

11. Brighton & Hove Multiple long-term conditions Needs Assessment: Appendix

11.1 Methodology

Steering Group

The project was delivered by members of the Brighton & Hove City Council's Public Health Team. The report authors are:

- Nicola Rosenberg, Consultant in Public Health
- Kate Gilchrist, Head of Public Health Intelligence

Specific sections were led by:

- Caroline Tudor, Public Health Information Specialist
- Emily Robinson, Public Health Specialty Registrar
- Emma King, Public Health Specialty Registrar

A steering group chaired by Dr Katie Stead, GP Clinical lead Primary Care Brighton and Hove Clinical Commissioning Group oversaw the production of the needs assessment. This comprised of statutory, voluntary, and community sector representatives, including representatives from Community Works via Age UK, Healthwatch, Patient Participation groups, GP practices, Brighton and Sussex University Hospital trust, Sussex Community Foundation Trust, Sussex Partnership Foundation Trust, Brighton and Hove Clinical Commissioning Group and Brighton and Hove City Council (Adult Social Care and public health). We would like to thank them for their commitment to, and advice on, this needs assessment and its recommendations.

The remit of the steering group included agreeing areas of focus, contributing to the development of the project methodology, providing specialist advice, commenting on analysis and drafts, contributing to recommendations, approving the final report and advising on dissemination.

The project was delivered over an 8 month period, concluding in November 2018.

Literature review

A transparent search strategy (see appendix 1) for relevant literature was used via the Pubmed, Embase and Cochrane databases. A search of grey literature was also conducted using criteria in appendix 1, in order to identify similar publications from other local authorities or national bodies.

Titles were reviewed, and publications or studies, including systematic reviews, were selected according to the below:

The main search terms are: Multimorbidity / multi-morbidity, multiple long-term conditions (MLTCs) or multiple chronic conditions. Although there is no set definition for the conditions included in studies of multi-morbidity, mental health conditions such as depression, bipolar, schizophrenia, diabetes, Chronic Obstructive Pulmonary Disease and heart failure.

Specific literature searches were done for the following topic areas:

- Self-care and self-management
- Community and voluntary sector support
- Patient / service user experience, feedback, views and perspectives
- Multiple long-term conditions and mental health including dementia
- Learning disabilities
- Managing patients with multiple LTCs

- Social care support
- Multi-disciplinary teams / support
- Multiple long-term conditions and protected characteristics: ethnicity, pregnancy, Learning disabilities, LGBTQ and equivalent and gender and trans
- Cross cutting themes

Data analysis

Local data sources have been used to describe the adult population with multiple long-term conditions in Brighton & Hove. The primary source of data is an extract of GP patient level data (provided by Sollis¹) which provides a snapshot of all adults in Brighton & Hove who are registered with a GP practice and consent to their data being used for research (estimated to be around 95% of the Brighton & Hove registered population). The extract is based on conditions mentioned in patient records, plus medications for those conditions, and has been linked at record level with secondary care data on hospital costs and activity. All identifiers were removed from the data before being provided for analysis. It provides a year's worth of activity up to March 2017 for 233,416 adults aged 20 and over.

Selection of the conditions most relevant to multi-morbidity was agreed by the steering group (section **Error! Reference source not found.**). The GP data were then used to describe the demographics of adults living with multiple long-term conditions in terms of age, sex and deprivation. We also assess how demographics vary in relation to co-occurring physical and mental health conditions.

A further data source from PHE provides observed age-sex-deprivation prevalence rates of multi-morbidities found in a large-scale study of just under 2 million people in Scotland.^{Error! Bookmark not defined.} The observed prevalence rates of multi-morbidities were applied to wards in Brighton & Hove and provide additional detail to that observed from the GP patient data. This analysis is particularly useful as the description of multi-morbidity is different (based on a set of 40 conditions) rather than the 41 agreed by our steering group. Thus it allows us to see whether patterns and trends are similar for different definitions of multiple long-term conditions.

In the GP patient data, we then consider the most common long-term conditions by age, sex and deprivation. A cluster analysis provides an informative summary of which combinations of long-term conditions an adult might have. This is used to describe healthcare patterns to see which conditions can be attributed to the largest category of cost (emergency admissions, A&E, outpatients, elective admissions). We also provide an analysis of frailty in relation to hospital costs.

