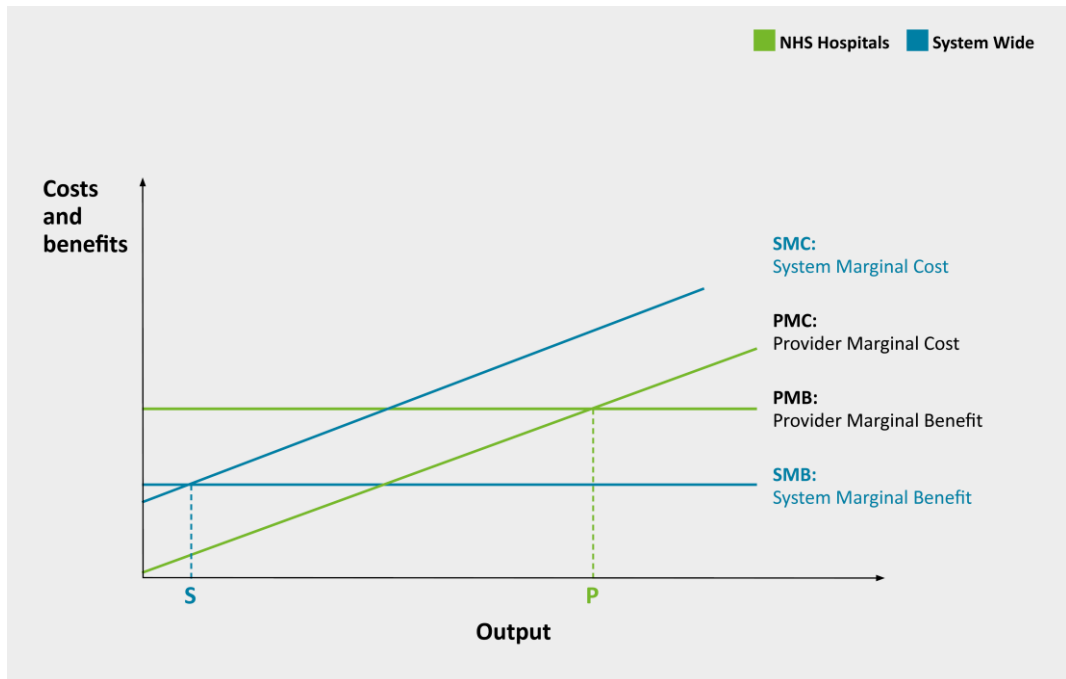
There were extensive costs associated with implementing the new model. For London it was estimated that £10 million was invested in capital and consultation (28), and that staff costs increased by £20 million in the first year (29). At 90 days, the model was cost effective, with £811 less costs per patient (28). However, these savings were largely realised in social care as patients were requiring lower levels of ongoing support due to higher levels of functioning and therefore lower social care needs. As a result, the cost benefit analysis when viewed at an individual hospital level would not justify the investment required to implement the service reconfiguration. The outputs in this instance, for example the number of patients who had had a stroke getting access to thrombolysis, are denoted by P (Figure 1-1). However, from a system-wide perspective, given the new model was cost effective at 90 days, and the investment required to implement the reconfiguration was recouped within two years, changing the configuration of services to achieve a new level of for example, thrombolysis, was achievable placing system level optimal outputs at point S. The benefits to patients were extensive, with reduced mortality and better levels of functioning. Therefore, the consequences associated with hospitals not implementing the new model of care would have been continued high levels of mortality from a stroke and poor levels of functioning for patients that survived. In this instance, hospitals were incentivised to implement the new model because the NHS system invested the £10 million required for capital and consultation and instituted a 50% increase in the tariff from £4765 to £7193 (29) to account for the increased staff costs, moving the marginal costs for the hospital from provider marginal cost (PMC) 1 to PMC2, and therefore moving the optimal level of outputs to the same as the system level.

Figure 1-1 The costs and benefits of stroke provision for hospital providers and the health system



In the stroke example, the provider marginal cost was higher than the system marginal cost, and the provider marginal benefit was lower than the system marginal benefit. An example of a counter scenario, where the provider marginal cost is lower than the system marginal cost and the provider marginal benefit is greater than the system marginal benefit is the introduction of activity-based costing for hospitals (Figure 1-2).

Figure 1-2 The costs and benefits of activity-based payment for hospitals for hospital providers and the health system



Activity-based payments for hospital activity, a.k.a. Payment by Results, were first introduced in 2003/4 in the NHS in England, a time of long waiting lists. With hospitals reimbursed by each unit of activity, there was an incentive to maximise productivity and technical efficiency in order to maximise hospital income. However, for the system, as hospitals increased efficiency and productivity, the cost to the system increased due to higher levels of activity to reimburse and a continued dominance of hospital services in the overall health budget. In other words, there was a negative externality associated with increasing activity levels. In addition, given payment by results was in effect payment for activity, the system benefit was less clear as quality was not originally part of the reimbursement process. In the context of a policy ambition to promote more integrated care, the dominance of activity-based payment for hospital services, including emergency care, in theory incentivises increased activity in this setting of care. In parallel, the dominance of block budgets for community services and per-capita payment for primary care services could disincentivise increased

activity. The underlying ambition of integration to shift care out of hospital and closer to the home, requires this imbalance to be addressed to prevent the incentives acting as a barrier. If care is to be shifted into the community, productivity improvements will be needed to manage increased activity, given current budgetary limitations.

In both examples, the marginal benefit is constant with outputs (constant marginal benefit), i.e. benefit increases at the same rate as the output increases. There may be examples where the marginal benefit will be down-sloping, for example immunisations. As more individuals are immunised, the marginal benefit of each additional immunisation decreases due to group and herd immunity. Similarly, the marginal costs are simplified as these too may be stepped, with, for example, step costs associated with particular thresholds of output (e.g., a provider may be able to accommodate a certain volume of activity, above which investment in additional capacity, be it clinical staff or facilities or both, is required).

The regulation of health and social care organisations encourages organisations to focus on those actions that have a positive impact on their own performance. Clinical, operational and financial performance is scrutinised to ensure individual organisations meet their regulatory obligations on an annual basis. Participation in broader initiatives that may have positive externalities to other settings or to the whole system, but that could either negatively impact organisation-level performance or have little short-term returns, are rarely achieved without government intervention. Whilst there is a system-wide ambition for integration and whole system working, the regulatory system still requires individual organisations to be stable and sustainable. In addition, the structure of financial incentives across services does little to support cross-sector working and

achieve policy ambitions of shifting care out of the hospital setting, with the payment systems often giving conflicting incentives (30).

In the stroke example, the cost portfolio would prevent providers from acting and as such the system would not get the anticipated population benefits from integration, and if the government/system did not encourage this via financial incentives, then this would incur a cost that outweighed the benefit from a provider perspective. In this instance the system encouraged integration by compensating hospitals by increasing the tariff (and paying upfront capital costs) and therefore removing the negative financial consequence.

Reversely, in the activity-based payment example, providers may do things that are in their interest (i.e., increasing activity to make efficient use of their resources and achieve technical efficiency) which could have a negative impact on the system (e.g., spiralling hospital commissioning costs). Understanding how to incorporate the consequences of hospital-level decisions to the system into decision making is important, particularly given the dominance of regulation driving organisations to focus on their individual performance.

This is explored further in Chapter 2.

1.3.2 Substitutes and complements

Other forms of interdependency between services, organisations and/or settings of care are complementarity and care substitution.

Complements are goods, or services, that are consumed together. If the price of X is increased then less of X is demanded; if less of Y is also demanded then X and Y are complements. On the converse, when the price of X is reduced, more is demanded of X; if Y is a complement more is demanded of Y also. Examples include: general practice (GP) appointments and prescriptions – if there are more

GP appointments there are likely to be more prescriptions; and surgery and anaesthetics – an increase in the number of surgeries is likely to increase the use of anaesthesia.

On the other hand, substitutes are goods or services that are consumed in place of one another. If the price of X goes up then less of X is demanded and more is demanded of Y if Y is a substitute. Care substitution refers to the notion that each patient may be expected to consume a certain “amount” of health service activity, but that in some circumstances one type of service use may be substituted for another. Shifting tasks from hospital care to primary and community care underlies much of the integrated care narrative, “moving care closer to home” (31). A 1998 King’s Fund systematic review on care substitution between primary care and emergency departments concluded that improving access to primary care where access was previously poor can reduce emergency department utilisation. Further mechanisms in primary care to act as a care substitute for hospital care include prevention or early disease diagnosis in primary care avoiding the need for hospital care and delaying the need for hospital care through proactive monitoring and disease management (32).

There are substantial substitution possibilities across the health care system and substitution can be at several different levels; for example, at organisation or setting level, such as the example of hospital and primary care above.

Substitution can also occur within organisations, such as the skill mix of staff; the potential for substitution between doctors and nurses is a dominant topic in the research literature on care substitution. In addition, substitution can come from outside the system. Much of the discourse on the role of informal carers rests on the economic assumption that informal carers are a substitute for formal care, with an hour of their time being directly comparable to an hour of a paid carer (33).

This is explored further in Chapter 6.

1.3.3 Welfare economics

Health problems are complex and in many cases a single health issue may be influenced by interrelated social, environmental and economic factors. By recognising the multiple influences on health status, and that the impact the health sector alone can have on health is limited (10, 11), there is an opportunity to collaborate with other sectors to create a more holistic approach and as such have a wider benefit. Furthermore, as health systems move towards greater integration of care as a mechanism to deliver allocative efficiency, collaboration across the healthcare sector is not enough, and wider collaboration with other sectors is required if wider social determinants of health are to be addressed.

Welfare economics is concerned with how the structure of markets and the allocation of goods and resources determines the overall well-being of society(24). Production-possibility curves are used to understand the different possible combinations of public and private sector goods, the opportunity cost associated with changes in the amount of different goods produced, and how to maximise efficient allocation of scarce resources (which is achieved when operating at the boundary of the production-possibility curve).

Figure 1-3 A production-possibility curve showing the different combinations of health sector and other public sector goods that can be produced when resources are limited



Figure 1-3 illustrates a production-possibility curve that rather than comparing public and private sector goods, compares combinations of health sector and other public sector goods. The quantity of health sector goods produced is measured on the horizontal axis, and the quantity of other public sector goods produced (for example education or housing) is measured on the vertical axis. Any point on the diagram, for example a, b, c and d, indicate an amount of each kind of good that can be produced. The curve separates attainable combinations (a, b and c) from unattainable combinations (e.g., d), where the scarcity of resources is such that combinations beyond the curve could not be produced. As more of one good is produced, this results in less of another. Moving from point a (c_0, g_0) to point b (c_1, g_1) implies producing an additional amount of health sector goods (measured as the change in G) at an opportunity cost of a reduction in other public sector goods (measured as the change in C). Points a and b are

efficient allocations of resources as they are on the curve, whereas point c represents either inefficient allocation of resources or failure to use all resources available.

Given the interdependency of health and well-being outcomes on more than the health sector, the combinations of health and other public sector goods that are produced will have an impact on the demand for health services. This is in line with the ambitions of Health in All Policies (HiAP) (34), a framework launched by the World Health Organization in 2011, which recognises that policies across government may have an impact on the social and environmental determinants of health and related health inequalities. HiAP emphasises the consequences of public policies on health determinants and aims to improve the accountability of policy makers for health impacts at all levels of policy making.

For example, there is a correlation between school readiness and positive future outcomes for an individual and society (higher school attainment, higher earnings capacity, lower rates of delinquency and crime) (35). Interventions that improve school readiness require action from multiple sectors, for example the health sector with the support provided to the mother through pregnancy, the education sector and the provision of early years support as well as high quality education. The improving school readiness programme quantified the future return on investment that is possible as a result of early intervention (Figure 1-4) (36).

Figure 1-4 School readiness: The return on investment in quality early care and education



There is not a consistent approach to supporting health services to collaborate with other sectors to address the wider social context of individuals, the lives they live, the environment in which they live and the families they live with. Allocation of resources between the health sector and other public sector services is made by central government, with local government making decisions about the allocation of resources across sectors other than health for their local communities. The extent to which decisions take into account the wider impact of decisions on a population's health and well-being is unknown. The move of public health into councils in 2013, from a policy perspective, provides an opportunity to increase HiAP. However, public health budgets have not been ring-fenced and have been subject to substantial cuts (37). In addition, the role of wider council collaboration in ICSs is unclear. Whilst the development of ICSs points to ambitions for improved population health, the formal requirement extends only to health and social care services, rather than the broader functions

of councils which can have a markedly larger impact on the future health needs of the population.

This is explored further in Chapter 5.

1.4 Scoping review to understand predictors of service utilisation by setting of care

Internationally, there is growing use of linked datasets to build more complete understanding of population profiles and population-wide health and care service utilisation. This can in turn provide information to inform how to improve allocative efficiency and to review the process and impact of moves towards more integrated care.

A review of the literature was conducted to understand variables associated with health and care service utilisation. This provided the foundation for developing a linked dataset for B&D, which is described further in Chapter 3 and is used for the research work in Chapters 4, 5 and 6.

1.4.1 Aim of the scoping review

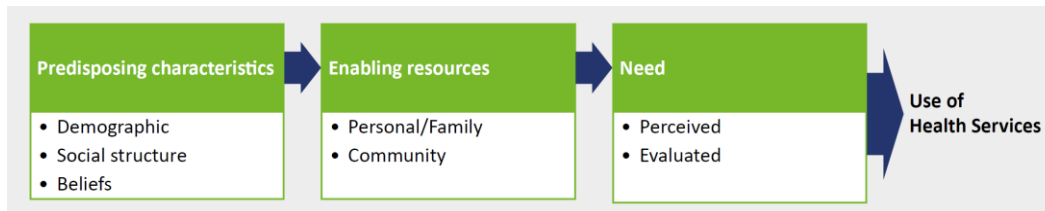
The scoping review aimed to identify demographic and socio-economic factors that are associated with health and/or care service utilisation by adults in the UK.

1.4.2 Conceptual framework for determinants of health service use

There are multiple conceptual models that have been used by health economists when reviewing determinants of health care utilisation. One frequently used for review of health care utilisation is the behavioural model of health care utilisation developed by Andersen(38) which was originally used to measure equitable access to health services and support development of policies to promote access. The original model consisted of three broad groups of factors that predict service use: predisposing, enabling and need (see Figure 1-5). Andersen's first

study focused on the family as the unit of analysis, later versions of the model focus on the individual as the unit of analysis(39).

Figure 1-5 Andersen’s behavioural model of health care utilisation (original model from 1968)



Predisposing factors consist of three different domains: demographic (for example, age and gender), social structure (for example education, ethnicity and occupation) and health beliefs of the individual (for example knowledge about health, beliefs, attitudes and values). All predisposing factors influence enabling factors. Enabling factors include personal, family and community resources.

Personal resources are factors that describe an individual’s ability to use services such as transport links, income levels, health care insurance. The community resources are the supply of health services including the number of doctors and nurses and the number of hospital beds per head of the population, as well as access to services.

The need factors are the dominant reason why individuals use the health system. This includes the perceived need of the individual (for example symptoms, level of pain) and evaluated need based on assessment by a clinical professional. The need variables have been shown to be the strongest predictors of health care service utilisation.

The model assumes that a sequence of factors determines the utilisation of health services: the predisposition to use services, the ability to use services and the need to use services. Overtime, the model has been refined and expanded to add contextual factors that can influence health service use, such as the external

environment and the healthcare system, and a feedback loop allowing, for example, an individual's health outcome to influence future health beliefs. These later additions have allowed more supply-side factors to be incorporated into the model, including health system policies and the availability and accessibility of providers.

In the context of this thesis, the model provides a helpful framework for summarising the outputs of the scoping review with regards to the different factors associated with health and care utilisation.

1.4.3 Search strategy

Published literature was searched using six databases – CINAHL (Cumulative Index to Nursing and Allied Health Literature), EMBASE, HMIC, Medline (via Ovid), PsycINFO and Social Care Online.

Following an initial scoping search in Medline, it became clear that a search by setting of care would enable the inclusion of different measures of utilisation that are specific to each setting of care. The search strategy was refined in consultation with a specialist librarian and is included in Appendix 1. Search terms combined four domains – health care service use or utilisation, social care service use or utilisation, service specific utilisation measures, predictors or factors associated with service use and the NHS in England. For pragmatic reasons, searches were limited to English language literature. Searches were limited to adults given the known differences in service use between adults and children, and were limited to studies conducted in the UK. The review was conducted in January 2018.

The title and abstract of the literature searches from each database were compiled into one list and duplicates identified and removed. Papers were screened for relevance using the inclusion criteria set out in Table 1-1. The full

text of all remaining articles was retrieved and screened using the same inclusion criteria. A sample of the studies were screened by a second reviewer to check consistency in screening application, and any records for which inclusion was unclear were discussed in detail. The results are presented descriptively, and no data extraction or meta-analysis was attempted due to heterogeneity of the results. PRISMA recommendations for conducting and reporting scoping reviews were used to guide the approach.

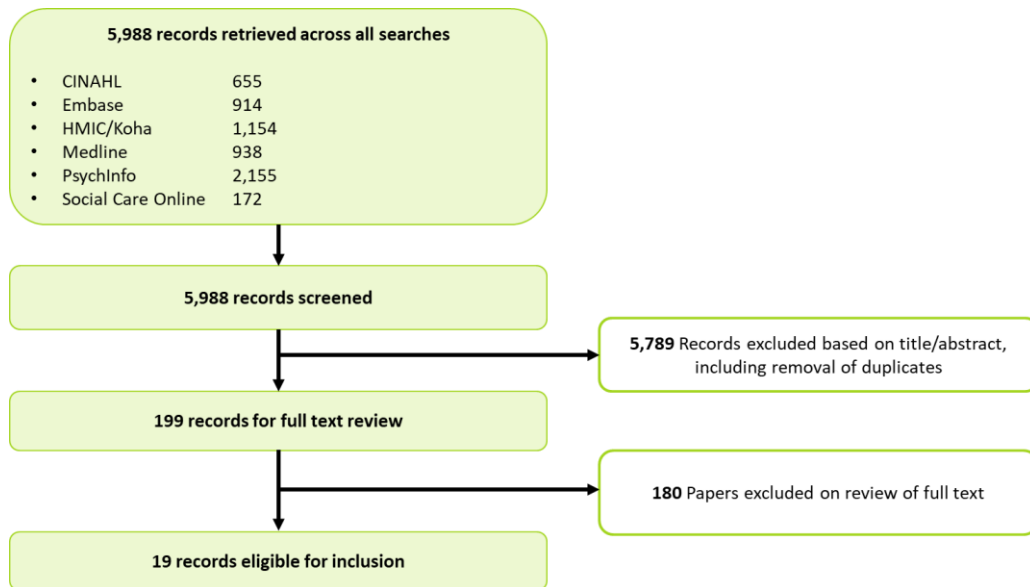
Table 1-1 Inclusion criteria applied during abstract and full-text screening

Inclusion criteria	
General	<ul style="list-style-type: none"> English
Country	<ul style="list-style-type: none"> Based in the UK
Service utilisation	<ul style="list-style-type: none"> Inclusion of measures of service use or service utilisation of health or social care services
Intervention	<ul style="list-style-type: none"> Investigation of a specific intervention that did not include assessment of service use or service utilisation
Year	<ul style="list-style-type: none"> Published after 2004

1.4.4 Results

The searches of the electronic databases identified 5,988 records. Screening of titles and abstracts and removal of duplicates resulted in 5,789 records being excluded, leaving 199 records for full text review. 19 of these were eligible for inclusion. Several of the records excluded after full text review assessed the experience of access rather than variables associated with service use, or investigated help-seeking behaviours without detailed measurement of health service use. Figure 1-6 sets out the number of studies excluded at each stage using the inclusion criteria outlined in Table 1-1. Of the 19 records included, 5 were systematic reviews.

Figure 1-6 Study selection diagram



The results of the scoping review are summarised in Appendix 2, Table 10-1 and discussed below.

There were different measures of service utilisation used in each of the records and different populations of interest. Hospitals were the most frequent setting for measures of service utilisation, present in twelve of the 19 records. There were no studies that considered the determinants of community care and only two that included social care. The included studies considered a wide range of disease populations (e.g dementia, CVD and COPD), age groups, geographical areas (including multi-site studies), and specific services (e.g. GP and A&E). In addition, there were two systematic reviews that included a wider collection of health systems than just the U.K.

Variables of interest also varied greatly. These are discussed further below, within each of the domains of Andersen’s behavioural model:

Predisposing characteristics: The majority of records included adjustments for age and gender, with older and female being associated with increased service use. Assessment of ethnicity found that non-white ethnic groups were associated

with higher level of service use. However, there were inconsistencies across settings of care. Fernández de la Cruz et al(40) and Kapadia et al(41) found minority ethnic groups to use fewer mental health services compared to white, despite similar patterns of prevalence.

One study included marital status and found being a widower to be a predictor of home care service use(42). A systematic review of people with mental health conditions found that divorced, separated or widowed individuals were associated with increased service use across primary, hospital and mental health services(43).

Despite Marmot's assessment of the impact of unemployment on long term health(9), only two records included employment status. Both found that unemployment (measured as the rate of unemployment) was associated with a higher number of A&E attendances(44, 45).

Associations were inconclusive between service use and social isolation, social networks and access to an informal carer.

Enabling resources: Measures of deprivation were considered in eight reviewed studies, the majority of which used the Index of Multiple Deprivation (IMD), a composite score across seven domains to measure the level of deprivation in an area relative to the rest of England. High levels of deprivation were found to be positively associated with A&E attendances and non-elective admissions. However, mental health inpatient services were found to be pro-rich, with higher service use among the less deprived.

Only one study assessed the impact of access to health care, by investigating the effect of out of hours primary care provision on A&E service use. It found that those registered to GP practices with low levels of access to out of hours services had higher A&E attendance(46).

Car ownership was included in two studies. Not having a car was positively related to home care service use. There was no association with mental health service use.

Associations were inconclusive between service use and housing tenure.

Need: The presence of a long-term condition was associated with increased service use in primary care, hospital and mental health settings. A proportion of studies reviewed specific patient populations, for example mental health users, and compared service use for those with physical conditions versus no conditions. There were different mental health conditions reviewed in the different studies, including depression, dementia, Obsessive Compulsive Disorder (OCD) and Serious Mental Illness (SMI). The presence of a mental health condition was consistently associated with increased A&E attendances(43, 47, 48). Studies that assessed the impact of multi-morbidity used different definitions of multi-morbidity, but they all found the presence of multi-morbidity to be associated with higher service use. Furthermore, three studies found that the use of health services at one time point was correlated with future health care utilisation(43, 49, 50).





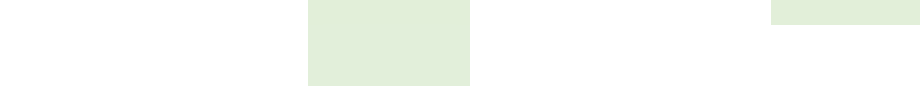
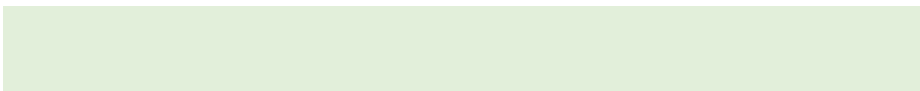
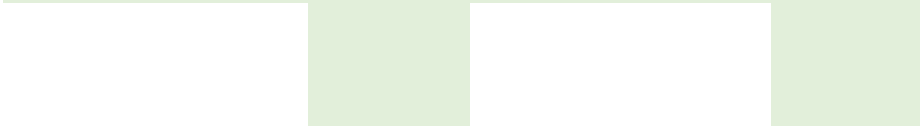
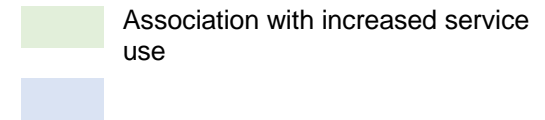
 Association with increased service use
 Association with increased service use but for a different category

Table 1-2 A summary of variables associated with higher service use

Andersen's Behavioural Model			Care setting and measure of utilisation					
			Primary Care		Hospital care			
Domain	Variable	Category associated with higher service use	GP visits	Number of prescriptions	A&E attendance	Outpatient visit	Elective admission	Non-elective admission
Predisposing	Age	Increasing age						
	Gender	Female						
	Ethnicity	Non-white ethnicity						
	Marital status	Divorced / separated / widowed						
	Employment status	Unemployed						
	Education	Low education attainment						
Enabling	Social deprivation (IMD)	More deprived						
	Access to out of hours primary care	No or low access to OOH						
Need	Car Ownership	No car						
	Long-term conditions	COPD, CVD and Dementia						
	Multi-morbidity	Higher morbidity						
	Mental Health diagnosis (including SMI, depression, dementia, psychosis, OCD)	Presence of a diagnosis						
	Previous service use	Either contact with a service or service use in last 12 months						



Andersen's Behavioural Model			Care setting and measure of utilisation				
			Mental Health		Social care		
Domain	Variable	Category associated with higher service use	Care contacts	Outpatient services	Inpatient admissions	Cost weighted service utilisation	Home care
Predisposing	Age	Increasing age	Association with increased service use				
	Gender	Female	Association with increased service use				
	Ethnicity	Non-white ethnicity	Association with increased service use				
	Marital status	Divorced / separated / widowed	Association with increased service use				
Enabling	Employment status	Unemployed	Association with increased service use				
	Education	Low education attainment	Association with increased service use				
	Social deprivation (IMD)	More deprived	Association with increased service use				
Need	Access to out of hours primary care	No or low access to OOH	Association with increased service use				
	Car Ownership	No car	Association with increased service use				
	Long-term conditions	COPD, CVD and Dementia	Association with increased service use				
	Multi-morbidity	Higher morbidity	Association with increased service use				
	Mental Health diagnosis (including SMI, depression, dementia, psychosis, OCD)	Presence of a diagnosis	Association with increased service use				
	Previous service use	Either contact with a service or service use in last 12 months	Association with increased service use				

1.4.5 Discussion

This thesis conducted a scoping review of predisposing, enabling and need factors of health and social care service use. The 19 studies identified in the review included a wide range of populations of interest, measures of service utilisation and care settings, and different types of factors. There were consistent findings with regards to increased service use, predominately hospital activity, for those who are older, female, and who had prior service use. The presence of a long-term condition diagnosis and increasing multi-morbidity was also associated with increased service use.

The differences across the populations, settings and variables used meant it was not possible to conduct meta-analyses and there was limited scope for comparison across studies.

Hospital utilisation, in particular A&E attendance, dominated measures of service use. This may be due to both data availability and the policy focus on reducing inappropriate emergency care attendances. Mental health was featured across the records, but measures of utilisation were often of A&E attendance rather than mental health service use. There were no studies relating to community service use, and only two for social care. As such, wider settings of care and service utilisation within them are areas that this thesis will hope to shed further light on.

The majority of the factors assessed were within the predisposing and need domains. Studies that included enabling factors predominately assessed the impact of area level deprivation on service use. Household income and housing tenure were included in two studies but the association with service utilisation was not assessed. Two studies reviewed car ownership, one of which found not owning a car to be a predictor of home care use. As such there remains limited

research on the association between household variables and service use, and this is an area that will be explored further in this thesis. Access to services and the supply of services are also categorised as enabling factors by Andersen. Only one study assessed access, which evaluated the impact of out of hours primary care provision on A&E service use. It is surprising not to have found more records assessing supply side variables given the wide acknowledgement of the association with service use(51). The research for this thesis is focused on a geographical area in east London, with data analysis for one borough. As such there may be little variation in supply side factors.

For some factors, their impact was evaluated on a limited range of health care utilisation measures. For example, employment status was only considered in two papers and the assessment of its impact was limited to A&E service use. There is an opportunity to assess the impact on service utilisation in additional areas of hospital activity, outpatient appointments and inpatient admissions, as well as in other settings of care.

The search was deliberately limited to the UK to improve the relevance of the findings and ensure consistency with the empirical analysis conducted in this thesis (which is based on the English NHS). Given access to services and the quality of services has an impact on resultant service use, this was felt to be an important design decision to maximise relevance, however wider search criteria would have increased the studies and variables assessed. Two of the included papers (systematic reviews) covered studies conducted in the UK as well as other countries. To help mitigate any discrepancies across health care systems, this review only included the results from the UK studies within those systematic reviews in the summary of findings.

1.4.6 Conclusion

This scoping review has reinforced the dominance of primary and hospital care settings in the assessment of health and social care utilisation in research to date. Less is known about predictors of health and care service use in mental health, community care and social care settings. These findings have informed the choice of variables included in the dataset described in Chapter 3 and informed the rationale for and design of the research conducted in Chapters 4 and 5.

1.5 Aims and objectives of the thesis

1.5.1 Aims

To create a novel individual level data resource to explore the use of health and social care services in multiple settings, to evaluate the factors associated with this use, and the extent to which these factors vary by setting of care for residents of B&D in 2016/17.

1.5.2 Research objectives

- To understand the perspectives and experiences of health and social care leaders of working across organisation, setting and sector boundaries
- To compare the distribution of service use across five different settings of care for the adult population and review the combinations of service use where individuals use more than one setting of care
- To identify the variables associated with health and social care utilisation in each setting of care to understand if there are specific population groups that would benefit most from cross-setting collaboration
- To understand if people with a carer have different levels of service use across the five settings of care when compared to those who do not have a carer but have similar characteristics

1.6 Summary

This introductory chapter has outlined the current state of scarce resources across health and social care, and the ambition of the English national health system to better integrate care across settings to improve allocative efficiency.

The chapter draws on key insights from the economic literature to help understand important drivers influencing how organisations and settings of care work in practice and the relationship with a system-wide perspective. Due to fragmented service delivery and fragmented data collection, it is difficult to create a system-wide overview of the current use of services across settings, such that integrated care interventions can be targeted where they are most needed or to facilitate understanding of allocative efficiency. This thesis does not intend to conduct an evaluation of integrated care or an assessment of allocative efficiency. Rather it intends to develop understanding on the current perspectives of leaders working within the system with regards to implementing population-wide integrated care, and to develop understanding of the current service use patterns of different populations. The research work was based in B&D due to both the development of an Accountable Care Organisation (ACO), which is described in more detail in Chapter 2, Section 2.1, and due to the unique circumstances that made development of a linked dataset across all settings of care and wider determinants of health feasible. This is described in more detail in Chapter 3, Section 3.2.

This chapter has provided the background and rationale for this thesis, including economic concepts that are relevant to the research work that follows, and described the aims and objectives. A case study in Chapter 2 provides the perspectives of working across setting boundaries from leaders in B&D, Havering and Redbridge (BHR). In Chapter 3, I report the details of a linked dataset that was created to aid understanding of individual level service use across five settings of care. It forms the dataset for the subsequent research work. I describe the analysis of service use and population volumes for 32 possible combinations of service use across five settings of care in Chapter 4. In

Chapter 5, I investigate the associations between covariates and health and social care service use by setting of care, using a two-part regression model. I then review the impact of having an informal, unpaid carer on service use by setting of care using a matched cohort analysis in Chapter 6. Chapter 7 summarises the findings of the thesis and discusses the implications for policy and research.

2 System-wide collaboration? Health and social care leaders' perspectives on working across boundaries

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As outlined in Chapter 1, better integration across settings of care has been a long-standing ambition of the NHS in England. The current NHS payment system employs a blend of different payment methods across different services and sectors. Financial incentives have been identified as a key barrier to enabling organisations to work together, with separate payment systems often giving conflicting incentives (30, 52). Recent policy changes promote pooling of budgets on a larger scale, including the development of ACOs and, more recently, ICSs.

2.1 Background

A growing, ageing population that are living longer with more complex care needs has reinforced the international call for integration across services. Coupled with the £22 billion efficiency gap the NHS in England needs to close by 2020 (2), the current delivery model of services is unsustainable. Now, more than ever, organisations need to work together across professional, organisational and sectoral boundaries to drive quality and efficiency improvements in service delivery, although obstacles to collaborating across boundaries have been identified (53, 54).

One of the key obstacles identified as a barrier to enabling organisations to work together is financial mechanisms, with the separate payment systems often giving conflicting incentives (30, 52). Examples of incentive schemes to promote quality improvement and efficiency savings across care organisations and sectors are increasing. International examples include implementing integrated care management alongside pooled budgets (Australia, Canada, USA), and structural integration alongside pooled budgets (Sweden) (55, 56). In England, these include: localities pooling budgets across pathways and population groups (2); the Better Care Fund (BCF), which aims to accelerate integration of health and social care (57), and provide implementation levers for Health and Wellbeing Boards; recent policy changes to facilitate devolution of budget accountability allowing pooled budgets on a larger scale (58); and development of ICSs and ACOs to move budgetary control for multiple settings into one organisation (52, 59).

In response to The London Proposition (60), which set out ambitions for further devolution to London in support of public service reform, the three boroughs of

BHR began working together to develop an ACO for the 750,000 population they serve. Overcoming conflicting organisational responsibilities and priorities, and funding of individual bodies, were key drivers for the new approach.

Furthermore, the creation of ICSs and ACOs has become a core component of the delivery of the “NHS Five Year Forward View”, which was published in 2014 and set out a shared view on how services would need to change, proposing seven new models of care (2). A group of eight ICSs were announced in June 2017 (61, 62). ICSs have collective responsibility for the resources and health and wellbeing of a defined geographical population, whereas an ACO also holds a single contract with a single organisation for the provision of health and care services for that population (62).

The BHR ACO aimed to remove commissioner-provider distinctions by taking ownership of, and applying new ways of contracting and distributing, the combined health and social care budget. The partners had established working relationships at a system level through the: Urgent Care Board, established in June 2013 as an advisory board to drive improvement in urgent care; the BHR System Resilience Group, in part triggered by the ongoing performance challenges in the local acute trust; and the Chief Executives’ Forum. In 2016 the governance structures were further refreshed creating the Integrated Care Coalition, chaired by a local authority chief executive and the forum through which the ACO work evolved. The Integrated Care Coalition is an advisory board to oversee strategic change across health and social care, and replaces the previous Chief Executives’ Forum. It was created to develop a joint approach to integrated care (commissioning and delivery) to build a sustainable health and social care system.

Key features of the BHR ACO proposal include:

- Whole population coverage, 750,000 residents
- Eight partnership organisations – three local clinical commissioning groups (CCGs); three local authorities (London boroughs of Havering, Redbridge and B&D); an acute hospital provider (Barking, Havering and Redbridge University Hospitals NHS Trust); and a community and mental health provider (North East London NHS Foundation Trust; NELFT)
- Devolved budget of £1.2 billion per year, combining health budgets with adult social care and public health
- Ambition to achieve improvements in population health outcomes alongside efficiency gains
- Facilitating changes to service delivery and system-wide investment to meet a forecast gap of £430 million by 2018/19. Underpinning this was a desire to reduce acute care expenditure and move activity into community settings
- Increased focus on health promotion, prevention and community-based interventions to reduce reliance on acute care

The development of an ACO in BHR, a geographical location with existing strong leadership relationships, provided an opportunity to explore some of the questions arising from the literature on integration in more detail. In particular, how do the partnership organisations work collaboratively across the full system of care? Are there settings for which integration remains a challenge? In particular, are there specific challenges associated with integrating across sectors, in this case health and social care? The policy ambitions for integrated care, described above, included the implementation of financial mechanisms to facilitate collaboration across health and social care. With financial incentives

continuing to be widely acknowledged as a barrier to integration, what does this mean in practice? What is the difference between having the financial mechanisms to collaborate, and the financial incentive to do so? With growing policy attention on ACOs, is there alignment on the need for a structural solution to integration within a site that has existing strong leadership and a history of collaboration? This research project sought to understand local leaders' perspectives on collaboration across settings of care and across health and social care, enablers and barriers to collaborative working, including the role of financial mechanisms, and whether a structural solution is required.

2.2 Aim and research questions

This was a qualitative case study, with semi-structured interviews with key leaders and decision makers across health and social care organisations in BHR, and national leaders, between April 2016 and August 2016. National leaders were included to place BHR in a wider context and to compare insights from this case study with developments in other areas nationally. The interviews sought to understand:

- Experiences of working across organisation and sector boundaries for the benefit of the population, including enablers and barriers encountered
- How system-wide financial incentives influence working across organisation and sector boundaries
- Aspirations for the ACO, what it is hoped to achieve and how, and potential limitations

2.3 Methodology

A qualitative case study was conducted to explore the implementation of ACOs in the context of a local system. In-depth interviews were conducted with staff in senior leadership positions, who make operational and/or financial decisions for their organisation, in organisations that commission or deliver health and/or social care to the population of BHR. There are 12 organisations within the three boroughs. Relevant roles included: Chief Executive Officer, Director of Finance, Medical Director, Director of Commissioning and Director of Adult Social Services. A combination of purposive sampling and snowball sampling was used (63). Eligible participants were identified through documentary analysis and validated by key leaders in BHR. In addition, participants were asked to recommend colleagues to be interviewed. A maximum of 30 interviews was anticipated to ensure feasibility.

2.3.1 Data collection

Of the 48 people invited to participate, 35 agreed to be interviewed; interviews lasted between 25 and 55 minutes (Table 2-1).

Table 2-1 Type of organisation and role of interview participants

<i>Type of organisation</i>	<i>Role</i>	<i>Number of participants</i>
Health provider (acute, mental health, community)	Chief Executive Officer	1
	Finance Director	1
	Medical Director	2
	Nurse Director	1
	Other	4
	Total	
	ACO lead	1
	Chief Executive Officer	1

<i>Type of organisation</i>	<i>Role</i>	<i>Number of participants</i>
Clinical Commissioning Group (CCG)	Chief Operating Officer	1
	GP chair	1
	Total	4
General Practice (GP)	GP Federation Chair	4
	GP	1
	Total	5
Local Authority	Chief Executive Officer	2
	Director of Adult Social Services	2
	Director of Public Health	3
	Other	2
	Total	9
Policy makers	Chief Executive Officer (Policy think tanks)	2
	Director of Public Health	1
	GP	1
	Other	4
	Total	8
Total		35

Potential participants were invited to participate by email, which included the information sheet and consent form as attachments (see Appendix 4 and 5). On acceptance, a date and location for the interview were confirmed. All interviews were conducted in a private setting; the majority took place in the participant's work office. In several instances a telephone interview was requested. Consent forms were collected at the interview (or emailed by telephone participants), with verbal consent reconfirmed at the start of the interview.

Interviews followed a topic guide (see Appendix 6), using methods described by Britten and Patton (64, 65). The interviews explored: respondents' experiences of working across organisation and sector boundaries for the benefit of the

population, including enablers and barriers encountered; their perspectives on the role system-wide financial incentives play in facilitating or hindering multi-sectoral working; and their aspirations for the ACO. Interviews were audio-recorded and transcribed, with primary data stored on a secure server. The data were managed using qualitative analysis software, QSR International's NVivo 11. Data from the interviews were analysed using thematic content analysis (66). Emerging concepts were identified, coded, refined and compared iteratively in order to extract robust themes from within and across interviews. This provided transparency on coding schemes and ensured study rigour with all themes being traced back to source quotes and set in the context of the interviewees' wider responses.

2.4 Results

Four themes emerged from the thematic analysis with regards to the experience of and perspectives on working across organisation and sector boundaries:

- There are operational differences between councils and the NHS which could hinder multi-sectoral working
- Financial mechanisms are in place to support cross-organisation working but organisations do not participate if doing so negatively impacts their financial or operational performance
- Primary care is central to place-based working but the terms of participation need to recognise the different perspectives and scale of individual practices
- To make population health a priority requires overcoming short-term crisis management and finding ways to make long-term improvements

Each theme is described below. In addition, participants shared their perspectives on the emerging ACO, and whether it could overcome some of the difficulties associated with multi-sectoral working identified in the themes from the interviews.

2.4.1 Differences between councils and the NHS

Participants described the challenge associated with the local democratic leadership of councils in contrast to the “command and control” NHS. The different governance and operational arrangements lead to different freedoms and behaviours. For example, the NHS has centrally driven policy and operational targets, whereas councils have locally set agendas.

“You get political pressures nationally for the NHS around what you must and must not do. At the same time you’ve got that democratic bit that plays in around the local authorities, or individual providers, and sometimes we need to be braver. I think you’ve always got one eye on what is the ask of you nationally for the NHS. Then what you look to do is try and reconcile or align those with the system asks.” **CCG**

Interviewees described differences between councils and the health system with regards to the concept of failure:

“...in local government service failure precedes financial failure. Financial failure is the ultimate sin. In health care financial failure always precedes service failure and service failure is the ultimate sin.” **Policy maker**

The inability of NHS organisations to achieve annual financial balance was described by several local authority respondents as impacting their appetite for partnerships.

The operational differences between councils and the health system were described with regards to the process of commissioning. Several interviewees described health service commissioning as “playing shop” with the financial risk never actually present:

“Well because actually we're not transferring any genuine risk, it's all on the government's risk. We bear ... we take ... we don't change any of the public sector's risks or responsibility. We move around who, within the bits of the public sector organisations, are directly accountable for that, but all of the money sits on the government, the Department of Health's balance sheet” **Policy maker**

“...an enormous amount of effort in the NHS goes in to playing shop. There's some really talented people and if we freed some of these really talented people up to stop playing shops, writing contracts that aren't worth the paper they are written on, to actually improve the service, we'd make progress” **Local Authority**

One interviewee highlighted the importance of the different funding models, with social care subject to means testing and user charges whereas NHS services are free at the point of delivery. Creating one organisation across health and social care could challenge these differences and change eligibility criteria for services for local populations.

Local partners managed the tensions described above through reliance on the strength of relationships. Local authorities referenced frustration at the differences with how NHS organisations are managed and regulated, but had an overriding commitment to overcoming tensions due to the importance of health services to the voting constituents.

In summary, the operational and regulatory differences between the health system and councils were seen by interviewees as a barrier to multi-sectoral

working, inhibiting the collaboration of health services with council departments (including social care).

2.4.2 Financial mechanisms

Participants described financial mechanisms that are in place (e.g., Section 75 agreements and pooled budgets) that allow organisations to work together across sectors.

“[financial barriers are] a bit like PFI in relation to financial failure. It's the convenient and publicly acceptable excuse for not doing things....So actually there is nothing, as I understand it at the moment, that would stop most local authorities and health bodies signing really comprehensive Section 75 agreements and pooling huge amounts of their money. Not to say it's not difficult, it does have its own challenges and things but actually there's a legislative vehicle there that's been around for a long time.” **Policy maker**

However, local authority and commissioner participants highlighted that using these mechanisms requires strong leadership and relationships between individuals and organisations.

“I don't think we'd have made the progress with that particular organisation if we hadn't had strong working relationships and trust. I do think we can do all the numbers, all of the checking out of the costs and where the budget's going and all the rest of it, but actually if you don't trust each other and have that strong relationship then you wouldn't get agreement to it” **Local Authority**

Organisation priorities can often be in conflict with system-wide priorities due to both statutory duties and financial accountability. When this happens, the default action is to act at an organisation level, ensuring that financial and operational

performance can be maintained, not putting in place cross-organisation interventions even if the outcome is beneficial at a system level.

“...you’ve got a number of sovereign organisations that are driven by tariffs, charges and contractual roles that don’t necessarily align with cross-sector working.” **Local Authority**

Site participants referenced specific examples of system-wide initiatives where organisations did not benefit but leadership enabled them to participate regardless. The most frequently referenced local initiative was the Joint Assessment and Discharge (JAD) service. The council invested in 7-day social worker presence in the hospital to accelerate discharge of patients and reduce length of stay. The investment in that instance came from the council, but the health commissioners benefitted from reduced expenditure on acute services.

Emerging financial models to promote integration have not had widespread traction, and commissioner and provider participants described minimal gain relative to the local and national effort that has gone into testing different contracting tools.

The BCF is a national pooled budget across councils and NHS organisations, announced in 2013, to shift resources into social care and community services from the NHS budget in England; the BCF was used by several participants as an example of a national facilitator for multi-sectoral working by providing new money to fund collaboration (57, 67). It was often referred to as a “tick box exercise” rather than a mechanism to change behaviours or an incentive, and few thought it had achieved the ambitions of promoting health and social care collaboration.

"It's [BCF] nothing like new money, so all the rhetoric around this is all new money and opportunity I'm afraid isn't the case for us in [XX]. We felt the first round of Better Care Fund was a bit farcical to be perfectly honest... So the public think they're giving more money to social care, but they're not giving more money they're giving the existing money." **Local Authority**

There was consistency in the perspectives of site participants in the responses regarding financial mechanisms, and policy participants referenced and acknowledged the disconnect between some of the policy ambitions and how these were translated at a local delivery level.

In summary, the literature suggested financial incentives in the system hinder cross-organisation and cross-sector working. In contrast, interviewees described financial mechanisms that are in place to facilitate collaboration but the system incentives drive organisations to prioritise their own sustainability. Therefore, except for exceptional circumstances, cross-organisation collaboration will only happen when all participant organisations receive a benefit or at least no negative impacts.

2.4.3 Primary care

When asked for examples of integration, local authority and health provider interviewees shared examples where organisations had worked together to change how services were delivered. Examples included the development of the JAD team in an acute hospital, the creation of a joint health and social care service in one borough following the transfer of the social care team to an NHS organisation, and an Urgent Care Centre. By contrast, all GPs interviewed provided examples of integration at a micro service level. For example, one

described how changing the way in which a community nurse worked improved support for sexual health. Another described the positive impact of the ability to email hospital colleagues on working time efficiency and access to second and expert opinions.

Primary care interviewees, including those that chair CCGs, described that being a small business had an effect on their ability to participate in system-wide change, such as the emerging ACO. They referenced the difference in budget size between large acute providers and single practices, and the financial risk associated with participating in some of the proposed changes to service provision. Although GP leaders were able to engage in conversations at a system level, the delivery implications reverted back to perspectives of individual primary care practices and how to achieve action across the collective GP provider community.

“they've got huge amounts of money in the hospital that they're moving around but your [GP] entire livelihood and life is in their rounding number.” **Policy maker**

“there have been times that we felt under pressure to provide something with a financial level of risk that we don't feel is acceptable, and I think that does reflect the financial constraints and position of our Commissioners. So they're obviously always trying to find a way of getting more efficiency and they want to transfer some of the financial risk to us. Which we obviously have to resist, because that's the way the company works.” **GP**

Interviewees also described the challenge of engaging with GPs given that primary care is commissioned centrally by NHS England.

“there isn't an ability of the local services to call primary care, or GPs as businessmen, to account, because their accountability isn't local, it still really sits

with NHS England. So unless there is a real motivation amongst primary care to do that, rather than be businessmen, I think that's problematic" **Health provider**

In summary, primary care is a collection of small practices in contrast to the large scale of other health providers. Interviewees described how this impacts both the perspective of primary care providers, who focus on the micro delivery of care, and the ability of those providers to participate in large-scale change where financial risks are considerably larger than those that can be absorbed by small businesses.

2.4.4 Population health

Several of the interviewees acknowledged that short-term crisis management continues to dominate priorities and system activities, with little opportunity to step back and focus on longer-term interventions. This is further reinforced through the nature of a politically responsive system, with a three-year political cycle and ambition to make changes within that timeframe. Whilst delivering improvements in population health was the core motivation referenced by most interviewees for the development of the ACO, the time horizon for impact was consistently acknowledged as a challenge for shifting attention and investment.

"public health cannot demonstrate that people will be dead in the street as a result of not doing things, so it always gets trumped by the need for people to take resources and fix the immediate crisis, of which there seem to be endless amounts" **Policy maker**

Several local authority staff discussed the changes happening within their council, moving from support being accessed and managed at a department level to a more comprehensive service. This was in recognition of the large number of users that span departments and the opportunities to offer more

holistic support when addressing their multiple needs together. This is similar to the transition in health services, moving from disease-based care to better manage people with multiple long-term conditions and elderly populations by looking at their holistic health and care needs.

In summary, high cost hospital service users have dominated the focus of initiatives to achieve cost savings for the NHS. The interviewees described that the need for an immediate short-term impact on closing the funding gap made investment in upstream prevention with longer-term outcomes harder to action, even within an ACO.

2.4.5 Perspectives on the BHR ACO

There were consistent aspirations for the BHR ACO, with interviewees describing ambitions for improving population health alongside creating a financially sustainable system. However, there was no consensus as to whether a single organisation was needed to achieve these ambitions or whether system alliances across the partners would suffice. Descriptions highlighted different perspectives on the definition of an ACO, with some describing the ACO as a mechanism to achieve collaboration, but with organisations maintaining individual sovereignty, whereas others described the need for one organisation, an ACO, as essential to overcome the challenge of organisations' self-interested behaviour. Irrespective of this, the majority of those interviewed did not think the ACO would be able to capture the scale of savings required to be financially sustainable in either the short or medium term. All interviewees described the financial implications of the ACO as having an influence on their organisations' participation in the ACO, with the majority placing this as the biggest influencing factor. The second most frequently referenced factor was the strength of leaders

to deliver the ACO, with some referencing the need for strong relationships between leaders and trust in one another. Further influencing factors mentioned included whether resources would be available to deliver the programme, the reputational impact of either participating or not participating, and the importance of health services for the local population and, therefore, the importance of councils' participation to political leaders.

2.5 Discussion

2.5.1 Comparison with the literature

There were four principle findings with regards to working across organisation and sector boundaries. Firstly, differences between councils and the NHS. It seems unlikely that the implementation of ICSs and ACOs will be able to overcome them without making fundamental changes nationally. In creating one organisation across health and social care, the differences in funding (means-tested social care and tax-funded health services) need to be acknowledged. There are risks that the boundaries between services with different funding models could be obscured and eligibility criteria changed, and, in turn, more services could become self-funded and health inequalities potentially widened (68). The "Greater Manchester Agreement: Devolution" (58) changed the financial flows, but did not address the tension described by interviewees between a centrally run NHS and locally led council or change the incentives associated with maintaining organisational financial performance as a priority reinforced through regulation.

Secondly, financial mechanisms. Across published literature there is wide recognition that the structure of financial payments across services does little to

support cross-sector working and achieve policy ambitions of integration and shifting care out of the hospital setting (30). The implementation of policy initiatives to create financial mechanisms to allow collaboration across health and social care is, in part, recognition of the operational differences interviewees described across the two sectors. Furthermore, although it was acknowledged that financial mechanisms did not facilitate organisations to participate in cross-sector working, they were not perceived by interviewees as a barrier. Rather, the biggest challenges are having in place trusting relationships among leaders and strong leadership (69) that is able to have the confidence to invest in system-wide priorities even when they are in conflict with their own organisation's priorities. Perspectives on what constitutes strong leadership in the evolving health and social care system are also changing, with a call for system leaders equipped to work across traditional system boundaries (70, 71).

Thirdly, primary care is central to place-based working but the terms of participation need to recognise the different perspectives and scale of individual practices. The reflections of interviewees were largely associated with primary care operating as a series of small businesses. Nationally, the landscape of primary care provision is changing. There are increasing examples of organisations that have enabled GP practices to work together in different formats, either under umbrella organisations or as a larger organisation (72, 73). In the NHS in England, three-quarters of practices are now working collaboratively in larger-scale organisations (72). Madan et al. (2017) suggested that working across groups of practices is required in order to be able to integrate with other providers, the primary care perspective of those working in such groups may differ from that shared by the interviewees. However, many of these collaborations are in place to achieve operational efficiency for practices

and to implement electronic tools, such as electronic prescribing, new booking systems and appointment allocation. The results of the interviews suggest that GPs are influenced by initiatives that impact their operational day to day. GP input into strategic and system-wide initiatives may still remain a challenge given the wide-ranging perceptions across the GP community. The tensions between GP leaders in commissioning organisations and their role as providers remain. Recognising the operational reality of primary care may facilitate progress.

