# 2. Our approach to needs assessment

### **Brighton & Hove JSNA 2014**

#### What is needs assessment?

The needs assessment process aims to provide a comprehensive analysis of current and future needs of local people to inform commissioning of services that will improve outcomes and reduce inequalities.

To do this, needs assessments should gather together local data, evidence from the public, patients, service users and professionals, plus a review of research and best practice. Needs assessments bring these elements together to look at unmet needs, inequalities and overprovision of services. They also point those who commission or provide services towards how they can improve outcomes for local people.

The common name for these needs assessments is Joint Strategic Needs Assessment (JSNA). Joint reflects that they should be carried out jointly by the NHS and councils as a requirement, but in terms of good practice should also include others locally with expertise to offer. Strategic reflects that they should be about providing the 'big picture' in terms of identifying local needs.

#### National policy and guidance

The Local Government and Public Involvement in Health Act (2007) placed a duty on local authorities and Primary Care Trusts to work in partnership and produce a JSNA.<sup>1</sup>

The 2012 Health and Social Care Bill set out changes, with the transfer of Public Health to councils, new Clinical Commissioning Groups (CCGs) and the creation of Health and Wellbeing Boards from April 2013. Department of Health guidance states that councils and CCGs have equal and explicit obligations to prepare a JSNA; this duty discharged by Health and Wellbeing Boards.<sup>2</sup>

The guidance signalled an enhanced role for JSNAs to support effective commissioning for health, care and public health as well as influencing the wider determinants that influence health and wellbeing, such as housing and education.

#### Our local approach

In Brighton & Hove there are three elements to the needs assessment resources available:

**Overarching documents:** The JSNA summary, the City Snapshot Report and Annual Reports of the Director of Public Health

The JSNA summary gives a high level overview of Brighton & Hove's population and its health and wellbeing needs. It is intended to inform the development of strategic planning and identification of local priorities.

The information is primarily drawn from the city's needs assessment portfolio, which includes the Annual Reports of the Director of Public Health along with specific needs assessments and strategies. The JSNA summary is also used for the City Snapshot Report which provides high level facts and figures about the city.

**Rolling programme** of needs assessments on a specific theme or population group

A rolling programme of comprehensive needs assessments forms part of a portfolio of resources for the city. Themes may relate to specific issues e.g. mental health and wellbeing, or population groups e.g. children and young people. Needs assessments are publicly available and include recommendations to inform commissioning.

**Community Insight** - the information resource for the city, supported by Brighton & Hove Connected

#### **Brighton & Hove Connected**

(http://www.bhconnected.org.uk/content/local-intelligence) is the Strategic Partnership data and information resource for those living and working in Brighton & Hove and is the home for needs assessments and their supporting data and evidence. Community Insight provides local data on and maps of the population of the city <a href="http://brighton-hove.communityinsight.org/">http://brighton-hove.communityinsight.org/</a>.

#### City needs assessment steering group

Since August 2009, a steering group has overseen the programme of needs assessments. This includes the JSNA, but is broader and encompasses

<sup>&</sup>lt;sup>1</sup> Department of Health. Guidance on Joint Strategic Needs Assessment. 2007. Available at:

www.dh.gov.uk/prod consum dh/groups/dh digitalassets/@dh/@en/docu ments/digitalasset/dh 081267.pdf [Accessed 23/04/2012]

<sup>&</sup>lt;sup>2</sup> Department of Health. Statutory guidance published on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies. 2013. Available at: <a href="http://healthandcare.dh.gov.uk/jsnas-jhwss-guidance-published/">http://healthandcare.dh.gov.uk/jsnas-jhwss-guidance-published/</a> [Accessed 18/07/2003]

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needs assessments typically outside of health and wellbeing.

In 2011 the group broadened its membership to reflect this and now includes the Community and Voluntary Sector Forum (CVSF), Sussex Police and the two universities, in addition to the existing members from the city council, Clinical Commissioning Group and HealthWatch.

#### **Local consultation**

The JSNA summary develops from feedback and consultation. 2012 in particular saw changes to the way it was produced. These changes were informed by the new guidance, Outcomes Frameworks for Public Health, Adult Social Care and the NHS, but also from consultation with local partners and the community and voluntary sector. In particular:

- The CVSF conducted a gap analysis of the JSNA summary in January 2012.
- In March 2012 we held a seminar for thematic partnership chairs, councillors, commissioners, community and voluntary sector representatives and providers on plans for the JSNA and Joint Health and Wellbeing Strategy.
- In July 2012, the draft summary was consulted on and the JSNA informed by the responses.
- The 2013 update included evidence gathered from a call to evidence from the community and voluntary sector.
- In 2014 a small number of sections were updated to reflect evidence from the in depth needs assessment completed in the previous year.

#### Inequalities and protected groups

Over the last two years the summary has more systematically identified local inequalities in terms of equalities groups, geography and socioeconomic status. Each report section has inequalities clearly evidenced. The 2011 Census and 2012 Health Counts Survey have added considerably to this evidence for the 2013 summaries. In addition, there are sections which bring together the key needs of protected groups.

#### **Joint Strategic Assets Assessment**

JSNAs should not focus solely on needs but also identify assets of local communities. Our approach to building assets into needs assessments is given in section 6.5.4. This was informed by the March 2012 event. The 2010 Annual Report of the Director of Public Health mapped community resilience<sup>3</sup> and is an important resource for JSNA.

#### Voice

The voice of professionals, patients, service users and the public provides important evidence for the JSNA. This is embedded throughout this summary, and where we do not currently have this evidence it is included in 'what we don't know'.

#### What we don't know

Throughout the summary, where there is a lack of local data, if possible other studies and evidence have been used to produce estimates for the city. Where this is the case it is clearly identified.

#### **Assessing impact**

In previous years we have listed the health and wellbeing issues for the city. In 2012 we tried to identify more systematically the impact on the city's population. The approach is set out in Section 3 along with the highest impact issues for the city. This fed into the prioritisation process for the Joint Health and Wellbeing Strategy and will be repeated to inform the next Strategy/refresh.

#### **Joint Health and Wellbeing Strategy**

The Health and Wellbeing Board have jointly agreed what the greatest issues are for local people based on the evidence in the JSNA. The Strategy sets these out along with what the Board will do to address them and what outcomes it intends to achieve. It does not include everything, but focuses on the key issues that make the biggest difference by partners working together.

#### **Further information**

This summary, along with the portfolio of needs assessments and local data is available at: <a href="http://www.bhconnected.org.uk/content/needs-assessments">http://www.bhconnected.org.uk/content/needs-assessments</a>

<sup>&</sup>lt;sup>3</sup> NHS Brighton and Hove and Brighton & Hove City Council. Resilience: Annual Report of the Director of Public Health 2010. http://www.bhconnected.org.uk/content/reports

#### Why is this issue important?

The term transgender, or trans, is used as an umbrella term to describe people whose gender identity differs from their biological sex at birth. Some transgender people will choose to transition socially and some will also take medical steps to physically transition to live in the gender role of their choice.

The term trans also includes a broader group of people who find their personal experience of their gender differs from the assumptions and expectations of society, such as people who are intersex, androgyne, polygender or genderqueer. They may also experience some of the issues related to being labelled by others as a gender that doesn't match their gender identity.

National research reveals significant inequalities in health and wellbeing faced by trans people<sup>1,2,3</sup> including an increased risk of mental ill health.

There is no reliable information regarding the size of the trans population in the UK. Recent estimates<sup>4</sup> suggest that 0.6% to 1% of adults may experience some degree of gender variance. A small proportion will have presented for, and undergone, medical gender transition (approximately 12,500 and 7,500 respectively).

#### **Key outcomes**

#### **National outcomes**

None of the indicators in the national Public Health, NHS or Adult Social Care Outcomes Frameworks are specifically focussed on trans people, but cover all people. However gender reassignment is a 'protected characteristic' in the Equality Act 2010 and public sector organisations are required to have due regard to the need to advance equality of opportunity and eliminate discrimination faced by trans people.<sup>5</sup>

# <sup>1</sup> Browne K, Lim J. Count Me In Too. Trans People. Additional Findings Report. University of Brighton and Spectrum; 2008.

#### Local outcomes

In 2013 a Brighton & Hove Trans Equality Scrutiny Panel made a set of recommendations to address trans needs and set up some clear outcomes for the Council and NHS. Both the Council and NHS have adopted these recommendations and are in the process of turning them into outcomes.

Following this, a needs assessment is currently in progress and will report by the end of March 2015 – this JSNA section will then be updated to reflect the evidence within the needs assessment.

#### **Impact in Brighton & Hove**

In 2006, a survey, Count Me In Too<sup>1</sup>, was conducted of the LGBT population of Brighton & Hove. Of a total of 804 respondents, 5% (43) were trans, although it is unclear if this representation is proportionate.

A 2009 report<sup>6</sup> used data from health services to estimate the prevalence of "people who have presented with gender dysphoria" by police force area level. This suggested that Sussex had the highest prevalence in England (more than twice the national average) and the report concluded that this was related to the perception that Brighton & Hove is a favourable environment for trans people.

In the 2012 Brighton & Hove Health Counts survey 0.9% of respondents (18 out of 2,014) indicated that they did not identify as the gender they were assigned at birth.

Allsorts, a project based in Brighton to support and empower young people under 26 years who are lesbian, gay, bisexual, trans\* or unsure (LGBTU) of their sexual orientation and/or gender identity, are in contact with 55 young trans\* people. Each quarter Allsorts survey the young people they are in contact with and the latest survey (January-March 2013) was completed by nine trans\* young people. All had experienced mental health problems (things like depression and anxiety that had left them feeling unable to cope) and had felt low and had been troubled by fears, obsessive thoughts or habits.

With a small sample it is not possible to compare exact percentages from this survey with all young

<sup>&</sup>lt;sup>2</sup> Williams et al. The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document; 2013

<sup>&</sup>lt;sup>3</sup> MacNeil et al. Trans Mental Health Study 2012. The Scottish Transgender Alliance, 2012

<sup>&</sup>lt;sup>4</sup> GIRES. The Number of Gender Variant People in the UK - Update 2011.

<sup>&</sup>lt;sup>5</sup> Mitchell, Howarth. Trans Research Review. Equality and Human Rights Commission. Research Report 27; 2009.

<sup>&</sup>lt;sup>6</sup> Reed et al. Gender Variance in the UK: Prevalence, Incidence Growth and Geographic Distribution. GIRES; 2009

Allsorts submission in the 2013 JSNA call for evidence

people, however the results indicate some significant health and wellbeing issues within this group. More than two thirds of respondents, in the last three months had:

- suffered some form of homophobic/ biphobic/transphobic incidents/ discrimination/ harassment or bullying
- difficulties with relationships
- been drunk

More than a third of respondents had:

- done something to injure or harm themselves
- contemplated suicide
- had unprotected sex<sup>7</sup>

In 2013 the results of the Brighton & Hove Trans Equality Scrutiny Panel were published. This aimed to highlight the challenges and inequalities facing transgender people locally and to make some recommendations for change. It set out to answer the question: what needs to be done to make things fairer for trans people to live, work and socialise in the city?

The panel identified:

- A lack of knowledge on numbers and needs of trans people accessing services. The report recommended a needs assessment is conducted.
- The importance of health and health services including experience of primary care and the transition pathway (including Gender Identity Clinic), and mental health needs. Therefore a number of recommendations are made for health bodies, including the Clinical Commissioning Group.
- Some evidence of inadequate or inappropriate service provision in Housing, adult social care, sports and leisure. Many of these findings echoed those reported in Count Me In Too.

#### Where we are doing well

The community has a number of assets, in the form of independent support groups, including the Clare

Project, Transformers (run by the Allsorts Youth Project), FTM Brighton and MindOut.

Local good practice includes:

- the publication of a Trans\* Inclusion Toolkit for schools and colleges<sup>9</sup> (jointly produced by Brighton and Hove City Council and Allsorts Youth Project)
- the LGBT Health and Inclusion Project, which is commissioned by the City Council and the Clinical Commissioning Group to consult local LGBT people, and use the information gathered to improve access to services, service provision and delivery.

The Allsorts survey suggests that less than a third of young trans\* people they surveyed had taken drugs in the last three months, and over two thirds had never smoked. Although over a third of young people had had unprotected sex in the last three months, the same number had been tested for an STI in the same period.<sup>7</sup>

#### Local inequalities

Overall, Count Me in Too demonstrates higher needs among trans people than the LGB community. Directly comparable information is not available in all cases for the whole population, so in some cases the results below are compared with the LGB community.

Count Me In Too<sup>1</sup> found that the majority of the trans respondents were White British (93%) and identified as female (67%). Trans respondents were significantly more likely to be over 45 years than the LGB respondents, with only 9% under 26. Over a third of trans people surveyed (35%) reported a disability or long-term health impairment. This is significantly higher than the proportion of disabled working age women and men in the city (19% and 20% respectively for 2010/11).

As well as being more likely to report long-term health impairments, only 44% of trans people reported that they were in 'good/very good' health, compared with 76% of all people in the city. <sup>10</sup>

<sup>&</sup>lt;sup>8</sup> Brighton & Hove City Council. Brighton & Hove Trans Equality Scrutiny Panel. 2013

<sup>&</sup>lt;sup>9</sup> Brighton & Hove City Council. Trans Inclusion Toolkit: Supporting transgender and gender questioning children and young people in Brighton and Hove schools and colleges; 2013

<sup>&</sup>lt;sup>10</sup> Brighton & Hove City Council. The Place Survey; 2008.