A further dataset from adult social care was assessed and contrasted with the evidence from the GP patient records. Without an integrated dataset we have unfortunately not been able to look at the pathways of care between health and social care, or the combined costs for individuals with multiple long-term conditions.

Professional/stakeholder qualitative evidence

Semi-structured interviews were conducted with 19 health and social care professionals across the system and 8 community and voluntary sector representatives². These interviews were conducted by Emma King (Public Health Specialty Registrar) and Emily Robinson (Public Health

¹ Sollis is a health analytics company working with the NHS to provide software and analytical services.

² This included Healthwatch, Southdown Housing Association, Brighton Housing Trust, Trust for Developing Communities, Volunteering Matters, Hangleton and Knoll Project, Impact Initiatives and Impetus Brighton & Hove Adults with multiple long-term conditions needs assessment 2018

Specialty Registrar) with written consent provided. The interviews were recorded and key points transcribed. The analysis presents a summary of key themes found across the interviews.

The Community and Voluntary Sector Interviews were conducted with organisations which tended to support people with more acute needs, compared to the wider population of people with MLTCs. They highlighted particularly vulnerable groups, including those living in supported housing, with learning disabilities, dementia, psychiatric diagnoses, low mood and depression, substance misuse problems, communication issues due to second-language English, low literacy, and hearing problems, and those living alone or without a carer.

Adults with multiple long-term conditions, and their carers, qualitative evidence

Within the timescale of the needs assessment there was limited time to conduct new qualitative data collection on local people's experience with the management of their conditions. However, the following methods were used for to gather voice evidence:

- NHS England provided extra tables from the 2018 NHS GP patient survey for Brighton & Hove (splitting results by those with 0, 1, 2 and 3+ long-term physical or mental health conditions) for over 3,600 patients giving views of their management of their conditions and experience of primary care.
- An online survey for adults with multiple long-term conditions (MLTCs), and their carers, open from 30th July to the 2nd September was disseminated through the council and CCG links and via Community Works to the community and voluntary sector. There were 111 responses from adults with MLTCs and 36 from their carers.
- Older people were invited to focus groups arranged by Age UK Brighton & Hove. However, there were unfortunately not enough participants registered for the focus groups to go ahead. Those participants registered were sent the details of the online survey to complete, with an offer of telephone support to complete the survey.
- Voluntary and community sector organisations were invited to submit evidence particularly in relation to older people, Learning Disabilities, alcohol and substance misuse, mental health and improving self-care of / support for people with MLTCs and carers of people with MLTCs.

11.2 Final list of 41 long-term conditions included in the needs assessment

Table 1: List of the 41 long-term conditions included in the definition of MLTCs and their prevalence in adults aged 20+, Brighton & Hove, March 2017

Condition Type	Condition in GP patient records	Prevalence in all adults aged 20+	Count of adults aged 20+
Cancer	Cancer in past five years	3%	6,431
Blood, blood forming organs and immune mechanism	HIV/AIDs	<1%	219
	Sickle cell disease	<1%	101
Digestive	Inflammatory bowel disease	1%	1,693
	Chronic liver disease	1%	2,527
Endocrine/ metabolic and nutritional	Obesity	4%	8,925
	Diabetes	4%	10,348
	Hypothyroidism	4%	9,816
Neurological	Gout	2%	4,827
	Multiple sclerosis	<1%	543
	Parkinson's disease	<1%	475
	Muscular dystrophy	<1%	116
Skin	Peripheral neuropathy	1%	2,127
	Paralytic syndromes	<1%	570
	Cerebrovascular disease	2%	3,628
	Chronic skin ulcer	<1%	667
	Musculoskeletal	Osteoporosis	<1%
Urological	Rheumatoid arthritis	1%	1,618
	Degenerative joint disease	2%	4,888
	Chronic renal failure	3%	7,861
Respiratory	Asthma	11%	26,144
	COPD (including Emphysema, Chronic bronchitis, COPD)	2%	4,722
Eye	Blindness and/or Age-related macular degeneration	1%	1,853
Ear	Deafness, hearing loss	1%	1,515
Cardiovascular	Hypertension	12%	28,740
	Congestive heart failure	1%	1,864

