Living with more than one long term condition in York

A Health Needs Assessment

2020

Peter Roderick

Specialty Registrar in Public Health

City of York Council

Contents

A note on terminology and anonymity

Throughout this document the terms 'living with more than one condition', 'living with multiple conditions', 'comorbidities' and 'multimorbidity' are used interchangeably. The latter two phrases are widely used in health and social care, but are recognised to be examples of jargon and inappropriate when talking about individual patients and service users. They do however have the benefit of being short, hence their use in this document to refer to population groups.

The identities of people living with multiple conditions who contributed to this work have not been included in this document, and any names connected with 'stories' have been changed and are included for illustrative purposes only.

Executive Summary

7 reasons multimorbidity matters

#1 It's big
Around 25% of the population now live with more than one long term condition

#2 It's growing
By 2035 the proportion of the population with more that 4 conditions will double

#3 It's tragic
By 2035 women will live 2.1 more years (and men 1.9) with multiple conditions

#4 It's inequitable
Onset of multimorbidity occurs 10 to 15 years earlier for people in deprived areas

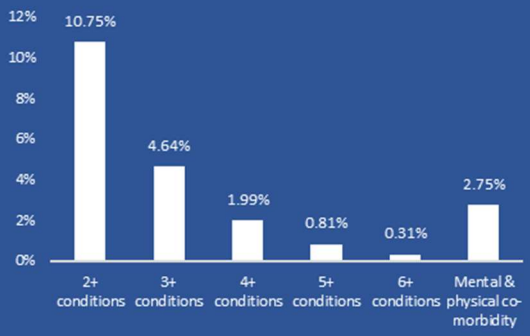
#5 It's preventable
The most common disease 'clusters' include diabetes, CVD and respiratory diseases, all preventable

#6 It's costly
£7 in every £10 in health and social care is spent on people living with multimorbidity

#7 It's complex
Multiple medical specialties; seen by primary, secondary and social care; overlaps with frailty and polypharmacy

The numbers in York

More than 1 in 10 York residents have multiple long term conditions. Whilst age-related, 13.8% of the multi-morbid population is under the age of 65. Multi morbid patients account for nearly a third of hospital patients, with nearly twice the average length of stay. They had on average double the number of GP appointments per year, and more than double the average number of prescriptions. 25% of CYC social care clients are multimorbid.



Rates of some key risk factors are higher in those with multiple conditions:

- 1.1x Smoking
- 2.5x Obesity
- 5x High BP

Living with multimorbidity was highly correlated with deprivation

- 2x DSR of 906 per 100k in least deprived decile vs 1,753 per 100k in most deprived

There were a number of common clusters of conditions:

- Coronary Heart Disease + Diabetes
- Asthma + Depression
- Chronic Kidney Disease + Diabetes

The experiences of York residents

- Basic levels of care and support rated well; people didn't feel supported with the things that were most important for them
- People really struggled with getting healthcare professionals to communicate with them, and with one another
- People were in general less happy and more anxious than the York population.

'in terms of daily living, my multiple conditions feel like a restraining order'

'We need improved transport, appointment availability (e.g. out of hours), and less jargon

'Independence is empowering and very important to maintain if you can'

'continuity of care seems to have been non-existent'

1. Multimorbidity: 7 reasons it matters

Multimorbidity is set to become one of the defining features of public health and healthcare in the twenty-first century.

Over the last seventy years, the burden of disease in the UK has shifted from acute infections, such as pneumonia and diphtheria, to chronic, non-communicable diseases, such as diabetes and heart failure. These are often termed 'long term conditions', which the Department of Health and Social Care defines as

> *'conditions which cannot at present be cured but can be controlled by medication and other therapies'*

Over this period, life expectancy has risen, but it has become more common for individuals to live a significant part of that extra life in poor health. Increasing numbers of people are living not with just one long condition but with clusters of conditions, 'multimorbidity', often causing much physical and mental distress, an accelerated loss of mobility or bodily function, deterioration of social and mental wellbeing, and a higher rate or premature death. This was recognised as a major issue facing the NHS in its 2019 Long Term Plan:

> People are now living far longer, but extra years of life are not always spent in good health... They are more likely to live with multiple long-term conditions, or live into old age with frailty or dementia, so that on average older men now spend 2.4 years and women spend three years with 'substantial' care needs (NHS England 2019)

Yet it could be argued that our primary model of health is still single-disease focussed, both in terms of prevention and treatment. Patients are often treated by single-disease teams, by doctors trained in a single specialism, in services planned on a single-disease model. This is despite well-established evidence that having one disease markedly increases the risk of developing further conditions, and that high quality treatment for multiple diseases requires a type of patient-centred care co-ordination (across specialisms, teams, primary and secondary care) which is not always achieved.

There are number of key reasons multimorbidity matters for health professionals and the public in York, reasons which provide the impetus for this health needs assessment:

Reason #1: It's big

The key and most relevant recent national epidemiological study on multimorbidity, carried out in Scotland, found that from a cohort of 1.7m people registered with over 300 GP practices, 23.2% of patients had 2 or more long term conditions (Barnett 2012). Modelling for York's population bears this

out: while nearly half of our population are living with a long term condition (Health Foundation 2019), half again of these people are living with 2 or more conditions, a quarter with 3 or more, and 1 in 6 with physical and mental health co-morbidity (PHE 2019).

Although multimorbidity is more common in older age groups, Barnett and colleagues found that actually the absolute number of people living with more than one condition under the age of 65 was higher than in the over 65 population, meaning that this problem needs to be disentangled from the concept of the 'ageing society', and seen as something which affects all ages.

Analysis of data from the Whitehall II study cohort has shown that multimorbidity is associated with a 4.1 times increased risk of mortality, a larger scale of risk than either frailty (2.4 times) or disability (1.7 times) (Dugravot 2019).

Reason #2: It's growing

As the number of people with long term conditions increases so does the number of people with multimorbidity; but evidence shows that this second change is occurring at a faster rate. One modelling study suggests that between 2015 and 2035 there will be an expansion of morbidity in England: the proportion of people with 4+ diseases will almost double, and two out of three from this group will have mental ill-health (Kingston 2018). Looking retrospectively at a German health insurance scheme population, one study found that over 10 years the expected lifespan of study subjects with multimorbidity expanded, but people's multimorbidity-free years decreased because of the earlier onset of chronic conditions (Teztlaff 2017).

Reason #3: It's tragic

This leads to one of the tragedies of the multimorbidity era, whereby our society's life expectancy gains are likely to be offset, or even surpassed, by an increase in the number of years living with multiple conditions, meaning that effectively all we are doing is increasing the absolute amount of ill health. Kingston (2019) models lifespan gain at age 65 between 2015 and 2035 as 3.6 years for men and 2.9 years for women, whereas the increase in years spent with multi-morbidity is forecast to be 5.5 years for men and 5.0 years for women. In response to the Health Aging Challenge, the UK government have set an aspiration to increase healthy life expectancy by at least 5 years by 2035 for England, while also reducing the gap in life expectancy between the richest and the poorest groups within the population (DOHSC 2018). Some policy options to achieve this have recently been set out (Marteau 2019), but without significant policy investments these long term trends will be hard to reverse.

Reason #4: It's inequitable

One of the starkest messages from the work on multimorbidity in Scotland was that onset of multimorbidity occurred ten to fifteen years earlier in people living in the most deprived areas (Barnett 2012). Socioeconomic deprivation was particularly associated with multimorbidity that included mental health disorders. As well as onset of multiple conditions, this also extends to mortality, with a Danish study showing that overall 1 year death risk at for people with four or more conditions was raised in people at a lower economic level, an association that held for premature death (Jensen 2017). While some of this difference can be explained by lifestyle choices, access to quality healthcare may also play a part: a study of 47 GP practices in Glasgow showed patients with multimorbidity in affluent areas received longer consultations than patients without multimorbidity, whilst in deprived areas this was not the case. Primary care funding in England does not adequately reflect the contemporary morbidity burden, which is higher in more deprived areas (Kontopantelis 2018). Clinical evidence and guidelines are largely created for individual diseases, and most randomised trials exclude multimorbid people (Van Spall, 2007)

Reason #5: Its often preventable

Some of the most common long terms conditions have a highly preventable component:

- cardiovascular diseases can be avoided by keeping healthy blood cholesterol levels through physical activity, healthy diets and in some cases taking statin medication
- stroke and transient ischaemic attack can often be avoided by good blood pressure control
- diabetes is closely related to a number of modifiable factors, including living an inactive life, having a high sugar intake, having a BMI over recommended levels, and smoking
- COPD is closely related to smoking and poor air quality

Research by Guys+St Thomas charity found that 96% of people in two London boroughs with multimorbidity had more than 1 'risk factor', including a high QRisk2 score, hypertension, obesity, cholesterol and alcohol consumption. Genetic and other environmental factors play their part in causing long term conditions, as does the close relationship with socioeconomic status and the wider determinants of health such as income and housing. But it is clear that many of the drivers of long term conditions are modifiable through lifestyle change and primary care.

When it comes to multimorbidity, a single condition can itself be a risk factor for the development of a second condition: for instance, diabetes is a risk factor for cardiovascular and chronic kidney disease, atrial fibrillation is a risk factor for stroke/TIA, and childhood asthma is a risk factor for later development

of COPD. Hypertension, classed as a long term condition by most health systems, is a risk factor for a large number of circulatory diseases and internal organ damage.

Analysis of data from the Whitehall II study cohort has shown that socioeconomic status affects the risk of multimorbidity, frailty, and disability, but does not affect the risk of mortality after the onset of these adverse health conditions; the authors of this study conclude therefore that primary prevention (preventing diseases occurring in the first place) is key to reducing social inequalities in mortality, rather than focussing entirely on better healthcare after the diseases arise (Dugravot 2019).

Reason #6: It's costly

Long term conditions account for 50% of all GP appointments, 64% of all outpatient appointments and over 70% of all inpatient bed days - in total representing around £7 in every £10 of total health and social care expenditure (DoH 2012). A study of 60,000 patients registered with GPs in Stoke on Trent found the average 3-year total costs per multimorbid patient for hospital admissions ranged from between £2289 and £5344. The adjusted costs were significantly higher for six multimorbid groups compared with their respective single disease groups (Kadam 2013). In terms of emergency department attendance, a retrospective cohort analysis of linked primary and secondary care records in London found a sixfold increase in ED attendance rates in those with four or more comorbidities (Hull 2018). It is clear that people living with multiple long term conditions are higher users of healthcare and for each 'unit' of healthcare they present more complex symptoms which cost the system more to treat.

Reason #7: It's complex

Care and treatment for people living with more than one long term condition is often complex. Whilst diseases which fall within the same body system – such as peripheral arterial disease and cardiovascular disease – might be amenable to some similar treatments, this is not the case with diseases in different bodily systems e.g. epilepsy and diabetes. Drug-drug, Drug-disease and disease-disease interactions are frequent, and difficult clinical decisions are often to be made, for instance weighing up the use of a non-steroidal anti-inflammatory drug in rheumatoid arthritis or after stroke with harms in other disease areas such as the risk of gastric bleeding or the increased risk of fluid retention and its effects in heart failure.

When patients are under several specialists who may never meet one another, when clinical guidelines focus on single diseases, and when continuity of GP in primary care is not guaranteed, the management of multimorbidity can often need substantial amounts of coordination. In older people, multimorbidity also overlaps with frailty, cognitive and functional impairment, and will often involve social care as well as healthcare, adding another layer of complexity.

The patient often bears the highest burden of treatment, attending multiple medical appointments, arranging transport, losing earnings from time taken off work, facing the burden and occasionally harm of taking multiple medications (polypharmacy), dealing with side-effects of medication, and regularly having to self-monitor health issues e.g. blood glucose levels. Patient testimony from Guys+St Thomas charity graphically illustrates the effect this can have on daily life:

> *"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*

> *"One of the by-products of the granulomatosis is Type 2 diabetes. It was just a reaction to the vast amounts of steroids that I had to take. A couple of the drugs altered my liver functions, so I went to a liver specialist a few times." Lindsay, 56*

This can seriously affect quality of life, with one study finding the mean EQ-5D score for participants with no conditions was 0.945 compared to 0.355 for participants with five or more conditions (Li 2016). Much of this is related to chronic pain, which one study suggests is coded on patient records for one in ten multimorbid patients in primary care (Casall 2018).

Finally, people with multimorbidity who also experience complex social needs, such as addiction, housing issues, debt, contact with the criminal justice system may also struggle to engage with healthcare, leading to late presentation and diagnosis of problems and poor adherence to treatment.

Case study one: Susan, 51, from Tang Hall

Conditions: Susan lives in one of York's more deprived wards. She has inflammatory Arthritis, Rheumatoid and Osteoarthritis, early stage Multiple Sclerosis, Sleep Apnoea and Coeliac disease. Susan is also a carer for her daughter who has Autism, Anxiety disorder, Obsessive Compulsive Disorder, Dyspraxia, Asthma, Dyscalculia and Coeliac disease; she also has seizures.

Impact on life: Susan uses a wheelchair or mobility scooter, and has had to have various adaptations made to her home. She is unable to work and finds it more difficult to do daily tasks such as cooking due to weakness in her left arm. Susan has to make arrangements for alternative care for her daughter if she herself needs to attend hospital appointments and organise transport. Everything in life seems to take longer, for example, shopping together when the family has a combination of physical, mental health and behavioural issues.. Holidays cost more due to family rooms not being accessible, and it is difficult to find meaningful activity for her daughter.

What could services do to make things easier: Susan would find her life easier if she could get a regular break. If staff looked at records so that she didn't have to explain everything every time, or if there was better continuity of staff, this would help. She finds her GP practice generally good, but in one example a difficulty she was sent an appointment to discuss how a procedure had gone when she had not yet had the procedure; when ringing to point this out she was questioned and disbelieved. Recent issues have included problems accessing a dentist who is both physically accessible and able to cater for someone with anxiety.

2. Epidemiology of multimorbidity in York

2.1 Methodology and data sources

One of the first challenges in exploring the distribution pattern of multiple long term conditions in any local population is the availability of data. Published data sets invariably focus on one long term condition at a times, instead of combinations of conditions. The key data sources to understand the epidemiology of multimorbidity are:

- GP disease registers, collecting data on the prevalence of 16 of the most common long term conditions
- Hospital admissions data, in which long term conditions are coded as either the reason for admission or recorded as a pre-existing condition on the patient's notes
- Data collected by other providers on their service users, for instance social care.

In the York area, these three datasets do not 'speak to one another', so it is currently impossible to crossmatch patients across areas of health and social care. For example, we could not say how many people in receipt of a homecare package with a diagnosis of osteoarthritis and dementia have been admitted to hospital for fractures last year. Positive work on data linkage and infrastructure to support this type of analysis is being undertaken, and may mean in the future we can gain this deeper level of understanding of our population's health needs.

For the purposes of this project, we have looked at this information as three separate datasets. To do this we have worked with:

- The LMC and through the York Integrated Care Team to extract data on multiple conditions from practice registers held in primary care
- York Teaching Hospitals NHS Foundation Trust to extract data on patients admitted with multiple conditions in 2018/19
- City of York Council's Business Intelligence Hub to extract data on social care service users with multiple conditions

This data has been extracted under strict data protection agreements, and specifically we have worked with YorLMC to ensure that primary care data has been shared with the public health team in a manner consistent with GDPR. Data is presented in this report in aggregate form to prevent any patient from being identifiable.

For the qualitative aspects of this report in other chapters, we define a long term condition under its widest definition from the Department of Health and Social Care as any condition which cannot at present be cured but can be controlled by medication and other therapies. In this chapter, due to the way data is coded on healthcare records we define long term conditions according to the 19 QOF prevalence registers (NHS England 2019). These conditions included are shown below.

Long Term Conditions included in our analysis of multimorbidity

Diabetes	Depression	Dementia	Chronic Kidney Disease
Asthma	Atrial Fibrillation	Stroke & TIA	Coronary Heart Disease
Heart Failure	Osteoporosis	Rheumatoid Arthritis	Peripheral Arterial Disease
Epilepsy	Hypertension	Severe Mental Illness[1]	Learning Disabilities
COPD	Cancer	Palliative care	

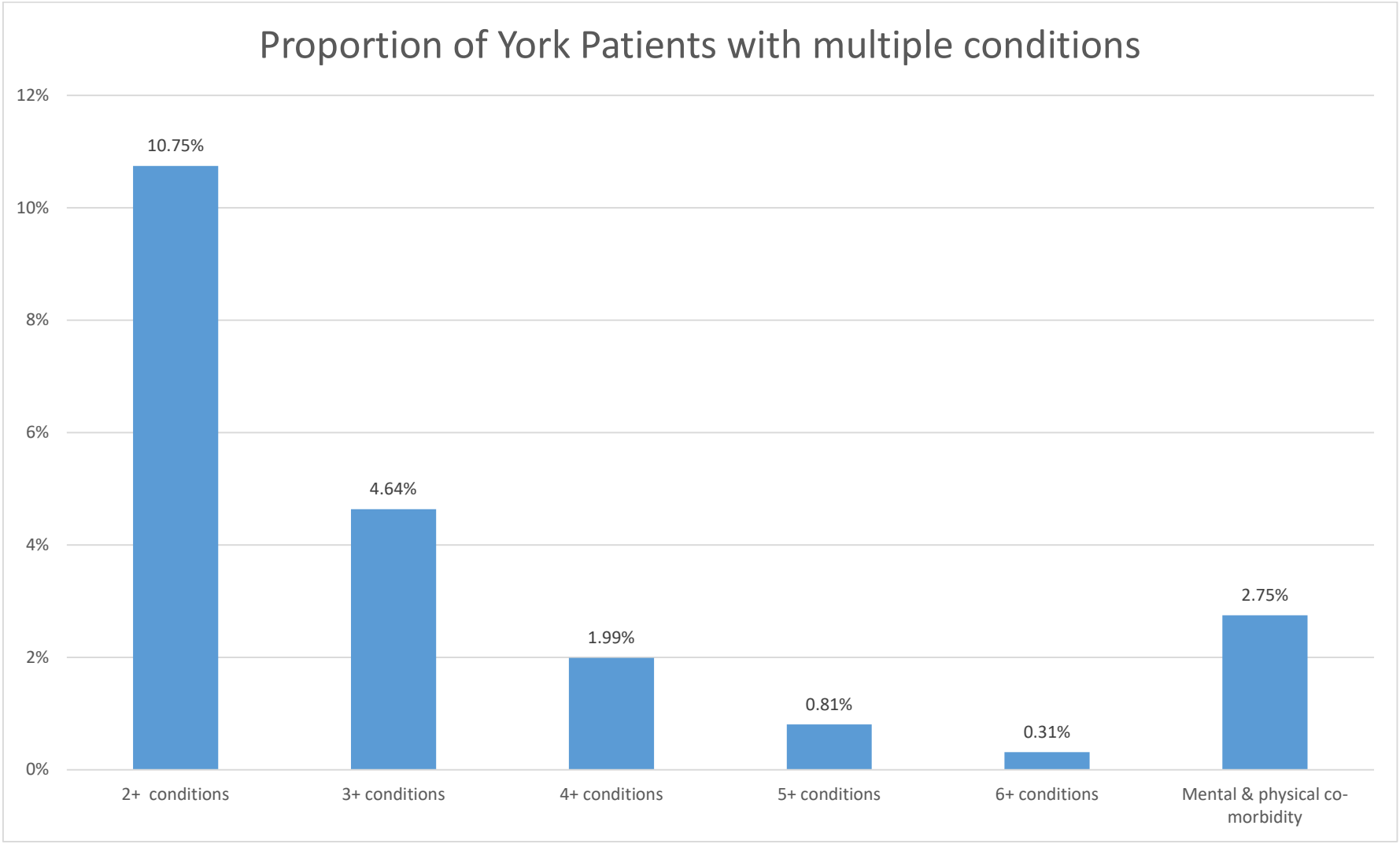
2.2 Multimorbidity recorded by GP practices

Primary care records give the fullest picture of who in the city of York is living with multiple conditions. Most of the conditions listed above are diagnosed in primary care, and practices keep specific disease registers on all their patients as part of the Quality and Outcomes Framework (QOF). While there are some groups who have lower levels of GP registration (students, recent migrants, those who are homeless), in general most of the population in York are registered with a GP.