Count Me In Too found that trans people report difficulties in accessing a trans friendly or non-transphobic GP; find sexual health information that is appropriate to their gender identity or sexuality; and that there is general dissatisfaction with gender reassignment services. Opinions echoed those found nationally<sup>11</sup>: that there were delays in access to the service and that the 'one size fits all' approach was unacceptable.

Count Me In Too<sup>1</sup> reported that trans people were twice as likely to have thoughts of suicide and five times more likely to have attempted suicide in the past year than LGB people, with only 26% reporting 'good/very good' emotional wellbeing. 86% of trans people reported mental health difficulties, including depression (76%) and anxiety (71%). Respondents described the need for mental health support both during and after transition.

Trans people are more likely to experience hate crime both in the street and at LGBT venues, with 26% reporting experiences of physical violence. 47% reported direct or indirect discrimination from providers of goods, services or facilities in the city, and 64% had experienced domestic violence, compared with 18% of men and 28% of women nationally.

The apparent under-reporting of hate crime, including trans related incidents, was noted by the Trans Equality Scrutiny Panel.<sup>7</sup> There is a need to improve the processes and systems for the recording of transphobic crimes and incidents.

Count Me In Too<sup>1</sup> also highlighted inequalities in employment and housing. Trans respondents were 11 times less likely to earn over £30,000 a year and the majority earned less than £10,000 a year. A third of trans respondents lived in social housing; over half reported that they had struggled to find housing; and 36% had experienced homelessness.

#### **Predicted future need**

As the trans population of Brighton & Hove ages, they will have additional needs for health and wellbeing. Little is currently known about what

these needs will be, as this will be the first generation who have taken hormone therapy for a prolonged period, or undergone gender reassignment surgeries in the 1960s or 1970s. 12

#### What we don't know

The number and demographics of trans people living in the city is unknown. With no published research into the health and wellbeing of trans people since Count Me In Too it is unclear if the inequalities above have changed. Indeed, work has been done to reduce them, e.g. the LGBT Health and Inclusion Project intervention ('Clued Up') to increase uptake of sexual health services among trans people.

The trans needs assessment, to be published by the end of March 2015, should address some of these evidence gaps.

#### Key evidence and policy

The Equality and Human Rights Commission, the Government Equalities Office and the Home Office recently published guidance for public authorities on meeting the needs of trans people, including recommendations for healthcare providers, local government and social care. <sup>13</sup> <sup>14</sup> <sup>15</sup>

#### **Recommended future local priorities**

- 1. Implement the action plan agreed based on the recommendations of the Brighton & Hove City Council Trans Equality Scrutiny review.
- Continue joint working with the trans community through the LGBT Health and Inclusion Project.
- 3. Improve knowledge by conducting a multiagency needs assessment.
- 4. Support existing assets of the trans community: independent, volunteer-run support groups.

http://consult.brighton-hove.gov.uk/portal/lsp/place/place08 [Accessed 06/08/2013]

<sup>&</sup>lt;sup>11</sup> Equality and Human Rights Commission. A review of access to gender reassignment services (England

 $<sup>{\</sup>tt Only); 2011} \underline{{\tt http://www.equalityhumanrights.com/legal-and-policy/equality-act/}}$ 

<sup>&</sup>lt;sup>12</sup> Age UK. Transgender issues in later life. Factsheet 166; 2010.

<sup>&</sup>lt;sup>13</sup> Equality and Human Rights Commission. Provision of Goods, Facilities and Services to Trans People. Guidance for public authorities in meeting your equality duties and human rights obligations; 2010.

<sup>&</sup>lt;sup>14</sup> Government Equalities Office. Equality Act 2010: What do I need to know: A quick start guide to gender reassignment for voluntary and community organisations in the provision of goods and services; 2010.

 $<sup>^{15}</sup>$  Home Office. Advancing Transgender Equality: A plan for action. HM Government. London, UK; 2011

#### Key links to other sections

- Emotional health and wellbeing;
- Suicide prevention

#### **Further information**

Count Me In Too http://www.countmeintoo.co.uk/

The LGBT Health Inclusion Project <a href="http://lgbt-hip.org/">http://lgbt-hip.org/</a>

Brighton & Hove Trans Equality Scrutiny Panel <a href="http://www.brighton-hove.gov.uk/content/council-and-democracy/councillors-and-committees/trans-equality-scrutiny-panel-2013">http://www.brighton-hove.gov.uk/content/council-and-democracy/councillors-and-committees/trans-equality-scrutiny-panel-2013</a>

#### Last updated

August 2014

# 5.1 Life expectancy and healthy life expectancy

#### Why is this issue important?

Life expectancy tells us how long a baby born today would be expected to live if they experienced the current mortality rates of the area they are born in throughout their lifetime.

Whilst other factors, such as biological or genetic disposition, are important, social inequalities are a key driver of ill-health. It has been estimated that the NHS contribution to any future reduction in the life expectancy gap, whilst significant, is limited and that other factors (the social determinants of health) such as education, employment and housing have a greater impact.

#### **Key outcomes**

- Increased healthy life expectancy (Public Health Outcomes Framework)
- Reduced differences in life expectancy and healthy life expectancy between communities (Public Health Outcomes Framework)
- Life expectancy at 75 for males and females (NHS Outcomes Framework)

#### **Impact in Brighton & Hove**

Table 1: Life expectancy and healthy life expectancy

	Brighton & Hove	Regional Centres	South East	England		
Life expectancy at birth (2011-2013)						
Males	78.8	78.1	80.4	79.4		
Females	83.1	82.5	83.9	83.1		
Life expectancy at 65 years (2011-2013)						
Males	18.6	18.1	19.3	18.7		
Females	21.2	20.8	21.7	21.1		
Healthy life expectancy at birth (2010-2012)						
Males	63.6	67.9	65.8	63.4		
Females	66.5	72.0	67.1	64.1		

Source: Office for National Statistics

Life expectancy in Brighton & Hove is 78.8 years for males and 83.1 for females (2011-2013). Whilst females in the city can expect to live the same length of time as nationally, life expectancy for

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males is seven months lower than in England (79.4 years for males and 83.1 years for females).

With healthy life expectancy of 63.6 years for males and 66.5 years for females this means, on average, males live for 15.1 years with a limiting long-term illness or disability and females 16.5 years (2010-12). This also has implications in terms of the increasing retirement age, which will mean people are working with health conditions, or on sickness/disability benefit.

Life expectancy at age 65 years is 18.6 years for males and 21.2 years for females in the city compared with 18.7 and 21.1 years respectively for England.

#### Where we are doing well

Life expectancy in the city is as high as it has ever been, and is continuing to increase at a pace of around five months each year for both males and two months each year females (2006-08 to 2011-13).

Mortality rates are falling, and this is the case for the most affluent and most deprived people in the city.

Female life expectancy is the same as nationally.

#### Local inequalities

Despite the narrowing gap in life expectancy between men and women, men tend to develop and die from many conditions earlier than women.

The slope index of inequality in life expectancy gives a measure of the hypothetical difference in life expectancy between the most deprived and least deprived individuals. It is a more sensitive measure than the difference in mortality between the most deprived and least deprived quintiles of population as it looks at differences in life expectancy across the whole population.

In 2010-2012 the slope index was 8.7 years for males and 6.0 years for females in Brighton & Hove (Table 2). For both males and females this gap is now narrower than nationally.

The gap has narrowed from 10.6 years for males in 2006-10 and from 6.6 years for females.

Mortality rates in the city are falling in all groups (and therefore life expectancy rising), and between

# 5.1 Life expectancy and healthy life expectancy

2006-2010 and 2009-2013 the relative inequality gap has remained the same, an improvement as this had been widening previously. However there are still large inequalities in the City with the mortality rate of the most deprived person being nearly twice that of the least deprived (1.8 in 2006-10 and 2009-2013).

For the five years 2009 to 2013, 19% of deaths were attributable to deprivation – that equates to 2,534 deaths, around 500 deaths per year.

Table 2: Life expectancy inequality (in years) by gender, Brighton and Hove

	Brighton & Hove	England				
Inequality in life expectancy <sup>2</sup> at birth (2010-2012)						
Males	8.7	9.2				
Females	6.0	6.8				
Inequality in healthy life expectancy <sup>5</sup> at birth (2010-2012)						
Males		19.4				
Females		19.8				

Source: Public Health England. Public Health Outcomes Framework Data Tool.

#### **Predicted future need**

A challenge in reducing health inequalities is that while the mortality rate for all groups in the city is expected to improve, it is improving faster in more affluent areas, so local inequalities are expected to increase without intervention:

- The mortality rate in the most deprived quintile in the city is projected to become twice that in the least deprived by 2012.<sup>3</sup>
- Whilst mortality rates are lower for females, the relative gap is expected to increase to

<sup>1</sup> South East Public Health Observatory. Health Inequalities Gap Measurement Tool. <a href="http://www.sepho.nhs.uk/gap/gap-national.html">http://www.sepho.nhs.uk/gap/gap-national.html</a> [Accessed on 21/08/2012].

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almost the level of the gap in men by 2012 (2.0 for males and 1.9 for females).<sup>4</sup>

#### What we don't know

Ethnicity is not recorded on death registration in England. Information on death certificates is restricted to the deceased's country of birth - traditionally used as a proxy for ethnic origin. However, the value of this has diminished over time as subsequent generations have been born in England. In 2012, Scotland became the first UK country to record ethnic origin on death certificates. Death registration also does not record religion, sexual orientation, transgender or whether someone was a carer and life expectancy is not calculated based upon marital status as it is a whole population measure.

Current figures on healthy life expectancy are partly based upon 2001 Census data and are therefore relatively old. The Office for National Statistics is due to publish revised figures, incorporating 2011 Census data on health status, but this is not yet available.

#### Key evidence and policy

Fair Society, Healthy Lives, the Marmot Review of Health Inequalities provides a strategic review of health inequalities in England. A life-course based approach is taken, because of the cumulative impact of social, economic, psychological and environmental experiences on health and health inequalities. Five age groups are identified:

- Pre-birth and early years (up to age 5)
- Children and young people in early education (age 5–16)
- Early adulthood (age 17–24)
- Adults of working age (age 25–64)
- Adults of retirement age (age 65+)

Looking at the contribution of specific causes of death to the life expectancy gap between the most

<sup>&</sup>lt;sup>2</sup> Inequality in life expectancy and disability free life expectancy are measured by the slope index of inequality and are measured in years. More information on the indicator is available at <a href="http://www.apho.org.uk/default.aspx?RID=110504">http://www.apho.org.uk/default.aspx?RID=110504</a> [Accessed on

http://www.apho.org.uk/default.aspx?RID=110504 [Accessed or 21/08/2012].

<sup>&</sup>lt;sup>3</sup> Mortality data has a time lag in its availability and so 2012 data are projected figures.

<sup>&</sup>lt;sup>4</sup> South East Public Health Observatory. Health Inequalities Gap Measurement Tool. <a href="http://www.sepho.nhs.uk/gap/gap">http://www.sepho.nhs.uk/gap/gap</a> national.html [Accessed on 21/08/2012].

<sup>&</sup>lt;sup>5</sup> Marmot, Fair Society, Healthy Lives: Strategic Review of Health Inequalities Post 2010, 2010. Available at:

http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review [Accessed 21/08/2012]

# 5.1 Life expectancy and healthy life expectancy

deprived quintile in Brighton & Hove and the national average for men, the biggest contributor is coronary heart disease, followed closely by lung cancer, chronic cirrhosis of the liver, suicide and undetermined injury, and other accidents. For women, coronary heart disease and other cardiovascular diseases are the biggest contributors to the gap, followed by lung cancer, other cancers, and suicide and undetermined injury. <sup>6</sup>

The Department of Health has identified the key interventions for reducing the life expectancy gap between the most and least disadvantaged areas (based upon previous PCT areas):

- Greatly increasing the capacity of smoking cessation clinics
- Increasing the coverage of effective therapies for secondary prevention of cardiovascular diseases in people aged less than 75 years
- Primary prevention of cardiovascular disease (all ages) and hypertension through treatment with antihypertensives and statins
- The early detection of cancer
- Interventions aimed at reducing mortality from respiratory diseases, alcohol-related diseases and infant mortality

Matrix for Health England developed a prioritisation method to inform investment in preventative health interventions, based upon the cost-effectiveness, impact on health inequalities, and percentage of people affected. The results for Brighton & Hove are shown in Table 3.

#### **Recommended future local priorities**

The Public Health Strategy for England is adopting the Marmot Review<sup>8</sup> approach and this will be built on locally. Marmot concluded that reducing health inequalities would require action on six policy objectives:

1. Give every child the best start in life

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- Enable all children, young people and adults to maximise their capabilities and have control over their lives
- 3. Create fair employment and good work for all
- 4. Ensure a healthy standard of living for all
- 5. Create and develop healthy and sustainable places and communities
- 6. Strengthen the role and impact of ill-health prevention

Recommendations around inequalities are throughout the relevant JSNA sections.

#### Key links to other sections

This section links to many within the JSNA but sections with specific reference here include:

- · Main causes of death
- Coronary heart disease
- Cancer
- Suicide and suicide prevention
- Alcohol
- Maternal and infant health
- Smoking
- Physical activity
- Diet

#### Last updated

November 2014

<sup>&</sup>lt;sup>6</sup> London Health Observatory, Health Inequalities Intervention Tool available at: <a href="http://www.lho.org.uk/LHO">http://www.lho.org.uk/LHO</a> Topics/Analytic Tools/HealthInequalitiesInterventionToolkit.aspx

http://help.matrixknowledge.com/

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Table 3: Matrix for Health England order of priority for preventative health interventions evaluated to date for Brighton & Hove – national and local interventions.

