

# From one to many

Exploring people's progression to multiple long-term conditions in an urban environment



### About Guy's and St Thomas' Charity

We're an independent, place-based foundation. We work with Guy's and St Thomas' NHS Foundation Trust and others to improve the health of people in the London boroughs of Lambeth and Southwark.

#### We're about:

**Place.** We work in Lambeth and Southwark, supporting new approaches to health and sharing insights and learning with anyone facing similar challenges.

**Focus.** Our programmatic approach focuses on a few complex health issues at a time. Currently we're aiming to reduce childhood obesity and improve health for people with multiple long-term conditions.

**Connecting.** We bring great minds together, within and outside the NHS, to come at problems from different angles. And we collaborate, partnering with anyone – here and in other cities – to find, develop and deliver the best possible approaches to better health.

**Vision.** Great ideas sometimes need the space and resource to reach their potential – so we take a long-term view with a very open mind.

**Impact.** We're led by evidence and focussed on outcomes – always testing, evaluating, learning and adapting for greater results. By combining our resources with others, we create the kind of fire-power that achieves meaningful change now and for future generations.

## Foreword

At some point in our lives most of us will develop a long-term health condition. Many of us will develop more than one. But how we each get to that point varies hugely – both in when we develop our first condition, and how quickly we progress from one to many. This variestican data post least to be reacted by Dether, it seems

This variation does not look to be random. Rather, it seems to track issues of deprivation, culture, lifestyle and place.

As a foundation we focus on big health challenges that affect inner-city areas. Multiple long-term conditions are key amongst these. As a result, we're in the early stages of a ten-year programme to address the issue with our local communities.

This research, the first of its kind, looks in detail at the progression to complexity for people with long-term health conditions. It combines analysis of local health data alongside people's experiences of the issue. We hope it contributes a helpful perspective to an important national debate, as well as act as an invitation to partners looking to tackle the same challenges.

#### The report's findings suggest three key insights, and many more questions, all of which require further exploration.

The first insight is that this is not just a problem of old age. For example, in our boroughs over a third of people with multiple long-term conditions are middle aged or younger. The average age of diagnosis for some mental health conditions is when people are in their thirties.

The second is that a single disease focus may miss the combined impact on the person. On the one hand it can mask prevalence. For example, while just over 5% of our local population have diabetes, over 60% of people with multiple long-term conditions do. On the other, it can underplay the cumulative impact of multiple conditions on people's quality of life, their family, relationships, finances and ability to work.

#### Our belief is that it's in all this variation that opportunity exists. If we can better understand what sits behind it, then we can each do more to address it.

And it's urgent that we do. The burden of multiple long-term conditions carries great cost, both for individuals and for the state. It also requires quite profound shifts for how we both think about and coordinate services around health.

In short, if our goal is to delay the progression from one condition to many, there's no time to lose.

#### **Kieron Boyle**

Chief Executive Guy's and St Thomas' Charity



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## Introduction

Over 15 million people in the UK live with one long-term health condition and around three million have three or more.<sup>1</sup> It is a complex and growing phenomenon which has a significant impact on people, their carers and communities. It also places huge pressure on our health and care systems.

Although they are most common in people over the age of 65, the presence of three or more conditions is becoming increasingly prevalent in people under 65.<sup>2</sup> However, despite the scale of the problem, little is currently known about the journey from one condition to multiple, and the contributory interplay of the risk factors and context fuelling it.

As a place-based health foundation, we focus on the major health issues affecting people living in urban, diverse and deprived areas. When we look at multiple long-term conditions, we believe that these factors are combining to impact on people's ability to keep healthy for longer. We want to understand better what contributes to developing multiple long-term conditions, what solutions can help us slow down progression and, as a result, improve people's quality of life.

Working in partnership with King's College London and Lambeth and Southwark public health teams, we have explored multiple long-term conditions in our communities in detail. This has involved both looking at the data on prevalence and distribution, as well as talking to residents for whom life with several conditions is a daily reality.

The objectives of this work were to:

- Map the prevalence and distribution of a portfolio of long-term conditions, risk factors and multiple long-term conditions
- Improve our understanding of the issue in our communities to inform how and where we might work
- Understand more about progression from single to multiple conditions and transition from risk factors through to disease
- Better understand the lived experience of the issue
- Contribute to the body of evidence around multiple long-term conditions with a deep-dive exploration within a contained geography

We see Lambeth and Southwark as good examples of the complex dynamics of inner-city areas. By sharing what we learn here we can provide insights for those working on the issue in other places and nationally. Our aim is to use this work as a starting point for a wider conversation around multiple long-term conditions, the implications for people and systems, and potential opportunities for intervention.

# About multiple long-term conditions

Long-term conditions are health conditions for which there is currently no cure, but which can be managed with drugs and other treatments.<sup>3</sup> A long-term medical condition is one that has lasted, or is expected to last, longer than three months. As appropriate disease management can improve the quality of life for people with these conditions, early detection, diagnosis and treatment is important. For the purpose of this paper, we define multiple long-term conditions as the presence of three or more long-term medical conditions that may be related to physical and / or mental health – e.g. chronic kidney disease, diabetes or depression.

Multiple long-term conditions is a complex issue which affects many people nationally and locally.

The impact on the individual is often significant. Repeated appointments and medications take a toll on both physical and mental health. The ability to work and progress professionally is constrained by long periods of absence or disability; affecting self-esteem, finances and housing. Meanwhile, family ties and friendships can be transformed dramatically, particularly if the individual takes on caring duties and feels unsupported.

There is also huge pressure on the health system, with 70% of national NHS budgets spent on 30% of the population who have at least one long-term condition. Research shows growing rates of single and multiple long-term conditions are being seen nationally and now account for around 50% of all GP appointments, 64% of all outpatient appointments, over 56% of hospital admissions and 79% of all prescriptions. Furthermore, almost 70% of all health and social care budgets are now directed towards treating people with long-term conditions.<sup>4</sup>

Our healthcare systems were designed to deal with individual health conditions. The increasing prevalence of multiple long-term conditions is highlighting a need to consider a different approach that recognises the impact as far greater than the sum of individual conditions. Indeed, one such approach is being taken across the two boroughs of Lambeth and Southwark, where health and care partners have a shared ambition to provide more population-focussed, joined up and holistic health and social care in order to improve the health and wellbeing of local people.<sup>5</sup>

# The demographics in Lambeth and Southwark

With a combined population of around 600,000, the London boroughs of Lambeth and Southwark are two of the most densely populated boroughs in the country, with projections indicating 20% growth over the next eight years.<sup>6</sup>

- The population is young, with half of residents aged 35 years or under.
- It has a complex ethnic mix with just under 50% of people belonging to black, Asian and other ethnic groups and 52% born outside the UK.
- There are high levels of income inequality within the boroughs with notable pockets of high deprivation across both.
- Almost one in five local residents (140,000) lives with at least one long-term condition and over 19,000 live with three or more.<sup>7</sup>

#### Guy's and St Thomas' Charity multiple long-term conditions programme

In 2017, we started a ten-year programme of work focussed on tackling multiple long-term conditions. The aim of our programme is to work in partnership with Guy's and St Thomas' NHS Foundation Trust and others to improve the lives of people living with multiple long-term conditions in Lambeth and Southwark. We hope to draw out a deeper understanding of the issue in the context of areas that are urban, diverse and deprived. We do this by concentrating on:

- Slowing down the progression to multiple long-term conditions by identifying people at risk of developing multiple health conditions and intervening early.
- Improving quality of life by focusing on what matters to people living with multiple conditions and supporting approaches to care that are centred around the person.

We are particularly interested in the urban, diverse and deprived nature of the boroughs and how these local factors influence people's overall health and wellbeing, as well as their likelihood of developing individual and multiple long-term conditions.

As part of this work we've joined forces with The Richmond Group of Charities and the Royal College of General Practitioners (RCGP) on a ground-breaking new Taskforce on multiple long-term conditions. The Taskforce will lead a collaborative programme of activity to bring together experts from health, social care and inequalities with people living with multiple long-term conditions to learn more about the causes of, and potential solutions to, this complex issue.



## **Executive summary**

Over 15 million people in the UK live with one long-term health condition and around three million have three or more. By better understanding the diseases that people develop over time or people's progression to multiple health conditions, we may begin to understand some of the complexity, underlying issues and impact on quality of life. And by focusing on the lives of people with multiple long-term conditions rather than a set of individual conditions, we begin to understand more about how we might be able to intervene early to prevent progression from one to many long-term conditions.

### Key observations

#### This is not just a problem of old age

The common view of multiple long-term conditions is that it is just about older people. Whilst age is clearly a major factor, this narrative does not take into account where progression from single to multiple conditions begins, the role of risk factors, nor significant influences of ethnicity and gender and the complex interplay between them.

Whilst old age is a significant factor in predicting the likely prevalence of multiple long-term conditions, it is by no means the only factor. In Lambeth, around a third of people with multiple long-term conditions are diagnosed under the age of 65. People living in deprived areas are more likely to develop multiple long-term conditions on average 13 years earlier than people living in more affluent areas.<sup>8</sup> Our analysis also suggests that there may be a link between ethnicity and the risk of developing multiple long-term conditions. Our evidence has shown that members of the South Asian and black communities acquire them at a younger age than the white population.