Patients are described as having multimorbidity if the GP records showed they had two or more QOF conditions. The following data draws from the patient records of 10 GP practices within York Primary Care Networks.[2]

A breakdown of the multi-morbid population by the number and type of conditions, gender, and age band is shown in the graph and table below.

[1] This includes all patients with a diagnosis of schizophrenia, bipolar affective disorder and other psychoses
[2] Elvington Medical Practice was not covered by the York Integrated Care team at the time this report was written, and data was not able to be extracted from the Practice. A synthetic estimate has been made when presenting York-wide data to include Elvington; the methodology is described in Appendix x


Proportion of York Patients with multiple conditions
12%
10%
8%
6%
4%
2%
0%
10.75%
4.64%
1.99%
0.81%
0.31%
2.75%
2+ conditions
3+ conditions
4+ conditions
5+ conditions
6+ conditions
Mental & physical co-morbidity

Category		No.	%	Denominator for %
Breakdown by no. of conditions	2+ conditions	24,124	10.75%	Total practice population
	3+ conditions	10,408	4.64%	
	4+ conditions	4,469	1.99%	
	5+ conditions	1,812	0.81%	
	6+ conditions	704	0.31%	
Breakdown by gender	2+ conditions male	11,646	10.64%	Gender specific practice pop'n
	2+ conditions female	12,478	10.85%	
Breakdown by age band	2+ conditions 0-24	214	0.31%	Age specific practice population
	2+ conditions 25-44	1,457	2.39%	
	2+ conditions 45-64	5,924	10.92%	
	2+ conditions 65-84	12,835	37.31%	
	2+ conditions 85+	3,694	67.71%	
Breakdown by physical / mental health conditions	2+ mental health only	257	0.11%	Total practice population
	2+ physical health only	17,700	7.88%	
	2+ mental and physical health mixed	6,167	2.75%	

In summary:

- There were a total of 24,124 patients with 2 or more QOF conditions across the 10 practices. This represents 10.75% of the total all age aggregated practice population. The multi-morbid patients were primarily aged 15+ (only three patients were aged 0-14). The multi-morbid cohort represents 12.51% of the 15+ total aggregated practice population.
- Some multi-morbid patients have a more than 2 conditions e.g. 4,469 patients (2% of the total practice population) have 4 or more conditions.
- There is no significant difference in the percentage of men and women who have multi-morbidity: 10.64% of males (95% CI 10.46%-10.82%) and 10.85% of women (95% CI 10.67%-11.03%).
- The prevalence of multi-morbidity increases with age e.g. 67.1% of people aged over 85 have multi-morbidity compared with 10.92% of people aged 45-64.
- The majority of multi-morbid patients (73%) have a combination of physical health conditions only. 26% have a combination of physical and mental health conditions and 1% have a combination of mental health conditions only.

98.3% of the multi-morbid cohort found in GP records were York residents. 419 multi-morbid patients out of 24,124 were non York residents who are registered with a York GP practice. These patients are

included in the analysis in this section but are not included in subsequent analysis by ward and deprivation decile.

2.3 Rates of multi-morbidity by GP practice

The number and proportion of patients on practice registers with multiple conditions varies considerably by practice, with Haxby Group having the highest and Unity the lowest proportion of registered patients on two condition registers (Unity, as noted, has a very different population to other practices in York). A proportion has also been calculated for patients over the age of 15.

GP Practice	Total multi-morbid patients	Total patients in Practice (all ages)	Total patients in Practice (all 15+)	% multi morbid (out of total practice population)	% multi morbid (out of 15+ practice population)
Front Street	1,138	8,118	6,935	14.0%	16.4%
Haxby Group	5,062	32,486	27,704	15.6%	18.3%
The Old School	898	7,481	6,267	12.0%	14.3%
Priory Group	6,834	58,715	48,330	11.6%	14.1%
York Medical Group	5,122	44,586	38,592	11.5%	13.3%
Dalton Terrace	948	8,434	7,279	11.2%	13.0%
Unity Health	613	22,066	21,020	2.8%	2.9%
Yorvik Gillygate	1,796	20,973	18,393	8.6%	9.8%
My Health	1,446	19,300	16,180	7.5%	8.9%
East Parade	267	2,334	2,073	11.4%	12.9%
Total	**24,124**	**224,493**	**192,773**	**10.75%**	**12.51%**

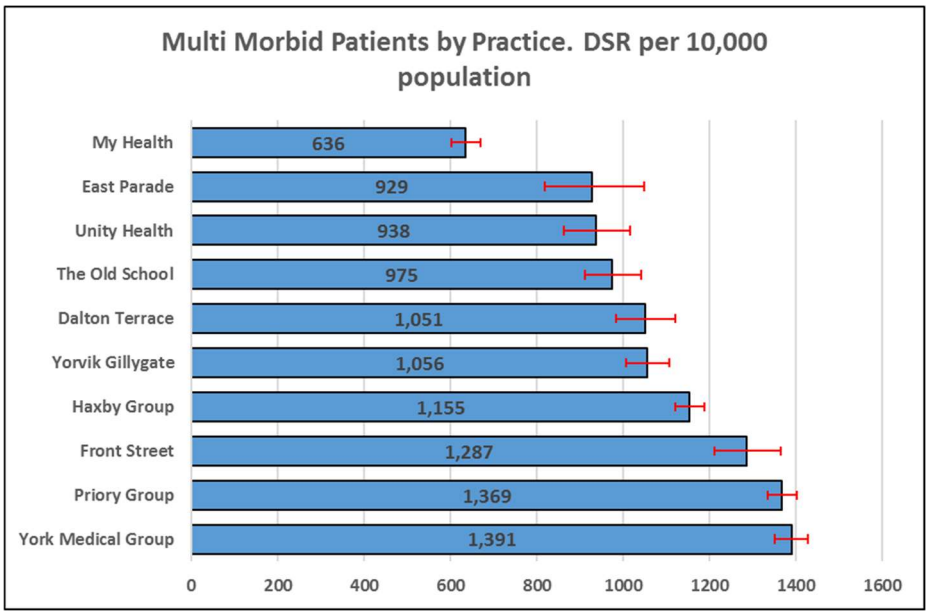
Rates of multimorbidity increase with age, and the age profiles of the GP practices are different[3] so to ensure a valid comparison, directly age standardised rates for each practice have been calculated. The directly standardised rates of multi-morbidity vary twofold from 636 patients per 10,000 of practice population in My Health to 1,391 per 10,000 in York Medical group, with an all practice average of 1,163 per 10,000.

Differences between rates by practice should be interpreted with caution, and it is helpful to consider the three main reasons which may lie behind such variation:

- True differences in population health need: the health of the registered populations for each practices differs, and with it the rate at which long term conditions are incident. This would be strongly linked to deprivation (see below).

[3] For example 56.8% of the Unity Health practice population is aged 0-24 compared with a York average of 31%. The age profiles for each practice are shown the appendices.

- Differences in the way long term conditions are managed, meaning a second condition is less likely to occur for some patients
- Some practices may be more successful in inviting patients in to diagnose certain conditions e.g. Diabetes and hypertension which are well known to lie undetected for several years before patients become symptomatic enough to seek medical help.



Differences between rates by practice should be interpreted with caution, and it is helpful to consider the three main reasons which may lie behind such variation:

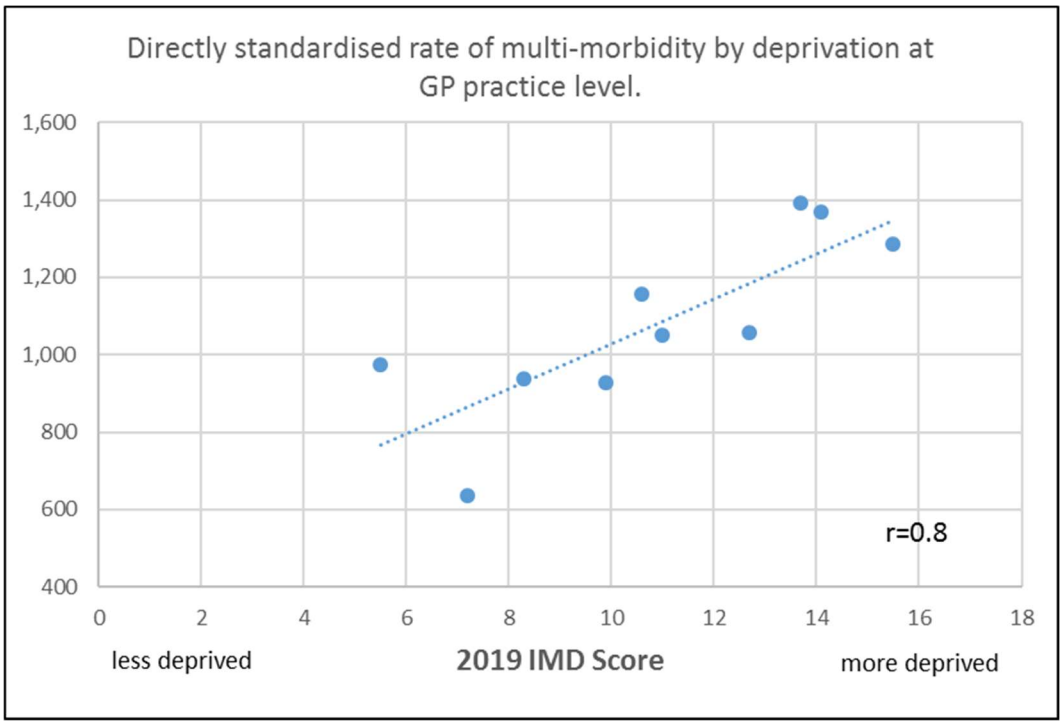
- True differences in population health need: the health of the registered populations for each practices differs, and with it the rate at which long term conditions are incident. This would be strongly linked to deprivation (see below).
- Differences in the way long term conditions are managed, meaning a second condition is less likely to occur for some patients
- Some practices may be more successful in inviting patients in to diagnose certain conditions e.g. Diabetes and hypertension which are well known to lie undetected for several years before patients become symptomatic enough to seek medical help.

2.4 Deprivation and multimorbidity by GP practice

As the graph below shows, there is a significant positive correlation between the rate of multi-morbidity and deprivation at GP practice level i.e. higher rates of multimorbidity are associated with higher levels of deprivation, as measured using the Index of Multiple Deprivation 2019 score for each practice, which is a

composite national measure aiming to reflection deprivation in income, employment, health, education, crime, housing and environment.

At individual level, this relationship with deprivation is very strong, as analysis later in this document demonstrates. It is noticeable however that even at practice level in York – with some GP practices covering large and diverse areas of the city – practices with more deprived populations have worse outcomes in terms of multiple long terms conditions, suggesting that weighting resource to practices by deprivation may contribute to tackling health inequalities in the city.



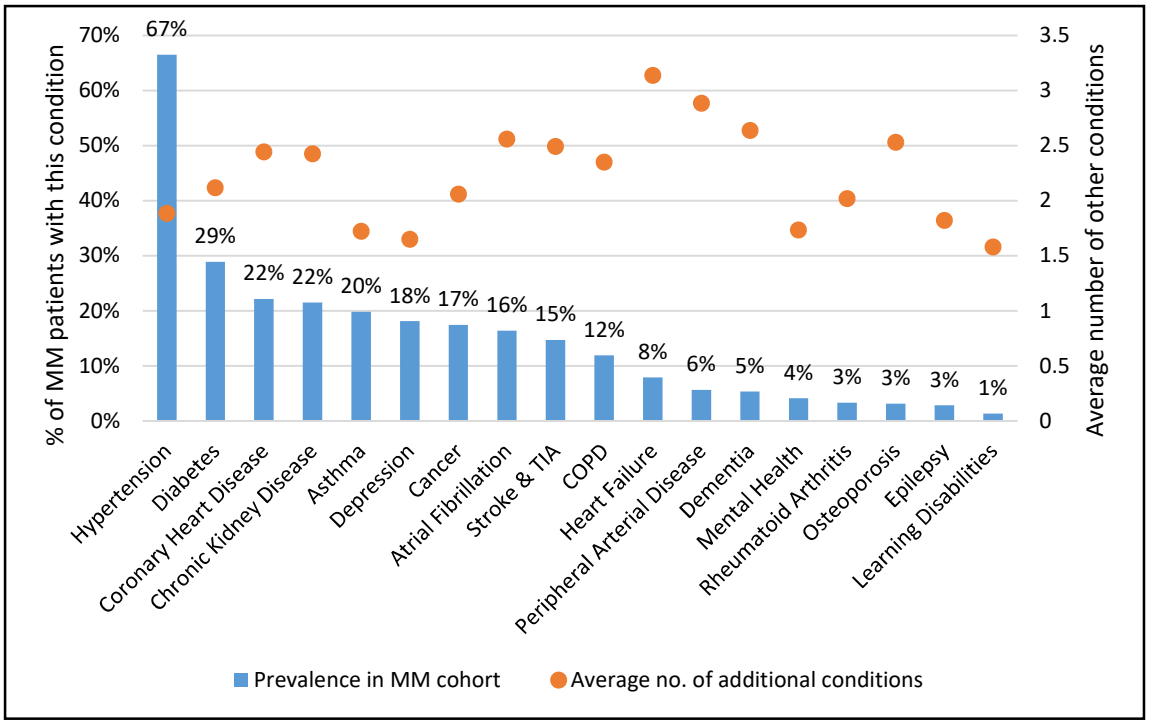
2.5 Clustering and distribution of long term conditions by GP Practice

As seen in the literature review below, there are common patterns or 'clusters' of long term conditions in the data which could indicate opportunities for targeted work on prevention or better management.

Firstly it is helpful to understand the most frequently occurring single conditions amongst multi-morbid patients. These are hypertension (66.5%); diabetes (28.9%); coronary heart disease (22.1%) and chronic kidney disease (21.5%), and this suggests they are a very strong component of multimorbidity: most people living with more than one long term condition in York has one or more of these conditions.

Condition	No. of multi-morbid patients with this condition	% of multi-morbid patients with this condition (n=24,124)
Hypertension	16,041	66.5%
Diabetes	6,970	28.9%
Coronary Heart Disease	5,335	22.1%
Chronic Kidney Disease	5,176	21.5%
Asthma	4,784	19.8%
Depression	4,378	18.1%
Cancer	4,188	17.4%
Atrial Fibrillation	3,967	16.4%
Stroke & TIA	3,543	14.7%
COPD	2,862	11.9%
Heart Failure	1,910	7.9%
Peripheral Arterial Disease	1,348	5.6%
Dementia	1,278	5.3%
Mental Health	989	4.1%
Rheumatoid Arthritis	793	3.3%
Osteoporosis	747	3.1%
Palliative care	703	2.9%
Epilepsy	665	2.8%
Learning Disabilities	321	1.3%

As the following chart shows however, the conditions which are most common in the multimorbid cohort are not necessarily the conditions which 'cluster' the most. The blue bars indicate the prevalence of the condition amongst our cohort, but the dots indicate the average number of other conditions people with each condition have. This shows that – for example – while only 6% of the multimorbid cohort live with Peripheral Arterial Disease, those who do have this condition have an average of 3 other conditions, whilst those who live with hypertension (67%) have an average of 2 other conditions.



The tables overleaf show the top ten clusters of conditions, firstly by two conditions, then by three conditions, and then with hypertension excluded (given the fact that it is a very prevalent condition). After this, a diagram shows each condition matched against all other conditions, with particularly strong correlations shown.