	Atrial fibrillation	3%	6,315
	Ischemic Heart Disease and/or generalised atherosclerosis and/or cardiovascular disorders	3%	7,985
	Peripheral vascular disease	<1%	334
Psychological	Substance misuse (inc. alcohol dependence)	3%	7,613
	Moderate/severe depression	4%	8,825
	Learning disability	<1%	1,015
	Anxiety	13%	30,184
	Schizophrenia and affective psychosis and/or bipolar disorder	1%	3,137
	Seizure disorders	1%	2,766
	Dementia	1%	2,578
General and unspecified	Chronic pain	<1%	244
	Immunosuppression	<1%	132
	Cerebral Palsy	<1%	185
	Urinary incontinence	4%	8,882
	Autoimmune diseases	1%	3,394

Source: GP patient data (Sollis)

11.3 Long-term conditions available in the GP patient data (Sollis) and whether used in the needs assessment

Chronic condition (based on the 287 EDC codes available)	Match
Transplant status	Matched to Immunosuppression
Asthma w/o status asthmaticus Asthma with status asthmaticus	Both matched to Asthma
Ischemic heart disease (excluding acute myocardial infarction)	Matched to IHD or Generalised atherosclerosis or Cardiovascular disorders
Congestive heart failure	Matched to Congestive Heart Failure
Cardiac arrhythmia	Matched to Atrial Fibrillation
Generalized atherosclerosis	Matched to IHD or Generalised artherosclerosis or Cardiovascular disorders
Hypertension, w/o major complications Hypertension, with major complications	Both matched to Hypertension
Cardiovascular disorders, other	Matched to IHD or Generalised artherosclerosis or Cardiovascular disorders
Deafness, hearing loss	Matched to Deafness, Hearing Loss
Osteoporosis	Matched to Osteoporosis
Hypothyroidism	Matched to Hypothyroidism
Type 2 diabetes, w/o complication Type 2 diabetes, w/ complication Type 1 diabetes, w/o complication Type 1 diabetes, w/ complication	All matched to Diabetes
Blindness Age-related macular degeneration	Both matched to Blindness or Age Related Macular Degeneration
Inflammatory bowel disease	Matched to IBD
Chronic liver disease	Matched to Chronic Liver Disease
Peripheral vascular disease	Matched to Peripheral Arterial Disease
Incontinence	Combined with a frailty marker to give Urinary incontinence
Sickle cell disease	Matched to Sickle cell disease
HIV, AIDS	Matched to HIV/AIDS
High impact malignant neoplasms Malignant neoplasms, breast	All matched to Cancer in the past five years

Malignant neoplasms, cervix, uterus Malignant neoplasms, ovary Malignant neoplasms, esophagus Malignant neoplasms, kidney Malignant neoplasms, liver and biliary tract Malignant neoplasms, lung Malignant neoplasms, lymphomas Malignant neoplasms, colorectal Malignant neoplasms, pancreas Malignant neoplasms, prostate Malignant neoplasms, stomach Acute leukemia Malignant neoplasms, bladder <u>Note: Skin cancer was removed but melanoma left in.</u>	
Degenerative joint disease	Matched to Osteoarthritis
Peripheral neuropathy, neuritis	Matched to Peripheral neuropathy
Cerebrovascular disease	Matched to Cerebrovascular disease
Parkinsons disease	Matched to Parkinson's disease
Seizure disorder	Matched to Seizure disorder
Multiple sclerosis	Matched to Multiple sclerosis
Muscular dystrophy	Matched to Muscular dystrophy
Dementia and delirium Dementia	Both matched to Dementia
Quadriplegia and paraplegia Paralytic syndromes, other	Both matched to Paralytic Syndromes
Cerebral palsy	Matched to Cerebral Palsy
Obesity	Matched to Obesity
Anxiety, neuroses	Matched to Anxiety
Substance use	Matched to Substance misuse (and includes alcohol dependence)
Schizophrenia and affective psychosis Bipolar disorder	Both matched to Schizophrenia/Bipolar
Depression (severe and moderate depression)	Matched to Depression in past five years
Chronic ulcer of the skin	Matched to Chronic Skin Ulcer
Chronic renal failure	Matched to Chronic Renal Failure
Emphysema, chronic bronchitis, COPD	Matched to COPD