### A single disease focus may miss the combined impact on the person

Rather than managing many sets of individual symptoms, our analysis shows common patterns in people's diagnosis of long-term conditions. Looking at the most frequent journeys to multiple health conditions can help us identify patterns of acquisition and how best to tackle these. For example, diabetes is the starting point for the majority of the most common journeys and chronic pain is a common feature in more than half of recorded journeys in Lambeth.

Our view is that multiple long-term conditions and the progression from one to many should be approached as a collective, specific and complex issue, requiring particular care, treatment and support.

#### The importance of social context

Like many urban areas, Lambeth and Southwark's dense environment, complex ethnic and social mix and high levels of income inequality provide important context to the health of residents.

A close review of Lambeth data suggests that a person's ethnicity may play a role as a driver of multiple long-term conditions. Both black and Asian ethnic groups are overrepresented in the total multiple long-term conditions patient group. The data indicate that, as well as developing multiple conditions on average 10 years earlier than white people, black people are doing so over a timespan that is 11.5 years shorter. This suggests that black people are more likely to live longer with complex health conditions, disproportionately impacting their lives.

Similarly, there are clear patterns of health inequalities linked to levels of deprivation in Lambeth. Data from people attending A&E in Lambeth show that people from the most deprived areas acquire multiple long-term conditions around five years earlier than those living in the least deprived areas by the time they're 50.<sup>9</sup>

Our data do not confirm whether ethnicity and deprivation are compounding factors that would predict even earlier diagnosis of initial or multiple long-term conditions.<sup>10</sup> However, they provide a signal, down to neighbourhood level, that a person's social context plays a role in their progression to multiple conditions.

#### Building on these insights

This research is just getting going and, by its nature, raises more questions than it gives answers. These questions may give helpful hints as to how we, and we hope others, can build on these insights, especially given the embryonic stage of research into multiple long-term conditions. We would like to work with others to explore some key points:

- How do we reframe the issue of multiple long-term conditions as a challenge distinct from a collection of individual diseases and something that affects people of all ages?
- How do we better understand progression to multiple long-term conditions by understanding the experience of individuals and utilising existing data?
- How do we work with communities that are disproportionately affected to identify opportunities to act – to slow down progression and improve the quality of lives for people living with multiple long-term conditions?



This is **not** just a problem of **old age** 

A common view of multiple long-term conditions is that it is just about older people. Whilst age is clearly a major factor, this narrative does not take into account where the 'journey' from single to multiple conditions begins, the role of risk factors nor the influence of ethnicity, deprivation and gender and the complex interplay between them.

### Age

Whilst age is a significant factor in predicting the likely prevalence of multiple long-term conditions, it is by no means the only factor. In Lambeth, around a third of people with multiple long-term conditions are diagnosed under the age of 65.

We have observed that people living in more deprived areas are more likely to develop multiple long-term conditions on average 13 years earlier than people living in the most affluent areas.

Evidence also suggests a link between ethnicity and both, an increased likelihood of developing multiple long-term conditions, and acquiring them at a younger age. We explore these two factors in more depth on pages 42 and 45.

### **Risk factors**

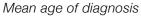
There are a number of commonly associated risk factors with multiple long-term conditions. When looking at these risk factors – such a smoking, high blood pressure or obesity – we see that whilst each individual risk factor increases the likelihood of specific long-term conditions, a combination of each raises the overall risk of acquiring multiple conditions.

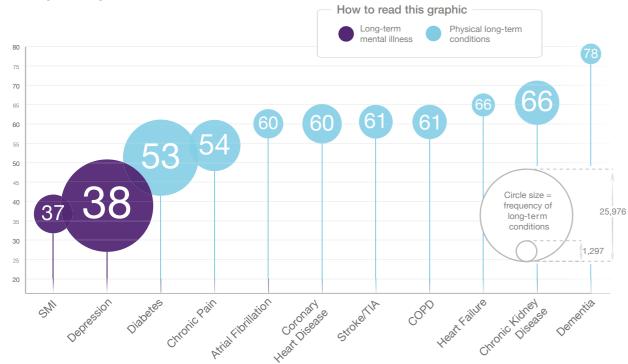
#### Gender

Rates of multiple long-term conditions in our population are higher among men below the age of 60. This changes above the age of 60, when women represent a higher proportion of the patient group. The data do not show detailed reasons for such gender discrepancy; meriting further investigation.

## This is not just a problem of old age

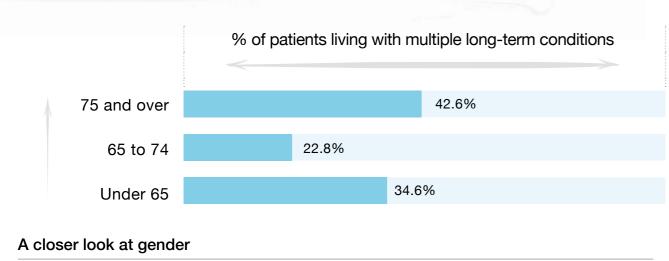
#### Long-term conditions do not only affect older people

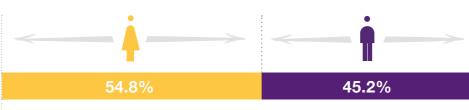




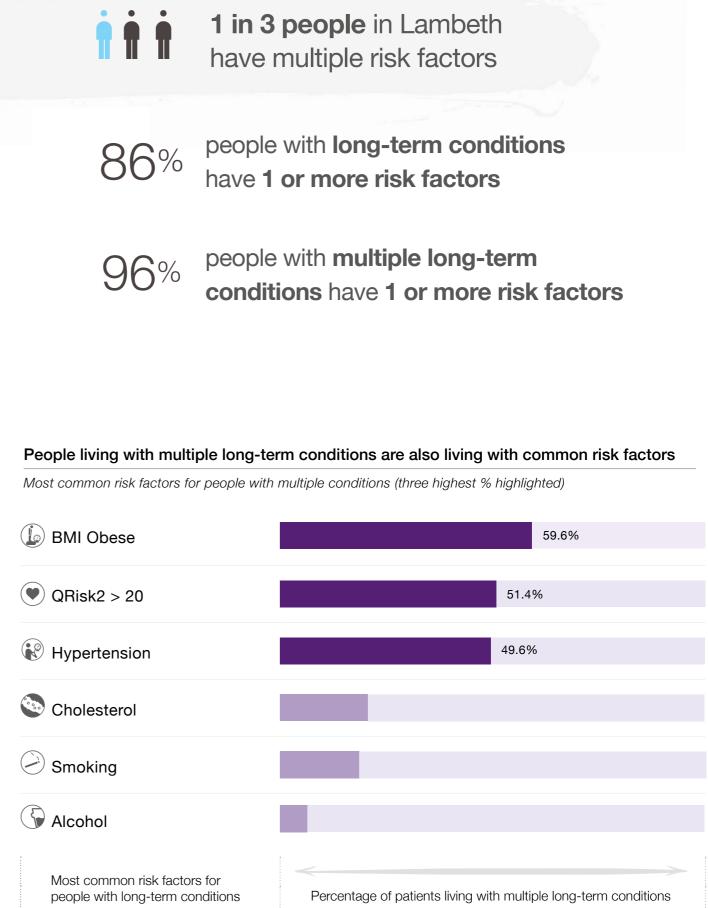
A closer look at age

1 in 3 people with multiple long-term conditions is under 65





% gender split across multiple long-term conditions patients



Quantitative analysis based on primary care data in Lambeth. Reference: Ashworth, Durbaba et al (May, 2018). Journey to mLTCs data: analysis of Lambeth DataNet database.



Mario came to the UK from his native Portugal pursuing a better life for his family. A former semi-professional footballer, he developed health issues early in life, which have affected his mobility and ability to work. He finds strength in his loved ones and his passion for cooking.

I love London and the neighbourhood. I really enjoy living here.

I came over from Portugal in 2004 because I have a brother who had been living here for many years. I came to be closer to him and to have a better life for my children, me and my wife.

When I was a child I had asthma and bronchitis. My next health problem was in 1998, in my early thirties, a sarcoidosis problem in the lung. I now have a problem with my lungs, my bones, my pancreas and diabetes.

I started taking cortisone as a treatment for my lungs after an operation in 2002. I took this for eight years and it was after that my other problems started. That was when I had problems with my bones, the avascular necrosis of the head of the femur.

Back in Portugal, I played soccer for many years as a semiprofessional but I had to leave football to work, to support my family. I worked in construction. I did everything, painting, tiling and so on. In 2007 I had to give up work completely because of my health conditions.

"I had asthma and bronchitis as a child and developed sarcoidosis in my early thirties."

Mario, 51 Vauxhall, Lambeth

I was 12 or 13 years old when I started work. To stop the activity as a man makes me feel very, very bad. And financially too, it makes a huge impact on me. Emotionally as well.

Very often, I'm short of breath because of my sarcoidosis, and I still take a lot of medication for that health problem. I get tired a lot. If I have to go upstairs, I get tired. Almost every day I have to take painkillers because it's an unbearable pain to walk.

I'm waiting for an operation for my hip, to put a prosthesis on the hip. It will mean the pain will go away or decrease in a way where I can at least walk more comfortably, and I will not limp, as I'm limping already over my right leg, and it will make my life easier.

What I think is that there's always someone worse off than me. I feel good because I have my family with me. I've never been a person to let myself be defeated. I've always been an optimist.