These tables and diagrams demonstrate that:

- The most frequently occurring pairs of conditions amongst multi-morbid patients were: hypertension and diabetes (20.6%); hypertension and chronic kidney disease (16.7) and hypertension and coronary heart disease (13.8%).
- The most frequently occurring sets of three conditions amongst multi-morbid patients were: diabetes, hypertension and chronic kidney disease (4.7% of multi morbid population); diabetes, hypertension and coronary heart disease (4.0%); chronic kidney disease, hypertension and coronary heart disease (3.8%).
- If hypertension is excluded from the analysis, the most frequently occurring pairs of conditions are: coronary heart disease and diabetes (6.4%): asthma and depression (5.9%) and chronic kidney disease and diabetes (5.8%). Given hypertension is an underlying risk factor of all these diseases,

`

Pairs of Conditions (top 10)	No, of patients with this pair of conditions	% of multi morbid population (n=24,124)	% of total practice population (n=224,493)
Hypertension and Diabetes	4,961	20.6%	2.2%
Hypertension and Chronic Kidney Disease	4,034	16.7%	1.8%
Hypertension and Coronary Heart Disease	3,321	13.8%	1.5%
Hypertension and Atrial Fibrillation	2,588	10.7%	1.2%
Hypertension and Cancer	2,554	10.6%	1.1%
Hypertension and Stroke & TIA	2,437	10.1%	1.1%
Hypertension and Asthma	2,221	9.2%	1.0%
Hypertension and Depression	1,716	7.1%	0.8%
Hypertension and COPD	1,607	6.7%	0.7%
Coronary Heart Disease and Diabetes	1,546	6.4%	0.7%

Combinations of three conditions (top 10)	No. of multi-morbid patients with these conditions	% of multi morbid population (n=24,124)
Diabetes, Hypertension, Chronic Kidney Disease	1,129	4.7%
Diabetes, Hypertension, Coronary Heart Disease	954	4.0%
Chronic Kidney Disease, Hypertension, Coronary Heart Disease	908	3.8%
Chronic Kidney Disease, Hypertension, Atrial fibrillation	742	3.1%
Coronary Heart Disease, Hypertension, Atrial fibrillation	715	3.0%
Diabetes, Hypertension, Atrial fibrillation	628	2.6%
Chronic Kidney Disease, Hypertension, Stroke & TIA	613	2.5%
Diabetes, Hypertension and Stroke & TIA	604	2.5%
Coronary Heart Disease, Hypertension, Stroke & TIA	588	2.4%
Atrial fibrillation, Hypertension, Stroke & TIA	586	2.4%

Pairs of Conditions (top 10) no hypertension	No, of patients with this pair of conditions	% of multi morbid population (n=24,124)
Coronary Heart Disease and Diabetes	1,546	6.4%
Asthma and Depression	1,422	5.9%
Chronic Kidney Disease and Diabetes	1,407	5.8%
Coronary Heart Disease and Chronic Kidney Disease	1,317	5.5%
Atrial Fibrillation and Coronary Heart Disease	1,161	4.8%
Atrial Fibrillation and Chronic Kidney Disease	1,007	4.2%
Heart Failure and Coronary Heart Disease	990	4.1%
Heart Failure and Atrial Fibrillation	924	3.8%
Atrial Fibrillation and Diabetes	898	3.7%
Stroke & TIA and Coronary Heart Disease	873	3.6%

Co-morbidities on GP registers in York

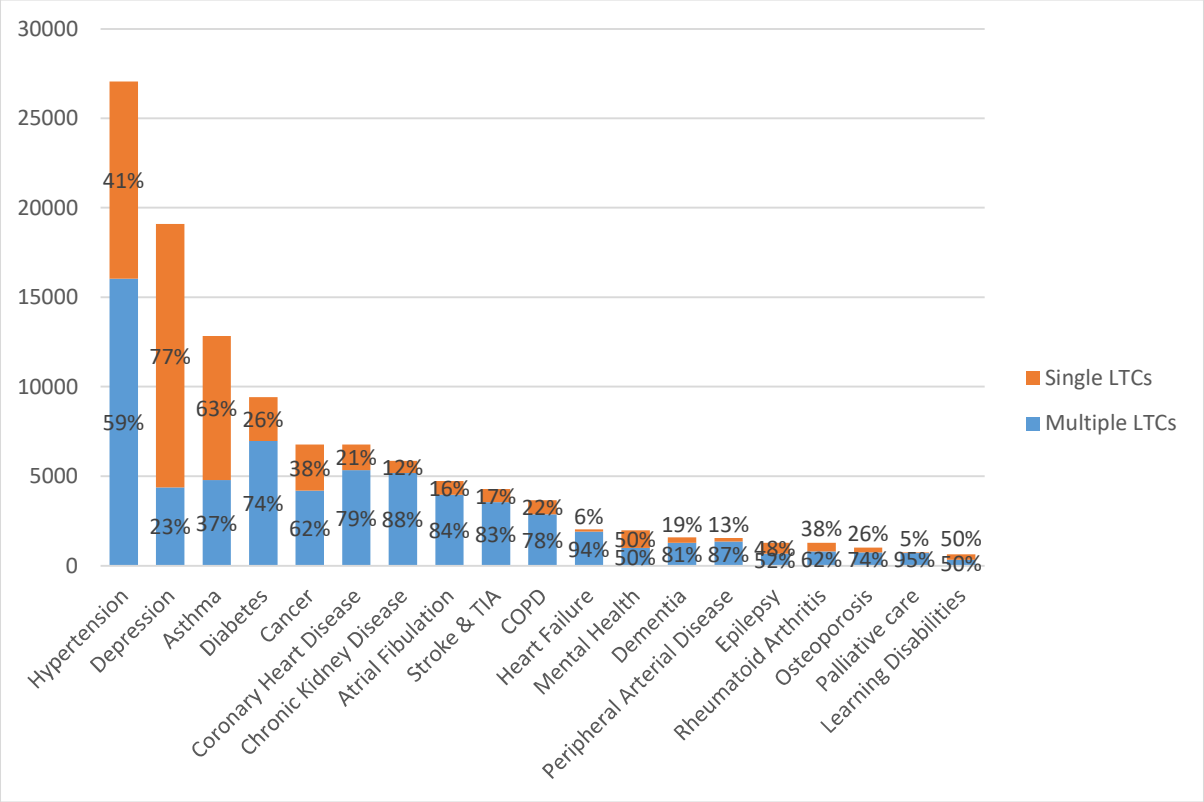
Patients with these conditions →

Who also have these conditions

Depression	Dementia	Chronic Kidney Disease	Cancer	Asthma	Coronary Heart Disease	Atrial Fibrillation	Stroke & TIA	COPD	Palliative care	Osteoporosis	Rheumatoid Arthritis	Peripheral Arterial Disease	Mental Health	Learning Disabilities	Hypertension	Heart Failure	Epilepsy	
826	277	1407	836	812	1546	898	828	589	180	109	137	474	200	55	4961	518	91	Diabetes
	115	319	464	1422	448	279	314	379	55	67	115	114	283	36	1716	167	107	Depression
		345	153	81	305	267	316	123	180	109	29	83	32	14	801	108	35	Dementia
			736	424	1317	1007	812	502	176	208	134	346	112	15	4034	614	50	Chronic Kidney Disease
				520	754	620	469	434	277	92	91	205	69	18	2554	273	50	Cancer
					533	378	320	643	69	88	124	91	169	41	2221	188	115	Asthma
						1161	873	658	196	147	113	494	88	11	3321	990	79	Coronary Heart Disease
							871	421	152	138	88	249	47	13	2588	924	50	Atrial Fibrillation
								382	147	141	75	264	93	15	2437	341	130	Stroke & TIA
									103	109	93	274	82	11	1607	280	35	COPD
										49	26	53	17	6	401	113	12	Palliative care
											26	40	20	4	468	64	10	Osteoporosis
												29	11	1	450	45	10	Rheumatoid Arthritis
													20	1	935	194	21	Peripheral Arterial Disease
														75	319	40	37	Mental Health
															75	6	110	Learning Disabilities
																1101	243	Hypertension
																	26	Heart Failure

Finally, it is possible to compare the number of people who have each condition in the multimorbidity cohort used for this project with the total number of people registered at York GP practices on disease registers. The comparison is inexact, as the data source of the total number of people on a register (National General Practice Profiles, PHE) is different to the direct GP extract used for the rest of this project, however both draw on the same underlying practice records.

As the diagram below shows, the proportion of people with each condition who are 'single morbid' and 'multimorbid' varies hugely. Less than a quarter of those living with depression in York have another condition, whereas only 6% of those living with Heart Failure do *not* have another condition.



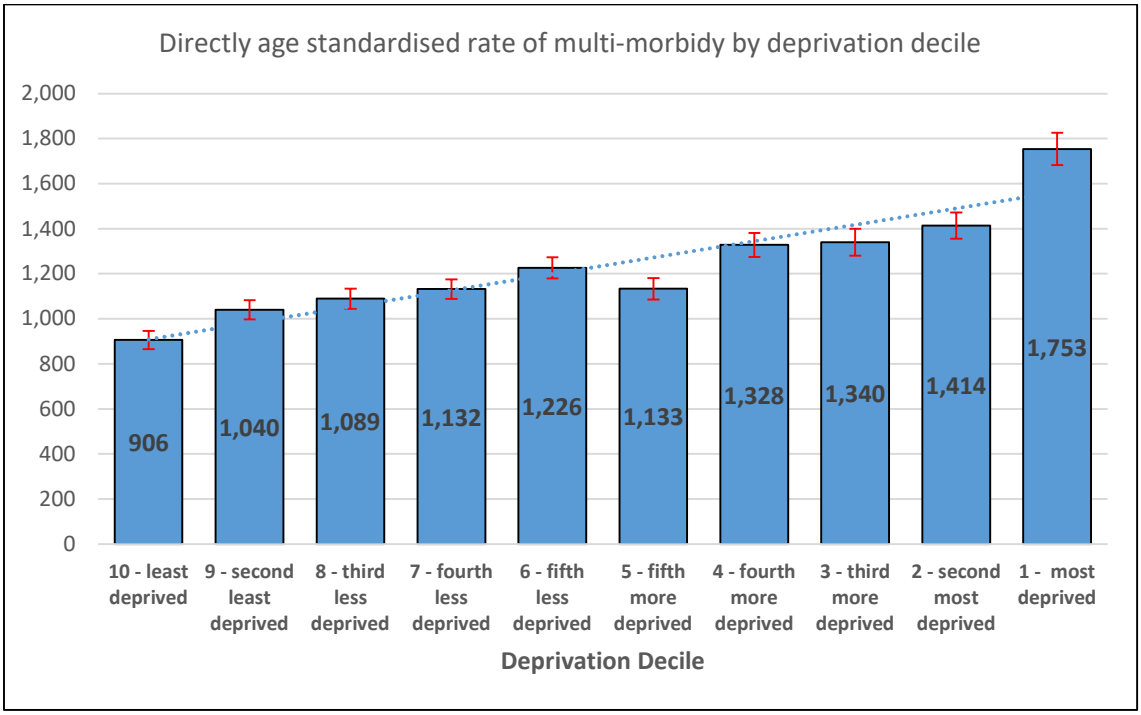
This suggests that services for some conditions could benefit from the presumption of multimorbidity and are much more likely to call for care coordination, multidisciplinary team working and need strong input on use of multiple medications and psychological / social support.

2.6 Multimorbidity by geographical area

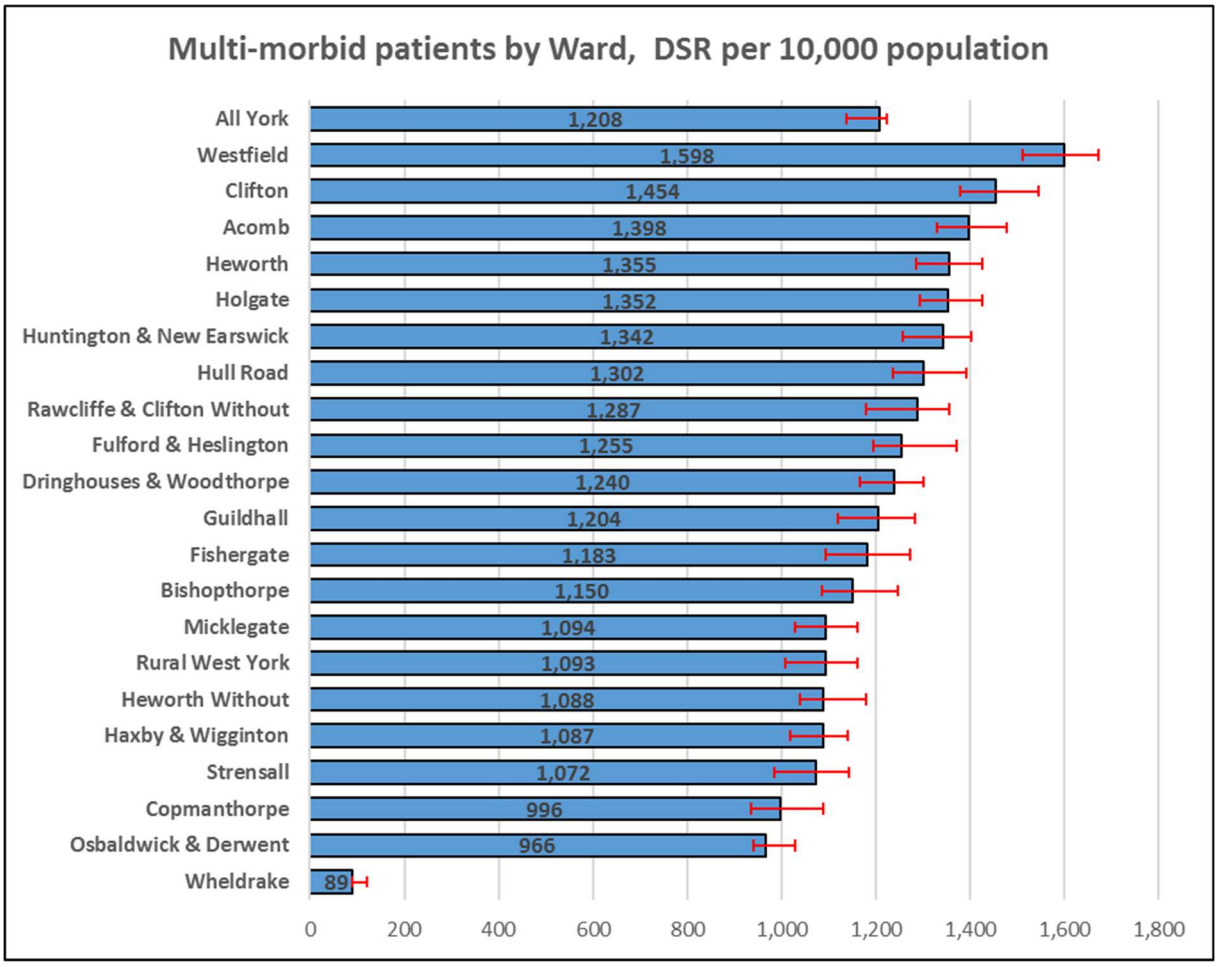
There were a total of 23,705 York residents with multi-morbidity. This represents 11.3% of the total population of York (209,893) and 13.2% of the 15+ population of York (179,013). This is likely to be an underestimate as 4,139 York residents who are registered with Elvington Medical Practice were not included in the analysis.

The directly standardised rates of multi-morbidity vary from 906 patients per 10,000 of population in the least deprived decile to 1,753 per 10,000 in the most deprived decile with a York average of 1,208 per 10,000. Higher rates of multi-morbidity are associated with higher levels of deprivation.

Decile	(DSR per 10,000)	95% CI DSR lower	95% CI DSR upper
10 - least deprived	906	866	946
9 - second least deprived	1,040	998	1,084
8 - third less deprived	1,089	1,045	1,135
7 - fourth less deprived	1,132	1,089	1,175
6 - fifth less deprived	1,226	1,179	1,274
5 - fifth more deprived	1,133	1,086	1,181
4 - fourth more deprived	1,328	1,275	1,382
3 - third more deprived	1,340	1,281	1,400
2 - second most deprived	1,414	1,356	1,473
1 - most deprived	1,753	1,683	1,826
All CYC	1,208	1,192	1,223



The directly standardised rates of multi-morbidity vary from 966 patients per 10,000 of population in Osbaldwick and Derwent to 1,598 per 10,000 in Westfield with a York average of 1,208 per 10,000. Higher rates of multi-morbidity are associated with higher deprivation (r=0.8).[4]

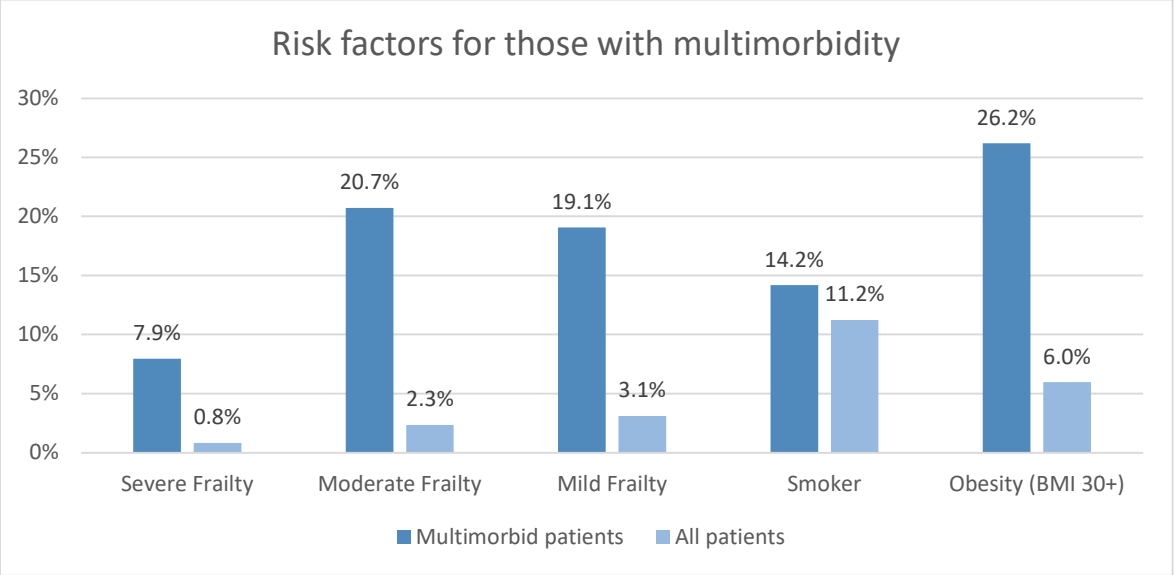


2.7 Risk factors and other features of those living with multimorbidity

The graphs and chart on the following page demonstrate that those living with multiple long term conditions often also live with frailty, a complex set of circumstances which increase vulnerability to stressors due to a dynamic, non-linear, and multidimensional depletion of physiological reserve and redundancy. The levels of mild, moderate and severe frailty are all higher in this multimorbid population. In addition, levels of smoking are higher, particularly in those with mental health problems and with COPD, and levels of high BMI are higher particularly in those with a learning disability and with diabetes. While these risk factors may have caused the onset of people's chronic conditions, they are likely to

[4] The rate for Wheldrake (89 per 10,000 of population) is significantly lower than for any other ward. It is likely that this rate is not a valid estimate due to the absence of data from Elvington Medical Practice. The majority of the York residents registered with Elvington Medical Practice reside in the Wheldrake Ward. The rate for Osbaldwick and Derwent may also be an underestimate.

exacerbate them future and lead to complex multimorbidity with a greater number of long term conditions arising sooner.