Category	Intervention	Priority Ranking	Priority Score	Affordability	Certainty
Alcohol	Increases in taxation to reduce population consumption of alcohol	i	11.30 %	常育育	黄黄黄
Smoking	Increases in taxation to reduce population smoking rates	2	9.62 %	***	***
Smoking	National mass media campaigns for reducing population smoking rates	3	9.46 %	常常食	京京会
Diet, physical activity, obesity	National mass media campaigns to reduce population levels of obesity	4	9.10 %	***	***
Smoking	Brief interventions delivered in GP surgeries to improve quit rates	5	8.98 %	音音音	<b>京京</b> 京
Alcohol	Brief interventions delivered in GP surgeries to reduce problem drinking	6	8.70 %	★★☆	★★☆
Diet, physical activity, obesity	Brief interventions delivered in GP surgeries to improve uptake of physical activity	7	8.63 %	東東京	常常会
Smoking	Nicotine replacement therapy to improve quit rates	8	8.25 %	***	***
STI / teenage pregnancy	Screening and treatment for reducing the prevalence of Chlamydia	9	7.38 %	常常食	實實實
Diet, physical activity, obesity	School based group education to reduce population levels of obesity	10	7.25 %	***	***
STI / teenage pregnancy	School based group education for increasing rates of condom use and reducing STIs and unwanted pregnancy	11	6.00 %	東東京	***
Statins	Statins for primary prevention of stroke and heart disease (demonstrating QALYs for two example CVD risk groups)	12	4.26 %	★☆☆	***
Mental health	Assessment and support of caregivers for preventing depression in caregivers	13	0.95 %	***	實實官
Mental health	Screening and treatment to prevent depression in retirees (age over 65 years)	14	0.12 %	***	***

Source: Matrix for Health England

#### Why is this issue important?

We need to know how many people are born and die each year – and the main causes of their deaths – in order to have well-functioning health systems.<sup>1</sup>

#### **Key outcomes**

- Mortality rate from all cardiovascular disease (including heart disease and stroke) in persons less than 75 years of age (Public Health Outcomes Framework, NHS Outcomes Framework)
- Mortality rate from cancer in persons less than 75 years of age (Public Health Outcomes Framework, NHS Outcomes Framework)
- Mortality rate from Liver Disease in persons less than 75 years of age (Public Health Outcomes Framework, NHS Outcomes Framework)
- Mortality rate from respiratory disease in persons less than 75 years of age (Public Health Outcomes Framework, NHS Outcomes Framework)

Figure 1: Cause-specific mortality profiles for Brighton & Hove and the South East, 2005-2009 (directly age standardised rate per 100,000)

### Excess under 75 mortality rate in adults with serious mental illness (Public Health Outcomes Framework)

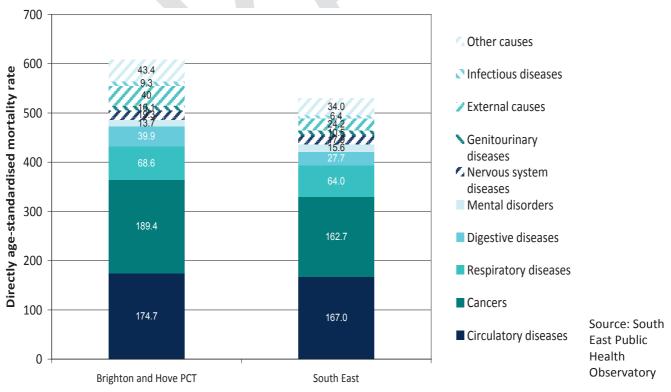
**Brighton & Hove JSNA 2014** 

#### **Impact in Brighton & Hove**

The commonest causes of death within the city are cancers, circulatory diseases, respiratory diseases and digestive diseases (including liver diseases).

In 2013 there were a total of 2,065 deaths of Brighton & Hove residents. The main causes of death were cancer (29%), followed by circulatory conditions (27%) and respiratory conditions (13%). However just over one in twenty deaths in the city (6%) are not caused by disease – these are predominantly accidents or suicide (See figures at end of section).

The main causes of death in the city are similar to the South East but in Brighton & Hove mortality rates are higher for all disease groupings with the exception of mental disorders and genitourinary diseases (Figure 1).<sup>2</sup>



<sup>&</sup>lt;sup>1</sup> World Health Organisation. Civil registration: why counting births and deaths is important. Fact sheet N°324; 2007.

<sup>&</sup>lt;sup>2</sup> South East Public Health Observatory. Health Inequalities Gap Measurement Tool. Available at <a href="http://www.sepho.nhs.uk/gap/gap\_national.html">http://www.sepho.nhs.uk/gap/gap\_national.html</a> [Accessed on 21/08/2014]

Cancer: Mortality from all cancers in under 75 year olds is higher in Brighton & Hove than England and significantly higher than across the South East. Mortality rates for cancer in this age group in the city had been increasing since 2002-04 but in 2008-10 were around the 2002-04 level, and have continued to fall. Cancer is explored in more detail in the cancer section.

Heart disease and stroke: Between 2010 and 2012 in Brighton & Hove the mortality rate among the under 75s due to heart disease & stroke was 80 per 100,000 population, compared with 81 in England and 69 in the South East. This is explored in more detail in the relevant section of the report.

**Respiratory diseases:** The mortality rate in the city for respiratory diseases for those aged under 75 years is similar to the England rate, but for mortality from respiratory disease considered preventable it is significantly higher (2010-2012).

Liver disease & chronic liver disease: Mortality rates in those aged under 75 years are significantly higher in Brighton & Hove than in England (2010-12). This is also the case for liver disease considered preventable.

Excess under 75 mortality rate in adults with serious mental illness: Excess premature mortality in adults with serious mental illness is high, both nationally and in Brighton & Hove with mortality rates in the city for those in contact with Secondary Mental Health Services almost three times higher than those not in contact with these services (2011/12). Across England this excess is over three times higher but we do not do significantly better than England.

#### Where we are doing well

The recent trend in circulatory disease deaths and cancer deaths for those aged under 75 years in Brighton & Hove has been downwards, with premature cardiovascular mortality almost halving since 2001-2003 and premature cancer mortality at its lowest rate for the last decade.

The mortality rate for communicable diseases is significantly lower in Brighton & Hove than England and continues to fall.

# **Brighton & Hove JSNA 2014**

#### **Local inequalities**

Age: The breakdown of cause of death is very different for children, adults and older people. Since there are a small number of deaths in children in the city each year it has not been possible to produce charts showing the main causes of death. In 2013 there were 11 deaths of children aged under one year, with an additional five deaths of children aged 1-14 years.

In 2013 there were 712 deaths of people aged under 75 years (see figures at end of section). Here, the main cause of death is cancer (40%) followed by circulatory disease (17%). Death not caused by disease is the third most common causes of death in this age group and comprises over one in 10 deaths (13%).

For those aged 75 years or over (see figures at end of section), the most common causes are circulatory diseases (31%), cancer (23%) and respiratory diseases (16%). In 2013 there were 1,353 deaths in this age group.<sup>3</sup>

**Gender:** The main causes of death (for all ages) are similar for males and females. The main difference is the higher proportion of deaths in males to external causes (mainly accidents, suicide and drug or alcohol poisoning). The proportion of deaths to circulatory diseases and cancer are similar for both males and females.

Ethnicity: In England information on death certificates is restricted to the deceased person's country of birth which is traditionally used as a proxy for ethnic origin. However, the value of this has diminished over time as subsequent generations have been born in England. In 2012, Scotland became the first UK country to record ethnic origin on death certificates.

In Brighton & Hove 90% of deaths registered were of individuals born in the UK. This picture has remained fairly constant since 1999 when 91% were. This picture is very different to that seen in births where the proportions born outside the UK are considerably higher but this is because births are more responsive to recent changes in immigration due to the younger age of people migrating to the UK.

<sup>&</sup>lt;sup>3</sup> Office for National Statistics. Vital Statistics Tables. 2012

Table 1 shows the top ten countries of birth (outside of the UK) of registered deaths in 1999, 2003, 2007 and 2011. There has been little change over the 13 year period, with Ireland, India, Poland and Germany the commonest countries of birth across most years shown.

Table 1: Deaths (numbers) for the ten most common countries of birth for non-UK born individuals, Brighton & Hove 1999, 2003, 2007 and 2011

1999		200	2003		2007		2011	
Country	Number	Country	Number	Country	Number	Country	Number	
Ireland	67	Ireland	49	Ireland	58	Ireland	54	
India	25	India	21	India	22	India	18	
Poland	13	Germany	19	Germany	16	Poland	10	
Germany	11	France	13	Poland	13	Germany	8	
Italy	10	Canada	9	Canada	9	Australia	7	
Canada	8	Austria	7	South Africa	8	Italy	7	
France	8	Italy	7	Egypt	6	South Africa	7	
South Africa	7	Poland	7	France	6	Iran	6	
Egypt	6	South Africa	7	Italy	5			
Australia	5	United States	7					
All deaths	2,995	Total	2,792	Total	2,366	Total	2,081	

**Source:** Office for National Statistics, registered deaths in the given year

**Deprivation:** Figure 2 compares mortality rates for the most deprived quintile and the least deprived quintile in the city. The large difference seen in overall mortality is present for all commonest causes of death except for diseases of the nervous system or genitourinary system.

Circulatory death rates have been falling overall, for the most and least deprived quintiles in the city. However the mortality rate is higher in the more

# **Brighton & Hove JSNA 2014**

deprived areas. Between 2008 and 2010 circulatory death rates in those aged under 75 years in the most deprived quintile of the city were three times higher than for the least deprived quintile. This difference has increased: for the period 2001-2003 the rate in the most deprived quintile was twice

that in the least deprived quintile.

For cancer, under 75 deaths rates are increasing in the most deprived group. In 2001-2003 cancer mortality for the under 75s was 1.5 times higher in the most deprived quintile compared with the least deprived and by 2007-2009 this had increased to 1.9.

#### Predicted future need

If current trends continue, the ONS projects that by 2016 there will be 1,900 deaths per year and deaths will remain at this level until 2030. Without a change in current trends, inequalities in all deaths and early deaths from cancer and circulatory diseases will widen.

#### What we don't know

Ethnicity is not recorded on death registration in England, nor is religion, sexual orientation or gender reassignment or caring status.

See specific sections for recommended future local priorities

#### **Key links to other sections**

- Coronary heart disease
- Cancer
- Respiratory disease
- Suicide

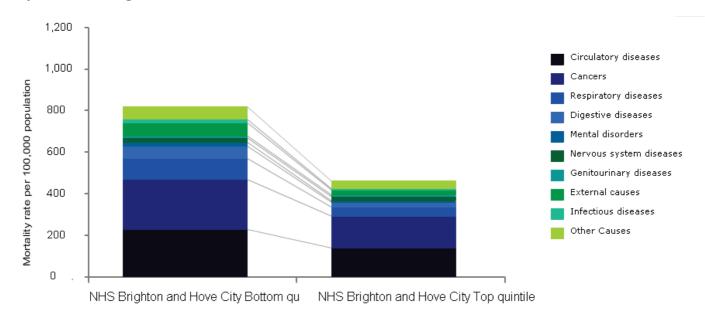
<sup>&</sup>lt;sup>4</sup> ONS sub national population projections (2012 based). Available at: http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Sub-national+Population+Projections#tab-data-tables [Accessed on 27/08/2014].