Finally, to make population health a priority, the ambition for which underpins the move to more integrated working, requires overcoming short-term crisis management and finding ways to make long-term improvements. The dominance of acute activity in health spending in the NHS continues despite decades of policy initiatives to move investment upstream (74). In addition, following the move of public health into councils in 2013, projections suggest decreased expenditure on public health and decommissioning of several prevention services (e.g., smoking cessation and sexual health promotion). Population health was a term broadly used by interviewees. Research suggests use and understanding of the term are wide ranging (75). The health of a population is influenced by a wide range of factors and the interactions between them. Although health care services play an important role in keeping people healthy, estimates suggest that wider social, economic and environmental factors play a greater role (10). There is established evidence on the impact specific initiatives can have; however, local information is not always readily available to present and contrast with shorter-term investment decisions and priorities. In addition, investment upstream where benefits are realised over a long time horizon and potentially on another organisation's balance sheet, requires overcoming the challenges associated with cost and benefit allocation.

2.5.2 Strengths and limitations

The interviewees were from a wide set of roles, providing a breadth of perspectives and opportunity to identify alignment across different organisations: front-line providers, system leaders and national policy makers. The recording and transcription of interviews facilitated a detailed analysis of the themes and provided clarity on the level of alignment across different interviewees, as well as providing quotes to support these findings. This approach reduced bias by ensuring that themes were not enforced but reflected outputs of the interviews. Interviews with national leaders were conducted to understand if perspectives were specific to the case study site or more generally present across England. The selection of a case study that included characteristics associated with successful integration was deliberate to aid understanding of whether a policy ambition for structural solutions to integration was required. Although in-depth interviews were not conducted with participants of parallel programmes, such as Greater Manchester devolution or with the four other boroughs who were delivering programmes in response to the London proposition, information about these programmes was incorporated into the analysis.

The interviews were conducted between April 2016 and August 2016, since then the policy environment has developed further. This includes: the publication of STPs (3), which for BHR includes four additional boroughs; the publication of the London announcement for “Health and Care Devolution” (60); and the announcement of eight ICSs across England (61). All sustainability and transformation partnerships across the NHS in England are expected to become ICSs by April 2021 (13).

2.5.3 Implications for policy and practice

For organisation leaders across health and social care, these findings suggest that although participation in system-wide collaboration could have financial and operational impacts on their organisations, there may be mechanisms in place to enable participation, even when their organisations will be negatively impacted.

The stroke example described in Chapter 1, Section 1.3.1, highlighted challenges associated with delivering initiatives or changes which have negative impacts on provider stability (financial or operational). In that instance, national action was required to make progress and change the financial consequences for providers. The example of the JAD team from the interviews is another scenario in which the benefits of investment from one organisation (and sector) were realised in another organisation, with social care funding social worker staff in the hospital, at a cost to the council, to deliver improvements in hospital efficiency. This was delivered by local leaders without the need for national intervention and reinforces the view that disconnects between organisation and system perspectives can be overcome when strong leadership is in place. In addition, in the JAD example, the information on the cost and consequences was more accessible at the point of decision making, unlike the stroke example.

The perceptions and perspectives of the primary care community are worth noting when developing approaches to move towards more place-based care, given the dominant role GPs have in the delivery system.

The implications of these findings for policy makers are important. With the continuing ambition for health and social care integration (76), progress will require acknowledging the fundamental financial and operational differences, described above, in how the NHS and councils work. To achieve progress in

population health, policies need to reflect the role all organisations can play in implementing change, as has been highlighted by the HiAP framework (34), and find mechanisms to balance short-term operational priorities with longer-term outcomes.

Policy for integrated care may see an increase in the creation of ACOs. There was no consensus across interviewees as to whether creating a single organisation would overcome the challenges described, namely, the fundamental differences in leadership, funding and regulation between councils and the NHS. Future research would be beneficial to understand the contrasting approaches of ICSs and ACOs for different STPs and their ability to increase cross-sector working between NHS organisations and councils.

2.6 Conclusion

The financial position of the system was described by interviewees as motivation for participating in cross-sector working. Health and social care expenditure continues to be dominated by high cost acute services. Given the wider role social, economic and environmental factors play in achieving improvements in population health (10), future research would be beneficial to understand if there are specific population groups that would particularly benefit from cross-sector working with NHS organisations . This will need to include analysis of costs of service utilisation in each setting of care in order to control for the dominance of acute costs.

The next chapter sets out the creation of a dataset containing the costs of individual level service utilisation for residents of B&D for five settings of care and socio-demographic, health and household variables that may influence that

service use. This dataset was used for the analysis described in Chapters 4, 5 and 6.

3 Creating an individual level linked dataset across health, social care and council administrative data

In order to understand population service use across all settings of care, I created a linked dataset across five settings of care: hospital, primary, community, mental health and social care. The dataset variables were informed by the literature summarised in Chapter 1 that outlined variables associated with health and social care spending in the UK. This chapter summarises the dataset which is then used for the analysis in the three chapters (4, 5 and 6) that follow.

3.1 Linked datasets

A Wellcome Trust report on data linkage defined it as “*the linkage of health data within and across organisations, and as well as linkage between different data sources such as hospital admissions, cancer registries, and socio-economic surveys*” (77).

Internationally, there is growing use of linked datasets to build a more complete understanding of population profiles and population-wide health and care service utilisation. Public health and epidemiology research in particular have been enhanced by connecting different sets of information together. There are countries where the infrastructure of data records about individuals makes the linking process accurate and feasible. In particular, Sweden has been able to connect data registers together due to the identification numbers that are given to every resident; the identification numbers are used on government, employment and health records and are unique for each individual.

In the UK there is substantial investment at a national level into programmes to enhance data linkage and access for both research and service delivery purposes. Examples include the establishment of Health Data Research UK (78), the LHCRE programme (79) and Digital Innovation Hubs (80).

The NHS number, a unique individual identifier, facilitates linkage of individual records across different datasets to provide a richer understanding of individual health and social care utilisation by care setting and overall. To date, research into service utilisation has focused on individual settings, such as emergency attendance (81), specific disease pathways, such as diabetes (82), or sub-cohorts of the population, such as patients diagnosed as having five or more long-term health conditions (83, 84) and patients aged over 65 (85).

The NHS identification is used on health records and a growing number of social care records, but not on wider data registries. Employment data (which use National Insurance numbers), schools (which use education reference numbers) and electoral registries (which use individual electoral registration numbers) all use different individual identifiers, making data linkage both inaccurate and hard to implement. A review conducted by Nesta into eight case examples of councils linking data within the council and in some instances with health data outlined 11 discrete uses of connected data, from informing public service transformation through to testing what works (86). However, in most instances the uses of connected data were discrete and small scale.

In the UK, at the time of the research programme initiation there was no existing dataset that contained unit level activity from all five settings of care or one that could be linked to household information (see Table 3-1). I therefore built a bespoke data resource.

Table 3-1 Examples of linked datasets across health and social care in the UK

Dataset	Description	Geography	Time period	Settings covered					
				Hospital	Primary	Community	Mental health	Social care	Council data
Kent Integrated Dataset (KID)	The Kent Integrated Dataset (KID) aims to provide insight into system-wide health and care utilisation for the whole population of Kent and Medway.	Kent and Medway, 2 million population	April 2014 onwards, with new data added monthly	X	X	X	X	X	
SAIL databank: Secure Anonymised Information Linkage for Wales	The SAIL databank contains multiple different datasets about the Welsh population over a 20-year period that can be linked together using a linkage key. It includes health, screening data, disease registries, the address register and education attainment.	Wales, 3 million population	2007 onwards	X	X	/			/
CRIS: Clinical Record Interactive Search system	Mental health activity and free text data from patient records from South London and Maudsley NHS Foundation Trust.	South London, 1.2 million population but only contains those that have had a mental health service contact	2007 onwards	X			X		/
Connected Health Cities	Initiative across four sites in the North of England that was launched in 2016, aiming	4 million population across Liverpool, Greater	Data only partially live in 2019, with	X	X	X	X	X	

Settings covered

Dataset	Description	Geography	Time period	Settings covered					
				Hospital	Primary	Community	Mental health	Social care	Council data
	to bring together data on health care, social care and council information.	Manchester, Yorkshire and North East and North Cumbria	council data due to be added in subsequent years						
Clinical Practice Research Datalink (CPRD)	CPRD collects de-identified patient data from 674 GP practices in the UK, with coverage of over 11.3 million patients. It is possible to link to other datasets which include hospital activity and demographic data.	Sample of the UK population, with 674 practices and 4.4 million active patients	Variables dating back to 1988, with on average 5 years of data per person	/	X				
Whole Systems Integrated Care (WSIC)	A database in North West London, updated monthly, providing front-line staff with dashboards that identify activity in other settings their patient has received. Access for external research purposes is unclear.	North West London, 2.4 million population	April 2014 onwards	X	X	X	X	X	

Dataset	Description	Geography	Time period	Settings covered						
				Hospital	Primary	Community	Mental health	Social care	Council data	
Scottish Longitudinal Study (SLS)	The Scottish Longitudinal Study was created as a longitudinal study to mirror those run by the ONS in England and Wales. Census, vital events and education data are maintained as a single databank accessible to researchers on a project-by-project basis; health data are added for specific projects on a time-limited basis.	5.3% sample of the Scottish population, with 274,000 individuals selected from 20 random birthdates in 1991. Data contains information on individuals and people in their household	1991 onwards, with census data updated every 10 years (2001, 2011)	X						X

Key:

X – Data available;

/ – Data partially available;

ONS – Office for National Statistics

3.2 B&D

B&D is a densely populated urban borough with 210,700 residents and high levels of deprivation, ethnic diversity and a young average age compared to the rest of the country.

The population was chosen as the cohort for the linked dataset for several reasons:

- **Relationships:** There were good relationships in place across senior leaders in health and council teams, such that there was support and ambition to achieve the linked dataset.
- **Data quality:** The council had invested extensive time internally to link datasets across different departments to triangulate information about residents in the borough. This was primarily to support a greater understanding of the functions of the council and to identify areas of duplication and potential efficiency gains. This provided a uniquely strong starting point, with higher levels of understanding of data quality and data completeness.
- **Data storage:** There was an established accredited Data Safe Haven in BHR CCG that provided the information governance processes and procedures to collate and store the data. This Data Safe Haven contained linked data on primary care and hospital activity and cost information for the population of BHR. The multiple uses of the dataset, including commissioning, performance monitoring, quality improvement and research had led to greater knowledge of data quality and data gaps

and an improvement over time in the quality of coding in the primary care records.

- **Population:** As a highly deprived borough, with high levels of unemployment, it was anticipated that there would be a large number of people in the population with social determinants of health that may make them more predisposed to ill health. As such it may make identifying cohorts for whom councils and health services could target collaboration easier.

3.3 Linking process

3.3.1 Information governance

The BHR Information Governance group oversaw the process and ensured all data transfers, storage and processing were in line with legal requirements. The programme operated within UK and European data and information governance laws to protect confidentiality. Access to person-level data for health services research is protected by certain controls that arose in response to concerns for individuals' rights, consent and ownership (87). In the UK, the requirements of the Data Protection Act have been interpreted as requiring that access to person-level data can only be allowed where there is explicit consent or in situations where the data can be anonymised (88). The dataset was created prior to the introduction of General Data Protection Regulation (89), following which additional requirements are in place for informed consent from the public on the use of data.

Individuals were able to opt out of record sharing. This was advertised on the BHR CCG website (and applicable to the full dataset they work with), which

provided information for individuals on arrangements to ensure fair processing of the data and information and on how to request information to be removed from analysis and data processing (90, 91). The data and information on individuals who request to opt out are removed at source, and nothing can be known about their attributes or characteristics.

In line with governance requirements to protect individual confidentiality, the patient and resident identifiers are held separately from the dataset and there is a separation between researcher access to the information and NHS staff access to the information, ensuring researchers have no access to the identifiers or identification key codes.

Given the inconsistent use of NHS numbers on records in the council datasets, sensitive information was required including name, date of birth and address to facilitate linking individuals from the council dataset to NHS numbers and therefore information from the other datasets. A data sharing agreement was put in place between London Borough of B&D (LBBD) and BHR CCG to facilitate the transfer of resident data and social care activity data. This was reviewed by their respective information governance groups and signed by both the Caldicott Guardians and the executive directors who held accountability for information governance and data sharing for their respective organisations.

Data transfers from NELFT for community and mental health data were in line with existing data sharing agreements that were in place for service delivery and commissioning purposes, and were all within the N3 network, a secure NHS environment for the sharing of person-level data.

3.3.2 Ethics

An overview of the creation of the dataset, information governance arrangements and research protocols were reviewed by the University College London ethics team. The Health Research Authority tool confirmed that NHS Research Ethics Committee review was not required as the proposed research activities were consistent with service evaluation and deemed as usual practice for public health. The dataset creation, storage, management and processing were all completed within the BHR accredited Data Safe Haven. Given no data were to be extracted from that environment, all analysis conducted within the environment and that the researcher only had access to de-identified information, it was deemed that no further ethical approvals were required.

3.3.3 Data variables

The variables of interest were informed by a review of the characteristics that are associated with health and/or social care utilisation in the UK (Chapter 1, Section 1.4). Practical consideration was given to availability of data and the quality of information available. The variables were separated into socio-demographic characteristics, health variables and household variables (see Table 3-2). These are described further in Section 3.6. The prime outcome variables were cost-weighted utilisation, which were calculated from individual level activity for each setting of care. The method used to calculate costs differed by setting and is described in Section 3.7.

Table 3-2 The variables contained in the research dataset

Variable	Description	Values	Source
Socio-demographic characteristics			
Age	Age group of the individual	19–49, 50–64, 65–74, 75–84, 85+	Primary care records
Gender	Whether the individual is Male or Female as documented in the primary care record	Male, Female	Primary care records
Ethnic group	The ethnic group of the individual, applying the ONS ethnicity groupings to the ethnicity documented in the primary care record	White, Black or Black British, Mixed, Other, Asian or Asian British, Unknown	Primary care records
Carer	Whether the individual is a carer, has a carer or both as documented in the primary care record	None, Has a carer, Is a carer, Has and is a carer	Primary care records
Health variables			
BMI category	The BMI category of the individual, assigned using the BMI value recorded in the primary care record	Underweight, Healthy, Overweight, Obese, Morbidly obese, Unknown	Primary care records
Smoking category	The smoking status of the individual, assigned using the smoking status recorded in the primary care record	Non-Smoker, Ex-Smoker, Smoker, Unknown	Primary care records
Count of long-term conditions	The count of how many of the 16 conditions, listed below, the individual has been diagnosed with	0–1, 2, 3, 4, 5+	Primary care records
Conditions	Whether or not the individual has been diagnosed with each of 16 conditions: Atrial Fibrillation, Asthma, Cancer, Congestive Heart Disease (CHD), Chronic Obstructive Pulmonary Disease (COPD), Dementia, Depression, Diabetes, Epilepsy, Heart Failure, Hypertension, Hypothyroidism, Learning Difficulty, Mental Health, Palliative Care, Stroke	1 if they have been diagnosed with the condition, 0 if not	Primary care records created from Read Codes. A full list of Read Codes assigned to each condition is available.
Household variables			

Variable	Description	Values	Source
Socio-demographic characteristics			
Benefits	If the individual is in receipt of Housing Benefit, Council Tax Benefit or both, the additional benefits they are also in receipt of	None, Employment Support Allowance (ESA), Pension, Income Support, Job Seeker's Allowance, Standard	B&D council housing department
Tenure	The legal status under which people have the right to occupy their accommodation	Owner occupied, Private rented, Social housing, Reside, Unknown	B&D council housing department
Occupancy	The number of people living in the household, grouped into categories	1, 2-4, 5-7, 8-10, 11+	B&D council housing department
B&D IMD quintile	The raw value of overall deprivation from the 2015 Index of Multiple Deprivation (IMD) (Office for National Statistics) was applied to the Lower Super Output Area of the address of the individual, and assigned to quintiles according to the distribution within B&D	1 (least deprived in B&D), 2, 3, 4, 5 (most deprived in B&D)	National dataset
Outcome measures: Service utilisation			
Total cost-weighted utilisation	The sum of individual level costs across hospital, primary care, community health, mental health and social care activity	Numeric value	Calculated in the dataset
Hospital cost	The sum of individual level costs for emergency department, elective and non-elective inpatient activity and outpatient activity	Numeric value	Hospital Episode Statistics (HES)
Primary care cost	The sum of individual level costs for GP contacts, non-GP contacts and prescriptions	Numeric value	Primary care records
Community health cost	The sum of individual level costs for community service activity	Numeric value	NELFT, the local community care provider

Variable	Description	Values	Source
Socio-demographic characteristics			
Mental health cost	The sum of individual level costs for inpatient and outpatient mental health activity	Numeric value	NELFT, the local mental health provider
Social care cost	The sum of individual level costs for social care activity	Numeric value	B&D council, adult social care department

3.3.4 Data flows

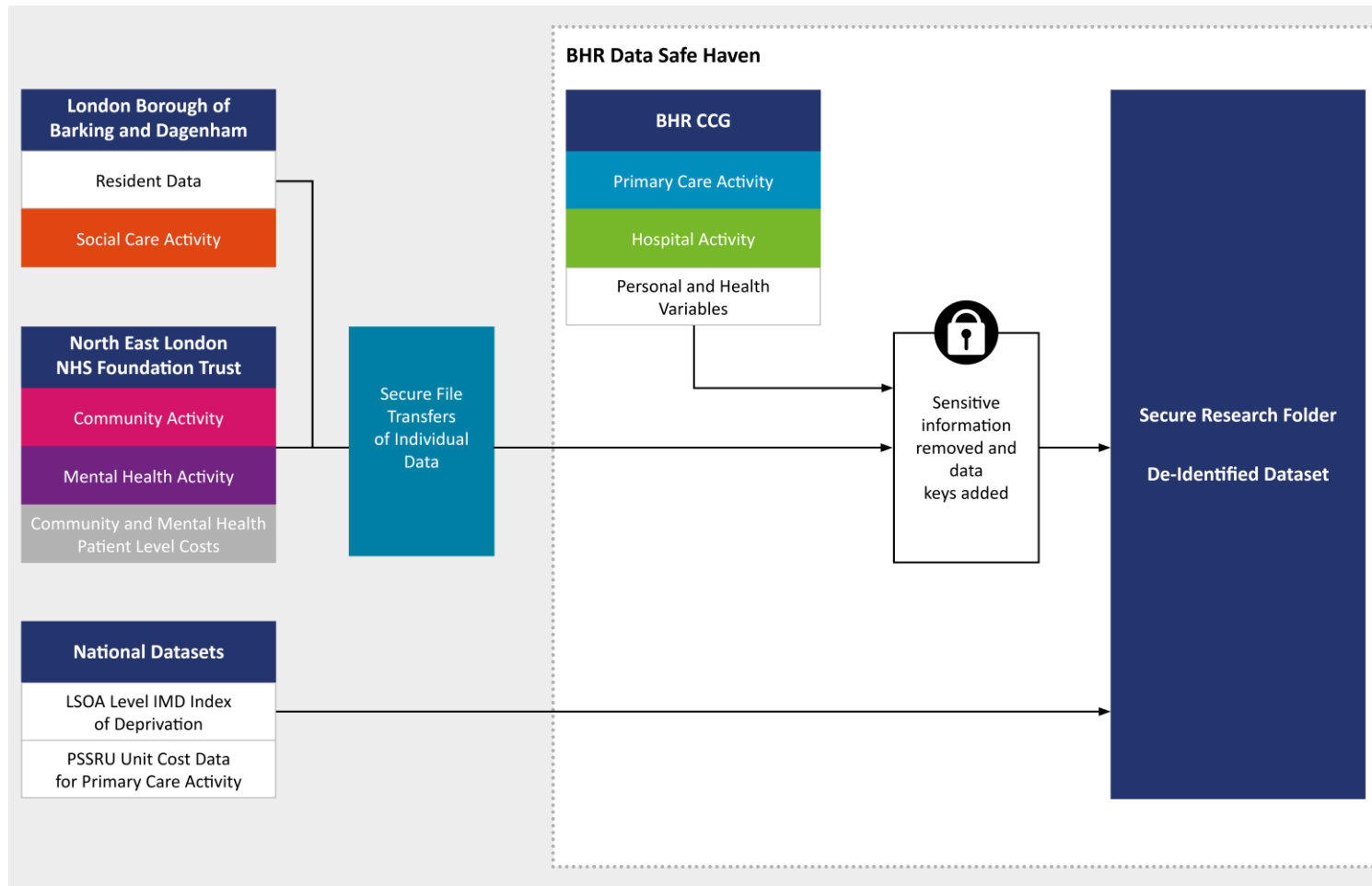
Figure 3-1 outlines the data flows. Primary and hospital data, and the information from primary care records on socio-demographic characteristics and health variables, were already in the BHR CCG accredited Data Safe Haven. There were two further organisations providing data, LBBD and NELFT.

The project uses individual level data in order to link different datasets together at the individual level. Most datasets included the individual NHS number, which was used for linking; however, where this was missing, fuzzy logic was applied using first name, surname, date of birth and postcodes. In order to ensure confident linking across datasets, sensitive data were required. The anticipated research work did not require individual identifiable data once the datasets had been linked together. Therefore, once the data had been linked, which was done by staff within the NHS, the full dataset was de-identified and put into a secure folder within the BHR accredited Data Safe Haven. Names and addresses were removed, dates of birth were replaced with year of birth, and dates of death were replaced with month and year of death. A linkage key was created, assigning an individual identification code in place of NHS numbers and a household identification code in place of Unique Property Reference Number (UPRN). Access to the linked dataset was limited to the research team and controlled

within the information governance protocols of the BHR accredited Data Safe Haven.

In addition, given the risk associated with each transfer of data, I agreed to perform the research analysis within the BHR accredited Data Safe Haven rather than extracting the data into a research environment. As the lead researcher, I was given an honorary contract with BHR CCG, the host organisation, for BHR accredited Data Safe Haven, and performed all analysis and data work from within a secure environment on the second floor of Becketts House, Ilford or through a secure remote access portal. Secure mechanisms for transferring data between organisations were in place for existing purposes and were utilised for transferring datasets from organisations to the BHR accredited Data Safe Haven as required.

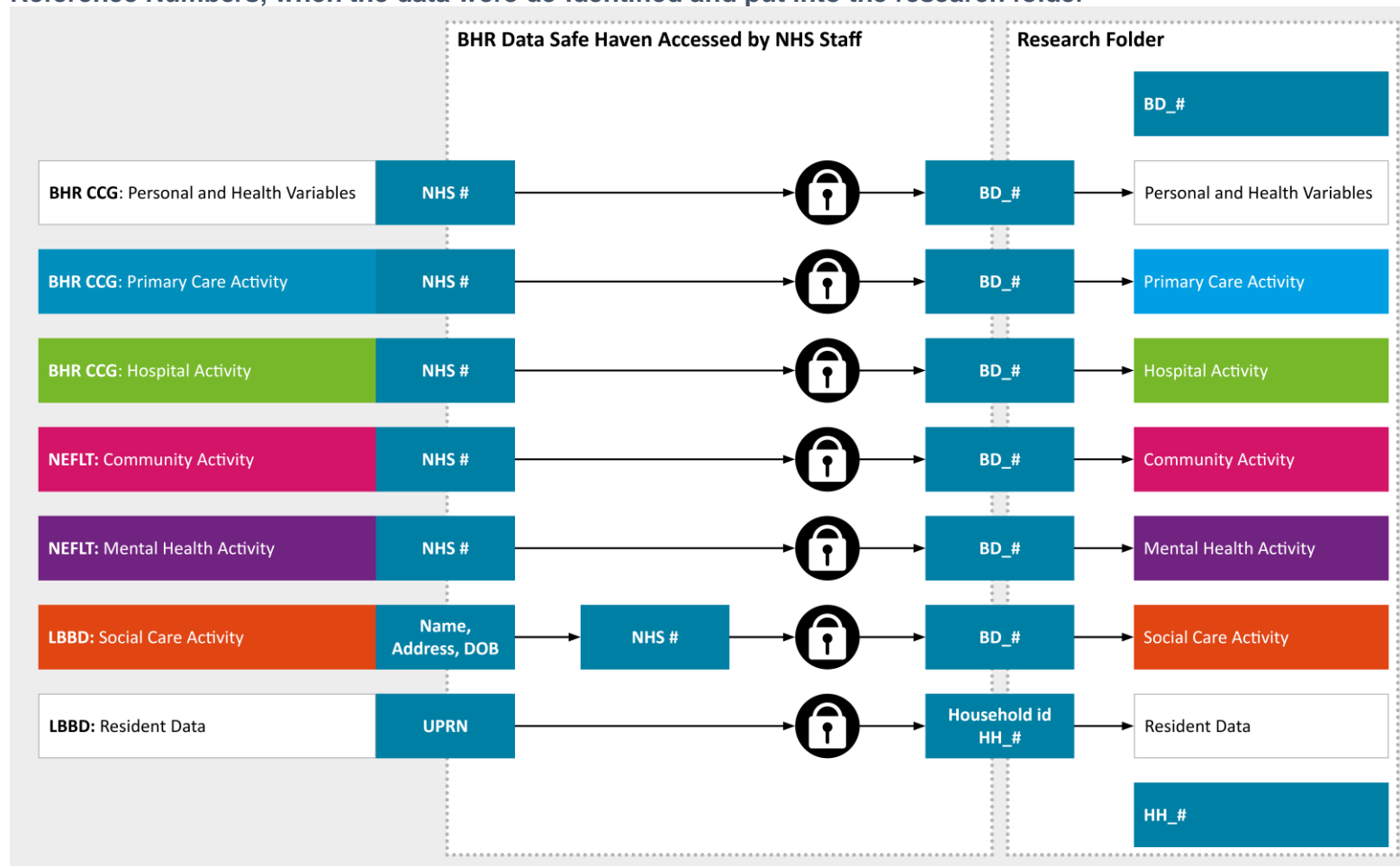
Figure 3-1 Data flow diagram of the sources of information for the Barking and Dagenham cohort dataset



3.3.5 The linking process

In line with best practice, for confidentiality and other reasons, there was a separation of data linkage processes and analysis of linked data. The identifiable data were only accessed by NHS staff who created the linkage keys, whilst the research group only accessed de-identified attribute data required for analysis. These linkage keys were passed to researchers, who could then merge the corresponding attribute data (e.g., activity from the different settings of care) required for the analysis (without ever seeing any identifiers). This linkage model creates enduring links that are stored in perpetuity within the system, meaning that records do not need to be repeatedly matched for different studies (92) and therefore sets the basis for further use of the dataset once the initial research programme is complete. This model builds on those used by others, in particular the Secure Anonymised Information Linkage databank in Wales which does not hold identifiers, but retains an Anonymous Linking Field, which is unique for each person and used to link multiple datasets together for different research programmes (93). Figure 3-2 illustrates how linkage keys were applied to the datasets.

Figure 3-2 Unique identifiers were added to the individual records in the dataset, replacing NHS numbers and Unique Property Reference Numbers, when the data were de-identified and put into the research folder



For all NHS activity, the NHS number was used on all records. This enabled exact matching which is both certain and simple to implement. Cross-checks were performed by NHS staff on age, gender and address to ensure accuracy.

Despite national policy in the UK recommending all social care records to include the NHS number by 2013 (94), fewer than 60% of the social care records included the NHS number. Where NHS numbers were not available, fuzzy logic was used to assign NHS numbers to council records using first name, surname, address and date of birth. The council team conducted extensive data cleaning across the records before transferring them for matching to ensure minimum data entry errors, for example in the formatting of date of birth, in the use of middle names in the first name field, and in transforming incomplete words into full names and addresses. Social care records across all years of data included 49,030 contacts, of which 8,003 were both missing NHS numbers and unable to be matched to an NHS number through fuzzy logic. Of the 8,003 contacts, 4,078 had activity in 2016/17 and 427 of those contacts had costs associated with them.

For council information on education, benefits, tenure and occupancy, fuzzy logic was used to identify individuals and assign them an NHS number in instances where an NHS number was not contained in the record. For those records where the matching could not be completed with confidence, in order to create a narrative on the service use and understand potential confounders, these records were still included in the dataset and marked “unmatched”.

On the council dataset, all individuals had the UPRN included. This was critical to facilitate grouping individuals into their households. The household data were

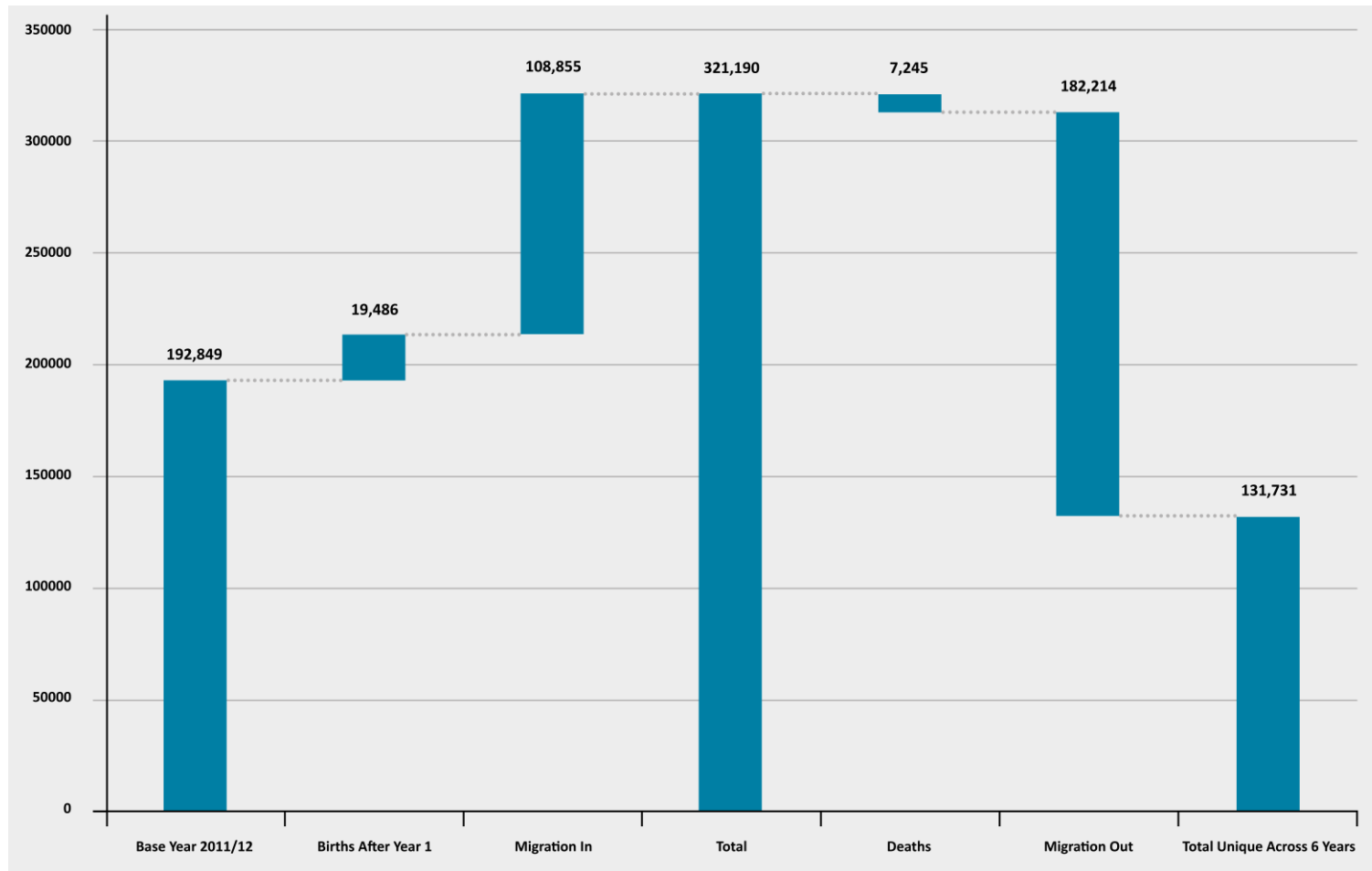
available for each UPRN. On transfer to the NHS data analyst team, the UPRN was replaced by a “householdid” identifier on both the household data and the individual records. This allowed household information in the research datasets to be linked to the individual information. There were some records that could be matched to a UPRN but not to an NHS number. These were kept within the base dataset to enable review of the level of overlap in the unmatched cohorts as well as provide the ability to conduct research at the household level in the future as appropriate.

There was also multi-level linking where additional data were brought into the dataset from nationally available datasets and applied at the Lower Layer Super Output Area (LSOA) level, for example for Index of Multiple Deprivation (IMD) values.

For the curation of the linked research dataset used in the analysis that follows, extracts from primary care records were used as the base information – including address and ethnicity – and overrode council records where there were differences. It was agreed that rather than include in-year changes to core fields (such as address and therefore UPRN and potentially also LSOA, or individuals changing the GP they were registered with), the dataset would take a snapshot of the socio-demographic characteristics and health variables on 1st April each data year.

The six-year dataset had a total of 321,190 individuals, of whom 131,731 were present in all six years of the dataset (Figure 3-3).

Figure 3-3 Total cohort numbers for Barking and Dagenham residents who were also registered with a B&D or Havering GP practice between 1st April 2011 and 31st March 2017



3.4 Cohort summary

The data request sought to facilitate both cross-sectional and longitudinal research work. As such, six years of data were collected from 1st April 2011 to 31st March 2017. There were limitations to the data quality for mental health and community services, with poor data accuracy before 1st April 2016 when clinical recording systems were not fully electronic. From 1st April 2016 activity data were captured electronically in RiO (a software system used for electronic patient records in community, mental health and children's services); (95). Data prior to 1st April 2016 were therefore not available. In addition, LBB Council was in the process of transitioning to new activity data capturing software for children's social care services. In the period of transition, it was not possible to get access to historic data records, with data availability from 1st January 2018 onwards only. Table 3-3 provides a summary of the years available for each of the components of the dataset. As such I made two decisions on the cohort to use for the rest of the research programme. Firstly, my research aim was to investigate factors associated with service use across health and social care. It was therefore agreed to focus on cross-sectional analysis for 2016/17 where activity data were available for all five settings of care. Secondly, given that children's health and care service use is different in nature from adults' and the lack of availability of social care activity data for children, it was agreed to focus the analysis on adults only. The full dataset was cleaned and maintained and is being used for additional research programmes as described in Chapter 7.

Table 3-3 The data years for which each of the dataset extracts were available

Data year	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
Socio-demographic characteristics and health variables from primary care	✓	✓	✓	✓	✓	✓
Household variables	✓	✓	✓	✓	✓	✓
Hospital activity	✓	✓	✓	✓	✓	✓
Primary care activity	✓	✓	✓	✓	✓	✓
Community activity	x	x	x	x	x	✓
Mental health activity	x	x	x	x	x	✓
Adult social care activity	✓	✓	✓	✓	✓	✓

Participants eligible for inclusion in the research dataset used for the analysis in the rest of the research programme were adults (age 19 or over) who were confirmed residents of B&D between 1st April 2016 and 31st March 2017 and who were registered with a GP practice in either B&D or Havering (a neighbouring borough for which I also had access to health data). Confirmed residents are defined as those who are present on the address register and on either another council dataset, the GP register or both (96). Whilst those in Venn diagram sections 4, 6 and 7 of Figure 3-4 were all confirmed residents, I only included those in sections 4 and 7 in order to ensure all individuals in the cohort were registered with a B&D or Havering GP practice and therefore health information

was available. In 2016/17, 91% (104,200) of the cohort were registered with a B&D GP and 9% (10,193) were registered with a Havering GP.

The full population was included to maximise generalisability of the findings and provide large enough cohorts for individuals to remain anonymous in analysis and outputs. Children were excluded because their patterns of service use differ from that of adults. Those who died during the year or who moved out of B&D before the 1st April 2017 were excluded from the cohort as they had less than 12 months of activity data, and the known increase in health care utilisation at the end of life (97, 98) could bias results. Figure 3-5 sets out the resulting cohort numbers. As described below the main outcome measure used in subsequent analysis is cost-weighted utilisation. Table 3-4 provides a summary of the total cost overall and by setting of for those included in the cohort, alongside the costs for the excluded populations of children (those aged 0-18) and those that died within year. The costs for children do not include those that were born between 1st April 2016 and 31st March 2017 as a result of the base of the dataset structure being those who were alive and resident in the borough on the 1st April 2016. Social care costs were also not available for children.

Table 3-4 The total costs by setting of care for the cohort included in the analysis in chapters 4, 5 and 6, alongside the excluded populations separated into children, people that died in-year, and the remainder.

<i>Setting of Care</i>	Total cost for adult cohort used for subsequent analysis n=114,393 £m	<i>Excluded from subsequent analysis</i>			Total across all categories £m	Costs for the cohort used in subsequent analysis as a percentage of total costs available %
		Total cost for children n=52,968 £m	Total cost for those that died between 1 st April 2016 and 31 st March 2017 n=952* £m	Total cost for those that moved out of the borough between 1 st April 2016 and 31 st March 2017 or were no longer a confirmed resident n=17,746 £m		
Total Cost	180.1	25.2	8.8	14.8	228.9	79
<i>Hospital</i>	63.3	7.2	5.3	5.4	81.2	78
<i>Primary Care</i>	42.5	4.9	0.6	2.0	50.0	85
<i>Community services</i>	32.6	10.2	1.0	1.8	45.6	71
<i>Mental health</i>	19.4	2.9	0.2	1.7	24.2	80
<i>Social care</i>	22.0	Not available	1.7	3.6	27.6	80

Figure 3-4 The Harper-Mayhew method was used to create the residents' matrix

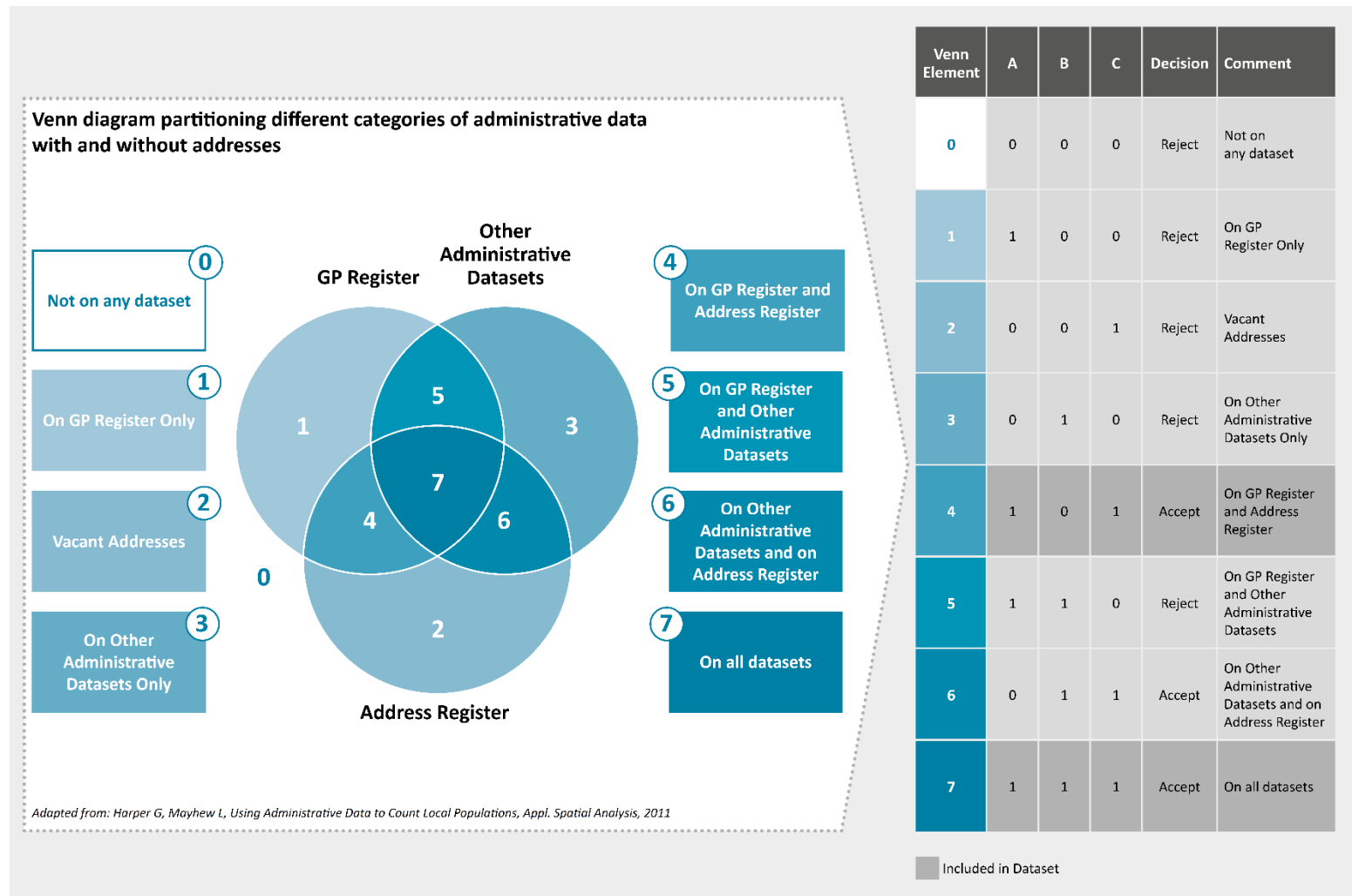
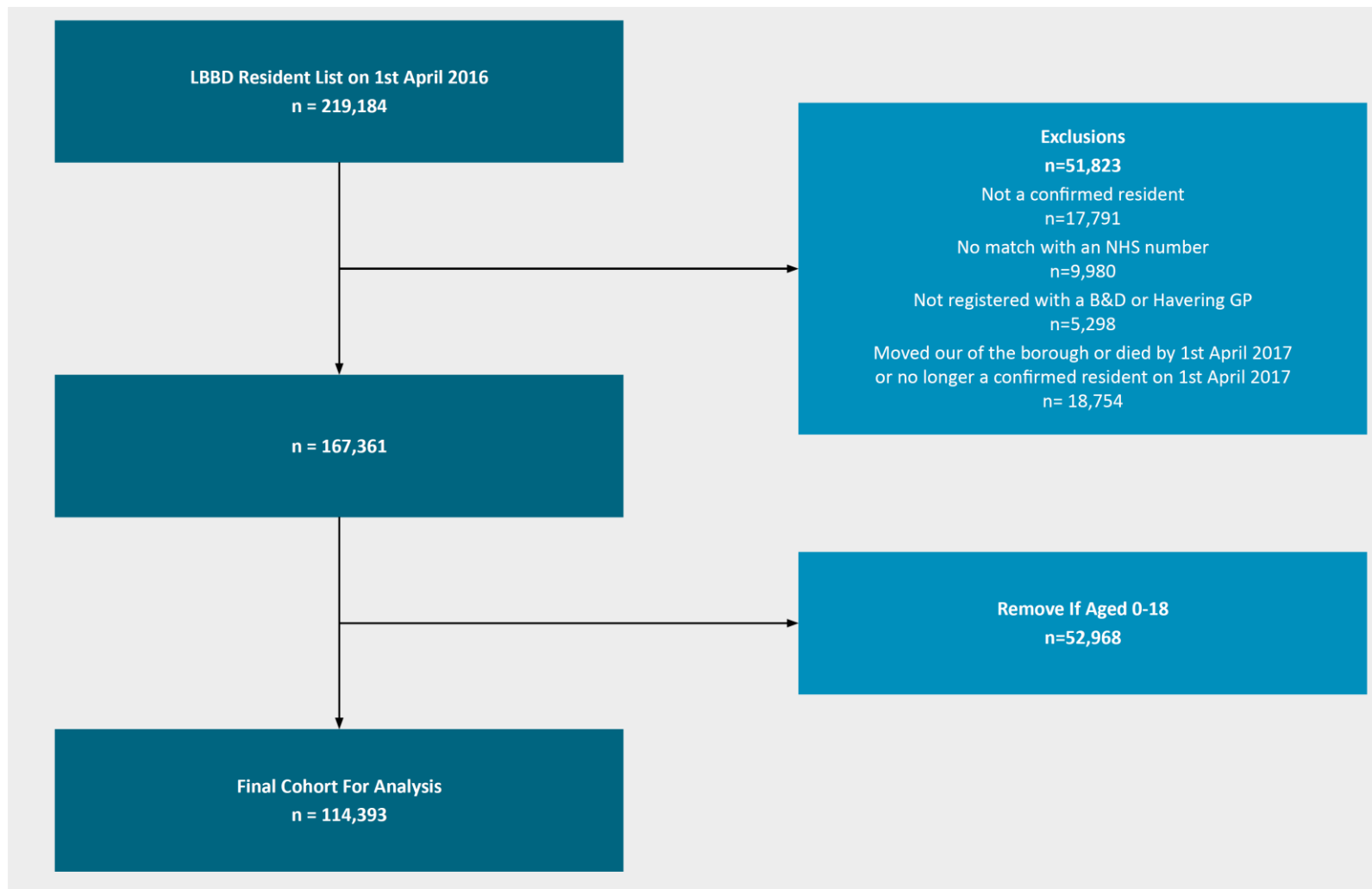


Figure 3-5 A flow chart showing the exclusions to the dataset and resultant cohort number



3.5 Data cleaning and missing data

3.5.1 Data quality

Aspects of the dataset design and content were enhanced by the development of coding across NHS services since the introduction of Payment by Results for hospital services (99) and of the Quality and Outcomes Framework for primary care (100). This links reimbursement and organisation-level incentive schemes to the content of data extracts. Accurate coding can ensure organisations receive the correct reimbursement level.

As with all research, the use of administrative data, where information is collected for routine care rather than bespoke data collection for research, can result in variable quality. Robust data quality reviews and data cleaning were required to understand data gaps and weaknesses in more detail.

Some variables in the dataset were recorded infrequently, were underreported or not reported at all. For example, whether or not someone is or has a carer is likely to be underreported. The prevalence from primary care records is less than 1%, whereas the true prevalence is expected to be ~10% in B&D: 8.7% of the adult population reported being informal carers in the 2011 census (101), with the borough reporting that 1 in 10 of the adult population were informal carers in April 2019 (102). In addition, due to the dataset being grounded in the primary care record of the resident population, there are certain populations that are excluded, such as prisoners, patients not registered with a GP practice, those receiving private health services (in 2015, an estimated 10.5% of the UK population had private voluntary health insurance(103), this is likely to be lower for B&D given the levels of deprivation) and the homeless.

In the curation of the dataset there was a practical balance struck between ensuring high quality data with confidence in linking different data together and ensuring a breadth of information across variables of interest. As such, there were some datasets with known limitations that were included to support progression of research insight.

3.5.2 Data cleaning

The linking process used the `_merge` variable to understand and document the scale and scope of linking across the different datasets. The data was received in several separate files. There were three files containing information about the cohort (council extract with household variables, primary care extract with socio-demographic and health variables). There were eight files containing activity data for the settings of care (four files for hospital activity which was split into emergency, elective, non-elective and outpatient care, and one file for each of primary care, community, mental health and social care). Data linkage was conducted in Stata using the “uniquepatientid” and the “householdid” fields, which were linkage keys applied by the NHS staff in place of NHS number and UPRN.

Data cleaning included formatting the datasets for use in Stata. This required appropriate formatting of different variables including converting values to date variables. It also identified missing data and data gaps. Data cleaning reviewed the quality of the data, any anomalies in variable values and duplications. Four examples of the data cleaning process are described in more detail below to illustrate the level of data interrogation.

Prescription data: I identified a collection of patients with a high number of prescriptions. I worked with the BHR CCG analyst team to conduct a detailed

review of the prescriptions for those individuals. This involved sharing the uniquepatientid for the relevant individuals with the BHR CCG analyst team. They then re-identified the patients and conducted a spot check of the specific prescriptions they had been prescribed (this was not a dataset that was part of the data request, but information that the analyst team had access to as part of their analyst role at the CCG). An anonymous report was shared which provided examples of the prescriptions and confirmed that the data were correct. A key driver of high numbers of prescriptions for an individual was dressings for wounds, which are administered as separate prescriptions.

Duplicate records from education: The initial dataset included adult and children data. I found 234 duplicates in the council records for children. This included children being assigned to different households. A review of the duplicates confirmed that these originated from the education returns. When an individual applies for special educational needs they can often be registered with two schools in parallel, during the review of support, up until the point that there is an outcome and a confirmed support level for the child. Each of the 234 cases was individually reviewed; it was agreed to use the record that documented the furthest progress in the review journey and contained the most complete information.

Ethnicity coding: I used the Office for National Statistics (ONS) five groupings of ethnicity as described below. When reviewing the cohort profiles against other summaries of the B&D population, there were more “Mixed” and fewer “White” in the cohort than other B&D population profiles. On review of the sub-categories for ethnicity, many people had been coded as “British or Mixed British” in the primary care record which was used in the 2001 census and categorised as “Mixed” in the ONS groupings. The discrepancies in the population profiles were

driven by this. I agreed to use the ONS five groupings as they stand, rather than putting the “British or Mixed British” into “White”, so as not to add data inaccuracies as I could not be confident that those coded as “British or Mixed British” could be appropriately re-categorised as “White”.

Social care activity dates: Records of social care contacts had two sets of dates associated with them. The first was the service actual start and end dates, and the second was the client service dates, which referred to activity that has a weekly cost assigned to it, such as residential or nursing homes, or a specific package of home care. There were data gaps in the dates. Calculation of the number of weeks individuals received the costed package was required in order to assign the weekly costs to the activity. This was calculated by counting the number of weeks between the client service start date and the client service end date. If there was no client service start date, the start date from the service actual start date was applied. If there was no client service end date, the service actual end date was applied. If both the client service start date and service actual start date were missing, 1st April 2016 was used. If there was no client service end date and no service actual end date, it was assumed the activity was ongoing. Those with assumed ongoing activity were given an end date of 31st March 2017 (the end of the dataset year) so the weeks the individual received care in 2016/17 could be calculated and costed.

3.5.3 Missing data

There was variability in the level of completeness of the data. Restriction to those with complete data can result in biased analysis. For example, body mass index (BMI) may be recorded more frequently in patients with regular interaction

with health services. Complex statistical techniques and algorithms are often required to address missing data (104).

There are three forms of missing data in the dataset. Firstly the “unmatched”, those for whom I could not match their information with an NHS number and therefore a primary care record; these individuals were excluded. Secondly, those with “partially observed” data, those for whom at least one variable had an unknown value; I included these individuals in the summary of the dataset that follows and used the missing indicator method for the research in Chapters 5 and 6. Thirdly, the “unknowns”, these were individuals who were not in the dataset and about whom nothing was known. This refers to individuals who were not registered with a GP practice (given that GP practice and confirmed residency of B&D were prerequisites of being included in the cohort) and individuals who had requested to opt out of GP record sharing for whom information was removed at source and nothing could be known about them.