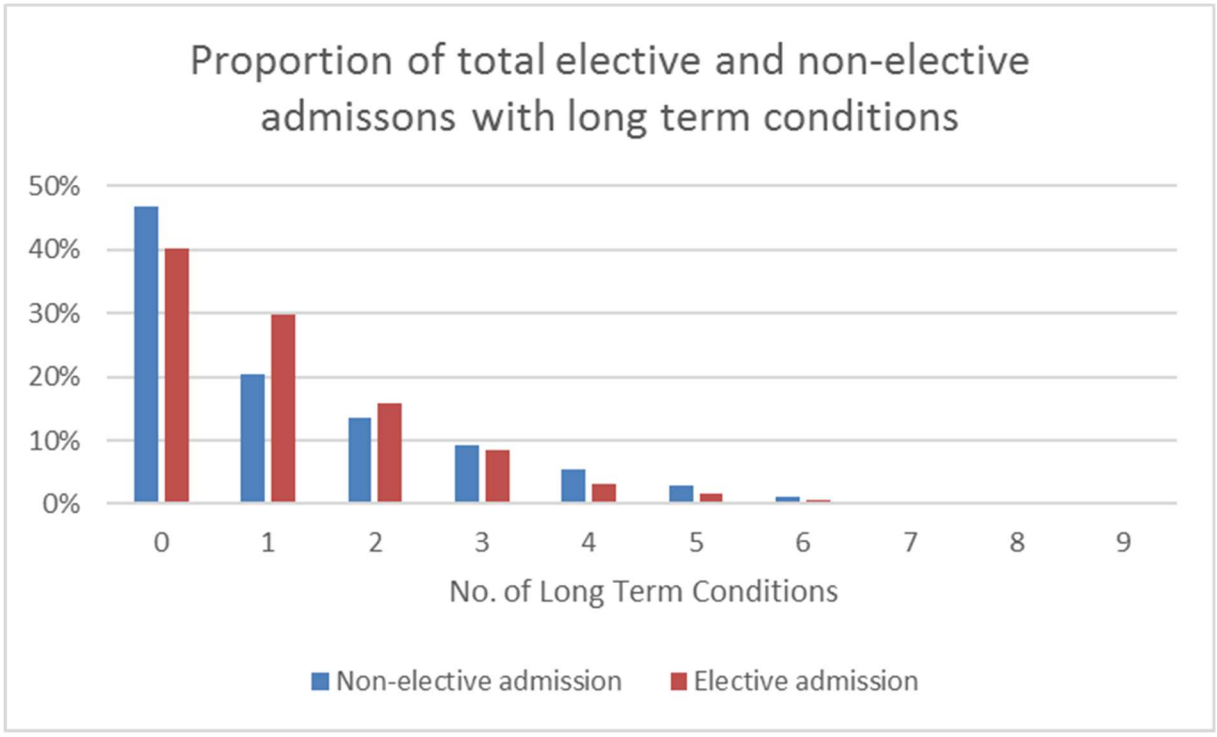
	Severe Frailty	Moderate Frailty	Mild Frailty	Current smoker	Obese (BMI 30+)
Diabetes	10.9%	18.8%	23.8%	13.3%	45.5%
Depression	3.9%	9.0%	12.1%	24.0%	26.8%
Dementia	30.9%	16.4%	39.0%	5.2%	9.3%
Chronic Kidney Disease	16.8%	21.3%	31.3%	8.6%	22.6%
Cancer	7.0%	19.3%	20.4%	10.8%	21.1%
Asthma	5.1%	14.2%	16.0%	17.3%	28.6%
Coronary Heart Disease	15.6%	20.7%	27.6%	11.6%	26.3%
Atrial Fibulation	17.1%	20.8%	31.3%	7.5%	22.7%
Stroke & TIA	17.7%	19.3%	29.1%	12.0%	19.2%
COPD	12.9%	19.0%	27.7%	31.9%	23.7%
Palliative care	51.2%	10.2%	25.6%	8.3%	12.2%
Osteoporosis	23.8%	19.0%	35.7%	7.6%	11.4%
Rheumatoid Arthritis	10.6%	18.0%	23.5%	12.6%	23.0%
Peripheral Arterial Disease	18.8%	16.9%	32.3%	23.8%	22.0%
Mental Health	5.9%	12.5%	14.4%	33.0%	27.2%
Learning Disabilities	5.0%	13.7%	17.1%	16.8%	38.6%
Hypertension	9.2%	20.8%	22.7%	11.0%	28.3%
Heart Failure	24.4%	15.0%	33.9%	10.6%	25.5%
Epilepsy	6.3%	12.9%	18.9%	17.4%	23.0%

2.8 Secondary care usage

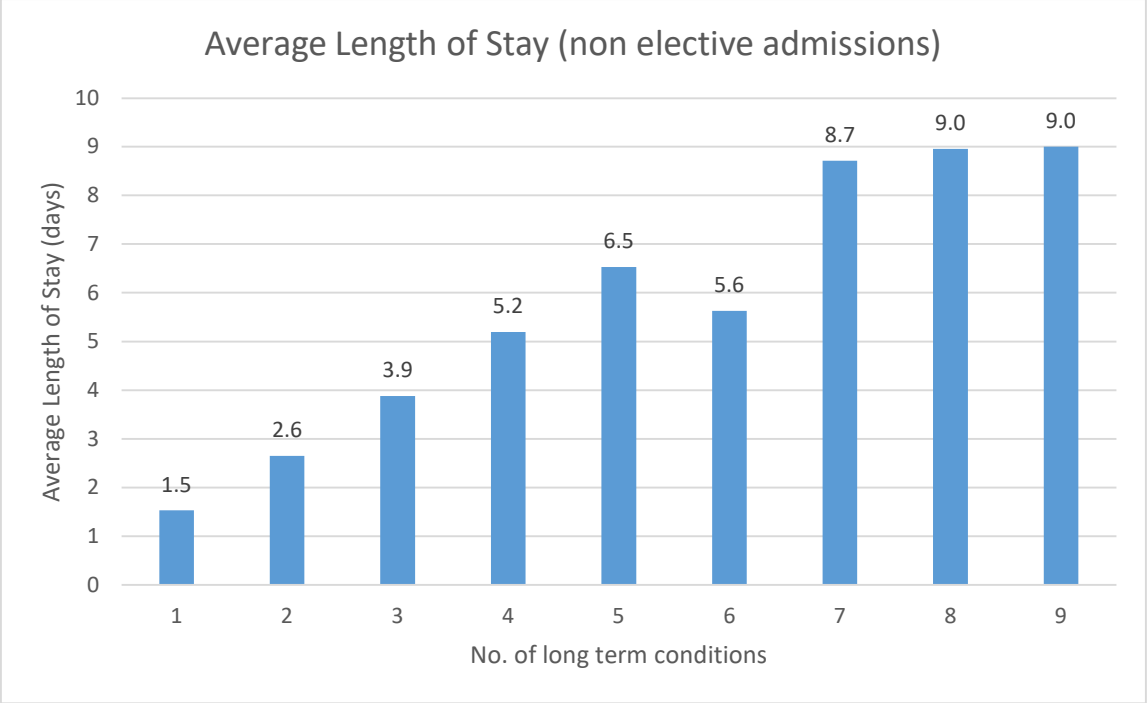
Using data from 2018-19 supplied by York Teaching Hospitals NHS Foundation Trust, and restricting the analysis to all patients with a City of York postcode, all non-elective and elective spells in hospital have been analysed by the long term conditions recorded in patient notes. For this analysis, QOF conditions were mapped onto hospital ICD-10 codes, but it should be noted that long term conditions are not always recorded in a patient's notes, and the presence of a long term condition does not indicate a reason for admission to hospital.

32.6% of people admitted as a non-elective admissions and 29.8% of people admitted as an elective admissions had two or more long term conditions. This means that nearly 1 in 3 patients at York hospital, whether admitted in an emergency or as part of planned care, lives with multiple long term conditions.

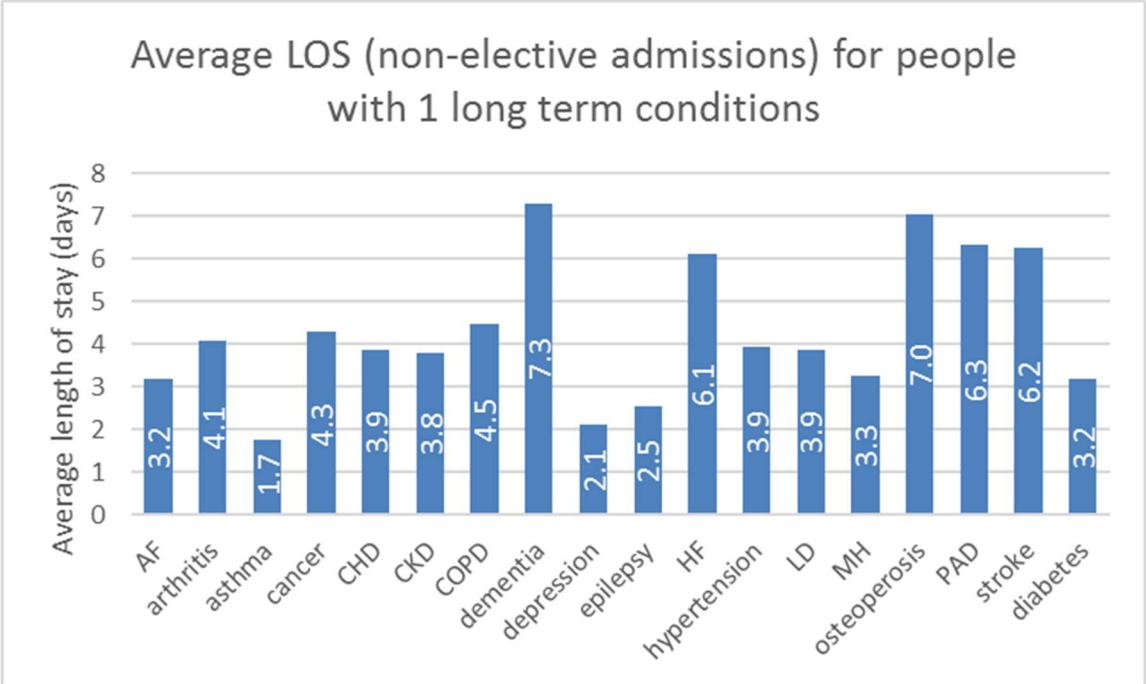
As the graph below shows, people with an elective admission were more likely to have 1 or 2 long term conditions than people with a non-elective admission; but people with a non-elective admission were more likely to not have a long term condition at all, or to have 3 or more long term conditions.



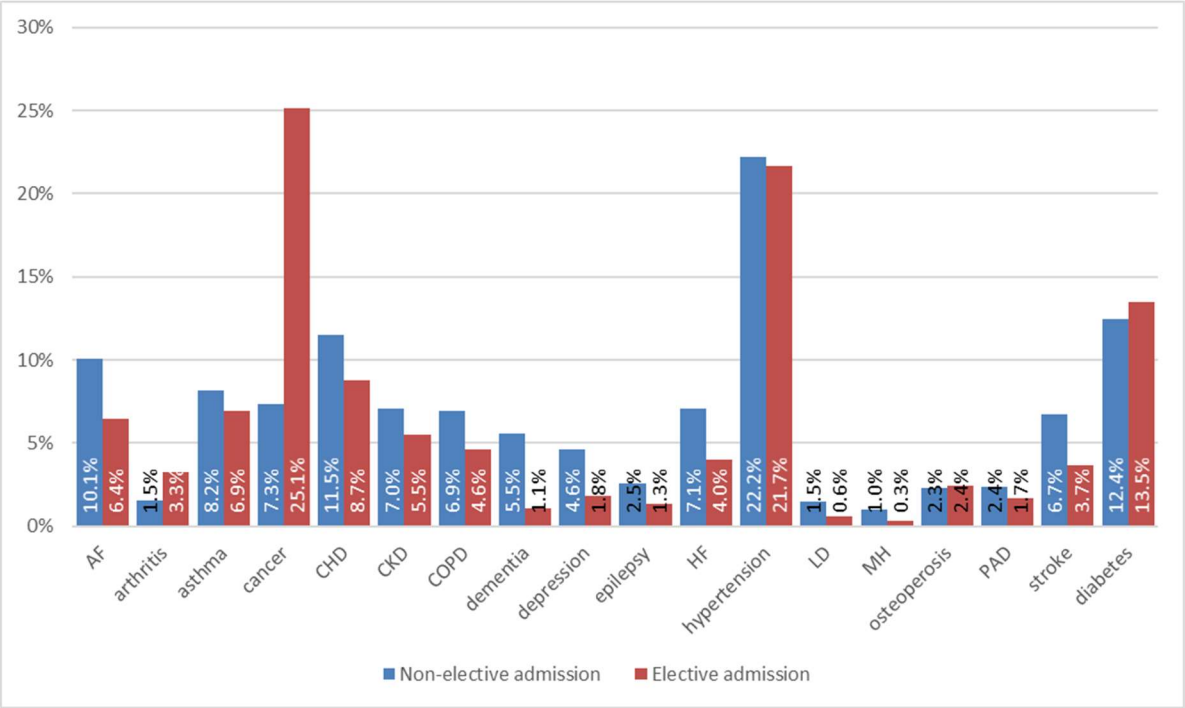
For all non-elective admissions in this year at York Hospital, the average length of stay in hospital was 3.8 days, while for people with two or more long term conditions the average length of stay was longer, at 6.3 days. The chart below shows that as long term conditions accrue for each individual, the average length of stay in hospital in the circumstance of an unplanned (non-elective) admission increases dramatically.



As the combinations of t is not possible to attribute

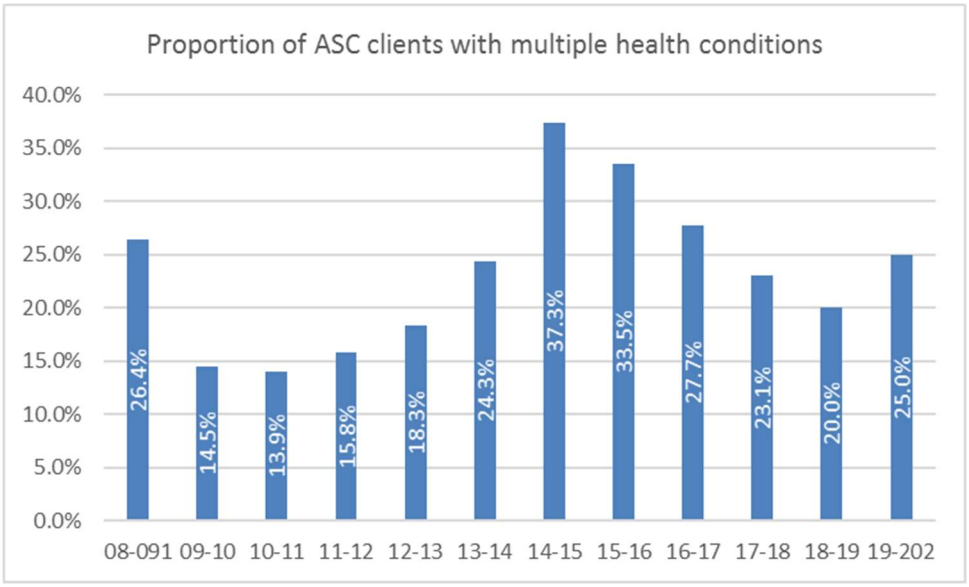


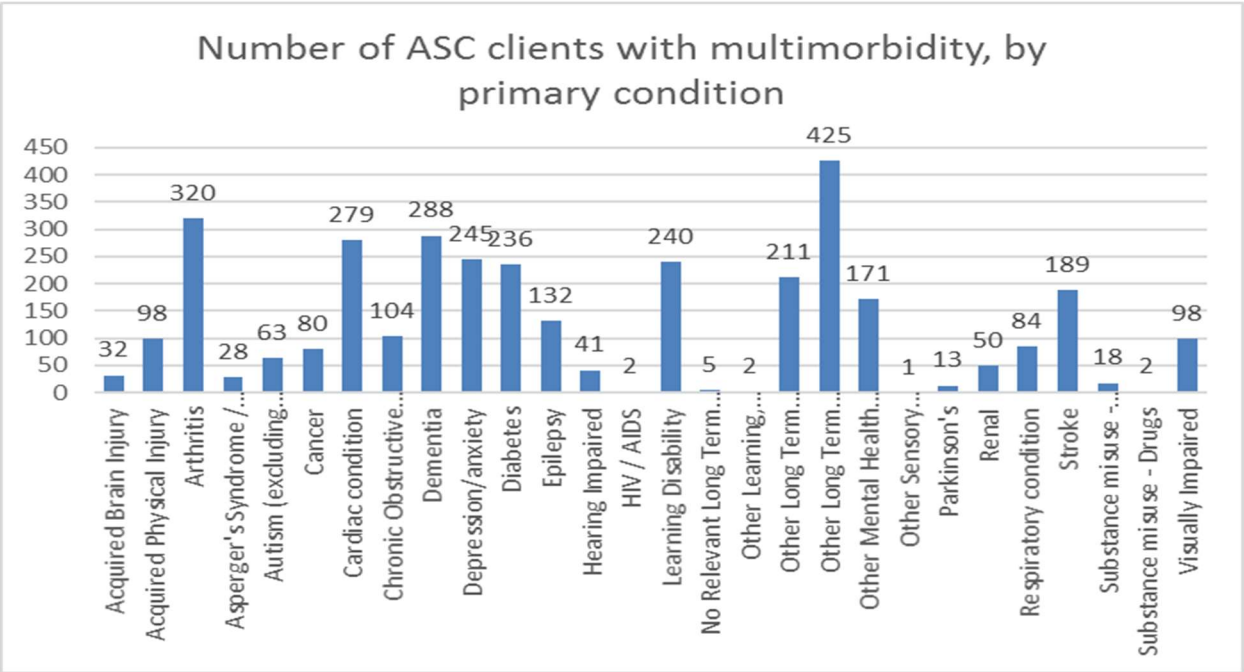
The percentage of admissions where a long term condition was present varied by conditions. A higher percentage of non-elective admission was seen in patients with cardiovascular diseases (atrial fibrillation, coronary heart disease, heart failure, stroke), depression and dementia, whilst a higher percentage of elective admission was seen in patients with cancer and rheumatoid arthritis.



2.9 Social care and multimorbidity

The proportion of social care clients with multimorbidity fluctuates year by year, with changes in recording of client information meaning the data should be treated with caution (in addition, social care assessments do not always require the collection of health condition information. In 2018 / 19 25.0% of clients in were recorded as having multiple health conditions. Most common conditions (in order) were Arthritis, Dementia, Cardiac diseases, Depression, and Diabetes.