Autoimmune and connective tissue diseases	Matched to Autoimmune disease
Gout	Matched to Gout
Rheumatoid arthritis	Matched to Rheumatoid Arthritis
Chronic pain	Matched to Chronic pain in past five years
Learning disability	Matched to Learning Disability
Low back pain	Not included as may be double counted in Chronic Pain
Congenital abnormalities	Not included as less prevalent in adults
Irritable bowel syndrome	Not included
Various blood disorders	Not included
Lipid disorders	Not included
Migraine	Not included
Glaucoma	Not included
Late effects of cerebrovascular disease	Not included
Endometriosis	Not included
Prostate disorders	Not included

*** If the EDC code name is not listed here, then it is not included in the needs assessment.

11.4 List of health conditions in Care First (Adult Social Care data)

Based on health conditions that were in CareFirst system at the time of writing the report.

Acquired (eg injury/amputation/fractures/other)	Liver condition
A.D.H.D (Attention Deficit Hyperactivity Disorder)	M.E/Chronic Fatigue Syndrome
Adults Health Condition	Motor Neurone Disease
Arthritis	Multiple Sclerosis
Aspergers Syndrome/High Functioning Autism	Musculo-Skeletal problems
Asthma	Osteoporosis
Autism - Excl Aspergers/High Functioning Autism	Other Mental Health problem
Auto-Immune disease	Other Neurological Condition
Bariatric condition	Other Physical conditions (including Circulatory)
B.E.S.D (Behavioural/Emotional/ Social Diff)	Parkinsons
Bowel/digestive condition	Personality Disorder
Cancer	Physical Impairment
Cardiac condition - Atrial Fibrillation	Pregnancy
Cardiac condition - Cardiovascular disease	Respiratory condition
Cardiac condition - Coronary Heart Disease	Serious infection (viral or bacterial)
Cardiac condition - Heart Failure	Severe Mental Illness
Cardiac condition – Other	Skin condition
Cerebral Palsy	Spinal injury
Chronic Kidney Disease	Stroke or Transient Ischaemic Attacks (T.I.A)
C.O.P.D	Substance Misuse
Dementia (inc Alzheimers)	Thyroid condition
Depression/anxiety	Visual Impairment
Diabetes	
Dual Sensory impairment	
Epilepsy	
Fibromyalgia	
Head Injury (including A.B.I)	
Health Condition - Autistic Spectrum disorders	
Health Condition - Learning Disability	
Health Condition - Mental Health	
Health Condition - Neurological	
Health Condition – Physical	
Health Condition – Sensory	
Hearing Impairment	
H.I.V/A.I.D.S	
Huntingtons disease	
Hypertension (high blood pressure)	
Hypotension (low blood pressure)	
Learning - Developmental/Intellectual - Other	
Learning Disability	

The conditions are part of the NHS Digital Equalities and Classifications framework. Guidance on the framework and how conditions are reported can be found here:

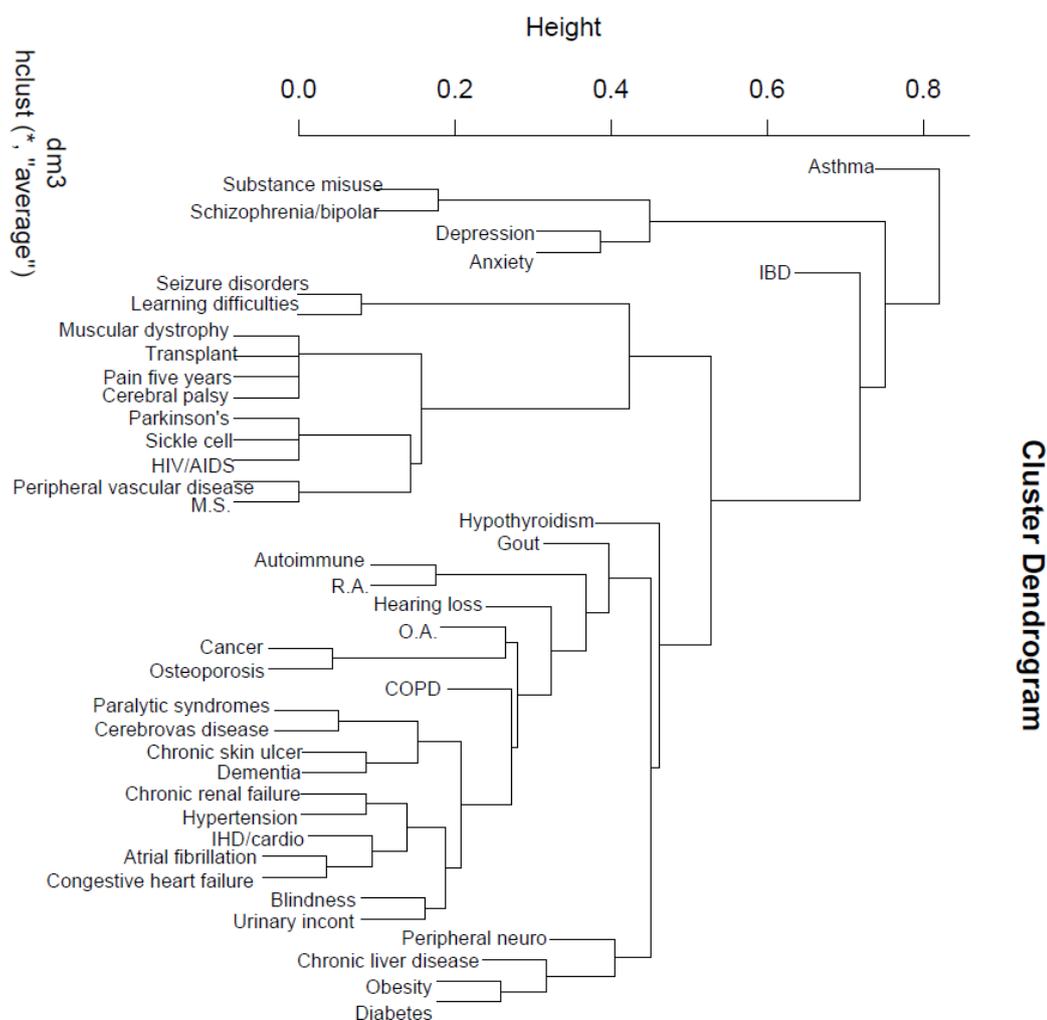
https://digital.nhs.uk/binaries/content/assets/website-assets/data-collections/social-care-collections-2018/eq-cl_2017-18_framework.pdf

11.5 Cluster analysis

Dendrogram - results of cluster analysis of the 41 long-term conditions

Cluster analysis was performed in the statistical software R according to the methodology in Deruaz-Luyet et al (2016). The data were binary with 1 indicating presence of disease/condition and 0 without. Odds ratios were found between every pair of conditions and these were converted to distance measures. Hierarchical clustering was used: each condition started in its own cluster, and pairs of clusters were formed moving up the hierarchy. The criteria for merging was based on clusters of nearest distance to each other with the average distance between clusters minimised. The method was applied to the Brighton & Hove adults with MLTCs only (as in the paper).

The cluster “dendrogram” shows conditions which cluster together with the height reflecting the strength of association. Branches indicate clusters of disease e.g. the cluster of peripheral neuropathy, chronic liver disease and obesity. Asthma and IBD did not appear to associate with any other condition in particular. Asthma/IBD/depression /anxiety/substance misuse/schizophrenia being at the top of the hierarchy are assumed to be overarching (given that all adults have multiple conditions) and associated with all other clusters.



10.6 Further cluster analysis

N'Goran reported four major clusters when applying the same methodology.³ Their four major clusters were: (1) cardiovascular disease risk factors and conditions; (2) age-related and metabolic conditions; (3) tobacco-related and alcohol-related conditions and; (4) pain, musculoskeletal and psychological conditions. This is broadly similar to our findings, although in Brighton & Hove psychological conditions cluster more closely to tobacco-related and alcohol-related conditions. Pain, in our cluster analysis, was more closely associated with neurological conditions.