#### Local prevalence

Looking at the most prevalent long-term conditions in more detail can help us to understand more about the local population.

Locally, we are seeing the four most prevalent long-term conditions in Lambeth diagnosed in younger people. For example, serious mental illness and depression are diagnosed in people with an average age of 37 and diabetes is diagnosed at an average age of 53.

As well as being common long-term conditions, diabetes, chronic pain and depression in particular are frequently seen within the most common sequences of multiple conditions. As well as being common long-term conditions, diabetes, chronic pain and depression in particular are frequently seen within the most common sequences of multiple conditions.

#### Frequencies – most common long-term conditions\* in Lambeth

	Population level patients:		Multiple long-term conditions patients:	
Condition	Frequency	Valid %**	Frequency	Valid %**
Diabetes	17,408	5.4%	3,488	62.3%
Chronic Pain	8,070	2.5%	2,359	42.2%
Chronic Kidney Disease	5,943	1.9%	2,312	41.3%
Chronic Heart Disease	4,770	1.5%	2,128	38.0%
Depression	25,976	8.1%	1,978	35.3%
Morbid Obesity***	10,031	3.1%	1,498	26.8%
Stroke/TIA	3,445	1.1%	1,434	25.6%
COPD	3,547	1.1%	1,251	22.4%
Atrial Fibrillation	2,676	0.8%	1,246	22.3%
Heart Failure	1,634	0.5%	1,140	20.4%
Serious Mental Illness	4,556	1.4%	630	11.3%
Dementia	1,297	0.4%	627	11.2%

\*Adult population level prevalence (over 18 years) \*\*Valid % - Some missing data; some % values not for whole sample \*\*\*Morbid obesity: BMI ≥40

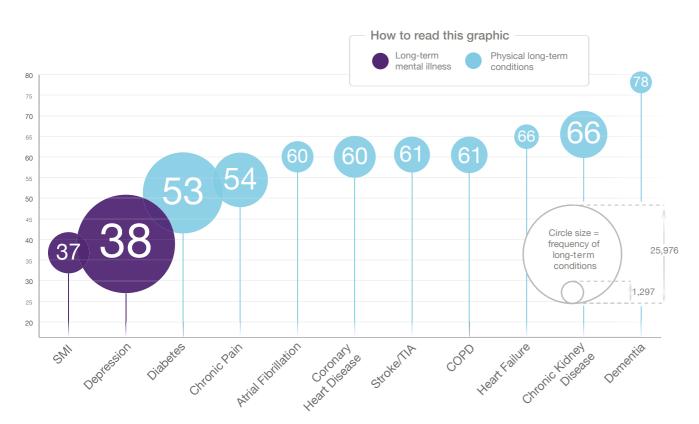


#### Age of diagnosis

The fact that many younger people are developing multiple Depression and Type 2 diabetes are the most prevalent conditions has profound implications for services and support. A focus on older people or frailty may miss opportunities to intervene for people earlier in their lives.

A closer look at the median age of diagnosis for long-term conditions reinforces that multiple long-term conditions is not just a phenomenon of ageing.

individual conditions. It is notable that they mainly affect a much younger group of people (average diagnosis age is 38 and 53 years of age respectively).



Serious mental illness has the youngest average age of diagnosis at just over 37. For people diagnosed at a relatively young age, the long-term nature of these conditions is likely to impact their quality of life for many years ahead.

Data from Southwark also reinforce that multiple long-term conditions affect people of all ages.

For both depression and serious mental illness, the overwhelming majority of cases in Southwark occur in those aged under 70, with almost half found in those under 40.

Significantly more women (8.0%) live with depression than men (4.9%) whereas the numbers for severe mental health are similar for both (average 1.2%) with men prevailing under 70 years of age and women prevailing over 70 years of age.11

Atrial fibrillation, chronic kidney disease and heart failure are most prevalent in people over 70 years of age. The percentage of the population living with long-term conditions increases significantly as people reach and exceed 90 years of age.

"I was in my twenties when my stomach problems started. I was diagnosed with diverticular disease and soon after with osteoarthritis."

Lynda, 61 Brixton



Southwark data shows us multiple long-term conditions affect people of all ages:

	Number of patients	Proportion of all cases		Prevalence of condition in population		
Condition		Under 70	Over 70	Male	Female	Persons
Heart Failure	1,481	42%	58%	0.5%	0.4%	0.4%
Atrial Fibrillation	2,416	36%	64%	0.8%	0.6%	0.7%
Chronic Kidney Disease	5,695	40%	60%	1.5%	2.0%	1.7%
Stroke & TIA	2,954	49%	51%	0.9%	0.9%	0.9%
Diabetes	16,719	72%	28%	5.3%	4.9%	5.1%
COPD	4,456	56%	44%	1.4%	1.3%	1.4%
Depression	21,223	95%	5%	4.9%	8.0%	6.4%
Serious Mental Illness	4,079	91%	9%	1.3%	1.1%	1.2%
Receiving pain medication	7,401	62%	38%	1.9%	2.6%	2.2%
3+ long-term conditions	3,503	44%	56%	1.0%	1.1%	1.1%

Southwark CCG. EMIS-web extract dated: 04.04.2018. NHS Digital, Patients Registered at a GP Practice, March 2018

#### **Risk factors**

In our exploration, we looked at the data on six uncontrolled risk factors associated with multiple long-term conditions for patients in Lambeth:

- High blood pressure (hypertension)
- Smoking
- Alcohol consumption
- High body mass index (obesity)
- High cholesterol
- QRisk a predictive algorithm for cardiovascular disease based on age, ethnicity, deprivation, systolic blood pressure, body mass index, total cholesterol: high density lipoprotein cholesterol ratio, smoking, family history of coronary heart disease in a first degree relative aged less than 60 years, type 1 diabetes, type 2 diabetes, treated hypertension, rheumatoid arthritis, atrial fibrillation, chronic kidney disease.<sup>12</sup>

### In Lambeth, 96% of people living with multiple long-term conditions have more than one associated risk factor.

Whilst each risk factor increases the likelihood of specific long-term conditions, a combination of each raises the total risk of acquiring multiple long-term conditions.

A singular focus on later life may miss sufficient attention to risk factors throughout a person's life course and the valuable clues they provide on likelihood of developing multiple long-term conditions.

#### Gender

Rates of multiple long-term conditions in our population are higher among men below the age of 60. This changes above the age of 60, when women represent a higher proportion of the patient group.

One possible explanation could be the differences in life expectancy for men and women.

### In absolute terms in Lambeth, more women live with multiple long-term conditions than men.

For the group of less prevalent long-term conditions, men are slightly more likely than women to have chronic obstructive pulmonary disease, stroke and Transient Ischaemic Attack (TIA), atrial fibrillation and heart failure. Women, however, are slightly more prone to chronic pain and chronic kidney disease. The analysis did not show detailed reasons for such gender discrepancy. We believe data could be investigated further to explore links with deprivation and ethnicity as well as lifestyle and social risk factors.



A single disease focus may miss the combined impact on the person

People living with long-term conditions don't tend to identify themselves by individual conditions. They view some of their symptoms as a result of single conditions and others as a result of having multiple long-term conditions. They also explain that how they view their multiple conditions can affect their view of their health and, in turn, how they manage them.13

Rather than managing many sets of individual symptoms, data from Lambeth and Southwark show that there may be a link between potential patterns in a person's diagnosis of long-term conditions. Here we explore further the correlations between patterns of diagnosis and how more person-centred care may help improve care for people with multiple long-term conditions.

### Impact of treatment and care

Multiple long-term conditions present health challenges greater than the sum of the individual conditions. The unique nature of everyone's combination of conditions - and the fact that many are living with them for a long period, often also juggling multiple risk factors at the same time - has significant impact on how we support, treat and care for them.

By better understanding the diseases that people develop over time or people's 'journey' to multiple health conditions, we may begin to understand some of the complexity and impact on quality of life.

#### Understanding the patterns

Part of why a single disease focus may miss the reality of a person's lived experience with multiple long-term conditions is that the development over time of additional conditions often follows common diagnosis patterns. Looking at people's progression from one long-term condition to many may help us consider why certain groups of conditions occur and suggest possible opportunities for intervening early.