The 2018/19 Adult social care users Survey found that compared to client s with only one or no long term conditions recorded, multimorbid clients were less satisfied with the care and support they received, rated the quality of their life lower, but said they were more able to spend their time as they want, doing things they value or enjoy, and felt more supported by services to do so.

3. Evidence synthesis

This section of the needs assessment aims to present a summary of the key evidence on multimorbidity from the national and international literature. The first section surveys what we know about the impact of multimorbidity on health and social needs, and the impact and challenges to the healthcare systems multimorbidity presents. The second section surveys what the evidence tells us may work in helping prevent and delay the progress of long term conditions, and improve the quality of care and life of those who live with multiple conditions.

3.1 The impact of multimorbidity: health impacts

Frailty

There is a large connection between the development of multiple long term conditions and progression to loss of function and frailty. Villacampa-Fernández conceptualises the difference between multimorbidity and frailty helpfully:

'Frailty identifies the increased vulnerability to stressors due to a dynamic, non-linear, and multidimensional depletion of physiological reserve and redundancy, whereas multimorbidity refers to the coexistence of two or more clinically manifest chronic diseases'

A number of ways of defining frailty exist, including those used in the Cardiovascular Health Study and the Edmonton Frail Scale. In England general practices use the electronic frailty index which uses existing electronic health records and a 'cumulative deficit' model to measure frailty on the basis of the accumulation of a range of deficits, including clinical signs (e.g. tremor), symptoms (e.g. vision problems), diseases, disabilities and abnormal test values. The eFI has been used in analyses presented in this needs assessment.

In one recent systematic review of prevalence and cross-sectional studies, 7 out of 10 frail adults present with multimorbidity and almost a fifth of adults with multimorbidity also present with frailty. Multimorbidity increased the likelihood of being frail almost twofold. However the review notes that the proportion of the population who are both frail and multimorbidity was comparatively low, and a large difference between those presenting only multimorbidity (42%) and those presenting only frailty (3%) (Vetrano 2019).

This suggests that while the size of the frail older population – who often have high healthcare needs and poorer long-term outcomes – will be highly affected by growth in the number of people with multimorbidity, the vast majority of people with multimorbidity are not frail, live with little functional loss due to their conditions, and if deterioration is prevented may live active and independent lives.

Alternatively, a less desirable cycle of multimorbidity, disability and deficit accumulation can result in the 'tipping point' into frailty, as described by Villacampa-Fernández 2019.

Hanlon 2018, using UK Biobank data, explores this pre-frailty / frailty tipping point within multimorbidity and finds that prevalence of both is high in patients with multimorbidity; the most common co-morbid conditions predictive of frailty were multiple sclerosis, chronic fatigue syndrome, chronic obstructive pulmonary disease connective tissue disease and diabetes. There was an association of frailty with mortality which was independent of the number of long term conditions, leading the authors to recommend assessment of frailty in patients with complex multimorbidity, and that frailty identification and interventions should be broadened to include the large and increasing number of younger people with multimorbidity, to allow targeted intervention to those with the greatest complexity.

Disability

In an analysis of healthcare data from 20 European countries multimorbidity was associated with greater likelihood of disability, with the ten most common multimorbidity groups associated with significantly greater rates of ADL-IADL disability compared to healthy respondents. The research found that multimorbidity groups that include high depressive symptoms may be more disabling than combinations that include only somatic conditions (Sheridan 2019).

Ageing

Whilst there as many people with multimorbidity in the UK population under 65 as there are over 65, older people are far more likely to live with multiple conditions. This is most apparent in the very old: Collerton (2016) found that in a sample of 710 men and women over 85, 92.7% of subjects had multimorbidity. Cluster analysis identified five distinct subgroups of participants with similar patterns of morbidity. The two most prevalent clusters, accounting for 60% of the sample, showed very high levels of morbidity; one was predominantly disease-based, whilst the other comprised a mix of diseases and geriatric conditions. The healthiest profile accounted for only 5% of the sample and, even in this "healthy" cluster, participants still had an average of three conditions.

There is an obvious link between multimorbidity and long-term care dependency. Koller 2014 found in a cohort of older adults that people with multimorbidity had were nearly twice as likely to become dependent on long term care within five years, with the condition cluster with the highest risk being what they labelled 'Neuropsychiatric disorders' e.g. Parkinsons or Dementia.

The UK population is slowly ageing, and absolute numbers of older people are growing due to the long term demographic effects of high post-war birth rates. However there is no inevitable link between ageing and the onset of many chronic conditions, with data comparing affluent and more disadvantaged communities demonstrating a wider age gap in the onset of single and multiple conditions (e.g. Barnett 2015) and suggesting that wider determinants of health and lifestyle factors play a larger part in the age

at which chronic conditions typically occur. In addition, the rising demands on healthcare which are often attributed to ageing in fact have a more complex basis, with changes in disease incidence, overdiagnosis / overtreatment and patient expectations likely to play more of a role in driving the pressures on healthcare services than the 'ageing population' per se (Fell 2016). Proximity to death, at whichever age, is a more accurate predictor of healthcare use than either age or number of long term conditions, accounting in some estimates to as much as 10–12% of total healthcare costs (Bardsley 2018).

Treatment and management of multiple conditions in those who are older may differ from those who are younger, and there are medical, preferential and moral decisions to be made around the levels of care which are appropriate. For instance, drugs with particularly severe side effects, treatment with deleterious consequence or significant time commitments, and use of preventative medication e.g. statins must all be weighed up against how the patient would like to lead their life, and the balance between quality of life and prognosis. Jeroen (2018) presents a 'compact deliberation framework' to guide professionals and patients in these complex decisions, based on four simple questions:

1) What is known about the patient's aims and preferences?

2) Will the intervention be effective?

3) Will the intervention support the aims and preferences of the patient?

4) In view of the aims and preferences, will the risks and benefits be in balance?

As covered below, NICE clinical guidelines (NG56) on Multimorbidity emphasise care based on assessing the person's individual needs, preferences for treatments, health priorities, lifestyle and goals.

Pain

Chronic pain, itself not always considered a long term condition, is much more likely to be suffered by those with multimorbidity; Barnett 2015 found that 46% of those presenting with chronic non cancer pain had three or more long-term conditions, whilst a study on GP-registered patients in Lambeth found 43% prevalence of chronic pain in multimorbid patients vs 2% in healthy patients from the same practice. According to a clustering study by Scherer 2016, the most common condition in multimorbid primary care patients suffering from chronic pain is chronic low back problems, followed by cardiometabolic conditions. In women, mental health issues like depression are also common.

Pain management is a complex field, with Bruggink 2019 noting that 'a predominant focus on biomedical treatment is unlikely to be effective in the long term. In multimorbidity, 'Red flag' conditions need to be screened for, then treatment typically involves medication deprescription, or non-initiation, and transition to multidimensional supported self-management'. The issue of prescription opoid addiction has recently been highlighted in an evidence review by Public Health England, which found that 5.6 million people (13% of the population) were prescribed opiod pain medicines. Rates of prescribing were

higher for women (1.5 times those of men), and the rates generally increased with age and were strongly associated with deprivation

Mental health

There is a stong link between poor mental and poor physical health, with data on a global scale from the World Health Survey suggesting that two, three and four or more physical health conditions were present in 7.4, 2.4 and 0.9% of non-depressive individuals, compared with 17.7, 9.1 and 4.9% among people with any depressive episode, respectively (Stubbs 2017). Whilst physical health and mental health issues can occur independently of one another, having one can make the other more likely: long term conditions can affect mood and general levels of mental fitness, whilst poor mental health can manifesting in a somatic way or lead to lifestyle choices which risk the development of chronic conditions. The interplay between the two is complex and differs for each individual, but a large review of evidence found that the risk for depressive disorder was twice as great for people with multimorbidity compared to those without multimorbidity and three times greater for people with multimorbidity compared to those without any chronic physical problems. (Read 2017).

People with physical and mental health comorbidities often experience two parts of the health and care system with historic problems in joint working, and treatment pathways which do not always align. Consequently, they often suffer the worst outcomes within the multimorbidity cohort. One review of studies found that people with mental health conditions are at higher risk of developing physical illness, have those conditions diagnosed later and have much higher mortality rates. Conversely, people with a diagnosis of physical illness, especially cardiovascular disease, diabetes and cancer have a greater chance of developing a mental health problem. When both mental and physical illnesses conditions are present together, there are higher overall rates of morbidity, healthcare utilisation, and poorer quality of life. (Doherty 2014).

There is some evidence that tailoring mental health interventions when a patient is multimorbid can increase the benefit of treatment. The University of York is currently leading a large NIHR funded research programme on Multi Morbidity in Older Adults with Depression (MODS), which aims to test interventions such as the use of behavioural activation vs CBT in patients with 3 or more long term conditions. One intervention asses in the CASPR trial showed that depression prevention in older adults with multimorbidity halved the rate of progression to depression in a sub clinical group.

Learning disabilities

People with Learning Disabilities have higher rates of chronic disease and lower life expectancy. One cross sectional study from Scotland in 2017 found an astonishing level of long term conditions in people receiving social care support for learning disability. Patients received a comprehensive health assessment where a wide definition of long terms conditions based on ICD-10 was taken; the mean number of physical health conditions per participant was 11, and 98.7% of the cohort had multimorbidity. The five

most prevalent conditions were visual impairment, obesity, epilepsy, constipation and ataxic/gait disorders, and unlike the rest of the population multimorbidity was spread over the life course. The extent of multimorbidity in the adults with Down syndrome was similar to that of the adults without Down syndrome. Tyrer 2019 investigated the link between multimorbidity and lifestyle risk factors in people with learning disability, and found a significant relationship with physical activity, but not with age, smoking or diet. Thus the physical disease profile for those with learning disabilities is likely to differ that that of the general population, and is likely to depend more on access to healthcare and disease identification.

Polypharmacy

One of the key issues multimorbidity raises is that of polypharmacy, where patients are often taking a complex range of medications to treat multiple conditions several times a day. The Yorkshire Health Study found that the mean number of medications used for those without multimorbidity was 1.81 compared to 3.81 for those with at least two long-term conditions, and 7.47 for those with 5+ conditions. (Li 2016)

Appropriate polypharmacy, well managed by GP and pharmacist, can significantly increase quality of life and care; however inappropriate polypharmacy adds to the burden of treatment, negatively affects quality of life, and makes the risk of non-compliance with treatment regimens more likely, as well as significant adverse events from contraindicated medication which can be as high as 1% per year (Amaia Calderón-Larrañaga, 2012).

Even with good quality prescribing all medications come with side effects, and the cumulative effects of these when a patient has multiple conditions can be equivalent to having another full long term condition (Kings Fund 2013). Drugs for one condition can exacerbate or even precipitate the onset of another condition, for instance long term use of NSAIDS and Chronic Kidney Disease, or they can make an adverse event more likely, for example the risk of falls in patients with blood pressure-lowering medication. Prescription medication addiction is also a growing problem in England, including drugs used to treat chronic pain and long term use of antidepressants (PHE 2019).

Since many clinical trials exclude patients with multimorbidity, the effectiveness of many standard medications in this population is less well understood, and drug-drug and drug-condition interactions may be harder to predict, meaning that people with multiple conditions perversely receive a lower standard of pharmacology than those with single conditions.

A Japanese study identified five multimorbidity patterns (cardiovascular/renal/metabolic, neuropsychiatric, skeletal/articular/digestive, respiratory/dermal, and malignant/digestive/urologic), and found that malignant/digestive/urologic and cardiovascular/renal/metabolic patterns showed the

strongest associations with excessive polypharmacy and the number of concurrent over the counter medications. (Aoki 2018)

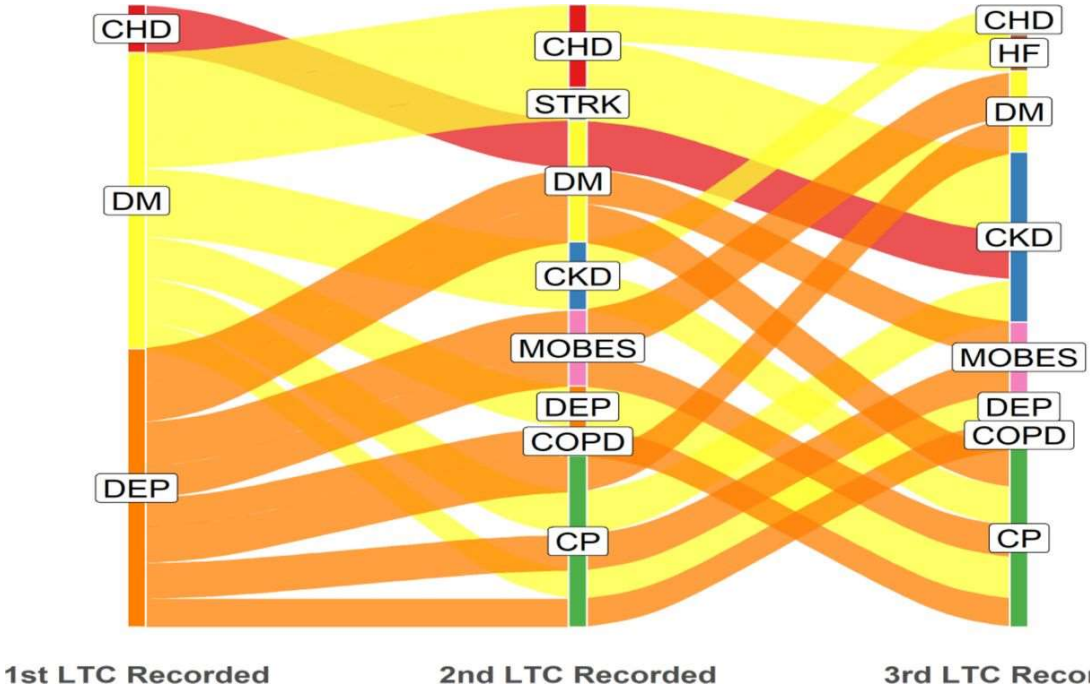
Survival and mortality

People with multimorbidity have a greater risk of premature death (Health Foundation 2015). This is varying across condition groups and is affected by external factors such as frailty, genetics and environmental / lifestyle factors. One longitudinal health record study grouped multimorbidity into clusters and found that in men conditions within the digestive-respiratory pattern had a higher risk of death, whilst in women, the cardiovascular pattern was associated with the highest risk (Ibarra-Castillo, 2018)

Condition clustering

Certain long term conditions are more likely to cluster together, and multiple studies in the literature identify clusters of conditions which are more common. Clustering profiles are affected by age, with one study finding that the most common 2 condition set in 0–19 year olds was depression and asthma whereas the most common dyad in persons ≥80 years was hypertension and cancer in men and hypertension and arthritis in women (St Saveur 2015)

A recent study utilizing routine health records conducted across two London Boroughs in 2018 charted the journey from one condition to many for this cohort of patients. They found that the at diabetes and depression were the most common starting conditions for patients with multimorbidity, diabetes particularly in older and black ethnic groups; and depression particularly in younger, more deprived and white ethnicity groups. Diabetes was also relatively common as the second or third acquired LTC, whereas depression was predominantly a first-onset LTC. Chronic pain was less common as an initial condition. Morbid obesity was among the more common starting conditions in the most deprived cohort and younger age cohort. However, in other sociodemographic samples, morbid obesity was more common as a second or third acquired LTC. The study showed that deprivation and ethnicity where significant shaping factors in the multimorbidity profile in all ages. The alluvial plot shown below demonstrates some of the most common flows from 1 to 3 long term conditions.



3.2 The impact of multimorbidity: social impacts

Financial impacts

Long term conditions impact on individual and family income, and can lead to extra financial stress and loss of earnings. More than half of all those with significant disability live below the average household income due to loss of earning capacity and the increased living costs associated with their condition, such as heating and laundry (McEvoy 2013). Financial hardship is common, and the complexities of the benefit system and well-recognized stressors such as PIP assessments, benefit sanctions and the move to universal credit are all more likely to be experienced by those living with multimorbidity. JRF research found that individuals with long-term conditions required substantial flexibility in employment, due to pain, fatigue, unpredictable symptoms and health appointments which this could conflict with employers' needs for reliability and lead to job loss; overall, carers were more likely than those with long-term ill health to miss out on social participation. Low income affected social contact, and ill health could make contact less enjoyable and supportive (JRF 2015)

Employment impacts

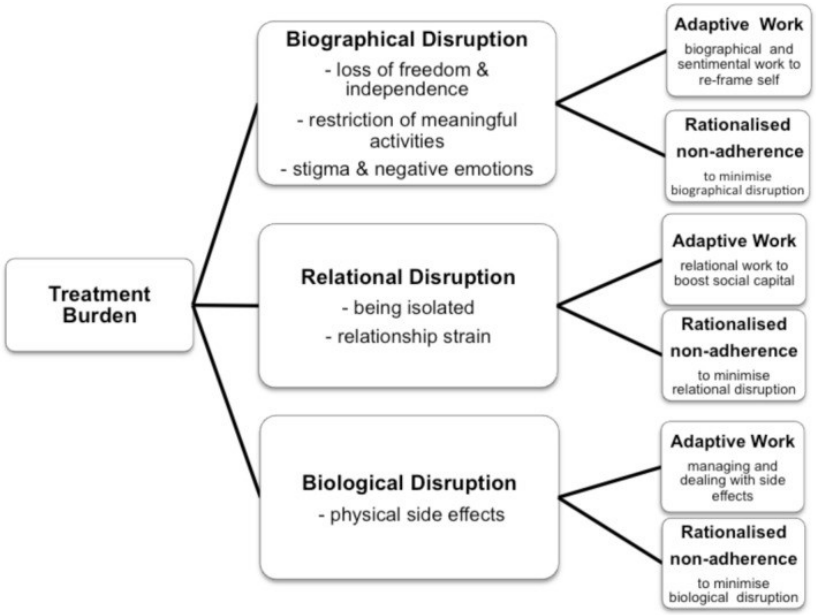
Developing multimorbidity can lead to a changing relationship with employment, either though greater difficulty in finding employment or in long term conditions necessitating the giving up, reducing or changing employent. Nationally there is a 11.5% gap between the employment rate in those without long term conditions and those without (2018/19); in York this gap is smaller at 5.6%. A recent systematic review found that workers with multimorbidity had a higher risk of transitioning to partial retirement (HR 1.45), disability (HR 1.84) and full retirement (HR 1.63) (Van Zohn 2020)

One evidence review of the topic notes 'whilst one may anticipate that employment will lead to better health outcomes, the literature gathered indicated that this may not always be the case, especially in instances of unfavourable working conditions, such as having low job control. Simply helping those with long-term conditions and mental health issues into work will not be sufficient to raise their quality of life and additional support may be required to enable them to remain in employment while managing their health condition. Labour market conditions, the structure and generosity of the welfare system, as well as the implementation of employment interventions were all noted as being key determinants of employment' (Nathwani 2015). Research from the St Guys and Thomas' project on multiple long term conditions found that people who are better supported to self-manage their condition, and feel empowered to do so, are more motivated to access employment. The project is piloting four interventions:

- Supporting employer change, including setting up peer support and mentoring programmes, testing anti-discrimination training for employers and providing guidance for managers to create supportive environments.
- Testing new forms of employment, including facilitating phased returns to work, paid work trials or remote working.
- Supporting long-term unemployed people, including expanding volunteering opportunities or promoting adult education programmes that focus on self-management.
- Testing condition management, including supporting industry-wide campaigns to increase awareness about specific conditions or offering specialised programmes to increase resilience. (GTTS 2017)

Treatment burden

'Treatment burden' refers to the extra workload and pressure carried by people with long term conditions in order to manage their condition, and includes arranging appointments, medication adherence, symptom and health awareness e.g. blood pressure, taking longer over everyday tasks, and the sociological and psychological effects of existing in the 'patient role'. These impacts are often felt to some extent or equally by carers. Validated tools to measure this phenomenon have been developed, for instance the Bristol treatment burden Questionnaire (Duncan 2018) and the Cumulative Complexity Model (Shippee 2012). A systematic review of qualitative research on this effect found that treatment burdens were experienced as a series of disruptions, illustrated in the diagram below:



The authors recommend that clinicians need to engage with patients in honest conversations about treatment disruptions and the 'adhere-ability' of recommended regimens. Patient-centred practice requires management plans which optimise outcomes and minimise disruptions. (Demain 2015)

Social isolation

There is emerging evidence on the relationship between multimorbidity and social isolation. One population based study found that the more physical diseases patients had, the higher odds for loneliness, increasing from 1.34 to 2.82 between one and ≥5 physical diseases. This association was particularly strong in the youngest age group (i.e. 16-44 years), and was significantly mediated by stressful life events, anxiety, and depression (Stickley 2018). Another study found that having a supportive social environment increases the survival of people with multiple physical illnesses (Olaya 2017).