Demographic analysis of disease clusters

- **Disease clusters and risk factors:** In the Brighton & Hove, 28% of adults with no long-term conditions are current or ex-smokers. This compares to 40% of adults with a single condition. Almost half, or above, of all adults with multiple long-term conditions with conditions in all clusters are current or ex-smokers.
- **Disease clusters and age:** The clusters vary most in terms of age profile with clusters 1 (mental health and substance misuse), 2 (learning difficulties and seizure disorders), 3 (asthma) and 4 (IBD) being more prevalent amongst younger adults. Adults with multiple long-term conditions in clusters 6 (older age) and 7 (brain) are more likely to be aged 65 years or over.
- **Disease clusters and frailty:** A disproportionately high percentage of adults with MLTCs in cluster 5 (neurological) and 7 (brain) are moderately or severely frail.
- **Disease clusters and gender:** A higher percentage of adults with multiple long-term conditions having conditions in clusters 2 (learning disabilities) and cluster 5 (neurological) are males compared to the overall percentage for all adults with multiple long-term conditions, and a higher percentage of adults with multiple long-term conditions having conditions in clusters 8 (immune inc. arthritis) and 3 (asthma) are females compared to the overall percentage for all adults with multiple long-term conditions (Table 2).
- **Disease clusters and deprivation:** In the under 65s, prevalence of the disease clusters in the most deprived quintiles is more than double compared to the least deprived quintiles for clusters 1 (mental health and substance misuse), 2 (learning disabilities and seizure disorders), 5 (neurological) and 9 (metabolic) (Table 3). In contrast, for adults aged 65 years or over the prevalence of the disease clusters is similar in the most and least deprived quintiles.

³ N'Goran AA, Blaser J, Deruaz-Luyet A, Senn N, Frey P, Haller DM, Tandjung R, Zeller A, Burnand B, Herzig L. From chronic conditions to relevance in multimorbidity: a four-step study in family medicine. *Fam Pract.* 2016 Aug;33(4):439-44.

Table 2: Further analysis of the disease clusters, Brighton & Hove, March 2017

Disease cluster	% current or ex-smokers	% aged 65+	% aged 65+ with moderate or severe frailty	% male
All adults with MLTCs	52%	46%	18%	47%
1. Mental health and substance misuse	56%	24%	20%	45%
2. Learning disabilities	46%	26%	22%	52%
3. Asthma	55%	26%	24%	43%
4. IBD	49%	32%	21%	49%
5. Neurological	56%	47%	31%	54%
6. Age-related	51%	69%	20%	49%
7. Brain	50%	77%	35%	47%
8. Immune incl. arthritis	53%	58%	21%	42%
9. Metabolic/ endocrine	56%	46%	23%	49%

Table 3: Prevalence of each disease cluster in adults with MLTCs aged under 65, for the most and least deprived quintiles, Brighton & Hove, March 2017

Disease cluster	Prevalence in least deprived quintile (LDQ)	Prevalence in most deprived quintile (MDQ)	Prevalence MDQ/LDQ
1. Mental health and substance misuse	14%	29%	2.1
2. Learning disabilities	14%	32%	2.3
3. Asthma	15%	28%	1.9
4. IBD	20%	20%	1
5. Neurological	13%	28%	2.2
6. Age-related	18%	27%	1.5
7. Brain	15%	28%	1.9
8. Immune incl. arthritis	18%	28%	1.6
9. Metabolic/ endocrine	15%	32%	2.1

Source: GP patient data (Sollis)

10.7 Literature search strategy

A transparent search strategy for relevant literature was used via the Pubmed, Embase and Cochrane databases, and a search of grey literature was conducted via google, using the below search terms:

Multiple long term conditions

OR Muti-morbdity

OR Mutimorbdity

OR Multiple chronic conditions

Then the above terms in combination with the following:

- Patient / service user experience, feedback, views and perspectives
- Mental health including dementia
- Learning disabilities
- Protected characteristics: ethnicity, pregnancy, Learning disabilities, LGBTQ and equivalent and gender and trans
- Self-care AND self-management AND home management
- Community care / community support / voluntary sector
- Carers
- Identifying patients
- Community health services
- Frailty
- Managing patients with multiple LTCs
- Social care AND social work AND social services
- Primary care AND GP
- Secondary care AND hospital
- Care homes AND nursing homes
- MDTs AND Multidisciplinary teams/working
- Integrated care
- Coordinated care
- Polypharmacy AND medicines management
- Discharge AND delayed discharge
- Home First AND Discharge to Assess
- Admission AND unnecessary admission AND avoidable admission
- Patient records AND patient information systems AND record management
- Technological solutions AND technology