The unmatched and partially observed cohorts are described further below.

3.5.3.1 Unmatched

For individual records where it was not possible to link the individual data to an NHS number, the record was included in the source data and the entries were marked “unmatched” in order to facilitate understanding of the differences between the service use and characteristics of the unmatched cohorts with those that were included.

There were two dimensions in which there were unmatched entries. Firstly, the social care records dimension (see 3.3.5), which contained records without NHS numbers or records of individuals that could not be matched with NHS numbers.

Of the 4,078 contacts in 2016/17 that could not be matched, 427 of those contacts had costs associated with them.

Secondly, the council records dimension, where residents were either not registered with a GP practice in B&D or Havering ($n=5,298$) or the residents could not be matched with NHS numbers ($n=9,980$).

3.5.3.2 Partially observed

For ethnicity, BMI, smoking status and tenure data, there were a total of 9 individuals who had missing data in all four variables, and 19,193 who had missing data in at least one of the four variables.

With four different variables for which there may be a missing value, there are 15 possible missing data patterns. This is calculated as follows:

Number of combinations: $nCr = \frac{n!}{r!(n-r)!}$

n=	r=		nCr=
4	1	$\frac{4!}{1!(4-1)!}$	4
4	2	$\frac{4!}{2!(4-2)!}$	6
4	3	$\frac{4!}{3!(4-3)!}$	4
4	4	$\frac{4!}{4!(4-4)!}$	1
Total combinations			15

A summary of how the 19,193 was distributed across the four variables by reviewing the 15 missing data patterns is provided in Table 3-5. There was at least one observation of each missing data pattern. Gaps in ethnicity codes were the largest contributor to missing information (46%) followed by missing BMI

values (24%). As a proportion of the total 114,393 cohort, the missing values were 12,248 (11%) for ethnicity, 8,781 (8%) for BMI, 2,334 (2%) for smoking status and 969 (1%) for tenure.

Table 3-5 The number of records and % of total incomplete records for each combination of missingness across the four variables: Ethnicity, BMI, Smoking status and Tenure

	Ethnicity	BMI	Smoking	Tenure	n	% of total missing
1	x				8,838	46.05%
2	x	x			2,403	12.52%
3	x		x		177	0.92%
4	x			x	67	0.35%
5	x	x	x		743	3.87%
6	x	x		x	9	0.05%
7	x		x	x	2	0.01%
8	x	x	x	x	9	0.05%
9		x			4,675	24.36%
10		x	x		898	4.68%
11		x		x	33	0.17%
12		x	x	x	11	0.06%
13			x		490	2.55%
14			x	x	4	0.02%
15				x	834	4.35%
				TOTAL	19,193	100%

In order to review the incomplete records, a variable was created that took the value 1 if all variables were complete, and 0 if at least one of the four variables had a missing value. Given the variables in the dataset are categorical, chi-squared tests were run to review the difference in the distribution patterns of the complete and the incomplete cohorts across all other variables; this is provided in Table 3-6. With the exception of palliative care, the *p* values all showed a statistically significant difference between the complete and incomplete cohorts for each variable. This is likely to be due to the large sample size; therefore, a review of the proportion of individuals in each category in each variable was more appropriate.

Ethnicity, BMI and smoking status information are all from the primary care records. Given that individuals in regular contact with services are more likely to have complete records, we would expect the incomplete cohort to have younger individuals, male individuals and a lower prevalence of long-term conditions. This is seen in the differences between the proportions of the complete and incomplete cohort: the latter were found to be younger (72% 19 to 49-years old), predominantly male (59%) and to have a higher proportion of people with 0–1 long-term conditions (91%).

Table 3-6 A comparison of the characteristics of the full cohort of adult residents in Barking and Dagenham 2016/17 between individuals with incomplete information and individuals with complete information

		<i>Full cohort</i> N=114,393, % of full cohort	<i>Incomplete information</i> n=19,193, % of those with incomplete records	<i>Complete information</i> n=95,200, % of those with complete records	Pearson's chi- squared and <i>p</i> value of the difference
<i>Age</i>	19–49	62%	72%	60%	1100, <i>p</i> <0.01
	50–64	23%	16%	24%	
	65–74	8%	6%	9%	
	75–85	5%	4%	5%	
	85+	3%	2%	3%	
<i>Gender</i>	Female	53%	41%	55%	1300, <i>p</i> <0.01
	Male	47%	59%	45%	
<i>Ethnic group</i>	White	14%	7%	15%	68000, <i>p</i> <0.01
	Black or Black British	16%	6%	18%	
	Mixed	42%	16%	48%	
	Other	2%	1%	2%	
	Asian or Asian British	15%	6%	17%	
	Unknown	11%	64%	0%	
<i>Carer</i>	None	98%	99%	98%	61.05, <i>p</i> <0.01
	Has a carer	1%	1%	1%	
	Is a carer	1%	0%	1%	
	Both has and is a carer	0%	0%	0%	
<i>BMI category</i>	Healthy	29%	18%	32%	47000, <i>p</i> <0.01

		<i>Full cohort</i>	<i>Incomplete information</i>	<i>Complete information</i>		
<i>Smoking category</i>	Underweight	3%	4%	3%		
	Overweight	31%	16%	34%		
	Obese	24%	13%	27%		
	Morbidly Obese	4%	3%	5%		
	Unknown	8%	46%	0%		
	Non-smoker	61%	57%	62%	12000, $p<0.01$	
	Ex-smoker	16%	12%	17%		
	Smoker	21%	19%	21%		
	Unknown	2%	12%	0%		
<i>LTCs</i>	0–1	83%	91%	82%	881.21, $p<0.01$	
	2	10%	6%	11%		
	3	4%	2%	4%		
	4	2%	1%	2%		
	5+	1%	1%	1%		
<i>Conditions</i>	AF	1%	1%	2%	14.04, $p<0.01$	
	Asthma	10%	7%	11%	230.65, $p<0.01$	
	Cancer	3%	2%	3%	79.11, $p<0.01$	
	CHD	3%	2%	4%	131.04, $p<0.01$	
	COPD	3%	1%	3%	183.03, $p<0.01$	
	Dementia	1%	1%	1%	46.16, $p<0.01$	
	Depression	8%	6%	8%	127.83, $p<0.01$	
	Diabetes	9%	4%	10%	580.21, $p<0.01$	
	Epilepsy	1%	1%	1%	4.67, $p=0.031$	
	Heart failure	1%	0%	1%	32.32, $p<0.01$	
	Hypertension	19%	10%	21%	1,100, $p<0.01$	
	Hypothyroidism	4%	2%	5%	205.91, $p<0.01$	
	Learning difficulty	1%	0%	1%	9.00, $p<0.01$	
	Mental health	1%	1%	1%	22.84, $p<0.01$	
	Palliative care	0%	0%	0%	0.12, $p=0.733$	
	Stroke	2%	1%	2%	7.70, $p<0.01$	
	<i>Benefits</i>	None	70%	73%	70%	110.26, $p<0.01$
		Employment Support Allowance	6%	6%	6%	
		Pension	5%	4%	5%	

		<i>Full cohort</i>	<i>Incomplete information</i>	<i>Complete information</i>	
<i>Tenure</i>	Income Support	3%	3%	3%	
	Job Seeker's Allowance	2%	2%	2%	
	Standard	14%	13%	15%	
	Owner occupied	53%	52%	53%	4,900, $p<0.01$
	PR	20%	17%	20%	
	Social Reside	26%	26%	26%	
	Unknown	1%	0%	1%	
<i>Occupancy</i>	2 to 4	59%	59%	59%	257.28, $p<0.01$
	1	13%	11%	13%	
	5 to 7	24%	25%	24%	
	8 to 10	4%	3%	4%	
	11+	1%	2%	1%	
<i>B&D IMD quintile</i>	1	21%	22%	20%	95.62, $p<0.01$
	2	20%	20%	20%	
	3	20%	21%	19%	
	4	20%	19%	20%	
	5	19%	18%	20%	

There are several different methods that have been developed for handling missing data. These include complete case analysis, missing indicator method, single value imputation, sensitivity analysis and multiple imputation. Each of these methods has advantages and limitations (105). For the partially observed cohort the missing indicator method was used.

The nature of the research work described in the chapters that follow, required exclusion of the unmatched social care cohorts, as the information could not be linked to individual records. For the unmatched council cohorts, these were also excluded as the definition of the research cohort excluded those who could not be confirmed as both residents of B&D and registered with a B&D or Havering GP practice.

3.6 Covariates

The outputs of the scoping review described in Chapter 1, Section 1.4 summarising variables associated with health and social care spend informed the covariates included in the dataset. These were grouped into three categories: socio-demographic characteristics, health variables and household variables.

3.6.1 Socio-demographic characteristics

For all individuals I included age, gender, ethnicity, and whether the individual was a carer, had a carer or both.

The dataset included the year of birth for each individual which was used to group individuals into one of five age categories (19–49, 50–64, 65–74, 75–85, 85+). Given, for pseudonymisation purposes, I only had year of birth rather than date or month of birth, individuals' ages were calculated on the difference between their year of birth and 2017, to denote the oldest age someone would be in the dataset. Those born in 1999 were excluded because if their birthdate was between April and December, they would only be 17 in the dataset. I included all those born in 1998 and categorised them in the “19–49” age category, although those born between April and December 1998 would have been 18. The year of birth by age category is displayed in Table 3-7.

Table 3-7 The age category to which individuals were assigned according to their year of birth

Age category	Year of birth
19–49	1968–1998
50–64	1953–1967
65–74	1943–1952
75–85	1933–1942
85+	1932 and before

Gender was categorised as either female or male, consistent with the categories used in the primary care records in the year of data collection. Since then further categories have been launched for gender identification.

For ethnicity, the ethnicity codes were extracted from primary care records and then grouped according to the five categories used by the ONS and a sixth category “unknown” to account for missing data (see Table 3-8).

Table 3-8 Office for National Statistics list of 5 broad ethnicity groups and 18 ethnicity categories for population ethnicity coding (106)

Ethnic groups	
<i>White</i>	English / Welsh / Scottish / Northern Irish / British Irish
	Gypsy or Irish Traveller
	Any other White background
<i>Mixed / Multiple ethnic groups</i>	White and Black Caribbean
	White and Black African
	White and Asian
	Any other Mixed / Multiple ethnic background
<i>Asian / Asian British</i>	India
	Pakistani
	Bangladeshi
	Chinese
	Any other Asian background
<i>Black / African / Caribbean / Black British</i>	African
	Caribbean
	Any other Black / African / Caribbean background
<i>Other ethnic group</i>	Arab
	Any other ethnic group

A carer variable was included that documented whether someone had a carer or was a carer. In this instance, carer refers to someone who is unpaid and often described as a “lay”, “informal” or “family” carer (107), rather than a paid carer or care professional. The information was taken from the primary care records and refers to the collection of Read Codes that identify if someone has an unpaid carer (918F) or if someone is an unpaid carer (918G). Individuals can be identified as an unpaid carer regardless of the relationship they have with the care recipient, for example, they can be family members, neighbours or friends. Despite the ability to code within Read Code 2 and Clinical Terms Version 3 (CTV3) guidance details on the kind of person you are caring for (e.g., 918M caring for a person with a terminal illness, 918W caring for a person with learning difficulties, 918Y caring for a person with sensory impairment), these codes were seldom used. Where they had been used, I assigned these individuals to the overall category of being an unpaid carer. Four fields were created: “None” if the individual had no record of either being or having a carer, “has a carer” if the Read Codes identified the individual to have a carer, “is a carer” if the Read Codes identified the individual as being a carer, and “is and has a carer” if both were present in the individual’s records.

3.6.2 Health variables

BMI and smoking status are commonly associated with declined health status and were included as a marker of individual health risk factors.

For BMI, I used the value recorded in the primary care record. This was then categorised into one of five categories defined by the NHS as follows: underweight (below 18.5), healthy (between 18.5 and 24.9), overweight (between 25 and 29.9), obese (between 30 and 39.9) and morbidly obese (over

40). To account for missing data, individuals for whom the BMI was recorded as unknown or if there was a missing value were assigned to a sixth category “unknown”. The date at which the BMI value was recorded was also available in the dataset.

For smoking status, again the date this was last recorded was available in the dataset. Individuals’ smoking status was gathered from their primary care records. They were categorised as non-smoker, ex-smoker, smoker or unknown. The fourth category included those recorded as unknown, preferred not to say, and missing values.

I included a wide range of health indicators to control comprehensively for morbidity in the models using diagnosis information from primary care records. The presence of one or multiple diagnoses of 16 long-term conditions as well as the count of the number of long-term conditions an individual had were included.

The literature on multi-morbidity is growing, but as yet there is no consensus on the conditions to include or the threshold for someone to be “multi-morbid”.

Multiple long-term conditions present physical and mental health challenges and, as such, mental health and learning difficulties, which have traditionally not been part of multi-morbidity analysis, were included in the conditions recorded for the data set. For example, the Charlson Comorbidity Index (108) is one of the most widely used comorbidity indices but does not include mental health conditions other than dementia, despite the known impact serious mental illness can have on overall utilisation of care (109).

In the UK, the National Institute for Health and Care Excellence (NICE) published guidelines defining multi-morbidity as:

“the presence of 2 or more long-term health conditions, which can include: defined physical and mental health conditions such as diabetes or schizophrenia; ongoing conditions such as learning disability symptom; complexes such as frailty or chronic pain; sensory impairment such as sight or hearing loss; alcohol and substance misuse” (110).

I used this definition as a base and worked with local clinicians and data managers to agree a collection of long-term conditions for which there was good quality data. As part of a centrally funded programme, The Prime Minister’s Challenge Fund (NHS England, 2015), B&D CCG were involved in the implementation and testing of a new model of care for people with multiple long-term conditions named Health 1000. Individuals were deemed eligible for the service if they had five or more of a specific set of eight chronic conditions (see Table 3-9). As such there was good quality data collection for these conditions in the primary care records of the B&D and Havering practices. A combination of local primary care improvement work, national initiatives, and conditions identified as relevant from the literature, led to eight further conditions being added. Consultation with local clinical leads and data analysts ensured that there was a high level of confidence in the quality of the data for these additional conditions. Conditions where the data quality was deemed to be poor were not added, for example musculoskeletal and pain management, despite the known association with increased health service use(111). The full list of Read Codes confirming the specific diagnosis included in each category is documented and available on request. Table 3-9 provides the list of the 16 conditions included in the dataset.

Table 3-9 The 16 conditions recorded in the dataset

Eight conditions used for Health 1000 to identify eligible patients	Eight additional conditions added to the dataset following consultation with BHR clinical leads and data analysts
<ul style="list-style-type: none"> • Coronary heart disease (CHD) 	<ul style="list-style-type: none"> • Atrial fibrillation (AF)
<ul style="list-style-type: none"> • Chronic obstructive pulmonary disease (COPD) 	<ul style="list-style-type: none"> • Asthma
<ul style="list-style-type: none"> • Diabetes 	<ul style="list-style-type: none"> • Cancer
<ul style="list-style-type: none"> • Depression 	<ul style="list-style-type: none"> • Epilepsy
<ul style="list-style-type: none"> • Dementia 	<ul style="list-style-type: none"> • Hypothyroidism
<ul style="list-style-type: none"> • Heart failure 	<ul style="list-style-type: none"> • Learning difficulty
<ul style="list-style-type: none"> • Hypertension 	<ul style="list-style-type: none"> • Mental health
<ul style="list-style-type: none"> • Stroke 	<ul style="list-style-type: none"> • Palliative care

For the count of the long-term conditions, a comprehensive treatment of comorbidity effects would allow for all possible combinations of the 16 long-standing illnesses. I adopted a more parsimonious count structure that yielded the effects of having two, three, four or at least five long-term conditions by averaging over the effects of each different combination of two, three, four or at least five long-term conditions.

3.6.3 Household variables

Four household variables were included: occupancy, tenure, benefits and deprivation.

For modelling purposes, I grouped household occupancy into five categories: living alone, 2–4, 5–7, 8–10 and more than 11 people in the household. The household occupancy data were received from the council and were a metric collected by the housing department, rather than calculated in the dataset. This meant that individuals who lived with someone who died in 2016/17 or moved

out of the borough in 2016/17 will have had those individuals reflected in their household occupancy figure, regardless of whether they had been excluded from the dataset. This also meant that children and people who used a primary care practice outside the borough were also reflected in the household occupancy figures.

The tenure of the household included owner occupied, privately rented, social housing, and a local category “reside” which is a programme specific to B&D offering access to affordable rental properties for those in employment. These data are recorded alongside the UPRN by the council and in the dataset they were applied to all the people with the same householdid. The data are collected annually and where there were data gaps, a fifth category “unknown” was used.

Data on benefits were collected from the council for all individuals in receipt of Housing Benefits. A national programme in the UK referred to as “passport benefits” allows individuals or households also in receipt of one or more passported benefits to automatically be entitled to Housing Benefit(112).

Passported status is sourced from the benefit claim form where all other benefits the claimant or partner receives must be recorded at the reference date. As such, the council documents both people in receipt of Housing Benefit and whether they receive that benefit because they are passported, that is, eligible because of being in receipt of other benefits: Income Support, Job Seeker’s Allowance (Income Based), Guaranteed Pension Credit, Employment Support Allowance (ESA) (Income Related) or not passported and therefore Housing Benefit is either the only benefit they receive or the first one they have applied for. In the dataset, the benefits variable had six fields (see Table 3-10).

Table 3-10 The benefits variable had six data fields

Field	Definition
None	Not in receipt of Housing Benefits
Employment Support Allowance	“Passported” to receive Housing Benefit because someone in the household receives Employment Support Allowance
Pension	“Passported” to receive Housing Benefit because someone in the household receives Guaranteed Pension Credit
Income Support	“Passported” to receive Housing Benefit because someone in the household receives Income Support
Job Seeker’s Allowance	“Passported” to receive Housing Benefit because someone in the household receives Job Seeker’s Allowance
Standard	In receipt of Housing Benefit but “Not passported”, and therefore not in receipt of other benefits

The benefits data were recorded alongside the householdid and are at a household rather than an individual level. It was not possible to identify the individual in the household that was eligible for and in receipt of the specific benefits. As such, the information was applied to all individuals in the household. There will therefore be more people coded as having benefits than those directly receiving them, but this does provide scope for understanding the household impact of living in a household that is in receipt of benefits. All households receiving a benefit in the dataset were on Housing Benefits. Given that the benefit information was received from the housing records, there will be a subset of the population in the cohort in receipt of benefits for whom I do not have information. To understand the potential volume of people this may refer to I reviewed the number of benefit recipients at an LSOA level in 2016/17 (Table 3-11). The research dataset contains only adults. It is possible that of the individuals in households receiving benefits, for example Pension Credits, more than one individual may be in receipt of this benefit, such as married couples living together aged over 65. I therefore reviewed the ONS figures against both

the individuals in receipt of the benefits as documented in the dataset and the number of households. With known exclusions in the dataset (i.e., those who were registered with a GP practice outside B&D or Havering, those that had died in the year and those who had moved out of the borough in the year), a review of the difference between the ONS figures and the cohort levels with colleagues at the council deemed the difference appropriate and in line with expectations given the cohort makeup.

Table 3-11 A comparison of benefits received by the Barking and Dagenham population from the ONS returns and for the B&D cohort

Benefit	Average of ONS returns for B&D**	B&D dataset: Number of individuals	B&D dataset: Number of households	Individuals in B&D cohort as a % of ONS figures	Households in B&D cohort as a % of ONS figures
Employment and Support Allowance or Incapacity Benefit claimants*	8,103	6,497	3,539	80%	44%
Pension Credits	5,955	5,589	3,460	94%	58%
Income Support	3,468	3,506	2,195	101%	63%
Job Seeker's Allowance claimants	2,363	2,024	1,206	86%	51%

*The number of Incapacity Benefit claimants is reducing due to Incapacity Benefits being replaced by Employment Support Allowance

** Average of four returns: May-16, Aug-16, Nov-16, Feb-17, data accessed at www.data.london.gov.uk

As a marker of deprivation in the area individuals live, the 2015 English IMD scores were included. The IMD is the official measure of relative deprivation for small areas in England. It is the most widely used of the Indices of Deprivation and ranks every small area in England (LSOA) from 1 (most deprived area) to 32,844 (least deprived area). The index combines information from seven domains to produce an overall relative measure of deprivation. The domains are

combined using the following weights: Income Deprivation (22.5%), Employment Deprivation (22.5%), Education, Skills and Training Deprivation (13.5%), Health Deprivation and Disability (13.5%), Crime (9.3%), Barriers to Housing and Services (9.3%), Living Environment Deprivation (9.3%). These were matched at LSOA level into the dataset, with LSOA level included for all individuals from the primary care record according to their recorded postcode of residence. IMD is usually reviewed in national quintiles. However, given the high levels of deprivation in B&D, there were no residents in national quintiles 1 or 2. Local deprivation quintiles were therefore calculated for B&D to allow for greater spread within the dataset, with individuals assigned to five quintiles based on the spread of IMD scores in the dataset (see Section 3.8).

3.7 Outcome measurement: health and social care utilisation

Cost-weighted utilisation was used by setting, and overall, as the outcome measurement for analysis in the next three chapters of this thesis. The cost was estimated from activity data, with different methods used for the different settings of care. The total cost for the financial year was calculated for each individual by aggregating cost across five settings of care: hospital, primary care, community, mental health and social care.

3.7.1 Hospital

Activity was collated across four domains of hospital care: emergency department attendances, elective inpatient stays (including day cases), non-elective inpatient stays (including people admitted but staying for less than 24 hours) and outpatient attendances.

For emergency department attendances, the mode of arrival, date of attendance and discharge location were included in the dataset. For inpatient stays, one diagnostic code and one primary procedure code was included per attendance, alongside the date of admission, date of discharge and length of stay in days. Outpatient attendances included the specialty department the appointment was with and whether the patient attended or did not attend the appointment.

The dataset included the national Healthcare Resource Group (HRG) tariff cost assigned to each unit of activity, using the HRG grouper and tariff costs in place for the 2016/17 financial year (113). The actual cost of treating patients may vary for each provider (114). The costs used were reflective of the true cost to the commissioner of the activity. The Reference Costs provide a national average cost based on the HRG code for the spell (a spell is the period that a patient spends in hospital from admission to discharge), taking into account the type of admission (day case, elective, non-elective or regular attender). Non-elective cases are assigned different costs for short stays (less than two days) and long stays (two days or longer). Outpatient costs differ according to the specialty of the department and agreed thresholds of new to follow-up ratios.

There was activity that had no cost attached to it, for example outpatient visits that exceeded the tariff trim point. This activity was therefore not reflected in the total hospital costs. Table 3-12 shows that this was most relevant for outpatient attendances, 40% of outpatient attendances did not have a tariff cost assigned to them. As such this activity is not reflected in the analysis that follows. There are several implications. Firstly, the scale of patient contact with the hospital system may be mis-represented if much of the activity was beyond the trim point. Secondly, individuals for whom they only had activity beyond the ratio could be misrepresented as not using hospital services.

The rationale for excluding activity with no cost was to ensure consistency in the costing methodology. Across the NHS in England, restrictions are put in place on the ratio of new to follow-up patient contacts in order to encourage discharging patients to primary or community care for ongoing monitoring rather than prolonging hospital contacts unnecessarily which are perceived as high cost. Given the hospital activity was costed using the tariff, excluding the activity with no cost rather than assigning a unit cost to it reflects the true commissioning cost of the activity.

Table 3-12 The proportion of hospital activity for the individuals in the cohort that did not have a cost assigned to it

<i>Hospital activity</i>	<i>Total patient contacts with no cost assigned</i>	<i>Total patient contacts</i>	The number of patient contacts with no cost assigned as a percentage of total patient contacts, %
<i>Emergency department attendances</i>	1,107	34,775	3%
<i>Elective admissions</i>	1,989	19,481	10%
<i>Non-elective admissions</i>	490	9,954	5%
<i>Outpatient appointments*</i>	72,871	180,757	40%

* Outpatient attendances where the patient not attend (due to cancellation by the hospital, cancellation by the patient, not arriving on the day, or arriving to late to be seen) are excluded from these figures. There were 73,998 outpatient appointments for the cohort that were categorised as did not attend. All of these had zero tariff cost.

3.7.1.1 Emergency department attendances

The cost for each attendance varied depending on the type of emergency department (consultant-led emergency departments; consultant-led mono-specialty services; other types of minor injury departments; and NHS walk-in centres), whether the patient was admitted or not, and whether they arrived at the emergency department by ambulance. These adjustments were made by the

HRG grouper and the unit costs of each individual level activity reflected these adjustments.

There were 20,186 individuals (17.6% of the total cohort) who had at least one emergency department attendance between 1st April 2016 and 31st March 2017. Emergency department unit costs for the 2016/17 activity data ranged from £57 to £311 and total emergency department costs for an individual who had attended the department ranged from £57 to £9,562. The total costs for emergency department attendances was £4.9 million.

3.7.1.2 Elective inpatient stays (including day cases)

The unit costs for elective inpatient stays varied according to the specialty of the department, the type of admission, diagnostic tests and procedures performed during the inpatient stay and the overall length of stay for the patient.

There were 13,462 individuals (12% of the total cohort) who had at least one elective attendance between 1st April 2016 and 31st March 2017. Elective attendance unit costs for the 2016/17 activity data ranged from £141 to £37,028 and total elective care costs for an individual who had had an elective attendance during 2016/17 ranged from £141 to £40,658. The total cost for elective activity was £24.7 million.

3.7.1.3 Non-elective inpatient stays (including people admitted but staying for less than 24 hours)

The unit costs for non-elective inpatient stays varied according to the specialty of the department, the diagnostic tests and procedures performed during the patient's stay and the overall length of stay for the patient. A distinction was made between short-stay and long-stay patients, with a payment applied at a

daily rate to all HRGs where the length of stay of the spell exceeded a trim point specific to the HRG, and a reduced tariff for short stays.

There were 6,330 individuals (6% of the total cohort) who had at least one non-elective attendance between 1st April 2016 and 31st March 2017. Non-elective attendance unit costs for the 2016/17 activity data ranged from £184 to £38,300 and total non-elective care cost for an individual who had had a non-elective attendance during 2016/17 ranged from £184 to £54,655. The total cost for non-elective activity was £18.4 million.

3.7.1.4 Outpatient activity

The tariff for outpatient attendances varied according to the specialty the individual was visiting, whether it was a first appointment (new) or a follow-up and the commissioning threshold for new to follow-up ratios, which can lead to some appointments not having a reimbursement value.

There were 36,472 individuals (32% of the total cohort) who had at least one outpatient attendance between 1st April 2016 and 31st March 2017. The mean outpatient attendance unit cost for those with a costed activity was £145 and total outpatient cost for an individual who had had an outpatient attendance during 2016/17 ranged from £43 to £19,687. The total outpatient cost was £15.6 million.

3.7.2 Primary care

For primary care, the activity data provided the monthly count of attendances with a GP, with a non-GP, and the number of prescriptions for each individual.

3.7.2.1 Attendances with a GP

The activity data provided a count of GP contacts per month, without a distinction between face-to-face consultations in the surgery, telephone consultations or home visits. There was no time or date associated with visits, so it was not possible to distinguish out-of-hours contacts.

Unit costs from the 2016/17 “Unit Costs of Health and Social Care”(115) were used for GP attendances. The report calculates costs for GP services by comparing salary, overheads and other costs for the practice to perform the activities taking into account how long each activity takes. I used the 2016/17 unit cost of £38 per visit, which includes direct staff costs, qualification and training, for a surgery consultation with a GP. This assumes attendances are, on average, 9.22 minutes in duration.

There were 81,408 individuals (71% of the total cohort) who had at least one appointment with a GP between 1st April 2016 and 31st March 2017. The total number of attendances for an individual ranged from 1 to 76, and the total cost for an individual ranged from £38 to £2,888. The total cost for GP attendances was £11.3 million.

3.7.2.2 Attendances with a non-GP

The activity data provided a count of the number of attendances an individual had per month with a “non-GP”. Non-GP attendances may be with a practice nurse, pharmacist or health care assistant. Unit costs from the 2016/17 “Unit Costs of Health and Social Care” for GP practice nurses were used, which was £42 per hour with qualifications. It was assumed that a nurse would see four people per hour, providing a unit cost of £10.50 per visit, and, as with the GP

attendances, no distinction was made between face-to-face and telephone consultations.

There were 66,813 individuals (58% of the total cohort) who had at least one appointment with a non-GP between 1st April 2016 and 31st March 2017. The total number of attendances for an individual ranged from 1 to 105, and the total cost for an individual ranged from £10.5 to £1,102.5. The total cost for non-GP attendances was £1.9 million.

3.7.2.3 Prescription costs

The local prescription data provided total prescription costs per practice and total number of prescriptions per practice for 2016/2017. This enabled the calculation of a unit cost per prescription for each practice and was applied to calculate prescription costs for each patient within that practice.

There were 81,502 individuals (71% of the total cohort) who had at least one prescription between 1st April 2016 and 31st March 2017. For individuals who had received at least one prescription (29% had no prescriptions), the total number of prescriptions for an individual ranged from 1 to 1,256, with 539 individuals with more than 500 prescriptions. The average unit cost for a prescription was £8.30. The total cost for prescriptions was £19.4 million for the cohort of 114,393 adults.

3.7.3 Community services

Activity data were extracted from the RiO system of the local community provider, NELFT. This provided information on the referral source and primary reason for referral, the cost centre the activity was assigned to (to facilitate matching of activity to unit costs), the type of consultation (new or follow up), location of the care contact (e.g., clinical setting or individual's home) and

whether it was in person or a telephone consultation. Each of these impacted the unit cost of the activity.

Data from the Patient Level Information and Costing System from NELFT were used to calculate unit costs for each component of the activity. This was calculated by NELFT analysts by distributing the budget within each department across the activity of the department. Unit level costs were then provided per department for each type of activity (new or follow up, in person or by phone, location of care contact).

There were 11,930 individuals (10% of the total cohort) who had at least one community service contact between 1st April 2016 and 31st March 2017. For the 114,393 cohort, there were a total of 755,709 community service contacts. The total cost was £42.5 million with individual level costs ranging from £16 to £158,255 for the year.

3.7.4 Mental health

As with community services, activity data were extracted from the RiO system of the local community provider, NELFT. This provided information on the referral source and primary reason for the referral, the cost centre the activity was assigned to (to facilitate matching of activity to unit costs to the appropriate department), the type of consultation (new or follow up), location of the care contact (e.g., clinical setting or individual's home) and whether it was in person or a telephone consultation. Each of these impacted the unit cost of the activity.

In 2013 the NHS launched Payment by Results for mental health trusts, with more comprehensive roll out from 2016 onwards (116). However, it is still in its infancy with only 21 treatment clusters and therefore a very wide range of costs, such that, unlike acute services where there are over 4,500 different categories,

it is not yet an accurate tool for costing purposes. I therefore used the information from the Patient Level Information and Costing System developed internally by NELFT. This was calculated by the trust by distributing the budget within each department across the activity of the department. Unit level costs were then provided, by department and cost centre, for each type of activity (new or follow up, in person or by phone, location of care contact).

There were 3,666 individuals (3% of the total cohort) who had at least one mental health service contact between 1st April 2016 and 31st March 2017. Of these, 540 had an inpatient mental health stay and 3,558 had at least one contact with outpatient services. For inpatient care, there were a total of 14,222 care contacts, with individual cost ranging from £89 to £114,094 and total cost of £2.1 million. The total number of outpatient mental health service contacts was 138,973, with individual cost ranging from £43 to £249,350 and total cost of £17.3 million. The total cost of mental health services was £19.4 million.

3.7.5 Social care

Local authority social care costs were obtained from council data which lists the billed cost for each care package per week for each care recipient. Care packages included costs for crisis intervention, home care, supported living placements, and residential and nursing home placements. This provided the granularity on in-year changes to packages and the resultant change in package costs. Data on self-funded social care were not available; data on equipment, transport and home adaptation costs were not available as these were held in different departments of the council.

The data extracted from the council included both referrals for social care support and resultant care packages. Information on the primary reason for

support was also available because all records from 2014 onwards used the Short and Long Term Support return data definitions.

There were 2,056 individuals (2% of the total cohort) who had a social care package between 1st April 2016 and 31st March 2017. The unit cost of an individual weekly package for an individual ranged from £11 per week (for support managing a personal budget) to £24,171 per week (for a long-term residential home placement), and the total annual costs for an individual ranged from £9 to £210,124. The total cost for social care was £22.0 million.

As described above, the data received for each of the settings of care and the method used to assign costs differed. A summary of the data simplification required to prepare the activity files for analysis is provided in Table 3-13.

Table 3-13 A summary of the data simplification required to prepare health and social care activity data for inclusion in the analysis

<i>Setting of Care</i>	<i>Data received</i>	<i>Simplification process completed to prepare data for analysis</i>
<i>Hospital: A&E</i>	For each individual there was a separate line for each A&E attendance that happened between 1 st April 2016 and 31 st March 2017	Activity was aggregated for each individual, calculating the total number of contacts and the sum of the cost of those contacts using the HRG tariff. Cross-checks were completed to ensure aggregated totals matched those in the source data.
<i>Hospital: Elective care</i>	For each individual there was a separate line for each elective care attendance that happened between 1 st April 2016 and 31 st March 2017. This included day case activity.	Activity was aggregated for each individual, calculating the total number of elective care admissions (including daycases) and the sum of the cost of those contacts using the HRG tariff provided. The HRG grouping process allocated the cost for the admission. Using the dates of admission and dates of discharge it was possible to identify which of the admissions were day cases, however this sub-category was not required for the analysis given the costs had already been assigned. A dataset was created with one row per individual, the sum of the cost of elective care and a count of the total number of elective admissions.
<i>Hospital: Non-Elective care</i>	For each individual there was a separate line for each elective care attendance that happened between 1 st April 2016 and 31 st March 2017.	Activity was aggregated for each individual, calculating the total number of non-elective care admissions and the sum of the cost of those contacts using the HRG tariff provided. The HRG grouping process allocated the cost for each admission. This provided a dataset with one row per individual, the sum of the cost of non-elective care and a count of the total number of non-elective admissions.

<i>Setting of Care</i>	<i>Data received</i>	<i>Simplification process completed to prepare data for analysis</i>
<i>Hospital: Outpatient care</i>	For each individual there was a separate line for each outpatient care attendance that happened between 1 st April 2016 and 31 st March 2017.	<p>Activity was aggregated for each individual, calculating the total number of outpatient appointments and the sum of the cost of those contacts using the HRG tariff provided.</p> <p>This provided a dataset with one row per individual, the sum of the cost of outpatient attendances.</p> <p>As shown in Table 3-12, 40% of the outpatient activity had no cost assigned to it. This activity was therefore not reflected in the aggregate figures.</p>
<i>Primary care</i>	The dataset received had one data line for each individual with columns providing the count of attendances by month for each of GP contacts, non-GP contacts and prescriptions	<p>Additional columns were added to the dataset to provide a total count of attendances for GP contacts, adding the count of each month to provide an aggregate figure, and to provide a total count of attendances for non-GP contacts. A unit cost was then applied to each of the aggregate figures, to calculate the total cost for GP contacts and the total cost for non-GP contacts for each individual.</p> <p>For prescriptions, an aggregate figure was created for each individual by adding the count of prescriptions for each month. A unit cost was assigned to each individual using the practice they were registered with to assign a practice-specific prescription unit cost. A total prescription cost was then calculated by multiplying the practice-specific prescription unit cost by the total number of prescriptions for that individual.</p> <p>This provided a dataset with one row per individual, the count and cost of each of: GP contacts, non-GP contacts, prescriptions.</p> <p>All activity had a cost assigned to it.</p>

<i>Setting of Care</i>	<i>Data received</i>	<i>Simplification process completed to prepare data for analysis</i>
<i>Community services</i>	For each individual there was a separate line for each care contact happened between 1 st April 2016 and 31 st March 2017.	<p>Two stages of data preparation were required. Firstly, integrating the unit cost data received in a separate file. This required matching the cost centre, type of consultation, location of the care contact and mode of contact to assign the appropriate unit cost. Secondly once costs had been assigned to each activity, the costs were aggregated for each patient.</p> <p>This provided a dataset with one row per individual, and the sum of the cost of community services.</p>
<i>Mental health</i>	For each individual there was a separate line for each care contact happened between 1 st April 2016 and 31 st March 2017.	<p>The same process was followed for Mental health as above for community services. Activity was distinguished between inpatient care and outpatient care.</p> <p>This provided a dataset with one row per individual with the sum of the cost of mental health inpatient services, mental health outpatient services, and the total cost of all mental health services.</p>
<i>Social care</i>	For each individual there was a separate line for each care package received between 1 st April 2016 and 31 st March 2017.	<p>Two stages of data preparation were required. Firstly, calculating the cost of each package of care. Weekly unit costs were provided in the dataset, and dates for when the package started and if it had ended, the date for that. These dates were used to calculate the number of weeks the individual was in receipt of the care package. The unit cost was then applied to get a total package cost for the financial year. There were some gaps in dates, the approach for which is described above in 3.5.2. Individuals could have parallel activity and may be in receipt of multiple care packages at any one time. The second stage was to aggregate the costs for each individual.</p> <p>This provided a dataset with one row per individual, and the sum of the cost of social care services and how many weeks the individual had been in receipt of at least one service.</p>

The next section provides a snapshot of the cohort and some graphs of the distribution of costs across each setting of care.

3.8 Compendium of figures providing an overview of the B&D cohort

A summary of the B&D cohort of adult residents who were also registered with a B&D or Havering GP practice between 1st April 2016 and 31st March 2017, excluding those that died or moved out of the borough in year ($N=114,393$).

3.8.1 Socio-demographic characteristics of the B&D cohort

Figure 3-6 The number of individuals by age and by gender

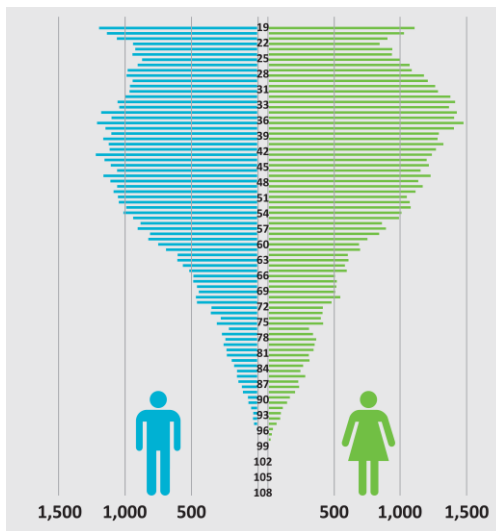


Figure 3-7 The distribution of males and females across the five age categories

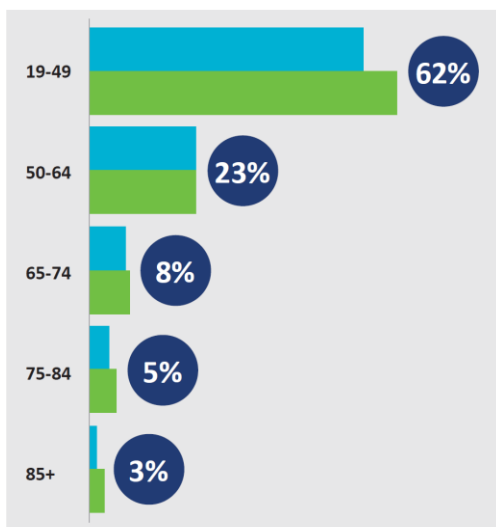


Figure 3-8 The ethnicity of the cohort

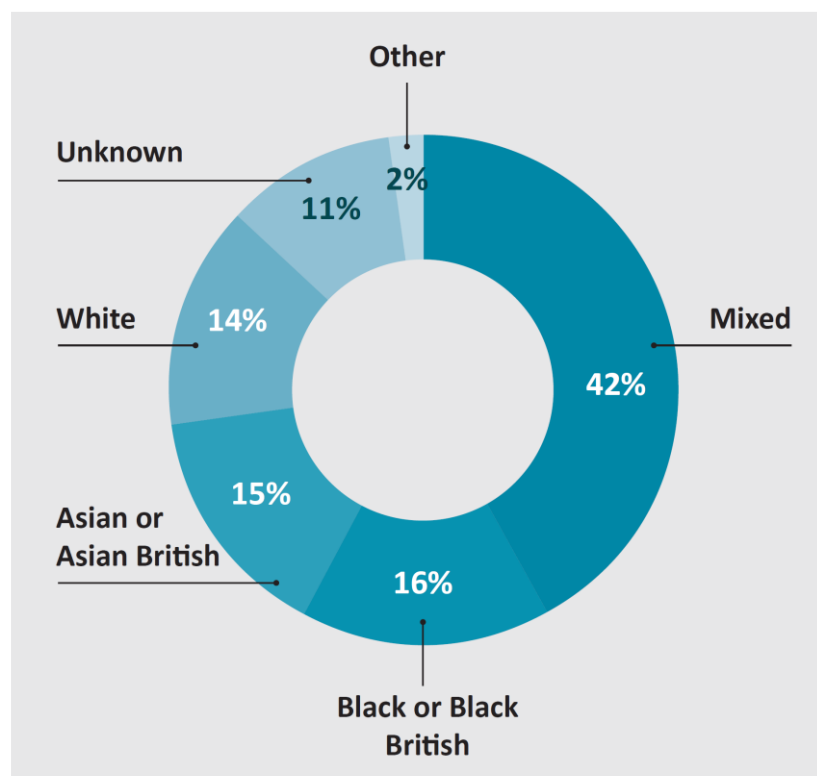





Figure 3-9 The age and mean number of long-term conditions according to carer status as recorded in the primary care record

Carer Status	Mean age, years	Average count of long-term conditions
Is a carer n=1,328 	53	1.0
Has a carer n=861 	66	2.3
Has AND is a carer n=101 	69	2.4

3.8.2 Health characteristics of the B&D cohort

Figure 3-10 The distribution of the cohort by category of body mass index and by gender

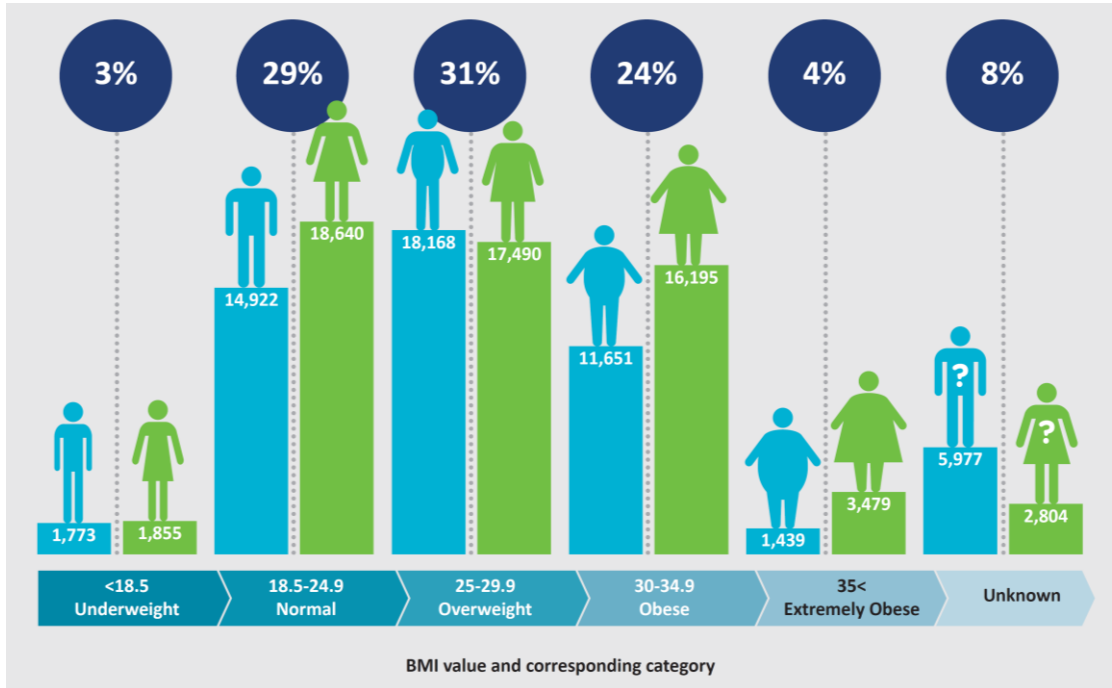


Figure 3-11 The distribution of the cohort by smoking status, age and gender

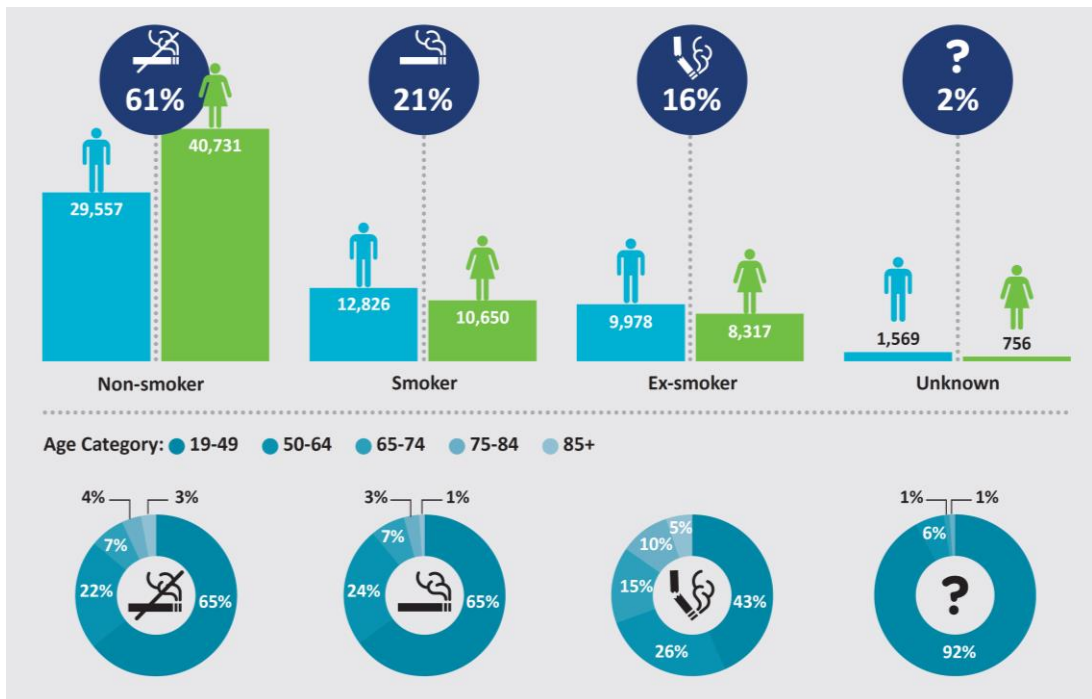


Figure 3-12 The mean age of diagnosis for each of 16 long-term conditions

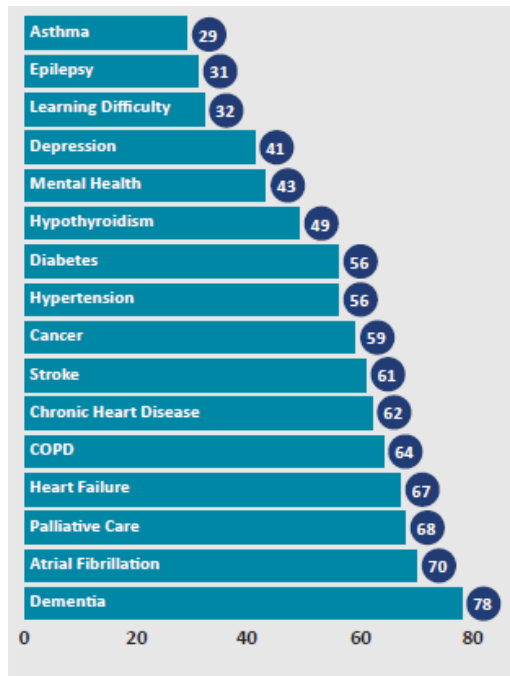


Figure 3-13 The age distribution of the cohort by the count of long-term conditions

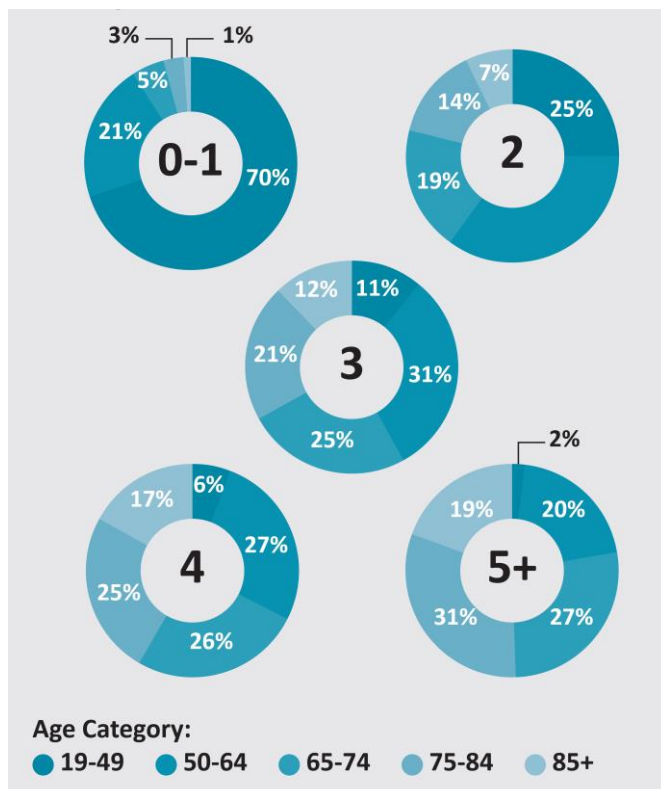
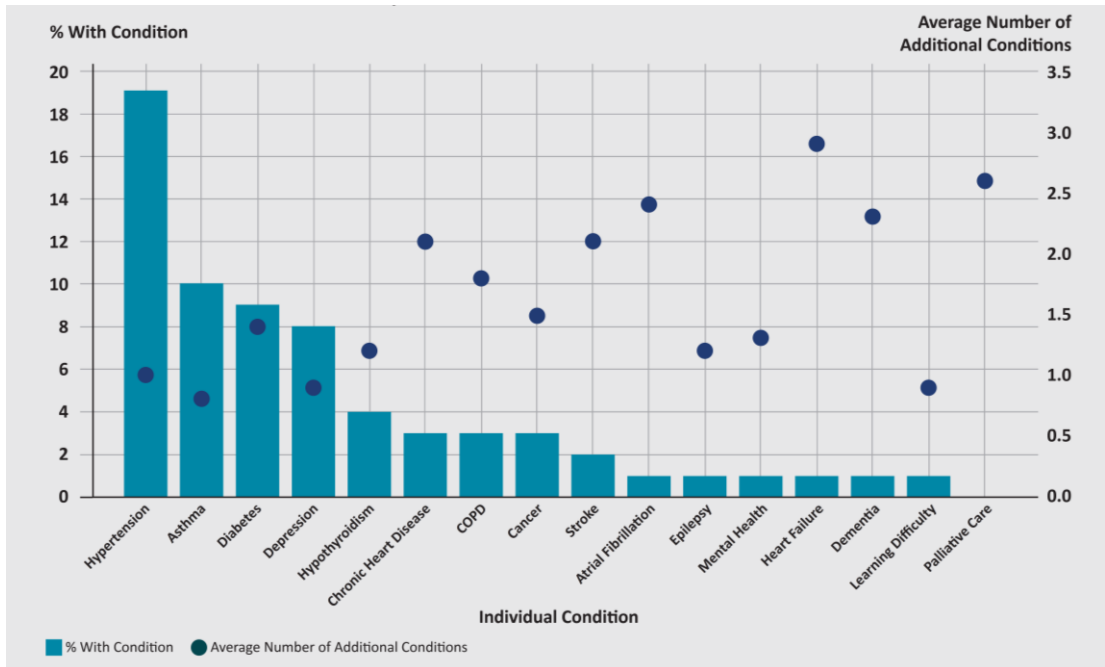