3.3 The impact of multimorbidity: System impacts

Healthcare utilisation

Long term conditions account for 50% of all GP appointments, 64% of all outpatient appointments and over 70% of all inpatient bed days - in total representing around £7 in every £10 of total health and social care expenditure (DoH 2012). It is clear from the research that this utilisation and cost of healthcare is not evenly spread, but that multimorbidity has a 'multiplier' effect where healthcare costs grow in an exponential rather than linear fashion the more conditions one has.

A study of 60,000 patients registered with GPs in Stoke on Trent found the average 3-year total costs per multimorbid patient for hospital admissions ranged from between £2289 and £5344. The adjusted costs were significantly higher for six multimorbid groups compared with their respective single disease groups (Kadam 2013). In terms of emergency department attendance, a retrospective cohort analysis of linked

primary and secondary care records in London found a sixfold increase in ED attendance rates in those with four or more comorbidities (Hull 2018). The authors conclude that the burden of multimorbidity is 'the strongest clinical predictor of ED attendance'. Outpatient care use is higher amongst patients with multiple conditions (Glynn 2011), as is social care, so it can be seen that multimorbidity is a driver of demand across all parts of the healthcare system.

Workforce, generalism and specialism

Multimorbidity requires a different approach to the clinical and professional management of a patient's health, and to the organisation of services. Typically, medicine tends to treat people in single disease 'siloes', with many medical specialities focussing on one bodily system (e.g. respiratory medicine). The exception to this are the specialties of paediatrics and geriatrics, and general practice; indeed many would advocate GPs should be seen as a 'specialist generalists' as they bring the specialist skills of dealing with multiple long term conditions and a holistic approach to treatment.

Within hospital medicine, the use of multidisciplinary teams is well established in many areas as a way of ensuring good care across clinical teams, utilising consultant specialism but also input from Allied Health Professionals such as physio, pharmacy, and mental health. Several learning and improvement tools are available to support MDT development, eg 'Making it happen' (NHS England 2018).

Even within general practice, those living with multiple conditions may not receive support appropriate to their complexity. Health Foundation (2018(research found that the average GP consultation time was not strongly related to the number of conditions. Patients with 4+ conditions received only an additional 14 seconds per consultation on average, compared with patients with a single condition. The RCGP have set out a vision for multimorbidity in general practice, which recommended:

- Develop multidisciplinary teams around general practice to ensure that GPs are able to gain rapid access to the care that patients with multimorbidity need e.g. mental health services, district nursing and support for social care needs.
- Prioritise longer consultations for those with multimorbidity to provide them with more time to discuss the complexities of their multiple conditions.
- Improve communication at the interface of primary and secondary care to ensure patients
- Integrated care e.g. use of in-reach teams and advice lines for GPs and other primary care staff.
- Give patients living with multiple long-term conditions the opportunity to form on-going relationships with those providing their care in general practice. Practices should monitor the proportion of patients with multiple long-term conditions receiving continuity of care and take steps to improve this when necessary.
- Develop tools for GPs and patients with multiple long-term conditions to enable them to make informed decisions, such as apps / improved guidance e.g. on deprescribing. (RCGP 2018)

Case study two: Julie, 53, from Clifton

Name: Julie Moore

Age: 58

Conditions: Julie has bilateral Aniridia and is registered blind, she has had a recent eye infection and just heard that her corneal transplant has failed. She has recurring water infections, a prolapsed womb and awaiting surgery. She also has Mortens Neuroma, causing pain in her foot.

Julie's daughter is at University, has the same eye condition and also has anxiety. Her son has Autism and suicidal thoughts. Julie's husband also has mental health issues.

Impact on life: Julie often puts her own condition on the back burner. She finds her situation tiring, time consuming and is constantly juggling appointments and trying to access services for example has to travel South for her appointments which can be tricky on public transport. She finds it difficult to manage everyday medications as she cannot see. Issues such as a change to how a particular tablet looks can be very difficult to manage. She also works and has no time for herself.

What could services do to make things easier: The family have a key worker / care coordinator which works well and makes a huge difference. Communication is key- not making promises that can't deliver; seeing things through; being honest; different departments listening; organisations working on the same page are all aspects that Julie has identified would be helpful. Also provision for some respite is poor.

4. What Works – a list of interventions to consider

Best clinical practice for caring for patients with multiple long term conditions in primary and secondary care can be found in the 2016 NICE Guidance on Multimorbidity: Clinical Assessment and Management (NG56). The interventions listed below, whilst by no means exhaustive, aim to summarise the key interventions healthcare systems should consider to improve individual and population health in the context of multimorbidity.

Primary Prevention:

- Lifestyle improvement:
    - Stop smoking
    - Achieve and maintain a healthy weight (BMI less than 25 kg/m2
    - Reduce alcohol intake below CMO recommended 14 units a week
    - 5 x 30 minutes of moderate exercise per week
- Structural and wider determinants:
    - Community connections
    - Adequate income and employment
    - Clean air

Secondary Prevention:

- Preventive treatment (e.g statins for Cardiovascular risk, anti-coagulation to prevent stroke in Atrial Fibrillation)
- Self-management (eg inhaler technique, Blood pressure monitoring, glucose control)
- Structured education in diabetes, Diabetes Prevention Programme
- Rehabilitation (Cardiac, Pulmonary)
- Alcohol and substance misuse interventions

Managing Polypharmacy:

- Deprescribing
- STOPP/START
- Assessing the benefit of preventive medicines e.g. anti-hypertensives when multimorbidity is present
- Medicine optimisation
- Work to reduce dependence on opioids e.g. CROP

Social interventions:

- Social prescribing
- Financial support and welfare advice
- Exercise on referral

General evidence-based multimorbidity approaches:

- Care coordination and integrated care
- Bristol Treatment burden questionnaire
- 3D approach
- Multi-disciplinary teams (MDTs)

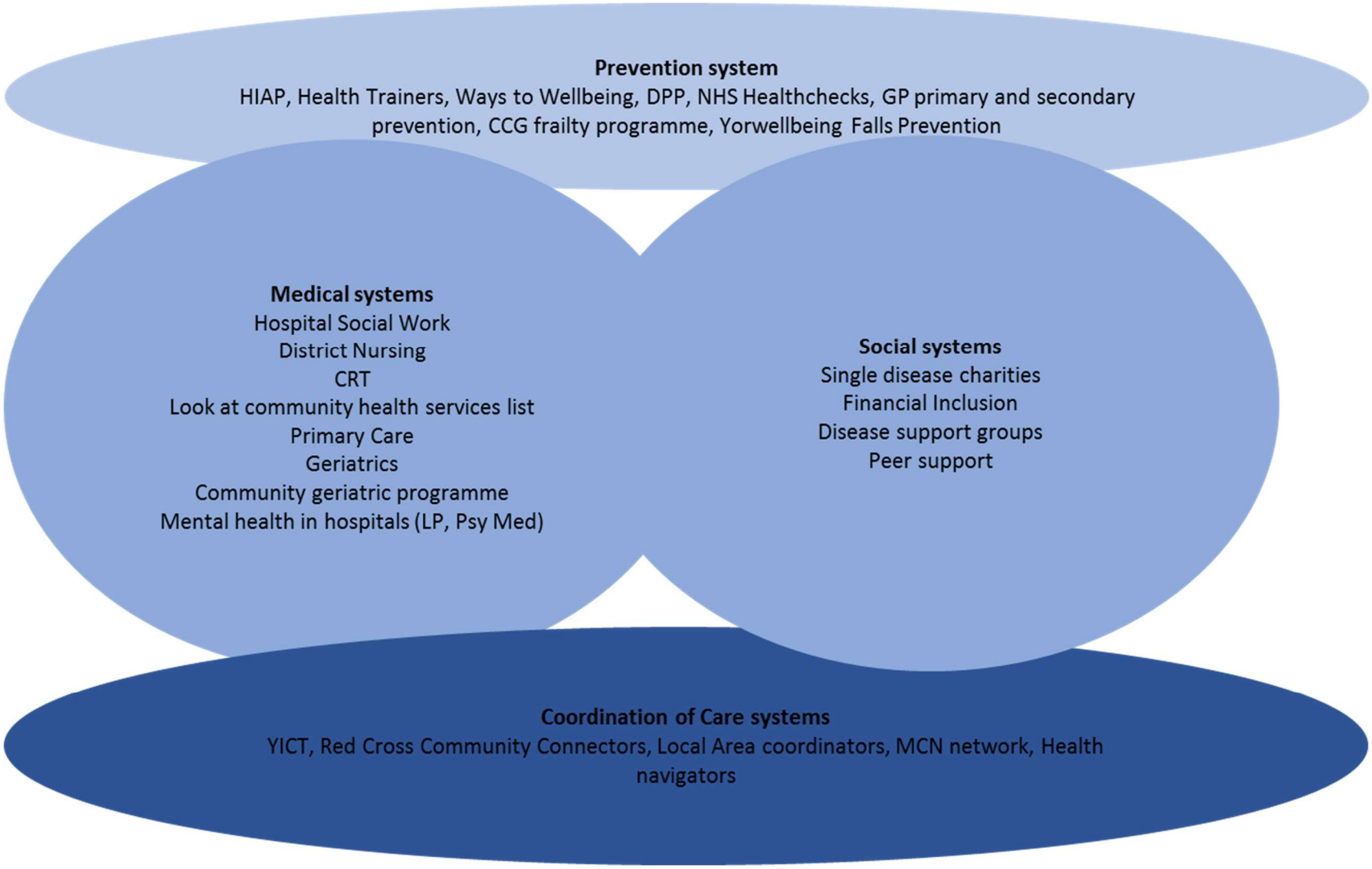
For older people:

- Comprehensive geriatric assessment
- Formative care

Improving patient experience:

- Personalisation / Personalised Health Budgets
- Shared decision making
- Ariadne principles
- Patient activation
- Health coaching / health champions
- Peer support

5. Systems map of Multimorbidity in York



6. Engagement

Expert By Experience group

In Summer 2019, four 'experts by experience' were recruited to help shape this project. Together this group:

- Met to comment on the Needs Assessment project plan and what they felt it should focus on
- Designed the public survey and contributed questions
- Helped recruit to the focus groups

Public survey

In November 2019 a public survey was conducted on the CYC website on 'Living with multiple long term conditions in York'. 64 people completed the survey.

In summary, it showed that:

- Basic levels of care and support rated well, but people didn't feel supported with the things that were most important for them, or with the social / leisure / active aspects of their care
- There was a progressive loss of confidence in the system as our questions move from those around 'support' to those around 'regular conversations' with professionals and to 'having a plan'
- People found self-management of their conditions relatively straightforward, but really struggled with getting healthcare professionals to communicate with them and with one another
- People who responded to the survey were in general less happy and more anxious than the York population.

The survey results are included in full at Appendix 2

Focus groups

Following the survey, two focus groups were convened to explore the findings further. The focus group notes are included in full at Appendix 3. Some key themes were:

- Out of hours appointment times would be beneficial.
- More appointment availability in general
- Improved transport across City – this can be a real issue for those that don't drive if need to get across City to appointments.
- Communication – this needs to be improved across the journey.
- Jargon / pronunciation guides are needed

7. Acknowledgements and thanks

We would like to thank:

- Liz Buckton for convening the 'experts by experience' group
- Nick Sinclair, George Scott and Jen Saunders for advising the project as part of the York JSNA group
- Terry Rudden for supplying Social Care Data
- The YICT team, especially Tom Dolman, for supplying the primary care data
- John Watson at York THT for supplying the secondary care data
- Our four 'experts by experience'
- All who responded to the survey

Appendix 1 Population estimate for Elvington Medical Practice

If the average age specific multi-morbidity rates for all the practices are applied to the Elvington Practice Population then the estimate for the number of multi-morbid patients would be **960**. If we apply the rates from the practice most similar in terms of the deprivation (The Old School Medical Practice) then the estimate would be **801**. 58% of the Elvington Practice population lives within the York boundary so the estimates for multi-morbid York residents would be 556 and 464 respectively.

Elvington Medical Practice		**Using all practice average multi-morbidity rate by age band**		**Using The Old School multi-morbidity rate by age band**	
Age Band	No.	%	Estimated No. of multi-morbid patients in Elvington	%	Estimated No. of multi-morbid patients in Elvington
0 to 4	300	0.01%	0	0.00%	0
5 to 9	423	0.00%	0	0.00%	0
10 to 14	456	0.02%	0	0.00%	0
15 to 19	413	0.24%	1	0.51%	2
20 to 24	297	0.75%	2	1.43%	4
25 to 29	257	1.39%	4	0.39%	1
30 to 34	314	2.05%	6	1.38%	4
35 to 39	316	2.69%	9	2.24%	7
40 to 44	455	3.74%	17	2.41%	11
45 to 49	552	5.86%	32	3.04%	17
50 to 54	619	8.75%	54	4.24%	26
55 to 59	573	12.84%	74	9.34%	54
60 to 64	478	17.60%	84	10.29%	49
65 to 69	424	24.80%	105	20.47%	87
70 to 74	474	33.19%	157	28.27%	134
75 to 79	270	46.15%	125	52.53%	142
80 to 84	211	56.91%	120	49.00%	103
85 to 89	135	65.79%	89	70.27%	95
90 to 94	81	71.61%	58	51.52%	42
95+	33	69.00%	23	69.23%	23
All ages	**7,081**		**960**		**801**

The York residents who are registered with Elvington Medical Practice predominantly live in the least deprived and second least deprived deciles so the rates in those deciles may be slightly underestimated.

Decile (1=most deprived)	No. of York residents registered with Elvington practice in each deprivation decile	%
2	11	0.3%
3	16	0.4%
4	31	0.7%
5	378	9.1%
6	11	0.3%
7	5	0.1%
8	651	15.7%
9	1,679	40.6%
10	1,357	32.8%
All	**4,139**	**100.0%**

Appendix 2 Multimorbidity Needs Assessment Survey

City of York Council

Living with Multiple Long Term Conditions in York

November 2019

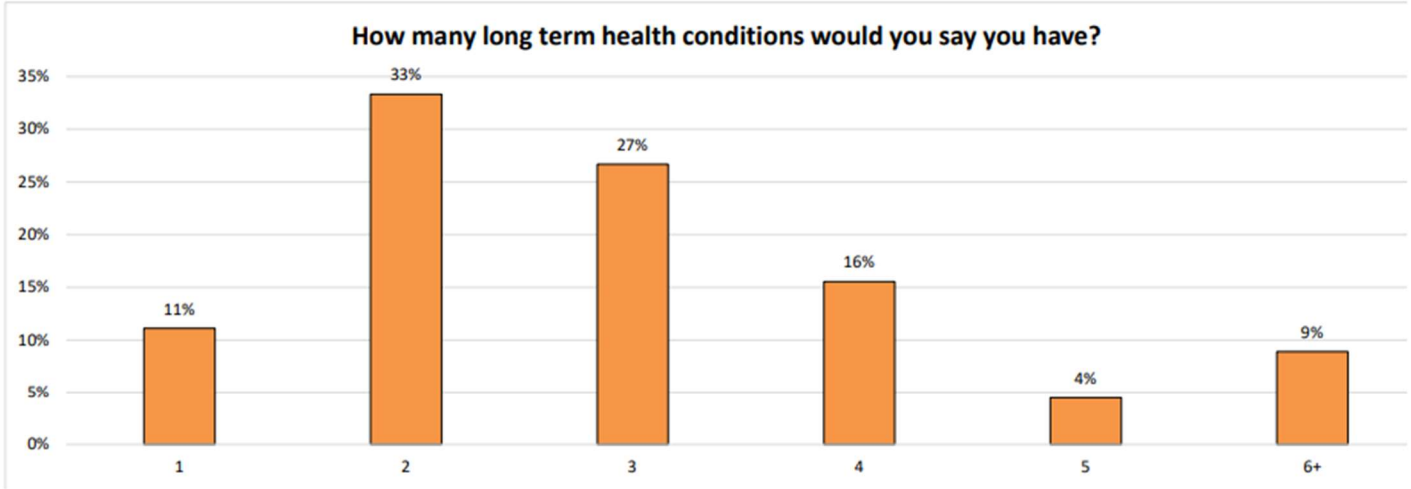
The Living with Multiple Long Term Conditions in York survey ran from 17th October 2019 to 25th November 2019. The survey aimed to obtain a better understanding of the different aspects of people's lives in York who have multiple long term health conditions. A total of 64 people participated, with an average survey completion rate of 59%.