# **Brighton & Hove JSNA 2014**

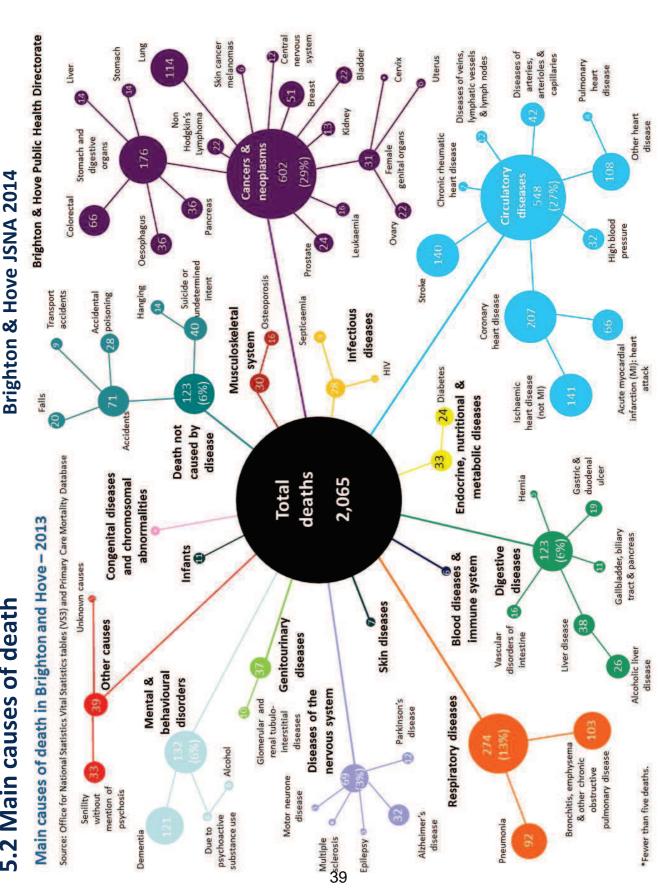
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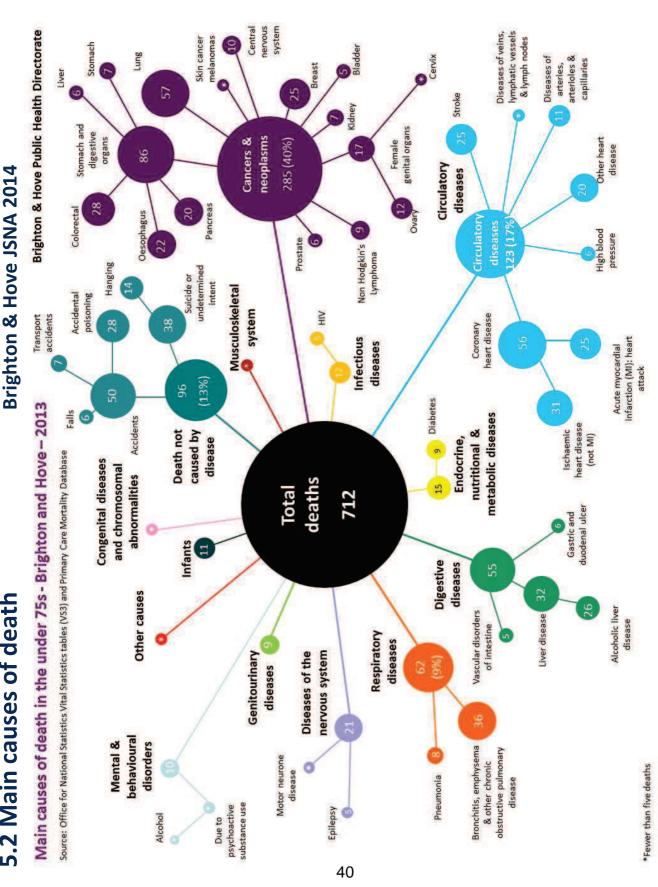
November 2014

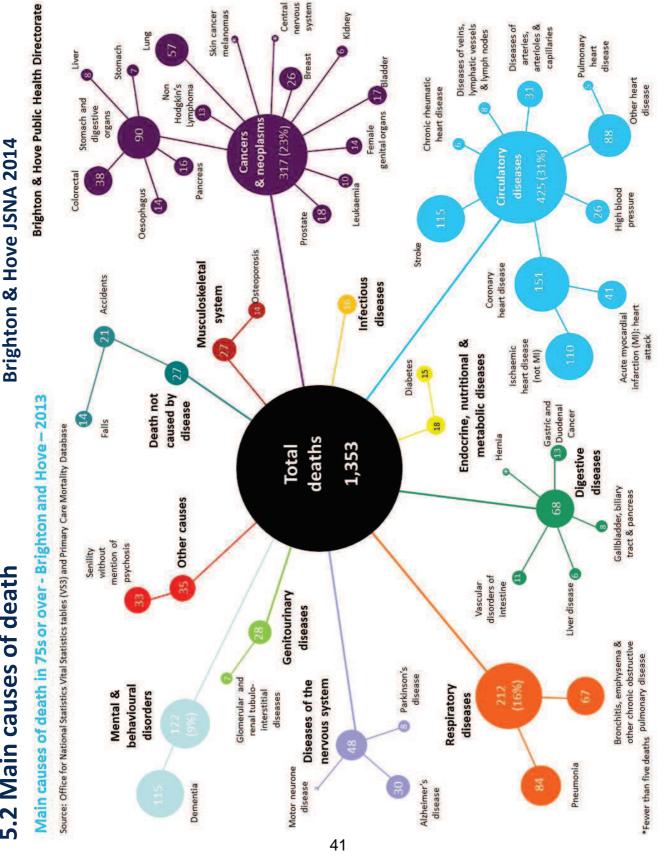
Figure 2: Mortality rate per 100,000 population for the most and least deprived quintiles of deprivation in Brighton & Hove, 2005-2009



Source: South East Public Health Observatory Health Inequalities Gap Measurement Tool







#### Why is this issue important?

This section summarises the needs of people who are sleeping rough on the streets and includes those in insecure, temporary accommodation such as hostels.

Homelessness and rough sleeping have been increasing nationally in recent years. Between Autumn 2010 and Autumn 2013 the national rough sleeper snapshot count rose 37% with numbers rising most rapidly in London and the South of England.<sup>1</sup>

Health and wellbeing needs are high among rough sleepers. In particular, there is a high prevalence of mental ill-health and drug and alcohol dependency. Other common problems include physical trauma (especially foot trauma), skin problems, respiratory illness and infections (including hepatitis A, B & C).<sup>2</sup>

Nationally, it is estimated that the use of inpatient hospital care by people who are sleeping rough or living in insecure accommodation (such as hostels) is eight times higher than in the general population aged 16-64 years.<sup>2</sup>

The average age of death for a homeless person is 47 years old compared to 77 for the general population, with death from drugs and alcohol being particularly common.<sup>3</sup>

#### **Key outcomes**

Rough sleeping is not included as an indicator in NHS, Public Health, or Adult Social Care Outcomes Frameworks. There are a number of related indicators including suicide and alcohol hospital related admissions.

The Common Data Framework (formerly the 'Supporting People Outcomes Framework') enables local authorities to monitor outcomes for vulnerable adults accessing housing-related support. Key outcomes measure how client needs have been met across key areas of economic wellbeing, work and learning, health, accommodation and enabling choice and control.

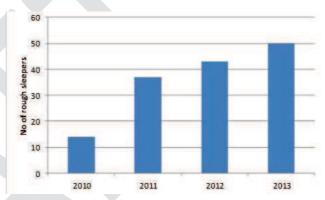
One of the key performance indicators for Band 2 hostel accommodation is planned moves to greater

independence. Of those leaving hostels in 2011/12 53% moved on to greater independence, an increase of 3% on the previous year. In Supported Band 3 accommodation 89% moved on to greater independence, this was also an increase of 3% on the previous year.

#### **Impact in Brighton & Hove**

Locally there has been a sharp increase in the number of recorded rough sleepers in the city. In November 2010 the official rough sleeper street count figure was 14, in 2011 it was 37 and in 2013 this figure had risen to 50 (Figure 1).

Figure 1: Total rough sleepers found on the annual street count 2010-2013



Source: Department for Communities and Local Government

The rough sleeper count does not give a complete picture of the scale of the issue. A group of partner agencies, led by the council, took part in an estimate exercise in March 2013. The aim of the exercise was to estimate the number of people sleeping rough on one 'typical' night in Brighton & Hove. The final estimate figure was 90 individuals. CRI, who deliver services to this group locally, worked with 588 rough sleepers in 2010/11, 732 in 2011/12 and 1,163 in 2012/13 a 98% increase over three years.

This increase in rough sleepers places pressures on health, housing support services and other statutory partners.

In 2013 a Homeless Health Needs Audit was conducted in Brighton & Hove homeless services, which included analysis of data from 302 respondents. This confirmed the high levels of physical, mental, and substance misuse needs in this population. For example:

 84% reported at least one physical health problem

<sup>&</sup>lt;sup>1</sup> Department for Communities and Local Government. 2014

<sup>&</sup>lt;sup>2</sup> Wright NMJ and Tompkins. How can health services effectively meet the health needs of homeless people? Br J Gen Pract. 2006 April 1; 56(525): 286–202

<sup>&</sup>lt;sup>3</sup> Crisis. Homelessness Kills. 2012

- 85% reported at least one mental health issue (nearly four in ten had been diagnosed with depression)
- 40% reported that they were a drug user or recovering from a drug problem
- 26% reported that they used alcohol at a harmful level
- Many had other health risks, for example, 73% were smokers (of whom one in two said they would like to stop)
- Coverage of flu vaccination amongst those eligible was low
- 39% had attended A&E at least once (the most common reasons for the visit were accidents, mental health and alcohol use)
- 25% had been admitted to hospital (the most common reasons were alcohol use, accidents and stomach pains).

This audit built on findings reported in previous JSNAs that indicated high mortality rates and high levels of hospital attendances, admissions and readmissions in homeless people<sup>4,5</sup>.

Current Housing Commissioning strategies<sup>6</sup> include priorities that aim to improve outcomes by:

- Helping clients to move on to more independent accommodation through the Brighton & Hove Integrated Support Pathway<sup>7</sup>
- Increasing accommodation options for locally connected rough sleepers
- Increasing housing and support options for people with no local connection to find accommodation and support outside of the city
- Developing psychological intervention support
- Developing personalisation in support packages
- Focusing on the recovery and reintegration agenda
- Improving support and access for those with a Dual Diagnosis or multiple complex needs

Preventing unplanned hospital admissions.

#### Where we are doing well

Local commissioned services working with this client group are well co-ordinated within a successful local partnership structure which includes commissioned and non-commissioned services. These include:

- The 'No Second Night Out' project. This aims to target those new to rough sleeping and move them off the streets before they become entrenched. In 2012/13 this project saw 76 individuals supported with 98% being accommodated. Within CRI rough sleeper services 1163 individuals were supported with 90% of these having a positive accommodation, treatment or care outcome. Less than 1% of those who were supported to leave the streets by CRI returned within 2 weeks.
- At First Base Day Centre in 2011/12 an average of 52 rough sleepers were seen per day; of these 397 had a planned support programme, 225 accessed sport and fitness programmes, 308 were seen by St Johns Ambulance and 313 were seen by an oral hygienist.
- Brighton & Hove operates a severe weather shelter (SWEP) to ensure that rough sleepers are housed when the temperature drops below 0 degrees for three nights in a row. The provision run by Brighton Housing Trust has coped with increasing demand in 2012/13
  - In 2011/12 SWEP was open for 21 nights and provided 541 bed spaces between January and February 2012.
  - In 2012/13 SWEP was open for 44 nights providing a total of 1714 bed spaces from November 2012 to April 2013.
  - The average (mean) number of individuals accommodated each night during SWEP was 26 in 2011/12 and 40 in 2012/13.
- The alcohol nurse was introduced to work intensively with hostel residents with alcohol dependency issues. Between May 2011 and May 2012 the cohort of clients worked with reduced their emergency call outs (Ambulance) by 37%, their presentations at A&E by 29% and their hospital admissions by 18%. Evictions

<sup>&</sup>lt;sup>4</sup> NHS Brighton and Hove and Brighton & Hove City Council. Vital: Annual Public Health Report of the Director of Public Health. 2011.

<sup>&</sup>lt;sup>5</sup> www.bsuh.nhs.uk/EasySiteWeb/GatewayLink.aspx?alld=387306 [Accessed 25/08/2012].

<sup>&</sup>lt;sup>6</sup> Homelessness Strategy 2014-19 and Commissioning Strategy for Housing-Related Support, 2011-2015.

<sup>&</sup>lt;sup>7</sup> For more details see the Brighton & Hove Homelessness Strategy.

from hostel accommodation were also greatly reduced for this client group.

A major local initiative to improve services and the health and wellbeing of the homeless has been established as part of the Better Care programme to transform housing and social care for homeless people by 2016. Involvement of representatives of homeless people is at the heart of designing the new services, which will be closely linked with existing housing related support and mainstream health services. In addition to long established health services (such as Brighton Homeless Healthcare at Morley Street) the initiative brings together newly established services including:

- Hostels Health Team, established in 2013 by Sussex Community Trust to provide assessment, treatment and advice for those with chronic conditions and physical health needs.
- Pathway Plus, which aims to improve outcomes by improving hospital admission and discharge, and follow up, linking with existing housing and health services.

#### Local inequalities

The rough sleeper and single homeless population is not representative of the wider population of Brighton & Hove. The characteristics of respondents to the homeless health audit were:

- 78% male; 22% female
- 69% were aged 45 or under; 28% were aged 45-65; and 3% were aged over 65
- 72% were White British and 28% from a Black and Minority Ethnic group
- 89% indicated that they were UK nationals
- 50% reported that they had a disability
- 13% were lesbian, gay or bisexual (LGB)
- 2% identified as transgender (although this finding was based on small numbers)
- 7% indicated that they had left care services for young people in the last five years

Some key findings in relation to inequalities were:

 Respondents aged 46 or over had significantly higher rates of physical health problems, and 26-45 year olds had a higher rate of mental health conditions

- LGB respondents were significantly more likely to have a physical health problem and a diagnosed mental health problem
- There were significantly higher rates of smoking and drug use in White British and hostel residents.

#### Predicted future need

The impact of the Welfare Reform Bill is still being felt with reductions in council tax relief, changes to Disability Living Allowance, the reduction of Housing Benefit to over occupiers, the cap on overall benefits payments and the introduction of Universal Credit still being rolled out in England and Wales. We predict that these changes will increase the number of individuals unable to sustain their accommodation in the coming year.

The significant increase in numbers of rough sleepers which we have witnessed in recent years has placed unprecedented pressure on existing services and we expect this to continue at a time of decreasing funding.

#### What we don't know

We don't know about many of the hidden homeless in our city who may be living in squats, sleeping on sofas, and staying with friends and family, and are therefore not captured in local needs data. Nationally one study has shown that of 437 single homeless individuals 62% were hidden homeless and a quarter had never accessed any accommodation provided by a homeless or housing organisation.<sup>9</sup>

We cannot estimate the number of people affected by welfare reform who will subsequently have an episode of rough sleeping.