Figure 3-14 Percentage prevalence of individual conditions and mean number of additional long-term conditions for adults of B&D 2016/2017



3.8.3 Household characteristics of the B&D cohort

Figure 3-15 Housing tenure and housing occupancy

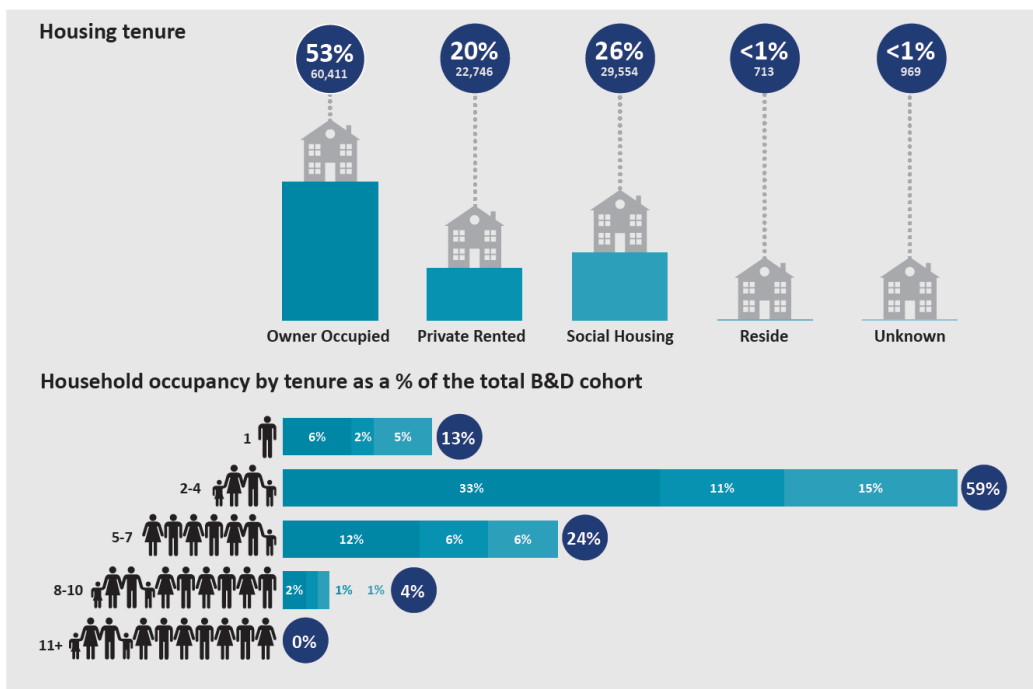


Figure 3-16 The number of individuals in each of the national quintiles of the indices of deprivation, and in each of the rebased quintiles using B&D distributions of the indices, based on 2015 IMD indices by LSOA

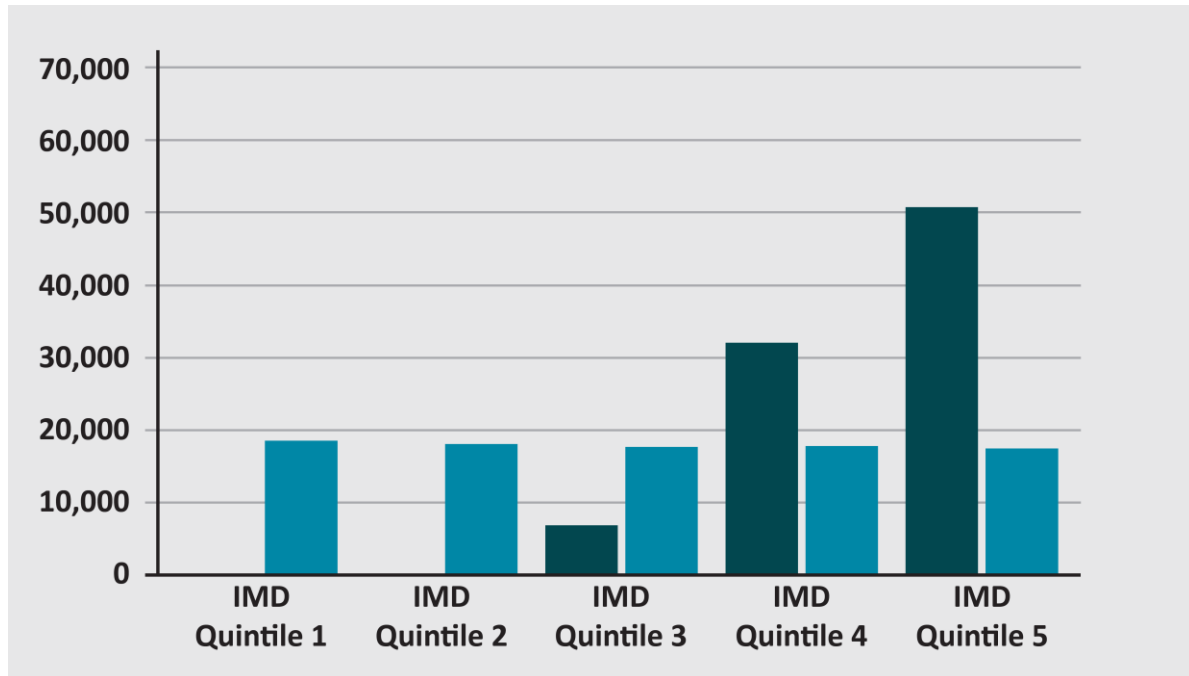
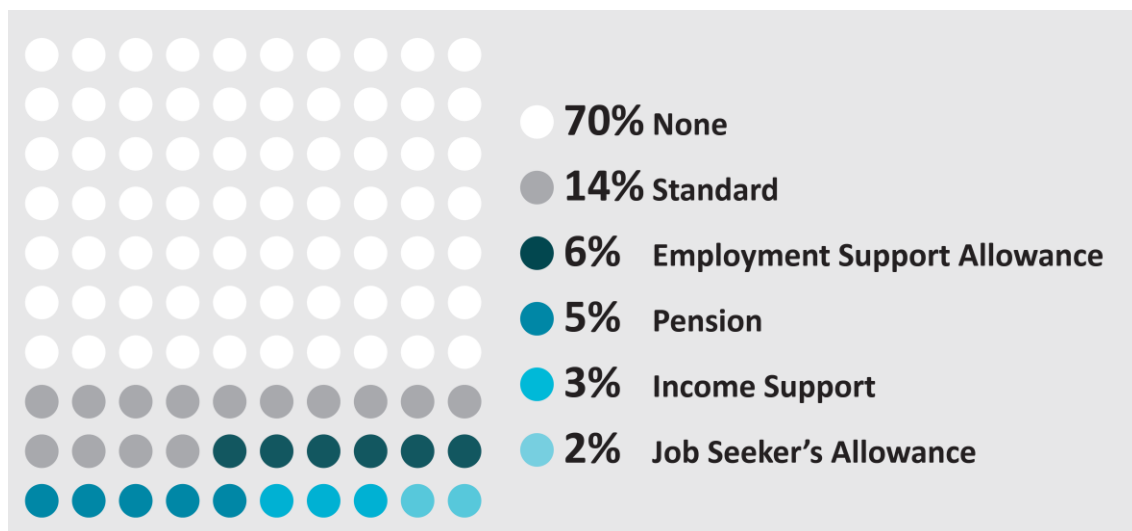


Figure 3-17 The percentage of individuals living in a household in receipt of housing benefits, by type of benefit



3.9 Compendium of graphs of the cost distribution by setting of care

For the adult population of B&D between 1st April 2016 and 31st March 2017, who were residents for the full year and did not die in year, the histograms for the cost distribution for each setting of care and the total cost are presented below.

Figure 3-18 The distribution of costs across settings of care

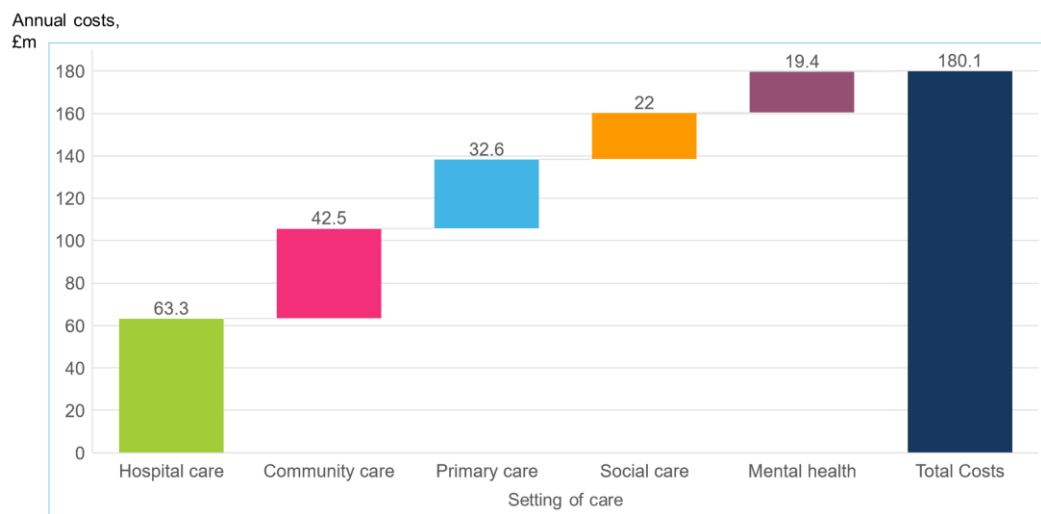


Figure 3-19 Histogram of total costs

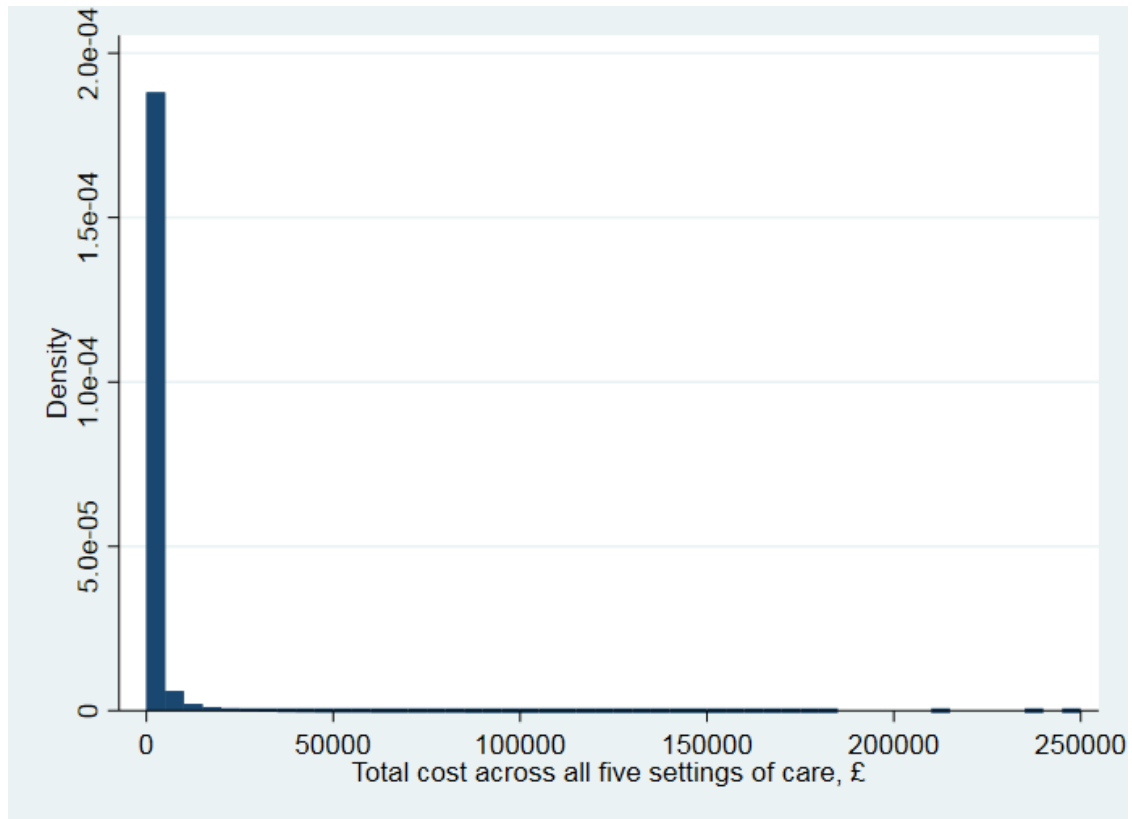


Figure 3-20 Histogram of total hospital costs

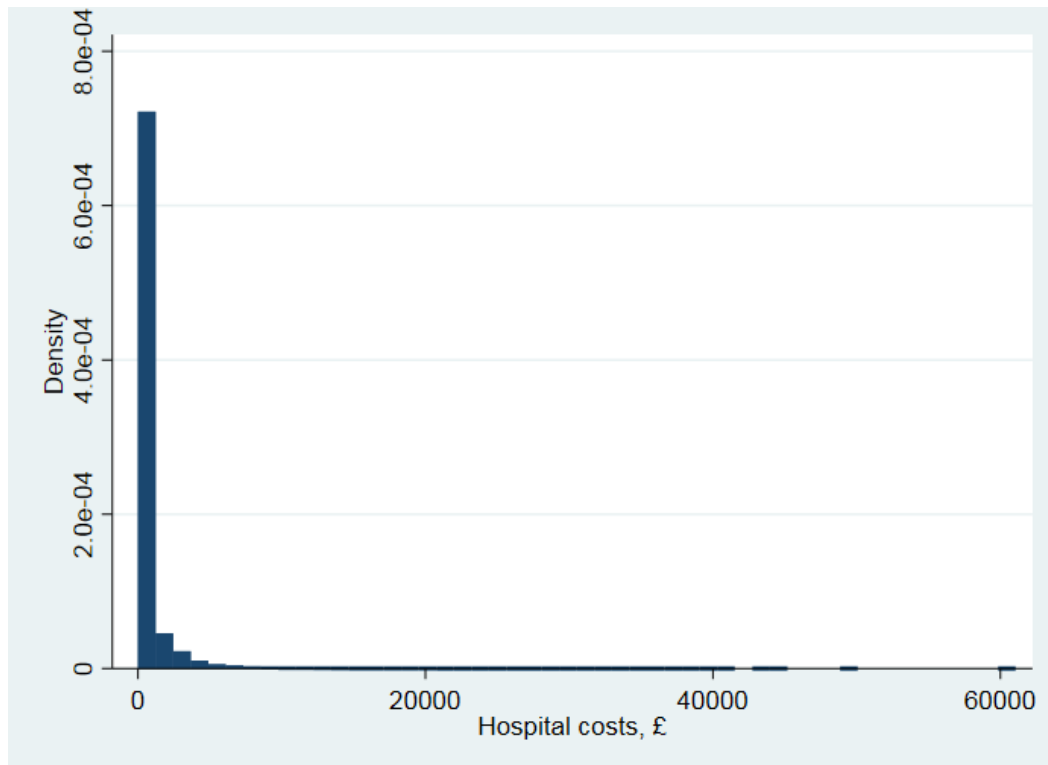


Figure 3-21 Histogram of total primary care costs

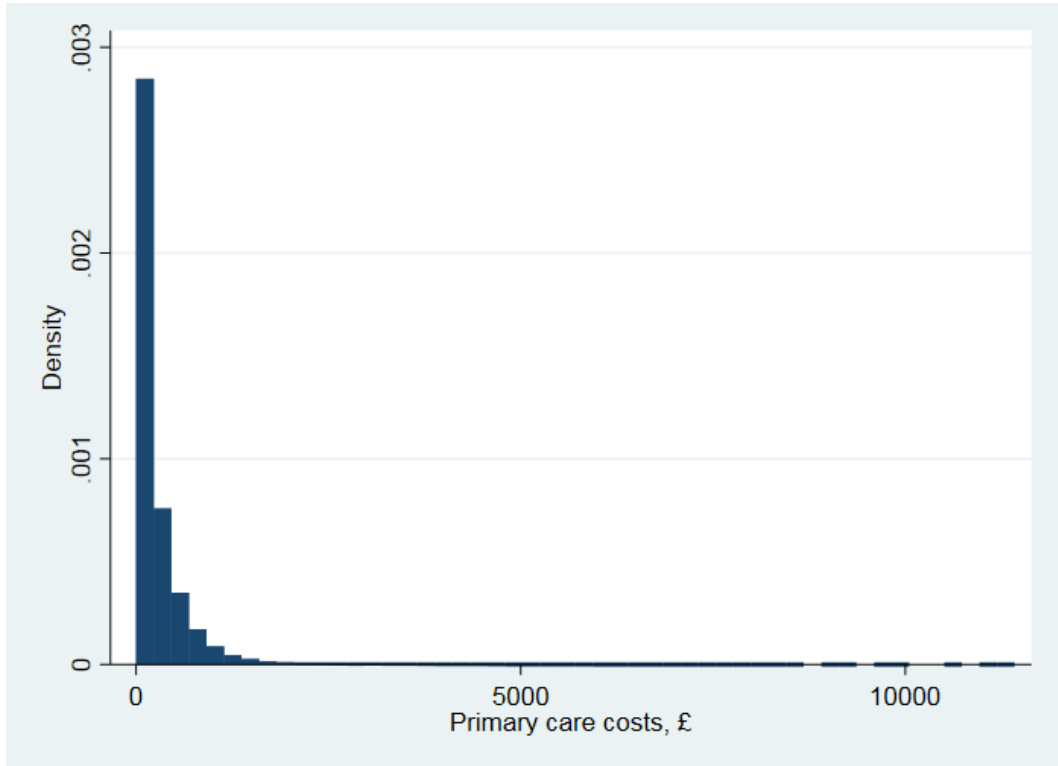


Figure 3-22 Histogram of total community care costs

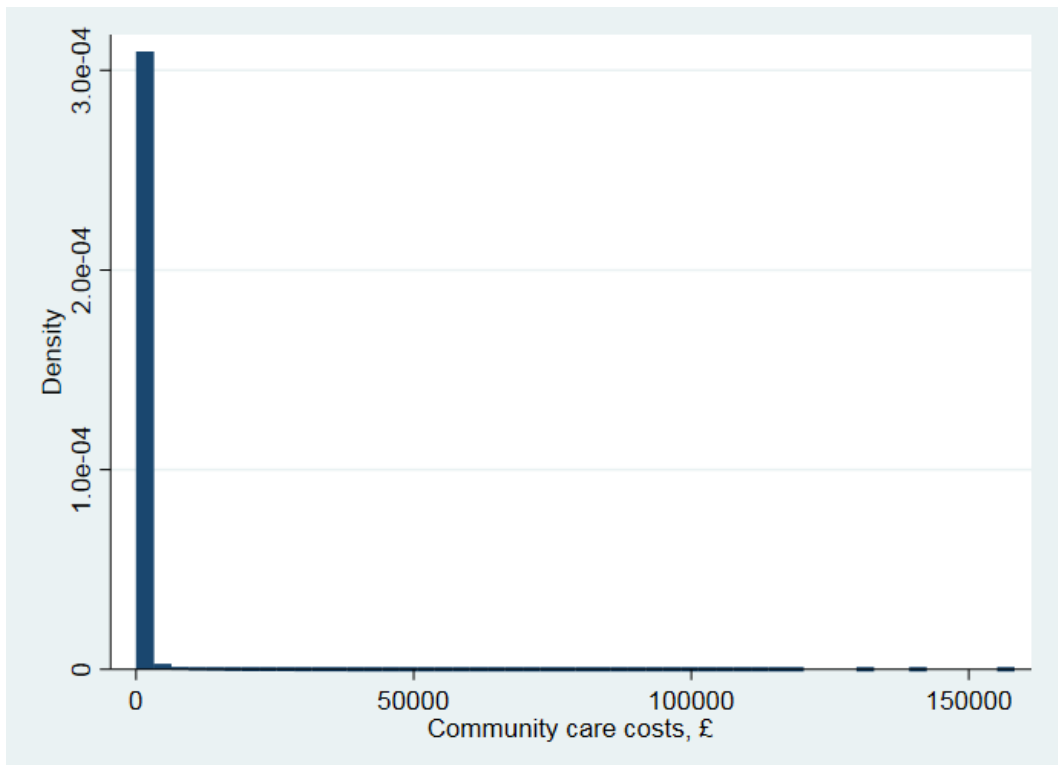


Figure 3-23 Histogram of total mental health costs

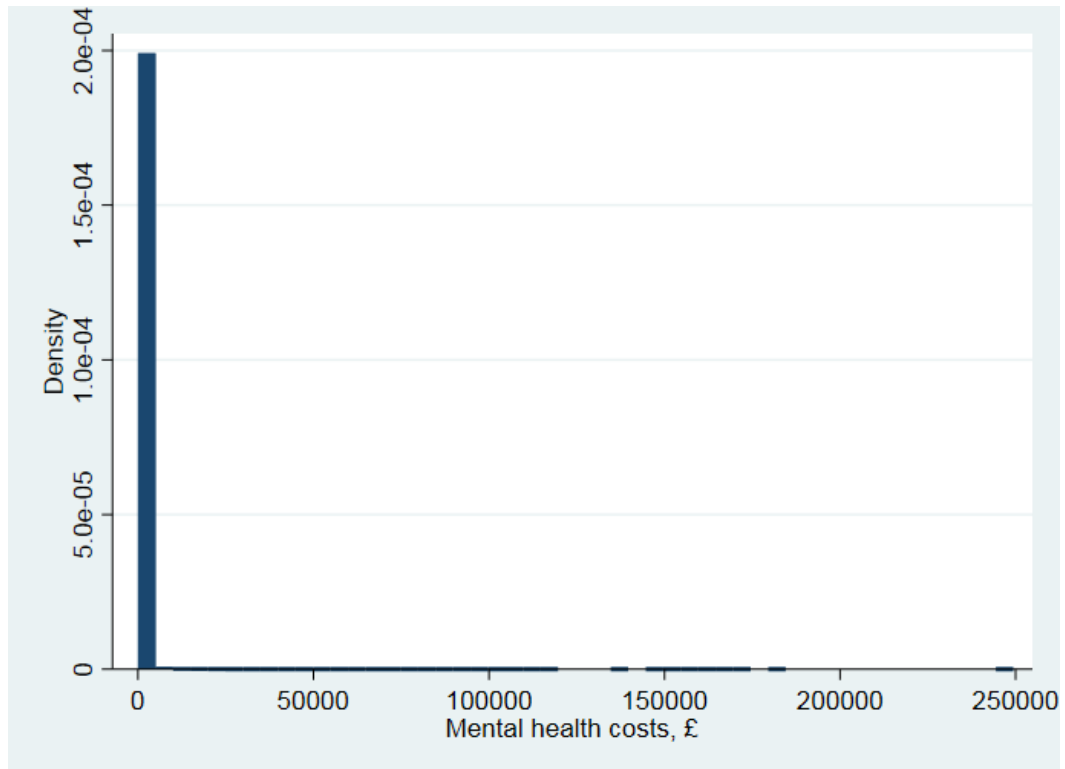
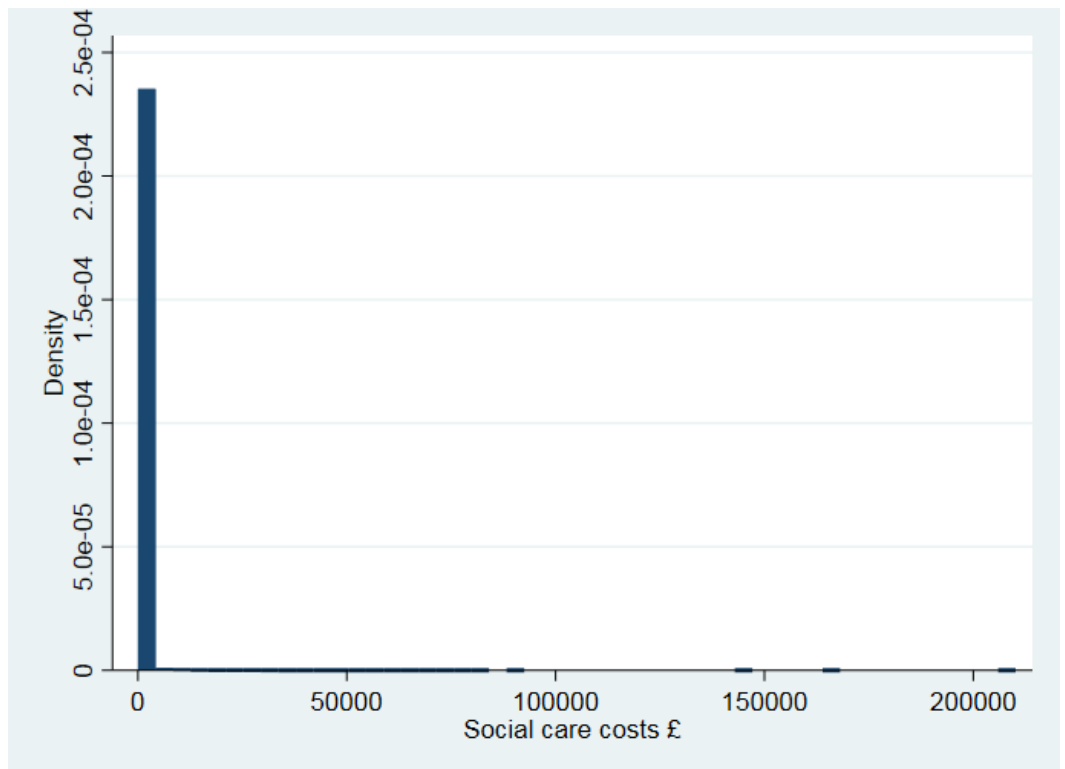


Figure 3-24 Histogram of total social care costs



4 Understanding health and care costs by setting – who matters to whom?

The interviews described in Chapter 2 found that the financial position of the system was the key motivation described by interviewees for participating in cross-organisation and cross-sector working. Health and social care costs continue to be dominated by high cost acute services. This study aimed to conduct an assessment of service use across a wider range of settings. The study analysed the proportion of the population and the proportion of costs, overall and for each of five settings of care (hospital, primary, community, mental health and social care), associated with different combinations of service use.

4.1 Background

The growing prevalence of chronic diseases and an ageing population (1), coupled with a funding gap (2), are challenging the sustainability of the NHS in England. NHS planning guidance includes an emphasis on better integration across settings within health services and with social care and other local authority services. This has been further reinforced in the NHS long-term plan (117). Although the NHS in England is a national tax-funded system, its component parts operate as separate organisations. Social care services are delivered by a mix of for-profit and not-for-profit organisations (118). The introduction of ICSs (61) aimed to bring these separate organisations and settings of care together to promote population-based planning and delivery of care for defined populations. Overspend in hospital care inevitably dominates the agenda, reflecting both where the system's highest costs are and the need to make short-term progress (4).

The NHS number, a unique individual identifier, facilitates linkage of individual records across different datasets to provide a richer understanding of individual health and social care utilisation by care setting and overall. To date, research into service utilisation has focused on individual settings, such as emergency attendance (81), specific disease pathways, such as diabetes (82), or sub-cohorts of the population, such as patients diagnosed as having five or more long-term health conditions (83, 84) and patients aged over 65 (85).

The reliability and availability of hospital and primary care datasets have led to a concentration in research on these two settings. Findings demonstrated an association between age and morbidity (most frequently measured as the number of long-term conditions an individual has) with increased service utilisation (119). Consequently, frail elderly populations and populations with multiple long-term conditions are policy and service priorities. However, this is only part of the system-wide picture as it excludes care settings, namely mental health, community services and social care. Whilst representing a smaller proportion of the total NHS and social care costs, these services may serve different population groups for whom integration or other interventions may be beneficial.

This descriptive study expands on the perspective adopted by existing research through an assessment of service use across five settings of care (hospital, primary, community, mental health and social care). The study analyses the proportion of the population and the proportion of costs, overall and for each setting of care, associated with different combinations of service use.

4.2 Methodology

This is a quantitative study using a subset of the linked dataset described in Chapter 3. Data from local government, health providers and health commissioners serving the B&D population were linked at the individual level to create a dataset that includes individual level demographic, socio-economic factors, markers of poor health, and health and social care service use.

B&D is a densely populated urban borough with 210,700 residents and high levels of deprivation, ethnic diversity and a young average age compared to the rest of the country. Participants eligible for inclusion were adults (age 19 or over) who were confirmed residents of B&D between 1st April 2016 and 31st March 2017 and who were registered with a B&D or Havering GP practice. Confirmed residents are defined as those who are present on the address register and on either another council dataset, the GP register or both (96)). Children were excluded because their patterns of service use differ from that of adults (120). Those who died or moved out of B&D before the 1st April 2017 were excluded from the cohort as they had less than 12 months activity data (and those who died have specific patterns of health care utilisation) (97, 98).

4.2.1 Health and social care costs

Cost-weighted utilisation was used by setting and overall for the analysis. We included the following types of care: hospital services (A&E attendances, elective and non-elective inpatient stays and outpatient appointments); primary care contacts; prescriptions; community care contacts (home visits, appointments with community teams including nurses, pharmacists and allied health professionals); mental health services (inpatient stays and outpatient appointments); and social care (weekly care packages which included costs for crisis intervention, home

care, supported living placements, and residential and nursing home placements). The care costs were estimated from activity data, with different costing approaches use for each setting that are described in detail in Chapter 3, Section 3.7. For hospital services, we used the HRG national tariff (113). For primary care, unit costs from the 2016/17 “Unit Costs of Health and Social Care” (121) were used for the GP visit and non-GP visit costs. For prescription costs, local prescription data allowed calculation of a unit cost per prescription per practice that could be applied to individual prescription counts. For mental health and community services, data from the Patient Level Information and Costing System from NELFT (the local provider) were used to calculate unit costs for each care contact. Local-government-funded social care costs were obtained from data which list the weekly billed cost for each care package provided (including in-year package revisions). Data on self-funded social care were not available; data on equipment, transport and home adaptation costs were not available as these are held in different departments of the council. The total cost for the financial year was calculated by aggregating individual costs across all settings.

4.2.2 Analysis

For each setting of care a binary measure was created taking the value one if the individual had any service use in that setting and zero otherwise. For each individual the number of settings in which they incurred a cost was counted. This provided information on both the settings in which an individual had a service use (and therefore a cost) and the combination of settings.

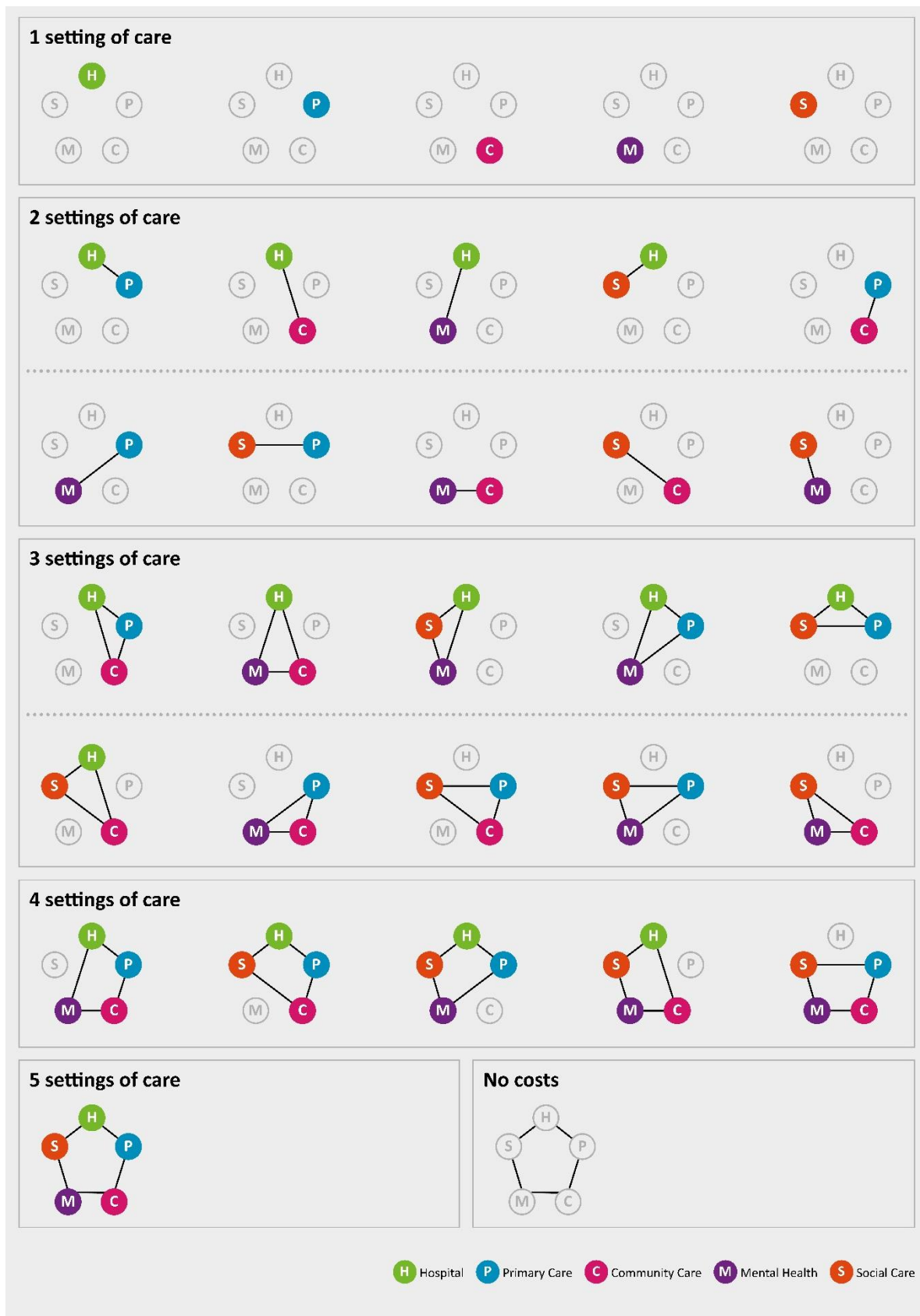
With five settings of care in the dataset, there are 32 possible combinations of setting costs (including having no costs in any settings). This is calculated as follows:

Number of combinations: $nCr = \frac{n!}{r!(n-r)!}$			
n=	r=		nCr=
5	0	$\frac{5!}{0!(5-0)!}$	1
5	1	$\frac{5!}{1!(5-1)!}$	5
5	2	$\frac{5!}{2!(5-2)!}$	10
5	3	$\frac{5!}{3!(5-3)!}$	10
5	4	$\frac{5!}{4!(5-4)!}$	5
5	5	$\frac{5!}{5!(5-5)!}$	1
Total combinations			32

Figure 4-1 shows the 32 possible combinations of setting costs (including having no cost in any settings). I identified which of these combinations were most dominant in terms of total population and cost volumes. I also reviewed which combinations were most prevalent for each individual setting by reviewing the proportion of service users and cost in that setting.

The analysis was conducted using Stata version 15.1 (122).

Figure 4-1. The 32 possible combinations of setting-based service use



4.3 Results

4.3.1 Cohort

There were 201,393 records of confirmed residents of B&D on 1st April 2016. Of these, 18,754 were excluded due to leaving the borough within the year (including deaths), 9,980 were excluded because they could not be matched with an NHS number, 5,298 were excluded due to being registered with a GP practice outside the borough and 52,968 were aged between 0 and 18-years old. The 114,393 remaining adult individuals (77% of all adult residents) were included in the cohort. They lived in 58,929 households. The total cost for the cohort for 2016/17 was £180.1 million, distributed across settings as follows: 35% (£63.3 million) hospital care, 24% (£42.5 million) community care, 18% (£32.6 million) primary care, 12% (£22.0 million) social care services and 11% (£19.4 million) mental health. Table 4-1 provides a summary of the cohort characteristics.

Table 4-1. Summary characteristics of the cohort, mean total cost and standard deviation

		Total N=114,393		Total cost	
		n	%	Mean	SD
Age	19–49	70,564	62%	807	3,749
	50–64	25,827	23%	1,591	6,194
	65–74	9,376	8%	2,794	8,018
	75–85	5,751	5%	5,008	11,695
	85+	2,875	2%	9,436	16,697
Gender	Female	60,463	53%	1,790	6,514
	Male	53,930	47%	1,334	5,940
Ethnicity	White	15,767	14%	925	4,083
	Black or Black British	18,355	16%	999	4,284
	Mixed	48,305	42%	2,351	8,186
	Other	2,394	2%	801	3,083

		Total N=114,393		Total cost	
		n	%	Mean	SD
Body mass index (BMI)	Asian or Asian British	17,324	15%	1,041	4,064
	Unknown	12,248	11%	1,122	4,763
	Underweight	3,628	3%	1,967	8,624
	Healthy	33,562	29%	1,443	6,039
	Overweight	35,658	31%	1,491	5,923
	Obese	27,846	25%	1,895	6,531
	Morbidly obese	4,918	4%	2,677	8,898
	Unknown	8,781	8%	628	3,914
Smoking status	Non-smoker	70,288	61%	1,432	5,904
	Ex-smoker	18,295	16%	2,403	7,754
	Smoker	23,476	21%	1,489	6,199
	Unknown	2,334	2%	254	1,345
Conditions	AF	1,674	1%	8,551	16,649
	Asthma	11,436	10%	2,445	7,986
	Cancer	3,339	3%	4,967	10,925
	CHD	3,423	3%	6,108	12,331
	COPD	3,423	3%	6,196	13,110
	Dementia	740	1%	18,351	23,181
	Depression	9,045	8%	3,277	9,944
	Diabetes	10,325	9%	4,207	10,648
	Epilepsy	1,566	1%	5,314	13,430
	Heart failure	881	1%	11,132	19,001
	Hypertension	21,671	19%	3,555	9,626
	Hypothyroidism	4,840	4%	3,664	10,569
	Learning difficulty	694	1%	15,932	26,981
	Mental health	1,452	1%	9,738	18,888
	Palliative care	291	<1%	15,474	24,236
	Stroke	1,849	2%	8,393	16,824
Benefits	None	80,337	70%	1,130	4,492

		Total N=114,393		Total cost	
		n	%	Mean	SD
Housing tenure	Employment Support Allowance	6,497	6%	3,291	10,085
	Pension	5,589	5%	5,274	13,139
	Income Support	3,506	3%	2,218	9,441
	Job Seeker's Allowance	2,024	2%	966	2,419
	Standard	16,440	14%	1,751	6,929
	Owner occupied	60,411	53%	1,307	5,092
	Private rented	23,459	20%	1,193	5,441
	Social	29,554	26%	2,275	8,220
	Unknown	969	1%	6,185	13,382
Household occupancy	1	14,362	13%	3,751	11,009
	2 to 4	67,606	59%	1,416	5,591
	5 to 7	27,293	24%	886	3,899
	8 to10	4,009	4%	772	2,522
	11+	1,123	1%	2,933	9,081
Deprivation (2015 Index of Multiple Deprivation, national quintiles)	Quintile 3	8,818	8%	1,342	5,375
	Quintile 4	40,873	36%	1,474	5,752
	Quintile 5	64,702	56%	1,671	6,655

4.3.2 Individual cost profiles by setting

Of the 32 possible combinations, 2 combinations were dominant with regards to both population volume and proportion of total cost: primary-hospital care (27% total cost, 30% population) and primary-hospital-community care (21% total cost, 6% population) (Figure 4-2). However, when reviewing cost for each individual setting, eight further cost combinations were identified as being dominant proportions of the cost and user volume of at least one setting of care. Primary care is present in all of these combinations. For mental health, there were three groups which had significant proportions of overall mental health cost but were

not present when viewing the total system-wide cost. For example, hospital-primary-mental health accounted for 37% of the mental health service user population and 31% of total mental health cost, but only 1% of the total user population and 5% of the total cost.

Figure 4-2 Cumulative total cost by cumulative total population, overall and by setting of care

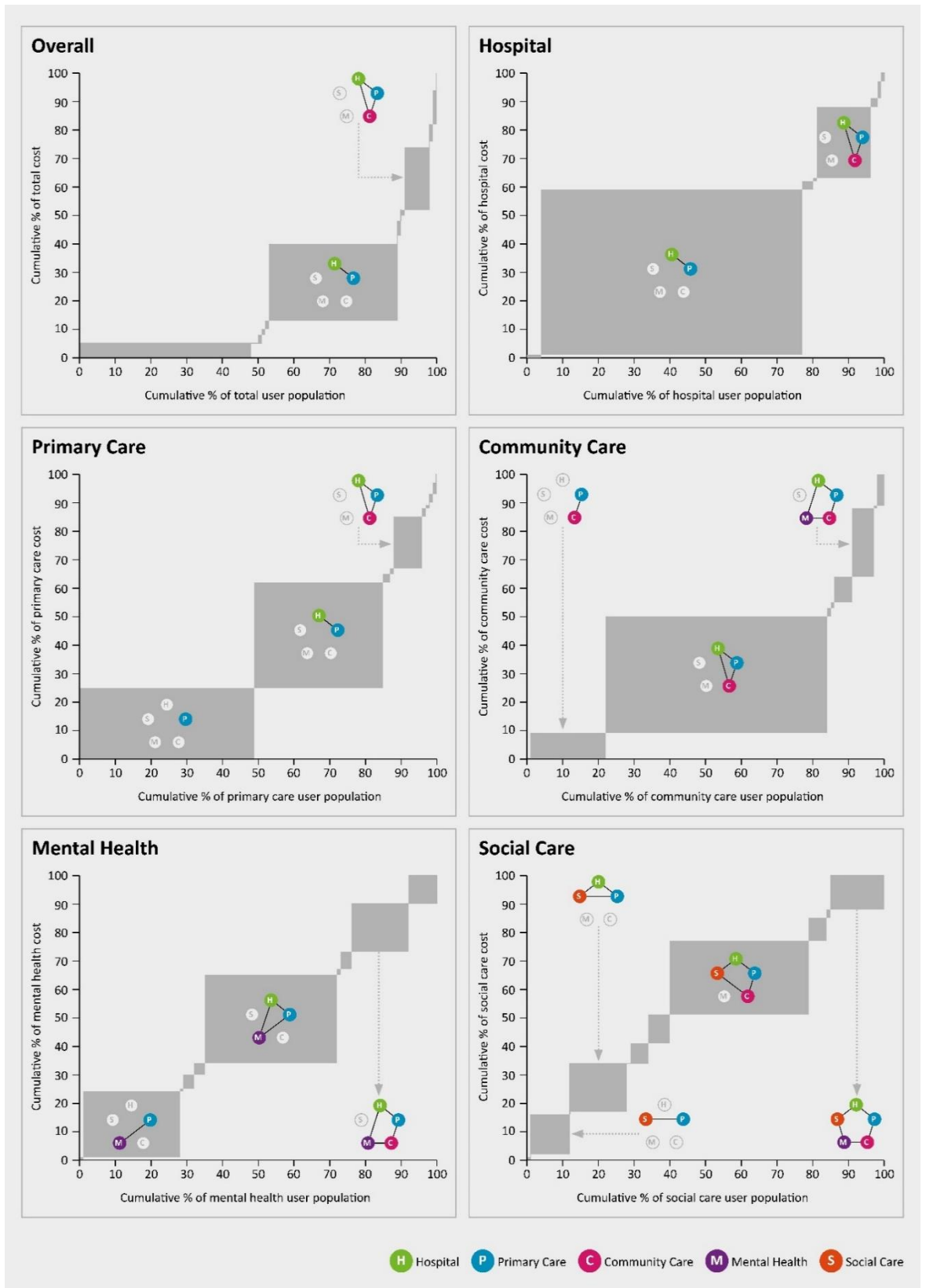
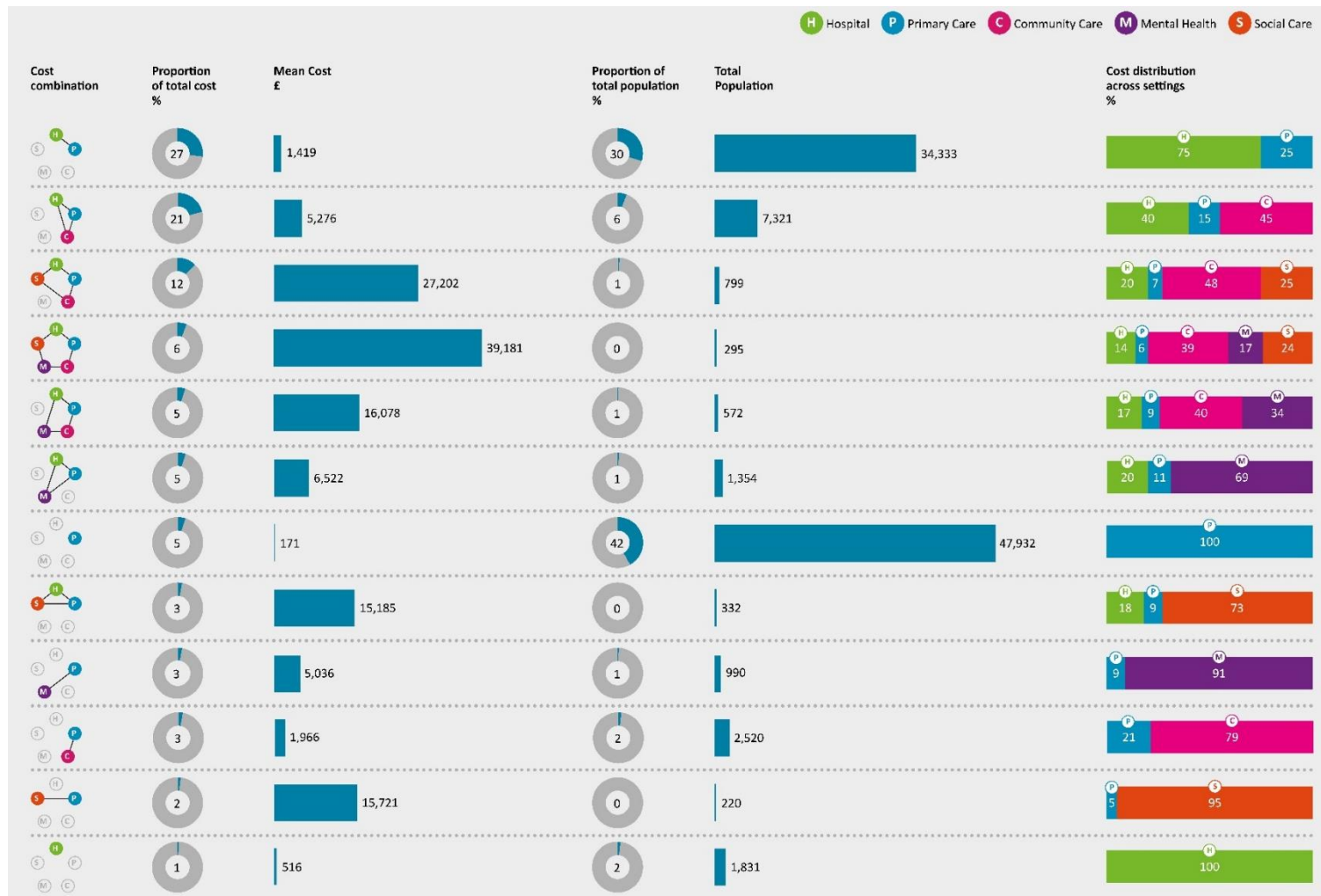
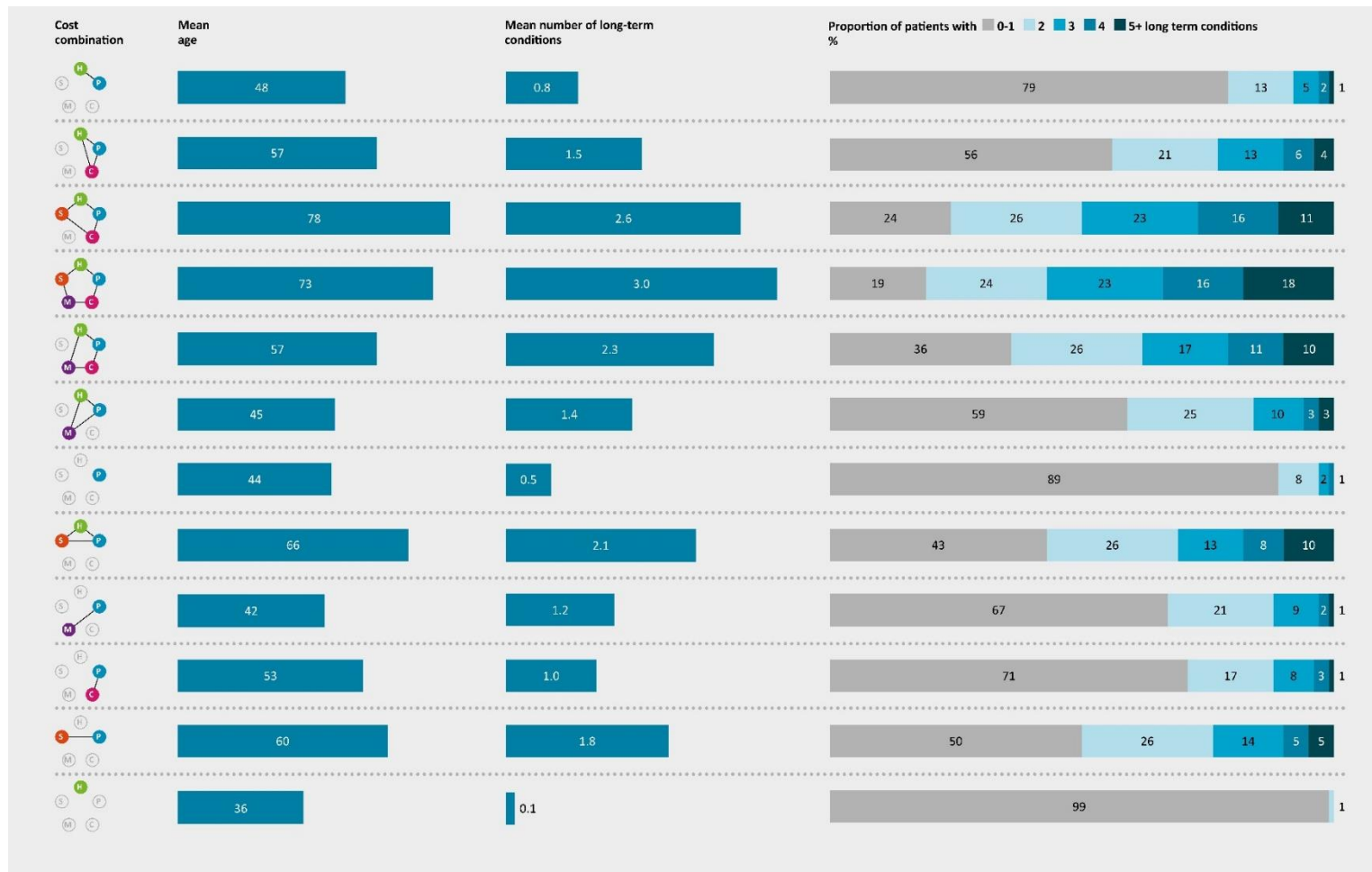


Figure 4-3 A summary of the 12 cost combinations that had more than 150 service users



Appendix 7 provides the full results table across all settings of care for each of the 32 combinations. Figure 4-3 provides a summary of 12 cost categories that had more than 150 service users. Only 0.3% (295) of the population incurred cost in all five settings of care. They were older, with a mean age of 73, and had higher levels of multi-morbidity with mean long-term conditions of 3.0 (Figure 4-4). The mean age and the mean number of long-term conditions increased as the number of settings increased. Mean cost increased significantly as the number of settings increased. Community care was a dominant proportion of the mean cost for combinations that included four or five settings of care. Combinations that included mental health had a lower mean age from those that did not and had fewer long-term conditions. Where there was mental health service use, mean cost increased significantly (see Figure 4-3). For example, hospital-primary care had a mean cost of £1,419, whereas hospital-primary care-mental health had a mean cost of £6,522, a 460% increase. The move from four settings without mental health, to five settings with mental health was a 144% increase (£27,202 to £39,181).