Produced by the Business Intelligence Hub

Living with Multiple Long Term Conditions in York

Question 1: How many long term health conditions would you say you have?

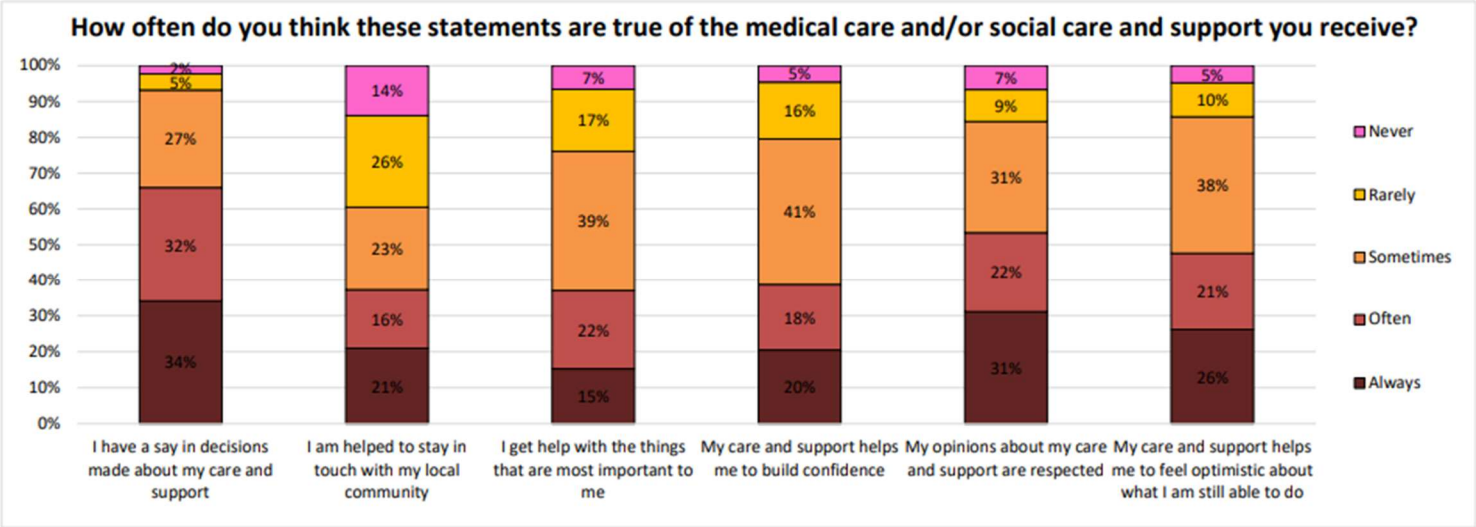
Answer Choices	Responses	Percentage of total responses
1	5	11%
2	15	33%
3	12	27%
4	7	16%
5	2	4%
6+	4	9%
Total	**45**	



Produced by the Business Intelligence Hub

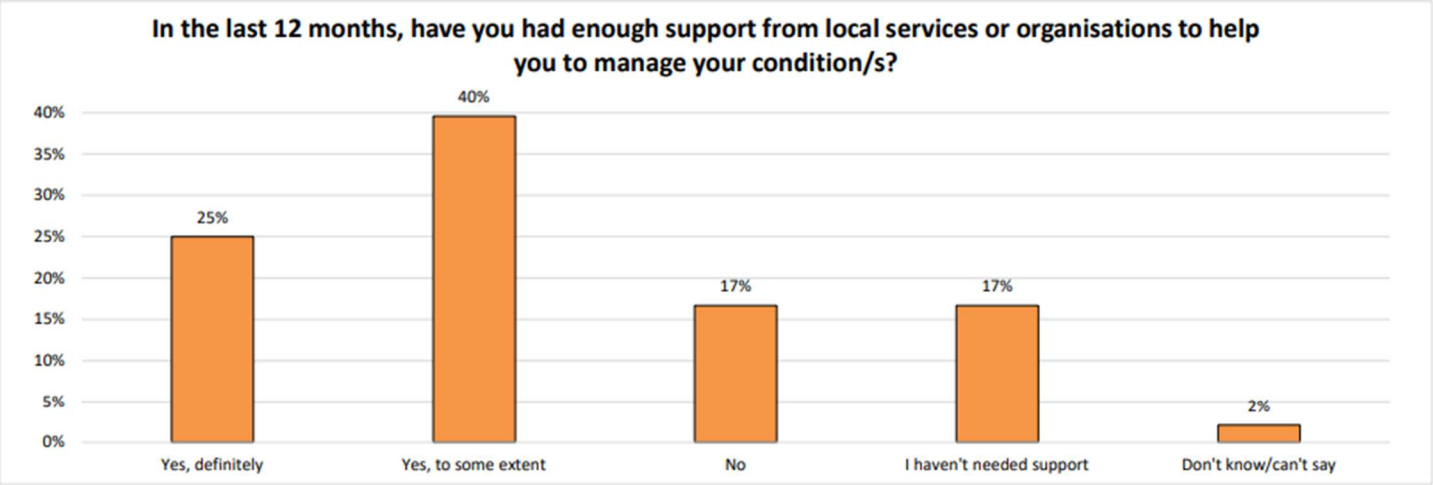
Question 2: How often do you think these statements are true of the medical care and/or social care and support you receive?

Answer Choices	Always		Often		Sometimes		Rarely		Never		Total
I have a say in decisions made about my care and support	15	34%	14	32%	12	27%	2	5%	1	2%	**44**
I am helped to stay in touch with my local community	9	21%	7	16%	10	23%	11	26%	6	14%	**43**
I get help with the things that are most important to me	7	15%	10	22%	18	39%	8	17%	3	7%	**46**
My care and support helps me to build confidence	9	20%	8	18%	18	41%	7	16%	2	5%	**44**
My opinions about my care and support are respected	14	31%	10	22%	14	31%	4	9%	3	7%	**45**
My care and support helps me to feel optimistic about what I am still able to do	11	26%	9	21%	16	38%	4	10%	2	5%	**42**



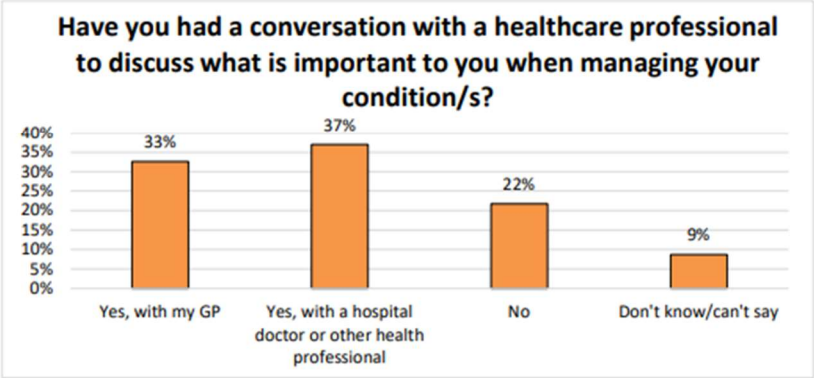
Question 3: In the last 12 months, have you had enough support from local services or organisations to help you to manage your condition/s?

Answer Choices	Responses	Percentage of total responses
Yes, definitely	12	25%
Yes, to some extent	19	40%
No	8	17%
I haven't needed support	8	17%
Don't know/can't say	1	2%
Total	**48**	



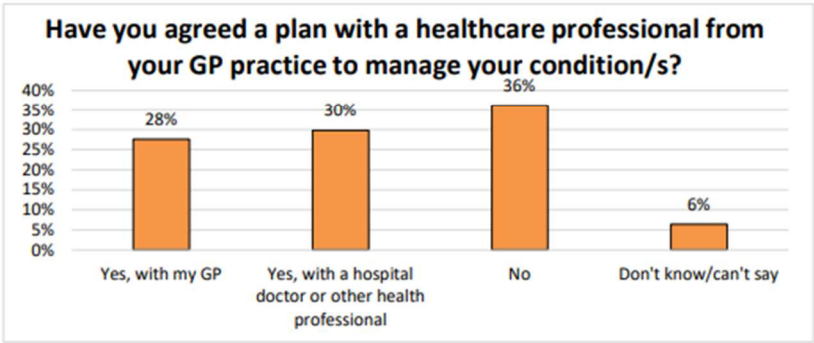
Question 4: Have you had a conversation with a healthcare professional to discuss what is important to you when managing your condition/s?

Answer Choices	Responses	Percentage of total responses
Yes, with my GP	15	33%
Yes, with a hospital doctor or other health professional	17	37%
No	10	22%
Don't know/can't say	4	9%
Total	**46**	



Question 5: Have you agreed a plan with a healthcare professional from your GP practice to manage your condition/s?

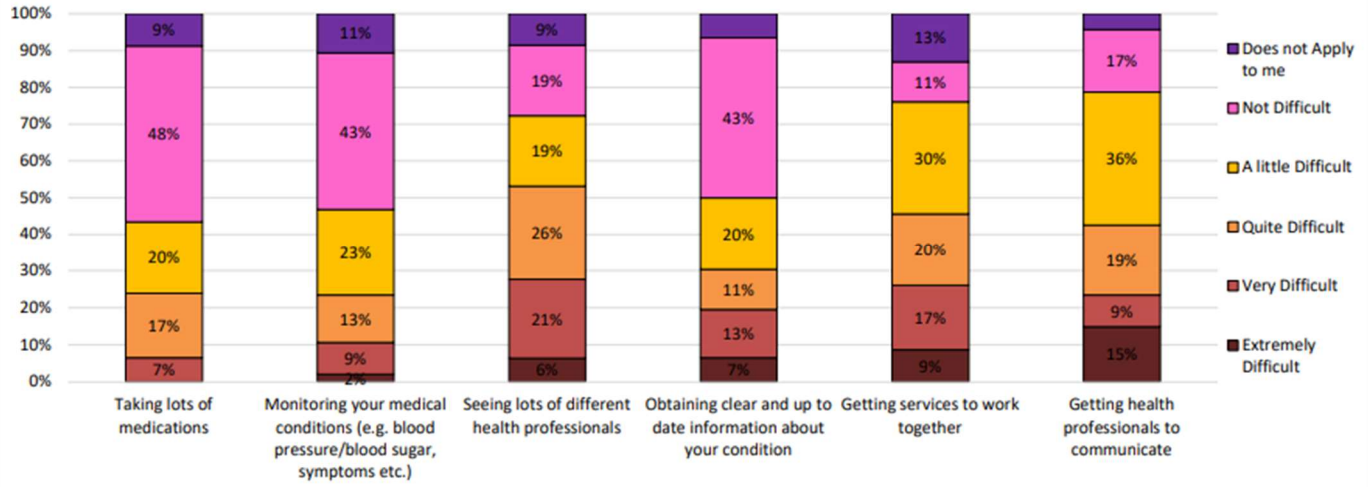
Answer Choices	Responses	Percentage of total responses
Yes, with my GP	13	28%
Yes, with a hospital doctor or other health professional	14	30%
No	17	36%
Don't know/can't say	3	6%
Total	**47**	



Question 6: How difficult do you find the following?

Answer Choices	Difficult		Quite Difficult		Not Difficult		Does not Apply to		Total
Taking lots of medications	3	7%	8	17%	31	67%	4	9%	**46**
Monitoring your medical conditions (e.g. blood pressure/blood sugar, symptoms etc.)	5	11%	6	13%	31	66%	5	11%	**47**
Seeing lots of different health professionals	13	28%	12	26%	18	42%	4	9%	**47**
Obtaining clear and up to date information about your condition	9	20%	5	11%	29	63%	3	7%	**46**
Getting services to work together	12	26%	9	20%	19	41%	6	13%	**46**
Getting health professionals to communicate	11	23%	9	19%	25	53%	2	4%	**47**

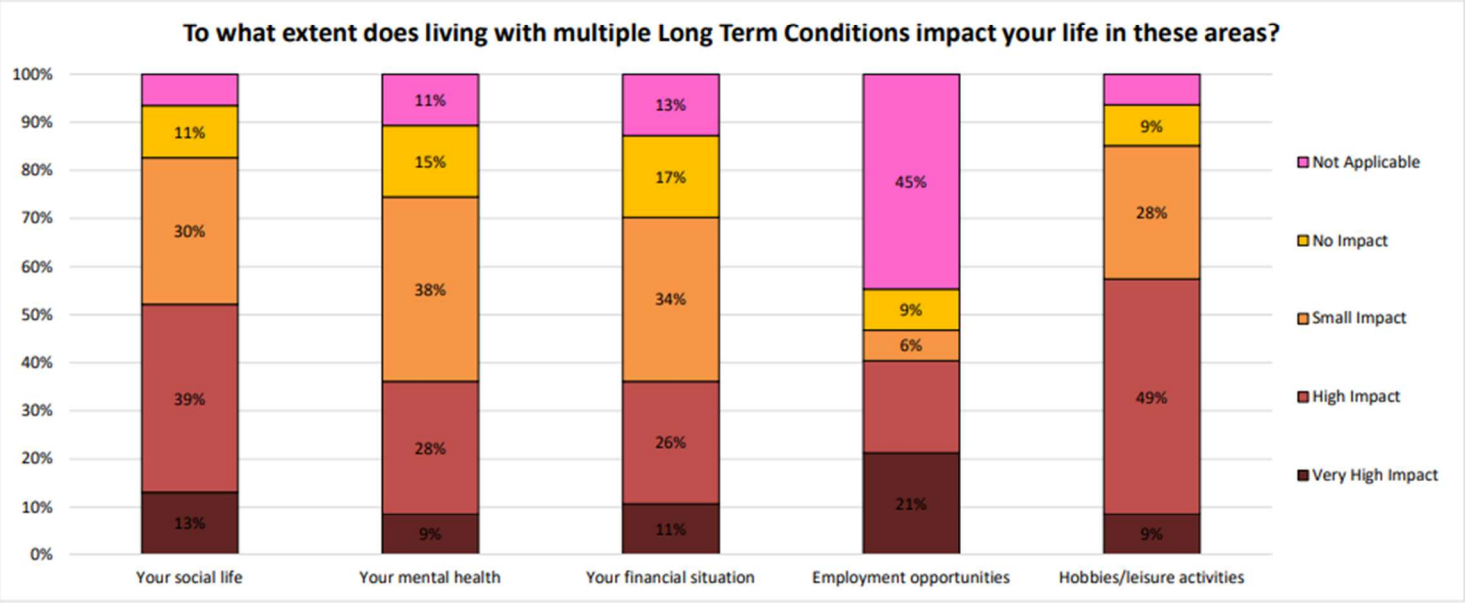
How often do you think these statements are true of the medical care and/or social care and support you receive?



Living with Multiple Long Term Conditions in York

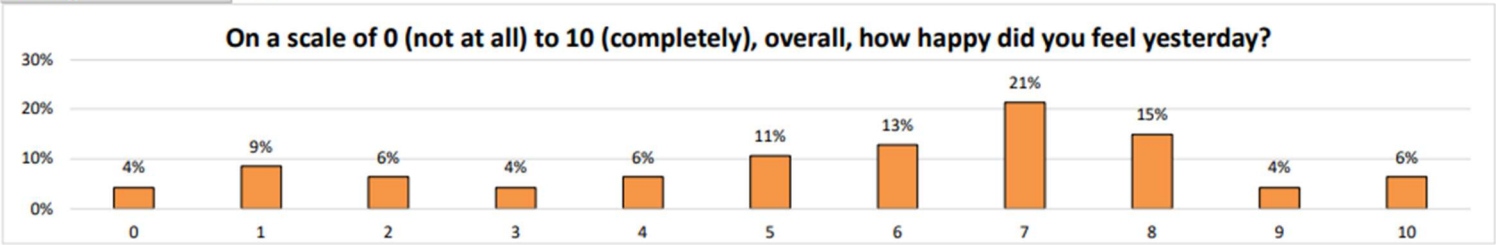
Question 7: To what extent does living with multiple Long Term Conditions impact your life in these areas?

Answer Choices	Very High Impact		High Impact		Small Impact		No Impact		Not Applicable		Total
Your social life	6	13%	18	39%	14	30%	5	11%	3	7%	**46**
Your mental health	4	9%	13	28%	18	38%	7	15%	5	11%	**47**
Your financial situation	5	11%	12	26%	16	34%	8	17%	6	13%	**47**
Employment opportunities	10	21%	9	19%	3	6%	4	9%	21	45%	**47**
Hobbies/leisure activities	4	9%	23	49%	13	28%	4	9%	3	6%	**47**



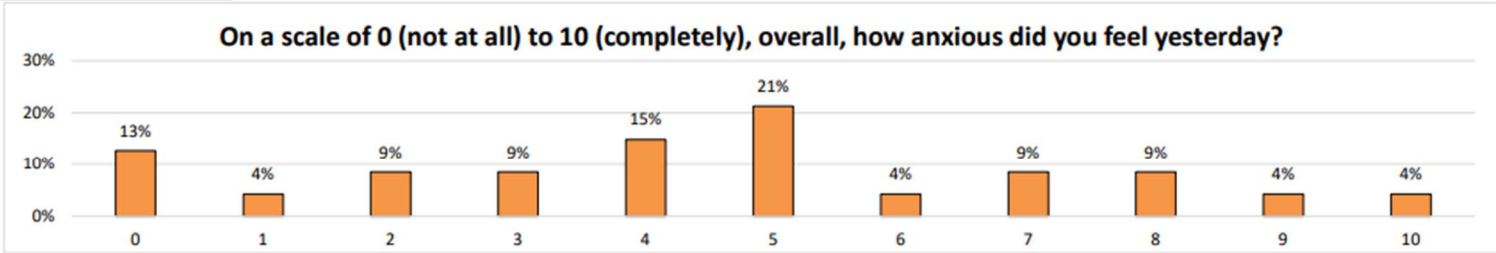
Question 8: On a scale of 0 (not at all) to 10 (completely), overall, how happy did you feel yesterday?

Answer Choices	0		1		2		3		4		5		6		7		8		9		10	
Responses	2	4%	4	9%	3	6%	2	4%	3	6%	5	11%	6	13%	10	21%	7	15%	2	4%	3	6%
Total Respondents	47																					
Average	6.4																					



Question 9: On a scale of 0 (not at all) to 10 (completely), overall, how anxious did you feel yesterday?