#### Key evidence and policy

Vision to end rough sleeping: No Second Night Out nationwide, 2011. Department for Communities and Local Government

<sup>&</sup>lt;sup>8</sup> Homeless Link response to Welfare Reform Bill 2011 http://homeless.org.uk/news/homeless-link-response-welfare-reform-bill [Accessed on 25/08/2012].

<sup>&</sup>lt;sup>9</sup> Crisis, K Reeve with E Batty, The Hidden Truth about Homelessness – Experiences of Single Homelessness in England, May 2011

http://www.communities.gov.uk/publications/housing/visionendroughsleeping

Making every contact count – a joint approach to preventing homelessness August 2012 www.gov.uk/government/publications/making-every-contact-count-a-joint-approach-to-preventing-homelessness

#### **Recommended future local priorities**

- 1. Develop a more integrated approach to improving outcomes by transforming health and social care for homeless people
- 2. Commission services and resources to support the No Second Night Out strategy and implement the refreshed 2014-2019
  Homelessness Strategy Develop further rough sleeping prevention initiatives across Sussex with neighbouring authorities

#### Key links to other sections

- Housing
- Mental health
- Substance misuse
- Alcohol
- Dual diagnosis
- Urgent care

#### **Further information**

Brighton & Hove City Council homelessness webpage

http://www.brighton-

hove.gov.uk/index.cfm?request=c306

2014 Homeless Health Audit and Rough Sleeping and 2013 Single Homeless Needs Assessment are available at:

http://www.bhconnected.org.uk/content/needsassessments

#### Last updated

October 2014

# 5.1 Children and young people with Autistic Spectrum Conditions

#### Why is this issue important?

Autistic Spectrum Conditions (ASC) are developmental disorders causing differences in reciprocal social interaction and social communication, combined with restricted interests and rigid repetitive behaviours, often with lifelong impact. People with ASC also frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems. These problems can substantially affect a person's quality of life, and that of their families and carers, and lead to social vulnerability. ASC is a spectrum which means that, although people with ASC share certain difficulties, their condition affects them in different ways.

People with ASC have high levels of additional needs with 70% having at least one other mental or behavioural disorder and 40% having at least two disorders, most commonly anxiety, Attention Deficit Disorder (ADHD) and Oppositional Defiant Disorder (ODD).<sup>2</sup>

Children and young people with ASC may be diagnosed at various ages, and this process can be lengthy. Transitioning between primary and secondary school and between children and adults services can cause added worry and disjointed care, this is particularly the case in children without significant learning disabilities who may go from being supported to having nothing on transitioning to adult services.<sup>2</sup>

#### **Key outcomes**

None of the indicators in the Public Health, NHS or Adult Social Care Outcomes Frameworks are specifically focused on ASC.

#### **Impact in Brighton & Hove**

There are 59,000 children and young people aged 0-19 resident in Brighton & Hove,<sup>3</sup> and around 31,550 children and young people attending

schools in the city (excluding independent schools).<sup>4</sup>

Prevalence of ASC in the UK is estimated at between 0.2 and 1%, 5,6 data from the UK General Practice Research Database showed diagnosed prevalence of ASC in 8 year olds of 3.8 per 1000 boys and 0.8 per thousand girls. The Special Needs and Autism Project looking at children in South Thames found higher rates estimated at 1% prevalence in 9-10 year olds when children with SEN are screened for ASC.

**Brighton & Hove JSNA 2014** 

This means that we would estimate between 118 and 590 children and young people aged 0-19 in the city to have a diagnosis of an ASC at any time, and around 65 to 315 children and young people in Brighton & Hove schools.

Each local authority has a statutory responsibility to hold a register of disabled children. In Brighton & Hove this is The Compass database administered by Amaze, a local parent support CVS organisation. Registration on the Compass is voluntary and there has been a steady increase in the number of registered children with up-to-date records from 1,480 in 2008/09 to 1,908 in 2012/13 (29% increase). The associated incentive leisure/sporting card means the voluntary register has a much higher sign-up than most local authority registers.

In July 2014 The Compass had 481 0-19 year olds registered with an ASC, this is the most common diagnosis accounting for 29% of all aged 0-19 registered on the database. Males were more heavily represented with 390 registrations compared to 91 female. Between April 2009 and April 2014 the number of children 0-19 registered on Compass with ASCs has risen by 24%, in line with the general rise of 0-19 year olds registered on the database. There has been substantial work increasing access to register on the database, which may explain this overall rise.

<sup>&</sup>lt;sup>1</sup> National Institute for Health and Care Excellence. Autism, January 2014. NICE Quality Standard 51 (QS51) http://guidance.nice.org.uk/qs51

<sup>&</sup>lt;sup>2</sup> Brighton & Hove City Council, Services for Children with Autism Scrutiny Panel report, April 2014 <a href="http://present.brighton-">http://present.brighton-</a>

 $<sup>\</sup>frac{hove.gov.uk/Published/C00000728/M00004870/Al00039830/\$Final report for Services for children with a utism final April 2014 without DRAFT marks. doc.pdf accessed 23/9/2014$ 

<sup>&</sup>lt;sup>3</sup> ONS mid-year estimate 2013 aged 0-19 years in Brighton 59,009, rounded in text

http://ons.gov.uk/ons/taxonomy/index.html?nscl=Population+Estimates#tab -data-tables accessed 3/10/14

<sup>&</sup>lt;sup>4</sup> Schools, Pupils and their characteristics: January 2014. Office of National Statistics, Department for Education local authority and regional tables:SFR15/2014 <a href="https://www.gov.uk/government/statistics/schools-pupils-and-their-characteristics-january-2014">https://www.gov.uk/government/statistics/schools-pupils-and-their-characteristics-january-2014</a> accessed 3/10/14

 <sup>&</sup>lt;sup>5</sup> Baird G, Simonoff E, Pickles A et al. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet 2006 Jul 13;368(9531):201-5
 <sup>6</sup> Taylor B, Jick H, MacLaughlin D. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open* 2013;3:e003219 doi: 10.1136/bmjopen-2013-003219

<sup>&</sup>lt;sup>7</sup> Amaze Compass data 2014

# **5.1 Children and young people with Autistic Spectrum Conditions**

Nationally, 20.8% of statements of Special Educational Needs (SEN) are for autism8. In Brighton & Hove there are 185 children with ASC with a statement, representing 18% of children with SEN statement.<sup>9</sup>

The Autistic Spectrum Condition Support Service (ASCSS) offers support for state schools with one or more pupils with a diagnosis of an ASC. There are currently 285 pupils with ASC on the diagnosed pupil database of the ASCSS: pupils included are in pre-school settings, and mainstream Primary and Secondary Schools, in Brighton & Hove. <sup>10</sup>

For an ASC diagnosis in Brighton & Hove children and young people have to be referred by a professional to Seaside View Child Development Centre (Seaside View). The process for assessment has two stages: a general development assessment at stage 1 and a more detailed multi-disciplinary ASC specific clinic at Stage 2. An estimated 86 children were seen from July 2012 - July 2013 and around 64% of these received a diagnosis of an ASC. <sup>11</sup>

51.6% of children with ASC on the Compass database have moderate to profound learning difficulties, the majority of these have moderate difficulties, at 27.0%, or severe difficulties, at 22.5%. 12

#### Where we are doing well

An ASC working group was established in the spring 2013, with representation from parents/carers, the voluntary sector and professionals from education, health (including the Child and Adolescent Mental Health Service (CAMHS)) and social work services. This group has been instrumental in taking forward a partnership approach to developing services for children and young people with ASC.

# **Brighton & Hove JSNA 2014**

In April 2014 Brighton & Hove City Council published the Services for Children with Autism Scrutiny Panel report. This examined services for children and young people with autism within Brighton & Hove and included input from parents/carers and service providers. The report laid out 20 recommendations for action around home support, available information, pathways to diagnosis, training and awareness. <sup>13</sup> Responses to the recommendations were accepted by the Health and Wellbeing Board in July 2014. <sup>14,15</sup>

#### **Local inequalities**

Of the 421 children registered with ASC within Brighton & Hove, 390 were male compared to just 91 female, this equates to a ratio of approximately 4:1 male to female, which is what is seen nationally. <sup>16</sup>

83% of those on the Compass database are White British.

#### Predicted future need

The number of children and young people living in Brighton & Hove is predicted to slowly increase and is projected at 62,000 persons aged 0-19 in 2024, <sup>17</sup> compared with 59,000 in 2013. Although there has been a marked increase in diagnosis of ASC in the last 30 years, the numbers have plateaued since the early 2000s so we wouldn't expect much change in prevalence in the coming years. <sup>18</sup>

 $<sup>^{8}</sup>$  Department for Education, Statistics Children with special educational needs: an analysis – 2013

https://www.gov.uk/government/publications/children-with-special-educational-needs-an-analysis-2013 accessed 3/10/14

<sup>9</sup> REF Alison's report

<sup>&</sup>lt;sup>10</sup> Figure provided by ASC Support Service on 7/10/14

<sup>&</sup>lt;sup>11</sup> Brighton & Hove City Council, Services for Children with Autism Scrutiny Panel report, April 2014 http://present.brighton-

 $<sup>\</sup>frac{hove.gov.uk/Published/C00000728/M00004870/Al00039830/\$Finalreportfor}{Services for children with autism final April 2014 without DRAFT marks.doc.pdf}{accessed 23/9/2014}$ 

<sup>&</sup>lt;sup>12</sup> Amaze Compass data 2014

<sup>&</sup>lt;sup>13</sup> Brighton & Hove City Council, Services for Children with Autism Scrutiny Panel report, April 2014 <a href="http://present.brighton-">http://present.brighton-</a>

hove.gov.uk/Published/C00000728/M00004870/Al00039830/\$Finalreportfor ServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf accessed 23/9/2014

<sup>&</sup>lt;sup>14</sup> Agenda item 16, Health and Wellbeing Board, Brighton & Hove City Council. 29 July 2014

http://present.brighton-

hove.gov.uk/Published/C00000826/M00005481/Al00041396/\$Item16ResponsetotheScrutinyPanelresponsefinal16714v4GRedit.doc.pdf accessed 3/10/14

<sup>&</sup>lt;sup>15</sup> Minutes Agenda item 16 Health and Wellbeing Board 29 July 2014 http://present.brighton-

 $<sup>\</sup>frac{hove.gov.uk/ielssueDetails.aspx?IId=43067\&PlanId=0\&Opt=3\#AI41396}{accessed 3/10/14}$ 

<sup>&</sup>lt;sup>16</sup> Taylor B, Jick H, MacLaughlin D. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open* 2013;**3**:e003219 doi:10.1135/bmjopen-2013-003219

 $<sup>^{17}</sup>$  ONS 2012 based Subnational Population Projections for Regions in England, 29-May 2014

http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Sub-national+Population+Projections#tab-data-tables accessed 18/9/2014

<sup>&</sup>lt;sup>18</sup> Taylor B, Jick H, MacLaughlin D. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open* 2013;**3**:e003219 doi: 10.1136/bmjopen-2013-003219

# **5.1 Children and young people with Autistic Spectrum Conditions**

**Brighton & Hove JSNA 2014** 

Taking the higher estimate of 1% prevalence we would expect 620 people with ASC in this age group. This means there will be a moderate increase of 25 extra young people with ASC in Brighton & Hove in 10 years.

#### What we don't know

There is not a single definitive database of children and young people with a diagnosis of autism in the city, the reporting through Compass is voluntary, and so does not contain full information regarding local patterns of ASC.

#### Key evidence and policy

National Institute for Health and Care Excellence (NICE), Autism Quality Standard, Jan 2014 (QS51). This quality standard covers autism in children, young people and adults, including both health and social care services.

#### http://guidance.nice.org.uk/qs51

National Institute for Health and Care Excellence. Autism diagnosis in children and young people (CG128): Recognition, referral and diagnosis of children and young people on the autistic spectrum, September 2011

http://www.nice.org.uk/guidance/CG128

The NICE pathway for Autism works in line with the guidance:

#### http://pathways.nice.org.uk/pathways/autism

Children and Families Act 2014. This bill aims to make life better for children and young people with SEN. The existing system for Educational Statements, School Action and School Action Plus, will be replaced by a single Education, Health and Care Plan (EHCP) that will remain in place until a young person is 25 years old (up from 18 years at the moment).