Figure 4-4 The mean age and number of long-term conditions for the 12 cost combinations that had more than 150 service users



4.4 Discussion

4.4.1 Summary of results

Firstly, there is a significant proportion of total cost (47%) that is incurred outside hospital and primary care services. Secondly, the inclusion of cost data for all five settings of care can provide a more holistic view of individual service use than viewing costs for any one setting in isolation. Thirdly, while mental health service use accounts for 11% of all costs, having mental health service use significantly increases mean cost per patient.

4.4.2 Implications for policy and practice

Primary care was present in all dominant setting combinations. This is consistent with the role of primary care as both a gatekeeper to other services and as an important part of ongoing care management (123). People with multiple conditions attend a GP practice more than any other NHS service and rely on primary care to coordinate their care. This role has been recognised by policy makers (2). For primary care, there was a large proportion of activity that was not linked to other settings, which is important to recognise when designing integration programmes and engaging the primary care community.

There is growing attention on mental health from the policy and service re-design point of view (124). In our study, mental health users had lower mean ages and fewer long-term conditions than service users of other settings. However, the addition of mental health to the cost of combinations increased mean cost – for example hospital-primary mean cost was £1,419 but hospital-primary-mental health was £6,522 – suggesting age and morbidity levels may not be the main drivers of cost in all settings. This is contrary to the focus of integration efforts to

date, which are predominantly targeted at the frail elderly and those with multiple long-term conditions.

The potential for integration to address NHS efficiency challenges is centred on the wide variation in avoidable use of hospital care, and the need to reduce fragmentation and improve experience for people using multiple services (52). This analysis shows that a large proportion of cost is incurred outside hospitals. Whilst the highest volume of cost was in primary and hospital services, if the aim of integration is to both improve efficiency and experience, different types of integration for different patterns of service use may be required. There may be less dominant service users who could benefit from integration who are not in the hospital-primary care combination. This study shows the potential for large, linked databases to provide a deeper level of understanding of the different service use patterns across settings of care.

4.4.3 Strengths and limitations

The main strength of this study was that it included all five settings of care and used a large population cohort, which can enable a deeper understanding of patient flows. Whilst age segmentation and long-term condition counts can enable policy makers, commissioners and providers to identify the small proportion of high users (and by inference those with high needs) who account for a large proportion of total cost, it can risk over prioritising those with existing high needs rather than those with emerging needs. In addition, it does not provide clarity on how specific patient journeys and utilisation patterns can be influenced and altered or which settings of care need to be engaged to implement the changes. Current policy promoting ICSs requires all settings of care to collaborate for the whole population. This work highlights that only a

small minority of the population use services across all settings in any one year; therefore, more bespoke collaborations may be more appropriate.

There are several limitations. Firstly, data were drawn from a single year and hence longitudinal patterns were not evaluated. It was therefore not possible to discern how stable the categorisation into a combination of service use was. It may be that some combinations are consistent with persistent users, whereas other combinations contain episodic users (e.g., those with single a high-cost event) but when assessed over time are more accurately in a different service combination. For example, someone may rarely use health services but a bicycle accident may have led them to have a hospital admission via A&E, physiotherapy in the community and a follow up GP appointment. This would suggest they were in the Hospital-Primary care–Community combination of service users, alongside, for example, people with Chronic Obstructive Pulmonary Disease who have annual appointments with a consultant in a hospital, often non-elective admissions for exacerbations, pulmonary rehabilitation in community services and regular appointments with their GP. The former would be an example of an episodic user, whereas the latter is a persistent user. There is also the constraint that for new cases of a health problem that materialise within year the pattern of health service use might be different to the longer term. For example, there may be more acute hospital care in the first year, and a shift to community, primary, and/or social care in the longer term. Focusing on a one-year snapshot, and without analysis of incident and diagnosis dates, makes it difficult to evaluate this.

Understanding trends over time and the proportion of each service combination that are stable users compared to episodic users would provide more accurate understanding of the cost profiles of the different service combinations.

Assessing how service utilisation varies over time provides an interesting avenue for further research.

Secondly, by defining multi-morbidity as a simple count of long-term conditions, our analysis weighted all diseases equally, although the effect of multi-morbidity on individuals can vary with combination and severity of conditions. Thirdly, we did not take into account how long the individuals had had the conditions. This could change the pattern of service use as, for example, the diagnostic pathway and first year of living with a condition can require different service use than subsequent disease management.

Although the cohort was large, this is a very deprived population with no individuals in the two least deprived national quintiles. This may have an impact on the generalisability of findings, particularly given the known associations between deprivation and increased prevalence of illness and multi-morbidity in deprived populations and increased service use (125).

4.5 Conclusion

Linked electronic health and council records provide an opportunity to inform integration strategies by clarifying which settings of care are most relevant to different population groups. This study found that a system-wide perspective risks oversight of population groups that are dominant proportions of the volume and cost profile of an individual setting, particularly mental health users.

The next chapter shares research that reviews the individual characteristics associated with costs in each setting of care and overall, to understand further the similarities and differences in the characteristics of service users by setting of care.

5 Understanding the individual characteristics that drive health and social care utilisation – using a linked dataset across five settings of care

Chapter 4 found that the characteristics of service users differed by setting of care. For example, users of mental health services had a lower mean age, had fewer long-term conditions, and higher mean cost. The linked dataset created and described in Chapter 3 provides more comprehensive information on the characteristics of the individual service users beyond age and number of long-term conditions, including personal characteristics, health characteristics (risk factors and prevalence of conditions) and household characteristics. These enable adjustment for some of the wider social determinants of health described in Chapter 1. This study builds on the findings of Chapter 4 by exploring variables associated with cost in each setting of care to provide a more detailed understanding of the service users of each care setting.

5.1 Background

There is policy commitment, in the UK and internationally, to the promotion of integrated care across settings of care, to improve efficiency and quality of care delivered, and with other sectors, to improve prevention of ill health and reduction of health inequalities. The reliability and availability of hospital and primary care datasets have led to a concentration in research on these two settings. Findings demonstrated an association between age and morbidity (most frequently measured as the number of long-term conditions an individual has) with increased service utilisation (126). Consequently, frail elderly

populations and populations with multiple long-term conditions are policy and service priorities (13). However, this is only part of the system-wide picture as it excludes other care settings, namely mental health, community services and social care, and overlooks the wider determinants of health.

The NHS number allows us to link individual records across different datasets to provide a richer understanding of individual health and social care utilisation.

Progress to link datasets across settings of care is slow, and data linkage with other sectors is notoriously challenging. Previous studies illustrated the extent to which this type of extended linkage can help address important clinical and policy questions (77, 127-129). However, the breadth and depth of the linked information included in the dataset described in Chapter 3 has not been achieved or considered before.

Research into health service utilisation has focused on specific settings of care, diseases, evaluation of interventions and on health inequalities. Inequalities research distinguishes between need variables, which should directly influence health and care use, and non-need variables, which should not, to understand whether people with the same needs use different amounts of care due to non-need factors (51). The social determinants of health described in Chapter 1 highlight the importance of reviewing both need and non-need variables. In this project, I have not attempted to distinguish between need and non-need variables, with judgement required to make the distinction. Instead, I included a wide range of variables that the literature suggests are associated with health and social care use. These included markers of poor health (diagnosis of specific conditions), health behaviours (BMI and smoking) and socio-economic characteristics (ethnicity, household occupancy, deprivation and benefits receipt).

This project aims to understand the variables associated with higher health and social care utilisation, specifically:

- Which factors determine the probability of using health services overall and by setting of care (hospital, primary care, community care, mental health, social care)?
- Which factors are associated with health care costs, overall and by setting of care?
- Do the factors that are associated with higher service use differ between settings of care?

5.2 Methodology

This is a quantitative study that uses individual level data within a regression framework to understand the associations of different demographic and socio-economic factors with both the odds of having service use and the resultant health and social care costs in each setting of care. The choice of variables included in the regression analyses were informed by a scoping review (see Chapter 1.4).

5.2.1 Dataset and variables

This is a quantitative study using a subset of the linked dataset described in Chapter 3. The dataset of adults who were confirmed residents of B&D between 1st April 2016 and 31st March 2017 were used as the base for the analysis. As with the previous chapter, those who died during the year or who moved out of B&D before the 1st April 2017 were excluded from the cohort as they had very specific patterns of health care utilisation or less than 12 months of activity data (97, 98).

The primary outcome measures were total service cost and setting level service cost for hospital, primary care, community care, mental health and social care. I included variables that may have an association with health and social care cost across three categories: individual socio-demographic characteristics, individual health characteristics and household characteristics. Table 5-1 summarises the variables in each of these categories and confirms which value was used as the reference group in the modelling.

Table 5-1 A description of the variables included in the two-part model and the values used as the reference group for the modelling

Variable	Description	Values	Reference group for the two-part modelling
Socio-demographic characteristics			
Age	Age group of the individual	19–49, 50–64, 65–74, 75–84, 85+	19–49
Gender	Whether the individual is male or female as documented in the primary care record	Male, Female	Female
Ethnic group	The ethnic group of the individual, applying the ONS ethnicity groupings to the ethnicity documented in the primary care record	White, Black or Black British, Mixed, Other, Asian or Asian British, Unknown	White
Carer	Whether the individual is a carer, has a carer or both as documented in the primary care record	None, Has a carer, Is a carer, Has and is a carer	None
Health variables			
BMI category	The BMI category of the individual, assigned using the BMI value recorded in the primary care record	Underweight, Healthy, Overweight, Obese, Morbidly obese	Healthy
Smoking category	The smoking status of the individual, assigned using the smoking status recorded in the primary care record	Non-smoker, Ex-smoker, Smoker, Unknown	Non-smoker
Count of long-term conditions	The count of how many of the 16 conditions, listed below, the individual has been diagnosed as having	0–1, 2, 3, 4, 5+	0–1
Conditions	Whether or not the individual has been diagnosed with each of 16 conditions: Atrial fibrillation, Asthma, Cancer, CHD, COPD, Dementia, Depression, Diabetes, Epilepsy, Heart failure, Hypertension, Hypothyroidism, Learning difficulty, Mental health, Palliative care, Stroke	1 if they have been diagnosed with the condition, 0 if not	No condition

Variable	Description	Values	Reference group for the two-part modelling
Household variables			
Benefits	If the individual is in receipt of Housing Benefit, Council Tax Benefit or both, the additional benefits they are also in receipt of	None, Employment Support Allowance (ESA), Pension, Income Support, Job Seeker's Allowance, Standard	None
Tenure	The legal status under which people have the right to occupy their accommodation, provided from council records	Owner occupied, private rented, social housing, unknown	Owner occupied
Occupancy	The number of people living in the household, provided by council records	1, 2 to 4, 5 to 7, 8 to 10, 11+	2 to 4
B&D IMD quintile	The quintile to which the overall score from the 2015 Index of Multiple Deprivation (IMD) should be assigned, rebased to B&D quintiles, from Office for National Statistics and applied to the Lower Super Output Area of the address of the individual	1 (least deprived), 2, 3, 4, 5 (most deprived)	1 (least deprived in the borough)

5.2.2 Two-part model

The aim of the project was to understand the variables associated with health and social care cost-weighted utilisation. The histograms of costs overall and by setting of care (Chapter 3) confirmed that there is a large mass of zeros, particularly for community services, mental health and social care. Table 5-2 shows the proportion of individuals in each setting of care that had zero cost and the proportion that had non-zero cost. The cost-weighted utilisation is semi-continuous data, with a point mass at zero followed by a right-skewed continuous distribution with positive support. The zeros represent a subpopulation of patients who do not use health or social care services, while those with a cost have a continuous distribution that describes the level of cost among the health and social care services users. I wanted to obtain the effect of covariates on the overall population mean cost of service use.

Table 5-2 The proportion of individuals that either had no costs or had a cost in each setting of care

Setting	Individuals with no costs, n	% of total cohort n = 114,393	Individuals with costs, n	% of total cohort n = 114,3932
Hospital	67,377	59%	47,016	41%
Primary care	17,211	15%	97,182	85%
Community care	102,463	90%	11,930	10%
Mental Health	110,727	97%	3,666	3%
Social care	112,337	98%	2,056	2%
Total costs	15,170	13%	99,223	87%

Heavily skewed distributions of health care costs is a common problem in the analysis of health care data. Heavily skewed dependent variables in standard regression models such as Ordinary Least Squares (OLS) can lead to non-

normal residuals which yield inconsistent estimates of marginal and treatment effects.

One approach to dealing with skewed distributions of dependent variables in regression analysis is to transform the dependent variable by taking its natural logarithm to ensure that the disturbance approximates normality. This approach is common in the health economics literature, particularly in the modelling of utilisation and spending on health resources. (130 - 132).

A second approach to dealing with skewness is to use a Generalized Linear Model (GLM). This approach has increasingly been applied in health economics research (133). The GLM framework allows the mean of the dependent variable to be a function of the linear index of covariates and at the same time allows the variance of the dependent variable to be a function of its predicted value through the choice of a suitable distribution family. The log-link and gamma family is a common choice for GLM models of health care expenditures and costs (133). GLM's are especially useful because they model heteroskedasticity directly and they avoid the re-transformation of the outcome variable back to the raw scale as with log-linear models, which means that marginal and incremental effects can be calculated more easily.

The OLS and GLM models are both conditional on an individual having positive service use. This condition results in a loss of information since those individuals who do not have any service use in the first place are excluded.

Table 5-2 shows there are a proportion of individuals that have no service costs. Two-part models attempt to account for this. Using statistical models that ignore this mass at zero might mean that the effects of the explanatory variables on the outcome cannot be generalised to the whole population. Specifically, OLS and

GLM only describe the effect at of the co-variates on health and social care service use for those already in receipt of services, however this effect might differ from the effect of the co-variates on whether or not a person accesses services in the first instance. Thus, it is important to explicitly model the mass at zero, and subsequently calculate marginal and incremental effects which account for this. The two-part model involves first estimating the probability of having a non-zero outcome via probit or logit, and subsequently estimating the mean of the outcome, conditional on having a non-zero outcome via OLS or GLM. Two-part models have widely been used and discussed in the health economics literature (130-132,134) and have been shown to outperform other models when a large proportion of zeroes exist in the data (131).

Choosing between different models and making assessments of which model is most appropriate is often informed by Akaike Information Criteria (AIC) and Bayesian Information Criteria (BIC), and statistical tests including the Box-Cox and Modified Park tests. AIC is a fined technique based on in-sample fit to estimate the likelihood of a model to predict/estimate the future values. A good model is deemed to be one that has minimum AIC among all the other models. Bayesian information criterion (BIC) is another criteria for model selection that measures the trade-off between model fit and complexity of the model. A lower AIC or BIC value indicates a better fit.

A two-part model was used in this instance, firstly modelling the odds of an individual having a cost in that setting using a logistic regression model, and secondly, conditional on having a cost in that setting, a generalised linear model (GLM) of individual cost-weighted utilisation against variables the literature suggests are likely to be associated with cost. A two-part model was chosen due to being able to calculate the combined effect of both the probability of service

use and the level of service use if there was one. The two-part model allowed for separate investigation of the effect of covariates on the extensive margin (logit model, if the individual was a service user) and on the intensive margin (GLM, the level of service use measured in costs for service users). In doing so, it accounted for the fact that the users and non-users of services may be systematically different in the way the variables or determinants affect resultant costs.

The model equation is as follows:

$$E(y|x) = \Pr(y > 0|x) \times E(y|y > 0, x)$$

$\Pr(y > 0|x)$ is modelled using logit regression for binary outcomes, with the health costs at zero if no cost is observed or non-zero if a positive cost is observed. For those where a positive cost is observed, a GLM is used given that the costs are a continuous outcome. For the second part, $E(y|y > 0, x) = g^{-1}(x\gamma)$, where g is the link function in the GLM, due to the non-normal distribution of costs. The dependent variable (cost-weighted utilisation) had distributions that were right skewed. The two-part model therefore accounted for this.

Post estimation margins are reported on the joint impact on mean cost for each variable and the joint significance (Wald test) of each variable in the two-part model. The margins reporting the joint impact on mean cost were computed by predicting the value of y_i using the following equation:

$$\hat{y}_i | x_i = (\hat{p}_i | x_i) \times (\hat{y}_i | y_i > 0, x_i)$$

Where $(\hat{p}_i | x_i)$ is the predicted probability that $y > 0$. Stata's `twopm` command was used to estimate the two-part models and the post estimation margins (135).

All data processing, linking and analysis was conducted using Stata version 15.1 (122).

5.3 Results

There were 201,393 records of confirmed residents of B&D on 1st April 2016 (where confirmed residents are defined as those who are present on the address register and on either another council dataset, the GP register or both(96)). Of these, 18,754 were excluded due to leaving the borough within the year (including deaths) and therefore did not have a full 12 months of utilisation data, 9,980 were excluded because they could not be matched with an NHS number and therefore the health data, 5,298 were excluded due to being registered with a GP practice outside the borough and 52,968 were aged between 0 and 18-years old. The 114,393 remaining adult individuals were included in the cohort. They lived in 58,929 households. Table 5-3 provides a summary of the cohort characteristics with total mean cost and standard deviation and mean cost and standard deviation by setting of care.

Six models were run to understand the correlation between different variables and cost-weighted utilisation overall for total cost and for each of the five settings of care: hospital services, primary care, community services, mental health services and social care. The results of the two-part models are shown in Tables 5-4 to 5-9.

Table 5-3 Summary characteristics of the cohort, mean cost and standard deviation overall and by setting of care

		Full cohort n=114,393, %	Total cost		Hospital		Primary Care		Community		Mental Health		Social Care	
			Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Socio-demographic characteristics														
Age	19–49	62%	807	3,749	366	1,203	146	246	71	1,001	124	2,264	100	2,132
	50–64	23%	1,591	6,194	615	1,851	352	551	259	2,771	214	3,807	152	1,983
	65–74	8%	2,794	8,018	962	2,396	576	733	816	5,124	204	2,938	236	2,118
	75–85	5%	5,008	11,695	1,385	2,957	822	977	1,864	7,995	342	4,093	595	3,073
	85+	3%	9,436	16,697	1,730	3,341	1,073	1,124	4,321	12,093	425	4,566	1,888	5,472
Gender	Female	53%	1,790	6,514	646	1,752	323	543	430	3,624	182	3,043	210	2,330
	Male	47%	1,334	5,940	456	1,681	243	508	307	3,264	156	2,770	173	2,303
Ethnic group	White	14%	925	4,083	407	1,375	182	396	159	1,930	106	2,294	70	1,177
	Black or Black British	16%	999	4,284	410	1,310	205	363	178	2,431	86	1,614	120	2,046
	Mixed	42%	2,351	8,186	738	2,071	388	644	634	4,629	272	3,841	319	3,027
	Other	2%	801	3,083	357	1,138	181	357	121	1,299	86	1,706	56	1,095
	Asian or Asian British	15%	1,041	4,064	445	1,318	263	473	167	2,043	77	2,188	88	1,453
	Unknown	11%	1,122	4,763	447	1,677	185	393	239	2,630	118	1,796	132	1,629
Carer	None	98%	1,426	5,683	541	1,680	274	502	333	3,252	142	2,633	136	1,903
	Has a carer	1%	12,769	20,701	1,611	3,486	1,035	1,299	2,915	9,313	2,444	11,796	4,765	11,298
	Is a carer	1%	2,869	10,002	858	2,162	465	766	1,268	8,027	129	1,442	149	1,359
	Both has and is a carer	0%	8,403	15,262	1,311	2,333	1,040	1,169	1,833	6,203	1,211	5,484	3,009	9,279
Health variables														
BMI category	Healthy	29%	1,443	6,039	501	1,593	233	461	371	3,566	133	2,225	206	2,725
	Underweight	3%	1,967	8,624	490	1,764	201	489	710	5,628	214	3,383	352	2,942
	Overweight	31%	1,491	5,923	554	1,663	293	514	328	3,127	164	3,170	151	1,823
	Obese	24%	1,895	6,531	689	1,993	377	614	419	3,494	205	3,170	205	2,311
	Morbidly Obese	4%	2,677	8,898	833	2,090	493	738	646	4,604	437	4,901	268	2,268

		Full cohort n=114,393, %	Total cost		Hospital		Primary Care		Community		Mental Health		Social Care	
			Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
	Unknown	8%	628	3,914	230	1,054	81	230	110	1,945	47	1,025	161	2,167
Smoking category	Non-smoker	61%	1,432	5,904	505	1,584	260	487	308	3,016	144	2,802	215	2,473
	Ex-smoker	16%	2,403	7,754	851	2,267	431	677	730	5,049	182	2,842	209	1,858
	Smoker	21%	1,489	6,199	522	1,670	270	518	318	3,328	250	3,413	129	2,253
	Unknown	2%	254	1,345	134	609	45	113	16	278	29	483	29	956
LTCs	0–1	83%	861	3,811	398	1,276	171	264	126	1,721	83	1,967	83	1,787
	2	10%	3,590	9,337	1,056	2,568	630	680	902	5,308	470	4,816	532	3,618
	3	4%	5,740	12,294	1,451	2,926	980	969	1,988	8,239	564	5,019	757	3,852
	4	2%	8,702	16,841	2,004	3,753	1,367	1,251	2,832	10,092	1,127	8,771	1,372	5,043
	5+	1%	14,132	21,112	3,110	4,779	2,027	1,681	5,712	14,224	1,379	8,685	1,903	5,848
Conditions	AF	1%	8,551	16,649	2,284	3,878	1,267	1,300	3,512	11,088	548	6,454	939	3,753
	Asthma	10%	2,445	7,986	801	2,089	484	755	605	4,340	288	4,011	266	2,847
	Cancer	3%	4,967	10,925	2,060	3,788	690	848	1,493	6,992	276	3,962	447	2,641
	CHD	3%	6,108	12,331	1,889	3,544	1,122	1,194	2,195	8,724	273	3,202	629	3,113
	COPD	3%	6,196	13,110	1,624	3,227	1,008	1,053	2,704	9,682	316	3,230	544	2,810
	Dementia	1%	18,351	23,181	2,197	3,998	1,640	1,401	6,375	14,055	3,022	12,915	5,117	9,080
	Depression	8%	3,277	9,944	898	2,197	560	853	714	4,789	766	6,351	338	2,899
	Diabetes	9%	4,207	10,648	1,154	2,879	870	1,008	1,405	6,880	326	3,989	452	2,951
	Epilepsy	1%	5,314	13,430	973	2,448	662	1,036	1,062	5,777	735	6,243	1,882	7,627
	Heart failure	1%	11,132	19,001	2,962	5,005	1,491	1,486	5,030	14,148	273	3,511	1,375	4,556
	Hypertension	19%	3,555	9,626	1,071	2,623	684	854	1,160	6,306	232	3,406	407	2,652
	Hypothyroidism	4%	3,664	10,569	1,016	2,377	705	868	1,042	6,001	404	5,440	497	3,132
	Learning difficulty	1%	15,932	26,981	590	1,957	587	848	1,092	5,320	4,314	18,682	9,350	16,985
	Mental health	1%	9,738	18,888	747	1,996	906	1,251	1,344	7,679	5,298	14,307	1,442	5,601
	Palliative care	0%	15,474	24,236	3,600	5,684	1,300	1,366	8,346	19,645	236	1,638	1,992	5,476
	Stroke	2%	8,393	16,824	1,700	3,261	1,148	1,249	3,296	12,167	552	5,031	1,697	5,444
Household variables														
Benefits	None	70%	1,130	4,492	485	1,545	229	402	234	2,506	83	1,940	100	1,533
	ESA	6%	3,291	10,085	847	2,335	517	806	518	3,566	871	7,034	538	4,209
	Pension	5%	5,274	13,139	1,181	2,881	771	1,064	2,061	9,099	401	4,163	860	3,655

		Full cohort n=114,393, %	Total cost		Hospital		Primary Care		Community		Mental Health		Social Care	
			Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Income Support Job Seeker's Allowance Standard		3%	2,218	9,441	619	1,740	286	527	341	3,699	378	4,751	595	5,520
		2%	966	2,419	443	1,156	235	412	146	1,221	108	1,098	33	675
		14%	1,751	6,929	577	1,724	308	562	450	3,906	201	3,191	216	2,742
Tenure	Owner occupied	53%	1,307	5,092	525	1,634	263	468	315	3,068	97	2,109	106	1,466
	PR	20%	1,201	5,495	442	1,415	219	459	195	2,222	143	2,840	201	2,689
	Social	26%	2,275	8,220	695	2,035	374	656	612	4,715	324	4,123	271	2,769
	Reside	1%	949	3,324	521	1,276	197	335	158	2,410	62	826	10	265
	Unknown	1%	6,185	13,382	931	2,762	576	846	916	5,024	633	4,250	3,130	9,352
Occupancy	2 to 4	59%	1,416	5,591	558	1,689	270	473	305	3,082	144	2,666	139	2,074
	1	13%	3,751	11,009	923	2,486	556	882	1,254	6,645	484	5,284	535	3,284
	5 to 7	24%	886	3,899	388	1,255	191	344	115	1,515	87	1,794	104	1,991
	8 to 10	4%	772	2,522	378	1,389	202	393	121	1,346	44	705	26	515
	11+	1%	2,933	9,081	498	1,814	338	639	264	2,921	95	886	1,739	6,982
B&D IMD quintile	1	21%	1,338	4,996	533	1,656	274	494	252	2,452	116	2,366	162	2,051
	2	20%	1,551	6,230	532	1,665	270	489	440	4,142	130	2,015	178	2,001
	3	20%	1,598	6,226	557	1,731	288	547	363	3,143	186	3,260	205	2,270
	4	20%	1,687	6,757	588	1,864	294	547	410	3,723	212	3,526	183	2,016
	5	19%	1,714	6,932	572	1,685	301	564	398	3,619	206	3,174	237	3,094

Table 5-4 Two-part model outputs for total cost

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Table 5-4 Total costs											
Socio-demographic characteristics											
Age	19–49							1,236	1,162	1,309	.
	50–64	1.25	1.19	1.32	0.15	0.10	0.21	1,459	1,369	1,548	
	65–74	2.36	2.07	2.70	0.46	0.38	0.54	2,033	1,872	2,194	
	75–85	2.91	2.33	3.65	0.85	0.75	0.96	3,025	2,739	3,312	
	85+	2.94	2.05	4.21	1.27	1.14	1.41	4,604	4,012	5,197	
Gender	Female							2,146	2,010	2,282	0.00
	Male	0.38	0.37	0.40	- 0.34	- 0.38	- 0.29	1,477	1,381	1,573	
Ethnic group	White							1,609	1,477	1,740	0.00
	Black or Black British	1.27	1.19	1.35	0.06	- 0.02	0.13	1,722	1,586	1,857	
	Mixed	1.50	1.42	1.59	0.15	0.09	0.22	1,909	1,793	2,025	
	Other	1.01	0.90	1.13	- 0.09	- 0.24	0.06	1,469	1,245	1,694	
	Asian or Asian British	1.71	1.60	1.82	0.13	0.05	0.20	1,862	1,712	2,011	
Unknown	0.94	0.88	1.00	0.05	- 0.04	0.13	1,680	1,533	1,827		
Carer	None							1,723	1,624	1,821	0.00
	Has carer	1.68	1.01	2.82	0.51	0.32	0.69	2,912	2,393	3,430	
	Is a carer	2.95	1.95	4.47	0.14	- 0.08	0.35	2,032	1,589	2,475	
	Is and has carer	1.00	1.00	1.00	- 0.12	- 0.73	0.50	-	-	-	
Health variables											
BMI category	Healthy							1,742	1,625	1,859	0.00
	Underweight	0.69	0.63	0.76	0.17	0.04	0.29	2,021	1,758	2,284	
	Overweight	1.30	1.24	1.36	0.01	- 0.05	0.06	1,769	1,652	1,886	
	Obese	1.45	1.37	1.53	0.08	0.03	0.14	1,918	1,790	2,047	
	Morbidly obese	1.51	1.32	1.72	0.25	0.15	0.35	2,268	2,027	2,509	
Unknown	0.66	0.62	0.71	- 0.11	- 0.21	- 0.02	1,524	1,361	1,686		

Wald test of joint significance

Table 5-4 Total costs		PART 1 - Logit			PART 2 - GLM			Two-Part			prob>chi2=
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		
Smoking category	Non-smoker							1,798	1,685	1,910	0.00
	Ex-smoker	1.32	1.24	1.40	0.08	0.02	0.14	1,972	1,830	2,114	
	Smoker	1.93	1.83	2.03	-0.03	-0.09	0.02	1,778	1,652	1,904	
	Unknown	0.71	0.64	0.78	-0.38	-0.56	-0.20	1,211	982	1,441	
LTCs	0-1							2,932	2,391	3,473	0.00
	2	0.67	0.53	0.84	-0.06	-0.16	0.04	2,727	2,358	3,096	
	3	0.22	0.13	0.37	-0.37	-0.53	-0.21	1,926	1,673	2,180	
	4	0.02	0.01	0.03	-0.77	-1.01	-0.54	1,084	893	1,275	
	5+	0.00	0.00	0.01	-1.31	-1.64	-0.98	532	407	657	
Conditions	AF = 0							1,721	1,626	1,817	0.00
	AF = 1	12.48	5.06	30.79	0.67	0.50	0.84	3,506	2,918	4,094	
	Asthma = 0							1,753	1,648	1,858	
	Asthma = 1	2.11	1.94	2.30	0.31	0.24	0.39	2,456	2,242	2,670	
	Cancer = 0							1,717	1,618	1,817	
	Cancer = 1	5.03	3.62	6.98	0.71	0.59	0.83	3,643	3,187	4,099	
	CHD = 0							1,675	1,582	1,768	
	CHD = 1	5.78	3.86	8.66	0.63	0.51	0.76	3,278	2,877	3,678	
	COPD = 0							1,689	1,593	1,786	
	COPD = 1	8.16	5.10	13.07	0.72	0.60	0.85	3,639	3,167	4,111	
	Dementia = 0							1,643	1,566	1,721	
	Dementia = 1	7.39	2.29	23.82	1.43	1.18	1.67	7,139	5,431	8,848	
	Depression = 0							1,700	1,599	1,801	
	Depression = 1	2.33	2.07	2.63	0.49	0.41	0.57	2,837	2,578	3,097	
	Diabetes = 0							1,580	1,489	1,671	
	Diabetes = 1	12.34	9.55	15.95	0.69	0.60	0.77	3,308	3,008	3,607	
Epilepsy = 0							1,776	1,674	1,878		
Epilepsy = 1	2.73	2.10	3.54	0.63	0.46	0.80	3,420	2,835	4,005		

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Table 5-4 Total costs											
	Heart failure = 0							1,732	1,637	1,827	0.00
	Heart failure = 1	12.19	2.93	50.67	0.88	0.65	1.11	4,358	3,372	5,343	
	Hypertension = 0							1,591	1,491	1,691	0.00
	Hypertension = 1	5.95	5.23	6.77	0.31	0.24	0.38	2,277	2,119	2,436	
	Hypothyroidism = 0							1,788	1,680	1,895	0.00
	Hypothyroidism = 1	5.60	4.27	7.35	0.26	0.15	0.36	2,401	2,135	2,668	
	Mental health = 0							1,630	1,548	1,711	0.00
	Mental health = 1	9.67	5.73	16.30	1.61	1.44	1.78	8,530	7,036	10,024	
	Palliative care = 0							1,759	1,665	1,853	0.00
	Palliative care = 1	4.84	1.16	20.29	1.27	0.90	1.64	6,465	4,076	8,853	
	Stroke = 0							1,677	1,588	1,766	0.00
	Stroke = 1	8.69	4.41	17.13	0.96	0.80	1.12	4,570	3,846	5,293	
	Learning difficulty = 0							1,685	1,591	1,780	0.00
	Learning difficulty = 1	3.16	2.01	4.98	2.28	2.02	2.54	16,946	12,478	21,414	
Household variables											
Benefits	None							1,551	1,453	1,649	0.00
	ESA	1.60	1.44	1.77	0.70	0.61	0.79	3,185	2,871	3,499	
	Pension	1.01	0.89	1.15	0.30	0.21	0.40	2,104	1,896	2,313	
	Income Support	1.32	1.16	1.49	0.44	0.32	0.56	2,435	2,132	2,738	
	Job Seeker's Allowance	1.14	0.99	1.31	0.13	- 0.02	0.28	1,770	1,488	2,052	
	Standard	1.25	1.18	1.33	0.18	0.11	0.24	1,866	1,723	2,009	
Tenure	Owner occupied							1,699	1,593	1,804	0.00
	PR	0.86	0.81	0.90	0.02	- 0.04	0.08	1,717	1,591	1,843	
	Social	1.04	0.98	1.09	0.13	0.07	0.18	1,934	1,808	2,060	
	Reside	1.40	1.11	1.77	0.30	0.05	0.55	2,323	1,731	2,914	
	Unknown	1.28	0.99	1.65	0.47	0.25	0.69	2,738	2,136	3,339	
Occupancy	2 to 4							1,743	1,635	1,852	0.00
	1	0.89	0.83	0.95	0.21	0.15	0.28	2,147	1,989	2,305	

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-4 Total costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
	5 to 7	0.96	0.92	1.00	- 0.10	- 0.15	- 0.05	1,573	1,458	1,687	
	8 to10	0.85	0.77	0.93	- 0.08	- 0.20	0.03	1,594	1,395	1,792	
	11+	0.71	0.60	0.84	0.05	- 0.17	0.27	1,810	1,413	2,208	
B&D IMD quintile	1							1,746	1,620	1,872	
	2	0.97	0.92	1.03	0.07	0.01	0.13	1,868	1,735	2,002	
	3	0.93	0.88	0.99	0.05	- 0.02	0.11	1,827	1,696	1,957	
	4	0.85	0.80	0.91	0.05	- 0.02	0.11	1,819	1,690	1,949	
	5	0.88	0.82	0.93	0.09	0.02	0.15	1,894	1,758	2,029	
	cons	- 2.93	- 3.02	- 2.84	6.28	6.20	6.36				

Table 5-5 Two-part model outputs for hospital costs

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-5 Hospital costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Socio-demographic characteristics											
Age	19–49							487	472	502	0.00
	50–64	1.09	1.05	1.13	0.08	0.04	0.12	549	530	568	
	65–75	1.24	1.18	1.31	0.16	0.10	0.23	638	603	672	
	75–85	1.59	1.48	1.70	0.26	0.19	0.33	778	727	830	
	85+	1.73	1.57	1.91	0.32	0.22	0.41	855	775	934	
Gender	Female							663	647	678	0.00
	Male	0.66	0.64	0.67	-0.20	-0.23	-0.17	446	433	458	
Ethnic group	White							517	491	543	0.00
	Black or Black British	1.08	1.03	1.13	-0.04	-0.10	0.02	514	490	538	
	Mixed	1.16	1.11	1.21	0.06	0.01	0.12	590	575	605	
	Other	1.00	0.91	1.10	-0.12	-0.25	0.00	457	400	514	
	Asian or Asian British	1.20	1.15	1.26	0.03	-0.04	0.09	579	550	607	
	Unknown	0.97	0.92	1.02	0.04	-0.03	0.11	527	497	557	
Carer	None							557	546	567	0.00
	Has carer	1.10	0.96	1.26	0.23	0.11	0.36	733	633	834	
	Is a carer	1.29	1.12	1.48	0.02	-0.14	0.18	634	529	739	
	Is and has carer	0.92	0.60	1.43	0.00	-0.42	0.43	538	284	791	
BMI category	Healthy							530	512	547	0.00
	Underweight	0.87	0.80	0.93	0.05	-0.05	0.15	520	467	574	
	Overweight	1.07	1.03	1.10	0.02	-0.02	0.06	557	540	574	
	Obese	1.14	1.11	1.18	0.08	0.04	0.12	611	591	631	
	Morbidly obese	1.30	1.22	1.39	0.09	0.02	0.17	655	608	702	
	Unknown	0.75	0.70	0.79	-0.05	-0.13	0.03	436	398	473	
	Non-smoker							538	525	551	

Table 5-5 Hospital costs		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Smoking category	Ex-smoker	1.18	1.14	1.23	0.10	0.06	0.15	645	620	670	0.00
	Smoker	1.04	1.00	1.07	0.02	-0.02	0.06	559	537	581	
	Unknown	0.62	0.55	0.70	-0.15	-0.32	0.03	364	296	432	
LTCs	0-1							567	538	595	0.00
	2	0.91	0.86	0.98	0.10	0.02	0.17	601	571	631	
	3	0.73	0.65	0.81	0.03	-0.09	0.14	504	459	549	
	4	0.46	0.39	0.55	0.00	-0.17	0.17	389	332	447	
	5+	0.38	0.30	0.49	-0.08	-0.31	0.16	326	252	399	
Conditions	AF = 0							548	538	559	0.00
	AF = 1	2.48	2.17	2.83	0.27	0.16	0.38	1,025	908	1,141	
	Asthma = 0							547	536	558	
	Asthma = 1	1.43	1.37	1.50	0.06	0.00	0.11	676	640	713	
	Cancer = 0							524	514	534	
	Cancer = 1	3.85	3.50	4.22	0.48	0.41	0.56	1,385	1,277	1,493	
	CHD = 0							534	523	544	
	CHD = 1	2.02	1.85	2.21	0.35	0.27	0.43	1,013	927	1,098	
	COPD = 0							547	536	558	
	COPD = 1	1.87	1.71	2.04	0.16	0.08	0.25	834	760	908	
	Dementia = 0							557	547	568	
	Dementia = 1	1.53	1.28	1.84	0.28	0.11	0.44	879	726	1,032	
	Depression = 0							548	537	559	
	Depression = 1	1.49	1.41	1.57	0.06	0.00	0.12	689	648	730	
	Diabetes = 0							534	523	545	
	Diabetes = 1	1.66	1.57	1.75	0.13	0.07	0.19	757	711	802	
Epilepsy = 0							558	548	569		
Epilepsy = 1	1.57	1.41	1.76	0.12	0.00	0.25	764	667	862		
Heart failure = 0							551	540	561		
Heart failure = 1	2.27	1.88	2.73	0.45	0.30	0.59	1,185	1,005	1,365		

		PART 1 - Logit		PART 2 - GLM			Two-Part			Wald test of joint significance	
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Table 5-5 Hospital costs											
	Hypertension = 0							519	506	533	0.00
	Hypertension = 1	1.43	1.37	1.50	0.10	0.05	0.15	676	647	704	
	Hypothyroidism = 0							558	547	569	0.35
	Hypothyroidism = 1	1.45	1.35	1.55	-0.03	-0.10	0.05	635	587	683	
	Mental health = 0							563	552	573	0.00
	Mental health = 1	1.05	0.93	1.18	-0.08	-0.22	0.05	529	453	605	
	Palliative care = 0							557	546	567	0.00
	Palliative care = 1	2.19	1.58	3.04	0.56	0.33	0.78	1,321	996	1,645	
	Stroke = 0							553	542	563	0.40
	Stroke = 1	1.92	1.71	2.15	0.20	0.09	0.30	875	778	971	
	Learning difficulty = 0							562	552	573	
	Learning difficulty = 1	0.96	0.80	1.14	-0.13	-0.35	0.08	481	373	589	0.00
Household variables											
Benefits	None							532	519	544	
	ESA	1.54	1.46	1.63	0.19	0.13	0.26	778	727	829	
	Pension	1.05	0.99	1.12	0.07	0.00	0.14	584	544	624	
	Income Support	1.27	1.18	1.37	0.15	0.06	0.24	685	622	748	
	Job Seeker's Allowance	1.19	1.08	1.31	-0.06	-0.18	0.06	542	475	610	0.00
	Standard	1.10	1.05	1.14	0.03	-0.02	0.08	569	543	596	
Tenure	Owner occupied							539	525	554	
	PR	0.92	0.88	0.95	0.08	0.03	0.13	562	537	587	
	Social	1.05	1.01	1.08	0.08	0.04	0.12	597	576	617	
	Reside	1.31	1.12	1.53	0.22	0.02	0.42	754	599	909	0.02
	Unknown	1.06	0.92	1.22	0.16	-0.01	0.32	648	536	760	
Occupancy	2 to 4							565	552	579	
	1	1.00	0.96	1.04	0.07	0.02	0.11	604	577	631	
	5 to 7	0.93	0.90	0.96	-0.06	-0.10	-0.02	517	497	538	
	8 to10	0.90	0.83	0.96	-0.03	-0.13	0.06	520	469	571	

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-5 Hospital costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
	11+	0.83	0.73	0.95	-0.06	-0.24	0.11	487	397	577	
B&D IMD quintile	1							560	538	582	
	2	1.02	0.98	1.06	-0.01	-0.06	0.04	558	537	579	
	3	1.05	1.01	1.10	-0.03	-0.08	0.01	553	533	574	
	4	1.03	0.99	1.08	0.01	-0.04	0.06	576	554	598	
	5	1.01	0.97	1.05	0.00	-0.05	0.05	562	540	584	
	cons	-2.93	-3.02	-2.84	6.84	6.77	6.91				

Table 5-6 Two-part model outputs for primary care costs

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Table 5-6 Primary care costs											
Socio-demographic characteristics											
Age	19–49							211	208	214	.
	50–64	1.33	1.26	1.40	0.29	0.27	0.31	288	284	293	
	65–75	2.52	2.22	2.85	0.52	0.50	0.55	375	366	383	
	75–85	3.04	2.46	3.74	0.71	0.68	0.75	456	442	469	
	85+	2.65	1.94	3.63	0.87	0.82	0.92	531	508	554	
Gender	Female							337	333	341	0.00
	Male	0.37	0.36	0.38	-0.26	-0.28	-0.25	245	241	248	
Ethnic group	White							258	252	263	0.00
	Black or Black British	1.27	1.20	1.35	0.08	0.06	0.11	283	278	289	
	Mixed	1.47	1.39	1.55	0.13	0.11	0.15	300	296	303	
	Other	1.02	0.91	1.14	0.01	-0.04	0.06	261	248	273	
	Asian or Asian British	1.78	1.67	1.90	0.30	0.28	0.33	360	353	367	
Unknown	0.95	0.89	1.01	-0.06	-0.09	-0.03	242	237	248		
Carer	None							292	289	295	0.00
	Has carer	2.03	1.26	3.27	0.17	0.11	0.23	357	335	379	
	Is a carer	2.92	1.99	4.30	0.11	0.04	0.18	340	316	364	
	Is and has carer	1.00	1.00	1.00	0.16	-0.05	0.36	0	0	0	
BMI category	Healthy							269	265	274	0.00
	Underweight	0.64	0.59	0.70	-0.08	-0.12	-0.03	242	232	252	
	Overweight	1.29	1.23	1.35	0.08	0.06	0.10	296	292	301	
	Obese	1.44	1.37	1.52	0.15	0.13	0.17	319	314	323	
	Morbidly obese	1.50	1.32	1.69	0.26	0.22	0.29	356	344	367	
	Unknown	0.65	0.61	0.69	-0.22	-0.26	-0.19	209	202	216	

Table 5-6 Primary care costs		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Smoking category	Non-smoker							289	285	292	0.00
	Ex-smoker	1.35	1.27	1.43	0.08	0.06	0.10	317	312	323	
	Smoker	1.92	1.82	2.02	-0.04	-0.05	-0.02	288	283	292	
	Unknown	0.72	0.66	0.79	-0.27	-0.34	-0.21	215	201	228	
LTCs	0-1							456	435	477	0.00
	2	0.66	0.54	0.81	-0.18	-0.22	-0.15	374	363	386	
	3	0.22	0.14	0.35	-0.52	-0.58	-0.47	251	240	262	
	4	0.02	0.01	0.04	-0.94	-1.02	-0.86	134	124	145	
	5+	0.00	0.00	0.01	-1.52	-1.63	-1.41	59	51	67	
Conditions	AF = 0							283	280	286	0.00
	AF = 1	11.25	5.21	24.32	0.67	0.61	0.73	587	554	620	
	Asthma = 0							275	272	278	
	Asthma = 1	2.13	1.97	2.31	0.47	0.44	0.49	454	443	465	
	Cancer = 0							287	284	290	
	Cancer = 1	3.58	2.75	4.67	0.39	0.35	0.43	443	425	461	
	CHD = 0							271	268	274	
	CHD = 1	5.47	3.80	7.87	0.74	0.70	0.78	599	575	622	
	COPD = 0							276	273	279	
	COPD = 1	8.37	5.41	12.97	0.71	0.66	0.75	595	571	619	
	Dementia = 0							286	283	289	
	Dementia = 1	5.75	2.29	14.43	0.89	0.81	0.98	739	679	800	
	Depression = 0							276	273	279	
	Depression = 1	2.21	1.98	2.47	0.48	0.45	0.51	463	451	476	
	Diabetes = 0							243	240	245	
	Diabetes = 1	12.67	9.95	16.12	0.87	0.85	0.90	628	612	645	
	Epilepsy = 0							289	286	292	
Epilepsy = 1	2.59	2.04	3.28	0.68	0.62	0.74	593	560	626		

Table 5-6 Primary care costs		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Heart failure = 0							287	284	290	0.00	
Heart failure = 1		5.54	2.20	13.98	0.67	0.59	0.74	590	545	635	
Hypertension = 0								232	229	235	0.00
Hypertension = 1		6.43	5.68	7.27	0.55	0.53	0.58	435	428	443	
Hypothyroidism = 0								280	277	283	0.00
Hypothyroidism = 1		5.28	4.13	6.76	0.55	0.52	0.58	513	496	531	
Mental health = 0								287	284	290	0.00
Mental health = 1		5.61	3.84	8.18	0.86	0.80	0.92	714	673	756	
Palliative care = 0								292	289	295	0.00
Palliative care = 1		3.35	1.19	9.42	0.73	0.61	0.86	635	556	715	
Stroke = 0								283	280	286	0.00
Stroke = 1		4.61	2.86	7.45	0.71	0.66	0.76	605	574	637	
Learning difficulty = 0								293	290	296	0.00
Learning difficulty = 1		2.74	1.84	4.10	0.57	0.48	0.65	536	489	584	
Household variables											
Benefits	None							266	262	269	0.00
	ESA	1.53	1.39	1.69	0.54	0.51	0.57	468	454	481	
	Pension	1.01	0.89	1.14	0.18	0.14	0.21	316	307	326	
	Income Support	1.32	1.18	1.48	0.26	0.22	0.29	348	334	361	
	Job Seeker's Allowance	1.11	0.97	1.27	0.20	0.15	0.25	327	310	344	
	Standard	1.25	1.18	1.32	0.15	0.13	0.17	312	306	318	
Tenure	Owner occupied							284	280	287	0.00
	PR	0.88	0.83	0.92	0.04	0.02	0.06	292	286	297	
	Social	1.04	0.99	1.10	0.08	0.07	0.10	309	304	314	
	Reside	1.53	1.21	1.92	0.22	0.13	0.30	359	329	389	
	Unknown	1.25	0.99	1.59	0.22	0.15	0.29	357	332	383	
Occupancy	2 to 4							288	284	291	0.00
	1	0.88	0.82	0.94	0.11	0.09	0.13	320	314	326	

Table 5-6 Primary care costs		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
	5 to 7	0.97	0.93	1.01	-0.02	-0.04	0.00	282	277	287	
	8 to10	0.84	0.77	0.92	0.01	-0.02	0.05	289	278	300	
	11+	0.69	0.59	0.81	0.03	-0.04	0.10	290	269	311	
B&D IMD quintile	1							292	287	297	
	2	0.98	0.92	1.03	0.01	-0.01	0.03	296	291	301	
	3	0.92	0.87	0.97	0.01	-0.01	0.03	293	288	298	
	4	0.85	0.80	0.90	0.00	-0.03	0.02	288	283	293	
	5	0.87	0.82	0.93	0.04	0.02	0.07	303	298	308	
	cons	-2.93	-3.02	-2.84	4.70	4.68	4.73				

Table 5-7 Two-part model outputs for community care costs

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-7 Community care costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Socio-demographic characteristics											
Age	19–49							134	118	151	.
	50–64	1.30	1.22	1.37	0.22	0.08	0.36	204	181	227	
	65–75	1.68	1.55	1.82	0.75	0.57	0.93	417	359	475	
	75–85	2.41	2.20	2.63	1.23	1.04	1.42	860	732	989	
	85+	4.47	4.00	5.00	1.53	1.31	1.75	1683	1378	1988	
Gender	Female							458	414	501	0.00
	Male	0.64	0.61	0.67	-0.04	-0.14	0.07	342	303	381	
Ethnic group	White							338	278	398	0.01
	Black or Black British	0.95	0.87	1.03	0.29	0.09	0.50	440	363	518	
	Mixed	1.03	0.96	1.11	0.21	0.04	0.38	423	383	462	
	Other	0.89	0.75	1.06	-0.08	-0.50	0.34	292	171	413	
	Asian or Asian British	1.22	1.12	1.33	0.07	-0.13	0.27	405	336	474	
	Unknown	0.82	0.75	0.91	0.12	-0.11	0.35	343	275	410	
Carer	None							401	363	438	0.00
	Has carer	1.36	1.18	1.56	0.05	-0.20	0.30	497	372	622	
	Is a carer	1.11	0.91	1.36	0.24	-0.20	0.68	542	298	787	
	Is and has carer	1.40	0.89	2.21	-0.46	-1.30	0.38	303	40	566	
BMI category	Healthy							415	366	464	0.00
	Underweight	1.05	0.92	1.20	0.58	0.28	0.88	764	532	996	
	Overweight	1.03	0.97	1.09	-0.14	-0.27	-0.02	365	323	407	
	Obese	1.19	1.12	1.26	-0.16	-0.29	-0.04	387	343	431	
	Morbidly obese	1.41	1.29	1.55	0.08	-0.13	0.28	541	434	647	
	Unknown	0.62	0.54	0.71	0.09	-0.24	0.42	342	225	459	