#### Recognising complexity

### A single disease focus may miss the combined impact on the person

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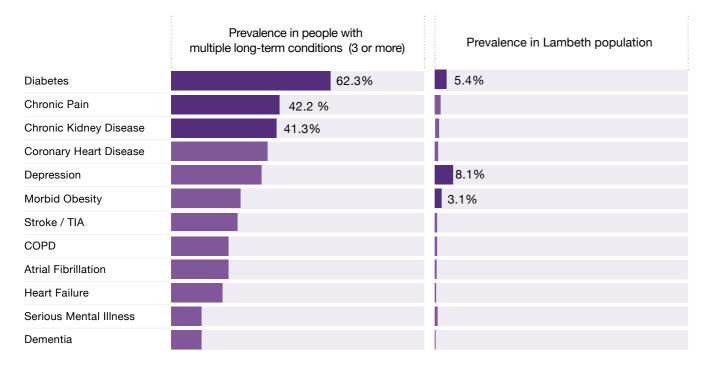
#### Understanding the prevalence of conditions may help target action

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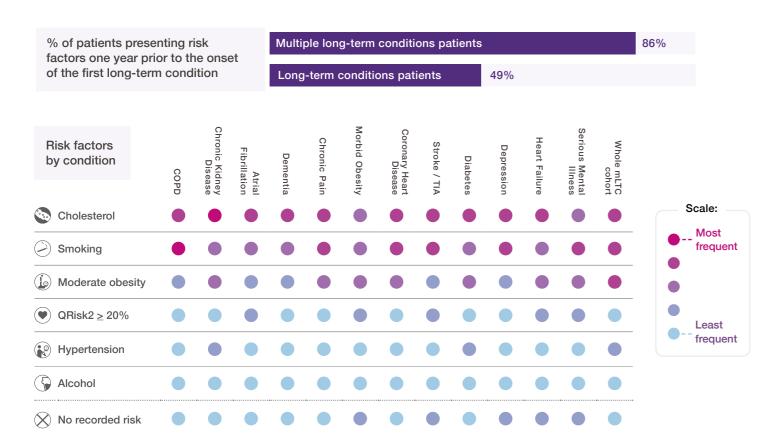
Most prevalent long-term conditions in people with multiple conditions against the whole Lambeth population (three highest % highlighted)

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The high prevalence of risk factors in people with multiple conditions presents opportunities for earlier intervention



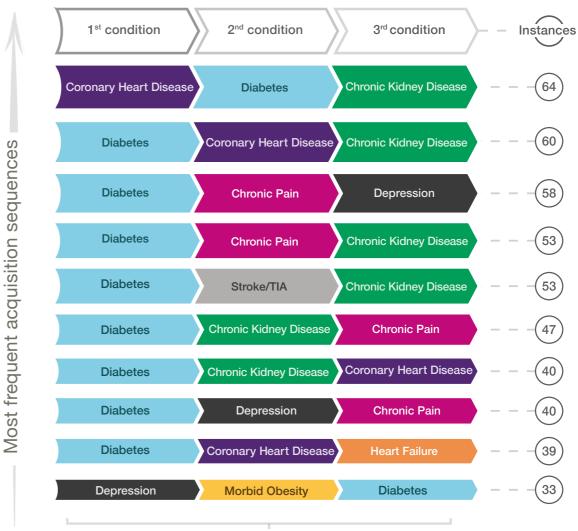
#### Understanding progression to multiple conditions could help with prevention

Frequencies of long-term condition acquisitions

Diabetes	
Chronic Pain	
Coronary Heart Disease	
Chronic Kidney Disease	
Depression	
Stroke/TIA	
Morbid Obesity	
COPD	
Atrial Fibrillation	
Heart Failure	
Serious Mental Illness	
Dementia	

A closer look at the sequence of acquisition of multiple conditions

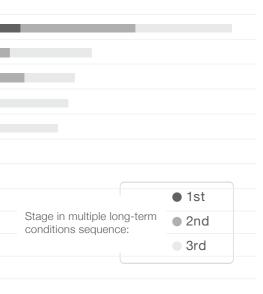
Ten most frequent aquisition sequences in multiple long-term condition patients in Lambeth



Long -term conditions

Quantitative analysis based on primary care data in Lambeth. Reference: Ashworth, Durbaba et al (May, 2018). Journey to mLTCs data: analysis of Lambeth DataNet database.

Most frequent risk factors recorded at any time for people with long-term conditions



## Lindsay's story



Lindsay has struggled with mental health his whole life. A diagnosis of depression was followed by granulomatosis - a rare condition of the blood vessels and Type 2 diabetes. He volunteers as a gardener and is looking to get back into work.

I was born in Dunedin in New Zealand. When my mother died, my father and I moved up to Christchurch to be with my grandparents. Dad had ill health. He had mental health problems himself.

When I was 23, I decided to travel a bit and ended up working in London and I've been here ever since.

The first time I got unwell, the first time I was diagnosed, was with depression in about 1996 or 1997. It had probably been going on for quite a while. I'd had the condition for many years, since my late teens, early twenties, and it wasn't until I was 35 or 36 when it was diagnosed.

I used to binge drink, go out and have a large quantity of alcohol at various points in time and then give it up for about three or four months. Then have a few weeks of going to the pub every night of the week. I suppose it was my way of coping with the depression.

The next thing was the granulomatosis. I had been struggling along with shortness of breath, and I'd almost collapsed a couple of times. They thought it was cancer for quite a while because it was the same symptoms. Finally, I was diagnosed with Wegener's, which they now call

"The first time I was diagnosed was with depression. It had probably been going on for quite a while."

Lindsay, 56 Elephant and Castle, Southwark

- granulomatosis. I'm in remission from that at the moment, but I was told it always has a 50 per cent chance of it recurring.
- One of the by-products of the granulomatosis is Type 2 diabetes. Not that it caused the diabetes, it was just a reaction to the vast amounts of steroids that I had to take.
- I think the hearing loss had been happening over a number of years. They said it could be one of the symptoms of the granulomatosis. It has made life very difficult, but you just have to get on with it.
- I've had a great deal of help from the NHS. I'm very lucky. I have a very fine GP, so I've been guite switched on to all my conditions.
- They've always been there on the end of a phone. They've always been there with advice, and if I have a relapse it's dealt with quickly.
- I don't like the words 'battle' or 'brave'. It's just something which happens. You just have to cope with it. No-one's going to wave a magic wand and take it away.

#### Understanding the patterns

Looking at the most common journeys to multiple health conditions can help us see whether there are certain patterns of acquisition and then think about possible opportunities for intervening early. Our analysis has explored the common patterns of conditions, the order of acquisition and the prevalence rates of second and third conditions associated with a primary condition.

The variability and compounding effect of different individual conditions on each other, as well as the time between the first and second diagnoses, the second and third and subsequent diagnoses, makes multiple long-term conditions a complex issue. However, some patterns are clear. For example, diabetes is the starting point for the majority of the most common sequences in our study and chronic pain is a common feature in more than half recorded sequences in Lambeth.

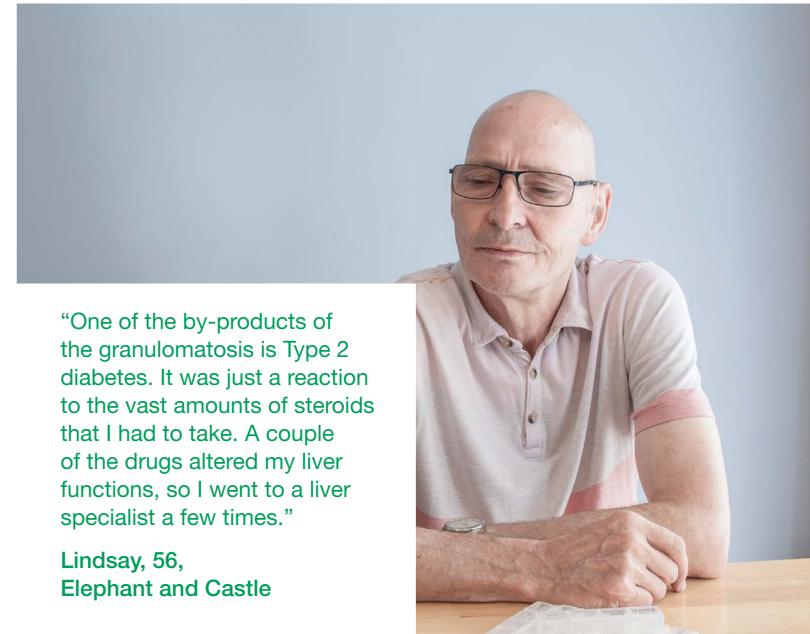
#### Recognising the complexity

Our data support moving from a 'one-size-fits-all' approach to a person-centred and holistic approach, which may help to address the causal factors and likely subsequent conditions on an individual basis rather than simply managing a set of symptoms.

The following are examples of possible combinations of conditions and progression:<sup>14</sup>

Depression is likely to be diagnosed at a younger age (average age 37.7). It is also a common precursor to diabetes, morbid obesity and chronic pain. It may result from a life of poor health, pain and poor mobility and other life-limiting effects of other associated conditions. As both a leading and lagging condition it is important to understand and address.

Diabetes is the most common starting point and is strongly linked with morbid obesity, chronic pain and depression, both as a primary condition as well as a subsequent one. Similarly, diabetes is closely associated with cardiovascular conditions including chronic heart disease, chronic kidney





disease, stroke and TIA. Being typically diagnosed at a relatively young age (average age 52.8), diabetes is a common first or second condition for a greater than average number of patients living with multiple long-term conditions.

Morbid obesity is most frequently associated with diabetes, depression and chronic pain. Whilst morbid obesity is less often acquired as a result of diabetes, it is commonly associated as a secondary condition resulting from depression and is frequently a pre-condition to diabetes.

Serious mental illness doesn't feature within the data on common sequences in Lambeth, but given its early age of diagnosis it is also relevant to mention. Generally diagnosed at a younger age than any other long-term condition, serious mental illness most frequently leads to diabetes, morbid obesity, depression and chronic pain.

### Managing risk

Risk factors are a key part of our understanding of multiple conditions, pointing at opportunities for both primary prevention and, perhaps most interestingly, ways to prevent progression from one to many.