# http://www.legislation.gov.uk/ukpga/2014/6/cont ents/enacted

There is no national policy specifically in relation to children and young people with ASC. However, The Autism Act (2009) requires each local authority to develop a local autism strategy for the provision of health and social care services for people with autism (aged 14 years and older).

http://www.legislation.gov.uk/ukpga/2009/15/introduction

#### **Recommended future local priorities**

Summary of Scrutiny Report Recommendations:

- Nominated key workers for all children with ASC
- A pathway for children with autism but neither learning difficulties nor mental health Issues
- Improved home support for families
- CAMHS and Seaside View services to put parents at the heart of their provision
- CAMHS and Seaside View to have open and accountable monitoring frameworks
- Clearer accountability lines for all tiers of CAMHS
- Improve links between Health Visitors and GPs
- All schools take up training to become 'autism aware'
- All Governing Bodies to undergo SEN training and be given copies of Scrutiny Report
- Consideration to be given to increasing funding of ASC support service
- Monitoring of all relevant plans and strategies including those for transition to adulthood
- Appoint an Autism Champion
- ASC working group to oversee Scrutiny Panel recommendations
- Joint Strategic Needs Assessment (JSNA) to include a section on children with autism
- Creation of a youth club for young people with autism

#### **Key links to other sections**

- Children and young people with disabilities
- Adults with Autistic Spectrum Conditions

#### **Further information**

Services for Children with Autism Scrutiny Panel report, April 2014:

http://present.brighton-

hove.gov.uk/Published/C00000728/M00004870/AI 00039830/\$FinalreportforServicesforchildrenwitha utismfinalApril2014withoutDRAFTmarks.doc.pdf

# **Brighton & Hove JSNA 2014**

# **5.1 Children and young people with Autistic Spectrum Conditions**

Draft Plan for families and children with ASC. Working in Partnership to meet the needs of children and Young People with Autism in Brighton & Hove 2013-2017. 'Better outcomes, better lives' Response to the scrutiny panel report: Services for Children with Autism, this was the report taken to the Health and Wellbeing Board:

http://present.brighton-

hove.gov.uk/Published/C00000826/M00005481/AI 00041396/\$Item16ResponsetotheScrutinyPanelres ponsefinal16714v4GRedit.doc.pdf

#### Last updated

October 2014



#### Why is this issue important?

Older people (those aged 65 or over<sup>1</sup>) are the fastest growing population group in England and Western Europe. Growing old is not the same as growing infirm. The rate of decline in health and wellbeing is largely determined by factors related to lifestyle as well as external social, environmental and economic factors and people can take some control over their ageing. There is solid evidence that promoting physical and mental health in older people prevents or delays the onset of disability as do public policy measures, such as promoting an age-friendly living environment. <sup>2,3,4,5</sup>

Material conditions, social factors and the interaction between them influence how well individuals age. The life satisfaction and general wellbeing of older people is reduced when they are isolated, poor, in ill-health, living alone or in unfit housing and rundown neighbourhoods, when they require or are a carer or live in a care home. Bereavement presents an additional threat to quality of life. Transport is another important factor in determining older people's ability to access vital amenities and allowing older people to remain independent and active in later life as well as helping people stay connected.

There has been a national policy shift towards an adult social care and health service that has prevention, early intervention and enablement at its core, as well as choice and control over services through personalisation. This approach has the potential to enhance wellbeing and save money.

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#### **Key outcomes**

- Older people's perception of community safety (Placeholder) (Public Health Outcomes Framework)
- Falls and injuries in the over 65s (Public Health Outcomes Framework)
- Health related quality of life for older people (Public Health Outcomes Framework)
- Hip fractures in the over 65s (Public Health Outcomes Framework)
- Excess winter deaths (Public Health Outcomes Framework)
- Dementia and its impacts (Public Health Outcomes Framework)
- Fuel Poverty ( Public Health Outcomes Framework)
- Enhancing the quality of life for people with dementia (NHS Outcomes Framework)
- Enhancing the quality of life for people with long term conditions (NHS Outcomes Framework)
- Helping older people to recover their independence after illness or injury (NHS Outcomes Framework)
- Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into re-ablement/rehabilitation service (Adult Social Care Outcomes Framework)
- Enhancing quality of life for people with care and support needs (Adult Social Care Outcomes Framework)
- Delaying and reducing the need for care and support (Adult Social Care Outcomes Framework)
- Ensuring that people have a positive experience of care and support (Adult Social Care Outcomes Framework)

 $<sup>^{1}</sup>$  In the absence of any guidance as to definition of 'older', this summary is using 65 or over as the starting point .

<sup>&</sup>lt;sup>2</sup> Banks J, Breeze E, Lessof C, Nazroo, J. Retirement, health and relationships of the older population in England: The 2004 English Longitudinal Study of Ageing (Wave 2). 2006.

<sup>&</sup>lt;sup>3</sup> Bassey EJ. Physical capabilities, exercise and ageing. Reviews in Clinical Gerontology 1997; 7(4): 289–297.

<sup>&</sup>lt;sup>4</sup> Center for Lifespan Psychology. Annual report 2003–2004. Available at: <u>www.mpib-berlin.mpg.de/sites/default/files/media/pdf/25/lip</u> report 11.pdf . [Accessed April 2011]

World Health Organization. Global age-friendly cities: a guide. 2007. Available at:

http://www.who.int/ageing/publications/Global age friendly cities Guide English.pdf [Accessed 16/05/2013]

<sup>&</sup>lt;sup>6</sup> Brighton & Hove Annual Report of the Director of Public Health 2010: Resilience. Available at:

http://www.bhlis.org/needsassessments/publichealthreports [Accessed 26/05/2013]

#### **Impact in Brighton & Hove**

Currently there are 35,800 people aged 65 or over in the City; 20,100 females and 15,800 males<sup>7</sup>, with the ratio of women to men increasing with age.<sup>8</sup>

The largest percentage of residents aged 65 years and over are in five wards, with over half the City's older people living in the 40% most deprived areas for older people in England, and some in the 4% most deprived. The West locality has the highest number of older people and prevalence of stroke, diabetes and dementia. In seven wards, fewer than one in ten people is aged 65 years or over.<sup>9</sup>

Brighton & Hove has a relatively large proportion of older people living alone and potentially isolated who are more dependent upon public services. Single pensioner households are higher than average (14,500 households comprise single people aged 65 or over) and the majority of people aged 75 or over live alone; of those living alone, 34% are male, 61% female. 61, 10

The City has almost twice the national suicide and undetermined injury death rate in older people. Up to 16% of people aged 65 and over have depression, 2–4% have severe depression. <sup>6</sup>

Older people feel less safe in their neighbourhoods after dark, particularly those on low income or in more deprived areas – 45% of those aged 75 and over compared to 23% of all residents. 11

The majority (62%) of people with a limiting disability (more likely to be older people) do no 30 minute sessions of moderate intensity sport and active recreation a week compared to 38% of people without a limiting disability. Only 7% of adults aged 55 years and over participate in at least three 30 minute sessions of sport per week.<sup>12</sup>

Some older people require assistance and support to be able to make use of free travel.<sup>6</sup>

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Many older people in the City may not claim the benefits to which they are entitled and which would increase their resilience. <sup>6</sup>

In some areas of the City, 12% of men over 50 have an average weekly alcohol consumption of over 35 units, well above recommended limits. <sup>13</sup>

There are many carers, including 11,500 aged over 50, with increasing numbers of older parent carers of adults with LD/autism. Significant numbers of carers report feeling out of control of their daily life, lonely and detached from society and want support for their own issues. <sup>14</sup>

Across all sectors older people are presenting with more complex needs.

Older people with increasing levels of need are being discharged early from hospital to be supported at home by informal/formal carers, this potentially increases their isolation.

The Brighton and Hove Better Care Plan<sup>15</sup>, published in 2014, has a focus on improving outcomes in 'frail' people (it should be noted that not all older people are frail and many of our frail population are in younger age groups, however much of the action described within this plan will benefit older people). The plan describes how improved services for our frail and vulnerable population will help them to stay healthy and well by providing more pro-active preventative services that promote independence and enable people to fulfil their potential.

There are an estimated 92 Extra Care and Sheltered housing schemes in Brighton &Hove providing 2,929 homes specifically for older people. Extra Care Housing is housing designed with varying levels of care and support available on site. People who live in Extra Care Housing have their own self contained homes, their own front doors and rights to occupy the property.

A Business Case for Extra Care Housing is currently being commissioned. It will establish detailed

<sup>&</sup>lt;sup>7</sup> Figures do not sum due to rounding

<sup>&</sup>lt;sup>8</sup> Office for National Statistics. Population Estimates for England and Wales, Mid-2011 (2011 Census-based). Released: 25 September 2012. Available at <a href="http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-262039">http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-262039</a> [Accessed 17/07/2013]

Census 2011. ONS

<sup>&</sup>lt;sup>10</sup> Institute for Public Care. Projecting Older People Population Information System (POPPI). Available at: <a href="http://www.poppi.org.uk/">http://www.poppi.org.uk/</a> (registration required). [Accessed 30.05.2013]

<sup>&</sup>lt;sup>11</sup> Brighton and Hove Safe in the City Partnership. Older people and Community safety – extract from the Strategic Assessment of Crime and Disorder: 2010.

<sup>&</sup>lt;sup>12</sup> Brighton & Hove physical activity and sport needs assessment. 2012 http://www.bhlis.org/needsassessments

<sup>&</sup>lt;sup>13</sup> University of Kent. Health Counts: Analysis of a survey of people aged over 50 in Hangleton and Knoll and Queen's Park. 2005/6.

<sup>&</sup>lt;sup>14</sup> Department of Health. Government Information for Carers. www.carers.gov.uk .

<sup>&</sup>lt;sup>15</sup> Available at <a href="http://www.brighton-hove.gov.uk/content/council-and-democracy/councillors-and-committees/health-wellbeing-board">http://www.brighton-hove.gov.uk/content/council-and-democracy/councillors-and-committees/health-wellbeing-board</a> [Accessed 03/10/2014]

<sup>&</sup>lt;sup>16</sup>Brighton &Hove City Council. Adult Social Care. Market Position Statement. March 2014

short, medium and long term local demand/need projections to enable identification of the types of provision that will most appropriately meet the objective of reducing residential care costs.

New forms of sheltered housing and retirement housing have been pioneered in recent years to meet the needs of older people.

There are 12 independent home care providers who hold a contract with the council and there are 43 home care providers registered with the CQC across the city. <sup>15</sup> Home care services provide assistance with personal care, practical tasks and support for informal carers. There are different levels of support available, from maintaining and improving levels of independence, to providing high levels of support to people who are highly dependent, including End of Life Care.

Personalisation and personal budgets should have significantly changed the way services are delivered to improve the older person's experience, however outcomes are mixed and take-up of direct payments by older people locally has declined.

People can choose to have a home care provider or Personal Assistant (PA) to provide their care. "Support with Confidence" is the approved Brighton &Hove City Council PA scheme, that includes training and background checks.<sup>15</sup>

There are 2,326 registered care home beds in the city, provided in 29 nursing homes and 81 residential homes. There is estimated to be a low level of vacancies within care homes in the city. The council spent £43, 289m on care homes in 2012/13, double the amount spent on home care/community support and over half the Adult Social Care budget. The average length of stay is 33 months in a care home and 21 months in a nursing home. The council has four care homes providing short stay rehabilitation and reablement services, in the city.

A number of people are placed in care homes out of the city, including 179 people over 65 and 174 people with dementia. This can be to live near a family member but for some it is due to lack of capacity in the city. 15

The local NHS and Brighton & Hove City Council (BHCC) both fund 'gateway' organisations to ensure older user voices inform decision making,

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including BME elders. There are many older people user-led organisations/groups including MindOut (peer support for LGBT elders with mental health issues); Hangleton and Knoll 50+ Group which coordinates health activities; The Neighbourhood Care Scheme which is directed by users and is a good neighbour scheme to primarily isolated older people; Lifelines volunteers (all 50+) which designs and delivers individual and group activities in partnership with an extra care housing scheme.

Local research evidences that older people want a person centred approach to daily living. <sup>17</sup> Findings have also been developed into learning resources and are feeding into local policy and practice.

Research also reveals the very different experiences that constitute old age and the varied factors that affect wellbeing at this stage of life. Relationships of different types are important and the resources and capacities that people have to adapt to personal and social changes can make a big difference to people's sense of being well in old age. In addition, security, feeling like you 'belong', and being confident that help is there if you need it are all important.<sup>15</sup>

Research suggests that there is a danger that definitions that emphasise physical health, people's capacity to plan and set goals, and to be active within their communities, may exclude people for whom old age is accompanied by illness, a reduction in physical horizons because of mobility problems and who, because of advanced old age, are focused on being well in the present rather than planning for the future. <sup>15</sup>

#### Where we are doing well

Brighton & Hove has recently been affiliated by the WHO into its Age Friendly City network. This will encourage active ageing by optimizing opportunities for health, wellbeing and participation. This strategic approach which has cross-party support will raise the profile of older people, prevention and wellbeing services.

Brighton & Hove has nearly double the national average of independent active older people and a smaller proportion with high care needs. Healthy

Ward L. Barnes M. Gahagan B. Well-being in old age: findings from participatory research. University of Brighton & Age UK Brighton & Hove. 2012. <a href="http://www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/Full-report.pdf">http://www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/Full-report.pdf</a>

life expectancy and disability-free life expectancy at age 65 years are higher for females in Brighton & Hove than in England.<sup>6</sup>

The new Ageing Better partnership has identified best practice engagement, including outreach, home visits, a range of information dissemination and proactive engagement to enable access by older people, in neighbourhoods or across communities of identity/interest.

Day activities were reviewed by older people and their carers, resulting in a radical new way of commissioning services.

Free bus travel has helped reduce social isolation among older people.

Older people in the City appear to be more satisfied with their local area than those in younger age groups, with those aged between 65-74 years most satisfied. They are also more likely than to be satisfied with public services and feel they work to make areas cleaner and greener. 18

Although older people are less willing to give up smoking, once they have decided to quit they seem to be more successful than younger age groups. By the age of 75 years or over, for males and females, smoking prevalence reaches its lowest point (5% for males and 10% for females). 19

The 2012 Health Counts Survey showed that residents aged 65-74 years were most happy: 78% for men and 77% for women compared with 72% for all adult respondents. In addition, whilst just 58% of survey respondents felt very or fairly strongly that they belonged to their immediate neighbourhood, this feeling increases with age for both men and women: 78% of those aged over 75 years feel very or fairly strongly that they belong compared to just 46% of those aged 18-24 years. <sup>20</sup>

Older people in some wards in Brighton & Hove appear to have a better diet than the average younger person.<sup>21</sup>

 $^{\rm 18}$  Brighton & Hove City Council. Brighton and Hove Place Survey. 2008.