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-7 Community care costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Smoking category	Non-smoker							405	363	447	0.01
	Ex-smoker	1.09	1.03	1.15	0.01	-0.12	0.13	427	376	478	
	Smoker	0.83	0.78	0.88	0.08	-0.06	0.22	395	337	453	
	Unknown	0.39	0.28	0.56	-0.22	-1.11	0.67	185	14	356	
LTCs	0-1							545	341	750	0.96
	2	1.01	0.92	1.11	0.02	-0.20	0.24	559	435	684	
	3	0.92	0.79	1.07	-0.16	-0.50	0.18	447	374	520	
	4	0.77	0.62	0.95	-0.45	-0.92	0.02	307	243	371	
	5+	0.46	0.34	0.62	-0.56	-1.20	0.08	212	145	280	
Conditions	AF = 0							383	348	419	0.00
	AF = 1	1.91	1.67	2.18	0.23	-0.02	0.48	682	517	848	
	Asthma = 0							391	355	427	0.00
	Asthma = 1	1.33	1.23	1.43	0.15	-0.02	0.33	532	437	628	
	Cancer = 0							399	362	437	0.00
	Cancer = 1	1.61	1.45	1.79	-0.02	-0.23	0.19	505	399	611	
	CHD = 0							382	346	419	0.00
	CHD = 1	1.48	1.33	1.64	0.17	-0.04	0.38	562	449	675	
	COPD = 0							343	312	374	0.00
	COPD = 1	2.79	2.52	3.09	0.52	0.32	0.73	1008	805	1211	
	Dementia = 0							361	332	391	0.00
	Dementia = 1	2.77	2.32	3.31	0.80	0.50	1.10	1389	970	1808	
	Depression = 0							392	356	427	0.00
	Depression = 1	1.41	1.31	1.53	0.13	-0.05	0.30	535	438	633	
	Diabetes = 0							313	283	344	0.00
	Diabetes = 1	3.09	2.86	3.33	0.39	0.23	0.56	869	736	1001	
Epilepsy = 0							398	363	434	0.00	
Epilepsy = 1	1.38	1.19	1.61	0.54	0.21	0.87	812	533	1090		

Wald test of joint significance

		PART 1 - Logit		PART 2 - GLM			Two-Part			
		Odds Ratio	95% CI	Coefficient	95% CI		Margins, £	95% CI	prob>chi2=	
Table 5-7 Community care costs										
	Heart failure = 0						378	346	410	0.00
	Heart failure = 1	2.38	2.01 2.82	0.53	0.23 0.82		1015	714	1316	
	Hypertension = 0						354	309	399	0.00
	Hypertension = 1	1.17	1.09 1.26	0.17	0.00 0.33		457	404	510	
	Hypothyroidism = 0						401	365	438	0.01
	Hypothyroidism = 1	1.17	1.06 1.29	0.08	-0.13 0.30		474	371	577	
	Mental health = 0						393	359	426	0.00
	Mental health = 1	1.23	1.05 1.44	0.85	0.50 1.19		1023	658	1389	
	Palliative care = 0						377	347	407	0.00
	Palliative care = 1	3.15	2.40 4.13	1.35	0.92 1.78		2612	1453	3772	
	Stroke = 0						359	329	389	0.00
	Stroke = 1	2.00	1.76 2.26	0.71	0.47 0.95		1066	807	1325	
	Learning difficulty = 0						404	368	440	0.00
	Learning difficulty = 1	1.79	1.43 2.23	0.68	0.20 1.16		1081	543	1618	
Household variables										
Benefits	None						328	293	363	0.00
	ESA	1.73	1.59 1.89	0.46	0.26 0.65		698	563	833	
	Pension	1.21	1.12 1.31	0.34	0.17 0.50		511	433	590	
	Income Support	1.64	1.46 1.83	0.41	0.14 0.67		645	469	821	
	Job Seeker's Allowance	1.20	1.01 1.42	0.19	-0.20 0.59		440	260	621	
	Standard	1.18	1.11 1.26	0.16	0.02 0.30		423	363	483	
Tenure	Owner occupied						377	336	417	0.00
	PR	0.97	0.91 1.04	0.04	-0.11 0.20		387	326	449	
	Social	1.03	0.97 1.09	0.18	0.06 0.30		457	405	510	
	Reside	1.37	1.04 1.79	0.50	-0.16 1.16		738	238	1237	
	Unknown	1.23	1.01 1.50	-0.10	-0.51 0.32		382	223	541	
Occupancy	2 to 4						356	320	392	0.00
	1	1.09	1.02 1.15	0.32	0.20 0.45		516	455	577	

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-7 Community care costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
	5 to 7	0.92	0.87	0.97	-0.05	-0.18	0.09	323	273	374	
	8 to10	0.78	0.68	0.90	0.16	-0.17	0.49	362	236	487	
	11+	0.90	0.72	1.13	-0.02	-0.52	0.47	328	162	494	
B&D IMD quintile	1							349	300	399	
	2	1.18	1.10	1.26	0.25	0.10	0.41	493	429	557	
	3	1.18	1.10	1.26	0.03	-0.13	0.18	393	342	444	
	4	1.19	1.12	1.28	0.02	-0.13	0.18	394	344	444	
	5	1.10	1.02	1.18	0.12	-0.03	0.28	417	362	472	
	cons	-2.93	-3.02	-2.84	6.41	6.19	6.62				

Table 5-8 Two-part model outputs for mental health costs

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-8 Mental health costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Socio-demographic characteristics											
Age	19–49							180	146	214	
	50–64	0.59	0.53	0.66	0.10	-0.18	0.37	147	114	179	
	65–75	0.56	0.47	0.67	0.41	-0.03	0.84	195	118	272	
	75–85	0.95	0.79	1.14	0.23	-0.25	0.72	221	128	313	
	85+	1.01	0.80	1.27	-0.06	-0.62	0.51	171	85	257	
Gender	Female							178	151	205	0.77
	Male	0.97	0.90	1.05	-0.01	-0.21	0.19	173	144	203	
Ethnic group	White							170	110	229	0.42
	Black or Black British	0.98	0.82	1.17	-0.30	-0.76	0.16	124	83	166	
	Mixed	1.48	1.29	1.70	-0.11	-0.47	0.24	190	163	217	
	Other	0.96	0.67	1.37	-0.07	-1.01	0.87	154	14	294	
	Asian or Asian British	0.94	0.78	1.13	-0.13	-0.63	0.36	143	88	199	
	Unknown	1.16	0.97	1.38	0.07	-0.40	0.54	199	126	271	
Carer	None							167	145	190	0.00
	Has carer	1.58	1.31	1.91	0.16	-0.21	0.53	256	166	345	
	Is a carer	0.88	0.57	1.35	0.05	-1.03	1.13	163	-18	344	
	Is and has carer	0.90	0.45	1.77	-0.09	-1.52	1.35	144	-70	358	
Health variables											
BMI category	Healthy							148	119	178	0.14
	Underweight	1.20	0.98	1.47	0.21	-0.28	0.70	203	105	301	
	Overweight	0.88	0.80	0.97	0.29	0.03	0.54	183	146	220	
	Obese	0.86	0.77	0.95	0.25	-0.02	0.52	175	139	211	
	Morbidly obese	0.96	0.81	1.15	0.65	0.20	1.10	277	164	391	
	Unknown	0.97	0.80	1.16	-0.28	-0.79	0.24	110	55	166	

Table 5-8 Mental health costs		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Smoking category	Non-smoker							185	153	217	0.41
	Ex-smoker	1.07	0.96	1.19	-0.10	-0.37	0.18	174	130	218	
	Smoker	1.28	1.16	1.41	-0.25	-0.50	0.00	165	133	197	
	Unknown	0.89	0.60	1.33	-0.04	-1.16	1.08	167	-24	358	
LTCs	0-1							230	117	343	0.00
	2	0.68	0.58	0.80	-0.05	-0.47	0.38	181	135	227	
	3	0.35	0.27	0.46	-0.15	-0.83	0.53	118	83	153	
	4	0.18	0.12	0.26	0.05	-0.93	1.03	102	49	155	
	5+	0.09	0.05	0.15	0.20	-1.16	1.57	81	12	150	
Conditions	AF = 0							173	151	195	0.00
	AF = 1	2.20	1.69	2.86	0.20	-0.47	0.87	329	108	550	
	Asthma = 0							164	142	186	
	Asthma = 1	1.94	1.70	2.21	0.09	-0.25	0.44	262	177	347	
	Cancer = 0							174	152	196	
	Cancer = 1	1.97	1.60	2.43	-0.11	-0.66	0.45	229	104	355	
	CHD = 0							174	151	196	
	CHD = 1	1.93	1.56	2.37	-0.11	-0.62	0.39	224	112	337	
	COPD = 0							175	152	197	
	COPD = 1	1.60	1.30	1.97	-0.10	-0.62	0.42	206	101	311	
	Dementia = 0							156	136	176	
	Dementia = 1	37.83	30.25	47.31	0.60	0.08	1.12	2305	1129	3481	
	Depression = 0							132	113	152	
	Depression = 1	4.57	4.06	5.14	0.23	-0.07	0.53	422	312	531	
	Diabetes = 0							167	143	190	
	Diabetes = 1	1.96	1.68	2.30	0.01	-0.40	0.42	247	156	339	
Epilepsy = 0							176	153	199		
Epilepsy = 1	2.35	1.89	2.93	-0.36	-0.87	0.16	200	99	301		

		PART 1 - Logit		PART 2 - GLM			Two-Part			Wald test of joint significance	
Table 5-8 Mental health costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
	Heart failure = 0							177	155	199	0.81
	Heart failure = 1	1.06	0.72	1.56	-0.28	-1.21	0.64	137	8	266	
	Hypertension = 0							174	145	203	0.00
	Hypertension = 1	1.40	1.21	1.62	-0.15	-0.54	0.24	181	125	237	
	Hypothyroidism = 0							171	149	194	0.00
	Hypothyroidism = 1	1.94	1.62	2.33	0.01	-0.45	0.47	252	141	364	
	Mental health = 0							103	90	116	0.00
	Mental health = 1	47.42	40.63	55.34	0.86	0.53	1.19	3181	2189	4174	
	Palliative care = 0							176	154	198	0.03
	Palliative care = 1	1.82	1.12	2.97	-0.65	-1.83	0.53	129	-27	285	
	Stroke = 0							173	151	196	0.00
	Stroke = 1	2.36	1.88	2.97	-0.08	-0.63	0.47	260	118	401	
	Learning difficulty = 0							152	133	171	0.00
	Learning difficulty = 1	14.05	11.18	17.66	0.90	0.38	1.42	1822	865	2779	
Household variables											
Benefits	None							123	98	147	0.00
	ESA	4.13	3.66	4.66	0.24	-0.07	0.54	374	285	463	
	Pension	1.53	1.31	1.79	0.12	-0.28	0.51	180	117	243	
	Income Support	2.19	1.84	2.60	0.08	-0.37	0.54	217	126	308	
	Job Seeker's Allowance	1.62	1.24	2.10	-0.13	-0.81	0.56	146	46	245	
	Standard	1.54	1.37	1.74	0.18	-0.14	0.49	193	141	244	
Tenure	Owner occupied							186	142	230	0.00
	PR	1.05	0.92	1.19	-0.20	-0.53	0.14	157	116	198	
	Social	1.19	1.07	1.33	-0.14	-0.42	0.15	179	149	210	
	Reside	1.19	0.66	2.16	-0.01	-1.56	1.55	204	-118	527	
	Unknown	1.80	1.35	2.41	-0.31	-0.91	0.30	191	80	302	
Occupancy	2 to 4							156	132	180	0.00
	1	1.43	1.29	1.58	0.30	0.06	0.54	261	207	315	

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-8 Mental health costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
	5 to 7	0.84	0.76	0.94	0.01	-0.29	0.30	142	102	183	.
	8 to10	0.93	0.72	1.21	-0.77	-1.49	-0.05	70	19	120	
	11+	0.40	0.26	0.62	-0.63	-1.51	0.26	49	4	93	
B&D IMD quintile	1							178	128	228	
	2	0.94	0.83	1.07	-0.05	-0.40	0.30	164	123	205	
	3	1.02	0.90	1.16	0.04	-0.30	0.38	188	145	231	
	4	1.00	0.88	1.13	0.06	-0.27	0.40	189	148	231	
	5	0.97	0.85	1.11	-0.08	-0.42	0.25	161	127	196	
	cons	-2.93	-3.02	-2.84	7.96	7.45	8.46				

Table 5-9 Two-part model outputs for social care costs

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Table 5-9 Social care costs											
Socio-demographic characteristics											
Age	19–49							120	102	138	
	50–64	2.06	1.72	2.47	-0.27	-0.44	-0.10	152	128	175	
	65–75	4.34	3.48	5.42	-0.61	-0.83	-0.40	180	146	214	
	75–85	10.98	8.79	13.72	-0.56	-0.78	-0.35	360	297	424	
	85+	26.51	20.94	33.54	-0.46	-0.68	-0.24	740	600	880	
Gender	Female							206	188	224	0.00
	Male	0.83	0.74	0.92	-0.02	-0.12	0.09	179	161	197	
Ethnic group	White							150	114	186	0.00
	Black or Black British	1.66	1.28	2.16	0.17	-0.08	0.43	247	197	297	
	Mixed	1.25	1.01	1.55	0.11	-0.09	0.31	193	178	209	
	Other	0.74	0.39	1.39	-0.15	-0.77	0.47	106	30	181	
	Asian or Asian British	1.52	1.15	2.01	0.05	-0.22	0.32	207	160	254	
Unknown	1.16	0.89	1.52	0.11	-0.14	0.37	185	147	223		
Carer	None							168	154	181	0.00
	Has carer	2.39	2.02	2.83	0.23	0.09	0.36	381	320	441	
	Is a carer	0.89	0.54	1.46	-0.16	-0.63	0.30	131	54	207	
	Is and has carer	0.97	0.51	1.86	0.16	-0.37	0.70	194	59	328	
BMI category	Healthy							205	182	228	0.00
	Underweight	1.87	1.45	2.41	-0.14	-0.35	0.07	265	200	331	
	Overweight	0.76	0.66	0.87	-0.05	-0.17	0.08	163	143	182	
	Obese	0.89	0.78	1.03	-0.07	-0.20	0.06	177	156	198	
	Morbidly obese	1.38	1.10	1.74	-0.14	-0.35	0.07	219	170	269	
	Unknown	1.71	1.29	2.27	0.38	0.12	0.63	421	298	545	
	Non-smoker							209	192	226	0.02

Wald test of joint significance

		PART 1 - Logit			PART 2 - GLM			Two-Part			
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Smoking category	Ex-smoker	0.83	0.73	0.95	-0.03	-0.16	0.09	180	155	204	
	Smoker	0.70	0.60	0.82	0.00	-0.15	0.15	166	138	194	
	Unknown	0.33	0.12	0.92	0.03	-1.01	1.08	103	-27	234	
LTCs	0-1							244	177	310	0.00
	2	0.68	0.54	0.85	0.10	-0.10	0.31	217	186	248	
	3	0.41	0.28	0.59	0.02	-0.29	0.34	149	127	171	
	4	0.23	0.14	0.39	0.23	-0.21	0.66	130	98	162	
	5+	0.08	0.04	0.17	0.30	-0.34	0.94	73	41	105	
Conditions	AF = 0							191	178	205	0.00
	AF = 1	1.95	1.52	2.49	-0.16	-0.37	0.05	250	187	312	
	Asthma = 0							187	173	201	
	Asthma = 1	1.91	1.56	2.34	-0.13	-0.31	0.05	248	198	297	
	Cancer = 0							192	178	206	
	Cancer = 1	1.85	1.48	2.32	-0.23	-0.43	-0.02	226	172	280	
	CHD = 0							189	175	203	
	CHD = 1	1.91	1.54	2.38	-0.15	-0.34	0.04	247	194	301	
	COPD = 0							190	176	204	
	COPD = 1	2.30	1.84	2.88	-0.22	-0.42	-0.03	257	199	315	
	Dementia = 0							166	153	178	
	Dementia = 1	8.74	6.83	11.18	0.27	0.09	0.46	922	707	1138	
	Depression = 0							183	170	197	
	Depression = 1	2.08	1.70	2.54	-0.05	-0.23	0.14	279	223	335	
	Diabetes = 0							177	163	192	
	Diabetes = 1	2.32	1.91	2.82	-0.01	-0.19	0.16	299	244	355	
Epilepsy = 0							179	166	193		
Epilepsy = 1	4.39	3.37	5.71	0.03	-0.19	0.25	480	356	604		
Heart failure = 0							189	176	203		
Heart failure = 1	3.34	2.52	4.43	-0.05	-0.28	0.18	387	278	496		

		PART 1 - Logit		PART 2 - GLM			Two-Part			Wald test of joint significance	
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
Table 5-9 Social care costs											
	Hypertension = 0							181	162	201	0.00
	Hypertension = 1	1.62	1.35	1.94	-0.13	-0.29	0.03	217	187	247	
	Hypothyroidism = 0							188	174	202	0.00
	Hypothyroidism = 1	1.76	1.41	2.20	0.00	-0.19	0.20	271	210	332	
	Mental health = 0							183	170	196	0.00
	Mental health = 1	5.30	4.10	6.86	-0.04	-0.26	0.17	502	376	629	
	Palliative care = 0							191	178	205	0.00
	Palliative care = 1	3.89	2.63	5.75	-0.01	-0.30	0.28	446	280	612	
	Stroke = 0							176	163	189	0.00
	Stroke = 1	4.73	3.79	5.92	0.13	-0.05	0.31	548	430	666	
	Learning difficulty = 0							140	130	151	0.00
	Learning difficulty = 1	62.17	48.15	80.27	0.49	0.26	0.71	3589	2753	4425	
Household variables											
Benefits	None							126	112	139	0.00
	ESA	4.92	4.02	6.01	0.14	-0.06	0.33	413	334	491	
	Pension	2.24	1.92	2.60	0.24	0.10	0.37	274	235	312	
	Income Support	3.23	2.43	4.29	0.29	0.04	0.54	368	265	471	
	Job Seeker's Allowance	0.67	0.33	1.38	-0.37	-1.08	0.34	66	9	123	
	Standard	1.53	1.30	1.79	0.19	0.03	0.34	202	170	234	
Tenure	Owner occupied							155	137	174	0.00
	PR	1.34	1.12	1.60	0.21	0.04	0.37	233	195	270	
	Social	1.19	1.04	1.37	0.04	-0.08	0.16	182	164	201	
	Reside	0.34	0.04	2.65	-0.10	-2.19	1.99	65	-104	235	
	Unknown	2.72	1.98	3.75	0.38	0.11	0.65	442	305	579	
Occupancy	2 to 4							164	148	180	0.00
	1	1.72	1.53	1.94	-0.03	-0.14	0.08	229	205	254	
	5 to 7	0.79	0.65	0.97	0.14	-0.06	0.33	161	126	196	
	8 to10	0.54	0.31	0.92	-0.08	-0.64	0.48	99	32	166	

		PART 1 - Logit			PART 2 - GLM			Two-Part			Wald test of joint significance
Table 5-9 Social care costs		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		prob>chi2=
	11+	1.25	0.80	1.94	0.95	0.58	1.33	494	267	721	.
B&D IMD quintile	1							180	153	206	
	2	1.06	0.90	1.26	-0.03	-0.18	0.13	182	157	206	
	3	1.13	0.95	1.33	0.05	-0.11	0.20	204	177	230	
	4	1.06	0.90	1.26	0.01	-0.15	0.17	188	163	214	
	5	1.09	0.92	1.29	0.12	-0.04	0.27	213	186	241	
	cons	-2.93	-3.02	-2.84	9.12	8.81	9.44				

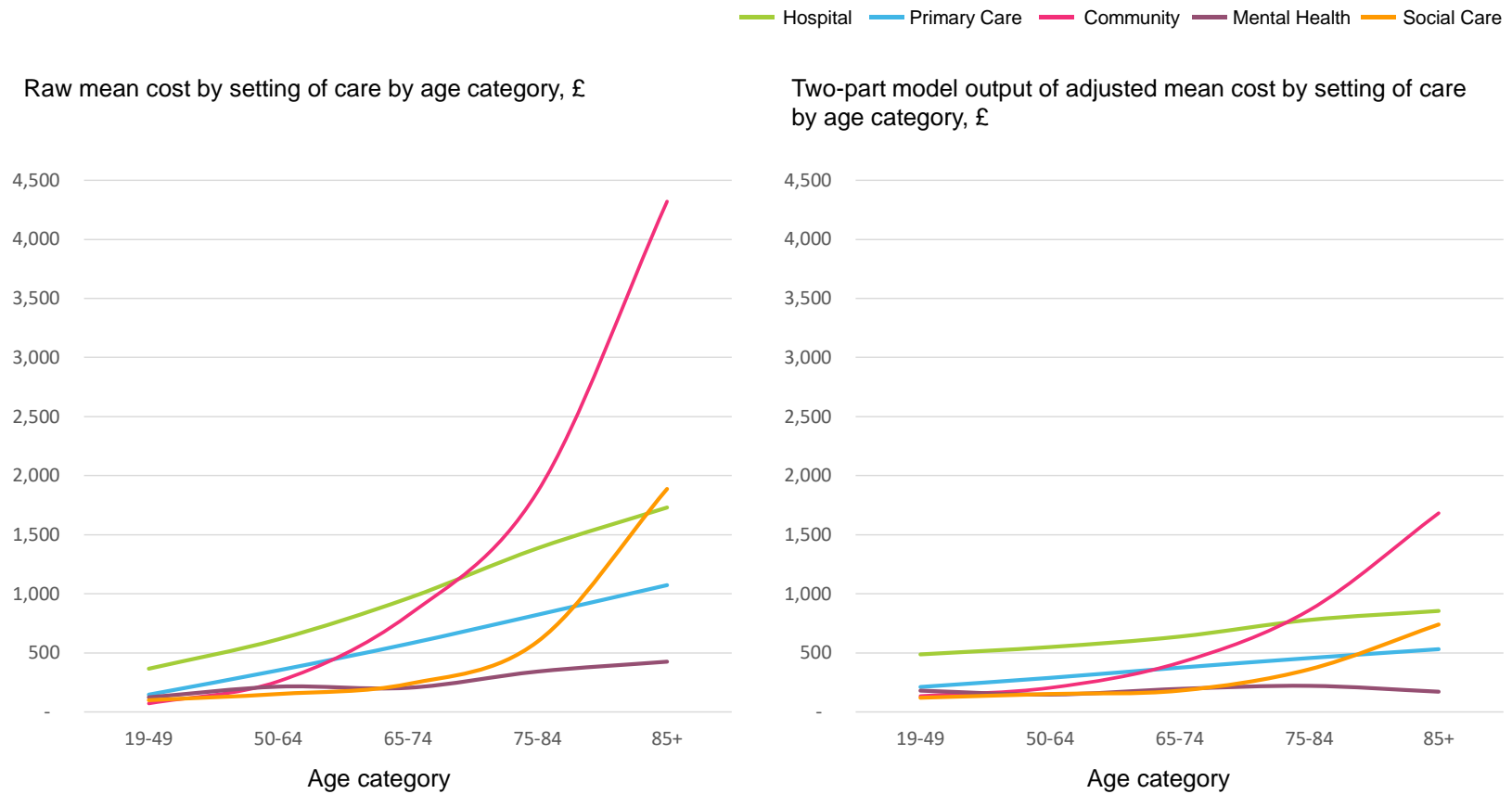
5.3.1 Socio-demographic characteristics

Age: The odds of being a service user and the resultant mean total cost increased with age.

However, the effect of age differed by setting (Figure 5-1). In primary care there was a slight tail off in odds of having a cost for over 85s, but the mean cost if they did have a cost was still higher. In community and social care the gradient of the association was much steeper.

The exception was mental health, where there was not a significant association with age and the likelihood of having a cost or the mean cost. This is in part due to mental health conditions having a lower mean age of diagnosis (mental health 43 years, depression 41 years, learning difficulties 32 years) than physical health conditions (mean of 58 years across the 13 conditions in the dataset).

Figure 5-1 The mean cost and adjusted mean cost for each setting of care by age category



Gender: Females had a higher likelihood of using services and higher total mean cost (£669). This was the case for all settings of care with the exception of mental health, which had no significant association. However, the impact on mean cost was only significant for hospital (£217) and primary care costs (£92).

Ethnicity: Asian or Asian British (1.71OR, CI 1.60 1.82), Mixed ethnicity (1.50OR, CI 1.42 1.59) and Black or Black British (1.27OR, CI 1.19 1.35) had higher odds of service use, with statistically significant increased service use for Asian or Asian British (£253) and Mixed ethnicity (£300).

At a setting level, Asian or Asian British, Mixed ethnicity and Black or Black British had increased odds of service use in hospital, primary care and social care. Only in primary care was there a statistically significant impact on adjusted mean costs for these three ethnicity groups, and in hospital care for Mixed ethnicity. Asian or Asian British had increased odds of service use in community care and Mixed ethnicity had increased odds in mental health.

Individuals who had a carer and/or who were a carer: Individuals who had a carer had increased odds of services use and an increased level of service use (1.68OR, CI 1.01 2.82, £1,189). Carers also had increased odds of service use (2.95OR, CI 1.95 4.47) but the level of cost was not significant. Individuals who were both a carer and had a carer had a primary care cost and therefore the first part of the two-part model (the odds of having a cost) was not applicable for total cost or primary care.

Individuals who had a carer had increased odds of service use across all settings of care, and a statistically significant increase in mean costs for all except hospital care. Those that were a carer had increased odds of using

services in hospital (1.29OR, CI 1.12 1.48) and primary care (2.92OR, CI 1.99 4.30), but the impact on mean cost was only significant in primary care (£41).

5.3.2 Health variables

Risk factors

BMI: Being overweight (1.3OR, 1.24 1.36), obese (1.45OR 1.37 1.53) and morbidly obese (1.51OR 1.32 1.72) increased the chance of having a cost. The increase in mean cost was statistically significant for obese (£176) and morbidly obese (£526).

On a setting level, the increased chance of cost was present in hospital, primary and community care for those that were overweight, obese and morbidly obese, but only in primary care was it associated with a statistically significant change in mean cost. For social care, those who were underweight (1.87OR, CI 1.45 2.41) and morbidly obese (1.38OR, CI 1.10 1.74) had higher odds of having a cost.

Smoking: Ex-smokers (1.32OR, CI 1.24 1.40) and smokers (1.93OR, CI 1.83 2.03) had higher odds of service use, but the impact on the mean cost was only significant for ex-smokers (£174). This was also the case for hospital care. In primary care, ex-smokers (1.35OR, CI 1.27 1.43) and smokers (1.92OR, CI 1.82 2.02) had increased likelihood of a cost compared with non-smokers, and there was a significant association with increased mean cost for both groups. Smoking is a modifiable behaviour that could be affected by disease onset, so the ex-smokers may have had higher odds and cost in primary and hospital care due to the prevalence of other health conditions, such that if health conditions had not been in the model the association may have been greater.

Number of long-term conditions: Given there is an interaction between the count of long-term conditions and the prevalence of individual conditions, I ran three separate models which included the covariates and: 1, the count of long-term conditions; 2, individual conditions; and 3, the count of long-term conditions and individual conditions (the main model results which are shown in Tables 5-4 to 5-9).

When I ran the model with the long-term condition counts, but not the 16 conditions, the presence of more than one long-term condition significantly increased the odds of having service use, and there was a significant increase in service costs as the number of conditions the individual had increased (Table 5-10).

Table 5-10 Two-part model outputs for the count of long-term conditions when the two-part model included all variables but excluded the conditions (age, gender, ethnic group, carer, BMI category, smoking category, count of long-term conditions, benefits, tenure, household occupancy, B&D deprivation quintile)

		PART 1 - Logit			PART 2 - GLM			Two Part		
		n=114,393	Odds Ratio	95% CI	Coefficient	95% CI	Margins , £	95% CI		
LTCs	0-1	95,317					1,043	1,005	1,080	
	2	11,601	8.66	7.17 10.44	0.81	0.74 0.87	2,542	2,388	2,696	
	3	4,702	14.93	9.49 23.50	1.09	0.99 1.18	3,386	3,071	3,700	
	4	1,791	6.97	3.93 12.36	1.33	1.17 1.48	4,265	3,631	4,898	
	5+	982	7.37	3.05 17.85	1.72	1.52 1.93	6,345	5,074	7,617	

In the full model, where I also adjusted for the specific conditions, there was an interaction between the count of conditions and the conditions themselves. The individual conditions controlling for the count led to increases in the mean cost at an individual level across all settings, but the additional effect of the number of conditions the person had on mean cost, conditional on the individual conditions, was sub-additive.

Health conditions: All conditions increased the likelihood of having a cost and the mean total cost. The change in use was most pronounced for learning difficulties (3.16OR, CI 2.01 4.98, £15,261), mental health (9.67OR, CI 5.73 16.3, £6,900), dementia (7.39OR CI, 2.29 23.82, £5,496), palliative care (4.84OR, CI 1.16 20.29, £4,706) and stroke (8.69OR, CI 4.46 17.13, £2,893). However, this varied by setting of care.

For hospital care, there was an increased likelihood of cost for all conditions except learning difficulties and mental health. The highest odds and resultant change in mean costs were for cancer (3.85OR, CI 3.50 4.22, £861), atrial fibrillation (2.48OR, CI 2.17 2.83, £477), heart failure (2.27OR, CI 1.88 2.73, £764), palliative care (2.19OR, CI 1.58 3.04, £764) and congestive heart disease (2.02OR, CI 1.85 2.21, £479).

In primary care, all conditions increased the likelihood of cost and increased the mean cost. The highest odds ratios were for diabetes (12.67OR, CI 9.95 16.12), atrial fibrillation (11.25OR, CI 5.21 24.32) and chronic obstructive pulmonary disease (8.37OR, CI 5.41 12.97), and the largest impacts on mean cost were for dementia (£453), mental health (£427), diabetes (£385), palliative care (£352) and stroke (£322).

For community care, all conditions increased the likelihood of cost and increased the mean cost. The highest odds ratios were for palliative care (3.15OR, CI 2.40 4.13), diabetes (3.09OR, CI 2.86, 3.33) and dementia (2.77OR, CI 2.32 3.31), and the largest impacts on mean cost were for palliative care (£2,235) and dementia (£1028). In mental health, whilst all conditions increased the likelihood of cost, the impact on the mean was only significant for dementia (£2,149), mental health (£3,079) and learning difficulties (£1,670). This was similar for social care, where all conditions increased the likelihood of cost, but the change in the mean was only significant for learning difficulties (£3,449) and dementia (£757).

5.3.3 Household variables

Household occupancy: All household occupancy levels had lower odds of service cost compared to two to four person households. The change in mean cost was only significant for single person households (£403) and five to seven person households which had a reduced adjusted mean cost (- £171).

Living alone was associated with decreased odds of having a cost in primary care (0.88OR CI 0.20 0.14), but if you had a cost it increased mean cost by £32. Living alone increased odds of having a cost and the level of cost in community care (1.09OR, CI 1.02 1.15, £160), and mental health (1.43OR, CI 1.29 1.58, £105). For social care there was an increased likelihood of having a cost (1.72OR, CI 1.53 1.94) but the impact on mean cost was not significant.

Benefits: All benefits were associated with increased odds of using services, but this was only statistically significant for ESA (1.60OR, CI 1.44 1.77), Income Support (1.32OR, CI 1.16 1.49) and Standard (1.25OR, CI 1.18 1.33). There was

a significant increase in mean cost for all except those in receipt of Job Seeker's Allowance. The most pronounced increase was for ESA (£1,634).

Being in a household in receipt of benefits increased the likelihood of having a hospital cost, with the exception of households in receipt of pensions. If individuals did have a cost, the change in adjusted mean was significant for ESA (£246), pensions (£52) and Income Support (£153).

For primary care, there were significant increases in the odds of having a cost for ESA (1.53OR, CI 1.39 1.69), Income Support (1.32OR, CI 1.18 1.48) and Standard (1.25OR, CI 1.18 1.32). If an individual did have a cost the adjusted means were higher and statistically significant for all types of benefits. For community there were increased odds of having a cost and an increase in mean costs for all types of benefits, with the exception of Job Seeker's Allowance where the coefficient of the GLM model was not significant. For mental health, all benefits had increased odds of having a cost which was most pronounced for ESA (4.13OR, CI 3.66 4.66). For social care, all benefits had increased odds of having a cost, with the exception of Job Seeker's Allowance. There were significant GLM coefficients for Pension Credits, Income Support and Standard.

Tenure: Private rentals had reduced odds of total service cost compared to owner occupied (0.86OR, CI 0.81 0.90); "reside" (the local B&D programme for providing access to affordable housing for those in employment) had increased odds of service use and increased mean costs (1.40OR, CI 1.11 1.77, £624).

Across the settings, privately rented had reduced odds of a service use when compared to owner occupied for hospital (0.92OR, CI 0.88 0.95) and primary care (0.88OR, CI 0.82 0.94), and increased odds of cost for social care (1.34OR, CI 1.12 1.60). There was little impact on adjusted means. For hospital care,

social housing and reside had increased odds of a cost and higher adjusted means than owner occupied. For primary care reside had increased odds of a cost. There was a small increase in adjusted mean for all tenures. For community care, reside had significant odds of a cost (1.37OR 1.04 1.79), and the adjusted mean was only significant for social housing (£81). For mental health, social housing had increased odds of a cost (1.19OR, CI 1.07 1.33).

Deprivation: Despite using the local deprivation quintiles, rebased to the B&D population given the high levels of deprivation, there was no significant association with deprivation quintiles and either the odds of having a cost or the level of cost overall or in any of the settings of care. This is probably due to the lack of variation in the IMD score which is already skewed towards higher levels of deprivation (mean score 34.54, min. 15.76, max. 56.57, SD 7.28).

5.3.4 Summary of setting comparison

Across the total cost and the setting level models, there were similarities and differences in the findings. There were similar findings for each setting with regards to the following:

- Increasing age was associated with increased odds of having a cost and increased cost
- All conditions were associated with increased odds of having a cost
- ESA increased odds of having a cost and increased adjusted means
- Living alone increased the odds of having a cost in three of the five care settings, and had a statistically significant increase in the level of cost in all settings except social care

The main differences were with regards to age and gender for mental health, and the individual conditions that were most strongly associated with increased

adjusted means at the setting level; these were often different from those with the greatest odds of having a cost. However, given that all conditions had higher odds of a cost in all settings, the following is a list of those conditions that had the largest difference in adjusted means:

- Hospital: cancer (£861), heart failure (£634), palliative care (£764)
- Primary care: dementia (£453), mental health (£427)
- Community: palliative care (£2,235), dementia (£1,028)
- Mental health: dementia (£2,149), mental health (£3,079), learning difficulties (£1,670)
- Social care: learning difficulties (£3,449) and dementia (£747)

Notably, dementia has a high adjusted mean cost in all settings of care but is smallest in the hospital setting where the adjusted mean cost of dementia was £322 higher in hospital than for people without dementia.

For household variables, there were consistent findings across all settings with regards to ESA. For household occupancy, living alone was only of interest to community, mental health and social care. Tenure and deprivation did not lead to significant findings within or across settings.

5.4 Discussion

5.4.1 Summary of results

A key contribution of this thesis has been to demonstrate which factors have the largest impact on both the probability of being a service user and the level of health and social care utilisation, across the different settings of care. By including a breadth of variables and five settings of care it provides a more holistic understanding of determinants of health and social care service use.

Different factors are associated with the probability of a cost for different settings of care. Secondly, as part of the integration agenda, services are being encouraged to take a more holistic view of an individual's needs. However, the outputs of this research have shown that diseases remain a strong predictor of service use and therefore it may be important to maintain an element of disease-based care and planning, particularly when understanding the differences across settings of care.

Including variables linked to social context and socio-economic determinants of health provides a wider perspective on what drives health and social care service utilisation. This study found that having a carer, being in receipt of benefits and living alone are clearly associated with higher health and social care costs.

5.4.2 Comparison with the literature

Our findings are consistent with the literature for age and gender; for example, the association between age and increased service use and cost is well established (126, 136). However, as found in our study, this relationship is not observed for mental health use, partly because the age of onset of mental health conditions is much lower than physical health conditions (137). Gender differences in health and health care utilisation are also well documented.

Women generally experience poorer health than men, have a higher propensity to seek health care, and therefore have higher service use (138-141), which is consistent with our findings that men are less likely to be service users than women and men are associated with lower mean costs across settings.

Findings on associations between service use and ethnicity (142), smoking status (143) and body mass index (144, 145) were observed. However, despite

literature on an association between deprivation and service use (129, 146, 147), this was not observed in our study. This may be in part due to a lack of variation for IMD values in B&D.

There are four areas where the findings were more nuanced. Firstly, the count of long-term conditions. Definitions for multi-morbidity vary extensively, from detailed measurement tools adjusting for severity of different conditions, to simple count structures in which those with more than two conditions are defined as multi-morbid (148). The latter is adopted by NICE, with the requirement that at least one of the conditions must be a physical health condition (149). Our study found that an increase in the number of long-term conditions was associated with increased probability of service use and increased levels of cost; however, when also adjusting for the conditions there was a sub-additive effect. This may suggest efficiency in service use as a result of conditions being treated together and, as such, not requiring separate visits or care contacts. As health care policy in the UK, and internationally, increasingly promotes a move away from disease-based care, these findings suggest that some of the benefits of integration may be being experienced already, although disease prevalence continues to be a major predictor of the care required.

For the individual conditions, the dominance of mental health conditions in the adjusted mean cost for primary care, community care, mental health and social care, reinforce the findings of Chapter 4: the addition of a mental health condition leads to a substantial increase in mean cost. What this study adds is that this increase remains after adjusting for other factors.

It is largely acknowledged that being a carer has a negative impact on the individual's health and wellbeing (101, 150 - 152). Our findings corroborate this

by showing that being a carer increases the odds of using a health service across all settings, except social care. However, I found that, conditional on other socio-demographic and economic factors, being a carer is not associated with the amount of health care use. For those that had a carer, there are mixed views in the literature as to whether informal carers are care substitutes (153, 154). If they are, we may expect there to be lower service use for those with carers, particularly in community and social care where some of the tasks may be unskilled and able to be performed by informal carers. Our study found that having a carer increased the odds of health care use and the level of health care costs. This may reflect the increased acuity of the people that have a carer, and therefore having a carer may be another marker of service need. In addition, carers may be supporting the individual to get increased access to services, for example as an advocate or coordinator of care. Chapter 6 explores this further.

Those out of work due to long-term illness or due to temporary illness or injury, identified in our dataset as those on ESA or Income Support, are more likely to use health services relative to those who are not in receipt of these benefits.

Since I already controlled for age, the specific disease diagnosis and the combined effect of multiple long-term conditions, the increased odds of a cost suggest that the set of morbidity variables do not capture the full effect of ill health on the need for service use for this cohort. For example, short-term mental or physical health needs will not be reflected in the long-term conditions. Blindness, deafness and other long-standing disabilities are also not included as variables. As with having a carer, ESA could therefore be acting as another marker of acuity of need. The increased adjusted means may in part be due to some of these groups attending services for administrative reasons, such as sickness certification. We would expect to see that in primary care, where

sickness certification is most commonly provided, but in our cohort increased mean cost was present in all settings of care for individuals living in households in receipt of benefits, particularly for ESA. The data on ESA are available at a household level and applied to all individuals in that household regardless of whether they are the prime reason for ESA benefit receipt. The strong association with increased mean cost in all settings may imply that there is an effect on the service utilisation levels of all members of the household.

It is widely accepted that a person's living arrangements influence their health (155); however, few studies have examined the association between living arrangements and health care utilisation. The inclusion of household occupancy enabled us to explore this. Studies have shown an association between living alone and increased health care utilisation (155-157). In the NHS, there is acknowledgement that people who live alone will probably have longer lengths of stay as they do not have the same post discharge support network (158). This was not observed in the analysis; further investigation of the individual components of hospital activity may be beneficial (emergency attendances, elective and non-elective inpatient stays and outpatient visits). The associations between living alone and increased community and mental health service use suggest further work is required to understand the specific additional needs of those who live alone once other factors, such as age and disease, have been accounted for.

5.4.3 Strengths and limitations

A strength of the study was the use of two-part modelling: assessing the impact of a variable on the chances of being a service user and on the level of health and social care utilisation. The breadth of services included was novel (i.e., five

settings of care); in particular, the inclusion of community services, mental health and social care, which are often omitted from existing studies. There are few studies that have access to linked individual level data across health and care utilisation and social factors; hence, the richness of the information included in our analysis is an important strength of the study. The inclusion of individual measures and household characteristics, and area-level measures is, in particular, unique.

There are several limitations to note. Firstly, this was a cross-sectional analysis with variables and utilisation data drawn from a single year. Longitudinal patterns were not evaluated; this would have provided more clarity on whether the impact of the factors explored in this study is likely to change over time.

There were missing data for some of the variables, namely ethnic group, BMI category, smoking status and tenure. I categorised missing data into an “unknown” category for each of these variables. This was done to maximise the sample size as unknowns were not present for all categories for all individuals, and there was still substantial data that could be used for other variables. A potential limitation of this approach is that the additional “unknown” category may have included individuals who are systematically different according to important prognostic factors. However, to help mitigate this, as an alternative, I considered a complete case analysis in which individuals with missing observations would be dropped from the analysis. This approach assumes that, conditional on the variables included in our substantive model, the missing data were unrelated to other observed and unobserved values. I applied this approach by re-running our “base-case” two-part model (on the overall health service use) and found that the results were similar to those presented above (see Appendix 8).

By defining multi-morbidity as a simple count of long-term conditions, our analysis weighted all diseases equally, although the effect of multi-morbidity on individuals can vary with combination and severity of conditions. The definitions of multi-morbidity vary widely and there are increasingly refined lists of conditions that people use in their research of multi-morbidity. As such, the selection of 16 conditions may not be a comprehensive picture of diseases that influence service use patterns.

The modelling conducted did not include interaction within each of models between the co-variates. Interacting gender and age is often done in health care cost analysis and could have been implemented within the models in this research project. This could impact interpretation of results as the effect of gender on the probability and scale of service use may be different for different age categories.

Finally, although the cohort was large, this is a very deprived population with no individuals in the two least deprived national quintiles. This may have an impact on the generalisability of the findings, particularly given known associations between deprivation and increased prevalence of illness and multi-morbidity in deprived populations (159) and increased service use (125).

5.4.4 Implications

Policy for promotion of integrated care tends to focus on small groups of people who have complex care needs; however, there are other communities for whom integration can also be important. The narrative on integration has promoted a shift from disease-based models of care to population-based models that reflect the wider needs of individuals. Our findings on, for example, ESA and living alone, support this shift; however, given the strong association with individual

diseases and service use across all settings of care, disease-based planning remains important. In addition, identifying the settings most dominant in the service use profile for different conditions may help better target interventions.

The narrative surrounding integrated care suggests it may deliver efficiencies in care provision by removing duplication within and across settings of care. This creates risks of cost-shifting versus true efficiency gains, particularly in the context of care for people with multi-morbidity. Data on the whole system of care, such as I have included here, may help with evaluations and system-wide decision making on resource allocation. Most interventions, to date, focus on reducing hospital activity, however, our analysis suggests mental health service users, although small in number, have high mean cost, potentially warranting more detailed analysis and attention.

Further research would be beneficial to understand the findings in more depth. Conducting longitudinal analysis to review changes in patterns of service use over time would further enhance the research findings. In addition, introducing interaction between some of the co-variates (for example gender and age) within the models would improve understanding. The costs in each of the five settings of care were modelled as independent outcomes, there is scope for further research to explore modelling the costs as joint outcomes, introducing interaction between the models.

5.5 Conclusion

This project investigated the extent to which socio-demographic, health and economic factors determine health care use and the level of health and social care costs, overall and by setting of care. Our findings suggest that the relative

impact of these factors differs according to setting of care. Large, linked datasets, such as the one considered in this study, provide extensive opportunities to improve our understanding of service user patterns and the wider determinants of health.

6 A matched analysis of the impact having a carer has on an individual's health and social care utilisation across five settings of care

The linked dataset described in Chapter 3 and used for the research in Chapters 4 and 5 provided information on care utilisation for B&D residents across five settings of care: hospital, primary, community, mental health and social care. However, it did not include additional services that individuals may be receiving that could impact the care they require or their service utilisation patterns. For example, the voluntary or third sector has long been recognised as an important contributor to social care and home-based support and is a delivery partner for many of the recommendations in the “NHS Long Term Plan” (13). Definitions vary, but they include services provided by charities, voluntary and community organisations, social enterprises and others, including family members as informal carers. Informal care often constitutes a significant part of health care provision, for example, for patients with disability, multi-morbidity and long-standing mental health illnesses. However, the impact of informal care on care utilisation is not well understood.

The regression modelling in Chapter 5 included a variable about carers; specifically, whether someone was a carer, had a carer or both (was and had a carer), or none of these, as recorded in the primary care records. After adjusting for other variables, individuals who had a carer had increased odds of using services across all settings of care (odds ratio for having a cost was 1.68OR, CI 1.01 2.82) and an increased level of service use (the difference of the adjusted mean of total cost for someone with a carer compared to the base of someone without a carer was £1,189). The exception was hospital services where the

increased odds of having a cost in that setting were not significant. However, people with a carer differ in many respects from those who do not have a carer: those with carers are older (mean age of those with a carer was 65 years vs 45 years for those without a carer) and have a greater degree of morbidity (mean count of long-term conditions was 2.3 for those with a carer vs 0.65 for those without a carer). The regression modelling in the previous chapter had several limitations. It relied on the correct specification of the linear model (e.g., age has a non-linear relationship with health care costs) and it required distributional assumptions, specifically a normal distribution for the second part of the two-part model. In this chapter I aim to address these limitations by using matching techniques to assess the causal effect of having a carer on health and social care cost-weighted utilisation.

6.1 Background

There are an increasing number of people with long-term conditions and social care issues who are managed at home due to the support of informal carers. Across the UK today, an estimated 6.8 million people are carers, supporting friends and family who are older, disabled or seriously ill (160). Each day 6,000 more people become carers (33). These carers are unpaid and often described as “lay”, “informal” or “family” carers (107). It is estimated that the economic value of the contribution made by carers is worth £132 billion a year (160). This is calculated by multiplying the total hours of care provided by carers (using an estimate of the number of carers and responses from the “Personal Social Services Survey of Adult Carers in England 2014-15”(161) to determine the average hours of care each carer provides) by the unit cost of an hour of replacement homecare for an adult (£17.20). Reliance on carers appears to be

increasing, with reductions in local authorities' budgets resulting in fewer people getting access to formal support (8).

There are mixed perspectives in the literature on the impact of carers on the care recipient's health and social care utilisation patterns. On the one hand, the estimations of the economic value of the contribution of carers described above assume that carers are a substitute for other paid care, and by having a carer you require fewer hours of paid homecare (160). On the other hand, having a carer could increase service utilisation as the individual has an advocate who can help to gain access to services, transport the individual to appointments, help overcome denial that more care is needed and ensure the individual is able to get their full care needs met. Research in Canada found both of these to be the case for end-of-life patients: having an informal carer reduced the need for home-based care services, but increased the utilisation of physician and nurse visits (162). A review of informal care across nine European countries found care substitution for unskilled tasks, such as cleaning and domestic tasks (153).

Research to date highlights the complexity associated with looking at substitution of care between formal and informal care services (154, 163) and the different roles the different care types provide (164). Regardless, there is alignment that a growing ageing population alongside reductions in funding for state-funded social care will lead to a greater reliance on informal care in the future (165).

The NHS in England has a policy commitment to improve identification of informal carers and strengthen support for them, not only to address their individual health needs in recognition of the impact being a carer can have on a carer's health, but also to be able to maintain their care giving role (13). Better identification of carers has led to primary care documenting whether or not someone is a carer, has a carer or both is and has a carer in their records using

Read Codes(166). In some instances, formal recognition of having a carer is required for the carer to get access to benefits and respite support.

This study aimed to understand if people with a carer have different levels of service use across the different settings of care when compared to those who do not have a carer but have matched characteristics.

6.2 Methodology

This is a quantitative study using person-level data to assess the impact of having a carer in terms of the differences in cost-weighted utilisation relative to a matched control group.

6.2.1 Dataset

The study used a subset of the linked dataset described in Chapter 3. The primary outcome measures were total cost and setting level costs for hospital, primary care, community care, mental health and social care.

The variable of interest was from the primary care records and refers to the collection of Read Codes that identify if someone has an unpaid carer (918F) or if someone is an unpaid carer (918G). Individuals can be identified as an unpaid carer regardless of the relationship they have with the care recipient, for example, family members, neighbours or friends. Despite the ability to code within Read Code 2 and CTV3 guidance details on the kind of person you are caring for (e.g., 918M caring for a person with a terminal illness, 918W caring for a person with learning difficulties, 918Y caring for a person with sensory impairment), these codes were seldom used; therefore, where the codes had been used, we assigned these individuals to the overall category of being an unpaid carer.

We did not have access to information on how many hours per week carers provided support and did not attempt to assign costs to the carers' activities.

6.2.2 Cohort

The dataset of adults who were confirmed residents of B&D between 1st April 2016 and 31st March 2017 was used as the base for the analysis. As with Chapters 4 and 5, those who died during the year or who moved out of B&D before the 1st April 2017 were excluded from the cohort as they had less than 12 months of activity data, and the known increase in health care utilisation at the end of life (97, 98) could bias results. Of the remaining 114,393 adults, the following individuals were then excluded:

- **Those who had a carer and were a carer ($n=101$)** as the nature of their care needs could be different given their ability to be a carer. Spouse carers, which are a growing cohort (167), who both care for their spouse and receive care from their spouse will have been excluded.
- **Those who were a carer ($n=861$)** as the impact of being a carer on their own health needs could be complicated by the known associations between being a carer and declined health status (101, 150, 151) and including these in the dataset would make it possible for individuals who are carers to be a matched control which would impact interpretation of results.
- **Individuals who lived in households with an occupancy of 11 or more ($n=1,115$, which included 33 individuals who had a carer).**
Individuals living in households with an occupancy of 11 people or more were assumed to be in a care home setting and were therefore excluded from both the treatment group and control group as their health and

social care use are likely to be different from those residing in their own home (168).

The remaining dataset had 112,316 adults. The treatment group were defined as those who had been documented as having a carer in their primary care records ($n=1,295$).

6.2.3 Matching

People with a carer differ in many respects from those who do not (e.g., those with carers are older and have a greater degree of morbidity), such that the mean costs of the two groups are not directly comparable (see Table 6-1 and Table 6-2). In this study, we sought to create two comparable groups that were identical with respect to all observed characteristics, except the exposure to a carer.