Our work to date has only considered medical risk factors associated with multiple long-term conditions and further work will be needed to look at wider, non-medical, risk factors,

#### Individual risk

The number of people presenting with one or more risk factors is just under 150,000 (46.8% of the Lambeth population). For people presenting with one risk factor only, smoking is the most common factor, followed by high cholesterol and then obesity.

For all people presenting with at least one risk factor prior to onset of the first condition, smoking is most common for 38.5% of the population, high cholesterol for 25.7%, obesity for 19.3%, alcohol consumption greater than 14 units per week for 10.7%, uncontrolled blood pressure for 2.4% and QRisk for 1.5% of the population.

For people presenting with two risk factors, high cholesterol is the most common risk, and remains so for all subsequent increasing combinations of risk factors. For two risk factors smoking is the second most common with obesity third. It is notable that when only two risk factors are present, the prevalence of hypertension increases disproportionately as the associated risk with high cholesterol.15

Even for people with four risk factors, the combination of smoking, high cholesterol and obesity remain the most common risks for 58.4% of the identified group.

Even for people with four risk factors, the combination of smoking, high cholesterol and obesity remain the most common risks for nearly 60% of the identified group.

Whilst smoking, high cholesterol and obesity are the most common risk factors across the population of Lambeth, there are well-established evidence-based interventions to tackle diet, alcohol consumption, hypertension and smoking cessation. In the same way that multiple long-term conditions need to be tackled and managed collectively, our analysis suggests that multiple risks could also be best tackled as a collective group of risks within the context of social, cultural and lifestyle factors.

### Risk factors in people living with multiple conditions

96% of people living with multiple long-term conditions in Lambeth have more than one associated risk factor. Indeed, when looking back over two years from when a person was first diagnosed with multiple long-term conditions, 80% of people had more than one risk factor.

These risk factors not only point to potential health conditions in the future, but often need managing and dealing with in their own right and highlight the complexity of people's experiences.

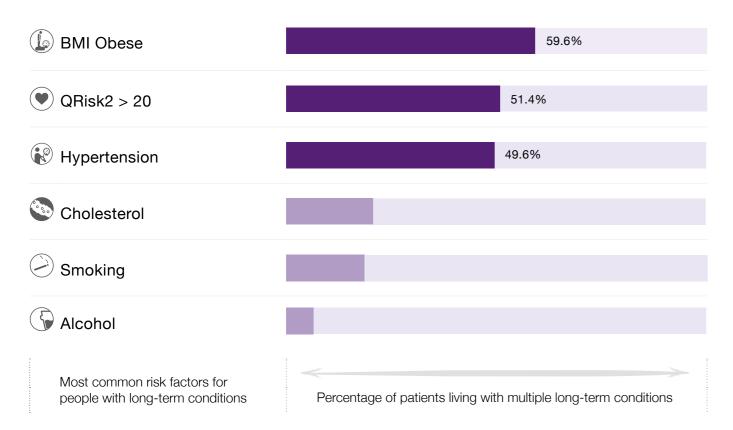
Looking at the risk factors associated with individual long-term conditions may help us understand this complex picture and provide clues on how to halt progression.

In the same way that multiple long-term conditions create greater health complexity than the sum of the individual conditions, so multiple risk factors create a similar compound effect on each individual condition and even more so on multiple long-term conditions.

96% of people living with multiple long-term conditions in Lambeth have more than one associated risk factor.

#### People living with multiple long-term conditions are also living with common risk factors

Most common risk factors for people with multiple conditions (three highest % highlighted)



#### Risk factors may help us understand the complex picture of long-term conditions

Risk factors by individual long-term condition



Hypertension – Over 10% of the population in Lambeth is on the hypertension register (35,233) with almost 30% of these (10,282) being uncontrolled with a further 21,600 people with blood pressure that would be categorised as uncontrolled.<sup>16</sup> It is estimated that around 50% of all hypertension cases are undiagnosed and carry a significant risk of developing into a related, but avoidable, long-term condition.<sup>17</sup>

Smoking - 20% of Lambeth's population are current smokers, with a similar number being ex-smokers. Whilst the ex-smokers are no longer consuming tobacco, the long-term effects on their lungs and blood pressure remain significant risks to related long-term conditions.<sup>18</sup>

Alcohol consumption – Of the 65% of the adult population in Lambeth who had their alcohol consumption measured, almost 106,000 (33% of the population) consume between one and 14 units per week with a further 26,184 (8% of the population) consuming more than 14 units per week.<sup>19</sup>

**Obesity** – In 2016, 61% of the adult population in England were overweight or obese (BMI 30-39.9). 35% of adults were classed as overweight and a further 26% obese. Over three quarters (78%) are among those aged between 35 and 64.<sup>20</sup> Adults living in the most deprived areas of England are 46% more likely to be obese than adults living in the least deprived areas of England.<sup>21</sup> In Lambeth, almost 40% of the adult population (125,682) are overweight or obese.<sup>22</sup>

Total cholesterol – Around 44% of adults in Lambeth (143,800) have had their total cholesterol measured. Of this tested group, 41% (57,520) had a reading of over five. Of this group, 20% of people (11,471) have been prescribed statins to lower their cholesterol levels and reduce the risk of cardiovascular and other related conditions.23

People are living with multiple conditions for a long period, often also juggling multiple risk factors at the same time - focusing on individual conditions misses the reality of people's lived experience.

Most frequent risk factors recorded at any time for people with long-term conditions

#### Impact of treatment and care

Whilst individual conditions have their own complexities, these are compounded when a second or third condition is acquired. Multiple long-term conditions present physical and mental health challenges greater than the sum of the individual conditions and also carry additional burdens of multiple health appointments and polypharmacy.

#### Use of services

People with multiple long-term conditions are significant users of both primary and secondary care services.

Data from Lambeth show that people living with multiple long-term conditions are five times more likely to attend A&E.<sup>24</sup> Many people attending are affected by heart failure, dementia and atrial fibrillation, particularly high cost conditions.

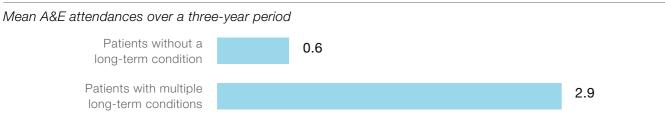
The mean A&E tariff cost over a three-year period for patients without a long-term condition is  $\pounds$ 62, while the mean cost in the same period for patients with multiple long-term conditions is  $\pounds$ 435.

People affected by multiple conditions are also high users of primary care and, over a three-year period, use six times as many GP consultations as those without long-term conditions. Lambeth data show people with multiple long-term conditions are five times more likely to attend A&E and use six times as many GP consultations as those without long-term conditions.

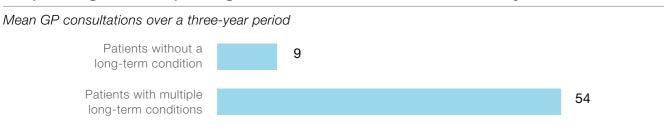
#### Polypharmacy

When we spoke to people living across the two boroughs, the volume of medication they took and the impact on their conditions and daily lives featured strongly. Our data show that 49% of all people with multiple long-term conditions have polypharmacy (eight or more medicines). Likewise, people living with multiple long-term conditions are almost seven times more likely to be prescribed polypharmacy than people without any long-term conditions. The risk of polypharmacy is also affected by increasing age, gender (in our data, women are more than twice as likely to have polypharmacy than men) and ethnicity (in our data, black people are twice as likely, and Asian people more than twice as likely, to have polypharmacy than white people).

#### People living with multiple long-term conditions are five times more likely to attend A&E



People living with multiple-long term conditions use six times as many GP consultations





"The worst year I had for appointments – 52 weeks in a year and I had 68 appointments. Different departments, different checkups. That was doctors, GP, hospital, diabetes check, eye checks and everything else. I had to give up work because of it."

Lynda, 61 Brixton

People's background and social context play an important role

London is a multicultural city and Lambeth and Southwark are prime examples of inner-city areas. The dense urban environment, complex ethnic and social mix, and high levels of income inequality provide important context to the health of local people. A deeper look at local data highlights the impact that a person's background and social context has on their experience of multiple long-term conditions.

#### Ethnicity

People from black and Asian communities within Lambeth are experiencing a greater burden of multiple long-term conditions than people from white ethnic groups. There is a higher prevalence of people living with three or more long-term conditions in black and Asian ethnic groups and people from these communities are often diagnosed years earlier than their white neighbours.

#### Deprivation

Levels of deprivation also seem to play a crucial role on the burden of multiple long-term conditions experienced by a community. People living in our most deprived wards are diagnosed with multiple long-term conditions earlier than their more affluent neighbours.

#### Neighbourhoods

Drilling down to data at the neighbourhood level provides helpful insights into the prevalence and distribution of multiple long-term conditions in a discrete geography. It is essential in helping us rethink how services and community assets are mobilised to support people who need them the most, and may also offer clues to others facing similar challenges elsewhere.

### People's background and social context play an important role

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. .....

Multiple long-term conditions disproportionately affect BAME communities

Population size

.....

27% of people with multiple long-term conditions are black

. ....