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A relatively high proportion of older people have higher level qualifications and the proportion with no qualifications is lower than England. Brighton & Hove has a large number of organisations providing adult learning at affordable cost.<sup>6</sup>

A higher proportion of older people participate in groups making decisions affecting their local area and a significant proportion contribute through volunteering, in line with the national picture. 15 Sense of belonging increases with age for both males and females, with 78% of those aged over 75 years feeling very/fairly strongly that they belong compared to 46% of those aged 18-24 years. 16

Older people are less likely than younger people to be victims of crime or a repeat victim of crime. 15

The City has a strong and broad range of voluntary and statutory sector services which support vulnerable older people and enable them to participate in community activities, including older people/user led organisations/groups. Public sector funding for Voluntary and Community organisations (VCOs) is dependent on evidence of user involvement in design and delivery of services which continue to evolve in response to feedback.

Arts organisations have engaged older residents to help redesign programming, exhibitions and staff training to increase the older audience, now up by 6% on 2003.

The City's Active for Life team designs and delivers activities with older people in targeted neighbourhoods, which helps raise awareness of what is on offer, significantly improving uptake.

Independence is important to older people; older people's home care services are increasing in line with a decrease in care home placements. Similarly the demand for Extra Care Housing is increasing. Assistive technology is being actively promoted demonstrating positive outcomes. There are over 5,000 telecare users in the city supported by the council's CareLink Plus service. There is a need to expand telecare into new areas, including medication dispensing and reminding solutions. Home care and care home providers also need to use telecare as a cost effective way of meeting an individual's goals for a more independent life. 15

<sup>&</sup>lt;sup>19</sup> Brighton & Hove City Council. Health Counts in Brighton & Hove 1992-2012  $^{\rm 20}$  Brighton & Hove City Council and NHS Brighton & Hove. Annual Report of the Director of Public Health. Happiness: the eternal pursuit. 2012/13. Available at: http://www.brighton-hove.gov.uk/sites/brightonhove.gov.uk/files/Director%20of%20Public%20Health%20Annual%20Report %202013 web 0.pdf [Accessed 15/08/2013]
<sup>21</sup> University of Kent. Health Counts: Analysis of a survey of people aged over

<sup>50</sup> in Hangleton and Knoll and Queen's Park. 2005/6.

#### Local inequalities

Relative to East Brighton and other deprived parts of the City, the deprivation scores of the wards where higher numbers of older people live are quite low.

Brighton & Hove has a relatively high proportion of 'non-decent homes', and the highest rates are where the head of household is aged 85 years or over. <sup>22</sup>

The oldest owner occupiers (85+) are more likely than all other older people to move into communal establishments that may offer less independence, which could be due to a shortage of private sheltered or extra care housing schemes that also provide an element of support.

Some LGBT groups experience significant marginalisation and are less likely to feel that their local area is inclusive. Older LGBT groups experience discrimination, especially in communal accommodation.

There are isolated BME elders, including travellers. Service providers find it difficult to reach out to them - the BME needs assessment due in 2013 will inform future service development.<sup>23</sup>

Healthy life expectancy and disability free life expectancy at age 65 years is similar for males in Brighton & Hove and in England, but longer for females. The majority of people aged 75 years and over in Brighton & Hove live with a long term condition, as do a significant proportion of those aged under 75 years (38% of males aged between 65-75 years). Those who are married, in a civil partnership or living as a couple were significantly less likely to have a limiting long-term illness (21%) than all respondents, those who were separated or divorced (42%) or widowed (56%) were significantly more likely to have a limiting long-term illness. <sup>16</sup>

There is a clear relationship between self-perceived health and age, with the percentage of respondents who say they are in good or better health falling from 93% of 18-24 year old to 54% of those aged 75 years or over in 2012.<sup>16</sup>

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Eating five a day is significantly more common in females (59%) than males (46%). For females, the percentage increases with age from 18-24 year (50%) to 65-74 years (75%) but falls in those aged 75 years or over. For males there is an increase in the percentage eating five a day from 32% at 18-24 years to 52% of 35-44 year olds, the figures for those aged 45-74 are then similar with a fall to 48% for those aged 75 years or over. <sup>16</sup>

The Integrated Household Survey 2009-2010 indicates that Brighton & Hove has the lowest level of religious belief in the country, however the data are not broken down by age or gender.

Males aged 50 years and over are more likely to be victims of crime than women aged 50 years and over.<sup>9</sup>

Nationally, 42% of carers are men and 58% women. This is reflected in the figures for carers aged 50 and over in the City; 43% of whom are men and 57% women. 24

#### Predicted future need

Although the proportion of older people living in the City has fallen in recent years, the population aged 65 years or over is predicted to increase and become more ethnically diverse. The largest projected increases are in the 70-74 and 90 and over age groups. <sup>25</sup> This will have implications for housing need.

The City is currently a high user of care homes but is committed to providing alternative accommodation options, in particular extra care housing. It's predicted there will be a need for an additional 700 places in Extra Care Housing by 2030. Ideally new models will include provision designed by older people, keeping them active and less socially isolated.

The council's Independence at Home team will work closely with Community Short Term Services to support people at risk of hospital admission, support people being discharged and promote opportunities for reablement.<sup>15</sup>

<sup>&</sup>lt;sup>22</sup> Brighton & Hove Private Sector House Condition Survey. 2008

<sup>&</sup>lt;sup>23</sup> Brighton & Hove Gypsy and Traveller Rapid Health Needs Assessment. 2012. Available at: http://www.bhlis.org/needsassessments

<sup>&</sup>lt;sup>24</sup> Department of Health. Government Information for Carers. Available at:

<u>www.carers.gov.uk</u> [Accessed 18/04/2013]

<sup>25</sup> Office for National Cast Manual Cast

<sup>&</sup>lt;sup>25</sup> Office for National Statistics. Interim 2011 based sub national population projections. <a href="http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-274527">http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-274527</a> [Accessed 12/06/2013]

Increasingly, older people will be purchasing care using their personal budgets and advocacy services will become more important as people navigate their way around the health and social care system.<sup>15</sup>

Baby boomers have different aspirations and are keen to lead service design, which could lead to innovative and inclusive solutions for older people.

#### What we don't know

We do not have information on all protected characteristics of older people including ethnicity, religion, marital status and we lack comprehensive information on sexual orientation.

We need to know more about Extra Care Housing, with the commissioning of the Business Case.

#### Key evidence and policy

World Health Organization. Global age-friendly cities: a guide. 2007.

whqlibdoc.who.int/publications/2007/9789241547 307 eng.pdf

NICE Guidance: PH16 Mental wellbeing and older

people: 2008

http://guidance.nice.org.uk/PH16

#### **Recommended future local priorities**

- There is a need to raise the profile of older people in the City and develop a joined up approach to service provision that places older people firmly at the core and emphasises prevention and early intervention - the WHO Age-Friendly City approach will provide a vehicle to take this forward, as will the Council's new Commissioning Prospectus approach to commissioning and co-ordinating day services for older people.
- 2. Older people's active participation and contribution to community groups, schools and other neighbourhood activities should be encouraged as it builds resilience.
- 3. Better partnership working between agencies that support older people would help to mitigate the risk of cuts in public spending the Ageing Better partnership is a good example.
- 4. Services and benefits should be publicised in the right places to ensure that older people

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- access them, with information in a range of formats not just web based.
- 5. Loneliness and isolation of older people, including carers, BME and LGBT elders should be addressed along with increasing the number of older people actively participating in a full range of activities and services. Some older people need to be assisted and accompanied to ensure they access services. Ways to provide such support need to be developed.
- 6. It is important to focus not just on the very elderly but also on the younger cohort of older people if future health and wellbeing problems and associated costs are to be reduced.
- 7. We need culture change across the City so that participation and engagement by older people is actively encouraged and older people are visible and involved as leaders in the City. Strategic involvement of older people in service design and delivery, along with active promotion of positive images of ageing, are important steps to taking this forward.
- 8. Adult Social Care will work to deliver its commitments set out in the Market Position Statement, 2014.

#### Key links to other sections

- Social connectedness, community resilience and community assets
- Emotional health and wellbeing
- Dementia
- Fuel poverty
- Housing

#### **Further information**

Ward L. Barnes M. Gahagan B. Well-being in old age: findings from participatory research. University of Brighton and Age UK Brighton & Hove. 2012.

http://www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/Full-report.pdf

As Time Goes By: Thoughts on Well-being in Later Years. University of Brighton and Age UK Brighton & Hove. 2012

Brighton & Hove Annual Report of the Director of Public Health 2010: Resilience. http://www.brighton-

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<u>hove.gov.uk/content/health-and-social-care/health-and-wellbeing/annual-report-director-public-health</u>

Adult Social Care. Market Position Statement. March 2014.

http://www.brighton-hove.gov.uk/sites/brighton-hove.gov.uk/files/FINAL%20MARCH%20ASC%20Commissioning%20Statement%20Report.pdf

#### Last updated

September 2014



#### Why is this issue important?

Dementia presents a huge challenge to society and will do increasingly in the future. There are approximately 662,373 people aged 65 and over in England with dementia. Dementia costs the UK economy £23 billion a year and this will rise to over £27 billion a year by 2018; the number of people with dementia in the UK doubles every 20 years and will rise to 1.7 million by 2050.

Dementia is a syndrome which results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Individuals may also develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness. There are different types of dementia caused by different diseases of the brain, including Alzheimer's disease and vascular dementia. These diseases affect the brain in different ways and produce different symptoms.

Carers of people with dementia are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life. Dementia is a terminal condition but people can live with it for 7–12 years after diagnosis.<sup>2</sup>

The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age range from 30 onwards. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years are attributable to dementia.<sup>1</sup>

There is evidence that people with dementia have worse clinical outcomes than people with the same conditions without dementia. This contributes towards longer length of stay in general hospitals. Nationally, it is estimated that two thirds of people in care homes have dementia and 40% of these people are not in specialist dementia care homes.<sup>3</sup>

Apart from family members or friends, who provide the vast bulk of care and support, home

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care is probably the single most important service involved in supporting people with dementia in their own homes. The Commission for Social Care Inspection (CSCI) has found that good-quality, flexible home care services contribute significantly to maintaining people's independence, reducing social isolation, preventing admissions to care homes and hospitals, and supporting carers.<sup>4</sup>

Historically, dementia has been under diagnosed, both locally and nationally. It is estimated that only a third of people with dementia receive a formal diagnosis or have contact with specialist services at any time in their illness. Also, such diagnosis and contact often occur late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed.<sup>4</sup>

Contrary to social misconception, a great deal can be done to help people with dementia. Dementia should be diagnosed early and well so that people with dementia and their carers can receive treatment, care and support to enable them to live as well as possible with dementia.

#### **Key outcomes**

- Health related quality of life for older people (Public Health Outcomes Framework)
- Estimated diagnosis rate for people with dementia (Public Health and NHS Outcomes Framework)
- Improving experience of healthcare for people with mental illness: Patient experience of community mental health services (NHS Outcomes Framework)
- Enhancing quality of life for people with dementia -estimated diagnosis rate for people with dementia (NHS Outcomes Framework and Public Health Outcomes Framework); a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life (Adult Social Care Outcomes Framework, Placeholder and NHS Outcomes Framework)

<sup>&</sup>lt;sup>1</sup> Institute for Public Care. Projecting Older People Population Information System (POPPI). Available at: <a href="www.poppi.org.uk">www.poppi.org.uk</a> (registration required) [Accessed 30<sup>th</sup> September 2014]

<sup>&</sup>lt;sup>2</sup> Alzheimer's Society. Facts on Dementia. Available at: http://www.alzheimers.org.uk/site/scripts/documents info.php?documentI D=535&pageNumber=2 [Accessed 23/05/13]

<sup>3</sup> Commission for Social Care Inspection (CSCI). See me, not just the dementia. 2008

 $<sup>^{\</sup>rm 4}$  Commission for Social Care Inspection (CSCI). Time to Care? London: TSO. 2006

<sup>&</sup>lt;sup>5</sup> NICE/SCIE. Dementia: Supporting people with dementia and their carers in health and social care. London: TSO. 2006

 $<sup>^{\</sup>rm 6}$  National Audit Office. Improving services and support for people with dementia. London: TSO. 2007

#### **Impact in Brighton & Hove**

It is estimated that in 2014 there are 2,849 people aged 65 years or over with dementia in the City, based on applying national prevalence rates to the local population. It is estimated that there are currently 61 people with early onset dementia. 7

Dementia has been included in the Quality and Outcomes Framework (QOF) measures for GP practices since 2006/07. Since that time the proportion of the GP registered population on local practice dementia registers has increased slightly from 0.3% to 0.4% in 2011/12 (reflecting an increase in actual numbers from 937 to 1,132). This compares to 0.6% in England and in the South of England Commissioning Region. It is also lower than the 12 other Surrey and Sussex Commissioning Groups. QOF data is not adjustable by age, so care should be taken when making comparisons to other CCGs, particularly those in Surrey and Sussex, as Brighton & Hove has a lower proportion of people aged 65 or over.