Table 6-1 Summary of the characteristics of residents of Barking and Dagenham in 2016/17 who had a carer and those who did not

		<i>Have a carer</i>		<i>Do not have a carer</i>		<i>p value of Pearson chi2 of the difference</i>
		<i>n=1,295</i>	<i>%</i>	<i>n=111,021</i>	<i>%</i>	
Personal characteristics						
Age	19–49	318	25%	69,019	62%	<i>p=0.00</i>
	50–64	188	15%	25,217	23%	
	65–74	182	14%	9,041	8%	
	75–85	353	27%	5,249	5%	
	85+	254	20%	2,495	2%	
Gender	Female	706	55%	58,544	53%	<i>p=0.201</i>
	Male	589	45%	52,477	47%	
Ethnic group	White	70	5%	15,412	14%	<i>p=0.00</i>
	Black or Black British	75	6%	18,006	16%	
	Mixed	895	69%	46,695	42%	
	Other	11	1%	2,322	2%	
	Asian or Asian British	101	8%	16,639	15%	
	Unknown	143	11%	11,947	11%	
Health variables						
BMI category	Underweight	55	4%	3,508	3%	<i>p=0.00</i>
	Healthy	372	29%	32,573	29%	
	Overweight	382	29%	34,668	31%	
	Obese	395	31%	26,924	24%	
	Morbidly obese	75	6%	4,744	4%	
	Unknown	16	1%	8,604	8%	
Smoking category	Non-smoker	785	61%	68,122	61%	<i>p=0.00</i>
	Ex-smoker	300	23%	17,709	16%	
	Smoker	207	16%	22,920	21%	
	Unknown	3	0%	2,270	2%	
Number of LTCs (Count of the 16 conditions listed below)	0–1	421	33%	93,310	84%	<i>p=0.00</i>
	2	387	30%	10,983	10%	
	3	240	19%	4,332	4%	
	4	146	11%	1,571	1%	
	5+	101	8%	825	1%	
Conditions	Atrial fibrillation	106	8%	1,521	1%	<i>p=0.00</i>
	Asthma	175	14%	11,062	10%	<i>p=0.00</i>
	Cancer	175	14%	3,101	3%	<i>p=0.00</i>
	Congenital heart disease	169	13%	3,546	3%	<i>p=0.00</i>
	Chronic obstructive pulmonary disease	164	13%	3,185	3%	<i>p=0.00</i>
	Dementia	114	9%	509	0%	<i>p=0.00</i>
	Depression	196	15%	8,675	8%	<i>p=0.00</i>

		<i>Have a carer</i>		<i>Do not have a carer</i>		<i>p value of Pearson chi2 of the difference</i>
		<i>n=1,295</i>	<i>%</i>	<i>n=111,021</i>	<i>%</i>	
	Diabetes	266	21%	9,792	9%	<i>p=0.00</i>
	Epilepsy	105	8%	1,417	1%	<i>p=0.00</i>
	Heart failure	68	5%	785	1%	<i>p=0.00</i>
	Hypertension	600	46%	20,590	19%	<i>p=0.00</i>
	Hypothyroidism	146	11%	4,591	4%	<i>p=0.00</i>
	Mental health	196	15%	1,206	1%	<i>p=0.00</i>
	Palliative care	54	4%	214	0%	<i>p=0.00</i>
	Stroke	111	9%	1,654	1%	<i>p=0.00</i>
	Learning difficulty	339	26%	323	0%	<i>p=0.00</i>
Household variables						
Benefits	None	609	47%	78,444	71%	<i>p=0.00</i>
	Employment Support Allowance	129	10%	6,242	6%	
	Pension Income	255	20%	5,196	5%	
	Support Job Seeker's Allowance	72	6%	3,318	3%	
	Standard	6	0%	1,975	2%	
Tenure	Owner occupied	224	17%	15,846	14%	<i>p=0.00</i>
	PR	607	47%	58,834	53%	
	Social Reside	168	13%	21,988	20%	
	Unknown	491	38%	28,713	26%	
		2	0%	704	1%	
Occupancy	2 to 4	27	2%	782	1%	<i>p=0.00</i>
	1	714	55%	66,266	60%	
	5 to 7	436	34%	13,810	12%	
	8 to 10	123	9%	26,984	24%	
B&D IMD quintile	1	22	2%	3,961	4%	<i>p=0.068</i>
	2	244	19%	22,819	21%	
	3	236	18%	22,462	20%	
	4	262	20%	21,957	20%	
	5	289	22%	22,094	20%	
		264	20%	21,689	20%	

Table 6-2 Mean costs for each setting of care for those who have a carer compared with the full cohort of people who did not have a carer in Barking and Dagenham in 2016/17

	Have a carer n=1,295		Do not have a carer n=111,021		T-test result of the difference in means
	Mean (£)	Standard deviation	Mean (£)	Standard deviation	
Total costs	12,680	20,797	1,415	5,648	$p=0.00$
Hospital	1,606	3,486	542	1,680	$p=0.00$
Primary care	1,014	1,292	274	501	$p=0.00$
Community	2,969	9,416	334	3,254	$p=0.00$
Mental health	2,499	11,939	142	2,644	$p=0.00$
Social care	4,593	11,155	123	1,799	$p=0.00$

Matching has been a long-standing approach to assessing treatment effects in research (169, 170). The basic idea of matching is to replicate a randomised experiment when using observational data by creating comparable groups, which only differ according to the exposure. In practice, matching involves balancing the distribution of covariates in the exposed and unexposed (to a carer) groups (171) in order to control for any systematic differences between these groups and provide unbiased estimates of treatment effect. In this study, the exposure or “treatment” is “having a carer”, and the outcome of interest is health and social care cost-weighted utilisation.

Conducting matching analysis required consideration of different methodologies for creating the comparison group:

- Propensity score matching:** The propensity score for individual i is defined as the probability of having a carer given the observed covariates: $e(X_i) = P(T_i = 1|X_i)$. In other words, the propensity scores summarise the probability of having a carer into a single measure.

Matching can then use the propensity score measure to balance the individuals between comparison groups according to propensity score (this is similar to balancing the comparisons groups according to the observed characteristics). There are several ways to apply the propensity score in matching. One example is caliper matching, where unexposed individuals are matched to exposed individuals by only using those unexposed individuals for whom the propensity score is within a defined range. Another example is nearest neighbour matching. This approach selects control individuals for whom the propensity score is closest to that of the treated individual and discards controls who are not selected as matches. For example, 1:1 nearest neighbour matching selects from each treated individual i the control individual with the smallest distance (in terms of propensity score) from individual i . As such, a large number of individuals are often excluded from the unexposed cohort.

- **Exact matching:** This approach matches unexposed cases to exposed individuals with exactly the same covariate values. A key strength of this matching approach is that it provides transparency on the matching process as it does not require estimating a propensity score model. However, it can lead to large numbers of control cases being excluded from the analysis where an exact match cannot be found.

Guidance on selecting matching methods recommends using the method that yields the best balance of covariates. Different combinations of variables can be used to run the matching analysis. We reviewed inclusion of all variables known to be related to both treatment assignment (having a carer) and the outcome (health and social care cost-weighted utilisation). We focused on the latter, as

there is increased variance of including variables that are unrelated to the outcome but highly related to the treatment assignment (172).

Requiring exact matches can lead to many individuals being excluded, which can result in larger bias than if the matches are inexact but more individuals remain in the analysis (173). As such, a review of the matching scenarios considered the quality of the match with regards to the variables included as well as the resultant sample size. Exact matching was considered first, matching on all variables, to understand the number of match results and therefore low sample sizes. If exact matching yielded very low sample sizes, nearest neighbour matching was then to be considered, with a review of the standardised differences of the matched cohorts to understand the balance of covariates across the exposed and non-exposed groups.

Nearest neighbour matching with a minimum of one match was used for the analysis. The approach determines the “nearest neighbour” by using a weighted function of the covariates for each observation. The distance measure is Mahalanobis in which the weights are based on the inverse of the variance–covariance matrix:

$$D_{ij} = (X_i - X_j)' \Sigma^{-1} (X_i - X_j)$$

Where D_{ij} is the distance between individuals i and j for matching and Σ is the variance–covariance matrix of X in the pooled treatment and full control groups.

Nearest neighbour matching matches unexposed individuals to the exposed group (in this case, individuals with a carer) and discards those who are not selected as matches. In 1:1 nearest neighbour matching, the control individual with the smallest distance from individual i is selected for each treated individual i . The resultant cohort is 1:1, with the same number of exposed and unexposed.

The true number of unexposed for the i th observation may not equal one because of ties; in this instance several controls may form the comparison for an individual case.

The balance of the matched cohort compared with that of the full dataset was compared using the standardised difference in means (174). This is calculated by the difference in means of each covariate between those with a carer (X_t) and those without (X_c) divided by the standard deviation in the full matched cohort (SD):

$$\frac{(X_t - X_c)}{SD}$$

Smaller values indicate better matches. A standard difference of more than 10 has been denoted by some as indicating meaningful imbalance (175). A review of standardised mean differences was used to assess the balance of the exposed and non-exposed groups in the matched cohort. Before matching, there were substantial differences, particularly for age (112) and the count of long-term conditions (107). The next section will report the standardised differences before and after matching.

6.2.4 Implementation

The primary outcome measure was cost-weighted utilisation for total costs and setting level costs. We assessed the significance of any differences found between those with a carer and those without a carer using the Stata `teffects` command (172) which reports the average treatment effect (ATE).

Of the 112,316 individuals included in the analysis, 1,295 people had a carer and 111,021 people did not have a carer. Nearest neighbour matching was used, matching on age, gender, ethnicity, deprivation, BMI category, smoking status,

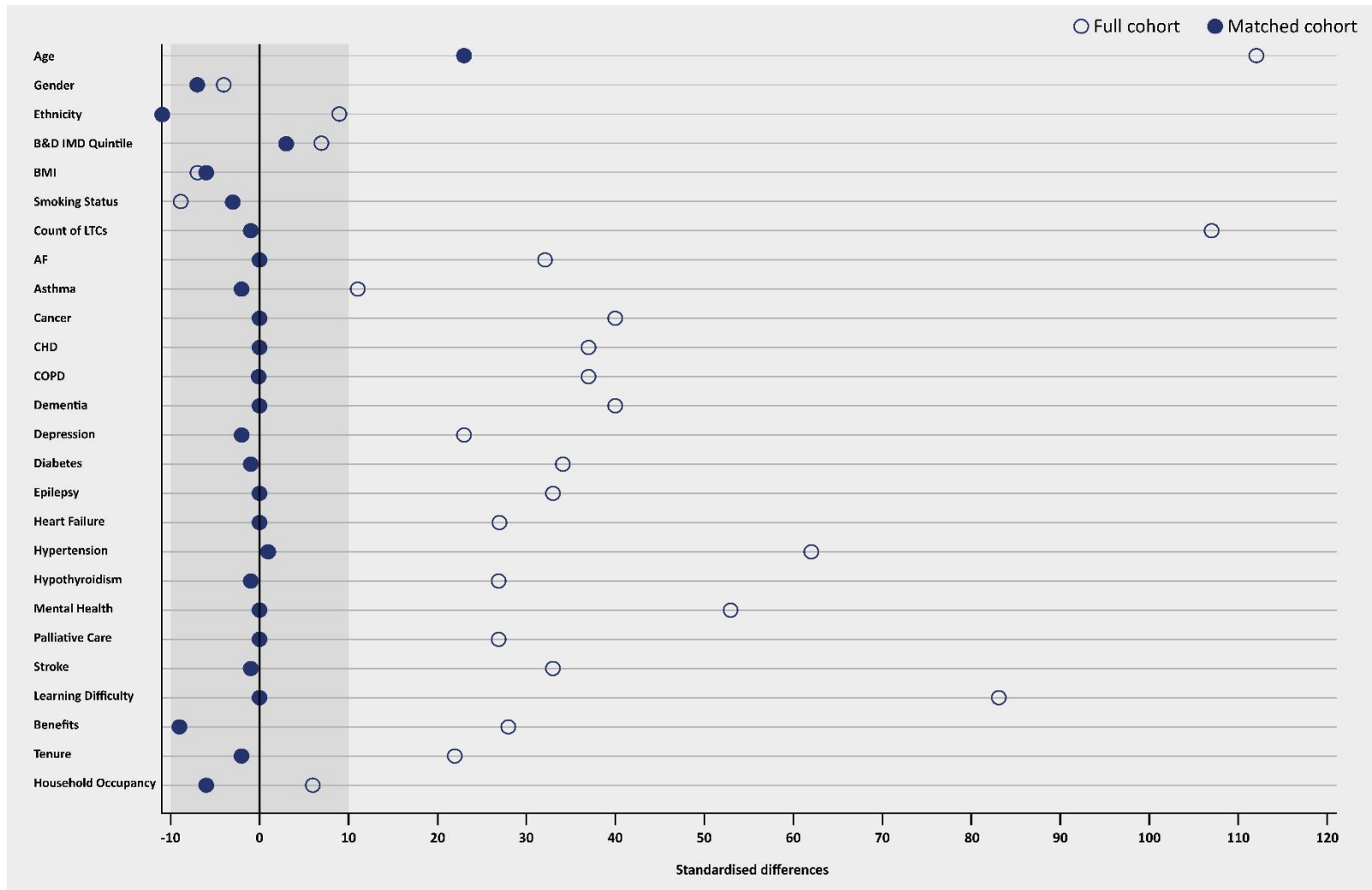
the number of long-term conditions, the prevalence of 16 conditions, housing tenure, benefits received and housing occupancy. This created a matched cohort of 2,590, with 1,295 individuals that had a carer and 1,295 individuals that did not have a carer.

After matching, the similarities between the exposed and unexposed group improved across all variables, with standardised differences brought within the threshold for meaningful balance (Figure 6-1). There were two exceptions, namely the standardised difference for age was 23 after matching, and the standardised difference for ethnic group was borderline at 11. Specific robustness checks were therefore conducted for age in our analysis, including an exact match on age category as a variable to understand if the treatment effect remained the same, which is described in Section 6.3.1.

The ATE was computed to calculate the difference in costs between people who had a carer and people who did not, using nearest neighbour matching.

All data processing, matching and analysis were conducted using Stata version 15.1 (122).

Figure 6-1 The standardised differences for key variables for the full dataset and for the matched cohort



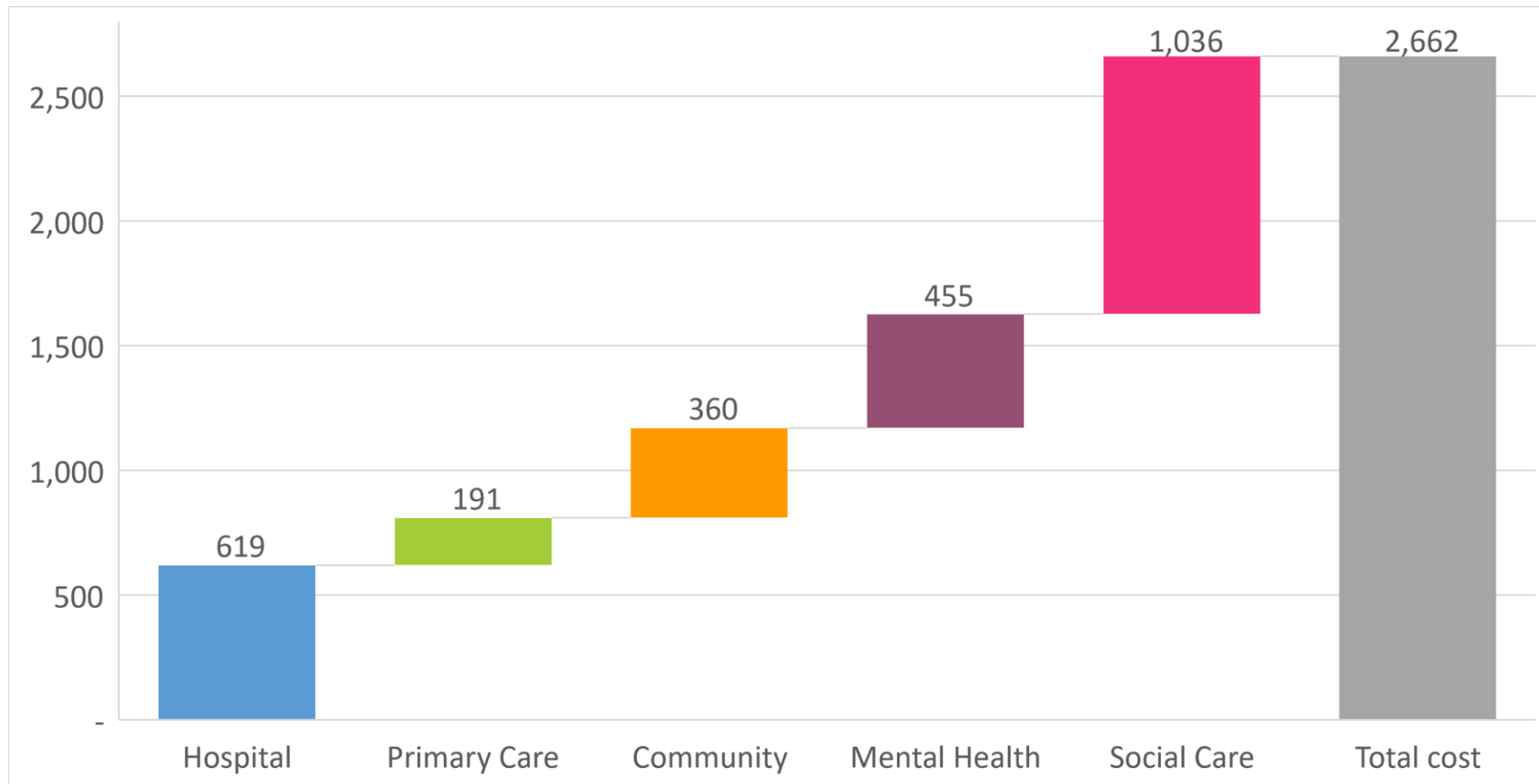
6.3 Results

A comparison of people who had a carer with those who did not found that having a carer was associated with 27% increased cost (mean difference of £2,662, CI £1,595 - £3,729, $p < 0.001$). The increase in cost was found across all care settings, but social care was the largest contributor, accounting for £1,036 (39%) of the overall difference in costs. The difference in cost in mental health was not statistically significant. Table 6-3 and Figure 6-2 show the results for the mean difference in total costs and the mean difference in costs by setting of care.

Table 6-3 The differences in mean cost by setting for people with a carer vs those without a carer (controls), matched on age, gender, ethnicity, deprivation, BMI category, smoking status, the number of LTCs, the prevalence of 16 conditions, housing tenure, benefits received and housing occupancy

	Mean			<i>p</i>	Median, £	
	ATE of having a carer, £	95% CI			Have a carer <i>n</i> =1,295	Matched controls <i>n</i> =1,295
Total cost	2,662	1,595	3,729	0.00	3,627	229
Hospital	619	75	1,164	0.03	228	0
Primary care	191	108	274	0.00	572	127
Community	360	134	587	0.00	0	0
Mental health	455	-30	941	0.07	0	0
Social care	1,036	474	1,598	0.00	0	0

Figure 6-2 The differences in mean cost by setting for people with a carer vs those without a carer (controls), matched on age, gender, ethnicity, deprivation, BMI category, smoking status, the number of LTCs, the prevalence of 16 conditions, housing tenure, benefits received and housing occupancy



I ran a sub-analysis for the outpatient and inpatient costs within the mental health setting to understand if there were different levels of statistical significance for the different types of services. The difference in mental health costs was not significant for either inpatient or outpatient activity.

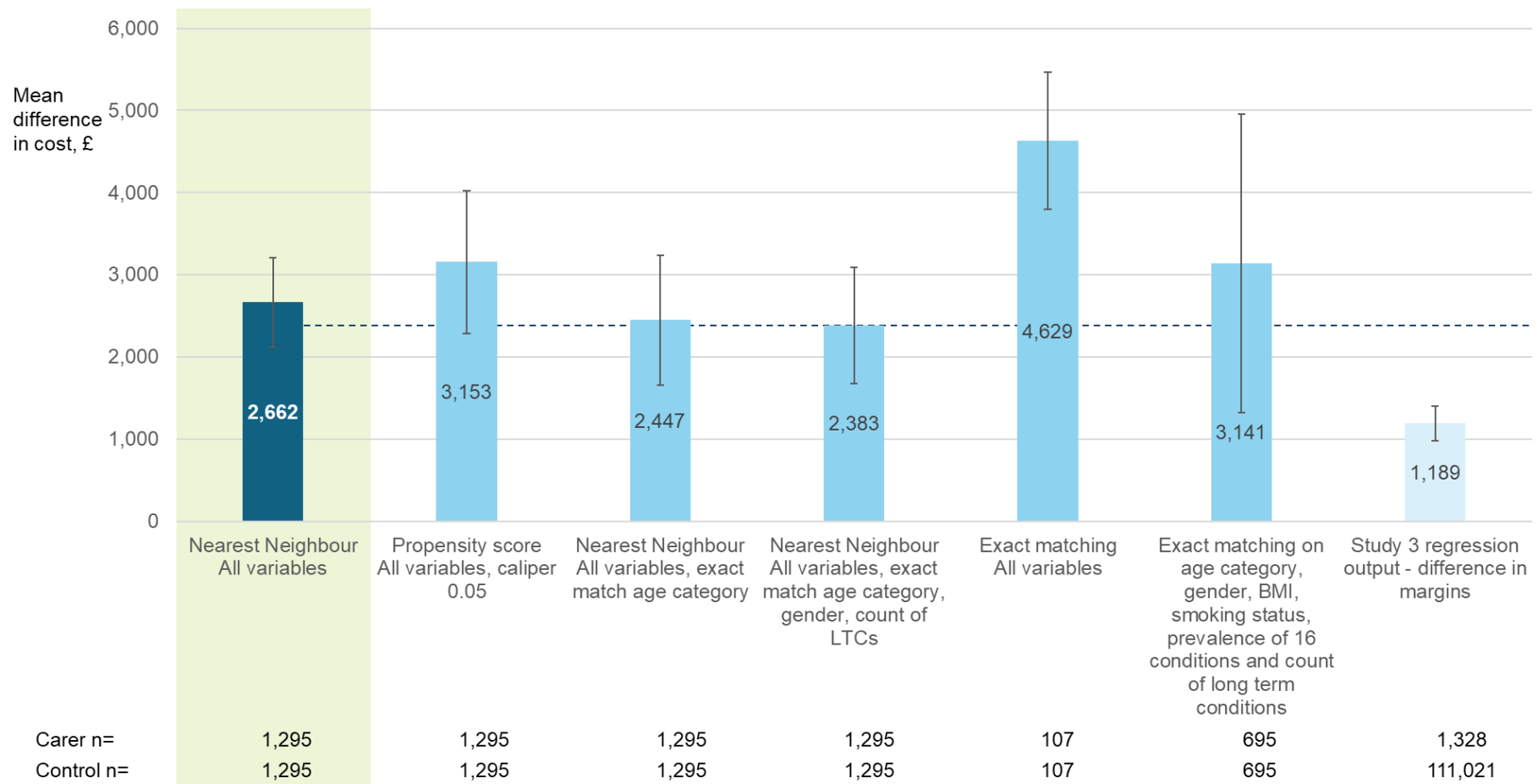
6.3.1 Robustness checks

To test the validity of the results I ran several further matching scenarios. These were:

- Propensity score matching on all variables with a specified caliper of 0.05
- Nearest neighbour matching on all variables, with exact matching on age category
- Nearest neighbour matching on all variables, with exact matching on age category, gender and count of long-term conditions
- Exact matching on all variables
- Exact matching on age category, gender, BMI category, smoking status, prevalence of 16 conditions and count of long-term conditions

This showed similar differences in costs for people with a carer and those without; thus, providing confidence that the results of the analysis were reflective of the true difference in costs between people with a carer and people without (Figure 6-3).

Figure 6-3 Comparing the mean difference in total costs for people with a carer compared to those without for different matching scenarios



Exact matching on all of the variables was only possible for 107 (8%) of the people with a carer. A large proportion of people with a carer were therefore excluded, in particular those with more long-term conditions and in the older age categories. The difference in costs for people with a carer compared to those without was £4,629 (CI £1,027 £8,231) suggesting that even in people with potentially lower levels of need, there is a significant increase in costs between those with a carer and those without.

Given the standardised difference for age (23) in the analysis, I conducted nearest neighbour matching in combination with exact matching on age category. The difference in costs was £2,447 (CI £895 £3,999) confirming that the increase in costs remains in a matching scenario where the standardised difference for age is brought within the threshold of meaningful balance. I also conducted nearest neighbour matching with exact matching on age, gender and number of long-term conditions which again showed a similar output.

6.4 Discussion

6.4.1 Summary of results

For the adult residents of B&D between 1st April 2016 and 31st March 2017, health and care costs were £2,662 (27%) higher for people registered in their primary care records to have a carer compared to those who were not registered as having a carer. Social care accounted for the majority of this difference (39%). Cost patterns differed by setting, with the widest differences between the people with carers and the matched controls in social care costs and in hospital costs.

The findings reinforce the outputs of the regression modelling in Chapter 5, that people who have a carer have higher costs across all settings of care compared

to those without a carer. However, they show the difference between people who have a carer and people who do not to be greater.

6.4.2 Comparison with the literature

There are conflicting perspectives in the literature with regards to whether having a carer increases or reduces an individual's health and social care service utilisation. There is extensive literature on the different methods to cost the contribution of informal carers (177). This assumes that carers provide an element of care substitution with the presence of a carer replacing the need for paid care(160). The findings, that people without carers have lower costs across all settings, suggest that if there is care substitution from having a carer, those without not only do not have the care provided by the informal carer but they also have lower use of other services, potentially widening health inequalities.

There are several possible explanations in the literature for the increased costs observed for the cared for cohort. Firstly, a caregiver acting as an advocate for a patient can increase utilisation of some types of care, for instance by facilitating visits to the emergency department of a hospital or helping to overcome denial that more care is needed (178). Some studies have found interdependent and potentially conflicting patient and caregiver preferences with regards to service access, with carers more likely to proactively seek help when the care recipient would have not, or to preference longer active treatment than their care recipient (179, 180). In addition, the Newcastle 85+ study found that individuals reported that they had high health and functional ability despite significant levels of disease and impairment (20). Individuals without a carer may have reduced access to services and this may explain the increased emergency department attendances for those with a carer, where someone else may have shown

concern about the care recipient's symptoms and prompted the care recipient to seek help when they may not have done so themselves.

People with a carer may have different levels of care need that cannot be identified by the covariates used in the matching process. In particular, it may be that without an informal carer the people with a carer would be in a care home, which could mean that the people with a carer have a higher acuity of need than the matched controls. The extent of the covariates included in the analysis make this possibility unlikely.

Having a carer has been shown to improve the quality of life for the care recipient (181) and, as such, people with a carer are likely to have a higher quality of life than those without. It may be that higher access to services and having an advocate contributes to that quality of life. As such, the increased service use observed for the cared for cohort would need to be assessed in the context of the wider health and wellbeing outcomes that having a carer provides. There is little evidence on the impact having a carer has on the health outcomes of the care recipient.

With regards to mental health, the increase in cost was not significant for people with a carer. This may reflect the different nature of mental health service provision, it may be that the carers of people with acute mental health needs are not registered in the primary care records or it may be reflective of the ongoing impact the existence of stigma of mental illnesses has in determining the health-seeking behaviour of the care recipient (182) and their carer.

6.4.3 Strengths and limitations

A strength of the study was the breadth of services included (five settings of care), in particular community services, mental health and social care. This

allowed us to have a broader picture of the impact of carers on health and social care costs compared to previous studies.

By considering both exact matching and nearest neighbour matching we have sought to minimise any systematic differences in observed confounders between individuals exposed and unexposed to carers. In addition, unlike regression modelling, these matching approaches make weaker parametric assumptions, and are expected to provide more robust estimates about the effect of carers on health and social care costs.

There are several limitations to note. Firstly, the analysis identified people who had carers from primary care records. This is likely to underestimate the number of people with carers, as the true prevalence is expected to be ~10% in B&D but less than 1% were identified in the dataset: 8.7% of the adult population reported being informal carers in the 2011 census (101) and the borough reported that 1 in 10 of the adult population were informal carers in April 2019 (102). One of the reasons for the low levels of carers identified through primary care is the uncertainty around the definition of the term “carer”. There is extensive literature confirming that many carers do not identify themselves as a carer and are protective of their relationships with the person they care for, seeing caring as part of their role as a spouse, parent or child and not wanting to formalise or label the care they provide (183-186). The number of people with carers is lower than we would expect it to be, creating a risk that the unexposed cases may contain people who have carers but the carer has not been formally registered with primary care, therefore misrepresenting them as controls. In addition, those who had been identified as having a carer may have a higher level of need such that having a carer is another marker of increased acuity. As such, there may be people who have a carer but have not been identified to have a carer in our dataset who have lower levels of service use. If this is the case, the research

findings may over-estimate the effect of having a carer on service use as it may be higher levels of need rather than the presence of a carer that are associated with the increased service use. Whilst the matching process included variables that attempt to control for the need/health status of individuals with carers they might not fully capture the full care needs. If need is not fully captured by the included covariates in the model, the carer variable may act as a proxy for need. Further investigation with more detailed information on individual care needs and the nature of care given by the carer would be necessary to investigate this further.

It was not possible to confirm whether or not the recording of having a carer was missing at random and as such the extent to which it could introduce selection bias. Related to this, the sub-sample of people with a carer that are captured in the primary care records might be systematically different from unpaid carers in the general population, for example with regards to the care they provide or the nature of their needs. Given the carer variable was entered in primary care records, practice level variation could have been beneficial. This would have identified whether specific primary care practices have a higher reporting rate than others regardless of the population characteristics. Including the general practice the individual is registered with in the matching process is one way of adjusting for potential practice variations in reporting. The role of the carer and the nature of the caring activities can vary widely. The literature indicates several dimensions of the role of the carer and the nature of the caring activities that are important markers of variation; these include the prime reasons the care recipient required carer support, the different roles carers provide, the number of hours the carer provides support, the length of time the individual had had a carer, whether the carer lived with the care recipient and the characteristics of the carer (age, gender, education and employment status). The “Personal Social

Services Survey of Adult Carers” confirmed that each of these dimensions can vary greatly for carers in the UK (187). The dataset we used did not have access to documentation of these dimensions so it could not be adjusted for these dimensions.

Information on other forms of voluntary services or on services individuals may have paid for privately was not available; this would have been particularly important for the control group: their reduced service use could have been due to receiving other forms of care not accounted for in the dataset. However, the deprivation profile and low average earnings of households in B&D suggest that the proportion of people able to self-fund their care is likely to be low(188).

Further limitations include lack of longitudinal analysis, which could have provided a greater understanding of whether the differences in service utilisation between people with a carer and those without changed over time and the sequencing of service use. Conducting a regression model for the carer indicator would have provided greater clarity on the pattern of the variable across population groups.

Furthermore, while we have not identified any major factors that could be an important predictor of health and social care costs that have not been measured, there may still be unobserved confounding.

6.4.4 Implications

In the UK, much of the discourse on the role of informal carers rests on the economic assumption that informal carers are a substitute for formal care, with an hour of their time being directly comparable to an hour of a paid carer. As such, policy priorities are to identify carers, provide them with information, and support them to continue their care giving role by addressing their own health and wellbeing needs. With a growing ageing population, it is anticipated that the

need for informal care will continue to grow and supporting individuals to continue to be informal carers will reduce the burden on the care system. The findings of this project challenge some of these assumptions as individuals with carers were found to have higher health and social care costs than those without. This raises questions on the relationship between informal carers and the formal care system. The project did not attempt to conduct a full impact assessment of informal carers but rather to understand the impact having a carer has on an individual's health and social care utilisation. The increased costs across all settings of care suggest that informal carers do not provide care substitution of the tasks and activities completed by the health and social care system or, at least, that additional service use induced by the carer may dominate any substitution effect. If there was care substitution, we may have expected to see reduced service use in social care, and potentially community care settings, for people with a carer where some of the tasks can be completed by an unskilled workforce. The informal carers may be filling unmet needs, such as coordinating care, advocating for the care recipient, providing emotional and social support, all of which may have a positive impact on the quality of life of the person being cared for.

There is an opportunity to reflect on the relationship between informal carers and the formal care system and identify interventions that could support more care substitution. This may include providing bespoke training and education and seeing informal carers as an extension of the care workforce. Over the past couple of decades, patient education for self-care has become a core function of the NHS, recognising that an individual spends more time caring for themselves than interacting with health and care professionals. The same logic may be applied to informal carers, that they spend more time with the care recipient than health and care professionals; however, carer education is largely delivered by

the voluntary sector and as yet has not become an explicit role of the NHS, despite the potential for impact.

Health inequalities are a growing challenge for all societies and are of global concern, although the magnitude of the problem varies across countries.

Reducing health inequalities means giving everyone the same opportunities to lead a healthy life. Action has focused on those at greatest risk of poor health and given focus to social determinants of health. The findings of this work suggest people without carers may be experiencing inequitable access to services. This should be investigated further.

6.5 Conclusion

This research has shone important new light onto the health and social care utilisation levels of people with carers. It suggests that such support may be a key element in enabling individuals to access services and, as such, there may be wider inequalities in access to services for people without a carer. In a society that is ageing with projections suggesting that there will be more people without carers in the future, these inequalities need to be addressed.

Further research would be beneficial to understand the differences in costs in more depth; in particular, reviewing different categorisations of the people who have a carer, including the scale and nature of care received and investigating longitudinal patterns. Including regression modelling of the carer variable and analysis of practice level variation could also enhance future research work. It would be beneficial to have access to health and wellbeing outcomes from the people who are cared for, their carers and control groups to understand the wider impacts of having a carer on an individual's health and wellbeing. This would facilitate a fuller assessment of the net impact of informal care.

7 Conclusion

7.1 Summary of the thesis

This research programme aimed to create a novel individual level data resource to explore the use of health and social care services in multiple settings, to evaluate the factors associated with this use and to evaluate the extent to which these factors vary by setting of care for residents of B&D in 2016/17.

There were four research objectives:

1. To understand the perspectives and experiences of health and social care leaders of working across organisation, setting and sector boundaries
2. To compare the distribution of service use across five different settings of care for the adult population and review the combinations of service use where individuals use more than one setting of care
3. To identify the variables associated with health and social care utilisation in each setting of care to understand if there are specific population groups that would benefit most from cross-setting collaboration
4. To understand if people with a carer have different levels of service use across the five settings of care when compared to those who do not have a carer but have similar characteristics

These objectives were addressed by firstly conducting interviews with leaders in B&D and nationally to understand the perspectives and experiences of health and social care leaders of working across organisational, setting and sector boundaries. The outputs were consistent with the examples outlined in the

introduction with regards to observed tensions between organisation level and system level actions when there is a risk of destabilising financial or operational performance for an individual organisation. There were four main findings. Firstly, there are fundamental differences in levels of autonomy and operational priorities between councils and the NHS. Secondly, existing financial mechanisms can be used to overcome sectoral boundaries but require strong leadership to implement them. Thirdly, there are challenges associated with primary care participating in integration, including the reluctance of small organisations to adopt the risk associated with large-scale programmes. Fourthly, short-term crisis management continues to dominate the agenda, making it difficult to make longer-term investments such as those required to progress population health.

Next, I created a bespoke dataset by linking data spanning five settings of care (primary, hospital, community, mental health and social care) with information from the B&D council on wider social determinants of health. This data resource was used to compare the distribution of service use across the five different settings of care for the adult population of B&D between 1st April 2016 and 31st March 2017. I found that, firstly, there is a significant proportion of total cost (47%) that is incurred outside hospital and primary care services. Secondly, the inclusion of cost data for all five settings of care can provide a more holistic view of individual service use than viewing costs for any one setting in isolation. Thirdly, while mental health service use accounts for 11% of all costs, having mental health service use significantly increased mean cost per patient. This supports the need to have information on the system-wide impact of different actions, as outlined in the stroke example in Section 1.3.1. For example, the new model of care for dementia diagnosis and treatment includes integration of primary care (GP visits) and mental health settings (memory clinics), with the aim

to reduce the number of GP visits and reduce avoidable hospital admissions. A whole system perspective allows investigation of the impact on utilisation across different settings of care.

This PhD then sought to identify the variables associated with health and social care utilisation in each setting of care using. To achieve this, I have used a two-part model that allowed for adjusting for the probability of being a service user (identified by having a positive service cost – first part) and adjusting for the level of health and social care utilisation (measured as cost-weighted utilisation – second part). Different factors were associated with the probability of having a cost and the level of cost for different settings of care. Consistent with the literature, I found ageing to be associated with increased odds of having a cost and higher total mean cost. The presence of a long-term condition is also a strong predictor of service use and the total mean cost. In addition, both Employment Support Allowance (ESA) and living alone increased the odds of having a cost and were associated with higher adjusted mean cost. These findings were mostly consistent across each individual care setting, with two exceptions: i) the pattern of mental health service use was not associated with age, and ii) the association between the different long-term conditions and mean health care costs differed slightly according to setting of care. Findings were not restricted to health variables and confirmed the potential role for other sectors in reducing need for health and social care, as outlined in the HiAP described in Section 1.3.3. Being in a household in receipt of benefits (particularly ESA), the occupancy of the household (particularly living alone) and the tenure of the household were all associated with different levels of service use and total costs.

I then used a subset of the B&D dataset (that included the subgroup of individuals who were registered with a carer) to do a matched analysis to understand if people with a carer had different levels of service use across the

five settings of care when compared to those who did not have a carer but had similar characteristics. I found that health and social care costs were £2,662 (27%) higher for people registered in their primary care records to have a carer compared to those who were not registered as having a carer. Social care was the largest contributor to this difference (39%). Cost patterns differed by setting, with the widest differences between the people with carers and the matched controls in social care costs and in hospital costs. The increased cost associated with having a carer across all settings of care suggests that the informal carer does not appear to act as a substitute for the tasks and activities completed by the health and social care systems. If there is any care substitution, the additional service use induced by the carer appears to dominate any substitution effect.

Beyond the findings of each of the components of research, this thesis advances the current literature by providing a more complete assessment of service utilisation, incorporating activity data from five settings of care, than research to date in which hospital and primary care settings dominate. The findings with regards to informal carers are of note, particularly given the policy and system assumption that informal carers are care substitutes to formal care.

7.2 Contributions of the thesis

The research activities of the thesis described above have made several contributions to research.

The interviews have added to the literature on integrated care. Outputs of the research described in chapter 2 were published in a peer reviewed journal. Some of the themes reinforced what is known from the literature, including the tension between the operational and governance boundaries between the NHS

and social care, and the long lead-time required to make an impact on population health. There were new findings regarding the role of financial payment structures and incentives. These were not felt to be barriers in the way that the literature currently describes. Secondly, the perspectives of primary care, and the tensions associated with participating in system wide reform when running small businesses, has not been present in the integrated care literature to date.

The dataset created was novel. Linked data at the individual level in the UK, aside from discrete populations participating in bespoke research programmes, has been dominated by primary and hospital care. National surveys are also used, but these pertain to a sample of the population rather than full coverage. The novelty of the dataset developed for this thesis mainly lied in the number of settings and data sources included, spanning five settings of care and council information. It included the full population of the borough. In addition, the inclusion of the unique property reference number allowed for people to be grouped into households with confidence. To date researchers using electronic health records predominately use information from the primary care record based on the patient's address. The costing methodology for mental health and community services is unique, owing to the use of patient level costing in the providers budget management systems and the relationships with the organisation allowing us to access that internal cost data. The potential of the dataset is extensive and other research projects are underway to build on the research of this thesis. There has been significant interest from national policy makers regarding how the dataset was created and the linking process, with presentation and discussion at multiple forums to disseminate the findings and the learning experience with others.

Using five settings of care has widened understanding of health and social care service utilisation. Research to date has been dominated by primary and

hospital care data and utilisation with less analysis of utilisation of other settings of care. The analysis in chapter 4 confirmed that there is a significant proportion of total cost (47%) that is incurred outside of hospital and primary care services. It provides the rationale for future research into population service use to include wider settings of care given the proportion of service use that sits outside of hospital and primary care.

Chapter 5 used advanced econometric techniques, such as generalised linear modelling and two-part models, to assess the determinants of health and social care utilisation. The outputs shed light on which factors have the largest impact on both the probability of being a service user and the level of health and social care utilisation, across the different settings of care. The inclusion of variables linked to social context and socio-economic determinants of health provided a wider perspective on service utilisation. In particular, the research in this thesis found that having a carer, being in receipt of benefits and living alone are associated with higher health and social care costs.

Having an informal carer increased care utilisation across all settings of care. The economic calculations for the contribution of informal carers assumes each hour of informal care is a direct substitute for formal care. The research in this thesis found that having a carer increased health and social care utilisation across all settings of care. It suggests that such support may be a key element in enabling individuals to access services and, as such, there may be wider inequalities in access to services for people without a carer. Contrary to current understanding, this suggests that informal and formal care are likely to be complements, not substitutes. In a society that is ageing with projections suggesting that there will be more people without carers in the future, these inequalities need to be addressed. In addition, the methodology for the economic calculations may need to be revisited.

7.3 Implications

7.3.1 Implications for policy

7.3.1.1 Integrated care

With the continued ambitions for health and social care integration (76), progress will require acknowledging the fundamental financial and operational differences between how the NHS and councils operate as described in Chapter 2. To achieve progress on population health, policies need to reflect the role all organisations can play in implementing change, as has been highlighted by the HiAP framework (Local Government Association, 2016), and find mechanisms to balance short-term operational priorities with longer-term outcomes.

The analysis in Chapter 4 confirmed that only a very small proportion (<1%) of our study population used all five settings of care. In addition, interviewees' responses indicated that strong leadership with the confidence to make decisions is required to make progress on integrated care, rather than structural integration, even when the decisions have a negative impact on their own organisation. These two findings suggest that the current policy in the NHS in England to implement ICSs that cover the whole population and move towards more formal structural integration may not be necessary. Rather, more targeted work bespoke to those groups of the population who use all or multiple services may be both more appropriate and more impactful.

7.3.1.2 Primary care

Recognising the operational reality of primary care may facilitate progress towards better integration of care. In Chapter 2, the findings highlighted the tension associated with running a small business and participating in wider system reform, with the former making daily operational work the forefront of

decision making. Chapter 4 further reinforced this, with 49% of the care contacts in primary care being with individuals who did not go on to use any other settings of care in that year. The two-part model in Chapter 5 showed that patients with dementia and mental health concerns had the highest mean costs in primary care, which is reflected in current policy to move towards Primary Care Networks, with patients with mental health concerns as a specific sub-cohort of the population for whom care should be better organised. The Primary Care Networks are population-wide. The analysis run in this thesis may help to create more targeted population groups for whom care can be better organised. The tension of primary care as both a small business delivering a service for its registered patients, which is met through that interaction, and its wider role as a gatekeeper to the wider system of care remains. Primary Care Networks continue to place emphasis on the role as a connector to the wider system but do not necessarily acknowledge the volume of care that GP practices provide in the former role.

7.3.1.3 Mental health

Mental health service users were shown to be younger with fewer long-term conditions than users of other settings of care (Chapters 4 and 5). Integration policy has been dominated by frail elderly populations, those with long-term conditions and, increasingly, those with more than two long-term conditions (multi-morbidity). However, given the lower average age, lower morbidity levels and the high mean costs for mental health service users, age and morbidity levels may not be the main drivers of cost in all settings of care. A whole population approach is likely to overlook the mental health cohort given their small proportion of total activity and total costs at a system-wide level. In addition, those with dementia and learning difficulties were high users of services across multiple settings but were not dominant users of hospital care.

7.3.1.4 Informal carers

This research has shone important new light onto the health and social care utilisation levels of people with informal carers. It suggests that such support may be a key element in enabling individuals to access services and, as such, there may be wider inequalities in access to services for people without a carer. In a society that is ageing with projections suggesting that there will be more people without carers in the future, these inequalities need to be addressed. There are two specific areas in which policy makers could respond to these findings. Firstly, there is an opportunity to reflect on the relationship between informal carers and the formal care system and identify interventions that could support more care substitution. This may include providing bespoke training and education and seeing informal carers as an extension of the care workforce. This is similar to the rise in investment in patient education, which recognises that individuals spend more time caring for themselves than interacting with health and care professionals. There is potential for impact if the NHS takes more ownership of informal carer training. Secondly, the findings of this work suggest that people without carers may be experiencing inequitable access to services. This should be investigated further.

7.3.1.5 Linked datasets

There is great potential for large, linked databases to provide a deeper level of understanding of the different service use patterns across settings of care to build a more complete understanding of population profiles and population-wide health and care service utilisation. However, progress to link datasets across settings of care is slow, and data linkage with other sectors which contain much of the information on social determinants of health is notoriously challenging.

The data resource created in this research programme demonstrated that it is possible to link several different datasets together at an individual level, to

maintain high sample numbers, and to include a wide range of variables that can enhance our understanding of health and social care utilisation. Often data linkage is subsumed in the wider ambitions to create live electronic health records across settings of care. However, given the frequency of data collection in many of the council departments and the process required to ensure accurate linkage with health records, more static data resources can still be informative. Datasets such as the one used in this research may form a critical resource for population health management (often used interchangeably with population health intelligence), a requirement of all ICSs from April 2021. With both local commissioning and local delivery of services differing across the country, coupled with the strong leadership support required to overcome information governance challenges, creating these data resources may best be done on a local level. The mental health and community service data included in the analysis were much more extensive than those which are accessed on a national level (given the slow development of Payment by Results); strong relationships across providers, commissioners and public health can help to ensure access to appropriate data.

7.3.2 Implications for research

7.3.2.1 Integrated care

Progress towards integrated care has been slow and formal evidence of its impact remains undeveloped. Financial incentives, in particular conflicting payment mechanisms, have often been sighted as a key barrier to integration. The findings of the interviews described in Chapter 2 provide another layer of understanding of the facilitators of and barriers to collaborating across settings of care. Financial mechanisms did not appear to have the same dominance for the interview cohort as they do in the literature, and strength of leadership remains a

key facilitator. The role of structural integration was also questionable. Future research into integrated care may benefit from these contrasting perspectives.

Frail elderly populations and those with long-term conditions have been a focus of integrated care research to date. Most interventions aim to reduce hospital utilisation, particularly emergency department attendances and non-elective admission rates. The dominance of hospital and primary care settings in research to date has largely been driven by availability and quality of data. Less is known about service use in other settings aside from bespoke analysis for discrete population groups. Going forwards, this research highlights the need to review wider service use, particularly given the finding that a significant proportion of care is delivered outside hospital and primary care services. The data resource developed provides a practical example of data sources that could be used to understand service utilisation in other settings of care in future research work.

7.3.2.2 Cost-weighted utilisation

Analysis of cost-weighted utilisation is an established methodology in health economics research. This thesis provides a detailed description of the methodology used to calculate cost-weighted utilisation in each of the five settings of care. The methodologies used in mental health, community and social care may be of particular interest to the wider research community. These will be used by future studies conducting research within the dataset. In addition, the mean costs presented for each variable for each setting of care may be of use when developing research proposals or conducting feasibility studies, when primary data collection is not possible.

7.3.2.3 Carers

The assumption that informal carers act as substitutes for formal care underlies much of the discourse on informal carers in the NHS in England. However, there is less consistency within research literature, which remains inconclusive. The breadth of services included in the analysis in Chapter 6, with the five settings of care, provides a broader picture of the impact of informal carers on health and social care service use compared to previous studies. In particular, the inclusion of community and social care services, where substitution may be more likely to occur. This could guide future research to consider development of new methods of quantifying the impact of informal carers on the health system.

7.3.2.4 Linked data

My research has demonstrated that linked data can enhance our understanding of service utilisation patterns. Data linkage is a powerful and established tool to improve the accuracy and completeness of patient information used for public health research purposes. This research provides others with an understanding of the practical challenges and decisions required when creating a bespoke dataset.

For others wanting to replicate the data linkage, there are several practical components to note. Firstly, understanding the data sources, how and where they will be linked together and for what purpose is important for building data flow diagrams and gaining system support for the data flows. In particular, the introduction of GDPR has increased the scrutiny required for what data linkage is appropriate from a public perspective and reduced the acceptability of unnecessary data flows or more data than is required. Developing clear data flow diagrams can help to overcome this and provide clarity. Including details of when personal identifiers are required and at what point de-identification occurs (if relevant) was particularly valuable in this work. Secondly, data definitions and

identifiers can vary across datasets. Whilst the use of the NHS number is widespread in health datasets, it was not used as the base identifier in the social care data or in other council datasets. As such matching techniques needed to be used, in this instance fuzzy logic matching, which reduced confidence and accuracy for linking data together and led to individuals being excluded from the sample as a result of not being able to match them with an NHS number. There is rapid progress being made on the inclusion of NHS numbers on social care datasets. However, including council data where identifiers are different will remain a challenge. To overcome this, there is growing guidance on different matching techniques that can be used, and triangulation of data sources can aid data quality and completeness checks. The overview of data quality, data cleaning and the handling of missing data provided in 3.5 will be relevant to other teams interested in linking health and social care datasets together.

The strongest lesson from the dataset creation was developing a detailed understanding of the readiness of B&D as a system to support the creation of the dataset as described in Section 3.2. This is particularly relevant for researchers wanting to create similar bespoke datasets. The system level buy-in, the level on data linkage work across departments within the council, and the availability of the data storage environment were all assets for the work. This final domain, data storage, is important to note for researchers. Remote access to the source data, removing the need for data transfers into the university data environment, simplified approvals processes and made data quality checks quicker with NHS staff able to access queries and update the dataset as required quickly. A final lesson was the value of data triangulation. In future work with the dataset, adjustments have been made to increase the robustness of data quality checks. For example, the concerns with ethnicity coding as described in section 3.5.1 were in part exacerbated by the design decision to use the primary care record

information as the base source. In future, adding parallel information from other sources, for example the council records of ethnicity, is being included in the dataset design to facilitate more comprehensive data quality assessment and enable different teams to make their own decisions on cohort composition and data design as appropriate for the research work in question.

7.4 Strengths and limitations

Across the components of research presented in this thesis, there are several strengths to highlight. The breadth of services included was novel, with the five settings of care, in particular community services, mental health and social care, which are often omitted from existing studies. There are few studies that have access to linked individual level data across health and care utilisation and social factors; hence, the richness of the information included in our analysis is an important strength of the study. The inclusion of both individual measures and household characteristics, and area-level measures is particularly unique.

There are several limitations to note. Firstly, the work was from one geographic area in England. The interview research included interviews with national leaders to understand if perspectives were specific to the case study site or more generally present across England. However, for the quantitative research no comparator analysis was conducted. Although the cohort was large, it is a very deprived population, with no individuals in the two least deprived national quintiles. This may impact generalisability of findings nationally and internationally, particularly given known associations between deprivation and increased prevalence of illness and multi-morbidity in deprived populations(155) and increased service use(125).

The quantitative work used cross-sectional analysis with variables and utilisation data that are drawn from a single year (2016-2017). Longitudinal patterns were not evaluated. This would have provided more clarity on whether the impact of the factors explored in this research change over time. This is a core opportunity for further research as described in section 7.3.2.