18.5% of people in the whole patient population in Lambeth are black



Difference in diagnosis age

#### Average age (years) 40 50 60 (i) 15 Difference (vears) • ()-• Black patients Difference in diagnosis age Black and white people -(7.8)-• \_ 6.5 (i) 15 Difference (years) • -• White patie Asian patier age Asian and Difference in diagnosis white people 2.5 0.9 15 Age gap (years) Gap -Social deprivation Difference in diagnosis age (average in years) 10 (9.9)

Average age (years)

• (5.4) ·

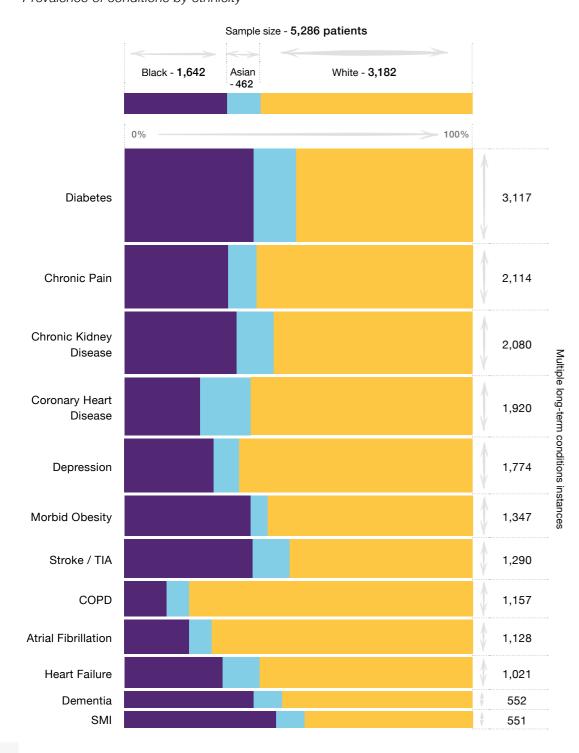
Quantitative analysis based on primary care data in Lambeth. Reference: Ashworth, Durbaba et al (May, 2018). Journey to mLTCs data: analysis of Lambeth DataNet database.

Prevalence of conditions by ethnicity

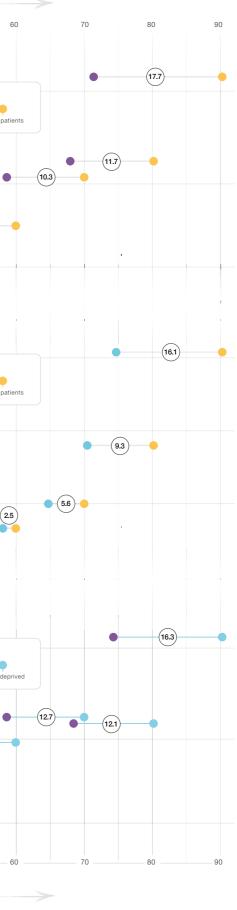
All population

mLTC population

A look at diversity









"I've always suffered from bronchitis, every winter. I've lived in damp accommodation, and I mean damp."

Sue, 75 Clapham Park Estate, Lambeth Londoner Sue has multiple long-term health conditions including diabetes and vascular disease. Sue has struggled financially and, as an adult, combined studies with work to ensure a better life for herself and her children. She has received an MBE for her services to the community.

Diabetes is in the family, high blood pressure is in the family, I've got it, my brothers and sisters had it, my mother had it and it just won't seem to go away.

Arthritis was my first ailment. The arthritis condition is a bugger. Doesn't matter if you walk, sit, lie, you always got the pain there and all they give you is painkillers. That causes another problem because you suffer from constipation.

Later I was starting to get very thirsty, to go to the toilet a lot so the doctor sent me up to the Diabetic Clinic at St Thomas' Hospital and that's when they confirmed I had diabetes. I had it for quite a while before the diagnosis.

I got vascular disease according to the hospital because of smoking, but I don't believe them, because I've got family members who've got it and they don't smoke.

I've always suffered from bronchitis, every winter. Certainly, the last two winters prior to this one. Even in damp accommodation, and I mean damp.

When the children were little, I had a flood. There was a tank up in the ceiling and the ballcock went and all the water came down in my flat and ruined so much, it was ridiculous.

Just before Christmas, I got this cough. They discovered I've got the little nodules in a cluster on my lung. I call them mushrooms, myself. Anyway, I come home, and I have to go to the special clinics. I go to the Cancer Centre at Guy's. I go to the chest department in St Thomas'. I've been to



- The Lung where they test your lungs. He said to me, my lungs are pretty good for my age and considering I smoke. It gets monotonous because I'm not getting an answer I want. That is what's wrong with me at diagnosis.
- So you're taking tablets like they're going out of season for this thing or the other. You get fed up, believe you me.
- When these people, consultants and doctors turn around and say to me, I should give up smoking. I turn around and say, "Don't go down that road". I've been smoking since I was 15. A cup of tea and a fag has got me through many, many crises
- I worked and studied simultaneously, because when you're destitute, and I really mean destitute, there's only one way to go and that's up. And I thought that was through education.
- It's soul destroying. I sat in the dark, in the cold, and ate what I could. It wasn't regular. I got that hungry at one time when I was put down to a meal, I couldn't eat it.
- Eventually, I became part of the New Deal for Communities (NDC) government scheme to improve housing. Having gone through bad accommodation myself, I just wanted something good for my neighbours. I got a civic award as well and I felt really proud, actually
- When I got my MBE, I said "I'm taking this on behalf of the Clapham Park Project for the community", and Prince Charles gave it to me. He asked me what I did, and he said to me, "Thank God there's people like you".

#### Multiple long-term conditions disproportionately affect diverse communities

<		Population size	
All population	18.5%	of people in the whole patient population in Lambeth are black	
mLTC population	on	27% of people with multiple long-term conditions are black	

#### The relationship with ethnicity

A close review of Lambeth data reveals disparity in age of diagnosis and types of long-term conditions between different ethnic groups. Our evidence suggests that a person's ethnic background may play a role in their progression to having multiple long-term conditions.

#### **Proportion disparities**

Around 55% of our local population belong to white ethnic groups and 45% to black, Asian and other ethnic groups.

Black and Asian communities in Lambeth have a higher proportion of people living with multiple long-term conditions than white communities. While black ethnic groups make up only 18.5% of the local population, this same group represents 27.1% of the total patient group with multiple long-term conditions.

Similarly, Asian groups make up only 6.8% of the local population but 8.6% of the people living with multiple long-term conditions.

When you delve deeper into the local data, the picture becomes more complex. Compared to the white population of Lambeth and Southwark, the unadjusted data shows that people from black communities are 50% more likely to acquire three or more long-term conditions. Meanwhile, those from Asian communities are 30% more likely.

Compared to the white population of Lambeth and Southwark, the unadjusted data shows that people from black communities are 50% more likely to acquire three or more long-term conditions. However, when these figures are adjusted for the same age, gender and typical risk profiles as white people, black people are found to be around 15% less likely to acquire three or more long-term conditions than the white community. The figure for people from Asian communities, on the other hand, remains at around 30% higher risk.

These data suggest factors beyond ethnic background may explain why multiple long-term conditions are found more frequently in black communities and why, on average, these conditions may appear 10 years before they do among white people. However, further work is needed to improve our understanding of what drives this difference.

#### Differences in condition types

We also see variety in the types of long-term conditions people of different ethnicities develop. Diabetes is the most common long-term condition for all people with multiple long-term conditions. However, when looking at different ethnic groups with multiple long-term conditions, 76.8% of black and 78.5% of Asian people have diabetes, compared with 52% of white.

The next most prevalent long-term conditions for all ethnicities are chronic kidney disease and chronic pain.

Our view is that a close look at the specific mix of conditions people experience depending on their ethnic background may provide important cues for the co-design and delivery of interventions with those communities.

#### Mental health and ethnicity

Our data indicate that mental health plays a significant role in multiple long-term conditions. This also applies when looking at the data in relation to people's ethnic group.

For example, depression is one of the most common long-term conditions experienced by people living with more than three conditions. It is interesting to note in this data that there is a higher prevalence of depression in people from white ethnic groups living with multiple conditions (just under 40%) than people from black or Asian groups.

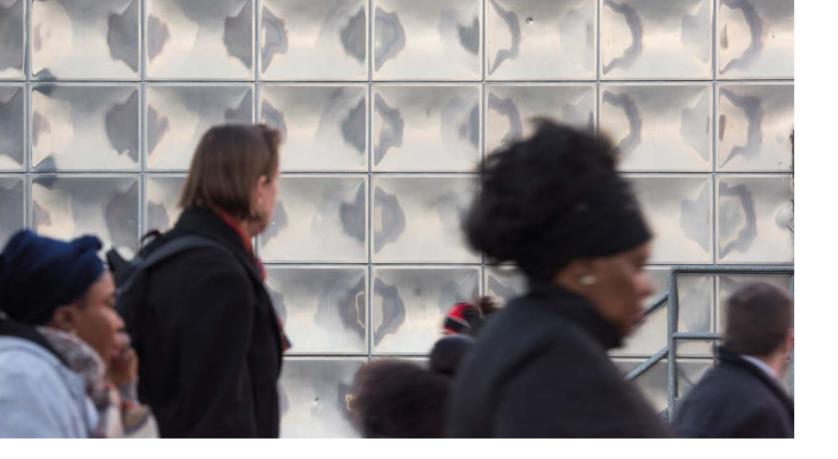
In contrast, serious mental illness has a significantly higher prevalence in black groups.

Reviewing this data through a lens of ethnicity provides some interesting reflections about how mental health impacts on different people from different groups.