Answer Choices	0		1		2		3		4		5		6		7		8		9		10	
Responses	6	13%	2	4%	4	9%	4	9%	7	15%	10	21%	2	4%	4	9%	4	9%	2	4%	2	4%
Total Respondents	47																					
Average	5.3																					



Question 10: As someone living with multiple long term conditions, what is the most important thing you need us to know?

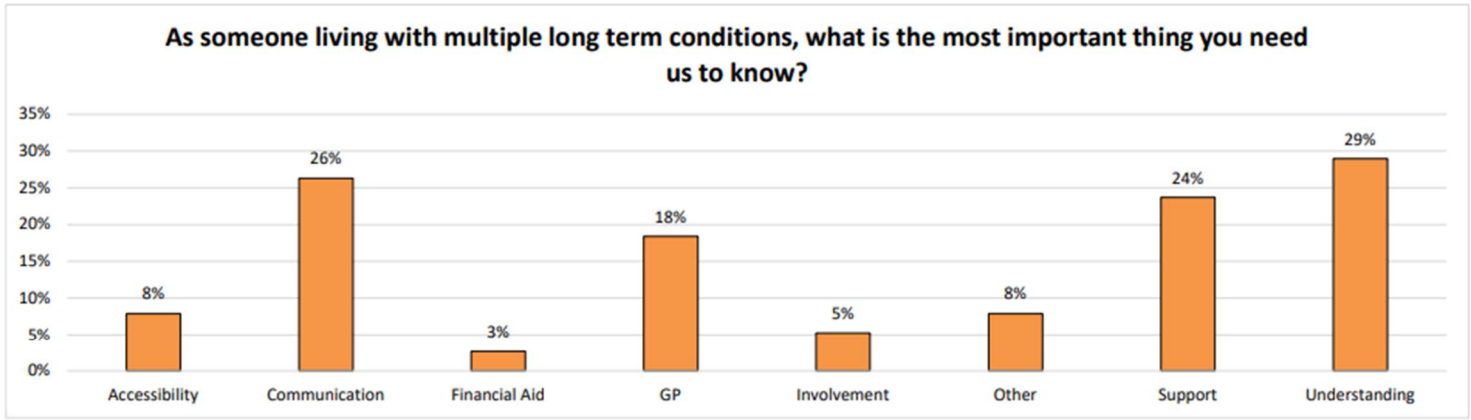
Responses Related To:	Responses	% of total respondents
Accessibility	3	8%
Communication	10	26%
Financial Aid	1	3%
GP	7	18%
Involvement	2	5%
Other	3	8%
Support	9	24%
Understanding	11	29%
Total Respondents	**38**	

Summary of Common Themes

Understanding - comments related to professionals understanding the individual needs of the person, that every patient is different and that not all conditions are physical.

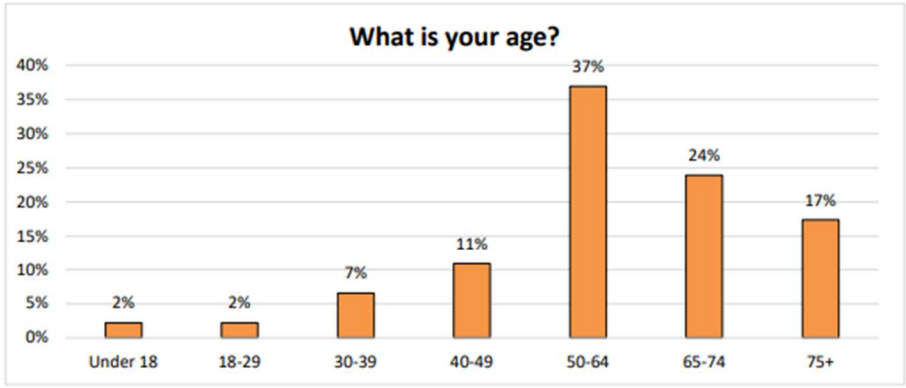
Communication - comments related to healthcare professionals listening to patients, simplifying language when diagnosing and all services involved in care/treatment to communicate effectively with each other.

Support - comments related to providing more support for mental health conditions, housing options, information about support available for family members and support needs being filled if/when family can no longer fill the role.



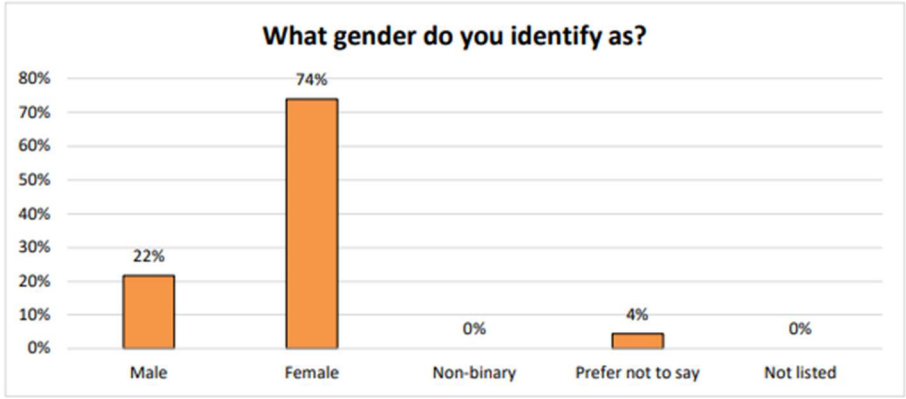
What is your age?

Answer Choices	Responses	Percentage of total responses
Under 18	1	2%
18-29	1	2%
30-39	3	7%
40-49	5	11%
50-64	17	37%
65-74	11	24%
75+	8	17%
Total	**46**	



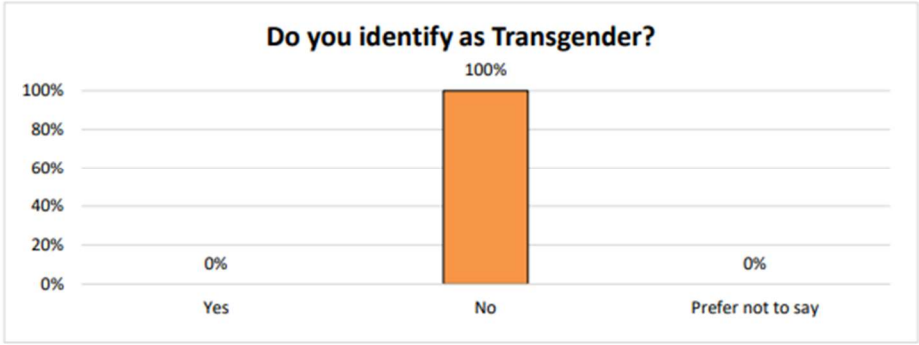
What gender do you identify as?

Answer Choices	Responses	Percentage of total responses
Male	10	22%
Female	34	74%
Non-binary	0	0%
Prefer not to say	2	4%
Not listed	0	0%
Total	**46**	



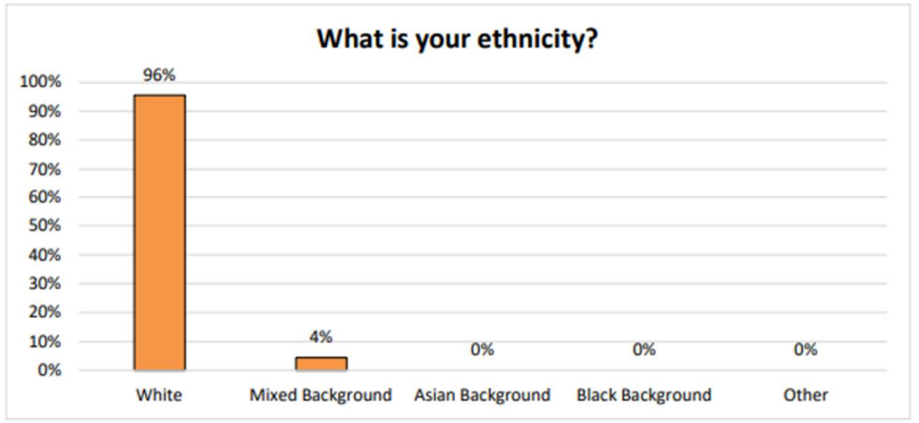
Do you identify as Transgender?

Answer Choices	Responses	Percentage of total responses
Yes	0	0%
No	21	100%
Prefer not to say	0	0%
Total	**21**	



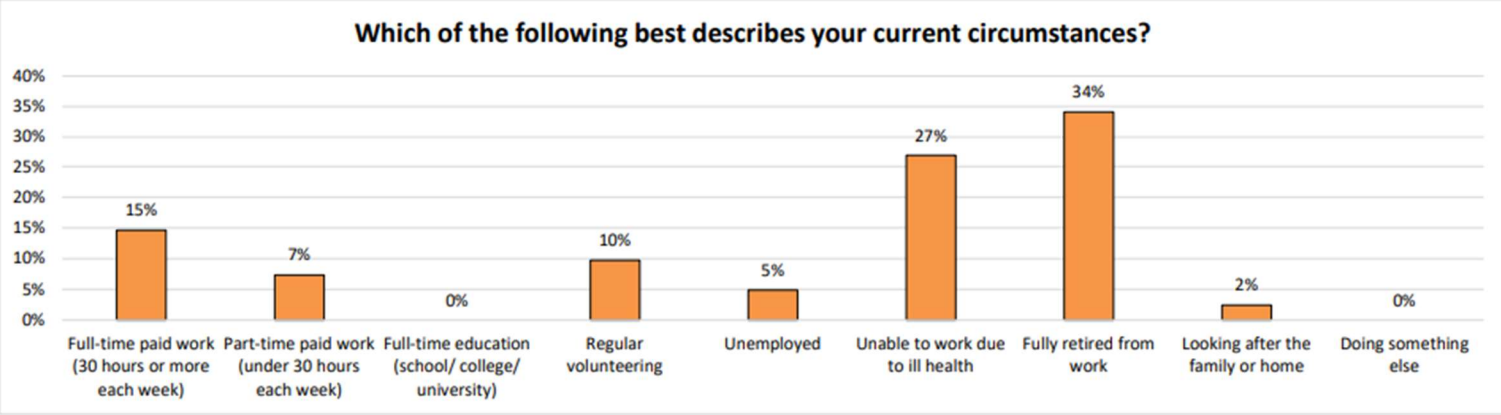
What is your ethnicity?

Answer Choices	Responses	Percentage of total responses
White	43	96%
Mixed Background	2	4%
Asian Background	0	0%
Black Background	0	0%
Other	0	0%
Total	**45**	



Which of the following best describes your current circumstances?

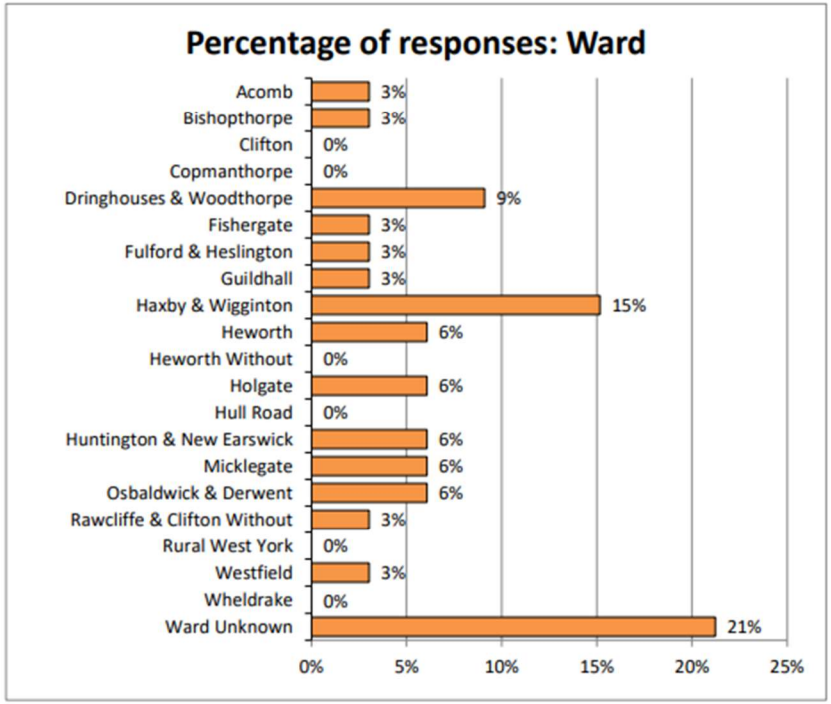
Answer Choices	Responses	Percentage of total responses
Full-time paid work (30 hours or more each week)	6	15%
Part-time paid work (under 30 hours each week)	3	7%
Full-time education (school/ college/ university)	0	0%
Regular volunteering	4	10%
Unemployed	2	5%
Unable to work due to ill health	11	27%
Fully retired from work	19	34%
Looking after the family or home	2	2%
Doing something else	0	0%
Total	**41**	



Question: Please enter your home postcode

33 respondents who gave their post codes have been matched into York Wards. A further 4 post codes came from Selby.

York Wards	Responses	Percentage
Acomb	1	3%
Bishopthorpe	1	3%
Clifton	0	0%
Copmanthorpe	0	0%
Dringhouses & Woodthorpe	3	9%
Fishergate	1	3%
Fulford & Heslington	1	3%
Guildhall	1	3%
Haxby & Wigginton	5	15%
Heworth	2	6%
Heworth Without	0	0%
Holgate	2	6%
Hull Road	0	0%
Huntington & New Earswick	2	6%
Micklegate	2	6%
Osbaldwick & Derwent	2	6%
Rawcliffe & Clifton Without	1	3%
Rural West York	0	0%
Strensall	1	3%
Westfield	1	3%
Wheldrake	0	0%
Ward Unknown	7	21%
Total	**33**	



Appendix 3 Notes of Multimorbidity Focus Groups

Focus Groups held Monday 13th January / Monday 27th January 2020

Question 1

Thinking about your particular conditions and the help you receive with them, when does your care and support work best, and when worst?

Professionals don't always seem to know how multiple conditions interact. For example, Diabetes and Heart condition, issues and confusion with diet and conditions of the foot – health professionals didn't seem to connect these together and there was conflicting advice. Sometimes the evidence is unclear, like with medication that prevents stroke but may increase the likelihood of bleeding.

More routine problems get the attention in care – one participant had cardiac and thyroid problems as well as an essential tremor, and the latter had caused the most suffering over the years but was the most under treated. He felt in 50 years no one had ever 'dug deep into the problem'.

Care and support seems to work better when there is effective cross over. This doesn't always happen and can then feel like 'band aiding' elements of multiple conditions.

Example given about numerous appointments but only seen the same health professional twice during that period of care. One participant with T2DM had his foot looked at in 8 different locations across York in 16 months

Positive experiences with care and support seem to be dependent on the condition and the services provided for this as some have clearly had more positive experiences than others.

One participant – continuity of care seems to have been non-existent

Seems to work best when you (patient) know what you need, have researched the condition and have the confidence to ask and question. The internet is useful!

Good example of positive experience – medication review through Pharmacist at the GP Practice/Community Pharmacist – this was helpful and felt empowering.

Local Council services (OT) providing practical aids have been very good – positive, practical support.

Sometimes the treatment leads to significance burden e.g. multiple testing and check ups.

GP is very good, provides good support, but has to tell the GP what she wants, do the research herself. Doesn't have any help and support other than the things she seeks out for herself outside of this.

With this particular condition (Parkinson's) there seems to be little understanding and a need for much more education. There is a need for more secondary support (only 1 trained

Parkinson's disease specialist Nurse at the Hospital in York). Little understanding of the condition amongst other health professionals. The Consultant is very good but only sees them once per Year.

The parkinsons team weren't supportive of the participant giving advice to other Parkinon's patients through a community support group – but with a very threadbare service the options are limited!

Independence is empowering and very important to maintain if you can. GP is positive and supportive. This participant has been confident enough to sort one condition out for herself by being able to go private for Hearing Aids. A support group for her other condition has been very helpful – feels safe and supported there.

At the start of a condition there is a lot of action and support is good…but then it tails off

Online prescriptions are very good, this has been positive. The Consultants that this participant has seen have been good and explained the conditions well. There are perhaps some 'layers' of professional care where there is a lack of understanding and therefore the support has not been so good. Example given of Hospital stay where staff didn't show understanding of medications, in particular the importance of timing of medications and acknowledgement that the Patient knows what is required.

Question 2

Thinking ahead, do you feel supported about making decisions regarding your health?

The group generally seem to be proactive about doing their own research and knowing what they want, However if you are not able to do this or not confident, then making decisions could be more difficult. This means people who are articulate (people who 'shout') may receive better care

A two way conversation is really important but if you can't get to see who you need to see, then it is much more difficult. Dialogue is really important to support decision making.

Decision making can be dependent on the particular condition in question and the health professional's knowledge around it.

Multiple medications can be challenging (interaction of different drugs) it needs ongoing dialogue to help manage effectively/make decisions.

Challenges with this are ongoing but there are positive things happening through the sharing of knowledge to work towards agreement in decision making.

Feeling that decisions/things are not always tailored to participant's particular situation. Managing daily multiple medications can be difficult. This participant requested 8 weekly repeat scripts to cut down on trips to the Pharmacy, however he was assertive and had the confidence to do this – may not be the case with everyone.

[Has anyone ever been asked 'what's important to you?' No-one said yes]

Question 3

The survey showed that almost half of respondents felt that getting health professionals to communicate and work together was difficult. Why do you think this is?

Experienced delays in communication especially from the Hospital back to the GP. The pathway from symptoms/diagnosis to resolution or management doesn't need to be so long and drawn out. Understands however that this can be due to resource issues (sharing of data, poor software etc.). These factors can mean that things take longer.

One participant experienced such a delay that he ended up going private to access the treatment he was waiting for. This was due to the length of time/delays in communication between primary and secondary care

Question 4

The survey showed that living with multiple long term conditions had a significant effect on people's lives. What could be done about this?

Participant organises his life now around having a general 'low level of energy'. This means he can still enjoy things – it could be better but can still enjoy life. Does things to help himself – supplements etc.

One participant felt a real effect on his social life through restrictions due to celiac disease (eg beer drinking)! Feels like a restraining order.

With medication can manage, although always has discomfort – can walk but not long walks in the Countryside, so there are restrictions.

Need to acknowledge the difference between conditions that can take your life and those that you live with, but with constant discomfort/restrictions.
Need to think about what could be done to support quality of life?

For one participant, work were very supportive which really helped. They were flexible.

Financial restraints were not identified as an issue for this group, however it was acknowledged that this could be significant for others and have a negative impact on people's ability to live full lives.