The cohort design decisions included the exclusion of children, people that left the borough in-year and those that died in-year. This was done due to the known differences in service use for children and at the end of life, and for those that left the borough in-year because they had less than 12 months activity so mean annual costs would be skewed. However, these design decisions present potential limitations with regards to the results of the analysis in chapters 4, 5 and 6. The design decisions may introduce selection bias into the results. For children, the drivers of health service activity are different and therefore new and different analysis would have been required that was beyond the scope of this research project. With regards to the exclusion of people that died within the year, the potential bias is due to proximity to death which is positively correlated with costs and has been shown to be a stronger driver of costs than age.

Excluding those that died can under-estimate the association of specific conditions with service use, where the prevalence of that condition is associated with high costs at the end of life. For those that moved out in-year, no analysis was completed on the characteristics of those individuals such that we do not know if they differed systematically from those that were included in the cohort, again risking selection bias. The inclusion criteria was developed to allow investigation of economic and socio-demographic drivers of service use. Given the distinct and different drivers of service use for the excluded populations, inclusion could have distorted the explained variability with, for example, proximity of death overriding other factors for people in the last year of life.

Causal inference was beyond the scope of the research conducted in this thesis. As with all cross-sectional observational studies, the associations observed can be used to generate hypotheses but cannot demonstrate causality nor explain any observed associations. The analysis allowed for investigation of the associations between different user characteristics and resultant health and social care utilisation, rather than assessing cause and effect. Furthermore, while we have not identified any major factors that could be an important predictor of health and social care costs that have not been measured in the dataset, there may still be unobserved confounding.

By defining multi-morbidity as a simple count of long-term conditions, our analysis weighted all diseases equally, although the effect of multi-morbidity on individuals can vary with combination and severity of conditions. The definitions of multi-morbidity vary widely and there are increasingly refined lists of conditions that people are using in their research of multi-morbidity. As such, the selection of the 16 conditions may not be a comprehensive picture of diseases that influence service use patterns. In addition, it limits the capacity for comparison with other studies.

7.5 Further research

This thesis raises several avenues for further research. Firstly, it is important to note that the engagement of senior leaders across the system in both the analysis conducted to date and the future potential of the data resource resulted in agreement to update the dataset on an annual basis. There are ambitions to launch the dataset to a wider research community and to extend its use across analysts within the health and social care system. The information governance approvals are now in place to do so. Research grants have been submitted to

secure additional funding, both for ongoing management and curation of the dataset and for additional research activities.

7.5.1 Excluded population groups

The descriptive analysis in Chapter 4 and the two-part model in Chapter 5 could be repeated for the excluded populations, namely those in the last year of life and children. They were excluded from this research project because their patterns of service use were known to differ from the patterns of service use of adults not in the last year of life. However, the dataset can be used to enhance understanding for these cohorts also. For example, we know that a large proportion of hospital use is concentrated in peoples' final year of life, as deteriorating health in this period often leads to acute hospital admissions; however, far less is known about care use in other settings.

7.5.2 Longitudinal patterns

The data resource described in Chapter 3 has access to six years of data for some components of the dataset, and a minimum of two years for the full dataset. With the commitment to update the data resource, this will increase to four years for the full dataset by June 2020. Conducting longitudinal analysis to review changes in patterns of service use over time would further enhance the research findings.

7.5.3 Multi-morbidity

Over the time horizon of this research programme, there has been a rise in research activity with multi-morbid populations. However, definitions and measures of multi-morbidity continue to evolve. Given the inclusion of date of diagnosis in the dataset, there is an opportunity to analyse:

- Differences in service use according to how long the individual has been diagnosed as having the condition. This could change the pattern of

service use, as, for example, service use during the diagnostic pathway and first year of living with a condition can differ from service use during subsequent disease management. For example, for heart failure, NICE guidelines require hospital consultants to confirm the diagnosis and agree the disease management plan, but the ongoing management is predominantly based in primary care (189).

- Sequencing of diseases to understand common patterns of development from one disease to having multiple conditions and the different combinations of these conditions. This could also include different weighting of diseases to better reflect differences between alternative combinations of conditions.
- Combined with the longitudinal analysis there is an opportunity to look at more detailed patient pathways and sequencing of events to understand the impact of different exposures on resultant health and social care utilisation.

7.5.4 Household factors

The dataset includes several household level variables. There is capacity to conduct household level analysis, characterising households according to the inhabitants, for example children living with parents that have certain diagnosed conditions and understanding subsequent service use.

7.6 Concluding remarks

It is commonly accepted that demand for health care always outstrips resources. In the UK's publicly funded health system, it is important to look at how and where costs are being incurred to maximise the use of limited resources. The move towards more integrated care has become a long-standing ambition of

health policy nationally and internationally as a means to achieving efficiency gains alongside improved patient experience and outcomes.

This thesis has challenged some of the policy assumptions behind integrated care, particularly whether structural integration is required and which population groups should be targeted. It has provided deeper understanding of service use by setting of care and developed particular insights into the patterns of service use for individuals with informal carers. Overall, it has demonstrated how linked data can be used to deliver new and actionable insights about the health system, service use and population health.

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9 Appendix 1. Scoping review search strategy

For each of the six databases, the following search terms were used:

("health care" OR "health service*") ADJ4 (use OR access OR utilis* OR utilis*).ti,ab

("social care" ADJ4 (use OR access OR utilis* OR utilis*).ti,ab

("mental health" ADJ (care OR service*)ADJ4 (admission* OR admit* OR use* OR access* OR utilis* OR utilis*).ti,ab

(psychiat* ADJ (care OR service*)) ADJ4 (admit* OR admission* OR use* OR access* OR utilis* OR utilis*).ti,ab

("community services" OR "community care") ADJ4 (use OR access* OR utilis* OR utilis*).ti,ab

(primary ADJ2 care) ADJ4 (use OR access* OR utilis* OR utilis* OR appointment*).ti,ab

("general practice" OR "GP") ADJ4 (use OR access* OR utilis* OR utilis* OR appointment*).ti,ab

("emergency service*" ADJ4 (use OR access OR utilis* OR utilis*).ti,ab

("accident and emergency" OR "A&E") ADJ4 (use OR access OR utilis* OR utilis*).ti,ab

("emergency department*" ADJ4 (use OR access OR utilis* OR utilis*).ti,ab

("emergency care" OR "urgent care") ADJ4 (use OR access OR utilis* OR utilis*).ti,ab

("emergency visit" OR "emergency attendance").ti,ab

("out-of-hours" ADJ4 (use OR access OR utilis* OR utiliz*)).ti,ab

("minor injur*" ADJ4 (use OR access OR utilis* OR utiliz*)).ti,ab

("hospital" ADJ4 (use OR access OR utilis* OR utiliz*)).ti,ab

(hospital ADJ4 (attendance* OR visit* OR outpatient* OR appointment*)).ti,ab

AND

(predictor* OR reason* OR factor* OR need*).ti,ab OR

("help-seeking" OR "health-seeking").ti,ab

AND

(UK OR "united kingdom" OR Britain OR England OR Scotland OR Ireland OR
Wales OR NHS OR "national health service").ti,ab

Results were limited to English Language, and 2004 onwards.

The following subject headings were also utilised in each database (which
slightly varied across databases):

exp "EMERGENCY SERVICE, HOSPITAL"/ exp "EMERGENCY MEDICAL
SERVICES"/

OR exp "PRIMARY HEALTH CARE"/

OR exp "COMMUNITY HEALTH SERVICES"/

OR exp "MENTAL HEALTH SERVICES"/

OR exp "HOME CARE SERVICES"/

AND exp "HEALTH SERVICES ACCESSIBILITY"/ "HEALTH RESOURCE
UTILIZATION"/ "HEALTH CARE UTILIZATION"/

10 Appendix 2. Scoping review output

Table 10-1 Outputs of the scoping review: A summary of the studies eligible for inclusion in the review

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
<i>Browne, J., et al (2017)</i> (190)	A population-based retrospective cohort study to examine the association between comorbidities and service use in the UK Dementia population. Those diagnosed with Dementia (between March 2008 and February 2009) were followed up for 5 years. N=4,999	Clinical Practice Research Datalink (CPRD) linked to Hospital Episodes Statistics (HES) data	Age Gender	Socio-economic status (measured by Index of Multiple Deprivation)	Dementia Long-term conditions Multi-morbidity	Primary care: GP visits Number of prescriptions Hospital: Inpatient admission	Increasing age and socioeconomic deprivation were observed in those with higher numbers of co-morbidities. After adjusting for age and gender, those with high numbers of co-morbidities had a significantly higher utilisation rate across primary, hospital and prescriptions when compared to a reference group with fewer co-morbidities.	> Large cohort, but high rates of loss due to people changing GP practice and due to death > Missing data for hospital utilisation (40% unlinked records) > Data did not differentiate between elective and non-elective hospital utilisation

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
Vallejo-Torres, L; Morris, S (2013) (191)	Economic analysis of income-related inequity in cardiovascular disease (CVD) related healthcare utilisation. Population was those reporting a history of CVD living in England, 10,254 across the two years (2003, 2006).	Health Survey for England (HSE) 2003 and 2006	Age Gender Ethnicity Marital status Education	Household income	CVD diagnosis and disease specific metrics	Primary care: GP visits Number of prescriptions Hospital: Outpatient attendance Inpatient admission	Socio-economic inequity was found in healthcare utilisation for CVD, with poorer individuals having proportionately more GP visits but fewer hospital outpatient visits and fewer hospital inpatient admissions.	> Only those reporting CVD history were asked about health utilisation in the survey data, which may lead to underreporting > Utilisation was self-reported and binary. It did not distinguish between NHS and private service providers or between elective and non-elective attendances. This may mean the pro-rich inequity is underestimated

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
<i>Twomey, C.D., et al (2015) (43)</i>	Systematic review to identify variables that predict health service utilisation by adults with mental disorders in the UK. 28 studies were reviewed. The population were adults with a range of mental health conditions, all were UK-based.	Systematic Review	Age Gender Marital status Occupation	Housing Tenure Qualifications Family situation	Mental health diagnosis Co-morbidity Previous service use Activities of Daily Living	Primary care: GP contacts Number of prescribed medications Hospital: A&E attendances Inpatient admissions Outpatient visits Mental Health: Care contacts (Psychiatrist contacts, psychotherapy attendances)	A range of variables predict health service use across the studies. Co-morbidity, age, female, divorced/separated/widowed, non-white ethnicity, neurotic symptoms, personality disorder, high previous service use and activities of daily living were all associated with increased health service use.	> The quality of the studies was mixed > Wide variation in the predictors and the measures of utilisation used across studies, limiting scope for cross-study comparisons

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
<i>Kapadia, D., et al (2017)</i> (41)	Systematic review of the utilisation of primary and mental health services for Pakistani women with mental health diagnosis compared to other ethnic groups to clarify usage rates, including assessment of social networks and how they may influence mental health service use	Systematic Review	Ethnicity	--	Mental health diagnosis	Primary care: GP visits Mental Health: Outpatient services Inpatient admissions	Pakistani women were less likely than white women to use specialist mental health services. There was no difference in primary care use.	> Inconsistency in ethnicity coding which impacts data quality > Little literature on the subject, of the ten included in the report, different utilisation measures and research questions for each making cross-comparison challenging
<i>Tammes, P., et al (2017)</i> (45)	Longitudinal analysis of associations of general practice and practice population characteristics with emergency care service attendance rates in England 2009/10–2012/2013.	GP Patient Survey (GPPS), linked to publicly available datasets for practice level service use and deprivation	Age Gender Unemployed	Social deprivation (male life-expectancy)	--	Hospital: A&E Attendance	Population influences on higher attendance rates included more elderly, more female and more unemployed patients, and lower male life-expectancy and urban location.	> Linked survey and routine data, with variable response rates for the survey and potential sample bias (e.g., response rates increase with age)

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
Scantlebury, R., et al (2015) (192)	A cross-sectional population-based study to identify population and primary care characteristics associated with A&E attendance rates, for individuals registered with a GP practice in England 2011-2012	General Practice Patient Survey (GPPS) 2011-2012	--	Social deprivation (IMD index)	Long term conditions	Hospital: A&E attendance	Strongest predictor of A&E attendance rates was social deprivation (IMD index), followed by population morbidity	> Used survey data and population data clustered at GP practice level, which may mask variations within practices > The survey data excludes those not registered with a GP practice > Data on service utilisation was self-reported
O'Cathain, A., et al (2014) (44)	National ecological study to identify system-wide factors explaining variation in age and gender adjusted admission rates for avoidable admissions (defined as relating to one of 14 conditions) across 152 emergency and urgent care systems in England between 2008-2011	Hospital Episode Statistics (HES) data, 2008-2011	Age Gender Unemployed	Social deprivation (IMD index)	--	Hospital: A&E attendance	Factors outside of the health system explained variation in A&E use, particularly unemployment (explained 72% of the variation)	> Whole population analysis, rather than specific to adults Analysis restricted by data availability > Focus on avoidable admissions (defined as relating to one of 14 conditions) rather than all A&E attendances

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
<i>Keene, J., Rodriguez, J. (2007)</i> (47)	An examination of associations between mental health and A&E service use across populations with mental health and total population of A&E service users, using linked data for a 3-year period in one health authority in England, for individuals aged over 15.	Data from the health commissioner (N=625,964), linked to data from the mental health provider (N=18,899) and A&E data (N=66,973)	Age Gender		Long-term conditions Mental health diagnosis Contact with mental health services	Hospital: A&E attendance	Mental health patients were almost five times more likely to be A&E attendees than those who were not in contact with mental health services. There were differences between A&E patients with and without mental health conditions regarding age, gender and other health conditions	> Only includes those who utilised services which may underestimate associations > Does not confirm the data years for the three years of data used for the analysis
<i>Whittaker, W., et al (2016)</i> (46)	Difference in difference analysis of the impact of extended open hours for primary care on A&E attendance of patients registered with practices in Greater Manchester.	Hospital Episode Statistics (HES) data, 2011 to 2014	--	Access to out of hours primary care	--	Hospital: A&E attendance	In Greater Manchester, primary care practices that extended opening hours in 2014 demonstrated a 26.4% reduction in patient-initiated A&E attendances for minor problems	> There may be residual confounding Extending hours was not a standardised intervention across the different practices

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
<i>Huntley, A., et al (2014)</i> (193)	A systematic review to identify studies that describe features of primary care services that impact on levels of utilisation of unscheduled secondary healthcare across Organisation for Economic Co-operation and Development (OECD) countries	Systematic Review	Age Lower education attainment	Socio-economic status	Long-term conditions Multi-morbidity	Hospital: A&E attendance Non-elective admission	Patient factors associated with increased A&E attendance and increased non-elective admissions were increased age, reduced socioeconomic status, lower educational attainment, chronic disease and multimorbidity.	> Included results from OECD countries rather than UK specific, so cross comparison may be inappropriate given different health systems
<i>Dorning, H., et al (2016)</i> (48)	Analysis of hospital service use for people with mental health conditions. Population were adults aged 18 to 75 years with an indication of mental ill health in each year between 2009/10 and 2013/14.	Hospital Episode Statistics (HES) data, 2009/10, 2013/14		Social deprivation (IMD index)	Mental health diagnosis	Hospital: A&E attendances Non-Elective admissions	Service use across A&E and non-elective admissions was higher for people with mental health conditions than physical health conditions. Deprivation was associated with increased service use in all cohorts.	> Analysis was limited to hospital activity and did not adjust for different levels of service use in other settings (e.g. primary care or mental health services)

Reference	Study type and population	Data Source(s)	Predisposing	Enabling	Need	Health and care settings and measures of utilisation	Findings	Limitations
Wallace, E., et al (2014) (49)	Systematic review of validated risk prediction models for predicting emergency hospital admissions in community-dwelling adults. Included results from five countries (US, UK, Italy, Spain, Canada)	Systematic Review	Age Gender	--	Long term conditions Prior service use	Hospital: Non-elective hospital admission (at least one overnight)	Most used predictors of service use include increasing age, prior hospitalization, specified medical diagnoses, gender.	> International review, including 9 UK studies and 16 from other countries, so cross comparison may be inappropriate given different health systems > Assessment was of the risk prediction tools rather than predictors of service use, although these are interrelated
Martin, A., et al (2012) (194)	Analysis of Chronic Obstructive Pulmonary Disorder (COPD) patients in 140 GP practices	Primary care data from 140 general practices in east London	Age Gender Ethnicity	--	--	Hospital: Inpatient admissions (elective and non-elective)	COPD prevalence and severity differed by ethnicity. Black patients were more likely to be admitted to hospital for any cause, and for COPD-related admissions than white or South Asian groups.	> Service utilisation was only assessed for a third of the cohort due to data availability. > Population was limited to those diagnosed with COPD

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
<i>Fernández de la Cruz, L., et al (2015) (40)</i>	Analysis of the ethnic distribution of patients with Obsessive–compulsive disorder (OCD) seen between 1999 and 2013 in South London and the Maudsley (a secondary and tertiary mental health provider in London). Service use was compared with general population using census data.	Local Mental Health dataset linked to census data, 1999-2013	Ethnicity		Mental health diagnosis (OCD)	Mental Health: Inpatient admissions Care contacts	Individuals from ethnic minority groups used fewer mental health services than the white majority, despite OCD being as prevalent in those age groups.	> Mixed quality of ethnicity recording, and different categories used in the mental health provider and census data > Data from one provider in London, different ethnic groups could have chosen to go to other local providers (private or public)
<i>White, J., et al (2014) (195)</i>	Analysis of five years (2006–2010) of panel data to assess socio-economic equity of hospital care utilisation for patients with Serious Mental Illness (SMI) and how it has changed over time.	Hospital Episode Statistics (HES) data, 2006 to 2010	--	Social deprivation (IMD index)	Mental health diagnosis (SMI)	Mental Health: Inpatient admissions	Admission for SMI is shown to be pro-poor for all years - a one percentage point increase in area income deprivation is consistently associated with a 1.5% proportionate increase in SMI admissions ($p < 0.001$ in all models).	> Deprivation is measured at an area level which may not capture all individual level variation in deprivation > Lack of data means that analysis did not capture all the factors the literature suggests are potentially associated with SMI admissions

Reference	Study type and population	Data Source(s)	Predisposing	Enabling	Need	Health and care settings and measures of utilisation	Findings	Limitations
<i>Bhui, K., et al (2003)</i> (196)	A systematic review of all quantitative studies comparing use of mental health services by more than one ethnic group in the UK, to understand ethnic variations in service use.	Systematic Review	Age Gender Ethnicity	--	Long-term conditions Multi-morbidity	Mental Health: Inpatient admissions	Most studies compared service use between Black and White patients, finding higher rates of in-patient admission among Black patients.	> Measures of ethnicity were inconsistent across studies, as were measures of utilisation, making comparison challenging
<i>Bansal, N., et al (2014)</i> (197)	Retrospective cohort study, using linked data to examine ethnic variations in mental inpatient service use (psychiatric hospitalisations and compulsory treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003) in Scotland, 2001-2008.	2001 census data linked to health data (hospital day case and inpatient discharge data) in Scotland, 2001-2008	Age Gender Ethnicity	Car ownership Housing tenure	--	Mental Health: Inpatient admissions	There was wide variation in service use by ethnicity. Minority groups used fewer services despite similar prevalence.	> Small sample sizes for several ethnic groups, and mixed quality of ethnicity coding, making comparison challenging

Reference	Study type and population	Data Source(s)	<i>Predisposing</i>	<i>Enabling</i>	<i>Need</i>	Health and care settings and measures of utilisation	Findings	Limitations
<i>Bardsley, M., et al (2011)</i> (50)	Using linked data to predict which older people will begin receiving intensive social care in the next 12 months. Population where those over 75 registered with a GP in one of five areas in England.	Primary data collection from health commissioners and social care providers in four areas of England.	Age Gender Social isolation Access to an unpaid carer		Prior service use (health and/or social care) Visual or hearing impairment Activities of daily living/functional markers	Social care: Cost weighted service utilisation	Increasing age, being female and prior use of hospital and social care services were the strongest predictors of receiving intensive social care in the next 12 months.	> Data quality for social care was low > Wide range of variables were included in the models which could have led to over-fitting
<i>Stoddart, H., et al (2002)</i> (42)	Analysis of survey responses to identify determinants of home care service use (statutory and private) by older people living in the community. Population were a random sample of 2000 over 65-year olds registered with 11 GP practices in Bristol in 1997.	Primary data collection via a survey in 1997	Age Education Marital status Social networks	Car ownership	Declining health	Social care: Home care	Increasing age, not owning a car and being a widow were associated with greater use of both statutory and private home care services, as was worse self-reported overall health. Worse physical functioning, worse emotional health, problems with cognition, foot problems and a greater number of falls were determinants of use of statutory and private services.	> The populations of the 11 practices were more affluent than the national average, with lower morbidity > Data collection was in 1997 so very dated > 21% non-responders who were older and less healthy, so may underestimate associations with high service use

11 Appendix 3. Ethics approval letter

**UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES**



22 March 2016

Dr Simon Turner
Department of Applied Health Research
UCL

Dear Dr Turner

Notification of Ethical Approval

Project ID: 6981/001: The economics of multi-sectoral working. How do financial incentives help or hinder organisations to work together to create a financially stable health and social care system?

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that I have approved your study for the duration of the project i.e. until 21st March 2017.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': <http://ethics.grad.ucl.ac.uk/responsibilities.php>
2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator (ethics@ucl.ac.uk) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

On completion of the research you must submit a brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely



Chair of the UCL Research Ethics Committee

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University College London
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12 Appendix 4. Participant information sheet

DEPARTMENT OF APPLIED HEALTH RESEARCH

1-19 Torrington Place
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WC1E 7HB



Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: The Economics of Multi-Sectoral working: How do financial incentives help or hinder organisations to work together to create a financially stable health and social care system?

This study has been approved by the UCL Research Ethics Committee (Project ID Number): **6981/001**

Chief Investigator Dr Simon Turner

Lead Researcher Jenny Shand

Work Address Department of Applied Health Research, 1-19 Torrington Place,
University College London, London ,WC1E 7HB

Contact Details [REDACTED]

We would like to invite you to participate in this research project.

Details of Study

With a projected funding deficit for the NHS in England of £22bn by 2020, health and social care systems are under increasing pressure to contain costs whilst not compromising quality. Following The London Proposition, there is support to conduct a devolution pilot in Barking and Dagenham, Havering and Redbridge (BHR) to develop an Accountable Care Organisation (ACO).

A defining feature of an ACO is that providers are collectively held accountable for achieving pre-defined outcomes within a given budget for their patient population over a period of time. For BHR key features of the proposal include:

- Whole population coverage, 750,000 residents across the three boroughs
- Devolved budget of £1.2bn combining health budgets with adult social care and public health across the three boroughs
- Ambition to achieve improvements in population health outcomes alongside efficiency gains
- Facilitate changes to service delivery and system wide investment to find new ways of collectively meeting a forecast £430m gap by 2018/19
- Increased focus on health promotion, prevention and community based interventions to reduce reliance on acute care

This is an exploratory study that will involve semi-structured interviews with key leaders and decision makers across health and social care organisations in BHR, and national leaders and academic experts, to understand:

- Experiences of working across organisational and sector boundaries for the benefit of the population, including enablers and barriers encountered
- Perspectives on the role system wide financial incentives play in facilitating or hindering working across organisational and sector boundaries
- Aspirations for the ACO, what it is hoped to achieve and how, and potential limitations
- Perspectives on the role financial incentives may play in the development and implementation of the ACO

The findings of the project will inform further research into financial incentives that promote organisations to work together across health and social care with

the aim of achieving cost efficiency gains without compromising quality. It will also contribute to the current literature on the planning and implementation of ACOs in England.

This information sheet aims to help you understand why the research is being done and what taking part would involve for you. We hope it will help you decide whether or not you would like to take part.

1. Why have I been invited to take part?

To understand how existing financial mechanisms influence decision making it is important that we obtain views from a range of people from a wide range of organisations. This includes representatives of social care provision, healthcare provision, local authorities, commissioning organisations, and national bodies such as NHS England, the Department of Health, and, NHS Improvement, as well as academic leaders. We would value the opportunity to hear about your perspectives and learn what you think about the existing financial mechanisms, the incentives they promote in the system, and how the development of an ACO might present alternatives.

2. What does taking part involve?

You will be asked to participate in a one-to-one interview that will last up to 1 hour. We would like to interview you at some point in the next few weeks. The interviews will take place at a time and place that suits you. If required, your travel expenses will be covered. In the interview, the researcher will ask about your perspectives on experiences of working across organisational and sector boundaries and the aspirations of the BHR ACO. We may write notes on what you say during the discussion. We will also audio record the discussion. This recording will be anonymised, then professionally transcribed for analysis. We may ask you to participate in a follow up interview at a later date.

If you are willing to participate, you will be given this information sheet in advance and asked to sign a consent form before the interview commences.

3. Do I have to take part?

No, it is up to you to decide whether or not to take part. Whatever you decide, you will not be disadvantaged in any way.

4. Is what I say confidential?

We will not inform anyone outside the research team that you have participated in this research.

All data will be collected and stored in accordance with the Data Protection Act 1998. Your personal information (for example your name) will never be attached to any information you provide (for example interview transcripts). All information from the study will be stored securely and will only be accessed by members of the research team. Your personal data will be destroyed within a year of the study's completion. We will not identify you by name in any reports.

5. What if I change my mind?

It is up to you to decide whether to take part or not. Choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason. If you withdraw, we will hold onto the information you provided before withdrawing.

6. What are the risks of taking part?

Helping us with this study will take up a little of your time, but we will do our best to minimise any inconvenience to you by arranging to meet at a time and place that suits you. Some people may feel uncomfortable discussing their views on the financial position of their organisation, or system behaviours that exist

between organisations. If you become uncomfortable during an interview, the researcher conducting the interview will ask you whether you would like to stop. You will be reminded that you can stop the interview at any time, and without giving a reason for doing so. If you have concerns or questions, we encourage you to contact the study team at any time.

7. What are the benefits of taking part?

The findings from our research will be shared with all interview participants. In addition, they will be shared with national government and NHS leaders to inform how best to proceed with implementing reforms to the financial system at a national level. The research will also provide useful information to other organisations proposing to pilot devolution and / or set up Accountable Care Organisations.

8. What will happen to the results of the research study?

At the end of the study, we will produce a full report which will be shared with all interviewees and published on UCLPartners website. We will submit an article summarising our findings to scientific journals and present them at national and international meetings and conferences as relevant.

9. What happens if something goes wrong?

University College London (UCL), as the research governance sponsor of this project, has systems in place to investigate complaints and to deal with irregular or inappropriate research conduct. If you wish to complain, please contact the Chief Investigator for the study, Dr Simon Turner, whose details are given below. The Chief Investigator is under an obligation to forward all complaints to UCL's Joint Research Office, whose staff will process the complaint and liaise with you.

Address: [REDACTED]
[REDACTED]

Email: [REDACTED]

10. Where can I find out more about the research?

If you wish, please discuss the information above with others, such as colleagues. Alternatively, please ask us if there is anything that is not clear or if you would like more information. Contact details are given below.

[REDACTED]

[REDACTED]

[REDACTED]

February 2016

13 Appendix 5. Participant consent form

DEPARTMENT OF APPLIED HEALTH RESEARCH
1-19 Torrington Place
University College London
London
WC1E 7HB



Informed Consent Form for participants in Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: The Economics of Multi-Sectoral working: How do financial incentives help or hinder organisations to work together to create a financially stable health and social care system?

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 6891/001

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I _____

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- consent to the processing of my personal information for the purposes of this research study.
- understand that my participation will be taped and I consent to use of this material as part of the project.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- understand that the information I have submitted will be published as a report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.
- agree to be contacted in the future by UCL researchers who would like to invite me to participate in follow-up studies.

Signed:

Date:

14 Appendix 6. Interview topic guide

Project Title: The Economics of Multi-Sectoral working: How do financial incentives help or hinder organisations to work together to create a financially stable health and social care system?

Topic Guide, February 2016

Background

- How would you describe your organisation?
- What role does it play in the broader health and social care system?
- What is your role within it?
- How would you describe your organisations financial performance at present?
- How would you describe the financial performance of the local health economy?

Multi-sectoral working

1. Experiences of working across organisational and sector boundaries for the benefit of the population, including enablers and barriers encountered

- What has been your experience of working across organisational and sector boundaries - including health and social care integration?
- Can you give an example from the last 5 years of when integration has worked well? What defined success for you? What were the enablers and barriers encountered?
- Can you give an example from the last 5 years of when integration has been less successful? Can you explain why? What were the enablers and barriers encountered?
- How do you balance organisation priorities with system wide priorities?
- Can you provide examples when the two have been in conflict? Was it resolved? If so how?

2. Perspectives on the role system wide financial incentives play in facilitating or hindering working across organisational and sector boundaries

- In its current form, providers and commissioners of health and social care have separate budgets and payment systems for different services – Is this your experience? If so how does this influence joint working?
- What influence do the existing financial arrangements have on the decisions you make for your organisation? How do these decisions align or conflict with system wide perspectives?
- There are emerging financial models to promote integration – including ‘year of care’ approaches, pathway payments and pooled budgets – what has been your experience of local pilots of these approaches?

Accountable Care Organisation – Intervention

3. Aspirations for the Accountable Care Organisation (ACO), what it is hoped to achieve and how

A defining feature of an ACO is that providers are collectively held accountable for achieving pre-defined outcomes within a given budget for their patient population over a period of time.

For BHR key features of the proposal include:

- Whole population coverage, 750,000 residents across the three boroughs
 - Devolved budget of £1.2bn combining health budgets with adult social care and public health across the three boroughs
 - Ambition to achieve improvements in population health outcomes alongside efficiency gains
 - Facilitate changes to service delivery and system wide investment to find new ways of collectively meeting a forecast £430m gap by 2018/19
 - Increased focus on health promotion, prevention and community based interventions to reduce reliance on acute care
- What are your aspirations for the BHR ACO?
 - What do you hope it will achieve?
 - What will need to be in place to deliver that ambition?
 - What are the main risks to delivery?

4. Perspectives on the role financial incentives may play in the development and implementation of the ACO

- Do you believe the ACO will deliver financial sustainability for the system? If so how? Is an ACO uniquely placed to achieve this relative to other organisational forms or models of care delivery?
 - In the BHR application to be an ACO it stated “*core obstacles to dealing with the challenges faced by the region are the conflicting responsibilities, priorities and funding of the individual bodies currently involved*” – can you expand on your perspective on those obstacles?
 - The literature describes the interdependency of productivity across health and social care organisations, for example:
 - Inappropriate social care can lead to hospital admission
 - Hospital care that reduces impairment may reduce social care costs
- Which financial incentives do you believe need to be in place to account for this interdependency? How should they be linked to quality and outcomes?
- What three things will have the biggest influence, financial or otherwise, on your decision making as an organisation?

Accountable Care Organisation - Implementation

- What needs to happen to facilitate implementation of the ACO? What are the key enablers that need to be in place? What are the key barriers and risks to implementation?
- What three things will have the biggest influence, financial or otherwise, on your organisations participation in the ACO?

Do you have any other comments or reflections you would like to share?

15 Appendix 7. Results table of proportion of total cost and proportion of total population for total costs and for each setting of care.

Table 15-1 Total costs: For each combination of service use, proportion of total costs and proportion of total population

Combination of costs	TOTAL COSTS					
	n	%	mean	SD	total cost	% cost
MH	32	0	5,307	10,430	169,824	0
GP	47,932	42	171	232	8,192,791	5
SC	22	0	12,477	10,012	274,503	0
CH	77	0	690	1,479	53,127	0
HC	1,831	2	516	1,053	944,419	1
MH + GP	990	1	5,036	14,298	4,985,158	3
MH + SC	5	0	20,608	9,491	103,039	0
MH + CH	1	0	328	.	328	0
MH + HC	18	0	4,681	7,873	84,261	0
GP + SC	220	0	15,721	18,558	3,458,728	2
GP + CH	2,520	2	1,966	4,871	4,955,303	3
GP + HC	34,333	30	1,419	1,892	48,724,844	27
SC + CH	1	0	24,067	.	24,067	0
SC + HC	4	0	17,203	6,452	68,813	0
CH + HC	43	0	1,341	1,840	57,669	0
MH + GP + SC	112	0	28,493	26,422	3,191,168	2
MH + GP + CH	141	0	15,602	27,432	2,199,875	1
MH + GP + HC	1,354	1	6,522	14,396	8,830,792	5
MH + SC + CH		0			-	0
MH + SC + HC	1	0	19,975	.	19,975	0
MH + CH + HC	2	0	2,666	1,541	5,333	0
GP + SC + CH	119	0	23,825	15,958	2,835,179	2
GP + SC + HC	332	0	15,185	15,363	5,041,387	3
GP + CH + HC	7,321	6	5,276	8,470	38,628,986	21
SC + CH + HC	3	0	12,326	10,557	36,977	0
MH + GP + SC + CH	35	0	42,656	35,666	1,492,968	1
MH + GP + SC + HC	107	0	30,645	25,844	3,279,022	2
MH + GP + CH + HC	572	1	16,078	22,901	9,196,828	5
MH + SC + CH + HC	1	0	7,267	.	7,267	0
GP + SC + CH + HC	799	1	27,202	24,107	21,734,286	12
MH + GP + SC + CH + HC	295	0	39,181	29,436	11,558,348	6
None	15170	13	-	-	-	0
TOTAL	114,393				180,155,264	

Table 15-2 Hospital: For the population that used hospital services, for each combination of service use the proportion of total hospital costs and the proportion of the population that used hospital services

Combination of costs	HOSPITAL					
	n	%	Mean £	SD	Total cost £	% cost
MH	-	-	-	-	-	-
GP	-	-	-	-	-	-
SC	-	-	-	-	-	-
CH	-	-	-	-	-	-
HC	1,831	4	516	1,053	944,419	1
MH + GP	-	-	-	-	-	-
MH + SC	-	-	-	-	-	-
MH + CH	-	-	-	-	-	-
MH + HC	18	0	861	1,881	15,492	0
GP + SC	-	-	-	-	-	-
GP + CH	-	-	-	-	-	-
GP + HC	34,333	73	1,067	1,777	36,617,174	58
SC + CH	-	-	-	-	-	-
SC + HC	4	0	238	122	951	0
CH + HC	43	0	1,078	1,828	46,353	0
MH + GP + SC	-	-	-	-	-	-
MH + GP + CH	-	-	-	-	-	-
MH + GP + HC	1,354	3	1,294	2,617	1,751,779	3
MH + SC + CH	-	-	-	-	-	-
MH + SC + HC	1	0	78	.	78	0
MH + CH + HC	2	0	444	533	888	0
GP + SC + CH	-	-	-	-	-	-
GP + SC + HC	332	1	2,751	4,325	913,167	1
GP + CH + HC	7,321	16	2,140	3,366	15,666,354	25
SC + CH + HC	3	0	5,469	457	16,408	0
MH + GP + SC + CH	-	-	-	-	-	-
MH + GP + SC + HC	107	0	1,456	2,675	155,825	0
MH + GP + CH + HC	572	1	2,666	4,056	1,525,043	2
MH + SC + CH + HC	1	0	4,437	.	4,437	0
GP + SC + CH + HC	799	2	5,392	5,810	4,308,038	7
MH + GP + SC + CH + HC	295	1	5,634	6,705	1,662,079	3
None	-	-	-	-	-	-
TOTAL	47,016				63,628,486	

Table 15-3 Primary care: For the population that used primary care services, for each combination of service use the proportion of total primary care costs and the proportion of the population that used primary care services

Combination of costs	PRIMARY CARE					
	n	%	Mean £	SD	Total cost £	% cost
MH	-	-	-	-	-	-
GP	47,932	49	171	232	8,192,791	25
SC	-	-	-	-	-	-
CH	-	-	-	-	-	-
HC	-	-	-	-	-	-
MH + GP	990	1	472	621	467,452	1
MH + SC	-	-	-	-	-	-
MH + CH	-	-	-	-	-	-
MH + HC	-	-	-	-	-	-
GP + SC	220	0	841	1,067	185,023	1
GP + CH	2,520	3	414	473	1,042,999	3
GP + HC	34,333	35	353	431		37
					12,107,653	
SC + CH	-	-	-	-	-	-
SC + HC	-	-	-	-	-	-
CH + HC	-	-	-	-	-	-
MH + GP + SC	112	0	822	1,051	92,104	0
MH + GP + CH	141	0	1,108	1,216	156,267	0
MH + GP + HC	1,354	1	726	940	983,484	3
MH + SC + CH	-	-	-	-	-	-
MH + SC + HC	-	-	-	-	-	-
MH + CH + HC	-	-	-	-	-	-
GP + SC + CH	119	0	1,491	1,358	177,465	1
GP + SC + HC	332	0	1,386	1,404	460,026	1
GP + CH + HC	7,321	8	765	905	5,603,594	17
SC + CH + HC	-	-	-	-	-	-
MH + GP + SC + CH	35	0	1,397	1,287	48,881	0
MH + GP + SC + HC	107	0	1,357	1,311	145,250	0
MH + GP + CH + HC	572	1	1,472	1,571	841,867	3
MH + SC + CH + HC	-	-	-	-	-	-
GP + SC + CH + HC	799	1	1,812	1,508	1,448,060	4
MH + GP + SC + CH + HC	295	0	2,283	1,826	673,355	2
None	-	-	-	-	-	-
TOTAL	97,182	100			32,626,271	100

Table 15-4 Community care: For the population that used community care services, for each combination of service use the proportion of total community care costs and the proportion of the population that used community care services

Combination of costs	COMMUNITY CARE					
	n	%	Mean £	SD	total cost £	% cost
MH	-	-	-	-	-	-
GP	-	-	-	-	-	-
SC	-	-	-	-	-	-
CH	77	1	690	1,479	53,127	0
HC	-	-	-	-	-	-
MH + GP	-	-	-	-	-	-
MH + SC	-	-	-	-	-	-
MH + CH	1	0	66	.	66	0
MH + HC	-	-	-	-	-	-
GP + SC	-	-	-	-	-	-
GP + CH	2,520	21	1,553	4,768	3,912,305	9
GP + HC	-	-	-	-	-	-
SC + CH	1	0	472	.	472	0
SC + HC	-	-	-	-	-	-
CH + HC	43	0	263	227	11,316	0
MH + GP + SC	-	-	-	-	-	-
MH + GP + CH	141	1	8,570	19,044	1,208,426	3
MH + GP + HC	-	-	-	-	-	-
MH + SC + CH	-	-	-	-	-	-
MH + SC + HC	-	-	-	-	-	-
MH + CH + HC	2	0	539	552	1,077	0
GP + SC + CH	119	1	8,238	14,087	980,273	2
GP + SC + HC	-	-	-	-	-	-
GP + CH + HC	7,321	61	2,371	6,999	17,359,043	41
SC + CH + HC	3	0	6,237	10,341	18,712	0
MH + GP + SC + CH	35	0	12,503	22,185	437,619	1
MH + GP + SC + HC	-	-	-	-	-	-
MH + GP + CH + HC	572	5	6,383	14,090	3,651,284	9
MH + SC + CH + HC	1	0	333	.	333	0
GP + SC + CH + HC	799	7	12,969	20,747	10,362,519	24
MH + GP + SC + CH + HC	295	2	15,361	20,414	4,531,622	11
None	-	-	-	-	-	-
TOTAL	11,930	100			42,528,193	100

Table 15-5 Mental health: For the population that used mental health services, for each combination of service use the proportion of total mental health costs and the proportion of the population that used mental health services

Combination of costs	MENTAL HEALTH					
	n	%	Mean £	SD	total cost £	% cost
MH	32	1	5,307	10,430	169,824	1
GP	-	-	-	-	-	-
SC	-	-	-	-	-	-
CH	-	-	-	-	-	-
HC	-	-	-	-	-	-
MH + GP	990	27	4,563	14,166	4,517,706	23
MH + SC	5	0	4,530	2,264	22,650	0
MH + CH	1	0	262	.	262	0
MH + HC	18	0	3,821	7,989	68,769	0
GP + SC	-	-	-	-	-	-
GP + CH	-	-	-	-	-	-
GP + HC	-	-	-	-	-	-
SC + CH	-	-	-	-	-	-
SC + HC	-	-	-	-	-	-
CH + HC	-	-	-	-	-	-
MH + GP + SC	112	3	8,502	21,251	952,218	5
MH + GP + CH	141	4	5,923	15,915	835,181	4
MH + GP + HC	1,354	37	4,502	14,119	6,095,529	31
MH + SC + CH	-	-	-	-	-	-
MH + SC + HC	1	0	505	.	505	0
MH + CH + HC	2	0	1,684	1,522	3,367	0
GP + SC + CH	-	-	-	-	-	-
GP + SC + HC	-	-	-	-	-	-
GP + CH + HC	-	-	-	-	-	-
SC + CH + HC	-	-	-	-	-	-
MH + GP + SC + CH	35	1	11,007	28,710	385,229	2
MH + GP + SC + HC	107	3	10,468	17,767	1,120,051	6
MH + GP + CH + HC	572	16	5,557	16,205	3,178,636	16
MH + SC + CH + HC	1	0	2,093	.	2,093	0
GP + SC + CH + HC	-	-	-	-	-	-
MH + GP + SC + CH + HC	295	8	6,840	18,208	2,017,940	10
None	-	-	-	-	-	-
TOTAL	3,666	100			19,369,962	100

Table 15-6 Social care: For the population that used social care services, for each combination of service use the proportion of total social care costs and the proportion of the population that used social care services

Combination of costs	SOCIAL CARE					
	n	%	Mean £	SD	Total cost £	% cost
MH	-	-	-	-	-	-
GP	-	-	-	-	-	-
SC	22	1	12,477	10,012	274,503	1
CH	-	-	-	-	-	-
HC	-	-	-	-	-	-
MH + GP	-	-	-	-	-	-
MH + SC	5	0	16,078	10,681	80,389	0
MH + CH	-	-	-	-	-	-
MH + HC	-	-	-	-	-	-
GP + SC	220	11	14,880	18,626	3,273,703	15
GP + CH	-	0	-	-	-	0
GP + HC	-	0	-	-	-	0
SC + CH	1	0	23,595	.	23,595	0
SC + HC	4	0	16,966	6,430	67,862	0
CH + HC	-	0	-	-	-	0
MH + GP + SC	112	5	19,168	17,774	2,146,846	10
MH + GP + CH	-	-	-	-	-	-
MH + GP + HC	-	-	-	-	-	-
MH + SC + CH	-	-	-	-	-	-
MH + SC + HC	1	0	19,392	.	19,392	0
MH + CH + HC	-	-	-	-	-	-
GP + SC + CH	119	6	14,096	9,785	1,677,439	8
GP + SC + HC	332	16	11,049	15,217	3,668,195	17
GP + CH + HC	-	-	-	-	-	-
SC + CH + HC	3	0	619	340	1,858	0
MH + GP + SC + CH	35	2	17,750	19,433	621,238	3
MH + GP + SC + HC	107	5	17,364	21,713	1,857,897	8
MH + GP + CH + HC	-	-	-	-	-	-
MH + SC + CH + HC	1	0	403	.	403	0
GP + SC + CH + HC	799	39	7,028	8,156	5,615,670	26
MH + GP + SC + CH + HC	295	14	9,062	10,646	2,673,351	12
None	-	-	-	-	-	-
TOTAL	2,056	100			22,002,342	100

16 Appendix 8. Two-part model outputs for total costs for complete cases only

Table 16-1 Two-part model outputs for total costs for complete cases only

N=95,109		PART 1 - Logit			PART 2 - GLM			Two-Part			prob>chi2=
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		
Socio-demographic characteristics											
Age	19-49							1,278	1,203	1,353	0.00
	50-64	1.3	1.3	1.4	0.2	0.1	0.2	1,507	1,416	1,597	
	65-74	2.4	2.1	2.8	0.5	0.4	0.5	2,090	1,922	2,259	
	75-85	3.3	2.5	4.3	0.9	0.8	1.0	3,143	2,834	3,451	
	85+	3.4	2.2	5.3	1.3	1.1	1.4	4,815	4,156	5,475	
Gender	Female							2,183	2,046	2,319	0.00
	Male	0.4	0.4	0.4	-0.3	-0.4	-0.3	1,528	1,430	1,625	
Ethnic group	White							1,651	1,515	1,786	0.00
	Black or Black British	1.1	1.0	1.1	0.1	-0.0	0.1	1,764	1,626	1,903	
	Mixed	1.2	1.1	1.2	0.1	0.1	0.2	1,940	1,825	2,054	
	Other	0.9	0.8	1.1	-0.1	-0.2	0.1	1,519	1,283	1,754	
	Asian or Asian British	1.1	1.0	1.2	0.1	0.0	0.2	1,903	1,751	2,056	
Carer	None							1,771	1,672	1,869	0.00
	Has carer	1.4	0.8	2.4	0.5	0.3	0.7	3,075	2,484	3,665	
	Is a carer	2.9	1.9	4.6	0.1	-0.1	0.3	2,050	1,595	2,505	
	Is and has carer				-0.3	-0.9	0.3				
BMI category	Healthy							1,763	1,645	1,881	0.00
	Underweight	1.2	1.1	1.4	0.2	0.0	0.3	2,078	1,791	2,365	
	Overweight	1.0	1.0	1.1	0.0	-0.0	0.1	1,812	1,694	1,931	

N=95,109		PART 1 - Logit			PART 2 - GLM			Two-Part			prob>chi2=
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		
	Obese	1.1	1.0	1.2	0.1	0.0	0.1	1,960	1,829	2,091	
	Morbidly obese	1.3	1.2	1.5	0.3	0.2	0.4	2,350	2,096	2,604	
Smoking category	Non-smoker							1,842	1,728	1,956	0.00
	Ex-smoker	1.1	1.0	1.2	0.1	0.0	0.1	2,025	1,878	2,172	
	Smoker	1.0	0.9	1.0	-0.0	-0.1	0.0	1,830	1,699	1,962	
LTCs	0-1							2,858	2,341	3,374	0.0003
	2	0.9	0.9	1.0	-0.1	-0.2	0.0	2,666	2,321	3,012	
	3	0.7	0.6	0.8	-0.3	-0.5	-0.2	1,924	1,676	2,172	
	4	0.5	0.4	0.6	-0.8	-1.0	-0.5	1,063	874	1,253	
	5+	0.3	0.2	0.4	-1.2	-1.6	-0.9	545	410	681	
Conditions	AF = 0							1,781	1,684	1,879	0.00
	AF = 1	10.1	4.1	25.0	0.6	0.5	0.8	3,490	2,869	4,112	
	Asthma = 0							1,794	1,688	1,900	
	Asthma = 1	2.2	2.0	2.4	0.3	0.3	0.4	2,550	2,324	2,776	
	Cancer = 0							1,762	1,664	1,861	
	Cancer = 1	5.0	3.5	7.1	0.7	0.6	0.8	3,633	3,166	4,101	
	CHD = 0							1,723	1,628	1,818	
	CHD = 1	5.0	3.3	7.5	0.6	0.5	0.8	3,413	2,981	3,845	
	COPD = 0							1,731	1,634	1,827	
	COPD = 1	8.0	4.9	13.0	0.7	0.6	0.9	3,733	3,238	4,228	
	Dementia = 0							1,722	1,640	1,804	
	Dementia = 1	4.3	1.3	14.0	1.5	1.2	1.7	7,762	5,658	9,866	
	Depression = 0							1,748	1,646	1,850	
	Depression = 1	2.2	1.9	2.5	0.5	0.4	0.6	2,897	2,626	3,169	
	Diabetes = 0							1,619	1,528	1,709	

N=95,109		PART 1 - Logit			PART 2 - GLM			Two-Part			prob>chi2=
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		
Diabetes = 1		11.5	8.8	15.0	0.7	0.6	0.8	3,316	3,013	3,618	
Epilepsy = 0								1,844	1,737	1,950	0.00
Epilepsy = 1		2.9	2.1	3.9	0.5	0.4	0.7	3,240	2,654	3,826	
Heart failure = 0								1,788	1,692	1,885	0.00
Heart failure = 1		12.3	3.0	51.5	0.8	0.6	1.1	4,274	3,270	5,279	
Hypertension = 0								1,638	1,535	1,740	0.00
Hypertension = 1		5.6	4.9	6.4	0.3	0.2	0.4	2,319	2,157	2,481	
Hypothyroidism = 0								1,840	1,733	1,948	0.00
Hypothyroidism = 1		5.7	4.2	7.7	0.2	0.1	0.3	2,392	2,121	2,662	
Mental health = 0								1,691	1,605	1,777	0.00
Mental health = 1		9.3	5.3	16.3	1.6	1.4	1.8	8,980	7,330	10,629	
Palliative care = 0								1,814	1,719	1,908	0.00
Palliative care = 1		3.9	0.9	16.4	1.3	0.9	1.7	6,963	4,173	9,754	
Stroke = 0								1,741	1,649	1,833	0.00
Stroke = 1		7.3	3.7	14.5	0.9	0.8	1.1	4,583	3,814	5,352	
Learning difficulty = 0								1,750	1,651	1,849	0.00
Learning difficulty = 1		3.8	2.2	6.5	2.2	2.0	2.5	16,779	12,131	21,428	
Household variables											
Benefits	None							1,585	1,487	1,683	0.00
	ESA	1.7	1.5	1.9	0.7	0.6	0.8	3,281	2,945	3,617	
	Pension	1.1	1.0	1.3	0.3	0.2	0.4	2,135	1,921	2,349	
	Income Support	1.3	1.1	1.5	0.4	0.3	0.5	2,440	2,122	2,757	
	Job Seeker's Allowance	1.4	1.2	1.7	0.1	-0.1	0.3	1,774	1,479	2,069	
	Standard	1.3	1.2	1.4	0.2	0.1	0.2	1,910	1,764	2,057	
Tenure	Owner occupied							1,780	1,667	1,893	0.00

N=95,109		PART 1 - Logit			PART 2 - GLM			Two-Part			prob>chi2=
		Odds Ratio	95% CI		Coefficient	95% CI		Margins, £	95% CI		
	PR	0.8	0.8	0.9	0.0	-0.1	0.1	1,789	1,654	1,925	0.00
	Social	1.0	1.0	1.1	0.1	0.1	0.2	2,038	1,901	2,174	
	Reside	1.3	1.0	1.6	0.3	0.1	0.6	2,533	1,863	3,203	
Occupancy	2 to 4	0.9	0.8	1.0				1,806	1,696	1,916	0.00
	1	0.9	0.9	1.0	0.2	0.1	0.3	2,178	2,017	2,339	
	5 to 7	0.9	0.8	1.0	-0.1	-0.2	-0.0	1,631	1,511	1,751	
	8 to10	0.7	0.6	0.9	-0.1	-0.2	0.0	1,675	1,459	1,892	
	11+	1.7	1.5	1.9	-0.1	-0.3	0.2	1,636	1,228	2,044	
B&D IMD quintile	1							1,780	1,650	1,910	0.00
	2	1.0	1.0	1.1	0.1	-0.0	0.1	1,880	1,745	2,015	
	3	1.0	0.9	1.1	0.1	-0.0	0.1	1,903	1,765	2,040	
	4	0.9	0.8	1.0	0.1	-0.0	0.1	1,897	1,762	2,032	
	5	0.90	0.84	0.96	0.09	0.02	0.16	1,942	1,803	2,082	
	cons	1.44	1.36	1.52	6.27	6.18	6.35				