"I've got chronic pains. I was going to the pain clinic thinking that I would finally find a cure for it. No, they don't have a cure for pain. I said to her, I said, 'Well, what do I do?' She said, 'You just have to learn to manage it and use things to manage it."

Jaqueline, 54, Denmark Hill



#### Age of diagnosis

People from black and Asian communities are also carrying a greater burden of multiple long-term conditions, according to Lambeth data.

This is demonstrated clearly by the difference in diagnosis ages. A black person is likely to develop a long-term condition earlier than their white peer and this 'gap' increases with age. Whilst a white person might be diagnosed with a long-term condition at the age of 50, a comparable diagnosis might occur at 43.5 for a black person (a gap of 6.5 years).

Similarly, a long-term condition diagnosed in a white person aged 90 will typically be diagnosed in a black person aged 72 (a gap of 18 years).

People from black and Asian communities are carrying a greater burden of multiple long-term conditions, according to Lambeth data.

The age span of the comparative white group being diagnosed and living with multiple long-term conditions was 40 years (between 50 to 90 years of age). It is concerning that the comparable group of black people was only 28.5 years (between 43.5 to 72 years of age) – a timespan that

is 11.5 years shorter. Put another way, the data suggest that black people in our local areas are acquiring their individual conditions at a younger age and progressing at a more rapid rate than white people.

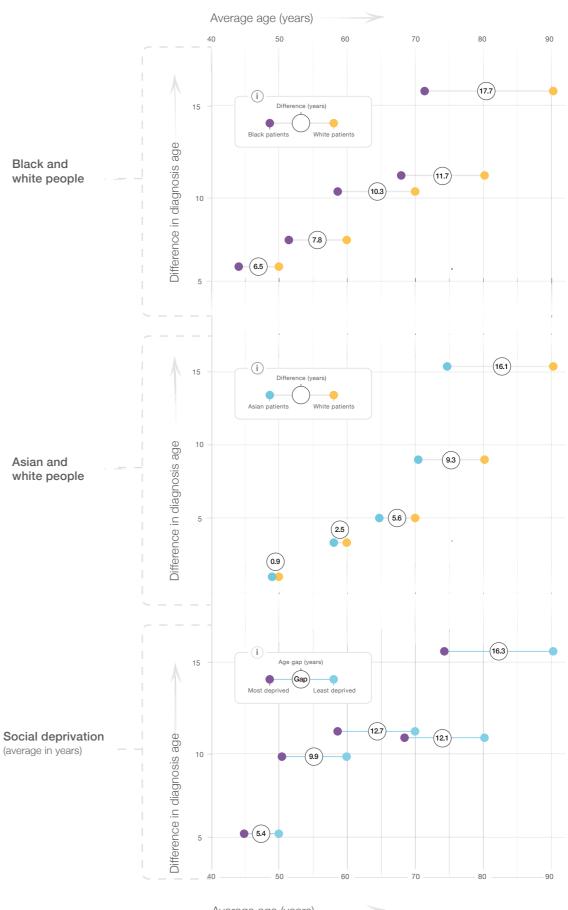
# The role and influence of deprivation

National research has shown that people living in deprived areas experience multiple long-term conditions earlier than those living in more affluent ones.<sup>25</sup> Our look at the deprivation data available to us from Lambeth A&E attendees supports this and also suggests this gap increases with age – 10 years when people are in their sixties and 12.7 in their seventies.

Our data do not confirm whether ethnicity and deprivation are compounding factors that would predict even earlier diagnosis of the first condition or multiple long-term conditions. However, it does suggest that people living in deprived communities are shouldering the greatest burden of multiple long-term conditions. Whilst we will need to understand more about the interplay between ethnicity and deprivation, there is much we can act on now to ensure we are focusing on health inequalities when we look to tackle multiple long-term conditions in inner cities.

#### Black and Asian communities carry a greater burden of multiple long-term conditions

Difference in diagnosis age

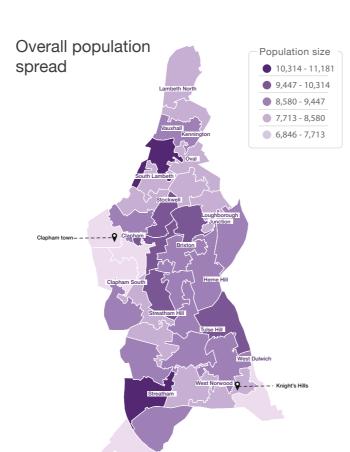


Average age (years)

#### A neighbourhood look at ethnicity and deprivation

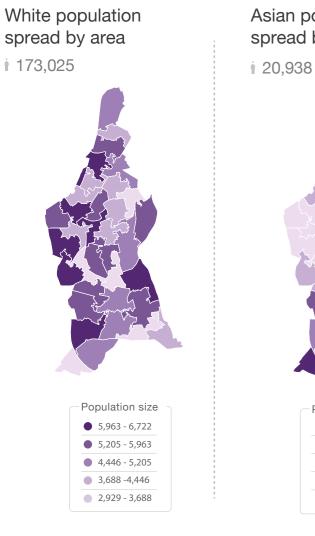
As a health foundation with a specific place-based focus on Lambeth and Southwark, we're interested in whether we can see any patterns when we map the data across the boroughs. This helps us in our work with local colleagues to think about where and how best to target interventions. It may also help others elsewhere to draw comparisons with their own areas.

These maps show that ethnicity and deprivation may have a part to play in the development and progression of multiple long-term conditions. We can see darker shaded areas, where we find higher prevalence of longterm conditions, overlapping with areas with higher levels of deprivation. In addition, areas with higher percentages of black population seem to align with higher prevalence areas too. Interestingly, areas with higher percentages of Asian population (though a much smaller sample size) show a much less clear picture when compared with both, prevalence of multiple long-term conditions and with levels of deprivation.



### Population spread by Index of Multiple Deprivation Score

Deprivation index



Asian population spread by area

Population size

1,303 - 1,546

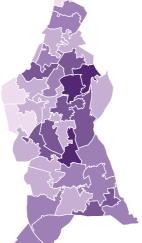
• 1,060 - 1,303

817 - 1,060

574 - 817

331 - 574

spread by area 78,542

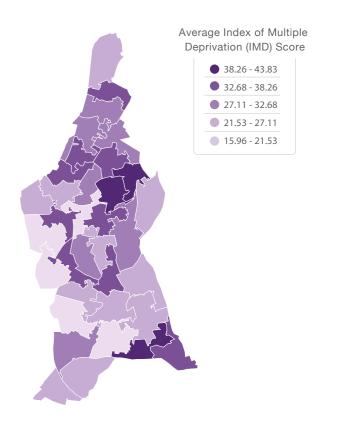


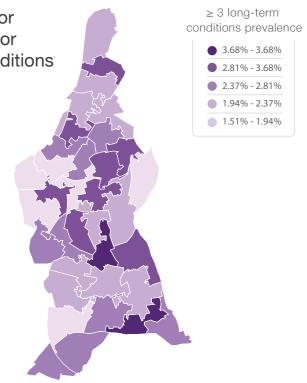
Black population

Population size 3,362 - 4,053 2,671 - 3,362 1,979 - 1,671 1,288 - 1,979 597 - 1,288

Population spread for people living with 3 or more long-term conditions

All data above shown in MSOA format. Data for the average Index of Multiple Deprivation Score was provided in LSOA format. The average has been formulated to provide a clear comparison with the MSOA data.





#### Comparing neighbourhoods within boroughs

Take specific neighbourhoods within the wards of Clapham Town and Knight's Hill, both in Lambeth, for an interesting comparison. Just under four miles apart, they show very different pictures:

	A neighbourhood in Knight's Hill	A neighbourhood in Clapham Town
Prevalence of 3+ conditions	3.68%	1.51%
IMD Score*	41.03	24.40
% BAME	43%	18%

All data calculated at MSOA level

\*Index of Multiple Deprivation Score

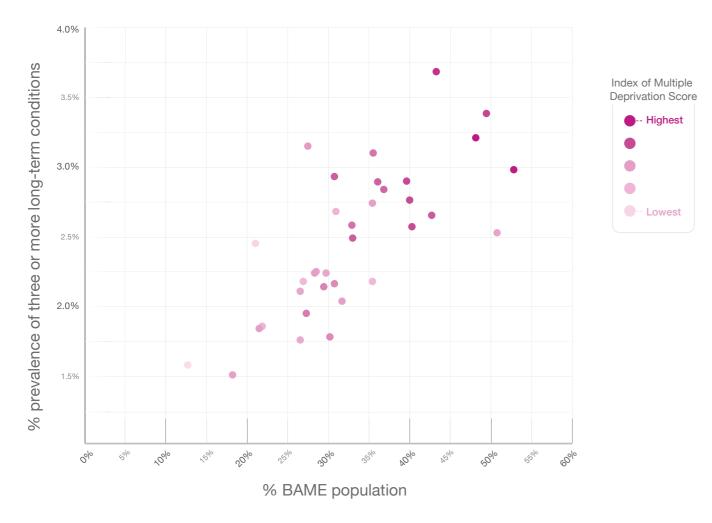
A neighbourhood in Knight's Hill has over twice the prevalence rate of people with three or more long-term conditions than a neighbourhood in Clapham Town (3.68% compared to 1.51%).<sup>26</sup> The former has more than double the proportion of the Black, Asian and Minority Ethnic (BAME) population than the latter (43% compared to 18%)<sup>27</sup>, and the area is more deprived. The two wards in which these neighbourhoods are located have a median household income difference of nearly £10,000 (in Clapham Town, the median income stands at £44,960 while it is £36,950 in Knight's Hill).28

When looking at data at a ward level, we can see that these two areas each have relatively young populations with just under 7% of people in Clapham Town aged over 65, and just over 9% in Knight's Hill.29

Whilst the correlation and insights can be debated in detail, the central premise arising from these data is that ethnicity, age and deprivation seem to play intriguing and potentially interlinked - parts in the development and progression of multiple long-term conditions. Although we cannot draw any hard conclusions based on the data available to us at this point, we take it as a useful point for further exploration and discussion.