Explanations put forward for under-diagnosis include the stigma associated with dementia which prevents people from going to their GP about memory loss, as well as dementia being considered by some people, including GPs, as a normal part of ageing. <sup>10</sup> Lack of diagnosis is a key factor that prevents people seeking the treatment they need and gaining support during early stages. <sup>11</sup>

Since 2010/11 the number of anti-dementia drugs prescribed in primary care has doubled from 7,250 to 14,211 in 2012/13. This is likely to be due to changes in prescribing practice as NICE guidance lifted restrictions on limiting these drugs from patients with moderate to severe dementia and extending them to those with early stage dementia. Anti-psychotic prescribing is now relatively low compared to 2009. In 2011/12, 52% of patients were having their medication reviewed at least every 12 weeks.<sup>9</sup>

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There were 522 admissions to secondary care where dementia was the primary or secondary condition between 2010/11 and 2012/13. This is likely to be an under estimate as dementia is unlikely to be the primary reason for admission and is not always recorded as the secondary condition. Since October 2012 a dementia CQUIN has been in place to assess patients aged 75 or over admitted for over 72 hours, for a diagnosis of dementia.

Between June 2013 and March 2014, 236 assessments were completed by the Memory Assessment Service (MAS), 180 dementia diagnoses made and 56 carers assessments were also completed.

Patients with dementia should be reviewed within primary care at least every 15 months. In 2011/12 local performance was 76% which was slightly lower performance than for England and the South East Coast Strategic Health Authority (79% and 78% respectively). 12

Brighton & Hove has 111 registered care homes with 2,326 beds. A recent survey of 43 homes representing 1,239 beds, self- reported 854 residents (69%) with dementia – this is likely to be an underestimate.<sup>9</sup>

The council spent £15.7 million on home care in 2012/13. There are no figures available on the proportion of these clients with dementia but most home carers will be supporting someone with memory loss.<sup>9</sup>

As the cost of care for people with dementia is embedded across the whole of the health and social care system, including acute hospitals, mental health services, residential and nursing homes, it is difficult to determine the precise costs of dementia care.

#### Where we are doing well

The Heath and Wellbeing Board have identified dementia as a priority for the city and the Joint Health and Wellbeing Strategy includes a section on dementia. A Dementia Joint Strategic Needs Assessment was completed in 2013 and has informed the development of the Brighton & Hove Dementia Joint Strategic Delivery Plan 2014/17.

<sup>&</sup>lt;sup>7</sup> Institute for Public Care. Projecting Adult Needs and Service Information. Available at: <a href="www.pansi.org.uk">www.pansi.org.uk</a> (Registration required) [Accessed 01.10.2014] 

<sup>8</sup> Health and Social Care Information Centre . QOF prevalence data tables 2011/12 available at: <a href="https://catalogue.ic.nhs.uk/publications/primary-care/qof/qual-outc-fram-11-12-pct/qual-outc-fram-11-12-pcts-prev.xls">https://catalogue.ic.nhs.uk/publications/primary-care/qof/qual-outc-fram-11-12-pct/qual-outc-fram-11-12-pcts-prev.xls</a> [Accessed on 23/05/2012]

<sup>&</sup>lt;sup>9</sup> BHCCG and BHCC. Dementia Needs Assessment. May 2014.

<sup>&</sup>lt;sup>10</sup> NHS Brighton and Hove and Brighton & Hove City Council. Annual Report of the Director of Public Health. Brighton & Hove. 2011

 $<sup>^{11}</sup>$  Brighton & Hove Joint Dementia Plan. NHS Brighton & Hove, Brighton & Hove City Council. 2012

<sup>&</sup>lt;sup>12</sup> Health and Social Care Information Centre. Quality and Outcomes Framework (QOF). 2011/12. <a href="http://www.hscic.gov.uk/qof">http://www.hscic.gov.uk/qof</a> [Accessed on 23/05/13]

Progress made since the 2012/15 Dementia Plan includes:

- Launch of the Memory Assessment Service, which includes support from Dementia Advisers and Carers' Needs Assessment Workers.
- Secured Department of Health capital funding to make the environment dementia friendly in primary care, acute, community services and care home settings e.g. the refurbished Brunswick Ward at Nevill Hospital has reopened as the Lindridge Nursing Home.
- Reconfiguration of mental health services to create a Living Well with Dementia Team.
- Expansion of the Care Home In-Reach Service to support independent sector care and nursing homes, in particular identifying alternatives to anti-psychotic medication.
- The Alzheimer's Society provides Dementia Café's, Singing for the Brain, the Carer Information and Support Programme, Dementia Support Service, Home Support Respite Service and Carers' Support groups.
- Increased capacity in the Community Rapid Response Service to offer crisis and Short Term Community Support, to enable more people with dementia to be supported at home and avoid hospital admission.
- A dementia champion and specialist dementia nurse posts have been funded at Royal Sussex County Hospital. A dementia pathway has been developed in the hospital to provide a memory screen to 90% of patients over 75 who have been admitted for more than 72 hours. The hospital has also adopted the Butterfly scheme to promote education and a common care approach to patients with dementia. The Emerald Unit specialist dementia ward has opened at Royal Sussex County Hospital.
- A Dementia Friendly Guide has been developed for use by community groups and organisations.
- Specialist resources are being developed to improve the End of Life Care for people with dementia.

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#### **Local inequalities**

Dementia affects men and women in all social and ethnic groups. There is limited local evidence available on whether dementia has a differential impact on equality groups. Nationally, dementia is more common in women with two thirds of people with dementia being women.<sup>3</sup> This is largely due to longer female life expectancy. Research suggests early onset dementia is more common in men.<sup>9</sup>

Although there is no good quality data available on the prevalence of dementia in different ethnic groups, it is likely to be more prevalent amongst Asian and Black Caribbean elders. This is because some of the risk factors for dementia (high blood pressure, diabetes, stroke and heart disease) are more common in these communities. Nationally it is estimated dementia will increase seven-fold by 2051 in BME groups as these populations age. <sup>13</sup>

Nationally, it is known that people with Downs syndrome are at greatly increased risk of developing dementia with a lower age of onset than the general population. This is of increasing importance as the life expectancy of people with Downs syndrome is increasing. Rates of dementia are also higher in people with learning disabilities other than Downs syndrome. <sup>14</sup> There are currently 13 individuals on the Community Learning Disability Team's dementia care pathway, aged between 45 and 80 years, seven of them have Down's Syndrome. <sup>9</sup>

Lesbian, Gay and Bisexual people with dementia are more likely to require Adult Social Care support, as they are more likely to live on their own and less likely to have children or see family members. They may also fear prejudice and discrimination from support groups and residential care staff, which may put them off seeking help with their dementia. 15

Based on national research it is likely that at least 71% of people with dementia have a carer. In

<sup>&</sup>lt;sup>13</sup> All Party Parliamentary Group on Dementia. Alzheimer's Society. Dementia Does Not Discriminate. July 2013.

http://www.alzheimers.org.uk/site/scripts/documents info.php?documentI D=103

D=103
 Musingarimi, P (2008). Social Care issues affecting Older Gay, Lesbian and Bisexual People in the UK. A policy brief. London ILC. Cited in Don't Look Back? (2010) Equality and Human Rights Commission, Manchester.

Brighton & Hove this equates to over 2,300 carers or 10% of all carers in the city. <sup>16</sup>

Research findings indicate that abusive behaviour by family carers towards people with dementia is common, with a third reporting important levels of abuse and half some abusive behaviour. <sup>17</sup> A YouGov survey commissioned in 2008 found that 19% of carers of people with Alzheimer's sometimes or often feel threatened by the person they care for. <sup>18</sup>

Brighton & Hove is included in the Pan Sussex Integrated End of Life Dementia Pathway. This aims to improve the end of life care for people with dementia, and enable more to die in their preferred place of death; increase advance care planning for people with dementia; and increase practitioners' knowledge and skills about end of life dementia care.

Other inequalities experienced by some people with dementia include people in the early stages not being referred for diagnosis by GPs. There is also a lack of affordable local authority funded specialist dementia beds in the city, so that 150-200 people are placed in accommodation outside the city (some people will have chosen this to live nearer relatives). People with severe dementia have less choice of care homes and people who can't afford to pay for their own respite have to wait longer to access it. Those without their own transport can face long journeys travelling to and from day centres.<sup>9</sup>

#### **Predicted future need**

By 2030, it is projected that the number of people aged 65 years or over with dementia will increase to 3,892 (Table 1).<sup>1</sup>

The number of people with early onset dementia is projected to increase by 21% (to 69) by 2020.<sup>7</sup>

However, these figures do not take into account the current under-diagnosis of dementia. If levels of diagnosis improve, the proportional increases could be much greater (The Memory Assessment Service has been set a target of increasing the

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dementia diagnosis rate from 54% to 67% by 2015). Nor do they take account of the anticipated decrease in dementia due to the reduced number of people at risk of cardio-vascular disease, though this is likely to be offset by the increase in obesity.

Table 1: Number of people aged 65 or over predicted to have dementia by age, 2014 and 2020 projection

	2014	2030
65-69 years	143	189
70-74 years	222	302
75-79 years	392	507
80-84 years	647	909
85-89 years	728	889
90 plus	717	1,097
Total 65 +	2,849	3,892

**Source:** Institute for Public Care. Projecting Older People Population Information System. www.poppi.org.uk

#### What we don't know

The Dementia JSNA found gaps in information in the following areas: the number of people with a dementia diagnosis living in care homes or receiving home care; how many people with dementia receive personal budgets or direct payments, how many people are self-funding their dementia care; the extent of dementia by ethnic group or protected characteristic groups, apart from gender; the number of people with dementia being admitted to acute hospitals.

#### Key evidence and policy

The Prime Minister's Challenge on Dementia was published in 2012. This made key commitments for driving improvements in health and care; developing dementia friendly communities that understand how to help and better research. <a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/146773/dh\_133176.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/146773/dh\_133176.pdf</a>

A National Dementia Strategy was published in 2009 and updated in 2010. It identified four

<sup>&</sup>lt;sup>16</sup> Brighton & Hove Multi-Agency Commissioning and Development Strategy for Carers Refresh 2012-2013

<sup>&</sup>lt;sup>17</sup> Cooper C et al. Abuse of people with dementia by family carers: representative cross sectional survey. BMJ 2009;338:b155

<sup>&</sup>lt;sup>18</sup> YouGov. YouGov / Channel Four Survey Results. 2008. http://iis.yougov.co.uk/extranets/ygarchives/content/pdf/C4%20results%20 alzheimers.pdf [Accessed on 26/08/2012]

priority areas to improve the quality and outcomes of care for people with dementia and their carers:

- Good quality early diagnosis and intervention for all
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of antipsychotic medication <a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/168220/dh\_094051.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/168220/dh\_094051.pdf</a>

Other key documents include:

Quality standard for supporting people to live well with dementia – NICE April 2013 <a href="https://www.nice.org.uk/guidance/qs30/resources/guidance-quality-standard-for-supporting-people-to-live-well-with-dementia-pdf">https://www.nice.org.uk/guidance/qs30/resources/guidance-quality-standard-for-supporting-people-to-live-well-with-dementia-pdf</a>

The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care. National Collaborating Centre for Mental Health. 2006. Modified October 2012

http://www.scie.org.uk/publications/misc/dementia/

A report into prevalence. Dementia UK. 2007 <a href="http://www.alzheimers.org.uk/site/scripts/downlo">http://www.alzheimers.org.uk/site/scripts/downlo</a> ad.php?fileID=2

Quality outcomes for people with dementia:
Building on the work of the National Dementia
Strategy. Department of Health. 2010
<a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/135771/dh\_119828.pdf.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/135771/dh\_119828.pdf.pdf</a>

Living well with dementia: A national dementia strategy - good practice compendium. DH. 2011 <a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/147541/dh\_123475.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/147541/dh\_123475.pdf</a>.

Brighton & Hove Clinical Commissioning Group and Brighton & Hove City Council. Dementia Needs Assessment. May 2014.

http://www.bhconnected.org.uk/sites/bhconnected/files/JSNA%20dementia%202014.pdf

#### **Recommended future local priorities**

The Brighton & Hove Dementia Joint Strategic Delivery Plan 2014-17 sets out the key action areas for development, based on the JSNA findings:

- Develop a single point of dementia information for public, professionals and carers.
- Workforce dementia training, including care home, homecare workers, sheltered housing,

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extra care housing, homeless services, learning disability services, community and voluntary workers.

- Good quality early diagnosis and support before and after diagnosis.
- Develop advice, support and capacity building in primary care.
- Ensure joined up integrated care for people with dementia and their carers.
- Create a Dementia Action Alliance to develop a Dementia Friendly Community.
- Ensure mainstream services are dementia friendly.
- Encourage uptake of direct payments and personal health care budgets by people with dementia and their carers.
- Continue to improve: number of carers receiving assessments, access to respite, training, awareness and support.
- Explore how to involve wider community in sheltered and extra care housing.
- Consider how to increase dementia friendly design of homeless accommodation.
- Explore ways of increasing dementia awareness of Estate Agents and Landlords.
- Promote telecare and telehealth to staff.
- Continue to develop and implement the End of Life Care in dementia pathway.

#### **Key links to other sections**

- Ageing well
- Mental health
- Adults with learning disabilities

#### **Further information**

NHS Brighton & Hove, Brighton & Hove City Council. Brighton & Hove Dementia Joint Strategic Delivery Plan 2014-17.

#### Last updated

October 2014