#### A look at deprivation, population diversity and multiple long-term conditions in Lambeth

A view at neighbourhood level (MSOA)



Average % of BAME population vs. Average % prevalence of three or more long-term conditions. Colour scale shows average Index of Multiple Deprivation Score. Details are shown for each MSOA in Lambeth.





"When I had the stroke, I said, I'll do a bit of physio to help myself, help to move my arms and things a bit better. Because of the stroke, it took me a long many, many years to able to use my left side better. Since I went to the Dragon Café, to the Tai Chi, to the reflexologist, the massage I took, the dancing, the singing, the artwork I do, it relaxes you and you try to make the brain remember things and all of that. It helps."

Jaqueline, 54 Denmark Hill

## **Building on these findings**

Multiple long-term conditions are now a fact of life for millions of people in the UK and for our healthcare and social care providers. The impact on people's lives is clear, affecting not only a person's physical and mental health but also their family, relationships, finances and ability to work.

We hope that by sharing this research into the prevalence and distribution of multiple long-term conditions in two London boroughs, we will have prompted helpful reflections for others grappling with similar challenges elsewhere in the UK or beyond.

Our view is that multiple long-term conditions should be approached as a collective, specific and complex issue in its own right, requiring particular care, treatment and support.

This research was preliminary in its scope and, by its nature, raises more questions than it gives answers. Our aim is to build on these insights as our programme develops and we improve our understanding of how our urban environment, diverse population and high levels of income inequality are impacting on people's ability to keep healthy for longer. Working in partnership with others, our ten-year goal is to improve people's quality of life by slowing down the progression from one to many long-term health conditions.

These questions may give helpful hints as to how we, and we hope others, can build on these findings.

# This is not just a problem of old age

By looking closely at place-based data we begin to see the many connections between multiple long-term conditions and variables including risk factors, gender and where people live. This contributes to a richer understanding of the complexity of the issue and can help us shift the widespread notion that multiple long-term conditions is just the result of ageing. With this in mind:

- How do we begin to reframe multiple long-term conditions as a phenomenon that affects people of all ages?
- What are the implications of a younger patient population on services and support?
- Do we need to understand more about the gender differences highlighted in this data?

#### A single disease focus may miss the combined impact on the person

Our work to date suggests significant variance in the progression from one condition to many for different population groups. By understanding the individual conditions that people commonly develop over time we can begin to unpick the complexity beyond multiple long-term conditions and develop successful strategies for early intervention. This may come from understanding the common clusters of conditions that people often develop overtime as well as looking at the interplay with associated risk factors. With a greater understanding, we may be able to slow down the progression from one condition to many. With this in mind:

- How might we intervene earlier to prevent progression from one to multiple long-term conditions?
- This research only utilised primary care data, which gives us a limited picture and may miss some people with complex needs. How do we better integrate a wide variety of data across primary, secondary, mental health and social care and non-health sources to show what truly needs to be addressed?
- In parallel, how can we utilise data to align practice with what matters to people?
- How do we now look beyond the medical model of risk factors to look at different types of risk factors (social, behavioural and psychological) and exposure to persistent life events that may impact on a person's likelihood of developing multiple conditions (for example, adverse childhood events, divorce and bereavement)?
- How do we develop an understanding of positive deviance to understand how we can best intervene to prevent progression from one condition to many? (For example, can we learn more from when where people haven't followed a 'typical' progression, 'coped' with their progression, and 'maintained' their quality of life?)

#### People's background and social context play an important role

We believe that where people live plays a major role in the health issues facing our communities. This research supports a view that the complex interplay of an urban environment, diversity and deprivation may be limiting people's ability to keep healthy for longer. With this in mind:

- Can we develop a deeper understanding of the relationship between multiple long-term conditions and social context, ethnicity and disease constructs?
- Can we learn more about the interplay of mental health and health inequalities?
- How do we work with communities that are disproportionately affected to identify opportunities to act – to slow down progression and improve the quality of lives for people living with multiple long-term conditions?
- How best can we work with our communities to ensure we are co-producing solutions that work for them?

# **Glossary of terms**

Long-term conditions or chronic diseases are conditions for which there is currently no cure, but which can be managed with drugs and other treatments. As appropriate disease management can improve the quality of life for people with these conditions, early detection and diagnosis is important.

Multiple long-term conditions describe the presence of two or more long-term conditions – such as asthma, diabetes or depression. These may be related to physical and/or mental health, and are often referred to as multiple-morbidity.

**Co-morbidity** describes a one or more diseases co-occurring with a primary condition. Co-morbid conditions may or may not be related.

**Multimorbidity** describes a number of unrelated multiple long-term health conditions. Whilst the individual conditions are not caused by the primary condition, the limitations of and medication for each can have significant adverse impacts on the person. An example of a multimorbid patient might be one living with depression, chronic pain and atrial fibrillation.

**Polypharmacy** is defined as the use of eight or more medications, which might include drugs to manage each core condition, as well as other drugs to counteract the effects (nausea, etc.) of the primary medicines working against each other.

# Methodology

The King's College London team undertook quantitative analysis based on primary care data in Lambeth DataNet (LDN), producing:

- Descriptive data: Care Coordination1 patient characteristics based on LDN data. Descriptives including demographic characteristics (e.g. ethnicity, language, country of origin, deprivation), lifestyle data (smoking, alcohol), long-term conditions and patterns/clustering of long-term conditions.
- 2. Trajectories: the journey toward becoming a Care Coordination patient including multi morbidity combinations which are most likely to propel a patient into the Care Coordination category.
- 3. Health inequalities: defining the types of patients and types of communities which are most vulnerable to the development of Care Coordination status.
- 4. Mapping: (using Lower Layer Super Output Area (LLSOA) data to produce heat maps of the multi morbidity combinations associated with Care Coordination status and trajectory toward Care Coordination, identifying communities with a high proportion of residents who are close to Care Coordination status.
- Care Coordination staging: a series of recommendations based on the data which identify options for 'prevention' of the development of Care Coordination status.

Data analysis followed previously developed methods including data cleaning, data validation testing, univariate analyses (frequencies, means, variance) and graphical data displays. Multivariate analyses was used to build multi-level regression models incorporating both fixed and random effects in order to define the predictors of health inequalities (based on ethnicity, deprivation, age, gender) for Care Coordination patients.

The analytic approach was guided by a rapid scoping literature review on multi morbidity, the causes of multi morbidity and the prevention of multi morbidity.

The team at Southwark Public Health undertook a quantitative analysis of primary care data in Southwark working with local GP Federations (Quay Health Solutions Ltd and Improving Health Ltd), producing:

 Descriptive data: Care Coordination2 patient characteristics based on Southwark primary care records. Descriptives including demographic characteristics (e.g. age and gender) and the prevalence and distribution of the care coordination long-term conditions.

#### Please note:

- This research does not differentiate between medical conditions that occur because of a pre-existing condition, or ones that occur in spite of it.
- The majority of the data presented in this paper is drawn from primary care records. Southwark data is based on EMIS data extracted in January 2018 and April 2018. The data presented is based on absolute prevalence and not age standardised data. It is based on people with recognised diagnosis on their healthcare records.
- For Lambeth, the data was extracted from Lambeth DataNet, the borough's system for the collection of anonymised data from GP records, in April 2017 and it offers the most complete data set out of the two boroughs. Figures presentation are based on people with recognised diagnosis. Again, no attempt has been made to estimate undiagnosed cases.
- Data on deprivation is taken from primary care records for a cohort of people with multiple long-term conditions who attended A&E.
- The list of long-term conditions chosen for this study is based on the conditions identified by the Lambeth and Southwark Expert Patient Reference Group. The conditions on the list are:
  - Diabetes
  - Chronic Pain
  - Chronic Kidney Disease
  - Coronary Heart Disease
  - Depression
  - Morbid Obesity
  - Stroke/TIA
  - COPD
  - Atrial Fibrillation
  - Heart Failure
  - Dementia
  - Serious Mental Illness

There are limitations to the data as it is taken from GP records in Lambeth and Southwark, and therefore does not capture those living with long-term conditions without a formal or recorded diagnosis.

Neighbouring London boroughs are defining multiple long-term conditions and analysing their data in different ways. Whilst we looked at a common set of nine long-term conditions in both boroughs and a set of 12 long-term conditions in Lambeth, for the purpose of this paper, other researchers such as Barnett and Guthrie<sup>30</sup> used a list of 40 long-term conditions that showed an even greater proportion of the population living with individual and multiple long-term conditions.

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